Experiences of teenage and young adult ambulatory cancer care: Community-Based Participatory Research to inform service provision

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Thesis submitted for the degree of Doctor of Philosophy

March 2023

Declaration

I, Alison Finch confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Alison Finch, Clinical Doctoral Research Fellow, NIHR ICA-CDRF-2018-04-ST2-034 was funded by Health Education England (HEE) / National Institute for Health and Care Research (NIHR) to undertake this research. The views expressed in this thesis are those of the author and not necessarily those of the NIHR, HEE, NHS or the UK Department of Health and Social Care.

A community is fostered in realisations of people who want to be part of something together – an idea, a hope, a purpose or possibility – and that in coming together they can create something greater than they could have alone.

(Wolf, 2022, p.1)

Abstract

Background

In 2011, the English National Health Service (NHS) introduced Ambulatory Care (AC) for Teenage and Young Adult (TYA) cancer patients, offering chemotherapy regimens and treatment that traditionally require hospitalisation on an ambulatory basis. This treatment modality is made possible using portable infusion pumps, with young people residing close to the hospital overnight.

Aims

This research set out to explore the experiences of those receiving and delivering AC: building knowledge to inform current and future services for those aged 16-24 and their families. A key aim was to understand whether refinements to the service were needed to better support young people and their companions.

Methods

Through a *Community-Based Participatory Research* approach, young people and companions from the TYA cancer community became co-researchers and contributed to every stage of the research process. The study design included a scoping review of the literature and consultation with health professionals. Through semi-structured, peer and photo-guided methods, 43 participants (18 young people, 13 companions and 12 staff) participated in interview conversations; participation was also a feature of data analysis. In addition, four young associate researchers took part in an evaluation of their co-researcher experience.

Findings

Ambulatory Care contributes positively to young people's experiences of cancer treatment. It retains aspects of life that are important to young people whilst fostering their wellbeing and autonomy. Informing this is young people's agency, with AC supporting them to feel and be agentic in their care pathway. Advance preparation, partnership working and respect for autonomy – underpinned by a clinical safety net – enables the effective operationalisation of AC. Critical to young people's positive experience is the opportunity to be accompanied, and AC may not be feasible without a companion's involvement.

This research offers the TYA cancer community evidence to inform policy, practice and future research inquiry and proposes a series of recommendations for the further development of TYA Ambulatory Care.

Impact Statement

As the first comprehensive primary research study to have investigated staff and service users' experiences of Ambulatory Care (AC) in a Teenage and Young Adult (TYA) cancer context, this PhD contributes benefits to healthcare practice, policy, the public and academia.

The study team included young people and parent co-researchers with personal experience of cancer. Working within a Community-of-Inquiry, co-researchers volunteered over a two-year period, and engaged fully in every stage of the study, including data analysis. This impacted the co-researchers themselves: building personal capacity and contributing to curriculum vitaes. It also motivated one co-researcher to source grant funding to develop and co-lead workshops at the study site, addressing unmet support needs of young people's companions.

Community-of-Inquiry membership included two national charity partners. Preliminary findings of my PhD informed Young Lives vs Cancer developing and appointing a national programme manager for Ambulatory Care. Teenage Cancer Trust, the other third-sector partner, will implement the findings in different ways that feed into the practices of staff roles that they financially support, and their ongoing investment in dedicated TYA cancer services.

Considering impact on clinical practice, I have been invited by Teenagers and Young Adults with Cancer (TYAC), the UK's professional association for those involved in the treatment, care and support of TYA with cancer, to lead authorship of a best practice guideline. Within the TYA cancer community, national dissemination of the findings will be of benefit to cancer services scoping their own AC service, and to the new national specialist interest group for children's and TYA AC, hosted by TYAC and the Children's Cancer and Leukaemia Group. Other important areas where the insights will be of service includes using the research to broaden the conceptualisation and practise of age-appropriate care.

As a demonstrable contribution to healthcare policy, I responded to a call for evidence for the government's future 10-year cancer plan, submitting findings to the UK Department of Health in April 2022. The research has been recorded and monitored by NICE, with potential for the findings to inform specialist commissioning of cancer services.

An important piece of public engagement work was a co-curated photograph exhibition. Exhibiting the research findings visually to a wider clinical and public audience in a hospital gallery space and online over a six-week period, fostered further interest in AC, with feedback indicating that it had revised people's perceptions of cancer treatment.

In terms of academic impact, this thesis contributes methodologically through the development and application of a triad interview method – an approach in which two interviewers guide an exploratory three-way conversation with an interviewee. As the first Community-Based Participatory Research project within the TYA cancer academic field, it is an exemplar of how young people can successfully fulfil co-researcher roles. More broadly, throughout the research there have been opportunities to inform and influence thinking around AC and participatory research methods through presentations at meetings and conferences. Further dissemination of the research through journal publication and other media will enhance the potential impact of this PhD to wide audiences.

Acknowledgments

This thesis reports research funded by HEE and the NIHR as part of their Clinical Doctoral Research Fellowship programme. Alongside the NIHR, I acknowledge my employer University College London Hospitals NHS Foundation Trust (UCLH) for supporting me to pursue this fellowship. I thank my academic supervisory team: Professor Rosalind Raine, Professor Faith Gibson, Dr Silvie Cooper and Dr Rachel Taylor. I especially acknowledge Silvie's commitment to my academic development and her support of me more personally.

Both the research and my PhD experience have been enriched by the participation and voluntary contributions of eleven members of the young people's cancer community. In particular, I would like to thank Sadhia Ali, David Chang, Emma Haslam, Michela Quecchia, Robert Rietz and Kristy Wang who volunteered as co-researchers and contributed to every stage and phase of this research. I acknowledge the professionals from the teenage and young adult (TYA) service at UCLH who supported study recruitment, together with sister Lauren Jordan, and charity collaborators Teenage Cancer Trust and Young Lives vs Cancer. Forty three individuals took part in this research, and I recognise every contribution.

I thank Professor Heather Waterman who supported my NIHR grant application and was a member of my supervision team until her retirement in 2020. I also acknowledge and thank Dr Nicole Brown and Dr Jill Russell for their mentorship around creative and qualitative research methods respectively, and Dr Darren Sharpe for his support helping co-facilitate the preparation of co-researchers. I extend my appreciation to colleagues within the UCL Department of Applied Health Research for their support and generosity. Also, Julia Poduska, formerly of UCL for her assistance with formatting this document. I thank UCLH Royal Literary Fund Fellows: Peter Forbes for his interest in the literary composition of the text, and Wendy Wallace for her writerly wisdom and encouragement. I remain immensely appreciative of Nilkunj and Sylvie who have quietly stood by throughout my studies, creating the headspace that I needed to write this thesis. I dedicate this work to Sylvie.

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List of Acronyms

AC	Ambulatory Care
CBPR	Community-Based Participatory Research
MDT	Multi-disciplinary Team
NHS	National Health Service
PI	Principal Investigator
PIS	Participant Information Sheet
TYA	Teenage and Young Adult

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Chapter 1 Background and context of the research

My background and relationship to this research is framed around professional experience of cancer. I am a registered nurse and have practised in the cancer speciality most of my clinical career, predominantly with young people. I have worked at University College London Hospitals NHS Foundation Trust (UCLH-the research site) for over two decades within the young people's and broader cancer specialities. Since 2014 I have been fulfilling a Trust wide nursing leadership role. Whilst lead nurse of the young people's cancer service at UCLH, I helped set up their Ambulatory Care (AC) service for the Teenage and Young Adult community. Once it was established, and the perceived benefits of the pathway became anecdotally known, I became committed to developing an evidence base about young people's experiences of AC. I was awarded a Health Education England (HEE) and National Institute for Health and Care Research (NIHR) funded clinical doctoral fellowship to conduct this research in December 2018. Conceptual development of this work began in late 2016, at a time when I no longer had operational or leadership responsibilities for the AC service.

From the outset, I designed the research as a participatory endeavour, to build knowledge with, alongside and for, the Teenage and Young Adult cancer community. Nursing is fundamentally a collaborative, team-orientated profession and so it felt fitting and appropriate to extend this approach to a research context. Convention suggests that a PhD thesis focuses on demonstration of individual research competence, within the context of a solitary project (Klocker, 2012). This research, however, has been the antithesis of the lone endeavour often associated with doctoral study. Both the research and my PhD experience have been enriched by the participation and voluntary contributions of others (young people, family representatives and professionals), who contributed to every stage and phase of the research over a 30-month period whilst volunteering as co-researchers.

Participatory research, by its very nature is a collaborative process, and this written account integrates perspectives of the collective, whilst knowing that it is my work and contribution to knowledge that is being examined. I have made conscious use of the pronouns ‘we’ and ‘our’ throughout the thesis, to uphold the ethos of participatory research and to clearly position that knowledge was generated in a community. Some components of the research I undertook alone (denoted in the narrative as ‘I’) and, more fundamentally perhaps, I facilitated and directed the project.

This thesis sets out to show the story of how the research developed iteratively in and with a community, as much as it provides a written account of the work and its contribution to knowledge about experiences of Ambulatory Care. It has been highly satisfying to reflect in the design and fulfilment of my PhD project, the principles of engagement that are fostered in TYA cancer care and research.

1.1 Changing culture of healthcare

Until the late 1970s, healthcare in the United Kingdom (UK) was predicated on the basis that the hospital ward was a place of safety. Care was organised around the inpatient bed as the centrepiece, involving clinical practices that prioritised routinisation of care. However, from that time on there was debate and a range of plans to reform the culture, efficiency and effectiveness of healthcare (Enthoven, 1985; Department of Health, 1992; NHS, 2000a), as evidence emerged that there was a relationship between the way healthcare was delivered, its impact on patient outcomes and, arising from this, quality of care.

A move towards more holistic models of healthcare followed. This can be traced back to the United States of America (USA), where in the 1960s it was referenced as person-centred care (Armad *et al*., 2014). Following this, within nursing, innovations in US approaches, such as the notion of self-care as described by Orem (1991), began to have an influence on how care was delivered in the UK, reframing patients as active partners. Simultaneously, over time, advances in technology, alongside shifts in law and human rights, have all contributed to the move towards individualised, collaborative, patient-centred care delivery (Murphy, Williams and Pridmore, 2010).

This shift has also mirrored moves in healthcare organisation and culture: from one dominated by notions of biomedicine as ‘all knowing’ or omnipotent, to aspirations for a more person-centred system within which patients and the public are afforded, invited even, to exercise greater autonomy in relation to their health (Goodrich and Cornwell, 2008; Seale, 2016). Alongside this shift is the UK national context of increasing healthcare demand. Within the cancer speciality alone, since the early 1990s, incidence rates for all cancers combined have increased by more than a tenth (12%) in the UK (Cancer Research UK, 2022). There are currently over 375,000 new cancer diagnoses every year (2016-18), with incidence rates having increased 19 per cent since the 1990s in those aged 0-24 (Cancer Research UK, 2022).

1.1.1 Demand-driven innovation towards patient involved care

Growth in healthcare demand universally has driven innovations in care design and delivery. Concurrently within the cancer specialty, improved treatment, technology and supportive care have helped foster greater opportunities for self-care; many protocols, formerly requiring hospital admission, can now be given on a day care or ambulatory basis. Consequently, many cancer patients now spend proportionally more time away from the inpatient setting during treatment. Considered less disruptive to people’s lives, these ambulatory pathways also help meet increasing demand for services by freeing up inpatient hospital beds (Bakhshi, Singh and Swaroop 2009, Sive *et al.,* 2012).

Beyond the cancer specialty, the shift away from inpatient care is gaining momentum. NHS England and NHS Improvement (2022) are asking all integrated care systems (ICSs) to extend or introduce the virtual ward model by December 2023, creating additional ‘bed’ capacity through efficient, productive use of resources whilst facilitating patients to take more responsibility for care themselves. Enabled through technology, virtual wards support patients who would otherwise be in hospital to receive in their own home, the acute care, monitoring and treatment that they need for conditions such as acute respiratory infection or frailty (NHS England and NHS Improvement, 2022). Alongside the opportunity to promote more person-centred care delivery is the fact that, according to the King’s Fund (Ewbank *et al*., 2021), the total number of NHS hospital beds in England has more than halved over the past thirty years, from approximately 299,000 to 141,000 while the number of patients requiring treatment has grown.

Concepts such as involvement in care, self-care and self-management did not become embedded in UK health policy until the turn of the millennium (Armad *et al.*, 2014). Whilst more engaged, person-centred care is now a feature of healthcare commitment (NHS England, 2019a, 2019b), and there is a move towards more shared responsibility for health (Ham, Charles and Wellings, 2018), opportunities to enact this in a transformative way remains less developed within acute care specialties than in community settings. Ambulatory Care (AC), the subject of this research, strives to embed these concepts. Developing knowledge, evidence and a full understanding of patient experience in the AC setting has become an imperative in this new healthcare context as much of patients' daily life occurs away from the purview of the healthcare team.

1.2 Defining ambulatory care

Within healthcare contexts globally, the term 'Ambulatory Care' frequently refers to any type of clinical care being provided for an outpatient without the need for hospital admission overnight (NHS England, 2019c; Agency for Healthcare Research and Quality, 2022; Institute for Patient- and Family-Centered Care, 2022). In the UK cancer context, it denotes the hospital-led coordination and delivery of cancer treatment on an outpatient basis that would, throughout the National Health Service (NHS), usually require inpatient hospitalisation. First piloted in the UK in 2003, within the adult cancer service at UCLH, AC went on to become established as a mainstay of cancer treatment delivery. The care model was extended to the Teenage and Young Adult (TYA) setting in 2011 at UCLH, premised on AC's capacity to offer a less clinical experience during cancer treatment.

Ambulatory Care usually supports the delivery of chemotherapy, although it is also used for post-chemotherapy monitoring and supportive care. Distinct from a day care chemotherapy pathway, AC is offered when the protocol involves a continuous infusion (facilitated using a pre-programmed portable pump) or daily intravenous treatment over several days. Some treatment protocols can be managed entirely on an AC basis; other pathways, for example, allogeneic haematopoietic (stem cell) transplant, have a pre-determined time when patients are brought into the inpatient ward for the most intensive period of supportive care and/or immunosuppression. All patients may require inpatient admission on an unplanned basis if they become clinically unwell (e.g. due to treatment related toxicity, side-effects or uncontrolled symptom management), or in circumstances where young people are not able to self-monitor. Distinct from adult AC, young people can opt into the service or, for protocols where AC has become the standard mode of treatment delivery, opt out of AC according to personal circumstances.

When not accessing clinical care, AC involves young people staying at home (if within 60 minutes travel distance of UCLH), in a patient hotel in the vicinity of the hospital, a third-sector, charity-funded home-from-home, or commercial hotel accommodation. Young people return daily to the AC unit for review and/or administration of treatment, with 24-hour telephone access to a senior nurse. Those over the age of 18 can ambulate alone (unless receiving chemotherapy that poses risk of neurotoxicity), although it is usual for young people irrespective of their age to be accompanied by a companion. When not required on the AC unit for treatment, young people can pass time as they choose and as their health status allows.

Literature to date suggests that AC fosters independence (Statham, 2005; Statham, 2012; Mcmonagle, 2015; Comerford and Shah, 2018) and creates opportunities for young people to experience individualised care (Anderson *et al.*, 2013; Brown and Walker, 2016). Among TYA cancer professionals, there is an emerging consensus that AC offers the potential to reduce some of the well-recognised negative psychosocial effects associated with long hospital stays (Grinyer, 2007a). Irrespective of age however, the demands on an AC patient may be high. Patients need to self-administer timed medications, monitor for signs of infection, observe for treatment-related toxicities and undertake clinical measurements that if staying on a hospital ward would be completed by nurses and other healthcare professionals. In practice, many young people rise to this challenge, regarding it as an opportunity to become more practically engaged in their treatment, whilst others may look to their companion residing with them to help take on some of this role.

Since 2016, the National Institute for Health and Care Excellence (NICE) in the UK has recommended that AC should be considered for adults and young people with haematological malignancies in remission, a recommendation that was based on clinical opinion in the absence of empirical evidence. Their guidance called for audit and evaluation of AC (NICE, 2016). I have undertaken this PhD, which has been tracked by the NICE surveillance team at UCLH, to help address this need for evidence, from the perspective of building understanding about service users' experience.

1.3 Ambulatory Care activity

University College London Hospitals has the only fully developed Ambulatory Care service for TYA cancer care in the UK. Other TYA cancer centres, for example Sheffield and Leeds, have developed some AC pathways, and more recently Manchester has established an AC service. Within the North Thames TYA Cancer Operational Delivery Network, there approximately 250 new cancer diagnoses recorded per year among those aged 13-24, of which 191 registrations are from UCLH (IAM, 2022). Around 40% of all new cancer registrations in the network are haematological malignancies; among oncology registrations, 20% are sarcomas. The diagnostic distribution of the remaining 40% of cancer registrations is reflective of national data, as set out in section 1.4.

While the incidence of sarcoma accounts for less than 5% of all new cancer diagnoses registered nationally (Public Health England, 2021), UCLH is part of one of the largest sarcoma services in Europe. Between January 2020 and May 2022, out of 143 sarcoma treatment regimens given in those aged 13-24, 129 (90%) were given on an ambulatory basis for at least one treatment episode (Ingley, Birkett, *et al.*, 2022).

Between 2012-2018, there were 1,520 AC admissions at UCLH amongst 339 young people aged 13-24, with 81% in the 16-24-year age group (UCLH, 2018). The onset of the Covid-19 pandemic, in spring 2020, reframed the potential benefits of AC. Throughout the pandemic, AC provided a practical alternative to hospital admission whilst avoiding cancer treatment delays. More recent local data (UCLH, 2021) evidenced around 280 AC admissions per year among young people aged 13-24. Across all diagnostic groups and treatment pathways, there is a mean average of nine young people aged 13-24 accessing treatment via AC at UCLH each day (Birkett, 2022). A summary of the main treatment protocols given in AC at the research site, UCLH, is detailed in Appendix 1[1].

1.4 Epidemiology of Teenage and Young Adult cancer

In England, there is an average of 2,110 cancer cases per year among those aged 15-24 (Public Health England, 2021). More broadly within the UK, whilst young people aged 15-24 account for less than 1% of all new cancer diagnoses, 41 young people are diagnosed with cancer every week (Cancer Research UK, 2022). From the perspective of diagnostic distribution, among TYAs (aged 15-24) lymphomas account for 20% of all cancer registrations, germ cell, trophoblastic and gonadal tumours for 16%, central nervous system tumours for 12%, malignant melanomas for 10%, leukaemia for 9%, and soft-tissue sarcomas, skin carcinomas and thyroid carcinomas each for 5%. Carcinomas (other than renal, hepatic and gonadal) and malignant melanomas account for 30% of cancers among TYAs (Public Health England, 2021).

Although cancer mortality rates for those aged 15–24 in the UK remain higher than those in the Nordic countries, the Netherlands, Germany, Canada and Australia (Public Health England, 2016), five-year survival for TYAs aged 15-24 has increased from 79% for those diagnosed between 1997 and 2001 to 87% in 2012-16 (Public Health England, 2021). Significant improvements in survival outcomes reflect, in part,

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[1] Throughout this thesis, underlined text denotes hyperlinked content.

earlier diagnosis and more centralised and increasingly specialised TYA cancer care, combining clinical expertise and access to clinical trials.

1.5 Teenage and Young Adult Cancer Services

Viner and Keane (1998) posit that the Department of Health's report on the Welfare of Children and Young People (Department of Health, 1991) was the first to consider seriously the need to develop specialist adolescent health services in England. At that point in time, the field of TYA cancer had already been in development. What first started as a nascent specialty in 1990 and centred on a teenage cancer ward at the Middlesex Hospital in London (Whiteson, 2003), led to the establishment of the specialty in the UK. The field of TYA cancer has since developed internationally, notably within the USA, Canada and Australia (Thomas, Albritton and Ferrari, 2010).

Cancer in adolescence and young adulthood can have a distinct biological and clinical profile (Barr *et al.,* 2016). National cancer strategies have recommended that cancer among TYAs should be managed by professionals with age-appropriate expertise both in the cancers that occur at this age and in the holistic care of young people (Public Health England, 2021). The UK was one of the first countries to describe a philosophy of TYA cancer care, distinct from child or adult focused care (Vindrola-Padros *et al*., 2016); it respects the unique needs of patients at this life-stage, and combines contributions from multiple perspectives: health professionals, researchers, policy makers, charitable organisations and philanthropists, who collectively advocate for this differentiation in pursuit of meeting the needs of young people and strengthening their outcomes (Carr *et al.,* 2013; Cable and Kelly, 2018).

Enacting this philosophy has emphasised investment in the built environment. Twenty-eight Teenage Cancer Trust units have been funded and built in the last thirty years across the UK (Teenage Cancer Trust, 2022). It is within these units that the philosophy and care practices of the TYA community have been cultivated. This includes the concept of age-appropriate care (Fern *et al*., 2013; Lea *et al*., 2018), used to describe the principles, values and components of how the needs of young people should be met. Age-appropriate care has become synonymous with the TYA specialty;

as Cable and Kelly (2018) assert, it has also become part of the NHS lexicon. Foregrounded within age-appropriate care, and the coordination and delivery of clinical care to young people in the UK, is the developmental stage of adolescence and young adulthood.

1.6 Developmental stage of adolescence and early adulthood

The period of adolescence and young adulthood is customarily described as a transitional life stage, significant from the perspective of biological, emotional, cognitive and social development (Coleman, 2011). Thirteen years has traditionally been considered the start of the teenage or adolescent period, while reaching 18 years affords legal adult status. In practice, however, the stage is less neatly defined. At the earlier end of the spectrum, there has been the emergence of a pre-teenage cohort. While at the other end, young people up to the age of 39 in the USA are considered young adults (U.S. Department of Health and Human Services, 2006). While there is no universal definition of when the period begins or ends, there is growing agreement that the life-stage of adolescence and early adulthood has altered and lengthened in recent decades. What is known, is that young people in their teenage years and twenties have different characteristics, concerns, and needs from those of either children or of older adults (Thomas, Albritton and Ferrari, 2010; Lea, Taylor and Gibson, 2022), and the biological and psychosocial processes that young people are required to navigate during this period are not determined by, or reflective of, chronological age.

From a biological perspective, puberty is associated with development of the reproductive and cardiovascular systems, with hormonal changes and the associated physical maturation. Cognitively, changes to brain structure, functioning and connectivity (National Academies of Sciences, Engineering, and Medicine, 2019) lead to improvements in brain processing and cognitive function (Keating, 2004). There are changes to the limbic system and neurotransmitters of the brain, with limbic system changes associated with heightened emotions and developing emotional maturity (Coleman, 2011). These changes may be associated with a desire for novelty, compulsion and risk-taking (Blakemore and Choudhury, 2007), that is often regarded as characteristic of this developmental stage – although the absolute implications of these changes for adolescent development are open to debate. More generally accepted is that peer and romantic relationships gain importance at this time, as young people seek increasing independence from parent/s on their journey to becoming more autonomous. Issues around self-esteem are commonplace as young people begin to differentiate themselves from others, and establish a coherent identity (youth.gov, 2022).

Add to this a cancer diagnosis in teenage or young adult years, and this can have profound impact on a young person's life: body image, self-esteem, mental wellbeing, independence, study or work and social relationships are all affected. The demands of cancer treatment can mean that these impacts become more pronounced, with increased dependence on a parent to support care practically and/or emotionally.

The complex nature of how the changing social, economic, digital and demographic landscape has impacted and continues to define the teenage and young adult period, along with globalisation and altering family structures, has been the subject of more contemporary consideration of this period in life (Coleman, 2011; Bonnie *et al.*, 2019). Traditionally, adolescence has been characterised by a period of strife with peers, and family, crises in identity, and even recklessness. However, more current thinking posits adolescence more positively as a journey towards increased agency on the part of young people, when they can leverage developmental opportunities to flourish (National Academies of Sciences, Engineering, and Medicine, 2019). Developmental context also increasingly informs more recent thinking, examples being better understanding of the closeness of young adults' relationships with their parents (Bertogg and Szydlik, 2016) and the significance of how young people and their families reciprocally influence one another (Fingerman, Huo and Birditt, 2020).

1.7 Age ranges in Teenage and Young Adult cancer specialty

Similar to the debates around defining the life-stage of adolescence and early adulthood, a chronological age definition to use when describing TYA cancer services also remains variable (Aubin *et al.,* 2011). Whilst TYA cancer service provision in the

UK typically focuses on the period 16-24 years inclusive (NICE, 2005; NICE, 2014), the service specifications allow for flexibility in age ranges according to local resources and expertise; TYA services may flex the lower age range down to 13 years and some paediatric services may flex their upper age limit to 18. Bracketing younger teenagers with young adults in the UK does create complexity; it broadens variance within the community from the perspective of developmental age, life-experience, home situation and life context. This broader age-framing does however align more closely to the field of Adolescent and Young Adult (AYA) oncology being advanced in the USA where the U.S. Department of Health and Human Services (2006) and National Cancer Institute (2022) regard the AYA population as between the ages of 15 and 39. Thus in my and others appraisal of literature about TYA (or AYA) cancer, it is important, therefore, to consider how teenagers (or adolescents) and young adults are defined and conceptualised. In the last decade, Teenage Cancer Trust has supported the development of a dedicated young adult inpatient haematology ward for individuals aged 20 to 25 at UCLH. Prioritising psychosocial support of a young adult (Carr *et al.,* 2013), it operationally forms part of the clinical configuration of adult cancer services and is staffed by professionals committed to delivering TYA care.

1.8 Configuration of Teenage and Young Adult cancer services

In England, TYA cancer care is currently centralised around 13 Principal Treatment Centres (PTC), alongside linked "designated" hospitals (Lea *et al*., 2018) with a remit to deliver tumour site-specific expertise in conjunction with psychosocial support for young people and their families. This service configuration was first directed by Improving Outcomes Guidance (IOG) for Children and Young People, published by the National Institute for Health and Care Excellence (previously Clinical Excellence) (NICE 2005). The IOG guidance recommended that young people aged 16-18 would have their treatment provided at a PTC, and those aged 19-24 should be offered the choice to receive treatment at a PTC or at a local hospital that is designated to provide care for young adults. Irrespective of the location of care, it is expected that both teenagers and young adults will have unhindered access to age-appropriate multidisciplinary team support, coordinated in part through a weekly multidisciplinary team meeting held at the PTC. This meeting ensures that young people's care and psychosocial needs are being accessed and supported by professionals with expertise in TYA cancer.

Cancer services for children and young people are coordinated nationally by NHS England Specialised Commissioning, supported by a Clinical Reference Group (CRG) comprising clinical or professional representatives, and professional associations (NHS England, 2022a). A key part of the CRG's work is the delivery and quality assurance of service specifications, which define the standards of care expected from PTCs, designated hospitals and more recently across the Operational Delivery Network. Service specifications aim to improve the outcomes, survival and experiences of teenager and young adults with cancer (NHS England, 2018), guided by a principle that care must be age-appropriate, safe, effective and delivered as locally as possible (Royal College of Paediatrics and Child Health and Paediatric Intensive Care Society, 2019).

1.8.1 A move to networked care

In around 2012, the Teenage and Young Adult Cancer Network Commissioning Group (TYACNCG) was established to bring together service providers within a geographical network. An extensive review was undertaken in 2017 by NHS England, with the support of the Children's and Young People's Clinical Reference Group (CYP CRG). Whilst the TYACNCGs were considered valuable, they were found to be somewhat 'toothless', lacking the power and resources they required. New TYA service specifications which went out to public consultation in 2021 will be published early 2023. They strengthen the old TYACNCGs by defining them as formal Operational Delivery Networks (ODNs), with a cancer commissioner co-chair and specific new funding to employ network leads across the country.

Operational Delivery Networks were launched in 2013 within the NHS to coordinate patient pathways over a wide geographical area, with the aim of improving outcomes and experience through access to specialist support (NHS Commissioning Board, 2012). Children, Teenage and Young Adult Cancer Operational Delivery Networks

(ODN) were first established in 2021, coordinating care across Integrated Care Systems (ICSs). The research study site is part of the North Thames Operational Delivery Network for children's and TYA cancer and is hosted by the North Thames Paediatric Network. This ODN is in a stage of relative infancy, having only been established since June 2022.

1.9 The COVID-19 pandemic context

The outbreak of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) associated disease (Covid-19), placed immense pressure on the National Health Service (NHS). During the first year of the pandemic between March 2020 and July 2021, 400,000 Covid-19 patients were admitted into English hospitals, with fears that the NHS system might be overwhelmed (Warner and Zaranko, 2021). Wards were reconfigured and clinical services temporarily relocated to accommodate a clinical need for acute hospital care. Whilst cancer treatment remained a priority for the NHS, with the expectation that essential and urgent cancer treatments must continue (Palmer *et al*., 2020), balancing this with a national Covid-19 response and the risk posed by the virus to individual patients, meant that triaging patients based on clinical need, or transition to different modalities of cancer treatment, sometimes became a requirement.

Within the speciality of young people's cancer, the continued referral, diagnosis and treatment of cancer was considered essential. At UCLH the TYA AC service accommodated increased referrals throughout 2020, to ensure continuity of treatment and care. Ambulatory Care remained a safe alternative to hospital admission: facilitating on-time treatment, whilst enabling patients to practise social-distancing and isolation in a comfortable, non-clinical environment. As visiting became prohibited in hospital, receiving treatment in AC meant that unlike many young people nationally who were facing treatment alone (BBC News, 2021), those being treated at UCLH had the option to be accompanied.

1.9.1 Adjustments to the research in response to Covid-19

This research had been originally designed as an in-person interview-based study. Modifications to the draft protocol were made in April 2020, which enabled the study to continue safely in a way that retained its relational basis, without burdening staff or NHS services. Methods were transitioned to an online, virtual format and whilst the pandemic created new technical and ethical considerations associated with this research, alongside this, it opened opportunities to learn about working with virtual methods.

1.10 In summary

I have undertaken this PhD research (a NIHR Clinical Research Network portfolio study) at UCLH, home to Europe’s first adult, and most comprehensive TYA Ambulatory Care service. I aimed to contribute to the developing evidence base: specific to the TYA cancer specialty, and the perspectives of both providers’ and recipients’ experiences of ambulatory cancer care.

I set out to build experiential evidence to evaluate and inform development of TYA AC at UCLH. Beyond the study site, this evidence would be of relevance to national charity partners’ investment and support, and PTCs who are developing AC pathways and services. The research also held a methodological interest: I was keen to appraise the participatory design and ethos and the extent to which this could become embedded within the study’s conduct. From a theoretical perspective I wanted to consider the concept of age-appropriate care (Lea *et al.*, 2018), and how this informs and is experienced in the ambulatory context.

1.11 Thesis overview

This thesis comprises nine chapters:

Chapter 1 has introduced the background and historical context of this research. I have described the shifting healthcare landscape which has promoted innovations that have led to more patient-involved care. Ambulatory Care as a distinct cancer service in the UK has been defined and an overview of the Teenage and Young Adult cancer specialty presented.

Chapter 2 sets out the theoretical underpinnings of the research, its epistemological basis, and the scope of the qualitative research inquiry. Key tenets of its engaged, participatory approach are described, together with the aims and objectives of the research. I discuss the convening and preparation of the Community-of-Inquiry, in which the research was rooted and from which it was taken forward.

In Chapter 3, a scoping review of the Ambulatory Care literature is reported, exploring the international AC evidence base with respect to the pathway's contribution to experience of care. I explore the provenance of AC, building understanding of its foundations and developmental drivers, whilst appraising the evidence from the Teenage and Young Adult setting related to AC's potential to support delivery and receipt of age-appropriate care.

Chapter 4, a methods chapter, states the research questions arising from the scoping review, and details the study design. I present the methods chosen and the data collection procedure undertaken, together with ethical considerations of this research.

Chapter 5 explores our approach to participatory data analysis. Eakin and Gladstone's (2020) 'value-adding' analysis is introduced, with rationale, as the overarching analytic approach. I explain the participatory analytic procedure undertaken. The chapter addresses reflexivity, that was integral to the interpretative process.

Chapters 6 and 7 present research findings and discussion. Across the two chapters, an integrated, interpretative account of AC experience is presented, offering practical, thematic and conceptual understanding of the experiences of TYA patients, companions and staff.

Chapter 6 opens by describing characteristics of the Ambulatory Care setting. Extending beyond description, a thematic interpretation of how the AC service shaped people's experience of cancer treatment is presented. This chapter closes with a conceptual interpretation and a summary of components critical to TYA AC.

Chapter 7 is where the research findings are appraised in relation to age-appropriate care. The findings are further considered from a conceptual basis, and with reference to wider healthcare agendas. The chapter concludes with learning for development of TYA AC services.

Chapter 8 revisits the methodological approach through an evaluation of young associate researchers' experience. More broadly, the chapter offers a critical appraisal of our engagement with Community-Based Participatory Research, and how the resulting study aligned with my founding expectations.

Chapter 9 details the contributions of this research, alongside implications for policy and practice, and recommendations for the service development of TYA AC.

Within the closing chapters of this thesis, I report more generally on the ongoing dissemination of the research.

Chapter 2 Theoretical and conceptual underpinnings

2.1 Introduction

In this chapter the theoretical underpinnings of the research are detailed. The scope of the research is set out, within which I summarise the aims and objectives. Thereafter, I describe the epistemological basis of the inquiry, and the tenets of Community-Based Participatory Research (CBPR), my chosen participatory research approach.

The second part of this chapter explains in more detail how the participatory imperative was enacted. This focuses on my convening of a community of co-researchers (a Community-of-Inquiry) who, through their membership, became actively engaged in all aspects of the research process. I consider the ethical and practical considerations of convening and preparing co-researchers for their roles as members of the Community-of-Inquiry.

2.2 Patient experience

The NHS needs to ensure that clinical services are clinically safe, effective, meet patients' needs and represent value for taxpayers' money (Department of Health and Social Care, 2021). Whilst it has been established that AC is safe and effective, the broader question of meeting service user needs has been more difficult to evidence. In 2017, when writing a grant application for this research, existing literature suggested that an important component would be to consider the potential tension between system drivers underpinning the delivery of more community or outpatient-based services, and the goal of successfully meeting the care needs and supporting the wellbeing of young people.

Alongside safety and efficiency, positive patient experience is upheld as an important indicator of quality care (Department of Health, 2010; NHS Improvement, 2018; Department of Health and Social Care, 2021), although in practice the term 'patient experience' is often imprecisely defined, with little explanation about what is meant by the concept (Wolf *et al.,* 2014).

A 14-year synthesis of literature used to define patient experience undertaken by Wolf and colleagues (2014) derived a set of concepts evidenced as critical to 'patient experience'. Important was the perspective that experience reflects "occurrences and events that happen independently and collectively across the continuum of care", not just at a specific time point (Wolf *et al.,* 2014, p.7). Experience is, according to Wolf and colleagues, a relational concept. Thus, experience does not happen to someone in a one-directional transaction; it actively engages those who receive, provide and support delivery of care, whilst also strongly tied to people's expectations, and the extent to which these have been realised (Wolf *et al.,* 2014). Considering patient experience through this lens and definition situates it as an individual, personalised concept, which is informed by its relational context (Wolf *et al.,* 2021). This research has been informed by the perspective of 'patient experience' delineated by Wolf and colleagues (2014; 2021).

2.3 The scope of this research

The research set out to explore experiences of AC from the perspectives of those who receive care and deliver the service. Its intent was to build local knowledge for the TYA AC service at the study site, and generate evidence for wider NHS and third-sector charitable stakeholders.

2.3.1 Research aims

The research aimed to generate qualitative understanding and evidence about AC experience that would be of service to practice: to learn how it may benefit young people and their companions, ascertain whether changes or refinements are needed to support and not burden young people and their companions, and to build an explanatory interpretation of AC's relationship with age-appropriate care (Lea *et al.*, 2018). More widely, the study set out to build clinical and academic knowledge about an emergent model of cancer care within the NHS, to inform further development of the service.

2.3.2 Research objectives

The overarching objective of this research was to explore experience of teenage and young adult (TYA) Ambulatory Care (AC) at an individual, family and service-provider level to inform the development of current and future services. To achieve this, a series of incremental objectives were set:

1. To understand the commissioning context and drivers that encourage interest in the development of TYA AC services through scoping review and stakeholder consultation;
2. To iteratively 'tell the story' (describe, explain and build understanding) of AC from its philosophical and operational foundations, informed by a participatory research approach;
3. To contextualise, through qualitative data collection, the experience of receiving and delivering TYA AC at UCLH in relation to what the service sets out to deliver;
4. To build evidence and generate understanding about the features of AC most valued by service users and their accompanying companions, and describe the characteristics required of TYA AC to best support delivery of age-appropriate care;
5. To make recommendations that inform NHS provider, charitable partner and local commissioning decisions around investment in this type of pathway and service;
6. To evaluate young co-researchers' experiences of participating in the research, to include the value of their contribution to the evidence generated, together with more personal impacts.

These objectives were confirmed following my consultation with seven young people, three companions and several nurses working in TYA AC at the study site, facilitated by an NIHR Enabling Involvement fund. The research objectives were developed separate to the formation of a Community-of-Inquiry who thereafter became embedded into the research team.

2.4 The epistemological foundations of this research

Qualitative research methodologies are underpinned by different interpretive paradigms. These paradigms encompass ontological, epistemological, and methodological understandings regarding the nature and process of inquiry, and convey a set of beliefs that guide action (Guba, 1990; Hunt, 2009; Bradbury, 2015). Often, nurses' methodological approach to qualitative research derives from those developed for answering questions in the social sciences, informed by the associated discipline's understanding of how knowledge operates, and for what purpose (Thorne, Stephens and Truant, 2016). Social scientists, Thorne proposes, are interested in health issues as an opportunity to study some expression of the human psychological, social or cultural essence: "that is the core business of their discipline" (Thorne 2011, p. 447). By comparison, health professional researchers she posits, study problems to solve them, to inform practice and as a basis for action (Thorne, 2011).

In working with traditional research approaches 'borrowed' from other disciplines, nurses may feel duty bound to fit the objects and methodological rules of another discipline (for example anthropology) to the study of applied health and clinical problems (Morse and Chung, 2003; Thorne *et al.*, 2004). This can become problematic because, Thorne suggests, it poses the potential of privileging some knowledge or finding, and obscuring others, which, if not congruent with the research question, can complicate the internal logic of a study's design (Thorne *et al.*, 2002).

Recalling a conversation with a colleague who was metaphorically tied-in-knots with the task of demonstrating mastery of a methodology with an underpinning epistemology that needed to be learned, I found myself wondering whether their research would become more about preserving the integrity of the methodology than the research topic itself. Yet during the first few months of my doctoral studies, I found myself experiencing the same point of tension. Around this time, whilst presenting at the International Institute of Qualitative Methodology Health Research Methods conference in autumn 2019 (Finch and Cooper, 2020), I participated in a workshop on interpretative description, led by nursing Professor Sally Thorne.

Interpretive description (Thorne, Kirkham and MacDonald-Emes, 1997; Thorne, 2016), is a qualitative research approach that aligns with a constructivist, naturalistic orientation to inquiry. Attending to the type of experiential research questions nurses and other applied practitioners might be inclined to ask, it articulates a qualitative approach to clinical description, whilst exploring meanings and explanations that may yield practice implications (Thorne, Kirkham and MacDonald-Emes, 1997). Interpretive description acknowledges the contextual and constructed nature of human experience whilst at the same time accommodating multiple shared realities (Thorne*,* Kirkham and MacDonald-Emes*,* 1997). Principles of naturalistic inquiry (Lincoln and Guba, 1985) underpin the theoretical framework informing the research logic and design.

Interpretative description was born from the philosophical core of professional nursing’s disciplinary knowledge: an epistemology rooted in concern for, among others, the uniqueness and multiplicity of human experience; attention to patterns whilst being open to variance; the concept of holism (Thorne, 2016); and a professional mandate for agency (Thorne 2016, Thorne, Stephens and Truant, 2016).

Once I had become orientated to interpretive description, I found myself reflecting on its congruence with the principles and research design logic of participatory research, the application of nursing’s disciplinary epistemology and furthermore, the intended Community-Based Participatory Research (CBPR) approach (section 2.6.1). This led to my decision to work with interpretive description to scaffold the CBPR research inquiry and inform the epistemological grounding to this work – a decision which felt emancipating, but also, importantly, logical and authentic.

Community-Based Participatory Research was introduced to me by Professor Heather Waterman, who both supported my NIHR application and was on my academic supervisory panel during the first year of this PhD. My decision to work with CBPR was, for the most part, informed by its relational basis, which aligned with the essence of my practice as a registered nurse. More personally, the fact that CPBR operates from a position of knowledge democratisation and reciprocity, was in keeping with principles and values I uphold. The conceptual framing of community partners as experts (Bermúdez Parsai *et al.*, 2011), felt respectful as well as cogent – with a potential to generate knowledge that is culturally meaningful and arguably more readily translated into practice than that derived from theory alone (Wallerstein *et al.*, 2018).

In a research study in which my professional judgement and experience led to the conclusion that there were limitations in current knowledge and evidence, it would have been difficult to 'bracket out' that practice insight from the research itself (Thorne, Stephens and Truant, 2016). In this context, my positionality thus became integral to the generation of knowledge; this served as a reminder too that I needed to pay attention to disciplinary biases (Hunt, 2009). It was intended that I might address these, through CBPR's commitment to building knowledge in partnership with others within the ethos of a TYA cancer community.

2.5 The participatory imperative and working with communities

Working in partnership with communities constitutes one aspect of a noticeable shift in academia towards more egalitarian (and less hierarchical) research practices. Research inquiry that encompasses the values and cultural understanding of a community is often characterised by a participatory imperative that is operationalised through being *with*, *for*, and *alongside*, not delivered to the community it serves (International Collaboration for Participatory Health Research (ICPHR) (2013a). Congruent with this approach, is respect for collective production and non-linear, less process driven knowledge.

The participatory imperative underpinning this research was informed by BRIGHTLIGHT (https://www.brightlightstudy.com/), a programme of NIHR-funded studies that evaluated specialised cancer care for TYAs in England. It had measurable success incorporating the perspectives of young people within the development of the various research projects (Taylor *et al*., 2018). Participatory research does not, however, simply ask patients or the public to comment or give advice on what *is*; rather, it challenges people to work together to shape what *could be* (ICPHR) (2020). I wanted to build on the success of BRIGHTLIGHT yet go further and extend young people's involvement in the research beyond an advisory role, to that of a co-researcher who contributed within every stage of the research process. Guided by a co-researcher model piloted by charity partner Young Lives vs Cancer (formerly CLIC Sargent), the research set out to work towards democratising knowledge generation, taking notice and explicit interest in the provenance of the community-generated findings and their capacity to inform practice and service development.

2.5.1 Knowledge democratisation

Since embarking on my doctoral studies, academic commitment to a decolonisation of traditional research and its processes has strengthened in academia. Decolonising methodologies now extend beyond research undertaken with marginalised, oppressed, or indigenous communities to a broader frame, encompassing relationships and power (Tuhiwai Smith, 2017). Describing the community-based participatory ethos of this research to peers and colleagues initially required lengthy explanation. Four years later, it is more usually appreciated if not fully understood.

Acknowledging shifting discourses about participation within research involving young people (Percy-Smith, McMahon and Thomas, 2019), I reflected on what I saw as a propensity for young people with cancer to feel disenfranchised or forgotten within national agendas. An example of this was the Covid-19 pandemic, within which being 'clinically extremely vulnerable' according to one of this research's young co-researchers, had been generally associated in the media with 'being old'. From the outset, I committed to ensuring the TYA community perspective remained central to knowledge generation and to the practice that this research informs.

2.5.2 Defining ‘community’

‘Community’ in this context comprised persons who had a vested interest in TYA AC, from the perspective of receipt or delivery of AC services. Community members were those who had experience of AC: young people; their family or partners; healthcare providers; academics; and those who represented the community such as charities and commissioners of services. The objective was that knowledge would be built in a participatory context, with and for the TYA cancer community.

2.6 Research orientation

This research was action-orientated – it foregrounded being able to inform decisions, identify areas for improvement and support service development, whilst advancing academic knowledge in the TYA cancer field. Early framing of this research’s methodology was informed by the work of developmental evaluator Patton (2010), who describes change and ongoing innovation as being organically linked within the research process. Having deconstructed and attempted to reconstruct the methodological framing of this research once I had started this PhD, I became more hesitant to classify the methodology into a precise typology. I came to realise that this apparent stumbling block was helpful; it created opportunity to explore methodological research questions aside from those that orientated around AC.

I continued working with the emergent and non-linear nature of participatory research (ICPHR, 2013a) to guide my methodological decision making. Community-Based Participatory Research (Wallerstein *et al.*, 2018) was prioritised as a distinct participatory approach and as a valued set of principles with which to facilitate the research inquiry, whilst drawing on the applied qualitative lens of interpretive description (Thorne, 2016).

2.6.1 Community-Based Participatory Research

Community-Based Participatory Research (CBPR) embeds the principles of co-production by including all relevant stakeholders as partners in research inquiry. It is a research approach predicated on action, and the translation of new knowledge in a way that is designed to be of practical benefit (Israel *et al*., 1998, Minkler and Wallerstein, 2008), with participation intended to be transformative for those involved (Wallerstein *et al*., 2018). Striving for maximum feasible participation (Andrews *et al*., 2012), CBPR encompasses "collaborative efforts among community, academic and other stakeholders who gather and use research and data to build on the strengths and priorities of the community" (Wallerstein *et al*., 2018, p.3). Participation in the context of CBPR can include identifying the issue to be addressed; the design and delivery of the research; analysis of data; and dissemination of its findings.

Importantly, CBPR is an orientation to research and not a method. Wallerstein and colleagues (2018) draw on the work of Cornwall and Jewkes (1995) to explain that what is distinctive about the CBPR approach is not the methods, but the methodological contexts of their application: "the attitudes of researchers, which in turn determine how, by and for whom research is conceptualised and conducted" and "the corresponding location of power at every stage of the research process" (Cornwall & Jewkes 1995, p.1667, cited In Wallerstein *et al*., 2018, p.4). What matters, according to Wallerstein and her colleagues, is a partnership relationship between the researcher and the community being researched, alongside a commitment to redress power and privilege differences (Wallerstein *et al*., 2018). A researcher's positionality, reflectivity and engagement are therefore critical to the enactment of the research. This raises the importance of reflexivity, which, on an ongoing basis, led me to consider the different intersectionalities (Muhammad *et al*., 2014) I inhabited throughout my engagement in the research, between the TYA community, broader hospital, and my personal and academic world.

Community-Based Participatory Research centres on four domains – context, partnerships, interventions and health/social justice outcomes – within which four concepts are fundamental to CBPR: participation, knowledge democracy, power and Freirean praxis. A more detailed visual summary of a CBPR conceptual model can be found in Appendix 2. 'Praxis' (Freire, 1972) can be understood as 'informed action', arising from dialogue and critical reflection; the point of a Freirean type of dialogue being to inform actions that make a difference (Wallerstein *et al*., 2018).

Although a less commonly featured approach within qualitative research literature, young people's communities are considered a good fit for CBPR (Jacquez *et al*., 2013). A brief review of the existing literature in 2019 identified 59 international studies (1989-2019) focusing on CBPR projects in which community partners were children or young people. In August 2020, joined by one of the research's young associate researchers, I participated in a week-long virtual CBPR 'Summer Institute' at the University of New Mexico led by Professor Nina Wallerstein. As I began to learn more about CBPR, my interest in knowledge generation within the relational context of community deepened, and this remained with me as a point of curiosity throughout this research.

2.6.2 CBPR principles

Community-Based Participatory Research has become well established in North American health research. While it is a relatively new to UK research practice, the principles and ideological commitments are evident in both 'action' and 'participatory' research approaches (Wallerstein *et al*., 2018). What differentiates the two however are their historical roots: the more pragmatic fact-finding, action and reflection cycles of action research is usually attributable to the 1940s psychologist Kurt Lewin, whereas the more emancipatory approach to inquiry characteristic of participatory research and participatory action research often derives from educator Paulo Freire's liberatory work in 1970s Brazil (Wallerstein *et al*., 2018). These different approaches to CBPR vary in name, roots and underpinning theories; however, they share a set of core participatory principles first articulated by Israel and her colleagues in 1998 (Israel *et al.,* 2018), which are summarised below:

1. CBPR recognises community as a unit of identity and builds on the strengths and resources within the community
2. CBPR is participatory and collaborative, involving a power-sharing process that attends to social inequalities

3. CBPR involves partnership development and promotes co-learning and capacity building among partners.

The community-based component of CBPR originates from USA community public health practices, with its social justice basis creating commonality with other emancipatory research approaches. In North America, research with indigenous or more marginalised communities is often underpinned by a CBPR approach. Community-Based Participatory Research is inherently unrestrictive in character. Israel (Israel *et al.*, 1998) and Wallerstein (Wallerstein *et al.*, 2018) and their colleagues indicate flexibility may be required to apply and adjust the CBPR principles to different contexts. Moreover, it is not expected that all members of the community will contribute equally to all CBPR activities (Israel *et al.*, 2018; Wallerstein *et al.*, 2018).

2.6.3 My engagement with CBPR

From the outset, I remained receptive to developing understanding about how this research might successfully embody different elements of the more emancipatory research traditions that are associated with CBPR. The fact that CBPR as an approach had not been fully explored within UK research contexts made the endeavour more interesting. My starting point was recognition of the TYA cancer community as a unit of identity: one in which young people unite, yet may feel marginalised from others, from the broader cancer population and at times from wider society. Working within a CBPR approach, I proposed, would help ensure that the community remained central – both to the research and the knowledge that it generated.

Whilst CBPR is action orientated, ‘action’ is not just restricted to action phases. Its emphasis on iterative and dynamic learning implies consideration for the process of knowledge generation. I felt curious to know whether the research approach itself would contribute to changes in AC culture and practice, aside from any defined intervention, through different members of the TYA AC community being actively engaged in the research process.

2.7 My convening of a Community-of-Inquiry

Community-Based Participatory Research requires structures to centre and facilitate participation. A concept developed by Etienne Wenger (1998), and often associated with CBPR, is *communities-of-practice;* this describes groups of people who share a passion or concern for which they engage in a process of collective learning (Wenger-Treyer, 2015). More than a community of interest, argue Etienne and Beverly Wenger-Treyer (2015), community-of-practice members are practitioners, and this practice takes time and sustained interaction with the subject and each other (Wenger-Treyer, 2015). Keen to retain the underpinning values and structure of communities-of-practice, I did not believe that inclusion of ‘practice’ in the name, however, accurately conveyed the primary character, intent or purpose of our work. Noting a mainstreaming of participatory approaches (Hickey and Mohan, 2004), which may include the uncritical adoption of participatory language (Cooke and Kothari, 2001), I had heard *community-of-practice* referenced variously in health and business writing, often loosely framed, and I had concern that this might dilute the emphasis of our work. After deliberation and consultation with co-researchers, so as to place emphasis on augmenting knowledge that went beyond ‘practice’, the noun was substituted with ‘inquiry’ giving prominence to the community’s raison d'être.

2.7.1 Community-of-Inquiry membership

The intention had been to welcome, as members of the Community-of-Inquiry, up to eight young people who were well on treatment or who had completed cancer treatment (aged 16-24), three companions unrelated to the young people (e.g. a parent, partner, sibling), and two nursing staff from the TYA AC service. Joining me would be representation from charities Teenage Cancer Trust and Young Lives vs Cancer. Having formerly worked in the TYA service, yet unknown to community members in this context, I would become the facilitator of the group. Using charity collaborator Young Lives vs Cancer’s associate researcher role as a template, I developed a young associate researcher role outline in discussion with the charity (Appendix 3). Based on this, a role outline was developed for staff and companion associate researchers for which it was not expected that those who fulfilled the role would have experience of care at the research site.

Following targeted communication in January 2020 from Teenage Cancer Trust and Young Lives vs Cancer via their social media channels, together with posters and flyers on the TYA unit, I followed up each expression of interest with a telephone call to explore personal interests, areas of experience and hopes and expectations of involvement in the research. Whilst acknowledging that long term commitment might seem impractical or confining, it felt important that prospective co-researchers could envisage committing for a twelve-month period – to help promote cohesion and ensure that all members had been equally trained for their roles. Furthermore, as we had originally intended using in-person research methods and meeting face-to-face, geography was also relevant. Members needed to be willing to travel to London three times a year at a minimum (with expenses paid) and for those interested in leading interviews, more frequently during this aspect of field work.

2.7.1.1 Young associate researchers

Ten young people initially expressed interest in the young associate researcher role, with eight young people aged between 19 and 25 (6 female, two male) joining. Seven of the co-researchers lived in London or the South East of England; two people were studying in Wales; and one person lived in the North East of England. Apart from one young adult who was working full time, all the other young associate researchers were studying when they first joined the Community-of-Inquiry. Five had completed cancer treatment, two were on oral medication management and one young person described themselves as still receiving cancer therapy. Motivations to get involved were personal, yet coalesced around gaining new skills, experience of research methods and wanting to make a genuine difference in the field of young people's cancer. Except for one co-researcher who had accessed care (blood tests) on the research site for a brief period whilst they were studying, no others had experience of care at the research site.

To encourage interest from those who identified as male, and other less represented groups, in February 2020 other national TYA cancer groups were contacted. This resulted in me welcoming a male who had just turned 25 years old. Given that representation is a recognised challenge of user involvement more broadly (NIHR, 2019), although efforts to promote greater diversity continued via word of mouth and charity partners' social media platforms, by the beginning of June 2020, once the Community-of-Inquiry had stabilised its core membership, this was no longer pursued.

2.7.1.2 Associate co-researchers: companions

Four associate companion co-researchers expressed interest in joining the Community-of-Inquiry (three mothers, a father and a partner) with three companions joining the group (two mothers and a father) contributing diverse perspectives. The two mothers had some experience of the research site, primarily in different clinical settings to the AC service.

2.7.1.3 Associate co-researchers: staff

Involving associate co-researchers from the AC nursing team was more challenging. Whilst there was keen interest from a clinical nurse specialist and a staff nurse, the pressures of the pandemic meant that realising commitment became more difficult. It was not until October 2021 that a member of the AC nursing team was able to join the Community-of-Inquiry to participate in data analysis.

2.7.1.4 Charity membership

There were two charity stakeholder members who participated from a less embedded perspective. One was a charity-funded lead nurse with previous experience of AC at the study site who represented Teenage Cancer Trust, the other was the research and policy lead from the charity Young Lives vs Cancer. Their engagement became more advisory and consultative than originally intended (again due to the pandemic and the need to re-prioritise commitments).

2.8 Timeline and objectives

The Community-of-Inquiry was established by March 2020, with the second male joining three months' later. Our first Community-of-Inquiry meeting took place virtually in April, having originally been planned as an in-person event. Our primary purpose was to get to know one another, and for me to share the aims of this research. More formally, the meeting had four initial objectives:

1. To provide orientation to the research study, its methodology and the principles of participatory research;
2. To consider, discuss and then informally contract the role and responsibilities of a Community-of-Inquiry member;
3. To offer a sense of the project by experiencing a 'taster' of the proposed visual research methods;
4. To consider preparatory training needs and areas of personal interest in the research.

In subsequent weeks I engaged with co-researchers one-to-one or on a smaller group basis. We refined the study methods and design, whilst I was supporting the pandemic response in my clinical role. During this time a co-researcher set up a secure messaging programme (Slack Technologies) to share information and help foster cohesion within what became, for the next 18 months, a virtual research team.

There were other aspects that I needed to consider with respect to the Community-of-Inquiry which included attrition in membership due to illness or conflicting priorities or perceived power-imbalances which might affect co-researchers' capacity to contribute. Communities are not static entities, and so, specifically thinking about attrition, I initially welcomed eight young to the Community-of-Inquiry. Teenage and young adult years can be characterised by a state of flux, even without an illness experience, and I had anticipated that attrition in membership might be high. By the time that field work started in earnest, three young people had stepped away: two due to health reasons, and a third with whom I lost contact once they had started full-time employment. From December 2020 until the research closed, core membership stabilised at five young associate researchers, two companion associate co-researchers and me. Staff, charity and academic participation in the research continued from a less embedded perspective.

2.8.1.1 A working agreement for practice

A working agreement for our engagement together resulted from our initial Community-of-Inquiry meeting, detailed in Appendix 4. Also arising from this meeting was the potential that being so actively involved in the research methods might resonate personally for some co-researchers, with the potential for this to feel emotionally challenging. Alongside my commitment to supporting co-researchers through informal supervision, I set up an agreement with the hospital's TYA psych-oncology team that they would offer trained psychological support to co-researchers if it became needed.

2.1 Ethical considerations related to working in communities

Research ethics is a subject area that traditionally covers consideration of the harms and benefits of research, the rights of participants to information, privacy, and anonymity, and the responsibilities of researchers to act with integrity (ICPHR, 2013b). Participatory research embeds this standard yet requires a consideration of ethics that extends beyond procedural expectation to encompass ethics of care (Tronto, 1998). Participatory research, therefore, in addition to legal or procedural ethics, demands consideration of the relational responsibilities inherent in engaged research, with regard for the interplay and complexity of human relationships in this context (ICPHR, 2013b).

The ICPHR (2013b) has developed a set of ethical principles, promoting standards such as those that relate to qualities of character, and the responsibilities attached to relationships. These principles were consulted, and the ICPHR 'ethical principles, practice principles and guideline' informed the development and enactment of this research. Rather than write a separate section to describe the study's ethical considerations from a relational perspective, throughout this thesis I describe how these principles were constituted. Notwithstanding this, the Health Research Authority and NHS Research Ethics Committee expect that specific legal and governance aspects of research ethics are identified and explicated, and the key aspects are detailed in Chapter 4. Specific to the community-of-Inquiry, however, there were several considerations that associated with my convening and facilitation of this community of co-researchers, and I outline the main aspects below.

2.1.1 Safeguarding

Demonstration of appropriate and proportionate steps to safeguard prospective research participants was required, for which I took advice from my clinical employer's safeguarding team. Co-researchers would, it had been envisaged from the outset, be meeting under my supervision with research participants one-to-one. To ensure appropriate governance, I organised through my employer's voluntary services department that young associate researchers and associate co-researchers would be formally appointed into voluntary co-researcher roles. Once the exact nature of their involvement with patient and family participants was determined, Enhanced Disclosing and Barring Service (DBS) and standard DBS checks were processed on a voluntary basis for the young associate researchers and associate co-researchers respectively. Although I had an Enhanced DBS check in place that met my employer's requirements, a repeat application was processed in 2020, which I updated annually thereafter.

2.1.2 Co-researcher training

With consideration for the well-being and safety of those involved in the research as co-researchers (as well as those taking part as study participants), there is an expectation from UK Research Ethics Committees that any public member should have adequate training, support and supervision considered appropriate and proportionate, as would be expected for any member of a research team (HRA/INVOLVE, 2016). I developed a co-researcher training programme in collaboration with a participatory researcher I had approached, drawing on his expertise of developing a youth commissioning model. We determined that the preparation of co-researchers would focus on a series of workshops, helping to ensure that co-researchers would be safe and feel confident to engage in the co-researcher role. The resulting programme comprised four 90-minute workshops between October 2020 and January 2021, delivered online every 4-to-6 weeks on a weekday evening. An overview of each workshop session is detailed in Appendix 5.

2.1.3 Co-researcher recognition

Inherent to democratic participation is the recognition of those who contribute. Recognition took many forms, including letters of support, or references. In addition, financial acknowledgement was expected by the NIHR, the funder of this research, and had been costed within the grant award working with what had been HRA/INVOLVE (2016) expectations at the time. Using the budget allocated as a basis, a recognition framework (Appendix 6) was developed in consultation with co-researchers, so that it was clear from the outset how the time, skills and experience that they contributed to the research would be acknowledged, separate from the reimbursement of any personal costs incurred (e.g. travel, materials or refreshments). There remains no absolute guidance about suitable monetary amounts to recognise co-researcher participation (NIHR, 2022), although there is advice that receiving payments received could be considered earnings which might have tax implications for some people. Following discussion with co-researchers about their circumstances and preferences, a decision was made to offer gift and shopping vouchers to recognise commitment, with co-researchers offered a choice between two providers on each occasion that recognition was due.

2.1.4 Other considerations

More broadly, the ethical principles underpinning CBPR emphasise democratic participation in the research process (Centre for Social Justice and Community Action (CSJCA), 2012). Enacting democratic participation in practice involves meaningful contribution to decision making, and the use of methods that build on the interests of co-researchers (CSJCA), 2012; ICPHR, 2013b). It requires working towards more equal sharing of power. Alongside this, when working within the principles of participatory research and CBPR (CSJCA, 2012; ICHPR, 2013a), principles such as mutual respect; equity and inclusion; integrity; co-learning and working together to achieve positive change for the community become relevant.

2.2 Chapter summary

This chapter has focused on the theoretical underpinnings of this research highlighting a participatory orientation to the research process and the constitution of knowledge. The resulting research foregrounded Community-Based Participatory Research as an approach to generate new knowledge about experiences of TYA AC, a topic with a limited evidence base, yet well-grounded in the community's interests. Whether this research would be able to authentically uphold principles of CBPR could not be determined in advance; thus, the methodological journey also became integral to the research inquiry.

Community-Based Participatory Research is based on a commitment to sharing power, resources and developing knowledge in a participatory context. To structure and facilitate the participation of community stakeholders, a Community-of-Inquiry was convened, in which the research was rooted and driven. The processes that were involved in my establishing of the Community-of-Inquiry have been set out. Beyond procedural and institutional ethics, there were considerations specific to the participatory ethos that I needed to consider; key aspects have been summarised in this chapter. As described, the preparation of co-researchers was seen as critical to the roles they would fulfil, fostering competence, mutual support and confidence, whilst ensuring ethical research practice.

At the timepoint when I was convening the co-research community, I undertook a scoping review of the AC literature. This is the focus of the next chapter and I return to the theoretical underpinnings of the research in Chapter 4, where I present the study design, methods, sample and recruitment.

Chapter 3 A Scoping review of the literature

3.1 Introduction

In writing the fellowship proposal for this research in 2018, I found the Ambulatory Care literature was disparate across academic and professional sources with only a few primary research studies reported. Research published in the field focused almost exclusively on the feasibility and safety of the care pathway with little inquiry into patient experience beyond functional appraisal of 'satisfaction'. I determined that as a starting point, a scoping review of the literature would establish a more composite understanding of patient and provider experiences of TYA AC.

A scoping review of the literature was undertaken to explore the AC evidence base with respect to experience of care, whilst building understanding about the pathway's philosophical, operational and commissioning foundations. The first section of this chapter describes the scoping review methodology and its application to this review. The results are presented, then subsequently discussed, and implications for research are stated.

3.2 Scoping Reviews

A scoping review is a form of evidence synthesis (Munn *et al.,* 2022) that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to an emerging area or field. This occurs by systematically and iteratively searching, selecting, summarizing and potentially synthesising existing knowledge (Colquhoun *et al.*, 2014). Scoping reviews are becoming relatively common, particularly in health fields (Pham et al., 2014). Designed to map the literature in a field of interest (Peters *et al*., 2021), a scoping review can be undertaken either as a forerunner to undertaking a systematic review, or as a comprehensive review process.

Unlike a systematic review, the scoping method involves the identification of both research and other material (Arksey and O'Malley, 2005). Scoping reviews classically provide a broad overview of the reviewed material without formal quality appraisal (Pham *et al.,* 2014). Within a health topic known to have a disparate evidence base, and in mapping the emergence of Ambulatory Care as a unique kind of healthcare culture, casting the net wide was useful for capturing both the genesis and complexity of this service model.

3.3 My approach to this scoping review

Being familiar with some, but not all the AC literature, the scoping methodology facilitated orientation to both the breadth and detail of the literature base, enabling full consideration of the questions posed. Committed to undertaking a scoping review demonstrating “procedural and methodological rigour in its application” (Davis, Drey and Gould, 2009, p.1398), I set out to ensure that the search and retrieval process provided the transparency and detail for it to be replicable. It drew on ‘all of what was known’ to answer the review questions, and to refine my research inquiry.

I refer to the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco *et al*., 2018), to structure my presentation of the review (see Appendix 7). Although not expected within the scoping review methodology, I decided to refer to a hierarchy of inquiry developed by Davis, Drey and Gould (2009), as detailed in Appendix 8 to support me to engage more critically in the review process. My brief appraisal of this is discussed in the concluding section of this chapter, alongside more general strengths and limitations of this scoping review.

Consistent with the scoping review methodology, I did not attempt to weight and formally appraise the strength of each individual study’s evidence. Instead, I refer to the GRADE (Grading of Recommendations, Assessment, Development and Evaluation) criteria (NICE, 2012) to frame my discussion of the literature where, for instance, the make-up of a study population, or limitations in the study design may affect consideration of the findings.

3.4 Scoping review aim and review questions

The scoping review of ambulatory cancer care was undertaken with a clear purpose, namely: “To provide a panoramic and intellectual overview of what is currently known … [drawing] attention to areas where there are prominent knowledge gaps” (Davis, Drey and Gould, 2009, p.1396).

Reporting chronologically, the review began by mapping the ‘storyline’ of the development of AC services before focusing on experience of care. Adult, child and TYA ambulatory cancer services were included within the search and selection strategy with the express intent of mapping the full scope of the field.

Three review questions were developed to build incremental evidence and understanding:

1. What were the drivers that informed the development of Ambulatory Care in the UK?
2. How does Ambulatory Care meet the needs of patients (of all ages), and how does it contribute to their experience of care? *
3. What is the potential for Ambulatory Care to support delivery and receipt of age-appropriate care within teenage and young adult cancer services? *

Review questions 2 and 3 (*) also formed part of a narrative synthesis registered with PROSPERO (the International Prospective Register of Systematic Reviews) in February 2020 (registration number CRD42020167756).

3.5 Scoping review methodology

Unlike a systematic review, the scoping method involves the exploratory and iterative mapping of literature in a field, inclusion of unpublished literature, typically no quality assessment of included studies, and a consultation phase (Arksey and O’Malley, 2005; Levac *et al.,* 2010; O’Brien *et al.*, 2016). Scoping reviews do not entail the exclusion of articles based on the quality of research methodology (Khalil *et al.*, 2016), yet within this broad and iterative framework, demonstration of rigour is an expected part of the review method (Peters *et al.,* 2021).

Arksey and O'Malley's (2005) original six-stage methodological framework for conducting scoping reviews involved: identifying the research question; searching for relevant studies; selecting studies; charting the data; collating, summarising and reporting the results; and optional consultation with stakeholders to inform or validate study findings. In 2010, modifications were proposed to enhance the rigour, clarity and application of the review process (Levac *et al*., 2010). The scoping review methodology was then further refined, and corresponding guidance developed by a working group from the Joanna Briggs Institute (JBI) and JBI Collaboration (Peters *et al.* 2020). Both frameworks (Levac *et al*., 2010, Arskey and O'Malley, 2005) and the JBI guidance (Peters *et al*., 2021) underpinned my approach to this scoping review. A summary of the defining characteristics of the evolving scoping review methodology is detailed in Appendix 9.

The review began with the development of a working protocol with inclusion and exclusion criteria that related directly to the three review questions. The Population, Concept and Context (Peters *et al*., 2020) were defined, working with the definition of Ambulatory Care previously outlined in Chapter 1, section 1.2. Thereafter, the search strategy was developed for the review and checked with a clinical librarian. To comprehensively explore the scope of the AC field, all types of published and grey forms of literature were eligible for inclusion from database inception until September 2019 if published in English or a Latin script. Adult, child, teenage and young adult ambulatory cancer services were included. Working with the same search strategy, an updated search was undertaken on the 20 June 2020, and then again on the 22 April 2022, to account for new publications. The reference lists of included studies were reviewed to identify additional papers that could be relevant. As well as key author searching, citations within articles were also searched and captured for review using the snowball technique (Naderifar, Goli and Ghaljaie, 2017). Title and abstract relevance screening were undertaken, and a second reviewer became involved thereafter, who, working with the agreed inclusion and exclusion criteria, completed a test of relevance amongst all records selected for full text review.

3.5.1 Consultation exercise

A recommended component of the scoping methodology is a consultation exercise (Levac *et al.,* 2010). This was undertaken in parallel to the synthesis of the literature and comprised a conversation with six healthcare professionals considered critical to the development or delivery of AC. It followed a topic guide and involved sharing findings from the literature with the purpose of bringing insight and additional perspectives (Levac *et al.,* 2010). The consultation helped inform the ensuing review and analysis by offering conceptual clarity and/or indications of complexity within a topic area with a limited evidence base. NHS Ethics and Health Research Authority (HRA) review was not required for this consultation process. Steps were taken to ensure that professionals approached, understood how their contribution would be presented, and all willingly engaged in the exercise. Although not taken up, each professional was given an opportunity to read the review in draft form.

Whilst most professionals preferred to waive their anonymity (Grinyer, 2002a), a decision was taken to refer to each person by role only, whilst taking account of the fact that some individuals might be identifiable, based on their contribution. The professional roles of the six professionals who participated in the consultation exercise are detailed in Appendix 10. Except for one individual, all others professionally contributed to the development of ambulatory services at UCLH.

3.5.2 Evidence synthesis

The scoping review initially categorised and descriptively reported literature from a wide range of academic and ‘grey’ sources. A narrative synthesis (Boell and Cecez-Kecmanovic, 2014) was then applied to the review, moving beyond description of findings and outcomes towards a critical analysis and interpretation of the literature. Each section of the review integrated narrative from the consultation exercise to help explain and contextualise findings. The review also drew on my own practice-based knowledge (Thorne, 2016), to provide factual context to the pathway development at UCLH. I took a reflexive attitude towards my pre-existing familiarity with much of the AC literature.

This hermeneutic approach to synthesis of the literature (Boell and Cecez-Kecmanovic, 2014) worked with a framework that they describe "as "fundamentally a process of developing understanding that is iterative in nature" (Boell and Cecez-Kecmanovic, 2014, p.257). Embedded within the scoping review process, it integrated the analysis, interpretation and search for new literature within two hermeneutic circles of inquiry: a search and acquisition circle and a wider analysis and interpretation circle that built on one another (Appendix 11). It extended the categorisation, comparing, contrasting and synthesis inherent in scoping review methodology (Colquhoun *et al*., 2014), to more critical engagement, in a manner that considered the relationship of each individual reference to the emerging whole body of AC literature.

3.6 Literature sources and search strategy

3.6.1 Literature sources

The review compiles literature from a wide range of sources to answer the review questions posed. Nine academic databases were selected across the fields of medicine, social science, nursing, psychology and healthcare (Medline, CINAHL Plus, SCOPUS, Embase, Web of Science, British Nursing Index (BNI), Psych INFO, Applied Social Sciences Index and Abstracts (ASSIA) and International Bibliography of the Social Sciences (IBSS), utilising their entire cataloguing date fields. I consulted a clinical support librarian to help inform database selection in relation to the review topic. A manual search was undertaken across the National Institute for Health and Care Excellence (NICE), the International Prospective Register of Systematic Reviews (PROSPERO), the University of York Social Policy Research Unit, Cochrane, Google websites. A hand search was undertaken of policy, guidelines and meeting minutes at the research study site who had introduced AC, for evidence or information related to Ambulatory Care.

3.6.2 Search strategy

The nomenclature “ambulatory care” can often refer to standard day care hospital services within the UK and internationally. When building the search strategy, it proved difficult to restrict the focus of the search to the UK definition of *Ambulatory Care*.

The initial search strategy was built in OVID Medline and checked with a specialist librarian for consensus and advice. The search strategy was then employed across each database, with modifications where necessary according to the configuration requirements of each database. The strategy was built around keywords and subject headings taking account of the different synonyms for *Ambulatory Care*, including both North American and English spellings. Search terms and subject headings were combined using Boolean operators with results limited by title or abstract. Full use of wildcards, nesting of terms and parentheses alongside phrase searching and adjacency spacing (e.g. ‘outpatient ADJ1 administration’) were used where possible to refine the citations each search yielded.

Table 3-1 depicts the main subject headings and search terms used across each database search with Appendix 12 detailing the full search strategy for each of the nine databases. The same keywords and search terms were used to search the websites for relevant grey literature.

Table 3-1: Subject headings and search terms employed across each database

Search terms:	ambulatory care, ambulatory cancer care, ambulatory pathway, chemotherapy AND outpatient, outpatient administration
Subject headings:	‘Cancer’, ‘haematology’, ‘oncology’, ‘neoplasm’ and ‘haematopoietic transplant’ (and its various associated terms) were the key subject fields taking account of North American and UK English spelling differences

3.7 Citation management and selection process

3.7.1 Citation management

During the initial search of the literature in 2019, a total of 2,853 citations were exported to Endnote X9 and later EndNote 20 (Clarivate Analytics). The search strategy was re-run within each of the nine databases on the 29 June 2020, generating 132 new citations for screening. Six new citations were imported into Endnote X9 (Clarivate Analytics) for full-text review. On 22 April 2022, when the search was run again, this generated 157 new records and resulted in the inclusion of two papers that had been identified through citation searching. Duplicates were removed in all three searches (n=917 in 2019, n=14 in 2020, n=11 in 2022) and through further manual removal where required during title screening (n=12). Additional records were identified through hospital sources (n=3), citation searching (n=6) and the consultation exercise (n=6). After duplicate records were removed in all three searches, a total of 2203 records remained for title level screening.

3.7.2 Citation selection

The search and selection process I undertook is detailed in the PRISMA decision flow chart (Figure 3-1) which combines the results of all three searches. Citations were exported to Endnote X9 (subsequently Endnote 20) where title and abstract relevance screening were undertaken, working with the inclusion and exclusion criteria (

Table 3-2). Given the diversity of AC definitions, I also worked with my clinical knowledge to screen and filter relevant publications. In becoming more familiar with the literature, 'post-hoc' exclusion criteria were added (Levac *et al.*, 2010); so that reference selection became more relevant and refined. Google Translate was used to undertake an initial screen of titles and abstracts not published in English to assess their relevance before making requests for full-text publications.

Records identified for full-text review were shared with an independent reviewer [supervisor RT] who, working with the agreed inclusion and exclusion criteria, completed a test of relevance amongst all full text records selected for both inclusion and exclusion. Where there was no consensus, these records were shared with a named clinician in the field for their independent review and two records were reintroduced on this basis.

Table 3-2: Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Cancer-related treatment or care that is usually given in an inpatient setting All publications and responses directly related to delivery or receipt of Ambulatory Care that: • Describe the context within which AC has been introduced • Describe the drivers for service introduction • Describe theoretical literature which speaks to the AC service • Consider the philosophy underpinning the service • Report the experience of service users • Report the benefits and challenges of the service • Allow consideration of common features across AC services	Non-cancer focused Refer to standard day care, outpatient or domiciliary services Refer to surgical management of cancer/surgical pathways Refer to a community coordinated ambulatory care service (i.e. not hospital led) Focus is palliative care Exclusive focus on medication safety or pharmacology Management of neutropenia in a home setting Focus on cancer screening, pre-diagnosis or cancer prevention Report clinical, toxicity, safety, or efficacy outcomes uncontextualised to patient experience or wellbeing Thromboembolism or its prevention Exclusive focus on myeloma, breast, urological, prostate or lung cancer patients or services Primary focus on staffing or workforce requirements

Papers were sourced via UCL Explore, NHS Athens or through a British Library interlibrary loan request. Every effort was made to obtain conference abstracts and foreign language publications, with only one full text paper unobtainable (and subsequently rejected on this basis). If they met the inclusion criteria, conference abstracts were taken through to final full text review, as they form part of the chronology of Ambulatory Care's development.

3.8 Summary of results

A total of 3,142 records were identified through database searching, of these 2,853 were identified in the initial search in 2019, and 132 and 157 new records were added following the subsequent searches in 2020 and 2022. After duplicates had been removed this totalled 2,188 unique records to which a total of fifteen records were added that had been identified through other sources: hospital documents (n=3); consultation exercise (n=6); reference lists of full-text records screened (n=6). The number of full-text records assessed for eligibility totalled 105, from which 48 records were subsequently excluded. The scoping review of the AC literature thus comprised a total of 57 records as detailed in Figure 3-1.

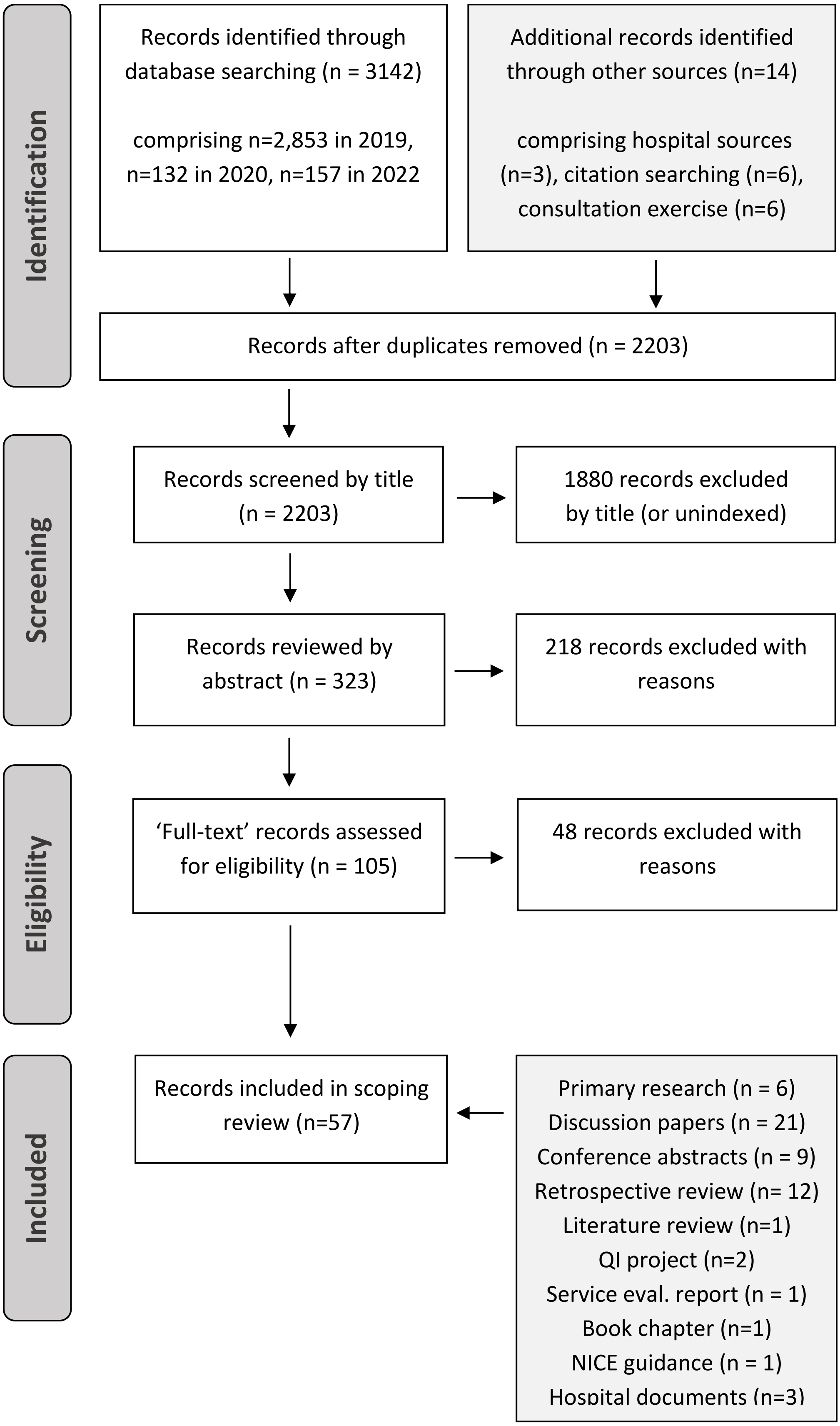

Figure 3-1: Scoping review of the Ambulatory Care literature: search decision flowchart

3.9 Characteristics of the Ambulatory Care literature

The full range AC literature included (n=57) covers the chronological period 1979-2022. The distribution of published literature (n=51) is presented by date and geographical source origin in Figure 3-2 and Figure 3-3 respectively. Dominant countries of source origin were the USA (28 records) and the UK (17 records). Amongst the 38 academic journal publications included, just three reported primary research outcomes; the majority provided descriptive accounts of AC services. Twelve of the 17 publications (which included published conference abstracts) from the UK were from UCLH, with Sheffield Teaching Hospital being the other NHS organisation to have published their experience (Nield *et al.*, 2012).

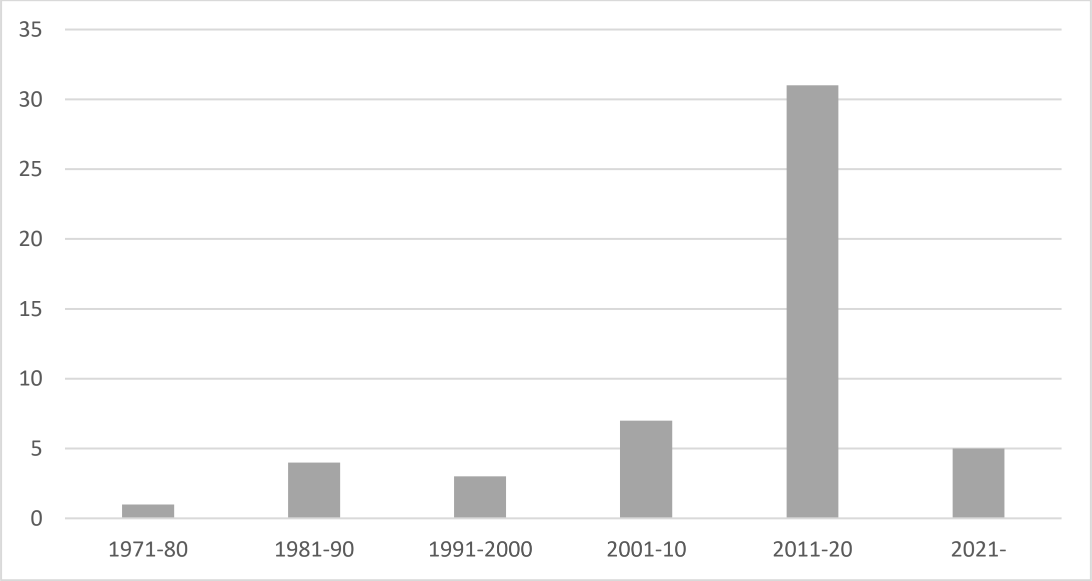

Figure 3-2: Distribution of published literature by chronological date

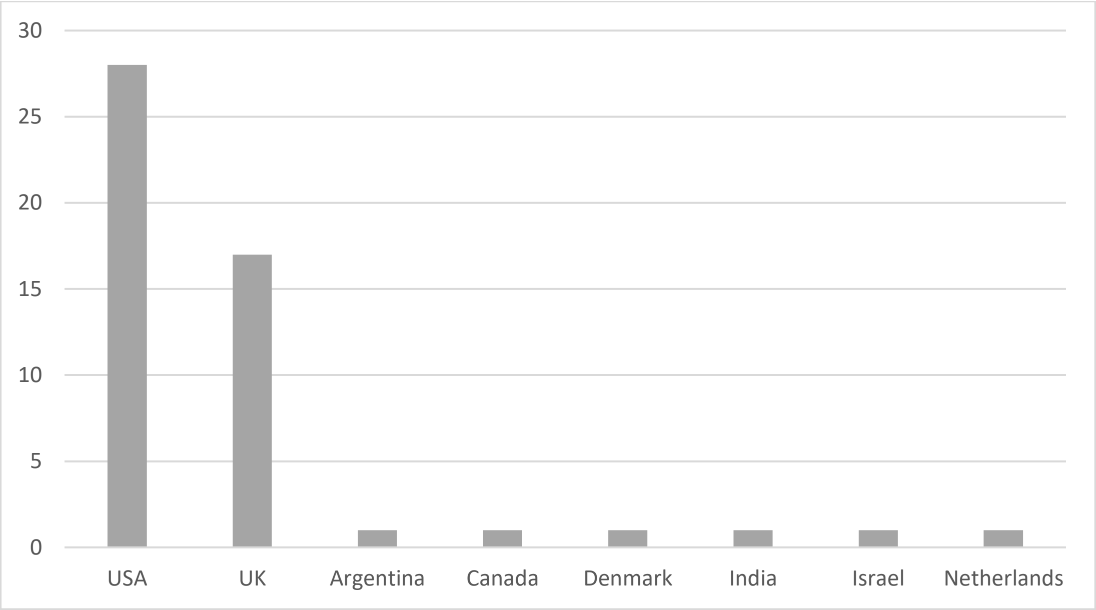

Figure 3-3: Distribution of published literature by geographical origin

3.9.1 Primary research

Six papers were categorised as primary research, comprising three academic publications (Tighe *et al.* 1985; Nissim *et al*., 2014; Grimm *et al.,* 2000) and three research dissertations (Statham, 2005; Morrison, 2010; Mcmonagle, 2015). Characteristics and study methods are presented in Appendix 13 and comprise qualitative interviews (n=4); questionnaires (n=1), and instrument measurement (n=1). Amongst the studies, two focused on nursing practice in Ambulatory Care (Tighe *et al*., 1985; Morrison, 2010). Among the other three research studies, Grimm and colleagues (2000) explored the role and needs of caregivers whereas Statham (2005), Nissim and colleagues (2014) and Mcmonagle (2015) explored the experiences of AC patients.

3.9.2 Retrospective data studies

Twelve publications were categorised as retrospective studies that report analyses of existing health services data, characteristics of which are detailed in Appendix 13.

Published between 2008 and 2021 with one outlier from 1982, each review emphasised demonstrating feasibility, safety, clinical outcomes and efficiencies associated with the AC pathway within differing international settings (Rosen and Nirenberg, 1982; Zelcer *et al*., 2008; Bakhshi, Singh and Swaroop, 2009; Mahadeo *et al.,* 2010; Sive *et al.,* 2012; Graff *et al.,* 2015; Reid *et al.,* 2016; Villegas *et al*., 2017; Fridthjof *et al.*, 2018; Li *et al*. 2021a; Li *et al*., 2022b). All studies were undertaken from the perspective of analysing clinical rather than patient-reported outcomes within which five describe children's services.

3.9.3 Conference abstracts

Typically, conference presentations are delivered by clinicians, disseminating clinical experience critical developing understanding of practice, that may otherwise remain unpublished in peer reviewed journals. Nine conference abstracts met the inclusion criteria, published between 2012 and 2019 (Bates and McMonagle, 2012; Nield *et al*., 2012; Allen *et al*., 2013; Ingram *et al*., 2013; Breen *et al.* 2016; Overbeek, Vos and Koene, 2016; O'Reilly, Finch and Soanes, 2017; Glincher, Lin and Durney*,* 2018; Ingram and Smith, 2019). Four abstracts centred on adult patient populations (Bates and McMonagle, 2012; Nield *et al*., 2012; Allen *et al*., 2013; Overbeek, Vos and Koene, 2016) and three service design and delivery (Bates and Mcmonagle, 2012; Ingram *et al*., 2013; O'Reilly, Finch and Soanes, 2017; Ingram *and Smith*, 2019). Two abstracts, Breen and colleagues (2016) and Overbeek, Vos and Koene (2016) explored caregiver education which they describe as critical to safety in the ambulatory cancer setting. Several abstracts described the role of experienced cancer nurses in helping to establish and innovate within the AC field (Bates and Mcmonagle, 2012; Ingram *et al*., 2013; Breen *et al.,* 2016; Overbeek*,* Vos and Koene, 2016; Glincher, Lin and Durney*,* 2018; Ingram and Smith, 2019). Conference abstracts did not report primary research activity.

3.9.4 Other literature and records

There were two qualitative improvement projects (Beaty *et al.,* 2015; Ranney, Hooke and Robbins, 2020), a service evaluation (Brown and Walker 2016) and a form of literature review (Richie, 2005), see Appendix 13. The remaining literature comprised published discussion papers (n=21) which focused on the AC context, setting up of AC services or professional accounts of the benefits or challenges of the care model (Appendix 14). In addition, there was a published guideline (NICE, 2016), a book chapter (Mcmonagle, 2018) and local hospital documents (n=3) which comprised an operational policy (Statham and Stivala 2008), patient questionnaire responses (UCLH, 2012), and an AC case study manuscript (Statham, 2012) (see PRISMA, Figure 3-1).

3.10 Discussion

The narrative synthesis of the literature integrated with the consultation findings facilitated the identification of four themes that reflected the drivers for the development of AC: *financial drivers*; *optimisation of bed capacity*; *advances in technology and supportive care*, and *professional motivation to improve cancer experience*. The resulting synthesis of the literature presents a critical, yet descriptive analysis.

3.11 Exploring the results in relation to scoping review Question 1: Drivers that informed ambulatory care service development in the UK

The main driver for the development of AC in the UK was usually understood to be the ability to increase cancer treatment capacity (Sive *et al.,* 2012; Brown and Walker, 2016). A body of work confirmed the safety of the pathway (Zelcer *et al*., 2008; Mahadeo *et al*., 2010; Sive *et al.,* 2012; Anderson *et al*., 2013; Villegas *et al*., 2017; Ranney, Hooke and Robbins, 2020), but there was less literature about the context and the individual storyline of AC's development, something that this review aimed to address. When interpreting the chronology of the review findings context becomes important: many treatments that used to require prolonged hospitalisation are now routinely given on a day care basis. This literature, whilst helping inform understanding about the drivers for AC, is not necessarily reflective of contemporary AC practice. Shifts in societal thinking on more actively engaging with health- and self-care have also evolved considerably over the last three decades – the period this review covers.

3.11.1 Financial drivers

Practitioners working in the UK's first AC service often described a site visit to Memorial Sloan Kettering Cancer Center (MSKCC), New York in the early 2000s as the precursor to piloting ambulatory cancer care in the UK (Kelly, 2005). Ambulatory Care as a concept was conceived in the USA where, by 1995, significant progress had been made to shift inpatient cancer treatment to outpatient and ambulatory pathways (Nirenberg and Rosen, 1979; Rosen and Nirenberg, 1982; Schulmeister, 1991; Mikhail, Swint and Kurtin, 1995). According to Schulmeister (1991), AC became something of a misnomer, as non-ambulant patients also accessed services.

"A very expensive venture" (Moore, Arnall and Plesca, 2018, p.1824), cancer and its treatment comes at a cost in the USA, borne either personally, by one's insurance provider, or government funded programmes such as Medicaid or Medicare to help people on low or no income. Within this context, efficiencies in care can be seen as one of the key drivers influencing the development of AC in the USA. These efficiencies centre on treatment cost reduction (Esparza, Young and Luongo, 1989; Bakhshi, Singh and Swaroop, 2009; Allen *et al*., 2013; Glincher, Lin and Durney, 2018, Moore, Arnall and Plesca, 2018) or cost containment (Schulmeister, 1991).

Ambulatory Care is cheaper than an overnight hospital-stay primarily due to reduced staffing and inpatient overheads (Sive *et al*., 2012). In their literature review of outpatient autologous haematopoietic stem cell transplant (AHSCT), Richie (2005) noted how the cost of AHSCT drove the ambulatory model in the USA and Canada. Efforts to demonstrate safety and feasibility of AC in Argentina, amongst what the authors describe as a poorly resourced population (Villegas *et al*., 2017), cite reduced cost as the driver for, and the associated benefit of the pathway. It is not clear however from the literature who the intended beneficiary is within this drive for reduced healthcare costs: the provider, the individual requiring treatment, or the wider system.

3.11.2 Optimisation of bed capacity

Rather than cost savings, the UK literature described a lack of inpatient beds to ensure delivery of timely cancer treatment as the main contributing factor to AC's development (Kelly, 2005; Richie, 2005; Bates and Mcmonagle, 2012; Sive *et al*., 2012; Comerford and Shah, 2019a). Sive and colleagues described the opportunity to increase treatment capacity as the impetus for establishing AC within the UK at UCLH in 2004 (Sive *et al.,* 2012). Here, an additional 1443 adult cancer treatment episodes were successfully delivered via AC across the 6-year period 2005-2011, avoiding treatment delays, maximising treatment outcome, and freeing up hospital beds for acutely unwell patients (Sive *et al*., 2012). Within other international, non-USA literature, avoiding delays in treatment due to limited bed capacity was also described by Bakhshi, Singh and Swaroop (2009) as one of the drivers for piloting the ambulatory model to give consolidation chemotherapy to paediatric haematology patients in India.

3.11.3 Advances in technology and supportive care

The first published examples of AC originate from the US four decades ago and involve the administration of high-dose methotrexate (HDMTX) (Nirenberg and Rosen, 1979; Rosen and Nirenberg, 1982; Esparza, Young and Luongo*,* 1989). Other clinicians followed, demonstrating the safe ambulation of HDMTX, typically used to treat osteosarcoma or acute leukaemia (Zelcer *et al*., 2008; Mahadeo *et al*., 2010; Anderson *et al*., 2013; Villegas *et al*., 2017; Ranney, Hooke and Robbins, 2020).

Confidence in the safety and efficacy of the pathway has extended the AC treatment portfolio in some larger cancer centres to include other high-dose chemotherapy (Corrigan Wandel *et al*., 1990; Kelly, 2005; Richie, 2005; Bakhshi, Singh and Swaroop, 2009; Sive *et al.,* 2012; Nissim *et al*., 2014; Beaty *et al*., 2015; Ingram, 2017; Comerford and Shah, 2018; Fridthjof *et al*., 2018; Mcmonagle, 2018; Li *et al.* 2021a; Li *et al*., 2021b). Autologous haematopoietic transplant (Grimm *et al*., 2000; Ganzel and Rowe, 2012; Sive *et al.,* 2012; Newton and Ingram, 2014; Reid *et al*., 2016; Comerford and Shah, 2018), allogenic haematopoietic transplant (Grimm *et al*., 2010;

Solomon *et al*., 2010; Ganzel and Rowe, 2012; Sive *et al*., 2012; Comerford and Shah, 2018) and more recently, new modalities of care including chimeric antigen receptor T-cell (CAR T) therapy (Pirschel, 2019; Borogovac *et al*., 2021; Cunningham *et al*., 2021; Myers *et al*., 2021) are also being managed on an ambulatory basis.

Alongside the drive to bring about healthcare efficiencies in response to lower inpatient bed availability or increased inpatient costs (Moore, Arnall and Plesca, 2018), advances in technology and supportive care medications have also influenced the transition of historically inpatient chemotherapy treatment into the ambulatory setting. The creation of portable infusion pumps in the 1960s paved the way for safer treatment delivery, and when they became more commercially available in subsequent decades, they enabled infusion of chemotherapy, supportive medication and/or hydrating fluids on an ambulatory basis (McKeag, 2015; Mcmonagle, 2018).

Eleven publications cite portable infusion devices, programmable to give continuous as well as intermittent infusions, as a key influencer in the drive to pilot Ambulatory Care (Schulmeister, 1991; Mikhail, Swint and Kurtin, 1995; Kelly, 2005; Anderson *et al*., 2013; Newton and Ingram 2014; McKeag, 2015; Ingram, 2017; Comerford and Shah, 2018; Fridthjof *et al*., 2018; Mcmonagle, 2018; Moore, Arnall and Plesca, 2018). Transitioning chemotherapy to an AC regimen usually requires protocol adjustment to ensure drug stability (Comerford and Shah, 2019b) and sequencing so that treatment can run safely with minimal intervention (Ingram, 2017), enabling patients to take care of the infusion progress and monitoring requirements themselves.

Whilst the potential to make use of portable infusion technology in the ambulatory setting has been an option since the late 1970s (Nirenberg and Rosen, 1979), treatment related toxicities (such as those seen with HDMTX, ifosfamide, cisplatin or cytarabine) in conjunction with chemotherapy induced nausea, vomiting, and myelosuppression of the immune system, meant that inpatient treatment remained the mainstay. It was the development of haematopoietic growth factors that reduce severity and length of myelosuppression, alongside better anti-emetics and other supportive care medications, which instigated more widespread piloting and development of AC (Mikhail, Swint and Kurtin, 1995; Solomon *et al*., 2010; Moore, Arnall and Plesca, 2018).

3.11.4 Professional motivation to improve cancer experience

Biomedicine is often presented as the driving force behind improvements in cancer care, but alongside this, there has been a reconceptualisation of living with cancer (Kerr *et al*., 2018): with patients increasingly regarded as active partners in care (Ham, Charles and Wellings, 2018; NHS England, 2019b). Undertaking elements of self-care is fundamental to AC. Independence (Corrigan Wandel *et al*., 1990); control (Corrigan Wandel *et al*.,1990; Ingram *et al*., 2013; Knott, Brown and Hardy, 2013; Newton and Ingram, 2014), and promotion of normalcy (Nirenberg and Rosen 1979; Kelly, 2005; Knott, Brown and Hardy, 2013; Newton and Ingram 2014; Ingram, 2017; Brown and Walker 2016) were reoccurring themes in the review findings, and this was associated with enhanced patient experience. These authors also conveyed a willingness or acceptance of the requirement to undertake self-care responsibilities. More clearly stated was a professionally held belief that not all patients require continuous nursing care during cancer treatment (Kelly, 2005; Bates and Mcmonagle, 2012; Comerford and Shah 2018).

Across the USA, *Ambulatory Care* refers to all outpatient treatment, irrespective of illness or disease group. Since its inception in the 1990s in the USA, the professional specialty of Ambulatory Care nursing has emphasised both the individuality of a patient and the central role of nursing (Mastal, 2018). The set-up of AC requires medical, and not least pharmacy expertise, and once established, AC requires multidisciplinary coordination and management. The literature, however, suggests that in the UK the operational running of AC is, for the most part, a nurse-led service.

Concern for patient experience often sits within the nursing domain: across the 21 publications that promoted the potential of AC to enhance patient experience as a driver for development and adoption of the service, nine nurse authors led 16 publications. Eight of the nine nurses contributing to this literature are from UCLH within the UK, within which five are from the TYA Service. It is within the TYA specialty that concern for experience is emphasised, and this often extended to the young person's family (Nirenberg and Rosen 1979; Knott, Brown and Hardy, 2013, Brown and Walker, 2016; Ingram, 2017).

Nirenberg is a central nursing figure in the 'storyline' of AC. In their 1979 paper titled "The Day Hospital: ambulatory care" she and a clinical colleague described the set-up of an adolescent unit at MSKCC, driven by motivation to promote a degree of normality in young people's education and social life during treatment for cancer (Nirenberg and Rosen, 1979). It is thought that their early, revolutionary approach went on to inform the establishment of the children's AC service at MSKCC, dispelling any worries a patient's family might have about safety in the ambulatory setting. The idea that people should not be defined by their cancer was central, as well as the critical role of the family in supporting delivery of care. Noteworthy is the fact that Nirenberg has not previously been cited in the UK literature. With the specialty of adolescent cancer being established in the UK c1990 (Whelan, 2003; Whiteson, 2003), Nirenberg could be considered a forerunner of TYA cancer care.

3.12 The consultation exercise

This section concludes by assimilating findings from the consultation with key stakeholders to further explicate the drivers for AC. The consultation was undertaken to help build understanding of Ambulatory Care's development in the UK.

Concurrent with a synthesis of the literature, I consulted with six professionals about their involvement in developing AC. During this exercise I described some of the literature, to help build a more composite and contextualised understanding of the findings. For example, during the consultation, a specialist pharmacist contributed their first-hand experience of listening to the AC team from MSKCC present at a conference in c2002. Hearing about how MSKCC had successfully transitioned High dose Methotrexate (HDMX) to an ambulatory pathway had compelled this pharmacist to propose the idea to pilot a similar model in a UK hospital. They recalled the realisation that with protocol adjustments, education, and the use of technology, the osteosarcoma population who were young, and often only in hospital for intravenous hyperhydration, fluid monitoring and administration of folinic acid, did not need to be confined to a hospital ward. Critical to this were portable infusion pumps contained in a backpack, which facilitated treatment away from the clinical setting. A visit to MSKCC followed and oncology patients diagnosed with osteosarcoma became some of the first adult AC patients in the UK to ambulate with HDMX, which helped demonstrate safety and confidence in the service (Statham, 2012). I heard, through the consultation, that as confidence in the pathway grew, there were recurrent conversations between doctors, pharmacists and nurses to identify other chemotherapy protocols that could be transitioned to an ambulatory basis.

The consultation exercise also helped explicate some of the literature findings, for example the imperative to innovate to manage inpatient bed capacity. The NHS Cancer Plan (NHS, 2000b) directed the centralisation of specialist services, in a drive to improve cancer outcomes in England. A haematologist described that whilst centralisation of cancer treatment 'pooled' expertise and strengthened outcomes, it both increased the size of cancer services, and entailed patients having to travel long distances for treatment. There became, they explained, an imperative to invest in AC. They contextualised this by describing that if many of the complex cancer treatments required inpatient admission, these would not only place pressure on beds and timely treatment, but they would also require separation of the patient from their family. Besides being more cost-efficient, the haematologist understood that this was why large cancer hospitals in the USA had a commercial hotel on the campus, where the accompanying companion could also help share care.

Consistent with the literature, the haematologist spoke about the need to optimise bed capacity as the primary driver for the development of AC in the UK. Within haematology, inpatient services consistently run at 95% occupancy, explained a senior nurse I consulted, indicating that this fact alone drove the requirement to transition some treatment to an ambulatory setting. They explained how many complex treatments had a step-down component with less care or supervision requirements than at other points, and during month-long admissions, there were periods where patients were not particularly unwell but were considered at risk. Through consultation, I learnt how some of the first haematology AC treatments were determined based on ‘well but at risk’, a concept evident within the hospital’s first formal adult AC policy published in 2008. Another driver reported in the consultation, was the opportunity to develop more clinical research and trial activity through having a larger patient cohort.

The consultation exercise identified that the adult service at UCLH was founded on offering a choice to ambulate or be admitted to the ward. Once the service became established however, the alternative to ambulation became being put on a waiting list for an inpatient bed. It was relayed by those consulted that this would invariably delay treatment, impacting experience, and perhaps clinical outcomes, and so for many people they felt they had no choice at all. Although AC has become standard care in adult services at UCLH for some treatment protocols, there was a suggestion that other UK cancer centres might continue to offer AC on an optional basis.

Initially, within the adult service it was almost exclusively a commercial hotel ambulatory model, explained a senior nurse, unless a patient lived within 60 minutes travel, in which case they could ambulate from home (Statham and Stivala, 2008). Then, in 2012, a hospital hotel opened to coincide with the opening of the University College Hospital (UCH) Macmillan Cancer Centre (outpatient facility), also in 2012. The nurse said that these facilities together supported more efficient treatment and cost management, while helping realise the potential to enhance cancer patients’ experience in a less clinical environment.

Teenage Cancer Trust made significant investment in the UCH Macmillan Cancer Centre, with a whole floor dedicated to TYA services. Ambulatory Care was piloted for the TYA service (Statham, 2012), with patients initially staying in an adjacent Young Lives vs Cancer home-from-home and able to make use of their kitchens and communal recreation areas. Statham (2005) who had been involved in the set-up of adult AC, subsequently became matron for the TYA cancer service. During consultation she indicated that as demand for the home-from-home grew (amongst younger patients requiring overnight stay during radiotherapy treatment), the TYA service became reliant on the use of the patient, and occasionally commercial hotels.

When asked about why other cancer centres in the UK have been slow to establish AC despite reconnaissance visits to UCLH, both the adult and TYA senior nurses I consulted, suggested that it would be challenging for clinicians to prioritise investment in the infrastructure required alongside the operational running of a clinical service. The set-up requirements have also been reported by NICE (2016); Comerford and Shah (2019a) and Ingram (2019) as something that should not be underestimated.

3.13 In summary

This review set out to understand Ambulatory Care from its commissioning and philosophical foundations. Whilst Ambulatory Care is still regarded as somewhat novel in the UK, by the 1990s, in the USA the pathway was well established. The impetus for AC was the ability to safely manage increased service demand, whilst ensuring timely access to cancer treatment and efficient management of costs. Advances in infusion therapy devices and haematopoietic growth factors, alongside better anti-emetics and other supportive care medications have culminated in AC becoming increasingly feasible. Concern for patient experience is evident within the literature, but rarely positioned as the primary driver.

3.14 Exploring the results in relation to scoping review Question 2: How Ambulatory Care meets the needs of patients and contributes to their experience of care

Within healthcare we often report that a service ‘meets the needs of patients’ as the ultimate achievement or outcome, yet ‘needs’ themselves are not universally defined. Having set this review question unproblematically, I found myself in the same bind of imprecision. Yet it presented opportunity to make a full scope of the literature to understand how, and where AC answers the needs of patients, and from whose perspective this claim originates.

To begin answering this question I consulted the AC literature for examples of where meeting the needs of patients had been evidenced. Certain principles recurred, framed around clinical outcome, safety, timeliness, choice, location, information and involvement in healthcare. When considering the concept, in most cases meeting need within the context of ambulatory care was associated with ensuring safety and was conveyed from the perspective of no increased mortality, infection, toxicities or unplanned hospital admissions (Rosen and Nirenberg 1982; Zelcer *et al*., 2008; Bakhshi, Singh and Swaroop, 2009; Solomon *et al*., 2010; Sive *et al*., 2012; Villegas *et al*., 2017; Fridthjof *et al*., 2018). Attempts to answer the question of meeting need explicitly from a patient's perspective was limited to one publication (Comerford and Shah, 2018) and a local questionnaire (UCLH, 2012). Comerford and Shah (2018) identified through a survey that amongst 130 adult cancer patients treated at UCLH, 96% indicated their emotional, practical, psychological and spiritual needs had been met. In a questionnaire that was distributed to TYA patients in 2012, all those who responded (n=32) indicated they valued choice about where they received their treatment, expressing they felt safe, in control and independent whilst receiving treatment in Ambulatory Care (TYA AC Clinical Team, 2012).

What is prevalent amongst the AC literature is a description of patients' ability to exercise choice (Esparza, Young and Luongo, 1989; Ingram *et al*., 2013; Newton and Ingram, 2014; Brown and Walker, 2016), to feel empowered (Statham, 2005; Kelly, 2005; Brown and Walker 2016) and independent (Statham, 2012; Ingram *et al*., 2013; Comerford and Shah 2018). Experiencing freedom from the hospital environment (Ingram, 2017) and receiving personalised care (Pirschel, 2019) because of AC were additionally reported.

Across the literature there were indications that AC positively contributes to patient experience (Nirenberg and Rosen 1979; Kelly, 2005; Statham, 2005; Grimm *et al*., 2010; Knott, Brown and Hardy, 2013; Newton and Ingram 2014; Nissim *et al*., 2014; Beaty *et al*., 2015; Mcmonagle, 2015; Brown and Walker, 2016; Ingram, 2017; Comerford and Shah 2019a; Ingram and Smith, 2019; Pirschel, 2019). Improved Quality-of-life (Bakhshi, Singh and Swaroop, 2009; Anderson *et al*., 2013), preference

(Mikhail, Swint and Kurtin, 1995) and satisfaction with care (Beaty et al., 2015; Moore, Arnall and Plesca, 2018) were also reported. However, this was often based on professional opinion (Richie 2005; Reid *et al*., 2016; Pirschel, 2019) or was not substantiated beyond demonstration of satisfaction (Beaty *et al.,* 2015; Comerford and Shah, 2018).

Overall, the scoping exercise found ten results that included attempts to understand the patient-reported perspective. This comprised a survey/questionnaire (UCLH, 2012; Comerford and Shah, 2018); quality improvement project (Nield *et al.,* 2012; Beaty *et al.,* 2015; Ingram and Smith 2019; Ranney, Hooke and Robbins, 2020); service evaluation (Brown and Walker, 2016); or primary research (Statham, 2005; Nissim *et al*., 2014, Mcmonagle, 2015).

The study designs, however, impact consideration of the findings. Aside from the small sample (seven patients) within a quality improvement (QI) project that set out to measure child (median age 8.5) and carer satisfaction receiving vincristine, dactinomycin, and cyclophosphamide (VAC) chemotherapy in the outpatient setting (Beaty *et al*., 2015), confidence in the findings is undermined by their reliance on parental proxy reporting. In the QI project by Ranney, Hooke and Robbins (2000), appraisal of quality-of-life was limited by a completion rate of 50% (five families) in their survey of child (mean age 7) and carer satisfaction with home ambulation following HDMTX, and no child-derived responses are reported. Alongside this, whilst Nield and colleagues (2012) and Ingram and Smith (2019) indicated positive patient experience in relation to adult AC, the partial detail provided by a conference abstract precludes more detailed analysis.

3.14.1 The contribution of primary research

Looking to primary research for a more composite understanding of how AC contributes to a patient's experience of care yielded three studies (Statham, 2005; Nissim *et al*., 2014; Mcmonagle, 2015). The first study is an unpublished Masters dissertation from a cancer nurse (Statham 2005), who explored adult patients' (n=7) lived experiences of receiving a BEAM haematopoietic stem cell transplant (HSCT) on an ambulatory basis at UCLH, whilst staying in a nearby commercial hotel. Key findings from this qualitative interview study suggested that treatment in AC was an empowering experience, which facilitated the implementation of various coping mechanisms such as an increased level of patient control, greater normality and privacy (Statham, 2005). The inquiry also highlighted that a supportive social network, personal commitment and motivation were essential prerequisites for a positive ambulatory experience.

Nissim *et al.* (2014) explored, through qualitative interviews, perceptions of experience during transition from inpatient to Ambulatory Care amongst 35 adult participants (median age of 49) with Acute Myeloid Leukaemia who received their consolidation chemotherapy on an AC basis. Participants described successfully adjusting to the intensity of AC and the need to assume greater responsibility for their treatment. They expressed a desire to understand their longer-term care plan: being away from the inpatient ward setting allowed ambulatory patients to be more future-focused, in comparison to patients in an inpatient ward setting, who were found to focus more on the present (Nissim *et al.*, 2014).

Mcmonagle (2015), a cancer nurse, explored adult patients' (n=8) experience of receiving an autologous bone marrow transplant within the AC setting with the aim of gaining insight into the experiences of patients with a diagnosis of lymphoma (n=4) or multiple myeloma (n=4) at three intervals: on admission to AC, during planned admission to the ward, and at first follow-up appointment following discharge. Not all patients had been accompanied overnight initially and reported feeling comfortable with this arrangement. As they became more unwell, however, their perceived need for a companion increased. Patients could often recognise when they were too unwell to remain in AC and needed admission to the ward. Overall, the study reported what was described as good patient satisfaction with AC experience (Mcmonagle, 2015).

Although the diagnostic profile of participants in the three studies is different, all highlighted adjustment to the responsibilities of Ambulatory Care in the adult setting.

Statham (2005) and Nissim *et al.* (2014), however, indicated that this was dependent on individuals having the capacity and motivation to engage in the self-care required. Within the TYA speciality, there has been professional commitment to build knowledge about patient and other stakeholder experiences through qualitative inquiry (Brown and Walker 2016). Insight from this study is discussed further in answering the next review question in section 3.15.

This scoping review found no other attempts to understand how AC contributes to experience of care, suggesting that experience is yet to be comprehensively explored. At UCLH, Sive and colleagues indicated that their reports of positive patient experience were derived from "anecdotal patient feedback" (Sive *et al.*, 2012, p.2403). Whilst patient experience is positioned as "the real benefit" of the adult AC service at UCLH (Comerford and Shah, 2019a, p.S7), opportunities to understand how adult patients make sense of AC experience, and the extent to which it meets their needs have been limited. During consultation with a haematologist, they indicated that the initial priority had been to build the case for AC and demonstrate clinical confidence in the pathway, rather than explore patient experience. A senior nurse for adult cancer day- and ambulatory care services that I consulted, acknowledged ongoing efforts to understand the nuance of people's experience beyond satisfaction have been unsophisticated, attributing this to nurses not having the research capacity to undertake more considered inquiry within their clinical roles.

3.14.2 The role of companions

Whilst the second scoping review question was set from the position of understanding patient perspectives, the scoping exercise revealed that the literature often referred to the role of a companion practically and emotionally supporting patients to access AC (Nirenberg and Rosen 1979; Corrigan Wandel *et al*., 1990; Grimm *et al*., 2000; Richie, 2005; Statham, 2005; Anderson *et al*., 2013; Mcmonagle, 2015; Brown and Walker, 2016; Ingram, 2017; Moore, Arnall and Plesca, 2018; Comerford and Shah 2019b; Pirschel, 2019). There is evidence that the role of a companion or caregiver positively contributes to experience of AC (Statham, 2005; Mcmonagle, 2015; Brown and Walker, 2016). Kelly (2005) and Statham (2005) described the fact that a partner or family member can stay with a patient as something that supported adult patients on an emotional level, helping contribute to a sense of normality that would otherwise be hindered in a ward environment.

Reliance on family has furthermore been described as critical to the feasibility of AC. In their report of 5000 children's AC treatment episodes, Rosen and Nirenberg (1982) indicated treatment was often safer in AC as a consequence of parents being more diligent in undertaking the monitoring required, in comparison to overstretched inpatient staff. Whilst in consultation with Nirenberg, an emeritus professor of nursing, she explained that in the 1970s and 80s, when she was involved in transitioning high-dose cisplatin and methotrexate to an AC pathway, nurse staffing and skill mix meant that children's treatment could often be delivered more safely by an attentive parent with the right education and support. In a conference abstract more recently (Breen *et al.*, 2016), caregiver education was described as a cornerstone of patient safety within the AC setting, which infers that the requirements of the role are not insignificant.

It became evident within the literature that irrespective of patient age, the availability of companion support is a factor informing feasibility (Rosen and Nirenberg, 1982), suitability and access to AC (Corrigan Wandel *et al.*, 1990; Richie, 2005; Moore, Arnall and Plesca, 2018). Alongside this, professionals indicated consideration should be given to the added costs to caregivers (Ingram, 2017), who may need safeguarding from burden (Brown and Walker, 2016; Comerford and Shah, 2019b), burnout and compassion fatigue (Pirschel, 2019).

Only one study was identified (adult focused) that explored the experiences of companions (Grimm *et al.*, 2000). It compared the emotional responses and needs of caregivers (n=43) who had undergone bone marrow transplantation in an inpatient/outpatient (ambulatory) setting with those in an inpatient ward (Grimm *et al.*, 2000). Their findings suggested that the ambulatory model is less emotionally distressing for caregivers and better meets their needs. Once again, the importance of caregiver education to prepare and support companions in their role was highlighted as a key implication for practice (Grimm *et al*., 2000).

3.14.3 In summary

The clearest examples of the benefits of Ambulatory Care from the perspective of meeting need involved the safety of the AC pathway. Beyond a survey that posed questions with a Likert-type response about meeting need (Comerford and Shah, 2018), no other published reviews, research or retrospective analyses relevant to ambulatory cancer care could be identified that explicitly set out to answer the question of meeting need (or identify AC patients' needs) from the perspective of patients. Nevertheless, within the literature there is inference that the requirement to engage in self-care is a foundational need, and this has been informally associated with ambulatory patients' positive experience of care. Comerford and Shah (2019b) premise that there is a link between self-care and patient satisfaction, but satisfaction scores are known to be only weakly associated with specific aspects of patient experience (Jenkinson *et al*., 2002). What becomes critical therefore, in pursuit of deepening our understanding, is to identify specifically which experiences matter to patients (Griffiths, Richardson and Blackwell, 2012). Statham (2005), Nissim and colleagues (2014), Mcmonagle (2015) and Brown and Walker (2016) offer important qualitative insights. Although they form a basis from which to build knowledge about AC experiences from the perspective of service users, with one exception (Nissim *et al*., 2014), these insights are derived from a small number of participants (< n=8).

3.15 **Exploring the results in relation to scoping review Question 3: The potential for Ambulatory Care to support delivery and receipt of age-appropriate care within teenage and young adult cancer services**

Across the wider literature it was evident that the transition of inpatient services to AC has been largely driven by the needs of healthcare providers, and this is reflected in the dominance of literature from the US. Within the UK, in the specialty of young people's cancer, AC was driven by the desire to promote independence and normalise lengthy cancer treatments within an empowering context (Knott, Brown and Hardy, 2013; Newton and Ingram, 2014; Brown and Walker, 2016).

The primacy of young people's needs based on their life stage were vital to the creation of TYA cancer services in the UK in 1990s. Living as normal a life as possible during cancer treatment also became an inherent aim of the emerging TYA specialty in the 1970s within the USA. A consultant oncologist I consulted, who had been central to the development of TYA cancer care in the UK, spoke of the 'homespun' philosophy of early TYA care. Putting young people at the centre was entirely deliberate, I was told, as was triangulation in the coordination of care, between a young person, their family and the multi-professional team. This formed the foundation for a TYA cancer philosophy, which paid attention to the TYA's life-stage: a philosophy and practice conceptualised within the Improving Outcomes Guidance (NICE, 2005) as age-appropriate care. Publications now extend and establish age-appropriate care as the defining philosophy for the TYA cancer specialty (Fern *et al*., 2013; NICE, 2014; Smith *et al.*, 2016; Vindrola-Padros *et al*., 2016, Lea *et al*, 2018). Conceptually, central tenets include best treatment; communication/interactions/relationships; healthcare professional expertise; promoting normality; recognising individuality; empowering young people and the environment (Lea *et al*., 2018). While there was limited TYA literature from which to undertake a narrative synthesis, the records included in the review were appraised from the perspective and conceptual basis of age-appropriate care.

There were four UK publications (service evaluation, n=1; practice initiative, n=1, and discussion papers, n=2) that posited views about AYA ambulatory care experience. These publications originated from a group of nursing authors who have all been involved in the establishment of the service at UCLH (Knott, Brown and Hardy, 2013; Ingram *et al*., 2013; Brown and Walker, 2016; Newton and Ingram, 2014). This highlights the team's commitment to advancing the speciality of TYA cancer care, a relatively small professional community within the UK. It conveys a consistency in the professional narrative aligning with age-appropriate care, yet within (and perhaps because of) this, a consensual view is presented.

3.15.1 Promoting normality and recognising individuality

Brown and Walker (2016) offer insight into the experiences of patients aged 13-20 who stayed in a Young Lives vs Cancer home-from-home, hotel or at home during their AC admission. When the TYA AC service at UCLH was being piloted in 2011, attempts were made to understand different stakeholders' perspectives through an action research approach to inquiry. It was led by STEER (Service Transformation Education Evaluation and Research) a group comprising professional, patient and family members. Along with a nursing academic, I co-led the group and its activities in 2011-13. This early work found that most young people valued time away from the clinical setting: the opportunity to rest, sleep and eat when desired as opposed to when expected as part of the hospital routine. It formed the basis for a Foundation of Nursing Studies (FoNS) grant that enabled STEER to continue exploring the perspective of a small number of different stakeholders which included young people (n=6), their companions (n=3) and staff (number not stated) (Brown and Walker, 2016). The project design included a focus group, young people's narrated stories, a 'claims, concerns and issues' exercise and questionnaires from staff.

Further afield, there are two US based publications to help broaden and re-contextualise understanding (Nirenberg and Rosen, 1979; Anderson *et al.*, 2013). Whilst they provide a rich narrative account of their AC services, the perspectives of young people are not reported. Yet it is clear within both the TYA (Nirenberg and Rosen, 1979; Anderson *et al.*, 2013; Knott, Brown and Hardy, 2013; Newton and Ingram, 2014; Brown and Walker, 2016) and wider AC literature (Kelly, 2005; Statham, 2005; Grimm *et al.*, 2010; Nissim *et al.*, 2014; Beaty *et al.*, 2015; Mcmonagle, 2015; NICE, 2016; Ingram, 2017; Ingram and Smith, 2019; Comerford and Shah, 2019a; Pirschel, 2019) that the AC pathway is believed to positively contribute to the experience of care. This was thought to derive from AC's ability to promote normality and independence, achieved by a young person taking on elements of self-care, which includes responsibilities for monitoring and measuring health status: tasks that would traditionally be undertaken by nurses.

The two US publications (Nirenberg and Rosen, 1979; Anderson *et al*., 2013) both convey a partnership approach to care between family member and patient, conceptualised by Anderson *et al.* (2013) as “family-centred care” (Anderson *et al*., 2013, p2), a concept more associated with children’s nursing in the UK.

3.15.2 The environment

Within the UK, since 1990, a Teenage Cancer Trust ward environment has been central to the experience of age-appropriate care: a physical setting within which a sense of “being in the same boat” can foster a sense of shared understanding (Kelly, Pearce and Mulhall, 2004). From the outset, the ethos in the TYA cancer service centred on the ability to treat and care for acutely ill patients, in an environment that brought young people together and “encouraged social interaction rather than isolation” (Carr *et al*., 2013, p.259). Knott and colleagues (2013) in reporting staff experience of embedding patient-led urine monitoring on the inpatient ward in preparation for AC, remarked that there was potential for peer support, a critical component of age-appropriate care, to be challenged by the Ambulatory Care model as young people were less co-located with cancer peers (Knott *et al*., 2013). Brown and Walker (2016) found that one of the worries expressed by young people embarking on AC was that they would lose the security that they had come to know on the inpatient ward.

The oncologist who participated in the consultation exercise had been part of the TYA service for the past three decades. For them, the centrality of the physical space was key to the traditional enactment of the TYA philosophy of care. They postulated that if hospital management compromised on this space, teams would have to work harder to create peer and professional support. If a patient just turns up to AC for treatment, then leaves, he explained, they will miss out on what the TYA cancer philosophy has to offer. The oncologist said that this would be especially important as discussions around what is required to deliver the philosophy can be overlooked by the need to maximise every available space for clinical care. This suggested that what the ambulant TYA service sets out to deliver needs to be brought to the fore, juxtaposed and checked against the established TYA inpatient ethos. It impresses the importance of understanding the totality of AC experience, aside from the clinical delivery of services.

3.15.3 Health professionals’ role in the TYA AC setting

If one appraises the literature for understanding the role of professional contribution in the delivery of age-appropriate care within the AC setting, both Brown and Walker (2016) and Knott and colleagues (2013) indicate that the shift in care-giving responsibilities from the clinical team to the TYA and their companion initially presented conflict for some nursing staff. Whilst the AC pathway was being piloted, to established confidence and safety, TYA patients were admitted to the ward, usually to complete a first course of chemotherapy whilst being educated to undertake self-monitoring and care. Here, inpatient ward nurses described sometimes feeling pressured by time and conflicting priorities (Knott, Brown and Hardy, 2013), perceiving the performance of clinical tasks themselves to be quicker and safer. In addition, some nurses felt a reluctance to ‘let go’ from delivering technical and procedural care, worrying that it would create additional work for the family, whilst others felt the more facilitative style of practice required of the AC pathway challenged their professional identity as a cancer nurse (Brown and Walker, 2016).

The scoping review identified two other studies investigating professional roles in the ambulatory setting, though both were from the adult cancer environment (Tighe *et al.*, 1989; Morrison, 2010). In her qualitative research interviewing adult cancer nurses (n=21), Morrison (2010) identified five themes reflecting expert ambulatory nursing practice: being a content expert, creating positive relationships, listening with attuned skill, advocating for the patient, and developing long-term patient and family relationships. These findings offer helpful insight, although the extent to which they transfer to a TYA care culture is unknown. Whilst one research paper (Tighe *et al.*, 1989) met the inclusion criteria, its exclusive focus on technical aspects of ambulatory nursing meant that the contribution of this paper was limited. No other attempts to understand the experiences of the healthcare team delivering AC were identified from an adult or TYA perspective.

3.16 In summary

Whilst the UCLH TYA AC service established by 2012 can report safety, feasibility and efficiency comparable to adult AC services (O'Reilly, Finch and Soanes, 2017), we do not know enough about patient, companion/carer and staff experiences. The AC model aspires to offer the choice and control patients often lose on diagnosis and throughout cancer treatment (Newton and Ingram, 2014); however, it also creates new responsibilities for TYA patients including undertaking self-monitoring of their own health status. The literature does not reveal the extent to which young people are able to engage in the aspects of self-care and self-monitoring required. As the first ambulatory cancer care service in the UK, the STEER group felt a responsibility to help understand experiences of AC. This offered preliminary insights (Brown and Walker, 2016), at an early stage of the service's establishment, generating a descriptive account of experiences. Overall, limited evidence and small participant samples have challenged the depth of the synthesis and interpretation in answering this research question, rearticulating the importance of more primary research, whilst emphasising the value of a consultation exercise in helping contribute additional knowledge and contextualisation.

3.17 Implications for research inquiry

The literature describes ways in which Ambulatory Care can positively contribute to patient experience, whilst avoiding treatment delays, unnecessary hospital stays and financial burden. This scoping review has established that whilst patient experience has been posited as a benefit of AC, few authors have investigated this as the primary research focus. There were just four exceptions: a study from Canada (Nissim *et al.*, 2014) and two from the UK (Statham, 2005; Mcmonagle, 2015) which all set out to explore adult experiences of care, and from the TYA setting, a service evaluation (Brown and Walker, 2016).

Among the studies there are challenges in the relevance and confidence one can derive from research findings relevant to the TYA AC context, on account of study size, participant age and, or diagnosis which strengthens the value of further research. Emerging questions from the literature centre on a need to build understanding about experience from the perspective of those who deliver and receive AC, including accompanying companions. More specifically, Brown and Walker (2016) identified that whilst young people valued the opportunity to feel more empowered through AC, they sometimes felt anxious about ambulating, and invite further exploration of this theme. The literature to date has overwhelmingly posited the positive aspects of AC. The research that has been undertaken, whilst presenting what AC is purported to offer (for example, *independence* or *normality*), is discussed with limited explanation about thematic connections, relationships or conceptual consideration.

When a young person is diagnosed with cancer at such critical, transitional life stage, demands of treatment bring about increased reliance on family, at a time when peers are gaining independence (Grinyer, 2007a). Grinyer's work exploring the impact of cancer on parents (Grinyer, 2002b) and young people (Grinyer, 2007b) suggests that this can become a difficult tension to negotiate. While the ambulatory care pathway supports independence, the companion role appears critical for the safety and support of patients. The relationship between the young person and their accompanying companion in the facilitation of AC remains underexplored. Amongst the young adult population (> 18 years) for whom a companion is not mandated, the literature tells us little about how ambulating alone might impact on their AC experience.

Many young people can now commence and receive all their cancer treatment on an ambulatory basis. This requires a different kind of professional engagement in delivering age-appropriate care. AC has become 'routine care' for many treatment protocols but there is no patient-derived evidence of what is required to deliver the TYA care philosophy in the AC context. It is not known whether any changes or adaptations to the current AC model are required to better meet the needs of teenagers and young adults. Furthermore, the transferability of the evidence defining the culture of TYA cancer care (Lea, Gibson and Taylor, 2019; Lea, Taylor and Gibson, 2022) requires further investigation in the context of AC.

Lea and colleagues (2018), in their analysis of the young people's cancer care literature identified seven overarching themes that captured age-appropriate TYA cancer care in the UK, within which environment and peer support feature. They invite consideration of these in different health contexts. Ambulatory Care is based on an argument that life should be closer to normality during cancer treatment. But thought must also be given to founding premise of why, since 1990 professionals have advocated bringing young people together into a teenage cancer ward to receive care in the UK. Building qualitative, nuanced understanding directly from patients and their companions about the AC health context feels critical, given much of this experience takes place unwitnessed by the hospital team.

In summary, the Ambulatory Care rhetoric is excellent, and completely aligns with the philosophy of young people's cancer care. With a dearth of evidence derived from patients' perspectives however, the rhetoric is perhaps reductive and limited in its transferability.

3.18 Strengths and limitations of the scoping review

Undertaking a literature review was an integral part of writing the fellowship application for this research in 2018. Completing a full scoping review exercise was beneficial, however, in building confidence that all literature that contributes knowledge and evidence about AC had been identified. The ability to synthesise a diverse body of knowledge which presents a coherent picture of the storyline of Ambulatory Care's development; and the current state of AC knowledge and evidence related to experience, was effectively achieved through the scoping review approach. Not placing restrictions on publication date enabled a more extensive exploration of the literature than previously reported and I report the first chronological and international presentation of the provenance of the AC pathway. Another strength of this review process was its ability to comprehensively identify claims and concepts attributed to the ambulatory care model which could be further explored through research.

Upon completion of the scoping review, the PRISMA-ScR checklist (Tricco *et al.,* 2018) was completed to appraise this review against the expected reporting standard (Appendix 7). For example, the JBI Manual for Evidence Synthesis recommends that record selection is undertaken by at least two independent reviewers from the point of title/abstract screening (Peters *et al*., 2020). In my case, given this was a PhD rather than team-based research, the process of record selection involved secondary review from the stage of identifying all full-text publications that met the pre-specified criteria for inclusion.

From the outset, I set out to self-appraise my leadership of the scoping review, referenced against a hierarchy of inquiry as described by Davis, Drey and Gould (2009), within which four different levels of inquiry ranging from preliminary descriptive surveys to more substantive conceptual approaches have been positioned (Appendix 8). The limited and mixed nature of the review material included meant it was difficult to make comparisons between studies. The search and identification process evidenced procedural and methodological rigour, strengthened by the inclusion of a consultation exercise and the resulting synthesis of the literature enabled critical, yet descriptive analysis. The nature of this literature review meant the knowledge and understanding derived was iterative: it represented an ongoing process of developing understanding (Boell and Cecez-Kecmanovic, 2014). Working with a hermeneutic approach to interpretation helped delineate the conceptual base of Ambulatory Care, through a critique and interpretation of the material included which, according to Davis, Drey and Gould (2009) is more indicative of classification towards the apex of their hierarchy of inquiry.

The review achieved its aims, although it was not without its limitations. As the literature originated from a small group of authors, it became apparent that claims about Ambulatory Care were often repeated or became homogenised into a few typologies. The resulting synthesis of the literature therefore may over emphasise or underplay the relevance of different aspects of AC knowledge. Whilst the consultation exercise helped inform conceptual clarity and understanding, the very fact that contributing experts came from within the same cultural context is not unproblematic.

At the time this review was drafted, two young people and a parent co-researcher were invited to read and contribute to this literature review. They were asked to consider the credibility of the review findings from their experiential perspective and to consider the implications of the review for our research inquiry. This approach was taken to build trust in the synthesis and interpretation of the literature (Oliver *et al.*, 2014), whilst embedding the principles of a community-based, participatory orientation to research inquiry. One of the considerations raised from this exercise was whether AC is experienced differently among young people and families from minority ethnic communities, who are known to report being less involved in decisions about their cancer care (Williamson, 2020).

Much of the literature included in this scoping review originated from one clinical setting (UCLH). Extending the consultation exercise to include key professionals from other UK centres, where AC services are being considered or set up, would have contributed a more diverse perspective. A possible second limitation is the wording of the review questions prior registering the narrative synthesis with PROSPERO. When engaged in answering these questions, I became concerned about the use of ‘meeting the needs of’ in question two as this is not a clear or concrete construct.

3.19 In conclusion

The aim of this review was to identify what the literature tells us about the development of ambulatory cancer care, and how it contributes to patient experience during intense cancer treatment. More specifically the review set out to understand how AC contributes to TYA experience of cancer care.

The review suggests that the relationship between system drivers for AC, responsibility for care, and the pathway’s ability to contribute to positive experience is not fully delineated. Beyond clinical confidence in the safety of the ambulatory pathway, stating that Ambulatory Care meets the emotional, psychosocial and other needs of young people is not currently corroborated by strong evidence. The literature reports a consensus that AC positively contributes to experience, but this has been largely ascertained from professional opinion and/or patient satisfaction. There remains a paucity of primary research within the field from which to build knowledge and nuanced understanding of experience across all ages. In arriving at this conclusion, I do not imply that clinicians have been too hasty to make claims about the success of the pathway in the absence of research evidence. Rather, it is perhaps characteristic of the fact that being operationally focused, professionals can rarely prioritise research inquiry. I have been in an unusual and privileged position, having a research fellowship that kept me close to, but not consumed by full time clinical practice.

The scoping review provided an important foundation for this research inquiry validating the need to develop understanding, and explanations of experience, both from the perspective of those who receive and provide TYA AC. The review surfaced gaps, speculations and unknowns within the literature which were used to refine the research objectives and questions. In framing the research through a community-based, health equity lens, this facilitates consideration of diversity: respecting not every young person will have equal capacity to engage in, and benefit from Ambulatory Care. Respect for, and consideration of the diversity of patient communities was noticeably absent throughout the entire scoping review literature.

The following chapter describes the PhD study informed by the scoping review, and the implications for research that have been identified. Whilst Chapter 2 described the methodological approach underpinning this research, Chapter 4 sets out and explains its study design and methods.

Chapter 4 Study design

4.1 Introduction

Having described the theoretical underpinnings of this research in Chapter 2, this chapter presents the study design, methods and data collection procedures used. It also explicates the associated legal and governance related ethical considerations. Unlike a controlled trial, participatory research is, by nature, an iterative and relational endeavour; as such, the precise, sequential details of a study's enactment cannot be determined upfront. Inherent is a degree of uncertainty, which is considered a positive characteristic of engaged research inquiry (Cook, 2021). This led to refinements to the research process as knowledge developed and I have included both the intended approach, and the final study design that was employed to explore stakeholders' experiences of AC.

Perspectives of young people and family members informed the study design from the outset. In 2017, I invited seven young people to consider, rank and discuss their priorities for the research using a card-sorting technique (Finch, 2017). Six of the seven young people I consulted suggested that the research should consider AC's impact on their entire family. The study design was consequently developed to include the experiences of accompanying companions. During this early public engagement phase, young people additionally shared feedback about the commitment intended of participants together with the research methods being proposed. These contributions informed my application to the NIHR. Once the Community-of-Inquiry had been established, co-researchers shaped the final research protocol (summarised in this chapter), and all participant-facing materials, as well as supporting the conduct of this research.

4.2 Research questions

The research posed five questions:

1. What is the commissioning and philosophical context that underpins Ambulatory Care?
2. How do young people, their companions and staff experience Ambulatory Care?
3. What features are critical to delivering teenage and young adult Ambulatory Care?
4. What can we learn to inform the development of teenage and young adult Ambulatory Care services?
5. Can a Community-Based Participatory Research approach engage young people and contribute methodologically?

4.3 Setting

The teenage and young adult (TYA) Ambulatory Care (AC) service at University College London Hospitals NHS Foundation Trust (UCLH) was the setting for this single site study. As mentioned previously, the uniqueness of this setting is that it is the only fully established AC service in TYA cancer within the UK. The setting set out to include the range of residential settings that informed young people's experience of AC: the hospital hotel; charity funded home-from-home; commercial hotel; hospital managed apartment; and home environment.

4.4 Participants

Young people receiving cancer care (aged 16 to 24), their accompanying companions, and health professionals delivering or supporting AC (to this population) were the participants of this research. An additional cohort of research participants were those young associate researchers who had consented to take part in the evaluation of their experience.

4.4.1 Eligibility criteria

The inclusion and exclusion criteria for this study were as follows:

4.4.1.1 Inclusion criteria

A safety requirement of AC is the ability to summon help, describe symptoms and access telephone advice in English. Participants unable to do so are ineligible for AC and therefore eligibility for participation included being able to converse in English and communicate verbally.

1. Young people: aged 16-24 years who had current experience of AC for all or a proportion of their cancer treatment at UCLH;
2. Companion: an adult who had resided with and supported a young person whilst in AC;
3. Staff: healthcare professionals from the multi-disciplinary team who were directly involved in the clinical delivery of AC or who supported AC patients in their role;
4. Co-researchers: members of the Community-of-Inquiry.

4.4.1.2 Exclusion criteria

1. Those unable to give informed consent to take part in the study;
2. Young people aged under 16 and over 25;
3. Patients who received all their cancer treatment outside of the study setting;
4. Those with a new cancer diagnosis or who were completing a first course of cancer treatment;
5. Companions where their young person had not participated;
6. Co-researchers who had not consented to the evaluation of their experience.

4.5 Overview of the study design

Through a CBPR approach, the research explored the foundations of AC and stakeholders’ experiences. This involved a scoping review of the literature with a consultation exercise, followed by young people, companions and staff discussing their experiences of TYA AC in interview conversations. The study design featured four iterative phases, continuous data collection and interview field work that extended over 18 months. Young people were the primary research respondents; however, for navigating through this thesis, the methods and data collection procedure are presented according to the order in which they were undertaken. Figure 4-1 presents an overview of the phased study design detailing the research questions, methods, and participant sample set for recruitment.

Each research question in aligned to a phase of the study as depicted in Figure 4-1. Phase 1 comprised the scoping review of the literature which was the focus of Chapter 3. Phases 2 and 3 centred on young people, their companion, and staff experiences, and incorporated the recursive collection and analysis of data.

Phase 4, an evaluation of young co-researchers' experience, was a distinct activity undertaken at set time points, whilst embedded within our critical inquiry throughout. Despite a growing evidence base for public involvement, there is limited understanding of the impact of public, and in particular young people’s, involvement in research (Brady and Preston, 2017; Brady and Preston, 2020; Das *et al*., 2020). The evaluation was undertaken as a methodological appraisal, within which I considered personal and broader impacts. The detail of this evaluation is presented and discussed separately in Chapter 8.

As indicated in Figure 4-1, throughout the interview field work, which commenced in January 2021, the Community-of-Inquiry met at staged intervals to discuss the methods, engage in participatory analysis and consider the contribution of this research.

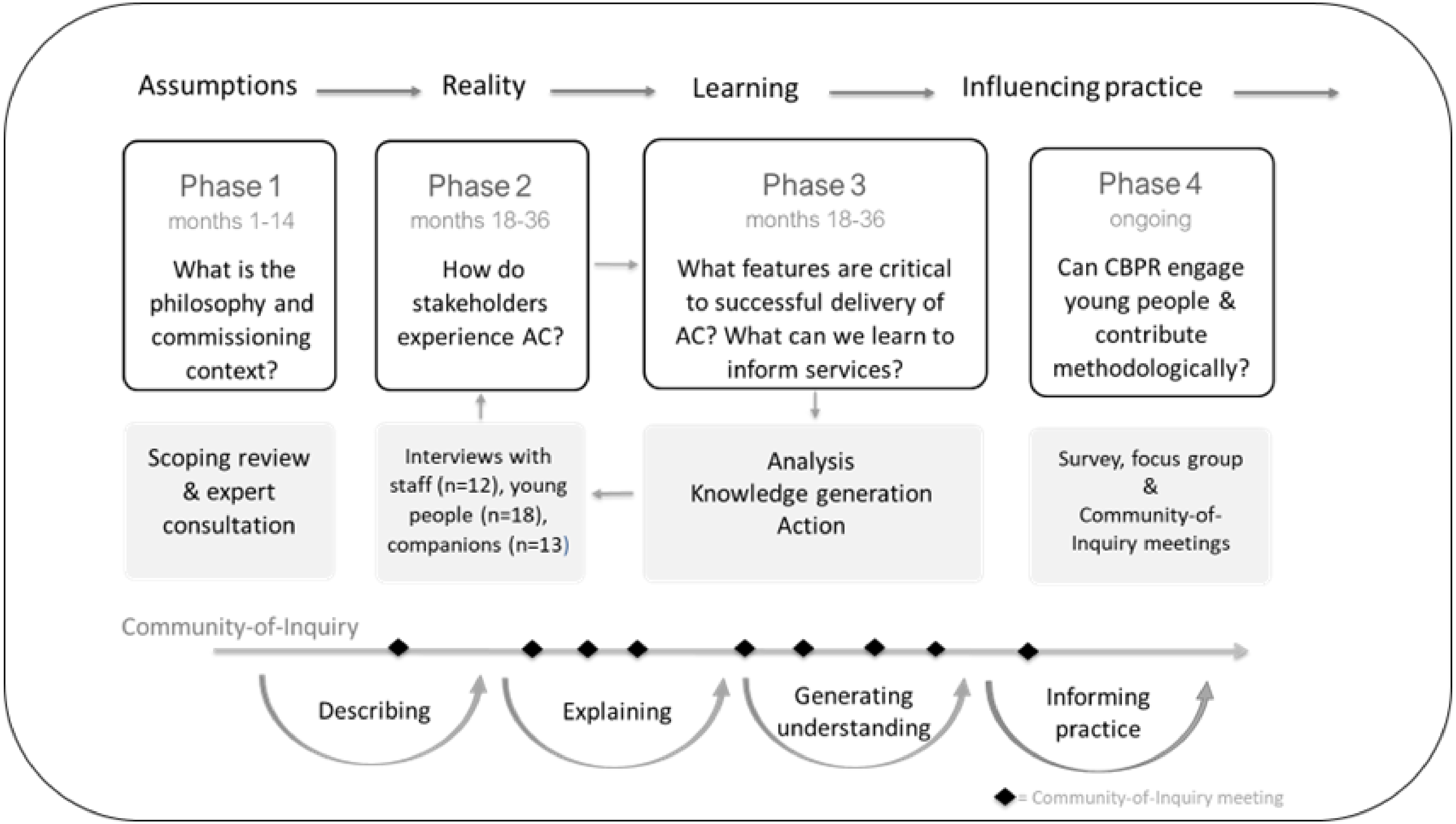

Figure 4-1: Overview of the study design

4.6 Sample

As a qualitative study, the aim was to achieve depth and richness in data collected. Consideration was given to the aims of the research, and methodological approach in setting the sample size for this study (Palinkas et al. 2015), with the participant sample for this research determined as follows:

4.6.1.1 Young people (TYAs)

A sample of between 15 to 20 young people, with size based on comparable CBPR studies (Chen *et al.*, 2010; Duckett, Kagan and Sixsmith, 2010; Flicker *et al.*, 2018). Sampling set out on a convenience basis, and it became more 'purposeful' (Coyne, 1997) i.e. targeted in latter stages of recruitment – to help ensure variation and breadth among participants on aspects such as age, gender, cancer treatment or AC residential setting.

4.6.1.2 Companions

Between 10 and 15 companions. This number was predicated on the basis a) that a proportion of participants would be unaccompanied (if over 18 years), and b) among those who were accompanied, not every young person would nominate their companion to receive study information.

4.6.1.3 Staff

A sample of six to 12 healthcare professionals from across the multidisciplinary team. Approximately 20 staff contribute to TYA AC, and the sample size sought representation from nursing, medicine, and allied health professional teams. Sampling set out on a convenience basis. The original sampling target had been set as 10 staff. In practice, once recruitment reached 10 participants, this was formally amended to 12, to facilitate greater representation from the nursing profession.

4.7 Data collection methods

'Data' comprised interview narrative, photographs, observations of practice and Community-of-Inquiry discussions. In addition, stakeholder consultations contributed data to the scoping review of the AC literature. The evaluation of co-researchers' experiences included survey data and focus group discussion.

The main data collection technique employed was semi-structured interviews, a method which has been effectively applied in research with both young cancer patients and healthcare professionals (Grinyer, 2009; Vindrola-Padros *et al.* 2016; Kenten *et al.* 2017; Marshall *et al.* 2018; Lea, 2019). Framed by a topic guide, the semi-structured format anchored and provided direction to the conversation yet offered flexibility in the sequence and wording of questions posed. This created space for participants to lead the flow of conversation and integrate perspectives that felt pertinent to them.

During our training and preparation period, video-interviews were piloted among the co-researcher community. At the point of protocol finalisation, contingency was made to work with virtual (video) interviews for all participant groups, to enable the research to continue during the Covid-19 pandemic. This alternative approach to in-person interview, required justification to the Research Ethics Committee at a timepoint when there was less published evidence about the conduct of qualitative research interviews within a virtual setting. To facilitate the committee's consideration, the perspective of a young associate researcher was included in the ethics application. "I think that video calls do become more normal for us TYA cancer patients anyway," she offered, on account of needing to restrict social contact due to immunosuppression. Contributory too, was her perspective that the online format "might ease anxieties some people may have [had] about participating in person," at such a vulnerable and tiring time.

Favourable ethical opinion was confirmed by London – Chelsea Research Ethics Committee on the 2 September 2020 which included Health Research Authority (HRA) approval for this study (IRAS 273131). It enabled in-person or virtual interview for all participant groups. This created flexibility which was relevant at the time given it was uncertain how long pandemic related restrictions might endure. The approved study, therefore, had different contingencies 'built in'. Additional flexibility was gained through several variations to the standard semi-structured interview method, the details of which I now summarise.

4.7.1 Interviews with staff

Semi-structured interviews with health professionals, took place with me as interviewer, and used a topic guide (Appendix 15) developed from the scoping review findings. Participating staff could choose between a virtual interview, or to meet in-person at a hospital location of their choice. In-person interviews included the possibility of a 'walk-along' interview within the TYA Day Care and AC unit, as an alternative to the traditional 'sit-down' format.

'Walk-along' interview methods have become established in social research to help explore people's relationship with 'place' (Carpiano, 2009; Bergold and Thomas, 2012; Errico and Hunt, 2019). It was intended that accompanying staff in their everyday work, whilst interviewing them 'in motion', would enhance my exploration of the philosophy, characteristics, and care practices that associated with AC. Given the protracted nature of the pandemic, however, its restrictions and clinical pressures, walk-along interviews were not considered by me to be feasible. Instead, participating staff could invite me to accompany them in practice for a shorter period of approximately 20 minutes, on a separate occasion to their interview, in circumstances where a participant considered beneficial to illuminate or further explicate an aspect of their interview conversation.

4.7.2 Photo-guided peer interviews with young people

The BRIGHTLIGHT research programme had shown that peer-interviews were able to elicit honest disclosure (Fern *et al.,* 2013), whilst helping to redress the power differential often felt between researcher and researched (Livingood *et al.*, 2016). Following training (that included qualitative methods, interviewing, visual methods, research ethics and safeguarding), young associate researchers conducted photo-guided video interviews with TYA participants, exploring their experiences of AC. Interviews took place virtually, through an approved video-conferencing platform. With permission (reconfirmed at the start of an interview), the conversation was audio-recorded, anonymised by me, and then sent to a UK based company for verbatim human transcription.

At the time of grant submission, with some knowledge of creative methods, and following consultation with young people during the PPI phase, I had selected a photo-guided interview approach (Holm, 2020), in which TYA participants' own photographs, taken for the purposes of the research, would become the basis of a peer-interview conversation. This was with the recognition that for both young people (Pearce *et al*., 2020), and adults (Pink, 2015), it is not always easy to connect with and describe experiences through conversation alone.

Collier and Collier (1986) were early proponents of the capacity of photographs to enrich research interviews. Since then, the value of research methods that encompass a sensory perspective, for example photo-elicitation in which participants are invited to choose and discuss pre-existing images (Capello, 2005), or research approaches such as sensory ethnography (Pink, 2015), are often used in social research, taking account of the multisensory nature of life's experiences. Looking at photographs and thinking with them have been shown to help people process and articulate experiences in nuanced and textured ways (Tinkler, 2013).

Distinguishing of the method chosen was that participants would take photographs themselves, sometimes referred to as "participatory photography" (Holm, 2020, p.576). This was considered positively on the basis that this type of approach might be more likely to foster choice and control among participants, concerning the focus and direction of their interview conversation, compared to a 'standard' interview. Relevant too, was that when prospective participants considered taking part, it was envisaged that the interview would not evoke feelings of formality or be perceived as an interrogatory experience. This latter aspect was pertinent given participants' age and the ethos of the CBPR project.

In addition, I had determined that being participant-led, the approach would be suited to the safe conduct of peer interviews: enacting the method would not require overtly complex methodological training, and, if following the participants' lead was upheld, the approach would be unlikely to take a participant down an unforeseen line of questioning. The interview approach more broadly centred related experience – the experience of living with a cancer diagnosis that interviewer and interviewee shared – as contributory to both rapport and the data collected.

The photo-guided peer interview method was piloted in a training workshop among young associate researchers who, working in pairs, interviewed one another using photographs taken to convey an aspect of their experience of the Covid-19 pandemic. The interview topic guide for the TYA participant group was shaped by the scoping review and our co-researcher discussion following piloting (Appendix 16). Prior to data collection commencing, we had viewed participants' photographs as 'stimuli' or a conduit to accessing participants' experiences (Slutskaya *et al.*, 2012). Once enacted in practice however, and the relationship between participants' images and their conversation was seen, the photographs were regarded as an additional dataset as I will discuss later in Chapter 5.

Peer-to-peer interviews were facilitated by one of four young associate researchers. To support young associate researchers to conduct interviews, I developed and shared a co-researcher toolkit. This included aspects such as 'starting well', channelling the conversation, 'ending well', general safety and taking field notes. Young people who consented to take part in the research were invited to take photographs on their smart phone during their AC admission of different aspects of their AC experience that felt notable or important, selecting up to seven images to discuss in their interview. An information sheet to guide prospective TYA participants about taking photographs was shared with participants (Appendix 17), within which it was explained that to help preserve anonymity, they should not capture human faces. This was relevant as, with their consent, the images might be shared during data analysis within Community-of-Inquiry meetings (Jones *et al.*, 2015), and could be used to help communicate the research findings. If preferred, or in circumstances where this was needed, the loan of a digital camera was offered although this was not required.

There was provision for an optional follow up interview in circumstances where we wanted to build understanding about how a participant's experience may have changed during subsequent AC admissions or, during analysis, to consult with a young person about a theme in the data. Follow-up interviews did not include photographs.

4.7.3 Triad interviews with companions:

It had been intended that I would interview a participant's nominated companion in-person, at a time and location of their choice, working with a topic guide developed from the scoping review literature in consultation with companion co-researchers. Prior to study finalisation, a companion co-researcher posed a challenge: "*Why, given that data collection with young people drew on related cancer experience, were interviews with companion participants not peer led as well?"* This led to our development of a three-way exploratory interview method which we piloted and subsequently employed to collate data about companions' experiences of AC.

When a third party is involved in a medical consultation, it is known as triadic communication (Smith, Critoph and Hatcher, 2020). Less commonplace in a research context, the interview method that companion associate co-researchers and I developed, comprises two interviewers and an interviewee. The result was a three-way conversation, framed by a topic guide that comprised two parts – experiences of care, and future service development.

I had considered it beneficial to retain a closeness to participants' firsthand experiences which had informed my original intent to interview companions alone. I welcomed the query being posed however, and over the following weeks the companion associate co-researcher and I mapped the practicalities of how a two-to-one interview might work, and the ethical considerations raised by a change to our data collection approach.

We noted our growing appreciation for the methodological potential of a two-to-one interview as the basis for a supportive, exploratory conversation with companion participants about their experiences of AC. Having considered the nature of the interview topic, the likely virtual interview context, and the skill required of a lone interviewer to be 'present' and engaged, whilst simultaneously alert to the non-verbal cues of participants during the format of an online interview, we tentatively suggested that it might be possible to hold a conversation of this nature more attentively, with two interviewers working alongside one another. Thought was given to whether partnering as interviewers from different experiential standpoints might successfully facilitate interview conversation that balanced the research aims of both understanding experiences of care, and the needs of future AC service delivery. Additionally, through participants knowing that one of their interviewers had personal experience of cancer this would inform and could benefit the interview dynamic, and the data collected, we proposed.

The 'two interviewer - one interviewee' method was piloted in a one-hour 'interview' between me, this co-researcher and the second companion co-researcher in the team. He took on the role of interviewee, in a conversation about an aspect of his son's cancer experience using the topic guide developed for the one-to-one interviews as a basis. The three of us subsequently reviewed this interview encounter in conversation, exploring not only the procedural steps involved, but the extent to which the 'interviewee' felt psychologically safe, supported, and able to contribute. The companion topic guide (Appendix 18) was refined thereafter, and, having considered the ethical and safeguarding considerations that associated with the proposed change, a study amendment was requested, and approved on a non-substantial basis in February 2021.

The revised participant information and written consent sheets stated that the interviews would take place with a cancer nurse and PhD researcher (me), who would be joined by a co-researcher with experience of supporting a young person through cancer treatment. Being interviewed by two interviewers was presented as an option to companion interviewees; consenting participants could choose a one-to-one interview with me if they preferred. Interviews, with permission, were audio-recorded, were anonymised by me before I electronically transferred the file to the human-transcription company. Similar to the procedure with TYA, the study design included the opportunity for a follow-up interview with companion participants, to clarify findings or consider their experience in a longitudinal context.

Oxford Learner's Dictionaries defines the noun *triad* as "a group or set of three related people or things" (Oxford Learner's Dictionaries, 2022). While other dictionary definitions emphasise the need for similarity between the people or things making up the group (Collins English Dictionary, 2022), consistent across all definitions is the concept of relatability. Reconnecting in conversation about the interview approach, we determined that critical to this interview dynamic was that it coalesced around shared experience of cancer. This led to appropriation of the noun *triad* to define the interview configuration and dynamic created. In Chapter 9, I discuss my reflections on the interview method's contribution to the generation of knowledge about companion experience, and more broadly as a research method.

4.7.4 Community-of-Inquiry meetings

Throughout the research the Community-of Inquiry met at staged intervals. Although not a distinct method, our conversations within Community-of-Inquiry meetings were regarded as data generating; elements of our conversations were audio-recorded for consideration during data analysis, with verbal consent assured from co-researchers immediately prior to the recording commencing. Excerpts from our discussion that had been recorded were electronically transferred and transcribed verbatim by the same human-transcription company.

4.8 Recruitment and data collection procedure

Covid-19 restrictions, which included the advice for immunocompromised persons to shield, remained in place when the recruitment of young people and companions was due to commence. As favourable ethical approval was in place for interviews to be hosted online, all interviews for these two participant groups were conducted on this basis. Whilst it had been deemed possible to accommodate in-person interviews with staff as I was working clinically at the study site, participants often elected to take part in the evening time, or when they were 'off duty', and this could be more easily facilitated through a virtual approach.

4.8.1 Identifying participants

The research site supported recruitment to the study displaying an A3 sized advertisement, with A4 size copies for interested persons to pick up and take away. The advertisement invited those interested, to contact me for further information about the research. More usually, however, nurses working in AC shared information about the research whilst in conversation with eligible young people, whilst taking account of their current health and emotional status. I had briefed the Young Lives vs Cancer social work team, clinical nurse specialists, youth support coordinator and the occupational- and physiotherapists at the study site, who additionally shared information with those eligible to take part. All expressions of interest in this research irrespective of eligibility were documented, to facilitate my consideration of the study design and recruitment strategy.

Staff at the research site were already familiar with the proposed research following a series of briefing events. Healthcare professional participants were identified via a generic email that I sent about the research to members of the multidisciplinary team, with an invitation to contact me directly for further information about taking part. Therefore, staff supported recruitment from two perspectives: putting themselves forward as potential participants and informing young people about the research.

The recruitment and participation of staff preceded that of young people and companions. This facilitated progressive consideration of the philosophy, practice and resulting care experiences of TYA AC.

4.8.2 Recruitment of staff and data collection procedure

Healthcare professionals who expressed interest received a Participant Information Sheet (PIS) and were provided with an opportunity to ask questions before being given an Informed Consent Form – Staff (Appendix 19). Participating staff were invited to offer their preferred interview format and suggest suitable dates and times for their interview with me. Once determined, the interview was scheduled for an hour. Consent was re-confirmed prior to the interview commencing, together with permission to audio-record. Interviews with staff took place over a two-month period, in advance of the recruitment of young people and companions.

4.8.3 Recruitment of young people and data collection procedure

Young people had no prior involvement with me or a young associate researcher in a professional or personal capacity prior to their involvement in the research. The recruitment of young people resulted from either a prospective participant emailing or texting me, having seen the advertisement on display, or after receiving study information from a member of the multidisciplinary team. On an occasional basis, I was invited by the young person to talk with them in person when they were next on the unit receiving treatment, so they could meet me, hear more about the research, and ask questions. Irrespective of the first contact, if not received as a paper copy, I emailed a copy of the PIS – Young Person (Appendix 20) and the Informed Consent Form – Young Person (Appendix 21).

The interview for consenting young people was organised in one of two ways. Either they shared their date and time preferences, and I liaised with one of the young associate researchers, or with permission I introduced the participant to the young associate researcher over email, so that they could establish a mutually convenient time. In either circumstance, I needed to be available as the online interview was hosted via my university account. I sent an electronic meeting invitation and would always open the interview and stay for introductions before muting myself and turning off my camera to enable the young associate researcher to answer any outstanding questions, seek permission to record and re-confirm informed consent. I stepped away from my computer and the room it was in (and thus the interview), until such time that I received a text from a young associate researcher to return and end the interview recording. Both parties knew that they could contact me by text to my work mobile if they wanted me to re-join the interview at any point during their conversation.

In advance of the interview, participants shared their photographs to my email account. In circumstances where a young associate researcher had been liaising directly with the participant, photographs were sometimes shared initially via email with them. Immediately prior to the interview I would glance through the images as I uploaded them into a Microsoft PowerPoint presentation file, I did this, so that in the unexpected event I was brought into an interview conversation, I had some sense of the aspects of their salient AC experiences. I shared participants' photographs with a young associate researcher ahead of the interview time. During the interview, young associate researchers screen shared photographs one-by-one, taking the participant's lead, facilitated by the topic guide that had been practiced and refined during training (Appendix 16).

In terms of determining who would facilitate an interview, although all young associate researchers were invited, I considered their availability and the number of interviews each had undertaken.

4.8.4 Recruitment of companions and data collection procedure

Young people who had consented to take part in the research were invited to nominate their companion to receive study information. In circumstances where more than one family member or partner accompanied them in AC, they were invited to suggest the person who usually resided overnight. Young people would ask their companion if they were interested in receiving study information and share their companion's contact number or email if they agreed. Prospective participants received a PIS by email along with an invitation to talk with me about what taking part involved. I would follow-up with a telephone conversation in advance of sharing the Informed Consent Form – Companions (Appendix 22). Having ascertained a participant's availability, I approached both companion associate co-researchers to ascertain who was available to join me to co-facilitate the interview. Over time, I considered the number of interviews each co-researcher had completed, and more purposefully approached individual co-researchers in latter stages of recruitment.

4.9 Ethical considerations

Together with the ethical considerations associated with the relational basis of this research (discussed in Chapter 2), the HRA Research Ethics Committee expect that specific legal and governance aspects of research ethics have been identified and explicated. The key elements of which are now summarised.

4.9.1 CBPR and ethical approval

Prior to data collection, the Community-of-Inquiry's work had been in an advisory capacity with no requirement for ethical approval. The proposed research activities involving co-researchers were checked against the HRA tools (http://www.hra-decisiontools.org.uk/research/), and NIHR and INVOLVE definitions (2016). It was determined, based on a joint statement from INVOLVE and the HRA (2016) that ethical approval was required when members of the public are involved in primary research activities or are taking part in research. This research included both circumstances. Six members of the Community-of-Inquiry would receive training to undertake peer interviews and analysis, with an additional two-four members helping to analyse qualitative data in a co-researcher capacity. Meanwhile, the research set out to evaluate young associate researchers' experience of their engagement. Ethical issues arising from the community's engagement in the research therefore related to two distinct aspects: 1) members of the Community-of-Inquiry who engaged in a co-researcher capacity; and 2) young associate researchers being research participants from the perspective of an evaluation of their experience of participation in the research. This was fully explicated in the research's IRAS form submitted to the HRA Research Ethics Committee, with key aspects summarised in the forthcoming sections of this chapter. As detailed in Chapter 2, critical to the conduct, capacity, support and assurance of ethical practice among the Community-of-Inquiry was their training and supervision. This was a priority, both before the study opened to recruitment, and throughout the fieldwork phase.

4.9.2 Assuring informed consent

The youngest participants were 16 years old and were considered able to consent for themselves. As AC requires young people to take responsibility for aspects of care, only those who demonstrate capacity to understand the self-care requirements and monitoring required are eligible to access the AC service. Capacity to give consent was therefore expected, although this was always appraised during the consenting process. All participants recruited to the research were asked to complete an Informed Consent Form before taking part.

As part of the consenting process, a detailed verbal explanation of the information provided on the PIS was offered to all potential participants. Time and care were taken to explain what was involved, to field questions and ensure that participants' consent was informed. If English was a second language, and where (regardless of conversational ability) full comprehension of the written PIS was difficult, a detailed verbal explanation of the research was offered to support understanding.

The consent process stressed the voluntariness of participation; that every effort would be taken to ensure confidentiality and anonymity; and participants were free to withdraw from the study at any time, without reason. Assurance was given that this would not affect NHS care or any support that they received from the NHS, or partner charities: Young Lives vs Cancer or Teenage Cancer Trust. Although the young people's consent form made provision for a young associate researcher to take consent, and while co-researchers were integral to the consenting process, in practice, the completion of the informed consent form was completed by me across all participant groups. In circumstances where information about the research had been shared via telephone, the consenting process was undertaken remotely using typed initials and an electronic signature entered onto an PDF version copy of the consent form. Consent was considered an ongoing process and was reconfirmed prior to the start of interview (and any follow up interviews).

A young person's consent to take part in the research was not dependent on their companion volunteering to take part; the recruitment of companion participants was linked but considered a separate recruitment process. Potential participants had at least 24 hours between the time that they received the PIS and giving consent, so they were able to think about their decision and ask questions.

4.9.3 Safeguarding wellbeing of participants

As a Community-of-Inquiry, we worked together to promote the wellbeing of participants throughout the duration of the study, with responsibility for this resting with me as Principal Investigator (PI). All research participants were informed that they could ask questions, express concerns or withdraw at any point. The young associate researchers and companion associate co-researchers who facilitated interviews were trained to looked for signs of distress or discomfort during interviews. All interviews were conducted with sensitivity, and recognition for the emotive nature of participants' experience formed part of co-researcher training.

If an interview needed to be stopped, participants would be given time to recompose themselves, asked if they would like to continue or to meet again on another date, although in practice this was not required. Some participants did become tearful or emotional during interview. It was accepted that talking about cancer experiences can sometimes be emotional which was acknowledged by the interviewer, and the conversations continued sensitively, taking the participants' lead. For one-off or more ongoing psychological support, provision had been made with the young people's psych-oncology service at the study site to accept referrals for all participants in this study.

4.9.4 Management of personal data

Whilst co-researchers may have received participants’ email addresses (with their verbal consent) for the purposes of arranging interviews, access to other personal data, for example, home address or diagnosis was restricted to me as study PI. Safeguards were in place to ensure that data were processed in accordance with data protection principles. This included co-researchers, who had been educated about confidentiality and data protection within the preparatory training workshops.

Following their informed consent, all participants were allocated a numerical identification (ID) number, and their data were anonymised in this way thereafter. Full participant details were stored on a secure UCL encrypted network, password protected and accessible only by me. Two electronic folders were created: one that had the ID number alongside the full name and contact details of a participant (data management file) for which only I had access. A second folder, stored separately from the data management file, contained the interview data set and anonymised participant demographic information. Members of the Community-of-Inquiry had access to anonymised interview transcripts for the purposes of data analysis. To help ensure confidentiality of personal data, young people were given guidance for taking photographs/video which included not taking selfies. If participants did present images at interview that identified themselves or others, they were digitally edited to obscure identification.

Interviews were electronically transferred in an anonymised, coded format from a UCL approved server for transcription. After transcription had been checked, they were deleted from the server. Transcription involved removing any names referenced, places and other identifiable information from the transcript – this was checked by me on receipt of the transcript, and anything missed was manually removed. Participants were asked at the close of their interview if they would like to be kept informed about study progress and findings. The purpose for collating and retaining a participant's home address, year of birth, ethnicity, cancer diagnosis, email and telephone contact were either a) to report on the participant demographic case mix or b) maintain contact to share study updates and findings.

4.9.5 Considerations related to being a single-site study

One of the most relevant ethical considerations associated with this research was its status as a single-site study. It engaged a TYA community that members of the multidisciplinary team knew. These members supported recruitment to the research, describing and sharing study information, and in some circumstances, they may have become staff participants of the research themselves.

Nurses working in the Day Care and AC unit shared information with young people who were eligible to take part. Given this is a population they knew well, it presented challenges to the assurance of complete anonymity for participating patients, a perspective that has been described by Saunders, Kitzinger and Kitzinger (2015). Operating on a continuum (Scott, 2005) anonymity requires the balancing "of two competing priorities: maximising protection of participants' identities and maintaining the value and integrity of the data" (Saunders, Kitzinger and Kitzinger, 2015, p.617). What became important in this study's context was that the detail of participants' narrative fully represented their experiences yet could not be attributed to a known individual. Beyond the boundaries of the clinical unit, whilst the safeguards detailed in the ethics application provided this assurance, I introduced additional measures when writing this thesis to obscure young people's and companions' identities. In Chapter 6, within my presentation of the research findings, to enhance anonymity and delink a participant's photograph ID from their cited interview narrative, I took the decision to omit the ID in circumstances where a) a photograph has been included, and its curator is known to the nursing team or b) where the nature of this participant's narrative could be considered identifying or sensitive. Critical to this research, however, was the importance of conveying a truthful, candid account of experiences, and I revisit the details of how the findings are presented in the opening section of Chapter 6.

4.10 Chapter summary

In this chapter the study design developed to answer five research questions has been described, with the methods and data collection procedures relevant to each phase and participant group set-out and explained. Associated ethical issues have been highlighted, recognising the additional challenges of being a single-site study, collecting data with TYAs, and working with young associate researchers. Chapter 5 follows, where data analysis is examined in detail, and I explain how this analysis was co-produced in a participatory context.

Chapter 5 Data analysis

5.1 Introduction

Central to participatory research is that the generation of knowledge is not seen as a single-event process; it is constructed in community dialogue within an emergent and iterative dynamic (Cook 2012; Paulus *et al.* 2008). The CBPR approach to participatory analysis is similarly based on the epistemological belief that knowledge is socially constructed through conversations, the goal of these being critical thinking and action (Wallerstein *et al.*, 2018).

According to Tandon (1988), authentic participation requires those involved to also take part in analysis. Whilst it cannot be assumed that all participatory research embeds participatory analysis (Nind, 2011; Clarke *et al*., 2018), or that within CBPR studies this is always achieved beyond a consultative role (Jackson, 2008), engaging in a more egalitarian type of team-based analysis was key to the design of this research. On account of this not being commonplace, I have dedicated a chapter to explaining the analysis stage in detail.

The underpinning principle guiding the analytical approach was its enactment as a Community-of-Inquiry. From the outset, while upholding a commitment to this, and to the CBPR paradigm, I accepted that my professional biography and my role as ‘research lead’ would both influence and confer certain expectations of myself in relation to data analysis; these are explored in the context of this chapter.

I open this chapter articulating the methodological intent. After introducing the methods I chose to structure data analysis, I then show how, as a community of co-researchers we engaged in the analytic process. This chapter focuses on the analysis of young people and companion and staff data (phases 2 and 3 of the study) as depicted in Figure 5-1. Analysis of the co-researchers’ experiences of participating in this research (phase 4) is discussed in Chapter 8.

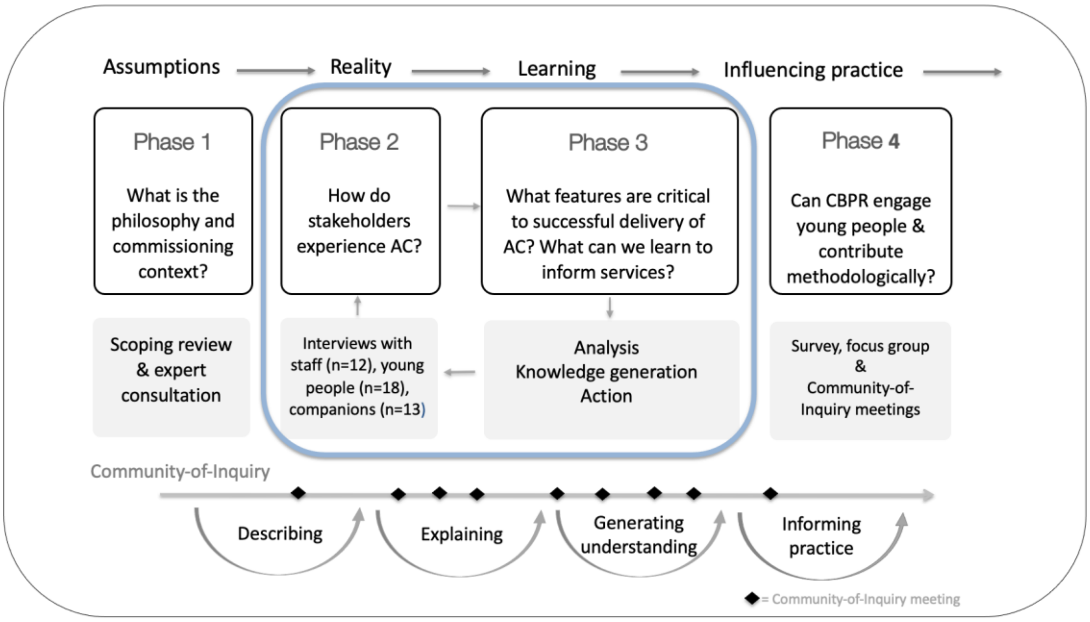

Figure 5-1: Overview of the phased research design (2019-2022) with analysis highlighted

5.2 Theoretical underpinnings

At its foundation, qualitative analysis involves comprehending data, synthesising meanings, theorising relationships and recontextualising data into findings (Morse, 1994). Our approach to analysis aimed to embed this structure. As in all interpretive research processes, in this study, data collection and analysis informed one another iteratively, shaping and directing the research inquiry (Thorne, Kirkham and MacDonald-Emes, 1997, Thorne *et al*., 2004). It was enacted in a way that both acknowledged the constructed, contextual nature of individual experience (Thorne, 2016; Eakin and Gladstone, 2020) and the creation of a participative reality (Heron and Reason, 2008).

Epistemologically, direct access to participants' reality was not considered possible; rather, reality was conveyed through participants' language and conversation, photographs and our observation. Hence, analysis was not regarded as a finite act or stage of the research; the practices of analysis and interpretation were considered, as Denzin and Lincoln (2018) posit, "always ongoing, emergent ... [and] embedded in an ongoing historical and political context" (*ibid*, p.757). The fact that data were collected during a pandemic drew attention to the perspective that context was of relevance to our research inquiry. Illustrative too of the emergent nature of analysis is the example of how, during an interview, in-the-moment interpretation of what an interviewee said when offered back by the co-researcher interviewing, became as Brinkmann and Kvale (2018) describe, part of the interview conversation.

5.2.1 The analytic aim

There are different analytic methods I could have employed in the context of this study. However, just as ontology and epistemology determine a research's theoretical perspective, methodology and then methods, this same scaffolding remained relevant when defining an analytic framework that would inform the knowledge generated and build credibility in the provenance of the research findings. The analytic aim was to describe experiences, construct understanding, and offer explanations within a critical interpretative process. Within this, extending beyond explanation and interpretation, it was intended that the knowledge generated would be of service to clinical practice and would promote action.

After a period of weeks researching and determining suitable methods to enact data analysis, I chose 'value-adding' Analysis (Eakin and Gladstone, 2020) as the overarching analytic approach. The 'value-adding' approach to qualitative analysis is "constituted by principles of interpretation, contextualisation, criticality and the 'creative presence' of the researcher" (Eakin and Gladstone, 2020, p.1). It premises the researcher as the primary mechanism for transforming data into what Eakin and Gladstone posit as the "key products of qualitative research – concepts, accounts and explanations" (Eakin and Gladstone, 2020, p.1).

5.2.2 Value adding analysis

The descriptor 'value-adding' is borrowed from economics (Eakin and Gladstone, 2020), and it refers to "the increased value of the knowledge produced by a process of analysis that specifically reaches beyond 'face-value' (self-evident) meanings of data” (Eakin and Gladstone, 2020, p.2). As an end point, value-adding analysis requires more than the identification of themes. It seeks to construct “concepts that characterise findings at a more abstract level” (*ibid*, p.2).

Value-adding analysis does not pre-suppose subject expertise from another research discipline, nor is it aligned with a particular research methodology. Whilst Eakin and Gladstone have not specifically described its use in a participatory context, I determined its suitability for this research as it aligned with our analytical intent and the ethos of the participatory approach. Extending data interpretation to “theorise data” by exploring how concepts relate to one another (Eakin and Gladstone, 2020, p.2), was similarly self-appraised not to be at odds with the action imperative of CBPR, nor my personal alignment with the disciplinary logic of interpretative description (Thorne, 2016).

It was important that all members of the Community-of-Inquiry could engage in analysis without the requirement for lengthy methodological training. Having proposed working with value-adding analysis to the Community-of-Inquiry, there was consensus that it felt accessible. I accepted, however, that irrespective of this, I would be required to interpret and facilitate its enactment. Part of this facilitation included writing an abridged account of Eakin and Gladstone’s approach, which I incorporated into Part 2 of the co-researcher handbook to support co-researchers’ practical engagement (Appendix 23).

Eakin and Gladstone (2020) describe analytic devices (actions, strategies, thought exercises) to help operationalise, extend and enrich analytic practice. Namely, *putting reflexivity to work; everything is data; reading for the invisible; reading for anomaly; generative coding; reading for gestalt* (the whole being greater than the sum of its parts); *heuristics for theorising* (thinking theoretically); and *writing as analysis* (Eakin and Gladstone, 2020). I strove to foreground and embed these principles, whilst acknowledging that the task of writing for analysis, beyond the naming and describing of themes and concepts, lay with me.

To help structure our engagement in the analytic process I identified different 'methods', namely: the Sticky Notes Method (Burgess *et al*. 2021), an interactive framework for identifying and sorting data in team-based qualitative analysis (reported in section 5.4.3) and in the case of the photo-guided peer interviews, Systematic Visuo-Textual Analysis (Brown and Collins, 2021), a method of analysing combined visual and textual data (see 5.4.5 and 5.4.6). I appraised both from the perspective of their potential contribution to analysis, and how accessible they were to a community of co-researchers. Given that a fundamental characteristic of participatory research is its nonlinear research process, I knew, from the outset that the methods chosen to enact the analysis would need to be applied with flexibility. In writing this chapter I have chosen to incorporate both the methods chosen and piloted to enact the analysis, and those we took forward to build a descriptive, then explanatory interpretation of the data.

Figure 5-2 depicts a Venn diagram to summarise how data analysis was scaffolded from its epistemological basis (left-hand side) to the methods used to enact analysis (on the right). I drafted this diagram prior to engaging in analysis, to ensure that I coherently rooted our approach. The diagram describes three intersecting and overlapping spaces within which I articulate how one space informed and contributed to the next.

5.2.3 Defining the analytic process

The analysis undertaken was inductive. It set out to describe AC experience, then build understanding, develop explanations and interpretations within and across different data in a manner that iteratively built knowledge to inform practice, whilst advancing conceptual understanding of age-appropriate care (Lea *et al*., 2018).

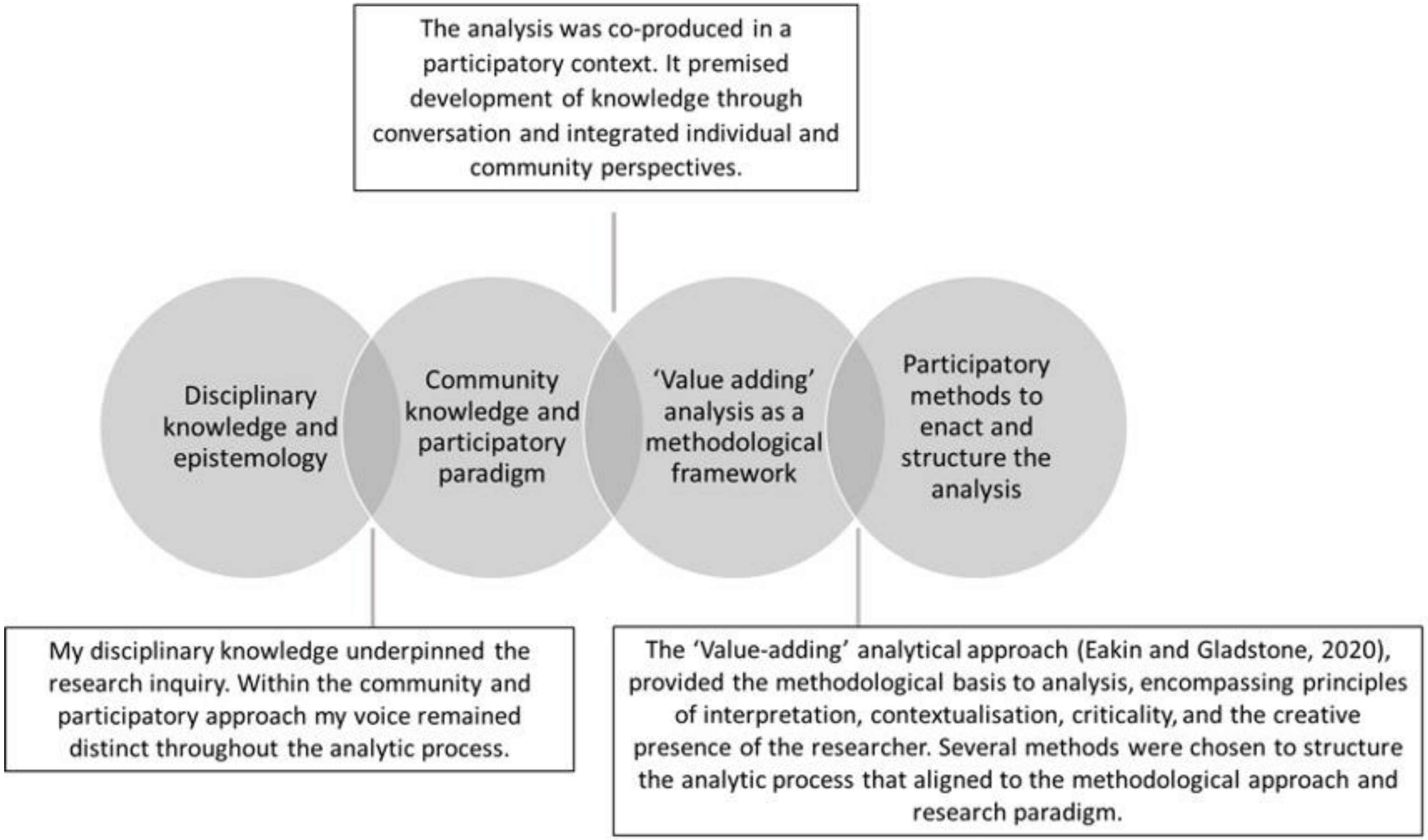

Figure 5-2: Intersectional spaces of data analysis

5.2.4 Defining data for analysis

Data, a “signifier on which knowledge rests” (St. Pierre, 1997, p.185), is pivotal to the work of analysis. In the context of this research, data went beyond interview transcripts to encompass photographs, observations, field notes and Community-of-Inquiry meeting discussion. Uniting this definition of data were two premises: data are not passive and stable entities (Koro-Ljungberg, 2016, p.462), nor do data speak for themselves (Thorne *et al*., 2004; Eakin and Gladstone, 2020). Therefore, working as a Community-of-Inquiry, our critical and reflexive engagement with the data not only informed the analysis, but created further data in and of itself deriving from these conversations – extending interest beyond *what* knowledge was generated to consider *how* it was formed. The co-creation of research knowledge was a robust yet creative endeavour in which criticality, experience and relationships were centred (Langley *et al*. 2018).

Analysis was therefore perceived as ‘relational and engaged’ work (McCorkel and Myers, 2003; Greenhalgh *et al*., 2016; Duncan and Oliver, 2019). It leveraged opportunities to integrate multiple personal biographies and types of knowledge within interpretation of the data, working towards what Wallerstein and Duran (2010) refer to as ‘knowledge democracy’.

Having described the methodological basis to analysis, the following sections focus on how we engaged in analysis and report the participatory approach.

5.3 Undertaking the process of analysis

The analytic process was interactive, starting with staff interview data, then progressing to the young people’s and companions’ data sets. It commenced in October 2021, three months after completion of staff interviews, and just over half-way through young people and companions being recruited to the study. Analysis comprised both individual engagement with the data and a series of five in-person

Community-of-Inquiry workshops[2], held on Saturdays at community locations within the geographical vicinity of the hospital. Upon the suggestion of co-researchers, the fifth analysis workshop was held in March 2022 at the TYA Day and AC unit (research site). This helped co-researchers tangibly connect with the environment described by participants. Appendix 24 details the format of each of the five workshops and the composition of co-researchers who participated.

5.3.1 Key principles and foundations

The approach taken prioritised conversational inquiry over complex coding procedures. Keeping a sense of the whole narrative was important at every stage of analysis, as opposed to the dissection of data into discrete words or segregation of individual's experience. Our engagement with the data was invariably practical, involving annotating paper copies of transcripts and photographs, drawing relational mind-maps and trying out analytic tools. Within this, it involved cycles of presenting, naming, interpreting, contextualising, then re-presenting and reinterpreting the data as the analysis progressed over time.

5.3.2 Enacting analysis

Value-adding analysis (Eakin and Gladstone, 2020) formed the foundational basis to our approach, the analytic procedure enacted in such a way that it extended from basic description of experience (where we were working closely with the data), to a level of abstraction and conceptualisation. To ensure we did not overlook the practical imperative of the research, at every stage of inquiry, evidence that had a clear service improvement focus was noted and grouped separately. We held and managed this evidence dynamically, using it to shape conversations with stakeholders during latter stages of the research.

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[2] Meeting in person had been risk assessed and approved by the university department with steps taken to mitigate risk of Covid-19 transmission and infection. The feasibility of holding an in-person meeting was reappraised prior to each scheduled meeting. Co-researchers exercised their choice to attend.

Arguably, analysis had already taken place during and after interview conversations, within field note memos, transcript checks, and at other contact points where we were thinking about the data. However, analysis formally took place within the workshop series, where together we read transcripts, annotated notes and diagrams, shared and contrasted our reading of data before engaging in a one-, or two-hour discussion which we voice recorded.

Four analysis workshops ran for approximately six hours (with a break for lunch), had a minimum of five attendees and had a clear analytic focus. In Workshop 1 we focused on analysing staff experiences of AC. We progressed to analyse young people's experiences of the service in Workshop 2. In addition, the companion associate researchers and I met separately (Workshop 3) to undertake preliminary analysis of companions' experience. This was then integrated and advanced within Workshop 4.

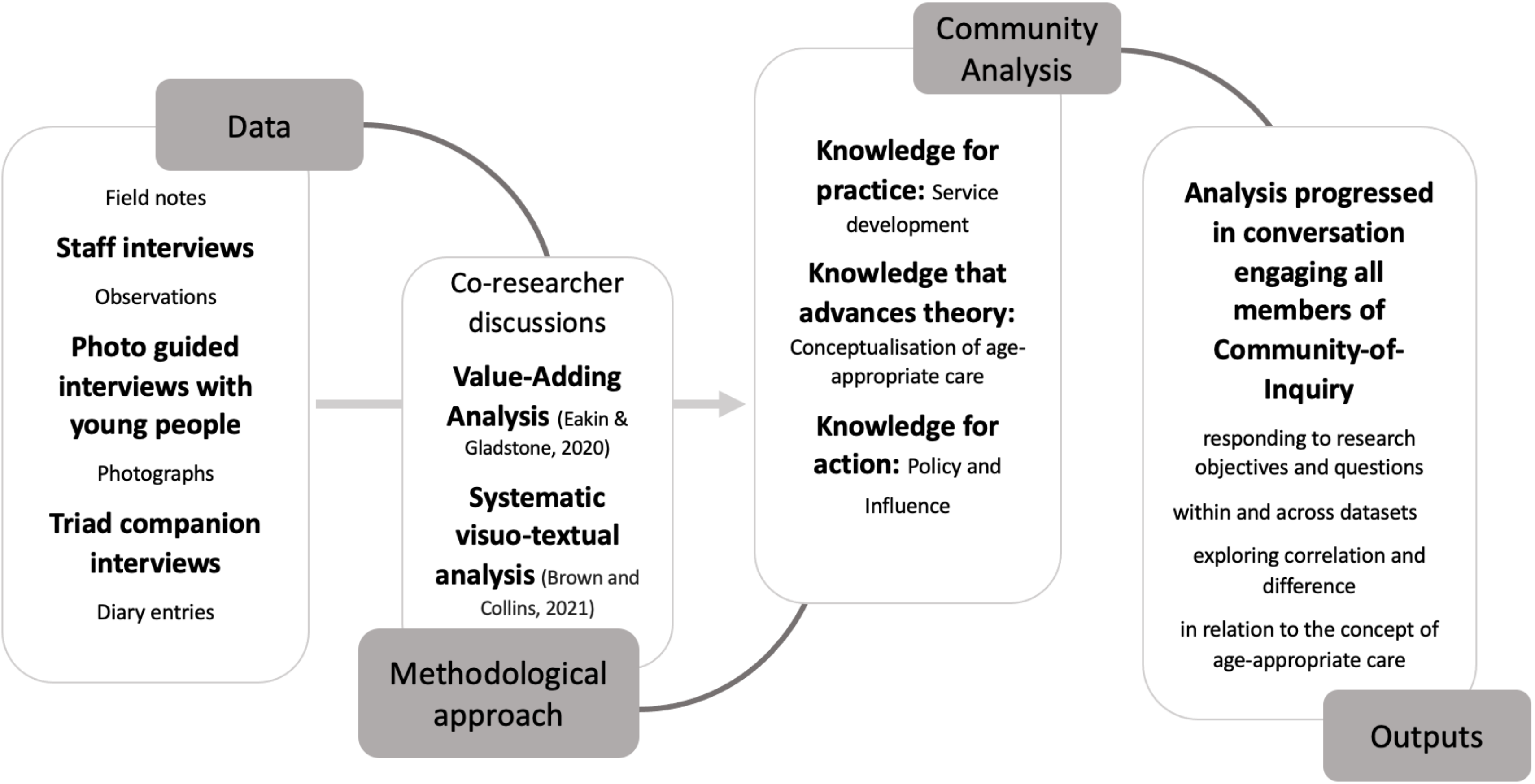
All Community-of-Inquiry meeting dates were negotiated in terms of their day, timings, breaks and length. Sometimes we worked in pairs, but usually we sat together as a whole group around a large table. Irrespective of the meeting venue, we surrounded ourselves with A4 sized coloured photocopies of different participants' photographs of their experiences; pinned to the wall, these helped us remain visually connected with AC experiences. This felt especially important for the co-researchers as they had no personal experience of AC. Whilst each meeting focused on different participant data, we moved iteratively within and between different data sets in all the workshops, always opening with individual and shared reading of an interview transcript. This helped root our discussion; it served too as a useful way of checking that our developing analytic interpretation was clearly evidenced within participants' interview narrative.

The scoping review literature was revisited during analysis to consider our findings in relation to AC's reported contribution to experience of care. We did not commence this until Workshop 4, so as not to default to a more deductive approach by searching for pre-existing themes. We returned to this literature once analysis had advanced to a thematic and conceptual level. Similarly, we did not consider our emerging interpretation in relation to the concept of age-appropriate care until the latter stages of analysis. Throughout the process, we remained cognisant of factors such as a TYA's age, location of AC, socio-economic status, or a participant's support network. To help extend our analytic focus, in Workshop 4, I distributed six coloured index cards among the co-researchers present (including me). Each card detailed a different analytic lens that was pertinent to either CBPR, value-adding analysis or the research objectives (Appendix 25). During the workshop we considered the data and our interpretation through the lens of the card we had chosen. We then revisited each lens: *power and equity; our use of language; context; assets and resources; general versus specific* and the *TYA philosophy of age-appropriate care,* sharing our notes and what we had evidenced from the data in conversation. In Workshop 5 we revisited the different analytic lenses, although by this time the index cards felt superfluous as the perspectives had become an embedded part of data interpretation.

The Co-Researcher Handbook (Appendix 23) written and distributed prior to Workshop 1 details the principles of our analytic approach. Figure 5-3 offers a visualisation of how data, the overarching analytical approach, and methods all aligned in service of answering the research questions.

5.4 The analytic procedure

I now provide an overview account of the analytic procedure undertaken. The analytic procedure, whilst undertaken in a participatory context, required me to prepare data for analysis and progress coding alone. The presentation of this process is described within two analytic stages: individual (me as lead researcher) and participatory. This is visually represented in Figure 5-4, and I now describe the process in some detail.



Data

Field notes

Staff interviews

Observations

Photo guided interviews with young people

Photographs

Triad companion interviews

Diary entries

Methodological approach

Co-researcher discussions

Value-Adding Analysis (Eakin & Gladstone, 2020)

Systematic visuo-textual analysis (Brown and Collins, 2021)

Community Analysis

Knowledge for practice: Service development

Knowledge that advances theory: Conceptualisation of age-appropriate care

Knowledge for action: Policy and Influence

Outputs

Analysis progressed in conversation engaging all members of Community-of-Inquiry

responding to research objectives and questions

within and across datasets

exploring correlation and difference

in relation to the concept of age-appropriate care

Figure 5-3: Links between Data, methodological approach, community analysis process and outputs

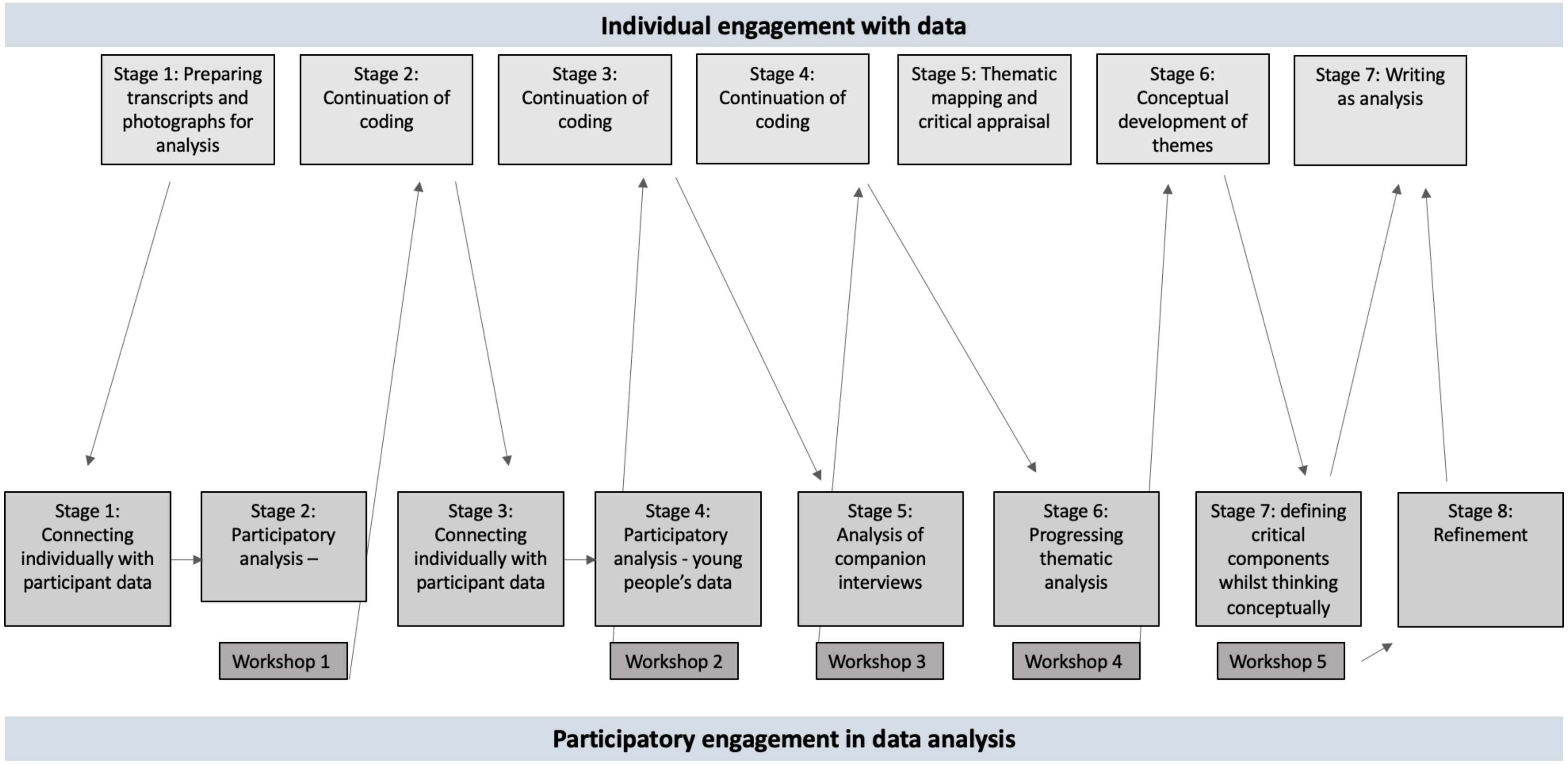


Figure 5-4: The analytic procedure

5.4.1 Individual stage 1: Preparing transcripts and photographs for analysis

Interviews were transcribed in preparation for analysis. I transcribed six interviews to gain some experience in this skill, and the remainder were transcribed by a UK based human-transcription company. Silences and pauses were included, along with hesitation, ‘ums’ and ‘errs’. Each transcript was checked whilst I listened to the audio file; edits were made to ensure anonymity while retaining pauses and emphasis in narrative. Each transcript was set out in a line-numbered Microsoft Word document. Interview data were also stored in NVIVO 2020, under UCL license, to facilitate data handling and auditable management of the vast amount of data being manually coded. Participant photographs were checked to ensure anonymity and were grouped and saved securely on the UCL server as a PowerPoint slide series (along with a back-up anonymised copy of the participant’s interview transcript).

Each Community-of-Inquiry analysis meeting focused on a different participant group. Usually two, sometimes three transcripts were selected for each co-researcher attending and were shared in advance of the workshop. The choices aimed to reflect diversity from the perspective of participant role, age, gender, ethnicity, diagnosis and treatment pathway or profession. The distribution of transcripts was such that more than one co-researcher received the same transcript so that one’s individual reading of the narrative and preliminary coding could be compared, contrasted and discussed with a second reviewer.

5.4.2 Participation stage 1: Connecting individually with participant data

Co-researchers were invited to read their two selected transcripts line-by-line before the workshop and to connect broadly with the data, e.g. noting what stood out as striking, interesting or perhaps contradictory. Co-researchers were encouraged to ask questions of the data and to consider ‘the key parts of the story’, as well as make notes on their transcript copies and review field notes and logs before coming together as a team.

5.4.3 Participation stage 2: Engaging in participatory analysis

Although we had been working together since February 2020, the first time we had connected in person was in the initial analysis workshop in October 2021. After re-introductions, we talked generally about our analytic approach: ‘What were our guiding principles?’; ‘What might we expect to see and hear?’; ‘How do we check whether something really is critical to experience?’; ‘What might we do if the task felt too emotive at times?’ We returned to an iteration of these questions at the start of each subsequent meeting.

Each workshop encompassed line-by-line reading of transcripts, shared discussion of our individual readings, noting significance (whether key words or sections of narrative) and exploration of this together in conversation.

Workshop 1: Staff experience of Ambulatory Care

Workshop 1 centred staff experiences of Ambulatory Care. We categorised broadly within the data to describe the AC setting, drivers for AC, defining characteristics of AC, preparation for AC, how the pathway intersects with one’s disciplinary approach to care, its perceived benefits to young people and families and AC’s contribution to delivery of age-appropriate care. As Workshop 1 progressed, it became evident that whilst it was advantageous to develop a stand-alone analytic interpretation of staff experience, these data’s most potent analytic utility consisted in helping advance conceptual understanding of AC.

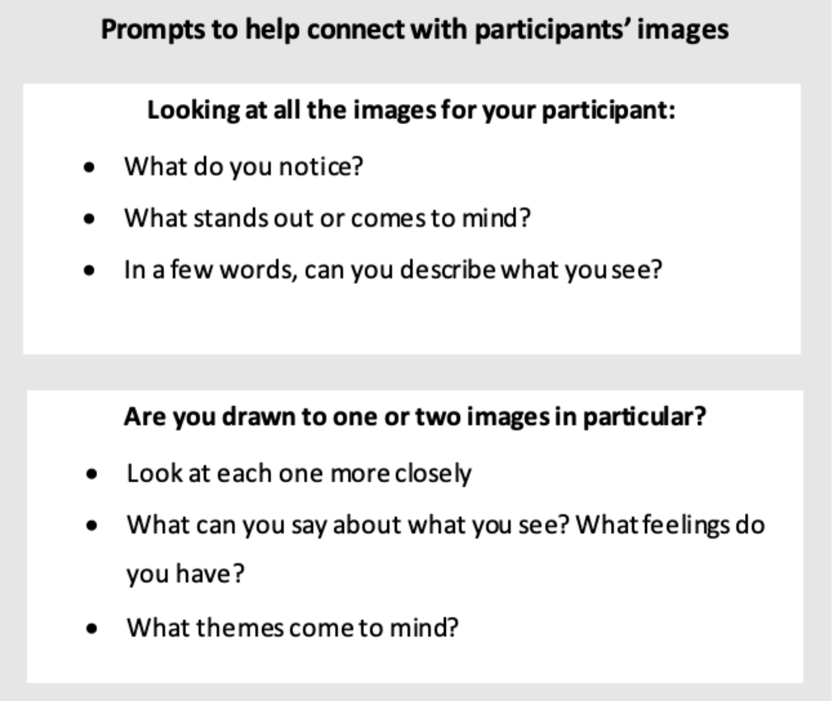
I had in addition researched the “Sticky Notes” Method (Burgess *et al*., 2021), as an interactive framework to help organise the data. This included discussing its potential use with the paper’s corresponding author, who had developed it for use within a CBPR study. Arriving to the workshop with a pile of coloured sticky notes, it had been intended that we would pilot the method as an additional analytic tool in Workshop 1, to help shape and organise coding. As it transpired, however, we became immersed in discussion, mapping categories, patterns and relationships out loud and on a flipchart; the sticky notes became redundant. Although the notes remained to hand, we did not pursue this method in the other workshops.

5.4.4 Individual stage 2: Continuation of coding

I systematically mapped the coding from Workshop 1 into an NVIVO 2020 file. Six transcripts had been coded and discussed in the workshop. Over the course of the following weeks, I individually coded the remaining six transcripts by hand, using NVIVO 2020 to manage the coding structure.

5.4.5 Participation stage 3: Connecting individually with participant data

In preparation for Workshop 2, young people's interview data and photographs were shared with co-researchers attending the meeting, accompanied by an introduction to Systematic Visuo-Textual Analysis (Brown and Collins, 2021), a framework for analysing visual and textual data. Co-researchers attending Workshop 2 received two transcripts and the accompanying photographs so that when we met, each participant's dataset would have been read by two co-researchers. Co-researchers were invited to revisit the online tutorial on visual methods that had been developed as part of co-researcher training, before connecting with participants' images to consider their response to the 'prompts' posed in Figure 5-5 below.



Prompts to help connect with participants' images

Looking at all the images for your participant:

- What do you notice?
- What stands out or comes to mind?
- In a few words, can you describe what you see?

Are you drawn to one or two images in particular?

- Look at each one more closely
- What can you say about what you see? What feelings do you have?
- What themes come to mind?

Figure 5-5: Prompts to support visual analysis of participants' photographs

5.4.6 Participation stage 4: Analysing young people's data

Workshop 2: Young People's Experiences of Ambulatory Care

Twelve photo-guided peer interviews with young people had been completed when we reconvened as a community in Workshop 2. The room was set up with all the participants' photographs on display and grouped by each participant. We revisited the image 'prompts' before working in pairs to re-read and begin analysis of the data: photographs and transcripts together (Brown and Collins, 2021). Visually present as A4 colour copies pinned to the wall, the photographs facilitated our movement within and between interviews and images as our analysis progressed in conversation.

At the study design stage of the research, it had been anticipated that participants' photographs would act as a conduit to the interview conversation, facilitating a richer and more nuanced understanding of experience. Once engaged in fieldwork however, our consideration of the images amplified to their becoming data 'in and of themselves' (Chapman, 2017). We saw an analytic requirement to analyse the visual and textual data individually, yet also together as two interrelated, yet different facets of data (Brown and Collins, 2021, p.1280), and thereafter we adopted this approach.

Following the presentation of a worked example by me, we worked through the steps of Brown and Collins (2021) Systematic Visuo-textual Analysis framework with five of the six interview transcripts during Workshop 2. Described as a “weave between three elements and two levels” (Brown and Collins, 2021 p.1281) commencing with noticing, then focusing, before moving to conceptualisation. Appendix 26 illustrates the process, offering an example of how participants’ photographs and images came together as an interpretive whole.

Workshop 2 was used to capture the Community-of-Inquiry’s methodological insights thus far: ‘Was there a line of questioning that felt underexplored in the interview schedule?’; ‘Was there emerging evidence of something that we might like to focus on within the remaining interviews with young people?’ I invited feedback about the peer-interview approach, asking co-researchers: what they had noticed about the interviews taking place; how the conversations(s) might have been different with an academic researcher or a clinician; and what role did they think the photographs played within the articulation of experience – which I revisit in Chapter 8.

Our visuo-textual analysis of six participants’ data was revisited in a separate conversation after Workshop 2. We were concerned that some analytic opportunities may have been missed due to the analytic approach being led by photographs, followed by the accompanying transcript. Would some of the interview narrative not get coded as a result? On appraising the visuo-textual analysis templates, Systematic Visuo-textual analysis ‘stood up’ as sound, and my mapping of coding from the transcripts onto NVIVO 2020 by complete sentence or paragraph was more about data management; it ensured that the product of visuo-textual analysis could be understood in detail and context.

5.4.7 Individual stage 3: Continuation of coding

Following the second workshop, I mapped the coding from Workshop 2 into an NVIVO 2020 file. This was not to create a duplicate of the visuo-textual analysis, rather it was to collate and organise codes and themes that we had mapped on paper and in conversation. The remaining six interviews that had been completed (at this time-point) were analysed and mapped following the same process.

5.4.8 Participation stage 5: Analysis of companion interview

Workshop 3: Companions' experiences of Ambulatory Care

Workshop 3 focused on reading, coding and progressing thematic analysis of the companion interviews. An associate (companion) co-researcher and I met in person, and we were joined virtually by the second companion co-researcher. We each had six transcript copies to read prior to the meeting. Following the previous format, we shared our respective reading and annotations of each transcript together, then engaged in discussion to thematically map the developing analysis, and propose explanations, before returning to the transcripts to reconsider our explanations against participants' data.

We explored the dynamic of the triad interview conversation in this workshop: sharing experiences from our respective standpoints on the piloting of the approach and its contribution to the interview conversation, which is discussed further in Chapter 9, section 9.2.2.

5.4.9 Individual Stage 4: Continuation of coding

Following preliminary analysis of the companion interviews, I again mapped the coding into a NVIVO 2020 file. The remaining four (and subsequent companion interviews) were read by me and the associate co-researchers, hand coded, then coded to NVIVO inductively. This meant that some new codes were created, as well as data being assigned to existing codes.

Interview transcripts were also coded from the perspective of the triad interview approach to help progress our consideration of the method. Three categories were created: *the methodological approach*, notion of *relatable experience* and '*other'*. The coded data were shared with the associate companion co-researchers and used as the basis for an additional discussion about the contribution of the triad method that we had developed.

5.4.10 Participation stage 6: Progressing thematic analysis

Workshop 4: Thematic development of findings

We reconvened as a Community-of-Inquiry three months after first meeting, to progress our interpretation of the young people's, companion and staff interview experiences in a fourth workshop. This workshop focused on the thematic development of our interpretation within and across different data. New participant interviews (i.e. those completed since our last meeting) were brought to the workshop for individual then collective reading and coding. We then engaged in discussion about the data collated thus far as a whole. I offered the themes we had developed to the group, printed on unassembled slips of paper, and invited co-researcher colleagues to discuss how they saw the data fitting together. They helped create the basis of a visual map to express relationships in the data. We returned to transcripts and photographs to evaluate the strength of the explanation being proposed. We considered the data through the different analytic lenses described in Appendix 25.

5.4.11 Individual Stage 5: Thematic mapping and critical appraisal

After Workshop 3, relationships within and between data were remapped on flip chart paper. I revisited the NVIVO 2020 files to reconsider our developing interpretation against the coded data.

5.4.12 Participation stage 7: Defining critical components whilst thinking conceptually

Workshop 5: Thinking conceptually

Our final analysis workshop took place on the TYA day and AC unit at the study site, at the request of the co-researcher community. We spent time exploring the facilities offered by the service, and its geographical relationship to the hotel and hospital. This not only helped 'bring to life' what so many participants had described to co-researchers, it also helped contextualise and inform the ensuing interpretation.

I presented a visual map of the interpretation thus far and summarised the themes within and across the data that we had defined in our previous workshop discussions. We then revisited the different analytic lenses as we progressed our interpretation in conversation, with the visual map centre stage. We tentatively proposed a conceptual interpretation, which was explored in a recorded discussion. At this stage, the conversation was anchored by consideration of our findings in relation to the concept of age-appropriate care (Fern *et al*., 2013; Lea *et al.,* 2018) and the culture of young people's cancer care (Lea, Taylor and Gibson, 2022). As we wrestled with the definition, hierarchy, or alignment of different concepts, co-researchers drew diagrams and pictures to help further explain and give added meaning to themes and relationships within the data.

Workshop 5 also encompassed an action imperative which was central to our discussion: to describe the critical components of AC as evidenced by the data, and to define where practice could be strengthened at the study site. We explored what would be required of new AC services to best support young people and their families.

5.4.13 Individual Stage 6: writing as analysis

Following Workshop 5, I began the process of drafting a written account of the research findings. The analytical map that we had used to anchor and progress the analysis, was updated to reflect the progress we had made in the final workshop. Before the research closed to recruitment in June 2022, I had the opportunity to partially address the gender weighting of participants, recruiting a female TYA and her partner. These transcripts were analysed by me and the co-researchers who had interviewed the participants.

5.4.14 Participation stage 8: refinement

Prior to being finalised, my conceptual advancement of the findings was shared among the Community-of-Inquiry to gauge representativeness and canvas further analytic insight.

5.5 Centring relationships: extending reflexivity to all those involved

The nature of participatory methodologies demands suspension of the "search for a singular knowledge which is owned by ourselves" (Clarke *et al.,* 2018, p.1421), instead requiring attentiveness to the affordances of different co-researchers' perspectives. Reflexivity, being integral to the interpretative process (Paulus *et al.* 2008), thus takes on plural meanings in a participatory research context (Muhammad *et al.* 2014), focusing on the "juxtaposition of self and subject matter – multiple voicing" (Clarke *et al*., 2018, p.1421).

Participatory analysis requires a different consideration of reflexivity, one which is inclusive of all involved (Muhammad *et al.* 2014). Our individual and collective histories, experiences and perspectives become relevant, in this context, as too our relationships with (and to) one another. Greenhalgh and colleagues (2016), in positing relationships as contributory to analysis, suggest that in community-academic partnerships, the nature and quality of these partnerships influence the co-creation of knowledge.

5.5.1 Positionality and the generation of knowledge

Reflecting on our partnerships, at the time of commencing analysis, the Community-of-Inquiry had been established for about one and a half years. We had built stable, trusting relationships and co-researchers regularly reflected on their own experiences, or shared alternative positions or perspectives in our discussions together.

The six co-researchers who had been engaged in data collection (four young associate researchers and two companion associate researchers) joined me as core members of the participatory analysis team. We were twice joined by an experienced clinical nurse from the AC unit, and on two occasions by an academic colleague and supervisor with a health sociology background.

From the research's conception, the knowledge derived from co-researchers' personal experience had been considered an asset (Clarke *et al.* 2018). Co-researchers brought perspectives from their academic studies, work and/or personal interests. Together, these created a myriad of different knowledges and positionalities that extended beyond personal knowledge and experience of cancer. Collectively, we brought to the analytic table more than the sum of our 'expertise by experience' or (in the case of me and my professional and academic colleagues) 'expertise by profession' (Gillard *et al.* 2012). This characteristic is a methodological strength. Yet within it, subjects such as positionality and identity, as experienced by individual members and in relation to the generation of knowledge, became relevant.

'Power sharing' is a core CBPR principle, demanding "explicit attention to power as it relates to the identity and intersectional positionality of researchers" (Muhammad *et al.* 2014, p.3). More specifically, where power and status intersect is, Muhammad and colleagues (2014) suggest, is rarely articulated. This perspective extends CBPR consideration of *community* as a single unit of identity, to consider how researcher team identity informs effective CBPR practice (Muhammad *et al.* 2014). Community membership as well as relationship dynamics and positionalities, thus become relevant to the enactment of participatory data analysis within CBPR. If one also supports the perspective that "the researcher[s], not the recipe, is driving the interpretation" (Thorne *et al*., 2004, p.6), it creates an imperative to consider who is engaged in analysis and how they might shape the construction of knowledge.

My own relationship to this research was multifaceted: it encompassed intersecting aspects which included motivation (to build an evidence base), professional roles (nurse, student researcher, principal investigator), expectations (being a recipient of public grant funding with the inherent responsibilities this entailed) and biography (professional and family experience of cancer). I had more in-depth and applied knowledge of the AC literature and clinical service than other members of the Community-of-Inquiry, and the research's objectives were grounded in my professional experience of AC. I concurred with Tuffrey-Wijne and Butler (2010) that irrespective of the participatory ethos, authority would still lie with me, the academic researcher. This extended beyond analysis to the conduct of the research overall.

In a role which involved coordinating the work of the community, facilitating workshops and directing our overarching approach, it would have been difficult for me not to impact the conduct of data analysis. The juxtaposition of this understanding with a genuine commitment for analysis to be a co-constructed endeavour, at times left me feeling conflicted. I tried to mitigate the inherent contradiction by encouraging co-researchers to lead on aspects of our work together if they wished. During workshops I consciously created space for others to talk and did not lead or direct the conversation or next steps unless it felt needed. On an ongoing basis however, I respected the fact that co-researchers' other commitments would have a bearing on what was practically possible (Cook, 2021). I accepted that it was my role to manage the project and provide overall direction.

Wallerstein and Duran (2010) pragmatically assert that there is never a perfect equilibrium, with research undergoing cycles of greater and lesser participation and ownership. As a Community-of-Inquiry we discussed how our co-researcher engagement and contribution to analysis, as in every stage of the research, would be influenced by perceptions of positionality, identity, time and people's availability. Most critically, we felt this would be reflected in the production of our analysis, depending, for example on how comfortable, at ease, available or prepared members felt in their ability to contribute.

5.6 In summary

To summarise, analysis was approached as a co-researcher community and was conceptualised as a co-constructed endeavour. Yet our engagement involved working with individual co-researcher interests, health status, perceptions of positionality and on a practical basis, co-researchers' availability. Analysis and the development of knowledge thus extended beyond our focus on 'data' to reflexive inquiry that included exploring a dialectic between researchers and what was being researched (Denzin and Lincoln, 2000).

In a participatory research context, where different types of knowledge and relational dynamic intersect, reflectivity takes on plurality of meaning. While this can be considered a methodological strength, there was the potential for it to create tensions. One might like to think that in the context of this research ownership was shared, and that as the lead researcher I was primarily facilitating. However, although I strove for it to be egalitarian, I acknowledge that in practice my involvement led the analytic process. Furthermore, if the act of writing is considered both research inquiry (Mitchell and Clark, 2021) and analysis (Eakin and Gladstone, 2020), the fact remains relevant that the articulation of this analysis whilst generated in community has been reconstructed in text through my authorship.

5.7 In conclusion

Data analysis was a critical, iterative, interpretative endeavour which embedded a robust, creative process. Although the analysis described articulates distinct participatory stages, further development occurred within and between these stages of knowledge creation, in dialogue between the Community-of Inquiry. Motivation within the community remained high, our relationships strong and our commitment to the participatory ethos resolute.

Changes were integrated into the analytic process as tools and models were piloted in practice. Changes in thinking about AC were also seen among co-researchers and members of the AC nursing team throughout analysis. Analysis did not end abruptly after the last workshop; my conversations with co-researchers continued as we began to refine the presentation of our analysis and think about conceptualising research impact (ICPHR, 2020).

It is said that “change happens when people are motivated to make it happen” (ICPHR, 2020, p.12). During the six-month data analysis period, engagement and dissemination of the research was ongoing throughout the process. We were invited to present the research topic and methodology in different forums. This created an early opportunity for the research to inform and shape thinking about AC practice. Amongst stakeholders, it created a sense of anticipation for the research findings. Further consideration and appraisal of the various ways in which change occurred within the research, along with a discussion of the impact of the research, is a feature of Chapter 8. The next chapter presents and discusses the results of our participatory analysis.

Chapter 6 Findings and discussion Part A: Ambulatory Care's contribution to experience of cancer treatment in the TYA context

6.1 Introduction

In this chapter the findings of data analysis are presented, integrated with a discussion of broader literature and context. Rather than report the qualitative findings in detail by participant group, it integrates evidence from within and across data sets: young people, companions and healthcare staff, to respect the intersecting nature of different stakeholders' experiences of Ambulatory Care (AC). The chapter opens describing characteristics of the physical environments that comprise the ambulatory service. Whilst remaining close to participants' data, the narrative then extends beyond the physicality of the setting, to evidence and present an interpretation of how the AC service shaped people's experience of cancer treatment and care. The second part of the chapter reports components of the service critical to successful delivery, that may be transferable to other cancer centres.

In the subsequent chapter, my discussion will extend to consider the research findings in relation to the concept and philosophy of age-appropriate care, and with reference to wider healthcare agendas, aligning with normative styles of integrated results and discussion chapters in qualitative research (Clarke and Braun, 2021). This thesis reports the main substantive findings: those that respond to the research objectives and questions set at the study's outset, as detailed in the research protocol. I am appreciative that there will be other opportunities to share findings beyond this academic text.

As previously stated, our process of analysis developed incrementally from the identification of categories and themes. As the analysis progressed, although recursive, it extended from a place of description (where we were working very closely with participants' words) to explanation and a higher level of abstraction. My articulation of the research findings similarly extends from description to interpretation within this and the next chapter. Some of the photographs taken by young people to represent distinct aspects of their AC experience are featured in this written account. Capturing suggestions for service improvement was an inherent part of the research's imperative to be of practical use. These types of data (for example, the need to consider more accessible showering facilities) were categorised separately and are presented standalone in Appendix 27, as well as being used to inform discussion of the relationships within the findings.

The organisation of this chapter also aligns with features of the analytical approach. For example, section 6.12 explores analysis as contextualisation (Eakin and Gladstone, 2020), to consider the research findings within the context of the Covid-19 pandemic, along with consideration of AC experience within the broader context of negotiating a diagnosis of cancer over time. Responding specifically to the interests of Community-Based Participatory Research, the findings are appraised through the lens of equity, to consider service access and provision alongside determinants that may have impacted on participants' experience of AC.

Throughout the chapter, I use the pronoun "our" to respect co-researchers' full participation in the analysis. I also use "I" to denote the accountability I take for the conceptual development and comprehensive writing-up of the findings, which, as I have previously noted, should be considered a further act of analysis in itself (Eakin and Gladstone, 2020). Quotations from participants are detailed verbatim and, in latter stages of this and the next chapter, I also integrate quotes from co-researchers, derived from our audio-recording of Community-of-Inquiry meeting discussions.

6.2 Participants

Forty-five participants were recruited to this research study between March 2021 and June 2022, with forty-three individuals taking part (12 staff, 18 TYA patients and 13 companions), meeting the target sample range (n=33-47). Two participants were interviewed twice, resulting in a data set of 45 interviews. The first cohort to participate (March to June 2021) were twelve members of the TYA multidisciplinary team. From April 2021 until February 2022, seventeen young people and twelve companions took part. To help balance the age and gender distribution of the cohort, the study remained open to recruitment until June 2022 with the express intent of recruiting further young people who were either younger or identified as female. One further female and her partner subsequently participated.

6.2.1 Healthcare staff

A total of twelve staff members of the multidisciplinary team took part in research interviews. Except for one participant, all were female, and the most dominant role represented was nursing (n=7). The distribution of professional roles within this participant cohort comprised nursing (staff nurses, clinical nurse specialists, advanced nurse practitioners), therapists (occupational and physio-), clinical medicine (haematology and oncology doctors) and pharmacy.

Interviews took place virtually. Although approval was in place to facilitate walk-along interviews, the clinical pressures of the pandemic meant that these did not take place in a formal way as intended. Instead, on three occasions, I was invited to shadow a participant in practice for 30 minutes on a separate occasion to their interview, to help contextualise what they had conveyed in conversation.

6.2.2 Young people

Nineteen young people were recruited. Interviews were completed with eighteen individuals: ten with an oncology and eight with a haematology cancer diagnosis. Most participants were only interviewed once (due to health status, completion of treatment or not being asked). An unexpected change in health status meant that one young person who had consented did not participate. There was one follow up interview with a young person who had gained experience of AC in a second, different residential setting. This resulted in a dataset of 19 interviews: 16 photo-guided and three (one follow-up and two stand-alone) without the integration of images. The two young people who chose not to include photographs in their interviews were recruited in between AC admissions; they wanted to participate before their next cycle of treatment whilst they were feeling well.

All young people had experience of at least one previous AC admission prior to taking part in the research. One young person had completed nine chemotherapy cycles on an ambulatory basis. The mean average number of previous AC admissions was four. Young people had a range of cancer diagnoses, and their treatment pathways were reflective of the type of protocols typically given at the study-site in AC. Ten young people had a diagnosis of sarcoma comprising five (n=5) with osteosarcoma, of which four young people were receiving MAP chemotherapy (methotrexate, doxorubicin, cisplatin) on an ambulatory basis. Other diagnostic groups represented were Ewing or soft tissue sarcomas (n=5).

Eight young people had a haematology diagnosis: either B-cell Acute Lymphoblastic Leukaemia (B-ALL), Acute Lymphoblastic Leukaemia (ALL), Acute Myeloid Leukaemia (AML) or non-Hodgkin Lymphoma. The cancer treatment protocols, chemotherapy agents or care that the 18 participants were receiving in AC is summarised in Appendix 28. Aside from administration of chemotherapy, among participants AC had been used as a step down from the ward post allogenic stem cell transplant, and for systemic antibiotic treatment.

The participant cohort ranged in age from 16 to 24, with a mean age of 20 years. Eleven (61%) of the participants were male, aged between 17 and 25 (mean age 20). Seven females took part who were aged between 16 and 24 (mean age of 20). Except for one 21-year-old male, all participants were always accompanied by a companion in AC. Whilst this male was usually accompanied, he sometimes spent occasional nights on his own.

Young people were invited to state their ethnicity. Eleven young people (61%) who took part were from a white British background, with 11% from other white backgrounds. In total, 28% of the participants recruited were from ethnic groupings other than white.

6.2.3 Companions

Fourteen companions were recruited. One participant, a girlfriend, did not proceed to interview once her partner was admitted to the ward. Interviews took place with thirteen companions, and all chose to be interviewed by two researchers as a triad. Seven companions (54%) taking part were mothers, two (15%) were fathers, three (23%) were female siblings and there was one female partner (8%). Participants were not asked to disclose their age or state their ethnicity. One sibling together with the young person she had been supporting, was approached to take part in a second interview on the basis they had both transitioned from staying in the hospital hotel during AC admissions, to their home. The sibling participated (her sister declined, saying she wanted to focus on treatment), leading to a total of thirteen companion interviews.

Not every young person taking part in the research nominated a companion to approach for interview. Reasons for this included wanting to take part alone (n=2), not wanting to bother their companion (n=1) or their companion not being able to communicate in English (n=2).

6.2.4 Additional expressions of interest

The research attracted considerable interest on the Day Care and AC unit. Seven young people and companions expressed interest in taking part who did not meet the study criteria, having responded to open expressions of interest via flyers on display. The most usual reasons for ineligibility were age (too young), or non-ambulatory status. In addition, over the recruitment period, five young people who, having received study information, had expressed interest in taking part, were subsequently admitted to the ward for treatment. They did not return to AC, completing their treatment on the inpatient ward.

6.2.5 A note about anonymity in the presentation of the findings

The TYA cancer service at UCLH is a small clinical community. Nurses working in the TYA team at the study site were integral to the recruitment of participants. Whilst care was taken to retain the anonymity of young people and companions who took part, among some members of the team, a young person's participation in the research might have been known. For this reason, because this work is likely to be shared amongst the wider clinical community, it did not feel appropriate to use young people's assigned participant ID numbers alongside excerpts from their interviews in this chapter; it also seemed depersonalising. Yet assigning a pseudonym felt labelling – I take the view that the process of me assigning a name confers subjective judgement.

In retrospect, I could have invited those who took part to choose their own pseudonym. Instead, participants were re-assigned a unique, random alphabetical initial (A-R) and direct quotes from their interview narrative use this, alongside their role within the text (e.g. YA, Young person A). Quotes include their age and gender in stand-alone participant citations (e.g. YA, 17-year-old female). Companion participants were similarly re-assigned a new ID following the corresponding format, e.g. CA (Companion A). I have chosen to omit participants' re-assigned ID from some photographs included within this chapter, and on occasion from some direct citations, to enhance anonymity as described in Chapter 4, section 4.9.5. Healthcare staff who participated are referred to by role only within stand-alone quotations of narrative, and by either their role or reassigned alphabetical ID e.g. SK (Staff K) within shorter in-text quotations. Attention has been given to achieving staff participant anonymity. However, given the small number of staff working in some roles, participants knew that it might be difficult to assure this to readers familiar with the UCLH service.

6.3 Descriptive presentation of the findings

6.3.1 Place and space

During analysis, we noticed that participants' experiences of care, whilst integrative, were framed by their engagement with distinct geographical places, and social spaces. Movement within and between *place, space,* and *spaces between,* was one of the defining characteristics of AC. Humanistic geographers have long taken interest in the concept of place and space to explore and explain people's relationship with their environment (Tuan, 1979; Agnew *et al*., 2003; Cresswell, 2004; Massey, 2005). The concept *place* can refer to the "where of something" (Cresswell, 2011, p.236), the physical structure that informs experience; and yet places are not universally defined by their materiality or physical presence. Among thinkers such as Tuan (1979) and Massey (2005), place is created and shaped by human experiences, and more fundamentally exists 'of space' (Tuan, 1979).

Among some academics, therefore, place is "more primary, and space derivative" (Kearns and Milligan, 2020, p.113); others conceptualise the reverse. While accounting for the lack of uniformity in the constitution of the concepts, their being dependent on disciplinary lens and theories (Lawrence-Zuniga, 2017), I found it helpful to employ the concepts of place and space to scaffold presentation of the descriptive findings. I make the differentiation as follows. *Place* focuses on the physical set-up and operational delivery of the AC service, with *space* concerned with AC as experienced: how people engaged with the different relational spaces created by AC. During analysis we identified a third notion of *spaces between,* that shaped our thinking about participants' connection with the social world during AC.

In this first part of the chapter descriptive findings from the research are shared, organised by *place, space,* and *spaces between*. It opens describing the characteristics of the AC setting, first by physicality then 'as experienced'. It should be noted furthermore that the terms 'place' and 'space' were used interchangeably by those who took part in the research: participants did not make a distinction in the way I do here, and their use of the word 'space' for example may sit within a narrative that informs consideration of place, and vice versa.

6.3.2 TYA Ambulatory Care Service: characterisation by place

At the study site, Ambulatory Care is an integrated part of TYA Day Care, located on the third floor of a stand-alone cancer day centre that neighbours the main hospital site. The TYA service occupies an entire floor of the cancer centre, and comprises treatment, recreation and outpatient clinic areas. Experience of AC extended beyond one physical setting. Participants described five locations (places) that informed their experience of AC: the day care unit, hospital hotel, inpatient ward and for three young people, their homes. A new self-contained apartment arrangement supplemented the physical framing of the AC setting for a further two participants.

6.3.2.1 TYA Day Care

The TYA Day Care and AC unit combines an open plan recreation area and a clinical hub with eight treatment chairs, two side rooms and in addition three further treatment chairs extending into a re-purposed area. Staff sometimes referred to the non-clinical area as *'the other side'*[3] to denote a segregation between two sections of the floor. The clinical and recreation areas are separated by an open light shaft in the footprint of the floor which obscures one side of the service from the other. Were it not for closed blinds, the unit would offer a view down onto the adult service occupying the floor below.

Within the unit, there is integration of different kinds of day, outpatient and AC admissions. This amalgamation of services was perceived positively by staff:

> I think the third floor has that advantage that it's the same place, whether you're ambulating, whether you're in 'day care - day care' for the day or whether you're coming to clinic - it's all the same space. Older adults being on two separate floors does make a bit more of a distinction between the two services: the ambulatory care service and day care. But on the 3rd floor, it is fairly seamless I would say. (doctor)

This integration offered an early indication of how the service was premised on the needs of patients as young people who shared a diagnosis of cancer, rather than the requirements of their clinical appointment. Many staff held a view that AC patients themselves did not differentiate their treatment pathway from others, and often referred to their AC status simply as *being on the third floor*:

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[3] text in italics denotes a) categories that were coded in the data or b) themes arising from our analysis of the categories and codes.

> They see it all as part of the third floor. In adult services you've got Ambi [Ambulatory] care – one unit, Day Care – another unit, Supportive care – another. The third floor is a mash-up. You can come to the third floor for a Covid swab, or a bone marrow transplant [laughs]. (senior nurse)

A characteristic of the setting's clinical hub was the continued presence of nursing, with other clinicians moving in and out on a visiting basis. Registered nurses with clinical experience within the TYA cancer speciality ran the unit seven days a week, led by a sister and two advanced nurse practitioners. Staff from other professional disciplines orientated their practice more to '*the other side'*, within the clinic rooms or non-clinical areas of the floor. Exceptions to this were the youth support coordinator, physiotherapist and occupational therapist who worked peripatetically, alongside young people wherever they were.

6.3.2.2 Hospital hotel

Most research participants during treatment stayed overnight in UCLH's hospital hotel, situated approximately 200 metres around the corner from the cancer centre. Since the start of the Covid pandemic, the hotel had been reserved for the exclusive use of adults and young people with cancer diagnoses, and their accompanying companions. The Cotton Rooms hotel, funded by the hospital charity, is managed via a hospital estates contract on a residential rather than clinical basis. Akin to a modern business hotel, each room has either a twin or a double bed, an ensuite bathroom with a shower over the bath, or in some rooms a wet room set-up. Rooms are equipped with desks, tea and coffee making facilities, small fridges, televisions and Wi-Fi. The communal areas of the hotel comprise a sitting and dining room from which, pre-pandemic, a buffet breakfast was offered. The dining room was closed during the pandemic to support social distancing and access to microwaves - hot drinks and crockery were the only cooking or dining facilities retained. Instead, those staying at the hotel, including interview participants, selected their breakfast choices from a menu delivered to their room each morning.

6.3.2.3 Home

Three research participants had experience of ambulating from home each night. The AC policy offers this option to young people if they live within one hour's travelling distance by car to the hospital. The first lived a 10-minute drive away and had not realised that 'home AC' was an option from initiation of chemotherapy treatment. Sometimes, confidence to ambulate was gained through experience in the hospital hotel in preparation for AC from home. This was the case for this young person who had transitioned to home AC, following surgery, for the duration of their remaining chemotherapy. The opportunity to ambulate from home forms part of the service configuration, and thus the home environment is a defined place, that contributes to experience of AC.

6.3.2.4 Self-catering apartment

Two participants had experience of residing in a self-catering apartment whist undergoing proton-beam therapy treatment. Furnished in a similar way to the hospital hotel, the main differentiator from a physical perspective was that the apartments offered separate bedrooms for the young person and their companion, a sitting area, and cooking and laundry facilities. The participants stayed in different apartments at the time of their interviews; one had access to a hospital bus that took them for proton-beam cancer therapy, the second used public transport.

6.3.2.5 Inpatient ward

When defining the AC service from the perspective of *place*, the Teenage Cancer Trust inpatient ward, alongside adult wards in the hospital, remain critical to service delivery. The inpatient ward setting contributed to the safety net of the AC service: offering a 24-hour nurse-led telephone advice line to young people and their companions, whilst facilitating access to clinical care and hospital admission if needed out of hours. The geographical proximity of the hospital hotel to the inpatient ward (about 400 metres) was evidenced as contributory to feeling safe in AC (see section 6.3.3.5).

Among young people over the age of twenty, although supported by the TYA advice line out of hours, the configuration of inpatient services meant that changes in clinical status that required hospital admission, would lead to being placed on either the young adult, or an adult cancer ward. The young adult participant cohort considered their age in relation to the place of inpatient admission as a factor that contributed to their decision to elect for AC. It was one of the factors that created anxiety if they were to become unwell and need admission - given this could be to an adult ward.

Figure 6-1 provides an illustration of the geographical relationship between some of the physical settings (places) that comprise the TYA AC service. Having set this context as a starting point, this description progresses beyond the static physicality of the different places that comprise AC to consider how stakeholders subjectively sensed, connected with, and experienced the different dynamic *spaces* of the AC setting. In essence, this responds to the second research question: *How do stakeholders – young people, their companions and staff experience Ambulatory Care?*

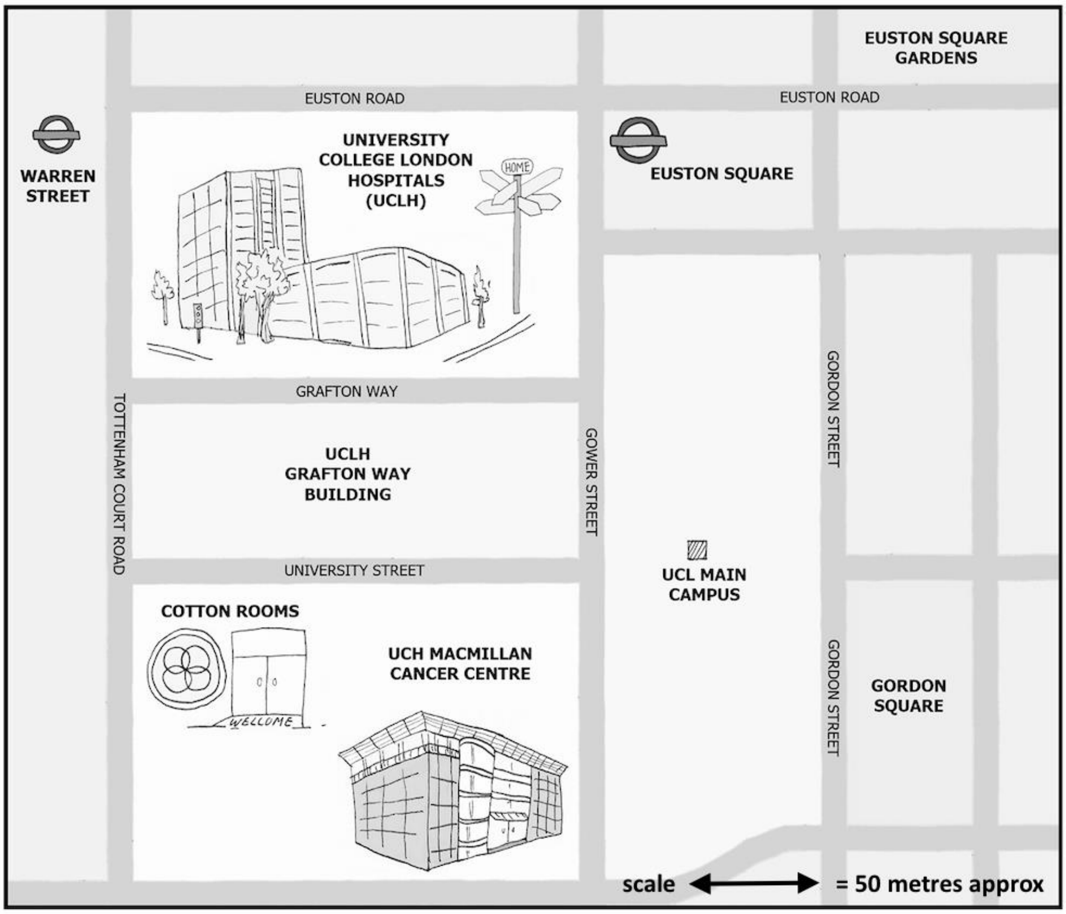

Figure 6-1: Ambulatory care: the geographical setting

6.3.3 TYA Ambulatory Care service: characterisation by space

6.3.3.1 TYA Day Care

The TYA Day Care and Ambulatory Care unit was a central feature of participants' conversations about their experiences of AC. The space was consistently described in terms of "a lot less clinical" (YE), "doesn't feel so hospital-y" (YG) and similarly "not at all a hospital-y feel" (YP). The integration of colour and texture into the furnishings and vinyl wall coverings often featured in young people's photographs and informed conversations about their experiences of the setting. Being visually surrounded by colour and images of nature were associated with feeling "physically warmer", "relaxation, and worrying less" (YE). This young person further explained if in a "clinical, plain, bland setting I'll feel a lot more like I'm in hospital and that I'm a patient and that I’m unwell” (YE). This culminated in the space feeling “a bit more normal, and a bit more like the real world rather than this clinical setting” (YE, Figure 6-2). This held resonance across several interviews, and the pool table, comfortable seating, chill-out area, and computers were described as representative of normality, and feeling relaxed. The addition of a jukebox helped “make it feel like you are not in a hospital” (YR); “the sounds in hospitals are somehow much worse than sitting in silence”, this young person clarified.

Figure 6-2: The recreation area of the TYA unit

> If you saw this photo, you wouldn't assume it was a hospital, you might assume it was like a student common room, or something, and I think that's really nice, because it takes away from the clinical side, as I've mentioned a few times, and it does bring this, kind of, level of normality, this level of relaxation. (YE, 24-year-old male)

Consistent among young people, companion and staff interviews were references to the open plan setting. One young adult described how “being out in the open space” had felt “freer” (YB), as she had not felt confined. “They can’t shut you indoors,” she went on to explain. Staff attributed a sense of peer support, “by virtue of how open the environment is" (SF), and the opportunity that this created to build "organic connections" (SB). Other young people similarly drew attention to the openness and described how this fostered connections with others in a positive way:

> It felt more open, as opposed to coming into the hospital ward, going to a bed, leaving. You're more involved, and more connected in a way. It was definitely easier to meet people through Ambulatory Care, particularly as there is more of an opportunity to socialise with others who are experiencing the same or similar difficulties with their treatment process, and with hospital, you are often confined to a room. (YQ, 22-year-old male)

Being able to "sit out in the open with other people" (YP) was a characteristic of the space described by many young people. When this was considered more analytically, we found this was associated with feeling unrestricted, respectful of one's personality and individual choices, and feeling part of a supportive cancer community:

> Sometimes [on the ward] when you do spend 24 hours a day with people, for two weeks, it gets quite tense. It gets quite, like, 'Ugh'. So, in a way, ambulatory, you go there, and you have a different person to talk to, even if it is just sitting-, Even if you are just sitting on the comfy side, just talking to other people, it just feels a bit more inclusive. You walk down the corridor, [say] 'Hiya.' You don't really have that in a ward. You normally just stick to yourself, really, in between your four curtains, kind of thing, I would say. (YN, 17-year-old male)

Young people described seeing "others going through the same experience" (YB) as beneficial; they felt less alone as it was an experience that others could relate to and share. "So, when you go there, it's the normality that everyone is connected to a certain machine" said YB, a young adult with experience of both AC and the inpatient ward. The TYA Day Care and AC unit not only fostered choice about where time was passed, it facilitated fluid, organic connections with others. "There were more opportunities to speak with people in ambi care, and make connections through there," one young adult said. He explained that it felt possible to exercise choice and say to someone "right, shall we go for a coffee…or just chill?" (YC).

Being able to socialise on one’s own terms was identified as an important feature of the AC space: it offered distraction and fostered support whilst “dialing down on the clinical nature of the environment” (SG), and the purpose for being there. “In some cases, I forget where I am”, explained a nineteen-year-old, “you're just chatting to someone about any old rubbish, really” (YQ). It was rare for young people to talk about friendships that had been established in the Day Care and AC unit. This did not detract, however, from feeling supported by a peer community through the opportunity to talk to other patients about their experiences: “It’s good because they can really understand what you’re going through,” said YE, a twenty-four-year-old female. Significant too was that there was no pressure to commit to friendship:

> I met one guy when I was on my first treatment because he had a very similar thing to me and my knee. I would say he's the only one I've actually added on Instagram. We don't really talk. In fact, we don't talk at all. I'm friendly with him, I'm his acquaintance. I feel like he's more just someone who went through a similar thing to me, and we'd be on friendly terms rather than an actual friend. (YJ, 21-year-old male)

There was consideration for other people’s feelings and situations within the characterisation of TYA’s experience of peer support. One of the younger participants, aged 16, explained how “when you're in chemo you're going to have your off days where you don't want to talk to people at all…so I don't want to make anyone uncomfortable” (YM). A 24-year-old male mentioned how many of the young people he had met during treatment “didn’t have the energy or desire to be social” (YD). The ability to feel a sense of peer support and connection with peers encompassed reciprocal recognition and accommodation for others’ health status and wish to sometimes be more reserved. There are “young people that I know who don't even connect with other young people much,” said one clinical nurse specialist, “but they're just reassured by the fact they aren't the only one, and to feel that there are others around them going through something similar to them is helpful” (SH).

This experience of peer support was common in the interviews, although by no means universal. A young adult who, like others with a haematology diagnosis, had been cared for in a single room on the inpatient ward, compared her hospital experience which had felt “very strict” (YB), with the more relaxed atmosphere and opportunity to meet others on the Day Care and AC unit. She described one friendship that she had made whilst spending time on the third floor, and she envisaged that they would remain friends in the long term.

Staff interviewed thought that the continuity of returning to the unit each day distinguished relationships that were seen to develop among AC patients, from day care attenders. To foster these types of connections would typically take “more facilitation from health care professionals on the inpatient ward” (SB). What made young people feel more able to form such links with one other was attributed to “some kind of vibe,” (SB) yet this was not just left to happenstance; the nursing team said they were “pretty aware about facilitating stuff where they think it is appropriate”. By way of an example, a senior clinical nurse, cited colleagues who had encouraged families who were going through similar experiences to sit near one another during treatment, and this discrete facilitation and enactment of the TYA philosophy of care, had meant that they “ended up talking naturally” (SB). There were mixed thoughts about how well more structured group activities (such as craft sessions) facilitated support. Account was taken for the fact that they had not been a feature of people’s (and therefore participants’) experience of the unit since the start of the Covid pandemic. However, there was the view that “sometimes, with the best of intentions…it’s not to say that [group activities] don’t always work, but that left on their own, then young people sort it out themselves” (SI).

The *organic connections with others*, and sense of being integrated within *a supportive cancer community* consistently evidenced within young people’s interview data, although experienced as uncontrived by participants, is intentional when professionally delivering the concept of age-appropriate care. One example of this was the clinical hub, photographed by YQ (Figure 6-3), which had been purposefully designed by Teenage Cancer Trust in partnership with the clinical team to offer privacy during treatment, whilst fostering connections with others:

Figure 6-3: The seating arrangement in the clinical hub

> As you can see in the picture, it's four chairs that face inward to each other, so you can communicate with other people, and you can get to know others who might have a different type of cancer. It gives you, most certainly, something that you don't get in a hospital. It becomes more communal, which is really nice. (YQ, 21-year-old male)

Although the choice to receive chemotherapy in the recreation area of the floor was sometimes offered, young people's treatment centred on the clinical hub. This was accepted as part of their experience of the space, and participants often took photographs of the area as a factual and acknowledged reminder of the purpose for their visit. Being closely situated to others was associated with having "people, kind of, with me doing chemotherapy, not so much going past for coffee or tea" (YB), which conversely had been described of the non-clinical side of the floor.

Experiences of the built environment and design of the third-floor space were strongly elicited through young people's images. Two young people photographed, then described a favourite treatment couch; a third young person also spoke about having a favourite seat. A particular couch was singled out by two young people as providing a good vantage point: "a good angle of everybody and everything" (YM), where you could see and be seen. It also, according to YJ, signified positivity: "it represents to me, staying active". Claiming a favourite chair, was seen to elicit a sense of familiarity, also comfort and relaxation. As well as physical attributes of the unit, activities fostering a sense of familiarity or normality (Figure 6-4) had powerful resonance for young people.

Figure 6-4: Fostering normality

> I feel like having something so normal like Domino's [pizza] in such a clinical area lightens up the mood. Everyone is so happy when Domino's comes, even the nurses are in a better mood, and it just creates such a nice environment, and it makes me enjoy Fridays and want to come in. (YF, 23-year-old female)

The emerging picture of how young people experienced the Day Care and AC unit space, would be incomplete without the inclusion of the Youth Support Coordinator role, evidenced as contributory to young people's experience. The post had been vacant at the start of field work, and once filled, young people and companions would often bring the youth support coordinator into their interview as someone "very important" (YE), providing distraction through conversation, and activities which were described as emotionally supportive. Evidenced within the data was the support worker's discrete, peripatetic way of working which in equal measure extended individualised support and fostered being a community. The contribution of ‘Friday pizza’ to the experience was self-evident; less pronounced perhaps was the likely intention of its orchestration – to bring young people together in the clinical hub where often their experience was only shared with their companion and members of the healthcare team. The youth support coordinator role also featured in interviews with companions when describing experiences of the Daycare and AC unit space, as one of the key professionals who provided psychosocial support.

6.3.3.1.1 Companion experience

Companions’ experience of the third-floor space also foregrounded feeling connected with a community that accommodated the uniqueness of everyone’s situation, yet leveraged related experience:

> Being over there, and just seeing other parents. And you look and think, ‘Well, I’m not the only one, there’s so many of us here,’ even if they’ve just gone in for the day. Because a lot of the children go in just for the day, don’t they, and then go home. It's quite nice to see-, it’s nice that other parents are there, you don’t feel so isolated. (CR, mother to a 22-year-old male)

Whilst referring to the openness of the floor, a father suggested that this meant “you get to talk more”:

> In a way, it felt more open, as opposed to coming into a hospital ward, going to a bed [and] leaving. You're more involved, you’re more connected in a way, aren’t you? I got to know the whole team. It’s a little family, isn’t it? I think that made the whole thing more bearable (CK, father to a 19-year-old male).

There was more uncertainty, however, around the extent to which sibling companions felt a similar sense of inclusion in the time that they spent on the unit. “I’m just the carer,” a 24-year-old sibling replied when asked about how they thought they were regarded by staff, and they experienced little sense of support from being with other companions: “the others I met were all, like, adults I would say, mostly adults, yes” (CD), conveying a disconnect or a feeling of distance. A more considered and critical analysis of this and other companions’ experience is detailed in section 6.10.

6.3.3.1.2 Staff experience

Staff communicated how the Day Care unit held significance from a disciplinary perspective; it facilitated a dynamic of practice that was described as distinct from that on a ward. “We've got a lot of space because everyone is not crammed in,” explained an advanced nurse practitioner: “and there's more to do rather than be like, 'Okay, right, now bye ...’ they [young people] can sit there for a while, and then you can go back and have a chat with them, rather than, 'Right, you're in this chair for this, then we need you out’ because we need the chair”. Clinicians said that the third floor space gave them more time.

“I think that AC patients like coming, it breaks up the day a little bit, otherwise they may just be in their hotel room,” said a staff nurse. The fact that patients often passed time on the unit meant that they were able to access care, on a continued, responsive, and less rigid basis compared with experiences of the inpatient ward:

> I saw, like, the OT, for instance, and the physio as well who were roaming around and just spoke to me, which was quite nice. And sometimes the oncologists, I may occasionally, just, sort of, by chance, bump into them… there were occasions where I may not have seen the physio for, like, a couple of weeks, for instance, I may have missed them each time, so we'd arrange, 'Okay, I'll be back on Tuesday, so we'll see each other on Tuesday,' for instance, yes. (YC, 24-year-old female)

“The acute setting is not really set up for rehab. It’s more discharge, and then the rehab at home” said one of the therapists. They described how the unit facilitated ongoing clinical assessment of mobility and function within a more “normal, community setting” and in contrast to the ward, appointments did not have to hinge around a defined number of minutes, predicated on discharge, at the bedspace. “Here we get a much bigger opportunity to do rehab which is brilliant” a therapist said, also referencing the choice for young people to access the unit gym.

In summary, across all participant groups, the Day Care and AC unit space was experienced as a supportive environment. The relaxed, non-clinical feel of the setting and opportunity to connect with others on one's own terms helped evidence the unit's positive contribution to experience of AC. Throughout the pandemic the fact that young people could only be accompanied by one companion became relevant to people's experiences. Staff were aware of this contextualisation, and sometimes referenced "before," when "friends have been able to visit them, sit with them during chemo and play pool" (SG), to explain how experiences of the unit, if compared, might feel inherently different. Irrespective of this, the setting was credited with fostering important relationships at a critical time of life, whilst acknowledging the uncertain nature of cancer treatment. It is a "buzzy place" said one nurse (S9), "and it seems to be the best it can be, almost to get them through it".

6.3.3.2 The hospital hotel

The hotel was characterised across all participant groups as a relaxed, non-clinical environment and the level of comfort it offered was likened to a commercial hotel. "All I can just say is it's like a Premier Inn" said one young person (YH): "You would never have thought it was a hospital…there are carpets outside, and the bathroom was the nicest thing".

The hotel's proximity to the hospital was critical to young people's positive experience of the setting: it helped them, and their companions feel reassured that clinical expertise and support was close by if needed. Within participants' photographs or accounts, experiences of the hotel were typified by an amalgamation of comfort, privacy and perceptions of normality; "they're all factors that build up my journey really. They're all things to represent what I've been through. Without one you might not have the other, so without the privacy you wouldn't feel comfortable and without the ownership you wouldn't have normality" said one young male, aged 17.

The gratitude that families felt for being able to stay in "a nice hotel" (YR) was consistently evident in the data. Some likened it to a treat, others associated a relaxed, almost carefree feeling to the setting. Young people and their companions talked about the customer care and service they received in the hotel in such a way that they felt more like a holidaymaker, not a patient or carer: “It's literally like a hotel abroad, it was lovely”, one mother, (CH) said. Some participants used the fact that bed linen was changed daily, and rooms were immaculately clean, to signal feeling emotionally cared for as well as clinically safe. They described hotel staff working around their daily routine and timings as beneficial, which were often negotiated rather than having to follow set times.

Being able to sleep and rest undisturbed was often raised by young people and their companions as one of the most appreciated features of the hotel. This was facilitated by comfortable beds and the peace that the hotel rooms created, away from the clinical sights and sounds of the day care unit or ward. As one young person explained:

> Because you're not in a hospital setting the whole time, because you have the freedom to move about and do stuff, because it's a hotel setting, not just at the hospital, so you can get a better sleep because there's not beeping and everything going on. You also can unwind and relax and there's a TV and stuff, and you have your privacy as well. (YP, 20-year-old male)

Across accounts in the data, *being unobserved* and able to *pass time unwitnessed* by the healthcare team featured as one of the defining characteristics and perceived benefits of AC. Having one’s own personal space which offered *privacy* was seen as critical to young people’s experience of the service.

Being able to return to the hotel and close the room door, knowing that no one would walk in unexpectedly, enabled participants to experience respite from the intensity of treatment and exercise choice about how they spent their time. Young people talked about being able to chat with friends or have conversations with family without feeling self-conscious that they could be overheard or needing to make consideration for others. Young people often made comparisons to their experiences on an inpatient ward when describing their experience of the hotel. They could take naps, watch television, enjoy food and come and go from the hotel as they chose and as their health status allowed. The hotel offered opportunities to experience *freedom* from the rigidity of hospital routines and to *exercise choice* and *social independence*, evidenced even among those who felt too fatigued to leave their room.

Except for one young adult who had spent an occasional night alone, the hotel experience included a companion. Families described *spending quality time* together in the hotel room: watching films, playing chess, resting or engaging in idle conversation. There were references to fun and a lightness that they deliberately engendered: “we made jokes, we played games, we would laugh at the silliest things” (YJ), with a 22-year-old associating his experience as “just like staying in a hotel, apart from having the pump and everything…It's great to have someone there and just have a laugh” (YR). Creating a positive environment was often led by the companion to offset the significance or onerous nature of treatment:

> I think there's a conscious effort that then becomes unconscious of being calm, being supportive, being positive, wanting no ounce of negativity to enter the whole situation because you're focused on, 'This is about getting better.' (CJ, father a 21-year-old male)

For some, the comfort of the hotel setting provided a distraction from the nature of why they were there in the first place; for others, their experience re-framed their perceptions of what they thought cancer treatment would be like. It is “amazing” YD said: “I didn't have a clue this was even possible really, I thought you had to be on a ward, but apparently not”.

A sense of *togetherness* (section 6.5.2) between the young person and their companion was evidenced across data within how time was passed, responsibility for care shared and emotional support was extended. Togetherness encompassed but extended beyond physicality to practical and emotional support: “we're sleeping in the same room, together the whole time, we're supported” (CJ). Young people spoke about a renewed appreciation for their family, engendered by their cancer diagnosis, which the AC setting was seen to foster:

> It's a good feeling of support I found. I was happy that they were there. We managed to not get on each other's nerves, so that was always fine…I was grateful to have their support there personally. (YK, 19-year-old male)

This renewed sense of togetherness became simultaneously, a means for AC to be feasible as an option for some young people. “I couldn't have done it on my own if they weren't there,” said YM a younger participant, who talked about her sister who helped with her medications and supported her mobility whilst she was dependent on a wheelchair. Similarly, for YC, who could not weight bear or stand without two crutches, “to just have to have my parents carry kit to the bathroom or help with whatever I need” had been considered a much-needed help. YB, had doubts whether she would be able to emotionally cope without her mother: “Me and my mum do Ambulatory Care together … I don't think without my mum, I could go through this experience” she said.

Nevertheless, within the context of a young person's developmental life stage, which had invariably encompassed increasing social independence from family pre-diagnosis, both parties conceded that time spent living together in one room was not usual.

> Yes, I mean I haven't spent as much time physically with my son in years. You know what kids are like and teenagers in particular, you don't see them, you don't see them for weeks on end sometimes. And I think I would say that for me I think as a family we have been brought really close together by the whole experience. (CJ, father to a 21-year-old male)

Togetherness had been borne through perceived necessity, yet amid this young people and companions spoke of a re-connection with one another in the hotel which they valued:

> Something that I personally have struggled with quite a lot is becoming a lot more reliant on my parents. I'm 19, so I feel like I should be out doing my own thing, and not putting this extra pressure on my parents to look after me if you like, although at the same time it was really nice to do nice things and have a bit of time together again. (YK, 19-year-old male)

The sense of *privacy* created by the hotel room was referenced across all the young people's experiences. Specifically, the hotel was described as a refuge, a safe space away from the clinical demands of treatment; a place where they could let their guard down and be themselves. "You're on a little holiday, until you leave the room and go to the hospital" stated YR, who had stayed on four occasions in the hotel and appreciated the respite it offered. Perhaps similarly for YJ, it was the fact that the space was protected from the encroachment of others that he appreciated most:

> Ambulatory Care is a lot more, you have your own space, you've been in the hospital all day getting treatment, you can then take a step back and relax, be in your own room with whoever you want to, or you can be on your own if you want. You can play chess, you can watch TV, you can go on an app on your phone, listen to music, and not really have to worry about anyone else because you've got your own space. (YJ, 21-year-old-male)

This sense of privacy was also appreciated by companions. Comparison was sometimes made with companion experiences of the inpatient ward where they had felt on show, and vulnerable to the judgement of others. A sibling talked about the need to put on a façade in the presence of the team to appear emotionally strong, whilst a mother spoke about needing to keep busy on the ward, to avoid appearing lazy or complacent to staff. Among companions, the *privacy* of the hotel setting enabled rest, and this was described as restorative. Also, in contrast to the ward, there was *provision for the companion*: during interview, companions drew our attention to the fact that there were two beds, two sets of towels, two dressing gowns and two breakfasts routinely provided to communicate that they felt cared about, and that their role as a companion was to an extent validated.

Notwithstanding this, the hotel space fostered independence as much as it nurtured: it anchored young people and their companions in a space within which they were able to draw on their own resources and the strengths of their social network to navigate care requirements, rather than be dependent on members of the healthcare team. In the hotel space, it was the convergence of *independence* and *privacy* that participants valued, that concurrently created the requirement to self-monitor and manage elements of one’s care. “When you’re in hospital you become so heavily reliant on the nurses” said one young adult (YQ), in contrast to the need to be more independent in AC.

The hotel setting was not experienced as lonely or isolating. Participants described a sense of connection with others as they passed in the corridors of the hotel or met briefly in communal spaces. The fact that other patients using the hotel were not necessarily of the same age or generation did not seem to matter; what felt important was that there was a sense of *connection with others* from within the cancer community. A community within which it was possible to navigate one’s own individual experience: to step in and step out of sight, be visible, or more private. This contributed to the hospital hotel being perceived as a *protected space*: from constantly feeling exposed or bearing witness to other’s illness, a space within which young people did not need to experience the constant interruptions, however well-intended, of staff. The hotel was simultaneously experienced as a space within which the visible and invisible effects of cancer were accommodated; “you’re with other people that are just like you or just like me” (YQ); there was no need to have to explain one’s situation as it was implicitly understood.

The hotel also took on the identity of being “quite home-y” (YG), “homelike” (YM) and a “halfway house” (YL). It offered comforts of home in comparison to the hospital, yet distinctively it was not home. “This is still only a temporary place that you’re coming in … so it’s just at the end of the day this isn’t home” (YL). This was upheld as significant by four young people completing chemotherapy, as it meant that the most acute aspects of cancer treatment did not encroach on the home environment. This, in turn, helped retain a demarcation between cycles of treatment, and between the AC setting and their home. Furthermore, the perceived temporary nature of each admission was associated with a sense of accomplishment that another cycle of treatment had been ticked off:

> … a lot of people dread going up to get the chemo and I get why, but I don't. I quite like being proactive, I like going up there and ticking parts of the treatment off. I have five doses on my current regime, I've done two of them already. (YJ, 21-year-old male)

Some interviews with young people or companions explored how they would feel about completing treatment on an ambulatory basis from home, with the hotel often being their preference. Participants described a unique experience that would be difficult to recreate were they to ambulate from their home. "It's just a bit less stressful" (YD) said one young adult male who referenced things at home that he did not have to concern himself with in AC, which resulted in this young person having "*more time*" for himself. Also, the *rest* and *quality time* with their companion that AC engendered was consistently valued, and young people described how the hotel safeguarded this from being compromised by the inevitable responsibilities and routines of life at home. Being away from home therefore, potentially offered gains as well as losses.

Life in the hotel was described as akin to being in "its own little bubble" (YQ), a place betwixt and between two worlds, within which efforts focused on attending to the needs and wishes of the young person. Yet within this, the hotel fostered reciprocal support. "I just sort of wanted to be in my little bubble with my mum. It just felt like a very private thing" YF said. This participant described how she and her mum "had to find a way to help each other emotionally to, kind of keep that going, a positive mentality". One father described support as feeling "mutual almost", seeing his son "being okay as opposed to him being away somewhere, imagining how he's feeling 70 miles away on some ward in the middle of the night" (CJ). The fact that young people and companions could exert influence and control over the atmosphere with limited infringement, and without bearing witness to others' cancer experiences was evidenced as important.

Staying in the hotel also fulfilled a role in building confidence to self-care, in preparation for times between treatments at home. For example, young people talked about learning how to self-manage their symptoms by independently adjusting their anti-emetic medications, knowing that they had direct access to the support of the Day Care nurses and pharmacist if needed, in a way that would help them feel more knowledgeable and able to routinely manage their medicines at home. Young people appreciated the opportunity to safely personalise their treatment, in contrast to succumbing to the routines of the ward. One young person described this in terms of “finding a balance…sometimes I'll wake up at 10 o'clock to take my morning medication, and then I space it out six hours from then” (YB).

6.3.3.2.1 Hotel facilities and access

Families often enthused about the hotel breakfast during interviews as something they looked forward to each day, to the extent that the most frequently photographed aspect of young people’s experience was the continental breakfast tray. Alongside being able to make healthy choices, their supporting narrative described having the flexibility to then choose when to eat breakfast or being able to save some breakfast items for a later time. As we have learned, breakfast was also offered to companions and, in contrast to the inpatient ward, this signaled that their nutritional and emotional wellbeing was considered too.

The hotel space also facilitated social aspects of eating. Participants described being able to bring in takeaway food or accept deliveries, which were often considered a treat. Whilst young people enjoyed eating what and when they wanted, for companions, thinking through mealtimes could preoccupy their time, trying to work out what to provide that was microwavable or could be served cold. The small size of the mini-bar fridge in the rooms was often cited (and in one case photographed) as something needing attention, as this limited what could be purchased and stored. The topic of food became a theme across the data; it took on practical and representational meaning.

There were mixed and conflicting thoughts about how well designed or accessible the hotel rooms were, and the extent to which they met the personal needs of young people and their companions. Whilst everyone consistently commented on how much they appreciated having their own hotel grade bathroom, the accessibility of the space and extent to which it supported the needs of day-to-day life could be problematic. One companion commended the design, suggesting that therapists had clearly contributed to the layout of the rooms given the space between amenities, although this view was not universally held. Experiences of the ensuite bathrooms were the most varied. Some young people found that stepping into a bath to access the shower, and then standing to wash was difficult, or sometimes impossible due to pain, restricted mobility or fatigue:

> For me, even just standing, let alone the process of washing myself, is very physically tiring, and it left me out of breath to the point where I had to sit down in the shower because I felt like I was going to faint. (YQ, 21-year-old male)

This participant said that he would have appreciated a bath "in such circumstances, because it would have made it much easier" (YQ) to wash, as well as promote his independence. Finding it difficult to access the shower was also described among participants with a diagnosis of sarcoma, at the pre-surgery stage of treatment. One young person recalled how he had elected to stay on the inpatient ward due to "a step going up to the shower" (YC) in the hotel bathroom which meant that on a previous AC admission he could not keep himself clean. What was described as "the simple tasks of getting in and out of the bath" (YR) had been something that another young person had needed help with. Conversely, the provision of a bath was welcomed by two young people who described how it promoted relaxation or helped manage pain. "If I'm having a tough time, I find the baths are quite helpful to unwind" YP said. Getting into the bath or shower with restricted mobility and sometimes the added awkwardness of an infusion required companion help, as well as their help on occasions with other personal aspects of care.

Therapists interviewed were familiar with the physical set-up in the hotel: this informed their risk assessment and consideration of suitability for AC. Few nurses interviewed, however, had visited the hospital hotel, which led to suppositions about the facilities offered there. "To be honest I don't know exactly how it works over there", said a clinical nurse specialist; "I've never actually been" said a staff nurse working in AC.

Data suggested more could be done to support accessibility. Navigating the hotel room space invariably required the help of a companion. One young person discussed reliance on her companion to be able to enter and leave the hotel room: "I literally couldn't open the [fire] door at the hotel from the wheelchair on my own" (YM). Like others, and out of appreciation for what the space offered overall, she had not thought to mention challenges to activities of daily living to the healthcare team. Wall hooks in the shower were often critical to negotiating a wash whilst attached to an infusion pump, yet they did not seem to be universally installed. Similarly, whilst there were several walk-in wet room showers, families did not know how they could be requested or were allocated.

Data relating to young people's and companions' engagement with the hospital hotel setting that had a clear service improvement focus were categorised separately. They form part of the suggested areas for service development and will be revisited in relation to the research's implications for practice. It became apparent during interviews with young people and companions that they did not have knowledge about the range of services on offer in the hotel, and/or how they could be requested or accessed, which led to inconsistencies and potentially inequality of experience. This is considered further in Chapter 7, section 7.4.8, in relation to families' preparation for AC.

6.3.3.3 Home

Three young people had experience of home AC. The first, a young person, with a haematology diagnosis, had transitioned from inpatient care, to continue her treatment in AC, staying overnight at home. For her, the comforts of home felt irreplicable:

> I started crying, because I was like, 'This is my comfort place.' I missed so much. Now that I'm in ambulatory care, I think it is an incredible system, because it gives me the opportunity to ambulate from home. That's given me a lot of independence. It's given me a lot of freedom, a lot of happiness. I get to sleep in my own bed, be around familiar surroundings. That's so important for your mental health, because, towards the end of my hospitalisation, I started to go crazy, because I was in these walls, and I couldn't leave. It was almost suffocating. So, this picture almost represents to me that freedom that ambulatory care has given me. (YF, 23-year-old female)

The young person shared a photograph of decorations that had been put up by one of her cousins to welcome her return home: "Although it mentions cancer, it's quite colourful, because there's a lot of happiness that I can ambulate from home". Her mother also perceived the experience positively as it enabled her to see her son and keep on top of running the house:

> Regardless of how long it takes, we know we can jump in a car, drive back, have a dinner, spend some time in our own bedrooms and I can be next to my son, see my dogs, take care of the house, and she can talk to her friends. She can be in her room, you know, she loves her room. So, this was one of the best things that could have happened to us, actually, to have this opportunity. (CF, mother to a 23-year-old female)

The comforts of being in one's own bedroom were also conveyed by a sibling who had experienced home AC, having previously accompanied her sister in the hospital hotel:

> In the [hotel] the windows don't open, it is very small, well compact. I guess for how she's feeling sometimes on medication it might feel a bit suffocating, but she also doesn't have enough energy to take a walk frequently. So, in the house she has her own room, and it is big enough, it's a decent size, and she has a window that goes wide open and mum's there to cook her meals instead of ordering meals all the time. She has her TV and all these things like that. It's just the comfort of your own home. (CM, sibling to a 16-year-old female)

Beyond home being a "nicer, more pleasant experience" (CM), the familiarity of home was perceived as comforting when feeling unwell. One companion, CF, described how the moment her daughter had come home, she was "really not feeling well”. Steroids had meant that her blood glucose was unstable, and “she had a very high blood pressure”. She spoke of her daughter’s experience of “being at home and around the dogs, and inside her own room, it really helped her a lot”.

The perception that the home AC setting contributed to wellbeing was present in another companion interview, which suggested the familiarity of home could be associated with feeling more in charge or in control:

> I think he feels that when he’s at home he’s not the patient all the time, he’s in his own bedroom, with his own linen and own comforts- your own bathroom, you’ve got your TV and a sofa to lie on. So, I think from that point of view you have much more control of your environment and your situation… I think that the tiny bit of familiarity that you’re holding onto is just to have your own space, I think. (CE, mother to a 24-year-old male)

Being more integrated within the family, also meant that there was the potential for the supportive role fulfilled by a companion to be shared:

> My auntie brought food for us every day religiously, you know, my cousin would wash my clothes and bring them back to me. It just shows how everyone, kind of, said, 'Okay, this is the situation. We all need to do something to help her in this'. (YF, 23-year-old female)

Whilst not unique, this experience was not necessarily commonplace. One younger person whose mother was unable to pause work was supported by her sibling in AC. When her sister transitioned from the hospital hotel to home AC, this created an opportunity for her sibling to share the responsibilities of the companion role with others: “if she’s at home there's many people there; there's my mum, my other younger sister – I'm not the only one who has to look after her” (CM). This participant thought that what was required of a companion “may be even harder” because of her youth, at age twenty-two. Home AC enabled her to go out in the evening and continue her studies “whilst knowing that she’s being cared for by my other family members.”

The home setting also offered space for both parties to retreat, in contrast to the hotel or hospital for whom this companion said, "we can't escape*";* offering a sense of the intensity of emotion felt at times.

> I think when we're at home, we all have places to escape, whether it's our rooms or-, and we all have things that comfort us, which, kind of, keeps us, not completely sane but more sane. (CM, sibling to a 16-year-old female)

Furthermore, this sibling said at home there were "other people that can, kind of, come in between and settle the waters a little bit and help me, as well as help my sister" (CM).

Data that encompassed the experience of ambulating from home derived from two young people, a sibling, and two parents. It is difficult to extrapolate their experiences beyond a descriptive account, nevertheless it suggested some of the perceived benefits of the home AC setting centre on being more integrated in family life and the opportunity for caring responsibilities to be shared. Views about ambulating from home did not feature in other young people's interview narratives, or within the existing primary research exploring experiences of AC.

Views about ambulating from home, however, were present in companion interviews from the perspective of factors that informed families' choice whether to elect for hotel, or home-based AC. Companions talked about their young person "not travelling well," (CN) being "sick in the car" (CG) or the pronounced fatigue that they experienced during chemotherapy in a way that made home AC feel an unfeasible option. One companion expressed anxiety about having to go to their local hospital, where they were unknown, if it was not practical or safe to return to the principal treatment centre out of hours. The security of knowing that they were staying 'right there' nearby if needed, had underpinned their choice.

Alongside distance, and not being known to staff, the configuration of cancer services at the local hospital also informed decisions on whether to elect for home AC:

> We've had to go once on an adult ward in our local hospital and (a) we had to fight for me to stay with him, and (b) he was literally surrounded by old men and that's really, really hard for him. So, ambulating from home, I think we possibly might just be that little bit too far away from the hospital, and what we wouldn't have wanted to do was run the risk that they say 'No, go to [local hospital].' Because going there means fighting to stay with my son. (CN, mother to a 17-year-old male)

Admission to an adult ward, which invariably meant that a companion could not stay overnight, was a risk that this companion was not prepared to take. However, home AC became a more considered option once families had more experience of chemotherapy. Whilst ambulating from home was perceived to be “a worry” (CH), if undertaken from the beginning, it increasingly felt more possible once confidence had been built:

> We're more confident about, you know, which medications to take and which ones she has to take, and which ones she doesn't have to if she doesn't feel like taking them, and also what to do if it [the pump] starts beeping. Like, we know all these things now and we're quite experienced so we're a bit more comfortable. I think if we started ambulating from home from the beginning of her treatment, it would've been chaotic, I think I would've gone bald. Because it's so far into the treatment, probably passed the halfway point completely now, so I think that's why we could do it from home. (CM, sibling to a 16-year-old female)

Families’ consideration of home AC took account of their unique personal circumstances, yet within this, travelling distance; the effects of treatment; and the age of the young person were seen to inform decision making – often culminating in the hospital hotel being their preferred choice.

6.3.3.4 Self-catering apartment

The two participants who resided in a self-contained apartment whilst receiving proton-beam therapy treatment also had experience of the hospital hotel, which they sometimes referred to as a point of comparison. Both young people had appreciation for the additional space that the apartment offered, and this was contextualised by the fact that their treatment was 6-weeks duration, rather than the 5-day admissions that they were used to during chemotherapy when they stayed in the hospital hotel:

> My treatment is only like an hour long and so the space is more important. So here we've got a living room, a TV, we've got two separate bedrooms and a whole kitchen area where you can properly cook, whereas in the hotel there's only a microwave. I know after the first few days of having it [own food] again it made me feel good to have something from back home. (YL, 21-year-old male)

The other young person, who had experience of staying in a different apartment, drew attention to the fact that she and her companion each had their own bedrooms. "Even though my mum and I get on really well, it was amazing to have my own space" YI said, before describing how she could close the door and take naps without her mother having to compromise what she wanted to do. She explained that in the apartment everything was "sort of our own space, and everything was ours, you know [...] we had a big fridge so that was great food wise, just to be able to you know come home and just eat what you want, and or just cook" (YI). Being able to take care of laundry was also put forward as a benefit of having a space to call their own.

"I think one of the best parts was we were actually allowed to have our dog with us" said the same participant who described how her pet "made such a difference", helping her and her mum to remain positive. She described that whilst the hospital hotel was comfortable for a few days, it did still feel like a hotel, whereas the apartment was "like a home away from home". For YL, the apartment remained "a temporary place to stay", and he thought it positive to think that "at the end of the day isn't like home". This held importance for him as he associated the need to stay there with his progression through treatment, whilst safeguarding the comforts and constancy of home.

Both young people needed to journey 15 minutes by transport to the treatment centre each day. When asked about how they felt about staying a further distance away from the hospital, both described how confidence to self-monitor their health status, manage infusions and treatment related symptoms had been established during earlier experiences of AC. This enabled them to feel safe and confident to reside further away from the vicinity of the hospital.

6.3.3.5 The inpatient ward

Experiences of the inpatient ward were present across interview narratives and were often referenced when demarcating or describing what was different about their experiences in AC. Evidenced within the data were young people's association and experiences of the Teenage Cancer Trust ward as a place of safety where one would go if acutely unwell. It was associated with a requirement for closer monitoring, additional treatment, or the need for isolation. In effect, it featured as a critical component of the *safety net* of AC within and across data from young people, companions and staff.

Young people's experiences of the inpatient unit were characterised by the more passive role that they took on as patients in this environment, as recipients of care. They talked about their experience of needing to share space with the healthcare team, and the lack of privacy that this engendered. For example, the constant task-based interruptions, questions about bodily functions and a need to relinquish one's own daily structure to premise the structure and routines of the hospital and healthcare team. The independence, choice and control that young people so frequently conveyed in association with their experience of the hotel or home, was conversely described in more restricted terms on the ward. Young people referred to feeling "confined" (YB), "tied down" (YA), "constantly observed" (YN) and the frustration of not being allowed to step beyond the ward threshold. One young person, who had elected to be interviewed at a time when she was an inpatient, was interrupted six times during the 60-minute conversation. She, like others, talked about sleep deprivation experienced on account of not being able to safeguard time to rest.

Others who had experience of being unaccompanied in an inpatient setting talked about loneliness, despite knowing that they were on a ward with others who had relatable experiences, in view of the need to remain isolated in a single room. Among those receiving care in a hospital bay, being exposed to the illness experiences of others did not always foreground the benefits of related experience. Privacy remained important when an inpatient, yet being able to negotiate this was difficult, irrespective whether one was in a single room or bay. A young person noted that even among those with no experience of AC, attempts were made to create a more private experience in a bay-bed by drawing curtains around the bedspace.

Among companions, the Teenage Cancer Trust ward fostered a sense of community among mothers, who spoke about meeting other mothers on an unplanned basis in the kitchen whilst making drinks. Paths would cross, and conversations would ensue in the times when breaks were taken from the bedside. This sense of community support did not feature in interviews with fathers or siblings, although reasons for this were not fully explored during interviews. The Teenage Cancer Trust ward physically accommodated companions to stay overnight at the bedside, and this acknowledged their emotional contribution to care. Companions sometimes described feeling “helpless” or making a less defined contribution to care delivery, however, when they compared their role on the ward to that in AC. With little practical provision throughout the hospital for companions (e.g. showers, beds, meals), companions additionally described their practical needs feeling less formally recognised on the inpatient ward compared to AC. Among participants 20 years old and over, a requirement for hospital admission meant going to either the young adult unit, or to one of the adult cancer wards. The most defining difference here, cited by both young people and their companions, was the inability to be accompanied overnight in the adult setting.

Many young people who took part in the research had experience of both the ward and AC. When describing experiences of AC, across all participant groups, a distinction was often made between being able to go outside when an AC patient, and the restrictions characteristic of being on an inpatient ward. “When you're in hospital you only get to stay in one space all day long” said a young adult “… if you try and go off the ward, they're going to tell you, 'Where are you going?'” (YA). The focus of care on the inpatient ward centred on the bedspace: care was often described as ‘coming to’ a patient, who became a passive recipient of care. Young people spoke about being attentively observed, monitored, attached to machinery and invariably unable to leave the ward. They described less respect for their personal time and daily structure; if “a dressing was not changed one day, it could roll over as a task for the next” (YB). The acuity of the service, and organisation of care throughout the hospital, required young people to relinquish elements of choice, control and independence, irrespective of the inpatient setting and the team’s commitment to an age-appropriate philosophy of care.

What may feel like a dichotomy between the inpatient ward and AC, however, once disentangled, was found to be less opposing and more reciprocal than overtly conveyed. Confidence to ambulate was often associated with the proximity, security and direct access to the inpatient ward and expertise of the healthcare team. Participants described feeling reassured knowing that the ward was there for times when they required close monitoring, lacked confidence or if clinically unwell. In these circumstances young people described being willing to relinquish the freedoms, flexibility and choice they could exercise in AC, to take on a more passive, cared for role. Another present, although less frequently articulated feature of the ward, was its role in building confidence to undertake elements of self-care and monitoring, in preparation for step-down to AC. In essence, even though one of the defining characteristics of AC was the transition of care away from the inpatient ward, the AC pathway was only seen to work well because of the inpatient environment: the inpatient ward was evidenced as critical to the safety net of AC.

6.3.4 Spaces between

Consistently present within young people’s experiences were conversations about parks, cafes, shops, streets and even theatres in the vicinity of the hospital, that positively contributed to their experience of AC. Young people’s photographs captured eating out, walking in green spaces and seeing local landmarks. Significant was articulation of how these spaces informed their experience: this led to the framing of young people’s engagement with the local community through a lens of *spaces between*; beyond and between the space of the clinical or residential setting.

The most frequently cited word within young people’s interview narratives was the noun *freedom,* along with its related adjectives, which became a theme evidenced across the data. A thematic summary of *freedom* is detailed in Appendix 29. Among other things, freedom was associated with being able to go outside and not feel constrained by, or tethered to, the structures or routines of the clinical setting. Being able to step outside into the wider community and exercise choice about how time was passed, was upheld within data as a critical feature of AC. It was experienced as inherently positive on a practical level as a form of distraction, yet it was also associated with fostering mental wellbeing:

> Just the freedom to go out is important to me. Just to have that option is really nice. So, as long as I have the energy, we do try and get out and do at least something, even if it's just popping into a shop just to have a look around. Just get some air, have a bit of normality, just be out for a meal. It's nice to do something a bit different really. (YI, 21-year-old female)

Freedom also associated with a sense of normality engendered through being able to visit community spaces. “Being able to disassociate a bit and think that I’m normal” (YD) was experienced as comforting, yet more than that, it conveyed feeling integrated as part of society and less defined by their diagnosis of cancer.

Figure 6-5: Freedom

> So, this image is linked strongly to the idea of freedom, in the sense that whilst you're in Ambulatory Care, when you're not in the clinic receiving treatment, you're able to go out and go where you want. One thing that I did almost on a daily basis is went out to somewhere where there was a bit of greenery, somewhere that's quiet, where you can just sit and relax and become part of society again. (YQ, 21-year-old male)

This young person also aligned freedom with "feeling more in control again" and independent (YQ, Figure 6-5). Being able to exercise choices, and experience social independence correlated closely with perspectives of freedom evident more broadly across the entirety of young people's data. This was, however, particularly present within data that foregrounded experiences of time passed in the geographical spaces between the clinical and residential setting, and in relationships with a 'non-cancer' community.

Being able to "come and go" (YN) and "wander around" (YD) was representative of exercising freedom. For many young people, taking a walk, even the 200 metres from the hospital hotel to the cancer centre, or, being pushed in a wheelchair to Regent's Park, was regarded as daily routine of importance that helped maintain a positive mindset, whilst supporting mental wellbeing. Attention was often drawn to the benefits to one's mobility, limb function and energy levels derived from physically engaging in activities of daily living within the community around the radius of the hospital. The backpack infusion (Figure 6-6), although described as "heavy" (YI) and "an annoyance" (YK) was upheld as critical to being able to go out and experience freedom, in the case of YK and YI in the form of a theatre trip and a meal out with family.

Figure 6-6: The backpack

Feeling connected with nature, green spaces and for three young people, seeing the sky, were attributes experienced in the space between the clinical and residential setting that held significance. Data indicated that these experiences communicated relaxation, offered a sense of reassuring constancy, or conveyed a feeling of calm or wellbeing for many young people. Feeling a sense of relationship with the world that felt more existential in nature than ephemeral was also evidenced:

> Your eyes tend to lose focus when you're in hospital because everything is so close together [...] and your sense of scale tends to become quite poor because you can't really focus on objects that are far away. Going outside and, you know, being able to look up and see the BT Tower, see something properly big, properly far away, let my eyes focus on something like that, it just felt really good. (YD, 24-year-old male).

Further consideration of this, and the relationship of AC to wellbeing is a feature of the forthcoming sections.

Experiences of the *spaces between* were invariably accompanied. Young people's photographs offered a sense that their companion was present, either as the photographer, or through the inclusion of their presence in some, discrete way. Young people often used "we" when they talked about their experiences, and the sense of *togetherness* evident in their experience of the clinical and residential environments remained present within the data relating to *the spaces between*. In some cases, participants' narratives emphasised how, were it not for the practical support of their companion carrying kit, walking alongside or pushing them in a wheelchair, they would not be able to spend time outside due to restricted mobility, weakness and fatigue. Young people universally welcomed and were appreciative of their companions' support, and positively framed the experiences that they shared.

Being able to meet and socialise outside became an important feature for many families, given the social distancing restrictions that had been in place when they took part in the research. Evident within the data was how parks, cafes and even the street pavement enabled the integrity of a family to be maintained. This included siblings, who could continue to visit in a way that was less encumbered by a clinical setting, whilst offering an opportunity to feel involved as depicted by CP:

> We went for a meal with my friend, my son, and his brother. We went for a lovely meal. He's just amazing with his brother, he's carrying the backpack, he's helping him down the stairs, he's pushing the wheelchair [...] and he [the brother, underlined for emphasis] felt involved. And, I think for the whole family, you must involve people. (CP, mother to a 20-year-old male)

The perspective of eating out and experiencing what the neighbourhood had to offer was a feature of most young people's interview conversation. Less pronounced in this dataset, yet raised in companion interviews, was a conscious intent to offset the intensity of treatment with what were described as 'treats' that became a characteristic of the AC experience. "We spoiled him, we went to get coffees and meal deals from the supermarket and Deliveroo [takeaway delivery company]" said one father (CK) who acknowledged that he was "just compensating for the physical situation to give him [his son] some mental light relief". A mother, CH similarly spoke about how she had "kind of promised" her eighteen-year-old daughter that they would "have fun" once in AC and do a lot of eating out, as "a treat because it had been really hard for her on the ward".

Both young people and companions spoke about positive memories that they would cherish that had been created through the freedom and opportunities that AC offered, in contrast to the rigidity of the inpatient ward. What became discernible however, was that this almost intuitive response to "make the most" (CH) of what the *spaces between* offered, came at considerable financial cost to companions - or for young people who did not have this experience, an inequity of AC experience might exist. "He loves bubble tea, so there was so many bubble tea shops in Central London, and he's very picky" said a sibling, CD, accompanying her brother in AC. "He'd be like, 'I want it from this shop or this shop,' and I'd be like, 'I'm going, I'm going'," she recounted, saying that she spoilt him so much. Making the most of the availability and choice that the geographical area had to offer was evidenced as almost an expected, or inherent part of AC. Yet this juxtaposed with a more understated, albeit evident, concern for the financial cost or burden this created was seen within companion data, and perhaps reflective of a context where families of children with cancer are known to experience significant financial hardship (Aaronson *et al*., 2014; McNeil *et al*., 2019, NIHR, 2021a). This is revisited in section 6.13.3.

6.4 Building relational understanding of place and space

Young people's and their companions' experiences of AC were characterised by fluid transitions between *place, space,* and *spaces between*. In considering our categorisation and descriptive characterisation of experience however, what arose was contention for a co-constructed, relational understanding of space and place. Place is more than a location according to Massey, a humanistic geographer who proposed that place is created by human experiences, and that space and place are inextricably linked, not static, and therefore always in the process of being made

(Massey, 2005; Meegan, 2017). Our understanding of space “is related to the places we inhabit, which in turn derive meaning from their spatial context" suggest Seamon and Sowers (2008, p.44). In revisiting staff, young people’s and companions’ experiences of AC through this lens, it became evident that the affective qualities of AC they described had been constructed, re-constructed and co-constructed through their interaction with the physicality of the settings and through human relationships. This was underpinned by, and contributed to, the enactment of a distinct philosophy and approach to care within which both shared, and personal experience co-existed.

Before considering the data in relation to TYA cancer care, I investigated how space and place informs experience of care more broadly. This interplay of human connection with the built environment in forging experiences of health care has become an established field of scholarship within the discipline of health geography (Kearns and Milligan, 2020). Gesler (1992) was the first to develop the construct ‘therapeutic landscape’, to describe the interaction of physical, social and symbolic spaces in contributing to experience and wellbeing. The spaces of hospital (for example Water and colleagues (2018) exploration of children’s outpatient departments), and experiences of hospice day care (Moore *et al.*, 2013) have been researched from the perspective of space, place and the ideas of Gesler’s therapeutic landscapes. Relationally constructed, spaces of care are not pre-constituted, nor are they intrinsically always therapeutic or experienced in the same way by different people (Watson et al., 2007; Water *et al.*, 2018). Pausing to explore our research data through this lens, helped extend my consideration the findings.

Although there was no predetermined intent to analyse the research data through the perspective of ‘therapeutic landscapes’, reappraising the findings in consultation with the literature in the field of human, health and social geography, offers a more considered, critical explanation of those data. If we consider Manzo’s (2003) consideration of home, not being a residence, but a way of being in the world, this helps reappraise participants’ characterisation of the hospital hotel from being ‘homely’ to consider the meaning that this might hold for families. The hotel breakfast, watching a DVD, or taking a walk to a café, were activities that were repeatedly foregrounded in the data, and were communicated as important by participants. These activities and routines were experienced as familiar, comforting, offering constancy, or associated with more carefree times pre cancer diagnosis. For example, to the surprise of his mother, one young person had associated completing a craft kit, with being on holiday. “He sees it as a holiday kind of thing, if that makes sense?... He says, 'Do you remember when we used to do these on holiday, mum?'“(CR).

The underlying reality of not being at home, is perhaps kept at a distance, suggest Moore and colleagues (2013), through one's engagement in activities that matter. It feels possible to tentatively suggest that young people and companions experienced what phenomenologist Svenaeus (2001) positions as a “being at home that keeps the not being at home in the world from being apparent” (Svenaeus, 2001, p.94). For some, there seemed to be a genuine appreciation for the fact that they were not at home, safeguarding their home environment from the most intensive parts of cancer treatment.

It is well known that a diagnosis of cancer in adolescence and young adulthood is profoundly disruptive (Zebrack, 2011). Feeling anchored in aspects of normal life or engendering a feeling of normality are evidenced as important to young people (Lea at al., 2018) and integral to the culture of young people’s cancer care (Lea, Taylor and Gibson, 2022). Our analysis of the data found that what was associated with a perspective of normality in the hospital hotel, was not ‘normal’ or usual per se. Young people would not normally be sleeping in a room with a parent. “We wouldn’t usually be having a take-away on a Wednesday night” one father, CK said. A pizza or curry, whilst considered both a treat and something familiar, engendered a sense of remembered normality or perhaps became a proxy for feeling normal-like. This was especially evident among participants who described a comparison with clinical experiences of the hospital ward. Associations with normality communicated a closer relationship to usual life. This was more pronounced among young people and particularly companions who stayed in the apartment or in their own home, through being able to take care of work, home responsibilities and usual routines, with the integrity of the family experienced as more intact.

Experiencing care whilst in the sanctuary of a residential setting, with only temporary visits to the clinical hub was seen to provide a “pause from the turmoil of a cancer diagnosis” (Martin and Roe, 2022, p.7), whilst ‘enabling care’ (*ibid*, 2022) in a way that positively informed experience of cancer treatment, and was seen to dynamically contribute to the ethos and practices of AC. Juxtaposition of experiences in AC as ‘non-clinical’ and more ‘normal’ against the ‘clinical’ nature of time on the inpatient ward, contributed to AC helping young people remain emotionally connected with who they were as individuals. Critical to this was being able to exercise choice, feel a sense of independence, go outside, experience nature and feel relationally connected to the world. Whilst the benefits of both being out and about (Moore *et al*., 2013) and parks and green spaces for people and communities are becoming increasingly recognised (Dobson *et al*., 2019), this aspect of experience has yet to be reported in the literature in association with AC.

As we have seen, *place* was as important as *space* to young people’s sense of wellbeing. Therapeutically, ‘enabling places’ can be understood as an assembly of material, affective and social resources (Kearns and Milligan, 2013). In the UK, the architectural design of Maggie’s Centre buildings, each one unique, is integral to providing material, affective and social resources to people with cancer (Maggie's’ Centres, 2015; Martin and Rowe, 2022). Teenage Cancer Trust similarly invest expertise in the design aesthetics of their units, recognising how the built environment contributes to experience of care. Borrowing Duff’s original theory of ‘enabling places’ (Duff, 2012), Maggie’s have been able to evidence how the physical features, affective qualities (atmosphere), and the social networks provided by their centres coalesce to positively support and shape experiences of wellbeing (Martin and Rowe, 2022). Within our data, the relaxed atmosphere, friendliness of staff and the social resources provided by the physicality of the Day Care and AC unit, were evidenced as critical to families’ experience of care. This contribution of *place*, the built environment, to *space*, experience, was found to be particularly evident in relation to the recreational side of the unit. Its role in “opening up social networks and social resources” (Martin and Rowe, 2022, p.2), enabled access to staff in a way that felt more person-centred, whilst the openness of the environment fostered connections and sense of community, and this was a feature of participants’ articulated advocacy for AC.

Having described the AC setting and components of the environment, whilst not losing sight of the relevance of *place*, *space,* and *spaces between,* presentation of the research findings will now integrate these perspectives to articulate what was communicated within the data from a thematic perspective. A theme can be thought of as “a meaningful essence that runs throughout the data” (Morse, 2008, p.727): integral to the presentation is propositional explanation for the meaning held within, and across these themes. Themes arose from our scrutiny and questioning of data coding and categorisation during participatory analysis, and our questioning: “what is this about?”; “what is this an example of?”, whilst considering the relationships within, and connections across the data.

6.5 A sense of oneself

Our consideration of the *places*, *spaces* and *spaces between* culminated in a description of AC experience that was representative of feeling more anchored in aspects of usual life during treatment, and because of this a sense of connection with feeling *able to be you*. Respect for personhood was evidenced to be an all-encompassing characteristic of young people’s experiences that the AC service facilitated, and *able to be you*, an overarching theme that encompassed the essence of what AC offered, which through discussion, was distilled by the young associate researchers to be about, and encompass, a sense of oneself.

The AC literature cites *choice* (Esparza, Young and Luongo, 1989; Newton and Ingram, 2014; Brown and Walker, 2016), *normality* (Kelly, 2005, Statham, 2005; Ingram 2017; Anderson *et al.*, 2013; Brown and Walker 2016) and *independence* (Statham, 2012; Brown and Walker, 2016; Comerford and Shah 2018) in association with the benefits of the AC pathway. The scoping review (Chapter 3) identified that these nouns are cited in the literature in relation to the affordances of AC, usually without explanation or contextualisation. Choice, according to one of the doctors I interviewed, was considered "relative when facing the demands of cancer treatment that has curative intent". And yet, although relative, it was the principle of being able to exercise choice that became critical to young people's experience. One young person, in describing a photograph he had taken for the research said:

> I know it's very beige, but I took it because that's what I love, like, chips, chicken nuggets, hash browns. I chose to have that, and I could have that. That was my choice. So, you do what you want really, within reason, obviously. (YN, 17-year-old male)

Our findings evidence that choice was not unilaterally experienced; critical to exercising choice were aspects such as one's clinical status or the availability and support of a companion. Financial means might also limit or restrict choice, which will be revisited later in the chapter. Yet what choice enabled was the fostering of individuals' agency: a capacity to act freely without restriction was evident in the data, often communicated through everyday experiences such as whether to chat on the phone or what to select for breakfast.

From the perspective of normality, a father described how "being rooted more in normality, the constants of life, the bits that [his son] could fall back on" was "priceless" (CK) at a time when everything had changed in life. Being able to "pop to the shops for a browse" (YI) for a young adult female, was illustrative of her normality. Another young person conveyed how he would have had more confidence expressing intimacy with his girlfriend "partially as we wouldn't have nurses coming in on a regular basis, but also as there is an element of normality that is reintroduced that would make me feel more comfortable in doing so".

Interpreting these and other data that communicated 'normality', 'choice' and 'independence' collectively, and from a more integrated perspective beyond their defining nouns, conveyed how respect for personhood encompassed relational acts that anchored young people socially. Rather than normality per se, it encompassed structures and acts that emphasised what felt usual or familiar. "To have some semblance of normal; reduce that degree of change in a way because then you still have what would look like a normal bed instead of one of those air mattresses" suggested a young associate researcher during one of our analytical discussions. Often what was most valued was modest; "I've been able to get up, go around, do things like making myself a cup of tea. So, that's, kind of, the positive side of independence is being able to make tea" (YE). Not only did this foster comfort, choice and independence, it enabled the young person to take back control. Being in control of one's own medicines in AC was another example from the data of where control featured and was experienced in relation to independence: "I prefer to take my medicines just because it makes me feel a bit more in control of my own treatment, I'm not along for the ride", said YJ. Feeling in control if then taken away could evoke frustration, with potential to adversely impact wellbeing:

> Another thing I hated about being in hospital was that I was in pain all the time, 24/7, and the thing is you can't self-administer your own pills like you can in Ambi Care, you have to tell them, well, ask permission for them. (YA, 22-year-old female)

Experiences of the inpatient wards commonly featured during interviews where reliance on others was presented as the antithesis of feeling independent or in control. Foregrounded in those narratives was dependence on members of the healthcare team to fulfil activities of daily living. This included help with moving; "I was just stuck in bed all crooked, I couldn't move" (YA), toileting or waiting to receive a hot drink. Regaining or maintaining control of aspects of daily life in AC amid a context that operates tight controls and regulation (i.e. the need for organisational controls to ensure safety and promote efficacy of cancer treatment), was not only evidenced as possible, but it was also one of the perceived benefits of AC. Revisiting previous AC research identified that in the qualitative study by Statham (2005), AC was similarly found to promote increased levels of patient control, greater normality and privacy among adult patients, that fostered perceptions of empowerment (Statham, 2005).

Embedded within articulation of independence in our data was reference to feeling empowered, and this encompassed self-reliance. This self-reliance was a pre-requisite for the safety of patients in the AC service. Many nouns and adjectives were used by participants to describe a sense of personhood, or oneself. These included, but were not limited to independence, choice and control. Composite consideration of these various attributes more collectively was therefore necessary to build understanding of people's experiences of AC as what the data recurrently conveyed usually held more generative meaning. Whilst the words (or photograph titles) normality, independence, choice and flexibility were commonly chosen by participants, the fact that these attributes were used interchangeably when integrated in interview dialogue, implied more representational meaning. Considered together, what they evidence is that AC helped retain aspects of life that were important to these young people: eating out, relationships with family, 'home' friends, and connections with public spaces and society; aspects that helped them feel less defined by their cancer diagnosis and more able to retain a sense of familiarity associated with daily life, and a connection to who they were as people. This remained present even at times when their symptoms or the impact of their treatment had placed restrictions on their mobility, or if they felt sick, or overwhelmingly fatigued. During participatory analysis, we debated the naming of what this conveyed. "I don't think it needs to be a fancy word" said one young associate researcher. "No, I don't think so", said another before we settled on *able to be you* and then *sense of oneself* to encompass what the data communicated.

Young people's engagement with the healthcare team also contributed to retaining a sense of oneself. "They all know my name because I go there so often" said YA, a young adult female aged 22. "That's what I like, they remember their patients. They don't have to remember who I am, but they do" (YN). Being remembered as an individual beyond one's cancer was critical to these encounters. A young male, aged 18 took a photo of his work tools, football and tennis racquet, titling his image My Life:

> If people said, 'What is your life?' I'd say, 'Being up a scaffold, building a loft, or playing football with my mates.' That's what I'd say, really. In Ambulatory Care they [staff] take an interest in what you actually do, bar what they're there for. It's not like, 'I'm just here to give you chemo, then you go.' You walk in, and there's a bit of banter, like, 'Oh, Arsenal didn't play very well in the week,'... It's nice that they remember. They actually care, and take an interest in your life, apart from the cancer.

Taking a personal interest in young people's lives demonstrated respect for personhood and individuality, a central tenet of age-appropriate care (Lea *et al.*, 2018). Feeling remembered provided assurance for some young people that although less observed during AC, you were still being thought about, and held. Data indicated that young people were able to stand in their own independence in a way that was less hindered by the organisational structures and routines of the wards. This was considered during our analytical conversations as fundamental to the ethos of AC.

Still, as evidenced by young people who included photographs of their clinical encounters during interview, time spent in AC had a clear purpose: to receive cancer treatment. Having confidence in the healthcare team was contributory to their overall experience. It was this juxtaposition of access to clinical care and the tailored expertise of the AC unit, with the ability to pass time unattended by the healthcare team, that fostered a psychological space within which it was possible to feel *able to be you:* experience a sense of oneself and feel grounded at a time of huge uncertainty. The life that could be lived between going to the AC unit and sleeping overnight was fundamental to this experience. However, often the simple act of being able to rest and sleep undisturbed was critical to feeling more like one's usual self. Whilst choice and independence have clear boundaries within the context of cancer treatment, "the little things", as many participants described them, for example talking freely on the phone, or having one's own toilet, fostered personhood which, along with being able to exercise choice, positively framed experiences of care. It reorientated young people to things that were familiar, whilst centring them in a way that fostered autonomy in contrast to feeling more passively positioned as a recipient of care on the hospital ward.

Our proposition that AC fosters a sense of oneself and personhood, arose from analytical consideration of young people's engagement with *place, space,* and *spaces between*, and four themes that were advanced from within the data: *respect for privacy*; *togetherness with a companion*; *holding and retaining structure*; and *time and time passing,* the composition of each I now explain.

6.5.1 Respect for privacy

Ambulatory Care is, by definition, rooted in a residential setting, with patients moving out to the clinical setting to access care. Being less visible and unobserved by members of the healthcare team becomes a consequence of accessing care from a distance. Respect for privacy was a theme embedded throughout staff, young people's and companion data: a summary of this first theme is detailed in Appendix 30. Respect for privacy enabled downtime, sleep, being able to pass time without feeling judged; it also enabled the passing of quality time with friends and family.

Privacy facilitated being able to frame one's mindset positively without confounding factors, in a way that supported emotional wellbeing. Young people described feeling appreciative that the energy required to witness others' cancer journeys was limited to time spent on the clinical unit. They had choice about how they would navigate their own journey – on their own terms. A photograph depicting a close-up image of closed venetian blinds was titled 'Privacy' and used by one young person to show how "having my own space is a big thing". "Some people might want to get through their treatment with lots of people around them" he said. "For me, not wanting everyone to know everything about me is a big thing" (YN). What was important to him was that he felt in control of who knew the details of his cancer diagnosis and experience.

On a practical basis respect for privacy was experienced as upholding dignity at what is known to be a significant developmental life stage. Having a personal toilet, and shower within which one could negotiate the impacts of treatment – urinating in a jug for measurement, losing one's hair, taking a shower, without feeling visible or hurried – meant that it became a less exposing experience:

> The bathroom… this is where most of it happens, that's when it hits you, the reality of it, and you see that you're losing your hair. You know that, at one point, you will lose all your hair… it almost acts as a constant reminder of the fact that you have cancer, which isn't nice. (YQ, 21-year-old male)

Appreciation that experiences like this could be negotiated in privacy, both emotionally as much as practically, resonated in other data. Respect for privacy rarely reflected solitude, however. "When I started treatment, I just sort of wanted to be in my little bubble with my mum. It just felt like a very private thing" (YH), this young female, said. Throughout the data, explicit within young people's accounts was the presence of a companion. Navigating treatment in AC became a shared endeavour and in all but one interview a companion had always accompanied the young person in AC.

6.5.2 Togetherness with a companion

The second theme was togetherness with a companion. "I think some people really look to their parents for support and help, whereas others are really independent" a clinical nurse specialist said. Yet, asked whether they would choose to ambulate alone, every young person we interviewed, except for one (who had a few nights' experience of this), said that they would not want to, or did not think that they could. Perceptions of the support experienced from being accompanied helped mitigate loneliness, alleviated fear and supported emotional wellbeing. Furthermore, as previously proposed, it was often considered a necessity on a practical basis: "My left arm wasn't working because of the tumour, then the right arm for a bit due to the PICC [Peripherally Inserted Central Catheter Line]" (YA). Other young people talked about the "worry of forgetting" timed medications due to tiredness or what was sometimes described as "brain fog" (YD).

Togetherness between young people and their companions was a theme present across the data. This was without exception framed positively, with appreciation for their companion conveyed during the natural course of an interview conversation, rather than the result of more directive questioning. Togetherness was characterised by journeying together, being alongside to practically and emotionally support care. There was a physicality to togetherness: companions were observed to take position next to their young person during time spent in treatment on the third floor, and for those staying at the hotel, they remained close by overnight, ‘on-call’. There was comfort in this togetherness, derived from familiarity and feeling understood. “My parents, I'm most familiar with, I know them inside out and they know me inside out” (YQ) a young adult male said. “You look to them to support you in the times when you are feeling down or negative”, “it’s intuitive”, he then said. As another young person offered:

> I think when you’re going through a cancer diagnosis and everything and all your treatment and stuff, I think it’s probably like there's so many new things going on that you have to face, I think it's quite normal to just want to be with what's familiar and your family. I mean, for me, my family is what's most comforting to me, and often I don’t really want to see lots of people if I'm feeling unwell. You just want to be with the people who know you best and don’t care what you look like. (YH, 18-year-old female)

The comfort derived from being accompanied by family felt more effortless, and mitigated having to take on additional anxieties which, for some, had been their experience on the ward. “I feel like that gives me less anxiety when she's [mum’s] here, than when I'm by myself” said YA a 22-year-old female, who explained:

> I’d rather have my family who I know and trust than a stranger looking after me because it’s just that comfort for me as well. Obviously, who wants a nurse getting you dressed? Especially because of my age, I’m 22.

Togetherness also fostered positive relationships and amplified the passing of quality family time that may have become diminished with growing independence. There was recognition that being brought together had been through adversity, although within this, as one young male supported by his sister described: “we’ve shifted our personalities to be more family-orientated, to appreciate our family and our friends more” (YD). Sharing physical and emotional space rarely felt overbearing from the young persons’ perspective. Often the support it engendered avoided the need for

AC admission, and it appeared to facilitate, rather than disenable, perceptions of personhood.

6.5.3 Holding and retaining structure

The third theme that contributed to a sense of oneself was holding and retaining structure. Ambulatory Care held structure in a way that underpinned and contributed to the *safety net* of the service. Alongside this, data suggested that AC enabled young people to create their own structure and rhythm to daily life on their own terms. Present were the enactment of routines that felt comforting or distracting. These were often mundane acts of familiarity. When analysed from an integrative perspective these data suggested that young people incorporated or built daily routines of significance to help anchor themselves in a way that contributed to being *able to be you*; oneself. Routines were often supported or facilitated by their companion. The frequency and different contexts within which reference to a routine was stated underlined this as an activity that held importance.

From the perspective of structure, comparison was sometimes made with the inpatient ward which had been described as tightly or highly structured. Simultaneously, there was a perception that the culture on an inpatient ward was not facilitative of promoting personal structure, for example, the promotion of sleep-wake cycles. A mother, CR compared experiences of the ward – “When they're in hospital, all they do is bath and put their pyjamas on and get back in bed-” – with her son’s daily routine in AC:

> Whereas, when you're in Ambulatory Care, I help him get up in the morning and he has breakfast, he has a shower, we get dressed, and we have to go out to the Ambulatory Care. So, he’s had to do some exercise with getting dressed etc., and then getting to the Centre, then he has his treatment and then we go back to the Cotton Rooms [hotel] in the evening or in the afternoon. (CR, mother to a 22-year-old male)

Another mother conveyed how the effort required to get ready and go to the AC unit could be demanding, “but actually, he knows when he’s had a bath he feels better, he knows when he’s got dressed, he feels better, he knows when he’s got outside and had fresh air he feels better, because he’s got that emotional intelligence, he’s 20 [years old]” (CP). In contrast to the ward, where it was considered usual for young people to sleep until late morning, data indicated that young people valued having a reason for getting up, getting dressed and going outside. It suggested that young people were inviting structure – of a type that was negotiated and respected their choices, preferences and needs. Getting up and out each day was perceived as being ‘mentally healthier’ (CE), centring young people in an active and engaged way: “Some days where I just have no energy or I just didn't really feel up to it, I just knew that I needed to get certain exercise and to get out just for my own wellbeing, like a routine” YH conveyed.

“They have to make sure that they are up on time, that they go to their appointment on times, it’s not like they are just lying in a hospital bed, and everything will come to them” SJ, a staff nurse said. Needing to present to the unit at an agreed time was seen to accommodate and align the AC service’s need for clinical and operational structure with young people’s appreciation for being mobile, going outside and connecting with society in a way that converged to promote a sense of wellbeing.

Daily routines were usually internally mediated and foundational: “So this is just my usual morning routine and before I go to bed” (YL) said one young person, who had taken a photograph of his oral care. His narrative conveyed the routine as a necessary requirement whilst it also suggested that there was something about the rhythm of repeating the activity that he found comforting and affirming.

“I think it's very important to have something that you do every day, a routine that regardless of what situation you're in or how you're feeling, you must do it, like brushing your teeth, even if you don't feel the greatest…,” (YM) a 16-year-old said. The accompanying photograph depicted her skincare routine – various cosmetic products lined up on the bathroom shelf:

> I wanted to show that if have a routine, it does help…I think it helps me a lot mentally, physically, emotionally, everything like that. I think having a routine’s very important. (YM, 16-year-old female)

At a time when this young person was adjusting to a new diagnosis of cancer that had required her to embark on unfamiliar and uncertain treatment, her narrative conveyed how the familiarity of the routine engendered a feeling of reassurance and constancy. A young person and a father's data conveyed how AC itself had become "a routine" (YG, CK) which had similarly "reduced some of the shock and awe of the whole experience" (CK). Daily rituals also became routine, "a nice breakfast, bit of telly with mum" (YI), that promoted enjoyment and positivity. A young person photographed his medicines laid out in his room: "It signifies getting into the routine of things with the Ambulatory Care", where "your routine goes from being about you, to being about your health, just solely that aspect" (YJ). "I think it's really important to keep in mind that if all you're thinking about is treatment and health, you're going to go crazy", he explained. Our explanation of the data proposes that keeping a routine was also used as a distraction, to not let cancer feel defining, or encroach on every area of life:

> I have a routine of a framework of health, like my meds, appointments, but then I also try and throw in other things like try another language, go to the gym even though I'm on chemo, which I'm doing today, cooking as well is another really good one I've gotten into, because it keeps your mind busy. You can overthink things so much, especially with cancer. (YJ, 21-year-old male)

Given this was something not previously discussed in the AC literature, I looked to extant texts for consideration of the finding that routines hold significance in the AC context. This led me to philosopher Henri Lefebvre. His academic work centred on rhythmanalysis: the ways in which every day social life is patterned by rhythms of repetition (Lefebvre, 2004). The principles of his work became a useful frame from which to think about the routines that young people described.

Rhythm, according to Lefebvre, is a means of grasping both space and time (Elden, 2006) in a way that is temporal, repeated or cyclical (Lefebvre, 2004). For Lefebvre, "everywhere where there is interaction between a place, a time and an expenditure of energy, there is rhythm" (Lefebvre, 2004, p.15). Reconsidering data as a co-researcher community through the lens of rhythm helped refine our consideration of people’s experiences of space, and spaces between. “We are only conscious of our rhythm when we begin to suffer some irregularity” posited Lefebvre (2004, p.75). This drew our attention to the significance of rituals and routines in the AC context, and how, if reconsidered from a broad perspective of Lefebvre’s rhythmanalysis, it demonstrated that these acts not only retained a quality to everyday life but encompassed meaning (Lyon, 2019).

We noted how data that described routines had a rhythmic quality that communicated movement, a forward momentum and variance. Routines premised a rhythm of journeying and progression through treatment; “The first thing you do is get your key card and the last thing you do is give it in” (YL) one young person communicated when discussing how he moved through cycles of treatment. Routines also communicated stability. Irrespective of their anchoring status, however, the data conveyed how routines were not resolutely set. There was tolerance for the fact that “every day would be different” (YQ). Individuals’ journeys through treatment were unique. After describing her daily routines of importance, YH said “I take each day as it comes”, conveying that she never knew how she would be feeling. “Some days, even now, I'd have no energy, or some days I'll feel completely fine” (YH). Considering the data from the perspective of rhythm suggested that the theme *holding structure and routine* when considered alongside the next theme of *time and time passing* coalesced in a way that felt psychologically progressive.

6.5.4 Time and time passing

In contrast to the ward, where time was evidenced as not feeling one’s own, the AC environment fostered more control over clock time, and choice about how non-clinical time was spent. Data conveyed demarcation of time; days of the week, times of the day that resonated or more closely aligned with young people’s usual routines. Ambulatory Care supported a more normative time for waking, having breakfast, or sleeping, less hindered by organisational structures. Whilst making accommodation for the impact and care requirements of treatment, for example the need to frequently urinate during the night from being hyperhydrated with intravenous fluids, time passed in AC was associated with promoting natural cyclical rhythms of the body, such as circadian rhythms that regulate the body’s internal clock.

“The only thing I would say [about Ambulatory Care] is that it’s time well spent” said the first young person interviewed, YR to describe the flexibility and sense of ownership he had over his time. “Often, my treatments, don't start till the afternoon, so we will be like, 'shall we go grab some breakfast and then pop into a shop' so yes, it's definitely one of the best parts, I think” said YI, a female aged 21, reiterating the choice and flexibility that AC offered. Yet it was the repetition, or repeated pattern associated with rhythm (Lefebvre, 2004) that perhaps suggested more fundamental meaning. The momentum of moving through time in AC had a forward, future focus that was associated with positivity and progress. This aligned with a finding from an interview-based study reported in the scoping review (Nissim *et al.*, 2014), which found that among adult patients, transitioning from inpatients to AC, a future focus became more pronounced, in comparison to those in an inpatient ward setting who were found to focus more on the present time (Nissim *et al.*, 2014).

A clear demarcation to each 24-hour period was evidenced in the data, and the antithesis of this had often been communicated in association with people’s experiences of the ward, where clock time governed medications, clinical observations and treatment, with little personal time within which to exercise choice. There was acknowledgement for the need to still encounter a clinical experience to access care on the TYA AC unit. It was the respite from this setting in the knowledge that another day of treatment had been ticked-off, that held importance:

> You take yourself away from […] the nurses and doctors rushing about left and right. You just get there; you've got your rucksack behind you… just go down this nice hallway. And as you're walking down you can just think, 'Man, I can't wait to get in. I can't wait to get into my room, sit down, and just relax and wait for tomorrow.' (YJ, 21-year-old male)

Ultimately, in the context of time and time passing the data suggested that the more experience people had built in AC, the more confident they became. “I was anxious at the beginning” said YN, although he explained how “it wouldn't have mattered if it was ambulatory, the ward – you're going to be anxious about everything. As time goes on, I definitely feel more comfortable on ambulatory care”. Further consideration for the passing of time in relation to how this fostered adjustment to living with a cancer diagnosis is discussed in section 6.13.

Building on the theme of sense of oneself, of retaining personhood, this appreciation for elements of control over one’s own time conveyed above all, the perspective of autonomy. Figure 6-7 provides a summary of how *place*, *space*, and *spaces between* contributed to a sense of oneself and autonomy.

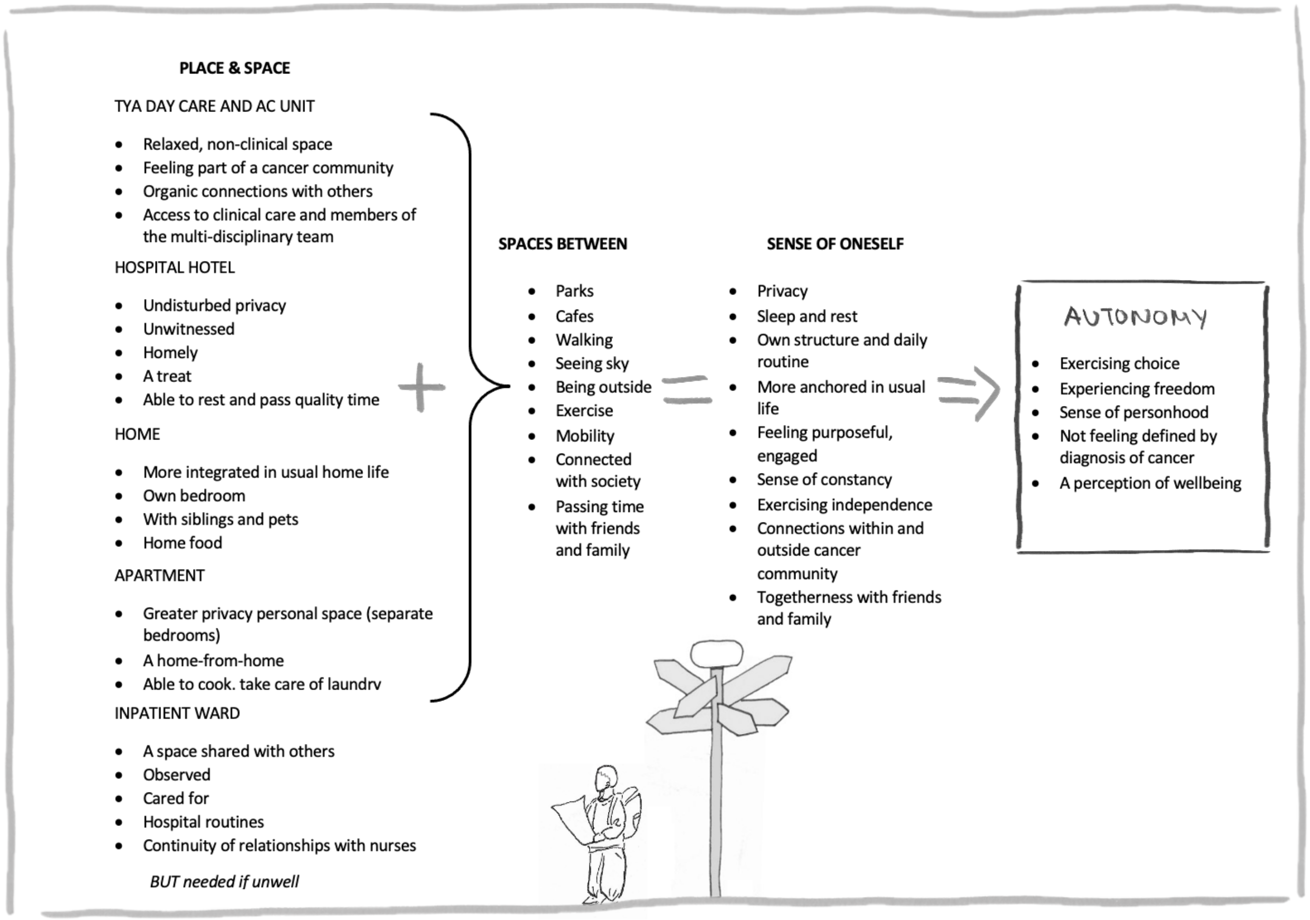

Figure 6-7: How *place*, *space,* and *spaces between* contribute to young people’s autonomy in Ambulatory Care

6.6 The perspective of autonomy

In a healthcare context, respect for autonomy is often concerned with informed choice. However, it is a term that is rarely used by patients themselves (Ells, 2001). Autonomy had not been cited within the AC scoping review literature. Likewise, a key word search across our research dataset identified that the noun had not been explicitly used by young people when discussing their experiences of AC. Our interpretation of the data, and specifically consideration of the themes generated, indicated that young people's experiences strongly communicated autonomy, however, as a primary and overarching concept.

The Cambridge dictionary defines autonomy as the ability "to make your own decisions without being controlled by anyone else" (Cambridge Dictionary, 2022a). Autonomy is often defined in relation to self-governance, self-determination and independence (Internet Encyclopaedia of Philosophy, 2022). In a healthcare context, capacity for control (Wicks and Mitchell, 2010) has been leveraged in relation to the developing autonomy of young people. More broadly, respect for autonomy is used to underpin clinical policies and practices about informed choice or the right to refuse treatment (Ells, 2001). Much contested, and theorised, rather than try to align our interpretation of the data to an academic school of thought, we evidenced autonomy to be about what mattered and was important to young people whilst negotiating cancer treatment through AC. The themes generated coalesced around a sense of oneself which helped give meaning and substantiate our use of the concept. I now explain how autonomy was constituted.

"It's about ownership, it's your thing", said YN, a seventeen-year-old male. Feeling independent and in control was a component of autonomy: being able to exercise choice not only about how time was passed, but more fundamentally feeling in control of one's experience. Exercising autonomy involved negotiating the time that one came to the AC unit to access care. Moreover, it encompassed personhood: respect for, and facilitation of, what the young person needed beyond their clinical needs – choice; freedom; ownership; intact relationships; feeling secured by the constants of life that bore some resemblance to normalcy; feeling relationally connected with others from the cancer community yet anchored socially as a young person and a member of society.

“Life saving treatment isn’t normal- Yes, I do have cancer, I’m receiving chemotherapy and whatever, but I don’t want this to define me and who I am. I want to maintain the things that I enjoyed when I didn’t have cancer” said YE, aged 24. Autonomy in the AC context thus embedded a sense of oneself: “you have much more freedom, you become much more like yourself, whereas, in hospital, you're definitely just a patient, that is your entire identity when you're in there” said YD, a 24-year-old male. Often, the elements that evidenced autonomy could be distilled to what might be perceived as simple acts:

> I mean, if I narrowed it down to one really specific thing [that I value about AC], I’d literally say making tea for myself. Just because it’s a very therapeutic act as a whole. It's, kind of, repetitive, because you're doing the same things you're familiar with, and then it’s comforting, because you get that warm drink. So, for me, that's really important, and a really positive experience as a whole. So, if I had to narrow it down to a single thing, that would be it. (YE, 24-year-old male)

Autonomy was constituted by more than the facilitation of choice by members of the healthcare team; it embedded respect for individuality and personalised care. Not being defined by one’s diagnosis fostered autonomy and was a prominent feature of retaining personhood, and the theme of *sense of oneself*. Respecting autonomy was concerned with recognising what was central to one’s character. One father noted how his son had been embarrassed because most of the photographs that he had taken for his interview were to do with food and eating out. “It’s a small thing, but it’s so central to his character” (CK) he offered, almost apologetically. A senior nurse explained the importance of adjusting a young person’s treatment so that they could go to the school prom, to articulate how she tailored care to what was important to each person.

Autonomy derives from the Greek word for self (auto) and nomos (law). Theories of autonomy are often grounded on a theory of the self (Ells, 2001) and yet cancer can entail “a shifting self” within which (according to Bowman (2019) a clinical ethicist and author), one is simultaneously oneself, yet fundamentally different. The demands and consequences of treatment, for example loss of limb function, fatigue, nausea, or cumulative weariness, contextualised the non-static nature of how ‘self-law’ was evidenced in our data. “Autonomy is elusive and complex” states Bowman (2019). “It is often characterised as the expression of an essential self, yet illness changes us. Who we are is both constant and altered” Bowman posits, in a Radio 4 programme about her own experience of negotiating cancer (Patient Undone, 2019), an excerpt of which was used during analysis Workshop 4 to aid our practical consideration of autonomy and its emergent positioning as an overarching concept. Layer onto this the complexities of adolescence and early adulthood, where a shifting sense of oneself may be extra pronounced, and we considered this sense of flux to be even more fundamental, leading to the importance that was manifest in the data of young people feeling anchored and grounded intrinsically, relationally and socially.

My consultation of literature from the field of young people’s cancer typically saw autonomy positioned alongside independence, or focusing on capacity for independent decision making, during a life stage characterised by the transition from dependence to independence (Davies, Kelly and Hannigan, 2015). Restrictions in everyday life culminating in feeling a loss of autonomy were reported by Wicks and Mitchell (2010) in an interview-based study with ten young people (aged 16-22) who were negotiating inpatient cancer care, with evidence of frustration and a desire to control their treatment process in the smallest of ways. Autonomy in the AC context conveyed the antithesis of the dependence on others so often associated with experiences of the inpatient setting. One of the mind maps used to anchor our participatory interpretation of the data (see Appendix 31), depicted a seesaw which we later refined to a set of balanced scales. Initially freedom was noted as the counterpart to security, which we refined to independence countered by dependence. This was once again refined and relabelled ‘autonomy’. The data indicated that young people were able to stand in their own autonomy in AC, unless a change in health status meant that they could not – or they chose not to.

Autonomy embedded independence and was counter to feeling dependent, passive, or ‘being done to’; “like a lab rat being prodded and poked” (YD). Autonomy was not experienced alone, but rather manifested as a shifting negotiation between the young person and others: healthcare staff, companions and family. Whether to seek help with aspects of self-monitoring, or even elect to receive treatment on the inpatient ward, were examples of how autonomy was upheld.

Classically, autonomy might be thought about as being independent in the literal sense i.e. doing things on one’s own. My appraisal of the concept of autonomy evidenced in the findings, alongside literature from the field of disability, facilitated more contextualised interpretation of the findings. I noted a critical distinction between ‘dependence’ and ‘autonomy’ that was evidenced through a ‘being with, alongside and doing together’ within the data. The findings conveyed, among young people, that autonomy was not singularly experienced; it was relationally situated – one example being the togetherness that was evidenced between a young person and their accompanying companion. Autonomy in the context of AC was upheld though a partnering between the young person, their companion and members of the healthcare team who worked together to foster what was individually important to a young person: with this being the focus of all efforts and care.

Dimensions of disability include impairments, activity limitations and participation restrictions, which can arise in acute or chronic contexts to include cancer (Ells, 2001). Autonomy, in the context of disability, can be understood as an alternative kind of independence that is distinct from pursuing or undertaking tasks without assistance or on one’s own (Barron, 2001). Neither can it be considered in purely individualistic terms argues Barron (2001); it has a social, relational dimension. Her account of the different ways that autonomy is expressed among people with disabilities helps articulate a distinction between receiving assistance, in the sense of others doing various things for the individual and being assisted – doing things oneself with support (Barron, 2001, p.437). This resonated within our data and supported a more pluralistic consideration of the concept.

In the data, the ‘togetherness’ so frequently present between a young person and their companion, was an enabling dynamic that worked towards increasing autonomy on behalf of the young person. This contrasts with perspectives such as Epelman (2013), who suggests that relationships with parents may be characterised by complexity, dependence or regression among young cancer patients who “because of their health status tend to become more dependent upon their parents, at least temporarily” (Epelman, 2013, p.328).

Beyond articulation of autonomy as a critical feature of AC must be appreciation therefore, for its very essence; as fundamentally relational. Also, consistent across the data and critical to AC experience was the overarching ethos of the pathway: that as a patient you remain anchored in an autonomous space, from which you move out to access care. Found to be informing this autonomy was the concept of agency and a proposition from the findings that not only does AC support young people to feel and be agentic, but this is a defining characteristic of the pathway itself.

Figure 6-8 provides a pictorial representation of how agency was evidenced in the data, and its relationship to the autonomy described. Four themes that contributed to autonomy being evidenced have been presented in this chapter thus far. As I continue my discussion of the findings, I introduce two further themes, *trust (trusting oneself, trusting others and being trusted)* and *being informed and feeling informed*, and I refer to Figure 6-8 ‘the scales of agency’ diagram.

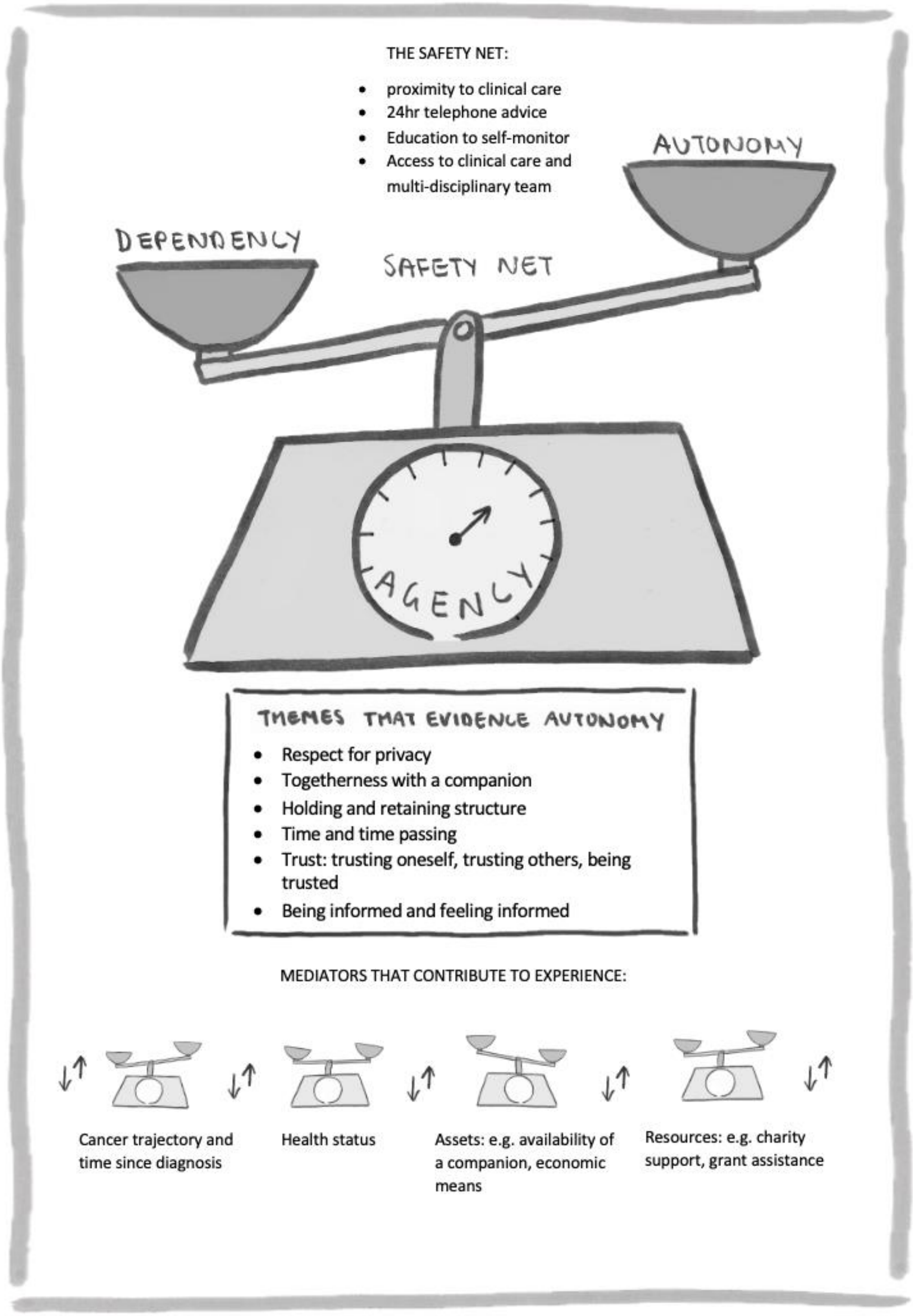

Figure 6-8: The scales of agency

6.7 The perspective of agency

The principal finding that AC fosters autonomy required delineation to be more fully understood. If, at a conceptual level, autonomy was an outcome experienced through AC, what was contributing to the autonomy evidenced? We extended our interpretation of the data to explore this. The findings evidenced that the intrinsic orientation to care in AC (as summarised by a young associate researcher during our analytical discussions), “is that you are active, you are the one physically moving towards clinical care, it is not coming to you”. This had been consistently advanced by participants as a key, positive characteristic of the service. This core feature of AC encompassed descriptions of mobility, momentum and progress, which often stood in contrast to young people’s articulated experiences of the inpatient ward. Young people’s experiences in AC did not just happen to them: the data evidenced making choices and feeling in charge. In our analytical discussions, we explored this notion of mobility and progress further.

‘It’s about feeling empowered?’ offered a co-researcher, and this explanation was tentatively held whilst the notion of empowerment and the inverse, feeling disempowered, was considered. Although sometimes used by staff in the context of their perception of what AC offered, the noun empowerment was rarely chosen by young people themselves to describe their own AC experiences. We revisited one instance: “Allowing people to live their lives, and still have cancer. It’s so empowering” (YF), to consider how empowerment conveyed permission, a unidirectional passing of power, something that was granted or consciously handed down. Yet data consistently suggested that the driver of young people’s autonomy was more internally mediated and emergent, for example: “The fact that you can take back some of your own power over your treatment is also very important” (YJ). After deliberation and mind mapping during an analysis workshop, we defined this empowerment as ‘agency’.

“When I think about agency, I think about an autonomous individual exercising decisions without other forms of power impinging; with less encroachment of the power structure of the ward and the hospital in Ambulatory Care,” said a young associate researcher. “The very nature of how the AC service is construed: that you aren't observed, you are less visible to the healthcare team not only anchors you more in society and connects you with what feels more like you, but at the same time, the overarching orientation to care is that it is not rigidly structured, and you feel more in control and have agency,” suggested a different associate researcher, as we looked at the thematic map of our analysis. Beyond consideration for how time was passed when less encumbered by a clinical setting, receiving treatment in AC created a need to take responsibility for elements of care that would otherwise sit with the nursing team. “You are exercising choice to the extent that you want to participate in the responsibilities to keep you safe” a co-researcher offered. “Yes”, said a nurse who had participated in the analysis: “and the onus is on you to report back any concerns, and vocalise your needs”. At the core of each of these examples, and others, was a proposition that the young person was exercising their agency.

The concept of agency is associated with making decisions (Alderson, 2001), exercising choice (Bandura, 2001), experiencing freedom (Moosa-Mitha, 2005) and capacity to act (Sorbring and Kuczynski, 2018). It does not just materialise however, agency embeds intentionality, forethought and consciousness (Bandura, 2001; Raithelhuber, 2016). Agency thus involves not only the capacity to make choices and action plans, but the ability to motivate and regulate their execution (Bandura, 2001, p.8). Different academic disciplines demarcate different understandings of agency which I acknowledge, although will not attempt to detail here. Our understanding of agency was premised on how it was evidenced in the findings, set alongside my consideration of the academic literature.

In the findings, not only did perspectives such as privacy, freedom, choice and control contribute to young people’s and staff perceptions of autonomy, but enacting these components was found to be driving experience itself. “I like the idea of the responsibility myself, because it brings back the idea of independence, it makes you feel you’re in control again, or I am in control” said YQ, aged 21. “I like to know what’s the plan, what’s the deal, and with Ambulatory Care you get that” said YN, a 17-year-old male.

Agency is often positioned counter to dependence, reliance on others, or placed in a dichotomy with rigid structures (Alderson, 2001; Hartung, 2017). Whilst AC experience was characterised as being less impeded by hospital structures, cancer treatment is necessarily organised around protocols, and in AC around a governance structure that ensures safety and mitigates risk. Young people noted and expressed appreciation for the structure of AC, for example, the requirement to present to the unit at a negotiated time, or the expectation that they would call the 24-hour telephone line to facilitate hospital admission if they became febrile or unwell.

The structure and organisation of AC provided a safety net and reassurance, whilst at the same time creating time to build one's own structure, fostering the conditions for young people to exercise agency. Part of exercising agency included the choice not to elect for AC, or to hand responsibility for care back to the nursing team and take on a more dependent role:

> I found actually it got quite tiring, because I couldn't walk. So, I think particularly the toing and froing, was a bit of a problem. I felt like the security of the nurses on the ward was the right thing to do…and things like wet rooms so that I could go and have a wash. (YC, 24-year-old male)

"I think it's important for people to know that inpatient care is still an option," said a nurse (SH), who discussed a patient who wanted his subsequent cycles of chemotherapy as an inpatient as he found it easier: "he was getting tired and couldn't face all the dipping his wee and all that stuff anymore" (SH). Reverting to our pictorial representation of the weighing scales, with dependence counterbalanced by autonomy, it became clear that it was agency that regulated the central mechanism of balance. In choosing to receive care on the inpatient ward, and assume a more 'cared for', dependent and less autonomous role, young people were still exercising their agency.

6.7.1 Trust

A fifth theme arising from the data had been *trust – trusting oneself, trusting others and being trusted.* This created contention for a relational dynamic between trust and the concept of agency. “I’m quite proactive with things, if I’ve got a temperature, I’ll call straight way” (YE); “I know my body more than I ever have” (YF), were two examples to exemplify trusting oneself. There were others:

> So, after my stem-cell transplant, my blood count started dropping quite quickly and I just felt quite poorly-. At this moment I realised that I couldn’t be kept in the hotel because if the diarrhoea got too bad, my electrolytes would drop, then my other bodily functions would get worse. I knew I had to just get on the wards. (YD, 24-year-old-male)
>
> I just feel like when you know your body, you know when you’re not feeling well, I will seek the medical attention I need. A doctor doesn’t give me the reassurance that I’m feeling well, I can only get that from myself or from my mum…I just know when my body doesn’t feel right. I know that I can’t do anymore for myself, that now I need help from someone else. (YB, 20-year-old female)

Underpinning this relationship between trust and agency is a proposition that young people were realising their agency, and this contributed to the safety of the AC service. Consistent across young people’s narratives were implicit understandings about when, and in which circumstance they needed to relinquish the autonomy experienced in AC, to be more closely monitored and cared for on the wards. This embedded a continued state of vigilance around symptom appraisal and readiness to act, first described by Hochbaum in 1958, and further explicated by Armstrong (2014) in association with the concept of agency. “I think that that is important to show patients that we trust them, and we trust them to trust their bodies” said SL, a clinical nurse specialist during her interview.

Young people are increasingly regarded as able to engage as partners in making sense of, and taking action in, their own lives (Kirby et al., 2003). Teenagers and young adults are not passive victims of circumstance, assert Shah and colleagues (2021); they have agency that contributes to their own wellbeing, and this remains present even in adverse or difficult situations Sorbring and Kuczynski (2018) maintain. Whilst negotiating the demands of cancer treatment was both difficult and unpredictable, the findings evidenced a sense of wellbeing among young people, and a perception of mental health associated with AC. Having the opportunity to embed one's own *structure and routine*, prefaced both looking forward, and forethought, in a way that provided "direction, coherence and meaning" (Bandura, 2001 p.7).

"I knew that I needed to get certain exercise and to get out for my wellbeing"(YI); "Going outside lifts my mood" (YH); "If I'm not actively putting energy into having positive mental health, I'll develop a negative, bad mental health, because of everything going on" (YE); "to think about good things to do in the future, positive things you can do, is vital: it keeps motivating you to get better" (YJ) were four examples of how personal agency was exercised in the milieu of *place, space, and spaces between* to coalesce and support young people's wellbeing. Implicit to the concept of agency is an individual's belief in their capacity to exercise choice and control in ways that are not just motivating but self-enhancing, states Bandura (2001).

Thoits (2006), in writing about personal agency in the context of stress, proposed that when faced with difficulties in one area of life, people in better mental health are able to "deliberately work to transform their meaning or to compensate for these difficulties" by investing in other roles or activities that contribute to perceptions of wellbeing, building higher self-esteem, whilst generating more positive experiences in the process (Thoits, 2006, p.314-315). Those with higher self-esteem, proposes Thoits, have lower symptoms of anxiety when negative events occur. Whilst this research did not set out to appraise anxiety in the context of AC, young people's expressed worries or anxieties usually associated with a period close to diagnosis, or the first admission to AC. "When you first start out, you're like, 'God, is anything going to go wrong?'" said YI. Thereafter, young people talked about "getting the hang of it" (YG) or "acclimatising" to what was expected (YK), which then contributed to 'feeling well'. Perceptions of wellness were reinforced through young people knowing that if you were considered ‘ill’, the clinical team would advise treatment on the ward and AC would not even be presented as an option.

The wellbeing experienced, however, did more than shield young people from what can be a tumultuous cancer journey. The capacity to exercise choice over the nature and quality of one’s life was described by Bandura in his social cognitive theory, as the very essence of humanness (Bandura, 2001, p.2). When our findings were considered through the lens of Thoits, and also Sorbring and Kuczynski (2018), it became apparent that the young people were not only engaging in agentic acts, but were agents, capable of acting in a way that positively influenced their own wellbeing.

Perceptions of wellbeing were also associated with the physicality of being active: up and about, and “functioning as a member of society” (YF). “I think they maintain a better sense of self…I think you know who you are a little bit more, if you get to either go home or to the hotel every night” said an advanced nurse practitioner:

> I think you can't underestimate that 300 metre walk you do outside every day from the hotel to day care. Even if you're being wheeled in a wheelchair, it's a change of scenery. You're changing from your hotel to day care, you’re seeing different people, you're getting fresh air, well, as fresh as central London air is. I just think psychologically, you're seeing the sky and I think that makes such a big deal to how you feel.

This nurse’s perception was confirmed within young people’s data. Walking or being assisted to the cancer centre each day was perceived as progressive, supporting energy levels and muscle tone, as well as promoting mental wellbeing and a less defining cancer experience. Accessing the unit gym was similarly associated with progress and wellbeing: “… it helps me strengthen and progress my mobility, it shows that you’re getting somewhere with the treatment and starting to recover” (YK).

The findings evidenced that an important part of exercising agency, was being able to choose to spend time outside. The health and wellbeing benefits of access to green spaces are increasingly understood (Dobson *et al*, 2019; Wendelboe-Nelson *et al.,* 2019); even in urban settings such access has been found to promote psychological relaxation and stress alleviation, whilst promoting a sense of social connection and cohesion (Cattell *et al*., 2008; World Health Organization, 2016). As one young person explained:

> Just going outside, sitting on a bench in the middle of a park and just relaxing, not thinking anything, just feeling the breeze, birds chirping and the like-. (YR, 22-year-old male)

This perception of wellness, whilst internally driven, was derived through being relationally connected both with the natural environment and with others, with family, peers, and through being integrated both within the cancer community and as a member of society. Evident was that young people stood in a network of social relations – exercising agency was not an individualistic endeavour. What holds therefore is contention for a less personal and more relational understanding of agency, one that exists in interconnectedness and interdependence (Abebe, 2019; Raithelhuber, 2016), and becomes constituted through the combination of "various interconnected persons and things" (Raithelhuber, 2016, p.98). People do not live in isolation asserts Bandura (2001), reiterating how exercising agency encompasses a dynamic interplay of relationships and structures. Authors more generally now seek to understand young people's agency not only in terms of context and structure, but also through relationships and interdependence (Esser *et al*., 2017; Hartung, 2017; Sorbring and Kuczynski 2018; Abebe, 2019, Shah *et al*., 2021). How children and young people express themselves as agents, or how their actions are enabled or constrained, thus depends on their connection to others, with relationships enabling agency and giving it direction (Sorbring and Kuczynski, 2018).

The findings uphold a dynamic within which young people's relationships with their companion, family, peers, society and the healthcare team shaped and supported their expression of agency. Responsibility for care was shared or passed back and forth in AC between the TYA and their companion in a flexible way, that took account of health status and took the young person's lead. "I prefer doing it myself, it's just a lot of hassle" said YG, whose mother conveyed in her own interview that their approach to the need to monitor fluid input and output, had been to share the responsibility. Examples like this were consistently maintained in the *togetherness with a companion* that had been thematically identified in the findings.

The theme of trust – *trusting oneself, trusting others and being trusted* also supported consideration for a more relational perspective of agency. Young people valued being trusted by the nursing team to be "proactive enough to take medicines" (YJ), or to adjust their own antiemetics. A father, when discussing the need to be vigilant, commended his son who was "very physically aware-, we could trust him to tell us if there was something amiss" (CK). Equally it took time to trust others; "like at the beginning it's hard because you don't even know what's going on but the more familiar you become with the people [staff], the more easy it is for you to let them do what they have to do, because you can trust what they're doing" (YB).

Young people expressed a willingness or need to trust their companion or members of the healthcare team to help support treatment. Yet critical to this remained feeling in control, a sense of engagement, negotiation and awareness. This sat in contrast to the ward where you "were more clueless" and "might never really know what's happening next because the nurses would do so much of it" explained YG, aged 18. By way of an example: "I'd be asleep and then I'd wake up and my chemo would be nearly finished" this participant said. Asked whether she minded waking up to that "surprise", YG conveyed that she "would have liked to have known".

A component of agency was not just intentional acts, it was situational awareness and engagement which contributed to perceptions of autonomy and embedded trust. Characteristic of this trust, was that it was fostered in a relational circle:

> We're putting trust in them to understand what their treatment is, what it means, and they have to trust us that we can hang their chemo and get them through this, but we have to trust them that they are going to help us out by being safe, responsible and doing the things we ask of them. Like we're guiding them to do that stuff and we're advising them, but we have to trust them that they'll do it. (staff nurse)

6.7.2 Being informed and feeling informed

The sixth theme evidenced in the findings was *being informed and feeling informed*. *Being informed* encompassed how young people and families were prepared by staff to engage in AC. “The consultants often mention it, but it will be quite a brief sentence or two ‘and you'll be expected to measure and dip your wee and take your medications at certain times’ would probably be the extent of what's said about Ambulatory Care initially” said (SH) a clinical nurse specialist. Preparation to ambulate usually then centred on a briefing conversation on the first day of chemotherapy, led by one of the AC nurses and revisited during each subsequent day of treatment.

> I do always say, 'It sounds like a lot.' We talk about the chemo and everything, there is a lot of information to take in but that, you know, ‘we go through it time and time again with you and that the AC nurses will explain it really clearly, and they’ll give you all the information you need to know, the numbers that you need. Then once you’ve done it for a night, it will become really clear. (clinical nurse specialist)

Being informed prefaced the responsibilities of being an AC patient which were in the main, grouped and communicated as monitoring tasks, administration of medication and the need to be vigilant for changes in clinical status. Taking responsibility for safety and risk management in AC became a shared endeavour between the clinical team, young person and companion. Families generally felt comfortable with the expectations being asked, with the reassurance that there was a 24-hour clinical telephone line for help and advice. Ambulatory Care education focused on the oral delivery of information, supplemented with handouts and a booklet. Education was orientated to clinical tasks and monitoring, for example temperature taking, fluid balance chart keeping, monitoring each void for blood, recording urinary pH or checking the infusion pump. Observations of practice suggested this was a routine conversation for the nursing or pharmacy team, which was typically delivered over 20-30 minutes, with dialogue usually focused on the clinical task:

> They will come with all your meds and they'll say, 'Okay, you'll take this at this time, this at this time…you'll get a chart literally telling you how to do it. They'll give you a number to call if you aren't sure, which you can call 24/7. (YJ, 21-year-old male)
>
> I think what makes a big difference is, it's not just that we give them what they're taking and sending them off. They come in each day. There are medications which they take the next day which it's really important that they do take, it would be detrimental if they didn't, and I guess the safety net is obviously we'll give the patient their medication on day one, we'll run through it all with them, and the nurses would check in with them each day. And they'd check, 'Have you taken this, have you taken that?' There is a safety net there to make sure these things didn't get missed. (staff nurse)

Staff placed emphasis on the telephone advice line as key to assuring safety whilst in AC: "… they give you the numbers to ring if anything goes wrong" (YI). If a young person (or their companion) phoned, it would sometimes lead to having to go to the inpatient ward, for clinical review. One young person talked about difficulties that she had encountered with her infusion pump alarming in the middle of the night, an event other families had experienced: "they just said go to the ward and they'd sort it out" (YH). This young person conveyed appreciation that help was on hand, whilst conceding: "I think them talking it through might have been better". She described wishing that she had felt better informed to be able to help herself and had felt more in control. While YH's experience may indicate a need for practical education, this finding reiterates a sense of young people looking for opportunities for greater agency.

Another young person described their perspective of the responsibilities required of AC: "you have to keep an eye on your fluid intake, and how much you're urinating and stuff, obviously your own medicines … if you take it seriously and you understand why you are doing it, it's not that much of a chore" (YK). The responsibilities were often described as achievable, and worth the effort. For example, "remembering to take my meds versus being stuck on a hospital floor for a week, it's a no-brainer," (YJ) said.

> If you feel like there's a lot, and you don't really know, you can literally go up to them [the staff] and just be like, 'Hey, I'm a bit confused on this part. Could you help me out?' And they are so happy to help out, really, and give some support. (YM, 16-year-old female)

From young people's point of view, the responsibilities were not construed to be either overly complex, or anxiety provoking. Contributory to this was the fact that the enactment of what was being required was usually shared with, or led by, their companion. In the case of the youngest participant, aged 16, she did not "feel it as responsibility as all" (YM). "Maybe that's something I need to ask my sister, just because, I will be really honest, I am being babied by her so much, the whole entire time" (YM), something she said that was appreciated. One young person said he could "get quite confused on chemotherapy" (YC), and there were other instances where young people doubted or did not trust themselves, looking to their companion to take responsibility for defined aspects of care such as medicines management.

The criticality of companions to the ambulatory pathway will be reconsidered in more detail in section 6.11.1. What feels important at this juncture, is to convey that the companion was usually present during preparatory conversations about *being informed* and that AC education prioritised undertaking tasks that helped ensure safety or addressed potential risks. In contrast, *feeling informed* was closely linked to *trusting oneself,* which was achieved through gaining practical experience, and building confidence over time. As a staff member commented:

> When they first come, we always notice the first couple of cycles, but the education is repeating it all the time, about what needs to be done, but by the end of treatment they're telling us what to do. Yeah, they know exactly what they're doing. They're educating us on how their treatment's going [laughs] (a senior nurse).

The mastery of technique that they accrued, closely correlated with a young person's personal accommodation of living with cancer, of knowing and trusting oneself. Just as *being informed* contributed to the safety net of the service, so did *feeling informed*. While 'being informed' was crucial to safety, only arriving at the sense of *feeling* *informed* developed and upheld the sense of agency that young people identified as a defining characteristic of AC.

Feeling informed could also take on a more practical focus. As previously stated, this research was conducted during the Covid-19 pandemic with accompanying pressures and restrictions. However, a consequence of conversations with the nursing team being more clinically orientated in nature, was that on occasion families sometimes only learned of resources and services that offered support by coincidence, or through word of mouth. One example being access to the complementary team, whose services were generally well known to inpatients:

> In Ambulatory Care, no one's even told me about them, they're not advertised anywhere, the nurses don't mention it to you. Even the social support worker doesn't mention it. I guess they, kind of, just assume that this is knowledge that everyone knows, but perhaps maybe some people don't know that this is a service that is offered. (YF, 23-year-old female)

Families also raised not knowing which grants or benefits they may be entitled to, or how to access psychosocial support in Ambulatory Care. Young people and companions described learning from other families about the resources available more often than from the healthcare team:

> Then you learn as you go along all the things you can do to make life a bit easier. So, the congestion charge, the fact that you can order some food at the Cotton Rooms [hotel], which was enormously helpful, because you just don't know. By the time we'd realised we could get a disabled badge, we could get the congestion charge waived, and all the rest of it… if we'd known that straight off the bat, it would have been really, really helpful. (CJ, father to a 21-year-old male)

As we have seen, the ethos of AC places responsibility on the young person and their companion to be agentic, the driver of their own experience; it promoted individuality and personalised care. However, this same emphasis on self-reliance contains the potential for inequity of experience amongst families, notably in terms of access to information about available support. "On the ward you unexpectedly gain access to support by being there" suggested YQ, a 22-year-old male, suggesting that there was perhaps more equity of experience in inpatients, with less emphasis on seeking out support yourself required. Also put forward was that it took effort to be agentic in AC, which could, at times, feel overwhelming:

> They gave us loads of leaflets and I went through all of them, and I contacted charities and stuff like that but it's almost like, you know, the information that they give you, it's very general. It's almost like I want to talk to a person…because then I can tailor my questions and be able to get tailored answers, whereas I find websites, especially when going through chemo, quite overwhelming, knowing where to look for these answers. (YQ, a 22-year-old male)

Another young person noted:

> We were given, like, the Macmillan website which was really useful for applying for the PIP grant, so that was pretty cool. So, it is nice to know that I have charities thinking about me and stuff, but I do feel like charities need to be more proactive rather than waiting for us to reach out to them. Some weeks I barely even message my friends because I'm so tired, I'm so overwhelmed, I'm so stressed, and the last thing on my mind would be like, 'Let me go find on a charity website how to put on a wig,' and stuff, you know. (YF, a 23-year-old female).

The perspective of equity is revisited later in this chapter in section 6.13 and in Chapter 7, section 7.4.11.

6.8 Revisiting the agency autonomy dynamic: the perspective of staff

Passing time unwitnessed by the healthcare team was one of the key aspects that young people valued about AC. Companions and healthcare staff confirmed the privacy that this afforded to be a positive feature of the service. Being less visible however, whilst affording these benefits, created a requirement to share management of care and risk together with the healthcare team. Findings suggest that responsibilities inherent to AC were held by the young person, companion and clinical team. Enactment of these responsibilities was seen to pass between people within the boundaries of place, space, and spaces between.

On the ward, patients are often in sight of the healthcare team. There are handovers between shifts during which one nurse’s appraisal of how a patient is doing, becomes the nursing team’s concern; that is part of what it means to be held as an inpatient. In AC, the young person and their companion were seen to work more actively in partnership with the nursing team, contributing to a different dynamic of feeling held. During analysis, thought was given to the lost constancy of being so visibly held by the nursing team on a ward. “I don’t think there’s any way around it” said an associate co-researcher, “you either want to be observed 24/7, in which case you are on the ward, or you’re in ambulatory care in which case you’re not”. This led us to premise a foundational requirement of the AC model: the need to communicate. For AC to work, young people must be able to speak up for themselves, report back to staff, articulate their needs, and express when they require help. This proposition arose from our consideration of the composite data. Contributory to this perspective was the juxtaposition of being less present to the nursing team in AC alongside a busy clinical service.

> I think ACs really grown, and I think that's a real testament to the success of it. It's grown massively since I've been involved, which is six, seven years. We have got eighteen patients in AC this week, which is remarkable really…If they all needed a bed on the ward, then they'd need to be delayed and that has obvious implications to patients' care. I think the AC has become the answer to a lot of things. We're expanding and we're growing massively and the number of nurses we've got and the amount of space we've got and rooms we've got needs to grow with that, because we don't really say no to anybody. We make it work…the only thing that we can't do is the full TBI [total body irradiation] transplant. (advanced nurse practitioner)

Young people commended the upbeat, friendly and approachable attitude of staff, yet signs that the TYA Day Care and AC service was a busy, sometimes stretched unit had also been present in those data. Friendly banter, and staff taking a personal interest, had been cited in young people’s narratives in association with expressions of autonomy. Less present however was evidence of conversations about young people’s emotional wellbeing. The propositional explanation for this was two-fold: the *togetherness with a companion* challenged health care professionals’ one-to-one time with a young person, and the busy nature of the unit also meant that it was possible for all parties to feel that there was less time to talk. “I just wish those connections, and that special bond that I made with the nurses [on the ward], I wish that carried through to Ambulatory Care” said YF, aged 23, who had valued the time she spent talking with nurses, often alone during the nighttime on the young adult ward. “Perhaps in ambulatory care, because they know you're not in that, kind of intense treatment phase, they're perhaps not as-, not attentive, because they are very good nurses, and they do a very good job, but maybe they don't feel like they need to calm you as much, and communicate with you as much, because it's more casual now, and less intense” she explained. For one young person, this culminated in a perspective of feeling less noticed:

> So, I often find myself just waiting, and it's, like, that lack of communication. I don't know. I'm just getting a bit stressed, because some days I would wait, like, two hours, and no one would get to me, and I would think, 'Did they forget about me? Am I going to be seen?' Maybe they genuinely were busy, which is completely understandable, but if they had just said to me, 'I'm going to do your bloods in an hour, because we're very busy.' It's that communication that would put a lot of stress off me. I can say, 'Okay, I can go for an hour. I can go and talk to people. I can go and use the facilities' It's that freedom, and it gives you that independence again.

This young adult conveyed how being asked to sit in “the red chairs”, an overflow treatment area out of direct sight of nurses in the clinical hub, meant it was possible to feel forgotten. “I became very conscious of my treatment times, wanting to get on and get out” said another young adult (YB) who vocalised feeling overlooked whilst waiting for her chemotherapy on the non-clinical side of the floor. While this frustration clearly had negative aspects, it demonstrates too that young people found it uncomfortable to be thrown into the passive mode of ‘waiting’; they expected to be able to maintain their agency and autonomy in relation to timeframes for treatments and the reliability of appointments.

The findings suggest that young people and companions’ experience of the clinical AC hub focused on administration of clinical care, exercise of vigilance ('Have you taken this, have you taken that?') and the imparting of information to manage risk and ensure safety. Increased pressure on the service meant that this last aspect had to be prioritised, given it was such a critical component of the safety net of AC:

> I would say is it is getting busier and busier, and that the TYA Day Care are maxed out in AC in terms of their staffing. Erm, there probably is a little bit less time for them to spend with patients than they used to. It is a little bit more get them in, get them out…I think in some respects they have to be a little bit more, move through people a little bit quicker. Yet, the complexity of treatments being undertaken in AC means that patients actually need more time. (clinical nurse specialist)

"I think what we've really struggled with in Ambulatory Care is getting any kind of acuity scoring to inform staffing" said a senior nurse, who acknowledged the growing clinical pressure on the service. "You can't just look at the AC numbers and get a sense of the week, you must look at day care as well. It can't just be about numbers; it must be about the intensity". The fact that AC is an innovative model of cancer care in the NHS means that to date there is no validated tool to set appropriate staffing. "What ends up being prioritised is direct care, who is in front of us right now, not the fact that there is another cohort of patients we remain responsible for sitting somewhere else in the unit or out in the hotel" said a staff nurse.

The findings suggest the pressures of the clinical service, juxtaposed with less time to make holistic assessment of patients, further contextualised by less time spent in a clinical setting, together had potential to negatively impact meeting of young people's emotional needs. Attempts to explain relationships between those findings became part of our discussion in Workshop 4, as I will now explain.

"Face-to-face treatment time in ambicare is reduced, which again is fed back as making it so wonderful for patients' own identity in terms of sense of self, but that reduction in face-to-face treatment time does then provide less opportunity for the nurses to make their ongoing, non-formal assessments" said the senior nurse from the unit who participated in data analysis. Whilst the youth support coordinator role was evidenced as integral to young people feeling emotionally supported, the companion role was found to be critical – not only in terms of supporting the requirements of care and helping manage risk, but also carrying the emotional aspects, at times where it felt more absent from the nursing team.

One of the foundational elements of nursing practice is the assessment and support of activities of daily living (Roper, Logan and Tierney, 2000). The findings indicate that in AC, elements of the model such as eating and drinking, or personal cleansing and dressing, became components of care that sat almost entirely with the family. “So, yeah, the parents have responsibility for their medications and also urines, making sure that the child's drinking enough and doing their urine dips,” said a staff nurse participant. “We look to the companion to pick up the triggers for the young person, mobility issues, food issues” said the nurse who joined data analysis, although this was not explicitly explained during education for AC.

Being less present to the healthcare team also created unknowns: “What happens for food?”, “How do people get by?” raised co-researchers. The data indicated there was supposition. On the part of staff, there was a very deliberate intent not to encroach on the residential setting and to respect the privacy that it offered. Without prior knowledge about the space however, this created a knowledge and service provision gap. Findings suggested the need for a means for AC patients and companions to store food, prepare healthier meals, or have easier access to shower. Respecting privacy and space also created the potential for other foundational aspects of nursing care to become overlooked, for example when a staff member related that “what comes up occasionally is pressure care and things; we had a patient who had a pressure sore or was developing a pressure sore” (SJ), suggesting the addition of a fourth, metaphorical ‘space’: one in which boundaries of responsibility for care had the potential to become blurred.

“It’s not like everything’s been handed over to the young person and companion and it’s relinquished from the team, it’s just a shift in emphasis”, said a staff nurse: “We are still responsible for all the patients in the hotel, and likewise, if they are with us [on the unit] we’d still expect them to be responsible for themselves when they are in our presence”. Yet, for both groups, this suggested a level of hidden or unarticulated responsibility and a space that was still not clearly delineated, recognised or attended to.

During our consideration of this during data analysis, a nurse from the AC unit described “a structure focused on treatment administration, which doesn’t leave much time for observation which healthcare professionals are very good at; I think we lose that to some extent”. “You can observe a clinical issue, so if someone’s sick we observe that, and treat it, but the psychology of the companion, of the patient, issues with not eating, issues with mobility, affecting showering, dressing, all those kinds of things, we’re going to miss them” she suggested, during our discussion of data that collectively conveyed the premising of clinical care. “So, the emphasis is always going to be on the patient or companion to shout out” said another co-researcher during participatory analysis, mirroring the finding that young people needed to both recognise their own needs and to speak out to assert them. It was suggested that this emphasis could be more clearly communicated to patients as they embarked on AC.

6.9 In summary

In the findings, not only did perspectives such as privacy, freedom, choice, and control contribute to young people’s and staff perceptions of autonomy, but enactment of these components was found to be driving experience itself. Critical to AC experience and consistent across the data was the overarching ethos of the pathway: that as a patient you remain anchored in an autonomous space, from which you move out to access care. The structure and organisation of AC provided both reassurance and a safety net, whilst at the same time creating time for young people to build their own structures; this fostered the conditions to be agentic. There was plurality to people’s experiences; expression of perceptions such as freedom, choice, independence, and security, which were integrative and non-binary. Important was people’s capacity to both physically and psychologically flex and move between place and space, and between autonomy and dependency. At the heart of this, driving young people’s experiences was agency, which informed their sense of personhood: of being oneself.

Concepts of autonomy and agency are proposed and evidenced to offer an explanatory framework about experiences of AC. These concepts are underpinned and were connected to six themes that were generated through the course of description, explanation and interpretation of the research data: *respect for privacy; togetherness with a companion; time and time passing; holding and retaining structure; trust – trusting oneself, trusting others, and being trusted*; and *being informed* and *feeling informed*. Ambulatory Care was found to foster young people's autonomy through expression of these themes, within the context of *place, space,* and *spaces between*. Underpinning autonomy was the concept of agency and a proposition from the findings that not only does AC support young people to feel and be agentic, but this is a defining characteristic of the pathway itself. Figure 6-8, 'the scales of agency', provides a visual explication of these findings and presents an interpreted 'whole'.

The research findings suggest that the philosophy shaping AC experience concerns agency. This philosophical stance has not previously been identified as an underpinning value among proponents of AC. Agency, in this context, is not an act of empowerment, a conscious transferring of power. Rather, it was found to be emergent in nature, emanating 'from within'. Agency helped engender autonomy of a kind that felt positive and progressive, and contributed to perceptions of wellbeing.

The 'agency' that AC fostered connected less with the healthcare team's conscious enactment of a pre-determined approach to care, and more from what was allowed to emerge in AC in the absence of many of the organisational structures and routines of the inpatient ward. Hotel, apartment and home settings were not controlled by the healthcare team; they were environments of which clinicians intentionally had little knowledge. Feeling more self-governing yet held by a clinical safety net (which included staying near the hospital and the assurance of 24-hour advice and support), young people had the opportunity to explore and direct their experiences of cancer treatment, drawing on their own assets and resources.

Experiences of the treatment hub on the TYA Day Care and AC unit were conversely described in terms of being clinically orientated. This, in some cases, created a tension between autonomy, the expression of agency and nurses' provision of emotional support and advice. Critical to young people's experience of AC was a companion, described by both young people and staff as 'key', not only to supporting the responsibilities inherent to AC, but also to emotional wellbeing.

6.10 Role of the companion

The Cambridge English Dictionary defines a companion as 'a person that you spend a lot of time with often because you are friends or because you are travelling together' (Cambridge Dictionary, 2022b). This definition conveys a positive relationship, contextualised by journeying alongside, over time. This generic dictionary description, and others consulted, bore some resemblance to the characterisation of a companion derived from this research. It does not however infer practical and emotional engagement in supporting another individual, which was found to be an inherent part of the AC companion role – a type of relational basis to patient experience that can often be central to care provision, according to Mclaughlin (2019).

The role of a companion in the AC pathway has not yet been clearly delineated in the AC literature. Whilst there has been appreciation for a relative or partner's contribution to alleviating loneliness in adults (Mcmonagle, 2015), and positive patient experience derived from being accompanied (Statham, 2005), what the role entails has until now not been fully explicated. In fact, use of the term 'companion' had been put forward for the purposes of this research during protocol development, to present clarity about how the study design was described, and to promote inclusivity about who might fulfil the role. Those accompanying young people in AC at the study site, had formerly been referred interchangeably as parents, carers or without any definitive role name prior to this time within written information provided to families. There had not been any consensual definition or standardised expectation of the companion role articulated during conversations with staff, and those who took part in this research often felt unprepared for the reality of what was required.

> Things like knowing in advance that you've got to check his urine, intake, output, and measure all that sort of thing […] When you go there first of all you are just given a-, please don't think I'm criticising the nurses, you get given a pot for urine and stuff, and you're thinking, 'I think I've got an idea what we are doing here, but how am I going to get it from the hospital to the hotel thing in a way that isn't embarrassing for my son?' Just subtle things that could be given to you upfront. (CJ, father to a 21-year-old male)

A father CK, recalled the time when he was being briefed about the expectation of AC as a time of "functioning shock". A sibling accompanying her brother recalled being "very nervous" (CD). She had worried "if something did go wrong, you know, 'would I be able to keep a clear head and deal with everything?'" This was also exemplified by a mother of an 18-year-old who said that she had been "petrified" when "sitting beside a nurse who's saying, 'right we need you to do this, and this, and this'[…]" (CH). She recalled how her daughter had picked up on how she was feeling and had begun to cry: "and we just sat with my anxiety" (CH). Education about AC often took place on the same day as starting treatment and coincided with a relatively new cancer diagnosis, information about protocols and clinical trials. This initial experience was contextualised by a time of heightened anxiety and worry, and there was a perception that companions could be better prepared.

Companions described feeling that the expectation was "a lot", yet "you just do it" (CH) or "deal with it" (CF). The findings indicated that often, once practical experience had been accrued, things like "dipping urine became really easy to do" (CH). The everyday nature of companions' involvement, however, extended beyond monitoring tasks. Interviews with staff had suggested that the constituent elements of a companions' contribution to care were not known, or fully understood, being lived out in private, without the encroachment of the healthcare team.

These research findings help illuminate the nature of the companion role in AC. Some of this detail has been integrated into earlier sections of this chapter from the context of *place, space,* and *spaces between*. In effect, alongside clinical monitoring, companions were seen to support more foundational aspects of daily living, both practically and emotionally. “I always go, and I walk in front of her, and when she needs to go upstairs, I walk behind her so I'm, kind of, there all the time. I don't really leave her side” said CF, mother to a 23-year-old, who worried about her daughter’s strength, balance, and therefore safety. A sense of continued presence, energy and tireless effort on the part of the companion as someone always on-duty was also evident, which was exemplified by a sibling’s account of how she supported her younger brother:

> For him, I am all of the supportive things. For emotional, for practical, for everything. In the toilet, I go with him. To eat, I did it for him. When he was feeling sick or tired-. You know when you give up, because he was feeling depressed in himself, I tried to make him happy and to joke with him and to take his mind away the sickness. So, I have done all of the things to help him, to make him happy or to try to give him strength. I don’t know how to say it in English, but I am trying to do everything for him just to be-, help him be happy. (CO, sibling to an 18-year-old male)

The research findings demonstrated that an accompanying companion was key to young people’s experience of care; moreover, the role was found to be critical to the relational perspective of autonomy evidenced. It extended beyond support with clinical tasks to encompass what was needed to uphold and maintain a sense of personhood in the patient. The relationships that people are in throughout their lives inform sense of self, “what makes people who they are” suggests Mclaughlin (2019, p.48), a health sociologist. At times of ill health, it is those others who often help sustain the individual, Mclaughlin posits. Extending this perspective, therefore, is support for the proposition that young people’s lived and enacted AC experiences are embedded in the relationships that shape them as a person (Lindemann and Lindemann Nelson, 2008).

When reading and considering CO’s account of supporting her brother, thoughts of dependency may come to mind. Reconsidered from the perspective of agency, of a type previously explicated in section 6.7 suggests that the support could, however, promote the converse. Family involvement can preserve agency, asserts Ho (2008), helping “to maintain a range of identifications that can promote the patient's own sense of integrity and worth” (Ho, 2008, p.131). Characteristic of the agency identified in the findings was that it was intrinsically fluid, and negotiated between young person and companion:

> I know she likes to be in charge, likes to take charge, she likes to know all the information she can know. And I take a back seat when she’s like that, I let her lead, I let her have that independence when she can have it. But when she's sleepy or when she's under the influence of the chemo and it's been a long day, then we kind of swap roles. And then I kind of have to take over, I have to remember all the information and take charge. So that's how we do it, we swap back and forth. (CA, partner to a 22-year-old female)

Upholding autonomy was a relational endeavour underpinned by a foundational premise that both the young person and their companion had agency, to the extent that they assumed joint responsibility for much of the care, with practical aspects of clinical involvement sometimes experienced as unnerving as YA further explained:

> She gets a bit anxious sometimes when they're coming over and they’re fiddling with things, and she’s thinking, 'What are they doing, what’s going to happen?' And similarly, I'm the same, if they come over and they start doing something and they don’t particularly say anything, then I’m thinking, 'Is there something wrong, is there an issue?' But nine times out of ten it’s not, I think it's just because we're so used to doing it on our own, that when someone else comes in and does, it's nice, but then you're still thinking, 'What are they doing and why are they doing it?'

Within this context, companions described a sense of purpose in being able to contribute tangibly to care:

> I think one of the things as a parent when you first get that diagnosis and the whole hospital thing kicks in, it feels like everyone else is in control of what's happening to your child except you. And I think when I thought about taking part in this [research] and I started to think about our experience, I think it's given me a sense of purpose during this whole thing. I've felt like, at a time when my son really needed me, I could do these things for him. Even though I can't take the cancer away, I can look after him in this way by being there with him in Ambulatory Care and us-, me being the person to care for him. (CJ, father to a 21-year-old male)
>
> I did find it a bit more hard to study but that doesn't take away from the fact that I rather would have, you know, spent all that time with him than spent it at home. I feel like I am doing my bit. (CD, sibling to a 24-year-old male)

Across the whole data set, it became apparent that vulnerabilities were expressed, which extended beyond recognition of the young person's often precarious situation. Vulnerabilities were relational, and experienced as shared (Mclaughlin, 2019). Just as young people were found to value a sense of feeling anchored amid change and uncertainty, among companions this was also found to be so. Vulnerability and worry were steadied through fulfilling a practical and purposeful role, by being physically present alongside the young person, and this helped maintain companions' own sense of wellbeing. This contribution to wellbeing was in part derived through not having to imagine how their young person was coping: they could see for themselves.

> I think even the mental health for the carer, I think, in a way, Ambulatory Care helps it a lot because when you can't see what's going on but you know what's going on, you know-, [on the ward] you just start to think of the most horrible things that are happening and that you can't be there to help and I think, in a way, it just helps you as well, when you're in Ambulatory Care. (CD, sibling to a 24-year-old male)
>
> We don't have to worry about her being on her own, and her struggling. Just to know that we can always be there, it makes me feel relaxed. (CA, partner to 22-year-old female)

Being present often felt intuitive, even among siblings who became companions. "Even though it's not the easiest thing to do sometimes, it's something that is kind of normal to me or I don't expect to be anywhere else but helping her really," said CM.

Whilst responsibilities inherent to AC were held by the young person, companion and clinical team, the data indicated that during times when young people were not on the AC unit, there was a perception among companions that the weight of responsibility for the safety of the young person rested with them. “You're in charge. So, you've got no nurses around. You're completely in charge” said CG, a mother. ‘I’ve bitten off more than I can chew here’ […] ‘I’ve signed all these papers and I’m not a nurse’.” said another mother (CN) to a seventeen year-old son about her initial experience of AC. Confidence to ambulate was built through gaining experience, staying in close proximity to care, and being informed, which included having an emergency contact number and “training on things like backpacks, so you know what to expect” (CG). Practical experience of needing to respond to a change in health status whilst at home (as with CD who had previously called an ambulance for her brother), also built companions’ confidence that they had capacity to fulfil what was required.

“So, they’re saying ‘you are taking over care, you agree to all of this. You agree that, if there are any problems, you’re going to do this’” said CG, who described feeling initially overwhelmed by what was being asked. An anomalous juxtaposition occurred in her interview narrative, since what followed directly afterwards was that her daughter signed papers to say that she accepted responsibility for this herself: “because she’s over eighteen” (CG). This same dynamic, where education to ambulate was directed to the companion, yet agreement to engage in the requirements required was provided by the young person was replicated elsewhere:

> They spoke more to me, [daughter’s name] was there and she listened, she is actually classed as an adult now, she signs her own consents and everything now. Yes, that was more aimed at me, but that suited me fine actually, it’s my responsibility, not hers. She had to get well. (CH, mother to an 18-year-old female)

Considered together, these data suggest again the existence of a metaphorical ‘space’, in which blurred lines of responsibility are likely to occur, with a need for more formal elucidation of where these responsibilities, or shared responsibilities, are seen to belong within AC.

6.10.1 The perspective of vigilance

The composite findings from companion interviews identified that maintaining a continued state of vigilance over their young person’s wellbeing became an inherent part of the companion role and examples have been provided earlier in this chapter. Considered fundamental to the role of registered nurses is clinical vigilance or “watchful attention” (Meyer and Lavin, 2005). Meyer and Lavin (2005) describe components of nursing vigilance: interpretation of clinically significant observations, signals, and cues; calculation of risk; and readiness to act. In our data, to varying extents, these attributes were present among companions, beyond their engagement in monitoring tasks. A request from staff ‘to keep careful watch’ was sometimes communicated to companions, accompanied by information about what would trigger the need to seek help. Implicit was an expectation that companions would understand what was required of them in this context.

Promoting clinical safety thus became acted out as a partnership between healthcare professionals and the family. What was less appreciated was that companions often had no knowledge about what was normal in the context of acute cancer treatment, from which to gauge their assessments. Companions referred to themselves as being ‘like a nurse’ to convey having mastered the monitoring requirements. However, the continued professional vigilance and overall responsibility that the nursing team maintained for AC patients may not have been apparent to companions.

Although found to be critical to safety in the AC setting, the emphasis on things such as fluid balance or checking urinary pH levels perhaps overshadowed the more subtle vigilance work that the companions undertook, which included appraisal of emotional wellbeing. For example, one companion conveyed that even when her brother’s response to a nurse asking, ‘how are you?' might be 'I'm fine', she would think “no, I know you're not doing very well today” (CD) which would focus her efforts on cheering him. During our discussion of the findings as a Community-of-Inquiry, we posited that companions’ association of a nurse’s practice with clinical tasks might account for a perception, among companions, that support for emotional wellbeing was not always seen as a component of a registered nurse’s role.

6.10.2 Emotionally difficult

Engaging in the companion role for the most part felt positive and purposeful. Notwithstanding this, it required sustained emotional effort, which expended physical and emotional energy, as exemplified from the perspective of two fathers and a sibling:

> I would hide in the bathroom while he wees into the thing, do the dip, that's every two, three, four hours all night long and then I've got to go back to work having had no sleep for those days. It just adds to the stress because you're so tired… (CK, father to a 19-year-old male)
>
> I just feel that it's just a waking nightmare, basically. It's very difficult not to think about it all the time. I wouldn't say I'm on the ragged edge at the moment, but it's tricky. It's very, very hard to deal with. It's very frustrating, as I'm sure you know. It's very difficult when you can't control things when it comes to a loved one. (CJ, father to a 21-year-old male)
>
> For me, I've never looked after anyone in my life apart from myself, so it was difficult, I had to grow up very quickly [silence]. (CM, sibling to a 16-year-old female)

Another companion described feeling alone in her experience, not being able to turn to her partner, the person she would usually look to for support:

> So when it's just me, it kind of was like, 'Okay this is all on me, on my own.' Sometimes it could be a bit lonely because obviously when someone's had chemo, they're very tired, that conversation doesn't necessarily flow as much because they're just sleeping all the time. So having that pressure of having to look after her, but then not having that person to offload on, because she's usually the person that I will converse with, but I can't converse with her because she's half asleep, or she's under the influence of her chemo. I find that quite difficult. (CA, partner to a 22-year-old female)

There were also experiences in companion data of absorbing other families' stress, a consequence of being part of the cancer community that they simultaneously valued and could find depleting:

> There was a mum in there and she was absolutely in floods of tears […] and I cuddled her and then I went to [daughter’s name] who having a bad time and I just laid on my bed and cried for that other mum. So, you draw strength from them, but equally you can kind of, absorb everything that they and their families are going through and that’s really hard. (CH, mother to an 18-year-old female)

“I'm finding it extremely difficult” reiterated CJ, during his interview conversation. “Just recognition that ‘I’m here, I am taking on a lot here that is not seen’” said the other father, CK. The interview topic guide included a question: ‘Do you feel that your support needs have been met?’ This elicited some critical accounts balanced by respect for the AC nurses and other members of the healthcare team, alongside remarks about the busyness of the unit.

Perceptions of support strongly coalesced around companions’ articulation that in general they had not felt supported on a day-to-day basis by the AC nursing team, with little appreciation for how they might be feeling:

> They were very nice. [pause]. They were very nice, and they were very welcoming and very kind. Although I wouldn't say supported. No, I don't think they supported me at all. But it’s just because I'm a carer … (CD, sibling to a 24-year-old male)

Consistent within the data was a compelling sense that companions felt unsupported in their experience with Appendix 32 offering a more composite presentation of the perspectives that were shared.

Companions conveyed lack of awareness of the resources available that offered emotional support. “We can ask them [staff] questions about her medication, but in terms of me, where do I go? I don't necessarily know what avenues or what things are out there for the person who is supporting the cancer patient. I don't know what they are, if there is something” CA, a partner, said. There was also a perception that support might be there, but the onus was on the individual to access it: “I'm just assuming that if I go to a hospital and seek that kind of help that it will be there” said CM, a sibling. The requirement to exercise one’s agency in the context of seeking out support was also conveyed by a father: “I think the person that's suffering, as I am, needs to come forward for help…” (CJ). Companions (like young people interviewed) raised how the effort required to organise one’s own support, at a time when their primary focus was supporting their young person, meant that they often pushed their own needs to one side.

> I think when there’s so much going on and my focus is on [partner’s name], sometimes I forget about myself, so someone kind of prompting that, and coming along and saying, 'These are the things that are available to you’. (CA, partner to a 22-year-old female)

“Right now, if I do want any help, I would say it’s mentally, therapist type advice” CM conveyed whilst making reference to also being a student and balancing work. “It's not like I don't want help. I am on a waiting list for a counsellor to discuss all about this stress I am under,” said CJ. During interviews, four companions indicated that they were currently paying for private counselling services. When they had felt they could no longer contain how they were feeling, or cope, and requested help, the NHS was not able to respond. Referrals to the children and young people’s psych-oncology service could not be accepted on a routine basis from the point of diagnosis. Similarly, increasing demand on their services, and long waiting lists, meant that the team did not have the capacity to respond so reactively to support companions. Invariably however, it was not professional counselling or psychological involvement that companions sought; it was recognition for their role.

6.10.3 Feeling on the fringes

The focus of care was found to premise the young person, with companions sometimes articulating that they felt overlooked, or on the fringes of care delivery.

> I get lots of texts from Macmillan [cancer support service] about various different things, and it all seems to be, and perhaps rightly so, aimed at the actual patient as opposed to the supporter. (CK, father to a 19-year-old male)

> There’s a chap at the Macmillan who comes round, and he talks to [son’s name] about stuff and everything else, and sometimes I think, 'Well, what about me? I've got to support [son’s name], and I'm finding it extremely difficult. (CJ, father to a 21-year-old male)

This sense of lack of recognition of the needs of companions was perhaps most acutely conveyed in an extract from a sibling interview:

> I think in a way the service was just for the patient, but because it was just for the patient the entire focus was just on the patient. So, you, kind of, have to, like, detach from yourself because when you're taking them to the hospital, you’re just so concerned with making them feel good I guess you never think for a second, like, 'Oh, maybe I should just talk to the nurses just to let them know maybe how I’m feeling.' And because they're also so focused on the patient they don't really look at the carer. I mean, they've talked to me when they're explaining things just so I understand as well for the benefit of [the patient] but other than that it wasn't really much of a focus of myself at all.

There was appreciation for the attentiveness shown to ‘the patient’, and comparisons made with their own experience. “They’re getting all treated” conveyed a sibling, whilst her perception was that those in support role were alone, “slipping in a way because it’s so much to deal with”. Similarly, “she is getting the support that she needs in most aspects, but then, I don't feel like I'm getting support in any aspects” thought a partner: “I feel like I'm just there to do what the carer’s role is in the situation, and that's that”.

6.10.4 Being brought in from the fringes

Companions sought recognition and validation for their role. This was strongly communicated in the data. For the most part a “checking in” (CK); “a small conversation to ask if I needed support” (CF); “even if it's just a conversation with someone, I think if someone offered that, then that would be helpful” (CA), rather than anything more comprehensive. The findings inferred that companions were seeking acknowledgement. They wanted to be brought in from the fringes of care delivery to feel included – as a partner in care provision, but more fundamentally as a person with care needs too. Companions said they would have liked to feel that there was space and time available to raise how they were feeling yet were conscious that staff time appeared stretched.

“The other thing missing is the counselling side” said CP, who conveyed that “they sort of say it’s there, but no one refers you”. The findings also suggested inconsistencies in how information about what was available was communicated. When a mother was asked if she would have been receptive to psychological support after she had raised this during interview as an area for service development, she responded that she “definitely would, even if it was one or two sessions” to help relieve the emotions that she held. Occasionally, when discussing experiences of AC, interview data referred to a clinical nurse specialist, the young person’s named key worker, although there was little perception from participants that the role of a clinical nurse specialist included extending emotional support to a companion or wider family. In one interview where the clinical nurse specialist role was mentioned (“they help me quite a lot” (CM)), the orientation of this support was directed towards the young person. “She just made me feel like I can just call her whenever … and if I'm having a problem with my sister if she doesn't want to go in or things like that… they'll just instruct me,” CM said.

6.11 Further consideration and appraisal of the companion role

Companions fulfilled more than the ‘accompanying’ role that might be associated with people’s common use of the noun. The person accompanying the young person played a critical role in ensuring patient safety in the AC setting: supporting practical care requirements, helping foster wellbeing, and moreover sharing the enactment of clinical vigilance. Companions felt purposeful through having a tangible role; they were appreciative that they could play a part in supporting their young person. Although initial experiences of what was being asked of them by the nursing team (or implicitly understood as required) could be worrisome or anxiety provoking, companions developed tacit knowledge and confidence during the first AC stay, and they derived reassurance through knowledge of the safety net of access to nearby clinical services.

Importantly, the togetherness between themselves and the young person they were accompanying was thought to positively contribute to the young person's wellbeing. "I think it's just different when a family member takes care of you" said CD, who made comparison between "being taken care of by a nurse compared to your own sister" as contextualised in the extract below:

> I think people don't really value or understand how someone can literally just start getting better or feeling better-, and maybe it's a placebo effect, I'm not sure, but they start to get better when they're around people that, you know, they love. It really, really does help. (CD, sibling to a 24-year-old male)

As well as the data explicating how companions contributed positively to the wellbeing of those they supported, also evident was that this act of helping contributed to the mental health of the companion. Being alongside, able to support care delivery, rather than worrying about how the young person was feeling (if, for example, they needed to stay alone on the ward) were data that supported this finding. Yet, within this context of emotional wellbeing, data indicated that the mental health of the companion was overlooked by nurses and other members of the healthcare team. This might stand out as one of the starkest research findings, as well as one with clear implications for development of practice.

Data suggested that there had not been any deliberate intent to marginalise the experience of companions; rather, the focus of care was seen to concentrate, almost universally, on the young person. Our interpretation of the findings also indicated that companions upheld the busy nature of the unit as a factor that led to their prioritising asking about clinical monitoring and appraisal of wellbeing (i.e. safety), over inquiries about their own wellbeing:

> I don't think they meant to be like that, I think that's just how it is. I don't think it's a case of they don't necessarily care, I feel like especially in Day Care, especially when it's busy, there's just so much going on, so it's just like when would they find the time to do it? (CA, partner to a 22-year-old female)

It would be uncomplicated to critically assert that staff working in the TYA Day Care and AC unit did not recognise emotional wellbeing of companions as important or lacked the capacity to extend psychological care. A more considered examination of the structural constraints and mechanisms within which they work is required in such circumstances, emphasises Nairn (2009); this is explored in Chapter 7, section 7.4.4).

Also relevant is that prior to the start of this research, the person accompanying the patient in AC had not universally been referred to within the service as a ‘companion’. As such, there was no overarching, clear and consensual definition among the healthcare team about what was expected of the role. Interviews with staff had suggested that the constituent elements of companions’ contribution to care were not known, or fully understood, since they were lived out in private, without the infringement of the healthcare team. This was manifest in the fact that a coordinated package of support for a companion had not been developed.

Staff data often referred to a ‘parent’ or a ‘mother’ in conjunction with the role. The participant distribution of those interviewed however, suggests more variance in how the role is constituted. Among sibling companions and the partner who participated, the fact that they too were a young person was not necessarily acknowledged by members of the AC team. Importantly, these young companions did not describe the same sense, that parents had conveyed, of informal peer support from within the unit’s young people’s cancer community, raising the potential for a more isolating experience than that of parents fulfilling the companion role. “At the end of the day, all of the companions and mums and dads and everyone else, they're all individuals” said CJ, a father, who had recognised that not every companion was a parent. He suggested that one size does not fit all in terms of support; what was needed had to be individualised and tailored. Fundamental however, beyond any formal package of support, was a wish for more ‘checking in’ and being asked about as a person.

6.11.1 A new appraisal of companions: their role and requirements

The companion role was found to be critical to the relational perspective of autonomy evidenced in young people’s data. It extended beyond support with clinical tasks to encompass what young patients needed as people. Autonomy was a relational endeavour underpinned by a foundational premise that both the young person and their companion had agency to navigate the requirements of care. Although they might initially experience apprehension, at no time did companions convey feeling burdened by what their role entailed.

Whilst companions were found to be pivotal to the autonomy and expression of agency evidenced through this research, our discussion of the conceptual findings led one of the young associate researchers to ask: “there’s the big question of are we taking away from the companions’ sense of self?” Was AC giving the companion a new identity, that altered from their own sense of personhood she then said. “I feel like that [the role] has got to surely pull away from their sense of who they are as a person, whether it’s a parent at home or very career focused,” said another co-researcher.

“A lot of our relationship now is focused around her care” said CA a partner, which she described as requiring a big emotional adjustment “because we're still both young, we were still living and enjoying life, and now our life is basically focused around her cancer and her chemo”. It might be trying to suggest that this companion’s sense of herself had not been impacted by her partner’s diagnosis. The extent that this could be attributed to AC and her experiences of accompanying her partner through this care pathway is more difficult to fathom. What this account upholds more generally, however, is that supporting someone through cancer treatment can be an all-consuming experience.

“Could a parent, pull away from the ward, with assurance that their child is under supervision more [easily] than they could pull away from AC because they’re a key cog in the care provision?”, raised a senior nurse from the unit during one of our analysis workshops. “I think it’s a core time for us to promote the parent to leave the unit for a break, for their own wellbeing when the young person is in our care.” As the conversation continued, she noticed her use of ‘parent’ and conceded that assumptions were often made that the parent would be the accompanying companion. Among those who took part in the research, there were different constitutions of family, each with unique dynamics. “When you're a single parent, everything is difficult because you're alone. I have another child who I am also carer to”, said one companion. The two sibling companions conveyed that their mothers’ work commitments had meant that they were the ones who had greater capacity to take time out of home life to stay in the hotel. Further discussion about different factors and resources that may influence young people’s experience of AC continues in section 6.13.

6.12 Analysis as contextualisation

Before concluding this chapter with a summary description of the features of TYA AC found to be critical to service delivery (Research Question 3), it is important to contextualise these research findings. As an approach to data analysis, value-adding Analysis (Eakin and Gladstone, 2020) is constituted by principles of contextualisation.

The Covid-19 pandemic was without doubt the most pronounced, externally mediated context present throughout field work. Between June 2021 and February 2022, the period when patient and companion data were collected, the UK government had enforced varying restrictions both to everyday life and to healthcare practice. Although many young people described appreciation for feeling integrated socially, for instance visiting parks, cafes and shops, some of the freedoms that they articulated would have been relative to what was permissible at the time, for example, visiting an outdoor café, rather than dining in.

From a healthcare perspective, one of the most significant changes to patient experience during the pandemic was a ‘no visiting’ policy. Two young people who took part in the research had experience of staying alone on an inpatient ward. Among others, the fact that AC facilitated being accompanied, informed their choice to elect for Ambulatory Care. Within the TYA Day and AC service, young people could come with one companion during daily visits to the unit, with the same companion staying overnight in the hospital hotel or apartment. The *togetherness with a* *companion* that was found to be thematically evident in the findings, may have been intensified by this arrangement. "The model prior to Covid-19, was bring in the family" said the AC unit nurse during data analysis, and we heard it was not unusual for different family members to share the companion role. Parents or others could swap with each other during an AC stay, making it potentially easier to maintain responsibilities at home. During the pandemic, young people diagnosed with cancer who elected for AC, would not have experienced the opportunity to invite others to the TYA unit. For companions, the fact that the role could not be shared may have posed additional stressors that shaped their experience of AC.

6.13 Other mediators of experience

If we revisit the 'scales of agency', Figure 6-8 underneath the illustration I propose several factors derived from the data that could influence and impact families' experience of AC more generally, which I now briefly summarise.

6.13.1 Adjusting to a cancer diagnosis over time

Initial experiences of AC often coincided with a new diagnosis of cancer. Although the study's eligibility criteria meant that young people or companions taking part had at least one previous experience of AC, some of the heightened anxiety conveyed when describing initial experiences of the pathway, may have been mediated by experiences of negotiating a new cancer diagnosis. Evident within the findings, was a relationship between people's confidence to ambulate, and chronological time passed since diagnosis, during which period young people developed tacit knowledge to navigate their own unique experience as evidenced in the themes *trusting oneself* and *feeling informed*. Among companions, confidence to fulfil what was implicitly needed was developed through lived experience, over time.

During analysis, care was needed to separate out aspects of experience that could be more generically associated with accommodating a diagnosis of cancer, versus those that were specific to AC. For example, the "shock and awe" (CJ) that had been positioned in one interview, was suggestive of the overwhelming nature of a new diagnosis. More discrete, was hearing that several companions had not been able to continue working during their young person's treatment in AC. "It doesn't relate exactly to Ambulatory Care", CF explained: "it relates to having somebody with that condition, having to take care of them, it doesn't matter where you are, whether an inpatient or an outpatient". Being receptive to factors that were more representative of accommodating a diagnosis of cancer became important contextualisation, that informed interpretation of the findings.

6.13.2 Fluctuating health status

Whilst there was a relationship between accrued experience of Ambulatory Care and confidence to ambulate, also relevant were young people's fluctuating symptoms and supportive care needs, which had bearing on how agency was enacted. A nurse interviewed, SH, suggested that as young people became more tired due to the cumulative effects of multiple cycles of chemotherapy, the self-monitoring requirements of AC could become onerous for some. The data supported the perspective that confidence to ambulate was not linear; once gained, it would not necessarily remain resolute. Appreciation of the fluctuating and non-static nature of how young people were feeling, beyond their clinical status, became relevant. This informed not only their choice to ambulate, but how responsibilities were shared.

6.13.3 Assets

In a health context, assets premise factors that contribute to wellbeing (PHE, 2015; Rippon and Hopkins, 2015). Here, assets relate to the capacity of individuals to positively navigate care within a familial and social perspective. The personal assets that young people and their companions held also became relevant contextualisation. The availability of a companion to accompany a young person was perhaps the most notable asset that positively impacted people's experiences of AC, given the critical nature evidenced of the role. The study did not interview anyone who was unaccompanied: the fact that every participant irrespective of age was supported by a companion perhaps further demonstrates the role's contribution to care and emotional support. Such was the criticality of the role to positive experience, that when I appraised the nature of companions' involvement, a question of equity of experience arose. Would those over the age of eighteen who reside unaccompanied in AC face greater challenges with a more compromised experience? Another asset that may inform AC experience is personal motivation.

Socio-economic status is, I propose, another factor that may come into play in the AC context. Comfortable financial means is an asset that becomes relevant to experiences of AC. Less present in young people's data, but consistently present in companions', was a financial cost associated with AC. Often, people's positive experiences of the pathway were enhanced by eating out, visits to shops, and the enjoyment of other treats. A family without the economic means to make this kind of provision might have a different experience of AC. I did not collect information on economic means, although it is reasonable to expect that among the 18 families who took part there would be variance in family circumstances. The data suggested that irrespective of financial means, spending on food whilst staying away from home became a requirement. Items such as coffees or snacks became an inherent part of the AC experience that were associated with perspectives of autonomy and feeling part of society. Ambulatory Care often came at financial cost to families, as illustrated by an extract from CF's narrative, although this was typically communicated amid gratitude for what the service offered overall:

> I haven't been able to work, what if my employer didn't decide to pay me for the time off? What would I have done, for example? How could I provide my daughter these comforts? I don't know, would anybody give me that money to support her and provide her comfort, you know, to travel there, to provide her care, to extra-, buy good food for her, nice fruit and everything? You know, I think that's quite a dark part of everything in Ambulatory Care.

When CA, a partner was asked to indicate how much she spent over a three-day admission, she approximated £150. Other companions said that the additional cost required careful budgeting, or that they were accruing debt, which had been considered "worth it", based on how AC benefited their young persons' experience overall. Costs were not limited to finance, the need to take time out of work came at a price to job security. Also, whilst companions were willing to fulfil their role, it was found to be emotionally demanding. Other, non-financial, costs that were conveyed included the impact on other children at home, given the time commitment required as a companion. As a single parent, one companion said that that this had been difficult to navigate.

6.13.4 Resources

Those who took part in the research sometimes described resources that had been of help and benefit during AC, for example, help with accessing financial grants and benefits, congestion charge waivers, or a blue disabled badge. Two companions described learning that hospital meals could be ordered during the day, to be taken and heated in the hotel. Two staff referred to shopping vouchers from a supermarket which could be offered to families who would benefit.

National charities such as Teenage Cancer Trust and Young Lives vs Cancer did help with costs as well as information. However, across datasets, there was either ambiguity or inconsistency about access to the resources available (or those that were offered), with a perception among young people and companions that the onus was invariably on them to seek out this type of support. This is suggestive of a potential inequity in resource provision informing experiences of AC.

6.14 Features of TYA AC found to be critical to service delivery

I close this chapter with a summary of the features of AC that have been evidenced relevant to service delivery. Research question three sought to establish: '*Which features are critical to delivering Teenage and Young Adult Ambulatory Care?*'. 'Critical' in this context concerned aspects of the service that were found to be foundational, key and consistently evidenced within the data from the perspective of service delivery. This summary is designed to be of relevance to practice.

Underpinning staff, young people's and companions' experiences of AC, was a relational context. This also shaped and informed experiences of care delivery and was fostered through the intentionality of the built environment, and the enactment of an approach to care that centred people's resourcefulness and capacity for agency. Experiences of AC were mediated by professional interactions and organisational structures, yet fundamental to young people's experiences was something less deliberate and more emergent; it was the gain in autonomy that resulted from staying overnight in a residential setting away from a hospital ward. Being able to move between clinical, residential and community settings contributed to the overwhelmingly positive experiences of AC evidenced in the findings. Twelve features were found to be critical to delivering TYA AC, as listed in Table 6-1.

Table 6-1: Twelve features of teenage and young adult Ambulatory Care critical to service delivery

	Features of AC relevant to service delivery
1	The Day Care and AC Unit: the physicality of the setting
2.	The residential setting
3.	The clinical safety net
4.	Choice to ambulate
5.	Commuting to care
6.	Privacy
7.	Spending time outside
8.	Retaining a sense of oneself
9.	Working in partnership
10.	Respect for structure
11.	Being accompanied
12.	Food

6.14.1 The Day Care and AC unit

The Day Care and AC unit was experienced as a supportive environment. The relaxed, non-clinical feel of the setting and opportunity to meet others with related experience contributed to this perspective. Young people's treatment centred on the clinical hub. Although young people could receive infusion therapy in the non-clinical areas of the floor, being situated close to others during treatment enhanced perceptions of peer support. Treatment chairs facing inwards towards one another promoted a sense of connection with others, whilst respecting personal space and privacy.

Beyond being a hub for delivery of clinical care, the unit was central to fostering a sense of belonging to a cancer community. The integration of day attenders, outpatients and AC patients foregrounded the needs of patients as young people who shared a diagnosis of cancer, rather than the requirements of their clinical appointments. The unit was critical to fostering a sense of belonging to the TYA cancer community.

The non-clinical, recreation side of the floor enabled young people to relax and connect with others. Being able to “sit out in the open with other people” was a characteristic of the open plan space that meant that experience felt supportive, whilst respecting choices and individuality. The design aesthetic and intentionality behind the open plan feel of the setting, promoted connections with others that were organic in nature; this included peer support, without imposing a need to commit to friendship.

The recreational side of the floor supported members of the healthcare team to work peripatetically, particularly the youth support coordinator and members of the occupational therapy and physiotherapy team. The open nature of this setting enabled young people to stay for as long as they wished following review or treatment; this also created opportunities to connect with members of the healthcare team in a less formal or hurried way. For physio- and occupational therapy in particular, this area (which included a gym), facilitated ongoing clinical assessment of mobility, function and activities of daily living, within a more normal community setting – in comparison to the ward where interventions were usually predicated on safe discharge.

6.14.2 The residential setting

The hotel, apartment or home setting created opportunities to experience freedom from the rigidity of hospital routines. Residing at a distance to clinical care entailed the need to take on elements of self-care. Through devolving choice, decision making and responsibility to the young person, resourcefulness and agency were promoted, whilst contributing to a less defining cancer experience.

The comfortable, homely setting was appreciated, and for some young people, the fact that the hotel or apartment was not home held significance, as it meant that the most acute aspects of cancer treatment did not encroach on the home. Among other young people, the familiarity of home was perceived as comforting. Some of the perceived benefits of home-based AC centred on young people remaining more integrated in family life, with the opportunity for caring responsibilities to be shared.

The impact of a young person's diagnosis and treatment meant that being able to access the facilities of the residential setting could be problematic for those with mobility difficulties, however, making activities of daily living difficult to negotiate without help.

6.14.3 The clinical safety net

The juxtaposition of access to clinical care and the tailored expertise of the AC unit, with the ability to pass time unattended to by the healthcare team, balanced safety and positive experience in AC. The safety net of the AC service comprised: proximity to clinical care, access to a 24-hour telephone advice line, and undertaking aspects of self-monitoring (according to treatment requirements). Being prepared to ambulate focused on briefing conversations which emphasised monitoring tasks to ensure safety. Feeling confident to ambulate, however, was developed through gaining practical experience. Clinical vigilance, a perspective associated with registered nursing practice, became a shared endeavour in the AC context enacted by a young person, their companion and the nursing team.

Inpatient wards were evidenced as critical to the safety net of AC. Participants described feeling reassured knowing that the ward was there for times when they required close monitoring, were acutely unwell or lacked confidence to ambulate.

6.14.4 Choice to ambulate

Whilst many treatment protocols were routinely given on an AC basis, the fact that young people could exercise choice whether to ambulate or receive treatment on the ward was a fundamental feature of the TYA AC service. Importantly, being able to exercise this choice respected that over the course of a treatment protocol, as young people's symptoms fluctuated, or perceptions of wellbeing altered, beyond a clinical requirement to be admitted into hospital, they also had the option to relinquish the responsibilities inherent in AC and receive some courses of treatment on the inpatient ward. Enabling choice embedded the perspective of autonomy. Exercising choice was seen to involve a shifting negotiation between the young person and others: healthcare staff, companions and family. Whether to seek a companion's help with self-monitoring, or whether to elect to receive treatment on the inpatient ward, were examples of how choice, and autonomy were upheld.

6.14.5 Commuting to care

All-important was the ethos of AC: that as a patient you remain autonomously anchored in a community space, from which you move out to access clinical care. This feature was associated with physical benefits, for example, energy levels, muscle tone and limb function derived from engaging in activities of daily living within the community around the radius of the hospital. Benefits to mental health and wellbeing were also evidenced derived through feeling free, socially independent and able to spend time outside connected to wider society. The opportunity to leave the boundaries of a clinical setting was a fundamental benefit of AC, particularly when contrasted with ward experience.

6.14.6 Privacy

Being unobserved and able to pass time in private, unwitnessed by the healthcare team, was one of the defining characteristics and perceived benefits of AC. Members of the healthcare team did not meet people outside or visit residential settings; maintaining this boundary was an intentional feature of the service. Spending time in protected privacy, and at a distance from clinical care, anchored young people and their companions in a space in which, rather than be dependent on members of the healthcare team, they were able to draw on their own resources and the strengths of their social network to navigate care requirements. Privacy also enabled downtime, rest and the passing of quality time with friends and family. The privacy that AC afforded, fostered feelings of independence and self-reliance, which contributed to perceptions of autonomy.

6.14.7 Spending time outside

Freedoms associated with AC were closely related to being able to visit community spaces. Evidenced in the findings was that AC helps retain aspects of life that are important to young people: eating out, visiting shops, and connections with public spaces and society; aspects that helped young people feel less defined by diagnosis of cancer, and more able to retain a sense of familiarity associated with daily life and anchored to who they were as people.

6.14.8 Retaining a sense of oneself

Young people were able to stand in their own emerging independence in a way that was less hindered by the organisational structures and routines of the wards. Critical to this was the ability to exercise choice, feel a sense of independence and feel relationally connected to a wider world. One of the consistent features of AC evidenced, was that the independence it fostered enabled the young person to take back control, for example in the matter of taking their own medicines. Collectively, this helped young people feel in control and grounded at a time of uncertainty. Feeling independent and in control was a component of autonomy: being able to exercise choice not only about how time was passed, but more fundamentally feeling in control of one’s experience. Exercising autonomy involved time management. Moreover, it encompassed personhood: respect for, and facilitation of, what the young person needed beyond their clinical needs – choice; freedom; ownership; intact relationships; feeling secured by the constants of life; feeling relationally connected with others from the cancer community yet anchored socially as a young person and a member of society.

6.14.9 Working in partnership

Having trust and confidence in the healthcare team was contributory to young people's experience as was being trusted by members of the AC nursing team. Characteristic of the AC approach to care was a triumvirate partnering between the young person, their companion and members of the healthcare team who worked together to foster what was individually important to a young person. The findings make a compelling case for a companion to be recognised as integral to this partnership.

6.14.10 Respecting structure

Ambulatory Care maintained structure in way that underpinned and contributed to the safety net of the service, for example through treatment and medication times, or set periods within which to undertake monitoring. Needing to present to the unit at an agreed time was seen to accommodate and align the AC service's need for clinical and operational structure, with young people's own appreciation for structure which included having a reason for being up, dressed, mobile, spending time outside and connecting with society.

Young people themselves invited structure – of a type that centred them in an active and engaged way, was negotiated and respected their choice and preferences. Alongside this, AC enabled young people to create their own structure and rhythm to daily life which enhanced feelings of autonomy. The structure of AC and the routines that this engendered, both personal and organisational, created a rhythm and a demarcation between days of treatment. The momentum of moving through time in AC had a forward, future focus and was associated with positivity and progress.

6.14.11 Being accompanied by a companion

The availability and support of an accompanying companion in AC was critical to young people's positive experiences of AC. The companion role was characterised by journeying together, being alongside to support both activities of daily living and clinical care practically and emotionally. The findings conveyed young people's appreciation for the support of a companion, which included, mediating feelings of loneliness, and the facilitation and sharing of responsibility for care. Companions felt purposeful through having a definite role. The sense of togetherness with a companion whilst framed positively, however, meant that it was sometimes challenging for staff to support a young person (or companion), independent of the other party.

6.14.12 Food

Food featured in the research findings from a multidimensional perspective. Being able to exercise choice about what one ate, and when, was relayed as integral to upholding autonomy, with food being described as central to a young persons' character. The comfort of eating familiar meals, including those that took account of cultural preferences contributed to this perspective. Being able to eat in cafes or restaurants, and accept takeaways associated with perspectives of familiarity. Furthermore, eating together in the company of others helped maintain the integrity of families, and in particular sibling relationships. Experiences of AC were enhanced by treats; these came at a cost, however, often borne by the companion. Financial costs also associated with more fundamental aspects of food provision. Whilst the opening of a Lidl supermarket adjacent to the hospital had a positive impact on the choice and affordability of food items, there was limited food storage, preparation and heating facilities in the hospital hotel. Beyond breakfast, provided by the hotel, there was a necessary reliance on takeaway food or sandwich-based meals. Concern was raised among companions about implications of such a diet for health. Conversely, if residing in the apartment, this came with access to a kitchen for which one could shop to prepare meals.

6.14.13 In summary

Twelve features were found to be foundational to delivering the TYA AC service. These features were embedded within the six themes generated through analysis: *respect for privacy; togetherness with a companion; holding and retaining structure;*

time and time passing; trust – trusting oneself, trusting others and being trusted; and *being informed and feeling informed*. All were experienced in an organisational context, namely, the *safety net of AC*.

6.15 Chapter summary

In this chapter an interpretation of the research findings has been presented, integrating the perspectives of staff, young people and their companions. Beyond description and thematic consideration of the findings, critical consideration of data led to the concept of autonomy being identified as both intrinsic to, and an outcome of AC, with the overarching concept of agency as pivotal to AC experiences.

Further discussion of the thematic and conceptual findings continues in the subsequent chapter, in relation to the concept of age-appropriate care. The next chapter in addition encompasses more focused consideration of the scoping review findings, in relation to the interpretation of participants' experiences of the AC pathway, before I delineate the knowledge that this research contributes.

Chapter 7 Findings and discussion Part B: Informing further development of Teenage and Young Adult Ambulatory Care services

The preceding chapter presented an integrated description and interpretation of the research findings responding to research question two: *How do young people, their companions and staff experience Ambulatory Care?* Through the process of participatory analysis, it has been possible to build contextualised understanding and explanation of young people, companions and staff experiences whilst delineating the features of AC most valued by service users and their companions. Responding to Research Question 3, the chapter closed by summarising the features found to be critical to service delivery. Evidenced contextually within six overarching themes (Figure 6-8), these encompassed the characteristics and essence of ACs contribution to experience of cancer treatment in the TYA context.

The research findings evidenced that these themes, alongside an organisational structure that assured a clinical safety net, contributed to fostering a sense of autonomy among young people accessing AC. The findings demonstrated how the perspective of agency underpinned autonomy, contributing to young people's positive experience and advocacy for the service. Agency accounted for fluctuations in health status across the cancer trajectory, embedded choice and feelings of control. This included the option to relinquish autonomy if unwell or emotionally fatigued, and assume a more dependent, cared for role on an inpatient ward.

Research question four asked: *What can we learn to inform the development of Teenage and Young Adult Ambulatory Care services?* Before answering this by appraising the research findings in relation to the scoping review literature, I first return to the overarching aims and objectives of this study. These included consideration of AC's relationship to the speciality-specific concept of age-appropriate care, with regard for the characteristics required of TYA AC to support delivery of this concept.

7.1 Age-appropriate care

Age-appropriate care is an explicit term used when communicating the nature of specialist care for the teenage and young adult cancer population (Lea *et al.*, 2018). Moreover, it has been evidenced as a concept that underpins the culture of healthcare delivery within the young people's cancer specialty (Lea, Gibson and Taylor, 2019; Lea, Taylor and Gibson*,* 2022). The term age-appropriate "has currency" in the clinical field (Lea *et al*., 2018, p.161), directing and helping advocate for services that are tailored to the evidence-based needs of young people, as distinct from those of adults or children. 'Age-appropriate' is now used across young people's cancer services in the UK, irrespective of the age-configuration of discrete services (Lea *et al*., 2018). For example, services could encompass 13 to 19 years inclusive, or 16-24 years.

In the UK, from a service delivery perspective, age-appropriate services include the following: access to a specialist environment (NICE, 2005; DOH, 2017); referral to, and discussion within a TYA multidisciplinary team (MDT) meeting, as well as a cancer site specific MDT; consideration for clinical trial recruitment; and the provision of tailored information to include opportunities to preserve fertility and access to a TYA clinical nurse specialist, psychologist, social worker or youth support coordinator (Fern *et al*., 2021). Beyond organisational structure, however, is a culture that foregrounds a young person-centred approach to care (Lea, Gibson and Taylor, 2019), within a national context that comprises different service configurations and care environments.

As part of the BRIGHTLIGHT programme of research (https://www.brightlightstudy.com), a foundational aspect of the work was the development of a conceptual framework of teenage and young adult experience of cancer, presenting a trajectory from diagnosis to the re-establishment of identity (Fern *et al*., 2013). Developed from an interview-based study, eight core themes were identified – impact of cancer diagnosis; information provision; place of care; role of health professionals; coping; peers; psychological support; and life after cancer – to conceptualise lived experience of cancer (Fern *et al*., 2013). Research by Lea and colleagues (2018) built on this conceptualisation, to develop an evidence-based, contextually relevant model that defined age-appropriate care for teenagers and young adults with cancer, with the term 'care' encompassing not only the intentional act, but also treatment, facilities and environments (Lea *et al*., 2018).

Lea and colleagues (2018) conducted a mixed-methods study, synthesising semi-structured interviews (n=46) and an integrative literature review (150 documents) that identified use of the term age-appropriate care and mapped key components for young people with cancer. Seven core components were identified and developed into a conceptual model that encompasses: best treatment; health care professional knowledge; communication, interaction and relationships; recognising individuality; empowering young people; promoting normality; and the environment. Age-appropriate care is considered optimal when all seven components are evident (Lea *et al*., 2018). The development of this conceptual model was not specific to an ambulatory context; interview data derived from young people (n=17) and health professionals (n=29), from a range of national locations (both specialist principal treatment hospitals and local designated hospital settings), and the literature review was guided by use of the term age-appropriate and its derivatives, not a TYA setting. This enhanced the relevance and utility of considering the relationship of our research findings to age-appropriate care, to appraise how far findings aligned with, and embedded, the conceptual model developed by Lea and colleagues, while asking how the components were evidenced in an AC context. Whilst we took time to broadly consider the relationship of participants' AC experience through the lens of age-appropriate care during participatory analysis, I advanced my own, more detailed consideration of this alone. I now consider the research findings in relation to each of the seven components of the conceptual definition of age-appropriate care proposed by Lea and colleagues (2018).

Best treatment is a foundational component of age-appropriate care (Lea et al., 2018): an element that includes access to clinical care, recruitment to research trials, and associated communication with healthcare professionals. Focusing on experience, the AC research did not set out to appraise this construct. Indirectly however, the fact that every participant interviewed (n=43) advocated for AC, suggests staff, patients and companions had confidence in the safety of the service. Across the three datasets, with regard to clinical treatment, an equivalence with inpatient treatment was observed when discussing AC; no one thought that clinical treatment was compromised in any way by electing to receive cancer treatment on an ambulatory basis.

The second component of the conceptual model, **health care professional knowledge**, includes both clinical expertise and holistic competence (Lea *et al*., 2018). Understanding the developmental, psychosocial and practical challenges of teenage and young adult cancer has been evidenced as important to health care professionals when caring for TYAs (Lea *et al*., 2018, p.154). In our research, staff conveyed how they tailored their approach to care, foregrounding what was important to a young person. Consistent within the findings was young people's respect for the healthcare team, alongside positive regard for the approachable, friendly nature of nurses working in the Day Care and AC unit, who took time to remember their interests and get to know them as people. More specifically, young people often conveyed confidence in the technical ability of nurses, alongside appreciation for individualised and tailored care. Less well represented, however, within interview data were nurses' appraisal of young people's emotional wellbeing. The AC service was seen to leverage conversations about safety and surveillance alongside the delivery of technical care – which compromised more composite aspects of holistic competence. Access to specialist staff, trained and confident to recognise psychological issues and provide psychological support, is a facet of holistic competence (Lea et al., 2018, p.157, Lea, Gibson and Taylor, 2021). Although the configuration of TYA services ensures that every young person is discussed within an MDT meeting, there were signs within this research that not every young person knew how to initiate or access psychological support themselves.

The component of **communication interaction and relationships** in age-appropriate care, centres relationships between health care professionals and young people, from the perspective of "meaningful conversations and seeking advice" (Lea et al., 2018, p.157). The research findings depicted relationships between young people and members of the healthcare team characterised by professional rapport, friendliness and familiarity. Evidenced were young people feeling confident to seek clinical advice from nurses working in AC, or their clinical nurse specialist. Less present in interview conversations, however, were opportunities for conversations with nurses in the AC setting about emotional vulnerability or wellbeing. More considered appraisal of this suggests professionals may have to work harder in the AC context to accommodate such conversations. The physical togetherness of young people with their companions, plus limited time on the unit (compared with an inpatient ward), alongside the prioritisation of clinical care may challenge conversations of this nature being initiated or fostered. Simultaneously, there was an inference in the data that young people interpreted staff busyness and prioritisation of clinical care as a signal that there was limited capacity for conversations about feelings or emotional wellbeing. The youth support coordinator was referenced in the data for being pivotal as a source of emotional support, corroborating other research findings (Lea, Gibson and Taylor, 2021). Nevertheless, young people and companions were seen to draw more on the support of one another in the AC context, rather than a reliance on external agents, and usually looked to family, existing friendships and support networks.

Recognising individuality is the fourth aspect of the conceptual model of age-appropriate care (Lea *et al*., 2018). This domain was consistently present in the findings and took account of young people's life stage and personal circumstances. The autonomy associated with AC discerned in this research, embedded individuality as a fundamental characteristic. It became possible to delineate that AC both recognises and fosters individuality as a distinguishing feature of the service.

The component of **empowering young people** in the context of the model is characterised by being kept informed, with health care professionals providing the right resources in the right way (Lea *et al*., 2018). According to Gibson and colleagues, this component places emphasis on giving young people control through partnership working. It builds on what was already known about partnering between professionals and young people in ways that foster young people's empowerment (Gibson *et al*., 2012).

A different derivative of empowerment was seen to develop in the TYA AC context, in our findings, more intrinsically derived, and independent of the partnership between professional and patient. Previously explicated in Chapter 6, section 6.13, I contend that in an AC context, the concept of agency respects the emergent nature of the capacity developed among young people in AC, as something intrinsically orientated, more than an intentional act by staff to empower young people by giving them control. Whilst preparation to safely ambulate centred on oral delivery of information with handouts and staff appraisal of understanding, *feeling informed*, by comparison, was experientially mediated. It was this notion of experiential learning that fostered autonomy and feelings of control which was encapsulated in one young person's use of 'empowerment'.

From the perspective of *being informed*, the timing of information is known to be critical, alongside different methods of education to support understanding in the AC context (Knott *et al*., 2013, Lea et *al*., 2018). Our findings indicated that processing information about AC requirements whilst simultaneously negotiating a new cancer diagnosis, could feel overwhelming or anxiety provoking at times. Whilst there was no criticism from families about the way that information or resources were imparted, the findings substantiate the value of developing accessible information, so that young people can revisit information in their own time. This aligns with the evidence we generated that young people wanted to feel informed and in control of their treatment. Use of other modalities, for example video would also promote standardisation of information and resources shared, whilst freeing clinical time for psychosocial support.

The sixth component of age-appropriate care, **promote normality**, emphasises retention of normality (Lea *et al*., 2018). As already explicated, the research findings indicated that once participants' use of the noun 'normality' was delineated and critically appraised, it posited a perspective of normality that prefaced minimising the degree of change to one’s life, alongside a sense of familiarity and ‘usualness’. Maintaining daily routines of importance helped anchor young people in more constant aspects of life, in a way that contributed to a life that felt less defined by cancer. Perspectives of temporality were associated with young people’s journeying and progressing through cancer treatment in the AC context, and this also introduced a requirement to consider normality in transitory and non-static terms. The research findings advocate for a redefined understanding of normality associated with age-appropriate care relevant to the AC setting that centres ‘usualness’ and being anchored in aspects of life that are constant, familiar or routine, within the context of what remains a not ‘normal’ and often uncertain situation.

One aspect of a health professionals’ role in promoting normality described by Lea and colleagues is the continuation of young people’s education (where appropriate to age and circumstances). Two nurses interviewed raised concern during interview that the AC service, being located on a different site to the hospital school, meant that education featured less prominently in AC. Recognising education as important to age-appropriate care, staff suggested that attention was needed in this area. Whilst two sibling companions indicated that it had been challenging continuing their studies whilst fulfilling a companion role, education or work did not feature during young people’s interview conversations (although the topic guide did not include this aspect).

The environment is the seventh component of age-appropriate care, encompassing both physical and social aspects. The physical aspect takes interest in the therapeutic value of the design aesthetic and its contribution to young people’s experience of the environment, whereas social aspects centre the affective qualities, from the perspective of psychosocial support (Lea *et al*., 2018). Architectural design qualities are known to contribute to both enhanced experience and notions of support in ambulatory settings (Sadek and Willis, 2019). Present across the Day Care and AC unit, hospital hotel, self-catering apartment, and usual home environments, receiving care in a less overtly clinical environment with homely features was evidenced in our findings as beneficial to young people, companions and staff.

Having a window to the outside world specifically features in Lea and colleagues' definition of an age-appropriate environment, for its capacity to support wellbeing (Lea *et al.*, 2018). The research findings uphold and extend this perspective, evidencing how spending time outside, connected with both green and urban spaces and with wider society supported perceptions of wellness. Having space away from the bedspace is posited as important by Lea and colleagues for the freedom that this fosters. Explicitly and recurrently cited in our research findings among young people who had experiences of inpatient care as well as AC was an association between not feeling confined to a bedspace, and the freedom that it enabled. Fundamental to the freedom and independence cited by young people in AC was being able to spend time outside. The findings resolutely conveyed that receiving care in AC maximised perspectives of freedom.

Beyond the physicality of the setting, **social aspects of the environment** feature in the conceptual definition of age-appropriate care as contributing to a positive experience. Here peer support is fostered through "a social environment of togetherness and solidarity between young people" who share a cancer diagnosis (Lea *et al.*, 2018, p.159). The research findings strongly uphold the value of a dedicated social area for young people's experiences of AC: it was integral to the perspective of autonomy evidenced, whilst fostering connections with a cancer community. The availability of a dedicated, non-clinical space also supported access to members of the MDT, facilitating conversations and interventions with members of the healthcare team, without the need for a fixed appointment, that were less time pressured, and more holistically orientated.

The perspective of peer support described by Lea and colleagues as a component of age-appropriate care was less present in the research findings. During the period when data collection took place, Covid-19 pandemic restrictions meant that young people could only be accompanied by their nominated companion on the TYA Day and AC unit. The unit was much quieter consequently, and this may have impacted on opportunities to cultivate peer support. Irrespective of this, whilst young people valued feeling a sense of connection through sitting 'out in the open' with others who had related experiences, as previously stated, few discussed a wish to develop peer friendships. More important to young people in the AC context was the maintenance of existing relationships from home. This associates with overarching experiences of AC which centred maintaining a personal identity within existing community.

7.1.1 The relationship of AC to age-appropriate care: a critical appraisal

From the outset, the research sought to consider young people's, companions' and staff experiences of AC in relation to the concept of age-appropriate care. To enact this, the defining characteristics of the seven components of the conceptual model of age-appropriate care (Lea *et al.*, 2018) have been appraised in relation to the research findings. Whilst aspects of each of the seven components were evident, I contend that in some domains, different derivatives are constituted in the AC context.

Firstly however, closely aligning with the conceptual model, was the importance of the care environment to experiences of age-appropriate care. The provision of a dedicated physical space is a core element of specialist TYA care (Taylor *et al.*, 2011; Lea, Gibson and Taylor, 2019), along with a social space to unite young people (Gibson *et al.*, 2010; Lea *et al.*, 2018). Within our findings, this was repeatedly demonstrated. The importance of a dedicated physical area to the promotion of community connections is well evidenced in the TYA context (Darby, Nash and Nash, 2014; Kelly, Pearce and Mulhall, 2004; Mulhall, Kelly and Pearce, 2004). In AC, given that young people reside at a distance, this was seen to enhance the criticality of a physical TYA space for developing a sense of community. Young people's experience of feeling part of a TYA cancer community, however, was not found to be contingent on developing peer friendships in the AC context. Young people looked more to their companion, family, existing friendships and support networks.

Also fully upheld in the research findings was the component of the model of age-appropriate care: 'recognising individuality'. The findings did convey that within the domain 'communication, interaction and relationships', professionals' capacity to both appraise and meaningfully support emotional wellbeing in AC, can be challenged by a clinical context in which technical care delivery, and conversations about care requirements are prioritised. Also relevant to the AC setting was an orientation to care contingent on self-reliance, with young people raising care or support needs themselves. Whilst supporting young people's fundamental capacity for agency, at times this could feel too onerous to uphold. Additionally, some young people did not feel there were opportunities to share non-clinically orientated aspects of their experience with members of the nursing team.

While explicating the model, Lea and colleagues drew on data that described how young people wanted to be treated like adults (Lea *et al*., 2018, p.159). This lends support to my proposition, previously articulated, that young people fundamentally value being respected for their capacity and resourcefulness. As already stated, however, the perspective of empowerment, found to be a critical component of age-appropriate care, requires delineation in AC.

Whilst a relationship is positioned between effective communication, information sharing and patient empowerment in the model of age-appropriate care developed by Lea and colleagues, this does not take full account of young people's capacity, or consideration for 'agency' as distinct from 'empowerment'. Lea and colleagues refer to "giving autonomy to empower young people" within their narrative description of age-appropriate care (Lea *et al*., 2018, p.159). The research findings conveyed that a different derivative of autonomy and empowerment arises in the AC context: more intrinsically rooted than something 'given' or transferred from professional to patient. Agency underpinned and drove expression of autonomy in AC, with autonomy the self-generated outcome, not the gift of professionals as described in Lea and colleagues' work.

Another aspect of the model calling for more distinctive definition in the AC context is 'promote normality'. Emphasis is placed on both promoting feelings of normality and restoring normality within the conceptual framing of age-appropriate care. I have proposed that a re-framing of normality is required when considering age-appropriate care in the AC context, which orientates around a promotion of constancy and minimisation of change to young people's lives, and an anchoring in familiarity and 'usualness', rather than striving for restoration of pre-existing normalcy.

More broadly, appraising the findings in conjunction with the model was beneficial for its capacity to evidence the value of a dedicated non-clinical area in the TYA AC context. This is especially relevant given that historically, there has been a need to defend the value of the open plan non-clinical part of the TYA unit at the study site, within a context where hospital environments are increasingly configured to prioritise clinical care. Also, the act of considering characteristics required of TYA AC to meet the expectations of the age-appropriate care model accentuates a professional imperative, raised during participatory analysis, to consider ways that clinical care can be (re)aligned in AC to be more facilitative of emotional and psychosocial support.

There was, however, a facet of AC experience recurrently present in the findings that is not reflected in the definition and characterisation of age-appropriate care – the role of a companion does not feature. Whilst the TYA specialty upholds the value of communication between professionals, young people and parents/family in the TYA cancer setting (Lea, Gibson and Taylor, 2019), the specific contributions of parents, siblings or romantic partners to 'age-appropriate' care delivery and experience, are not highlighted in Lea and colleagues' model, and are absent more generally within publications associated with BRIGHTLIGHT. Notable perhaps, and providing explanatory context, is that with the exception of Martins and colleagues (2019) BRIGHTLIGHT evaluation of caregiver support and information needs, few primary research studies in the TYA cancer field incorporate the perspectives of a companion. Our research findings indicate how, irrespective of age, young people perceive physical and/or emotional vulnerabilities. The findings have explicated ways in which familial relationships and romantic partnerships not only contribute to, but tangibly inform care delivery and support young people's cancer treatment in AC, in ways which are welcomed and appreciated by young people. Moreover, in this service context, the availability of a companion often made the choice to ambulate possible.

Parents are known to support young people financially, as well as physically and emotionally into young adulthood and beyond within contemporary society (D'Agostino *et al*., 2001; McCarthy *et al*., 2018). Current thinking within TYA cancer in the UK, I propose, does not integrate this perspective, foregrounding the emerging independence of an individual with less emphasis on family. Our findings include the perspective of siblings and a partner who fulfilled the companion role – who were young people themselves. Yet the service model did not recognise their youth, in the context of their own support needs beyond their role as carer. The inclusion and contributions of relationships other than parents is poorly defined in UK teenage and young adult cancer practice (personal experience and communication) and absent within the conceptual development and definition of age-appropriate care (Fern *et al*., 2013; Lea *et al.,* 2018). Lea and colleagues suggest parity of their model with the themes of the Department of Health's You're Welcome quality criteria for young-people-friendly health services (DoH, 2011), more recently updated for piloting (Public Health England, NHS England, DoH, 2017). The You're Welcome themes (DoH) were found to exclusively foreground the capacity of young people (except in mental health settings), although in 2017 there was the addition of an essential criterion to indicate that care plans should take account of how young people would like their parent or carer to be involved. There is growing recognition of the need for health professionals to understand how young people partner with their family caregivers to enact support (Martins *et al*., 2019) which, according to Alfano and colleagues (2019), also calls for routine assessment of caregivers' needs.

In UK practice generally, not just in a cancer context a family-centred approach to care is characteristic of children's nursing. Having been developed in North America in the late 1980s, it places the child and family at the centre of care decisions, whilst fostering collaborative partnerships between them, their family and healthcare professionals (Shelton *et al*., 1987; Ahmann, 1994; MacKean *et al.*, 2005). The scoping review I undertook for this research identified examples of a family focused positioning to the support of teenagers and young adults accessing AC within North American settings, in a more defined and weighted way than current practice in the UK (Nirenberg, 1979; Anderson *et al*., 2013). Within Australia, the role of parents and family in the support of a TYA with cancer is recognised (McCarthy *et al*., 2018). In the UK, however, this orientation to care becomes less present as a feature of specialist adolescent cancer care and practice. Our research findings indicate that within conceptual and practical understanding of age-appropriate care in the TYA AC context, there is more need to consider the role fulfilled by family, particularly the accompanying companion.

Consistent in our findings was young people's appreciation for their companion: a positive relationship characterised by togetherness and mutual support. The existing literature upholds this perspective, reporting the importance of family to perspectives of support among young adults with cancer (Reblin *et al*., 2019), and a closeness described by Bertogg and Sydlik (2016) that often characterises young adults' relationships with their parents. As evidenced in our research, such relationships are now understood to embed the notion of reciprocal support (Fingerman, Huo and Birditt, 2020). In a recent study (Reblin *et al.*, 2019), for example, whilst pre-existing dynamics and roles were found to be informing factors, young adults (aged 19-29) were seen to work cohesively with their family caregivers whilst negotiating cancer treatment.

7.1.2 In summary

Whilst the term age-appropriate care underlies the agreed philosophy of care for the TYA cancer population (Lea *et al*. 2018, p.150), this section closes by proposing the need for reflexive consideration of the construct across different TYA cancer contexts. Although I set out to appraise the characteristics required of AC to support delivery of age-appropriate care, rigid adherence to this would have overlooked the contribution of a young person's family or romantic partnerships. Less linear, more reflexive engagement extended the utility of the model, with potential to develop it further. In this instance, it has upheld the companion role for consideration as a component of age-appropriate care in the TYA AC context, with scope for more broadly appraising the contribution and support needs of this role in relation to the model.

I now continue the discussion of the findings, addressing the fourth research question which posed: *What can we learn to inform Teenage and Young Adult Ambulatory Care services?* Before doing so, I first return to the research's aims.

7.2 Revisiting the research aims

I set out to build an explanatory interpretation of AC experience from the perspective of different stakeholders: young people, their companions and members of the healthcare team. This has been accomplished through the development of an integrated, interpretative account of AC experience (Chapter 6), offering practical, thematic and conceptual understanding of the experiences of different stakeholders.

The overarching objective was to develop evidence about experiences of TYA AC that would be of service to clinical practice. To delineate the research's contribution to the field of TYA AC, I revisit the scoping review evidence, against which I appraise the study's findings. This section of the chapter ends with a summary of key points; these are revisited when making recommendations in the concluding chapter of this thesis.

7.3 Summary of principal findings

Fundamentally, across the participant groups, no one believed that electing to receive cancer treatment on an ambulatory basis compromised clinical treatment. Furthermore, the evidence generated by this research upholds a perspective, consistent with the scoping review findings, that the AC pathway contributes positively to experiences of cancer treatment and care.

The scoping review identified that among all age groups, receiving cancer treatment on an ambulatory basis was associated with positive experiences (Nirenberg and Rosen 1979; Kelly, 2005; Statham, 2005; Grimm *et al*., 2010; Anderson *et al*., 2013; Knott, Brown and Hardy, 2013; Newton and Ingram 2014; Nissim *et al*., 2014; Beaty *et al*., 2015; Mcmonagle, 2015; Brown and Walker, 2016; Ingram, 2017; Comerford and Shah 2019a; Ingram and Smith, 2019; Pirschel, 2019). The pathway's positive contribution to patient experience was also characteristic of the TYA AC literature

(Nirenberg and Rosen, 1979; Anderson *et al*., 2013; Knott, Brown, and Hardy, 2013; Newton and Ingram, 2014; Brown and Walker, 2016; Mcmonagle, 2018). For TYAs, benefits were thought to derive from AC's ability to promote normality and independence (Nirenberg and Rosen 1979; Knott, Brown and Hardy, 2013; Newton and Ingram 2014; Brown and Walker 2016), achieved by a young person taking on elements of self-care, which includes responsibilities for monitoring and measuring health status.

Patient experience, however, is one of the least researched aspects of AC in the literature. The scoping review identified just three primary research studies relevant to understanding patient experiences of AC (Statham, 2005; Nissim *et al*., 2014; Mcmonagle, 2015). All had been undertaken with adult patient populations, thus contextual relevance of the findings had inherent limitations.

Our research findings contribute new evidence. Apart from the three above-mentioned qualitative studies among adults (Statham, 2005; Nissim *et al*., 2014; Mcmonagle, 2015), and a service evaluation from the TYA setting which included the perspective of six young people (Brown and Walker, 2016), most accounts of patients' AC experiences have been based on professional views or appraisal of satisfaction. This study, by comparison, contributes substantial evidence from the perspective of patients themselves. Findings confirm the presence of attributes previously reported either more generally or among older patients in association with AC, whilst offering contextualised and specific understanding of their manifestations in the TYA context.

The findings uphold appreciation for the opportunity to rest, sleep and eat when desired as opposed to when required as part of the hospital routine (Brown and Walker, 2016). They evidence perspectives of independence (Corrigan Wandel *et al*., 1990; Statham, 2012; Comerford and Shah 2018); choice (Esparza, Young and Luongo, 1989; Newton and Ingram, 2014; Brown and Walker, 2016); control (Corrigan Wandel *et al*., 1990; Knott, Brown, and Hardy, 2013; Newton and Ingram, 2014); and freedom (Ingram, 2017). All had been reported in the scoping review literature in association with the AC pathway.

Distinctively however, our findings have generated more explicit (re)interpretation of these attributes. Promotion of normality, for example, was a recurrent notion in the scoping review, associated with enhanced patient experience in the TYA AC setting (Nirenberg and Rosen 1979; Kelly, 2005; Knott, Brown and Hardy, 2013; Newton and Ingram 2014; Ingram, 2017; Brown and Walker 2016). I suggest that a different derivative of normality arises in TYA AC, as distinct from restoration of normalcy. We have learned that normality in TYA AC centres familiarity, a sense of constancy and 'usualness', derived through the maintenance of routines that hold significance, connection to peers and family, and through remaining rooted within one's usual community.

While sharing photographs and describing experiences of AC, the noun most frequently cited by young people was 'freedom': a sense of freedom derived from not feeling confined on a ward, but rather being independent and retaining the ability to exercise personal choice. Freedom was the most valued aspect or outcome of AC experience for TYAs and was key to the overarching concept of autonomy. Extending what has been previously reported, data showed how being able to spend time outside, beyond the boundaries of both the clinical and residential settings, was critical to young people feeling free. As previously noted, whilst the benefits of parks and green spaces for people and communities are becoming increasingly recognised (Dobson *et al.*, 2019); this aspect of patient experience has not until now been reported in the literature in association with the AC pathway. Relevant too, and unreported in the AC literature, was the act of moving from one place to another, which was associated with momentum and making progress. The therapeutic qualities of such movement are becoming more generally recognised in relation to wellbeing and health (Gatrell, 2013), and the findings indicate that this was an important aspect of AC experience that contributed to young people's positive mindset and wellbeing.

The privacy offered by AC was described by young people, their companions and staff as a critical feature of this model of care. Primary research by Statham (2005) found that among adult AC cancer patients (n=7) privacy was one of the most appreciated aspects of experience. In the TYA context our findings also evidenced privacy as one of the most valued features. The findings demonstrate how this privacy was not only valued at this life stage of emergent independence but served to actively foster young people's autonomy.

Beyond confirming evidence of the characteristics of AC that were valued, this research extends what has been descriptively reported in the AC literature, to offer an explanatory interpretation of the relationships between the attributes and facets of people's experiences. For example, whilst the literature associated feelings of independence and normality with taking on elements of self-care (Anderson *et al*., 2013; Knott, Brown, and Hardy, 2013; Newton and Ingram, 2014; Brown and Walker, 2016), conceptual advancement of the findings contributes a more integrative and expansive perspective. Self-care speaks to the theme of involvement in healthcare, and the findings demonstrate how AC, in promoting self-care, increases autonomy and agency. Autonomy was not maintained solely through engaging in self-care, however. Further appraisal of the six themes evidenced in the findings were developed into an evidenced analysis of how concepts of autonomy and agency were central to both service provision and experiences of care.

7.3.1 Importance of autonomy: retaining a sense of oneself

Ambulatory Care helped retain aspects of life that are important to young people: eating out, relationships with family, home friends, and connections with public spaces and society. These all helped young people to feel less defined by their cancer diagnosis and more able to retain a sense of familiarity associated with daily life, and a connection to who they were as people. Engaging in routine activities that mattered and had meaning evoked purpose and calm among young people, whilst contributing to a feeling of a sustained relationship with the world, a relationship that was less dominated by cancer than many young people had anticipated.

Concurrent with this maintained sense of agency, a common feature of young people's experiences was confidence in receiving clinical care in AC. This was fostered through trust: trust in the clinical team to ensure that their treatment would be initiated safely; being trusted to take on what was required, for example in terms of self-monitoring; and trust in themselves – a facet of experience that was developed as young people got to know and understand more personally the impact of their cancer treatment. This deeper understanding created the means for TYAs to self-appraise and support themselves autonomously.

We have learned how AC fostered young people's autonomy within the context of *place* (TYA Day Care and AC unit, hospital hotel, apartment, home and inpatient ward), *space* (place as experienced), and *spaces between* (wider society). Critical to people's experiences were contributions from the Day Care and AC unit; this was where young people went for their treatment to be initiated and for daily clinical review, and it facilitated access to the support of the MDT, which was central to feeling held within a supportive cancer community. Yet, it was the time that was spent away from the clinical setting that was seen to foster young people's autonomy most. The three AC options of hospital hotel, apartment or home became spaces where young people were protected from feeling constantly exposed or bearing witness to others' illness; these were spaces within which they did not need to experience the constant interruptions, however well-intended, of staff.

In the hotel space, it was the convergence of independence and privacy that participants valued; this concurrently created the requirement to self-monitor and manage elements of their care. Staying in an apartment setting further accentuated perspectives of autonomy, offering separate bedrooms and means to cook. Ambulatory Care from home, however, divided opinion; it was either considered to be the most comfortable option or disregarded on the basis that the most intensive aspects of cancer treatment might impinge on the protected space of the home. Although derived from just three participants' accounts who had experience of AC from home, our findings suggest that the familiarity of home could for some be associated with greater feelings of self-control, with the additional potential for the supportive role fulfilled by a companion to be shared amongst family members or friends. Families' consideration of home AC took account of their unique personal circumstances, yet within this, travelling distance and the effects of treatment were seen to inform decisions – often culminating in the hospital hotel being their preferred choice.

7.3.2 Agency: respecting the capacities of young people

The term 'empowerment' has been associated in the literature with AC experience (Statham, 2005; Kelly, 2005; Brown and Walker 2016). I have explained how our data evidenced a different derivative of empowerment in TYA AC. Empowerment was associated less with an intent to transfer power from professional to patient, and more by the innate capacity demonstrated among young people, who, supported by their companion, exercised agency to negotiate the requirements of AC. I propose the concept of agency as more relevant to the TYA AC context, respecting the emergent nature of the capacity that arises in AC. With less infringement of the rigidity of clinical routines and organisational structures of the hospital ward, AC supported young people to realise their agency.

Agency has not been identified in the literature as an underpinning value among proponents of Ambulatory Care. More broadly within the TYA cancer field, the theory of agency had been explored to demonstrate how there are fluctuations in personal agency across the cancer trajectory (Davies, Kelly and Hannigan, 2018). Davies and colleagues' study was a late finding in my reading for this chapter; in their research 'agency' was regarded as a stable construct from which young people's experiences could be aligned and appraised. Agency in the AC context was not, as explicated by Davies and colleagues (2018), found to be something that is disrupted, lost and then regained, nor an act of empowerment, a conscious transferring of power. Rather, agency was found to be continually present and fostered through AC.

The concepts of agency and autonomy were not experienced singularly; they were relationally constituted. Most critical was the role of a companion in young people's experiences of AC. Extending beyond the 'accompanying' that one might often associate with companionship, the findings convey more active components of the companion role. These were significant, to the extent that, within young people's data, the feasibility of AC was evidenced as contingent on the practical and emotional support of a companion. Two young people said that they could get quite confused on chemotherapy; in other instances, young people doubted or did not trust themselves, looking to their companion to take responsibility for defined aspects of care, for example medicines management. Every young person who took part in the research explicitly said that they appreciated their companion's support; moreover, they expressed doubts that they would be able to negotiate life as an AC patient on their own.

Social support is known to help TYAs with cancer cope, and overcome feelings that they are alone (Zebrack, 2011; Soanes and Gibson, 2018). It is perhaps unsurprising therefore that during the Covid-19 pandemic, when a no-visiting policy meant that young people aged 20 and over had to stay alone on adult wards, the option to be accompanied overnight was a key motivation to elect for AC. This was the case irrespective of age, across the participant age group (16 to 24 years). Once undergoing AC, young people appreciated the company and emotional support of their companion, alongside their practical help in negotiating daily life while experiencing restricted mobility or in circumstances where, for example, they felt exhausted or nauseated. Furthermore, many participants' narratives emphasised how, were it not for the practical support of their companion in carrying kit or pushing them in a wheelchair, they would not be able to spend time outside due to fatigue or restricted mobility.

All the young people who took part in the research resided usually in the family home. Irrespective of their place of AC residence, young people universally welcomed and were appreciative of their companions' support and framed positively the experiences that they shared. As well as being considered a necessity among some young people on a practical basis, the support that derived from being accompanied was found to help mitigate loneliness, build confidence and support emotional wellbeing. A clear sense of *togetherness* between the young person and their companion was found across data within how time was passed, responsibility for care shared and emotional support extended. More generally, young people spoke of a renewed appreciation for their family since their cancer diagnosis.

Among those who stayed in the hotel, *togetherness* had often been borne through a sense of necessity. Yet, amid this, young people and companions spoke of a re-connection with one another which they valued, arising in the hotel. Families described spending quality time together in the hotel room, with references to positivity, fun and lightness. Young people described how the hotel setting safeguarded this from being compromised by the inevitable responsibilities of life at home. Teenagers and young adults with cancer are known to suffer poor sleep quality and sleep disturbances (Fortmann *et al.,* 2021), and their ability to rest, on their own terms, was consistently valued. Within the context of a young person's life stage, which pre-diagnosis had invariably been characterised by increasing social independence from family, both young people and companions, however, conceded that time spent living together in one room was not usual. Yet a feature of sibling, partner or parent-young person relationships was a positive, close and supportive dynamic.

An exploration of young persons' relationships with their companions in the context of AC did not feature within the literature review findings. Looking to the existing literature, Soanes and Gibson (2018), who interviewed young adults aged 19-24 recently diagnosed with cancer (n=11), found that they appointed an 'emotional anchor'; a family member or friend who provided emotional support whilst assisting with aspects of self-management. Often this role was fulfilled by parents, found to be key members of young adults' social network. A study by Stanley and Quinn (2018) among young adults aged 19-29 (n=15) and their mothers (n=8) found that every young person who took part expressed a desire for the emotional support of their parent whilst undergoing cancer treatment. Often it was the 'being there', the fact that they were being accompanied, that these young people valued most (Stanley and Quinn, 2018), and the emotional support derived from this was reciprocal. This latter aspect (e.g. that companions found it emotionally supportive) was evident in our findings as characteristic of the togetherness between a young person and their companion. Our findings thus may help dispel more generalised concerns about the impact of the intensity of a parental relationship on young people's emotional wellbeing in the context of chronic illness (Anderson, 2004; Duncan *et al.*, 2013), or in the cancer context, increased reliance on family at a time when peers are gaining independence (Grinyer, 2007a). We have learned that irrespective of age, young people appreciated the emotional support and practical assistance of a companion, which supports the case for the AC model incorporating the companion role across the age-range. The findings convey as well, the merits of young people having the option to be accompanied in the inpatient setting, particularly in adult settings wherever possible.

7.4 Informing the development of Teenage and Young adult Ambulatory Care services

I now present a more explicit consideration of the research findings in relation to the scoping review and related literature, and their implications for future practice. Answering research question four, I frame this response to focus attention on what the TYA cancer community can learn from the research findings to inform the development of AC services.

7.4.1 Young people themselves actively contribute to the safety of AC

During my consultation with professionals as part of the scoping review, I learned how some of the first haematology AC treatments were determined based on patients being 'at risk' from clinical deterioration, but clinically 'well'. The research findings explicate how vigilance and self-surveillance, enacted through undertaking monitoring tasks, formed critical components of risk management in the AC setting. Mcmonagle (2015), whilst exploring adult haematology patients' experiences of receiving an autologous transplant on an AC basis, indicated that patients recognised when they were no longer well enough to remain in AC. Consistent in our data was evidence that confirmed young people also understood when, and in which circumstances, they needed to relinquish the autonomy experienced in AC, to be more closely monitored and cared for on an inpatient ward. This finding builds confidence, not only in the capacity of young people to engage in AC, but in their ability to help manage their own risk.

Young people noted and expressed appreciation for the structure of AC, for example, the requirement to present to the unit at a negotiated time, or the expectation that they would call the 24-hour telephone line to facilitate hospital admission if they became febrile or unwell. From an organisational perspective this assured a safety net for patients that mitigated risk, whilst enabling young people to have the flexibility to build their own daily structure and routine. An individual's autonomy is informed by structure, posits Giddens (1984), a social theorist, for whom structures are maintained through the exercise of agency, which in turn facilitates the production of one's own structure. The relationship between autonomy and agency is thus not static, as our findings illustrate within young people's navigation of AC. Whilst expressions of agency were continually present, they would flex and be enacted in different ways. For example, agency could also inform the desire for more dependence and to be 'cared for'. This upheld the trust that was evidenced thematically; both the *being trusted* that typically derived from nurses trusting young people, and the *trusting oneself* which encompassed not just young people's preferences, but them 'knowing themselves' – as evidenced by a situation where a young adult, although clinically well, chose to opt whilst reliant on crutches, to navigate a ward setting rather than AC.

The findings evidence how the proximity of the inpatient ward to the overnight AC setting, with 24-hour access to clinical care, was critical to the perceived safety of AC. It instilled confidence among families that they would be safe, close to clinical expertise if needed. However, nurses from the inpatient service, although providing advice to AC patients via the telephone advice line overnight (alongside clinical care if admitted), had usually never visited the hospital hotel or apartment. There were incorrect suppositions about the set-up and facilities available; more notably, this lack of first-hand knowledge of the residential facilities was present too among nurses based on the TYA Day Care and AC unit.

This situation arose from the very deliberate intent on the part of staff to respect the non-clinical nature of the residential setting, and the privacy that it offered. Consequently, within both the adult and TYA AC service, clinical staff never entered an apartment or the hotel (in emergency situations the hospital would be alerted, and an ambulance called). In AC, much of daily life takes place hidden from the healthcare team; this emerged as important to young people and was critical to their advocacy for the service. They said the very fact that they were not continually observed, or 'on show' as some termed it, was one of the main things that they valued. Nurses' lack of prior familiarity with the details of the setting, however, created a knowledge and service provision gap. Beyond awareness of families' gratitude and appreciation for the comforts of the hotel or apartment, nurses had limited awareness of the extent to which navigating the setting with restricted mobility, taking care of laundry, or preparing meals posed challenges to be negotiated. The safety of young people who needed to make their own way to the hospital during the nighttime for clinical assessment if they became unwell was also raised as a concern by two companions. A father said that, based on this alone, he would not countenance his 21-year-old son undertaking AC unaccompanied. Taking account of these issues, and arising from other data, the findings supported the proposition of an additional metaphorical 'space', in which unknowns, suppositions and less clearly delineated aspects of responsibility for care in AC between professionals and patients were found. Defining the parameters of this 'space' would provide learning that could offer a clear focus for the development of the service. Nonetheless, the overriding perspective of families was that AC promoted an enabling dynamic which supported perceptions of wellbeing.

7.4.2 Ambulatory Care can positively foster young people's mental health

A key finding from a study among adult patients was that those receiving treatment on an AC basis were more future focused than inpatients, who by contrast were found to focus more on the present (Nissim *et al.*, 2014). Interestingly, this finding was also reflected in our data. In contrast to participants' inpatient experience, having a clear demarcation to each 24-hour period was characteristic of young people’s experiences of AC, along with a sense of rhythm and momentum to time. This was conveyed from the perspective of actively journeying through treatment, of making progress and looking ahead. These data informed the theme *time and time passing,* associated in AC with young people’s wellbeing and mental health. Such data often derived from aspects of interview dialogue in which comparisons were made with experiences of the inpatient ward: there, ‘clock time’ was said to govern medications, clinical observations and treatment, and young people felt required to assume a more passive, dependent role. Evidencing a future focus and outlook in TYA AC, that had been previously found among adults (Nissim *et al*., 2014), this shared finding merits further exploration within a context where the relationship of AC to wellbeing remains not fully understood, as highlighted by the scoping review.

Not eligible for inclusion in the scoping review (on account of its patient population) was a study that employed instrument measurement to investigate health promoting lifestyles among adult ambulatory patients (Frank-Stromborg *et al*., 1990). The study demonstrated that a perception of wellness accompanied by self-efficacy was associated with health promoting behaviours in AC, which could maintain or enhance health status despite chronic illness. Whilst our research did not set out to distinctively appraise wellbeing, nor could it objectively measure the construct, the findings indicate a strong connection between AC experience, and a sense of wellbeing, or mental health. Having control over one’s life and a sense of purpose are important attributes of wellbeing, a concept that combines both feeling good, and functioning well (Hubbert, 2009).

This finding resonates with an account of a TYA AC service within a US health context (Anderson *et al*., 2013). In a video abstract that accompanies their paper, ‘Justin’, an osteosarcoma survivor, described his experiences of ambulatory cancer care. Having space and distance from the clinical cancer environment was perceived as beneficial to this young adult and contributed to him feeling emotionally well. Justin said: “Receiving treatment as an outpatient secluded me from the hospital … I didn’t have a sick state of mind as I wasn’t seeing a nurse or doctor every two minutes. Not having to see other sick people all the time has helped manage my anxiety" (Anderson *et al.*, 2013). Justin's personal experience mirrors our general findings.

Mental health is an inherently complex construct, requiring more theoretical explanation than can be offered here. Nonetheless, it became possible to show that, by young people's own account, AC supported mental health partly through physical activity. According to young people and their companions, undertaking elements of self-care, being mobile, 'up and about', and engaged in activities of daily living built or maintained muscle strength, limb function and energy levels. These were offered as examples of how both physical and mental health were supported through AC. On an emotional level, central tenets included feeling autonomous, rooted in society, and able to exercise one's agency in a way that together coalesced, like 'Justin', to enable young people not to feel defined by a diagnosis of cancer. The idea that people should not be defined by their cancer was central to the earliest development of TYA AC in the USA (Nirenberg and Rosen, 1979).

Wellness thus typically derived from personal perception that one was 'doing well' by being able to continue with AC, alongside the maintenance of an active life that upheld both physical activity and autonomy, and within which significant relationships remained intact. Agency helped engender autonomy of a kind that felt positive and progressive, and this contributed to a perception of wellness. Within the construct of wellbeing, however, was young people's and companions' recognition for the vulnerable and precarious nature of their situation, and their need for emotional support.

7.4.3 A requirement for further emotional support

Core to AC's ethos, we found, is the notion of self-reliance and the aspect of vocalising one's own needs. Young people and companions were seen to look to one another for emotional support in AC, with little reliance on the healthcare team. However, the findings suggest that it may become more difficult to access emotional support from members of the nursing or wider psych-oncology team, in a healthcare model that premises agency, where contact time with professionals is more limited, and permission to raise emotional needs may not be felt. Within the findings, the acute and busy nature of the clinical service saw the prioritisation of technical care alongside conversations about safety and self-surveillance; this may have intensified this situation. The value of social, non-clinical areas of the unit, where support could be accessed more peripatetically, in a less hurried setting, was evidenced as therapeutic as well as critical to feeling integrated within a cancer community. This area facilitated young people meeting with the youth support worker, occupational therapist, physiotherapist or other members of the multidisciplinary team. Absent from young people's interview conversation, however, was evidence of more informal engagement with nurses. One AC nurse recollected how once she had the time, for instance, to play table tennis with a young person, a game during which she undertook a holistic assessment. This theme of informal engagement with nursing staff did not appear in young people's accounts. In a growing and increasingly busy service, there was no longer time for such informal but potentially beneficial engagement, explained this nurse.

A further limitation of the possibility of nurses extending informal support may arise as a latent consequence of the AC model itself. As noted, the togetherness between the young person and their companion extends to time spent whilst on the unit, sitting together in the treatment area for example. This 'togetherness' can make it challenging for staff to extend support to a young person independent of their companion – or indeed a companion independent of the young person – highlighting a potential need for staff to promote some time apart for TYA and their companions.

Young people's and companions' relationships with nurses in AC usually developed in the clinical hub, which comprised eight treatment couches. Next to each couch was a chair, in readiness for an accompanying companion. The hub focused on delivery of clinical treatment and amid some more informal banter, conversations between staff and young people were usually orientated around clinical care. The findings strongly communicated that to encompass more psychosocial support, alongside a review of staffing numbers, nursing care may need to be configured differently in order to release capacity for unstructured, yet therapeutic conversations to take place.

In the ‘overflow’ area, where an additional three treatment chairs were located, there was even less emphasis on interaction and conversations with staff. Here, beyond the sight of the nursing team, young people described feeling forgotten or overlooked. Whilst young people valued their privacy when not on the unit, they wanted to be seen and treated promptly whilst present so that they could retain control of their day. This exemplifies how young people found it uncomfortable to be thrown into the passive mode of ‘waiting’: they wanted to maintain their agency, and it felt uncomfortable, more generally, to feel unseen.

The nursing team indicated they would welcome the opportunity to extend more emotional and holistic support to patients within their practice. Nurses who took part in the research described their passion and advocacy for both the TYA specialty and AC, in terms of the opportunity to maximise delivery of care framed around the individuality of the young person: a central tenet of age-appropriate care. Young people’s narratives conveyed nurses’ friendliness, evoking Morrison’s (2010) notion of nurses ‘journeying’ with patients during treatment. Nurses taking an interest in young people personally helped TYAs feel known, and provided reassurance that although less observed in AC, they were part of the TYA community. Whilst young people valued these informal aspects, there was a disconnect, however, between this and the absence of conditions facilitating more structured support for emotional wellbeing.

Nairn (2009), in explicating nursing structure, impresses the importance of considering structural mechanisms independent of the individuals concerned. I found my reading of this paper constructive; it encouraged me to take a step back and consider the structures and context that may have contributed to this dynamic.

7.4.4 A need for further consideration of the impact of the nursing workforce

The service evaluation by Brown and Walker (2016) indicated that nurses sometimes felt that the more facilitative style of practice required of the AC pathway had challenged their professional identity as cancer nurses. This was not apparent in our findings, with data suggesting that nurses’ approach to care had become more directive in response both to the AC service's growth and to increased pressures. Drawing on my own nursing experience, I suggest other tentative considerations about the relationship between the predominance of technical care delivery, and diminution of psychosocial support, that was evident in young people's and companions' interview accounts.

A personal observation from practice is that when the service was first established, those caring for AC patients were the most experienced cancer nurses. Such nurses would work partly intuitively, based on their extensive knowledge derived from many years of practise. If considered through the lens of nurse theorist Benner (1982), a characteristic of such expert nursing is the ability consistently to focus on the whole picture (and thus patient), even when performing tasks. Nurses with the least experience, at the beginner stage, Benner's model explains, necessarily practise with a high level of focused attention on the fulfilment of clinical skills. In between the most and least experienced reside the stages of advanced beginner, competent and proficient levels of competence, characterised by an ascending focus from task to holistic awareness (Benner, 1982). Although it would be impossible to align Benner's model, no matter how well renowned, with the Agenda for Change role progression and renumeration scheme currently used in the NHS, their juxtaposition generates helpful insights. Led by an experienced sister, and two advanced nurse practitioners, young people were cared for at the study site by Band 6 senior staff nurses, within a unit that integrated different kinds of day, AC and outpatient admissions. In London, within this AC service, a registered nurse with two years' post registration experience could be appointed into a Band 6 role (personal communication). If considered through the lens of Benner's model, although intended to be fulfilled by a proficient practitioner, workforce pressures have seen the employment of more junior nurses – thus contributing a potential explanation for the emphasis seen on technical care.

A more absolute 'known' is that there are no validated measures to inform nurse staffing appropriate to AC (as distinct from day care) in a UK cancer context. Thus, components of a clinical nurse's role in AC, such as the need to remain vigilant and responsible for an additional cohort of patients in the community as well as those present in the clinical hub, or embodiment of the psychosocial aspects of holistic competence (Lea *et al*., 2018, Lea, Gibson and Taylor, 2021), are either not recognised, or become constrained or negated within workforce planning models that prioritise direct, technical care.

The findings present a compelling case for the need for a workforce planning model appropriate to AC, that is sensitive to the complexity of care delivery and patients' requirements. The findings furthermore present a requirement for such models to recognise holistic competence as fundamental to service delivery in the TYA AC setting. Moreover, evidenced within the findings is a professional imperative to broaden the conceptual framing of age-appropriate care to be more considerate of the contribution and needs of a young person's family in AC, and specifically, the young person's accompanying companion (section 7.1.1). Thus, greater emphasis within the domain of psychosocial and emotional support would extend to a family-focused perspective.

7.4.5 Young people and their companions adjust well to the responsibilities of AC, contingent on adequate preparation and developing expertise

The three known primary research studies that report AC experiences (Statham, 2005; Nissim *et al*., 2014 and Mcmonagle, 2015), all highlighted positive adjustment to the responsibilities of AC in the adult setting, with Statham (2005) and Nissim and colleagues (2014) indicating that this could be dependent on individuals having the capacity and motivation to engage in the self-care required. While capacity was not formally appraised, our findings indicate that young people adjusted well to the need to assume greater responsibility for their treatment and care requirements, although this was not a lone endeavour. We show that whilst young people adapted to the need to be vigilant and take on aspects of self-surveillance, the practical enactment of monitoring requirements (for example urine measurement) was negotiated with their companion and shared. Such responsibilities were seen to pass back and forth in AC between the young person and their companion, in a flexible way that took account of their health status and agency, taking the young person's lead.

The service evaluation by Brown and Walker (2016) identified that young people sometimes felt anxious about ambulating, inviting further exploration of this aspect of AC. This research did not set out to appraise or measure anxiety; however, the worries or anxieties that participants expressed in association with AC related more to the time period close to diagnosis, or the first AC admission. Although young people conveyed some initial anxiety, about AC, they felt reassured by the presence of their companion.

Seventeen of the 18 young people who took part in this research had experience of the Cotton Rooms hospital hotel. Experiences of home AC were less reflected in the data (n=3), although the distance from clinical care, alongside negotiating London traffic daily when nauseous or fatigued was associated with greater worry compared with experiences of staying close by in the hospital hotel. Home AC became a more commonly considered option, however, once families had experience of chemotherapy and confidence of what to expect had been built.

Companions described initial apprehension about taking on what was being expected; they felt that much was being asked. This extended beyond the clinical tasks to encompass a perception that they were taking on responsibility for their young person's care when not on the unit. Young people's and companions' confidence to ambulate was built during the initial AC admission through practical undertaking of what was required; within this, however, the inherent sense of responsibility perceived by companions remained characteristic of their experience. Further confidence to ambulate among young people and their companions was built by nurses revisiting explanatory conversations and skills that were needed to support self-care, with confidence developing over time and with more experience.

7.4.6 A non-clinical area on the TYA unit is critical to developing connection with others, and makes an important contribution to a sense of self within community

Across all participant groups, the Day Care and AC unit space was experienced as a supportive environment. Critical to this was the non-clinical, recreational side of the setting. The physical openness of the environment fostered connections and a sense of community, and this featured within participants' articulation for AC. The relaxed, non-clinical feel of the setting and opportunity to connect with others on one's own terms without the enforced company of others (Trujillo *et al*., 2017) helped evidence the unit's positive contribution to experience of AC. Whilst connections with others fostered reassurance that TYA were not alone in their experience, the environment also facilitated the possibility of reciprocal recognition among young people of a wish to remain more reserved.

The AC literature had raised the potential for peer support, a component of age-appropriate care (Lea *et al*., 2018), to be challenged by AC as in contrast to the ward, young people do not reside with cancer peers (Knott *et al*., 2013). Whilst young people valued 'sitting out in the open' among other young people in the recreational area, developing friendships with young people from the cancer community was found to be less important to young people in the AC context. Although sense of peer connection to others with a diagnosis of cancer engendered through contact time on the unit was experienced as emotionally supportive, maintaining existing relationships from home was consistently upheld as more valuable.

Companions similarly derived a sense of peer support through feeling connected with others who shared a similar experience. Notably however, among siblings and a romantic partner, they did not describe the same sense that parents had conveyed of informal peer support, or the fostering of organic connections with others from within the unit's young people's cancer community. They generally reported a more isolating experience than that of parents fulfilling the companion role.

7.4.7 Relational perspectives of autonomy and agency: being accompanied appears key to young people's positive experience

As previous explicated, a sense of 'togetherness' between a young person and their companion resonated across the data. This togetherness was generally characterised by a supportive, enabling, and negotiated dynamic that worked towards increasing the autonomy of the young person. Thus, whilst AC's capacity to promote individualised, personalised care (Pirschel, 2019) was upheld in our findings across participant groups, this was not merely individually experienced. Rather, a young person's companion, wider family and peer network were critical to expressions of autonomy.

Young people's autonomy manifested as a shifting negotiation between the young person and others: healthcare staff, companions and family. Autonomy in the context of AC was upheld through a triumvirate partnering between the young person, their companion and members of the healthcare team who worked together to foster what was individually important to the TYA. Such was the emphasis on the young person, however, that companions' own needs could become overlooked. Companions were found to be critical to the healthcare model, yet felt on the fringes of care provision, substantiating how service development of AC must consider more deeply the contribution and needs of a companion.

The scoping review identified that being accompanied by a companion had potential to support patients access AC on a practical and emotional level (Nirenberg and Rosen 1979; Corrigan Wandel *et al*., 1990; Grimm *et al*., 2000; Richie, 2005; Statham, 2005; Anderson *et al*., 2013; Mcmonagle, 2015; Brown and Walker, 2016; Ingram, 2017; Moore, Arnall and Plesca, 2018; Comerford and Shah 2019b; Pirschel, 2019), whilst contributing positively to experiences of care (Kelly, 20015; Statham, 2005; Mcmonagle, 2015; Brown and Walker, 2016). This had been substantiated in two primary studies among adults (Statham, 2005; Mcmonagle, 2015) and featured in the TYA service evaluation led by Brown and Walker (2016) which included perspectives from companions (n=3).

Drawing on the self-reported experiences of thirteen companions, I have been able to elucidate the nature of the companion role. Components of the role included enacting clinical monitoring requirements; the exercise of clinical vigilance; administering timed medications; checking infusion pumps; assistance with mobility; undertaking personal care, for example help with toileting and washing; shopping; preparing meals; and creating a positive, nurturing and emotionally supportive environment in ways that upheld the autonomy of their young person. This latter aspect included facilitating access to outdoor spaces, meals out and social shopping trips. Inherent within companion data was a sense that they felt ‘in charge’; entrusted by the healthcare team to fulfil clinical tasks and watch for symptoms. Vigilance was key: the companion always on the alert for what their young person might need.

As evidenced in the scoping review, the education of caregivers has been described as critical to safety in the AC setting (Breen *et al*., 2016; Overbeek, Vos and Koene, 2016). The importance of education to prepare and support caregivers in their role was also highlighted as a key implication for practice within the one study (adult focused) known to have explored the experiences of companions (Grimm *et al*., 2000). This emphasis on education suggests the importance of the responsibilities enacted, and moreover the significance of the role.

7.4.8 Complexities of preparation to ambulate and enacting the responsibilities required

Preparation for AC often coincided with a new cancer diagnosis, taking place at the same time as delivery of information about treatment and clinical trials. The initial AC experience was thus contextualised by a time of intensified information that required processing, heightened anxiety and worry, and there was a perception among companions in particular that they could be better prepared by health professionals. Whilst the articulated ethos of TYA AC strove to align and embed the principles of age-appropriate care (Lea *et al.,* 2018), less defined in this model as previously explained, is the role undertaken by a family member, in this context a companion. Yet staff implicitly and perhaps subconsciously took account of companions’ practical contribution to AC, as evidenced through a dynamic where education to ambulate was directed to a companion as much as it was to the TYA. The pharmacist and members of the nursing team would actively ensure that wherever possible, companions were present when a young person was informed about what engaging in AC entailed. A dichotomy arose where, in some cases, education was directed almost exclusively to the companion, yet the required written agreement to engage in AC was provided by the young person. In practice what was seen to occur on occasion, was a recruitment of companions to receive information and enact responsibilities on behalf of the young person, even though the ethos of age-appropriate care foregrounds providing information directly to the young person (Palmer *et al.*, 2007).

On a practical level, the monitoring requirements were not experienced as arduous. Some companions who were parents described feeling accomplished having mastered such skills and associated themselves with being ‘like a nurse’. Such an association with nursing, however, naturally accentuates the ‘task’ whilst diminishing other composite yet less visible elements of the nursing profession to companions, such as professional vigilance (Meyer and Lavin, 2005), clinical judgement or more emotionally therapeutic elements of a nurse’s role. Furthermore, there were signs in the data that the nature of responsibilities that companions took on thereafter, coupled with nurses’ requests for companions to remain vigilant and ‘report back’, became conflated in the minds of some companions to signify that when not in attendance on the unit, they were fully responsible for the safety and wellbeing of their young person. Whilst heightening a sense of responsibility, this may have concurrently contributed to companions’ perceptions that support for their own emotional wellbeing was less validated.

The finding that companions felt responsible for aspects of clinical care exemplifies that in the absence of clearly delineated responsibilities between healthcare team, young person and companion, it becomes less clear where the boundaries of responsibility reside. Heath, Farre and Shaw (2017) indicate that parents can be key facilitators in supporting young people to become expects in their own conditions and care. In order to do so however, they require clarification on their role and the support of the healthcare team. Relevant is that prior to the start of this research, the person accompanying the patient in AC had not universally been referred to within the service as a ‘companion’, but rather as the TYA’s mother, father or whomever. As such, there was no overarching, clear and consensual definition among the healthcare team about what was expected of the role. Professionals who took part in the research often assumed that especially from mid adolescence, enacting responsibility for self-monitoring was typically undertaken by the young person, unless they became unwell, or towards the end of a treatment protocol when the AC requirements could become more demanding, and the responsibilities might be shared. As exemplified, the companion role was found to be critical – not only in terms of supporting the requirements of care and helping manage risk, but also carrying the emotional aspects, at times to balance where it felt more absent from the nursing team. Our findings show how not only were companions always present, even if in the background providing reassurance, but that they typically fulfilled a practical and safety critical role. Several companions shouldered the weighted of this responsibility.

The AC nurse who engaged in data analysis explained how in practice, the team often looked to the companion to pick up cues from the young person, for example, mobility issues, diet or symptoms related to the side effects of treatment. Hence, the AC model, through the respect that was upheld for young people's privacy, along with their capability, and that of their companion, also created the potential for foundational aspects of nursing care to become overlooked, as highlighted through a nurse's mention during their interview of one patient's development of the beginnings of a pressure sore. For both groups, this suggested a level of hidden or unarticulated responsibility and a space that was not clearly delineated or attended to. This further indicated how through respect for independence, there is the potential for some care requirements to become missed amid blurred care boundaries between professionals, young people and their companions. Within what remains an acute cancer context such blurring could compromise safety or introduce risk.

7.4.9 Companions fulfil a purposeful role requiring recognition and resourcing

Within the scoping review literature, nursing authors expressed regard for the experiences of caregivers, who may need safeguarding from burden (Brown and Walker, 2016; Comerford and Shah, 2019b), burnout and compassion fatigue (Pirschel, 2019). Although companions might have initially experienced apprehension, and recognised their emotional vulnerability, our findings strongly convey that at no time did companions feel burdened by what their role entailed, nor show signs of what I understand to be compassion fatigue. By contrast, companions felt purposeful and appreciated the opportunity to fulfil a definitive role which also helped counter feelings of helplessness amid an uncertain outlook.

Only one empirical study was identified (adult focused) that explored the experiences of companions in AC (Grimm *et al.*, 2000). It found that through the act of accompanying, the ambulatory model was less emotionally distressing for caregivers compared to inpatients. Whilst our findings cannot make comparisons with an inpatient perspective, they do qualitatively evidence that, whether a parent, partner or sibling, the act of being physically present and together with the young person helped attend to companions' own anxieties. Companions did not have to worry imagining how their young person was feeling. Being practically engaged in care also helped ground companions in a way that offered distraction from continual worry; this together with feeling emotionally present and engaged, coalesced to feel supportive.

Irrespective of their relationship to the young person, or the sense of purpose derived from their role, companions felt vulnerable, and they did not feel that this was acknowledged among the healthcare team. Companions described their experiences as emotionally difficult, which may be representative of supporting a loved one through cancer treatment as much as AC, yet it is important to highlight that nearly a third (four out of thirteen) companions had independently organised their own private counselling or psychological support. As well as drawing attention to the support needs of companions (see also Martins *et al.*, 2019), this illustrates one of three possible perspectives. Firstly, was the perceived emphasis on helping oneself such that a parent and a sibling took this to mean that they needed to independently organise counselling without bringing their needs to the attention of the healthcare team? The second perspective evidenced by their data, was that these companions had not realised that a psychologist was available. The final perspective is that of pressure on resources, since when two parents had raised a self-identified need for professional help, the unit’s psych-oncology team’s waiting list meant that they were not able to respond.

Lack of capacity meant that referral to the psycho-oncology team could not be routinely initiated for young people or companions from the time of diagnosis. The need for more specialist psychological intervention may not have been indicated by companions or young people at this time, or thereafter. Among companions, when asked, they said that what they would have liked most was a ‘checking in’ periodically to see how they were, or more simply for greater eye contact, a conversation that did not have a clinical focus, or to be seen not as a carer, but as a person. Companions wanted recognition and validation for their role. They felt themselves to be on the fringes of healthcare delivery and wanted to be brought to the conscious awareness of staff, as key contributors to care, whilst also being recognised as independent people with emotional needs too.

In relation to parents, and resonating with our findings, one of the most acute needs identified in a survey study among 196 TYAs and 204 parent participants was acknowledgment of parents’ emotional distress and a wish for peer support (Sawyer *et al*., 2017). Our findings indicated, moreover, that there was an assumption by staff that a companion would be a parent, typically a mother. The siblings and partner who participated in the research felt that to staff they were less recognised in their caring role than parents. This suggests the consequences of validating a particular set of relationships above others, no matter how unintentionally. The findings illustrated that there is variance in how the companion role is constituted and, paradoxically, that young companions did not feel that their own youthfulness was recognised, despite their presence in a TYA setting. I propose that a broadening of the lens on age-appropriate care among TYA professionals would organically direct a more precise focus on companions and their individual needs.

7.4.10 The importance of extending perspectives of age-appropriate care

Earlier in this chapter, I articulated how the research findings present the companion role for consideration as a component of age-appropriate care (Lea *et al*., 2018) in the TYA AC setting. I explained how this should extend beyond acknowledgement of their, and other family or partners' contribution to care, and to the consideration (and resourcing) of their own practical and supportive needs. Companions felt acknowledged in terms of basic needs in AC, unlike experiences of the inpatient ward, where it had been difficult to find somewhere to shower or have access to a hot meal. The aspect that was absent related to support for companions' own emotional wellbeing, which was needed, they said, to fulfil what was being required.

7.4.11 Means to promote equity in AC

Negotiating treatment in AC was dependent on self-reliance and the resourcefulness of families to help themselves. Whilst this leveraged the capacity of young people and their companions, which they welcomed, a consequence of this ethos, our findings suggest, was a potential for inequity among patients' experience. Families said that they did not always know about the resources available to support them, with parents in particular describing how they found out about things from other parents, for example, information regarding financial help with travel, or the presence of the Macmillan support and information centre within the hospital. In contrast to the inpatient ward setting, where access to different resources were thought to be more readily offered as a consequence of being present, a characteristic of families' experience in AC was the need to ascertain and seek out their own support.

The Covid-19 pandemic may have accentuated a self-referral model, with less presence of some team members (e.g. social worker, complementary therapist), alongside the realignment of national charities' capacity and resources towards more digitally based provision of information, help and support. What the findings indicate, however, is that in the absence of a standardised AC resource package, whilst there may not be an impact on clinical outcome, there is potential for variance in people's experience linked to their knowledge of, and access to resources. This could come at a personal financial cost, as well as potentially a cost to wellbeing.

Ingram (2017), a nurse, whilst reporting her account of helping establish an AC service, indicated consideration should be given to the added costs to caregivers. Our findings are that companions' experiences did come at a cost, both financially, because of spending on food, travel, and treats, but also emotionally given the intensity of the role. There was in addition a cost to companions' normal lives, in terms of interruptions to work or study; other relationships at home could become strained due to the commitment to reside away overnight, although this could also be said of some experiences of inpatient care. On a practical basis, it became apparent during interviews with young people and companions that they did not have knowledge about the range of services on offer, for example access to a washing machine, evening meals or complementary therapy, and did not understand how they could be requested or accessed. This led to inconsistencies among families in the support that they received, as well a financial outlay, as illustrated by one companion who approximated £150 over a four-day AC admission. Whilst the AC pathway has been demonstrated to be not only financially viable for the NHS, but efficient in the UK (Sive *et al*., 2012), our findings highlight the need to ensure that families are not financially or emotionally disadvantaged through electing for the AC model without being fully informed about available supports.

7.5 What the TYA cancer community can learn from the research findings: key points

1. The importance of TYA autonomy to experience: retaining a sense of oneself.
2. Recognising agency: respecting the capacities of young people.
3. Young people themselves actively contribute to the safety of AC.
4. Young people and their companions adjust well to the responsibilities of AC, contingent on adequate preparation and developing expertise.
5. Ambulatory Care can positively foster young people's mental health.
6. An open-plan recreational area on the TYA unit is critical to developing connection with others and makes an important contribution to young people's sense of self within the community.
7. There is a need for further emotional and practical support for young people.
8. The presence of a companion was critical to young people's positive experience of AC.

9. Companions fulfil a purposeful role, but require greater recognition, psychological support and resourcing.
10. Better understanding of the complexities of preparation to ambulate, and more clear delineation of shared responsibilities, is required to avoid misunderstanding.
11. It is incumbent on AC staff to broaden perspectives of age-appropriate care, including to better recognise the youth of some companions.
12. Standardisation of the available help and resources is needed to promote equity in AC.
13. At a time of greater pressure in AC, due to increased workload and sometimes less experience, nurses have less capacity to care for the whole person.
14. A need exists for further consideration of the AC nursing workforce.

7.6 Consideration of the research findings in relation to wider healthcare agendas

Throughout this thesis, I have made the case for a dynamic, relational and social understanding of agency. This understanding respects the interconnecting relations between young people, their companions and the healthcare team in AC, enacted through individuals' engagement with different geographical places and experiential spaces. Our findings emphasise how AC helped retain young people in their usual communities during cancer treatment, and that this contributed to TYA's positive experience of care.

Since AC was conceived, and in the context of ever-increasing pressures on the NHS, there has been a shifting emphasis in NHS policy from hospital focused healthcare towards community health and social care services (NHS England, 2014; Charles *et al.*, 2018, NHS England, 2019a). Whilst AC necessarily remains a hospital-led service, the research findings strongly convey how AC embeds many of the principles being promoted nationally within contemporary healthcare planning and practice, most notably personalised care. The personalised care agenda (NHS England, 2022b) foregrounds individuality, and the delivery of healthcare that offers the sense of choice and control that people have come to expect in other aspects of their lives. I suggest that the evidence generated by this research highlights AC as an exemplar not just of personalised care (Macmillan Cancer Support, 2022; NHS England, 2022b) but of how service transformations can enhance and benefit patients' experiences. Additionally, as evidenced by the scoping review, the TYA AC service is a working example of how care pathways can be transformed in ways which help manage capacity. I now examine what collective understanding and meaning could be derived from the findings that is of value to commissioners of services.

According to NHS England (online, 2022), personalised care is based on 'what matters' to people. It addresses needs whilst drawing on people's strengths and capabilities to become actively engaged in managing their own care. Ambulatory Care achieves this and goes further, I propose. These research findings provide a powerful description of how TYA AC creates opportunities for young people to shape their own experience of cancer treatment in unprecedented ways. This became most apparent whilst viewing a photographic exhibition in the hospital's public gallery that I co-curated with two young people. Titled *Sense of our selves*, it exhibited a selection of participants' photographs alongside excerpts from their interview narrative (Appendix 33). Unmistakable was the collective sense that these young people were living their lives with a diagnosis of cancer in life-affirming ways. Standing back to 'take in' the whole collection of photographs, I saw a profound shift in emphasis from the sense of 'getting people through treatment' that would have been more representative of my formative years as a cancer nurse, to a vision of patient autonomy and agency.

This concept of autonomy has been positioned as a principal finding, and as an outcome of young people's engagement in AC. Like agency, autonomy was found to be relationally constituted – sustained in partnership with a companion, health professionals and through broader familial, social and societal networks. Whilst the facilitation of clinical care and the TYA setting were important, fundamentally a sense of autonomy came from what was enabled in the space that was created, free from the rigidity of the structures and routines of a hospital ward. It is an overarching organisational structure that remains present even within a specialist TYA inpatient ward, that associates with delivering healthcare at scale.

Our findings present a compelling account of how AC contrasts with traditional models of healthcare, which emphasise needs addressed by professional interventions on behalf of an individual (Rotegard *et al*., 2010), and where patients are passive recipients of services, rather than active agents in their own lives (Foot and Hopkins, 2010). The findings have identified how a salient characteristic of AC is the pathway's trust in the innate strengths and capabilities of a young person and their support networks. Although the safety net of AC provided the vital structure needed to coordinate delivery of care, it was young people themselves, in the context of their social networks and their engagement in a space that was less monitored, that fostered the conditions in which they could harness greater control over their treatment and their lives.

In latter stages of analysis, as my personal consideration of the research findings progressed, it became apparent that characteristic of the TYA AC service was its confidence in the assets that young people held. 'Assets' in the context of healthcare are the collective means that individuals and communities have at their disposal, which protect against negative health outcomes, and promote health status (Glasgow Centre for Population Health (GCPH), 2011). Rather than solely focusing on needs, asset-based approaches focus on the capacity, skills, knowledge and connections in individuals and communities (GCPH, 2011; Rippon and Hopkins, 2015; South and Stansfield, 2022).

Whilst some of the attributes of assets-based healthcare can be seen in the AC literature, this orientation to care had not been positioned as a driver for the development of AC in the scoping review; neither an assets-based approach nor its principles have been associated with the AC model of care. I make a findings-informed proposition, however, that the defining basis of the AC pathway embeds principles of asset-based healthcare. Notable in my appraisal too is a developing relationship in the study findings between assets, the perspective of autonomy experienced and young people's accounts of how AC supported their wellbeing.

7.6.1 Assets-based healthcare

Assets-based care takes a whole person approach, through noticing, supporting and strengthening factors that bring together and support both physical and emotional wellbeing (Rippon and Hopkins, 2015, South and Stansfield, 2022). Taking an assets-based approach to healthcare, in which people's strengths are positioned as a starting point, and then leveraged through participation and engagement, is known to make an important contribution to psychosocial wellbeing and to health (Marmot 2012; Rippon and Hopkins, 2015; PHE, 2015). Our findings contribute preliminary data about the factors that uphold wellbeing in a TYA AC setting. Furthermore, they offer insights into an emerging relationship between AC and sustained perceptions of wellbeing across the trajectory of cancer treatment.

The assets literature features the capacity to build reserves of wellness, regardless of illness or clinical status (PHE, 2015). This is discussed in relation to the theory of salutogenesis, which takes interest in the factors that support positive health and investigates why some individuals in adverse situations remain more well than others; a sense of manageability, coherence and meaning are thought to be contributing factors (Lindström and Eriksson, 2005; Mittelmark *et al*., 2022; South and Stansfield, 2022). The data conveyed that young people can be helped to feel physically and mentally healthy because of AC, and, beyond the practical advantages, AC seems to give them an overriding pattern of meaningfulness in their life: it creates a new coherent story to replace the sense that their existence might be dominated by cancer or that their life has been put on hold.

Taking an assets-based approach calls for a reframing of how services are conceived and delivered (Rippon and Hopkins, 2015). The aim of the approach is to balance meeting needs with the nurturing of strengths, knowledge, capacity and the resources of people and communities (Morgan *et al*., 2010; Rippon and Hopkins, 2015; NICE and Social Care Institute for Excellence, 2019). Contributions of family are regarded as key assets (Hills *et al.*, 2010) and in the context of AC this has been exemplified in our findings. Using companions as an example, integrating insights from an 'assets' perspective directs the need to align resources so that they support not only the patient, but their associated 'assets'. In this context, the assets lens provokes a new consideration, or a re-definition, of the composition of the healthcare team. A "redefinition of 'who' is in the system and what are the available or potential assets" (Health Foundation, 2015, p.5) therefore creates opportunity to plan, invest and align resources differently. Health professionals' role is to support people to recognise and mobilise the assets that they have (Foot and Hopkins, 2010); inherent is that engagement of patients' assets, complements rather than replaces the healthcare team's overarching responsibility for safety and risk.

In brief, assets-based healthcare works with people's capacities and resources rather than their deficits or needs. Assets can be social, financial, physical, or environmental, and can include education or employment as well as resources such as support of third-sector organisations (Harrison *et al.*, 2004). Considering TYA AC through an asset-based lens, whilst facilitative of young people's autonomy also focuses concern for health equity. In AC, this could include the perspective of families with limited financial or educational means, or those young patients who do not have, for example, the support of a companion. It raises consideration of equivalence of experience among young people in AC, as well as those who do not have the assets to ambulate and receive treatment instead on the ward. This could be as a consequence of lack of assets such as speaking English, or an available companion, or the confidence or practical ability to ambulate alone.

Beyond its focus on strengths, an assets-based approach embeds an imperative to consider social and economic disadvantage, and other potential barriers to young people having a positive experience of AC. Our findings have highlighted, for example, that some families were unaware of the resources available to support them, whether in the form of information, emotional support or monetary assistance. This indicates a need for greater intentionality in AC, to promote equity of access to resources, and as the TYA community learns and builds more evidence about AC, to make sure that in service planning there is, as far as possible, equivalence of access to factors that contribute positively to experience and wellbeing.

7.6.2 In summary

The research findings support my contention for AC to be considered as assets-based healthcare in action. Aligning and considering AC through an assets-based lens respects the capability and resourcefulness of young people and their families, whilst its concern for health equity may be used to better direct investment of resources. More formal consideration of AC from an assets-based approach furthermore provides a framework through which attributes of the service can be appraised and delineated in the future. This could include further exploration and empirical measurement of the emerging relationship of AC to perceptions of wellbeing.

7.7 Chapter summary

This chapter has presented a continuation of my discussion of the research findings. It opened considering AC's relationship to the speciality specific concept of age-appropriate care. Taking interest in the characteristics required of TYA AC to support delivery of age-appropriate care, I appraised our findings against Lea and colleagues (2018) model. My reflexive engagement with the model upheld the companion role for consideration as a component of age-appropriate care in the TYA AC context, along with a more relational and family-focused consideration of the philosophy of age-appropriate care.

My discussion of the findings progressed to focus on answering research question four: *What can we learn to inform the development of teenage and young adult AC services?* After re-presenting a summary of the principal findings, I framed this response through an appraisal of these findings in relation to the scoping review and wider related literature to help discern the contribution of this research. I have presented what the TYA cancer community can learn from the research findings to inform practice, summarising with a list of the key points raised.

The closing section of this chapter considered AC from the perspective of health-assets and my consideration of the findings through the principles of assets-based healthcare. I have discussed how shifting the discourse about AC from a meeting of need to assets-based health recognises the service's qualities from the perspective of experience, and in addition how it guides focus on alignment of resources to further support young people and their companions and help realise their assets. This also highlights the need to ensure more equivalence of access to the resources that support positive experience and may contribute beneficially to wellbeing.

Inherent to the methodological orientation of participatory research and particularly CBPR is an emphasis on the collective assets of the research community. This research set out to embed this principle. Throughout my engagement and leadership of the research, I took care to try and foster a way of working which actively drew on co-researcher capabilities and strengths in service of the project, whilst creating an environment in which these qualities could be actively developed in ways that might be of personal benefit to each co-researcher. The final research question encompassed an evaluation of the co-researcher role, which is the focus of the next chapter. I return to the research findings in the concluding chapter to make recommendations and summarise the research's contributions to knowledge and practice, where I also consider the methodological and academic contribution of this thesis.

Chapter 8 An evaluation and appraisal of the CBPR approach

A subsidiary aim of this research was to build an understanding of Community-Based Participatory Research (CBPR), a contemporary research approach, through its application within a UK context among the TYA cancer community. In doing so, I took a methodological interest in how evidence could develop collectively, within a relational and participatory dynamic. Bringing a group of people together as co-researchers as I did, however, does not necessarily equate to authentic participation and knowledge democracy (Cook *et al.*, 2019). When setting out the theoretical underpinnings of this research in Chapter 2, I recognised that these aspects could not be pre-determined, and as a point of methodological curiosity I questioned whether the research could fulfil the principles of CBPR. I now revisit the participatory basis of this research and the principles of CBPR to undertake a methodological appraisal.

Community-based Participatory Research focuses principally on domains of context, partnerships, interventions and health or social justice outcomes (Wallerstein *et al.*, 2018). Within these domains, concepts of participation, knowledge democracy, power and 'informed action' (arising from dialogue and critical reflection) are considered fundamental hallmarks of CBPR (Wallerstein *et al.*, 2018). As with all participatory research, no single form of knowledge whether experiential, academic or practitioner is given primacy (Cook, Noone and Thomson, 2019). The intention is that through a research process that involves shared engagement and critical, collaborative inquiry, those involved learn with and from each other in service of the research aims (Cook *et al.*, 2019; ICPHR, 2020).

This penultimate chapter of my thesis focuses on the fifth research question set at the outset of this study: *Can a CBPR approach engage young people, support authentic participation and contribute methodologically?* Engagement was considered primarily from the perspective of young associate co-researchers, but also through my reflexive consideration of TYA participants' engagement in the research process.

To help answer this research question, I undertook an evaluation of young associate co-researchers' experiences, within the context of their membership in the Community-of-Inquiry. As set out in Chapter 4 (study design), whilst not overlooking the contributions of companion co-researchers, the case for capturing the contributions and impact of young people's involvement in research has been well documented (Schäfer and Yarwood, 2008; Percy-smith and Thomas, 2010; Brady and Preston, 2020; Das *et al*., 2020; Young Minds, 2020). Additionally, within this chapter, I consider the topic of rigour from the perspective of validity (Morse, 2018) and quality (Emden and Sandelowski, 1999) and how this has been impacted by this engaged, participatory approach.

To further these aims, I have organised this chapter as follows:

a) an evaluation of young associate co-researchers' experiences;
b) appraisal of the evaluation findings in relation to the principles of participatory research and the hallmarks of CBPR;
c) methodological considerations and learning.

8.1 An evaluation of young associate co-researchers' experiences

As previously detailed, two principles are upheld for involving young people in research: a rights-based argument that it is 'the right thing to do', and an evidenced-based argument that involvement has benefits, both for these individuals and the focus of the research inquiry, leading to services that better reflect young people's priorities and concerns (Brady *et al.*, 2018; Brady and Graham; 2019; Brady and Preston, 2020). Furthermore, participatory research is a way to counter exclusions of young people from service planning, whilst fostering greater understanding and a less hierarchical relationship between young people and research (Alderson, 2000; Schäfer and Yarwood, 2008). It was these perspectives that led me to build evaluation into the study design; this considered young associate researchers' participation and the associated impacts on the research as well as impacts on the young people involved.

8.1.1 Methods

The "need to better collate and disseminate evidence on young people's involvement in research" has been well evidenced (Brady and Preston 2020, p.194). There are toolkits and resources available to facilitate evaluation in this context (for example, Gawler, 2005; Powers and Tiffany, 2006; Young Minds, 2020; NCCP, 2022). However, efforts to introduce a standardised means to evaluate the nature and impact of young people's engagement, taking into account how this adds benefits to the research, those involved and wider society through the impact of the research (Brady and Preston, 2017; Reed *et al*., 2018, Brady and Preston, 2020; Das *et al*., 2020), remain partially addressed.

Nonetheless, Young Minds (2020) propose formative ongoing evaluation, appraising the relationship between processes and outcomes of participation, whilst Sciencewise and UK Research and Innovation (2019) suggest that evaluation should involve three stages: comprising baseline assessment, interim appraisal and final assessment in the context of the overall project and its impact. Relevant too is that evaluations reflect criteria of good practice in public involvement (Howe et al., 2009), such as the NIHR's "Being inclusive in public involvement in health and care research" document (NIHR, 2021b). This was pertinent as the research was publicly funded. My evaluation considered these criteria, centred on three time-points, and collated data from several activities that became embedded within my facilitation of the overall research as outlined below:

1. Young people completed an e-survey on first joining the Community-of-Inquiry enabling me to understand drivers for participation so that I could help tailor research and wider interests to their co-researcher role.
2. Mid-way through data collection, I facilitated an online 90-minute 'pause and review' meeting with young associate co-researchers, to explore experiences of the co-researcher role, as well as appraise the photo-guided interview method. This was voice recorded and transcribed verbatim.
3. Once the study had closed, the co-researchers participated in a second e-survey to appraise the impact of their involvement in the research – both at a

personal level and on the research itself. Participants were given a copy of their completed baseline survey to read prior to completing the second survey. This time, young people's responses were aggregated for me to review.

4. Additionally, in June 2022 when the research closed to recruitment, young associate co-researchers participated in a focus group discussion. This was facilitated by the same academic who had accompanied me to co-lead co-researcher training workshops. The 90-minute meeting was voice-recorded, and I subsequently received an anonymised written transcript from the facilitator.
5. Finally, interview learning logs (Appendix 34) formed part of the evaluation data. These had been completed after each interview, contributing information about confidence and capacity built in a longitudinal context, as well as facilitating further consideration of the interview methods.

8.1.2 Analysis

I undertook an analysis of the data described, working with those principles of value-adding analysis (Eakin and Gladstone, 2020) that focused on descriptive categorisation and consideration of themes. Although undertaken alone, the fact that activities such as the mid-point review and closing focus group were undertaken 'in community' meant that young associate researchers' reflections and critical appraisal of their roles could be considered an analytic act that contributed a participative dimension to the evaluation.

8.1.3 Participants

Five young associate researchers consented to the evaluation of their experience. All five completed the baseline survey and participated in the mid-point review meeting. Around this time, after eighteen months, in response to other commitments, a co-researcher withdrew from the Community-of-Inquiry. Four co-researchers completed the closing e-survey, participated in the focus group meeting and shared completed learning logs.

The baseline survey was also completed by three additional young associate researchers in January 2020; it had been sent to all co-researchers to help me shape and align their co-researcher experience to their interests and other commitments. These individuals declined to take part in the evaluation of the co-researcher role, uncertain of their capacity to commit to the project long-term.

Three of the four co-researchers who participated in the evaluation were female and one was male. At baseline, three had been university students, with one co-researcher in full-time employment; two years later, two were in full-time employment, one co-researcher worked part-time and the fourth was a university student. On first joining, one co-researcher was completing cancer treatment; two years later all had completed treatment between 1 and 4 years.

8.1.4 Findings

In this section, the findings of this evaluation are organised and presented by categories. Given that the focus group transcript did not identify individual co-researchers by name, direct quotes are not accompanied by a pseudonym or identifier.

8.1.4.1 Motivations and commitment

8.1.4.1.1 Motivations

Among the four co-researchers who took part in the evaluation and the eight young people who completed the baseline survey, getting involved in research was their primary motivation. This was followed by advocacy work within TYA AC. All four young associate co-researchers who participated in the evaluation ‘agreed completely’ that their experiences had aligned with their initial motivations for becoming involved, with one young person explaining:

> I expected to have a chance to develop research skills, such as interviewing, and have a role in making a positive contribution…I feel like my expectations have been exceeded. This project left me with a deeper insight into the Ambulatory Care experience, re-kindled an interest in civil society and healthcare policy, and gave me the opportunity to develop presentation skills. Overall, while I did expect to be part of the project, I believe the role that Alison allowed me to play was larger than expected (in a very positive way).

“I could develop and use skills in a positive way,” said a different young person; “I feel like I have been given so many opportunities to make input in the research,” said another. Yet beyond the development of skills, another consistent motivation articulated by three individuals was that they wanted to make something positive of their experience of cancer. “I fully believe it is my duty as a survivor to help the future generations affected by cancer,” conveyed one young associate researcher; “a chance to do something good,” said another. As well as altruistic motivations, however, co-researchers perceived that their participation would offer a valuable experience that would develop new knowledge and skills, with the potential to enhance their curriculum vitae. The vision for the project was described as “great” with “promise to have such a big impact on young people’s lives” and as something that “resonate[d], for obvious reasons.” This vision was sustained and gained momentum in co-researchers’ accounts of their experiences over time.

8.1.4.1.2 Commitment

“I joined when I was nineteen,” said a co-researcher: “I think that was two years ago now, coming up to three years…it’s been a very long time, yes, and it’s gone quite quickly, and I’ve really enjoyed being part of it”. Notable was that the four young associate researchers who had remained committed until the study closed took on key roles facilitating interviews, and all engaged in participatory data analysis. These young co-researchers became critical to the conduct of the study and, through hearing participants’ experiences first-hand, participating in analysis or presenting to stakeholders, this active participation had fostered their continued commitment.

The topic of renumeration became part of the focus group discussion, specifically recognition in the form of vouchers that were provided to acknowledge co-researchers' time and skills, although it was not found to have a bearing on any of the co-researchers' commitment. "It's nice, but that wasn't my motivation," said a co-researcher. All agreed, "what I really appreciated was that travel expenses were covered," said one. Beyond the commitment of their time, they described how this minimised barriers to staying involved. Scheduling training for an evening, and analysis workshops on a Saturday, was found to also support involvement, and the fact that participants invariably chose an evening time to be interviewed helped manage the time commitment of all involved.

While one young associate researcher felt that they had not been able to commit as much time as they wanted due to work commitments, they appreciated that opportunities to participate were always offered. More generally, in response to the question: *Do you feel that you have been given enough opportunity to get involved in the research to the extent that you wanted?* – all four co-researchers indicated that they had. A co-researcher explained:

> Alison offered me plenty of opportunities to take part in interviews, discussions but also presentations and other events such as the photo exhibition. I was also made to feel comfortable whenever an issue arose that meant I couldn't attend or needed to pass on an opportunity.

Whilst CBPR makes a point of equitably involving all partners (Foster *et al*., 2012), this does not mean that co-researchers are required to contribute an equivalence of time or take 'equal share' (Israel *et al*., 2018; Wallerstein *et al*., 2018). Young associate researchers' accounts conveyed respect for one another's other commitments, for example understanding that there would be times when they were not available. Importantly, within the closing focus group discussion, a perception was conveyed of all having contributed similarly.

8.1.4.2 Authenticity

Pronounced within the closing survey and focus group was the topic of authenticity – the perspective that co-researchers' engagement felt contributory and genuine as opposed to supplementary or tokenistic:

> It feels like it was really authentic… [Alison] didn't shy away from the fact it was a Community-of-Inquiry. This was very apparent in the research. When Alison submitted evidence [from the research to the Department of Health and Social Care], she cited us all on it, so to me, I feel like it's been very authentic.

Being publicly acknowledged as members of the research team contributed to young associate researchers' understanding that their participation was both genuine and valuable. More foundationally, the perspective of authenticity upheld co-researchers' feeling of being able to engage openly and to see how these contributions became integrated into the research. Thus, "authenticity extended to feedback; I never felt like I had to filter my feedback if I saw something that might not work," a co-researcher explained. "I could say, and we would talk about it." My remembering of co-researchers' backgrounds was also relevant to their feeling that my interest in and respect for their individual contributions was being integrated into the research:

> Alison would remember our interests or backgrounds and tie them through. For example, when it came to discussing agency, we had a few talks about the data, just me and her. So, the way that she empowered us, but also made the best use of our interests and strengths…

8.1.4.3 Preparation and support

Meaningful collaborative relationships within participatory research are known to require extensive preparatory work (Eisenstadt and McLellan, 2020), with the time necessary to build rapport and facilitate authentic engagement with CBPR an aspect that may be under-resourced or overlooked (Hally *et al.,* 2020). I had invested considerable time and care into developing a preparatory training package, financed from within my grant award. In response to the closing survey question *Do you feel* *that you have had enough training and support to participate to the extent that you wanted?* all four participants agreed that they had. Co-researchers said that they benefited from the preparatory training programme. This was seen as a foundation, with the support that I honed over time experienced as important to building their confidence. As one co-researcher highlighted: “there was good support throughout the project with workshops for training and Alison was easily accessible to discuss any issues”.

Considerable emphasis was placed on preparation to facilitate peer interviews. “I think it was good when we had those practice interviews,” said one young person, “as we got to see what it was going to be like for the interviewee…we all shared photos of our own experience, and I found that quite challenging…so it allows you to appreciate what the other side’s going through”. A different co-researcher explained how this “gave you a level of empathy going into that context”. The workshop that focused on holding silence, alongside tips to help progress and deepen interview conversation were noted for helping build co-researchers’ skill sets and confidence. Support extended to the debrief that I facilitated after each interview: “so afterwards you would always have that debrief chat”. A less active aspect of feeling supported furthermore derived from the awareness that there was a ‘safety net’:

> The fact that you knew you could text her [Alison] anyway, even though you didn’t need to text her you knew that you could. Also, the participant knew that they could, and they knew that they could pause the interview if they wanted to. So, I think sometimes it’s knowing that there’s a net – you feel supported without having to use it.

In summary, there was high interest in the foundational research ‘training’ workshops; appreciation for my recognition of their interests; and, as we got to know one another, their strengths. I invested time to prepare all co-researchers for their roles. My support of co-researchers was maintained on an individual basis throughout field work, with further group preparation prior to our engagement in data analysis. This evaluation indicated that this sustained their commitment, and facilitated co-researchers’ proficiency, developing their capacity to think critically and engage with candour.

8.1.4.4 Emotional work

The process was nonetheless not without personal challenge. Despite co-researchers feeling prepared for the young associate researcher role, it was deeply personal work as highlighted during the focus group discussion:

> It was reminding me of my own experience, and it was weird, like you have to learn how to deal with emotions a bit more, and sort of compartmentalise those emotions during interviews.

Notwithstanding this, their engagement ‘peer-to-peer’ in interview conversation was simultaneously described as “almost therapeutic,” on account of co-researchers discovering how “shared and common” those emotions were among TYA participants. The fact that we were perceived to be “tackling quite an emotive topic, which probably had high emotions tied to it as well” was perceived as both “challenging,” whilst at the same time “rewarding”, said a different co-researcher. Importantly, co-researchers felt held, supported, and equipped to fulfil responsible roles, and they valued feeling entrusted to engage with TYA participants one-to-one. One co-researcher found this remarkable because of her youth: “It seems like you must be the head of the project to do interviews, whereas here it was actually like, [I was being told] ‘yes, I trust you to do interviews, and then we can look at them together’; it was a valuable experience”.

8.1.4.5 Capacities gained

Central to CBPR is a focus on strengths with concern for learning and “capacity building impacts” (Foster *et al.,* 2012; Colins *et al*., 2018). The capacities gained by the young associate researchers orientated around personal growth, academic or professional development and there were examples where their experiences led to new opportunities.

8.1.4.5.1 Personal growth

Young associate co-researchers described how their experiences of cancer had been of benefit to the research, whilst describing benefits from working collaboratively:

> My experience in haematology was quite lonely, I didn't get to meet cancer patients my own age, so this was a way of meeting other people with similar experience.

"It's nice to meet people, not in the cancer environment, but in a different environment where we're all working together towards a positive cause," another co-researcher said. In the learning logs that were completed after each interview, co-researchers described growing confidence, both in their enactment of the methods, and growth in personal confidence through being practically involved in facilitating interviews with strangers (young people who they did not know). During the focus group, a co-researcher explained how the nature of their engagement contributed to the confidence gained:

> …things like compassion that I can take forward in my job. It's given me the opportunity to talk to people I don't know and present things. I think that this has given me a really good platform to grow as a person.

This gain in personal confidence extended into professional impacts that they attributed to their involvement: "Right now, in my line of work, I feel much more confident; I've gained lots of transferable skills".

8.1.4.5.2 Academic and professional development

The four young associate researchers had all completed undergraduate education and described how the co-researcher role had positive impacts professionally. "I think one of the key things I learned was research skills. Being able to deliver well-run interviews on quite complex emotional, 'not easy to talk about' issues," said a co-researcher, who recognised that their personal experience of cancer was a strength in this context and positioned them well to engage with interviewees. "I interview people at work, but actually, it's such a different environment," said this co-researcher, again alluding to the emotive nature of the topic, the challenge and the personal skills gained.

Beyond interviews, being able to participate in data analysis was described as one of the "highlights" of co-researchers' experiences:

> Definitely going to the analysis workshops, I had quite low expectations actually. I thought we would be talking about the interviews we conducted, but I didn't know how much we would actually take from it. We basically did all the coding and analysis together…it was fantastic.

Within CBPR studies, participatory involvement in data analysis can contribute important insights for the research; however, few studies extend participation to analysis (Foster *et al*, 2012). As seen here, co-researchers experienced personal growth and in addition, through their perspectives, lived experiences and engagement, they were able to contribute significantly to analysis of the research findings.

For one co-researcher, the culture of collaboration I instilled within the research, contributed a different perspective to their professional development. They talked about "something that I didn't expect" and proceeded to describe my role-modelling:

> Seeing how Alison led our group, the way she shared power and in effect promoted our agency. I think that is definitely something that I want to take on…and see how I can work within this framework in my own professional life.

Moreover, the capacities gained were found to contribute positively at a life stage and within a cancer community that is known to miss career development opportunities due to the demands of cancer treatment (Zebrack and Isaacson, 2012). An example was provided by one co-researcher who explained: "I joined when I was in my second year at university – now that I've finished uni[versity], it's given me so many skills that I've been able to talk about in my interviews". They had secured postgraduate employment in their chosen field, and they believed this was on account of these assets and the confidence that they had gained. Professional impacts were reported by others, offering an indication of extended positive contributions to future career opportunities and earning potential.

8.1.4.6 *More existential gains*

Beyond the skills and capacities gained, consistently present among co-researchers' accounts was a sense that they had done "something positive", with wider impacts for the TYA cancer community:

> We used our experience and our developing skills to try and make things better for other people. You can't put a price on what that means to you personally and emotionally. That surpasses anything you get from it in terms of career development or things like that.

"I took part to give back to the cancer community," a different co-researcher explained in the focus group "but it's given me back a lot". "Public speaking, I had never done that before, it really, really helped skills and confidence". They valued the opportunities this created to engage with public audiences and advocate for improvements to young people's cancer care, in ways that upheld their founding motivations for becoming involved.

8.1.4.7 *New opportunities*

For two co-researchers, being members of the Community-of-Inquiry had contributed to new opportunities. Staley (2017) found that researchers gained new knowledge and skills through involvement which can change people's priorities, and an iteration of this was present among co-researchers' accounts. For example, "it made me realise this is what I want to pursue as a career and, because of this project, I got a job as a research assistant with one of my lecturers". This, alongside the thirty-months commitment to the research, had made this young associate researcher's career intentions feel more resolute:

> As someone who is interested in working in research and policy, I feel like this experience has given me a strong motivation, but also basic knowledge of what is required in my preferred professional field.

For the other co-researcher, their experience shaped their priorities differently: “I’ve always been quite interested in academic work, and I think having this experience has actually swayed me to go down a different route” they conveyed.

8.1.5 In summary

Whilst it is known that young people can learn transferable skills, develop self-confidence, and a sense of empowerment through engagement in participatory research (Powers and Tiffany, 2006; Day, 2008; Shaw *et al*., 2011; Das *et al*., 2020), I had not anticipated that the capacities gained would be so precise or pronounced. Underscoring co-researchers’ experiences was a consistent theme – they described drawing positively on their own experiences of cancer, channelling these to be of service to others.

“It feels great to be part of a project that is changing how teenagers and young adults live cancer,” a co-researcher noted in their survey response. Drawing on different experiences and knowledge in this way, both pre-existing and those gained, had been not just in service of the research it had also built personal capacities. Their participation created opportunities that fostered young co-researchers’ transition from their own cancer journey to pursuing their professional interests and chosen careers.

8.2 Further methodological appraisal in relation to the principles of participatory research and hallmarks of CBPR

Alongside, and drawing on the evaluation of co-researchers’ experiences, I appraised the extent that the research was able to embed the principles of participatory research and the ‘hallmarks’ of CBPR, namely: participation, knowledge democracy, power, and informed action (Wallerstein *et al*., 2018). This included my reflexive consideration of the approach, and one of the principal methods: the photo-guided peer interview.

8.2.1 Participation

As exemplified in the evaluation findings, the participatory dynamic can be seen in various stages of this research, and more broadly from a range of voices within the Community-of-Inquiry. The contributions of different community members, however, varied according to their representing roles. Although it had been envisaged that staff and charity members of the Community-of-Inquiry would become practically involved at every stage, the pressures of the Covid-19 pandemic required revisions to intended commitments. Charity and staff members remained conversant, engaged and contributed to the progression of the research, with practical engagement in the methods enacted by young associate researchers, companion associate co-researchers and me. The reintegration of an AC nurse (staff member) once the pressures of the pandemic had eased, is an example of how the flexibility integral to participatory research was utilised in service of the research aims. Our transition to online interviewing had not been anticipated at the start. Along with our development and/or piloting of different methods, this transition exemplifies the emergent characteristics and adaptability of participatory approaches.

8.2.2 Knowledge democracy

Young associate researchers were integral to the generation of the research evidence, as shown by the evaluation findings. These co-researchers saw how their involvement shaped the research inquiry: "You weren't just doing the interview; you were actually contributing to identifying the findings of it, and what you were contributing was being valued". As a research community, we would "build on one another's discussions" said a different young associate researcher, who described the impact of their contributions:

> I think we all contributed equally. And you can see how the methods and the approach to the research was changing based on our involvement. I feel like that in itself was quite powerful!

A characteristic of participatory research is the perspective that those with lived experiences of the research topic become co-creators of knowledge (Lenette *et al.*, 2019). Knowledge democracy, a hallmark of CBPR, counters more empirical ways of validating and understanding knowledge that silence the expertise and insights of others (Duncan and Oliver, 2017). "Young people ask different questions, have different priorities and concerns” and thus “make an important contribution to knowledge" that can only be made by young people themselves, posit Schäfer and Yarwood (2008, p.122). The involvement of young associate researchers within every stage of the research process not only contributed important insights; it leveraged their 'youth', cancer experience and their other knowledges and expertise in ways that will now contribute to the TYA AC services that the research set out to inform.

Disrupting the concept of an interview as a one-on-one format is a further example of how the sharing of a research agenda can bring people together in such a way that reciprocal collaboration can also lead to innovation (Ochocka and Janzen, 2014). The development and piloting of the triad interview arose as a direct result of my sharing of the research aims, and my concern for upholding the principles of knowledge democracy.

There might be concern among some proponents of CBPR for the capacity of the research to truly achieve knowledge democracy, being academically facilitated, within an orientation to research where academics are perceived as powerful, and co-researchers considered to have more vulnerable status (Lenette, *et al.*, 2019). The fact that young associate researchers all came from educated backgrounds informs, and perhaps revises, perceptions of 'academics' and 'vulnerability' in the context of research, whilst at the same time raising questions about how representative these researchers were of the wider TYA cancer community. This research maintained an intentional focus on diversity and inclusion (Das *et al.*, 2020), with a concern for health disparity (Collins *et al.*, 2018) from the outset. However, when convening the community of co-researchers, it became necessary to proceed in the knowledge that there were limitations to co-researcher representativeness from the perspective of younger age and educational background. Just as the intricacies and complex nature of relationships in CBPR are far from procedural or clear-cut (Lenette et al, 2019), pragmatism is sometimes required. In a small community of co-researchers, full representativeness – however that is defined – is likely to be unachievable. Indeed, Price and colleagues suggest that there has been a "misplaced emphasis" on including only "representative" patients or service users, as "their role is not to represent others in the data sense of representativeness; it is to provide a range of perspectives about an experience" (Price *et al.*, 2022, p.1044).

Furthermore, in relation to knowledge democracy, my own position was not only that of a PhD researcher. This research required me to walk different paths as a researcher, nurse, academic and member of the TYA cancer community, which I revisit at the close of this chapter. I reflect that my blended background may have been of benefit, enabling me to traverse different environments, whilst remaining cognisant of my positioning in each context.

8.2.3 Power

A characteristic of CBPR, derived from its concern for social equity and social justice, is a commitment to redress power and privilege differences (Wallerstein *et al*., 2018). This extends to representation among co-researchers, and whilst funders such as the NIHR in England have recently published guidance on inclusivity in health research (NIHR, 2021b), prospective volunteer co-researchers may not have, or perceive, equivalence of time, capacity or assets. Efforts to both involve and retain individuals from more disadvantaged social backgrounds (Howe *et al*., 2009), or those with cognitive impairment or from ethnic minority backgrounds (BJGP Life, 2021) remain a known challenge.

This does not mean, however, that this research was not socially just. Cultural humility (Wallerstein *et al*., 2018), was cultivated through our research inquiry, with, as these evaluation findings have illustrated, recognition of the impact of personal background and experiences on the generation of knowledge. More broadly, equitable distribution of power and responsibility is often considered challenging in the context of funded research, on account of research delivery conventions. I had recognised this potential difficulty from the start. Nevertheless, whilst accounting for the small size of this evaluation, and the educational profile of co-researchers, these findings convey that those co-researchers had felt enabled in their roles – able to influence not only data collection, but also analysis and outcomes of the research. Underpinning this aspect was the theme of 'trust', considered to be essential to effective CBPR partnerships (Lucero and Wallerstein, 2013), as exemplified by a co-researcher who remarked, "she [Alison] trusted my opinion, my lived expertise". There were other examples. In the context of our preparations to co-present at a conference, highlighted was that: "she trusted what I was going to say [...] we worked together well, and I thought this was a great instance of power-sharing".

Analogous to how we had evidenced 'agency' to be more representative than 'power' to delineate the emergent and intrinsic nature of autonomy experienced among TYA participants, here too conversations within the co-researcher community were found to foreground the concept of agency. Whilst interest in 'power' is more characteristic of CBPR, participatory research discourse often foregrounds the 'active agency' of those whose life or work is the subject of the research (Cook, Noone and Thomson, 2019; Cook, 2021).

In my appraisal of our CBPR dynamic, agency held more resonance than hierarchical consideration of empowerment as related to the notion of a transfer or levelling of power. The active agency of co-researchers – young people, companions, staff and charity collaborators – can be seen throughout the research process. When those with lived experience are meaningfully involved, more fundamentally they are exercising their agency as citizens (Groot *et al.,* 2018). "There were lots of points in the process where [Alison would] pause to ask, 'what does this mean' or 'what do you think?' said a co-researcher, "it's hard to pick one example because it happened all the time". Still, as much as I uphold a revision of my initial concern for 'power', to that of 'agency', this does not detract from my commitment to CBPR's regard for equity of power relations, which remained integral to this research.

8.2.4 Informed action

Principally CBPR is undertaken to inform action. Whilst the research design had originally envisaged a definitive ‘action cycle’ in the form of introducing service change within the study design (to be evaluated by the AC nursing team), the impact of the pandemic on the research’s timelines meant that this now sits outside its scope. Notwithstanding this, the research embedded ‘action cycles’ derived from our recursive engagement with the data. ‘Informed action’ could be seen within how the research had begun to inform practice, channel investment, and raise the profile of TYA AC before the research closed. This illustrates how through CBPR impact can occur at any point during the co-construction of knowledge. Other examples of ‘informed action’ arising from our participative approach are described within Chapter 9.

8.3 Methodological considerations and learning

8.3.1 Peer interview method

My appraisal of the research approach extended to consider the photo-guided peer interview method and what I could learn about its use in a virtual setting with young people. The decision to work with participants’ photographs as the basis for research interviews was premised on generating a rich, textured account of experiences (Tinkler, 2013), with the recognition that it may be challenging to articulate affective experience through words alone (Brown, 2018a; Pearce *et al.*, 2020). I had thought that this latter aspect could become more pronounced within the format of a standard online interview. Primarily however, the integration of photographs introduced choice. For TYA participants, being able to take and select images that held meaning intended to foster a sense of autonomy, whilst retaining control over the direction and content of their interview. Underpinning the method, the peer approach centred ‘relatability’, that derived from a shared experience of cancer. I had furthermore reasoned that engaging in interview conversation with someone of a similar age might redress constraining impacts of hierarchy between researcher and researched (Livingood *et al.*, 2016).

This summary of my consideration of the photo-guided peer interview method is presented from the perspective of four domains grounded by the evaluation findings: *the virtual approach*, *participants' perspectives*, the *contribution of photographs* to interview conversations and the topic of *relatable experience*.

8.3.2 The virtual approach

On a practical basis, co-researchers saw technology as an enabler that made the logistics of the interview feel easier for the interviewer and interviewee. Sharing photographs online had not been problematic, although some young people were reliant on their personal mobile telephone reception and data allowance. There were two occasions where internet connectivity had been weak; to reduce bandwidth, conversations continued with participants' cameras turned off. In addition, one young person, feeling self-conscious, asked if they could take part without their video camera on, and the interview proceeded on this basis.

Symbolic of the merits of the virtual approach was that interviews could take place from the setting of participants' choice:

> …they're in their own environment, aren't they? Instead of bringing them [the participant] into an environment, and they maybe have their guard up, they're actually at home or somewhere else of their choice, chilling out, and I think they're maybe a bit more open because of it.

Whilst the advantages of being in one's own environment were foregrounded, for one co-researcher being able to 'read' and gain a sense of someone was thought to be "easier face-to-face". "When you get online, you're there for the interview [whereas] if going into a room, you might have had a bit more of a chit-chat outside first," they explained. "It's easier when you can see more of a person than their head, I feel like you get more of a gauge," this co-researcher clarified. Brown (2018), in her appraisal of video-interview methods, noted that whilst the format facilitates choice in terms of how much individuals show of themselves, coherence and authenticity may be more difficult to appraise, and, as discussed by Lo Iacono and colleagues

(2016), it is possible that the virtual context may limit both rapport and reading of non-verbal cues.

Contrasting with this perspective, a different co-researcher indicated “it might have been tougher for me personally”. “Talking with someone face-to-face you pick up more emotional cues which are useful for the interviewer and the conversation, but sometimes, because you have experience of cancer, they impact us,” they explained. The virtual format had facilitated some emotional distance which they appreciated, as it helped retain their focus on the interview. Upheld as important to all co-researchers, however, was the perspective that a virtual interview prioritised the comfort of the young person who took part:

> I was thinking about the pain and the soreness and the tiredness that you feel during cancer. I feel like it allowed them to make themselves more comfortable, and be like, ‘Actually, I’m just going to put my phone down, I’m just going to rearrange myself’ and that’s fine because they’re not in the room. Sometimes I would only see a forehead for 10 minutes, but they were making themselves comfortable, and I thought it was great.

8.3.3 Participants’ perspectives

Young people who took part in the research did not question the fact that the interviews would take place virtually. At this point in the research timeline, online conversations had become commonplace because of the pandemic. More notable perhaps were participants’ engagement with the photo-guided approach. When opening an interview, as an ‘ice-breaker’ co-researchers would often ask how they found the experience of taking and selecting photographs. “It was nice to have something else to think about during my 5-day treatment” conveyed a TYA participant (YE). “It was a bit of fun really, to think of things that I was doing that would document my experience or be meaningful,” another (YQ) said.

Perceptible in my reading of TYA participants’ transcripts, were idioms and a style of speech representative of youth, and a relaxed conversational narrative. At the close of an interview, or in circumstances where I followed up with participants,

participants would sometimes remark that they had valued talking with a peer. The matching of interviewers to interviewees based on criteria such as age may not automatically facilitate a closer relationship in an interview posit Schäfer and Yarwood (2008). When young associate researchers were asked in the closing survey on a scale of 1 to 5 (where 1 equalled not at all and 5 equalled completely) to what extent they had considered themselves a peer to the young people they had been interviewing, no one selected a ‘1’ or ‘2’. The four co-researchers had varying perceptions based on the age of the four or five young people they had each interviewed - with a ‘4’ being the highest response (n=2).

8.3.4 Contribution of photographs to interview conversations

Beyond photographs being seen as an “ice breaker,” or “a good entry point” the images that participants shared became “a tool for expression,” that both informed interview data, whilst being a data set in themselves. When screen shared and viewed together, the photographs were found to both anchor and direct the interview conversations:

> As well as helping to illustrate their experiences to us, the photos help me to understand more. They help me with my questioning…I can ask better questions about the room for example, because I’ve seen it with them.

Photographs fostered curiosity and facilitated wider questioning: “Things like, ‘who is in the second bed?’ or if there are someone’s feet in the photo, ‘whose feet are they?’” to explore the young person’s support network. Initially, there were concerns among co-researchers that this technique might be too ‘directing’ of the conversation. With growing experience and confidence, this type of “talking around the photographs” became embedded in the interview approach. It “inspired the path of the conversation” and extended the potential of the images. The fact that photographs had been self-curated respected participants’ autonomy. As one co-researcher suggested, “they feel comfortable because it’s something that they know about”. This latter aspect was considered advantageous in situations where participants "seemed quite tired" or might find it hard to concentrate due to the impact of their treatment.

"I think at the end of the day, some people are more visual than others, and so some participants will connect more with the approach," summarised a co-researcher. "I had two very different experiences in my initial interviews," said another; "the first one [young person] was very talkative, and the other was more like 'I have no feelings about that'". A further consideration was that many participants' photographs orientated around food or a comfortable bed. On the first few viewings, the significance of these photographs was not immediately apparent. When reviewing all the photographs together, however, the frequency of the photographs' subject matter enabled us to recognise their importance to the TYA participant group.

In terms of different young associate researchers' approach or technique, some co-researchers had consistently invited participants to think of a title for each of their images, whereas others did not follow this so methodically. Irrespective of approach, it had not fundamentally impacted the contributions from participants, or the codes generated from individual participant's data. On an unrelated point, adjustments to the method were introduced. Following the mid-point review, to achieve a balance between sharing photographs and in-depth conversation during the 60-minute interviews, rather than incorporating seven images, participants were invited to select five.

8.3.5 Relatable experience

Accounts from young associate researchers suggested that shared experiences of cancer had positively informed the interview dynamic. "I think my involvement [in interviews] helps me build rapport easily with participants. They are more ready to share because of our shared experiences," said a co-researcher, evoking the perspective of an interview as 'journeying together'; a process of shared knowledge construction (Brinkman and Kvale, 2015). As one co-researcher explained:

> In one interview I saw she had a PICC line, and near the start I said, ‘Oh, this is like what my scar looks like now’ and the way they responded, I felt like it made her so much more comfortable, knowing that we've both been through something similar.

“You understand their nuances more” on account of related experience, suggested a different young associate researcher, with a perception that this both strengthened their interview technique and the quality of the conversation. Learning logs completed after each interview created opportunities for reflexivity: ‘*How might my involvement be impacting on the research’* was one question posed, to which a young associate researcher wrote in response:

> I think it’s important to use related experiences to build rapport…however I think it’s very important to find the line where your own experiences could bias the participant’s responses, or your interpretation of it.

Although it “slows things [the interview] down,” this young associate researcher noted, “I like to clarify what interviewees mean”. Important to this co-researcher and others, was awareness “that everyone’s journey is unique in every aspect,” demonstrating how active reflexivity was pivotal (Brown, 2018b, Brown, 2019) in ensuring that ‘pre-understandings’ did not encroach.

If there had been any doubts about the merits of the photo-guided approach, however, these were dispelled when a hospital visitor, who had paused to view our photographic exhibition conveyed: “well, as someone much older, I can’t claim to truly understand these young people’s experiences, but to me, these photographs tell a story about agency”. Nowhere had ‘agency’ been written or captioned, yet to someone with no connection to the TYA cancer community, this had been communicated through visual means.

In summary, the photo-guided peer interview approach achieved the methodological aim of generating a rich, textured account of experiences, one that respected young people’s autonomy and promoted choice. Premising relatability, shared experiences positively contributed to the interview dynamic. Furthermore, co-researchers commented on the importance of seeing peers. “I think sometimes it's nice to see someone that’s had cancer and they’re okay, and they’ve moved on, with their life” suggested a young associate researcher, and others concurred. Thus, beyond the impact on data, being interviewed by a young associate researcher in this peer-interview approach may have instilled hope in the TYA participants.

8.3.6 Credibility

The non-linear, iterative nature of participatory research means that unless research processes are clearly detailed, the provenance of research findings may be more difficult to appraise or delineate. In qualitative research, tenets of reliability and validity are built into the processes of inquiry (Morse, 2018; Meadows and Morse, 2001), with a focus on ‘goodness’ (Emden and Sandelowski, 1999), transferability and positionality as more suitable principles for the appraisal of quality and rigour (Morse, 2018); with the understanding that no one set of criteria ‘fits all’.

According to Emden and Sandelowski (1999), the quality of research can be appraised when complexities are made visible. My integration of co-researchers’ first-hand accounts in this chapter facilitates this consideration in a participatory context. Literature suggests that the credibility of participatory research benefits from the collective dynamic, with research findings informed by multiple perspectives strengthened on account of this methodological basis (Morse, 2018; Reed *et al*., 2018). Viewed from this perspective, our study design, which integrated different participant groups and data sets, helps foster trustworthiness. Furthermore, when analysis is undertaken in a participatory context, its integrity is enhanced, being both ‘ground-truthed’ and ‘cross-checked’ by those directly involved (Pain *et al*., 2015). Just as every relational research project is unique on account of the individuals as well as methods involved, there were other distinctive aspects of this research that foster credibility. My relationship with the young associate and associate co-researchers was independent to that of my supervisory team. Working together for over two years, we gained one another’s trust. From this trust came confidence to challenge and share differences of opinion; this became characteristic of our participatory dynamic. I held myself accountable to co-researchers, they to me, us to one another, similar to the relational accountability described by Reich and colleagues (2017) and Southby (2017). In the latter stages of the research, this meant that not only were the research findings verified collectively from within the co-researcher community, but this embedded a high level of criticality. As part of this process, the findings were also shared with members of the TYA nursing team at the study site, which introduced a peer review process to clarify and verify the research findings.

Eisenstadt and McLellan (2020) raise that extensive preparatory work is required to build meaningful collaborative relationships; this is something that develops over time and cannot be rushed. Although co-researchers may not have envisaged committing to their role for the length of time that they did, with intended plans and opportunities to socialise or travel curtailed by the pandemic, it is my view that the research benefited from the relationships we built that associated with the length of their extended tenure.

8.4 More personal considerations

Despite their potential to generate transformative knowledge and action, participatory research approaches are renowned for being emergent (ICPHR, 2013a), destabilising (Cook *et al*., 2019) and rather ‘messy’ (Cook, 2009; Thulien *et al*., 2022). Yet I noticed that the type of engagement required was not dissimilar from how I navigate my professional work as a registered nurse. At its core nursing is a relational profession, one which increasingly focuses on fostering people’s capacity, beyond attending to needs. Although participatory research is sometimes considered to be more emotionally taxing on account of its relational basis (Alexandra, 2017), I felt comfortable (although not immune from feeling challenged) working in this space and a co-researcher had commented that I seemed to “walk the line with ease”.

My scaffolding of the research within a community ethos incorporated a disciplinary perspective in the form of interpretive description (Thorne, 2016). This integrated my (and other nurses’) disciplinary knowledge and experiences, with the recognition that it would be difficult, and probably not beneficial, to ‘bracket out’ practice insight from research about TYA AC – a nurse-led clinical service.

As stated in Chapter 2, at the centre of the nursing discipline is regard for the uniqueness and multiplicity of human experience; attention to both patterns and variance; holism (Thorne 2016); and a professional mandate for agency (Thorne 2016, Thorne, Stephens and Truant, 2016). Whilst carrying out this PhD, I was very aware of my positionality in relation to the research; this included my nursing background and my experiences as a leader. Reflecting on co-researchers’ feedback, it became possible to see how this same disciplinary epistemology and my professional experience, alongside what I see as nursing’s commitment to teamwork, meaningful relationships, reciprocity and trust, aligned to positively inform the way that I led myself and the Community-of-Inquiry. This may have contributed to the sense of learned familiarity and relative comfort that I felt, as I engaged in, and facilitated, this recursive and relational approach to research.

On a personal level, young associate researchers described ways in which they appreciated being part of a community, in which “we’re all working towards a common cause”. Setting the evaluation findings to one side, the sense of support, friendship and peer connections that had developed through our work together was present within my conversations with companion co-researchers too. This was not unidirectional. I derived a significant sense of support from all co-researchers. I respected and felt encouraged by their commitment and the care that co-researchers extended to me personally.

8.5 In conclusion

Whilst not usually the primary purpose of research, the processes of participatory research can provide important outcomes for all involved (Duncan and Oliver, 2018). This has been evidenced within the benefits young co-researchers described in the evaluation findings; among companion co-researchers, who also described personal gains; and during the life of the study, in how the participatory process has informed charity collaborators’ prioritisation and future investment in AC.

The photo-guided peer interview method aligned with the principles of participatory research, fostering relational development of knowledge and autonomy. Undertaking virtual interviews created flexibility for all concerned, particularly around interview timings. A characteristic of the interview dynamic was its centring of caring and respectful relationships with a high level of critical awareness evident among young associate researchers. Care was and must be taken, however, to recompense any expenses incurred by interviewees that associate with virtual participation.

My reflexive appraisal of the research process and outcomes upheld my founding idea that this orientation to research is fundamentally strengths-based. Respecting the agency and capacity of co-researchers deepened their engagement, whilst building credibility and value to the research. An aspect of methodological inquiry, however, left open earlier in this thesis was whether this study could be regarded as CBPR. In my consideration of this, I appraised our enactment of the research alongside the evaluation findings.

This research sits within the wider field of participatory research, and more specifically participatory health- or participatory action research. Having been embedded and driven from within the TYA cancer community, this aligns its methodological orientation to CBPR. A distinguishing mark too of CBPR, is concern for equity and social justice, and a commitment to redress marginalisation or privilege differences (Wallerstein *et al*., 2018). Our commitment to these features, both in the fulfilment of the study, and through how the findings have, and will continue to inform practice, further identifies this work with the qualities of CBPR. These aspects of CBPR are both relevant to the founding priorities of the research, and accurately reflect the way it was enacted. Additionally, my commitment to CBPR as a distinct approach helps ensure that, going forward, attention is paid to aspects of social equity when developing or commissioning TYA AC pathways. In conclusion, whilst this work has not been driven by service users, it nonetheless retains and embeds the hallmarks of CBPR.

8.6 Chapter summary

This chapter focused on the final research question: *Can CBPR engage young people, support authentic participation and contribute methodologically?* To answer this, I undertook an evaluation of young associate co-researchers' experiences. More reflexively, I have considered our methodological approach alongside the hallmarks of CBPR (Wallerstein *et al.*, 2018). Ochocka and Janzen (2014) outline how, alongside the production and mobilisation of knowledge, another function of CBPR is mobilisation of the community. Being embedded within the TYA cancer community meant that dissemination of the research could begin in the latter stages of the study, rather than being undertaken as a subsequent activity. In the next, concluding chapter, I present the contributions of this research and explain ways in which the research has begun to shape and inform TYA AC.

Chapter 9 Contributions and implications of this research

9.1 Thesis overview

The overarching objective of this research was to explore experiences of Teenage and Young Adult (TYA) Ambulatory Care (AC) at an individual, family and service-provider level to inform the development of current and future services. To achieve this, six incremental objectives were set. My research posed five questions; these were explored through qualitative inquiry and a participatory methodological approach. This thesis responds to these research questions, providing an explanatory account of the findings and their contribution to academic knowledge and healthcare practice. As part of the introduction to what follows, Figure 9-1 provides a visual reminder of the different phases of the research, detailing how each of the five questions were explored.

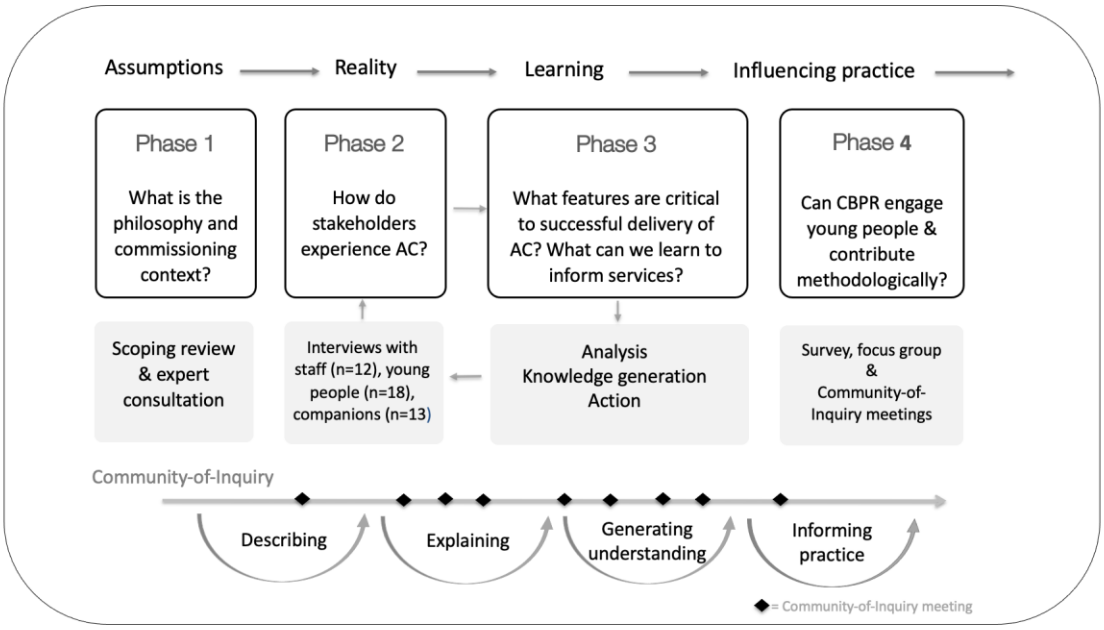

Figure 9-1: Overview of the study design

9.2 Contributions of this research

This PhD and research makes an original contribution as the first study undertaken within the TYA setting to have comprehensively explored the AC experiences of different stakeholders. It contributes a sixth primary research study exploring experiences of AC. Previous research has focused on adult patient experience (Statham, 2005, Nissim *et al.,* 2014, Mcmonagle, 2015), the role and needs of caregivers (Grimm *et al*., 2000) and the role of professional nursing in the ambulatory setting (Morrison, 2010). In addition, Brown and Walker (2016) engaged a small number of young people and their parents in qualitative inquiry within a service evaluation of TYA AC.

The research has been undertaken with, alongside and for the TYA cancer community. Findings can be used in practical or theoretical ways, whilst informing or contributing to future research and healthcare policy. Whilst research contribution and impact can often be seen as an endpoint, the opportunity to realise impacts during the life of a project is a characteristic of participatory research. A distinguishing feature of this work has been the development of "living knowledge" (Facer and Enright, 2016, p.146): its capacity to inform practice and investment in TYA AC in parallel to the finalisation of this PhD. The impact statement in the opening section of this thesis summaries demonstrable impacts to date. In addition, the work makes several other contributions which are now described.

9.2.1 Contributions to the literature

The scoping review is the first summary of international AC literature to offer a chronological presentation of the provenance of the AC pathway, starting from its origins in the USA in the 1970s. Not placing searching restrictions on publication date enabled an extensive exploration, and the identification of papers previously uncited in AC literature. A strength of this review process was its inclusion of a consultation exercise (Arksey and O'Malley, 2005; Levac *et al.,* 2010; O'Brien *et al*., 2016) and the ability to clearly explicate the drivers for the development of AC. My synthesis of the literature, integrated with the consultation, identified four drivers: financial, optimisation of bed capacity, advances in technology and supportive care, and professional motivation to improve cancer experience.

The diversity of communities was rarely reported within the scoping review literature. In this research, 28% of young people who took part were from communities other than those with a white British background. Office for National Statistics data from 2019 (ONS, 2021) estimates that 57% of the population in London, and 21.6% of the English and Welsh population identify other than white British. The ethnic diversity achieved across participant groups thus enhances its contribution to the AC literature, as well as informing its interpretation and relevance to those developing AC services nationally. The diversity achieved among young associate co-researchers and companion co-researchers, included three individuals who identified as being from backgrounds other than white British.

9.2.2 Methodological contributions

The research findings offer a rich, contextualised interpretation of the AC experiences of young people, their companions and staff. In terms of its study design, the research comfortably achieved the recruitment targets set for each participant group, building confidence in the findings reported. Furthermore, it is the first known CBPR project to have been undertaken within the young people's cancer community, offering TYA cancer researchers an example of how CBPR can be successfully employed. The research is an exemplar of how young people can productively fulfil co-researcher roles to enhance the relevance and reach of the research inquiry, whilst developing capacity and transferable skills among young researchers.

Qualitative methods are dynamic and are redesigned as they are enacted in practice (Nordstrom, 2013). This was characteristic of our Community-of-Inquiry's experience, and the research makes methodological contributions through the development of a new research method, and the application of existing methods to new contexts. We successfully transitioned photo-guided interviews to an online format, at a time when the literature offered few examples of using video-meetings for qualitative research purposes. The virtual format seemed to enhance recruitment to the study, facilitating participation from the comfort of a home setting, and with no travel time required, interviews could be accommodated outside core business hours.

During the research co-researchers shaped innovations to the methods. For example, the triad interview approach. This arose from a companion co-researcher querying why my original intent had been to interview companions alone, suggesting this might overlook the potential merits of peer interviewing (relatable experience) in our interviews with young people's companions.

Although dyad interviews have become more widely used in research (Morgan *et al.* 2013), little has been published about a triad interview approach, within which two interviewers guide an engaged three-way conversation with an interviewee. A search of the literature at this time identified no known precedents of a two-to-one interview method. One paper (Matteson and Lincoln, 2009), stated how, due to time constraints, their last scheduled interview was spontaneously conducted with both interviewers present. The approach I would subsequently define as a 'triad interview' was emergent. The two companion co-researchers and I worked beyond methodological convention, carefully appraising the potential contribution of the triad method, before piloting and employing it in practice. The interview format was optional, and all thirteen companion participants chose to be interviewed via the triad method rather than by one researcher. Interviewees said that they had engaged in conversation with peers who understood their own situation, and that they found the experience supportive. In some cases, interviewees described their experience as cathartic – this, however, may convey an unmet need for emotional support, as much as the merits of the triad interview. In summary, this process generated rich in-depth data that might not otherwise have been elicited using a traditional interview approach.

During the course of our data collection period, Monforte and Úbeda-Colomer (2021) published their use of a two-to-one interview approach to qualitatively evaluate aspects of physical disability participation among Spanish university students. Then, when finalizing this thesis, I revisited the literature and noted Velardo and Elliott

(2021) had also published experience of ‘co-interviewing’ six doctoral students about a topic related to emotional wellbeing, citing an earlier example of co-interviewing from Rosenblatt (2012). While sharing some commonality with our experiences of developing the triad interview, these authors’ considerations and reflections on their co-interviewing approach do not address the role that, in our experience, shared experience and empathy plays in bridging and balancing each parties’ contribution to the interview dynamic.

The triad interview is distinct from another kind of supportive or facilitated conversation. It is a ‘coming together’ in a conversation with a clear purpose, namely, to help support answering a research question. Consistent amongst definitions of ‘triad’ is the concept of relatedness or relatability. The triad interview we developed upholds the design integrity of the two-to-one interview developed by Monteforte and Úbeda-Colomer (2021) and has similarities with the co-interviewing described by Rosenblatt (2012) and Velardo and Elliott (2021); yet is it is distinguished by virtue of a characteristic that pivots around related experience. In essence, rather than “double teaming” as interviewers, it foregrounds a dynamic three-way conversation.

Through our piloting of a triad approach, perspectives such as positionality and enhanced rapport (Harris, 2015; Monteforte and Úbeda-Colomer, 2021) have been seen to positively impact exploratory interview conversation. I concur with both Monteforte and Úbeda-Colomer (2021) and Velardo and Elliot (2021) that ‘two-interviewer interviews’, however they are defined, are an unnoticed, perhaps neglected, qualitative research method. Specifically, I tentatively suggest that the triad interview may be an underexplored methodological innovation that is worthy of further exploration and could be highly beneficial in some person-centred research contexts.

Additional methodological contributions include the novel application of Eakin and Gladstone’s (2020) ‘value-adding’ data analysis approach to a participatory format; it offers a worked example of how value-adding analysis can be applied to team-based analysis and a non-traditional academic context. Similarly, use of systematic visuo-textual analysis (Brown and Collins, 2021) with co-researchers not only extended their framework beyond its original intended purpose for academics, but also deployed it in a participatory context.

9.2.3 Conceptual and theoretical contributions

The research from the outset had a service delivery focus, but also a conceptual one, including AC's relationship with age-appropriate care. Through my appraisal of the model of age-appropriate care (Lea *et al.*, 2018) in relation to AC experience, I evidenced the requirement for more reflexive consideration of the construct. This includes the notion of normality, and the companion role as a component of age-appropriate care in the TYA AC context – with greater scope for appraising the contribution of this role in relation to the model. An additional notable finding was the positive dynamic between young people and their accompanying companion that embedded reciprocal support. This offers a perspective that balances some prevailing concerns in the literature about dependency or regression as characteristic of parent-adolescent relationships when negotiating cancer treatment.

In parallel to widening the professional lens to be more encompassing of a family-focus to age-appropriate care, this research also introduces the concept of 'agency' as the defining basis of AC, and as a starting point from which to develop further understanding and evidence. My advancement of our team-based thematic consideration of the findings to a conceptual interpretation, facilitated an explanation of how autonomy and agency underpinned people's experiences of AC. This contributes a new and significant academic understanding of AC experience. When this interpretation is further extended and aligned with principles of 'assets' and features of assets-based healthcare (PHE, 2015; Rippon and Hopkins, 2015; NICE and Social Care Institute for Excellence, 2019, South and Stansfield, 2022), it fosters opportunities for the findings to contribute a baseline of theoretical explanation, from which future research or critical appraisal of the evidence can be positioned.

9.3 Implications for practice

This research raises many implications for clinical practice. It has already begun to make contributions to the evidence base for AC, and importantly to clinical practice. It identified twelve critical factors supporting positive experience for TYA and key learning for service development. At a local level, these factors and learning are being used as a basis for the study site to further invest or align allocation of resources. It is intended that findings will be of use to new and emerging AC services nationwide too, through their contribution to a best-practice guideline commissioned through TYAC, the professional forum for the TYA cancer community.

From a service development perspective, the findings identified many practical facilities that would enhance or improve people's experiences of AC, for example, more accessible showers or access to cooking facilities. These findings facilitate the practical consideration of options to secure improvements in the care environment and have begun to inform my conversations with the study site and third-sector partners who support TYAs navigating cancer treatment.

Young people's 'assets' were identified as central factors affecting their autonomy, for example, capacity for self-reliance, or self-appraisal of health status. This directs professionals to help maximise opportunities for young people to realise their agency. It also foregrounds the requirement for equitable access to resources that may impact experience, contributing the need for more standardised provision of information and thus access to holistic care. This research was conducted close to practice, with members of the nursing team supporting recruitment to the study and a senior nurse engaged in participatory analysis. This proximity supported professionals' critical thinking, impacting conversations and AC practice at the study site as the research progressed. One consequence of this has been a new understanding of the role of the companion in AC. This insight is now underpinning allocation of further resources and emotional support. Furthermore, a new appreciation of the benefits to wellbeing from time spent outside the clinical setting, and in society, are offering fresh ideas to the structure and nature of the environment for inpatient care. Even those TYA not eligible for AC can potentially benefit from aspects borrowed from the AC model whilst they are inpatients. These may include time spent outside, a no-disturbance time window and retaining elements of self-care for both clinical (medications), and activities of daily living, for example the opportunity to remain independent and make oneself a cup of tea.

9.4 Implications for policy

The scoping review highlighted that an important component of this primary research would be to consider the potential tension between system drivers underpinning the delivery of more community, outpatient-based services, and how far the AC pathway successfully meets care needs and supports the wellbeing of young people. The findings evidence how AC contributed positively to young people's experiences. They demonstrate how, beyond concern for 'meeting needs', it becomes possible to recognise the service's transformative qualities in relation to autonomy and the perspective of wellbeing. Through its evidenced explication of the factors that contribute to experience, its conceptual alignment with agency and principles of assets-based health, the research has simultaneously raised the need to consider barriers that may impact people's experience. This research has highlighted that in the TYA AC setting, whilst the built environment remains important to young people's experiences, along with the expertise of the multidisciplinary team (MDT), there is a need to direct further investment in resources that support young people and their companions to realise their assets, so that they remain, as far as possible, anchored in their usual lives and communities during treatment.

This PhD has raised the profile of AC, instigating some of the issues relevant to putting in place the support that young people need. My ongoing dialogue with the national charity Young Lives vs Cancer has meant that the findings of the research contributed to the charity developing and appointing into a national programme manager for AC and their home-from-home accommodation. The charity's renewed interest and investment in supporting AC aligns with growing interest in the pathway among clinicians nationally. This creates potential to further leverage and expedite development of services through charities' contributions to (or support of) the infrastructure required. The launch of a Special Interest Group (SIG) for children and young people’s AC, hosted by the Children Cancer Leukaemia Group (CCLG) and the professional group for the Teenage and Young Adult Cancer specialty in the UK (TYAC) in October 2022, of which I have become a member and deputy chair, has potential to further influence how the findings may impact clinical policies and practice nationally.

As a demonstrable contribution to healthcare policy, I responded to a call for evidence for the UK government’s future 10-year cancer plan, submitting findings to the UK Department of Health in April 2022. Teenage Cancer Trust and Young Lives vs Cancer also used the research evidence to inform their own submissions to the call, emphasising AC’s contribution to personalised cancer care.

9.5 Limitations

Although the research reported in this thesis makes a demonstrable contribution to the field of TYA AC, I note some considerations relevant to interpretation of its findings. With data collection taking place entirely at UCLH, this has been a single-site study: albeit the only service that was available in the UK. My inquiry has focused on different stakeholders' experiences of an established TYA AC service that was founded in 2011, in the context of an organisation that first created an adult ambulatory cancer service in 2003. The findings set out the conditions in which young people were able to prosper during cancer treatment and offer learning with a depth and richness that may be beneficial to new and developing TYA AC contexts.

The research was undertaken within an established and well-resourced TYA service. The findings do not take account of different cancer service configurations or differing cultures of care; this may impact their transferability to other cancer centres.

In terms of the demographic composition of participants, among the TYA cohort, more males than females participated in the research (eleven to seven respectively). Whilst every effort was made to balance the gender distribution of young people who participated, through purposeful sampling during the closing weeks of the study, there were approximately two-thirds more males than females accessing the AC service during the data collection period, which impacted potential recruitment. This disparity was coincidental; it did not associate with known gender variances within cancer diagnostic groups. The research did not set out to compare experiences of those who identify as male or female, favouring instead a rich, contextualised perspective. Nevertheless, the gender imbalance remains relevant to readers' consideration of the findings. Younger voices were also slightly less represented among the TYA 16-24 age cohort, with six of the eighteen participants aged 16 to 19 compared with twelve participants aged 20 to 24. Another consideration informing interpretation of the findings is that apart from one young adult, who had experience of staying overnight alone on an occasional basis during a lengthy AC admission, experiences of undertaking AC unaccompanied were not captured.

Most young people stayed in the Cotton Rooms hospital hotel, with experiences of AC from home or an apartment setting featuring less within the data collected. Notable in our data was that experiences of the Young Lives vs Cancer home-from-home, located adjacent to the study site, were absent. Whilst the TYA AC service had been set-up with this residential setting in mind, in more recent years increasing demand for rooms from different hospitals, coupled by a period of closure for renovation and restrictions due to the pandemic, meant that by 2020 the TYA service rarely used the home-from-home for AC.

My intention from the outset had been to explore experiences both of those delivering and those receiving AC. Presentation of the research findings has been weighted to the experiences of young people and their supporting companions, with those of the healthcare team less pronounced, or contributing contextualisation. In a clinical and academic field where there has been very limited research inquiry into young people's experiences of AC, or those of their companions, this is arguably a strength of this work. There remain unanswered questions as a consequence of choosing to place less analytic emphasis on the experiences of staff, however, for example how AC impacts on the professional identity of nurses. This offers scope for a future study.

Interview conversations were informed by participants' photographs and orientated around what arose as most salient to the TYA. Opportunity to focus on certain subjects, for example whether young people had been able to continue their studies or maintain work whilst receiving care on an ambulatory basis, did not always arise, despite my interest in this area. Whilst staff interviews highlighted a need for greater emphasis on the educational needs of young people receiving care on an AC basis, interviews were not purposefully steered to address this and, in some domains, understanding from the TYA perspective remains limited.

Self-motivation has previously been found to be a factor that informed adults' experiences of AC (Statham, 2005). On account of its methodology and study design, this research could not appraise how an individual's personality and motivation inform their experiences of AC. Both TYA and companions demonstrated the desire and capacity to be agentic, which arguably suggests the involvement of motivation, although the relationship of motivation to AC in a TYA context requires further investigation.

The research was undertaken during the Covid-19 pandemic during a period when there were visiting restrictions throughout the NHS, and widespread re-deployment of staff. Whilst the running of the AC service was not directly affected, other components of the service, for example TYA being able to invite friends to the AC unit or have in-person visits from a social worker, were impacted. Furthermore, the running of the unit had to factor staff sickness or need to isolate, which may have compounded the clinical pressures reported. The themes identified in the findings resonated across interview data, including the time period when restrictions had been lifted in autumn 2021, extending into summer 2022. Whilst it feels important to emphasise that insights derived from this research may have been intensified by the Covid-19 context, the data's consistency over a longer time trajectory supports confidence in the findings.

9.6 Recommendations for practice and service development

The research makes a series of recommendations for practice and service development. These are aimed at the study site and for services developing TYA AC. Many of these recommendations, with consideration, may be transferable to adult AC practice. Additionally, some recommendations may be applicable to children's AC services under development, with the expectation that the companion role in children's AC will be even more involved and will therefore require further appraisal, education and support.

Refinements and innovations in AC practice:

1. The development of a decision-making tool, informed by the research findings, would enable TYAs to a) self-appraise their suitability for AC and b) identify additional resources required.
2. Young people in AC need to understand the expectation that they will speak out to assert their own needs; to further this, clearer articulation of the AC model is needed concerning how and in what circumstances they can seek advice and access to support.
3. In conjunction with this, healthcare professionals should advocate for, and remain receptive to, creating space and time for young people to raise their needs, some of which may extend beyond clinical care.
4. In terms of education and preparation to ambulate, use of other modalities, for example video, would promote standardisation of information and resources shared. This would enable TYAs to revisit the information in their own time, whilst freeing clinical time for psychosocial support.
5. Use of video tutorials could facilitate some young people's wish for greater knowledge to address issues themselves. They could learn, for example, how to safely trouble shoot an alarming pump, rather than immediately defaulting to the clinical team.
6. In a healthcare context where self-reliance is promoted, beyond signposting to digital resources there remains a need for staff, charity and third-sector

partners to help young people navigate bespoke information and support in person.

7. A review of TYA AC documentation is required to reduce an existing reliance on generic hospital templates (e.g. self-administration of medicine) or information from adult AC. Investment in this review is considered pivotal to clearer differentiation of the responsibilities that become shared in AC between the TYA, their companion and the clinical team. Bespoke documentation will clarify how responsibilities are shared between these three parties and help prevent care requirements becoming overlooked.

The environment:

8. Current and future TYA AC services should ensure young people have unlimited access to a social and recreational area on the clinical unit. Where possible, consider retaining or creating an open plan environment that will organically foster peer connections, whilst maintaining some TYA preferences for personal space and privacy.
9. Consideration needs to be given to ensuring that young people do not feel forgotten or overlooked if on the unit and beyond the sightline of the clinical team.
10. The non-clinical space can help facilitate more fluid and responsive conversations with members of the MDT. Access to both scheduled and unscheduled support from team members should be encouraged.
11. The unit environment should identify or preserve areas to facilitate this activity, promoting activities important to health and wellbeing from a less clinical, and more community orientated setting.
12. Clinical staff working in AC need first-hand knowledge of the hotel or apartment environment, or awareness of the configuration of a young person’s home. Their induction and orientation to AC should include a visit to AC residential settings linked to the hospital. For AC from home, this can be maintained through MDT working, e.g. occupational therapy sharing assessments with the AC nursing team.

13. The proximity of the residential setting to the clinical service is a key consideration when setting up or extending AC services; nearness to clinical assistance if required informs families' capacity and confidence to ambulate.
14. A regular audit cycle of existing service arrangements in place at UCLH is needed as part of AC's assurance framework (for example, that a security officer would accompany a TYA from AC to the hospital if required overnight). Audits should include how these arrangements are communicated and become known among patients and staff.
15. For new AC services, service level agreements should be in place, linked to the wider hospital service delivery and governance frameworks, to delineate responsibilities, clarify accountability and mitigate risks.

Facilities and access to resources:

16. Hospital hotel accommodation, including bathrooms, needs to be fully accessible for wheelchair users, or those with mobility restrictions, without the assistance of a companion.
17. In addition, all AC accommodation should offer adequate means to store and cook simple food to support independence and mitigate a reliance on takeaways or sandwich-based meals.
18. All TYA and companions must be fully informed of available facilities. At UCLH, for instance, these include laundry facilities, or access to a free microwavable evening meal. Equity of access should be promoted, including through a standardised resource package.
19. All young people and families need to be fully informed of available resources or grants to ensure that neither young people nor families are financially disadvantaged through electing for AC.

Workforce:

20. There is a need for a workforce planning model appropriate to TYA AC, that is sensitive to the complexity of care delivery and the requirements of holistic care.
21. Level 2 psychological training is recommended across the NHS to health professionals working in cancer and palliative care, particularly cancer nurse specialists. Since they are in the frontline of working with young people and their companions, this training would benefit all nurses working with TYA in AC.
22. The case for further investment in psych-oncology services has been demonstrated, with access to trained and accredited professionals (level 3) or mental health specialists (level 4) embedded within the TYA AC pathway.
23. It is incumbent upon the TYA community to become more considerate of age-appropriate care as it relates to companions. In addition, this consideration could better address the needs of all those who support TYA in the AC context, whether parents, siblings, partners or friends.
24. Greater focus is needed regarding the education, work, or career aspirations of young people in AC; without defined investment, the configuration of the service could result in this becoming overlooked.
25. Investment in the youth support coordinator role is critical. Youth support coordinators enhance young people’s positive experience of the unit, foster connections, whilst also providing one-to-one psychosocial support.

Companions:

26. An information booklet and/or video that outlines components of companion responsibilities in TYA AC would address the need for clarity about the expectations and boundaries of the role.
27. Companions would benefit from a package of information and support. This should include the offer of psychological support at the point of diagnosis or commencement of treatment in AC. Within an inclusive TYA orientation to

care, this support should take account of the youth of sibling or partner companions.

28. Time apart for TYA and their companions should be promoted to facilitate respite breaks and to create opportunities for staff to engage one-to-one with a young person, and/or provide emotional support for their companion.

9.6.1 Additional considerations for practice

The research findings strongly conveyed psychological benefits associated with remaining independent during cancer treatment, and with time spent away from the clinical setting. Yet, there remains a cohort of patients who are ineligible for AC on account either of clinical status, not being able to converse adequately in English, or lacking a suitable companion. This supports a recommendation that where possible and clinically feasible, TYA inpatients could be enabled to experience some of the articulated benefits of the AC pathway, notably those that relate to autonomy and agency or, on a practical basis, time spent off the ward. For services considering developing their own AC practice, who do not yet have the infrastructure required, this also raises the potential for a hybrid AC model in which portable infusions are used, enabling TYA to spend time off the ward and return to an inpatient bed overnight.

Among those for whom English is a second or additional language, the development of resources for young people and companions in other languages would enhance families understanding and engagement in AC. This would further promote safety, and through making information more fully accessible, it could address residual anxiety among TYA and companions.

Finally, I recommend an executive summary of the research findings (currently underway), to enable clinical services and charity partners to consider their own independent response to this research evidence.

9.7 Recommendations for future research

This thesis highlights several areas for future research relating to patients, workforce and theory.

Patient care and experience:

1. Further exploration, and empirical measurement, of the relationship of AC to young people's wellbeing.
2. In the absence of a dietician's regular involvement in TYA AC at the study site, and in the context of AC promoting an active lifestyle during cancer treatment, research is needed to a) develop a baseline understanding of the nutritional and energy requirements associated with AC and b) appraise nutritional intake and status achieved, and its relationship with clinical outcomes and wellbeing.

Workforce:

3. The identification, appraisal and validation of a nursing establishment tool (workforce planning model) sensitive to the TYA AC context.
4. As a nurse-led service, AC requires a more facilitative style of nursing practice. Research is required to consider in more detail how AC impacts on nurses' professional identities, alongside the enablers and barriers to practising with a more facilitative approach.

Theory:

5. Further research should explore a) the transferability and applicability of key concepts identified in this thesis i.e. autonomy and agency, to other TYA AC research and to other AC settings.
6. Additional research is required to discern whether the alignment in this PhD of AC to assets-based healthcare provides a new framework that can be used as a baseline of theoretical explanation to a) inform the operationalisation of

AC, b) be further evidenced through research inquiry and c) inform the development of a TYA AC conceptual model of care.

Policy:

7. To facilitate local decision making and national commissioning of TYA AC, an economic evaluation is needed to appraise the value of AC to the NHS, patients and families. The methods of evaluation should reflect the full range of costs, for example individual and third-sector costs, embedding a societal perspective.

9.8 Conclusion

As we enter an era of national interest in young people's AC, this research offers the TYA cancer community evidence to inform: a) practice, b) service development, and c) future research inquiry. I conclude this thesis by situating the findings and contribution of the work dynamically, leveraging the research's capacity to inform action.

Ambulatory Care contributes positively to young people's experiences of cancer treatment. It retains aspects of life that are important to young people, whilst fostering their autonomy. Critical to TYA AC experience is maintaining a personal identity within community: as a patient you are anchored in an autonomous space, from which you move out to access care. Informing autonomy is young people's agency, with AC supporting young people to feel and be agentic. Partnership working, preparation and respect for autonomy underpinned by a clinical safety net, informs the operationalisation of this concept. Agency also informs the desire for more dependence; young people remain agentic through exercising a choice not to elect for AC for a course of treatment and instead to assume a more 'cared for' position on the inpatient ward.

The research has evidenced AC's contribution to positive health and wellbeing during cancer treatment. Journeying daily to care creates a requirement to go outside and stay mobile which was reported to help maintain strength, energy levels and support a sense of wellbeing. It creates a demarcation between each day of treatment which was found to feel emotionally progressive. A sense of wellbeing also derived through connections to nature and society, and from feeling anchored in aspects of usual life and relationships. Within this, feeling part of a cancer community and having unrestricted access to the clinical unit and the full complement of the multi-disciplinary team is a critical component of feeling safe, not alone in one's experience, and supported.

Having undisturbed privacy and being less visible to the healthcare team was something that research participants valued most about AC. This creates responsibilities for aspects of clinical monitoring and care, which are typically shared, or may at times rest with the young person's accompanying companion. Young people value and appreciate the opportunity to be accompanied in AC: a positive relationship characterised by togetherness and mutual support. In many cases, AC may not be feasible without a companion's involvement. The research calls for sustained investment in the psychological and psychosocial support of young people receiving treatment in AC, yet also for parents, siblings and partners who must increasingly be seen as an asset and instrumental in supporting delivery of ambulatory cancer care.

For healthcare professionals, caring for patients who are at risk, but well, requires a different kind of clinical vigilance and orientation to care. Moreover, as a nurse-led service AC creates an additional cohort of patients to case-manage. As cancer services grow in demand and complexity, having the right workforce in place to support young people and their families is both critical to experience of care and to a sense of professional fulfilment. This research calls for sustained investment in workforce numbers and skill mix to ensure nurses can meet the holistic care requirements of young people and their companions.

I conclude this thesis positioning AC as an exemplar of assets-based healthcare, that not only aligns with, and reflects the shifting emphasis of healthcare to a more self-managed, community-based model, but as a service that draws on the capacities, assets and agency of young people and their supportive networks, in ways that positively inform experience of cancer treatment. Shifting discourse about AC from concern about whether it meets needs, to assets-based health, recognises the service's transformative qualities from the perspective of patient, family and professional experience. It also focuses concern for health equity and embeds an imperative to assess barriers to young people having a positive experience of AC, with the aim of directing investment of resources to help young people and their companions to realise their assets.

This research provides new evidence, developed with and for the TYA cancer community to support further investment in, and development of, AC. Through leveraging the voices and agency of those with lived experience in shaping the research, it makes significant methodological contributions, identifies implications for practice, improved service development and theory about Ambulatory Care in TYA cancer.

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Appendices

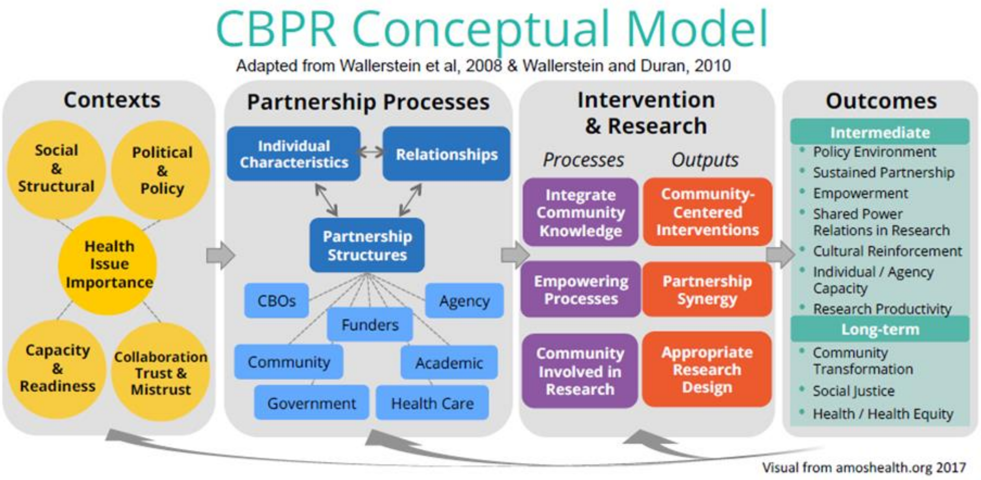
Appendix 1 AC chemotherapy protocols

A summary of the main chemotherapy protocols given in Ambulatory Care at the research site

	Protocol	Chemotherapy Agents	Usual length of stay (nights)
Osteosarcoma	MAP	Methotrexate ‘M’ Cisplatin Doxorubicin (+dexrazoxane) ‘A P’	4-5
	I/E	Ifosfamide Etoposide	5
	OLIE	Ifosfamide Etoposide +/- Lenvatinib	3
Ewings Sarcoma	I/E	Ifosfamide Etoposide	5
	HD Ifos	Ifosfamide	5
Synovial Sarcoma	Dox/Ifos	Doxorubicin Ifosfamide	3
Rhabdomyosarcoma	IVADO	Ifosfamide Vincristine Actinomycin Doxorubicin	2
	IVA	Ifosfamide Vincristine Actinomycin	2
Acute Lymphoblastic Leukaemia (ALL)	UKALL - consolidation	Cyclophosphamide Vincristine PEG asparaginase Cytarbine IT methotrexate	2-week blocks
	UKALL delayed intensification	Dexamethasone Vincristine Doxorubicin PEG asparaginase Cyclophosphamide Cytarabine 6-mercaptopurin	2-week blocks

	Protocol	**Chemotherapy Agents**	**Usual length of stay (nights)**
Acute Promyelocytic Leukaemia (APML)	Arsenic/Atra	Arsenic Tretinoin	5
Acute Myeloid Leukaemia (AML)	**HD-ARAC**	Cytarabine	8
	DA	Daunorubicin Cytarabine	11
	FLA-Ida	Fludarabine Cytarabine Idarubicin	8
	CPX	CPX	5
Hodgkin Lymphoma	**IGEV**	Vinorelbine Gemcitibine Ifosfamide	5
Non-Hodgkin Lymphoma	**R-CYM**	Rituximab Methotreacte Cytarbine IT methotrexate & hydrocortisone & cytarabine	7
	HD MTX	Methotrexate	6
Autologous haematopoietic transplant	**Leam auto**	Lomustine Cytarabine Etoposide Melphlan	7 days conditioning
CAR-T transplant	**Kymriah**	Fludarabine cyclophosphamide	7 days conditioning
Allogeneic haematopoietic transplant	**RIC FMC60**	Fludarabine Campath	7 days conditioning

Appendix 2 Community-Based Participatory Research Conceptual Model



Visual from amoshealth.org 2017

There are four domains of the model:

1. **Contexts** are the social, cultural, economic, political, and other factors that ground partnerships in local, state, or national conditions.
2. **Partnership Processes** are practices for successful partnering. These include: individual characteristics (skills & attitudes academic-community partners bring to the partnership); relationships (how partners make decisions, and interact with each other to achieve goals); and structural features (who are the stakeholders and what are their agreements, values, and guidelines for partnering).
3. **Intervention/Research Designs** are then shaped by the nature of partnering and the extent of equal contribution of knowledge from different partners, including community members, clinicians, health professionals, government, and academic members.
4. **Outcomes** include a range of intermediate system and capacity changes, i.e., new policy environments, sustainability of project and partnership, shared power relations, and increased capacities; as well as long-term outcomes of community and social transformation, health and health equity.

Kastelic *et al.,* (2018, p.80) In: Wallerstein *et al*., (Eds), Community-Based Participatory Research for Health, CA: Jossey-Bass

Appendix 3 Young associate researcher role outline

An invitation to join a research project as a Young Associate Researcher

Hello, I am Alison Finch. I am a cancer nurse and PhD researcher. I am looking for a small group of young people to help with a research project exploring experiences of ambulatory cancer care at University College London Hospitals NHS Foundation Trust.

What is ambulatory cancer care?

Ambulatory Care delivers a range of cancer treatments such as bone marrow transplants and high dose chemotherapy on a day care basis without having to stay in hospital overnight. Eligible patients visit the day care unit each day and sleep either in a hotel or at home (if living within 60 minutes travel time). It's made possible by mobile infusion pumps and by people taking responsibility for some aspects of the care that would typically be undertaken by nurses. We know the service is safe, but we don't know enough about young people's experience of this form of care and whether changes or adaptations are needed – which is why this research is needed.

Who is conducting and funding this research?

This research is funded by Health Education England and The National Institute for Health Research and is being undertaken with University College London. Two charities, CLIC Sargent and the Teenage Cancer Trust, are supporting this research project.

What is the purpose of the role?

As a Young Associate Researcher, you'll play a key role in developing this research and making sure it's creative, relevant and has impact: by that I mean it makes a difference. Crucially, you'll ensure the voices of young people who have experienced cancer are heard in every stage of the research itself.

What's involved?

If you join us, you will become a member of a Community-of-Inquiry - a group of previous young patients, family members, academics, clinicians and CLIC Sargent and Teenage Cancer Trust representatives. You'll be collaborating on a 2-year research project exploring young people's experiences of ambulatory care. At the start, you'll be advising on the research priorities and questions. Depending on your interests, you might then be:

- Advising on and testing research methods and tools
- Carrying out primary research activities including research interviews
- Helping to interpret findings
- Joining me to present and promote the research findings nationwide

What is the commitment?

You will ideally feel able to commit to being part of the project for at least a year. You'll be able to attend a meeting in London 2-4 times a year, and to engage periodically via an online platform. You will be sharing this role with 4-5 other young people. Working together you will make sure that at least two of the group can attend meetings, representing one another where needed.

Who can apply?

We're looking for a small group of around six young people aged 16-24 who have experience of cancer and have received treatment in the last three years. You may have received some of your care on an ambulatory basis, but you do not need experience of this pathway to be eligible.

What skills or experience do I need?

The only thing you'll need is an interest in research and a passion to make the voice of young people with cancer heard.

What can I expect from the role?

You will receive 1-2 days training to prepare you for your role as a Young Associate Researcher within the Community-of-Inquiry. You'll receive ongoing training on qualitative research methods and the ethics of research. You'll also form part of a team of young people like yourself, alongside professionals and academics who are passionate about understanding the support needs of people living with cancer. You will have the opportunity to work with leading academics, professionals, CLIC Sargent and Teenage Cancer Trust staff.

Overall, the project will give you valuable skills and experience for your future. Importantly, you will help shape how care is delivered to young people with cancer in the UK.

What other details do I need to know?

The research project runs from January 2020 to December 2021. Ideally, you'll be available for a couple of hours a month to contribute remotely to the group, with 2-4 face-to-face meetings each year. You can be based anywhere in the London/South East/Midlands/South Wales region. Ideally you can travel to London occasionally (with standard travel expenses and refreshments covered).

How do I apply for this opportunity?

If you’re interested in finding out more about being a Young Associate Researcher, an unpaid voluntary role, please contact:

If you’re feeling unsure whether this might suit you or have any questions, just send me an email so we can chat informally about the role.

Appendix 4 Working agreement for engagement

Principles for engagement

This agreement sets out our shared expectations for the research, creating a respectful environment that values the contribution of all Community-of-Inquiry members.

1. **Respect for each person's expertise, knowledge, skill and personality**

- Every voice matters
- We listen to one another
- We respect everyone's contribution
- We value each member's expertise equally

2. **Confidentiality is maintained where it is needed**

- We treat people's personal information with care and respect
- We consider what we share about our role publicly, in person or online
- We take care to balance the value of communicating the research with lawful management of personal data

3. **Every effort is taken to maintain a safe, trusted space**

- We are honest in our communication with one another
- We are open to the extent that we feel comfortable
- We don't expect others to disclose information that we would not be prepared to disclose ourselves
- We avoid making assumptions about one another
- We keep the detail of the group's conversation private by sharing themes and topics only with others

4. **We make time to reflect on our contribution and its impact on the research**

- We take time to reflect on the knowledge, preconceptions and biases that we bring to the research
- We actively discuss our ideas, learning, progress and its impact on the research
- We value the principle of reciprocity and opportunity to gain personally from being involved

Appendix 5 Co-researcher training

Details of the preparatory co-researcher 'training' workshops

Workshop Number	Focus of workshop
Workshop 1	Principles and practice of community-based participatory research (principles revisited, refining the study design, re-confirming interests and roles).
Workshop 2	Introduction to visual methods (images as data theory and practice, analysing visual data, practical exercise sharing and interpreting personal photographs in pairs). A video accompanied this workshop which was developed for the Community-of-Inquiry by visual and creative researcher Nicole Brown.
Workshop 3	Art of interviewing (introducing the topic guide, structuring an interview, interviewer/interviewee safety, practical exercise interviewing in pairs). The interviewing exercise involved sharing a photo that represented an aspect of our experience of the pandemic, which was used explore the proposed photo-guided interview approach.
Workshop 4	Building confidence in interviewing (use of techniques such as an invitational tone, pause, and punctuation)
Workshop 5	Research ethics (informed consent, confidentiality, anonymity, handling personal information, self-disclosure, self-care and support)

Appendix 6 Reward and recognition framework

Recognising involvement: a guidance document

This guidance outlines the recognition and reward framework for the following research study: *Experiences of delivering and receiving ambulatory cancer care: Community-Based Participatory Research to inform teenage and young adult cancer services.* The involvement of lay and professional co-researchers is a central feature of the study design.

The research brings together a community of young people, parents and professionals who are actively involved in each stage of the research, volunteering their time. Known as a *Community-of-Inquiry*, the group meets throughout the research project. Alongside this, members take on additional research roles and responsibilities.

The research organisers commit to ensuring that relevant and timely recognition is given to the contribution of community members on a fair and equitable basis. They also commit to ensuring no one is financially disadvantaged by taking part, and that members' involvement feels meaningful and of value. All contributions from young associate researchers and associate researchers will be acknowledged. This may be through offering recognition, certification, a development opportunity, or reward. It may also involve (with informed consent) sharing how these contributions have shaped the research and its outcomes.

Professionals, who contribute to the research on a voluntary basis in their free time outside of working hours, will be offered the same recognition for their involvement.

This recognition framework has been developed following consultation with Community-of-Inquiry members. It also takes account of the National Institute for Health Research (NIHR) reward and recognition guidance. This research is funded by Health Education England and the NIHR, grant reference ICA-CDRF-2018-04-ST2-034. The grant makes financial provision for the fulfilment of this framework.

Principles & our commitment to co-researchers

It is hoped that being a part of the research project will feel a rewarding experience. Given the voluntary nature of the Community-of-Inquiry role, time contributed cannot be remunerated per hour given. Other approaches are used to thank and acknowledge member contributions.

Apart from the reimbursement of out-of-pocket expenses (e.g. travel), e-vouchers for John Lewis or Amazon will be used. Co-researchers will be asked their preference by the Principal Investigator, in advance of a voucher being organised.

Other forms of acknowledgement may also be offered, for example: participation in learning opportunities and training courses, certification, references (highlighting knowledge and skills gained) and inclusion in research publications. The levels of recognition and reward used will be clarified as far as possible in advance of the participation activity.

The research does not want to exclude a member of the Community-of-Inquiry because they do not have the means to participate (e.g. access to a mobile phone or computer). Co-researchers are encouraged to discuss anything that makes it difficult to be involved with Alison, the Principal Investigator in confidence.

Co-researchers will not be required to cover out-of-pocket expenses. Any training requirements will be at no cost to *Community-of-Inquiry* members.

Examples of activities and recognition offered

Activity	Recognition offered
Participation in a Community-of-Inquiry meeting or training workshop.	£35 voucher for between 2–4-hour involvement £75 voucher for a full day
Reviewing documents, literature or other research material. Engaging in data analysis.	£25 voucher per activity (with an indicative time commitment of up to 3 hours £50 voucher per activity (with an indicative time commitment of around 6 hours, either in 1 session or across 2/3 sessions)
Field work: organising and conducting interviews.	£35 voucher per interview
Communicating the research: producing information in different formats, writing for publication, blogs, meetings with charitable partners, presenting, giving interviews	£25 voucher per activity (with an indicative time commitment of up to 3 hours £50 voucher per activity (with an indicative total time commitment of around 6 hours)

Travel and accommodation

The Principal Investigator will book travel and accommodation at no cost to a member. For organised day, and half day activities, meals and refreshments will be either provided or reimbursed to members by the Principal Investigator, where possible on the same day costs are incurred.

The examples of activities are not exhaustive. The value of vouchers offered will be used to guide how other activities are acknowledged. Co-researchers are advised that if in receipt of state benefits, any payment of fees and expenses may affect a benefit claim. For free, confidential advice Community-of-Inquiry members can contact the Benefits Advice Service for involvement. In relation to this and other matters, you may also find it useful to refer to INVOLVE's guide: What you need to know about payment: An introductory guide for members of the public who are considering active involvement in NHS, public health or social care research (2011).

Appendix 7 PRISMA-SCR Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	54
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	55-61
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	53-55
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g. population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	55
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g. a Web address); and if available, provide registration information, including the registration number.	Not registered
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g. years considered, language, and publication status), and provide a rationale.	61

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Information sources*	7	Describe all information sources in the search (e.g. databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	58
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix 12
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e. screening and eligibility) included in the scoping review.	60-61
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g. calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	60-61
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	n/a
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	54
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	56, 60-61
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	63
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Appendices 13 & 14

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	n/a
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	65-86
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	65-86
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	65-86
Limitations	20	Discuss the limitations of the scoping review process.	88-90
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	86-88
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Click here to enter text.

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g. quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

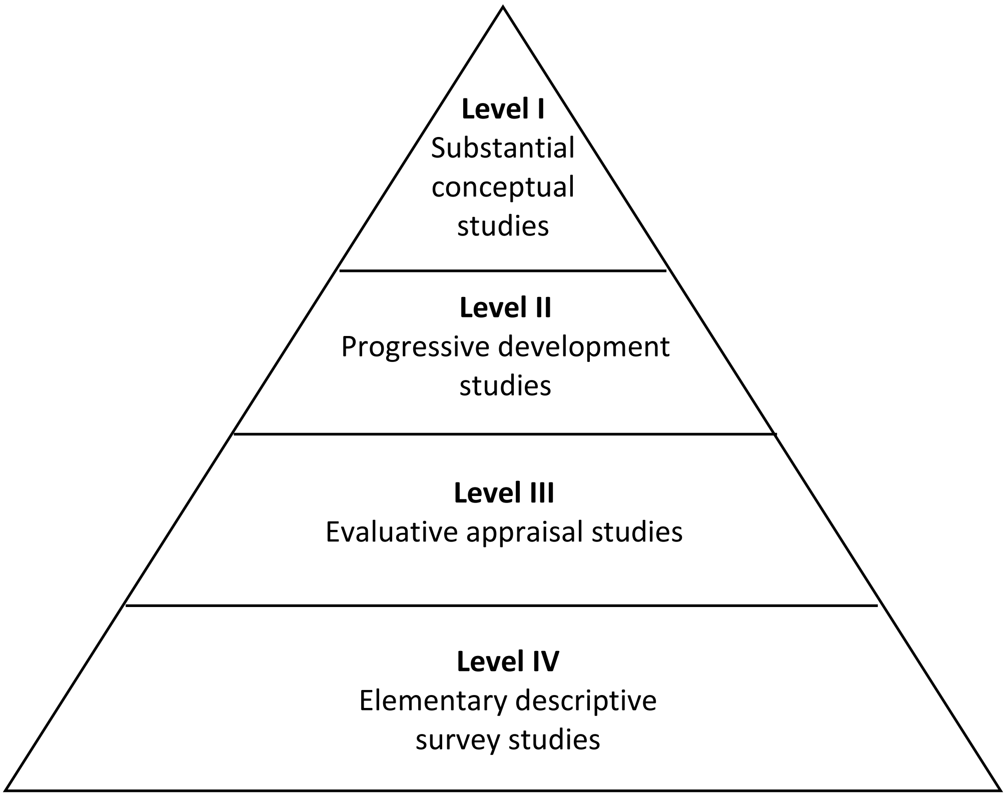
‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g. quantitative and/or qualitative research, expert opinion, and policy document).

Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, *et al.* (2018) PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. *Ann Intern Med*. 169:467–473. doi: 10.7326/M18-0850.

Appendix 8 A hierarchy of scoping review inquiry

Critical appraisal of scoping: a hierarchy of levels of inquiry in nursing related scoping studies



Reproduced from: Davis, K., Drey, N., & Gould, D. (2009) What are scoping studies? A review of the nursing literature. *International journal of nursing studies*, 46(10): 1386–1400

Appendix 9 Scoping Review Framework

	Arksey and O'Malley framework (2005, p. 22-23)	**Enhancements proposed by Levac et al. (2010, p. 4-8)**	***Enhancements proposed by Peters et al (2015, 2017, 2020)**
1.	Identifying the research question	Clarifying and linking the purpose and research question	Defining and aligning the objective/s and question/s
2.	Identifying relevant studies	Balancing feasibility with breadth and comprehensiveness of the scoping process	Developing and aligning the inclusion criteria with the objective/s and question/s
3.	Study selection	Using an iterative team approach to selecting studies and extracting data	Describing the planned approach to evidence searching, selection, data extraction, and presentation of the evidence.
4.	Charting the data	Incorporating a numerical summary and qualitative thematic analysis	Searching for the evidence
5.	Collating, summarising and reporting the results	Identifying the implications of the study findings for policy, practice or research	Selecting the evidence
6.	Consultation (optional)	Adopting consultation as a required component of scoping study methodology	Extracting the evidence
7.			Analysis of the evidence
8.			Presentation of the results
9.			Summarizing the evidence in relation to the purpose of the review, making conclusions and noting any implications of the findings

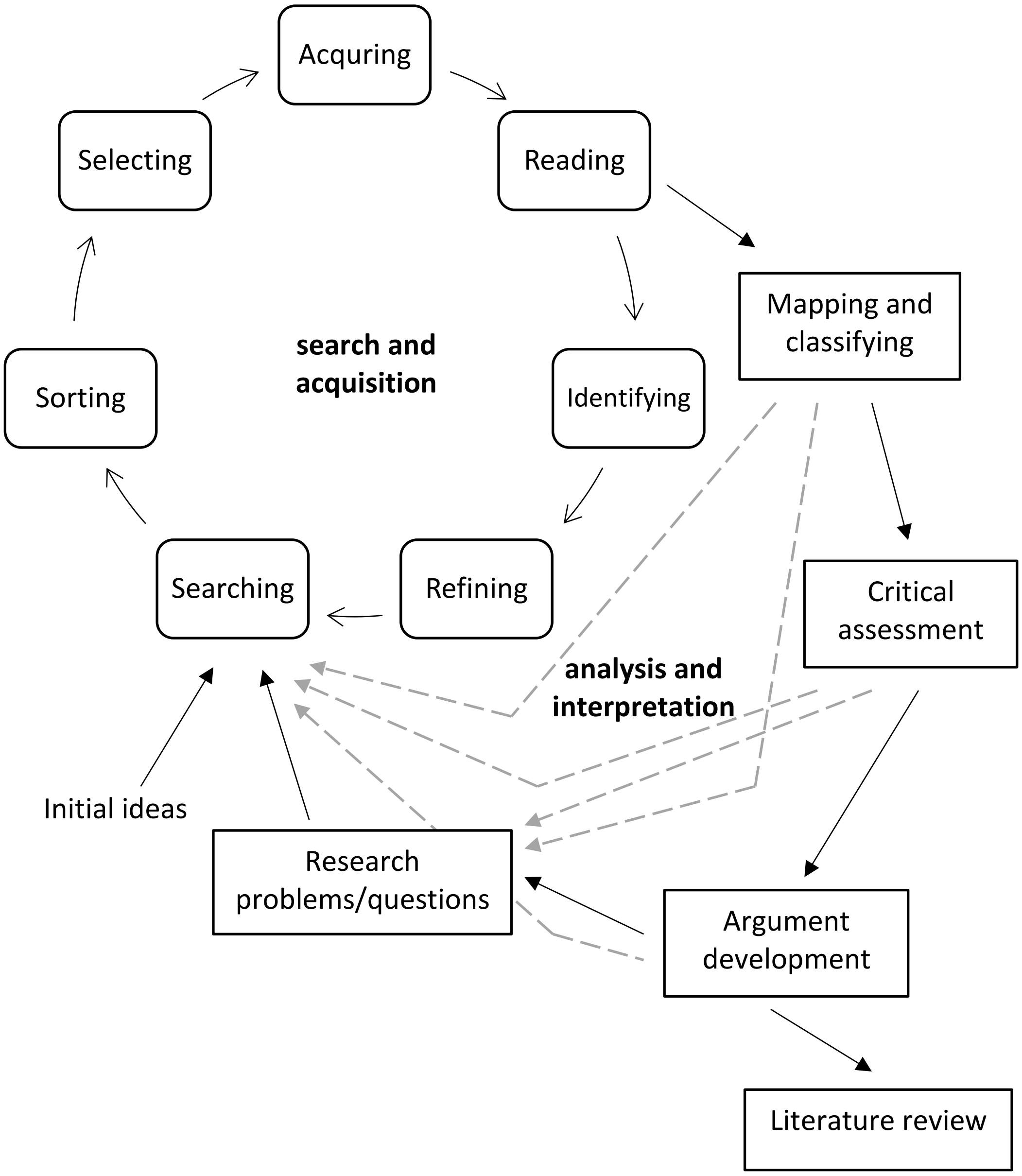
Reproduced from: Chapter 11.1.3 The Scoping Review Framework In: Peters, M.D.J., Godfrey, C., McInerney, P., Munn, Z., Tricco, A.C., Khalil, H. (2020 version) Chapter 11: Scoping Reviews In: Aromataris, E., Munn, Z. (Editors) JBI Manual for Evidence Synthesis. https://jbi-global-wiki.refined.site/space/MANUAL/4687752/11.1.3+The+scoping+review+framework

Appendix 10 Roles of stakeholders who engaged in consultation

Role
Consultant Haematologist, UCLH
Matron, Adult Day Care and Ambulatory Care service, UCLH
Matron, TYA cancer service, UCLH
Specialist pharmacist, formerly of UCLH
Emeritus Professor of Nursing, New York
Consultant Oncologist, UCLH

Appendix 11 A hermeneutic framework

A hermeneutic framework for the literature review process



Reproduced from Boell, S. K., & Cecez-Kecmanovic, D. (2014). A Hermeneutic Approach for Conducting Literature Reviews and Literature Searches. Communications of the Association for Information Systems, 34, pp-pp. https://doi.org/10.17705/1CAIS.03412

Appendix 12 Search terms used across the nine databases

1. Ovid Medline Database: MEDLINE(R) ALL

Ovid MEDLINE(R) ALL <1946 to 2022 April 22>

1. (ambulatory adj2 care).tw
2. outpatient administration.tw
3. out-patient administration.tw
4. hotel based.tw
5. 1 or 2 or 3 or 4
6. haematology.tw
7. hematology.tw
8. oncology.tw
9. cancer.mp or neoplasms/
10. 6 or 7 or 8 or 9
11. 5 and 10
12. 11 not (palliat* or surg* or urolog*).mp

2. CINAHL Plus Database: CINAHL Plus

Source of information for the professional literature of nursing, allied health, biomedicine, and healthcare. Date of most recent search: *22 April 2022*

S1. MM ambulatory care

S2. SU ambulatory care nursing

S3. AB outpatient administration

S4. AB home based

S5. S1 OR S2 OR S3 OR S4

S6. SU cancer

S7. AB oncology OR AB haematopoietic transplant* OR AB hematology OR AB (haematology or h#emato-oncology OR h#ematopoetic stem cell transplant*)

S8. S6 AND S7

S9. S5 AND S8

S10. SU breast cancer

S11. AB prostate cancer

S12. SU (palliative care OR end of life care)

S13. S10 OR S11 OR S12

S14. S9 NOT S13

S15. SU prophylaxis or prevention OR prophylactic

S16. S14 NOT S15.

3. SCOPUS

Multi-disciplinary database. Date of most recent search: *22 April 2022*

(TITLE (ambulatory W/4 care) OR TITLE ({outpatient administration}) AND TITLE-ABS-KEY (cancer))

4. EMBASE (via Ovid) Database: Embase

Comprehensive biomedical and pharmacological database. Embase <1974 to 22 April 2022>

1. Ambulatory care mp. OR *outpatient treatment/
2. (ambulatory adj2 care). tw.
3. outpatient administration.tw
4. out-patient administration.tw
5. (hotel adj1 based).tw.
6. 1 or 2 or 3 or 4 or 5
7. haematology.tw
8. hematology.tw
9. oncology.tw
10. cancer.mp or neoplasms/
11. 7 or 8 or 9 or 10
12. 6 and 11
13. 12 not (palliat* or surg* or urolog*).mp

5. WEB OF SCIENCE: WOS (Core Collection)

Database containing scholarly journals, books, and proceedings in the sciences, social sciences, and arts and humanities. WOS (Core Collection) Date of most recent search*: 22 April 2022*

((mainsubject (cancer) AND ab ((ambulatory NEAR/1 care OR outpatient NEAR/1 administration OR out-patient NEAR/1 administration OR ambulatory))) NOT palliat*) NOT surg*

6. BNI (British nursing Index), (ProQuest)

Date of most recent search*: 22 April 2022*

((mainsubject (cancer) AND ab ((ambulatory NEAR/1 care OR outpatient NEAR/1 administration OR out-patient NEAR/1 administration OR ambulatory))) NOT palliat*) NOT surg*

7. PsycINFO (Ovid) Database: APA PsycInfo

Index of literature in psychology and psychological aspects of related disciplines. Database: APA PsycInfo <1806 to 2022 April 22>

1. ambulatory care.mp. OR Outpatient Treatment/
2. (ambulatory adj1 care).tw
3. (outpatient adj1 administration).tw
4. (out-patient adj1 administration).tw
5. ambulatory.ti

6. 1 or 2 or 3 or 4 or 5
7. cancer.mp or neoplasms/
8. 6 and 7
9. 8 not palliat*.ti.
10. 9 not surg*.ti.

8. ASSIA: Applied Social Sciences Index and Abstracts (ProQuest)

ASSIA covers the literature of health, social services, psychology, sociology, economics and politics. Date of most recent search*: 22 April 2022*

(noft("ambulatory NEAR/1 care" OR "outpatient*" OR "out patient*") OR MAINSUBJECT.EXACT("ambulatory health care") OR MAINSUBJECT.EXACT("outpatient treatment")) AND (MAINSUBJECT.EXACT ("cancer") OR MAINSUBJECT.EXACT ("haematology") OR noft(cancer* OR h?matolog*)) NOT (noft(palliat* OR surg*))

9. IBSS: International Bibliography of the Social Sciences (ProQuest)

Index of literature in the social sciences and related subjects. Date of most recent search*: 22 April 2022*

((mainsubject.Exact("ambulatory care facilities" OR "ambulatory care" OR "ambulatory medical care" OR "ambulatory health care") OR ti(ambulatory OR outpatient OR out-patient) AND su(cancer) NOT ab((palliat* OR surg* OR emergency OR HIV OR tuberculosis))) NOT ti(abortion OR pregnancy)) NOT ti(alcohol OR diabet* OR cardiac OR asthma OR respiratory OR obesity OR suicide OR dental OR substance misuse OR abortion)

Appendix 13 Characteristics of data papers included in the scoping review

(most recent first)

	Author (Year)	**Country of origin**	**Study methodology & design**	**Study population**	**Outcomes measured**	**Key findings reported**
Primary research	Mcmonagle (2015)	UK	Qualitative interview; three time intervals; phenomenological approach	8 adult participants with a mean age of 58 (range 35-67) undergoing Melphalan or LEAM (lomustine, etoposide, cytarabine, melphalan) autograft in Ambulatory Care *Lymphoma (n=5) and Multiple Myeloma (n=3)*	Patient experience	Patients appreciated the privacy that Ambulatory Care afforded. Initially most unaccompanied patients were content to stay on their own, but their need for companionship increased as they became more unwell. Often patients could recognise when they required hospital admission to complete treatment.
	Nissim *et al.* (2014)	Canada	Qualitative interview; grounded theory	35 adult participants with median age of 49 (range 26-71) *Acute Myeloid Leukaemia*	Perceptions of experience during transition from inpatient to ambulatory care.	Participants described adjusting to the intensity of Ambulatory Care and the need to assume greater responsibility for their care. They reported a focus on understanding their long-term

	Author (Year)	Country of origin	Study methodology & design	Study population	Outcomes measured	Key findings reported
Primary research				Consolidation chemotherapy delivered on an ambulatory basis		care plan, compared to a focus on the present time.
	Morrison (2010)	USA	Qualitative interview	21 registered nurse participants *Cancer population*	Adult nurses' experiences of delivering Ambulatory Care	Identified five themes reflecting expert ambulatory nursing practice: being a content expert; creating positive relationships; listening with attuned skill; advocating for the patient; and developing long-term patient/family relationships.
	Statham (2005)	UK	Interpretive phenomenology using qualitative interview	7 adult participants with mean age of 50 (range 40-63) *Lymphoma* BEAM (BCNU, etoposide, cytarabine, melphalan) autograft	Patient experience	Treatment in Ambulatory Care is an empowering experience, which facilitates the implementation of various coping mechanisms such as an increased level of patient control, greater normality and privacy. Results revealed that the *importance of relationships* was

	Author (Year)	Country of origin	Study methodology & design	Study population	Outcomes measured	Key findings reported
Primary Research						the most dominant theme, in particular family and friends. A supportive social network, personal commitment and motivation were found to be essential prerequisites for a positive ambulatory experience.
	Grimm *et al*. (2000)	USA	A longitudinal, descriptive study to compare the emotional responses and needs of the caregivers of patients who undergo bone marrow transplantation in an inpatient-outpatient with those in an inpatient setting. Data were collected at six	43 caregivers were selected, n=26 from the inpatient unit and n=17 from the ambulatory setting *Haematological malignancy* Patients undergoing either autologous or allogeneic bone marrow transplantation	Emotional responses were measured by the Profile of Mood States. The importance and satisfaction of information, patient care, and psychological needs were assessed by a Caregiver Needs Survey.	Findings support the inpatient-outpatient model of care as being less emotionally distressing for and better meeting the needs of family caregivers. Specific implications for practice include the importance of caregiver education.

	Author (Year)	Country of origin	Study methodology & design	Study population	Outcomes measured	Key findings reported
Primary Research			points across the BMT trajectory, from before the procedure to 12 months after.			
	Tighe *et al*. (1985)	USA	A conceptual framework of ambulatory care nursing activities was used to help describe the role of the oncology and non-oncology nurse at a large federal hospital.	84 questionnaires were given to nurses with a 60% response rate *26% of participants were oncology nurses, the remaining 74% were classified as 'non-oncology*. Type of treatment not stated	A self-report questionnaire based on the conceptual framework was developed to obtain information about nursing practice. Respondents indicated the frequency they had engaged in individual activities.	Oncology nurses engaged in greater involvement in therapeutic care and communication activities within the ambulatory cancer setting compared with non-oncology nurses.
Retrospective studies	Li *et al*. (2021b)	USA	Retrospective chart review of 253 cycles of high-	118 adult patients *Acute Myeloid Leukaemia*	Safety, feasibility, bed days saved and	No patients required hospitalisation during chemotherapy.

	Author (Year)	Country of origin	Study methodology & design	Study population	Outcomes measured	Key findings reported
Retrospective studies			dose and intermediate dose cytarabine given at a shorter time interval to facilitate administration as an outpatient	Cytarabine given in a shorter interval of every 10hr instead of 12 hrs	need for hospitalisation	43 (36%) patients required hospitalisation following admission, most commonly due to neutropenia. Report 1265 bed days saved, and significant income generated.
	Li *et al*. (2021a)	USA	Retrospective chart review of 193 cycles of dose-adjusted EPOCH (etoposide, prednisone, vincristine, cyclophosphamide, doxorubicin) given via an ambulatory infusion pump on an outpatient basis.	219 cycles of dose-adjusted EPOCH were given to 56 patients with a diagnosis of *B-cell lymphoma* with 193 cycles administered in the outpatient setting.	Safety, financial analysis and bed days saved	No patients required hospitalisation during outpatient administration of resulting in 965 saved hospital days. There were 26 inpatient cycles administered with the most common reason for inpatient administration being close monitoring required for tumour lysis syndrome. 23 patients required 40 hospital admissions between cycles, most commonly due to neutropenia. Safety reported alongside financial profits.

	Author (Year)	**Country of origin**	**Study methodology & design**	**Study population**	**Outcomes measured**	**Key findings reported**
Retrospective studies	Fridthjof *et al.* (2018)	Denmark	Retrospective review of 177 ambulatory care chemotherapy courses. Service coordinated by a hospital with patients residing at home.	84 patients aged 20-74 years (median age = 46-58) *Acute myeloid leukaemia, acute lymphoblastic leukaemia, non-Hodgkin lymphoma, Hodgkin lymphoma* Induction and consolidation chemotherapy	Safety, ability to undertake self-care requirements using a portable programmable infusion pump	Homebased Ambulatory Care is safe and frees up in-hospital beds for patients in need. Safe use of portable programmable infusion pumps demonstrated, and improved patient experience suggested. Authors indicated a national implementation study in six regional centres in Denmark to investigate the feasibility of portable infusion pumps and homecare based advanced chemotherapy in AML was planned.
	Villegas *et al.* (2017)	Argentina	Retrospective analysis of ambulatory High Dose Methotrexate (HDMX) during April 2007 to December 2010.	Children aged 7 to 17 years (mean age = 12.6) *High grade osteosarcoma* HDMTX administration with oral hydration,	Feasibility, safety	Successful ambulatory administration was defined as the lack of need for hospital admission within the first 24 hours after HDMTX administration. 91.2% of treatments were successfully completed on an ambulatory basis demonstrating

	Author (Year)	**Country of origin**	**Study methodology & design**	**Study population**	**Outcomes measured**	**Key findings reported**
Retrospective studies			150 of 447 courses of HDMTX (31.4%) were given on an outpatient basis among 24 patients.	alkalinisation, and leucovorin rescue		feasibility and safety in a less well resourced population.
	Reid *et al*. (2016)	USA	Retrospective chart review of 58 patients who received BCNU, etoposide, cytarabine, melphalan (BEAM) conditioning on an outpatient basis, compared to a prior cohort of 49 patients who received inpatient BEAM conditioning	Outpatient cohort mean age 58 years. Inpatient cohort mean age 59 years *Hodgkin or non-Hodgkin lymphoma* BEAM chemotherapy prior to autologous hematopoietic stem cell transplantation	Feasibility, cost, complications, and clinical outcomes	Length of hospital stay reduced by 6 days for the outpatient (OP) cohort resulting in cost savings. Fewer complications, infections and toxicities occurred in the OP cohort. Authors conclude a likely improvement in patient satisfaction and quality of life associated with AC pathway.

	Author (Year)	Country of origin	Study methodology & design	Study population	Outcomes measured	Key findings reported
Retrospective studies	Graff *et.al*. (2015)	USA	Retrospective cohort study of 230 patients who underwent autologous hematopoietic cell transplantation for myeloma or lymphoma (135 inpatient and 95 outpatients).	In the outpatient cohort, aged 21-76 years, 66.3% had *myeloma* and 33.7% had *lymphoma*. (median age 59yrs)	Toxicities and adverse events. Transplant outcomes	With daily evaluation and supportive care outpatient transplantation can result in acceptable toxicity and good clinical outcomes. The impact of outpatient on quality of life requires additional study from perspective of patient and family. Acknowledges the requirement for a companion to take responsibility for a patient.
	Sive *et al.* (2012)	UK	Retrospective analysis of data from 1443 AC patient episodes across 6-year period 2005-2011	Patients aged 18-79 years (median age 41 years) *Haematological malignancies (82%), Sarcoma (17%)* Among the 1443 admissions to ambulatory care, 1203 were for administration of chemotherapy, haematopoietic	Safety, feasibility, and hospital capacity management	Creation of bed capacity described as a driver. Safety and efficiencies of pathway demonstrated. Report anecdotal patient feedback had been generally positive, with appreciation for less time spent on the ward and more with family members.

	Author (Year)	**Country of origin**	**Study methodology & design**	**Study population**	**Outcomes measured**	**Key findings reported**
Retrospective studies				stem cell transplant or monitoring of neutropenia		
	Solomon *et al*. (2010)	USA	Retrospective review of 100 consecutive patients who underwent a matched-related donor myeloablative allogeneic haematopoetic stem cell transplant (HSCT) on an ambulatory basis between January 2000 to February 2006. Patients were required to have a caregiver with	Patients aged 21-64 years (median age 44 years) *Haematological malignancies* Haemopoietic stem cell transplant	Safety, need for hospitalisation, clinical outcomes	Outpatient myeloablative allogeneic HSCT with expectant in-patient management can be accomplished safely. Advances in supportive care medications have made transplant possible on an outpatient basis. Safety and efficiencies of pathway demonstrated. Authors suggest efforts to decrease hospital utilisation may translate into improved patient satisfaction and quality-of-life, reduced exposure to nosocomial pathogens, lower costs and reduced pressure on available beds.

	Author (Year)	Country of origin	Study methodology & design	Study population	Outcomes measured	Key findings reported
Retrospective studies			them available on a 24hr basis.			
	Mahadeo *et al*. (2010)	USA	Retrospective analysis of 97 ambulatory HDMTX administrations amongst 12 patients	Patients aged 7 to 22 years with a mean age of 15 years *High grade osteosarcoma* HDMTX	Safety, feasibility, and cost of outpatient administration	99% of AC admissions (n=97) were successfully completed demonstrating safety, feasibility and cost-effectiveness, whilst improved quality-of-life suggested.
	Bakhshi, *et al* (2009)	India	Retrospective review to assess the outcomes of 90 cycles of Acute myeloid leukaemia consolidation given to 30 patients between July 2003 and July 2007	Children aged 1.5-15 years (mean age 8) *Acute myeloid leukaemia* High dose cytosine arabinoside consolidation	Safety, feasibility	Among 69 cycles given on an outpatient basis, 44 cycles managed entirely on an AC basis, 25 cycles required readmission to hospital (36.2%) associated with febrile neutropenic episodes or documented infections. Increasing attention to quality of life and to healthcare costs, bigger demand for existing inpatient resources, and high risk of severe multi-resistant infections seen as a driver for

	Author (Year)	**Country of origin**	**Study methodology & design**	**Study population**	**Outcomes measured**	**Key findings reported**
Retrospective studies						the service. Avoiding delays in treatment due to bed capacity regarded a benefit. Outpatient chemotherapy is safe and resulted in a shorter duration of febrile neutropenia.
	Zelcer *et al*. (2008)	USA	Retrospective review of 708 chemotherapy cycles during 6-year period 1996-2002	82 children and young people aged 6-32 (median age 16 years) *High grade osteosarcoma* HDMTX	Safety and feasibility	82% were successfully completed as an outpatient demonstrating ambulatory pathway is safe and feasible.
	Rosen and Nirenberg (1982)	USA	Review of experience delivering HDMTX on an ambulatory basis among 5000 treatments during 5-year period 1977-1982	Adult and adolescent oncology *High grade osteosarcoma* HDMTX	Safety and feasibility	Outpatient administration of high-dose methotrexate (HDMTX) was safe, and often safer if delivered in an outpatient setting as patient and family members were often more diligent undertaking the monitoring required.

	Author (Year)	**Country of origin**	**Study methodology & design**	**Study population**	**Outcomes measured**	**Key findings reported**
						Reduced cost of treatment a benefit of the service.
Quality improvement and service evaluation	Ranney *et al.* (2020)	USA	Quality improvement project: Home ambulation following high dose methotrexate delivered in hospital for Acute Lymphoblastic Leukaemia amongst 10 patients who completed a total of 38 chemotherapy cycles, A Quality-of-Life (QOL) mixed-methods survey was administered to patients and	Age range: 2 to 16 years with a mean age of 7 years *Acute Lymphoblastic Leukaemia* HDMTX	Outcomes measured: laboratory results of renal function and medication clearance, length of hospitalisation, and family-reported quality of life	Project sought to improve the QOL for patients and their families during period post HDMTX infusion without compromising safety. Families reported that measured Quality of Life improved in most domains with family time and sleep having largest improvement, while level of stress remained the same (completion rate 50% = 5 families). The opportunity to use families' developed support system, coping skills, and connection to friends and family reported.

	Author (Year)	Country of origin	Study methodology & design	Study population	Outcomes measured	Key findings reported
Quality improvement and service evaluation			their caregiver to measure concepts related to QOL			
	Beaty, R. *et al*. (2015)	USA	A quality improvement project to establish a process for the administration of vincristine, dactinomycin, and cyclophosphamide (VAC) chemotherapy in the outpatient setting to improve patient satisfaction and reduce costs.	7 patients aged 1-16 years (median age of 8.5 years) who received 31 cycles of outpatient VAC The majority of patients were male (n=6) *Rhabdomyosarcoma* Vincristine, dactinomycin, and cyclophosphamide (VAC) chemotherapy	Caregiver satisfaction and cost	Alongside clinical outcomes patient and caregiver satisfaction was measured via a modified Likert scale survey (parental proxy reporting). 100% of patients reported they prefer outpatient over inpatient administration. Reduced costs seen as a driver for pathway alongside the release of inpatient beds for other patients.

	Author (Year)	Country of origin	Study methodology & design	Study population	Outcomes measured	Key findings reported
Quality improvement and service evaluation	Brown and Walker (2016)	UK	A service evaluation exploring different stakeholder perspectives of AYA ambulatory care via focus group, a claims, concerns and issues exercise with nurse specialists (n=unknown), questionnaires to nursing staff (n=14) and doctors (n=5).	Age range 13-24 years (age of participants not stated) *Adolescent and Young Adult Cancer* Focus group participants: patients n=3, carers n=2 Type of treatment not stated	Experience	Stakeholders identified opportunities for Ambulatory Care to empower TYA patients as a result of the pathway which enables young people to get involved and take more responsibility for their care, whilst living as normal a life as possible. The potential for anxiety associated with the pathway was acknowledged.
Literature review	Richie (2005)	UK	Described as a 'mini-review', the aim of the literature search was to assess whether	Four databases searched, 10 references screened by abstract, and four studies were	Bed occupancy and morbidity	Limited bed capacity a driver for shift to ambulatory pathways. Studies included were from the United States and Canada where the cost of AHSCT was a driver

	Author (Year)	Country of origin	Study methodology & design	Study population	Outcomes measured	Key findings reported
			outpatient autologous haematopoetic stem cell transplant (AHSCT) in as effective as inpatient.	included in the review		for the outpatient (ambulatory) model. Availability of care giver support may affect feasibility. A perception that ambulatory AHSCT offers better Quality of Life but little evidence available to support this.

Appendix 14

Characteristics of discussion papers included in the scoping review

(most recent first)

Author Year Name and title of publication	**Country of origin**	**Topic**	**Patient population**	**Salient points raised that relate to the scoping review question**
Borogovac *et al*. (2021)	USA	Safety and feasibility of outpatient chimeric antigen receptor CAR-T cell therapy on an outpatient basis	Adult haematology	The potential for CAR-T cell therapy services to be planned on an outpatient basis from inception.
Cunningham *et al*. (2021)	USA	Nursing's role in supporting CAR-T cell therapy on an outpatient basis	Not specified	Describe the nurses' role as critical to the service and that outpatient tisagenlecleucel administration is preferred by patients, supports an increased level of activity, better nutrition, and decreased exposure to infectious organisms compared with inpatient admission.
Myers *et al.* (2021)	USA	Perspectives on outpatient administration of CAR-T cell therapy	Adult haematology	Outpatient CAR-T cell therapy can be feasible and safe with policies, procedures and governance arrangements in place. Expansion of CAR-T cell therapy on an outpatient basis is likely as expertise develops.

Author Year Name and title of publication	**Country of origin**	**Topic**	**Patient population**	**Salient points raised that relate to the scoping review question**
Pirschel (2019)	USA	Explores the role of the oncology nursing in ambulatory care.	Adult cancer	Ambulatory Care helps make sure patients are not defined by their cancer diagnoses. It is an evolving field: new treatments are moving from the inpatient to ambulatory setting. The need to focus on carer givers as well as patients. Improved QoL positioned as a key driver for the service.
Comerford and Shah (2019a)	UK	Explores the practicalities of starting, staffing and managing an ambulatory cancer service.	Adult haematology and oncology	Ability to increase bed capacity across a cancer service a driver and benefit of Ambulatory Care whilst avoiding treatment delays. The benefit to patients' experience should remain the priority when implementing the pathway.
Comerford and Shah (2019b)	UK	Explores ambulatory care as a nurse-led service, alongside importance of team collaboration. Describes eligibility criteria and safety features of the service.	Adult haematology and oncology	Suitability for AC should be reviewed on a case-by-case basis. The role of the nurse as critical to running an AC service. Educating patients to self-care is critical to their safety. Caregivers may need safeguarding from burden.
Moore et *al*. (2018)	USA	Discusses drivers for AC in the US, and a guide to the transition of different chemotherapy regimens.	Adult haematology	Lower inpatient bed availability, increased care costs and commitment to increase patient satisfaction described as drivers for ambulatory

Author Year Name and title of publication	**Country of origin**	**Topic**	**Patient population**	**Salient points raised that relate to the scoping review question**
				care alongside improvements in supportive care medications and continuous infusion pumps. Patient and caregiver education critical to safety. Caregiver support and availability can influence suitability for AC.
Comerford and Shah (2018)	UK	Sets out to discuss the AC approach from the perspective of patient experience. Explores the roles of the multidisciplinary team and their part in patient safety, and the benefits, challenges and cost considerations of an AC service.	Young adult & adult haematology and oncology	Not all patients require a hospital inpatient bed and continuous nursing care, despite undergoing intensive cancer treatment. Describes the routines, eligible protocols and responsibilities of AC from a multidisciplinary perspective. Presents results of patient experience captured via electronic survey in 2017 (average responses to each question = 104) which included perceptions of safety and confidence alongside quotes from services users suggesting service well suited to meet their needs. AC delivers tailored care enabling independence.

Author Year Name and title of publication	**Country of origin**	**Topic**	**Patient population**	**Salient points raised that relate to the scoping review question**
Ingram (2017)	UK	Describes drivers for ambulatory care in the UK and the planning and guidance required to set-up services.	Haematology and oncology – age not specified.	The portable nature of treatment delivery gives patients freedom from the hospital environment, provides families time together and allows a degree of normality to remain. Consideration should be given to the potential added costs to patients and caregivers.
McKeag (2015)	UK	Describes the evolution of infusion pumps since the 1960s which have facilitated Ambulatory Care.	Cancer	Portable ambulatory infusion pumps which can be used to infuse chemotherapy or hydrating fluids have made Ambulatory Care possible.
Newton and Ingram (2014)	UK	Describes the key features of the AYA Service with emphasis on infusion pumps as a facilitator of Ambulatory Care.	Adolescent and Young Adult cancer	The experience of Ambulatory Care is empowering as it enables teenage and young adult patients to take control of their care and can promote normalcy. Patient education is vital to running a safe service.
Knott *et al*. (2013)	UK	Describes the preparation of patients and experiences of staff engaging in self-monitoring. Explores the development of a teenage and Young Adult ambulatory service	Adolescent and Young Adult cancer	Self-monitoring on the ward is a first step to preparing patients for ambulatory care. Focus on nurse-led to patient led monitoring can challenge the philosophy and culture of nursing care on the ward.

Author Year Name and title of publication	**Country of origin**	**Topic**	**Patient population**	**Salient points raised that relate to the scoping review question**
		from a change project perspective.		The concept of peer support could be challenged by the Ambulatory Care model.
Anderson *et al.* (2013)	USA	The clinical team share their philosophy, strategies and tools to support adolescents and young adults to receive treatment for osteosarcoma on an outpatient basis.	Adolescent and Young Adult Cancer	Portable infusion pumps and advances in supportive care medications have made ambulatory chemotherapy possible. Role of family in practically and emotionally supporting the patient to receive treatment on an outpatient basis. Improved QoL positioned as key driver for service. Philosophy of care ‘family-centred’.
Ganzel and Rowe (2012)	Israel	Commentary paper which explores the ‘revolutionisation’ of haematology care.	Adult haematology	Portable infusion pumps, effective supportive care medications and residing close to the hospital make Ambulatory Care effective and safe. Ask whether the expansion of Ambulatory Care might involve mobile teams going out to give treatments and support patients at home.

Author Year Name and title of publication	**Country of origin**	**Topic**	**Patient population**	**Salient points raised that relate to the scoping review question**
Mastal (2018)	USA	Describes the evolution of the Ambulatory Care professional nursing specialism in the USA.	Ambulatory Care nursing in general	The professional speciality of Ambulatory Care nursing was first conceptualised in 1998 emphasising the individuality of the patient and the role of different outpatient and community providers. The American Academy of Ambulatory Care Nursing professionally leads the specialty, although not synonymous with the transition of inpatient treatment to the outpatient setting,
Kelly (2005)	UK	Discusses development, rationale and details of an Ambulatory Care programme at UCLH.	Adult haematology	Describes the programme in its infancy where up to six patients ambulate from a nearby hotel for treatment. Service informed by visit to US AC service. Describes strong clinical drivers: managing increased patient activity alongside creation of more normality for patients. Positioned as empowering for patients. Captures patient feedback via questionnaire. Recommends using a pilot project approach including through audit, regular patient feedback and financial evaluation when introducing Ambulatory Care services.

Author Year Name and title of publication	**Country of origin**	**Topic**	**Patient population**	**Salient points raised that relate to the scoping review question**
Mikhail *et al.* (1995)	USA	Describes and contextualises the shift to Ambulatory Care in the USA.	Cancer services in general	Describes progress made by 1995 in a shift to outpatient and ambulatory cancer care. Increased effectiveness and efficiency alongside patient preference and US legislative attempts to increase equity described as a driver. Infusion therapy devices, surgical advances, and haematopoietic growth factors to reduce myelosuppression made Ambulatory Care feasible alongside better anti-emetics and other supportive care medications.
Schulmeister (1991)	USA	Discusses how nurse led patient education programmes meet the need of ambulatory patients	Cancer services in general	Positions Ambulatory Care as a cost containment strategy in the US. Describes 'ambulatory care' as a misnomer as non-ambulant patients also access services. Describes the role of the nurse as critical to patient education and therefore safety in this setting. Technology and the promotion of self-care have led to the need for greater emphasis on patient education. Notes providers have started to competitively market their AC services.

Author Year Name and title of publication	**Country of origin**	**Topic**	**Patient population**	**Salient points raised that relate to the scoping review question**
Corrigan Wandel *et al*. (1990)	USA	Describes and Ambulatory Care service within the context of the expanded scope of a nurse.	Adult haematology	Describes the successful management of consolidation chemotherapy amongst 23 patients in the ambulatory setting. Indicates this provides patients with independence and control over their care. Poor family support described as something that limits suitability for Ambulatory Care.
Esparza *et al.* (1989)	USA	Discusses ambulation of high dose cisplatin and MTX alongside conceptual factors informing Ambulatory Care. Describes service set up and coordination of care	Cancer services in general	Drivers for Ambulatory Care include technical developments and patient choice, based on quality of life, convenience, and economics (keeping costs down). Describes 24 hr access to clinical services as a key feature of the ambulatory cancer centre, within which patients can retain their normal lifestyles and exercise choice.
Nirenberg and Rosen (1979)	USA	Describes the set-up of an ambulatory care unit at Memorial Sloan Kettering, and the philosophy of care informing the service.	Adolescent oncology	Describes over 200 adolescent patients received high-dose methotrexate for osteosarcoma on an outpatient basis enabling them to live at home and participate to some degree in their normal educational and social life and maintain newly acquired independence. Promotion of a degree of normal lifestyle described as a driver.

Appendix 15 Interview topic guide – staff interviews

Topic guide for staff interviews

Written consent will be assured prior to interview. Following the opportunity to ask any outstanding questions the consenting process will take place on the same day as the interview, either in the hours before, or immediately before, depending on the time that a participant has available.

Setting:
The participant will either consent to a walk-along interview a traditional face-to-face interview, or a combination of both e.g. commencing with a walk-along approach and then settling somewhere private to continue the interview conversation. In the event that an in-person interview is not possible, or if preferred, it will be offered via video-conference. The format and type of interview will be agreed in principle prior to the interview taking place. The participant will be made aware they can decide to continue the interview in private at any point, or to request reconvening in private at another time that day to continue the conversation.

In the instance of walk-along interview, clinical staff in the vicinity of the interview will be made aware of the time it is due to take place. Patients and family members in the vicinity will also be briefed and given the opportunity to request that they are not part of the interview setting. Depending on the staff member's role and the circumstances the researcher may suggest the interview takes place at another time if a patient or family member objects, or the patient may be offered the choice to being cared for by another members of the team if receiving clinical care and this is considered by the nurse-in-charge to be appropriate.

The interview:
After explaining the purposes of the interview, the participant will be reminded they can request the interview pauses or stops entirely at any point and will be asked if they would like to use a visual cue to advise the researcher of this.

In a walking interview context:
Initially the participant will be invited to talk about how long they have worked with/in ambulatory care and the nature of their involvement. This open, and quite general line of questioning also hopes to settle the participant.

The researcher will then ask if they can accompany the staff member in practice.

The researcher will introduce themselves to patients and family members who are likely to be in the study setting. They will explain that any conversation taking place between the staff member and researcher will be audio-recorded and that once transcribed any dialogue from anyone else will be removed.

The researcher will accompany the participant in practice. The culture in the clinical setting is open with young people actively involved and included in discussion about their care. Participant's questions will be asked openly, framed to build understanding and some may be asked in the presence of the patent if appraised as appropriate, otherwise they will be asked when 'in motion' between patients or tasks.

Questions will be exploratory, focusing on their engagement with the patient and family in relation to Ambulatory Care (AC). For example:

- Can you talk me through what you have just explained?
- Do you consciously choose to approach it this way?
- Why, I wonder?
- How might this intervention/engagement help me understand a bit more about the philosophy behind AC?
- Thinking about the time we are spending together, what more can you say about AC?
- How does this play out in your practice?

During the interview the researcher will explore the participant's thoughts about their understanding of the drivers or reasons for AC. For example:

- What's your understanding of how AC developed here at UCLH
- Do you have any other experience of ambulatory cancer care?
- What, for you are the most important features of AC?
- What do you value most as someone who cares for TYA patients?
- In your experience what do you think patients value most? How do you think TYA patients might describe their experience of AC?

If participants describe one of the reasons for AC is that it supports delivery of age-appropriate care this will be explored. For example:

- What, in your view are the key characteristics of age-appropriate care?
- In your experience how does AC help provide/deliver age-appropriate care?
- How might 'age-appropriate care' differ between the hospital and AC setting?
- To what extent do you think the delivering age-appropriate care is contingent on having a dedicated physical space?

To close the interview the participant may be invited to consider the broader context of AC. For example:

- Are you aware of any other complex interventions/pathways that have transitioned from inpatient to AC?... [Invite participant to share their thoughts/understanding about what may be similar or different]

In a traditional interview context, the topic guide questions will be used, and adapted to the 'sit-down' format.

***

The participant will be asked if there is anything else they had hoped to talk about in relation to AC that they have not had the opportunity to discuss.

They will be thanked for their time at the end of the interview conversation and will be reminded of the contact details on the participant information sheet they can contact if they have any questions or concerns afterwards.

Appendix 16 Interview topic guide – TYA participants

Topic guide for photo guided peer-interviews

Following the opportunity to ask questions and after reconfirming a participant's consent, the interview will commence.

The participant will be reminded they can request that the interview pauses or stops entirely at any point, or that they can request to move on if they do not want to discuss something. They will be asked if they would like to use a visual cue to tell the researcher this. The type of cue will be agreed.

The interview structure involves the co-researcher inviting the participant to share and discuss each of their chosen images in turn. Participants will be reminded that there are no correct or expected things to say.

- Open the interview with a broad question to settle the participant. This is sometimes referred to as a warm-up question. For example:

  How did you find taking and then choosing photos for this interview?

- Perhaps ask the participant when they took their photos – At certain times of the day? In a planned way to capture different aspects of how they were feeling? Or more spontaneously, for example.

This open, and quite general line of questioning is intended to put the participant at ease.

The main part of the interview can be approached in one of two ways whichever feels best suited to the flow of the conversation, either:

a) inviting the participant to talk through each photo one-by-one working with the questions detailed below before covering the second set of questions in the topic guide or,
b) blending the second set of questions in with the questions you ask about the images.

Questions:

1. Would you like to discuss your first [update as appropriate] photo with me?
2. What can you say about the image you have chosen in relation to your Ambulatory Care experience?
3. Have you given your image a title or name? How have you described it [if so]?
4. How might this image help me understand a bit more about your experience of Ambulatory Care?
5. What feelings do you attach to this?
6. What meaning does this hold for you/ what does the image signify? Or represent?
7. Is it possible to capture the feeling or meaning you have just described in two or three words? [If not already offered a caption].
8. What else?

The participant will then be invited to consider and answer the following aspects:

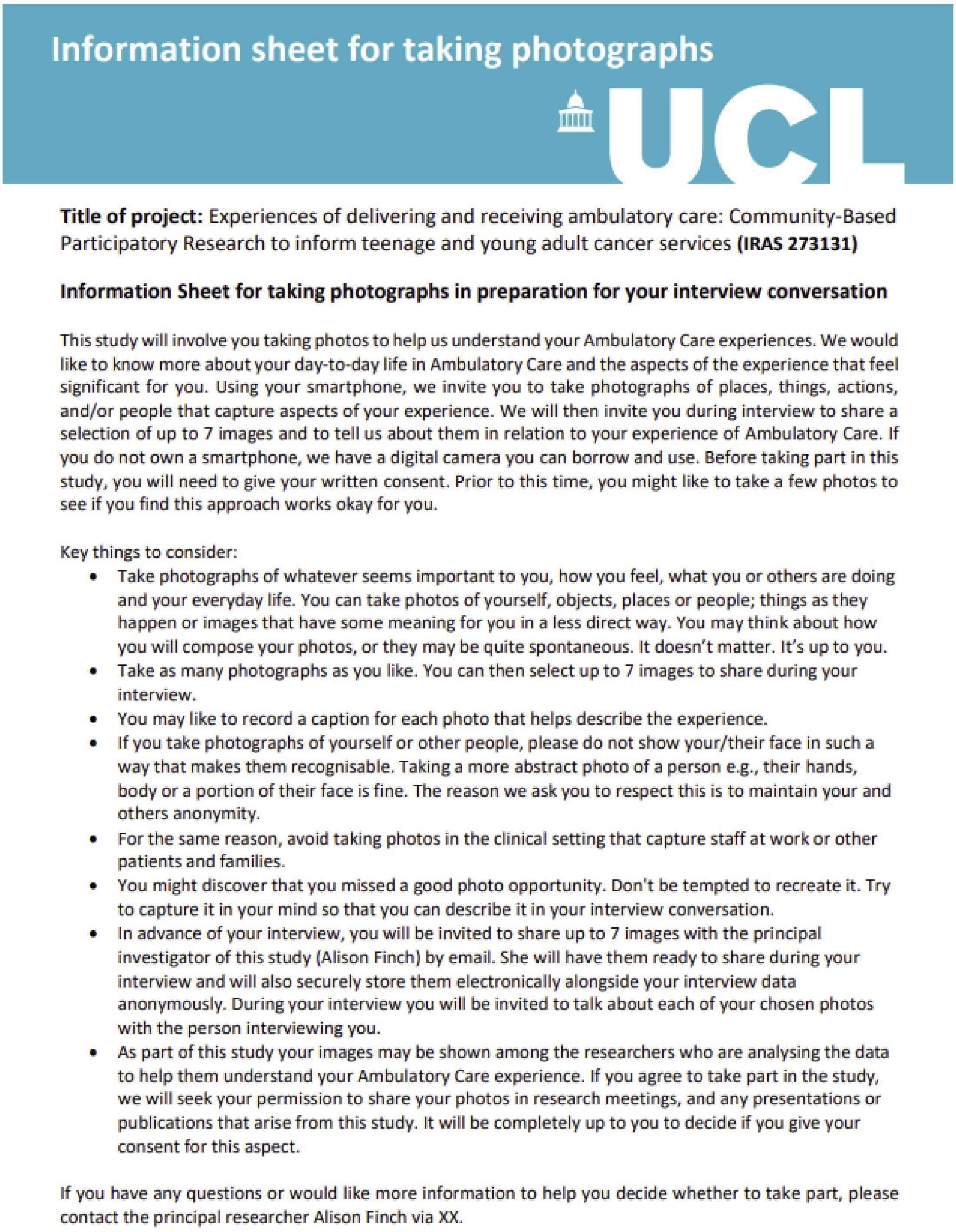
9. What more/else can you say about your experience of Ambulatory Care? How do you manage the responsibilities of Ambulatory Care?
10. Do you have any experience of feeling worried or anxious at times? [Invite participant to talk around this if appropriate. How have their emotional needs been met?]
11. Who has been critical to your support whilst in Ambulatory Care? Any why?
12. What for you are the most important features of Ambulatory Care? What do you value most, compared for example with being on a hospital ward? [if they have experience of both]
13. If you were talking to another young person who doesn't know whether Ambulatory Care is for them, what would you say?
14. Do you have anything further to say about your Ambulatory Care experience to those who design and plan NHS services for young people with cancer?

***

The participant will be asked if there is anything else they had hoped to be able to talk about in relation to their ambulatory experience that they've not had the opportunity to share. They will be asked if they are willing to be contacted again to take part in a shorter, follow up interview.

They will be thanked for their time at the end of the interview conversation and will be reminded of the contact details on the participant information sheet that they can use if they have any questions or concerns afterwards.

Appendix 17 Guidance on taking photographs



Information sheet for taking photographs

UCL

Title of project: Experiences of delivering and receiving ambulatory care: Community-Based Participatory Research to inform teenage and young adult cancer services **(IRAS 273131)**

Information Sheet for taking photographs in preparation for your interview conversation

This study will involve you taking photos to help us understand your Ambulatory Care experiences. We would like to know more about your day-to-day life in Ambulatory Care and the aspects of the experience that feel significant for you. Using your smartphone, we invite you to take photographs of places, things, actions, and/or people that capture aspects of your experience. We will then invite you during interview to share a selection of up to 7 images and to tell us about them in relation to your experience of Ambulatory Care. If you do not own a smartphone, we have a digital camera you can borrow and use. Before taking part in this study, you will need to give your written consent. Prior to this time, you might like to take a few photos to see if you find this approach works okay for you.

Key things to consider:

- Take photographs of whatever seems important to you, how you feel, what you or others are doing and your everyday life. You can take photos of yourself, objects, places or people; things as they happen or images that have some meaning for you in a less direct way. You may think about how you will compose your photos, or they may be quite spontaneous. It doesn't matter. It's up to you.
- Take as many photographs as you like. You can then select up to 7 images to share during your interview.
- You may like to record a caption for each photo that helps describe the experience.
- If you take photographs of yourself or other people, please do not show your/their face in such a way that makes them recognisable. Taking a more abstract photo of a person e.g., their hands, body or a portion of their face is fine. The reason we ask you to respect this is to maintain your and others anonymity.
- For the same reason, avoid taking photos in the clinical setting that capture staff at work or other patients and families.
- You might discover that you missed a good photo opportunity. Don't be tempted to recreate it. Try to capture it in your mind so that you can describe it in your interview conversation.
- In advance of your interview, you will be invited to share up to 7 images with the principal investigator of this study (Alison Finch) by email. She will have them ready to share during your interview and will also securely store them electronically alongside your interview data anonymously. During your interview you will be invited to talk about each of your chosen photos with the person interviewing you.
- As part of this study your images may be shown among the researchers who are analysing the data to help them understand your Ambulatory Care experience. If you agree to take part in the study, we will seek your permission to share your photos in research meetings, and any presentations or publications that arise from this study. It will be completely up to you to decide if you give your consent for this aspect.

If you have any questions or would like more information to help you decide whether to take part, please contact the principal researcher Alison Finch via XX.

Appendix 18 Topic guide – companions

Topic guide for companion interviews

Written consent will be assured prior to interview. After explaining the purpose of the interview, the participant will be reminded they can request the interview pauses or stops entirely at any point and will be asked if they would like to use a visual cue to tell the researcher this. The type of cue will be agreed.

The companion will be asked whether they have found a safe and private space to talk.

The interview structure is designed to be conversational, and participants will be invited to share their experience and perspectives of Ambulatory Care (AC).

1. Initially the participant will be invited to talk about their relationship to the young person they are supporting and how long they have been accompanying them through cancer treatment.

They will be invited to share details about this AC admission; is it their first or have they had previous experience? How does this experience compare with others?

2. They will be invited to share the kind of role they fulfil in support of their family member/partner. What kind of things/activities/emotional support do they provide?

How do they feel about this? Were they prepared by anyone? ... What was explained about their role? Did they / do they feel adequately prepared to take this on?

And if they have experience of the ward, how does this role compare with the role that they fulfil in the ward setting?

3. Companions will be invited to think about what Ambulatory Care offers:

- to them
- to their young person
- to their family/social network/work/study.

Has any aspect or feature of Ambulatory Care worked particularly well?

What goes on behind the scenes at home to make this work?

What was their life like prior to the young person's diagnosis?
Integrate and reflect on that in the context of the role they now describe.

4. They will be invited to share whether they have felt anxious or worried at times during this (or other) AC admissions?

Did they share this with anyone? Did anything help? How have they managed or coped?

5. Besides the clinical care, do they think that their/their family's more holistic needs have been met? (e.g. emotional, cultural, educational, spiritual or practical needs)

6. Does Ambulatory Care come at a cost to them? The researcher will explore the type and nature of any cost experienced.

7. Who has been critical to their support whilst in Ambulatory Care?

8. They will be invited to think about talking to another companion [parent/partner/sibling] like them who doesn't know much about Ambulatory Care. What would they say?

9. They will be asked if they have anything to say to those who commission and develop services in the NHS for young people with cancer in relation to ambulatory care.

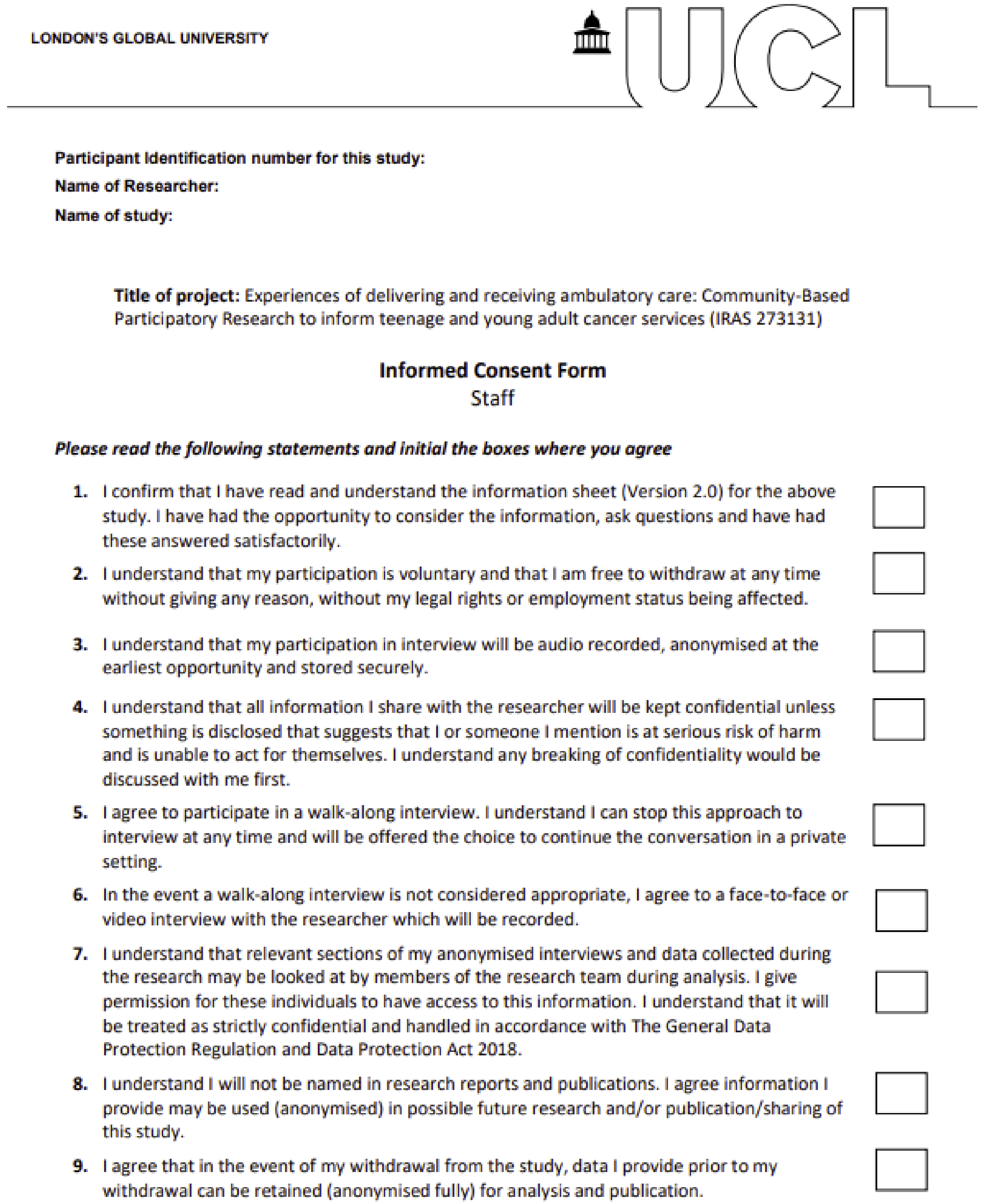
***

Integral to the conversation will be whether they think Covid has had an impact on their Ambulatory Care experience.

The participant will be asked if there is anything else they had hoped to be able to talk about in relation to their ambulatory experience that they've not had the opportunity to share.

They will be thanked for their time at the end of the interview conversation and will be reminded of the contact details on the participant information sheet they can contact if they have any questions or concerns afterwards.

Appendix 19 Informed Consent Form – Staff



LONDON'S GLOBAL UNIVERSITY UCL

Participant Identification number for this study:
Name of Researcher:
Name of study:

Title of project: Experiences of delivering and receiving ambulatory care: Community-Based Participatory Research to inform teenage and young adult cancer services (IRAS 273131)

Informed Consent Form
Staff

Please read the following statements and initial the boxes where you agree

1. I confirm that I have read and understand the information sheet (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights or employment status being affected. ☐
3. I understand that my participation in interview will be audio recorded, anonymised at the earliest opportunity and stored securely. ☐
4. I understand that all information I share with the researcher will be kept confidential unless something is disclosed that suggests that I or someone I mention is at serious risk of harm and is unable to act for themselves. I understand any breaking of confidentiality would be discussed with me first. ☐
5. I agree to participate in a walk-along interview. I understand I can stop this approach to interview at any time and will be offered the choice to continue the conversation in a private setting. ☐
6. In the event a walk-along interview is not considered appropriate, I agree to a face-to-face or video interview with the researcher which will be recorded. ☐
7. I understand that relevant sections of my anonymised interviews and data collected during the research may be looked at by members of the research team during analysis. I give permission for these individuals to have access to this information. I understand that it will be treated as strictly confidential and handled in accordance with The General Data Protection Regulation and Data Protection Act 2018. ☐
8. I understand I will not be named in research reports and publications. I agree information I provide may be used (anonymised) in possible future research and/or publication/sharing of this study. ☐
9. I agree that in the event of my withdrawal from the study, data I provide prior to my withdrawal can be retained (anonymised fully) for analysis and publication. ☐

10. I agree to being contacted in spring 2022 to ask if I would like to hear about the results of this research. ☐

11. I agree to take part in this study. ☐

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

You will be asked to sign two copies of this consent form – one of which you will keep. The second copy will be kept securely in the central research file.

Appendix 20 Participant Information Sheet (PIS) – Young Person

Title of project:

Experiences of delivering and receiving ambulatory care: Community-Based Participatory Research to inform teenage and young adult cancer services

Participant Information Sheet

Young people

Hello, I am Alison Finch, a cancer nurse and PhD student. I would like to invite you to take part in a research study. Before you decide it is important you understand why the research is being done and what it will involve for you so, please read this leaflet carefully. Talk to your care team or others about the study if you wish. I am also more than happy to talk with you if you would like some more information or if something is not clear.

What is the research?

We have funding from the National Institute for Health Research (NIHR) to evaluate people's experiences of ambulatory cancer care. We know Ambulatory Care is safe. However, we don't understand enough about people's experiences of Ambulatory Care. We want to know if any changes are needed to meet young people's needs at UCLH. Doing the research now is important as Ambulatory Care is being set up in many Teenage and Young Adult cancer units within the NHS, and we want to ensure that these services are supporting young people well.

Why have I been invited?

You have been invited to take part because you are aged 16-24 and are currently receiving part or all of your cancer treatment on an ambulatory basis at UCLH. We would like to invite you to share your personal experience of Ambulatory Care because it will help us build a picture of different patients' experience of the service. Around 20 young people will be involved in this study.

How do I take part?

Taking part in this study involves one or two interviews with a researcher to discuss your experiences. The first interview is called a photo-guided interview and involves you taking a number of photographs on your smart phone that capture your feelings about Ambulatory Care or are symbolic of your Ambulatory Care experience in some way. You will then be invited to a pre-arranged interview with a researcher where you will share up to 7 photos and will talk about what they represent and mean for you. The interview will also involve being asked a few questions about your experience by the researcher. We expect the interview conversation will last around 1 hour and will be audio recorded.

We would like to invite you to consider taking part in a second interview a few weeks after your photo-guided interview conversation. This would help us better understand whether your experience of ambulatory care has changed with more experience of the pathway. It would also allow us to talk with you about your experience in relation to what some of the other study participants have had to say. We expect this interview would be slightly shorter, perhaps 40 minutes and would not require you to take or share photos unless you chose to.

Who will interview me?

This research study involves several young people with experience of cancer who are actively involved in different parts of the study as co-researchers, working under the guidance and supervision of the principal investigator. By involving young people in the conduct of the research, we hope the study findings will be of more relevance and benefit. For the photo-guided interview you will be interviewed by a young person who has been appropriately trained in this interview method. If you agree to taking part in a second interview this will be undertaken by Alison Finch, a cancer nurse and PhD student.

Where will the interviews take place?

The interviews will take place by video conference e.g. Zoom. The interviews will take place in private with just you and the researcher. When the photo-guided interviews are taking place Alison will be in the vicinity to provide support if required but she won’t be listening in.

How do I go about taking the photos? Is there any guidance for this?

Yes, an information sheet has been produced which details the kind of images to capture, and some practical tips to keep your identity private.

What else is involved?

We would like to interview parents/partners/siblings to understand their perspective of Ambulatory Care. We will invite you to tell us if there is someone who stays with you during your Ambulatory Care admission, and we will ask if you might share details of this study with them. A separate information sheet has been developed for parents/partners/siblings and we will give you a copy to pass on. It is completely up to them whether they take part, and your ability to participate in this study is not dependent on them also agreeing to take part.

Why should I take part?

Whilst there is no direct benefit to you by taking part, you may find talking with the researcher a supportive experience. This study is the first research of its kind looking into people's experiences of Ambulatory Care. Finding out about the experiences of young people, alongside family members and staff experiences will help us build a comprehensive picture of the service. You will be helping guide how cancer services are provided to future patients. The results of the research will be used to improve the existing Ambulatory Care service at UCLH and will support the provision of new services for young people across the NHS. At the end of the study, you will be invited to an event to hear the research findings, and how they have, and will continue to influence practice.

Do I have to take part?

No, you do not have to take part in this study. It is completely up to you whether you take part. Your current and future care within the health service and the support you receive from CLIC Sargent or the Teenage Cancer Trust (who have lent their support to this study) will not be affected in any way if you decide not to take part. If you decide to take part, then you will be asked to sign a consent form before/at the time of the first interview. You will be given a copy of the consent form and this information sheet to keep. You are completely free to withdraw from the research at any time during the study without giving a reason.

What are the possible disadvantages and risks of taking part?

We do not think that there are any significant risks involved by taking part in this study. If you find that you experience any discomfort because of taking part you will be free to stop at any point, and this will not have any effect on your future treatment and care.

We are asking you to give up some of your time to take part in this study which could be seen as a disadvantage, so it is important for us to explain the time involved. Each interview will take between 40 minutes and an hour. Taking photographs should not take any more than a few moments each day over 1 day or a few days (depending on the length of your admission). You will be invited to think about a caption for the photo you would like to share in your interview which may take a little longer. It will be completely up to you how you wish to do this and how often.

If you incur any travel or other personal costs as a consequence of taking part in this study, please talk to your researcher so that we can reimburse you.

Will my taking part in the project be confidential and anonymous?

All information you provide will be kept strictly confidential and used only for the purposes of this study. Everything you say, and all information collected is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else. We will not tell anyone that you have taken part. We will not pass your contact details onto anyone else. Only the researchers interviewing you will know your identity, and from that point on your information will be anonymised. Once anonymised your interview will be transcribed (written out) in preparation for analysis. The written transcript will be sent to co-researchers as a password protected word document for the purposes of data analysis. With your permission your data may be shared with public and academic audiences as part of sharing the research findings. Short, anonymised sections of your interviews may be used in written reports, academic publications, conference publications or any other materials produced for the study. We will not use your name and will make every effort to protect your identity.

What about data security?

We will record your interview on an encrypted, password-protected digital audio recorder. Recordings will be transferred onto a secure computer network and deleted from the recorder. Recordings will be typed up by a professional company, who have a service and confidentiality agreement in place with University College London. Personal names will be removed before analysis takes place. Any information that could identify you will not be shared outside of the research team and will not be included in reports or publications. Apart from the professional transcription company who have access to the recordings, only the lead researcher will have access to your personal data (i.e. name, email address). Your data will be kept securely in a computer drive at University College London (UCL) with access restricted to Alison Finch, the principal investigator. Any paper documentation will be kept in a locked drawer in the Department for Applied Health Research at UCL before it is uploaded into an electronic file. Images/film footage you send to the researcher will be kept securely on the UCL computer drive. Your identifiable data will be stored securely for up to three years after the end of the project and then destroyed securely. Your anonymised data will be archived for 10 years.

What will happen to the results of the research project?

Findings will be shared in a variety of ways including reports, publications and presentations to a variety of clinical, academic, charity and public audiences. If you would like to see a copy of any publication resulting from this research, please let us know and we would be happy to send these to you.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London-Chelsea Research Ethics Committee.

Who is organising and funding the research?

The study is funded by the National Institute for Health Research (NIHR) Academy, Grant Reference Number ICA-CDRF-2018-04-ST2-034. The study is managed by Professor Rosalind Raine, Professor of Healthcare Evaluation and Head of Department of Applied Health Research, University College London (UCL), who is responsible for the design, conduct and reporting of the study. The principal researcher is Alison Finch, a cancer nurse and PhD student at UCL. The research is supported by CLIC Sargent and the Teenage Cancer Trust.

What do I do if there is a problem?

If you have any problems or concerns, you should speak with your researcher if you feel able or you can contact the people whose details are at the end of this information sheet. If you have any complaints about the way in which this study has been, or is being carried out, please try to discuss this with the researchers. If problems are not resolved, or you wish to comment in any other way, please contact the study's chief investigator, Professor Raine. You can also speak to the Patient Advice and Liaison Service (PALS). When contacting them, please quote the study number that can be found on the first page of this information sheet. Details can also be obtained from the Department of Health website: http://www.dh.gov.uk.

What if something goes wrong?

If something goes wrong and you want to make a complaint about the conduct of the research, or would like help or advice following your participation, you can contact the study's principal or chief investigator. You can find their details on the last page of this information sheet. Every care will be taken in the course of this study. However, in the unlikely event that you come to harm as a result of you taking part, compensation may be available. After discussion with the principal or chief investigator please make the claim in writing to xx. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff or about any side effects (adverse events) you may have experienced due to your participation in the study, the normal National Health Service complaints mechanisms are available to you. Please ask your researcher if you would like more information on this.

If you feel you might benefit from some confidential emotional support as a consequence of taking part in this study, provision has been made with the young people's psych-oncology service at UCLH. Please contact your researcher if you would like to be referred to this service.

Data Protection Privacy Notice

University College London (UCL) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep identifiable information about you for three years after the study has finished. The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we would like to keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information by contacting the UCL Data Protection Office at data-protection@ucl.ac.uk or by looking at the following website: https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice.

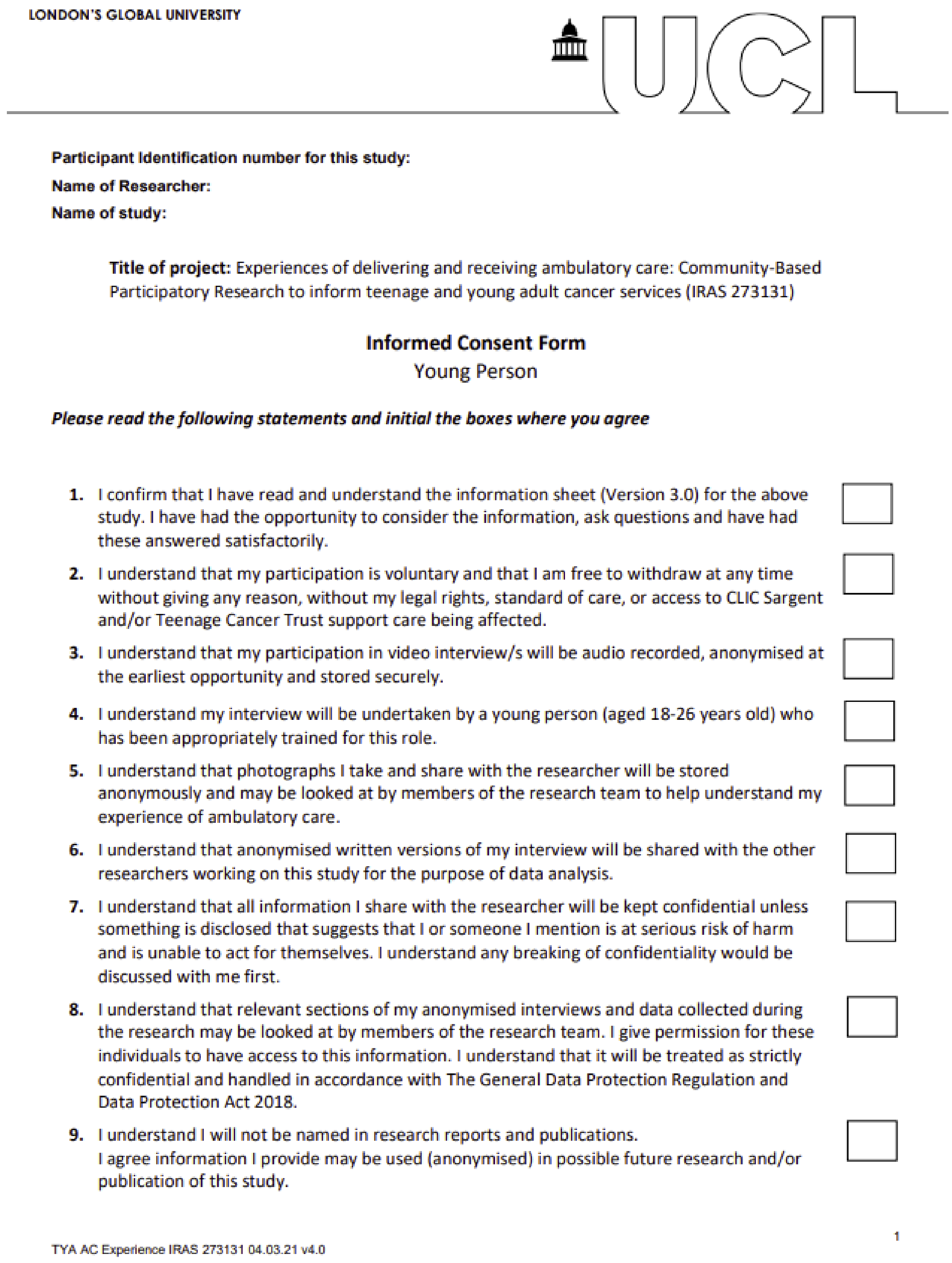
What if I have any other questions?

If you would like to take part, would like this information in a different format or have any questions, please contact:

Principal Researcher	**email:**
Chief Investigator	**email:**

Thank you for reading this information sheet and for considering taking part in this research study. If you take part, you will be given a copy of this information sheet to keep and you will be asked to sign two copies of a consent form - one of which you will keep.

Appendix 21 Informed Consent Form – Young Person



LONDON'S GLOBAL UNIVERSITY

UCL

Participant Identification number for this study:

Name of Researcher:

Name of study:

Title of project: Experiences of delivering and receiving ambulatory care: Community-Based Participatory Research to inform teenage and young adult cancer services (IRAS 273131)

Informed Consent Form

Young Person

Please read the following statements and initial the boxes where you agree

1. I confirm that I have read and understand the information sheet (Version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights, standard of care, or access to CLIC Sargent and/or Teenage Cancer Trust support care being affected. ☐
3. I understand that my participation in video interview/s will be audio recorded, anonymised at the earliest opportunity and stored securely. ☐
4. I understand my interview will be undertaken by a young person (aged 18-26 years old) who has been appropriately trained for this role. ☐
5. I understand that photographs I take and share with the researcher will be stored anonymously and may be looked at by members of the research team to help understand my experience of ambulatory care. ☐
6. I understand that anonymised written versions of my interview will be shared with the other researchers working on this study for the purpose of data analysis. ☐
7. I understand that all information I share with the researcher will be kept confidential unless something is disclosed that suggests that I or someone I mention is at serious risk of harm and is unable to act for themselves. I understand any breaking of confidentiality would be discussed with me first. ☐
8. I understand that relevant sections of my anonymised interviews and data collected during the research may be looked at by members of the research team. I give permission for these individuals to have access to this information. I understand that it will be treated as strictly confidential and handled in accordance with The General Data Protection Regulation and Data Protection Act 2018. ☐
9. I understand I will not be named in research reports and publications.
   I agree information I provide may be used (anonymised) in possible future research and/or publication of this study. ☐

1

TYA AC Experience IRAS 273131 04.03.21 v4.0

10. I agree that my photographs may be shared in presentations, exhibitions and publications of this study. ☐

11. In the event of my withdrawal from the study, data I provide prior to my withdrawal can be retained (anonymised fully) for analysis and publication. ☐

12. I agree to being approached to take part in an optional follow-up face-to-face or video interview with for which I will be asked to verbally reconfirm my written informed consent. ☐

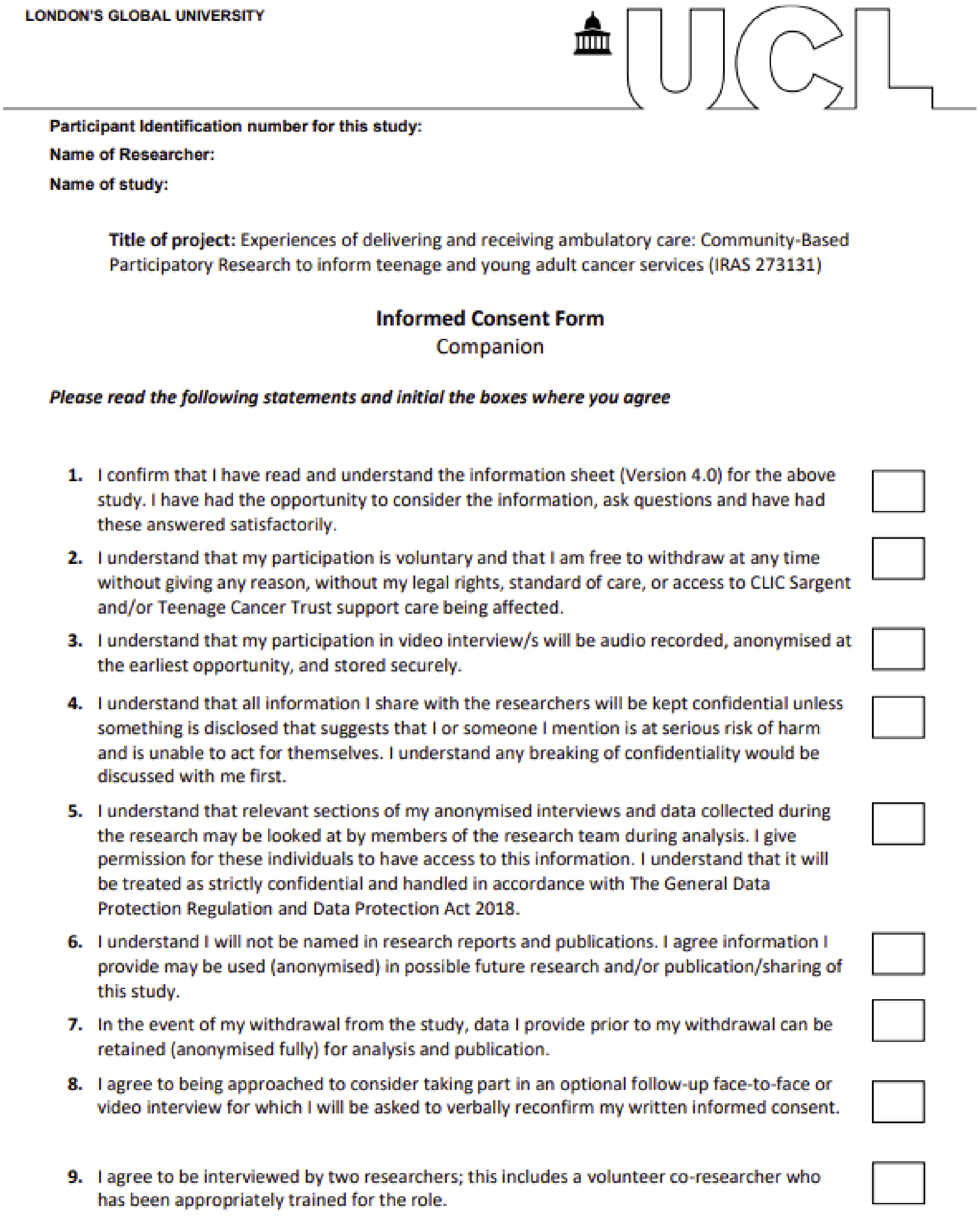
13. I agree to being contacted in spring 2022 to ask if I would like to hear the results of this research. ☐

14. I agree to take part in the above study. ☐

______________________	______________	________________
Name of participant	Date	Signature
______________________	______________	________________
Name of person taking consent	Date	Signature
______________________	______________	________________
Witness to consent	Date	Signature of Primary Investigator

You will be asked to sign two copies of this consent form – one of which you will keep. The second copy will be kept securely in the central research file.

Appendix 22 Informed Consent Form – Companions



LONDON'S GLOBAL UNIVERSITY

UCL

Participant Identification number for this study:

Name of Researcher:

Name of study:

Title of project: Experiences of delivering and receiving ambulatory care: Community-Based Participatory Research to inform teenage and young adult cancer services (IRAS 273131)

Informed Consent Form
Companion

Please read the following statements and initial the boxes where you agree

1. I confirm that I have read and understand the information sheet (Version 4.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights, standard of care, or access to CLIC Sargent and/or Teenage Cancer Trust support care being affected. ☐
3. I understand that my participation in video interview/s will be audio recorded, anonymised at the earliest opportunity, and stored securely. ☐
4. I understand that all information I share with the researchers will be kept confidential unless something is disclosed that suggests that I or someone I mention is at serious risk of harm and is unable to act for themselves. I understand any breaking of confidentiality would be discussed with me first. ☐
5. I understand that relevant sections of my anonymised interviews and data collected during the research may be looked at by members of the research team during analysis. I give permission for these individuals to have access to this information. I understand that it will be treated as strictly confidential and handled in accordance with The General Data Protection Regulation and Data Protection Act 2018. ☐
6. I understand I will not be named in research reports and publications. I agree information I provide may be used (anonymised) in possible future research and/or publication/sharing of this study. ☐
7. In the event of my withdrawal from the study, data I provide prior to my withdrawal can be retained (anonymised fully) for analysis and publication. ☐
8. I agree to being approached to consider taking part in an optional follow-up face-to-face or video interview for which I will be asked to verbally reconfirm my written informed consent. ☐
9. I agree to be interviewed by two researchers; this includes a volunteer co-researcher who has been appropriately trained for the role. ☐

10. I agree to being contacted in spring 2022 to ask if I would like to hear about the results of this research. ☐

11. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

You will be asked to sign two copies of this consent form – one of which you will keep. The second copy will be kept securely in the central research file.

Appendix 23 Co-Researcher Handbook

Co-Researcher Handbook Part 2

Analysis

Part 2 of this handbook has been written as a practical guide to support you in your data analysis role. It sits alongside the interviewing handbook and the virtual workshop programme from 2020. Part 2 starts off recapping the overarching objectives of the Ambulatory Care research and questions being asked, before describing a qualitative approach to data analysis.

The information contained in this guide orientates you to the principles we will adopt. Further detail about the participatory (group) analysis approach will be shared in our face-to-face meetings when we decide together the methods that we will use. In the meantime, you may like to read a written interview transcript immediately after reading these pages, to practically connect with what is described.

The analysis we now embark on is such a critical research phase requiring care and dedication. The outputs of our analysis will inform, shape and develop young people's cancer services in the hospital, with potential to contribute to care nationwide. I remain immensely appreciative of your commitment to this research and our work together. Thank you.

A brief note about wellbeing

In your co-researcher role, you have been hearing about different people's cancer experiences that may be similar or very different to your own. As you begin to read more about people's experiences if you notice that you feel affected by the content and you would like to talk, please let me know in confidence. If you do not feel able to let me know, then do approach one of the other co-researchers that you trust.

Research overview | a recap

A brief reminder of the aims and objectives of the research, and the questions we have set out to answer.

1. The aim of this research

The study sets out to understand the first-hand experience of delivering and receiving Ambulatory Care from the perspective of different stakeholders: staff, patients and their companions. Alongside identifying what is valued about the service, the research also wants to find out if adaptations are needed in order to better meet the support needs of young people and those who support them during treatment.

The scoping review of published and unpublished literature identified that Ambulatory Care may promote choice, control, independence and self-care, and a daily life that is not bound by the routines of a hospital ward. There is a suggestion that patients like taking or sharing responsibility for their clinical care – but patients themselves have not been asked about this to date. We do not yet fully understand how far we are delivering what is intended of Ambulatory Care, alongside the extent that we are meeting people's support needs. Internationally, there has been little research in this field, yet investment in Ambulatory Care within cancer is growing.

2. The research objectives

The research wants to build practical and academic knowledge about Teenage and Young Adult (TYA) Ambulatory Care, specifically:

1. To understand the commissioning context and drivers for Ambulatory Care;
2. To build knowledge about the experience of receiving and delivering TYA Ambulatory Care in relation to what the service sets out to deliver;
3. To understand the features of Ambulatory Care valued by service users and explore this in relation to age-appropriate care;
4. To make recommendations that inform commissioning decisions around investment in this type of pathway and service;
5. To evaluate the co-researcher role and its impact.

3. The research questions

To fulfil the research objectives, the study poses five questions:

1. What is the philosophy and commissioning context that underpins Ambulatory Care?
2. How do stakeholders – young people, their carers/companions and staff <u>experience</u> Ambulatory Care?
3. <u>What features are critical</u> to successful delivery of young people's Ambulatory Care?
4. <u>What can we learn</u> to inform the development of teenage and young adult Ambulatory Care services?
5. Can a Community-Based Participatory Research approach engage young people (participants and co-researchers), and contribute methodologically?

Our interviews help answer research questions 2, 3 and 4. They involve working with photographs to help convey Ambulatory Care experience.

As you will now know, Community-Based Participatory Research (CBPR) is an active approach to research inquiry. It is concerned with doing research to inform action and to practically influence - rather than doing research to solely build academic knowledge. So, in the context of our research, yes, we want to develop nuanced understanding and description of people's experiences, and how this might relate to the whole concept of age-appropriate care (the overarching philosophy of Teenage and Young Adult Cancer Services). But it's also about using our findings to shape and inform how care is delivered going forward.

The original study design made provision for implementing changes to the way Ambulatory Care is delivered during the life of the project, which would then be evaluated by the Ambulatory Care nursing team. Considerable time has been lost due to Covid, so whilst this may still be possible, the implementation and evaluation would most likely sit with the hospital team (supported by me) in the future, rather than within the scope of our research.

4. Principles of qualitative analysis

Qualitative analysis is concerned with eliciting meaning from data, in our case interview transcripts and photographs. The output of analysis is evidence. In CBPR, the underpinning belief is that analysis is an intellectually creative, rather than technical process.

Often qualitative analysis focuses on the identification of themes which are presented as findings. It is important to stress that themes do not lurk in data, waiting to be fished out or found like a word search puzzle. The research findings are the product of our engagement and thinking, with and about data.

This requires us to think beyond the surface level presentation of things, to consider interrelating concepts and distil their meaning.

This kind of qualitative analysis is called *inductive*: it is rooted in participant's experiences and our interpretation of their data. This is in contrast to a deductive analytical approach which would require us to look within data for instances of pre-existing themes, for example 'independence' and to then perhaps count frequency of its occurrence.

Our analysis is participatory, which means that whilst we will read transcripts alone to start off with, it will be undertaken as a group in conversation with one another. Our *dialogue* with one another, and the pooling of our experiences and insights is what informs and enriches the analysis. Yet within this we must follow a robust auditable process so that the study findings can be defended and traced back to raw data.

5. Our analytic aim

In essence we are setting out to describe then build understanding about people's experiences, then develop explanations and/or interpretations. We might re-consider and critique these interpretations in relation to existing theory or conceptual frameworks about young people's cancer or Ambulatory Care.

There are no universal procedures for doing qualitative analysis. However, all forms of analysis require a method or structure. Whilst different research traditions have particular analytical frameworks, our research is not wedded to a particular theoretical approach, beyond one which follows CBPR principles.

To structure our analysis, the approach we have chosen embeds a number of analytic steps (or points of focus) to guide how we work with data. It is an approach developed by authors Eakin and Gladstone (2020) described in their paper: *Value-adding analysis: doing more with qualitative data.* Key points are summarised here, and if you would like me to send you a copy of the full publication, please let me know.

We will apply the same overarching principles in our analysis of each participant group (staff, young people and companions). There may be some differences to the way we approach the analysis of each data set to account for photographs and other data. Observations, field notes, photographs, and learning logs are also all considered data which may be integrated into the analysis.

6. The essence of "value added" analysis

Returning to our overarching approach, here is a summary:

Authors Eakin and Gladstone (2020) describe borrowing the term 'value added' from economics to refer to the increased value of the knowledge produced through an analysis that reaches beyond the self-evident or surface value meanings of data. To add value, they say, requires us to penetrate the data and surface possibilities for meaning and interpretation. This type of analysis is interested in characterising findings at a more abstract level, alongside consideration of how different concepts relate to one another.

The authors describe four principles that frame the analytic approach which I have contextualised in relation to our data:

1. *Analysis as interpretation*

   The data we have generated does not exist independently of how it is conveyed in an interview or photograph. Data therefore do not truly reflect reality or speak for themselves – this is constructed by us as we interpret data (assign meaning), conceptualise data (begin to see data as instances of concepts) and then link and explain the data.

2. *Analysis as contextualisation*

The meaning of data is understood to be produced by the context in which it is situated i.e. we need to take context into account in assigning meaning. An example of this might be the Covid pandemic and how this has influenced Ambulatory Care. But there will be other contexts – for example different family and social support structures that have bearing on experience of Ambulatory Care. We will need to work out which context matters to the data and how we might use this in our interpretation.

3. *Analysis as the creative presence of the researcher(s)*

What this means is that the involvement of researcher insight and experience is not seen as a source of bias, rather a source of insight. As researchers our role is to constantly interpret and reinterpret data as our analysis is progressed, trying out different explanatory frameworks. Eakin and Gladstone call this 'creative presence'.

4. *Analysis as critical inquiry*

This means that we do not take things as given fact, but we think about some of the assumptions that underpin why things are the way they are. It also relates to issues of power and how/where it is exercised in the generation of data or in people's experience of care and how it relates to the knowledge we generate.

These principles underpin our approach to analysis. Eakin and Gladstone (2020) then describe several practical 'actions' to help us take forward these principles to generate value added findings, namely:

1. Use one’s own knowledge as a resource when analysing data – it can be a valuable source of comparison and insight. This may encompass thoughts about how the data has been influenced by you/us being involved in its generation.
2. Everything is data – photos, learning logs, field notes and reflections are all data for consideration which can deepen interpretation of the interview transcripts.
3. Read for the invisible – reading between the lines of what is said. This refers to consideration of meaning that is embedded in use of metaphor, or where what is said may be a metaphor for something else. This also includes reading for hesitation or silence.
4. Read for anomaly – we often search for similar words or phrases in transcripts, but it is also important to consider what is different or doesn’t fit.
5. Generative coding – codes are labels used to mark sections of text of significance. But Eakin and Gladstone caution that these labels refer to what *we think* they mean, and this can be limiting. The assignment of codes makes managing and sorting through the data manageable, but we must make sure that we don’t close off other possible interpretations as we interact with the data. The advantage of completing the analysis in a group is that we can challenge our different interpretations.
6. Read for a sense of the whole – by breaking down data into codes it can make data more manageable but being mindful of the overarching context is important.
7. Writing as analysis – this refers to the process of naming or conceptualising something as a process of analysis in itself. Our choice of language is central to how meaning is constructed and communicated.

So how do we practically engage in analysis? The next section offers an overview which will be expanded upon in the face-to-face meetings.

7. Thematic analysis

The most accessible form of analysis follows some form of thematic structure. Commonly this involves the grouping of data into categories and themes for further interpretation, and later to organise how the findings are presented.

But what exactly is a category and a theme?

As you begin to work with the interview data, knowing the distinction may help.

A category is a collection of similar data organised into the same place so that as researchers we can describe the characteristics of the category. The Cotton Rooms breakfast for example would be a category, grouping all narrative about the breakfast together, which may help us give feedback about the service. A theme however is "a meaningful essence that runs throughout the data" (Morse, 2008, p.727). Something like 'privacy' might be considered a theme, from which we might build an interpretation of what privacy means in an ambulatory context, alongside it's value to young people.

Categories are developed by grouping similar types of text together, so that example after example of the same thing can be examined and the commonalities described. Categories can be useful to organise some data but do not lend themselves to higher levels of abstraction or interpretation.

Identifying a theme, however, requires more analytic thought. Morse (2008) explains that to identify a theme, the researcher reads the interview paragraph by paragraph whilst asking "what is this about?". We might then try to ask: "what is this an example of" before trying to explain the essence of the theme from the data. Morse makes a further distinction: whereas a category might relate to a certain part of the interview, a theme is more likely to run right through the data.

8. Analysing interview transcripts

When you first see an interview transcript you will notice that there is a large margin to the right of the page. This is there for you to make notes. You will also see that each line is numbered. When we start to combine different participants' data, including the participant number and text line number will ensure we have an audible trail back to the original source.

Before we come together in a group, you will be invited to familiarise yourself with one or two transcripts. Here is a suggested approach for this initial phase of analysis.

Stage 1:

Re-orientate yourself with the research questions (page 2) and interview topic guide (see page 10).

Read through the transcript without making notes to familiarise yourself with the content.

What stands out for you? What feelings do you have about what is described? Is there something missing that you expected to hear? How might you now organise what you notice?

Stage 2

Read the transcript again. Start to highlight or label sections of text to highlight what you have interpreted as important. You could make notes in the margin using the literal words of the participant, a feeling, or label with a possible category name or emerging theme label. Read with curiosity and try to embed the principles described by Eakin and Gladstone. Read from different standpoints, for example in the staff interviews, you might read from the perspective of a professional, a commissioner of services and a patient. Or as a young co-researcher you might read from your standpoint as a young person who has accessed cancer services. When highlighting text, keeping a sense of the whole sentence/paragraph rather than pulling out individual words can keep the label you are assigning contextualised.

Stage 3

We will then come together to progress the analysis in pairs or in 1 or 2 groups. Each transcript will have been read in detail by 2 researchers at this stage.

We will share and compare how we have begun to interpret the transcripts, and we will progress the analysis in conversation with one another. We might ask:

- What's consistent?
- What's contrasting?
- What's beneath the surface (words)? What might be going on here?
- How does the data support us to answer the research questions?
- Is there enough evidence of [name of theme/concept] for this?
- How can we organise what we are learning?

This will be a 'hands-on', conversational tabletop exercise, and may involve coloured sticky notes!

Stage 4: Additional considerations for staff interviews

We will consider our interpretation in relation to the drivers for Ambulatory Care that informed the commissioning of the service in the NHS.

We will consider what we are learning in relation to the concept of age-appropriate care. How does our interpretation align or differ?

Alison will continue the analysis on the remaining staff transcripts. The data from each transcript will be brought together using a software package to facilitate consideration of the findings as a whole. We will revisit these together once we have begun analysing the young people's interview transcripts and photographs.

Stage 5: Additional considerations for photo-guided interviews with young people

We will consider our analysis in relation to the research questions (page 2) focusing on how young people experience of Ambulatory Care. Within this we want to understand which features of the service are valued most by young people; this will help us to define those that are critical to the successful delivery of the service. To do this we will connect with the written transcript and accompanying photographs. Before we begin it may help to revisit the interview topic guide (Appendix 2).

You may recall from our training workshops in 2020 that the photographs taken by participants are considered data for analysis. Dr Nicole Brown is a participatory researcher who works with visual methods. She has described an approach to analysing visual and textual data alongside one another, which is described in a published paper here: Systematic Visuo-Textual Analysis: A Framework for Analysing Visual and Textual Data (ucl.ac.uk)

Nicole and her colleague Jo Collins explain how to connect the visual and textual (word) element of participants contributions, first looking at the photographs, then the interview narrative, and then connecting the two together. To understand what is meant by this, you might like to follow the hyperlink through to see the example of how they analysed Lego model constructions and interview text from participants (PhD students).

9. Engaging in the process

Before diving into reading an interview transcript, do take a few minutes to connect with the participant's photos, and make some notes to describe what you notice. Working through the following questions may help you do this:

- What do you notice?
- What stands out or comes to mind?
- In a few words can you describe what you see?
- Are you drawn to one or two images in particular? Why?

This is the 'noticing and describing' level of analysis described by Brown and Collins, summarised in the box below (element 1).

	Element 1 visual only	**Element 2 textual only**	**Element 3 visuo-textual combined**
Level 1 noticing and describing	artistic in visuals (use of colour, space, composition)	linguistic in textual work (use of words, phrases, structures)	connect the visual and the textual (structure, meanings, expressions)
Level 2 conceptualising	essential elements that unite artefacts	words/phrases that capture patterns/themes	connections between artefacts and themes

After you have read and familiarised yourself with the written transcript and have made notes (element 2), do you notice connections between the visual and textual data (element 3)?

Then, as you connect with the interview transcript more closely, return to the set of photographs:

1. What can you say and note down about what you see as a whole?
2. What feelings do you have?
3. What themes or concepts come to mind?

We will then take your preliminary analysis to a group format to progress the Level 2 analysis.

As you read the transcripts and connect with the photographs you will be seeing the data through the lens of your lived experience - similarly I cannot separate out my professional experience from my engagement with the data. Where you find yourself reflecting on your own experiences in relation to the data, do note/place mark this as it could be helpful to either quietly revisit yourself or share during our discussion of the analysis together.

10. In summary

The principles of qualitative analysis require us to connect creatively with the transcripts, and to think around and beyond the words on the page. The methods described in this handbook intend to equip you with a toolkit of resources; they do not require rigid adherence. The analytic approach chosen does not require you to have any research experience, rather it draws on your lived and professional experience and on your capacity for analytic thought. It's designed to be a robust, yet fun experience, and one of the benefits of undertaking analysis together is that it will be strengthened by the contribution of different perspectives.

References:

Brown, N., & Collins, J. (2021). Systematic Visuo-Textual Analysis: A Framework for Analysing Visual and Textual Data. The Qualitative Report, 26 (4), pp.1275-1290. https://doi.org/10.46743/2160-3715/2021.4838

Eakin, J and Gladstone, B (2020) “Value-adding” analysis: doing more with qualitative data. *International Journal of Qualitative Methods* 19, pp.1-13

Morse, J (2008) Confusing categories and themes *Qualitative Health Research* 18(6), pp.727-728

Appendix 24 Format of the analysis workshops

Workshop no.	Date of workshop	Venue	Analytical Focus	Co-researchers: number and composition present at workshop
1	2nd October 2021	Community Centre	Staff experiences	n = 6 • 2 young associate researchers • 2 associate companion co-researchers • academic (research supervisor) • research lead (PI)
2	30th October 2021	Community Centre	Young People's experiences	n = 6 • 2 young associate researchers • associate companion co-researcher • academic (research supervisor) • member of AC nursing team • research lead (PI)
3	6th December 2021	Library study room & virtual	Companion experiences	n = 3 • 2 associate companion co-Researchers • research lead (PI)
4	29th January 2022	Library study room	Thematic interpretation, building explanations across participant datasets	n = 5 • 2 young associate researchers • 1 associate companion co-researcher • member of AC nursing team • research Lead (PI)

Workshop no.	Date of workshop	Venue	Analytical Focus	Co-researchers: number and composition present at workshop
5	5th March 2022	Teenage and Young Adult Service (study site)	Defining the critical components of Ambulatory Care Advancing conceptual interpretation of the research findings	n = 5 • 3 young associate researchers • associate companion co-researcher • research lead (PI)

Appendix 25 Analytic lenses that informed data analysis

Different analytic lenses adopted by co-researchers to help inform data analysis

Six index cards were distributed on index cards: power and equity; our use of language; context; assets and resources; general versus specific and the TYA philosophy of care.

1. Analytical lens: **Power and equity**

   Does status, power and hierarchy feature? If so, where, and how?
   Do social demographics influence experience of Ambulatory Care?
   What about different family configurations?

2. Analytic lens: **Our use of language**

   How inclusive is our language? How is it shaped by the data?
   Considerations for the action imperative of the research – how does this play out in our analytic discussion?
   What else do we notice or hear?

3. Analytic lens: **Context**

   Thinking about ‘analysis as contextualisation’ (Eakin and Gladstone, 2020), what becomes relevant when considering the findings through this lens?
   The data belongs to a chronological time and an organisational context. To what extent does the strength of our findings transcend this?
   What else?

4. Analytic lens: **Assets and resources**

   Thinking about the assets or resources of a young person and their family, what becomes relevant from the perspective of:
   - partnerships
   - managing own risk and care requirements
   - motivations

   What else?

5. Analytic lens: **General versus specific**

   Is a finding more general to the experience of living with a cancer diagnosis, or is it more specific to Ambulatory Care?
   Do you notice any examples of this?
   How are we contextualising someone's experience whilst ensuring that our analytic focus remains on Ambulatory Care?

6. Analytic lens: **TYA philosophy of care**

   How do the findings align with what you know about age-appropriate care
   What do you notice in relation to this?

Appendix 26 An example of Systematic Visuo-textual analysis

	Element 1 Visual only	**Element 2** Textual only	**Element 3** Visuo-textual combined
Level 1 Noticing and describing	‘Treatment’ Image of a PICC line with chemotherapy running into right arm	Treatment is a large part of the whole process. It's probably the hardest part as well (10). As you can see in the image, that's intravenously, but I also take tablets as well, and I have injections. So, there's various different ways in which the drugs are administered, but it, kind of, takes over your life (13-15). I’ve had to learn to take each day as it comes, and in some ways to not really think about it, and to just do it. Because I feel like sometimes thinking about the treatment and the whole idea of having cancer, it creates a negative atmosphere and that's one thing that you can't have. You've got to stay as positive as you can (45-48). I don’t like the treatment, although it does make you weaker, mentally it makes you stronger because you're dealing with it (389-90).	Treatment a large part of process but not defining of whole cancer experience. A need to be mentally engaged in care and accepting that things may change. Not always able to be in control. Remaining positive, a future focus; ‘dealing with it’.
Level 2 conceptualising	Accepting of treatment Symbolic of cancer treatment		
Level 1	‘Contemplating’	You have freedom (58)	Fresh air and freedom to choose where you go when not receiving treatment.

	Element 1 Visual only	**Element 2** Textual only	**Element 3** Visuo-textual combined
Noticing and describing	Walking alone in a public park area close to the hospital, being with nature, blue sky.	Where in the hospital, you are confined to your room. You are not able to get any fresh air (61). You have to go into the Cancer Centre to get your treatment, but once that's done, you've got that freedom again to go and do as you please (187-188) This image is linked strongly to the idea of freedom, in the sense that whilst you're in Ambulatory Care, when you're not in the clinic receiving treatment, you're able to go out and go where you want (243-245). One thing that I did almost on a daily basis is went out to somewhere where there was a bit of greenery, somewhere that's quiet, where you can just sit and relax and become part of society again, as anyone would really (245-247). Appreciating the little things in life (250). You do contemplate…prepare yourself mentally for the what ifs (267). I feel lucky, lucky to be where I am (275) Maintaining a focus on the future (279)	Appreciating the little things Positivity, time to oneself, not being defined by treatment. Structure and routine Being part of society again
Level 2 Conceptualising	Time one’s own, freedom to choose Not journeying alone (someone took photo) Movement, progression		

	Element 1 Visual only	**Element 2** Textual only	**Element 3** Visuo-textual combined
Level 1 Noticing and describing **Level 2** conceptualising	‘Treatment’ Clinical area all set up for the day, or at the end of a day Treatment couches facing into the room Mural recreating a nature scene on the wall Waiting Expectancy, being expected	This is in the Cancer Centre, this is the clinic… it's important again to document where it all happens and what the atmosphere was like (196-198). The primary purpose was as a record of this is what I can show other people, this is what it was like, that's the chair that I sat in (201-202). As you can see in the picture, it's 4 chairs that face inward to each other, so you can communicate with other people, and you can get to know others who might have a different type of cancer. It gives you, most certainly, something that you don’t get in a hospital, because you're in your own room, and it just gives you that chance to socialise (212-15). …Assuming that COVID wasn't an issue, you would be able to go and sit in there {Cotton Room lounge] and socialise with the people that you met in the clinic, and learn a bit more about them, make some friends. I’ve got three people, I think, that I've got their contact details, and I message them every now and again, see how they're doing, just, 'Hope you're okay, hope treatment's going well.' It's nice to get a response as well, have somebody else ask how I am, how things are for me. Because they know what it's like, they'll be going through cancer as well.	Importance of environment and seating position. Where the clinical treatment happens Sociable. Able to meet others who understand

	Element 1 Visual only	**Element 2** Textual only	**Element 3** Visuo-textual combined
Level 1 Noticing and describing **Level 2** conceptualising	'Change' Image of a bathroom in the Cotton Rooms. Overhead shower and bathtub. Hotel standard except plastic shower head noticeable. Personal toiletries on the side. Privacy Vulnerability	Baths are more relaxing for my body (288). This is where most of it happens, that's when it hits you, the reality of it, and you see that you're losing your hair (295-6). It almost acts as a constant reminder of the fact that you have cancer (299). Ambulatory Care becomes its own little bubble, separate from society, where everyone's in a similar position. Everyone's going through change, be it physical with their bodies, mentally, emotionally (315-18).	Being vulnerable in privacy Everyone's going through change in Ambulatory Care
Level 1 Noticing and describing	'Support' Poster on the wall promoting free condoms (c-card) Closed shutters in background Painted rainbow mural	So, this is just an example. It's something I noticed whilst being in the Cancer Centre, and it's not particularly the photo I'd have wanted to take, but I used it as an example. It goes to the idea of support (362-4). But I also wanted to discuss charities as well, because charities are very supportive, and there's a lot of different ways that charities can support you (366-8). Being in Ambulatory Care, you build an even stronger relationship with whoever is staying with you, and you look to them to support you in the times where you're feeling down or negative (386-88). Though I don't think we would have had any intimacy ourselves, I would certainly have had	Support and advocacy of charities Strength in relationships Intimacy challenged by cancer at a time when so much is not normal A more normalised environment in Ambulatory Care, which supports confidence and promotes normality Promotion of independence

	Element 1 Visual only	**Element 2** Textual only	**Element 3** Visuo-textual combined
		more confidence than being in hospital were we to have any intimacy. That's partially as we wouldn't have nurses coming in on a regular basis, but also as there is an element of normality that is reintroduced that would make me feel more comfortable in doing so. I think the offerings of charities, such as the one in the image also play a significant role in helping encourage this in people (420-25).	
Level 2 conceptualising	Privacy Hope, positivity normality	The most important feature to me is the ability to do things independently, and the idea of being reintegrated back into a normal lifestyle from being in hospital (431-2).	

Appendix 27 Suggestions for service improvement

1. Create a welcome pack setting out the range of facilities available in hospital or charity supported AC residential settings, together with how to access them.
2. Ensure information about parking permits and other dispensations is shared in the provision of information at the start of treatment.
3. Ensure the availability of fridge space to accommodate groceries and drinks (with additional access to a communal freezer).
4. Ensure there is the option to select or order free evening meals.
5. Facilitate access to basic grocery supplies (milk, bread, fruit) on an opt in basis at no charge to patients or companions.
6. Offer the means to prepare and heat/cook simple food irrespective of the residential setting. Consider a compact hob, fridge and kitchen sink arrangement in hotel rooms.
7. Appraise the feasibility of an ice machine or regular access to cold compresses (e.g. for the weeks following surgery).
8. Offer access to laundry facilities.
9. Ensure hotel and apartment room fire doors facilitate entry and exit in a wheelchair without need for companion/others assistance.
10. Review the bathroom set up in the hospital hotel to ensure consistent availability of hooks to hang backpacks.
11. Ensure the healthcare team and families know the procedure to follow to request access to a hotel room with a wet room shower or bath, according to preference.
12. Reconfirm security arrangements with respect to how young people can request being accompanied to the main hospital site out of working hours and share this information on each AC admission.

Appendix 28 TYA participants – treatment pathways

Cancer treatment protocols, chemotherapy agents or care being received on an AC basis among the eighteen young people who participated

Diagnosis	Treatment protocol
Osteosarcoma	MAP (methotrexate, doxorubicin, cisplatin)
	Ifosfamide, etoposide
Ewing sarcoma or soft tissue sarcoma	VDC-IE (vincristine, doxorubicin, and cyclophosphamide, alternating with ifosfamide and etoposide)
B-cell Acute Lymphoblastic Leukaemia (B-ALL)	UKALL
	Treatment of localised infection
Acute Lymphoblastic Leukaemia (ALL)	Venetoclax, azacytidine
	Post allogenic transplant
Acute Myeloid Leukaemia (AML)	High-dose ARA-C (cytarabine)
Non-Hodgkin Lymphoma (NHL)	LEAM Autograft transplant
	R-CYM

Appendix 29 Thematic summary of freedom

Code	Example quotes
Freedom to go outside	"It's nice to go out to the shops and be pushed around in a wheelchair, or after the operation when I was able to walk on crutches and things, it was nice to have that freedom. Yes, it was just nice to be outside, not always on a ward or whatever" (YC) "Just having the freedom to …just go outside when I wanted" (YD) "It gives me the freedom to be out and about" (YI)
Not feeling constrained	"I can go out, get my own food, go for a walk when I want to go for a walk, so there's no restriction on what you do" (YB) "That sense of freedom, I think that's the biggest thing really. Not constrained to hospital environments" (YI)
Feeling more like yourself	"When you're not, you know, in hospital, you have much more freedom, you become much more like yourself" (YD) "It's just a selfie of me just having a beer. I think that makes a point in itself if you see what I mean. I had the freedom to go out and do that" (YK).
Freedom to exercise choices	"It was just quite freeing to be able to do something as simple as go out and get ice cream, really. It just felt like I wasn't trapped, like I could do what I wanted to. Like I could still experience things that I would experience even when I was, you know, healthy" (YD). "You have to go into the Cancer Centre to get your treatment, but once that's done, you've got that freedom again to go and do as you please" (YQ). "Freedom to do, eat, drink what you want to drink, do what you want to do. Normality. You're in charge. You decide. You're not being told what to do" (YN)
Freedom to help oneself	"My mental health was better since being in Ambulatory Care just because of that freedom… it just allowed me to have the freedom to help myself if that makes sense" (YF) "I think freedom is definitely a word, I think I'd say it's about being positive, supporting my mental health" (YC)

Freedom to live one’s life	“That freedom you get. For me, that's the most attractive thing, you know, allowing people to live their lives, and still have cancer. It is so empowering” (YF) “The freedom to, even on care, actually do some of the things you like makes you think, well if I can do some of the things I like on care, then I can think of ways around doing things I want to when I'm off care. The freedom allows you to really see that, it makes you adapt” (YJ) “It's much better than the hospital because you are more free. You can recover yourself, slowly, slowly and live” (YO)

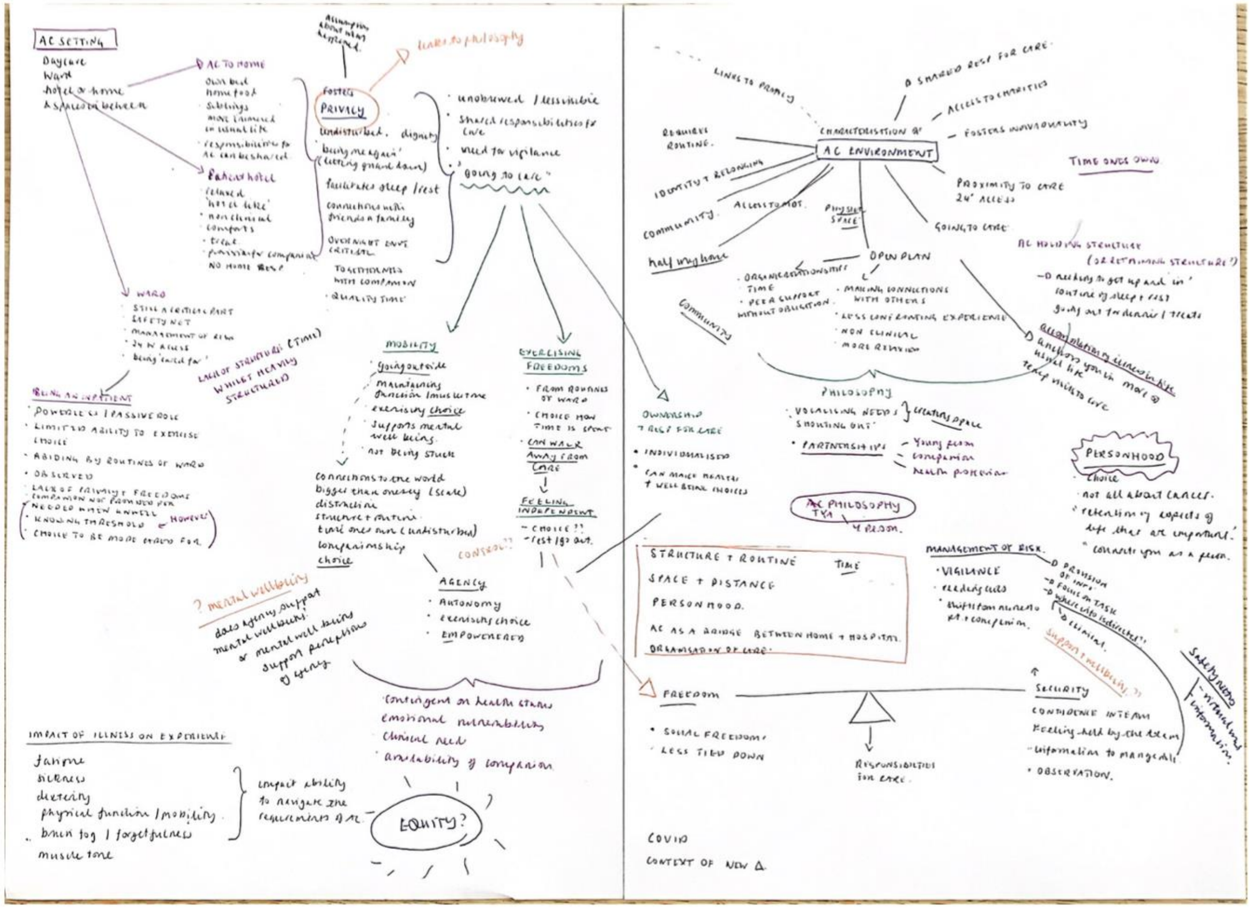
Appendix 30 Different aspects of the theme ‘privacy’

Code	Example quotes
A more private environment	“In Ambulatory Care, and going to the Cotton Rooms, you do have that privacy, a space you can kind of recede to after your treatment, and you can be yourself more- and have some peace, and quiet, and space”. (YE) “That’s the one thing you really begin to appreciate: privacy. Because on the wards you don’t really have any privacy”. (YD) “…you’ve got your own toilet…compared to in a hospital where you’ve got to share it with, like, four other people”. (YR)
Respecting personal privacy	“…when you're on the ward, and the doctors do their ward rounds, they don't whisper to you. Everyone can hear what is wrong with you, and why you're there. It's not nice when you hear, like, doctors talking to other people about their problems either. Yes, it's just more private”. (YN) “In the hospital you’ve got no privacy, you can hear everyone around you…Privacy is especially important for cancer patients, a lot of the time you are measuring your [urine]. If you’re in a room with a bunch of other random people that’s going to be pretty strange, so it’s good to have a certain level of privacy”. (YJ) “It’s just nice to be in your own space and not to have to be around other people, I would say”. (YH)
A more private experience	“You have more privacy, definitely. You can go out and you don’t have as many eyes on you, so I think that’s amazing”. (YM) “On the ward your guard’s always slightly up because you’re constantly in a vaguely social situation, so you can’t truly relax”. (YD)
Less need for consideration of others	A big thing during this is, like, Facetiming other family members. So, you feel like you can say what you want in the Cotton Rooms. You don't have to-, 'Oh, can they hear us?' It's, like, a private conversation. Or if we call at night, we're going to wake them [other patients] up”. (YJ)

Undisturbed privacy	"I would certainly have had more confidence than being in hospital were we to have any intimacy. That's partially as we wouldn't have nurses coming in on a regular basis". (YQ) "Being able to go back to somewhere more private at night is very nice. In the hospital, you constantly have people coming into your room, whether it's cleaners, whether it's the nurses, doctors, healthcare assistants checking your vitals, or the people bringing or taking away trays of food. You're constantly having people coming in and out, so you don't really feel you have that privacy at all". (YE)
Privacy and choice	"I wanted to take this picture to show that you also get the privacy when you want it. It's one of the things I really think is beneficial about the Ambulatory Care is definitely the privacy. It's nice to just be in your own hotel room and have a shower when you want and stuff". (YI) "Some people might want to get through treatment with loads of people around them, but then some people try to keep it private…I didn't really want to talk about it when I didn't need to". (YN)
Privacy and freedom	"I definitely prefer being able to have like the relaxation of being in the hotel just because, on the ward, it's a bit-, you have more privacy here, I think. And it's more natural, like you can do more, you have more freedom". (YG)
Privacy and normality	"Because in a normal world and in a normal life you have that privacy. You have your bedroom" (YE)

Appendix 31 Analytic mind map

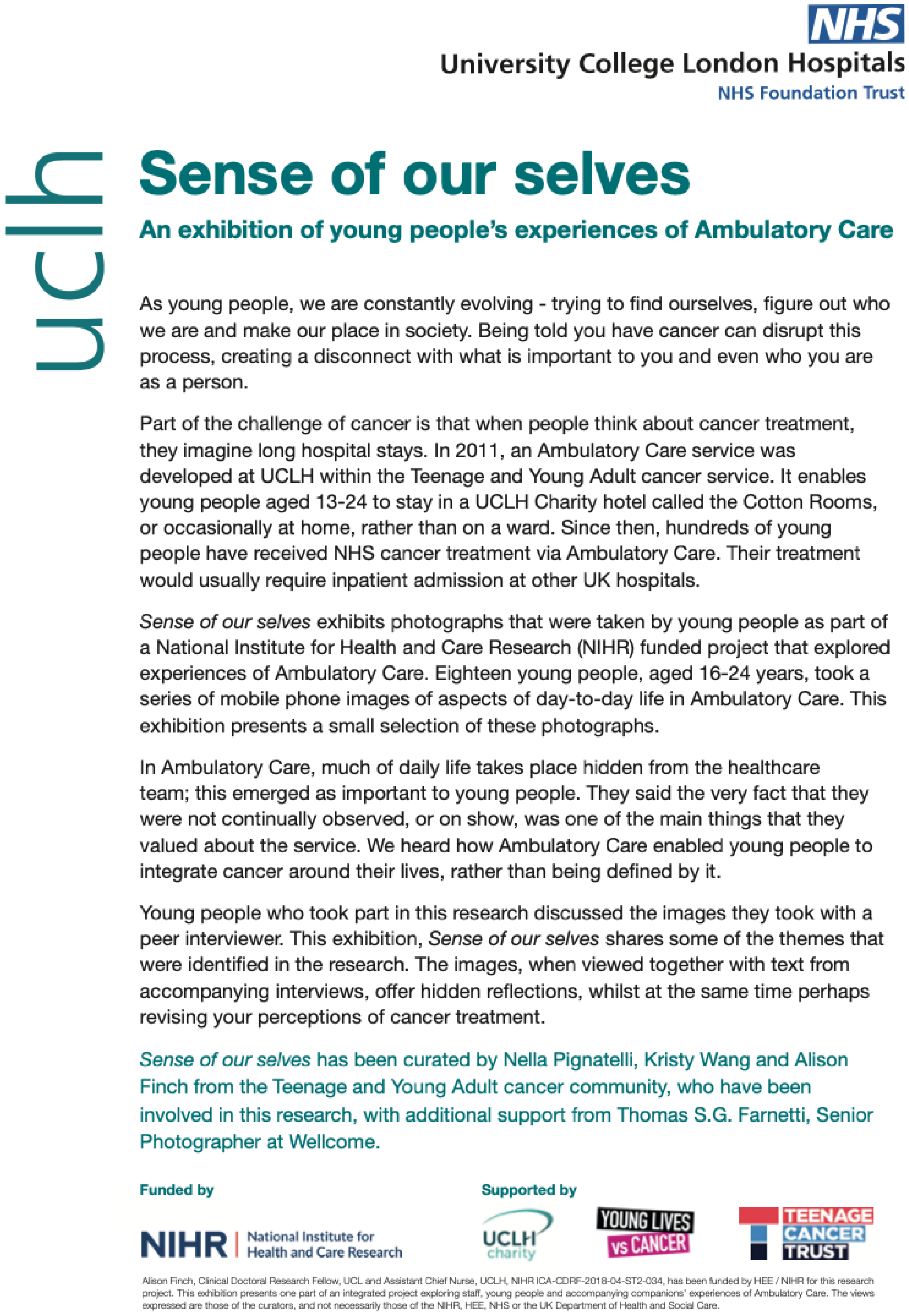
An example of an analytic mind map used to anchor and progress our participatory interpretation of the data



Appendix 32 Companion perceptions of emotional support

	Do you feel that your support needs have been met?
CA, partner	To be honest I don't think so. I think that the support is more for [partner’s name] and I feel like when we go to day care for example, the focus is very much her and how [she]'s doing. Which is normal, that's how it's supposed to be. But then on the other side of it, it's kind of like, ‘yes she is the patient, but then I'm supporting her’, and her mum's supporting her, where do we go for that support?
CJ, father	No, I haven't received any discernible offers of support that I'm aware of. In fact, this conversation we've had tonight so far has probably been the most cathartic conversation I've had, to be honest. Because it's with a couple of strangers until now, who are obviously very clued-up with what's been going on.
CH, mother	I'm not resentful when I say this, but I didn't have anybody asking me how I was doing. I have my family for that, thank goodness. No, no questions-. I'm so grateful for everything that we've received so I don't mean that disrespectfully at all, but no one asked, ‘how am I doing?’
CF, mother	One thing I'd note is that nowhere, at any point, that anybody came to me and asked me, 'Are you coping? Do you need to talk to anyone?' What I felt most was I'm unimportant. Not that I wanted to be important but in order for me to provide this care for [daughter’s name], I needed to be stable. I don't want to sound ungrateful because staff and everyone have been amazing, all they have done for her so far-.

Appendix 33 'Sense of our selves' photography exhibition



NHS
University College London Hospitals
NHS Foundation Trust

uclh

Sense of our selves

An exhibition of young people's experiences of Ambulatory Care

As young people, we are constantly evolving - trying to find ourselves, figure out who we are and make our place in society. Being told you have cancer can disrupt this process, creating a disconnect with what is important to you and even who you are as a person.

Part of the challenge of cancer is that when people think about cancer treatment, they imagine long hospital stays. In 2011, an Ambulatory Care service was developed at UCLH within the Teenage and Young Adult cancer service. It enables young people aged 13-24 to stay in a UCLH Charity hotel called the Cotton Rooms, or occasionally at home, rather than on a ward. Since then, hundreds of young people have received NHS cancer treatment via Ambulatory Care. Their treatment would usually require inpatient admission at other UK hospitals.

Sense of our selves exhibits photographs that were taken by young people as part of a National Institute for Health and Care Research (NIHR) funded project that explored experiences of Ambulatory Care. Eighteen young people, aged 16-24 years, took a series of mobile phone images of aspects of day-to-day life in Ambulatory Care. This exhibition presents a small selection of these photographs.

In Ambulatory Care, much of daily life takes place hidden from the healthcare team; this emerged as important to young people. They said the very fact that they were not continually observed, or on show, was one of the main things that they valued about the service. We heard how Ambulatory Care enabled young people to integrate cancer around their lives, rather than being defined by it.

Young people who took part in this research discussed the images they took with a peer interviewer. This exhibition, *Sense of our selves* shares some of the themes that were identified in the research. The images, when viewed together with text from accompanying interviews, offer hidden reflections, whilst at the same time perhaps revising your perceptions of cancer treatment.

Sense of our selves has been curated by Nella Pignatelli, Kristy Wang and Alison Finch from the Teenage and Young Adult cancer community, who have been involved in this research, with additional support from Thomas S.G. Farnetti, Senior Photographer at Wellcome.

Funded by

NIHR | National Institute for Health and Care Research

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Alison Finch, Clinical Doctoral Research Fellow, UCL and Assistant Chief Nurse, UCLH, NIHR ICA-CDRF-2018-04-ST2-034, has been funded by HEE / NIHR for this research project. This exhibition presents one part of an integrated project exploring staff, young people and accompanying companions' experiences of Ambulatory Care. The views expressed are those of the curators, and not necessarily those of the NIHR, HEE, NHS or the UK Department of Health and Social Care.

Appendix 34 Learning log template

Learning Log

Reflexivity is a critical component of qualitative research. After the interview, before carrying on with your day, try to pause and consider these questions in relation to your interviewing experience.

Date: **Interview number:**

How was that?

It felt awful   not bad   getting better   quite good really   I thought it went well

What do I notice about myself?

What am I learning?

What seemed to work well?

What will I do more of next time?

What might I refine?