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Understanding how prognostic decisions are made within a specialist palliative care multidisciplinary team

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Declaration

I, Andrea Bruun, 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.

Date	Andrea Bruun

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Abstract

Clinicians' prognoses of dying patients may be improved by involving a multidisciplinary team (MDT). However, the process of MDT prognostic decision-making is not well understood. This thesis investigated how members of hospice MDTs formulate and make prognostic determinations. Three studies were conducted, applying a mixed methods research approach to address the study aims.

A scoping review revealed that prognoses were primarily made by doctors and nurses and were often subsumed in discussions of other aspects of care. The review showed a prominent lack of research from specialist palliative care settings. Furthermore, there was an evidence gap regarding quantitative studies investigating MDT decision-making and how MDT members formulate prognoses.

For this reason, an online Randomised Controlled Trial study evaluating how prognostic "judges" weighed the advice of prognostic "advisors" (including algorithmic advisors) was conducted. The study found that palliative care MDT members (regardless of professional background and experience) integrated prognostic advice more when they perceived it to come from a prognostic algorithm rather than from another clinician with a different profession.

To understand how prognoses were formulated, a conversation analytic study of hospice MDT meetings was conducted. The study found that prognoses were rarely explicitly discussed during MDT meetings. Prognoses were sometimes discussed when prompted (by an item on the meeting template) or could be mentioned as part of a wider discussion of care. Prognostic time estimates often just included statements that the patient was "dying" or used unspecific timeframes. Specific time estimates rarely occurred. Prognostication was also shown to be an interactionally delicate matter.

The use of mixed methodologies provided a greater understanding of prognostic decision-making within hospice MDTs. The findings may be used to guide future research and to inform recommendations for hospice MDT prognostic communication and the discussion about the implementation and feasibility of prognostic algorithms in clinical practice.

Impact Statement

The findings from the research will potentially benefit palliative care professionals and academics in the field, thus having benefits both outside and inside academia.

Benefits outside academia

To effectively improve prognostic communication within hospice MDTs, it is necessary to base any intervention on how MDTs currently communicate in clinical practice. However, the scoping review in this thesis showed that there has been very limited evidence available on how prognostic discussions are carried out in specialist palliative care MDT settings. Based on findings from analyses of video recordings of naturally occurring hospice MDT interactions, the thesis provides such evidence. The detailed analysis of MDT members' prognostic talk can be used to make MDT professionals aware of their own practices when discussing prognosis. Evaluating and reflecting on current practice would be the first step to potentially change practice and/or identify good ways of doing MDT prognostication. Therefore, the study findings presented in this thesis can be used to inform recommendations or guidelines for prognostic communication in palliative care MDTs.

The thesis showed that clinicians integrate advice more from a prognostic algorithm than from another clinician in an online experimental setting. This finding can be useful for clinicians to consider when using such algorithms in practice. Professionals should be aware of their own biases and make sure they make an informed decision when dealing with input from both a prognostic algorithm and a colleague. The findings can also be used to facilitate a discussion about the implementation and feasibility of prognostic algorithms in clinical practice, which requires further exploration.

Thesis findings have been presented to collaborating hospices, where they have prompted reflections on prognostication such as *how* the MDT prognosticates, difficulties with prognostication, *when* a prognosis is relevant, and the potential of prognostic algorithms in clinical practice. These discussions offer a space for knowledge exchange between professionals about prognostication, which could have a positive impact on their prognostication practices.

The overall thesis work has also been presented to the Marie Curie policy and research team, where it might be useful in the work the organisation is doing on prognostication and access to benefits.

Benefits inside academia

This thesis is the first study focusing on MDT prognostication, and thus the findings offer novel insights into this area of research. Through a mixed methods approach, the thesis expands the evidence base and takes the first step in exploring and understanding prognostication in this setting. In this way, the thesis applies established research methods into the novel field of palliative care MDT prognostication, which provides the groundwork for future research.

Impact from this thesis has been brought about through dissemination in academic journals, international conferences, and social media platforms. Two papers have been published, one on the scoping review (Bruun, Oostendorp, et al. 2022) and one on the online RCT (Bruun, White, et al. 2022). Further three papers from the conversation analytic study are planned (i.e., initiating prognostic talk; time estimates in prognostic talk; and delicacy of prognostication).

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Publications and presentations

Publications

Bruun A., White N., Oostendorp L., Vickerstaff V., Harris A. J. L., Tomlinson C., Bloch S., & Stone P. 2022. An online randomised controlled trial of prognosticating imminent death in advanced cancer patients: clinicians give greater weight to advice from a prognostic algorithm than from another clinician. *Cancer Medicine: 00: 1-10. doi:10.1002/cam4.5485.*

Bruun A., Oostendorp L., Bloch S., White N., Mitchinson L., Sisk A-R., & Stone P. 2022. Prognostic decision-making about imminent death within multidisciplinary teams: a scoping review. *BMJ Open:* 12:e057194. doi: 10.1136/bmjopen-2021-057194.

Manuscripts in preparation

Bruun A., White N., Oostendorp L., Stone P., & Bloch S. Initiating prognostic discussions: a conversation analytic study of hospice MDT meetings.

Bruun A., White N., Oostendorp L., Stone P., & Bloch S. Time estimates in prognostic talk: a conversation analytic study of hospice MDT meetings.

Bruun A., White N., Oostendorp L., Stone P., & Bloch S. Prognostication as an interactionally delicate matter: a conversation analytic study of hospice MDT meetings.

Conferences

Oral presentations

Bruun A., White N., Oostendorp L., Stone P., & Bloch S. 2023. When discussing death is still a sensitive matter: prognostication within the hospice multidisciplinary team. International Conference on Conversation Analysis, 26 June to 2 July 2023, Brisbane, Australia.

Bruun A., White N., Oostendorp L., Stone P., & Bloch S. 2022. Discharge planning as a facilitator for discussing patients' prognosis during hospice multidisciplinary team meetings. Digital Meeting for Conversation Analysis, 31 October to 4 November, online.

Bruun A., White N., Oostendorp L., Stone P., & Bloch S. 2022. Time Estimates in MDT Prognostic Discussions: A Conversation Analytic Study of Prognostication within Multidisciplinary Team Meetings from a UK Hospice. *Palliative Medicine*: 2022;36(1_suppl):3-122. doi:10.1177/02692163221093145. 12th World Research Congress of the European Association for Palliative Care, 18 to 20 May, online.

Bruun A. 2021. Predicting the future: how hospice teams provide prognoses for terminally ill patients. 3 Minute Thesis Competition, Faculty of Brain Sciences Postgraduate Research Student Conference, 27 May, online.

Poster presentations

Bruun A., White N., Oostendorp L., Vickerstaff V., Harris A. J. L., Tomlinson C., Bloch S., & Stone P. 2022. Palliative Healthcare Professionals Prefer Advice From a Prognostic Algorithm Rather Than Another Professional When Prognosticating Imminent Death in Advanced Cancer Patients: The ADJUST Study. *Palliative Medicine*: 2022;36(1_suppl):3-122. doi:10.1177/02692163221093145. 12th World Research Congress of the European Association for Palliative Care, 18 to 20 May, online.

Bruun A., White N., Oostendorp L., Vickerstaff V., Harris A. J. L., Tomlinson C., Bloch S., & Stone P. 2021. Palliative healthcare professionals give greater weight to advice from a prognostic algorithm rather than advice from another healthcare professional when predicting 2-week survival: the ADJUST study. The National Cancer Research Institute Festival, 8-12 November, online.

Bruun A., Oostendorp L., Bloch S., White N., Mitchinson L., Sisk A-R., & Stone P. 2021. Prognostic Decision-making within Multidisciplinary Teams: A Scoping Review. *Palliative Medicine*: 2021;35(1_suppl):1-243. doi:10.1177/02692163211035909. 17th World Congress of the European Association for Palliative Care, 6 to 8 October, 2021, online.

Related publications

Anantapong K., **Bruun A.**, Walford A., Smith C. H., Manthorpe J., Sampson E. L., & Davies N. 2023. Co-design development of a decision guide on eating and drinking for people with severe dementia during acute hospital admissions. *Health Expectations*: doi: 10.1111/hex.13672.

Mitchinson L., Chu C., **Bruun A.**, Sisk AR., Armstrong M., Vindrola-Padros C., Kupeli N., Candy B., & Stone P. 2022. How best to capture the impact of complementary therapies in palliative care: A systematic review to identify and assess the appropriateness and validity of multi-domain tools. *Palliative Medicine*: doi: 10.1177/02692163221122955.

Stewart E., Tavabie S., McGovern C., Round A., Shaw L., Bass S., Herriott R., Savage E., Young K., **Bruun A.**, Droney J., Monnery D., Wells G., White N., & Minton O. 2022. Cancer centre supportive oncology service: health economic evaluation. *BMJ Supportive & Palliative Care*: doi: 10.1136/spcare-2022-003716.

Anantapong K., **Bruun A.**, Walford A., Smith C. H., Manthorpe J., Sampson E. L., & Davies N. 2021. Talking about eating and drinking for people with severe dementia during hospital stays. Retrieved from:

https://www.ucl.ac.uk/psychiatry/sites/psychiatry/files/eating_drinking_hospital_dementia.pdf

Invited presentations

PhD project presentation for the student society "ViGør" at Aarhus University, Denmark, 18 March 2022, online.

PhD project presentation for the Marie Curie Policy and Research team, 09 March 2022, online.

List of Abbreviations

AB	Andrea Bruun
ADJUST	Advice and Decision-making on prognosis using the Judge-advisor System within multidisciplinary Teams
AH	Prof Adam J. L. Harris
AMC	Academic Medical Centre
A-RS	Ali-Rose Sisk
CA	Conversation Analysis
CAG	Confidentiality Advisory Group
CI	Confidence Interval
CNS	Clinical Nurse Specialist
CONSORT	Consolidated Standards of Reporting Trials
CPR	Cardiopulmonary resuscitation
CT	Dr Christopher Tomlinson
DNR	Do Not Resuscitate
DoLS	Deprivation of Liberty Safeguards
DSPT	Data Security and Protection Toolkit
EAPC	European Association for Palliative Care
EOL	End-of-life
EN	Enrolled Nurse
GP	General Practitioner
HCA	Healthcare Assistant
JAS	Judge-Advisor System
KPS	Karnofsky Performance Status
ICU	Intensive Care Unit
IRAS	Integrated Research Application System
LCP	The Liverpool Care Pathway for the Dying Patient
LO	Dr Linda Oostendorp
LM	Dr Lucy Mitchinson
MDT	Multidisciplinary Team
NA	Nurse Assistant
NHS	The National Health Service
NICE	The National Institute for Health and Care Excellence
NW	Dr Nicola White
OSF	Open Science Framework
PA	Physician Assistant
PC	Palliative Care
PiPS	Prognosis in Palliative Care Study
PPI	Patient and Public Involvement
PPS	Palliative Performance Scale
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
PS	Prof Patrick Stone
RCT	Randomised Controlled Trial
REC	Research Ethics Committee
RN	Registered Nurse

SB	Prof Steven Bloch
SD	Standard Deviation
TR	Time Reference
UCL	University College London
VA	Veterans Health Administration
VV	Dr Victoria Vickerstaff
WOA	Weight of Advice

Table of Contents

List of Tables

List of Figures

List of Appendices

Chapter 1 – Introduction

Prognosis is essential to clinical decision-making about a patient's future treatment (Gill 2012). A prognosis also enables patients and families to make decisions, feel prepared for death, and it can help families to spend time with their loved ones before they die (Pontin and Jordan 2013). When being diagnosed with a terminal illness and, particularly, at the late stages of advanced disease, doctors report that questions such as "*how much time do I have left?"* or simply "*when?"* arise from patients (Christakis 1999). These are difficult questions to answer, and the sensitive nature of them also means that it is important to get them right. It is recommended that a patient's prognosis should be discussed by the palliative care team (National Institute for Health and Care Excellence 2015). The additional input from other team members with different professional expertise and backgrounds may be needed and valued, and it may help refine the prognosis (Chu et al. 2020). Additional input from prognostic tools may also be sought for verification reasons and is recommended to ensure the most accurate prognosis (Maltoni et al. 2005). The question is then: How do members of a palliative care multidisciplinary team (MDT) make decisions about patients' prognoses?

To gain an understanding of how members of the specialist palliative care MDT make decisions about patients' prognoses, three research studies were conducted: a scoping review, an online Randomised Controlled Trial (RCT), and a study using Conversation Analysis (CA). The specific research aims that these studies address are presented in Chapter 2. In this introductory chapter, the background for the thesis is presented. Relevant literature on palliative care, MDTs, decision-making, and prognostication is drawn upon to provide the reader with a context for the research.

1.1 Palliative care

The thesis is situated within the field of palliative care. That is, the treatment, care, and support for people with a life-threatening illness, and their family and friends (Marie Curie 2018). Palliative care prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial or spiritual (World Health

Organization 2020). Thus, the approach involves taking care of issues beyond patients’ physical symptoms and encompasses a holistic approach to patient care.

The primary aims of palliative care have been described as optimising quality of life before a timely, dignified, and peaceful death (Murray et al. 2005). Palliative care is also explicitly recognised under the human right to health (World Health Organization 2020). It is not restricted to specific medical diagnoses, it should be available for all patients with life-threatening diseases (Radbruch et al. 2009). However, the majority of patients receiving palliative care have chronic diseases such as cardiovascular diseases and cancer (World Health Organization 2020).

Palliative care uses a team approach to support patients and their caregivers, which includes addressing practical needs and providing bereavement counselling (World Health Organization 2020). Moreover, palliative care is interdisciplinary in its approach and should be available in any location including hospital, hospice, and community (European Association for Palliative Care 2020). Specialist palliative care services are those whose main activity is the provision of palliative care for patients with complex needs (Radbruch et al. 2009) such as hospices, palliative care units in hospitals, and community palliative care teams. These services require a team approach that combines a multi-professional team with an interdisciplinary mode of work (Radbruch et al. 2009).

This thesis focuses on the MDT within the hospice specialist palliative care setting. The scope of the thesis is further explained in Chapter 2. To provide the reader with an understanding of this setting, a brief overview of hospice care is presented below.

1.1.1 Hospice care

The hospice sector supports more than 225,000 people with terminal and life-limiting conditions each year in the UK (Hospice UK n.d.-a). In 2020-2021, UK hospices supported an estimated 300,000 people, which included people at the end of life, families, carers, and bereaved relatives (Keeble, Scobie, and Hutchings 2022). In the UK, there is no charge for people accessing hospice care (Care Quality Commission 2017), and most hospices are primarily funded through fundraising (Hospice UK 2016). Besides hospice inpatient care, hospice care involves community-based/home care, day hospice care and outpatient care services (Hospice UK 2016).

Hospices can provide care throughout a patient's disease trajectory, not only at the very end of someone's life (Hospice UK n.d.-b; Marie Curie 2022). There is no specific prognosis mandated for hospice terminal care admissions, however it has been speculated that most hospices are operating with a prognosis of less than two weeks (Chu, White, and Stone 2019). A service evaluation study of two hospices in Scotland showed that the majority of in-patient hospice admissions was for active end-of-life care, and that two-thirds of the patients in the study died during their admission (Haraldsdottir et al. 2023). Thus, most patients were approaching the end-of-life, where the care provided focused on symptom management and support in the last days and weeks of life (Haraldsdottir et al. 2023). Despite the study only including two hospices in Scotland, these findings support figures from Hospice UK (the national charity for hospice and end-of-life care in the UK) stating that the average length of a hospice stay in the UK is 15 days (Hospice UK 2016). Hospice care is, as described in the previous section, provided by MDTs to support individuals and their loved ones (Hospice UK 2016).

1.2 Multidisciplinary teams

To gain an understanding of how members of the hospice MDT make prognostic decisions, it is necessary to begin with defining what an MDT is.

> "When we have a health or social need it is rare that one profession alone is able to meet our needs. We can usually benefit from the skills and knowledge of different specialists – so long as their help is well coordinated." (Øvretveit 1993: 1)

An MDT includes members from different healthcare and non-healthcare professions and disciplines, who work together to provide care for patients (Radbruch et al. 2009). The primary goal of the MDT is to improve care management of patients (Ruhstaller et al. 2006). MDTs can comprise a wide range of professionals such as doctors, nurses, occupational therapists, physiotherapists, and social workers, where some professionals might only be involved in patient care on an *ad hoc* basis to meet specific needs (NHS National End of Life Care Programme 2013). They may specialise in certain conditions, such as cancer, and decisions about patient treatment and care can be based on reviews of clinical documentation such as case notes, test results, diagnostic imaging etc. (NHS Digital 2020). Besides oncology, MDTs are found within several disciplines such as care of the elderly and in mental health services (Ke et al. 2013). It has been noted that MDTs are the gold standard of modern healthcare systems and particularly in cancer patient management (Independent Cancer Taskforce 2015).

Effective MDT working has several benefits such as safer patient care, reduced patient anxiety, and continuity of care (Kidger et al. 2009). Weekly MDT meetings may improve team communication because they provide team members with more opportunities to talk (Kidger et al. 2009). Thus, the MDT facilitates communication between different professionals, which can improve the working environment and provide learning and development opportunities (Taylor et al. 2010).

Despite being the gold healthcare standard, the MDT faces several limitations. It has been noted that other professions are often outnumbered by doctors (Thornton and Dodwell 2012). This is often seen in cancer care where MDTs often consist of several doctors with different expertise. Doctors and nurses tend to be the dominate professional group represented in MDT meetings with relatively few of other professions regularly in attendance. The lack of professions in the MDT challenges its core multidisciplinary aspect. Another potential issue with the MDT is that the time designated or available for discussing patient cases is often very limited (sometimes less than five minutes) (Thornton and Dodwell 2012). Time pressures may not allow for a sufficiently (multidisciplinary) and well-thought through discussion. A systematic review of decision-making in cancer MDTs found that excessive workload and time pressure could result in reduced attendance and rushed decision-making (Lamb et al. 2011). A study of cancer MDTs in Ireland also showed that an MDT discussion did not result in significantly better quality decisions about patient treatment (Kee, Owen, and Leathem 2004). Another potential critique of the MDT is its lack of direct patient involvement. Patients' cases are discussed, but patients themselves are usually not present at MDT meetings. The exclusion of patients from MDT discussions conflicts with the NHS' "no decisions about me, without me" strategy, where patients should be involved in decisions about their care and treatment (Department of Health 2012). Patients are also unlikely to know basic principles and details about the MDT and meetings in which they are discussed, for example that meetings may include professionals and attendees who are not core team members, the number of team members actually involved, or the very limited time their case is likely to receive (Thornton and Dodwell 2012). This implies that despite the benefits of the MDT, it still has its issues and challenges.

There are several ways of referring to a healthcare team consisting of different professionals working together. Terms such as "multidisciplinary", "interdisciplinary", "multi-professional" and "interprofessional" are commonly used, but there is inconsistency in the way these terms are used within literature (Chamberlain-Salaun, Mills, and Usher 2013; McCallin 2001). There are different parameters that can be used to differentiate types of teams (Øvretveit 1996; Crawford and Price 2003). However, *multidisciplinary* is most frequently used to describe healthcare teams (Chamberlain-Salaun, Mills, and Usher 2013). A literature review found that regardless of the terminology used in papers, they all referred to the structural composition of the team, where teams are composed of members from a range of professional backgrounds and disciplines (Chamberlain-Salaun, Mills, and Usher 2013). In this thesis, the term *multidisciplinary team (MDT)* will be used, since this is the word most commonly used in literature and in healthcare settings. Furthermore, this is the term that was used by the hospice collaborator from one of the studies (see more on the conversation analytic study in Chapter 5) thus, reflecting the terms used in practice.

1.2.1 Palliative care multidisciplinary teams

MDTs are an essential mechanism for providing holistic care for palliative patients, including pain relief, psychological, and spiritual aspects of care (Vissers et al. 2013). Literature reviews on the effectiveness of MDTs within palliative care have shown that they can have positive effects, such as improving patients' satisfaction and reduce the overall cost of care (Leclerc et al. 2014; Hearn and Higginson 1998). Guidelines by the European Association for Palliative Care (EAPC) state:

> ”Palliative care is supposed to be provided within a multi-professional and interdisciplinary framework. […] the complexity of specialist palliative care can only be met by continuous communication and collaboration between the different professions and disciplines in order to provide physical, psychological, social and spiritual support.” (Radbruch et al. 2009: 284)

Thus, the MDT is an essential part of palliative care. In the UK, the government has acknowledged that end-of-life care requires MDTs working in partnership to deliver high quality and safe care to patients (NHS Finance and Operations 2016). A literature review also suggests that an MDT approach is best suited in order to deliver optimum palliative care (Fernando and Hughes 2019). As holistic palliative care includes both physiological, psychological, and spiritual symptoms and needs, the palliative care team needs professionals with different expertise. In order to make a potential broad range of professions work together effectively, the MDT with an interdisciplinary function has been proposed, where team members contribute from their particular expertise and with the team sharing information and working interdependently (Crawford and Price 2003). Moreover, clinical guidelines by The National Institute for Health and Care Excellence (NICE) recommend that a “multi-practitioner” approach to care is favourable, and that the skills and expertise of many specialties and disciplines are needed to meet patients’ varied and changing needs (National Institute for Health and Care Excellence 2019). Since the establishment of the palliative care concept, MDTs have had an important role to play, especially when dealing with particularly difficult clinical and family problems (Saunders 2000).

In 2022, the EAPC revised their recommendations on standards and norms for palliative care in Europe (Payne et al. 2022). The recommendations (still) had several points related to MDTs such as:

- “Specialist palliative care service requires multiprofessional and interdisciplinary work style”

- “Palliative Care Units require a highly qualified, multidisciplinary team. Staff members in palliative care units are supposed to have specialist training. The core team consists of physicians and nurses. The extended team comprises relevant associated professionals, such as psychologists, physiotherapists, social workers or chaplains”
- “There should be regular multidisciplinary team meetings (minimum weekly) to review palliative care patient’s referrals and care plans”

The last point regarding the MDT meeting, where the MDT gathers to discuss patient care, is a key component of palliative care practice in the UK (Borgstrom et al. 2021).

1.3 Decision-making

This thesis centres around the concept of making prognostic decisions, thus it is necessary to begin by understanding how people make decisions in general.

A common way to look at judgement and decision-making is through Brunswik’s Lens Model (Cooksey 1996), where the decision-maker reviews information, “cues”, and then bases the decision on these cues. Some cues may be regarded as being more important than others, and some may be discarded depending on the judgement and decision to be made. The Lens Model has also been applied to medical decision-making (Schwartz and Griffin 2012). where the clinician reviews cues about a patient (e.g., blood test results, mobility, medical history) in order to make a medical judgement and decision. The cues which have been found to be most influential when making prognostic decisions will be discussed later in this chapter.

Another decision-making theory is the dual-process theory (see Pelaccia et al. 2011). This theory suggests that people make decisions using two types of cognitive processes: System 1 thinking, which is fast and more intuitive; and system 2 thinking, which is slow, analytical, and more thorough. System 1 involves those decisions that are instantly arrived at. This process is often used by experts. In a medical context, an expert clinician may identify specific patterns and match them to previous patient examples, based on their extensive experience (Taylor, Dowding, and Johnson 2017). On the other hand, system 2 is non-immediate, requires more cognitive effort, and is characterized by being conscious, controlled and rule based (Taylor, Dowding, and Johnson 2017).

Another model is known as the emotion-imbued choice model (Lerner et al. 2015). This model accommodates how emotions permeate the decision-making process. It expands the more traditional rational choice models by including, for example, the utility for each decision outcome being judged also by predicting the decision-maker’s emotional response to that outcome and to include the impact of current emotions of the decision-maker. This may be particularly relevant when dealing with decision-making around prognoses and dying. The emotional aspect of prognostic decision-making will be further elaborated in later sections of the thesis.

This thesis focuses on how individuals in the MDT, make and are influenced by their own prognostic decisions; as well as how they discuss prognosis as a group (within an MDT). The next section therefore presents an overview of how decision-making operates in the MDT.

1.3.1 Decision-making in multidisciplinary teams

Healthcare teamwork has been described as a dynamic process involving healthcare professionals having a common or tangential goal, which includes assessing, planning, performing, and evaluating patient care (Klarare et al. 2013). Relevant to the work of assessing, planning, performing, and evaluating patient care, are the actual decisions that the team makes. For this reason, decision-making is a key activity in the practice of healthcare (Schwartz and Bergus 2008). When looking closer at decision-making within MDTs, Øvretveit (1993: 140-41) explains:

> “A multidisciplinary team without differences is a contradiction in terms. The point of a team is to bring together the different skills that a client needs, and to combine them in a way which is not possible outside of a team. If a team does not organize to combine different perspective and efforts, then there is no point in going to the expense of having a team.”

The author then states that the right decision-making process is critical in order to use these different professionals’ expertise in the best way possible. Quinlan and Robertson (2010) explain that when healthcare professionals are organised into MDTs it collectivises their clinical decision-making. In this way, the traditional divisions of labour are disrupted, and the accompanying logic of autonomous decision-making does not hold. In the MDT, team members need to interact with each other to frame problems and validate and share crucial information while making their team-based clinical decisions (Quinlan and Robertson 2010). The MDT interaction itself then becomes essential to decision-making. This has also been shown in a study where team members understood cooperation in a palliative care team in terms of communication (Jünger et al. 2007). Furthermore, the study found that communication and coordination were essential criteria for effective team work – and that lack of communication was a barrier (Jünger et al. 2007). It has been stressed that in order to maintain and increase the quality of decision-making, effective interaction processes and communication is crucial to help the team through the different stages of group decision-making; problem identification, information-sharing, and critical evaluation (of the information and consequences of different options) to formulating the decision and implementing it (Soukup, Lamb, et al. 2020).

It has been shown that information-exchange has a key role in group decision-making (Christensen and Larson 1993). Different team members might have different information because of differential access to family members and/or variability in the patient's self-reports (Christensen and Larson 1993). If there is unshared information between team members that is important for the patient's case, it is even more important that this information is brought up and shared with the team. This has been supported by guidelines by the UK General Medical Council, which state that doctors "…must communicate effectively with other members of the health and social care team or teams involved in a patient's care, sharing with them the information necessary to provide the patient with safe, effective and timely care." (General Medical Council 2010: 21-22). In this way, it is important that there are arrangements in place for information-exchange between team members.

Another way of looking at information-sharing between team members is through the lens of *advice*. The information that team members exchange when making decisions about a patient can be framed in terms of giving and receiving advice. The next section further describes the role of advice in decision-making.

1.3.2 Advice

The UK General Medical Council guidelines state that doctors should consult other members of the team who might have information, knowledge and experience that might help in managing the patient (General Medical Council 2010). That doctors should consult other team members is another way of formulating that clinicians should seek advice from others when making clinical decisions.

Using advice is an essential practice in making decisions in real life as well, whether it is as simple as seeking directions in an unfamiliar environment or more complex situations such as those involving legal or (as in this case) medical issues (Yaniv 2004b). Advice is usually sought from someone with more expertise or providing a different perspective (as noted in the UK General Medical Council guidelines), because of a need to improve the accuracy of a judgement and the expectation that advice will help (Yaniv 2004b; Sniezek and Van Swol 2001). Group or team decision-making is known to be more effective than individual decision-making due to the sum of several members' knowledge compared to that of a single member (Van Swol and Prahl 2018).

It has also been stressed in the advice literature that in team decision-making, group members might not frame their contributions as "advice" but instead they might be sharing information and opinions in order to reach consensus (Van Swol and Prahl 2018). Nonetheless, seeking advice from and sharing information with other MDT members is essential in order to make appropriate clinical decisions about patient care.

1.4 Prognostication

The word prognosis is derived from Greek and means "foreknowledge" (Rizzi 1993). The word is used within a variety of fields such as economics, meteorology, lotteries, and election results, where the meaning in these contexts being a forecast or an estimate of a final outcome based on preliminary data and calculations (Rizzi 1993). In short, a prognosis is a prediction whether certain events will occur or not (Rizzi 1993).

A medical prognosis refers to a forecast of the probable course and/or outcome of a disease (Medical Dictionary for the Health Professions and Nursing 2012). Prognosis has been identified as central to clinical decision-making (Gill 2012; Hui 2015). Although prognostication can involve more than life or death, predictions of life expectancy are what most clinicians consider when they hear the word prognosis (Glare and Sinclair 2008). Other phrases for prognostication include “recognising dying” and “identifying dying”. The phrase “diagnosing dying“ is sometimes used as well (Taylor and Johnson 2011).

1.4.1 Prognosis in palliative care

Within palliative care, early identification of end-of-life patients, and more generally estimating patients’ length of survival, can guide clinicians to use relevant care pathways, and patients might be granted access to certain benefits based on this information (Chu, White, and Stone 2019). Studies have shown that patients, their carers, and clinicians, all value accurate prognostic information (Adams, Boulton, and Watson 2009; Degner et al. 1997; Kirk, Kirk, and Kristjanson 2004; Kutner et al. 1999; Steinhauser et al. 2001). Information on how much time a patient has left to live can help the patient and family members to make important decisions, feel prepared for death, and help family members prioritise commitments and plan treatment and care in the hospital or community (Pontin and Jordan 2013). It is particularly important and relevant for clinical decision-making to recognise when patients are *close* to death because discharge planning, code status discussions, goals of care, hospice transfers, and enrolment onto integrated care pathways are all dependent on prognosis (Perez-Cruz et al. 2014).

Different terms are used for the stages that palliative care patients encounter in the disease trajectory. The term “end-of-life” is often used to refer to patients who are approaching the last year of life (General Medical Council 2010). When patients are within the last days or hours of life, they are more appropriately referred to as “imminently dying” (Chu, White, and Stone 2019; Leadership Alliance for the Care of Dying People 2014). Among palliative care specialists, the “terminal” phase often refers to patients within the last hours or days of life (Chu, White, and Stone 2019; Leadership Alliance for the Care of Dying People 2014).

Prognostication has been on the healthcare agenda as a priority for more than a decade now. In 2008, the NHS End of Life Care Strategy highlighted identifying people who are approaching the end-of-life as a key area that needed to be addressed (Department of Health 2008). Recognising when a person may be in the last days of life was also a key recommendation in the 2015 NICE guidelines (National Institute for Health and Care Excellence 2015).

Despite the importance, appreciation, and positive impact of prognosis, providing accurate estimates of patients' length of survival is a difficult task. The evidence shows that clinicians' estimates are often inaccurate and over-optimistic (Glare et al. 2003; Gwilliam et al. 2013; White et al. 2016; Christakis and Lamont 2000). However, it may not even be possible to prognosticate with 100% accuracy (Hui 2015). Some of the difficulties with estimating prognoses are that diseases affect individuals in various ways, where patients will die at different stages along the disease trajectory, and the rate of progression may vary as well (Murray et al. 2005). The challenge of providing accurate prognoses seems to relate to the fact that it represents an attempt to grasp an elusive future, and moreover that the true prognosis can never be known definitely in a specific patient (Christakis 1999).

Literature reviews have shown that clinicians are often reluctant to formulate and communicate prognostic estimates (Hagerty et al. 2005; Hancock et al. 2007). Prognostic uncertainty and lack of confidence and training in discussing this with patients have been listed as reasons for clinicians to avoid prognostic discussions (Travers 2016). Discussions around patients dying and their prognoses are also emotionally difficult or hard (Mack and Smith 2012). Professionals working within palliative care, and particularly in hospices, where prognosis, death and dying are everyday topics, are doing *emotional labour*. This term has been described as "the management of feeling to create a publicly observable facial and bodily display" (Hochschild 2012: 7). The work requires professionals to manage and somehow supress their feelings in emotional situations. This may have an impact on how they make prognostic decisions. This was highlighted earlier in this chapter with the emotion-imbued choice model (Lerner et al. 2015). Within palliative care, research has shown that professionals limit their emotional expressions and how they manage their emotions through different strategies such as lack of eye contact (Brighton et al. 2019). Thus, the emotional impact of having prognostic discussions is another barrier to having them.

1.4.2 Prognostic decision-making

The process of providing or arriving at a prognosis for a patient can be rather complicated to grasp. Prognostication has been described as a multi-stage process involving five key steps: prognostic prediction, prognostic disclosure, prognostic awareness, prognostic acceptance, and prognosis-based decision-making (Hui, Mo, and Paiva 2021). In this thesis, the term “prognostic decision-making” will be used to refer to the process in which a clinician makes a decision about how long a patient has left to live.

The decision-making process can be studied in various ways. Studies have been conducted using interviews (Clarkson, Selby, and Myers 2013; Taylor, Dowding, and Johnson 2017) and Judgement Analysis (White et al. 2018) to identify the most important information for clinicians when making prognostic decisions. However, studying decision-making can be complicated, where difficulties have been pointed out with clinicians articulating their subconscious thought processes underlying their decisions (Chu, White, and Stone 2019). Clinicians have expressed that they are unable or find it difficult to describe their decision-making processes in detail, and that the process is subconscious or like a “sixth sense” rather than an explicit rational reasoning process (Taylor, Dowding, and Johnson 2017). It has also been stressed that there is a need for a better understanding of clinicians’ prognostic decision-making process (Hui et al. 2019).

Prognostic decision-making is mostly carried out in practice through use of one or other of two approaches: clinical predictions of survival and/or through use of a prognostic tool.

1.4.2.1 Clinical prediction of survival

Prognostic decision-making usually involves a clinician's prediction of survival. Clinical prediction of survival is subjective and depends on the clinician's assessment of the individual patient (Maltoni et al. 2005). Clinicians collate a wide variety of information about the patient to make predictions about imminent death. Factors such as the general condition of the patient (known as the "performance status") and their breathing patterns have been shown to be influential in clinicians' prognostic decision-making (White et al. 2018). The information clinicians collate can come from their own observations or from others, and as clinicians acquire further information, they review their prognostic decisions (Taylor, Dowding, and Johnson 2017). Thus, prognostic decision-making is an ongoing and iterative process (Taylor, Dowding, and Johnson 2017).

Clinicians' predictions of survival can be formulated in different ways. When clinicians articulate that they expect a patient to live for a specific period of time such as a certain number of days, weeks or months, this is known as continuous temporal predictions (Chu, White, and Stone 2019). Clinicians can also provide a prediction in discrete categories such 0 to 2 days, 3 to 7 days, or greater than 7 days. Such predictions are known as categorical temporal predictions (Chu, White, and Stone 2019). Probabilistic estimates of survival are when clinicians frame their predictions in terms of probabilities, such as the likelihood of a patient dying in the next week or month (Chu, White, and Stone 2019). Finally, clinicians can also use the *Surprise Question* (i.e., "would I be surprised if this patient died in [specific time frame]?"). Instead of providing a number as with temporal predictions, the answer to the Surprise Question is either yes or no to whether the clinician would be surprised if the patient died within the predefined period of time (Hui 2015).

As noted earlier, clinical prediction of survival is often inaccurate and over-optimistic (Christakis and Lamont 2000). Nonetheless, studies have showed that probabilistic predictions are more accurate than temporal ones (Perez-Cruz et al. 2014; Hui et al. 2011).

1.4.2.2 Prognostic tools

The EAPC recommends that clinicians' prediction of survival should be used in combination with other prognostic factors or scores to improve prognostic accuracy (Maltoni et al. 2005). Several prognostic tools have been developed to inform and support clinicians in estimating patients' prognoses; for example, the Palliative Prognostic Score (Maltoni et al. 1999; Pirovano et al. 1999), the Palliative Prognostic Index (Morita et al. 1999), the Palliative Performance Scale (PPS) (Anderson et al. 1996) and the Prognosis in Palliative care Scales (Gwilliam et al. 2011; Kalpakidou et al. 2018). To make a prediction, each tool requires different information such as whether specific symptoms are present, the patient's functional status, or blood results. Moreover, each tool presents the proposed prognosis in different (often probabilistic) formats (i.e., the probability of the patient surviving the next [number of] days/weeks).

Limitations of prognostic tools or scores are that most of them have been developed predominantly (or exclusively) in advanced cancer populations (Chu, White, and Stone 2019). This means that these tools cannot be directly transferred and used to prognosticate in other advanced diseases. Moreover, some of the tools rely more or less on clinicians' prediction of survival, which complicates the situation in which clinicians want to use a prognostic tool to provide an "objective" estimate uncontaminated by their own subjective judgement (Chu, White, and Stone 2019). Although clinical predictions are known to be inaccurate, very few existing prognostic tools have consistently been shown to provide a superior performance (Chu, White, and Stone 2019).

Despite the variety and availability of several prognostic tools, clinicians have not adopted them routinely in clinical practice, whereas many clinicians still rely solely on clinical judgement (Hui, Maxwell, and Paiva 2019). Most clinicians rely on clinical prediction of survival because it is instantaneous, convenient, and easy to understand (Hui 2015).

1.5 Multidisciplinary teams and prognostication

Despite clinicians' challenges with estimating accurate length of survival, a few studies have shown that a slight improvement in prognostic accuracy can be seen after an MDT discussion (Kee, Owen, and Leathem 2007; Gwilliam et al. 2013). These studies will be examined below.

Kee and colleagues' study explored the impact of an MDT discussion on clinicians' survival predictions in hospital lung cancer MDTs in Ireland. The researchers collected prognostic estimates from clinicians before and after an MDT discussion. A proforma was developed and circulated to clinicians to collect their estimates. The authors found that the MDT discussion did not significantly improve clinicians' individual prognostic accuracy, however the group as a whole performed better and became slightly more accurate. It is important to note that the authors report that the use of the proforma helped clinicians "… focus the discussion a little more than it would have been otherwise." (Kee, Owen, and Leathem 2007: 312). This implies that the proforma seems to have changed the way in which the MDT discussions would normally have been carried out. This questions whether the improvement in prognostic accuracy is due to the MDT discussion itself or due to the influence of the proforma. Another limitation of the study is the lack of what the implications are for clinical practice. It is somehow unclear what the finding about the group as a whole performing better compared to the individual clinician actually means.

In the study by Gwilliam and colleagues, the researchers obtained prognostic estimates from both doctors and nurses independently in palliative care services in England. The study also included an MDT estimate, which was generated by looking at clinicians' individual estimates. When a doctor and a nurse agreed about a patient's prognosis that was seen as representing a combined multi-professional estimate. In situations where clinicians disagreed about the prognosis, they were asked to discuss the patient case and arrive at an agreed prognostic estimate. The study results showed that the MDT was better at predicting patients' survival than doctors and nurses alone. Despite the study aiming at "mirroring day-to-day clinical practice" (Gwilliam et al. 2013: 483), the ecological validity of the MDT estimate in the study can be challenged. Whether only one doctor and one nurse are enough to constitute an MDT is questionable. Another limitation of the study is that it does not report on the process of these MDT discussions. It has been stressed in previous research that there is a lack of evidence of the internal processes of MDT meetings (Furman et al. 2018). This gap in research will be further demonstrated and elaborated on throughout the thesis. There may also be issues with the pressure of clinicians having to arrive at an agreed estimate, and underlying power dynamics between professions also needs to be considered.

Nonetheless, an EAPC working group suggests that a second opinion might be useful in order to ensure prognostic accuracy (Maltoni et al. 2005). A doctor may also seek advice or a second opinion for social reasons, including self-affirmation and sharing of responsibility, knowing the difficulties of prognostication and having concerns about the consequences of making an inaccurate prediction (Kennedy, Kleinmuntz, and Peecher 1997; Yaniv and Milyavsky 2007).

Another recommendation is that when possible, a discussion with a multi-professional team should be conducted as this may help refine the prognostic estimate (Chu et al. 2020). A clinical review also suggested that the most important element in prognostication is that team members caring for the patient agree that the patient is dying (Ellershaw, Neuberger, and Ward 2003). The authors emphasise that team disagreement can result in mixed messages together with opposed goals of care which can lead to poor patient management and confused communication. NICE guidelines have also recommended healthcare professionals to use “other information gathered from the multi-professional team… to help determine whether the person is nearing death, deteriorating, stable or improving” (National Institute for Health and Care Excellence 2015: 8) and to “discuss the dying person's prognosis with other members of the multi-professional care team” (National Institute for Health and Care Excellence 2015: 10).

It has been argued that the lack of an MDT-based approach is an under-appreciated barrier to effective prognostic communication (Sisk, Dobrozsi, and Mack 2020). The authors stress that, within the oncology team, a shared understanding of the following information is needed: (1) the patient's current prognosis; (2) the extent to which the patient desires prognostic information, as well as decisions that might necessitate provision of prognostic information regardless of patient preferences; and (3) who will be responsible for this communication (Sisk, Dobrozsi, and Mack 2020). They also mention that the team might agree that prognostic disclosure is an ongoing process that might change over time. In order to establish this shared understanding, they state that intentional effort and planning is required, which includes open communication and coordination within the team. Also, that clinical teams need to track and monitor whether prognostic communication has occurred. Although this study focuses on the oncology team, relevant links can be made to the palliative care MDT.

Recommendations that prognoses should be formulated by MDTs (rather than individual clinicians) combined with (relatively scarce) evidence that prognostic accuracy actually improves after an MDT discussion led to focus the thesis on a better understanding of how members of the specialist palliative care MDT formulate and make decisions about the prognoses of patients in the hospice (see Chapter 2). Prognostic accuracy of the palliative care MDT and its members have been of interest (Higginson and Costantini 2002), while the evidence lacks more in-depth exploration of the internal team decision-making processes. Understanding how the hospice MDT currently makes prognostic decisions is an essential step in order to understand how decision-making could be improved or transferred to other MDT settings. Members of the specialist palliative care hospice MDT were the focus of this thesis due to their expertise and the frequency with which they work with dying patients. As it will be seen throughout the thesis chapters, it is rather unexplored how the MDT makes prognostic decisions both from the perspective of the individual MDT member and from the MDT as a group. With this research, this thesis takes the first step in order to address this gap within the evidence.

1.6 Chapter summary

Hospice palliative care uses a holistic approach to patient care and is usually delivered through several professionals being part of the MDT. Patients' prognoses are essential to clinical decision-making in order to ensure good quality palliative care. However, providing accurate prognoses are difficult. To aid professionals in prognostic decision-making and to ensure prognostic accuracy, it has been recommended that they seek advice. The involvement of an MDT and/or the use of prognostic tools have been recommended as ways to improve prognostication.

In the next chapter, the specific aim and objectives of the thesis will be presented. The different research studies will be presented as well as why these specific study designs were used to address the aims.

Chapter 2 – Thesis aims and outline

This thesis reports on a PhD project that is part of the ‘Improving care, assessment, communication and training at end-of-life’ (I-CAN-CARE) programme of research. The overall aim of this programme is to improve end-of-life care for patients and their families by better assessment of dying patients, by improved understanding of how clinicians identify dying patients, by improving clinicians’ skills in making prognostic decisions, and by understanding how prognoses are communicated to relatives of dying patients (https://bit.ly/3feFHLC). This PhD was funded by the Marie Curie Chair’s grant (MCCC-FCH-18-U).

Preliminary work had previously been undertaken in the UCL Marie Curie Palliative Research Department involving an evidence synthesis of prognostic estimates at the end-of-life (White et al. 2016); including prognostic accuracy of medical doctors (White, Reid, et al. 2019), and how prognosis is communicated between clinicians and patients’ next of kin (Anderson et al. 2021, 2020). This thesis further developed this work by expanding the research into the MDT environment.

2.1 Thesis aims

This thesis aimed to understand how members of the specialist palliative care MDT formulate and make decisions about the prognoses of patients in the hospice.

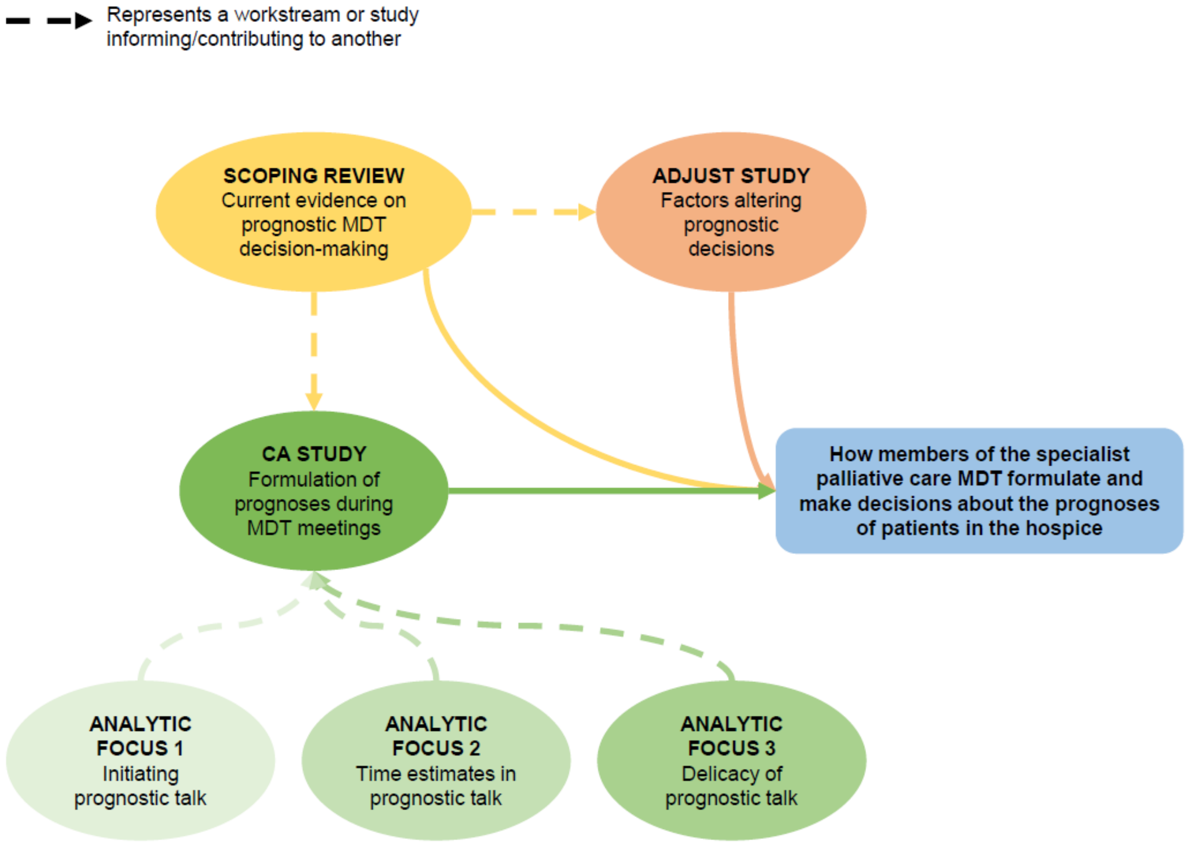
The overall objectives of the research were:

(1) To explore what factors (if any) can alter prognostic decisions and the extent to which this occurs
(2) To understand how members of the specialist palliative care team interact, including their formulation of prognoses during MDT meetings

2.2 Outline of research

The aims of the thesis were met through a convergent mixed methods study design involving three workstreams: A scoping review, an online RCT, and a qualitative conversation analytic study. An overview of the three thesis workstreams is illustrated in **Figure 2-1**, and each workstream is presented in the sections below.

Figure 2-1: Thesis outline diagram



2.2.1 Workstream 1 – Scoping review of prognostic decision-making in multidisciplinary teams

Chapter 3 detailed a scoping review exploring the literature on prognostic decision-making within MDTs. The review focused on how MDTs make decisions about which patients are imminently dying. The aim of this study was to summarise the evidence of what is already known and to identify gaps in the evidence.

2.2.2 Workstream 2 – Factors altering prognostic decisions

To explore factors potentially altering prognostic decisions, an RCT called "Online trial of Advice and Decision-making on prognosis using the Judge-advisor System within multi-disciplinary Teams (ADJUST)" was conducted. The ADJUST study used the Judge-Advisor System (JAS) methodology to explore palliative care clinicians' prognostic decision-making. Participants were asked to provide estimates of patients' probability of two-week survival and received prognostic advice from an advisor (either another clinician or a prognostic algorithm). This study is described in Chapter 4.

2.2.3 Workstream 3 – Multidisciplinary team meeting interactions about prognosis

To address the objective of understanding how members of the MDT interact and formulate prognoses, a qualitative study using CA was conducted. Weekly hospice MDT meetings were video recorded, and the interactions were subsequently thoroughly analysed. The purpose of the study was to understand how prognostication was carried out during hospice MDT meetings. The study is described in Chapter 5 of the thesis.

The conversation analytic study is divided into three results chapters: Chapter 6 on how prognostic talk was initiated; Chapter 7 on how times estimates were used in prognostic talk; and lastly, Chapter 8 on how prognostication was interactionally delicate work. All the workstream findings, strengths and weaknesses are detailed in a separate summary chapter, Chapter 9.

2.2.4 Discussion

The final chapter, Chapter 10, brings together the findings from the three workstreams and discusses them in relation to the wider literature. Thesis implications, strengths and weaknesses are presented as well. Finally, directions for future research are proposed before the thesis ends with a conclusion.

2.3 Thesis study designs

The thesis aims and objectives guided the design of the individual research studies. The initial study designs were influenced by previous work from the UCL Marie Curie Research Department and the I-CAN-CARE programme within which this PhD project was accommodated. When the PhD project commenced, the idea of doing a literature review, an online RCT, and a conversation analytic study had already been proposed. However, decisions about the final study designs were an iterative process, in which ideas were shaped as the project progressed and new knowledge was gained. This section further explains how the particular study designs were arrived at.

In the first instance, a scoping review of current literature on prognostic decision-making within an MDT setting was conducted. This enabled the identification of what is already known about the topic, any gaps in the knowledge, and potential areas of interests to consider throughout this thesis.

The first objective (1) was to understand what factors influenced decision-makers when asked to predict survival. An RCT (quantitative) methodology was adopted to address this objective. This methodology enabled the standardisation and manipulation of the information that participants received. Whilst using this methodology inevitably reduced the ecological validity of the findings, it had the benefit of enabling effective measurement of the impact of a second opinion on the decision-maker’s original prognostic estimate. The chosen methodology allowed for an exploration of the evidence for the EAPC recommendation that clinical prediction of survival should not be used alone but in conjunction with other prognostic factors and that a second opinion from a more experienced professional might be useful (Maltoni et al. 2005). The study built upon previous work from the UCL Marie Curie Palliative Care Research Department that involved an online prognostic test and an online RCT (see White et al. 2018; White, Oostendorp, et al. 2019). This meant that the relevant expertise, skills, and knowledge were available.

The second objective (2) was to understand how prognostic decisions were formulated within an MDT. To do this, it was essential to investigate the interaction between MDT staff members by closely exploring how prognostic decisions were made during real-life MDT discussions. A qualitative approach, adopting a CA method was selected to do this. The study design was inspired by several recommendations mentioning that the MDT should be used for discussing prognostic estimates (see Chu et al. 2020; Ellershaw, Neuberger, and Ward 2003; National Institute for Health and Care Excellence 2015). As with the first objective (1), this design was inspired by previous work in the department in which CA had successfully been used to investigate prognostic discussions (Anderson et al. 2021, 2020).

These three workstreams, using a synthesis of existing evidence and a combination of quantitative and qualitative research methodology, provided a richer understanding of prognostic decision-making by hospice MDT members. Alternative methodologies that could have addressed the study aims (which were considered, but not adopted) are discussed in the last chapter of the thesis, Chapter 10.

2.4 Convergent mixed methods approach

The thesis combined a quantitative RCT study with a qualitive CA study, and therefore a mixed methods approach was used to address the research aims. Benefits of doing mixed methods research include being able to study a research question from different perspectives, where it “…can combine rich, subjective insights on complex realities from qualitative inquiry, with the standardized, generalizable data generated through quantitative research” (Regnault, Willgoss, and Barbic 2018: 2). In this way, mixed methods research can draw upon the strengths and limitations of both qualitative and quantitative methodology.

This thesis applied a convergent mixed methods approach. This approach is defined as a procedure where quantitative and qualitative data are converged or merged in order to provide a comprehensive analysis of a research problem (Cresswell and Cresswell 2018). With this approach, the researcher collects quantitative and qualitative data, analyses them separately, and then the results are compared to see if they confirm or disconfirm each other (Cresswell and Cresswell 2018). Convergent mixed methods studies have been particularly useful within healthcare research where they avoid a second phase of participant recruitment, which can be difficult in healthcare environments where patients might become difficult to reach (e.g., due to discharge) (Doyle, Brady, and Byrne 2016).

The thesis combined a naturalistic conversation analytic approach that dealt with MDT meetings as they occur “in the wild” with the individual team member’s decision-making process explored through a psychological experimental approach. In this way, different perspectives were explored, which provided a broad perspective on the area and contributed to the understanding of how prognostic decisions were made by members of the hospice MDT. Had the scope of the overall thesis aim been narrower, it might have been relevant to consider alternative study designs.

Lastly, it should be noted that the underlying thought behind combining these two empirical studies (i.e., online RCT and CA study) was to apply a “two sides of the same coin” approach, where the unifying concept was the role of advice in prognostication (as mentioned previously with the EAPC recommendations). The online RCT focused exclusively on advice-taking (on the individual level), and it was assumed and hypothesised that advice would be a prominent factor in the MDT meeting discussion as well (on the group level). For this reason, it was deemed appropriate to conduct these two, potentially rather distinct, empirical studies to address the overall thesis aim to understand how members of the specialist palliative care MDT formulate and make decisions about the prognoses of patients in the hospice.

2.5 Scope of the thesis

The thesis focuses on how members of the specialist palliative care MDT make decisions about dying patients in the hospice. One reason for choosing the hospice MDT as a focus was due to their specific expertise in prognostication and the frequency with which they work with dying patients. However, it should be acknowledged that end-of-life care is also provided in other settings, such as hospitals and nursing homes. Specialist palliative care teams operate in many ways, and teams may involve different team members dependent on their location. This project focused on the hospice as the end-of-life care setting. Similarities between cancer MDTs and other specialist palliative care teams might be drawn upon, but the scope was limited to this setting and type of specialist palliative care MDT. The focus on the hospice MDT was chosen as there is a dearth of research within this setting, particularly research focusing on prognostication. This issue is further discussed in relation to the findings from the scoping review in Chapter 3, where the specific gaps in the literature are identified.

The focus of the thesis was on how prognoses were made when patients had hours or days left to live (i.e., when patients were imminently dying). In this way, the thesis did not deal with prognoses given earlier during the disease trajectory for example in relation to when patients were first given a terminal diagnosis, or when they had months or more to live. Neither did the thesis deal with prognoses that did not involve predictions of survival (for example, prognoses of treatment outcomes). It was necessary to decide a timeframe in order to have a manageable scope of the thesis. The imminently dying timeframe was chosen as it has been shown to be important to identify patients who are close to death (see Chapter 1). The average length of stay in a UK hospice is 15 days (Hospice UK 2016), and as the thesis dealt with the hospice MDT, it seemed sensible to work with this timeframe. The reasons why *inpatient* hospice MDT meetings were used for the CA study will be further explained in Chapter 5.

Overall, the thesis was not limited to specific terminal and advanced diseases such as cancer. However, the ADJUST study was based on a dataset where patients had an advanced cancer diagnosis (see more in Chapter 4), and most of the patients admitted to the collaborating hospice also had advanced cancer (rather than another terminal illness).

Referring back to the model of prognostication presented previously, this thesis focused on how MDTs made prognostic predictions. The thesis did not deal with communicating prognosis to patients (or their next of kin) nor dealing with their prognostic awareness or acceptance.

The thesis used a descriptive approach to studying decision-making. A descriptive approach to decision-making has been defined in the following way:

> "Descriptive models are associated with studies that observe, describe and analyse how decisions are made by managers and professionals in relation to their day-to-day responsibilities. Descriptive models are evaluated regarding their empirical adequacy in supporting assumptions made about decision-making processes with relevant examples from a suitable period of observation." (Standing 2010: 8)

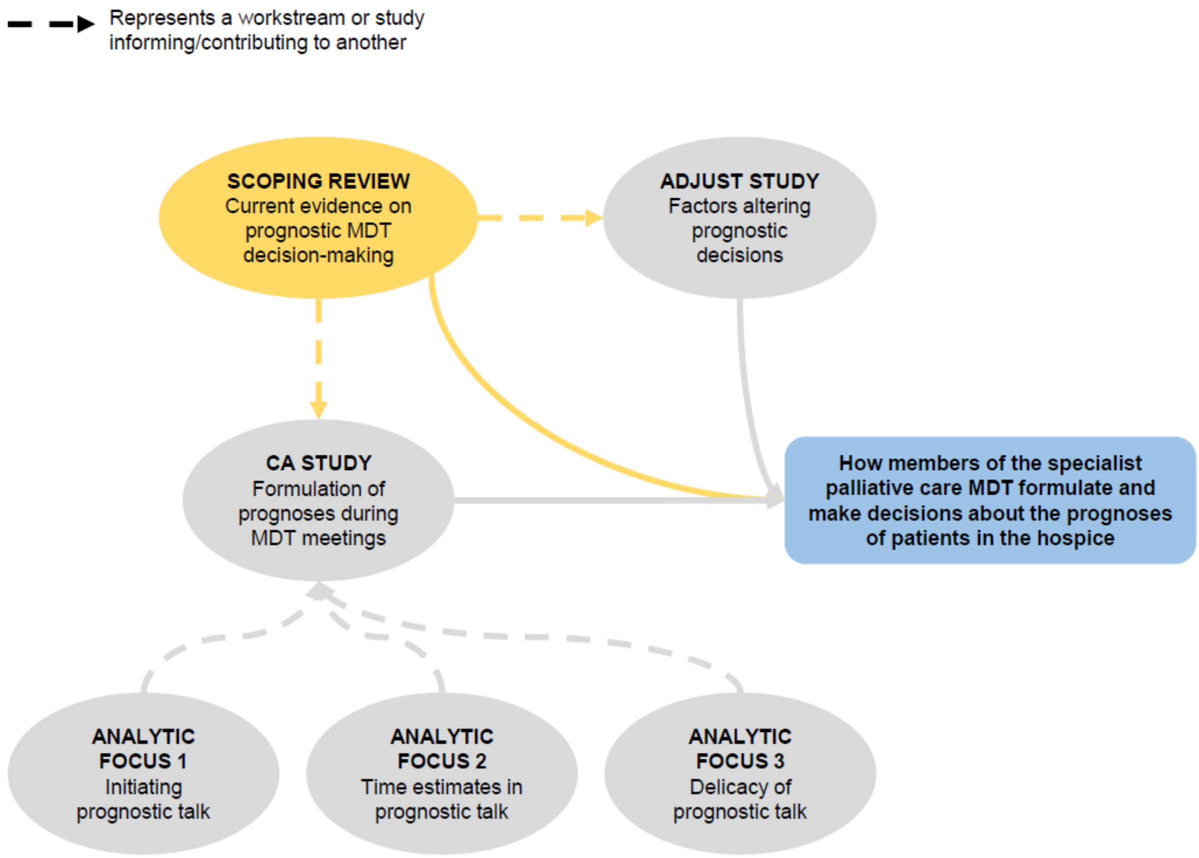
No specific (group) decision-making theory was used. The thesis applied this descriptive approach that aimed at exploring and describing the decision-making process instead. Lastly, the thesis did not investigate the internal (cognitive) aspects of decision-making. However, it should be acknowledged that the mentalisation process is an important aspect of decision-making.

Chapter 3 – Scoping review of prognostic decision-making about imminent death within multidisciplinary teams

3.1 Chapter overview

In order to understand how members of the specialist palliative care MDT formulate and make decisions about the prognoses of patients in the hospice, it is relevant to begin by looking at the current evidence within the field. For this reason, a scoping review was conducted to get an overview of what was known already, identify any gaps in the evidence, and propose directions for future research (see **Figure 3-1**).

Figure 3-1: Thesis outline diagram – scoping review



The review also looks closely at the MDT decision-making process, the evidence from specialist palliative care settings, and barriers and facilitators to decision-making. By systematically scoping the literature, this review provides a general understanding and overview of the field and a context for the other studies of the thesis. The scoping review was published in *BMJ Open* in April 2022 (Bruun, Oostendorp, et al. 2022).

3.2 Introduction

In Chapter 1, a recommendation was presented in which it was mentioned that research should be undertaken to better identify imminently dying patients and to understand how MDTs make prognostic decisions and communicate uncertainty (Neuberger, Guthrie, and Aaranovitch 2013). However, the existing literature has focused mostly on the efficiency of MDTs rather than prognostic decision-making processes (Pillay et al. 2016; Soukup et al. 2018). For example, Soukup and colleagues (2018) give an overview of the existing MDT literature but the primary objective of the review was to explore how to successfully implement MDTs in cancer care rather than to look at prognostic decision-making or communication. A similar focus on outcomes has also been found in those reviews conducted specifically on MDTs in palliative care (Hearn and Higginson 1998; Leclerc et al. 2014; Zimmermann et al. 2008). For this reason, this scoping review was conducted to explore how MDT prognostic decision-making was described and studied in the literature.

The scoping review also identified gaps in the existing literature on MDT decision-making about identification of dying patients. According to the overall thesis aim of understanding how prognostic decision-making works in hospice MDTs, the review also includes a further exploration of the decision-making process, particularly in specialist palliative care settings.

3.3 Study aims

The overall review aim was to identify how the decision-making process was reported in the literature in order to highlight gaps in the evidence. The primary research question was:

- What is known, from the existing MDT decision-making literature, about the identification of patients who are dying?

The secondary research questions were:

- How is the decision-making process described in the literature?

- What are the characteristics of decision-making about the identification of dying patients in specialist palliative care settings?
- Are there any decision-making barriers, opportunities and/or recommendations?

3.4 Methods

A scoping review approach was chosen to address the study aims. This type of review is suitable for highlighting significant gaps in the evidence (Arksey and O'Malley 2005; Armstrong et al. 2011) and provides an alternative to systematic reviews when clarification around concepts or theory is required (Munn et al. 2018). Scoping reviews are still systematic in their approach and include identifying a research question, developing a comprehensive search strategy for identifying relevant studies, establishing eligibility criteria for study selection, systematically charting the data, and finally, collating, summarising, and reporting the results (Arksey and O'Malley 2005). A key difference between scoping reviews and systematic reviews is that a scoping review has a broader research question than traditional systematic reviews, and they will therefore often involve more expansive inclusion criteria (Munn et al. 2018). These broad research questions and expansive criteria are necessary when wanting to “only” scope and map the literature more broadly. Moreover, scoping reviews do not usually involve critical appraisal of included studies, but they focus on providing an *overview* of the evidence instead (Munn et al. 2018). By providing this overview of the evidence base, scoping reviews can often identify areas for future systematic reviews or other types of evidence synthesis (Peters et al. 2020).

As the overall aim of the thesis was to understand how members of the specialist palliative care MDT formulate and make decisions about the prognoses of patients in the hospice, it was deemed appropriate to take a broader perspective and conduct a scoping review as opposed to a traditional systematic review. Rather than addressing a narrow specific question (as traditional systematic reviews frequently do), the purpose of the scoping review was to provide an overview of the evidence to gain a broader understanding of the field. Also, as initial searches of the literature revealed that limited research had been conducted on this specific topic, it was more sensible to apply a broader research question, strategy, and selection criteria.

The review was conducted using the theoretical framework for scoping reviews introduced by Arksey and O'Malley (2005) and also by following current guidelines within the field (Peters et al. 2020). The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al. 2018) was followed. A study protocol was developed, and the final version was registered with the Open Science Framework (OSF) on 26 August 2020 (www.osf.io/sv5te).

3.4.1 Search strategy

Databases were initially searched from inception until 29 April 2020, and the search was updated on 18 May 2021.

The following six electronic databases were searched:

- AMED
- CINAHL
- Embase
- MEDLINE
- PsychINFO
- Web of Science

These databases were chosen because they cover the breadth of studies on MDT decision-making conducted in different settings using both qualitative and quantitative methods. No date limit was applied to the search in order to capture the breadth of literature. Grey Literature Report (www.greylit.org) and Open Grey (www.opengrey.eu) were searched to identify further potentially eligible studies that were not published in peer-reviewed journals and not listed in databases. Forward and backward citation searches were undertaken as well. Web of Science was used for conducting the forward citation search, and reference lists of included studies were searched to identify further relevant studies.

Since the review aim was to provide an overview of the field and identify knowledge gaps, a highly sensitive search strategy was developed. Different domains and combinations were trialled before settling on the following four domains:

- Palliative population
- MDTs
- Decision-making
- Prognosis/dying

Each domain comprised several search terms using synonyms and similar concepts for keywords. Search terms were based on relevant literature and systematic reviews exploring one (or more) of the domains (for the palliative population domain see (Rietjens et al. 2019); for MDTs (Ke et al. 2013; Basta et al. 2017); for decision-making (Laidsaar-Powell et al. 2013; Légaré et al. 2018; Stacey et al. 2017); and for prognosis/dying (White et al. 2016; Glare et al. 2003; Altman 2001)). Search terms were tailored to each database's search engine and terminology. The search was limited to English language papers and human subjects. The MEDLINE search strategy can be found in Appendix 1.

3.4.2 Eligibility criteria

Eligibility criteria were discussed and then piloted within the study team by screening a small number of publications (AB and LO). Following the pilot, the criteria were refined. To ensure that review aims and eligibility criteria were comprehensible, another pilot involving screening a small number of publications was carried out with the reviewers external to the study team (A-RS and LM).

The following eligibility criteria were applied during the screening process. No studies were excluded on the basis of study design.

3.4.2.1 Inclusion criteria

- English-language full-text papers
- Studies presenting original data (either qualitative or quantitative) related to MDT decision-making about the identification of patients who are imminently dying

- Studies reporting on the process and/or content of MDT meetings or discussions, either by studying the team as a whole, or individual team members (e.g., surveys of doctors' and nurses' individual reflections on MDT communication)

3.4.2.2 Exclusion criteria

- Non full-text and non-peer-reviewed publications (e.g., conference, poster, and meeting abstracts, dissertations, and theses)
- Studies involving children (subjects under 18 years old)
- Studies conducted exclusively in Intensive Care Units (ICUs), Emergency Departments, or similar acute care settings
- Teams that did not consist of members with different professional roles
- Studies concerning patients who were not imminently dying (estimated length of survival longer than hours/days)
- Studies exploring how team members interacted with patients and/or family carers rather than between themselves
- Studies concerning clinicians’ reflections on MDT discussions in which they did not participate (e.g., medical directors’ reflections upon MDT working)

Studies conducted solely in acute care were excluded because prognosticating imminent death in these settings was deemed likely to involve significantly different processes from prognosticating in non-acute settings and therefore to fall outside of the scope of the review. In this review, acute care settings were defined as ICUs, Emergency Departments, and similar acute settings. In these acute care settings, decisions often need to be made quickly and there may be little time for MDT deliberation. Prognostication of imminent death in ICU, for example, may be complicated by decisions about withdrawal of immediately life sustaining therapies (e.g., intubation). Studies conducted in both acute and non-acute care settings were deemed eligible for inclusion.

The definition of what constituted an MDT for the purpose of prognostic decision-making was kept broad to avoid excluding potentially relevant literature. Studies were deemed eligible if they reported on decision-making between at least two professionals with different roles or disciplines.

3.4.3 Selection of sources of evidence

Publications were initially screened by title and abstract by two reviewers independently (AB and A-RS/LM/LO). If reviewers did not agree on eligibility of a publication, or if eligibility was unclear, the paper was retained for further scrutiny. Reviewers met regularly throughout the screening process to discuss uncertainties and to refine the selection criteria if needed.

The research question posed several complications during the screening process. Based only on titles and abstracts, it was difficult for reviewers to decide whether a study involved MDT discussions about the identification of dying patients and whether any MDT decisions were made. Due to these issues, the first screening resulted in a high number of potentially eligible papers for full-text screening (see **Figure 3-2**).

The second round of screening involved review of full-text papers that met the inclusion criteria or had unclear relevance. Full-text screening of papers was also done independently by two reviewers (AB and LO). Any remaining disagreements were resolved through consensus in the study team.

During the full-text screening process, two further exclusion criteria were applied. It was decided that papers that were not full-text and peer-reviewed (e.g., conference abstracts, dissertations, and theses) should be excluded. Furthermore, studies conducted solely in acute care settings were excluded.

3.4.4 Data extraction and analysis

A data extraction sheet was developed, and then reviewed and approved by the study team. The sheet was piloted by extracting data from five papers (AB and LO). The pilot outcome was discussed with the rest of the study team and any issues or disagreements were resolved. The sheet was then edited according to the pilot outcome and a final version was agreed upon. Data extraction was completed independently by two reviewers (AB and LO). The extracted data included the following study information:

- Paper characteristics (authors, year of publication, and country of origin)
- Study aims
- Methods of data collection

- Methods of data analysis
- Study design (clinical setting, patient type [if specified/or focusing on a specific population], and number and profession of participants)

Prognostic decisions were identified either by direct quotes from MDT members or authors' descriptions of decisions, following relevant guidelines (Noyes et al. 2019). These data are referred to as "excerpts". Following closer investigation of the excerpts, it was decided to extract decision-making characteristics for each decision as reported in the included papers. Decision-making characteristics included the following information:

- Staff members involved in the decision
- Topic of the decision
- Description of the decision-making process

Barriers and recommendations reported in study implications sections (if any) of included papers were extracted. Themes within the data were identified during the data extraction process as well.

Following closer investigation of the decision-making excerpts, and during the screening process as well, it became apparent that there is an overlap between recognising dying, managing dying, and treating acute illness. The process by which dying is recognised cannot always be clearly separated from other processes of clinical care which take place at the same time (Taylor, Johnson, and Dowding 2020). Decisions were therefore categorised according to the "topic" of the decision being discussed or made by the MDT. All excerpts involved MDT members' decisions about identifying imminent death, however some also involved other related aspects of care.

After identifying the relevant decision-characteristics, it was decided to categorise the decision-making process according to the degree to which they were deemed to be collaborative. This involved making a decision about whether excerpts described either full, partial, or no collaboration. On one end of the continuum was non-collaborative/individual-based decision-making, in which the decision was made by one staff member. On the other end of the continuum was shared/joint/collaborative decision-making. In these cases, MDT staff made the decisions together. Judgements about the level of collaboration were based on whether excerpts provided evidence for information-sharing between staff and/or evidence of joint decision-making. This approach was inspired by literature on participation in decision-making (see Thompson et al. 2007). If the excerpt did not provide evidence for either information-sharing or joint decision-making, the decision was labelled as providing no evidence for collaboration. If the excerpt included evidence for both information-sharing and a joint decision-making process, it was labelled as providing evidence for full collaboration. A partial collaboration process included evidence for either information-sharing or joint decision-making. Each decision-making excerpt was then labelled based on the information provided in the paper:

- No evidence for collaboration
- Evidence for partial collaboration either:
    - Evidence for information-sharing
    - Evidence for joint decision-making
- Evidence for full collaboration

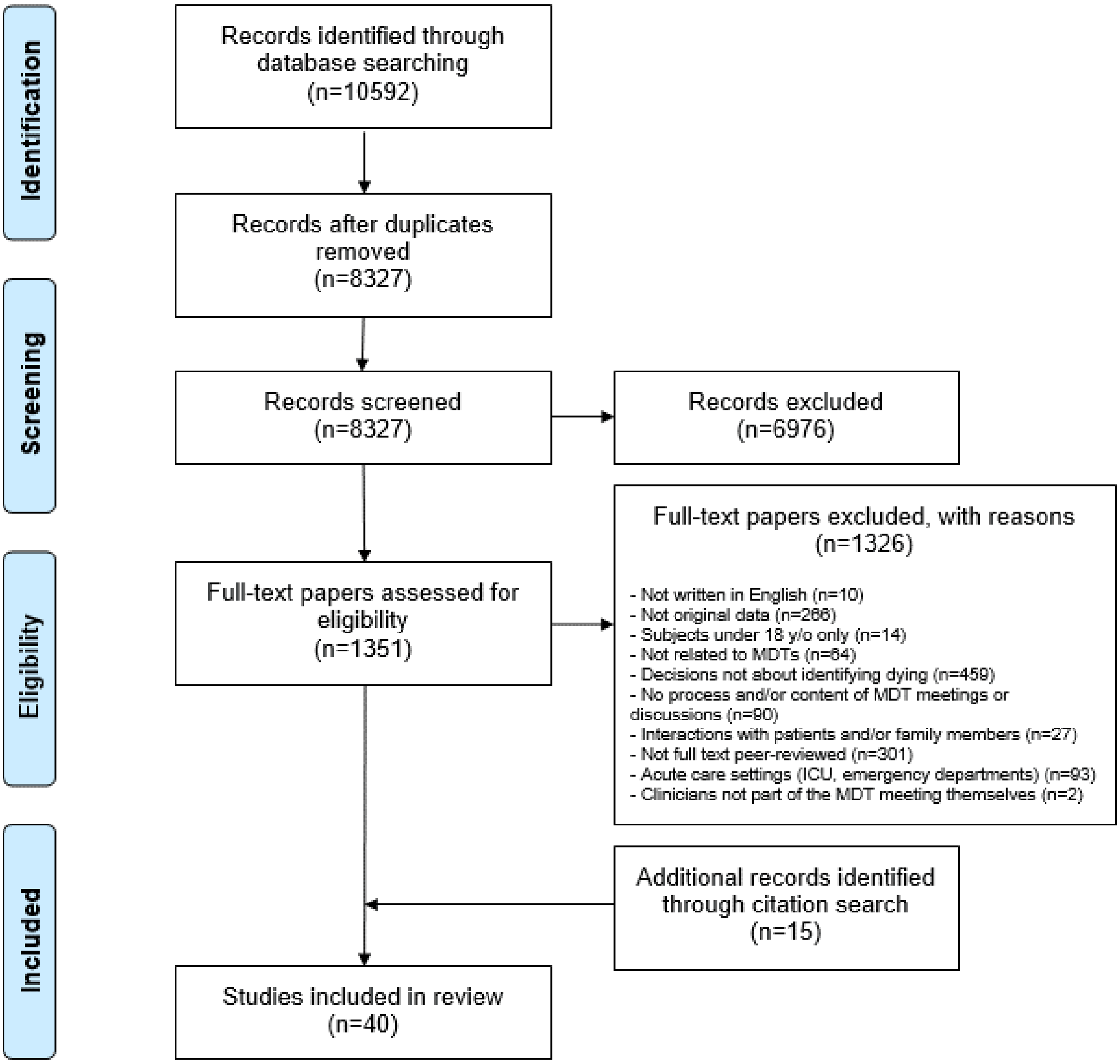
Excerpts were labelled independently by reviewers (AB and LO) and in cases of disagreement a third reviewer (NW) was consulted. In addition, subthemes were identified when excerpts were categorised.

Study information, decision-making excerpts, and themes/categorisations were extracted and managed using Microsoft Word. A narrative review approach was applied, resulting in a narrative synthesis of the scoped research.

3.5 Results

The search strategy initially identified 10592 publications. After removing duplicate records, the number was reduced to 8327. The first round of title and abstract screening yielded 1351 potentially eligible publications. These publications went through a second round of full-text screening. The full-text screening identified 25 papers eligible for inclusion in the review. An additional 15 papers were identified following backward and forward citation searches. This resulted in a total of 40 papers (**Figure 3-2**). These papers yielded 67

Figure 3-2: PRISMA diagram (from Bruun, Oostendorp, et al. 2022)



excerpts relevant to MDT decision-making about identification of patients who were imminently dying.

3.5.1 Characteristics of included studies

Key characteristics of the 40 included studies are shown in **Table 3.1.**

3.5.1.1 Country of studies

Studies were conducted in ten countries, with most of the studies being from the UK (n=14) (Caswell et al. 2015; Costello 2001; Dee and Endacott 2011; Glogowska et al. 2016; Gott et al. 2011; Hockley, Dewar, and Watson 2005; Johnson et al. 2014; Pontin and Jordan 2013; Freemantle and Seymour 2012; Gambles et al. 2006; Reid et al. 2015; Ryan et al. 2012; Willard and Luker 2006; Standing et al. 2020). Other countries were Australia (n=6) (Bloomer et al. 2018, 2019; Bostanci et al. 2016; Bloomer et al. 2013; Borbasi et al. 2005; Tan et al. 2014), USA (n=5) (Bern-Klug et al. 2004; Chuang et al. 2017; Gidwani et al. 2017; Travis et al. 2005; Hanson, Henderson, and Menon 2002), Sweden (n=5) (Andersson et al. 2018; Nappa et al. 2014; Wallerstedt and Andershed 2007; Pettersson, Hedström, and Höglund 2020, 2014), Canada (n=4) (Hill et al. 2018; Nouvet et al. 2016; Oliveira et al. 2016; Strachan et al. 2018), New Zealand (n=2) (Clark et al. 2012; Fryer et al. 2016), Saudi Arabia (n=1) (Abu-Ghori et al. 2016), the Netherlands (n=1) (Lemos Dekker, Gysels, and van der Steen 2018), Thailand (n=1) (Prompahakul et al. 2021), and China (n=1) (Lai, Wong, and Ching 2018). Years of publication ranged from 2001 to 2021.

3.5.1.2 Methods of data collection

Data were mostly collected using qualitative approaches. Interviews were completed in 27 of the included studies; either as the sole method of data collection (n=15) (Bern-Klug et al. 2004; Dee and Endacott 2011; Gidwani et al. 2017; Glogowska et al. 2016; Hill et al. 2018; Nouvet et al. 2016; Lai, Wong, and Ching 2018; Borbasi et al. 2005; Freemantle and Seymour 2012; Gambles et al. 2006; Oliveira et al. 2016; Strachan et al. 2018; Wallerstedt and Andershed 2007; Bloomer et al. 2018; Pettersson, Hedström, and Höglund 2014) or alongside other methods. These other methods included focus groups (Andersson et al. 2018; Gott et al. 2011; Reid et al. 2015; Ryan et al.

2012; Caswell et al. 2015; Standing et al. 2020), collaborative learning groups (Hockley, Dewar, and Watson 2005), observations (Caswell et al. 2015; Costello 2001; Hockley, Dewar, and Watson 2005; Johnson et al. 2014; Bloomer et al. 2013; Lemos Dekker, Gysels, and van der Steen 2018; Willard and Luker 2006), field notes (Costello 2001; Hockley, Dewar, and Watson 2005; Johnson et al. 2014; Nappa et al. 2014), review of case notes (Caswell et al. 2015), documentary analysis (Hockley, Dewar, and Watson 2005) and questionnaires (Hockley, Dewar, and Watson 2005). Studies also reported conducting focus groups alone (Chuang et al. 2017; Pontin and Jordan 2013; Travis et al. 2005; Hanson, Henderson, and Menon 2002; Tan et al. 2014; Fryer et al. 2016) or in combination with surveys (Clark et al. 2012). Other methods included reflective journaling and field notes (Abu-Ghori et al. 2016); free-text comments of questionnaires (Pettersson, Hedström, and Höglund 2020); retrospective observational audit of patient deaths (Bloomer et al. 2019); and reviewing patients’ medical records (Bostanci et al. 2016).

3.5.1.3 Methods of data analysis

Methods of data analysis were qualitative as well, and most often involved identification of themes. Most studies reported having conducted a general analysis of themes (n=22) (Hockley, Dewar, and Watson 2005; Johnson et al. 2014; Nouvet et al. 2016; Freemantle and Seymour 2012; Gambles et al. 2006; Hanson, Henderson, and Menon 2002; Ryan et al. 2012; Caswell et al. 2015; Hill et al. 2018; Strachan et al. 2018; Costello 2001; Glogowska et al. 2016; Gott et al. 2011; Lemos Dekker, Gysels, and van der Steen 2018; Willard and Luker 2006; Wallerstedt and Andershed 2007; Dee and Endacott 2011; Abu-Ghori et al. 2016; Fryer et al. 2016; Travis et al. 2005; Reid et al. 2015; Borbasi et al. 2005). Studies reported having conducted content analysis (Andersson et al. 2018; Bern-Klug et al. 2004; Bloomer et al. 2018, 2019; Bostanci et al. 2016; Lai, Wong, and Ching 2018; Bloomer et al. 2013; Tan et al. 2014; Pettersson, Hedström, and Höglund 2020, 2014), and thematic analysis that involved a specific framework (Chuang et al. 2017; Gidwani et al. 2017; Oliveira et al. 2016; Pontin and Jordan 2013; Prompahakul et al. 2021; Standing et al. 2020). Other methods of analysis included narrative analysis (Nappa et al. 2014); basic descriptive analysis (Clark et al. 2012); and matrix analysis (Gidwani et al. 2017).

3.5.1.4 Clinical setting

The majority of studies were conducted in hospital settings (n=28) (Hill et al. 2018; Abu-Ghori et al. 2016; Caswell et al. 2015; Gidwani et al. 2017; Chuang et al. 2017; Clark et al. 2012; Costello 2001; Bostanci et al. 2016; Nappa et al. 2014; Nouvet et al. 2016; Pontin and Jordan 2013; Gott et al. 2011; Lai, Wong, and Ching 2018; Bloomer et al. 2013; Borbasi et al. 2005; Freemantle and Seymour 2012; Oliveira et al. 2016; Reid et al. 2015; Ryan et al. 2012; Strachan et al. 2018; Wallerstedt and Andershed 2007; Willard and Luker 2006; Tan et al. 2014; Glogowska et al. 2016; Bloomer et al. 2018, 2019; Pettersson, Hedström, and Höglund 2014, 2020; Prompahakul et al. 2021). Other clinical settings included care homes (n=10) (Andersson et al. 2018; Bern-Klug et al. 2004; Hockley, Dewar, and Watson 2005; Johnson et al. 2014; Travis et al. 2005; Hill et al. 2018; Lemos Dekker, Gysels, and van der Steen 2018; Hanson, Henderson, and Menon 2002; Fryer et al. 2016; Standing et al. 2020), hospices (n=5) (Dee and Endacott 2011; Gott et al. 2011; Borbasi et al. 2005; Gambles et al. 2006; Ryan et al. 2012), community (n=5) (Lai, Wong, and Ching 2018; Gidwani et al. 2017; Glogowska et al. 2016; Borbasi et al. 2005; Standing et al. 2020) and primary care (n=4) (Gott et al. 2011; Glogowska et al. 2016; Ryan et al. 2012; Standing et al. 2020). Some studies included multiple settings.

Nurses were most often included in the sample under investigation. 11 studies included only doctors and nurses as part of the sample (Costello 2001; Dee and Endacott 2011; Lai, Wong, and Ching 2018; Nouvet et al. 2016; Pontin and Jordan 2013; Andersson et al. 2018; Glogowska et al. 2016; Freemantle and Seymour 2012; Gambles et al. 2006; Strachan et al. 2018; Pettersson, Hedström, and Höglund 2020). Ten studies included doctors, nurses, and other types of healthcare professionals (Bloomer et al. 2018; Clark et al. 2012; Gott et al. 2011; Hill et al. 2018; Ryan et al. 2012; Lemos Dekker, Gysels, and van der Steen 2018; Hanson, Henderson, and Menon 2002; Reid et al. 2015; Hockley, Dewar, and Watson 2005; Standing et al. 2020). Three studies included only nurses and other healthcare professionals (Travis et al. 2005;

Johnson et al. 2014; Tan et al. 2014). 13 studies focused on a particular group of professionals such as nurses (Abu-Ghori et al. 2016; Nappa et al. 2014; Bloomer et al. 2013; Borbasi et al. 2005; Oliveira et al. 2016; Wallerstedt and Andershed 2007; Willard and Luker 2006; Pettersson, Hedström, and Höglund 2014; Prompahakul et al. 2021), doctors (Bern-Klug et al. 2004; Gidwani et al. 2017), physician assistants (Chuang et al. 2017) or healthcare assistants (Fryer et al. 2016). Two studies included any type of clinician who wrote an entry in patients' medical records (Bloomer et al. 2019; Bostanci et al. 2016). Lastly, one study did not specify the professionals involved but study quotes came from doctors and nurses (Caswell et al. 2015).

Table 3.1: Study characteristics (from Bruun, Oostendorp, et al. 2022)

Author(s) and publication year	Country of study	Study focus[1]	Method(s) of data collection	Method(s) of data analysis[2]	Clinical setting[3]	Relevant sample size[4]
Abu-Ghori et al. 2016	Saudi Arabia	Examine nurses' lived experience and the meaning of their involvement in EOL care after a DNR decision has been made on medical units	Reflective journaling technique and field notes	General analysis of themes	Hospital (general medical units) *Patients with a DNR code*	26 nurses
Andersson et al. 2018	Sweden	Describe care professionals' experiences of using the LCP in the care of dying residents in residential care homes	Focus groups and individual interviews	Content analysis	Residential care homes	10 ENs/NAs, 9 RNs, and 5 GPs
Bern-Klug et al. 2004	United States	Improve understanding of nursing home physicians' perspectives regarding EOL care	Individual interviews	Content analysis	Nursing home	12 physicians (10 were medical directors)
Bloomer et al. 2013	Australia	Explore nurses' 'recognition of' and 'responsiveness to' dying	Individual interviews, focus groups and non-	Content analysis	Hospital (2 acute medical wards)	25 nurses, including ward nursing staff and nurse managers

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[1] If a study has several study foci, then only the one(s) relevant for the review is(are) mentioned.
[2] The label "General analysis of themes" is used for studies reporting having analysed themes where the study team has not been able to identify a specific approach or framework in the study paper. If authors named a specific form of thematic analysis, then the "thematic analysis" label is applied.
[3] Patient type is only described if it is not clear from the clinical setting itself what type of patients it involves, or if only a certain type of patients is included in the study.
[4] If the study includes other types of participants such as patients, relatives etc., then only the relevant sample size of MDT staff members is mentioned.

		patients and to understand the nurses' influence on EOL care in the acute hospital (non-PC) setting	participant observation			
Bloomer et al. 2018	Australia	Explore communication of EOL care goals and decision-making among a multidisciplinary geriatric inpatient rehabilitation team	Individual and group interviews	Content analysis	Hospital (geriatric inpatient rehabilitation facility)	8 RNs, 4 ENs, 5 allied healthcare clinicians, and 2 doctors
Bloomer et al. 2019	Australia	Investigate EOL care provision for older people in subacute care	Retrospective observational audit of inpatient deaths	Content analysis	Subacute care facility (rehabilitation, functional restoration, transitional care, aged and mental healthcare)	Any clinicians who wrote an entry in the medical records of one of the 54 deceased patients
Borbasi et al. 2005	Australia	Explore the views of nurses on EOL care for patients with end stage heart failure	Individual interviews	General analysis of themes	3 hospitals (ICU, cardiac ward, medical ward) and 1 community nursing/hospice facility	17 nurses (9 RNs, 7 clinical nurse consultants or clinical nurses, 1 nurse manager)
Bostanci et al. 2016	Australia	Explore reasons for the hospitalisation and place of death outcomes of terminal cancer patients	Review of medical records	Content analysis	2 hospitals Advanced cancer patients (prostate, breast, lung, or haematological)	Any clinicians who wrote an entry in the medical records of one of the 39 patients

Caswell et al. 2015	United Kingdom	Understand the factors and processes which affect the quality of care provided to frail older people who are dying in hospital	Non-participant observation, individual interviews, focus group, and review of case notes	General analysis of themes	Hospital (acute admissions ward, specialist medical and mental health unit for older people with cognitive impairment, and 2 health care of older people wards) *Frail older people*	32 interviews with staff members and 1 focus group with 5 members of the PC team Review of 42 patient records
Chuang et al. 2017	United States	Explore roles PAs serve in communicating with terminally ill patients/families, and PAs attitudes and opinion about communication roles	Focus groups	Thematic analysis	3 acute care hospitals *Inpatients on medical, surgical, and intensive care units*	34 PAs
Clark et al. 2012	New Zealand	Staff perceptions of EOL care following implementation of the LCP in the acute care setting	Survey and focus groups	Basic descriptive analysis	Hospital (2 acute wards)	41 (survey), 1 medical focus group (n=6), 2 nursing focus groups (n=9), and 1 allied health focus group (n=3)
Costello 2001	United Kingdom	Explore the experiences of dying patients and nurses working in 3 elderly care wards focusing on the	Participant observation, individual interviews, and field notes	General analysis of themes	Hospital (female rehabilitation ward, continuing care ward, and acute assessment ward)	29 qualified nurses, 8 physicians (2 consultants, 2 registrars, and 4 senior house officers)

		management of care for dying patients			*Older (dying) patients*	
Dee et al. 2011	United Kingdom	Identify factors that clinicians consider when a patient is dying, enabling implementation of the LCP	Individual interviews	General analysis of themes	Hospice (inpatient unit)	5 nurses and 5 doctors
Freemantle et al. 2012	United Kingdom	Understand why patients dying of cancer in oncology wards were, or were not, supported by the LCP	Individual interviews	General analysis of themes	Hospital (3 oncology wards)	4 doctors and 7 nurses
Fryer et al. 2016	New Zealand	Explore the experiences of HCAs in caring for imminently dying residents in aged care facilities	Focus groups	General analysis of themes	6 aged residential care facilities	26 HCAs
Gambles et al. 2006	United Kingdom	Explore hospice-based doctors' and nurses' perceptions of the LCP	Individual interviews	General analysis of themes	Inpatient hospice	3 doctors and 8 nurses
Gidwani et al. 2017	United States	Characterize oncologists' perceptions of: primary and specialist PC; experiences interacting with PC specialists; and the optimal interface of PC and oncology in providing PC	Individual interviews	Matrix and thematic analysis	Community, AMCs, and VA *Cancer patients*	31 oncologists (9 in community, 11 in AMCs, 9 in VAs, and 2 in administrative roles)
Glogowska et al. 2016	United Kingdom	Explore perceptions and experiences of health	Individual interviews			7 GPs in primary care, 12 doctors and

		care professionals working with patients with heart failure around EOL care		General analysis of themes	Primary, secondary, and community care *Severe or difficult to manage heart failure patients*	nurses in secondary care, and 5 nurses in community care
Gott et al. 2011	United Kingdom	Management of transitions to a PC approach in acute hospitals	Focus groups and individual interviews	General analysis of themes	Primary (general practices) and secondary (acute hospital, hospice, specialist PC unit) care settings	4 consultants, 9 junior doctors, 6 GPs, 4 practice nurses, 11 CNSs, 19 with other specialties, and 5 allied healthcare professionals
Hanson et al. 2002	United States	Describe unique characteristics of death in a nursing home and define essential elements of care that participants perceive as necessary for a good death in this setting	Focus groups	General analysis of themes	2 long-term care facilities	77 participants, including NAs, RNs, licensed practical nurses, and physicians
Hill et al. 2018	Canada	Investigate experiences of long-term care staff delivering PC to individuals with dementia	Individual interviews	General analysis of themes	Long-term care homes *People with dementia*	9 RNs, 3 personal support worker, 2 registered practical nurses, 2 social worker, 1 pharmacist, 1 volunteer, 1 volunteer coordinator, 1

						physician, 1 recreational therapist, and 1 chaplain
Hockley et al. 2005	United Kingdom	Evaluating implementation of an ‘integrated care pathway for the last days of life’ as a way of developing quality EOL care in nursing homes	Action research (documentary analysis, non-participant observations, group interviews, questionnaires, collaborative learning groups, and field notes)	General analysis of themes	Nursing homes	Nursing home staff (trained staff, care assistants, nursing home managers) and GPs
Johnson et al. 2014	United Kingdom	Report complexities facing relatives, residents and nursing home staff in the awareness, diagnosis, and prediction of the dying trajectory	Individual or small group interviews; focus groups; participant observation, and field notes	General analysis of themes	Nursing homes	14 HCAs and senior HCAs, 12 RNs, and 2 managers
Lai et al. 2018	China	Explore the experiences of health care providers in caring for patients at the EOL stage in non-PC settings	Individual interviews	Content analysis	2 hospitals and 1 community health care centre (providing acute, sub-acute, and primary care) *Patients with cancer or non-cancer chronic disease*	13 physicians and 13 nurses

Lemos Dekker et al. 2018	The Netherlands	Analyse professional caregivers’ experiences with the LCP in dementia	Non-participant observation and interviews	General analysis of themes	Nursing home (11 dementia care units)	4 specialist elderly care physicians, 1 nurse practitioner, and 20 nursing staff
Näppä et al. 2014	Sweden	Explore challenging situations experienced by RNs when administering palliative chemotherapy treatments to patients with incurable cancer	Individual interviews and field notes	Narrative analysis	Hospital (chemotherapy units) *Patients with incurable cancer receiving palliative chemotherapy*	17 RNs
Nouvet et al. 2016	Canada	Identify barriers and ideas for improving EOL communication and decision-making with seriously ill patients in hospital	Individual interviews	General analysis of themes	3 hospitals (inpatient medical wards) *Patients with non-surgical serious illness*	18 physicians (staff physicians or residents) and 12 nurses
Oliveira et al. 2016	Canada	Describe nurses’ experiences providing EOL care and to identify factors that support and hinder EOL care in an acute medical unit	Individual interviews	Thematic analysis	Hospital (2 medical units)	10 RNs
Pettersson et al. 2014	Sweden	Investigate haematology and oncology nurses’ experiences and perceptions of DNR orders	Individual interviews	Content analysis	4 hospitals (8 hematology and oncology departments)	15 nurses

Pettersson et al. 2020	Sweden	Describe and explore what ethical reasoning physicians and nurses apply in relation to DNR-decisions in oncology and haematology care	Questionnaires (free-text comments)	Content analysis	7 hospitals (16 hematology and oncology departments)	46 nurses (15 haematology nurses, 31 oncology nurses) and 43 physicians (14 haematology physicians, 29 oncology physicians)
Pontin et al. 2013	United Kingdom	Explore hospital specialist PC professionals' experience of prognostication	Focus group	Thematic analysis	Hospital (specialist PC) *Patients with advanced malignant and non-malignant life-limiting diseases*	4 hospital specialist palliative medicine consultants, 3 senior doctors in training, and 9 CNS
Prompahakul et al. 2021	Thailand	Describe the experience of moral distress and related factors among Thai nurses	individual interviews	Thematic analysis	2 hospitals (31 acute care units and 17 critical care units)	20 RNs
Reid et al. 2015	United Kingdom	Explore healthcare professionals' views on delivering EOL care within an acute hospital trust	Focus groups and individual interviews	General analysis of themes	Acute hospital trust (orthopaedic, 2 different medical and healthcare of the elderly wards)	2 consultants, 4 specialist registrars, 6 junior doctors, 1 staff grade doctor, 5 ward sisters, 8 staff nurses, 2 HCAs, and 7 nurses
Ryan et al. 2012	United Kingdom	Explore the experiences of health care practitioners working in PC in order to establish the issues relating to EOL	Focus groups and individual interviews	General analysis of themes	Acute hospital, general practice, hospice, and specialist PC unit	4 consultants, 9 junior doctors, 6 GPs, 4 practice nurses, 11 CNS, 19 other nurses, and 5

		care for people with dementia			*People with dementia*	allied healthcare professionals
Standing et al. 2020	United Kingdom	Examine how professional boundaries and hierarchies influence how EOL care is managed and negotiated between health and social care professionals	Focus groups and individual interviews	Thematic analysis	Community care (including GP practices and care homes)	7 GPs, 2 out of hours GPs, 10 nurses, 11 specialist EOL nurses, 3 formal carers, 10 paramedics, 6 social workers, 4 pharmacists, 4 hospital doctors, and 5 other supporting professions
Strachan et al. 2018	Canada	Examine nurse and physician perceptions of the nurse's role in goals of care discussions and decision-making with patients experiencing serious illness and their families	Individual interviews	General analysis of themes	3 hospitals (acute medical units)	12 nurses, 9 staff physicians, and 9 medical resident physicians
Tan et al. 2014	Australia	Staff experiences of EOL care for older people in a subacute rehabilitation facility	Focus groups	Content analysis	Subacute facility for people over 65, with a focus on evaluation and rehabilitation	8 junior nurses, 7 junior allied healthcare professionals, and 5 senior multidisciplinary staff
Travis et al. 2005	United States	Describe how MDTs in long-term care settings identify when a resident is approaching end-stage	Focus group	General analysis of themes	2 Nursing homes	14 team members representing nursing, social work, physical therapy, admissions, and medical records

		disease or is entering terminal decline				
Wallerstedt et al. 2007	Sweden	Describe nurses' experiences in caring for dying patients outside special PC settings	Individual interviews	General analysis of themes	Primary home care (district care), community (home care and nursing home care), and hospital (surgery, medicine, and gynaecology)	9 nurses
Willard et al. 2006	United Kingdom	Explore challenges faced by professionals in delivering EOL care in acute hospitals	Individual interviews and non-participant observation	General analysis of themes	5 hospital trusts *Cancer patients*	29 nurses (3 nurse practitioners, 2 research nurses, 11 tumour-specific CNSs, 9 PC CNSs, 4 CNSs with combined tumour-specific and PC roles)

Abbreviations: EOL, End-of-life; DNR. Do Not Resuscitate; LCP, The Liverpool Care Pathway for the Dying Patient; ENs, Enrolled Nurses; NAs, Nurse Assistants; RNs, Registered Nurses; GP, General Practitioner; PC, Palliative Care; PAs, Physician Assistants; HCAs, Healthcare assistants; AMCs, Academic Medical Centres; VA, Veterans Health Administration; CNSs, Clinical Nurse Specialists

3.5.2 Multidisciplinary team prognostic decision-making

The included studies yielded 67 excerpts related to MDT decision-making processes about whether a patient was imminently dying (see Appendix 2). The decision-making information came from either actual study data (i.e., interview quotes, free-text comments, and medical notes) or/and from authors' summarised descriptions of data. The decision-making characteristics are shown in **Table 3.2**.

3.5.2.1 Staff members involved in decision-making

Various staff members were involved in decision-making (see **Table 3.2**). Studies most often reported decisions that involved nurses and doctors (Abu-Ghori et al. 2016; Bloomer et al. 2018, 2019; Clark et al. 2012; Dee and Endacott 2011; Costello 2001; Nappa et al. 2014; Hill et al. 2018; Glogowska et al. 2016; Johnson et al. 2014; Andersson et al. 2018; Gott et al. 2011; Nouvet et al. 2016; Pontin and Jordan 2013; Bloomer et al. 2013; Freemantle and Seymour 2012; Gambles et al. 2006; Oliveira et al. 2016; Reid et al. 2015; Strachan et al. 2018; Wallerstedt and Andershed 2007; Tan et al. 2014; Borbasi et al. 2005; Willard and Luker 2006; Pettersson, Hedström, and Höglund 2014, 2020; Prompahakul et al. 2021). The evidence also showed that decision-making between different types of nurses (Andersson et al. 2018) and between doctors with different specialties (Gidwani et al. 2017; Ryan et al. 2012) occurred. Decision-making occurred between doctors and "other" or "unspecified" staff members (Bern-Klug et al. 2004; Dee and Endacott 2011; Lemos Dekker, Gysels, and van der Steen 2018; Chuang et al. 2017; Bostanci et al. 2016; Standing et al. 2020) and between nurses and other staff groups (Caswell et al. 2015; Dee and Endacott 2011; Lai, Wong, and Ching 2018; Oliveira et al. 2016; Glogowska et al. 2016; Hockley, Dewar, and Watson 2005; Strachan et al. 2018; Fryer et al. 2016) [5] as well. Allied healthcare professionals were reported as being involved in the decision-making process in four of the included studies (Bostanci et al. 2016; Bloomer

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[5] In these cases, the paper specified either a doctor or a nurse as taking part in the decision but details regarding the other part were not present. Instead, papers referred to the other part as a group of healthcare professionals with general and broad terms such as *nursing staff*, *other staff (members), ward team* etc.

et al. 2018; Hill et al. 2018; Oliveira et al. 2016). Two studies reported how other specified healthcare professionals such as carers and physician assistants were involved in decision-making (Chuang et al. 2017; Hockley, Dewar, and Watson 2005).

3.5.2.2 Topic of decisions

The topic of the decision most often involved healthcare professionals recognising or judging whether a patient was dying. Almost half of the decisions concerned identifying dying (n=32) (Bloomer et al. 2018; Clark et al. 2012; Hockley, Dewar, and Watson 2005; Lai, Wong, and Ching 2018; Gidwani et al. 2017; Travis et al. 2005; Reid et al. 2015; Bloomer et al. 2013; Freemantle and Seymour 2012; Hanson, Henderson, and Menon 2002; Strachan et al. 2018; Willard and Luker 2006; Gambles et al. 2006; Borbasi et al. 2005; Bostanci et al. 2016; Glogowska et al. 2016; Hill et al. 2018; Johnson et al. 2014; Oliveira et al. 2016; Pontin and Jordan 2013; Ryan et al. 2012; Fryer et al. 2016; Standing et al. 2020). The excerpts included descriptions such as whether the patient was at the end-of-life or was considered "palliative". Formulations also included whether a palliative approach should be initiated, and how staff recognised changes that were related to patient deterioration.

However, identifying dying was usually not the only or even the main decision being discussed by professionals. Other care aspects or issues, related to the identification of dying patients, were deciding whether to use a specific end-of-life care pathway (n=13) (Andersson et al. 2018; Clark et al. 2012; Dee and Endacott 2011; Johnson et al. 2014; Bloomer et al. 2018; Lemos Dekker, Gysels, and van der Steen 2018; Freemantle and Seymour 2012; Tan et al. 2014); discussing or clarifying patients' goals of care (n=9) (Bloomer et al. 2019; Bostanci et al. 2016; Caswell et al. 2015; Chuang et al. 2017; Gott et al. 2011; Oliveira et al. 2016; Strachan et al. 2018; Prompahakul et al. 2021); making do-not-resuscitate (DNR) orders (n=5) (Abu-Ghori et al. 2016; Costello 2001; Glogowska et al. 2016; Pettersson, Hedström, and Höglund 2014, 2020); whether specific (aggressive) treatments were appropriate and/or should be continued (n=4) (Nappa et al. 2014; Nouvet et al. 2016; Oliveira et al. 2016; Prompahakul et al. 2021); communication and consensus (n=3)

(Bern-Klug et al. 2004; Gott et al. 2011; Hill et al. 2018); roles in care or decision-making (n=3) (Costello 2001; Hill et al. 2018; Wallerstedt and Andershed 2007); life-sustaining interventions (n=2) (Strachan et al. 2018; Willard and Luker 2006); unspecified decisions (n=2) (Bostanci et al. 2016; Costello 2001); and decisions about eating and drinking (n=1) (Bloomer et al. 2018).

3.5.2.3 Decision-making process

The decision-making process referred to *how* healthcare professionals made decisions about the identification of whether a patient is dying. Excerpts were categorised as to whether they provided evidence for collaboration (see **Table 3.2**).

Out of 67 excerpts, five provided evidence for full collaboration. Most of the excerpts (n=44) showed evidence for a partial collaboration process, where information-sharing (n=32) was more common than joint decision-making (n=12). This implied that on many occasions, although information was shared within the team, decision-making was undertaken by only one staff member. Some excerpts (n=18) provided no evidence for collaboration.

A recurring subtheme in the excerpts was professionals expressing that there was disagreement between team members. Another theme that was prominent throughout the data was how doctors were often described as final or sole decision-makers. These two themes often appeared together.

Table 3.2: Decision-making characteristics (from Bruun, Oostendorp, et al. 2022)

Author(s) and publication year	Decision no.[6]	Staff involved in decision-making	Topic of decision	Decision-making process
Abu-Ghori et al. 2016	D#1	Nurse and doctor	DNR order	No evidence for collaboration
Andersson et al. 2018	D#2	Registered nurse and enrolled nurses	Pathway usage	Evidence for joint decision-making
	D#3	Registered nurse and responsible nurse or doctor	Pathway usage	Evidence for joint decision-making
	D#4	Registered nurses, enrolled nurses, and GPs	Pathway usage	Evidence for full collaboration
Bern-Klug et al. 2004	D#5	Physician and nursing staff (certified nurse assistant)	Communication and consensus	Evidence for information-sharing
Bloomer et al. 2013	D#6	Nurses and medical officer	Recognising dying	No evidence for collaboration
	D#7	Nurses and doctors	Recognising dying	Evidence for information-sharing
Bloomer et al. 2018	D#8	Nurse, senior nurse, and doctor	Recognising dying	Evidence for full collaboration
	D#9	Speech pathologist and the team	Recognising dying; Pathway usage; Eating and drinking	Evidence for information-sharing
Bloomer et al. 2019	D#10	Doctor and nurse	Goals of care	Evidence for information-sharing
Borbasi et al. 2005	D#11	Nurses and medical officers	Recognising dying	Evidence for information-sharing
Bostanci et al. 2016	D#12	Physiotherapist and doctor	Recognising dying	Evidence for information-sharing

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[6] Decision-making excerpts were numbered, and the numbers refer to the full excerpts that can be seen in Appendix 2.

	D#13	Healthcare professionals and medical doctors	Goals of care	Evidence for joint decision-making
	D#14	Allied health staff and the medical team	Unspecified decision	No evidence for collaboration
Caswell et al. 2015	D#15	Nurses and other staff members	Goals of care	Evidence for information-sharing
Chuang et al. 2017	D#16	Physician assistants and attending physicians	Goals of care	No evidence for collaboration
Clark et al. 2012	D#17	Nurse and doctors	Pathway usage	Evidence for joint decision-making
	D#18	Consultant and nurses	Recognising dying; Pathway usage	Evidence for joint decision-making
Costello 2001	D#19	Nurses and physicians	Unspecified decision	Evidence for joint decision-making
	D#20	Nurses and physicians	Roles in care/decision-making	Evidence for information-sharing
	D#21	Nurses and physicians	DNR order	Evidence for joint decision-making
Dee et al. 2011	D#22	Nurses and doctors	Pathway usage	No evidence for collaboration
	D#23	Nurses and other clinicians	Pathway usage	No evidence for collaboration
	D#24	Doctor and nursing staff	Pathway usage	No evidence for collaboration
Freemantle et al. 2012	D#25	Nurse and registrar	Pathway usage	Evidence for information-sharing
	D#26	Doctors and nurses	Recognising dying	Evidence for information-sharing
	D#27	Nurse and consultant	Recognising dying	No evidence for collaboration
Fryer et al. 2016	D#28	Healthcare assistants and registered nurses	Recognising dying	Evidence for information-sharing

Gambles et al. 2006	D#29	Doctors and nurses	Recognising dying	No evidence for collaboration
Gidwani et al. 2017	D#30	Oncologists and palliative care physicians	Recognising dying	No evidence for collaboration
	D#31	Oncologists and palliative care specialists/physicians	Recognising dying	No evidence for collaboration
Glogowska et al. 2016	D#32	Community specialist heart failure nurse and consultant	DNR order	Evidence for joint decision-making
	D#33	Hospital specialist heart failure nurse and doctor	Recognising dying	Evidence for information-sharing
	D#34	Hospital specialist heart failure nurse and a palliative care service	Recognising dying	No evidence for collaboration
Gott et al. 2011	D#35	Geriatric specialist registrar and other clinicians involved in patient's care, including consultant	Communication and consensus	Evidence for information-sharing
	D#36	Nurses, registrar, and consultant	Goals of care	Evidence for joint decision-making
Hanson et al. 2002	D#37	Physician and nurses	Recognising dying	Evidence for information-sharing
Hill et al. 2018	D#38	Registered nurse and physician	Recognising dying	Evidence for joint decision-making
	D#39	Nurses and physicians, social workers, chaplains, and recreation therapists	Communication and consensus; Roles in care/decision-making	No evidence for collaboration
Hockley et al. 2005	D#40	Nurses and other staff, including doctors (specifically the GP)	Recognising dying	Evidence for full collaboration
	D#41	Nurses and ward team	Recognising dying	Evidence for joint decision-making
	D#42	X and carers	Recognising dying	Evidence for joint decision-making
	D#43	Carer and X	Recognising dying	Evidence for information-sharing

Johnson et al. 2014	D#44	Senior nurse and GP	Recognising dying; Pathway usage	Evidence for full collaboration
Lai et al. 2018	D#45	Nurses and other healthcare providers	Recognising dying	No evidence for collaboration
Lemos Dekker et al. 2018	D#46	Doctor and nursing staff	Pathway usage	No evidence for collaboration
Näppä et al. 2014	D#47	Nurse and physician	Treatment decisions	Evidence for information-sharing
Nouvet et al. 2016	D#48	Nurse and attending physician	Treatment decisions	Evidence for information-sharing
Oliveira et al. 2016	D#49	Nurses and doctors	Treatment decisions	No evidence for collaboration
	D#50	Nurses and doctors	Goals of care	No evidence for collaboration
	D#51	Nurses, residents/medical students, and staff physician	Recognising dying	Evidence for information-sharing
	D#52	Nurses and other healthcare professionals (registered respiratory therapists and a palliative care consult service)	Goals of care	Evidence for information-sharing
Pettersson et al. 2014	D#53	Nurses and physicians	DNR order	Evidence for information-sharing
Pettersson et al. 2020	D#54	Nurse and physician	DNR order	Evidence for information-sharing
Pontin et al. 2013	D#55	Specialist registrar and nurses	Recognising dying	Evidence for information-sharing
Prompahakul et al. 2021	D#56	Nurses and doctors	Treatment decisions	Evidence for information-sharing
	D#57	Nurses and doctors	Goals of care	Evidence for information-sharing
Reid et al. 2015	D#58	Nurses and doctors	Recognising dying	Evidence for information-sharing

	D#59	Junior doctors, nurses, and senior doctors	Recognising dying	No evidence for collaboration
Ryan et al. 2012	D#60	Geriatrician and psychiatrist	Recognising dying	Evidence for information-sharing
Standing et al. 2020	D#61	Doctor and care home staff	Recognising dying	Evidence for information-sharing
Strachan et al. 2018	D#62	Nurse and doctor or team members	Goals of care	Evidence for information-sharing
	D#63	Nurses and doctors	Recognising dying; Life-sustaining interventions	Evidence for information-sharing
Tan et al. 2014	D#64	Nurses, registrar, and consultant	Pathway usage	Evidence for information-sharing
Travis et al. 2005	D#65	Members of the MDT and physician	Recognising dying	Evidence for full collaboration
Wallerstedt et al. 2007	D#66	Nurses and doctors	Roles in care/decision-making	Evidence for information-sharing
Willard et al. 2006	D#67	Palliative care clinical nurse specialist and consultant	Recognising dying; Life-sustaining interventions	Evidence for information-sharing

3.5.3 Prognostic decision-making in specialist palliative care settings

One of the secondary research questions of the review involved further exploration of decision-making in specialist palliative care settings. Six of the included studies were conducted in such settings. Studies were conducted in hospital specialist palliative care units (Pontin and Jordan 2013; Gott et al. 2011; Ryan et al. 2012); hospices (Dee and Endacott 2011; Gambles et al. 2006; Gott et al. 2011; Ryan et al. 2012); and one community nursing/hospice facility (Borbasi et al. 2005). Three of the studies were conducted in multiple settings, including specialist palliative care (Gott et al. 2011; Ryan et al. 2012; Borbasi et al. 2005). However, the relevant excerpts from these papers did not specifically involve staff from specialist palliative care and therefore these could not be used to describe decision-making characteristics in that setting. This meant that only three studies provided relevant data from specialist palliative care settings.

Dee and Endacott (2011) conducted a study in which they interviewed doctors and nurses from an inpatient hospice unit in the UK. The extracted excerpts reported no evidence for collaborative decision-making. An example of non-collaborative decision-making is illustrated in excerpt D#22 below.

> However, there was a suggestion that some nursing staff may feel that their opinions are not considered, which could be a frustration and could sometimes prove to be a barrier to the implementation of the LCP.
>
> “The doctors go in for a short period and maybe for that period the patient is able to say ‘this is fine’ but then you go and move somebody and you know that they’re in excruciating pain.” (Nurse 4, patient not on LCP) (D#22 from Dee and Endacott 2011)

This and the other excerpts from this study showed how nurses felt their opinions were not considered, and how there were issues with communication between nursing staff and doctors (see D#22-24 in Appendix 2).

Similarly, the study by Gambles and colleagues (2006), which involved interviewing doctors and nurses from a UK inpatient hospice, also provided no evidence for collaboration. However, the relevant excerpt reported that nurses had more influence, responsibility, and that they could act as decision-makers:

> There was evidence that nurses have much more influence over the diagnosis of dying and the decision to commence a pathway in this environment:
>
> “The good thing as well is …here the nurse would start a pathway. That is a very good thing … It doesn't necessarily have to be the doctor… here most of the medication would be prescribed anyway … you don't have to convince the doctors that somebody is dying …so you don't have to argue.” [doctor 1] (D#29 from Gambles et al. 2006)

The excerpt also showed that this non-collaborative process was viewed positively by doctors. This finding stands in contrast to the recurring theme in which doctors were described as sole decision-makers.

Pontin and Jordan’s (2013) study from a UK hospital specialist palliative care setting involved focus groups with specialist palliative medicine consultants, senior doctors in training, and clinical nurse specialists. The excerpt from their study showed evidence for a partial collaborative decision-making process:

> So I think that is why nurses are much better at prognosticating than doctors because we are seeing an absolute snapshot and sometimes that is useful because you can come back and say that’s a really dramatic change in 24 hours. And maybe that isn’t apparent to the nurses who just, just keep doing things but often it is the nurse who says ‘well actually the last time they could mobilize to the bathroom and now they can’t’. (spr001319) (D#55 from Pontin and Jordan 2013)

This excerpt showed how nurses shared information and kept the doctors up to date, and how doctors valued nurses’ assessments and regarded them as better prognosticators because of their contact level with patients.

3.5.3.1 Evidence from hospice settings

As the focus of the thesis is on the specialist palliative care hospice setting, a closer investigation and assessment of the two studies providing relevant data from hospices will be conducted. Both studies focused on aspects of The Liverpool Care Pathway for the Dying Patient (LCP) and involved interviews with hospice doctors and nurses in the UK.

The study by Dee and Endacott (2011) identified factors that enabled or hindered clinicians in implementing LCP. This was done through interviews with five doctors and five nurses from a UK hospice. However, the study faces a number of methodological limitations. Firstly, the analytical rigour of the study is questionable as it is unclear whether the analysis involved multiple researchers conducting the coding and thematic analysis to ensure interrater reliability. Secondly, the authors mention that a senior member of the hospice team was in charge of data collection, and it is highlighted that it is unknown how this may have influenced or biased participants' disclosure during the interviews. No topic guide is provided and it is unclear how participants were prompted when they were "asked to describe factors that influence them when they are diagnosing dying, what factors help and hinder this process and to describe the management of the last few days of a patient that had died recently" (Dee and Endacott 2011: 187). This is of particular interest as it was established in Chapter 1 how describing prognostic decision-making processes can be difficult for clinicians (see Taylor, Dowding, and Johnson 2017; Chu, White, and Stone 2019). Lastly, detailed description of the sample is absent as no participants' demographics is provided. It is only disclosed how participants were part of either the permanent medical or senior nursing team.

The other study providing relevant data from the hospice setting was conducted by Gambles and colleagues (2006). The aim of this study was to explore hospice-based doctors' and nurses' perceptions of LCP. This aim was addressed by interviewing three doctors and eight nurses from an inpatient hospice in the north-west of England. A major limitation of this study is that it was conducted in the hospice in which LCP was originally developed. It is unclear how this may have biased the clinicians' (positive) perspective of LCP and thus the overall study findings. It is mentioned that each interview "was carried out by a team leader or a research fellow based at the hospice" (Gambles et al. 2006: 416), but it is unclear whether that is someone from the hospice management team and if so potential bias should be addressed. Similar to the study by Dee and Endacott (2011), there is very limited demographic information about the participants who took part in the study, where only participants' sex and clinical grade are listed.

As demonstrated above, one of the studies was of poor methodological quality, while both studies involved potential bias, and therefore the findings should be treated with caution.

3.5.4 Decision-making barriers, opportunities, or recommendations

Half of the included studies (n=20) reported barriers, facilitators, or recommendations about MDT decision-making in their study implications sections. The implications involved more effective communication, improved collaboration and teamwork, and end-of-life training. Communication and collaboration were often closely linked together.

The most prominent theme across studies was the need for improved communication (Borbasi et al. 2005; Chuang et al. 2017; Freemantle and Seymour 2012; Gidwani et al. 2017; Ryan et al. 2012; Tan et al. 2014; Hanson, Henderson, and Menon 2002; Gott et al. 2011; Bern-Klug et al. 2004; Oliveira et al. 2016; Johnson et al. 2014). Training in communication skills might ease role anxiety and make professionals more effective (Chuang et al. 2017). One study suggested that communication should address priorities of care especially out of hours, ensuring regular senior review of all dying patients and supporting frontline staff (Freemantle and Seymour 2012). Study authors also proposed better collaboration and communication across services (Borbasi et al. 2005; Gidwani et al. 2017; Clark et al. 2012), including more structured communication about prognostic information to avoid duplication and fragmentation of services (Gidwani et al. 2017). Another study detailed how the healthcare environment itself presented challenges to communication and collaboration, and that research was needed on how to better support and structure healthcare environments (Oliveira et al. 2016).

A need for better collaboration and teamwork was also reported (Bern-Klug et al. 2004; Abu-Ghori et al. 2016; Hanson, Henderson, and Menon 2002; Oliveira et al. 2016; Gott et al. 2011; Standing et al. 2020; Fryer et al. 2016; Pettersson, Hedström, and Höglund 2014). The need to respect contributions from all professional groups and avoid discounting the knowledge of staff in subordinate positions was highlighted (Standing et al. 2020). One study recommended that research should aim to understand the perspectives of team members to enhance understanding of the support and optimal teamwork required to manage end-of-life care (Abu-Ghori et al. 2016). Another study proposed that scheduled team rounds might facilitate teamwork in order to better meet complex care needs of dying patients (Hanson, Henderson, and Menon 2002). Studies mentioned the importance of reaching team consensus on patients’ palliative care needs in order to make adequate changes to their care (Gott et al. 2011). Thus, care and communication processes should be restructured to facilitate consensus (Bern-Klug et al. 2004).

The need for more effective MDTs was also addressed (Bloomer et al. 2018; Chuang et al. 2017; Bostanci et al. 2016). One study recommended that healthcare professionals from every discipline should be prepared to care for dying patients (Bloomer et al. 2018). The need for research and training on improving understanding of end-of-life roles and responsibilities of MDT members was highlighted as well (Bloomer et al. 2018; Chuang et al. 2017). One of the studies further proposed redesigning workflows, which should include interdisciplinary team rounds (Chuang et al. 2017). The potential input of allied healthcare professionals into end-of-life discharge planning was also addressed (Bostanci et al. 2016).

Studies also reported the need for educating staff in end-of-life care and about the dying process (Tan et al. 2014; Clark et al. 2012; Reid et al. 2015; Borbasi et al. 2005; Hill et al. 2018; Johnson et al. 2014; Fryer et al. 2016). Studies claimed that appropriate end-of-life care could only be delivered if the culture accepts death and dying as a possible outcome for patients (Reid et al. 2015), and all team members should be prepared to “let go” at an appropriate time (Borbasi et al. 2005). Training should increase awareness of the dying process to ensure that patients had timely access to palliative care and to provide staff with the knowledge and tools to make decisions regarding initiating palliative care (Hill et al. 2018).

3.6 Discussion

The discussion section is divided into three sections. The first section summarises the overall findings of the review. Then follows a discussion of some of the key findings. Lastly, a comprehensive overview of areas for future research is presented.

3.6.1 Main study findings

A systematic approach to scoping the available literature identified 40 papers that reported on studies from ten countries describing the process of MDT decision-making about the identification of imminently dying patients. Information on the prognostic decision-making process often came from interview quotes involving nurses and doctors. Most decisions focused specifically on professionals recognising that patients were dying. The results showed that decisions also focused on whether specific end-of-life care pathways should be initiated or dealt with clarifying patients' care goals. Most excerpts provided evidence for a partial collaborative approach to decision-making, with information-sharing being more common than joint decision-making. Issues with decision-making were articulated through disagreement between staff members. This was closely related to the fact that doctors were often described as the final or sole decision-maker.

Limited information was available from specialist palliative care settings. Decision-making in these settings provided evidence for either no or partial collaboration. However, nurses were reported to act as final decision-makers in this setting in contrast to findings from other settings.

Study authors considered that staff collaboration and communication were important and should be improved. Redesigning workflows, including scheduled team rounds, and facilitating consensus within the team might improve MDT working. They also expressed the view that more end-of-life training should be provided to staff.

3.6.2 Staff disagreement and medical authority

The findings showed that the decision-making process most often did not involve joint decision-making. 50 of the 67 excerpts involved a decision made by only one staff member (i.e., partial collaboration only involving information-sharing [n=32]; no evidence for collaboration [n=18]). Moreover, there were reoccurring themes of disagreement and doctors being perceived as being final and sole decision-makers. This suggested that barriers related to medical authority and power relations might be present.

In the decision-making excerpts that involved disagreement between staff members, it was often a doctor who made the final decision and overruled other healthcare professionals' judgements. This might be due to doctors having medical authority and legal accountability for patient care (Gair and Hartery 2001). In another study, it was also described how responsibility for prognostic decisions was ultimately seen as resting with (senior) doctors (Taylor, Dowding, and Johnson 2017). However, it can be problematic if doctors overrule other staff members in cases where others have strong opinions about whether a patient is dying. Disagreement among staff members about a patient's prognosis can influence the interpersonal relationship and result in inconsistent patient management and confused communication (Ellershaw, Neuberger, and Ward 2003). A causal relation between disagreement and doctors being sole decision-makers may be present. If members of the MDT disagree and therefore cannot reach consensus, then the doctor will have to make a decision. The outcome of the decision is then likely to support the doctor's own opinion and view. It is important to stress that because the included data only involved staff members' retrospective accounts, it cannot be known for sure how decisions were actually negotiated between members nor the doctors' rationale for making a decision.

3.6.3 Areas for future research

The aim of the scoping review was to provide an overview of the evidence base and to identify significant gaps in the literature. Based on the findings, several areas where there is a need for further research were identified. The review results suggested that research should:

- Focus specifically on investigating MDT prognostic decision-making
- Include a greater variety of study methods (especially, recording MDT discussions)
- Explore the role of allied and other types of (non-)healthcare professionals in prognostic decision-making

- Address the topic in community, primary, and especially specialist palliative care settings
- Focus on expanding the evidence base to include studies from more countries

Each of these areas will be elaborated in the following sections.

3.6.3.1 Focus on MDT prognostic decision-making

MDT decision-making on the identification of patients who are dying was not the main focus of any of the included papers (see the study aims column in **Table 1**). This meant that there was a lack of relevant data since the actual decision-making process was not described in any detail. The relevant data often only involved a few lines of text within the whole paper. This lack of data on the process of decision-making was a prominent issue in the literature. Despite having established that there is a need for this type of research, this review showed that this still appears to be a gap within the evidence base.

3.6.3.2 Methods of data collection and analysis

Most of the study data from the included papers were obtained from interviews, and the analysis most often involved identifying themes. Interviews and qualitative analysis of themes can provide detailed insights into the decision-making process. However, during the analysis, it became apparent that the included papers often only reported one side of the decision-making process. If one opinion or experience was expressed, then it was not explained how the same process was perceived by other team members. This is potentially an issue when it is common that team members have different understandings of how decisions are or were made (Øvretveit 1993). Therefore, it is important to investigate how decisions are actually made between team members. The review identified how the evidence base lacks a diverse range of study methods, particularly more quantitative study methods. There is a need for research exploring the decision-making process that does not rely on team members' retrospective accounts.

Future studies could explore decision-makers' rationale for making decisions. Methods such as Judgement Analysis (Cooksey 1996) or the JAS methodology (Sniezek and Buckley 1995) might be able to map how inputs from different team members are weighted by the decision-maker. In cases of MDT discussions, you would expect the decision-maker to encounter different opinions and views from multiple professionals, and it would be interesting to look at how these inputs are considered.

Another way of exploring the decision-making process is through audio and video recordings of MDT discussions. Audio or video recordings of MDT discussions would allow for in-depth analyses of team communication related to these decisions. Recordings allow for a more detailed investigation of the decision-making process. This type of analysis would deal with decisions as they occur *in situ* as opposed to interviews that rely on subjective recall of decision-making. Moreover, one study has stressed that future research should pay more attention to the details of MDT meetings, suggesting that researchers should make more use of video recordings whenever feasible (Seuren et al. 2019).

The review findings also showed that studies often recommended that communication and collaboration should be improved. Study authors mentioned that workflows and communication processes should be restructured to facilitate collaboration and consensus. This argues for future research exploring MDT prognostic decision-making from an interactional point of view. Such research would be able to inform evidence-based recommendations on how collaboration and communication could be carried out more effectively. A few studies have recorded MDT meetings and investigated decision-making using CA (Dew et al. 2014; Seuren et al. 2019), discourse analysis (Arber 2008) or looked at aspects such as collaborative communication practices (Wittenberg-Lyles et al. 2010), and information-sharing (Demiris et al. 2008). However, these studies did not focus on *prognostic* decision-making.

3.6.3.3 The role of other types of professionals

The review found that nurses were most often included in the samples of included studies. Future research should include and consider allied and other types of (non-)healthcare professionals when investigating MDT workings. Guidelines by the EAPC state:

> "…the complexity of specialist palliative care can only be met by continuous communication and collaboration between the different professions and disciplines in order to provide physical, psychological, social and spiritual support." (Radbruch et al. 2009: 284)

Integrating the expertise of different individuals into palliative care planning may ensure that patients are managed in a holistic manner, and it is each professional's individual expertise that *together* enables the broad spectrum of patient care (Fernando and Hughes 2019). A study on teamwork in prognostic communication in oncology also proposed that clinical teams should consider including psychosocial MDT members in prognostic conversations (Sisk, Dobrozsi, and Mack 2020). The authors describe that these professionals have unique training, experiences, and skills that can be benefitted from. It is therefore important to consider the role of other types of professionals in prognostic decision-making.

Nurses and doctors were most often involved in decision-making. In the process of reviewing the literature, the reviewers did encounter occasions in which allied healthcare professionals were part of decision-making processes. Unfortunately, these decisions were often not directly related to identifying dying patients and were not eligible for the review. However, non-clinical professionals such as chaplains and social workers, although not professionally trained to recognise the same signs of deterioration as doctors and nurses, may provide a different (or similar) perspective to the identification of dying patients. In Chapter 1, it was explained that the decision-making process involves clinicians collating information that can come from their own observations or from others, and as further information is acquired, they review their decisions (Taylor, Dowding, and Johnson 2017). Allied and other types of professionals may contribute to the decision by sharing observations, supporting other staff members, or providing input that adds important details to overall patient care. As noted earlier, it is highly important that team members caring for the patient agree that the patient is dying (Ellershaw, Neuberger, and Ward 2003). For this reason, future research should aim to explore in more detail what role allied and other types of professionals have in the decision-making process.

3.6.3.4 Specialist palliative, community, and primary care settings

Only three studies provided relevant data from specialist palliative care settings. The results from the decision-making excerpts were inconclusive. However, the finding that nurses, rather than doctors, were reported to be final decision-makers needs further elaboration and investigation. Future research should aim at exploring MDT prognostic decision-making in the specialist palliative care setting. It is important to further explore this area, especially since palliative care professionals are specialised in providing end-of-life care and because prognostication is central to care planning.

A limited number of studies were conducted in the community (n=5) (Lai, Wong, and Ching 2018; Gidwani et al. 2017; Glogowska et al. 2016; Borbasi et al. 2005; Standing et al. 2020) and primary care settings (n=4) (Gott et al. 2011; Glogowska et al. 2016; Ryan et al. 2012; Standing et al. 2020). More research in these two settings is needed and important because many patients wish to die in their homes (Higginson and Sen-Gupta 2000). Moreover, facilitating home-deaths is included as a recommendation in the World Health Organization (2018) guidelines on palliative care. A systematic review on barriers and facilitators influencing home-deaths identified recognising death and prognostication difficulties as a barrier (Wahid et al. 2017). They also identified coordinated care and effective communication as facilitators for enabling patient home-deaths (Wahid et al. 2017). This further supports the need for research specifically investigating how community and primary care MDTs make prognostic decisions.

3.6.3.5 The need for more international research

The results showed that studies were conducted in ten countries globally, and that most of the studies were from the UK. Future research should aim at exploring this topic in a wider international context. As palliative care is explicitly recognised under the human right to health (World Health Organization 2020), and since MDTs are an essential part of palliative care, this should be a research priority within any country. Moreover, studies conducted in more countries provides the opportunity for comparison, knowledge-sharing, and general learning opportunities between countries.

3.6.4 Study findings in relation to the thesis

Different gaps in the evidence base have been described in previous sections of the chapter so far. These findings were used to inform the other research studies in this thesis.

The review showed that no studies had focused specifically on investigating MDT prognostic decision-making. The evidence available showed that limited research had been done in specialist palliative care settings. Only two studies provided relevant evidence from hospice settings, focusing on either the implementation or perception of LCP from the perspective of doctors and nurses. However, these studies report on LCP, which in the meantime has been withdrawn and is no longer used in the UK following an extensive review (Neuberger, Guthrie, and Aaranovitch 2013). One of these studies also lacked methodological rigour, while both studies were subject to substantial bias. This advocates for the need for new and updated evidence from the hospice specialist palliative care setting, minimising bias and ensuring methodological robustness.

The lack of evidence from specialist palliative care settings could indicate that MDT involvement is not a key feature of prognostication in this setting. However, as described in Chapter 1, prognostication is still central to clinical decision-making, particularly when patients are approaching death. This further justified the need for choosing and exploring these particular settings. Different specialist palliative care MDTs might deal with prognosis in distinct ways (e.g., prognostication in hospital versus hospice), and there is a need to understand how prognostication is done in *all* specialist palliative care settings. This thesis only focused on exploring the hospice setting, although future research should further explore other specialist palliative care settings.

Previous studies mostly used qualitative methods of data collection and analysis that relied on staff members' retrospective accounts such as interviews analysed thematically. There were no studies further exploring prognostic decision-making by recording MDT discussions and analysing the communication between staff members. This was identified as a clear gap in the evidence base and justified the decision to conduct a CA study to systematically analyse video recordings to find out *how* MDT members formulate prognoses.

The review search strategy and eligibility criteria were kept broad in order to include studies using a wide range of both qualitative and quantitative research methodologies. However, the review did not identify any quantitative studies systematically trying to explore MDT prognostic decision-making. This also appeared as a prominent gap in the literature, which advocated for the methodology used in the online RCT to explore factors altering prognostic decisions.

The review finding about the lack of other types of professionals in the sample under investigation informed the ADJUST study of the thesis. This meant that any professional as part of the MDT could participate in the study, and not only doctors and nurses as initially planned.

3.6.5 Study strengths

This scoping review followed the PRISMA-ScR and current guidelines to add robustness to the methodology and keeping in with good practice within the field. Multiple databases were searched, and a broad search strategy was applied to identify relevant literature. The screening approach was inclusive to ensure that relevant publications and data were not excluded. Screening and data extraction were completed by two reviewers independently, with disagreements resolved through consensus in the study team.

3.6.6 Study limitations

There are no agreed search terms for the domains covered by this review. Despite basing terms on previous literature, the database search still resulted in a high number of papers and citation searches yielded several more. The additional studies often focussed exclusively on decision-making between doctors and nurses. It could be questioned whether two professionals having a discussion about a patient is sufficient to constitute an MDT. In real clinical practice, an MDT would not normally consist of only doctors and nurses. This preponderance of studies on doctor-nurse communication may have been due to the broad definition of MDTs used in this review. As presented in Chapter 1, there are several ways of referring to a healthcare team consisting of professionals working together (i.e., “multidisciplinary”, “interdisciplinary”, “multi-professional” and “interprofessional”) but there is inconsistency in the way these terms are used within literature (Chamberlain-Salaun, Mills, and Usher 2013; McCallin 2001). However, multidisciplinary is most frequently used to describe healthcare teams (Chamberlain-Salaun, Mills, and Usher 2013). In order to be inclusive, all studies with two or more professionals with different roles or disciplines were included in the review. Future reviews exploring palliative care MDTs might consider refining the search strategy.

Another study limitation and complication were the lack of a clear definition of the meaning of “imminent death”. This term and other related ones such as “end-of-life”, “terminally ill” and “palliative phase” do not consistently refer to the same time points in the disease trajectory, and there is a lack of agreement about their definition (Hui et al. 2014). Studies concerning goals of care for seriously ill or deteriorating patients, or whether they should be resuscitated were understood to concern, at least partially, whether or not the patient was imminently dying. If a publication did not clearly define these terms in the title or abstract, it was necessary to retrieve the full text for further inspection. This resulted in a high number of papers needing to be read through and discussed within the study team to reach consensus about whether or not they fulfilled the eligibility criteria.

For several papers there was some initial uncertainty about whether or not they were conducted solely in an acute care setting. These studies were discussed to reach consensus about whether to include or exclude them. The study team decided to apply an inclusive approach if the study setting was unclear. This meant that papers were included if they reported relevant information on MDT prognostic decision-making despite the clinical setting being described as acute or subacute, as long as this was clearly not identified as ICUs, Emergency Departments, or similar acute care settings.

Methods of data analysis reported in included papers were often unclear as well. Several papers did not clearly report what methods of thematic analysis authors had applied. For this reason, the expertise of a third reviewer (SB) was called upon to clarify which methods had been used. This involved detailed investigation of the papers’ methods sections and looking at relevant references cited in these sections. The labels used in the review were based on the descriptions provided in the papers. However, several papers with rather poor and conflicting methodological descriptions were encountered. For this reason, and since the review did not include critical appraisal of study methods, it was deemed appropriate to use the label “general analysis of themes”. This label captured studies which reported having identified and analysed themes, but where the study did not report having used or referenced a recognisable analytical framework. If the study did report or reference a recognisable analytical framework, the label “thematic analysis” was applied.

The data available on decision-making about identifying imminently dying patients were limited. As mentioned earlier, the relevant data was rather limited within each paper, which meant that several excerpts had to be extensively discussed within the study team to reach consensus about whether they specifically concerned identification of imminently dying patients and also whether the involved professionals constituted an MDT.

3.7 Chapter summary

In this chapter, the evidence on how MDTs make decisions about the prognosis of imminently dying patients was scoped. This provided a general understanding of the evidence base on prognostic decision-making and identified where the gaps were. The findings were used to justify and inform decisions about approaches used in the other workstreams of thesis.

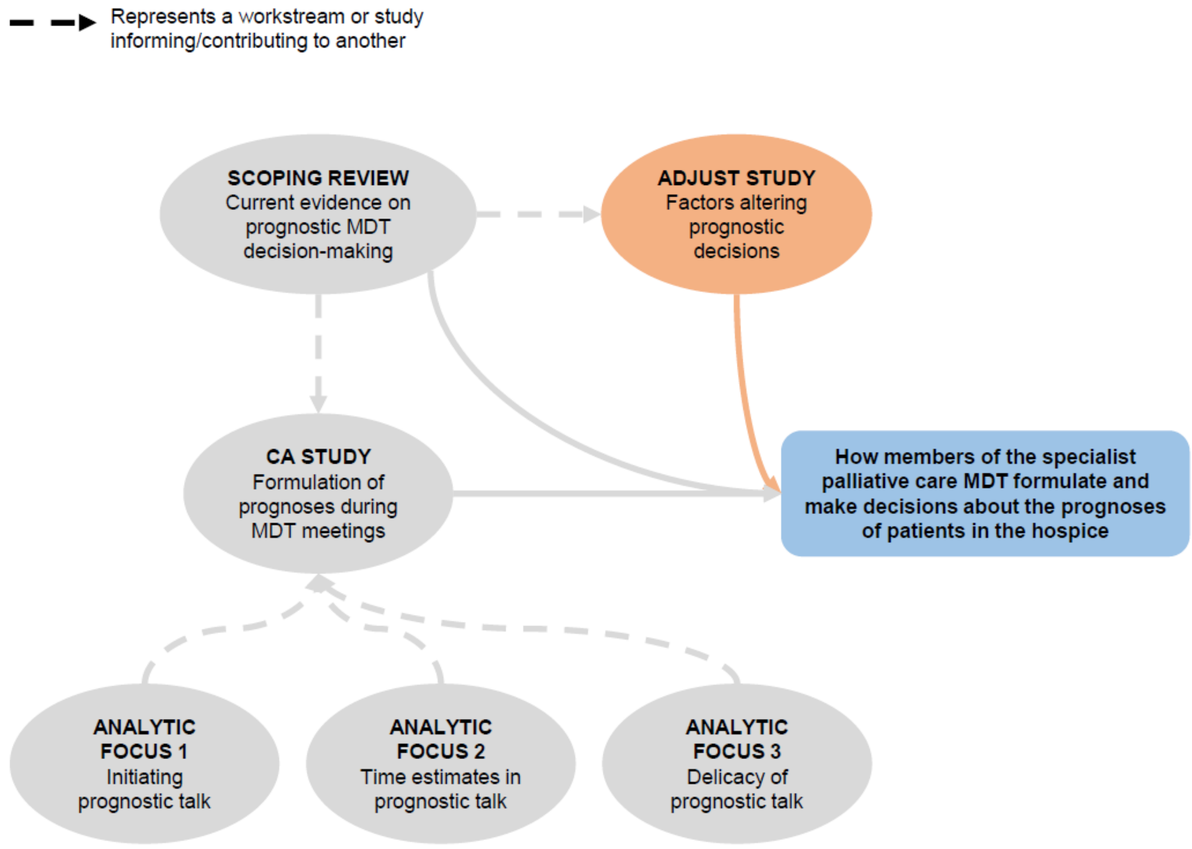
This scoping review was the first step of the thesis in order to understand how members of the specialist palliative care MDT formulate and make decisions about the prognoses of patients in the hospice. With this review, it was ensured that the evidence base was scoped to gain an overview of the evidence within the field. As demonstrated above, the review provided a framework for the other thesis workstreams. The review also further ensured that the thesis methods addressed evidence gaps and did not duplicate previous research.

Chapter 4 – Study of Advice and Decision-making on prognosis using the Judge-advisor System within multidisciplinary Teams (ADJUST)

4.1 Chapter overview

This chapter addresses the aim of the thesis about exploring what factors (if any) can alter MDT members' prognostic decisions and the extent to which this occurs **Figure 4-1**.

Figure 4-1: Thesis outline diagram – ADJUST study



This was done through an online RCT that involved palliative care clinicians completing a decision-making task where they had to provide estimates of advanced cancer patients' probability of surviving two weeks. The study involved clinicians receiving advice from different sources (another clinician or from a prognostic algorithm) to see if that influenced their prognostic decision-making. Characteristics of the clinicians making the decision and the advice they received were also explored to see if they had an impact on prognostication. The study was published in *Cancer Medicine* in November 2022 (Bruun, White, et al. 2022).

4.2 Introduction

It was established in Chapter 1 that information-exchange between healthcare professionals was a key factor in decision-making. The scoping review (Chapter 3) also showed that there was often evidence for information being shared between MDT members. In Chapter 1, it was explained how seeking advice from other team members was essential in order to make appropriate prognostic decisions. This had also been recommended by the EAPC, who advised that a second opinion might be useful for improving prognostic accuracy, and as mentioned in Chapter 1, that clinical prediction of survival should be used in conjunction with other prognostic factors (Maltoni et al. 2005). Since these recommendations mention that clinicians should seek information, or advice, from colleagues or prognostic algorithms when making survival predictions, it is relevant to investigate how and to what degree prognostic advice from either of these sources is taken into account.

4.2.1 Advice from prognostic algorithms

Evidence suggests that human barriers to algorithm adoption are substantial in clinical practice (Kelly et al. 2019), and there is conflicting evidence about whether people generally prefer advice from humans or algorithms (Dietvorst, Simmons, and Massey 2015; Logg, Minson, and Moore 2019; Yeomans et al. 2019). Concerns have been expressed about prognostic models leading to overconfidence and excessive prognostic certainty (Hallen et al. 2015). A fear of over-reliance on prognostic algorithms resulting in a loss of human connection and relationship with patients has been expressed (Parikh et al. 2022). Research has also highlighted that algorithms lack interpretability and do not reflect clinical applicability (Hui et al. 2019; Kelly et al. 2019). Some prognostic algorithms might not be appropriate for use in advanced cancer patients, where there can be practical, organisational, and ethical issues related to obtaining the required inputs for the model (e.g., blood tests) (Stone, Kalpakidou, et al. 2021). Many prognostic algorithms also rely to some extent on clinical prediction of survival, which may complicate the usage of such algorithms if an objective estimate is sought or needed (Chu, White, and Stone

2019). However, there is a lack of research within this area, where it has been stressed that it is important to study how predictions from prognostic algorithms are used to update clinical predictions and influence decision-making (Gensheimer et al. 2021).

4.2.2 Expertise and advice-taking

Expertise has previously been shown to have an impact on advice-taking, with experts tending to discount advice more than non-experts (Yaniv 2004b), despite decision-making research showing that using advice increases accuracy (Yaniv 2004a; Yaniv and Milyavsky 2007). Experts might make more accurate domain-specific estimates, but they might also be overly confident in their knowledge in the domain (Larrick and Feiler 2015). Decision-makers who are over-confident in their own expertise or abilities are less likely to see advice as necessary (Van Swol, Paik, and Prahl 2018). Chapter 1 described how experts often use the fast and intuitive System 1 thinking, which is different from the strategies used by novices.

Limitations with expert decision-making have been noted. It is important to acknowledge that there are different types of expertise (Shanteau 1988), and therefore more nuance may be needed when defining or labelling someone as an expert. It is common, for instance, to select medical experts on the basis of seniority or years of experience (White et al. 2018). Based on a medical professional’s seniority and years of experience, it may be assumed that they have given more prognoses, and therefore they are more of an expert. However, the assumption that seniority equates to expertise may be questioned. Perhaps more senior clinicians are less expert prognosticators because they have had less recent experience “at the coalface”, or perhaps their prognostic abilities are negatively affected by the relative lack of time that they spend with patients compared to more junior colleagues.

The scoping review indicated that doctors and nurses were more directly involved with prognostication than allied and other types of healthcare professionals. This could potentially lead to more familiarity with, and expertise in, prognostication and thus more discounting of prognostic advice. However, there is conflicting evidence regarding whether experience improves prognostic accuracy, and there is no clear evidence about whether some types of professionals are better prognosticators than others (White et al. 2016). It is still unanswered whether professional background and/or experience influence the degree to which individuals take advice from others when making prognostic decisions.

4.3 Study aims

The overall aim of the ADJUST study was to understand how clinicians form intuitive judgements about the prognoses of palliative care patients after receiving advice perceived as coming from either another clinician or an algorithm.

The primary study objective was:

- To assess the level to which clinicians incorporate advice received from other clinicians or an algorithm into their estimates of the prognosis of palliative care patients

The secondary study objectives were:

- To investigate the extent to which clinicians' integration of advice is influenced by *the characteristics of the judge*
- To investigate the extent to which clinicians' integration of advice is influenced by *the advice itself*

4.4 Methods

4.4.1 The Judge-Advisor System

To address the study aims, the JAS research method was used. JAS offers a robust basis from which hypotheses on advice-giving and decision-making in dyads or groups can be tested (Van Swol and Sniezek 2005). A key component of the JAS framework is the differentiation between the roles of the *judge* and the *advisor*. The judge is the decision maker who assesses information concerning a specific decision and subsequently makes the final decision. An advisor is the person who offers advice, information, or suggestions to the judge (Sniezek and Buckley 1995). While the actual decision-making power resides solely with the judge, the advisor may influence or have an impact on the judge's decision (Sniezek and Buckley

1995). Most JAS studies involve the following three steps (Van Swol, Paik, and Prahl 2018), where the judge:

1) makes an initial judgment
2) receives advice from an advisor
3) makes a final judgment

The judge's final post-advice judgment may or may not be revised in light of the advice received. JAS studies have been conducted in the field of social and organisational psychology (see Bonaccio and Dalal 2006). Recently, the framework has also been successfully applied in clinical research (Kaliuzhna et al. 2012; Hofheinz et al. 2017; Scheunemann, Fischer, and Moritz 2021).

The JAS framework was selected for this project because it provided a systematic way of studying individuals' decision-making. It allowed the researcher to vary the different factors involved in decision-making to see what effect they have on the final prognostic estimate. In contrast to qualitative methods, this type of experimental design made it possible to correlate the "input" factors with the "outcome" factors of a decision in an objective and measurable way (Taylor 2006). The experimental nature of the JAS framework also allowed the researcher to conduct the study in a systematic way. For this reason, it was decided to also follow RCT principles in order to ensure methodological robustness.

4.4.2 Study design

Following the JAS framework, palliative care clinicians were recruited as *judges* and asked to complete a decision-making task. The study was an online double-blind RCT using 1:1 allocation ratio, where participants were randomised into two study arms: the algorithm arm and the clinician arm. The task was for clinicians to provide probability estimates for two-week survival for five advanced cancer patients before and after receiving advice from an *advisor*. The trial intervention was the perceived nature of the advisor in the two arms. In one arm, participants were told the advice came from the PiPS-B14 prognostic algorithm (see Stone, Kalpakidou, et al. 2021), whilst in the other arm, participants were told the advice came from another clinician. In fact, the advice received was the same in both arms (and came from the prognostic algorithm).

The RCT was reported following the Consolidated Standards of Reporting Trials (CONSORT) 2010 guidance (Schulz, Altman, and Moher 2010). The study was prospectively registered on the ClinicalTrials website (NCT04568629), where the study protocol can be accessed.

4.4.2.1 Website development

A website was created for the purpose of the study. It was created by website developer Dr Christopher Tomlinson (CT), who had been involved with website development in another similar online prognostication study (see White et al. 2018; White, Reid, et al. 2019).

Website development was an iterative process between members of the study team (CT, LO, and AB). LO and AB were responsible for working on website content, finding errors, and updating relevant information that CT edited accordingly. The website was tested internally by the supervisory team (PS, SB, and NW) and the thesis committee (AH and VV). Based on feedback, errors were corrected, and relevant changes were made. The study website was then approved for the pilot phase.

The website was piloted in September 2020 by clinicians working in the UCL Marie Curie Palliative Care Research Department. Four clinicians participated in the pilot by completing the study and provided feedback on their experience. The clinicians were two nurses and two doctors (a consultant and a specialist registrar in palliative medicine). Minor changes were made in response to their feedback, and the website was finalised and then made open for recruitment.

4.4.2.2 Vignette development

For the decision-making task, participants were presented with five patient summaries, also called “vignettes”. These vignettes were constructed using anonymised patient information from the Prognosis in Palliative care Study II (PiPS2) (Kalpakidou et al. 2018). The original PiPS study developed predictive models of survival based on a cohort of 1018 advanced cancer patients from 18 specialist palliative care services across England (Gwilliam et al. 2011). The predictive models provide prognostic estimates that do not rely on clinicians' intuition (Gwilliam et al. 2011). Four prognostic models where developed which predict the probability of survival at 14 days and 56 days in patients without (PiPS-A) or with (PiPS-B) blood tests available. The PiPS2 study validated the prognostic models developed in the original PiPS study (see Stone, Kalpakidou, et al. 2021).

PiPS2 data were used to create the study vignettes as the dataset was based on real patients where clinical information about patients and their length of survival were collected. Using real patient data to create vignettes added validity to the study task and findings. Whilst other prognostic tools could have been used, PiPS2 had been validated in a UK cohort (Stone, Kalpakidou, et al. 2021). Moreover, supervisor Prof Patrick Stone (PS) was involved with conducting the PiPS2 study, which meant that the anonymised dataset was accessible. Predictions from the PiPS-B14 model (i.e., predicting 14-day survival when blood tests are available) were used as the model had been shown to be as accurate as an agreed multi-professional survival estimate (Stone, Kalpakidou, et al. 2021), which aligned with the MDT aspect of the thesis.

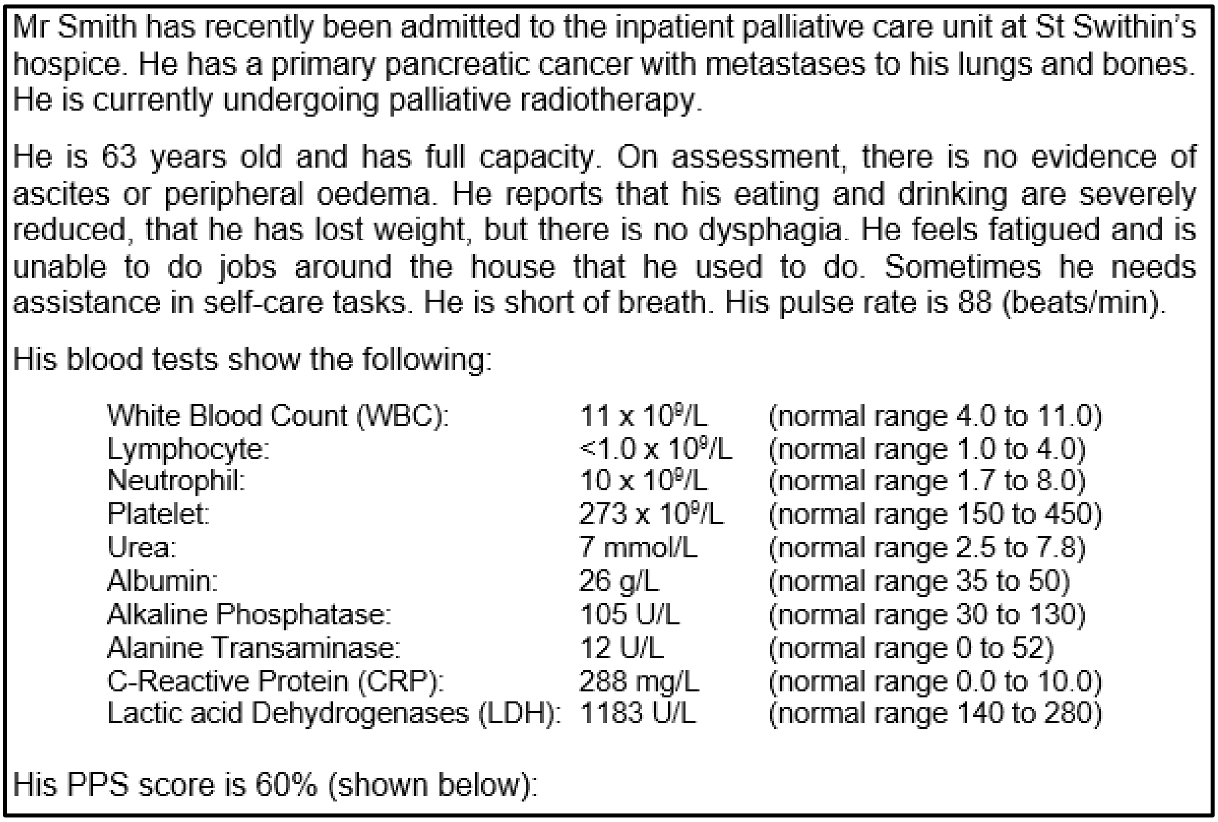
Prognostic data collected from five participants in the PiPS2 study were used as the basis for short narratives about each patient in this study. Each vignette included the following patient information:

- Location and setting of admission (i.e., hospice inpatient palliative care unit)
- Demographic information (gender, age, and capacity)
- Disease information (type of primary cancer, number of primary cancers, presence of metastases, and whether the patient was undergoing therapy)
- Physical health (evidence of ascites and peripheral oedema, oral intake, weight loss, dysphagia, fatigue, activity level, dyspnoea, and pulse)
- Blood test results

- PPS score[7]

The structure of each vignette was kept as similar as possible (if not identical), with only the key prognostic information varying, in order to minimise bias. An example vignette can be seen in **Figure 4-2** below, and the full example vignette with the PPS table can be seen in in Appendix 4.

Figure 4-2: Example vignette (without PPS table)



Mr Smith has recently been admitted to the inpatient palliative care unit at St Swithin's hospice. He has a primary pancreatic cancer with metastases to his lungs and bones. He is currently undergoing palliative radiotherapy.

He is 63 years old and has full capacity. On assessment, there is no evidence of ascites or peripheral oedema. He reports that his eating and drinking are severely reduced, that he has lost weight, but there is no dysphagia. He feels fatigued and is unable to do jobs around the house that he used to do. Sometimes he needs assistance in self-care tasks. He is short of breath. His pulse rate is 88 (beats/min).

His blood tests show the following:

White Blood Count (WBC):	11 x 10^9/L	(normal range 4.0 to 11.0)
Lymphocyte:	<1.0 x 10^9/L	(normal range 1.0 to 4.0)
Neutrophil:	10 x 10^9/L	(normal range 1.7 to 8.0)
Platelet:	273 x 10^9/L	(normal range 150 to 450)
Urea:	7 mmol/L	(normal range 2.5 to 7.8)
Albumin:	26 g/L	(normal range 35 to 50)
Alkaline Phosphatase:	105 U/L	(normal range 30 to 130)
Alanine Transaminase:	12 U/L	(normal range 0 to 52)
C-Reactive Protein (CRP):	288 mg/L	(normal range 0.0 to 10.0)
Lactic acid Dehydrogenases (LDH):	1183 U/L	(normal range 140 to 280)

His PPS score is 60% (shown below):

The five cases were selected from among the 1018 recorded in the PiPS2 database. Vignettes were selected so that the estimated probabilities of survival (using the PiPS-B14 algorithm) were either 90%, 75%, or 50% (see more in the Intervention section). In this way the vignettes represented cases with a range of expected survival probabilities. The study also included a practice vignette (**Figure 4-2** and Appendix 4) in which the estimated

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[7] Permission was obtained from Victoria Hospice (https://victoriahospice.org/) to include PPS scores in the vignettes and to use the official table and document describing the scale (see Appendix 3).

probability of survival (again using the PiPS-B14 prognostic algorithm) was 80%. Patient vignettes were not selected if:

- The patient lacked capacity
- The patient's date of death was not recorded in the PiPS2 data set, or if the patient survived much longer than 14 days
- Any prognostic information was missing (e.g., age or observations required for the PiPS-B14 calculation)

Patients who lacked capacity were not selected as vignettes because not all of the relevant clinical information was recorded in the PiPS2 dataset for these patients. It would also have been complicated to include vignettes relating to patients with and without capacity, as the prognostic factors used for predicting survival in patients without capacity (PiPS-A) are different from those used for predicting survival in patients with capacity (PiPS-B). As the focus of the research was on two-week survival, patients who were still alive at the end of the PiPS2 study or lived for a long time (such as years) were excluded since inclusion of such patients would have lacked face-validity. Lastly, if patient information was missing, it would not have been possible to populate the vignette template.

The final cases were chosen to represent patients with a variety of diagnoses, a mix of genders, and a range of ages, but also with other information to make the cases distinctive. Supervisor PS is a palliative care consultant and checked the vignettes to ensure face-validity from a clinical perspective. In this process, some vignettes were deemed too complicated or too rare for the purpose of the study. These cases were not selected to avoid unnecessary confusion or frustration among respondents, even though reflecting real-life patient cases.

When planning the study, it was considered how many vignettes participants should complete. A large number of vignettes would increase study generalisability, but it would also add to the study burden for participants and the risk that participants would not complete the study. A similar prognostication study included a large number of vignettes (n=20), which resulted in a low completion rate (White et al. 2018). It was considered that five vignettes would represent a suitable balance between generalisability and study burden.

4.4.3 Study participants

Participants were eligible for the study if they were:

- Clinicians working in adult palliative care services
- Willing and able to provide written informed consent

Purposively, no definition of “clinician” was specified in order to capture any type of palliative healthcare professional who might be part of the MDT.

If participants did not meet the two inclusion criteria listed above, they were not eligible for participation and were excluded from the study.

4.4.4 Recruitment

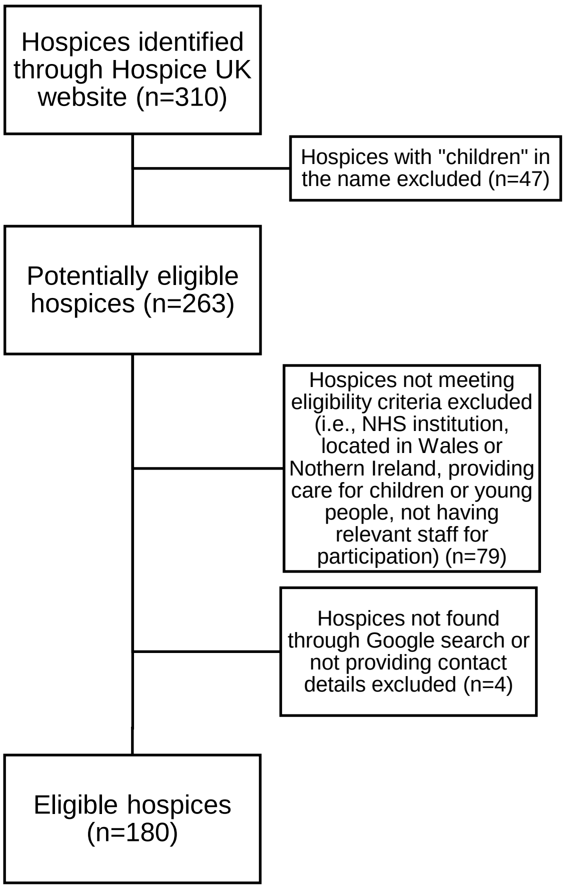
The study website was open for data collection from October 2020 until April 2021. Clinicians were recruited to complete the online study in two ways: by asking hospices to invite their clinical staff to take part, and by directly inviting clinicians who attended online educational seminars to complete the study. Each recruitment pathway is described in the following sections.

4.4.4.1 Hospices

To identify and then subsequently approach eligible hospices, the Hospice UK website was used. This website includes a database listing adult and children’s hospice care providers in the UK (https://www.hospiceuk.org/about-hospice-care/find-a-hospice). At the time of recruitment, the database included 310 hospices, of which 47 hospices had the word ‘children’ in their name. Since the study only concerned clinicians working in *adult* palliative care services, these hospices were not invited to participate in the study. Moreover, as a result of the scope of the research ethics approval, the study did not involve recruitment from NHS services or hospices located in Northern Ireland and Wales.

The remaining hospices were looked up online to find their contact details and to check other relevant information about their eligibility for participating in the study (i.e., to confirm whether they were a non-NHS institution, which nation they were located in, and whether they looked after patients over 18 years old). If it was not clear whether the hospice was eligible, an email requesting clarification was sent. If the hospice did not get back with the relevant information, it was deemed ineligible based on the information available. From the remaining 263 potentially eligible hospices in the hospice directory, 79 were not eligible for participating in the study. One hospice did not have relevant staff for study participation. Details for three hospices could not be found through Google searches, and one hospice did not provide an email address on their website. This resulted in 180 eligible hospices. **Figure 4-3** is a flowchart of the process of identifying eligible hospices for the study.

Figure 4-3: Process of identifying eligible hospices



Email contact was individually made with each eligible hospice to inform them about the study (see Appendix 5). If the hospice agreed to participate, they were required to state so in an email, which was later sent to the UCL Research Ethics Committee (REC) as confirmation of collaboration (see more under Ethical considerations). A template for an invitation email to be circulated to their clinicians (including the link to the study website) was then forwarded to participating hospices (see Appendix 6).

4.4.4.2 Online seminars

Clinicians were recruited at online seminars or educational events where supervisor PS was scheduled to give presentations on prognostication. The study was presented before the seminar event and attendees were invited to complete the study in preparation for the seminar (see Appendix 7 for the study invitation email). In addition, the study was advertised as part of a seminar on prognostication organised by the UCL Marie Curie Palliative Care Research Department. The study could be completed by international clinicians attending the online seminars. Participants were asked not to distribute the link or complete the study if they had already done so (e.g., if their hospice was already participating or had they participated in other seminars where the study was advertised).

4.4.5 Sample size

The study aimed to recruit between 100-200 clinicians during the seven months recruitment period (October 2020 to April 2021). This sample size was based on the following considerations, and calculations were undertaken in collaboration with the trial statistician, Dr Victoria Vickerstaff (VV).

The study aimed to compare the means of “Weigh of Advice” (WOA) scores of the participants in the two study arms with a confidence interval (CI) of 95%. WOA is a measure of the extent to which judges change their opinion in the light of the advice received (see section 4.5.1). Based on calculations from a similar study by Logg, Minson, and Moore (2019), it was expected that the standard deviation (SD) of the mean difference in WOA scores between arms would be between 0.3 and 0.4. For a sample size of 100-200, this would give a width of the CI between 0.17 and 0.31, depending on the sample size and the SD (see **Table 4.1** below). These numbers were based on and calculated from the guidelines by Machin et al. (2018). On this basis, a sample size between 100-200 respondents would be sufficient to detect a significant difference between the mean WOAs of the study arms if the mean difference was greater than 0.085 to 0.155. In the absence of pre-existing data about the minimally important difference in WOA, this magnitude of difference was considered to be both feasible to detect and likely to be reflective of important differences between arms.

Table 4.1: The width of the CI varying by sample size and SDs

Sample Size	Expected SD for mean difference in WOA	
	$\sigma = 0.3$	$\sigma = 0.4$
100	0.24	0.31
150	0.19	0.26
200	0.17	0.22

A sample size of 100-200 was therefore deemed sufficient to address the primary study aim. The risk of encountering difficulties with recruitment was also considered and for this reason, the study did not aim for a larger sample size. Due to uncertainty in the assumptions that contributed to the sample size estimates, recruitment continued for seven months despite the minimum target being exceeded.

In the early stages of the study, different study designs were considered which involved more than two study arms. However, increasing the number of study arms would also mean an increase in study participants required to get significant results. These issues are further discussed in Chapter 10.

It should be noted that although the paper by Logg, Minson, and Moore (2019) was used to calculate the sample size for this online RCT, there were some differences between the two studies which may call into question the use of these data as the basis for the sample size calculation. Nonetheless, this paper represented the best data available at the time on which to estimate the sample size and although not directly comparable, both studies did use WOA for the primary analysis, and compared algorithmic and human advice.

4.4.6 Randomisation

The study website randomly assigned participants to one of the study arms. This was done after the participant had provided their demographic information. Blocked randomisation lists (with blocks of size 4, 6 and 8) stratified by nurses, doctors and other clinical backgrounds were created by the trial statistician (VV). Vignettes were presented in random order to prevent any order effects.

4.4.7 Blinding

The research team and participants were blind to intervention allocation, whilst the database specialist (CT) was not blinded to allocation. CT was not blinded as he was monitoring the database. Group allocation was only revealed to the research team once the database had been locked and analyses had been completed.

4.4.8 Study procedure

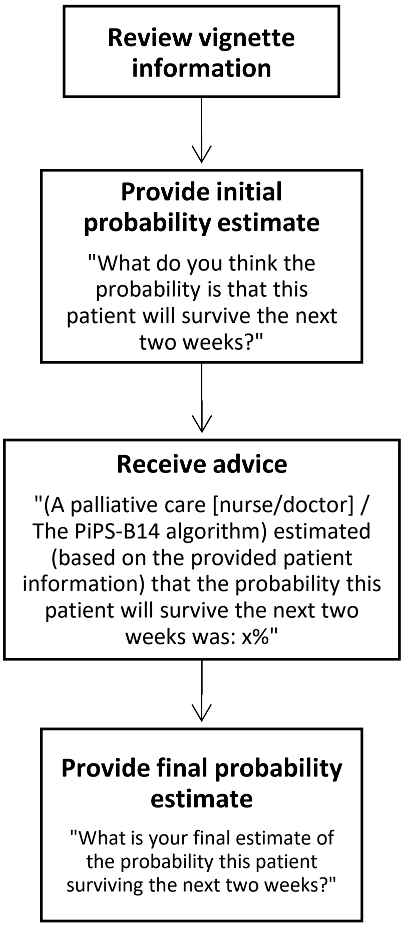
Participants accessed the website, where they received information about the study purpose and relevance. On the website, participants could download the Participant Information Sheet (PIS) (see Appendix 8). They were asked to provide consent to participate in the study. After obtaining consent, participants were asked to provide relevant demographic and clinical information about themselves (profession; age; gender; work environment; country of employment; years of overall experience; and years of palliative care experience). Participants were then presented with instructions detailing the study procedures. To ensure that participants understood the task, the study started with a practice vignette. After completing the practice vignette, participants were reminded about the study instructions and then directed sequentially to the five study vignettes.

Each vignette (including the practice vignette) involved the following four steps (see **Figure 4-4**):

1. Read and review the vignette
2. Estimate the probability that the patient will survive the next two weeks (estimate on a 0-100% scale; 0% ‘certain to die’ to 100% ‘certain survival’)
3. Receive advice. This was a probability estimate of either 50%, 75%, or 90%, with the perceived source of advice varying depending on study arm
4. Provide a final (possibly revised) probability estimate

Figure 4-4 includes the relevant questions and text that participants saw on the study website. The vignette information was available for participants throughout the task of providing probability estimates and receiving advice. This meant that participants could read vignettes again and review the information. Participants had to click a button to access the blood test results and PPS score before being able to provide an initial probability estimate. This was to ensure that participants considered all the information available before providing their initial estimate. Participants' initial estimate was displayed while they received the advice and were asked to provide a final estimate.

Figure 4-4: Vignette procedure



Review vignette information

Provide initial probability estimate

"What do you think the probability is that this patient will survive the next two weeks?"

Receive advice

"(A palliative care [nurse/doctor] / The PiPS-B14 algorithm) estimated (based on the provided patient information) that the probability this patient will survive the next two weeks was: x%"

Provide final probability estimate

"What is your final estimate of the probability this patient surviving the next two weeks?"

After completing the five vignettes, a final debrief page was displayed, and participants were thanked for their participation. They had the opportunity to download a certificate of participation (see Appendix 9) and share their contact details if they wanted to receive the study results and/or were willing to participate in future research. Screenshots of the website content are provided in Appendix 10.

4.4.9 Intervention

Participants were randomly assigned to one of two study arms where the perceived source of advice differed. The two arms were the algorithm arm and the clinician advice arm.

Participants in the algorithm arm were informed that prognostic advice came from the PiPS-B14 prognostic model. It was assumed that the PiPS-B14 may be unfamiliar to participants. For this reason, participants were informed that in a previous study the PiPS-B14 risk categories for predicting two-week survival were as accurate as a doctor's or a nurse's prediction.

In the clinicians' advice arm, participants received advice labelled as coming from another clinician. Doctors received advice labelled as coming from nurses. Nurses received advice labelled as coming from doctors. Participants with other clinical backgrounds (i.e., neither doctor nor nurse) received advice labelled as coming from a doctor.

The advice given was identical for each vignette in both arms and was based on PiPS-B14 calculations for the vignettes selected from the PiPS2 database. Participants in the clinician arm were not aware that advice emanated from PiPS-B14. This low-level deception was necessary to determine the impact of the source of advice on participants' prognostic estimates.

As described in the Vignette development section, estimates of 50%, 75%, and 90% were used. Two of the vignettes included advice given as a 90% estimate, another two were 75% estimates, and the last vignette was a 50% estimate. These measures were chosen to explore the secondary study aim of investigating the extent to which clinicians' integration of advice was influenced by the nature of the *advice itself*. The 90% estimates represented advice given with "high" certainty, 75% represented a somewhat lower certainty, and finally the 50% estimate which was equivocal. By varying the strength of the advice, it was possible to explore how this might have an impact on participants' weighting policies.

4.4.10 Ethical considerations

The UCL REC approved the study on 02 September 2020 (Protocol ID: 17031/001) (see Appendix 11 for an approval letter). The study was registered on ClinicalTrials.gov (ClinicalTrials.gov ID: NCT04568629).

It was a requirement from the UCL REC to provide confirmation from hospices that they agreed to collaborate prior to being used for recruiting clinicians. For this reason, each hospice had to confirm in an email or a letter that they were willing to participate in the study, before the study link was shared. At the end of the study, the confirmation emails and letters were forwarded to the UCL REC.

Study participants were anonymised and assigned a study ID. Their email addresses were only used to enable them to pause the study and log back in to complete it at a later time. Email addresses were also necessary if participants wanted a certificate to confirm their participation in the study, and if they wanted to sign up for results and future research. Due to participant anonymisation, it was not possible to provide participation numbers for the collaborating hospices. This meant that the participating hospices could not document or otherwise demonstrate how many of their staff members had participated in the study.

4.5 Data management and analysis

Prior to data analysis a statistical analysis plan was created and made available on ClinicalTrials.gov (NCT04568629). A per-protocol analysis was conducted, including only those who completed the study. All analyses were repeated and completed while blinded, using Stata version 15 (StataCorp 2017) or above. The research team members (except CT) were blinded during analysis. Unblinding occurred after the primary analysis was completed.

4.5.1 Outcome measure

The primary outcome was the difference between participants' initial and final probability estimates of two-week survival for each vignette. These data were used to calculate a WOA score. WOA is a measure of the extent to which participants change judgement in light of advice received and is a standard analytical approach in psychological experiments of this type (Van Swol, Paik, and Prahl 2018). Participants' final probability estimate can be represented as a weighted combination of the participant's initial estimate and the advice received, with the weights being proportional to the extent of the shift towards (or away from) the advice. The definition of WOA is: $\mathrm{WOA} = |f - i|/|a - i|$ (Yaniv 2004b). In this equation, (f) represents the final estimate, (i) is the initial estimate, and (a) is the advice. The WOA was calculated for each participant for each vignette.

WOA ranges from 0 (100% discounting of advice) to 1 (0% advice discounting) (Yaniv and Kleinberger 2000). If a participant adheres completely to their initial estimate (referred to as 100% discounting of the advice), the WOA score will be 0. If the participant decides to shift their initial estimate so that it completely coheres to the advice received, then the WOA score will be 1 (0% discounting). Intermediate weights indicate that positive weights were assigned to the initial estimate and the advice (partial discounting).

4.5.2 Data handling

One participant entered an invalid (nonsensical) value as one of their estimates for one vignette (i.e., the respondent entered a figure of "805%" which is not within the permitted 0-100% range). Although this probably represented a typographical error, this could not be assumed (nor could the "correct" figure be inferred), and therefore, their data were excluded from analysis.

Participants could choose between three options when providing demographic information about their professions: "doctor", "nurse", or "other". In the "other" category, participants could specify in free text what their other healthcare role was. The same applied to a subcategory called "other nurse". When going through the free text responses, five instances were identified when participants had used the apparently "wrong" label to describe their profession. One participant had chosen the "other nurse" label but had elsewhere specified their role as a healthcare assistant. For consistency, this respondent was relabelled as "other". Four participants had chosen the "other" label but had elsewhere clearly specified that they were in fact nurses (i.e., Advanced

Nurse Practitioner; Clinical Nurse Specialist; Nurse Consultant; and research nurse). These participants were relabelled as nurses.

One respondent had chosen the “other” label but had also specified that they were a “registrar”. Although it is likely that this individual was a “doctor” (i.e., a medical registrar), in the absence of any definitive statement to confirm this it was decided to exclude this participant from the analysis.

1241 WOA datapoints were used for analysis. There were 177 instances where the first estimate given by the participant was the same as the advice that they received. In these circumstances participants were not expected to revise their initial estimate (and none did so). However, in these cases it is not possible to calculate WOA (since this would necessitate division by 0, which is incomputable). These instances were therefore not included in the analysis (the Stata software records them as missing).

Rarely, participants “over-reacted” to the advice received (e.g., initial estimate 60%; advice received 70%; final estimate 80%). In those circumstances the WOA could potentially be higher than 1, and these outliers could result in anomalous results. Therefore, in keeping with previous research (Wang and Du 2018), WOA values higher than 1 were capped at 1 (n=12).

4.5.3 Data analysis

Demographic details about participants and data were summarised using descriptive statistics (means and SDs). Multilevel linear regression analyses were conducted to compare mean WOA scores between study arms (primary aim) accounting for repeated measures within each participant and further regression analyses included clinician characteristics and strength of advice (secondary aims).

Based on the distribution of participant demographics, it was decided to explore the following participant characteristics: profession, years of overall experience, and years of palliative care experience.

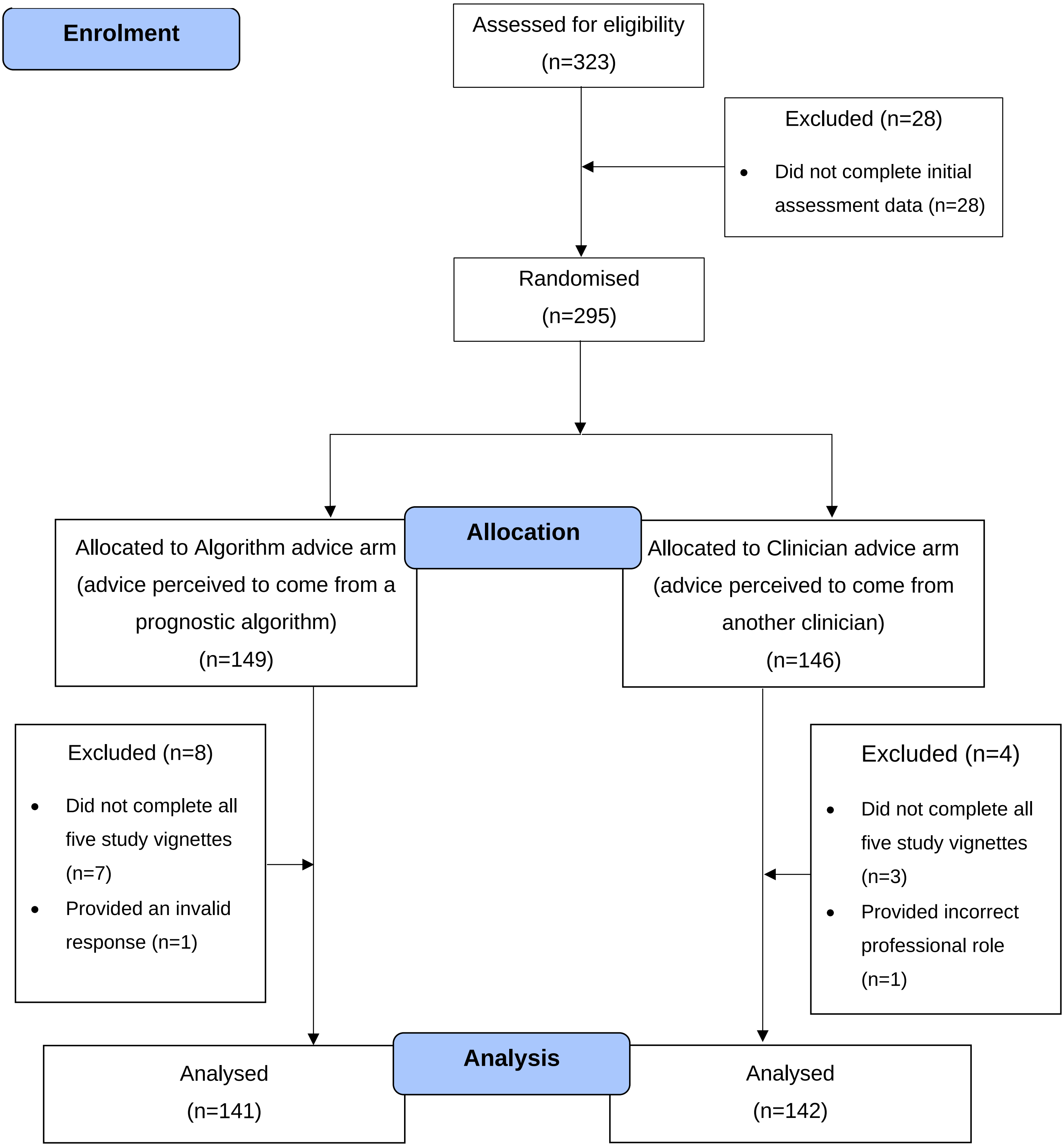
The distribution of the WOA values were not normally distributed. The WOA values tended to cluster around 0 (100% discounting), 0.5, and 1 (0% discounting), creating a “w” distribution of values. Therefore, to account for this uneven distribution, and to ensure the robustness of the findings, a non-parametric (sensitivity) analysis was also conducted. In line with previous research (Soll and Larrick 2009), five WOA categories were created (<0.2; 0.2-<0.4; 0.4-<0.6; 0.6-<0.8; 0.8-1), and a multilevel ordinal logistic model was used.

4.6 Results

61 hospices agreed to participate in the study. Some hospices involved multiple sites – in the hospice directory, these were listed as distinct institutions. For this reason, the actual number of participating institutions was approximately 76. The number of hospices that declined to participate in the study was 18. Common reasons for declining to participate included a lack of adequate staffing and other competing studies being conducted in the hospice. A number of hospices did not reply to the invitation email and others stopped replying and never got to proceed with the study (n=86).

323 participants enrolled in the study of whom 283 were included in the analysis. 40 participants were excluded because they did not complete the vignettes. Two participants were excluded for other reasons detailed in the section on Data handling. Participant flow is illustrated in the modified CONSORT flow diagram in **Figure 4-5**. The flow diagram was modified because unlike an interventional RCT there was no follow up assessment.

Figure 4-5: Modified CONSORT flow diagram



Participants' demographic information is summarised in **Table 4.2**. The majority of participants were doctors, female, between 41-50 years old, working in a hospice setting in the UK, had 15+ years of general clinical experience and had between 6-14 years of palliative care experience.

Table 4.2: Participants' demographic information (from Bruun, White, et al. 2022)

	Total	**Algorithm advice arm**	**Clinician advice arm**
	n (%)		
Sample size	283 (100)	141 (50)	142 (50)
Profession			
Doctors	138 (49)	70 (49)	68 (48)
Nurses	116 (41)	56 (40)	60 (42)
Other healthcare professionals	29 (10)	15 (11)	14 (10)
Occupational Therapist	6 (21)	3 (20)	3 (22)
Physiotherapist	7 (24)	5 (33)	2 (14)
Healthcare Assistant	7 (24)	3 (20)	4 (29)
Other or not specified[8]	9 (31)	4 (27)	5 (35)
Age (years)			
21-30	19 (7)	9 (6)	10 (7)
31-40	67 (24)	32 (23)	35 (25)
41-50	109 (38)	52 (37)	57 (40)
51+	88 (31)	48 (34)	40 (28)
Gender[9]			
Male	23 (8)	12 (9)	11 (8)
Female	260 (92)	129 (91)	131 (92)
Work environment			
Hospice	157 (55)	78 (55)	79 (56)
Hospital	27 (10)	14 (10)	13 (9)
Community	28 (10)	12 (9)	16 (11)
Other	2 (1)	1 (1)	1 (1)
Multiple settings	69 (24)	36 (25)	33 (23)
Country of employment			
GBR	266 (94)	132 (94)	134 (94)
Other countries[10]	17 (6)	9 (6)	8 (6)
Years of experience			
Less than 6 months – 14	100 (35)	51 (36)	49 (35)
15+	183 (65)	90 (64)	93 (65)
Years of palliative care experience			
Less than 6 months – 5	85 (30)	39 (28)	46 (32)
6 – 14	102 (36)	51 (36)	51 (36)
15+	96 (34)	51 (36)	45 (32)

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[8] Includes the following roles: Social worker; Pharmacist; Speech and Language Therapist; AHP (Allied Health Professional); Deputy Head of Inpatients; Advanced Clinical Practitioner

[9] Gender categories included “other” or “prefer not to say”, however no participants chose these options and therefore not listed in the table

[10] Includes the following countries: Hong Kong; Ireland; Gibraltar, Spain; United Arab Emirates; United States of America

4.6.1 Primary aim analysis

Participants' mean initial and final probability estimates and WOA scores are shown in **Table 4.3** below. These values were used to assess the level to which clinicians integrated advice from the prognostic algorithm or another clinician into their prognostic estimates.

Table 4.3: Participants' probability estimates of the patient surviving the next two weeks and WOA scores

	Initial estimate	Final estimate	WOA
	Mean (SD)		
Overall	64.93 (19.07)	69.19 (16.97)	0.37 (0.35)
Algorithm advice arm	64.56 (18.87)	69.19 (16.52)	0.44 (0.36)
Clinician advice arm	65.30 (19.28)	69.20 (17.42)	0.31 (0.33)

Participants in the clinician advice arm had a significantly lower WOA score than participants in the algorithm advice arm (WOA difference = -0.12 [95% CI -0.18 to -0.07], *p*<0.001). Indicating that participants were more likely to incorporate advice perceived to have come from an algorithm.

The non-parametric sensitivity analysis using five WOA categories rather than mean WOA values was in keeping with this result (the difference between study arms remained significant; *p*<0.001).

4.6.2 Secondary aims analysis

Table 4.4 describes the relationship between WOA, the characteristics of participants and the strength of the prognostic advice received, by study arm. These values were used to address the secondary aims: how professionals' advice integration was influenced by participant characteristics and the advice itself.

Table 4.4: WOA and interaction between clinicians' demographics, strength of advice and study arm (from Bruun, White, et al. 2022)

	WOA		
	Overall	**Algorithm**	**Clinician**
	Mean [95% CI]		
Profession			
Doctor	0.34 [0.30, 0.37]	0.40 [0.35, 0.46]	0.27 [0.22, 0.32]
Nurse	0.39 [0.35, 0.43]	0.46 [0.40, 0.51]	0.32 [0.27, 0.38]
Other healthcare professionals	0.50 [0.42, 0.58]	0.52 [0.40, 0.63]	0.48 [0.37, 0.60]
Overall experience (years)			
up to 14	0.36 [0.32, 0.41]	0.43 [0.37, 0.50]	0.29 [0.23, 0.36]
15+	0.38 [0.35, 0.41]	0.44 [0.39, 0.49]	0.32 [0.28, 0.37]
Palliative care experience (years)			
up to 5	0.43 [0.38, 0.48]	0.49 [0.42, 0.56]	0.37 [0.30, 0.43]
6–14	0.35 [0.30, 0.39]	0.40 [0.33, 0.46]	0.30 [0.24, 0.36]
15+	0.36 [0.31, 0.40]	0.44 [0.38, 0.50]	0.27 [0.21, 0.34]
Strength of advice received (probability estimate)			
50%	0.40 [0.35, 0.44]	0.48 [0.42, 0.54]	0.31 [0.25, 0.37]
75%	0.31 [0.28, 0.35]	0.36 [0.32, 0.41]	0.27 [0.22, 0.31]
90%	0.43 [0.40, 0.47]	0.50 [0.45, 0.55]	0.37 [0.32, 0.42]

4.6.2.1 Advice integration influenced by participant characteristics

Participants with other clinical backgrounds had higher WOA scores (0.50 [95% CI 0.42, 0.58]) than nurses (0.39 [95% CI 0.35, 0.43], WOA difference = -0.11 [95% CI -0.20, -0.21]) and doctors (0.34 [95% CI 0.30, 0.37], WOA difference = -0.16 [95% CI -0.25, -0.07]). There was no interaction between profession and study arm on WOA (*p*=0.150).

Participants who had 15+ years of overall clinical experience had a slightly higher WOA score (0.38 [95% CI 0.35, 0.41] than participants who had less experience (0.36 [95% CI 0.32, 0.41], WOA difference = 0.016 [95% CI -0.040, 0.072]). There was no interaction between overall experience and study arm on WOA (*p*=0.935).

WOA scores of participants with up to five years of palliative care experience were higher (0.43 [95% CI 0.38, 0.48]) than those with 6-14 years palliative care experience (0.35 [95% CI 0.30, 0.39], WOA difference = -0.081 [95% CI -0.15, -0.015]) and those with 15+ years of experience (0.36 [95% CI 0.31, 0.40], WOA difference = -0.073 [95% CI -0.14, -0.01]). There was no interaction between palliative care experience and study arm on WOA (*p*=0.152).

4.6.2.2 Advice integration influenced by the advice itself

Advice given as 75% probability estimates had a lower WOA (0.31 [95% CI 0.28, 0.35]) than advice received at either the 50% (0.40 [95% CI 0.35, 0.44], WOA difference = 0.08 [95% CI 0.04, 0.12]) or 90% level (0.43 [95% CI 0.40, 0.47], WOA difference = 0.12 [95% CI 0.085, 0.15]). The overall interaction between strength of advice and study arm on WOA was significant (*p*<0.001).

4.7 Discussion

4.7.1 Main study findings

This online RCT found that palliative care clinicians (regardless of their professional background, general healthcare experience, or years spent specifically working in palliative care) integrated prognostic advice more when they perceived it to be coming from an algorithm rather than from another clinician, when prognosticating imminent death. The results also showed that clinicians integrated advice more if it was given at the 90% and 50% level rather than at 75%.

4.7.2 Discussion in relation to other findings

The finding that clinicians integrate advice from a prognostic algorithm more than advice from other clinicians is in line with evidence suggesting that prognostic algorithms can be helpful in clinical practice. Going back to Brunswik's Lens Model (Cooksey 1996), this may imply that clinicians perceive cues from the prognostic algorithm to be more important or influential than cues from another clinician. Evidence has shown that algorithms can be used as confirmatory tools, validating clinicians' predictions, correcting prognostic impressions, or overcoming tendencies to ignore or overestimate prognoses (Hallen et al. 2015; Parikh et al. 2022). Using prognostic algorithms may also increase clinicians' confidence and thereby encourage communication of prognostic information and its use in clinical decision-making (Hallen et al. 2015). There is some evidence to suggest that prognostic algorithms could be used as educational tools, especially for professionals with less experience (Stone, Kalpakidou, et al. 2021). Prognostic algorithms can also increase prognostic authority by reducing ambiguity in cases of disagreement (Hallen et al. 2015; Stone, Kalpakidou, et al. 2021). In cases of professional disagreement, prognostic algorithms could serve as an (objective) external source of advice.

It is interesting to note that clinicians integrated advice perceived to be coming from an algorithm more than advice perceived to be coming from a clinical colleague, even though they were informed that such advice was only as accurate as a doctor's or a nurse's prediction. As noted previously, prognostic algorithms have not consistently shown superiority to clinical predictions of survival (Stone, Vickerstaff, et al. 2021). Given that prognostic tools are as good as, but no better than, clinical predictions of survival, clinicians should exercise due caution when evaluating how much confidence to place in algorithmic predictions.

The findings showed that the length of participants' professional experience did not affect how they integrated advice. Despite the fact that doctors and nurses might be more involved and experienced in making survival predictions, there is conflicting evidence regarding whether experience improves prognostic accuracy, and there is no clear evidence about whether some types of professionals are better prognosticators than others (White et al. 2016). One study has also highlighted seniority as influential in prognostic decision-making (Taylor, Dowding, and Johnson 2017). It was mentioned previously that according to the dual-process theory (see Pelaccia et al. 2011), an expert clinician may use System 1 thinking to identify specific patterns and match them to previous patient examples, based on their extensive experience (Taylor, Dowding, and Johnson 2017). In this study, there was no significant difference between participants' level of experience and their WOA. The study results therefore do not confirm this assumption. However, this study did not do any detailed analysis to explore the System 1 and 2 thinking patterns. Instead, these findings could indicate that the measure of an expert in this context needs to be refined, and further analyses could be done to explore prognostic accuracy as an "expert" factor in this context.

The only factor that had a significant impact on participants' advice integration was the strength of the advice. When participants received advice that a patient had a 75% probability of surviving two weeks, they were less likely to integrate the advice into their estimates compared to advice given with lower or higher strength. The fact that participants would integrate 50% advice more than 75% advice seems counterintuitive, and the reasons for this finding are unclear. Potential explanations might include the hypothesis that clinicians are biased towards accepting extreme (rather than intermediate or non-committal) advice, or perhaps the finding could be explained by participants' averaging strategies. Future research would be needed to further explore this issue.

By the nature of the study design, the results do not shed light on the optimal strategy for combining initial prognostic judgements with advice. The methodology did not allow for study participants to share their thoughts or reasoning behind their decisions. Future studies should aim at exploring this in greater detail. There is a need for more research on understanding human-algorithm interaction (Kelly et al. 2019) and clinicians' prognostic decision-making processes (Hui et al. 2019). If prognostic algorithms are to find a place in palliative care clinical practice, then it is important to understand how they are used by clinicians and to ensure that their outputs are used appropriately, neither treated with undue scepticism nor with misplaced trust. This has been reflected in another study exploring how clinicians make prognostic decisions. The study authors recommend that studies seeking to assess professional decision-making in comparison with mathematical models should seek to do so realistically, by presenting a decision-maker with time-dependent information, and giving them opportunities to reassess and review decisions (Taylor, Dowding, and Johnson 2017).

The JAS methodology used in this study could easily be adapted to explore additional research questions. This study only explored how the advisor, the advice itself, and the profession and experience of the judge impacted decision-making. Other characteristics of the judge could have been explored, such as gender and age. However, due to an uneven distribution of participants with these characteristics, it did not make sense to compare groups. Future research could aim for a larger or more balanced sample size or simply target certain characteristics of the judge. Moreover, this study explored how professionals integrated advice from a colleague with a different professional background than themselves. Future studies could investigate this further by exploring other attributes of the advisor as well. It would be interesting to see if advisor attributes such as profession, age, gender, or experience influence advice integration. Using data collected for this study, prognostic accuracy could also be explored. Lastly, the data could be analysed to determine which variables (e.g., blood results, pulse, PPS score) were most influential in clinicians' decision-making.

4.7.3 Study strengths

This study involved 283 palliative care professionals, which is a relatively large sample size for a palliative care study. The study followed a rigorous RCT design, analyses were conducted blinded, and sensitivity analyses were conducted to add robustness to the findings. Study procedures were pre-tested several times to ensure feasibility prior to starting recruitment. The experimental design permitted several variables involved in prognostic decision-making to be controlled, which allowed isolation and quantification of the degree to which clinicians' integration of advice was influenced by the source of the advice. It would have been difficult to achieve the same quantitative outcome, had the study relied on observations or interviews involving participants' strategies or attitudes towards integrating prognostic advice from colleagues or algorithms.

4.7.4 Study limitations

By necessity, the experimental set-up was rather artificial and therefore lacked some ecological validity. Clinicians could not review patients face-to-face before providing prognostic estimates. Study vignettes were based on information collected as part of the PiPS2 study, this meant that some clinical information, which may have been useful in prognostic decision-making, was not available. For example, many clinicians regard patients' rate of overall decline as important for recognising imminent death (Taylor, Dowding, and Johnson 2017). However, this information (and other potentially relevant prognostic data) was not included in the vignettes, because it was not available in the original PiPS2 dataset. Another limitation of the study set-up was the formulation of patients’ two-week survival in terms of percentage probability estimates. Percentages were used in this study since probabilities of this type are the output of most prognostic tools (including PiPS-B14), and they allow for a clear measure of advice integration. However, it should be acknowledged that this is not necessarily how prognostication is carried out in the real world. Therefore, the clinical (rather than statistical) importance of the differences that was observed between the clinicians’ integration of algorithmic or human advice, is unclear. Future research should aim at studying how prognostic advice is actually used in clinical practice.

Study participants were primarily doctors and nurses, while other types of healthcare professionals only represented 10% of the overall sample. This raised issues related to comparing other types of healthcare professionals with the other professions. However future studies should aim at recruiting a greater number and variety of other types of healthcare professionals, creating a more balanced cohort of professional backgrounds.

Recruitment occurred during the COVID-19 pandemic where the UK was under a severe lockdown and the healthcare system was under substantial pressure. This might explain the number of hospices which declined to participate or to respond to the invitation. It also became clear during the recruitment process that the term “clinician” might have been rather ambiguous. Many hospices requested clarification about the meaning of the term, and it was often perceived as only including doctors and nurses. To provide greater clarity, it was specified that any staff member who was part of the MDT was eligible to participate in the study. However, the lack of clarity of terminology could have meant that some hospices only distributed the study link to doctors and nurses. This could have biased recruitment and might explain the low number of other types of healthcare professionals in the study. Future research should be aware of this limitation and should use more explicit terminology.

The results from the other types of healthcare professionals should be treated with caution. As these participants did not have a medical background, they might not have been able to interpret some of the information presented in the vignettes (e.g., the blood tests). That the vignette included information that some participants could not meaningfully use might challenge why they should have been included in the study. However, as evident from the scoping review findings, there was limited evidence on how these professionals make prognostic decisions and it was therefore considered important to explore their role in MDT decision-making. If involved in prognostication in clinical practice, it is possible that these professionals would pay less attention to medical test results (which they may find difficult to interpret) and would instead base their prognostic predictions on more familiar clinical information. Collaborating hospices were informed that although some information might be unfamiliar to other types of healthcare professionals, they should base their decisions on the information that they understood. Furthermore, this study did not set out to address *which* information professionals based their decisions on. It is quite possible that even the participating doctors and nurses did not focus on the test results when making their prognostic decisions. Future studies could explore further which data different professionals actually used for prognostic decision-making and which data they disregarded.

Participants were recruited as part of online seminars or educational events, which might have led to potential bias in terms of recruitment. As PS was presenting at these events, clinicians might have felt obliged to participate in the study and also might have found it difficult to not provide consent or withdraw from the study. However, it should be stressed that it was mentioned that participation was voluntarily and that all recruitment procedures were approved by the UCL REC. Another potential issue with bias is the question of whether the participants knew that PS had been part of developing the PiPSB-14 prognostic algorithm. This could have influenced their responses and the finding that participants integrated advice more when it was perceived to come from the algorithm rather than from another clinician. In future research studies, an attempt at limiting such potential issues with bias should be made.

Outlying WOA values were capped at 1, in line with previous analytic methods for this type of study (Wang and Du 2018). However, it could be argued that capping the WOA values at 1 was not always the appropriate statistical approach. For instance, if a person “over-reacted” to the advice received (e.g., initial estimate 60%; advice received 70%; final estimate 80%), this would lead to a WOA higher than 1. However, a WOA of 1 means “0% advice discounting”, and in such cases, it could be argued that the participant did somehow discount the advice by providing an estimate even higher than the advice. Thus, WOA may have limitations as a means of assessing advice integration.

4.8 Chapter summary

Information-sharing, and advice, was previously identified as essential to healthcare team decision-making (see Chapter 1). By exploring advice-taking in a controlled environment, the ADJUST study generated knowledge on how clinicians make prognostic decisions while being influenced by common (and recommended) advisors; a colleague and a prognostic tool. The findings provided insights into how clinicians react to prognostic advice from different sources, which can be used to better understand decision-making in the naturalistic setting as displayed through the findings from the conversation analytic study presented in subsequent chapters.

The ADJUST study used a pre-defined and clear prognostic decision-making task, where there were fewer professional, personal, or social stakes to consider such as time pressure, having to cope with providing a wrong prognosis, rejecting a piece of advice, or having to directly interact with the patient and their next of kin. The study focussed on selected controllable, clearly measurable, and tangible factors in palliative care clinicians’ decision-making. The factors shown to alter MDT members’ prognostic decisions were the source of advice (i.e., prognostic algorithm rather than another clinician), and strength of the advice received (i.e., 50% and 90% probability estimates rather than those of 75%). Certain characteristics of the decision-maker were shown not to be factors altering their decisions (i.e., profession and experience).

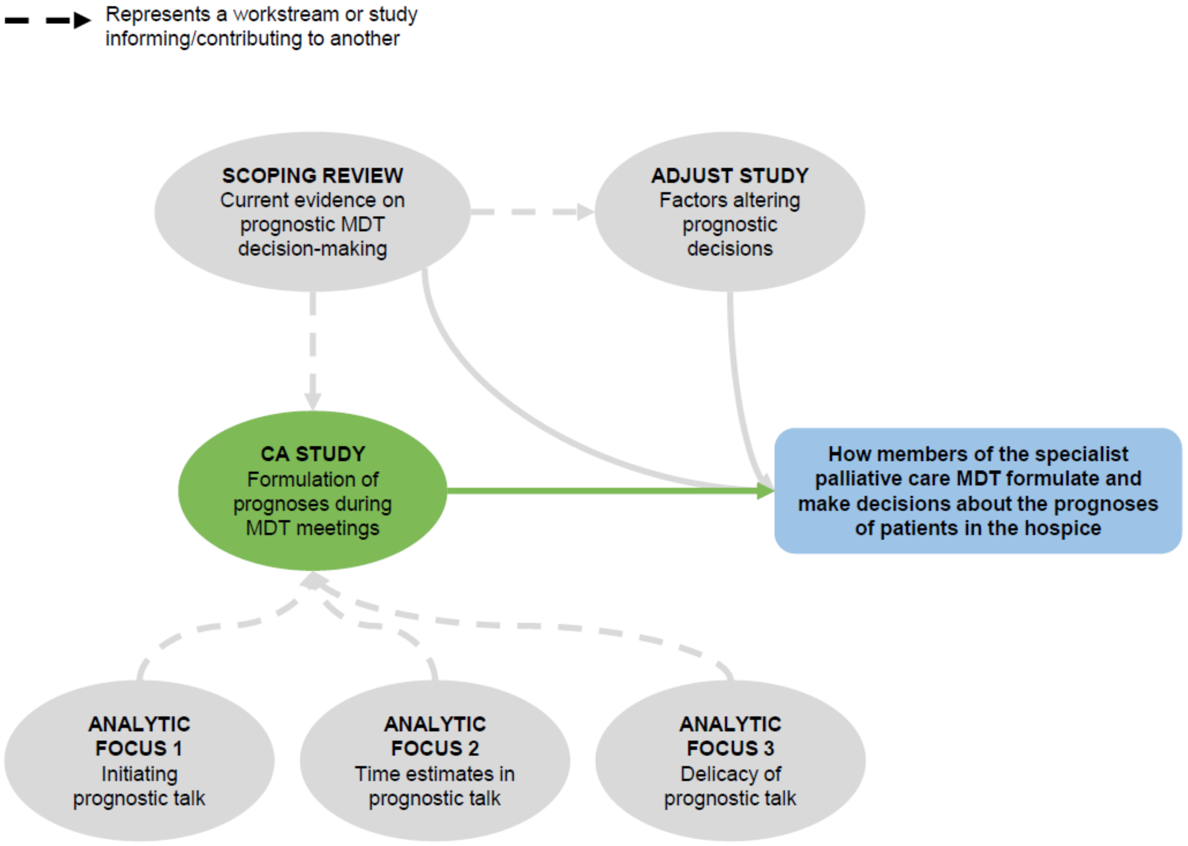
By understanding how individual MDT members behave when making prognostic decisions, a better understanding of what might be at stake when making such decisions as a team, is gained. In this way, the findings contribute to the understanding of how members of the palliative care MDT make decisions about patients’ prognoses.

Chapter 5 – Conversation analytic study: Background and methods

5.1 Chapter overview

This chapter describes the conversation analytic study of the thesis, which addresses how members of the MDT interact and formulate prognoses during MDT meetings (see **Figure 5-1**). This study involved collecting 24 video recordings of hospice MDT meetings and analysing them using CA.

Figure 5-1: Thesis outline diagram – CA study



In this chapter, the background and study methods are presented, which is followed by an ethnographic background section. Three aspects of prognostication are introduced in the subsequent results chapters: initiating prognostic talk (Chapter 6), temporality of prognostic utterances (Chapter 7), and sensitivity of prognostic discussions (Chapter 8). In Chapter 9, the three results chapters are summarised, and overall study strengths and weaknesses are provided.

5.2 Introduction

It was established in Chapter 1, that communication is essential to MDT prognostic decision-making. A literature review also highlighted that communication is a research priority within palliative care (Hasson et al. 2020). The review showed that there is a need for evidence that will improve communication at every level, which includes communication *between* services and *across* specialties (Hasson et al. 2020). The authors mention that good communication between doctors working in *different places* as a key area where communication can be improved (Hasson et al. 2020). This has also been stressed in the NICE guidelines for service delivery for end-of-life care for adults, where recommendations are proposed regarding communication and sharing information within the MDT (National Institute for Health and Care Excellence 2019). The guidelines recommend that care should be coordinated between professionals within and across services to ensure good communication and shared understanding. These points seem to imply a need for research specifically exploring communication within MDTs. Since communication is a key factor of prognostication, this is a highly important issue to address.

It has also been specifically stressed that there is a need to investigate ways by which accurate information about *how* and *when* patients' prognosis can be best communicated (Hasson et al. 2020). This has been stressed in previous literature as well where a report recommended that research should be undertaken to better identify end-of-life patients, and to understand how MDTs make decisions and communicate uncertainty related to prognosis (Neuberger, Guthrie, and Aaranovitch 2013). However, the scoping review findings (Chapter 3) showed that there was a lack of research focusing on how MDT members discuss patients' prognosis. Most research focuses on how healthcare professionals communicate prognoses to patients and their next of kin (for example Pino and Parry 2019b; Anderson et al. 2021, 2020). There are several guidelines on how to deliver prognoses and how to engage in such conversations for example SPIKES (Kaplan 2010) and COMFORT (Wittenberg-Lyles, Goldsmith, and Platt 2014). But there does not seem to be much guidance on how MDTs should engage in prognostic discussions from a team internal perspective.

Looking specifically at studies exploring the communication during palliative care MDT meetings, as noted in the Chapter 3, some studies have recorded MDT meetings and investigated decision-making in the interaction without focusing explicitly on prognosis. One study explored the clinical content during MDT meetings (Powazki, Walsh, and Shrotriya 2014). The authors explain that the MDT meeting is intended to provide information-exchange about important issues such as life expectancy. However, the aspect of life expectancy is not mentioned further (or elsewhere) in the paper.

The evidence presented in this section shows that there is a paucity of research exploring the interaction about prognosis during MDT discussions. One way of analysing MDT interactions is through the methods of CA. This method allows for a detailed and systematic investigation of MDT members' talk during their meetings to be conducted (see more in section 5.4.1). Therefore, this method is particularly useful in order to shed light on *how* MDT members formulate and make decisions about patients' prognoses during these meetings.

5.3 Study aims

This conversation analytic study explored how prognoses were discussed between MDT members in a hospice. The overall aim of the CA study was:

- To examine how healthcare professionals organise their institutional activities through interaction, and especially how survival predictions are carried out, during MDT meetings in a hospice

The outcome of this study was to collect, classify and describe specific patterns of communication behaviour related to prognostic decision-making during MDT meetings in a hospice.

Based on the overall study aim and by looking at the data, three analytical foci were decided: how prognostic talk is initiated (Chapter 6), how time estimates are used in prognostic talk (Chapter 7), and how prognostication is an interactionally delicate matter (Chapter 8).

5.4 Study methods

In this section, the overall study methods are described. A study protocol was developed, and the final version was registered with OSF on 04 June 2021 (https://osf.io/bdf3t).

The information presented in this section, and in this chapter overall, is relevant to all three analytic results chapters that follow. Therefore, references to this chapter are made throughout the subsequent chapters.

5.4.1 Conversation Analysis

The methods of CA were used to address the study aims. CA as a research approach systematically analyses social interaction. The CA method was developed in the 1960s by sociologist Harvey Sacks through a series of lectures (see Sacks 1992). The conversation analytic approach is inspired by the work of Erving Goffman and Harold Garfinkel (see Sidnell 2010) and describes everyday social interaction as an ordered and orderly phenomenon, as a locus of social order (Couper-Kuhlen and Selting 2018). On a basic level, the objective of CA is to describe "…the procedures by which conversationalists produce their own behaviour and understand and deal with the behaviour of others" (Heritage and Atkinson 1985: 1). However, the cognitive aspect of speakers is not taken into account, instead the focus is on how utterances are organised and structured, and what that can convey about or between speakers (Maynard 2012). CA takes a structural approach to the analyses and assumes that social interaction is orderly at a minute level of detail (Stivers and Sidnell 2012); "order at all points" as Sacks formulated it (Sacks 1984: 22). In this way, the aim of the analyses is to describe the overall structure of interactions in terms of how practices, actions, and activities are organised by and between speakers.

CA has developed its own methodological tools for the investigation of social interaction (Couper-Kuhlen and Selting 2018). These tools are used to study both ordinary everyday and institutional talk and include audio and video recordings of naturally occurring interactions and detailed transcriptions of these data. Transcriptions should be precise and detailed in order to faithfully represent interactions and thereby allow a comprehensive analysis of the interactional structure. They therefore indicate elements such as speech volume, stress, and pauses in the talk (see Jefferson 2004; Hepburn and Bolden 2012). The actual analysis then often involves finding patterns in the data and explicating their logic (ten Have 2007).

5.4.1.1 Institutional applied Conversation Analysis

Institutional applied CA involves shedding light on routine institutional interaction (Antaki 2011). The analyst does not aim at solving the institution’s problems but instead, they curiously seek to investigate how the institution carries out its work (Antaki 2011). The objective of using the methods of CA on institutional interactions is often “to describe how particular institutions are enacted and lived through as accountable patterns of meaning, inference, and action” (Drew and Heritage 1992: 5). Through analyses of institutional talk, it is possible to gain insights into how everyday business gets done but also interactional and organisational business that is accomplished through that talk (Boden 1997). CA researchers have dealt with interactions from a wide range of institutional settings such as healthcare (Heritage and Robinson 2011), psychotherapy (Peräkylä 2012), and in classrooms (Gardner 2012). CA research studies have also been conducted within palliative care (see Ford, Hepburn, and Parry 2019; Anderson et al. 2021, 2020).

Institutional interactions have been defined as interactions that are task-related and involve at least one participant representing a formal organisation (Drew and Heritage 1992). These interactions are shaped and constrained by participants’ orientations to the different roles of the institution as either their representatives or their clients (Drew and Heritage 1992). For an interaction to be institutional does not require it to happen in a certain institutional setting such as a workplace location. It is through the timing, placing, pacing, and patterning of verbal interaction, organisational members actually constitute the organisation as a real and practical place (Boden 1997). This means that interactions are institutional to the extent that the institutional or professional identities of the participants are made relevant to the work activities they are engaging in (Drew and Heritage 1992).

5.4.1.2 Meetings as an interactional activity

When dealing with hospice MDT meetings, it is relevant to bear in mind that these are first and foremost *meetings*. Meetings are the essential mechanism through which organisations create and maintain the practical activity of organising (Boden 1997). They involve a certain type of institutional talk, and there are features that are crucial in defining formal meetings as organisational phenomena and communicative events (Asmuß and Svennevig 2009). These include situational characteristics that involves meetings occurring at a prearranged time and place and having one or more purposes to be achieved. Asmuß and Svennevig (2009) explain how meetings involve participants who meet and act in their institutional roles and deal with institutional problems and issues. They engage in institutionally specific activities and typically orient to achieving certain goals in the form of decisions, agreements, solutions, or ideas. Finally, the authors mention characteristics related to the interaction in meetings in terms of turn taking and topic progression. They specify that turn taking is different from ordinary conversation and expert-lay interaction in that it is most often administered by a chairperson, and that topic organisation is also special in that it is constrained by the agenda and administered by the chair. Meetings are often characterised by the multimodal use of devices or other artefacts such as slide presentations, papers, other documents or diagrams (Smart and Auburn 2018).

Several studies have used CA methodology to analyse MDT meetings. One study explored how MDTs made decisions and mapped the organisation of meetings in an Emergency Department (Seuren et al. 2019). This study highlighted that the primary goal of an MDT meeting was generally to come to a shared decision for the patients who are discussed; cases were presented not simply to inform other team members, but to get their input in order to improve patient care. Other conversation analytic studies looked at MDT meetings in rehabilitation settings (Keel and Schoeb 2017; Schoeb, Staffoni, and Keel 2019; Barnard, Cruice, and Playford 2010) and geriatric case conferences (Nielsen 2009). A few other studies explored MDT meetings in cancer care using CA in combination with other quantitative methods and approaches (Soukup, Murtagh, et al. 2020; Soukup et al. 2021) or drawing upon CA methodology (Dew et al. 2014; Dew 2016). However, no studies have been conducted using CA on hospice MDT meetings.

5.4.1.3 Decision-making in interaction

In Chapter 1, MDT decision-making was described from a more general (communicative) perspective. However, from a more detailed interactional perspective, decision-making can be more complicated. Sometimes it may be implied that decisions are something very clear, like a specific “thing” that can be easily identified. However, when dealing with decisions from an interactional perspective, it is not (always) straightforward to identify the moment when a decision is made (Huisman 2001). Boden (1997: 83) even states that “decision-making is a diffuse and incremental process which occurs in all organisational meetings”. They also mention that decisions are often invisible, and that decisions are virtually never stand-alone affairs but rather part of a sequence of tinkering with some organisational problem (Boden 1997). Huisman (2001: 75) defines decision-making during meetings in the following way:

> “… a decision in a meeting is a product of an interactional process in which participants jointly construct the formulation of states of affairs, and through further assessment and formulation build commitment to particular future states of affairs. Apart from the fact that decisions cannot be attributed to one specific utterance, but rather are emergent, it is important to notice that decisions do not necessarily get explicated as such.”

In this way, decision-making from an interactional perspective can be more complex to identify and therefore study. Here, the method of CA becomes particularly useful because of the focus on the turn-by-turn organisation between speakers and a context-sensitive approach to the analysis and interaction.

The CA method was selected for this thesis as it allows for careful examination of how the MDT discusses patients’ prognoses. The benefits of using CA include analysis of *naturally occurring* interactions. In this way, the analyses and findings are based on what actually happen during the interaction between people and, as mentioned in the scoping review (Chapter 3), not on people’s retrospective accounts of (or opinions about) the interaction. The analyses do not use coded representations (e.g., themes), but instead the analyses are data-based and focus on the moment-by-moment unfolding of the interaction between the participants.

5.4.2 Study setting

The data for this study were collected from a UK hospice. The hospice provided services for patients with advanced life-limiting diseases and consists of an inpatient unit, day care and outpatient facilities. The inpatient unit had two wards with 15 beds each. An MDT meeting was held once a week for each ward and for the hospice outpatients. The purpose of the MDT meetings was for staff members to discuss and plan the care of patients.

Patients or their relatives did not participate in the MDT meetings. There is conflicting evidence about including patients and relatives in MDT meetings (Taylor, Finnegan-John, and Green 2014; Furman et al. 2018). The collaborating hospice in this study, in keeping with standard practice in this area, only included staff members in their meetings. Although the question about whether to involve patients or relatives in MDT meetings is an important one, it was not the focus of this research which was concerned with professional communication within MDTs as they were organised by the hospice.

5.4.3 Study participants and recruitment

Study participants were hospice staff members attending the MDT meeting. All staff who attended a meeting during the data collection period and were willing and able to provide informed consent were eligible for the study.

The study was presented to staff members to inform them about it and to allow them to ask any questions. Posters were put up in the hospice to inform and remind both staff and patients about the study (see Appendix 12 and Appendix 13).

The MDT meetings involved many varying staff members and staff joining the meetings at different times. This meant that it was not possible to inform all the MDT attendees about the study in one information meeting, or to inform and obtain consent just before staff members entered the meeting room as initially planned. For this reason, the study was also presented in a morning handover meeting to inform as many staff members as possible.

5.4.4 Participant consent

MDT meeting attendees were asked to participate in the study by reading the PIS (see Appendix 14) and by signing a consent form (see Appendix 15) either before or after attending the MDT meeting. If a staff member did not consent to participate in the study, the meeting was still recorded. However, data relating to staff members who refused consent were not used for analysis. This is the same process described in similar studies recording MDT meetings (Nic a Bháird 2015; Raine et al. 2014) and was approved by the REC. A form was also created where participants could withdraw their participation in the study (see Appendix 19). No one requested to withdraw their participation in the study and therefore, the form was not used.

Patient consent was not obtained for this study. This was because any personal information that was recorded about patients was only captured incidentally to the research aim, and moreover any such information was subsequently anonymised. Most of the hospice patients were terminally ill and a key consideration of research during this time is to avoid unnecessarily burdensome processes or procedures. Moreover, patients might have lacked capacity and time to provide fully informed consent due to their frail state. New patients could be admitted every day to the hospice, but also quickly die, or be discharged again. Therefore, obtaining consent from all patients prior to their cases being discussed in the meeting would have been practically very difficult. It was also not possible to predict which patients would yield relevant data for the study. Thus, attempting to consent all patients admitted to the hospice would potentially have led to unnecessary bother and distress to many patients whose cases would never actually had been discussed at the MDT meeting or even if their case had been discussed it would not have provided relevant data. In light of the decision not to obtain patient consent, despite the unavoidable necessity of capturing patient identifiable data, an application to the Confidentiality Advisory Group (CAG) was needed. More details on CAG are provided in the section on ethical considerations.

5.4.5 Ethnographic observations

Prior to the formal data collection, ethnographic observations of MDT meetings in the hospice were made. Within CA research, it is acknowledged that fieldwork and ethnography shape important decisions about what and how to record the type of interaction under investigation (Mondada 2012). Such work can even be required for entry into inaccessible settings, for the understanding of local activities, identification of events to be recorded and for the arrangement/positioning of recording equipment (Maynard 2003).

In this study, ethnographic observations were primarily used to gain insights into how the hospice worked. Observations were made during different MDT meetings held in the hospice as these meetings were the focus of the study. However, to make the researcher familiar with the hospice environment and provision of specialist palliative care, clinical consultations with a palliative care consultant and patients, and hospice ward rounds were attended and observed.

A key function of the ethnographic observations was to inform how the MDT meetings were constructed and how to best collect the video data. Observations were used to inform decisions about what recording equipment was needed and where it should be placed in the meeting room. They were furthermore used to inform which MDT meetings to record. Based on observations of the outpatient MDT meeting, it was decided not to record these meetings, since they involved patients with a significantly longer disease trajectory. Many of the patients discussed at these meetings had been involved with the hospice for a long time (several months or even years), and since this project focused on imminently dying patients, it was decided to only work with the inpatient MDT meetings.

5.4.6 Data collection

Data were collected in the hospice for a period of six months (May to December 2021). Video recording equipment (two cameras and an audio recorder) were set up in the allocated meeting room before each meeting. Two cameras were deemed sufficient to capture the interaction prior to starting data collection.

Video recordings were used in order to capture multimodal aspects of interactions such as gaze, body movement, and usage of objects. Non-verbal communication forms a great part of social interaction, and multimodal elements as the ones listed above and others such as gestures, facial expressions, and body positions are very important in how people build meaning and understanding (Parry 2010). If people have visual access to each other during the interaction (e.g., being present in the same room), then it makes sense for the researcher to have visual access to the interactions as well in order to better understand what is happening. Audio recordings might be sufficient for analysing other types of interactions such as telephone conversations where the speakers themselves cannot see each other. Video recordings are also particularly helpful when the interaction involves multiple people, where they can be used to confirm when someone is present and who is speaking. Using video recordings are also particularly helpful (and crucial) if the interaction involves activities performed simultaneously with talk. In such situations, research that can systematically deal with both verbal and non-verbal (multimodal) elements is obvious (Parry 2010). For this reason, it was decided to video record the MDT meetings.

The first MDT meeting recording was treated as a practice recording, to pilot the study processes, to evaluate camera angles, and ensure good sound quality. However, when initiating the data collection process, it became apparent that the existing cameras could not capture all angles of the interactions between staff members. Despite this, after discussions within the research team, it was decided not to use more cameras in order to minimise researcher influence on the meetings and to make recordings as unobtrusive as possible (Parry et al. 2016).

The original plan had been for the researcher not to participate in the meetings themself in order to avoid any researcher influence on interactions. However, when the data collection process started, it was deemed acceptable that the researcher was present during the meetings. This decision was made in order to ensure that meeting attendees had signed the consent form or that retrospective consent was sought for staff members. Furthermore, due to the unexpected number of varying/changing staff members participating in the meetings, the presence of the researcher was deemed necessary to inform new staff members about the study and to ensure on-going consent and comfort around recordings. The role of the researcher in video data has been the focus of recent research (Katila et al. 2021). It has been argued that “researcher-participants do not (necessarily) challenge the local “naturalness” of the data, and the situated accountability of the researcher-participant will display how the co-participants make sense of the researcher’s presence” (Hofstetter 2021: 2). It has also been argued that researcher participation can be useful for fieldwork providing evidence for the researcher’s unique adequacy and for gaining access to the activity (Hofstetter 2021). In this study, the researcher occupied an observational role. It should be mentioned that visitors and/or observers commonly participate in these meetings, and thus the presence of visitors is not regarded as being unusual.

5.4.7 Data management

Recordings were audibly masked before being securely stored. Audibly masking the data involved “beeping out” all participant identifying information from the recordings such as patient and staff members’ names, locations etc. The video editing software Premiere Pro CC version 15.0 or above was used for this purpose.

5.4.8 Data transcription and analysis

Each video recording was watched by the researcher, and timepoints were noted when something that sounded like prognostication occurred. The sequences in which these prognostic utterances occurred were then transcribed and subsequently analysed.

Recordings were transcribed following standard CA conventions (Jefferson 2004; Hepburn and Bolden 2012). The transcription key can be seen in Appendix 20. Multimodal elements were indicated with curly brackets, and only multimodal elements relevant for the analysis were included. In transcripts, patients were either given a pseudonym or simple referred to as ((name)) if their name was mentioned. MDT staff members were referred to by their institutional role such as nurse or NUR. The transcription software CLAN version 2021-04-28 or above was used for transcription. Among other features, this software enables linkage of transcriptions to the video/audio files (MacWhinney 2000).

Single-case analyses (Pomerantz and Fehr 1997) were conducted, and these analyses were used to create a collection of cases (i.e., collection analysis). Collection analyses systematically explore how a phenomenon appears in interaction and in this way, the analyses aim to identify any criteria for the particular phenomena (see Hoey and Kendrick 2017). In subsequent analytic chapters, transcription excerpts are provided to illustrate key analytic points. Excerpts are followed by a section presenting a detailed turn-by-turn analysis to show the different actions performed by the speakers and how their utterances relate to each other. This is followed by another section summarising the overall points made in the turn-by-turn analysis.

The thesis aimed at exploring how prognostication unfolded in MDT discussions, but the exact analytic aspects or specific research questions were not decided beforehand. As described above, the study simply began with identifying and subsequently analysing cases of prognostication. In this way, all the analyses involved prognostication, however a data driven approach was used in order to identify the specific foci of analyses. This is in line with the CA concept of “unmotivated looking”, which is an analytic strategy where the analysist is open to discovering phenomena in the data rather than searching for instances that are already defined, described, or somehow pre-formulated in terms of what the phenomena should look like (Psathas 1990). The three analytic foci were selected as they seemed interesting and particularly relevant in order to explore prognostication within the interactions. Moreover, these foci were discussed with the supervision team and were deemed appropriate for addressing the thesis aims.

It is relevant to note that all the cases of prognostication in the data can be analysed through different analytic lenses. Sidnell (2013: 92) explains that “any single case (…) can provide the basis for many different collections precisely because any single case is the product of multiple, interlocking practices of speaking”. When beginning to look at the data, it was the data itself and ethnographic observations that led to the three specific analytic aspects (initiation, time estimates, and sensitivity) that this thesis covered. However, the pool of cases where prognosis occurred were the same, the same “database”, and the analyst could look at them in different ways.

5.4.8.1 Data sessions

Data and analyses were also discussed in CA data sessions. Data sessions are a common practice within the CA community, where researchers meet to look at other researchers’ data (see Stevanovic and Weiste 2017). Such sessions have been described as being integral to the method of CA (Joyce et al. 2022).

The researcher hosting the data session selects a piece of data and the related transcripts to be presented at the session. The researcher briefly presents the data by explaining the study setting, the purpose of the overall study, participants in the data etc. The group then listens to or watches the data multiple times. Questions might be asked about the context of the data, and the transcript might also be refined. The researcher can have a certain analytic aspect that they want the other researchers to focus on, or the focus can be more loose where researchers can focus on whatever they find interesting in the data. Then everyone has a set amount of time (e.g., 10-15 minutes) alone to analyse the data. Following the analysis time, the group shares their observations, analyses, and thoughts about the data. This leads to a discussion about the data and the analysis.

Data from the thesis were presented at data sessions at UCL; Aarhus University, Denmark; and at the Loughborough Doctoral Network Meeting. Participants were asked to sign a non-disclosure agreement before being given access to the data (see Appendix 18).

5.4.9 Patient and Public Involvement

Patient and Public Involvement (PPI) members were contacted to provide feedback on the research design. This was also a requirement for the CAG application, and necessary to obtain their support. PPI members were provided with a research summary detailing the study design and were then asked to consider specifically the aspect of not obtaining patient consent for the study. Two members of the Marie Curie Research Voices Group and one palliative care outpatient were contacted and reviewed the study design. Marie Curie Research Voices Group members are people with personal experience of terminal illness who are involved in research. The feedback was summarised and included in the CAG application.

Most PPI feedback was supportive of the study. One PPI member was concerned and expressed the opinion that MDT meetings should not occur without patients or their next of kin being present. For this reason, this PPI member felt that patient consent (or caregiver approval) should be sought before meetings were recorded. While respecting this viewpoint, the nature of the research was to understand the workings of MDT meetings as they were constructed in the hospice, rather than to implement changes to their format (MDT meetings at the hospice are professional meetings at which the patient being discussed, or their next-of-kin, are not present).

5.4.10 Ethical considerations

The study received a favourable opinion by the London – Camden & Kings Cross REC (IRAS Project ID: 276367; REC Reference Number: 20/LO/1168) on 04 December 2020 (see Appendix 16). In England and Wales, an application to CAG is required where confidential patient information is accessed without consent. As the study only obtained consent from participants attending the meeting, and not the patients being discussed during the meeting, CAG approval was sought. The study received CAG support (CAG reference: 20/CAG/0141) on 06 April 2021 (see Appendix 17).

The study protocol was reviewed by a colleague from Loughborough University with experience in conducting CA research and collecting data from palliative care settings. The UCL Joint Research Office required that a non-disclosure agreement was used when bringing data for CA data sessions. The assigned officer developed such agreement (Appendix 18). Signed agreements were either stored in a locked cabinet within a restricted office area within the UCL Division of Psychiatry or securely stored online.

To obtain CAG support it was necessary that NHS Digital conducted a review of the hospice’s Data Security and Protection Toolkit (DSPT). The hospice General Data Protection Regulation team was contacted and a data sharing agreement with the hospice was created. The data sharing agreement was drafted and approved by the UCL legal team and the hospice legal team. An honorary contract was signed between the researcher and the hospice as well. The process of approving the DSPT and creating the data sharing agreement was time consuming and meant that CAG support was not obtained until a few months after receiving approval from the REC. Throughout the process, there was close collaboration with the UCL Information Governance team, who provided invaluable guidance. To comply with the UCL DSPT, it was necessary to register the study with the UCL Data Safe Haven system.

To comply with data protection regulations, data were transferred to an encrypted laptop to be audibly masked before being securely stored. Participant consent forms were securely stored in a locked cabinet within a restricted office area within the UCL Division of Psychiatry.

As a requirement of REC and CAG approval, posters were put up to inform patients and their next of kin about the study and about the option for patients to opt out of the study. No patients nor their next of kin expressed concerns about the study nor requested to opt out.

5.5 Study data

Within the data collection period, 24 video recordings of MDT meetings were collected. Each MDT meeting involved 10-15 attendees and was approximately one hour long, yielding 24 hours of data. Consent was provided by 65 MDT attendees. A few staff members decided not to provide consent. Due to the COVID-19 pandemic, only one of the two hospice wards was open. This meant that data were only collected from one ward.

These recordings provided the dataset for the analyses presented in the subsequent results chapters.

5.6 Ethnographic background

This section describes the overall structure of the MDT meetings. This is to provide a better understanding of the MDT meeting and the hospice as an organisation before presenting the analyses in the following chapters. The description is based on ethnographic observations, participation in the MDT meetings, and documents obtained from the hospice to better understand the structure of the meetings. Throughout the analysis presented in the chapters to come, the MDT meeting itself might be referred to only as the “MDT”. This is simply the language that staff members used to refer to the meeting. However, to minimise confusion, the term “MDT” will be used when referring to the team, and “MDT meeting” or only “meeting” when referring to the actual meeting.

The collaborating hospice had a weekly ward MDT meeting where all inpatients were discussed. The meeting was on the same day and time each week and lasted about one hour. The following staff members attended the meeting on a regular basis and made the “core” of the MDT:

- Bereavement coordinator
- Social worker
- Chaplain
- Physiotherapist
- Occupational therapist
- Doctors
- Ward manager
- Nurses
- Healthcare assistants

Occasionally, other professionals attended the meeting on an *ad hoc* basis such as the hospice pharmacist, psychological therapists, and staff in administrative and management roles. Some of the core team members might not attend the meeting if they were on annual leave or otherwise unavailable. As noted previously, patients or their next of kin did not participate in the meetings.

5.6.1 Before the hospice multidisciplinary team meeting

Before the meeting, a member of the administrative staff would set up in the allocated meeting room. If the meeting was held in the hospice seminar room, then this involved logging into a laptop and making sure the laptop screen was displayed on an external screen. The meetings were often held in the ward family room so nurses could easily attend the meeting and be closer to the patients. An external screen was not used in this room. Instead, the administrative staff member would ensure that one of the mobile computer stations was in the room and that the logon details were available.

The MDT chair rotated on a weekly basis between different professionals. The chair made sure that the MDT information was recorded on the relevant paperwork. Often, the chair did not play a prominent role in the meeting, but they might need to ensure that the discussion was summarised, that the meeting stayed on task, and finished on time. The chair did not decide who was permitted to speak during the meeting.

Printed handover sheets that contained information about each inpatient were available for the attendees. The handover sheet included the following patient information:

- Name/age/diagnosis/history/allergies
- (Resuscitation) Status and Date of Admission
- Phase of Illness/Karnofsky Performance Status (KPS)
- Pressure sores/infection
- Medical (main problems, outstanding results, outpatient appointments)
- Nursing (care plan, issues, syringe driver)
- Bowels
- Therapy (patient goals, input, and referrals)
- Visitors
- Discharge plans/borough

Each MDT attendee also had to sign an attendance sheet with their name and role.

5.6.2 During the hospice multidisciplinary team meeting

In the beginning of the MDT meeting, the bereavement coordinator would list the inpatient deaths since the last meeting. The coordinator would mention the deceased patient’s name, then the patient’s next of kin was mentioned. It was then discussed what support was needed for the bereaved. Most often the next of kin would receive a phone call from the social worker or the bereavement coordinator to talk about their loss and to discuss what support might be needed. If young children were involved then a Children and Young Person's Counsellor might be involved or if further psychological needs were present, then a psychologist might be contacted. If no additional support was required, the next of kin would receive what the team referred to as "routine support".

After having discussed the inpatient deaths, the bereavement coordinator would leave the meeting, and the meeting went on to discuss the inpatients. This was done through patient "presentations". During the MDT meeting, nurses or healthcare assistants presented the patients for whom they had been responsible for caring for during the day of the meeting. The patient presentation followed a certain format, where the healthcare professional filled in a template for each patient. The template consisted of the following patient information:

- Name and age
- What Matters to Me
- Phase of Illness
- Diagnosis and main issues
- Action points from last week's MDT

During the day of the MDT meeting, the healthcare professional would ask the patient to fill in a "What Matters to Me Today" sheet (often just referred to as "what matters to me"). If the patient could not fill in the sheet themself, then the healthcare professional completed the sheet for them – still reflecting what mattered to the patient. However, if the patient lacked capacity, was sleeping or unconscious, the sheet might not be filled in. In these cases, if the patients' relatives or friends were around at the time for filling in the What Matters to Me, then they might be asked if they knew what mattered to them. The healthcare professionals would leave the MDT meeting after having discussed their patients. This meant that they only attended part of the meetings. These patient presentations created the basis for the discussion.

In the electronic hospice system, an MDT template must be filled in for each patient. One staff member (usually one of the doctors) was in charge of completing this form during the meeting. The template included different aspects of care, which can be seen in **Table 5.1**.

This information must be filled in when the patient was discussed at the meeting for the first time. In subsequent meetings, only certain information might be added and updated according to the patient's situation. The template then often acted as an agenda and as guide for the meeting.

At some of the later meetings, the MDT would have printed the patient's Integrated Palliative care Outcome Scale (IPOS) (Schildmann et al. 2016), which could also be used to support the discussion.

The meeting ended when all inpatients had been discussed. If a patient was admitted on the day of the MDT meeting, the patient would be discussed at the next meeting to allow the team to get to know them.

Table 5.1: MDT template

Page	Item
Demographics	Has What Matters to Me been completed?
	Phase of Illness
	Date of Admission
	Diagnosis
	Reason for inpatient stay
	Admitted from
Symptom Control	Spiritual Care
	Main symptoms
	Mobility, transfers
	Personal Care
	Medication needs
	Psychological and psychosocial needs
	Has the patient been offered/referred to complementary therapy?
	Concerns with Cognitive/Capacity
	Is Deprivation of Liberty Safeguards (DoLS) required?

Next of kin/Social/ Will	Next of kin/Carer/Family/Friends/Lasting Power of Attorney/Young Children
	Social Situation (e.g., family complexities, living arrangement, main support, Package of Care)
	Has the patient completed a will/are they aware of the [organisation name] will writing service?
Wishes and Planning	Preferred place of care
	Preferred place of death
	Ceiling of treatments
	Coordinate My Care record
	Should CPR commence?
	Organ Donation wishes

5.6.3 Hospice as an organisation

Besides knowing the internal structure of the MDT meetings, it is also necessary to consider the wider hospice context. When participating in the MDT meetings and subsequently analysing the data, an orientation toward the hospice as being a “business” sometimes appeared. Occasionally, it was mentioned that the hospice “needed” the beds. In these cases, it was apparent that the hospice was an organisation, and they would refer to the service that they provided (i.e., specialist palliative care). If a patient was not in need of specialist palliative care or not close to dying, they might be discharged. Therefore, it is necessary to bear in mind that the hospice has organisational rules, norms, and goals that they needed to comply with.

5.6.4 COVID-19

Data collection was completed when COVID-19 was still impacting the UK (May to December 2021), and therefore also influencing the hospice as a healthcare institution. All staff members and visitors had to wear face masks when entering the hospice. It was also required that visitors had a negative COVID-19 test – staff members were tested multiple times during the week. During the data collection period, there were different restrictions on how many visitors that patients were allowed to have. Hospice volunteers were either not allowed in or only allowed in into the hospice with limited capacity. In this way, there might be some issues and decisions in the data that were specific to COVID-19 and did not represent the normal routine in the hospice before the pandemic.

5.7 Chapter summary

In this chapter, the background and methods of the conversation analytic study were presented. A background of the CA methodology and relevant CA research on institutional interactions were provided, and the specific study methods (e.g., participants, data collection and analysis) were described. An ethnographic background was presented as well to provide a better understanding of the MDT meeting before presenting the results of the study.

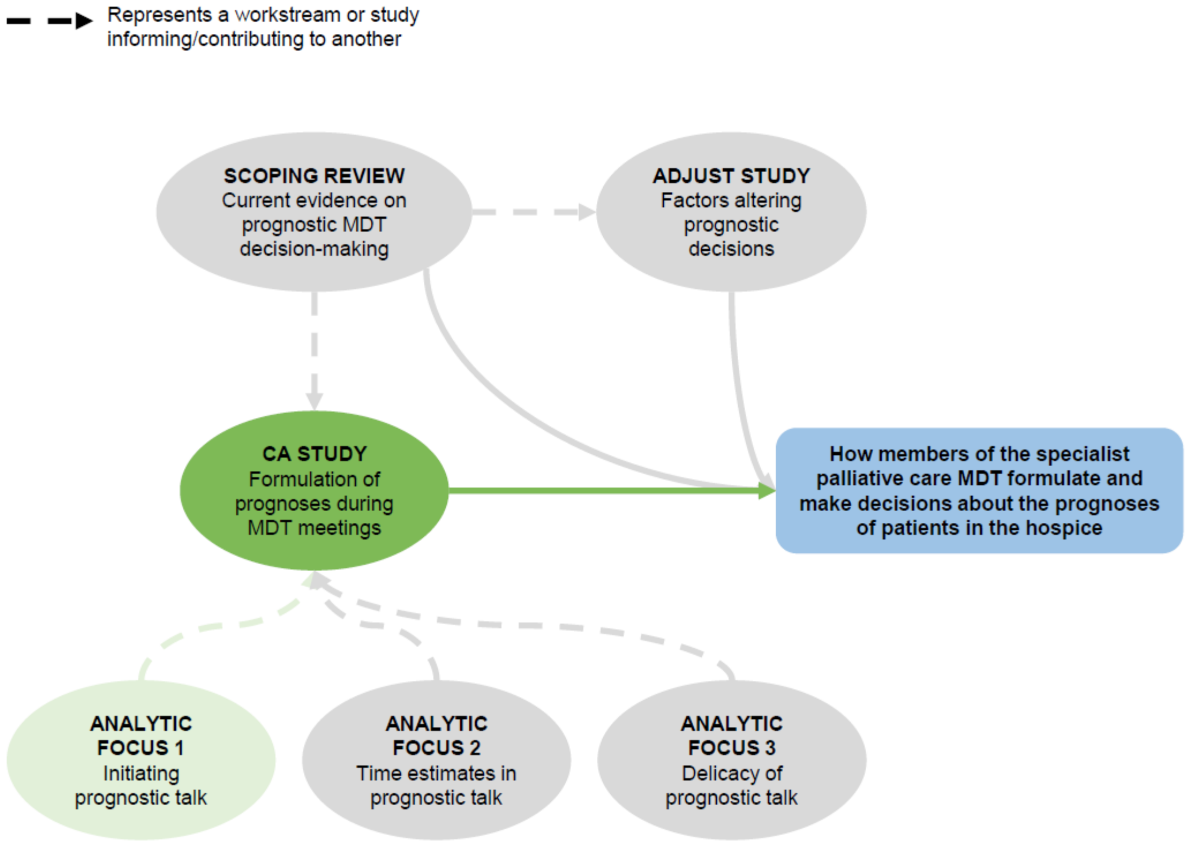
This chapter sat the scene in which the results were identified to address the thesis aim of understanding how members of the specialist palliative care team interact, including their formulation of prognoses during MDT meetings. As noted earlier, the methods presented in this chapter applied to all the analytic chapters (Chapter 6, Chapter 7, and Chapter 8).

Chapter 6 – Conversation analytic study: Initiating prognostic talk

6.1 Chapter overview

This chapter covers the first analytic focus of the CA study, which deals with how prognostic talk is initiated during hospice MDT meetings (see **Figure 6-1**). This study explored how the MDT opened up discussions of prognosis in order to understand *how* and *when* prognostic discussions *occurred* during these meetings. Through CA, the study identified different ways in which prognostic discussions were launched and how recipients responded to them in the interaction.

Figure 6-1: Thesis outline diagram – CA focus 1



6.2 Introduction

Research has been conducted on how end-of-life care discussions are initiated (Shaw et al. 2020; Pino et al. 2016; Anderson 2020). It has been shown how professionals employ different strategies to navigate these discussions. When engaging in prognostic discussions, a systematic review identified different communicative strategies professionals used such as ‘fishing questions’ (open questions seeking patients’ perspectives), indirect references to difficult topics, and linking to what a patient has already said (Parry, Land, and Seymour 2014). Another study had similar results, where doctors did not address the subject directly, instead a stepwise approach using certain communicative strategies (e.g., open elaboration solicitations) was used to get patients to voluntarily introduce the topic and take the lead in these discussions (Pino et al. 2016). Despite prognoses potentially being a delicate matter, studies have shown how patients and their relatives request prognostic information from clinicians but also how this involves collaborative management of uncertainty between parties (Pino and Parry 2019a; Anderson et al. 2020).

However, these studies were conducted on interactions between professionals and patients or their next of kin. As it will be described further in Chapter 8, these conversations are often characterised by the sensitive nature of professionals delivering bad news to patients. This is not the case within MDT meetings, where the focus is on inter-professional communication rather than communication with patients or their relatives. For this reason, a different picture might appear when dealing with how professionals open up discussions about prognosis during the MDT meeting. In these meetings, and as stressed in Chapter 1, the prognosis of a patient is a relevant matter to consider in order to provide optimal patient care. Despite prognosis being an important aspect of patient care, it is yet unexplored how the hospice MDT *initiates* prognostic talk during their meetings.

In this chapter, the initiation of prognostic talk during the MDT meeting will be described. The analytic focus is on how prognostication is made relevant in the interaction, which means how prognostic talk is launched. This is done by looking at the interactions that lead up to the target prognostic utterance. Finally, the analyses cover how the prognostic utterance is received, relating to how participants respond to it. In this chapter, and the following ones, the terms “prognostic utterance” and “prognostic talk” will be used. “Prognostic utterance” refers to an utterance that conveys a prediction of a patient’s death.

“Prognostic talk” more generally refers to the whole sequence leading up to and following the prognostic utterance.

6.3 Research questions and methods

This analytic focus explored how MDT staff initiated prognostic talk during their meetings. The study was guided by two research questions:

1. How is prognostic talk initiated in the interaction?
2. How are prognostic utterances responded to?

CA was used to explore these questions, and the methods and data are described in the background CA chapter (Chapter 5).

6.4 Results

The analyses revealed different patterns of how prognostication was carried out. The first way of initiating prognostic talk involved recording the patient’s prognosis as part of filling in information in the MDT template, most often delivered by a nurse or healthcare assistant. Another way involved discussion of the patient’s prognosis in relation to certain care aspects, in which clarifying, stating, or agreeing on prognosis was important for other care decisions, most often delivered by a doctor. These different approaches of initiating a prognostic discussion are described in the sections below.

6.4.1 Prognosis in response to patient presentation items

A common way for MDT staff members to initiate prognostic talk was through the patient presentation. As described in the section on the MDT meeting structure, nurses and healthcare assistants presented the patients they had overseen using a specific presentation format or template. In these cases, the patient’s prognosis was included within items that the staff member filled in and presented during the meeting. When prognoses occurred as part of the patient presentation, it was often only stated that the patient was dying, and the talk would move on to discuss any final plans for the patient.

The patient presentation part of the discussion of each patient had a certain interactional structure that needs to be considered. When the nurses (or healthcare assistants) presented their patients, it was clear from the structure that the MDT engaged in a type of storytelling activity where the nurse had the interactional floor. When a speaker is producing a storytelling, speakers work together to suspend the usual turn-by-turn talk, so the teller can produce an extended turn-at-talk (Mandelbaum 2013). Here, the term *alignment* becomes crucial. When a recipient *aligns* with a telling, they support the structural asymmetry of the storytelling activity: that a storytelling is in progress and the teller has the floor until story completion (Stivers 2008). This means that the recipients will remain silent or only provide minimal responses through continuers (*hm*, *uh huh, yeah*, and nods) that treat the turn as still in progress (Stivers 2008). During patient presentations, the presenter had the floor until they were done with the presentation that most often ended with the action points from the last meeting (see more in the ethnographic background section in Chapter 5).

It is also relevant to note that during the patient presentation, the nurse or healthcare assistant would read aloud from the template. They would often read aloud the template items and their responses to them based on their time with the patient and the care they had provided during the day. In this way, they would also engage in a sort of reported text activity (Brown et al. 2018). During the patient presentation, they might switch between formulations that clearly reflected what they had written down between more loose or free non-text-based utterances.

6.4.1.1 Response to Phase of Illness and Karnofsky Performance Status Scale

The dataset revealed several cases where discussions or mentions of patients' prognoses were initiated through the patient's Phase of Illness as part of the presentation. Phase of Illness is a tool used in advanced illness to describe four distinct stages, or phases, of an illness (i.e., stable, unstable, deteriorating or dying) according to the individual's care needs (Mather et al. 2018). When having to assess the patient's Phase of Illness, prognosis is an inevitable aspect to consider – especially when considering the last two phases (*deteriorating* and *dying*).

The excerpt below shows how the patient's Phase of Illness conveys prognostic information. The nurse (NUR) begins the presentation of the next patient for discussion at the MDT meeting.

EXCERPT 1 (a) – Phase of illness (2021.11.03)

```
01    NUR:  the next patient side room four we have
02          ((name)) eighty five years o:ld,
03          (0.2)
04    NUR:  phase of illness (.) dy:ing (.)
05          diagnose and main issue i- there were
06          bladder cancer with liver (.) (also)
07          coronary heart disease?
08          (0.2)
09    NUR:  the action points it's not applicable he
10          °wasn't here he was (out in the district)°.
11          (1.3)
```

The nurse follows the presentation format and begins with the patient's room in the hospice, followed by his name and age. She then continues with his Phase of Illness in line 04, where the patient is recorded as *dying.* This is the first utterance describing the patient's prognosis, which is initiated by the nurse having assessed the patient's Phase of Illness. The nurse then lists the patient's diagnosis and main issues, and the lack of action points from last week's MDT.

In this excerpt, the prognostic utterance occurred during the nurse's patient presentation. The prognosis was a response to a presentation template item about the patient's Phase of Illness. This meant that the patient's prognosis was part of, or embedded, into the nurse's patient presentation. As noted previously, the nurse had the interactional floor until she had completed the presentation. Aligning with the extended turn-at-talk structure, the nurse did not receive responses that either confirmed, rejected, or questioned the prognostic utterances during the presentation. This was a common way for the presenting staff member to initiate prognostic talk. Often the Phase of Illness would be followed by the patient's KPS score since these two were listed together on the handover sheet.

6.4.1.2 Accounting for lack of item response

Looking at the rest of this patient presentation from Excerpt 1 (b), another prognostic utterance occurs shortly after the one presented in the section above.

EXCERPT 1 (b) – PHASE OF ILLNESS (2021.11.03)

12 NUR: and u:h (.) he's unresponsive and in-
13 imminently dying (x x x x).
14 (0.9)
15 NUR: °and I: (.) couldn't get the what matters
16 to me°.
17 (3.0)
18 UNK: (mh)
19 (1.4)

In line 12, the nurse states that the patient is unresponsive, which is followed by the prognostic utterance in line 13. In this utterance, the nurse is saying that the patient is *imminently dying*, which is followed by something uninterpretable. After a pause, it is stated that the nurse could not obtain the What Matters to Me from the patient. In this way, the statement of unresponsiveness and the prognosis of imminently dying account for the lack of a What Matters to Me from the patient. Aligning with the extended turn-at-talk, this does not receive a response from other team members. After this excerpt, the ward manager begins to discuss that a colleague has spoken to the patient's daughter. With the ward manager's utterance, they depart from the prognostic talk, and the topic of prognosis is not discussed further for this patient during the meeting.

This analysis shows how a prognostic utterance was used as an account for not having obtained the What Matters to Me. However, this prognostic utterance was the nurse's *own* assessment of the patient compared to the response to the Phase of Illness item presented in the previous section. That this was the nurse's own assessment was seen through the word *imminently* that went beyond the four possible Phases of Illness (i.e., *stable, unstable, deteriorating* and *dying*). Moreover, this was also upgrading the prognosis, where the patient was not only *dying* but *imminently* dying, and thereby the prognosis was more specific.

Similar to the first prognostic utterance produced by the nurse presented in the previous section, this one was also part of the patient presentation, where the nurse still had the interactional floor and the other team members aligned by remaining silent. Interestingly, the prognostic utterances did not receive responses from other team members *after* the patient presentation, when the floor was open for other team members to comment.

6.4.1.3 Response to main diagnosis and main issues

A prognosis could also occur as a “result” of the patient’s diagnosis and main issues item of the presentation format. In the excerpt below, a nurse presented different symptoms, assessments, and interventions, which then led her to provide an upgraded prognosis for the patient.

Just before the excerpt below, the nurse (NUR) has introduced the patient and her “What Matters to Me”.

EXCERPT 2 – SHE'S DETERIORATING FURTHER NOW (2021.10.13)

```
01    NUR:  s- doesn't have any energy basically and
02          she's deteriorating now forty percent?
03          (0.5)
04    NUR:  so her diagnose and main issues are lung
05          (.) so diagnose lung cancer pulmonary
06          embolism_
07          (0.2)
08    NUR:  S (.) VC obstruction and main
09          issues are SOB pain.
10          (0.2)
11    NUR:  quite low mood u:hm_
12          (0.7)
13    NUR:  a:nd (.) so we've had to increase her
14          driver today she >was<_
15          (0.4)
16    NUR:  quite unsettled over night?
17          (0.5)
18    NUR:  and >(it) gave a couple< of PRNs (.)
19          u:h they gave midaz (.) oxynorm (.)
20          so we've u:hm increased (.) the driver from
21          (.) sixty (.) u:hm_
22          (0.4)
23    NUR:  from forty to sixty oxynorm and twen-
24          ten to twenty midazolam_
25          (0.6)
26    NUR:  had to give her PRN today cause (.)
27          she (.) she falls asleep she wakes up
28          she's very very distressed cause she:'s_
29          (0.5)
30    NUR:  obviously she's very short of breath_
31          (0.5)
32    NUR:  u::hm_
33          (0.1)
34    NUR:  I think she's deteriorating further now.
35    DR1:  yeah.
```

The nurse presents the patient’s Phase of Illness and KPS score, diagnosis, and then she continues with the main issues. The presentation of the main issues involves the unfolding of a sequence where the nurse presents multiple symptoms, assessments, and interventions from line 09-30. This type of sequence will be referred to as a *statement-assessment sequence*. These sequences are statements and/or assessments of the patient where several observations, symptoms, assessments, and sometimes interventions are listed. This type of sequence seems to have an informing function, in that it collates information about the patient to be shared with the MDT. The sequence ends with the prognostic utterance in line 34, where the nurse states that she thinks the patient is *deteriorating further now*. In this way, the statement-assessment sequence accounts for the nurse's prognosis. This seems to be a common function of the statement-assessment sequence that, when it occurs with a prognosis, it accounts for the provided prognosis. The prognostic utterance in line 34 also has a summarising character, where the utterance seems to conclude or be a product of the statement-assessment sequence of the patient, that the patient is now declining further. In this way, the statement-assessment sequence leads to an *upgraded* prognosis compared to the prognostic utterance provided by the nurse in line 02 (*deteriorating now at 40%*). Lastly, the prognostic utterance receives an affiliative response from the doctor (DR1) that agrees with the nurse. After the excerpt, the nurse continues with describing the patient's current situation.

The analysis above displays how a prognosis could occur as a conclusion or result of a statement-assessment sequence when the nurse listed the patient's main issues. The statement-assessment sequence accounted for the prognosis and provided evidence for why the nurse arrived at this prognosis. In this way, a prognosis was justified and grounded within the statement-assessment sequence. Moreover, it was seen how the statement-assessment sequence led to an upgraded prognosis of the patient.

In this section, three ways of initiating prognostic talk were presented. What these different ways had in common is that they did not elicit a further discussion from other team members. Most often they did not receive a response, and if they did, it was usually a minimal response simply confirming or accepting the prognosis.

6.4.2 Prognoses as conditional to other care aspects

Following the patient presentation, prognoses were most often formulated by doctors and occurred in relation to discussing other care aspects. In these cases, it was relevant or even necessary to discuss the patient’s prognosis when making other care decisions. This section shows how the question of discharge planning often initiated prognostic talk, and how prognoses could be used as topic management and as a means to redirect the discussion back to a previous issue. Lastly, this section will demonstrate how staff members sometimes made explicit prognostic requests.

6.4.2.1 Discharge planning

The data and analyses revealed that the question of discharge planning often initiated prognostic talk. Here the patient’s prognosis was crucial to consider in relation to whether the patient was suitable for being discharged. As mentioned in Chapter 5, it was part of the MDT template and also an organisational aspect to consider patients’ suitability for discharge. Discharge discussions usually involved consideration of the options for either discharging the patient home or to a nursing home. If neither of these were applicable due to the patient approaching death, then a third option would be that the patient stayed in the hospice (until they died). In these cases, it appeared uncertain whether the patient’s prognosis was ”poor enough” for the patient to stay in the hospice or whether they could be managed elsewhere.

Before the excerpt below, the nurse (NUR) has just completed the patient presentation and has presented the patient’s action points from the last MDT meeting. One of the action points was discharge planning.

EXCERPT 3 – VERY LIKELY TO DETERIORATE AND DIE (2021.10.13)

```
01    NUR:  so: with (.) ((name)) >do yo- did you< (.) well I think
02          you saw him yesterday bout the_
03          (0.9)
04    NUR:  discharge planning a:nd_
05          (0.8)
06    NUR:  implementing things with that then (.) today (.)
07          reviewed a:nd_
08          (1.2)
09    NUR:  >there was a< (.) bit of a decline he's [now since]=
10    DR1:                                          [yeah     ].
11    NUR:  =been out to the toilet.
12    DR2:  [okay   ].
13    DR1:  [okay   ].
14    NUR:  [so I do]n't know if_
15          (0.3)
16    UNK:  hh
17          (0.1)
18    DR1:  it's f- I think i- (.) he: [uh  ] ((name)) u:hm
19    NUR:                             [yeah].
```

```
20    DR1:  obviously has a lot of_
21          (0.5)
22    DR1:  comorbidities alongside his his cancer uhm (.) .th
23          (0.5)
24    DR1:  and_
25          (0.2)
26    DR1:  I- (.) we maybe caught him at a bad ↑time↑ (.) but equally
27          he's (.) very likely to deteriorate and (.) and die.
28          (0.5)
29    DR1:  u:hm.
30          (1.4)
31    DR1:  u:h (.) and I think he would (.) based on my discussions
32          yesterday (.) he would very much like to stay here,
33    DR2:  mhh,
34    DR1:  u:hm (.) yesterday he didn't look like a man who:_
35          (0.4)
36    DR1:  was deteriorating but then (.) >I think< if you catch
37          him at the wrong time he £pr(h)obably d(h)oes£ so >it's<
38    NUR:  yea.
39          (0.3)
40    DR1:  w- I think (we're) tricky (.) it's tricky.
41          (0.4)
42    DR1:  probably need to see two days of complete <stability>
43          before you'd say you'd want to transfer him.
```

In line 01-09, the nurse produces utterances directed to the doctor (DR1) about the doctor having seen the patient regarding discharge planning. These utterances are so called A-statements about B-events (Labov and Fanshel 1977), where one speaker (A) makes a statement about events involving another speaker (B). Such statements are often used as declarative questions (Stivers 2010), where the other speaker (B) should confirm or reject the first speaker's (A's) statement. In this case, the nurse's utterances seek confirmation from the doctor as they involve the doctor's work with the patient. The nurse's utterances seem to express a fluctuating picture of the patient's state where the team was planning on discharging the patient yesterday, but then the day after the patient deteriorated. However, the patient was also able to go to the toilet on the same day, which indicates that the patient instead is doing better. This unstable picture of the patient seems to cause confusion, where the nurse ends with, *so I don't know if* in line 14, which implies a lack of knowledge of what the plans regarding discharge are.

This leads to the doctor stating that the patient has several comorbidities that makes him unstable, which seems to account for the following prognostic utterance in lines 26-27. The doctor stresses the uncertainty of the patient's unstable state by saying that this might be a current (bad) time for the patient but also that this could be a step in the trajectory where the patient is very likely to deteriorate and die. The prognostic utterance is followed by a statement of the patient's own wish to stay in the hospice. The doctor then provides a statement-assessment sequence that orients towards the difficulty of the patient's fluctuating state and prognosis in lines 34-40. She then states the condition for discharge planning is that the patient should be stable for two days. After the excerpt, the discussion continues on the subject of discharge plans in the course of which other prognostic utterances and statement-assessment sequences also occur. After a while, they agree on postponing the discharge plans for the following week.

The nurse's utterances in the beginning of the excerpt displayed that decline impacted discharge plans – and that improvement (or stability) did as well. Instead of providing a prognosis herself, she provided an opportunity for the next speaker to elaborate on the decline and to potentially provide a prognosis. The doctor was expected to respond since she had a discussion about discharge plans with the patient. Instead of providing a straightforward answer to the discharge issue, the doctor then provided an account and a prognostic utterance. By providing the prognosis at this point in the interaction, it appeared relevant or even conditional to consider the patient's prognosis when deciding on discharge plans. In this way, the doctor aligned with the nurse's invitation to elaborate on the decline, which led the doctor to provide the prognosis. In this way, there was orientation from both the nurse and the doctor towards decline and prognosis as conditional to discharge plans. It is noteworthy that the prognostic utterance (line 26-27) did not receive a verbal response despite the long pause following it, which provided a clear opportunity for other team members to respond. This might have led the doctor to self-select as next-speaker and continue speaking. It should be mentioned that in the recording, there was no visual access to the nurse so she could be confirming non-verbally (e.g., by nodding).

This excerpt illustrated how discharge plans for the patient were dependent on the patient's clinical state and therefore prognosis. There was an orientation from both the nurse and the doctor towards prognosis as being conditional to discharge planning. The prognosis was provided by the doctor in response to the nurse's statement about the doctor's work with the patient. Lastly, it was shown how the prognostic utterance did not receive a response from other team members.

6.4.2.2 Prognosis as topic management

Prognoses could also be introduced and refer back to another aspect of care presented earlier in the talk. In this way, the prognosis could be used in topic management and to redirect the talk back to prior topics. Thus, clarifying or stating the patient’s prognosis was important for accomplishing other actions. The analysis of Excerpt 4 below shows how a doctor’s prognostic utterance was launched by a statement-assessment sequence from a nurse. The prognostic utterance was followed by another statement-assessment sequence that further accounted for the prognostic utterance.

In the excerpt below, staff members are discussing a patient whose mental capacity they have questioned. This has led the team to plan for the patient to undergo a capacity assessment to clarify whether DoLS involvement is necessary. The social worker has confirmed that they will do a capacity assessment after the MDT meeting. Just before the excerpt, a doctor has asked whether the patient’s Phase of Illness and KPS score should still be recorded as being unstable 40%.

EXCERPT 4 – SHE’S A DYING WOMAN (2021.12.08)

```
01    NUR:  yea.=
02    WAR:  =is sh- is she (rest) >did she< get out of bed [(x)]?
03    NUR:                                                 [uhm].
04          (0.4)
05    NUR:  well_
06          (0.3)
07    NUR:  yesterday_
08          (0.2)
09    NUR:  she was quite concerningly a lot <drowsy> slept
10          <through> and then in the afternoon (.) she was (.) went
11          (.) like aggressive a:nd (wake/went) up (.) quite_
12          (0.5)
13    NUR:  quite (jammed).
14    DR1:  yeah_=
15    NUR:  =she had subcut fluids (.) a:nd_
16          (0.6)
17    NUR:  u::hm_
18          (1.7)
19    NUR:  I think that was the only ↑change↑.
20          (0.1)
21    NUR:  she just [had s]ubcut fluids.
22    WAR:           [yeah ]_
23          (1.3)
24    NUR:  well I think (name) saying this morning in the handover
25          that she was (.) she puts up more in the afternoons too.
```

26 (0.6)
27 NUR: u:h I think (.) but from when I last looked after her
28 she seemed a lot worse yesterday then I had but then in
29 the afternoon she was_
30 (0.3)
31 NUR: she's still getting out onto the commode and (.)
32 passing urine but.
33 (0.1)
34 NUR: she's just really withdrawn_
35 (0.1)
36 NUR: a::.
37 (2.7)
38 NUR: yea I think she's getting more confused and.
39 (1.4)
40 NUR: like she was just swearing at the family and just very
41 (look/like).
42 (0.2)
43 NUR: and she was asking for alcoho:l (and was)_
44 (0.2)
45 DR1: oh gosh.
46 (0.6)
47 UNK: mhh_
48 (0.5)
49 NUR: [at po-]
50 DR2: [I me-] my: (.) my impression I- I- I feel like a dols
51 might (.) I think she's dying.
52 (0.2)
53 DR2: she's #dying# °[immi]nently and°_
54 DR1: [yeah].
55 UNK: ↑yes↑.
56 (0.3)
57 DR2: I s- she's got extensive brain mets (.) which are
58 pressing on both (x) things which (can make this kind
59 of) behaviour really abnormal at times as well as (.)
60 really difficult symptoms of sickness (and things).
61 (0.9)
62 DR2: u:hm_
63 (1.1)
64 DR2: u::h_
65 (0.2)
66 DR2: I- (.) she: yea?
67 (0.8)
68 DR2: but I only make two opport- she couldn't (.) weight up.
69 (0.8)
70 DR2: and (.) she can't really retain,
71 DR2: ((sniffle))
72 (0.5)
73 DR2: and she doesn't (feel) capacity_
74 DR2: but u:hm_
75 (1.6)
76 DR2: equally that is because she is a dying (.) woman.
77 (0.5)
78 DR2: so I'm not sure dols is actually_
79 (0.1)
80 WAR: okay.
81 (0.3)
82 DR2: needed.
83 WAR: °okay°.
84 (0.9)
85 DR1: fair play.

In lines 05-43, the nurse (NUR) is producing a statement-assessment sequence with several utterances stressing the rather abnormal and inappropriate behaviour of the patient. This sequence is a response to the ward manager's (WAR) yes/no question about whether the patient got out of bed. However, the nurse never answers this question directly. Instead, these utterances seem to provide a greater picture of the patient's situation and current state. In this way, the nurse is displaying that the ward manager's question is not straightforward to answer and that multiple factors are relevant to consider. The nurse's statement-assessment sequence leads to the doctor (DR2) providing the prognostic utterance in line 50-51. The utterance comes after several restarts, where the doctor mentions the DoLS, but this project is abandoned. Despite this abandonment, it still seems to re-direct the talk back to the topic of DoLS and issues relating to the patient's capacity. The doctor then finally arrives at the statement where she says that she thinks the patient is dying. This is followed by a stronger statement about the patient dying *imminently*. This utterance receives confirmation from other team members expressing agreement with the doctor's prognostic utterances.

The prognostic utterances are followed by a statement/assessment-sequence, where the doctor explains that the patient's abnormal behaviour might be explained by brain metastases and issues with the patient's capacity as well. This sequence accounts for the patient's behaviour that the nurse described, but it also seems to account for the prognosis provided. This becomes clear in line 76, where the doctor states that these issues with capacity are also due to the patient dying. In this way, the doctor's statement-assessment sequence accounts for the prognosis provided in line 50-53, but it also accounts for the later prognosis in line 76. The statement-assessment sequence then seems to be pivotal in the sense that they post-account for the first prognostic utterance and pre-account for the second one. At the end of the excerpt, it becomes clear that the doctor is providing the prognosis in response to the DoLS involvement when she rejects the need for it in line 78-82. Here, the doctor shows that it is relevant and necessary to consider the patient's prognosis when discussing the patient's abnormal behaviour and lack of capacity. This also displays how a prognosis can be used in topic-management to direct the talk back to the issue of DoLS.

In this excerpt it was illustrated how a doctor’s prognosis followed a statement-assessment sequence produced by *another* participant (the nurse). It was shown how the prognosis was relevant for an issue discussed earlier in the conversation regarding patient capacity. In this way, the prognosis was part of re-directing the conversation back to a prior topic, where the prognosis was essential to consider. The prognostic utterance was followed by a statement-assessment sequence accounting for it, but also leading up to, and therefore further accounting for, another prognostic utterance as well. The first prognostic utterance received confirming responses agreeing with the prognosis, whereas the second prognostic utterance did not receive a verbal response.

6.4.2.3 Explicit requests for prognoses

The data revealed that staff members rarely asked for a patient’s prognosis explicitly. However, there were some cases where such requests were present. The excerpt below shows how prognostication could be essential when discussing discharge planning. This was shown through an explicit request for a patient’s prognosis before answering a prior question regarding discharge. The patient’s prognosis occurred with a statement-assessment sequence that accounted for the prognosis.

Below is an excerpt from a discussion about whether a patient should be discharged from the hospice. The topic of discharge planning is initiated by the chaplain (CHA) who is also chairing the meeting.

EXCERPT 5 – WHAT HIS PROGNOSIS, DOCTOR? (2021.09.01)

```
01    CHA:  [so],
02    DR1:  [so],
03          (0.2)
04    CHA:  in the sense o:f (.) prepared.
05          (0.5)
06    CHA:  place of ca:re_
07          (0.6)
08    CHA:  and death (.) a:nd {<treat#men:t#>.
      DR1:                     {pointing down
09          (0.2)
10    CHA:  and how that fits in with what we have in mind whe-
11          ↑where we↑ {at?
      CHA:             {gaze towards DR1
```

```
12  com:  ((laughter))
13  CHA:  heh[ehehe                  ]he
14  SOC:     [yeah discharge         ].
15  DR1:     [brilliant (thought/one)]hehehe
16  SOC:  he he he he
17        (0.3)
18  DR1:  .th (.) ↑u[:hm↑.   ]
19  CHA:            [cause he] wants to be here.=
20  DR1:  =I know he [wants to] be h[e:re ].
21  SOC:             [mhh     ].    [°mhh°].
22  UNK:                            [yeah ].
23        (0.4)
24  DR1:  what does the MDT: thinkhh.
25        (0.7)
26  SOC:  wh[at's hi]s prognos[is      ] ((DR1 name))?
27  CHA:    [hm     ].        [°(okay)°].
28        (0.3)
29  DR1:  ↑I mean↑ it's not <great because> u:hm (.) he's got this
30        SCC see I mean it's quite invasive now and he's uh not
31        for any further treatment (.) plus he's had a massive
32        stroke as [#well#].
33  SOC:            [mhh   ].
34        (0.3)
35  NUR:  mh[h (he can be)],
36  DR1:    [he's bedbound] (.) he's cachectic he's now got an
37        <u:lcer> >pressure ulcer< you know.
38        (0.2)
39  DR1:  there's a lot going [on ]=
40  UNK:                      [mhh].
41  DR1:  =he's not well ma[n  ].
42  SOC:                   [mhh].
43        (.)
44  DR1:  u::hm he's got all these secretions he's at risk of
45        {infections=
    com:  {WAR, HQC, SOC nodding
46  UNK:  =mhh.=
47  DR1:  =he's at risk of {(.) u:hm .th
48  DR2:                   {nodding
49        (0.2)
50  DR1:  u- e- he's at risk of even u:hm .th (.) the: (.) u:h
51        tumor [inva]ding=
52  UNK:        [mhh ].
53  DR1:  =so there's a [lot] of things that could lead to quite=
54  SOC:                [mhh].
55  DR1:  =a quick (.) >deterioration< which is why I am kind of just
56        (.).hh taking m[y time] a bit with him because I just feel=
57  SOC:                 [mhh   ].
58  DR1:  =like he's kind of (teetering) on the edge at the mo[ment],
59  SOC:                                                      [yeah].
60        (1.1)
61  HQC:  and actually he pra- he wouldn't be: (.) you know.
62        (0.2)
63  HQC:  he's not in a good place to be sending him anywhere at
64        the minute [anyway].
65  DR1:             [I know] I know [I just           ] f[e:el].
66  SOC:                             [(he's palliative)].
67  CHA:                                                 [okay].
68  HQC:  mh[h    ].
69  DR1:    [I  fe]el like we are (.) best place to [man]ag[e him].
70  HQC:                                            [mhh].
71  SOC:                                                   [mhh  ].
```

```
72    CHA:  °okay°.=
73    DR1:  =u:hm: (.) because he's (.) he's got the needs that I
74          think we got the most exp[erti]se for,
75    HQC:                           [mhh ].
76    CHA:  °okay°.=
77    DR1:  sending him to a nursing home I'm n[ot I think]=
78    WAR:                                     [.th oh    ]_
79    DR1:  =they would [pani[c  ].
80    NUR:              [(can't) ] manage him=
81    SOC:              [mhh     ].
82    WAR:  =[he's going] to ask us [why if he sho]uld go to a=
83    SOC:   [mhh       ].
84    NUR:                          [(well yeah)  ].
85    WAR:  =nursing[home].
86    SOC:          [mhh ].
87    WAR:  [(in/he)] (.) definitely ask for (that).
88    DR1:  [#yeah# ].
89    DR1:  so I think they will just not mess- but anyway let's see
90          maybe give him a bit more time here to [see how he f-]
91    SOC:                                         [revi        ]ew=
92          =in the[week]
93    DR1:         [yeah] hehe
```

In the beginning of the excerpt, the chaplain asks a question about where the team is at regarding the patient’s preferred place of care, death, and treatment. This is followed by laughter from several team members, which seems to orient to the fact that this is somehow a complex or non-straightforward question to answer. The question of discharge planning is made clear by the social worker (SOC) in line 14, which is followed by the chaplain stating that the patient wants to stay in the hospice. Several team members agree with the statement, which leads to the doctor (DR1) asking a question to the whole team to share what they think. After a long pause, which might be due to issues with who should take the next turn, the social worker asks the doctor what the patient’s prognosis is. This request for the patient’s prognosis postpones a potential answer to the discharge question. The social worker’s prognostic question then indicates that the patient’s prognosis must be dealt with before an answer to the discharge question can be provided. Moreover, the question is directed to the doctor by using the doctor’s name. In this way, the doctor is selected as the next speaker who is expected to provide an answer. By speaker-selecting the doctor out of multiple possible other recipients, the social worker shows that this is the doctor’s knowledge domain, positioning them as more knowledgeable, which is also labelled or called “K+” in epistemic terms (see Heritage 2013). In response to the request for the patient’s prognosis, the doctor states that the prognosis is *not great* in line 29, and this is followed by a statement-assessment sequence that accounts for the prognosis. Based on the statement-assessment sequence, the doctor explains that this could lead to a quick deterioration in lines 53-55. These statements provide evidence and justify why the first prognosis in line 29 was given, but it also provides evidence for why the second prognostic utterance regarding the possibility of the patient deteriorating quickly was arrived at. This displays the pivotal function of the statement-assessment sequence.

Following the prognostic utterance in lines 53-55 comes an account detailing the reason why the doctor is taking their time with the patient. It is unclear whether this statement refers to the social worker’s prognosis question and the fact that the doctor cannot give a more specific prognosis, or whether it refers to the initial discharge planning question. The Head of Quality and Clinical Practice (HQC) then directs the conversation back to discharge planning by saying that the patient is not suitable to be discharged. The prognosis is not explicitly addressed in this statement, but the HQC does seem to agree with the doctor’s prognosis with her assessment of the patient not being in a good place. This statement rejects the option of discharging the patient and indicates that the discharge planning question is not relevant for now. The doctor agrees, and they continue with another assessment about the hospice being the best place to manage the patient. They mention that discharging the patient to a nursing home is not an option due to the patient’s substantive care needs, and it is also raised how the patient would question that himself. This seems to further account for the fact that the patient will have to stay in the hospice. They then arrive at the decision to wait for a while before making a final decision.

This excerpt illustrated how prognosis was relevant for discharge planning by postponing the discharge question through a specific request for the patient’s prognosis. The format of the request showed that it was the doctor who was responsible for providing a prognosis. A statement-assessment sequence both accounted for the prognosis occurring before the sequence and the one after it. The prognosis was agreed with by another team member and the question of discharge planning was postponed for the time being.

6.5 Discussion

6.5.1 Main study findings

This chapter explored how prognostic talk was initiated in hospice MDT meetings. The main finding of the analysis was that prognostication was embedded within other aspects of the MDT discussion. This meant that patients' prognoses would not be discussed as a separate or explicit topic, instead they occurred when team members were discussing other things during the meeting.

The data revealed that when prognoses occurred during the patient presentation, they were formulated by either nurses or healthcare assistants. During the patient presentation, prognostic utterances appeared as simple responses to patient presentation items such as the Phase of Illness (and KPS score). A prognosis could also account for a lack of response to certain presentation items such as the What Matters to Me item. Lastly, it was shown how prognoses could occur as a result of a statement-assessment sequence as part of the diagnosis and main issues item on the MDT template.

Prognoses occurring later in the patient discussion were most often formulated by doctors. They often appeared where it was necessary to consider the patient's prognosis when making other care decisions, particularly discharge planning. They could also be initiated and used to redirect talk back to certain care aspects. Lastly, it was shown how explicit requests for prognosis were rare in the data.

If prognostic utterances were responded to, they most often received confirming minimal responses from other team members. In this way, they were rarely responded to in a manner that directly challenged or further negotiated them. Across the analyses, there was a pattern of prognostic utterance most often appearing with statement-assessment sequences that accounted for them.

6.5.2 Discussion in relation to other findings

One of the main study findings were that prognostication was not a separate or isolated action during the MDT meetings. The analysis found that MDT prognostication was embedded in other social actions or care aspects instead.

This is in line with the findings from the scoping review, where it was shown how prognoses were often discussed in relation to other care aspects. Prognoses in relation to discharge planning was reflected in another study exploring the views of MDT members on the difficulties of discharging hospice patients to care homes at the end-of-life (Thomas, Clarke, and Barclay 2018). In this study, the authors reported that hospice MDTs made decisions about discharge plans on the basis of the patient's stability and prognosis. This is in line with the findings of this analysis, where patients' prognoses frequently occurred when discussing discharge plans.

The finding that the response to the Phase of Illness item initiated prognostic talk is somehow controversial when considering the Phase of Illness as a tool. Phase of Illness is not reliant on the stage of disease and prognosis, but it has been mentioned that the *dying* phase is an exception (Mather et al. 2018). When considering the wording of the *deteriorating* phase, this implies prognostic information and mirrors the language that MDT members use to express a patient getting worse and thereby closer to death. This point will be elaborated further later in the thesis.

When prognoses were embedded in the patient presentations, they did not receive much response. This might be due to the extended turn-at-talk that the presenter is performing. As described earlier, when performing an extended turn-at-talk, recipients should align by "giving" the floor to the speaker and until the presenter has completed the extended turn. If another team member should provide more than minimal responses to the prognosis verbally, then they would *disalign* with the structural asymmetry. Interrupting the extended turn would be potentially accountable and problematic in the interaction. In this way, the patient presentation, and therefore any embedded prognosis, does not necessarily invite inputs from other team members. However, it has been shown that nodding, when provided mid-telling, conveys preliminary affiliation with the teller's position and that the story is on track towards preferred uptake at story completion (Stivers 2008). A detailed multimodal analysis of other team members' head movements has not been conducted, but staff members frequently nod and thereby display agreement with each other. It should be stressed, that despite nods being an indicator of affiliation, the presenter would most likely not see them due to the focus on the documents used for the presentation format. Future research should aim at exploring this in more detail. However, when considering the response to prognoses it is also relevant to note how institutional meeting interactions might differ from other types of interactions. One previous study has shown how formulations that are not responded to are treated as being accepted, whereas group silence is the preferred and sufficient response (Barnes 2007).

According to Housley (1999), role is viewed as a primary mechanism through which different knowledge bases (disciplines) inform the decision-making practices and communicative acts within the MDT framework. In this study, it was shown how nurses were often in charge of providing the prognosis in response to certain patient presentation items. When prognoses occurred outside of the patient presentation, they were most often provided by the doctor. Also, there were some cases (e.g., the explicit request for prognosis) where it was clear that the doctor was seen as the one who should provide prognoses. This implies that it is particularly doctors' domain to provide prognoses. This is in line with the evidence from the scoping review that showed that prognostic discussions primarily happened between doctors and nurses (see Chapter 3). This displays their epistemic authority in these types of discussions. However, it needs to be further explored what role profession and staff members with another background have when it comes to MDT prognostication.

It is noteworthy that it was rather rare to find cases where team members explicitly requested a prognosis. Despite prognostication being important and essential in palliative care provision, it is interesting that prognosis is not something that the MDT deals with as an explicit and primary concern. This will be further elaborated upon in the general discussion chapter of the thesis.

6.6 Chapter summary

This chapter demonstrated how members of the MDT initiated prognostic talk during their meetings. The results showed that discussions about patients' prognoses were often initiated as a response to MDT meeting template items. Prognosis could also be mentioned or considered when making other care plans, such as discharge planning, or they could use prognoses to change the direction of the discussion. Rarely, professionals explicitly asked the team for patient's prognosis. If prognostic utterances were responded to, they most often received confirming minimal responses from other team members.

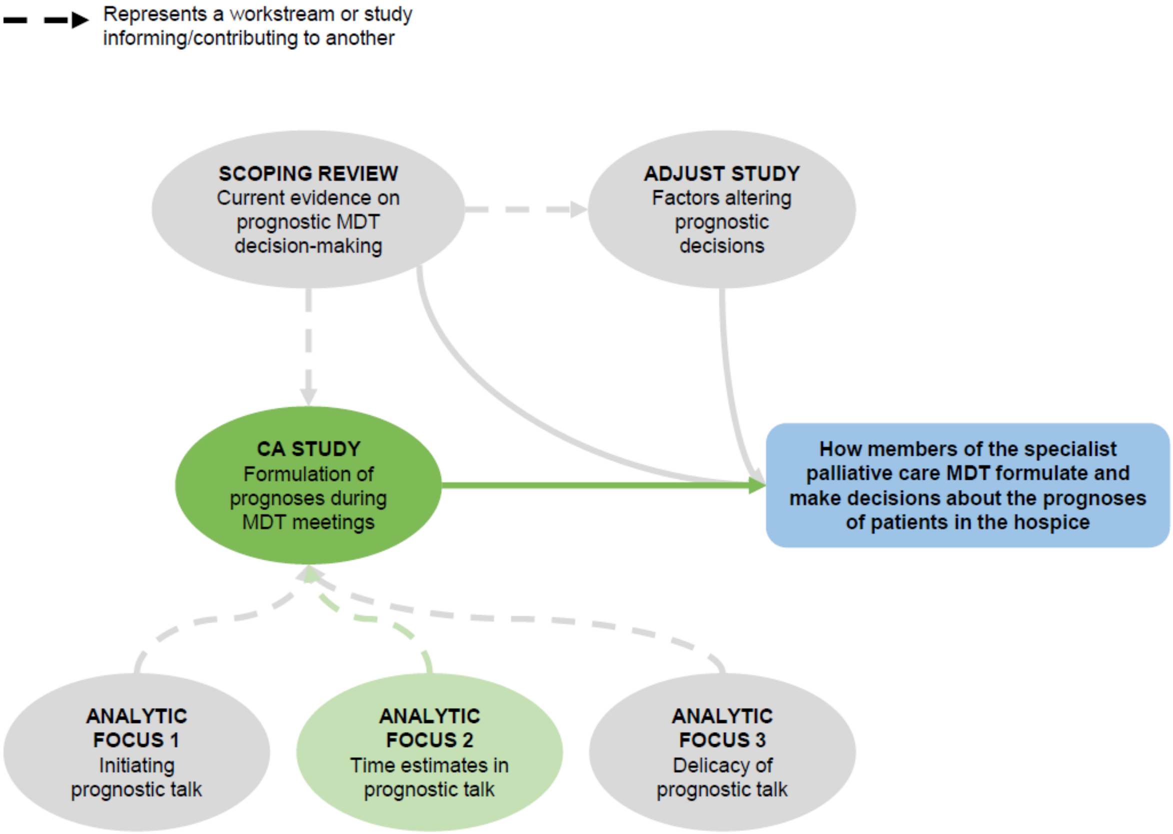
This chapter answered questions such as *when* or *in which context* does patients' prognosis occur during the meeting, which were the first step in order to understand how prognostic decisions are made within the hospice MDT.

Chapter 7 – Conversation analytic study: Time estimates in prognostic talk

7.1 Chapter overview

Following the chapter on initiating prognostic talk, this chapter focuses on the temporality of prognostic talk (see **Figure 7-1**). The chapter explores how time estimates are used when MDT members formulate patients' prognoses. The analysis identifies ways of using references to time that differ in specificity and recognisability, and how other team members respond to them.

Figure 7-1: Thesis outline diagram – CA focus 2



7.2 Introduction

An essential and important part of prognoses seems to be the aspect of time or temporality. This is clear when prognoses are being dealt with as questions about *how much time* a patient has left to live or *when* a patient might or is expected to die. But how is time or temporality in relation to prognoses being handled during the hospice MDT meeting?

In this thesis, "time estimates" are defined as utterances conveying temporality in relation to when patients are expected to die. This can be done through a direct time reference (TR). TRs have been defined as "the repertoire of social and linguistic resources available to members of a given society to indicate particular points on the timeline" (Raymond and White 2017: 111-12). An example of a TR could be "*she might die **today***" in which temporality is expressed using a specific time expression ("today"). Another way of expressing temporality could be by using a particular grammatical tense such as "*she **is dying***". In this sentence, temporality is expressed through use of a progressive present tense but without a specific time indicator. Instead, it refers to the sense being that the patient is dying *right now*. As it will be presented in this chapter, temporality in prognostic utterances can be done in different ways.

In order to understand what temporality means when predicting the future, it can be helpful to use a timeline continuum. On one end of the continuum is the present time, the *now*, whilst on the far other end of the continuum is the "indefinite" future (see **Figure 7-2**).

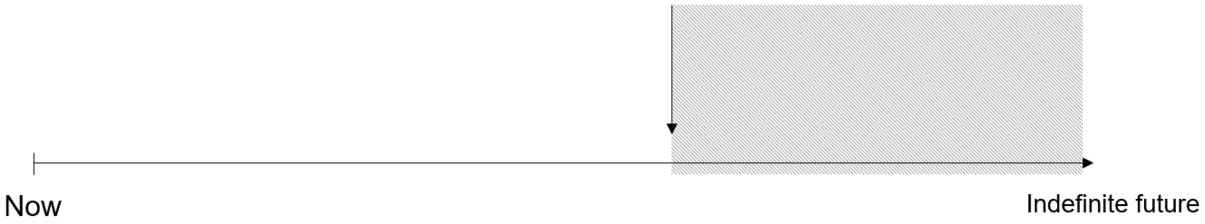
Figure 7-2: Timeline

There is, within reason, an indefinite amount of future time available for a prognostic estimate. As an example, an estimate could be that someone is dying within the next hour (very close to *now*) as in **Figure 7-3** below. Here the arrow indicates the time of death, and the grey marking from the arrow and onwards indicates the, now, unavailable future timepoints for that person.

Figure 7-4: Patient dying in an hour

A prognosis could also be further in the future for example if someone might die in 30 years. Then we would see a different picture of the continuum (**Figure 7-4**). In this case, the estimate leaves more "available" time for the patient (i.e., where the patient will be alive), and a lower amount of time that will be unavailable.

Figure 7-3: Patient dying in 30 years



Each of these estimates specifies a point on the timeline and hence narrows down the indefinite future. Estimates can be very specific such as when a prognosis is given as a certain date (e.g., Monday 25th of February). Such references to time are known as *absolute TRs* and have been defined as a reference form that is accessible to all through its use of shared constructs for parsing the timeline (Raymond and White 2017).

Time estimates can also be more vague and only specify a certain timeframe or time unit such as *weeks* (see **Figure 7-5**). These have been referred to as *absolute categorical TRs* (Anderson et al. 2020). In **Figure 7-5**, the space between the two arrows indicates a time period or interval that the patient is expected to die within. The patient is expected to die sometime from now until some weeks in the future. These types of formulations involve a degree of uncertainty due to the bigger pool of remaining options for when a patient might die than more specific formulations leave.

Figure 7-5: Patient having weeks left to live

Raymond and White (2017) have proposed a taxonomy of time referencing in interaction that spans from the aforementioned absolute TRs to *event-relative* ones that are dependent on the knowledge shared between parties. They introduce another thing to consider when analysing references to time, the notion of *recognitionality* (Raymond and White 2022). When speakers reference time, some references might invoke a great sense of recognisability, or, as the authors call it, recognitionality. References with a high level recognitiality are specific universal dates while low-level recognitional references are event-relative or simply vague and unspecific ones (Raymond and White 2017). For example, consider the difference between a TR stating a meeting time such as “Monday 24th of February” compared to one stating it as “in the near future”. However, it is important to stress that it is the participants themselves in the interaction who decide or express whether a TR conveys a satisfactory level of recognitionality (Raymond and White 2022).

In Chapter 1, it was shown from a more clinical point of view how clinicians articulate prognoses. These included continuous temporal predictions (e.g., certain number of days, weeks or months); categorical temporal predictions (e.g., 0 to 2 days, 3 to 7 days, or greater than 7 days); and probabilistic estimates of survival (e.g., the likelihood a patient dying in the next week or month) (Chu, White, and Stone 2019). After scoping the literature, there seems to be a paucity of research on how time is conveyed in interaction. A few studies have been conducted on references to time; for example, in psychotherapy as a way to manage coherence across multiple tellings within patient updates (Clark and Rendle-Short 2016) and the work by Raymond and White (2022, 2017). The latter provides the framework for this study. However, it has not yet been explored how references to time are used in relation to prognosis, and particularly how the hospice MDT uses time estimates when they discuss patients' prognoses.

7.3 Research question and methods

This study explored how temporality was expressed or used in prognostic talk. The research question was:

- How is temporality conveyed in relation to patients' prognoses during MDT meetings?

The method and analysis are described in Chapter 5. As part of developing this analysis, the data were discussed at an "office hour" meeting with Associate Professor Chase Raymond, University of Colorado Boulder, USA, who has done significant work on time estimates in interaction (see Raymond and White 2017, 2022). The office hour meeting was organised by the CORE-ILCA group, which is a community of early-career researchers in Interactional Linguistics and CA (https://coreilca.wordpress.com/). In the meeting, early-stage analyses were discussed and refined.

7.4 Results

The data revealed different ways in which participants referred to or conveyed temporality when talking about patients' prognoses. These included describing the patient's current state or the use of specific and unspecific references to time. Each of these ways is presented in the sections below.

7.4.1 Patients' current state

At one end of the timeline, there were formulations that involved professionals stating patients' current situation as dying. These cases seemed to describe a patient's current state, and therefore these formulations did not involve a future prediction of death *per se*. In these types of formulations death was mentioned as something that was happening in the moment, and the patient was (very close to) actively dying. These patient cases would also be the shortest for the team to discuss since they would often not involve consideration of interventions, treatment, or discharge plans.

In the excerpt below is an example of such a formulation, where a doctor (DR1) and a ward manager (WAR) discuss whether a patient should stay at the hospice. As it will be presented in the analysis below, a patient cannot be discharged if they are in a poor state that requires substantial (medical) interventions. Prior to this excerpt, a nurse had presented the patient, and she and other team members had been presenting "evidence" of the patient not doing well, implying that the patient was at the very end of life.

EXCERPT 6 – HE'S DYING (2021.05.19)

```
01    WAR:  okha:y (.) >so he's staying here< yea,
02          (0.2)
03    DR1:  yea: (.) he's dying.
04          (4.9)
05    WAR:  mka:y.
06          (2.2)
07    WAR:  PPC PPD here?
08          (0.3)
09    UNK:  ·th
10          (0.5)
11    NUR:  same [home home       ].
12    DR1:       [it's always been] home h[hh       ]
13    WAR:                                [oh really],
14    SOC:  yea:.
15    DR1:  unfortunately yeah.
16          (0.2)
17    DR1:  home home home.
```

The discharge discussion sequence begins in line 01 with the ward manager producing a declarative statement that summarises the prior discussion regarding the patient's poor state, *so he's staying here*. This is an A-statement about AB-events (Labov and Fanshel 1977), where the nurse (A) produces a statement about an event (the patient discussion so far) that is known to both the nurse and other MDT members (AB). This statement seems to seek confirmation from the recipients, where the final tag question, *yea*, seems to stress this by further seeking a response and confirmation from the others. The doctor treats the ward manager's utterance as a question and provides the confirmation in line 03. He expands his utterance and produces a declarative prognostic statement, *he's dying*. This statement seems to account for the doctor's confirmation, and after a long pause the ward manager confirms this statement followed by a question regarding the patient's

Preferred Place of Care (PPC) and Preferred Place of Death (PPD) in line 07, which are standard items on the MDT meeting template to fill in.

The prognostic utterance occurs in line 03 as a confirmation of the ward manager's summarising statement and tag question in line 01 about the patient staying in the hospice (until he dies). The prognosis then seems to account for the doctor confirming the ward manager's statement. From a grammatical point of view, the prognostic utterance contains the verb phrase *is dying* in present participle. This means that the patient is currently dying as they speak; the patient is dying *now*. There are no other references to time than that indicated by the grammatical tense of the verb. Moreover, a lack of words or other interactional markers implying uncertainty or empathy make the statement appear rather strong. This could have been displayed through additional words and formulations such as *I think* or *unfortunately/sadly he's dying* or through hesitation markers such as *uhm* and cut-offs. Lastly, the prognostic utterance receives a confirmation before the conversation moves on to deal with the patient's PPC and PPD. Here, the prognosis is further confirmed by the doctor's usage of *unfortunately* in line 15 that seems to orient to the fact that they will not be able to meet the patient's preference to die at home. As mentioned earlier, patients are not discharged if they are very close to dying. In this case, the patient can no longer be safely discharged due to their poor prognosis, which is unfortunate from a person-centred care point of view.

This excerpt showed how a prognosis was provided as an account for expressing agreement with the patient not being eligible for discharge. The prognosis did not involve providing a clear reference to time. Instead, it simply involved a professional identifying that a patient is (imminently) dying. This formulation of a patient's prognosis was confirmed by another staff member and thereby it was shown that such an expression was sufficient and acceptable.

This way of formulating a patient's prognosis, simply stating that a patient is dying, was one of the most common ways for MDT members to provide prognoses. They included variations such as "x *is deteriorating*" as well. They often occurred in response to the Phase of Illness item on the MDT template (as shown in Chapter 6).

7.4.2 Specific reference to time

In the data, there were a few occurrences of prognoses involving absolute references to time such as specific dates, days, or times during the day. Such time estimates appeared when the patient's prognosis somehow conflicted with another mentioned timeframe relevant to the patient's care plans.

Excerpt 7 below is from a discussion regarding the number of allowed visitors due to COVID-19 restrictions in the hospice. Just before the excerpt, a nurse has presented the patient, explains that she could not get much out of the patient, and states that he is deteriorating. She describes the patient's symptoms (breathless) and explains that they are starting him on a syringe driver. Lastly, she mentions that the doctor agreed for the family to come and stay with him, which has resulted in quite a long list of family members who want to visit.

EXCERPT 7 – HE'S GONNA DIE BEFORE MONDAY (2021.05.19)

```
01    WAR:  [that's a very la:rge list].
Line omitted
03    DR1:  £is it really£.
04    WAR:  it's (.) it's about,
05          (0.6)
07    WAR:  about ten to fifteen people.
08    DR1:  IS ↑IT↑
09    DR2:  mh ((nodding))
10    WAR:  yea,
11          (1.1)
12    DR1:  that went on a bit didn't it?
13    DR2:  ((laughter))
14    WAR:  [and they got   ]_
15    DR1:  [(xxx that) many],
16    WAR:  and they were standing in the corridor calling them all
17          being like ↑yea come on in↑.
18    DR1:  [hahahaha    ]
19    UNK:  [((laughter))]
20    UNK:  [(uh)        ]=
21    SOC:  =that's what they'd all been saying (.) yea (.) we found
22          that conversation with the son actually.=
23    WAR: =I've had it many times saying no and I said I did say to
24          him yesterday cause he asked me yesterday I said no (.)
25          not until Monday where then you can have six named.
26    DR1:  we we wor- (.) wor- he's he's gonna die before [Monday].
27    WAR:                                              [oh is ] he=
28    WAR:  =[gonna die] okay.
29    DR1:   [he: i:   ]
30    DR1:  so that's changed.
31    WAR:  maybe we need to: (.) scale it back [from that hav-]
```

```
32    DR1:                                      [ten to        ]
33    DR1:  fifteen is more than they said to us in the room.
```

In the beginning of the excerpt (lines 01-12), there is an exchange of assessments both from the ward manager (WAR) and the doctor (DR1) about this supposedly long list of visitors. This leads to the ward manager providing a short telling from lines 14-17 about how family members were calling other family members asking them to come into the hospice. A social worker (SOC) provides a statement agreeing with the telling from the ward manager explaining that they have experienced the same thing, and that they have had that conversation with a family member already (lines 21-22). This leads to the ward manager explaining that she has had that conversation with the family member several times and she even had it very recently (yesterday). At the end of her utterance, she reports how she told the family that they cannot invite people in until Monday, where they then can name six visitors. In line 26, the doctor produces the prognostic utterance *he's gonna die before Monday*. The ward manager then responds with a change-of-stake token *oh* (Heritage 1985) and then partially repeats the doctor's utterance. A change-of-stake token normally displays that a speaker has changed from somehow "unknowledgeable" to "knowledgeable". In other words, the ward manager now knows something that she did not know before, which is the patient dying quite soon. The doctor confirms his statement in line 29 and then explains that this is a change. This leads to the team discussing how they might ease the hospice visiting rules, allowing more visitors, since the patient is going to die soon.

In the prognostic utterance in line 26, the doctor provides an *uncounted absolute* TR by saying *before Monday*. This specifies that the time of the patient's death is to be expected within the next four days (the meeting being held on a Wednesday). However, it should be noted that it seems to be problematic to produce such a rather strong or specific TR with the utterance being initiated with several repetitions and cut-offs. The doctor restarts the utterance and ends up with a prognostic statement implying a strong sense of certainty by being able to provide such a specific reference to time. Moreover, the statement seems to be prompted by the ward manager mentioning new rules being in place from Monday in lines 24-25. The ward manager’s TR then leads the doctor to produce a similar TR, but this time about the patient’s prognosis. In this way the first TR elicits the second one that then points towards a specific problem with the prior turn; this specific part of the discussion (regarding anything from Monday and beyond) is not relevant in this case since the patient will not be alive at that time.

In this excerpt, a prognosis was formulated by using an *uncounted absolute* TR in line 26. It was shown how this statement indicated interactional trouble since it implied a natural higher sense of certainty than other types of (more unspecific) formulations. This strong and specific time estimate was prompted by another (non-prognostic) TR in the conversation (line 25) that makes the next (prognostic) TR relevant (line 26). When another more specific TR was used, this might lead to a similar one – either challenging or not-challenging whether this was relevant for the current situation. In this way, a specific absolute TR could constrain the discussion and make certain future events and actions (ir)relevant, prompting the need to provide a similar specific absolute prognostic TR.

The same pattern was seen in another excerpt. In Excerpt 8 below, the team discusses a patient who wants to be repatriated when she dies. This has led the MDT to discuss what they should do in case the patient dies overnight. There seems to be some time sensitivity regarding getting the patient’s body out of the hospice as soon as possible after death. However, they mention that they cannot release patients’ bodies without death certificates. There seems to be some issues related to getting the doctors to come in during the night to sign the certificate, where it has been mentioned that the family will have to wait until the morning. The social worker (SOC) has been exploring the option of getting on-call registrars to sign the certificate.

EXCERPT 8 – WE’RE MORE TALKING ABOUT TONIGHT (2021.09.15)

```
01    SOC:  so I spoke to ((name)) before the MDT (.)
02          and I said ((name)) (.) that if eh
03          eh if ((name)) dies over the wee[kend].
04    NUR:                                  [yeah],
05          (0.2)
06    SOC:  u:hm our doctors will come (.) on the
07          sunday (.) not overnight and then they'll
08          do the medical death certificate then they
```

```
09          (post x).
10          (0.5)
11    DR2:  but I don't think she's gonna make it to
12          the weekend we're more talking about (.)
13          tonight [it's more after agreement at this point].
14    NUR:          [it's it's about overnight              ] yeah,
15          (0.3)
16    DR2:  u[:hm  ]_
17    NUR:   [cause] uhm_
18          (0.6)
19    NUR:  cause obviously ((name)) made that decision
20          she_
21    CNS:  [I      ] kno[:w (that)].
22    NUR:  [because]    [yeah     ] you know all
23          about that and then (and) but then was
24          ((name)) saying that should never have
25          [happen]ed (.) so we're all a kind of bit=
26    DR2:  [yeah  ].
27    NUR:  of [where we need to have a                        ]
28    DR2:     [well I think ultimately it's kind up to ((name))]
29          (0.2)
30    DR2:  management [so I] guess we'll have to talk
31    CNS:             [yeah].
32    DR2:  about it after the MDT.
```

The social worker explains that she has spoken to the registration office about getting doctors to sign the death certificate (lines 01-09). She mentions that if the patient should die over the weekend, then the doctor will come on the Sunday, but not overnight. After something uninterpretable and a longer pause, the doctor (DR2) provides the prognostic utterances in lines 11-13. He states that he thinks the patient will die before the weekend. The doctor states that they are more talking about the patient dying tonight, which receives confirmation and agreement from a nurse (NUR). The doctor's statement conflicts with the information that the social worker has provided and makes it appear less relevant to the current situation. This statement seems to repair some interactional trouble with the social worker's information, where the doctor corrects the social worker's utterance involving a certain (wrong) timeframe/prognosis by clarifying what the actual (right) timeframe/prognosis is. However, the social worker does not respond to this information. Instead, the nurse continues with explaining the patient's wishes and a previous unfortunate case they had. Then she, in line 27, produces an incomplete utterance, *where we need to have a*. This might refer to some kind of procedure or guideline for what to do in this situation. The doctor then states it is up to someone (probably the medical director) and/or management. The excerpt ends with the doctor proposing that they will have to talk further about it after the MDT meeting.

In this excerpt, the doctor produced two prognostic utterances following each other in lines 11-13. His first prognostic utterance contained the TR and was produced as a response to the TR produced by the social worker. The doctor said that the patient would die before the weekend (the MDT meeting being held on a Wednesday) and thereby provided a rather specific reference to time; the patient would die sometime from the time of the interaction until the weekend. This prognostic utterance conflicted with the TR that the social worker presented about what to do if the patient died over the weekend. In this case, the doctor implied that this procedure or scenario was not relevant because the patient would die before then. The doctor then produced a second TR, where he said that they were talking about the patient dying *tonight*. In this way, he upgraded the prognosis by making it even more specific. Through this utterance he narrowed the timepoints available for the patient from “before the weekend” to “tonight”. This then became an even more specific reference to time. This prognosis received confirmation from another team member and resulted in the team having to postpone making a decision about this matter since they needed management input.

These two excerpts showed how another non-prognostic TR made a prognostic TR relevant in the interaction. The first non-prognostic TR prompted the prognostic TR due to a conflict of time. The first non-prognostic TR would specify a timepoint relevant to the patient’s care plans that clashed with the patient’s actual prognosis. In these cases, the proposed plan of action that involved the non-prognostic TR was irrelevant because the patient would be dead before then. For this reason, a prognostic TR was provided to change the course of action due to the conflict.

It is important to note that the specific TRs presented in the two excerpts were still rather vague in terms of indicating the exact time of the patient’s death. In Excerpt 7, the prognostic utterance was “*before* Monday” and in the other excerpt it was “tonight”. These two formulations still left several available timepoints where the patient could die. In the first example, the patient could die anytime from the time of the interaction until the Monday. In the second example, the patient could die anytime during the evening/night depending on how *tonight* is defined timewise (e.g., from 17.00-04.00). In this way, these references clearly defined a timeframe for the patient's death, but further specification did not occur.

7.4.3 Unspecific reference to time

The third way that MDT professionals conveyed temporality was through unspecific references to time. In this category, utterances did not include a specific timepoint or the references were somewhat vague. In these types of formulations, it was not clear where the exact timepoint on the timeline would be. This meant that it appeared uncertain when the patient was expected to die. This was the most common way for professionals to convey temporality when providing prognoses.

In the data, there were several ways of making unspecific references to time. In the excerpt below, a doctor (DR2) uses the formulation *her prognosis is short*. It should be mentioned that the chaplain (CHA) is chairing this meeting.

EXCERPT 9 – HER PROGNOSIS IS SHORT (2021.09.29)

```
01    CHA:  we: have her as unstable at forty?
02          (.)
03    CHA:  is [that]_
04    UNK:     [(hh)]
05          (0.9)
06    WAR:  ye[a  ] because we are still having (.) some=
07    NUR:    [mh.]
08    WAR:  =intervention and all.
09    DR2:  yea: [it dep]ends on what her response to the=
10    WAR:       [so s: ]
11    DR2:  =[anti]biotics is if she's still getting sicker (.)
12    DR1:   [mh. ]
13    DR2:  after she's had a few days >of antibiotics< than she
14          (0.6)
15    DR2:  (might) be deteriorating but at the moment we wou- (.)
16          she's better than she was when she was septic.
17    CHA:  right.
18          (0.1)
19    DR1:  yea.
20    DR2:  so we just need to see (.) but she's not her prognosis
21          is short.
22    HCA:  yea.
23    DR2:  and something either a big blee:d.
24          (0.5)
25    DR2:  it was okay but (that having) (.) or (.) you know
26          (an overwhelming) infection will kill her soon.
27          (1.2)
```

This sequence begins with the chaplain asking whether it is appropriate that they have recorded the patient as *unstable at forty* (i.e., unstable phase of illness and Karnofsky performance status of 40%). The ward manager (WAR) confirms the chaplain's question and accounts for the patient assessment. A doctor (DR2) further accounts for this and explains why the patient is recorded as "unstable", which is due to the patient receiving antibiotics (lines 09-16). This account includes the doctor expressing uncertainty about whether the patient is deteriorating or not. This is confirmed both by the chaplain and another doctor (DR1) in lines 17-19. In the beginning of line 20, the doctor (DR2) then provides a statement orienting towards the uncertainty, *we just need to see*. This leads to the prognostic utterance, *but her prognosis is short*. This utterance is confirmed by a healthcare assistant (HCA). The doctor then provides an account explaining other potential trajectories for the patient in lines 23-26. After the excerpt, the participants continue talking about the difficulty with and uncertainty of this patient's case.

The doctor explains that the prognosis (i.e., phase of illness and Karnofsky performance status) is dependent on the patient's response to the antibiotics in lines 09 and 11. This seems to preface and indicate an uncertainty of the disease trajectory, where more information is needed to provide a more specific prognostic estimate. In lines 20-21, the doctor produces the prognostic utterance with the unspecific reference to time, *her prognosis is short*. This reference does not specify a timepoint when the patient is expected to die. Instead, this statement indicates a length for the patient's prognosis, which relates to the time the patient has left to live. It does not further specify the amount of time left, indicating uncertainty. The utterance is initiated with the word "but" that normally introduces sentences that contrast with something. Moreover, the utterance begins with *she's not*, but this project is abandoned, and instead the prognostic formulation occurs. In lines 15-16, the doctor states that the patient is doing better, which might indicate a better prognosis. However, the prognostic utterance in lines 20-21 downgrades this by stating that the patient's prognosis is indeed short. In this way, the doctor potentially ensures that there is no misunderstanding regarding what the outcome of *so* *we need to see* will be. This utterance is confirmed by the healthcare assistant, who seems to agree with DR2’s prognosis.

In Excerpt 9, an unspecific reference to time occurred. This reference indicated that the patients’ prognosis was short, but it was not clear for the analyst what period of time “short” was supposed to indicate. Going back to the timeline presented earlier in the chapter, it did not indicate a clear point on it, but instead it was a vaguer reference to time. However, this formulation was not challenged by co-participants seeking a more recognisable and specific timeframe. This lack of seeking recognitionality potentially indicated that there was a shared understanding between MDT members around what a short prognosis meant – and moreover what it meant in that specific context, for this specific patient. This was an argument for prognostication being a context-sensitive practice dependent on the information and knowledge shared between members regarding the patient’s disease trajectory.

In the excerpt below is another prognostic discussion, where four occurrences of references to time occurred. The excerpt displays how unspecific references can be more or less unspecific, ranging on a continuum. However, none of them indicate a specific timepoint on the timeline. Prior to this excerpt, a doctor (DR1) has asked another doctor (not speaking in the excerpt) and a nurse (NUR) for their thoughts about whether the patient might stay in the hospice.

EXCERPT 10 – NOT HAVE LONG TO GO (2021.05.09)

```
01    DR1:  but going back to (.) the question about where she goes.
02    DR1:  °I mean° she's clearly not gonna be able to look after
03          herself now.
04          (0.5)
05    NUR:  no.
06          (0.2)
07    DR1:  and even if she had four times daily carers,
08          (0.4)
09    DR1:  she won't be able to manage.
10          (0.3)
11    DR1:  so:,
12          (0.3)
13    DR1:  so either a nursing home.
14          (1.5)
15    DR1:  or it's here.
16          (0.6)
17    DR1:  and I agree I think she's declined.
18          (1.2)
19    DR1:  functionally anyway she declined very quickly.
20          (1.6)
21    DR1:  so:.
```

22 (0.3)
23 DR1: I suspect she wi:ll.
24 (0.7)
25 DR1: not have long to go,
26 (0.5)
27 DR1: she's talking a little bit like that too,
28 (1.7)
29 NUR: yea even today just uh when ((name)) came to the room.
30 (0.2)
31 NUR: she got two or three teddy bear uh saying this one
32 go with me in the box (.) when I'm going.
33 DR1: wow.
34 (0.5)
35 DR1: okay.
36 (1.2)
37 DR1: so uhm.
38 (3.5)
39 DR1: °we will see°.
40 (1.5)
41 PHY: are we talki:ng (.) °weeks:°?
42 DR1: maybe.
43 (0.9)
44 UNK: ((sniffle))
45 DR1: yea:.
46 (0.3)
47 DR1: I do I certainly don't think it's months.
48 (0.8)
49 PHY: no,
50 (0.2)
51 DR1: [weeks but how many weeks I don't know].
52 NUR: [( )] huh?

The doctor redirects the talk back to the question about where the patient goes in line 01, which is followed by a statement about the patient's current state, *she's clearly not gonna be able to look after herself now*. This statement is confirmed by the nurse in line 05, where *no* in this case confirms the negating statement by the doctor. Lines 02-03 combined with his statement in line 07 forms an argument against discharging the patient to her own home; *she won't be able to manage*. The doctor then presents the remaining options; either a nursing home or that the patient stays at the hospice (lines 11-15). This prompts a presentation about how the doctor sees the current state of the patient, including the fact that he agrees with prior talk about the patient's decline (lines 17-19). This leads to the doctor providing a statement about the patient's prognosis, *she will not have long to go* (lines 23-25). This statement appears vague with the word *suspect*, implying some level of uncertainty, which might be the reason why he adds that the patient might agree with this (line 27) potentially accounting for this statement. In the next lines (lines 29-32), the nurse displays affiliation and provides more evidence for the doctor's statement about the patient’s awareness of her own prognosis. The doctor produces a receipt that seems to express surprise about the nurse’s telling (line 33) and concludes that they will have to wait and see (line 39), the latter further underlining the presence of prognostic uncertainty.

In this sequence, the doctor provided an unspecific reference to time in lines 23-25. The prognosis expressed some sense of uncertainty through the word *suspect*, while the word *will* implied a stronger sense of certainty as opposed to a word such as *might*. However, while the word *suspect* did imply uncertainty, one could argue that it might actually strongly imply that something will happen. The exact reference to time occurred in line 25, *not have long to go*. This reference did not indicate a specific timeframe (e.g., referring to a certain time or date) despite this being what *not have long to go* might be considered to imply. It only conveyed that the timeline was *not long* but was unclear about the duration of time, which displayed a low level of recognitionality. However, there seemed to be shared knowledge about what *not have long to go* implied between staff members, which was displayed by the nurse affiliation in lines 29-32 and the lack of members challenging or questioning what *not having long to go* implied.

In this excerpt, a request for clarification regarding the proposed prognosis occurred as well. In line 41, a physiotherapist (PHY) asks a yes/no question, requesting clarification regarding whether the patient has weeks left to live. This question seems to aim at getting a more specific prognosis for the patient involving a certain timeframe. The doctor says maybe (line 42), neither confirming nor rejecting the question. He follows up with a *yea* and then a statement rejecting that the patient certainly does not have months left to live, rejecting a longer timeframe than the physiotherapist initially proposed. Then he confirms the original request from line 41, moreover stating that he cannot provide a more specific prognosis; *how many weeks I don’t know*.

In the second half of the excerpt, the first reference to time was produced by the physiotherapist in line 41, where it was seen that the absolute categorical *weeks* was used in a request. The request pursued a more recognitional reference to time than the *not have long to go*-statement by asking about whether they were working with *weeks*. However, the request did not involve specifying the number of weeks. In this case, the clarification that the physiotherapist requested did not involve the number of weeks but just whether *weeks* was the appropriate unit in this case as opposed to other units such as *hours*, *days*, or *months*. Lastly, the absolute categorical reference was vaguely confirmed by the doctor in line 45.

The third reference to time in line 47 was also an absolute categorical one; *months*. This utterance occurred after the doctor had vaguely confirmed the physiotherapist's request and then he rejected the *months* unit as being appropriate for the patient's current situation. This utterance also confirmed that the doctor did not perceive the physiotherapist's request from line 41 as a request for a specific number of weeks but indeed was about whether *weeks* was the appropriate unit. Lastly, this third reference to time displayed a strong level of conviction with the word *certainly*.

The final reference to time in this excerpt occurred at line 51. Here, *weeks* was repeated, stressing that this was the appropriate unit. However, with this utterance, the doctor also stated that he did not know how many weeks they might be working with. This rejected his ability to provide a more recognitional reference to time such as one including a specific number of weeks. It should be mentioned that line 51 could be seen as the doctor actually treating the physiotherapist's request from line 41 as seeking a specific number of weeks. However, the sequence ended there, and the team started talking about other matters.

There seemed to be a shared knowledge of what different references to time implied in-between hospice staff members such as the phrase *not have long to go*. The physiotherapist's question challenged this uncertain and rather vague statement. However, it was being done in a way that still oriented to the lack of being able to provide more specific references to time (e.g., a certain date or number of days/weeks). Instead, the participants were operating with and accepting absolute categorical references. It appeared to be easier for professionals to work with these types of categories in which for example the doctor displayed strong certainty when rejecting a longer timeframe (i.e., months). Even though these references appeared to invoke low recognition for people outside of the interaction, these references were not further challenged or discussed between the participants. This seemed to display a shared knowledge (or uncertainty) between staff members, acknowledging the inability of providing more specific references to time.

7.5 Discussion

7.5.1 Main study findings

In this section, different ways that professionals convey temporality when providing prognoses of dying patients during hospice MDT meetings were presented. This could be done by describing the patient’s current state as dying or by using either specific or unspecific references to time.

Most formulations involved a staff member simply stating that a patient was deteriorating or dying as part of the patient’s current state of affairs. These formulations did not include a reference to time *per se* but were describing the patient’s current situation (as dying) instead. Rarely, specific references to time were used. These references occurred where another specific reference had been provided before that constrained the time frame, where the patient’s death would occur and create conflict with other care plans. Staff members would instead use unspecific reference to time, where it appeared vague when the patient was expected to die.

Across the different practices of conveying temporality, it was seen that they were most often confirmed by minimal responses from other MDT members. This advocated for acceptance of these references due to lack of other team members challenging or pursuing different (more specific) references to time and implying shared knowledge between staff.

7.5.2 Discussion in relation to other findings

The results showed that MDT members do not operate with absolute references to time such as specific dates or certain timepoints. The most common way for MDT members to provide prognostic time estimates is through unspecific reference to time. Although unspecific references to time are a distinct category of prognostic estimates, the other two categories also appear rather vague and unspecific. Even when it is stated that a patient *is* *dying,* this is an indication that a patient is considered to be imminently dying – rather than indicating that the patient is dying in the exact moment that the utterance is being produced. Similarly, the specific references to time are “only” specific in the sense that they indicate a timeframe in which the patient is expected to die. Whilst this type of reference narrows the available timepoints on the timeline, it still leaves multiple timepoints available in which the patient could be expected to die. In this way, there seems to be a continuum of reference specificity present.

The results imply that prognostication involves an underlying uncertainty and maybe inability (or reluctance) to provide a more specific timeframe. This notion of uncertainty has also been found in research about how professionals discuss prognoses with patients’ relatives (Anderson et al. 2020). It has also been noted that it might be difficult emotionally to provide a specific number when making temporal predictions of survival (Hui 2015). This seems to underline the impact of the emotional aspect when having to make such decisions, which may be further explained and explored by the emotion-imbued choice model (Lerner et al. 2015). Describing the patient’s current state might be easier for professionals, where it has been stressed that doctors believe that there is inherently more uncertainty associated with predicting the future than with determining the patient’s present state (Christakis 1999). This might explain why MDT members often used time estimates in relation to the current state of the patient.

Another aspect to consider is that using rather unspecific and vague references leaves the prognosticator less accountable for the prognosis given. Providing a specific time estimate such as “on Friday” also comes with the risk of being held up on the precise prediction. Specific estimates are either true or not in the strictest sense; if the patient is still alive at 00.01am on the Saturday, then the prognosis was wrong. Using unspecific estimates with multiple possible timepoints where the patient could potentially die, and thereby implying a low level of recognitionality, leaves less space for other professionals to hold the prognosticator accountable for the prediction. In this way, the professional might be “covering their bases” by providing unspecific prognoses. By limiting the available timepoints and specifying a time, the professional can be held more accountable for the prediction. Comparing this with the formulations introduced earlier (continuous and categorial temporal predictions and probabilistic estimates), a sort of continuum seems to take form as well. Continuous temporal predictions such as a certain number of days, weeks, or months project a high level of accountability whereas proving the likelihood of a patient dying in the next week or month (probabilistic estimates) projects less accountability for the prognosticator. This advocates for taking the aspect of accountability, together with the format of the reference to time and the level of recognitionality, into account when dealing with prognostic time estimates in the MDT meeting.

These findings contrast with the (often quantitative) literature working with trying to accurately predict when patients are going to die (see White et al. 2016). In the hospice MDT meeting, staff members did not display an orientation towards predicting patients' *exact* time of dying as a priority or necessity. As noted previously, it was rare for other staff members to pursue a specific timeframe or challenge the prognosis given. In this way, these findings show a different picture of what prognostication looks like in clinical practice.

The fact that the professionals most often accepted the proposed prognosis and did not request a more specific one might suggest that there is a shared understanding between professionals. Even in the rare cases where clarification was sought, it was still done in a way that oriented towards an acceptance of uncertainty and inability to provide specific timepoints. Here the importance of using next-turn proof procedure (Edwards 2004) becomes highly relevant. It is the speakers and the participants themselves that decide what is a meaningful and (non-)acceptable reference to time for them (Raymond and White 2022). In this way the notion of recognitionality can be rather intangible from an analytical point of view, since CA does not attempt to get into the minds of speakers (Maynard 2012). Thus, if it is not apparent from the interaction that a reference to time appears inadequate for the speakers due to a lack of recognitionality for the analyst, then this would be poor analytic work. Recognitionality is context-sensitive and something that the *speakers* either accept or challenge (Raymond and White 2017). The results did show that despite the references appearing vague from a temporality point of view, this was not a problem for the participants themselves.

The results suggest that uncertain, unspecific, and vague references to time are sufficient for the activity being carried out. It might be that this shared understanding and institutional knowledge of palliative care patients and their disease trajectories combined with an acknowledgment of the difficulties of providing more specific time estimates, makes these vague references acceptable and meaningful for the speakers. Moreover, this raises the question about whether more specific references to time are needed in this specific context. This will be discussed in greater detail in the overall discussion chapter of the thesis.

7.6 Chapter summary

In this chapter, the thesis continued with exploring how members of the specialist palliative care team formulate prognoses during MDT meetings. Since prognostication inevitably involves *temporal* predictions of patient survival, the focus was on how time estimates were used in prognostic utterances. The chapter described three ways that MDT members conveyed temporality in their prognostic utterances (i.e., describing the patient’s state as dying, using specific or unspecific references to time) and showed how recipient team members most often confirmed or accepted the utterances.

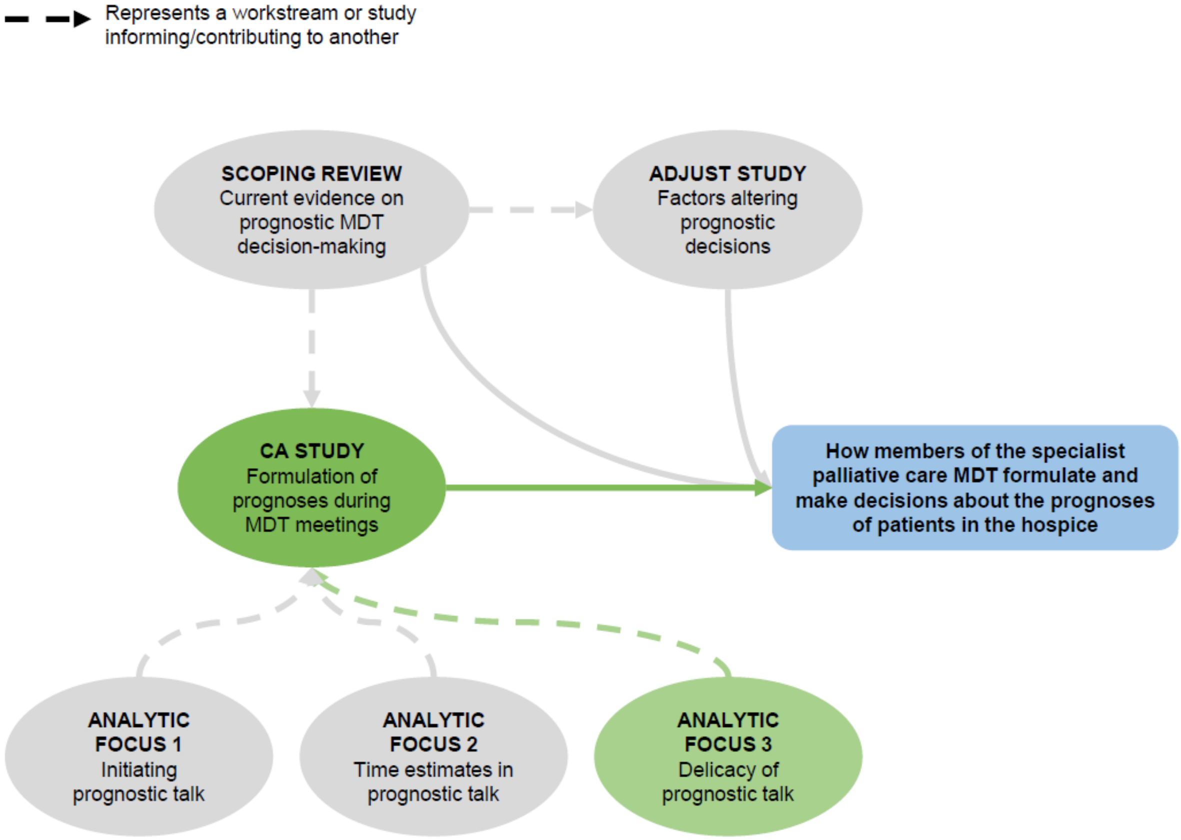
By exploring how references to time were used in prognostic utterances, the thesis gained insights into how MDT members frame and construct prognoses during their team interactions.

Chapter 8 – Conversation analytic study: Prognostication as interactionally delicate work

8.1 Chapter overview

This chapter explores how prognostication is an interactional, sensitive, and delicate matter during the MDT meeting. Different markers are identified that indicate interactional delicacy related to providing a patient's prognosis.

Figure 8-1: Thesis outline diagram – CA focus 3



8.2 Introduction

Death and dying are often seen as cultural taboos that are difficult or delicate to discuss. This has been seen in both everyday interaction (Holt 1993) and palliative care settings. Several studies show how clinicians employ different communicative strategies that orient to the sensitive and delicate matter of these discussions (Parry, Land, and Seymour 2014; Pino et al. 2016; Pino and Parry 2019b; Ekberg et al. 2021). As noted previously, the evidence focuses on how professionals talk about death and dying with either patients or their relatives. These interactions are often characterised or looked at as cases of "bad news" delivery (see Maynard 2003). Since the focus of this thesis is on how MDT professionals discuss dying and prognoses, this removes the bad news delivery aspect. Staff members of the hospice MDT are used to dealing with and discussing death and dying as this is an essential part of working in a hospice. However, whether there is an orientation to death and prognoses as being delicate matters in this interactional setting is an unexplored topic.

8.2.1 Interactional delicacy

Despite being a cultural taboo, topics are not necessarily pre-labelled as being sensitive or delicate in interaction. It is the speakers themselves that orient to them as being so. This means that it is through the interaction that the speakers will display an orientation to something as being a sensitive or delicate matter. In this way, delicacy is something that is locally oriented to and managed by participants (Silverman 1997). In a study about how sexuality was discussed during gynaecological consultations, the authors reported that strategies such as delay, avoidance and depersonalisation were applied to navigate delicacy (Weijts, Houtkoop, and Mullen 1993). This has been labelled as "expressive caution" (Silverman 1997). Expressive caution can mark delicate objects through delay, various speech perturbations, and elaborations and story-prefaces to mark and manage these delicate items (Silverman 1997). Delay can for example be a pause in the interaction occurring before a delicate term (Silverman and Peräkylä 1990) or through a hesitation marker such as *uh(m)* (Lerner 2013). Pauses or silences are often seen as indicators of interactional trouble due to turns normally being produced without gaps and overlaps in order to minimize silence between turns (Sacks, Schegloff, and Jefferson 1974). Another way of displaying orientation towards delicacy and sensitivity can be through indirect formulations (Traverso, Ticca, and Ursi 2018). Certain expressions are known for indicating interactional "trouble" such as *well*-prefaced responses (Lerner and Kitzinger 2019). Laughter can also be used to display delicate orientations to potentially embarrassing or troublesome issues (Beach and Prickett 2017). Lerner (2013) provides a brief overview of other strategies such as explicitly attending to the delicacy of an expression, whispering, or using a softer voice, and euphemistic formulations.

Generally, they mention that self-repair can indicate delicacy and sensitivity in interaction. Within CA, *repair* generally orients to potential *issues* with speaking, hearing, and understanding talk (Schegloff, Jefferson, and Sacks 1977). Self-repair is when the speaker themself deals with some kind interactional trouble in their own talk.

When considering interactional delicacy or sensitivity, it can also be relevant to look at accounts. Providing an account is the procedure of explaining the reasons for performing some action. In interaction, situations are often encountered in which participants are doing accountable actions in need of explanation, clarification, or justification (Nielsen 2009). However, it is interesting to investigate *when* and thereby *what* people account for, and what that conveys about the interaction. By looking at when a speaker provides an account, it can potentially be identified when something is not entirely straightforward – when something yields to be handled in a way that requires explanation, clarification, or justification. For example, Stokoe (2010) showed how participants treat some relationship histories as more accountable than others in her study on speed-dating interactions. Here it is again the speakers themselves that display that something is accountable and therefore indicating that something potentially problematic is present.

In summary, it is speakers themselves that constate something as delicate and sensitive through the specific interactive practices used in introducing, pursuing, and closing the business at hand in the interaction (Yu and Wu 2015). Therefore, there is a need for closely examining the interaction to uncover *when* and *how* the speakers treat certain topics, actions etc. as sensitive and delicate. The presented strategies described above all display that something in the interaction is not straightforward. They all relate to additional interactional work being employed to mitigate something potentially problematic and in the interaction. This definition of delicacy will be used throughout this chapter and the rest of the thesis.

8.3 Research question and methods

This particular conversation analytic study explored how hospice staff members oriented to prognostication as being a sensitive and delicate matter. The study was guided by the following research question:

- How do hospice staff members display an orientation to prognostication as being a sensitive and delicate interactional matter?

The methods and analysis are described in Chapter 5.

8.4 Results

Different features of hospice staff members' talk displayed an orientation to prognostication as being a sensitive matter. The data revealed that certain markers were present, which included pauses and self-repair organisation such as cutting off words and restarts. As noted in previous chapters, prognostic utterances also often occurred with statement-assessment sequences accounting for the prognosis. These all indicated that prognostication was not a straightforward action to do. Each of these markers are described in the sections below.

It should be noted that the features presented above overlap a great deal. In this way, there will both be delicacy markers, accounts, and display of non-straightforwardness in each of the analyses. However, the focus will be on only one feature of each excerpt in order to highlight them individually.

8.4.1 Delicacy markers

To display the occurrence of delicacy markers, a specific part of an excerpt from Chapter 6 (see Excerpt 4 below) is revisited. In this excerpt, the doctor (DR2) mentioned the patient's prognosis and redirected the talk back to the subject of DoLS.

EXCERPT 4 – SHE'S A DYING WOMAN (2021.12.08)

```
50    DR2:  [I me- ] my: (.) my impression I- I- I feel like a dols
51          might (.) I think she's dying.
52          (0.2)
53    DR2:  she's #dying# °[immi]nently and°_
54    DR1:                 [yeah].
55    UNK:  ↑yes↑.
56          (0.3)
57    DR2:  I s- she's got extensive brain mets (.) which are
58          pressing on both (x) things which (can make this kind
59          of) behaviour really abnormal at times as well as (.)
```

```
60          really difficult symptoms of sickness (and things).
```

In the first line (line 50), the doctor initiates an utterance with a cut-off phrase *I me-*. This is followed by a prolonged *my:* and a short pause. Then she produces *my impression* which would be expected to project a verb such as *is*. However, she abandons this project and provides three cut-off *I*s followed by the verb *feel*. Here the doctor is presenting a feeling about the DoLS, but this project ends early with another incomplete sentence; *a dols might*. After another pause, she says that she thinks the patient is dying. This time the doctor is using the verb *think* which implies an opinion or thought. In line 52, another pause occurs, and then she states that the patient is dying imminently. The word *dying* is said with a creaky voice and the rest of the utterance is produced with low speech volume. The utterance ends with an *and,* which, as a conjunction, is highly projective. The doctor continues in line 57, where she after a restart provides a statement-assessment sequence that accounts for her prognostic utterance in line 53.

In this excerpt, the doctor ended with a rather strong prognostic utterance in line 53, however before arriving at this utterance, there had been several markers of interactional trouble. There were multiple occurrences of self-repair such as cutting off words, restarting utterances, and several pauses as well. There were also other linguistic indicators that oriented to interactional trouble such as the shifting between formulations that related to the doctor's assessment of the patient (*my impressions*, *I feel*, and *I think)*, creaky voice and low speech volume. Lastly, the doctor ended with a statement-assessment sequence accounting for the prognosis. In this way, there were several markers or indicators of interactional delicacy in the interaction when providing a patient's prognosis.

8.4.2 Accounts

The data revealed that prognoses were often formulated with additional information accounting for them. This was often done through statements and assessments of the patient's state. This led to the introduction of the statement-assessment sequence in Chapter 6. The statement-assessment sequence consisted of statements about and/or assessments of the patient where several observations, symptoms, assessments and sometimes interventions were listed, collating information about the patient's state. These sequences often functioned as accounts when occurring either before or after prognostic utterance.

In Excerpt 11, the nurse (NUR) begins her presentation of the next patient.

EXCERPT 11 – SHE'S REALLY TAKEN A DIP (2021.11.17)

```
01    NUR:  ((name)) uhm sixty five year old ↑lady↑ she's been with
02          us for a while now_
03          (0.3)
04    NUR:  u:hm so_
05          (0.6)
06    NUR:  what matters to ((name)) today so she wants to go
07          home and: the pain to be gone.
08          (0.3)
09    NUR:  ((name)) is now actually not even deteriorating >would
10          we< say dying?
11          {(0.5)
      DR1:  {nods
12    DR1:  #yeah#,
13    NUR:  ((name)) [yeah] she's been really_
14    DR1:           [yeah],
15          (0.3)
16    NUR:  it started end of my shift yesterday evening and
17          overnight she's really taken a dip.
18          (0.1)
19    NUR:  and we [start- co]mmenced on a syringe driver today.
20    CHA:         [°okay°   ].
21          (0.3)
22    NUR:  I think she (.) probably be a smatter of days really
23          [from now].
24    DR1:  [mh:     ],
25          (0.2)
26    DR1:  yeah,
27    NUR:  she's o- she's barely barely (.) talking cannot even
28          hear us: she's really (.) gone downhill_
29          (0.5)
30    DR1:  so I'd say dying (.) tw- twenty?
31    UNK:  mhh.
32    DR1:  yeah,
```

The nurse begins the presentation by mentioning the patient's name, age, length of admission, and then the patient's What Matters to Me. In line 09, she produces a prognostic utterance, where she states that the record of the patient's Phase of Illness is not "deteriorating", where she asks the team whether they should say "dying" and thereby change the phase. The doctor (DR1) confirms and agrees with the nurse through nodding and her *yeah* in lines 11-12. The nurse then mentions that the patient's decline started the evening before, and that her condition has gotten worse overnight. Here, the nurse initiates a statement-assessment sequence, where she shares her observations and assessments of the patient. This sequence seems to account for why they should change the Phase of Illness. She continues by mentioning that they have started the patient on a syringe driver (line 19). This leads to her producing a second upgraded prognostic utterance, where she says that she thinks the patient has a small number (*smatter*) of days left to live from now. Her prognosis receives confirmation from the doctor in both line 24 and 26. The nurse then provides another short statement-assessment sequence where she says that the patient is barely talking and cannot hear the staff, which implies that the patient has deteriorated. This seems to provide evidence of the patient's poor state and thereby account for the provided prognosis. Lastly, this leads to a proposal of changing the record of the patient's Phase of Illness and KPS score, which the doctor confirms. After the excerpt, the nurse continues with the patient presentation and lists the patient's diagnosis and main issues.

In this excerpt, there were several occasions where the nurse accounted for her prognostic utterance. The nurse provided a statement-assessment sequence after having proposed that they should change the record of the patient's Phase of Illness. After providing her second prognostic utterance, the nurse again accounted for the prognosis through another statement-assessment sequence. This displayed an orientation to and treatment of prognosis as something that needed to be explained or justified in (clinical) evidence. Here, the evidence was the nurse's observations and assessments. This became even more clear, when the nurse simply could have continued with the update of the Phase of Illness and KPS score (as seen at the end of the excerpt) after the doctor's confirmation. Instead, she accounted for the change and her proposed prognosis. Returning to the update of the record after having provided several justifications for the change displayed that the nurse treated this as something needing to be accounted for.

This section showed how participants displayed an orientation to and treatment of prognosis as something needing to be based on clinical evidence. It was shown how evidence such as observations and assessments were used to justify and therefore account for the provided prognosis. The evidence was often provided through the statement-assessment sequence with multiple utterances describing the patient's state.

8.4.3 Prognostic request as non-straightforward

So far it has been shown how delicacy markers and accounts display an orientation to prognostication as being a sensitive action. As noted earlier, this implies that prognostication is a non-straightforward practice in the interaction. This notion of non-straightforwardness will be further explored in the analysis of Excerpt 12 below. This excerpt will show that a request for prognostic information is not straightforward for a doctor to respond to and it will also show how the doctor manages this interactionally.

In the excerpt below, the patient's daughter has concerns about discharging her mother from the hospice. This has led the MDT to discuss the patient's current state, where they seem to agree that there has been a decline.

EXCERPT 12 – HOW LONG DO WE THINK THE DECLINE'S GONNA BE (2021.12.15)

```
01    WAR:  that's what I'm trying to gauge at how
02          (.) how long do we think th- (.)
03          decline's gonna [be],
04    DR1:                  [s-] soo- (.)
05          u:hm (.0 .mh I- (.) her liver is just
06          full of (.) m- m- m- mets.
07          (0.2)
08    DR1:  she doesn't,
09          (0.5)
10    DR1:  u- und-
11          (0.2)
12    DR1:  she is in bed_
13          (0.5)
14    DR1:  .th
15          (0.2)
16    DR1:  I mean essentially she's in bed the whole
17          time [really] isn't she apart from=
18    UNK:       [mhh   ].
19    DR1:  =getting up maybe for a
20          (0.3)
21    DR1:  what (.) fifteen minutes in the total of
22          the [↑day↑]?
23    NUR:      [yeah] she i- and it's [just         ]
24    DR2:                             [poor(ly) lady].=
25    NUR:  =she was [trying to put out once]_
26    DR1:           [she's a poorly #lady# ].
27    NUR:  ye[ah].
28    DR1:    [ye]:ah (.) I d-
29    DR2:  yeah.
30    DR1:  I d- although I don't I imagine we're (.)
31          at most looking at short weeks?
32    DR2:  yeah_
33          (0.2)
```

34 DR1: given the (.) trajectory anyway.
35 UNK: mhh.

In the first lines (01-03), the ward manager (WAR) provides an explicit request for the patient's prognosis through the question; *how long do we think the decline's gonna be*. One of the doctors (DR1) then produces an utterance in lines 04-06. This utterance begins with two cut-off words followed by a pause and then a prolonged *uhm*. After another pause, she makes a click sound and produces another cut-off word. She then states, after several cut-off words, that the patient's liver is full of *mets* (metastases). However, before completing this utterance, several pauses and more cut-off words occur. With this statement of the patient's liver, it becomes clear, that the doctor is initiating a statement-assessment sequence of the patient's current state. The doctor then continues by referring to something about the patient in line 08, but the utterance appears incomplete with the cut-off words in line 10. This project is abandoned, and instead the doctor states that the patient is in bed and continues by explaining that the patient only gets up for a very limited time during the day. Other team members agree with the doctor's statement. Through these statements, it also becomes more apparent that the ward manager's question is not straightforward for the doctor to answer. The type-conforming response (Raymond 2003) to her question would be some kind of timeframe relating to *how long* the patient's decline is going to be. Instead, the doctor provides a non-type conforming response with an assessment or statement of the patient being close to bedbound.

The doctor's statement leads to another doctor (DR2) mentioning that the patient is poorly (line 26), which receives affiliative responses in the following lines. The first doctor (DR1) then initiates a new utterance that begins with *I* and a cut-off word. She then says the words *although*, *I don't* and *I imagine*, where the doctor restarts the utterance several times. The utterance ends with the doctor's prognostic utterance in line 31, where she says they are looking at a prognosis of short weeks. In this way, the answer to the ward manager's question in lines 01-03 is provided several turns later, not until line 31. The other doctor (DR2) agrees with this prognosis in line 32. Then the first doctor (DR1) provides an account for this prognosis by saying that it is based on the disease trajectory. After this excerpt, the doctor further accounts for the prognosis by explaining some of the patient’s blood results.

This excerpt showed how several markers of interactional trouble or delicacy occurred. There was a display of a request for prognostic information as being non-straightforward to accept. There were multiple (long) pauses, cut-offs, and restarts indicating a lack of straightforwardness in the interaction. The non-straightforward aspect was also seen through the use of accounts. The actual type-conforming answer to the prognostic question occurred several turns later in the interaction, after the doctor had produced a statement of the patient being close to bedbound. After answering the question, further accounting from the doctor occurred as well.

8.5 Discussion

8.5.1 Main study findings

This study showed how MDT members oriented to prognostication as being a delicate interactional matter. Prognostication appeared to be a non-straightforward action to perform in the interaction. This was seen through markers indicating interactional trouble such as occurrences of pauses, word cut-offs, restarts, and rather significant accounts when staff members provided prognoses.

8.5.2 Discussion in relation to other findings

The results are in line with other conversation analytic studies showing that discussing death is a sensitive or delicate matter (Holt 1993; Parry, Land, and Seymour 2014; Pino et al. 2016; Pino and Parry 2019b; Ekberg et al. 2021). As noted previously, the hospice MDT meeting is a different interactional situation compared to those in which professionals are talking about death with patients and/or their relatives and from everyday conversations. In the MDT meeting, participants do not have to deal with the emotional aspect of communicating bad news to patients or their next of kin. Instead, the MDT meeting is an institutional meeting between hospice professionals to discuss their organisational tasks and “clients” that then involves death. Death and dying is a common topic for these professionals since the hospice is caring for terminally ill patients who are close to death. It is, or becomes, everyday routine for staff to deal with death and dying. For this reason, it is noteworthy that there is still a display of delicacy and sensitivity present when discussing prognosis.

Despite the hospice staff being used to deal with death and dying, the emotional labour and the emotional impact of a patient's poor prognosis on the professionals themselves might explain why there is still this sensitivity around these discussions. It might be less emotional to discuss death and prognosis with the MDT, but nonetheless is the hospice work overall emotionally challenging for the professionals by having to both care for the dying and supporting patients' relatives (see Funk, Peters, and Roger 2018) – and also by having to deal with one's own emotions. This may further highlight that the emotional component is important, as displayed through the emotion-imbued choice model (Lerner et al. 2015), when looking at how these decisions are made.

There is another layer than just discussing death present when dealing with prognostication. An explanation for why there is an orientation towards death and dying as a sensitive matter might be an underlying issue of providing an accurate prognosis. Instead of the delicacy and sensitivity orienting towards death *per se*, it might also orient towards an uncertainty and difficulty with predicting length of survival. When providing specific prognoses, professionals could be held accountable for their predictions. Prognostic uncertainty has also been listed as a reason for clinicians avoiding prognostic discussions with patients (Travers 2016). It has also been shown how clinicians navigate prognostic uncertainty in conversations with patients and their next of kin (Anderson et al. 2020). However, clinicians might be held accountable in a different way compared to when providing prognoses to patients and their next of kin. During the MDT meeting and in the hospice as a workplace, there is a professional reputation to maintain and there is a risk of jeopardising that by providing an inaccurate prognosis. In this way, the one providing the prognosis could be held (negatively) accountable by their colleagues. Here there could be substantial face-work for the professionals to maintain. The notion of *face* is a sociological concept, which relates to an individual's image of self in terms of approved social attributes from others (Goffman 1955). By providing a wrong or inaccurate prognosis, a doctor's self-image can be challenged if colleagues hold the doctor negatively accountable for it. However, one study showed that doctors tend not to hold colleagues accountable for prognostic errors (Christakis and Iwashyna 1998). The analyses presented in this chapter did not deal with professional reputation nor facework, thus it needs to be further explored what role uncertainty and accountability plays in these interactions.

8.6 Chapter summary

Prognostication was shown to be a sensitive matter during the MDT meetings. This was displayed through MDT members' usage of different interactional markers such as delay, self-repair, and accounts. This indicated that providing a prognosis was non-straightforward from an interactional perspective.

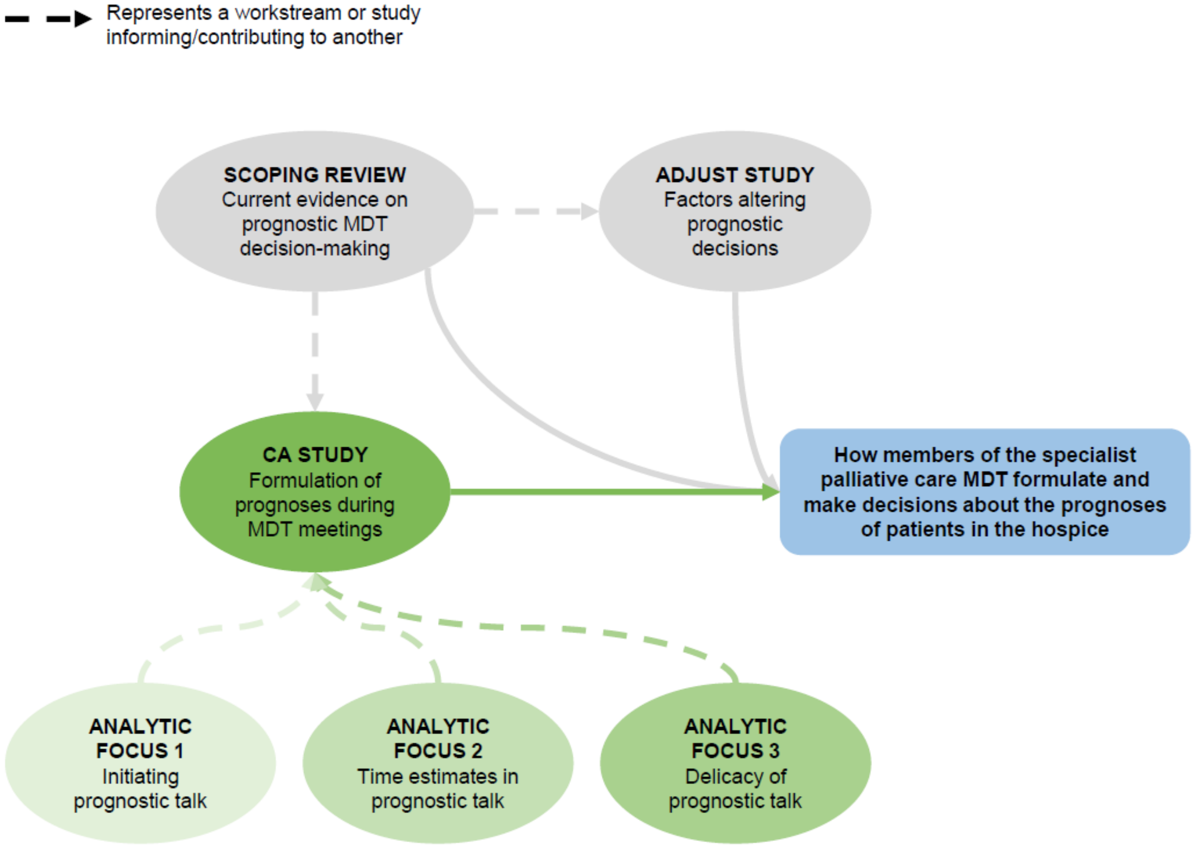
In this last analytic chapter, the thesis took a step back and looked more generally at how the action of prognostication is delicate for a team member perform. These findings yield possible interpretations of why that might be such as potential issues with accountability and uncertainty.

Chapter 9 – Conversation analytic study: Summary chapter

9.1 Chapter overview

Following the three analytic chapters from the CA study (Chapter 6-8), this chapter is dedicated to summarising the findings from all the chapters in order to provide an overview of the findings and to contextualise and relate them back to the thesis aims (see **Figure 9-1**).

Figure 9-1: Thesis outline diagram – CA study (summary)



As each analytic chapter included a “local” discussion of the findings in relation to the wider literature, this chapter only provides a brief discussion of some of the overall findings. The results will be further discussed in the overall discussion chapter (Chapter 10). At the end of this chapter, overall study strengths and limitations are presented.

9.2 Summary of study findings

The CA study addressed the thesis aim about understanding how members of the specialist palliative care team interact, including their formulation of prognoses during MDT meetings. This was done through analysing 24 video recordings of MDT meetings from a UK hospice. Recordings were analysed using CA, which allowed a detailed investigation of how the moment-by-moment unfolding of the social interaction between speakers (see Chapter 5). Three analytic foci of the interaction were explored to address the thesis aim: initiating prognostic talk (Chapter 6); time estimates in prognostic formulations (Chapter 7); and sensitivity of prognostic talk (Chapter 8). Findings from each of these foci are summarised in the sections below.

Chapter 6 detailed how prognostic talk was initiated during the hospice MDT meeting. This could either be done as a response to specific items on the MDT template (e.g., phase of illness) or it could occur when prognoses were relevant to other aspects of care (most commonly when discussing discharge plans). Prognosis could also be used as a tool to redirect talk back to other matters, where the prognosis was important to consider. Lastly, staff members rarely made explicit requests for prognoses, and most often prognostic utterances would receive minimal responses from other team members confirming them.

In Chapter 7, it was explored how temporality was conveyed in prognostic talk. Here it was shown that staff members would most often simply state the patient’s current situation of health as dying. Temporality could also be conveyed through specific and unspecific references to time. Specific references to time were rare in the data and occurred when another specific reference had been used prior to the prognostic utterance. Here, a specific time estimate was used when a matter was somehow time sensitive, and the patient might die before another specified event. With unspecific references it was unclear exactly when the patient was expected to die. These formulations were often vague with a low level of recognitionality for the recipients. However, it was important to note that staff members rarely requested more specific and recognisable time estimates. This chapter showed that overall, the references to time used were most often confirmed and thereby accepted by other team members. In this way, MDT members did not need to arrive at specific time estimates when discussing prognosis.

Chapter 8 demonstrated how MDT members displayed an orientation to prognostication as being an interactionally delicate matter. Prognostication was a non-straightforward action to perform in the interaction, which was shown through the occurrence of delicacy markers such as delay or pauses, word cut-offs, restarts, and the presence of clinical evidence serving as accounts for the given prognosis.

These chapters provided a better understanding of how MDT members interacted with each other about the prognoses of hospice patients. The findings contributed to the overall thesis aim about understanding how members of the specialist palliative care MDT formulate and make decisions about the prognoses of patients in the hospice.

9.3 Discussion

In the background chapter of the CA study (Chapter 5), it was explained that decision-making might not be straightforward from an interactional point of view. It was mentioned that decisions are often invisible and rarely stand-alone affairs. The findings from all analytic chapters confirm this assumption when considering prognostic decision-making. As seen in Chapter 6 and Chapter 7, prognostication was often not initiated as a direct question or topic nor was it aimed at clarifying or providing a patient's (accurate) prognosis. In all chapters, it was demonstrated that if a prognosis was provided, then it was most often simply accepted or confirmed through minimal responses. This might seem to depart from a "traditional" way of thinking about prognosis as a clear decision needing to be made or negotiated by team members within the meeting. On the other hand, prognoses appeared with delicacy markers indicating that it might be rather difficult to discuss, despite the hospice staff being specialist palliative care professionals used to dealing with death.

Through the data (and partially the subsequent analyses) collected in the CA study, it was apparent that the MDT agenda did not cover specific prognoses for patients. As shown in Chapter 6, the findings suggest that discussions about prognosis are launched by other meeting topics, especially discharge planning. However, most cases did not include a discussion of prognosis. This raises the question about whether prognostication might happen elsewhere in the care process and organisation.

Based on the knowledge obtained from the hospice induction, ethnographic observations and the weekly visits when collecting data, the care organisation of the hospice provided other opportunities for professionals to discuss prognosis. The hospice had daily handover meetings in the morning, at which information from the night shift was passed on between colleagues. These meetings looked fairly similar to MDT meetings with nurses, physiotherapists, and social workers (amongst others) attending. This type of morning meeting is not unique to the collaborating hospice but is a regular feature of other hospice facilities as well (see Williams 1997). Daily ward rounds were completed as well, at which doctors visited each patient accompanied by the ward manager (and potentially other professionals). In-between seeing patients, discussions around care needs occurred and information was exchanged. Moreover, there was an afternoon handover meeting that doctors and nurses attended.

Beside these planned and formal “meetings”, there were other more casual opportunities to discuss prognosis. A staff member might discuss prognosis with a colleague in the hallway, at the nursing station when writing up clinical notes, or maybe even in the breakroom. People working in institutions talk everywhere from large formal planned-in-advance meetings to informal doorway chats. As described by Boden (1997: 76):

> “Some of the most synoptic yet informative conversations happen in the many transition zones of the organisations, in elevators, around the departmental secretary’s desk, at the copying machine, in the mail room, in the buzz at the beginning and endings of meetings, and the like.”

In another study, one hospice staff member said that “Believe it or not, there's twice the communication that goes on [outside the meeting].” (Dugan Day 2012: 62). This could imply that prognostication could happen elsewhere. Another study found that doctors and nurses appreciated having informal chats with each other and found them more ideal than formal meetings

(Mahmood-Yousuf et al. 2008). However, this also complicates studying such a phenomenon, because it is unsure where the researcher should look for it.

Just because prognostication might not (explicitly) happen during the MDT meeting does not mean that it does not happen at all. It may just be the case that the MDT meeting is not the place at which prognoses are discussed in any great detail. This underlines the need for more research on prognostic discussions occurring in other settings outside of the formal MDT.

The question about where prognostication happens is based on the premise that prognostication only occurs when it is articulated verbally – and moreover, in a recognisable way for the analyst. However, prognostication can be an internal and unconscious process happening all the time. Although at an individual level it is difficult for staff to articulate their prognostic decision-making processes (Chu, White, and Stone 2019; Taylor, Dowding, and Johnson 2017). It is unclear whether MDT members had a prognosis in mind when providing care for a patient that was just not verbally expressed to other team members during the meeting. This calls for more research trying to explore the processes underlying prognostication at the individual level (see Chapter 10).

9.4 Study strengths

This study was the first one to use CA on specialist palliative care hospice MDT meetings and furthermore, the first one to explore how prognoses were discussed during these meetings. Through detailed analyses of the moment-by-moment interaction as it naturally occurred during MDT meetings, the analyses shed light on how prognostication was carried out. The use of video recordings ensured that findings were based on real interactions from clinical practice and that multi-modal aspects could be included in the analysis. The analyses therefore had a naturalistic approach simply working with and analysing what happened in real life. The data consisted of 24 video recordings of MDT meetings, which was a sufficient number of recordings to allow for patterns to occur and to be identified.

Data and preliminary analyses were discussed at multiple data sessions ensuring transcription accuracy and validation of findings. Invaluable analytic input was provided by one of the experts within the field of time in interaction (Dr Raymond). Analytic discussions with Dr Raymond informed the figures that were used to express the timeline (Figure 7-2, Figure 7-3, Figure 7-4, and Figure 7-5) and to understand how time estimates can narrow the available time points for the patient in Chapter 7. It was also discussed to use a definition of the term “time estimates” that involved temporality in a broader sense so grammatical tense could be included, despite this definition departing from the one of time references used in the framework (Raymond and White 2017). In this way, these discussions ensured that the decisions made throughout the analysis were robust and analytically sound from a CA perspective.

9.5 Study limitations

One unavoidable limitation of the study was that data were collected while COVID-19 restrictions were in place within the UK. This meant that all hospice staff members and visitors had to wear face coverings when entering the hospice. Participants wearing face makes complicated the analysis because access to participants’ mouth expressions was lost. In cases where it was not entirely sure who was speaking, participants’ mouth movements could not be used for clarification. This meant that transcription often relied on recognising participants’ voices and making (reasonable) assumptions about who was speaking. However, this explains the frequent use of “unknown speaker (UNK)” in the excerpts.

Another limitation was limited visual access to participants due to cameras not being able to capture all angles of the meeting. Participants were often seated in a U-formation or a (close to full) circle or ellipse, which made it difficult to capture the front of every staff member’s face. This also meant that some participants were not captured at all because they were seated outside the cameras’ range. This meant that it was often not possible to see or use non-verbal responses and cues or how they affected the conversation. Therefore, there sometimes was a limited focus on the multimodal aspect of these conversations. It is recognised that non-verbal interaction is crucial to social interaction and future research should try to overcome this limitation by obtaining better recordings of this type of meeting.

Ethnographic notes could have been collected to support the analysis and the lack of visual access to participants' bodily interaction. However, the foci of the overall CA study were not decided until rather late in the data collection process. This made it difficult to predict which type of ethnographic notes that would have been useful to support the analysis. Also, it would have been practically difficult for the researcher to decide among several speakers whose movements might be relevant or important to note in the moment of the unfolding of the interaction. Lastly, such ethnographic notes would not be able to capture the level of detail needed for a comprehensive multimodal analysis, where the exact timing of the bodily interaction needs to be carefully considered. Despite these challenges, future research studies should explore the supportive role of ethnographic notes when having multiple participants not within camera range.

Poor sound quality of the recording also sometimes influenced the analysis. In one of the meeting rooms, the hospice family room, there was background noise from a refrigerator or building work being carried out that sometimes made it difficult to hear and therefore transcribe what participants said. Despite having three devices capturing sound from different positions, it was sometimes very difficult to hear what was being said. Often the same audio had to be replayed from both cameras (located in each end of the room) and the audio recorder (placed somewhere in-between the cameras) to determine what was being said. Sometimes it was still not possible to hear and determine what the speaker said. This explains the (frequent) use of brackets in transcriptions that propose a possible interpretation but where it was not entirely clear what the speaker actually said.

It could be perceived as a limitation that the researcher was present during the meetings. Because of this, it was not possible to completely eliminate researcher influence on the interactions. However, as addressed in the methods chapter, due to the regular attendance of visitors in the MDT meeting, it was decided a priori that this would not impact the authenticity of the recordings. Another point regarding authenticity of the recordings was whether staff members acted in certain ways in response to being recorded. This is also known as the phenomenon *observer's paradox* (see Labov 1972). It is possible that the participants altered their language or avoided expressing certain (potentially sensitive) things that they did not want captured in the recordings.

Some staff members did not provide consent and therefore their data could not be used in the study. To respect this, it meant that there were certain elements of the talk that could not be used for analysis because they were produced by non-consenting staff. One staff member that did not provide consent was a ward manager. The ward manager played a relatively significant role during the MDT meeting. This meant that there were six recordings that were very difficult to analyse as she participated in those meetings but had not given consent for her data to be used. For this reason, it was decided to simply avoid, or limit analyses of those recordings.

The issue with non-consenting staff was a major concern during the initial stages of data collection. It became apparent that some staff members did not seem keen on, or comfortable with, being recorded. Different strategies were used to attempt to mitigate these concerns. An additional information meeting was held, and staff members were approached individually and were offered the opportunity to share any concerns regarding the study. The ward manager not wanting to consent seemed to influence certain other staff members, which highlighted her authority within the hospice. The medical director was also contacted, and the supervision team was consulted to discuss these issues and potential solutions. Also, the hospice was a busy environment, and it was difficult to catch staff at the right time and place where they could properly discuss the study – especially those members of staff who were more reluctant to consent. However, it should be stressed that most hospice staff provided consent and did not express any concerns about the study.

Future research should thoroughly consider who are the gatekeepers in the institution and ensure that they agree with the study procedures. Also, it is important to factor in adequate time for the researcher to build personal relationships with staff and thereby to ensure trust around recordings. If time had permitted, it would have been useful to undertake preliminary work with hospice staff members prior to initiating the project, so they could have had a say about the research that they were asked to participate in. Other ways of gathering staff members to inform them about the study could also have been explored. However, the large number of participants in the meetings, the fact that the staff members in attendance changed quite a lot, the presence of many visiting participants, and the busy healthcare environment all combined made it difficult to plan (for) these types of things.

Doing such preliminary work in the way described above can be complicated within CA studies. If the researcher has a specific objective or research question in mind, this is not normally shared with the research participants before recording their interactions. This is because this might influence the talk if participants believe the researcher has a certain agenda. In this way, the data could appear less natural compared to how they would normally discuss things. In this study, the medical director was the only one who knew about the focus of the study – as he was the one approving the research being conducted at the hospice – and he participated in some of the meetings. It is not entirely clear whether this influenced his way of speaking about prognosis. However, after working with the data it could be reasonably assumed that this has had limited impact on the recordings, since it was still possible to find patterns across speakers. Lastly, his behaviour or way of discussing prognoses did not stand out to the analyst nor did other team members display an orientation to his behaviour as being somehow unusual.

In Chapter 7 on time estimates prognostic talk, initial observations and analysis involved labelling or mentioning that there was a *lack of* time estimates in prognostic utterances. However, issues arose with labelling something as lacking in the interaction. Problems with observing and dealing with things that are lacking have been dealt with before. Schegloff (2007b: 19) calls these “negative observations” and states the following:

> “There is an indefinitely large and extendable number of things that have not been said, of events that have not happened, of persons who are not speaking, of actions that are not being performed by someone who is speaking (…) Any asserted observation of an absence is at risk of being but one of a virtual infinity of absent occurrences of activities,

> and in that sense a trivial observation or assertion (however true)."

For something to be noticeably absent, there is a need for a rule that makes it relevant for that something to happen (Schegloff 2007b). In other words, one can always claim or observe that something is missing or lacking in the interaction. Therefore, in order for something to be noticeably ("properly") missing, there must be some kind of rule stating that something *should* occur. Then if this something does not occur according to the rule, it would be appropriately referred to as missing or lacking. This meant that the issue with a lack of time estimates was thoroughly discussed and then changed to the practice presented in this chapter; patients' current state. In this way, the analysis moved away from dealing with time estimates as being absent from the interaction to describe and explain what was happening instead. However, one could argue whether describing the patient's current state as dying is actually a *prediction* of death. It might be more useful to think about it in terms of one of the other phrases for prognostication, such as *recognising* dying. Either way, one of the key points of this chapter was that professionals did not frequently use stereotypical time estimates nor use specific references to time (i.e., a certain day or date) when talking about a patient's prognosis.

Lastly, it should be noted that the findings from this study might lack generalisability across hospice MDTs. Despite the aims of the study never being to try and generalise the findings, the practices and results might be specific for the collaborating hospice. This means that other findings might occur if the study were to be replicated in another hospice setting. It would have strengthened the study findings if several hospices were part of the study, but this would also significantly add to the study burden. However, the lack of hospices in the study is not a limitation *per se*, but instead it should be seen as an encouragement that more research like this is needed, which would then allow comparison across settings. In the same way, the findings might also represent how prognosis were discussed while the hospice was impacted by COVID-19. Had the data been collected at another time (i.e., pre and post the pandemic or when the pandemic was peaking), the findings might be different.

9.6 Chapter summary

The conversation analytic study of the thesis zoomed in on the interaction and provided in-depth insights into the interaction as they naturally occurred during hospice MDT meetings. Different analytic foci were explored in order to provide a general understanding of prognostication within these meetings. The first analytic focus showed different ways of initiating how the discussion about a prognosis began during the meetings. The second analytic focus involved looking closer at the actual prognostic utterances to see how they were formulated in relation to time and temporality. The third and final analytic focus looked at the whole action of doing prognostication and explained that this was particularly sensitive or interactionally delicate to do. The analyses produced evidence which broaden the understanding of how members of the specialist palliative care team interact, including their formulation of prognoses during MDT meetings.

Chapter 10 – Discussion

10.1 Chapter overview

In the final chapter of the thesis, the overall findings from the three workstreams are summarised, linked, and discussed in relation to the wider literature. Strengths, limitations, and practical implications are also presented and discussed before the thesis ends with some conclusive remarks.

10.2 Overview of research aims

The overall aim of the thesis, as described in Chapter 2, was to understand how members of the specialist palliative care MDT formulate and make decisions about the prognoses of patients in the hospice. The scope of the thesis was on how prognostic decisions were made about imminently dying patients using a descriptive approach to studying decision-making.

To address this research aim, a scoping review of MDT decision-making about imminently dying patients was conducted. This was followed by an online RCT to identify factors affecting palliative care MDT members' prognostic decisions. Using the methods of CA, it was explored how staff discussed prognosis during MDT meetings in a hospice.

10.3 Summary of thesis findings

The scoping review (Chapter 3) provided an overview of the evidence base and found that previous research showed that MDT prognostic decision-making most often occurred between clinical staff members such as doctors and nurses. Prognostic discussions were characterised by often being part of discussing other care decisions. The decision-making process involved a partial collaborative approach where staff would share information with each other, but the final prognostic decision would be made by one team member. Issues with decision-making were often characterised by disagreement and doctors being the sole decision-maker. The evidence yielded a need for studies exploring prognostic decision-making in specialist palliative care settings and research going beyond qualitative interview methods.

The ADJUST study (Chapter 4) addressed if any factors altering MDT members' prognostic decisions were present. This was done through an online

RCT involving palliative care clinicians completing a prognostic decision-making task. The findings showed that, when palliative care professionals were offered prognostic advice, the perceived source of advice affected their final prognostic decisions. When the advice was perceived to come from a prognostic algorithm, the professionals would take greater account of the advice, than if it was perceived to come from a colleague. Role or experience of the professionals receiving the advice did not make them take the advice more or less into account. Instead, professionals tended to prefer advice given with a certain level of strength when receiving advice as a probability percentage estimate.

The CA study (Chapter 5-8) sought to understand how members of the specialist palliative care team interact, including their formulation of prognoses during MDT meetings. This was done through analyses of staff members' interactions during hospice MDT meetings. The results showed that the hospice MDT rarely discussed patients' prognoses explicitly during their meetings. Instead, consideration of patients' prognoses could be initiated through responses to patient presentation items on the MDT meeting template. Staff members also often considered patients' prognoses when making specific care plans, particularly discharge plans, or they could use prognoses to change the direction of the discussion. However, it was rare for professionals to ask the team for a patient's prognosis explicitly. When formulating a prognosis that involved a reference to time, professionals often just stated the patient's current situation as dying. Commonly, they would use unspecific and vague references to time that did not clearly indicate when the patient was expected to die. It was rare for the professionals to use specific time estimates and such prognostic estimates only occurred when the prognosis conflicted with another timeframe relevant to the patient's care plans. Overall, it was often sensitive to provide a prognosis, where the talk would often be perturbated, displaying that such an action was not straightforward for the professional to perform. This was further illustrated by the way in which professionals often provided several statements and assessments accounting for the provided prognosis. However, when professionals formulated a prognosis, it was most often simply accepted by other team members and agreed with.

As the study designs were rather distinct, in line with a convergent mixed methods approach (see Chapter 2, section 2.4), the discussion of the findings in relation to the wider literature also involves linking the thesis findings together. The discussion has an important role in bringing together and linking all the thesis findings. The next section contains an explanation of the extent to which the thesis findings converge (or diverge).

10.4 Discussion in relation to other findings

To facilitate the overall discussion of the thesis findings, the section is separated into three sections. The first two sections refer to the two objectives of the thesis: what factors alter prognostic decisions; and how members of the specialist palliative care formulate prognoses during MDT meetings. The last section discusses the key notion of uncertainty within prognostication in relation to the thesis findings.

10.4.1 Factors altering prognostic decisions

The first objective of the thesis was to explore what factors (if any) can alter prognostic decisions and the extent to which this occurs. In the sections below, key findings in relations to the objective are discussed.

10.4.1.1 Professionals in the multidisciplinary team

The review finding that MDT prognostic discussions most commonly occurred between doctors and nurses was corroborated by the results of the conversation analytic study where it was shown how doctors were asked or expected to provide prognoses. As noted previously, asking doctors about prognoses may be logical due to their clinical professional backgrounds. In the ADJUST study, it was shown how professional role (doctor, nurse, or other types of healthcare professionals) did not impact how clinicians integrated advice when making prognostic decisions. One hypothesis had been that other types of healthcare professionals might integrate advice more since they were less experienced in prognostication due to their professional background. However, the results implied that there was no professional role that accepted advice more than others.

Despite palliative care advocating a holistic and multidisciplinary care approach, it has been shown that palliative care teams do not always mirror this aspiration, since medical and nursing perspectives are dominant by force of numbers (Klarare et al. 2013). One study also showed that the time in MDT meetings was mostly dedicated to nursing and medical issues with only 13% being apportioned to social work and chaplaincy services (Dugan Day 2012). The study further described the information-exchange during the team meeting as a “medical report”. In the EAPC’s 2022 revised recommendations on standards and norms for palliative care in Europe, the following specific occupational roles were not regarded as essential in the MDT: occupational therapist, speech therapist, complementary therapist, lymphoedema therapist, trainer and librarian (Payne et al. 2022). This seems to advocate for less of a multidisciplinary approach. In the conversation analytic study, there were a few cases displaying the involvement of other professionals, where it was seen for example that a social worker requested a prognosis in Chapter 6, and that a physiotherapist requested a more specific prognostic timeframe in Chapter 7. However, it still needs to be further explored what role allied healthcare professionals have in MDT prognostication.

Despite not having a significant role in formulating or communicating prognoses, allied healthcare professionals might play a bigger role in the steps of prognostic awareness and acceptance. For example, a study has showed how a chaplain could engage in prognostic communication when a doctor’s attempt was unsuccessful (Goldsmith et al. 2009). This calls for further exploration of how prognostication is being dealt with by different professionals.

In general, there is evidence that experience influences advice-taking (Yaniv 2004b), and in the ADJUST study it was hypothesised that professional experience of the participants might influence decision-making. However, this was not found to be the case. The experience of the professionals in the conversation analytic study was unknown since demographic information about the participants were not collected. From an interactional point of view, most personal and “invisible” aspects (such as experience) would only be relevant in the interaction if the participants display an orientation to it as such.

However, there are some approaches that CA could use to explore such factors further for example through the lens of epistemics and deontics. Further details on these approaches are provided in the future research section.

10.4.1.2 Algorithmic advice

The key finding from the ADJUST study was that palliative care professionals preferred advice from an algorithm rather than from another clinician when making prognostic decisions as part of an online experiment. These findings expand the evidence base showing that people prefer advice from algorithms over human-advice (Logg, Minson, and Moore 2019). This is a novel finding within the field of palliative care prognostication, and it raises further questions about how prognostic algorithms are used in clinical practice.

Despite their interesting and novel findings on algorithm appreciation, limitations of the work by Logg, Minson, and Moore (2019) should be noted. It is important to first of all acknowledge the context of their study. They conducted psychological *experiments* and therefore caution should be taken when attempting to transfer or generalise their findings into other (non-)experimental settings. Their work involved different types of forecasting tasks that lacks ecological validity, for example the experiment that resembles the ADJUST study involved participants guessing an individual's weight from a photograph. It is important to acknowledge that algorithm appreciation may be a factor in certain isolated contexts. Despite their findings having great theoretical implications, their practical implications may be limited. Similar to the ADJUST findings, the theoretical implications are great, but it should be stressed that the clinical implications at this point are limited. Such experiments do provide insights into human behaviour, but they also mostly hold true in the (artificial experimental) contexts in which they are held (see Holleman et al. 2020). Regarding the ADJUST study, clinicians integrated advice more from a prognostic algorithm in that specific context and experimental set-up that it involved (i.e., predicting two-week survival, using PiPS-B14 as the advice source, providing prognosis as a response to a question in a specific pre-defined quantitative format etc.).

The CA study did not address the question of how professionals preferred advice from prognostic scores more than input from other team members, simply because the MDT did not routinely use any such prognostic scores. They used the Phase of Illness and KPS score but these are not considered to be prognostic algorithms, but rather prognostic factors or indicators. Therefore, as discussed in the ADJUST chapter (Chapter 4), there is a need for more research on understanding human-algorithm interaction (Kelly et al. 2019), and the issue of how clinicians use prognostic algorithms in clinical practice largely remains unexplored. It has also been stressed that more research is needed on how prognostic tools can guide clinical decisions (Hui 2015). Since clinicians seem to integrate prognostic algorithm-advice more in an online experimental setting there is a need for further research to investigate the real-life implications of this finding.

10.4.2 Formulation of prognoses during multidisciplinary team meetings

The second objective of the thesis was to explore how members of the specialist palliative care team interact, including their formulation of prognoses during MDT meetings. In the following sections, key findings are discussed in relation to the objective.

10.4.2.1 Structure of prognostic decisions

The scoping review found that the decision-making process was most often shown to involve information-sharing between professionals. This was mirrored in the conversation analytic study in the way the meeting was set up with patient presentations from nurses and healthcare assistants sharing patient information with the MDT. Information-sharing was also displayed when MDT members produced the comprehensive statement-assessment sequences describing and assessing the patient’s information. In this way, the background literature stating that information-sharing between professionals is key in MDT decision-making was supported by the review findings and the findings from the conversation analytic study.

During the MDT meetings, patient’s prognoses were not discussed as an actual decision or prediction needing to be made. Whether this is because it is simply difficult to provide a prognosis due to uncertainty or else the responsibility and accountability for such decisions is unclear. However, as noted in the summary CA chapter (Chapter 9), it can be difficult to even identify decisions from an interactional point of view. Prognoses were considered when discussing other care aspects such as discharge planning. This aligns with the findings from the scoping review, where it was also shown that prognostic decisions were often embedded when discussing other aspects of care. These findings seem to support the claim that the process of recognising dying cannot always be clearly separated from other care processes which take place at the same time (Taylor, Johnson, and Dowding 2020). The authors highlight that their key finding is that prognostication is not a clear, objective, one-off decision, but instead it is a fluid, ongoing and iterative process.

The prognostic decision-making process is fluid because the distinction between active patient management and dying is blurred (Taylor, Johnson, and Dowding 2020). This research showed that prognoses often occurred with statement-assessments where several observations, symptoms, assessments, and sometimes interventions were listed. When an MDT member lists certain assessments of, or statements about, the patient (e.g., the patient is no longer eating and drinking, lacks mobility and is sleeping a lot) it might imply that the patient is now close to dying. They then make the necessary care decisions and next steps that might all actually involve prognostication by reacting to certain prognostic factors. In this way, prognostication might not be a traditional prediction *per se*. A reflection on prognostication as a concept also proposed an approach that calls for more than a simple prediction or estimate, and in this way work with prognostication as something that goes beyond the use of prognostic tools and does not necessarily involve quantified estimates (Thomas, Cooney, and Fried 2019).

The issue with identifying prognostic decisions was also present when conducting the scoping review. As noted in the study limitations section, it was difficult to judge whether an actual prognostic decision was made. Moreover, when having to characterise the decision-making process, it was difficult to judge when a decision was made together. Issues with what a joint decision would “look” like were discussed as well. Similar links can be made to the conversation analytic study where other staff members did not openly disagree with a prognosis, but it could be challenged whether the decision was made *together.* Rather, the decision was overheard by others, who had an opportunity to object, and any related clinical decisions were recorded, which implies that the responsibility is then shared between them.

10.4.2.2 Disagreement

The scoping review showed that issues with prognostic decision-making were articulated through disagreement between MDT members. However, in the conversation analytic study, there was no evidence of people displaying disagreement with the proposed prognoses. Other staff members most often simply confirmed or accepted the prognosis. It is relevant to consider that expressing disagreement is interactionally challenging and often a sensitive matter requiring additional interactional work. Especially if formulated by a doctor that might have more (medical) knowledge and authority to provide prognoses. Even before collecting the data, the hypothesis or assumption was that this would be a complicated aspect to explore as it might not be a thing that would frequently occur in the data. In the ADJUST study, it was seen how participants generally integrated advice through their WOA scores, which were all higher than 0 (100% advice discounting). This indicates that participants agreed to some extent with the advice provided and therefore took it into account. The notion of MDT disagreement in relation to prognostic decision-making needs to be further explored.

10.4.2.3 Time estimates

The results from the conversation analytic study showed that most of the prognostic discussions did not involve specific references to time. There seems to be an underlying wish among researchers to precisely and accurately predict when someone is dying, especially when looking at the wider quantitative literature (White et al. 2016; White, Reid, et al. 2019; White et al. 2017; Chow et al. 2001; Glare et al. 2003; Zhou et al. 2013; Coventry et al. 2005). Also, the fact that some evidence shows that professionals, patients, and their next of kin all value *accurate* prognostic information (Steinhauser et al. 2001). However, when looking at how prognosis was discussed during the MDT meeting, there was no such orientation present from the MDT members themselves. The results did not show that staff members pursued nor insisted on accurate prognostic predictions during the MDT meeting in order to do their jobs. This raises the question of whether the hospice MDT *needs* this information in order to provide high quality care for patients.

It was noted that those unspecific references to time identified in Chapter 7 could be rather difficult to argue against and equally difficult for prognosticators to be accountable for. It is, after all, not necessarily inaccurate to say that a patient “does not have long to go”, that their prognosis is “short”, or that a patient will die “soon” - whether they live a few hours, days, weeks or even months. As the patients are terminally ill and admitted to a hospice, this could be the case for a lot of them (i.e., Haraldsdottir et al. 2023). Would that mean that all of these prognoses are then *accurate*? Or does accuracy need to be more quantitative in the sense that it requires a specific estimate? It has been mentioned that accuracy is “an elusive concept in prognostication research” (Hui 2015: 3), due to how prognostic accuracy can be measured in different ways (also dependent on the measure being used).

As noted in Chapter 7, there might be a shared understanding or knowledge of what these unspecific and vague time estimates imply. Such prognoses might be rather contextual and make sense for the ones using them in the particular situation. A “short prognosis” and “soon” most likely mean completely different things to someone just having received a terminal diagnosis compared to another patient who has potentially lived with an advanced illness for many months or years. In a hospice, most of the patients would be imminently dying and this context needs to be taken into account when considering these more unspecific references to time.

The patient’s prognosis was not an explicit item on the MDT meeting agenda, at least not in terms of trying to predict accurately when the patient was going to die. This could imply that this aspect is not a top priority within these meetings. Instead, there might be an overlying orientation to provide good care to patients and not to spend time trying to accurately predict their date of death. As noted previously, the patient’s prognosis does play a role in the care needed and provided, but there might be more important and pressing issues to deal with during this meeting. Since the MDT did not seem to regard this information as essential in order to carry out and continue their work, the MDT might focus on other aspects of information-sharing and decision-making instead.

Research from the US has shown that actually knowing the *timing* of one's death was of less importance for patients, their next of kin and healthcare professionals compared to other factors (Steinhauser et al. 2001; Steinhauser et al. 2000). In this research, participants (i.e., patients, bereaved family members, doctors, and other care providers) rated the importance of 44 factors that had been identified as attributes of a good death. Other attributes related to preparing and planning for death, which link closely to when someone is expected to die, were part of the list as well. Some planning and preparation aspects may require more precise predictions of imminent death for example when relatives and friends should come and say a final goodbye. The study showed that saying goodbye to important people was deemed very important for patients, their families, and healthcare professionals (Steinhauser et al. 2000). Research from the UK has also stressed the importance of saying goodbye, particularly when not being allowed to due to the COVID-19 pandemic (Selman, Sowden, and Borgstrom 2021; Hanna et al. 2021). In these circumstances, when key aspects of care are time dependent, (e.g., saying goodbye before someone dies), a more accurate prediction of length of survival can be helpful. It has also been suggested that it is easier for professionals to predict when death is imminent compared to longer timeframes (also known as the "horizon effect" phenomenon) (Chu, White, and Stone 2019). This might be because marked deterioration of vital signs often shows in the very last hours of life, and therefore these changes may serve as a predictor of death within the same day (Mori et al. 2022). One study confirmed this by showing that clinicians were indeed very good at predicting imminent death (Stone et al. 2022).

In the time estimates chapter (Chapter 7), the results showed that the MDT most often simply stated that a patient was dying, and this statement in itself was felt to be sufficiently clear. The cases that required more discussions were the ones where it was more uncertain when the patient was expected to die, and therefore the patient could potentially be discharged from the hospice. These findings align with the horizon effect and the fact that professionals are better at prognosticating imminent death.

10.4.3 Uncertainty

A crucial thing to consider when trying to understand how prognostic decisions are made within the specialist palliative care MDT, is the aspect of uncertainty.

Uncertainty seems to be the root of the problem when researching and discussing prognosis and prognostication. Prognostic uncertainty has also been listed as a reason for clinicians avoiding prognostic discussions with patients (Travers 2016). Going back to the etymology of prognosis, ‘foreknowledge’, and its meaning of being a prediction about whether certain events will occur or not (Rizzi 1993). It is not uncommon for clinicians to avoid prognostic discussions with the reason being that one cannot possibly predict the future (Martin and Widera 2020). Perfect prognostication is not possible because the disease trajectory may depend on random events that are intrinsically unpredictable (Cowie 2002). Similarly, it has been stressed that it is important to recognise that there will always be uncertainty in prognostication due to the inherent nature of (cancer) deaths (Bruera and Hui 2008).

In the conversation analytic study, the findings point towards difficulties with prognostication from an interactional perspective. The fact that MDT members provided significant and rather long statement-assessment sequences when discussing patients’ prognoses, combined with often vague and unspecific time estimates, and the general orientation to prognostication being a delicate matter could be due to an underlying uncertainty about the future. The ADJUST study showed that overall, participants moved towards the advice received. This indicated that professionals do welcome advice (whether it is from an algorithm or a colleague). This could potentially mean that making prognostic decisions is difficult and therefore advice or input is generally perceived as being beneficial or helpful. This could also be due to the uncertainty of making such predictions.

One study highlighted that there seems to be a clash present, where doctors dislike making these precise prognoses that patients and policymakers often seem to want (Christakis and Iwashyna 1998). This might be due to the inherent uncertainty that prognostication comes with. One might ask, if the true prognosis of a patient can never be known for sure, then why does research continue focusing on prognostic accuracy? Hui (2015: 8) asks (and answers) a similar question:

> “…why should we still strive to improve the accuracy of survival prediction? It is because a higher accuracy can offer health care professionals greater confidence when communicating with patients and families while also bringing greater clarity to decision-making.”

10.5 Thesis implications

This thesis has taken the first step towards understanding how prognostic decisions are made within the hospice MDT. The research provides important insights that can be used to inform clinical practice.

The scoping review showed how there is a lack of evidence within this area of research. Several implications for future research were presented in Chapter 3, particularly regarding *where* and *what* type of research is currently needed. By summarising the evidence base, the literature review highlights areas for future research studies.

It has been stressed throughout the thesis that patients’ prognoses should be discussed within the MDT (see for example, Chu et al. 2020; Ellershaw, Neuberger, and Ward 2003; National Institute for Health and Care Excellence 2015). However, as noted previously, there was no information about *how* prognosis should be discussed. It is necessary to understand how patients’ prognoses are discussed in MDT meetings, before identifying limitations and proposing solutions to improve interprofessional communication. Future research may be able build upon on the thesis findings to develop interprofessional communication guidelines or recommendations about how to improve prognostic communication within MDTs and to identify “good practice”.

Better prognostication ought to also have a positive impact on patient care and management such as discharge planning, code status discussions, goals of care, and enrolment onto integrated care pathways (Perez-Cruz et al. 2014). Knowing how to discuss prognosis as a team might also be helpful for the individual clinician having to disclose prognosis, where the individual team member might feel more confident and prepared to have the conversation with others. Preparing clinicians better to have prognostic conversations with patients and/or relatives might improve the quality of these discussions as well. Gained confidence through the MDT discussion could positively impact how the clinician presents the relevant information and reduces poorly managed (or even unsuccessful) discussions (see Butow, Clayton, and Epstein 2020).

Prognostic accuracy can be important to ensure that patients’ families and friends have the opportunity to say a final goodbye. Since MDTs may improve prognostic accuracy (Kee, Owen, and Leathem 2007; Gwilliam et al. 2013), more focus should be on the ways in which this could be utilised to improve prognostication in real clinical practice. One way of improving accuracy is through prognostic tools. As this research showed that clinicians welcome advice from a prognostic algorithm (even more than advice from their colleagues), it should be better understood if such tools should be implemented in clinical practice and how. As the study was in an online experimental context involving prognostic advice in the form of a short written statement, the findings may not be transferable to real-life settings when advice may be provided differently (e.g., informally, verbally, and in non-quantitative terms). There may be potential benefits of using prognostic algorithms, however more research is needed within the field.

The main clinical impact of the thesis is to make clinicians reflect on *how* they prognosticate. The online RCT study design and its findings can be used to facilitate discussions around how palliative care clinicians prognosticate. This was seen when presenting the study to hospice collaborators when recruiting and conducting the study and after the results were published. The study vignettes can be used to prompt discussion among professionals about what factors they base their prognostic estimates on and to reflect on the difficulties with prognostication. The vignettes and results also offer professionals an opportunity to get feedback, which may be helpful in order to improve (and reflect on) their predictions. The study can also make professionals critically reflect on whether a probability estimate (as opposed to a non-numerical estimate) is more or less meaningful.

The study finding that professionals integrated advice from the prognostic algorithm more than advice from another professional may lead them to reflect on their own biases when being presented with prognostic advice. Providing knowledge on prognostic algorithms can lead professionals to critically consider how feasible it would be to implement prognostic algorithms into clinical practice.

The findings and recordings from the conversation analytic study could be used for training and to make professionals reflect on how they discuss prognosis together as a team. This may foster a discussion about (effective) prognostication, which is often a topic that is not easy to grasp and articulate.

10.6 Thesis strengths and limitations

In this section the overall strengths and limitations of the thesis are presented. Strengths and limitations for each individual study have been presented in previous chapters (see Chapter 3 for the scoping review, Chapter 4 for the ADJUST study, and Chapter 9 for the conversation analytic study). This section takes a broader perspective on the thesis and provides a reflection of what could have been done differently in hindsight.

10.6.1 Strengths

This thesis provided novel insights into the understanding of how prognostic decisions were made by members of the hospice MDT. Each workstreams contributed with original findings to the field of MDT prognostication within palliative care. The scoping review was the first of its kind to examine the evidence on MDT prognostic decision-making. The ADJUST study was the first online RCT to explore factors altering professionals’ prognostic decisions, and the conversation analytic study was the first to explore prognosis in hospice MDT interactions using CA.

The mixed methods approach used in the thesis, provided a greater understanding of prognostication in MDTs from different perspectives by combining the individual-based decision-making process with the more complex and dynamic team-based decision-making observed through video recordings of MDT meetings. In this way, the thesis drew upon rather distinct ways of studying decision-making and combined them. The thesis was then able to benefit from the strengths of both quantitative and qualitative research methodologies.

10.6.2 Limitations

The methods employed in the ADJUST and the CA studies were rather distinct. The study using CA illustrated how the MDT prognostic decision-making process is much more dynamic and complex than any simple experimental set-up would suggest. Prognostic decisions were not made nor formulated as they sometimes appear in the experimental psychological literature. In the initial stages of setting up the studies, it was hypothesised how prognostication and advice might have been utilised during MDT meetings. However, when actually exploring the video-data, the reality was rather different compared to what the experimental study was capturing – bearing in mind that the ADJUST study was initiated and completed before the conversation analytic study. In the analysis of the recordings from the CA study, the aspect or notion of “advice” was not a striking feature of the interactions. Professionals do not frame prognostic decision-making as a clear-cut task through utterances such as, “Now we have to predict when Miss Smith is going to die”, “When do you think Miss Smith is going to die?”, or, “Nurse, what do you think the probability of Miss Smith surviving the next week is?”; the latter reflecting the task presented to participants in the ADJUST study. In Chapter 1 it was mentioned that in team decision-making, advice was more often framed as sharing information and opinions in order to reach consensus (Van Swol and Prahl 2018). Similarly, in the conversation analytic study, professionals were rarely specifically asked for their opinions when actually engaging in prognostic discussions, and neither did the professionals offer (stereotypical) advice or input when someone provided a prognosis. This might challenge the approach taken in this thesis. However, it simply reflects the inductive data-driven approach of CA, where the data leads the way. As a consequence, that can make the link between the two studies rather challenging. It might have been a different picture had the conversation analytic study been conducted before designing the ADJUST study. This approach was recommended in another paper on combining CA and psychological experimental methods, in which the authors proposed that experimental hypotheses should be formulated based on CA studies using maximally detailed recordings of natural interaction (de Ruiter and Albert 2017). It is worth considering this point in future studies considering using other mixed methods approaches.

The section above underlines one of the main challenges of doing convergent mixed methods research, when the results instead of converging actually diverge (Doyle, Brady, and Byrne 2016). The initial unifying concept of advice, that partly justified this design, did not hold true in this thesis. When mixed methods results diverge, it has been advised to collect more data (Dawadi, Shrestha, and Giri 2021), and that this may lead to future research studies (Fetters, Curry, and Creswell 2013), which address the divergence. However, this is not always possible with limited study periods (Doyle, Brady, and Byrne 2016). Several ideas and directions for future research are proposed in the next section.

In hindsight, it would have been interesting to have further explored the MDT aspect of the ADJUST study to see how professionals integrate advice from different types of colleagues. The study only explored how professionals integrated advice from a colleague with a different professional background than themselves. It would have been interesting to include more advisors. For example, a research design allowing a nurse to receive advice from another nurse, a doctor, and another type of healthcare professional. This would have provided more insights into the MDT aspect of working within a team with different types of professionals than the current study design allowed. However, increasing the number of study arms would have required a much larger sample size to ensure that the arms could be compared from a statistical point of view and adjustments would have been needed to account for multiple significance tests.

Alternatively, spending more time observing the MDTs in the hospice could potentially have been one way to avoid some of the mixed methods pitfalls. More observations over a longer time period might have enabled the researcher to plan accordingly and make relevant decisions in order to merge the studies more meaningfully. Similarly, having had enough time to collect the data, analyse and interpret the findings from one study before conducting the next one, would have been useful. However, as mentioned previously, this would have been challenging given the limited study period.

The analyses undertaken as part of the conversation analytic study should not be seen as exhaustive, in the sense that the practices identified should not be considered to be the only ways of doing prognostication within the MDT meeting. The analyses simply provided and identified ways this *could* be done. Further evidence and analyses would be needed in order to provide more generalisable findings. A bigger dataset involving multiple hospices could potentially show whether patterns occur across different hospice MDTs, which would add strength to study findings.

Although a scoping review was presented in Chapter 3, other review approaches were also considered and may have had merit. Refining and focusing the research questions and conducting another type of review (e.g., systematic review of both qualitative and quantitative evidence), could have provided a more in-depth synthesis. However, as mentioned in the review chapter, the initial searches and scope of the literature (and hence the scoping review findings) revealed that a limited body of research was available, which was why a broader approach was applied. As the review was the first step in the overall research process, an overview of the evidence was warranted. Another focus could have been chosen and multiple reviews could have been conducted, such as one for each thesis research question. The thesis findings themselves may also be used to guide future systematic reviews.

10.7 Future research

The thesis is the first study to focus on hospice MDT prognostication, more research focusing explicitly on this topic is needed. More research would allow evidence-based guidelines to be developed on how MDTs should discuss prognoses, and how prognostic information should be elicited, recorded, and used in MDT meetings.

It would be interesting to experiment with different interventions that targeted how MDT members could discuss prognoses (perhaps comparing different MDT *pro formas* for instance) to see if that had an impact on the ways in which prognoses are negotiated or used in clinical care. Similarly, it would be interesting to ask MDT members, how they perceive their current prognostic discussions, and how they would prefer them to happen. In this way, interventions or guidelines could be developed *with* the professionals and not *for* them. Since it was seen that MDT meetings rarely contained explicit discussions of prognoses or specific time estimates, it would be interesting to further explore what these professionals think is the “optimal” way of having these discussions and what prognostication means to them. This could be done for example through interviews, focus group discussions or other (co-design) workshop methods. Another way of exploring this, would be through interventions such as the Conversation Analytic Role-play Method (Stokoe 2014). This intervention involves professionals watching recordings and transcripts of their own conversations and then “analysing” and reflecting on them. Similarly, hospice MDT members could watch and work with recordings of their own prognostic discussions.

The results implied that prognostication might happen outside the formal MDT meeting. Therefore, there would be scope for using conversation analytic techniques with other less formal hospice interactions to understand the extent to which prognostic discussions occur in these settings. This might, for instance, include investigating handover meetings and ward rounds. Moreover, informal non-structured chats such as ward hallway and nursing station interaction might provide additional insights into how prognoses are being discussed. This would provide a better, more comprehensive, picture of how prognostication is done throughout the care process.

This conversation analytic study only focused on three aspects of MDT prognostication, but there are several other aspects that could have been explored. For example, future studies could map the decision-making process during MDT meetings. This has been done in another study focusing on decision-making during Emergency Department MDT meetings where the different steps in the organisation of decision-making were described (Seuren et al. 2019). Further studies could investigate how, and potentially why, prognostication primarily occurred between doctors and nurses during the MDT meeting. Here, it could be relevant to look closer at membership categorisation (Schegloff 2007a) to see how members display their different institutional roles in relation to prognosis. Another interesting aspect would be to explore how knowledge domains or epistemics (Heritage 2013) are organised between speakers during the meeting with regards to prognostication. Epistemic stance involves how participants position themselves in interaction with respect to one another as concerns who knows what and how they came to know it (Couper-Kuhlen and Selting 2018: 3). Here it could also be relevant to further study the deontic stance when discussing prognoses. Deontic stance involves how entitlement and authority is displayed in interaction to decide within some domain of action what is necessary or desirable to do (Couper-Kuhlen and Selting 2018). These two aspects would add an additional layer to the analysis MDT prognostication and further shed light on the finding that it is doctors and nurses who are the professional groups who provide prognoses. Another focus of future analyses could be to explore how staff members deal with patients’ lack of prognostic awareness or acceptance. In this way, future CA studies could (further) explore and map the remaining steps of the prognostic decision-making process (i.e., prognostic prediction, prognostic disclosure, prognostic awareness, prognostic acceptance, and prognosis-based decision-making) (Hui, Mo, and Paiva 2021).

This thesis has focused on how patient prognoses were discussed in the hospice MDT. Future research should explore other specialist palliative care teams such as hospital palliative care units or community palliative care teams. The hospital palliative care MDT might look different to the hospice MDT, perhaps more like a typical cancer MDT, with more specialist (doctors) involved and thereby potentially with more of a medical focus. The community MDT might be expected to work more closely with GPs and might experience other types of difficulties related to not being based in a certain institution and having to provide palliative home care (see DeMiglio and Williams 2012). These are simply hypotheses, and there might be differences and similarities between these different types of environments. As shown in the scoping review, Chapter 3, there is a need to further explore MDT prognostication in other specialist palliative care settings.

Uncertainty has previously been mentioned as an inevitable aspect of prognostication. Future research should explore how uncertainty is managed when the MDT discuss prognosis. This could be done through a deeper detailed interactional linguistic analysis focusing on how professionals express prognostic uncertainty and navigate it. Such an analysis would deepen an understanding about what part uncertainty plays in these discussions. Aspects such as confidence and the reasoning behind participants' decisions would also further elaborate on the notion of uncertainty.

Chapter 7 and Chapter 8 discussed the possibility that accountability might play a part in explaining why professionals avoided providing more specific prognoses. It would be interesting to further explore the notion of prognostic accountability between staff members. The study by Christakis and Iwashyna (1998), showed that doctors tend not to hold colleagues accountable for prognostic errors. If these findings still hold true in a similar and more recent study, they could then be used in future guidelines stressing that the MDT meeting is a safe space, without negative judgments from colleagues, when providing (inaccurate) prognoses.

The question of how allied healthcare professionals contribute to prognostication in MDT meetings remains to be explored. The thesis findings indicate a limited involvement for these professional groups in prognostication, but this needs to be further investigated. Social workers and chaplains, for instance, might play a part in other parts of the prognostic decision-making process even if they are not involved to a large extent in formulating or communicating prognoses. It would be interesting to try and discover how they are involved. As proposed in this section, this could include interview and focus groups methods to explore their perceptions of and experiences with prognostication, but also by exploring (using conversation analytic approaches) their informal chats with patients. It could also be relevant to explore if prognosis is mentioned when they are having discussions with colleagues with the same professional background as themselves.

The ADJUST study results suggested that there is a need for further research exploring how MDT members prognosticate and how they use advice in this process. In particular, there is much greater scope for exploring the role of prognostic algorithms in clinical practice. One approach could be to use ethnographic observations of professionals to capture the use of prognostic tools “in real life”. Wider questions also arise about evaluating the impact of using prognostic tools in clinical practice, and how such outcomes could be measured.

Future studies (using modifications of the ADJUST methodology) should strive to create an experimental setting that better mirrors real-life clinical situations. Findings could more easily be applied if the experimental set-up mirrored the real-world situation as closely as possible. This could be done, for example, by using recordings of MDT meetings and using these to create the experimental setting.

It was noted that there is a need for more research trying to explore the processes underlying prognostication at the individual level. Surveys could try and map whether professionals had considered a patient’s prognosis following a consultation, and if so, what they thought the patient’s prognosis was at that point of time. Following an MDT meeting, the professionals could fill in another survey to see if their view about the prognosis had changed. The theoretic decision-making models presented in Chapter 1 (i.e., Brunswik’s Lens Model, the dual-process theory, and the emotion-imbued choice model) could also be further explored by setting up new experiments in which relevant professionals complete decision-making tasks.

10.8 Conclusions

As it is inevitable that everyone is going to die at some point, and with an expanding and ageing population, with complex and multiple health needs, it is important to improve health services in order to better manage end-of-life care patients. The MDT is considered the optimal way of delivering end-of-life palliative care and as prognostication is essential for clinical decision-making, it is important to deepen the understanding of how such decisions are arrived at by the MDT.

This thesis was the first to investigate how members of the specialist palliative care MDT make prognostic decisions. The research, using both a synthesis of the evidence and a combination of quantitative and qualitative research methodologies, provided a greater understanding of prognostic decision-making within the hospice MDT.

The literature review demonstrated how the topic of MDT prognostic decision-making has been underexplored. Previous research showed that prognostic decisions involved sharing information with other MDT members. Information coming from different team members can be seen as advice coming from different sources. Despite the MDT fostering decisions made together or being agreed upon by multiple people, the task of prognostication within the MDT is maintained by doctors and nurses. When being told that prognostic advice came from a prognostic algorithm, MDT members took the advice more into account when making their prognostic decisions. Traditional characteristics, such as an MDT members' level of experience or their profession, that may influence how they integrate advice, did not hold true in this thesis. Instead, it was seen how the nature of the advice itself might impact whether professionals take advice onboard when making prognostic decisions.

During MDT meeting discussions, information-sharing was evident, but prognoses were not discussed as a decision to be made. Prognostic discussions were sometimes prompted as a response to one of the items on the meeting template and sometimes arose in other contexts (such as when the MDT was discussing discharge plans). The way prognoses were formulated was either by stating the patient was dying or using unspecific time estimates. MDT members generally welcomed advice when having to make prognostic decisions, which might indicate that the decision was difficult. In the MDT meeting, it was also seen how discussing prognoses was sensitive and delicate from an interactional point of view. This seems to underline the struggle that professionals encounter when having to predict when someone dies and the inherent uncertainty that it involves.

The results from these studies constitute the first step towards the development of future interventions, recommendations, and clinical guidelines. Study findings in combination with future research will hopefully contribute to improving prognostication of imminent death within the specialist palliative care hospice MDT.

References

Abu-Ghori, I. K., M. M. Bodrick, R. Hussain, and G. Rassool. 2016. 'Nurses' involvement in end-of-life care of patients after a do not resuscitate decision on general medical units in Saudi Arabia', *Intensive and Critical Care Nursing*, 33: 21-29.

Adams, E., M. Boulton, and E. Watson. 2009. 'The information needs of partners and family members of cancer patients: a systematic literature review', *Patient Educ Couns*, 77: 179-86.

Altman, D. G. 2001. 'Systematic reviews of evaluations of prognostic variables', *BMJ*, 323: 224.

Anderson, F., G. M. Downing, J. Hill, L. Casorso, and N. Lerch. 1996. 'Palliative performance scale (PPS): a new tool', *Journal of Palliative Care*, 12: 5-11.

Anderson, R. J. 2020. 'Communication with the relatives and friends of imminently dying patients in a hospice', Doctoral thesis, UCL (University College London).

Anderson, R. J., P. C. Stone, J. T. S. Low, and S. Bloch. 2020. 'Managing uncertainty and references to time in prognostic conversations with family members at the end of life: A conversation analytic study', *Palliative Medicine*, 34: 896-905.

———. 2021. 'Transitioning out of prognostic talk in discussions with families of hospice patients at the end of life: A conversation analytic study', *Patient Education and Counseling*, 104: 1075-85.

Andersson, S., O. Lindqvist, C. J. Furst, and M. Brannstrom. 2018. 'Care professional's experiences about using Liverpool Care Pathway in end-of-life care in residential care homes', *Scandinavian journal of caring sciences*, 32: 299-308.

Antaki, C. 2011. 'Six Kinds of Applied Conversation Analysis.' in Charles Antaki (ed.), *Applied Conversation Analysis: Intervention and Change in Institutional Talk* (Palgrave Macmillan UK: London).

Arber, A. 2008. 'Team meetings in specialist palliative care: Asking questions as a strategy within interprofessional interaction', *Qualitative Health Research*, 18: 1323-35.

Arksey, H., and L. O'Malley. 2005. 'Scoping Studies: Towards a Methodological Framework', *International Journal of Social Research Methodology*, 8: 19-32.

Armstrong, R., B. J. Hall, J. Doyle, and E. Waters. 2011. 'Cochrane Update. 'Scoping the scope' of a cochrane review', *J Public Health (Oxf)*, 33: 147-50.

Asmuß, B., and J. Svennevig. 2009. 'Meeting Talk: An Introduction', *The Journal of Business Communication (1973)*, 46: 3-22.

Barnard, R. A., M. N. Cruice, and E. D. Playford. 2010. 'Strategies Used in the Pursuit of Achievability During Goal Setting in Rehabilitation', *QUAL HEALTH RES*, 20: 239-50.

Barnes, R. 2007. 'Formulations and the facilitation of common agreement in meetings talk', 27: 273-96.

Basta, Y. L., S. Bolle, P. Fockens, and K. Tytgat. 2017. 'The Value of Multidisciplinary Team Meetings for Patients with Gastrointestinal Malignancies: A Systematic Review', *Ann Surg Oncol*, 24: 2669-78.

Beach, W. A., and E. Prickett. 2017. 'Laughter, Humor, and Cancer: Delicate Moments and Poignant Interactional Circumstances', *Health Communication*, 32: 791-802.

Bern-Klug, M., C. E. Gessert, C. W. Crenner, M. Buenaver, and D. Skirchak. 2004. '"Getting everyone on the same page": nursing home physicians' perspectives on end-of-life care', *Journal of Palliative Medicine*, 7: 533-44.

Bloomer, M. J., M. Botti, F. Runacres, P. Poon, J. Barnfield, and A. M. Hutchinson. 2018. 'Communicating end-of-life care goals and decision-making among a multidisciplinary geriatric inpatient rehabilitation team: A qualitative descriptive study', *Palliative Medicine*, 32: 1615-23.

———. 2019. 'End-of-life care for older people in subacute care: A retrospective clinical audit', *Collegian*, 26: 22-27.

Bloomer, M. J., R. Endacott, M. O'Connor, and W. Cross. 2013. 'The 'dis-ease' of dying: challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study', *Palliat Med*, 27: 757-64.

Boden, D. 1997. *The business of talk: Organizations in action* (Polity Press: Cambridge, UK).

Bonaccio, S., and R. S. Dalal. 2006. 'Advice taking and decision-making: An integrative literature review, and implications for the organizational sciences', *Organizational Behavior and Human Decision Processes*, 101: 127-51.

Borbasi, S., K. Wotton, M. Redden, and Y. Champan. 2005. 'Letting go: a qualitative study of acute care and community nurses' perceptions of a ‘good’ versus a ‘bad’ death', *Australian Critical Care*, 18: 104-13.

Borgstrom, E., S. Cohn, A. Driessen, J. Martin, and S. Yardley. 2021. 'Multidisciplinary team meetings in palliative care: an ethnographic study', *BMJ Supportive &amp; Palliative Care*: bmjspcare-2021-003267.

Bostanci, A., D. Horey, K. Jackson, L. William, L. Pittmann, J. Ward, G. Moore, P. Martin, P. Hudson, and J. Philip. 2016. 'Insights into hospitalisation of advanced cancer patients: a study of medical records', *European Journal of Cancer Care*, 25: 190-201.

Brighton, L. J., L. E. Selman, K. Bristowe, B. Edwards, J. Koffman, and C. J. Evans. 2019. 'Emotional labour in palliative and end-of-life care communication: A qualitative study with generalist palliative care providers', *Patient Education and Counseling*, 102: 494-502.

Brown, B., K. O'hara, M. Mcgregor, and D. Mcmillan. 2018. 'Text in Talk: Lightweight Messages in Co-Present Interaction', *ACM Transactions on Computer-Human Interaction*, 24: Article 42.

Bruera, E., and D. Hui. 2008. 'Practical Model for Prognostication in Advanced Cancer Patients: Is Less More?', *Journal of Clinical Oncology*, 26: 5843-44.

Bruun, A., L. Oostendorp, S. Bloch, N. White, L. Mitchinson, A. Sisk, and P. Stone. 2022. 'Prognostic decision-making about imminent death within multidisciplinary teams: a scoping review', *BMJ Open*, 12: e057194.

Bruun, A., N. White, L. Oostendorp, V. Vickerstaff, A. J. L. Harris, C. Tomlinson, S. Bloch, and P. Stone. 2022. 'An online randomised controlled trial of prognosticating imminent death in advanced cancer patients: Clinicians give greater weight to advice from a prognostic algorithm than from another clinician with a different profession', *Cancer Medicine*.

Butow, P. N., J. M. Clayton, and R. M. Epstein. 2020. 'Prognostic Awareness in Adult Oncology and Palliative Care', *Journal of Clinical Oncology*, 38: 877-84.

Care Quality Commission. 2017. 'The state of hospice services in England 2014 to 2017'. https://www.cqc.org.uk/sites/default/files/20171013_state_of_hospice_services.pdf.

Caswell, G., K. Pollock, R. Harwood, and D. Porock. 2015. 'Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study', *BMC Palliative Care*, 14: 35.

Chamberlain-Salaun, J., J. Mills, and K. Usher. 2013. 'Terminology used to describe health care teams: an integrative review of the literature', *Journal of multidisciplinary healthcare*, 6: 65-74.

Chow, E., T. Harth, G. Hruby, J. Finkelstein, J. Wu, and C. Danjoux. 2001. 'How accurate are physicians' clinical predictions of survival and the available prognostic tools in estimating survival times in terminally ill cancer patients? A systematic review', *Clinical Oncology (The Royal College of Radiologist)*, 13: 209-18.

Christakis, N. A. 1999. *Death foretold: prophecy and prognosis in medical care* (The University of Chicago Press: London).

Christakis, N. A., and T. J. Iwashyna. 1998. 'Attitude and Self-reported Practice Regarding Prognostication in a National Sample of Internists', *Archives of Internal Medicine*, 158: 2389-95.

Christakis, N. A., and E. B. Lamont. 2000. 'Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study', *BMJ*, 320: 469-72.

Christensen, C., and J. R. Larson. 1993. 'Collaborative Medical Decision Making', *Medical Decision Making*, 13: 339-46.

Chu, C., R. Anderson, N. White, and P. Stone. 2020. 'Prognosticating for Adult Patients With Advanced Incurable Cancer: a Needed Oncologist Skill', *Current Treatment Options in Oncology , 21 , Article 5. (2020)*.

Chu, C., N. White, and P. Stone. 2019. 'Prognostication in palliative care', *Clinical Medicine*, 19: 306-10.

Chuang, E., R. Lamkin, A. A. Hope, G. Kim, J. Burg, and M. N. Gong. 2017. '"I Just Felt Like I Was Stuck in the Middle": Physician Assistants' Experiences Communicating With Terminally Ill Patients and Their Families in the Acute Care Setting', *Journal of Pain and Symptom Management*, 54: 27-34.

Clark, J. B., K. Sheward, B. Marshall, and S. G. Allan. 2012. 'Staff perceptions of end-of-life care following implementation of the liverpool care pathway for the dying patient in the acute care setting: a New Zealand perspective', *Journal of Palliative Medicine*, 15: 468-73.

Clark, S., and J. Rendle-Short. 2016. 'Accomplishing a Continuing Relationship in Psychotherapy: Updates and the Role of Time References', *Australian Journal of Linguistics*, 36: 239-56.

Clarkson, R., D. Selby, and J. Myers. 2013. 'A qualitative analysis of the elements used by palliative care clinicians when formulating a survival estimate', *BMJ Support Palliat Care*, 3: 330-4.

Cooksey, R. W. 1996. *Judgment Analysis - Theory, Methods, and Applications* (Academic Press: San Diego).

Costello, J. 2001. 'Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards', *Journal of Advanced Nursing*, 35: 59-68.

Couper-Kuhlen, E., and M. Selting. 2018. *Interactional Linguistics: Studying Language in Social Interaction* (Cambridge University Press: Cambridge, UK).

Coventry, P. A., G. E. Grande, D. A. Richards, and C. J. Todd. 2005. 'Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review', *Age Ageing*, 34: 218-27.

Cowie, M. R. 2002. 'The fine art of prognostication', *European Heart Journal*, 23: 1804-06.

Crawford, G. B., and S. D. Price. 2003. 'Team working: palliative care as a model of interdisciplinary practice', *Medical Journal of Australia*, 179: 32-34.

Cresswell, J. W., and J. D. Cresswell. 2018. *Research design: qualitative, quantitative, and mixed methods approaches* (SAGE: Los Angeles).

Dawadi, S., S. Shrestha, and R. A. Giri. 2021. 'Mixed-Methods Research: A Discussion on its Types, Challenges, and Criticisms', *Journal of Practical Studies in Education*, 2: 25-36.

de Ruiter, J. P., and S. Albert. 2017. 'An Appeal for a Methodological Fusion of Conversation Analysis and Experimental Psychology', *Research on Language and Social Interaction*, 50: 90-107.

Dee, J. F., and R. Endacott. 2011. 'Doing the right thing at the right time', *Journal of Nursing Management (John Wiley & Sons, Inc.)*, 19: 186-92.

Degner, L. F., L. J. Kristjanson, D. Bowman, J. A. Sloan, K. C. Carriere, J. O'Neil, B. Bilodeau, P. Watson, and B. Mueller. 1997. 'Information needs and decisional preferences in women with breast cancer', *JAMA*, 277: 1485-92.

DeMiglio, L., and A. Williams. 2012. 'Shared care: the barriers encountered by community-based palliative care teams in Ontario, Canada', *Health & Social Care in the Community*, 20: 420-29.

Demiris, G., K. Washington, D. P. Oliver, and E. Wittenberg-Lyles. 2008. 'A study of information flow in hospice interdisciplinary team meetings', *Journal of Interprofessional Care*, 22: 621-29.

Department of Health. 2008. 'End of Life Care Strategy', Accessed 28/09/2022. https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life.

———. 2012. 'Liberating the NHS: No decisions about me, without me - Government response to the consultation', Accessed 08/02/2023. https://assets.publishing.service.gov.uk/government/uploads/system/u ploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf.

Dew, K. 2016. 'Purifying and hybridising categories in healthcare decision-making: the clinic, the home and the multidisciplinary team meeting', *Health Sociology Review*, 25: 142-56.

Dew, K., M. Stubbe, L. Signal, J. Stairmand, E. Dennett, J. Koea, A. Simpson, D. Sarfati, C. Cunningham, L. Batten, L. Ellison-Loschmann, J. Barton, and M. Holdaway. 2014. 'Cancer Care Decision Making in Multidisciplinary Meetings', *Qualitative Health Research*, 25: 397-407.

Dietvorst, B. J., J. P. Simmons, and C. Massey. 2015. 'Algorithm aversion: People erroneously avoid algorithms after seeing them err', *Journal of Experimental Psychology: General*, 144: 114-26.

Doyle, Louise, Anne-Marie Brady, and Gobnait Byrne. 2016. 'An overview of mixed methods research – revisited', *Journal of Research in Nursing*, 21: 623-35.

Drew, P., and J. Heritage. 1992. 'Analyzing talk at work: an introduction ' in Drew. Paul and John Heritage (eds.), *Talk at work: interaction in institutional settings* (Cambridge University Press: Cambridge).

Dugan Day, M. 2012. 'Interdisciplinary Hospice Team Processes and Multidimensional Pain: A Qualitative Study', *Journal of Social Work in End-of-Life & Palliative Care*, 8: 53-76.

Edwards, D. 2004. "Poof procedure." In *The SAGE Encyclopedia of Social Science Research Methods*, edited by Michael Lewis-Beck, Alan Bryman and Tim Futing Liao. Thousand Oaks, California: Sage Publications, Inc.

Ekberg, S., R. Parry, V. Land, K. Ekberg, M. Pino, C. Antaki, L. Jenkins, and B. Whittaker. 2021. 'Communicating with patients and families about illness progression and end of life: a review of studies using direct observation of clinical practice', *BMC Palliative Care*, 20: 186-86.

Ellershaw, J., R. J. Neuberger, and C. Ward. 2003. 'Care of the dying patient: the last hours or days of life', *BMJ*, 326: 30.

European Association for Palliative Care. 2020. 'What is palliative care?', Accessed 13/11/2020. https://www.eapcnet.eu/about-us/what-we-do.

Fernando, G., and S. Hughes. 2019. 'Team approaches in palliative care: a review of the literature', *International Journal of Palliative Nursing*, 25: 444-51.

Fetters, M. D., L. A. Curry, and J. W. Creswell. 2013. 'Achieving Integration in Mixed Methods Designs—Principles and Practices', *Health Services Research*, 48: 2134-56.

Ford, J., A. Hepburn, and R. Parry. 2019. 'What do displays of empathy do in palliative care consultations?', *Discourse Studies*, 21: 22-37.

Freemantle, A., and J. Seymour. 2012. 'Why is the Liverpool care pathway used for some dying cancer patients and not others? Healthcare professionals' perspectives', *BMC research notes*, 5: 524-24.

Fryer, S., G. Bellamy, T. Morgan, and M. Gott. 2016. '"Sometimes I've gone home feeling that my voice hasn't been heard": a focus group study exploring the views and experiences of health care assistants when caring for dying residents', *BMC Palliative Care*, 15: 78.

Funk, L. M., S. Peters, and K. S. Roger. 2018. 'Caring about dying persons and their families: Interpretation, practice and emotional labour', *Health & Social Care in the Community*, 26: 519-26.

Furman, M., L. Harild, M. Anderson, J. Irish, K. Nguyen, and F. C. Wright. 2018. 'The Development of Practice Guidelines for a Palliative Care Multidisciplinary Case Conference', *Journal of Pain and Symptom Management*, 55: 395-401.

Gair, G., and T. Hartery. 2001. 'Medical dominance in multidisciplinary teamwork: a case study of discharge decision-making in a geriatric assessment unit', *J Nurs Manag*, 9: 3-11.

Gambles, M., S. Stirzaker, B. A. Jack, and J. E. Ellershaw. 2006. 'The Liverpool Care Pathway in hospices: an exploratory study of doctor and nurse perceptions', *Int J Palliat Nurs*, 12: 414-21.

Gardner, R. 2012. 'Conversation Analysis in the Classroom.' in, *The Handbook of Conversation Analysis*.

General Medical Council. 2010. 'Treatment and care towards the end of life: good practice in decision making', Accessed 28/09/2022. https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life.

Gensheimer, M. F., S. Aggarwal, K. R. K. Benson, J. N. Carter, A. S. Henry, D. J. Wood, S. G. Soltys, S. Hancock, E. Pollom, N. H. Shah, and D. T. Chang. 2021. 'Automated model versus treating physician for predicting survival time of patients with metastatic cancer', *Journal of the American Medical Informatics Association*, 28: 1108-16.

Gidwani, R., A. Nevedal, M. Patel, D. W. Blayney, C. Timko, K. Ramchandran, P. A. Kelly, and S. M. Asch. 2017. 'The Appropriate Provision of Primary versus Specialist Palliative Care to Cancer Patients: Oncologists' Perspectives', *Journal of Palliative Medicine*, 20: 395-403.

Gill, T. M. 2012. 'The Central Role of Prognosis in Clinical Decision Making', *JAMA*, 307: 199-200.

Glare, P. A., and C. T. Sinclair. 2008. 'Palliative Medicine Review: Prognostication', *Journal of Palliative Medicine*, 11: 84-103.

Glare, P., K. Virik, M. Jones, M. Hudson, S. Eychmuller, J. Simes, and N. Christakis. 2003. 'A systematic review of physicians' survival predictions in terminally ill cancer patients', *BMJ*, 327: 195-8.

Glogowska, M., R. Simmonds, S. McLachlan, H. Cramer, T. Sanders, R. Johnson, U. T. Kadam, D. S. Lasserson, and S. Purdy. 2016. '"Sometimes we can't fix things": a qualitative study of health care professionals' perceptions of end of life care for patients with heart failure', *BMC Palliative Care*, 15: 3.

Goffman, E. 1955. 'On Face-Work: An Analysis of Ritual Elements in Social Interaction', *Psychiatry*, 18: 213-31.

Goldsmith, J., E. Wittenberg-Lyles, D. Rodriguez, and S. Sanchez-Reilly. 2009. 'Interdisciplinary Geriatric and Palliative Care Team Narratives: Collaboration Practices and Barriers', *Qualitative Health Research*, 20: 93-104.

Gott, M., C. Ingleton, M. I. Bennett, and C. Gardiner. 2011. 'Transitions to palliative care in acute hospitals in England: qualitative study', *BMJ*, 342: d1773.

Gwilliam, B., V. Keeley, C. Todd, M. Gittins, C. Roberts, L. Kelly, S. Barclay, and P. C. Stone. 2011. 'Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study', *BMJ*, 343: d4920.

Gwilliam, B., V. Keeley, C. Todd, C. Roberts, M. Gittins, L. Kelly, S. Barclay, and P. Stone. 2013. 'Prognosticating in patients with advanced cancer-observational study comparing the accuracy of clinicians' and patients' estimates of survival', *Annals of Oncology*, 24: 482-88.

Hagerty, R. G., P. N. Butow, P. M. Ellis, S. Dimitry, and M. H. N. Tattersall. 2005. 'Communicating prognosis in cancer care: a systematic review of the literature', *Annals of Oncology*, 16: 1005-53.

Hallen, S. A. M., N. A. M. Hootsmans, L. Blaisdell, C. M. Gutheil, and P. K. J. Han. 2015. 'Physicians' perceptions of the value of prognostic models: the benefits and risks of prognostic confidence', *Health Expectations*, 18: 2266-77.

Hancock, K., J. M. Clayton, S. M. Parker, S. Wal der, P. N. Butow, S. Carrick, D. Currow, D. Ghersi, P. Glare, R. G. Hagerty, and M. H. N. Tattersall. 2007. 'Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review', *Palliative Medicine*, 21: 507-17.

Hanna, Jeffrey R, Elizabeth Rapa, Louise J Dalton, Rosemary Hughes, Tamsin McGlinchey, Kate M Bennett, Warren J Donnellan, Stephen R Mason, and Catriona R Mayland. 2021. 'A qualitative study of bereaved relatives’ end of life experiences during the COVID-19 pandemic', *Palliative Medicine*, 35: 843-51.

Hanson, L. C., M. Henderson, and M. Menon. 2002. 'As individual as death itself: a focus group study of terminal care in nursing homes', *J Palliat Med*, 5: 117-25.

Haraldsdottir, Erna, Anna Lloyd, Martyn Bijak, Libby Milton, and Anne M. Finucane. 2023. 'Inpatient hospice admissions. Who is admitted and why: a mixed-method prospective study', *Palliative Care and Social Practice*, 17: 26323524231182724.

Hasson, F., E. Nicholson, D. Muldrew, O. Bamidele, S. Payne, and S. McIlfatrick. 2020. 'International palliative care research priorities: A systematic review', *BMC Palliative Care*, 19: 16.

Hearn, J., and I. J. Higginson. 1998. 'Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review', *Palliative Medicine*, 12: 317-32.

Hepburn, A., and G. B. Bolden. 2012. 'The Conversation Analytic Approach to Transcription.' in Jack Sidnell and Tanya Stivers (eds.), *The Handbook of Conversation Analysis*.

Heritage, J. 1985. 'A change-of-state token and aspects of its sequential placement.' in J. Maxwell Atkinson (ed.), *Structures of Social Action* (Cambridge University Press: Cambridge).

———. 2013. 'Epistemics in Conversation.' in Jack Sidnell and Tanya Stivers (eds.), *Handbook of Conversation Analysis* (Wiley-Blackwell: Chichester, UK).

Heritage, J., and J. M. Atkinson. 1985. 'Introduction.' in J. Maxwell Atkinson (ed.), *Structures of Social Action* (Cambridge University Press: Cambridge).

Heritage, J., and J. D. Robinson. 2011. '‘Some’ versus ‘Any’ Medical Issues: Encouraging Patients to Reveal Their Unmet Concerns.' in C. Antaki (ed.), *Applied Conversation Analysis: Intervention and Change in Institutional Talk* (Palgrave Macmillan UK: London).

Higginson, I. J., and G. J. Sen-Gupta. 2000. 'Place of care in advanced cancer: a qualitative systematic literature review of patient preferences', *J Palliat Med*, 3: 287-300.

Higginson, Irene J., and Massimo Costantini. 2002. 'Accuracy of prognosis estimates by four palliative care teams: a prospective cohort study', *BMC Palliative Care*, 1: 1.

Hill, E., M. Y. Savundranayagam, A. Zecevic, and M. Kloseck. 2018. 'Staff Perspectives of Barriers to Access and Delivery of Palliative Care for

Persons With Dementia in Long-Term Care', *American Journal of Alzheimer's Disease & Other Dementias*, 33: 284-91.

Hochschild, A. R. 2012. 'Exploring the Managed Heart.' in, *The Managed Heart* (University of California Press).

Hockley, J., B. Dewar, and J. Watson. 2005. 'Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life.'', *NT Research*, 10: 135-52.

Hoey, E. M., and K. H. Kendrick. 2017. 'Conversation Analysis.' in A. M. B. de Groot and P. Hagoort (eds.), *Research Methods in Psycholinguistics and the Neurobiology of Language: A Practical Guide* (Wiley Blackwell).

Hofheinz, C., M. Germar, T. Schultze, J. Michalak, and A. Mojzisch. 2017. 'Are depressed people more or less susceptible to informational social influence?', *Cognitive Therapy and Research*, 41: 699-711.

Hofstetter, E. 2021. 'Analyzing the researcher-participant in EMCA', *Social Interaction. Video-Based Studies of Human Sociality*, 4.

Holleman, Gijs A., Ignace T. C. Hooge, Chantal Kemner, and Roy S. Hessels. 2020. 'The ‘Real-World Approach’ and Its Problems: A Critique of the Term Ecological Validity', *Frontiers in psychology*, 11.

Holt, E. 1993. 'The structure of death announcements: Looking on the bright side of death', *Text - Interdisciplinary Journal for the Study of Discourse*, 13: 189-212.

Hospice UK. 2016. 'Hospice care in the UK 2016', Accessed 28/09/2022. www.hospiceuk.org/docs/default-source/What-We-Offer/publications-documents-and-files/hospice-care-in-the-uk-2016.pdf?sfvrsn=0

———. n.d.-a. 'Facts and figures', Accessed 10/09/2022. https://professionals.hospiceuk.org/about-hospice-care/media-centre/facts-and-figures.

———. n.d.-b. 'What is hospice care?', Accessed 27/07/2023. https://www.hospiceuk.org/information-and-support/your-guide-hospice-and-end-life-care/im-looking-hospice-care/what-hospice.

Housley, W. 1999. 'Role as an Interactional Device and Resource in Multidisciplinary Team Meetings', *Sociological Research Online*, 4: 82-95.

Hui, D. 2015. 'Prognostication of Survival in Patients With Advanced Cancer: Predicting the Unpredictable?', *Cancer Control*, 22: 489-97.

Hui, D., K. Kilgore, L. Nguyen, S. Hall, J. Fajardo, T. P. Cox-Miller, S. L. Palla, W. Rhondali, J. H. Kang, S. H. Kim, E. Del Fabbro, D. S. Zhukovsky, S. Reddy, A. Elsayem, S. Dalal, R. Dev, P. Walker, S. Yennu, A. Reddy, and E. Bruera. 2011. 'The accuracy of probabilistic versus temporal clinician prediction of survival for patients with advanced cancer: a preliminary report', *Oncologist*, 16: 1642-8.

Hui, D., J. P. Maxwell, and C. E. Paiva. 2019. 'Dealing with prognostic uncertainty: the role of prognostic models and websites for patients with advanced cancer', *Curr Opin Support Palliat Care*, 13: 360-68.

Hui, D., L. Mo, and C. E. Paiva. 2021. 'The Importance of Prognostication: Impact of Prognostic Predictions, Disclosures, Awareness, and Acceptance on Patient Outcomes', *Current Treatment Options in Oncology*, 22: 12.

Hui, D., Z. Nooruddin, N. Didwaniya, R. Dev, M. De La Cruz, S. H. Kim, J. H. Kwon, R. Hutchins, C. Liem, and E. Bruera. 2014. 'Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": a systematic review', *Journal of Pain and Symptom Management*, 47: 77-89.

Hui, D., C. E. Paiva, E. G. Del Fabbro, C. Steer, J. Naberhuis, M. van de Wetering, P. Fernández-Ortega, T. Morita, S. Suh, E. Bruera, and M. Mori. 2019. 'Prognostication in advanced cancer: update and directions for future research', *Supportive Care in Cancer*, 27: 1973-84.

Huisman, M. 2001. 'Decision-Making in Meetings as Talk-in-Interaction', *International Studies of Management & Organization*, 31: 69-90.

Independent Cancer Taskforce. 2015. 'Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020', Accessed 04/08/2022. https://www.cancerresearchuk.org/sites/default/files/executive_summary_meeting_patients_needs_improving_the_effectiveness_of_multidisciplinary_team_meetings.pdf.

Jefferson, G. 2004. 'Glossary of transcript symbols with an introduction.' in G. H. Lerner (ed.), *Conversation Analysis: Studies from the first generation* (John Benjamins Publishing Company: Amsterdam/Philadelphia).

Johnson, M., M. Attree, I. Jones, E. Al Gamal, and D. Garbutt. 2014. 'Diagnosis, prognosis and awareness of dying in nursing homes: towards the Gold Standard?', *International journal of older people nursing*, 9: 95-105.

Joyce, J. B., T. Douglass, B. Benwell, C. S. Rhys, R. Parry, R. Simmons, and A. Kerrison. 2022. 'Should we share qualitative data? Epistemological and practical insights from conversation analysis', *International Journal of Social Research Methodology*: 1-15.

Jünger, S., M. Pestinger, F. Elsner, N. Krumm, and L. Radbruch. 2007. 'Criteria for successful multiprofessional cooperation in palliative care teams', *Palliative Medicine*, 21: 347-54.

Kaliuzhna, M., V. Chambon, N. Franck, B. Testud, and J. B. Van der Henst. 2012. 'Belief revision and delusions: how do patients with schizophrenia take advice?', *PLoS One*, 7: e34771.

Kalpakidou, A. K., C. Todd, V. Keeley, J. Griffiths, K. Spencer, V. Vickerstaff, R. Z. Omar, and P. Stone. 2018. 'The Prognosis in Palliative care Study II (PiPS2): study protocol for a multi-centre, prospective, observational, cohort study', *BMC Palliative Care , 17 , Article 101. (2018)*.

Kaplan, M. 2010. 'SPIKES: a framework for breaking bad news to patients with cancer', *Clin J Oncol Nurs*, 14: 514-6.

Katila, J., Y. Gan, S. Goico, and M. H. Goodwin. 2021. 'Researchers' participation roles in video-based fieldwork: An introduction to a special issue', *Social Interaction. Video-Based Studies of Human Sociality*, 4.

Ke, K. M., J. M. Blazeby, S. Strong, F. E. Carroll, A. R. Ness, and W. Hollingworth. 2013. 'Are multidisciplinary teams in secondary care cost-effective? A systematic review of the literature', *Cost Effectiveness and Resource Allocation*, 11 (1) (no pagination).

Kee, F., T. Owen, and R. Leathem. 2007. 'Offering a prognosis in lung cancer: when is a team of experts an expert team?', *J Epidemiol Community Health*, 61: 308-13.

Kee, Frank, Tracy Owen, and Ruth Leathem. 2004. 'Decision Making in a Multidisciplinary Cancer Team: Does Team Discussion Result in Better Quality Decisions?', *Medical Decision Making*, 24: 602-13.

Keeble, E. , S. Scobie, and R. Hutchings. 2022. "Support at the end of life: The role of hospice services across the UK." In.

Keel, S., and V. Schoeb. 2017. 'Patient participation in action: patients' interactional initiatives during interdisciplinary goal-setting meetings in a rehabilitation clinic', *Text & Talk*, 37: 213-41.

Kelly, C. J., A. Karthikesalingam, M. Suleyman, G. Corrado, and D. King. 2019. 'Key challenges for delivering clinical impact with artificial intelligence', *BMC Medicine*, 17: 195.

Kennedy, J., D. N. Kleinmuntz, and M. E. Peecher. 1997. 'Determinants of the justifiability of performance in ill-structured audit tasks', *Journal of Accounting Research*, 35: 105-23.

Kidger, J., J. Murdoch, J. L. Donovan, and J. M. Blazeby. 2009. 'Clinical decision-making in a multidisciplinary gynaecological cancer team: a qualitative study', *BJOG: An International Journal of Obstetrics & Gynaecology*, 116: 511-17.

Kirk, P., I. Kirk, and L. J. Kristjanson. 2004. 'What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study', *BMJ*, 328: 1343.

Klarare, A., C. L. Hagelin, C. J. Fürst, and B. Fossum. 2013. 'Team Interactions in Specialized Palliative Care Teams: A Qualitative Study', *Journal of Palliative Medicine*, 16: 1062-69.

Kutner, J. S., J. F. Steiner, K. K. Corbett, D. W. Jahnigen, and P. L. Barton. 1999. 'Information needs in terminal illness', *Soc Sci Med*, 48: 1341-52.

Labov, W. 1972. 'Some principles of linguistic methodology', *Language in Society*, 1: 97-120.

Labov, W., and D. Fanshel. 1977. *Therapeutic Discourse: Psychotherapy as Conversation* (Academic Press: New York).

Lai, X. B., F. K. Y. Wong, and S. S. Y. Ching. 2018. 'The experience of caring for patients at the end-of-life stage in non-palliative care settings: a qualitative study', *BMC Palliative Care*, 17: 116.

Laidsaar-Powell, R., P. Butow, S. Bu, C. Charles, A. Gafni, W. Lam, J. Jansen, K. McCaffery, H. Shepherd, M. Tattersall, and I. Juraskova. 2013. 'Physician-patient-companion communication and decision-making: A systematic review of triadic medical consultations', *Patient Education and Counseling*, 91: 3-13.

Lamb, Benjamin W., Katrina F. Brown, Kamal Nagpal, Charles Vincent, James S. A. Green, and Nick Sevdalis. 2011. 'Quality of Care Management Decisions by Multidisciplinary Cancer Teams: A Systematic Review', *Annals of Surgical Oncology*, 18: 2116-25.

Larrick, R. P., and D. C. Feiler. 2015. 'Expertise in Decision Making.' in G. Keren and G. Wu (eds.), *The Wiley Blackwell Handbook of Judgment and Decision Making*.

Leadership Alliance for the Care of Dying People. 2014. 'One chance to get it right. Improving people's experience of care in the last few days and hours of life.', Accessed 28/09/2022. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf.

Leclerc, B., L. Blanchard, M. Cantinotti, Y. Couturier, D. Gervais, S. Lessard, and S. Mongeau. 2014. 'The effectiveness of Interdisciplinary Teams in End-Of-Life Palliative Care: A Systematic review of Comparative Studies', *Journal of Palliative Care*, 30: 44-54.

Légaré, F., R. Adekpedjou, D. Stacey, S. Turcotte, J. Kryworuchko, I. D. Graham, A. Lyddiatt, M. C. Politi, R. Thomson, G. Elwyn, and et al. 2018. 'Interventions for increasing the use of shared decision making by healthcare professionals', *Cochrane Database of Systematic Reviews*.

Lemos Dekker, N., M. Gysels, and J. T. van der Steen. 2018. 'Professional caregivers' experiences with the Liverpool Care Pathway in dementia:

An ethnographic study in a Dutch nursing home', *Palliat Support Care*, 16: 479-86.

Lerner, G. H. 2013. 'On the place of hesitating in delicate formulations: a turn-constructional infrastructure for collaborative indiscretion.' in G. Raymond, J. Sidnell and M. Hayashi (eds.), *Conversational Repair and Human Understanding* (Cambridge University Press: Cambridge).

Lerner, G. H., and C. Kitzinger. 2019. 'Well-Prefacing in the Organization of Self-Initiated Repair', *Research on Language and Social Interaction*, 52: 1-19.

Lerner, J. S., Y. Li, P. Valdesolo, and K. S. Kassam. 2015. 'Emotion and Decision Making', *Annual Review of Psychology*, 66: 799-823.

Logg, J. M., J. A. Minson, and D. A. Moore. 2019. 'Algorithm appreciation: People prefer algorithmic to human judgment', *Organizational Behavior and Human Decision Processes*, 151: 90-103.

Machin, D., M. J. Campbell, S. B. Tan, and S. H. Tan. 2018. *Sample Sizes for Clinical, Laboratory and Epidemiology Studies* (Chichester, UK: John Wiley & Sons, Ltd: Chichester, UK).

Mack, J. W., and T. J. Smith. 2012. 'Reasons Why Physicians Do Not Have Discussions About Poor Prognosis, Why It Matters, and What Can Be Improved', *Journal of Clinical Oncology*, 30: 2715-17.

MacWhinney, B. 2000. 'The CHILDES Project: Tools for Analyzing Talk (third edition): Volume I: Transcription format and programs, Volume II: The database', *Computational Linguistics*, 26: 657-57.

Mahmood-Yousuf, K., D. Munday, N. King, and J. Dale. 2008. 'Interprofessional relationships and communication in primary palliative care: impact of the Gold Standards Framework', *Br J Gen Pract*, 58: 256-63.

Maltoni, M., A. Caraceni, C. Brunelli, B. Broeckaert, N. Christakis, S. Eychmueller, P. Glare, M. Nabal, A. Viganò, P. Larkin, F. De Conno, G. Hanks, and S. Kaasa. 2005. 'Prognostic factors in advanced cancer patients: evidence-based clinical recommendations--a study by the Steering Committee of the European Association for Palliative Care', *J Clin Oncol*, 23: 6240-8.

Maltoni, M., O. Nanni, M. Pirovano, E. Scarpi, M. Indelli, C. Martini, M. Monti, E. Arnoldi, L. Piva, A. Ravaioli, G. Cruciani, R. Labianca, and D. Amadori. 1999. 'Successful validation of the palliative prognostic score in terminally ill cancer patients. Italian Multicenter Study Group on Palliative Care', *J Pain Symptom Manage*, 17: 240-7.

Mandelbaum, J. 2013. 'Storytelling in Conversation.' in J. Sidnell and T. Stivers (eds.), *The Handbook of Conversation Analysis* (Wiley-Blackwell: Chichester, UK).

Marie Curie. 2018. 'What are palliative care and end of life care?', Accessed 13/11/2020. https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care?gclid=EAIaIQobChMIteOEs-bm7AIVyIBQBh3N9QAGEAAYBCAAEgIvtPD_BwE.

———. 2022. 'Hospice Care', Accessed 27/07/2023. https://www.mariecurie.org.uk/help/support/diagnosed/practical-emotional-support/hospice-care#who.

Martin, E. J., and E. Widera. 2020. 'Prognostication in Serious Illness', *Medical Clinics of North America*, 104: 391-403.

Mather, H., P. Guo, A. Firth, J. M. Davies, N. Sykes, A. Landon, and F. E. M. Murtagh. 2018. 'Phase of Illness in palliative care: Cross-sectional analysis of clinical data from community, hospital and hospice patients', *Palliative Medicine*, 32: 404-12.

Maynard, D. W. 2003. *Bad news, good news: Conversational order in everyday talk and clinical settings* (University of Chicago Press: Chicago).

———. 2012. 'Everyone and No One to Turn to: Intellectual Roots and Contexts for Conversation Analysis.' in Jack Sidnell and Tanya Stivers (eds.), *The Handbook of Conversation Analysis*.

McCallin, A. 2001. 'Interdisciplinary practice – a matter of teamwork: an integrated literature review', *Journal of Clinical Nursing*, 10: 419-28.

Medical Dictionary for the Health Professions and Nursing. 2012. 'Prognosis', Accessed 13/08/2022. https://medical-dictionary.thefreedictionary.com/prognosis.

Mondada, L. 2012. 'The Conversation Analytic Approach to Data Collection.' in J. Sidnell and T. Stivers (eds.), *The Handbook of Conversation Analysis*.

Mori, M., T. Morita, E. Bruera, and D. Hui. 2022. 'Prognostication of the Last Days of Life', *Cancer Res Treat*, 54: 631-43.

Morita, T., J. Tsunoda, S. Inoue, and S. Chihara. 1999. 'The Palliative Prognostic Index: a scoring system for survival prediction of terminally ill cancer patients', *Supportive Care in Cancer*, 7: 128-33.

Munn, Z., M. D. J. Peters, C. Stern, C. Tufanaru, A. McArthur, and E. Aromataris. 2018. 'Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach', *BMC Medical Research Methodology*, 18: 143.

Murray, S. A., M. Kendall, K. Boyd, and A. Sheikh. 2005. 'Illness trajectories and palliative care', *BMJ*, 330: 1007.

Nappa, U., B. H. Rasmussen, B. Axelsson, and O. Lindqvist. 2014. 'Challenging situations when administering palliative chemotherapy - A nursing perspective', *European Journal of Oncology Nursing*, 18: 591-97.

National Institute for Health and Care Excellence. 2015. "Care of dying adults in the last days of life." In. London, UK.

———. 2019. 'End of life care for adults: service delivery.' in (National Institute for Health and Care Excellence (UK): London).

Neuberger, J., C. Guthrie, and D. Aaranovitch. 2013. "More care, less pathway: a review of the Liverpool care pathway." In. London: Department of Health.

NHS Digital. 2020. 'NHS Business Definitions: Multidisciplinary Team Meeting', Accessed 12/08/2020. https://www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions/m/multidisciplinary_team_meeting_de.asp?shownav=1.

NHS Finance and Operations. 2016. 'Our Commitment to you for end of life care: the Government Response to the Review of Choice in End of Life Care', Accessed 28/09/2022. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf.

NHS National End of Life Care Programme. 2013. *Optimising the role and value of the interdisciplinary team: providing person-centred end of life care* (NHS National End of Life Care Programme: UK).

Nic a Bháird, C. 2015. 'Multidisciplinary team meetings in community mental health care: a mixed-methods investigation of their functions and organisation', Doctoral thesis, UCL (University College London).

Nielsen, S. B. 2009. 'Accounts on the Behalf of Patients During Geriatric Case Conferences', *Research on Language and Social Interaction*, 42: 231-48.

Nouvet, E., P. H. Strachan, J. Kryworuchko, J. Downar, and J. J. You. 2016. 'Waiting for the body to fail: Limits to end-of-life communication in Canadian hospitals', *Mortality*, 21: 340-56.

Noyes, J., A. Booth, M. Cargo, K. Flemming, A. Harden, J. Harris, R. Garside, K. Hannes, T. Pantoja, and J. Thomas. 2019. 'Qualitative evidence.' in J. Higgins, J. Thomas, J. Chandler, M. Cumpston, T. Li, M. Page and V. Welch (eds.), *Cochrane Handbook for Systematic Reviews of Interventions* (Wiley-Blackwell: Hoboken, NJ).

Oliveira, I., F. Fothergill-Bourbonnais, C. McPherson, and B. Vanderspank-Wright. 2016. 'Battling a Tangled Web: The Lived Experience of Nurses Providing End-of-Life Care on an Acute Medical Unit', *Research and Theory for Nursing Practice*, 30: 353-78.

Øvretveit, J. 1993. *Coordinating community care : multidisciplinary teams and care management* (Open University Press: Buckingham).

———. 1996. 'Five ways to describe a multidisciplinary team', *Journal of Interprofessional Care*, 10: 163-71.

Parikh, R. B., C. R. Manz, M. N. Nelson, C. N. Evans, S. H. Regli, N. O'Connor, L. M. Schuchter, L. N. Shulman, M. S. Patel, J. Paladino, and J. A. Shea. 2022. 'Clinician perspectives on machine learning prognostic algorithms in the routine care of patients with cancer: a qualitative study', *Supportive Care in Cancer*, 30: 4363-72.

Parry, R. 2010. 'Video-based conversation analysis', *Sage handbook of qualitative methods in health research*: 373-96.

Parry, R., V. Land, and J. Seymour. 2014. 'How to communicate with patients about future illness progression and end of life: a systematic review', *BMJ supportive & palliative care*, 4: 331.

Parry, R., M. Pino, C. Faull, and L. Feathers. 2016. 'Acceptability and design of video-based research on healthcare communication: Evidence and recommendations', *Patient Education and Counseling*, 99: 1271-84.

Payne, S., A. Harding, T. Williams, J. Ling, and C. Ostgathe. 2022. 'Revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care (EAPC): A Delphi study', *Palliative Medicine*: 02692163221074547.

Pelaccia, T., J. Tardif, E. Triby, and B. Charlin. 2011. 'An analysis of clinical reasoning through a recent and comprehensive approach: the dual-process theory', *Medical Education Online*, 16: 5890.

Peräkylä, A. 2012. 'Conversation Analysis in Psychotherapy.' in J. Sidnell and T. Stivers (eds.), *The Handbook of Conversation Analysis*.

Perez-Cruz, P. E., R. Dos Santos, T. B. Silva, C. S. Crovador, M. S. Nascimento, S. Hall, J. Fajardo, E. Bruera, and D. Hui. 2014. 'Longitudinal temporal and probabilistic prediction of survival in a cohort of patients with advanced cancer', *Journal of Pain and Symptom Management*, 48: 875-82.

Peters, M. D. J., C. Marnie, A. C. Tricco, D. Pollock, Z. Munn, L. Alexander, P. McInerney, C. M. Godfrey, and H. Khalil. 2020. 'Updated methodological guidance for the conduct of scoping reviews', *JBI Evidence Synthesis*, 18: 2119-26.

Pettersson, M., M. Hedström, and A. T. Höglund. 2014. 'Striving for good nursing care: nurses' experiences of do not resuscitate orders within oncology and hematology care', *Nursing Ethics*, 21: 902-15.

———. 2020. 'The ethics of DNR-decisions in oncology and hematology care: a qualitative study', *BMC Medical Ethics*, 21: 1-9.

Pillay, B., A. C. Wootten, H. Crowe, N. Corcoran, B. Tran, P. Bowden, J. Crowe, and A. J. Costello. 2016. 'The impact of multidisciplinary team meetings on patient assessment, management and outcomes in oncology settings: A systematic review of the literature', *Cancer Treat Rev*, 42: 56-72.

Pino, M., and R. Parry. 2019a. 'How and when do patients request life-expectancy estimates? Evidence from hospice medical consultations and insights for practice', *Patient Education and Counseling*, 102: 223-37.

———. 2019b. 'Talking about death and dying: Findings and insights from five conversation analytic studies', *Patient Education and Counseling*, 102: 185-87.

Pino, M., R. Parry, V. Land, C. Faull, L. Feathers, and J. Seymour. 2016. 'Engaging Terminally Ill Patients in End of Life Talk: How Experienced Palliative Medicine Doctors Navigate the Dilemma of Promoting Discussions about Dying', *PLoS One*, 11: e0156174.

Pirovano, M., M. Maltoni, O. Nanni, M. Marinari, M. Indelli, G. Zaninetta, V. Petrella, S. Barni, E. Zecca, E. Scarpi, R. Labianca, D. Amadori, and G. Luporini. 1999. 'A new palliative prognostic score: a first step for the staging of terminally ill cancer patients. Italian Multicenter and Study Group on Palliative Care', *Journal of Pain and Symptom Management*, 17: 231-9.

Pomerantz, A., and B. J. Fehr. 1997. 'Conversation Analysis: An Approach to the Study of Social Action as Sense Making Practices.' in T. A. van Dijk (ed.), *Discourse as Social Interaction* (Sage Publications: London).

Pontin, D., and N. Jordan. 2013. 'Issues in prognostication for hospital specialist palliative care doctors and nurses: a qualitative inquiry', *Palliative Medicine*, 27: 165-71.

Powazki, R. D., D. Walsh, and S. Shrotriya. 2014. 'A Prospective Study of the Clinical Content of Palliative Medicine Interdisciplinary Team Meetings', *American Journal of Hospice and Palliative Medicine*, 32: 789-96.

Prompahakul, C., J. Keim-Malpass, V. LeBaron, G. Yan, and E. G. Epstein. 2021. 'Moral distress among nurses: A mixed-methods study', *Nursing Ethics*: 0969733021996028.

Psathas, G. 1990. *Interaction Competence* (University Press of America: Washington, DC).

Quinlan, E., and S. Robertson. 2010. 'Mutual understanding in multi-disciplinary primary health care teams', *Journal of Interprofessional Care*, 24: 565-78.

Radbruch, L., S. Payne, M. Bercovitch, A. Caraceni, T. De Vlieger, P. Firth, K. Hegedus, M. Nabal, A. Rhebergen, E. Schmidlin, P. Sjøgren, C.

Tishelman, C. Wood, and F. De Conno. 2009. 'White Paper on standards and norms for hospice and palliative care in Europe: part 1', *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 16: 278-89.

Raine, R., I. Wallace, C. Nic a’ Bháird, P. Xanthopoulou, A. Lanceley, A. Clarke, A. Prentice, D. Ardron, M. Harris, J. S. R. Gibbs, E. Ferlie, M. King, J. M. Blazeby, S. Michie, G. Livingston, and J. Barber. 2014. 'Improving the effectiveness of multidisciplinary team meetings for patients with chronic diseases: a prospective observational study', *Health Services and Delivery Research*, 2: 1-172.

Raymond, C. W., and A. E. C. White. 2017. 'Time Reference in the Service of Social Action', *Social Psychology Quarterly*, 80: 109-31.

———. 2022. 'On the recognitionality of references to time in social interaction', *Language & Communication*, 83: 1-15.

Raymond, G. 2003. 'Grammar and Social Organization: Yes/No Interrogatives and the Structure of Responding', *American Sociological Review*, 68: 939-67.

Regnault, A., T. Willgoss, and S. Barbic. 2018. 'Towards the use of mixed methods inquiry as best practice in health outcomes research', *Journal of Patient-Reported Outcomes*, 2: 19.

Reid, C., J. Gibbins, S. Bloor, M. Burcombe, R. McCoubrie, and K. Forbes. 2015. 'Healthcare professionals' perspectives on delivering end-of-life care within acute hospital trusts: a qualitative study', *BMJ supportive & palliative care*, 5: 490-5.

Rietjens, J. A. C., W. M. Bramer, E. C. T. Geijteman, A. van der Heide, and W. H. Oldenmenger. 2019. 'Development and validation of search filters to find articles on palliative care in bibliographic databases', *Palliative Medicine*, 33: 470-74.

Rizzi, D. A. 1993. 'Medical prognosis--some fundamentals', *Theor Med*, 14: 365-75.

Ruhstaller, T., H. Roe, B. Thürlimann, and J. J. Nicoll. 2006. 'The multidisciplinary meeting: An indispensable aid to communication between different specialities', *European Journal of Cancer*, 42: 2459-62.

Ryan, T., C. Gardiner, G. Bellamy, M. Gott, and C. Ingleton. 2012. 'Barriers and facilitators to the receipt of palliative care for people with dementia: the views of medical and nursing staff', *Palliative Medicine*, 26: 879-86.

Sacks, H. 1984. 'Notes on methodology.' in J. M. Atkinson and J. Heritage (eds.), *Structures of social action: Studies in conversation analysis* (Cambridge University Press: Cambridge).

———. 1992. *Lectures on conversation* (Blackwell: Oxford, UK).

Sacks, Harvey, Emanuel A. Schegloff, and Gail Jefferson. 1974. 'A Simplest Systematics for the Organization of Turn-Taking for Conversation', *Language*, 50: 696-735.

Saunders, C. 2000. 'The evolution of palliative care', *Patient Education and Counseling*, 41: 7-13.

Schegloff, E. A. 2007a. 'Categories in action: person-reference and membership categorization', *Discourse Studies*, 9: 433-61.

———. 2007b. *Sequence Organization in Interaction: A Primer in Conversation Analysis* (Cambridge University Press: Cambridge).

Schegloff, E. A., G. Jefferson, and H. Sacks. 1977. 'The Preference for Self-Correction in the Organization of Repair in Conversation', *Language*, 53: 361-82.

Scheunemann, J., R. Fischer, and S. Moritz. 2021. 'Probing the Hypersalience Hypothesis—An Adapted Judge-Advisor System Tested in Individuals With Psychotic-Like Experiences', *Frontiers in Psychiatry*, 12.

Schildmann, E. K., E. I. Groeneveld, J. Denzel, A. Brown, F. Bernhardt, K. Bailey, P. Guo, C. Ramsenthaler, N. Lovell, I. J. Higginson, C. Bausewein, and F. E. Murtagh. 2016. 'Discovering the hidden benefits of cognitive interviewing in two languages: The first phase of a validation study of the Integrated Palliative care Outcome Scale', *Palliative Medicine*, 30: 599-610.

Schoeb, V., L. Staffoni, and S. Keel. 2019. 'Influence of interactional structure on patient’s participation during interprofessional discharge planning meetings in rehabilitation centers', *Journal of Interprofessional Care*, 33: 536-45.

Schulz, K. F., D. G. Altman, and D. Moher. 2010. 'CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials', *BMJ*, 340: c332.

Schwartz, A., and G. Bergus. 2008. *Medical Decision Making: A Physician's Guide* (Cambridge University Press: Cambridge).

Schwartz, S., and T. Griffin. 2012. *Medical thinking: The psychology of medical judgment and decision making* (Springer Science & Business Media).

Selman, Lucy E, Ryann Sowden, and Erica Borgstrom. 2021. '‘Saying goodbye’ during the COVID-19 pandemic: A document analysis of online newspapers with implications for end of life care', *Palliative Medicine*, 35: 1277-87.

Seuren, L. M., W. Stommel, D. van Asselt, Ö. Sir, M. Stommel, and Y. Schoon. 2019. 'Multidisciplinary meetings at the emergency department: A conversation-analytic study of decision-making', *Social Science & Medicine*, 242: 112589.

Shanteau, J. 1988. 'Psychological characteristics and strategies of expert decision makers', *Acta Psychologica*, 68: 203-15.

Shaw, C., K. Connabeer, P. Drew, K. Gallagher, N. Aladangady, and N. Marlow. 2020. 'Initiating end-of-life decisions with parents of infants receiving neonatal intensive care', *Patient Education and Counseling*, 103: 1351-57.

Sidnell, J. 2010. *Conversation Analysis: An Introduction* (Wiley-Blackwell: Oxford, UK).

———. 2013. 'Basic Conversation Analytic Methods.' in J. Sidnell and T. Stivers (eds.), *Handbook of Conversation Analysis* (Wiley-Blackwell: Chichester, UK).

Silverman, D. 1997. *Discourses of Counselling: HIV Counselling as Social Interaction* (Sage: London).

Silverman, D., and A. Peräkylä. 1990. 'AIDS counselling: the interactional organisation of talk about ‘delicate’ issues', *Sociology of Health & Illness*, 12: 293-318.

Sisk, B. A., S. Dobrozsi, and J. W. Mack. 2020. 'Teamwork in prognostic communication: Addressing bottlenecks and barriers', *Pediatric Blood & Cancer*, 67: e28192.

Smart, C., and T. Auburn. 2018. 'Theorising Multidisciplinary Team Meetings in Mental Health Clinical Practice.' in C. Smart and T. Auburn (eds.), *Interprofessional Care and Mental Health - A Discursive Exploration of Team Meeting Practices* (Palgrave Macmillan: Cham, Switzerland).

Sniezek, J. A., and T. Buckley. 1995. 'Cueing and Cognitive Conflict in Judge-Adviser Decision-Making', *Organizational Behavior and Human Decision Processes*, 62: 159-74.

Sniezek, J. A., and L. M. Van Swol. 2001. 'Trust, Confidence, and Expertise in a Judge-Advisor System', *Organizational Behavior and Human Decision Processes*, 84: 288-307.

Soll, J. B., and R. P. Larrick. 2009. 'Strategies for revising judgment: how (and how well) people use others' opinions', *Journal of Experimental Psychology: Learning, Memory, and Cognition*, 35: 780-805.

Soukup, T., B. W. Lamb, S. Arora, A. Darzi, N. Sevdalis, and J. S. Green. 2018. 'Successful strategies in implementing a multidisciplinary team working in the care of patients with cancer: an overview and synthesis of the available literature', *Journal of multidisciplinary healthcare*, 11: 49-61.

Soukup, T., B. W. Lamb, A. Morbi, N. J. Shah, A. Bali, V. Asher, T. Gandamihardja, P. Giordano, A. Darzi, J. Sa Green, and N. Sevdalis. 2020. 'A multicentre cross-sectional observational study of cancer multidisciplinary teams: Analysis of team decision making', *Cancer Medicine*, 9: 7083-99.

Soukup, T., G. Murtagh, B. W. Lamb, J. S. A. Green, and N. Sevdalis. 2021. 'Degrees of Multidisciplinarity Underpinning Care Planning for Patients with Cancer in Weekly Multidisciplinary Team Meetings: Conversation Analysis', *Journal of multidisciplinary healthcare*, 14: 411-24.

Soukup, T., G. M. Murtagh, B. W. Lamb, A. Bali, T. Gandamihardja, A. Darzi, J. S. A. Green, and N. Sevdalis. 2020. 'Gaps and Overlaps in Cancer Multidisciplinary Team Communication: Analysis of Speech', *Small Group Research*, 52: 189-219.

Stacey, D., F. Légaré, K. Lewis, M. J. Barry, C. L. Bennett, K. B. Eden, M. Holmes-Rovner, H. Llewellyn-Thomas, A. Lyddiatt, R. Thomson, and et al. 2017. 'Decision aids for people facing health treatment or screening decisions', *Cochrane Database of Systematic Reviews*.

Standing, H., R. Patterson, S. Dalkin, C. Exley, and K. Brittain. 2020. 'A critical exploration of professional jurisdictions and role boundaries in inter-professional end-of-life care in the community', *Social Science & Medicine*, 266: 1-9.

Standing, M. 2010. 'Perceptions of clinical decision-making: a matrix model.' in M. Standing (ed.), *Clinical judgement and decision-making in nursing and interprofessional healthcare* (McGraw-Hill Open University Press: Maidenhead).

StataCorp. 2017. *Stata Statistical Software: Release 15* (College Station, TX: StataCorp LLC).

Steinhauser, K. E., N. A. Christakis, E. C. Clipp, M. McNeilly, S. Grambow, J. Parker, and J. A. Tulsky. 2001. 'Preparing for the end of life: preferences of patients, families, physicians, and other care providers', *J Pain Symptom Manage*, 22: 727-37.

Steinhauser, K. E., N. A. Christakis, E. C. Clipp, M. McNeilly, L. McIntyre, and J. A. Tulsky. 2000. 'Factors considered important at the end of life by patients, family, physicians, and other care providers', *JAMA*, 284: 2476-82.

Stevanovic, M., and E. Weiste. 2017. 'Conversation-analytic data session as a pedagogical institution', *Learning, Culture and Social Interaction*, 15: 1-17.

Stivers, T. 2008. 'Stance, Alignment, and Affiliation During Storytelling: When Nodding Is a Token of Affiliation', *Research on Language and Social Interaction*, 41: 31-57.

———. 2010. 'An overview of the question–response system in American English conversation', *Journal of Pragmatics*, 42: 2772-81.

Stivers, T., and J. Sidnell. 2012. 'Introduction.' in J. Sidnell and T. Stivers (eds.), *The Handbook of Conversation Analysis*.

Stokoe, E. 2010. '"Have You Been Married, or …?": Eliciting and Accounting for Relationship Histories in Speed-Dating Interaction', *Research on Language and Social Interaction*, 43: 260-82.

———. 2014. 'The Conversation Analytic Role-play Method (CARM): A Method for Training Communication Skills as an Alternative to Simulated Role-play', *Research on Language and Social Interaction*, 47: 255-65.

Stone, P. C., C. Chu, C. Todd, J. Griffiths, A. Kalpakidou, V. Keeley, R. Z. Omar, and V. Vickerstaff. 2022. 'The accuracy of clinician predictions of survival in the Prognosis in Palliative care Study II (PiPS2): A prospective observational study', *PLoS One*, 17: e0267050.

Stone, P. C., A. Kalpakidou, C. Todd, J. Griffiths, V. Keeley, K. Spencer, P. Buckle, D. Finlay, V. Vickerstaff, and R. Z. Omar. 2021. 'The Prognosis in Palliative care Study II (PiPS2): A prospective observational validation study of a prognostic tool with an embedded qualitative evaluation', *PLoS One*, 16: e0249297.

Stone, P., V. Vickerstaff, A. Kalpakidou, C. Todd, J. Griffiths, V. Keeley, K. Spencer, P. Buckle, D. Finlay, and R. Z. Omar. 2021. 'Prognostic tools or clinical predictions: Which are better in palliative care?', *PLoS One*, 16: e0249763.

Strachan, P. H., J. Kryworuchko, E. Nouvet, J. Downar, and J. J. You. 2018. 'Canadian hospital nurses' roles in communication and decision-making about goals of care: An interpretive description of critical incidents', *Applied Nursing Research*, 40: 26-33.

Tan, H., M. J. Bloomer, R. Digby, and M. O'Connor. 2014. 'End-of-life care in an Australian rehabilitation facility for older people: Staff focus groups', *Death Studies*, 38: 186-93.

Taylor, B. J. 2006. 'Factorial Surveys: Using Vignettes to Study Professional Judgement', *The British Journal of Social Work*, 36: 1187-207.

Taylor, C., J. Finnegan-John, and J. S. A. Green. 2014. '"No decision about me without me" in the context of cancer multidisciplinary team meetings: a qualitative interview study', *BMC Health Services Research*, 14: 488.

Taylor, C., A. J. Munro, R. Glynne-Jones, C. Griffith, P. Trevatt, M. Richards, and A. J. Ramirez. 2010. 'Multidisciplinary team working in cancer: what is the evidence?', *BMJ: British Medical Journal (Overseas & Retired Doctors Edition)*, 340: c951-c51.

Taylor, P., D. Dowding, and M. Johnson. 2017. 'Clinical decision making in the recognition of dying: a qualitative interview study', *BMC Palliative Care*, 16: 11.

Taylor, P., M. J. Johnson, and D. W. Dowding. 2020. 'Clinical decision-making at the end of life: a mixed-methods study', *BMJ supportive & palliative care*, 10: e26.

Taylor, P. M., and M. Johnson. 2011. 'Recognizing dying in terminal illness', *British Journal of Hospital Medicine*, 72: 446-50.

ten Have, P. 2007. *Doing Conversation Analysis: A Practical Guide* (Sage Publications Ltd: London, UK).

Thomas, J. M., L. M. Cooney, and T. R. Fried. 2019. 'Prognosis Reconsidered in Light of Ancient Insights—From Hippocrates to Modern Medicine', *JAMA Internal Medicine*, 179: 820-23.

Thomas, T., G. Clarke, and St. Barclay. 2018. 'The difficulties of discharging hospice patients to care homes at the end of life: A focus group study', *Palliative Medicine*, 32: 1267-74.

Thompson, A., J. Ruusuvuori, N. Britten, and S. Collins. 2007. 'An integrative approach to patient participation in consultations.' in, *Patient participation in health care consultations*.

Thornton, S., and D. Dodwell. 2012. 'Multidisciplinary team working: the emperor without clothes?', *British Journal of Hospital Medicine*, 73: 186-87.

Travers, A. 2016. 'What are the barriers to initiating end-of-life conversations with patients in the last year of life?', *International Journal of Palliative Nursing*, 22: 454-62.

Traverso, V., A. C. Ticca, and B. Ursi. 2018. 'Invitations in French: A complex and apparently delicate action', *Journal of Pragmatics*, 125: 164-79.

Travis, S. S., S. Moore, P. D. Larsen, and M. Turner. 2005. 'Clinical indicators of treatment futility and imminent terminal decline as discussed by multidisciplinary teams in long-term care', *American Journal of Hospice & Palliative Medicine*, 22: 204-10.

Tricco, A. C., E. Lillie, W. Zarin, K. K. O'Brien, H. Colquhoun, D. Levac, D. Moher, M. D. J. Peters, T. Horsley, L. Weeks, S. Hempel, E. A. Akl, C. Chang, J. McGowan, L. Stewart, L. Hartling, A. Aldcroft, M. G. Wilson, C. Garritty, S. Lewin, C. M. Godfrey, M. T. Macdonald, E. V. Langlois, K. Soares-Weiser, J. Moriarty, T. Clifford, Ö. Tunçalp, and S. E. Straus. 2018. 'PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation', *Annals of Internal Medicine*, 169: 467-73.

Van Swol, L. M., J. E. Paik, and A. Prahl. 2018. 'Advice Recipients: The Psychology of Advice Utilization.' in E. L. MacGeorge and L. M. Van

Swol (eds.), *The Oxford handbook of Advice* (Oxford University Press: New York, USA).

Van Swol, L. M., and A. Prahl. 2018. "Giving and Receiving Advice in Groups, Networks, and Organizations." In *The Oxford Handbook of Advice*, edited by E. L. MacGeorge and L. M. Van Swol, 111-32. Oxford University Press.

Van Swol, L. M., and J. A. Sniezek. 2005. 'Factors affecting the acceptance of expert advice', *British Journal of Social Psychology*, 44: 443-61.

Vissers, K. C. P., M. W. M. van den Brand, J. Jacobs, M. Groot, C. Veldhoven, C. Verhagen, J. Hasselaar, and Y. Engels. 2013. 'Palliative Medicine Update: A Multidisciplinary Approach', *Pain Practice*, 13: 576-88.

Wahid, A. S., M. Sayma, S. Jamshaid, D. Kerwat, F. Oyewole, D. Saleh, A. Ahmed, B. Cox, C. Perry, and S. Payne. 2017. 'Barriers and facilitators influencing death at home: A meta-ethnography', *Palliative Medicine*, 32: 314-28.

Wallerstedt, B., and B. Andershed. 2007. 'Caring for dying patients outside special palliative care settings: experiences from a nursing perspective', *Scand J Caring Sci*, 21: 32-40.

Wang, X., and X. Du. 2018. 'Why Does Advice Discounting Occur? The Combined Roles of Confidence and Trust', *Frontiers in psychology*, 9: 2381-81.

Weijts, W., H. Houtkoop, and P. Mullen. 1993. 'Talking delicacy: speaking about sexuality during gynaecological consultations', *Sociology of Health & Illness*, 15: 295-314.

White, N., P. Harries, A. J. L. Harris, V. Vickerstaff, P. Lodge, C. McGowan, O. Minton, C. Tomlinson, A. Tookman, F. Reid, and P. Stone. 2018. 'How do palliative care doctors recognise imminently dying patients? A judgement analysis', *BMJ Open*, 8: e024996.

White, N., N. Kupeli, V. Vickerstaff, and P. Stone. 2017. 'How accurate is the ‘Surprise Question’ at identifying patients at the end of life? A systematic review and meta-analysis', *BMC Medicine*, 15: 139.

White, N., L. J. M. Oostendorp, C. Tomlinson, S. Yardley, F. Ricciardi, H. Gökalp, O. Minton, J. W. Boland, B. Clark, P. Harries, and P. Stone. 2019. 'Online training improves medical students’ ability to recognise when a person is dying: The ORaClES randomised controlled trial', *Palliative Medicine*, 34: 134-44.

White, N., F. Reid, A. Harris, P. Harries, and P. Stone. 2016. 'A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts?', *PLoS One*, 11: e0161407.

White, N., F. Reid, V. Vickerstaff, P. Harries, C. Tomlinson, and P. Stone. 2019. 'Imminent death: clinician certainty and accuracy of prognostic predictions', *BMJ supportive & palliative care*: bmjspcare-2018-001761.

Willard, C., and K. Luker. 2006. 'Challenges to end of life care in the acute hospital setting', *Palliative Medicine*, 20: 611-5.

Williams, S. 1997. 'Early Morning Staff Meetings in Home Hospice', *Home Healthcare Now*, 15: 242.

Wittenberg-Lyles, E., J. Goldsmith, and C. S. Platt. 2014. 'Palliative Care Communication', *Seminars in Oncology Nursing*, 30: 280-86.

Wittenberg-Lyles, E., D. P. Oliver, G. Demiris, and P. Baldwin. 2010. 'The active intervention in hospice interdisciplinary team meetings: Exploring family caregiver and hospice team communication', *Journal of Computer-Mediated Communication*, 15: 465-81.

World Health Organization. 2018. *Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers* (World Health Organization: Geneva).

———. 2020. 'Palliative Care', Accessed 13/11/2020. https://www.who.int/news-room/fact-sheets/detail/palliative-care.

Yaniv, I. 2004a. 'The Benefit of Additional Opinions', *Current Directions in Psychological Science*, 13: 75-78.

———. 2004b. 'Receiving other people’s advice: Influence and benefit', *Organizational Behavior and Human Decision Processes*, 93: 1-13.

Yaniv, I., and E. Kleinberger. 2000. 'Advice taking in decision making: Egocentric discounting and reputation formation', *Organizational Behavior and Human Decision Processes*, 83: 260-81.

Yaniv, I., and M. Milyavsky. 2007. 'Using advice from multiple sources to revise and improve judgments', *Organizational Behavior and Human Decision Processes*, 103: 104-20.

Yeomans, M., A. Shah, S. Mullainathan, and J. Kleinberg. 2019. 'Making sense of recommendations', *Journal of Behavioral Decision Making*, 32: 403-14.

Yu, G., and Y. Wu. 2015. 'Managing Awkward, Sensitive, or Delicate Topics in (Chinese) Radio Medical Consultations', *Discourse Processes*, 52: 201-25.

Zhou, M., L. Holden, N. Lao, H. Lam, L. Zeng, and E. Chow. 2013. 'Accuracy of clinicians’ prediction of survival and prognostic factors indicative of survival: a systematic review', *Hong Kong Journal of Radiology*, 16: 168-82.

Zimmermann, C., R. Riechelmann, M. Krzyzanowska, G. Rodin, and I. Tannock. 2008. 'Effectiveness of specialized palliative care: a systematic review', *JAMA*, 299: 1698-709.

Appendices

Appendix 1 – Scoping review Database search strategy

Database: MEDLINE

Domain	Search terms
Palliative population	1. exp Palliative Care/ 2. palliative care.tw 3. exp Terminal Care/ 4. (terminal* adj2 care).tw 5. hospices/ 6. hospice care.tw 7. end stage.tw 8. late stage.tw 9. (advanced adj2 disease*).tw 10. (advanced adj2 illness*).tw 11. terminal* ill*.tw 12. end of life.tw 13. exp Advance directive/ 14. advance* directive*.tw
	15. OR 1-14
MDT	16. multidisciplin* 17. MDT.tw 18. interdisciplin*.tw 19. exp patient care team/ 20. exp interprofessional/ 21. interprofessional.tw 22. team*.tw
	23. OR 16-22 **24. 15 AND 24**
Decision-making	25. exp decision making/ 26. decision*.tw 27. decid*.tw 28. exp clinical decision making/ 29. exp communication/ 30. collaborat*.tw
	31. OR 25-30 **32. 25 AND 31**
Prognosis	33. exp prognosis/ 34. prognos*.tw 35. surviv*.tw 36. predict*.tw 37. mortality/ 38. dying.tw
	39. OR 33-38 **40. 15 AND 25 AND 32 AND 39**
Limits	English language Humans

Appendix 2 – Scoping review Decision-making excerpts (from Bruun, Oostendorp, et al. 2022)

Decision no.	Author(s) and publication year	Excerpt
D#1	Abu-Ghori et al. 2016	‘‘As nurse[s] we play a very minimal role in decisionmaking as a ‘No Code’ [DNACPR]. But nurses also can contribute factors like nutrition, family support, psychological and physical condition, emotional condition of the patient when they discuss about ‘No Code’. But here in the hospital, no doctor will ask the nurse’s opinion before taking a decision. May [be] [because] lot of western and foreign nurses [are] working in this country, and language is a barrier.’’ (RJ 03)
D#2	Andersson et al. 2018	“FG1-a: . . . we [RNs] didn’t think it was that sort of situation [EOL care] yet. // It almost felt as if it was a demand [from the ENs], that the resident should actually be put on the LCP, even though we didn’t think she fulfilled the criteria at that time.” (RNs)
D#3		“You hear that someone’s a bit worse, then you take the question to the responsible nurse and maybe the doctor, that it’s time to put them on the LCP, and this at least brings up the discussion a bit earlier than before, I think.” (RNs)
D#4		“No, I’ve also done that, when you have someone at the end of the week that you feel like, mm, well, you know, that we said if this happens, if it continues, so to speak, then they may proceed, start the LCP during the weekend and I’ll sign the paper afterwards.” (GPs)
D#5	Bern-Klug et al. 2004	The physicians noted their reliance and dependence on the nursing staff to keep them apprised of pain levels and physiologic status, usually by phone. When the staff did not know the residents, the physician did not get consistent information, as noted by one physician, “It’s very disconcerting when one shift says that a patient is very comfortable and is not suffering physical pain and is not alert and you have another shift telling you that they’ve been having to give Roxanol [morphine] every hour and the person is still agitated and uncomfortable.” Another physician stated, “If the nursing staff is turning over rapidly, there’s not a CNA [certified nurse assistant] bond with the patient . . . then I don’t get good feedback on the patient’s end-of-life needs because the staff doesn’t know the patient.”
D#6	Bloomer et al. 2013	During observation, it became apparent that recognition of dying was difficult, that is, nurses had difficulty differentiating between an acutely ill patient and a dying patient, most often deferring to, or waiting for, medical staff to make the distinction. … This demonstrated that some nurses may have an opinion that a patient was dying, or a sense that they were not responsive to rehabilitative care, but in the absence of a decision from a medical officer, acute resuscitative care often continued, and in one case, this caused distress to nursing staff after a patient’s death.

D#7		Focus group participants shared a frustration towards the ‘system’ and ‘practices’ that made care more challenging. Even when nurses acknowledged dying, acute care often continued until a medical officer confirmed this, often reluctantly: “The doctors don’t want to make those decisions on the weekends, they won’t do it ... but we need to make sure that, at least, we get some NFR [not for resuscitation] orders before the weekend, because the docs on the weekends won’t talk to families about dying and won’t make them palliative.” (Focus Group) “It’s hard to get through to the young doctors what is needed.” (Focus Group)
D#8	Bloomer et al. 2018	“If the nurse feels that that’s happening more rapidly than is being recognised, they would always discuss it with me or the senior nurses … and they would always take it to the doctor … but they’re looking for support. And so I think communication around patient handover is very open and it’s a place where we ask lots of questions.” (Int. 2, Registered Nurse)
D#9		“We sometimes find ourselves in a grey zone … when the patient’s not on the pathway yet but the team are saying, ‘Yeah, yeah. They’re probably end of life. They’re probably, you know, dying. They’re not for MET calls. They’re not for ICU admission’. But then we still get referred to make these decisions about eating and drinking.” (Int. 4, Speech Pathologist)
D#10	Bloomer et al. 2019	Medical entry “Clarification of goals of care. Goals: Comfort care ± end of life care. Poor prognosis given severe ischaemic cardiomyopathy and likely recent peritonitis (recent cardiogenic shock). Plan clarified with[doctor] with input from [nurse]. . . family updated.” (Case 23)
D#11	Borbasi et al. 2005	… Most participants felt referral was rare *“Patients have to be knocking on death's door with their lungs filled with fluid before the palliative care team is called*” (BC2). When referral does occur it was often too late to improve the quality of end-of life care: “*Palliative care is not thought of early enough and it is the nurses' responsibility to broach the subject with the* MOs [medical officers] - *many older* MOs *don't think about palliative care because 'it's not in their psyche'.*” (BC3)
D#12	Bostanci et al. 2015	Insights into the clinical status of patients by allied health staff did sometimes inform medical decision making. For example, when a physiotherapist noted that patient P-8 was ‘very fatigued’ and ‘liaised w[ith] medical staff about p[atien]t’s deteriorating physical status’, doctors discussed the deterioration with the patient’s daughter explaining that, if no reversible cause could be found, this may lead them to ‘consider a palliative approach’.
D#13		The existence of a decision hierarchy in health care was evident across all cancer groups. Actions related to care of patients were generally initiated by a health professional and ultimately required authorisation by a medical doctor, particularly if an alteration in care direction was signalled.
D#14		Potentially important insights into patient status and patient goals by other members of the care team, in particular allied health staff, were rarely taken into account in decisions of the medical team.

D#15	Caswell et al. 2015	Each of the wards had daily multi-disciplinary team meetings at which patients and plans for their care were discussed. Not all members of staff could be present at these meetings, and nurses described how they needed to read the medical notes of the patients for whom they were responsible on any given shift, so that they could be sure of what care and treatment was to be provided.
D#16	Chuang et al. 2017	While most PAs endorsed an active role, several felt that the attending should lead and manage these communications. “… the attendings are in charge of the patient care, ultimately. We don’t make the final decisions. So I don’t think it should be considered the PAs’ responsibility to initiate the goals of discussion. I think it should come from the attending. We can definitely follow-up …If anything, I do it on a daily basis, but it’s just like out of respect.” [F/G3/≥10Y]
D#17	Clark et al. 2012	“I have found that when we’ve tried, sometimes to get the patients started on it, that’s when the problems start with getting doctors to actually commit, to a name on the forms. Whereas, before the LCP if you asked for a patient to be made ‘comfortable’ they seemed to have less hang-ups about it.” NFG, Pg1
D#18		The complex and necessary tension around continuing to treat and/or recognizing dying was commented on by all professional groups. Nurses’ role in questioning the direction of care was described positively by a consultant. “It’s quite a traditional tension in some ways, I think the nurses have to try and keep the doctors realistic and point out things. We tend to press on, and the nursing staff say ‘do you really think this is appropriate,’ and certainly a little more pressure for the patient to go on the pathway—and I might say ;no, not yet’.” MFG, p10
D#19	Costello 2001	The data from both interview and observation in this study highlight the way in which nurses' decisions about dying patients were intimately connected to directives from physicians.
D#20		Nurses reported that their key role was to keep the patient comfortable and pain free. …, nurses sought support from doctors in prescribing medication and reporting any signs of distress. Physicians considered their role in terminal care to be decision-making…
D#21		… the imposition of DNR orders was not always based on a consensus opinion, although there was no evidence of nurses openly challenging medical decisions. Although physicians did write DNR instructions in the patients' medical notes, more detailed analysis revealed that in a number of instances nurses put pressure on doctors to make these orders. Nurses used similar strategies [informal covert decisions] to increase or decrease medication by making deference to the doctor explicit, but also clarifying informally that it is in the patient's best interests. When doctors ignored such strategies, nurses would express their feelings, by being passively aggressive, adopting go slow strategies or through non co-operation…
D#22	Dee et al. 2011	However, there was a suggestion that some nursing staff may feel that their opinions are not considered, which could be a frustration and could sometimes prove to be a barrier to the implementation of the LCP.

		“The doctors go in for a short period and maybe for that period the patient is able to say ‘this is fine’ but then you go and move somebody and you know that they’re in excruciating pain.” (Nurse 4, patient not on LCP)
D#23		“I did feel that he was dying, it was just wasted because I had to wait until people [other clinicians] thought he was dying as well.” (Nurse 5, patient not on LCP) Although the level of experience could possibly increase the accuracy of prognostication, it involved frustrations that could be barriers. This was because, although the clinicians were sure the patient was dying, they had no evidence with which to back up the judgment.
D#24		“So I was waiting for him to wake up so that I could assess what was going on. And then he had 1 mg of Lorazepam. There was no explanation anywhere in the notes as to why. The nursing staff had gone off duty, hadn’t passed it on to the next team and so I had no idea why he’d had this extra mg of Lorazepam.” (Doctor 5, patient not on the LCP) This communication failure resulted in the pathway not being implemented because the reason for the patient’s drowsiness was not known. The rationale for giving the medication was required to ensure that this was the appropriate way forward.
D#25	Dekker et al. 2018	Further, the uncertain trajectory of dementia makes it difficult to establish exactly when to initiate an LCP: “Sometimes we think yes, and the doctor doesn’t think so. And then you start it, and then you can stop it. We once had a woman for whom it [the LCP] started three times. How then to explain to the family that this time it’s for real? And so the fourth time we were, like, let’s wait a bit. But then we were too late.” (Nursing staff)
D#26	Freemantle et al. 2012	“On his last day we wheeled him outside, it was a really lovely day . . .after a couple of hours he took a turn for the worse, he wasn’t responding to us and the nurse looking after him, she was ringing the registrar saying, ‘Can we get him on the Pathway? Or can you at least come and see him because he has taken a turn for the worse? And they wouldn’t come and see him.” (Nurse: moderately experienced)
D#27		Although both junior doctors and nurses saw themselves as separate teams, intra- and inter-professional collaboration was evident. With the exception of one inexperienced nurse, all nurses appeared to be proactive in recognising dying and prompting the doctors to ask for guidance in decision making. This approach was accepted positively by the doctors: “They’re obviously very experienced with oncology patients and they realise these decisions need to be made and they’ll prompt us as juniors to approach the seniors about that.” (Doctor: moderately experienced)
D#28		A perception of inconsistency amongst consultant staff in approach to recognising the dying phase and implementation of care supported by the LCP resulted in situations where end-of-life decision making was delayed:

		“If the consultant is not around, people aren’t willing to make decisions, so we delay, waiting for a decision from a consultant.” (Nurse: moderately experienced)
D#29	Fryer et al. 2016	Indeed, participants recounted several stories of occasions when their concerns about dying residents had been largely ignored by more senior staff, typically the Registered Nurse on duty at the Facility. On most of these occasions, this refusal to listen to HCAs’ concerns resulted in significant negative repercussions. For example, the following excerpt highlights how the refusal of the trained nurse to take into account the HCAs’ knowledge and experience resulted in a poor outcome for the resident, the relatives and the staff: “HCA 2 ‘We spend a lot of time with them [residents]; sometimes the RN’s just don’t listen. And you think, they are dying and you can just tell… just deteriorating. HCA 4 [Resident], she had pneumonia in the end I think. She was just getting weaker and weaker and not talking. I said to [RN], you better call the family, but she didn’t. She [resident] died, and the family came in and got very upset with her because they expected to know. She should have called the family. HCA 5 It was a bad mistake HCA 1 You could tell with her breathing HCA 5 We work with them [residents] all the time you know, and sort of know, we pick up things what’s wrong with them then go and tell them [RN’s] then it’s up to them, it’s not up to us. HCA 2 They think, oh you’re just a caregiver; you don’t know what’s happening, but we’re with them every day.” (Focus Group 2)
D#30	Gambles et al. 2006	There was evidence that nurses have much more influence over the diagnosis of dying and the decision to commence a pathway in this environment: “The good thing as well is …here the nurse would start a pathway. That is a very good thing … It doesn't necessarily have to be the doctor… here most of the medication would be prescribed anyway … you don't have to convince the doctors that somebody is dying …so you don't have to argue.” [doctor 1]
D#31	Gidwani et al. 2017	However, the most serious concern expressed was that inpatient PC teams only see cancer patients at their most severe stage, leading them to believe that all cancer patients in the same stage of illness are similarly ill. For example, oncologists noted situations in which patients with Stage IV cancer were admitted to the hospital for pneumonia and received a hospitalist-activated PC consult, resulting in the PC physician telling the patient that he was going to die and switching him from antineoplastic treatment to comfort care. This posed concerns for oncologists, both because they felt they would be able to extend patient survival by treating the pneumonia and because it created problems in communicating with patients and families. One oncologist noted about PC physicians: ‘‘They don’t understand that a cancer patient can look really crappy but not be on death’s door; it’s the side effects of chemo or they have a kind of cancer that’s going to respond really well. [Palliative care physicians have] told people they were going to die that aren’t even dying, and then it’s this whole awful backpedaling and making us look bad. It’s just ridiculous. We’ve had a lot of meetings with them, trying to explain this,

		and now they have a rule where they're supposed to call us first but it doesn't always happen. I don't expect them to understand oncology and to understand what diseases might really turn around with treatment, but it's done a lot of damage, actually, between our relationship with our patients.''
D#32		With respect to prognosis, oncologists reported that they and the PC specialists often had different views for the same patient. Compounding the problem was that each discipline was unaware of the other's differing prognosis. This resulted in mixed messages given to the patient about prognosis and/or treatment options. Disparate prognoses across PC physicians and oncologists were perceived as linked to the largely inpatient nature of PC. Oncologists noted that PC physicians only saw those cancer patients who were the most ill—hence their admission into the hospital—and this colored their perception of all patients in that same cancer stage.
D#33	Glogowska et al. 2016	The HCPs' accounts also provided examples where they perceived the necessary discussions had not taken place and where patients in advanced heart failure had been aggressively treated for infections, instead of receiving palliative support: "I …thought this patient is dying …so I spoke to the consultant and said can you make this patient not for resus[citation] …his opinion was you've got to get better, you've got to fight this illness …I said to the patient I think your symptoms are quite a lot, you 're quite nauseous because I can tell by your, the way that you 're acting. He said I feel really really sick. So I called palliative care in and he did die …he had a false message, so I was trying to take it down the palliative route because I thought that was appropriate …but the clinician wanted to treat an infection …" [P20, community specialist heart failure nurse]
D#34		There was concern that lack of communication had consequences for choosing appropriate treatment and care: "We had a situation with a patient who was end stage and we said to the doctor straight away this chap's end stage …shouldn't we be thinking palliative should get involved, and they treated him for cellulitis, and said no, no we're going to treat him for that …you could see this chap was dying, going to die in hospital if somebody didn't do something …nobody's making the decisions here, the doctors are leaving it up to the patient, the patient is unwell, confused and can't make that decision for himself …It was really frustrating and I think that happens a lot." [P14, hospital specialist heart failure nurse]
D#35		However, in location 2, the uncertain course of heart failure made it difficult to judge when to put in place palliative care support, which could be offered on a time-limited basis only: "…the difficulty with end of life care and heart failure is the unpredictability of the time scale and so getting palliative care services involved and the sort of end of life package which you can get, which is very intensive and very good, is only for a short amount of time, and if you think they might live longer than that…they're probably saying well it's too soon for us to get involved…" [P12, hospital specialist heart failure nurse]

D#36	Gott et al. 2011	A critical first step in this process was seen to be communication within the hospital setting and, in particular, reaching a consensus among all clinicians involved in a patient's care that a palliative approach was now appropriate. The opinion and approach to treatment of the consultant was seen to be pivotal in this respect: "You've got to have some sort of consensus though about how you're going to treat the patient . . . and sometimes I think what happens in a hospital is that the consultant is seen as the be all and end all so their decision is what decides it, whereas actually you need to reach a decree amongst a number of people." (Secondary care, location 1, geriatric specialist registrar)
D#37		Problems of power within the professional hierarchy of the hospital were discussed within this context, both between medicine and nursing, and within medicine itself. The need for nursing staff to be provided with opportunities to raise their concerns about the approach being taken to a patient's care was identified: "I think maybe that point when the nurses start triggering and saying 'why are we doing this?' it would be nice for them to be able to, I don't know, circumvent or put up a flag so that somebody else gets involved, or some kind of mediator. Because I get a lot of nursing staff telling me 'why are we doing this? Why do you keep doing this?' And I say 'why didn't you ask yesterday when the consultant was coming round because it would be really nice for you to ask somebody more senior than myself what their intentions are in the situation.' But it's well 'you're here now, why aren't you doing something?' But actually I am, I'm following the plan that I have available to me and I can question it but I'm still not going to change that unless obviously something significant happens and it's an acute deterioration but I still feel there's a lot of . . . I don't know, stresses in the system." (Secondary care, location 1, geriatric specialist registrar)
D#38	Hanson et al. 2002	Physicians and nurses felt a need for shared communication to facilitate treatment decisions when a resident was dying. Nurses expressed frustration with the limited time and involvement of physicians, yet also expressed pride in their ability to judge clinical situations, report them by telephone, and get the orders they needed to give good care to dying residents. Physicians acknowledged their own unwillingness to spend more time in nursing homes, and their need to rely on nurses' skills. A physician described his dependence on nurses' assessments: "Whenever the patient isn't doing well and it looks like we will be dealing with a death, then the first thing I do is go to the nurses and say what do we know? I usually make it their job to do the scouting. It is less threatening for the nurse to act before I come on the scene."
D#39	Hill et al. 2018	Participants responsible for initiating palliative care used their experience and professional judgment to determine when palliative care was best initiated. Most said the assessments were based on common sense. One participant explained "When they're done, they're done. We just know." (Registered Practical Nurse). Usually, when a resident with dementia stopped eating and drinking, the RN made the decision to contact the physician and request that the resident be designated palliative. They also made assessments based on abnormal vital signs and uncharacteristic and distressing resident behaviors.

D#40		Nurses indicated that they did not have enough communication with physicians who were prescribing drugs and designating residents as palliative. Physicians were responsible for different long-term care homes and cared for many residents. Others such as social workers, chaplains, and recreation therapists also felt excluded at times. Additionally, staff at homes with no formal palliative care committee expressed frustration in making end-of-life decisions with no protocol to guide them and no one willing to lead in decision-making.
D#41	Hockley et al. 2005	Prior to the study there was a lack of confidence in some of the nurses' ability to take responsibility to initiate what was necessary for their residents' end-of-life care — whether this was talking to relatives, ensuring that there were drugs for distressing symptoms, or informing other staff in the nursing home that a resident was now dying. Often this was because it was seen as the GP's position to diagnose dying. However, in the majority of situations it was the nurse and, indeed, the carers who knew the resident and the family the best and were therefore able to contribute to the knowledge that someone was dying. "I think before it was more or less the doctors who decided. Now I feel the carers are as much involved." [KC1. NH.E, final evaluation: para. 49]
D#42		What was important about the ICP documentation was that it encouraged a joint decision to be made around the diagnosis of dying. The nurses' critical part, along with the ward team and resident/family, in initiating that process was being recognised by staff. It was encouraging to see nurses more accountable in this area of care and the recognition of this shift by nursing home managers. "We are taking a bit more responsibility….I think it has raised the standard of care of the dying." [NHM. NH.D, final evaluation: para. 53] "I think the trained staff . . . there is this real ability for them to be more in control . . . they feel that their professional opinions are being much more respected." [NHM. NH.E, interview: para. 79]
D#43		"I think from the carers' point of view that we are more involved with recognising different stages in the dying . . . and work together . . . much, much more aware of the whole dying process. And I feel more involved, . . ." [CA6. NH.B, final evaluation: para. 82]
D#44		"If one of the carers comes and says he sounds a bit funny, you know you won't say 'Well, they always sound a bit funny when they are dying.' You say, 'Well, OK, we'll go and have a look at them.' You know so you're getting all the information from everybody and you're acting on what you are getting. . . I think it's been really good." [SN. NH.A, final evaluation: para. 174]
D#45	Johnson et al. 2014	Senior Nurse Helen pointed out how sometimes you know people are near the end whether or not they meet the LCP criteria: "One lady that died had lung cancer and I wanted to do…I wanted the drugs and he (GP) came out to see her but she didn't meet any of the criteria. You know, she was talking, she was sat up but you know on intuition: you just know don't you? And after being a nurse for some time you do get to know and I went, 'No, I really want pathway drugs for this lady'." (Helen, Senior Nurse)

		The GP was cautious, but came the day after and realising the woman was in pain prescribed diamorphine. He could see what Helen could see and that the weekend would be difficult for the lady without sedation.
D#46	Lai et al. 2018	Although nurses were seldom involved in judging the end-of-life stage or dying phase, they instinctively provided more care to patients at the end-of-life stage
D#47	Näppä et al. 2014	In these stories, the nurses observed that the patients were in a poor condition and questioned the physicians about the appropriateness of the PCT. The physicians disagreed with the nurses and ordered the nurses to give the PCT as prescribed. According to the nurses, the PCT had dire consequences for patients who might have survived or been spared from suffering if the physicians had listened. For example, Nurse Ingrid, who had not met the patient before, explained her situation as follows: “And when I saw the patient, my first thought was that this patient is in such terribly bad shape; so haggard […] his skin was ashen grey, he had difficulty breathing. […] It just felt wrong to give the PCT. But when the doctor came, who had met the patient before, his assessment was, ‘Ah, it's alright’. So the treatment was given anyway. […] The patient died that evening after the PCT.” Ingrid concluded her story with this reflection: “It doesn't feel right to have given the PCT, but, at the same time, in this particular case, I did say what I thought beforehand. And then it's someone else above you who makes the decision.”
D#48	Nouvet et al. 2016	Several nurses recalled critical incidents in which health care team efforts to ‘do everything’ for a particular seriously ill patient collided with their ideal of care for that patient. One participant grew emotional as she remembered a particular case: “[T]his woman just wanted to pass away but we were just treating her and treating her and treating her to an extent that I think was more than what the situation called for. But the attending was just like, ‘No, we’re going to treat her symptoms.’ ‘Why not just make her palliative?’ ‘Well, we’re not at that stage yet.’ She [the attending physician] didn’t give me a clear rationale of why we were still treating her other than just symptom management right now. What’s the point of symptom management when she doesn’t even want a scope? Why are we still giving her lots and lots of blood products? That’s all she said. I never got a clear understanding of why we were still treating her. And I had said to her [the attending], ‘She doesn’t want to eat. She doesn’t want to drink. She just wants to be comfortable.’ [The attending] said, ‘Well, we’re going to treat her for now.” (Nurse)
D#49	Oliveira et al. 2016	Caring for patients in their final days of life was both an emotional and physical drain for the nurses. Ann explained, “We see it a lot . . . we still treat aggressively and that’s very demoralizing for nurses. To treat aggressively when we, through experience, or intuition, or just by knowledge of our training, we know that we’re battling

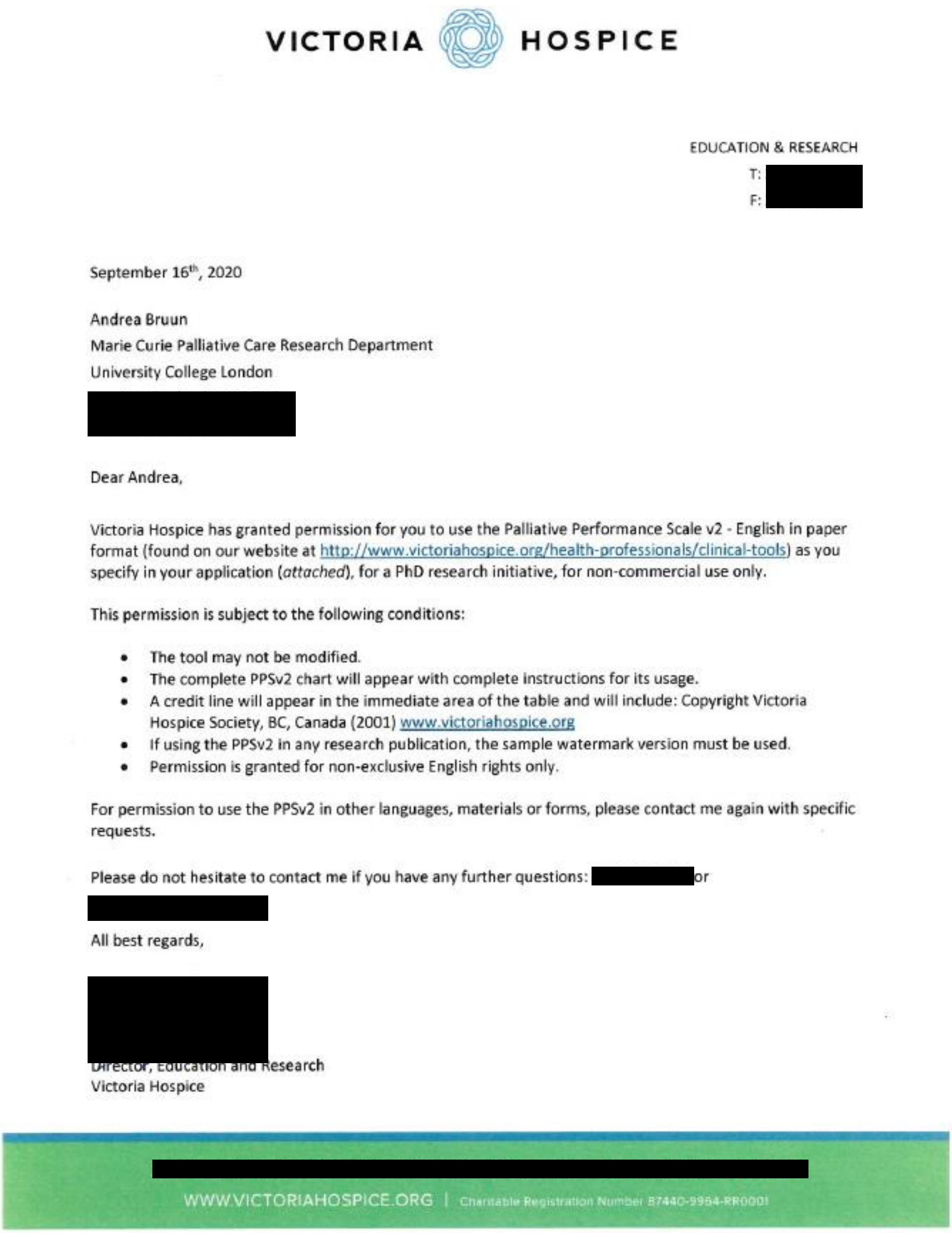
		a no-win battle. It's like professional judgment of that has been removed and we're not allowed . . . to make that decision . . . it's a real emotional drain and strain and struggle."
D#50		Communication was essential for teamwork and was integral in establishing the goals of care. However, nurses, who possessed intimate knowledge of patient care, were often not present at planned family meetings, either because they were not being invited or were unable to attend because their presence was required at the bedside. This was a significant barrier to communication and advocating for patients because it was often at these key meetings where the decision to move from aggressive curative goals to palliative care would be made.
D#51		One of the challenges in transitioning patients to an EOL plan of care was the layers of reporting structures within the physician medical team. As part of a teaching hospital system, patients on the medical unit were assigned to the care of a resident or medical student. Nurses were expected to report their concerns to the resident/medical student in charge of the patient's care; however, whether or not these concerns were relayed to the staff physician was left to the discretion of the residents/medical students assigned to the patient. Ultimately, the approval of the plan of care fell under the responsibility of the staff physician.
D#52		In an effort to challenge the appropriateness of the curative-focused plan of care, participants would align themselves with other health care professionals (HCPs) who would act as allies in trying to force a medical decision regarding goals of care. Registered respiratory therapists (RRTs) and the PCCS were identified by more than one participant as sources of support in prompting goals of care discussions.
D#53	Petterson et al. 2014	One nurse mentioned that it was always the physician who made the final decision and had the strongest arguments if there were disagreements on DNR orders because physicians have the most medical skills. But the nurse also emphasized the need for another type of skill: "An informal skill, I would say, that nurses have. Which they develop by being very close to a patient for a very long time." (Nurse 8)
D#54	Pettersson et al. 2020	Also, whether the team was involved in the decision or not varied, depending on the routines at the ward at stake. "I have experienced that the physicians asked for my opinion and I really appreciate that. But, it could be done more frequently!" (Nurse164, hematology) "If the nurse knows the patient better, the nurse's input can be valuable." (Physician 132, oncology)
D#55	Pontin et al. 2011	"So I think that is why nurses are much better at prognosticating than doctors because we are seeing an absolute snapshot and sometimes that is useful because you can come back and say that's a really dramatic change in 24 hours. And maybe that isn't apparent to the nurses who just, just keep doing things but often it is the nurse who says 'well actually the last time they could mobilize to the bathroom and now they can't'." (spr001319)

D#56	Prompahakul et al. 2021	Among the healthcare team, nurses perceived themselves as having little power in decisions about treatment. In many cases, participants knew the right thing to do for patients; however, they could not take action because nurses lack practice and independence to act. For example, six participants expressed that they knew that specialists from other departments such as palliative care should have been involved in a patient's care but that consulting the palliative care team was not their role and depended on the doctor's decision: "... ... Anyway, we need the doctors to sign on the consult form. The consultation needed an agreement from the doctors. If they don't agree, we couldn't consult. The patient would be treated aggressively. We are under them, we depended on them. Our profession was sometimes controlled by others." (N16)
D#57		Poor communication and collaboration impacted the quality of patient care in that nurses felt they were excluded as members of the team and could not communicate with patients and families sometimes because they were not sure about the goals of care: "The collaboration among the team wasn't bad but it wasn't good as it should be. We [nurses and doctors] had less discussion. We [nurses] were trying to be a part of team. We joined the morning medical rounds to know the goal and plan of each patient. But when they placed orders, they were totally different from what they had discussed during rounds. They changed the plan without informing us. They might feel that they don't need to tell us. When the patient asked us about the plan, I could just tell him to discuss it with the doctors. I know I should not say that but I wasn't really sure about the plan." (N15)
D#58	Reid et al. 2015	Medical and nursing staff had different opinions in terms of who should make the diagnosis of dying. Medical staff thought the nursing staff were first to raise the possibility that a patient might be dying, perhaps because they spent more time closely observing patients, but nurses looked to the medical team for confirmation. "Um it's still difficult, because we know that patients are coming in, you know, are admitted, and er there's a good chance sometimes that they might die on the admission, but it is difficult for us to know when to pick up this document [the EOL tool] and start. Because you take the lead really from the doctors." (Interview 4)
D#59		Junior doctors and nursing staff described needing validation of the diagnosis of dying by the senior medical staff (usually the consultant), and thus asked for this confirmation on the ward round. However, senior staff felt that they did not see patients frequently enough to be confident about diagnosing dying.
D#60	Ryan et al. 2012	One team noted how their experiences led them to believe that sound collaborative working between professions and consulting other 'specialists' in the field of dementia care had helped to facilitate transitions to palliative care: "I've got three people on the caseload at the moment that I think really are dying and it's purely as a result of dementia…. The doctors have wrestled quite a lot with that and they're really experienced geriatricians we've got on our team and each of those cases we sought a second opinion from a psychiatrist but also from another geriatrician as well to say 'what do you think?'." (Acute Hospital FG)

D#61	Standing et al. 2020	Feeling dismissed and downgraded by professional colleagues was particularly prevalent within the accounts of care home staff, who felt their professional status and expertise were afforded less value than that of other health care and social care professionals. Indeed, during the course of data collection care homes were repeatedly highlighted by other professional groups as a perceived weak link in end-of-life care, who inappropriately called on out-of-hours doctors and ambulance services against patient’s wishes. [...] “the care homes are absolutely petrified of litigation. They will call us for any change. Then you think, “Well, you have called me. The healthcare plan says, ‘Keep comfortable.’ […] She is breathing heavily but she is quite comfortable. What do you want me to do?”[…] they will be incredibly risk averse or they will expect us to make the decisions, but we haven’t got that information.” (out-of hours GP2) It was suggested that this fear of litigation meant care home staff were paralyzed when dealing with patients at the end of-life resulting in them abdicating the responsibility for decision making to other professional groups increasing the burden on other services who themselves may not necessarily be better placed to take on such responsibilities.
D#62	Strachan et al. 2018	Nursing surveillance during patient care positioned them to notice and alert the healthcare team, essentially ‘raising the red flag’ to the need for communication. Specifically, in response to cues about a decline in the patient's condition, and recognizing that communication and decision-making could be urgently needed in advance of crisis, nurses prompted other team members to the need for goals of care discussions and decision-making conversations that they anticipated would be imminently required to inform their interventions. A common scenario was described: “They're not as responsive to us anymore, their appetite has decreased and they're not swallowing well. They're just sleeping more and more. And I often ask (the physician) ‘What's the plan for this patient?’.” (Nurse, P10)
D#63		Even with this advocacy from nurses, it was not uncommon for discussions about life-sustaining interventions to be delayed until physicians agreed that death might not be avoided in the short term. “I had a patient who was very ill and she was still full resuscitation code and I started to see that she was really deteriorating and struggling with the treatment and not in a lot of comfort… I actually talked to the (medical) residents quite a few times saying ‘I really don't think she's coming out of this. Is it time to talk about her level (of care)?’ and they said ‘No, I think we can fix this.” (Nurse, P1)
D#64	Tan et al. 2014	A number of people may be first to recognize the approach of the final phase of life. “Nurses often recognise it first being with the patients 24=7’ […] The decision to formally engage the ‘Care of the Dying Pathway’ for treatment is a medical one. This can be problematic, resulting in delays.”

		“You can see that someone’s got maybe two or three days but when you go to the registrar they won’t do anything because they are waiting for the consultant who comes on Friday. By Friday the person may have only three or four hours. It can be very distressing because you can see clearly that the person needs different treatment . . . It is all very dependent upon the time of day, who’s on call and personalities between us. Weekends are particularly difficult.” (Group 2)
D#65	Travis et al. 2005	According to these teams, sharing observations occurs at several levels and uses a hierarchical order of consensus building. First, when a team member gets a gut feeling, he or she shares it with other team members. If others also see a change, there is an informal brainstorming session within a shift and then a more formal session across shifts. If a pattern emerges and a more comprehensive assessment of the person’s condition and behaviors confirms a change (often very subtle), the physician is notified. If there is a possibility that the change is reversible (recall that one team told us ‘most things can be reversed’), appropriate orders are requested. If everyone agrees that changes in the person’s condition are consistent with irreversible terminal decline, [the physician has a highly visible and intense role in discussing options with the resident, if possible, or the responsible family members.]
D#66	Wallerstedt et al. 2007	The nurses’ assessments and reports often constituted the basis for the doctors’ decisions and orders. They also described how they had to assume the responsibility for the doctors becoming involved in the care of the dying. It was assumed that the nurses could act independently, but they said their responsibility did not seem so overwhelming if they could share it among themselves. “That the way we treat patients, the way I act toward the patient is of such tremendous importance and can have such lasting effects. That my actions, my words can have such a lasting effect both on relatives and on the patient. That’s quite a heavy responsibility. What I’m responsible for is really the nursing care. Then there’s the medical care and orders and that’s the doctor’s responsibility. But in some way I have to be responsible that the doctor does that.”
D#67	Willard et al. 2006	Some of these issues are highlighted in the following interview extract, where a CNS describes how she and the consultant differed in their perception of a situation concerning a very ill patient with dysphagia, and the most ethical course of action: “The consultant felt as though he couldn’t let her die in that way, so I just said I thought she was dying, and it isn’t pleasant having a feeding tube put in, they don’t always work, there are complications and the risk of having all that for the outcome, I didn’t feel that it was justified. He could understand where I was coming from and it did make him think about it, but he still was saying well you know we should give it a go.” (Interview: palliative care CNS)

Appendix 3 – ADJUST PPS permission letter



VICTORIA HOSPICE

EDUCATION & RESEARCH
T: F: [redacted]

September 16th, 2020

Andrea Bruun
Marie Curie Palliative Care Research Department
University College London
[redacted]

Dear Andrea,

Victoria Hospice has granted permission for you to use the Palliative Performance Scale v2 - English in paper format (found on our website at http://www.victoriahospice.org/health-professionals/clinical-tools) as you specify in your application (*attached*), for a PhD research initiative, for non-commercial use only.

This permission is subject to the following conditions:

- The tool may not be modified.
- The complete PPSv2 chart will appear with complete instructions for its usage.
- A credit line will appear in the immediate area of the table and will include: Copyright Victoria Hospice Society, BC, Canada (2001) www.victoriahospice.org
- If using the PPSv2 in any research publication, the sample watermark version must be used.
- Permission is granted for non-exclusive English rights only.

For permission to use the PPSv2 in other languages, materials or forms, please contact me again with specific requests.

Please do not hesitate to contact me if you have any further questions: [redacted] or
[redacted]

All best regards,

[redacted]
Director, Education and Research
Victoria Hospice

[redacted]
WWW.VICTORIAHOSPICE.ORG | Charitable Registration Number 87440-9964-RR0001

Appendix 4 – ADJUST Example vignette

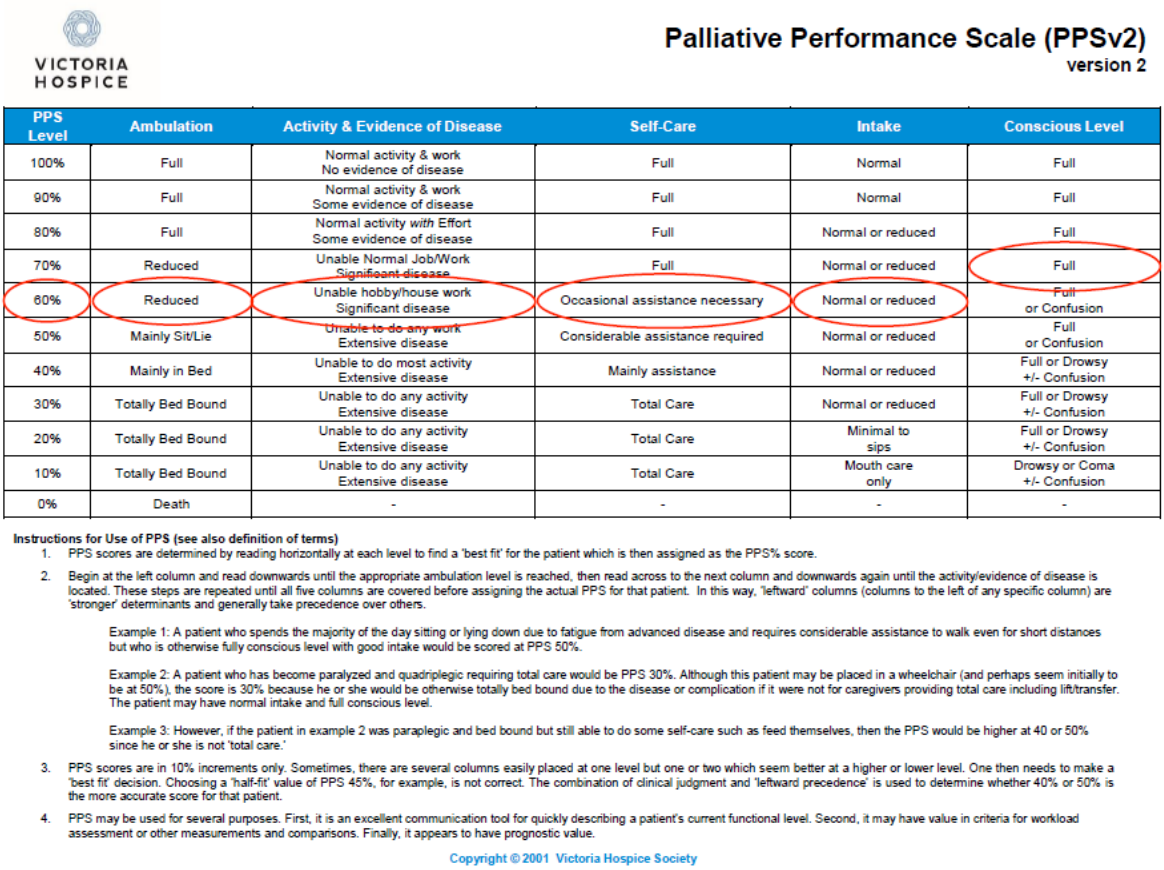
Mr Smith has recently been admitted to the inpatient palliative care unit at St Swithin's hospice. He has a primary pancreatic cancer with metastases to his lungs and bones. He is currently undergoing palliative radiotherapy.

He is 63 years old and has full capacity. On assessment, there is no evidence of ascites or peripheral oedema. He reports that his eating and drinking are severely reduced, that he has lost weight, but there is no dysphagia. He feels fatigued and is unable to do jobs around the house that he used to do. Sometimes he needs assistance in self-care tasks. He is short of breath. His pulse rate is 88 (beats/min).

His blood tests show the following:

White Blood Count (WBC):	11 x 10^9/L	(normal range 4.0 to 11.0)
Lymphocyte:	<1.0 x 10^9/L	(normal range 1.0 to 4.0)
Neutrophil:	10 x 10^9/L	(normal range 1.7 to 8.0)
Platelet:	273 x 10^9/L	(normal range 150 to 450)
Urea:	7 mmol/L	(normal range 2.5 to 7.8)
Albumin:	26 g/L	(normal range 35 to 50)
Alkaline Phosphatase:	105 U/L	(normal range 30 to 130)
Alanine Transaminase:	12 U/L	(normal range 0 to 52)
C-Reactive Protein (CRP):	288 mg/L	(normal range 0.0 to 10.0)
Lactic acid Dehydrogenases (LDH):	1183 U/L	(normal range 140 to 280)

His PPS score is 60% (shown below):



VICTORIA HOSPICE

Palliative Performance Scale (PPSv2)

version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	[✓ Full]
[✓ 60%]	[✓ Reduced]	[✓ Unable hobby/house work Significant disease]	[✓ Occasional assistance necessary]	[✓ Normal or reduced]	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.
2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

   Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'
3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. Ambulation

The items '**mainly sit/lie**,' '**mainly in bed**,' and '**totally bed bound**' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed 'bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs need to lie down.

'**Reduced ambulation**' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

2. Activity & Extent of disease

'**Some**,' '**significant**,' and '**extensive**' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

3. Self-Care

'**Occasional assistance**' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'**Considerable assistance**' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

'**Mainly assistance**' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'**Total care**' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. Intake

Changes in intake are quite obvious with '**normal intake**' referring to the person's usual eating habits while healthy. '**Reduced**' means any reduction from that and is highly variable according to the unique individual circumstances. '**Minimal**' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. Conscious Level

'**Full consciousness**' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. '**Confusion**' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. '**Drowsiness**' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. '**Coma**' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

Appendix 5 – ADJUST Hospice invitation email

Subject line: Invitation for participation in the UCL Marie Curie ‘ADJUST’ study

Dear [insert hospice name / medical director / head of nursing or matron / education and research lead],

We are contacting you because we believe that you are a charitably-funded hospice (that is, one that is not primarily funded by the NHS and is not part of the NHS organisationally). Therefore, we would like to invite your hospice to participate in the ‘ADJUST’ study. This study is conducted by researchers from the Marie Curie Palliative Care Research Department at University College London (UCL). The study is part of a PhD project and has been reviewed and approved by the UCL REC (ID number: 17031/001). The study is looking at how clinicians in multidisciplinary teams use information to estimate survival of palliative care patients. This study is part of the ‘Improving care, assessment, communication and training at end-of-life’ (I-CAN-CARE) programme of research. The overall aim of this programme is to improve end-of-life care for patients and their families by better assessment of dying patients, by improved understanding of how clinicians identify dying patients, by improving clinicians’ skills in making prognostic decisions and by understanding how prognoses are communicated to relatives of dying patients.

What does the study involve?
The study involves asking clinicians to visit a study website and review five patient summaries. They will be asked to provide estimates about the probability that each patient will survive two weeks. They will then be provided with a second opinion about each patient, and they will be given an opportunity to revise their original estimate (if they wish to do so). Participants will also be asked to provide some demographic information about themselves. The whole study takes approximately 15 minutes to complete, and participants can download a certificate of participation at the end of the study.

What would I need to do?
We would ask you to circulate an email to the clinical staff in your hospice. In this email, the study and its importance, and benefits are described, and a link to the study website will be provided. Whether you want your hospice to participate is completely up to you. If you are interested please, respond to this email and we will send you the study invitation email for the clinicians. If you are not interested, you do not have to provide a reason why, and this will not affect you or the hospice in any way. We are happy to have a chat about the study or come by your hospice and present the study if you are interested, just let us know.

Please, feel free to contact the study team if you have any questions. We are looking forward to hearing from you!

Kind regards,

ADJUST Study team
Marie Curie Palliative Care Research Department
Division of Psychiatry, University College London.
Email: [redacted]

Appendix 6 – ADJUST Clinician invitation email

Subject line: Invitation for palliative care clinicians to participate in the online UCL-Marie Curie 'ADJUST' study

Dear colleague,

We would like to invite you to participate in the 15-minute online 'ADJUST' study. This study is conducted by researchers from the Marie Curie Palliative Care Research Department at University College London (UCL). The study is part of a PhD project and has been reviewed and approved by UCL REC (ID number: 17031/001). The study is looking at how clinicians in multidisciplinary teams use information to estimate survival of palliative care patients.

What does the study involve?

- Visiting the study website to review five patient summaries
- Providing estimates about the probability that a patient will survive two weeks
- Being shown advice from an advisor and providing a final, possibly revised, estimate
- Providing some information about yourself

Why is recognising survival important?

- Enables patients and family members to make decisions and feel prepared
- Helps families to spend time with their loved ones
- Informs your clinical decision-making

What are the possible benefits of taking part?

- A certificate of participation at the end of the study
- Results summary at the end of the study

Participation is completely voluntary and you are able to withdraw at any point.

You can access the study via this link:
https://wwwdepts-live.ucl.ac.uk/psychiatry/adjust/.
(Please do not forward this link to anyone else)

Kind regards,

ADJUST Study team
Marie Curie Palliative Care Research Department
Division of Psychiatry, University College London.
Email: [redacted]

Appendix 7 – ADJUST Seminar invitation email

Subject line: Preparation for [insert seminar/lecture presentation title] at [seminar/conference title] [insert year]

Dear seminar/lecture attendant,

As preparation for the [insert presentation title] on [insert date], Professor Paddy Stone, would like to invite you to participate in the 15-minute online 'ADJUST' study. This study is being conducted by Professor Stone and researchers from the Marie Curie Palliative Care Research Department at University College London (UCL) as part of a PhD project. The study is looking at how clinicians in multidisciplinary teams use information to estimate survival of palliative care patients.

What does the study involve?

- Visiting the study website to review five patient summaries
- Providing estimates about the probability that a patient will survive two weeks
- Being shown advice from an advisor and providing a final, possibly revised, estimate
- Providing some information about yourself

The preliminary findings will be available at Professor Stone's seminar/lecture. Your responses will be anonymous, and you will not be able to identify yourself or others in any reports arising from this research.

Participation is completely voluntary and is not a requirement of attending the seminar/lecture. Even if you agree to participate in the study you are free to withdraw at any point.

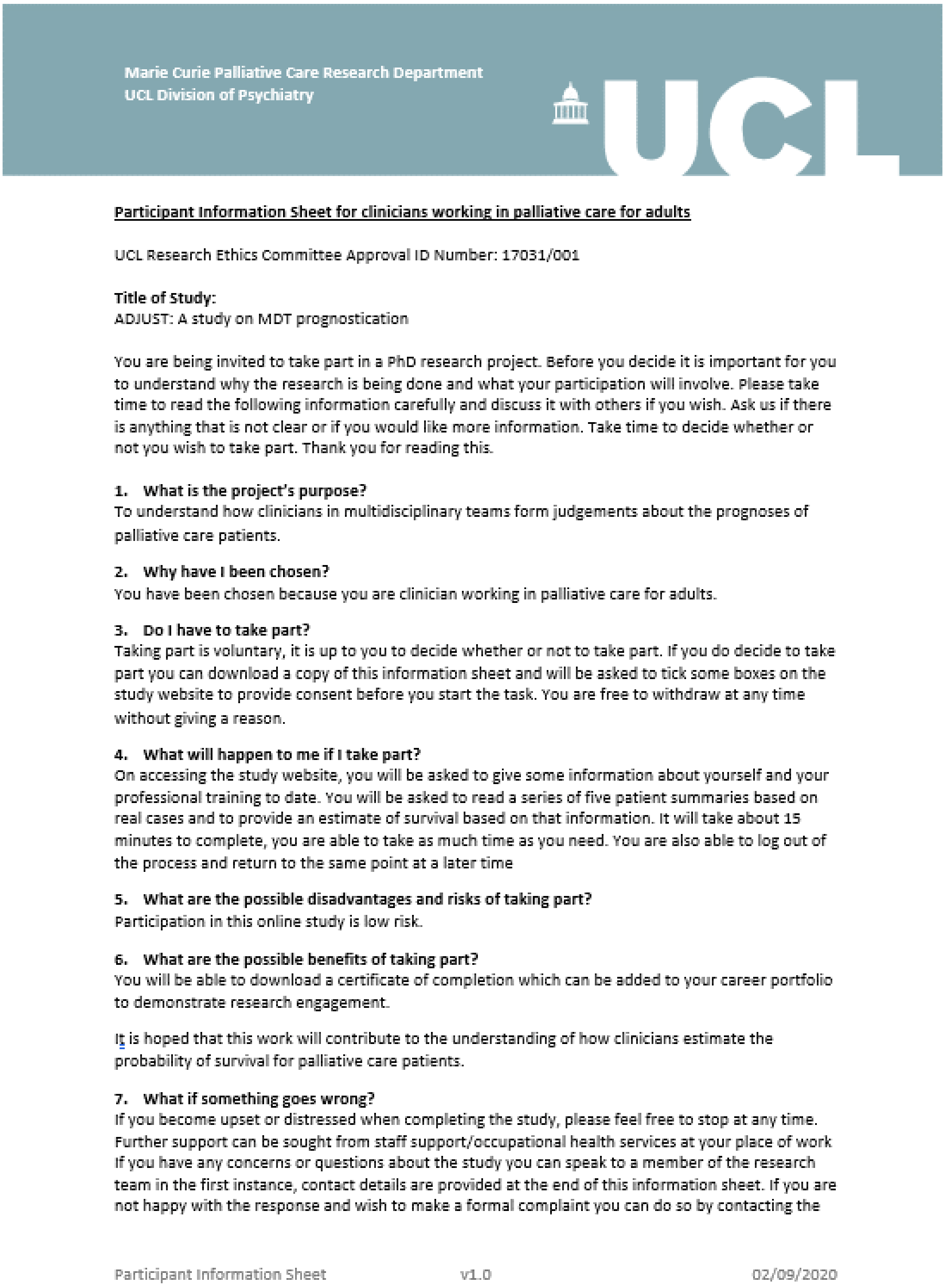
You can access the study via this link:
https://wwwdepts-live.ucl.ac.uk/psychiatry/adjust/

The study has been reviewed and approved by UCL REC (ID number: 17031/001).

Kind regards,

ADJUST Study team
Marie Curie Palliative Care Research Department
Division of Psychiatry, University College London.
Email: [redacted]

Appendix 8 – ADJUST Participant Information Sheet



Marie Curie Palliative Care Research Department
UCL Division of Psychiatry

Participant Information Sheet for clinicians working in palliative care for adults

UCL Research Ethics Committee Approval ID Number: 17031/001

Title of Study:
ADJUST: A study on MDT prognostication

You are being invited to take part in a PhD research project. Before you decide it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

1. What is the project's purpose?
To understand how clinicians in multidisciplinary teams form judgements about the prognoses of palliative care patients.

2. Why have I been chosen?
You have been chosen because you are clinician working in palliative care for adults.

3. Do I have to take part?
Taking part is voluntary, it is up to you to decide whether or not to take part. If you do decide to take part you can download a copy of this information sheet and will be asked to tick some boxes on the study website to provide consent before you start the task. You are free to withdraw at any time without giving a reason.

4. What will happen to me if I take part?
On accessing the study website, you will be asked to give some information about yourself and your professional training to date. You will be asked to read a series of five patient summaries based on real cases and to provide an estimate of survival based on that information. It will take about 15 minutes to complete, you are able to take as much time as you need. You are also able to log out of the process and return to the same point at a later time

5. What are the possible disadvantages and risks of taking part?
Participation in this online study is low risk.

6. What are the possible benefits of taking part?
You will be able to download a certificate of completion which can be added to your career portfolio to demonstrate research engagement.

It is hoped that this work will contribute to the understanding of how clinicians estimate the probability of survival for palliative care patients.

7. What if something goes wrong?
If you become upset or distressed when completing the study, please feel free to stop at any time. Further support can be sought from staff support/occupational health services at your place of work If you have any concerns or questions about the study you can speak to a member of the research team in the first instance, contact details are provided at the end of this information sheet. If you are not happy with the response and wish to make a formal complaint you can do so by contacting the

Principal Researcher (Prof Stone). If you are still not satisfied you can contact the UCL Research Ethics Committee [redacted]

8. Will my taking part in this project be kept confidential?
All the information that we collect about you during the course of the research will follow ethical and legal practice and will be handled in confidence. Your personal identifiable information will not be used for the analysis but will be stored in encrypted form on a secure server hosted by UCL.

9. Limits to confidentiality
Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case we would inform you of any decisions that might limit your confidentiality.

10. What if I want to withdraw my participation?
You are free to withdraw from the study at any time without giving a reason. At the end of the study, you will receive a results summary, and you can withdraw your data up until the time at which you receive this summary. When we have incorporated your response into analyses and/or written up the results, it will no longer be possible to withdraw your data from the study. The website will be open for participation until April 2021. Then the analysis and work on the results summary will begin and when the summary is finished, it will be sent to you.

11. What will happen to the results of the research project?
Study findings will be published in journals and presented at conferences. The study will also be published as part of a PhD thesis. Personal identifiable information will not be used for the analysis or reporting of any findings from this study.

12. Data Protection Privacy Notice
The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [redacted]

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

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 personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [redacted]

UK data protection law is regulated by the Information Commissioner's Office (ICO). If you are concerned about how your personal data is being processed, you may wish to submit a complaint to them. Contact details, and details of data subject rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

13. Who is organising and funding the research?

This study is part of a PhD project at UCL funded by Marie Curie.

14. Contact for further information

You are encouraged to ask any questions you wish, before and during the study. If you require any further information or have any concerns while taking part in the study, please contact Andrea Bruun at Marie Curie Palliative Care Research Department on [redacted]

You can have more time to think this over if you are at all unsure.

Thank you for taking the time to read this information sheet and to consider this study.

Department:
Marie Curie Palliative Care Research Department, Division of Psychiatry, UCL

The ADJUST study team
[redacted]

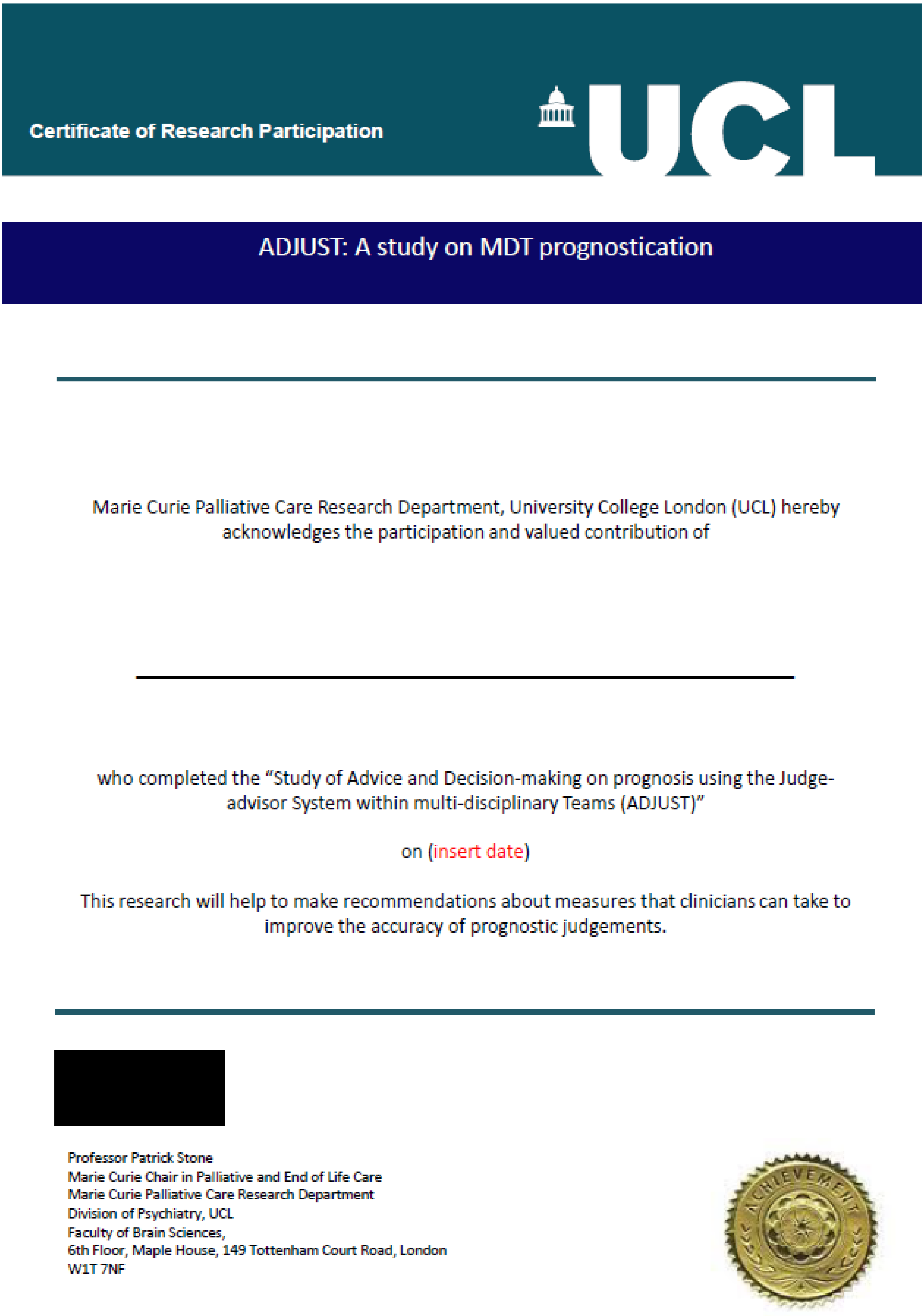
Researchers:
Andrea Bruun
[redacted]

Linda Oostendorp
[redacted]

Nicola White
[redacted]

Principal Researcher:
Patrick Stone
[redacted]

Appendix 9 – ADJUST Participation certificate



Certificate of Research Participation

UCL

ADJUST: A study on MDT prognostication

Marie Curie Palliative Care Research Department, University College London (UCL) hereby acknowledges the participation and valued contribution of

____

who completed the “Study of Advice and Decision-making on prognosis using the Judge-advisor System within multi-disciplinary Teams (ADJUST)”

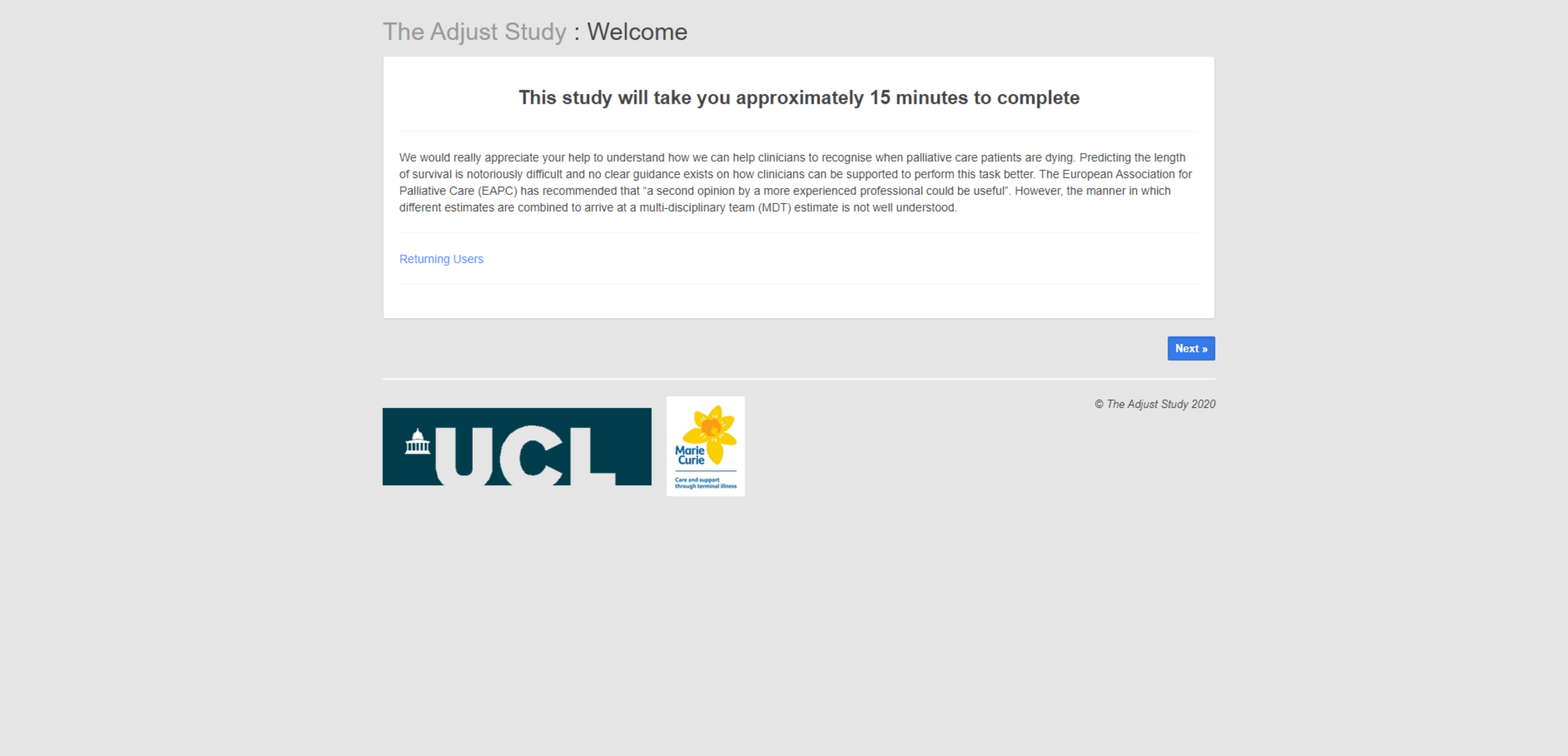
on (insert date)

This research will help to make recommendations about measures that clinicians can take to improve the accuracy of prognostic judgements.

[redacted]

Professor Patrick Stone
Marie Curie Chair in Palliative and End of Life Care
Marie Curie Palliative Care Research Department
Division of Psychiatry, UCL
Faculty of Brain Sciences,
6th Floor, Maple House, 149 Tottenham Court Road, London
W1T 7NF

Appendix 10 – ADJUST Study website content



The Adjust Study : Welcome

This study will take you approximately 15 minutes to complete

We would really appreciate your help to understand how we can help clinicians to recognise when palliative care patients are dying. Predicting the length of survival is notoriously difficult and no clear guidance exists on how clinicians can be supported to perform this task better. The European Association for Palliative Care (EAPC) has recommended that “a second opinion by a more experienced professional could be useful”. However, the manner in which different estimates are combined to arrive at a multi-disciplinary team (MDT) estimate is not well understood.

Returning Users

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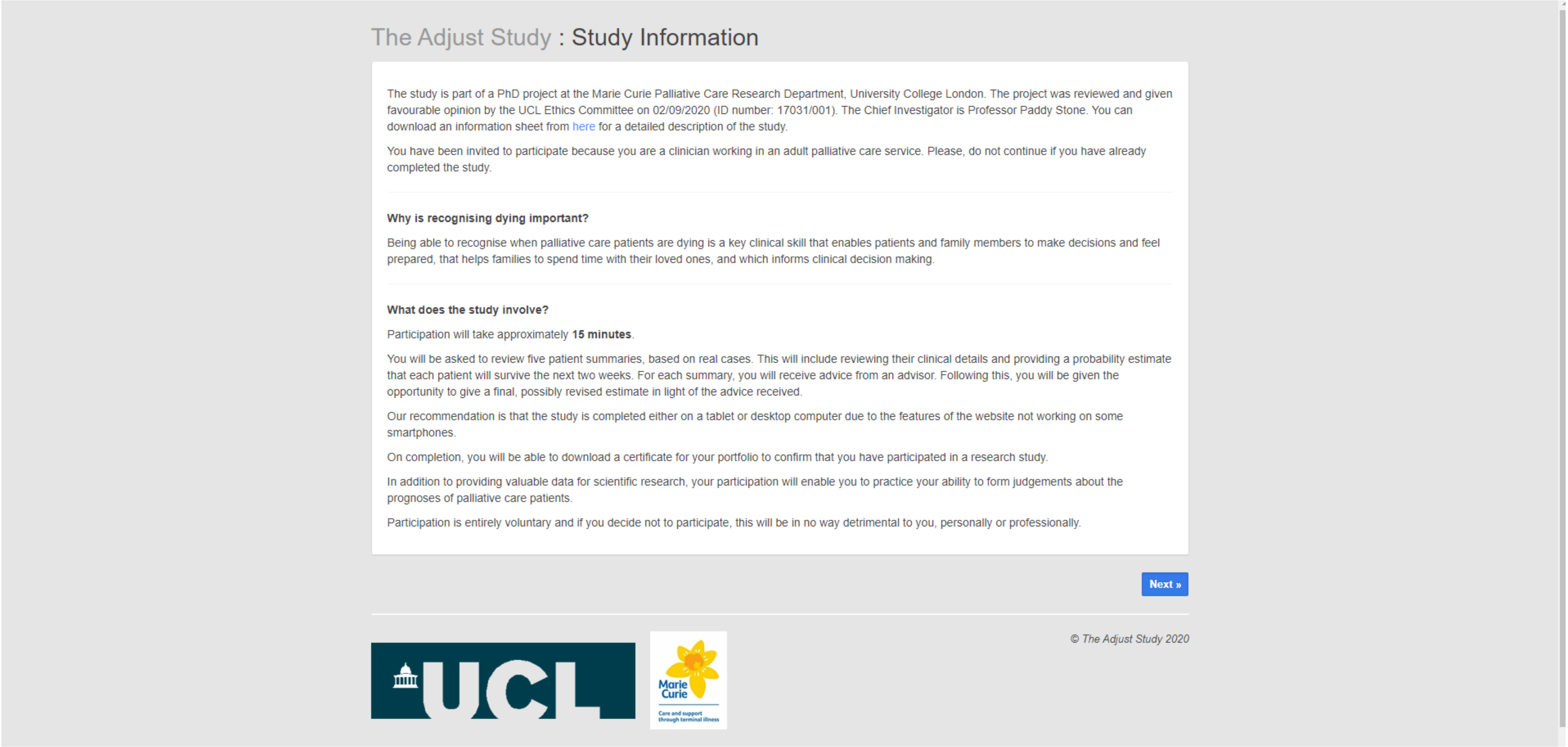


The Adjust Study : Study Information

The study is part of a PhD project at the Marie Curie Palliative Care Research Department, University College London. The project was reviewed and given favourable opinion by the UCL Ethics Committee on 02/09/2020 (ID number: 17031/001). The Chief Investigator is Professor Paddy Stone. You can download an information sheet from here for a detailed description of the study.

You have been invited to participate because you are a clinician working in an adult palliative care service. Please, do not continue if you have already completed the study.

Why is recognising dying important?

Being able to recognise when palliative care patients are dying is a key clinical skill that enables patients and family members to make decisions and feel prepared, that helps families to spend time with their loved ones, and which informs clinical decision making.

What does the study involve?

Participation will take approximately **15 minutes**.

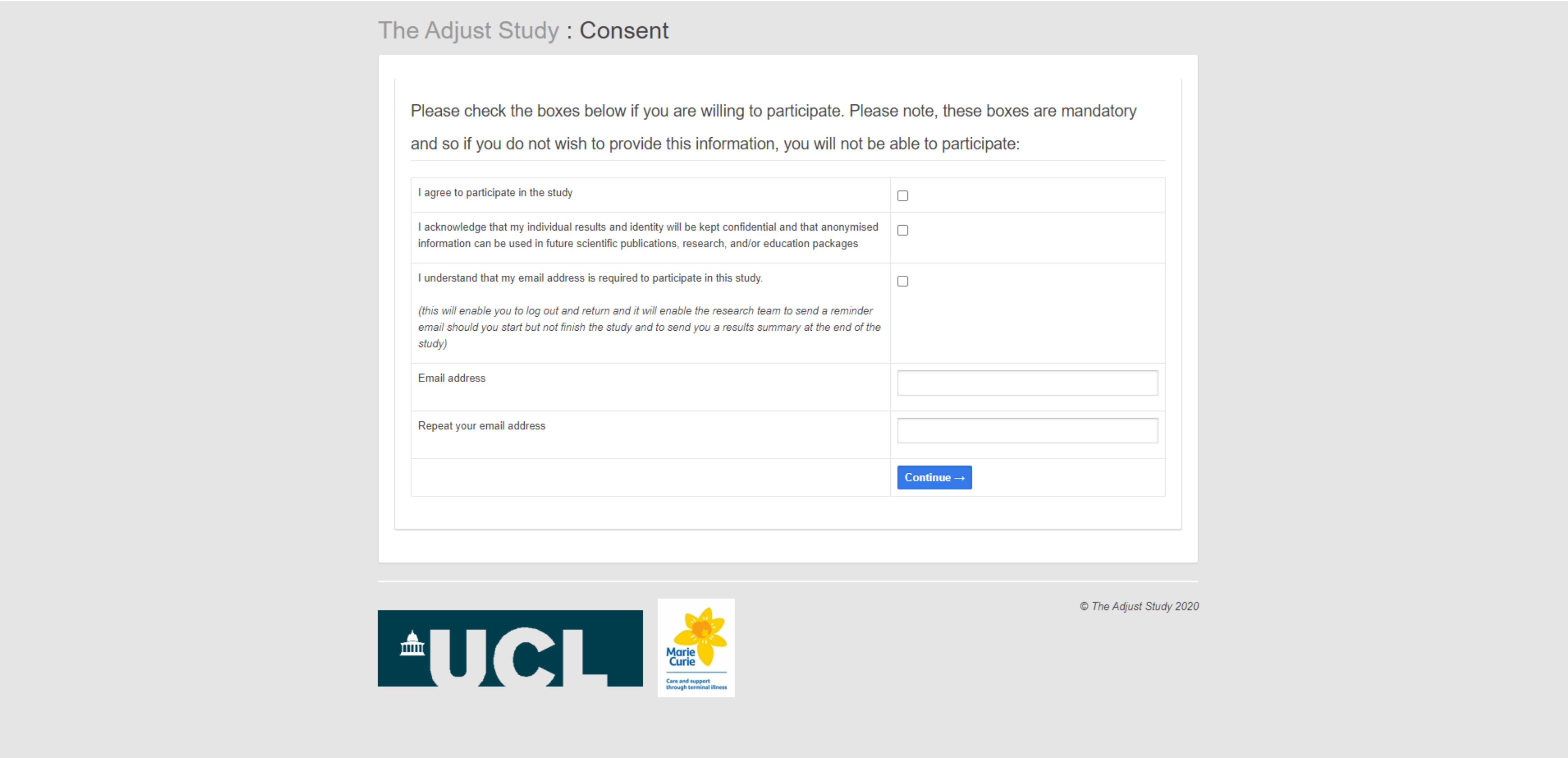
You will be asked to review five patient summaries, based on real cases. This will include reviewing their clinical details and providing a probability estimate that each patient will survive the next two weeks. For each summary, you will receive advice from an advisor. Following this, you will be given the opportunity to give a final, possibly revised estimate in light of the advice received.

Our recommendation is that the study is completed either on a tablet or desktop computer due to the features of the website not working on some smartphones.

On completion, you will be able to download a certificate for your portfolio to confirm that you have participated in a research study.

In addition to providing valuable data for scientific research, your participation will enable you to practice your ability to form judgements about the prognoses of palliative care patients.

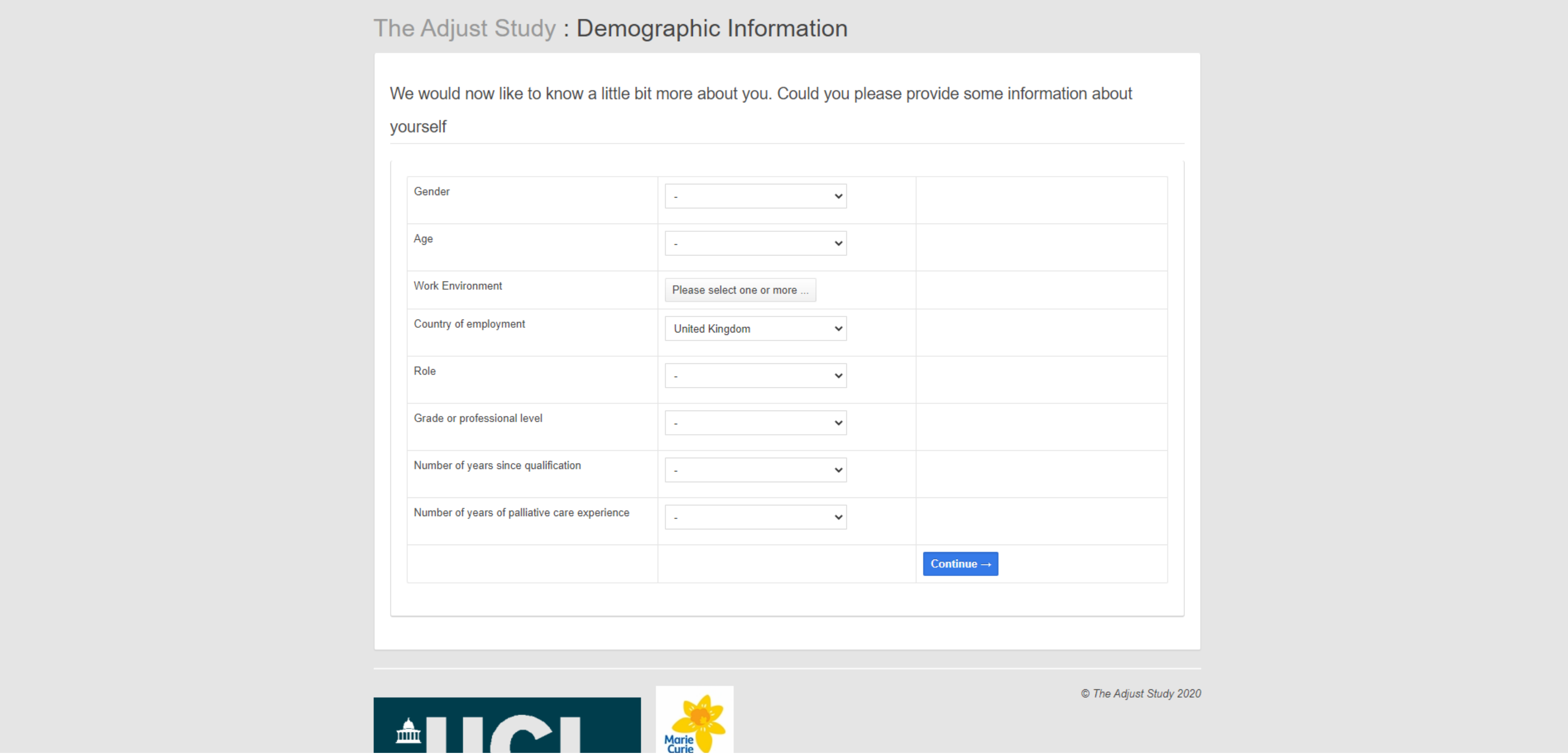
Participation is entirely voluntary and if you decide not to participate, this will be in no way detrimental to you, personally or professionally.



The Adjust Study : Consent

Please check the boxes below if you are willing to participate. Please note, these boxes are mandatory and so if you do not wish to provide this information, you will not be able to participate:

I agree to participate in the study	☐
I acknowledge that my individual results and identity will be kept confidential and that anonymised information can be used in future scientific publications, research, and/or education packages	☐
I understand that my email address is required to participate in this study. *(this will enable you to log out and return and it will enable the research team to send a reminder email should you start but not finish the study and to send you a results summary at the end of the study)*	☐
Email address	
Repeat your email address	



The Adjust Study : Demographic Information

We would now like to know a little bit more about you. Could you please provide some information about yourself

Gender	-	
Age	-	
Work Environment	Please select one or more ...	
Country of employment	United Kingdom	
Role	-	
Grade or professional level	-	
Number of years since qualification	-	
Number of years of palliative care experience	-	
		Continue →

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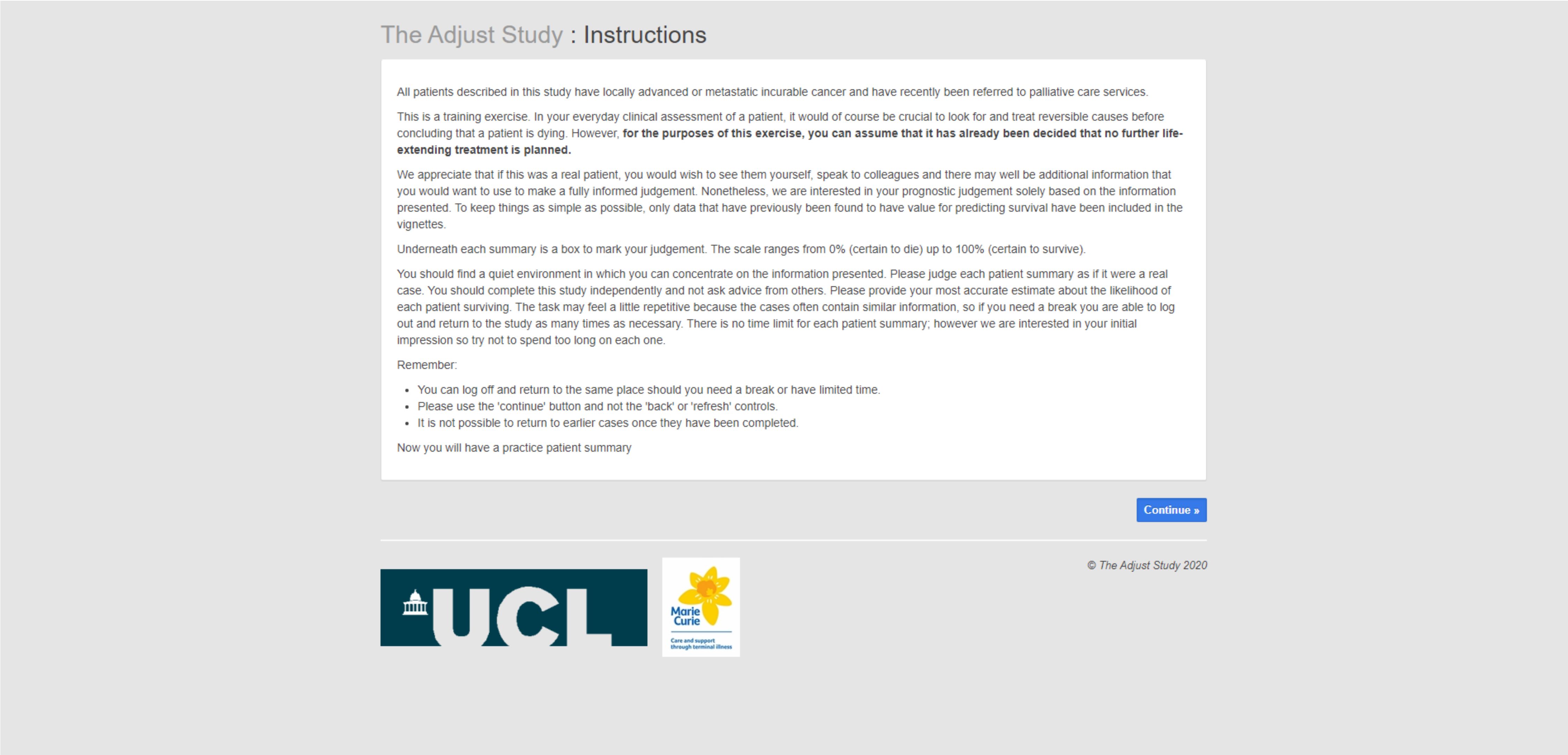

The Adjust Study : Instructions

All patients described in this study have locally advanced or metastatic incurable cancer and have recently been referred to palliative care services.

This is a training exercise. In your everyday clinical assessment of a patient, it would of course be crucial to look for and treat reversible causes before concluding that a patient is dying. However, **for the purposes of this exercise, you can assume that it has already been decided that no further life-extending treatment is planned.**

We appreciate that if this was a real patient, you would wish to see them yourself, speak to colleagues and there may well be additional information that you would want to use to make a fully informed judgement. Nonetheless, we are interested in your prognostic judgement solely based on the information presented. To keep things as simple as possible, only data that have previously been found to have value for predicting survival have been included in the vignettes.

Underneath each summary is a box to mark your judgement. The scale ranges from 0% (certain to die) up to 100% (certain to survive).

You should find a quiet environment in which you can concentrate on the information presented. Please judge each patient summary as if it were a real case. You should complete this study independently and not ask advice from others. Please provide your most accurate estimate about the likelihood of each patient surviving. The task may feel a little repetitive because the cases often contain similar information, so if you need a break you are able to log out and return to the study as many times as necessary. There is no time limit for each patient summary; however we are interested in your initial impression so try not to spend too long on each one.

Remember:

- You can log off and return to the same place should you need a break or have limited time.
- Please use the 'continue' button and not the 'back' or 'refresh' controls.
- It is not possible to return to earlier cases once they have been completed.

Now you will have a practice patient summary

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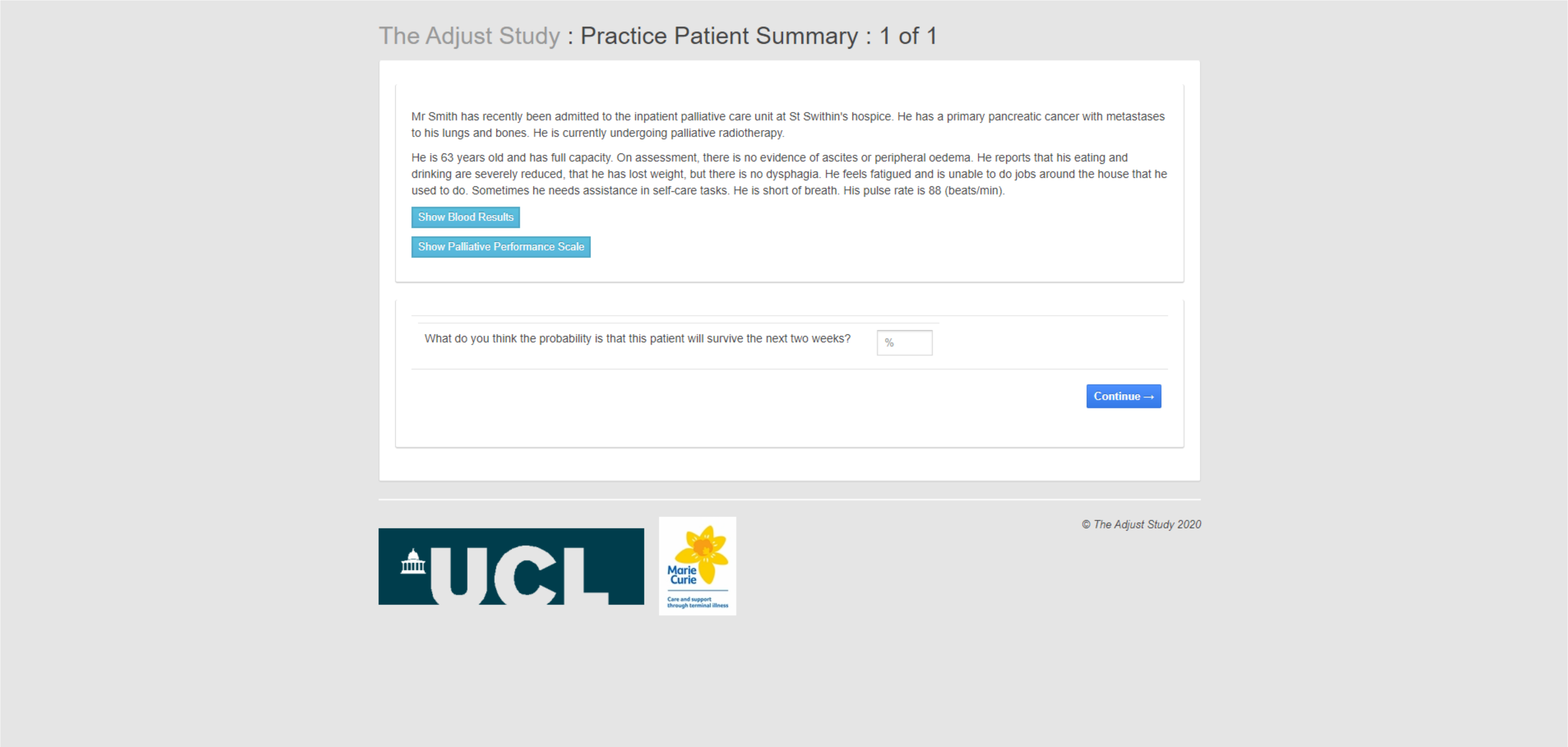
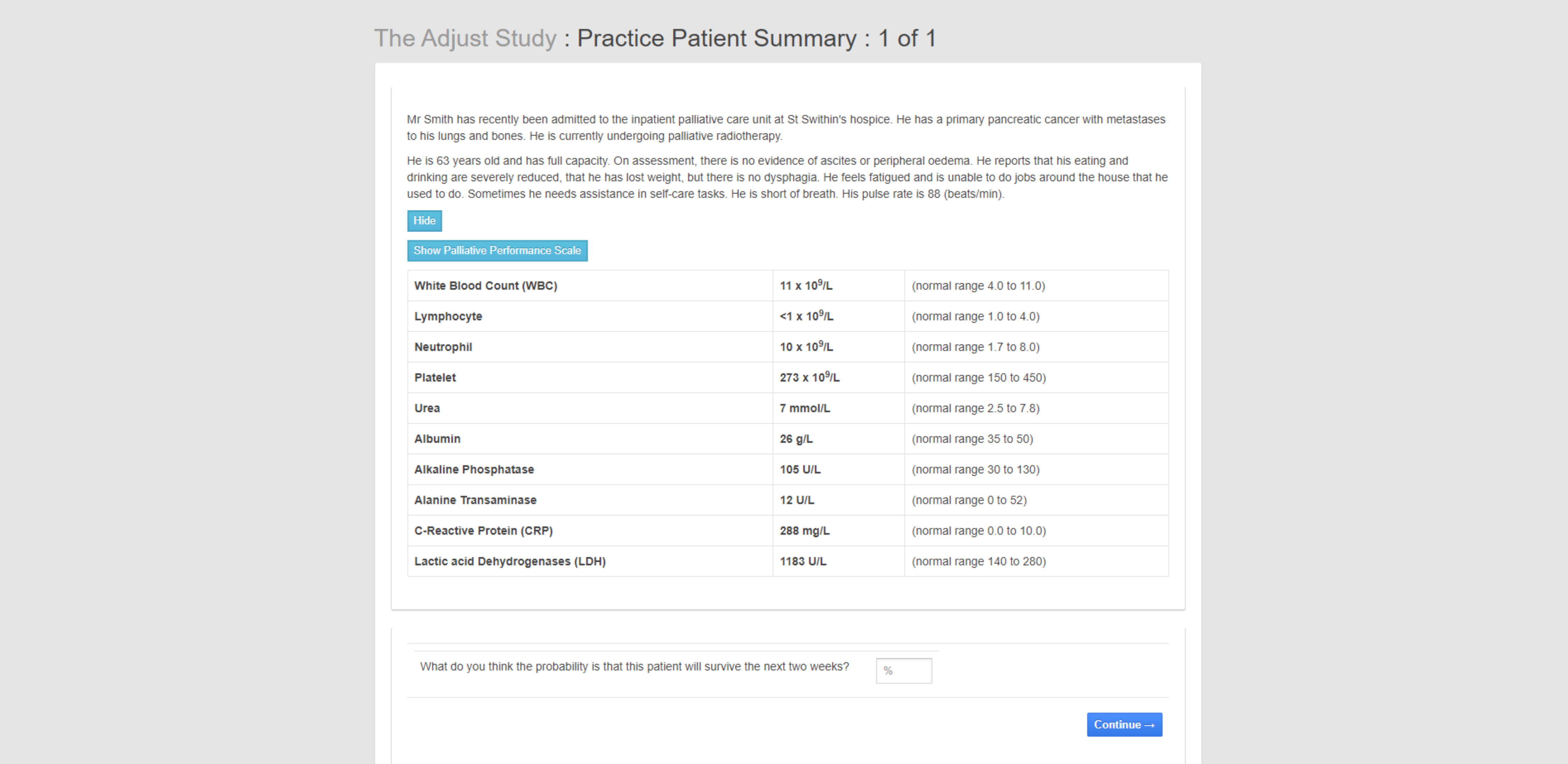


The Adjust Study : Practice Patient Summary : 1 of 1

Mr Smith has recently been admitted to the inpatient palliative care unit at St Swithin's hospice. He has a primary pancreatic cancer with metastases to his lungs and bones. He is currently undergoing palliative radiotherapy.

He is 63 years old and has full capacity. On assessment, there is no evidence of ascites or peripheral oedema. He reports that his eating and drinking are severely reduced, that he has lost weight, but there is no dysphagia. He feels fatigued and is unable to do jobs around the house that he used to do. Sometimes he needs assistance in self-care tasks. He is short of breath. His pulse rate is 88 (beats/min).

What do you think the probability is that this patient will survive the next two weeks? %



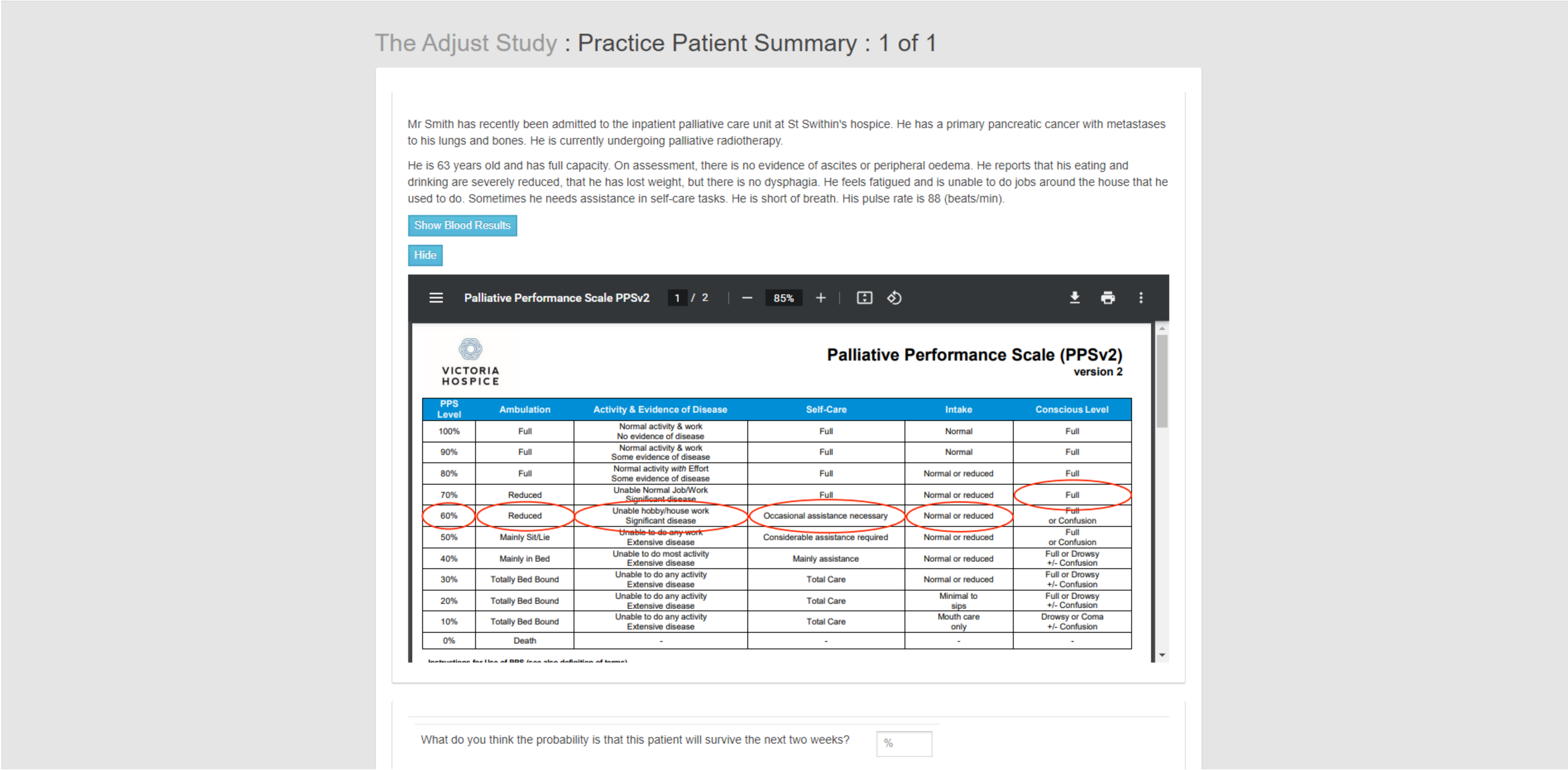
The Adjust Study : Practice Patient Summary : 1 of 1

Mr Smith has recently been admitted to the inpatient palliative care unit at St Swithin's hospice. He has a primary pancreatic cancer with metastases to his lungs and bones. He is currently undergoing palliative radiotherapy.

He is 63 years old and has full capacity. On assessment, there is no evidence of ascites or peripheral oedema. He reports that his eating and drinking are severely reduced, that he has lost weight, but there is no dysphagia. He feels fatigued and is unable to do jobs around the house that he used to do. Sometimes he needs assistance in self-care tasks. He is short of breath. His pulse rate is 88 (beats/min).

White Blood Count (WBC)	**11 x 10^9/L**	(normal range 4.0 to 11.0)
Lymphocyte	**<1 x 10^9/L**	(normal range 1.0 to 4.0)
Neutrophil	**10 x 10^9/L**	(normal range 1.7 to 8.0)
Platelet	**273 x 10^9/L**	(normal range 150 to 450)
Urea	**7 mmol/L**	(normal range 2.5 to 7.8)
Albumin	**26 g/L**	(normal range 35 to 50)
Alkaline Phosphatase	**105 U/L**	(normal range 30 to 130)
Alanine Transaminase	**12 U/L**	(normal range 0 to 52)
C-Reactive Protein (CRP)	**288 mg/L**	(normal range 0.0 to 10.0)
Lactic acid Dehydrogenases (LDH)	**1183 U/L**	(normal range 140 to 280)

What do you think the probability is that this patient will survive the next two weeks?



The Adjust Study : Practice Patient Summary : 1 of 1

Mr Smith has recently been admitted to the inpatient palliative care unit at St Swithin's hospice. He has a primary pancreatic cancer with metastases to his lungs and bones. He is currently undergoing palliative radiotherapy.

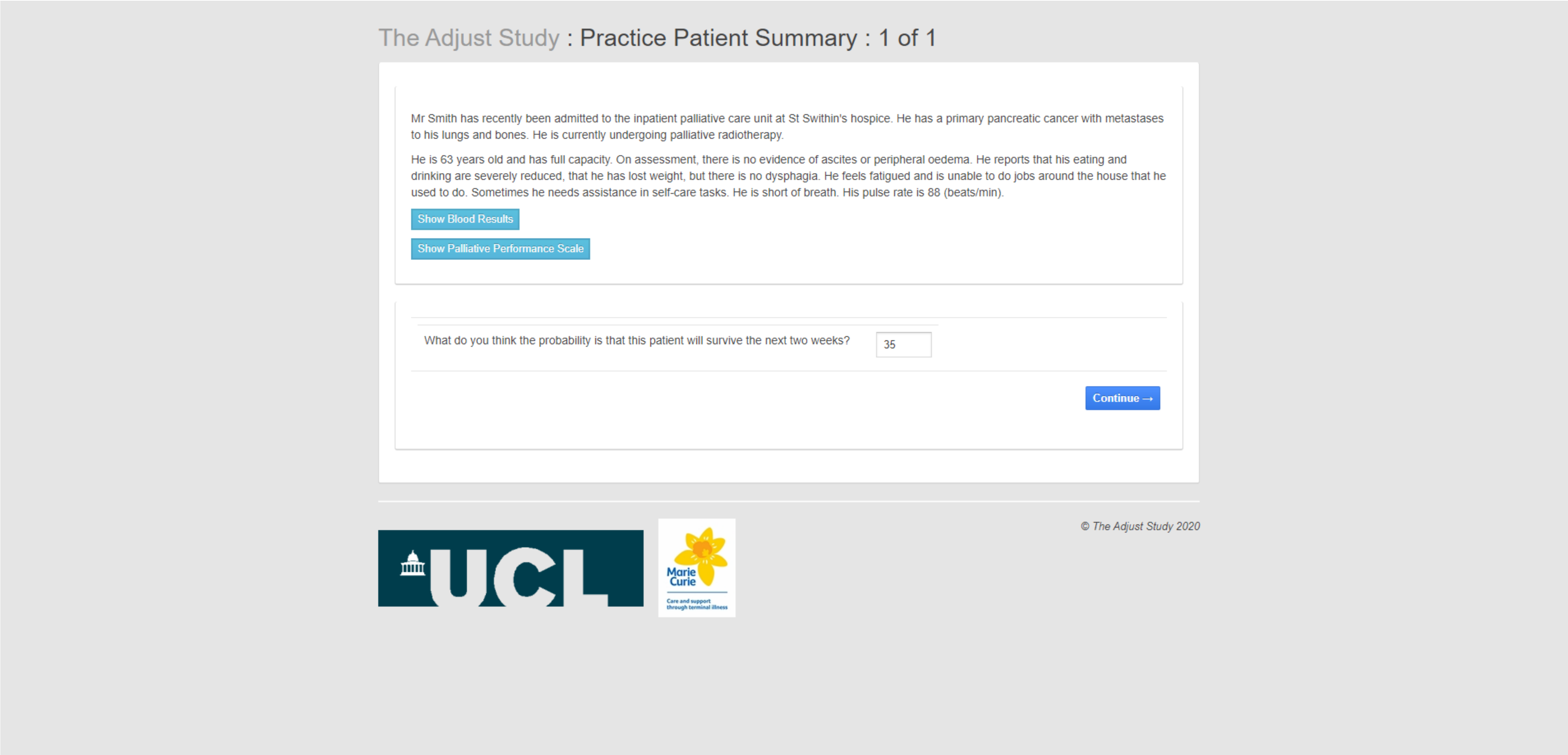
He is 63 years old and has full capacity. On assessment, there is no evidence of ascites or peripheral oedema. He reports that his eating and drinking are severely reduced, that he has lost weight, but there is no dysphagia. He feels fatigued and is unable to do jobs around the house that he used to do. Sometimes he needs assistance in self-care tasks. He is short of breath. His pulse rate is 88 (beats/min).

Palliative Performance Scale (PPSv2)
version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

What do you think the probability is that this patient will survive the next two weeks? %

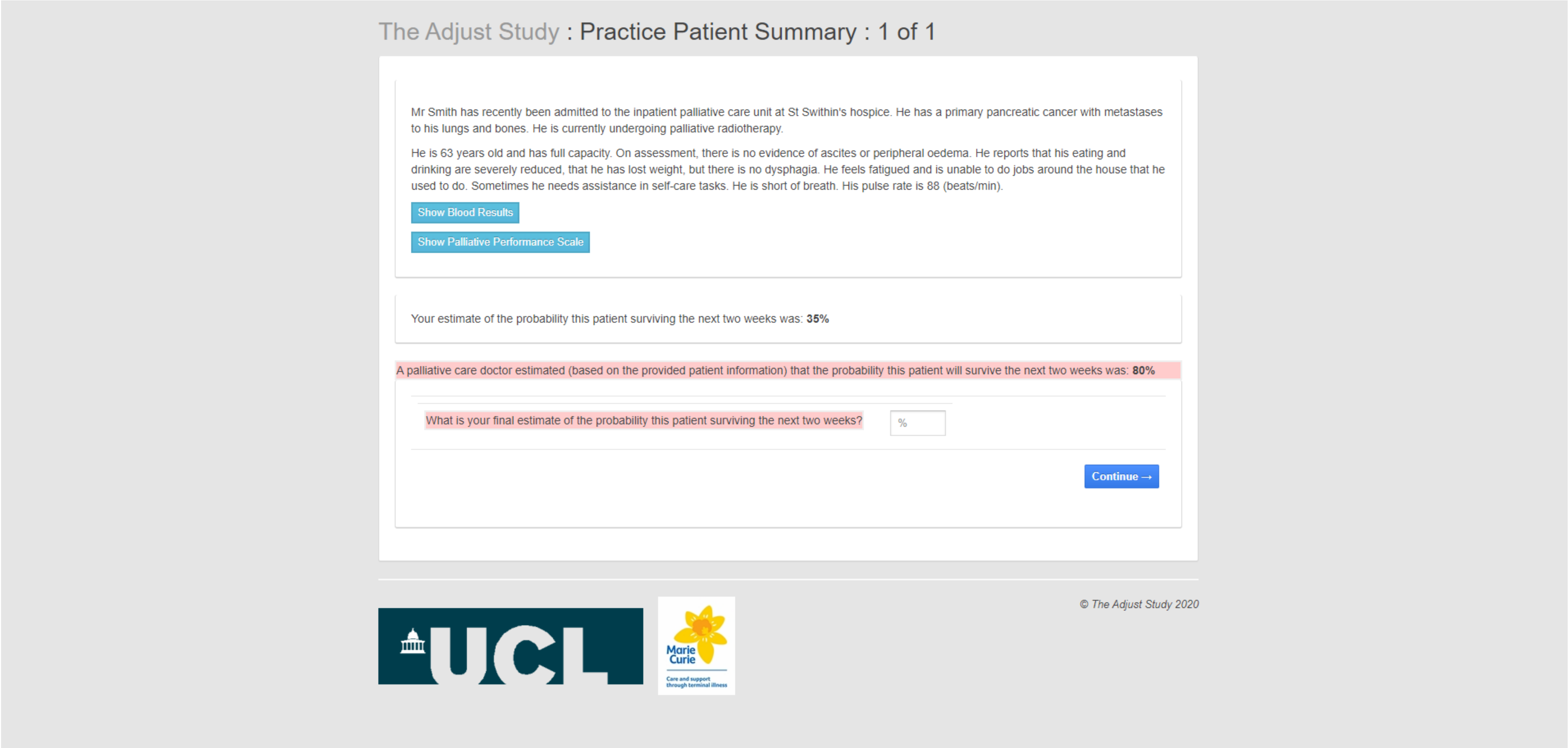


The Adjust Study : Practice Patient Summary : 1 of 1

Mr Smith has recently been admitted to the inpatient palliative care unit at St Swithin's hospice. He has a primary pancreatic cancer with metastases to his lungs and bones. He is currently undergoing palliative radiotherapy.

He is 63 years old and has full capacity. On assessment, there is no evidence of ascites or peripheral oedema. He reports that his eating and drinking are severely reduced, that he has lost weight, but there is no dysphagia. He feels fatigued and is unable to do jobs around the house that he used to do. Sometimes he needs assistance in self-care tasks. He is short of breath. His pulse rate is 88 (beats/min).

What do you think the probability is that this patient will survive the next two weeks? 35



The Adjust Study : Practice Patient Summary : 1 of 1

Mr Smith has recently been admitted to the inpatient palliative care unit at St Swithin's hospice. He has a primary pancreatic cancer with metastases to his lungs and bones. He is currently undergoing palliative radiotherapy.

He is 63 years old and has full capacity. On assessment, there is no evidence of ascites or peripheral oedema. He reports that his eating and drinking are severely reduced, that he has lost weight, but there is no dysphagia. He feels fatigued and is unable to do jobs around the house that he used to do. Sometimes he needs assistance in self-care tasks. He is short of breath. His pulse rate is 88 (beats/min).

Your estimate of the probability this patient surviving the next two weeks was: **35%**

A palliative care doctor estimated (based on the provided patient information) that the probability this patient will survive the next two weeks was: **80%**

What is your final estimate of the probability this patient surviving the next two weeks?

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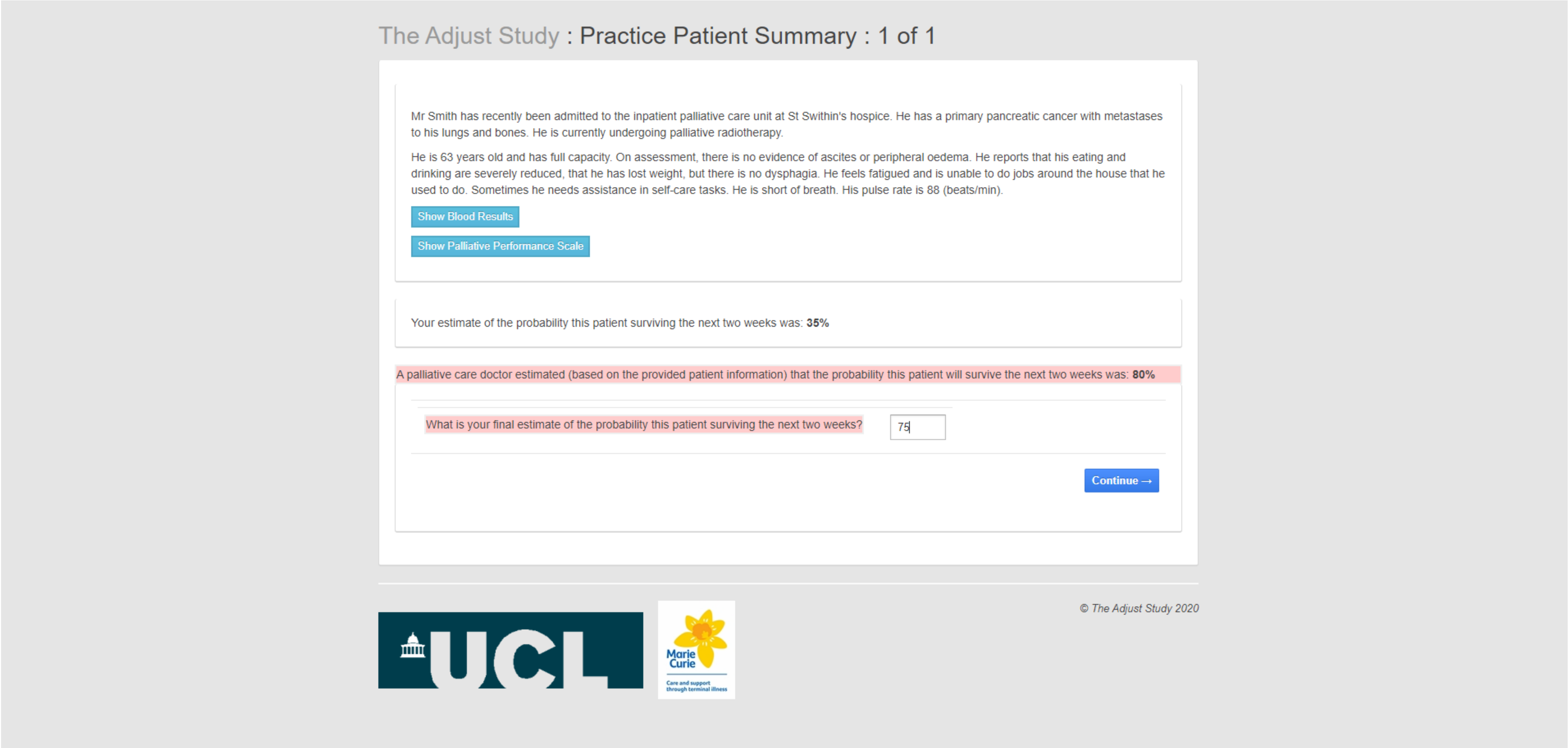

The Adjust Study : Practice Patient Summary : 1 of 1

Mr Smith has recently been admitted to the inpatient palliative care unit at St Swithin's hospice. He has a primary pancreatic cancer with metastases to his lungs and bones. He is currently undergoing palliative radiotherapy.

He is 63 years old and has full capacity. On assessment, there is no evidence of ascites or peripheral oedema. He reports that his eating and drinking are severely reduced, that he has lost weight, but there is no dysphagia. He feels fatigued and is unable to do jobs around the house that he used to do. Sometimes he needs assistance in self-care tasks. He is short of breath. His pulse rate is 88 (beats/min).

Your estimate of the probability this patient surviving the next two weeks was: **35%**

A palliative care doctor estimated (based on the provided patient information) that the probability this patient will survive the next two weeks was: **80%**

What is your final estimate of the probability this patient surviving the next two weeks? 75

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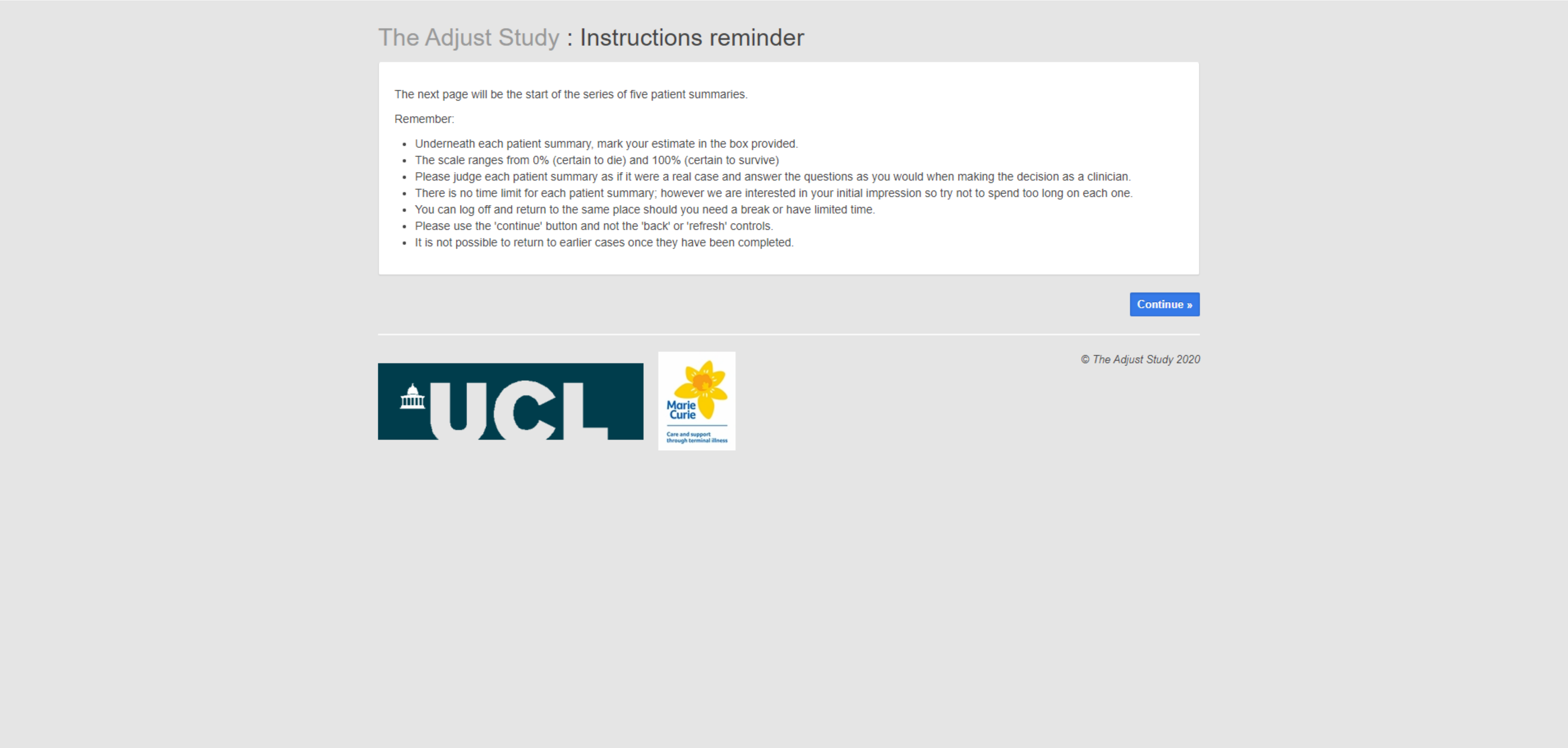
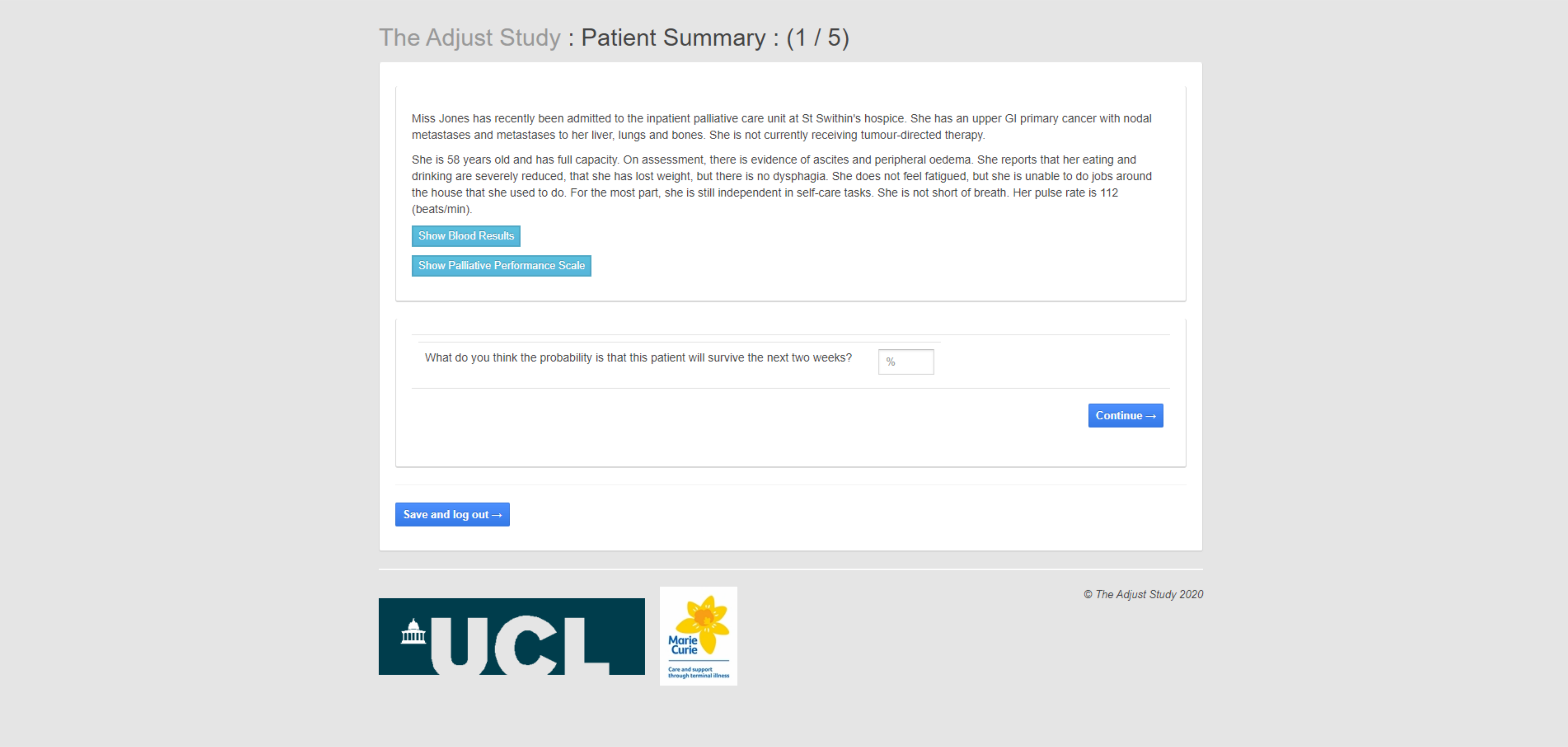


The Adjust Study : Instructions reminder

The next page will be the start of the series of five patient summaries.

Remember:

- Underneath each patient summary, mark your estimate in the box provided.
- The scale ranges from 0% (certain to die) and 100% (certain to survive)
- Please judge each patient summary as if it were a real case and answer the questions as you would when making the decision as a clinician.
- There is no time limit for each patient summary; however we are interested in your initial impression so try not to spend too long on each one.
- You can log off and return to the same place should you need a break or have limited time.
- Please use the 'continue' button and not the 'back' or 'refresh' controls.
- It is not possible to return to earlier cases once they have been completed.



The Adjust Study : Patient Summary : (1 / 5)

Miss Jones has recently been admitted to the inpatient palliative care unit at St Swithin's hospice. She has an upper GI primary cancer with nodal metastases and metastases to her liver, lungs and bones. She is not currently receiving tumour-directed therapy.

She is 58 years old and has full capacity. On assessment, there is evidence of ascites and peripheral oedema. She reports that her eating and drinking are severely reduced, that she has lost weight, but there is no dysphagia. She does not feel fatigued, but she is unable to do jobs around the house that she used to do. For the most part, she is still independent in self-care tasks. She is not short of breath. Her pulse rate is 112 (beats/min).

What do you think the probability is that this patient will survive the next two weeks? %

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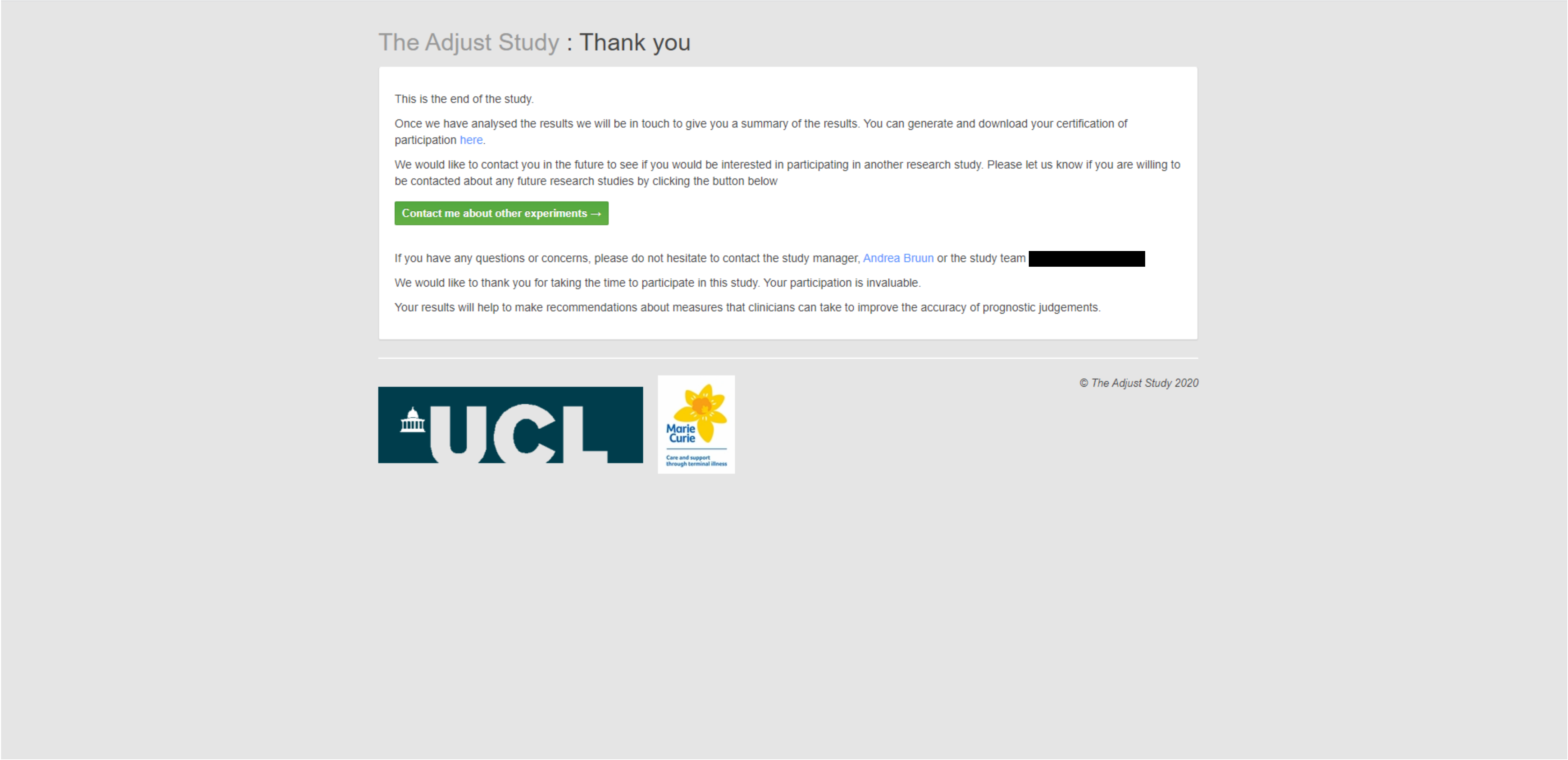

The Adjust Study : Thank you

This is the end of the study.

Once we have analysed the results we will be in touch to give you a summary of the results. You can generate and download your certification of participation here.

We would like to contact you in the future to see if you would be interested in participating in another research study. Please let us know if you are willing to be contacted about any future research studies by clicking the button below

If you have any questions or concerns, please do not hesitate to contact the study manager, Andrea Bruun or the study team [redacted]

We would like to thank you for taking the time to participate in this study. Your participation is invaluable.

Your results will help to make recommendations about measures that clinicians can take to improve the accuracy of prognostic judgements.

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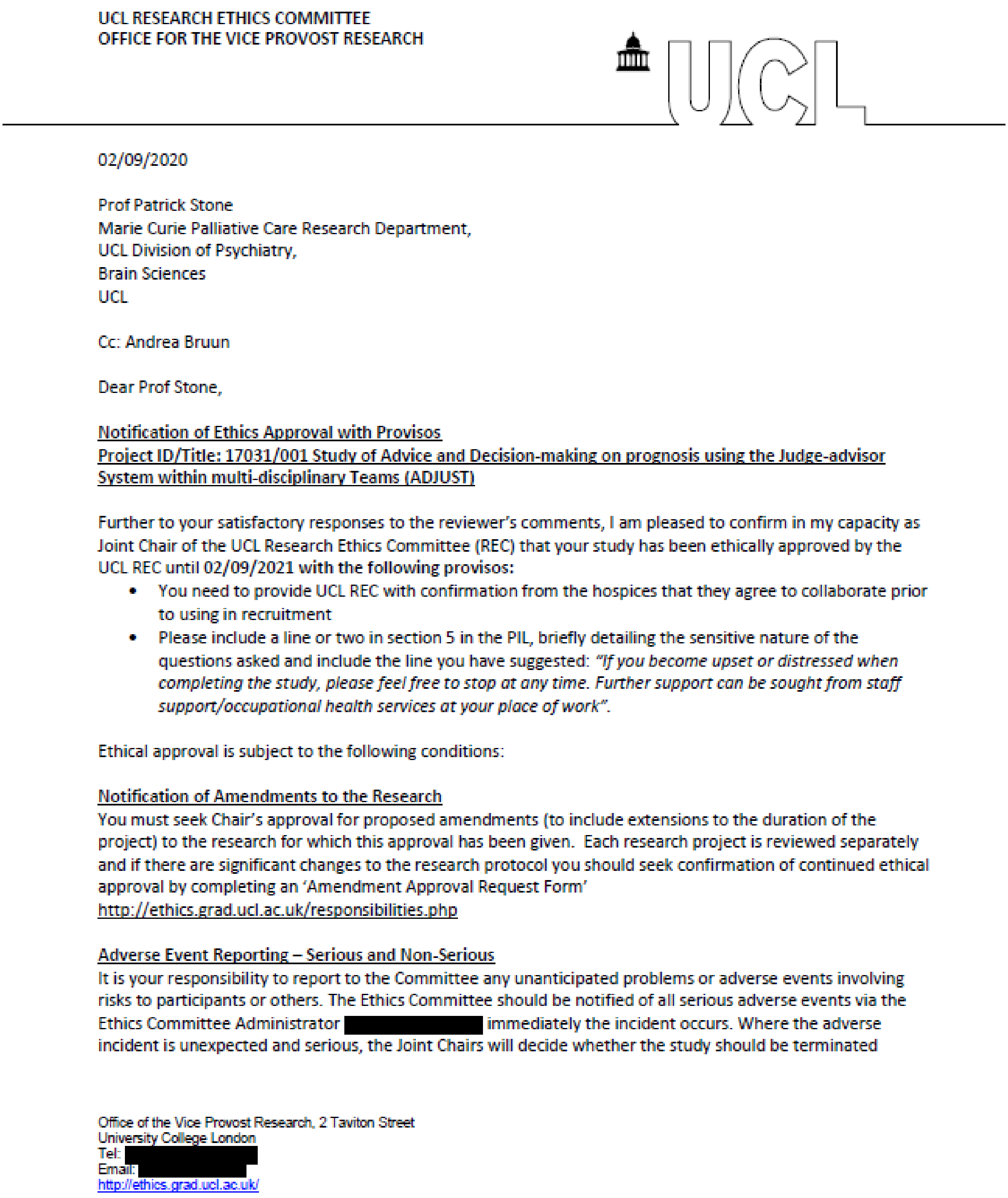
Appendix 11 – ADJUST UCL REC approval letter



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

02/09/2020

Prof Patrick Stone
Marie Curie Palliative Care Research Department,
UCL Division of Psychiatry,
Brain Sciences
UCL

Cc: Andrea Bruun

Dear Prof Stone,

Notification of Ethics Approval with Provisos
Project ID/Title: 17031/001 Study of Advice and Decision-making on prognosis using the Judge-advisor System within multi-disciplinary Teams (ADJUST)

Further to your satisfactory responses to the reviewer's comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **02/09/2021 with the following provisos:**

- You need to provide UCL REC with confirmation from the hospices that they agree to collaborate prior to using in recruitment
- Please include a line or two in section 5 in the PIL, briefly detailing the sensitive nature of the questions asked and include the line you have suggested: *"If you become upset or distressed when completing the study, please feel free to stop at any time. Further support can be sought from staff support/occupational health services at your place of work"*.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator [redacted] immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: [redacted]
Email: [redacted]
http://ethics.grad.ucl.ac.uk/

pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: www.ucl.ac.uk/srs/governance-and-committees/research-governance
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix 12 – CA study Staff information poster

UCL
University College London, Gower Street, London WC1E 6BT
Tel: +44 (0)20 7679 2000
email@ucl.ac.uk
www.ucl.ac.uk

NOTICE:

From May 12th – December 15th 2021 the ward MDT meetings will be video recorded by a researcher from the Marie Curie Palliative Care Research Department, UCL

Dear colleagues,

This is to remind you that MDT meetings will be video recorded during the time period above. The recordings will be used for ethically approved research on hospice MDT communication. This notice is relevant for everyone attending (or planning to attend) MDT meetings within this period.

No data relating to your involvement in the MDT will be used for this research without your written informed consent. If you have not yet done this and wish to do so, please contact Andrea Bruun in person or via her contact details below.

If you know of anyone attending a forthcoming meeting, but who is not a regular participant, please let them know that the meeting will be recorded. They will need to read the Participation Information Sheet and, if they wish to participate, sign a consent form as well.

Andrea will be present before, during, and after the MDT meeting, and will be available to answer any questions regarding the study.

Thank you for your help. We are looking forward to working with you.

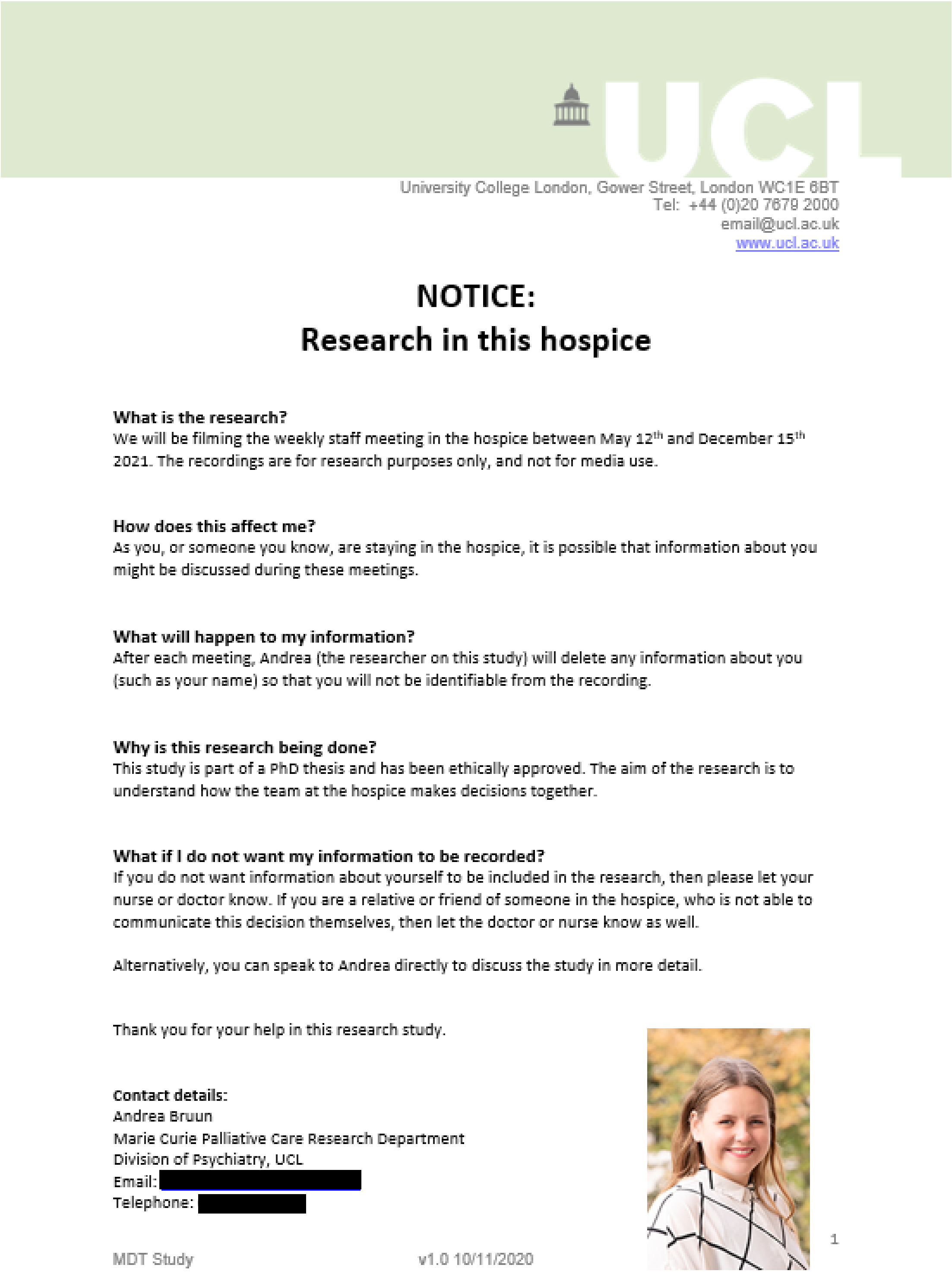
Best wishes,
Andrea

Contact details:
Andrea Bruun
Marie Curie Palliative Care Research Department
Division of Psychiatry, UCL
Email: [redacted]
Tel.: [redacted]

1

MDT Study v1.0 06/10/2020

Appendix 13 – CA study Patient information poster



University College London, Gower Street, London WC1E 6BT
Tel: +44 (0)20 7679 2000
email@ucl.ac.uk
www.ucl.ac.uk

NOTICE:
Research in this hospice

What is the research?
We will be filming the weekly staff meeting in the hospice between May 12th and December 15th 2021. The recordings are for research purposes only, and not for media use.

How does this affect me?
As you, or someone you know, are staying in the hospice, it is possible that information about you might be discussed during these meetings.

What will happen to my information?
After each meeting, Andrea (the researcher on this study) will delete any information about you (such as your name) so that you will not be identifiable from the recording.

Why is this research being done?
This study is part of a PhD thesis and has been ethically approved. The aim of the research is to understand how the team at the hospice makes decisions together.

What if I do not want my information to be recorded?
If you do not want information about yourself to be included in the research, then please let your nurse or doctor know. If you are a relative or friend of someone in the hospice, who is not able to communicate this decision themselves, then let the doctor or nurse know as well.

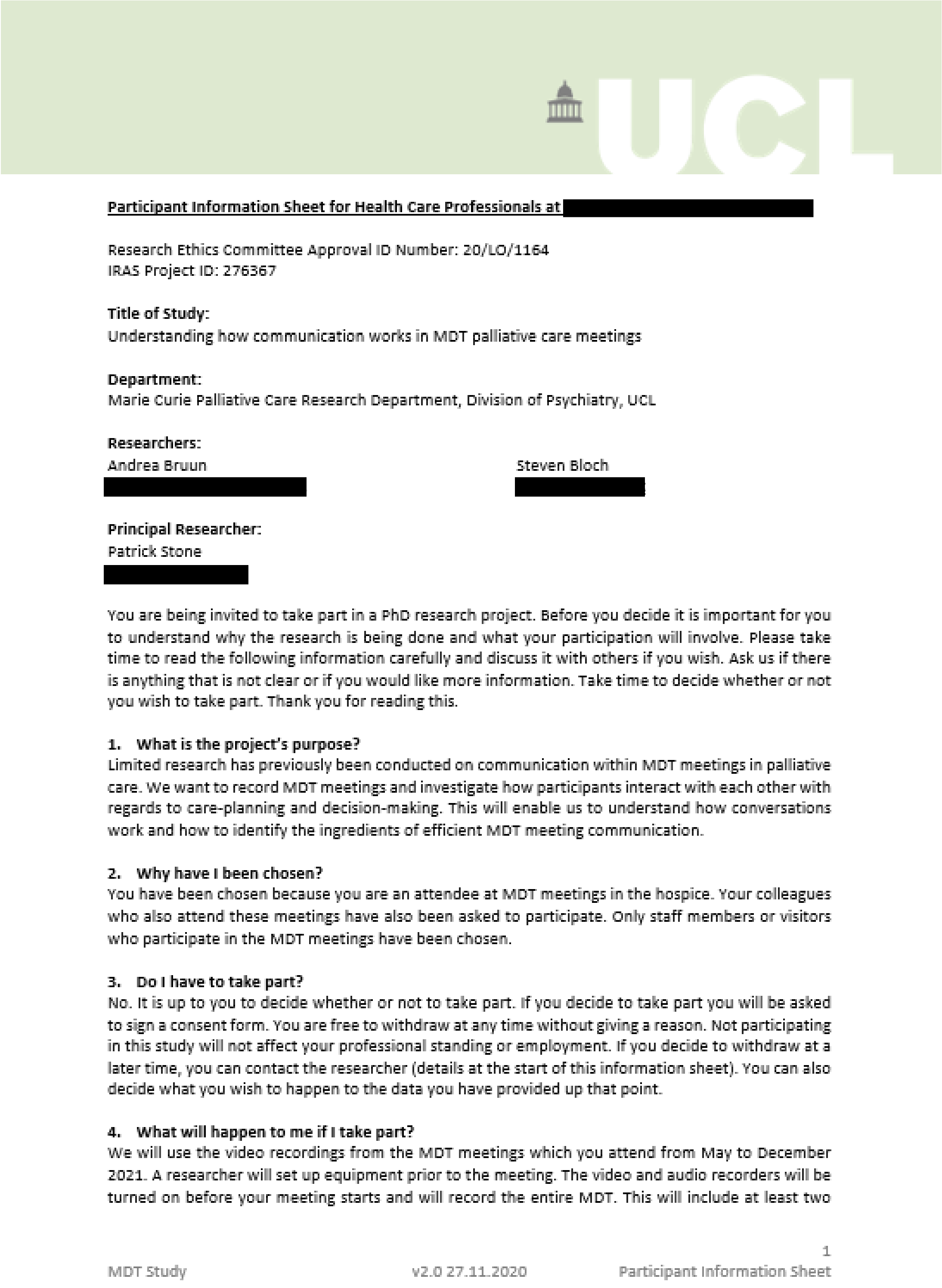
Alternatively, you can speak to Andrea directly to discuss the study in more detail.

Thank you for your help in this research study.

Contact details:
Andrea Bruun
Marie Curie Palliative Care Research Department
Division of Psychiatry, UCL
Email: [redacted]
Telephone: [redacted]

MDT Study v1.0 10/11/2020 1

Appendix 14 – CA study Participant Information Sheet



Participant Information Sheet for Health Care Professionals at [redacted]

Research Ethics Committee Approval ID Number: 20/LO/1164
IRAS Project ID: 276367

Title of Study:
Understanding how communication works in MDT palliative care meetings

Department:
Marie Curie Palliative Care Research Department, Division of Psychiatry, UCL

Researchers:

Andrea Bruun	Steven Bloch
[redacted]	[redacted]

Principal Researcher:
Patrick Stone
[redacted]

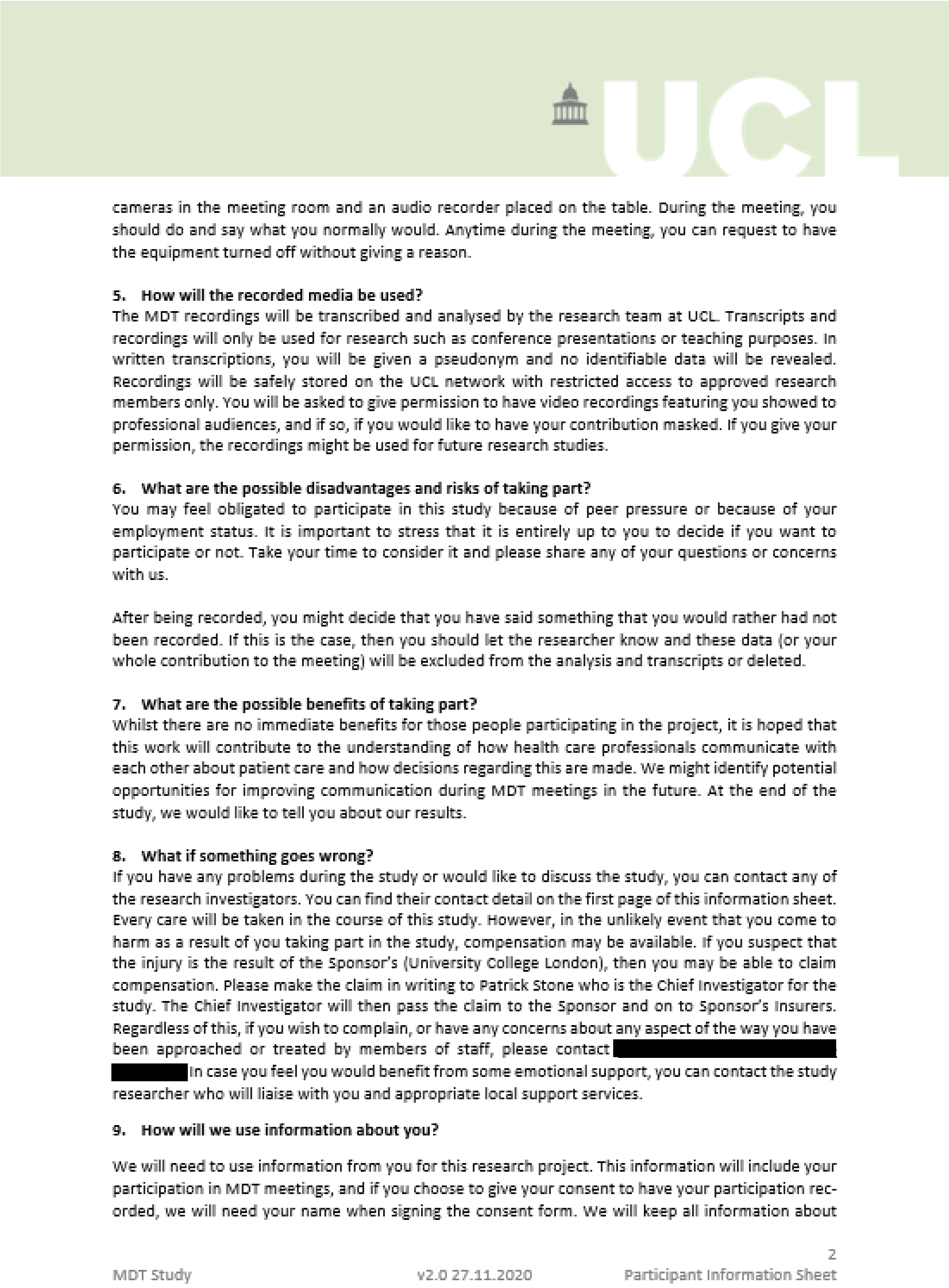
You are being invited to take part in a PhD research project. Before you decide it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

1. What is the project's purpose?
Limited research has previously been conducted on communication within MDT meetings in palliative care. We want to record MDT meetings and investigate how participants interact with each other with regards to care-planning and decision-making. This will enable us to understand how conversations work and how to identify the ingredients of efficient MDT meeting communication.

2. Why have I been chosen?
You have been chosen because you are an attendee at MDT meetings in the hospice. Your colleagues who also attend these meetings have also been asked to participate. Only staff members or visitors who participate in the MDT meetings have been chosen.

3. Do I have to take part?
No. It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. You are free to withdraw at any time without giving a reason. Not participating in this study will not affect your professional standing or employment. If you decide to withdraw at a later time, you can contact the researcher (details at the start of this information sheet). You can also decide what you wish to happen to the data you have provided up that point.

4. What will happen to me if I take part?
We will use the video recordings from the MDT meetings which you attend from May to December 2021. A researcher will set up equipment prior to the meeting. The video and audio recorders will be turned on before your meeting starts and will record the entire MDT. This will include at least two



cameras in the meeting room and an audio recorder placed on the table. During the meeting, you should do and say what you normally would. Anytime during the meeting, you can request to have the equipment turned off without giving a reason.

5. How will the recorded media be used?
The MDT recordings will be transcribed and analysed by the research team at UCL. Transcripts and recordings will only be used for research such as conference presentations or teaching purposes. In written transcriptions, you will be given a pseudonym and no identifiable data will be revealed. Recordings will be safely stored on the UCL network with restricted access to approved research members only. You will be asked to give permission to have video recordings featuring you showed to professional audiences, and if so, if you would like to have your contribution masked. If you give your permission, the recordings might be used for future research studies.

6. What are the possible disadvantages and risks of taking part?
You may feel obligated to participate in this study because of peer pressure or because of your employment status. It is important to stress that it is entirely up to you to decide if you want to participate or not. Take your time to consider it and please share any of your questions or concerns with us.

After being recorded, you might decide that you have said something that you would rather had not been recorded. If this is the case, then you should let the researcher know and these data (or your whole contribution to the meeting) will be excluded from the analysis and transcripts or deleted.

7. What are the possible benefits of taking part?
Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will contribute to the understanding of how health care professionals communicate with each other about patient care and how decisions regarding this are made. We might identify potential opportunities for improving communication during MDT meetings in the future. At the end of the study, we would like to tell you about our results.

8. What if something goes wrong?
If you have any problems during the study or would like to discuss the study, you can contact any of the research investigators. You can find their contact detail on the first 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 in the study, compensation may be available. If you suspect that the injury is the result of the Sponsor's (University College London), then you may be able to claim compensation. Please make the claim in writing to Patrick Stone who is the Chief Investigator for the study. The Chief Investigator will then pass the claim to the Sponsor and on to Sponsor's Insurers. 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, please contact [redacted] In case you feel you would benefit from some emotional support, you can contact the study researcher who will liaise with you and appropriate local support services.

9. How will we use information about you?

We will need to use information from you for this research project. This information will include your participation in MDT meetings, and if you choose to give your consent to have your participation recorded, we will need your name when signing the consent form. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, and you can decide what you wish to happen to the data you have provided up that point.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study. You will be asked to give your consent to this in the consent form.

10. Will my taking part in this project be kept confidential?
All of the information that we collect about you during the course of the research will follow ethical and legal practice and will be handled in confidence. Consent forms will be held securely in a locked cabinet within a restricted area office within UCL. Any identifiable information mentioned in the recordings will be audibly masked and anonymised in transcripts used for analyses and future publications. If you allow us to use your contribution to the meeting at conferences, you will be given the option to be audibly and visibly masked as well. Once the data is collected, we can mask your voice and appearance in the recordings using appropriate software. All information regarding the patients that you discuss will be handled in confidence as well, but due to their frail state we have not asked them to give their consent for this study. Being allowed to do so, we have sought the relevant ethics approval from the NHS, the Health Research Authority (HRA) Confidentiality Advisory Group (CAG).

11. Limits to confidentiality
Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case, we would inform you of any decisions that might limit your confidentiality.

12. What will happen to the results of the research project?
The research team will analyse the recordings, and the final results of the study will be published in journals and presented at conferences. The study will also be published as part of a PhD thesis. The results will be used by UCL for future research, and we will inform and share our results with the hospice as well.

13. Data Protection Privacy Notice
The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [redacted]

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice at https://www.ucl.ac.uk/legal-services/privacy, and then choosing the bullet for participants in health and care research studies. The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices. 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 personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [redacted]

UK data protection law is regulated by the Information Commissioner's Office (ICO). If you are concerned about how your personal data is being processed you may wish to submit a complaint to them. Contact details, and details of data subject rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

14. What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time. Please talk to a member of the research team if you wish to do so. You do not have to give a reason and you will not be penalised for withdrawing.

15. Who is organising and funding the research?

This research study is being organised by UCL. The study is part of a PhD project that is funded by Marie Curie.

16. Who has reviewed this study?

This study has been reviewed and given favourable opinion by London – Camden & Kings Cross Research Ethics Committee on 04/12/2020 and by the Confidentiality Advisory Group on 06/04/2021.

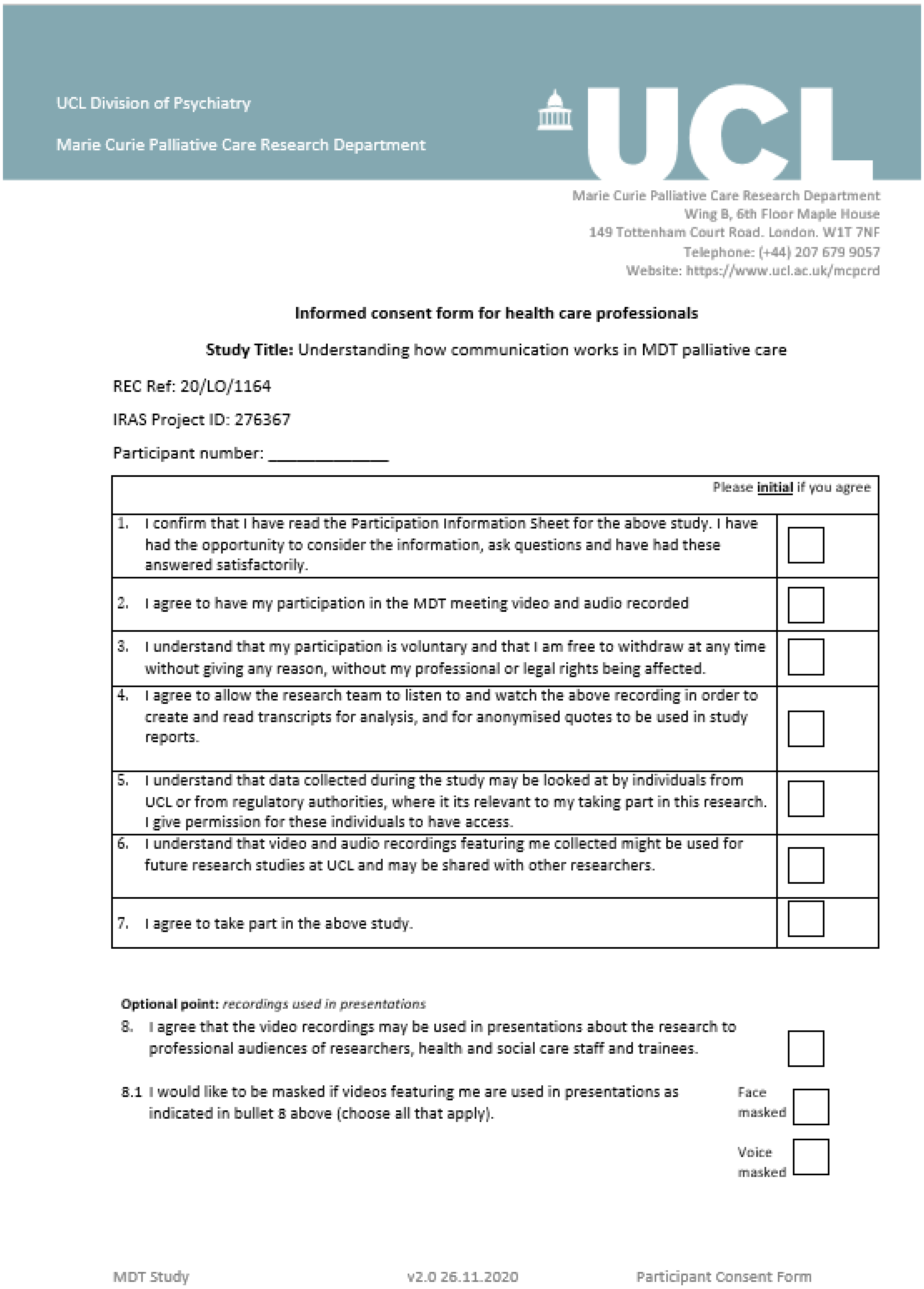
17. Contact for further information

You are encouraged to ask any questions you wish, before and during the study. If you require any further information or have any concerns while taking part in the study, please contact Andrea Bruun at Marie Curie Palliative Care Research Department on [redacted]

If you decide you would like to take part, we will give you a consent form for you to read and sign. You will be given a copy of this information sheet and the consent form to keep. A copy of the consent form will be filed at UCL.

Thank you for taking the time to read this information sheet and to consider this study.

Appendix 15 – CA study Consent form



UCL Division of Psychiatry

Marie Curie Palliative Care Research Department

Marie Curie Palliative Care Research Department
Wing B, 6th Floor Maple House
149 Tottenham Court Road. London. W1T 7NF
Telephone: (+44) 207 679 9057
Website: https://www.ucl.ac.uk/mcpcrd

Informed consent form for health care professionals

Study Title: Understanding how communication works in MDT palliative care

REC Ref: 20/LO/1164

IRAS Project ID: 276367

Participant number: ______________

	Please <u>initial</u> if you agree
1. I confirm that I have read the Participation Information Sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I agree to have my participation in the MDT meeting video and audio recorded	☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my professional or legal rights being affected.	☐
4. I agree to allow the research team to listen to and watch the above recording in order to create and read transcripts for analysis, and for anonymised quotes to be used in study reports.	☐
5. I understand that data collected during the study may be looked at by individuals from UCL or from regulatory authorities, where it its relevant to my taking part in this research. I give permission for these individuals to have access.	☐
6. I understand that video and audio recordings featuring me collected might be used for future research studies at UCL and may be shared with other researchers.	☐
7. I agree to take part in the above study.	☐

Optional point: *recordings used in presentations*

8. I agree that the video recordings may be used in presentations about the research to professional audiences of researchers, health and social care staff and trainees. ☐

8.1 I would like to be masked if videos featuring me are used in presentations as indicated in bullet 8 above (choose all that apply).

Face masked ☐

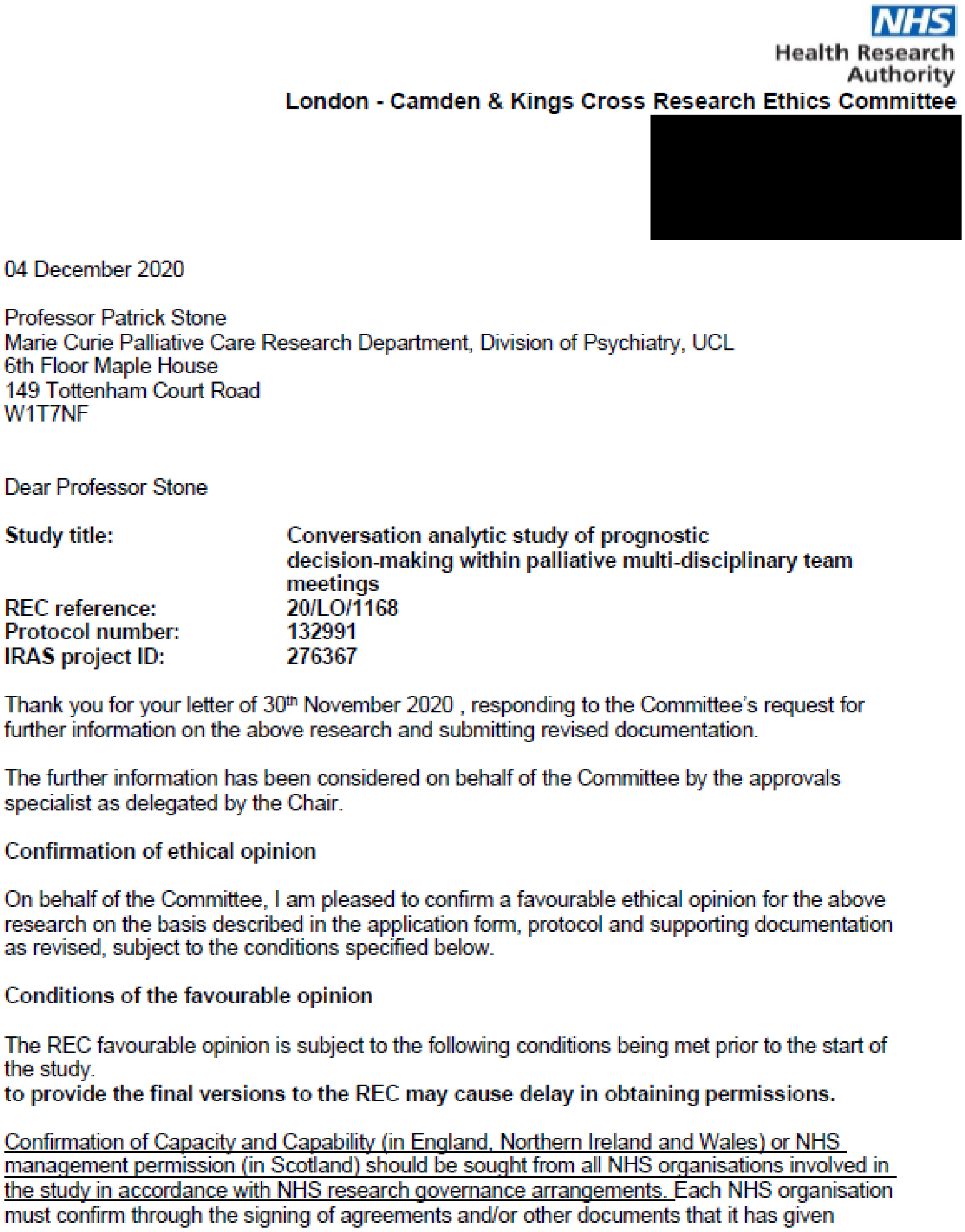
Voice masked ☐

MDT Study v2.0 26.11.2020 Participant Consent Form

______________________________	______________	______________________
Name of participant	Date	Signature
________________________________	____________	__________________
Name of person taking consent	Date	Signature

Two copies – one to participant, one to the research team

Appendix 16 – CA study REC approval letter



NHS
Health Research
Authority
London - Camden & Kings Cross Research Ethics Committee
[redacted]

04 December 2020

Professor Patrick Stone
Marie Curie Palliative Care Research Department, Division of Psychiatry, UCL
6th Floor Maple House
149 Tottenham Court Road
W1T7NF

Dear Professor Stone

Study title:	**Conversation analytic study of prognostic decision-making within palliative multi-disciplinary team meetings**
REC reference:	**20/LO/1168**
Protocol number:	**132991**
IRAS project ID:	**276367**

Thank you for your letter of 30th November 2020 , responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the approvals specialist as delegated by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.
to provide the final versions to the REC may cause delay in obtaining permissions.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Hospice Information Material]	1.0	06 October 2020
Covering letter on headed paper [Cover Letter]	1.0	30 September 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Verification of Insurance]	1.0	28 September 2020
Letter from funder [Award Letter]	1.0	22 July 2013
Letter from sponsor [Sponsorship Confirmation Email]	1.0	29 September 2020
Non-NHS/HSC Site Assessment Form [mNCA]	1.0	07 September 2020
Other [Non-Disclosure Agreement]	1.0	30 September 2020
Other [Withdrawal Form]	1.0	30 September 2020
Other [Tertiary Supervisor Brief CV - Linda Oostendorp]	1.0	09 June 2020
Other [Tertiary Supervisor Brief CV - Nicola White]	1.0	24 June 2020
Other [Consent Anonymisation Process]	1.0	30 September 2020
Other [REC Response Letter]	1.0	27 November 2020
Participant consent form [Consent Form]	2.0	26 November 2020
Participant information sheet (PIS) [Participant Information Sheet]	2.0	27 November 2020
REC Application Form [REC_Form_07102020]		07 October 2020
Referee's report or other scientific critique report [Academic Expert Review]	1.0	25 February 2020
Research protocol or project proposal [Study Protocol]	2.0	26 November 2020
Summary CV for Chief Investigator (CI) [Chief Investigator Brief CV - Patrick Stone]	1.0	18 May 2020
Summary CV for student [Student Brief CV - Andrea Bruun]	1.0	30 September 2020
Summary CV for supervisor (student research) [Brief CV - Steven Bloch]	1.0	09 June 2020

Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study Flowchart]	1.0	11 July 2020
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study Gantt Chart]	1.0	30 September 2020

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 276367 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

pp [redacted]

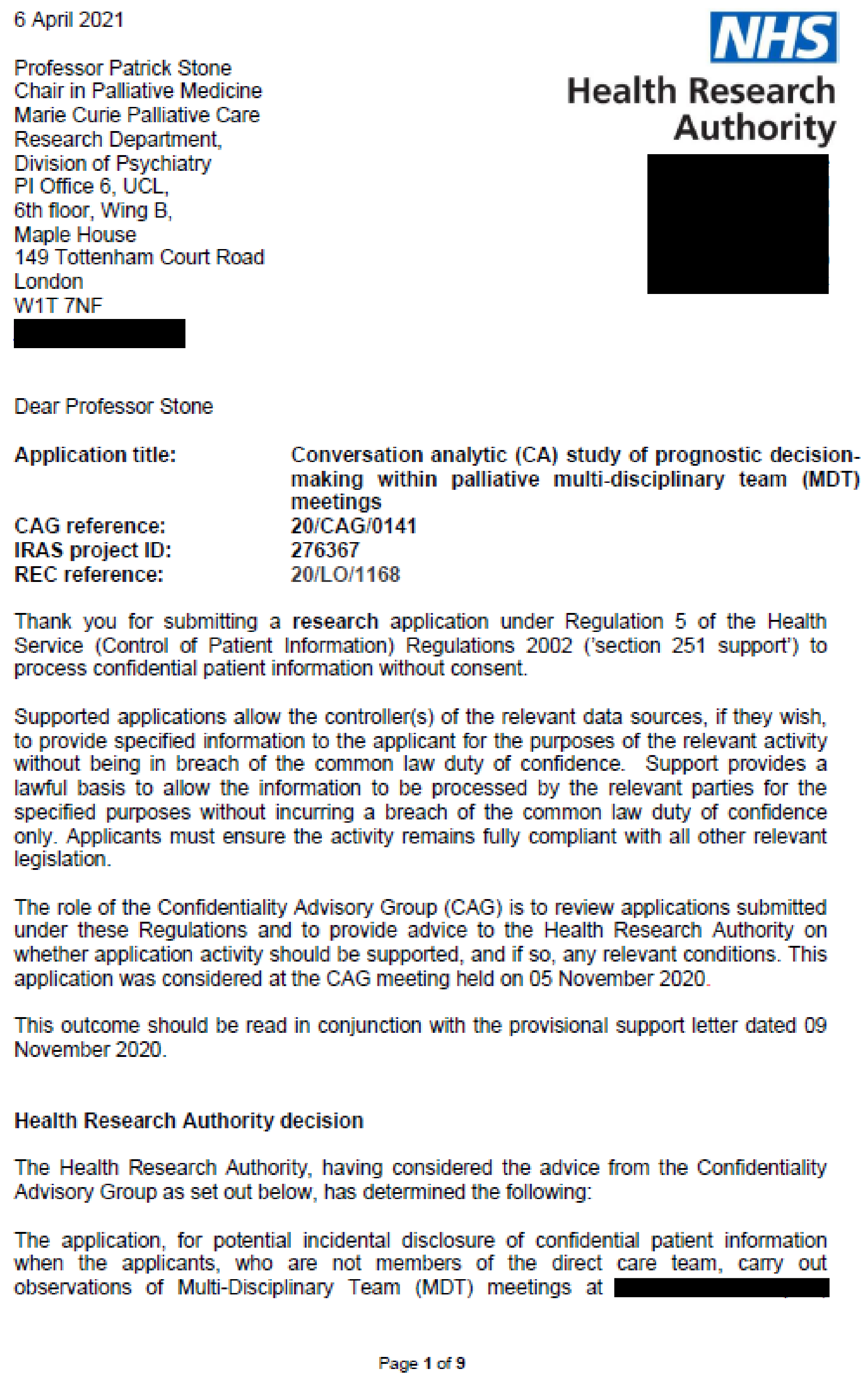
Mrs Rosie Glazebrook
Chair

Email: [redacted]

Enclosures: "After ethical review – guidance for researchers"

Copy to: Miss Andrea Bruun
Confidentiality Advise Team

Appendix 17 – CA study CAG support letter



NHS
Health Research
Authority
[redacted]

6 April 2021

Professor Patrick Stone
Chair in Palliative Medicine
Marie Curie Palliative Care
Research Department,
Division of Psychiatry
PI Office 6, UCL,
6th floor, Wing B,
Maple House
149 Tottenham Court Road
London
W1T 7NF
[redacted]

Dear Professor Stone

Application title:	**Conversation analytic (CA) study of prognostic decision-making within palliative multi-disciplinary team (MDT) meetings**
CAG reference:	**20/CAG/0141**
IRAS project ID:	**276367**
REC reference:	20/LO/1168

Thank you for submitting a **research** application under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 ('section 251 support') to process confidential patient information without consent.

Supported applications allow the controller(s) of the relevant data sources, if they wish, to provide specified information to the applicant for the purposes of the relevant activity without being in breach of the common law duty of confidence. Support provides a lawful basis to allow the information to be processed by the relevant parties for the specified purposes without incurring a breach of the common law duty of confidence only. Applicants must ensure the activity remains fully compliant with all other relevant legislation.

The role of the Confidentiality Advisory Group (CAG) is to review applications submitted under these Regulations and to provide advice to the Health Research Authority on whether application activity should be supported, and if so, any relevant conditions. This application was considered at the CAG meeting held on 05 November 2020.

This outcome should be read in conjunction with the provisional support letter dated 09 November 2020.

Health Research Authority decision

The Health Research Authority, having considered the advice from the Confidentiality Advisory Group as set out below, has determined the following:

The application, for potential incidental disclosure of confidential patient information when the applicants, who are not members of the direct care team, carry out observations of Multi-Disciplinary Team (MDT) meetings at [redacted]

[redacted] is conditionally supported, subject to compliance with the standard and specific conditions of support.

Please note that the legal basis to allow access to the specified confidential patient information without consent is now in effect.

Context

Purpose of application

This application from University College London, Division of Psychiatry, Marie Curie Palliative Care Research Department sets out the purpose of medical research that aims to explore how health care professionals with different backgrounds make decisions regarding prognosis for terminally ill patients during MDT meetings in a hospice. The analyses will use Conversation analytic (CA) methodology to give an insight in to how MDT prognostic decisions are initiated, structured, potentially challenged and negotiated, and finally closed. This application is a qualitative study of recorded interactions between healthcare professionals in MDT meetings in [redacted] [redacted], as part of a PhD project.

Studies show that there is value for patients and families in accurate prognostic information. Clinicians' predictions about length of survival are inaccurate and over-optimistic, and no clear guidance exists on how clinicians can be taught to perform this task better. Nonetheless, clinical predictions of survival remain the most common method of arriving at a prognostic estimate. This inaccuracy and inconsistency is maintained when the timeframe of the prognosis is reduced to days. One potential method to improve prognostication has been to look at decisions made by an MDT, however the manner in which different estimates are combined to arrive at an MDT estimate is not well understood.

Applicants plan to collect video recordings of 20-30 hospice-based MDT meetings. The collaborating hospice has two wards that each holds a weekly MDT meeting, during which staff members with different professional backgrounds discuss palliative patients' care planning. Before MDT meetings, a researcher will set up equipment (cameras, microphones) in the meeting room, and immediately before the meeting begins, the equipment will be turned on. The researcher will stay outside the meeting room, to avoid interfering in the processes of the meeting. All staff and visitors taking part in the MDT will have been approached by the researcher with an information sheet and asked to provide signed informed consent. If the staff member declines consent, their data will be excluded from analysis. A note on the door will also inform staff and visitors that the meeting is being recorded.

Data will be collected using encrypted recorders. Recordings will be uploaded electronically to a UCL encrypted laptop at the hospice site as soon as possible after the meeting, and then then deleted from the recorders. If the recordings are not immediately uploaded, they will be safely stored in a locked cabinet with restricted access at the hospice for a maximum of 72 hours. The laptop will be physically transferred back to UCL, where all patient identifiable information will be deleted or anonymised from the video recordings before transferring to the UCL s:drive for storage, and deletion from the laptop.

The researcher will make detailed transcriptions of the recordings, and information that might lead to identification of the patients being discussed or of the participants in the meetings will be anonymized and pseudonymised. This will be done by (1) using pseudonyms instead of participants' and patients' names, location etc. in transcripts etc. and by (2) beeping out"/audibly masking the identifiable information in the video recording. A list of pseudonyms will not be maintained so patients will not be able to be re-identified. No patient-identifiers will be retained because this information is not required for the study purposes. The method of CA closely investigates the sequential organisation and the interactional functions of naturally occurring talk as well as non-verbal behaviour. Therefore the applicants plan to use the transcription system CLAN (Computerized Language Analysis), to enable them to link the transcripts to media.

A recommendation for class 5 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential patient information requested

The following sets out a summary of the specified cohort, listed data sources and key identifiers. Where applicable, full datasets and data flows are provided in the application form and relevant supporting documentation as this letter represents only a summary of the full detail.

Cohort	For CAG purposes support is only given regarding patients at the Hospice, not for staff members or official visitors. The cohort is: patients treated [redacted], [redacted] who are being discussed during MDT meetings, whose information may be incidentally disclosed.
Data sources	1. Video recordings of MDT meetings at [redacted]
Identifiers required for linkage purposes	1. No items of confidential patient information will be collected for linkage purposes
Identifiers required for analysis purposes	1. No items of confidential patient information will be collected for analysis purposes
Additional information	Video recordings will be anonymised by • Using pseudonyms instead of participants' and patients' names, location etc. in written transcripts. Applicant has confirmed that a list of patient names and their identifiers will not be kept. • Audibly masking the identifiable information in the video recording by 'beeping out'

Confidentiality Advisory Group advice

This letter summarises the outstanding elements set out in the provisional support letter, and the applicant response. The applicant response was considered by a sub-committee of the CAG.

1. **Please confirm if it is possible for the recording to be turned off at the start of each patient discussion so that full name is not recorded? If this is not possible, please provide a full justification.**

   The applicant has detailed in their responses why this is not possible, as this would distort the naturally occurring flow of conversation, which is the intention of the study to record. Interrupting the MDT meetings in this way could use additional time, which hospice staff do not have to spare, and may therefore negatively impact patient care by reducing the time spend discussing patients in meetings. The CAG accepted this justification.

2. **Please provide an estimate of number of patients discussed in each MDT meeting.**

   There will be a maximum of 15 patients discussed in each MDT meeting. The CAG accepted this response.

3. **Please make it clear on the poster that '*this recording is for research purposes only, and not for media use*', and provide an updated poster to the CAG.**

   The updated poster has been provided and the Committee were satisfied with this.

4. **Please ensure that it is made clear on the poster that a relative could also opt out on behalf of a patient if they lacked capacity, and provide an updated poster to the CAG.**

   The updated poster has been provided and the Committee were satisfied with this.

5. **Please describe the practical steps that would be taken if a patient opted out.**

   The applicant described that if a patient opted out, the patient's discussion during the meeting will be deleted after the recording has been obtained and will not be included in the analysis. The CAG were content with this process.

6. **Please undertake further PPI, to ensure the views of patients are provided regarding whether the use of their confidential patient information without their consent would be acceptable to them, should they be a patient in the hospice.**

   The applicant has undertaken a further Patient and Public involvement exercise as requested, with a wider group of patients and carers. Three out of four people consulted supported the use of confidential patient information without consent, and were convinced by the justifications provided by the applicant. One patient representative found it confusing that consent would not be obtained and did not accept the justifications provided. However the applicant further explained the nature of the study and worked with the patient representatives to discuss other aspects of the study. Considering that one patient representative was not in full support of the proposed use of confidential patient information without consent, the CAG have provided a condition of support to undertake further patient and public involvement over the course of the next year, and provide an update to CAG at annual review.

Confidentiality Advisory Group advice conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Specific conditions of support

1. Wider patient and public involvement and engagement activity should be carried out to test the acceptability of the project and its methodology with a wider group. Feedback about the activity undertaken and the views expressed is required at the time of first annual review. If the views provided were negative, the CAG would take this into account when considering whether support can continue or whether further work is required.

2. Favourable opinion from a Research Ethics Committee.
   Confirmed 4 December 2020

3. Confirmation provided from the IG Delivery Team at NHS Digital to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. See section below titled 'security assurance requirements' for further information.
   Confirmed –

   The **2019/20** NHS Digital DSPT review for **UCL School of Life and Medical Sciences (EE133902-SLMS)** was confirmed as 'Standards Met' on the NHS Digital DSPT Tracker (checked 06 November 2020).

   The **2019/20** NHS Digital DSPT review for [redacted] was confirmed as 'Standards Met' on the NHS Digital DSPT Tracker (checked 06 April 2021).

As the above conditions have been accepted and met, this letter provides confirmation of final support. I will arrange for the register of approved applications on the HRA website to be updated with this information.

Application maintenance

Annual review

Please note that this legal support is subject to submission of an annual review report, for the duration of support, to show that the minimal amount of patient information is being processed and support is still necessary, how you have met the conditions or report plans, any public benefits that have arisen and action towards meeting them. It is also your responsibility to submit this report every 12 months for the entire duration that confidential patient information is being processed without consent.

The next annual review should be provided no later than **6 April 2022** and preferably 4 weeks before this date. Reminders are not issued so please ensure this is provided annually to avoid jeopardising the status of the support. Submission of an annual review in line with this schedule remains necessary even where there has been a delay to the commencement of the supported activity, or a halt in data processing. Please ensure you review the HRA website to ensure you are completing the most up to date 'section 251' annual review form as these may change.

For an annual review to be valid, there must also be evidence that the relevant DSPT submission(s) for organisations processing confidential patient information without consent are in place and have been reviewed by NHS Digital. Please plan to contact NHS Digital in advance of the CAG annual review submission date to check they have reviewed the relevant DSPTs and have confirmed these are satisfactory.

Register of Approved Applications

All supported applications to process confidential patient information without consent are listed in the published 'Register of Approved Applications'. It is a statutory requirement for the Register to be published and it is available on the CAG section of the Health Research Authority website. It contains applicant contact details, a summary of the research and other pertinent points.

This Register is used by controllers to check whether support is in place.

Changes to the application

The application and relevant documents set out the scope of the support which is in place for the application activity and any relevant restrictions around this.

Any amendments which are made to the scope of this support, including but not limited to, purpose, data flows, data sources, items of confidential patient information and processors, require submission of a formal amendment to the application. Changes to processors will require evidence of satisfactory DSPT submission. The amendment form can be found in the Confidentiality Advisory Group pages on the Health Research Authority website.

Support for any submitted amendment would not come into effect until a positive outcome letter has been issued.

Changes to the controller

Amendments which involve a change to the named controller for the application activity require the submission of a new and signed CAG application form and supporting documentation to support the application amendment. This is necessary to ensure that the application held on file appropriately reflects the organisation taking responsibility for the manner and purpose of data processing within the application, and that the legal support in place is related to the correct legal entity.

Applicants are advised to make contact with the Confidentiality Advice Team to discuss a change in controllership for an existing application in sufficient time ahead of the transfer of project responsibility to discuss the submission process timings.

Further information and relevant forms to amend the support is available on the HRA website.

Reviewed documents

The documents reviewed at the meeting are as follows.

Document	*Version*	*Date*
CAG application from (signed/authorised)		10 October 2020
CAG application from (signed/authorised) [XML]		10 October 2020
Covering letter on headed paper		01 October 2020
Other [UCL data protection registration form]		23 March 2020
Other [Study Flowchart]	1	11 July 2020
Patient Information Materials [Participant Information Sheet for Health Care Professionals]	1.0	06 October 2020
Research protocol or project proposal	1	30 September 2020
Write recommendation from Caldicott Guardian (or equivalent) of applicant's organisation		18 May 2020
PPI summary questions		
PPI summary responses		04 November 2020
Request for further information v1.0 [Response to provisional]	1	03 December 2020
PPI Review 03.12.2020		03 December 2020
Patient Information Material v1.0 10.11.2020 [Poster]		10 November 2020
276367 20.LO.1168 FIFO 04.12.20 [REC FO]		04 December 2020

Membership of the Committee

The members of the Confidentiality Advisory Group who were present at the consideration of this item are listed below.

No conflicts of interest were declared regarding this application.

Please do not hesitate to contact me if you have any queries following this letter. I would be grateful if you could quote the above reference number in all future correspondence.

Yours sincerely

Caroline Watchurst
Confidentiality Advisor
On behalf of Health Research Authority

Email: [redacted]

Enclosures:	*List of members who considered application* *Standard conditions of approval*
Copy to:	[redacted]

Confidentiality Advisory Group meeting attendance
05 November 2020

Members present:

Name	
Dr Tony Calland MBE	CAG Chair
Dr Martin Andrew	CAG member
Ms Sophie Brannan	CAG member
Dr Patrick Coyle	CAG vice-chair
Mr David Evans	CAG member
Ms Diana Robbins	CAG member
Mr Marc Taylor	CAG member

Also in attendance:

Name	*Position (or reason for attending)*
Ms Caroline Watchurst	HRA Confidentiality Advisor
Dr Paul Mills	HRA Confidentiality Advice Service Manager
Ms Natasha Dunkley	HRA Head of Confidentiality Advice Service

Standard conditions of support

Support to process the specified confidential patient information without consent, given by the Health Research Authority, is subject to compliance with the following standard conditions of support.

The applicant and those processing the information under the terms of the support will ensure that:

1. The specified confidential patient information is only used for the purpose(s) set out in the application.
2. Confidentiality is preserved and there are no disclosures of information in aggregate or patient level form that may inferentially identify a person, nor will any attempt be made to identify individuals, households or organisations in the data.
3. Requirements of the Statistics and Registration Services Act 2007 are adhered to regarding publication when relevant, in addition to other national guidance.
4. All staff with access to confidential patient information have contractual obligations of confidentiality, enforceable through disciplinary procedures.
5. All staff with access to confidential patient information have received appropriate ongoing training to ensure they are aware of their responsibilities and are acting in compliance with the application detail.
6. Activities must be compliant with the General Data Protection Regulation and relevant Data Protection Act 2018.
7. Audit of data processing by a designated agent is facilitated and supported.
8. The wishes of patients who have withheld or withdrawn their consent are respected.
9. Any significant changes (for example, people, purpose, data flows, data items, security arrangements) must be approved via formal amendment prior to changes coming into effect.
10. An annual review report is submitted to the CAG every 12 months from the date of the final support letter, for the duration of the support.
11. Any breaches of confidentiality around the supported flows of information should be reported to CAG within 10 working days of the incident, along with remedial actions taken/to be taken. This does not remove the need to follow national/legal requirements for reporting relevant security breaches.

Appendix 18 – CA study Non-disclosure agreement

NON-DISCLOSURE AGREEMENT

This non-disclosure agreement (the “Agreement”) is made and entered into [ ] between:

(i) UNIVERSITY COLLEGE LONDON, of Gower Street, London, WC1E 6BT (“UCL”) and

(ii) The Receiving Party, as set out in Schedule 1 to this Agreement

1. **Purpose**
   UCL and the Receiving Party (each a “Party” and together the “Parties”) wish to hold data sessions to discuss recordings obtained from the UCL-sponsored study entitled “Conversation analytic study of prognostic decision-making within palliative multi-disciplinary team meetings” (EDGE 132991). As a part of such discussions the Parties agree that UCL may disclose to Receiving Party certain Confidential Information, which the UCL desires Receiving Party to treat as confidential. Prior to UCL making any such disclosure to Receiving Party, UCL wishes to enter into this confidentiality agreement with Receiving Party to ensure that Receiving Party will keep such disclosures confidential and make use of them solely as specified in this Agreement.

2. **Confidential Information**
   Means any and all information or data disclosed by UCL to Receiving Party, either directly or indirectly, whether marked as confidential or not, in writing (including by the review of any documents, files, plans or other writings), orally, visually (including sketches, diagrams and drawings), electronically, by inspection, or by the provision of tangible objects, or in any other form, including without limitation:

   2.1 Patents and patent applications, copyright and copyright applications,
   2.2 Trade Secrets,
   2.3 Business Relationships and Business Opportunities,
   2.4 Proprietary information (ideas, concepts, inventions, techniques, works of authorship, models, inventions, know-how, finances, facilities, operations, development plans, strategies, processes, procedures, policies, techniques, technology, formulas, formulations, specifications, test data, manufacturing processes, customer lists, business and contractual relationships, marketing plans),
   2.5 Information that is confidential or proprietary to a third party, and is in the possession of UCL

3. **Exceptions**
   Confidential Information shall not include information which:

   3.1 is or becomes publicly known and generally available in the public domain, through no action or disclosure by Receiving Party,
   3.2 is disclosed by Receiving Party with the prior written consent of UCL,

3.3 was previously known by Receiving Party, as evidenced in writing, without any obligation to hold such information in confidence,
3.4 is disclosed by UCL to a third party without restriction on disclosure,
3.5 is disclosed to Receiving Party by a third party without any requirement of confidentiality where Receiving Party reasonably believes the third party had a legal right to do so,
3.6 is independently developed by Receiving Party at any time without use of or reference to the Confidential Information, as evidenced in writing,
3.7 is required by law, regulation or a valid court order to be disclosed by Receiving Party, but only to the extent and for the purposes of such required disclosure, provided that UCL is given prompt written notice prior to such disclosure.

4. Permitted Use

Receiving Party agrees to use the Confidential Information solely for the purposes of analysing the data together with UCL to broaden and get new perspectives on the analysis of the data at the data sessions.

5. Control and Reproduction

Receiving Party agrees that:

5.1 It shall take proper and all reasonable measures, not less than the degree of protection it takes to secure its own confidentiality, to protect the secrecy of and avoid disclosure and unauthorised use of the Confidential Information.

5.2 It shall only make such copies of the Confidential Information as are strictly necessary for the Permitted Use. Receiving Party shall reproduce all propriety and confidentiality notices on any approved copies in the same manner such notices were detailed on the original.

5.3 It will immediately inform UCL if it becomes aware that an unauthorised person has become aware of the Confidential Information, or if it receives any of the Confidential Information from a non-entitled party. Receiving Party will provide UCL with all reasonable assistance it requires to prevent any further unauthorised use or disclosure of the Confidential Information

6. Breach of Agreement

The Parties agree that a remedy of damages may not be an adequate remedy for a breach of this Agreement and that an injunction restraining Receiving Party from any breach of this Agreement, whether actual or threatened, shall be available to UCL, in addition to any other legal remedy which may be available.

7. Return of Materials

All documents and other tangible objects containing or representing Confidential Information which have been disclosed hereunder and all copies thereof in the possession of UCL shall remain the property of UCL and shall be either destroyed or promptly returned in a manner prescribed by UCL, upon UCL’s written request.

8. Term

Notwithstanding any termination of the Permitted Use or the return or destruction of all or part of the Confidential Information the obligations of Receiving Party hereunder shall survive until such time as all Confidential Information disclosed hereunder becomes publicly known and made generally available, through no action of Receiving Party, or for a period of 10 years from the commencement date.

9. General

9.1 Ownership of the Confidential Information and all intellectual property rights relating thereto shall remain solely with UCL and Receiving Party shall not by this Agreement acquire any right in title or licence to use the same, other than the limited right to use the Confidential Information for the Permitted Use.

9.2 Nothing in the Agreement shall be deemed to commit either Party to any further business transaction, venture or relationship, nor limit either Party in similar discussions with others, providing that the requirements of this Agreement are properly met.

9.3 The Parties agree that the terms of this Agreement are reasonable and necessary to protect the interests of UCL. In the event that any part of this Agreement is found by a court to be unreasonable, unenforceable or void, that part shall be severed and the remainder of the clause shall be enforceable with whatever deletion or modification as may be necessary to make it effective, and for such period as is found to be reasonable and valid in substitution for the period contained in the Agreement.

9.4 Parties shall comply with all applicable laws and regulations, including the Data Protection Act 2018 and the General Data Protection Regulation (EU) 2016/679 ("**Data Protection Legislation**"). In particular the Receiving Party shall:

9.4.1 ensure that appropriate technical and organisational security measures are in place sufficient to comply with at least the obligations imposed on a Controller under the Data Protection Legislation;

9.4.2 notify UCL promptly of any Data Subject Request, ICO correspondence, disclosure under statutory requirement, and actual or suspected Personal Data Breach (as defined in the Data Protection Legislation)

9.4.3 not do anything which shall damage the reputation of UCL;

9.4.4 not transfer Confidential Information to any a country, territory or jurisdiction outside of the European Economic Area which the EU Commission has not deemed to provide adequate protection in accordance with Article 45(1) of the GDPR

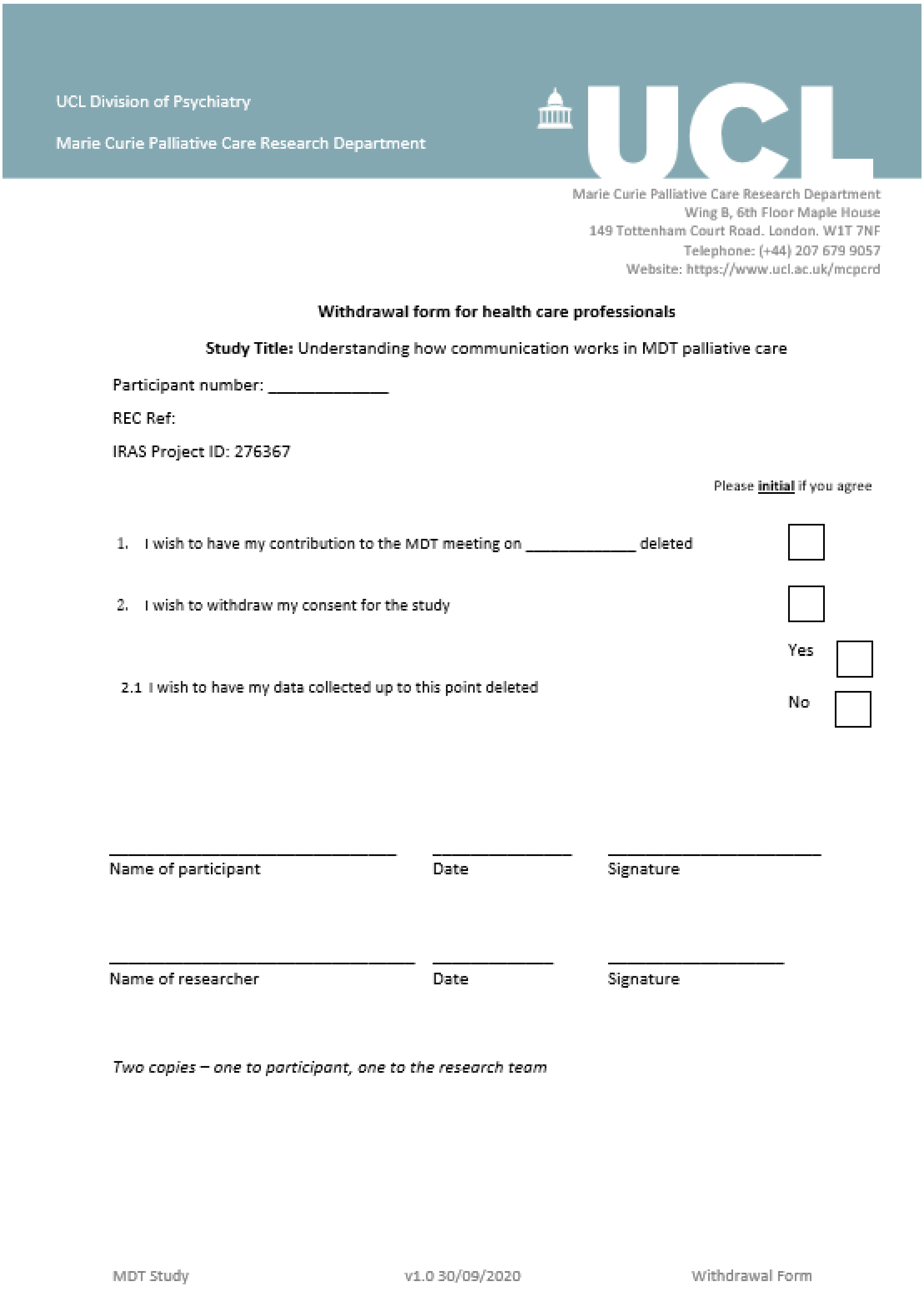
9.5 This Agreement shall be governed by the laws of England and the Parties hereby submit to the exclusive jurisdiction of the English courts.

9.6 This document contains the entire agreement between the Parties with respect to the subject matter hereof, and neither Party shall have any obligation, express or implied by law, except as set forth herein. Any failure to enforce any provision of this Agreement shall not constitute obligations waived, except in writing signed by both Parties hereto.

Schedule 1

Date	Name (readable)	Signature

Appendix 19 – CA study Withdrawal form



UCL Division of Psychiatry

Marie Curie Palliative Care Research Department

Marie Curie Palliative Care Research Department
Wing B, 6th Floor Maple House
149 Tottenham Court Road. London. W1T 7NF
Telephone: (+44) 207 679 9057
Website: https://www.ucl.ac.uk/mcpcrd

Withdrawal form for health care professionals

Study Title: Understanding how communication works in MDT palliative care

Participant number: ______________

REC Ref:

IRAS Project ID: 276367

Please **initial** if you agree

1. I wish to have my contribution to the MDT meeting on ____________ deleted ☐
2. I wish to withdraw my consent for the study ☐

2.1 I wish to have my data collected up to this point deleted Yes ☐ No ☐

_________________________ Name of participant

_____________ Date

____________________ Signature

_________________________ Name of researcher

_____________ Date

____________________ Signature

Two copies – one to participant, one to the research team

Appendix 20 – CA study Transcription key

Symbol/example	Explanation
[word] [word]	Overlapping speech
(0.2)	Pause in seconds
(.)	Micro-pause (under 0.1) seconds
word	Stress (more underlining indicates more stress)
wo:rd	Prolongation of the preceding sound (number of colons indicates length of prolongation)
word= =word	Latching of speech (no silence between turns/parts of one turn)
hhh	Outbreath (number of h indicates length)
.hhh	Inbreath (number of h indicates length)
WORD	Speech with loud volume
°word°	Speech with low volume
↑word ↓word	Marked pitch change, up (↑) or down (↓)
.	Final falling intonation
,	Slight rising intonation
_	Level/flat intonation
word-	Cut-off of preceding
>word<	Speeded up talk
<word>	Slowed down talk
#word#	Creaky voice
£word£	Smiling voice
{word {gesture	Multimodal element
(word)/(x)	Possible hearings/inaudible (x indicates the number of syllables)
((comment))	Transcriber’s comments

Adapted from Jefferson (2004) and Hepburn and Bolden (2012).