



Migrant child health outcomes and service development,
interventions and policy recommendations for unaccompanied
asylum-seeking children

**Thesis submission for
MD(Res) Clinical Research at UCL**

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“I, Alice Armitage confirm that the work presented in my thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.”

Abstract

Introduction

Migration status is a key determinant of health, but health outcomes among migrant children and young people (CYP, those under the age of 18) are poorly understood. Unaccompanied asylum-seeking children (UASC) are particularly vulnerable and require intensive and joined-up support. There has been a failure to hear the voice of migrant CYP in service development and research.

Methods

I undertook a systematic review of mortality and communicable diseases among migrant CYP. I described a novel “integrated pathway” for UASC, and explored implementation in a second London borough, presenting data on UASC engaged with this service. Finally, I explored the current model of patient and public involvement (PPI), including ethical considerations, as applied to UASC.

Results

I found a lack of data on mortality among migrant CYP with better quality evidence exclusively from high-income settings. Studies showed higher cause-specific but equivocal all-cause mortality compared with the host population. Rates of all communicable diseases were high among migrant CYP with the highest risk among adolescents and those from Africa.

The UASC evaluation showed high rates of communicable diseases, mental health problems, and physical and sexual abuse/assault. An integrated pathway was successfully implemented in two boroughs, showing the potential to improve outcomes and address barriers to engagement.

I demonstrated that blurred boundaries and contradictory advice in guidance on PPI present barriers to engagement with, and research about, vulnerable migrant CYP.

Conclusion

There is a paucity of research on health outcomes among migrant CYP and a failure to include their voice. An integrated pathway is an appropriate clinical approach for UASC and adds to the literature on best practice management of refugee children.

Improving migrant CYP health requires equity in healthcare provision, integration of services and a trauma-informed care approach. Participatory and longitudinal research with broad geographical scope is needed, including policy-impact studies.

Impact statement

Migrant child health is a vital and growing area in healthcare, research and policy. As demonstrated below, there is a paucity of research in this field. Findings of my research are internationally relevant and can inform interventions for migrant children and young people (CYP). The systematic review (Chapters 2-4) outlines research gaps and the current state of research in this important area. The protocol (Chapter 2) has been published in *BMJ Open*(1); the mortality (Chapter 3) and communicable diseases results (Chapter 4) have been presented nationally and published in abstract form(2, 3).

Vulnerabilities and health needs among newly arrived UASC are likely to persist and represent a significant current and future health burden for the young people and for health services. I presented the retrospective evaluation of the UASC pathway (Chapter 5) in the plenary session of the RCPCH annual conference and published the manuscript in *Archives of Disease in Childhood*(4), allowing widespread dissemination among UK paediatric doctors. I have shared these findings in multiple talks and lectures, including via voluntary organisations such as the Helen Bamber foundation and Refugee Action Kingston.

Skills and experience acquired during this MD(Res) have enabled me to contribute to several projects around service development for UASC. I am co-applicant on two grants informing UASC care and service development based on the integrated pathway model (Chapters 5 and 6). Descriptions of these projects with preliminary results and plans for next steps have been presented nationally and published in abstract form(5). I am a co-applicant and workstream lead on an NIHR Programme Development Grant around care of refugee CYP and UASC, with a view to expanding collaborations and generalising to other marginalised populations of CYP.

As part of this MD(Res) I have also developed my public speaking, writing and data analysis skills. I won the UCL Faculty of Population Health Sciences 3 Minute Thesis competition, allowing dissemination of my MD research within the university. I have supervised several junior doctors and researchers in projects on migrant child health, spoken and lectured extensively and contributed to several manuscripts on associated topics(6). I recently contributed to a podcast through UCL on migrant CYP.

Following my work around ethics and PPI in migrant CYP (Chapter 7) I contributed to a UCL project on the ethics of engaging CYP, presented this work at the RCPCH Annual Conference and published it in abstract form. I also advised a member of the UK Government's Age Estimation Scientific Advisory Committee (AESAC) on ethical approaches to research with UASC.

Acknowledgements

Firstly, I would like to thank my partner Simon and my daughters Clara and Juliet, without their love and support none of this would have been possible.

I would like to thank my primary supervisor, Prof Michelle Heys, for her friendship and guidance over many years. She has provided invaluable expertise and unwavering support across all of my projects. She has also enabled me to work with the East London Foundation Trust (ELFT), where I held an honorary contract, in implementing the integrated pathway for UASC in Newham.

I would also like to thank my supervisors Prof Pia Hardelid and Dr Veena Meetoo. Dr Hardelid has extensive expertise in epidemiology and health data and provided support and advice around the overview of data sources and in planning and designing the systematic review. Dr Meetoo has a background in sociology and experience across a range of qualitative research methods as well as with vulnerable children.

Thank you to my dear friends Joe Ward, Harriet Gunn and Anne-Lise Goddings, all paediatric clinical academics who have supported and inspired me throughout the last 5 years.

From 2018 to 2023 I held a Clinical Academic Training Fellowship in Child and Adolescent Health at UCL, and this MD(Res) has been made possible by this position and associated funding from UCL.

This thesis draws on work completed as part of two grant-funded projects: in 2019 we secured small grant funding from the Barts Charity to implement the integrated pathway in Newham pathway for unaccompanied asylum-seeking children (UASC) in East London Foundation Trust (ELFT), and in 2022 we secured large grant funding from the Barts Charity to expand the integrated pathway across multiple boroughs in North-East London.

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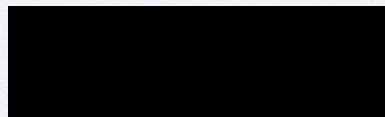


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Health outcomes in international migrant children: protocol for a systematic review

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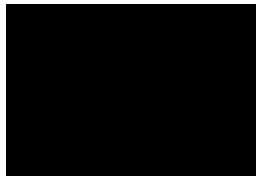
The protocol was conceived by all authors, written by Alice Armitage and reviewed by PH, MH and IL prior to submission. PH is the guarantor of the review.

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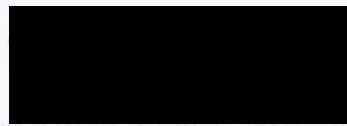


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Table of Contents

Abstract.....	3
Impact statement	4
Acknowledgements.....	5
UCL Research Paper Declaration Form	6
UCL Research Paper Declaration Form	8
Table of Contents.....	10
Acronyms and abbreviations.....	15
Positionality statement.....	16
Publications and other output during MD(Res).....	17
Contributions statement	20
Chapter 1: Overview and Introduction.....	22
1.1 Overview.....	22
1.2 Introduction: the health of migrant children.....	23
1.2.1 An overview of migration and health	23
1.2.2 Migrant children and young people (CYP).....	24
1.2.3 Legal frameworks and definitions	25
1.2.4 Unaccompanied asylum-seeking children (UASC).....	25
1.2.5 Developing services for migrant children	28
1.2.6 An introduction to trauma-informed care.....	29
1.3 Quantitative evidence on migrant children – literature review	30
1.3.1 Data on health of migrants.....	30
1.3.2 Migrant mortality – quantitative evidence	31
1.3.3 Migrant child health – quantitative evidence	31
1.4 Literature review on UASC views of health needs and health services	33
1.4.1 Overview	33
1.4.2 Mental health and emotional wellbeing	34
1.4.3 The hostile environment	34
1.4.4 Support and coping strategies.....	35
1.4.5 Perceptions of health and wellbeing.....	35
1.4.6 Listening to UASC	36
1.5 Migration trend and policy during this MD(Res)	37
1.5.1 Global migration trends.....	37
1.5.2 Global and UK migration policy	38
1.6 Research question and hypothesis.....	40
1.7 Aims and objectives with signposting	41
1.8 Patient and Public Involvement (PPI) statement	43

Chapter 2: Systematic review of health outcomes in international migrant children (Methods)	45
2.1 Research question and hypotheses.....	46
2.2 Aims and objectives.....	48
2.3 Methods and analysis.....	49
2.3.1 Eligibility	49
2.3.2 Outcomes of interest.....	50
2.3.3 Search Strategy.....	51
2.3.4 Selection process.....	52
2.3.5 Data synthesis and analysis	52
2.3.6 Statistical methods and meta-analysis	53
Chapter 3: Mortality among international migrant children: results from Systematic review	55
3.1 Research question and hypotheses.....	56
3.2 Aims and objectives.....	57
3.3 Results.....	58
3.3.1 Summary of results.....	58
3.3.2 Characteristics of included studies	59
3.3.3 Types of studies.....	60
3.3.4 Cause-specific mortality results.....	61
3.3.5 Refugee camp studies results.....	63
3.3.6 All-cause and ‘preventable’ mortality studies results	63
3.4 Discussion.....	67
3.4.1 Summary of key findings	67
3.4.2 Strengths and limitations	69
3.4.3 Interpretation and consistency with existing data	70
3.5 Conclusion	72
Chapter 4: Communicable diseases among international migrant children: results from Systematic review	74
4.1 Research question and hypotheses.....	75
4.2 Aims and objectives.....	76
4.3 Results.....	77
4.3.1 Summary of results.....	77
4.3.2 Characteristics of included studies.....	78
4.3.3 Infection-specific results - Tuberculosis	79
4.3.4 Infection-specific results – Hepatitis viruses	85
4.3.5 Infection-specific results – Parasitic infections	86
4.3.6 Infection-specific results – All other infections	86
4.4 Discussion.....	93
4.4.1 Key findings	93
4.4.2 Strengths and limitations	93

4.4.3 Interpretation and consistency with existing literature	94
4.4.4 Policy implications and next steps.....	95
4.5 Conclusion	96
<i>Chapter 5: Retrospective description and evaluation of an integrated pathway for UASC</i>	97
5.1 Research question and hypotheses.....	98
5.2 Aims and objectives.....	99
5.3 Methods.....	100
5.3.1 Description of the integrated pathway for UASC	100
5.3.2 Study design, population and period.....	101
5.3.3 Data sources, collection and analysis	102
5.3.4 Demographics, clinical variables and outcomes.....	103
5.3.5 Ethical approval and considerations.....	103
5.4 Results.....	105
5.4.1 Community paediatrics data	105
5.4.2 Mental and physical health symptoms.....	106
5.4.3 Recorded outcomes	107
5.4.4 Infectious Diseases screening results	107
5.4.5 Sexual health screening results	108
5.5 Discussion.....	109
5.5.1 Key findings	109
5.5.2 Strengths and limitations	109
5.5.3 Findings in context	109
5.6 Conclusion	111
5.7 Recommendations.....	111
<i>Chapter 6: Adaptation and pilot feasibility evaluation of the integrated pathway for UASC in Newham</i>	113
6.1 Research question and hypotheses.....	114
6.2 Aims and objectives.....	115
6.3 Background	116
6.3.1 Timeline	116
6.3.2 Challenges of implementation	118
6.3.3 Patient and public involvement (PPI) and engagement statement.....	118
6.3.4 Theoretical underpinning of methods.....	119
6.3.5 Adaptations	121
6.4 Methods.....	122
6.4.1 Study design, population and period.....	122
6.4.2 Data sources, collection and analysis	123
6.4.3 Demographics, clinical variables and outcomes.....	125
6.4.4 Ethical approval and considerations.....	126
6.5 Results.....	127
6.5.1 Pilot implementation metrics	127

6.5.2 Feasibility and acceptability (mixed-methods evaluation)	128
6.5.3 UASC demographics, baseline health needs and outcomes (process-related)	130
6.5.4 Comparison of results and analysis of data	131
6.5.5 Impact and next steps	133
6.6 Discussion.....	133
6.6.1 Key points	133
6.6.2 Strengths and limitations	134
6.6.3 Findings in context	135
6.7 Conclusion	136
6.8 Recommendations.....	137
<i>Chapter 7: Patient and public involvement (PPI) and ethics in migrant children: Exploration of structures, barriers and ethical dimensions</i>	<i>139</i>
7.1 Research question and hypotheses.....	141
7.2 Aims and objectives.....	142
7.3 Case example: ethical and practical challenges of engaging UASC.....	143
7.4 Background	145
7.4.1 Ethics in medical research	145
7.4.2 Patient and Public Involvement in research.....	146
7.4.3 PPI as a construct in the context of discourses of children's rights and participation	147
7.4.4 Literature review and the history of PPI.....	149
7.4.5 Distinguishing PPI from qualitative research.....	150
7.5 Discussion.....	151
7.5.1 Ethical and practical considerations of PPI.....	151
7.5.2 Ethical and practical considerations of PPI with migrant children/UASC.....	152
7.6 Conclusion	154
<i>Chapter 8: Discussion</i>	<i>156</i>
8.1 Summary of key findings by chapter	157
8.3 Strengths and Limitations	158
8.4 Methodological triangulation	160
8.4.1 Question 1:	161
8.4.2 Question 2:	162
8.4.3 Question 3:	164
8.4.4 Question 4:	165
8.5 Future directions and next steps.....	167
<i>Chapter 9: Bibliography</i>	<i>169</i>
<i>Appendices</i>	<i>186</i>
Appendix 1. – Listening to unaccompanied asylum-seeking children: A patient engagement study	187
Appendix 2. – Patient and public involvement (PPI): An invitation to participate.....	190

Appendix 3. – Proposed additional health outcomes for systematic review.....	192
Appendix 4. – Search strategies (Ovid/Medline)	194
Appendix 5. - Systematic review protocol amendments	199
Appendix 6. – NOS scoring Systematic review Mortality studies Quality assessment (Adapted NOS scoring).....	201
Appendix 7. – NOS scoring Systematic review Communicable diseases studies Quality assessment (Adapted NOS scoring)	204
Appendix 8. - Topic guide for semi-structured interviews	209

Acronyms and abbreviations

aOR	Adjusted odds ratio
CAMHS	Child and Adolescent Mental Health Services
CD	Communicable diseases
CYP	Children and Young People
ECRU	European Children's Rights Unit
ELFT	East London Foundation Trust
GHO	WHO Global Health Observatory
HBF	Helen Bamber Foundation
HIP	Health Improvement Practitioner
HRA	Health Research Authority
HUMA	Health for Undocumented Migrants and Asylum seekers
IGRA	Interferon Gamma Release Assays
ID	Infectious Diseases
IDP	Internally displaced people/persons
IHA	Initial Health Assessment
IOM	International Organization of Migration
LA	Local Authority
LAC	Looked-After-Children
LMIC	Low and middle-income countries
LTBI	Latent tuberculosis infection
MDT	Multidisciplinary team
NOS	Newcastle Ottawa Scale
OECD	Organisation for Economic Co-operation and Development
OR	Odds ratio
PPD	Purified protein derivative
PPI	Patient and Public Involvement
PROSPERO	International Prospective Register of Systematic Reviews
QI	Quality improvement
RHA	Review Health Assessment
REML	Restricted Maximum likelihood ratio
SDQ	Strengths and Difficulties Questionnaire
SMR	Standardised mortality ratio
TB	Tuberculosis
TIC	Trauma-informed care
TST	Tuberculin skin tests
UASC	Unaccompanied Asylum-Seeking Children
UN	United Nations
UNCRC	UN Convention on the Rights of the Child
UNHCR	UN High commissioner for refugees (The UN refugee agency)
WHO	World Health Organisation
YP	Young person

Positionality statement

I wish to address my positionality at the outset of this thesis, and acknowledge the context in which my research and analysis is carried out. I am a white British, English-speaking female; I identify as heterosexual, cis-gendered and consider myself to be socioeconomically privileged. During the course of this MD(Res) I became a mother and now share caring responsibilities for my two daughters with my partner. I am a medical doctor in paediatrics in the NHS, and have continued to work clinically throughout this degree; this has spanned the Covid-19 pandemic and junior doctors strikes. Clinically, I have an interest in safeguarding and work with children and young people who are victims of trauma, abuse and maltreatment, including the same populations that I have studied as part of this MD(Res). I also have experience working with women and children affected by female genital mutilation, and adolescents following sexual assault. I have worked as a doctor in Sub-Saharan Africa on several occasions, and in refugee camps in Bangladesh and Greece. I am moved by the stories and examples of individual cases I encounter, and I feel this is a significant motivation for my work.

I recognise that my background in empirical science has influenced my approach to research, and my exploration of the voice of the child with a supervisor from a social science background has been new to me. I have attempted to decolonise my approach and challenge my own biases and assumptions. I am aware that neither I, or any of my family, have been migrants in recent memory and I have no lived experience of the topic of my research.

Publications and other output during MD(Res)

Prizes and awards:

Co-applicant on grant application from the Barts Charity: Expanding a Trauma Informed Integrated Clinical Pathway for Unaccompanied Asylum-Seeking Young People across North East London, £647,848 – successful

Co-applicant on grant application for the Barts Charity: Engaging unaccompanied asylum-seeking children (UASC) in developing a pathway to meet their needs, £49,167 – successful

UCL Faculty of Population Health Sciences 3 Minute Thesis winner 2020

Publications from MD(res):

Barton G, Armitage A, Heys M, et al 777 Implementation of an integrated pathway for unaccompanied asylum-seeking children in Newham: service-users, carers and healthcare providers' views Archives of Disease in Childhood 2023;108:A329

Stinchcombe BE, Heys M, Hardelid P, Oyebode, O. and Armitage, A.J. 737 Communicable diseases among migrant children and young people (CYP): results from a systematic review on health outcomes among migrant CYP Archives of Disease in Childhood 2023;108:A94-A95.

Armitage A, Marcolin M, Lut I, et al 787 Mortality among migrant children and young people (CYP): results from a systematic review Archives of Disease in Childhood 2023;108:A95-A96.

Bruce G, Armitage A, Salvo L, et al 649 Evaluation of an integrated pathway for unaccompanied asylum-seeking children in Newham: demographics, baseline health needs, and preliminary health outcomes Archives of Disease in Childhood 2023;108:A62-A63.

Armitage AJ, Cohen J, Heys M, et al Description and evaluation of a pathway for unaccompanied asylum-seeking children Archives of Disease in Childhood Published Online First: 16 October 2021. doi: 10.1136/archdischild-2021-322319

Armitage AJ, Heys M, Lut I, Pia Hardelid Health outcomes in international migrant children: protocol for a systematic review BMJ Open 2021;11:e041173. doi: 10.1136/bmjopen-2020-041173

Armitage A, Cohen J, Eisen S, et al P06 Baseline characteristics and physical, sexual and emotional health needs of a cohort of unaccompanied asylum-seeking children presenting to a London borough Archives of Disease in Childhood 2020;105:A172.

Armitage A, Cohen J, Eisen S, et al G166 Service description: an integrated pathway for unaccompanied asylum seeking children Archives of Disease in Childhood 2020;105:A57-A58.

Selected presentations:

Armitage A, Cohen J, Eisen S, et al Baseline characteristics and physical, sexual and emotional health needs of a cohort of unaccompanied asylum-seeking children presenting to a London borough Oral Presentation at the RCPCH annual conference 2020 (plenary session)

Armitage A, Cohen J, Eisen S, et al Service description: an integrated pathway for unaccompanied asylum-seeking children Oral Presentation at the RCPCH annual conference 2020

Behrouz Nezafat Maldonado, Alice Armitage, Bhanu Williams Assessing variation in health assessment of unaccompanied asylum-seeking children (UASC): a cross-sectional survey across England Oral presentation at the British Association for community Child Health (BACCH) Annual Scientific meeting 2021 (Winner: Child Journal Prize, for best paper presented by a non-consultant)

Other publications during MD(Res):

Alladi S, Heys M, Armitage A, et al 784 Expanding a trauma-informed integrated pathway for unaccompanied asylum-seeking children (UASC) across North East London Archives of Disease in Childhood 2023;108:A329-A330.

Idoko P, Armitage A, Nyassi MT, Jatta L, Bah N, Jah A, Jabbie D, Bittaye M. Obstetric outcome of female genital mutilation in the Gambia—an observational study. African Health Sciences. 2022 Dec 23;4(4):386-95.

Nezafat Maldonado B, Armitage AJ, Williams B. Variation in initial health assessment of unaccompanied asylum-seeking children: a cross-sectional survey across England. BMJ Paediatr Open. 2022 Apr;6(1):e001435. doi: 10.1136/bmjpo-2022-001435.

Lut I, Woodman J, Armitage A, et al Health outcomes, healthcare use and development in children born into or growing up in single-parent households: a systematic review study protocol BMJ Open 2021;11:e043361. doi: 10.1136/bmjopen-2020-043361

Ekert JO, Luchesa Smith A, Ramsey CL, Robinson N, Love J, Gothard P, Armitage AJ.

Medical student-led simulation in COVID-19 crisis. Clin Teach. 2020; 00: 1– 6. <https://doi.org/10.1111/tct.13308>

Hodes D, Ayadi O'Donnell N, Pall K, Leoni M, Lok W, Debelle G, Armitage A, Creighton SM, Lynn M

Epidemiological surveillance study of female genital mutilation in the UK Archives of Disease in Childhood Published Online First: 06 October 2020. doi: 10.1136/archdischild-2020-319569

Ali S, Patel R, Armitage AJ, Learner HI, Creighton SM, Hodes D Female genital mutilation (FGM) in UK children: a review of a dedicated paediatric service for FGM Archives of Disease in Childhood Published Online First: 04 June 2020. doi: 10.1136/archdischild-2019-318336

Arrash A. Yassaee, Daniel Hale, Alice Armitage and Russell M. Viner The impact of age of transfer on outcomes in the transition from paediatric to adult health systems: a systematic review of reviews Journal of Adolescent Health J Adolesc Health. 2019 Jun;64(6):709-720. doi: 10.1016/j.jadohealth.2018.11.023

Other output:

Course organiser for module on Adolescent Health in Paediatrics and Child Health MSc at UCL – 2018-2023

Rapid reviewer for don't forget the bubbles Covid-19 paediatric literature 2020

Co-investigator on ESRC grant application: Understanding the Health and Education of Asylum-seeking and Refugee children in England (UNHEARD) - unsuccessful

Grant application for the UCL Beacon Bursary, funding for up to £2000 for UCL public engagement projects – unsuccessful

Application for UCL Policy Engagement and Impact Fellowship – unsuccessful

Contributions statement

Chapter 1 – Introduction

Prof Michelle Heys and Prof Pia Hardelid provided guidance and reviewed all sections of the introduction, several of which I have used in published manuscripts. The literature review on UASC views (Section 1.3) was written with supervision from Veena Meetoo.

Chapters 2-4 – Systematic review

With supervision from Prof Michelle Heys and Prof Pia Hardelid I developed the concept for this study. I designed the search strategy, undertook the literature searches, designed the data extraction tool and wrote the protocol manuscript for publication. Prof Michelle Heys and Prof Pia Hardelid approved the study concept and the manuscript for publication. In the mortality domain (Chapter 3) myself and Irina Lut dual screened literature search results against inclusion and exclusion criteria, then I extracted all data, assessed methodological quality, conducted evidence synthesis and meta-analyses. In the communicable diseases domain (Chapter 4) Beth Stinchcombe screened literature search results against inclusion and exclusion criteria and extracted data. I supervised this process including undertaking spot checks, consulting on unclear decisions and making final decisions on included studies. I conducted the evidence synthesis and meta-analyses.

Chapter 5 - Retrospective description and evaluation of an integrated pathway for UASC

The integrated pathway for UASC in Camden was designed and set-up by the community paediatrics team led by Dr Alli Ward. I collected data from initial health assessment reports and other patient records at Central and North West London NHS Trust. I collected infectious diseases data at University College London NHS Foundation Trust with help from a spreadsheet of UASC attending the service compiled by the paediatric infectious diseases team. Dr Chantal Oxenham provided data on Camden UASC attending a sexual clinic in Central and North West London NHS Trust. I synthesised and analysed the data and wrote the manuscript for publication. Dr Alli Ward and Dr Sarah Eisen conceptualised the study and reviewed the manuscript for publication. I was supervised throughout by Prof Michelle Heys and Prof Pia Hardelid. The manuscript was reviewed by all co-authors (Prof Michelle Heys, Prof Pia Hardelid, Dr Jonathan Cohen, Dr Sarah Eisen and Dr Alli Ward).

Chapter 6 - Implementation and prospective evaluation of an integrated pathway for UASC in Newham

I wrote the grant application for the Newham integrated pathway and am co-applicant on this grant alongside Dr Susan Liebeschuetz (PI) and Prof Michelle Heys (co-applicant). I contributed to the design and adaptations of the integrated pathway in Newham including writing standard operating procedures, designing job descriptions and person specifications and sitting on interview panels. I designed a data extraction tool for quantitative evaluation of the pathway and gave directions for data collection to team members. Dr Sveta Alladi was the clinic lead for the pathway in Newham and contributed to pathway implementation, adaptations and evaluation. Dr Sveta Alladi led a team who designed and undertook mixed-methods evaluations

including questionnaires for UASC and surveys for paediatricians. Gil Barton carried out semi-structured interviews with UASC carers and social workers. Two medical students (Ruby Abdi and Molly Townson) completed an audit of UASC seen in Newham in a one-year period prior to pathway implementation. I analysed and synthesised available data and wrote-up these findings which have been published as abstracts. Prof Michelle Heys supervised by work and advised on data analysis and write-up.

Chapter 7 - Patient and public involvement (PPI) and ethics in migrant children:
Exploration of structures, barriers and ethical dimensions

I wrote this chapter and Dr Veena Meetoo provided supervision for this chapter which involved qualitative and social science elements. Prof Michelle Heys also provided comments.

Chapter 1: Overview and Introduction

1.1 Overview

Migration status and health are intrinsically linked(7), but health outcomes among migrant children and young people (CYP), i.e. those aged under 18 years, are poorly understood. The global population of migrant CYP encompasses economic migrants and international students as well as forced migrants such as refugees and asylum seeker. A particularly vulnerable group of migrant children are unaccompanied asylum-seeking children (UASC) arriving in the UK, and their health needs and management exemplify many of the challenges of caring for refugee and forced migrant children worldwide. Services for vulnerable migrant CYP and research around their needs have not been developed in conversation with the young people themselves, representing a failure to give a 'voice' to this population.

In this introductory chapter, I will outline what we know in terms of all migrant CYP, what we know about the more vulnerable groups such as UASC, and what we don't know. I will describe the services currently available to UASC in the UK, consider how to change services for the better and how we need to involve and listen to CYP. To this end I will address the literature around UASC health needs in more detail, with a focus their own views of needs and experiences.

This introduction seeks to provide background and context for the research questions. It begins with definitions and an overview of migrant children globally, UASC in the UK and services for UASC. I then present a literature review of quantitative evidence on migrant child health and a literature review of the voice of UASC – their own views of health needs and experiences of healthcare. Global events and migrant policy over the duration of this thesis are summarised next, to describe the changing context over time. These sections provide context and rationale for the research questions and hypotheses. I provide aims and objectives for the whole thesis and signpost the reader to relevant chapters. The chapter ends with a statement of patient and public involvement (PPI) to outline the multiple ways that current or former migrant CYP and their representatives have informed this work.

1.2 Introduction: the health of migrant children

1.2.1 An overview of migration and health

There is no international consensus on the definition of migrant; here I will use the term to describe international migrants, in line with the United Nations definition: “someone who changes his or her country of usual residence, irrespective of the reason for migration or legal status”(8). The term migrant therefore encompasses forced migrants, such as refugees and asylum-seekers, as well as economic migrants and international students(8). The number of international migrants globally in 2020 was estimated at 281 million, representing 3.6% of the global population(9). Migration has nearly doubled since 2000, and the relative proportion of forced migration has increased further(9). Migration trends are projected to increase further in response to conditions such as conflict and economic inequality, while the climate crisis is projected to produce dramatic increases in global displacement of people(10).

Migration status is a key determinant of health(7), but existing evidence is limited in reflecting the global migrant population, including children and young people (CYP). Adult migrants may be young and healthy, and a “healthy-migrant” effect, whereby migrants have better health status than the population of the host country, has been demonstrated in multiple studies(7, 11, 12). However, scientific literature is predominantly from high-income countries, likely reflecting the outcomes of migrant workers and international students. Migration between low- and middle-income countries is poorly researched, and most forced migrants globally live in these countries(7, 11). Migrant populations experience poverty, social inequality or persecution at their destination, which could compound physical and mental health burdens associated with country of origin, reasons for displacement and circumstances of their journey.

Understanding migration as a social determinant of health necessitates addressing structures and hierarchies which interplay in migrant populations. Intersectionality theory considers how factors such as ethnicity, nationality, gender, socioeconomic status and sexuality of migrant individuals are interconnected(13). These factors overlap and interplay with the individual migrant status and are intrinsically linked with the lived experience of migration. Within migrant or refugee populations, individuals such as certain ethnic and religious groups, women, or those who identify as LGBTQI may face particular marginalisation(14, 15).

The global order and migration flows of the present day are rooted in colonial power structures of the past. The racism against those of non-European heritage has promoted and justified European racial dominance throughout history. Despite

ostensible reforms and awareness, structural racism and xenophobia persists in migration policy, law and discourse(16). The perpetuation of structural racism mediates discrimination on an individual level via multiple systems including those of healthcare delivery(17-19). The contemporary landscape of medical research and healthcare systems arose from these same structures which must be addressed when analysing and seeking to improve health among migrant populations(17).

Quantitative research methods such as systematic reviews methodology can be used to treat a social determinant of health, such as migration status, as a discrete exposure and attempt to adjust for other associated factors. This approach can be helpful and necessary in analysis of global data sets but has obvious limitations. Structural racism is closely associated with migration and leads both directly and indirectly to health inequities(18-20). Investigations of these issues requires a multi-faceted approach beyond strict quantitative methodology. Qualitative and mixed method analyses may allow more nuanced interpretation of available data that considers the interplay of factors that individual migrant CYP are affected by.

1.2.2 Migrant children and young people (CYP)

Unlike adults migrating for work or education, CYP are significantly less likely to be the drivers of their own migration. CYP who migrate face all the challenges of adult migrants while being further impacted by the health of their caregivers, and by their inherent physical and social vulnerabilities, particularly to malnutrition, communicable diseases, disrupted education, violence and exploitation(21-24). CYP make up only a small proportion of the total migrant population worldwide(25), but represent approximately half of all forced migrants(26), who are likely to have poorer health outcomes than economic migrants or international students(11). CYP's right to healthcare is enshrined in article 24 of the UN convention of the rights of the child (UNCRC)(27). Despite this, many high income countries place restrictions on migrant CYP's entitlement to health services(28), and unmet health needs in CYP are known to be associated with poor adult health(29). A possible exception to this trend is that families may migrate to seek healthcare for CYP with chronic conditions, thus improving their outcomes compared with non-migrants. It is not yet known whether CYP are subject to the "healthy-migrant" effect observed in adult migrants.

The health consequences and wider effects of migration are likely to be most pronounced in CYP who have themselves migrated, and lessons learnt from this group can be translated more widely. This thesis will therefore focus on the health needs of CYP who themselves have migrated internationally, i.e. between countries. Other definitions of migrant CYP, such as second-generation migrants (those who are born to parents who have migrated), or those who migrate within a country, such as internally displaced people (IDP), will not be directly addressed in this work.

In 2020 there were estimated to be 28 million international migrant children globally, representing 1.6% of the global population of children(9). Since 2000, although the total proportion of international migrants who are CYP has decreased, the numbers of forced migrants who are CYP have increased(9). Given the size of these numbers, the current state of research and the global increase in forced migration, I believe that this is an important and timely focus for this thesis.

1.2.3 Legal frameworks and definitions

Migration law and policy is governed by a number of national acts and legislations, and bound by international conventions such as the European Convention on Human Rights (ECHR), the 1951 Refugee Convention and the UN convention on the rights of the child (UNCRC). In the UK legislation is underpinned by the immigration act 1971, the British Nationality Act 1981 and the Immigration Act 2016, in addition to secondary legislation around asylum and immigration rules. Over the course of the projects in this MD(Res) both the Nationality and Borders Bill/Act 2022 and the Illegal migration Act 2023 were introduced. Some analysis of the progress and impact of these changes is provided in the Discussion chapter (Chapter 8.).

The term “refugee” is defined in international law, describing someone who has been forced to flee his or her country because of persecution, war or violence(30). Forced migration due to climate-related events is a rapidly increasing global issue(9), but at present these “climate refugees” do not fall within the international definition of refugees (under the 1951 Refugee Convention), presenting challenges in legal status and protection afforded(31). In this thesis, I will use the term refugee to include those displaced by climate- events.

“Asylum-seekers” are often grouped with refugees and there is significant overlap in these groups. Asylum-seeking is defined relative to the legal situation and asylum process in a specific country, but the term is often used more widely to encompass those who intend to seek asylum. “Undocumented migrants”, “irregular migrants” and “illegal immigrants” are all terms without fixed definition. I will use the term undocumented migrants to include those without legal recognition in a country, including those with rejected asylum-claims, no claim made, and those who’s legal status has expired. This population represent a particular challenge as they are typically invisible to authorities, and not appear in datasets or research around migrant populations.

1.2.4 Unaccompanied asylum-seeking children (UASC)

A particularly vulnerable group of migrant CYP are those who migrate alone, known in the UK as unaccompanied asylum-seeking children (UASC), and as “unaccompanied minors” or “separated children” in other high-income countries(32).

Data collection on this group internationally relies predominantly on asylum applications, which are likely to significantly underestimate numbers who are in transit between countries or undocumented for other reasons(33). Definitions of UASC or similar populations vary across countries, as do transparency and accountability of governments regarding data collection(34), presenting further barriers to research. Separated children may be fleeing conflict, violence, loss of home or other rights violations. Their migration may be their best or only hope of a better future. Policy and legislation both in the UK and globally has led to a failure of safe and legal routes of migration, and hostile asylum processes, both of which drive trafficking and child labour(33, 35). There are urgent rights-based arguments for improving and addressing the needs of UASC.

In the UK, UASC are legally defined as follows: *“a child who is claiming asylum in their own right, who is separated from both parents, and who is not being cared for by an adult who in law or by custom has responsibility to do so. Some will not qualify for asylum but may require “humanitarian protection”. Others may not qualify for any leave to remain in the UK. Their status will be determined by the Home Office”*(36), and are afforded protections in line with the Children’s Act 1989. Such young people are defined as UASC even if they have not chosen to claim asylum in the UK. There were 7,380 UASC in England at the end of March 2024(37), the majority of whom were male (96%) and aged 16 or 17 (76%)(37). In addition to the vulnerabilities of travelling alone, UASC are more likely to have migrated via irregular pathways, without legal protection. UASC have frequently suffered trauma, including rape and torture, in their country of origin or during their journey(38), and poverty, deprivation and reduced access to healthcare(39). They represent a vulnerable and diverse population with significant social, educational, mental and physical health needs(40).

The current management of UASC varies significantly by local area within England. Once they present to authorities, UASC come into the care of the local authority, becoming looked-after-children (LAC), the same status as children in foster care. As such, the young person is entitled to accommodation, education and health care. According to statutory guidance, UASC should be seen for an initial health assessment (IHA) within 20 working days(41). The assessment is performed by a medical professional, typically a paediatrician, and should address the emotional, physical and mental health of the young person, resulting in a comprehensive care plan(41). No standardised guidance for how IHA should be carried out exists in England(42) which can lead to variation in the expertise of medical staff undertaking assessments, time for appointments, translation facilities, thresholds for onward referrals and multi-disciplinary involvement between local authorities(43).

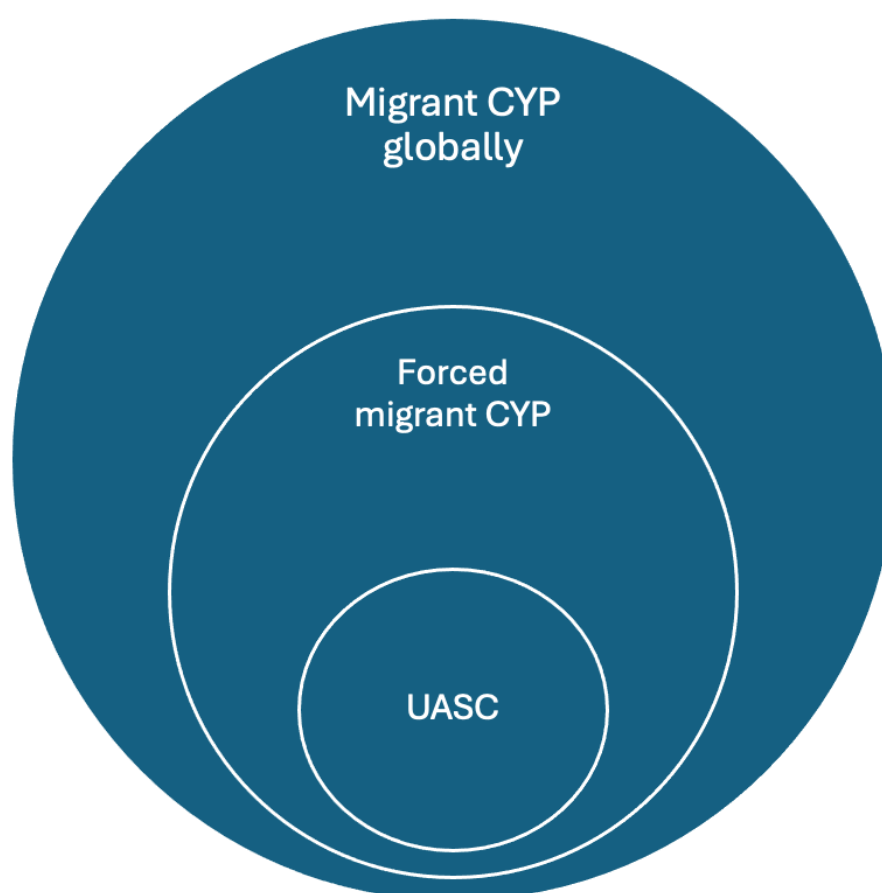
There is a lack of empirical data available on UASC, particularly more recent evidence from the UK(44). In England, data on LAC and their outcomes are collected; UASC status is recorded in this dataset but this is not routinely made available to researchers(45), presenting a barrier to research on the outcomes of this group.

Given their age profile, UASC tend to be LAC for only a short period before they turn 18, when they are no longer entitled to the same support. Language and cultural barriers make for limited suitable placements and barriers to engagement with services; the “Did not attend” (DNA) rate (i.e. when NHS appointments are not attended), may be higher among UASC(46). Trauma, complex needs and the additional stressor of asylum application during this period all present challenges in the optimal care of this group.

Most UASC are at risk of infectious diseases (ID) due to prevalence and, often, reduced access to healthcare in their country of origin, with additional risk from conditions of transit, including overcrowding and time in refugee camps. At the outset of this work, national guidance recommended tuberculosis (TB) screening for any person from a country with rates 40/100,000 population(47), and guidance for parasitic infections and blood-borne viruses screening was on a case-by-case basis(48). Pragmatically, guidance in the UK was open to interpretation and inconsistently followed.

In some cases, the Home Office contests that the young person is under the age of 18, and there is no documentary evidence of age. In these cases, the local authority undertakes an age assessment. If deemed to be over the age of 18, the young person is no longer entitled to support from the local authority. There is no accepted reliable medical method for accurately assessing age, and paediatric doctors in the UK, at present, do not take part in age assessments(49). As well as variation in care, another concern is that existing research and service configuration for UASC has not been developed in conversation with the young people themselves, with few groups actually asking them “what matters to you?”. There is a lack of research on UASC own views of services, with more emphasis on views of the adults around them(50), as well as a wider lack of advocacy for these young people and ethos of hearing their voices. One criticism is that services tend to focus on a narrow spectrum of outcomes defined by healthcare professionals, e.g. rates of blood-borne viruses, vaccine coverage, dental health and nutritional status(51), rather than a more holistic view of their needs. Outcomes that might be more meaningful to the young person, such as support for trauma, chronic pain, access to education, access to sport and their asylum claims, may not be considered. The failure to give a ‘voice’ to this group has been highlighted as a failure to uphold the rights of the child (52).

Figure 1. – Populations of migrant CYP addressed in this thesis



1.2.5 Developing services for migrant children

A recognised challenge in management of migrant CYP is the lack of consensus on best practice management. As noted in the WHO technical guidance on health of refugee and migrant children, there is a lack of evidence-based policy for care of migrant children, and a lack of evaluative research of specific interventions(53). The importance of identifying best practice interventions with the potential to be expanded has been highlighted nationally(54) and internationally(52, 53).

The prescribed management for UASC in the UK is described above. There is currently significant variation in UASC care, as shown in a recent survey of UASC management across 83 community paediatric teams in England, particularly around staff education, assessment duration, translator facilities and infectious diseases screening(55). These findings represent a gap between current and preferred practice in care of UASC, potentially representing serious unmet health needs and future individual and public health burden.

An approach to addressing some of these problems is through integrated care, with a view to delivering patient-focussed care by addressing the systems around the patient. There are various definitions in use but the WHO defines integrated care as “health services organized and managed so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money.”(56). Wolfe et al proposed a definition of child integrated care that expands the adult concept to include domains based on health determinants in childhood. Integrated child health therefore encompasses integration between primary and secondary care; integration between health, education and social care; consideration of age and developmental needs over time and underpinned by health policy and public health coordination(57).

Integrated pathways, also called integrated care pathways or clinical pathways, are a structure of healthcare delivery representing a formalised means of delivering integrated care. Definitions are not standardised, but key features include multi-disciplinary care, joined-up and holistic delivery of services, standardisation of care (supporting implementation of best-practice guidelines), continuous service evaluation and a patient-centred approach. Evidence from adult care suggests positive impacts from integrated pathways on service delivery and effective timely delivery of care, adherence to guidelines, reducing variation in care and improving patient experience(58-60). A 2020 systematic review and meta-analysis of integrated child health models showed evidence for improved health related quality of life and cost-effectiveness with integrated care models. However, for health service usage, educational attendance and other health outcomes the evidence was mixed(61).

A part of this thesis will focus on interventions for UASC that have the potential to bridge this gap with a view to improving UASC health outcomes, including an “integrated pathway” for UASC, first developed in Camden in London.

1.2.6 An introduction to trauma-informed care

Following patient and public involvement (PPI) input around developing services for UASC, and in view of new literature on mental health and trauma, a trauma-informed care approach was incorporated into service development. Trauma-informed care (TIC) and Trauma-informed approaches have had increasing recognition over the past few years in care of vulnerable populations across sectors(62, 63). TIC represents a framework grounded in an understanding of, and responsiveness to, the impact of trauma and adverse childhood experiences(63).

Many asylum-seeking and refugee children and young people have experienced trauma. Traditional service provider relationships may unintentionally replicate the dynamics of childhood trauma, and interactions with traditional service models risk

re-traumatisation(64). This is a particular risk in populations who have historically been discriminated against and abused by medical institutions(65).

A TIC approach seeks to recognise signs of trauma and to take active steps to avoid re-traumatisation in interactions. TIC approaches promote organisational change aiming to create environments providing physical, psychological, and emotional safety for both providers and survivors, and that create opportunities for survivors to heal within the structures of care provision(64). There is some variation in definitions of TIC but key common principles, with explanation for CYP, are listed below.

Key principles of TIC as applied to migrant CYP

Safety: Create a safe environment around CYP including considering their cultural, emotional and physical safety.

Trustworthiness and transparency: Be honest and open about what is happening and what services are able to help with. Be transparent about anything that is not in your power.

Collaboration and mutuality: Work in partnership with CYP to make decisions about their care and take a shared decision-making approach.

Choice: Offer choice and respect the dignity and wishes of CYP. Consider their ability to give informed consent and how trauma may affect this.

Empowerment: Offer recognition and validation, for example if CYP tells you their story or seeks help. Acknowledge strengths and seek to build on these.

These principles are referenced throughout this thesis and underpin much of the work on developing services for UASC.

1.3 Quantitative evidence on migrant children – literature review

1.3.1 Data on health of migrants

Health needs, and associated health outcomes, among migrant CYP are poorly understood(66) and infrequently reported in the literature, preventing a population-based approach to planning health services. This is in part due to poor quality and quantity of data on this topic. There is a lack of data on migrant health spanning larger geographical regions and crossing borders, barriers to data linkage, and an associated lack of large scale studies or reviews(67, 68). Routinely collected

healthcare data sets rarely include migration status, despite the need being emphasised by multiple international agencies(69). Within Europe, only 25 of 53 member states have systems to collect health data on migrants, and this data varies in quality and definitions, preventing cross-country analysis(69). The best available data are from Denmark and Sweden, but there remain limitations on individual-level data and barriers to researcher access(69). Most studies available on the health of migrants only include children as a subgroup, if at all(67). The lack of healthcare data on migrant CYP has been identified as an unmet research need(67), as well as a rights of the child issue(70).

1.3.2 Migrant mortality – quantitative evidence

A recent comprehensive systematic review on the mortality of international migrants of all ages provided evidence that, on average, international migrants have lower mortality than the host population(11). However, mortality from specific causes, such as violence and infectious diseases, was higher among migrants. This systematic review also highlighted a lack of data on the health of forced migrant groups such as asylum-seekers, refugees and undocumented migrants(11), and authors cautioned against generalising results to these groups. Similarly, the majority of studies addressed migration to high-income countries with a noted evidence gap for data on migrants, particularly refugees, in low- and middle- income countries(11). Health outcomes for migrants from different geographical regions and countries are likely to be related to the socioeconomic conditions of the origin and host countries. For example, a study of perceived wellbeing in adolescent migrants living in Canada showed different rates of health complaints based on country and region of origin(71). Although this systematic review included migrants of all ages there was no sub-group analysis by age. As mortality is a rare outcome in CYP, this review was not able to draw meaningful conclusions around mortality among migrant CYP.

1.3.3 Migrant child health – quantitative evidence

A 2018 systematic review of systematic reviews addresses perinatal outcomes among forced migrants, which includes outcomes on babies born to migrant mothers(72). Three systematic reviews looked at mortality among the offspring of migrants including still birth, death from preterm birth, neonatal and infant mortality. One systematic review showed evidence of increased stillbirth, neonatal and infant mortality in some migrant groups but not in others(73). A second systematic review showed evidence of excess fetal and infant mortality among migrants from North Africa and Asia, but not among other populations(74). The third systematic review demonstrated evidence of increased stillbirth, neonatal and infant mortality in migrant women(75). None of these systematic reviews disaggregated data by the time of

migration, and, given the framing of the research question it is likely that none of these children would have themselves migrated after birth.

Systematic review evidence from 2018 demonstrates that migrant children used healthcare services less than non-migrant populations, with the exception of emergency services, although their rate of hospital admission is higher(76).

Mental health and effects of trauma is a frequent focus of existing research on migrant CYP, particularly forced migrants such as refugees. A 2009 overview of the literature highlights challenges of defining mental health problems in differing cultural contexts and of migrant CYP engaging with health services(77). A 2017 systematic review of mental health challenges among migrant CYP identified more studies in refugee and asylum-seeking children than the wider definition of migrants. There have been several additional systematic reviews specifically addressing mental among refugee and asylum-seeking CYP(78-81), most recently in 2022(82). These show consistent evidence of increased rates of PTSD, depression and anxiety but all reviews comment on the significant variability between results identified in different studies. A 2020 meta-analysis of mental health among refugee and asylum-seeking CYP gives an estimated PTSD prevalence of 22.71% (95% CI 12.79–32.64), depression prevalence of 13.81% (95% CI 5.96–21.67), and prevalence of anxiety disorders of 15.77% (95% CI 8.04–23.50)(79), with authors commenting on the limited number of high-quality studies identified and heterogeneity between studies. Within migrant subgroups, evidence suggests that refugees and asylum-seekers have worse mental health outcomes compared with other migrants, particularly in the context of conflict, and that unaccompanied migrant children fare worse within this group.

Literature on the health needs of forced migrant CYP frequently highlights the importance of communicable diseases and the associated concern of vaccine coverage(53, 83, 84). There is limited research on the wider definition of migrant children with respect to communicable diseases, and a lack of systematic review evidence. While refugee children are thought to be at high risk of infections, WHO technical guidance states that differences between forced migrant CYP groups are often greater than those between migrant and host population(53).

In existing literature on health outcomes among CYP there is a lack of quality as well as gaps in the comprehensive nature of research. In view of the importance of the “healthy-migrant” effect in discourse around migration, I felt it was importance to direct investigate the evidence on mortality among migrant CYP. I chose a second focus of communicable diseases among migrant CYP given the importance of communicable diseases among forced migrants and the more vulnerable groups, and in view of the lack of systematic review evidence. In view of the gaps in the

literature, I would propose that several other migrant CYP health outcomes should be investigated with similar methodology informed by a life-course approach across childhood. Rather than seeing health outcomes as discrete and unrelated, this approach takes a comprehensive and holistic view of health. This allows for early influences on risk factors for long-term conditions potentially presenting later in life and the biopsychosocial model of child and adolescent health to be taken into account(85). Outcomes including non-communicable diseases, disability, abuse and assault were beyond the scope of this thesis but I propose to complete these in future, allowing a comprehensive overview of migrant child health.

1.4 Literature review on UASC views of health needs and health services

1.4.1 Overview

I undertook a literature review with a focus on UASC own views of their needs, their interactions with healthcare professionals and researchers, and their perceptions of services. The focus is on qualitative literature but relevant quantitative studies, for example questionnaire-based studies, have been included.

Formal searching of the scholarly literature using search terms around unaccompanied asylum-seeking children (UASC) in the UK yielded relatively few results, and out of papers identified there were more quantitative than qualitative studies. Broader searching using terms including separated children, child migrants and refugee children yielded some more results, although definitions of the population of interest varied. Hand-searching and informal search methods, including grey literature, yielded more results, as noted by other authors(50). The paucity of refugee and asylum-seekers voices in the literature has been highlighted previously, with even less from the perspective of children and young people(44, 50, 86). Existing research frequently focuses on a relatively narrow range of health issues, predominantly via questionnaire-based studies, and the 'voice' of the child is heard less frequently than that of the parents, carers or professionals (86-88). Although few studies on this exact group are available, studies with young adults or care leavers who were former UASC, literature from other countries, and literature from other groups of migrant children such as accompanied refugees, are included when helpful.

I have presented evidence from the available literature below, grouping the results by the dominant themes that emerged: mental health and emotional wellbeing, the

hostile environment, support and coping strategies, perceptions of health and wellbeing and listening to UASC.

1.4.2 Mental health and emotional wellbeing

The most common focus of existing qualitative research on migrant CYP in Europe is mental health and emotional wellbeing(86). High rates of mental health problems are well recognised, particularly among refugee children and those who are unaccompanied(89, 90). A longitudinal study of UASC in Norway demonstrates that failure of support structures and refusal of asylum claims further exacerbate mental health problems over time(91). UASC may have very different understandings of mental health than professionals in the UK, and our western definitions of mental health may be too narrow, preventing insight into the wider emotional needs of the young people(90). The language used around mental health in the UK, and concepts of services to promote this, may be poorly understood. UASC may not identify with notions of 'treating' mental health problems due to differing cultural understanding of health. There is evidence that some UASC benefitted from talking therapies; but there is a need to convey the concept of counselling in a way that avoids stigma and alienating some groups of young people who may resist the idea of counselling(90).

1.4.3 The hostile environment

In recent years the UK government have pursued a series of policies collectively known as the 'hostile environment', with the aim of making the circumstances of migrants in the UK, particularly asylum-seekers and undocumented migrants, as difficult as possible(92). These policies have been criticised for targeting not only undocumented migrants (sometimes referred to 'illegal immigrants' in the media) but the wider migrant population. The recent Nationality and Borders Bill has been condemned by the UNHCR for criminalising refugees and asylum-seekers, having no basis in international law, and denying refugee CYP their rights to family reunion and stability about their futures(93). It is against this backdrop that UASC are arriving in the UK, which may create an environment of hostility and systemic racism, and lead to barriers (actual and perceived) to engaging with services.

Several studies underline the impact of stigma and racism in the lives of UASC and adult refugees following arrival(94-96). Young people may avoid using the term 'asylum-seeker' due to perceived stigma around this(95), and feel that this is a label that defines them in the eyes of others. A study of adult Somali and Iraqi refugees in the UK also highlighted the stigma of the term 'asylum-seeker' that can be dehumanising, and the role that the media play in this(96). Some UASC feel wary of disclosing information around their background to professionals, fearing this may adversely influence their asylum claim(97). Adult asylum-seekers in Sweden described difficulties around understanding and negotiating an alien system with

cultural and language barriers(98). Studies from Europe and the UK highlighted that information around existing services for health, education and immigration support in Europe is difficult to access, patchy and frequently not provided in the correct language(86, 99).

1.4.4 Support and coping strategies

A recurring theme in the narratives of the UASC was loss of control, and a feeling of being controlled or objectified within the social care and immigration systems(94), which is echoed in a study with adult asylum-seekers in Sweden(98). Young migrants often discussed finding strategies to gain control and agency in their lives, including in a study of Sudanese minors in the US(100). UASC in the UK described coping strategies such as suppressing negative thoughts(95) or staying silent about their experiences, either to retain a degree of agency(94), or as a strategy to help forget their experiences(101).

UASC interviewed in the UK spoke about the importance of sources of support, which could be friendships with peers, or relationships with professionals(95). In a study of current UASC in the UK(94) and a study with former UASC the importance of a trusted person(102) was emphasised, who may be a professional involved in the care of the young person(103). In interviews with care leavers, some former UASC, and in a study of current UASC, examples were given of positive experiences with professionals who go 'above and beyond', particularly those who the young people perceive as easy to contact(42, 104).

1.4.5 Perceptions of health and wellbeing

Studies with UASC and former-UASC in the UK suggest that their major concerns included money, housing and other practical sources of support(104) as well as social isolation and immigration status(42). Health was rarely a priority for UASC, even where chronic health problems were present(103). Much more commonly, education was seen as the priority by UASC, particularly learning English(99). This is echoed a study of Sudanese minors in the US, where education was identified as the means to secure their futures(100).

Engagement with health services, and barriers and enablers to engaging, were addressed in several studies. Adult refugees described being mistrustful of health professionals and expressed concerns that any medical consultation could be used as evidence in their asylum claim. This mistrust of professionals extended to interpreters(98), dentists(103) and doctors. UASC may have had hostile or otherwise negative interactions with the police or the Home Office following their arrival and may be having their age contested. It may be difficult to convey the roles of different

professionals that UASC interact with and they may view all interactions as a possible test or assessment process.

1.4.6 Listening to UASC

For a range of reasons children who are marginalised are less well represented in the literature, and are frequently denied a 'voice' in relation to services and research around their own needs(105). As discussed, UASC often feel robbed of control and agency by the hostile and alien system they find themselves in. Silence may be used as means of preserving agency in a situation and setting where the YP is deprived of this(101). The literature suggests that UASC may be reluctant to disclose their stories, either choosing only trusted persons to speak to(94) or requiring that the process be revisited over time as they become more confident(42). When young people wish to tell their stories, they may then find difficulties in communicating as they wish to(94). The distinction between researchers and other health professionals may not be clear to the young people, and as Thomas and Byford (2003) explained: "young people from such troubled backgrounds are understandably wary of researchers asking about their past and are often resistant to discussion of experiences loaded with pain and guilt"(106).

An approach to undertaking research with this group requires significant preparation and consideration of the issues raised(106, 107). Reference should be made to an ethical checklist of priorities addressing harms and benefits, rights-of-the-child, consent and payment issues(108). Alternative methods than interviews have been used in several studies with this group and may improve the richness of the data as well as the experience of the young people. Examples include use of photo-based dialogue(97), participatory approaches(99), sports and visual data production.

1.5 Migration trend and policy during this MD(Res)

Since the outset of this project there have been significant geopolitical events and shifts in policy regarding migrants, both internationally and in the UK. These changes impact the demographics of migrant populations, the rights and protection afforded to migrant CYP and the social context in which migrant children arrive and live in host countries. As such, they impact the interpretation and policy implications of my research.

1.5.1 Global migration trends

A number of conflicts and humanitarian crises have newly arisen in the last 5 years, resulting in shifts in migration demographics and rapid movements of populations. In parallel, other conflicts have continued, perpetuating an outflow of refugees to safer countries. The civil war in Syria and subsequent refugee crisis has been ongoing since 2011, making Syria a constant in the top ten list of migrant origin countries(109). Similarly, the displacement of the Rohingya people from Myanmar, ongoing for several years, showed a sharp increase in 2017 following escalating violence against the ethnic group(9). The withdrawal from Afghanistan in 2021 caused a mass displacement of refugees, as did the 2022 Russian invasion of Ukraine.

Forced migration due to climate- and weather-related events is a rapidly increasing global issue, predominantly affecting LMIC. Since 2008 over 300 million people have been displaced due to climate change with a record number of 36 million displaced in 2022(9, 31). As described, these “climate refugees” at present do not fall within the international definition of refugees (under the 1951 Refugee Convention), presenting challenges in legal status and protection afforded(31). Due to the population distribution of affected countries, and the nature forced migration, CYP are disproportionately affected by climate change. In 2023, UNICEF reported 43 million CYP displaced by weather-related events in a 6-year period(10).

The Covid-19 pandemic temporarily reduced global movement and dropped migration levels to historic lows in 2020(9). However, there were particular risks posed to pre-existing migrant populations by the pandemic. Compared with the host population, migrants are more likely to be undocumented, and to be affected by poverty and poor housing conditions. Evidence in migrants of all ages showed an increased risk of infection among migrants, and excess Covid-19-associated mortality(109). Similarly, effects of lockdown disproportionately affected migrant populations, including mental health impacts(109). Although children were typically less susceptible to the direct health impact of Covid-19 infections(110), migrant CYP were extremely vulnerable to wider socioeconomic effects of the pandemic such as disruption of health and social services, reduced shelter and economic protection,

and increase stigma and discrimination associated with misinformation on migrants(110).

Migration numbers since the pandemic have recovered and even outstripped pre-pandemic levels. However, restrictions on safe and legal routes that were implemented during the pandemic remain, adversely affecting the safety of migrant populations(9), including CYP(33).

1.5.2 Global and UK migration policy

Economic, social and political factors interplay in changing the discourse around migration. In the last 5 years, many high-income countries have tightened borders and restricted migrant rights and movements. There has been a rise of nationalist and far-right governments in several countries, leading to restrictive and anti-migrant policies. In Europe, Finland, Italy and Hungary have hard-right parties in government, with the hard-right gaining ground in France, Greece and Germany. Globally, Donald Trump's first term in the US saw significant migrant rights violations with a travel-ban from Muslim-majority countries and separation of migrant children from their parents at the Mexican border(111). The US is the provider of 50% refugee aid globally(112), aid under significant threat based on early decisions in Trump's second term.

In 2015, the number of migrants and refugees arriving in Europe reached record numbers, in part driven by the refugee crisis from Syria; since this point, migration policy has been a major political issue in recent years with shifts in public opinion and media narratives. The media response is generally characterised by a lack of context to refugees arrival, with little attention paid to individual reasons for migration; a lack of the voice of the migrant themselves, particularly women or other marginalised groups; and the framing of the arrival of migrants as a "crisis" for the receiving countries(113). Parts of the media have driven and promoted hostility and frank racism towards migrants, including the use of hate speech(113).

In the UK, efforts to curb net migration have been ongoing since at least 2010, including raising the income level for skilled worker visas, restricting family reunification (90% of those affected are women and children(114)) and restricting student visas. Recent high-profile changes in UK legislation include the Nationality and Borders Act and the Rwanda policy. The Nationality and Borders Act became law in 2022, introducing a two-tier asylum system, criminalising those (including CYP) who have come to the UK via irregular routes, while legal routes have been cut-back or eliminated. Multiple groups have raised concerns about rights-violations and failure to comply with international conventions, including the UNCRC(115). Specific concerns about the impact on migrant CYP include reducing safeguarding

duties, increasing the risk of trafficking and expanding government powers in age assessment, leading to children being incorrectly identified as adults(115).

Conversely, there have been positive steps in terms of international coordination and migrant rights. The Global Compact for Migration (GCM), developed by the United Nations in 2018, is the first internationally agreement on an approach to migration(116). Although non-legally binding, the GCM takes a holistic and rights-based approach aiming to encompass all aspects of migration. The GCM includes specific provisions for migrant CYP, promoting existing legal protections and prioritising the best interests of the child(116). 164 countries have chosen to adopt the GCM, which includes commitment to improve data collection on migration, with countries listed above choosing to opt out. There is not yet good evidence for the impact of the GCM but it provides a framework to improve international coordination and data collection on migration.

1.6 Research question and hypothesis

This thesis seeks to map and describe the current state of global research on migrant child health outcomes, and to explore development of services for UASC, as an exemplar group of vulnerable migrant children. The overarching research question is: What do we know about the health of migrant children, how can we improve things for the most vulnerable groups and how can we involve young people in this?

Research questions for this thesis:

1. What is the current state of international research into migrant child health outcomes?
2. What do we know about health outcomes among migrant CYP?
3. How could services be better configured to meet the needs of migrant children (with a focus on UASC) in the UK?
4. What are the policy implications of these findings?

The main hypothesis is that the health of this important and growing global population is under-researched and that lessons learnt from developing services for the most vulnerable groups are widely applicable.

1.7 Aims and objectives with signposting

This MD(Res) aims to:

1. map the current state of research into migrant child health outcomes, and
2. explore how services could be better configured to meet the needs of migrant children, with a focus on UASC, as a particularly vulnerable group.

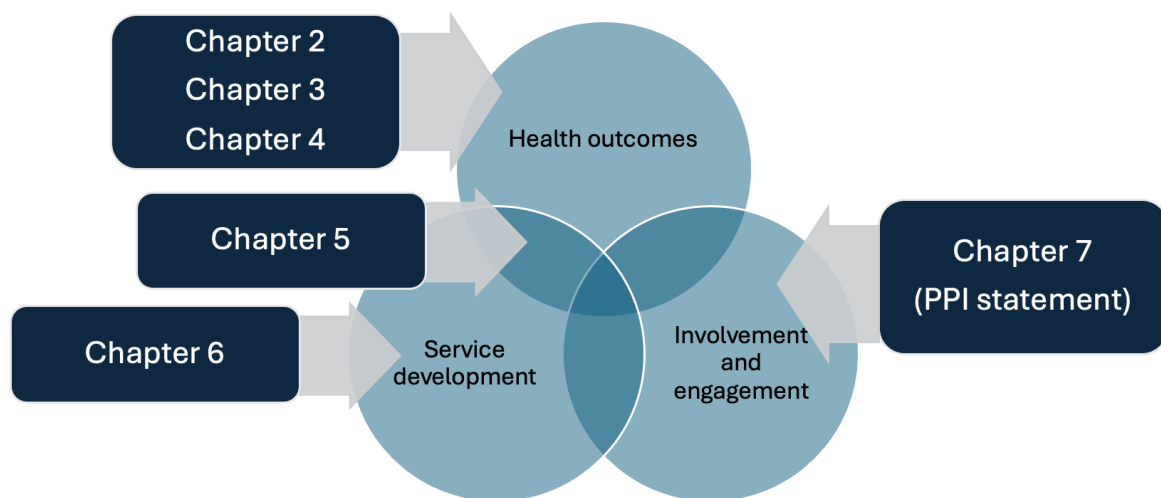
The longer-term goals of this MD(Res) are to improve the health service experiences of forced migrant CYP in England, and inform service development, interventions and research direction with a view to engaging, supporting and improving outcomes among UASC.

Objectives:

To achieve these aims, my MD(Res) is comprised of the following projects:

1. A systematic review, with meta-analysis, of health outcomes in international migrant children
 - a. Systematic review methods – Chapter 2
 - b. Systematic review results: Mortality among migrant CYP – Chapter 3
 - c. Systematic review results: Communicable diseases among migrant CYP – Chapter 4
2. Evaluation, development and improvement of services for UASC:
 - a. Description of an “integrated pathway” for UASC in Camden with evaluation of demographics, health needs and known outcomes of a population of UASC engaging with this service over a three-year period. – Chapter 5
 - b. Adaptation and pilot feasibility evaluation of the integrated pathway for UASC in Newham – Chapter 6
3. Exploration of structures, barriers and ethical dimensions around hearing the voice of vulnerable children in research, policy and service development; the example of UASC – Chapter 7

Figure 2. – Components of this thesis with chapter mapping



1.8 Patient and Public Involvement (PPI) statement

Engaging patients and the public is essential to all parts of my research, from informing the study question, designing projects, carrying out projects and disseminating results.

The population of UASC themselves are known to be vulnerable and difficult to access, with further barriers presented by the Covid-19 pandemic. I felt it was inappropriate to reach out directly to current UASC for PPI input around research and planning of services, in part because PPI events are exempt from ethical approval and because ethical considerations are paramount in any interactions with this group. When UASC were attending face-to-face appointments we used quick and convenient feedback methods to ensure input without requiring additional contact or recruitment. Ethical and practical considerations are explored in chapter 7.

To inform research and service development I have reached out to multiple organisations who work with migrant children or UASC, young people who may be former UASC or LAC, or other individuals or groups leading on PPI for research. The Newham LAC team and I formed a partnership with the Separated Child Foundation, a charity working with unaccompanied child refugees in the UK. The Separated Child Foundation have been involved in informing implementation of the integrated pathway for UASC in Newham, including working with the Health Improvement Practitioner and providing sleep and welcome packs for UASC. I discussed the planning of the UASC engagement project in Newham with several members of the organisation.

I linked up with the Helen Bamber Foundation (HBF), a human rights charity working with victims of trafficking and torture. Through this network I disseminated results from the Camden integrated pathway evaluation (Chapter 3), including to psychologists, GP and other physicians working with migrant populations. Members of HBF advised directly on the Newham UASC pathway project design (Chapter 6), including taking a trauma-informed care approach and the consideration of informed consent in this group.

I visited Refugee Action Kingston where I shared UASC findings and ongoing projects, including with a lawyer who is a trustee for charity Methoria. The Methoria charity programme First Rights launched the project Equal Justice for Migrant Children, aiming to promote a model of justice for migrant and separated children. Equal justice for migrant children.

I made contact with the Kings Cross Church who run a refugee service including football sessions, a drop-in café and English lessons to UASC. I shared my research findings and linked up the service with a family medical refugee service nearby.

I have been in contact with the study team for the CCoM study team (Children Caring on the Move), who are exploring separated child migrant's experiences of care and caring for others, around engagement approaches and designing the UASC pathway project in Newham. The CCoM team advised around complexities of consent and assent in this group, as well as use of youth-friendly materials and examples of these.

A young person who is a former UASC advised the team in Newham on the implementation of the integrated pathway model. This young person also sat on the interview panel for recruiting the Health Improvement Practitioner (HIP) role and was invited to be involved in planning the UASC engagement project.

An information leaflet about a proposed UASC engagement project (see appendix 1) was circulated via the people participation lead for East London Foundation Trust (ELFT) around networks including service users.

I contacted the lead for Patient and Public Involvement in Research at Great Ormond St Hospital (GOSH), and the Public Engagement Manager at UCL School of Life and Medical Sciences, both of whom advised on planning strategies for engagement.

An invitation for PPI in-put (see appendix 2), including contact details, was circulated to the following organisations:

- Refugee Education UK, a charity offering holistic support to young asylum seekers and refugees
- The Croydon Young Refugee Network, an umbrella group of around 30 organisations working opportunities and outcomes for young refugees and asylum-seekers in the Croydon area. I have also offered to give a talk to this group around access to medical school for young people.
- Love to learn, A mentoring and advocacy organisation for CYP from refugee backgrounds.
- Pangea Support Services, housing and support services for young unaccompanied minors and care leavers

Involvement with these groups and individuals has been an ongoing process throughout my research. I hope to maintain these contacts and networks to facilitate dissemination of research and policy recommendations.

Chapter 2: Systematic review of health outcomes in international migrant children (Methods)

My first objective was to undertake a systematic review of health outcomes among international migrant children, with a view to describing the existing state of quantitative data on the health of migrant CYP.

As outlined, there is a 'healthy-migrant' effect demonstrated among adult migrants, as shown in a comprehensive 2018 systematic review of mortality among international migrants(11), although these results may not be representative of the global migrant population. These results did not address the CYP population where data was too limited to draw conclusions.

The quantitative evidence on migrant child health is outlined in Chapter 1. There are gaps in the scientific literature exploring mortality among migrant CYP and health outcomes across the paediatric life course. This systematic review was therefore designed to address a range of meaningful health outcomes among CYP taking a holistic view from infancy to the start of adulthood (age 0-17). For the purposes of this thesis, I have focussed on the outcomes of mortality and communicable diseases among migrant CYP, which are presented in chapters 3 and 4. Mortality was addressed with a view to exploring the "healthy-migrant", a dominant part of discourse in migration, and whether there is any evidence that this applies to CYP. As described, communicable diseases, and the interrelated issue of vaccine coverage, presents one of the most significant challenges to migrant child health but comprehensive overviews of the research are lacking.

This chapter outlines the aims of this systematic review, the research question and hypotheses for testing, the PICOS question, the methods, analysis plan and protocol amendments. This systematic review was registered with PROSPERO (CRD42020166305) and was revised based on their recommendations. The protocol for this systematic review was been published in BMJ Open in 2021(1), deviations from the protocol are listed in appendix 5.

This chapter addresses the first aim of this MD(Res), to map the current state of research into migrant child health outcomes.

2.1 Research question and hypotheses

The research question for this systematic review is: What is currently known about the state of migrant child health? This chapter focused on methods and analysis plan for investigating mortality and communicable diseases among migrant CYP.

The mortality systematic review tests the hypothesis that the “healthy-migrant” effect will not be seen in CYP due to inherent additional vulnerabilities and the different make-up of the migrant population. The communicable diseases systematic review tests the hypothesis that migrant CYP are at greater risk of communicable diseases compared with the host population. The broader hypothesis is that health outcomes among migrant CYP is a relatively neglected topic with lack of good quality research and gaps in the literature.

The PICOS question is presented in Table 1.

Table 1. - Research question in PICOS format

i. Population, or participants and conditions of interest	Children and young people (CYP), defined as those under the age of 18
ii. Interventions or exposures	Migration status; any migrant CYP, i.e. living in a different country from that of their birth.
iii. Comparisons or control groups	1. CYP who have not migrated, described as ‘the host population’ 2. No control group – single arm studies are included to support the narrative synthesis
iv. Outcomes of interest	1. Mortality (age group: 1-17 years), infants are excluded unless clearly stated that they have migrated after birth. 2. Communicable diseases (incidence/prevalence)
v. Setting	Studies in any setting and from any country were included
vi. Study designs	All studies presenting original data, including observational (cohort, case-control and cross-sectional studies), systematic reviews, and randomised controlled trials reporting quantitative data on health outcomes in international migrant CYP.

2.2 Aims and objectives

The aim of the systematic review is to comprehensively summarise the available global evidence base on mortality and communicable diseases among migrant CYP. This chapter focused on methods and analysis plan.

The specific objectives of this chapter were to:

5. Provide detailed methods for identifying original quantitative research on mortality and communicable diseases including eligibility, search strategy and selection process.
6. Specify methods of data synthesis including narrative synthesis approaches
7. Define statistical methods for data extraction and analysis, including decisions around meta-analysing available data.

2.3 Methods and analysis

These systematic review methods were written with reference to the PRISMA-P reporting guidelines for systematic review protocols(117).

2.3.1 Eligibility

I included published studies presenting original data on health outcomes of migrant children and young people (CYP), i.e. those living in a different country from that of their birth, including observational studies (cohort and case-control studies, and cross-sectional surveys), population datasets and randomised controlled trials. Studies in any setting and from any country were included.

Only studies pertaining to first generation migrant children were included, i.e. I did not include studies on children born to parents who were migrants. In view of this, and in view of existing systematic review evidence, studies were excluded that focussed exclusively on maternal and/or perinatal outcomes, as these did not address the outcomes for CYP who themselves had migrated. Where it was explicitly stated that the child themselves had migrated, there was no lower age range for inclusion. Where this was not stated, I defined the perinatal and infant period from before birth up until the child's first birthday, and these were excluded. Where studies of all ages did not disaggregate data by age, in general, I made the decision to exclude. However, I included some studies where an age-range extended slightly beyond childhood, e.g. up to age 20.

I made the decision to include single arm studies with no control group for several reasons: From literature review and preliminary searches it was apparent that there would be a lack of high-quality studies and studies of specific migrant groups (such as undocumented migrants). Single arm studies frequently focussed on the most vulnerable groups of migrant CYP and on rare outcomes that are nonetheless significant. Studies presenting rates of communicable diseases or mortality among migrant groups can also be interpreted in the context of available national statistics for the host population. For these reasons I felt that including these studies would support the narrative synthesis and my ability to map the existing literature in migrant CYP health.

I excluded studies where health outcomes did not fall within defined areas of mortality and communicable diseases. In view of existing systematic review evidence and the defined outcomes areas, I did not include studies exclusively reporting overall hospital attendance or admission rates without other health outcomes presented. I excluded studies published prior to the year 2000. This decision was due to several factors: volume of published papers have increased exponentially over time and excluding older papers represents a relatively small proportion of

literature on any topic. Migration flows evolve and change over time as do health systems, diagnostic tools and data collection methods. Studies in this area from over 20 years ago are therefore unlikely to be generalisable to modern migrant populations or to represent transferable findings.

Further, I excluded research letters, studies where the abstract or full text was not available, and studies where it was not possible to obtain an English translation. Restricting systematic reviews to English language publications is routine practice and has been shown not to significantly affect results of empirical studies(118).

During the screening process it became clear that there are very few existing studies addressing mortality among migrant CYP. In many cases it was also challenging to apply the inclusion criteria due to inconsistent or unclear definitions migrants and few studies disaggregating data by paediatric age group. With the aim of being as inclusive as possible it was necessary to provide additional clarification to the inclusion criteria around certain recurring themes. A common example of this was studies set in refugee camps where the camp population was only briefly described. Refugee camps frequently house a combination of internally displaced persons (IDPs) as well as refugees who have migrated across an international border, and outcome data were typically not disaggregated by migrant group. Refugee camps are typically set up under emergency conditions in a humanitarian crisis. However, many camps remain in place for years or even generations due to socio-political factors preventing dispersal. In this case some or all of the children represented in the data have in fact been born in the camp, meaning they have not themselves migrated, and do not meet the definition of a migrant child. Studies on refugee camp data generally do not make clear what proportion of children have themselves migrated. Studies in newly formed refugee camps or those that disaggregate the results by time in refugee camp are therefore more pertinent to answering the research question. I made the decision to include studies presenting data from refugee camps, however, I analysed these results separately due to the considerations cited.

During study identification stage I made the decision to omit studies without control groups which presented fewer than 5 data points relevant to the research question. For example, a case series where one or two deaths in migrant children are presented. The conclusions that can be drawn from studies without control groups are very limited and with tiny numbers this can become meaningless.

2.3.2 Outcomes of interest

Following identification of studies, the outcomes were grouped into mortality and communicable diseases. I chose these two outcomes as the most relevant to my research question, to explore the “healthy-migrant” effect in migrant CYP and to

summarise evidence on the health impact most associated with the process of migration. These outcomes represent two of eight planned outcomes chosen to represent key health outcomes across the life course. These were chosen with reference to the Global Burden of Disease Study 2017(119) and to reflect the ‘survive and thrive’, strategy of the sustainable development goals(120). Please see appendix 3 for details of the additional six outcomes not addressed in this thesis.

When developing the search strategy for the health outcomes, more emphasis was placed on outcomes where quantitative data may be available, where definitions are recognised internationally and where the outcomes are plausibly affected by migration status. For communicable diseases (and the additional outcomes in appendix 3) a finite list of more common conditions has been chosen.

Mortality:

The search strategy focussed on death, cause of death and all measures of mortality including mortality rate, case fatality rate, survival rate. Where data were available, mortality rates were broken down by age-group and compared to mortality rates among the host population.

Communicable diseases (incidence/prevalence):

Systematic review evidence suggests that despite the “healthy-migrant” effect, rates of infectious diseases are higher among migrant populations(11). The search strategy focussed on HIV, Hepatitis B, Tuberculosis (active and latent), sexually transmitted diseases (Chlamydia and Gonorrhoea), Schistosomiasis and parasitic infections(11). In 2021, prior to searches being carried out, I included terms around Covid-19 (protocol deviation). This is a communicable disease that potentially disproportionately affects migrant populations and a significant body of literature had emerged between the protocol being finalised and the searches being undertaken.

Any case definition of communicable disease used by study authors was eligible for inclusion. In the case of tuberculosis (TB), active TB diagnosed by clinical or radiological criteria, culture, microscopy, molecular testing or a combination of these was accepted. In the case of latent TB (LTBI), Tuberculin skin tests (TSTs, also known as Purified protein derivative, PPD, or Mantoux), with threshold width defined by study authors, or Interferon gamma release assays (IGRA, also known as QuantiFERON or Elispot) were accepted.

2.3.3 Search Strategy

The electronic databases Pubmed/Medline, Embase and Cochrane were searched on 01/06/2021 with the date range of 01/01/2000 onwards. A grey literature search was also undertaken including the following websites: Organisation for Economic

Co-operation and Development (OECD), WHO Global Health Observatory (GHO), Health evidence network, Health for Undocumented Migrants and Asylum seekers (HUMA) Network and the International Organization of Migration (IOM). I undertook reference checking for selected manuscripts and search conference proceedings from international conferences relevant to migrant child health.

The search strategy used key words and index terms around migrant status, children and young people (CYP) and then around mortality and communicable diseases described above. The Ovid/Medline search strategy for Mortality and Communicable diseases are attached (Appendix 4).

2.3.4 Selection process

Search results were exported to EPPI-4 software for screening and selection. For mortality results two independent reviewers (myself and Irina Lut) screened titles and abstracts. Full manuscripts were screened when it was not clear from the title or abstract whether the study meet the inclusion criteria. Where there was disagreements between the two reviewers the study was escalated to a third reviewer (Michelle Heys) to resolve. For communicable diseases results screening was undertaken by another reviewer, Beth Stinchcombe, supervised by me. I undertook spot checks of screening decisions and we had regular meetings where I made the final decision on which studies to include. Following the screening of full-text, articles were assessed for eligibility; a PRISMA flow diagram was produced and the PRISMA checklist followed(121).

2.3.5 Data synthesis and analysis

Data were extracted to a Microsoft Excel spreadsheet by a single reviewer (AA, BS). I extracted the following data items: demographic features (age, sex and country/countries of origin of CYP), study design, country/countries of arrival (study setting), study period, study population, presence of control or comparator group, outcomes presented (using pre-defined categories as listed above), outcome measures (rate ratio, hazard ratio or odds ratio), follow-up period and funding source.

The NOS(122) assessment tool was used to assess the quality of studies. The NOS scale assigns a 'star system' judging across three domains: the selection of the study groups, the comparability of the groups; and the ascertainment of either the exposure or outcome of interest for case-control or cohort studies respectively. Where the NOS score is applicable, it is presented for each study. There were not sufficient results amenable to meta-analysis to run a sensitivity analysis.

Sufficient data were not available to undertake subgroup analyses, except breaking down the mortality results into two age ranges.

A narrative synthesis was undertaken of studies that were not included in the meta-analysis, informed by the Systematic review Without Meta-analysis (SwIM) guidelines(123). I set out why studies are not included in a meta-analysis; the diversity of studies is addressed (including populations, methodology and outcomes) and the completeness of outcome data. Studies were grouped for synthesis according to the pre-defined outcomes of mortality and communicable diseases (Table 1). Any quantitative effect sizes presented (that have not been amenable to meta-analysis) are presented in the narrative and tables. Statistics were not combined for presentation outside of the meta-analysis. Studies were prioritised based on assessed risk of bias, sample and effect size and relevance to the research question. For each outcome, a description of synthesised findings is made, and conclusions take account of quality of included studies and the assessed risk of bias.

Bias due to confounding must be considered when considering migration as a risk factor for health outcomes: migration is inevitably correlated with race/ethnicity, poverty and educational level(7). Bias due to missing data, selection bias and reporting bias were also be considered and addressed in the narrative synthesis and discussion.

2.3.6 Statistical methods and meta-analysis

The decision to carry out a meta-analysis depended on the availability of studies pertaining to the two outcomes. Studies presenting original data on mortality or communicable diseases were considered for inclusion in meta-analyses. The I^2 statistic was used to explore heterogeneity of studies and is presented for each meta-analysis. Due to significant heterogeneity of identified studies, meta-analyses were undertaken despite I^2 of >75% (protocol deviation, see appendix 5). A small number of studies (<3) was adopted as the threshold for decision not to undertake meta-analysis(124). Study results were summarised using a random effects model (Der-Simonian and Laird method)(125). This analysis method assumes study results are taken from a theoretical larger sample that are normally distributed with a mean of zero. Analysis therefore takes account of random variability between results(126). I pooled results for meta-analysis using the meta suite in STATA version 17 to fit the random effects model using the restricted maximum likelihood (REML) estimate to produce unbiased results of study variance. Results were presented in forest plots. Due to the small number of identified studies, it was not possible to use a funnel plot to explore the likelihood of publication bias.

To enable meta-analyses of communicable diseases results I attempted to obtain incidence rates, for both migrant and host populations, and incidence rate ratios (IRR) with confidence intervals for all studies. For some included studies the

incidence rates for either migrant or host populations had to be calculated, e.g. where incidence rates for host population were split by birth country of parents. This was possible when incidence rate and event number or denominator (in per years) was provided, or when event numbers and denominator were provided. For included studies it was necessary to calculate the incidence rate ratio by dividing the incidence rate among migrant children by the incidence rate for host population children. I was able to calculate confidence intervals around incidence rate ratios from the event numbers for the migrant and host groups using the Rothman/Greenland method(127). For some studies the data were only presented in a graph, in these cases I used webplot digitizer, a free open source software facilitating easy and accurate data extraction from a variety of plot types(128). For studies where sufficient information was available, IRR is presented. For studies where there was insufficient information, I have presented the most appropriate outcome measure given, including prevalence, odds ratio and relative risk. Incidence rate data requires follow-up over time, usually years, and therefore prevalence was instead presented for studies without a follow-up period. Some studies only presented numbers with insufficient information to derive any outcome measures; where data were available, outcomes measures for all studies are presented in tables. Meta-analysis of amenable results was performed in STATA version 17(129).

Chapter 3: Mortality among international migrant children: results from Systematic review

As outlined previously, multiple studies have demonstrated the so-called “healthy-migrant” effect among adult migrants(7, 130), and a systematic review in 2018 showed that migrants, on average, have a mortality advantage over the host population(11). However, the population of migrant CYP have significant differences from adult migrants; they are more likely than to be forced migrants(25, 26), are affected by the health and wellbeing of their care-givers, and have inherent additional vulnerabilities. It is not yet known whether the “healthy-migrant” effect, demonstrated among adult migrants, is also shown among migrant CYP. To attempt to answer this question I am undertaking a systematic review addressing mortality among migrant CYP. For a detailed explanation of methods please see Chapter 2.

In this chapter I present the systematic review results on mortality among migrant CYP, discuss the implications of these results and put them in context with existing literature. Of note, the outcome, in this case mortality, is during the period of childhood, therefore from age 0-17. This systematic review took an inclusive approach due to the paucity of data on this topic, and original data on all-cause and cause-specific mortality among migrant children were included. Studies without a control group have also been included to support the narrative synthesis.

The results of this systematic review are reported in line with the PRISMA 2020 checklist for reporting of systematic reviews results and discussion section(131), and the Systematic review Without Meta-analysis (SwIM) guidelines(123).

This chapter addresses the first aim of this MD(Res), to map the current state of research into migrant child health outcomes. For objectives of the systematic review please see chapter 2.

3.1 Research question and hypotheses

The research question for this systematic review is: What is currently known about the state of migrant child health? This chapter focuses on the outcome of mortality and provides results and discussion.

The central hypothesis being tested is that the “healthy-migrant” effect will not be seen in CYP due to inherent additional vulnerabilities and the different make-up of the migrant population. I hypothesise that data will be limited on this topic, so an inclusive approach is taken, including studies on cause-specific mortality and studies with no control group.

The PICOS question is presented in table 2. With the relevant section highlighted.

Table 2. - Research question in PICOS format

i. Population, or participants and conditions of interest	Children and young people (CYP), defined as those under the age of 18
ii. Interventions or exposures	Migration status; any migrant CYP, i.e. living in a different country from that of their birth.
iii. Comparisons or control groups	1. CYP who have not migrated, described as ‘the host population’ 2. No control group – single arm studies are included to support the narrative synthesis
iv. Outcomes of interest	Mortality (age group: 1-17 years), infants are excluded unless clearly stated that they have migrated after birth. - Cause-specific mortality - All-cause mortality
v. Setting	Studies in any setting and from any country were included
vi. Study designs	All studies presenting original data, including observational (cohort, case-control and cross-sectional studies), systematic reviews, and randomised controlled trials reporting quantitative data on health outcomes in international migrant CYP.

3.2 Aims and objectives

This chapter aims to summarise the available evidence base regarding mortality among migrant CYP.

The specific objectives of this chapter are to:

- 1) Critically appraise global original quantitative research on mortality among migrant CYP
- 2) Compare results to CYP in the host population where data were available. Where there was no control group or the control group were another migrant group, the studies were included in the quantitative narrative synthesis.
- 3) Undertake meta-analyses of measures of mortality where sufficient data are available.
- 4) Interpret these results to identify gaps in the literature and implications for future research and policy.

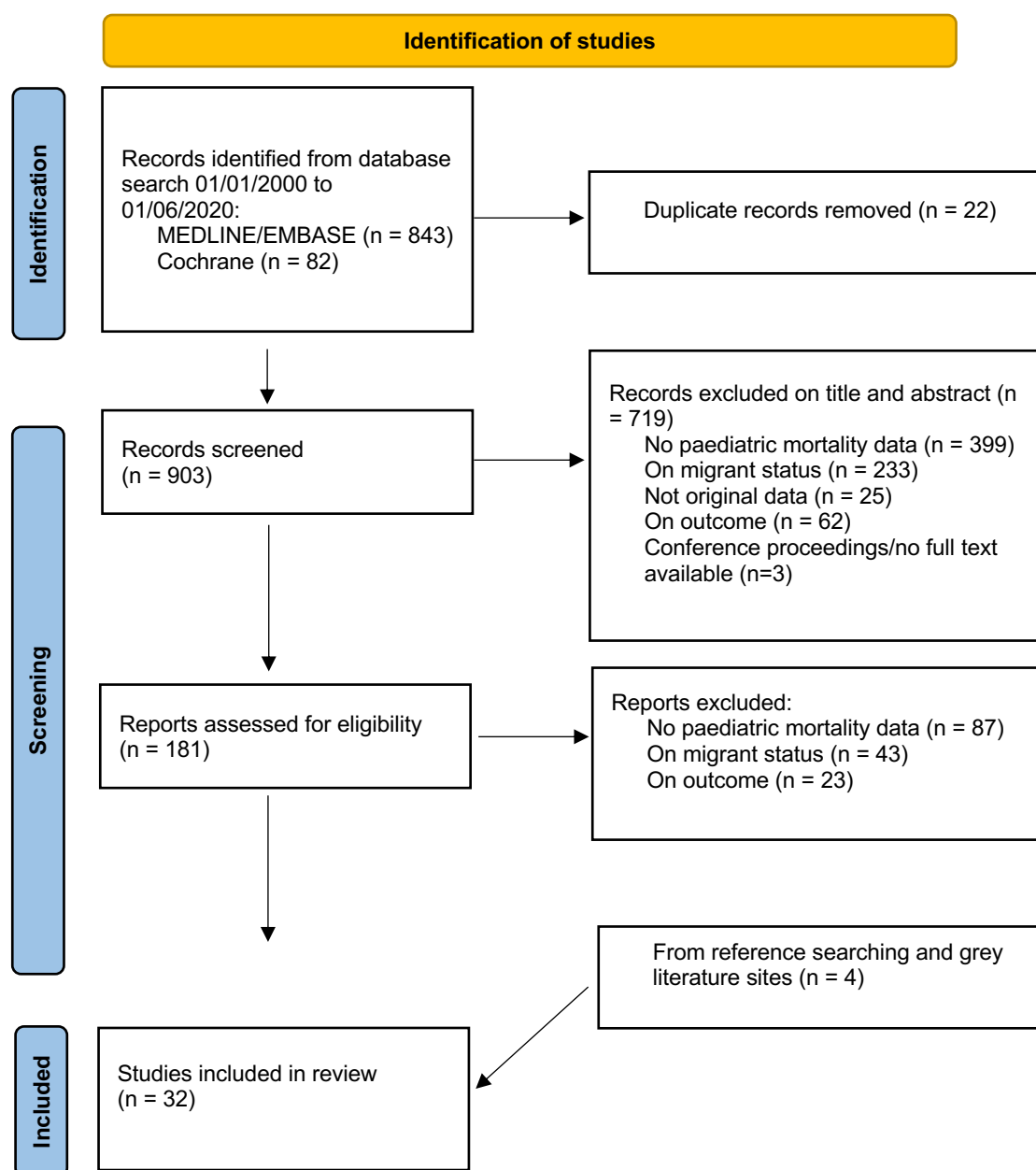
3.3 Results

3.3.1 Summary of results

I searched the Cochrane library, Medline and Embase databases on 01/06/2021 using the defined search strategy (see Appendix 4) with date range 01/01/2000 onwards. The search strategy yielded 925 articles of which 22 were duplicates. Of 903 articles screened, 719 were excluded on title and abstract and a further 3 were conference proceedings or full text was not available. 181 full texts were assessed for eligibility of which 29 met the inclusion criteria, agreed by two reviewers. A further 4 articles were identified by reference searching and from grey literature sites giving a total of 33 included articles (see figure 3 - PRISMA flow diagram for full details). Results were analysed and synthesised where possible, only 4 studies presented data that could be included in meta-analyses.

There were challenges in ascertaining which studies met the inclusion criteria. Studies were excluded where it was either unclear if CYP were included, or it was not possible to disaggregate results by age (See PRISMA flow diagram for numbers). Many studies used alternate definitions of migrant, such as second or third generation migrants or rural-urban migration. These were excluded unless disaggregated data were presented for CYP who had migrated internationally.

Figure 3. – PRISMA flow diagram for identification of mortality studies



3.3.2 Characteristics of included studies

Studies included data from 26 host countries, with some studies presenting data from multiple host countries. The most common host countries were the US (5 studies), Sweden (4 studies), Kenya (4 studies) and Canada (3 studies). Half of studies (50%) were from high income countries (according to the World Bank income classification(132)), 34% were from middle-income countries (16% upper middle income and 19% from lower middle income) and the remaining 16% from low-income countries.

3.3.3 Types of studies

All identified studies were observational and only 21/33 (64%) studies had a control group from the host population. Of these 21, there was one case-control study, three epidemiological surveillance studies, ten cohort studies from national databases and seven single or multicentre cohort studies. Of the 12 studies with no control group, eight were single or multicentre cohort studies, two were surveys and two were case series.

Of all included studies, 15 studies (45%) presented data on cause-specific or disease-specific mortality only and 18 studies (55%) presented data on mortality without a specific cause. Two of the studies without cause-specific mortality presented data on deaths in intensive care (single centre) and 10 presented refugee camp data without a control group. A total of 11 studies (33%) were from refugee camps or settlements, one of which presented data on mortality of refugees pre-migration, during migration and immediately post-migration, with pre-migration mortality representing the control group. There were 6 studies with control groups that addressed all-cause mortality among migrant groups and 1 study with control group addressing 'preventable mortality' among migrant groups. All but one of these used national or regional registry data from a high-income country. I used the NOS score to explore the quality of included studies with a control group (displayed in table 4 and table 5).

Three studies by the same research group with overlapping data were identified as meeting inclusion criteria. The three used the same data sources but had some differences in date range, age-range, outcomes and break-down by age, these are summarised below. The decision was made to include all three due to these differences but to take this into consideration in analysis and interpretation.

Table 3. – Characteristics of Hjern studies

Study (year)	Definition or subgroup of migrants	Age range	Dates of data collection	Outcome	Results (95% confidence intervals)	Summary of results
Hjern (2002)(133)	Intercountry adoptees from outside Europe arrived <age 7, and immigrant children into Sweden	7-25 at time of outcome (by my calculation)	Born 1970-79 and outcomes 1986-95	Suicide	Intercountry adoptees adjusted Odds ratio of suicide death compared to host population 3.6 (2.1–5.9) (immigrant results vs host population not given)	Significantly high odds of suicide in intercountry adoptees in teenage and early adulthood
Hjern (2002)(134)	Intercountry adoptees from outside Europe, arrived <age 7	11-30 at time of outcome (by my calculation)	Born 1968-79 and outcomes 1990-1998	Suicide	4.5 or 5.0 depending on adjustment	Uses very similar data to above study but greater proportion of adults in sample

Hjern (2004)(135)	Intercountry adoptees from outside Europe, arrived <age 7	8-27 at time of outcome (by my calculation) but one outcome given for age 13-17	Born 1973-1982, outcomes 1990-2000	Suicide, all-cause mortality and avoidable mortality	Relative risk of avoidable mortality compared with host population for age 13-17 2.3 (95%CI 1.3 to 3.8) (other outcomes not presented by paediatric age group)	Significantly higher relative risk of avoidable mortality among migrant children
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3.3.4 Cause-specific mortality results

Of the 14 studies presenting data on cause-specific mortality, 11 had a control group. The 3 studies without control groups were all from refugee camps and presented mortality numbers for malaria(136), malnutrition(137) and measles(138). The studies with control groups addressed mortality from tuberculosis (TB)(139, 140), road-traffic accidents(141), suicide(133, 134), burns(142), heat-related causes(143), work-related causes(144), cancer(145) and acute lymphoblastic leukaemia (ALL)(146). Of these 11, all but one showed excess mortality among migrant CYP. The one study of cause-specific mortality showing an advantage among migrants showed superior event-free survival among migrant children with acute lymphoblastic leukaemia in Canada (adjusted hazard ratio 0.33, 95% CI 0.12–0.98; $p = 0.03$)(146). A study of children with cancers (including acute lymphoblastic leukaemia) in Italy showed the opposite effect, with a hazard ratio of 1.7 among migrant children compared with the host population(145).

A further two studies looked at mortality within an intensive care unit(147, 148), both with a control group. One showed higher mortality in the host population and one showed higher mortality among migrants, but neither result was statistically significant. Results are summarised in Table 4. Meta-analysis was not possible due to inconsistent causes of mortality and inconsistent outcome measures. Where it was possible to calculate, the NOS score is shown in table 4 (please see appendix 6 for full details of NOS scoring).

Table 4. – Characteristics of cause-specific and setting-specific mortality studies

Study (Year)	Cause or disease addressed	Control group	Country (Host)	Results	Summary of results	Quality assessment
Abouzeid (2013)(139)	Tuberculosis	Yes	Saudi Arabia	Case fatality rate age 0-14: Host population CFR: 1.2% (95%CI: 3.274 - 2.296), Migrant CFR: 3.1% (95%CI: 2.565 -1.591)	Excess mortality among migrant children with TB	Low (NOS not applicable)
Al-Hajj (2020)(141)	Road injuries	Yes	Lebanon	Odds ratio of death compared with host population: Syrian: 2.03 (95% CI: 1.08 to 3.81)	Higher odds of death from road injuries among some groups of migrant children	Low (NOS not applicable)

				Palestinian: 1.28 (95%CI: 0.57 to 2.87) Other migrant: 1.24 (95%CI: 0.44 to 3.49)		
Buyukbese Sarsu (2018)(142)	Burns	Yes	Turkey	Mortality risk difference between migrant children (Syrian) and host population: 10.1% vs 1.28%	Higher mortality among migrant children with burns	Low (NOS not applicable)
Gafar (2019)(140)	Tuberculosis	Yes	Netherlands	Odds Ratio of death among migrants compared with host population: 1.49 (95%CI: 0.61-3.68)	Higher odds of death among migrant children with TB (but not statistically significant)	Moderate – 6 stars
Ganesan (2014)(147)	Paediatric intensive care (PICU) deaths	Yes	Malaysia	Mortality risk difference between migrant children and host population: 20% vs 27%.	Higher mortality risk in intensive care among the host population (but not statistically significant)	Low (NOS not applicable)
Gupta (2014)(146)	Acute lymphoblastic leukaemia (ALL)	Yes	Canada	Adjusted Hazard Ratio of 5-year event free survival among migrants compared with host population: 0.33 (95%CI 0.12-0.88)	Significantly superior survival in migrant children with ALL	High – 8 stars
Hjern (2002)(133)	Suicide	Yes	Sweden	Adjusted Odds Ratio of suicide for Intercounty adoptees compared with the host population 3.6 (95%CI 2.1–5.9)	Higher odds of suicide among migrant children and young adults	High – 8 stars
Hjern (2002)(134)	Suicide	Yes	Sweden	Adjusted Odds Ratio of suicide for Intercounty adoptees compared with the host population 4.5 or 5.0 depending on adjustment (NB: uses similar data to other Hjern study but age-range includes more adults – above study more relevant)	As above	High – 8 stars
Koker (2020)(148)	Paediatric intensive care (PICU) deaths	Yes	Turkey	Mortality risk difference between migrant children and host population: 22.8% vs 7%.	Higher crude mortality risk in intensive care among migrant children	Low (NOS not applicable)
Mahamud (2013)(138)	Measles	None	Kenya	5 deaths in age 0-4, 1 in age 5-14	No conclusion possible	Low (NOS not applicable)
Mostafa (2021)(149)	Surgical mortality in congenital heart disease	Yes	Lebanon	Surgical mortality rate among Syrian refugee children 10.1% compared with 2.9% for host population	Higher crude mortality rate among migrant children, not known if statistically significant.	Low (NOS not applicable)
Rauscher (2016)(144)	Work-related injuries	Yes	US	Relative risk of death compared with host population 4.35 (95%CI: 2.73, 6.72)	Significantly higher risk of death from work-related injuries among migrant children	Moderate (NOS not applicable)
Rondelli (2011)(145)	Cancer	Yes	Italy	10-year overall survival migrants 53.2% (SE 4.4), host 70.8% (SE 1.3), p<0.001 Hazard ratio for ALL survival among migrants compared with host population 1.70 (1.16-2.50), p 0.007	Significantly higher risk of death among migrant children with cancer and specifically ALL	Moderate – 6 stars

Saeed (2003)(136)	Malaria	None	Sudan	70 children died of malaria	No conclusion possible	Low (NOS not applicable)
Tappis (2012)(137)	Malnutrition	None	Kenya and Tanzania	For those <5 enrolled on Severe Acute Malnutrition programmes death rates were 4-9% across categories	No conclusion possible	Low (NOS not applicable)
Taylor Ethel (2018)(143)	Heat-related causes	Yes	US	Adjusted risk ratio for migrant children compared with host population Children < 5yrs: 0.6 (0.2, 2.4), 5–17yrs: 15.6 (10.6, 22.9)	Higher risk of heat-related deaths among migrant children aged 5-17. Results in younger children non-significant.	Moderate – 6 stars

3.3.5 Refugee camp studies results

Of the 11 studies presenting data from refugee camps(136-138, 150-157), 3 addressed cause-specific mortality, results above, and the remainder presented data on all-cause mortality, typically among children aged less than 5. One study on Somali refugees arriving in Kenya presented data for the refugees before leaving their host country, during transit and following arrival in the refugee camp(150). Under 5-mortality rate (U5MR - Deaths per 10,000 children aged <5 year per day) predeparture was 2.21 (95%CI 1.24-3.17), during transit 3.95 (0.08-7.81) and following arrival 1.53 (95%CI 0-3.25). None of the other studies had a control or comparator group. Five of the studies gave U5MR for the study period which ranged from 1.53 to 10.3. Two studies gave U5MR per 1000 children (in fact a cumulative incidence per 1000 live births rather than a mortality rate – this is a preferred measure of infant mortality in non-emergency settings(158)) ranging from 4.4 to 7.6. No studies presented disaggregated data for other paediatric age-groups. The NOS score was not applicable for any of these studies due to lack of control groups or methodology not consistent with cohort studies or case control studies.

3.3.6 All-cause and ‘preventable’ mortality studies results

There were five studies that addressed all-cause mortality and presented some mortality data for the paediatric age-group (see table 5). A further study presented data on ‘preventable’ mortality among migrant children, defined by authors as “deaths from natural causes related to alcohol and substance misuse, deaths from natural causes that could possibly have been avoided by proper medical care, and intentional and unintentional injuries”(135). All of these studies used national or regional registry data or databases and therefore included all (or a representative sample of) migrant children during the study period. Of note, none of these studies addressed outcomes among undocumented migrants. Characteristics, results and NOS scoring are shown in table 5 below.

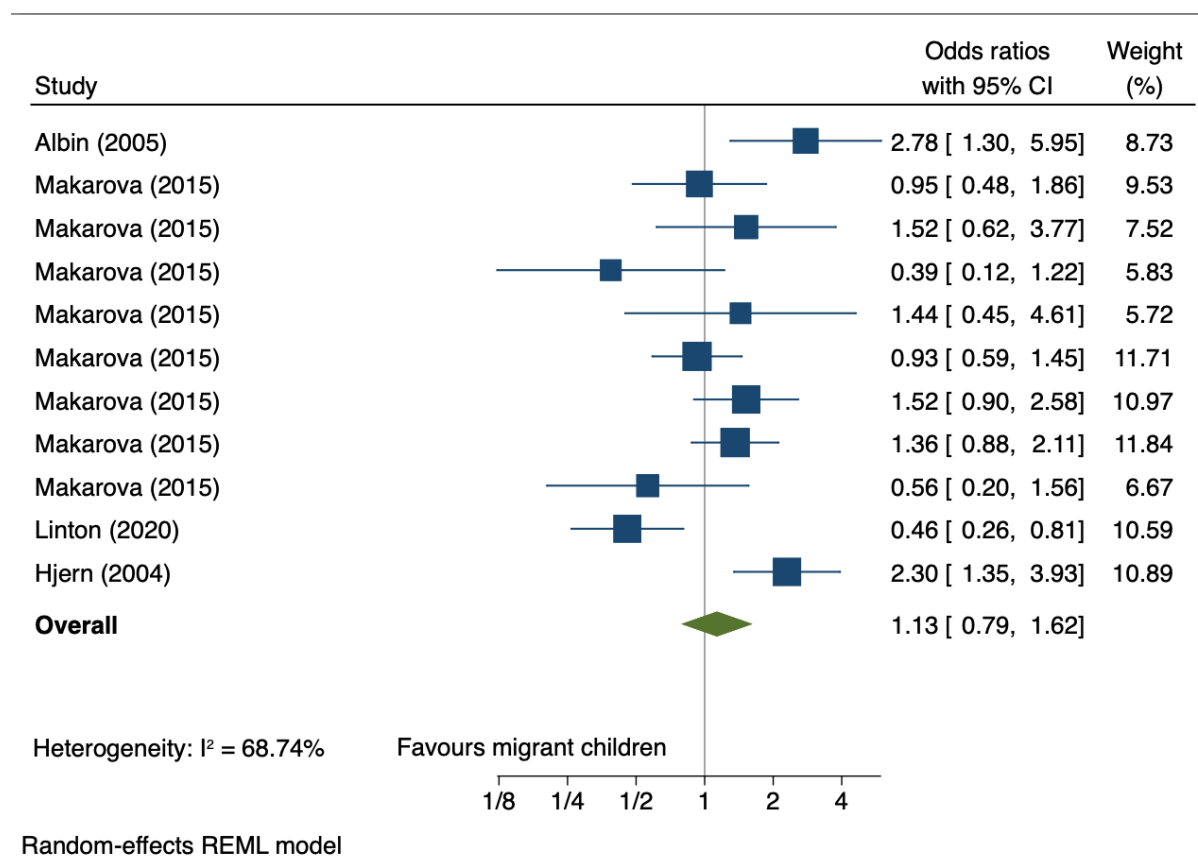
Table 5. – Characteristics of all-cause and preventable mortality studies

Study (year)	Country (Host)	Definition or subgroup of migrants	Age range	Dates of data collection	Type of study	Results (95% confidence intervals)	Summary of results	Quality NOS score
Albin (2005)(159)	Sweden	'foreign-born'	15-19	1970–1999	Case-control from national registry data (Retrospective)	Odds ratio of death among migrants age 15-19 compared with the host population. 2.78 (1.3-5.95)	Significantly higher odds of death among migrant CYP compared with the host population	7
DesMeules (2005)(160)	Canada	With immigration status in Canada – refugees and non-refugee immigrants	0-19	1980-1998	Historical cohort record linkage study	Standardised Mortality Ratios (SMR) in age 0-19 Refugees (M) 0.41 (0.29–0.53) Refugees (F) 0.64 (0.42–0.86) Non-refugee immigrants (M) 0.67 (0.54–0.80) Non-refugee immigrants (F) 1.80 (1.49–2.11)	Results among male and female refugees and male non-refugee immigrants indicate a migrant mortality advantage. Among female non-refugee immigrants the host population have a mortality advantage.	8
Makarov (2015)(161)	Germany	Former soviet union (FSU) immigrants and Turkish immigrants	0-4 and 5-19	2004-2010	Retrospective register-based linkage study (Cohort)	Risk ratio for age-adjusted deaths among immigrant groups compared with host population by sex FSU immigrants 0-4 M 0.95 (0.48-1.86) 0-4 F 0.39 (0.12-1.221) 5-19 M 1.52 (0.62-3.76) 5-19 F 1.44 (0.45-4.61) Turkish immigrants 0-4 M 0.93 (0.59-1.45) 0-4 F 1.36 (0.88-2.11) 5-19 M 1.52 (0.90-2.58) 5-19 F 0.56 (0.20-1.56)	Equivocal overall compared with host population	7
Linton (2020)(162)	US	Persons with refugee or special immigrant visas in Washington State	<18	2006-2016	Retrospective cohort record linkage study	Age-adjusted rate of death per 1000 person-years Migrant 0.20 (0.09–0.31) Host population 0.44 (0.43–0.45)	Striking evidence of “healthy-migrant” effect in <18s, but is not clear this is adjusted for neonatal and infant death which is likely to be missing from migrant group.	6
Hjern (2004)(163)	Sweden	Intercountry adoptees from outside Europe, arrived <age 7	13-17 Whole group 8-27 at time of outcome (by my calculation)	1990-2000	Prospective register-based linkage study (Cohort)	Adjusted Odds Ratio of avoidable death compared with host population (age 13-17): 2.3 (1.3 to 3.8) All-cause death rates/10000 person years for whole age group	Higher odds of avoidable mortality among migrant children. All-cause mortality among migrant children and young adults also higher than host population	8

						49.6 vs 25.5, p<0.001		
Trova o (2019)(164)	Canada	Foreign-born	Age ranges 0-4, 5- 9, 10- 14, 15- 19	Two study periods 2000– 2002 and 2010– 2012	Statistical modelling from national databases – census and mortality database	Hypotheses tested with log rate model. Lambdas measure net effect of predictors to raise or lower the expected death rate (negative Lambda favours migrants). Lambdas for all-cause mortality by age first model: There is a substantial negative coefficient for age 0–4 ($\lambda = -1.014$) whereas for ages 10–14 and 20–24, the terms are positive Second model: young immigrants aged 0–4, shows a small relative advantage; however, at subsequent ages 5 through 19, the change coefficients are positive, indicative of an increased risk	Equivocal evidence for “healthy-migrant” effect. Difficult to interpret alongside original data. Modelling may not take account of neonatal and infant death which is likely to be missing from migrant group.	4

There was considerable heterogeneity in identified studies. Meta-analysis was challenging due to inconsistency between presented outcome measures and insufficient detail provided to derive alternate outcome measures. Several authors were contacted with requests for original data without success. Where it was possible to extract odds ratios (OR) for childhood mortality among migrants and the host population these data have been meta-analysed. Figure 4 shows pooled estimates for all available odds ratios. This does not include results from one of the highest quality studies which only presented standardised mortality ratios (SMR)s. The odds ratio for Hjern (2004)(135) is adjusted but all other odds ratios are unadjusted. Summary OR for all ages is 1.13 (95%CI 0.79-1.62) indicating slightly increased odds of mortality among migrant children, but this result is not statistically significant.

Figure 4. - All-cause and ‘preventable’ mortality all ages



There were not sufficient data available to undertake subgroup analysis by the age groups outlined in the protocol but a meta-analysis of data from younger children (Figure 5) and older children (Figure 6) was undertaken, the data from Linton (2020)(162) which spans age 0-17, is included in both. Summary OR of all-cause mortality in younger children was 0.81(95%CI 0.52-1.25) and for all-cause mortality in older children was 1.29 (95%CI 0.76-2.19) Neither summary OR was statistically significant.

Figure 5. - All-cause mortality in younger children (0-4 years)

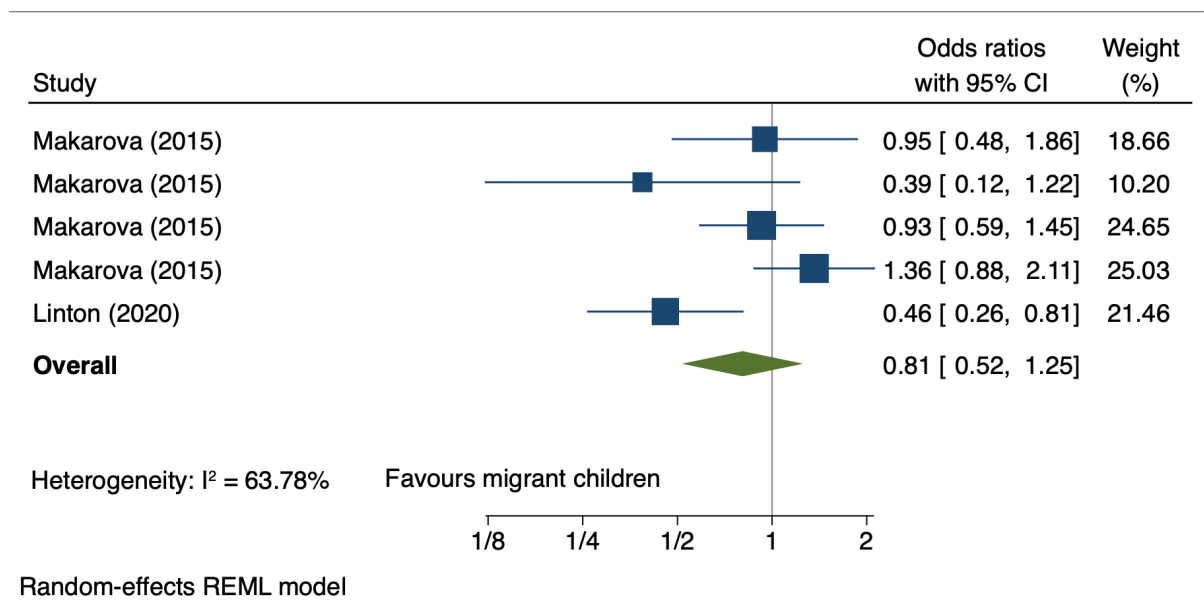
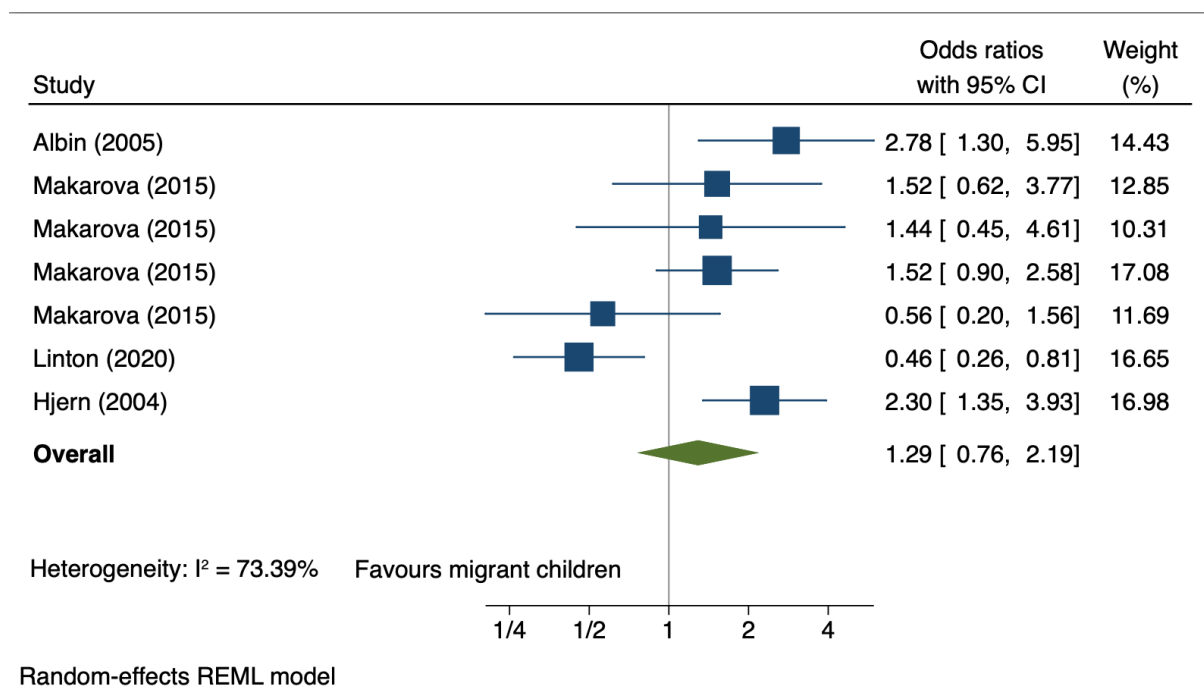


Figure 6. - All-cause and ‘preventable’ mortality in older children (5-17 years)



3.4 Discussion

3.4.1 Summary of key findings

To the best of my knowledge, this is the first systematic review addressing mortality (all cause and cause-specific) among migrant CYP (defined as those who have themselves migrated). As such, this addresses a crucial question on the existing international literature and summarises existing evidence for and against the

“healthy-migrant” effect in CYP. This is an important and growing area of interest, and comprehensive evidence is vital to inform policy and research gaps.

This systematic review demonstrated that there is very limited evidence currently available on the mortality of migrant children. Of studies on mortality from specific causes where migrant CYP were compared with the host population, all but one study showed excess mortality in the migrant group. Evidence synthesis and meta-analyses results from studies of all-cause mortality are more equivocal. All age meta-analysis showed a trend towards a host mortality advantage but this was not statistically significant. Meta-analyses of younger and older ages showed non-statistically different results.

Despite an inclusive approach, only a small number of studies met inclusion criteria and of those, only a small proportion were of sufficient scope and quality to draw meaningful conclusions. There was a significant paucity of evidence on CYP who themselves have migrated internationally. From the studies that were included, higher-quality evidence was exclusively from high-income host countries where the paradigm is that of migrants arriving from lower income countries, with lower quality health services and poorer outcomes, to a country with better outcomes. The evidence is therefore not reflective of the majority of forced migration globally, which takes place between low- and middle-income countries(9).

Results from identified studies addressing cause-specific mortality overall indicate excess mortality among migrants, although no pooling of data was possible. The majority of identified studies addressed causes that have strong associations with migrant status as a social determinant of health, for example communicable diseases (TB), and causes associated with deprivation (heat-related, work-related and road traffic accidents). These causes are the exception to the “healthy-migrant” effect in research among adults where migrants are known to have excess mortality from communicable diseases and external causes. The exceptions to this are two studies looking at mortality from cancer which showed opposite results, both in high-income countries. One study of acute lymphoblastic leukaemia (the most common childhood malignancy) showed improved survival among migrant CYP, and one on types of cancer including acute lymphoblastic leukaemia, which shows improved survival among the host population.

Comprehensive studies addressing all-cause mortality (those from national or regional data) show conflicting results, with some providing evidence of excess mortality among host CYP and some indicating excess mortality among migrant CYP. The summary statistics in the meta-analysis by age group suggests that there could be a migrant advantage among younger children and a host population advantage among the older age-group. Of note, one large comprehensive study

could not be included in the meta-analysis due to inconsistent outcomes measures. These results should be interpreted with extreme caution given the small number of highly heterogeneous studies and limitations described below.

Studies from refugee camps showed very high mortality in the under 5s, although this varied significantly between studies. Most refugee camp studies did not have a control group, and host population mortality may also be high in the countries in question, limiting the scope for interpretation. One study showed mortality among a group of refugees was lower following arrival in the refugee camp compared with pre-departure, with highest rates during the period of transit.

3.4.2 Strengths and limitations

This systematic review on mortality among migrant CYP addresses a clear knowledge gap and, to my knowledge, is the only systematic review addressing this research question. The search strategy was thorough, all results were dual screened and final decisions to include were agreed by at least two reviewers.

Conclusions are limited by the small number of studies identified, heterogeneity and risk of bias in included studies. I used the NOS score to explore the quality of included studies, but this was only possible for studies with a control group. The NOS tool was also limited in its application when studies did not fit with conventional methodology for study type, e.g. cohort studies. In studies of cause-specific mortality there were several that presented data for all cases of a disease either nationally or within a single centre; these results were then subdivided by migrant status but without giving numbers for population of migrant children within the region. Often risk or odds ratios for migrant child mortality were only presented in crude form, limiting the interpretation of results (due to differences in averages of population, for example). Studies with these limitations would still score well overall using the NOS system. Another limitation of quality assessment measures is failure to specifically account for considerations of paediatric data comparison. Mortality is not steady across the paediatric age group, with highest risk in the neonatal (0 to 28 days) and then infant periods, with 59% of all paediatric deaths occurring in children under one in the UK(165). Although some identified studies stated that the data were age-adjusted, there was no detail provided on whether this adjustment took account of the mortality risk across the paediatric group. This represents a significant potential source of bias in all included studies. The effect could account for the significant “healthy-migrant” effect shown in Linton (2020), where mortality for the host and migrant populations are presented for age 0-17; given that the children themselves had migrated this is likely to capture almost none of the younger age mortality among migrant children, rendering the results meaningless.

Studies on all-cause mortality were all from high income settings but international data suggests the majority of migrants live in low and middle-income countries(69). As such, results are not representative of the migrants globally. These results are similar to that found in the adult literature; in the 2018 systematic review of mortality among international migrants, although a much larger number of studies were identified, 97% of the mortality estimates were from high-income countries(11). Similarly, results did not include data for undocumented migrants or illegal immigrants and we should be wary of extrapolating any conclusions to these groups.

3.4.3 Interpretation and consistency with existing data

The majority of studies addressing cause-specific mortality among migrant children showed excess mortality risk among migrants. However, many of the diseases or risks addressed in the studies are plausibly higher among migrant populations. Previous research among adults or all-age migrants shows a higher risk of migrant mortality from infectious diseases and external causes(11), which would account for the findings in several of these studies. Work-related injuries and heat-related causes are two examples where migrant populations are likely to have increased risk related to poverty and living conditions. A US study demonstrating excess work-related mortality in migrant CYP compared with the host population (relative risk 4.35 (95%CI: 2.73, 6.72)) could be attributable to lack of regulation for working practices or a failure to comply with regulations. In either case this represents a striking illustration of the inequity in outcomes of migrant CYP in a high resource setting and failure to uphold the basic rights of the child.

Two studies address cancer mortality among migrant children and show opposite results(146, 166). The risk factors for childhood cancers are not well understood; evidence suggests ethnic differences in risk of developing cancer, with black and minority ethnic groups having lower risk compared with Caucasian children(167). However, following diagnosis, cancer morbidity and mortality is strongly associated with deprivation and ethnicity, with those from lower socio-economic groups and minority ethnic groups having significantly worse outcomes(168). There is a recognised phenomenon where some migrant children are brought to the host country to seek healthcare not available in their country of origin(169), and there could be a selection advantage in those who are able to travel to seek treatment. Conversely, travelling to seek treatment may delay presentation of cancer, and migrant populations who are already in a host country may also present late, due to barriers such as health system understanding, poverty and language(170). The intersection of these opposing factors may explain the difference observed between the two included studies, with marginal differences in migrant population and host factors altering the risk/benefit balance.

Two studies from the same research group showed an increased risk of suicide among intercountry adoptees(133, 134). A recent systematic review of suicide among immigrants/refugees (adult data) found slightly lower odds of suicide among migrants compared with the host population, however, they noted higher rates of suicidal attempts among migrants(171). The review also pointed out much high rates among refugees compared with other groups of migrants, with one study showing five times higher suicide rates in refugees compared with other immigrants(171). Given the data in CYP only applies to the specific migrant sub-group of intercountry adoptees, it is difficult to draw wider conclusions from these studies.

Results from the included all-cause mortality studies are inconsistent, with some studies showing higher mortality among migrant children and some showing higher mortality among the host population. There was also variation within studies between subgroups of children by age and by migrant subtype. However, compared with results from cause-specific mortality studies, all-cause mortality studies generally show a lower risk among migrants, indicating that the causes addressed in the included studies are not the only relevant causes of death across migrant and host CYP populations. Even the equivocal results for all-cause mortality may be important, given that we might hypothesise excess mortality among migrant children due to their vulnerability profile. The difference between the excess mortality in migrant CYP across cause-specific studies and the lack of evidence for this excess mortality in all-cause mortality studies provides tentative evidence for some “healthy-migrant” effect in causes or factors not identified in the existing research. None of the all-cause mortality studies presented enough data to disaggregate mortality by cause, unlike in the adult literature where all-cause migrant mortality can be broken down into cause by ICD-10 categories(11).

Mortality is generally a rare outcome in childhood and included study results generally present small numbers of deaths, even across national databases, increasing the risk of bias. As described above, there may also be errors due to failure to sufficiently control for variation in mortality risk across early childhood. In the subgroup analysis, there is a trend towards the healthy migrant effect in younger children, and the opposite among older children, but these results should be interpreted with caution. It is worth noting that one of the highest quality studies could not be included in the meta-analyses (due to inconsistent outcomes measures), and showed SMRs <1 (i.e. favouring the “healthy-migrant” effect) for three out of four groups of migrant children compared with the host population.

In this review there were no high-quality studies on forced migrants but the limited data from single-arm studies shows very high mortality among refugee CYP, predominantly in the context of refugee camps. This finding is at odds with the adult literature where evidence from the 2018 systematic review among migrants of all

ages showed a mortality advantage among refugees consistent with the “healthy-migrant” effect, although these estimates were only based on two studies(11). The same 2018 systematic review found no mortality difference identified among asylum-seekers although data were similarly limited(11). Due to the paucity of studies identified and the variation in definitions of refugees the findings among CYP should be interpreted with caution. As described in the protocol amendments, the refugee camp population may not all meet the definition of CYP who have themselves migrated internationally. Factors associated with increased mortality include recently formed refugee camps and populations who have recently migrated, as well as poor conditions such as sanitation, health services and disease control(172). One study with comparative mortality across the pre-migration period, transit and post-migration demonstrated the highest risk during the transit period and higher mortality pre-departure than post-arrival. As a control group pre-departure refugee mortality is more likely to be reflective of the conditions driving the forced migration, rather than being representative of mortality in the host population. This highlights the risks associated with forced migration itself for CYP, although these results cannot be extrapolated to other migrant populations. Refugees are known to have higher mortality during transit and soon after arrival(172), which is consistent with findings in this systematic review. Depending on the laws and policies in host countries, not all refugees and asylum-seekers will necessarily be included in datasets.

3.5 Conclusion

There is a lack of quality evidence on mortality among migrant children. Identified studies are of variable quality with significant heterogeneity. Six studies addressed all-cause mortality or preventable mortality, all were from registry data or national databases in high-income settings. Results were equivocal as to an overall “healthy-migrant” effect, with contradictory results between studies and between subgroups of children. Identified studies on cause-specific mortality showed higher mortality among migrant children compared with the host population, including from TB, road-traffic accidents, suicide, burns, heat-related causes and work-related causes. Two studies on children with various types of cancer showed conflicting results in risk of death among migrant children compared with the host population.

The lack of data on mortality among migrant children represents a clear research gap. More comprehensive data are needed including data disaggregated by age-group and controlled for mortality risk in childhood. Data are also lacking from low and middle-income countries and data on different migrant subgroups.

Chapter 4: Communicable diseases among international migrant children: results from Systematic review

Migrant populations globally are perceived as being at high risk of communicable, or infectious diseases, with discourse and policies focussing on monitoring and screening of migrant populations(173, 174). However, this perception assumes that migrants are moving from a country with high rates of communicable diseases to one with low rates, typically from a low-income to a high-income country. This narrative does not consider migration between low- and middle-income countries (LMIC), or consider whether the migration itself affects the susceptibility or rates of communicable diseases. Migrants may be more vulnerable due to conditions of transit, poor or disrupted access to medical care, and stigma and social isolation following arrival. Conversely, the ability to migrate might select for those with lower rates of communicable diseases, or those who are more likely to have the means to seek out screening and treatment. Existing research on migrants of any age shows that communicable diseases represent an exception to the “healthy-migrant” effect: migrant populations, on average, have higher incidence of communicable diseases and associated higher mortality than host population(11). CYP are inherently more susceptible than adults to communicable diseases, and this effect may be exacerbated by poor nutrition and incomplete vaccine coverage, both influenced by migration. The risk profile of migrant children to communicable diseases is likely to vary significantly with country of origin, circumstances of transit and migrant subgroup (with forced migrants likely to be more vulnerable). There is a lack of comprehensive evidence on communicable diseases among all migrant children(175).

To attempt to address this gap, in this chapter I will present systematic review results on communicable and infectious diseases among migrant CYP, I will discuss the implications of these results and put them in context with existing literature. These results are part of a systematic review, addressing a range of health outcomes across the paediatric life-course. For a detailed explanation of the background and methods please see Chapter 2. In this systematic review I took an inclusive approach to studies of communicable diseases among migrant CYP, and studies without a control group have also been included to support the narrative synthesis. The results of this systematic review are reported in line with the PRISMA 2020 checklist for reporting of systematic reviews results and discussion section(131), and the Systematic review Without Meta-analysis (SwIM) guidelines(123)

This chapter addresses the first aim of this MD(Res), to map the current state of research into migrant child health outcomes. For objectives of the systematic review please see chapter 2.

4.1 Research question and hypotheses

The research question for this systematic review is: What is currently known about the state of migrant child health? This chapter focuses on the outcome of communicable disease and provides results and discussion.

The central hypothesis is that migrant CYP are at greater risk of communicable diseases compared with the host population due to the high proportion of forced migrants, and relative vulnerability of all migrant populations. Although communicable diseases are relatively frequently addressed in the literature, I hypothesise there will be a paucity of high-quality studies and lack of research on the wider population of migrant CYP.

The PICOS question is presented in table 6. With the relevant section highlighted.

Table 6. - Research question in PICOS format

i. Population, or participants and conditions of interest	Children and young people (CYP), defined as those under the age of 18
ii. Interventions or exposures	Migration status; any migrant CYP, i.e. living in a different country from that of their birth.
iii. Comparisons or control groups	1. CYP who have not migrated, described as ‘the host population’ 2. No control group – single arm studies are included to support the narrative synthesis
iv. Outcomes of interest	Communicable diseases (in CYP aged 0-17) - Incidence (incidence rate, incidence rate ratio, cumulative incidence, clustered and non-clustered incidence) - Prevalence rate
v. Setting	Studies in any setting and from any country were included
vi. Study designs	All studies presenting original data, including observational (cohort, case-control and cross-sectional studies), systematic reviews, and randomised controlled trials reporting

	quantitative data on health outcomes in international migrant CYP.
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4.2 Aims and objectives

This chapter aims to summarise the available evidence base regarding communicable diseases among migrant CYP.

The specific objectives of this chapter are to:

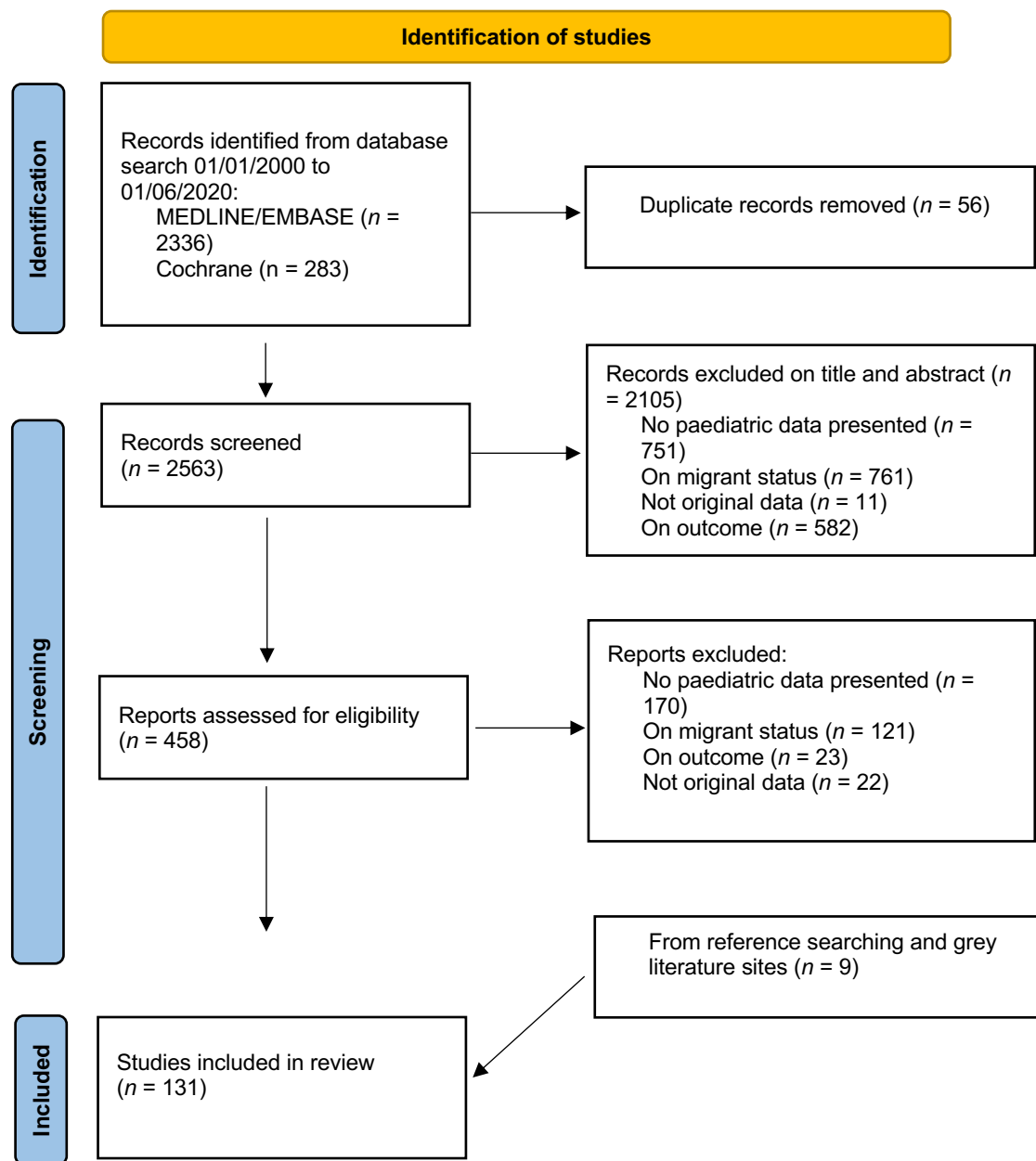
1. Critically appraise global original quantitative research on communicable diseases among migrant CYP
2. Compare results to CYP in the host population where data were available. Where there was no control group or the control group were another migrant group, the studies were included in the quantitative narrative synthesis.
3. Undertake meta-analyses of measures of communicable diseases where sufficient data are available.
4. Interpret these results to identify gaps in the literature and implications for future research and policy.

4.3 Results

4.3.1 Summary of results

I searched the Cochrane library, Medline and Embase databases on 01/06/2021 using the defined search strategy with date range 01/01/2000 onwards. The search strategy yielded 2619 articles of which 56 were duplicates. Of 2563 articles screened, 2105 were excluded on title and abstract; 458 full texts were assessed for eligibility of which 122 met the inclusion criteria. Screening was undertaken by another reviewer, Beth Stinchcombe, supervised by me. I undertook spot checks of screening decisions and we had regular meetings where I made the final decision on which studies to include. I identified a further 9 articles from reference searching and from grey literature sites giving a total of 131 included articles. Study details including demographic and outcome data were entered into a data extraction tool in Excel. Data extraction was completed jointly by myself and Beth Stinchcombe. I carried out the analysis and interpretation (see Figure 7 - PRISMA flow diagram for full details). STATA 17 software was used for meta-analyses and to produce forest plots.

Figure 7. - PRISMA flow diagram communicable diseases results



4.3.2 Characteristics of included studies

A total of 131 studies met inclusion criteria, with most from high income countries (according to the World Bank income classification(132)), 121/131 (92%), with 9/131 (7%) from middle-income countries and only one from a low income country (1%). The most frequent settings for studies were the USA (n=25), Australia (n=15) and Canada (n=15).

The most common communicable disease addressed in studies was Tuberculosis (TB), either active, latent or both; Over half of the studies were only on TB infection

(73/132, 55%), and a further 21 included TB as one communicable disease of several addressed. Other common topics were parasites (31 studies) and Hepatitis B (30 studies). Only one study addressed Covid-19 among migrants.

All studies were observational, often with low methodological quality and lacked control groups. There were a total of 111 cohort studies, 19 cross-sectional studies and 1 case control study. Of the cohort studies, 32 used disease registry data (e.g. national TB registry), 17 used migrant registry data (12 regional and 5 national), and one presented data from an international disease surveillance system. Of the remaining cohort studies, 38 were multicentre and 24 were single-centre. Of all studies, 50/132 (39%) presented some data for the host population, representing the control or comparator group; however, this was often the proportion of the national disease burden among the host and migrant populations, without a denominator or rate given, limiting interpretation.

I used the NOS score to explore the quality of included studies with a control group (displayed in table 7 and table 8). In presenting the results, I have grouped according to type of infection. Studies which presented IRR (or sufficient information to derive this) were pooled for meta-analysis. Outcomes measures for all studies are presented in tables 9,10, and 11 below.

4.3.3 Infection-specific results - Tuberculosis

In total, 94 studies presented data on TB among migrant children, of which 36 (38%) presented some data for a control group. All studies where incidence or prevalence were presented for both migrant children and the host population showed higher rates of TB among migrant children.

There were 15 comprehensive studies, of which 8 presented data allowing calculation of incidence rate ratios (IRR) for TB between migrant children and the host population. Where studies were not amenable to meta-analysis this was either due to the outcome measure (cumulative incidence, clustered and non-clustered incidence) or results presented by subgroup of migrant or host without sufficient information to combine these. Results from the comprehensive studies are presented in tables 7 and 8, with meta-analysis in figure 8. Of the other 79 studies, where an outcome measure for migrant children was presented these data are presented in tables 9, 10 or 11, depending on the outcome measure. Where studies allowed meaningful interpretation, these are included in the narrative synthesis below. Where two publications presented the same, or similar, data the most comprehensive is shown.

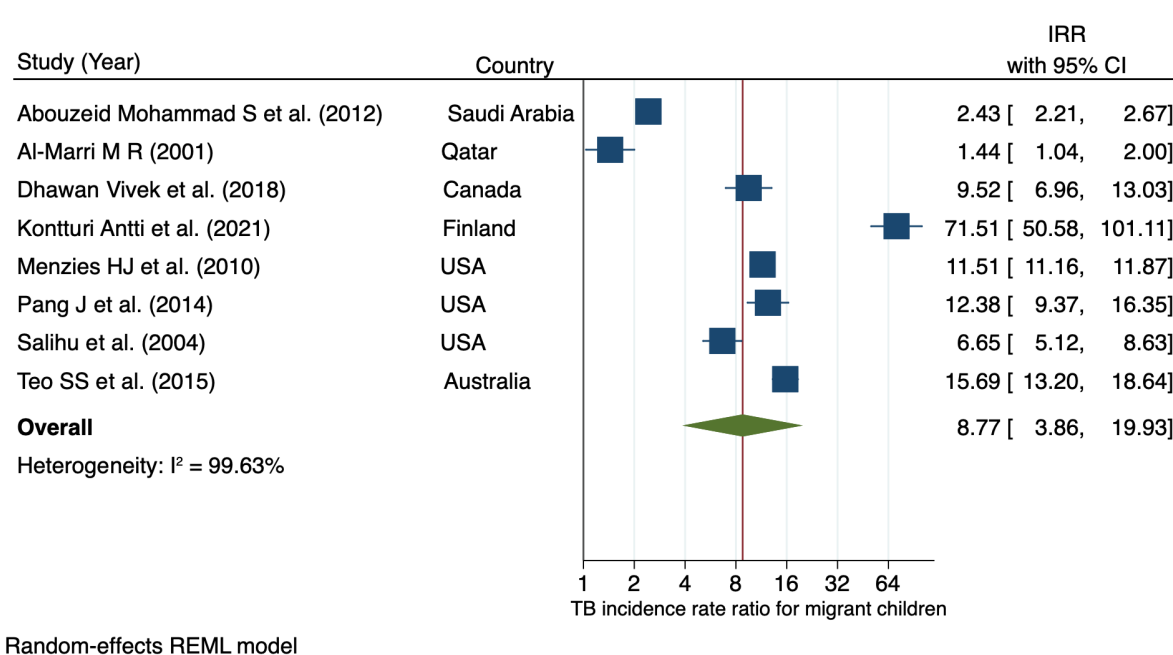
Eight studies of active TB among migrant CYP were included in the meta-analysis (figure 8), and these studies are summarised in Table 7. All studies scored 7/8 for

quality on NOS scoring. All studies lost a point due to not controlling for factors such as age and sex between migrant and host populations. It is also not possible to say that the sample was truly representative due to not including undocumented migrant CYP, see Appendix 4 for full details of NOS scoring. There was very high heterogeneity between studies, as reflected by the I² statistic of 99.63%. The pooled estimate should therefore be interpreted with caution, but the forest plot is a visual representation of the spread of incidence rate ratios (IRR) between studies.

Table 7. – Studies included in the meta-analysis, active TB in migrant children

Study (year)	Country (Host)	Definition or subgroup of migrants	Age range	Dates of data collection	Type of study	Quality NOS score
Abouzeid Mohammad S et al.(176)	Saudi Arabia	'Non-Saudi' (No further definition)	<15	2000-2009	Cohort study from national TB registry using census data for population	7/8*
Al-Marri M R(177)	Qatar	'foreign-born'	0-14	1983–1996	Cohort study from national TB registry with national data for population	7/8*
Dhawan Vivek et al.(178)	Canada	'foreign-born' (although foreign-born to Canadian parents are considered Canadian)	0-14	1990-2013	Cohort study from regional TB registry with census data for population	7/8*
Kontturi Antti et al.(179)	Finland	'foreign-born'	0-14	1995-2015	Cohort study from national TB registry and population register	7/8*
HJ Menzies et al(180)	USA	'foreign-born'	<18	1994-2007	Cohort study from national TB registry using census data for population	7/8*
Pang J et al(181)	USA	'foreign-born'	<5	2005-2006	Cross-sectional study across 20 US sites (TB surveillance) with census data for population	7/8*
Salihi Hamisu M; (182)	USA	'foreign-born' (although foreign-born to one US parents is considered US born)	<15	1993-1999	Cohort study from regional TB registry with census data for population	7/8*
Teo SS et al.(183)	Australia	Born overseas	<15	2003-2012	Cohort study from national TB registry using resident population data	7/8*

Figure 8. – Incidence rate ratio of active TB among migrant children



All studies show an IRR >1 for migrant CYP, which varies between 1.44 and 71.51. Pooled estimate for active TB IRR among migrant children is 8.77 (95% CI 3.86-19.93). Only one study from the US presented incidence rates broken down by age for both migrant children and the host population(180). These results showed the highest incidence rates in the youngest age group of migrant children, 32.2 per 100,000 person-years in children under 1 year. However, the largest IRR was in the adolescent age group: 18.75 (95% CI 17.7-19.86). I derived a summary statistic for IRR across all paediatric age groups from available data in this study: 14.25 (95% CI 11.26-18.03). This IRR is included in the meta-analysis above.

The remaining seven comprehensive studies (summarised in table 8) used national or regional registry data or databases and therefore included all (or a representative sample of) migrant children during the study period. Five of these studies presented outcome measures for the migrant and host CYP groups allowing direct comparison, including incidence rates, incidence rate ratio and cumulative incidence; these results are summarised in table 8. The remaining two studies did not present outcome measures allowing direct comparison between migrant and host populations. One was surveillance data of active TB across 27 countries, and another presented incidence rates for all migrant CYP to the UK from TB registry data. I have presented this with available data for UK-born CYP in the same period(184). Given their size and relevance these two studies are presented in more detail to support the overview of existing data. Quality of studies was explored using the NOS scoring tool, scores are shown in table 8, see Appendix 5. for full details NOS scoring.

Table 8. – Comprehensive studies of active TB incidence, including TB lymphadenitis, not included in meta-analyses.

Study (year)	Country (Host)	Definition or subgroup of migrants	Age range	Dates of data collection	Type of study	Results (95% confidence intervals)	Summary of results	Quality NOS score
Baker Brian J et al.(185)	US	Mexico-born and foreign-born other	<15	2005-2010	Cohort study from national TB registry and survey data for population	Incidence rates per 100,000 person-years Age <15 Non border states Mexico-born 5.5 FB other 9.4 US-born non-Hispanic 0.5 US-born Hispanic 2.5 Border states, non-border areas Mexico-born 5.0 FB other 7.1 US-born non-Hispanic 0.8 US-born Hispanic 1.9 Border states, border areas Mexico-born 8.9 FB other 6.9 US-born non-Hispanic 0.3 US-born Hispanic 4.3	Much higher rates of TB among migrant children compared with host population. About 20 times higher	7/8*
Chemtob Daniel et al(186)	Israel	'foreign-born' from Ethiopia, the former soviet union (FSU)	0-17	1990-1999	Cohort study from TB registry with demographic data from the Central Bureau of Statistics and from the Ministry of Absorption	Cumulative incidence rates/100,000 (over 10 year study period) Migrant children from Ethiopia 0-4 984.8 5-14 733 Migrant children from FSU 0-4 14.4 5-14 22.9 Jewish Israeli (host) 0-4 5.7 5-14 3.4 Arab Israeli (host) 0-4 6.0 5-14 3.5	The majority of paediatric TB in Israel is from Ethiopian migrant children. Rates over 100 times higher than host groups. Migrant children from FSU approx. double rates of the host population. Overall younger children have higher rates.	7/8*
Cook Victoria J et al(187)	Canada	Foreign-born	0-14	1990-2000	Epidemiological study from regional TB registry with census data	Incidence rate ratio 22.58 (95% CI 6.37-80.01)	Much higher rates of TB lymphadenitis among migrant children	7/8*
Kamper-Jorgensen et	Denmark	Foreign-born	0-19	1992-2006	Retrospective TB register-	Incidence rate per 100,000 person-years 0-19	Much higher rates of both clustered and non-clustered TB among	7/8*

al.(188)					based study linked with nationwide genotyping, laboratory, and notification data	Clustered TB Foreign-born 23.6 Host 0.4 Non-clustered TB Foreign-born 18.6 Host 0.1	migrant children 50-100 times higher	
Long R et al(189)	Canada	Foreign-born (although foreign-born to Canadian parents are considered Canadian)	0-14	1989-1998	Epidemiological study from TB registry with census data	Incidence rate per 100,000 person-years (data derived from graph) 0-14 Foreign born M 6.91 F 11.86 Canadian born M 0.5 F 0.83 'Treaty' Canadian (Indigenous population) M 23.44 F 21.84	Migrant child TB rates approx. 15 times that of host population, however, lower than indigenous groups	7/8*
Sandgren et al(190)	Sweden (but Europe-wide data)	Foreign-born	0-14	2000-2009	Descriptive analysis of surveillance data from across Europe (27 countries)	No rates (authors note lack of reliable foreign-body population figures for denominator)	15.3% of all paediatric TB in Europe in migrant children Greater proportion of foreign-born TB in low incidence countries compared with high incidence	6/8*
Aldridge, Robert W., et al.(191)	UK	Foreign-born (from 15 high-risk countries)	<15	2006-2013	Cohort study of migrants from high incidence countries screened for TB linked to UK TB registry data	Incidence rate per 100,000 person-years for migrants to UK screened before entry 101 (95% CI 77–132)	For reference, England rates in <15 over this period are between 3.5-5.0(184), i.e. migrant children from high risk countries have approx. 25 times the risk.	5/8*

The seven studies presented in table 8 were exclusively from high income countries and showed consistently significantly increased incidence of active TB among migrant children compared with the host populations. An Israeli study showed migrants from Ethiopia had much higher rates than migrants from the former Soviet Union(186); and in the US, Mexican-born migrants had slightly lower rates than other migrants, except along the Mexican border, where the trend was reversed(185). Europe-wide data suggests that migrant children contributed a greater proportion of TB in low-incidence countries than high-incidence countries(190), and that, within TB diagnoses, unknown site of disease was more common among migrant children(190). Host subgroups had different risk profiles for TB and in one case a host subgroup, indigenous children in Canada, had a higher TB incidence than migrant children(189). A Canadian study showed TB lymphadenitis was significantly

more common among migrant children(187), with a greater risk difference than is shown for all TB in another Canadian study from a similar time period(189). Of note, none of these studies addressed outcomes among undocumented migrants.

Six studies presented data on all cases of paediatric active TB in a region or country (140, 192-196) (but without denominators from population data, therefore no rate comparison was possible between migrant and host populations). In five of these studies more than half of the TB reported was among foreign-born children (87%(192), 59.4%(140), 53.1%(193), 78%(195) 61%(196)), with lower proportions in a Spanish regional study (19%)(194). Among these, two studies presented data on genotyping of TB; both showed that most migrant children were becoming infected with TB overseas rather than in the host country(193, 196). A study from the Netherlands showed migrant CYP with TB were more likely than the host population to be lost to follow-up, odds ratio 1.45(95% CI 1.03-2.03), more likely to have unfavourable outcomes (OR 1.58 (95% CI 1.23-2.03)) and that the highest risk of unfavourable outcomes were among illegal immigrants (aOR 5.10, 95% CI 2.15–12.10)(140). An Australian regional study with data for age brackets showed that the proportion of reported active TB among migrants increased throughout childhood (Age 0-5: 43%, age 6-10: 70%, age 11-15: 83%, age 16-20: 85%)(195). A Swedish study showed the majority of paediatric TB presenting in migrant children from the horn of Africa, particularly Somalia(196). A Spanish study presenting nation-wide data on paediatric HIV-TB co-infection showed an increasing proportion of disease among migrant children over time (1995-1999 0%, 2000-2009 8% and 2010-2016 67% (P = 0.0001)) and a greater extra-pulmonary TB rate in foreign-born children (42.9% vs. 33.3%, P = 0.035) (197). 3/6 cases of MDR TB in this group were in migrant CYP.

A single centre (referral centre) study in Spain presented data on paediatric pulmonary TB over a 30-year period and demonstrated that over time the proportion of TB seen in migrant children was increasing (2% in the period 1978–1987, 6% in 1988–1997, and 46% in 1998–2007 (P < 0.001))(198). A US study (included in meta-analysis above) also showed evidence of ‘re-emergence’ of paediatric TB, after a period of decline, with most TB occurring in migrant children(182).

Latent TB infection (LTBI) studies

A comprehensive study from Greece presented rates of LTBI for migrant and host children based on positive TST (primary school screening of all children)(199). Rates among both groups decreased over time but overall migrant children were more likely than the host population to have a positive TST, RR 3.76 (95% CI 2.89–4.84). Other studies with control groups addressing LTBI had a non-representative sample of the host population, commonly second-generation migrants or TB contacts, limiting the interpretation of these data. A Swiss study showed no significant

difference in rates of LTBI (diagnosed on TST) by migrant status (OR 1.087 (0.197-5.88)), but the host population in the study consisted of children of migrants and those screened as part of TB contact tracing(200). There were no other studies of LTBI where a representative sample of both the host population and migrant CYP had been screened.

TB studies (active and latent) without control groups

There were multiple small cohort studies without control groups in various groups of migrant children presenting prevalence rates of either latent TB (LTBI) or active TB infection. LTBI prevalence varied between 2.7% and 40.7% depending on migrant subgroup, year of study, host population, and method of diagnostic testing. Full results are shown in table 9. Prevalence of active TB ranged from 0% to 1.7%. Higher rates of TB were seen in more vulnerable groups of forced migrants, such as unaccompanied asylum-seeking children, and among migrant children from Africa. Of note, older studies generally used TST to diagnose latent TB, whereas newer studies typically used IGRA testing. Some studies compared these diagnostic tests and demonstrated much higher rates of positivity for TST compared with IGRA(201, 202) (now the gold standard), suggesting LTBI was likely to be significantly over-diagnosed in earlier studies.

4.3.4 Infection-specific results – Hepatitis viruses

A total of 30 studies presented any data on hepatitis among migrant CYP. Hepatitis B was addressed more frequently than hepatitis C, and many results were communicable diseases screening for a range of diseases in a small cohort of migrant CYP.

One German regional study presented IRR of active Hepatitis B (IgM-anti-HBc positive). Results showed an IRR for migrant CYP aged 0-20 of 8.40 (95% CI 5.68-12.43). Authors also break down results by five-year brackets, with the highest rate ratio among children 10-15.

A single (referral) centre study from Australia showed that the majority of paediatric Hepatitis B infections were identified among foreign-born children (76%)(203). An Australian study using electronic medical records for a region showed most paediatric Hepatitis B (64/79, 81%) among migrant children but the opposite trend for Hepatitis C (5/29, 17%)(204).

The remaining 27 studies presenting hepatitis data did not have a control group and most were small studies; prevalence of Hepatitis B (usually diagnosed by blood tests for Hepatitis B surface antigen) ranged from 0-7.9%, see table 9 for full results. The largest dataset was from a US study of refugee arrivals across several states (n=12,249 refugee CYP); Hepatitis B rates in refugee children were 0.9% among age

0-5 and 2.9% among age 6-18(205). There was some evidence that rates of Hepatitis B were higher among migrant children from African countries(206).

4.3.5 Infection-specific results – Parasitic infections

A total of 37 studies presented data on any kind of parasitic infection and almost all had no comparator group, likely due to parasitic infection rates being extremely low in most high-income countries. One Qatari study presented rates for Qatari residents as well as migrants, although the study population was taken from hospital inpatients (i.e. not a representative sample). This study showed (in graphical form) higher rates of all parasitic infection among migrant children from Africa, Asia and the Arabian peninsular (approx. 10% prevalence), with low rates among migrant children from the Eastern Mediterranean and host population (approx. 5% prevalence). Rates of any parasitic infection in migrant groups without control groups ranged from 2% to 50%, see table 9 for all included results. High rates were shown in forced migrant groups such as refugees (31.3%(207)) and unaccompanied minors (29.9%(208)) but also in migrant groups presumed to be less vulnerable, such as international adoptees(24.4%(209)). A Spanish study of a screening program for all immigrant minors showed 47.1% were positive for at least one parasitic infection (most commonly Strongyloides, Filariasis and Schistosoma), with 20.6% being infected with two or more; rates were higher among migrant CYP from Sub-Saharan Africa (57%) compared to the Northern African (27.9%) or Latin American (28.5%) patients ($p < 0.001$)(210). Two studies focussing on younger age groups showed rates of parasitic infections of 15% in refugees <5 years in New Zealand(211), and immigrant and refugee children arriving in Canada age <6 had rates of 33.6%(212).

Three studies cited scabies infection as the most common parasitic infection among migrant children(213-215). However, scabies is diagnosed clinically rather than having a diagnostic test, limiting consistency between studies and screening potential. Several studies demonstrated higher rates of parasitic infections among migrants from sub-Saharan Africa(206, 210, 216, 217). There was some inconsistency between studies due to definitions of a positive result (eosinophilia, serology samples or microscopy) and inclusion of parasites such as Blastocystis (of unclear clinical significance) and H.pylori infections.

4.3.6 Infection-specific results – All other infections

An American study on paediatric HIV from national surveillance data found that about half of cases diagnosed under age 13 were in migrant CYP (55.8%), but for age 13-19 only 8.5% of newly diagnosed HIV was among migrant CYP(218). Some included studies addressed rarer, tropical diseases, usually in small cohorts in high income countries. In one study in Canada on typhoid, 12/39 cases (31%) were among foreign-born CYP, but all associated with recent travel(219), with similar

results from a study in Australia (51% of cases foreign-born CYP)(220). A Turkish study on Cutaneous Leishmaniasis found that 14/16 cases (88%) were among migrant CYP. An Italian study on Malaria found that migrant children represented 46.5% of cases and that recent migrants recovered more quickly(221). One study reported on a Cholera outbreak on the Thai border with Myanmar with higher rates among Myanmar refugee children(222). A large pilot study in the US tested refugee children for Sexually transmitted diseases (STDs) showing low rates of positivity (no Chlamydia or Gonorrhoea identified; Syphilis in 0.22% and HIV in 0.42%)(223).

One study presented data on Covid-19 among migrant CYP(224). The study was set in Norway and the study population included those who have personal identification numbers, which includes most migrants (but would not include short-term tourists, workers or undocumented migrants). Data were presented for all notified cases of Covid-19 from the start of the pandemic until 18th October 2020. From the graph, migrant children aged 0-19 had a higher incidence of Covid-19 (about 1.6 time higher) than the host population.

Table 9. – Prevalence of communicable diseases among migrant CYP

Authors	Migrant population	Country	Universal screening	TB (all)		HBV	HCV	Syphilis	HIV	Scabies	Parasitic (any)	Schisto	Blastocystis	Giardia	Strongy	Diphtheria	Filariasis
				LTBI	Active												
Armitage A J et al.(4)	UASC	UK	Yes	25%		6%	0%		0%			13%					
Banfield Sally et al.(225)	Refugees	Australia	Yes	9.9%													
Barcellini L et al.(226)	Refugees	Italy	Yes	24.6%													
Belhassen-Garcia Moncef (227)	Immigrant children	Spain	Yes (implied)								17.7%						
Belhassen-Garcia Moncef (228)	Immigrant children	Spain	Yes (implied)	12.7%	1.1%	4.3%	2.3%	1.5%									
Belhassen-Garcia Moncef (210)	Immigrant children	Spain	Yes (implied)								47.1%	18.4%		6.9%	22.5%		36%
Bennet R et al.(229)	UASC	Sweden	No (but most)	9.5%	0.8%												
Boukamel M et al.(230)	Newly arrived migrants	Switzerland	Yes	6.3%	0.4%												
Buonsenso D et al. (209)	International adoptees	Italy	Yes								24.4.%						
Chironna M et al.(231)	Refugees	Italy	Yes			< 10 – 1% 10-20 – 2.3%	< 10 – 1% 10-20 – 2.3%										
Colgan K et al.(232)	Refugee and AS	Australia	Yes	11.9%	0%												
Eder K et al. (214)	UASC	Germany	Yes	30.9%	1.7%	7.7%			0.4%	14.2%							
Epstein R L et al(233)	Refugee and AS	USA	Yes	6.3%													
Esmaili E et al. (234)	Refugees	USA	No	5%		1.2%			0%		2%*						
Fontanelli Sulekova et al.(235)	Newly arrived migrants	Italy	Yes								50%**						
Genton et al.(213)	UASC	Switzerland	No		3.7%	2.8%				20.2%	1.8%						
Goodman et al.(215)	UASC	Germany	Yes		1.2%				0%	2.9%							

Heenan et al.(236)	Syrian and Iraqi refugee	Australia	For some conditions	11.8%		0%	0%		0%			0%			0%		
Huerga H et al.(237)	Symptomatic migrants	Spain	No	13%		6.7%	1.7%			6.4%	49.4%						31.2%
Laukamp et al.(238)	UASC	Germany	Most			4.2%				4.2%	8.7%			5.3%			
Marquardt L et al.(216)	UASC (UASA)	Germany	No		1/102 (1%)	8/101 (7.9%)				2.9%	19.6%	8/44 (18.2%)					
Martin JA et al.(239)	Refugees	Australia	Yes	27%													
Minodier Philippe et al.(240)	Immigrant children	Canada	Yes	22.8%													
Mitruka K et al.(205)	Refugees	US	Yes			0-5 0.9%, 6-18 2.9%											
Mockenhaupt FP et al.(241)	Syrian UASC	Germany	Yes			0%				0.6%	22%	1.4%	12%	7%			
Mueller-Hermelink M et al.(242)	Asylum seekers	Germany	Yes	6%	0.8%												
Ohd J et al.(243)	AS	Sweden	Yes	0-12 5% 13-19 19%													
Olivan-Gonzalvo G(244)	UASC	Spain	Yes	9.6%		2.6%	0%	0%	0%	0.6%	2.3%						
Pavlopoulou Ioanna D et al.(245)	Migrant children (mostly refugees)	Greece	Yes	2.7%		0%											
Paxton GA et al.(207)	Karen refugees (Myanmar)	Australia	No	15.9%		4.9%					31.3%	4.6%		22% of <6yr	11.7%		
Pohl C et al.(246)	Refugee and AS admitted in hospital	Switzerland	No			1.1%				3.2%		4.3%				2.2%	
Quddus A et al.(247)	Afghan refugees	Pakistan	Yes			5.6%											
Redditt VJ at al.(248)	Refugees	Canada	No			1.2%	0.6%		1.1%		21%	4.2			3.1%		
Rungan S et al.(211)	Refugee <5s	New Zealand	Yes	15%	0%	1%	0.6%	0%	0%		15%	4%					
Salehi L et al.(212)	Refugees <6	Canada	No			2.5%			0%		33.6%						
Sandell A et al.(249)	Refugees (2 cohorts)	US	No (but most)	14.6% 22.7%		3.8% 0%	0% 0%						41.6% 33.2%	22.4% 12.4%			

Sheikh M et al.(206)	Refugee	Australia	No	33%		4%						16%					5%
Stauffer WM et al.(223)	Refugees	US	No					0.2%	0.4%								
Taylor EM et al.(250)	All immigrants	US	Yes	12%													
Thee S et al.(251)	UASC	Germany	Yes	13.9%		7.9% (only LTBI pt)											
Theuring S et al.(208)	UASC	Germany	Most			1.7%				1.4%	29.9%	5.2%		7.6%			0.4%
Trauer JM et al.(252)	Refugee	Australia	Yes	<5 8.2% 5-14 19.2%													
Varkey P et al.(253)	Refugees	US	Half								<5 25% 6-18 24.4%						
Varkey P et al.(254)	Refugees	US	Most	<5 17% 6-18 40.7%	<5 0.3% 6-18 0.8%												
Wendorf KA et al.(202)	Refugees <5	US	Three quarters	4%													
Williams B at al.(255)	UASC	UK	Most	22%	1.2%	4.8%	0.5%		0%			16%		8.6%			
Wong YJ et al.(256)	Refugees	Malaysia	Yes	12.8%													

* Presumptive pre-treatment given for parasites

** Only 12 children total

Table 10. - Incidence of active TB among migrant CYP (rates per 100,000 person-years)

Authors	Migrant population	Country	Active TB
Marks G B et al.(257)	Refugees	Australia	age <2 38.5 (12.3-89.0), 2-9 26.1 (12.9-46.4), 10-19 60.3 (41.8-83.4)
Ospina JE et al.(258)	All immigrants (three time periods)	Spain	1991-1999 Age 0-9: 52, 10-19: 103, 2000-2005 Age 0-9: 59, 10-19: 63 2006-2013 Age 0-9: 33, 10-19: 60
Langlois-Klassen D et al.(259)	Immigrants	Canada	7.9
Panchal RK et al.(260)	Immigrants in leicester	UK	<16 years 45.4 (25.4 to 74.9)
van Burg JL et al.(261)	Asylum-seekers	Netherlands	49
Vos AM et al.(262)	All immigrants	Netherlands	13

Table 11. - Incidence of active TB and HBV (rates per 100,000 person-years) among migrant CYP and the host population

Authors	Migrant population	Country	Active TB		HBV	
			Migrant incidence rate	Host incidence rate	Migrant incidence rate	Host incidence rate
Aldridge RW et al.(191)	Migrants (pre and post migration)	UK	12 (4–38)	Pre-migration: 101 (77–132)		
Abouzeid MS et al.(176)	Non-Saudi	Saudi Arabia	5.24	2.16		
Al-Marri MRH et al.(177)	Foreign born	Qatar	11.4	7.9		
Cook VJ et al.(187)	Foreign born	Australian	5.08 (TB lymphadenitis)	0.13 (TB lymphadenitis)		
Dhawan V et al.(178)	Foreign born	Canada	9.29	0.54		
Diel R et al.(263)	Immigrant	Germany			2.9 / 12.9 / 24.2 / 55.8	0.6 / 0.7 / 0.7 / 10.2
Menzies HJ et al.(180)	Foreign born	US	<1 32.3	<1 2.5		
			1-4 30.5	1-4 2.8		
			5-12 10.8	5-12 0.7		
			13-17 15.0	13-17 0.8		
Pang J et al.(181)	FB	US	24.03 (16.2131.85)	1.94 (1.64-2.24)		
Teo SS et al.(183)	FB	Australia	9.57 (8.51-10.73)	0.61 (0.53-0.69)		

4.4 Discussion

4.4.1 Key findings

This comprehensive systematic review yielded a high number of studies of communicable diseases among migrant CYP, predominantly among forced migrant groups arriving in high-income countries. However, there was a paucity of high-quality studies presenting comparative rates among migrant and host populations. All studies with control or comparator groups show higher rates of communicable diseases, particularly active TB, among migrant CYP, with the highest rates among migrant CYP from Africa. Most studies were on TB, and significantly increased rates of active TB were demonstrated in migrant children compared with the host population (pooled estimate of IRR 8.77 in meta-analysis). There was some evidence that migrant children in the host country were more susceptible to epidemic infections and had worse outcomes once infected. Incidence rate differences in childhood were highest in the adolescent age group in two studies, and several studies showed the adolescent group of migrant CYP having higher rates of communicable diseases than younger age groups of migrant CYP.

4.4.2 Strengths and limitations

This comprehensive systematic review is the first, to the best of my knowledge, addressing communicable disease outcomes among all migrant CYP (who have themselves migrated). The search strategy was thorough, but the majority of screening was done by a single reviewer (with spot-checks and oversight by myself) rather than the optimal standard of dual screening. The conclusions are limited by studies being predominantly from high income countries and very few studies including undocumented migrants. The definition of migrants or migrant subgroup, and age-range of included children, was inconsistent between studies, limiting comparison. Although a large number of studies were identified, there were relatively few that presented data on a complete or representative sample of migrant children, with data on rates for both migrant children and the host population. A common type of included study presents data for all TB cases in a region or country but without denominator figures or incidence rates, limiting conclusions that can be drawn. The NOS tool is not applicable for studies without control or comparator groups; this tool was also limited in its application when studies did not fit with conventional methodology for study type, e.g. longitudinal case series. It was therefore not possible to formally assess the quality of many studies included.

The most common subject of included studies was TB, and a meta-analysis was performed for incidence rate ratios for active TB among migrant children. There was very significant heterogeneity in these results, limiting the interpretation of the pooled estimate. Systematic review results among groups of adult migrants found similar levels of heterogeneity between studies(264). This is explained by several factors: in

most of the world, paediatric TB rates have decreased over time, meaning later studies typically have lower incidence rates. There are significant differences in host country incidence rates of TB, and the profile of the migrant population varies significantly between high income countries. TB diagnosis in children is challenging and techniques have advanced rapidly in recent years(265), older studies are likely to have used different diagnostic techniques, causing further inconsistency in outcome measures.

4.4.3 Interpretation and consistency with existing literature

The finding of higher rates of communicable diseases among migrant CYP, with no evidence of the health migrant effect, is consistent with literature on adult migrants(7, 266). However, these results should be interpreted in the context of high-income settings with migrants typically from countries with higher rates of communicable diseases. Approximately a third of global migration is between low and middle-income countries (LMIC), and three quarters of forced migrants globally are in LMIC(9); included studies therefore do not reflect this group. Lack of data on undocumented migrants and on migration between LMIC is consistent with systematic review findings from adult migrants(11). The increased rates among migrant CYP may therefore reflect rates in country of origin and not migrant status itself. Existing literature indicates that infections such as TB, viral hepatitis and HIV in migrants reflect rates in country of origin but that poor living conditions following arrival also contribute(267).

Rates of communicable diseases appear to be higher among forced migrant CYP, providing more evidence that the circumstances of migration and conditions following arrival contribute to the risk profile. This systematic review identified several studies where migrant and host populations have supposedly the same exposure to an infection but higher rates were observed among migrant CYP (Covid-19 and Cholera)(222, 224). This is consistent with evidence among Syrian refugees showing rising rates infections in under 5s over time as the emergency situation continued(268). Two studies showed high rates of typhoid among migrant CYP(219, 220). Qualitative research suggests that migrant populations may not routinely seek medical advice prior to short-term travel back to their country of origin(269), presenting a particular risk to CYP, who are more susceptible to these illnesses.

Rates of TB, both active and latent, were significantly higher among migrant CYP, consistent with review evidence from the adult population(264). There was considerable variation in TB rates among migrant CYP by host country, this is likely to vary with TB rates in host country, age of migrant children and years of data collection. The epidemiology of TB in high-income countries is largely determined by immigration; several studies showed a large proportion of all paediatric TB was among migrant children, and that this proportion was increasing over time. Where

data were provided, migrant CYP had higher rates of extrapulmonary TB(187, 190, 197), and were more likely to be lost to follow-up(140). Among migrant CYP, undocumented migrants had the highest chance of poor outcomes(140). A review of qualitative studies on TB in migrant populations highlights the ongoing stigma around the disease, barriers to seeking healthcare and poor understanding of latent TB status(270), factors which are likely to contribute to worse outcomes among migrant children. There was only one study presenting rates of LTBI in a representative sample of both migrant children and the host population(199). Recognition of LTBI as a public health problem warranting treatment is a relatively recent phenomena(265), and the current gold standard for diagnosis, the QuantiFERON test, replaced the tuberculin skin test (TST) which significantly overestimated proportion affected(201).

When data were presented for subgroups of migrant CYP and the host population there were significant difference in rate by subgroup. A key finding was increased rates of TB and parasitic infection among migrant CYP from Sub-Saharan Africa, which could reflect both rates in country and circumstance of transit for these migrants. In one study a marginalised subgroup of host CYP had higher TB rates than migrant children(189). Comprehensive research on migrant CYP in Europe indicates that differences between migrant groups are greater than those between migrant children and the host population(53), consistent with these results.

The risk profile of migrant children across childhood is difficult to interpret; many studies only provided data for a single age range with variable upper limit. Younger children are known to be at higher risk of TB(265) and parasitic infections(271). Disrupted healthcare access, malnutrition, lack of immunisations and exposure to at risk groups may all increase this risk. However, this review provides some evidence that risk difference may in fact be higher in the adolescent age range(180, 263), a group who are often neglected in policy and fall between services.

4.4.4 Policy implications and next steps

There are significant gaps in the research on communicable diseases among migrant children in LMIC. Similarly, there are very few studies that include undocumented migrant children in datasets.

There have been longstanding discussions around the need for asymptomatic screening programs for migrant CYP(38). Many high-income countries have had TB screening in place for several decades, although often only for adults or older teenagers(257, 265). Some communicable diseases screening is in place in many high-income countries for refugee and asylum-seekers, with several countries having an equivalent of the initial health assessment (IHA) in the UK. However, screening

recommendations for migrant CYP may not be followed (<10% adherence in Australia(236)), and trauma and mental health crisis may take priority acutely in vulnerable migrant CYP(267). The results of this systematic review include multiple small studies of forced migrant CYP with high rates of LTBI, parasitic infections and hepatitis, indicating a need for comprehensive asymptomatic screening programmes, at least among forced migrant CYP.

TB infection in migrant children is a concern, although overall rates in high-income countries remain low. The availability of blood testing for QuantiFERON offers an accurate and convenient screening opportunity for LTBI, which, if treated, no longer presents a risk of re-activation. However, compared with adults, a much larger proportion of TB in children, particularly younger children, is new infection rather than reactivation(190). Risk is therefore strongly correlated with transmission within the host country, although travel to country of origin and re-activation among adult migrants are likely to also affect this. Due to challenges of diagnosis in children and low rates overall, TB screening of all migrants may not be feasible. However, awareness of key symptom of active TB is necessary among all healthcare workers providing migrant services(265).

4.5 Conclusion

This systematic review includes data from 131 studies of communicable diseases among migrant children. The main result is of high incidence of communicable diseases among migrant children, particularly those from African countries. Despite significant heterogeneity of studies, incidence rates of active TB were high among migrant children in all data presented. Other conclusions include a high proportion of paediatric TB in high income countries from migrant children, with this proportion increasing over time. Adolescents may have the largest risk ratio for communicable diseases within the paediatric age-group. Migrant children are at increased risk of tropical diseases, due to travel back to their country of origin, and have higher risk from epidemic infections in the host country. Parasitic infections are high in multiple subgroups of migrant children. There is a lack of research on migrant children in LMIC and undocumented migrants.

These results support the need for comprehensive health screening for migrant children arriving in high income countries and the need to prevent barriers to healthcare access following arrival.

Chapter 5: Retrospective description and evaluation of an integrated pathway for UASC

Recognising the unmet physical, emotional and sexual health needs among UASC (see section 1.2.3) in some areas there have been attempts to provide more intensive and joined-up support for this group. As described, a method of optimising and standardising care is via an integrated care pathway (see chapter 1). There is a statutory requirement for all UASC to be seen within 20 working days for an IHA, but there is significant variation in how IHAs are undertaken and management of UASC by area (see section 1.2.4 for details). In the London borough of Camden, in response to an increase in numbers of UASC arriving from 2014 onwards, the community paediatrics team developed an “integrated pathway” for UASC from 2015.

With a view to meeting the second aim of my MD(Res), exploring how services could be better configured to meet the needs of migrant children, I undertook to describe this service and to collect and analyse data for a cohort of UASC engaging with this service over a 3-year period.

5.1 Research question and hypotheses

The research questions for this chapter are:

1. What are the key features of the integrated pathway for UASC.
2. What are the demographics, health needs and known outcomes of a population of London UASC engaging with this service.

The hypothesis is that UASC have additional vulnerabilities over and above looked-after children and therefore may require a more comprehensive and holistic service than is typically delivered at IHA. A secondary hypothesis is that new services can be implemented within existing NHS contexts and shown to deliver appropriate care.

Table 12. - Research question in PICOS format

i. Population, or participants and conditions of interest	Unaccompanied asylum-seeking children (UASC) recently arrived in the London borough of Camden engaged with the service from 01 January 2016 to 30 March 2019.
ii. Interventions or exposures	An “integrated pathway” for UASC.
iii. Comparisons or control groups	No control group
iv. Outcomes of interest	Data on demographics, unmet health needs and known outcomes.
v. Setting	Unlinked data were collected from three services across three National Health Service (NHS) trusts in London.
vi. Design	Description of the integrated pathway (research question 1) and retrospective evaluation, using data from community paediatrics, infectious diseases (IDs) screening and a sexual health (SH) service (research question 2).

5.2 Aims and objectives

This chapter aims to explore this novel “integrated pathway” model for UASC, with a view to investigating how best to configure services for this group; and to describe the demographics and health needs of a recent population of London UASC.

To achieve this, I will undertake the following objectives:

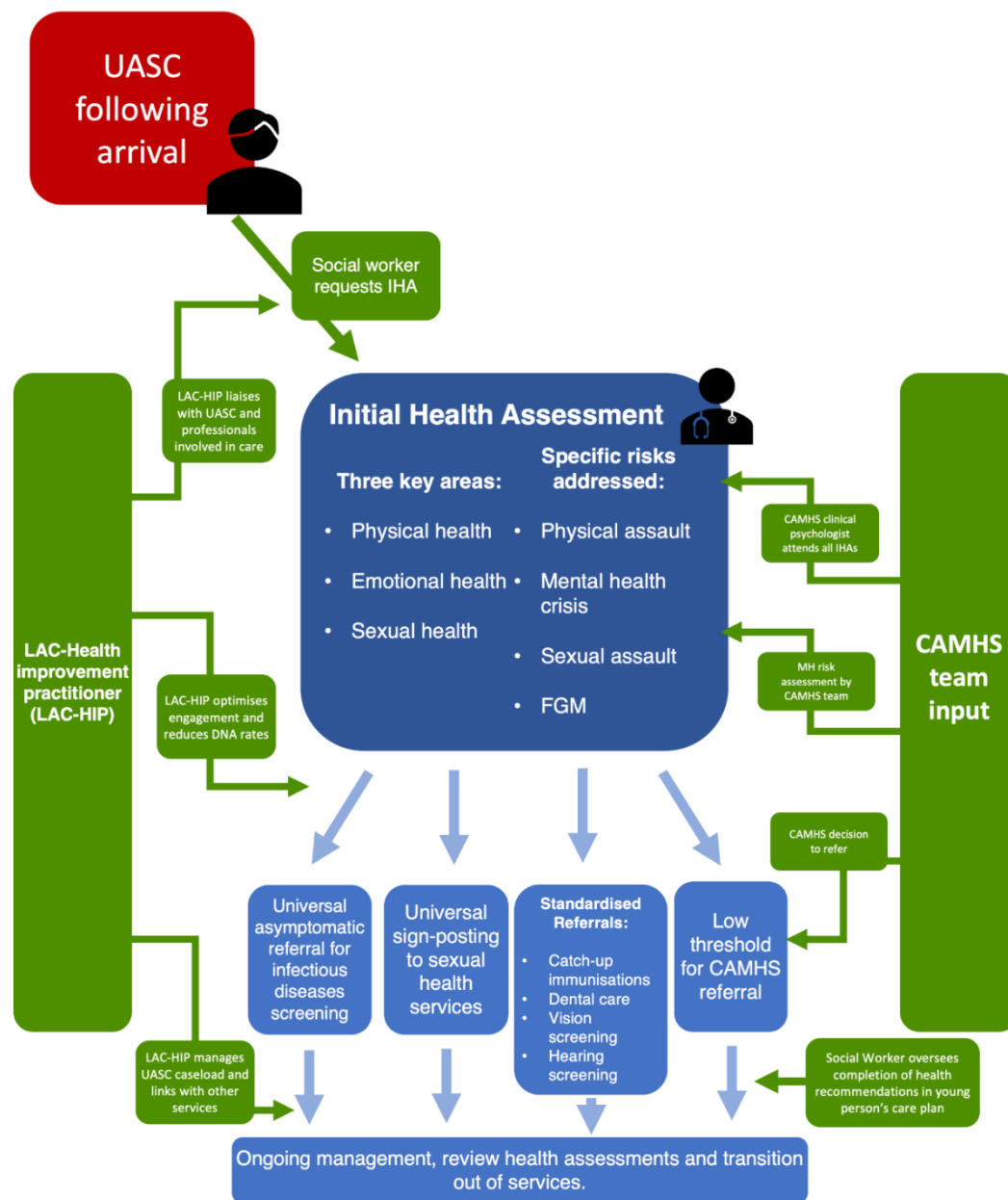
- 1) To provide a description of the integrated pathway model for UASC developed in a London borough
- 2) To present evaluation data from a population of UASC engaging with this service over a three-year period. These data will include the baseline and clinical characteristics, health needs and known outcomes collected from three different sources.

5.3 Methods

5.3.1 Description of the integrated pathway for UASC

The integrated pathway for UASC (see figure 9) was in place from early 2015 and was based around the statutory requirement of the IHA. It involved a multi-disciplinary approach and prioritised three key areas: physical, sexual and emotional health of UASC. A clinical psychologist from the Child and Adolescent Mental Health Service (CAMHS) team joined the paediatric doctor in the IHA and there was a low threshold for CAMHS referral after the appointment. Mental health symptoms including post-traumatic stress disorder, anxiety and depression as well as risk of self-harm and suicide were considered(272), and the Strengths and Difficulties Questionnaire (SDQ)(273) was used. After IHA, all UASC were referred for infectious diseases screening and signposted (provided with contact details and empowered to initiate contact with the service) to sexual health services, regardless of clinical presentation or risk factors. Specific risks were addressed in all appointments including historic physical and sexual abuse or assault, and female genital mutilation (FGM) for female UASC. Standardised referrals after IHA were made for vision screening, hearing screening, dental care and catch-up immunisations. A looked-after child (LAC) health improvement practitioner worked with the team liaising with UASC and the professionals around them (including the social worker) to optimise engagement with medical services and reduce missed appointments. Face-to-face interpreters were used whenever possible and appointments were re-booked if necessary to facilitate this.

Figure 9. – The integrated pathway for UASC



5.3.2 Study design, population and period

Study design: Retrospective observational study (service evaluation)

Inclusion criteria: UASC (Unaccompanied asylum-seeking children under the age of 18) seen during the study period at any of the three services in the borough of Camden. I included all UASC seen during the study period at these services. There

is a statutory requirement that all UASC presenting to authorities have an IHA with a month and social care are responsible for referring UASC to medical services.

Study period: 1st January 2016 until 30th April 2019

I chose these dates for the study period to reflect the population of UASC seen once the integrated pathway had been properly established until the last completed month prior to data collection.

5.3.3 Data sources, collection and analysis

Data sources: I collected data retrospectively from patient notes and electronic medical records from three services.

8. The Camden Community paediatrics service at the Royal Free London NHS Foundation Trust where IHAs took place.
9. The Paediatric Infectious diseases clinic at University College London Hospitals NHS Foundation Trust
10. The Archway Centre Sexual Health Clinic at Central and North West London NHS Foundation Trust

These three services are across three NHS trusts. This project was considered a service evaluation not requiring patient identifiable information sharing between trusts (which would require NHS research ethics committee approval). Data were therefore unlinked but were all defined as UASC in the borough of Camden during the study period. Due to statutory requirements for all UASC to have an IHA and the referral routes for the other services I believe these groups should be very similar. There may be small differences in the groups described at the margins of the study period due to time delays between appointments.

Data collection methods: I collected data from community paediatrics including IHA reports and any additional documentation available, such as letters and social care records. I accessed data via an electronic health record system, SystmOne. I accessed this on-site from computers in the trust where I held an honorary contract. I revised a data extraction tool used in a previous audit(274) to include additional detail, and entered data into an Excel spreadsheet in anonymised form.

I collected infectious diseases data from clinic letters and electronic medical records at UCLH with the aid of a spreadsheet identifying UASC presenting during the study period (populated by a clinical nurse specialist in the paediatric team). I accessed this on-site from computers in the trust where I held an honorary contract. I entered data into an Excel spreadsheet in anonymised form.

Sexual health screening data for UASC attending The Archway Centre Sexual Health Clinic were collected by Dr Chantal Oxenham, doctor in sexual health at North West London NHS Foundation Trust. These data were anonymised prior to exporting from the NHS trust.

Data analysis methods: I used excel spreadsheets to collection and analyse data. Data were anonymised prior to export from NHS trust as per service evaluation ethical guidance. I performed statistical analysis (calculations of percentages) using Microsoft Excel version 2016.

5.3.4 Demographics, clinical variables and outcomes

Demographic variables: Age, gender, country of origin, use of interpreter and language, type of accommodation, reasons for leaving country of origin, arrival in UK, circumstances of transit (including refugee camps) and contact with family. Where data was missing this was recorded.

Clinical variables: Past medical history, physical symptoms, mental health symptoms, history of sexual abuse or assault, history of physical abuse or assault, known vaccination history. Mental health symptoms including symptoms of trauma were recorded where they were documented by the assessing paediatrician. Clinical variables included weight and height, examination findings including scars and any signs of infection. Where data was missing this was recorded.

Outcomes: Results of a review health assessment (RHA) if undertaken, results and completeness of infectious diseases screening, results and completeness of sexual health screening and sexual health education given, onward referrals where recorded and attendance rates at scheduled appointments.

5.3.5 Ethical approval and considerations

Information and input on ethical considerations: I sought advice regarding the ethics and governance of this project from several sources including the Research Management and Governance Officer from the data protection team at UCL, the Public Engagement Manager for the School of Life and Medical Sciences and the Research ethics service for UCL. Prior to publication of the Camden UASC project I also sought advice from an editor at the journal around sufficient anonymisation and presenting small numbers of potentially identifiable characteristics.

Ethical conduct and oversight of projects not formally considered “research” is an area that I explore further in Chapter 7. Previously lacking in oversight there has

been increased focus and guidance published during the years that this project spans.

Ethical and governance framing: At the outset of this project, I investigated both the need for research ethics committee approval and the governance structures around this type of work. The NHS Health Research Authority (HRA) provide a *“Is my study research?”* online decision tool, based on the *“Defining Research”* table produced by the Research Ethics Service. If considered to be “research” in this context then formal NHS ethics committee approval is required and informed consent from participants would be required. According to the questions posed by the tool, this project would not be considered research by the NHS. This tool then provides a certificate which can be shared, including at publication stage.

With advice, I formally considered this project a service evaluation and I used service evaluation and audit governance approaches. An important ethical standard for non-research projects is that confidential patient information is not shared or exported outside the NHS trust. I therefore only accessed or collected identifiable information within an NHS trust and all data were anonymised prior to exporting. This meant that data were unlinked between NHS trusts meaning the population of UASC may not have been entirely consistent.

Anonymisation and confidentiality: Following data analysis and write-up I sought advice around presenting or publishing single or small numbers of diagnoses or characteristics that might risk identification of the individual. I was also aware of an ethical tension between the importance of reducing risk of identification in such a group, weighed against the importance of publishing on an under-researched and marginalised group. I was referred to the BMJ guidance on patient consent and confidentiality and their standards on anonymisation. Authors comment that *“true anonymisation” can never be 100% guaranteed* and acknowledge the need to *“balance between the protection of patient confidentiality whilst at the same time seeking to facilitate the serious communication of medical information”*(275). The BMJ recommendation around anonymisation is for only one direct identifier or no more than two indirect identifiers to be presented, and I therefore took this approach in write-up. With the journal editor I discussed the hypothetical risk that a young person might be able to identify themselves despite these measures. Given the paucity of available data on UASC health needs and the vulnerability of this group, we concluded that the benefits of publication outweighed the risks in this case.

5.4 Results

Data from IHAs were available for 101 UASC; one IHA was completed in absentia. Data were also available from 41 and 69 UASC from the same borough and study period seen at the local sexual health service and infectious diseases screening service respectively.

5.4.1 Community paediatrics data

Table 13 shows the demographic characteristics from the IHA data. Reasons for migration included fear of persecution (23/101, 23%), fearing for their lives following the death of family members (17/101, 17%), fleeing forced military service (17/101, 17%) and fleeing forced marriage (4/101, 4%). It was documented that 43/101 (43%) of the young people spent time in a refugee camp, most commonly the so-called 'Calais jungle'. Where information was available, 63/81 (78%) of UASC reported any duration of formal schooling in their country of origin, and 14/73 (19%) were currently in contact with their family back home. When the Red Cross tracing service was offered 5/101 (5%) of UASC refused, concerned that it might put their family back home in danger to have contact with them.

Table 13. – Clinical and demographic features reported at IHA

Clinical or demographic features	Number/ number of children with available data	Percentage
Male	85/101	84%
Age range (median, IQR)	14-17 (16, 2)	
Placed in foster care	32/101	32%
Placed in semi-independent accommodation	69/101	68%
Country of origin:		
- Eritrea	28/101	28%
- Sudan	16/101	16%
- Ethiopia	13/101	13%
- Vietnam	9/101	9%
- Afghanistan	8/101	8%
- Albania	8/101	8%
- Morocco	4/101	4%
- Syria	3/101	3%
- Other (Iran, Guinea, Algeria and others)	12/101	12%

Interpreter used (total)	87/90	97%
- Face-to-face interpreter	74/90	82%
- Phone interpreter	10/90	11%
- Foster carer translating	2/90	22%
Language spoken (where documented)		
- Arabic	22/80	28%
- Tigrinya	22/80	28%
- Oromo	9/80	11%
- Arabic	9/80	11%
- Other (Kurdish, Farsi, French, Pushto, Amharic)	18/80	23%
Mean BMI percentile (SD)	45.2 (26.1)	
BMI percentile <5% centile (underweight)	3/95	3%
Inconsistent name	13/101	13%
Inconsistent date of birth	11/101	11%
Date of birth beginning 01/01	15/101	15%

5.4.2 Mental and physical health symptoms

From IHA documentation, many UASC reported current physical and mental health symptoms at IHA. Common physical symptoms were body or limb pain (28/101, 28%), abdominal pain or gastro-intestinal symptoms (24/101, 24%), headache or dizziness (23/101, 23%), chest pain or palpitations (9/101, 9%) and symptoms of current or previous scabies infestation (11/101, 11%).

Three quarters (78/101, 77%) of UASC had any mental health symptom documented, mostly commonly sleep problems (50/101, 50%), signs of trauma or PTSD (43/101, 43%) and deliberate self-harm or suicide attempts (8/101, 8%).

Rates of physical and sexual assault and abuse, and examination findings are shown in table 14.

Table 14. - History of assault/abuse and examination findings

History or examination finding	Number/ number of children with available data	Percentage
History of physical abuse/assault	68/101	67%
History of torture	16/101	16%

Scars consistent with disclosures	55/101	54%
Evidence of harmful traditional practices	9/101	9%
Disclosure of sexual abuse/assault	13/101	13%
Disclosure of sexual abuse/assault (Female UASC)	6/16	38%
Suspicion of trafficking	12/101	12%
Suspicion of trafficking (Female UASC)	6/16	38%
Witnessed sexual abuse/assault	6/101	6%

When asked about hobbies or extra-curricular activities, many of the UASC described enjoying football 53/101 (53%) and swimming 11/101 (11%). CAMHS input was offered to 88/101 (87%) of UASC, of whom 20 initially declined, though some later consented to referral. 52/101 (51%) of UASC were directly referred to CAMHS, and a further 20 were signposted to services (provided with contact details and enabled to initiate contact with the service). Referrals for infectious diseases screening were documented for 93/101 (92%) of UASC and 52/101 (52%) were referred to sexual health screening while a further 36/101 (36%) were signposted. 9/101 (9%) of UASC were referred to specialised services for sexual abuse or assault.

5.4.3 Recorded outcomes

Records of a RHA (one year after IHA) were available for 26/101 (26%) of UASC. Other relevant documentation from social care or other health services was only available from a minority of young people. There were recorded examples of in-patient mental health admissions (2 cases), substance misuse (3 cases), police involvement (3 cases), break-down of placements (3 cases) and pregnancies among female UASC (2 cases). Commonly cited causes for psychological distress were pending asylum claims (3 cases) and the national transfer scheme (8 cases), whereby UASC are moved to accommodation in different boroughs to redistribute cost(276).

5.4.4 Infectious Diseases screening results

The infectious diseases service received 84 referrals for Camden UASC during the study period and data were available for 69 appointments, see table 15.

Only 60% of UASC attended for their initial appointment, but following attempts to optimise engagement a total of 71/84 (85%) UASC underwent infectious diseases screening in the service. In total 28/69 (41%) had an infectious disease warranting treatment. Common diagnoses included latent TB (25%), schistosomiasis (13%) and other parasitic infections (10%).

Table 15. – Infectious Diseases referrals, DNA rates and screening outcome

Infectious diseases referral characteristics	Number/ number of children with available data	Percentage
DNA first appointment	34/84	40%
Seen in paediatric infectious diseases clinic	66/84	78%
Underwent infectious diseases screening in the trust*	71**/84	85%
One or more positive result requiring treatment	28/69	41%
Two or more positive results requiring treatment	9/69	13%
Common diagnoses		
- Latent TB	17/69	25%
- Schistosomiasis	9/69	13%
- Other parasitic infections (Hookworm, Tapeworm, Giardia and Trichuris)	7/69	10%
- Hepatitis B	4/69	6%

* Some following transition into adult services

** In two cases this fell outside the study period therefore data are not presented here

5.4.5 Sexual health screening results

Data were available for 41 UASC who attended a local sexual health service (table 16), these data comprise both scheduled appointments and walk-ins. There were no positive results for chlamydia or gonorrhoea in this cohort. No new diagnoses of blood-borne viruses were made from sexual health screening (though 4 cases of hepatitis B were diagnosed in infectious diseases clinic). Of those seen, 90% of UASC had advice given on sexual health and consent.

Table 16. – Sexual health screening outcome

Sexual health referral characteristics	Numbers	Percentage
DNA first appointment	22/49	49%
Reported sexual activity	14/41	34%
Sexual abuse/assault reported	8/41	20%
Sexual health advice given	37/41	90%

5.5 Discussion

5.5.1 Key findings

These novel data on the health of UASC in a London borough demonstrated an extremely vulnerable population with identified high rates of infectious diseases warranting treatment, high rates of physical abuse/assault including torture, historical sexual abuse/assault and ongoing trafficking concerns. Almost all of these UASC reported mental health symptoms warranting CAMHS referral. I demonstrated barriers to accessing services among UASC including inconsistency around names and dates of birth, high rate of DNAs and requirement for translator facilities. As many of these young people were close to turning 18 there were a lack of data on longer-term outcomes with few RHAs or other follow-up recorded.

An integrated pathway for UASC is in keeping with the proposed framework for best practice in management of newly arrived refugee children (comprehensive health screening, coordination of care, integration of physical, psychological and emotional needs, data collection and advocacy(277)), and was successfully implemented as a clinical management approach for this complex and vulnerable population.

5.5.2 Strengths and limitations

Data from three different services provides a comprehensive picture of the emotional, physical and sexual health needs of this population. This information is not available in routinely collected NHS datasets. I have demonstrated that the integrated pathway model, in place since 2016, can be successfully implemented in a London local authority. However, the study size was small and limited to a single region. It was not possible to access data from the NHS trust where the CAMHS service was based, limiting the completeness of this data set. As a retrospective evaluation there was reliance on comprehensive documentation, and data were incomplete for some demographic and outcome measures. In the absence of comparative data (for example before-and-after or between boroughs) I am unable to prove that the integrated pathway improves outcomes.

5.5.3 Findings in context

These comprehensive data from 101 UASC including demographics and health needs are some of the largest contemporary data available on UASC in England. The proportion of female UASC here is higher than the England average (16% vs 9%)(278). Otherwise, the age and demographic characteristics are broadly representative of UASC across England.

These findings are consistent with data on the health of UASC internationally(38-40, 279-281). Systematic review evidence on screening of refugee children showed intestinal infections in 31%, latent TB in 11%, and hepatitis B 3%(83). In comparison,

Camden UASC had almost double the rates of latent TB (25%) and hepatitis B (6%), but lower rates of intestinal infection (10%, not including schistosomiasis). A study of UASC in Kent in 2016 reported modelled estimates for infectious diseases based on country of origin(51) (latent TB 19%, parasitic infection 28%, hepatitis B 5%), which are similar to the observed rates in Camden.

Kent UASC 2016 data reported 41% of UASC having psychological symptoms(51), substantially lower than the 77% in Camden UASC. Mental health needs in this study were subjectively assessed at the IHA with input from a CAMHS clinician. SDQ screening alone has been criticised for failing to identify the level of mental health need in this group(281), the Camden CAMHS team has recently replaced the SDQ with the RHS-15 Refugee Health Screener(282). 87% of Camden UASC were felt to meet the threshold for CAMHS involvement, a decision made with CAMHS input, suggesting that the close liaison with mental health services is justified.

The rates of reported physical assault/abuse are high in this study and half of young people had scars on examination consistent with these disclosures. The description of torture was used by one in six UASC, but there is an argument that all physical abuse or assault is a form of torture. Considering the known barriers to making a disclosure of sexual abuse/assault(283) this number in this cohort (13% UASC, 38% female UASC) is strikingly high. A further 6% denied personal sexual assault or abuse but described having witnessed or known of this happening to someone else. There is significant vicarious trauma of witnessing assault, but it is also recognised that children who feel unable to disclose their own abuse may describe this happening to another child(284). FGM is acknowledged to be a human rights violation. Many of the UASC come from the horn of Africa, which has some of the highest rates of FGM in the world. Documentation of physical evidence of torture or abuse, history of sexual assault/abuse and FGM may all have a significant impact on a young person's asylum claim. The IHA report should be made available to the young person in all cases, and they may choose to share this with their solicitors.

The barriers to engaging with services, including inconsistent names and dates of birth, and high DNA rates are consistent with other studies(40, 280). Face-to-face interpreters were used when possible, however, the interpreters had not received specific training and were not matched for gender of UASC. It is recognised that use of interpreters can be a barrier to UASC communicating their story(98), and that interpreters should be carefully selected if possible(99). Mistrust of health professionals is a significant barrier to understanding UASC health needs(280) and UASC may be wary of disclosing information, for example whether they are in contact with family at home, for fear that this might adversely affect their asylum claim. Many UASC also turn 18 soon after arrival, when they are discharged to primary care. A more flexible and individualised approach to transition to adult

services could be very beneficial in this group. Unmet health need in adolescence is associated with poor health outcomes in adult life(29), and long-term outcomes are improved by early intervention and coordination of services. The study data demonstrates that consistent and coordinated attempts to re-engage can address some of these barriers and improve the attendance rate (from 60% to 85%).

Results from this cohort demonstrate the high level of need among this UASC, which, in the absence of intense and sustained support from services is very likely to remain unmet. Unmet health need in adolescence is known to be associated with poor health outcomes in adult life(29), and long-term outcomes are improved by early intervention and coordination of services.

5.6 Conclusion

These results demonstrate that UASC are an extremely vulnerable population with high rates of infectious diseases, physical abuse/assault including torture, historical sexual abuse/assault and ongoing trafficking concerns. The majority of UASC require mental health support. Significant barriers were identified to engaging with services and initial follow-up attendance rates were low. As many of these young people were close to turning 18 there is a lack of data on longer-term outcomes or other follow-up recorded.

An integrated pathway is in keeping with the proposed framework for best practice in management of newly arrived refugee children (comprehensive health screening, coordination of care, integration of physical, psychological and emotional needs, data collection and advocacy(277)). I demonstrated that the integrated pathway successfully addressed some of the barriers to engaging with services and demonstrates the potential to improve outcomes. Based on these data, this is an appropriate clinical approach for UASC in the UK. Given the high rates of infectious diseases diagnosed (41%), I recommend universal asymptomatic ID screening of UASC arriving in the UK.

5.7 Recommendations

The results of this chapter are used to inform the following recommendations for UASC services and future research.

Area	Recommendations
Service delivery	1. Services for UASC should Multidisciplinary, comprehensive and holistic

	2. There should be CAMHS representation in all IHAs for UASC 3. Promote importance of case management and coordination of care (e.g. HIP) 4. Actively address barriers to engagement: rebook appointments, liaise with UASC and care givers, consider inconsistent names and DOB
Comprehensive and holistic screening	1. IHAs should include trauma screening for physical abuse/assault and sexual abuse/assault 2. Universal asymptomatic infectious diseases screening of all UASC 3. Sexual health screening and sexual health advice for all UASC
Referrals	1. All UASC require referrals for: GP registration, dental care, vision screening, hearing screening 2. A low threshold should be used for CAMHS referral 3. Universal asymptomatic infectious diseases referrals (if not screened at IHA)
Legal considerations	1. Share a copy of IHA report with young person 2. Empower UASC to share IHA report with solicitor or in asylum process 3. If evidence or history of torture consider referral for medico-legal report (e.g. Freedom from torture)
Future research	1. To assess the potential for adaptation and implementation of a similar service in other settings. 2. Impact assessment of the integrated pathway on outcomes across health, education and social care. 3. Longer-term outcomes data is required to assess UASC outcomes into adulthood.

Chapter 6: Adaptation and pilot feasibility evaluation of the integrated pathway for UASC in Newham

This chapter describes the adaptation and pilot feasibility evaluation of the integrated pathway model in a second borough. UASC represent a highly vulnerable population with high levels of need including trauma, mental health and physical health including communicable diseases (Chapter 1, Chapter 5). Existing NHS services show significant variability and limitation in meeting these needs(55). One approach to addressing UASC needs, and barriers to care, is via an integrated pathway model, as described in Chapter 5. This model served as the basis for a grant-funded initiative to implement a similar service in the London borough of Newham.

The implementation project started in October 2020 and involved locally-driven adaptation in consultation with UASC and stakeholders. Challenges encountered included the Covid-19 pandemic and capacity issues due to increased UASC referrals. Despite these, 59 UASC were seen between January 2021 and January 2022, 56% receiving care in the full integrated pathway model. Here, I will describe the process of health service development, including the challenges that were faced, in a real-world setting. I undertook secondary data analysis of a variety of data collected in the Newham team across acceptability, feasibility, qualitative and quantitative metrics. Please see Contributions statement for full details. There were challenges in secondary data analysis due to limited and incomplete data as described. I used available data to assess the needs of a cohort of UASC engaging with the pathway and compared with other available data sources to evaluate the impact of this.

Despite challenges of secondary data collection, this chapter demonstrates successful adaptation and implementation of the integrated pathway in a second borough. I showed positive results for feasibility and acceptability and added to the available data on health needs among UASC. The pilot implementation showed a positive impact on process-related outcomes and healthcare delivery, providing a foundation for maintaining and up-scaling the intervention.

This chapter addresses the second aim of this MD(Res), exploring how services could be better configured to meet the needs of UASC, by implementing and evaluating a second pathway for UASC, and to promote engagement of young people and public in this process.

6.1 Research question and hypotheses

The research questions for this chapter are:

1. What is the process of adaptation and implementation of the integrated pathway for UASC in a second borough.
2. What are the demographics, health needs and known outcomes of a population of London UASC engaging with this service.
3. What is the impact of the integrated pathway on short-term and process-related outcomes among UASC.

As described in chapter 5., the hypothesis is that UASC have additional vulnerabilities over and above looked-after children and therefore may require a more comprehensive and holistic service than is typically delivered at IHA. This chapter describes the implementation of such a service in a second borough. In this case the null hypothesis would be that there is no improvement of processes or changes in outcomes following implementation of the integrated pathway model.

Table 17. – Research question in ECLIPSE format (Alternative to PICO format proposed for health policy and management(285))

i. Expectation	To implement a service developed in one borough to a second borough, with a view to improving support for UASC.
ii. Client group	UASC and their care givers (foster carers or key workers)
iii. Location	Newham community paediatrics service
iv. Impact	- Measures of feasibility and acceptability - Data on UASC demographics, unmet health needs and known outcomes. - Effect on short-term and process-related outcomes among UASC
v. Professionals	Paediatric doctors, CAMHS practitioners, HIP and UASC social workers.
vi. Service	An “integrated pathway” for UASC.

6.2 Aims and objectives

The aims of this chapter are to:

1. Explore and evaluate the pilot implementation of the integrated pathway model to add to evidence-base around services for UASC
2. Promote engagement of UASC and interested parties in health service development and evaluation.

Secondary aims were to engage UASC in an understanding of their rights and access to health and social care, to facilitate friendships and network building, and to empower UASC to be involved in development of services and research.

Specific objectives are:

1. To describe the adaptation of the integrated pathway model for UASC in the London borough of Newham including challenges and barriers faced
2. To assess the feasibility and acceptability of the pathway using quantitative and qualitative methodologies
3. To prospectively collect data on the baseline demographics and health needs of UASC engaging with this pathway.
4. To analyse pre- and post- implementation data to evaluate the impact of the pathway on short-term and process-related health outcomes.

6.3 Background

Prior to implementation the Newham community paediatrics service consisted of a multi-disciplinary team including Community Paediatricians, junior doctors, the CAMHS service (psychiatrists, psychologists and nurses), LAC nurses and admin staff. The team were responsible for undertaking IHAs with UASC following referrals from social care. Prior to the integrated pathway implementation, IHAs with UASC were carried out by Paediatric doctors (consultants or junior doctors) in one-hour appointments. Although CAMHS were part of the MDT, there was no CAMHS presence in IHAs. There was no equivalent role to the health improvement practitioner (HIP) and UASC were not routinely referred for infectious diseases screening.

Building on the evaluation of the integrated pathway for UASC in Camden (chapter 5), with Michelle Heys, I applied for grant funding to implement a similar service in the London borough of Newham. The key features remained: a Multidisciplinary team (MDT) approach, face-to-face interpreters, universal screening for infectious diseases and signposting to sexual health. A member of the CAMHS team attending all IHAs and a Health Improvement Practitioner (HIP) promoting integrated care and working.

Due to the absence of comparative data (such as before and after data), the Camden evaluation did not provide robust evidence for impact, making this a focus for this grant application. As described in the literature review (see section 1.3) the voice of migrant CYP are rarely heard in the literature and there is a failure to involve this group in designing and shaping services and research for them. As such, patient engagement and PPI was a second aim of this grant application.

Barts charity funding of £49,167 over a one-year period was successfully secured to support these objectives (Project title: Engaging unaccompanied asylum-seeking children in a developing a pathway to meet their needs, Grant reference Number: MGU0494). The funding covered the salary for a Health Improvement Practitioner (HIP) position, supplementation for a member of the CAMHS team to be present in all IHAs, and a small amount to promote engagement of UASC.

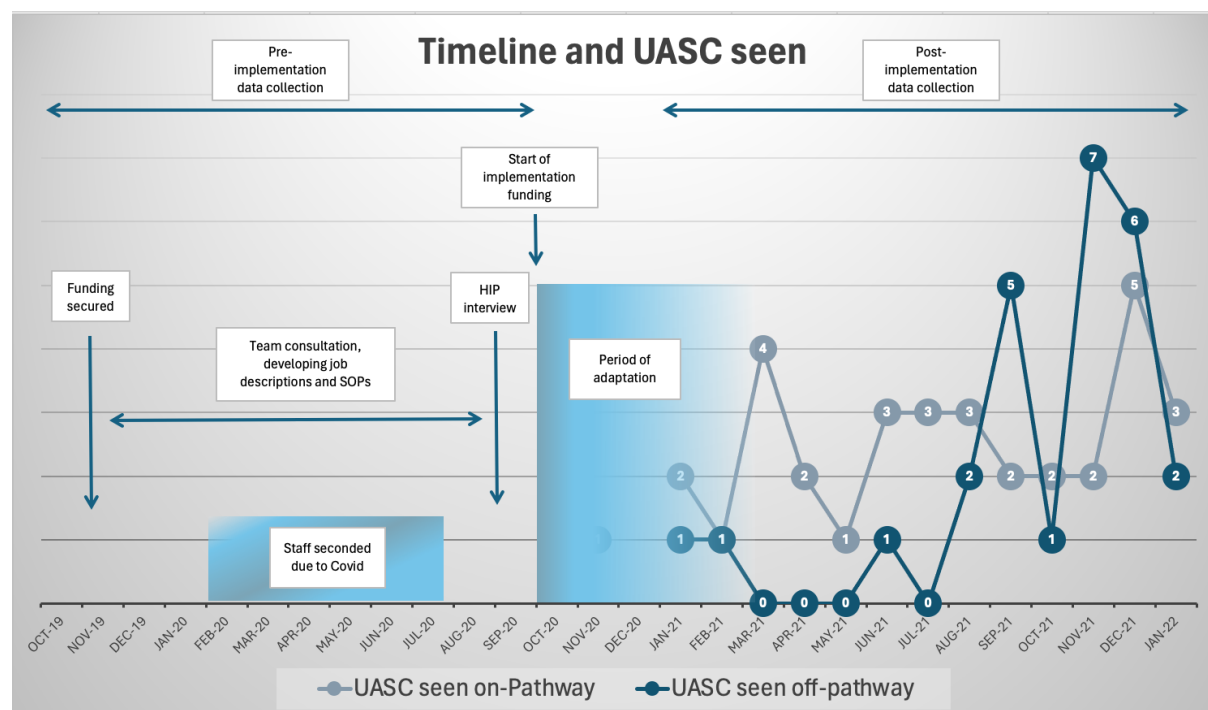
6.3.1 Timeline

Pre-implementation data for UASC, including a limited set of baseline characteristics, and process-related outcome measures, are available for a one-year period (October 2019 to October 2020). These data were collected by two medical students placed in Newham.

Following securing the funding from Barts charity at the end of 2019, the Covid-19 pandemic affected the timeline of grant delivery and our ability to deliver some aspects of the integrated pathway. In 2020 I wrote the job description and person specification for the health improvement practitioner (HIP) role. Following agreement from the NHS trust this post was advertised and I sat on the interview panel to recruit for this role in September 2020. The funding secured for CAMHS support was discussed with the CAMHS team at the trust and the decision was made that there was capacity and expertise within the existing team to provide the required support.

Funding for the integrated pathway started in October 2020, and was followed by a period of adaptation of elements of the pathway model (see below). The pathway was initially funded for a one-year period which started in October 2020. A no-cost extension was then requested from the Barts Charity to cover the evaluation until January 2022. Only one UASC was seen in the pathway model between October 2020 and December 2020. Data collection for UASC engaged in the integrated pathway model ran from January 2021 to January 2022. Due to a significant increase in UASC referrals over 2021, some UASC were seen “off-pathway” without all the features of the integrated pathway support, although all benefited from some CAMHS input. This timeline is illustrated in the diagram below.

Figure 10. - Timeline of implementation, adaptation and UASC data collection



6.3.2 Challenges of implementation

Implementation was significantly delayed due to the COVID-19 pandemic. Several members of the study team (AA and MH) were seconded to full time clinical work, and UCL was closed for face-to-face work for a period. This affected the timeline for implementation and the ability to collect data in the initial year, leading to the request for the no-cost extension to the pathway.

In September to December 2021 the number of UASC referrals in the borough approximately tripled. We are informed that part of this effect was due to two parallel referral systems being in place during a transition by social care. The lifting of COVID-19 travel restrictions may also have contributed to this effect. The integrated pathway model with new adaptations significantly increased the time requirements of a UASC IHA, as well as the number of professionals involved. Capacity was temporarily overwhelmed due to high referrals and some UASC seen in this period did not benefit from all features of the integrated pathway model, although contingency planning ensured that there was some CAMHS input for all UASC seen.

Screening for infectious diseases was a particular challenge due to a number of factors. Barts NHS trust were not taking referrals for asymptomatic CYP, despite evidence demonstrating at least 40% of asymptomatic UASC screened positive for significant infectious diseases (see Chapter 5). This led to a shift in approach to aim to screen UASC 'in-house' in the community. Collecting of samples was not always possible at the IHA visit due to time, staffing and success in obtaining samples such as stool and urine. Additional physical visits for sample taking became more difficult due to COVID-19 restrictions and there was a national blood bottle shortage, due to Brexit related procurement issues, further impacting our ability to screen asymptomatic young people as planned. As a result of these challenges, infectious diseases screening data were not available for UASC engaged in the Newham pathway.

Although I designed the tools for data collection, I relied on staff members within the team to collect this data. As described below, there were significant gaps and limitations to the quality and completeness of available data.

6.3.3 Patient and public involvement (PPI) and engagement statement

PPI is essential to all stages of research and service development, and UASC engagement was a specific aim of the Newham project. As explored below (see Chapter 7), there are challenges and ethical concerns arounds directly recruiting and working with young people who are current UASC in a PPI capacity. Instead, in the planning and implementation stage I reached out to multiple organisations who work

with migrant children or UASC, young people who may be former UASC or LAC, or other individuals or groups leading on PPI for research.

The Newham LAC team and I have formed a partnership with the *Separated Child Foundation*, a charity working with unaccompanied child refugees in the UK. The *Separated Child Foundation* were involved in informing implementation of the integrated pathway for UASC in Newham, including working with the Health Improvement Practitioner and providing sleep and welcome packs for UASC. I discussed approaches to promoting UASC engagement with several members of the organisation.

I linked up with the *Helen Bamber Foundation (HBF)*, a human rights charity working with victims of trafficking and torture. Through this network I have disseminated results from the Camden integrated pathway evaluation (Chapter 5), including to psychologists, GPs and other physicians working with migrant populations. Members of HBF advised directly on the Newham UASC project design, including taking a trauma-informed care approach and the consideration of informed consent in this group.

I have been in contact with the study team for the *CCoM* study team (Children Caring on the Move), who are exploring separated child migrant's experiences of care and caring for others, around the integrated pathway implementation and methods for engaging UASC. The *CCoM* team advised around complexities of consent and assent in this group, as well as use of youth-friendly materials and examples of these.

A young person who is a former UASC advised the team in Newham on the implementation of the integrated pathway model. This young person also sat on the interview panel for recruiting the Health Improvement Practitioner (HIP) role.

6.3.4 Theoretical underpinning of methods

There is a relatively new field of adaptation science, where the process of adapting an intervention into another setting is addressed systematically using structured frameworks. There has been a move away from viewing implementations and successful or unsuccessful(286); it is proposed that decision-making should be iterative and balance considerations of the adaptation with fidelity to the model and potential impact(287). The relationship between the intervention and context will change over time with moderating and mediating factors in play(288). As described in the recent ADAPT guidance: "*Implementing interventions ... in new contexts might be more efficient than developing new interventions for each context. Although some interventions transfer well, effectiveness and implementation often depend on the context. Achieving a good fit between intervention and context then requires careful*

and systematic adaptation.”(288) ADAPT guidelines offer a checklist of questions to guide teams in adapting interventions, these include forming an adaptation team; assessing the rationale for intervention, and considering intervention-context fit; planning for and undertaking adaptations; planning for and undertaking evaluation; and implementing and maintaining the intervention at scale. The four steps of the ADAPT framework are: Step 1: Assess the rationale for intervention, and consider intervention-context fit; Step 2: Plan and undertake adaptations; Step 3: Plan and undertake piloting and evaluation and Step 4: Implement and maintain the adapted intervention at scale(288). I will address both the checklist and the four steps in the description of the pilot implementation.

Forming an adaptation team (as per ADAPT checklist) is described in the PPI statement above, with stakeholders and those with lived experience all contributing to the adaptations and implementation process. Although the evaluation of the integrated pathway model in Camden indicated the potential for benefit, it cannot be assumed that replicating a strategy in a second setting will necessarily have the same outcomes. As per Step 1 of ADAPT guidance, the rationale for components of the intervention needs to be considered, including the theory for how the proposed intervention is expected to improve outcomes. In this case WHO Guidance for best practice in care of refugee and migrant children include key features of the integrated pathway model: a comprehensive individualised health plan soon after arrival, infectious diseases screening, vaccine uptake, linking with primary care and a holistic, collaborative approach to mental health(53). There is also evidence for the specific intervention of case management, a role taken by the HIP, which has been shown to improve outcomes among vulnerable and excluded populations(54). The intervention-context fit (Step 1 of ADAPT) is similar to the integrated pathway for UASC in the Camden services, also a well-established community paediatrics team with experience of working with UASC.

Modelling the expansion of the integrated pathway for UASC as a quality improvement (QI) project allows us to take an iterative approach to the proposed intervention. Instead of taking a “one size fits all” approach, implementation should be a dynamic process, responsive to local requirements, shifting conditions in a complex healthcare environment, the changing face of the NHS and funding constraints, and to the views of stakeholders(289). QI initiatives predominantly focus on improving process, and may not, at least in the short-term, be able to demonstrate measurable differences in patient outcomes(289). As such, although patient outcomes are a consideration, the evaluation of this project will include considerations such as systems change, patient experience, professional development and sustainability(290). Patient outcomes that can be assessed in the

short-term relate to process data, such as registering with a GP and immunisation uptake rate, that are themselves linked to health outcomes.

6.3.5 Adaptations

The service was adapted in line with the ADAPT principles (Step 2. Plan and undertake adaptations)(288) and QI methodologies(289). As per the ADAPT checklist, changes were in consultation with relevant stakeholder including local CAMHS, paediatric team and PPI groups including a former UASC. An iterative approach was taken to developing the new pathway around a plan-do-study-act (PDSA) cycle. Features were implemented then informed by testing and experience which often led to further adaptations from the original model. Several adaptations were made to increase the time available for appointment and to increase the multi-disciplinary and CAMHS input. Restrictions associated with the Covid-19 pandemic were in place through much of the planning and implementation stage, further driving responsive changes to the original model. One example of the PDSA cycle is the length of appointment time, which increased twice to facilitate conversations prior to the IHA to better prepare for the appointment. Another change that evolved during this time was the method and location of sample collection for infectious diseases screening. Despite differences in components of the model, the principle of providing more intensive and joined-up services for UASC has remained.

Adaptations included:

1. A Trauma-informed-care (TIC) approach for all aspects of the pathway. This included training of staff, consideration of physical setting, written materials and consideration of the rights and wellbeing of UASC. TIC fed into changes cited below.
2. Before the IHA, a pre-discussion between paediatric and CAMHS team
3. IHAs lasting at least 1.5 hours during which Mental health symptoms (e.g. Post-traumatic stress disorder (PTSD), suicide risk) are assessed. At the end of the session jointly identified health needs are fed-back to the young person.
4. Regular multi-disciplinary team meetings (MDTs) are held by the CAMHS team at which all UASC are discussed, this takes place approximately 6-8 weeks after IHA. Social workers and foster carers are invited to join the MDT. The MDT aims to map the needs of UASC, review support offered to-date and to formulate an individualised care plan.

5. The CAMHS team provide ongoing educational support for professionals, including paediatric trainees, working with UASC.

Other new elements in the pathway include provision of UASC welcome packs and sleep packs (funding sourced by the HIP), leaflets (developed using translations, pictograms and diagrams) to promote health literacy and summary GP and foster carers letters handed out at first contact. A virtual peer-to-peer session for Oromo-speaking UASC was held to develop friendships and support. Partnerships were developed with West Ham United Football Foundation and Newham Virtual School to support opportunities for UASC.

6.4 Methods

Methods were planned in-line with ADAPT framework (Step 3: Plan and undertake piloting and evaluation). I used a mixed-methods approach to evaluate the pilot implementation including feasibility and acceptability.

6.4.1 Study design, population and period

Study design:

1. Prospective observational study (service evaluation)
2. Retrospective observational study (service evaluation) for before/after comparison
3. Implementation/adaptation science evaluation

Inclusion criteria: UASC (Unaccompanied asylum-seeking children under the age of 18) seen for IHA during the study period by the Newham community paediatrics team. There is a statutory requirement that all UASC presenting to authorities have an IHA with a month and social care are responsible for referring UASC to medical services.

Study period: 1st October 2019 to 31st January 2022

These dates span the process of setting up the pathway (which coincided with the pre-implementation data collection), the period of adaptation and the post-implementation data collection.

6.4.2 Data sources, collection and analysis

Data sources:

I used various sources relating to the different components of this study which included quantitative, qualitative and mixed-methods metrics. For some data sources I relied on secondary data analysis of data collected by other researchers. Full details are included in the contributions statement.

Quantitative metrics to assess feasibility include recruitment of staff, involvement of other professionals within the MDT, realisation of the individual components of the pathway, and percentage of UASC seen within the pathway model.

Qualitative and mixed-methods data sources included feedback from UASC, semi-structured interviews with professionals caring for UASC who had engaged with the MDT meetings, and surveys undertaken with paediatricians working in the service. These were carried out by a research fellow (Gil Barton) working in the Newham team. Questionnaires for UASC were used to capture brief contemporaneous 'snapshot' feedback immediately after they were seen for IHA. This work was carried out by the Newham paediatricians and HIP.

Quantitative metrics on UASC health needs were available from two sources: An audit of UASC seen in Newham in a one-year period prior to pathway implementation completed by two medical students (Ruby Abdi and Molly Townson), and post-implementation data collection was undertaken for UASC engaged with the service.

Data collection methods:

I wrote the grant application and was a co-applicant on the grant to implement the integrated pathway in Newham where I held an honorary contract. Dr Sveta Alladi was the clinic lead for the pathway in Newham and, with her, I contributed to pathway implementation, adaptations and evaluation. I therefore collected data on feasibility, adaptations and implementation with further details shared by Dr Alladi.

Dr Alladi led a team who designed and undertook mixed-methods evaluations including questionnaires for UASC and surveys for paediatricians. These data were shared with me by Dr Alladi and Gil Barton. Full details are included in the contributions statement.

Gil Barton carried out semi-structured interviews with UASC carers and social workers who were invited to participate following engagement with the pathway. The topic guide focussed on goals, experiences, impacts and recommendations with prompts provided (see Appendix 6). Gil Barton also undertook surveys for

paediatricians using statements with likert scales and multiple-choice questions to explore paediatricians' views on the "emotional, social and behavioural needs of UASC in IHAs" and their level of confidence before they had worked jointly with the CAMHS team and after this point. Free-text questions were also used to explore paediatrician's perceived training needs, and asking what had been helpful or unhelpful. Eight paediatric doctors working in the Newham service were invited to participate. Gil Barton shared these results with me.

Anonymised data from the pre-implementation UASC audit had been collected retrospectively by two medical students. Anonymised data were shared with me by Dr Sveta Alladi.

I developed a data extraction tool based on the evaluation of the Camden UASC and shared this with the HIP and medical team in Newham. Data were inputted by healthcare staff in Newham. Data were collected prospectively from initial health assessment reports from UASC engaging with the integrated pathway between 1st January 2021 to 31st January 2022 (13 months). These data were inputted to an excel spreadsheet and anonymised prior to exporting out of the NHS trust.

All patient data were anonymised prior to export from NHS trust as per service evaluation ethical guidance.

Data analysis methods:

I undertook analysis and interpretation of feasibility, adaptations and implementation guided by QI methodology and the ADAPT framework as described.

I present results of questionnaires from UASC and surveys for paediatricians including quotations and grouping of themes from free-text questions.

I reviewed the transcripts of the semi-structured interviews to identify patterns and key recurring ideas or themes. I have also highlighted key points and exemplar quotes from individuals. Results are presented as a narrative description grouped by themes.

Excel spreadsheets were used to collect and analyse data on UASC demographics, health needs and engagement with the integrated pathway. I compared and analysed post-implementation UASC data with three other sources:

5. pre-implementation results from Newham
6. available data from the Camden UASC evaluation (Chapter 5) which includes a dataset across the same categories (same data extraction tool used).

7. Recent published UASC data from another London service

This enabled me to compare demographics and baseline health needs, as well process-related outcomes. I performed statistical analysis (calculations of percentages) using Microsoft Excel version 2016. I used Pearson's chi-square test to compare proportions of UASC meeting process-related outcomes (such as GP registration and ID screening) between the pre-implementation and post-implementation data.

I analysed and synthesised all available data and wrote-up these findings which have been published as abstracts. I used results collectively to explore the feasibility and acceptability of the integrated pathway model, including service-users, carers and healthcare providers' attitudes and experiences. These results are also relevant to evaluating the pilot implementation from a QI perspective and as per ADAPT framework; other considerations include the success of systems change, staff buy-in, the ability to scale-up the project and sustainability(290, 291).

6.4.3 Demographics, clinical variables and outcomes

Data including baseline demographics, health needs and process-related outcomes (immunisation, dental referral, infectious diseases screening and eye check). Variables are listed in Table 18.

Table 18. – Clinical, demographic and process data variables for evaluation

Clinical or demographic features	Process data variables
Country of origin	Arrival in UK (if known)
Male or female	Presented to authorities (if known)
Alternate name or DOB	Time to IHA
Religion (if stated)	CAMHS referral
Interpreter	ID referral
Type of accommodation (foster/shared)	Sexual health referral
Reasons for leaving country of origin	GP registration
Time in transit (if known)	Other referrals
Contact with family back home?	DNA rates
Time spent in refugee camp?	Immunisation uptake
Weight	
Height	
Physical symptoms	
Hx Physical abuse	
Hx Sexual abuse	
Mental health symptoms	
Scars	

Vaccination status (if known)	
BCG scar	
Education in country of origin	
Hobbies	
RHA completed?	

6.4.4 Ethical approval and considerations

Information and input on ethical considerations:

As for the Camden UASC data (Chapter 5.), I sought advice around the ethics of collecting, analysing and publishing UASC demographics and health need variables. I applied the same conclusions to the Newham UASC data here including governance framing and presenting and publishing potentially identifiable information.

As part of this project, I initially planned a patient and public involvement (PPI) project to engage UASC. At the stage of grant application, I designed engagement events for UASC to have input into development of services and research around their needs. I discussed this project with the Public Engagement Manager for the School of Life and Medical Sciences, the Research ethics service for UCL and a former chair of the Health Research Authority (HRA). Due to our own ethical concerns, unclear or contradictory guidance and administrative barriers this project did not progress. This process has fed into Chapter 7 where these issues are described in more detail.

A less ambitious piece of PPI work was undertaken in the Newham service where UASC were asked for brief feedback immediately after their IHA appointment (with the same translator support). This avoided the ethical complexities around recruiting to additional events and around asking questions with broader reach (risking re-traumatisation).

The surveys for paediatricians and semi-structured interviews for foster carers and social workers fall within HRA guidance that *“REC review is not normally required for research involving NHS or social care staff recruited as research participants by virtue of their professional role.”*(292) The Newham team and I did not consider that this project was likely to raise significant ethical issues (which would exceptionally require REC review).

Ethical and governance framing:

The “snap-shot” feedback questionnaires for UASC were formally considered to be PPI, and as such did not require research ethics committee approval according to NIHR and HRA guidance(293). However, practicing ethically was a major

consideration for myself and the Newham team as described, and led to adaptation of the project.

The evaluation of pre-implementation and post-implementation UASC demographics, health needs and outcomes were formally considered a service evaluation. Governance was as per service evaluation and audit guidance. Unlike the Camden evaluation only one NHS trust was involved. All patient identifiable information was anonymised prior to transfer out of the NHS trust.

Surveys for paediatricians and semi-structured interviews for foster carers and social workers were under the governance of “Research involving NHS staff”, and as such not requiring REC review(292).

Anonymisation and confidentiality:

As with the Camden UASC evaluation consideration was given to presenting or publishing single or small numbers of diagnoses or characteristics that might risk identification of the individual. I took the same approach of using only one direct identifier or no more than two indirect identifiers, as per BMJ guidance(275). As with the Camden UASC data, the ethical imperative to publish on improving services for this under-researched group was felt to outweigh the hypothetical risk that a young person might be able to identify themselves.

6.5 Results

6.5.1 Pilot implementation metrics

A health improvement practitioner (HIP) was successfully recruited to join the team and CAMHS practitioner time was identified from capacity within the existing CAMHS team. The integrated pathway model began in October 2020. The adaptations described above were in place from January 2021, including regular MDTs involving the medical team, CAMHS team, social workers and foster carers.

A total of 59 UASC were referred for IHA between January 2021 and January 2022, a significant increase on referrals from the previous year. Due to this increase, capacity was temporarily overwhelmed and 26 UASC were seen “off-pathway” without all the features of the integrated pathway support, although all benefited from some CAMHS input. Therefore 33/59 UASC (56%) were seen in the full integrated pathway model.

6.5.2 Feasibility and acceptability (mixed-methods evaluation)

A total of 4 feedback forms were collected directly from UASC engaged with the pathway (with translator support). These results indicate overall satisfaction with the pathway and that the young people felt the staff were trustworthy, friendly and listened to them.

Survey results are available from paediatricians who had experience performing IHAs jointly with the CAMHS team. Four of eight surveys were filled in and returned (50%), one survey was missing results for the section on post-joint IHA experience.

Before their experience of joint-IHA with CAMHS, all responding paediatricians (4/4) agreed that they had had an opportunity to reflect on the emotional, social and behavioural needs of UASC in IHAs and 3/4 agreed that they had a good understanding of these needs. Only 2/4 paediatricians agreed that they were confident in their existing skills and/or ability to assess/respond to the emotional, social and behavioural needs of UASC in IHAs.

After their experience of joint-IHA with CAMHS, 2/3 responding paediatricians said that their understanding of the emotional, social and behavioural needs of UASC were improved by the presence of CAMHS clinicians in IHAs. All (3/3) said that they learnt new skills and ideas regarding the emotional, social and behavioural needs of UASC and all (3/3) were satisfied with the CAMHS' clinician involvement in IHAs, with 2/3 being "extremely satisfied".

Free-text responses were received from four paediatricians to questions "Are there any areas you would be interested in receiving training on from the CAMHS clinician?" and "Please tell us more about what was helpful/unhelpful". Three respondents stated that it was helpful having a member of the CAMHS team at IHA, saying that this "*shortens workload in the long term and prevents patients from having to be seen twice*". One paediatrician commented that "*Every UASC IHA I have done has uncovered significant emotional and psychological health needs*", making it "*really helpful to triage these concerns and to agree on an action plan*". Two respondents talked about the importance of logistical knowledge from the CAMHS team: "*how referrals are screened, the pathways followed, how and where notes are written*" and "*[knowing] what resources are available inside CAMHS, such as knowing different teams available*". All four respondents referenced learning how to approach communication on mental health: "*How to...phrase delicate matters*", "*[learning about] phrasing sentences and framing questions*", "*Communication techniques with UASC*" and "*formally assessing emotional wellbeing in a structured sense*" etc, while two respondents referenced wanting to offer support and promote resilience in their consultations. One paediatrician raised some challenges around the model for IHA including "*I felt some YP were very daunted by the number of*

people in the room” and “It can make the sessions very long if we both have extended discussions with the young person- it’s already a tight squeeze for time”.

Results are available from four semi-structured interviews focussing on the MDTs, two with social workers and two with UASC foster carers. One of the foster carers gave an interview with her son translating due to a language barrier. I identified four common themes: the culture of MDT meetings, the value of mental health focus, improving insight into the needs of the YP and the continuity offered by this process.

There were observations on the positive culture of the MDT meetings, with respondents finding this *“very friendly and professional”, “really open...I could bring up whatever I wanted”, “fair, honest, and kind”* and professionals showing *“correct amount of sensitivity”*. The value of the focus on mental health was raised by both social workers and carers: *“The Mental health aspect of the follow up is very useful...physical issues can be much more easily seen/responded too, whereas mental health is trickier”* and *“At times [the young people] might also have mental health issues which come out at these meetings”*. One respondent commented that IHAs in the past had ignored the mental health aspects, and that this is helpful to discuss. The time gap between the IHA and MDT was described as helpful by one social worker, with both consideration of the acute trauma at IHA and of the additional understanding gained of the young person in the interim period: *“It was helpful to open the discussion again as I felt that at the IHA, [UASC name] had only just arrived here and the trauma [they] had been through was still very fresh and I am not sure if [they] had processed it all yet. Being able to reopen the discussion again at a later time, once [they] had settled in, was useful as it allowed us to re-evaluate [their] needs but with better understanding of [their] problems”*.

A theme among all four respondents was improving understanding the YP’s needs and helping to improve their care. This including insight into their mental health as well as practical aspects: *“we have more insight into what he likes to do (i.e., his hobbies and interests) also his diet and what he was lacking”*.

One theme that emerged was around the sense continuity of care from the pathway: *“the follow up meetings are...useful. [The CAMHS practitioner] was very good at following up and I find this very useful”. ...“checking in on anything that the young person needs”*, was felt to be helpful, perhaps in contrast to the IHA previously being a single event with no further follow-up.

The logistics of the process were raised by two respondents, one talking about the pros and cons of virtual attendance at meetings: *“face to face is better [than virtual] but more time consuming”*. One social worker suggested that the young person should be present at the MDT: *“I felt [they] were old enough to have a useful input in the conversation and have involvement in their own health care”*. Another social

worker suggested there should be more emphasis on the views of the carers who often “*have more insights than we [social workers] do*”.

Overall, the social workers and carers had positive experiences of the MDTs and felt this helped them in caring for the young people better.

6.5.3 UASC demographics, baseline health needs and outcomes (process-related)

Some data are available for 59 UASC seen in the Newham service from 1st January 2021 to 31st January 2022. As described, 33/59 were seen within the integrated pathway model. Reasonably comprehensive data are available for this group (from the data extraction tool), however, some variables were missing and there were alterations to the original tool provided. For the 26 UASC seen outside the pathway model the available data are more limited with significant missing values, particularly for process-related outcomes, limiting the scope for comparison.

Of the 33 UASC engaging with the integrated pathway during the study period 32/33 (97%) were male, and common countries of origin were Iran (12/33, 36%), Afghanistan (6/33, 18%) and Syria (3/33, 9%). All UASC had a native language other than English, most commonly Kurdish languages (15/33, 45%), Pashto (5/33, 15%) and Arabic (4/33, 12%). 13/33 (39%) UASC had their religion was documented as Muslim. 3/33 (9%) UASC reported spending time in a refugee camp. Following arrival, where documented, 12/30 (40%) of UASC were living with foster carers, 15/30 (50%) were in semi-independent accommodation, and 3/30 (10%) in temporary accommodation.

The majority of UASC seen in the integrated pathway model (27/33, 82%), had some mental health symptom documented, including sleep problems (17/33, 52%), PTSD symptoms (17/33, 52%), suicidality (4/33, 12%) and self-harm (4/33, 12%). 14/33 UASC (42%) reported historical physical abuse or assault and there was one disclosure of sexual assault. On examination, 3/33 (9%) UASC had signs of scabies infestation and 3/33 (9%) had consistent with their disclosures of physical abuse or assault. Only 9/33 (27%) had any results collected of infectious diseases or sexual health screening. Of these, no positive results were identified. Process-related outcomes for this group are presented in the next section.

For the 26 UASC seen outside the integrated pathway model the available results were more limited. Demographics were very similar to UASC seen “on pathway”: 25/26 (96%) were male, where data was recorded; common countries of origin were Iran (5/18, 28%), Afghanistan (4/18, 22%) and Syria (2/18, 11%). Where documented, one UASC spoke English and other common languages were Kurdish Sorani (7/18, 39%), Arabic (3/18, 17%) and Pashto (3/18, 17%). 12/26 (46%) of

UASC had their religion documented as Muslim. Accommodation data were missing for over half of UASC in this group (14/26, 54%); where documented, 10/12 (83%) were in semi-independent accommodation and 2/12 (17%) in foster care. The majority of data for baseline health needs were not collected in the data extraction tool for this group although one case of sexual abuse/assault was recorded.

6.5.4 Comparison of results and analysis of data

Data are available for comparison for 26 UASC seen in the Newham service October 2019 to October 2020 (prior to pathway implementation). These data are from an audit performed by two medical students in the Newham team. Of note, this period also covers some of the Covid-19 pandemic with subsequent effects on services.

Of 26 UASC seen for IHA, 10 had a virtual IHA, limiting the assessment in terms of physical examination. 88% were male, age-range 11-17, (median age 16, IQR 15-16). Common countries of origin were Afghanistan (42%) and Vietnam (26%). Reasons for leaving country of origin were domestic terrorism (30%) political instability and violence (12%), religious persecution (12%) and trafficking (8%).

Where documented, 23% of UASC reported physical abuse and there were no reports of sexual assault or abuse. Mental health symptoms were documented in 27% including nightmares and flashbacks of traumatic events. 31% experienced other manifestations of mental health problems, including behavioural difficulties reported by carers, somatic symptoms and general anxiety. Only 12% were referred to CAMHS, 8% being for a PTSD assessment.

Data are available on process-related outcomes including ID screening, catch-up immunisation coverage, vision screening, dental care and GP registration. These data are presented below.

Table 19. Process-related outcomes – pre and post implementation comparison

Pre- Pathway implementation (n=26)	Post -pathway implementation (n=33)	P-value
46% have had partial or full ID screen and blood tests (12/26)	67% have had partial or full ID screen and blood tests (22/33)	0.11
69% up to date with immunisations (18/26)	88% have had first immunisations (29/33)	0.08
73% attended follow-up eye check (19/26)	84% seen by an optician (28/33)	0.26

42% attended follow-up dental care (11/26)	70% seen a dentist (23/33)	0.03
92% were registered with a GP	100% were registered with a GP	N/A

On comparison, rates of all process-related outcomes improved from pre-implementation of the pathway compared with post-implementation (see table 19), although in most cases this was not statistically significant.

Other available sources of data on UASC include the Camden pathway evaluation (chapter 5) and the pre-pathway audit (results above). There has been a recent publication of an evaluation of the UASC service at another London hospital (Imperial College healthcare NHS trust)(294), which presents similar data to the Camden evaluation (Baseline demographics, social, mental health and journey details, infection screening and investigation results). Although there is not complete consistency between these datasets, comparison of available data are presented below.

Table 20. – Comparison with other available UASC data

	Newham pathway Post- implement ation 01/01/21- 31/01/22	Newham pre- implement ation 01/10/19- 30/09/20	Camden pathway	Imperial pathway
Percentage Male UASC	97%	88%	84%	89%
History of physical abuse/assault	42%	23%	67%	54%
Scars consistent with disclosures	9%	ND	54%	ND
Disclosure of sexual abuse/assault	3%	0%	13%	7.1%
Mental health symptoms reported	82%	27%	77%	47%
One or more positive result requiring treatment	ND	ND	41%	45%
Common diagnoses:				
- Latent TB	ND	29%*	25%	24%
- Schistosomiasis	ND	ND	13%	ND
- Other parasitic infections	ND	ND	10%	ND

(Hookworm, Tapeworm, Giardia and Trichuris)				
- Hepatitis B	ND	8% **	6%	5%

ND – Not documented or missing data

*Only 7 children screened

** Only 12 children screened

6.5.5 Impact and next steps

The integrated pathway service was nominated for an East London Foundation NHS Trust award for population health for two consecutive years. Following successful implementation and presentation of preliminary outcomes, funding for this model has now been taken on by Newham clinical commissioning group and the integrated pathway will become the standard of care in Newham.

These data informed a second successful grant application for £647,848 to the Barts Charity (Project title: Expanding a Trauma Informed Integrated Clinical Pathway for Unaccompanied Asylum-Seeking Young People across North East London, Grant reference number: G-002610), with a view to explore expansion of the integrated pathway model across multiple boroughs in North-East London, and the potential for national scale-up.

6.6 Discussion

6.6.1 Key points

The integrated pathway for UASC was successfully adapted and implemented, in-line with implementation science guidance, in a second London Borough. There was good fidelity to the original model with adaptations generally increasing the multi-disciplinary input and level of support available to UASC. Mixed methods evaluation indicates that this model was found to be feasible and acceptable to stakeholders, professionals and the young people in the Newham service. In terms of implementation, the main limitation was that there was not capacity for all UASC seen during the study period were able to benefit from all components of the pathway.

Available data on UASC engaging with this pathway add to the existing data on high rates of vulnerability and health needs among this population. Rates of identified mental health symptoms were extremely high when there was CAMHS representation in the IHA. Using comparison with pre-implementation data, I was able to demonstrate improvement in process-related outcomes for UASC engaging with the integrated pathway model, for the first time. As a piece of health service-development, this evaluation adds to the data on best practice and evidence-based policy in management of refugee and asylum-seeking children.

6.6.2 Strengths and limitations

The two main components of this work are the description of pilot implementation of the pathway and the data collection of UASC health needs. The health service development in a real-world context is described including multiple challenges around external events and barriers to implementation. As a QI project and using implementation guidance (ADAPT framework), the Newham pathway has been successful across a range of measures. The model was adapted in a responsive fashion to local requirements, changing circumstances and available resources. Mixed methods evaluation indicates positive views of this service among both UASC and healthcare professionals. Reciprocal learning was also demonstrated between healthcare professionals working within the team. Sustainability of the implementation has been secured with commissioner funding and the potential for scale-up is being explored in the expansion of the pathway across North-east London as described (as per ADAPT Step 4: Implement and maintain the adapted intervention at scale).

The UASC data add to the existing literature on demographics and health needs among this group. However, these results are from a single centre, only cover a one-year period and complete data are not available for the 26 UASC who were seen “off-pathway”. There were challenges in obtaining complete data as I relied on data collected by different staff members in Newham using the data extraction tool I designed. I found there were significant problems with inconsistent interpretation of some variables, inconsistent date formats (British vs American) and cells left blank rather marked as missing data. Due to UASC leaving the borough, undergoing age assessments and turning 18 it was difficult to obtain consistent numbers for the UASC population in Newham. The incomplete data for health needs and process-related outcomes for UASC seen off pathway, and infectious diseases screening rates and results, limited scope for comparison with other datasets. There were additional variables captured in the Camden dataset that were therefore not available for Newham, such as reasons for migration, time in refugee camps, inconsistent identifiable information and rates of failure to attend follow-up appointments. These missing variables further limit the interpretation in terms of barriers to accessing services and richness of information in terms of vulnerabilities. While process-related outcomes were improved in comparison to pre-implantation data, it is difficult to demonstrate changes in longer-term health outcomes due to limited follow-up period and YP leaving the service following turning 18.

A significant limitation of the dataset is the lack of infectious diseases screening results, as the high rates of positive results were a striking finding in the Camden pathway evaluation. This is in part due to incomplete screening, secondary to barriers described above, and in part due to incomplete data collection. Where

infectious diseases screening was performed this was split between GPs, community paediatrics, Barts Hospital NHS Trust and sexual health clinics.

The main limitations of this project are around the small sample size, limitations in data collection and capacity being overwhelmed. As described above, despite these limitations we secured funding for this pathway to become “business as usual” within Newham services and for a project to expand the pathway model across NEL with a view to addressing these limitations and undertaking a comprehensive evaluation of the integrated pathway model.

6.6.3 Findings in context

This evaluation demonstrates locally acceptable adaptation successful implementation, within available resources, of an intervention developed in another setting. When implementations are successfully adapted to another setting this both improves the belief in their efficacy(290) and the likelihood of further adoption(286). This evaluation also provides an initial evidence-base for an intervention that demonstrates improvements in process-related outcomes. As such, it represents an important addition to evidence-based policy in this area. Although the evidence is limited in this area, this intervention is in keeping with guidance for best practice on managing refugee children(39) and in-line with recommended interventions for refugee children (*“A comprehensive multi-modal service should include clear care pathways, case management, evidence-based trauma-focused interventions, consultancy, and training”*(295)).

These data add to the limited available literature on UASC health needs and demographics. These data are a smaller sample size than the Camden dataset of 101 UASC and there were differences in the demographics including fewer female UASC (1/33 vs 9/101) and no overlap in the three most common countries of origin. UASC arriving in the UK are known to be a heterogeneous group in transport routes and country-specific political situations can drive shifts in population from year to year(296).

Rates of documented mental health symptoms among Newham UASC were similar to the Camden cohort (82% and 77% respectively), both of which are much higher than rates from Newham pre-implementation data, which may reflect the increased pick-up rate with CAMHS input. Reported rates of symptoms as well as disclosures of abuse and assault are likely to vary significantly depending on whether the questions are routinely asked, as well as the manner in which they are asked. I hope that taking a trauma-informed care approach might increase the probability of a young person feeling able to make a disclosure, although we are not able to prove this in existing data. There is significant variation in the rates of reported physical and sexual abuse between the different pathways which may reflect these factors.

The lowest rates of reported physical and sexual abuse and assault are from the Newham pre-pathway data, which may be consistent with the questions not being routinely asked, staff not yet being trained in trauma-informed care, and no CAMHS support in consultations.

One challenge in the practice of trauma-informed care is that of whether to ask the young person to tell their story at IHA. Discussing or re-telling their story can be difficult, particularly to professionals they are meeting for the first time for a health appointment(297). Best practice in trauma care recommends that young people should only be asked to tell their story once, in a trauma-informed setting, and that consent should be sought to share this with other professionals as needed(298). In the process of applying for asylum in the UK, we know that UASC will often be required to repeat their story, risking further retraumatization and detrimental effects on their mental health(299). On balance, given the timing of the IHA (soon after arrival), and the ability of health professionals to document reports and make referrals, I believe that it is necessary to ask UASC to tell their story at IHA. This may represent the only opportunity to understand and provide support for experiences including rape and torture. However, I acknowledge the risk of retraumatization inherent in this approach, and believe that trauma-informed practices are of paramount importance.

Although the data for infectious diseases screening is not available for the Newham pathway, there is striking similarity between the rates of positive results between the Camden and Imperial data (41% and 44% for any positive result; 24% and 25% for positive TB results). This adds evidence for high rates of infectious diseases among UASC from different groups, further supporting the argument for universal asymptomatic infectious diseases screening.

6.7 Conclusion

The integrated pathway has been successfully implemented in a second London borough and is acceptable to service-users and professionals. For the first time, improvements have been shown in preliminary health outcomes amongst UASC in pre/post-implementation comparison. As a quality improvement project the implementation was successful in adapting in response to local requirements, changing systems and sustainability. Mixed-methods evaluation indicated positive experiences among service-users and carers with reciprocal learning demonstrated among health professionals looking after UASC. The quantitative evaluation adds to the existing literature on demographics, health needs, and preliminary health outcomes of UASC. As a piece of health service development in a real-world setting, the integrated pathway model adds to the literature on best practice management of refugee children.

The integrated pathway implementation has been shown to be successful in expansion to a second borough and now has sustainable funding attached. I am a co-applicant on a large grant application to support expansion of the integrated pathway for UASC across multiple London boroughs; this project will address many of the limitations of sample size and incomplete data while tying in with the final stage of ADAPT guidance for implementation.

6.8 Recommendations

These recommendations for developing services for UASC build on those from the previous chapter (section 5.7).

Area	Recommendations
Trauma informed care – systems level	1. Operate on the assumption that every patient may have a history of trauma 2. Arrange services so that UASC only need to tell their story a single time 3. Recognise that systems can unintentionally retraumatise young people 4. Consideration the impact of the physical environment 5. Ensure communications are language and age-appropriate
Trauma informed care – clinician level	1. All staff should be trained in trauma-informed care 2. Recognise the prevalence of trauma among UASC 3. Seek consent from UASC to share story with other professionals 4. The response to trauma needs should be evidence-based and multi-disciplinary
Training of staff	1. Address training requirements at local, regional and national levels 2. Survey training needs of new staff members to identify gaps 3. Consider the training needs of all professionals working with UASC 4. Embed a trauma-informed care approach in all training
Implementation science	1. Follow the ADAPT checklist to implement a service in new settings 2. Stakeholder input 3. Involve and engage UASC and their caregivers

	4. Continuous evaluation across staff, service users, known outcomes 5. Assess potential for scale-up
Future research	1. Focus on the potential for regional and national scale-up, including NHS capacity and health economics. 2. Data are required to assess impact of this service on outcomes across health, education and social care.

Chapter 7: Patient and public involvement (PPI) and ethics in migrant children: Exploration of structures, barriers and ethical dimensions

Throughout my research with migrant CYP and UASC, I have attempted to involve and engage individuals and groups, including current and former UASC, asylum-seekers and groups working with these populations, with a view to shaping and informing work that affects these groups. These efforts are part of a wider consideration attempting to explore and hear the voice of migrant children in research and service development. Some of these themes are discussed in the literature review in the introduction (see chapter 1).

As part of my work on the UASC pathway, I planned to work with UASC directly to try and understand and hear their views on services for them. As discussed in Chapter 1. The views of marginalised young people such as UASC are rarely heard, and I hoped to give a “voice” to this group in planning this work. Because of my background in quantitative methods, I sought input from qualitative researchers and started working with Dr Veena Meetoo as a supervisor. I initially planned to carry out a qualitative study, but I also explored whether this could be modelled as patient engagement, or PPI, given the focus was on service development, rather than asking a new research question. The interface between PPI and qualitative research is explored further in this chapter. Over the course of planning this piece of work I sought advice and discussed both the ethical considerations of any piece of qualitative work, and extensively read around and explored the guidance and current understandings of PPI. Attempting to undertake this project I encountered practical and ethical complexities which did not appear to be considered or addressed in existing guidance. I became frustrated by the inconsistency and apparent contradictions in guidance around PPI, and the implications of this including the logistical challenge of the NHS ethics process. I eventually made the decision to abandon this project due to a lack of consensus from institutions on ethical guidance, escalating ethical and practical concerns, and by my need to scale-back the scope of my MD(Res) to fit time-constraints. I subsequently participated in a project at UCL exploring the ethics of engagement, involvement and co-production, and presented my experiences.

This chapter is therefore an exploration of the current model of PPI, including ethical considerations, and how this applies to marginalised populations such as migrant children. I start this chapter with the case example of my own experiences trying to work with UASC to hear their views. I then explore the evolution of PPI in health

research, the applicability to UASC as the population of interest, and the practical and ethical implications of this.

There are several complexities and debates that I will address throughout this chapter, these include: the blurred lines and shifting definitions between qualitative research and PPI, the failure of PPI guidance to address inclusion or ethical considerations, the tension and risks of making PPI a mandatory requirement to carry out research.

This chapter addresses the second aim and long-term goals of this MD(Res): to explore how services could be better configured to meet the needs of migrant children, with a focus on UASC, as a particularly vulnerable group; and to improve the health service experiences of forced migrant CYP in England, and inform service development, interventions and research direction with a view to engaging, supporting and improving outcomes among UASC.

7.1 Research question and hypotheses

The research questions for this chapter are:

1. What is the history of, and current model of PPI
2. What are the ethical implications of involving and engaging children in research
3. How does PPI apply to marginalised populations such as migrant children.

I contend that current definitions and ethics requirements of PPI are unclear and often contradictory. My hypothesis is that this has ethical implications for migrant CYP; resulting in barriers to research and increasing inequities.

7.2 Aims and objectives

This chapter aims to explore the structures, barriers and ethical dimensions around hearing the voice of vulnerable children in research, policy and service development, with a specific focus on the discourse around patient and public involvement (PPI).

To achieve this, I will undertake the following objectives:

1. Describe the history of research ethics with a focus on marginalised populations
2. Describe the history and literature around the evolution of PPI, including how this applies to vulnerable children such as UASC
3. Illustrate, with a case example, some of the ethical complexities and barriers to engagement presented by the current model of PPI
4. Explore some of the ethical complexities of PPI with UASC
5. Propose an approach to an ethical approach to engaging UASC

7.3 Case example: ethical and practical challenges of engaging UASC

In 2020, I had secured grant funding to implement the integrated pathway for UASC in the borough of Newham. My proposal had been to use part of this money to carry out an engagement project with UASC. I planned to explore UASC experiences of existing services as well as what outcome measures they felt to be meaningful, i.e. “what matters to me”, and plans for future research direction. I began planning a piece of qualitative research and explored examples in the literature of novel ways to engage young people who are harder to reach, including navigating the language barrier. I settled on the idea of two creative workshops and two focus groups, both with translator support. Due to the grant and service implementation being through the NHS, I started an application via the Integrated Research Application System (IRAS), which includes multiple stages of ethical and research and development approval. An IRAS application also requires negotiation of frameworks between organisations involved; in this case the NHS Trust, the research office for the trust and the university. In the early stages of IRAS application a box needs to be ticked stating that you have had PPI input in your application. On reading around this recommendation, Health Research Authority, NIHR and university guidance made clear that the application would not be considered without prior PPI; the most common suggested example of PPI being focus groups with UASC, very similar to the project I was planning as qualitative research.

In view of the time and paperwork burden of the IRAS application, and the recommendation around PPI focus groups, I considered whether the engagement project I had planned could be reconceptualised to be PPI rather than qualitative research. I amended my protocol to only address UASC views on the service being developed, rather than asking new research questions. Although I was not intending to explore any prior experiences of UASC, I was cognisant of the risk that sessions may involve UASC sharing experiences from their country of origin, journey to the UK and difficulties following arrival. My main concerns were around the risk of unintentional re-traumatisation during discussions, as have been noted by other researchers(300). Another possibility was that new safeguarding concerns may come to light during sessions, including suspicions around trafficking and exploitation. Confidentiality within sessions was a further complexity, with not only the risk that UASC would want their stories kept confidential, but that there may be perceived barriers to disclosing any information to professionals for fear of influencing asylum claims (See chapter 1).

While developing this project I sought another form of input by engaging with charities and organisations who work with refugees and asylum-seekers. One impact of this was that I build a trauma-informed care approach into my protocol and

included plans for staff training around TIC. Another group I engaged with advised on complexities of gaining informed consent in UASC and the ethics of the interaction with the research team. I found this input very valuable and felt that it raised new considerations and improved the quality of my planned projects. There is some debate on whether this type of participation would be considered PPI or not. Charities often include those who are themselves current or former refugees and asylum seekers, where lived experience can be very valuable. On the other hand, being mostly trained professionals, any representatives would fall on the wrong side of the lay/expert divide, and we risk the scenario where young people are spoken for by adults, and where there may be 'filtering' of the voice of the child through adult professionals. These issues are explored further below.

In attempts to ameliorate some the ethical and safeguarding risks described, I gave consideration to methods for managing any new safeguarding concerns that were raised, and preserving confidentiality within sessions. A further ethical complexity was around the power dynamics of recruiting via the NHS service, where UASC may feel beholden or indebted to health professionals. Usually, paying UASC for their time, in line with most PPI guidance, was impossible due to undecided asylum claims. I was concerned that if recruitment of UASC was successful, it would be hard to be sure that the young people weren't being exploited.

I sought advice from the patient engagement team in my institute, specifically around the ethical dimensions of recruiting and working with such a vulnerable group. After some hesitation, the final advice was that any PPI activity undertaken with UASC would be considered research, itself requiring ethics committee approval. The initial advice was that this could be 'light touch' ethics approval, with a simpler application process via the university. I subsequently contacted the university ethics department to clarify, and was advised that due to the vulnerability of the patient population, my application would be considered 'high risk', with all the associated red tape.

This seemed to result in a circular impasse: I was unable to apply for ethical approval without PPI; and I could not engage in PPI without ethic approval. Alongside this process I was faced with needing to reduce the scope of my projects due to time-constraints. It became clear that I would be unable to navigate the contradictions and complexities described, and design an ethical project, with or without formal ethics approval, within the time scale available.

I made the difficult decision to abandon this project. I am aware that this represents another failure to hear the 'voice' of migrant children in services for them; and that this project would have been much more straight-forward if the population of interest were easy to reach, with fewer vulnerabilities and complexities. I felt that this experience highlighted inherent inconsistencies and ethical concerns in our current

construct of PPI, particularly as applied to marginalised children. I therefore chose instead to explore these issues further in this chapter to try and map the contemporary landscape of PPI discourse, explore emerging ethical considerations and highlight barriers to engaging UASC.

7.4 Background

7.4.1 Ethics in medical research

Although early considerations of medical ethics can be traced back thousands of years, the modern concepts of ethical research were shaped by a series of events in the 20th century. Many of these constituted abuses perpetrated on minority groups and those from non-white backgrounds.

Members of the Nazi regime were tried post-war medical experimentation without consent on Jewish prisoners in concentration camps. As a result of the subsequent Nuremberg trials, the Nuremberg code was created, a set of ethical research principles for human experimentation(301). At a similar time the first universal declaration of human rights was published in 1948, underpinning the rights-based approach for discussions around research. These publications codified the need for voluntary informed consent and prevention of death or suffering in research, among other principles. Another cornerstone of medical research ethics was the Helsinki declaration in 1964, revised in 1975 to enshrine the need for ethics committee oversight of research in international guidelines.

Despite these codes and policies, high-profile abuses continued in the following years. Henrietta Lacks was an African American woman who died from cervical cancer in 1951(302). Without her consent, her cells, and cell lines derived from them, continue to be used in research on cancer, HIV, radiation, viruses such as Covid-19 and IVF, saving and improving countless lives(302).

Arguably the most significant and shocking example of medical abuse post-Nuremberg was the Tuskegee syphilis study which ran from 1932 to 1972. Nearly 400 black men in Alabama with Syphilis were recruited to a US government study, and followed-up to describe the course of untreated syphilis. They were not informed as to the purpose of the study, and were denied treatment, despite Penicillin being the recommended drug of choice for Syphilis from 1947(303). The implications of this study coming to light included the Belmont report of 1979, and guidelines on ethical principles in research including ethics committee review(304). The Tuskegee study has also been cited as a root cause of distrust of medical institutions among black populations in the US, and associated with persisting racial inequity in healthcare outcomes(303).

As late as the 1990s, details of an “aggression” study performed on black children in America came to light. Although parents consented, they were financially incentivised to do so(305), and were not fully informed of the conduct of the experiment(302). These children were subjected to deprivation of food and water, exposed to a medication known to be unsafe, and denied regular medication such as for asthma(302).

As abuses and health inequities continue, it has been argued that our very conception of bioethics is shaped by structural racism(306), in part due to being driven and designed in the context of “whiteness as the norm”. Evolving ideas of ethical research increasingly consider “culturally appropriate” research, and the idea that research affecting peoples and communities should not be undertaken without the involvement of those peoples(307). Codes and statements of research ethics continue to be revised and updated over time, attempting to better reflect modern understandings of human rights, justice and equity. Patient and public involvement (PPI) in research is one strategy proposed to improve this process.

7.4.2 Patient and Public Involvement in research

Over the last two decades there has been increasing emphasis on seeking the views of, and involving, patients and the public, particularly those outside traditional models of academia, in research. Alongside this, a parallel discourse around moving away from paternalism, rebalancing power dynamics, and democratic representation in research has further promoted patient involvement and engagement. A variety of terms including patient and public involvement (PPI), patient engagement (PE), participation and co-production are commonly used to describe interconnected concepts, but here I use Patient and Public Involvement (PPI) as the representative concept.

PPI grew out of interlinked concepts of ‘patient-centred’ approaches, accountability and democracy, and has much in common with participatory action research, an approach used since the 1940s in qualitative research methodology. While qualitative research has traditionally been used to explore patient views and experiences, it requires formal ethics committee approval, training of researchers, and has rigorous methodological standards. Comparatively, PPI might be seen as more informal, pragmatic and requiring less oversight. Most models of PPI make use of qualitative methodologies(308) but the consensus has evolved, driven by guidance from funding bodies, that PPI and qualitative research are inherently separate (explored below). In this spirit, multiple attempts have been made to distinguish PPI and associated practices from qualitative research, and blending of the methodologies has been subject to criticism(293). Qualitative research in the UK requires ethics committee approval, so, crucially, if PPI is distinguished from research, then ethics committee approval may not be required. A 2016 joint

statement from Health research Authority and INVOLVE (NIHR) states: “You do not need to apply for ethical approval to involve the public in the planning or the design stage of research... even when those people are approached for this role via the NHS...”(293).

There is a distinction between ethics committee approval and practicing ethically. While the researcher should bear responsibility of the ethical conduct of their research, I recognise that this does not happen in a vacuum; ethical guidelines or lack thereof, as well as the requirement for formal ethics approval, are likely to have an influence on the ethical standards of any project that is carried out. As illustrated in the case example, PPI with marginalised populations such as UASC presents multiple ethical considerations and there is significant potential for harm. However, referring to the guidance on PPI, INVOLVE further states that “The active involvement of patients or members of the public does not generally raise any ethical concerns for the people who are actively involved” (309).

My contention is that the distinction between PPI and qualitative research is false, that the purpose, methodologies, process and outcomes clearly overlap, and that this false separation causes problems. The procedural rigor, representativeness of participants and methods of data collection that would be expected in qualitative research may all be absent from PPI. Similarly, due consideration of the ethical implications of undertaken the project including recruitment, informed consent, any risks of the activities and sharing confidential information, may all be ignored. As the case example illustrates, there does seem to be recognition at present that the guidance and methods of PPI may somehow be insufficient for more vulnerable populations such as UASC. The practical outcome of this lack of consensus seems to be delays and barriers to projects with vulnerable children, while conversely promoting work with populations who are easier to access and present fewer ethical considerations. I am concerned that the current model of PPI as both an absolute requirement and an ethical grey zone, can unintentionally perpetuate inequities in research access for vulnerable groups.

7.4.3 PPI as a construct in the context of discourses of children’s rights and participation

The concept of PPI in health research, as it is currently understood, has been constructed over the last two decades. As a construct this draws on other constructed notions, areas of study and movements. I will attempt to explore some of the interconnected constructs that inform this model of PPI, and interrogate the assumptions, contradictions and limitations of this model as applied to vulnerable children.

As described in the literature review, early models of PPI grew out of concepts of citizenship and citizen participation; ideas that are themselves constructed, and subject to various interpretations(310). The use of the term citizen in participation may be interpreted as a liberal-democratic concept, in which we are all born free and equal, as global citizens(310). But this interpretation may be at odds with the more literal meaning of citizenship as legal status within a particular country; this presents the idea that asylum-seekers may be somehow less entitled to the rights of citizen participation than others. Any conception of citizenship is likely to be viewed through the prism of political and moral assumptions.

Another concept informing PPI is that of 'lived experience', and the importance of exploring and representing this(311). Lived experience has been closely associated with longitudinal qualitative research, with the 'lived' component indicating time passing in relation to conditions, circumstances and policy(311). Lived experience is considered to have particular value in representing the subjective experience of marginalised people. But while the importance of lived experience may be intuitive, it raises issues of 'who' is eligible to be included. In PPI, the issue of who is appropriate to be a PPI participant should be raised, given that "what is any experience if not 'lived'"(311). To take the example given by Ives, a medical researcher who themselves is a cancer survivor would not normally be considered an appropriate PPI participant(312), posing the question of whether all lived experience is equally valid.

The right of the child to being heard and to have a voice in matters concerning them is enshrined in the UN convention on the rights of the child, article 12(27). The recognition of children's right to participation has evolved in parallel with the movement around hearing and representing the voice of the child(313). Across disciplines, the notion of voice of the child has been extensively interrogated; although the term is often used, how to capture and define the voice of the child is largely subjective and interpretative(314). How we approach participation with children and conceptualise their rights is informed by our constructs of childhood and adolescence. We conceptualise children variously as rights-holder, possessions or extensions of their parents, as powerless and as vulnerable and in need of protection(315). When we consider participation with UASC, this group are often not perceived as children or have their right to childhood denied. Some research focusses on the vicarious voice of the child, as represented by adult care-givers who know them well(314). Many examples of PPI around research with children is in fact with their adult carers(314), presumably drawing on this justification. A exploration of 'voice' in child protection highlights the danger of 'filtering' of the child's voice by adult professionals around them(313). In the case of UASC, few adult caregivers know the young people well, and professionals around them may have their own biases and preconceptions. Researchers are more likely to give a voice to those we

perceive to have capacity(316); and among groups such as UASC, how voices are heard and valued will inevitably be informed by the wider socio-political context. In examples of PPI activities, and practical guidance on undertaking this, there is a failure to conceptualise the 'voice' of vulnerable young people such as UASC. The realities of this situation are at odds with discourses of children and rights-holders and the child's right to participation.

A debate that informed the drafting of the UNCRC is that of the right 'not-to' as a mirror of the enshrined right to participate. This issue is echoed in other areas of social and legal policy, such as where a child's parents are separating, where it is recognised that placing responsibility on the child to be the decision-maker may be inappropriate(317). This recognition is largely absent from the discourse around PPI. The absolute requirement of PPI to secure research funding and ethics committee approval, without due consideration of the right not to participate, could represent a risk of exploitation of the groups in question(318).

It is clear that the construct of PPI is drawn from a series of interrelated and interdisciplinary traditions; However, in its current construction, may be oversimplified and certain complexities ignored, with consequences for both its practical application and for ethical research practice.

7.4.4 Literature review and the history of PPI

In the UK, from the 1990s there was a move towards citizen participation in healthcare, as well as in other fields such as law and education. There were increasing calls at this time for accountability, particularly of government-funded healthcare, and a move from a 'passive' conceptualisation of involvement mechanisms to more 'active' ones. Parallel movements around accountability to citizens in healthcare were taking place in other high-income countries, particularly Canada, the US and Australia. Prior to this period, at least in the NHS, there was perceived to be a 'democratic deficit', and historically decisions had lacked scope for local population decision-makers(319). The 1990s brought in a range of mechanisms for citizen involvement, the majority around healthcare decision-making such as priority setting, health systems and public health, rather than around health research. One example was 'Citizens juries', where a group or panel of citizens specifically informed decisions on rationing decisions in healthcare(320). Patient engagement, patient and public involvement and similar terms, both in healthcare decisions and in health research, start appearing in the medical literature from about 2004.

In the scientific literature on involvement practices in the 1990s and early 2000s, there are frank explorations of what PPI means, its purpose, and associated complexities and limitations. The definition of who the patient or public are is interrogated in several articles(320); there are warnings against conflating patients

with the public, highlighting that these are different groups with presumably different perspectives and agendas(320). Others questioned the representativeness of any small group, when recruitment is typically “purposive”(321). One review suggests three groups for potential involvement: patients, the public and organised patient interest groups(321), raising the issue of whether interest groups, or even activist groups with a defined agenda, are appropriate recruits for involvement. Several articles discuss the actual or perceived tensions arising from conflicting agendas in involvement(322, 323) and a 2002 Canadian discussion paper recommends the need to acknowledge tensions and conflicting goals in citizen involvement(323). A 2004 editorial highlights that the ethical issues around PPI require clarification, citing two possible stances on this: “some take the view that all investigation of patient and user perspectives is research and therefore subject to formal research ethics approval. Others say that the ordinary standards of market research are sufficient to cover patient surveys and other customer satisfaction measures.”(324) Nearly 20 years later, there is no consensus on this issue.

From the mid 2000s onwards, among UK research funding bodies, PPI was increasingly a requirement for grant applications and ethics committee applications. NIHR was a particular leader in this push, and the NIHR funded INVOLVE definition of PPI is often quoted: “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.”(325) In reviewing the PPI literature from this period, particularly from the fundings bodies, there appears to be a move away from the explorations of PPI described above. PPI is assumed to be an unequivocal good and becomes a prerequisite for funding and ethics applications. It is also striking how little attention was given to the ethical implications of PPI, with focus usually on the impact of PPI on the ethical conduct of the research, rather than any considerations for those involved in PPI as participants. Some examples in the literature from the last few years buck this trend, with increasing discussions around ethical implications of PPI and the interface between PPI and research. As illustrated in the case example, most institutions have no current consensus on these issues and researchers are therefore left with conflicting advice. As part of my work on this topic I contributed to a project at UCL around ethics in PPI and co-production. The report outlines a lack of clear definitions on when PPI is considered research, and inconsistent decision-making by institutions(326). A 2022 report from the Association for Young People’s Health echoes similar themes: that there has been a lack of focus on non-research forms of engagement and that necessary procedures are lacking(327). Both reports recommend that the process for ethical advice as well as formal ethical approval is less rigid and more dynamic throughout a project.

7.4.5 Distinguishing PPI from qualitative research

To support the concept that PPI and research are separate entities, funding bodies have created various tools and pieces of guidance to help researches distinguish

PPI from qualitative research. However, reviewing this literature exposes inconsistencies and contradictions inherent in this premise.

Several published tables compare features of qualitative research and PPI, side by side(308, 328, 329). Differences are suggested around the intent of the project, e.g., whether to inform the research (PPI) or to address the research question (qualitative research), the output of the activity (formal data in qual research) and the methods used. One distinction often cited is that research should produce “generalisable or transferable findings”(330), whereas PPI findings are not transferable. On reviewing the literature, this distinction does not appear to hold up to scrutiny. Common examples of the impact of PPI include improving information for patients, choosing appropriate outcome measures and advising on what would be ethical acceptable in research (331); it is not clear why these kind of PPI findings should not also be generalisable, at least to other research with the population of interest. The issue of whether ‘data’ is collected or not, and what constitutes data, is also problematic. Guidance stating PPI should not produce data(332), seems at odds with increasing pressure for PPI evaluation and impact assessment(333). One suggestion from a recent NIHR publication suggests that “informal” data collection is allowed in PPI, for example if this is restricted to “sticky notes”(308). Publication is another contested area, with examples of journals requiring ethics committee approval, even when the project was considered PPI(326).

Clearly, many of these assessments will be subjective, and which side of the research/PPI divide the project falls on may be influenced by the desire to avoid the complex process of formal ethics committee approval. None of the tools available for distinguishing research from PPI appear to consider whether the project would present ethical issues for the participants.

7.5 Discussion

7.5.1 Ethical and practical considerations of PPI

Some of the ethical justifications for undertaking PPI have been discussed above. Justice, accountability and value of lived experience all contribute to this model. Here I will address some of the ethical complexities of the process of involvement, and implications for PPI participants.

Firstly, I consider how participants are identified and approached for PPI. The paradigm of a PPI participant is that of an English-speaking, competent adult who desires to be involved in PPI. How to recruit for PPI is often left vague in the guidance, and where suggestions are given, these rely on participants being engaged in healthcare, education or the workplace(334). Reviews suggest that PPI

recruitment often happens through interpersonal networks(335), and that the same candidates are approached repeatedly for different PPI projects(336). Unsurprisingly, the typical PPI participant is white, educated, retired and often with a science background(334, 336). This lack of diversity or representativeness, and importance of addressing this, is widely acknowledged in PPI reports and literature(334, 336, 337), but concrete recommendations for going about this are limited. PPI guidance from 2017 suggests “going into their communities, targeting employers, contacting schools and university students”(334). This recommendation presents ethical concerns in relation to researchers ‘invading’ private spaces or using confidential information without consent for the purposes of PPI recruitment. A similar issue is present if recruitment is via the NHS, with potential ethical implications to when using confidential patient information for the purpose of PPI, exempt from formal ethical approval, in this way. The researcher, who is part of the medical team, and who approaches potential participants, introduces another dynamic; it might be difficult for potential recruits to say no, either due to a perceived obligation, or due to a power imbalance between themselves and the researcher.

If a participant is recruited for PPI there are often ongoing obligations associated with this. The same power dynamics that affect recruitment may continue to influence whether the PPI participant contributes and remains involved, even if they may not wish to be. There is conflicting guidance on whether informed consent is required for PPI(330, 338), meaning that participants may not be fully aware of their rights to not participate or withdraw at any stage. Whatever form PPI takes comes with a burden to the PPI participant, potentially their time, effort, emotional labour and requirements for training. There are several examples of unintentional breach of confidentiality being an issue during PPI events(325). Given the topic frequently relates to the medical conditions of participants, it is understandable that participants might share personal stories revealing their own diagnoses. Similarly, managing and communicating the outcome of the PPI presents ethical problems. Participants may understandably feel that they want to make a difference and that their input is valued, and perceptions of tokenism or PPI for box-ticking purposes undermine this(339). Some of the limits imposed on PPI impact, such as not being able to generalise findings, and barriers to publishing findings, can play into this, raising the possibility that participants may find the experience disempowering(325).

7.5.2 Ethical and practical considerations of PPI with migrant children/UASC

All of the examples above will also relate to children involved in PPI, but the status of childhood presents an additional set of ethical considerations. In the same way as among adults, examples of participation and involvement of children are based on the paradigm of an English-speaking, educated child with parents and no disability or mental health problem. The central assumption of all PPI recommendations is that the patients want to be involved. To take the example of UASC, their mental and

physical health, prior cultural and educational exposure, financial position and perceived vulnerability to decision-makers, will all add complexity to their situation. It is not unreasonable to question why UASC might want to be involved at all. The wider arguments about democracy and representation in science may not have personal resonance for them. The time and logistical requirements of attending events are more complex, with financial hardship, reliance on caregivers and the appointment burden across health and asylum claims all presenting barriers to engagement. Most PPI guidance recommends financial compensation for PPI activities at an hourly rate. However, it is illegal for any payment to be made to those who's asylum claims are undecided, and as such have no recourse to public funds. For the majority of UASC, an interpreter is required for any interaction. The challenges of interactions via interpreters, including the additional complexity of the interpreter's opinions and perceptions, has been extensively explored in qualitative literature. In my literature search around PPI, I was unable to find any guidance on PPI using interpreters, and the cost, logistics and risk of re-traumatisation all make this a more challenging area. The concept of PPI is often confusing to participants(336), even adults, and adequately explaining the purpose and requirements of PPI to UASC who may have limited education, via a translator, is likely to be even more challenging. Perceiving and understanding the differences between PPI and research also raises the issue of informed consent, and whether we can be confident this is obtained. As discussed in the literature review on UASC voices (Chapter 1), distinguishing between researchers, health professionals or other professionals interacting with UASC (home office staff, solicitors, police), assumes a level of understanding of the complex structures and systems that currently operate in the UK. This issue also plays into the power dynamics of recruitment, as UASC understandably concerned about their asylum claim may wish to please every adult in a position of power, without a clear understanding of the distinctions between roles.

A recent description of co-produced participatory research with young unaccompanied asylum seekers (aged 16-25) illustrates some of these complexities(300). The researchers describe adhering to strict ethical protocols in a project where young asylum seekers were peer researchers contributing to all stages of the research. It is slightly unclear whether the initial ethical considerations applied equally to the peer researchers as to the subjects being researched. But authors describe becoming aware as the research progressed that the peer researchers were struggling with the research in several ways, often related to their own experiences of trauma. The group responded by moving to a trauma-informed approach (see Chapter 1.) within the participatory research, intending to minimise harmful impacts on the peer researchers while continuing the project(300).

This example is unusual in the consideration given by the research team to ethical concerns, and the willingness to reflect on methods and adapt. Within the discipline of health research, in PPI “researchers” would not routinely have the same background or training as participatory researchers. As such, the ability to show reflexivity, consider power imbalances, to interrogate their own motivations, and challenge their own assumptions and desires is unlikely to be present.

The tension between the rights of a group to be included in research about them, and the problems or potential harms of that inclusion, has been acknowledged and explored(315). It may be helpful not to approach ethical decisions in absolute terms, and it has been proposed that there is no such thing as perfectly ethical research(315), but instead a balance of risks, a sentiment that can also be applied to PPI. However, given the multiple ethical barriers and complexities described, and the inconsistencies and limitations of PPI guidance, it is challenging to conceptualise a model of PPI with UASC that would not risk harm in undertaking.

7.6 Conclusion

Here I have reviewed and outlined the recent history and current construct of PPI. I have explored some interdisciplinary concepts that underpin this, raising questions about conflicting interpretations and inherent contradictions in our current understanding of PPI. Over the past couple of years there have been increasing discussions of the blurred boundaries and contradictory advice around PPI and qualitative research, and about the ethical dimensions of PPI, and I am not the first to point these out. To my knowledge, this is the first exploration of the implications of these issues for vulnerable groups such as UASC. I have used the case example of my own experiences attempting to work with UASC to highlight the effects of these issues in the current climate, demonstrating how inconsistent advice and ethical complexities, have ultimately prevented both engagement and research with this group.

I have used the example of UASC throughout this chapter to critique and explore the current model of PPI, but many of the issues and complexities raised would apply to other marginalised populations. My contention is that the mandatory requirement for PPI, and the limitations of the existing model of PPI may prevent research with many marginalised groups, unintentionally perpetuate the inequities it is designed to address.

Following my experiences described in the case example, I was invited to contribute to a UCL project on research ethics when working with people outside the university (for example in PPI). This report highlights similar issues to those raised in other

reports: the need for ethical considerations throughout the duration of any project, and that current ethics approval processes may not be the best way of doing this; the inconsistencies around definitions and PPI and research, and inconsistent advice on need for ethical approval; current ethics review processes being unsuitable for PPI activities; and issues around power sharing with public participants. However, despite these issues being highlighted, at present the issues are largely unresolved, and no changes have been made to ethics approval processes or PPI requirements.

There are examples in the literature of ethical research with UASC and similarly vulnerable groups. As I have argued, I believe that the PPI/qualitative research distinction is inherently problematic. To adequately consider and address the multiple ethical and practical considerations of engaging a group such as UASC, I believe that a much more considered and thorough approach is required, which is likely to require aspects of training for researchers and qualitative methodologies that would have more in common with models of qualitative research than what would usually be considered PPI.

The challenges of the current process for ethical approval, particularly within the NHS, has been highlighted. Key issues being the extensive red-tape and administrative burden, as well as the artificial nature of ethical approval happening at a single, fixed point in the research cycle. There are also issues around a process developed for medical research being largely not applicable, and fitting poorly, to the considerations of qualitative research. My contention is that there should be an ethically informed process throughout all stages of any engagement activity. Ethical considerations should also be guided by the nature of the group and project in question, rather than a 'one size fits all' model. While the current situation exists, I believe the mandatory requirement for PPI as a pre-requisite for starting research should be urgently removed and replaced with a more flexible, considered, model of promoting engagement, without losing focus on the needs of the group in question.

Chapter 8: Discussion

In this chapter I will present an overview of my key findings, chapter by chapter, with reference to the chapter hypotheses, and discuss the strengths and limitations of my research. I will address the overall aims of the thesis using methodological triangulation to synthesise findings from the different methodologies and projects forming sections of my thesis.

The chapter ends with policy recommendations, gaps in the research and next steps.

This discussion addresses both aims of this MD(Res) and the longer-term goals:

1. To map the current state of research into migrant child health outcomes, and
2. explore how services could be better configured to meet the needs of migrant children, with a focus on UASC, as a particularly vulnerable group.

The longer-term goals of this MD(Res) are to improve the health service experiences of forced migrant CYP in England, and inform service development, interventions and research direction with a view to engaging, supporting and improving outcomes among UASC.

8.1 Summary of key findings by chapter

The key findings from the chapters presenting results are shown here. These include the two chapters presenting systematic review results, the two chapters on data and services for UASC, and the chapter on ethics and PPI. The results of the various sections are discussed together with reference to the overarching aims of the thesis in the methodological triangulation section.

Chapter 3 - Findings of this systematic review demonstrate a paucity of research on mortality among migrant CYP, with existing research limited in quality and biased towards high-income settings. Findings show health inequities between migrant CYP and the host population in cause-specific mortality. The systematic review is the first, to my knowledge, to explore the “healthy-migrant” hypothesis in CYP, although data were too limited to draw conclusions. Evidence for a migrant CYP mortality advantage was lacking, with equivocal evidence for mortality risk in migrant CYP compared with the host population. Results of comprehensive studies from population datasets in high income countries showed contradictory results, warranting further research.

Chapter 4 – Results of this systematic review demonstrated a high number of studies on communicable diseases among migrant CYP but a limited number of higher-quality studies with control groups. Consistent with my hypothesis, the evidence base was not reflective of the global population of migrant CYP, being predominantly forced migrant populations in high-income countries. Identified studies with control groups showed higher rates of communicable diseases, particularly active TB, among migrant CYP as hypothesised. The highest rates of communicable diseases in identified literature were among migrant CYP from Africa. Most studies were on TB, and significantly increased rates of active TB were demonstrated in migrant children compared with the host population. There was some evidence that migrant children in the host country were more susceptible to epidemic infections and had worse outcomes once infected. Incidence rate differences in childhood were highest in the adolescent age group in two studies, and several studies showed the adolescent group of migrant CYP having higher rates of communicable diseases than younger age groups.

Chapter 5 - The UASC evaluation is a significant addition to the literature on health needs among separated migrant children, demonstrating an exceptionally vulnerable population. Consistent with the hypothesis, this UASC population demonstrated extremely high rates of communicable diseases warranting treatment, mental health problems, historic physical and sexual abuse and assault. Barriers to data collection and engagement with services were also demonstrated, including inconsistent names and dates of birth. An integrated pathway model was described representing a more comprehensive and holistic service than the standard of care for UASC. This

pathway was successfully implemented, representing a new service delivering appropriate care.

Chapter 6 - An integrated pathway model for UASC was demonstrated to be feasible and acceptable, with successful implementation in a second borough. Following input from patients and their communities, a trauma-informed care (TIC) approach was taken in developing this service. UASC health needs data support the hypothesis that UASC have additional vulnerabilities requiring a more comprehensive and holistic service. Pre/post implementation comparison demonstrated improvements in short-term and process-related outcomes following pathway implementation. These results support the hypothesis that the integrated pathway model has the potential to improve outcomes among UASC.

Chapter 7 - In the exploration of the ethics and PPI in migrant CYP, consistent with my hypothesis, I demonstrated blurred boundaries and contradictory advice in existing guidance. My contention is that the mandatory requirement for PPI, and the limitations of the existing model of PPI may prevent research with many marginalised groups, unintentionally perpetuating the inequities it is designed to address.

8.3 Strengths and Limitations

Strengths of this thesis include the broad scope and comprehensive search strategy of the systematic review, which addressed an important and previously unaddressed research question. Mapping the existing data to understand gaps and limitations is crucial to informing evidence-based policy and planning next steps in research. Systematic review methodology was in-line with up-to-date guidance on systematic reviews including PROSPERO recommendations, PRISMA checklist, the NOS scoring tool and SwIM guidance.

Limitations of the systematic review include searches being undertaken in 2021, meaning that they are now out-of-date with the potential for new evidence to have been missed. In this thesis only the communicable diseases and mortality results are presented, rather than all proposed health outcomes to take a life-course approach. I plan to complete the results for the remaining 6 domains in the next 2 years and work on two of these domains is ongoing at present. The systematic review also only addressed health outcomes within the period of childhood, therefore not capturing the longer-term impacts throughout the life-course.

The UASC evaluation was the largest of its type in the UK and added to the literature on health needs among separated migrant children. A comprehensive picture of health needs was possible through data compilation between three boroughs, providing a level of detail not usually available in NHS datasets. Although they represent only a small population numerically in the UK, UASC represent an exemplar group for health needs, service requirements and lessons learnt. They are children, recently migrated, and subject to forced migration, as well as being exceptionally vulnerable due to their unaccompanied status. Additionally, they are visible to services, including health, due to statutory requirements around their status as LAC. The universal requirement for the IHA has been the foundation of means of data collection and service development described in this thesis, and there are relatively clear data on numbers of UASC due to their legal definition. One of the major challenges around the care of migrant children globally are issues of visibility and means to define the population of interest.

The description of a pilot implementation of the UASC pathway had significant limitations. Data were incomplete across both implementation measures and evaluation of the health needs. Data that were collected were a very small sample size, limiting impact in terms of adding to the evidence-base around UASC. There were also multiple challenges around disruption associated with the Covid-19 pandemic, and cost limitations, meaning the timeline was extended and delivery of aspects of the service were delayed or prevented. However, as proof of concept in a real-world setting this project achieved some success, demonstrating improvement in process-outcomes leading to ongoing funding being secured.

The analysis in this thesis is predominantly based on cross-sectional data, and as such, cannot demonstrate a causal link between migration and health outcomes. However, this limitation is common to all social determinants of health, where it is not possible to randomise to truly assess causality. There are limitations of quantitative research methods, including those of meta-analysis, for social determinant of health such as migration status. Results must take account of potential for reverse causation or selection bias with migration, a likely contributor to the “healthy-migrant” effect in adults. The nature of migration, particularly forced migration, presents barriers to longitudinal data collection. It is rare to have pre-migration data, given that it is not usually known which individuals will migrate. Forced migration is often an emergency, involving disruption of usual pathways and methods of data collection, transit through multiple countries, who may be hostile to each other, with no means of data sharing or identification of migrants.

8.4 Methodological triangulation

I will use methodological triangulation to address a series of research questions, informed by the overall aims of this MD(Res). This will involve drawing on the three main components of my work: the systematic review, UASC service evaluations and the exploration of PPI ethics and implications for the voice of the child. These three components are underpinned by differing methodological approaches: the purely quantitative systematic review is protocol-driven, involving comprehensive review, data synthesis and statistical models for meta-analysis; the UASC service evaluations are predominantly quantitative but draw on more descriptive methods with the second evaluation utilising implementation science, iterative approaches, adaptation frameworks and QI methodology; and the PPI and ethics chapter is informed by qualitative and social science approaches to examine structures and ethical dimension, involving reflection, discourse review, and an exploratory approach informed by the political, social, cultural, economic factors. An additional source of perspective and context is provided by the existing literature, as outlined in the introduction, the changes in awareness and medical guidance throughout this MD(Res), and the shifting political discourse around migrants and migration.

Methodological triangulation is a technique to construct multiple perspectives or approaches to the same research question, which are derived from different methodologies(340). This technique has the advantage of adding depth and richness to conclusions derived where qualitative methods can complement the more quantitative approaches used in other projects. This may be particularly well suited to the topic of migrant child health, where the status of migration has social and cultural dimensions that may be poorly reflected in empirical studies alone. There is also a temporal dimension to both the state of migration over time and to the discourse around migrant rights and the voice of the child. The rapid changes in legislation and policy in the UK, alongside changes in the political discourse on migrants, migrant health and rights of migrant children and summarised above. Racism and xenophobia have been rising in mainstream political discourse with the rise of far-right politics in multiple countries. Again, single studies or metrics may inadequately reflect this and are unlikely to provide an up-to-date perspective on these changes. In this section I will draw on the overview of changes provided above to contextualise and update the implications of my findings. A further advantage of methodological triangulation is that of drawing a narrative between different groups and definitions of migrant CYP. As discussed, one challenge of research in this field is that of defining the population of interest and the visibility of various groups of migrants.

The first aim of this MD(Res) is to map the current state of research into migrant child health outcomes. The first two research questions address this aim. The second aim is to explore how services could be better configured to meet the needs of migrant children, with a focus on UASC, as a particularly vulnerable group. The third and fourth research questions address this aim.

8.4.1 Question 1:

What is the current state of international research into migrant child health outcomes?

The systematic review results demonstrate a significant paucity of research on mortality among migrant CYP. Only a handful of studies were identified that used regional or national datasets, and data were insufficient to draw meaningful conclusions on the mortality of migrant CYP compared with the host population. Communicable diseases were much more frequently addressed in the literature, but although numerically there were high numbers of studies of communicable diseases, very few were of high quality and few included a representative control group from the host population. For both outcomes, available data were often from within a larger study on all age-groups. There was rarely adjustment for confounding factors specific to the paediatric age-group; in the case of mortality, no studies made clear that the typical distribution of mortality risk across childhood was controlled for.

Existing literature, particularly comprehensive studies from population datasets, is predominantly from the global North. Although approximately two thirds of international migrants of all ages live in high income countries, we know that 80% of refugees live in LMIC(9), and relatively speaking, more migrant CYP are hosted in LMIC than adult migrants(341). The existing literature is therefore particularly poorly representative for migrant CYP. Very few studies were longitudinal, and given the dynamic process of migration, at present we have little insight into the impact of the various stages of migration, or the health impact across the paediatric life-course. Among older adolescents, including UASC, who are close to adulthood, studies only addressing the health impact under the age of 18 fail to reflect impact over time. At present, evidence on impact of childhood migration across the life-course is limited, with particularly limitations around establishing causality between childhood exposure and adult outcomes(342).

There are multiple studies on small groups of separated child migrants in high income countries, but the UASC evaluation appears to be the largest of these in the UK. There is an emerging body of literature around mental health in UASC or equivalent populations, but limitations include lack of studies across the period of transit and data on longitudinal outcomes. The UASC evaluation demonstrated

barriers to research with this group around inconsistent patient identifiable information (name order, name spelling and date of birth), even following arrival in the host country. These barriers are likely to be even more significant across international border when language, cultural norms around names and approaches to age estimation will all vary. The PPI ethics exploration demonstrated inconsistencies and contradictions in guidance that present structural barriers to research with groups such of UASC. This exploration was specific to UK guidance but there are likely to be similar barriers in other high-income settings. Our increasing awareness of the vulnerability of groups such as UASC may also mean that ethics committees are more likely to prevent research with these groups. These factors are all likely to have contributed to the limited evidence base on UASC health needs. In the absence of clear guidance and in the face of ethical and structural barriers, any research or engagement with UASC will continue to be challenging.

Accompanied refugee children are less well represented in the literature and undocumented migrant CYP have almost no studies addressing their health outcomes. It is difficult to know accurate numbers but a recent estimate places over 200,000 undocumented migrant CYP in the city of London(343). Across countries, migrants have variable legal status and CYP may not be recognised or afforded rights in line with their age. Aggressive measures around age assessment in the UK, including expanding the powers of the government in ruling young people are adults, are likely to further impact visibility of vulnerable migrant CYP.

The skew of existing research, including bias towards more visible groups, and towards strictly medical outcomes such as communicable diseases, is in keeping with research not being informed by the voice of migrant CYP themselves(86). Where migrant CYP's views have been sought, a broader and more holistic perspective of outcomes is favoured, including factors such as social integration, asylum claims and education(42, 99, 104).

The Global Compact for Migration recommends both to “*collect and utilize accurate and disaggregated data as a basis for evidence-based policies*” and to “*Ensure that all migrants have proof of legal identity and adequate documentation*”(116), although there is debate as to the logistics and impact of such a step(344). The data plan includes disaggregation by migrant subgroup and by child status (defined in GCM as <19 years). Both of these measures, if successful, would have significant impacts on the scope and quality of available data on migration.

8.4.2 Question 2:

What do we know about health outcomes among migrant CYP?

The systematic review showed excess cause-specific mortality among migrant CYP compared with the host population in almost all identified studies. However, for studies of all-cause mortality overall results were equivocal. Some individual studies suggested there may be a “healthy-migrant” effect among migrant CYP, but interpretation is limited as described. Evidence on communicable diseases showed higher rates among migrant CYP compared with the host population, but results should be interpreted in the context of high-income host settings with migrant CYP typically from LMIC. Both mortality and communicable disease rates were very high in studies of forced migrants and in refugee camps, but typically these studies had no control group. There was some indication in both the mortality and communicable diseases results that migrant adolescents may have increase risks compared with migrant children of other ages.

These findings are in keeping with the evaluation of the UASC pathways (Chapters 5 and 6) which did show significant rates of communicable diseases warranting treatment among UASC. Findings also showed high rates of mental health and historic physical and sexual abuse and assault, adding to the literature on health needs of UASC and providing some of the most pronounced evidence of vulnerability of any dataset. Typical UASC are in the adolescent age-group and a high proportion have migrated from Sub-Saharan Africa, both identified as higher risk groups in the systematic review results. The UASC evaluation showed higher rates of reported mental health symptoms and reported abuse/assault than other studies on similar groups. This finding may be explained by the involvement of mental health practitioner in assessments and the trauma-informed care approach taken by all staff, i.e. both asking the necessary questions and the way they are asked. As explored in the ethics and PPI section, there is a recent example of co-produced participatory research with young unaccompanied asylum seekers. This study did encounter challenges but took both a responsive and trauma-informed approach, to minimise potential harm while completing research informed by the voice of the migrant CYP(300). This approach may serve as a model for undertaking research with this group.

From the literature review on the voice of the child (Chapter 1) and the ethics and PPI exploration (Chapter 7), there is a lack of representation of the views and opinions of migrant CYP in research around their needs. The barriers demonstrated in the ethics exploration may go some way towards explaining the persistent failure to include migrant CYP, despite this being identified as need for several years.

The evaluations of the integrated pathway models demonstrate the potential for this model to improve health outcomes among UASC. Existing health services in the UK are insufficient to meet the high level of unmet need demonstrated in this study. Rates of trauma, social and educational need and language barriers all support the

need for an intersectoral approach, in keeping with technical guidance for refugee children(53).

8.4.3 Question 3:

How could services be better configured to meet the needs of migrant children (with a focus on UASC) in the UK?

Evidence suggests that forced migrant CYP have adverse health outcomes related to their migration status. Modelling in terms of the social determinants of health helps to considering potential targets for services to improve outcomes. The systematic review showed increased cause specific mortality among migrant CYP for causes such as road-traffic accidents, burns, heat-related causes and work-related causes. All of these are plausibly associated with poor living conditions, working conditions, and insufficient legal protections of migrant populations. These areas would not be amenable to strictly health-based interventions, and they support the argument for services for migrant CYP to be intersectoral and encompass accommodation, education or working conditions, and economic considerations. There are some limitations in the ability of interventions to address these risks, and living conditions for migrants need to be improved on a national level.

There was also evidence from the systematic review of inequitable outcomes between migrant and host CYP already living in the host country, for example having higher risk of contracting communicable diseases, late presentations for cancer and higher risk of disengaging with treatment. These inequities are similarly related to conditions in which migrant populations live in host population. Contributing factors include language and cultural barriers, stigma, poor education and poverty.

As described, the integrated pathway for UASC provides an example of a service with the potential to meet the health needs of UASC and address barriers to their engagement. There is an evidence-base behind individual components of the pathway such as case management by the HIP(54), a focus on communicable diseases and a holistic approach to mental health(53). Universal screening for communicable diseases at the outset of this thesis was rarely performed. This feature is supported by systematic review results which indicate a high risk of communicable diseases in migrant CYP, particularly forced migrants in high income countries. The integrated pathway has a focus on involving and including migrant CYP and their communities in development and implementation of services. Although not co-produced, a significant degree of involvement from current and former refugee children, and with organisations who work with this group, informed this work. The exploration of ethics in Chapter 7 demonstrates the difficulties around directly involving current UASC, at least within existing guidance, so professionals and stakeholders also played an important role in informing this service.

The PPI input into this thesis, the pilot implementation (Chapter 6) and the ethics exploration (Chapter 7), all support the need for a trauma-informed care (TIC) approach for migrant CYP. Although this approach is grounded in evidence on the impact of trauma and risk of re-traumatisation(63), there is limited evidence at present for TIC to improve outcomes. Increased rates of symptom reporting in the UASC evaluations (Chapter 5 and 6), particularly mental health and disclosures of abuse and assault, may be due to the TIC. Enshrining TIC in processes and service delivery requires training for all staff members involved. There is evidence from a recent survey of UASC care(55), and from the pilot implementation evaluation (Chapter 6) that healthcare staff feel they require more training in the care of UASC and benefit from being trained.

The integrated pathway for UASC in England is made possible by the statutory requirements around looked-after children including the need for an initial health assessment within a month, and the visibility of UASC in datasets. A much bigger challenge is how to design and target services towards other vulnerable groups of migrant CYP, such as accompanied refugee children and undocumented migrants. The situation in the UK may become more challenging with the impact of the Nationality and Borders Act, when children may be locked-up or inaccurately assessed as being adults. In the next steps section below, I describe a planned project to explore generalisability of existing interventions to other groups of migrant CYP.

8.4.4 Question 4.

What are the policy implications of these findings?

Policy should focus on equitable access of healthcare and equitable outcomes for migrant CYP. In the UK at present all migrant CYP should have access to healthcare, regardless of their legal status, and should not be subject to charging for healthcare. However, there are barriers to migrant CYP accessing and engaging with healthcare as outlined above; confusion around entitlement, fear of threat to their legal status and fear of being charged, also contribute to these barriers(170). Migrant children's right to healthcare is enshrined in the UNCRC, but despite this, multiple countries, including in Europe, place restrictions on healthcare access for this group(28). For the wider group of migrant CYP, including those who migrate with families, global policies should address structural racism and the social determinants of health. Housing, education, poverty and discrimination all contribute to outcomes among migrant CYP.

For more marginalised groups of migrant CYP services need to be holistic, comprehensive, integrated and multi-sector. There is guidance on best practice in this area(53, 277) and the findings of this thesis support these. Health needs such as

communicable diseases and mental health should be promoted, but a more holistic view of wellbeing should include consideration of friendships and social support, access to sport and education, advocacy and legal support. A close link with social care is required based on the historic evidence of abuse and assault as well as ongoing trafficking risks highlighted above. Based on my research, these services should also take a TIC approach and take measures to include and involve former and current migrant CYP and their communities. This approach potentially both improves mental health outcomes by addressing trauma, and builds trust and rapport between young people and professionals, helping to promote better overall care. There is a clear need for improved training of all staff working with migrant CYP, both in managing their health needs and providing a TIC approach. Standardisation of health protocols between countries would support the delivery of high quality healthcare to the more vulnerable groups of migrant CYP.

In view of the highlighted barriers to involvement and research of migrant CYP, updating of the current PPI guidance including removing mandatory requirements and clarity around the need for ethical approval is needed urgently. My research supports the need for reform of ethical approval processes, with a move towards a more dynamic and flexible approach, that is accessible by patients as well as researchers. Following this, research is needed on what approaches are needed to support and engage migrant CYP in dialogue around their health needs, research and services.

In the UK and internationally there is a need to advocate for and champion the rights of migrant CYP. Evidence suggests that numbers of forced migrant CYP are likely to continue to rise significantly in future years(9). At present they face discrimination and rights-violations in transit and following arrival. Additionally, unmet health, social and educational needs in childhood create a future individual and state burden of need. There are large numbers of advocacy and charity groups in the UK working in this area, but the overall political situation has objectively deteriorated in recent years.

There is a clear case for the need for better data collection around migrant CYP, particularly groups that may be less visible such as undocumented migrants. Coordinated systems are required to collect data across cross borders and wider geographical regions. There is a tension between the need for identification of migrants for research purposes, and the potential use of these same data to restrict migration or criminalise those involved. Measures to collect accurate disaggregated data on migrant populations need buy-in from international organisations and governments, which the GCM may help to promote. Political shifts and media narratives around migration are likely to impact these measures. Evidence is also required on the impact of various interventions to improve and promote migrant child health. At present, there is more research on interventions around mental and

physical health for marginalised populations, but scant evidence for inter-sectoral interventions such as housing, education and legal support. Evidence on views of migrant CYP themselves(54), and the findings in this thesis, support the need for interventions encompassing these broader elements. Research on implementation and adaption of interventions to different contexts requires different methodologies and outcomes measures, as described in Chapter 6. But real-world evaluations of implementation are crucial to inform evidence-based policies on interventions for migrant CYP.

8.5 Future directions and next steps

The next steps in terms of the research presented in this thesis will firstly include completion of all health domains in the systematic review. In addition to mortality and communicable diseases, the preliminary searches were undertaken for non-communicable diseases, over and under nutrition, mental health outcomes, disability, vaccine coverage, and accidental and non-accidental injuries (e.g. assault and abuse). All of these results will be valuable in mapping out the available evidence on migrant child health across the paediatric life-course. At the time of submission I have supervised a junior doctor undertaking analysis of the vaccine coverage results, and have recruited a second junior doctor to undertake the disability and abuse/assault domains. The literature overview and number of search results would indicate that these areas are under-represented in the literature, despite their importance.

As described above, I am part of a team who have secured Barts Charity funding (~£650,000) to expand and evaluate the integrated pathway for UASC across boroughs in North-East London. This project includes elements of qualitative research and will assess cost-effectiveness and potential for scale-up on a national scale. This project is in line with step 4 of the APAPT process (a framework for adapting implementations to new contexts) described in Chapter 6 is to “Implement and maintain adapted intervention at scale” while responding to the “Changes in intervention-context fit over time”(288).

I am also a co-investigator and workstream lead on an NIHR programme development grant (~£250,000) Advancing Equity for children and young people seeking asylum and refugees: a blueprint for Generalisable InterventionS (AEGIS). This proposal has several workstreams including co-produced qualitative research on outcome measures for migrant CYP, a scoping review of interventions for migrant CYP, and a data linkage project to identify social, educational and health outcomes among refugee children in a national database. This project involves a large collaborative team including social care, qualitative researchers, legal expertise and health professionals. We are also seeking to generalise lessons from UASC services to other populations of marginalised migrant children.

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Appendices

Appendix 1. – Listening to unaccompanied asylum-seeking children: A patient engagement study

Why?

Unaccompanied asylum-seeking children (UASC) are known to have high rates of physical and mental health problems but poor engagement with health services. We don't know how best to plan and design services to meet their complex needs.

Existing services, and healthcare outcomes, have not been developed in conversation with the young people, and the importance of giving a voice to this group has been highlighted.

We hope to engage UASC in Newham and to listen to their voices. We plan to use the results of this study to inform care and services for UASC, and to design future research and projects to support their needs.

Who?

UASC engaging with the Newham community paediatric service will be eligible to take part in this study. This group are

predominantly male and aged 16 or 17. Common countries of origin include Sudan, Ethiopia, Eritrea and Albania.

The study team are based at UCL and at East London NHS Foundation Trust. The study is funded by the Bart's Charity.

What?

The following sessions are planned:

1. Two one-hour long art and creative workshops for about 6 UASC with interpreter support. The output will be participant-directed but could include developing creative material on experiences, needs, and perceptions. This will also function as a scoping exercise to ascertain barriers to engagement and unmet needs of the group.

2. Two one-hour long focus groups with UASC and interpreter support. To explore topics including user experience of existing social and health services, meaningful outcome measures and future research directions.

Participants will be given £10 vouchers for each session attending in thanks for giving up their time.

When?

These interactive sessions are planned for 2022. We wish to hold these events face-to-face therefore after Covid-19 restrictions have lifted. If government restrictions do not allow this to take place safely, virtual alternatives will be offered.

How?

All UASC have a medical appointment with the community paediatric team soon after their arrival in the UK. At this appointment they will be asked if they are happy to be contacted regarding the study and provided with a leaflet explaining the study.

A member of the study team will then get in touch with the young people to take informed consent. Participation is entirely voluntary and there will be no difference in the care the young person receives if they do not participate.

What do we need from you?

We would like to hear feedback from patients and the public in East London, including those who have an association with UASC. Participation from yourselves allows a dialogue around planning and shaping research. Please get in contact with any ideas, thoughts or questions.

Many thanks for taking the time to read this leaflet.

Dr Alice Armitage

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Appendix 2. – Patient and public involvement (PPI): An invitation to participate.

Who are we?

We are a group of researchers planning a research study with unaccompanied asylum-seeking children (UASC). We are consulting young people and professionals across London boroughs who might be interested in this group. We are interested in the views of current or former migrant or refugee children, of young people who have had contact with the care system, or of professionals who have experience of working with these groups.

What is PPI?

PPI means working in partnership with patients and the public to plan, manage and design research. This partnership can also continue to the completion of the research and allow appropriate dissemination of results. Evidence shows that PPI improves the quality of research and end-results.

What to expect from participation

If you are interested in being involved, please contact us and let us know your role. We can offer dates to arrange a virtual event either as a group or one-to-one. We are also happy to receive email feedback or to share study materials such as the patient

information sheet, consent form or interview guide for more specific feedback.

We hope to maintain partnerships over time and may invite you to join an advisory group who will be consulted on all stages of the research.

There is no requirement that you take part in PPI and if you do choose to speak to us you may withdraw at any time.

How the PPI will inform the research study
We hope to work in partnership with yourselves to:

- identify and prioritise research topics
- develop appropriate written materials such as information leaflets and consent forms
- plan, design and manage research events
- report and communicate research findings.
- have ongoing dialogue past the end of the study around dissemination of results and future work

Why participate?

Participation in PPI provides opportunities for patients, service users, professionals and the public to inform and shape research. We hope that by undertaking research in partnership with yourselves we can improve the quality and output of this

work. Your input helps us to avoid assumptions around the research participants and to value lived experiences, either as patient or professional.

PPI members have reported feeling empowered to effect change and contribute to society. We have that PPI will be a mutually rewarding experience.

Background to the research

UASC are known to have high rates of physical and mental health problems but poor engagement with health services. We don't know how best to plan and design services to meet their complex needs. Existing services, and healthcare outcomes, have not been developed in conversation with the young people, and the importance of giving a voice to this group has been highlighted.

We hope to engage UASC in Newham and to listen to their voices. We plan to use the results of this study to inform policy and services for UASC, and to design future research and projects to support their needs.

The study team are based at the East London NHS Foundation Trust and UCL. The study is funded by the Bart's Charity.

Many thanks for taking the time to read this leaflet.

Dr Alice Armitage

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Appendix 3. – Proposed additional health outcomes for systematic review

3. Non-communicable diseases (NCDs)

The risk factors for NCDs may vary between migrant and non-migrant populations, and the medical care of children with NCDs may be a motivating factor for parents migrating. With reference to the Global Burden of Disease study, the search strategy will focus on neoplasms, asthma and other chronic respiratory conditions, epilepsy and Type 1 diabetes mellitus (T1DM). With chronic conditions characterised by occasional exacerbations, such as asthma, the focus will be on exacerbations of asthma as opposed to baseline prevalence.

4. Overnutrition and undernutrition

Forced migration of children may be associated with periods of food insecurity both before and during migration, with associated morbidity(53). Following migration to middle and high income countries migrant children are at risk of becoming overweight or obese(345). I am therefore seeking to identify studies addressing both undernutrition and overnutrition in migrant children. The search strategy will focus on terms around malnutrition, under-nutrition, underweight, low BMI, high BMI, overweight and obesity. Micronutrient deficiencies, such as vitamin deficiencies, which require blood tests for diagnosis, are considered outside the scope of this review.

5. Mental health outcomes

Poor mental health is increasingly recognised as an unmet health need in childhood and adolescence and being identified as prevalent among migrant populations(66, 346). The search strategy will focus on post-traumatic stress disorder (PTSD), psychosis, depression, self-harm and suicide.

6. Disability

Disability may be higher among migrant children from countries with poor health infrastructure and has been identified as a significant unmet health need among migrant children(53, 277). The search strategy will focus on hearing impairment, deafness, visual impairment, blindness, cerebral palsy, autism, learning difficulties and/or developmental delay.

7. Vaccine coverage and uptake

Lack of access to preventative health care and disruption to healthcare access in migrant CYP affects vaccination coverage. Post-migration catch-up immunisation programmes depend upon timely and coordinated healthcare in-put(277). The search strategy will focus on immunisation, vaccination and specific vaccine-preventable pathogen targets (polio, diphtheria, pertussis, measles, mumps, rubella, hepatitis B) combined with vaccine-specific terms.

8. Accidental and non-accidental injuries (e.g. assault and abuse)

Road traffic accidents and inter-personal violence are examples of accidental injuries that may be associated with migration. It is known that migrant CYP are at increased risk of assault and abuse both historically (in their country of origin and during transit) and following arrival in the host country(39, 53). Rates of sexual assault and abuse are also high, particularly among forced migrants, and will be included in this category. The search strategy will focus on road traffic accidents or injuries, interpersonal or domestic violence, physical or sexual assault or abuse, sexual violence and rape.

If sufficient data are available, the following sub-group analyses will be undertaken, by age group (1-4, 5-9, 10-17 years), migrant subgroup (refugee, asylum seeker, child of economic migrants, student), migrant destination (World Bank income group(132)) and study quality as assessed by the NOS scale tool.

Appendix 4. – Search strategies (Ovid/Medline)

Mortality search strategy

1. exp child/
2. adolescent/
3. infant/
4. pediatrics/
5. minors/
6. puberty/
7. schools/
8. (Infant* or Child* or Schoolchild* or School age* or Preschool* or Kid or kids or Toddler* or Adoles* or Teen* or Boy* or Girl* or Minors* or Pubert* or Pubescen* or Prepubescen* or Paediatric* or Pediatric* or schoolchild* or school-child* or schoolage* or school-age*).tw.
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. "transients and migrants"/
11. "emigrants and immigrants"/
12. refugees/
13. Human Migration/
14. Human Trafficking/
15. (refugee* or migrant* or migrati* or immigrant* or immigrati* or transients or asylum or displaced person* or displaced people or displaced child* or expatriate* or departee* or foreign-born or foreign born or foreign student or international student or human trafficking or people trafficking or trafficking in people or sex trafficking or child trafficking or trafficked people* or trafficked child*).tw.
16. 10 or 11 or 12 or 13 or 14 or 15
17. epidemiologic studies/
18. exp case control studies/
19. exp cohort studies/
20. (Multicenter study or multicentre study).pt.
21. (Case control or (cohort adj (study or studies)) or cohort analy* or (Follow up adj (study or studies)) or (observational adj (study or studies)) or longitudinal or retrospective or cross sectional or cross-sectional).tw.
22. 17 or 18 or 19 or 20 or 21
23. 9 and 16 and 22

24. Case report.tw.
25. letter/
26. historical article/
27. 24 or 25 or 26
28. proteins/
29. cells/
30. membranes/
31. animal migration/
32. birds/
33. (membrane* or cell* or bird migration).tw.
34. 28 or 29 or 30 or 31 or 32 or 33
35. 27 or 34
36. 23 not 35
37. limit 36 to (english language and yr="2000 -Current")
38. (shunt* adj migrati*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
39. (pin adj migrati*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
40. 38 or 39
41. 37 not 40
42. mortality/
43. "Cause of Death"/
44. Child Mortality/
45. fatal outcome/ or hospital mortality/ or infant mortality/ or mortality, premature/ or survival rate/
46. (mortalit* or case fatality rate* or death rate* or fatal outcome*).tw.
47. 42 or 43 or 44 or 45 or 46
48. 41 and 47

Communicable diseases search strategy

1. exp child/
2. adolescent/
3. infant/
4. pediatrics/
5. minors/
6. puberty/
7. schools/
8. (Infant* or Child* or Schoolchild* or School age* or Preschool* or Kid or kids or Toddler* or Adoles* or Teen* or Boy* or Girl* or Minors* or Pubert* or Pubescen* or Prepubescen* or Paediatric* or Pediatric* or schoolchild* or school-child* or schoolage* or school-age*).tw.
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. "transients and migrants"/
11. "emigrants and immigrants"/
12. refugees/
13. Human Migration/
14. Human Trafficking/
15. (refugee* or migrant* or migrati* or immigrant* or immigrati* or transients or asylum or displaced person* or displaced people or displaced child* or expatriate* or departee* or foreign-born or foreign born or foreign student or international student or human trafficking or people trafficking or trafficking in people or sex trafficking or child trafficking or trafficked people* or trafficked child*).tw.
16. 10 or 11 or 12 or 13 or 14 or 15
17. epidemiologic studies/
18. exp case control studies/
19. exp cohort studies/
20. (Multicenter study or multicentre study).pt.
21. (Case control or (cohort adj (study or studies)) or cohort analy* or (Follow up adj (study or studies)) or (observational adj (study or studies)) or longitudinal or retrospective or cross sectional or cross-sectional).tw.
22. 17 or 18 or 19 or 20 or 21
23. 9 and 16 and 22
24. Case report.tw.
25. letter/
26. historical article/

27. 24 or 25 or 26
28. proteins/
29. cells/
30. membranes/
31. animal migration/
32. birds/
33. (membrane* or cell* or bird migration).tw.
34. 28 or 29 or 30 or 31 or 32 or 33
35. 27 or 34
36. 23 not 35
37. limit 36 to (english language and yr="2000 -Current")
38. (shunt* adj migrati*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
39. (pin adj migrati*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
40. 38 or 39
41. 37 not 40
42. mortality/
43. "Cause of Death"/
44. Child Mortality/
45. fatal outcome/ or hospital mortality/ or infant mortality/ or mortality, premature/ or survival rate/
46. (mortalit* or case fatality rate* or death rate* or fatal outcome*).tw.
47. 42 or 43 or 44 or 45 or 46
48. 41 and 47
49. exp Communicable Diseases/
50. COVID-19/
51. maivirus/
52. exp Tuberculosis/
53. exp HIV Infections/
54. hepatitis b/ or hepatitis b, chronic/

- 55. hepatitis c/ or hepatitis c, chronic/
- 56. exp schistosomiasis/ or exp intestinal diseases, parasitic/ or exp sexually transmitted diseases/
- 57. ((communicable or infectious or contagious or parasitic) adj (disease* or illness* or infection*)).tw.
- 58. (Covid* or COVID-19 or SARS or SARS-CoV-2 or SARS-CoV-19 or novel cov* or coronavir* or HIV or human immunodeficiency virus or hepatitis B or hepatitis C or schistosom* or tubercul* or TB or STD* or STI* or sexually transmitted disease* or sexually transmitted infection* or chlamydia or gonorrh?ea or syphilis).tw.
- 59. 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58
- 60. 41 and 59

Appendix 5. - Systematic review protocol amendments

Following completion of the protocol at various stages of the systematic review it became clear that some minor amendments were necessary to clarify and improve the results. The rationale for each is given below.

Protocol Amendments for mortality outcome

Protocol amendment, clarifications: During the screening process it became clear that there are very few existing studies addressing the research question. In many cases it was also challenging to apply the inclusion criteria due to inconsistent or unclear definitions migrants and few studies disaggregating data by paediatric age group. With the aim of being as inclusive as possible it was necessary to provide additional clarification to the inclusion criteria around certain recurring themes. A common example of this was studies set in refugee camps where the camp population was only briefly described. Refugee camps frequently house a combination of internally displaced persons (IDPs) as well as refugees who have migrated across an international border, and outcome data were typically not disaggregated by migrant group. Refugee camps are typically set up under emergency conditions in a humanitarian crisis. However, many camps remain in place for years or even generations due to socio-political factors preventing dispersal. In this case some or all of the children represented in the data have in fact been born in the camp, meaning they have not themselves migrated, and do not meet the definition of a migrant child. Most studies on refugee camp data do not make clear what proportion of children have themselves migrated. Studies in newly formed refugee camps or those that disaggregate the results by time in refugee camp are therefore more pertinent to answering the research question. I made the decision to include studies presenting data from refugee camps, however, I will analyse these results separately due to the considerations cited.

Where data failed to disaggregate by age, in general, I made the decision to exclude as per the protocol. However, I included some studies where an age-range extended slightly beyond childhood, e.g. up to age 20.

Protocol amendment, omission: During study identification I made the decision to omit studies without control groups which presented fewer than 5 data points relevant to the research question. For example, a case series where one or two deaths in migrant children are presented. The conclusions that can be drawn from studies without control groups are very limited and with tiny numbers this can become meaningless.

Protocol amendment, inclusion: I had initially made the decision to exclude studies set exclusively in high-dependency or intensive care settings. This decision was based on the methodology used in the comprehensive systematic mortality of mortality among international migrants(11), where a large number of studies were identified. Due to the paucity of data on migrant child mortality I have decided to include studies in high dependency and intensive care settings to fully explore the existing data on migrant child mortality.

Protocol Amendments for communicable diseases outcome

Protocol amendment, inclusion: Between the time of the protocol being originally submitted for publication (June 2020) and the start of the preliminary searches (January 2021) a significant body of literature had been published around the Covid-19 pandemic. Because this is an infectious disease that potentially disproportionately affects migrant populations, terms around Covid-19 were added to the search strategy for Domain 2: communicable diseases, before the final searches were carried out.

Protocol amendment, deviation: Due to the large number of results from literature searching identified for the communicable diseases outcome, I did not have capacity to screen each result individually. Beth Stinchcombe undertook screening of results under my supervision. Any unclear decisions were discussed with me and I undertook spot-checks of her screening against inclusion and exclusion criteria. There was therefore not dual screening for all results.

Protocol amendment, clarification: Any case definition of communicable disease (CD) used by study authors was eligible for inclusion. In the case of tuberculosis (TB), active TB diagnosed by clinical or radiological criteria, culture, microscopy, molecular testing or a combination of these was accepted. In the case of latent TB, Tuberculin skin tests (TSTs, also known as Purified protein derivative, PPD, or Mantoux), with threshold width defined by study authors, or Interferon gamma release assays (IGRA, also known as QuantiFERON or Elispot) were accepted.

Protocol amendment, exclusion: As with mortality results, I excluded studies presenting fewer than 5 data-points for migrant CYP.

Protocol amendment, deviation: Due to significant heterogeneity of identified studies, meta-analyses were undertaken despite I^2 of $>75\%$.

Appendix 6. – NOS scoring Systematic review Mortality studies Quality assessment (Adapted NOS scoring)

Quality assessment (Adapted NOS scoring) – Cohort studies Selection

Studies	Selection										
	Representativeness of the exposed cohort/sample				Selection of the non-exposed cohort			Ascertainment of exposure			
	Truly representative (one star)	Somewhat representative (one star)	Selected group (no star)	No description of the derivation of the cohort/sampling strategy (no star)	Drawn from the same community as the exposed cohort (one star)	Drawn from a different source (no star)	No description of the derivation of the non-exposed cohort (no star)	Secure record (one star)	Structured interview (one star)	Written self report (no star)	No description (no star)
Abouzeid			0								
DesMeules (2005)		1			1			1			
Gafar (2019)		1			1			1			
Gupta (2014)	1				1			1			
Makarova (2015)		1			1			1			
Linton (2020)		1			1			1			
Hjern (2004)	1				1			1			
Rondelli (2011)	1				1			1			
Taylor Ethel (2018)		1			1			1			
Trovato (2019)		1			1			1			

Cohort studies - Comparability and outcome

Studies	Comparability		Outcome (one star per item)							
	Comparability on the basis of the design or analysis controlled for confounders		Assessment of outcome					Was duration of follow up explicitly indicated?		
	Study controls for relevant factors (e.g. age, sex) (one star)	Not comparable on the basis of study design or analysis (no star)	Independent blind assessment (one star)	Record linkage (one star)	Self report (no star)	No description (no star)	Other (no star)	Yes (one star)	No (no star)	Comment on the duration of follow-up
DesMeules (2005)	1			1				1		National death records obtained for 1980-1998 and linked to sample
Gafar (2019)		0	1					1		1993 to 2018, national records
Gupta (2014)	1			1				1		1995–2011, event free survival
Makarova (2015)	1			1				1		Regional death records 2004–2010
Linton (2020)		0		1				1		State-wide death records 2006–2016
Hjern (2004)	1			1				1		National death register 1990–2000
Rondelli (2011)		0		1				1		1999 to 2008 from database
Taylor Ethel (2018)		0		1				1		2005–2014
Trovato (2019)		0					0		0	Modelled from two short time periods - 2000–2002 and 2010–2012

Cohort studies - Outcome (continued)

Studies	Outcome						Total score		
	Adequacy of follow-up cohorts				Statistical Test				
	Complete follow up reported. All subjects accounted for (one star)	Subjects lost to follow-up are discussed or are unlikely to introduce bias (one star)	Subjects lost to follow-up are not discussed or may introduce bias (no star)	No reporting of subjects lost to follow-up (no star)	Are sufficient data presented to support the estimates or conclusions drawn? (measures of precision reported; denominators reported) (one star)	The statistical test is not appropriate, not described or incomplete (no star)	Numerator	Denominator (all studies = 8)	Percentage
DesMeules (2005)		1			1		8	8	100%
Gafar (2019)			0		1		6	8	75%
Gupta (2-14)		1			1		8	8	100%
Makarova (2015)			0		1		7	8	88%
Linton (2020)			0		1		6	8	75%
Hjern (2004)	1				1		8	8	100%
Rondelli (2011)			0		1		6	8	75%
Taylor Ethel (2018)			0		1		6	8	75%
Trovato (2019)		1				0	4	8	50%

Appendix 7. – NOS scoring Systematic review Communicable diseases studies

Quality assessment (Adapted NOS scoring)

Quality assessment (Adapted NOS scoring) – Cohort studies

Studies	Selection										
	Representativeness of the exposed cohort/sample				Selection of the non-exposed cohort			Ascertainment of exposure			
	Truly representative (one star)	Somewhat representative (one star)	Selected group (no star)	No description of the derivation of the cohort/sampling strategy (no star)	Drawn from the same community as the exposed cohort (one star)	Drawn from a different source (no star)	No description of the derivation of the non-exposed cohort (no star)	Secure record (one star)	Structured interview (one star)	Written self report (no star)	No description (no star)
Abouzeid Mohammad S et al. (2012)		1			1			1			
Aldridge, Robert W., et al. (2016)		1					0	1			
Al-Marri M R (2001)		1			1			1			
Baker Brian J et al (2013)		1			1			1			
Chemtob Daniel et al (2006)		1			1			1			
Cook Victoria J et al (2004)		1			1			1			
Dhawan Vivek et al. (2018)		1			1			1			
Kamper-Jorgensen et al.(2012)		1			1			1			
Kontturi Antti et al. (2021)		1			1			1			
Long R et al (2002)		1			1			1			
Menzies HJ et al. (2010)		1			1			1			
Pang J et al. (2014)		1			1			1			

Salihu et al. (2004)		1			1			1			
Sandgren et al (2011)		1			1			1			
Teo SS et al. (2015)		1			1			1			

Cohort studies - Comparability and outcome

Studies	Comparability		Outcome (one star per item)							
	Comparability on the basis of the design or analysis controlled for confounders		Assessment of outcome					Was duration of follow up explicitly indicated?		
	Study controls for relevant factors (e.g. age, sex) (one star)	Not comparable on the basis of study design or analysis (no star)	Independent blind assessment (one star)	Record linkage (one star)	Self report (no star)	No description (no star)	Other (no star)	Yes (one star)	No (no star)	Comment on the duration of follow-up
Abouzeid Mohammad S et al. (2012)		0		1				1		Incidence over 10 years
Aldridge, Robert W., et al. (2016)		0		1				1		Incidence over 2.5 years
Al-Marri M R (2001)		0		1				1		Incidence over 14 years
Baker Brian J et al (2013)		0		1				1		Incidence over 11 years
Chemtob Daniel et al (2006)		0		1				1		Incidence over 10 years
Cook Victoria J et al (2004)		0		1				1		Incidence over 11 years
Dhawan Vivek et al. (2018)		0		1				1		Incidence over 25 years
Kamper-Jorgensen et al.(2012)		0		1				1		Incidence over 15 years
Kontturi Antti et al. (2021)		0		1				1		Incidence over 11 years
Long R et al (2002)		0		1				1		Incidence over 10 years
Menzies HJ et al. (2010)		0		1				1		Incidence over 13 years
Pang J et al. (2014)		0		1				1		Incidence over 12 years
Salihu et al. (2004)		0		1				1		Incidence over 7 years
Sandgren et al (2011)		0		1				1		Incidence over 10 years
Teo SS et al. (2015)		0		1				1		Incidence over 10 years

Cohort studies - Outcome (continued)

Studies	Outcome						Numerator Denominator (all studies = 8) Percentage
	Adequacy of follow-up cohorts				Statistical Test		
	Complete follow up reported. All subjects accounted for (one star)	Subjects lost to follow-up are discussed or are unlikely to introduce bias (one star)	Subjects lost to follow-up are not discussed or may introduce bias (no star)	No reporting of subjects lost to follow-up (no star)	Are sufficient data presented to support the estimates or conclusions drawn? (measures of precision reported; denominators reported) (one star)	The statistical test is not appropriate, not described or incomplete (no star)	
Abouzeid Mohammad S et al. (2012)		1			1		7/8
Aldridge, Robert W., et al. (2016)		1				0	5/8
Al-Marri M R (2001)		1			1		7/8
Baker Brian J et al (2013)		1			1		7/8
Chemtob Daniel et al (2006)		1			1		7/8
Cook Victoria J et al (2004)		1			1		7/8
Dhawan Vivek et al. (2018)		1			1		7/8
Kamper-Jorgensen et al.(2012)		1			1		7/8
Kontturi Antti et al. (2021)		1			1		7/8
Menzies HJ et al. (2010)		1			1		7/8
Long R et al (2002)		1			1		7/8
Pang J et al. (2014)		1			1		7/8
Salihu et al. (2004)		1			1		7/8
Sandgren et al (2011)		1				0	6/8
Teo SS et al. (2015)		1			1		7/8

Appendix 8. - Topic guide for semi-structured interviews

Brief topic guide for semi-structured interviews with UASC carers and social workers (developed by Gil Barton). Follow-up discussion described is the MDT meeting that takes place 4-6 weeks following IHA.

Experiences of attending follow up discussion questions

Goals

- What were your hopes for this discussion?

Experiences

- What was the experience of attending the discussion like for you?
- What did you like/not like? Feelings before/during/after?

Impact

- What do you think is the value in having these meetings?
- How was the meeting helpful?
- Has your thinking about the needs of the young person changed after the discussion?
- Considering your initial hopes for the discussion, do you think these were met?
- Was there anything that you would you have liked to talk about that was not discussed?

Recommendations

- How could we make these discussions more useful for you/others?
- Do you have any suggestions on how should it be delivered? Who else would you like to attend?