Understanding why young people fall through the gap between child and adult mental health services and the associated impact and costs for young people, society, and the health service

by
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Thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Health Sciences

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Declaration

This thesis is submitted to the University of Warwick in support of my application for the degree of Doctor of Philosophy. It has been composed by myself and has not been submitted in any previous application for any degree.

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Abstract

This thesis explores the causes and effects of discontinuity of care at the upper age boundary of child and adolescent mental health services (CAMHS). We investigate why young people (YP) fall through the gap between child and adult services and the effect this has on their mental health, functioning, and associated healthcare and societal costs.

Mixed methods were used. A systematic review explored service use outcomes of young people after leaving CAMHS. Longitudinal data from 488 young people with an anxiety or depressive disorder, a neurodevelopmental disorder, or a personality disorder was analysed using multiple regression methods to examine predictors of transitioning, mental health and functioning outcomes, and resource use. Narrative interviews with thematic analysis was conducted with 15 YP and 15 parents of YP who fell through the gap. The results of all data analyses were synthesised using a Pillar Integration Process to generate new insights from the data.

The most common reason for falling through the gap was being deemed 'not ill enough' to access adult services. The current service structure does not meet the mental health needs of all YP, and several reported being unable to access mental health care or medication when needed. Falling through the gap caused frustration and anxiety for YP and parents, and some YPs struggled to manage without specialist mental health care. Those who were most ill typically used more health care resources.

This thesis sheds light on the causes and consequences of children falling through the gap between services. It concludes with seven recommendations for clinical practice and mental health policy to improve care for young people at the CAMHS transition boundary.

List of Abbreviations

Abbreviation	Explanation
ABCL	Adult Behaviour Check List
A&E	Accidents and Emergency department
ADHD	Attention Deficit Hyperactivity Disorder
AMHS	Adult Mental Health Services
ASD	Autism Spectrum Disorder
ASEBA	Achenbach System of Empirically Based Assessment
ASR	Adult Self Report
AWBS	Adult Wellbeing Services
BAME	Black, Asian and Minority Ethnic
CAMHS	Child and Adolescent Mental Health Services
CBCL	Child Behaviour Check List
CGI	Clinical Global Impression
CSRI	Client Service Receipt Inventory
DSM V	Diagnostic and Statistical Manual of Mental Disorders – 5th Edition
EU	European Union
GP	General practitioner
HoNOSCA	Health of the Nation Outcome Scale for Children and Adolescents
LOCF	Last Observation Carried Forwards
MICE	Multiple Imputation using Chained Equations

NEET	Not in Employment, Education or Training
NRES	National Research Ethics Committee
PC	Parent/Carer
PIP	Pillar Integration Process
RA	Research Assistant
REC	Research Ethics Committee
SLOF	Specific Levels of Functioning Scale
UK	United Kingdom
VIF	Variance Inflation Factor
WHO	World Health Organisation
WHOQOL-BREF	World Health Organization Quality of Life
YP	Young Person
YSR	Youth Self Report

Chapter 1: Introduction

1.1 Introduction

This chapter provides an overview of this thesis. It discusses the motivations for conducting a project in this research area and what this thesis aims to achieve. It also provides an overview of the content of the chapters which make up this thesis.

1.2 Overview of thesis

1.2.1 My background

I graduated from my undergraduate degree in Experimental Psychology from the University of Oxford in 2015. During my studies I became interested in clinical psychology with a focus on access to appropriate mental health services. As much of the research was lab-based, it left me wanting to focus on applied research with clearer real-world impact. Following graduation, I worked as an intern for the Solihull Approach before joining Warwick Medical School as a research associate on the MILESTONE (Managing the Link and Strengthening Transition from Child to Adult Mental Health Care Services) project in December 2015.

My role on MILESTONE involved meeting young people and their parent/carers to conduct assessments during the longitudinal study in addition to qualitative interviews and focus groups. During this work I became interested in the young people who fell through the gap between services and were not receiving mental health care after leaving child and adolescent mental health services (CAMHS), despite being unwell. As this group are underrepresented in existing literature and were not a focus of the MILESTONE project, I decided to apply for funding to conduct doctoral research to learn more about what effect falling through the gap between services has on these young people and their families.

1.2.2 Purpose of Study

This thesis reports a mixed-methods study exploring reasons why young people fall through the gap between child and adult mental health services, and what effect this has on them and their families. It also collates the findings of existing studies regarding the outcomes of young people who reach the CAMHS transition boundary, as well as exploring the costs to both the health service and wider society of falling through the gap versus transitioning to adult mental health services (AMHS). The results from this project are used to generate

recommendations for policy and clinical practice, with the wider aim to improve continuity of care for young people as they reach the upper age limit of their CAMHS.

1.3 Structure of thesis

Chapter 2 describes the definition of mental health used in this thesis and provides an overview of the existing literature regarding youth mental health, the structure of mental health services, and transitions in mental health. It will also provide an outline of the MILESTONE project – the wider research project to which this PhD is linked. It will conclude with a rationale for the current thesis project.

Chapter 3 presents the aims, objectives, and research questions for this thesis. It will outline the methodologies for this research and rationales for the study design and target population. It will also present the ethical considerations for this project.

Chapter 4 presents the methods and results of the systematic review which collated the results of 13 existing studies which explored the mental health and service use outcomes of young people after leaving CAMHS.

Chapter 5 explores the predictors of transitioning or falling through the gap and any impacts of service use destination on the mental health and functioning of young people after leaving CAMHS using quantitative analysis. This chapter presents the methods and results related to the statistical analysis.

Chapter 6 compares the resource use and costs between young people who transitioned and fell through the gap using health economic analyses. This chapter presents the associated methods and results for this analysis.

Chapter 7 explores both why young people fell through the gap between CAMHS and AMHS and what impact falling through the gap had on young people and their families. This chapter presents the methods of sampling, recruitment, data collection and analysis for the qualitative interviews with young people and their parent/carers.

Chapter 8 integrates the findings from the quantitative, health economic and qualitative chapters using a joint display method. The results of this chapter will be discussed in Chapter 9 as they relate to the thesis as a whole.

Chapter 9 contains a summary of the overall findings of this PhD and a discussion of how these findings relate to existing literature. It presents the strengths and limitations of this

thesis, as well as the implications of this work for future related research. Finally, it outlines the recommendations for clinical practice which have been generated from this research.

1.4 Chapter summary

This chapter has set the scene for this thesis, introducing the motivations for conducting this research and the purpose of the project. It has also outlined the content of the chapters constitute this thesis. The next chapter situates this project in the context of the existing literature on this topic.

Chapter 2: Youth Mental Health and Transition

2.1 Chapter Introduction

This chapter sets out the context and terminology used throughout this thesis. It starts by defining mental health and related concepts for reference within this thesis, before providing an overview of the existing literature regarding youth mental health. The second aim of this chapter is to explore existing literature regarding the problems faced by young people during the transition between mental health services and the costs associated with poor continuity of care. Finally, it describes the MILESTONE project, the wider project to which this PhD is linked.

2.2 Defining Mental Health

There is no single accepted definition of mental health, however it is important to acknowledge how mental health is defined in this thesis.

The World Health Organisation (WHO) define mental health as:

> *"... a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community" (World Health Organization, 2001 p1)*

The WHO also emphasises that mental health is more than just the absence of mental illness, it is a positive state whereby an individual can function effectively (World Health Organization, 2005). However, this definition has been criticised for failing to acknowledge the range of emotions (which can sometimes be negative) experienced by people in good mental health, which could exclude certain groups, including adolescents (Galderisi et al., 2015). Instead, Galderisi et al. (2015) have proposed a new definition, one that moves away from the idea of productivity as a feature of good mental health:

> *"Mental health is a dynamic state of internal equilibrium which enables individuals to use their abilities in harmony with universal values of society. Basic cognitive and social skills; ability to recognize, express and modulate one's own emotions, as well as empathize with others; flexibility and ability*

to cope with adverse life events and function in social roles; and harmonious relationship between body and mind represent important components of mental health which contribute, to varying degrees, to the state of internal equilibrium." (Galderisi et al., 2015 p231-232)

In this thesis, mental health is defined in accordance to the definition proposed by Galderisi et al. (2015). It is appropriate to use this definition due to the target population of this study, as references to productivity at work and contribution to the community stated in the WHO (2001) definition may not apply to adolescents and young adults. Also, by acknowledging the range of human emotion, this definition helps to distinguish between what is normal adolescent behaviour and what may require intervention from mental health services. Additionally, using a definition of good mental health which includes a range of emotions limits the pathologising of transient distress and disruptive behaviours which can be normal in adolescence (Paul et al., 2018).

2.3 Youth Mental Health

The majority of mental illness begins in childhood and young adulthood, with 50% of mental disorders emerging before the age of 14, and 75% by the age of 24 (Kessler et al., 2005). This is in contrast to the low incidence rates of physical illness in this population, meaning mental illness makes up the majority of years lost to disability in young people between the ages of 10 and 24 years worldwide (Gore et al., 2011). A recent survey conducted in 2020 estimated that 1 in 6 young people between the ages of 5 and 16 years in England had a probable mental disorder (Vizard, 2020). This report found no difference in likelihood of a probable mental disorder by sex, contradicting previous studies which identified higher rates of mental illness in girls after the age of 11 years, when girls started reporting more emotional problems and depressive symptoms (Care Quality Commission, 2018). There is some evidence that this disparity continues into older adolescence and young adulthood, as shown by a 2014 survey in England which found that females aged between 16 and 24 years are three times more likely to experience mental illness than males (Mental Health Foundation, 2016). Mental illness also disproportionally affects disadvantaged young people, with growing up in a poor household resulting in a three-fold increase in the risk of developing a mental illness (Green et al., 2005).

The prevalence rates of mental illness amongst young people are also thought to be increasing. Research in England which focused on young people between 4 and 24 years of age found prevalence rates rose from 0.8% in 1995 to 4.8% in 2014, showing a trend in the increased diagnosis of mental illness amongst this age group (Pitchforth et al., 2019). Likewise, the number of university students reporting poor mental health has doubled in a recent five-year period (Williams et al., 2015), whilst the numbers disclosing mental illness to their university in the UK was five times higher in 2015/16 than ten years previously (Thorley, 2017).

Mental illness during youth has also been linked to various negative future outcomes. For example, Patel et al. (2007) found that having a diagnosed mental illness between the ages of 12 and 24 years led to an increased risk of substance use, poor educational achievements, violence, abuse and poor sexual health. Therefore consequently, the social and economic effects of mental illness extend into adulthood. The Adult Psychiatric Morbidity Survey in the UK showed that young people (aged 16-25 years) with mental illness were more likely to be not in employment, education or training (NEET) and be receiving state benefits (Knapp et al., 2016). This research also highlighted other negative outcomes associated with youth mental illness: young people with mental illness were eight times more likely to have contact with the criminal justice system in the follow up period than those without mental health problems.

2.4 Mental Health Services for Young People

Similar to most physical health services, mental health services are divided into separate specialties for children and adults. Child and Adolescent Mental Health Services (CAMHS) offer treatments for a wide range of mental illnesses (Lamb and Murphy, 2013), with a focus on developmental problems and family issues (McGorry, 2007). Young people can continue to receive care at CAMHS until they reach the upper age limit of that service, which is normally between the ages of 16-18 years (Belling et al., 2014). The exact upper age limit for CAMHS varies between different geographic areas, depending on both the structure and funding of services in that locality.

Adult Mental Health Services (AMHS) usually accept referrals for young people aged 18 years and above. In contrast to CAMHS they have a much narrower focus, concentrating on treating those with a more severe mental illness (Lamb and Murphy, 2013) such as

psychosis. As opposed to caring for people with a wide range of conditions, AMHS are usually divided into distinct specialist services for different conditions, with separate services for illnesses such as eating disorders or addiction.

2.5 Accessing Mental Health Care

Despite an increase in mental illness amongst young people, this group is often the least likely to access help or support. For example, only 25% of young people with a diagnosable condition accessed local mental health services in England in 2017 (NHS Digital, 2018). Another study found that nearly two-thirds of young people between 21 and 25 years were not receiving the mental health treatment they needed (Knapp et al., 2016). This research also found that the treatment gap persists despite severe mental illness, with almost half of 16-25 year olds not accessing care. This gap between treatment and need is due to a variety of factors. Young people can be difficult to engage in mental health care (O'Brien et al., 2009) and are less likely to seek help for problems such as depression than older adults (MacKinnon and Colman, 2016).

Young people can also encounter problems when they do try and access support. Continuity of care can be poor, with obstacles such as fragmented care and lack of access to timely support cited as barriers (Ådnanes and Steihaug, 2013). Services can struggle to meet the demand for treatment: one study in Australia investigated young people whose referrals to a youth mental health service were rejected, and found nearly two-thirds had at least one diagnosis and a quarter had recently attempted suicide (Cosgrave et al., 2008). Services in the UK are also struggling to meet the need for care, with recent data showing over half of the young people referred to CAMHS in 2017/18 waited more than 18 weeks for their first appointment (Young Minds, 2018b). A likely cause is underfunding or lack of resources: CAMHS receive less than 1% of the total NHS budget, and only 8% of the total mental health budget is spent on CAMHS (Young Minds, 2018a).

One of the main obstacles to continuity of care exists when young people reach the upper age limit of CAMHS (Singh et al., 2005). If a young person requires further treatment and support when they reach the CAMHS age boundary, care should be transferred to an AMHS through a process known as transition. Data from several studies suggest that transition is often poorly managed, leaving young people at risk of falling through the gap between services (Singh and Tuomainen, 2015).

2.6 Transition between Mental Health Services

The transition of care from one service to another is more than a simple transfer of care from CAMHS to AMHS. Instead, definitions of transition focus on it being a planned, purposeful, and therapeutic process to allow for full continuity of care:

> *"Transition is defined … as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems." (Blum et al., 1993 p570)*

> *"Transition is a process requiring therapeutic intent, which may be expressed by the young person's preparation for transition, a period of handover or joint care, transition planning meetings (involving the young person and carer, and key CAMHS and AMHS professionals) and transfer of case notes or information summaries."* (Paul et al., 2013 p36)

The TRACK Study (Singh et al., 2008, Singh et al., 2010, Hovish et al., 2012, Paul et al., 2013) was the first to investigate the quality of transition between CAMHS and AMHS in England. Singh and colleagues used a retrospective case note analysis to identify the young people who had reached the upper age limit of CAMHS and traced whether they had completed the transition to AMHS. If transition had occurred, it was screened according to the four criteria of optimal transition mentioned in the definition above by Paul et al (2013): a period of parallel care, preparing the young person for transition, joint meetings between clinicians from both services and the young person, and full transfer of the young person's information to the new service. In total, of the 154 young people studied, 58% were accepted by AMHS, whereas 42% were not accepted by another service after reaching the CAMHS age boundary. Only 4% of participants who transitioned to AMHS experienced all four features of optimal transition. The results of this study suggest that the majority of young people do not transition, and for those who do, transition is poorly planned, executed and experienced. However, it should be noted that this study relied on clinician recall for identifying potential cases, therefore it may be that those with a more positive or negative transition were more likely to be included in this sample.

The TRACK study has since been replicated in Ireland and Northern Ireland (ITRACK Study, McNicholas et al. (2015) IMPACT, Leavey et al. (2019)) with findings echoing those of

TRACK; all four optimal features of transition were rarely adhered to. Another recent study focusing only on young people with ADHD found only 6% of those who had transitioned from services in the UK in a 12 month period received optimal transition (Eke et al., 2019). Other researchers have proposed more detailed beneficial features of transition services: having a young adult specific service or clinic; making sure the young person meets the adult team before transfer of care; promoting the young person's self-efficacy; the creation of a written transition plan; appropriate involvement of the parent/carer; the use of a key worker; a coordinated multi-disciplinary team; holistic life-skills training for the young person; and a transition manager to facilitate optimal working between team members (Colver et al., 2018). NICE guidance on transition (not limited to mental health services) was published in 2016, and stated that transition planning should actively involve the young person and take a holistic view of their life circumstances, involving their parent/carer where appropriate (NICE, 2016). These guidelines also emphasise that transition should take place when it is appropriate to do so, taking into account the young person's maturity, health and wider circumstances, as opposed to having a rigid age-based cut off for care at CAMHS. A further recommendation is the involvement of a named worker for each young person who can help them to navigate the transition between services and aid with continuity of care as the young person moves from CAMHS to AMHS.

2.7 Transition Experiences

The lack of a carefully planned and executed transition between CAMHS and AMHS can result in poor experiences of care during the move between services. Transition also occurs at a time when young people are having to navigate other concurrent life transitions, such as moving from school to university or work, or moving out of the family home (Hovish et al., 2012). This is also the time when looked after children (who are at particular risk of mental illness) will be transitioning to independence (Butterworth et al, 2017). Therefore, it is perhaps unsurprising that poor transition experiences can adversely impact the wellbeing of young people (Price et al., 2018).

Various qualitative studies have explored the transition experiences of young people. Poor communication between CAMHS and AMHS has been identified as a barrier to good transition (McNamara et al., 2017, van der Kamp, 2018). A lack of clinician time and the different care philosophies between services have been suggested to impair communication (Moscoso et al., 2015). Poor communication between the young person

and their clinician can result in young people being left out of the transition decision, meaning they are unable to have their say as to where or if their care will continue post-CAMHS (Wilson et al., 2015, Burnham Riosa et al., 2015).

Another difficulty faced by young people when they cross the transition boundary is leaving a well-established therapeutic relationship at CAMHS and having to start another, with someone new who they may not have met before (Lindgren et al., 2014). The arbitrary timing of transition can cause frustration, as can having to repeat their story again in AMHS to multiple new clinicians (Broad et al., 2017). This can be exacerbated by the fact that young people may experience fragmented care as they cross the transition boundary and have several moves between services or therapists during this time (Ådnanes and Steihaug, 2016). Research has also shown that a lack of preparation for moving on from CAMHS can lead to young people experiencing feelings of fear, anxiety and uncertainty about the new service (Dunn, 2017). Not receiving adequate information about AMHS can lead to negative expectations about the service, as well as contributing to worry and feelings of uncertainty (Lindgren et al., 2014).

In contrast, having a gradual transition to AMHS, fully preparing the young person for the transition, and aiding continuity of care through the use of a key worker or joint meetings can result in more positive experiences of transition (Hovish et al., 2012). Other facilitators to a good transition experience which have been identified by clinicians include: the availability of appropriate services, AMHS clinicians being notified in advance of the referral, and flexibility in the transition age to allow treatment to finish in CAMHS in cases where long term treatment in AMHS may not be required (van der Kamp, 2018).

The transition period from CAMHS to AMHS can also be a difficult time for the parent/carers of the young people involved. Parents have reported feeling “in the dark” after their child has been transitioned to AMHS (Hovish et al., 2012). They have also reported feelings of frustration arising from being excluded from decisions about their child’s care once they are legally an adult, even if that young person is still reliant on their parents for support at home (Jivanjee et al., 2009). Parents have also described difficulties balancing the need for the young person to become independent, whilst also being a source of support (Lindgren et al., 2014). Recent reviews of the literature have found that parents feel anxious due to being less involved in their child’s care after transitioning (Hill et al., 2019) and that parents would like to be more involved in their child’s care during the transition period (Reale and Bonati, 2015).

2.8 Falling through the Gap

Whilst we know that the transition between services can be problematic, not all young people are able to access continued care after leaving CAMHS, despite still being unwell. These young people are said to have 'fallen through the gap' between services. For example, out of the 154 participants recruited to the TRACK study, 64 did not continue care in AMHS (Singh et al., 2010). This was due to a variety of reasons including AMHS rejecting the referral, CAMHS clinicians not thinking AMHS would accept the referral, or disengagement from services. Only ten out of these 64 young people were recorded as no longer needing treatment. The ITRACK study measured the clinical need of young people as they crossed the transition boundary, and found that 45% were not referred despite indications that they required ongoing treatment (McNicholas et al., 2015).

Other studies have focused on young people with neurodevelopmental disorders such as Attention-Deficit Hyperactivity Disorder (ADHD) or autism spectrum disorder (ASD), as these groups have been identified as being at particular risk of falling through the gap between services. This has been attributed to a lack of specialist services available to meet the needs of these young people (McConachie et al., 2011, Hall et al., 2015). This may be due to the now out-dated view that neurodevelopmental disorders such as ADHD are disorders of childhood, with young people 'growing out' of them when they reach adulthood (Young et al., 2011). Whilst this may be the case for some young people, research has shown that a significant percentage are likely to need ongoing care after reaching the upper age limit of CAMHS, either due to a need for medication review or help with other comorbid disorders (Taylor et al., 2010, Tatlow-Golden et al., 2017). Many young people are referred back to their GP as opposed to being transitioned to specialist AMHS (Reale et al., 2018), however there is debate about whether GPs have the necessary expertise to manage ADHD without any input from specialist psychiatry services (Coghill, 2015). Currently, little is known about the outcomes for young people with ADHD who fall through the gap between services (Young et al., 2016).

Another reason young people can fall through the service gap is due to the difference in treatment thresholds between CAMHS and AMHS. CAMHS have child-centred, developmental approach to care (Birchwood and Singh, 2013), and treat a variety of developmental and emotional problems, whereas in contrast AMHS focus on more severe mental illnesses (Lamb and Murphy, 2013). This can lead to young people with emotional disorders failing to meet the AMHS treatment threshold once they have crossed the

CAMHS age boundary (Birchwood and Singh, 2013). These high eligibility thresholds at AMHS are thought to be in part caused by a lack of resources and staff shortages, with clinicians having to manage high caseloads (Belling et al., 2014). AMHS also have an emphasis on individual autonomy and place the responsibility on the client to manage their care, which can be difficult for young people moving from the more protective approach of CAMHS (Mulvale et al., 2015). Therefore, as young people are often poorly prepared for the transition, they can struggle to navigate the shift between two distinct models of care and as a result are at risk of disengaging from the adult service (Birchwood and Singh, 2013).

Together, the results of all these studies suggest that a significant proportion of young people fall through the gap after reaching the CAMHS age boundary. However, currently very little is known about what happens to these young people.

2.9 The Costs of Youth Mental Illness

In addition to the negative effect a poor transition has on the young person involved, there is also a likely economic cost to the health service or wider society. For example, one review estimated the average cost of mental illness to be between £5,000 and £44,000 per child per year. Importantly, these costs fall on not only the health service, but also to the education system, criminal justice system and social services, amongst others (see Table 1) (Suhrcke et al., 2008).

Table 1 The potential economic costs of youth mental illness (Adapted from Suhrcke et al. (2008))

Perspective	**Care costs**	**Productivity costs**	**Other costs**
Individual with mental disorders/problems	Treatment and service fees and payments	Reduced learning capacity (Future) work disability (Future) lost earnings	Suffering Treatment side effects Suicide Stigma Social exclusion
Family and friends	Informal care-giving	Time off work Reduced productivity	Psychological hardship/carer burden
Society		Reduced productivity	Loss of lives
Health system	Provision of mental health care and general care (taxation and insurance)		
Social services	Local authority care and accommodation, social work		
Education services	Educational psychologists, special education costs, education welfare officers, indirect costs incurred from worse educational attainment		
Youth justice system	Youth offending team, youth custody		

The costs associated with mental illness during childhood rise once the individual becomes an adult (e.g. Scott et al., 2001). Again, these costs fall on various agencies and include higher productivity costs, as a loss of earnings is now taken into consideration (something which is not the case when evaluating the costs associated with children). Mental illness during childhood reduces earning capacity as an adult, with family incomes reduced by an estimated 28% by the age of 50 (Goodman et al., 2011). Significantly, this research also found that mental illness during childhood had a much larger effect on subsequent outcomes than physical illness (Goodman et al., 2011). One study in the USA which investigated the long term economic costs of mental illness in childhood gave a

conservative estimate of the lifetime cost to family income to be $300,000 (Smith and Smith, 2010). However, these costs are not limited to the individual: lower levels of employment status and reduced wages have subsequent costs to society through lower income generated from taxation.

These studies highlight the need for early intervention and sustained care for those who need it, however continuity of care is often poor during late adolescence and early adulthood (Ådnanes and Steihaug, 2013). Despite a strong economic argument for early intervention (Knapp et al., 2016, McDaid et al., 2019), it is apparent young people are not always able to access early care before they reach crisis point. For example, during the transition period, young people can be told they are not ill enough for continuing treatment (Wilson et al., 2015). Current efforts to provide early intervention services have mainly focused on young people with psychosis, however researchers have called for this model to be rolled out to all mental illnesses (Vyas et al., 2015). Previous research has established that investing in mental health services for young people provides benefits to health services, education, and the criminal justice system in terms of reduced costs (McDaid, 2011). One study which evaluated a mental health service for transition-aged youth estimated a cost saving to the health service of almost £475,000 and found reductions in the use of health services and contacts with the criminal justice system (Brimblecombe et al., 2015). These cost savings are supported by the results of another study evaluating a specialist youth service (for young people aged 16-25) in London, which found that contacts with accident and emergency departments, the criminal justice system, and hospital visits decreased during treatment (Knapp et al., 2016). Whilst there is promising evidence to suggest that specialist youth mental health services can result in economic benefit, little is known about the costs of transition to AMHS versus falling through the gap between services. Additionally, NICE did not identify any research regarding health economic evaluations of transition interventions during their review of current evidence (NICE, 2017), indicating a need for further research in this area.

2.10 The MILESTONE Project

This thesis uses data collected as part of the MILESTONE project (Tuomainen et al., 2018), an EU FP7 funded project involving eight countries in Europe: UK, Ireland, France, Germany, Netherlands, Croatia, Belgium and Italy. MILESTONE, which ran between February 2014 and April 2019, aimed to understand and improve transitions in mental

health for young people in Europe. It comprised nine work packages, seven of which were linked with specific studies: mapping the CAMHS/AMHS interface in Europe, developing a suite of transition-related measures, a longitudinal cohort study, a cluster randomised trial of managed transition, economic evaluation of the trial, exploring the ethics of transition, and training linked to transitional care (Figure 1).

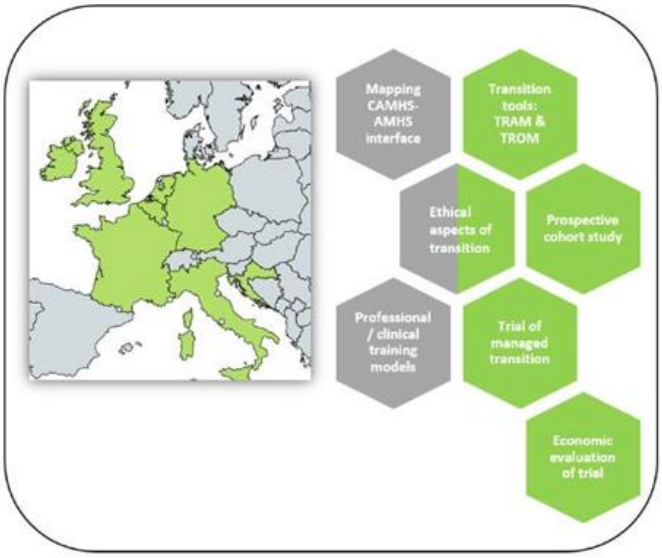

Figure 1 The countries involved in MILESTONE. Green hexagons represent research in these eight countries, grey hexagons represent research over the whole of Europe (Reproduced from Tuomainen et al., (2018)).

2.11 The MILESTONE Study

The "MILESTONE Study" included three work packages from the overall project: the longitudinal cohort study which followed up young people after leaving CAMHS; the cluster-randomised control trial testing the effectiveness of managed transition; and an economic evaluation of the study intervention (Singh et al., 2017, Tuomainen et al., 2018).

The MILESTONE study completed data collection in December 2018. Young people were recruited at around six months prior to the CAMHS transition age boundary and followed up for up to 24 months. Data were collected at four time points: T1 (baseline), T2 (+ 9 months), T3 (+ 15 months), and T4 (+24 months). 1004 young people were recruited from eight different countries, as well as 845 parent/carers. Data was also collected from their CAMHS or AMHS clinicians where possible. I was employed as a research assistant on the MILESTONE project from December 2015 to April 2019 and helped collect quantitative data from the UK participants.

2.12 Conclusion & Rationale for current project

Despite adolescence and young adulthood being a risky period for the onset of mental illness, continuity of care during this time is poor. Young people can find it difficult to access ongoing care after reaching the upper age limit of their CAMHS due to the separation between child and adult mental health care. This has led to the current system being described as having "maximum weakness and discontinuity… just when it should be at its strongest." (McGorry, 2007 p53). If a young person still requires ongoing care, care should be transferred to an AMHS through a therapeutic process known as transition. However, this transition is often poorly managed with long waiting lists and a lack of communication between services, meaning young people are at risk of disengaging from care. Some young people may fail to transition at all, as they do not meet the illness severity threshold to access care at AMHS, despite still being unwell. These young people are said to have fallen through the gap between services. We currently do not know what happens to this vulnerable group, something which has been identified as a "serious cause for concern" (Singh et al., 2010p 310) and a priority for future research. This thesis therefore aims to address this gap in the current literature and investigate the service use and mental health outcomes of young people who fall through the gap between services.

Previous research has established that mental illness in young people results in higher costs for the education system, criminal justice system and wider society, in addition to increased healthcare costs. Preliminary work investigating specialist services for transition-aged youth has found that these services can improve mental health outcomes for young people, with associated cost savings. So far, however, there has been no detailed investigation comparing the costs of transitioning to AMHS to falling through the gap between services, despite evidence to suggest that not all young people continue to receive appropriate care after leaving CAMHS. This thesis will therefore also investigate the economic burden of this failed transition.

2.13 Chapter Summary

This chapter has described how mental health will be defined in this thesis and provided an overview of the existing literature regarding youth mental health and mental health services for young people. It has also situated the current project within the existing transition literature, as well as providing a rationale for the current research. The next chapter outlines the aims, objectives and research questions for this thesis and their chosen methodology.

Chapter 3: Methodology and Rationale

3.1 Chapter Introduction

The previous chapter examined the existing literature regarding young people's mental health and the problems young people face when trying to access appropriate mental health care after reaching the upper age limit of their CAMHS. I have identified the current gaps in existing research and provided a rationale for why this project is an important piece of work, given the current inadequacies in mental health care for young people.

This chapter presents my aims, objectives and research questions. I then move on to present the rationale for my study design and justifications for the chosen characteristics of my study population. Finally, I outline the ethical considerations of this project and its contribution to knowledge in the field.

3.2 Aims and Objectives

This study has the following aims and objectives:

Aim 1: To investigate why people with certain mental health diagnoses fall through the gap between CAMHS and AMHS

- Compare baseline sociodemographic and clinical correlates of young people with certain diagnoses who fall through the gap and those who transition by analysing quantitative data collected during the MILESTONE Study (See Chapter 2, section 2.11)

- Explore the experiences of young people during their time at CAMHS before they reached the transition boundary through qualitative interviews

Aim 2: To explore the effect that falling through the gap has on the mental health and functioning of young people and their families.

- Investigate the outcomes of young people who have crossed the CAMHS transition boundary through a systematic review

- Compare longitudinal mental health and functioning data from young people with specific diagnoses who fell through the gap with those who transitioned over a period of 24 months

- Explore the experiences of young people with specific diagnoses and their parent/carers regarding accessing care and what effect falling through the gap has had on the mental health and functioning of the young person through qualitative interviews

Aim 3: To investigate the healthcare and societal costs of young people with certain mental health diagnoses falling through the gap

- Compare health and social care service use and cost data from young people who fell through the gap to those who made the transition to AMHS

3.3 Research Questions

This study attempts to answer the following questions:

- Why do young people with certain diagnoses fall though the transition gap between CAMHS and AMHS?

- What effect does falling through the gap have on the mental health and functioning of young people and their families?

- What are the healthcare and societal costs of young people falling through the gap?

3.4 Study Design

These research questions will be answered using a mixed methods design. Mixed methods research has been defined by (Johnson et al., 2007 p123) as:

> *"…the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration."*

Mixed methods studies can have either a sequential or simultaneous design (Creswell and Clark, 2017). In a sequential design, the qualitative and quantitative components are conducted separately, often with either first method used to inform the second (e.g.

qualitative interviews which inform the questions in a quantitative survey) or the second method adding meaning and context to the first (e.g. focus groups conducted with participants after taking part in a new intervention). In contrast, in a simultaneous design, both components are conducted during the same time frame and results integrated during data analysis (Kroll, 2009).

Mixed methods can also be further divided into qualitative dominant, quantitative dominant, or equal status, with the latter being a 'true' mixed methods design (Johnson et al., 2007). This research used a simultaneous mixed methods design, with both quantitative and qualitative components given equal weight during integration and interpretation of results.

3.5 Rationale for Study Design

As mentioned in the definition above, an advantage of a mixed methods study design is that it typically allows researchers to understand a subject in more depth and breadth, as opposed to focusing on either a qualitative (typically allowing for more depth, as studies involve a smaller number of participants studied in detail) or quantitative (typically a larger data set, without the same scope for detail) approach. This aligns with a pragmatic perspective, in which the most appropriate methods are chosen to answer the research questions. For example, when asking why young people fall through the gap between services, there is more value in looking for the answer from both a broad quantitative and in-depth qualitative method than in either method alone. Pragmatism can be viewed as a middle ground between the paradigms of realism and constructivism (Morgan (2013), see **Error! Reference source not found.** below) and is therefore a common paradigm used in mixed methods research.

Table 2 The relationship between different research paradigms (Adapted from Morgan (2013))

Realism	**Pragmatism**	**Constructivism**
Mostly used in quantitative research	Mostly used in mixed methods research	Mostly used in qualitative research
Assumes there is a 'real world' that exists separate to human experiences. We are able to objectively investigate this reality as we are separate from it.	Assumes that there is a reality that is separate from human experiences, but it can only be encountered through exploring human experiences.	Assumes that everyone has unique experiences and beliefs, and that no reality can exist outside of these perceptions. We learn through interpreting this information.

The advantages of mixed methods research have led to this approach growing in popularity in health sciences research in recent years (Zhang, 2014). The use of mixed methods in mental health research has been shown to be a successful method for evaluating the need for services and existing service provision (Palinkas et al., 2011). Researchers also argue that combining different methods of data collection is a useful way of understanding a complex issue e.g. (Farmer et al., 2006), making it particularly useful in health services research. Using a mixed methods design is therefore a beneficial method for this thesis as there is a lack of evidence in the literature regarding the outcomes of young people who fall through the transition gap. Therefore, using this approach allows for both a broad and detailed exploration of the research topic.

3.6 Research Approach

This thesis was divided into four different studies (see Figure 2), to enable a multi-stage and multi-method approach to answer these research questions, followed by a further analysis to synthesise the results from all four studies. The rationale for each method and a detailed description of the methods used are included in the dedicated chapter for each study (Chapters 4-8).

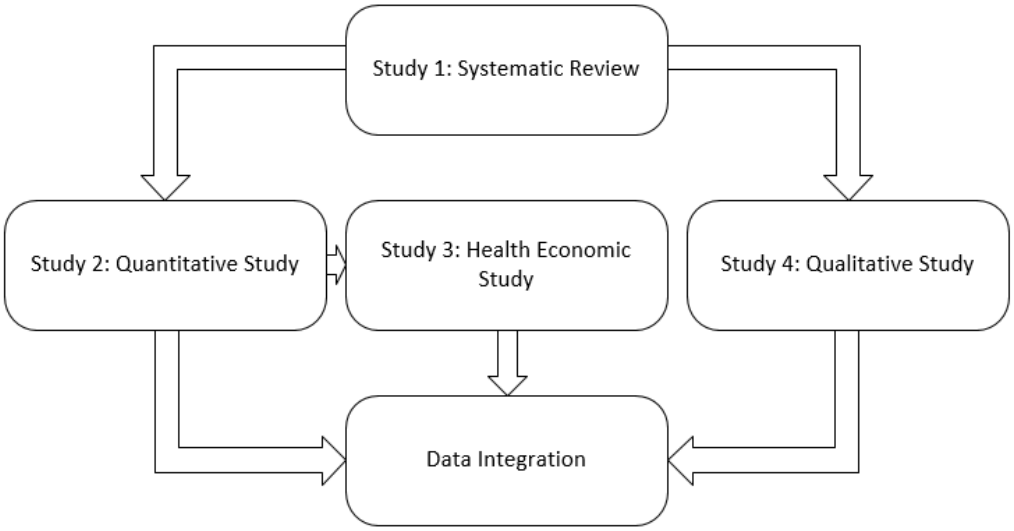

Figure 2 An overview of the structure of this thesis

3.7 Included participants

3.7.1 Defining falling through the gap

For the purpose of this study, participants were said to have fallen through the transition gap if they were either:

1) Discharged from CAMHS with no other referral despite having an ongoing clinical need.
2) Referred to AMHS and then discharged by the next data collection point despite having an ongoing clinical need.

Clinical need was assessed using the Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA) clinical interview (See Chapter 5, section 5.4.2 for more details), which explored overall health and functioning in the two weeks before data collection took place. This interview was completed by a trained research assistant at each of the four time points (See Chapter 2, section 2.11) throughout the study. A participant was said to have ongoing clinical need if they scored two or above on HoNOSCA questions relating to psychiatric symptoms. It was decided to use HoNOSCA in this way as there are no standardised scoring boundaries for this instrument to assess level of severity. Therefore, I chose to follow the method described by Burgess et al. (2009), in which a score of 2 or

above on each individual question is used as an indicator of need which requires monitoring or clinical intervention. I chose to restrict my criteria to the HoNOSCA questions relating to psychiatric symptoms only (Behaviour subscale Q1-4, symptom subscale Q7-9, and self-care, Q11), removing those relating to physical health, education or social problems. These questions were chosen based on experience from conducting HoNOSCA assessments during my work on MILESTONE and by consulting with two CAMHS clinicians.

3.7.2 Included diagnoses

My decision to include young people with neurodevelopmental disorders (including ADHD & ASD), anxiety or depressive disorders and personality disorders in my sample was based on evidence which showed that young people with these diagnoses are at risk of falling through the gap between CAMHS and AMHS (Singh et al., 2010, McNicholas et al., 2015, Hall et al., 2015). However, on closer inspection of the TRACK study results (Singh et al., 2010) as part of my systematic review, I noticed an inconsistency in the results and conclusions when referring to the group with emerging personality disorder. Despite the conclusion that young people with this diagnosis were most likely to fall through the gap, all four young people with emerging personality disorder in the cohort transitioned to AMHS. After consulting with members of the TRACK team, they confirmed that they had misinterpreted a null result to reach this conclusion.

As this finding reiterated the need for further evidence regarding the service use destinations of young people with emerging personality disorder, it was decided to keep this group in my sample to explore whether these young people are more likely to transition to AMHS or fall through the gap between services. Table 3 shows the definitions for these disorders, adapted from the DSM V (APA, 2013).

It is important to acknowledge that any young people included in the sample may also have other comorbid diagnoses, as the sample was not limited to those with only the diagnoses listed above.

Table 3 The definitions of the diagnoses included in this study (Adapted from the DSM V (APA, 2013))

Diagnosis	**Definition**	**Examples**
Neurodevelopmental disorders	A group of disorders with developmental onset which can affect social, personal, academic or occupational functioning and can frequently co-occur.	ASD, ADHD or social communication disorders.
Anxiety disorders	Disorders characterised by intense feelings of excessive fear or anxiety which can result in avoidance of the feared stimuli or situation.	Social anxiety disorder, or generalised anxiety disorder.
Depressive disorders	Disorders characterised by the presence of low mood, sadness or feelings of emptiness which significantly impair functioning.	Unipolar depression.
Personality disorders	Disorders with an onset in adolescence or early adulthood characterised by pervasive differences in personal experience or behaviour which significantly differ from cultural norms, resulting in distress and impairments to functioning.	Emerging personality disorder, or borderline personality disorder.

3.7.3 Included countries

This thesis uses data from seven countries which took part in MILESTONE: UK, Ireland, France, Germany, Netherlands, Belgium and Italy. I was unable to use Croatian data due to delays obtaining an appropriate data sharing agreement.

3.8 Ethical considerations

The MILESTONE study received ethical approval from National Research Ethics Service (NRES) Committee West Midlands - South Birmingham on 24th February 2015 (REC reference: 15/WM/0052). MILESTONE consent forms contained a point asking all participants to consent to their data being used for future research, which enabled my use of MILESTONE data for the quantitative and health economic analyses. Ethical approval was obtained from West Midlands - Black Country REC on 10th December 2018, prior to recruitment and data collection for the qualitative study (REC reference: 18/WM/0337, see Appendix 1). Interviews were designed to ensure they caused minimum distress to the participants, for example by taking place in their chosen location or using their preferred method of communication. Although interviews involved a potentially sensitive topic, the interview questions themselves were designed to be open-ended and allow the participant to decide how much detail they wanted to share. The participant information sheet also contained information to help the young person if they decided they would like to talk more to a mental health professional after the interview. Due to my previous experiences of working as a research associate on MILESTONE, I also had the knowledge of where to signpost participants if they required further support. I had also previously completed training on 'How to handle emotional conversations', so felt confident in how to interview participants about a potentially sensitive and emotive topic. I also have previous experience of conducting interviews in a research setting and completed a one-week training course in qualitative research ran by Warwick Medical School.

3.9 Contribution to knowledge

To the best of my knowledge, this thesis is the first study to address the current lack of evidence regarding what happens to young people who fall through the gap between CAMHS and AMHS. Specifically, it explores the causes and predictors of falling through the gap, as well as the effects which falling through the gap has on young people and their families. It also provides information on the costs associated with falling through the gap between services, something which is also lacking from the current literature. Overall, this thesis aims to generate recommendations for future research and mental health services. The results can be used to influence future policy regarding transitional care, and ultimately result in improved care for young people who reach the CAMHS transition boundary.

3.10 Chapter summary

This chapter has presented the research questions, study design and key concepts for this thesis. Rationales and detailed methodologies for each of the different studies which make up this thesis are described in later chapters (Chapters 4-8). A rationale has been presented for the use of mixed methods research, the results of which are reported in Chapter 9.

Chapter 4: Systematic Review

4.1 Introduction

This chapter reports the results of the systematic review, exploring the service use outcomes of young people after reaching the CAMHS transition boundary. The chapter begins with a rationale for this review before moving on to report the method and results of the review, and how findings relate to existing literature. This review has been published in European Child and Adolescent Psychiatry (Appleton et al., 2019). The methods, results and discussion are included in the same format as in the published paper.

4.2 Background and Rationale

Despite increased attention in transition research, only one scoping and one systematic review into transitions in mental health had been conducted before I began my review (Reale and Bonati, 2015, Paul et al., 2015). The review by Reale and Bonati (2015) identified two studies which have investigated the outcomes associated with transition (Singh et al., 2010, Paul et al., 2013), however I was aware of at least two more recent studies which could add to these findings (McNicholas et al., 2015, Stagi et al., 2015).

As little was known about the outcomes of young people who cross the transition boundary, there was a need to collate the existing evidence. I chose to conduct a systematic review as it is an important method of synthesising research commonly used in healthcare, and enables results to be easily accessible for providers and policy makers (Gopalakrishnan and Ganeshkumar, 2013). It also allows for a more thorough search of existing literature than other approaches such as a scoping review. Using this method enabled an exhaustive search of the literature to be conducted in order to collate the service use and mental health outcomes of all young people in existing research who have reached the CAMHS transition boundary. Findings from the systematic review are also used to identify gaps in the current research literature regarding the mental health and service use outcomes of young people after leaving CAMHS.

4.3 Research Questions

This chapter contributes to the second research question: What effect does falling through the gap have on the mental health and functioning of young people and their families?

Further information about the research questions, aims and objectives of this research can be found in Chapter 3, sections 3.2 and 3.3.

4.4 Method

This systematic review was conducted and reported in concordance with PRISMA guidelines. The protocol for this review was registered with PROSPERO, ID number CRD42018085916.

4.4.1 Search strategy

After initial scoping searches, six bibliographic databases were searched (Medline, PsycINFO, CINAHL, Embase and Web of Science) for relevant literature from their inception until December 2017. Search terms were developed in collaboration with an information specialist, and contained terms relating to transition, young people, and mental health. An example search strategy can be found in Table 4. The reference lists of relevant systematic reviews which were identified during title and abstract screening were hand searched for additional relevant studies, although none were identified.

Table 4 Example search strategy from Medline

#	Searches
1	continuity of care/ or exp transition to adult care/ or exp transitional care/ or care pathway.mp.
2	((transition or transfer* or continuity or interface) and care).mp.
3	1 or 2
4	mental health services.mp. or exp Mental Health Services/
5	mental health.mp. or exp Mental Health/
6	exp Mental Disorders/ or exp Psychiatry/ or psychiatr*.mp.
7	mental illness*.mp.
8	camhs.mp.
9	amhs.mp.
10	4 or 5 or 6 or 7 or 8 or 9
11	3 and 10
12	young adult.mp. or exp Young Adult/
13	exp Adolescent/ or adolescen*.mp. or exp Child/
14	teenager*.mp.
15	exp Pediatrics/ or p*diatric.mp.
16	12 or 13 or 14 or 15
17	11 and 16

4.4.2 Eligibility criteria

Studies were eligible to be included if they provided details of the clinical or functional outcomes of a cohort of young people (from mid-late adolescence to early adulthood) who crossed the transition boundary of children's mental health services, or if they provided details of the service pathway taken by a cohort of young people who crossed the transition boundary. Here we define transition boundary as the upper age limit of a CAMHS. Conference abstracts were eligible to be included if the research had not been published elsewhere. There were no language restrictions in this review.

We did not include research involving the transition of young people with physical illnesses, neurological conditions (e.g. epilepsy), young people with a severe learning disability or young people who were not transitioning in a mental health service. Case studies, editorials, literature or systematic reviews, opinion pieces and policy documents were also excluded.

4.4.3 Study selection

After de-duplication of references, titles and abstracts were screened by one reviewer (RA), and a random 10% were screened by another member of the research team (EF). Agreement was high between both reviewers (k_{max} = 0.85). Any references which met the inclusion criteria were then screened by full text by two reviewers independently (split between RA, EF, and CC). If the title and abstract did not contain sufficient information to decide on eligibility then they were included for full text screening. Any disagreement between reviewers was resolved through discussion.

4.4.4 Quality assessment

Quality assessment of included studies was conducted independently by two reviewers (RA and CC) using a modified version of the Newcastle-Ottawa Scale (Wells et al., 2011). This quality assessment tool as chosen as it is suitable for use with cohort studies and therefore was a good fit for the literature included in this review. The tool was adapted to change the requestions which focused on recruitment and comparisons between cohorts to questions which were more relevant to the included literature. A table showing all amendments is shown in Appendix 2. All studies were included regardless of quality due to the lack of research in this area, however, results of quality assessment were used to inform the narrative synthesis of results.

4.4.5 Data extraction

A data extraction tool was piloted on a small number of included studies, modified, and then used to extract data from all studies. It included the following headings: Year of publication, Country of origin, aims, study design, sampling method, methodology, results, and how results were presented. Data extraction was carried out by two reviewers independently (RA and CC).

4.4.6 Data synthesis

Data were synthesised narratively by one reviewer (RA) using steps adapted from Popay et al (2006). These are: 1) to develop a preliminary synthesis of findings of included studies; 2) to explore relationships in the data; 3) to assess the robustness of the synthesis. A meta-analysis was not conducted due to the heterogeneity of the included studies.

4.5 Results

4.5.1 Study selection

After duplicates were removed, 18287 studies remained for screening by title and abstract. 213 studies were included for full text screening, of which 200 studies were excluded to leave 13 studies for inclusion in this review, representing 10 different cohorts of young people crossing the CAMHS transition boundary. Figure 3 illustrates the paper selection process. Only one study explored mental health outcomes after transition (Memarzia et al., 2015), however this data could not be extracted as CAMHS leavers were grouped with looked after children. Therefore, only information on service use outcomes following transition will be discussed in this review.

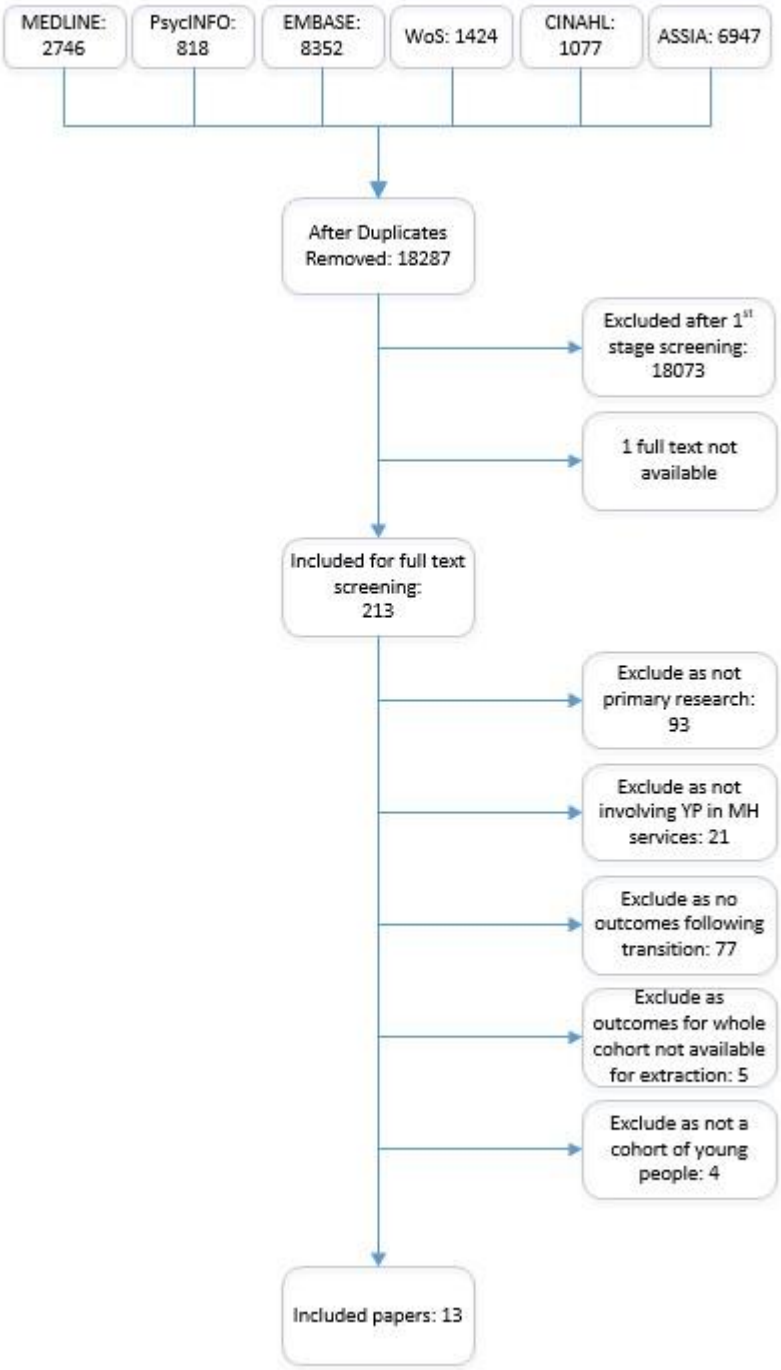

Figure 3 PRISMA flow chart showing screening of identified papers

4.5.2 Study characteristics

The 13 included studies represent research carried out in six different countries, Canada (Cappelli et al., 2016), England (Ogundele, 2013, Singh et al., 2010, Paul et al., 2013, Memarzia et al., 2015, Islam et al., 2016, Moosa and Sandhu, 2015) the Republic of Ireland (McNicholas et al., 2015, Tatlow-Golden et al., 2017), France (Schandrin et al., 2016),

Australia (Perera et al., 2017) and Italy (Stagi et al., 2015, Reale et al., 2015). Two studies were service evaluations (Cappelli et al., 2016, Moosa and Sandhu, 2015) one was a questionnaire study (Reale et al., 2015), one was a longitudinal study (Memarzia et al., 2015) and the remaining nine had a retrospective cohort study design (Ogundele, 2013, Paul et al., 2013, Singh et al., 2010, McNicholas et al., 2015, Islam et al., 2016, Tatlow-Golden et al., 2017, Schandrin et al., 2016, Perera et al., 2017, Stagi et al., 2015). Seven of the studies involved all young people in a cohort of CAMHS leavers, whilst four focused only on young people with ADHD (Ogundele, 2013, Moosa and Sandhu, 2015, Tatlow-Golden et al., 2017, Reale et al., 2015). The sample sizes in the included studies ranged from 20 – 4226 young people. Table 5 shows further details of the included studies.

4.5.3 Risk of bias

The quality of the included studies varied, with 10 being of good quality and three being of poor quality (see Table 5 for more details). Studies were rated as poor if they did not include a measure of clinical need to transition or a breakdown of transition for different subgroups (e.g. different diagnoses, age groups, severity of illness, etc), and if detailed baseline information of the cohort was missing.

Table 5 Description of included studies

Author & Date	Title	Country of Origin	Study Design	Age Group	Participants	Results	Quality Assessment
Cappelli et al (2014)	Transitioning youth into adult mental health and addiction services: An outcomes evaluation of the youth transition project	Canada	Service evaluation	Young people (YP) between ages of 16 and 24.	215 young people (YP) accessing CAMHS who were referred to the transition programme	Young people (YP) who transitioned were more likely to have a higher score on a measure of antisocial behaviour ($x^2(1,59)=3.84$, p=.05) or have an anxiety disorder ($x^2(1,199)=4.05$, p=.044) than those who engaged with services. YP who transitioned as opposed to remaining on the waiting list had a higher number of visits to the emergency department ($x^2(1,115)=4.76$, p=.029) and reported more unmet needs relating to psychological distress ($x^2(3,106)=10.98$, p=.012). YP who remained on the waiting list were more likely to have oppositional defiant disorder ($x^2(1,200)=7.64$, p=0.006) or ADHD ($x^2(1,200)=4.83$, p=0.028).	Good
Islam et al (2016)	Mind how you cross the gap! Outcomes for young people who failed to make the transition from child to adult services	England	Retrospective case note analysis	YP who reached transition boundary during 12 month study period and had not been transitioned to AMHS after reaching the CAMHS age boundary.	64 YP who had mental health needs but were not transitioned to AMHS	The majority of YP who did not transition to AMHS were those with a diagnosis of an emotional or neurotic disorder (48.4 %). The next most common diagnostic group who did not transition were those with a neurodevelopmental disorder (23.4%).	Good

McNicholas et al (2015)	Who is in the transition gap? Transition from CAMHS to AMHS in the Republic of Ireland	Republic of Ireland	Retrospective case note analysis	Cases included if YP were open to the service when they reached the upper age limit of that service in the 12 month study period.	62 YP who crossed CAMHS transition boundary	Several of the YP with an ongoing mental health need (n=47) were not referred to AMHS (45%). Refusal by the YP or their parent/carer was also a common reason for non-referral (23%). 32% of YP were referred to AMHS, with YP more likely to make the transition if they had a diagnosis of psychosis ($x^2(2,45)=8.96$, p=.02, V=.45). In contrast, YP with a diagnosis of ADHD were most likely to refuse the referral to AMHS ($x^2(2,45)=6.81$, p=.01, V=.44).	Good
Memarzia et al (2015)	Adolescents leaving mental health or social care services: predictors of mental health and psychosocial outcomes one year later	England	Longitudinal cohort study	YP aged 17-18 facing transition.	26 YP who were about to leave CAMHS and 27 looked after children	Of the YP who left CAMHS, the majority (82%) were discharged to their GP, whilst 14% were referred to AMHS. Mental health outcomes were recorded but could not be extracted for the CAMHS leavers, as data were grouped with the whole cohort.	Good
Moosa & Sandhu (2015)	Transition from children's to adult services for patients with ADHD: A model of care	England	Service evaluation	Adolescents 15 or over with a diagnosis of ADHD who were open to CAMHS.	247 YP with ADHD who were 15 or older in CAMHS	Before this scheme was introduced, 134 YP remained at CAMHS after they had reached the upper age limit of the service, which was reduced to 14 following its implementation. The referral rate to AMHS increased from 67% to 95% after the new initiative.	Good
Ogundele (2013)	Transitional care to adult ADHD services in a North West England District	England	Retrospective case note analysis	Adolescents with ADHD from childhood who were eligible for transition to AMHS, who reached 16 years old during study period.	104 YP who were eligible for transition to AMHS	65% of YP were discharged from paediatric services without referral, often due to disengagement or self-discharge. 15% of YP were referred to an AMHS, and 18% to a CAMHS service. Of these YP referred to another service, 32% were discharged within the following two years.	Poor

Paul et al (2013)	Transfers and transitions between child and adult mental health services	England	Retrospective case note analysis	YP who reached transition boundary during 12 month study period.	154 YP who crossed transition boundary	Of the 131 YP with an ongoing clinical need, 102 were referred to AMHS and 90 were accepted. The most common reasons for non-referral were the CAMHS clinicians thinking AMHS would not accept the referral or not having an appropriate service to refer to, delayed referral, or refusal by the YP or their parent/carer.	Good
Perera et al (2017)	Determinants of transition from child and adolescent to adult mental health services: A Western Australian Pilot Study	Australia	Retrospective case note analysis	CAMHS closed cases from 01/06/04 to 30/06/13 if YP were within transition age (16-21).	245 YP discharged from CAMHS at transition boundary	Four main transition pathways from CAMHS were identified: not referred, directly referred to AMHS, delayed referral to AMHS, and referred but not accepted. CAMHS diagnosis was associated with the likelihood of engagement at AMHS ($x^2(2)=10.99$, $p<.001$). In particular, YP with a neurotic disorder were less likely to be engaged at AMHS than those with a mood or other types of disorder (all $zs \geq 2.25$, $ps \leq .01$).	Good
Reale et al (2015)	Transition to adult mental health services for young people with attention deficit hyperactivity disorder in Italy: Parent's and clinician's experiences	Italy	Qualitative questionnaire study	Parents of adolescents with ADHD who reached adulthood - identified through mailing list of support group.	Parents and clinicians of YP with ADHD representing 24 young adults	Results showed that the most common outcome following transition from the children's service was no ongoing care (38%), excluding the YP who had been discharged because of good health (12%). No YP had been referred to the adult service from their children's service, although 21% were receiving care in a public adult mental health service and 17% by a private specialist. A further 12% of YP continued to receive care at the children's service after crossing the transition boundary.	Poor

Schandrin et al (2016)	Transition from child to adult mental health services: A French retrospective study	France	Retrospective case note analysis	Every patient whose transition from CAMHS to AMHS was initiated at a hospital during the 2 year study period.	31 YP who transition had been initiated	Transition was completed in 90% of cases, however YP often experienced discontinuity of care during their transition with an average gap of three months of no care between the services. At three months following transition to AMHS, 84% were actively engaged, although this fell to 45% at one to three years later.	Poor
Singh et al (2010)	Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study	England	Retrospective case note analysis	See Paul et al (2013)	154 YP who crossed transition boundary	YP were more likely to be referred to AMHS if they had been admitted under the Mental Health Act (OR 5.0; 95% CI clustered 1.6-15.5; p=0.01), had a severe and enduring mental illness (OR 2.82; 95% CI clustered 0.8-9.6; p=0.01), were on medication at the time of transition (OR 7.85; 95% CI clustered 1.5-40.9; p=0.01), or had a comorbidity (OR 2.36; 95% CI clustered 1.7-3.4; p<0.01). YP with emerging personality disorder were reported to be more likely to fall through the gap, however the numbers were too small to draw statistically significant conclusions.	Good
Stagi et al (2015)	Continuity of care from child and adolescent to adult mental health services: Evidence from a regional survey in Northern Italy	Italy	Retrospective case note analysis	YP aged 16 or older listed in a health database as having attended CAMHS in a 3 year period. Received formal diagnosis.	8239 YP who crossed the CAMHS transition boundary	Over the four year study period, 19.4% of YP were transferred to AMHS. Young people were more likely to make this transition if they had a diagnosis of schizophrenia or related disorders (OR 3.92; 95% CI 2.17-7.08), a personality disorder (OR 2.69; 95% CI 1.89-3.83) or a pervasive developmental disorder (OR 2.13; 95% CI 1.51-2.99). Of the 2771 YP referred to AMHS, 580 were accepted and an additional 241 received joint care from both services.	Good

Tatlow-Golden et al (2016)	Transitioning from child and adolescent mental health services with attention-deficit hyperactivity disorder in Ireland: Case note review	Republic of Ireland	Retrospective case note analysis	See McNicholas et al (2015). Sample of YP with ADHD included in this paper	20 YP who crossed CAMHS transition boundary and had a diagnosis of ADHD	None of these YP were directly referred to a public AMHS.	Good

4.5.4 Synthesis of results

The synthesis of individual study findings shows a care gap at the end of CAMHS, with only 24% of young people transitioning to AMHS after reaching their CAMHS age boundary (see Table 6 for details). Three studies (Singh et al., 2010, McNicholas et al., 2015, Memarzia et al., 2015) explored the service use destinations of young people who had an ongoing clinical need at the end of CAMHS and found that some did not receive an AMHS referral despite still being judged to need ongoing care, with figures ranging from 42-84% (the latter figure includes some looked after children in Memarzia et al (2015)). In addition, four studies (Moosa and Sandhu, 2015, Tatlow-Golden et al., 2017, Perera et al., 2017, Reale et al., 2015) showed that 103 young people were discharged from CAMHS, only for them to be referred to AMHS by their GP.

A quarter of young people remained at CAMHS after crossing the transition boundary whilst another quarter transitioned to AMHS. The other 50% had varied service use destinations, however in most studies the follow up periods were not long enough to find out what happened to these young people after being discharged from CAMHS. Disengagement was high, with all but four studies (Memarzia et al., 2015, Perera et al., 2017, Stagi et al., 2015, Reale et al., 2015) including disengagement as an outcome after young people left care at AMHS. The number of young people who were discharged due to disengagement was recorded in all but one study (Ogundele, 2013), with disengagement ranging from 3-40% of young people.

Two studies (Paul et al., 2013, McNicholas et al., 2015) reported young people not being referred to AMHS because CAMHS clinicians did not think young people would meet the inclusion criteria or that AMHS did not have the necessary expertise. Five studies recorded unsuccessful referrals to AMHS (McNicholas et al., 2015, Islam et al., 2016, Schandrin et al., 2016, Perera et al., 2017, Stagi et al., 2015), with percentages of referrals rejected ranging from 3-73%. Full details of young people's service use outcomes following reaching the upper age limit of their CAMHS service is shown in Table 6.

4.5.5 Optimal transition

Three studies evaluated young people's transition according to the four principles of 'optimal transition' identified by Paul et al (2013). In most cases optimal transition was not achieved, with percentages of young people having optimal transition recorded at 6% (Memarzia et al., 2015), 13% (Schandrin et al., 2016), and 4% (Singh et al., 2010).

4.5.6 Waiting times

Three studies explored the average waiting times young people experienced during their transition to AMHS (McNicholas et al., 2015, Cappelli et al., 2016, Schandrin et al., 2016). All found that young people experienced long delays, ranging from 55-110 days.

4.5.7 AMHS engagement

Three studies looked at engagement at AMHS following transition, the TRACK study (as reported by (Paul et al., 2013, Singh et al., 2010)), Ogundele (2013), and Schandrin et al (2016). Of the 134 young people in these studies who transitioned to AMHS, 115 (89%) had at least one appointment. Rates of engagement fell further after this first appointment, with 17% being discharged after one AMHS appointment in the TRACK study (Singh et al., 2010) and 55% being discharged in the one to three years following transition in the study by Schandrin et al (2016).

4.5.8 Outcomes of young people with ADHD

Four studies focused on young people with ADHD. One was a service evaluation following improvements to their transition process (Moosa and Sandhu, 2015), and this showed a much higher rate of transition to AMHS (38%) than the other three studies carried out in standard care (11%). In two of the studies involving young people with ADHD, none of the cohort were transitioned to an AMHS (Tatlow-Golden et al., 2017, Reale et al., 2015). Of the young people who were discharged to their GP following cessation of care in CAMHS, a third were then referred to an AMHS, implying that they were discharged despite having an ongoing clinical need for treatment.

Table 6 Service use outcomes of young people crossing the CAMHS transition boundary (number of young people)

Service use pathway after crossing transition boundary	Cappelli et al (2014)	TRACK Cohort Islam et al (2016); Paul et al (2013); Singh et al (2010)	ITRACK Cohort McNicholas et al (2015)	ITRACK Cohort - long term ADHD outcomes Tatlow-Golden et al (2016)	Memarzia et al (2015)	Moosa & Sandhu (2015)	Ogundele (2013)	Perera et al (2017)	Reale et al (2015)	Schandrin et al (2016)	Stagi et al (2015)	Total
Transition to AMHS	127	90	14		3	94	16	62		28	821	1255
Engaged at AMHS*		76					13			26		115
Not referred - discharged		3	9									12
Not referred - unknown		4		1	4			88				93
Not referred - CAMHS			12	1		80	1		3		1214	1311
Not referred - other**		20			1	9						30
Refused - disengaged			2	3								5
Refused - discharged		11	3	4								18
Refused - CAMHS			6									6
Unsuccessful AMHS transition			1					29			2191	2221

Unsuccessful - discharged		2										2
Unsuccessful - CAMHS		2								1		3
Unsucessful - CAMHS - GP		3										3
Discharged to GP (well)		9	15	3					3			30
Discharged to GP					18		68		9			95
Discharged then AMHS				1		31		66	5			103
Disengaged	47	5		5		33				2		92
Private				2					4			6
Other CAMHS							19					19
Transition pending	41	5										46
Total	**215**	**154**	**62**	**20**	**26**	**247**	**104**	**245**	**24**	**31**	**4226**	**5350**

* young people attended at least 1 appointment

** other reasons recorded include: uncertain asylum status, care ending, multiple reasons

† Numbers will not add up to column total

4.6 Discussion

4.6.1 Summary and interpretation of findings

The aim of this review was to synthesise existing research on mental health and service use outcomes of young people after leaving CAMHS to contribute to the second research question of this thesis: What effect does falling through the gap have on the mental health and functioning of young people and their families? Thirteen studies were included, all of which reported service use destinations of young people after leaving CAMHS. Only one study included mental health outcomes after transition, however, as these data were reported for the whole cohort which included young people leaving care, this review focuses on service use outcomes after leaving CAMHS.

The included studies show the wide range of service use destinations of young people who reach the upper age limit of CAMHS, with only around a quarter of young people continuing care in AMHS. Alternative destinations included: other CAMHS services, community-based services, private care, or transfer of care to a GP. There are a variety of different pathways taken by young people, and multiple changes of service are common during this transition period. A quarter of young people stayed in CAMHS despite reaching the upper age limit of that service, either due to non-referral or their referral to AMHS not being accepted. This high variability in transition outcomes reflects the different ways CAMHS services are funded and organised in different countries, as well as the availability of appropriate AMHS (Signorini et al., 2018, Signorini et al., 2017). In addition to variation between countries, there was also significant variation in outcomes between participants studied at a national level, in the United Kingdom. These results indicate that young people receive differing quality of care depending on where they live, with different service models and transition boundaries.

There was also evidence to show that some young people experienced high disruption during the transition period: some were not referred onwards despite still requiring treatment when they crossed the CAMHS age boundary, whilst very few of those who did transition received optimal transitional care. This suggests that young people were poorly prepared for transition and experienced poor continuity of care, something echoed in several research studies exploring young people's experiences of transition (e.g. Dunn, 2017, Hovish et al., 2012). Having a poor transition experience could result in poor engagement with the adult service (Mulvale et al., 2015), which is supported by the findings in this review as studies showed high levels of disengagement. Young people may

also find it difficult to engage with AMHS due to the significant difference in focus and culture between the two services, something which has been identified as a potential barrier to young people's engagement in continued mental health care (Birchwood and Singh, 2013). The results of this review suggest that services are not following current guidance for best practice, which states that transition planning should be started early and in conjunction with the young person, whilst taking into account their need for ongoing support and at what point transition would be most appropriate (NICE, 2017). Moving forward, services should aim to align clinical practice with current mental health policy in order to provide the best possible care for young people as they reach the upper age limit of CAMHS.

Four of the included studies focused on young people with ADHD, as young people with this diagnosis are among the groups least likely to transition to AMHS (Singh et al., 2010). In two of these studies, none of the young people were transitioned directly to AMHS, although a minority were referred to adult services by their GP or received private care after leaving CAMHS (Tatlow-Golden et al., 2017, Reale et al., 2015). This could reflect a lack of appropriate service provision in some areas, leaving CAMHS with no choice but to discharge the young person to their GP (Hall et al., 2013). In contrast, the service improvement study by Moosa & Sandu (2015) reported much higher rates of transition, suggesting that AMHS will accept referrals of young people with ADHD providing the transition is managed effectively.

As several young people were not transitioned directly to AMHS, but instead first discharged to a GP, it can be argued that they did not receive sufficient continuity of care during their transition between services. Studies did not explore why a direct transfer of care was not made. A further clinical implication of this review is the finding that around a quarter of young people studied remained at CAMHS, even after reaching the upper age limit for that service. In this case, CAMHS should receive the appropriate funding and resources to provide this ongoing care, without restricting their ability to accept new referrals. One way in which mental health services have responded to the need for streamlined care has been to introduce new 14-25 services, removing the traditional transition boundary at around 16-18 years of age (Wilson et al., 2017). Initial findings have indicated that this new service model can help to reduce the number of young people experiencing an abrupt end to their care when they reach 18 (Maxwell et al., 2019). However, in order for these services to operate effectively, appropriate funding and resources are needed to ensure other service users do not suffer as a result.

4.6.1.1 Implications for future research

This review has also highlighted gaps in the existing research regarding service use outcomes of young people who reach the upper age limit of CAMHS, in particular longitudinal research which includes longer term outcomes in the months or years after transition. In recent years, new transition guidelines have been released, however we are unable to fully assess what impact these guidelines have had on clinical practice due to the lack of research in this area. More longitudinal research is required to fully understand how these guidelines have been incorporated into practice and what impact they have had on the transition experiences of young people. The mental health outcomes of young people following transition are also currently unknown, something which should be made a priority in future research.

4.6.2 Strengths and limitations

To our knowledge, this is the first review which has systematically synthesised evidence for the service use destinations of young people after they have reached the upper age limit of CAMHS. This review has systematically collated and critically evaluated transition research from six different countries, giving a picture of transition outcomes across high income countries. A particular strength of the methodology employed was the use of a wide search criteria to minimise chances of missing relevant research. Searches also included grey literature and had no language restrictions. However, not all the studies included were of a high methodological quality, therefore there are some limitations which should be considered during the interpretation of these results.

Firstly, poor record keeping by the mental health services in some of the studies meant that the service use outcomes of some cases were unknown. Poor record keeping in some services also led to differences in the selection method of cases; some used record linkage whilst others used clinicians to retrospectively identify eligible cases as records were not available. It is possible that cases with a particularly good or bad transition were more likely to be remembered which could lead to bias in the sample. A further limitation is that some studies did not report long term outcomes, for example they did not show what happened to young people whose transition was recorded as ‘pending’, those who stayed in CAMHS or those whose referral to AMHS was unsuccessful.

Details about a young person’s mental health and illness severity were also missing from some studies. For example, not all studies evaluated ongoing clinical need at the transition boundary, in some cases this was not mentioned whilst in others, having a

diagnosis of mental illness was enough to imply an ongoing need. Therefore, we cannot draw firm conclusions regarding the true numbers of young people who were not transitioned to AMHS despite still being unwell and needing further care. Similarly, not all studies distinguished between young people who were discharged to their GP because they were well and so no longer needed treatment, those discharged to GP for continued medical review, and those who were discharged to their GP because there was no appropriate service for them to transition to.

Finally, heterogeneity between the analyses in the different studies meant that quantitative synthesis of results using a meta-analysis was not appropriate.

4.6.3 Conclusion

The findings from this systematic review of the literature revealed that only a quarter of young people continued to access care at AMHS after reaching the upper age limit of CAMHS. The remainder have varied service use outcomes, often characterised by multiple transitions during this period. No research included extractable data regarding the mental health outcomes of young people after CAMHS.

4.7 Chapter Summary

This chapter has reported the method and results of a published systematic review exploring the service use outcomes of young people after reaching the CAMHS transition boundary. A more detailed discussion of the results from this chapter can be found in Chapter 9. The next chapter reports the method and results for a quantitative study exploring predictors of transitioning to AMHS and long-term mental health and function of those who transitioned or fell through the gap.

Chapter 5: Exploring predictors and outcomes associated with falling through the gap

5.1 Introduction

This chapter reports the results of the quantitative study, featuring a secondary data analysis on a sub-section of the MILESTONE study dataset. This chapter begins with the rationale for this study, and is followed by the methods and results, which cover two of the research questions posed in this thesis. Finally, I discuss the results in the context of the wider literature and the strengths and limitations of this research.

5.2 Background and Rationale

The findings from the systematic review (see Chapter 4, Section 4.5) highlight the paucity of literature examining the service use destinations of young people after leaving CAMHS, and the absence of studies reporting mental health and functioning outcomes of young people after crossing the transition boundary. Some studies have looked into the predictors of transitioning, however these predictors are mainly at the diagnostic level (e.g. Singh et al., 2010, McNicholas et al., 2015) and do not consider other factors such as illness severity or age of the young person at the transition boundary.

This study used longitudinal data collected during the MILESTONE Study to examine whether there are any sociodemographic or clinical predictors of discharge from CAMHS despite having an ongoing clinical need. It also investigated young people's mental health and functioning outcomes over the following 24 months, with data collected at four times points in this period (Baseline, +9months, +15 months, +24 months). The first time point was when all young people were approaching their CAMHS transition boundary, therefore these intervals were chosen to capture baseline measures at CAMHS, then follow up measures after they had left CAMHS by the second time point. However in practice, 26 young people in my sample had been discharged from CAMHS at the first assessment time point (likely due to a gap between recruitment at CAMHS and arranging the appointment). The majority did leave CAMHS between T1 and T2 (n=372), although some young people remained at CAMHS after crossing the upper age limit, and were discharged between T2 and T3 (n=90).

The advantage of using longitudinal data to answer this research question is that it allowed for a comparison of outcomes over time, during a period in which young people are undergoing several concurrent life changes and transitions (Hovish et al., 2012). To our knowledge, this is the first large study which has collected longitudinal data from young people who have reached the transition boundary of their service, allowing the exploration of their long-term transition outcomes. The results of this analysis are used to help generate recommendations for how the young people who are the most likely to fall through the gap should be supported as they approach the CAMHS transition boundary.

5.3 Research questions

This chapter contributes to the first two research questions:

1. Why do young people with certain diagnoses fall though the transition gap between CAMHS and AMHS?

2. What effect does falling through the gap have on the mental health and functioning of young people and their families?

Further information about the research questions, aims and objectives of this research can be found in Chapter 3, sections 3.2 and 3.3.

5.4 Method

5.4.1 Inclusion and exclusion criteria

For this quantitative study, all young people recruited to the MILESTONE Study who had a diagnosis of anxiety or mood disorder, neurodevelopmental disorder, or emerging personality disorder were included in the analysis (for more information about the inclusion criteria, see Chapter 3, section 3.7). For this thesis, the DSM V classification for neurodevelopmental disorders was used to include any disorder which has an onset during early development (see Appendix 3 for full list of included diagnostic labels). Young people with these diagnoses are the focus of this study, as previous research into transition outcomes has shown that these are the groups most likely to fall through the gap between services (Stagi et al., 2015, McNicholas et al., 2015, Singh et al., 2010). It should be noted that people with emerging personality disorder have been included in this study despite contradictory findings regarding people this diagnostic group (Singh et al., 2010, Stagi et al., 2015) to add to the evidence regarding their outcomes following transition from CAMHS.

Participants were classified as falling through the transition gap if they were discharged from CAMHS with no other referral despite having an ongoing clinical need, or if they were referred to AMHS but discharged by the next data collection time point, whilst still indicating a clinical need. Clinical need was measured by a score of two or above on HoNOSCA questions relating to psychiatric symptoms (Burgess et al., 2009). Participants were classified as transitioning to AMHS if they were referred to an AMHS by their CAMHS clinician as they reached the transition boundary.

MILESTONE participants who did not have a diagnosis of an anxiety or mood disorder, neurodevelopmental disorder, or emerging personality disorder were excluded from the analysis.

5.4.2 Description of Study Instruments

Data collected using the following instruments as part of the MILESTONE Study were included in this analysis:

Sociodemographic and personal information: Demographic data was collected at each time point through semi-structured interviews. This included personal and family information (e.g. age, living situation, socio-economic status, family set up), as well as information about mental health care and service use in the previous six months.

Diagnostic data: Diagnostic data was collected from a young person's clinician or their clinical records at each time point where available (this required young people to be registered at a mental health service at follow up time points).

HoNOSCA – Health of the Nation Outcome Scale for Child and Adolescent (Gowers et al., 1999): The clinician-rated HoNOSCA (rated by trained RAs) was used to assess clinical need. It incorporates data from an interview with the young person, their parent/carer, and clinician if applicable, to assess the psychosocial severity of mental health problems over the previous two-week period. HoNOSCA section A consists of 13 questions divided into four separate sub-sections: behaviour, impairment, symptoms and social. Questions are scored from 0 (meaning no incapacity) to 4 (meaning significant impairment or very severe symptoms). The question scores can be added to give a total score ranging from 0 to 52, with lower scores indicating better overall health.

ASEBA instruments – Achenbach System of Empirically Based Assessment (Achenbach and Rescorla, Achenbach and Rescorla, 2003): Data from these scales was used to assess levels of functioning. Young people under 18 completed the **Youth Self Report (YSR),** whilst

those over 19 completed the adult equivalent **Adult Self Report (ASR).** Individual questions are scored on a range from 0 (not true) to 2 (very true or often true). This scale can be divided into internalising (e.g. mood or emotional problems) and externalising (e.g. conduct problems) subscales, with higher scores indicating more severe problems.

IBDCS – Independent Behaviour During Consultation Scale: This scale measures adolescents' self-efficacy (on a 5-point Likert scale ranging from 'never' to 'always') and independent behaviour. This questionnaire was adapted for MILESTONE from a study investigating adolescent's self-efficacy (van Staa, 2011).

CGI-S – The Clinical Global Impression - Severity scale (Guy, 1976): This is an observer-rated one item scale that measures illness severity on a 7-point scale, which was completed by the young person's clinician. A score of 1 represents no illness, whereas a score of 7 means that young person is amongst the most extremely ill patients.

5.4.3 Statistical Analysis

Data analysis included baseline descriptive statistics of the sample and comparisons of young people who transition or fall through the gap between services. Statistical analysis was conducted using STATA 16 (STATACORP, 2019). A significance level of 95% was used and all numbers are rounded to two decimal places unless otherwise stated.

5.4.4 Predictors of transitioning and falling through the gap

This section outlines the method used for my first research question: Why do young people with certain diagnoses fall though the transition gap between CAMHS and AMHS?

The logistic regression model is a variation of simple linear regression which allows for modelling data with a binomial distribution (when the values are either 0 or 1) based on the values of other predictor or control variables (Hilbe, 2016). The underlying mathematical concept of a logistic regression model is the logit function, or the natural logarithm of the odds ratio (Peng et al., 2002), which can also be written as:

$$ln = \frac{p}{1-p}$$

Where p is the probability of the response variable occurring.

Logistic regression analyses can be used to estimate odds ratios for each of the predictor variables, which represent how the odds of the response variable change with a one unit

increase in the predictor variable, holding all other variables constant. The odds ratio is the ratio of two odds, as shown by this formula:

$$OR = \frac{\frac{p_1}{1-p_1}}{\frac{p_0}{1-p_0}}$$

There are three main assumptions about the data which need to be satisfied in order for the logistic regression model to provide a good fit for the data (Hilbe, 2016):

1. The predictor variables are not correlated with each other
2. The predictor variables are significantly related to the response variable
3. The individual data are not correlated with each other

The predictors in the model were chosen based on both findings from previous literature and insight gained whilst collecting the quantitative data. The three main types of regression variable selection methods (forward selection, backward elimination and stepwise entry (Xu and Zhang, 2001) were considered for the current analysis. In forward entry, variables are entered in to the model one at a time, in order of highest significance. In the backward elimination method, all variables are entered into the model and insignificant variables are deleted one by one, beginning with the variable which has the smallest effect on the model. Stepwise entry is a combination of forward selection and backward elimination methods, with variables entered in turn and the significance of existing variables reviewed as each new variable is added to the model. Backwards elimination is generally viewed as the preferred method for variable selection as it minimises the impact of collinearity when compared to forward selection (Chatterjee and Hadi, 2015), therefore this method was used in my analysis.

A logistic regression was chosen as an appropriate method of analysis to answer my first research question ('Why do certain young people fall through the gap?') as the dependent variable has a binary outcome (transitioned or fallen through the gap). A logistical regression model was used to explore the predictors of young people falling through the gap. Independent variables include age, gender, nationality (to allow for cross-country comparisons), ethnicity, diagnosis, length of time at CAMHS, number of diagnoses, previous suicide attempt, severity of illness (using CGI for clinician-rated and HoNOSCA for researcher-rated), and independent behaviour score (using IBDCS). Odds ratios of

independent variables and associated 95% confidence interval were calculated to assess the impact of the independent variable on probability of transitioning. Any country-specific differences were compared to baseline mapping data of mental health services involved in MILESTONE to investigate if different healthcare systems impact whether young people with these diagnoses are referred to AMHS.

Post-analysis tests were conducted to check the model for specification (whether all appropriate variables are included in the model) and collinearity (whether the predictor variables are correlated with each other) errors. Pearson's chi squared and Hosmer-Lemeshow goodness of fit tests were used to assess the overall fit of the model to the data.

5.4.5 Mental health and functioning outcomes of transitioning or falling through the gap

This section outlines the method used for my second research question: What effect does falling through the gap have on the mental health and functioning of young people and their families?

Multilevel modelling of regression analyses is used to model the relationship between the dependent variable and explanatory variables, with different levels included in the model (Rabe-Hesketh and Skrondal, 2008). This method is commonly used to analyse longitudinal data (Diez-Roux, 2000), as data in longitudinal studies can be described as belonging to various nested groups, sometimes in a hierarchy. This occurs because data at one level of an analysis can be influenced by data at another, higher level (Nezlek, 2008). The classic example often used is in pupil performance: each individual pupil's academic performance is also affected by their teacher, or at a higher level, the school they attend. Therefore in order to account for this grouping of data and to avoid bias during analysis, data should be analysed using a multilevel perspective (Nezlek, 2008).

The equation for a multilevel model with longitudinal data is:

$$Y_{ij} = \gamma_{00} + \gamma_{01}C_j + \gamma_{10}I_{ij} + \gamma_{11}C_jI_{ij} + U_{0j} + U_{1j}I_{ij} + \varepsilon_{ij}$$

Where Y_{ij} = outcome variable for i^{th} individual in j^{th} group; C_j = group level, γ_{01} = the fixed effects of group level variables on the outcome; γ_{10} = the fixed effects of individual level variables on the outcome; γ_{11} = the fixed effects of the interaction of group and individual levels on the outcome; U_{0j} = random intercept; U_{1j} = random slope component; ε_{ij} = individual errors.

(Diez-Roux, 2000)

Due to the repeated data collected in multilevel modelling, separate levels can be introduced in the model to account for clusters caused by repeated measures for each individual (Scott et al., 2013), and data collection time points (Laird, 2013). I chose multilevel modelling as an approach as the data was also clustered across hierarchical nested groups (four time points, repeated measures), therefore this method would allow me to take these groupings into account and reduce potential biases. Other methods such as a standard multiple regression do not take this clustering into account as they assume the data are independent (Osborne & Waters, 2002), therefore multilevel modelling was the most appropriate method to fit the current dataset.

As well as creating separate levels of repeated measures and time points, I also chose to include country as a grouping level in the model to give three levels in total. In order to conduct this analysis, data needed to be converted from a wide to a long format, which allows data to be analysed within individuals, as opposed to within groups (Hox, 2013).

Multilevel regression models were used to compare outcomes of young people following transition. Outcomes of interest included severity of illness (as indicated by the total HoNOSCA scores) and level of functioning (measured by total ASEBA scores). The process of model development is described below in section 5.4.5.1.

5.4.5.1 Model development

A series of models increasing in complexity were created to explore the impact of covariates at each level (see Figure 4). An initial unadjusted regression model was conducted controlling for cluster. This was followed by a partially adjusted multi-level model controlling for baseline scores, as analysing baseline HoNOSCA and ASEBA scores indicated that those in the transition group may have been more severely ill at baseline (see Table 8). If not taken into consideration during analysis this could lead to bias, as those who are more severely ill have greater potential to improve over the course of a follow up period (Vickers and Altman, 2001). This is known as 'regression to the mean'. Alternatively, those in worse health states at baseline may be more likely to be in worse health states at follow up. Thus, it is important to adjust for these imbalances.

The final model was a fully adjusted multi-level model including baseline scores and covariates. This was conducted as imbalances between the covariates in the two groups may also lead to bias in the regression analysis. Including these covariates in the model

controls for any differences between the two groups. In this final model, baseline HoNOSCA or ASEBA scores were included in the model as a covariate, in addition to gender, age at baseline, ethnicity, primary diagnosis, IDBCS baseline score, length of time at CAMHS, and previous suicide attempt. This allowed the model to analyse the follow up measures whilst controlling for baseline scores (O'Connell et al., 2017). Post analysis tests were conducted to check the final models for specificity and collinearity.

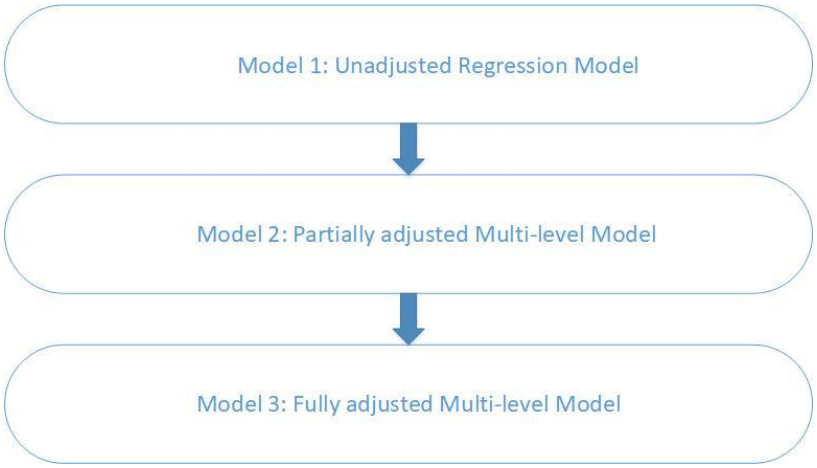

Figure 4 Process of model development

5.4.5.2 Sensitivity analyses

To determine the robustness of results of clinical research, it is important to conduct sensitivity analyses to check assumptions used in the original analysis (Thabane et al., 2013). It was decided to conduct two sensitivity analyses to check the results of the fully adjusted multilevel model. These were conducted as follows:

1. Dropping small variables

The first sensitivity analysis was to remove small categories from variables and re-run the model. Categories were removed if they made up less than 5% of the total data for each variable (e.g. gender = 'not set').

2. Multiple imputation of missing data:

Different methods of handling missing data such as complete case analysis and last observation carried forward (LOCF) were considered. However these were not chosen as they risk biasing the sample, for example LOCF underestimates the uncertainty around the

estimates (Mavridis et al., 2019), and assumes that the missing value remains unchanged over time (Kang, 2013), which may not be likely in the current sample. LOCF can also underestimate the variance of the estimates, therefore leading to an increased chance of results having a type 1 error (Lachin, 2016). In comparison, multiple imputation is the recommended method for dealing with large amounts of missing data as it can be applied to large complex datasets whilst acknowledging the uncertainty of estimates of missing data (Kenward and Carpenter, 2007, Kang, 2013). This approach has the advantage over other methods such as complete case analysis as it retains a larger sample and avoids altering the shape of the distribution (Kang, 2013). It was therefore decided to conduct the multilevel regression on a dataset with imputed values to minimise the impact of missing data on the results. Multiple imputation works by generating several new versions of the dataset, each with different predicted values estimated from other available data. The statistical analysis is then conducted on each imputed dataset, and the results combined using Rubin's rule (Rezvan et al., 2015).

Multiple imputation was conducted on the longitudinal dataset using chained equations (MICE), generating 20 imputed datasets. Predictive mean matching (k=5) was used for continuous variables, logit for binary variables, mlogit for categorical variables and ologit for ordinal variables. The variables used in the imputation with no missing data were gender, transition outcome, discharge time point, country, number of primary diagnoses and number of diagnoses. Imputed variables were baseline age, baseline HoNOSCA score, T2 HoNOSCA, T3 HoNOSCA, T4 HoNOSCA, baseline IBDCS score, baseline ASEBA internalising scores, T2 internalising scores, T3 internalising scores, T4 internalising scores, baseline ASEBA externalising scores, T2 externalising scores, T3 externalising scores, T4 externalising scores, baseline CGI, grouped primary diagnosis and previous suicide attempt. Ethnicity was not included in the multiple regression for the imputed model due to problems with non-convergence, caused by the small numbers of non-white people transitioning to AMHS (n=11).

5.5 Results

5.5.1 Missing data

Before starting data analysis, the amount of missing data was identified and examined. This will now be presented according to the two research questions.

5.5.1.1 Question 1: Predictors of transitioning or falling through the gap

For the baseline data used within the logistic regression analysis, all variables had less than 10% of missing data. Out of the 13 variables, 8 had no missing data. The variable with the highest percentage of missing data was the CGI (9% missing). This pattern of missingness can be explained as the CGI was a clinician-rated scale, and not all young people had a clinician who was willing to take part in the study. As the level of missing data was below 10%, it was decided that complete case analysis was sufficient for data analysis.

5.5.1.2 Question 2: Outcomes of transitioning or falling through the gap

As expected, the percentage of missing data increased over the course of the data collection time points. At T4, 19.8% of HoNOSCA data were missing (an increase from 2.1% at T1), as well as 28.3% of ASEBA data (an increase from 6.6%). As the level of missing data was above 10%, multiple imputation was used as a sensitivity analysis.

Analysing the patterns of missing data showed that 43.44% of all participants had no missing data. Only 10.45% of participants were missing data from 6 or more variables. Transition outcome and baseline HoNOSCA score were not significantly associated with missing data.

5.5.2 Description of sample

Screening MILESTONE longitudinal cohort data according to the inclusion criteria applied in this study resulted in 488 participants for inclusion in my quantitative analysis (of the 1004 recruited to MILESTONE). Out of these 488 participants, 336 were judged to have fallen through the gap, whilst 152 transitioned to AMHS. The sample comprised of slightly more females than males (58% females), were mostly white European (81%), and the most common primary diagnosis was emotional disorders including anxiety and depression (42%). A full breakdown of the demographic details of the sample is shown in Table 7. Transition outcome by country is also shown in Table 7, with the highest percentage of young people transitioning in Ireland (48%) and those with the lowest percentage of transitioning in Italy (12%).

Table 7 Baseline characteristics of participants

	Fell Through Gap	**Transitioned**	**All**
Age in years, mean (SD)	17.06 (0.58)	17.00 (.67)	17.04 (.61)
Gender, n (%)			
Female	186 (65.49)	98 (34.51)	284 (58.20)
Male	149 (73.40)	54 (26.60)	203 (41.60)
Not set	1 (100)	0 (0)	1 (0.21)
Ethnicity, n (%)			
White European	279 (70.63)	116 (29.37)	395 (80.94)
Other	26 (70.27)	11 (29.73)	37 (7.58)
Missing	31 (55.36)	25 (44.64)	56 (11.48)
Country, n (%)			
Belgium	35 (56.45)	27 (43.55)	62 (12.71)
France	27 (55.10)	22 (44.90)	49 (10.04)
Germany	37 (66.07)	19 (33.93)	56 (11.48)
Ireland	13 (52.00)	12 (48.00)	25 (5.12)
Italy	76 (88.37)	10 (11.63)	86 (17.62)
Netherlands	61 (72.62)	23 (27.38)	84 (17.21)
UK	87 (69.05)	39 (30.95)	126 (25.82)
Diagnosis, n (%)			
Neurodevelopmental	133 (73.89)	49 (27.22)	182 (37.30)
Emotional disorders	137 (66.51)	69 (33.50)	206 (42.21)

Personality/trauma	35 (62.5)	21 (37.5)	56 (11.48)
Eating disorders	9 (75.00)	3 (25.00)	12 (2.46)
Other	22 (68.75)	10 (31.25)	32 (6.56)
Number of Diagnoses, n (%)			
1	146 (77.25)	43 (22.75)	189 (38.73)
2	98 (64.05)	55 (35.95)	153 (31.35)
3	63 (61.77)	39 (38.24)	102 (20.90)
4	15 (75.00)	5 (25.00)	20 (4.10)
5	7 (70.00)	3 (30.00)	10 (2.05)
6	6 (54.55)	5 (45.45)	11 (2.25)
7	1 (33.33)	2 (66.66)	3 (0.62)
Length of time in CAMHS, n (%)			
1 year	45 (73.77)	16 (26.23)	61 (12.50)
2 years	60 (77.92)	17 (22.08)	77 (15.78)
3 years	48 (76.19)	15 (23.81)	63 (12.91)
4 years	78 (60.00)	52 (40.00)	130 (26.64)
5 years	57 (64.77)	31 (35.23)	88 (18.03)
6 years	39 (76.47)	12 (23.53)	51 (10.45)
Missing	9 (50.00)	9 (50.00)	18 (3.69)
Previous Suicide Attempt, n (%)			
No	233 (73.73)	83 (26.27)	316 (64.75)
Yes	88 (60.27)	58 (39.73)	146 (29.92)
Don't know	11 (84.62)	2 (15.39)	13 (2.66)
Missing	4 (30.77)	9 (69.23)	13 (2.66)

Table 8 Baseline HoNOSCA and ASEBA scores by transition outcome

	Fell Through Gap	Transitioned
Baseline HoNOSCA (mean, SE)	11.88 (0.34)	15.10 (0.61)
Baseline ASEBA (mean, SE)	33.94 (0.91)	41.36 (1.77)

There was also some variation in baseline illness severity by country (see Figure 5), with young people in Belgium and Germany showing the highest baseline HoNOSCA scores. In contrast, participants in France showed the lowest baseline illness severity.

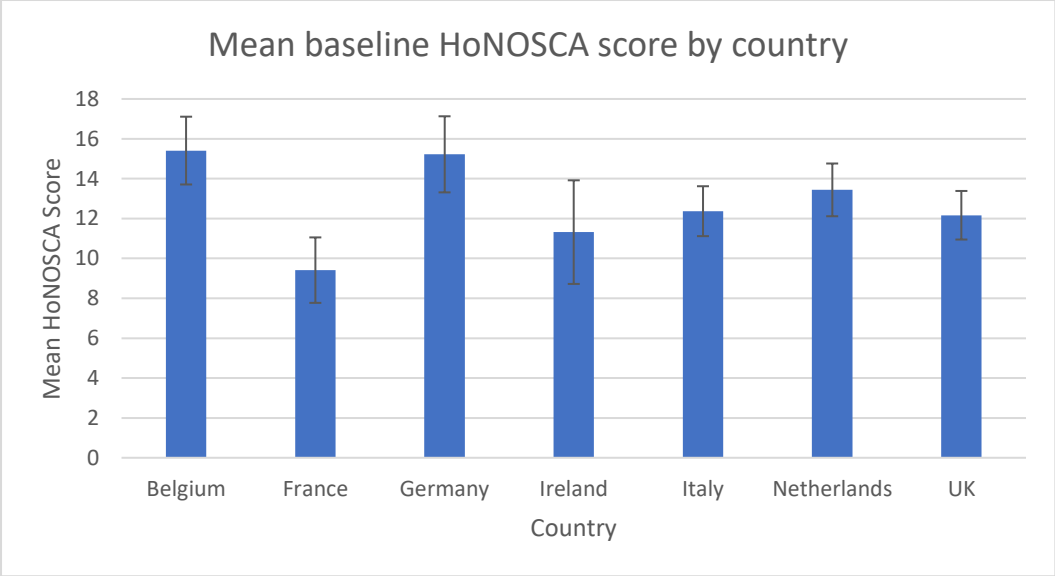

Figure 5 A graph showing the mean baseline difference in HoNOSCA scores by country and the associated 95% confidence intervals

ASEBA scores differed across countries, with young people in Ireland having the highest scores and participants in the Netherlands reporting the lowest levels of impaired functioning (Figure 6).

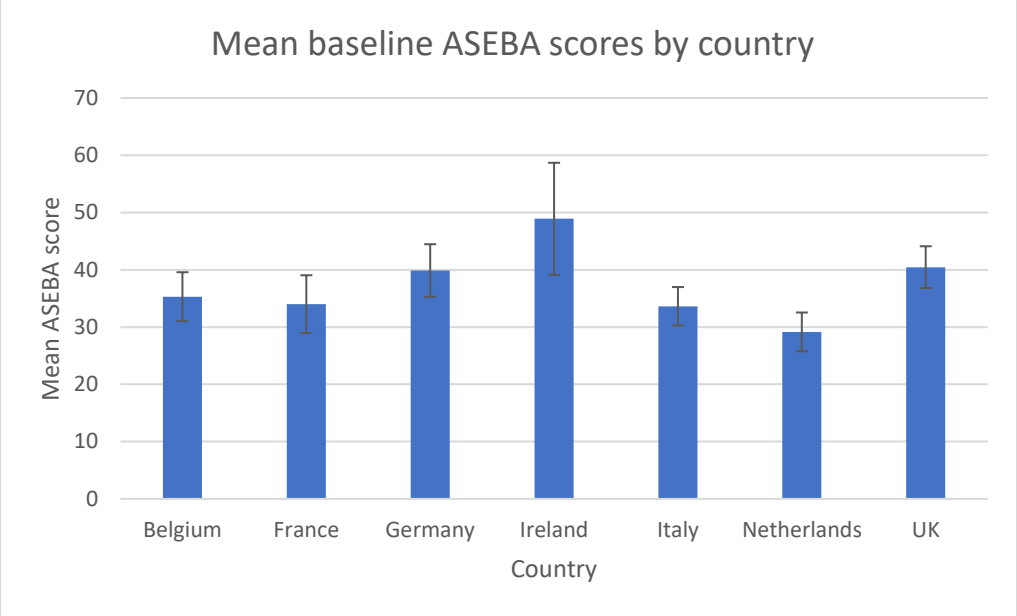

Figure 6 A graph showing the mean baseline difference in ASEBA scores by country and the associated 95% confidence intervals

5.5.3 Results for Question 1: Predictors of transitioning or falling through the gap

After removing missing data, 403 complete cases were included in this analysis. Being severely ill (as measured by a score of 6 on the clinician-rated CGI) was associated with a significantly increased probability of transitioning to AMHS (OR = 4.32, 95% CI 1.19-15.65), as was having a higher HoNOSCA score (OR = 1.06, 95% CI = 1.02-1.10), and higher IBDCS score (OR =1.05, 95% CI (1.01-1.09). In contrast, living in Italy (OR = 0.15, 95% CI 0.06 – 0.35), the Netherlands (OR =0.32, 95% CI 0.16-0.64) or the UK (OR = 0.48, 95% CI = 0.25 to 0.91) was significantly associated with reduced odds of transitioning to AMHS (as illustrated in Figure 7) compared to Belgium (the reference country in the model).

Although not statistically significant at the 95% level, previous suicide attempt (OR = 1.63, 95% CI 0.96-2.79) was associated with an increased likelihood of transitioning (p=0.07) to AMHS. Length of time in CAMHS was also positively associated with transition likelihood (OR = 1.15, 95% CI 0.96-1.38), whilst male gender (OR = 0.68, 95% CI 0.40-1.16) and living in Germany (OR = 0.51, 95% CI = 0.21-1.23) were both negatively associated with transition likelihood. These four variables were included in the overall model although the individual variables did not reach statistical significance at the 95% level as they are still important in aiding interpretation of the overall model findings. Furthermore, removing weak effects

may result in bias, as regression coefficients depend on the other variables included in the model (Heinze & Dunkler, 2017)

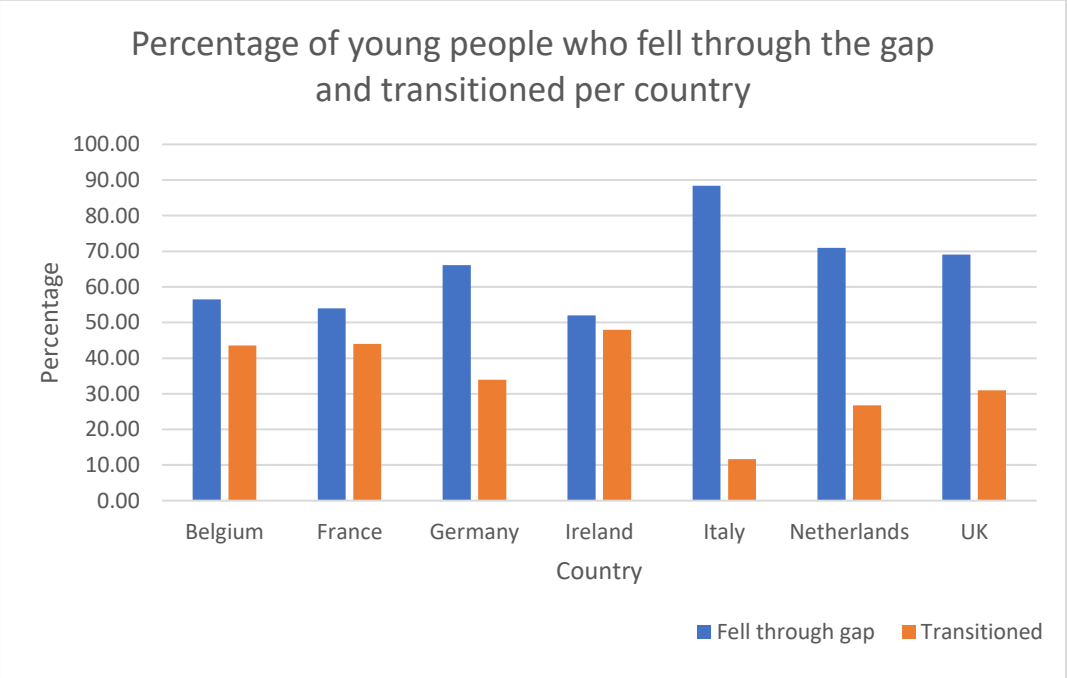

Figure 7 A graph showing the percentage of young people who fell through the gap or transitioned by country

As the variance inflation factor (VIF) for each predictor variable included in the model was below 10, we can conclude that the model does not contain any collinearity errors. The model was also found to not have any specification errors. The model was deemed to be an adequate fit to the data as results from the Pearson's chi squared and Hosmer-Lemeshow goodness of fit tests were not significant (Prob > chi^2 = 0.3024; Prob > chi^2 = 0.7150, respectively).

5.5.4 Results for Question 2: Outcomes of transitioning or falling through the gap

5.5.4.1 Unadjusted model

Firstly, an unadjusted regression analysis was conducted to explore the association between transitioning or falling through the gap on follow up HoNOSCA scores. The results of this model show that those who transitioned had higher follow up HoNOSCA scores than those who fell through the gap, indicating a higher illness severity (see Table 9).

Table 9 Results of Model 1 (HoNOSCA)

Predictor	Coefficient	Standard Error	t	P>t	95% CI
Transition Outcome*					
Transitioned	1.69	0.40	4.26	0	0.91 - 2.46
_cons	9.30	0.22	42.94	0	8.87 - 9.72

*Base category = Fell Through Gap

This model was also conducted with follow up ASEBA scores. The results show that those who transitioned had higher follow up ASEBA scores than those who fell through the gap, an indicator of poorer overall functioning (see Table 10).

Table 10 Results of Model 1 (ASEBA)

Predictor	Coefficient	Standard Error	t	P>t	95% CI
Transition Outcome*					
Transitioned	7.44	1.38	5.38	0	4.72 - 10.16
_cons	32.71	0.75	43.37	0	31.23 – 34.19

*Base category = Fell Through Gap

5.5.4.2 Partially adjusted model

When adding baseline HoNOSCA scores into the model, transitioning was no longer a significant predictor of higher HoNOSCA scores (Table 11). This can be explained due to baseline differences between those who transitioned and those who fell through the gap (see Table 8), which resulted in a significant difference in follow up HoNOSCA scores in Model 1. However, after controlling for baseline illness severity, the difference was no longer significant.

Table 11 Results of Model 2 (HoNOSCA)

Predictor	Coefficient	Standard Error	z	P>z	95% CI
Total HoNOSCA T1	0.40	0.04	11.26	0	0.33 - 0.46
Transition Outcome*					
Transitioned	0.62	0.51	1.22	0.22	-0.38 - 1.62
_cons	4.36	0.60	7.23	0	3.18 - 5.55

*Base category = Fell Through Gap

After controlling for baseline differences in ASEBA scores, the coefficient reduced from 7.93 to 3.62. However, this remained statistically significant (see Table 12), suggesting that those who transitioned had higher levels of impaired functioning during the follow up period than those who fell through the gap.

Table 12 Results of Model 2 (ASEBA)

Predictor	Coefficient	Standard Error	z	P>z	95% CI
Total ASEBA T1	0.75	0.04	18.25	0	0.67 - 0.83
Transition Outcome*					
Transitioned	3.62	1.58	2.29	0.02	0.52 - 6.71
_cons	6.64	1.83	3.62	0	3.05 - 10.24

*Base category = Fell Through Gap

5.5.4.3 Fully Adjusted model

As shown in Table 13, after the addition of covariates, there was still no significant difference in follow up HoNOSCA scores between those who transitioned and those who fell through the gap (p=0.06). Other covariates were significant predictors of higher follow up HoNOSCA scores: baseline HoNOSCA score (p=0.00), length of time in CAMHS (p=0.02) and a previous suicide attempt (p=0.00).

Table 13 Results of Model 3 (HoNOSCA)

Predictor	Coefficient	Standard Error	z	P>z	95% CI
Total HoNOSCA T1†	0.39	0.04	10.49	0	0.32 - 0.46
Transition Outcome*					
Transitioned	0.91	0.53	1.73	0.08	-0.12 – 1.94
Gender**					
Male	0.66	0.52	1.27	0.21	-0.36 - 1.67
Not set	-3.56	4.81	-0.74	0.46	-12.98 - 5.86
Age at Baseline	0.63	0.41	1.55	0.12	-0.17 - 1.44
Grouped Ethnicity***					
Other	-0.79	0.90	-0.88	0.38	-2.55 - 0.97
Missing	-0.19	1.11	-0.18	0.86	-2.37 - 1.98
Primary Diagnosis****					
Emotional disorders	-0.76	0.60	-1.26	0.21	-1.95 - 0.42
Personality/trauma	-0.36	0.86	-0.42	0.67	-2.06 - 1.34
Eating disorders	2.92	1.60	1.83	0.07	-0.21 - 6.05
Other	0.32	1.01	0.32	0.75	-1.67 - 2.31
Total Baseline IBDCS Score	0.05	0.04	1.09	0.27	-0.04 - 0.13
Length of time in CAMHS†	0.38	0.17	2.21	0.03	0.04 - 0.71
Previous Suicide Attempt*****					
yes†	1.60	0.54	2.95	0.00	0.54 - 2.67
don't know	1.94	1.37	1.41	0.16	-0.75 - 4.63
_cons	-8.83	7.00	-1.26	0.21	-22.56 - 4.90

† significant at the 95% level
*Base category = Fell Through Gap
**Base category = Female
***Base category = White European
****Base category = Depressive disorders
*****Base category = No previous suicide attempt

When adding all variables into the model as covariates, those who transitioned still had significantly higher follow up ASEBA scores (p=0.02) than those who fell through the gap

(Table 14). Baseline ASEBA scores were also significantly associated with higher follow up ASEBA scores (p=0.00).

Table 14 Results of model 3 (ASEBA)

Predictor	Coefficient	Standard Error	z	P>z	95% CI
Total ASEBA T1†	0.74	0.05	16.32	0	0.65 - 0.83
Transition Outcome*					
Transitioned	3.55	1.64	2.17	0.03	0.35 - 6.76
Gender**					
Male	2.58	1.66	1.56	0.12	-0.67 - 5.83
Not set	3.03	14.69	0.21	0.84	-25.76 - 31.82
Age at Baseline	-0.29	1.33	-0.22	0.83	-2.90 - 2.32
Grouped Ethnicity***					
Other	0.02	2.95	0.01	0.99	-5.75 - 5.80
Missing	-3.41	3.11	-1.10	0.27	-9.51 - 2.69
Primary Diagnosis****					
Emotional disorders	3.36	1.92	1.75	0.08	-0.39 - 7.12
Personality/trauma	5.28	2.76	1.91	0.06	-0.13 - 10.69
Eating disorders	7.58	4.98	1.52	0.13	-2.19 - 17.34
Other	3.38	3.24	1.04	0.30	-2.97 - 9.74
Total Baseline IBDCS Score	-0.11	0.13	-0.83	0.40	-0.36 - 0.15
Length of time in CAMHS	0.85	0.53	1.60	0.11	-0.15 - 1.90
Previous Suicide Attempt*****					
yes	1.97	1.77	1.12	0.26	-1.49 - 5.43
don't know	8.52	4.34	1.96	0.05	0.02 - 17.03
_cons	6.53	22.62	0.29	0.77	-37.80 - 50.87

† significant at the 95% level
*Base category = Fell Through Gap
**Base category = Female
***Base category = White European
****Base category = Depressive disorders
*****Base category = No previous suicide attempt

Table 15 and Table 16 show the process of model development for both the HoNOSCA and ASEBA outcome measures. Post analysis tests showed no evidence of collinearity for each of the final models (mean VIF=1.14). The final model using ASEBA showed no specification errors, however specification tests for the final HoNOSCA model suggested possible issues, indicating a possible specification error, for example not all appropriate variables may have been included in the model.

Table 15 Regression coefficients and associated p-values for all models using HoNOSCA

Predictor	**Model 1** *Coefficients [95% CIs] p values*	**Model 2** *Coefficients [95% CIs] p values*	**Model 3** *Coefficients [95% CIs] p values*
Transition Outcome*			
Transitioned	1.69 [0.91 - 2.46] p=0	0.62 [-0.38 - 1.62] p=0.22	0.91 [-0.12 – 1.94] p=0.08
Total Baseline HoNOSCA score		0.40 [0.33 - 0.46] p=0	0.39 [0.32 - 0.46] p=0

*Base category = Fell Through Gap

Table 16 Regression coefficients and associated p-values for all models using ASEBA

Predictor	**Model 1** *Coefficients [95% CIs] p values*	**Model 2** *Coefficients [95% CIs] p values*	**Model 3** *Coefficients [95% CIs] p values*
Transition Outcome*			
Transitioned	7.44 [4.72 - 10.16] p=0	3.62 [0.52 - 6.71] p=0.02	3.55 [0.35 - 6.76] p=0.03
Total Baseline ASEBA score		0.75 [0.67 - 0.83] p=0	0.74 [0.65 - 0.83] p=0

*Base category = Fell Through Gap

5.5.4.4 Sensitivity analyses

Results of both multilevel models were unchanged after running sensitivity analyses (see Table 17).

Table 17 Summary of results of sensitivity analyses

Sensitivity Analysis	**HoNOSCA follow up scores** *Coefficients [95% CIs] p values*	**ASEBA follow up scores** *Coefficients [95% CIs] p values*
Dropping small variables	1.00 [-0.06 – 2.05] p=0.06	3.83 [0.53 – 7.14] p=0.02
Multiple imputation of missing data	0.70 [-0.34 - 1.73] p=0.19	2.96 [-0.23 - 6.16] p=0.07

5.6 Discussion

5.6.1 Summary and interpretation of findings

5.6.1.1 Question 1: Predictors of transitioning or falling through the gap

The results of this analysis indicated that the young people with a diagnosis of depression or anxiety disorder, neurodevelopmental disorders or emerging personality disorder are more likely to transition to AMHS if they are more severely ill (as rated by their CAMHS clinician (CGI-S), or by higher scores on measures of mental health (HoNOSCA) and independent behaviour (IBDCS)). This concurs with other studies exploring predictors of transition, for example Singh et al. (2010) found that young people in the UK with a more severe and enduring mental illness were more likely to transition to AMHS. Other studies corroborate these findings: Stagi et al. (2015) explored transition from CAMHS in a province in Italy, and found that having a previous admission to inpatient mental health services was a predictor of transitioning to AMHS, whilst Bond et al. (2019) found that young people in Ireland who did not have inpatient care were more likely to be discharged to their GP after reaching the upper age limit of their CAMHS.

The fact that only the young people who are most severely ill transition to AMHS also reflects the way in which services are structured. AMHS have much higher eligibility thresholds than CAMHS (Belling et al., 2014), and have a focus on treating more severe and

enduring mental illness (Lamb and Murphy, 2013). These high eligibility thresholds are also thought to be caused by resource pressures and staffing shortages (Belling et al., 2014), indicating that a lack of service capacity may have led to only the most severely ill being able to access continued care in adult services after CAMHS. Evidence of high eligibility thresholds affecting referrals has been identified in other studies, for example McNicholas et al. (2015) found that just under half of young people with a mental health need at the CAMHS transition boundary were referred to AMHS, with reasons for non-referral cited as not meeting AMHS criteria, or AMHS not having the appropriate service to match the young person's need.

One novel finding of this research was the country variation in those who transitioned or fell through the gap. This research found that living in Italy, the Netherlands, and the UK was associated with a lower likelihood of transitioning to AMHS. One possible explanation for this country variation is the high heterogeneity between the characteristics of CAMHS in different European countries (Signorini et al., 2017) or the variations in type of CAMHS involved in MILESTONE (e.g. inpatient vs community services, or CAMHS specialising in different disorders).

To explore the reasons behind the country variation in transition further, the results were compared to the findings of a mapping study of 28 European countries exploring the interface between CAMHS and AMHS (Signorini et al., 2018). A lack of connection between CAMHS and AMHS was a commonly reported barrier to transition, and was identified by representatives from all eight countries involved in MILESTONE. Whilst this study offered some potential reasons for country variation, it was unable to provide a clear explanation for these results. For example, it is unclear from the mapping study why young people from the UK were amongst those most likely to fall through the gap, as the UK was one of two of the 28 countries surveyed to have written transition protocols to guide young people's transition between the services. It is possible that despite the existence of these guidelines, they are not implemented successfully in practice. One potential explanation for Italy having the lowest rate of transition could be that the proportion of young people estimated to need ongoing care after CAMHS was 0-24% (Signorini et al., 2017). However despite Signorini et al (2017) identifying 75-100% of young people from the Netherlands as needing ongoing care, they were among the countries in the present study associated with a lower likelihood of transition. It is likely that there are other drivers for the country-specific differences identified in the current research which need further exploration.

Other variables included in the model which were associated with increased likelihood of transitioning but which did not meet 95% significance alone were having a previous suicide attempt, and having spent more years in CAMHS. Again, these results suggest that those who are most severely ill are more likely to transition. Other variables included in the model associated with a decreased likelihood of transitioning were male gender and living in Germany. It may be that males were least likely to transition as they are more likely to have neurodevelopmental disorders than females, and research has found that there is a lack of adult services for over 18s with ADHD and ASD (McConachie et al., 2011, Hall et al., 2015).

5.6.1.2 Question 2: Outcomes of transitioning or falling through the gap

Although there was an initial association between transitioning and poorer longitudinal mental health, this disappeared once covariates were included in the model. However, transitioning was found to be associated with worse functioning outcomes as measured by the ASEBA. These findings relate to the results of question 1, which found that only those who are most severely ill transition to AMHS.

The differences found between the results for mental health outcomes (measured by HoNOSCA) and functioning outcomes (measured by ASEBA) could be explained by the different focuses of these two questionnaires. The total HoNOSCA score takes into account problems related to mental and physical health, social relationships and other impairments such as school attendance or speech problems, over a previous two week period (Gowers et al., 1999). Researchers have queried the use of the total HoNOSCA score, as it may underestimate the severity of illness for a young person who has one severe impairment (e.g. an eating disorder) which warrants clinical attention, as this would be scored in one HoNOSCA question only, thus giving a low overall score (Tiffin and Rolling, 2012). Instead, Tiffin and Rowling (2012) propose using two symptom or problem scales which assess externalising problems and emotional disturbances, as this would allow for a measure of the impact on functioning. The ASEBA captures mental health and functioning, with the CBCL and YSR questionnaires exploring eight different domains: Anxious/Depressed, Withdrawn/Depressed, Somatic Complaints, Social Problems, Thought Problems, Attention Problems, Rule Breaking Behaviour and Aggressive Behaviour (ASEBA, 2020). It may be that in the case of this research, the ASEBA questionnaires are a more sensitive measure of long-term mental health and functioning than HoNOSCA.

The finding that there were no significant differences between the long-term mental health outcomes of those who fell through the gap and those who transitioned could be explained by the fact that overall, MILESTONE participant's mental health improved throughout the study. This could be due to AMHS successfully improving the mental health of young people whose care moves there after CAMHS, or young people becoming better at managing their mental health as they reach adulthood.

It is difficult to relate the findings from this study to other research, as my systematic review identified no other studies which have explored the mental health or functioning outcomes of young people after leaving CAMHS (Appleton et al., 2019). One recent study exploring service use outcomes following transition from CAMHS in Ireland found high engagement rates (97% at 3 months) for those whose care had been transferred to a specialist young adult service (Bond et al., 2019). This is higher than engagement shown in other studies (e.g. Singh et al., 2010), suggesting that having a youth specific AMHS could possibly improve engagement.

5.6.2 Strengths and Limitations

To our knowledge, this is the first study to explore predictors of transitioning and falling through the gap for young people with the diagnoses most likely to experience discontinuity of care. It also adds an important contribution to the existing literature regarding the mental health and functioning outcomes of young people after leaving CAMHS, as this has not been explored in any other studies (Appleton et al., 2019). One particular strength of this study was the large sample size and international nature of this sample. This allowed for country-wide comparison, whereas all other studies which have explored service use outcomes after CAMHS are limited to one country only (Appleton et al., 2019).

The use of multi-level modelling is also a strength of this research. Multilevel modelling allows for the effect of grouping to be taken into consideration during the analysis, something which is not the case for simple regression models (Preacher et al., 2011). Conducting a fully adjusted regression model for the final analysis also allowed the impact of baseline variables and other covariates to be taken into consideration, thus reducing the chance of a Type 1 error.

Whilst this study contained a large sample compared to other literature regarding predictors of transition, there are likely to be some limitations in terms of representativeness of the sample. Firstly, as clinicians had to screen eligible participants for

suitability to take part in MILESTONE, the sample may not include the young people who are most severely ill. Young people who were more severely ill were also more likely to drop out of the study, which may have led to this group becoming further underrepresented. As this research further screened participants for eligibility by diagnosis, those who did not receive a diagnosis in CAMHS would have been excluded from this analysis. This may have led to some bias, as other research has indicated that those who do not have a psychiatric diagnosis are more likely to fall through the gap (Leavey et al., 2019). Young people with emerging personality disorder may also be underrepresented in this sample, as clinicians are often reluctant to give this diagnosis to someone under the age of 18 (Larrivée, 2013). Finally, this sample lacked diversity in the number of young people from BAME backgrounds who were recruited to take part in MILESTONE. This is significant as research has indicated that people from BAME backgrounds may be more likely to be dissatisfied with the mental health care received and more likely to disengage from services (O'Brien et al., 2009).

There were also some baseline imbalances between the groups of those who transitioned and those who fell through the gap. This highlights the difficulty in trying to capture balanced samples outside of a randomised controlled trial. In the current research, the effect of these baseline differences was taken into consideration during model development, adding baseline covariates to the models as a predictor. An alternative method which could be used in future studies is propensity score matching, in which participants from both groups are matched according to their propensity score (Austin, 2011). The treatment effect (in this case transition or fall through gap) is then estimated using these matched pairs, which reduces errors caused by baseline differences between groups.

A further limitation is that post-analyses tests revealed the multilevel model regarding longitudinal HoNOSCA scores had specification errors, potentially indicating that not all relevant variables were included in the model. This could be an example of omitted variable bias and is possibly caused by other factors which influence longitudinal mental health which were not measured by the MILESTONE assessment battery. It is also important to note that stepwise logistic regression (used for question one: exploring the predictors of transitioning) is for exploratory analysis only (Steyerberg et al., 1999), therefore it is necessary to be cautious when interpreting findings. Finally, an assumption of multiple imputation (used as a sensitivity analysis for question two: exploring the mental health and functioning outcomes of young people after leaving CAMHS) is that the data is

missing at random. This may not be true in all cases as some participants dropped out of the study because they were too unwell. However, despite this, multiple imputation was viewed as the most appropriate method of managing missing data in this thesis.

There were some other limitations concerning the analyses used in this research. The first is the use of HoNOSCA as the main outcome measure. This study used the clinician-rated HoNOSCA, which was conducted by research assistants at the various MILESTONE sites through the use of a clinical interview. There may have been some variation in how responses were scored by different research assistants, especially between different countries.

5.7 Conclusion

The results from this research suggest that young people with a diagnosis of depression or an anxiety disorder, neurodevelopmental disorders or emerging personality disorder are more likely to transition to AMHS if they are more severely ill. There were no significant differences in long term mental health outcomes between those who fell through the gap or who transitioned, although those who transitioned did show more impaired functioning over the course of the follow up period.

5.8 Chapter Summary

This chapter has presented the methods and results of the quantitative study which explored predictors of transitioning to AMHS and long-term mental health and function of those who transitioned or fell through the service gap. A more detailed discussion of these results can be found in Chapter 9. The next chapter reports the method and results for the health economic analysis comparing service use and associated costs for those who transitioned or fell through the gap.

Chapter 6: Exploring the economic costs associated with transitioning or falling through the gap

6.1 Introduction

This chapter reports the results of the health economic study, featuring secondary data analysis on a sub-section of the MILESTONE study dataset. The chapter begins with the rationale for this study and an outline of the methods used for analysis. Next, the results are presented. Finally, I discuss the results in the context of the wider literature.

6.2 Background and Rationale

Existing research (see Chapter 2) has explored the costs associated with improved mental health services for young people and indicated that investing in mental health services for young people will result in lower costs to the education system, the criminal justice system, and to health services (Lemer, 2013, McDaid et al., 2019). However, to the author's knowledge, there has been no health economic evaluations focused on the costs associated with transitioning to AMHS or falling through the gap between services (NICE, 2017).

The aim of this chapter was to compare the economic outcomes associated with falling through the gap and transitioning to adult services. A health economic analysis was chosen as this method is useful when investigating the resources used and the costs associated with illness and healthcare, in particular to inform decision making around how to best use scarce resources (Guiness and Wiseman, 2011). This is particularly relevant for mental health services which receive disproportionately low levels of funding compared to their disease burden (Mental Health Taskforce, 2016). It is also pertinent for this population group in particular, as the high number of young people who fall through the gap has been previously attributed to scarce resources in AMHS (Belling et al., 2014). Currently, little is known about the healthcare resource use associated with young people who reach the end of care at CAMHS. It is therefore important to explore the healthcare costs associated with falling through the gap or transitioning to AMHS. As the costs associated with mental illness are not limited to the health service (McDaid, 2011, Brimblecombe et al., 2015), this

analysis also explored the wider societal impacts of young people falling through the gap between services.

The results of the qualitative analysis (see Chapter 7, section 7.4) indicated that young people who fell through the gap reported accessing A&E and their GP instead of specialist mental health services after leaving CAMHS. Some young people also reported contacts with the criminal justice system. I therefore chose to examine the resource use and costs associated with these services within the health economic analysis.

This study analysed health economic and service use data collected in the MILESTONE Study from young people over a 24-month period (baseline, +9months, +15 months, +24 months).

6.3 Research questions

This chapter focuses on the final research question: What are the healthcare and societal costs of young people falling through the gap compared with transition to AMHS?

Further information about the research questions, aims and objectives of this research can be found in Chapter 3, sections 3.2 and 3.3.

6.4 Method

This analysis considers a health care and personal social services (PSS) perspective as well as a wider societal perspective including the criminal justice system (CJS) and other costs, meaning both healthcare and wider societal costs were taken into consideration in the analysis. A cost-effectiveness analysis or cost-utility analysis were not considered appropriate for the current study as it was not assessing an intervention, and so these other methods would not have been relevant to my research questions. A combination of t-tests, chi^2 tests and multilevel modelling were chosen as these were the most appropriate methods to answer my research questions (therefore aligning to the pragmatic perspective underpinning this thesis).

6.4.1 Sampling

This study used the same sample as the quantitative analysis in the previous chapter. All young people recruited to the MILESTONE Study with a diagnosis of an anxiety or mood

disorder, neurodevelopmental disorder, or emerging personality disorder were included in the sampling. The study compared those young people who had fallen through the gap between services or transitioned to AMHS. Participants were classified as falling through the gap if they were discharged from CAMHS with no other referral despite having an ongoing clinical need, or if they were referred to AMHS but discharged by the next data collection time point whilst having an ongoing clinical need. Clinical need was measured by a score of two or above on HoNOSCA questions relating to psychiatric symptoms (Burgess et al., 2009). Participants were classified as transitioning to AMHS if they were referred to an AMHS by their CAMHS clinician as they reached the transition boundary.

Further details of the inclusion and exclusion criteria for participants can be found in Chapter 5, Section 5.4.1.

6.4.2 Description of Study Instruments

MILESTONE specific Client Service Receipt Inventory (CSRI): This scale collects information about the use of health services (e.g. inpatient care, visits to GP or Psychologist/Psychiatrist, medication) and contacts with the CJS and has been adapted from a scale used in a study on schizophrenia (Chisholm et al., 2000). The CSRI was completed at all four timepoints by young people to facilitate the calculation of costs. This data was used to assess levels of service use in the young people who have fallen through the gap and those who transitioned to adult services.

EQ5D-5L: This is a five dimension questionnaire which measures participants' current health state. Dimensions include mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each of the first five questions is scored on a scale of 1 (no problems) to 5 (extreme problems) (Herdman et al., 2011). Health profiles from this measure can be combined with preference-weights (van Hout et al., 2012) to calculate utility scores. Utility scores are used in health economic research to represent the weighting that individuals give to different health states (Drummond et al., 2015). These utility scores were used to assess health-related quality of life for all MILESTONE participants at each data collection point.

6.4.3 Calculating cost

There are two key steps to calculating unit costs: 1) capturing resource use, and 2) attaching unit costs to resource use data. A unit cost refers to the cost associated with one item of resource use (e.g. the cost associated with one GP appointment). The CSRI was

used at each time point in the MILESTONE Study to capture resource use data, and this data were combined with unit costs to estimate the costs associated with young people who fell through the gap compared to those who made the transition to adult services. Examples of service use include inpatient care, outpatient care, and community care. Unit costs were combined with resource use data to calculate costs for each resource item. There is little consensus within the health economics literature in regard to what unit costs should be used within a multi-country analysis (Oppong et al., 2015). For this study we pragmatically adopted a one country pooled perspective whereby unit costs were derived from UK costing resources such as the NHS reference costs (Department of Health, 2016) and the Personal Social Services Research Unit (PSSRU) (Curtis and Burns, 2016). These unit costs were then attached to resource use data to calculate costs. Costs are presented in Belgium Euros (converted using purchasing power parity) for the price year 2015. Given the timeframe of the study, costs were not discounted. Unit costs are presented in Appendix 4.

6.4.4 Statistical analysis

6.4.4.1 Resource use components

Descriptive statistics were calculated for all cost components and the level of resource use was compared between those who did and did not fall through the gap. Based on the results of the qualitative component of this thesis, I was particularly interested in comparing visits to the GP and A&E, and contacts with the criminal justice system, as young people who fell through the gap reported accessing these services in the absence of specialist mental health care. Productivity impacts such as absence from school and work were also compared between groups. To test for difference between the two groups in resource use, t-tests were conducted for continuous variables and chi2 tests for categorical variables. The impact of multiple testing was taken into consideration when interpreting the results.

6.4.4.2 Analysis of cost

Inpatient, outpatient, and community care costs were combined to calculate total healthcare costs for each participant. These were then used to conduct an analysis of costs between those who transitioned and those who fell through the gap. Given the calculation of total cost requires complete data at all time points, large quantities of missing data were likely. Due to the high percentage of missing data (up to 28% at T4), multiple imputation was used as the base-case for the analysis of total cost. STATA 16 (STATACORP, 2019) was used to conduct the multiple imputation and regression models with the imputed data. The

method for multiple imputation was the same as outlined in Chapter 5 Section 5.4.5.2, using the chained equations method. Variables were included in the imputation model if they were to be included in the final multilevel model, or were variables that predicted missingness in the cost variables. The variables with no missing data in the imputation model were: country, gender, transition outcome, discharge timepoint, number of primary diagnoses, number of diagnoses, diagnostic group, and cluster. The variables which had missing data and were therefore imputed were: inpatient A&E costs, community GP costs, outpatient A&E costs, total inpatient costs, total outpatient costs, total community costs, HoNOSCA scores, ASEBA scores (all of the former at all four time points), and baseline age, IBDCS score, CGI score, previous suicide attempt, ethnicity, ASEBA internalising scores, and EQ5D Utility. The datasets generated by the multiple imputation were combined using Rubin's rule (Rezvan et al., 2015) to allow inferential statistics. Rubin's rule is a method of obtaining estimates from multiple imputation which combines the individual estimates and standard errors from each imputed dataset into an overall estimate (Marshall et al, 2009).

6.4.4.3 Model development

Multilevel modelling was also chosen as the most appropriate technique to analyse this data, as data is nested across hierarchies (for more detail see section 5.4.5). A series of regression models were then conducted to examine differences in the cost of healthcare service use between those who fell through the gap and those who transitioned. The process of model development was similar to that used in Chapter 5, Section 5.4.5.1., as a series of models were conducted, each increasing in complexity, in order to explore the impact of covariates at each level. An initial unadjusted regression model was conducted to compare EQ5D scores between those who transitioned and who fell through the gap. This was followed by a partially adjusted multi-level model controlling for country and cluster and baseline EQ5D scores.

The final models were fully adjusted, controlling for baseline scores and covariates. The covariates included in each model were: baseline EQ5D Utility, ASEBA scores, HoNOSCA scores, IBDCS scores, and CGI score, transition outcome, age at baseline, gender, ethnicity, primary diagnostic group, length of time at CAMHS and previous suicide attempt. The two levels in these models were country and cluster, as the data was nested across these hierarchies. The third level included in the quantitative analysis, participant ID, was not needed here as the model analysed cross sectional rather than longitudinal data. Post-analysis tests were conducted to check for collinearity errors.

6.5 Results

488 young people with the relevant diagnoses were identified from the complete MILESTONE sample as having transitioned to AMHS (n=152) or fallen through the gap (n=336). Details of the inclusion and exclusion criteria for this research are presented in Chapter 5, Section 5.4.1, whilst a full description of the sample used in this analysis can be found in Chapter 5 Section 5.5.2.

6.5.1 Missing Data

The percentages of missing data for the CSRI increased over the course of the four data collection points starting at up to 8% at T1, and rising to up to 28% at T4, as shown by Table 18 and Table 19 below. As the percentage of missing data was above 25%, the models to analyse cost data were conducted on an imputed dataset.

Table 18 A breakdown of the percentage of missing data for each resource use variable over time

Variable Name	**T1 (%)**	**T2 (%)**	**T3 (%)**	**T4 (%)**
Inpatient nights	6	15	24	27
Inpatient A&E visits	6	15	24	27
Outpatient A&E visits	7	15	24	28
Outpatient contact	7	15	24	28
GP visits	8	15	25	28
Community care contact	8	15	25	28
Criminal justice system contact	8	15	24	27
Time off work or study	7	15	24	27

Table 19 A breakdown of the percentage of missing data for each costing variable over time

Variable Name	**T1 (%)**	**T2 (%)**	**T3 (%)**	**T4 (%)**
Inpatient costs	6	15	24	27
Inpatient A&E costs	6	15	24	27
Outpatient A&E costs	8	15	27	28
Outpatient costs	8	15	27	28
GP costs	8	15	25	28
Community care costs	8	15	25	28

6.5.2 Resource Use

Firstly, t-tests and chi^2 tests were conducted to explore differences in resource use between those who transitioned to AMHS and those who fell through the gap. It is important to note that the data were heavily skewed, however medians and interquartile ranges were not informative due to large number of zero values, meaning they have not been included in the below tables.

1. Inpatient Contact

Comparing the percentage of young people who reported inpatient contact, the data indicates that those who transitioned were more likely than those who fell through the gap to be receiving inpatient care at all time points (see Table 20). Inpatient contact also decreased significantly for those who transitioned after T1, which indicates that around half of the young people who were receiving inpatient care when they were at CAMHS were transitioned to an adults' outpatient unit after leaving children's services.

Table 20 Comparing inpatient contact between those who fell through the gap (FTG) and transitioned to AMHS.

Timepoint	% 'yes'	χ^2 , p values
T1†	FTG (n= 315) = 13.33 Transition (n=142) = 32.39	χ^2 (1, 457) = 22.87, p < 0.01
T2†	FTG (n=294) = 3.40 Transition (n=122) = 14.75	χ^2 (1, 416) = 17.70, p < 0.01
T3†	FTG (n=267) = 4.12 Transition (n=105) = 13.33	χ^2 (1, 372) = 10.21, p < 0.01
T4†	FTG (n=250) = 3.60 Transition (n=104) = 11.54	χ^2 (1, 354) = 8.29, p < 0.01

† significant at the 95% level

2. Outpatient Contact

Comparing the number of contacts with outpatient services between those who fell through the gap and those who transitioned showed that at the third data collection point, those who transitioned reported significantly more contacts in the last six months (see Table 21).

Table 21 Comparing outpatient contact between those who fell through the gap (FTG) and transitioned to AMHS.

Timepoint	% 'yes'	χ^2 , p values
T1	FTG (n= 313) = 56.87 Transition (n=140) = 56.43	χ^2 (1, 453) = 0.01, p = 0.93
T2	FTG (n=292) = 35.96 Transition (n=121) = 40.50	χ^2 (1, 413) = 0.75, p = 0.39
T3†	FTG (n=267) = 28.09 Transition (n=103) = 44.66	χ^2 (1, 370) = 9.27, p < 0.01
T4	FTG (n=250) = 31.20 Transition (n=102) = 39.22	χ^2 (1, 352) = 2.09, p = 0.15

† significant at the 95% level

3. Community Contact

Levels of contact with community services (e.g. outpatient mental or physical health care) were high for both groups over the course of the study, and did not reduce over time, except for a decrease for those who fell through the gap between baseline and T2 (when they would have been discharged from CAMHS). The fact that community service use remained high for those who fell through the gap indicates that they still required some support for their health, even though they were not referred onwards after CAMHS. From T2, a higher proportion of those who transitioned rather than those who fell through the gap used community services (see Table 22).

Table 22 Comparing community care contacts between those who fell through the gap (FTG) and transitioned to AMHS.

Timepoint	% 'yes'	χ^2 , p values
T1	FTG (n=314) = 87.26 Transition (n=137) = 83.94	χ^2 (1, 451) = 0.89, p = 0.35
T2†	FTG (n=293) = 66.21 Transition (n=121) = 80.17	χ^2 (1, 414) = 7.98, p < 0.01
T3†	FTG (n=263) = 63.12 Transition (n=102) = 81.37	χ^2 (1, 365) = 11.30, p < 0.01
T4†	FTG (n=249) = 65.46 Transition (n=104) = 81.73	χ^2 (1, 353) = 9.29, p < 0.01

† significant at the 95% level

4. Number of A&E Overnight Admissions

At the first two time points, those who transitioned had significantly more overnight A&E admissions than those who fell through the gap (see Table 23). Those in the transition group still showed slightly higher numbers of A&E admissions in the remaining two time points, but this difference did not reach statistical significance.

Table 23 Comparing A&E overnight admissions between those who fell through the gap (FTG) and transitioned to AMHS.

Timepoint	Group Mean	Result
T1†	FTG (n=315) = 0.03 Transition (n=142)= 0.14	t(455)=-3.02, p<0.01
T2†	FTG (n=294) = 0.01 Transition (n=122) = 0.10	t(414)=-2.22, p=0.03
T3	FTG (n=267) = 0.02 Transition (n=105) = 0.06	t(370)=-1.45, p=0.15
T4	FTG (n=250) = 0.01 Transition (n=104) = 0.05	t(352)=-1.67, p=0.09

† significant at the 95% level

5. Number of Outpatient A&E Visits

The results of this analysis showed that young people who transitioned to AMHS had on average more outpatient A&E visits than those who fell through the gap at all time points, with this difference reaching statistical significance at time points one, two and four (see Table 24).

Table 24 Comparing outpatient A&E visits between those who fell through the gap (FTG) and transitioned to AMHS.

Timepoint	Group Mean	Result
T1†	FTG (n=313) = 0.15 Transition (n=140) = 0.32	t(451)=-2.15, p=0.03
T2†	FTG (n=292) = 0.10 Transition (n=121) = 0.27	t(411)=-2.02, p=0.04
T3	FTG (n=267) = 0.11 Transition (n=103) = 0.19	t(368)=-1.07, p=0.29
T4†	FTG (n=250) = 0.06 Transition (n=102) = 0.30	t(350)=-2.44, p=0.02

† significant at the 95% level

6. Community GP Visits

There were no significant differences between the number of GP visits for those who transitioned and those who fell through the gap across the data collection period (see Table 25).

Table 25 Comparing community GP visits between those who fell through the gap (FTG) and transitioned to AMHS.

Timepoint	Group Mean	Result
T1	FTG (n=314) = 1.94 Transition (n=137) = 1.58	t(449)=0.52, p=0.60
T2	FTG (n=293) = 1.23 Transition (n=121) = 2.00	t(412)=-1.87, p=0.06
T3	FTG (n=263) = 1.39 Transition (n=102) = 1.88	t(363)=-1.43, p=0.15
T4	FTG (n=249) = 1.59 Transition (n=104)= 1.78	t(351)=-0.65, p=0.52

7. Time off work or study

The results of this analysis show that significantly more of those in the transition group reported taking time off work or study due to their health at the first three time points (see Table 26).

Table 26 Comparing time off work or study between those who fell through the gap (FTG) and transitioned to AMHS.

Timepoint	% 'yes'	χ^2 , p values
T1†	FTG (n=312) = 45.19 Transition (n=141)= 56.74	χ^2 (1, 453) = 5.18, p = 0.02
T2†	FTG (n=294) = 32.65 Transition (n=122) = 44.26	χ^2 (1, 416) = 5.04, p = 0.03
T3†	FTG (n=267) = 31.46 Transition (n=105) = 45.71	χ^2 (1, 372) = 6.69, p = 0.01
T4	FTG (n=250) = 32.80 Transition (n=104) = 31.73	χ^2 (1, 354) = 0.04, p = 0.85

† significant at the 95% level

8. Contact with Criminal Justice System

There was no difference in the number of contacts with the criminal justice system between those who transitioned and those who fell through the gap across the data collection period (see Table 27), although it should be noted that contacts were extremely low overall across both groups.

Table 27 Comparing time off work and study between those who fell through the gap (FTG) and transitioned to AMHS.

Timepoint	% 'yes'	χ^2, p values
T1	FTG (n=309) = 4.85 Transition (n=141) = 9.22	χ^2 (1, 450) = 3.16, p = 0.08
T2	FTG (n=294) = 3.40 Transition (n=122) = 5.74	χ^2 (1, 416) = 1.20, p = 0.27
T3	FTG (n=267) = 2.25 Transition (n=105) = 1.90	χ^2 (1, 372) = 0.04, p = 0.84
T4	FTG (n=250) = 2.80 Transition (n=104) = 2.88	χ^2 (1, 354) = 0.00, p = 0.97

6.5.3 Costs over time

Overall, inpatient costs fell over the course of the study (see Figure 8). Those who fell through the gap (FTG) had lower inpatient costs at baseline than those who transitioned, whilst at T4 mean inpatient costs were similar between the two groups.

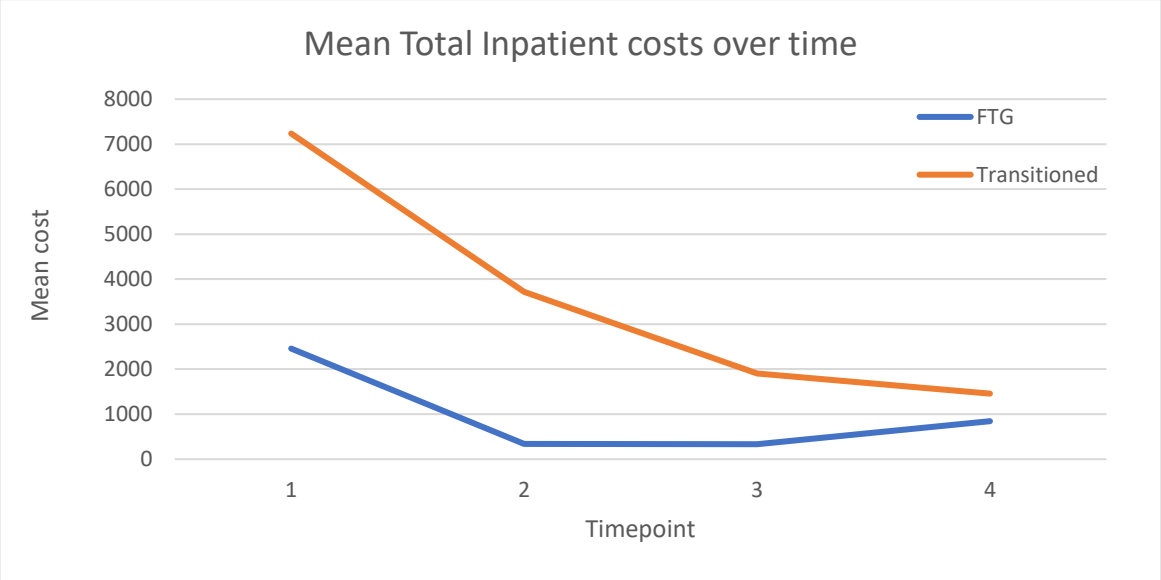

Figure 8 A graph showing the mean total inpatient costs over time

Total outpatient costs also declined for both groups over the course of the study (Figure 9). At T2, those who fell through the gap showed higher mean outpatient costs, whereas at T3 this figure was higher for young people who transitioned to AMHS.

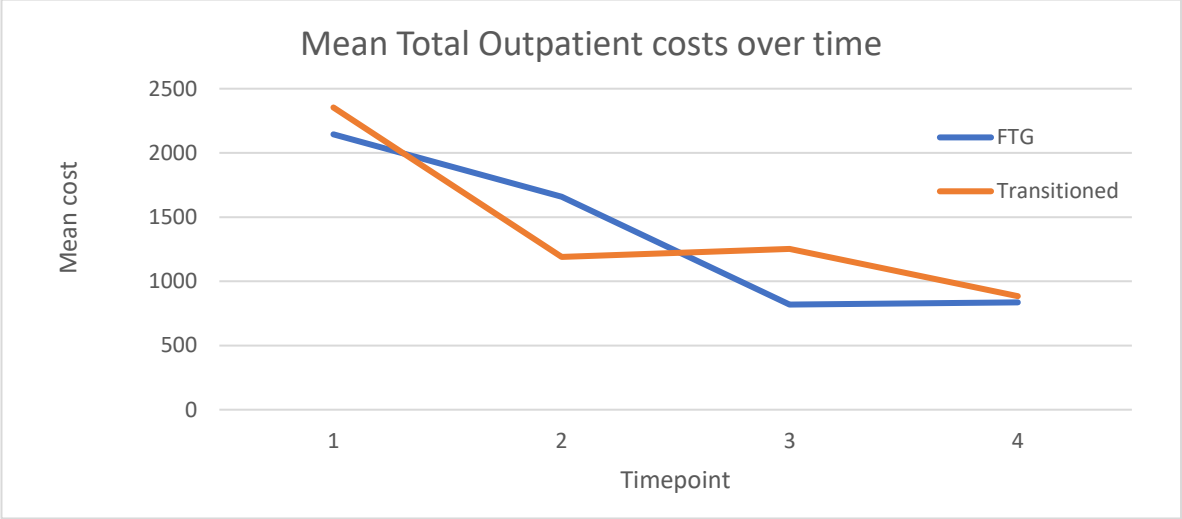

Figure 9 A graph showing the mean total outpatient costs over time

Total community costs also declined over the course of the study, although they decreased more for those who fell through the gap when compared to those who transitioned to AMHS (Figure 10). Although mean total community costs were similar between both groups at baseline, those who transitioned showed higher community costs at all follow up time points.

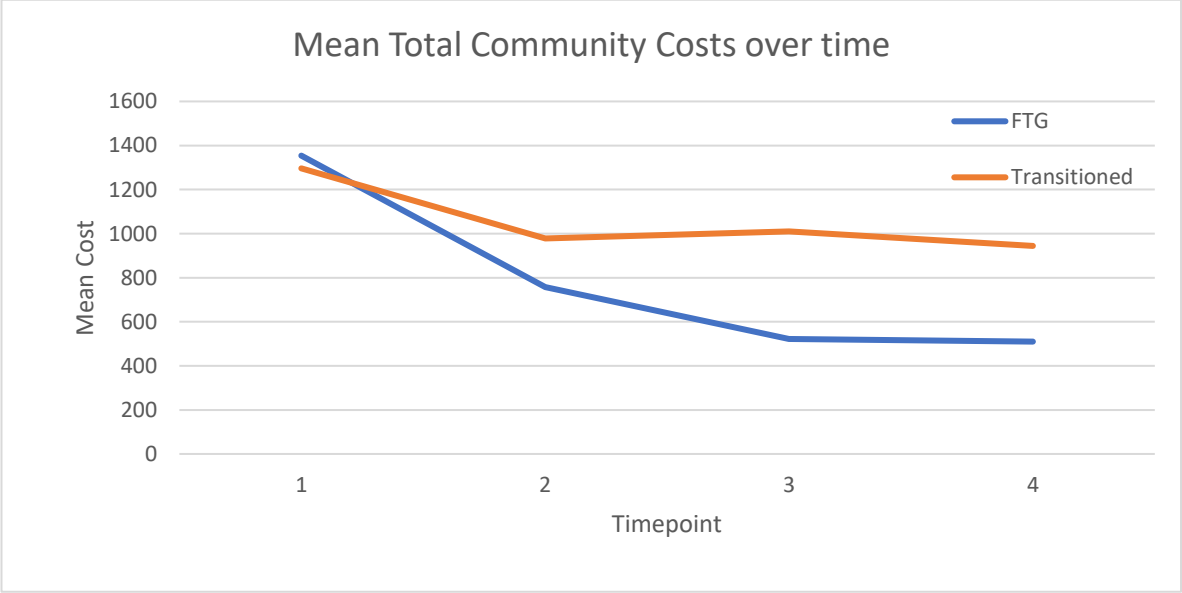

Figure 10 A graph showing the mean total community costs over time

Mean A&E overnight admissions costs were similar for those who fell through the gap and those who transitioned at baseline, T2 and T4 (Figure 11). At T3, young people in the transition group showed significantly higher mean inpatient A&E costs than those who fell through the gap.

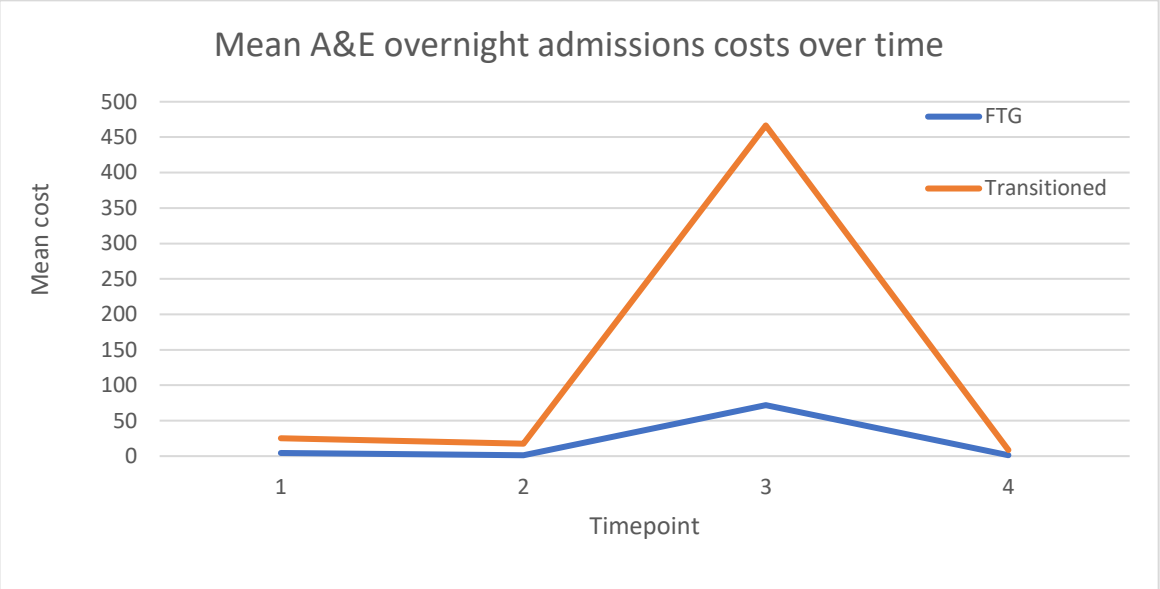

Figure 11 A graph showing the mean total inpatient A&E costs over time

At baseline, those who transitioned showed significantly higher mean outpatient A&E visit costs than those who fell through the gap (Figure 12). This figure declined to T3 but rose again at T4 to almost the same as baseline. At every time point, those who transitioned had higher mean outpatient A&E costs than those who fell through the gap. It should be noted that the high figure for those who transitioned at T3 is skewed by a small number of participants who reported high costs.

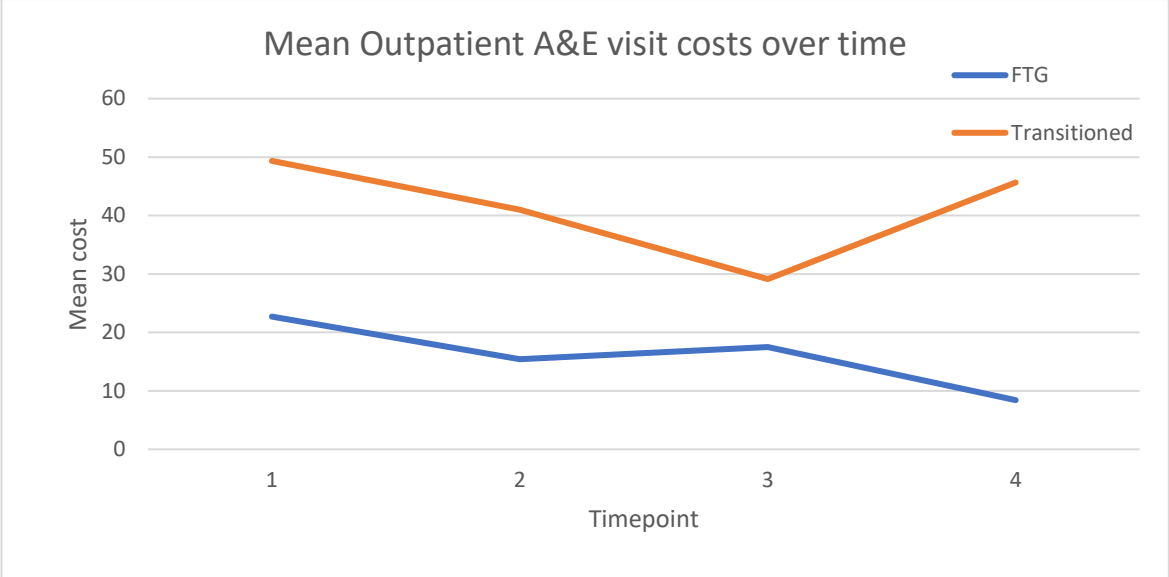

Figure 12 A graph showing the mean total outpatient A&E costs over time

Mean GP costs were higher at baseline for those who fell through the gap, compared to those who transitioned (Figure 13). At all other time points mean GP costs were higher for those who transitioned than those who fell through the gap, although this gap decreased by T4 as mean GP costs increased for young people who fell through the gap.

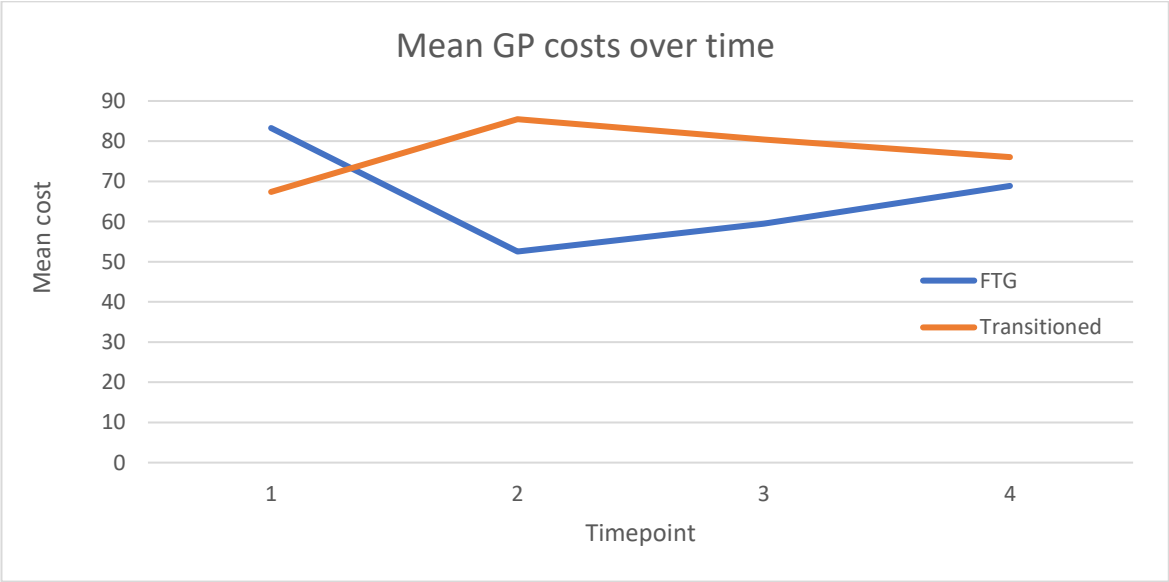

Figure 13 A graph showing the mean total GP costs over time

6.5.4 Predictors of cost

6.5.4.1 Total inpatient costs

Predictors of higher total inpatient costs were transitioning to AMHS (p<0.01) and previously attempting suicide (p<0.01). Predictors of lower total inpatient costs were having a higher baseline EQ5D utility score (indicating a higher quality of life) (p=0.01), having a lower age at the transition boundary (p=0.01), not being white European (p=0.03), having a diagnosis of an emotional disorder (p=0.01), and being at CAMHS for a longer length of time before transitioning (p<0.01) (see Table 28 for details of all predictors).

Table 28 Predictors of total inpatient costs

Imputed Total Inpatient Costs	Coefficient	Standard Error	t	P>t	95% CI
Baseline EQ5D Utility score†	-11850.90	4633.65	-2.56	0.01	-20932.60 - -2769.08
Total baseline ASEBA score	-41.08	57.12	-0.72	0.47	-153.04 -70.88
Total baseline HoNOSCA score	-76.64	145.07	-0.53	0.60	-360.97 - 207.69
Transition Outcome*					
Transitioned†	12199.74	1847.21	6.6	0.00	8579.28 - 15820.19
Gender**					
Male	2069.39	1788.45	1.16	0.25	-1435.91 - 5574.68
Age at Baseline†	-3990.78	1551.76	-2.57	0.01	-7032.18 - -949.37
Ethnicity***					
Other†	-7485.99	3405.13	-2.2	0.03	-14159.90 - -812.05
Primary Diagnosis****					
Emotional disorders†	-5513.45	2095.85	-2.63	0.01	-9621.25 - -1405.65

Personality/trauma	-3440.16	2882.42	-1.19	0.23	-9089.59 - 2209.27
Eating disorders	3178.22	4799.61	0.66	0.51	-6228.84 - 12585.27
Other	-6300.02	3394.18	-1.86	0.06	-12952.50 - 352.45
Total Baseline IBDCS Score	-85.80	137.39	-0.62	0.53	-355.09 - 183.49
Length of time at CAMHS†	-2114.61	566.96	-3.73	0.00	-3225.84 - -1003.39
Previous Suicide Attempt*****					
yes†	5925.28	1769.23	3.35	0.00	2457.66 - 9392.91
_cons	93572.71	26650.49	3.51	0.00	41338.71 - 145806.70

NB. It is important to note that the inclusion of other diagnoses in these tables is due to them being a comorbidity to the diagnoses that are a focus of this study.
† significant at the 95% level
*Base category = Fell Through Gap
**Base category = Female
***Base category = White European
****Base category = Depressive disorders
*****Base category = No previous suicide attempt

6.5.4.2 Total outpatient costs

Predictors of higher outpatient costs were total baseline HoNOSCA score (p<0.01), transitioning to AMHS (p=0.03), not being white European (p<0.01), and having a diagnosis of a personality or trauma disorder (p<0.01), or an eating disorder (p=0.01). The predictors of lower outpatient costs were baseline EQ5D utility score (p<0.01) and having an 'other' diagnosis (p=0.04) (see Table 29 for details of all predictors).

Table 29 Predictors of Total Outpatient Costs

Imputed Total Outpatient Costs	Coefficient	Standard Error	t	P>t	95% CI
Baseline EQ5D Utility score†	-10261.60	1989.86	-5.16	0.00	-14161.66 - -6361.57
Total baseline ASEBA score	-1.72	24.13	-0.07	0.94	-49.01853 - 45.58

Total baseline HoNOSCA score†	217.99	62.90	3.47	0.00	94.71421 - 341.27
Transition Outcome					
Transitioned†	1754.92	782.36	2.24	0.03	221.5145 - 3288.33
Gender					
Male	225.77	766.54	0.29	0.77	-1276.615 -1728.16
Age at T1	346.30	657.54	0.53	0.60	-942.4454 - 1635.05
Ethnicity					
Other†	4709.57	1423.35	3.31	0.00	1919.85 - 7499.30
Primary diagnosis					
Emotional disorders	-334.67	899.79	-0.37	0.71	-2098.218 -1428.88
Personality/trauma†	3447.54	1211.44	2.85	0.00	1073.168 - 5821.92
Eating disorders†	5314.92	2092.94	2.54	0.01	1212.841 – 9417.00
Other†	-2931.07	1449.98	-2.02	0.04	-5772.984 - -89.15
Total Baseline IBDCS Score	36.43	59.23	0.62	0.54	-79.65152 - 152.52
Length of time at CAMHS	270.41	240.58	1.12	0.26	-201.1273 - 741.94
Previous Suicide Attempt					
yes	910.10	755.93	1.20	0.23	-571.50 - 2391.69
_cons	1195.64	11326.96	0.11	0.92	-21004.79 - 23396.07

NB: One outlier was removed in this model due to invalid data.
† significant at the 95% level
*Base category = Fell Through Gap
**Base category = Female
***Base category = White European
****Base category = Depressive disorders
*****Base category = No previous suicide attempt

6.5.4.3 Total community costs

Predictors of higher community costs were transitioning to AMHS (p<0.01) and previously attempting suicide (p<0.01). Predictors of lower total community costs were baseline EQ5D utility score (p<0.01), being male (p=0.01), and having an 'other' diagnosis (p<0.01) (see Table 30 for details of all predictors).

Table 30 Predictors of total community costs

Imputed Total Community Costs	Coefficient	Standard Error	t	P>t	95% CI
Baseline EQ5D Utility score†	-5643.24	852.5161	-6.62	0.00	-7314.14 - -3972.34
Total baseline ASEBA score	-9.77	10.48856	-0.93	0.35	-30.32 - 10.79
Total baseline HoNOSCA score	37.41	27.05752	1.38	0.17	-15.62 - 90.44
Transition Outcome					
Transitioned†	1112.22	338.41	3.29	0.00	448.95 - 1775.49
Gender					
Male†	-870.49	333.06	-2.61	0.01	-1523.27 - -217.70
Age at T1	235.52	285.44	0.83	0.41	-323.93 - 794.97
Ethnicity					
Other	-545.97	653.62	-0.84	0.40	-1827.03 - 735.10
Primary diagnosis					
Emotional disorders	-42.25	386.20	-0.11	0.91	-799.19 - 714.69
Personality/trauma	-83.03	529.08	-0.16	0.88	-1120.01 - 953.96
Eating disorders	-200.39	937.89	-0.21	0.83	-2038.62 - 1637.84
Other†	-2391.14	638.20	-3.75	0.00	-3641.98 - -1140.30
Total Baseline IBDCS Score	37.03	25.32	1.46	0.14	-12.5915 - 86.65

Length of time at CAMHS	-39.14	105.15	-0.37	0.71	-245.22 - 166.94
Previous Suicide Attempt					
yes†	1194.54	327.08	3.65	0.00	553.4715 - 1835.61
_cons	2806.64	4921.70	0.57	0.57	-6839.71-12452.99

† significant at the 95% level
*Base category = Fell Through Gap
**Base category = Female
***Base category = White European
****Base category = Depressive disorders
*****Base category = No previous suicide attempt

6.5.4.4 Total healthcare costs

Predictors of higher total costs were transitioning to AMHS (p<0.01), and previously attempting suicide (p<0.01). Predictors of lower total costs were baseline EQ5D utility score (p<0.01), having an emotional disorder (p=0.01) or 'other' diagnosis (p=0.01), and having a longer length of time at CAMHS (p<0.01) (see Table 31 for details of all predictors).

Table 31 Predictors of Total Healthcare Costs

Imputed Total Cost	Coefficient	Standard Error	t	P>t	95% CI
Baseline EQ5D Utility score†	-18134.70	5461.27	-3.32	0.00	-28838.54 - -7430.77
Total baseline ASEBA score	-74.63	66.30	-1.13	0.26	-204.58 - 55.32
Total baseline HoNOSCA score	175.24	174.46	1.00	0.32	-166.70 - 517.17
Transition Outcome					
Transitioned†	14676.07	2153.40	6.82	0.00	10455.49 - 18896.66
Gender					
Male	51.94	2143.08	0.02	0.98	-4148.41 - 4252.30
Age at T1	-3179.70	1803.30	-1.76	0.08	-6714.10 - 354.70

Ethnicity					
Other	-6616.59	4032.70	-1.64	0.10	-14520.53 - 1287.34
Primary Diagnosis					
Emotional disorders†	-6293.34	2465.80	-2.55	0.01	-11126.22 - -1460.46
Personality/trauma	1274.81	3353.94	0.38	0.70	-5298.79 - 7848.41
Eating disorders	-1804.09	6240.77	-0.29	0.77	-14035.77 - 10427.58
Other†	-11569	4097.25	-2.82	0.01	-19599.44 - -3538.52
Total Baseline IBDCS Score	-112.70	162.56	-0.69	0.49	-431.32 - 205.91
Length of time at CAMHS†	-2097.15	666.14	-3.15	0.00	-3402.75 - -791.54
Previous Suicide Attempt					
yes†	6728.77	2095.12	3.21	0.00	2622.40 - 10835.14
_cons	89747.48	30961.55	2.90	0.00	29063.95 – 150431.00

NB: One outlier was removed in this model due to invalid data.
† significant at the 95% level
*Base category = Fell Through Gap
**Base category = Female
***Base category = White European
****Base category = Depressive disorders
*****Base category = No previous suicide attempt

Collinearity was examined for all predictor variables included in the above models. The VIF for each predictor variable was below 10 (mean VIF: 1.25), meaning that collinearity is unlikely to be problematic.

6.6 Discussion

6.6.1 Summary and interpretation of findings

This study compared resource use and healthcare and societal costs for young people who transitioned to AMHS and who fell through the gap between services. Young people were from seven different European countries (the UK, Ireland, France, Germany, the Netherlands, Italy and Belgium), and had a diagnosis of a neurodevelopmental disorder, an anxiety or depressive disorder, or a personality disorder. A number of these young people had comorbidities (e.g. eating disorders), therefore were likely to have more complex or severe mental health problems.

6.6.1.1 Resource use

The results of the resource use analysis indicate that, as expected, those who transitioned were more likely than those who fell through the gap to be engaged with services after crossing the transition boundary. In particular, those who transitioned had more contacts with inpatient services, community services, more A&E visits (both as an inpatient and an outpatient) and were more likely to take time off from work or study due to their health. There were no significant differences between resource use at any time point for GP visits or contacts with the criminal justice system. These results indicate that young people who fall through the gap struggle to access any support after leaving CAMHS. However, as there was no significant difference between GP visits between the two groups, this could suggest that young people who fall through the gap visit their GP in lieu of receiving mental health support elsewhere. This fits in with the results of my qualitative study, which found that some young people were having regular appointments with their GP for them to monitor their mental health as they did not meet the threshold for care at AMHS.

6.6.1.2 Costs

Overall, mean total inpatient, outpatient and community costs decreased over the 24 months the young people were involved in MILESTONE. This may be due to a number of factors. For example, other research has indicated that young people can find it difficult to engage with care at AMHS, resulting in disengagement from services (Birchwood and Singh, 2013). There was a general decrease in costs for all young people after T1, which was the time when most young people would have reached the upper age limit of CAMHS. This therefore suggests that the intensity of support received by young people decreased after leaving CAMHS, even if they transitioned to AMHS. A reduction in the intensity of support received after CAMHS has also been shown in other studies, for example a recent

systematic review of young people with ADHD's experiences of leaving CAMHS found that AMHS often only gave medication, with no psychological therapy (Price et al., 2019). Young people may often experience long gaps of up to six months between appointments at AMHS which they can find difficult when compared to the regular appointments they received in CAMHS (Appleton et al., 2020). Finally, some of the decrease in healthcare costs could be due to young people's mental health improving over time, as HoNOSCA scores decreased over the course of the study.

There was also no significant difference in GP costs between those who transitioned and those who fell through the gap. This again could be due to young people who fell through the gap visiting their GP more often to try to receiving support for their mental health, or referrals to other mental health services. It is important to note that we did not measure the quality of a young person's transition to AMHS, therefore some of these young people may have also had to visit their GP for medication, or to ask for referrals elsewhere (for example those who had been accepted by AMHS but were on a waiting list, something which has commonly been identified by other studies (e.g. Hovish et al., 2012, Butterworth et al., 2017).

Predictors of higher healthcare costs across all settings were transitioning to AMHS and previously attempting suicide. A predictor of lower healthcare costs across all settings was a higher EQ5D utility score, indicating better quality of life. Both of these results fit in with the results of my quantitative study, which found that those who transitioned were the young people who were most severely ill. As transitioning involves using healthcare services, it is therefore logical that this should result in an increased cost, compared with those who fell through the gap. Conversely, the fact that young people who fell through the gap were less likely to have higher healthcare costs indicates that they struggle to access any kind of support after leaving CAMHS, despite still being unwell. This is also supported by the finding that emotional disorders (which included anxiety and depressive disorders) was also a predictor of lower costs. It has been well documented that young people with anxiety and depression can fail to meet the eligibility criteria for AMHS (e.g. Singh et al., 2010), and are therefore more likely to fall through the gap. As this study focused on young people with these diagnoses, those who transitioned were therefore likely to be much more severely ill to warrant a transition to AMHS, which could explain why there were much higher costs for the transition group.

Another finding of this research was that being male was a predictor of lower community healthcare costs. This may be due to young men being less likely than young women to seek help for any health problems (Nam et al., 2010) or being more reluctant to visit their GP (Wang et al., 2013).

6.6.2 Strengths and limitations

To our knowledge, this is the first study to compare healthcare costs between those who transitioned and those who fell through the gap between CAMHS and AMHS. It therefore adds to the body of existing literature regarding the costs of transitioning to AMHS, and of youth mental illness after young people have left CAMHS. A further strength of this study is that the analysis was conducted on a large international sample, which therefore provides a picture of resource use during the transition period across seven different European countries. The use of multi-level modelling when determining predictors of cost was also a strength of this study, as it meant the results controlled for clustering of data by site type and country, therefore acknowledging the effect this grouping might have on individual participants (Diez-Roux, 2000).

However, it is important to acknowledge some limitations when interpreting the results of this analysis. Firstly, as with the quantitative study in the previous chapter, there were some baseline imbalances between the groups of those who transitioned and those who fell through the gap, with those who transitioned having a higher illness severity at baseline. However, this was accounted for during model development by controlling for differences between the two groups at baseline. There were also some limitations regarding the data used in this analysis. Firstly, there is no guarantee that the costs captured by the CSRI are attributable only to mental health, as this questionnaire did not specify between contacts with healthcare services for physical or mental health problems. There were also some problems with the quality of the data received, for example medication data was extremely poor (due to free text response and participants answering in their native language and no distinction between 'no' and 'missing'), meaning that it was unusable for the purposes of this study. Finally, there was a relatively high percentage of missing data (up to 28% at T4). This data may not have been missing at random: some participants declined to continue with the study due to their poor mental health. However, despite this, multiple imputation remained the optimal method for dealing with missing data as it takes into consideration the uncertainties of estimating missing values in complex

datasets, unlike other methods such as last observation carried forward (LOCF) (Kang, 2013).

6.6.3 Conclusion

The results from this study indicate that those who transition to AMHS go on to use more healthcare services, including more visits to A&E and outpatient services than those who fall through the gap. These results corroborate with the results of the quantitative analysis, which indicated that those who transition are more severely ill than those who fall through the gap. This is also shown here as young people who transitioned were more likely to have time off work or study due to their health than those who fell through the gap. Healthcare costs were higher for those who were more severely ill.

6.7 Chapter Summary

This chapter presented the methods and results of the health economic study which compared resource use and associated costs between young people who transitioned and fell through the gap. A more detailed discussion of these results can be found in Chapter 9. The next chapter reports the method and results for the qualitative study, which explored why young people fall through the gap, and the effect this had on them and their families.

Chapter 7: Exploring why young people fall through the gap and the effect this has on them and their families

7.1 Introduction

This chapter reports the results of the qualitative study exploring the experiences of young people who have fallen through the gap between CAMHS and AMHS, and the experiences of their parent/carers. Reporting is based on the COREQ guidelines (Tong et al., 2007). This chapter begins with a rationale for this work, and a discussion of the methodology behind the chosen methods. The themes identified during data analysis are then presented and their implications discussed.

This research has been published in the Journal of European Child and Adolescent Psychiatry (Appleton et al., 2020).

7.2 Research questions

This chapter addresses the following research questions:

1. Why do young people with certain diagnoses fall though the transition gap between CAMHS and AMHS?

2. What effect does falling through the gap have on the mental health and functioning of young people and their families?

Further information about the research questions, aims and objectives of this research can be found in 3.2Chapter 3, sections 3.2 and 3.3.

7.3 Methodology

7.3.1 Background & Rationale

Exploring patient experiences is commonly used in healthcare research to improve patient care and influence healthcare policy (Gann, 2013). Qualitative methods are appropriate to answer my research questions as they allow exploration of what is important to the

participants, as well as the meanings they attach to their experiences (Ziebland et al., 2013).

Existing research into the experiences of young people who have reached the upper age limit of CAMHS indicates that for the majority of young people, transition is not well managed, resulting in anxiety and uncertainty (Broad et al., 2017, Butterworth et al., 2017, Dunn, 2017).

Although previous research has looked at the experiences of young people who cross the CAMHS transition boundary (Butterworth et al., 2017, Hovish et al., 2012, Newlove-Delgado et al., 2018b), to my knowledge no studies have specifically focused on the experiences of young people who have fallen through the gap between services. In addition, no previous studies have interviewed a cohort of young people over a year after leaving CAMHS, or those who may no longer be receiving any kind of mental health support. As this thesis was linked with an existing longitudinal cohort of young people, I had the unique opportunity to approach participants who were no longer in a service and would have been unidentifiable through standard recruitment methods.

A poor transition can also adversely affect a young person's parent or carer, leaving them feeling excluded from their child's care once the young person has left CAMHS (Hovish et al., 2012). Parents can also struggle to navigate the delicate balance of supporting their child whilst allowing them to have increasing autonomy as they reach adulthood (Young et al., 2016). Therefore, I felt it was important to include parent/carers in my sample.

7.3.2 Narrative research

Data were collected through qualitative interviews with a narrative approach. This method assumes lived experiences are understood through a narrative, as "individuals and groups construct identities through storytelling" (Riessman, 2008). Narratives are stories with a defined beginning, middle and end, and occur over longitudinal time period (Greenhalgh and Hurwitz, 1999). Narrative interviewing encourages participants to tell their stories and talk in-depth about their experiences whilst putting them into a wider context (Muylaert et al., 2014). They are particularly valuable when used to give a voice to a population who have not been heard from before (Lieblich et al., 1998), making them appropriate for use with young people who have fallen through the gap: a group under-researched in the current literature. Narratives are also commonly used in the field of health research, with

illness narratives collected to provide a patient's perspective and context to a medical condition (Greenhalgh and Hurwitz, 1999). In addition to patient's illness narratives, this approach has also been used with carers as a way of understanding their lived experiences (Chamberlayne and King, 1997).

Narrative interviewing also assumes that hearing the participant's story is the best way of obtaining their perspective on a certain situation, as opposed to the question-answer format of traditional interviews (Jovchelovitch and Bauer, 2000). Using narrative interviews therefore allows for a deeper understanding of participant's experiences than using quantitative data analysis alone, or an alternative interview technique such as semi-structured interviews. This method also allows the participant to direct the topic of the interview, therefore allows the participant to say what they think is important, as opposed to the researcher setting the agenda for the interview with a structured topic guide.

7.3.3 Research approach

I chose to use an inductive approach to analyse this qualitative data, as I aimed to find new knowledge from the participant's stories, as opposed to working with an existing hypothesis or framework.

7.3.4 Reflexivity

Reflexivity has been defined as "a researcher's deliberate self-scrutiny in relation to the research process" (Hellawell, 2006 p483). Several researchers (e.g. Attia and Edge (2017), Finlay (2002)) have emphasised the importance of regular reflexive practice by those conducting qualitative research, as a way of acknowledging our potential biases and how they could affect our interpretation of the data. For example, if we come to our research topic with existing experience, beliefs, and knowledge, these might influence how we undertake our research project and analyse the data.

A reflexive journal was kept throughout data collection and analysis. As part of this practice, I acknowledged my own potential biases. One source of potential bias was my own characteristics as a researcher. I am a White British female in my 20s with no history of mental illness. Being a young researcher may have facilitated a rapport between myself and the young people interviewed and may have helped participants view me as an approachable figure. In contrast, my professional background may have led some participants to view me as an expert or authority figure due to my links with the University. This could have resulted in participants giving socially desirable responses, as opposed to

being completely honest about the true extent of their symptoms. Another potential bias was my motivations to conduct the research, as I decided to develop a PhD project on this topic after hearing experiences of poor care and the affect this has had on young people whilst collecting data for the MILESTONE study. Therefore, I was careful not to ask leading questions which could have caused participants to say what I was expecting to hear. I was also mindful of this during the analysis phase, to ensure that I did not let my prior experiences cloud my view of the data, resulting in a more unbiased interpretation.

As I had previously worked on the project, I was aware that this could bias some of the interviews. I knew some of the participants reasonably well before the narrative interview, having met them up to four times already, whereas some I had never spoken to before. For the latter participants, some were noticeably nervous and less talkative at the start of the interview, which may have affected the amount of information received. By acknowledging this bias beforehand, I was able to prepare for these scenarios and minimise the impact on data collection, for example by chatting more with the new participants before turning on the recorder, to allow them to relax and feel more comfortable with me prior to beginning the interview.

7.3.5 A note on sample size and data saturation

I chose a sample size of 24-30 participants (12-15 young people and 12-15 parent/carers) for this study. This was based on the principle of maximum variance sampling (Polit and Beck, 2008) to generate a variety of different views in my interviews. The sample size was also chosen based on pragmatism - what would be a realistic number of interviews to conduct and analyse as a PhD researcher.

As I was aiming to gather a variety of different perspectives for inclusion in my study, I did not base my sample on the principles of data saturation. This term originated in grounded theory (Glaser and Strauss, 1967), but has come to be applied to many types of qualitative research. The original meaning referred to no new data being found to add to the conceptual categories, although this has since evolved and now the term ‘data saturation’ has many meanings and different interpretations (Low, 2019). I agree with authors such as O’Reilly and Parker (2012) and Low (2019) that the most common definition of data saturation - to collect data until no new information emerges, is problematic and an inadequate method to determine research quality. Firstly, there is no definition of what this ‘new information’ is and how this takes into account the nuances and variations between participants. This was particularly apparent in my research as I was using a

narrative approach in which every participant told their own unique story, meaning each interview did contain 'new' information to some extent. Secondly, as there are no clear guidelines to aid identification of when saturation has been reached, the term is often applied ambiguously, without a statement of how it was measured (Francis et al., 2010). Other methods such as reviewing coding and themes with a second coder and my supervisors and keeping a reflexive research journal were used instead to ensure the quality of my findings.

7.3.6 Sampling and Recruitment

Participants were sampled using purposive stratified sampling (Patton, 2002). This method was chosen to ensure that the interview sample had sufficient variation in order to hear from young people from different backgrounds, with different diagnoses, and attending different services.

Once I had identified the participants who had fallen through the gap in the UK, I then sorted them by diagnostic category (anxiety, depression, neurodevelopmental, personality disorder). The second step was to take each diagnostic category in turn and sort by ethnicity, transition boundary of the service they attended, and gender. I then picked the first female from each ethnic group who attended a service with each transition boundary (either 16, 17, or 18), and then did the same for the first male. If there was only one person or one gender in a category then the first (or only) person was chosen. If a young person who was identified had a parent/carer taking part in the study then the parent/carer was also invited to participate.

Study information packs (see Appendix 5) were sent out by post to all participants identified. If there was no response after two weeks then these participants were followed up by phone or text. Once all participants from the first round had been contacted, the second round of eligible participants were selected using the same method as the first. In total, 3 rounds of stratified sampling were completed, with the last round focusing on participants who were underrepresented in the first two rounds of interviews.

7.3.7 Data Collection and Preparation

Interviews took place from February to April 2019. Data were collected using a narrative interview technique. This allowed the participants to guide the conversation to aspects of their care and transition from CAMHS which were most important to them, rather than

having been identified previously by the researcher. Participants were asked whether they would prefer the interview to take place face to face or by telephone. Skype interviews were not offered due to potential reliability issues. Example questions included "What was your experience of CAMHS like?" and "Can you tell me about how your care at CAMHS came to an end?" A full topic guide is included in Appendix 6. The main body of the interview was followed by a period of purposeful questioning (Bertaux and Kohli, 1984) to enable clarification of things mentioned during the interview without interrupting the participant's story. All participants received a small voucher (£10) as a thank you for taking part. Fieldnotes were written before and after all interviews. All interviews were audio-recorded and transcribed verbatim (without removing discourse markers) by the researcher. It was decided not to check the content of transcripts with participants due to time constraints.

7.3.8 Data Analysis

Data were analysed thematically, using the principles of thematic analysis identified by Braun and Clarke (2006). These are:

1. Familiarisation with data (including transcription of verbal data)
2. Generating initial codes
3. Searching for themes
4. Reviewing themes (at the level of coded extracts, then once more with the whole dataset)
5. Defining and naming themes
6. Writing the report

Transcripts were read several times to ensure familiarity with the data and imported into NVivo (QSR International Pty Ltd, 2018) for coding. The first round of coding consisted of using a combination of descriptive, in vivo, and simultaneous coding (Saldaña, 2015). All transcripts were coded by myself, with 50% coded by another PhD student with experience of qualitative analysis. The codebook used in data analysis can be found in Appendix 7. Participant checking was not used to validate the results, although participants were asked whether they would like to receive a summary of the results following data analysis.

7.4 Findings

7.4.1 Sample Description

In total, 42 young people and 31 parent/carers were invited to take part. Of these potential participants, 11 young people and five parent/carers declined to participate, with reasons cited including a lack of time or the young person being too unwell. Fifteen young people and 15 parent/carers took part, representing 19 unique individuals' transition stories. In 11 cases, both the young person and the parent/carer were involved. Four young people took part in the study without their parent/carer, and four parent/carers took part in the study without their son or daughter. Full demographic details for the young people linked with each transition story are presented in more detail in Table 32.Demographic details for parent/carers were not recorded. In total, 25 interviews were conducted. Of the 11 matched young people and parent/carers, five interviews were conducted jointly and the remaining six as separate interviews with young people and their parent/carers. Twenty-two of the participants were interviewed in person, with the remaining eight all being by telephone. Face to face interviews took place either in the participant's home, or an alternative preferred location (e.g. library). Occasionally, the parent/carer was present for the young person's interview if this made the young person feel more comfortable. Individual interviews ranged from 14 minutes to 1 hour 21 minutes (average = 36 minutes), whilst joint interviews ranged from 40 minutes to 1 hour 22 minutes (average = 56 minutes).

Table 32 Demographic details of the young people linked with each transition story

Age in years, mean	19.42
Gender n, (%)	
Female	10 (53)
Male	9 (47)
Ethnicity n, (%)	
White British	17 (90)
British Asian	1 (5)
Mixed	1 (5)
Diagnosis n, (%)	
Anxiety disorders	4 (21)
Depression	2 (11)
Depression & Anxiety disorder	2 (11)
Emerging personality disorder	1 (5)
Neurodevelopmental	2 (11)
Neurodevelopmental & Anxiety disorder	3 (16)
Neurodevelopmental & Depression	1 (5)
Neurodevelopmental, Anxiety disorder & Depression	2 (11)
Neurodevelopmental & other comorbidity	2 (11)
Time since transition	
1-2 years	16
3-4 years	3
Current employment status	
University student	9
College/6th form student	3
Full time employment	3
Not in education, employment, or training	4
Current living situation	

Family home	10
University accommodation & family home	7
Moved out of family home	2

7.4.2 Results of thematic analysis

7.4.2.1 Reasons for falling through the gap

Following thematic analysis, two main themes were identified that addressed the reasons for falling through the care gap (Aim 1): systemic barriers to continuity of care and problems with the quality of care received (see Figure 14 below). These will each be described in turn, illustrated with examples from the transcripts. Participant identifiers included after each quote reflect whether it was from a young person (YP) or parent/carer (PC), the linked young person for parent/carer quotes (where applicable) and the diagnosis of the young person.

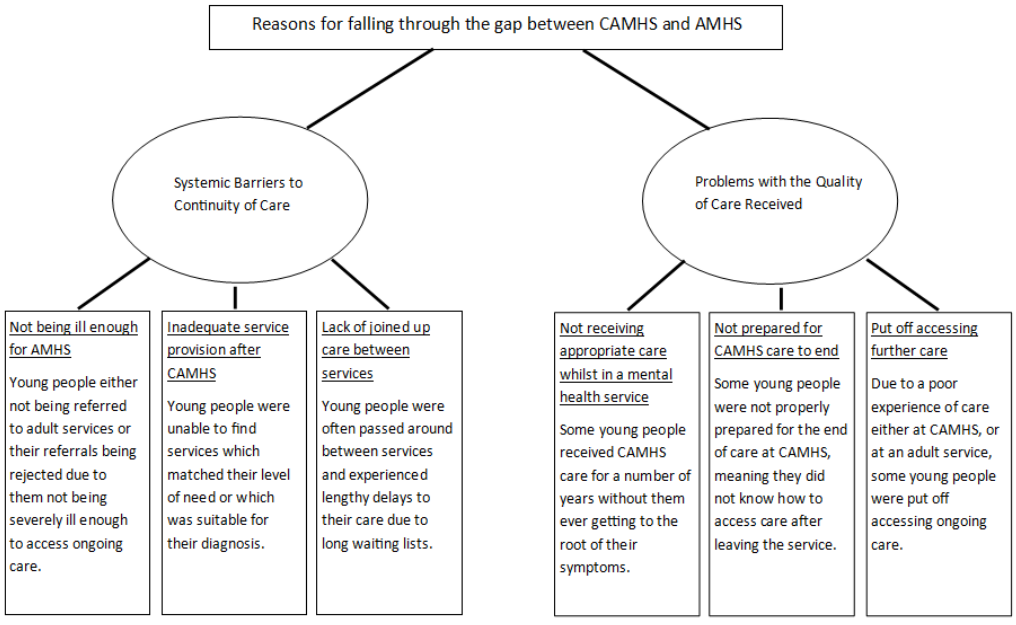

Figure 14 Diagram showing the themes and subthemes for young people and parents views as to why young people fell through the gap between services

Systemic Barriers to Continuity of Care

Systemic barriers to continuity of care captures anything related to the structure or culture of mental health services which makes access to appropriate care difficult after the young person has crossed the CAMHS transition boundary. There were three sub-themes identified: not being ill enough for AMHS; inadequate service provision after CAMHS; and a lack of joined up care between services.

Not being ill enough for AMHS

According to the parent/carers and young people interviewed, one of the main barriers to continuity of care was young people not judged as being severely ill enough to access ongoing care. In some cases this decision was made by their CAMHS clinician who chose not to refer them to adult services, whilst in others, young people's referrals to adult or community mental health services were rejected following an assessment of their mental health. Young people were commonly told that they were 'not ill enough' to meet the threshold criteria to receive care at AMHS.

> *"she [CAMHS clinician] very much disregards the fact if you want to go to adult mental health services, she doesn't really allow that, unless you're really really bad I guess." [YP6, Neurodevelopmental & Anxiety]*

> *"yeah they all wanted to help me and offer me support, but … you've got to fit certain criteria." [YP15, Neurodevelopmental with ED]*

AMHS seemed to be reluctant to accept referrals unless that young person was in crisis at the time of the referral, illustrating the high thresholds that young people must reach to successfully transition from CAMHS.

> *"…he hasn't been able to access adult services, because what we've been told is that unless he attempts suicide etc, or in hospital, then he won't be able to access the services." [PC8 (YP7, Neurodevelopmental & Anxiety with substance misuse)]*

It was also not enough for young people to have been at crisis point in the months leading up to their transition. Two young people were not referred to AMHS despite attempting suicide in the months before their CAMHS care ended.

"And a couple of months before my care ended, I took a big overdose of my medication… they still said I wasn't able to go to adult mental health." [YP13, Neurodevelopmental, Anxiety & Depression]

In some cases, participants described a reluctance by CAMHS clinicians to give a definitive diagnosis. Receiving a diagnosis was seen as a way of 'opening doors' and enabling that young person to receive appropriate care after CAMHS.

"So that's all I really wanted from [Service] was an official diagnosis because I felt as though once I had a diagnosis I would be able to get the professional, the specific help I needed" [YP1, Depression & Anxiety]

The absence of receiving a diagnosis in CAMHS led to some young people struggling to access other care after they had crossed the transition boundary:

"Every time there was diagnosis, you know, we'd talk about that 'oh well they're very young, we don't like to do that with young people'. Well you know, hello, you know, she's now 18 and we're waiting for it because they didn't do it" [PC1 (YP3, Anxiety)]

The high eligibility thresholds at adult or other community services led in some cases to young people's referrals being rejected. When the reason for rejection was communicated to the young person or their family, it was because the young person was not judged to be severely ill enough to access care at that service.

"She referred me again to the autism clinic, a bunch of times actually, and they kept on refusing my case…" [YP1, Depression & Anxiety]

"[They said] that their care wouldn't suit me, and that I should go to [Community Mental Health Service] which I'd already tried." [YP9, Anxiety]

Young people were not always told why their referrals were rejected, which led to feelings of frustration and abandonment.

"I don't even know why my autism referral got denied, because it got denied so many times and the doctor was so baffled, my GP was so baffled, because she said it's so rare for them to refuse a referral

without even interviewing you, and it's even more rare for them not to even give a reason." [YP1, Depression & Anxiety]

A common method of assessing illness severity and the need for continued care and acceptance at a service was via a telephone assessment. However, telephone assessments can be difficult for some young people, and resulted in further stress and anxiety:

"The thing is, it's difficult… because I've got social anxiety and picking up that phone can be climbing a mountain sometimes, and certain days you just feel like, torture, talking to a stranger over the phone…" [YP9, Anxiety]

Telephone assessments were often described as short and impersonal, which raises questions about the suitability of this as a method for accurately assessing clinical need.

"I think it was a 5 minute phone call, I mean how can you assess someone's mental health requirements with a 5 minute phone call?" [PC11 (YP9, Anxiety)]

The use of telephone assessments also raises ethical issues regarding successfully managing the young person's expectations and emotions raised during the assessment in a non-face-to-face setting:

"I think it was a phone call assessment they gave me at the time, and I remember I was, I think I was at work, and they phoned me… and they wanted a lot of background information, so I literally told them everything, up until the point of that day in my life, and then they basically said 'Well sorry, we can't offer you anything until 10-12 months' time, it may even be at a push 18 months'. So I was just really taken aback, I was just like 'So I've said all of this to you, and yet you can't offer me anything'. And I was like, at the time I was really upset, I was really angry, I was really emotional, and they were just like 'Well it's the waiting list, we can't do anything, here are numbers that you can call if you do feel low'." [YP4, Depression]

Another common reason why young people were unable to access continued care was that care was often withdrawn during times of stability, as at that time they did not currently meet the treatment threshold.

"I did go back once but I saw someone else, and then they put me on a… to see a mental health counsellor there. She was quite good, but then that stopped, because at the time, by the time it took me to go to counselling I was feeling a bit better, so the lady there thought there's no point really me being there, because I wasn't struggling." [YP13, Neurodevelopmental, Anxiety & Depression]

Inadequate service provision after CAMHS

Young people also reported struggling to find appropriate care which matched their level of need after leaving CAMHS.

Some were offered a lower intensity of support, such as online or group therapy. However, all of the young people who were offered these types of therapy were reluctant to engage with them, believing these formats of treatment were not suitable and would result in further anxiety.

"The counselling team, again, there's group stuff as well isn't there? And online, online solutions, as well as group solutions, which, isn't necessarily what you need, you know?" [PC13 (YP11, Neurodevelopmental)]

"they were of the belief that we would go to IAPT I think really, I think Dr [Name] gave us the leaflets and everything… but obviously not a lot of people want to go to group, not a lot, not everybody wants to go to a group session, do they?" [PC14 (YP12, Neurodevelopmental & Anxiety)]

"it's obvious that adult mental health don't want me, and no matter how much you tell me to sign up to an internet, or talk anonymously to someone, I'm not going to do that, that's not, me." [YP6, Neurodevelopmental & Anxiety]

In these instances, it seemed as though young people had not been given a choice of where to go, meaning if they did not access group therapy they would not be able to access care at all.

In some cases, young people could not access any further care after leaving CAMHS, despite repeated attempts to reach out to adult or community mental health services:

> *"it's just sort of a brick wall, there's no help whatsoever for him." [PC8 (YP7, Neurodevelopmental & Anxiety with substance misuse)]*

> *"It will, but how long's that going to take, that's the thing. I mean she's 21 now, this has been going on since she was 18. And she's not really had anything that we could say 'yes, that's been a really good piece of work that somebody's done with her'. So, it's very disappointing, I'd say." [PC3 (YP4, Depression)]*

For some young people, this lack of help was due to the fact that there was no service suited to their level of need. This means they were stuck between being 'too ill' for community services, but 'not ill enough' for AMHS:

> *"Then it's like adult mental health, but they wouldn't, say like you had to meet a certain criteria, they kept saying 'You don't meet that criteria', … I tried to go to [Community Service]… but they wouldn't take me on because I was fresh out of CAMHS and I was too big of a risk." [YP13, Neurodevelopmental, Anxiety & Depression]*

In the absence of other, appropriate care, young people and their parent/carers reported being signposted to other organisations to make up for the shortfall. The parents of two young people were told to contact the criminal justice system if they required urgent help for their sons:

> *"So as I say, there's no help there really for him, it's just 'Phone the police', but that's your son." [PC8 (YP7, Neurodevelopmental & Anxiety with substance misuse)]*

In other cases, young people and their parents were told to go to A&E departments if they were at risk of harming themselves:

> *"And then they just said that if you think that [Name] may harm herself, in terms of seriously harming herself, or somebody else, then to take her to the hospital. But, you know, have you ever tried to take someone to the hospital who's suicidal? They just don't go." [PC1 (YP3, Anxiety)]*

In the absence of being offered services on the NHS, some parents paid for their child to attend some sessions of care with a private counsellor. However due to the high costs of private appointments this was not accessible to everyone.

> *"Months, we had to wait months. Erm, and there was nothing else. We had no option, other than private, but I couldn't afford private." [PC1 (YP3, Anxiety)]*

Most participants acknowledged that the lack of appropriate care was linked with the current financial status of the NHS overall, and that all areas of the NHS were compromised due to a lack of available funds.

> *"As I say, the GP wasn't, well it wasn't able to offer the help, it just wasn't available somehow was it? There should be funding, they just didn't have the resources I suppose." [PC15 (YP15, Neurodevelopmental with ED)]*

> *"I mean I guess it's to do with funds and employment, but I think there should be more chances just to go there [AMHS]" [YP6, Neurodevelopmental & Anxiety]*

Nine of the young people who took part in the study were at university. These young people therefore had the chance to access further care from university support services, something that was unavailable to those who did not continue to higher education. There were also inequalities between the care received by different students, as the quality of care provided by universities varied considerably:

> *"My University mental health team is very good, best in the country I think." [YP1, Depression & Anxiety]*

> *"The University's rubbish. They say they've got a good mental health team but they're terrible." [YP11, Neurodevelopmental]*

Lack of joined up care between services

Young people and parents also attributed their experiences of discontinuity of care to a lack of joined up care between CAMHS and AMHS. This resulted in young people experiencing multiple transitions and contacts with different services after leaving CAMHS.

For example, some young people were not directly referred to AMHS by their CAMHS clinician, instead referred back to their GP, who then made the referral to AMHS.

> *"At the end of care, she was - obviously she had her last session with her counsellor, and we were told that we'd go onto adult mental health services. And we'd have to go back to our doctor. We went back to the doctor, the doctor didn't really have a clue what we were talking about…" [PC3 (YP4, Depression)]*

This lack of direct referrals also led to some young people spending a significant amount of time waiting to access care, without being offered any kind of alternative support during that time.

> *"…she just said to me that it would be a 6 month waiting list for group therapy and to see a psychotherapist." [PC3 (YP4, Depression)]*

Other, community based mental health services required a young person to self-refer to them, as opposed to receiving a referral from a clinician. This was seen as a barrier for most young people who seemed reluctant to contact a new service themselves, despite having a need for continuity of care.

> *"and it was self, self-referral as well. So, getting round to that, it took a while after I turned 18." [YP9, Anxiety]*

> *"it would be up to me to find an alternative if I needed it." [PC8 (YP7, Neurodevelopmental & Anxiety with substance misuse)]*

Some clinicians were also unsure about what services a young person would be able to access. In one case, this resulted in a parent being told to contact a service which was unable to help them because they lived outside the catchment area.

> *"Dr [Name] mentioned Autism West Midlands to us, who I did get in touch with but was told that they effectively only look after the [City] area, which isn't really a great help to anyone else is it?" [PC6 (YP not interviewed, Neurodevelopmental & Depression)]*

In young people with more complex mental health difficulties, services seemed reluctant to take responsibility for that young person's care, resulting in them being passed around to several services without actually being able to access support. For example, one young person reported being unable to access further care due to an alcohol addiction:

"the doctors should have referred then him over to, for instance counselling, CBT, anger management, but he couldn't do that because of the alcohol problem, and just said 'Come back when you're not drinking'." [PC8 (YP7, Neurodevelopmental & Anxiety with substance misuse)]

Problems with the quality of care received

This theme captures any problems a young person had with their care when they were registered at a service which resulted in them falling through the gap between CAMHS and AMHS. This theme is divided into three sub-themes: not receiving appropriate care whilst in a mental health service; not prepared for CAMHS care to end; and put off accessing further care.

Not receiving appropriate care whilst in a mental health service

Several young people and their parents reported not feeling as though they received appropriate treatment when they were under care at CAMHS. This meant that young people were receiving care at the service for several years without experiencing an improvement in their mental health. The lack of appropriate care may have contributed to young people falling through the transition gap.

"if they'd understood more about the condition I had more, that would have been a lot more helpful, earlier on, if they'd done that with me, rather than me having to go through 6 years" [YP10, Neurodevelopmental, Anxiety & Depression]

"I didn't really like the idea of cognitive behavioural therapy, because at CAMHS they sat me in a room with pieces of paper to read through and then answer questions about how this person feels, what they could have done different, but that wasn't helping me. It made me not want to go, because it felt like doing school work. I didn't want to go to just fill out forms. No one was in the room with me, she'd go out and then come back after." [YP13, Neurodevelopmental, Anxiety & Depression]

In some cases this was linked with a reluctance of CAMHS clinicians to give a clinical diagnosis, which meant the young person was not able to receive the recommended treatment for their illness.

> *"because it [the diagnosis] took so many years, when they finally were like 'Oh you need CBT therapy', it was 5 years too late." [YP2, Depression]*

Some CAMHS services were also criticised for putting too much of a reliance on medication, as opposed to talking therapies:

> *"Especially, like my earlier team… they just kind of put you on medication and think 'that's that, you're fine now'. They did do, therapy, like talking sessions but not many" [YP3, Anxiety]*

This meant that some young people felt as though CAMHS never helped them to get to the core of their symptoms. Therefore, despite having sometimes lengthy care at CAMHS they were still struggling with their mental health when they reached the upper age limit of their CAMHS service.

> *"And when we left CAMHS, again they said 'Oh I'm sure it will be alright now' – how can it be alright if they never got to the root of the problem?" [PC1 (YP3, Anxiety)]*

In the majority of cases, young people who were able to access ongoing care at AMHS or community mental health services also experienced a poor standard of care that did not meet their need.

> *"I think he's now with I-A-P-T service, just looking at the card he's got pinned up. He's got one more session tomorrow, so basically they've done nothing either." [PC6 (YP not interviewed, Neurodevelopmental & Depression)]*

A particular problem identified was the infrequent nature of appointments, in some cases with young people waiting months between sessions, which meant they struggled to receive a benefit from them:

> *"But then obviously you go there, you have the assessment, and then you're waiting months again. So how does that even help?" [PC3 (YP4, Depression)]*

"[Name] had a few appointments, but there was no consistency" [PC11 (YP9, Anxiety)]

Not prepared for CAMHS care to end

Some young people were not adequately prepared for care at CAMHS to end. This meant that they were not informed about where else they could access care or go to for help. Consequently, they struggled to manage on their own. In most cases, young people did not feel adequately prepared due to a sudden cut off of care at CAMHS and withdrawal of all support.

"I just think, I mean there's no reduction, it's like with medication, you don't just stop medication, you reduce it. Saying that you're 18 now, sorry, bye." [PC6 (YP not interviewed, Neurodevelopmental & Depression)]

This poor transition planning meant that young people felt rushed and under pressure to make a decision about their future care:

"she talked through the options but it did feel a bit rushed, because now this was my last meeting, I need to make a decision" [YP6, Neurodevelopmental & Anxiety]

Young people also reported not receiving appropriate information about the next steps after CAMHS ended:

"it was just kind of normal really, it was just kind of like you were there, and then you weren't, they obviously gave you some advice, like a leaflet, but it was almost, otherwise it was like just a normal appointment really." [YP8, Neurodevelopmental]

Some young people also reported not being involved in the decision-making process regarding their end of care at CAMHS, meaning they were not informed about future care options.

"she was like 'We'll do your last sessions and then, you've got to go' basically." [YP2, Depression]

In contrast, a few young people were very well prepared for their care to end, which helped them and their parents manage their illness and continue to receive other care if needed.

> *YP: "I think he wanted to, well he was, he was very realistic and he said that, if I left it was going to be hard. And also, erm, he will do, he was helping Mum organise..." [YP11, Neurodevelopmental]*
>
> *PC: "He was helping you prepare, wasn't he? He was helping you to prepare from the step from school into university life and [Mental Health Nurse] was very good." [PC13 (YP11, Neurodevelopmental)]*
>
> *"He gave us lots of advice of places to turn to didn't he? He did advise us it was going to be a rocky road probably, it wouldn't all be plain sailing." [PC15 (YP15, Neurodevelopmental with ED)]*

Put off accessing further care

Having bad experiences of care at CAMHS or having referrals to other services rejected led to some young people being put off from accessing further care, despite needing ongoing help after CAMHS.

> *"But [Name] because she had such a bad experience, she didn't want to see anyone, that was the other issue, that was another problem." [PC1 (YP3, Anxiety)]*

For example, several participants emphasised the importance of having a trusting relationship with their clinician, which made them reluctant to have to 'start again' with someone new.

> *"I am very aware for [Name] or people like her that it wouldn't be a case of just going to a drop in centre or somebody, she'd need to trust somebody. There needs to be a build up of a relationship before she could trust someone enough to say 'this is what's happening today'" [PC5 (YP6, Neurodevelopmental & Anxiety)]*
>
> *"I have to get to know someone before I'm going to talk to them first, and I want to know as much about them, the individual, as they want to know about me. To me, they're a stranger, whether they're a*

professional or not. I have to meet them at least 5 or 6 times before I'll open up." [YP7, Neurodevelopmental & Anxiety with substance misuse]

For the young people who did go on to access adult or community care after leaving CAMHS, a lack of consistency meant they had to keep repeating their story to new healthcare professionals, which some found very difficult.

"and it was just seeing all these different people, and you had to start over again explaining yourself to all these different people" [YP13, Neurodevelopmental, Anxiety & Depression]

"it's just ridiculous because you want to get over what's happened and move forward, but every time you go on to a different waiting list it's like 'oh, can we hear your history?' and then you go back at square one" [YP4, Depression]

Several young people felt that there was no point engaging with care after CAMHS if their referrals were always going to be rejected or if they found the service to be too impersonal and different to CAMHS.

"In the end, you just think 'What's the point?' I'm not going to waste my time keep turning up for appointments for them to show me the door." [YP7, Neurodevelopmental & Anxiety with substance misuse]

"And some of the doctors who I dealt with at [Service], they were just kind of so half hearted, I always felt as though I was being a bother to them just by showing up, and that just made me feel so bad. And it's like I only see you once a month anyway, I had to move heaven and earth just to be able to see you, and now I feel as though I'm inconveniencing you. And like, everyone who dealt with the adult services, none of them were as nice as the people at CAMHS, they all seem, I always felt like guilty for being there" [YP1, Depression & Anxiety]

There were also cases of young people being put off engaging with further care because they wanted to be in control and have care ending on their terms.

"Because if it comes to the part where you tell me I've got to let go I

don't think I will be able to, so I'd like to do that on my terms, so I just said 'this will be the last sort of session'. But she was like 'I can offer you two or three more sessions' and I was like 'I don't think I want to go that far and then for you to tell me that I can't come back'." [YP4, Depression]

In one case, this was also linked with a desire not to be stigmatised.

"And I think once he became older, his concern was the fact that being a male, being a black male, that statistic basically, he didn't want to fall into that statistic, and so he just wouldn't engage." [PC9 (YP not interviewed, Personality Disorder)]

7.4.2.2 Effects of falling through the gap

The findings linked to effects of falling through the gap are divided into separate themes for young people and parent/carers as shown in Figure 15 below.

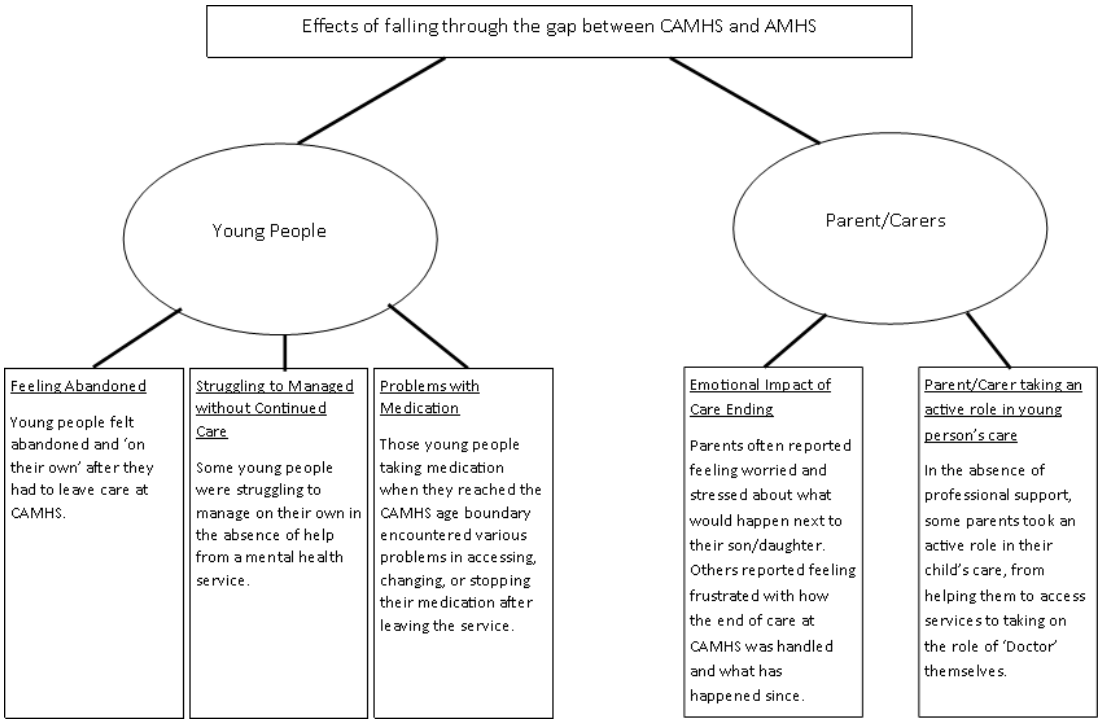

Figure 15 Diagram showing the themes for the effects of falling through the gap between services

Effects on Young People

The effects on young people are categorised into three themes: Feeling abandoned, struggling to manage without continued care, and problems with medication.

Feeling Abandoned

A common effect of falling through the gap between services was that young people felt as if they had been abandoned; that they had been let down by the system and no one cared about them.

> *"It just feels like we've been let down, massively… I mean if somebody's suicidal and you have to wait 6 months... how is that any good? It's appalling isn't it?" [PC3 (YP4, Depression)]*

> *"I mean, I never liked taking the medication in the first place… but on the other side I thought I really should be taking some medication and it kind of made me feel unsafe, because no one cares enough to give me the proper treatment." [YP1, Depression & Anxiety]*

The language used by young people emphasised their feelings of abandonment, with phrases such as *'lied to'*, *'pushed into the wilderness'* and *'shut the door on me'* used to describe how they felt about what happened when their CAMHS care ended. This language also suggests that young people did not have a choice as to when their care would end and what happened next.

> *"To me, I felt like I was doing alright, I was in college, I was doing work placements, I wasn't doing too bad. And then they just shut the door on me when I turned 18." [YP7, Neurodevelopmental & Anxiety with substance misuse]*

As health services were perceived as uncaring, most young people reported feeling as though they were 'on their own', without any support.

> *"I suppose they're meant to transfer you to other care things, but it was more like 'you've got to do it yourself now'" [YP3, Anxiety]*

> *"But literally like you've got to stop drinking before you can get the counselling, but the underlying problem that counselling would solve,*

is the reason I'm drinking. So it's like, how is that going to work?" [YP7, Neurodevelopmental & Anxiety with substance misuse]

In some cases, feeling abandoned by mental health services had a negative impact on the young person's mental health, in particular when young people were told they were 'not a priority' by clinicians in adult or community mental health services. This led to young people feeling as though they were not worthy of help and questioning if they would ever be able to get better.

For some young people, feelings of abandonment were intensified as CAMHS ended at a time when they needed help the most due to other, stressful life events. This led to increased anxiety and a loss of confidence about how they would cope with this stressful period alone.

"I was going through a court case at the time, it had only just started, and I needed someone really to talk to about that. But then, being… erm, I was like sent away from CAMHS, there was no one there." [YP13, Neurodevelopmental, Anxiety & Depression]

"I was saying I would like to have that safety bank, because if it all goes wrong now, I haven't just got school on the edge and that, I've got uni, and that's something I really wanted to do. So that was very much on the back on my mind, if this all comes back in my face, I've lost my whole career idea" [YP6, Neurodevelopmental & Anxiety]

Struggling to Managed without Continued Care

The majority of young people struggled to manage on their own after leaving CAMHS. In the most severe cases, young people were viewed by their parents as missing out on normal life due to a lack of appropriate support:

"he's not living the life that he should be living, I do feel he's being let down. He never leaves the house now, he hasn't left the house since April [10 months before the interview]. But he's not the person he should be, and he does need help, and we can't access that help because of alcohol." [PC8 (YP7, Neurodevelopmental & Anxiety with substance misuse)]

Other young people were taking time out of work, education or training due to struggles with their mental health:

> *"Well he's had no, he's had no help for 2 years, effectively. And he needs help, those 2 years could have been making a massive difference for him, you know? But it hasn't. He's not, I wouldn't say he's, you are better, aren't you [Name], but certain pressures aren't there now in that, erm, he dropped out of 6th form because of the pressure of the school as much as anything." [PC11 (YP9, Anxiety)]*

In contrast, a few young people were able to manage their mental health well without the need for continued care.

> *"I mean she's still, you know sort of, not struggling with your OCD, because you manage it, don't you, but you've still got it, but she manages it well, and I think she's done that since she left CAMHS" [PC14 (YP12, Neurodevelopmental & Anxiety)]*

For these young people, having very supportive parents was critical to them being able to manage, for example one young person required extra support from her parents when away at university.

> *"For people like [Name], there's no transition, there's nothing. She is very lucky, in the family she's got, without blowing our trumpets, we would drop anything to be there." [PC5 (YP6, Neurodevelopmental & Anxiety)]*

The majority of young people who were coping well without care were also prepared well for CAMHS to end, which seemed to increase their confidence in their abilities to manage without formal mental health care.

> *"because he gave us plenty of warning I had time to ask questions and sort of plan strategies for how we would cope, the practicalities of it." [YP15, Neurodevelopmental with ED]*

Due to previous referrals and attempts to access care being rejected, some young people who felt as though they still needed ongoing support did not know where they should go to access it.

"Yeah, there is certainly times, a lot of times, where I feel like I should need some help, but I don't know where to go exactly. Which sucks." [YP9, Anxiety]

Despite legally being an adult, the majority of young people felt as though they would still need help from their parent/carer when it came to organising care post-CAMHS. This suggests that although they have reached adulthood, young people with mental illness continue to rely on their parents for support.

"obviously my mum did it all for me, it scared me the fact that I'd have to do it myself, because I'm not great with things like that." [YP3, Anxiety]

Problems with Medication

Almost all young people who were taking medication as they approached the upper age limit of their CAMHS age boundary encountered various problems in accessing, changing, or stopping their medication after leaving the service.

For some young people, falling through the gap between CAMHS and AMHS meant they had no choice but to stop their medication once their existing prescription ran out.

"I'm not on medication now, and I haven't been since I was 18, basically since I needed to be seeing a doctor to be able to be prescribed me more meds, I didn't have one at the time." [YP1, Depression & Anxiety]

Although some young people were able to continue taking their medication, they were not given information about what to do if they wanted to change their dosage or stop the medication all together.

"I'm not sure. I haven't had a medication review for a… ages actually. So I probably could go to the Doctors down here, but then again, last time I went to discuss about my medication they said they couldn't do it, so, I'm not too sure." [YP13, Neurodevelopmental, Anxiety & Depression]

Some young people who were coping well without any treatment apart from medication were also unsure whether they should even be taking it, and how long they should be

taking it for. These thoughts were only prompted by the interview, showing that their GP had not discussed it with them.

Effects on Parent/Carers

The effects on parent/carers of young people falling through the gap between CAMHS and AMHS are divided into two themes: Emotional impact of CAMHS care ending and Parent/Carer taking an active role in the young person's care.

Emotional Impact of Care Ending

All parents interviewed spoke about the emotional impact that the end of their child's care at CAMHS had on them. In particular, parents spoke of seeing CAMHS as a kind of 'safety net' in which their child was looked after, and the end of CAMHS led them to worry about what would happen in the future, especially if their child's mental health deteriorated.

> *"I think it would be nice to have like, a sort of contact person, in that department that you could call and say 'She's relapsed, can we access somebody, a specialist immediately, rather than having to go back through the Doctor to be referred because obviously if you relapse you almost need immediate help, don't you?" [PC15 (YP15, Neurodevelopmental with ED)]*

For some parents, these feelings were exacerbated as the end of CAMHS came as a shock. This implies that parents were not adequately prepared for when and how CAMHS would end. One parent in particular was surprised when CAMHS ended when his daughter turned 16, less than a year after she began receiving care:

> *"we'd just worked out the routine and what was going on, and it was pulled from under us, so it was, that was part of the shock really, that thing had gone, as it had only just got going really." [PC2 (YP not interviewed, Anxiety)]*

Many parents also reported feelings of frustration due to the poor experiences of transitional care, in which young people were left without appropriate support.

> *"'I can't treat you anymore, you go over there', and it was just like that, you know. Quite frustrating really, as you can tell." [PC11 (YP9, Anxiety)]*

In some cases, parents were also frustrated by the fact they were left out of decisions about what care their child should receive after CAMHS, with parents reporting feeling 'on the outside' and excluded from information about their child's health.

> *"I do believe, first of all, [Psychologist] didn't want me to be in the meeting, she didn't want to talk, or allow me to say anything." [PC5 (YP6, Neurodevelopmental & Anxiety)]*

> *"that switch from CAMHS to adult was the worst time, we just felt so bad and so outside of it all, we couldn't do anything." [PC2 (YP not interviewed, Anxiety)]*

Parent/Carer taking an active role in young person's care

The other main effect on parent/carers was that in the absence of professional support for their child, they ended up taking an active role in their care. At the most extreme level, this meant that parents took on the role of 'Doctor', finding information about strategies which could help their child's mental health or helping to wean them off medication when they were unable to renew their prescription due to falling through the gap.

> *"I weaned myself off it, I mean with my mum's help and supervision. So I started taking less, a lower dosage over time so that I could wean myself off it, because we discovered that I wouldn't be able to get another prescription without my doctor seeing me, and my doctor wasn't seeing me because the CAMHS people wouldn't see me again." [YP1, Depression & Anxiety]*

In the less extreme cases, most parents reported helping their child to access care, for example by making GP appointments for them or finding out information regarding what care they could access at university.

> *"And I did ask, when we went to all the open days, I'd kind of sneak off and ask about what support there was there." [PC2 (YP not interviewed, Anxiety)]*

However, several parents reported difficulties in helping their child access support once their child had turned 18. Many reported having to fight to access the appropriate care for their child.

> *"I'm not sure how my mum managed to get me to [Service], but I'm pretty sure in the end she just annoyed them so badly by directly contacting them that they begrudgingly gave us an appointment." [YP1, Depression & Anxiety]*

In some cases, this led to parents feeling as though they were being labelled as over-protective or paranoid by healthcare professionals, although this did not deter them from continuing to push for help for their child.

> *"As parents we struggle. We don't know whether we're doing right, we don't know whether we're doing wrong. It's difficult to explain to the GP, it's difficult to explain to everybody. They think you're just being awkward, overprotective." [PC4 (YP5, Anxiety)]*

Some parents also spent a significant amount of time providing emotional support for their child, going above and beyond a usual parent-child relationship.

> *"I think he may rely more on me and his mother to just provide him with that sound board, if he needs it, that sense of safety if he needs it, by just being there." [PC7 (YP not interviewed, Depression & Anxiety)]*

> *" …a lot further than what I would have done for another child anyway, if that makes sense – I had to do things I wouldn't have to do so that she can do all of that. She'll still phone and say there's a problem, and I do more than I would for a peer of her age" [PC5 (YP6, Neurodevelopmental & Anxiety)]*

Most young people emphasised how important they found the support of their parents in the absence of professional support, showing the value of having a supportive family to help young people cope with their mental health.

> *"I'm really lucky that I've got really loving parents who look after me and make sure that I'm not in danger, but if I had any less of a support system I'd probably be dead by now because it took them so long to do anything." [YP1, Depression & Anxiety]*

7.5 Discussion

7.5.1 Summary and interpretation of findings

This chapter has explored the perceptions and experiences of young people who had fallen through the gap between CAMHS and AMHS, as well as the views of their parents, obtained through qualitative in-depth interviews. This chapter contributed to the first two research questions: why young people fall through the gap, and what effect this has on them and their parents. Participants were recruited to take part if they had fallen through the gap between CAMHS and AMHS and had a diagnosis of a neurodevelopmental disorder, a personality disorder, an anxiety or depressive disorder. There did not appear to be any differences in reasons for falling through the gap or experiences after leaving CAMHS depending on gender, ethnicity, diagnosis, living situation or employment status.

Firstly, this study explored why young people and their parents felt as though they had fallen through the gap between services. Analysis identified systemic barriers to continuity of care as well as problems with the quality of the care received, which led to young people failing to transition to adult mental health services. The systemic barriers included young people judged as not being ill enough to access continued care, inadequate service provision, and a lack of joined up care between services. This was often related by the participants to issues around resources and the current financial state of the NHS. In particular, this research identified a group of young people who were not ill enough to access AMHS but were too ill for other/non-specialist community based mental health services, such as IAPT. Some young people also mentioned the problems they had encountered whilst they were receiving care, such as not being prepared for CAMHS to end, not receiving the appropriate level of care when in a service, or being put off accessing further treatment after a bad experience in mental health care. Of particular concern were those young people who were signposted to the criminal justice system or A&E due to no available mental health care. These findings support previous research that has attributed A&E and police involvement in mental health crisis care to the decline in specialist community based mental health services (Care Quality Commission, 2015, Mclean and Marshall, 2010) and shows that the shortfall in mental health services can result in an increased use of resources elsewhere.

The findings also suggest that having a poor experience of care, either during CAMHS or at the transition boundary, can result in young people disengaging from mental health services. These results also emphasise the importance of adequately preparing young

people for their transition from CAMHS to other specialist services or discharge to their GP, as those who were well prepared reported lower levels of dissatisfaction and worry about accessing care than those who did not receive this information.

Secondly, we explored what effect falling through the gap had on young people and their parents. This experience was overwhelmingly negative, with young people reported feeling abandoned and on their own, which in some cases adversely impacted their mental health. In the most severe cases, young people struggled to manage on their own without professional help, leading them to be described by their parents as *"not living the life that [young person] should be living"* or *"treading water".* Several young people who were on medication as they crossed the CAMHS age boundary also encountered problems; some were unable to continue with their medication without being seen by an adult psychiatrist, whilst others had problems changing the dosage or knowing who they should speak to about coming off their medication. Parents described feeling worried about their child's future and what should happen if their child urgently needed to access mental health care. These worries were exacerbated by the high costs of private mental health care, meaning it was not always an option parents could consider. Parents also reported their frustrations at a perceived lack of appropriate care for their child, and how they often had to fight in order for their child to access services after leaving CAMHS. In some cases, young people described their parents taking on the role of doctor in the absence of professional mental health support and spoke about the importance of having a supportive family in terms of their ability to manage their mental illness. This raises the problem of who is there to support young people who do not have a supportive family network, such as those who are looked after by local authorities or young people estranged from close family.

7.5.1 Relation to existing literature

This study explored why young people fall through the gap between CAMHS and AMHS, and what effect falling through the gap between services has on young people and their parent/carers. I focused only on those young people who had fallen through the gap between services and interviewed them between one and three years after leaving

CAMHS. I was therefore uniquely positioned to examine the long-term effects of poor transitional care, something which has not been examined in existing research.

7.5.1.1 Relation to other research

When exploring why young people fall through the gap between services, these findings corroborate with other qualitative studies which have reported barriers to transition. A recent systematic review explored the transition experiences of parents and clinicians (Hill et al., 2019), and identified several barriers to a good transition, including a lack of available adult services and poor communication between services, which made transition difficult. These findings were also echoed by a study conducted in the USA, which found that there were a lack of community resources for young people over the age of 18 (Jivanjee et al., 2009). This lack of resources for over 18s with mental illness was also identified in the current study for those young people who were too ill to attend wellbeing or counselling services (in this thesis these services will be referred to as Adult Wellbeing Services, or AWBS), but not ill enough to meet the illness threshold for AMHS. This service gap has also been identified in a systematic review of the transition experiences of young people with ADHD, with young people reporting difficulties in accessing care which met their needs after leaving CAMHS (Price et al., 2018). One solution to this service gap could be through enhanced provision in primary care: a recent report by the Centre for Mental health proposed that GPs, in particular through new primary care networks, could be best placed to meet the mental health needs of those who fall between AWBS and specialist AMHS (Naylor et al., 2020).

Young people were not offered a choice of available support after CAMHS, therefore if they did not feel that IAPT or group therapy was right for them, there was no alternative care they could access. Young people seemed to be reluctant to engage with online support or group therapy, which contradicts the findings of relevant systematic reviews which have found good levels of acceptability for these methods of support for adults with anxiety and depression (Ichikura, 2014, Andrews et al., 2010).

The findings from the present study also emphasise the importance of receiving optimal care when in a mental health service. For example, some young people were under the care of CAMHS for several years without feeling as though they had received appropriate care, and therefore were not well equipped to manage on their own after reaching the transition boundary. In other cases, young people's appointments at AMHS were so infrequent, they did not feel as though they were being cared for at all. Of the two

participants who were registered with an AMHS at the time of interview, one had yearly medication reviews for ADHD, whilst the other had received two appointments in a year for their depression. These findings also show how receiving inadequate mental health care can result in young people being put off from accessing future care, something which could explain why rates of disengagement are relatively high during the transition period (Singh et al., 2010, O'Brien et al., 2009). Not being adequately prepared for care at CAMHS to end has also previously been identified as contributing to a negative experience of transition (Broad et al., 2017).

Other studies have reported the effects of a poor transition, with young people feeling let down after leaving CAMHS (e.g. Butterworth et al. (2017)) or mental health services described as uncaring (Dunn, 2017). The findings of the present study add to the existing literature by highlighting the problems young people face without any support from mental health services. For example, some young people struggled to manage their mental illness and as a result dropped out of education or work, whilst others had problems trying to access or change their medication after leaving CAMHS. A lack of expertise in psychotropic medications by GPs has been previously identified by parents in a study in the USA (Jivanjee et al., 2009), and by GPs in the UK in relation to prescribing medication for ADHD without specialist input (Newlove-Delgado et al., 2019). However, to our knowledge this study is the first in the UK to show that young people who remain on medication after leaving CAMHS do not know how to alter their dosage or stop taking medication entirely.

Most participants were only able to receive care from their GP after leaving CAMHS, with discharge to their GP at the CAMHS transition boundary a common outcome. However, young people reported variable quality of mental health support from their GP. This has implications for clinical practice, in particular how GPs are trained to help young people manage their mental illness and their knowledge of appropriate services to refer young people to. This finding is similar to other research in the UK, which has identified GP training needs for managing young people's emotional distress, suicidality, and ADHD (Roberts et al., 2013, Michail et al., 2017, Tatlow-Golden et al., 2016).

7.5.1.2 Relation to other studies with parent/carers

Jivanjee et al (2009) also reported that parents had a significant caring responsibility for their children even when their child was over the age of 18, something also identified in the current research. A particularly important finding of our study was the extent to which parents became involved in their child's mental health care in the absence of other

professional support, with parents taking on the role of 'Doctor' to help work through self-help therapy or wean their child off medication. Parents who supported their child through self-help therapy or weaning off medication reported they gained their knowledge either through their own research or lived experience. When asked, all but one parent said they had never received any support themselves as to how to cope with their child's mental illness, and only a minority were given information regarding how they could best help their child manage their mental health. These findings were echoed in a report by the Association for Young People's Health, which found that parents worked hard to help their child access support as soon as symptoms first arose, and ended up taking on a significant caring role, especially in the absence of professional services (Association for Young People's Health, 2016).

One sub-theme identified in this research was young people and parents feeling as though they did not receive appropriate care whilst in a mental health service. This raises the question of who knows best about what care is appropriate. The young people and parent carers interviewed felt as though they knew more about the type or quantity of care they needed than their clinician, or that their clinician did not really understand them or their illness. This links with literature regarding patients as experts, moving away from the traditional paternalistic model of medicine in which patients are passive recipients of care to one where they are viewed as experts in their own right (Kennedy, 2003). According to (Coulter, 1999), a successful partnership between doctor and patient is one where both parties can contribute their own expertise, share information and make joint decisions. In the cases where participants felt as though they received inappropriate care, it is unlikely this partnership of care took place. There is a need for further research exploring the expertise of young people with mental illness and their parents, and how this knowledge is used by clinicians in mental health services.

7.5.2 Strengths

This study was the first of its kind to only interview young people (and the parents of young people) who had fallen through the gap between CAMHS and AMHS, therefore it contributes to the current literature regarding the challenges faced by these young people. One of the main strengths of this study was that I was able to recruit young people who had fallen through the gap after leaving CAMHS between one and three years after leaving children's services. This allowed us to explore the longer-term impacts of falling through

the gap on young people and their families. Another strength was the high heterogeneity of participants recruited via purposive stratified sampling. This allowed us to include the views of young people with different diagnoses, backgrounds, and who were from different regions of England. I was also able to recruit an almost equal number of males and females to this study, which is a higher proportion of males than was recruited to the MILESTONE study in the UK and other qualitative transition research (Butterworth et al., 2017, Dunn, 2017, Lockertsen et al., 2020a, O'Hara et al., 2020).

There also seemed to be no difference in the depth or quality of interviews conducted either face to face or over the telephone. I believe this is because I asked participants their preferred method for data collection to ensure all participants were as comfortable as possible. I also made sure to establish a rapport with the participants before beginning the interview to minimise any nerves they may have had before starting collecting data.

The use of a reflexive approach to data collection and analysis is also a strength of this methodology, as it allowed for any potential biases caused by the background, experiences, or views of the researcher to be acknowledged and therefore minimised their impact on the analysis.

7.5.3 Limitations

This study also contained some limitations. There was likely to be some response bias from participants due to the recruitment method chosen, whereby participants received information about the study (at first by post and then follow up by text or phone) and responded to the researcher if they were interested in taking part. It is also likely that those with a particularly bad experience of transition may have been more willing to take part. There may also have been some bias in joint interviews if participants were reluctant to speak honestly in front of the other responder. The data collection method may have discouraged some from taking part, as some potential participants declined to participate as they were too unwell. The length of time since leaving CAMHS and the interview may also have resulted in participants forgetting some details about what had happened or where they were referred to, which could have impacted on the accuracy of the data collected. However, as I was interested in how participants experienced the end of care at CAMHS, the overall accuracy of the data is not a significant cause for concern.

Through the data collection for the MILESTONE study, I had previously met some of the participants multiple times, whereas others met me for the first time to conduct the narrative interviews. In the case of a few participants, this may have impacted on the quality and amount data received, as they appeared more nervous and less talkative at the beginning of the interview.

There was also some discrepancy between the diagnoses we had on file for these participants which were obtained from either their CAMHS clinician or clinical records, and the diagnoses identified by the participants themselves. This could be due to diagnoses changing over time, or a misunderstanding between the clinician and participant, and likely reflects the challenges of diagnosing adolescents and young adults. It was decided to use all participant-reported diagnoses in this thesis as these were likely to be the most up to date, although this may not reflect the formal clinical diagnoses. As many of these young people were no longer registered with a mental health service, we were unable to obtain up to date diagnostic information.

Finally, although this study sampled broadly from a cohort of young people who had fallen through the gap, there is potential that a larger or more diverse sample (e.g. from other areas of the UK) may have resulted in changes to the themes identified.

7.5.4 Conclusion

The findings of this study suggest that young people can fall through the gap due to a mismatch between the type of services available and the type of care young people need after leaving CAMHS. Available services often have high illness thresholds, and there is a lack of communication and joined up care between them. Young people can also fall between AWBS and AMHS, as there is no service provision to meet their mental health needs. Falling through the gap between CAMHS and AMHS can have a negative impact on the wellbeing of both young people and their parents, with young people struggling to manage without professional support and uninterrupted access to medication. In the absence of professional support, many parents take on the responsibility for their child's mental health, which can in turn impact their ability to continue with everyday activities. This study is the first comprehensive investigation of the experiences of young people who have fallen through the gap between CAMHS and AMHS and contributes to our understanding of how falling through the gap can impact both young people and their parents.

7.6 Chapter Summary

This chapter has presented the results of the qualitative interviews with young people and their parents who had fallen through the gap between services. The implications of these results have been discussed, and strengths and weaknesses of the methods identified. These qualitative findings are integrated with the results of the quantitative and health economic analyses in Chapter 8. Further discussion of how these findings relate to existing literature and recommendations resulting from this research are reported in Chapter 9.

Chapter 8: Integrating the Results

8.1 Introduction

This chapter reports the results of the synthesis of findings from the previous studies (a systematic review, a quantitative study, a health economic study, and a qualitative study) in this thesis. This chapter begins with the rationale for this work, followed by a description of the method chosen for synthesising the data in this thesis. The results of data synthesis are then presented in a tabular form.

8.2 Rationale

Using a mixed methods approach and combining findings from quantitative and qualitative research has the advantage of allowing for both broader and more detailed exploration of a research topic (Johnson et al., 2007). Combining results of different methods of data collection is commonly used in health research, as it is a way of understanding a complex issue (Farmer et al., 2006). Using a mixed methods approach was particularly useful in this research project, as it explored the experiences and outcomes of young people who fall through the gap between CAMHS and AMHS, something which we currently do not know much about. Therefore, the complexity of this topic may be missed by simply carrying out a quantitative or qualitative study alone.

The purpose of mixed methods research is to generate findings which are more than the sum of its parts (Molina-Azorin, 2016), therefore it is important not to only conduct studies using different methodologies and add the findings together, but to integrate their results to generate new insights from the data in a higher level analysis (Fetters and Freshwater, 2015). It was therefore decided to integrate the findings from the previous studies in this thesis to generate new insights from the data.

8.3 Method

I chose to synthesise the data from the previous studies in this thesis using the Pillar Integration Process (Johnson et al., 2017). PIP is a method of integrating quantitative and qualitative data using a joint display format (as shown in Figure 16). I chose this method for data synthesis as it allows for synthesis of data which is not from the same participants: we had quantitative data for all participants, but only collected qualitative data from a sub-sample of participants in the UK.

PIP is also aligned with the pragmatic approach to mixed methods research, as its development was underpinned by a subtle realist epistemology (Johnson et al., 2017). This model therefore fits well with the current study, which was underpinned by a pragmatic perspective during design, data collection and analysis.

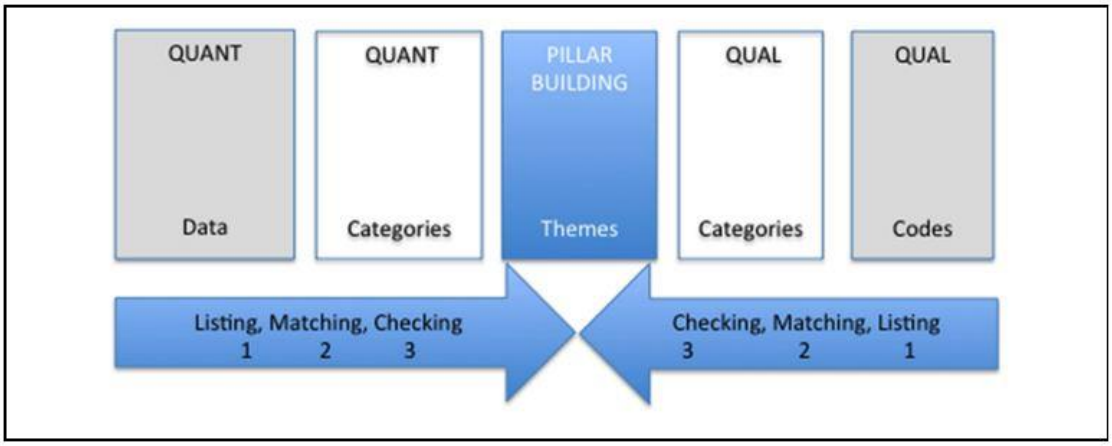

Figure 16 The stages of the Pillar Integration Process. (Reproduced from Johnson et al (2017))

PIP consists of four stages: listing, matching, checking, and pillar-building, starting from the outside column and working inwards towards the central pillar. Each row of the table starts with a piece of data, either quantitative data or qualitative codes. The model allows for listing to start with either the quantitative or qualitative data. Themes are then generated from initial data in the 'categories' column, which are integrated in the 'pillar' column. These pillars can then be used to help generate overall themes and conclusions from both sets of data.

This research used a simultaneous mixed methods design, with both quantitative and qualitative components given equal weight during integration and interpretation of results. Therefore, PIP could have started with either the quantitative or qualitative component. It was decided to start PIP with qualitative data in the first column, with quantitative data matched to the qualitative results, as the qualitative data was extremely rich, therefore had more findings than the quantitative components of this thesis. Qualitative findings were used for data synthesis as opposed to individual codes due to the volume of codes identified during qualitative analysis. The PIP was conducted separately for each of the three research questions:

1) Why do young people with certain diagnoses fall though the transition gap between CAMHS and AMHS?

2) What effect does falling through the gap have on the mental health and functioning of young people and their families?

3) What are the healthcare and societal costs of young people falling through the gap?

For the first question, qualitative findings were matched with the results of the logistic regression which identified predictors of transitioning to explore why young people fall through the gap. For the second research question, qualitative findings were matched with the results of the multilevel regression models to explore effects of falling through the gap. Finally, for the third research question, qualitative findings were matched with the results of the health economic analyses to explore the costs associated with falling through the gap.

8.4 Results

The results of data synthesis for each research question are shown for each research question below.

8.5 Q1: Why do young people with certain diagnoses fall though the transition gap between CAMHS and AMHS?

There were three main themes for why young people fell through the gap between CAMHS and AMHS (see Table 33 for more information). Firstly, young people were not deemed 'ill enough' for continued care, and therefore were unable to access care after CAMHS. This was identified by young people taking part in the qualitative study, who reported being told they did not meet the criteria for adult services, either because their symptoms were not considered severe enough to warrant further care, or because they did not have the appropriate diagnosis to access AMHS. This finding was also identified by the logistic regression, in which being more severely ill, having higher HoNOSCA (indicating poorer mental health) and IDBCS (indicating poor level of independence) scores predicted young people transitioning to AMHS.

Young people also reported falling through the gap as the current service structure did not meet their needs. This was identified by young people and parents during qualitative interviews, who reported a lack of service provision after CAMHS. Some young people described being told they were 'too ill' for wellbeing services, but 'not ill enough' for AMHS. Others were only offered online or group therapy after leaving CAMHS, which they did not believe was suitable for their needs. Young people with complex difficulties struggled to be

accepted by any service, and services were characterised by long waiting lists and infrequent appointments. This finding was corroborated by the quantitative results, which indicated that there were significant country variations between the number of young people falling through the gap and transitioning to AMHS, indicating that the structure of mental health services in a specific country can affect how likely young people are to transition. In particular, the UK was identified as one of the countries where young people were more likely to fall through the gap than transition to AMHS.

Finally, young people reported falling through the gap as their poor experience of mental health care meant that they disengaged from mental health services. This was identified by the qualitative study only, as there were no quantitative measures of engagement with services. Young people reported poor experiences of care in CAMHS which made them reluctant to seek help elsewhere, or experienced repeated rejected referrals which caused them to become disillusioned with the system. Some young people reported dissatisfaction with the frequency of appointments at AMHS and AWBS, or struggled to make progress due to poor continuity of care and seeing different clinicians at each appointment. Some young people were also poorly prepared for CAMHS to end, meaning they did not know where to go to for help after leaving the service.

Table 33 Reasons why young people fell through the gap between CAMHS and AMHS

Qualitative Findings	Qualitative Categories	Pillar Building	Quantitative Categories	Quantitative Findings
Young people 'not being ill enough' for AMHS High eligibility thresholds for AMHS Problems with the use of telephone assessments to determine eligibility Care withdrawn during times of stability Diagnosis 'opening doors' to further care	Not meeting illness threshold for AMHS Eligibility not reliably assessed to determine continued need	Not deemed 'ill enough' for continued care	Only those who are most severely ill are referred to AMHS	Predictors of transitioning: Being severely ill (a score of 6 on the clinician-rated CGI) (OR = 4.32, 95% CI 1.19-15.65) Having a higher HoNOSCA score (OR = 1.06, 95% CI = 1.02-1.10) Having a higher IBDCS score (OR =1.05, 95% CI (1.01-1.09)
Inadequate service provision after CAMHS No help available after CAMHS	Structural barriers which prevent continuity of care	The current service structure does not meet the need of all transition aged young people	Service provision not homogenous across countries studied	Country variation in transition to AMHS, with young people less likely to transition if in:

Problems accessing care if young person has complex difficulties Provision gap between AMHS & AWBS Lack of joined up care between services Long waiting lists for care after CAMHS Barriers to accessing care caused by self-referral			UK amongst those countries less likely to transition YP to AMHS	Italy (OR = 0.15, 95% CI 0.06 – 0.35) the Netherlands (OR =0.32, 95% CI 0.16-0.64) UK (OR = 0.48, 95% CI = 0.25 to 0.91)

Not knowing where to get help for mental health after CAMHS Young people not adequately prepared for CAMHS to end Not receiving appropriate care when in a mental health service Young people put off accessing further care Feeling as though there is no point engaging with care if referrals are rejected	Poorly prepared for transition Disengagement at transition boundary	Poor experience of mental health care impacting continued engagement with mental health services	Not identified	Not identified

8.6 Q2: What effect does falling through the gap have on the mental health and functioning of young people and their families?

Integrating the results from the qualitative study and multilevel modelling identified five themes regarding the effect that falling through the gap has on young people and their parents (see Table 34 for more information). Firstly, both young people and parents reported feeling frustrated by the way the end of care at CAMHS was handled, with several young people reporting feeling abandoned by mental health services. Parents were frustrated as they were left out of decisions about their child's care, which occurred both at the CAMHS transition boundary and later if the young person had contact with AWBS or AMHS. No data to match this finding was identified in the quantitative study as there were no questionnaires regarding experiences and views of care.

The burden of young people falling through the gap is not limited to mental health services. Young people and their parents reported being signposted to A&E or the criminal justice system if they were in crisis after leaving CAMHS. No participants thought either of these services were appropriate for a young person experiencing a mental health crisis. No data to match this finding was identified in the quantitative study as there were no questionnaires regarding experiences and views of care.

Some young people were also struggling to manage without specialist care. In the most serious cases, young people's mental health had deteriorated since leaving CAMHS, and they were unable to continue with their usual activities. For other young people who still experienced problems with their mental health, they found their current needs were not being met by services. No data to match this finding was identified in the quantitative study.

However, although young people identified some problems with their mental health after leaving CAMHS in the qualitative interviews, the quantitative analysis found that there was no overall difference between those who transitioned and fell through the gap in terms of mental health symptom severity. Young people who transitioned showed more impaired functioning over the follow up period than those who fell through the gap, indicating that they were more severely ill. There is no match to this finding as the qualitative study focused only on those who fell through the gap, so no comparisons were available to those who transitioned.

The final theme relates to the parents' role in caring for their children who fall through the gap. Qualitative findings indicate that parents sometimes take on the burden of responsibility for their child's mental health after leaving CAMHS, especially where the young person is not able to access care elsewhere. This occurs even though the young person is legally an adult and may be living away from the family home for university; several of the young people in this study were still reliant on their parents for day to day support. No data to match this finding was identified in the quantitative study as parents were not asked to quantify the time they spent taking care of their child due to their mental health.

Table 34 Effects of falling through the gap between CAMHS and AMHS

Qualitative Findings	Qualitative Categories	Pillar Building	Quantitative Categories	Quantitative Findings
Young people left feeling abandoned and frustrated Having to repeat story to new healthcare professionals each time they start a new service Parents frustrated with poor quality of care Parents left out of decisions about child's care	Frustration at poor care at transition boundary	Poor quality of care at the transition boundary leaves young people and families feeling abandoned by services and frustrated by experience.	Not identified	Not identified
Signposted to the CJS and A&E in the absence of specialist care	Signposted to services other than mental health services	Burden of care not limited to mental health services	Not identified	Not identified
Some young people struggled to manage without specialist support	In need of specialist mental health support	Current needs not being met by services	Not identified	Not identified

Problems receiving medication after CAMHS Unable to obtain medication review after leaving CAMHS	Needs not met by community care/GP			
Not identified	Not identified	Longitudinal functioning poorer for those who transitioned than those who fell through the gap	Young people who transitioned to AMHS more severely ill	Transitioning to AMHS was a predictor of higher ASEBA scores over the course of the study (p=0.03)
Some young people are able to manage their mental health on their own Supportive parents important in absence of professional support Parents taking on active role in young person's care	Managing without professional support, with help from parents	Parents take on burden of responsibility for child's mental health	Not identified	Not identified

8.7 Q3: What are the healthcare and societal costs of young people falling through the gap?

There were five themes identified by integrating findings from the qualitative and health economic studies regarding the healthcare and societal costs of falling through the gap between CAMHS and AMHS (see Table 35 for more information). Firstly, this research identified higher costs for those who were more severely ill. Young people who took part in qualitative interviews reported being told they would be unable to access specialist mental health services unless they were in crisis, and that they did not meet the threshold for care at AMHS. This finding was supported by the health economic analysis, which found that predictors of higher costs were transitioning to AMHS, and previously attempting suicide (indicating higher illness severity). As young people who transitioned received more mental health care than those who fell through the gap, this resulted in higher healthcare costs.

In contrast, those who fell through the gap reported struggling to find services which met their needs. This leads to the second theme – a care gap after CAMHS in which there is no available care to meet the needs of young people. The matched finding from the health economic study is that there was a decrease in resource use after T1 (the time when most young people would have left CAMHS), as total community care costs, inpatient costs, outpatient costs and GP costs fell sharply between T1 and T2.

A related theme is that young people were often not accessing any further care after CAMHS. Some young people who took part in the qualitative study reported not being able to receive any support in the years after leaving CAMHS, despite trying to access it. Other young people had decided they did not want to access further mental health care and were able to manage their mental health well on their own, or with the help of their parents. This finding was also supported by the health economic study, which found that after the drop off in resource use after T1, levels of resource use did not rise to same level again throughout the two year follow up period.

There were also personal and societal economic impacts associated with falling through the gap, although these were harder to measure in terms of cost. Around a third of young people who fell through the gap reported taking time off work or study due to ill health. In some cases, poor mental health had had a significant impact on their ability to work or study. Some young people were not in education, employment or training at the time of interview, and reported they had had to drop out of education or work due to their poor mental health.

Finally, costs were lower for those who fell through the gap than those who transitioned to AMHS, potentially due to the impact of informal care in the absence of specialist services. This finding can be explained by qualitative data, which found that parents provided significant amounts of emotional support for their child after leaving CAMHS, in some cases replacing role of healthcare professional and acting as 'Doctor' themselves.

Table 35 The healthcare and societal costs of falling through the gap

Qualitative Findings	Qualitative Categories	Pillar Building	Quantitative Categories	Quantitative Findings
Young people not ill enough to access care at AMHS Only able to access care during crisis Inadequate service provision after CAMHS Gap between AMHS and AWBS	Unable to access specialist mental health care after CAMHS unless severely ill	Higher costs for those who are more severely ill	Young people who transition & are more severely ill are more likely to have higher healthcare costs	Predictors of higher total healthcare costs were: Transitioning to AMHS ($p<0.01$) Previously attempting suicide ($p<0.01$)
Lack of joined up care between services Inadequate service provision	Gap between CAMHS and being able to access other mental health care	Care gap after CAMHS: care not meeting need or no available care	Lower intensity of mental health care after leaving CAMHS	Drop off in resource use after T1: Total community care costs, inpatient costs, outpatient costs and GP costs fell sharply after T1 (when most young people would have left CAMHS)

Young people still without support over two years after leaving CAMHS, despite repeated attempt to access help No point engaging if referrals rejected Some managing okay with help from parents	Not able to access care after CAMHS Not trying to access further care after CAMHS	Not accessing further care after CAMHS	Young people not accessing care after leaving CAMHS	Drop off in resource use after T1 for those who fell through the gap, and did not rise to same level again throughout data collection
Young people dropped out of education or work due to poor mental health	Struggling to manage illness without professional support	Economic impacts of poor mental health	Not able to continue with usual activities due to poor mental health	Time off work or study due to ill health (around 30% after leaving CAMHS)
Parents take on active role in young person's care Parent's taking on role of 'Doctor'	Parent replacing role of healthcare professional	Lower costs due to informal care	Lower healthcare costs for those who fell through the gap	Lower healthcare costs for those who fell through the gap than those who transitioned

Importance of supportive family for young people who fall through the gap				

8.8 Discussion

The results of the data synthesis will be discussed in detail in Chapter 9 in relation to existing literature, alongside the implications of the results of this study for future research, clinical practice, and healthcare policy.

8.8.1 Strengths and Limitations

The main strength of this study is that integrating data from different methods allows for a deeper interpretation of findings. Through using PIP, I was able to make links between the qualitative and quantitative data which I had not previously identified. For example, I had not previously considered the link between parents taking on the role of 'Doctor' and the lower healthcare costs for those who fell through the gap than those who transitioned. This could be particularly relevant when considered in terms of the wider cost savings due to informal care in the UK: McCrone et al (2008) estimate that by 2026, the costs of informal care due to mental illness will be higher than costs to the NHS. This example illustrates the wider advantage of mixed methods research: through integrating the results of different methods of data collection, the result is something greater than the sum of its parts (Fetters and Freshwater, 2015).

A strength of PIP is the use of a joint display method which allows patterns in the data to be easily identified. For example, it is clear where there are quantitative findings which relate to findings from the qualitative research, and where there are findings with no corresponding data.

However, it is important to acknowledge some limitations in this research when interpreting the results. Firstly, the quantitative data was from seven different European countries, whereas the qualitative data was collected only in the UK. Therefore, this may have resulted in a slight UK bias to interpreting the quantitative results. It was also clear from integrating the data regarding the second research question that any mental health or functioning effects of falling through the gap were less severe than the long-term mental health and functioning impairments of the young people who transitioned. It was therefore difficult to integrate the data from these two studies, in particular as the qualitative study did not include a 'comparator' group to allow matching of qualitative and quantitative data from young people who transitioned. However, the richness of the qualitative data means that this thesis is still able to answer all research questions.

8.9 Chapter Summary

This chapter presented the methods and results of a mixed methods synthesis of the findings from the four previous studies in this thesis. The next chapter discusses the findings from this synthesis in relation to existing literature, and reports recommendations for research, policy and clinical practice based on these results.

Chapter 9: Discussion

9.1 Introduction

This chapter summarises the main findings of this thesis and discusses them in relation to existing literature. It also presents the strengths and limitations of the research, as well as future research directions. Finally, it presents recommendations for policy and clinical practice and outlines the contributions of this thesis to the field.

9.2 Summary and Discussion of findings

This thesis comprises a systematic review and a mixed methods study exploring why young people fall through the gap between CAMHS and AMHS, and what effect falling through the gap has on young people and their families. I also explored the costs associated with transitioning to AMHS versus falling through the gap. This research focused on young people who had a diagnosis of a neurodevelopmental disorder, an anxiety or depressive disorder, or a personality disorder, as previous research has indicated young people with these diagnoses may be more likely to fall through the gap. Young people who have not transitioned to AMHS are underrepresented in existing transition literature as they are hard to recruit (as they are not receiving care in a mental health service), and there is little evidence to explore what happens to them after leaving CAMHS. Additionally, despite some evidence suggesting cost-effectiveness in investing in transition services for young people (Barr et al., 2017), there has been no detailed investigation to compare the costs of transitioning to AMHS with falling through the gap between services. This thesis addresses these gaps in the literature.

I will present a summary and discussion of the main findings for each research question in turn.

9.2.1 Q1: Why do young people with certain diagnoses fall though the transition gap between CAMHS and AMHS?

9.2.1.1 Not being 'ill enough' for continued care

The main reason young people fell through the gap between CAMHS and AMHS appeared to be due to not being deemed 'ill enough' to access continued care. Young people and parents who took part in qualitative interviews commonly reported being told that they were not ill enough to meet the threshold for care at AMHS, despite still wanting to access mental health care after CAMHS. This finding is corroborated by the results from the quantitative analysis, as predictors of transitioning to AMHS were a) being rated by their CAMHS clinician as being severely ill, or b) having higher HoNOSCA or IBDCS scores, which indicate more severe symptoms. Young people not meeting the

threshold for care at AMHS is a commonly reported barrier to continuity of care, with several studies identifying the high threshold for care at AMHS as one of the main problems faced by young people and their parents as they cross the transition boundary (Jivanjee and Kruzich, 2011, Street et al., 2018, Price et al., 2018). The difference in eligibility criteria between CAMHS and AMHS can be explained by the different service models between the two services: CAMHS often offer more holistic care and focus on less severe mental illness, whereas AMHS has a focus on more severe mental illness, with a biomedical approach to care (Vyas et al., 2015, McLaren et al., 2013, McGorry, 2007). The fact that AMHS focuses on more severe and enduring mental illnesses could explain why the numbers transitioning in this study were relatively low, as the sample had a diagnosis of a disorder identified by previous research as most likely to fall through the gap.

Young people and parents raised concerns over how their needs for continuing treatment were assessed in AMHS or AWBS. A telephone assessment often caused anxiety or distress for young people who did not like speaking over the telephone and this method was also criticised for being too short to adequately assess a young person's mental health needs. This raises ethical concerns regarding the method of assessment as it occurred outside of a clinical setting, with no support in place. There is little published data on the acceptability of telephone assessments in mental health services, however research has indicated that assessment using standardised scales gives the same results in face or over the telephone, despite a strong patient preference for face to face assessment (Evans et al., 2004). IAPT clinicians have also expressed concerns about how to manage risk over the phone and pick up non-verbal cues (Jones et al., 2013). However, some advantages to this method were identified, including increased accessibility of the service as patients do not have to take time off work to attend an appointment, or for those who are too anxious to attend in person (Jones et al., 2013). Therefore, it may be best to offer patients a choice of face to face or in person appointments to assess their eligibility at that service.

The assessment for continued care after leaving CAMHS often did not take into consideration important concurrent life events, or the variability in the nature of the young person's symptoms. There were several young people in the qualitative study in which CAMHS care had ended abruptly at the age cut-off point with little account for their personal circumstances. This is a systemic failing and is in contradiction to NICE guidelines, which state that transition should occur at a time which is suitable for the young person, taking into account their current life circumstances (NICE, 2017). Participants also reported that care was often withdrawn at a time of stability, but with no easy access to support if the young person's mental health worsened. Schrader and Reid (2017) propose a service model which includes close monitoring of young people who leave CAMHS, with rapid access back into mental health services should be possible if their symptoms worsen. This would have

alleviated the anxiety of some of the participants who took part in the qualitative study, who reported concerns when CAMHS ended about how they would access further support if their mental health deteriorated after leaving the service.

9.2.1.2 Current service structure not meeting young people's mental health needs

Another reason young people in this study fell through the gap after leaving CAMHS is inadequate service provision for over 18-year olds. Some participants in the qualitative study reported not being able to transition, as in some Trusts there were no AMHS which the young person could be referred to after CAMHS, and there were no other forms of care available. Young people in Italy, the Netherlands, and the UK were more likely to fall through the gap than transition to AMHS, highlighting variation between countries. This reflects the disparity in the funding and delivery of CAMHS across different European countries (Signorini et al., 2017). Previous studies corroborate these findings, with research conducted in the UK indicating that most young people do not transition to AMHS (Singh et al., 2010, Ogundele, 2013, Memarzia et al., 2015). Research in Italy has also found that a small number of young people transition to AMHS, likely due to the structure of services and AMHS taking only the most severe cases (Stagi et al., 2015, Reale et al., 2015).

Accessing appropriate care is often more difficult for young people with complex difficulties. The young person in the qualitative study with ADHD, depression, and alcohol addiction was unable to access any support for his depression until he stopped drinking, but alcohol was one of the methods used to cope with the depression. This problem of fragmented services and strict eligibility criteria has been identified in the transition literature, with young people referred to separate services for substance abuse and mental health problems, despite wanting a more holistic approach to their care (Ådnanes and Steihaug, 2016). A lack of accountability, with individual services not wanting to take responsibility for a young person's care has been identified as a significant challenge for young people with complex needs, and was highlighted as a priority for reform in the 2015 Future in Mind report (Department of Health, 2015).

This study was also the first to identify a group of young people who have poor continuity of care at the transition boundary as they are 'not ill enough' to access care at AMHS but were 'too ill' for AWBS such as IAPT or health and wellbeing teams. One young person was signposted to an AWBS but was turned down because she was too much of a risk due to her CAMHS history. This group of young people who fall between AMHS and AWBS have been mentioned in a recent report by the Kings Fund on mental health in primary care networks (Naylor et al., 2020). Further research needs to be conducted to identify how the needs of these young people can be best met by mental health services – this will be discussed further in Section 9.5 below.

Lack of joined up care between CAMHS and other mental health services, and between AMHS and AWBS was a common dilemma. Information was rarely shared between services, meaning young people had to repeat their story each time they made contact with a new service. Similar frustrations at having to repeat their story has been identified by several other qualitative studies exploring young people's experience of accessing mental health care after CAMHS (Street et al., 2018, Broad et al., 2017), which can in turn negatively impact motivation to improve mental health (Lockertsen et al., 2020a).

9.2.1.3 Poor experiences of mental health care negatively impacting engagement with services

Poor experiences of care in CAMHS, especially due to a high turnover of clinicians or disorganisation, left some young people reluctant to seek further care elsewhere. CAMHS were also criticised by some participants for being too reliant on medication and 'not getting to the root of the problem'. As a result, some young people were still unwell when they reached the transition boundary despite several years at CAMHS, but not ill enough for AMHS. Poor quality of care at CAMHS leading to young people falling through the gap is a novel finding from this study and should be explored further in future research.

Some young people were also poorly prepared for CAMHS to end and so were not aware of alternative places of support. Other studies have also reported poor preparation resulting in young people feeling anxious and uncertain about where to receive further care (Dunn, 2017, Care Quality Commission, 2014, Cleverley et al., 2020, Lockertsen et al., 2020a), illustrating the importance of successful preparation at the end of CAMHS. Existing research has attributed this poor preparation to a reluctance by clinicians to discuss transition early due to uncertainty about who will need to transition, the availability of services, and when the discussion should take place (Schraeder et al., 2019). In contrast, those who were well prepared for CAMHS to end had more confidence in their ability to manage their mental health alone or with support from family, as they had been given coping strategies and information about other services they could contact if they needed further support. This finding is supported by previous research which suggests that young people who are well prepared before leaving children's services show increased transition readiness and feel more positive about the transition process (Syverson et al., 2016).

Young people in the qualitative study also reported negative experiences of accessing AWBS after CAMHS. These services were often criticised for being disorganised, with appointments regularly cancelled or changed at the last minute. Continuity of care was also poor, as young people often did not see the same clinician each time. A small number of young people had also been referred to

AMHS, but experienced long waiting lists and infrequent appointments, which were often only to renew their prescription rather than including talking therapy. These are not rare occurrences, with several other studies reporting young people experiencing similar problems when referred to AMHS (Butterworth et al., 2017, Hovish et al., 2012, van der Kamp, 2018). Several young people I spoke to were disillusioned with mental health services and put off from seeking further support. Having a referral rejected made them feel worse so they avoided trying to access care at all in order to not feel let down, something also identified by other research (Street et al., 2018).

9.2.2 Q2: What effect does falling through the gap have on the mental health and functioning of young people and their families?

9.2.2.1 Problems accessing appropriate care

The findings of my systematic review indicated a paucity of current literature regarding the mental health outcomes of young people after leaving CAMHS. Only 13 studies were identified, all of which focused on young people's service use outcomes. One study included information about mental health, but this data was not in an extractable form. Whilst it is therefore difficult to draw conclusions about the mental health and functioning impacts of falling through the gap from this piece of work, there was evidence that some young people experienced significant disruption to their care during the transition period. Some young people were not referred to AMHS despite having a clinical need, whilst only a small number of participants experienced an optimal transition to AMHS. All the studies which explored the average waiting times to access care at AMHS found that young people experienced long delays, ranging from 55-110 days. Collating the results of previous research identified that only around a quarter of young people transition to AMHS, suggesting the need for other sources of support.

The qualitative study showed that falling through the gap had overwhelmingly negative impacts on both the young person and their parents. Both young people and parents reported frustrations at the poor transition process, for example not being informed why they did not meet the threshold for care at AMHS, as well as feelings of abandonment after care at CAMHS ended. Young people described feeling let down and as though no one cared about them, something also identified in other studies into transition experiences (e.g. Butterworth et al., 2017, Dunn, 2017, Lockertsen et al., 2020a).

Some of the young people in this study had problems accessing their medication after leaving CAMHS, a finding which has also been identified in other studies (Price et al., 2018, Newlove-Delgado et al., 2018a). A novel finding was that young people who remained on medication also experienced problems. Several young people had not had their medication reviewed in the years

since leaving CAMHS, leaving them unsure as to whether they were taking the correct dosage, or in some cases whether they needed to be taking medication at all. This finding mirrors that of a recent study in which GPs described a reluctance to prescribe specialist medication to young people with ADHD discharged from CAMHS without input from AMHS (Newlove-Delgado et al., 2019). However, there is a lack of research into GPs experiences of prescribing for other common mental health conditions.

9.2.2.2 Impacts of falling through the gap on parents

Parents often reported being left out of decisions and meetings regarding transition as the young person was legally an adult, which left them feeling in the dark about decisions on their child's care. Similar experiences have been reported by parents in other studies (Jivanjee et al., 2009, Hovish et al., 2012, Reale et al., 2015) and by clinicians, who stated that there was often a lack of time to involve parents in AMHS, which could lead to parents losing trust in mental health services (Lockertsen et al., 2020b). This finding is despite NICE transition guidance stating that transition should involve the young person's family if appropriate (NICE, 2017). However, the qualitative study found that at the same time as being excluded from their child's care, parents were having to step up and fill the gap once care at CAMHS ended. A novel finding is that in the absence of specialist mental health care, parents took on the role of 'Doctor' themselves to try and help support their child. This ranged from helping push for access at other mental health services and initiating contact with healthcare professionals (such as counsellors, GPs, or university mental health services), to taking part in 'self-help' CBT-style programmes with their child to improve their symptoms. This occurred despite the young person being an adult; most were still reliant on their parents for support. In the most serious cases, young people reported their parents helped to wean them off their medication, as they were not able to access another prescription after leaving CAMHS.

9.2.2.3 Mental health impacts of falling through the gap

A few of the young people in the qualitative study were able to manage their mental health well on their own or with the support of their family at the time of interview. However, some of the young people were struggling to manage their mental health without any professional support. This finding is echoed by another study which focused on young people with anorexia nervosa, in which participants who experienced a poor transition reported subsequent negative effects on their mental health (Cleverley et al., 2020). In the most serious cases in the present study, young people had dropped out of education or training, and in one case a young man was confined to his house due to his poor mental health.

However, the results of the longitudinal study suggest that falling through the gap does not lead on average to young people having poorer mental health or functioning than those who transitioned to AMHS. Longitudinal HoNOSCA scores between the two groups were the same when controlling for illness severity and other covariates including diagnosis, gender, age, ethnicity, length of time at CAMHS, or previously attempting suicide. A difference was however identified in longitudinal ASEBA scores, with those who transitioned showing significantly higher scores than those who fell through the gap, indicating poorer functioning for those who transitioned even after controlling for baseline differences. This result could be explained by the fact that young people who transitioned to AMHS were rated as being more severely ill at baseline than those who fell through the gap, most likely due to more chronic or complex mental illnesses. As this research focused only on those with diagnoses which were most likely to fall through the gap, those who transitioned may have been significantly more ill than those who did not. It could also be explained by poor continuity of care experienced by both those who fell though the gap and those who transitioned: previous research has found young people struggle with long waiting lists to access AMHS (Hovish et al., 2012, Butterworth et al., 2017) and infrequent appointments (van der Kamp, 2018, Merrick et al., 2020). AMHS have also been criticised for being too reliant on medication (Cheung et al., 2015, Matheson et al., 2013). Therefore, although we did not collect data regarding the quality of transition, young people who transitioned to AMHS may have also experienced discontinuity of care, or dissatisfaction with care after leaving CAMHS. Therefore, although this group received some form of mental health support, they still had poorer functioning than young people who fell through the gap.

9.2.3 Q3: What are the healthcare and societal costs of young people falling through the gap?

9.2.3.1 Comparing costs and resource use

The results of the economic analysis indicated that there are higher costs for young people who transition to AMHS compared to those who fall through the gap. This finding makes logical sense, as those who transition are more likely to use services, which therefore results in higher costs. This result was supported by the findings from the qualitative study, as several young people reported being unable to access specialist mental health care because they were not ill enough to meet the threshold for services.

Findings from both the economic and qualitative studies indicate that young people who fell through the gap were unable to access any mental health care in the years after leaving CAMHS. Analysing resource use showed a significant drop off in service use after T1, in which total community care costs, inpatient costs, outpatient costs and GP costs fell sharply after T1 (when most young people

would have left CAMHS). Young people reported being unable to find any services which met their mental health needs. In the absence of NHS involvement, some reported accessing private care at significant costs to them and their families. The lower intensity of mental health service use coupled with the qualitative findings for those who fell through the gap suggests young people who do not transition to AMHS struggle to access any mental health support. This care gap should be urgently addressed by future research and mental health policy (for a more detailed discussion, see Section 9.6 below).

9.2.3.2 The economic costs of falling through the gap

However, findings from the qualitative study indicated that although the costs of falling through the gap are lower than for those who transition, there are other individual and societal costs associated with falling through the gap. Six young people in the qualitative study had dropped out of education or post-education training due to their poor mental health. Around a fifth of the young people were not in education, employment, or training at the time of interview. The economic study found that the percentage of participants who took time off work or study was higher in the group that transitioned; nevertheless, in each of the follow up time points, around a third of young people who fell through the gap reported taking time off work or study due to their poor mental health. Therefore, for a third of young people who fell through the gap, their poor mental health negatively impacted their productivity. This finding is corroborated by the results of a recent Australian study which found productivity costs mode up the majority of the total financial costs of ADHD (Sciberras et al., 2020), one of the diagnostic groups included in this thesis. Whilst there is currently a paucity of literature exploring the financial impact of transition from CAMHS (especially in the UK and Europe), initial evidence suggests that transition can result in a financial burden for young people and their families (Barr et al., 2017).

There is therefore an economic argument for increasing the availability of mental health services to those who need them. Expanding existing service availability in order to reduce the numbers not receiving treatment is likely to result in net savings, due to higher costs recouped through increased employment than spent on services (McCrone et al., 2008). Interventions to improve the mental health and wellbeing of children and adolescents have also consistently been shown to result in a net benefit to society, regardless of the moral imperative of investing in the mental health of the young (McDaid et al., 2019). It is also possible that improving a child's mental health will improve the mental health and productivity of their parents, for example through less absenteeism and improved parental mental health. These findings regarding the cost-benefits of improved access to mental health care are particularly relevant when considering that the total cost of mental illness caused by

lost employment has been projected to rise to £28.1 billion by 2026 in England alone (McCrone et al., 2008).

The costs of mental illness affect not only the person experiencing mental health problems, but also those closest to them. Child mental health can also have substantial spillover effects on the health-related quality of life of their parents (Brown et al., 2019). In the absence of specialist mental health support, parents reported taking on a significant amount of responsibility for their child's care. In some cases, this meant providing regular (sometimes daily) emotional support, beyond what they would do in a usual parent-child relationship. Some parents went further than this: in a stand-in 'Doctor' role they researched their child's symptoms and potential treatments, helping to provide self-help therapy programmes, or in more serious cases, weaning their child off their medication due to a sudden withdrawal of all support. The costs of informal care are hard to measure due to a lack of standardisation (Van den Berg et al., 2004) and are therefore missing from the current health economic analysis. To our knowledge, there are no current figures linked to the costs of informal care in young people's mental health. However, costs to the family have been identified to include time off work and reduced productivity, as well as the psychological burden of caring for someone with poor mental health (Suhrcke et al., 2008).

9.3 Strengths and Limitations

The strengths and limitations of each study are presented in their corresponding chapters. This section therefore explores the strengths and limitations of the thesis as a whole.

A strength of this thesis is that it answered all research questions and completed the aims of all studies. The qualitative study is unique compared to other research as I was able to recruit and interview young people who had fallen through the gap between CAMHS and AMHS – a group who are hard to recruit as they are often not receiving any mental health care. This therefore allowed me to conduct the first transition study, to my knowledge, which has focused only on young people who have fallen through the gap and explore their long-term experiences in the years after leaving CAMHS.

The use of a mixed methods study design allowed for the research questions to be explored with the breadth of quantitative research, but the depth of qualitative research. This resulted in a more detailed exploration of the problems than if a single method had been used alone. The results of the individual studies were also integrated to allow for new insights to be generated from the findings.

The interview data was extremely rich, allowing for in depth analysis of the experiences of young people and parents who fell through the gap between CAMHS and AMHS.

It is important to acknowledge some potential limitations of the MILESTONE dataset used in this thesis. Firstly, no data was collected on young people who declined to take part in the wider study, meaning that there may have been some differences between those who consented and those who declined to take part. This, coupled with the fact that clinicians screened potential participants for those well enough to take part, may have resulted in selection bias (Tripepi et al., 2010), with young people less seriously ill at the time of recruitment more likely to take part.

MILESTONE used self-report data from young people and parents, which is also susceptible to bias, for example through poor recall or participants wanting to give socially desirable responses. Social desirability response bias could be particularly prevalent in this study, as several questionnaires asked personal questions about the young person's mental health, contacts with criminal justice system, and family situations. Research has suggested there is an increased likelihood of socially desirable reporting for questionnaires which measure items with a high social value (Van de Mortel, 2008). This bias could also potentially have affected the qualitative interview data, with participants showing reluctance to talk about certain problems such as addiction. It is possible that the qualitative data was biased towards those who had extremely good or extremely bad experiences of transition rather than those with an average experience, as participants seemed keen to tell their stories.

There were also some limitations within the MILESTONE dataset. The data on medication use was of poor quality, meaning I was unable to include it in the cost analysis. There was also no quantitative data on the effect that falling through the gap has on parents, which would have been useful for the mixed methods analysis and data synthesis. By T4, there were reasonably high amounts of missing data (up to 28% in the health economic study), which was also not necessarily missing at random as young people missed data collection if they were too unwell to participate. This could lead to an underreporting of mental states, with health-related quality of life scores biased upwards. Clinical need was also calculated using HoNOSCA scores, as this was the primary outcome measure used in MILESTONE. However, it may not have been the most appropriate measure to do so, as the economic analysis found that EQ5D scores predicted costs more accurately than HoNOSCA scores.

Finally, this thesis focused only on young people who had a diagnosis of an anxiety or depressive disorder, neurodevelopmental disorders, or personality disorders, yet the number of those with the latter diagnosis was small. Young people with a personality disorder may be underrepresented in this sample as clinicians are often reluctant to give this diagnosis to someone under the age of 18

(Larrivée, 2013), and this study used baseline diagnoses from when the participants were still at CAMHS. Two of the qualitative study participants reported that their CAMHS diagnosis of depression changed to personality disorder when they had some contact with AMHS. Taking these findings into account, it is difficult to generalise the current findings to other young people with a personality disorder.

9.4 Reflections

Conducting a mixed methods study for my PhD has been an enjoyable and challenging experience. I initially struggled with the individual nature of a PhD, having been used to working as part of a large international research team. However, over the course of the process of conducting this research I feel I have been able to grow as a researcher, both in terms of skills and confidence in my abilities.

The most rewarding part of the PhD was conducting the qualitative interviews with young people and their parents. It was eye-opening to hear their stories even though at times they were hard to listen to, especially when participants described the consequences of not being able to access appropriate mental health support. I found keeping a reflexive diary extremely useful during the process of conducting and analysing these interviews, as it gave me a place to record the thoughts and emotions generated during data collection. I am extremely grateful to my participants for giving up their time to tell me their stories and am glad that in some cases, being able to recount their experience was helpful to them, as it was often the first time they had been able to talk to someone about what had happened since leaving CAMHS. During recruitment I was surprised by the number of positive responses to my initial invitation letter and did not need to approach all the potential participants to meet my recruitment target. Reflecting on this now, it is clear that due to the nature of the topic participants were keen to tell someone about their experiences as they had been unable to access appropriate support for their mental health. Several participants mentioned altruistic motivations for taking part, hoping that telling someone their experiences would result in other people having a more positive experience than they did. I hope I have presented a faithful account of their experiences and will continue to work to ensure the findings from this research can generate improvements in mental health care for young people.

Although I had previous experience with conducting and analysing qualitative research, quantitative and health economic analyses were less familiar to me. To improve my knowledge of these methodologies I attended Statistics and Health Economics courses at Warwick Medical School, which I found extremely useful. I am grateful for the support of my supervisors in helping me overcome challenges in the analysis of the quantitative data. There were also some compromises I had to make in my study design as I was working with an existing data set. If I were to conduct this study again I

would alter some of the measures used, for example including a more objective measure of clinical need and adding specific questions about mental health service use after leaving CAMHS. However, I am extremely grateful for the opportunity to be able to conduct a PhD which is linked to a large international project, as this allowed for access to data above what would have been feasible to collect as a lone researcher.

9.5 Implications for future research

There are several implications of the results of this thesis for future research. Firstly, the systematic review identified a lack of existing research into the mental health outcomes of young people after leaving CAMHS. The results of the longitudinal cohort study within MILESTONE will be the first study outside of the thesis to explore the long-term mental health outcomes of young people associated with different transition outcomes. However, there is scope for other research to be conducted across different settings to corroborate these findings.

As young people were often referred back to their GP after leaving CAMHS (sometimes with little or no preparation or handover of care to the GP), an idea for future research is to test interventions which improve this handover of care and increase the ability of GPs to manage young people with mental health problems. Young people in the qualitative study had mixed satisfaction with mental health support from their GP, therefore there is potential for work to be done to upskill GPs to support young people who do not meet the threshold for AMHS but still require medication or occasional mental health support. Research into how GPs can best help meet the needs of those who fall between the gap of IAPT and AMHS in terms of illness severity has also been identified as a priority for future policy initiatives in a recent report by The Kings Fund and the Centre for Mental Health (Naylor et al., 2020), therefore further research in this area is warranted.

This thesis identified a group of young people who were not deemed ill enough to transition to AMHS but who were also too ill for AWBS such as IAPT. The needs of this group of young people were unmet at the time of interview and they were in urgent need of support. As this finding was identified by the qualitative study, further quantitative research is needed to explore the extent of the problem and how many young people fall between these services. There is also an urgent need for research on the type of service that could best meet the needs of these young people, whether in primary care or elsewhere.

There is also the potential for technological approaches to improve transition, as preliminary research has indicated that digital communication can improve some of the boundaries to continuity of care at the transition boundary. Martin et al (2020) examined qualitative data exploring barriers

and facilitators of the transition to AMHS and found that digital communication could improve clinician-service user relationships, access to services, young person's autonomy and patient safety. Although trials are needed in this area to assess the benefits to young people's mental health and engagement with services (as well as assessing the health economic impact), enhancing digital communications at the transition boundary could have clear benefits. For example, young people who are not referred to AMHS could stay in touch with a healthcare professional, either at CAMHS or at their primary care network to help reduce feelings of abandonment after leaving CAMHS.

Technology could also aide continuity of care through the use of digital 'transition passports' for young people. The use of transition passports has previously been identified by service users as a method of improving continuity of care, and preventing young people having to repeat their story every time they see a new healthcare professional (NHS England, 2015). Young people can choose what information to include in their passport, such as a summary of their mental illness, history, or preferences, which can be sent to clinicians digitally or on paper. As one of the main frustrations identified by the qualitative study participants was having to repeat their story to several different clinicians, a digital transition passport could have the potential to improve continuity of care and help the young person create a relationship with a new healthcare professional. Further research is needed to explore how digital transition passports can be best used to improve transition experiences and outcomes for young people.

Finally, it was difficult to assess the wider societal costs of falling through the gap in this current study. Future research could explore what impacts poor mental health has had on transition age youth (e.g. dropping out of college, not doing well in exams or not feeling well enough to go to university – all things mentioned in this qualitative study) and the associated societal costs. This research could provide a strong rationale for increasing the amount of funding available to improve mental health care for young people.

9.6 Recommendations for clinical practice & policy

I have chosen the below recommendations for clinical practice and policy based on the findings from this thesis. In particular, these recommendations are aimed to bridge the gap in need identified in some of the studies included in my systematic review and in my quantitative, resource use, and qualitative findings that several young people who fall through the gap struggle to access appropriate support for their mental health after leaving CAMHS. They are also designed to make sure the needs of parents are also taken into account at the transition boundary, as these were identified in my qualitative analysis as factors which caused parental anxiety. I have also chosen to include recommendations regarding medication and the use of telephone assessments which were

identified as significant problems for young people during the qualitative interview study. It should be noted that as these recommendations mainly derive from my qualitative findings (due to the richness of the data and number of findings compared to the other components of this thesis), further quantitative research or patient and public involvement (PPI) involving service users, staff and parent/carers, should be conducted to determine both the validity and priorities to be given to these recommendations.

The following recommendations for clinical practice and transition policy have been developed from the findings from this thesis:

1. The NICE guidance (2017) regarding a flexible age boundary should be enforced, to ensure that young people leave CAMHS at a time that is most suitable for them. In particular, leaving CAMHS should occur at a time of stability, whilst taking into account the transient nature of some mental health problems. If a young person is at risk of their symptoms worsening again, this should be taken into account when they leave CAMHS.

Rationale: This recommendation is based on the findings from my qualitative study, in which several participants were discharged from CAMHS at their 18th birthday, regardless of their current circumstances or stage in treatment, which had a detrimental impact on their mental health. However, this practice is in contradiction to the recent NICE guidance on transition, therefore it is important that guidance is followed correctly.

2. There should be a gradual reduction of support if no transition will be made to AMHS, rather than a sudden cut-off from care at CAMHS. A direct link back to CAMHS within six months after discharge may help to alleviate young people's and their parents' anxiety. If a young person's mental health did start to deteriorate, a direct referral could be made to AMHS, without young people having to go back to their GP and join a long waiting list for care.

Rationale: This recommendation is based on the findings from my qualitative study, particularly from interviews with parents. It was clear that the end of CAMHS caused considerable anxiety for young people and their parents, and a direct route back into care would alleviate some of this anxiety (see 7.4.2.2). The ability for a direct link back to CAMHS would also have helped some of the participants in my qualitative study who required further support but were struggling to access it. My health economics study also indicated a dramatic drop-off in contacts with services after young people left CAMHS (see 6.5.3), something which could also be reduced through a direct link back to CAMHS. Complex service use pathways (from CAMHS to GP to

AMHS) were also mentioned by studies included in my systematic review (4.5.4). A direct link to CAMHS for a referral elsewhere would help to improve continuity of care for young people at the transition boundary.

3. Parents should be involved in the transition decision and informed about their child's care (providing the young person consents to parental involvement). Parents should be provided more help and guidance in the transition phase in order to be better prepared if their child is not transitioned to adult services. Parents should also be given information about services they can contact if their child's mental health deteriorates.

Rationale: Again, this recommendation is based on the findings from my qualitative study, in which parents reported feeling excluded from decisions around their child's care (see 7.4.2.2). Parents had to provide care for their child once CAMHS ended and were often instrumental in trying to find other sources of care their child could access.

4. Young people should be adequately prepared for care at CAMHS to end and given strategies for self-management and advice on who they can contact if they require mental health support. This should be more than simply providing young people with a leaflet or a link to a website, it needs to be tailored to that individual, their mental health, and current circumstances.

Rationale: This recommendation is based on the finding from my qualitative study that young people did not feel adequately prepared to leave CAMHS, and were therefore unsure about how to access further support if needed (see section 7.4.2.1). This may also help reduce the reduction in service use contacts identified in the health economic study (6.5.3).

5. A medication continuation plan should be discussed with young people prior to leaving CAMHS. GPs should not be required to prescribe specialist medication without a shared care arrangement from specialist services, to ensure that young people do not have to suddenly stop medication after leaving CAMHS. A shared care arrangement would also mean young people are still able to access medication reviews and assess whether medication is still necessary after leaving CAMHS.

Rationale: All the participants who were in my qualitative study had problems with their medication after leaving CAMHS (see 7.4.2.2). This also links with the finding from my health

economic study that young people who fell through the gap experienced a dramatic reduction in contact with mental health services after leaving CAMHS (6.5.3), which in turn may have impacted their ability to speak to a specialist about their medication.

6. Telephone assessments should not be routinely used to assess clinical need, unless a preference for remote assessment is indicated by the patient. Assessments should take place face to face where possible, and any explanation for why a young person did not meet the eligibility threshold for care at that service should also occur in person.

Rationale: The use of telephone assessments was discussed by several participants in my qualitative study, with no participants reporting a positive experience (see section 7.4.2.1). Several participants had anxiety which made it difficult for them to speak over the phone. I therefore felt it was important to give service users the choice as to whether assessments take place in person or over the telephone.

7. Services should be structured to ensure that the needs of all young people are met. There needs to be a reform of the current system to allow for services tailored to the mental health needs of young people who are too ill for AWBS but not ill enough to meet the threshold at AMHS.

Rationale: This recommendation is designed to meet the gaps in service provision identified by the findings from my systematic review (4.5.4), the reduction in service use for those who fell through the gap indicated by my health economic study (6.5.3), and the needs of young people identified in the qualitative interview study (7.4.2).

9.7 Conclusion

Overall, this thesis has made a substantial contribution to knowledge as it has addressed gaps in existing literature regarding the service use and mental health outcomes after falling through the service gap, and the costs associated with falling through the gap or transitioning to AMHS. It has also built upon the existing literature regarding why young people fall through the care gap between CAMHS and AMHS, with reasons including young people not being viewed as 'ill enough' to access care at AMHS and a lack of alternative service provision that meets their needs. Poor experiences of transitional care were common, which could also lead to young people disengaging from mental health services.

This thesis features the first systematic review of service use outcomes of young people after reaching the CAMHS age boundary, which found that around a quarter of young people transition to AMHS. The majority of young people do not continue care in adult services and may instead experience multiple service transitions in a short space of time. Existing findings regarding the mental health outcomes of young people were sparse, something which should be made a priority in future research.

This thesis also identified the predictors of transitioning for young people with the disorders most likely to fall through the gap across seven European countries, and found that being more severely ill was a predictor of care continuing in AMHS, although there was significant country variation in the proportions of young people transitioning or falling through the gap. Findings from this research also illustrate the long-term mental health outcomes of young people after leaving CAMHS in an international sample of young people with a diagnosis of a neurodevelopmental disorder, anxiety or depressive disorder, or a personality disorder. This thesis also included the first study of our knowledge to compare the healthcare and societal costs with transitioning and falling through the gap, with young people who transitioned to AMHS using more healthcare resources than those who fell through the gap.

To our knowledge this thesis features the first qualitative study to explore the long-term effects of falling through the gap between CAMHS and AMHS for young people and their parents. This research found that for some young people, the effects of falling through the gap can be long-lasting, and they can struggle to manage on their own without specialist mental health care. This qualitative research also identified a group of young people whose needs are not being met by the current structure of mental health services in the UK, as they are deemed 'too ill' for AWBS such as IAPT, but not ill enough for AMHS. The needs of this group of young people should be a priority for future policy and service reform. The qualitative interviews also generated new findings regarding the struggles young people face when accessing medication after CAMHS and the actions of parents who take on responsibility for their child's care in the absence of specialist support.

The findings from this thesis were used to generate recommendations for clinical practice and mental health policy, with a view to improving transitional care for this patient group.

> *"if there is anything good to come out of this study, it would be on how to do that transition better." [PC2]*

Outputs from this thesis

Findings from this thesis have been presented and published in the following:

Appleton, R. Mental Health, Young People & Transition. Keynote Presentation, Adult and Children's Social Care Conference, London Borough of Sutton. 7th February 2020

Tuomainen, H., **Appleton, R.**, Street, C., & Singh. S.P. Hitting a Mental Health Milestone at 18. British Science Festival, University of Warwick, 10th September 2019

Appleton R. Falling Through The Cracks. Pint of Science. 14th May 2018

Appleton, R., Mughal, F., Giacco, D., Tuomainen, H., Winsper, C & Singh, S.P. (2020) New models of care in general practice for the youth mental health transition boundary. BJGP Open.

Appleton, R., Elahi, F., Tuomainen, H., Canaway, A. & Singh, S.P. (2020) "I'm just a long history of people rejecting referrals" Experiences of young people who fell through the gap between child and adult mental health services. European Child and Adolescent Psychiatry.

Tuomainen, H., **Appleton, R.** & Singh, S.P. (2020) Care transition from Child/Adolescent to Adult services. In: Mental Health and Illness Worldwide: Mental Health and Illness of Children and Adolescents. Springer

Appleton, R., Connell, C., Fairclough, E., Tuomainen, H. & Singh, S.P. (2019) Outcomes of young people who reach the transition boundary of child and adolescent mental health services: a systematic review. European Child and Adolescent Psychiatry.

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Appendices

Appendix 1: Ethical Approvals

NHS
Health Research Authority

West Midlands - Black Country Research Ethics Committee

The Old Chapel

Royal Standard Place

Nottingham

NG1 6FS

10 December 2018

Professor Swaran Singh
Professor of Social and Community Psychiatry
University of Warwick
Warwick Medical School, Coventry
CV4 7AL

Dear Professor Singh

Study title:	**Life after CAMHS: experiences of the end of care at child and adolescent mental health services**
REC reference:	**18/WM/0337**
IRAS project ID:	**251863**

Thank you for your letter. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 29 November 2018

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant information sheet (PIS) [YP participant information sheet clean version]	v1.3	30 November 2018
Participant information sheet (PIS) [YP Participant Information Sheet track changes]	v1.3	30 November 2018

Participant information sheet (PIS) [PC participant information sheet clean version]	v1.3	30 November 2018
Participant information sheet (PIS) [PC participant information sheet track changes]	v1.3	30 November 2018

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Warwick Public Liability Insurance]		27 July 2018

GP/consultant information sheets or letters [GP letter]	v1.0	13 November 2018
Interview schedules or topic guides for participants [Narrative Interview Topic Guide]	v1.0	06 August 2018
IRAS Checklist XML [Checklist_16112018]		16 November 2018
Letter from funder [PhD Scholarship]		20 March 2017
Letter from sponsor [Sponsorship Approval letter]		26 September 2018
Letters of invitation to participant [Invitation Letter YP]	v1.0	06 August 2018
Letters of invitation to participant [Invitation Letter PC]	v1.0	06 August 2018
Other [Email Confirmation]		11 October 2018
Other [REC Cover letter]	v1.0	15 November 2018
Participant consent form [YP consent form clean version]	v1.2	13 November 2018
Participant consent form [YP consent form track changes]	v1.2	13 November 2018
Participant consent form [PC consent form clean version]	v1.2	13 November 2018
Participant consent form [PC consent form track changes]	v1.2	13 November 2018
Participant information sheet (PIS) [YP participant information sheet clean version]	v1.3	30 November 2018
Participant information sheet (PIS) [YP Participant Information Sheet track changes]	v1.3	30 November 2018
Participant information sheet (PIS) [PC participant information sheet clean version]	v1.3	30 November 2018
Participant information sheet (PIS) [PC participant information sheet track changes]	v1.3	30 November 2018
REC Application Form [REC_Form_08102018]		08 October 2018
Referee's report or other scientific critique report [Upgrade Report]		23 July 2018
Research protocol or project proposal [Protocol]	v1.1	28 August 2018
Summary CV for Chief Investigator (CI) [Swaran Singh CV short version]		05 October 2018
Summary CV for student [Rebecca Appleton CV]		05 October 2018
Summary CV for supervisor (student research) [Swaran Singh CV short version]		05 October 2018
Summary CV for supervisor (student research) [Helena Tuomainen]		

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

Yours sincerely

[redacted]

Vic Strutt
REC Manager

E-mail: [redacted]

Copy to: *Miss Rebecca Appleton*
Jane Prewitt

Appendix 2: Adaptations to the Newcastle-Ottawa Scale

Newcastle-Ottawa Scale	**Amendment**
Selection	**Selection**
1) Representativeness of the exposed cohort a) Truly representative (one star) b) Somewhat representative (one star) c) Selected group d) No description of the derivation of the cohort	
2) Selection of the non-exposed cohort a) Drawn from the same community as the exposed cohort (one star) b) Drawn from a different source c) No description of the derivation of the non exposed cohort	2) Baseline information of cohort presented e.g. age, diagnosis a) Baseline information included for whole cohort (one star) b) Some baseline information included c) No baseline information included
3) Ascertainment of exposure a) Secure record (e.g., surgical record) (one star) b) Structured interview (one star) c) Written self report d) No description e) Other	Exposure = transition
4) Demonstration that outcome of interest was not present at start of study a) Yes (one star) b) No	4) Demonstration that the young person has crossed the transition boundary of their CAMHS service a) Yes (one star) b) No
Comparability	**Comparability**
1) Comparability of cohorts on the basis of the design or analysis controlled for confounders a) The study controls for age, sex and marital status (one star)	1) Assessment of clinical need during transition & comparisons within sample a) The study measures clinical need to transition when the young person reaches the transition boundary (one star)

b) Study controls for other factors (list) _____ (one star) c) Cohorts are not comparable on the basis of the design or analysis controlled for confounders	b) The study uses subgroup analysis to compare transition outcomes of groups within the cohort (one star) c) No measure of clinical need to transition or subgroup analysis
Outcome	**Outcome**
1) Assessment of outcome a) Independent blind assessment (one star) b) Record linkage (one star) c) Self report d) No description e) Other	
2) Was follow-up long enough for outcomes to occur a) Yes (one star) b) No Indicate the median duration of follow-up and a brief rationale for the assessment above:_____	
3) Adequacy of follow-up of cohorts a) Complete follow up - all subjects accounted for (one star) b) Subjects lost to follow up unlikely to introduce bias - number lost less than or equal to 20% or description of those lost suggested no different from those followed. (one star) c) Follow up rate less than 80% and no description of those lost d) No statement	

Appendix 3: Included Diagnostic labels

Personality disorder

Clinical - Personality disorder

Global - Personality disorder

ICD-10 - Specific personality disorders'

Disorders of adult personality and behaviour

Global - Personality Disorders / Disorders of adult personality and behaviour

Global - Paranoid personality disorder

Global - Dependent personality disorder

Global - Other specified personality disorder

Global - Unspecified personality disorder

Global - Schizoid personality disorder

Global - Schizotypal Personality Disorder

Global - Dissocial / Antisocial personality disorder

Global - Emotionally Unstable / Borderline personality disorder

Global - Histrionic personality disorder

Global - Narcissistic personality disorder

Global - Anankastic / Obsessive-compulsive personality disorder

Global - Anxious / Avoidant personality disorder

Neurodevelopmental Disorders / Behavioural and emotional disorders with onset usually occurring in childhood and adolescence

Global - Communication Disorders / Specific developmental disorders of speech and language (and subtypes)

Global - Tic disorders

Global - Provisional/transient tic disorder

Global - Persistent (chronic) motor or vocal tic disorder

Global - Tourettes disorder (Combined vocal and multiple motor tic disorder)

Global - Other (specified) tic disorder(s)

Global - Unspecified tic disorder

Global - Specific Learning Disorder / Specific developmental disorders of scholastic skills (and subtypes)

Global - Motor Disorders / Specific developmental disorder of motor function

Global - Mixed specific developmental disorders

Global - Autism spectrum disorder / Pervasive developmental disorders

Global - Other Neurodevelopmental Disorders

Global - Other disorders of psychological development

Global - Unspecified disorder of psychological development

Global - Attention-deficit/Hyperactivity Disorder / Hyperkinetic disorders

Global - Attention-deficit/hyperactivity disorder Predominantly inattentive presentation (Disturbance of activity and attention)

Global - Attention-deficit/hyperactivity disorder Predominantly hyperactive/impulsive presentation (hyperkinetic conduct disorder)

Global - Attention-deficit/hyperactivity disorder Combined presentation (hyperkinetic conduct disorder)

Global - Other specified attention-deficit/hyperactivity disorder

Global - Unspecified attention-deficit/hyperactivity disorder

Depressive, Bipolar and Related Disorders / Mood [affective] disorders

Global - Major Depressive disorder, Single episode / Depressive episode

Global - Major Depressive Disorder, Recurrent episode / Recurrent depressive disorder

Anxiety Disorders

Global - Anxiety Disorders

Global - Separation anxiety disorder

Global - Selective mutism

Global - Agoraphobia

Global - Social anxiety disorder / Social Phobia

Global - Specific phobias

Global - Panic disorder

Global - Generalized Anxiety Disorder

Global - Other anxiety disorder

Global - Unspecified anxiety disorder

Appendix 4: Unit Cost Information for WP3

Health Care Resource	Unit cost uninflated (£)	Inflation adjusted unit cost 2015 (£)	Euros PPP (2015)	Source of unit cost
Inpatient Stay (nights):				
Acute psychiatric ward	404	392	466.56	PSSRU 2017[1]
Psychiatric rehabilitation ward	404	392	466.56	PSSRU 2017[1]
Long stay psychiatric (low secure psych ward)	404	392	466.56	PSSRU 2017[1]
Emergency crisis centre (walk in emergency clinic)	794	918.87	1094.47	NHS ref costs 2010/11[2]
A&E (overnight stay)	145.64	150.21	178.92	NHS ref costs 2014/15[3]
General Medical ward	222	222	264.42	NICE costing statement[4]
Paediatric ward	682	661	787.61	NHS ref costs 2016/17[5]
Residential rehab centre: admitted alcohol	447	433	516.22	NHS ref costs 2016/17[5]
Residential rehab centre: admitted drugs	448	434	517.37	NHS ref costs 2016/17 [5]
Outpatient care (per attendance):				
Psychiatric outpatient (adult mental illness)	283.98	275	327.95	NHS ref costs 2016/17[5]
Other hospital outpatient	119.84	116	138.40	NHS ref costs 2016/17[5]
Day hospital	356	345	411.13	NHS ref costs 2016/17[5]
A&E (without overnight stay)	122.29	126.13	150.23	NHS ref costs 2014/15[3]
Group therapy	7.80	8.56	10.20	PSSRU 2008[6]
Community-based health service				
GP	37	36	42.73	PSSRU 2017[1]
Psychiatrist	108.00	105	124.72	PSSRU 2017[1]
Psychologist	100.00	97	115.49	PSSRU 2017[1]
Paediatrician	37	36	42.73	PSSRU 2017[1]

District nurse	39	38	45.26	PSSRU 2015[7]
Community psychiatric nurse/case manager	44	43	50.81	PSSRU 2017[1]
Social worker	59	57	68.14	PSSRU 2017[1]
Occupational therapist	42	41	48.50	PSSRU 2017[1]
Home help/care worker	22	21	25.41	PSSRU 2017[1]
Community drug and alcohol service worker	45	44	51.97	PSSRU 2017[1]
Advanced/specialised nurse	52	52	61.94	PSSRU 2015[7]

1. Curtis, L. & Burns, A. (2017) Unit Costs of Health and Social Care 2017, Personal Social Services Research Unit, University of Kent, Canterbury. 2. https://www.gov.uk/government/publications/2010-11-reference-costs-publication. 3. https://www.gov.uk/government/publications/nhs-reference-costs-2015-to-2016. 4. https://www.nice.org.uk/guidance/ng27/resources/costing-statement-pdf-2187244909 5. https://webarchive.nationalarchives.gov.uk/20200501111106/https://improvement.nhs.uk/resources/reference-costs/ 6. Curtis, L. (2008) Unit Costs of Health and Social Care 2008, Personal Social Services Research Unit, University of Kent, Canterbury. 7. Curtis, L. (2015) Unit Costs of Health and Social Care 2008, Personal Social Services Research Unit, University of Kent, Canterbury.

Appendix 5: Recruitment Material for WP4

Young Person Invitation Letter

Dear

Following your participation in the MILESTONE study, I am writing to invite you to take part in my PhD study called "Life after CAMHS" which focuses on those young people whose care ended when they reached the upper age limit of CAMHS.

As part of my study, I would like to interview you and your parent/carer to find out more about what happened when you left CAMHS. Very little is known about young people whose mental health care ends at the transition boundary and what experiences they make afterwards. I am also interested in hearing your views about your care ending and current situation.

The interview will feel more like an informal discussion and will be conducted without a questionnaire with specific questions. It will take place at a time and location which is convenient for you, and will take around an hour. There are no right or wrong answers; I am only interested in hearing your views, thoughts and experiences.

If you choose to participate, you will receive a gift voucher as a token of appreciation for your time, and we'll reimburse reasonable travel expenses. The enclosed participant information sheet explains everything in more detail, and if you have any further questions please feel free to get in touch by phone, text, or email.

If you would like to take part in an interview, please read the attached participant information sheet and contact Becky:

Becky Appleton

Tel. [redacted]

Mobile: [redacted]

Email: [redacted]

Best wishes,

Becky Appleton

Warwick Medical School

Parent/Carer Invitation Letter

Dear

Following your participation in the MILESTONE study, I am writing to invite you to take part in my PhD study called “Life after CAMHS” which focuses on those young people whose care ended when they reached the upper age limit of CAMHS.

As part of my study, I would like to interview you and your son/daughter to find out more about what happened when they left CAMHS. Very little is known about young people whose mental health care ends at the transition boundary and what experiences they make afterwards. I am also interested in hearing your views about care ending and their current situation.

The interview will feel more like an informal discussion and will be conducted without a questionnaire with specific questions. It will take place at a time and location which is convenient for you, and will take around an hour. There are no right or wrong answers; I am only interested in hearing your views, thoughts and experiences.

If you choose to participate, you will receive a gift voucher as a token of appreciation for your time, and we’ll reimburse reasonable travel expenses. The enclosed participant information sheet explains everything in more detail, and if you have any further questions please feel free to get in touch by phone, text, or email.

If you would like to take part in an interview, please read the attached participant information sheet and contact Becky:

Becky Appleton

Tel. [redacted]

Mobile: [redacted]

Email: [redacted]

Best wishes,

Becky Appleton

Warwick Medical School

Young Person Participant Information Sheet

"Life after CAMHS" Interview Participant information sheet

Young person

Study Title:	Life after CAMHS: experiences of the end of care at child and adolescent mental health services
Investigator(s):	Rebecca Appleton, Professor Swaran Singh, Dr Helena Tuomainen, University of Warwick

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

The MILESTONE Study focuses on the period when young people attending a children and adolescent mental health service (CAMHS) need to move on (or "transition") to an adult mental health service (AMHS), if they still require care or treatment. We know from other research that transition from CAMHS to AMHS is not always properly managed and that improving the

transition process can have a positive impact on the health and wellbeing of young people in this position.

This “Life after CAMHS” study focuses specifically on those young people in the MILESTONE study whose mental health care ended when they reached the upper age boundary of their CAMHS. This research will be part of Becky Appleton’s PhD thesis.

Why have I been invited?

You have been invited because you took part in the MILESTONE Study. We want to find out more about your views on your care and what has happened since you left CAMHS.

Do I have to take part?

It is entirely up to you to decide. This information sheet which you can keep describes the study. **If you are interested in taking part, you will need to sign and return the Consent form (2 copies),** provided with this information leaflet, to us.

By signing the consent forms you confirm that you agree to take part. You will be free to withdraw at any time, without giving a reason and this will not affect you or your medical care in any way. If you do decide to withdraw, any data already collected will be retained by the research team.

What will happen to me if I take part?

If you agree to participate, you will be contacted by Becky Appleton from the MILESTONE research team at the University of Warwick, to talk through the study. This will provide you with the opportunity to ask any questions you may have.

If you would still like to take part then Becky will arrange for an interview to take place at a location which is convenient for you. This would ideally be face to face, although could take place over Skype or telephone if you prefer, and will last around an hour. Becky will take written consent from you before the interview takes place. The interview will feel more like an informal discussion (conducted without a questionnaire with specific questions) and will focus on your journey from when you started to receive care at CAMHS to what happened when CAMHS ended. This will help us understand your experiences of leaving CAMHS and your views on care ending. If you permit, the interview will be audio recorded to help us to keep an accurate record of what is

discussed. The recording will be kept confidential and only listened to by members of the research team.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

There are no known or anticipated risks associated with participation in this study.

However, participants may feel upset when talking about their experiences. Given that the research will be conducted by an experienced researcher this will be sensitively handled. Any person deemed to be significantly upset, will be supported. The Chief Investigator, who is a clinician, will be advised of the difficulties and appropriate support will be suggested. If you feel as though you need urgent help, please contact your local crisis team or visit A&E.

What are the possible benefits of taking part in this study?

There are no direct benefits from taking part in this study. However, the information collected as part of this study will help enhance the quality of mental health services for young people across Europe.

Expenses and payments

You will receive a token of appreciation for your time. Reasonable travel expenses will be reimbursed. If you need someone to travel with you, then please also discuss this with the study team. You will need to retain all travel tickets so we can reimburse you.

Will my taking part be kept confidential?

During your interview with our Research Assistant, you will be asked to nominate a health or care professional with whom we may make contact should we become worried for your safety. This health/care professional may be your GP or any other clinician you feel comfortable with us contacting. Only in the event that we become concerned for your safety, will we contact your nominated health/care professional and discuss your situation with them. This will only be done if we are genuinely concerned for your safety. We will make every effort to discuss this with you before we contact them.

We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes Part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

This study is organised by researchers from the University of Warwick. The study is funded by Warwick Medical School as part of a PhD Scholarship.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

If you agree to participate, you may withdraw from the study at any time without this affecting you in any way.

You have the right to withdraw your data from the study completely until it has been anonymised (up to 2 weeks after the interview has taken place) and decline any further contact by study staff after you withdraw.

What if there is a problem?

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue, please contact **the Director of Delivery Assurance**, University of Warwick (details below).

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a Senior University of Warwick official entirely independent of this study:

Head of Research Governance

Research & Impact Services

University House

University of Warwick

Coventry

CV4 8UW

Email: researchgovernance@warwick.ac.uk

Tel: 024 76 522746

Will my taking part be kept confidential?

The University of Warwick will keep your name and contact details confidential and will not pass this information to anyone outside this organisation. We will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from The University of Warwick and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

The University of Warwick is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Warwick will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting

[redacted]

What will happen to the results of the study?

The results of this study will be written up as part of a PhD thesis and may also be published in peer-reviewed journals and presented at conferences. The researchers involved in the MILESTONE study may use the data in future research. However, all information will be treated in a confidential manner, and your personal details will not be included in any reports and you will never be identifiable in any way.

The MILESTONE team will be applying for funding to enhance the impact of the research findings by presenting them to a wider audience. In these public engagement activities, we would develop narratives about different experiences of transition, and are planning to use some small excerpts from anonymised transcribed interviews but rarely word for word. If verbatim extracts would be used, then personal details, such as gender and context, will be changed so individuals can't be identified. The plan is to present this at science festivals in the UK and other European countries, at other relevant venues (e.g. conferences), and to share any filmed output on social media. Participants will receive a study information leaflet summarising the findings of the research and/or a link to the project website with this information.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the West Midlands - Black Country NHS research ethics committee.

What if I want more information about the study?

If you have any questions about any aspect of the study or your participation in it not answered by this participant information leaflet, please contact either the person who gave you this information or:

Becky Appleton
Tel. [redacted]
Mobile: [redacted]
Email: [redacted]

Dr Helena Tuomainen
Tel. [redacted]
Mobile: [redacted]

Thank you for taking the time to read this participant information leaflet.

Parent/Carer Participant Information Sheet

"Life after CAMHS" Interview Participant information sheet

Parent

Study Title:	Life after CAMHS: experiences of the end of care at child and adolescent mental health services
Investigator(s):	Rebecca Appleton, Professor Swaran Singh, Dr Helena Tuomainen, University of Warwick

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

The MILESTONE study focuses on the period when young people attending a children and adolescent mental health service (CAMHS) need to move on (or "transition") to an adult mental health service (AMHS), if they still require care or treatment. We know from other research that transition from CAMHS to AMHS is not always properly managed and that improving the transition process can have a positive impact on the health and wellbeing of young people in this position.

This “Life after CAMHS” study focuses specifically on those young people in the MILESTONE study whose mental health care ended when they reached the upper age boundary of their CAMHS. This research will be part of Becky Appleton’s PhD thesis.

Why have I been invited?

You have been invited because you took part in the MILESTONE Study. We want to find out more about your views on the care your son/daughter and what has happened since they left CAMHS.

Do I have to take part?

It is entirely up to you to decide. This information sheet which you can keep describes the study. **If you are interested in taking part, you will need to sign and return the Consent form (2 copies),** provided with this information leaflet, to us.

By signing the consent forms you confirm that you agree to take part. You will be free to withdraw at any time, without giving a reason and this will not affect you or your medical care in any way. If you do decide to withdraw, any data already collected will be retained by the research team.

What will happen to me if I take part?

If you agree to participate, you will be contacted by Becky Appleton from the MILESTONE research team at the University of Warwick, to talk through the study. This will provide you with the opportunity to ask any questions you may have.

If you would still like to take part then Becky will arrange for an interview to take place at a location which is convenient for you. This would ideally be face to face, although could take place over Skype or telephone if you prefer, and will last around an hour. Becky will take written consent from you before the interview takes place. The interview will feel more like an informal discussion (conducted without a questionnaire with specific questions) and will focus on the journey from when your son/daughter started to receive care at CAMHS to what happened when CAMHS ended. This will help us understand your experiences of CAMHS and your views on care ending. If you permit, the interview will be audio recorded to help us to keep an accurate record of what is discussed. The recording will be kept confidential and only listened to by members of the research team.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

There are no known or anticipated risks associated with participation in this study.

However, participants may feel upset when talking about their experiences. Given that the research will be conducted by an experienced researcher this will be sensitively handled. Any person deemed to be significantly upset, will be supported. The Chief Investigator, who is a clinician, will be advised of the difficulties and appropriate support will be suggested. If you feel as though you need urgent help, please contact your local crisis team or visit A&E.

What are the possible benefits of taking part in this study?

There are no direct benefits from taking part in this study. However, the information collected as part of this study will help enhance the quality of mental health services for young people across Europe.

Expenses and payments

You will receive a token of appreciation for your time. Reasonable travel expenses will be reimbursed. You will need to retain all travel tickets so we can reimburse you.

Will my taking part be kept confidential?

We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes Part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

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What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

If you agree to participate, you may withdraw from the study at any time without this affecting you in any way.

You have the right to withdraw your data from the study completely until it has been anonymised (up to 2 weeks after the interview has taken place) and decline any further contact by study staff after you withdraw.

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Head of Research Governance
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Will my taking part be kept confidential?

The University of Warwick will keep your name and contact details confidential and will not pass this information to anyone outside this organisation. We will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from The University of Warwick and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

The University of Warwick is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Warwick will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting [redacted]

What will happen to the results of the study?

The results of this study will be written up as part of a PhD thesis and may also be published in peer-reviewed journals and presented at conferences. The researchers involved in the MILESTONE study may use the data in future research. However, all information will be treated in a confidential manner, and your personal details will not be included in any reports and you will never be identifiable in any way.

The MILESTONE team will be applying for funding to enhance the impact of the research findings by presenting them to a wider audience. In these public engagement activities, we would develop narratives about different experiences of transition, and are planning to use some small excerpts from anonymised transcribed interviews but rarely word for word. If verbatim extracts would be

used, then personal details, such as gender and context, will be changed so individuals can't be identified. The plan is to present this at science festivals in the UK and other European countries, at other relevant venues (e.g. conferences), and to share any filmed output on social media.

In order to develop the various scenarios of real experiences we would be planning to use some small excerpts from anonymised transcribed interviews but rarely word for word. If verbatim extracts would be used, then personal details, such as gender and context, will be changed so individuals can't be identified.

Participants will receive a study information leaflet summarising the findings of the research and/or a link to the project website with this information.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the West Midlands - Black Country NHS research ethics committee.

What if I want more information about the study?

If you have any questions about any aspect of the study or your participation in it not answered by this participant information leaflet, please contact either the person who gave you this information or:

Becky Appleton
Tel. [redacted]
Mobile: [redacted]
Email: [redacted]

Dr Helena Tuomainen
Tel. [redacted]
Mobile: [redacted]

Thank you for taking the time to read this participant information leaflet.

Centre Number: Participant Identification Number for this study:

Young Person Consent Form

Study title: Life after CAMHS: experiences of the end of care at child and adolescent mental health services

Name of Researchers: Rebecca Appleton, Professor Swaran Singh, Dr Helena Tuomainen, University of Warwick.

Please initial box

1. I confirm that I have read and understand the information sheet version number ....., dated..... for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. I also understand that any data collected prior to my withdrawal will be retained by the research team once data has been anonymised. ☐

3. I agree to take part in an interview for this research study, and agree that it can be audio-recorded and transcribed for analysis. ☐

4. I give my permission for the research team to use this information for writing about this study. I understand that my details will be kept confidential and my name will not appear on any report or documents. ☐

5 I agree that anonymous quotes from my interview may be used in the write up of the study and may be published. ☐

6. I agree to my data being securely stored on university computers. ☐

7. I agree for data collected during this study to be used in data analysis in future related research which has undergone ethical approval. This data may include my personal contact details. ☐

8. I understand that data collection may be delayed in the event that I am unwell and that contact between the researcher and my parent/carer/clinician may be necessary. ☐

9. I understand that confidential information relating to me will only be shared with my nominated health professional in the event that the research team become concerned for my safety. ☐

10. In the event that the research team become concerned about my safety, I consent to the research team contacting my nominated health professional and discussing the situation with them. ☐

11. I understand that data collected during the study may be looked at by responsible individuals from the University of Warwick, from regulatory authorities, or from the NHS Trust, where it is relevant to my taking part in this research. ☐

12. I agree to take part in the study. ☐

	YES	NO
13. I agree that an anonymous version of the information I provide can be used as part of future public engagement activities.	☐	☐

_____	_____	_____
Name of Participant	Signature	Date

_____	_____	_____

Name of person taking consent (if different from researcher)	Signature	Date
_____	_____	_____
Name of Researcher	Signature	Date

Centre Number: Participant Identification Number for this study:

Parent/Carer Consent Form

Title of Study: Life after CAMHS: experiences of the end of care at child and adolescent mental health services

Name of Researchers: Rebecca Appleton, Professor Swaran Singh, Dr Helena Tuomainen, University of Warwick.

Please initial box

1. I confirm that I have read and understand the information sheet version number ....., dated..... for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I also understand that any data collected prior to my withdrawal will be retained by the research team once data has been anonymised. ☐
3. I agree to take part in an interview for this research study, and agree that it can be audio-recorded and transcribed for analysis. ☐
4. I give my permission for the research team to use this information for writing about this study. I understand that my details will be kept confidential and my name will not appear on any report or documents. ☐
5. I agree that anonymous quotes from my interview may be used in the write up of the study and may be published. ☐
6. I agree to my data being securely stored on university computers. ☐
7. I understand that data collected during the study may be looked at by responsible individuals from the University of Warwick, from regulatory authorities, or from the NHS Trust, where it is relevant to my taking part in this research. ☐

8. I agree for data collected during this study to be used in data analysis in future related research. This data may include my personal contact details. ☐

9. I agree to take part in the study.

	YES	NO
10. I agree that an anonymous version of the information I provide can be used as part of future public engagement activities.	☐	☐

_____	_____	_____
Name of Participant	Signature	Date

_____	_____	_____
Name of person taking consent (if different from researcher)	Signature	Date

_____	_____	_____
Name of Researcher	Signature	Date

Appendix 6: Interview Topic Guide for WP4

Narrative Interview Topic Guide

This topic guide shows the topics which will be discussed during the interview and example questions and prompts.

Before recording starts:

- Introduce interview format, and that I'm interested in their experience of CAMHS and what happened to them after they left. Mention that this is separate from the MILESTONE data collection and I'm doing this work for my PhD.
- Make sure to state confidentiality and risk statement – find out the details of their preferred healthcare professional (or parent if they don't have a healthcare professional).
- Check that the participant is still happy to take part in the interview and for it to be recorded. Ask again whether they have any questions.

YP interview

Time at CAMHS

- Can you tell me about the time when you first started receiving care at [name of service]
    - Prompts including: 'Can you expand on that/tell me more about that?'; 'What happened next?'

Experience of CAMHS care

- What was your experience at CAMHS like?
    - Prompts including: 'How long were you at CAMHS for?', 'What was your clinician like?', 'Any positive/negative experiences you'd like to mention?'

What happened at the end of care?

- How did you experience the end of care at [name of service]?
    - Prompts including: 'When was the end of CAMHS first introduced to you?'; 'Any positive/negative experiences you'd like to mention?'; 'What did your clinician say at this time?' 'What happened next?'

What has happened since care ended – thoughts & feelings?

- What has happened since you left [name of service] in terms of accessing other services?
    - Prompts including: 'How do you feel about what happened when CAMHS ended?'; 'How do you feel as this experience has affected you/your mental health?'; 'What happened next?'

- **[Questions on topics discussed in interview if more information is needed]**

- **Is there anything else you'd like to add which we haven't talked about yet today?**

Thank you very much for your time.

[end recording]

PC interview

Time at CAMHS

- Can you tell me about the time when [name] first started receiving care at [name of service]
    - Prompts including: 'Can you expand on that/tell me more about that?'; 'What happened next?'

Experience of CAMHS care

- What was [name]'s experience at CAMHS like?
    - Prompts including: 'How long were you at CAMHS for?', 'What was [name]'s clinician like?', 'Any positive/negative experiences you'd like to mention?'

What happened at the end of care?

- How did [name] experience the end of care at [name of service]?
    - Prompts including: 'When was the end of CAMHS first introduced to you?'; 'Any positive/negative experiences you'd like to mention?'; 'What happened next?'

What has happened since care ended – thoughts & feelings?

- What has happened since [name] left [name of service] in terms of accessing other services?
    - Prompts including: 'How do you feel about what happened when CAMHS ended?'; 'How do you feel this experience has affected [name] or their mental health?'; 'How has this affected you/your family?', 'What happened next?'

- **[Questions on topics discussed in interview if more information is needed]**

- **Is there anything else you'd like to add which we haven't talked about yet today?**

Thank you very much for your time.

[end recording]

Appendix 7: Codebook for Thematic Analysis

Thematic Analysis Codebook

Name	Description	Example
Addiction	Used when participants mention addiction.	"Well, I do think there should be some sort of counselling there, regardless of his drinking. At least to attempt something, it's not like he's, hang on [Name], he's not paralytic drunk, at every opportunity, so I do think if they had at least attempted to do some counselling, and if obviously it didn't work, then okay fair enough, we've tried, and we could try and do a reduction plan on the drinking. But, it's just sort of a brick wall, there's no help whatsoever for him."
Anxiety about CAMHS ending	Used to code participant's anxiety about CAMHS ending.	"Yeah, especially when you're going through the transition as well. Because you're scared like, when you've been there as long as I have, you're scared for it suddenly to just drop back, and it wasn't handled in a good way at all really."
Concurrent life events	Used when participants mention other significant life events that they are navigating at the same time as the end of CAMHS.	And at, also at this time, mid A level courses, she turned 16, and that's when she, we were just told that CAHMS had finished,

Name	Description	Example
		CAMHS finishes at 16 so you're now into adult world, adult care, whatever that means.
Exam stress	Used when participants are talking about effect exams had on their/the young person's mental health.	"she was getting very stressed at college because at the time she was studying for 4 A levels"
University	Used when participants talk about going to university, how they're getting on at university/living away from home, or using university support services.	"she's gone to uni, she's doing law, which is what she wanted to do, and it's a difficult subject, but she's really getting into it. She doesn't have much of the social life, so she's' not out partying every night, but she's got a small group of friends."
Worry about future	Used when participants mention feeling worried about the future.	"I mean when she went to university, you actually filled in their application form, didn't you, because we were worried that there was no support and she was going off."
Safety net	Used to code participant's feelings of reluctance for care to end.	"It came as a bit of a shock to me, when he sort of suddenly said 'Oh, do you think you're ready to sort of finish these sessions' because I was surprised at them being weekly, and then you do get used – I mean I wouldn't say I'm kind of a dependent person, but I think you do develop that, because you think 'Oh if anything goes wrong, he's always there, he'll advise'."

Name	Description	Example
Barriers to accessing care	Used when participants mention any barriers which have stopped them from being about to access care.	"Autism West Midlands to us, who I did get in touch with but was told that they effectively only look after the [City] area, which isn't really a great help to anyone else is it? So why call it Autism West Midlands, was my initial question"
Admin problems	Used to code administrative problems young people and their parents have had whilst trying to access care.	"And the people who were providing the administrative side of things were pretty poor, and I'm sure that's more to do with the fact that they were under-resourced, and didn't really know what was going on in terms of the centre's longevity at that, so having no sense of certainty that a particular counsellor was going to be around was very difficult both, for [Name] and for us, because we didn't know how we could provide support alternatively."
Cost of care after TB	Used to code mentions of costs of accessing care after leaving CAMHS.	"We had no option, other than private, but I couldn't afford private."
Fitting care around work, school	Used when participants mentioned difficulties in fitting in care around work or school.	"Erm, well I had time off work, because at that stage I was in full time work, so I'd take time off to attend the, I suppose not meetings, the appointments."

Name	Description	Example
Moved location	Used when participants are talking about how moving location, either permanently or to go to university has affected their care.	“But then obviously I moved house, yeah, yeah, they were going to do DBT or something, or CBT, but then I had to move my GP and they found out. Do you get what I mean? So obviously I’ve moved over, but then I’m not getting any help now.”
Becoming an adult	Used when participants talk about the way the CAMHS-AMHS divide is represented as moving from being a child to being an adult.	“also at this time, mid A level courses, she turned 16, and that’s when she, we were just told that CAHMS had finished, CAMHS finishes at 16 so you’re now into adult world, adult care, whatever that means.”
Independence	Used to describe the balance for independence vs involvement of parents in the move from CAMHS or young people growing up in general.	“And that’s not to say that we want to be on everything, we want her to be independent, as I said, you know it’s just like overnight 15 to 16, and its like the world just thinks ‘right you’re grown up now, that’s it, you’re cut loose’.”
Maturity	Used when participants are talking about maturity as young people have to take on more responsibility for their care.	“We didn’t feel that [Name] was mature enough to have all that thrown at her, and make all those decisions, without any input from us.”
Turning 18	Used to code mentions of the impact of turning 18.	“I think, yes we were, we were pointed in the right direction, but this ridiculous thing is that once the clock chimes midnight on your

Name	Description	Example
		18th birthday, and magically you don't need anybody, is so ridiculous."
Bullied	Used when participants mention being bullied.	"when I was at primary school, I was having loads of problems even then, I have basically been bullied since I was born, and so I had a lot of problems when I was at primary school."
CAMHS TB	Used for any references to when the young person reached the upper age limit of their CAMHS service.	"I think it was a case of, yeah, it was something like 'So you're next meeting with us will be the last one, because you're getting to 16, and we don't carry on after that. We will then hand you over to adult care.' And that was it really."
Care after CAMHS	Used to code any mention of care received after CAMHS which did not come from an NHS mental health service.	"Of course, you go to your GP, and they try and help where they can, and I did go to IAPT, but [Name] couldn't cope. She locked herself in the car, she wouldn't get out. She couldn't cope with talking to this person, because it isn't right for her. Because we know why it's not right for her."
Digital support	Used when participants describe digital/online support e.g. Facebook groups, apps, forums etc.	"there's Facebook groups for people with problems. I was on a couple of them because I was really struggling"

Name	Description	Example
Involvement of GP	Used for any reference relating to the involvement of the GP in the young person's care.	"I think it was down to the GP, I think really. The main signpost was 'go and see your GP'. I think CAMHS may have spoken to our GP, and the GP was very good."
Private care	Used for any mention of receiving or thinking of receiving private care.	"Erm, and at that time I was, partly with the shock of CAMHS ending, it was like 'okay what are we going to do?' We don't mind, we'll spend any money, you know, do anything for our daughter."
Support at Uni	Used when participants mention the support available at university, or using university support services.	"I don't think she's accessing any formal support from the college, she certainly never mentions it, all she does there is go along to lectures, sleeps, she still sleeps a lot, so yeah I don't think there's any formal thing."
Comparison with physical health	Used to code instances of participants comparing their mental health care with physical health care.	"If it was a physical condition, if I was in a wheelchair, when I turned 18 would they have said to me 'Off you go, you can go and walk'. It's like being said to me 'You're an adult now, you've got to deal with all your problems on your own with no support'."
Confidentiality	Used when participants describe how information sharing is made more difficult by confidentiality agreements after the YP becomes	"I think there needs to be a recognition perhaps, that okay yeah patient confidentiality is one thing, but this is a 16-year-old girl,

Name	Description	Example
	an adult in the eye of that service. Could relate to sharing info with parents, university, between departments etc.	who up until the previous week had all this level of support and all this involvement from us, and now you've just shut us out."
Diagnosis	Used for any reference to a diagnosis, trying to get a diagnosis, or views on their particular diagnosis.	"my diagnosis says depression disorder, anxiety disorder, and attachment issues, which I don't think's a disorder, but anyway, that's what it says."
Effect on PC and family	Used when participants are talking about how the YP's mental illness, or experiences of care has affected them, or the family as a whole.	"I've talked about it a few times now, and yeah, it's getting easier to talk about, it can be quite emotional at times, but I think now we're in those better days that I talked about, we're not quite - the sun's not shining fully, but we're over the worst of it I think."
Fight for support	Used to code any mention of having to fight to access support for their mental health.	"Any kind of support for anybody with autism, is just isn't there, automatically, you really have to dig, and fight, and plan, and hopefully collaborate."
Frustration	Used to code feelings of frustrating relating to experiences of care or accessing services.	"And it was really frustrating, because in essentially a month's difference from before to now, just because she's gone through a birthday, she's no older really, no more mature, she's still our daughter, we love her. If anything we felt even more cut out then, erm, so that was really difficult."

Name	Description	Example
Feeling suicidal	Used for anything relating to feeling suicidal.	"But there was times when I was like 'I'm actually going to kill myself', and I'd plan it out, and then at the last minute I'd think 'Maybe I should just talk to someone'. And I'd try and talk to my mum, and I don't think my mum, she doesn't even still now understand, it's been years."
Good experience of CAMHS	Used to describe participant's good experiences of CAMHS See also: Bad experience of CAMHS	"And we thought, okay, she's getting good service, getting good treatment here. And then… so that went on, I can't remember how many visits we had, but we had a number of visits to the local CAMHS, which was [Town], not too far away,"
Consistency in CAMHS	Used to code mentions of consistent care in CAMHS.	"I think, you know, it was weekly sessions, and I think they were trying cognitive behavioural therapy with me, I'm not sort of, and assessing my mood and everything. Don't remember too well in detail what each session was like but… I mean it did help to some degree, but, yeah, I don't know what else to say."
Good relationship with clinician	Used to code participants' mentions of having a good relationship with their clinician.	"You know, sort of, CAMHS, [Name's] involvement with CAMHS really started off, you went to see [Counsellor & Counsellor] didn't you? There's a chappie [Mental Health Nurse] who actually was [Name's] saviour in the end, you had a good relationship with

Name	Description	Example
		[Mental Health Nurse] didn't you? And [Mental Health Nurse] carried –"
Ideal scenario	Used when participants describe what they would have liked to have happened instead, either during CAMHS or when they reached the transition boundary.	"I think there could be, more of like a phased approach. So that age between 16 and 18, where parents need to still be involved I think. So it could be pretty much how CAMHS was done, where we'd all go along to the doctors let's say. We'd have time with [Name] and the doctor alone, but then call the parents in to say 'okay, this is the kind of thing we talked about, this is how [Name] feels, this is how you can help' because we just got none of that."
Importance of having supportive parents	Used to code young people talking about the importance of having supportive parents.	"I'm really lucky that I've got really loving parents who look after me and make sure that I'm not in danger, but if I had any less of a support system I'd probably be dead by now because it took them so long to do anything."
Inappropriate provision	Used to describe participant's experiences of care which they haven't felt met their needs.	"I had to do a big thing online, like a few, about 20 minutes or so, and you could tell the questions were just asking, every time it refers back to, 'Are you having suicidal thoughts, are you trying to harm yourself?' and then if no, then you just – so I saw him 5 or 6 times, and I got really annoyed, a number of times I almost just

Name	Description	Example
		walked out, because it was just, it's not helpful, it's a waste of time."
CJS	Used to any mentions of the criminal justice system.	"If you asked any questions, he was like 'We've just said to you, it's only if he gets to such a stage where he's arrested etc, and then they'd put him in somewhere like [Psychiatric hospital] it's called locally'."
Group therapy	Used to describe participant's experiences of group therapy, or views on being offered group therapy.	"She went to the course that the doctor had arranged, which I think wasn't so much one on one talking, it was more a group of, I don't know, 10, 15, and they were all talking in a group. I don't think she found that very useful."
Signpost to A&E	Used when young people were told to go to A&E (or their parent carers told to take them to A&E) if they needed support because of their mental health.	"They just said a long time, they didn't say how long. And then they just said that if you think that [Name] may harm herself, in terms of seriously harming herself, or somebody else, then to take her to the hospital. But, you know, have you ever tried to take someone to the hospital who's suicidal? They just don't go."

Name	Description	Example
'You need more specialist help'	Used when participants describe being too ill for some of the community services that are offered to them after CAMHS. See also: Transition gap	"when I told them I was already diagnosed, they were like 'you'll need more specialist help'. So they said they'd contact me again and they kind of just haven't, so…"
Infrequent appointments	Used when participants spoke about infrequent or irregular appointments at a mental health service.	"But with [Community Mental Health Service], there wasn't any, there's no consistency at all, and it was very random, the when and where the appointments were going to be, which is not what [Name] needs"
Cancelled appointment	Used when participants mentioned that their appointment at a mental health service was cancelled.	"And I got a text saying that the appointments been cancelled, and then I was like 'that's not good'. So I text my mum and I said 'It's been cancelled, blah blah blah, she's gonna ring me to rearrange'. And then the next week again, it was exactly the same thing, and I was just like 'right, this is getting ridiculous now'."
Involvement of PC	Used to code either how involved the parent/carer was in the young person's care, or views of how involved the parent/carer should be.	"we were in the room with her for most, most of the time – you know how it works, there were times when we went along with her, there were times when we were called into the room and they'd talk to us as a family, there were times when they'd talk to her on her own, and that's fine, but they always brought us into the

Name	Description	Example
		room at the end to say 'This is what will happen, this is what we're going through'."
Labelling PC	Used when parent/carers talked about feeling as though they were labelled by healthcare or school staff as being overprotective or paranoid.	"So no, nobody talked to us really, we were just paranoid people, I was just a paranoid mother, but, you know that was certainly not the case at all."
Lack of communication	Used to code any mention of a deficit in communication.	"It is, there's a lack of communication, and I know there's so much red tape, there's also data protection. I think one of things, whether it be CAMHS or any other organisation, there has to be more, as I say, sharing of quality information and working together. And certainly, okay its not CAMHS at university, but there is a lack of willingness for whatever reason."
Lack of communication between services	Used specifically when participants were talking about a lack of communication between services.	"And yeah, again, it's money issues, and you know, people don't communicate, there isn't communication, [Name] as you said, the transition coming out of CAMHS and going to University and he was supported, but it didn't count for an awful lot, because they're adult services, and they do it a different way and what have you."

Name	Description	Example
Lack of communication to parents	Used specifically when parent/carers were talking about a lack of communication from services about their child's mental health.	"Well I think, it's quite difficult, because obviously there's the confidentiality aspect between [Name] and his counsellor, but I think it would have helped if we were told 'These are the sorts of things you can do, these are the sorts of strategies' or some sort of family counselling."
Not involved in decision making	Used when participants spoke about decisions about their care being made for them, without being consulted themselves.	"What we feel is, what I feel is, [Name] was chucked out of CAMHS into nothing basically, it was like 'You're 18, that's over, off you go now'."
Lack of engagement	Used when a young person doesn't engage with care.	"We did that, one came along for one session, but [Name] was like 'no, not doing that again', I don't know what happened in there, whether it as the attitude of the therapist, the attitude of that person, or the probing questions she did, I don't know. [Name] wasn't comfortable with it anyway, so we didn't do that again."
Lack of support for parents	Used when parents mentioned not being supported by mental health services.	"And that's not coping with things, being at school, not being understood. And maybe she wouldn't have done that if we'd had the right help, I don't know. Do you know what CAMHS told me to do? They said 'right well what you need to do, is you're obviously going to have to be with her all the time, she can't be left alone at

Name	Description	Example
		all, (I had a job) and you need to make sure the razor blades are clean', and all that. And I just thought 'what am I doing?', 'what's this all about?' – nobody really helped me, and to this day no one's ever offered me any real explanation as to why they can't help me."
Managing illness on your own	Used when participants (or their P/C) mentioned that they were able to cope with their mental illness without professional support.	"I mean she's still, you know sort of, not struggling with your OCD, because you manage it, don't you, but you've still got it, but she manages it well, and I think she's done that since she left CMHS so, yeah I can't really comment because we haven't actually been put in that position"
Fresh start	Used when young people described leaving CAMHS or moving to have a fresh start.	"Erm, and then she moved 6th form because, well basically you wanted a fresh start, didn't you?"
'I learnt to deal with it on my own'	Used when participants mentioned learning to cope or reduce their symptoms on their own.	"So in the end, I was like, I'm not going to be able to have a life if I keep being anxious."
Medication	Used to code any reference to medication and managing medication.	"my wife was keeping an eye on the medication she was on, and my wife's a nurse so she knows a bit about the medication and

Name	Description	Example
		what they all need. And really it was then just a period of time of trying to keep [Name] on the straight and narrow really,"
Accessing medication	Used to code any mention of accessing medication after leaving CAMHS	"I'm not on medication now, and I haven't been since I was 18, basically since I needed to be seeing a doctor to be able to be prescribed me more meds, I didn't have one at the time."
Changing dosage	Used to code any mention of wanting to change their dosage of their medication	"I'm not sure. I haven't had a medication review for a… ages actually. So I probably could go to the Doctors down here, but then again, last time I went to discuss about my medication they said they couldn't do it, so, I'm not too sure."
Coming off medication	Used to code mentions of coming off, or wanting to come off medication	"I've just been taking it, but I haven't really thought about 'Oh, should I still be taking this or should I not, do I need it?'"
Cost of medication	Used to code any reference to the cost of medication	"And the other problem we have is with the medication, they don't put it on a repeat for her, and if they do it's only for 4 weeks. So she's paying a prescription charge every month. And so I said to the doctor yesterday, when it's on a repeat can you give her 3 months at least? You know, they've got all this other stuff going on in their head, they don't want to be worrying about money as well, and it's not fair is it?"

Name	Description	Example
Reliance on medication	Used to code any mention of feeling as though mental health services had a medicalised approach, without offering alternative therapies.	"And you just sit there and you talk to a psychiatrist, and a psychiatrist they just seem to zone in on medication, it was all medication, they didn't really tackle what was going on, the issues. That was it, they just give you a prescription, and that's it, you're on your way."
MH awareness	Used to code mentions of increased/improved mental health awareness in the current social climate.	"And obviously, they're meant to have training in it now, I can understand 5, 10 years ago, but now it's meant to be a thing they learn about, and how to like, if a patient's like 'I'm feeling suicidal' they're not meant to go 'Oh that's not a medical problem, there's not really a lot we can do'."
MH service provision	Used when participants talk about things to do with availability of services or service provision more generally. See also: Waiting lists.	"I understand it's the way the system works as in, there's so many people. I knew that, sometimes you'd wait weeks for an appointment, because there's so many kids, with all different issues and problems, and there were people more severe than me and people not as severe, so like I knew that I wasn't first priority, I knew that."

Name	Description	Example
Missing out on life	Used when participants described missing out on usual activities due to their mental health.	"And also when, there was a period last year where I was really down, and I didn't leave my bedroom for a few, for the week, and I wasn't eating or drinking,"
NEET	Used when participants explain that their currently not in employment, education or training.	"I kind of, don't have the stress of a job or anything at the moment, so it's not like things can go majorly downhill for me, do you get what I mean?"
Not living up to potential	Used specifically when participants mentioned having poorer grades or not finishing education due to their mental health.	"No, because I finished school and then that was it. I couldn't cope with college, yeah, it was just like too many people, and yeah."
Multiple clinicians	Used when participants mention more than one change of clinician, or seeing multiple clinicians at the same time.	"the thing that annoyed me at CAMHS was the fact that every 6 months they'd change, someone, like they'd do their 6 month course, or, you know what I mean, for them to get to a higher point, and then they'd swap you. So just, I'd finally got close to [Name] and opened up to her about my anger and all these things, and then she got swapped, and then the person who came after her wasn't like [Name], and I didn't like them."
Negative effect on YP	Used when participants described any negative which had resulted from falling through the gap.	"Erm, I felt a lot less, sort of confident. Erm, like because I suddenly felt a lot of pressure to get this second, get into this next stepping

Name	Description	Example
		stone. Sort of felt very nervous about it… more new people, new routine to familiarise myself with as well… which felt like, uncomfortable as well. Yeah, just felt awkward and stuff, don't know. I'm not explaining it the best, but it's just, nah, I don't really know how to put it exactly."
Blaming self	Used when participants blamed themselves for not getting accepted into a mental health service.	"Err, I thought, well even the GP was surprised. I think, maybe, I hadn't described my situation properly maybe, I don't know, it's…. I don't know. I also thought 'Where do I go then? What do I do?'"
Feeling let down	Used when participants described feeling let down by mental health services.	"It just feels like we've been let down, massively. And I know that she's not the only one in the same situation,"
Feeling like no one cares	Used to code participant's feeling as though no one in mental health services cares about them.	"It kind of hurt, it kind of felt like no one really cares and no one really wants to help me because and they're just like, they don't care. It's like, I feel like when you're under 18 if something happens then it's someone's fault and they're going to get sued for it but once you're over 18 no one, no one would suffer from it so they'd just leave you to die."

Name	Description	Example
Feeling unsafe	Used when participants mentioned feeling unsafe in regards to their treatment.	“I didn’t mind that I wasn’t taking any of the medication anymore but on the other side I thought I really should be taking some medication and it kind of made me feel unsafe, because no one cares enough to give me the proper treatment.”
Feeling unsupported	Used for any mention of feeling unsupported.	“It's kind of, made it worse I think because she feels like she's not getting the support. She's, she feels like there's nobody there for her, and if she can't talk to me, then who does she talk to?”
No joined up care	Used to code examples of poorly joined up care.	Interviewer: “Okay no problem. And so then back when CAMHS care came to an end, do you know why you weren’t referred onwards to an adult service?” Responder 2: “They said there wasn’t an automatic referral.”
Not holistic care	Used to code examples of care not taking into account all of the young person’s symptoms	“We did try, to get counselling. Erm, and [Name] you’ve got to be honest with us now, right. [Name’s] got an alcohol problem. Don’t be embarrassed! And he’s had a bit of a tough time in the last couple of years, and we felt he needed some counselling. But he can’t get counselling until he doesn’t drink. So we’re stuck in this no-win situation again.”

Name	Description	Example
Self-referral	Use when participants spoke about having to self-refer to a service.	“and it was self, self-referral as well. So, getting round to that, it took a while after I turned 18.”
Not ill enough	Used when participants feel or are told that they aren’t ill enough to access ongoing treatment, or are on a waiting list because they aren’t severe enough to be seen straight away. See also: Not a priority.	“And if someone’s like ‘their scars are deeper than yours, your cuts’ then they’re obviously trying to kill themselves. But it’s not like that”
AMHS not accepting that YP	Used when participants spoke of not being accepted for care at AMHS.	“Then it’s like adult mental health, but they wouldn’t, say like you had to meet a certain criteria, they kept saying ‘You don’t meet that criteria’, and still I don’t know what that criteria is.”
Not getting a diagnosis	Used when participants mentioned the impact that not getting a diagnosis had on their ability to access future care.	“So as I say, they wouldn’t really diagnose, well they rarely do. They don’t like labelling ADHD or anything like that, they don’t like labelling children full-stop. So they do nothing, they do absolutely nothing.”
Not in crisis	Used when participants described not being able to access help because they weren’t currently experiencing a mental health crisis.	“Oh that was another thing, when I went to see the mental health team, they would always ask ’Have you thought about harming yourself, or attempted suicide?’, then, if you say no, they literally

Name	Description	Example
		just say 'Well, you're fine'. That, it is honestly, it's as obvious as that."
Not severely ill enough	Used when participants described a struggle to access care because they were not severely ill enough to meet the treatment threshold.	"I do feel there's this black hole before you go into the adult, and I just got the impression that [Name] wasn't severe enough, if anything did happen, she wasn't severe enough to really go into the adult mental health services or her case wouldn't have been taken as seriously, because there's a lot worse cases in there."
Rejected referral	Used to code any mention of a referral being rejected.	"He referred me ASD, is that what it's called? Oh yeah to the autism panel, so they could give me a diagnosis, but we didn't hear back from them either, they'd refused my case or something"
Not involving PC	Used when parent/carers reported not being involved in decisions about their child's care.	"You get a contact, and then it's a case of 'He's got to be independent', and you'd say 'I never interfered, unless there was a crisis, and I was hitting crisis point with [Name]' and I got so many push backs essentially 'He's 18, and therefore he's got to get on with it'."

Name	Description	Example
On the outside	Used when parent/carers mentioned feeling not included in their child's care.	"I did find it hard, it's the fact that she's 18 and an adult, how much can I be involved and how much can I speak on her behalf and will they listen to me, that's the difficult thing."
Not knowing where to go for help	Used when participants described not knowing where they could go for help for their mental health.	"Yeah, there is certainly times, a lot of times, where I feel like I should need some help, but I don't know where to go exactly. Which sucks."
On your own	Used when participants mentioned feeling on their own after leaving CAMHS.	"But in terms of CAMHS, the 18 issue, yes, magically when someone turns 18, they do not, not require the same support and the same service. But it's a case of 'Well, you're on your own'. And that's very sad."
PC help after CAMHS	Used to code any mention of parent/carers helping their child with practicalities after leaving CAMHS.	"I can't help but think, I was lucky my Mum did it. What if I was one of those kids who's in the care system, and all of a sudden at 18, I've got to organise all myself, I'm an 18 year old kid just thrown out in the world to get a flat, not knowing a clue, no one to back me up and support me like my Mum did."
PC helping YP to access care	Used to code parents helping their child to access mental health care.	"I actually made a self, I made the referral myself, which they did take off me as a Mum, which was quite unusual. Because of the

Name	Description	Example
		Asperger's, they did take it off me, and then we accessed that directly."
PC keeping an eye on YP's mental health	Used to code parents monitoring their child's mental health.	"I mean now, obviously [Name's] at university so I don't see her every day. And sometimes when we're all ticking over quite nicely, I almost forget about it almost, it's not always on your mind. But then suddenly something happens and I think 'Oh, oh no, it's still an issue, we've got to keep our eye on it', it's still something that happens when you're stressed or something, or if it's a bad day, and I think 'Oh okay, we do still need to keep an eye on things', and you know, not let things slip or slide."
PC providing emotional support	Used for any mention of parent/carers providing emotional support to their child.	"Oh well I always speak to Mum, I speak to her most days, she always knows what's going on."
PC taking on role of 'Doctor'	Used when parent/carers were described or described themselves carrying out the role of a doctor in their child's care.	"My mum's been ill since I was born, she takes a lot of medications for fibromyalgia, so she knows all about weaning people off medication, so she helped me. Over Christmas and with the new prescription she helped me wean off the medication properly, I didn't have any bad side effects…"

Name	Description	Example
Planning for transition	Used for any mention of transition planning.	“It was almost like, when I turned 17 wasn’t it that he was like ‘At some point we’re going to have to start thinking about what happens when you turn 18’.”
Coping strategies	Used to code any mention of CAMHS clinician helping provide coping strategies before leaving the service.	“because he gave us plenty of warning I had time to ask questions and sort of plan strategies for how we would cope, the practicalities of it.”
Good information at TB	Used when participants mentioned being given useful information at the CAMHS transition boundary.	“Erm, well in terms of, in terms of transition, I think we were fortunate because we worked, and prepared, and planned for [Name], not, no longer seeing [MHN],”
Involved in decision making	Used when participants mentioned being involved in decisions around the end of CAMHS.	“it was very much like ‘Choose when you want it to end’ not like them saying.”
Joint meeting	Used to code anything about a joint meeting with CAMHS and AMHS and the young person.	“I wouldn’t say it was ever communicated to me, because when I had that meeting with the woman from the adult mental health service, she, anything I kind of went to say, my actual CAMHS clinician would butt in, and she’d be like ‘Yeah, but it’s anxiety we’re treating here, and that’, and the other person from the adult mental health service, she did come to the conclusion at the end,

Name	Description	Example
		she was like 'Yeah, I don't think we can do anything for you'. But I don't know if it would have been different if she'd just heard what I was to say, rather than what my clinician had to say. So it didn't feel like I was ever seen as a case, it did kind of feel like before I'd seen both of them, she had said 'Don't let her go to adult mental health, she doesn't need it'. It was very uncomfortable."
Lack of information at TB	Used to code participants feeling as though they received poor information at the CAMHS transition boundary.	"to do these things. It seems like 'Here's another leaflet, go away and read the leaflet, make the phone call, look on the website' – I mean [Name's] not that severe, and he doesn't want to do it, he's not confident doing it, not the kicking off, the first stage. And I get constantly frustrated about giving him leaflets and stuff, even reading a book isn't so good"
Poor transition planning	Use for any mention of poor transition planning in CAMHS.	"No, he told me nothing. Literally it was like, they mentioned adult services, and then that was it. They didn't tell me what they were, how to contact them. Really I think they should have contacted them for me and referred me over, that's their job, not mine. But they didn't even give me a leaflet, that's how bad it was"

Name	Description	Example
Sudden cut off	Used for any mention of a sudden end to care at CAMHS.	“I agree with [Name] exactly, he was just, it came to a sudden end, that was the thing. One day they’re there, the next day they’re not.”
Poor experience of AMHS	Used when participants are describing a poor experience with adult mental health services. AMHS are NHS mental health services, usually based in hospitals. Don’t use for community mental health services.	“this is AMHS, it’s the adult one, it’s next door, or over the road or whatever it was, this is where people who are over 17 plus go and stuff. And that was it really.”
Lack of help from AMHS	Used to code participants view that they haven’t received enough care from AMHS	“I mean even now, she had an appointment at [Name] hospital last August, I think it was, and since that date, she's only just had another appointment last Friday, and now they've told her she's got to wait another 6 months. What does she do in the meantime? She's got nothing, absolutely nothing other than the medication.”
Poor experience of CAMHS	Used to code poor experiences of care at CAMHS	“I must have had about 30 people altogether over the years, possibly more, from psychiatrists to just counsellors, to students, I’ve had all of them really. And you have to explain the same thing to them again and again and again. And then they swap them again. So, in the end, I had the attitude of ‘what’s the point?’, and I hated going to CAMHS.”

Name	Description	Example
CAMHS not offering recommended treatment	Used when participants were explaining that they weren't offered the recommended therapy for their diagnosis/they mention just receiving general counselling e.g. 'asking about their week' rather than any targeted therapy.	"because it took so many years, when they finally were like 'Oh you need CBT therapy', it was 5 years too late. I'd finished high school, had scars, already tried to commit suicide god knows how many times, flunked high school, and then they were like 'oh we could possibly offer you this therapy but you might be on this waiting list for a year'."
Not getting to the core of symptoms	Used to code instances of CAMHS not treating the root of the young person's symptoms, or in this case, starting to do it (but years after she started at CAMHS) but not finishing, because she reached the CAMHS transition boundary.	"Because at that point, I was like 'What's the point in even going to this?' Because you're meant to do a certain number of sessions, this is what she said to me. You're meant to do a certain amount of sessions, because each session's different and… it's to do with getting to the, what's the word… I don't know what the word is… the centre or the core of your problem and where your anxiety stems from."
Poor experience of CMHS	CMHS = Community Mental Health Services Used when participants are describing a poor experience with community mental health services e.g. counselling service, drop in service.	"And [County] do Healthy Minds. It works where you have to refer yourself, which is all fine, but it takes a while, so I had to call them, and then they had to call me back, and that was a week later, and they do an assessment over the phone."

Name	Description	Example
Poor needs assessment	Used when participants described having a negative experience with an eligibility assessment for a mental health service.	"I think it was a 5 minute phone call, I mean how can you assess someone's mental health requirements with a 5 minute phone call?"
Telephone assessment	Used when participants describe having a telephone assessment to determine whether they can access mental health services.	"I had to call them, and then they had to call me back, and that was a week later, and they do an assessment over the phone. Yeah they do an assessment over the phone, whenever they send you an email or a letter or."
Put off accessing further care	Used when participants mentioned being put off accessing further care due to problems with care received.	"I've got to that stage with them now where I can't be arsed with them. If they can't be arsed with me, I can't be arsed with them. I'm not going to be their little ball, that they keep on pinging from pillar to post, just so they can fill in statistics. They can either help me, or not help me, and if they're not going to help me they may as well just tell me straight to my face, and stop wasting both of our times."
Being in control	Used to code participants not wanting to continue care because they wanted to be in control of what it was and when it ended.	"Because if it comes to the part where you tell me I've got to let go I don't think I will be able to, so I'd like to do that on my terms, so I just said 'this will be the last sort of session'. But she was like 'I can offer you two or three more sessions' and I was like 'I don't think I

Name	Description	Example
		want to go that far and then for you to tell me that I can't come back'."
Difference between child and adult care	Used to code participants being put off due to the differences between child and adult services.	"We had the time, and obviously it was the right time I think, and erm, he did make adult mental health services sound not too appealing really, you know, you have to, like when you're a child, people look after you, don't they? But when you're an adult, people are less perhaps – I don't know whether it's because he thought we were ready to go, and he thought 'I can transfer you but it's not, there's no point', so I wonder if he was trying to persuade us that we should stand on our own two feet a bit."
Needing trusting relationship with clinician	Used when participants described being put off accessing further services because they didn't want to see someone new.	"Like I said, I have to get to know someone before I'm going to talk to them first, and I want to know as much about them, the individual, as they want to know about me. To me, they're a stranger, whether they're a professional or not. I have to meet them at least 5 or 6 times before I'll open up."
Poor relationship with clinician	Used when participants talk about a poor relationship with any health professional.	"So just, I'd finally got close to [Name] and opened up to her about my anger and all these things, and then she got swapped, and then the person who came after her wasn't like [Name], and I didn't like

Name	Description	Example
		them. So I ended up swapping them again, and by the time I saw any, I don't think I actually saw anyone again, that I really like clicked with, that I could open up to,"
Repeating story	Used when participants mention having to repeat their story to different clinicians or services. See also: Multiple clinicians	"There's no… I don't know how to explain it, there's no.. a lot of the doctors I saw just looked at a file, some of them didn't even read the file, and just asked me the exact same questions, and then it was explaining the same thing again."
Stigma	Used to code feelings of stigma. See also: MH awareness	"I've got that one [a scar] that I hate, and whenever I notice it I get upset. When did I start going out, when I turned 18 and stuff, people would notice it and be like 'Oh what's that?' and I'd be like 'Oh I was attacked by a dog', that's what I'd say."
Trust	Used for any mention or implied mention of Trust, either between young person and clinician, or young person and parent/carer.	"And it got to the point that every time she went somewhere, we'd drill into her that 'Okay, you must let us know when you get there, let us know if there's a problem, let us know this, let us know that'."

Name	Description	Example
Wanting to be normal	Used when young people talked about wanting to be normal (in terms of not being treated differently in terms of their mental health)	“I remember you just saying like, when you used to get upset, saying you just wanted to be normal. You wanted to be like everybody else, you didn’t want to keep coming out of school”
'What's the point'	Used to code participants feelings that there isn’t any point to attending care at a particular service. See also: Lack of engagement	“Because at that point, I was like ‘What’s the point in even going to this?’ Because you’re meant to do a certain number of sessions, this is what she said to me. You’re meant to do a certain amount of sessions, because each session’s different”
Quote	Used to code quotes which could be useful during the write up.	“So it was a big, there was no step down as you call it, it was like a cliff, you know, you’ve got this level of support, then you fall off a cliff and it’s nothing.”
Self-harming	Used to code any mention of self-harm	“And that’s how they see you as a priority, it’s like ‘oh you’ve got more cuts this week, you’re more depressed’ or something.”
Serious effects of lack of support	Used when participants mentioned any life threatening consequences of not receiving mental health care.	“I’m really lucky that I’ve got really loving parents who look after me and make sure that I’m not in danger, but if I had any less of a support system I’d probably be dead by now because it took them so long to do anything.”

Name	Description	Example
Specialist service	Used to code any mention of a specialist mental health service, such as the crisis team or any condition – specific service.	“he had an intensive weekly programme, and then it went to monthly, and then it was two monthly, three monthly, and they agreed it with him, and then there was a therapist I could check in with who actually”
Crisis team	Use for any mention of the crisis team.	“So went he went into A&E, he was put into the emergency pool of counsellors, and he spent I think, it must have been about 2 or 3 months with that particular counsellor. But the policy was that he couldn’t remain with that particular counsellor, because they were only there for emergency provision.”
Inpatient care	Use for any mention of inpatient care.	“Yeah. And even then, once they did that it’s a case of… ‘Okay, where are we going to put him?’ He was fortunate, he did go, there was a, I can’t remember what it’s called, the name of it, it’s a psychiatric unit for adolescents, which he was placed, however at the time, they were, they were decorating, so they had to relocate to another unit, which meant it had gone from a 12 place, to 8 place.”

Name	Description	Example
Stability	Used when participants describe periods of stability (often associated with withdrawal from services, or services withdrawing from them).	"When I was seeing this woman at CAMHS, she asked me if I thought I needed help with AMHS, and I said no, because I didn't want to go through the process – I was actually doing pretty well at the time too, I'll admit that, I was in a relationship and had started a new job, I was doing pretty well. Things hadn't fell apart at this point, so to me, it was like, I was like, I know they're there, I'll contact you if I need you. And she was like 'okay then'… and that was it really. And then, I think, I had a complete meltdown,"
Start of care at CAMHS	Used when participants describe how their care at CAMHS started.	"I first started receiving care at CAMHS, not exactly sure how old I was, but I was in junior school, and I think I was about 9… don't quote me on that one, I think, I was in year 5, struggling with the loss of my uncle, and grief counselling wasn't doing,"
Support at School	Use to code any mention of support the young person received for their mental health at school.	"But really, with going back to school, he had support at school, he always had a support teacher. And then suddenly you go to college and he's back, he's suddenly in this adult world again, there's no one to support him. And this is where things start deteriorating, because he's just the same as anybody else there, and he's not. And he's not going to be, so he needed that extra support."

Name	Description	Example
Support for parents	Use to code any mention of support for parents from mental health services or schools to help them manage their child's mental health.	"But I think because of the support we got, in particular family therapy, it was the worst time of our life but it was the best time of our life, because as a family unit, we became so close and worked really well together. And because with - it was constantly, constantly reinforced, you know to stay calm, stay compassionate, deal with it, you know, I think it was, was it something called family, not family therapy, I can't remember, the Maudsley technique anyway, that they were using, that they were teaching us."
Support from friends	Used to code mentions of young people receiving support for their mental health from their friends.	"Erm, he has lots of female friends, and I think he would. And I think most of these female friends, he's met via mental health issues, so I think they do share a lot, and do have a lot in common."
Surprise	Used when participants describe feeling surprised or shocked about their mental illness, reaching the transition boundary or service provision. See also: 'Came out of the blue'	"So there were a number of things going on at the same time, and it all really, it seemed like, not every day but every week, there'd be another shock, another surprise for us, what next, you know?"
Transition Gap	Used when participants specifically describe a gap after CAMHS.	"I think there is this big gap, and people underestimate the change that you go from loads of support with CAMHS, lots of involvement

Name	Description	Example
		with the parents, and you're fully in the picture, you know what's going on, and you feel like you're involved and you feel like you can help. At the end of the day it wasn't just CAMS, we hadn't absolved any responsibility, it was like, you know, CAMHS was there to help, we'll help, and we'll all get through it. But then take CAMHS away, and then it was like, overnight, you're and adult now, you're in adult care, we can't tell your parents what's going on, and we relied then on [Name] really to tell us how she was feeling, and what had gone on, and of course she was in no mood to tell us."
Uncertainty	Used to code any feelings of uncertainty after leaving CAMHS.	"So I did feel that, you know, where would we turn after CAMHS if anything went downhill"
'What happens then'	Used to describe the uncertainty faced by YP and P/C as CAMHS came to an end. See also: CAMHS TB & Transition Gap.	"To be fair, as I said, we were pretty late into the process anyway, because she was 15 at the time. Sot we were just getting into the steam of things, and then before we knew it, it was like 'oh okay, this next one will be your last one'. And then it was like 'oh, what happens then?' You know?"

Name	Description	Example
Unmet care need	Used to code any mention of having a need for care, which they were unable to access.	“But he can’t get counselling until he doesn’t drink. So we’re stuck in this no-win situation again.”
Waiting list	Used for any mention of a waiting list, waiting a long time between appointments or waiting for services.	“they were like ‘oh we could possibly offer you this therapy but you might be on this waiting list for a year’. So in the end, I was like, what’s the point?”
YP-PC relationship	Used when participants mention the relationship between YP & PC. See also: Trust.	“like obviously I’ve got quite a supportive family, and yeah I’ve had problems with my mum with it, believe me for years because she didn’t believe that I was ill for a long time and all these things.”