

In transition between child and adult services for young people with
Attention Deficit Hyperactivity Disorder (ADHD);
the need for transition and the use and usefulness of the National
Institute of Health and Care Excellence (NICE) guidelines

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Abstract

This thesis focussed on the transition between child and adult services for young people with Attention Deficit Hyperactivity Disorder (ADHD). It aimed to estimate the incidence of transition, and identify guidelines and protocols for transition and how these are implemented. It also considers the influence of the National Institute of Health and Care Excellence (NICE) guidelines within current health service provision.

A multi-method approach was used. A systematic review of existing guidelines for ADHD transition was conducted, providing an overview of current literature. A surveillance study was carried out to estimate the incidence of transition, and to identify whether clinicians adhere to the elements of optimal transition. Clinicians from the surveillance study were invited to participate in a qualitative interview, to gain further insight into their perspectives of the NICE guidelines and how these are used. Finally, the NICE guidelines are considered in a legal context and the question of whether the law can play a part in the transition of young people with ADHD is discussed.

In 2016, 315 young people in the British Isles required a transition to an adult service, but only 22% of them completed the transition and were seen in the adult service. An estimated incidence rate of transition was calculated between 202.9 and 511.2 per 100,000 population aged 17-19 per year. The estimated rate of successful transition ranged between 38.5 and 96.9 per 100,000 population aged 17-19 per year. The only available guidelines for transition are the NICE guidelines, and any locally produced protocols are based on what NICE recommend. Interviews with clinicians (n=38) indicated that information transfer occurs between services, but joint working and continuity of care is often not evident, despite the surveillance study demonstrating that a period of joint working is a strong predictor of successful transition. Full implementation of the NICE guidelines could enhance the transition process and have a positive impact on the wellbeing of the young person. However, NICE guidelines are not mandatory, and adherence is poor.

In summary, the findings of this thesis highlight the substantial need for transition in ADHD. Current practice does not closely follow the NICE guidelines.

Considering the long term implications of poorly managed ADHD and transition for young people and society, it raises questions about the purpose of NICE guidelines if there is a lack of adherence, and clinicians do not consider them a priority.

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Firstly I would like to thank my supervisors. Dr Astrid Janssens has supported me daily in this work and pushed me out of my comfort zone, always believing that I could succeed with every paper or presentation. Thank you for the support, friendship, and for teaching me so much about how to run a research project. Your door was always open to every single question (of which I had many!), I have learned so much from you and will always be thankful. Professor Tamsin Ford and Professor Anne Barlow, thank you for guiding me, being so confident in my ability and so interested in my work, particularly in the legal element. All three supervisors have been pivotal in my thesis, and I am sincerely grateful for all of their support. I could not have completed this thesis without their knowledge and experience. I am incredibly lucky to have had the opportunity to work alongside, and learn so much, from three such strong, successful, academic women. I look forward to continued collaboration with them in the future.

I would like to thank my colleagues at the University, in particular the CATCh-uS team who have been a huge part of this work and have helped me endlessly along the way. Thanks also go to my wonderful family and friends who have believed I could do it from day one.

Finally, I would like to dedicate this thesis to my parents. They won't get the chance to read this thesis, but they always supported whatever path I chose to take. They would have encouraged me without question, been the first to cheer at my successes, and without them I would never have taken the opportunity to do this work or got to where I am today.

“Difficult roads often lead to beautiful destinations”

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Author's declaration

This PhD has been conducted alongside a larger collaborative National Institute of Health Research (NIHR) funded study at the University of Exeter Medical School (UEMS). The study was called CATCh-uS – children and adolescents with Attention Deficit Hyperactivity Disorder (ADHD) in transition from child to adult services (Ford et al., 2015). I was employed as an Associate Research Fellow on the CATCh-uS project while undertaking the PhD.

I will outline below the parts of the CATCh-uS project which have been used for the PhD, where they appear in the thesis, and my individual contribution to the work. All other parts of the thesis not described in this declaration are my own.

Surveillance study (Chapter Three):

The surveillance study presented in Chapter Three was developed as part of the CATCh-uS protocol using an existing standardised and regulated methodology. I conducted and managed the surveillance from the beginning of the study independently, including data collection and management, and I have led the data analysis and write up. The chapter on the surveillance study in this thesis consists of a full write up of the surveillance study, a very similar version of which has also been used as part of the final NIHR study report for CATCh-uS (to be published in 2019). I have led the write up of this chapter and liaised with co-authors for their contributions. I have also led and written a research paper which summarises the findings of the surveillance study that has been published in the British Journal of Psychiatry (Eke et al., 2019a). A copy of this paper can be found as Appendix Three.

Chapter Three also reports on a comparison of the surveillance methodology with an electronic case note review. This part of the chapter was not part of the CATCh-uS protocol and was entirely developed and conducted by myself for the thesis, whilst using data collected through the surveillance for comparison and triangulation. I have led the data collection, data analysis and write up of this study and liaised with co-authors for contributions. The findings of the comparison of the two methodologies have been written in a research paper, and published

in the journal BMC Medical Research Methodology (Eke et al., 2019b). A copy of this paper can be found as Appendix Two.

Qualitative study (Chapter Four):

The qualitative study presented in Chapter Four was developed as part of the CATCh-uS protocol, which included interviews with clinicians, young people and parents. For the purposes of this thesis I have only presented in detail the data that has been collected in the interviews with clinicians working in child and adult services, who were recruited for interview via the surveillance study and mapping study streams of the CATCh-uS study. I have summarised some of the findings from the interviews with young people and parents to provide further context. I led recruitment for the interviews with clinicians, and conducted 25 of the 38 interviews which were completed. I was part of a team of researchers that analysed and summarised the interview data. The chapter presents the methods used, and a detailed analysis and discussion of the findings related to clinicians use of the NICE guidelines, in order to answer the research questions of the thesis.

A research paper that combines the surveillance data and interview data that are specifically related to the use of NICE guidance has also been written from this chapter, which was not part of the original CATCh-uS protocol. I have led the data analysis and write up for this paper and liaised with co-authors for contributions. The paper has been submitted for publication to the journal Child: Care, Health and Development and is currently under review. A copy of this paper can be found as Appendix Four.

Definitions and abbreviations

AADD-UK – a United Kingdom unfunded charity for and by adults with ADHD

ADHD – Attention Deficit Hyperactivity Disorder

AGREE – Advancing guideline development, reporting and evaluation

AMHS – Adult Mental Health Services

ASD – Autism Spectrum Disorder

BAP – British Association of Psychopharmacology

BPSU – British Paediatric Surveillance Unit

BRC – Biomedical Research Centre

CADDRA – Canadian Attention Deficit Hyperactivity Disorder Resource Alliance

CAG – Confidentiality Advisory Group

CAMHS – Child and Adolescent Mental Health Services

CAPSS – Child and Adolescent Psychiatry Surveillance System

CATCh-uS – Children and Adolescents with ADHD in Transition between Child and Adult Services

CCG – Clinical Commissioning Group

CG72 – NICE guideline for Attention deficit hyperactivity disorder: diagnosis and management (prior to 2018)

CI – Confidence Interval

CPA – Care Programme Approach

CRD – Centre for Reviews and Dissemination

CRIS – Clinical Records Interactive Search

DDA – Disability Discrimination Act

DoH – Department of Health

EHC – Education, Health and Care Plans

GP – General Practitioner

HRA – Health Research Authority

HS&DR – Health Services and Delivery Research

HSIB – Healthcare Safety Investigation Branch

INOPSU – International Network of Paediatric Surveillance Units

IRAS – Integrated Research Application System

MeSH – Medical Subject Heading

NG43 – NICE guideline 43 Transition from children’s to adults’ services for young people using health or social care services

NG87 – NICE guideline 87 Attention deficit hyperactivity disorder: diagnosis and management

NHS – National Health Service

NICE – National Institute of Health and Care Excellence

NIHR – National Institute for Health Research

ONS – Office of National Statistics

PALS – Patient Advice and Liaison Service

PPI – Patient and Public Involvement

PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses

RCGP – Royal College of General Practitioners

RCPCH – Royal College of Paediatrics and Child Health

RCPsych – Royal College of Psychiatrists

REC – Research Ethics Committee

ROI – Republic of Ireland

SLaM – South London and Maudsley NHS Trust

SQL – Structured Query Language

SSC – Study Steering Committee

UEMS – University of Exeter Medical School

UK – United Kingdom

US – United States

WHO – World Health Organisation

Chapter One: Introduction and overview of thesis

1.1 Introduction

This thesis focusses on the transition between child and adult services for young people with Attention Deficit Hyperactivity Disorder (ADHD). Recent studies have highlighted the difficulty with transition, particularly for young people with neurodevelopmental disorders such as ADHD. To date there has not been an in-depth study on transition in ADHD that addresses the need, or that considers what should be happening in transition, and how the process of transition is implemented in practice. Using a multi-method approach, the thesis aimed to estimate the incidence of transition, identify guidelines and protocols for transition in services that support young people and adults with ADHD, and identify how the guidelines are implemented. It also aimed to consider the legal influence that the National Institute of Health and Care Excellence (NICE) guidelines have within current health service providers and organisations.

This chapter will discuss the history and role of guidelines in clinical practice. It will then introduce and explain the condition of ADHD, and provide a brief background to the condition and the issue of transition. Finally, it will present the overall research objectives and provide an overview of each chapter and each individual study presented in the thesis.

1.2 Background and rationale for study

The use of clinical guidelines has developed over the past thirty years, as a tool to help health care clinicians provide consistent and efficient care (Woolf et al., 1999), but the origin of the concept of guidelines dates back to Plato's notion of codifying majority decisions (Hurwitz, 1999). Whilst the concept of guidelines about the provision of appropriate care is not new, the emphasis on a systematic evidence base is new (Field and Lohr, 1992). Integrating majority clinical expertise with the best available evidence from systematic research in order to support the clinician in making healthcare decisions, is more currently known as

evidence based medicine (Jackson and Feder, 1998, Sackett et al., 1996). Clinical guidelines summarise the evidence base for patients and practitioners (Lim et al., 2008), but the role of evidence in health care practice has been a topic of debate for those planning, providing and receiving health care services, with many mixed perceptions about its purpose and relevance (Sackett et al., 1996).

Whilst there is increased interest and support in developing guidelines (Eccles et al., 1996) there exists controversy regarding the quality and quantity of the evidence used in development, and the overall effectiveness of guidelines, and thus guidelines can often be misleading or misinterpreted (Woolf et al., 1999, Grimshaw and Russell, 1993). There is also now a wealth of different guidelines, which previous research has suggested is often contradictory or out of date, does not help clinicians with the problem, and removes the autonomy and discretion of clinicians to individualise care to the patient in front of them (Jackson and Feder, 1998, Haycox et al., 1999, Sackett et al., 1996). Further, the implementation of an invalid or poorly evidence based guideline may lead to wasted resources and poorer clinical outcomes (Eccles et al., 1996). Clinical guidelines developed from the best available evidence however, potentially provide the bridge between the evidence and the practice, which can improve health outcomes, consistency and quality of care, as well as providing patients with up to date information about what their clinicians should be doing. Although guidelines are not mandatory, the presence of a clinical guideline could empower the patient with the potential to influence policy, and advocate for better delivery of services to those who need it (Woolf et al., 1999, Eccles et al., 1996). Using guideline implementation to advocate for better services, and the discretionary nature of guideline use, is discussed in more detail in Chapter Five.

The National Institute of Health and Care Excellence (NICE) was established in 1999 by the Department of Health, in order to provide clear standards of care for clinicians working in the National Health Service (NHS). Based on the model of evidence based medicine, the guidelines are developed using expert committees and the best available evidence to achieve clinical and cost-effective impact, with the aim of reducing variation in practice and service provision (Culyer, 2005, Sheldon et al., 2004, NICE, 2017b). NICE currently provide a range of clinical information and have developed clinical guidelines, technology appraisals, quality standards and care pathways. Currently there are over 300 clinical guidelines

and 500 technology appraisals covering the breadth of diagnoses and services within the NHS (NICE, 2018c). Previous commentaries have highlighted that this breadth of available information causes clinicians to be inundated with clinical guidelines which makes it difficult to use them in practice (Jackson and Feder, 1998). NICE became a public body and established in primary legislation in 2013, and hence is applicable to England only (NICE, 2018d).

There is a NICE clinical guideline for the diagnosis and management of Attention Deficit Hyperactivity Disorder (ADHD), originally labelled CG72 but now NG87, which was originally published in 2008 and has since been updated in March 2018. ADHD is a neurodevelopmental disorder characterised by impairing levels of inattentive, hyperactive and impulsive behaviours that are both age inappropriate and present across a range of settings (Furman, 2005, American Psychiatric Association, 2013). It is one of the most common neurodevelopmental disorders managed by child mental health and paediatric services (Ford et al., 2007) and has a worldwide population prevalence in school-age children estimated at 3-5% (Faraone et al., 2015, Faraone et al., 2003). Traditionally, ADHD has been viewed as a childhood disorder but more recent research has shown that 15% of those with childhood ADHD meet the full diagnostic criteria for the disorder at age 25; if those who only partially meet the full diagnostic criteria are included, this figure rises to 65% (Faraone et al., 2006).

Young people with ADHD are at increased risk of poor social, educational and health outcomes compared to the general population. Research has shown that a person with ADHD is more likely to have an addiction or a substance abuse disorder, to underachieve in education and employment, and to have more involvement with the criminal justice system (Faraone et al., 2015), and a study of prison populations showed that a quarter of inmates had a diagnosis of, or met the criteria for, ADHD (Young et al., 2015).

The NICE guidelines recommend that ADHD can be managed with pharmacological treatments or medications for children over the age of five years old, which help to control the core symptoms. Non pharmacological treatments are also recommended in the form of parent training programmes, group based support, and cognitive behavioural therapy (NICE, 2018a, Lange et al., 2018). As diagnosis and prescription rates for ADHD have risen in childhood over the last 30 years, the number of young people reaching the end of children's services has

increased rapidly (Timimi and Radcliffe, 2005, Renoux et al., 2016, Davidovitch et al., 2017), and an increasingly large cohort of young adults diagnosed and managed within children's services, are finding themselves unable to graduate to an adult service when they reach the age boundary of the child service (Hall et al., 2015). Several studies, government documents and policy guidelines highlight the difficulty for young people who require a transition between children's services (usually Child and Adolescent Mental Health Services (CAMHS) or paediatrics) and adult services (Singh et al., 2008). Transition between child and adult services often occurs in parallel with other life transitions such as from school to work, or living at home to living independently. The process of transition should support a young person towards and into a new life stage, extending beyond the simple transfer of clinical responsibility (Beresford, 2004b). A recent systematic review of mental health care systems found that neither the National Health Service (NHS) nor the United States (US) mental health system provided sufficient support or access to adult services for young people (Embrett et al., 2016). NICE provides a specific guideline for transition between child and adult services for young people using health or social care services (NG43) (NICE, 2016b), but these guidelines are generic and not specific to a condition or a diagnosis. The clinical guideline NG87 for general management of ADHD only provides a small and brief section specifically regarding transition for young people with ADHD (NICE, 2018a). Although NICE encourages clinicians to follow the guidelines and health service providers are encouraged to support clinicians in following them, it is important to note that the guidelines are not mandatory.

The success of transition is often evaluated using four defined criteria: 1) continuity of care, 2) parallel care, 3) focussed planning and 4) information transfer (Paul et al., 2013). Further, transition should be a multidimensional process that continues into adult care, marked by joint responsibilities and multidisciplinary working (McCarthy et al., 2012). Successful transition is enhanced by collaborative working among organisations and teams, and adequate resources, providing a continuity of care that meets the young person's needs. In 2011, the government presented a strategy stating how transition could be improved to prevent disengagement from services, which included careful planning, listening to the young person and providing appropriate information and

advice (Department of Health, 2011). If transition is poorly managed, young people with ongoing needs may disengage from services with adverse impacts on their health, but also societal costs as well (Singh et al., 2016).

The NICE guideline for transition (NICE, 2018a) and the Child and Adolescent Mental Health Service (CAMHS) Review (Hall et al., 2013) recommend that adequate transition to adult services for adolescents with ADHD still requiring treatment should include planning, having a lead person and focus on need rather than age (NICE, 2008). The limited literature available on transition in ADHD specifically suggests that these policy recommendations are not often translated into practice. Previous research has suggested that there is no clear monitoring of guideline compliance and that NICE guidance is unlikely to considerably impact clinical practice (Dent and Sadler, 2002). Another study showed that clinical guidelines were only followed in 55% of decisions (Gill, 2001). A good evidence base behind clinical guidelines does not necessarily translate in to good practice (Feder et al., 1999), and structural and organisational barriers have been reported as a reason for the failure to turn evidence into practice (Grimshaw et al., 2004). More recently, NICE have issued a resource impact report for transition from child to adult services in health and social care that states that no significant costs in implementation of transition guidelines are anticipated (NICE, 2016a). If no significant costs in implementation are anticipated, it raises questions around why transition for young people with ADHD remains problematic. A study of 28 European countries has highlighted a lack of transitional policies and support services, a lack of professional subject knowledge about transition, and thus suboptimal transition experiences (Signorini et al., 2018, Kooij et al., 2019). This lack of transition service provision for young people with ADHD may lead to avoidable increased public sector health, social care, welfare and criminal justice costs, and increased social and emotional burden on young people and their families (Lichtenstein et al., 2012, Young et al., 2011).

1.3 Research objectives

This thesis aimed to build on the existing sparse literature on transition in ADHD by investigating what should be happening in health services for young people

with ADHD requiring transition, and exploring what is actually happening in practice. The thesis had the following objectives;

- To provide an overview of existing guidelines and protocols in England for ADHD transition and what they recommend.
- To provide data on a national level about how many young people with ADHD are in need of a transition to adult services and how many successfully transition, and to describe this group of young people
- To explore clinicians' views and experiences of transition, and to identify and describe the factors that optimise or hinder transition.
- To reflect on the impact and consequences that poor transition between services has on the young person.
- To explore the legal context of current guidelines and protocols in England for ADHD transition, and to consider in what ways the law could play a part in reforming services or in advocating for better care.

1.4 Study design and rationale

This thesis used three main research methods in order to answer the research objectives, including a systematic review, a surveillance study and qualitative research. Figure 1 illustrates the whole thesis design.

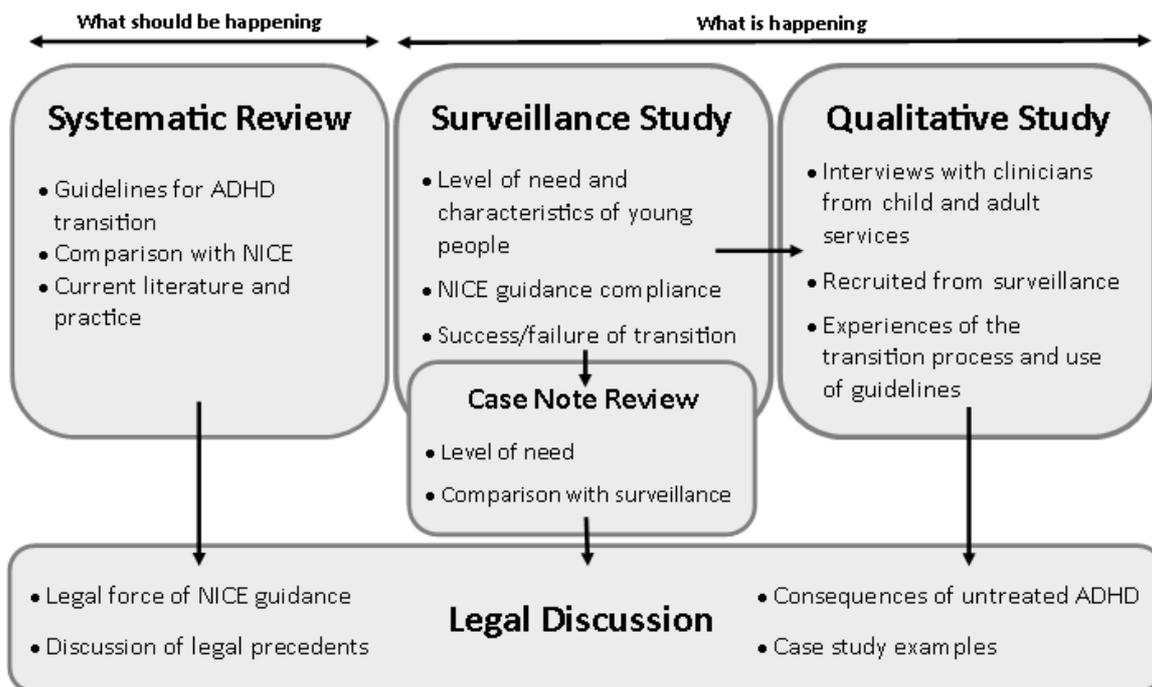


Figure 1. Overview of thesis chapters

These methods were chosen as the research objectives required both quantitative and qualitative approaches, but also because the methods could lead in to one another to enhance sampling, context, credibility, triangulation, and complementarity (Bryman, 2006, Greene et al., 1989).

The systematic review provides the background literature to the whole thesis with an overview of guidelines and protocols for transition specifically for ADHD. This established what should be happening in health services, answering research objective one. The surveillance study collected quantitative data on the need for and incidence of transition, the success of transition, and descriptive data on the young people requiring transition; answering objectives two and three. Due to the novel use of the surveillance methodology in order to estimate the numbers of young people going through the process of transition, a case note review was also conducted. This enhanced the surveillance data and provided triangulation of data and a comparison of relative strengths and weaknesses of the two methodologies. Qualitative data were collected using semi structured interviews, with interview participants being recruited via the surveillance study. Both the surveillance and qualitative studies explore what is actually happening in practice, in relation to implementation of the guidelines, and cover objective four. The surveillance and qualitative findings are combined in a research paper.

Finally, clinical guidelines are considered in a legal discussion, bringing together the findings from the systematic review, surveillance and qualitative work, to answer objective five and six.

The inter-related nature of this thesis draws on health and legal fields to provide a unique and novel picture of what is happening for young people with ADHD within the British Isles who require a transition to an adult service, and how guidelines are implemented in the transition process. It substantially contributes to the knowledge in the field of service transitions for ADHD, and raises important questions about current health service provision for this group of young people.

1.5 Overview of thesis chapters

The process of transition in ADHD was explored using multiple research methods, and there were links between the surveillance study, case note review and the qualitative study. Each of the chapters presented, contributed to the overall aim and research objectives of the thesis.

The systematic review of existing guidelines for ADHD transition (Chapter Two) was conducted in order to provide an overview of the literature relating to the NICE guidelines for transition in ADHD services. The research and literature gathered through the systematic review is used as the 'gold standard' throughout the rest of the thesis to illustrate the process of what should be happening in services that are transitioning young people with ADHD from children's to adult services. The review identified what guidelines currently exist in England, and compared and contrasted any locally available guidelines with the NICE guidelines. This review has been published in the journal of Child and Adolescent Mental Health (Eke et al., 2019c), a copy of which can be found as Appendix One.

The surveillance study and the qualitative study explore the need for and incidence of transition. The findings demonstrate what is actually happening in services in terms of the optimal transition processes in relation to the clinical guidelines for management of ADHD 2018 (NICE, 2018a, Paul et al., 2013). Chapter Three reports the findings of a surveillance study conducted in collaboration with the British Paediatric Surveillance Unit (BPSU) and the Child

and Adolescent Psychiatry Surveillance System (CAPSS). This study, carried out over a one year period, collected questionnaire data at two time points on the incidence of transition, and the characteristics of the young people with ADHD requiring transition. It also gathered data regarding the factors of the transition process that had or had not been implemented in line with the NICE guidance. A follow up questionnaire enabled the outcome of the reported transition to be determined. Alongside the surveillance study, a traditional electronic case note review was conducted using the Clinical Records Interactive Search (CRIS) at the South London and Maudsley Trust (SLaM). A comparison of the two novel methods, surveillance and an electronic case note review, were discussed in a research methodology paper and have been published in the journal BMC Medical Research Methodology (Eke et al., 2019b); a copy of the manuscript can be found as Appendix Two. The main findings from the surveillance study have been reported in a research paper that has been published in the British Journal of Psychiatry (Eke et al., 2019d). A copy of this paper can be found in Appendix Three.

Clinicians that reported ADHD transition cases via the surveillance study were invited to take part in a telephone interview, and 38 clinicians, recruited from both child and adult services, were interviewed (Chapter Four). Interviews were conducted in order to gather the clinician's opinions and experiences of the transition process and to explore how clinicians implemented the NICE guidelines in their practice. A research paper from this study has been submitted for publication to the journal *Child: Care, Health and Development* and is currently under review (Eke et al., in submission), which combined the qualitative findings from the interviews with the quantitative findings from the surveillance study regarding factors of optimal transition. A copy of this paper can be found as Appendix Four.

Finally, in Chapter Five, the NICE guidelines for transition in ADHD are considered in a legal context. Information and findings gathered in the previous chapters are brought together, and discussion centres on the legal force and purpose of guidelines. The chapter also considers how adherence to the guidelines can help the young person with ADHD in transition and why it is important to get transition right for young people with ADHD. Finally, questions are raised and options considered around whether the law has a role to play in

potential health service reform. Could making relevant NICE guidelines legally binding spread best practice and improve transitioning nationally? Or would this have limitation and unintended consequences? Are there other legal avenues to explore?

All studies are brought together in a final chapter of discussion to conclude what the need for transition in ADHD is, how guidelines are playing a part in the process, and potential avenues for future research.

1.6 References

All references included in this chapter, and all other chapters, have been collated in one list for the thesis. The reference list can be found on page 275.

Chapter Two: Systematic review

2.1 Overview of chapter

This chapter consists of a systematic review of existing guidelines for transition in Attention Deficit Hyperactivity Disorder (ADHD). The review was conducted in order to provide an overview of the literature relating to the National Institute for Health and Care Excellence (NICE) guidelines for transition between child and adult services for young people with ADHD. The research and literature gathered in this chapter are used as a 'gold standard' throughout the rest of the thesis to illustrate the process of what *should* be happening in services that are transitioning young people with ADHD from children's to adult services.

The review has two parts. The first part was conducted to identify and highlight what guidelines currently exist for transition in ADHD in England. The second part was conducted to compare and contrast the recommendations from any identified guidelines in part one, with the recommendations for transition in the NICE guidelines for ADHD NG87 (NICE, 2018a). The general principles for systematic reviews as recommended by the University of York (CRD, 2009) were used, and the two parts of the review were brought together in a narrative synthesis.

The rest of this chapter presents the review. I led the design, data collection, data analysis and the write up of the review which has been published in the journal of Child and Adolescent Mental Health. It was accepted for publication on the 9th August 2018, and first published on the 12th September 2018 (Eke et al., 2019c). A copy of the published manuscript can be found as Appendix One.

2.2 Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterised by impairing levels of inattentive, hyperactive and impulsive behaviours (Jick et al., 2004), that can impact on academic achievement, relationships and self-care (Kendall et al., 2008). It is one of the most common

neurodevelopmental disorders managed by child mental health and paediatric services (Ford et al., 2007) with prevalence rates in the United Kingdom (UK) of around 5% in children and adolescents (Faraone et al., 2015). Despite this, services and policies are often not set up to consider ADHD in isolation but as general mental health.

ADHD has traditionally been viewed as a childhood disorder but analysis showed that 15% of those with childhood ADHD met the full diagnostic criteria for the disorder at age 25. If those who partially meet the full criteria, or are considered to be in partial remission, are included this figure rises to 65% at 25 years (Faraone et al., 2006). This has led to the increasing recognition that ADHD is a lifespan disorder (Tatlow-Golden et al., 2018) which raises the issue of transition from child to adult services. Several studies, government documents and policy guidelines highlight the difficulty for young people who require a transition between children's services (usually Child and Adolescent Mental Health Services (CAMHS) or paediatrics) and adult services (Singh et al., 2008). Transition should support a young person towards and onto a new life stage, extending beyond the simple transfer of clinical responsibility (Beresford, 2004b); a successful transition has been described as being coordinated, purposeful, planned and patient centred (Singh and Tuomainen, 2015).

A report for commissioners highlights the vulnerability of young people aged 16 to 18, in a period of physiological, emotional and social change, who are at higher risk of transition problems. It is recommended that clinical support remains consistent and uninterrupted (Joint Commissioning Panel for Mental Health, 2013), and local policies for transition are important to enable that support.

In order to support young people in transition in the UK, the National Institute of Health and Care Excellence (NICE) and the CAMHS Review (Hall et al., 2013) recommend that adequate transition for adolescents who still require mental health services should include comprehensive planning, focus on *need* rather than *age*, and be coordinated by a lead person (NICE, 2016b). With recognition of ADHD as a long term condition, and increased prescription rates for ADHD in childhood, the number of graduates of ADHD from children's services has increased rapidly (Timimi and Radcliffe, 2005) which makes optimal transition particularly important. Potential barriers to an optimal transition include poor communication and collaboration, different funding structures, a lack of

understanding across services, and time and resource constraints, and it is reported that as few as 15% of the ADHD patients that require continued support and treatment make the transition successfully (Singh and Tuomainen, 2015). Additionally, research has shown that there are a lack of specialist services for ADHD in adulthood, and a lack of ways to access them (Young et al., 2011, Coghill, 2016, Hall et al., 2013).

The association between childhood ADHD and criminality in adulthood has previously been highlighted (Mordre et al., 2011, Fletcher and Wolfe, 2009) and a study of ADHD and criminality in Sweden has demonstrated how medication use can reduce criminal rates (Lichtenstein et al., 2012). Therefore it is important to manage the period of transition to adulthood well, as failure to do so can lead to unmet needs, disengagement from services and poor life outcomes (Singh and Tuomainen, 2015).

Two recent systematic reviews highlight a lack of services and guidelines for young adults with ADHD. The first, a systematic review of mental health care systems, found that neither the UK's National Health Service (NHS) nor United States (US) mental health system provided sufficient support or access to adult services for young people (Embrett et al., 2016). The second, an international systematic review of guidelines for ADHD (Seixas et al., 2012), suggests that there are limited data or studies about ADHD and transition.

The review of guidelines by Seixas, Weiss and Muller (2012) discussed ten different international guidelines and included recommendations for management of ADHD. Since publication, two included guidelines have been updated. The NICE guideline in the UK, and the Canadian Attention Deficit Hyperactivity Disorder Resource Alliance (CADDRA) (Canadian ADHD Resource Alliance, 2018, NICE, 2018a) were both updated in 2018. All included guidelines provide recommendations for clinical diagnosis and management of ADHD however only two of the included guidelines referred to any recommendations for transition from child to adult services; the British Association of Psychopharmacology (BAP) (Bolea-Alamanac et al., 2014) and the NICE guidelines for England (NICE, 2008). The BAP guidelines were the first guidelines to be produced on ADHD in adolescents and adults with ADHD in transition to adult services (Seixas et al., 2012), however they describe considerations and uncertainties in the diagnosis and management of ADHD for clinicians, and do not explicitly list

recommendations for a smooth transition process between services. The NICE guidelines (NICE, 2008) which were published after the BAP guidelines, provided a full review of diagnosis and management for ADHD across the lifespan, and were significant in developing improved service provision in the UK.

NICE was established in order to improve health and social care by reducing variation in the availability and quality of NHS treatments and care, and the organisation has been established in primary legislation since 2013. All of the NICE clinical or national guidelines are therefore applicable to England only (NICE, 2017). In March 2018 (previously published in 2008, with an update in 2016) NICE published an updated clinical guideline for the diagnosis and management of ADHD (originally CG72, now NG87) which explicitly lists a short detailed section with the following recommendations for transition to an adult service (section 1.1.4, 1.1.5 and 1.1.6 of NG87):

- Young person should be reassessed at school leaving age to establish need for transition
- Transition should be complete by age 18
- Plan for smooth transition should be made with details of anticipated treatment and service young person requires
- Formal meeting between child and adult service should be considered
- Information should be provided to young person about adult service
- Care Programme Approach (CPA) should be used
- The young person and parent/carer should be involved in planning
- After transition, young person should be re-assessed at adult service – to include personal, educational, occupational and social functioning

(NICE, 2018a)

The guideline NG87 published in 2018 has made no changes to the content of the transition recommendations that were listed in the 2008 and 2016 (CG72) versions. It does however now refer the reader to guideline NG43, the general guidelines for health and social care transitions that is not condition specific, published in 2016 (NICE, 2016b).

Although there has been an increased interest in transition and guidelines for the management of ADHD, there is still a scarcity of services and a lack of

successful transitions (Bolea-Alamanac et al., 2014, Singh et al., 2009). This current review therefore aims to understand what transition guidelines and protocols exist for ADHD services in England specifically, and to potentially identify any gaps in service protocols. The NICE guidelines include local NHS services in their consultation, and review current evidence, however it is not mandatory that health services implement them locally. The NICE guidelines have also not had the evidence base for transition reviewed or the recommendations updated since 2008. Focussing on England and ADHD transition specifically, this review aims to identify local ADHD service policies, if these are in line with the NICE guidance, and what variations exist. To our knowledge, there are no existing reviews to date looking specifically at ADHD transition guidelines.

2.3 Methods

This review followed the general principles for systematic reviewing published by the University of York (CRD, 2009). It consists of two parts; an overview of existing ADHD transition guidelines and recommendations in England, and a comparison of these guidelines with NG87 for the diagnosis and management of ADHD (NICE, 2018a). These two components are brought together with a narrative synthesis, which was chosen to summarise the findings primarily using text due to the qualitative nature of the data (Popay, 2006).

A critical appraisal of the identified guidelines and reviews was not conducted as part of the review, because the primary aim of the review was to collect information on what clinicians are currently advised is optimal practice. Critical appraisal focuses on identifying flaws and assessing the quality of the reviews (CRD, 2009), and would lead to exclusion of some guidelines that clinicians might be using. Methods exist that can be used to critically appraise an article on guidelines (Department of General Practice, no year) or a clinical guideline itself, such as the AGREE instrument, which involves assessing the scope and purpose of the guideline, stakeholder engagement, the methods and evidence used for development, clarity of presentation, bias and how applicable the guideline is (Brouwers et al., 2010). This review set out to only identify, and then compare and contrast the guidelines to the NICE guidelines, without discussion of the

quality or integrity of the information identified. Using a critical appraisal tool may have led to guidelines potentially being excluded from the review which would illustrate what is happening in practice. It was therefore judged that critical appraisal was not necessary for the purposes of this review.

2.3.1 Data sources and search strategy

Four sources of data were used. First, ten bibliographic databases were searched from the earliest date of the database to the present day (15/06/2018): EMBASE, MEDLINE, PsycINFO, Social Policy and Practice, Health Management Information Consortium (all accessed via OvidSP); CINAHL, ERIC (accessed via EBSCO); ASSIA (accessed via ProQuest); NICE Evidence Search and TRIP database (hand searching only). Databases were searched using three groups of terms or synonyms (combined by the Boolean “AND” operator) to describe ‘Attention Deficit Hyperactivity Disorder’, ‘Transition’, and ‘Guideline or Protocol’, identified from the title, abstract, key words or medical subject heading (MeSH) terms. An illustration of the search strategy used in EMBASE can be found in Appendix Five. The search terms were adapted for individual databases as required.

Secondly, an online search was completed using the search engine Google for protocols, guidelines or documents regarding ADHD and transition within NHS sites (using the syntax ‘site: nhs.uk’). The first ten pages of results were screened (approximately 200 results) and relevant documents identified and exported.

Thirdly, corresponding websites of professional and charitable organisations in the field (Appendix Six) were searched for protocols, guidelines, policy documents or patient leaflets providing transition recommendations for patients with ADHD.

Finally, backwards citation chasing (one generation) was completed using the references from all included documents in the review.

2.3.2 Inclusion / exclusion criteria

Table 1 summarises the inclusion and exclusion criteria used for the review. These were chosen to identify guidelines specific to the condition ADHD, specific to transition, and also to reflect the application of the NICE guidelines being specific to England only.

Table 1. Systematic review inclusion and exclusion criteria

Inclusion	Exclusion
<ul style="list-style-type: none"> • Age range 0-25years • Transition guidelines or protocols <u>specific to a clinical diagnosis of ADHD</u> from; <ul style="list-style-type: none"> - nationally recognised sources - local NHS services • Existing reviews of ADHD transition guidelines and protocols; <ul style="list-style-type: none"> - includes recommendations for ideal practice • Any type of study/review design; <ul style="list-style-type: none"> - editorial - evaluation - short report - discussion papers • From earliest date of database to present • Specific to England only • English language only 	<ul style="list-style-type: none"> • ADHD transition guidelines and protocols for age groups outside of 0-25years • General mental health transition guidelines or protocols • Transition guidelines or protocols relating to other diagnoses • No ‘working documents’, unpublished or draft guidelines • ADHD transition guidelines and protocols / reviews not specific to England • ADHD transition guidelines and protocols / reviews not in English language

2.3.3 Study selection

Records identified through the bibliographic databases were exported into Endnote X8 reference management software, and duplicate papers were identified and excluded. The abstracts and titles of all identified records were screened for relevance by one reviewer (HE) using the specified inclusion and

exclusion criteria. Twenty-five percent of records were independently screened by a second reviewer (BL and TR). Discrepancies were discussed and resolved. Full text copies were obtained for the selected studies and screened against the same inclusion and exclusion criteria.

Documents obtained via the online search and citation chasing were saved and uploaded in the same Endnote file; these were screened and reviewed following the same procedure.

2.3.4 Data extraction and synthesis

For the first part of the review, the relevant data from each included document was extracted and summarised descriptively. For the second part of the review, the key points for transition specified in sections 1.1.4, 1.1.5 and 1.1.6 of NG87 were used as a framework to organise the data and allowed extracted data from all documents to be compared and contrasted to the NICE guidance. The relevant data were extracted in to a spreadsheet specifically created for this review and then discussed in a narrative manner.

2.4 Results

2.4.1 Search and screen of results

The PRISMA diagram (Moher et al., 2009) in Figure 2 illustrates the sources from which references were identified, screened and selected.

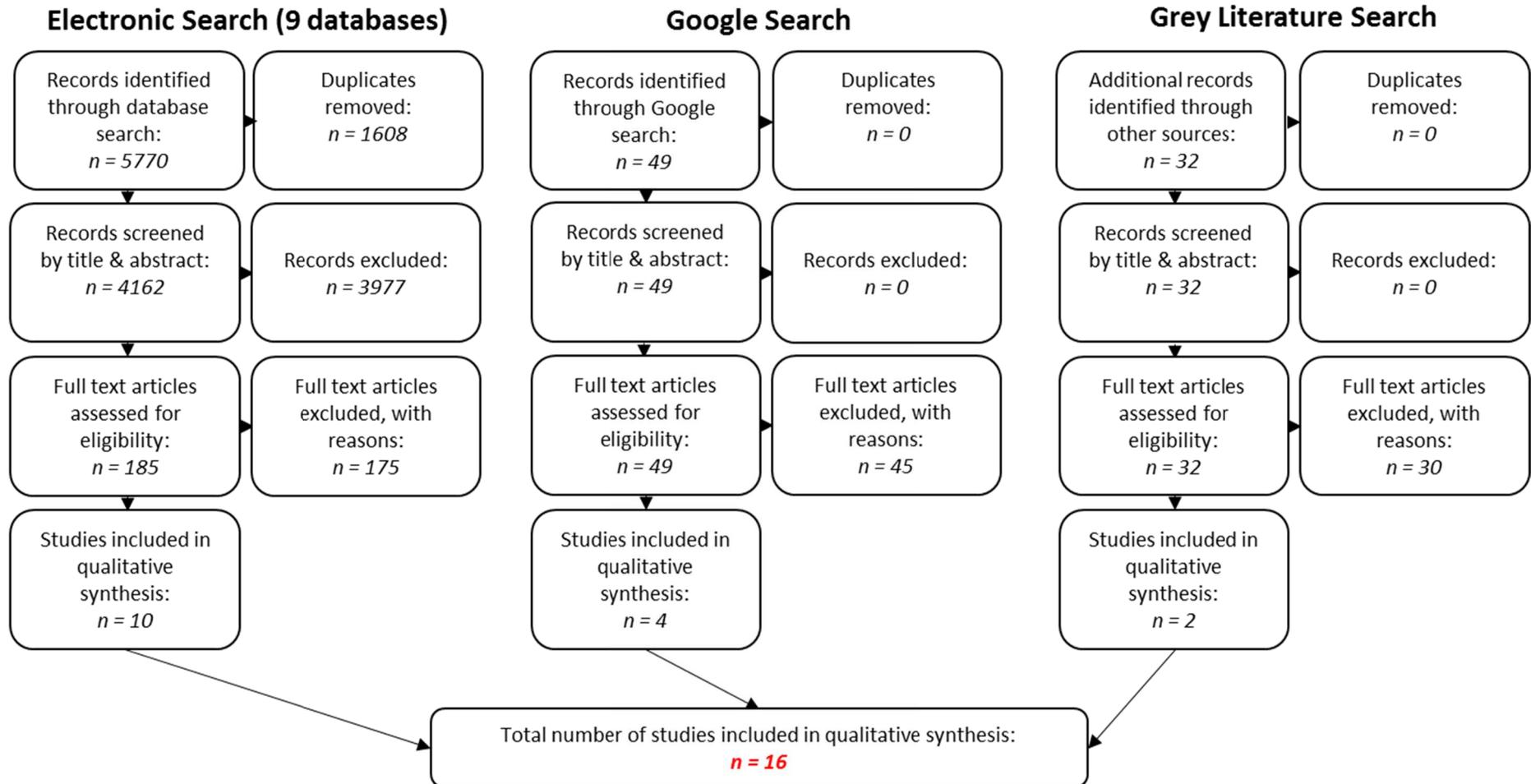


Figure 2. PRISMA diagram showing selection of sources

The electronic search, and title and abstract screen, of the TRIP database (n=326) identified 13 records for inclusion in the full text screen. When checked against the search results of the other nine databases, the 13 records were identified as duplicates. Therefore the numbers in the PRISMA diagram reflect the results in nine databases, excluding the TRIP results.

At full text screen stage, records were excluded for the following reasons;

- Not specific to: England, ADHD, Transition (n=210)
- Book chapter or review (n=3)
- Conference abstract or presentation (n=18)
- Clinical trial (n=1)
- Dissertation (n=1)
- Newsletter article (n=7)

Three were also identified as duplicates and excluded at this stage, and one was excluded for being a case study example of patients in transition which did not include recommendations for transition. Full text was unobtainable for five documents.

2.4.2 Description of included studies

Sixteen documents were included for review; seven peer reviewed papers, three NICE guidelines, four local NHS service guidelines, and two professional organisation guidance document. One peer reviewed paper (Hall et al., 2015) does not present recommendations for transition, however reports on a survey of ADHD services in mental health trusts in England that identified data in line with NICE guidance; for example, transition protocols and information sharing. It was therefore included.

All documents were published between 2009 and 2018, and all provide guidance for ADHD transition in England in varying detail. Table 2 summarises the content of each of the included documents.

Table 2. Summary of included studies

Author / Year	Title	Description
Asherson, P., et al. (2017)	Bridging the gap: Optimising transition from child to adult mental healthcare.	Professional guidance document. Expert policy paper. Reviews challenges associated with transition for general mental health, using ADHD as an example. Chapter 3 refers to recommendations for managing and planning transition for ADHD – very detailed.
Atkinson, M. & Hollis, C. (2009)	NICE guideline: attention deficit hyperactivity disorder	Peer reviewed paper. Reviews NICE guidelines with summary of key points related to transition. Details of transition are replica of NICE guideline.
Boilson, M. F., F. Quilter, M. Sutherland, C. (2013)	Royal College of Psychiatrists. Attention Deficit Hyperactivity Disorder (ADHD) Guidance for Transition from Child & Adolescent Services to Adult Services.	Professional guidance document. Clinician focused. Details transition process (replicated from NICE) and provides recommended key points of pathway and what details should be included in a case summary provided at transition.
Coghill, D. R. (2017)	Organisation of services for managing ADHD.	Peer reviewed paper. Updated version of paper published in 2016. Mainly focuses on barriers to transition. Refers to transition details from NICE guidance and UK Adult ADHD network; referral if significant symptoms require treatment, transfer by 18, and planning in advance from both child and adult service.
Fellick, J. (2014)	Attention Deficit Hyperactivity Disorder (ADHD) Guideline for the treatment and care of children and young people with ADHD. Wirral University Teaching Hospital NHS Foundation Trust.	Local NHS trust document. Regarding treatment and care of ADHD. Details transition process used in trust. Details of transition are replica of NICE guideline.
Fogler, JM., et al. (2017)	Topical Review: Transitional Services for teens and Young Adults with Attention-Deficit Hyperactivity Disorder: A process Map and Proposed Model to Overcoming Barriers to Care.	Peer reviewed paper. Provides a unique model of care to support transition. Includes; emphasising trust, respect and open communication, supporting patient independence, helping young person to navigate education and investing time to ensure young person is involved in care.

Hall, C. L., Newell, K., Taylor, J., Sayal, K., & Hollis, C. (2015)	Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: a national survey of mental health trusts in England.	Peer reviewed paper. No clear detailed transition process, but links NICE guidance to data collected in their survey of transition. Data collected on transition and shared care protocols and transition pathways, information sharing and joint working.
NICE (2016)	Attention deficit hyperactivity disorder: diagnosis and management: CG72.	Full clinical guidance from NICE. Diagnosis and management of ADHD. Section 1.6 details transition to adult services.
NICE (2017)	NICE Pathways: Attention deficit hyperactivity disorder overview.	Overview of NICE guidance and quality standards. Details transition process as laid out in NICE NG87.
NICE (2018)	Attention deficit hyperactivity disorder: diagnosis and management. NG87	Full clinical guidance from NICE. Diagnosis and management of ADHD. Updated from 2016. Section 1.1.4, 1.1.5 and 1.1.6 details transition to adult services.
Ogundele, M. O. (2013)	Transitional care to adult ADHD services in a North West England district.	Peer reviewed paper. Summarises literature around transition, and details ideal practice. Refers to NICE and Royal College of Nursing. Main points are early planning, young person and carer involvement, inter agency, comprehensive, holistic and developmentally appropriate.
South West Yorkshire Partnership NHS Foundation Trust (2018)	Attention deficit hyperactivity disorder (ADHD) service: Assessment process.	Local NHS trust document. Regarding transition from children's services for patient use. Details transition process used in trust. Details are in line with NICE guideline; assessed at 18, joint planning meeting, young person and carer involvement, information, reassessment at adult service.

Stockport ADHD Team (2015)	ADHD Care Bundle: Stockport CAMHS (Pennine Care NHS Trust).	Local NHS trust document. Limited detail of transition processes. States referrals should be made to adult ADHD team if patient required continued medication after 16 th birthday.
Tahir, O. and Sims, K. (2014)	Prescribing arrangements for the use of methylphenidate, dexamfetamine and atomoxetine in children with ADHD (attention deficit hyperactivity disorder) with transition to adult services in Berkshire. Berkshire Healthcare NHS Foundation Trust.	Local NHS trust document. Regarding treatment and care of ADHD. Details transition process used in trust. Includes: transition at 18 commencing 3 months before, comorbidities to be transitioned to community mental health, drug free trial prior to transition, to remain with CAMHS if remaining on medication, GP to continue care post 18, reassessment at adult service.
Young, S., et al. (2016)	Recommendations for the transition of patients with ADHD from child to adult healthcare services: a consensus statement from the UK adult ADHD network.	Peer reviewed paper. Details NICE guidelines, and provides their own general recommendations for transition, and more specific recommendations for ADHD. Follows NICE guidance with more specific detail.
Young, S., Murphy, C. M., & Coghill, D. (2011)	Avoiding the 'twilight zone': recommendations for the transition of services from adolescence to adulthood for young people with ADHD.	Peer reviewed paper. Summarises NICE guidance; then further expands and develops the NICE guidelines – very comprehensive guidance which follows NICE guidance with more detail. Very similar to 2016 paper by Young et al.

The documents published by NICE are the full clinical guideline for diagnosis and management of ADHD NG87, the previous NICE clinical guideline CG72 and an overview of the ADHD NICE pathway, which summarises NG87 (NICE, 2008, NICE, 2017a, NICE, 2018a). Ten documents (excludes Pennine Care, South West Yorkshire and Berkshire Healthcare NHS documents, and the paper by Fogler et al. 2017) refer to the NICE guidelines and base any guidance for ADHD transition on the recommendations in NG87; mostly quoting the NICE guidance verbatim. Four documents were identified through the online google search; these were documents by Stockport CAMHS (2015), Wirral NHS (Fellick, 2014), Berkshire NHS (Tahir and Sims, 2014), and South West Yorkshire NHS (2018). All records identified via electronic databases reference the NICE guidelines. Two documents were identified via the online search of professional and charity organisations, which were the Royal College of Psychiatrist's guidance on transition in ADHD (Boilson et al., 2013) and an expert policy paper from Asherson et al. (2017). Both of these documents reference the NICE guidelines.

2.4.3 Compare / contrast of guidelines

As NG87 was one of the 16 documents identified in this review, the main points of the recommended transition process were identified and the remaining 15 documents were compared against them. An example of the spreadsheet used can be found in additional files as Appendix Seven. Many recommendations for transition as suggested in the 15 included documents were within the scope of the NICE guidelines, but any recommendations for transition that were additional to or outside of the NICE guidelines were clearly highlighted using this process. Table 3 provides an overview of the comparison.

Table 3. Overview of compare/contrast of documents to NICE guidelines

NICE guidelines NG87 (2018)	Asherson et al. (2017)	Atkinson et al. (2010)	Boilson et al. (2013)	Coghill (2017)	Fellick (2014)	Fogler et al. (2017)	Hall et al. (2015)	NICE pathway (2017)	NICE CG72 (2016)	Ogundele (2013)	Stockport CAMHS (2015)	SW Yorkshire NHS (2018)	Tahir and Sims (2014)	Young et al. (2016)	Young et al. (2011)
Reassessed at school leaving age		✓			✓			✓	✓						✓
If ongoing treatment required – arrange for smooth transition with details of anticipated treatment		✓	✓		✓			✓	✓			✓		✓	
Should be complete by age 18		✓	✓	✓	✓			✓	✓				✓	✓	✓
Formal meeting involving CAMHS and AMHS	✓	✓	✓		✓		✓	✓	✓				✓	✓	✓
Information provided to the young person about AMHS		✓	✓		✓	✓	✓	✓	✓			✓		✓	✓
For age 16+ Care Programme Approach (CPA) should be used		✓			✓			✓	✓					✓	✓
Young person and parent carer involvement	✓	✓	✓		✓	✓		✓	✓	✓	✓	✓		✓	
Comprehensive assessment at AMHS		✓			✓			✓	✓			✓	✓		✓
Refers reader to NICE guideline NG43 on transition in health and social care services								✓							

Recommendations within the scope of the NICE guidelines

Age/reason for transition: The NICE guidelines recommend that transition should occur if the young person continues to have significant symptoms of ADHD, and this should be assessed when approaching the service age boundary. Ten of the documents stated the reason for transition should be significant symptoms of ADHD that require ongoing treatment or support. Four documents did not specify a reason for transition, while one specified continuation of *medication*. An age for transition is not specified by NICE, but it is suggested to be complete by age 18. Nine documents also specified completing transition by age 18, while six documents did not specify an age. Six documents specified reassessment at school leaving age to address transition need, three stated age 17 or 18, five did not specify, and one recommended starting at age 13/14.

Planning: The NICE guidelines recommend planning the transition with staff from both the child and adult services, via a joint meeting and the Care Programme Approach (CPA), and involving parent/carers and the young person. Echoing the NICE guidelines, six of the documents suggest using CPA in planning for transition. Seven documents did not specify details on planning, whilst the other eight agreed that planning in advance from services at both ends of the transition should occur. Nine documents did not specify staff involved, while Stockport ADHD team (2015) specified an ADHD nurse should coordinate the transition, and Young et al. (2016) recommend that a lead clinician coordinates the transition once the referral to an adult service has been accepted. One of the policy document also stressed the importance of appointing a case manager, to oversee the transition period (Asherson et al., 2017) which was also suggested by Fogler et.al (2017).

Ten documents specified that the parent and young person should be included in the planning. Only two documents suggested a timescale for the preparation of the young person for transition, one suggesting a minimum of a six months (Young et al., 2011), and one suggesting commencing three months prior to the eighteenth birthday (Tahir and Sims, 2014).

Information: The NICE guidelines recommend that information sharing between services should include details about treatment and services required, while information should also be provided to the young person about transition and

adult services. Half of the documents recommended providing information to the young person, but only three documents specified information sharing between services. One document listed the information that should be shared between services, including clinical evidence, current intervention, degree of engagement, and context of the young person. Five documents recommended shared care and information sharing with the General Practitioner (GP), something that was not specified by NICE under transition, but features in the wider guidelines for management of ADHD (NICE, 2018a).

Post transition: NICE recommend a comprehensive assessment is undertaken once the young person reaches the adult service, which is echoed in half of the identified documents. Two documents suggest psychological therapies should be considered by adult services, a recommendation not specified by NICE. One document also specifies that the adult service should acknowledge the referral, and the young person should not be discharged from the child service until they have attended the adult service.

Recommendations additional to the NICE guidelines

A number of important elements were identified by some authors that are not mentioned within the NICE guidelines. One document (Young et al., 2016) recommended that healthcare teams and clinicians should be mindful of comorbidities and parental ADHD, in order to provide appropriate support to the parent to be able to help their child move to more autonomy in their ADHD management. Young et al. (2011) also recommend continued professional development for clinicians to stay up to date with ADHD as a condition and the services available to support it, which is not mentioned in the NICE guidance. Another recommendation was for commissioners to take local resources into account when designing and planning transition services. This is not mentioned by NICE under transition, however it is added as an addendum in NG87 that it is the responsibility of commissioners to implement the guidelines.

Protocols to guide transition are not specified as a requirement in the transition recommendations section of NG87, although protocols for information sharing and shared care with GP's is mentioned in the wider guideline for general management of ADHD. Two documents in this review highlighted a need for

transition protocols to aid the process. It is suggested in these documents that protocols should be developed locally, and created jointly between services, taking in to account available resources, and enabling support for those who disengage with services prior to transition, those who are not accepted by adult services, and those who present in adulthood for the first time. The general health and social care transition guidelines (NG43) describe this process as a care plan (NICE, 2016b).

Two documents highlighted the need for the transition process and planning to be developmentally appropriate, although this term was not explicitly defined. Similarly, one of the policy documents that emphasised that support should be based on patient need, and should occur when the patient is clinically stable (Asherson et al., 2017)

2.5 Discussion

This review has systematically searched for existing guidelines or protocols, or reviews of guidelines, in England specifically outlining the preferred process to transition a young person with ADHD between child and adult services. The NICE guidelines have highlighted the need for transitional services for ADHD, but most health authorities have yet to establish clear protocols for transition (Bolea-Alamanac et al., 2014). This review was limited to transition guidelines specifically for ADHD transition in England, excluding any generic transition policies for general mental health. The searches were all conducted online; due to the variability in websites it is possible that services may have such documents, but they are not available or published online for public use. Direct contact with NHS services would be required to establish exactly what procedure, guidelines or protocols clinicians are using locally.

Results indicate that literature in this area is very strongly based on the NICE guidance for the management of ADHD NG87 (first published 2008, and updated 2016 and 2018) with a small number of authors expanding on the NICE recommendations. The systematic review by Seixas et al. (2012) identified thirteen guidelines, from ten different medical associations, however only two were relevant to England and ADHD transition; NICE CG72, and the ADHD

guidelines from the British Association of Pharmacology (BAP) (Bolea-Alamanac et al., 2014). The BAP paper was excluded from this review as it did not outline explicit recommendations for transition.

There were a number of points from the NICE guidance that were echoed in the majority of the reviewed documents; these included the reason and age for transition, information sharing, patient and family involvement, and prior planning. There were however, some additional recommendations highlighted in some of the included documents that are not mentioned in NG87 (or CG72 previously) which includes that transition should be developmentally appropriate, consider comorbidities and parental ADHD, the use of psychological therapies and continued professional development of clinicians. Two documents provide recommendations that are completely unique from NICE which include improving the education of healthcare professionals, increasing public awareness of ADHD, emphasis of trust and respect between patient and doctor, and supporting patient independence (Asherson et al., 2017, Fogler et al., 2017). These additional recommendations are based on the experience of a range of key experts and stakeholders, and recommend the best possible process for good transition (Asherson et al., 2017). These recommendations could enhance the transition process beyond that which NICE recommends, potentially having significant implications for patients and services.

The reviewed documents suggest transition should be completed by age 18, but consensus is growing that transition at 18 is not in the best interest of the young person (Dunn, 2017), and as a result a significant number are reported to remain within child services beyond 18 (Kooij et al., 2019). Further research has also emphasised the need to start transition planning early (Suris and Akre, 2015) to provide young people time to progress through transition once they feel ready (Dunn, 2017). Patients and carers also often do not anticipate the change and therefore commencing planning from the early teens can prevent transition failing (Coghill, 2016).

Others have argued that transition planning should incorporate a developmental perspective (Singh et al., 2016) which may be particularly important for young people with ADHD, who by definition have poor executive functioning and self-management (Fogler et al., 2017); the recommendations from the expert policy paper (Asherson et al., 2017) also emphasise that the transition should be

planned in a developmentally appropriate way for the patient which is not mentioned in the NICE guidelines for ADHD. The transition to an adult service also often occurs at a critical time when they are encountering changes in education, employment and independence from parents (Tatlow-Golden et al., 2018). Boilson et al. (2013) suggest that information regarding the patient's employment, social circumstances and quality of life is important to support effective transition, which is highlighted in the general NICE guidance (NG43), but overlooked in the more specific recommendations for ADHD (NG87). Developmentally appropriate healthcare has been suggested as a way of supporting young people with the demands of health services, and thus improve their engagement with the process (Dovey-Pearce et al., 2005). Incorporating this concept within the NICE guidelines could significantly improve the transition process, and hence improve longer term outcomes for young people with ADHD.

Information is key for transition; Hall et al. (2015) highlight the lack of local transition protocols and inadequate information sharing between child and adult services. Others have also underlined information sharing as a barrier to transition with clinicians citing insufficient information, poor communication and a lack of understanding between services (Dunn, 2017). Both papers by Young et al. (2011 and 2016) recommend that clear transition protocols between services are best developed locally, which outline timelines and responsibilities for transition, and describe pathways for those not accepted by adult mental health services, those who do not transition and those that re-enter services as an adult with ADHD (Young et al., 2016). Coghill (2016) also recommends that local detailed clinical pathways be developed. None of the other included documents refer to how to support young people who do not transition; particularly important when only 15% of cases make the transition (Singh and Tuomainen, 2015). One of the recommendations by Asherson et al. (2017) is to develop protocols for those patients that don't meet the criteria for adult services but still require ongoing support. Research suggests that there is huge variation in local practice and a lack of clear policies for transition (Muñoz-Solomando et al., 2010). As many fail to transition, the lack of information or protocols is surprising; following the guidance in NG87, providing information and comprehensive early planning may support more patients to transition successfully.

Despite the highlighted need for clear transition protocols and responsibilities to be developed locally (Young et al. 2016,) and systematic methods of searching, only four relevant NHS documents were found. It may be that ADHD is encompassed within general mental health policies and there are few local protocols specifically for ADHD transition; it was indicated by Hall et al. (2015) that services had care pathways but the majority were not specific to ADHD. Or perhaps it is a reflection of the availability and accessibility of the policies, despite the recommendation from NICE that full information is provided to the young person. Protocols or policies for transition should be readily available to guide young people and their parents/carers through the transition process. In the modern digital generation, young people would primarily use electronic media to gain information (Ford et al., 2013) and it is significant that this review was unable to identify more than four documents online.

The results of the survey by Hall et al. (2015) also emphasised a lack of staff training and knowledge in ADHD as a barrier to successful transition. Atkinson and Hollis (2009) emphasise the challenges that the NICE guidelines present for clinicians or those organising and planning services, and suggest that increasing numbers of young people requiring a transition to adult services will have implications for training and service delivery. Indeed the expert policy document identified by this review (Asherson et al., 2017) recommended improving the ADHD education, knowledge and experience of healthcare professionals. Furthermore, other studies have emphasised the lack of expertise, training and capacity of clinicians as a barrier to continuing care through transition (Montano and Young, 2012). A study of college and university health centres in the UK highlighted that 87% of clinicians had not attended any recent training for ADHD and many providing an adult service lacked the resources to facilitate transition (Baverstock and Finlay, 2003). Efforts should be made to educate and inform professionals about ADHD (Young et al., 2016) and there is a clear need to upskill clinicians to practically manage ADHD and treatment (Coghill, 2015). Without training, capacity and knowledge of ADHD and services, it could be argued that clinicians are lacking the ability to implement the guidelines appropriately or support patients with ADHD through transition. Continuing the professional development of clinicians, thus improving the knowledge and experience of ADHD as a lifelong condition, in combination with specific transition guidelines

that are systematically applied, should better equip medical professionals to manage the transition process and provide a continuity of care for young people (Asherson et al., 2017, Paul et al., 2013, Kooij et al., 2019).

Although the majority of the identified guidelines in this review were modelled on the NICE recommendations, some additional or unique recommendations were also identified. Whilst the inclusion of these additional actions would certainly have positive implications for young people, their omission from the NICE guidance but inclusion in expert commentaries, also highlights the likelihood that there is significant variation in service provision at transition which has been discussed in other research (Muñoz-Solomando et al., 2010). NICE state that professionals are expected to take clinical guidelines fully into account, but that the recommendations are not mandatory, while commissioners and service providers have a responsibility to enable the implementation of the guideline (NICE, 2008). This is conflicting, and presents a challenge for clinicians and local services to ensure that adequate ADHD services are provided, particularly for patients in transition.

2.6 Conclusion

This systematic review aimed to identify and describe guidelines and protocols for transition from child to adult services for patients with ADHD in England. The review identified sixteen documents that were mostly based around the NICE guidelines for ADHD diagnosis and management (NG87). Few independent guidelines were found although some documents provided additional or more detailed recommendations to the NICE guidelines, and many were peer reviewed papers which discussed the recommendations made by NICE. While this review used reliable systematic methods of searching, and followed the recommended steps for data screening and extraction, it is limited by specifically focussing on transition and England only.

The nature of health services and the changing needs of service users means that service changes occur, and guidelines are also amended or updated to meet the required need. However, the NICE guidelines for management of ADHD updated and published in March 2018 (NG87) do not provide any new or updated

recommendations for transition from the 2008 version, aside from referring the reader to the general NICE guidelines on transition in health and social care services (NG43). These provide more comprehensive recommendations for transition generally, however are not condition specific. It would be beneficial for NG87 to incorporate these recommendations and develop them to be specific for ADHD, in order to improve transition and long term outcomes for young people and services.

2.7 References

All references included in this chapter, and all other chapters, have been collated in one list for the thesis. The reference list can be found on page 275.

Chapter Three: Surveillance study

3.1 Overview of chapter

In the previous chapter, a systematic review provided background literature to elucidate what *should* be happening for young people with Attention Deficit Hyperactivity Disorder (ADHD) requiring transition from child to adult services. It highlighted that the National Institute of Health and Care Excellence (NICE) guidelines are the only guidelines that govern the process, and that any other identified guidelines closely followed the recommendations from NICE. The review demonstrated the main factors that should occur during the process of transition, as presented in the NICE guideline for management of ADHD NG87 (NICE, 2018a).

The aim of the surveillance study presented in this chapter was to explore what is *actually* happening for young people in transition. The study aimed to estimate the incidence of transition, in terms of the need and the success of transition, describe the group of young people with ADHD experiencing transition, and explore clinician's reported adherence to all individual elements of the NICE guidelines.

The surveillance study was developed as part of the CATCh-uS project protocol (Ford et al., 2015) and utilised the established surveillance organisations of the British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatry Surveillance System (CAPSS). The study ran from November 2015 to November 2016 with a nine month follow up period. I led and managed the surveillance study throughout, including the data collection, data management, data analysis and the write up.

An electronic case note review was also carried out in parallel to the surveillance study, which was not part of the original CATCh-uS project plan. This review used the Clinical Records Interactive Search (CRIS) at the South London and Maudsley (SLaM) NHS Foundation Trust in order to compare and triangulate the data that were collected using CAPSS surveillance. I led the protocol

development, the data collection, data analysis and the write up of this part of the study.

This chapter describes the whole surveillance study, including the methodology used, the results, and a discussion of the data collected. The content of this chapter will also form part of the full National Institute of Health Research (NIHR) report for CATCh-uS which will be published in 2019.

I have led the write up of the findings from the whole surveillance study, derived from this chapter, which have been summarised and shared in the research paper presented in Appendix Three. This manuscript was published on 4th June 2019 by the British Journal of Psychiatry (Eke et al., 2019a).

A second manuscript reporting on the comparison of two research methodologies used in this study, surveillance and electronic case note review, has been published in the journal BMC Medical Research Methodology. A copy of the manuscript can be found as Appendix Two. The manuscript compares and contrasts the use of surveillance using CAPSS versus a traditional electronic case note review using CRIS (Eke et al., 2019b).

3.2 Introduction

In order to plan services, commissioners and service providers need data on how many people may require that service. There are currently limited national and international data available on the need for transition between child and adult services for young people with Attention Deficit Hyperactivity Disorder (ADHD), although some studies have attempted to quantify national estimates. Two previous studies (Singh et al., 2008, Tatlow-Golden et al., 2018) have reviewed case notes narratively to identify transition cases between Child and Adolescent Mental Health Services (CAMHS) and adult mental health services (AMHS) for all children with all types of mental health conditions over a twelve month period. The first study identified an average of 12 neurodevelopmental cases per CAMHS team that were eligible for transition in one year, of which 40% were never referred to any adult service, with only 67% of those referred actually making the transition (Islam et al., 2016, Singh et al., 2008). This study was limited to a number of health trusts in one geographical area of England. The second study focussed on ADHD cases in Ireland, and identified 20 patients from four CAMHS teams that required a transition. None of these cases were directly transitioned to AMHS; they were either retained by CAMHS, referred to a private service, or discharged to the General Practitioner (GP) (Tatlow-Golden et al., 2018). Previous studies have reported on the proportion of young people still meeting diagnostic criteria for ADHD in adulthood (Faraone et al., 2006). However, few studies provide empirical data on the number of patients that wish to access ongoing care, or the number that successfully do so. Studies for common developmental disorders such as ADHD also rarely follow participants across developmental transitions (Glantz et al., 2009).

There are National Institute of Health and Care Excellence (NICE) guidelines for the management of ADHD (NICE, 2018a) which recognise the importance of ADHD in adults, however management mainly involves medication prescribed under a shared care agreement with GPs. NICE have also published more general guidelines for transition in health and social care (NICE, 2016b) however these are not condition specific and do not address barriers in the transition process. Existing work suggests that young people with developmental disorders such as ADHD are particularly likely not to transfer to adult mental health services

(Singh et al., 2008), and there has yet to be an in depth study of this issue in the United Kingdom (UK). The CATCh-uS surveillance study was the first national study that aimed to study how many young people with ADHD, with an ongoing need for medication, need a transfer to an adult service, and aimed to describe this population across the United Kingdom (UK) and the Republic of Ireland (ROI) (henceforth the British Isles).

Surveillance provides a method that allows the collection of reliable and timely information about health conditions in the population to improve health (Knowles et al., 2006). It is defined as the systematic ongoing collection of data, including analysis and interpretation, and by its continuous nature, is more than just routine outcome monitoring. It is also separate from screening, due to the broader focus on factors that influence prevalence and management, while screening often implies action will subsequently be taken at an individual level based on results (Ford et al., 2018). Surveillance of a condition over time has the potential to provide national estimates of incidence and highlight needs or gaps in service provision that should be addressed at policy level to inform commissioning.

Monthly surveillance with reporting via questionnaires in paediatric services was first developed in the 1980s to measure and monitor important infectious and rare diseases by the British Paediatric Surveillance Unit (BPSU); the unit was at the forefront of surveying and influencing child health policy and practice (Lynn et al., 2016). The BPSU studies the national incidence of rare conditions across the UK via monthly reports by consultant paediatricians. Much mental health surveillance has involved collection of data via morbidity surveys such as the Surveys of Psychiatric Morbidity (Jenkins et al., 1997) or enquiries and data collection at mental health services which still continues; however since the 1990s recognition of the impact that mental illness has on the health of the population has led to more continuous surveillance being conducted. The Child and Adolescent Psychiatry Surveillance System (CAPSS) was developed as a pilot in 2005 for a study of early onset eating disorders to maximise the identification of cases, and was fully established in 2009 (Gupta et al., 2016). It applies the same methods as BPSU but obtains reports from consultant child and adolescent psychiatrists. The current study focussed on surveying the incidence of a service need; the need for transition between child and adult services for young people with ADHD.

The objectives of the surveillance study were:

- To estimate the range and mean age for transition to adult services and variation within this across the British Isles for CAMHS and paediatrics.
- To estimate the incidence rate of young people with ADHD who require ongoing medication for ADHD after they pass the age-boundary for the service that they attend and variation within this across the British Isles.
- To describe the services offered to young people going through this age-boundary.
- To estimate the proportion of young people with ADHD judged in need of transition who successfully transfer to a specialist adult health service, defined as an accepted referral to a specialist adult service within the time frame of the current study.

3.3 Methods

This study used the BPSU and CAPSS to collect surveillance data on transition in health services that support young people with ADHD. As young people with ADHD (especially those who require medication) are most commonly seen by CAMHS or paediatric clinicians, the BPSU and CAPSS systems offered access to the most appropriate clinicians and care pathways. This was one of only five studies that has used the BPSU and CAPSS systems simultaneously, and was unique in that it focussed on the incidence of transition as a *process* in services for ADHD as opposed to the incidence of ADHD as a *condition*. ADHD itself is not rare, however existing research suggests a seamless transition process between services may be (Paul et al., 2013).

3.3.1 Surveillance methodology design

The methodology used by BPSU and CAPSS is well-established and now replicated in 14 countries worldwide. The results of surveillance studies using both BPSU and CAPSS have influenced management, planning and policy internationally (Grenier et al., 2007). Figure 3 illustrates how the system works.

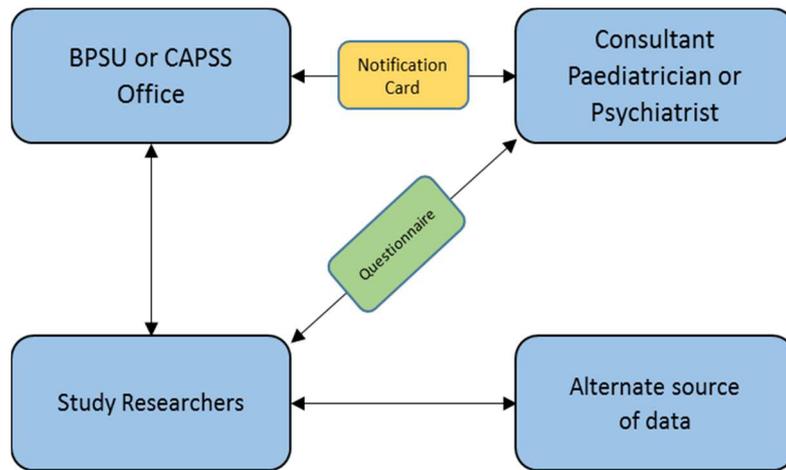


Figure 3. BPSU and CAPSS surveillance methodology

Over 3800 registered paediatricians from BPSU (RCPCH, 2018) and 1000 psychiatrists from CAPSS (RCPsych, 2018) are sent a surveillance orange/yellow ‘reporting card’ (now 90% via email) each month that lists the rare disorders or events currently under study. A limited number of research studies can be featured on the card at any one point in time. The reporting clinician returns the notification card to BPSU or CAPSS indicating how many patients they have seen that meet the relevant study criteria. The research team are informed weekly by BPSU or CAPSS of any reported cases, and the research team then send a questionnaire directly to the clinician. Usually BPSU and CAPSS studies run for thirteen months; the first month is considered a trial or pilot month to identify any potential difficulties from the study criteria, questionnaires or clinicians, with the remaining 12 months data included as the full study.

3.3.2 Governance and ethics

BPSU and CAPSS both have a two phase application process before approval to run a study is granted. Phase one assesses the suitability of the research question to this type of surveillance methodology, while phase two ensures that the surveillance definition and questionnaire cover only what clinicians would be expected to know, or be able to access from clinical notes. Respondent burden is a prime consideration.

The approval with BPSU and CAPSS for this surveillance study was initially for six months, with the intention to review progress at six months. As ADHD itself is not rare, both units were concerned that a large number of notifications would be received, that would be beyond the capacity of each organisation and thus swamp the system. The plan was to review at six months and extend to 12 months (which is the length of most surveillance studies) if warranted. At six months, 138 notification reports from BPSU and 118 from CAPSS had been received, which allayed the fears that both the clinicians and the surveillance organisations would be overburdened. The surveillance period was duly extended and in total ran from November 2015 to November 2016 with a nine month follow up post notification from August 2016 to August 2017. Responses were chased for three months post the end of the surveillance and follow up periods.

Relevant ethical approval was sought and granted for this study. Both BPSU and CAPSS have Health Research Authority (HRA) approval for access to case note information without patient/parent consent, provided the study has Confidentiality Advisory Group (CAG) approval;

- IRAS registration number: 159209
- REC reference: 15/YH/0426
- CAG reference: 15/CAG/0184

3.3.3 Case definition criteria

The surveillance asked for a consultant to report young people that they had seen in the previous month who met the following criteria;

- Young people with a clinical diagnosis of ADHD under the care of CAMHS or paediatrics, who were reviewed within six months of the service age boundary.
- Young people considered to require continued drug treatment for their symptoms of ADHD after crossing the age boundary of the child service.
- Young people with comorbid diagnoses, including learning / developmental disabilities, should be reported only if it is their ADHD that required ongoing drug treatment.

Cases were excluded from the study if;

- The young person had a diagnosis of ADHD but did not require medication.
- The young person required transition to an adult service only for a psychiatric comorbid condition.
- The young person had already been notified to the study.

The definition was designed in close collaboration with members of both BPSU and CAPSS. The definition had to be appropriate for both paediatricians and psychiatrists, to ensure that both sets of clinicians would identify young people in as similar manner as possible. The development of the definition required an iterative process of discussions and revisions.

The case definition criteria were developed to be precise, and to unequivocally specify the need for ongoing support from specialist adult mental health services, as outlined in the NICE guidelines (NICE, 2018a). The aim of the definition was to provide a minimum estimate of the number of young people requiring a transfer from CAMHS and paediatrics to adult services during the surveillance period. The age boundary was left unspecified to measure when transition was occurring rather than lose cases because not all children's services extend to the age of 18, and some extend beyond this age. The requirement for ongoing medication was chosen as a criterion in order to rule out subjectivity in the application of definitions of 'ongoing care'. It would not capture those who did not need or want medication but did need ongoing psychological support.

3.3.4 Questionnaires

Baseline notification and follow up questionnaires were developed using the corresponding systems' templates, which comprised structured questions (30 at baseline, and 19 at follow up) with two open text responses. The baseline notification questionnaire (see Appendix Eight) was sent to all clinicians that reported a case to the study; questions confirmed eligibility, and gathered semi-identifiable data on the patient (NHS number, gender, age in months, and truncated postcode) to allow duplicate reports of patients seen by general and specialist services, or by both CAMHS and paediatrics, to be identified. It also

collected details of patient treatment, and details of the planned transition to an adult service. Any professional with access to the patient notes could complete it on behalf of the lead clinician if necessary, although the reporting card was only sent to consultant paediatricians and child and adolescent psychiatrists. A nine month follow up questionnaire (see Appendix Nine) was sent to the same clinician that reported the case at baseline, with questions to confirm the outcome and details of the transition. There were nine elements of transition listed at follow up compared to only five at baseline; this was to reflect what was stated in the NICE guidelines, and it was anticipated that at follow up the transition would have occurred and clinicians would therefore be able to report on factors such as continuity and consistency that would not have been possible at baseline.

Email and postal reminders for non-returned questionnaires were sent after four weeks, again after six weeks, and finally a follow up telephone call was made if the questionnaire was still outstanding. As an incentive, clinicians were offered certificates to represent time committed to research, for use in appraisal or review, to acknowledge their participation in the study.

3.3.5 Challenges from case definition and questionnaires – BPSU and CAPSS responses combined

It became clear from queries to the researchers and the surveillance units that some consultants misunderstood the term '*first time*' used in the original surveillance definition. It was unclear to some clinicians if this meant the first time they had ever met the patient, or the first time the patient was reviewed in the surveillance period. This was resolved by changing the terminology to '*the first time the case is reported*' (see Table 4).

In addition to clarifications of the case definition as explained above, other detected errors from clinicians included; reporting a whole caseload of patients with ADHD rather than reporting just the patients that required a transition (n=2); reporting the same case each time the patient was seen in clinic (n=12); reporting a case but not remembering the patient details (n=31); reporting a case that did not meet one or more of the case definition criteria (n=90); and 'reporting in error' e.g. ticking wrong box on notification card, misreading the card, no recollection of

reporting (n=43). Queries were resolved by direct contact with the reporting clinician.

Table 4. Original and final case definition used in baseline questionnaire

ORIGINAL	FINAL
<ul style="list-style-type: none"> • Young person with a clinical diagnosis of ADHD under the care of CAMHS, who is reviewed for the first time when, within 6 months of reaching the services' age boundary, whatever this may be. Young people should only be reported once and those that have already been seen and reported in this time-scale should not be reported a second time. • Young person is considered to require continued drug treatment for their symptoms of ADHD after crossing the service age boundary. • Young person should not have been reported previously to the BPSU in relation to the current study. • Young people with ADHD and comorbid diagnoses, including learning / developmental disabilities, should be reported only if it is their ADHD for which on-going drug treatment in adult services is required. 	<ul style="list-style-type: none"> • Young person with a clinical diagnosis of ADHD • Young person currently receiving drug treatment for their ADHD • Young person requiring continuation of their drug treatment for their ADHD after transition from the current service • Young person within six months of the age boundary of the service • The first time this case is reported to the study by your service

3.3.6 Analysis of surveillance data

Descriptive analysis

A measure of compliance with a surveillance scheme is the proportion of reporting cards returned (Godward and Dezateux, 1996). Response rates at each stage of the study (notification, baseline and follow up) are described. The response rate was generated from the number of notification cards returned to BPSU or CAPSS (including positive and negative returns) divided by the total sent. The sociodemographic details of the reported cases by the reporting surveillance unit and overall are also described.

Analysis of incidence of transition

Incidence is defined as the number of new health related events, in a defined population, during a set period of time (International Epidemiological Association, 2014). Using the data collected in this surveillance study, the incidence rate was calculated by determining the number of confirmed cases of transition in patients with ADHD identified over the course of the study's twelve month surveillance period. The population at risk ($n=116,651$) was derived by applying the estimated prevalence of ADHD (approximately 5% in the child and adolescent population) (Faraone et al., 2015) to the total number of children aged 17-19 in the UK as reported in 2016 ($n=2,333,035$) (ONS, 2016). The total number of reported transition cases was then divided by the population at risk and multiplied by 100,000 to provide the incidence rate of transition per 100,000 people aged 17-19.

Two incidence rates were calculated; the incidence of young people who were eligible for transition, and the incidence rate of successful transition in the obtained sample. The incidence rate was adjusted to take in to account the non-returned or missing data from the surveillance study (via monthly reporting cards, and surveillance questionnaires) and the age of the reported cases. The following corrections were made:

1. Correction for unreturned BPSU/CAPSS notification cards

To account for incidence among unreturned cards, a correction to the observed incidence rate was applied, using two assumptions as suggested in a previous study (Byford et al., 2018, Petkova et al., in submission):

- *Assumption 1:* considers that the incidence observed in the study applies to *half* of the unreturned cards, assuming no incidence of transition among the remaining half of unobserved cases. The rationale for the assumption is that a larger proportion of missing notification cards are negative (i.e. those reporting no case that month) since it is more likely that people will fail to submit a nil return than a positive return. This assumption translates to a correction coefficient derived from (half of unreturned cards + percentage of returned cards)/percentage returned cards.
- *Assumption 2:* considers that the incidence observed in the study applies to *all* unreturned cards, assuming that all unreturned notification cards follow the same pattern of yes/no responses as those notification cards already received. This assumption translates to a correction coefficient (100/percentage unreturned cards).

2. Correction for unreturned baseline questionnaires

To account for incidence among the unreturned baseline questionnaires, a correction coefficient calculated from the return rate for baseline questionnaires (100/percentage returned baseline questionnaires) was applied.

The two correction coefficients described above were combined in the following adjusted incidence rates:

- *Adjusted Incidence Rate 1*
 - = Observed incidence rate X Correction for unreturned notification cards (Assumption 1) X Correction for unreturned baseline questionnaires
 - This estimate applied the study observed incidence rate to half of all missing cases due to unreturned notification cards and to all unobserved data due to unreturned baseline questionnaires.

- *Adjusted Incidence Rate 2*

- = Observed incidence rate X Correction for unreturned notification cards (Assumption 2) X Correction for unreturned baseline questionnaires
- This estimate applied the study observed incidence rate to all missing cases due to unreturned notification cards and to all unobserved data due to unreturned baseline questionnaires.

The Adjusted Incidence Rate 1 and Adjusted Incidence Rate 2 will provide a likely minimum and a maximum range within which the actual incidence rate is likely to fall.

Analysis of successful transition

Logistic regression is a statistical technique used to explore whether there is an association between independent variables such as risk factors, and a binary outcome (only two outcomes e.g. successful or unsuccessful transition) (Hosmer and Lemeshow, 1980, Hosmer and Lemeshow, 2013, Wakkee et al., 2014). Using the surveillance data collected using both BPSU and CAPSS, a logistic regression was carried out in order to explore which factors were associated with a successful transition from the child service to an adult service. Analyses were carried out using Stata SE version 15 (Stata, 2019).

Successful transition was defined as a referral made, referral accepted and the young person having attended an appointment in the adult service. The responses were transformed into a binary variable (Yes/No). Cases for which the consultant had responded with 'don't know' or had left the response blank (missing data), were amalgamated into the 'No' category. Potential predictor variables included in the analysis were collected from the baseline questionnaires sent to respondents from both BPSU and CAPSS, and were categorised into three groups: patient characteristics such as sex, ethnicity and comorbidities (Autism Spectrum Disorder (ASD) and non ASD); service characteristics, i.e. whether the patient was reported via BPSU or CAPSS and therefore seen in a paediatric or psychiatric service; and transition characteristics such as the

occurrence of a planning meeting, period of handover, information sharing or parental involvement. These transition elements are factors recommended in the NICE guidelines.

For each variable the percentage of cases who experienced a successful transition was calculated. Next, logistic regression was carried out in three stages. First, each predictor variable was included and analysed in a uni-variable unadjusted model, to estimate the odds ratios with 95% confidence intervals and accompanying p values. The odds ratio is the odds of the outcome occurring among those exposed to the predictor variable compared to those who were not exposed (Szumilas, 2010). The 95% confidence interval (CI) indicates the precision of the estimate, and provides the range of values in which the odds ratio would be expected to lie 95% of the time, were the data collected multiple times (Szumilas, 2010); i.e. the range in which we are 95% sure that the true value lies. A ratio of something to itself equals one; so if the confidence interval includes 1, there is no evidence of an association between the particular predictor variable and successful transition, which equates with a p value of less than 0.05 (Goodman, 1999). Secondly, the variables that were statistically significant at the $p < 0.05$ level were included in an adjusted multivariable model for each group of variables (patient, service, transition characteristics). Thirdly, any factors that were significantly associated with transition in these adjusted models were included in a final multivariable model.

Finally a 'goodness of fit' test was conducted on the final model using the Hosmer-Lemeshow test, which tests the null hypothesis that the model fits the data (Hosmer and Lemeshow, 1980).

3.3.7 Triangulation and validation of data

Most BPSU studies choose to reconcile their data with other sources to help improve completeness and accuracy (Nicoll et al., 2000). The process of using more than one data sources or methodology in order to develop a clearer understanding of the data and ensure credibility, is referred to as triangulation (Hastings, 2010, Heale and Forbes, 2013, Denzin, 1978)

In order to check the reliability and validity of the data collected in this surveillance study, additional data were collected using clinical case notes from the Maudsley Biomedical Research Centre (BRC) Clinical Record Interactive Search (CRIS) at the South London and Maudsley (SLaM) NHS Foundation Trust. CRIS provides authorised researchers access to secure, regulated, anonymised patient data extracted from electronic clinical notes (SLaM NHS Foundation Trust, 2017). Case data from CRIS were identified using the same time period, and applying the same criteria as the surveillance study. Comparison of the data could only be drawn against a subset of the data collected using CAPSS, and not data from BPSU, as SLaM provides only mental health services. Paediatrics is provided by a different organisation that does not have an equivalent electronic patient record system.

Only total numbers of cases and descriptive data captured by both systems could be compared; data linkage and protection governance meant that cases identified via CRIS could not be directly linked to the patient data collected in the surveillance study. The geographical boundary of SLaM could not be directly replicated in the CAPSS data as researchers are blind to patient data and the information provided on each case via surveillance related to the reporting consultant and not necessarily the service or clinic where the patient was seen. Therefore, the comparison with CAPSS reports could not get closer than the wider boundary of 'London'. This method enabled a real time data comparison and provided an indication of the completeness of the CAPSS reporting systems at collecting data on the incidences of rare events and processes in mental health services. It was expected that CRIS would reveal fewer cases, as SLaM encompasses only eight London boroughs, and the CAPSS data encompassed the whole of London.

The case definition criteria was the same as that applied to the surveillance study; criteria were operationalised into a structured query language (SQL), which was used to identify eligible cases in CRIS. This search produces an output of anonymous electronic records that meet the search criteria. Manual review of the electronic records by two researchers extracted the individual, clinical, and service related characteristics of the case, including details of transition (see Table 5). Two researchers were used as the process was time intensive. It also prevented bias that might occur from a single researcher; approximately 50% of

the case note records were double screened. Discrepancies were discussed and resolved by consensus.

The aim was, given the previously mentioned limitations, to replicate the data collected by the surveillance study. The incidence of successful transition collected via both systems was also compared. Data from each source were extracted by a researcher and collated in to a spreadsheet using Excel. Descriptive data were collated for the number of cases identified, gender, ethnicity, and the reviewing clinician. Further descriptive data were also collated for transition referral date, referral acceptance, first appointment in adult service, evidence of joint meetings and persons involved in transition. These were tabulated and directly compared to the data collected using surveillance.

CRIS was approved as an anonymised data resource for secondary analysis by Oxfordshire Research Ethics Committee (08/H0606/71+5). This project was reviewed and approved by the CRIS patient-led oversight committee (CRIS project ref: 961).

Table 5. Complete list of CRIS data outputs extracted for data collection

CRIS ID	Reason for appointment	Other medication 3
Gender	CAMHS or AMHS	Other medication 4
Ethnicity	Seen by clinician	CGAS score 1-100
DOB (specified)	Comorbidity 1	SDQ assessment date
Truncated postcode	Comorbidity 2	SDQ total score
Social deprivation	Comorbidity 3	Hyperactivity score
Date of diagnosis of ADHD	Comorbidity other	Impact score
CAMHS directorate	ADHD medication 1	Contact frequency
Last date seen	ADHD medication 2	DNA rate

3.4 Results

The surveillance period ran from November 2015 to November 2016. The first month in such studies is used to detect difficulties with the surveillance definition and because prevalence cases are often reported. The first month's data is therefore treated as a pilot and is not reported with the rest of the surveillance data. Therefore data as reported in this chapter were included from 1st December 2015 to 30th November 2016.

3.4.1 Surveillance responses

The mean response rate to the monthly orange/yellow cards was reported as 94% in BPSU and 57% in CAPSS. This is a lower response rate than CAPSS have reported previously (Ani et al., 2013, Lynn et al., 2012). Registration with BPSU and CAPSS is voluntary and therefore not all consultants practising within the UK may be registered to receive the reporting cards. Only consultant and associate specialist level clinicians are enrolled once identified; other clinicians, such as psychiatrists in training, nurses and clinical psychologists, may review patients with ADHD but would not be contacted to notify via BPSU or CAPSS. Some contact details provided by the surveillance organisations were out of date (n=8, 7%), which prevented the research team from reaching the clinician with the questionnaire. The research team made alternative efforts to reach the clinician, for example with help from the relevant surveillance organisation, or by using search engines and contacting the clinic or hospital directly.

In total 249 individual clinicians reported a total of 614 case notifications (314 BPSU, 300 CAPSS), all of whom were sent a baseline questionnaire for each notified case. This demonstrates more cases than existing reviews on transition have suggested in one year (Singh et al., 2008, Tatlow-Golden et al., 2018, Islam et al., 2016). Only cases confirmed as eligible in the baseline questionnaire were sent a follow up questionnaire nine months later; a total of 315 follow up questionnaires were sent to 148 individual clinicians. Table 6 illustrates the data responses for each stage of the surveillance study for the whole sample, and for BPSU and CAPSS separately.

The overall response rate to the baseline questionnaire was 90% from BPSU and 67% from CAPSS clinicians, and to the follow up questionnaire was 84% from BPSU, and 80% from CAPSS clinicians; these were slightly lower than reported by CAPSS in other studies (Lynn et al., 2016, Ani et al., 2013). The response rates take into account any contact with clinicians resulting in a reason for not returning the questionnaire; which included not remembering the patient, reporting the case in error, or the clinician realising that the case did not meet the definition criteria. Of the reported cases that were defined as ineligible for the study, 35% (BPSU) and 19% (CAPSS) were ineligible as they no longer required medication post transition.

There was no overlap in cases reported through the two surveillance organisations (i.e. there were no cases that were reported by both a paediatrician and a psychiatrist). This was also reported in previous surveillance studies jointly using BPSU and CAPSS (Ani et al., 2013, Nicholls et al., 2011). The 13 duplicate cases identified were from clinicians that reported the same case more than once in the surveillance period. There were 17 questionnaires that could not be completed at follow up; this was because the clinician either no longer had access to the patient file, or the clinician was no longer in post to contact for a response. There was no response at all from 42% of questionnaires (n=127), some questionnaires were returned blank or with missing data (n=86) and some clinicians reported when contacted that the questionnaires were time intensive to complete (n=17). The sections most frequently left blank at baseline were one or more of the elements regarding transition (see Q7.2 and 7.3 in Appendix Eight), and at follow up, one or more of the elements of optimal transition (see Q7.1 Appendix Nine). Responses were still included even if the questionnaire was not completed in full, and efforts were made to contact clinicians directly to complete any missing data.

Table 6. Surveillance study data November 2015-November 2016

Baseline (% based on total reported cases)	BPSU n=314	CAPSS n=300	Combined n=614
Not returned	29	27	56
-due to error/reason	(9%)	(9%)	(9%)
Not returned	41	127	168
-no reason	(13%)	(42%)	(27%)
Returned baseline questionnaire	238	139	377
	(76%)	(46%)	(61%)
Duplicate cases	6	7	13
	(2%)	(2%)	(2%)
Ineligible cases	36	26	62
	(11%)	(9%)	(10%)
Eligible cases	202	113	315
	(64%)	(38%)	(51%)
Follow up (% based on total eligible cases)	BPSU n=202	CAPSS n=113	Combined n=315
Returned follow up questionnaire	161	86	247
	(80%)	(76%)	(78%)
Not returned	12	8	20
-due to error/reason	(6%)	(7%)	(6%)
Not returned	29	19	48
-no reason	(14%)	(17%)	(15%)

3.4.2 Characteristics of eligible young people reported

The population of young people reported via the surveillance questionnaires was largely male (77%) and White British (91%) from both BPSU and CAPSS (see Figure 4). Cases were reported from across the British Isles, with the majority (over 85%) reported from England (see Figure 5). All cases reported from Wales, Scotland or Ireland were identified as White British or White Irish; ethnic diversity was only reported from within England.

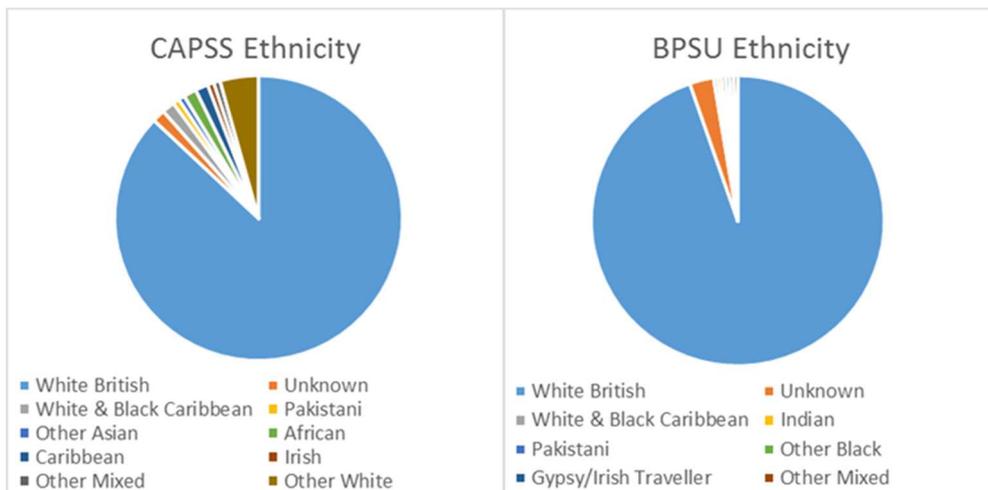


Figure 5. Ethnicity of reported population

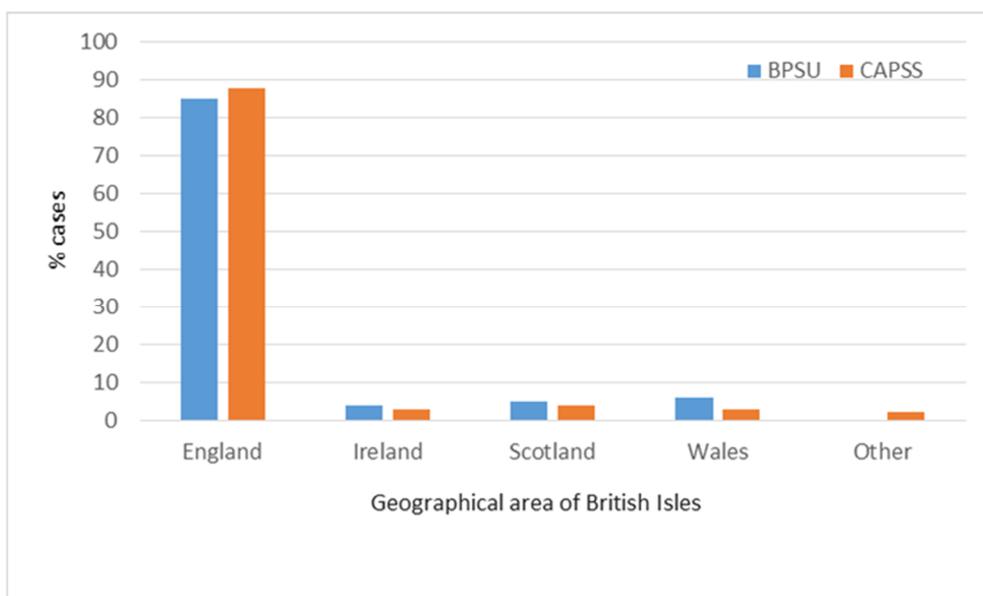


Figure 4. Geographical spread of reported cases

Table 7 shows the proportion of clinicians from each surveillance unit that reported each year of age as the boundary to which their service works, while Table 8 similarly shows the range of the age boundary by country. Two cases originated from the United States of America, but were registered students seen in private practice in England. Over 80% of reported cases were aged 17 or 18 years at the point of referral for transition, although the reported range extended from 14 to 20 years. A small percentage of clinicians (3%) stated that the age boundary for transition was variable. Child and adolescent psychiatrists reported more uniformity in age boundary than paediatricians, while Wales, Scotland and

Ireland appear to have more consistent age boundaries than those reported by services in England.

A large proportion of cases (56% from paediatricians, 68% from psychiatrists) were reported to have a comorbid condition and in 25% of reports the comorbid condition was autism spectrum disorder (ASD). Nearly a quarter (23%) of cases from paediatricians and over a third (41%) from psychiatrists were reported to be prescribed more than one medication, either for ADHD or a comorbid condition.

Table 7. Age boundary of child service as reported by clinicians

Age boundary	BPSU %	CAPSS %
14 - 14yrs 11m	0	1
15 - 15yrs 11m	0.5	0
16 - 16yrs 11m	12	0
17 - 17yrs 11m	17	12
18 - 18yrs 11m	63	83
19 - 19yrs 11m	3	1
Variable	3	0
Unknown / no data	2	3

Table 8. Reported age boundary of child service by country

	BPSU	CAPSS
England	62% age 18 range 15-19	82% age 18 range 14-19
Ireland	75% age 18 range 17-18	100% age 18
Wales	75% age 18 range 16-18	67% age 18 range 17-18
Scotland	80% age 18 range 16-19	100% age 18

3.4.3 Transition details reported

Figure 6 illustrates the range of services to which the transition cases were referred; half were referred to a specialist adult ADHD service, just over a quarter to general adult mental health services, and 10% were referred back to primary care. Referral destinations were similar regardless of whether the young person was reported by a paediatrician or a psychiatrist.

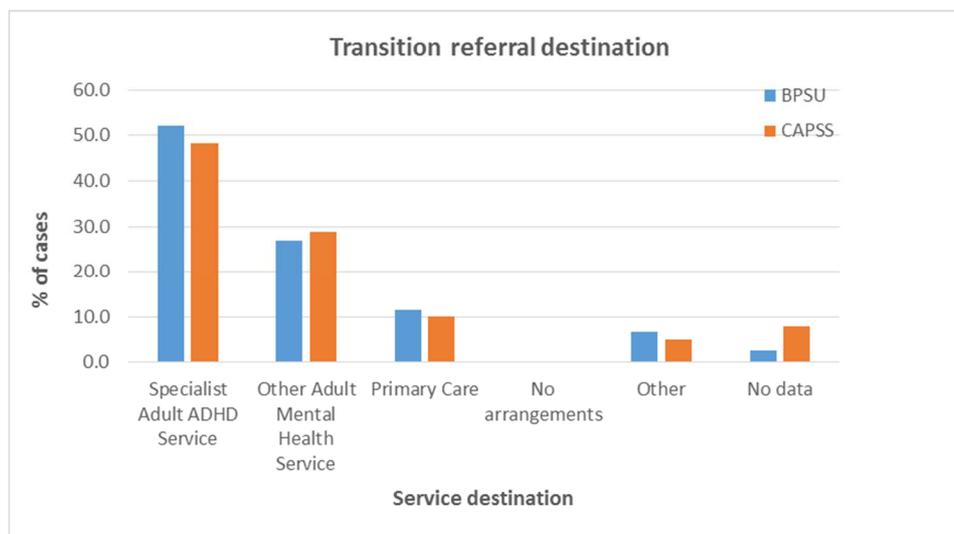


Figure 6. Transition referral destinations

In total, there were 315 confirmed cases reported that were eligible for transition (202 BPSU, 113 CAPSS) during the surveillance period. Of the 247 (161 BPSU, 86 CAPSS) that follow up data was completed for, 158 (64%) had a referral to an adult service accepted (84 BPSU, 74 CAPSS), and there were 55 (22%) cases (23 BPSU, 32 CAPSS) that were confirmed to be a successful transition (a referral made, accepted, and young person attended first appointment in the adult service) – see Figure 7.

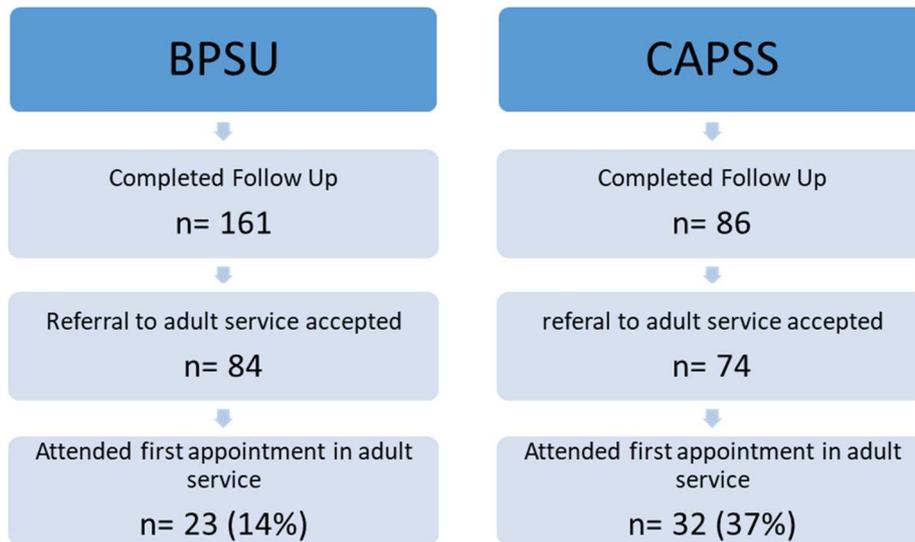


Figure 7. Success of transitions from all reported cases

Reasons that the adult services were reported to have failed to complete the referrals included; the patient disengaged and did not want medication or referral, the patient did not meet service criteria, there was no funding available, or the adult service was closed to new referrals due to lack of resources or long waiting lists.

Nearly all clinicians reported that the patient had been involved in the planning of the transition process (93%), and over 80% reported that the parent or carer was also involved in the process. More psychiatrists than paediatricians reported access to (81% vs 39%) and use of (66% vs 36%) a transition protocol.

There were nine elements of transition listed at follow up compared to five at baseline. At baseline notification, only 6% of paediatricians and 10% of psychiatrists indicated that all five listed criteria for optimal transition (as illustrated in Table 9) were apparent in the transition planning. At follow up only 2% of paediatricians and 6% of psychiatrists considered all nine criteria of optimal transition to have been adhered to (Table 10).

Some elements were reported significantly less at follow up than at baseline, suggesting that clinicians anticipate these elements, but when providing a retrospective report at follow up some elements are not carried out. These included information sharing (84.6% at baseline vs. 68.8% at follow up), young person involvement (81.4% vs. 69.6%) and joint working/handover (25.5% vs. 10.5%).

Table 9. Factors of optimal transition – pre transition

	BPSU n=202		CAPSS n=113		Combined n=315	
	Total 'Yes' response	%	Total 'Yes' response	%	Total 'Yes' response	%
Information sharing	176	87.1	93	82.3	269	84.6
Young person involvement	162	80.2	97	85.8	259	81.4
Planning meeting	23	11.4	29	25.7	52	16.3
Plan & agree care plan	49	24.3	46	40.7	95	29.9
Handover period	56	27.7	25	22.1	81	25.5

Table 10. Factors of optimal transition – post transition

	BPSU n=161		CAPSS n=86		Combined n=247	
	Total 'Yes' response	%	Total 'Yes' response	%	Total 'Yes' response	%
User/carer involvement	116	72	56	65.1	172	69.6
Information sharing	105	65.2	65	75.6	170	68.8
Care plan agreed	35	21.7	44	51.2	79	32.0
Joint working before transfer	12	7.5	14	16.3	26	10.5
Alignment of assessment procedures	9	5.6	12	14.1	21	8.5
Continuity of care	35	21.7	41	47.7	76	30.8
Consistency of care	13	8.1	36	41.9	49	19.8
Consideration of appropriate service	78	48.4	50	58.1	128	51.8
Clarity of funding & eligibility	66	41.1	51	59.3	117	47.4

3.4.4 Incidence of transition

Table 11 demonstrates the incidence calculations. There were 315 confirmed cases reported that were eligible for transition. From 247 follow up questionnaires

completed, 158 confirmed a referral to an adult service was accepted, and 55 cases were confirmed to be a successful transition.

As the NICE guidelines recommend that transition occurs at the age of 18, the population data used to calculate incidence was for the age group 17-19; 85% of cases reported via the surveillance systems were within this age range. However, there were 46 eligible cases (32 BPSU, 14 CAPSS) that were not aged 17 to 19 years, and therefore are not included in the incidence calculations. Of the 46 that are excluded from the following incidence calculation, only 13 cases (6 BPSU, 7 CAPSS) were confirmed to have a referral to an adult service accepted, and of those accepted referrals, only 4 (2 BPSU, 2 CAPSS) were confirmed to have a successful transition.

The Adjusted Incidence Rate 1 and Adjusted Incidence Rate 2 when applied to the reported cases and population aged 17 to 19 years, provide a likely minimum and a maximum range within which the actual rate of transition is likely to fall (see figures in blue in Table 11, p78 and 79).

Therefore, the following incidence rates are reported for cases seen in paediatric and psychiatric services;

Paediatric

- **Eligible** for transition: 17 – 204 per 100,000 people aged 17-19 per year
- **Successful** transition: 2 – 24 per 100,000 people aged 17-19 per year

Psychiatric

- **Eligible** for transition: 240 – 343 per 100,000 people aged 17-19 per year
- **Successful** transition: 76 – 108 per 100,000 people aged 17-19 per year

Of the 51 that were aged 17-19 and that were reported as successfully transitioned to an adult service, 30 were male (16 BPSU, 14 CAPSS), and 47 were White British (20 BPSU, 27 CAPSS). The majority, n=47, were cases seen across a geographical spread of regions in England (18 BPSU, 29 CAPSS), and were reported by 32 individual clinicians; 15 Paediatricians and 17 Psychiatrists.

Just over half (n=28) were referred to a specialist adult ADHD service (12 BPSU, 16 CAPSS) and 18 were referred to a general adult mental health service (4 BPSU, 14 CAPSS).

Table 11. Calculation of incidence rate of successful transition (per 100,000 people aged 17-19 per year)

	CAPSS	BPSU	COMBINED
Observed incidence all cases:			
<i>Incidence: eligible for transition</i> (all eligible cases identified in 12 months) per 100,000 per year	$(113 / 116,651) \times 100,000 = 96.9$	$(202 / 116,651) \times 100,000 = 173.2$	$(315 / 116,651) \times 100,000 = 270.0$
<i>Incidence: successful transition</i> (referral made, accepted and first appointment attended) per 100,000 per year	$(33 / 116,651) \times 100,000 = 28.3$	$(22 / 116,651) \times 100,000 = 18.9$	$(55 / 116,651) \times 100,000 = 47.1$
Observed incidence aged 17-19 only:			
<i>Incidence: eligible for transition aged 17-19</i> (all eligible cases aged 17-19 identified in 12 months) per 100,000 per year	$(99 / 116,651) \times 100,000 = 84.9$	$(170 / 116,651) \times 100,000 = 145.7$	$(269 / 116,651) \times 100,000 = \mathbf{230.6}$
<i>Incidence: successful transition aged 17-19</i> (referral made, accepted and first appointment attended) per 100,000 per year	$(31 / 116,651) \times 100,000 = 26.6$	$(20 / 116,651) \times 100,000 = 17.1$	$(51 / 116,651) \times 100,000 = \mathbf{43.7}$
Correction for non-returned notification cards (no age known):			
<i>Returned</i>	53.2%	94.2%	73.7%
<i>No response</i>	46.8%	5.8%	26.3%
<i>Assumption 1</i> (incidence applies to half non-returned)	$(23.4 + 46.8) / 53.2$ = coefficient 1.32	$(2.9 + 5.8) / 94.2$ = coefficient 0.09	$(13.2 + 26.3) / 73.7$ = coefficient 0.54
<i>Assumption 2</i> (incidence applies to all non-returned)	$100 / 53.2 =$ coefficient 1.88	$100 / 94.2 =$ coefficient 1.06	$100 / 73.7 =$ coefficient 1.36

Correction for non-returned baseline questionnaires (no age known):			
<i>Returned</i>	139 / 300 = 46.3% 100 / 46.3 = coefficient 2.15	238 / 314 = 75.7% 100 / 75.7 = coefficient 1.32	377 / 614 = 61.4% 100 / 61.4 = coefficient 1.63
Combined coefficients for cases aged 17-19 only:			
<i>Adjusted Incidence Rate 1</i> = incidence rate X Correction for unreturned notification cards (Assumption 1) X Correction for unreturned baseline questionnaires	Eligible for transition: 84.9 X 1.32 X 2.15 = 240.9 Successful Transition: 26.6 X 1.32 X 2.15 = 75.5	Eligible for transition: 145.7 X 0.09 X 1.32 = 17.3 Successful Transition: 17.1 X 0.09 X 1.32 = 2.0	Eligible for transition: 230.6 X 0.54 X 1.63 = 202.9 Successful Transition: 43.7 X 0.54 X 1.63 = 38.5
<i>Adjusted Incidence rate 2</i> = incidence rate X Correction for unreturned notification cards (Assumption 2) X Correction for unreturned baseline questionnaires	Eligible for transition: 84.9 X 1.88 X 2.15 = 343.2 Successful Transition: 26.6 X 1.88 X 2.15 = 107.5	Eligible for transition: 145.7 X 1.06 X 1.32 = 203.9 Successful Transition: 17.1 X 1.06 X 1.32 = 23.9	Eligible for transition: 230.6. X 1.36 X 1.63 = 511.2 Successful Transition: 43.7 X 1.36 X 1.63 = 96.9

3.4.5 Predictors of successful transition analysis

Table 12 shows the results from the uni-variable logistic regressions models that included each of the baseline variables from all three variable groups as potential predictors of successful transition. The number and percentage of cases who experienced a successful transition for each variable are also presented.

Within the patient characteristics, the presence of comorbid ASD was statistically significant and associated with increased odds of having a successful transition; the odds of a successful transition for those with ASD were estimated to be three times the odds for those without ASD. There was little evidence of an association between the presence of another (not ASD) comorbid condition and successful transition. The service that the young person is seen in (paediatrics or psychiatry), and some elements of transition were also associated with successful transition; the occurrence of a transition planning meeting between the referring and receiving service, establishing an agreed care plan, and a period of handover from the child to the adult service.

As there was only one significant factor for the patient or service variable that was significant (ASD and Service), the intermediate adjusted model was not required. Table 13 shows the results from the multivariable logistic regression for transition factors; having a period of handover remained significantly associated with successful transition, with the odds of successful transition being twice that of those without a period of handover.

The final multivariable model combining all significant predictors is described in Table 14. Overall the strongest predictors of having a successful transition were having a comorbid condition of ASD, attending a psychiatric service, and having a period of handover between the child and adult service.

The p value for the goodness of fit test conducted with the final model was $p=0.6$, indicating that the model was an acceptable fit to the data.

Table 12. Baseline variables predicting successful transition – results from uni-variable logistic regression models

	Variable at baseline	Total n = 247	% reported as successful transition	Estimated OR for successful transition (95% CI)	p value
Patient	Sex	Female n=54	22.22 (n=12)	Reference	p= 0.993
		Male n=193	22.28 (n=43)	1.00 (0.49- 2.07)	
	Ethnicity	White n= 229	22.27 (n=51)	Reference	p= 0.996
		Black & Ethnic minority n=18	22.22 (n=4)	0.99 (0.31-3.16)	
	Comorbidity (other than ASD)	No n=154	25.32 (n=39)	Reference	p= 0.139
		Yes n=93	17.20 (n=16)	0.61 (0.32-1.17)	
Autism Spectrum Disorder (ASD)	No n=184	16.85 (n=31)	Reference	p= 0.001	
	Yes n=63	38.10 (n=24)	3.04 (1.60-5.75)		
Service	Service	BPSU n=161	13.66 (n=22)	Reference	p= 0.000
		CAPSS n=86	38.37 (n=33)	3.93 (2.10-7.35)	
Transition	Young Person Involvement	No n=42	21.43 (n=9)	Reference	p= 0.886
		Yes n=205	22.44 (n=46)	1.06 (0.47-2.38)	
	Parent/Carer Involvement	No n=39	12.82 (n=5)	Reference	p= 0.130
		Yes n=208	24.04 (n=50)	2.15 (0.80-5.80)	
	Information Sharing	No n=33	15.15 (n=5)	Reference	p= 0.296
		Yes n=214	23.36 (n=50)	1.71 (0.63-4.65)	
	Transition Planning Meeting	No n=210	20.00 (n=42)	Reference	p= 0.045
		Yes n=37	35.14 (n=13)	2.17 (1.02-4.61)	
	Agreed Care Plan	No n=180	18.89 (n=34)	Reference	p= 0.038
		Yes n=67	31.34 (n=21)	1.96 (1.04-3.71)	
	Period of Handover	No n=183	17.49 (n=32)	Reference	p= 0.003
		Yes n=64	35.94 (n=23)	2.65 (1.40-5.01)	

Table 13. Multivariable logistic regression model of transition factors

	Variable at baseline	Total n = 247	% reported as successful transition	Estimated OR for successful transition (95% CI)	p value
Transition	Transition Planning Meeting	No n=210	20.00 (n=42)	Reference	p= 0.622
		Yes n=37	35.14 (n=13)	1.26 (0.50-3.17)	
	Agreed Care Plan	No n=180	18.89 (n=34)	Reference	p= 0.350
		Yes n=67	31.34 (n=21)	1.44 (0.67-3.09)	
	Period of Handover	No n= 183	17.49 (n= 32)	Reference	p= 0.018
		Yes n=64	35.94 (n= 23)	2.27 (1.15-4.47)	

Table 14. Final multivariable logistic regression model

	Variable at baseline	Total n = 247	% reported as successful transition	Unadjusted OR for successful transition (95% CI)	p value
Patient	Autism Spectrum Disorder (ASD)	No n=184	16.85 (n=31)	Reference	p= 0.001
		Yes n=63	38.10 (n=24)	3.11 (1.56-6.23)	
Service	Service	BPSU n=161	13.66 (n=22)	Reference	p= 0.000
		CAPSS n=86	38.37 (n=33)	4.62 (2.35-9.08)	
Transition	Period of Handover	No n= 183	17.49 (n=32)	Reference	p= 0.001
		Yes n=64	35.94 (n=23)	3.16 (1.56-6.41)	

3.4.6 Data validation results

In total 91 cases with a clinical diagnosis of ADHD were identified in the search of SLaM electronic case notes, who were within six months of the service age boundary, and therefore potentially eligible for transition. However, there was evidence in the case notes that 15 cases were discharged prior to transition or were no longer taking medication or requiring treatment, leaving 76 eligible for transition. The closest possible match to the geographical boundary of SLaM (London) was applied to the CAPSS surveillance study data, which identified 45 notified cases, 18 of which were confirmed eligible cases. However SLaM, and thus CRIS, is only one of nine mental health trusts in London, and only covers 8 out of 32 London boroughs (SLaM NHS Foundation Trust, 2018). CAPSS encompasses all of the London boroughs in this example. Figure 8 demonstrates the geographical SLaM boundary (in purple) amongst the rest of London. Table 15 shows a comparison between the CAPSS and CRIS data.

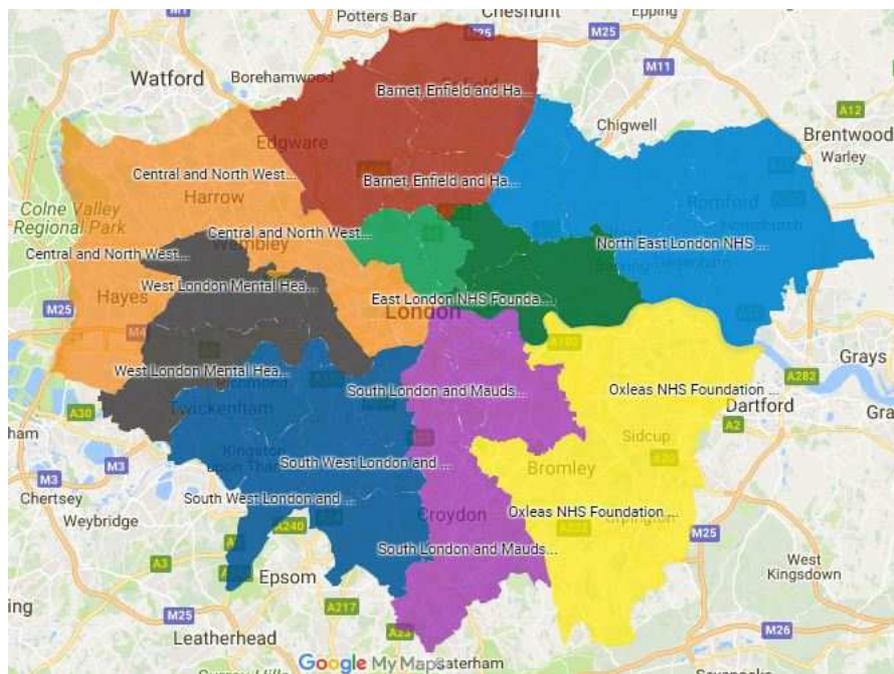


Figure 8. London mental health NHS trust boundaries

Table 15. Comparison of data collected by CAPSS and CRIS

	CAPSS	CRIS
Notifications / Identified cases (n)	45	91
Did not meet eligibility criteria (n)	27	15
Met all eligibility criteria (n)	18	76
Eligible cases only:		
Gender ratio (m%: f%)	83:17	87:13
Ethnicity (% White British)	72	55
Reported / Reviewed by consultant (n)	18	41
Reported / Reviewed by other health professional (n)	0	35
Transition referral made, accepted and first appointment offered in adult service (n)	10	37
First appointment confirmed as attended (n)	4	28

The ratio of males to females was similar in both sets of data (83:17% surveillance; 87:13% CRIS), however ethnic diversity was much greater in CRIS (55% White British compared with 72% White British in CAPSS), which more closely reflects the ethnicity seen in the London Boroughs served by SLAM (ONS, 2017). Only half (54%) of the 76 eligible CRIS cases were seen by a consultant psychiatrist, which is likely to explain much of the disparity in reporting as nearly all reporting clinicians on CAPSS are consultants. The remaining 46% of cases were seen by a range of clinicians that included; locum doctors, nurse practitioners or specialist ADHD nurses, ADHD specialist and clinical trainees, or it was not indicated in the case notes who had reviewed the patient.

There were lower levels of comorbidity among cases recorded in CRIS compared to those reported to CAPSS. Only a fifth of the cases identified by CRIS had a confirmed comorbidity (n=15, 20%), compared to half of the cases identified by CAPSS (n=9, 50%). Similarly in only a quarter of CRIS cases (n=18, 24%) the comorbidity was ASD, compared to 55% of cases from CAPSS. Evidence in the case notes of a completed transition (referral made, accepted and first appointment attended in AMHS) could only be found for 37% (n=28) of cases in CRIS and only 22% (n=4) of cases in CAPSS. Nearly half (n=33, 43%) of the

CRIS cases were referred to a specialist Adult ADHD service, compared to 61% (n=11) of CAPSS cases.

The CRIS comparison suggests that there were four times as many young people that were eligible for transition, and seven times as many successfully transferred, compared to cases reported by consultant psychiatrists via CAPSS.

The same incidence rate method as calculated for the surveillance CAPSS data was applied to the CRIS data. The population at risk was calculated from the total number of young people aged 17-19 in London as reported in 2016 (n=281,8757) (ONS, 2016). The same ADHD population prevalence estimate of 5% (Faraone et al., 2006) was applied, resulting in a population at risk of n=14,092. The date of birth of the case was specified in the CRIS SQL, and therefore all cases identified were aged 17 to 19.

In total, 76 cases from CRIS were potentially eligible for transition, 28 of which were confirmed to have had a referral made, accepted, and the patient had attended the first appointment in the adult service.

- **Eligible for transition:**

$$(76 / 14,092) \times 100,000 = 539.3 \text{ per } 100,000 \text{ people per year}$$

- **Successful transition:**

$$(28 / 14,092) \times 100,000 = 198.7 \text{ per } 100,000 \text{ people per year}$$

When compared to CAPSS (n=4 confirmed cases in London that successfully transitioned = incidence of 28.4 per 100,000), this validation exercise suggests that the surveillance study figures are likely to be a substantial underreporting; seven times more ADHD transition cases were identified via CRIS than CAPSS in the London area, albeit in an area known to have higher than average provision of services for both child and adult ADHD.

3.5 Discussion

This surveillance study was successfully conducted to address a rare health service need defined as an event and process (transition in ADHD). It was the first time that CRIS has been used to validate and compare the data collected using CAPSS, and suggests that for ADHD at least, the involvement of non-consultant practitioners in particular leads to a substantial underreporting via surveillance. Previous research has also highlighted that surveillance can only provide meaningful data if consultants are sufficiently involved in the case.

The findings suggest that the annual need for young people with ADHD to transition to adult services for ongoing support and medication would lie between 202.9 and 511.2 per 100,000 people aged 17-19 per year (240.9-343.2 per 100,000 people aged 17-19 per year among CAMHS attenders, and 17.3-203.9 per 100,000 people aged 17-19 per year from paediatrics). The estimated annual incidence of successful transitions lies between 38.5 and 96.9 per 100,000 people aged 17-19 per year (75.5-107.5 per 100,000 people aged 17-19 per year within CAMHS, and 2.0-23.9 per 100,000 people aged 17-19 per year in paediatrics). This is a wide range, relates only to those who require and are willing to take medications for their ADHD, and as discussed below, both the surveillance and CRIS data have limitations. However, these data broadly indicate that only a fifth of those requiring transition for ongoing medication successfully make the transfer. This is the best estimate at a national level of the number of patients with ADHD requiring transition, which clinicians are trying to manage in mental health services, available to date for commissioners and providers to consider.

Previous studies have only been able to estimate the number of transition cases in a small locality and suggest an average of 12 cases per team annually that require a transition to an adult service (Singh et al., 2008, Tatlow-Golden et al., 2018). The data collected through CRIS highlighted that surveillance using CAPSS only identified 25% of potential ADHD transition cases in the London area; assuming approximately 20% of CAMHS adolescents have an ADHD diagnosis (Health Service Executive, 2013) and there are approximately 1000 CAMHS teams in the UK (Barnes et al., 2006), the number of cases in one year demonstrated by this surveillance study is likely to be a significant under-

estimation of the actual need for transition in ADHD. A previous study in one locality found that only 15% of patients eligible for transition actually successfully transferred to the adult service (Ogundele, 2013), similar to the findings of this study.

Previous research has shown that children of Black and Minority Ethnicity are less likely to be diagnosed with ADHD than White children (McManus et al., 2016, Morgan et al., 2013). The gender ratio and ethnic origin of the cases identified in both the surveillance study and the CRIS study were in line with published national averages for the UK and England; the 2011 census confirmed London as 45% and the UK as a whole as 79% White British (ONS, 2011). Previous research has also shown the gender ratio for patients with ADHD to be between 3:1 in epidemiological studies, and 9:1 in clinical samples (Health Service Executive, 2013, Gershon, 2002); there is an under identification and diagnosis of girls with ADHD worldwide (Skogli et al., 2013). However, gender was not associated with the success of the transition in the regression analysis for this study. There is also a lack of epidemiological data on this age group; a recent report reviewing children and young people's mental health care highlighted a lack of data availability and monitoring of transition (Care Quality Commission, 2018), and further, reviews such as this only consider young people up to the age of 18 so knowledge of young adults is poor.

The findings of this surveillance study suggest poor adherence to the recommendations for transition from the National Institute for Health and Care Excellence (NICE). NICE recommend that a smooth transition between child and adult services should be complete by age 18, should involve a detailed care plan, should involve a formal joint meeting between the child and adult service, use the care programme approach, and involve the young person and the parent or carer (NICE, 2018a). In contrast, the surveillance study found that a joint planning meeting, the creation of a care plan and a joint handover period were conducted in less than 30% of cases in this study. Having a period of handover between the child and adult service was one of the strongest predictors of having a successful transition, a key factor that has also been highlighted in other research as optimal for transition (Paul et al., 2013).

Whilst the reported high level of involvement of the young person and carer in the transition process in this study is commendable, paediatricians in particular

reported poor continuity and consistency of care, which may reflect poorer links with adult mental health services for community paediatrics as opposed to CAMHS. This was also evident in the analysis, as being seen in a psychiatric service (and thus reported via CAPSS) was a stronger predictor of success at transition. Interestingly, previous research on effective transition models, although not specific to ADHD, has been focussed on paediatric rather than psychiatric services (Crowley et al., 2011, Doug et al., 2011); these studies also highlighted a lack of continuity of care between services, and the success of using joint clinic meetings to facilitate the process.

Other studies have also highlighted the lack of planning for transition of young people with ADHD specifically (Appleton and Pugh, 2011, Singh et al., 2008, Tatlow-Golden et al., 2018, Swift et al., 2014). A lack of planning is likely to undermine the potential for successful transition, and existing research has highlighted the need to adhere to recommendations to ensure effective transition (Young et al., 2016). Further, it is recommended that policies and guidelines are reviewed regularly so they can be operationalised and effectively translated in to clinical practice (Young et al., 2011).

This surveillance study collected the first national data to support an estimate of the national incidence of young adults who require and manage a transition to an adult service, based on their need for medication. This is a restrictive definition for the sake of precision and accurate surveillance, but obviously ignores the need for non-pharmacological treatment. The use of the BPSU and CAPSS systems presented a number of methodological challenges that will have impacted on initial notifications and subsequent return of questionnaires. Registration to receive the monthly reporting cards is voluntary and restricted to those in the consultant grade, therefore not all relevant clinicians may receive them. Some specialist ADHD services, in discussion with the researchers, organised for non-medical and non-consultant grades to assist with the reporting, but notification had to remain via the card system. There will be other services, particularly non-specialist, where eligible young people were seen but not reported. Indeed, the data validation exercise with CRIS demonstrated clearly that young people with ADHD may be clinically reviewed by higher specialist trainees, staff and associate grade doctors and non-medical prescribers. Other research has also demonstrated that patients may be reviewed in settings other

than paediatrics and CAMHS such as social care, education, primary care or forensic services (NICE, 2017a). Prescribing of medication will only be overseen by a consultant, and therefore reviews of patients in other settings should not prevent surveillance reporting. A study of surveillance approaches has highlighted the absence of surveillance in the private sector despite it playing an important role in health care provision (Kroll et al., 2015), perhaps particularly for young people with ADHD for whom there are few NHS services (Ford et al., 2015).

Incomplete data also presented a limitation, as non-response was experienced at each stage of data collection. The response rate to the questionnaires (58% at baseline and 83% at follow up) was slightly lower than reported in other surveillance studies (Lynn et al., 2016, Ani et al., 2013). Some contact details provided by both surveillance organisations were out of date (n=26), which prevented the research team reaching the clinician with the questionnaire. Questionnaires were returned blank (n=7), or with missing data (n=86), and some clinicians reported anecdotally that they struggled to find the time to complete the questionnaires (n=17). The latter is despite the fact that the questionnaires were short, with the baseline including only 30 and the follow up only 19 tick box questions. A proportion of attrition through incomplete or missing data can introduce bias and impact on the validity of the study (Edwards et al., 2002) and previous surveillance research has highlighted that non-returned data should be addressed for surveillance studies to succeed (Lynn et al., 2012). It was attempted to account for non-response when calculating incidence, but incomplete case ascertainment will have led to an underestimate of the incidence of young people requiring transition to adult services.

According to a census conducted by the Royal College of Paediatrics and Child Health (RCPCH) in 2013, there were 3718 registered consultant paediatricians whilst BPSU reports 3300 on the database, and a 2017 census by the Royal College of Psychiatrists (RCPsych) reported there to be 5395 consultant psychiatrists (approximately a quarter of which are child psychiatrists), whilst CAPSS have around 1000 on the database (RCPCH, 2014, RCPsych, 2017). Whilst the return rate of reporting cards by paediatricians via BPSU was excellent (perhaps as a result of longevity of the system), the average return rate of the reporting cards was much lower in CAPSS when compared to previously reported

surveillance studies (Ani et al., 2013, Lynn et al., 2012). The system was only adopted and replicated by CAPSS in 2009, and perhaps it is therefore yet to become normal practice for child and adolescent psychiatrists. The lower return rate of notification cards may indeed indicate a lack of awareness of the system and not necessarily be a reflection of clinicians actively being non-compliant. It is possible that the difficulties with the case definition could also have led to a lack of reported cases. Previous surveillance studies have also cited difficulties with reporting, case definitions and lower return rates (Okike et al., 2014, Ani et al., 2013, Nicholls et al., 2011, Tiffin and Kitchen, 2015). Reporting with no obligation potentially prevents reporting consistency (Kroll et al., 2015) so to encourage reporting and questionnaire response, the research team offered 'participation in research' certificates that could be used for appraisal. This incentive was generally received well, although there is no evidence to suggest that this had an impact on return of questionnaires. Research is enshrined in the NHS constitution as a core activity (NHS, 2015), however clinicians reported that current workloads made it difficult to respond to questionnaires, despite efforts from the research team to keep the questionnaires as brief as possible.

Data validation with the CRIS database to assess the completeness of case ascertainment was a strength of this study as it is important to attempt to quantify potential undercounting (Rahi and Dezateux, 1999) and verify findings. It is recommended that researchers conducting surveillance studies reconcile their data with other sources to help improve completeness and accuracy (Nicoll et al., 2000). Previous surveillance studies (Fortnum et al., 2001, Crowcroft et al., 2002, Knowles et al., 2006) have used 'capture recapture' analysis to maximise case ascertainment, but for this to be effective, matched cases must be identifiable and the population under study must be closed (Knowles et al., 2006). This was not possible in the current study of transition in ADHD. Data protection and governance meant that the data could not be directly linked between CAPSS and CRIS, which would have allowed more direct inference of the accuracy of CAPSS to be drawn. Interestingly, data protection rules may be more stringent than the attitudes of many patients and the public; a previous study has highlighted the benefits of linking data to provide information that is missing and reduce bias (Audrey et al., 2016) and a study of attitudes towards linking data concluded that it was perceived to be acceptable to share health data in a medical

Both methods of quantifying the incidence rate for transition have their strengths and also their weaknesses in terms of the robustness of estimates. The data collected using BPSU and CAPSS surveillance was pre-specified according to research questions, and required short, succinct responses. These questions were not simple variables that would be easily extracted from CRIS, and answering them via CRIS required a researcher to read and interpret data extracted from medical records. Inevitably, this involved some subjective judgements as the clinical notes may not necessarily include readily available concrete information such as prescribed medication, comorbidities or details of diagnosis.

While both methods require some interpretation, validity is likely to be higher when reported directly by the clinician working with the young person in a questionnaire tailored to answer specific questions, than with a researcher making assumptions from medical records that vary in completeness. The surveillance method has the advantage of gathering what the clinician remembers and knows, as well as what is recorded in the notes that they themselves may have written. It also has the advantage of its national cover, encompassing the whole of the British Isles rather than a narrow geographical region. However it is limited by the accuracy of the database of consultants, the exclusion of non-medical and non-consultant grades in reporting, and by response rate as a result of busy clinicians. The use of CRIS allowed estimation of the extent to which the national surveillance underestimated incidence, but it offered often poorer, less clear and less tailored information about the details of transition, and its reach was restricted to a single NHS trust in one geographical area. How representative these services and the young people attending them are of all young adults with ADHD is difficult to judge. Existing research has alluded that patients identified in case registers are not always representative of all cases with that disorder (Allebeck, 2009). Importantly, and a key limitation of this study is that the geographic location of SLaM clinics and hospitals could not be identically replicated in the surveillance data, as the correspondence address provided from the surveillance notifications was that of the clinician, which did not necessarily correspond to where the patient was seen. The broader term of 'London' was used which gathered cases from a wider boundary than is included in SLaM. Although adjustments have been attempted, it is acknowledged that the

adjustments are based on assumption that will not necessarily be completely accurate.

Previous research has suggested that traditional public health approaches for monitoring incidence of conditions is often too late, too costly and often inaccurate (Chao, 2014). Managing and running a surveillance study is labour intensive, both from the perspective of the surveillance organisation and from the individual study team, but it provides value for money as research studies can be conducted simultaneously (Elliott et al., 2001) and data can be gathered on a national level. It is worth noting that a case note review, even using an isolated system such as CRIS, is also labour intensive if the questions asked require active data extraction. For most conditions, surveillance studies are still the only source of national data (Grenier et al., 2007), but the existing surveillance organisations stress that studies should not generate more than 360 cases per year (RCPCH, 2018). For valuable national surveillance to be effective for more than just incidence of rare conditions, and to continue to inform public health policy (Grenier et al., 2007), these systems need to be properly funded and supported to enable implementation of large scale national studies. Previous research has highlighted that national data alone are not necessarily sufficient to address gaps and advance knowledge. The establishment of the International Network of Paediatric Surveillance Units (INOPSU) and the replication of the methodology in certain specialities, potentially provides methodological opportunities for researchers to gather invaluable data on uncommon conditions or health service events internationally (Grenier et al., 2009) that should be further explored.

Both the surveillance and CRIS studies had stringent governance and required considerable researcher time for data collection and analysis, but used in combination as opposed to in isolation, the methodology offers a more complete and accurate picture of the need and success of transition to an adult service among young people with ADHD.

3.6 Conclusion

National surveillance was combined with data extraction from CRIS to estimate the national incidence of young people requiring ongoing medication for their

ADHD, as well as those who successfully transitioned. The restriction of eligibility to those requiring and being willing to take medication, plus difficulties in case ascertainment, mean that the estimates of incidence provided represent the lower limit of the need for transition to adult mental service for ADHD. Attempts have been made to correct for incomplete ascertainment and provide a series of transparent estimates for policy, commissioning and service provision.

While certainly imperfect, these data are the best currently available and provide an insight in to the issue of transition for young people with ADHD nationally that has not been achieved by studies previously. These findings emphasise a relative lack of adherence to recommended guidelines for transition. A key aspect of the guidelines, a period of handover, is highlighted to be a strong predictor of a successful transition, however the findings of this study demonstrate the low proportion of eligible young people that experience successful transition and a continuity of care.

3.7 References

All references for this chapter have been collated in one list for the thesis. The reference list can be found on page 275.

Chapter Four: Qualitative study

4.1 Overview of chapter

This chapter builds on the data collected in the surveillance study in Chapter Three to explore what processes and procedures clinicians are following during transition from child to adult services for young people with Attention Deficit Hyperactivity Disorder (ADHD). The previous chapter used surveillance to collect data on the incidence and success of transition, details of the young people who require transition and details of the process of transition. This chapter presents some of the findings from qualitative interviews which were used to explore the views and experiences of clinicians, working with young people with a diagnosis of ADHD in both child and adult services, regarding the transition process.

This qualitative study was developed as part of the CATCh-uS project protocol. The clinicians interviewed for this study were recruited from a sampling pool created from the surveillance study (Chapter Three) and through an online mapping survey which was also conducted as part of the CATCh-uS study. Recruitment of a number of the clinicians for interview, which had reported to the surveillance study, enabled them to elaborate on the transition process they follow in their practice. I led the recruitment of clinicians from both child and adult services for interview, and conducted 25 of the 38 included interviews. I was part of a team of researchers that analysed the interview data using thematic and framework analysis in QSR International's NVivo10 qualitative data analysis software (Braun and Clarke, 2006, Ritchie et al., 2003). A copy of the interview topic guides used in the interviews with both child and adult clinicians can be found as Appendix Ten and Eleven.

The matters described and discussed in this chapter use only some of the data gathered using the clinician topic guides of the CATCh-uS project; in particular those interview excerpts relating to questions about NICE guidelines, the individual transition recommendations within the NICE guidelines, and transition protocols or guidelines. The overall findings of the interviews demonstrated that service organisation and functioning are key to transition and must support the

young person's needs; there must be adult services available for clinicians to refer young people in to, there must be relevant resources available to clinicians to facilitate transition, and clinicians and service providers must accept ADHD as a long term condition and be willing to continue medication in order for transition to be successful. These themes identified from the interviews using the child and adult clinician topic guides are being analysed and written up separately (Price et al., in submission-b, Price et al., 2019, Janssens et al., 2018, Janssens et al., in submission, Godfrey et al., 2019), of which I am a contributing author, but which fall outside of the remit of this thesis. For the purposes of this thesis chapter on the qualitative interviews, I have selected and reported in full the relevant interview data that relates only to clinicians use of the NICE guidelines, and thus answers the corresponding research question of the thesis.

The qualitative findings from the interviews with clinicians presented in this chapter have also been combined with quantitative data on factors for optimal transition collected using the surveillance study (Chapter Three). This provides a detailed account from a clinician perspective of the transition process for young people with ADHD from child to adult services, and the use and usefulness of the NICE guidelines. These combined findings have been shared in a research paper that has been submitted for publication to the journal *Child: Care, Health and Development*, and is currently under review (Eke et al., in submission). A copy of the manuscript under review can be found as Appendix Four.

4.2 Introduction

Attention Deficit Hyperactivity Disorder (ADHD) affects around 5% of the population (Faraone et al., 2015). Traditionally it has been seen as a childhood condition, with little or no impact in adult life (Asherson et al., 2010, Asherson et al., 2016). The number of graduates from children's services with ADHD has increased rapidly as prescription rates for ADHD have risen in childhood (Beau-Lejdstrom et al., 2016) and more recently it has been accepted as a potentially lifelong condition for some people with increasing recognition of the need for medical support in adulthood (Kooij et al., 2010).

Consequently, there is a group of young people with ADHD in need of continued service access for the management of their condition once they leave child services. The National Institute of Health and Care Excellence (NICE) guideline for ADHD (NG87) (NICE, 2018a) and the Child and Adolescent Mental Health Service (CAMHS) Review (Hall et al., 2013) recommend that adequate transition to adult services should include comprehensive planning and a lead person managing the process, at a time that is “needs-based” rather than age-based (NICE, 2008). Although the age boundary of healthcare services is variable and should be determined locally (NHS England, 2015), most services providing care for young people with ADHD in the UK currently limit attendance to under 18 years (Eke et al., 2019d). At the age of 18 healthcare competency is presumed, and by law the young person is considered an adult and thus supported by adult services (Larcher, 2005, Ross, 1997). The World Health Organisation (WHO) however, define those aged 10-24 years (WHO, 2006) as ‘emerging adulthood’, a distinct extended developmental period before a young person reaches an adult role (Arnett, 2000, Dovey-Pearce et al., 2005). More recent research has argued that transition should take in to account biological, psychological, social and vocational aspects of development, and be seen as a *developmental milestone*, as opposed to a negotiation of the structural boundary between, for example, child and adult services (Farre and McDonagh, 2017), with growing interest in the provision of youth services up to the ages of 25 years (Fusar-Poli, 2019)

Several studies, government documents and policy guidelines have highlighted the difficulty for young people who require a transition between children’s services (usually CAMHS or Paediatrics) and adult mental health services (Singh et al., 2008, Asherson et al., 2017, Department of Health, 2006). Transition between services should support a young person towards and into a new life stage, and this process extends beyond the simple transfer of clinical responsibility (Beresford, 2004b). However, a recent systematic review of mental health care systems found that neither the National Health Service (NHS) nor the United States (US) mental health system provided sufficient support or access to adult services for young people (Embrett et al., 2016). In addition, there is also a reported inverse relationship between the prevalence of mental health disorders in young people aged 16-24 and the use of mental health services (Catania et al., 2011).

Transition to an adult service for those with ADHD is therefore of key importance. By its very nature, young people with ADHD have significant difficulties with organisation, planning, impulsiveness, distractibility, and forgetfulness (Brugha et al., 2014); factors that would undermine the ability to effectively navigate complex service organisation or manage their condition independently. Young people with ADHD might not have reached healthcare competency therefore, something which is assumed when using adult services, at time of transition. A poorly managed transition can lead to needs being unmet, disengagement from services and ultimately poor life outcomes for the young person such as unemployment, under achievement in education and risk taking behaviour (Singh and Tuomainen, 2015, Young et al., 2011). A UK study found that only 12-15% of patients with ADHD made the transition successfully; with success being defined as referral made to the adult service and follow up care received (Ogundele, 2013). Similarly, a 2016-2017 surveillance study (see Chapter Three) found that only 22% of individuals requiring transition for continued medication for ADHD, successfully made the transition to an adult service, with success defined as a referral made, accepted and the young person attending the adult service (Eke et al., 2019d).

NICE was established twenty years ago by the Department of Health (DoH), in order to improve the standard of health and social care by reducing variation in the availability and quality of NHS treatments and care (NICE, 2018d, Culyer, 2005). NICE provides the evidence base for clinical governance, which is a framework that NHS organisations use to improve the quality of services and standards of care (Culyer, 2005, Gray, 2005). NICE issues guidelines, quality standards, and technology appraisals for a range of topics and specific conditions. Condition specific guidelines, such as NG87 for the management of ADHD (NICE, 2018a), or general service guidelines such as NG43 for transition from child and adult services for young people using health and social care (NICE, 2016b), aim to set out the most suitable standards of care for that condition or health care event, and promote integrated care where appropriate (NICE, 2018d).

The guideline for ADHD, NG87 (previously CG72), includes a section under 'service organisation' that details transition to an adult service and refers the reader to NG43 (NICE, 2016b).

Sections 1.1.4, 1.1.5 and 1.1.6 of NG87 refer to transition between child and adult services. The recommendations in summary are:

- The young person should be reassessed at school leaving age to establish the need for continuing treatment in adulthood (hence to determine if transition is required).
- A plan for a smooth transition should be made with details of anticipated treatment and service the young person requires.
- Transition should be complete by age 18.
- A formal meeting between the child and adult service should be considered.
- Full information should be provided to the young person about the adult service.
- The Care Programme Approach (CPA) should be used to aid transfer for young people aged 16+.
- The young person and parent/carer should be involved in planning.
- After transition, adult service should undertake a comprehensive assessment of the young person – to include personal, educational, occupational, social functioning and coexisting conditions.

(NICE 2018)

Previous studies have suggested that although NICE have issued over 200 clinical guidelines since initiation, there is variability in how they are updated and implemented (Drummond, 2016, Soheilipour et al., 2011, Alderson et al., 2014, Sheldon et al., 2004). Gill (2001) reported that guidelines are only followed in 55% of clinical decisions (Gill, 2001). Whilst guidelines are intended to be used in conjunction with clinical judgement, there are various 'non clinical' reasons why recommendations may not be followed, including financial and time investment, organisational or structural provision, patient choice or a lack of interest in the guidelines by the clinician (Gill, 2001).

Research has demonstrated that transition is important to ensure continuity of care, and to help minimise the risk of poor outcomes for young adults with ADHD (Young et al., 2011, Young et al., 2016, Paul et al., 2013). Barriers to successful transition reported in previous research were lack of information and preparation,

poor parent/carer involvement and a lack of flexibility in the process and accessibility of adult services (Reale et al., 2015, Young et al., 2011, Paul et al., 2013). Existing literature on transition for young people with ADHD which is qualitative in nature however is limited, but suggests that transition is inadequate and has a negative impact on the wellbeing of the young person (Matheson et al., 2013, Wong et al., 2009, Young et al., 2016, Price et al., in submission-b).

The CATCh-uS study conducted 142 interviews with different stakeholders of the transition process for young people with ADHD, including young people diagnosed with ADHD in childhood at different stages of transition; pre transition (aged 14-16 years), at transition, and young adults who had not transitioned into adult services but re-entered services at a later age, as well as parent/carers and clinicians from primary care, paediatrics, CAMHS and adult mental health services (Janssens et al., in submission).

The CATCh-uS study highlighted that the experience of transition for young people with ADHD is hugely varied and often inadequate. The most influential factors in transition were investment from all stakeholders to continue treatment, and the way the services were organised. Investment comprised interlinked factors including education, medication, parental involvement and preparation for adulthood, whilst the organisation of services included factors such as accessibility, information, remit and the role of the GP (Janssens et al., in submission). Many of these factors were multifaceted: for example educational influences included the impact of the school in identifying symptoms and the on the use of medication, as well as education of the child, parent and clinician around the condition of ADHD. Medication themes included the role of prescribing as well as the impact that taking medication had on the patient and access to or discharge from services. Parental involvement was a key facilitator for transition in terms of patient engagement and advocacy, managing medication and navigating services. Preparation for adulthood included ensuring young people and parents understood that ADHD is a long term condition and can impact adult life, providing adequate information about adult services and the transition process as well as how to access ongoing support (Janssens et al., in submission). The results suggested a lack of, or very limited, provision of information at transition, whilst the interviews with young people at different stages of transition found that effective and consistent communication of

information about transition and the adult service can contribute to a more satisfactory transition (Price et al., in submission-b, Janssens et al., in submission).

Some of the barriers to transition highlighted in the CATCh-uS and previous studies are recognised NICE guidelines. For example providing information to the young person about the transition, involving the parent or carer, and starting the transition process early. The fact that an absence of these factors was highlighted as a barrier to transition in the CATCh-uS study suggests a striking lack of adherence to the NICE guidelines in services for ADHD, which prompted further investigation on this topic. In this chapter therefore, the views of clinicians working in both child and adult services regarding the implementation of NICE guidelines for ADHD in their practice are discussed using data collected from the CATCh-uS qualitative interviews. It is important to understand how guidelines for ADHD are used by clinicians, what aspects of the guidelines are not implemented and why, and identify elements that might offer insight as to how NICE guidelines may or may not alter the transition process. Exploring the views and experiences of clinicians can provide an insight in to why a process is a success or failure (Craig et al., 2013) and the use of qualitative interviews enables the perspectives and accounts of clinicians to be explored and interpreted (Ritchie et al., 2003). The chapter particularly focusses on the processes and procedures that clinicians implement for transition between child and adult services for young people with ADHD, in relation to the recommendations for transition in the ADHD NICE guidelines. The qualitative work reported in this chapter had the following aim;

- To explore clinician's views and experiences of how NICE or hospital guidelines support or hinder the transition process for young people with ADHD.

4.3 Methods

This study was part of a wider three strand mixed methods National Institute of Health Research (NIHR) funded project on children and adolescents with ADHD in transition from child to adult services (CATCh-uS) (Ford et al., 2015). Stream one was a surveillance study to assess the need for and organisation of transition.

Details of the methodology and results of the surveillance study stream can be found in Chapter Three. The second stream was a qualitative study to understand the transition process (relevant elements of which are reported in this chapter), and the third stream was a mapping study to identify services for young adults with ADHD (Price et al., in submission-a).

The CATCh-uS project incorporated both a convergent parallel design and an explanatory sequential study design (Creswell and Plano Clark, 2017) to provide a better understanding of the research problem. Quantitative and qualitative methods were used in parallel; the quantitative data from the surveillance study informed the qualitative stream (research questions, sampling and data collection).

This chapter reports on some of the findings of the qualitative strand of the CATCh-uS study; in particular those related to clinicians working in both child and adult services. For the purposes of this thesis chapter, only the interviews conducted with clinicians are reported in detail; the remaining interviews conducted with young people and parents are summarised for information and triangulation only.

4.3.1 Recruitment of sample

Two groups of participants were recruited; clinicians with previous or current experience of child services and clinicians with current or previous experience of adult services. Participants were required to have a working knowledge of child or adult services for young people with ADHD.

A pool of clinicians from children's services (consultant paediatricians and psychiatrists) were identified via the surveillance study. Clinicians that indicated their consent on the returned surveillance questionnaire to be contacted again for an interview about transition in general were considered for the qualitative study.

Clinicians working in adult services were recruited from the follow up questionnaires of the surveillance study and also from the CATCh-uS pilot mapping study (Price et al., in submission-a). The surveillance follow up questionnaire asked the reporting clinician for details of the adult service, which was the intended destination following the patient's transition from the child

service. The details provided were used to identify and approach clinicians working in adult services with young adults with ADHD. The mapping study circulated an online survey via networks such as the Royal College of Psychiatrists (RCPsych), Royal College of General Practitioners (RCGP), Clinical Commissioning Groups (CCGs), AADD-UK, and ADHD Foundation. Clinicians reporting to the mapping survey were asked whether they knew of any services for adults with ADHD, and to provide details of any relevant service(s) (Price et al., 2019). At the end of the completed online survey, clinicians identifying as working in adult services could indicate their consent to be contacted for an interview on ADHD transition.

A purposive sample of clinicians working in child services and clinicians working in adult services were selected, taking into account clinician role, geographical location and the type of service that the clinician worked in. This purposive approach allowed exploration of the settings where transition is most likely to occur to be explored (Silverman, 2014) and ensured a range of health care professional experiences were represented. Recruiting interview participants from the clinicians reporting in the surveillance study also allowed the possibility of exploring reasons for any variation of findings elicited from the surveillance questionnaires. The aim was to recruit 15 participants working in child services, and 15 working in adult services. The decision regarding sample size was based on previous studies of transition and theory of qualitative work regarding the stage at which data saturation is likely to be reached (Beresford and Stuttard, 2014, Guest et al., 2006). Data saturation indicates that no new information or data are being identified using the sample and data collection method, and therefore further data collection or analysis are unnecessary (Saunders et al., 2018).

Clinicians who consented to be contacted were invited to participate via email and a suitable time for interview was arranged for the clinicians that responded positively to the invitation. Participation in the study was wholly voluntary, but as an incentive clinicians were offered a certificate to represent time committed to research, which could be used for appraisal or training evidence.

4.3.2 Consent and Confidentiality

Prior to the interview taking place, the researcher conducting the interview discussed and explained what the study was about, what would be required from the interview in terms of time commitment and topics of discussion, and offered the participant the opportunity to ask any questions. Once the participant indicated they were happy to proceed informed written consent was obtained. A copy of the participant information sheet and consent form used for the study can be found as Appendix Twelve.

Digital recordings and any researcher notes made during the interviews were stored securely in a locked filing cabinet on University grounds. Digital files and interview transcripts were then uploaded and stored securely onto the University server. To ensure confidentiality and anonymity, any potentially identifiable information of the patient, clinician or location in the interview notes and transcripts were deleted.

4.3.3 Data collection and management

All interviews were recorded between April 2016 and May 2017, were conducted over the telephone by one of the research team (HE, AP, AJ), digitally voice recorded, transcribed verbatim and anonymised before analysis. All interviews were transcribed using the same professional transcription service, who were given clear instructions on how to transcribe the recordings, and all transcripts were checked for accuracy against the original voice recording by a member of the research team to ensure reliability and validity of the transcript (Silverman, 2014).

Interviews were semi structured using a topic guide specifically developed for either the child or adult clinician participants. This ensured that the key themes were addressed consistently across all interviews, but allowed the researcher flexibility to shape the interview to the specific experiences of the clinician around transition (Ritchie et al., 2003). A copy of the interview topic guides for both child and adult clinicians can be found as Appendix Ten and Eleven. The topic guides were developed based on previous research, discussions with the CATCh-uS study Patient and Public Involvement (PPI) group and Study Steering Committee

(SSC), as well as initial findings from the surveillance study. Interview questions focused on themes such as transition protocols, procedures and practicalities, the use of the Care Programme Approach, drop out, medication use, involvement of the young person and their family in the process, factors of optimal transition and the clinician's experience of transition.

Each recruited interview participant was assigned a unique identifier code. All descriptive data gathered on the interview participants were inputted to an encrypted spreadsheet designed specifically for this study, password protected and stored securely on a University server. Interview recordings and transcriptions were anonymised and stored securely on an encrypted hard drive. Only the research team had access to the data. Once transcribed, interview data were managed using QSR International's NVivo10 qualitative data analysis software and were stored securely and password protected.

Table 16. Relevant extracts from interview topic guides

Clinicians from Child Services	Clinicians from Adult Services
What are your views and experiences of the transition of young people with ADHD?	Are you aware of a protocol for transition, either within your service or children's services? If so, do you refer to it and it is helpful? - If not, why might that be?
What are your thoughts about the NICE guidelines? Use of CPA (Care Programme Approach)? And any transition protocol or policy?	Do you usually receive appropriate information in the referral letter/documentation?
If there is a transition protocol: Do you use it? Why (not)? If so, is this protocol in accordance with the Care Programme Approach (CPA)? Have you found the protocol to be helpful in your practice?	What barriers have you experienced in working with children services?
Are GPs in your area able to prescribe ADHD medication?	What would optimal transition look like from your perspective?

4.3.4 Data analysis

As mentioned above, the surveillance study and qualitative study were conducted sequentially with findings from the surveillance study informing the topic guide for the interviews with clinicians. The qualitative data were designed to explore new findings from the surveillance study questionnaires. The qualitative study also allowed the exploration of new phenomena, not initiated by the surveillance survey findings. The overall aim of the CATCh-uS study was to integrate the results of the different studies during the overall interpretation to identify convergent and divergent elements from the different strands regarding the transition process (Ford et al., 2015). Therefore, a pragmatic view, typically associated with mixed methods research, informed this study. Mixed methods requires the mixing of qualitative and quantitative data collection, analysis and interpretation, and a key element is integrating or linking the data (Shorten and Smith, 2017). This approach was chosen over the post-positivist approach which is more typical for explanatory designs, because equal importance was placed on the quantitative and qualitative findings. In the CATCh-uS study there was an emphasis on the primary importance of the questions asked, rather than the methods applied to address them; the methods were chosen to, as much as possible, provide answers to the problem under study (Glogowska, 2011, Bishop, 2015).

The interviews were analysed using thematic and framework analysis by the research team (HE, AJ, AP, and TND). This approach has traditionally been used in social policy research, but has more recently been developed and used in medical and health research (Gale et al., 2013). Thematic analysis involves working systematically through the texts to identify topics, patterns and contradictions, while framework is an analysis tool that sorts the themes that are common across the data, summarises them and displays them in a matrix. This thematic framework approach maintains a link to the original data (Ritchie et al., 2003).

The analysis began with a detailed examination of the transcripts, reading and re-reading those transcripts of interviews not conducted by myself. Then, using an inductive technique, all transcripts were coded by four researchers, who underwent extensive training with the lead investigator of the CATCh-uS project

before data analysis, to ensure reliability and validity of the reported findings. This training included defining and reviewing the definition of each code and discussing identified examples of data that would match each code. The indexing process allowed the researchers to become familiar with the data and identify key issues or themes from the data that were relevant to the research questions. All interview transcripts were 'double' indexed by two researchers independently, who then discussed the themes or key concepts identified. After coding was complete, all researchers met to discuss their indexing and to create a thematic framework or 'coding tree' which involved identifying and labelling the key concepts. The tree was applied to a set of transcripts before researchers met again to discuss themes and subthemes; discrepancies in coding or use of the tree were resolved through group discussion. Changes were made to the tree, and definitions of codes and themes were recorded. This provided an overall framework of themes which was then applied to all interviews to 'code' the data and identify where the themes occurred.

The final stage involved creating summaries of each interview for each of the codes from the framework, which were used to compare and contrast, identify patterns or links, and to provide explanations of the findings (Ritchie et al., 2003, Braun and Clarke, 2006). The summaries were created in a matrix for each stakeholder group; adult clinicians and child clinicians. Identical to the thematic analysis, researchers created summaries for a limited set of themes before completing the whole set of transcripts. One researcher created summaries for all selected themes to allow for comparison and alignment of the summary crafting process.

I (together with the research team) conducted the indexing, developed the coding framework, coded, and completed the framework summaries, for all clinician interviews. A copy of the coding 'tree' can be found as Appendix Fourteen. Transcript excerpts relating to transition and implementation of the NICE guidelines (see Table 16 for topic guide questions eliciting these data) were analysed by one researcher (HE) in an iterative way applying thematic and framework analysis as described above.

The interviews were conducted in two phases to enable interim analysis to occur; a similar process to that described as constant comparison (Silverman, 2014, Charmaz, 2006). This ensured that any unexplored topics or newly acquired

information could be explored in more depth using updated topic guides in the remaining interviews. It also enabled targeted recruitment for the remaining interviews if necessary. The topic guides were amended as appropriate with the unexplored themes or topics based on learning from the first phase of interviews; this process also allowed recruitment to be ceased if it was felt that data saturation had occurred (Saunders et al., 2018). The additional or amended questions added to the topic guides related to the role of GP's in prescribing of medication and the overall transition process. These emerging themes from the initial phase of interviews also instigated a third phase of recruitment inviting GPs for interview as part of the CATCh-uS study. All questions described and shown in Table 16, and thus described and analysed for this thesis, however remained the same.

4.3.5 Data validation

In order to ensure the reliability and validity of the data collected, triangulation methods were employed. Triangulation refers to the use of different data sources or methods in order to develop a clear understanding of the topic under study (Patton, 1999). In this study, methodological, researcher and data triangulation was applied (Denzin, 1978).

Methodologically, data were simultaneously collected on the use of NICE guidelines using the CATCh-uS surveillance study to contribute to validating the findings of the qualitative interviews; the results of this will be briefly referred to in this chapter, but are reported in full in Chapter Three. A paper combining the findings of the surveillance study, and the interviews with clinicians from this chapter, has been submitted for publication to the journal *Child: Care, Health and Development*, and is currently under review (Eke et al., in submission). A copy of the manuscript under review can be found as Appendix Four.

The qualitative data were triangulated by collecting interview data from different stakeholders involved in the transition process, including young people (pre transition, at transition, and post transition young adults), parents, and the clinicians reported in full in this chapter. Researcher triangulation was also conducted, as all interviews conducted with clinicians, young people, and parents

were double coded and the summaries of each code and emerging themes were created by a team of researchers (HE, AP, AJ, and TND). The findings of the interviews with young people and parents are referred to briefly in this chapter but reported in full elsewhere (Janssens et al., in submission, Price et al., in submission-b).

4.3.6 Ethical considerations

The recruitment process for the qualitative interviews was designed and approved for use by the University of Exeter Medical School Research Ethics Committee in parallel with approval via the Confidentiality Advisory Group at the Health Research Authority (IRAS registration number: 159209, NHS REC Reference: 15/YH/0426, CAG Reference: 15/CAG/0184, UEMS Reference: 15/07/070).

4.4 Results

The interviews with clinicians provided an in-depth perspective of the transition between child and adult services for young people with ADHD, from the point of view of the referring and receiving clinician. The interviews with clinicians gathered a wealth of information regarding services and ADHD, but the main focus of this chapter relates to the data that directly links to clinicians' use of the NICE guidelines, the recommendations for transition within the guidelines, and how these impact on the transition process and the young person.

4.4.1 Descriptive summary of results

In total 38 interviews were conducted with clinicians; 22 with clinicians from child services and 16 from adult services. There was a mix of male and female clinicians (14:24 male to female ratio), and the clinicians were either a consultant paediatrician (n=15), a consultant psychiatrist (n=19), or another health professional, for example a mental health or ADHD nurse (n=4). The majority of

the clinicians worked within child or adult services in the NHS for young people with ADHD. Two of the participants worked in private practice with university students in England. Interviews were conducted from all four devolved countries of the United Kingdom, however the majority (92%) of clinicians worked in England. All interviewees had extensive current or previous knowledge of services for ADHD and were regularly reviewing patients with ADHD.

The analysis revealed three key themes; knowledge of guidelines, use and implementation of guidelines, and young person experience. The dominant experience reported by clinicians was that most were at least aware of the NICE guidelines and the recommendations within them for transition, but their daily practice was not led or influenced by the guidelines. The clinicians described a number of barriers which prevented them from following the NICE guidelines or from delivering an 'optimum' transition process, the majority of which were related to the service provision and resources of the local area. The impact of transition on the young person was also a key concern, with many clinicians highlighting the difficulties that young people face at transition, and how difficulties can escalate by a poorly managed transition.

These key themes that emerged from the interviews conducted with clinicians are discussed in more detail in the following sections. In the interview quotations that follow, 'CC' refers to clinicians interviewed from child services, and 'AC' refers to those interviewed from adult services.

4.4.2 Awareness and application of NICE guidelines

Most of the clinicians from both child and adult services indicated that they were aware of the NICE guidelines but it wasn't evident that clinicians prioritised or considered the recommendations within the guidelines in detail, and there was variation in clinicians' knowledge of the specific transition recommendations within the NICE guideline for ADHD.

"I'm familiar with guidance but not with the specific bit around transition" (CC03), "I'm aware of the NICE guidelines and CPA... we aim to meet the guidance ... beginning to do joint working" (CC15); "I'm aware they exist... I haven't read them with care" (CC12), "I can't

recall the guidelines without looking them up” (CC07), “can’t recall if they say anything about transition” (CC02).

There were differences in responses as to whether and why the NICE guidelines guided the clinicians’ practice around transition. Some clinicians acknowledged the importance of NICE guidelines and thus impressed that they should be followed

*“NICE guidelines are important and have to be followed” (CC08),
“they are a useful benchmark for what we should be doing” (CC11).*

Clinicians from children’s services in particular indicated that the NICE guidelines were not specific enough, although they did not specify which parts. There was also the suggestion that the guidelines were not highly valued, but that they tried to follow them anyway.

“I try to comply with the guidance” (CC01), “guidelines are very generic, very vague. I use them as a basis for some things but they’re not specific enough” (CC04).

“I’m not sure that those things [guidelines] are thought about carefully enough nor valued enough to give clinicians the time to be able to do things properly” (CC10).

In contrast, adult clinicians indicated that their practice was to follow NICE guidelines, or that the existing service provision (for example local NHS Trust service or local protocol) where they worked was already compliant with NICE recommendations, and indicated this to be helpful. Some alluded to their knowledge of the recommendations for transition by specifying procedures that occur in line with the guidelines;

“...protocol for transition [for all disorders] follows the NICE guidelines” (AC02), “service works to NICE guidelines, that’s why we have joint meetings” (AC38), “service fits the guidelines – it’s not rocket science but it helps” (AC02).

Some clinicians mentioned key aspects of the NICE guidelines and transition recommendations without referring to NICE directly. In particular, the Care Programme Approach (CPA), the use of joint meetings, and information transfer were discussed, at times in the interview not triggered by a question or prompt

from the interviewer regarding NICE. Their experiences varied as to whether these elements of the transition process occurred, and or the effectiveness of these aspects of the transition process;

“Ideally there should be early preparation and a handover period” (AC36), “services should sit together and handover” (AC39), “some clinicians are really good, send us all the relevant information, but very often it’s requesting information and not getting it” (AC04).

“We try and get hold of their notes but sometimes they’ve been archived or on a different site and they’re medical, not mental health, so we can’t access it which is really unhelpful” (AC12).

“We have joint transitional clinics...worked really well, there’s a visible handing over witnessed by the patient and parents” (AC13).

Some respondents indicated that there were specific protocols for transition which had been developed locally. However many clinicians, in both child and adult services, also indicated that there were no local policies despite this being a recommendation from NICE. There was no indication in the comments from clinicians as to whether they knew that having a local policy was a recommendation from NICE. Child clinicians also felt that the NICE guidelines would be more prominent if protocols were put in place locally, indicating that they were not aware that NICE already recommend having local protocols; however there were mixed views as to whether protocols or processes specifically for transition between the child and adult service were considered helpful or not;

“There is an agreed protocol between CAMHS and AMHS that is followed” (AC17), “there are clear protocols for what people do and the expectation for the transition period” (AC02).

“Trust has a transition protocol including ADHD” (CC10), “no protocol or policy within trust ... if you’ve got a protocol to follow it makes it easier for everybody to do the same thing” (CC08).

“There’s a general transition protocol written by CAMHS, then the reality – it doesn’t work. CAMHS fund the more complex cases that we can’t take” (AC39).

“If there was a document for transition, it would push the guidelines forward” (CC08), “having a transition document that says what should happen would make a big difference” (CC08).

4.4.3 Implementation issues

Clinicians from both child and adult services reported a number of reasons that prevented them from implementing the guidelines fully, thus having an impact on how the transition process actually occurred. The most prominent reason discussed by almost all of the clinicians was workload and resources, with the suggestion that more resources are required in order to fully implement guidelines. The overall perception was that NICE transition guidelines were unrealistic and unachievable due to insufficient service resources, in particular time. The guidelines might make sense but were considered unrealistic given the limited staff time available and workload pressures. Interviewees mentioned that their working conditions did not allow them to deliver a transition service according to NICE standards. Frustration with the unattainable standards outlined by NICE led to clinicians rationalising not providing NICE compliant services, or substandard services;

“We cannot be NICE compliant, we just simply do not have the resources” (CC15), “if you think they are impractical then you’re not going to follow them” (CC08), “NICE recommend stuff that is miles above what we will ever be able to provide” (CC11).

“Pragmatically services are so limited...we don’t have access and options” (CC04), “we try as much as one can with constraints of too much work and not enough time” (CC10) “reality is that no one has time – service is too big and has too many patients, there’s too many cuts and not enough money” (AC39).

“Services are beset by long waiting lists and shortage of resources” (AC36), “everyone is rushed, service is understaffed and overworked, [transition] is not done sufficiently” (AC36), “some of the NICE guidelines that come out have clearly been written by people who don't deliver the job” (CC08).

There were also reasons related to service structure and organisation which prevented them from following NICE guidelines; particularly elements related to the structural gap between both services. A lack of joint working and established processes or links between the child and adult service was mentioned as an explanation for non-adherence as well as a contributing factor to substandard transition. Clinicians described a situation where the adult and child service did not work together and did not know each other, and those working with children felt they lacked knowledge of the available services for adults. Adult clinicians tended to place responsibility for transition on the referring child clinician;

“There should be a linkage with CAMHS” (AC05), “adult clinicians don’t know child clinicians – there are no bridges” (AC05), “the issue is the commissioning – [adult service] aren’t part of our service so it’s hard to instigate any joint working” (CC18).

“Practicalities of knowing who to transition to is difficult” (CC10), “one of the many complications is trying to join it up, when it’s very un-joined up” (CC13).

Further, adult clinicians thought that a lack of commissioning also meant that clinicians were restricted on the service or support that could be offered to newly transitioned young people, in particular medications that could be prescribed for comorbid conditions. Adult clinicians explained that they have to refuse referrals because the cases, although they do have ADHD, do not fit the remit of the adult service, or because young people arrive with requests that they cannot meet. This leads to incomplete and unsuccessful transitions;

“Some are referred to us but the medication isn’t ADHD medication, unfortunately it’s not a referral we can accept” (AC06), “service is not commissioned to treat sleep disorders, lots of young people are on medication for sleep disorders and [adult services] won’t prescribe it” (AC05), “we want evidence of the symptoms, if not given we will send referral back” (AC33),

There was also further discussion around local commissioning, including services not supporting ADHD in adulthood, no adult ADHD services commissioned in the area, and higher eligibility thresholds for adult services, all of which have negative implications for the transition of young people requiring ongoing support;

“Local mental health service still do not recognise ADHD as adult diagnosis ... ideally I have tried to engage local AMHS but they have been so slippery” (CC18), “the issue is that the three consultants, one doesn't believe in it, one thinks they ought to sort themselves out... the only protocol [locally] is you don't diagnose and you don't treat it” (AC18).

“There isn't commissioning for adult ADHD locally” (CC05), “if you haven't got services commissioned within adult services to be the other side of transition than that is more of a challenge (CC09), “it depends what their other needs are, there's no one to hand them on to if they don't have very clear defined mental health needs” (CC08).

Clinicians reported that the more complex cases were easier or more likely to transition, but those with a diagnosis of ADHD and ASD were unlikely to meet the eligibility criteria for adult services. The remit in adult services for people with ADHD can be restrictive, which leads to unaccepted referrals;

“Some clinicians are more motivated to see ADHD transitioned patients than others, some questioned why the service took the patients” (AC17), “we have a few with ADHD and ASD, they need more support but don't quite meet the threshold” (CC13), “a lot of people will access CAMHS but they don't meet the criteria because adult mental health is more severe or more complex” (AC05),

As illustrated above, some comments in the interviews revealed cultural differences in the approaches of the child and adult service. These differences included the attitudes of adult clinicians towards ADHD as an adult or lifelong condition, the provision of medications for ADHD and comorbid condition, and the opinion of which service or clinician was responsible for the transition, all of which were differences that could potentially create challenges in transition.

4.4.4 Young person experience of transition

Some clinicians alluded to the impact that the transition process had on the young person undergoing it. The impact on the young person is heightened by a poorly managed transition as a result of poor adherence to the NICE guidelines. There

was recognition that the age of transition is a difficult time for young people, many of whom see the process as daunting, potentially increasing anxiety and decreasing self-esteem;

“The change to a new person [clinician] is daunting and difficult” (AC36), “young people are scared, they are anxious of the adult service” (AC38), “by the time a person transitions, their self-esteem may be low” (AC36).

“Transition isn’t just about transition in service, it’s usually when changing school, there’s a lot of anxiety” (AC05), “it’s often a source of anxiety for them, what will happen and they don’t always know” (CC16), “everything is changing and then they are thrown in at the deep end” (CC11).

Many clinicians also discussed how adequately (or inadequately) the young person was prepared for the transition. Clinicians recognised the need to communicate with the young person about transition, but mentioned a number of factors that hindered this discussion, including their own uncertainties. Other pressures such as the need to resolve crises during consultation, left little time to discuss the upcoming transition. Clinicians reported that providing adequate information about the adult service fostered familiarity and better prepared the young person for the jump to a service slightly different than what they were accustomed to. How and when they communicated this information varied amongst clinicians;

“There is a need to reassure and communicate” (AC33), “some families move from crisis to crisis so there’s less time to talk about transition” (CC15), “at 18 they haven’t been told what’s happening” (AC26), “I start saying about transition from 13, 14, 15” (CC01), “we alert them to a change at 18” (CC19).

“Services not good at preparing young people for transition, 60% are well prepared and adequately experienced, 40% don’t know what they are supposed to know, it depends on how it’s communicated to the patient by CAMHS colleagues” (AC02).

Similarly, there was a lack of information on the outcome of transition for the clinicians. Once the patient had been referred and transition had occurred, clinicians reported not having any information about the outcome, referring to the lack of information as a black hole;

“I don’t know what happens afterwards, I wonder about my patients, is it one of my patients that I have kind of pushed into the black hole” (CC01)

“I just write to them, sometimes they would write back to let me know the outcome but otherwise they disappear into a black hole from my perspective” (CC15).

It was also reported how the parent or carer of a young person plays a significant role in the transition process, and can help facilitate the process for young people. In terms of the young person’s experience, the presence of a parent engaged the young person with the transition and continued treatment, and prevented the potential for the young person to drop out of services. This however also emphasised the potentially different approach or ethos of the child and adult service;

“Often parents will bring [transition] up” (CC16), “their parents are more actively involved than routinely” (CC07), “having an engaged discussion with them, we tend to do that via parents or carers, in adult services that isn’t tolerated” (CC08), “half of them made the journey with their parents to adult psychiatry” (CC22), “if they’ve got a supportive family it’s OK, but if they don’t it’s a disaster” (CC04).

“We welcome families but it’s entirely up to the young person to make a decision” (AC04), “my experience is if the parents are still involved, the transition is often better, smoother” (AC16), “I think paediatrics and CAMHS are very much led by the parents, so all of a sudden they’re an adult and I’m directing questions at them” (AC15).

4.5 Discussion

The data gathered in this study used qualitative interviews to provide an insight into clinician's knowledge of the ADHD transition guidelines from NICE, the use and implementation of the guidelines by clinicians, and how some elements of the guidelines may help or hinder the transition process.

The responses gathered from the interviews with child and adult clinicians, indicated that although clinicians were aware of the guidelines and had some limited knowledge of what the specific recommendations for transition were, the recommendations from the guidelines were often not translated into practice. The World Health Organisation refer to this as the "know-do gap" (WHO, 2006); this gap is created where a lack of knowledge exchange occurs, and therefore the investment in research is not reflected in societal benefits (van den Driessen Mareeuw et al., 2015). Previous research has also highlighted that although knowledge of clinical practice guidelines or recommendations is considered important, it is rarely sufficient to influence practice; guidelines are often not used after dissemination and only followed in around half of decisions (NHS Centre for Reviews and Dissemination, 1999, Grol, 2001, Gill, 2001). The findings in this chapter have demonstrated a "know-do gap" between the evidence based recommendations for transition in the NICE guidelines (knowledge, and investment in research) and the practice that clinicians are undertaking (do). Clinicians reported numerous barriers to achieving an adequate or successful transitions (societal benefit). Further, there also appears to be a gap between working conditions within the NHS and the expected standards, leading to frustration for clinicians that fail to achieve the recommendations outlined by NICE.

A systematic review of guidelines has highlighted that adherence remains low even if awareness of, and agreement with, the guidelines is high (Mickan et al., 2011). This was very apparent in this study. On the whole, the clinicians in this study thought that the principles of the transition guidelines for ADHD made sense, yet, many of the recommendations for optimal transition (Paul et al., 2013) which are reflected in the NICE guidelines, were not being implemented as they were considered by clinicians working in both child and adult services, to be unrealistic or unattainable. Some clinicians considered that their service simply

did not have the capacity to follow the recommendations, viewing them as 'impractical' and 'miles above what could ever be provided'. Further, there also appears to be a gap between the working conditions within the NHS and the standards expected, leading to frustration for clinicians who are therefore set up to fail to achieve the recommendations outlined by NICE. Clinicians rationalised their non-adherence to the guidelines by referring to factors outside of their control for example a lack of resources. There was also the suggestion from clinicians that the guidelines were written by people who do not do the job. This criticism of 'unrealistic' guidance is not new; for example a study of implementation of the NICE guidance for schizophrenia found that workload, time pressures and a lack of specialist staff all meant that clinicians had doubts over the relevance and realism of the guidelines (Prytys et al., 2011). Similarly, concern was raised previously over how the development of guidelines may not include all relevant stakeholders, after a NICE appraisal panel did not include any geriatric psychiatrists for a review of anti-dementia drugs (Gupta and Warner, 2007). Whilst this has not been a reported concern for the NICE guidelines for ADHD, it is perhaps relevant to note that the recommendations for transition in ADHD are divided over two documents (NG87 and NG43), have not been updated since 2008, and could therefore potentially lack relevance.

Reasons for non-adherence to the guidelines, or a lack of implementation, discussed in this study often related to resources, high caseloads and other time pressures, which made it difficult for clinicians to arrange joint meetings or joint working across the child and adult services. These findings reflect the findings of previous studies which have highlighted inadequate time, high caseloads, staff shortages and a lack of information about the transition (Belling et al., 2011, Paul et al., 2015), as significant barriers to achieving continuity of care at transition. The rarity with which certain transition elements were reported to take place, particularly in relation to joint working, was also reported in the surveillance study reported in Chapter Three; in only 25% of cases clinicians reported a period of handover between the two services, and only 10% of clinicians confirmed that joint working occurred before transition (Eke et al., 2019a), despite a period of handover being a strong predictor of successful transition.

Clinicians reported a lack of local policies or protocols for transition that supported joint working between services. A lack of written protocols and support for

transition has been highlighted in another study of transition for all neurodevelopmental conditions (Signorini et al., 2018) suggesting that the findings in this study may generalise to all neurodevelopmental conditions, not just ADHD. Similarly, a study of mental health trusts in England found that only a third of trusts had protocols for shared care with GP's for ADHD (Hall et al., 2015), despite shared care being a recommendation outlined in the NICE guidelines. The surveillance study in this thesis (Chapter Three) found that 10% of the identified cases were referred back to primary care at transition (Eke et al., 2019a), and a similar study of community paediatricians found that half of cases were referred back to the GP (Marcer et al., 2008). This highlights the important role that GP's can play in transition. Parents interviewed as part of the CATCh-uS study however, indicated conflicting views and challenges when under the care of the GP for their child's ADHD; some indicated that their GP could not prescribe the appropriate medication, whilst others reported receiving valued support from their GP in referring and pushing to get a patient seen in services for ADHD. Clearly there is need to foster shared care processes with GP's in order to better support patients at transition.

Variation in, and barriers to, implementation of the guidelines are also dependent on a complex web of factors that includes the local organisational context and the attitudes of clinicians (Spyridonidis and Calnan, 2011), factors also mentioned by participants in this study. Some interviewees alluded to differences in the referring or receiving clinicians' opinion on ADHD as a long term condition, which impacts on the referral to adult services, and thus the transition. Clinicians also noted that physically separate child and adult services affected their ability to implement the NICE guidance by making it more challenging to communicate with colleagues in different services and harmonise protocols. Clinicians also gave more subtle indications that attitudes towards adult ADHD still influenced clinical practice in transition, and thus the process undertaken, with some quotes suggesting that ADHD was still viewed as an 'optional' and controversial diagnosis in the way that schizophrenia and depression (for example) are not. There has long been controversy around ADHD as a condition of adulthood (Asherson et al., 2010, Hill and Schoener, 1996), and it has recently been reported that treatment of adult ADHD is not yet common practice and centres to support it are often unavailable, despite the links between ADHD and psychosocial, functional and mental health

problems (Asherson et al., 2016). Whilst exploring clinicians attitudes to adult ADHD was not the focus of this study, comments made by participants echo the findings of Matheson et al's 2013 study, which reported negative and sceptical attitudes towards (adult) ADHD among health professionals (Matheson et al., 2013).

Addressing the education of clinicians regarding ADHD in adult populations and the key issues that are faced by this group of young people is important, and has previously been highlighted in an expert policy paper as a recommendation that could help facilitate more successful transitions (Asherson et al., 2017). The interviews with young people and parents in the CATCh-uS study, also mentioned how some clinicians rejected ADHD as an adult (and thus long term) condition, or a condition altogether, and how this led to complications during the transition. Many young people and parents reported not being informed about how ADHD can be a lifelong condition, and therefore require ongoing care and medication treatment. Concerns were voiced by parents and young people about how unprepared they felt for transition; clinicians indicated in these interviews that communicating with young people about transition was important, but that their own uncertainties hindered this (Janssens et al., in submission). The provision of adequate information to all stakeholders to improve preparedness, was highlighted as imperative to improve the transition process for young people and parents (Price et al., in submission-b).

The fixed transition age and the remit and organisation of adult mental health services may also negatively influence transition. The transition to an adult service comes at a time of many other transitions for young people, which may complicate the process and undermine the engagement of the young person. The social and biological transitions that young people are experiencing at the same time as health service transitions can be overwhelming and difficult to manage independently (HSIB, 2018, Dallimore et al., 2018). Clinicians interviewed in this study recognised that a poorly facilitated transition could ultimately have negative impacts on the young person, such as increased anxiety, low self-esteem, and ultimately drop out from services, which has also been highlighted in previous studies (Department of Health, 2006, Young et al., 2011). Similarly, the CATCh-uS study interviewed 21 young adults who had dropped out of services, whose stories echo the negative effects of a poorly managed transition. Many dropped

out of services due to a discontinuation of medication before transition, and many reported having anxiety, involvement with the criminal justice system as well as struggling socially and occupationally, before returning to services for continued medication and support (Janssens et al., in submission). It is therefore of key importance to address this impact with an effectively managed transition, and the recommendations in the NICE guidelines in theory can assist clinicians in providing an optimal transition process.

This study of clinicians' knowledge and use of NICE guidelines highlights a number of reasons why the transition recommendations in the NICE guidance for ADHD might not be fully implemented, and may indicate that implementation is not a high priority in an environment of limited resource and competing demands that may appear more immediate in terms of patient safety. Whilst regulations in England require commissioners to comply with recommendations in a NICE technology appraisal (e.g. for a new medication or procedure) (NICE, 2018b), NICE guidance itself is not mandatory, and the levers to drive implementation are more complex. Furthermore, full implementation of NICE guidance on transition in ADHD relies not only on the practice of individual clinicians but on a whole system structure which facilitates elements such as joint working and information sharing, and on an even more basic level, on the existence of a suitable adult service for people with ADHD.

A recent report mapping specialist adult ADHD services in the UK, highlighted the difficulty in accessing information about the availability of services, but the value to the public and patients in doing so (Price et al., in submission-a, Price et al., 2019). The availability of services to support adults with ADHD has also been highlighted as a barrier to transition in previous research, which has reported a lack of referrals from child to adult services due to the referring clinician assuming the patient will not meet the criteria of the adult service (Swift et al., 2013). Future research should therefore examine the views of service managers and commissioners on the challenges of implementing NICE guidance and their views on transition as a service priority.

Interestingly, although clinicians considered that current service capacity and resources made the guidelines 'unrealistic', the Resource Impact Report produced by NICE states that "no significant costs were anticipated in implementation", and anticipated instead that benefits would accrue due to the

avoidance of crisis presentation, and in the longer term, due to improved health and social care outcomes for young people (NICE, 2016a). There is indeed an evidence base to suggest that poorly managed transitions are costly (Singh, 2009, Lamb et al., 2008); consequences can include unemployment, antisocial behaviour, road traffic accidents and criminality, all of which have potentially high personal and societal costs (Gjervan et al., 2012, Halmoy et al., 2009, Fletcher and Wolfe, 2009, Young et al., 2015, Mordre et al., 2011). The fact that service change and investment may be required before the longer term benefits to young people with ADHD accrue, may contribute to a view amongst clinicians that resources are currently too limited to effectively implement the transition guidance as intended by NICE.

Clinicians in this study generally supported the recommendations for transition, agreed with their rationale, and acknowledged the negative impact of a poor transition on the young person. This irreconcilable tension between the lower level of service that they feel able to deliver and their aspirations for patients could also have detrimental consequences for clinicians, such as burnout and exit from the profession (Maslach and Leiter, 2016, Kumar, 2007). It highlights the importance of engaging clinicians in the process of developing guidance, something that NICE already do, but could be further strengthened. It also raises the possibility of a 'graded' system (gold, standard, minimum) building on positive aspects of the transition process that are feasible to deliver with the resources and service provision currently available to clinicians. A graded system of NICE guidelines for transition would outline a minimum expectation of provision for all patients, to facilitate clinicians to better support young people through the transition for ongoing care in adulthood. Involving young patients and parents in this process to elicit the most valued aspects of the transition recommendations, would further strengthen this approach.

The strengths of this study lie in the large, purposive and varied sample, and the clear, detailed methodology used in data collection and analysis. This included a constant comparison and Framework approach, as well as ensuring researcher reliability and demonstrating that data saturation was reached. Validation of data was also a strength, with triangulation demonstrated with different stakeholders and methodologies as part of the wider study (CATCh-uS). However the involvement of clinicians from only paediatric or CAMHS services may be

considered a limitation due to the different practices in these services. Further, the focus of this study with clinicians was particularly narrow, only identifying specific data related to clinicians' experiences of the NICE guidelines. The NICE guidelines were only one element of a comprehensive topic guide that was used in interview, and although the overall themes from the interviews have been summarised here, the detail of the interview transcripts outside of the NICE guidelines have not been expanded on in this chapter.

4.6 Conclusion

This study has demonstrated that clinicians involved in the transition process of young people with ADHD judged NICE guidelines to be unrealistic given the current service configurations and limited resources available. More work is therefore required to close the gap between the NICE guideline recommendations for transition, and what is feasible or realistic in practice. With ever increasing demands on NHS services and staff, it is likely that the feasibility of full implementation of the guidelines for transition in ADHD will continue to be unachievable, despite the potential that guideline implementation could have in improving transition. The findings from the interviews with clinicians in this chapter raises the question of the purpose of NICE guidelines; are we setting clinicians up to fail if the recommendations are far beyond what is possible in the realms of the current health service provision.

4.7 References

All references for this chapter have been collated in one list for the thesis. The reference list can be found on page 275.

Chapter Five: Does the law have a part to play in improving mental health services for young people with ADHD?

5.1 Introduction and overview of chapter

Previous chapters have highlighted that the National Institute for Health and Care Excellence (NICE) guidelines are the only guidelines that govern transition for patients with Attention Deficit Hyperactivity Disorder (ADHD) in England. NICE recommend that local systems and protocols be put in place between child and adult services (NICE, 2018a), however the systematic review in Chapter Two found that few locally produced protocols were reported in the literature. The surveillance study in Chapter Three has highlighted the clear need for transition but demonstrated that few of the transition recommendations from the NICE guidelines are adhered to, and only a fifth of cases successfully transfer. In addition, the qualitative interviews (Chapter Four) have shown that although clinicians are aware of the NICE guidelines, they are poorly adhered to, and rarely implemented in full. Previous research has also reported that guidelines are only followed in 55% of clinical decisions (Gill, 2001), raising the question of the purpose of the guidelines, and the benefit to the patient or clinician in using them. Non adherence to guidelines does not necessarily suggest malpractice or negligence. However, guidelines are meant to enhance quality of care, so in principle it is possible for courts to investigate why guidelines were not followed in clinical decisions, and whether the decision not to follow them is reasonable (Samanta et al., 2003).

Having discussed the clinical picture of transition and described research findings on the lack of optimal and successful transition, this chapter will now bring these research findings together to consider whether the law has a part to play in addressing the situation by challenging the current service provision. This discussion is particularly relevant currently as the government has indicated that further resources are to be made available to improve mental health services for young people (Department of Health, 2018). Research shows that transitioning young people with a mental health condition such as ADHD at a time based

purely on age, does not always result in optimal transition. Approaching the transition more flexibly, and taking into account the maturity level of the young person, can improve outcomes (Farre and McDonagh, 2017, Farre et al., 2016, Farre et al., 2015, HSIB, 2018). Most mental health services for children and adolescents in the United Kingdom (UK) have a strict transition boundary once a young person reaches the age of 18, and similarly, adult services have a rigid entry point at 18. This is regardless of maturity or level of need of the young person, which raises the likelihood of adverse outcomes and disengagement from services. Given that ADHD is likely to affect the age at which a young person gains maturity in decision making, this chapter questions the appropriateness of a strict age boundary for transition used by the majority of Clinical Commissioning Groups (CCGs) and health services in the UK. This in turn raises the question of how the situation can be improved, and whether the legal framework which governs CCGs, or more direct legal challenge or reform, can provide a solution or facilitate a way forward. Local CCGs were introduced in 2013 as statutory bodies that cover a specific geographic area and are responsible for planning, agreeing, procuring and commissioning services locally. They are now responsible for 65% of the National Health Service (NHS) budget (Checkland et al., 2013).

This chapter will therefore discuss the power and legal framework of the NICE guidelines in general, and specifically in relation to transition in ADHD. It will then consider the extent to which the law could be used to ensure consistent implementation of the guidance, and the potential unintended consequences or limitations that might arise as a result of using the law to enforce implementation of the NICE guidelines. Finally, the chapter will discuss whether legal reform could be achieved to replace the current criterion of transitioning at the age of majority, with a more flexible or an extended age range during which transition occurs. This would ensure that young people with ADHD are well supported in early adulthood and successfully transition in to an adult service for ongoing management of their condition.

5.2 The status and interrelationship between the National Institute of Health and Care Excellence (NICE) guidelines and National Health Service (NHS) structures: understanding the legal context

For over twenty years, NICE has issued clinical guidelines in England, with the aim and rationale of improving standards of care for patients and reducing inequalities in access to treatments, by assisting decision making and promoting best practice (Sheldon et al., 2004, Samanta et al., 2003). The guidelines issued by NICE are developed by expert committees using the best available evidence. A good evidence base does not necessarily translate in to good clinical practice however, and previous research has reported that structural and organisational barriers are a reason for the failure to turn evidence into practice (Grimshaw et al., 2004, Feder et al., 1999). Service providers and commissioners are encouraged to support clinicians in following the NICE guidelines, but guidelines are in fact not mandatory. Despite the fact the guidelines are not mandatory, it has been highlighted that just the presence of guidelines can put pressure on clinicians to conform within health providers, and removes the clinical discretion of clinicians to tailor patient care, which may lead to the needs of patients being unmet (Haycox et al., 1999). Guidelines are in theory meant to create better practice, but an unintended consequence is that in real life clinical practice where resources are restricted, and the patient groups are so large and varied, the benefits of care outline in guidelines are rarely fully realised (Haycox et al., 1999). The studies in this thesis have demonstrated this in transition, and highlighted that process at transition is not adequately supporting patients with ADHD, despite the presence of, and clinicians' knowledge of, the guidelines.

The legal force of the guidelines is dependent on challenges being brought to the attention of the courts. In the mental health context, studies have found that young people in all societies are burdened largely by mental health disorders, and mental health resources are scarce, unequal in distribution and inefficiently used (Patel et al., 2007, Saxena et al., 2007, Patel et al., 2018). Therefore, mechanisms are required to promote good practice, and to protect the interests of patients, whilst managing resources effectively and efficiently. In the UK it is thought that around 21% of the population (12% of adolescents) has a mental health disorder but only around 6% of the health budget is spent on mental health;

need and access varies inversely resulting in those that require the most mental health support not being adequately supported (Saxena et al., 2007).

The legal context varies within which the NICE guidelines operate. NICE provides a range of guidance which includes general and condition-specific recommendations for clinical, social, public health and medical practice, technology appraisals, interventional procedures, medical technologies, and diagnostics or specialised technologies (NICE, 2018c). However not all aspects of these guidelines carry the same legal force. Only the technology appraisals are subject to legal obligations, whereby there is a specific duty for CCGs to comply. However, it is stated in the content of the guidelines themselves that local commissioners and providers of healthcare have a responsibility to enable the guidelines to be applied, in the context of local and national priorities, and to eliminate unlawful discrimination, advance equality and reduce health inequalities. Professionals and practitioners are therefore expected to take the guideline fully into account (NICE, 2016b, NICE, 2018a, NICE, 2017b). Whilst it is not a duty to fully apply the guidelines, it does give the clinicians power to do so, and provides a responsibility for CCGs to facilitate application of the guidelines in their local health trusts. Exactly what legal force the NICE guidelines hold is not clear. They are guidelines not legal duties; however NICE is a statutory body, which is charged with ensuring best practice and improving standards of care. This means that the improper use or non-application of the NICE guidelines in specific cases could be challenged.

Perhaps the most likely avenue for challenge is that a patient or member of the public could use the Patient Advice and Liaison Service (PALS) at their local NHS trust to complain or contest the care they have received. PALS is a standard confidential advice and support service, present in most localities within England, which can help resolve concerns and manage the NHS complaints procedure for investigations of NHS services (NHS, 2018). PALS however are primarily an advice service and will try to resolve any issue informally, or will provide advocacy if the patient wants to make a formal complaint. In the case of lack of guideline implementation, the PALS service is therefore unlikely to have an impact on immediate service provision and the patient would need to embark on a more formal complaint procedure to get their concerns regarding lack of provision resolved.

In more serious cases, for example if the patient feels that they have been directly affected by non-application of the guidelines, the action of the service provider could be challenged on specific grounds through legal action in a process known as *judicial review* (discussed further below), during which issues concerning the guideline's legal status can be raised and determined by the High Court. The patient's right to claim for a complaint or judicial review is firmly outlined as part of the NHS constitution (NHS, 2015), and it has been used previously in relation to NICE guidelines.

In 2014, some clarification of the status of the NICE guidelines was given by the High Court in the reported decision of *Rose, R (on the application of) v Thanet Clinical Commissioning Group* [2014] EWHC 1182 (Admin) (hereafter *Rose*). This judgment sets a legal precedent on the issue of the status of NICE guidelines when considering access to treatment. In *Rose*, the court was asked to judicially review the decision made by the CCG and declare whether or not it was lawful. The court therefore had to consider whether the local CCG acted unlawfully by failing to implement a clinical guideline issued by NICE concerning access to NHS treatment for the technique of egg-freezing, prior to Ms Rose undergoing advised chemotherapy which was part of the treatment for her rapidly deteriorating condition as a result of Crohn's disease (Williams, 2014). The facts were that Ms Rose put in a funding request for the procedure; this was required as the treatment was not ordinarily funded in her locality. The local CCG's policy was to not fund the treatment unless exceptionality was demonstrated. Ms Rose's case was refused as the CCG did not deem her condition to be sufficiently different to any other and her case therefore failed the 'exceptionality' test imposed by the CCG (Johnson, 2017). NICE had issued new guidance prior to Ms Rose's funding request, which stated that this type of treatment should be funded, but as the new guidance did not specify an explicit duty to comply, the CCG failed to appreciate the legal significance. Despite going to appeal for a reconsideration of her case by the CCG, her request was not granted a second time. Ms Rose therefore sought judicial review (Johnson, 2017). In summary, the decision by the CCG stated that NICE guidelines were not mandatory and that commissioning priorities were decided by the CCG. The court however did not agree and ruled that "the CCG could not disagree with NICE, to do so would be simply irrational" (Williams,

2014). It therefore quashed the decision and found in favour of Ms Rose and ordered the CCG to reconsider the policy locally in light of the amended guideline.

More generally, the NHS Commissioning Board and CCG (Responsibilities and Standing Rules) Regulations (NHS, 2012) state that a relevant body (i.e. CCG) should have arrangements in place to make decisions and adopt policies on health care interventions. The arrangements should ensure that the CCG complies with NICE recommendations and should include arrangements for funding requests. The CCG should publish on their website a statement of reasons why particular healthcare interventions are made available, or not, and if funding requests are refused, the reasons for that must be provided in writing to the patient requesting it (NHS, 2012). This means that CCGs should have a prioritisation process to determine which healthcare interventions are made available, and provide reasons if a treatment is refused. These processes should ensure that NICE technology appraisals are always implemented, and should include arrangements for any requests for funding if there is no relevant NICE recommendation. In *Rose*, the judge's decision was based on the fact that the CCG should have had regard to the general policies and guidance provided by NICE, not just the technology appraisals, and a reasoned explanation should have been given for not following the NICE recommendations (Williams, 2014). NICE have responded to the court judgment from *Rose* by confirming that organisations that commission and deliver services (therefore including CCGs), are expected to take the relevant clinical guidelines into account when planning services in their locality, and if they are not considered, the organisation should be prepared to be challenged (NICE, 2014a).

In the context of a young person with ADHD who may not feel ready to transition to an adult service at the age of 18, considering a challenge to a CCG policy that requires immediate age based transition, may be helpful. First, it does in principle seem possible for a young person being referred to adult services at the age of 18 to challenge the decision to transition, or to challenge the process that was followed by the service they are being reviewed in, by way of judicial review. Such a person would have sufficient *locus standi* (i.e. the appropriate legal status) and may be eligible for legal aid to bring such a challenge, subject to meeting the required criteria. A young person would have a *prima facie* case if there is a blanket policy by a CCG with no statement as to why the NICE guidance is not

being followed as recommended, or alternatively the young person claims that the decision to transition is 'Wednesbury Unreasonable' (explained below). This would be relevant if the young person was unable to manage their own care, and thus the expectations on them to do so after the transition to adult services, as a result of their ADHD condition. A *prima facie* case means that there is an arguable case that the decision is unreasonable i.e. a clinician should always do as recommended by the NICE guidance unless there is an overriding reason not to (Bester, 2018). For example if a clinician does not follow the guidelines for transition, there is an arguable case that they have acted unreasonably. Such a case could therefore present the possibility to challenge the policy by way of judicial review as was achieved in *Rose*. This policy challenge may be one option when CCGs have such a blanket policy that is not supported by appropriate reasoning and justification. An example of such a blanket policy in services for ADHD was highlighted in the qualitative interviews with adult clinicians in Chapter Four; some clinicians indicated that there was a decision to provide no funding in adult services for certain ADHD medication, which is funded in child services. This therefore means that a young person, who has been stabilised on medication and requires continuation of it, can no longer access the medication after the age of transition. If such a policy was stated to apply without exception, the CCG would potentially have unlawfully fettered their discretion and could, through judicial review, be required by the court to reconsider the policy and provide lawful justification for it. Typically this should indicate in what exceptional circumstances such a policy may not apply.

Where there is a statement explaining the policy position appropriately, a young person may still have the possibility to bring a legal challenge of the decision to transition, in the context of their own situation. This second possible option may be to challenge a decision to transition an individual to adult services, on the grounds that it is '*Wednesbury Unreasonable*'. The *Wednesbury Unreasonable* test arose in 1948 from the leading case of *Associated Provincial Picture Houses Ltd. V Wednesbury Corporation [1948] 1 KB 223* case (Law Teacher, 2013b). The *Wednesbury* case set a precedent which must be followed in decision making by public authorities, and sets out the principles for judicial review of decisions. To be successfully challenged, such a decision needs to be one that is so illogical or immoral that no other person could come to the same conclusion.

The courts will normally only intervene if a public body, i.e. a CCG or NHS trust, with wide discretion, has exercised that discretion unreasonably (Wang, 2017, Dyer, 1987).

There have been other examples of precedents set through case law in different contexts which can suggest how the law would approach such a legal challenge by a young person with ADHD. A legal case against a CCG in 1997, *R v North Derbyshire Health Authority, ex parte Fisher* 38 BMLR 76 (hereafter *Fisher*), lays down the principles. In *Fisher*, a patient had been refused treatment with beta-interferon for multiple sclerosis from his local, and also neighbouring CCG, despite a NHS executive circular in 1995 asking health authorities to develop and implement local arrangements for continued prescribing of beta-interferon (MedLaw, 2014). The authority was challenged on Wednesbury Unreasonableness principles for failing to consider, or misapplying, the circular. The local policy was to only offer the drug if the patient was in a controlled medical trial, and the primary purpose of the trial was to test the efficacy of the drug and not to treat the patient. The judge therefore ruled that the authority's policy was not in accordance with the circular and would not give reasonable effect to the circular, and the policy was thus deemed unlawful (MedLaw, 2014).

The court rulings in the *Rose* and *Fisher* cases have set a precedent which, it is suggested here, could be used by analogy in appropriate ADHD transition cases, either where there is a blanket policy or where the impact of transition on the individual young person is clearly not appropriate.

In 2017, the impact of transition on young people with complex mental health conditions was highlighted, when the case of a young person with Autism Spectrum Disorder (ASD) made the news headlines due to a failed transition. The young person received therapy and medical treatment under the care of CAMHS but shortly before his 18th birthday he was told he would need to transition to an adult service. He expressed concern about the transition and loss of relationship with his CAMHS coordinator, and despite meeting with the adult service care coordinator and reassurance from CAMHS regarding the transition, he took his own life shortly after his last CAMHS appointment (HSIB, 2018). Clearly the decision to transition in this case had adverse outcomes for the patient. A national investigation by the Healthcare Safety Investigation Branch (HSIB) into the case was authorised following information gathering regarding safety issues that

contributed to the event. The findings of the investigation indicated that transition planning between child and adult services was hampered by high workloads, the Care Programme Approach (CPA) was not utilised, and CAMHS staff were not sure where to refer the young person for ongoing care (HSIB, 2018). Joint working and transition planning is stated in the current NICE guidelines for transition (NICE, 2016b), and in the case of ADHD, the use of CPA is also recommended (NICE, 2018a), thus indicating the recommended standard of care expected. These transition elements, or the appropriate standard of care, were clearly not applied in this ASD example. It is therefore suggested that the case of young people with ADHD in transition should be looked at in light of this ASD case; using it as an exemplar, it would strengthen the chances of success of a challenge by judicial review.

Another possible means of using the law to challenge the outcomes of poor transition policy focuses on the clinical decision taken by a clinician, and whether their decision could be considered as negligent. For the law of negligence, the Bolam test has traditionally been used to ascertain whether a doctor has provided the required standard of care (Samanta and Samanta, 2003). The Bolam test arose from the *Bolam v Friern Hospital Management Committee [1957] 1 WLR 583* in which the judge ruled that “a doctor is not guilty of negligence if he acted in accordance with a practice accepted as proper by a responsible body” (Law Teacher, 2013a). The required standard of care has to be one of ‘reasonable care’, which has to be supported by a body of medical professionals, and takes in to account all circumstances surrounding the situation (Samanta and Samanta, 2003, Warren Jones, 2000). It could be argued that NICE represents the body of medical professionals that provides recommendations for a standard of care, and therefore if the guideline recommendations are not met, the clinician in question could be challenged on the grounds of negligence. The Bolam test has previously been used in medical negligence cases (Samanta and Samanta, 2003, Kirby, 1995) and in order to prove negligence there has to be proof that there is a duty of care for the clinician, there has been a breach in the duty of care by the clinician, and there is some form of damage to the patient from the breach of the duty of care (Warren Jones, 2000).

Using the case of the young person with ASD who committed suicide as an example, it is suggested here that the actions of the clinicians responsible for his

care could be considered negligent by implementing the transition process in a way that was not compliant with recommendations in the NICE guidelines. Alternatively, if there was an example of there being an adult service available to refer to and the clinician did not refer, then that may also be considered negligent. However, given such cases are dependent on the facts of each individual case, and taking into account that NICE is the 'body of professionals' and CCGs are 'responsible bodies', it is at best difficult to predict with any certainty whether a referral to adult services in accordance with CCG policy at the age of 18, is likely to fall below the 'required standard of care'. In fact, the view taken here is that a challenge in court for negligence is probably unlikely to succeed in most cases. Even if an individual case with 'the right facts' was successful against a clinician, it is still less likely that it would result in a change or improvement to service provision or the transition process for the wider population, than a case where the CCG policy (or its application) was challenged by way of judicial review. Therefore by using the NICE guidelines to challenge the decision of CCGs to enforce transition at age 18 rather than at a time when the young person has the maturity and capacity to manage the transition, it is suggested that the use of the principles of *Wednesbury Unreasonableness* have more potential to impact and change service provision as a whole than an individual negligence case.

Judicial review decisions could potentially impact on adherence to the clinical guidelines provided by NICE across all health services, and can be used accordingly where there is a strong case. This is particularly significant when following reorganisation of the NHS in 2010, CCGs are free to allocate their resources and funding around the needs and choices of patients in their locality (Checkland et al., 2013).

Using the evidence from the research in this thesis, the case of transition in ADHD, like the ASD example, where age and not maturity is used as a cut off for the child service, may not be so clear cut. A young person with a mental health diagnosis such as ADHD, may be experiencing transitions not just in health services, but in personal, social and educational environments at the same time. Recommendations in the NICE guidelines tend to focus on the clinical problem and do not necessarily take into account other factors such as comorbid diagnoses, social or cultural issues. In addition, as discussed above, guidelines are not mandatory so can be interpreted in different ways (Gupta and Warner,

2007). Whilst bringing a case such as this to court may not necessarily result in a 'win' for the young person, it is nonetheless likely to raise interest and draw attention to important issues at a policy level. Providing a *prima facie* case can be demonstrated, such a challenge even if unsuccessful would be an important way to attract media attention, and the attention of local MP's and politicians, raising publicity around the issue of inappropriate transitioning policies for this group of young people. This in turn can encourage adherence to the guidelines and be a strong lever in building pressure for more far-reaching policy or legislative reform.

5.3 ADHD and optimal transition: why getting transition right matters

ADHD is one of the most common diagnoses that is managed by Child and Adolescent Mental Health (CAMHS) and paediatric services in the UK; it affects around 3-5% of the childhood population, and 15% of those diagnosed with ADHD in childhood still meet the full diagnostic criteria for the condition at age 25 (Faraone et al., 2006). Young people that require ongoing support for their ADHD once they reach the upper age limit of their child service, need to transition to an adult service, but many adult mental health services are not equipped to manage ADHD (McLaren et al., 2013). Previous studies have highlighted problems with transition (Singh et al., 2008); the process should reach beyond just transferring the clinical responsibility and it is considered that transfer is the suboptimal version of transition (Beresford, 2004b, Paul et al., 2013). Young people aged 16 to 18, regardless of mental health status, are particularly vulnerable and are in a period of rapid physiological, emotional and social change, and often experience other developmental transitions in education and social environments as well as the transition in health care at the same time (Paul et al., 2013). It is also a time when life changing decisions are made regarding education, relationships and child bearing, and habits such as diet, exercise, sexual activity and substance misuse are also formed (Patel et al., 2018). The cost of a failed transition at this point can be high and it is therefore important to ensure that the care received at transition is consistent and uninterrupted (Joint Commissioning Panel for Mental Health, 2013) to prevent the young person from disengaging with services and discontinuing treatment.

Over twenty years ago, it was highlighted that optimal transition should provide uninterrupted, coordinated, comprehensive healthcare, but at the time data showed that young people with impairments struggled to make the transition to adult care successfully (Blum et al., 1993). Whilst there has been an increase in research around transition, the situation has seen little improvement. More recent studies have described a successful transition as being coordinated, purposeful, planned and patient centred (Singh and Tuomainen, 2015), and it is recommended that transition should focus on need rather than age (NICE, 2016b). This is in line with a study by Paul et al. (2013) that described four criteria for optimal transition; continuity of care, a period of joint care, a planning meeting and information transfer (Paul et al., 2013). These factors also echo the transition recommendations outlined in the NICE clinical guidance for diagnosis and management of ADHD (NICE, 2018a). Potential barriers to an optimal transition can include poor communication and collaboration, different service funding structures, a lack of understanding across services, and time and resource constraints (Singh and Tuomainen, 2015, Davis and Sondheimer, 2005, Hovish et al., 2012).

A retrospective study has found that only 15% of the ADHD patients that required continued support and treatment made the transition successfully, and a further 2% of them were discharged after one attendance at the adult service (Ogundele, 2013). The surveillance study in this thesis confirms this, and found that that only 22% of the reported cases made the transition to an adult service successfully, and thus more than three quarters did not. In addition, the qualitative interviews with both child and adult clinicians in Chapter Four, highlighted the emotional impact that transition can have on the young person; *“YP are scared. They are anxious of the adult service and don't want to be there”*; *“ADHD population come in to service with low mood or self-harm”*; *“Transition isn't just about transition in service, there's a lot of anxiety and they are losing control”*. It was also described in interviews how the seemingly abrupt end to child services at the age of 18 is difficult for the young person; *“Everything is changing and then they're thrown in at the deep end”*; *“One boy coming to me since 7, carer said he'd be really nervous meeting anyone else. Seeing someone else after 11 years is quite frightening”*; *“All of a sudden they're an adult, they are 18, and I'm directing my questions to them. They really struggle”*. This is the sort of research evidence that

could be used to demonstrate that a policy or decision to transition, when considered against the negative clinical indicators, is illogical or immoral; the decision to transition could therefore be challenged on legal grounds as being unreasonable.

A poorly managed transition can result in a young person dropping out of services and thus receiving no medication which can have long term impacts. There are many reported consequences of the untreated symptoms of ADHD in young people, such as risky anti-social behaviour, smoking and lower academic performance (Fletcher and Wolfe, 2009). Research has shown that having a diagnosis of ADHD can also lead to implications at a personal and societal level, particularly as young people transition into adulthood. Adults with ADHD are more likely to be unemployed, take drugs, and are more likely to be involved in road accidents (Gjervan et al., 2012, Halmoy et al., 2009). The association between childhood ADHD and criminality in adulthood has also been highlighted (Mordre et al., 2011, Fletcher and Wolfe, 2009). Individuals with ADHD, particularly if untreated, have a higher rate of criminal justice contact (Young et al., 2015). A study of prison populations showed that 30% of youths and 26% of adults in prison, have a clinical diagnosis or meet the diagnostic criteria for ADHD (Young et al., 2018). In interviews conducted with young adults with ADHD aged 19-30 in England who had dropped out of services prior to transition, over half of the interviewees had current or previous criminal justice contact (Janssens et al., 2018). The clinician interviews in Chapter Four also highlighted how young adults with ADHD often have contact with the criminal justice system after transition; *“Parents are kicked out by statute, they [the young person] become legally responsible for their misdemeanours so a lot of my kids graduate to prison”* (clinician from child services reporting on what happens to their patients after transition).

The importance of continued treatment for ADHD has also been demonstrated in Sweden in a study of ADHD and criminality, which showed how medication management for ADHD can reduce criminal rates. The study found that criminality rates in patients with a diagnosis of ADHD reduced by 32% in men, and 41% in women who were taking their medication, when compared to periods off it (Lichtenstein et al., 2012). In the NICE guidelines, it states that medication should only be offered to young people aged 5 to 18 who still suffer significant

impairments once information on parenting strategies has been provided, group based support is offered, and environmental modifications have been made (NICE, 2018a); medication is therefore not necessarily a first line treatment for all. Despite this research evidence, interviewed clinicians (see Chapter Four) indicated that medication was often reduced prior to transition, a decision that is unlikely to be beneficial for the patient or society, and therefore could be considered immoral and unreasonable; *“once past GCSE exams we would try to wean medication down”*; *“we have a plan to test whether they can cope without meds”*; *“there’s a local barrier as we [adult services] aren’t commissioned to prescribe some ADHD meds – people are transitioning on meds and we aren’t able to continue to prescribe”*.

As previously cited research shows, there are societal and legal costs to untreated or poorly managed ADHD and it is therefore important to manage the period of transition to adulthood well, ensuring that treatment is continued if the young person would like it, as failure to do so can lead to unmet needs, disengagement from services and poorer life outcomes (Singh and Tuomainen, 2015, Department of Health, 2006).

5.4 Competency and capacity in ADHD: is the transition process ‘developmentally appropriate’ for young people with ADHD?

As the need for a successful transition and ongoing treatment for ADHD has been highlighted, this section now questions how and why transition may not be suitable for those with a diagnosis of ADHD. It is possible to consider ADHD a disability. According to the Disability Discrimination Act (DDA) 1995, a person has a disability if they have a physical or mental impairment which has a substantial and long term effect on the ability to carry out normal day-to-day activities (HM Government, 1995). The symptoms and characteristics of an ADHD diagnosis mean that a young person with ADHD is more likely to be dependent on others for care and support for day-to-day living (Rogers, 1997) and would therefore meet the DDA definition. Young people with medical and developmental disabilities are also considered a vulnerable group, and vulnerable groups can face multiple barriers to health care (Joshua et al., 2015, Fischella and Shin, 2005). A person with ADHD may always be more vulnerable and require more

support from a parent or carer than their peers, due to the traits associated with the condition. Autonomy or independence in health care is gained through maturity, competency and capacity, abilities that are likely to be gained much later in life by those with an ADHD diagnosis than without (Cadman et al., 2012, Young et al., 2011).

There is currently no legal test to assess the competency of young people to manage their healthcare (Ford and Kessel, 2001). In relation to healthcare in the UK, children under the age of 16 are presumed incompetent, those aged 16 and 17 can accept but not refuse treatment, and healthcare competency is presumed at the age of 18, at which point by law the young person is considered an adult (Larcher, 2005, Ross, 1997). By law, the term 'Gillick' competence is used to reflect the transition a child makes in to adulthood (Griffith, 2016). It is argued that there are three stages to development that a child reaches before becoming an adult which are in line with the three types of healthcare competencies described above; a child requiring parental responsibility, a Gillick competent child, and a young person aged 17 or 18 that can consent as an adult (Kennedy and Grubb, 1998). In order to be considered Gillick competent by law, the young person has to demonstrate maturity that includes managing influences on decision making, and intelligence that includes understanding, ability to weigh risks and benefits, and consideration of long term factors (Griffith, 2016).

The use of maturity as a benchmark is particularly important when considering those with ADHD, given that a mental health condition can impede information processing and retention (Ford and Kessel, 2001). A study in the US has demonstrated that development of the cerebral cortex, which is responsible for memory, speech, decision making, perception, cognition, awareness and sensory processing is delayed by 2 to 3 years in those with ADHD (Shaw and Rabin, 2009). The impulsiveness, inattention and hyperactivity traits of ADHD are likely to affect mastery of skills such as decision making, understanding and consideration of long term impacts. These characteristics may then prevent a young person from achieving competence by the time they reach the age where they would normally be transitioned to an adult service.

Maturity levels affect a young person's cognition, and therefore a young person's capacity to manage healthcare independently (Ford and Kessel, 2001). When considering capacity, the focus is on decision making and has two elements; a

functional element which requires evidence that the person is unable to understand, retain and use information and communicate the decision, and a diagnostic element, which requires evidence that the person is unable to make a decision due to an impairment of the function of the brain (Broach et al., 2016). A person with ADHD could potentially fall under this diagnostic element. Current practice within mental health provision means a young person with ADHD is presumed competent and autonomous once they reach the age of adulthood (Ross, 1997) and treated as such. The structures and processes between child and adult services are very different (Murcott, 2014), and adult services do not tend to take in to account the young person's mental capacity or maturity level, which is likely to be impaired in a young person with ADHD.

In the UK, there is clearly a difference in approach in health and legal terms regarding service provision being dictated by age or by competency, which is particularly relevant for young people with ADHD. In order to resolve this, other countries and organisations have recognised the age range when transition would occur as a unique group that should be considered by taking in to account both capacity and maturity. The World Health Organisation (WHO) define young people as aged 10 to 24 years (WHO, 2006) and this age group has been conceptualised as 'emerging adulthood', a distinct extended developmental period before a young person reaches an adult role (Arnett, 2000, Dovey-Pearce et al., 2005). A study of Australian mental health care has also suggested that the term 'youth' or 'young adult' for the period for young people between childhood and adulthood from age 14 to 25, implies the capacity to use services independently and consent to treatment independently (Newman and Birleson, 2012); something that a young person with ADHD may not be able to do effectively. In America, a pilot intervention to manage transition was implemented, which demonstrated that most of the group aged 18 to 23 were unable to manage their healthcare and were dependent on their parent or carer (McManus et al., 2015). It has been suggested that the peak age for negative impacts of illness in terms of social and economic outcomes is age 22 years (Murray and Lopez, 1996), and if young people do not fulfil their potential because of mental illness, it can lead to personal, social and economic disaster (McGorry and Purcell, 2009). The combination of ADHD characteristics and symptoms, and

the complexities of this age period, mean that transition is especially difficult and thus often unsuccessful.

In order to overcome the difficulties between services being dictated by age or competency, research has suggested that instead the focus should be on the needs and not the age of the young person (NICE, 2016b, Care Quality Commission, 2014). It is suggested that transition should be 'developmentally appropriate' (Blum et al., 1993) which is particularly pertinent when considering young people with ADHD who have reached the transition to adult services. Care is developmentally appropriate if it meets the needs of the person's developmental stage, associated with cognitive and social capabilities, and legal status (Newman and Birlleson, 2012). It focuses on development rather than chronological age (Farre et al., 2015) and takes the young person's developmental stage as a starting point for provision (Farre et al., 2015). Developmentally appropriate healthcare at transition should take in to account biological, psychological, social and vocational aspects of development, and be seen as a developmental milestone, as opposed to a negotiation of the structural boundary between the child and adult services (Farre and McDonagh, 2017). Although the age boundary of services is variable and should be determined locally (NHS England, 2015), most services providing care for young people with ADHD in the UK ceases at age 18 if in CAMHS, or often at age 16 if in paediatrics.

A person with ADHD is often characterised with symptoms and behaviours that include significant difficulties with organisation, planning, and struggle with impulsiveness, distractibility, and forgetfulness (Brugha et al., 2014). These are all factors that would imply that the person may not be able to effectively navigate services or manage their condition independently. A study has therefore highlighted that young people at the point of transition have low levels of knowledge and independence. It further suggests that the current transition process is inadequate, and that service provision and the transition process, should continue into young adulthood (Gleeson et al., 2012).

The transition process has also been described as being weakest at the point of highest need, as discontinuity in the system often occurs at the point when a smooth continuity of care is paramount (McGorry, 2007). Further, there is an inverse relationship between the prevalence of mental health disorders in young people aged 16 to 24 and the use of mental health services (Catania et al., 2011).

It is argued that services should therefore be changed to be developmentally appropriate in order to meet the needs of the young people using them (Gleeson et al., 2012). Independence and autonomy in healthcare is a goal of transition for young people, however the transition process can be long and complex, and the chances of it being a success are enhanced when support is continued (Osgood et al., 2010). A recent government green paper on transforming children and young people's mental health provision has also recognised the difficulty for this age group; £300 million of funding has been committed to implement proposals which plan to provide better access to mental health care for young people until the age of 24, regardless of whether they are in education or not (Department of Health, 2018).

5.5 Can the law help to reform services to be more developmentally appropriate?

This section will consider whether legislative reform can help to achieve a change to the age in which young adults with ADHD continue to access CAMHS. The age of majority, 18, is the normal test for children to become adults, and to be considered autonomous and no longer viewed as a child in need of protection due to their vulnerability. However there are exceptions where continued vulnerability has been demonstrated. To suggest continued vulnerability for a young person with ADHD would be an extension of a principle of policy already acknowledged in other areas.

The Children Leaving Care Act 2000 is an example of how the law has taken the vulnerability of the young person into account to make the service provision more developmentally appropriate (Department of Health, 2000). Previous to the year 2000, there was recognition that there were very poor outcomes for young people leaving care at age 18, including lower educational attainment, unemployment, homelessness, offending behaviours and poorer mental health (Stein, 2006, Gove, 2013). These are similar to the adverse outcomes of those seen in young people with ADHD, particularly if the condition is poorly managed. Research has shown that the transition from social care is often abrupt, especially for those with a disability (Parvaneh Rabiee, 2001). The amended Children Leaving Care Act (2000) therefore now obliges authorities to continue to provide assistance to

young people up until the age of 21, or up to the age of 24 if the young person is in an agreed education or training programme (Broach et al., 2016). The government invested £40 million over three years to support these policy changes (Gove, 2013). This provision will also fall in line with Education, Health and Care (EHC) plans. EHC plans were introduced in the most recent Children and Families Act 2014 for children and young people with special educational, health and social care needs. The plans have the aim of encouraging integration of services and joint arrangements, and provide provision for young people up until the age of 25 rather than up to school leaving age (HM Government, 2014).

More recently, new services have been developed in mental health services for ADHD to address the same issues as covered by the Children and Families Act. These are emerging services which are inclusive of young people aged 0 to 25 with mental health needs. This means that the transition to an adult service is delayed until a later age point, when the young person has potentially gained more competency and autonomy to cope with the transition to an adult mental health service. As previously discussed, it has been suggested that the peak age for negative impacts of illness in terms of social and economic outcomes is age 22 years (Murray and Lopez, 1996), so extending the age boundary of the child service to age 25 would provide the opportunity for young people to be better supported throughout this period of highest risk. A report by young people in Wales regarding transition from CAMHS has also emphasised that 38% of CAMHS users wanted more flexibility over the age that young people are transitioned from child to adult services, rather than the abrupt and disruptive transition when a young person turns 18 (Elliott and Roberts, 2016).

The idea to extend services for young people up until the age of 25 is not necessarily new, with many researchers highlighting the benefits of extending this period of youth (McGorry et al., 2013, Newman and Birleson, 2012), which is in line with the WHO definition of emerging adulthood previously highlighted (WHO, 2006). An extension of services has also been recognised and recommended in a recent report by the HSIB (highlighted earlier) (HSIB, 2018).

Forward Thinking Birmingham (Forward Thinking Birmingham, 2016), Youth Space (Birmingham & Solihull Mental Health Trust, 2018) and Rise (Coventry and Warwickshire Partnership NHS Trust, 2018) are all examples of service models providing mental health support for young people with ADHD up until the

age of 25 as opposed to the age of 18. These organisations provide integrated care, support and treatment through one organisation as opposed to multiple providers, for young people with mental health issues (Coventry and Warwickshire Partnership NHS Trust, 2018, Forward Thinking Birmingham, 2016), and do not transfer the care of the young person on to a sole adult mental health service until after the young person has turned 25. An evaluation of Forward Thinking Birmingham, using interviews and focus groups with stakeholders, found that the model was strongly supported, particularly the extended age range and the integration of child and adult services, and overall there were improvements in access to mental health services for all age groups. Conversely, the service was overwhelmed with patient referrals (Birchwood et al., 2017) indicating the high demand for this type of service. It is important to acknowledge that these service examples delay the transition point, which means that the young person is likely to be more able to manage the change in service provision, and the flexibility in age of transition is likely to minimise the barriers and risks associated with transition (HSIB, 2018). However, the evaluation of Forward Thinking Birmingham did not collect evidence to evaluate the management of the transition at the age of 25. Despite this, the success and acceptability of the Forward Thinking Birmingham service combined with other research showing that greater maturity is reached by those with ADHD much later than their peers, suggests that services that cater for young people up until the age of 25 are more likely to limit the difficulties that occur with transition at age 18, and be more acceptable for this unique group of young people.

5.6 Could the law be used to challenge the NICE guidelines for ADHD transition?

In the *Rose* legal case discussed earlier, it was ruled that the local CCG had failed to implement the clinical guideline and it was 'unlawful' to refuse treatment that the patient had requested without satisfactory justification of the reason to depart from the guidance or policy (NICE, 2014b). Similarly, the legal case *Fisher* in 1997 saw a patient refused treatment with beta-interferon for multiple sclerosis from his local, and also neighbouring CCG, despite a NHS executive circular in 1995 asking health authorities to develop and implement local arrangements for

continued prescribing of beta-interferon (MedLaw, 2014). The local authority was successfully challenged on Wednesbury Unreasonableness principles for failing to consider or misapplying the circular.

The NICE guidelines for ADHD transition provide recommendations that, if implemented as described, would mean patients *should* experience optimal transition. However, studies conducted as part of this thesis and previous research has shown that these recommendations are rarely implemented exactly and optimal transition rarely occurs. The surveillance study in Chapter Three found that all aspects of the transition recommendations in the ADHD NICE guidelines were implemented in only 6% of the cases notified. As NICE guidelines are not mandatory or enforceable, it is perhaps not surprising that they are not always followed. At the point of transition, the legal and organisational arrangements in health services changes; the service responsible for the young person changes from child to adult orientated, and the young person is no longer considered as a child or minor by law. Any failure in the transition process at this stage can contribute to a poorer quality of life and negative outcomes for a young person with ADHD (Broach et al., 2016).

The NICE guidelines demonstrate for patients what clinicians should be doing in services, setting best practice standards. However, it is perhaps also important to consider the potential unintended consequences that might arise from services being legally bound to implement all aspects of the NICE guidelines for transition. Early research on the development of guidelines has suggested that implementation of guidelines restricts clinician discretion to tailor care to the individual patient circumstances (Woolf et al., 1999, Haycox et al., 1999). The needs of individual patients may differ because of their particular predicament, but are also not the only priority when developing guidelines. Other priorities include service costs, societal needs or lobbying from special interest groups. Guidelines also potentially remove any attempts by local CCG's to respond to and support the local need. Whilst the implementation of a guideline may provide additional resources and cost effective provision for one health need such as transition, it may also result in redirection of resources from another (Haycox et al., 1999, Woolf et al., 1999). There is also the consideration that even if guidance is made mandatory and represents the minimum expectation, if the research

evidence behind it is inadequate then the treatment experienced by the patient is also likely to be inadequate (Jackson and Feder, 1998, Eccles et al., 1996).

Putting legal responsibilities on guidelines has been described as a double edge sword; it raises the possibility of guidelines being used as evidence in malpractice or negligence cases, but it is also likely to lead to more widespread compliance in the long term (Hyams et al., 1995). If guidelines were to be made mandatory, it should be made clear that they are present in order to be followed unless there was significant reasonable belief that following them would not be in the patient's best interests. To secure widespread best practice, diversion from the guidelines should only be permitted in situations where there are good clinical reasons not to follow them, as opposed to resource reasons which is often used currently.

The key questions from the research in this chapter to explore further are therefore, using *Rose* or *Fisher* as a precedent, could a young person with ADHD legally argue that their local CCG acted unlawfully or unreasonably by not providing an optimal transition process, thus impacting on continuation of treatment and poorer life outcomes? Could local CCGs be forced through judicial review to implement the transition process exactly as NICE recommend? The judge in the *Rose* case stated that any system that has to distribute finite resources should not do so in an arbitrary way, and should recognise the patient's fundamental human right to receive the same treatment as anyone else with the same clinical need (Williams, 2014). The clinicians in child and adult services interviewed in this thesis, often cited a lack of resources as a reason for not implementing the transition guidance; "*service is understaffed and overworked*", "*service is beset by long waiting lists and shortages of resources*", "*limited funds so we can only provide part of the pathway*", "*we do try to do things as best we can but everybody has too much to do and not enough time*". Other research has also shown the patchy provision of services and support for ADHD in adulthood (Young et al., 2011, Kooij et al., 2019). But in the situation of ADHD and crucial here, is whether a lack of resources is enough to be considered a 'reasonable' decision in court for not carrying out the transition process as it is recommended by NICE?

It is possible given the right case, that using judicial review the courts could intervene and enforce the guidelines, to ensure the transition to an adult service is seamless, and limit the adverse long term outcomes for a patient with ADHD.

If guidelines are dismissed as a matter of local protocol, then the NHS trust or CCG is clearly not adhering to their responsibilities which would leave them open to challenge on unreasonableness. However, as NICE guidelines are not mandatory, proving unreasonableness in the case of ADHD transition within the context of stretched resources is perhaps unlikely. Despite the *Rose* and *Fisher* rulings, it has been stated that CCGs can choose not to implement guidance if there is a good reason for doing so, and a lack of resources has been recognised previously as a reasonable decision in *Wednesbury* terms (Williams, 2014). If a lack of local resources for transition is genuine then the potential for judicial review is weaker, and investment in children's mental health services may provide an important avenue to widen the opportunities for challenge. Recent government pledges and papers have highlighted investment and intention to improve mental health services up until 2020 (HSIB, 2018), so public bodies could potentially be challenged on their use of funds using *Wednesbury* principles. Furthermore, cases such as *Rose* or *Fisher* will fuel publicity and draw attention to these transition issues which can help in building pressure for policy change and ultimately legislative reform, as happened in the care leaver's context. This would clarify the situation and give real choice based on clinical evidence about how and when transition should take place between the ages of 18 and 25.

Perhaps more likely to have a long term impact on transition success therefore is through exploiting the potential for statutory law reform. As the government has pledged to improve mental health provision for young people up until the age of 24, legal reform could address health service provision for young people with mental health conditions and raise the upper age boundary of all mental health services from the age of 18 to 25. This would recognise the unique and complex support that a young person with ADHD requires, and would achieve continued mental health support that is developmentally appropriate until the age of 25 as opposed to 18. As discussed previously, there are positive examples of services that already provide this in practice. Delaying the transition point to age 25 for young people with neurodevelopmental disorders such as ADHD, not only increases the chance that they are likely to be more competent and have the capacity to cope with the transition to an adult service and the change in service organisation, but also reduces the likelihood of health service transitions occurring at the same time as many other education, personal and social

transitions. This is likely to reduce the burden on the young person to manage their care independently, and increases the chances of successful transitions.

In order to achieve this, pressure needs to be put on all agencies involved in the process of transition in ADHD by using this and other research to bring about changes in individual cases, lobbying for reform through stakeholders who have experience of difficult cases, and using the media to its full potential to showcase this key issue. To do this at a time when mental health is a current topic of debate, and further investment in services is being made by the government, will only increase the potential impact. The fact that other research has shown clear positive personal and also societal outcomes in terms of criminal justice contact, is vitally important to build the argument which should inform an evidence based policy approach to mental health services in the future.

5.7 Conclusion

This legal discussion has brought together the main themes from the previous chapters of the thesis and provided a novel perspective on the use of guidelines in health service provision. NICE guidelines are very much ingrained in health services in England, but the findings of the studies in this thesis raise questions around their implementation and usefulness, and highlight the lack of successful transition for young people with ADHD at the age of 18. Whilst the government's pledge to invest in mental health services for young people is commendable and necessary, if this support is not continued and young people are not adequately supported out of the child service and enabled to receive ongoing care, then the benefits seen by investment at a younger age may be wasted.

Ensuring that the NICE guidelines are more legally binding alone may not significantly impact on providing adequate provision for young people at transition. However, putting forward such a proposal in this context based on the evidence in this study would be a key way of raising awareness of the issue among those affected. Potentially it builds a more effective lobby group around transition at a moment when injection of resources is under consideration by the government. Recognising young people with ADHD as a distinct group with unique developmental needs, and providing services that are better designed to

support them, could potentially improve the transition process and ultimately the clinical outcomes of the young adults that use them. This in turn would lead to fewer difficulties for this group and save on public expenditure, for example in criminal justice costs. Providing there is pressure from lobbying groups and stakeholders, the potential for changing service provision through legal challenge and reform is presented as a potential way of achieving more successful transitions for this group.

5.8 References

All references for this chapter have been collated in one list for the thesis. The reference list can be found on page 275.

Chapter Six: Discussion of conclusions

6.1 Introduction and overview of chapter

This thesis has focussed on the transition between child and adult services for young people with Attention Deficit Hyperactivity Disorder (ADHD). It used a multi-method approach, including a systematic review and legal discussion combined with both quantitative and qualitative primary research methods. It aimed to estimate the incidence of transition, identify guidelines and protocols for transition and how these are implemented, and to consider the influence that the National Institute of Health and Care Excellence (NICE) guidelines have within current health service provision and organisation. Finally, the use of NICE guidelines in health services is considered from a legal standpoint to consider if the law can help improve transition processes for young people with ADHD.

Each chapter has described the individual study undertaken and includes a discussion relating this body of work to existing research. Associated research papers that have been published from the chapter, or are in submission for publication, are also included in each chapter or as an appendix. In this final chapter, the findings of all the individual studies are drawn together. The strengths and limitations of the work, and the contribution to knowledge are highlighted, with some recommendations for potential future work.

6.2 Summary of key findings in relation to policy and practice

The findings from the individual studies in this thesis have suggested that the only guidelines that exist for ADHD transition within England are the NICE guidelines, and these recommendations are often not translated in to protocols locally to suit the geographical need. There is also a lack of adherence to the NICE guidelines, with important elements such as joint working and information sharing between the child and adult services not reported or evident in the process. These factors have previously been emphasised in research as being key for optimal transition, however the work in this thesis has shown that the key elements of the guidelines

rarely occur (Paul et al., 2013, Eke et al., in submission, Eke et al., 2019d). The qualitative interviews with clinicians demonstrated that workload, a lack of resources and different service structures and organisations between child and adult services, were the main barriers to implementation of the guidelines. The resulting negative impacts of a poorly managed transition on the young person were also highlighted in the interviews with clinicians.

The purpose of the NICE guidance is to improve outcomes for people using services within the National Health Service (NHS), to ensure equitable access to clinical treatments, and to promote integrated care for health service events such as transition. However, guidelines are not mandatory and with NHS staff under time and resource pressures, and with no incentives to implement the guidelines, adherence to them is poor. Poor guideline adherence was particularly highlighted in the surveillance study discussed in Chapter 3, despite the analysis also indicating that a period of joint handover (a key recommendation in the guidelines) was a strong predictor of successful transition. It is possible that full implementation of the NICE guidelines could enhance the transition process for young people with ADHD and have a positive impact on the wellbeing and life outcomes of the young person. The qualitative findings in this thesis suggest that grading the guidelines, including a minimum requirement, would be a step forward in improving outcomes for young people in transition. The sections of the NICE guidelines for ADHD that relate to transition have also not had the evidence base reviewed since 2008. It would perhaps be pertinent for NICE to review the transition recommendations to better reflect the need for transition, in light of the research presented in this thesis and other new research on the topic.

The surveillance study demonstrated a clear need for transition with 315 young people in the British Isles requiring a transition to an adult service reported to the study in 2016. An estimated incidence rate of transition for young people aged 17-19 was calculated between 202.9 and 511.2 per 100,000 population per year. The estimated rate of successful transition for young people aged 17-19 ranged between 38.5 and 96.9 per 100,000 population per year, and analysis showed that young people seen in psychiatric services were more likely to successfully transition than those seen in paediatric services. When compared to a more traditional case note review however, and taking in to account clinician reports of resource constraints and waiting lists, it is likely that these figures are a

substantial underestimation. An important finding from this study has been that approximately only a fifth of the cases reported to the study in 2016 completed the transition and were seen in the adult service. The strongest predictors of this success were being seen in a psychiatric service, having comorbid Autistic Spectrum Disorder (ASD) and having a period of joint working between the child and adult service. Previous research has highlighted poor outcomes for young adults with ADHD, particularly if left untreated and unsupported. It is therefore imperative that this drop in attendance at adult services following transition is addressed at a health service level both locally and nationally. It is important to note that this only accounts for those who needed and wanted to take medication, and so excludes many others who may also wish for and would benefit from psychological or other support to manage their ADHD. The significant lack of successful transitions may also be an indication of under provision for young people with ADHD after the age of 18. Stakeholders need to acknowledge and highlight strategies to better support this group of young people. The availability of adult ADHD services has been highlighted, and alternative sources of support for ADHD recognised, in a recent mapping exercise (Price et al., in submission-a).

The potential for the legal system to be used to reform service provision for young people with ADHD is an important consideration for the future. The studies in this thesis have clearly demonstrated that transition is not successful for a large proportion of young people for which it is required. It is therefore fair to suggest that legal action on some level may be needed in order to address this gap effectively, and to improve outcomes for young people at both a personal and societal level in the future. There are existing examples of successful legal action against health service providers that potentially provide a precedent. The legal discussion in this thesis highlighted the unique developmental needs of young people with ADHD, and some theory as to why transition at the age of 18 may not be appropriate for this group. Configuring services for young people with mental health conditions so that provision incorporates the period of young adulthood up until the age of 25, which would be in line with other education and care examples and therefore more suited to their developmental needs, would be one step towards improving the transition process for this group. Pressure for

legal reform from stakeholders could provide impetus to change service provision nationally going forward.

6.3 Strengths and limitations of the thesis

The individual studies in this thesis have a number of strengths and limitations. A systematic review is a thorough method of obtaining an overview of the existing research related to a topic, and this was successfully conducted for Chapter Two. A critical appraisal of the identified guidelines and reviews however was not conducted as part of the review, as the primary aim of the review was to collect information on what clinicians are currently advised is optimal practice. The inclusion criteria for the review were also very narrow, only incorporating England and specifically focussing on ADHD transition guidelines, and therefore may have missed guidelines of interest from other countries. These narrow criteria were required because the NICE guidelines are only applicable in England. The review also did not identify any locally produced protocols; it is possible that local organisations or services do have them but they are not accessible using the online search methods that were conducted for this systematic review. A previous study of protocols for transition in Greater London found thirteen policies in the locality but not all met the requirements set by government (Singh et al., 2008). The comparison of existing guidelines or local protocols with the NICE guidelines could have been further enhanced by contacting local NHS trusts directly for any policies or protocols related to ADHD transition. This could have assisted in illustrating what is being implemented at a local level.

The surveillance study in Chapter Three has provided the best estimates to date for incidence of transition in ADHD, compared to previous research studies. The TRACK study using case note review in two localities found a rate of potential transition referrals of 1.49 and 2.97 per 100,000 of the population, and a similar study in Ireland identified 20 ADHD cases but none were transferred to general adult services for ongoing care (Singh et al., 2009, Tatlow-Golden et al., 2018). By comparison, this surveillance study covered the British Isles (as opposed to England only in the systematic review), tracked cases over the course of the transition period and collected incident data at two time points over twelve months. It also compared, for a selected area, data using an electronic case note

review for case ascertainment. The limitations of the surveillance methodology are acknowledged (see section 3.5 and Appendix Two and Three) and include incomplete responses at every stage (notification, baseline and follow up), and the reliability of the surveillance databases used to contact paediatricians and child psychiatrists. Whilst missing data is often an issue with questionnaire surveys, it is likely that many of the non-returned notification cards were due to clinicians having not seen a case, and many of the non-returned questionnaires were due to ineligibility of the case. Incidence data was adjusted accordingly for this using previously published methods (Byford et al., 2018, Petkova et al., in submission), and additional analysis was conducted to identify the strongest predictors of success at transition.

A strength of the surveillance methodology is the ability to access large numbers of clinicians over a large geographical area in a relatively short space of time. By comparing a selection of the data collected to a more traditional case note review, it was possible to ascertain that the incidence estimates collated using surveillance are likely to be a significant underestimation of the actual number of ADHD transitions required each year. The discrepancy between the figures appears to be due to patients being reviewed by a range of health professionals, not just psychiatrists at consultant grade who are eligible to report via surveillance. The use of case note review enables all notes to be recorded, regardless of the role or grade of the health professional reviewing the patient, and therefore it is more likely that the patient would have been seen in the timeframe of the study. However despite this, the surveillance incidence still provides a figure which policy makers should consider as an absolute minimum, knowing that the number of potential transitions could be as much as four times higher in reality.

The case note review was reliant on the available data recorded in the clinical notes, which varied in detail depending on the person recording the notes. It also required a researcher to actively search for the specific transition details in order to compare to the surveillance data. In contrast, the surveillance questionnaires asked for specific data related to the transition process, but were only completed by consultant grade clinicians and did not necessarily provide the detail that clinical notes might have due to being mainly tick box responses. Further, the case note review is completed retrospectively looking back at clinical notes over

a period of time, whilst in comparison surveillance is prospective looking forward. Case note review also does not directly contact clinicians to collect the data, whilst surveillance contacts all consultants monthly for relevant information about their cases.

The purpose of the surveillance units used in this thesis is to draw attention to rare conditions, and in turn increase interest, knowledge and improve standards of care; something that is further discussed in Chapter Five in a legal context, as a way of building momentum for change. Data protection and ethical restrictions meant that it was not possible to directly link cases from both the surveillance study and the case note review. This would have potentially enabled a more detailed picture to be drawn of the transitions that were reported, identified any missing cases that were identified from the SLaM trust but not surveillance, and given some indication of the reliability and validity of the surveillance organisations' databases at reaching the appropriate clinicians that review ADHD cases.

The electronic case note review with CRIS demonstrated that there are a range of health professionals that might be reviewing and managing young people with ADHD, not just consultants. A previous study of transition highlighted that complexity and severity of the case was associated with the success of transition (Singh et al., 2009). It is assumed that consultants are more likely to see the more complex and severe cases, and thus nurse prescribers or ADHD nurses see the more straightforward cases. Cases managed by nurses will not have been notified via surveillance, due to the very nature of the surveillance systems. It would therefore indicate that the finding from surveillance that only a fifth of cases successfully made the transition (as reported by consultants), is only an indication of the most severe cases, and in fact the actual number is likely to be even lower if we assume that the more straightforward cases are less likely to successfully transition.

A strength of the qualitative study was the broad and systematic sampling frame for recruitment. Participants for interview were recruited via the surveillance study, from the range of consultant child and adolescent psychiatrists and paediatricians registered with the surveillance units who worked across the British Isles and returned a questionnaire to the study. The participants therefore had the opportunity to provide quantitative data through completion of the

surveillance questionnaires, and elaborate on the transition process by providing qualitative interview data. The combination of qualitative and quantitative data in this way provided links between the studies, added to the context and credibility of the data (Bryman, 2006), and allowed a more in-depth insight in to what is actually happening during transition for young people with ADHD.

As the case note review highlighted that many health professionals are responsible for reviewing patients with ADHD, a limitation of the qualitative work was that the interview participants were mainly restricted to consultant psychiatrists or paediatricians due to being recruited via the surveillance study. However there were four interviews with additional adult mental health practitioners recruited via a mapping study which was an additional research stream in the CATCh-uS study. Whilst it would add to this work to gather the experiences of additional health professionals, it does not necessarily mean that the experiences of transition, or the use of the NICE guidelines, would be significantly different from that of the consultants. All professionals managing young people with ADHD, regardless of grade, are likely to be working in the same organisations and under the same resource provision, so additional interview data may not have added anything new to the findings in this way.

6.4 Potential for future research

This thesis has demonstrated the level of need for, and relative poor success rate, of transition for young people with ADHD. It has also highlighted a lack of NICE guidance implementation, despite one of the key recommendations in the guidelines (joint working) being a strong predictor of success at transition. To build on the findings from this thesis, it would be interesting to investigate optimal or successful transition and NICE guideline implementation further, to explore if there is a relationship between the two. For example, if all aspects of the NICE guidance for transition are implemented, is the young person likely to receive optimal (and thus successful) transition? The factors of optimal transition described in other studies, are in line with what the NICE guidelines recommend, but the findings from the qualitative interviews highlighted that clinicians do not have the time, funding or resources in order to implement these elements

consistently or effectively. Further study could explore the provision of time and resources to a selection of trusts or organisations to enable the guidelines to be implemented fully. Gathering data on the incidence and success of the transitions in comparison to localities without adequate resource provision or with care as usual, could indicate the impact that full implementation of the NICE guidelines can have. Similarly, if NICE operated a graded system of guidelines to indicate the minimum requirement by health services as suggested in Chapter Four, it would be interesting to explore the potential that such a system could have on guideline adherence and work satisfaction of the clinician. I would hypothesise that in the majority of cases only the minimum guidance would be achieved, but that might arguably be more than is achieved at transition by health services currently.

Only a fifth of the transition cases reported in the surveillance study successfully transferred and were seen in an adult service. It would be beneficial to further investigate the fifth of cases that successfully transferred and continued to receive care and management in an adult service, to explore if any factors in the process differed to the young people that did not transfer. More detailed case note review would be required for this, as the surveillance data collected was mainly based on tick box responses. Reviewing the case notes of those cases that were successful at transition could provide more details of the transition processes carried out. This work however would be constrained to the availability and reliability of the content of the notes as discussed in relation to the CRIS study (section 3.3.7), and the ability of the researcher to extract the relevant information. Current data protection and governance of the surveillance organisations also means that identifying reported surveillance cases in order to more closely analyse the patient and service details is not possible; this is a hurdle that would have to be overcome to further identify the transition processes undertaken and the patient characteristics of those that are successful.

Further, it would be of interest to examine the 0 to 25 services presented in the legal discussion. Whilst existing examples suggest that delaying the transition to the age of 25 means that the young person is better able to cope with the transition, and there is less likelihood of disengagement from services, to my knowledge there is currently no evidence regarding the transition at age 25 and the outcomes for the young adult transitioning at this point. It would be useful for

policy makers and health services to know what impact an extension of the age range for the service would have on the young person's engagement with services post 18, on the ongoing treatment and support required and received post 18, and the cost of an extended CAMHS service that would be required. This would enable policy makers and service providers to make informed decisions about appropriate service provision in the future.

6.5 Summary

In summary, the findings of this thesis have highlighted the clear need for, but lack of, smooth and successful transition in ADHD in the British Isles. Current practice in CAMHS, paediatrics, and adult mental health services, does not closely follow the recommendations in the NICE guidelines. Considering the known significant long term implications of poorly managed ADHD and transition process for the young person and society, it raises questions about the purpose of NICE guidelines if they are not adhered to and clinicians do not consider them a priority. Future work should explore different service delivery models to gather evidence of the most effective way to support young adults with ADHD.

6.6 References

All references for this chapter have been collated in one list for the thesis. The reference list can be found on page 275.

Appendices

Appendix 1: Systematic Review – manuscript published 12th September 2018

The following manuscript describes the data collection and analysis of a systematic review, identifying guidelines related to transition in ADHD, and comparing any identified documents to the NICE guidelines. This manuscript has been published in the journal of Child and Adolescent Mental Health. It was accepted for publication on the 9th August 2018, and first published on the 12th September 2018. I led the data collection, data analysis and write up of this paper, and liaised with co-authors for their contributions.

Transition from children's to adult services: a review of guidelines and protocols for young people with Attention Deficit Hyperactivity Disorder (ADHD) in England

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Abstract

Background: In recent years, the difficulty for young people with mental health issues who require a transition to adult services has been highlighted by several studies. In March 2018 the National Institute of Health and Care Excellence (NICE) produced detailed guidelines for the diagnosis and management of Attention Deficit Hyperactivity Disorder (ADHD), updated from previous versions in 2008 and 2016, which included general recommendations for transition to an adult service. Yet, there is limited research on transition specifically for those with ADHD. This review aims to systematically identify, review and compare guidelines, specifically focussed on transition for young adults with ADHD within England.

Methods: Following the general principles for systematic reviewing as published by the University of York, ten electronic databases were searched. Further documents were identified through searches of grey literature and additional sources.

Results: Sixteen documents were included. Results indicate very limited publically accessible guidelines in England for transition of young people with ADHD. Nearly all identified documents based their recommendations for transition on the existing NICE guidelines. Neurodevelopmental conditions such as ADHD are often encompassed within one overarching health policy rather than an individual policy for each condition.

Conclusions: Guidelines should be available and accessible to the public in order to inform those experiencing transition; adjusting the guidelines to local service context could also be beneficial, and would adhere to the NICE recommendations. Further review could examine transition guideline policies for mental health in general to help identify and improve current practice.

Keywords: ADHD, Adolescence, Mental Health, NICE, Guidelines

Key practitioner message

- Transition for young people with ADHD who require continued support in adulthood is a current challenge for young people, their families and clinicians.

- This systematic review of guidelines on transition for young adults with ADHD focussed on England only, to mirror the remit of NICE. The NICE Clinical Guideline for ADHD (NG87) was found to be the only transition guideline publically available.
- Linking the NICE clinical guidance for ADHD (NG87) to those on transition of care between child and adult services (NG43) would provide more comprehensive guidelines for clinicians to ensure smooth and successful transition for young people with ADHD.

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterised by impairing levels of inattentive, hyperactive and impulsive behaviours (Jick et al., 2004), that can impact on academic achievement, relationships and self-care (Kendall et al., 2008). It is one of the most common neurodevelopmental disorders managed by child mental health and paediatric services (Ford et al., 2007) with prevalence rates in the United Kingdom (UK) of around 5% in children and adolescents (Faraone et al., 2015). Despite this, services and policies are often not set up to consider ADHD in isolation but as general mental health.

ADHD has traditionally been viewed as a childhood disorder but analysis showed that 15% of those with childhood ADHD met the full diagnostic criteria for the disorder at age 25. If those who partially meet the full criteria, or are considered to be in partial remission, are included this figure rises to 65% at 25 years (Faraone et al., 2006). This has led to the increasing recognition that ADHD is a lifespan disorder (Tatlow-Golden et al., 2018) which raises the issue of transition from child to adult services. Several studies, government documents and policy guidelines highlight the difficulty for young people who require a transition between children's services (usually Child and Adolescent Mental Health Services (CAMHS) or paediatrics) and adult services (Singh et al., 2008). Transition should support a young person towards and onto a new life stage, extending beyond the simple transfer of clinical responsibility (Beresford, 2004b); a successful transition has been described as being coordinated, purposeful, planned and patient centred (Singh and Tuomainen, 2015).

A report for commissioners highlights the vulnerability of young people aged 16 to 18, in a period of physiological, emotional and social change, who are at higher risk of transition problems. It is recommended that clinical support remains consistent and uninterrupted (Joint Commissioning Panel for Mental Health, 2013), and local policies for transition are important to enable that support.

In order to support young people in transition in the UK, the National Institute of Health and Care Excellence (NICE) and the CAMHS Review (Hall et al., 2013) recommend that adequate transition for adolescents who still require mental health services should include comprehensive planning, focus on *need* rather than *age*, and be coordinated by a lead person (NICE, 2016b). With recognition of ADHD as a long term condition, and increased prescription rates for ADHD in childhood, the number of graduates of ADHD from children's services has increased rapidly (Timimi and Radcliffe, 2005) which makes optimal transition particularly important. Potential barriers to an optimal transition include poor communication and collaboration, different funding structures, a lack of understanding across services, and time and resource constraints, and it is reported that as few as 15% of the ADHD patients that require continued support and treatment make the transition successfully (Singh and Tuomainen, 2015). Additionally, research has shown that there are a lack of specialist services for ADHD in adulthood, and a lack of ways to access them (Young et al., 2011, Coghill, 2016, Hall et al., 2013).

The association between childhood ADHD and criminality in adulthood has previously been highlighted (Mordre et al., 2011, Fletcher and Wolfe, 2009) and a study of ADHD and criminality in Sweden has demonstrated how medication use can reduce criminal rates (Lichtenstein et al., 2012). Therefore it is important to manage the period of transition to adulthood well, as failure to do so can lead to unmet needs, disengagement from services and poor life outcomes (Singh and Tuomainen, 2015).

Two recent systematic reviews highlight a lack of services and guidelines for young adults with ADHD. The first, a systematic review of mental health care systems, found that neither the UK's National Health Service (NHS) nor United States (US) mental health system provided sufficient support or access to adult services for young people (Embrett et al., 2016). The second, an international

systematic review of guidelines for ADHD (Seixas et al., 2012), suggests that there are limited data or studies about ADHD and transition.

The review of guidelines by Seixas, Weiss and Muller (2012) discussed ten different international guidelines and included recommendations for management of ADHD. Since publication, two included guidelines have been updated. The NICE guideline in the UK, and the Canadian Attention Deficit Hyperactivity Disorder Resource Alliance (CADDRA) (Canadian ADHD Resource Alliance, 2018, NICE, 2018a) were both updated in 2018. All included guidelines provide recommendations for clinical diagnosis and management of ADHD however only two of the included guidelines referred to any recommendations for transition from child to adult services; the British Association of Psychopharmacology (BAP) (Bolea-Alamanac et al., 2014) and the NICE guidelines for England (NICE, 2008). The BAP guidelines were the first guidelines to be produced on ADHD in adolescents and adults with ADHD in transition to adult services (Seixas et al., 2012), however they describe considerations and uncertainties in the diagnosis and management of ADHD for clinicians, and do not explicitly list recommendations for a smooth transition process between services. The NICE guidelines (NICE, 2008) which were published after the BAP guidelines, provided a full review of diagnosis and management for ADHD across the lifespan, and were significant in developing improved service provision in the UK.

NICE was established in order to improve health and social care by reducing variation in the availability and quality of NHS treatments and care, and the organisation has been established in primary legislation since 2013. All of the NICE clinical or national guidelines are therefore applicable to England only (NICE, 2017). In March 2018 (previously published in 2008, with an update in 2016) NICE published an updated clinical guideline for the diagnosis and management of ADHD (originally CG72, now NG87) which explicitly lists a short detailed section with the following recommendations for transition to an adult service (section 1.1.4, 1.1.5 and 1.1.6 of NG87):

- Young person should be reassessed at school leaving age to establish need for transition
- Transition should be complete by age 18
- Plan for smooth transition should be made with details of anticipated treatment and service young person requires

- Formal meeting between child and adult service should be considered
- Information should be provided to young person about adult service
- Care Programme Approach (CPA) should be used
- The young person and parent/carer should be involved in planning
- After transition, young person should be re-assessed at adult service – to include personal, educational, occupational and social functioning

(NICE, 2018a)

The guideline NG87 published in 2018 has made no changes to the content of the transition recommendations that were listed in the 2008 and 2016 (CG72) versions. It does however now refer the reader to guideline NG43, the general guidelines for health and social care transitions that is not condition specific, published in 2016 (NICE, 2016b).

Although there has been an increased interest in transition and guidelines for the management of ADHD, there is still a scarcity of services and a lack of successful transitions (Bolea-Alamanac et al., 2014, Singh et al., 2009). This current review therefore aims to understand what transition guidelines and protocols exist for ADHD services in England specifically, and to potentially identify any gaps in service protocols. The NICE guidelines include local NHS services in their consultation, and review current evidence, however it is not mandatory that health services implement them locally. The NICE guidelines have also not had the evidence base for transition reviewed or the recommendations updated since 2008. Focussing on England and ADHD transition specifically, this review aims to identify local ADHD service policies, if these are in line with the NICE guidance, and what variations exist. To our knowledge, there are no existing reviews to date looking specifically at ADHD transition guidelines.

Methods

This review followed the general principles for systematic reviewing published by the University of York (CRD, 2009). It consists of two parts; an overview of existing ADHD transition guidelines and recommendations in England, and a comparison of these guidelines with NG87 for the diagnosis and management of ADHD (NICE, 2018a). These two components are brought together with a

narrative synthesis, which was chosen to summarise the findings primarily using text due to the qualitative nature of the data (Popay, 2006).

Data sources and search strategy

Four sources of data were used. First, ten bibliographic databases were searched from the earliest date of the database to the present day (15/06/2018): EMBASE, MEDLINE, PsycINFO, Social Policy and Practice, Health Management Information Consortium (all accessed via OvidSP); CINAHL, ERIC (accessed via EBSCO); ASSIA (accessed via ProQuest); NICE Evidence Search and TRIP database (hand searching only). Databases were searched using three groups of terms or synonyms (combined by the Boolean “AND” operator) to describe ‘Attention Deficit Hyperactivity Disorder’, ‘Transition’, and ‘Guideline or Protocol’, identified from the title, abstract, key words or medical subject heading (MeSH) terms. An illustration of the search strategy used in EMBASE can be found in Appendix One. The search terms were adapted for individual databases as required.

Secondly, an online search was completed using the search engine Google for protocols, guidelines or documents regarding ADHD and transition within NHS sites (using the syntax ‘site: nhs.uk’). The first ten pages of results were screened (approximately 200 results) and relevant documents identified and exported.

Thirdly, corresponding websites of professional and charitable organisations in the field (Appendix Two) were searched for protocols, guidelines, policy documents or patient leaflets providing transition recommendations for patients with ADHD.

Finally, backwards citation chasing (one generation) was completed using the references from all included documents in the review.

Inclusion / exclusion criteria

Table 1 summarises the inclusion and exclusion criteria used for the review. These were chosen to identify guidelines specific to the condition ADHD, specific

to transition, and also to reflect the application of the NICE guidelines being specific to England only.

Table 1. Inclusion and exclusion criteria

Inclusion	Exclusion
<ul style="list-style-type: none"> • Age range 0-25years • Transition guidelines or protocols <u>specific to a clinical diagnosis of ADHD</u> from; <ul style="list-style-type: none"> - nationally recognised sources - local NHS services • Existing reviews of ADHD transition guidelines and protocols; <ul style="list-style-type: none"> - includes recommendations for ideal practice • Any type of study/review design; <ul style="list-style-type: none"> - editorial - evaluation - short report - discussion papers • From earliest date of database to present • Specific to England only • English language only 	<ul style="list-style-type: none"> • ADHD transition guidelines and protocols for age groups outside of 0-25years • General mental health transition guidelines or protocols • Transition guidelines or protocols relating to other diagnoses • No ‘working documents’, unpublished or draft guidelines • ADHD transition guidelines and protocols / reviews not specific to England • ADHD transition guidelines and protocols / reviews not in English language

Study selection

Records identified through the bibliographic databases were exported into Endnote X8 reference management software, and duplicate papers were identified and excluded. The abstracts and titles of all identified records were screened for relevance by one reviewer (HE) using the specified inclusion and exclusion criteria. Twenty-five percent of records were independently screened by a second reviewer (BL and TR). Discrepancies were discussed and resolved. Full text copies were obtained for the selected studies and screened against the same inclusion and exclusion criteria.

Documents obtained via the online search and citation chasing were saved and uploaded in the same Endnote file; these were screened and reviewed following the same procedure.

Data extraction and synthesis

For the first part of the review, the relevant data from each included document was extracted and summarised descriptively. For the second part of the review, the key points for transition specified in sections 1.1.4, 1.1.5 and 1.1.6 of NG87 were used as a framework to organise the data and allowed extracted data from all documents to be compared and contrasted to the NICE guidance. The relevant data were extracted in to a spreadsheet specifically created for this review and then discussed in a narrative manner.

Results

Search and screen of results

The PRISMA diagram (Moher et al., 2009) in Figure 2 illustrates the sources from which references were identified, screened and selected.

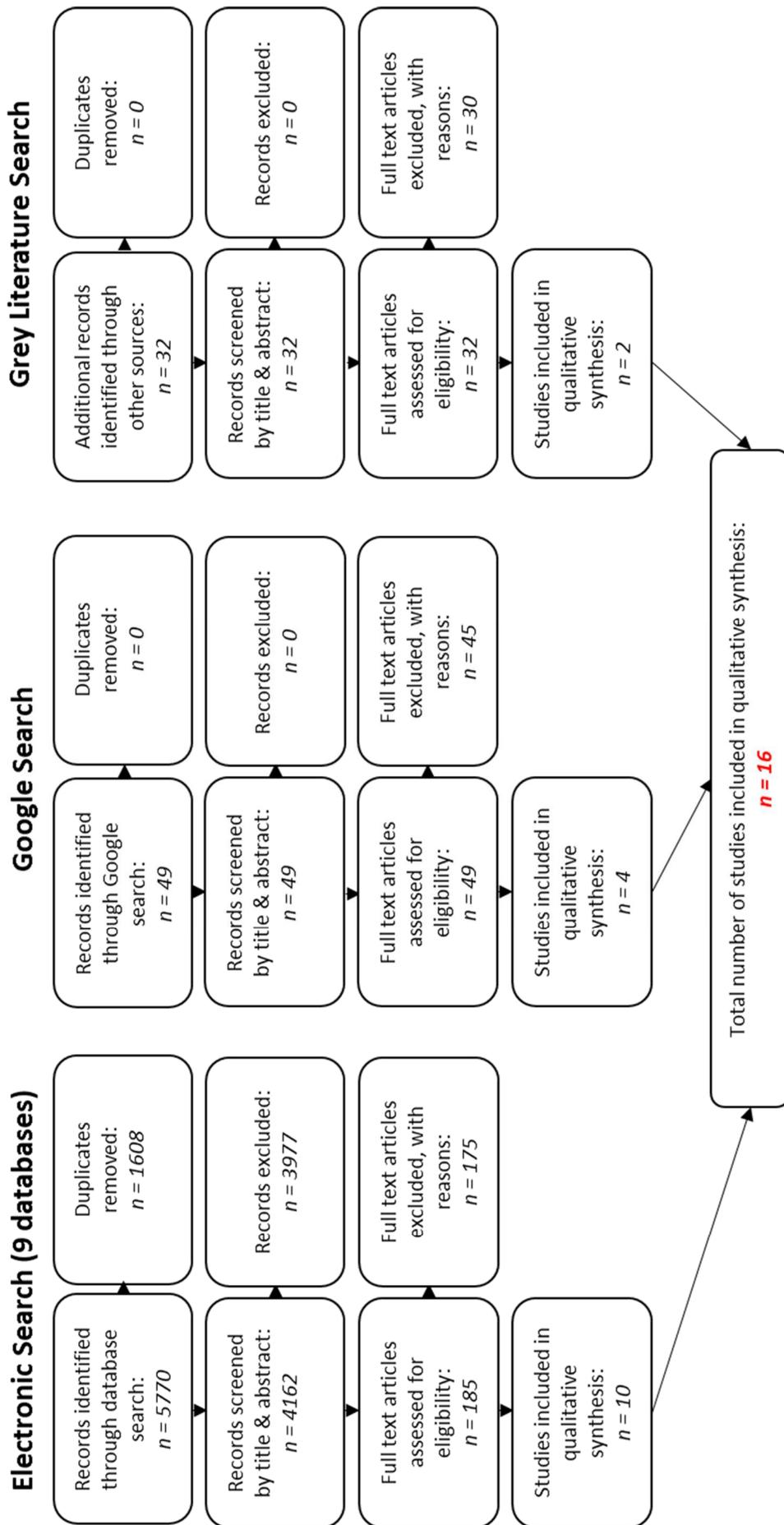


Figure 2. PRISMA diagram showing selection of sources

The electronic search, and title and abstract screen, of the TRIP database (n=326) identified 13 records for inclusion in the full text screen. When checked against the search results of the other nine databases, the 13 records were identified as duplicates. Therefore the numbers in the PRISMA diagram reflect the results in nine databases, excluding the TRIP results.

At full text screen stage, records were excluded for the following reasons;

- Not specific to: England, ADHD, Transition (n=210)
- Book chapter or review (n=3)
- Conference abstract or presentation (n=18)
- Clinical trial (n=1)
- Dissertation (n=1)
- Newsletter article (n=7)

Three were also identified as duplicates and excluded at this stage, and one was excluded for being a case study example of patients in transition which did not include recommendations for transition. Full text was unobtainable for five documents.

Description of included studies

Sixteen documents were included for review; seven peer reviewed papers, three NICE guidelines, four local NHS service guidelines, and two professional organisation guidance document. One peer reviewed paper (Hall et al., 2015) does not present recommendations for transition, however reports on a survey of ADHD services in mental health trusts in England that identified data in line with NICE guidance; for example, transition protocols and information sharing. It was therefore included.

All documents were published between 2009 and 2018, and all provide guidance for ADHD transition in England in varying detail. Table 2 summarises the content of each of the included documents.

Table 2. Summary of included studies

Author / Year	Title	Description
Asherson, P., et al. (2017)	Bridging the gap: Optimising transition from child to adult mental healthcare.	Professional guidance document. Expert policy paper. Reviews challenges associated with transition for general mental health, using ADHD as an example. Chapter 3 refers to recommendations for managing and planning transition for ADHD – very detailed.
Atkinson, M. & Hollis, C. (2009)	NICE guideline: attention deficit hyperactivity disorder	Peer reviewed paper. Reviews NICE guidelines with summary of key points related to transition. Details of transition are replica of NICE guideline.
Boilson, M. F., F. Quilter, M. Sutherland, C. (2013)	Royal College of Psychiatrists. Attention Deficit Hyperactivity Disorder (ADHD) Guidance for Transition from Child & Adolescent Services to Adult Services.	Professional guidance document. Clinician focused. Details transition process (replicated from NICE) and provides recommended key points of pathway and what details should be included in a case summary provided at transition.
Coghill, D. R. (2017)	Organisation of services for managing ADHD.	Peer reviewed paper. Updated version of paper published in 2016. Mainly focuses on barriers to transition. Refers to transition details from NICE guidance and UK Adult ADHD network; referral if significant symptoms require treatment, transfer by 18, and planning in advance from both child and adult service.
Fellick, J. (2014)	Attention Deficit Hyperactivity Disorder (ADHD) Guideline for the treatment and care of children and young people with ADHD. Wirral University Teaching Hospital NHS Foundation Trust.	Local NHS trust document. Regarding treatment and care of ADHD. Details transition process used in trust. Details of transition are replica of NICE guideline.
Fogler, JM., et al. (2017)	Topical Review: Transitional Services for teens and Young Adults with Attention-Deficit Hyperactivity Disorder: A process Map and Proposed Model to Overcoming Barriers to Care.	Peer reviewed paper. Provides a unique model of care to support transition. Includes; emphasizing trust, respect and open communication, supporting patient independence, helping young person to navigate education and investing time to ensure young person is involved in care.

Hall, C. L., Newell, K., Taylor, J., Sayal, K., & Hollis, C. (2015)	Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: a national survey of mental health trusts in England.	Peer reviewed paper. No clear detailed transition process, but links NICE guidance to data collected in their survey of transition. Data collected on transition and shared care protocols and transition pathways, information sharing and joint working.
NICE (2016)	Attention deficit hyperactivity disorder: diagnosis and management: CG72.	Full clinical guidance from NICE. Diagnosis and management of ADHD. Section 1.6 details transition to adult services.
NICE (2017)	NICE Pathways: Attention deficit hyperactivity disorder overview.	Overview of NICE guidance and quality standards. Details transition process as laid out in NICE NG87.
NICE (2018)	Attention deficit hyperactivity disorder: diagnosis and management. NG87	Full clinical guidance from NICE. Diagnosis and management of ADHD. Updated from 2016. Section 1.1.4, 1.1.5 and 1.1.6 details transition to adult services.
Ogundele, M. O. (2013)	Transitional care to adult ADHD services in a North West England district.	Peer reviewed paper. Summarises literature around transition, and details ideal practice. Refers to NICE and Royal College of Nursing. Main points are early planning, young person and carer involvement, inter agency, comprehensive, holistic and developmentally appropriate.
South West Yorkshire Partnership NHS Foundation Trust (2018)	Attention deficit hyperactivity disorder (ADHD) service: Assessment process.	Local NHS trust document. Regarding transition from children's services for patient use. Details transition process used in trust. Details are in line with NICE guideline; assessed at 18, joint planning meeting, young person and carer involvement, information, reassessment at adult service.

Stockport ADHD Team (2015)	ADHD Care Bundle: Stockport CAMHS (Pennine Care NHS Trust).	Local NHS trust document. Limited detail of transition processes. States referrals should be made to adult ADHD team if patient required continued medication after 16 th birthday.
Tahir, O. and Sims, K. (2014)	Prescribing arrangements for the use of methylphenidate, dexamfetamine and atomoxetine in children with ADHD (attention deficit hyperactivity disorder) with transition to adult services in Berkshire. Berkshire Healthcare NHS Foundation Trust.	Local NHS trust document. Regarding treatment and care of ADHD. Details transition process used in trust. Includes: transition at 18 commencing 3 months before, comorbidities to be transitioned to community mental health, drug free trial prior to transition, to remain with CAMHS if remaining on medication, GP to continue care post 18, reassessment at adult service.
Young, S., et al. (2016)	Recommendations for the transition of patients with ADHD from child to adult healthcare services: a consensus statement from the UK adult ADHD network.	Peer reviewed paper. Details NICE guidelines, and provides their own general recommendations for transition, and more specific recommendations for ADHD. Follows NICE guidance with more specific detail.
Young, S., Murphy, C. M., & Coghill, D. (2011)	Avoiding the 'twilight zone': recommendations for the transition of services from adolescence to adulthood for young people with ADHD.	Peer reviewed paper. Summarises NICE guidance; then further expands and develops the NICE guidelines – very comprehensive guidance which follows NICE guidance with more detail. Very similar to 2016 paper by Young et al.

The documents published by NICE are the full clinical guideline for diagnosis and management of ADHD NG87, the previous NICE clinical guideline CG72 and an overview of the ADHD NICE pathway, which summarises NG87 (NICE, 2008, NICE, 2017a, NICE, 2018a). Ten documents (excludes Pennine Care, South West Yorkshire and Berkshire Healthcare NHS documents, and the paper by Fogler et al. 2017) refer to the NICE guidelines and base any guidance for ADHD transition on the recommendations in NG87; mostly quoting the NICE guidance verbatim. Four documents were identified through the online google search; these were documents by Stockport CAMHS (2015), Wirral NHS (Fellick, 2014), Berkshire NHS (Tahir and Sims, 2014), and South West Yorkshire NHS (2018). All records identified via electronic databases reference the NICE guidelines. Two documents were identified via the online search of professional and charity organisations; the Royal College of Psychiatrist's guidance on transition in ADHD (Boilson et al., 2013) and an expert policy paper from Asherson et al. (2017).

Compare/contrast of guidelines

As NG87 was one of the 16 documents identified in this review, the main points of the recommended transition process were identified and the remaining 15 documents were compared against them. An example of the spreadsheet used can be found in additional files as Appendix Three. Any recommendations for transition that were additional to or outside of the NICE guidelines were clearly highlighted using this process. Table 3 provides an overview of the comparison.

Table 3. Overview of compare/contrast of documents to NICE guidelines

NICE guidelines NG87 (2018)	Asherson et al. (2017)	Atkinson et al. (2010)	Boilson et al. (2013)	Coghill (2017)	Fellick (2014)	Fogler et al. (2017)	Hall et al. (2015)	NICE pathway (2017)	NICE CG72 (2016)	Ogundele (2013)	Stockport CAMHS (2015)	SW Yorkshire NHS (2018)	Tahir and Sims (2014)	Young et al. (2016)	Young et al. (2011)
Reassessed at school leaving age		✓			✓			✓	✓						✓
If ongoing treatment required – arrange for smooth transition with details of anticipated treatment		✓	✓		✓			✓	✓			✓		✓	
Should be complete by age 18		✓	✓	✓	✓			✓	✓				✓	✓	✓
Formal meeting involving CAMHS and AMHS		✓	✓		✓			✓	✓				✓	✓	✓
For age 16+ Care Programme Approach (CPA) should be used		✓			✓			✓	✓					✓	✓
Young person and parent carer involvement		✓	✓		✓	✓		✓	✓	✓	✓	✓		✓	
Comprehensive assessment at AMHS		✓			✓			✓	✓			✓	✓		✓
Refers reader to NICE guideline NG43 on transition in health and social care services								✓							

Age/reason for transition: The NICE guidelines recommend that transition should occur if the young person continues to have significant symptoms of ADHD, and this should be assessed when approaching the service age boundary. Ten of the documents stated the reason for transition should be significant symptoms of ADHD that require ongoing treatment or support. Four documents did not specify a reason for transition, while one specified continuation of *medication*. An age for transition is not specified by NICE, but it is suggested to be complete by age 18. Nine documents also specified completing transition by age 18, while six documents did not specify an age. Six documents specified reassessment at school leaving age to address transition need, three stated age 17 or 18, five did not specify, and one recommended starting at age 13/14.

Planning: The NICE guidelines recommend planning the transition with staff from both the child and adult services, via a joint meeting and the Care Programme Approach (CPA), and involving parent/carers and the young person. Seven documents did not specify details on planning, whilst the other eight agreed that planning in advance from services at both ends of the transition should occur. Nine documents did not specify staff involved, while Stockport ADHD team (2015) specified an ADHD nurse should coordinate the transition, and Young et al. (2016) recommend that a lead clinician coordinates the transition once the referral to an adult service has been accepted.

Echoing the NICE guidelines, six of the documents suggest using CPA in planning for transition; two highlighted the need for the transition process and planning to be developmentally appropriate, although the latter was not explicitly defined. Only two documents suggested a timescale for the preparation of the young person for transition, one suggesting a minimum of a six months (Young et al., 2011), and one suggesting commencing three months prior to the eighteenth birthday (Tahir and Sims, 2014).

Ten documents specified that the parent and young person should be included in the planning, while one also recommended that healthcare teams should be mindful of comorbidities and parental ADHD, something not considered by NICE. Another recommendation was for commissioners to take local resources into account when designing and planning transition services. This is not mentioned by NICE under transition, however it is added as an addendum in NG87 that it is the responsibility of commissioners to implement the guidelines.

Information: The NICE guidelines recommend that information sharing between services should include details about treatment and services required, while information should also be provided to the young person about transition and adult services. Half of the documents recommended providing information to the young person, but only three documents specified information sharing between services. One document listed the information that should be shared between services, including clinical evidence, current intervention, degree of engagement, and context of the young person. Five documents recommended shared care and information sharing with the General Practitioner (GP), something that was not specified by NICE.

Protocols to guide transition are not specified as a requirement in NG87 but were highlighted by two documents in this review. It is suggested that protocols should be developed locally, and created jointly between services, taking in to account available resources, and enabling support for those who disengage with services prior to transition, those who are not accepted by adult services, and those who present in adulthood for the first time. The general health and social care transition guidelines (NG43) describe this process as a care plan (NICE, 2016b).

Young et al. (2011) recommend continued professional development for clinicians to stay up to date with ADHD as a condition and the services available to support it, which is not mentioned in the NICE guidance.

Post transition: NICE recommend a comprehensive assessment is undertaken once the young person reaches the adult service, which is echoed in half of the identified documents. Two documents suggest psychological therapies should be considered by adult services, a recommendation not specified by NICE. One document also specifies that the adult service should acknowledge the referral, and the young person should not be discharged from the child service until they have attended the adult service.

Discussion

This review has systematically searched for existing guidelines or protocols, or reviews of guidelines, in England specifically outlining the preferred process to transition a young person with ADHD between child and adult services. The NICE guidelines have highlighted the need for transitional services for ADHD, but most

health authorities have yet to establish clear protocols for transition (Bolea-Alamanac et al., 2014). This review was limited to transition guidelines specifically for ADHD transition in England, excluding any generic transition policies for general mental health. The searches were all conducted online; due to the variability in websites it is possible that services may have such documents, but they are not available or published online for public use. Direct contact with NHS services would be required to establish exactly what procedure, guidelines or protocols clinicians are using locally.

Results indicate that literature in this area is very strongly based on the NICE guidance for the management of ADHD NG87 (first published 2008, and updated 2016 and 2018) with a small number of authors expanding it. The systematic review by Seixas et al. (2012) identified thirteen guidelines, from ten different medical associations, however only two were relevant to England and ADHD transition; NICE CG72, and the ADHD guidelines from the British Association of Pharmacology (BAP) (Bolea-Alamanac et al., 2014). The BAP paper was excluded from this review as it did not outline explicit recommendations for transition.

There were a number of points from the NICE guidance that were echoed in the majority of the reviewed documents; these included the reason and age for transition, information sharing, patient and family involvement, and prior planning. Additional recommendations highlighted in some of the included documents but not mentioned in NG87 (or CG72 previously) include that transition should be developmentally appropriate, consider comorbidities and parental ADHD, the use of psychological therapies and continued professional development of clinicians. Two documents provide recommendations that are completely unique from NICE which include improving the education of healthcare professionals, increasing public awareness of ADHD, emphasis of trust and respect between patient and doctor, and supporting patient independence (Asherson et al., 2017, Fogler et al., 2017).

The reviewed documents suggest transition should be completed by age 18, but consensus is growing that transition at 18 is not in the best interest of the young person (Dunn, 2017). Further research has also emphasised the need to start transition planning early (Suris and Akre, 2015) to provide young people time to progress through transition once they feel ready (Dunn, 2017). Patients and

carers also often do not anticipate the change and therefore commencing planning from the early teens can prevent transition failing (Coghill, 2016).

Others have argued that transition planning should incorporate a developmental perspective (Singh et al., 2016) which may be particularly important for young people with ADHD, who by definition have poor executive functioning and self-management (Fogler et al., 2017); the recommendations from the expert policy paper (Asherson et al., 2017) also emphasise that the transition should be planned in a developmentally appropriate way for the patient which is not mentioned by NICE. The transition to an adult service also often occurs at a critical time when they are encountering changes in education, employment and independence from parents (Tatlow-Golden et al., 2018). Boilson et al. (2013) suggest that information regarding the patient's employment, social circumstances and quality of life is important to support effective transition, which is highlighted in the general NICE guidance (NG43), but overlooked in the more specific recommendations for ADHD (NG87).

Information is key for transition; Hall et al. (2015) highlight the lack of local transition protocols and inadequate information sharing between child and adult services. Others have also underlined information sharing as a barrier to transition with clinicians citing insufficient information, poor communication and a lack of understanding between services (Dunn, 2017). Both papers by Young et al. (2011 and 2016) recommend that clear transition protocols between services are best developed locally, which outline timelines and responsibilities for transition, and describe pathways for those not accepted by adult mental health services, those who do not transition and those that re-enter services as an adult with ADHD (Young et al., 2016). Coghill (2016) also recommends that local detailed clinical pathways be developed. None of the other included documents refer to how to support young people who do not transition; particularly important when only 15% of cases make the transition (Singh and Tuomainen, 2015). One of the recommendations by Asherson et al. (2017) is to develop protocols for those patients that don't meet the criteria for adult services but still require ongoing support. Research suggests that there is huge variation in local practice and a lack of clear policies for transition (Muñoz-Solomando et al., 2010). As many fail to transition, the lack of information or protocols is surprising; following

the guidance in NG87, providing information and comprehensive early planning may support more patients to transition successfully.

Despite the highlighted need for clear transition protocols and responsibilities to be developed locally (Young et al. 2016,) and systematic methods of searching, only four relevant NHS documents were found. It may be that ADHD is encompassed within general mental health policies and there are few local protocols specifically for ADHD transition; it was indicated by Hall et al. (2015) that services had care pathways but the majority were not specific to ADHD. Or perhaps it is a reflection of the availability and accessibility of the policies, despite the recommendation from NICE that full information is provided to the young person. Protocols or policies for transition should be readily available to guide young people and their parents/carers through the transition process. In the modern digital generation, young people would primarily use electronic media to gain information (Ford et al., 2013) and it is significant that this review was unable to identify more than four documents online.

The results of the survey by Hall et al. (2015) also emphasised a lack of staff training and knowledge in ADHD as a barrier to successful transition. Atkinson and Hollis (2009) emphasise the challenges that the NICE guidelines present for clinicians or those organising and planning services, and suggest that increasing numbers of young people requiring a transition to adult services will have implications for training and service delivery. Indeed the expert policy document identified by this review (Asherson et al., 2017) recommended improving the ADHD education, knowledge and experience of healthcare professionals. Furthermore, other studies have emphasised the lack of expertise, training and capacity of clinicians as a barrier to continuing care through transition (Montano and Young, 2012). A study of college and university health centres in the UK highlighted that 87% of clinicians had not attended any recent training for ADHD and many providing an adult service lacked the resources to facilitate transition (Baverstock and Finlay, 2003). Efforts should be made to educate and inform professionals about ADHD (Young et al., 2016) and there is a clear need to upskill clinicians to practically manage ADHD and treatment (Coghill, 2015). Without training, capacity and knowledge of ADHD and services, it could be argued that clinicians are lacking the ability to implement the guidelines appropriately to support patients with ADHD through transition.

NICE state that professionals are expected to take clinical guidelines fully into account, but that the recommendations are not mandatory, while commissioners and service providers have a responsibility to enable the implementation of the guideline (NICE, 2008). This is conflicting, and presents a challenge for clinicians and local services to ensure that adequate ADHD services are provided, particularly for patients in transition.

Conclusion

This systematic review aimed to identify and describe guidelines and protocols for transition from child to adult services for patients with ADHD in England. The review identified sixteen documents that were mostly based around the NICE guidelines for ADHD diagnosis and management (NG87). Few independent guidelines were found although some documents provided additional or more detailed recommendations to the NICE guidelines, and many were peer reviewed papers which discussed the recommendations made by NICE. While this review used reliable systematic methods of searching, and followed the recommended steps for data screening and extraction, it is limited by specifically focussing on transition and England only.

The nature of health services and the changing needs of service users means that service changes occur, and guidelines are also amended or updated to meet the required need. However, the NICE guidelines for management of ADHD updated and published in March 2018 (NG87) do not provide any new or updated recommendations for transition from the 2008 version, aside from referring the reader to the general NICE guidelines on transition in health and social care services (NG43). These provide more comprehensive recommendations for transition generally, however are not condition specific. It would be beneficial for NG87 to incorporate these recommendations and develop them to be specific for ADHD.

References

All references for this paper have been collated in one list for the thesis. The reference list can be found on page 275.

Acknowledgements

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Conflicts of interest

The authors have declared that they have no competing or potential conflicts of interest.

**Appendix 2:
Surveillance vs Case Note Review methodology – manuscript accepted for
publication to BMC Research Methodology 12th August 2019**

The following manuscript has been developed from some of the findings from the surveillance study described in Chapter Three. The paper compares and contrasts the use of two methodologies; surveillance and electronic case note review. The paper has been accepted for publication in the journal BMC Medical Research Methodology in August 2019. I have led the data collection, data analysis and write up of this paper, and liaised with co-authors for their contributions.

How to measure the need for transition to adult services among young people with Attention Deficit Hyperactivity Disorder (ADHD): a comparison of surveillance versus case note review methods

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Abstract

Background: Health services have not provided adequate support for young people with long term health conditions to transfer from child to adult services. National Institute of Health and Care (NICE) guidance on transition has been issued to address these gaps. However, data are often sparse about the number of young adults who might need to transition. Using Attention Deficit Hyperactivity Disorder (ADHD) as an exemplar, this study used an existing surveillance system and a case note review to capture the incidence of the transition process, and compared and contrasted the findings.

Methods: The Child and Adolescent Psychiatry Surveillance System (CAPSS) was used to estimate the incident transition of young people with Attention Deficit Hyperactivity Disorder (ADHD) from child to adult services. This involves consultant child and adolescent psychiatrists from the United Kingdom (UK) and Republic of Ireland (ROI) reporting relevant young people as they are seen in clinics. In parallel, a case note review was conducted using the Maudsley Biomedical Research Centre (BRC) Clinical Records Interactive Search (CRIS). The study period ran for twelve months with a nine month follow up to see how the transition proceeded.

Results: CRIS identified 76 cases in the study period, compared to 18 identified using surveillance via CAPSS. Methodological issues were experienced using both methods. Surveillance issues; eligibility criteria confusion, reporting errors, incomplete questionnaires, difficulties contacting clinicians, and surveillance systems do not cover non-doctors and psychiatrists who are not consultants. Case note review issues using CRIS included the need for researchers to interpret clinical notes, the availability and completeness of data in the notes, and data limited to the catchment of one particular mental health trust.

Conclusions: Both methods demonstrate strengths and weaknesses; the combination of both methods in the absence of strong routinely collected data, allowed a more robust estimate of the level of need for service planning and commissioning.

Keywords: Surveillance, CAPSS, CRIS, Case note review, ADHD, Transition, NICE

Background

Several studies, government documents and policy guidelines highlight the difficulty that young people face who require a transition from child to adult services (Singh et al., 2008). Transition between services is particularly difficult for young people with Attention Deficit Hyperactivity Disorder (ADHD) (Singh et al., 2008). Two types of transition can be conceptualised; *developmental* when a child moves from adolescence to adulthood, and *situational*, moving from one service to another (Singh et al., 2008). In the current paper, the term transition refers to a situational transition between child and adult mental health services, however this is driven by young people reaching a developmental transition. There is currently limited evidence available on the need for transition between services for young people with long term health conditions who require ongoing care. A case note review study would most commonly be used to capture the transition process; however it suffers from limitations such as requiring intensive researcher or clinician time, being very localised in focus, and the availability and quality of data are dependent on the clinician who records it (Stewart et al., 2009, Allebeck, 2009, Perera et al., 2016). This paper reports on two existing methods that have been adjusted to estimate the national need for young people with ADHD to transition to adult services; they were a surveillance system and an electronic case note review method. Paediatric surveillance studies have traditionally focussed on the incidence of rare conditions (Elliott et al., 2001), however the current study focussed on the incidence of transition between child and adult services for young people with ADHD as an *event or process* as opposed to the incidence of ADHD as a *condition*. ADHD itself is not rare; it is one of the most common long term conditions managed by child and adolescent mental health service (CAMHS) and community paediatric services (Ford et al., 2007).

The prevalence of ADHD is estimated at approximately 5% (Faraone et al., 2015), and population based studies suggest that 15% of those with childhood ADHD still meet the full diagnostic criteria for the disorder at age 25 (Faraone et al., 2006). However, existing research suggests a seamless transition process between child and adult services happens much less often than can be expected based on adult prevalence rates (Paul et al., 2013). Two previous studies (Singh et al., 2008, Tatlow-Golden et al., 2018) have reviewed case notes narratively to identify transition cases between CAMHS and adult mental health services (AMHS) over a twelve month period. The

first study identified an average of 12 cases of neurodevelopmental disorder per CAMHS team that were eligible for transition in one year, but 40% were not referred to any adult service, and only 67% of those referred actually made the transition (Islam et al., 2016, Singh et al., 2008). The study was based on a limited number of health trusts in England and identified neurodevelopmental cases in general, not ADHD specifically. The second study focussed on ADHD cases in Ireland, and identified 20 patients from four CAMHS teams that required a transition. No cases were directly transitioned to AMHS; they were either retained by CAMHS, referred to a private service, or discharged to their General Practitioners (GP) (Tatlow-Golden et al., 2018). Extrapolating from epidemiological studies can be helpful in the estimation of population level need, but does not necessarily provide information about service access and service-level need, and may not be relevant to populations other than those studied. An existing prospective North American longitudinal study used assessment at three time points from age 9 to 30 years, as a method to quantify patterns of transitions, and it was found that ADHD in particular showed a strong continuity across the transition from adolescence to adulthood (Copeland et al., 2013). Studies of long term conditions such as ADHD rarely follow participants across developmental transitions (Glantz et al., 2009) and national empirical data on the number of young people that wish to access ongoing care for ADHD in adulthood, or the number that successfully and seamlessly access follow up care in early adulthood, is sparse. This hampers commissioning and provision of services for this group.

The current paper describes how two existing methods were adjusted to assess the need for transition between child and adult services for those with ADHD at a national level; it evaluates how feasible and transferable these methods were to quantify and capture the need for transition or other rare events or processes in health services. To estimate incident service need for young people with ADHD to transition to an adult service we used a paediatric surveillance methodology, in particular the Child and Adolescent Psychiatry Surveillance System (CAPSS), and an electronic clinical case note search using the Maudsley Biomedical Research Centre (BRC) Clinical Records Interactive Search (CRIS) (SLaM NHS Foundation Trust, 2017).

Methods

This study was part of a larger National Institute of Health Research (NIHR) funded project on transition for young adults with ADHD (Ford et al., 2015), which included a surveillance study using the British Paediatric Surveillance Unit (BPSU) and CAPSS simultaneously. For the purposes of this paper, CAPSS and CRIS are discussed independently from the wider NIHR study.

Surveillance methodology

The CAPSS surveillance system was used to collect data on incident transition. This surveillance system provides a coordinated data collection system; it is designed to collect notification reports from clinicians, and to support research teams to gather data from the clinicians about each patient, with follow up to assess outcome and understand management (Nicoll et al., 2000). The methodology was developed by BPSU and is a well-established and very successful system traditionally used to study rare paediatric disorders and events across the United Kingdom (UK) and Republic of Ireland (ROI) without selection bias. The system has been replicated around the world for paediatric surveillance, but also for different specialities (Lynn et al., 2016); CAPSS is one example and collects notifications from Consultant Child and Adolescent Psychiatrists (Lynn et al., 2012).

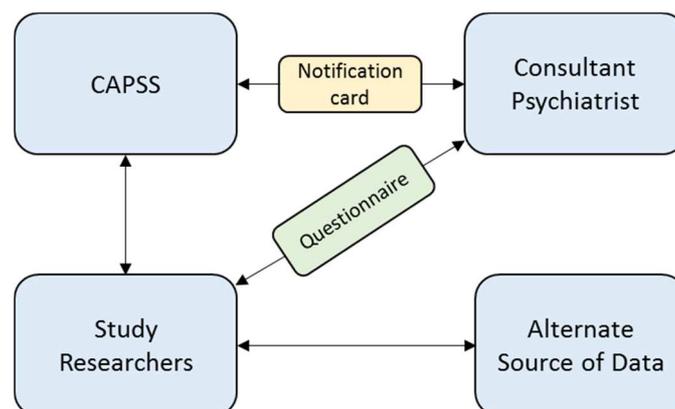


Figure 1. Surveillance methodology

Figure 1 illustrates the surveillance process. Approximately 1000 consultant child and adolescent psychiatrists are sent a surveillance 'reporting card' (now 90% via email) each month in order to report uncommon disorders to all current listed research studies. More details on the process are described elsewhere (Verity and Preece, 2002, Knowles et al., 2006, Knowles et al., 2012).

Relevant ethical approval was obtained. The governance structure for surveillance studies is complex, challenging and fluid. Surveillance data is not publically available and this type of surveillance required Health Research Authority (HRA) approval as cases may be reported from any NHS Trust that works with children across the UK. In addition, Section 251 approval is required from the Confidentiality Advisory Group (CAG) to permit clinicians to report anonymous case note information without patient/parent consent provided there is no requirement or expectation for additional patient contact as a result of the study. (HRA-IRAS reference 159209, CAG reference 15/CAG/0184).

CAPSS is set up to investigate rare childhood disorders (Knowles et al., 2012) defined as less than 1:20,000 incidence. Thus, conditions are accepted for study based on rarity and public health relevance. ADHD is not a rare condition, yet the successful transfer of care for a young person with ADHD between child and adult services is recognised as uncommon and of relevance to both paediatricians and child and adolescent psychiatrists (Paul et al., 2013). The first month of any surveillance study is treated as a pilot to iron out any difficulties with definitions and because prior experience indicates that prevalent cases are often reported due to interest about the study. CAPSS recognised the public health relevance of monitoring this event, but expressed concerns that this could result in large numbers of cases (more than 360 per year) which would overload the system (Verity and Preece, 2002, RCPCH, 2018). The study was initially approved for six months active surveillance (half the time period of typical surveillance studies) with the option to extend to a full year depending on the number of cases reported. In total the surveillance study ran for thirteen months from November 2015 to November 2016, which included the first pilot month. The follow up period ran from August 2016 to August 2017, and was at nine months for each reported case.

- *Case definition criteria*

This study was the first time that a surveillance case definition had described a health service process and not just a condition checked by a review of clinical symptoms. The surveillance definition was very different to usual surveillance criteria (Hudson et al., 2012). In addition, as this study was part of a larger project, the definition had to be appropriate for both paediatricians and psychiatrists, to ensure that both sets of clinicians would identify the same transition processes. Therefore, the case definition was designed in close collaboration with members of BPSU and CAPSS, and required repeated iterations involving stakeholders from an advisory group, and both BPSU and CAPSS scientific committees. The definition had to be agreed before the application for the study could be approved. The first pilot month also allowed for any issues with the case definition to be raised.

Table 1 lists the case definition criteria that had to be met in order for a case to be eligible for inclusion in the study.

Table 1. Case definition criteria

1. A young person with a clinical diagnosis of ADHD under the care of CAMHS, who is reviewed for the first time when, within 6 months of reaching the services' age boundary, whatever this may be. Young people should only be reported once and those that have already been seen and reported in this time-scale should not be reported a second time.
2. The young person is considered to require continued drug treatment for their symptoms of ADHD after crossing the service age boundary.
3. The young person should not have been reported previously to the BPSU/CAPSS in relation to the current study.
4. A young person with ADHD and comorbid diagnoses, including learning / developmental disabilities, should be reported only if it is their ADHD for which ongoing drug treatment in adult services is required.

The case definition criteria were developed to be precise and clearly defined, and to specify the ongoing need for support from specialist adult mental health services as concretely as possible, while echoing the recommendations outlined in the NICE guidelines for transition in health and social care services (NICE, 2016b). The aim of the case definition was to provide a minimum estimate of the number of young people

with ADHD who required a transfer from CAMHS or paediatrics to adult services during the surveillance period. As different CAMHS and Adolescent services are likely to have different protocols and service specifications, and there are also different types of services available to treat young people with ADHD such as 0-25 services, the age boundary was unspecified in the case definition in order to measure when the transition was actually occurring as a secondary aim. Requirement for ongoing medication was chosen as a criterion in order to rule out subjectivity in the application of definitions of 'ongoing care'. It would not capture those who did not need or want medication but did need ongoing psychological support.

- *Questionnaire Development*

Baseline notification and follow up questionnaires were developed according to guidance for developing a surveillance study (RCPCH, 2018), and each questionnaire was highly structured and as brief as possible. The baseline questionnaire was sent to all clinicians that reported a case to the study. The questions confirmed eligibility, and collected sufficient patient data to detect and remove duplicates. It also collected details of patient treatment, and details of the planned transition to an adult service. Any professional with access to the patient notes could complete the questionnaire on behalf of the consultant, but the notification card and report were always sent to the consultant child and adolescent psychiatrist via the relevant surveillance unit. A nine month follow up questionnaire was sent to the same reporting clinician to confirm the outcome and details of the transition. Email and postal reminders for non-returned questionnaires were sent after 4 weeks and after 6 weeks. Finally a follow up telephone call was made if the questionnaire was still outstanding.

Case note review

The electronic clinical case note system from the Maudsley Biomedical Research Centre (BRC) Clinical Record Interactive Search (CRIS) at the South London and Maudsley (SLaM) NHS Foundation Trust, was chosen as the system for the case note review methodology. CRIS is not publically available, but provides authorised researchers access to secure, regulated, anonymised patient data extracted from

electronic clinical patient notes (SLaM NHS Foundation Trust, 2017). Data from CRIS were used over the same time period, applying the same criteria as the surveillance study, to identify cases. Comparison could only be drawn against a subset of the data collected using CAPSS, as SLaM provide mental health services only. CRIS was approved as an anonymised data resource for secondary analysis by Oxfordshire Research Ethics Committee (08/H0606/71+5). This project was reviewed and approved by the CRIS patient-led oversight committee (CRIS project ref: 961).

The case definition criteria from the surveillance study was operationalised into a structured query language (SQL), which was used to identify relevant cases in CRIS. This search produces an output of anonymous electronic records that meet the search criteria. Manual review of the electronic records by two researchers extracted the individual, clinical and service related characteristics of the case, including any available details about transition (see Table 2). Two researchers were used as the process was time intensive. It also prevented bias that might occur from a single researcher; approximately 50% of the case note records were double screened.

Table 2. Complete list of CRIS data outputs extracted for data collection

CRIS ID	Reason for appointment	Other medication 3
Gender	CAMHS or AMHS	Other medication 4
Ethnicity	Seen by Clinician	CGAS score 1-100
DOB (specified)	Comorbidity 1	SDQ Assessment Date
Truncated Postcode	Comorbidity 2	SDQ total score
Social Deprivation	Comorbidity 3	Hyperactivity score
Date of Diagnosis of ADHD	Comorbidity other	Impact score
CAMHS Directorate	ADHD Medication 1	Contact frequency
Last date seen	ADHD Medication 2	DNA rate

Analysis of data from surveillance and case note review

A measure of compliance with a surveillance scheme is the proportion of reporting cards returned (Godward and Dezateux, 1996). The successful utility of the surveillance methodology is discussed by exploring the use and understanding of the case definition, errors with reporting and the case definition, compliance to monthly reporting cards and return of questionnaires, and the mechanisms of the surveillance databases used.

Data linkage and protection governance meant that cases from CRIS could not be directly linked to the patient data collected in the surveillance study, thus only estimates and descriptive characteristics of cases captured by the two methods could be compared. It was also not possible to directly replicate the same boundary of SLaM in the CAPSS data as researchers are blinded to identifiable patient data and the information provided on each case related to the reporting consultant and not the service or clinic. The wider boundary of 'London' was used in the CAPSS data to compare against.

The incidence of transition collected via both systems was compared. Data from each source were extracted by a researcher and collated in to a spreadsheet using Excel. Descriptive data were collated for the number of cases identified, gender, ethnicity, and the reviewing clinician. Further descriptive data were also collated for transition referral date, referral acceptance, first appointment in adult service, evidence of joint meetings and persons involved in transition. These were tabulated and directly compared.

Results

Overall acceptance of surveillance methodology

Over the twelve month period, there was a mean response rate to the CAPSS monthly reporting cards of 53% (total of 7016 cards sent). This is lower than CAPSS have reported previously (Ani et al., 2013, Lynn et al., 2012). In total there were 300 CAPSS case notifications; more cases than existing studies on transition have suggested in one year (Singh et al., 2008, Tatlow-Golden et al., 2018, Islam et al., 2016). The

response rate to the questionnaires (58% at baseline and 83% at follow up) was also slightly lower than reported by CAPSS in other studies (Lynn et al., 2016, Ani et al., 2013). Further descriptive results of the surveillance data collected are discussed in a separate paper (Eke et al., 2019d). For the purposes of this paper, only the CAPSS cases that were identified to be reported from within the boundary of London (n=45) were included in the analysis.

- *Surveillance Case definition*

The case definition raised some issues, particularly at the beginning of the surveillance period. Misunderstanding occurred around the term '*reviewed for the first time, within six months of the age boundary*'. It was unclear to some clinicians if it was the first time they had ever reviewed the patient, and thus a new diagnosis, or whether it was first time reviewed during the surveillance period. Queries were resolved directly with the clinician by explaining the terminology as '*the first time the case is seen during the surveillance period*'. Most errors that occurred due to this confusion occurred during the first pilot month; these data were excluded from subsequent analysis as per protocol.

Other errors in reporting from clinicians included; two consultants who reported a whole caseload of ADHD patients rather than reporting just the patients that required a transition and were at transition age; five cases were reported more than once as they were seen more than once during the study period (this was the reason for the "reviewed for the first time" criterion); consultants who were not able to remember the patient details when asked to complete the baseline questionnaire (n=16); cases that did not meet one or more of the five case definition criteria (n=30); and 'reporting in error' e.g. ticking wrong box on card, reading the card incorrectly, no recollection of reporting (n=19).

- *Surveillance Data collection*

Registration with CAPSS is voluntary and therefore not all consultants may be registered to receive the reporting cards. Only consultant and associate specialist level clinicians are enrolled once identified; other clinicians may review patients with ADHD at the transition boundary, particularly if they are clinically well, but would not be contacted to notify to CAPSS. Some contact details provided by the surveillance

organisation was out of date (n=8, 7%), which prevented the research team reaching the clinician with the questionnaire. The research team made alternative efforts to reach the clinician, for example with help from CAPSS, or by using search engines and contacting the clinic or hospital directly.

The response rate to questionnaires was in line with results of other surveillance studies, but there was no response at all from 42% of questionnaires (n=127), some were returned blank (n=1) or with missing data (n=39, 13%) and it was reported anecdotally as time intensive to complete (n=6, 2%). The sections most frequently left blank at baseline were the facts regarding transition, for example what service the patient was referred to. At follow up the questions most frequently left blank were the elements of optimal transition, for example whether a joint meeting between services took place. Efforts were made to contact clinicians directly to complete any missing data.

Comparison of methods

Table 3 compares the CAPSS surveillance and the case note review data collected using CRIS. The CRIS database identified 91 ADHD cases in SLaM who had a clinical diagnosis of ADHD, were within six months of the service age boundary, and therefore potentially eligible for transition. However, there was evidence in the case notes that 15 cases were discharged prior to transition or were no longer on medication or requiring treatment, leaving 76 that met all of the study criteria. There were 45 CAPSS cases identified based on the location of the reporting clinician, 18 of which were confirmed as eligible cases from the baseline questionnaire.

Table 3. Comparison of data collected by CAPSS and CRIS

	CAPSS	CRIS
Notifications / Identified cases (n)	45	91
Did not meet eligibility criteria (n)	27	15
Met all eligibility criteria (n)	18	76
<i>Eligible cases only:</i>		
Gender ratio (m%:f%)	83:17	84:16
Ethnicity (% White British)	72	46
Reported / Reviewed by Consultant (n)	18	41
Reported / Reviewed by other health professional (n)	0	35
Transition referral made, accepted and first appointment offered in adult service (n)	10	37
First appointment confirmed as attended (n)	4	28

All CAPSS cases were reported by a consultant level clinician, while only half (54%, n=41) of the 76 eligible CRIS cases were reported to have been seen by a consultant. The remaining 46% of cases were either seen by an alternative health professional or the case notes did not indicate who had reviewed the patient.

Discussion

A well-established surveillance method, and a case note review method have been used to assess the need for, and process of, transition between child and adult services for young people with ADHD. Utilised together, both methods have provided an insight into the need for transition of patients with ADHD in CAMHS settings in the UK.

CAPSS was chosen in order to most closely reflect the common health setting that patients with ADHD are reviewed in within the UK, and the monthly notification card completion rate throughout the study, which was similar to the average CAPSS rates, shows that this method of surveillance is successful. It also has the potential to be used to monitor a health service event seen by psychiatrists, in addition to incidence

of rare conditions which it is traditionally used for. CAPSS had the potential to provide a national picture, in contrast to the case note review that is localised. When compared to the clinical case note review via CRIS, there was a significant difference in the number of cases identified using CAPSS. However, the case note review method allowed all cases to be captured within a NHS trust that required transition due to ongoing medication needs, regardless of the treating or supervising clinician, whereas surveillance relies on the clinician to accurately report each case.

Using CAPSS, only consultant level psychiatry clinicians are sent reporting cards each month. The case note review with CRIS demonstrated clearly that ADHD patients in this mental health trust are frequently reviewed by other health professionals, such as junior doctors and specialist nurses. These clinicians would not be able to report to CAPSS. Similarly locum clinicians also may not be registered with, or reporting via CAPSS due to frequent employment moves. Even if locums are registered and do notify cases, they may have moved posts between notification and baseline questionnaire, or between baseline and follow up, and therefore not be able to provide data. Patients may also be reviewed in settings other than CAMHS, such as primary care or forensic services (NICE, 2017a), while a study of surveillance approaches has highlighted the absence of surveillance in the private sector despite it playing an important role in health care provision (Kroll et al., 2015). This is perhaps particularly relevant for young people with ADHD for whom there can be long waits for treatment in the public sector and gaps in the provision of adult services (Ford et al., 2015, Price et al., in submission-a).

Enrolment with CAPSS is voluntary, and therefore not all consultants may be registered to receive the reporting cards. A census in 2017 reported there to be 5395 registered consultant psychiatrists (approximately a quarter of which are child and adolescent psychiatrists), whilst CAPSS have approximately 1000 on their database (RCPCH, 2014, RCPsych, 2017, RCPsych, 2018). It is possible that although clinicians are registered with CAPSS, they may be academics and not hold relevant clinical caseloads, and would therefore not be reviewing patients with ADHD. Some contact details provided by the surveillance organisation were out of date, inevitably due to clinicians frequently changing NHS Trusts, location, role, retiring, or working as locum. Incomplete records present a factor in non-return despite efforts to update records and the use of alternative methods to contact clinicians.

The surveillance system relies wholly on accurate reporting from the clinician, and the average return rate of the reporting cards was low in CAPSS when compared to previous BPSU studies (Lynn et al., 2016). The BPSU system was adopted and replicated by CAPSS in 2009, and perhaps it is yet to become routine practice for child and adolescent psychiatrists. The lower return rate of notification cards may indeed indicate a lack of awareness of the system and not necessarily a reflection of clinicians actively being non-compliant. It is possible that the difficulties with the case definition could also have led to a lack of reported cases. Previous surveillance studies have also cited difficulties with reporting, case definitions and lower return rates (Okike et al., 2014, Ani et al., 2013, Nicholls et al., 2011, Tiffin and Kitchen, 2015). Clinicians were offered certificates to demonstrate time committed to research to be used for appraisal, as an incentive to return questionnaires to the study. There is no evidence to suggest that this had an impact on return of questionnaires, however certificates were generally received with thanks.

It is important to estimate the accuracy of case ascertainment in surveillance (Rahi and Dezateux, 1999) and verify findings (Ford et al., 2018). It is recommended that researchers conducting surveillance studies reconcile their data with other sources to help improve completeness and accuracy (Nicoll et al., 2000). Previous surveillance studies (Fortnum et al., 2001, Crowcroft et al., 2002, Knowles et al., 2006) have used 'capture recapture' analysis to maximise case ascertainment, but for this matched cases must be identifiable and the population under study must be closed (Knowles et al., 2006). This was not possible in the current study of transition in ADHD. The CRIS database was used as an alternative data source to estimate the incidence of transition among young people with ADHD and to compare against the data collected using surveillance.

There were limitations to this comparison. While clinicians completing the surveillance questionnaires had direct knowledge of the young people as well as the case notes that they themselves may have written, the data collected using CRIS relied on information recorded by other people in the clinical notes (Ford et al., 2018). Inevitably, this involved some subjective judgements on behalf of the researchers as the clinical notes may not necessarily include readily available concrete information such as prescribed medication, comorbidities or details of diagnosis. Similarly, the information gathered by the surveillance questionnaires was specified by the study researchers,

and required short, succinct responses. It was not always possible to identify the same succinct information from the clinical case notes.

While the surveillance system has the advantage of its national cover, the case note review was limited to a single NHS trust covering one part of a metropolitan city. How representative these services and the young people attending them are of all young adults with ADHD is difficult to judge. Existing research has alluded that patients identified in case registers are not always representative of all cases with that disorder (Allebeck, 2009). Importantly, and a key limitation of this study is that the geographic location of SLAM clinics and hospitals could not be directly replicated in the surveillance data, as the address provided from the surveillance notifications was that of the clinician, and not of the clinic or hospital in which the patient was seen. The broader term of 'London' was used in the CAPSS data which almost certainly gathered cases from a wider boundary than is included in SLAM. There are nine mental health trusts in London, of which eight have CAMHS services (NHS Office of London Clinical Commissioning Groups, 2018) (SLAM is one of them), suggesting that the data collected in CRIS only represents a fraction of the ADHD transition cases in London.

Data protection and information governance meant that data could not be directly linked which would have allowed more direct inference of the completeness of case ascertainment from CAPSS to be drawn. Interestingly, data protection rules may be more stringent than the attitudes of many patients and public. A previous study has highlighted the benefits of linking data to provide information that is missing and reduce bias (Audrey et al., 2016) and a study of attitudes towards linking data concluded that it was perceived acceptable to share health data in a medical context (The Wellcome Trust, 2013). A study using medication registers has previously been used to examine trends over transition (Newlove-Delgado et al., 2018), but not all trusts have such registers, and prescribing for ADHD is often led by primary rather than secondary health care.

While the case note review clearly provides the most efficient local data, both methods offer strengths and weaknesses in terms of our attempt to provide robust national estimates. While imperfect, these results, particularly when combined, provide an insight in to the issue of transition for young people with ADHD nationally that has not been achieved by studies previously. Ideally, routine data linkage could inform service

planning and provision at national and local levels in real time, but whilst systems like CRIS are located within a limited number of trusts, additional methods will be required. Many data protection and information governance issues currently mean that access to such data is difficult to obtain when it exists.

Previous research has suggested that traditional public health approaches for monitoring incidence of conditions is too late, too costly and often inaccurate (Chao, 2014). Managing and running a surveillance study is labour intensive, both from the perspective of the surveillance organisation and from the individual study team, but it provides value for money as research studies can be conducted simultaneously (Elliott et al., 2001) and data can be gathered on a national level. It is worth noting that case note review, even using an isolated system such as CRIS, is also labour intensive if the questions asked requires active data extraction. For most conditions, surveillance studies are still the only source of national data (Grenier et al., 2007). The existing surveillance organisations stress that studies should not generate more than 360 cases per year (RCPCH, 2018); for valuable national surveillance to be effective for more than just incidence of rare conditions, and to continue to inform public health policy (Grenier et al., 2007), these systems need to be properly funded and supported to enable large scale national studies to be carried out. Previous research has highlighted that national data are not necessarily sufficient to address gaps and advance knowledge; the establishment of the international network of paediatric surveillance units (INOPSU) and the replication of the methodology in certain specialities, potentially provides methodological opportunities for researchers to gather invaluable data on uncommon conditions or health service events internationally (Grenier et al., 2009) that should be further explored.

Conclusion

This is the first study to survey the incidence of ADHD transition using an existing surveillance methodology, and the first study to directly compare and contrast the feasibility of two existing methods (surveillance and electronic clinical case note review) in quantifying the need for transition. Both methods offer different strengths and weaknesses. The application of the combination of both methods, as conducted in this study, provided an insight in to the transition of care for young people with ADHD

at a national level, and suggests further work is needed to refine the methodologies in order to ensure that future such estimates are more robust.

References

All references for this paper have been collated in one list for the thesis. The reference list can be found on page 275.

List of Abbreviations

ADHD – Attention Deficit Hyperactivity Disorder

AMHS – Adult Mental Health Services

BPSU – British Paediatric Surveillance Unit

BRC – Biomedical Research Centre

CAG – Confidentiality Advisory Group

CAMHS – Child and Adolescent Mental Health Services

CAPSS – Child and Adolescent Psychiatry Surveillance System

CATCh-uS – Children and Adolescents with ADHD in Transition between Child and Adult Services

CRIS – Clinical Records Interactive Search

HRA – Health Research Authority

SLaM – South London and Maudsley NHS Trust

Declarations

Ethics approval and consent to participate

Relevant ethical approval was obtained. This type of surveillance required Health Research Authority (HRA) approval as cases may be reported from any NHS Trust that works with children across the UK. In addition, Section 251 approval is required from the Confidentiality Advisory Group (CAG) to permit clinicians to report anonymous case note information without patient/parent consent provided there is no requirement or expectation for additional patient contact as a result of the study.

Health Research Authority (HRA) approval – HRA-IRAS reference 159209
Section 251 Confidentiality Advisory Group (CAG) – CAG reference 15/CAG/0184

CRIS was approved as an anonymised data resource for secondary analysis by Oxfordshire Research Ethics Committee (08/H0606/71+5). This project was reviewed and approved by the CRIS patient-led oversight committee (CRIS project ref: 961).

Consent for publication

Not applicable

Availability of data and material

The datasets generated and/or analysed during the current study are not publicly available because they are part of ongoing research that is not yet published, but they are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

HE, AJ, JD and TF designed the study; HE and AJ collected, analysed and interpreted the data collection via surveillance and CRIS with supervision from TF, JD and RL; HE compiled the work and all authors (HE, AJ, JD, RL, CA, and TF) substantively contributed to and revised the manuscript. All authors (HE, AJ, JD, RL, CA, and TF) read and approved the final manuscript.

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Appendix 3:
Surveillance Study findings – manuscript published by the British Journal of Psychiatry 4th June 2019

The following manuscript has been developed from the surveillance study described in Chapter Three. The paper summarises the methodology and key findings from the study, and has been published in the British Journal of Psychiatry in June 2019. I have led the data collection, data analysis and write up of this paper, and liaised with co-authors for their contributions.

Transition between child and adult services for young people with ADHD: findings from a British national surveillance study

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Abstract

Background: Optimal transition involves continuity, joint care, planning meetings and information transfer. To plan services, commissioners and service providers need data on how many people require that service. Although Attention Deficit Hyperactivity Disorder (ADHD) frequently persists into adulthood, evidence is limited on transitions between child and adult services.

Aims: To estimate incidence of young people taking medication for ADHD that require and successful transition, and to describe the proportion that experienced optimal transition.

Methods: Surveillance over twelve months using the British Paediatric Surveillance Unit and the Child and Adolescent Psychiatry Surveillance System, including baseline notification and follow up questionnaires.

Results: Questionnaire response was 79% at baseline and 82% at follow up. 315 eligible cases were reported. For cases aged 17-19, incident rate of transition *need* was 202-511 per 100,000 people aged 17-19 per year, but *successful* transition of only 38-96 per 100,000 people aged 17-19 per year. Cases were mostly male (77%) with a comorbid condition (62%). Half were referred to specialist adult ADHD and 25% to general adult mental health services; 64% had referral accepted but only 22% attended a first appointment. Only 6% met optimal transition criteria.

Conclusions: Inclusion criteria required eligible cases to be on medication, meaning that estimates are likely to represent the lower limit of the need for transition. Two critical points were apparent; referral acceptance and first appointment attendance. Findings of low rates of successful transition and limited adherence to guidelines, indicates significant need for commissioners and service providers to improve transition experiences.

Key Words: Attention Deficit Hyperactivity Disorder, Surveillance, BPSU, CAPSS, Incidence

Introduction

In order to plan services, commissioners and service providers need accurate and timely data on how many people may require that service. There is currently limited data available on the number of young people with Attention Deficit Hyperactivity Disorder (ADHD) who need transition to adult services when they become too old for child services. ADHD affects approximately 5% of the childhood population, 15% of whom still meet the diagnostic criteria at age 25 (Faraone et al., 2015, Faraone et al., 2006). Consequently, there is a group of young people in need of continued support for the management of ADHD in early adulthood. Few studies (Singh et al., 2008, Tatlow-Golden et al., 2018) provide empirical data on the number of young people with ADHD who wish to access ongoing care in adulthood, or the number that successfully do so. Some studies have attempted to quantify national estimates for transition, but these studies have focussed on all neurodevelopmental conditions rather than just ADHD, or were limited geographically (Singh et al., 2008, Tatlow-Golden et al., 2018).

The current study aimed to estimate the incidence of young people with ADHD who need transition from child and adolescent services to adult services across the United Kingdom (UK) and Republic of Ireland (ROI) (henceforth, the British Isles). The main objectives of the study were; to describe the group of young people diagnosed with ADHD and requiring medication beyond the end of children's services in terms of range and mean age for transition, and the variation within this across the British Isles; to estimate the incidence rate of young people with ADHD who requiring ongoing medication for ADHD after they pass the age-boundary for the child service, and the variation within this across the British Isles; to estimate the proportion of young people with ADHD judged in need of transition to Adult Mental Health Services due to ongoing need for medication that successfully transferred to a specialist health service; to describe the proportion of young people who experience optimal transition (i.e. continuity, joint care, planning meetings and information transfer) among those who successfully transferred to adult services.

Methods

This study used the British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatry Surveillance System (CAPSS) to collect prospective surveillance data on the number of young people who undergo transition from children's health services that support young people with ADHD, to adult services. This was one of only five studies that have used the BPSU and CAPSS systems simultaneously (Ani et al., 2013). These surveillance units provide a method that allows the collection of reliable information about health conditions or events in paediatrics and child mental health services to improve health. Surveillance provides national estimates of incidence and highlights needs or gaps in service provision that could inform commissioning. The surveillance methodology is described in more detail elsewhere but is briefly summarised below (Verity and Preece, 2002, Elliott et al., 2001, Grenier et al., 2007, Eke et al., 2019b).

Young people taking medication for a clinical diagnosis of ADHD requiring transition to an adult service for continued treatment, were notified prospectively using the BPSU and CAPSS methodology over thirteen months from 1st November 2015 to 30th November 2016. The first month was discarded as per BPSU and CAPSS protocol. Consultant Paediatricians and Consultant Child and Adolescent Psychiatrists in the British Isles were systematically prompted using a monthly email and postal reporting card (orange and yellow for BPSU and CAPSS respectively). The clinician was asked to return the email or card indicating either the number of eligible cases they had seen in the previous month, or 'nothing to report'. Details regarding each reported case were subsequently gathered by study investigators using a notification questionnaire sent to the reporting clinician via email or mail according to their preference. Information on the outcome of the transition of eligible cases were collected using a follow up questionnaire nine months after notification. Baseline notification and follow up questionnaires were developed using the BPSU and CAPSS templates, which comprised structured questions (30 at baseline, and 19 at follow up) with two open text responses. Only cases confirmed as eligible at baseline were sent a follow up questionnaire nine months later. Duplicate reporting of cases was checked by matching minimal identifiers.

The study was approved by both BPSU and CAPSS Executive Committees. Health Research Authority (HRA) and Confidentiality Advisory Group (CAG) approvals permitted access to case note information without patient/parent consent (IRAS registration number: 159209, REC reference: 15/YH/0426, CAG reference: 15/CAG/0184).

Case definition criteria for notification

The case definition criteria were developed to be precise, and to specify the need for the young person to need ongoing support for medical treatment from specialist adult mental health services, as outlined in the NICE guidelines (NICE, 2018a). The definition was designed in close collaboration with both BPSU and CAPSS to ensure that both Paediatricians and Child and Adolescent Psychiatrists would identify young people in a similar manner. The surveillance asked for young people seen in the previous month to be reported if they met the following criteria;

- Clinical diagnosis of ADHD under the care of Child and Adolescent Mental Health Services (CAMHS) or Paediatrics, reviewed within six months of the service's upper age (transition) boundary.
- Considered to require and willing to take continued medical treatment for symptoms of ADHD after crossing the transition boundary of the child service.
- Comorbid diagnoses, including learning / developmental disabilities, were included only if it was the ADHD that required ongoing medical treatment in adulthood.

Data analysis

Analysis of data was descriptive. Response rates at each stage of the study are described, as are sociodemographic details of the reported cases. The population at risk (n=116,651) was derived by applying the estimated prevalence of ADHD (approximately 5% in the child and adolescent population) (Faraone et al., 2015) to the total number of children aged 17-19 years in the British Isles as reported in 2016 (n=2,333,035) (ONS, 2016). The age range 17-19 was used as this in the

age at which transition should occur according to the NICE guidelines (NICE, 2018a). As an incidence rate is defined as the number of new health related events, in a defined population, in a set period of time (International Epidemiological Association, 2014), the incidence rate was calculated by dividing the number of confirmed young people with ADHD who need transition identified over the course of the study's twelve month surveillance period, by the population at risk. The quotient was then multiplied by 100,000 to provide the incidence rate of transition per 100,000 population of people aged 17-19 per year. Two incidence rates were calculated; the incidence of young people who required transition as defined by the case definition criteria, and the incidence rate of successful transition in the obtained sample, defined as those whose referrals were accepted and attended their first appointment in the adult service. The observed incidence rate was adjusted to take into account current NICE guidance about the age of transition (18 years) and missing data (failures to notify or return questionnaires) as suggested in a previous study – see Table 2 (Petkova et al., in submission).

Results

Table 1 illustrates the return of questionnaires for each stage of the surveillance study. The mean monthly response rate was 94% in BPSU and 53% in CAPSS. A total of 614 cases were reported by clinicians. The overall response rate to the baseline questionnaire was 90% from BPSU and 67% from CAPSS clinicians, and at follow up was 84% and 80% respectively. The response rates include contacts with clinicians who provided an explanation for not returning the questionnaire, including for reasons such as inability to recall the patient reported, reporting the case in error, or subsequent realisation that the case did not meet the definition criteria.

There was no overlap in cases reported through BPSU and CAPSS (i.e. the same case was not reported by both a paediatrician and a psychiatrist). Thirteen duplicate reports were identified from clinicians that reported the same case more than once during the surveillance period. Seventeen questionnaires could not be completed at follow up as the clinician no longer had access to the patient's records, or was no longer in post. Some questionnaires at baseline and follow up

were returned blank or not fully completed (n=86). However, information from partially completed questionnaires was included in the analysis.

Table 1. Surveillance study data November 2015-November 2016

Baseline (% based on total reported cases)	BPSU n=314	CAPSS n=300	Combined n=614
Not returned - received clear explanation for why	29 (9%)	27 (9%)	56 (9%)
Not returned - no explanation	41 (13%)	127 (42%)	168 (27%)
Duplicate cases	6 (2%)	7 (2%)	13 (2%)
Returned baseline questionnaire	238 (76%)	139 (46%)	377 (61%)
Ineligible cases	36 (11%)	26 (9%)	62 (10%)
Eligible cases	202 (64%)	113 (38%)	315 (51%)
Follow up (% based on total eligible cases)	BPSU n=202	CAPSS n=113	Combined n=315
Returned follow up questionnaire	161 (80%)	86 (76%)	247 (78%)
Not returned - received clear explanation for why	12 (6%)	8 (7%)	20 (6%)
Not returned - no explanation	29 (14%)	19 (17%)	48 (15%)

Demographics of young people reported

The population of young people reported was largely male (77%) and White British (91%). Cases were reported from across the British Isles but most (over 85%) were seen in England. The mode age boundary between child and adult services was 18 years old, but ranged from 14 to 19 years. Two cases who did not originate from the British Isles, were students seen in private practice in England. Over 80% of reported cases were aged 17 or 18 years at the point of referral for transition, although the reported age range extended from 14 to 20 years.

A large proportion of cases (56% from paediatricians, 68% from psychiatrists) were reported to have a comorbid condition, which in 25% of cases was an autism spectrum disorder (ASD). Polypharmacy was common; 23% of cases from

paediatricians and 41% from psychiatrists were prescribed more than one medication.

Incidence of transition

Table 2 demonstrates the incidence calculations. In total, there were 315 confirmed eligible cases (202 BPSU, 113 CAPSS), with follow up questionnaires received about 247 cases. There were 55 cases (22 BPSU, 33 CAPSS) reported at follow up that confirmed that a successful transition was achieved (i.e. a referral made, accepted, and the young person attended first appointment in the adult service). When only the cases aged 17 to 19 years are extracted from this data, there remains 269 eligible for transition, and 51 that were reported to have a successful transition.

The Adjusted Incidence Rates provide a likely range within which the actual rate is likely to fall, which in terms of eligibility was between 202.9 and 511.2 per 100,000 aged 17-19 per year. Successful transition was less common at between 38.5 and 96.9 per 100,000 young people aged 17-19 per year. Figures in bold estimate the range for eligible and successful transition.

Table 2. Calculation of incidence rate of successful transition, for reported cases aged 17-19 years (per 100,000 people aged 17-19 per year)

Observed incidence for all reported cases:	
Incidence: eligible for transition (all eligible cases identified in 12 months) per 100,000 per year	$(315 / 116,651) \times 100,000$ = 270.0
Incidence: successful transition (referral made, accepted and first appointment attended) per 100,000 per year	$(55 / 116,651) \times 100,000$ = 47.1
Observed incidence for cases aged 17-19 only:	
Incidence: eligible for transition aged 17-19 (all eligible cases aged 17-19 identified in 12 months) per 100,000 per year	$(269 / 116,651) \times 100,000$ = 230.6
Incidence: successful transition aged 17-19 (referral made, accepted and first appointment attended) per 100,000 per year	$(51 / 116,651) \times 100,000$ = 43.7
Correction for non-returned notification cards (no age known):	
Returned	73.7%
No response	26.3%
Assumption 1 (incidence applies to half non-returned cards because clinicians are more likely to respond with cases to report)	$(13.2 + 26.3) / 73.7$ = coefficient 0.54
Assumption 2 (incidence applies to all non-returned cards; assumes no difference in incidence between cases that were reported and not reported)	$100 / 73.7$ = coefficient 1.36
Correction for non-returned baseline questionnaires (no age known):	
Returned	$377 / 614 = 61.4\%$ $100 / 61.4 = \text{coefficient } 1.63$
Combined coefficients for cases aged 17-19 only:	
Adjusted Incidence Rate 1 = incidence rate X Correction for unreturned notification cards (Assumption 1) X Correction for unreturned baseline questionnaires	Eligible for transition: $230.6 \times 0.54 \times 1.63 = \mathbf{202.9}$ Successful Transition: $43.7 \times 0.54 \times 1.63 = \mathbf{38.5}$
Adjusted Incidence Rate 2 = incidence rate X Correction for unreturned notification cards (Assumption 2) X Correction for unreturned baseline questionnaires	Eligible for transition: $230.6 \times 1.36 \times 1.63 = \mathbf{511.2}$ Successful Transition: $43.7 \times 1.36 \times 1.63 = \mathbf{96.9}$

Transition quality and outcomes

Half of the cases were referred to a specialist adult ADHD service, just over a quarter to general adult mental health services, and 10% were referred back to primary care. Referral destinations were similar regardless of whether the young person was reported by a paediatrician or a psychiatrist.

In total, 64% (n=158) of the 247 cases had their referral to an adult service accepted (BPSU 52%, CAPSS 86%). Despite this, only 22% (n=55) were reported to have attended a first appointment (14% BPSU, 38% CAPSS) – see Figure 1. Reported reasons for failed transitions included; the patient disengaged and no longer wanted to take medication, the referral did not meet adult service criteria, there was no funding available, or the adult service was closed to new referrals due to lack of resources or long waiting lists.

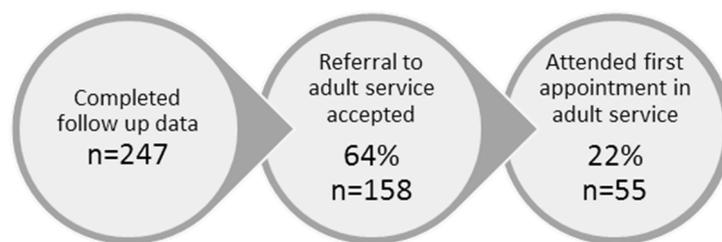


Figure 1. Success of transition from all reported cases

Nearly all (93%) clinicians reported that the young person had been involved in the planning of the transition process, and over 80% reported that the parent or carer was also involved. More Child and Adolescent Psychiatrists than Paediatricians reported access to (81% vs 39%) and use of (66% vs 36%) a transition protocol in their organisation.

At baseline notification, only 6% of paediatricians and 10% of psychiatrists indicated that all five optimal criteria pre-transition (see Table 3) were apparent in the transition planning. At follow up only 2% of paediatricians and 6% of psychiatrists considered that all nine optimal criteria post-transition had been adhered to. Some elements were reported considerably less frequently at follow

up than at baseline, which suggests that clinicians anticipate being able to complete these elements, but when providing a retrospective report at follow up some elements may either not have been recalled or not have been carried out. These included: information sharing (84.6% at baseline vs. 68.8% at follow up), young person involvement (81.4% vs. 69.6%) and joint working/handover (25.5% vs. 10.5%).

Table 3. Factor of optimal transition reported – pre and post transition

PRE TRANSITION	BPSU n=202		CAPSS n=113		Combined n=315	
	Total 'Yes' response	%	Total 'Yes' response	%	Total 'Yes' response	%
Information sharing	176	87.1	93	82.3	269	84.6
Young person involvement	162	80.2	97	85.8	259	81.4
Planning meeting	23	11.4	29	25.7	52	16.3
Plan & agree care plan	49	24.3	46	40.7	95	29.9
Handover period	56	27.7	25	22.1	81	25.5
POST TRANSITION	BPSU n=161		CAPSS n=86		Combined n=247	
	Total 'Yes' response	%	Total 'Yes' response	%	Total 'Yes' response	%
User/carer involvement	116	72	56	65.1	172	69.6
Information sharing	105	65.2	65	75.6	170	68.8
Care plan agreed	35	21.7	44	51.2	79	32.0
Joint working before transfer	12	7.5	14	16.3	26	10.5
Alignment of assessment procedures	9	5.6	12	14.1	21	8.5
Continuity of care	35	21.7	41	47.7	76	30.8
Consistency of care	13	8.1	36	41.9	49	19.8
Consideration of appropriate service	78	48.4	50	58.1	128	51.8
Clarity of funding & eligibility	66	41.1	51	59.3	117	47.4

Discussion

This surveillance study generated the first national data to estimate the number of young people with ADHD taking medication who require and complete a

transition to an adult service in the British Isles. Our findings suggest that the annual scale of the need for young adults with ADHD who require transition to adult services for ongoing medical treatment in the British Isles lies between 202.9 and 511.2 per 100,000 17-19 year olds per year. The estimated annual incidence of successful transitions lies between 38.5 and 96.9 per 100,000 young people aged 17-19 years per year. Given the study's inclusion criterion that the eligible young person had to need and want to continue with medication for ADHD, which does not take into account the demand for psychological support, these figures are likely to be a considerable underestimate of the actual need for service provision. The requirement that reported cases needed ongoing medication aimed to increase reliability in reporting eligible cases by having an unequivocal reference for the reporting clinician. Further, a comparison of the surveillance data collected in the current study with the Clinical Records Interactive Search (CRIS) at the South London and Maudsley Trust (SLaM) highlighted that surveillance using CAPSS only identified 25% of potential ADHD transition cases in the London area (Eke et al., 2019b). Sadly, there was no comparable data to triangulate with BPSU reports, but the CRIS data emphasise that our estimates should therefore be treated as conservative, but remain the best empirically-based British Isles data available for service commissioners and providers.

Previous studies have only been able to estimate the number of transition cases in smaller localities that are difficult to compare directly with our findings. A London-based study suggested an average of 12 neurodevelopmental cases per CAMHS team annually that require a transition to an adult service, with 8 of the 12 making the transition successfully (Singh et al., 2008). A study from Ireland used the same methodology and found 20 ADHD cases from 4 CAMHS teams annually requiring transition, with only 3 successfully transitioning to an adult service (Tatlow-Golden et al., 2018). Given the rise in prescriptions for ADHD over the last couple of decades (Newlove-Delgado et al., 2018), estimates may quickly become out of date as later cohorts are likely to contain a higher proportion of young adults who may have benefitted from medication and therefore wish to continue to take it. A recent report reviewing children and young people's mental health care highlighted a lack of data availability and monitoring of transition (Care Quality Commission, 2018), and further, reviews such as this

only consider young people up to the age of 18 so knowledge of the needs of young adults in their later teens or early twenties is poor.

The estimated annual incidence of successful transitions lies between 38.5 and 96.9 per 100,000 young people aged 17-19 years per year, which suggests that only a fifth of those requiring transition for ongoing medication successfully made the transfer. Similarly, a study of a locality in North West England reported that only 15% of patients eligible for transition actually successfully transferred to the adult service (Ogundele, 2013). These findings suggest a worrying discontinuity of service between child and adult services, given that patient registry studies of young adults who discontinue their medication show poorer outcomes compared to those who continue to take it (Lichtenstein et al., 2012). Others have demonstrated above predicted levels of medication cessation between the ages of 15 to 18, prior to transition, which may be influenced by the lack of availability of services (Bolea-Alamanac et al., 2014), with data from UK primary care suggesting that only 18% were still taking medication for ADHD at age 18 (Newlove-Delgado et al., 2018). Given the number of young people reported in this surveillance study that did not attend the first appointment in the adult service, it is possible that the transition referral for ongoing treatment might reflect a clinician decision regarding the need for treatment, rather than a decision made by the young person.

Our findings suggest poor adherence to the recommendations for transition from the National Institute for Health and Care Excellence (NICE) guidelines for ADHD. NICE recommend that a good transition between child and adult services should be complete by age 18, involve a detailed care plan, include a formal joint meeting between the child and adult service, use the care programme approach, and involve the young person and the parent or carer (NICE, 2018a). In contrast, we found that a joint planning meeting, a care plan and a joint handover period were conducted in less than 30% of cases. Other studies have also highlighted the lack of planning for transition of young people with ADHD (Appleton and Pugh, 2011, Singh et al., 2008, Tatlow-Golden et al., 2018, Swift et al., 2014). Whilst the reported high level of involvement of the young person and carer in the process is commendable, paediatricians in particular reported poor continuity and consistency of care. This may reflect weaker links with between paediatricians and adult mental health services when compared with CAMHS. A lack of planning

is likely to undermine the potential for successful transition, and the need to adhere to recommendations to ensure effective transition has been highlighted (Young et al., 2016). Further, it is recommended that policies and guidelines are reviewed regularly so they can be operationalised and effectively translated in to clinical practice (Young et al., 2011). A systematic review of guidelines has suggested that this does not occur and guidelines are often not incorporated in to protocols locally (Eke et al., 2018).

The use of the BPSU and CAPSS systems provided national level, prospectively collected data, but presented a number of methodological challenges. Registration to receive the monthly reporting cards is voluntary and mostly consists of those in the consultant grade. Therefore not all relevant clinicians may receive them (although non-consultant grades may report cases via the consultant). This is likely to be the main explanation for the discrepancy between CAPSS and the CRIS case note review (Eke et al., 2019b). Other research has demonstrated that patients may be reviewed in settings other than paediatrics and CAMHS such as primary care or forensic services (NICE, 2017a) who would not ordinarily be reached by either surveillance system. There is also a relative underrepresentation of clinicians reporting to the surveillance units in the private sector despite its increasingly important role in health care provision (Kroll et al., 2015) which may be particularly an issue for young adults with ADHD for whom there are few NHS services (Ford et al., 2015). Indeed, our findings highlighted referral back to primary care in 10% of cases. Incomplete data also presented a limitation; some contact details provided by both surveillance organisations were not up to date, some questionnaires were returned blank or with missing data.

Whilst the return rate of reporting cards by paediatricians via BPSU was excellent, which is perhaps due to longevity of the system (Lynn et al., 2016), the average return rate was much lower in CAPSS. CAPSS was set up more recently (2009), so is less ingrained in clinical practice for Child and Adolescent Psychiatrists than BPSU is for Paediatricians. Research is enshrined in the NHS constitution as a core activity (NHS, 2015), however clinicians reported that current workloads made it difficult to respond to questionnaires, and some service providers did not support their clinicians to participate.

Surveillance methodology has stringent governance and required considerable researcher time for data collection and analysis, but has offered a more complete

national picture of the need and success of transition to adult service among young people with ADHD than previous studies have achieved. Surveillance allows researchers to ask a wider set of questions than case note review alone. The findings emphasise a relative lack of adherence to recommended guidelines for transition, and the low proportion of eligible patients that experience successful transition and a continuity of care.

Attempts have been made to correct for incomplete ascertainment and to provide a series of transparent estimates for policy, commissioning and service provision. Despite some limitations, to our knowledge these data are the best currently available on this subject. European studies have similarly highlighted a lack of transition policy (Signorini et al., 2018) and the societal impact of ADHD if not managed (Lichtenstein et al., 2012). Our findings are significant for commissioners and service providers, internationally as well as in the British Isles, to address the drop in attendance from child to adult services. It is imperative that mental health services develop policy and strategy to better support this group of young people in the future.

References

All references for this paper have been collated in one list for the thesis. The reference list can be found on page 275.

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Author Contribution: HE led the CATCh-uS surveillance study and the collation and analysis of data with support from AP. The study was designed by TF and AJ in collaboration with CA, TND, MP, KS and SY. RL facilitated data collection via BPSU and CAPSS. All other authors contributed to writing the paper.

Data Availability: Data is currently stored securely by the University of Exeter Medical School, under embargo until the end of the CATCh-uS project (2019).

**Appendix 4:
Clinicians' Perspectives on the use of NICE guidelines - manuscript
submitted for publication to Child: Care Health and Development,
currently under review**

The following manuscript has been developed from the surveillance study described in Chapter Three and the qualitative study in Chapter Four. The paper combines and shares the data related to the use of NICE guidelines from the findings of the qualitative interviews conducted with clinicians and the quantitative surveillance data. This manuscript has been submitted for publication to the journal Child: Care, Health and Development, and is currently under review. I have led the write up of this paper, and liaised with co-authors for their contributions.

Clinician perspectives on the use of NICE guidelines for the process of transition in Attention Deficit Hyperactivity Disorder (ADHD)

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Abstract

Background: The UK National Institute for Health and Care Excellence (NICE) Clinical Guidelines recommends the following steps in the transition from child to adult services for young people with Attention Deficit Hyperactivity Disorder (ADHD): reassessment before and after transition, transition planning, formal meeting between services, involvement from young person and carer, completed by age 18.

Methods: A UK surveillance study asked clinicians to report young people on their caseloads with ADHD in need of transition to adult services in 2016 to support their continued access to medication need. Clinicians reported young people as they aged to within 6 months of the transition boundary. A prospective questionnaire prior to transition asked about intended transition and the use of local transition protocols. A retrospective questionnaire sent nine months later established which steps recommended by NICE were followed during transition. Clinicians (38) working in child or adult services were interviewed about their experiences of transition and the use of NICE guidelines during transition, and were analysed using a Framework approach.

Results: Information was shared between services in 85% of the 315 identified transition cases. A joint meeting was planned in 16% of cases; joint working before transfer occurred in 10% of cases. Clinicians were aware of NICE guidelines; they had mixed views on whether (local) guidelines or protocols were helpful. The main reason for not following guidelines was workload and resources: *“NICE recommends stuff that is miles above what we will ever be able to provide”*.

Conclusions: Clinicians involved in the transition process of young people with ADHD judged NICE guidelines to be unrealistic given the current limited resources and service organisation. More open dialogue is needed for recommendations on service models to bridge the gap between guideline recommendations and what is viewed as feasible, and how implementation of guidance is funded, monitored and prioritised. This may lead to valuable changes in the consultation process, for example, consideration of a layered (gold, standard, minimal) system for some NICE guidelines.

Key Messages:

- Clinicians have mixed views on the value of NICE guidelines for transition
- Many aspects of transition recommendations are not implemented, mainly due to constraints of workload and resources; guidelines are not mandatory and therefore may not be a priority for clinicians and commissioners
- We suggest a 'graded' system (gold, standard, minimum) of guideline implementation

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) affects around 5% of the population (Faraone et al., 2015). Traditionally it has been seen as a childhood condition, with little or no impact in adult life (Asherson et al., 2010, Asherson et al., 2016). The number of graduates from children's services with ADHD has increased rapidly as prescription rates for ADHD have risen in childhood (Beau-Lejdstrom et al., 2016) and more recently it has been accepted as a potentially lifelong condition for some people with increasing recognition of the need for medical support in adulthood (Kooij et al., 2010).

Consequently, there is a group of young people in need of continued service access for the management of their condition when they are too old to attend child services. The National Institute of Health and Care Excellence (NICE) guideline for ADHD (NG87) (NICE, 2018a) and the Child and Adolescent Mental Health Service (CAMHS) Review (Department of Health, 2008) recommend that adequate transition to adult services should include comprehensive planning and a lead person managing the process at a stage that is needs-based rather than age-based (NICE, 2008). Although the age boundary of healthcare services is variable and should be determined locally (NHS England, 2015), most services providing care for young people with ADHD in the UK currently limit attendance to under 18 years (Eke et al., 2019d). Healthcare competency is presumed at the age of 18, at which point by law the young person is considered an adult and thus supported by adult services (Larcher, 2005, Ross, 1997). The World Health Organisation (WHO) however, define young people aged 10-24 years (WHO, 2006) as 'emerging adulthood', a distinct extended developmental period before a young person reaches an adult role (Arnett, 2000, Dovey-Pearce et al., 2005).

More recent research has argued that transition should take in to account biological, psychological, social and vocational aspects of development, and be seen as a developmental milestone, as opposed to a negotiation of the structural boundary between child and adult services (Farre and McDonagh, 2017), with growing interest in the provision of youth services up to the ages of 25 years (Fusar-Poli, 2019)

Several studies, government documents and policy guidelines have highlighted difficulties for young people who require a transition between children's services and adult mental health services (Singh et al., 2008, Asherson et al., 2017, Department of Health, 2006). These transitions should support a young person towards and onto a new life stage, and is a process that extends beyond the simple transfer of clinical responsibility (Beresford, 2004a). A recent systematic review of mental health care systems, however, found that neither the National Health Service (NHS) nor United States (US) mental health system provided sufficient support or access to adult services for young people (Embrett et al., 2016). In addition, there is also a reported inverse relationship between the prevalence of mental health disorders in young people aged 16-24 and the use of mental health services (Catania et al., 2011).

Transition to an adult service for those with ADHD is therefore of key importance. By its very nature, young people with ADHD have significant difficulties with organisation, planning, impulsiveness, distractibility, and forgetfulness (Brugha et al., 2014); factors that would undermine the ability to effectively navigate complex service organisation or manage their condition independently. Young adults with ADHD might not have reached 'healthcare competency' therefore, something which is assumed when using adult services, at time of transition. A poorly managed transition can lead to unmet needs, disengagement from services and ultimately poor life outcomes for the young person such as unemployment, under achievement in education and risk taking behaviour (Singh and Tuomainen, 2015, Young et al., 2011). A UK surveillance study has recently found that only 22% of patients with ADHD who required transition made the transition successfully; success was defined as a referral made and accepted to the adult service and follow up care received (Eke et al., 2019d).

NICE was established twenty years ago by the Department of Health, in order to improve the standard of health and social care by reducing variation in the

availability and quality of NHS treatments and care (NICE, 2018d, Culyer, 2005). NICE provides the evidence base for clinical governance, which is a framework that NHS organisations use to improve the quality of services and standards of care (Culyer, 2005, Gray, 2005). NICE issues guidelines, quality standards, and technology appraisals for a range of topics and specific conditions. Condition specific guidelines, such as NG87 for the management of ADHD (NICE, 2018a), or general service guidelines such as NG43 for transition from child and adult services for young people using health and social care (NICE, 2016b), aim to set the expected standard of care for that condition or health care event, and to promote integrated care where appropriate (NICE, 2018d).

The guideline for ADHD, NG87 (previously CG72), includes a section under 'service organisation' that details transition to an adult service and refers the reader to NG43 (NICE, 2016b). Sections 1.1.4, 1.1.5 and 1.1.6 of NG87 refer to transition between child and adult services. The recommendations in summary are:

- Young people should be reassessed at school leaving age to establish need for continuing treatment in adulthood (hence to determine if transition is required)
- Plan for smooth transition should be made with details of anticipated treatment and service young person requires
- Transition should be complete by age 18
- Formal meeting between child and adult service should be considered
- Care Programme Approach (CPA) should be used to aid transfer for ages 16+
- Young person and parent/carer should be involved in planning
- After transition, adult service should undertake a comprehensive assessment of young person – to include personal, educational, occupational, social functioning and coexisting conditions

(NICE 2018)

Previous studies have suggested that although NICE have issued over 200 clinical guidelines since initiation, there is variability in how they are updated and implemented (Drummond, 2016, Soheilipour et al., 2011, Alderson et al., 2014, Sheldon et al., 2004). Gill (2001) suggests that guidelines are only followed in

55% of clinical decisions (Gill, 2001). Whilst guidelines are intended to be used in conjunction with clinical judgement, there are various 'non clinical' reasons why recommendations may not be followed, including financial and time investment, organisational or structural provision, patient choice or a lack of interest in the guidelines by the clinician (Gill, 2001). Transition ensures continuity and consistency of care, defined as a coordinated, coherent, linked and smooth progression experienced by the patient (Freeman et al., 2000, Reid et al., 2002). As continuity of care reduces the risk of poor outcomes for young adults with ADHD, it is important to understand how guidelines for ADHD are used by clinicians, what aspects of the guidelines are not implemented and why, and how this potentially impacts on the success of transitions.

In this paper the views of clinicians working in both child and adult services for ADHD regarding the use of NICE guidelines for ADHD are discussed, with a particular focus on the processes and procedures that clinicians implement for transition between child and adult services.

Methods

This study was part of a wider three strand National Institute of Health research (NIHR) funded project on children and adolescents with ADHD in transition from child to adult services (CATCh-uS) (Ford et al., 2015). Stream one was a surveillance study to assess the need for and organisation of transition. The second stream was a qualitative study to understand the transition process, and the third stream was a mapping study to identify services for young adults with ADHD (Price et al., in submission-a). The CATCh-uS project incorporated a convergent parallel design as well as an explanatory sequential study design.

This paper reports findings from two methods (a surveillance method and data from the qualitative stream) to provide a better understanding of the applicability and implementation of NICE guidance for the current analysis. The quantitative data informed the qualitative strand (research questions, sampling and data collection). Whilst collecting and analysing data separately, both data were integrated to obtain in-depth understanding of the problem and to explain the findings (Johnson et al., 2007). The protocol for the surveillance study and the qualitative interviews was designed and approved for use by the University of

Exeter Medical School Research Ethics Committee, in parallel with approval via the Confidentiality Advisory Group at the Health Research Authority ([REDACTED] [REDACTED] [REDACTED]).

Recruitment for surveillance survey

The surveillance study was run using the British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatry Surveillance System (CAPSS). Clinicians notified BPSU and CAPSS when a patient with ADHD on medication, within six months of the transition age boundary was seen; each individual could only be reported once should they attend the clinic more than once prior to transition. A baseline notification questionnaire prior to transition and a follow up questionnaire nine months later were sent to the reporting clinician for each eligible case (Eke et al., 2019d, Lynn et al., 2012).

Surveillance study questionnaire

Questionnaires were bespoke and used both structured questions and open text response boxes that recorded patient demographics, current medications, intended referral details, local transition protocols and procedures, and details regarding the transition process implemented by clinicians. Clinicians were asked to confirm using a tick-box yes or no response, whether they felt that each element of transition recommended by NICE had been adhered to as illustrated by Table 1.

Table 1. Relevant extracts from baseline and follow up surveillance questionnaires

Baseline Questionnaire	Follow Up Questionnaire
<p>Does your organisation have a transition protocol? Y/N Are you using it to plan the transition for this case? Y/N</p> <p>Partners involved? state which of the following are involved in the transition process – young person, parents, GP, care coordinator from adult team, care coordinator from child team</p> <p>Which of the following elements of transition have been initiated? Information sharing, young person involvement, transition planning meeting, plan and agree a care plan, period of handover or joint care</p>	<p>Has the referral been accepted? Y/N</p> <p>Have you received any feedback from the service to which you referred the young person? Y/N</p> <p>Did the young person receive an appointment? Y/N Did they attend? Y/N</p> <p>Were the following elements or processes present in the transition of the young person? User/carer involvement, information sharing, care plan agreed, joint working, assessment procedures, continuity of care, consistency of care, consideration of most appropriate service, clarity of funding arrangement.</p>

Recruitment for interviews

Two groups of participants were recruited; clinicians working in child services and clinicians working in adult services. A sample of clinicians from children’s services (paediatricians and psychiatrists) were identified via the surveillance study. Clinicians were selected from the consultant paediatricians and child psychiatrists who indicated their consent to an interview on their completed surveillance questionnaire. Geographical location and type of service (e.g. private vs NHS) were considered, to ensure a range of responses. Practitioners from adult mental health services were identified via the follow up surveillance questionnaire, but also from a pilot mapping study that sent out an online survey via networks such as the Royal College of Psychiatrists (RCPsych), Royal College of General Practitioners (RCGP), Clinical Commissioning Groups (CCGs), AADD-UK, and ADHD Foundation. Clinicians were invited to participate via email and informed written consent was gained from all participants prior to the interview taking place. Clinicians were offered a certificate to represent time committed to research, which could be used as evidence of research involvement.

Interview procedure

All interviews were conducted over the telephone by the research team (HE, AP, AJ), using a topic guide (see Table 2) and were digitally voice recorded. Face to

face interviews have traditionally been thought to provide a stronger communicative environment, however telephone interviews have been shown to better meet the needs of a busy and scattered sample (Ritchie et al., 2003).

The topic guide was developed based on previous research, findings from the surveillance study, and discussions with the study Patient and Public Involvement (PPI) group, and Study Steering Committee (SSC); questions focused on themes such as transition protocols and procedures, the Care Programme Approach, medication use, current contact with services, and experience of transition. Interviews were anonymised before analysis and transcribed verbatim using a professional transcription service, with no linguistic annotations and limited communication or linguistic style elements (e.g. long pauses, “umm”). All interviews were transcribed by the same professional service, and all interview transcripts were checked for accuracy against the original voice recording by the research team, to ensure reliability and validity of the transcript (Silverman, 2014). Interim analysis was conducted after 23 interviews were completed, to conduct preliminary analysis of the collected data and assess data saturation. As data saturation had not occurred, the interview topic guides were revised to ensure that any unexplored topics or newly acquired information could be explored in more depth in the remaining interviews.

Table 2. Relevant Extracts from Interview Topic Guides

Clinicians from Child Services	Clinicians from Adult Services
<p>What are your views and experiences of the transition of young people with ADHD?</p> <p>What are your thoughts about the NICE guidelines? Use of CPA, Care programme approach? And any transition protocol or policy?</p> <p>If there is a transition protocol: Do you use it? Why (not)? If so, is this protocol in accordance with the Care Programme Approach (CPA)? Have you found the protocol to be helpful in your practice?</p> <p>Are GPs in your area able to prescribe ADHD medication?</p>	<p>Are you aware of a protocol for transition, either within your service or children’s services? If so, do you refer to it and it is helpful? - If not, why might that be?</p> <p>Do you usually receive appropriate information in the referral letter/documentation?</p> <p>What barriers have you experienced in working with children services?</p> <p>What would optimal transition look like from your perspective?</p>

Data management and analysis

Each recruited participant was assigned a unique identifier code, and all data (demographics from interview participants and questionnaires, interview recording and transcripts) were stored on password protected encrypted hard drives; only the research team had access. Quantitative data were collated and summarised descriptively.

Once transcribed, interview data were managed using QSR International's NVivo10 qualitative data analysis software. The interviews (n=38) were analysed by the research team (HE, AJ, AP, TND) using a thematic and framework approach. Thematic analysis involves working systematically through the texts to identify topics and patterns, while the framework approach is an analysis tool that sorts the themes that are common across the data, summarises them and displays them in a matrix (Gale et al., 2013). This allowed for any patterns or contradictions to be identified while maintaining a link to the original data (Ritchie et al., 2003). The first stage involved 'indexing' a small sample of interviews, to gather an insight and overview of the data. A thematic framework or 'coding tree' was then created which identified key concepts, which was then used to code all of the interviews. The final stage involved creating summaries of each of the codes from the framework, which were used to compare and contrast, identify patterns or links, and to provide explanations of the findings (Ritchie et al., 2003, Braun and Clarke, 2006).

Results

Questionnaire findings

In total 315 eligible baseline questionnaires were received (202 from paediatricians and 113 from psychiatrists), all of which were sent a follow up questionnaire; 247 follow up questionnaires received (161 from paediatricians and 86 from psychiatrists). At baseline 55% (n=172) of clinicians indicated that the local trust in which they worked had a transition protocol; 86% (n=148) confirmed that they used the protocol. At follow up 64% (n=158) of clinicians indicated that the transition referral they had made had been accepted; only 30% (n=75) reported that they received feedback from the adult service about the

transition, and 35% (n=55) reported that the patient had attended the first appointment in the adult service and thus successfully transferred. A higher proportion of young people referred from psychiatry (45%, n=33) successfully transitioned than from paediatrics (26%, n=22).

Information sharing and young person involvement scored highly (over 65%) at both baseline and follow up. A joint planning meeting (a factor specified in the NICE guidelines) was particularly low with fewer than 30% of clinicians indicating that such a meeting occurred. Consistency of care (19%) and continuity of care (30%) was also infrequently reported. Table 3 and Table 4 illustrate the responses.

Table 3. Factors of optimal transition at baseline

	Responses n=315	
	Total 'Yes' response	%
Information sharing	269	84.6
Young person involvement	259	81.4
Planning meeting	52	16.3
Plan & agree care plan	95	29.9
Handover period	81	25.5

Table 4. Factors of optimal transition at follow up

	Responses n=247	
	Total 'Yes' response	%
User/carer involvement	172	69.6
Information sharing	170	68.8
Care plan agreed	79	32.0
Joint working before transfer	26	10.5
Alignment of assessment procedures	21	8.5
Continuity of care	76	30.8
Consistency of care	49	19.8
Consideration of appropriate service	128	51.8
Clarity of funding & eligibility	117	47.4

Interview findings

In total 38 interviews were conducted; 22 with clinicians from child services and 16 with clinicians from adult services. Nearly three quarters (27) were recruited via the surveillance study, and 11 via a Mapping Study (Price et al., in submission-a). Clinicians were mostly female (14:24 male to female ratio), and were either consultant paediatricians (n=15), consultant psychiatrists (n=19), or from other health disciplines e.g. mental health nurse or ADHD practitioner (n=4). Interviews were conducted with clinicians from all countries of the United Kingdom, but most (92%) worked in England. All interviewees had extensive current or previous knowledge of services for ADHD and were regularly reviewing patients with ADHD.

In the following quotes, 'CC' refers to clinicians interviewed from child services, and 'AC' refers to those from adult services.

Knowledge and use of NICE guidelines

Most of the clinicians from both child and adult services indicated that they were aware of the NICE guidelines but there was variation in clinician's knowledge of the specific transition recommendations. Some highlighted knowledge of the Care Programme Approach (CPA) or the use of joint meetings which are NICE recommendations;

"I'm familiar with guidance but not with the specific bit around transition" (CC03), "I'm aware they exist... I haven't read them with care" (CC12), "I can't recall the guidelines without looking them up" (CC07), "can't recall if they say anything about transition" (CC02), "service works to the NICE guidelines, that's why we have joint meetings" (AC38), "I'm aware of the NICE guidelines and CPA... aim to meet guidance... beginning to do joint working" (CC15).

There were differences in responses as to whether the NICE guidelines guided their practice for transition. Clinicians from children's services in particular indicated that the NICE guidelines were not specific enough or highly valued, but explained that they tried to follow them regardless. In contrast, adult clinicians

indicated that their practice was to follow NICE guidelines, or that their own existing service provision was already compliant with NICE recommendations;

“I try to comply with the guidance” (CC01), “NICE guidelines are important and have to be followed” (CC08), “guidelines are very generic, very vague” (CC04), “they are not valued enough” (CC10), “they are a useful benchmark for what we should be doing” (CC11), “...protocol for transition follows the NICE guidelines” (AC02), “service works to NICE guidelines, that’s why we have joint meetings” (AC38), “service fits the guidelines – not rocket science but it helps” (AC02).

Specific transition guidelines and policies

Some respondents indicated that there were specific protocols for transition which had been developed locally. However many clinicians, in both child and adult services, also indicated that there were no local policies despite the NICE recommendation. Child clinicians also believed that the NICE guidelines would be better known and implemented if local protocols were in place, but there were mixed views as to whether protocols specifically for transition were considered helpful or not;

“There is an agreed protocol between CAMHS and AMHS that is followed” (AC17), “there are clear protocols for what people do and the expectation for the transition period” (AC02), “trust has a transition protocol including ADHD” (CC10), “no protocol or policy... a protocol would make it easier” (CC08), “there’s a general transition protocol but reality – it doesn’t work” (AC39), “if there was a document for transition, it would push the guidelines forward” (CC08), “having a transition document that says what should happen would make a big difference” (CC08).

Implementation of guidelines

Clinicians from both child and adult services reported a number of barriers that prevented them from implementing the guidelines fully. The most prominent reason discussed by almost all of the clinicians was workload and resources;

there was a clear consensus that resources are required to implement guidelines effectively and that the current NICE recommendations were not possible to implement within current resources;

“We cannot be NICE compliant, we just simply do not have the resources” (CC15), “NICE recommend stuff that is miles above what we will ever be able to provide” (CC11), “pragmatically services are so limited...we don’t have access and options” (CC04), “if you think they are impractical then you’re not going to follow them” (CC08), “we try as much as one can with constraints of too much work and not enough time” (CC10) “reality is that no one has time – service is too big and has too many patients, there’s too many cuts and not enough money” (AC39), “services are beset by long waiting lists and shortage of resources” (AC36), “everyone is rushed, service is understaffed and overworked, it’s not done sufficiently” (AC36).

Service structure and organisation was also cited as preventing clinicians from following NICE guidelines. Examples include a lack of joint working and established processes between the child and adult service; clinicians described a situation where adult and child services did not work together and did not know each other, so that those working with children felt they lacked knowledge of the available services for adults;

“There should be a linkage with CAMHS” (AC05), “services should sit together and handover” (AC39), “adult clinicians don’t know child clinicians – there are no bridges” (AC05), “they aren’t part of our service so it’s hard to instigate joint working” (CC18), “practicalities of knowing who to transition to is difficult” (CC10), “one of the many complications is trying to join it up, when its very un-joined up” (CC13).

Some interviews revealed cultural differences in the approaches of the child and adult services, and clinicians’ attitudes towards ADHD as an adult condition, linked to a lack of ownership or responsibility for the transitioning patient. There was also discussion around local commissioning failing to support ADHD in adulthood, which therefore has implications for transition;

“local service do not recognise ADHD as adult diagnosis, tried to engage local AMHS but they are slippery” (CC18), “there isn’t commissioning for adult ADHD locally” (CC05), “the issue is that the three consultants, one doesn’t believe in it, one thinks they ought to sort themselves out... the only protocol [locally] is you don’t diagnose and you don’t treat it” (AC18), “paeds are prescribing but adults [services] don’t” (AC06), “some clinicians are more motivated to see ADHD transitioned patients than others, some questioned why the service took the patients” (AC17), “we want evidence of the symptoms, if not given we will send referral back” (AC33).

Young person experience

Some clinicians alluded to the impact that the transition process had on young people, and how this impact is heightened by non-adherence to the NICE guidelines. There was recognition that the age when transition occurs is a difficult time for young people, and they see the process as daunting, potentially increasing anxiety and decreasing self-esteem;

“the change to a new person [clinician] is daunting and difficult” (AC36), “young people are scared, they are anxious of the adult service” (AC38), “by the time a person transitions, their self-esteem may be low” (AC36), “transition isn’t just about transition in service, it’s usually when changing school, there’s a lot of anxiety” (AC05), “it’s often a source of anxiety for them, what will happen and they don’t always know” (CC16), “everything is changing and then they are thrown in at the deep end” (CC11).

Clinicians recognised the need to communicate with the young person about transition, but mentioned a number of factors that hindered this discussion, including their own uncertainties, and other pressures such as the need to resolve crises. Many clinicians also discussed how adequately the young person was prepared for the transition, how parents play a role in this process, and how far in advance the clinician started the process;

“there is a need to reassure and communicate” (AC33), “some families move from crisis to crisis so there’s less time to talk about transition” (CC15), “often parents will bring [transition] up” (CC16), “I don’t know what happens afterwards, it’s kind of pushing them in to a black hole” (CC01), “at 18 they haven’t been told what’s happening” (AC26), “they are supposed to start the transition at 16” (CC08), “I start saying about transition from 13, 14, 15” (CC01), “we alert them to a change at 18” (CC19), “it depends on how it’s communicated to the patient by CAMHS colleagues, it’s a bit hit and miss” (AC02), “60% are well prepared, 40% don’t know what they are supposed to know” (AC02).

Discussion

The data gathered in this study using both quantitative and qualitative methods, provided an insight in to clinician’s knowledge of the NICE ADHD guidelines, the use and application of the guidelines, and the reasons why the recommendations for transition in the guidelines might not be implemented.

The responses gathered from both the surveillance survey and the interviews with child and adult clinicians, indicated that although clinicians were aware of the guidelines and had some limited knowledge of what the recommendations for transition were, the recommendations from the guidelines were often not translated in to practice (Mickan et al., 2011). The World Health Organisation refer to this as the “know-do gap” (WHO, 2006). Although the knowledge of practice guidelines or recommendations is important, it is rarely sufficient to change practice; guidelines are often not used after dissemination and only followed in approximately half of clinical decisions (NHS Centre for Reviews and Dissemination, 1999, Grol, 2001, Gill, 2001). Our findings demonstrate a particularly large “know-do gap” for transition in ADHD between guideline recommendations and practice. The clinicians that were interviewed agreed with the principles of the guidelines for ADHD, yet, many of the recommendations for optimal transition were not being implemented. Clinicians recognised that a poorly facilitated transition could have negative impacts on the young person, such as increased anxiety, low self-esteem, and ultimately drop out from services,

which has also been highlighted in previous studies (Department of Health, 2006, Young et al., 2011). A recent international study of transition has highlighted a lack of written protocols and transition support (Signorini et al., 2018), which suggests that our findings are likely to translate to all neurodevelopmental conditions, not just ADHD.

Some clinicians considered that their service simply did not have the capacity to follow the recommendations. The theme of 'unrealistic' guidance is not new, for example clinicians expressed similar doubts about the relevance and realism of the NICE guidelines for Schizophrenia in relation to workload, time pressures and a lack of specialist staff (Prytys et al., 2011).

Reasons for non-adherence discussed in our study often related to resources, with high caseloads and other time pressures making it difficult to arrange joint meetings or joint working across child and adult services. Previous studies on achieving continuity of care have also highlighted inadequate time and high caseloads (Belling et al., 2011) as a significant barrier. However, variation in implementation is also dependent on a complex web of factors that includes the local organisational context and the attitudes of clinicians (Spyridonidis and Calnan, 2011), factors also reported in our study. Clinicians noted that separate child and adult services affected their ability to implement the NICE guidance by making it more challenging to communicate with colleague and harmonise protocols. They also gave more subtle indications that attitudes towards adult ADHD still influenced clinical practice in transition, with some suggesting that ADHD was still viewed as an 'optional' or controversial diagnosis in the way that schizophrenia and depression are not. Whilst exploring attitudes to adult ADHD was not the focus of this study, comments made by participants echo the findings of Matheson et al's 2013 study, which reported negative and sceptical attitudes towards (adult) ADHD among health professionals (Matheson et al., 2013).

Our study highlights a number of reasons why NICE guidance for transition in ADHD might not be fully implemented, and suggest that implementation may not be a high priority in an environment of limited resource and competing demands that appear more immediate in terms of patient safety. Whilst regulations in England require commissioners to comply with recommendations in a NICE technology appraisal (e.g. for a new medication or procedure) (NICE, 2018b), NICE guidance itself is not mandatory, and the levers to drive implementation are

more complex. Furthermore, full implementation of NICE guidance on transition in ADHD relies not only on the practice of individual clinicians but on a whole system structure which facilitates elements such as joint working and information sharing, and on an even more basic level, on the existence of a suitable adult service for people with ADHD. Future research should therefore examine the views of service managers and commissioners on the challenges of implementing NICE guidance and their views on transition as a service priority.

Interestingly, although clinicians considered that current capacity and resource made the guidelines 'unrealistic', the Resource Impact Report produced by NICE states that "no significant costs were anticipated in implementation", and anticipated instead that benefits would accrue due to the avoidance of crisis presentation, and in the longer term, due to improved health and social care outcomes for young people (NICE, 2016a). There is indeed an evidence base to suggest that poorly managed transitions are costly (Singh, 2009, Lamb et al., 2008), but the fact that service change and investment may be required before the longer term benefits accrue, may contribute to a view amongst clinicians that resources are too limited to implement guidance.

Clinicians in this study generally supported the recommendations for transition, agreed with their rationale, and acknowledged the negative impact of a poor transition on the young person. This irreconcilable tension between the lower level of service that they feel able to deliver and their aspirations for patients could also have detrimental consequences for clinicians, such as burnout and exit from the profession (Maslach and Leiter, 2016, Kumar, 2007). It highlights the importance of engaging clinicians in the process of developing guidance, something that NICE already do, but could be further strengthened. It also raises the possibility of a 'graded' system (gold, standard, minimum) building on positive aspects that are feasible to deliver.

Conclusion

This study has demonstrated that clinicians involved in the transition process of young people with ADHD judged NICE guidelines to be unrealistic given the current service configurations and limited resources available. More work is required to close the gap between guideline recommendations and what is

feasible. With increasing demands on NHS services and staff, it is likely that the feasibility of full implementation of the guidelines for transition in ADHD will continue to be unachievable. It raises the question of the purpose of NICE guidelines; are we setting clinicians up to fail if the recommendations are far beyond what is possible in the realms of the current health service provision.

References

All references for this paper have been collated in one list for the thesis. The reference list can be found on page 275.

Appendix 5: Systematic review search strategy

List of search terms and strings:

1. Generic terms or synonyms to describe 'Attention Deficit Hyperactivity Disorder'

Attention Deficit*

Hyperactivity Disorder*

ADHD*

ADDH*

Hyperactiv*

Impulsiv*

Inattent*

Overactiv*

Restless*

Hyperkinetic Disorder*

Disruptive Behaviour Disorder*

Attention Deficit Disorder with Hyperactivity/ (MEDLINE)

exp attention deficit disorder/ (EMBASE)

exp attention deficit disorder with hyperactivity/ (psychINFO)

Attention Deficit Disorder with Hyperactivity (SPP)

exp Hyperactivity/ (HMIC)

2. Generic terms or synonyms for 'Protocol' or 'Guideline'

(Protocol* adj5 (patient or care or health or service or ADHD or transition))

(Guideline* adj5 (patient or care or health or service or ADHD or transition))

(Contract* adj5 (patient or care or health or service or ADHD or transition))

(Practice* adj5 (patient or care or health or service or ADHD or transition))

(Procedure* adj5 (patient or care or health or service or ADHD or transition))

(Agreement* adj5 (patient or care or health or service or ADHD or transition))

(Recommend* adj5 (patient or care or health or service or ADHD or transition))

(Statement* adj5 (patient or care or health or service or ADHD or transition))

3. *Generic terms or synonyms to describe 'Transition'*

exp "Continuity of Patient Care"/ (MEDLINE)

transition to adult care/ (EMBASE)

exp "continuum of care"/ (psychINFO)

Continuity of Patient Care (SPP)

exp "Continuity of patient care"/ (HMIC)

Changeover*

Handover*

CAMHS to AMHS*

Continuity of Care*

(Transfer* adj5 (patient or care or pathway or health or service))

(Pathway* adj5 (patient or care or health or service or ADHD or transition))

(Transit* adj5 (patient or care or health or service or ADHD))

(Referral* adj3 (patient or adult or care or health or service or ADHD))

(Passage* adj5 (patient or care or health or service or ADHD or transition))

**Appendix 6:
List of professional and charity organisations included in systematic
review search**

Professional and charity organisations included in searches:

- Professional Societies
 - Royal College of Psychiatrists
 - Royal College of Paediatrics and Child Health
 - Royal College of General Practitioners
 - Royal Society of Medicine
 - Royal Society for Public Health
 - Royal College of Physicians
 - Royal College of Nursing

- Charities
 - Cerebra
 - Mind
 - Young Minds
 - Transition Programme - Newcastle University
 - South East Strategic Clinical Network
 - National Development Team for Inclusion (NDTi)
 - Council for Disabled Children
 - Young People's Health Special Interest Group
 - Contact a Family
 - Social Care Institute for Excellence
 - National Mental Health Development Unit (organisation closed in 2011)
 - Preparing for Adulthood
 - SEND
 - Transition Information Network
 - National Service Framework for Children, Young People and Maternity Services
 - Care Quality Commission

**Appendix 7:
Spreadsheet used for comparing/contrasting guidelines in systematic review**

					List of Protocols / Guidelines
				Name / Title	<u>Before/</u>During transition
				Source / Author	
				Reason for transition	
				Referral age?	
				Upper Age Boundary (complete by...)	
				Planned in advance / Transition planning meeting by CAMHS?	
				Planned in advance / Transition planning meeting by AMHS?	
				Use of CPA?	
				Formal joint/handover meeting?	
				Staff involved?	
				Lead Clinician?	
				Patient / family involvement?	
				Information sharing between services?	
				Information provided to YP about adult service	
				AMHS assessment of patient needs	<u>After transition</u>
				Timescale?	<u>Other details...</u>
				Medication?	
				Psychological Therapies?	
				Specialist Transition Clinic?	
				Review time? E.g. 6/12m	
				GP shared care?	
				Other	

**Appendix 8:
Surveillance study – baseline notification questionnaire**



BPSU No.

**Case notification form Questionnaire –
Strictly Confidential**

CATCh-uS (Children with ADHD in transition between children’s and adult services)

The first page of the case notification form will be stored separately from the rest of the questionnaire and personal identifying information for the case (young person) will be used only for linkage of records.

Reporting Instructions:

Please report any young person with ADHD taking medication for ADHD seen by you for the first time in the six months preceding the young person reaching your service’s age boundary. Please report any case even if you believe the case may have been reported from elsewhere.

Case Definition:

Section A: Reporter Details

- 1.1 Date of completion of questionnaire:
- 1.2 Consultant or specialist responsible for case: _____
- 1.3 Name of clinic and Trust/Provider: _____
- 1.4 Telephone number: _____ Email: _____

Section B: Case Details

- 2.1 NHS/CHI No:
- 2.2 Hospital No:
- 2.3 First half of postcode only Town of Birth (if ROI) _____
- 2.4 Sex: M F Age of case (Years/months) _____
- 2.5 Ethnicity*: Specify if any "Other" background: _____

**Please choose the correct ethnicity code from Appendix A overleaf*

Appendix A**Appendix A: Coding for Ethnic Group (ONS 2011 for UK wide data collection)**

	Ethnicity Code		Ethnicity Code
A White			
English / Welsh / Scottish / Northern Irish / British	1	D Black / African / Caribbean / Black British	
Irish	2	African	14
Gypsy or Irish Traveller	3	Caribbean	15
Any other White background, please describe	4	Any other Black / African / Caribbean background, please describe	16
B Mixed/ Multiple Ethnic Groups			
White and Black Caribbean	5	E Other ethnic group	
White and Black African	6	Arab	17
White and Asian	7	Any other ethnic group, please describe	18
Any other Mixed / Multiple ethnic background, please describe	8		
C Asian / Asian British			
Indian	9		
Pakistani	10		
Bangladeshi	11		
Chinese	12		
Any other Asian background, please describe	13		

Section C: Eligibility of case

3.1 Does the young person meet the following criteria for this study?

	Yes	No
1. Does the young person have a clinical diagnosis of ADHD?	<input type="checkbox"/>	<input type="checkbox"/>
2. Is the young person currently receiving drug treatment for their ADHD?	<input type="checkbox"/>	<input type="checkbox"/>
3. Does this case require continuation of their drug treatment <u>for their ADHD</u> after transition from your service (i.e. in adult services)? <i>Note: please ONLY tick 'yes' if this drug treatment is required for their ADHD rather than any existing comorbid diagnosis.</i>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is this case within six months of the age boundary for your service? – i.e. in ideal circumstances, within six months of transition?	<input type="checkbox"/>	<input type="checkbox"/>
5. Is this the first time this case is being reported to this study by your service? <i>Note: Please only report a case once - those who have already been seen and reported by you in this time-scale should not be reported a second time.</i>	<input type="checkbox"/>	<input type="checkbox"/>

3.2 Does this case meet all of the five criteria (yes to all questions) Yes No

- If so, please continue with the questionnaire.
- If not, thank you again for your time. There are no further questions to answer; please proceed on page 6 of this questionnaire.

Section D: Comorbidities and medication

4.1 Aside from their clinical diagnosis of ADHD, does this case have any other mental health or developmental diagnoses?

Yes No Not known to me

Please list any other diagnoses below:

<input type="checkbox"/> Autism spectrum condition	<input type="checkbox"/> Dyspraxia
<input type="checkbox"/> Chronic Tic disorder / Tourette's	<input type="checkbox"/> Problematic substance abuse
<input type="checkbox"/> ODD / Conduct disorder	<input type="checkbox"/> Other? Please specify:
<input type="checkbox"/> Anxiety disorder

4.2 Please list below the medication which the young person is currently prescribed for any mental health / developmental conditions and the indication. Please also indicate whether you consider that this medication requires continuation beyond the age boundary for your service.

Medication and indication	Requires continuation		
	Yes	No	Don't know
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section E: Referral of the case

5.1 What is the age boundary for your service?

__ years __ months

5.2 What is the current status of this case regarding reaching the age boundary of your service?

I last saw the young person __/__/____

Has the young person already reached the age boundary for your service? Yes No

Do you have another appointment with the young person? Yes No

Are you still responsible for the young person? Yes No

5.3 Have you started the transition process yet?

Yes – Please continue this questionnaire.

No – Please go to page 6 of the questionnaire.

5.4 What is the intended destination for this young person following transfer from your service, for the management of their ADHD? Please provide name and or contact details of the service.

Specialist Adult ADHD service: _____

Other Adult Mental Health Service: _____

Primary care / GP: _____

No specific arrangements are made

Other. Please give details or any other comments below:

Section F: The transition protocols and procedures

6.1 Does your organisation have a transition protocol?

Yes No

6.2 Are you using it to plan the transition for this case?

Yes No

Section G: Facts regarding the transition of the case

7.1 Key stages in the transition process: which of the following steps have you undertaken? Please give an indication of time if you have engaged in this element of the transition process (DD/MM/YYYY).

When did you first discuss a transfer to an adult service with your case?

Date: _____ Not yet Not known to me

When did you first refer the young person to an adult service?

Date: _____ Not yet Not known to me

How many services did you approach to find a match for your case?

Just one More than one: _____

If a referral was made, was the referral accepted?

Yes, Date: _____ No I am awaiting a response

7.2 Partners involved: State which of the following partners are involved in the transition process:

	Yes	No	Not known
Young person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care co-ordinator from adult team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care co-ordinator from child team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other? Please specify: _____			

7.3 Which of the following elements of the transition process have been initiated:

	Yes	No	Not known
Information sharing between services (case notes or summaries)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Young person's involvement in decision making	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organising a transition planning meeting (involving the young person and carer, and key professionals of both services)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Planning and agreeing on a care plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A period of handover or parallel/joint care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other elements you want to add:

Section H: Request to take part in follow-up

- 8.1 We wish to interview a sample of clinicians about their general experiences of managing transition, using a semi-structured telephone interview that will take approximately 30 minutes. Would you be willing to be contacted regarding taking part in such an interview? (This does not constitute any obligation to take part). We will not be discussing individual cases.

Yes

No

Thank you for taking the time to complete the questionnaire

Please print and return the completed form in the SAE to:

Prof Dr Tamsin Ford
Care of Research & Development Team (Liaison Corridor)
Devon Partnership NHS Trust - Wonford House
Dryden Road
Exeter EX2 5AF

If you have any questions about the study please do not hesitate to contact the investigators by email or telephone : Prof Tamsin Ford

Telephone: +44 (0) 1392 722973

Email: tj.ford@exeter.ac.uk

Ethical approval

This study has been approved by NRES South Yorkshire Ethics Committee – Yorkshire & The Humber (REC Reference: 15/YH/0426) and has been granted **Section 251 HRA-CAG permission (CAG Reference: 15/CAG/0184)**.

Appendix 9:
Surveillance study – follow up questionnaire



BPSU No.

Follow-up Questionnaire –
Strictly Confidential

CATCh-uS (Children with ADHD in transition between children’s and adult services)

The first page of the case notification form will be stored separately from the rest of the questionnaire and personal identifying information for the case will be used only for linkage of records.

Reporting Instructions:

This questionnaire has been sent to you as you have identified a case 9 months ago. You reported a young person with ADHD taking medication for their ADHD seen by you six months before the young person reached your service’s age boundary. Please could you answer the following question regarding this patient?

Ethical approval:

This study has been approved by NRES South Yorkshire Ethics Committee – Yorkshire & The Humber (REC Reference: 15/YH/0426) and has been granted Section 251 HRA-CAG permission (CAG Reference: 15/CAG/0184).

Case Definition:

Section A: Reporter Details

- 1.1 Date of completion of questionnaire:
- 1.2 Consultant responsible for case: _____
- 1.3 Name of clinic and Trust/Provider: _____
- 1.4 Telephone number: _____ Email: _____

Section B: Case Details

- 2.1 NHS/CHI No:
- 2.2 Hospital No:

Note: Abbreviation used: YP – Young person

BPSU No.

Thank you for taking the time to complete the questionnaire

Please print and return the completed form in the SAE to:

Dr Tamsin Ford
Care of Research & Development Team (Liaison Corridor)
Devon Partnership NHS Trust - Wonford House
Dryden Road
Exeter EX2 5AF

If you have any questions about the study please do not hesitate to contact Prof Tamsin Ford by email or telephone :

Telephone: +44 (0) 1392 722973

Email: tj.ford@exeter.ac.uk

Section C: Eligibility of case

3.1 ADHD medication

At the time of transfer was the YP prescribed medication for their ADHD?

- Yes
- | | |
|---|--|
| <input type="checkbox"/> Methylphenidate | <input type="checkbox"/> Dexamfetamine |
| <input type="checkbox"/> Atomoxetine | <input type="checkbox"/> Clonidine |
| <input type="checkbox"/> Lisdexamphetamine | <input type="checkbox"/> Atypical Antipsychotics |
| <input type="checkbox"/> Other, Please specify: | |
- No

Section D: Destination of case

4.1 When did you last see the young person?

Date: __/__/____

4.2 Where was the young person referred to for the management of their ADHD?

Please give name and contact details (telephone or email).

- Specialist Adult ADHD service:
- Other Adult Mental Health Service:
- Primary care / GP:
- No specific arrangements were made
- Other: please state here:

4.3 Has the referral been accepted?

- Yes Date: __/__/____
- No Please go to section F.
- I don't know

Section E: Facts regarding the transition of the case

5.1 Have you received any feedback from the service to which you referred the YP?

- Yes - Please continue with the questionnaire No – Skip Q. 5.2

5.2 Response from the service to which you referred the YP:

- | | Yes | No | I don't know |
|--|--------------------------|--------------------------|--------------------------|
| Did the young person receive an appointment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Did the young person attend the appointment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Section F*: Facts regarding a refused referral

* Only for cases that did not get accepted at the service to which you referred the YP.

6.1 Have you received any feedback from the service to which you referred the YP as to why the YP was not accepted? If so, please specify.

Yes: No

.....

6.2 Do you know whether the young person currently receives care for their ADHD elsewhere? If so, could you please give the name of the service/treating clinician?

Yes: No I don't know

.....

Section G: Elements of optimal transition

7.1 In your opinion/experience, were the following elements or processes present in the transition of this young person from your service?

	Yes	To some extent	No	Not known
User/carer involvement in decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information sharing between services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has a care plan been agreed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Joint working preceding transfer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alignment of assessment procedures between services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continuity of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consistency of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consideration of most appropriate service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clarity of funding arrangements and/or eligibility for adult services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7.2 Please add any other comments you have regarding whether transition was optimal in this case:

Appendix 10: Interview topic guide with professionals from child services

Topic guide 4: Professionals from children's services

Brief overview of your role in relation to ADHD

1. Transition from children's services to adult services

- I. What is the age boundary of your service?
- II. What are your views and experiences of the transition of young people with ADHD?
- III. What are your thoughts about the
 - NICE guidelines,
 - Use of CPA, Care programme approach and CPA care coordinator?
 - any transition protocol or policy

In case the professional needs probing, please use appendix 1 for this question.

2. Pre-transition drop-out

- Of those YP that drop-out (stop treatment or medication against your advice), do you know why they stop/drop-out?
- Do you feel *you* have been able to help the young person to make a sensible decision about "what to do after this service/care stops"? If so, how? What do you tell them?

3. The transition process

MAIN QUESTION:

- a) Who do you refer to? What services do you refer young people to within AMHS (is this a general policy within your service)? E.g. Generic adult CMHT, Generic adult CMHT with specialist ADHD service, Specialist Adult ADHD service, Other
- b) Are GPs in your area able to prescribe ADHD medication?
- c) If a YP misses appointments, are they discharged if they still have a need for ongoing support? What happens if a YP chooses not to use medication but still wants to be in touch with services? Is it possible to keep them 'in service'? How does this work?
- d) If the YP doesn't need ongoing medication do you still refer back to the GP anyway?
- e) If a YP doesn't want/need medication can they still have a service?

f) Transition planning and user/carer involvement

- Who is usually involved in the transition process? Probing questions: Is there any involvement from non-health services, e.g. education, social services, GP? To what extent are the young person and their family involved in transition planning and transition meetings?
- Who would you want to be involved?

4. Difficult transitions

- a) Have you encountered cases where transition has been particularly difficult?
- If yes, what have been the issues?
 - What steps were taken to resolve the difficulties?
- b) In your experience, does transition vary by diagnosis? If yes,
- Are there conditions that have positive transition process; and are there aspects that could be translated to the transition process for YP with ADHD?
 - Does it make a difference if there are comorbidities involved?
- c) Where the decision is made not to transfer into adult services,
- a. What are the most common reasons for this?
 - b. Do you discuss what other options are, or what to do when they want to re-enter services?

5. Optimal transition

How do they think the quality of transition / rate of good transfers of your patients with ADHD could be improved – in an ideal world and in the real world?

Appendix 1:

Does your service have a transition protocol?

If there is a transition protocol:

- a. Do you use it? Why (not)?
- b. If so, is this protocol in accordance with the Care Programme Approach (CPA)?
 - i. If so, do you appoint a care coordinator (who makes sure the NHS Trust Transition protocol is followed)?
- c. Is there one specifically for ADHD?
- d. Does it cover:
 - Risk
 - Responsibility

- Procedures
- Prescribing arrangements
- e. Do you share it with your colleagues from adult services?
 - Do you think colleagues in adult mental health services are aware of the protocol?
- f. Have you found the protocol to be helpful in your practice?
 - If yes, could you expand on how it has been helpful?
 - If no, what difficulties or problems have you encountered?

If you don't have a protocol or do not use it, how do you plan the transition process?

- a. At what age do you begin planning for transition?
- b. Do you have a transition worker or transition team?
 - If yes, what is their role and responsibility

Appendix 11: Interview topic guide with professionals from adult services

Topic guide 5: Professionals from adult services

1. Your service

- b) What adult service do you work in? (e.g. generic CMHT, specialist ADHD team, other)
 - If not specialist ADHD – do you have staff with an interest or expertise in ADHD within your team?
- c) What is the age boundary of your service?
- d) Does this age range vary for different diagnoses?

2. Referral into your service

- g) Who refers young adults with ADHD to your service? (children's services & other)
- h) How are these referrals dealt with?
- i) Transition planning
 - Are you aware of a protocol for transition, either within your service or children's services?
If so, do you refer to it and it is helpful? - If not, why might that be?
 - Do you usually receive appropriate information in the referral letter/documentation?
If not, what are the timeframes in which appropriate information is passed over to you?
- j) User/carer involvement:
 - Who is usually involved in the transition process?
Probing questions: Is there any involvement from non-health services, e.g. education, social services, GP? To what extent are the young person and their family involved in transition planning and transition meetings?
 - Who would you want to be involved?
 - Where referrals are not accepted, what are the most common reasons for this? Do you offer an alternative?

3. General experiences with the transition process

- a) What barriers have you experienced in working with children services? - Does it make a difference if your services are within the same organisation/Trust?

- b) What barriers have you experienced with referrals from elsewhere (young adults re-entering the system after they dropped-out of services at a younger age).

4. After transfer

- a) In your experience, how well prepared are young people for transfer into adult services?
 - If not well prepared, what could be improved?
- b) In your experience, how well prepared are young people's families for their transfer into adult services?
 - How could this be improved?
- b) How confident do you and your own colleagues feel in engaging young people who might find the transition difficult?
 - How could this be improved?
- c) When the young person is seen in your service, do you have access to the relevant notes from child services?

5. Optimal transition

- a) Do you feel that your service is able to meet the needs of young people in transition?
- b) Are there any specific changes that you think would make a difference?
- c) What would optimal transition look like from your perspective?

**Appendix 12:
Participant information sheet and consent form for qualitative study**



**INFORMATION SHEET AND CONSENT FORM
FOR PARTICIPANTS IN INTERVIEW**

**Practitioner working with young person with Attention Deficit
Hyperactivity Disorder (ADHD)**

VERSION NUMBER [1]: DATE [26/08/2015]



**Children and adolescents with ADHD in transition from
children's services to adult services**

Thank you for taking the time to learn about this project that focuses on what happens to young people with Attention Deficit Hyperactivity Disorder (ADHD) when they are too old for children's services. Please read this information sheet carefully before deciding whether or not to participate. It contains information about why this study is important and what we hope to show by doing it. It also provides contact details of the researchers.

What is this project about?

We know little about what happens or should happen to young people with ADHD once they transfer to adult services. Also, which UK areas have specialist services for young adults with ADHD? In this study we will examine how many young people are in need of services for ADHD as adults. We also want to explore how current service users and service providers experience this transition.

The project has three strands:

1. Identify how many young people with ADHD who are on medication need to transfer to adult services; to describe this population across the UK and the Republic of Ireland.

2. Interview young people with ADHD, their parents and professionals working with them, to explore their experiences with services and transition between services.
3. Map the services that are currently available for young adults with ADHD and describe what they provide.

The second strand of this research helps us identify factors influencing service use and factors leading to a successful transition. The findings of this study will have the potential to inform policy and practice.

Who do we want to talk to?

We want to hear from all people involved in the transition process, including practitioners working with young people/adults with ADHD. If you have referred young people with ADHD to adult services to continue their treatment for ADHD, or have been referred young adults with ADHD, you are the practitioner we would like to talk to you.

What will you be asked to do?

If you agree to take part in the study we will contact you by mail or phone to set a date for an interview. The interview will take place over the phone, at a time suitable to you. During the interview a researcher will ask you questions about your experiences with services your child uses to manage their ADHD.

Patient confidentiality

We will not talk about individual cases. We will ask you about practicalities related to the transition process (age-boundary of the service, existence and use of transition protocol), pre-transition drop-out, key elements of (optimal) transition and personal experiences with good and difficult transition.

Time commitment

The interview will take approximately 30 minutes.

Can you change your mind and withdraw from the project?

You may withdraw from the project at any time without any disadvantage to yourself or your patients. **Also, you can decide to stop the interview at any time.**

How will data or information be collected and what use will be made of it?

The interview will be recorded. The audio-tapes will be kept in a secure storage during the length of the study and will be destroyed once the study is finished. You can ask the researcher not to record the interview, and take notes instead during the interview.

Your name will never be mentioned, not when we write out the interview, or when we write up the results of the study.

NOTE: We have a list of topics that we want to talk to you about, but we don't have precise questions. As a consequence, the questions will depend on the way in which the interview develops. Therefore, the Ethics Committee has not been able to review the questions as they are asked during the interview.

In case you feel hesitant or uncomfortable about a question, you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.

What happens at the end of the study

The findings of this study will be captured in a report, commissioned by the National Institute for Health Research (NIHR). We will also communicate our findings to NHS service providers (clinicians, pediatricians, psychiatrists) and commissioners at various levels, so they gain insight in the transition process of young people with ADHD.

We plan to write up guidelines for parents and young people to help them on their journey to adult services, to facilitate the transition process. We will inform professionals about our findings, so they can learn from your experiences.

What if you have any questions?

If you have any questions about our project, either now or in the future, please contact Astrid Janssens at the University of Exeter Medical School. Call: 01392726002 or Email: a.janssens@exeter.ac.uk

Complaints

If you have any complaints please contact the Chair of the University of Exeter Medical School Research Ethics Committee:

Peta Foxall, PhD

Email: P.J.D.Foxall@exeter.ac.uk

This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee - UEMS REC REFERENCE NUMBER:

CATCh-uS

Children and adolescents with ADHD in transition from children's services to adult services

CONSENT FORM FOR PRACTITIONER - VERSION NUMBER [1] [26/08/2015] Copy Practitioner

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1.	my participation in the project is entirely voluntary;	Y/N
2.	I am free to withdraw from the project at any time without any disadvantage;	Y/N
3.	that the audio-tapes will be retained in secure storage while in use and will be destroyed once the study is finished.	Y/N
4.	the interview uses open-questionings and therefore the precise nature of the questions is not known in advance. I know that I can decline to answer any particular question and or stop the interview at any time.	Y/N
6.	that I can claim travel costs, and have received documentation what costs I can claim and how to do so.	Y/N
7.	that the results of the project may be published but my anonymity will be preserved.	Y/N

I agree to take part in this project.

Printed name of participant

Date and Signature of participant

Printed name of researcher

Date and Signature of researcher

This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee / UEMS REC REFERENCE NUMBER: (TO BE INSERTED ONCE ETHICAL APPROVAL HAS BEEN GRANTED)

CATCh-uS

Children and adolescents with ADHD in transition from children’s services to adult services

**CONSENT FORM FOR PRACTITIONER - VERSION NUMBER [1] [26/08/2015]
Copy Researcher**

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1.	my participation in the project is entirely voluntary;	Y/N
2.	I am free to withdraw from the project at any time without any disadvantage;	Y/N
3.	that the audio-tapes will be retained in secure storage while in use and will be destroyed once the study is finished.	Y/N
4.	the interview uses open-questionings and therefore the precise nature of the questions is not known in advance. I know that I can decline to answer any particular question and or stop the interview at any time.	Y/N
6.	that I can claim travel costs, and have received documentation what costs I can claim and how to do so.	Y/N
7.	that the results of the project may be published but my anonymity will be preserved.	Y/N

I agree to take part in this project.

Printed name of participant

Date and Signature of participant

Printed name of researcher

Date and Signature of researcher

This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee / UEMS REC REFERENCE NUMBER: (TO BE INSERTED ONCE ETHICAL APPROVAL HAS BEEN GRANTED)

**Appendix 13:
Coding tree used in qualitative Framework analysis**

CHILD CLINICIAN CODING TREE	
Header	Node
ADHD	Assessment Diagnosis Life outcomes / expectations of YP Long term condition Presentation Validity / Controversy of ADHD
Case Study Example	Case study examples
Education	College or University Primary – Secondary Transition School Nurse - Liaison Work
Patient Characteristics	Anxiety ASD Child Protection Co-morbidities Complex Needs Conduct Problems Criminal Justice Contact Learning Difficulties Looked after Children Non- severe SES YP - Moving out of area
Policy Guidelines	NICE guidelines Pathways Tension – between guidance and practice Trust Guidance Use of CPA - criteria
Role & responsibilities	Discussion YP – ADHD Discussion YP - Chronicity of ADHD Discussion YP - transition Information on services – lack of knowledge of clinicians Job Role of Clinician Signposting – at drop out Signposting – at transition Signposting – leaving service
Service Delivery	Specialist Nurses – role and responsibilities Funding for Clinician Funding for service Locality Model - structure

<p>Service Practice</p>	<p>Need for adult services No adult services available Non-joined up Resources Service for adolescence or young adults Age Boundary AMHS threshold criteria Assess needs post 18 CAMHS - AMHS Capacity& Case Load - of services Data monitoring Duplicate referrals Primary Care Shared care</p>
<p>Transition</p>	<p>Joint Handover Referral Transition – as a process Transition – best practice / ideal / future Transition - protocol Transition - reality Transition service or team</p>
<p>Treatment & Management</p>	<p>6 monthly review Alternative managing strategies of YP Career advice Clinician relationship with YP Continuing Medication Crisis management Drop out Family Involvement – role of parent Medical Reviews Medication Side Effects No Meds = Back to GP No Meds = Discharge Non NHS - Other support for YP 18+ Non NHS - Parent groups Non NHS - Voluntary services / agencies Re-accessing services Reducing Meds as process Who makes Medication Decision Who Prescribes?</p>
<p>Who Prescribes?</p>	<p>Can the GP prescribe or does it have to be from Psych/Paed?</p>

ADULT CLINICIAN CODING TREE

Header	Nodes
AMH Service	Accessibility Capacity / Caseload Characteristics Funding / commissioning Shared Care
CAMHS / Paeds	
Clinician	ADHD training Job role / background
Patient	Comorbidities Engagement Knowledge of ADHD New diagnosis as adult Parent/ family involvement Re-entry to services as adult
Referrals	Consent GP referral Other referral Process / pathway
Transition	Barriers / facilitators to transition Experience of transition by clinician / YP Gaps between services Information sharing / handover Others involved in transition Patient knowledge prior to transition Protocol / guidelines
Treatment	Recommendations Alternative treatments Assessments Medication prescriptions Medication reviews
	Patient input Stopping treatment

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