

Health service transitions for young people with attention deficit  
hyperactivity disorder (ADHD): investigating information provision  
and United Kingdom adult ADHD service availability

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## Abstract

Within this thesis I explored transition between child and adult services for young people with attention deficit hyperactivity disorder (ADHD); focussing on the role of information provision, and mapping current availability of and geographic variations in United Kingdom (UK) services for adults with ADHD.

A systematic review of stakeholder transition experiences was conducted, providing an overview of current literature. Qualitative interviews were conducted with young people (n=64) and parents/carers (n=28), to explore the role of information through transition. A national survey was piloted and then run to map UK health services for adults with ADHD. Finally, an analysis of regional differences in prescribing of ADHD medication and referrals to adult mental health services (AMHS) was conducted, using primary care records from the Clinical Practice Research Datalink (CPRD) database.

The systematic review identified negative transition experiences related to *limitations of adult mental health services, inadequate care*, and a need for better information. Three themes emerged from the qualitative study: *navigating information with help from parent/carer; information on ADHD into adulthood*; and *information about the transition process*, providing insight into how communication may affect transition. The UK mapping study had 2686 responses from commissioners, health workers and service users and identified 294 National Health Service (NHS), voluntary and private services. Of 44 dedicated NHS adult ADHD services, 27% provided all treatments recommended by National Institute for Health and Care Excellence. Analysis of CPRD data revealed significant regional differences in primary care prescribing of ADHD medication through the transition period as well as in referral rates to AMHS.

Findings highlight an urgent need to improve information provision and provide accessible adult ADHD services across the UK, to support transition for young people with ADHD and reduce health inequalities. Services need to recognise the crucial role of *parents/carers as information navigators*, and the importance of young people understanding about *ADHD into adulthood* and being informed about *transition processes*. Strategies are needed to reduce negative emotional experiences associated with this information vacuum. The limited number of

dedicated NHS adult ADHD services appears to represent a significant barrier to transition, however clarity is needed on optimum service configurations and the role of primary care.

## **Acknowledgements**

I would like to thank all my supervisors for their support and mentorship over the past three years. Dr Astrid Janssens has helped me to frame my curiosity into appropriate questions and invested hundreds of hours into supporting me as I have learned skills and developed my knowledge. Professor Tamsin Ford has shared the benefit of her experience and expertise and helped me to hold a steady course throughout the PhD. Dr Andrew James Williams has stepped in with statistical help, and provided a fresh perspective when needed.

I would like to thank my family and friends for their support, as well as the colleagues who have been available to share personal and professional insights and to offer friendly advice when needed. I would also like to thank Dr Rachel Hayes and Dr Tamsin Newlove-Delgado who have been amazing informal mentors and supervisors.

Finally, I would like to dedicate this thesis to the many people who contributed to this research. This includes the people with ADHD, their parents and carers, and the clinicians who shared their experiences of the transition process with me. Also all those who took the time to complete the mapping surveys. I have been humbled and moved by the stories shared, and am deeply grateful for high levels of engagement from our research partners. It is my sincere wish that these findings will contribute towards helping provide a better experience of health service transition for young people with ADHD in future.



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## **Author's declaration**

This PhD has been conducted alongside a larger collaborative National Institute for 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.

*Ethics approval and consent to participate:* Health Research Authority (HRA) approval – HRA-IRAS reference 159209. University of Exeter Medical School Ethics Committee (REC Application Number: 15/07/070)

I will outline below the parts of the CATCh-uS project as originally planned that have been included in this thesis, and outline my individual contribution to the work. All other parts of the thesis are my own work and were not part of the CATCh-uS study protocol.

*Qualitative study (chapter three):*

The qualitative study was developed as part of the CATCh-uS protocol, which included interviews with clinicians, young people and parents. I jointly led recruitment for the interviews, and conducted 43 of the 92 interviews completed with young people and parents. I was part of a team of researchers that analysed and summarised the interview data. For the purposes of this thesis I have only used data that have been collected in the interviews with young people and parents. This resulted in the paper presented in chapter three, which focuses on interview data that are specifically related to the role of information provision in young people's experiences of transition into services for adult ADHD. I have led the data analysis and write up for this paper and liaised with co-authors for contributions.

*Mapping study (chapter four):*

The mapping study was planned as presented in the CATCh-uS protocol, although piloting and developing the novel mapping methodology was led by myself and considerably extended the initial brief from NIHR. I conducted and managed the mapping independently from the beginning of the study, including the pilot and definitive study, data collection and management, and I have led the data analysis and write up. The chapter on the mapping study in this thesis is in two parts:

- Part one consists of a research paper which is a full write up of lessons learned when developing the novel mapping methodology. This was not part of the CATCh-uS protocol and was entirely developed and conducted by myself for the thesis. I have led the data collection, data analysis and write up for this paper and liaised with co-authors for contributions.
- Part two consists of a full write up of the mapping study, part of which forms the basis 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.

## Definitions and abbreviations

AADD-UK	A United Kingdom charity for and by adults with ADHD
ACAMH	Association for Child and Adolescent Mental Health
ADHD	Attention Deficit Hyperactivity Disorder (also known as Attention-Deficit/Hyperactivity Disorder)
AMHS	Adult Mental Health Services
ASD	Autism Spectrum Disorder
BACCH	British Association for Community Child Health
BMC	BioMed Central
CAMHS	Child and Adolescent Mental Health Services
CATCh-uS	Children and Adolescents with ADHD in Transition between Child and Adult Services
CCG	Clinical Commissioning Group
CMHT	Community Mental Health Team
CPRD	Clinical Practice Research Datalink
CRN	Clinical Research Network
FOI	Freedom of Information
GP	General Practitioner
HRA	Health Research Authority
HS&DR	Health Services and Delivery Research
IRAS	Integrated Research Application System
LD	Learning Disability
MeSH	Medical Subject Heading
MHCN	Mental Health Commissioners Network
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NRES	National Research Ethics Service
PenCLAHRC	Collaboration for Leadership in Applied Health Research and Care South West Peninsula

PhD	Doctor of Philosophy
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QGIS	Open-source Desktop Geographic Information System
RCGPs	Royal College of General Practitioners
RCPCH	Royal College of Paediatrics and Child Health
RCPsych	Royal College of Psychiatrists
REC	Research Ethics Committee
UEMS	University of Exeter Medical School
UK	United Kingdom
UK-AAN	UK Adult ADHD Network
WHO	World Health Organization

## **Chapter one: introduction and overview of thesis**

### **1.1 Introduction**

Due to the organisation of mental health services, young people with long term conditions, such as attention deficit hyperactivity disorder (ADHD), have to transition from child and adolescent to adult services if their difficulties persist (Signorini et al., 2017, Singh et al., 2010b). This change takes place during the developmental challenges of adolescence, a critical time of life when young people become independent, develop social skills and learn behaviours likely to last the rest of their lives (Fuhrmann et al., 2015, World Health Organization, 2014). During adolescence, defined by the World Health Organization (WHO) as occurring between the ages of 10 and 19, young people face a range of health risks including substance abuse, road traffic accidents and increased risks of developing mental health difficulties (Collishaw et al., 2004, World Health Organization, 2014).

Transitional healthcare is defined as the purposeful and planned movement of adolescents with long term conditions from child to adult health care systems (Blum et al., 1993) and should be distinguished from transfer, since it is more than an administrative event (Paul et al., 2013). However, for the purposes of this thesis, the term transition is broadly defined to include instances of 'transition in practice', to enable an exploration of instances transition, transfer between services, referrals to a General Practitioner (GP), and ceasing to access health services (Paul et al., 2015).

Evidence shows that the structural break between child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) poses particular challenges for young people with long term conditions, including loss of contact with healthcare, and increased use of crisis care, which is associated with poor outcomes (Paul et al., 2015, Singh and Tuomainen, 2015). Identified weaknesses in the management of transition include poor transfer of information between services, failure to include parents in the process, and difficulties finding

age-appropriate and accessible services (Singh et al., 2010a). Studies have highlighted that young people with neurodevelopmental disorders, such as ADHD are particularly likely to experience difficulties in transition (Montano and Young, 2012, Singh et al., 2010a, Singh and Tuomainen, 2015).

To date there has not been an in-depth study on transition in ADHD that explores the role of information provision, or maps the current availability of, and geographic variations in, United Kingdom (UK) services for adults with ADHD. Using a multi-method approach I aimed to do the following:

- provide an overview of current research evidence relating to experiences of transition between child and adult health services for young people with ADHD, in order to understand the impact on wellbeing of existing service configurations
- explore ways in which a better understanding of the role of information in transition could help reduce distress and suffering of young people with ADHD, their families and communities as they approach adulthood
- provide national information about adult ADHD services from the perspectives of service users, health workers and commissioners to inform service development and to educate stakeholders about what is available
- explore differences in reports of adult ADHD service provision between stakeholder groups, to highlight potential inequities in knowledge of services and potential links to inequity in access to care
- analyse evidence of regional variations in provision of care by geographic region, using prescription records and referral rates as a proxy indicator

With the overarching aim of enhancing wellbeing and reducing suffering by facilitating optimum care for young people with ADHD into adulthood.

This chapter will introduce and provide a brief background to the condition of ADHD, and issues around transition, with a focus on the role of information provision and availability of adult services. It will then present the overall research objectives and provide an overview of each chapter and study presented in the thesis.

## **1.2 Background and rationale for study**

### **1.2.1 ADHD**

ADHD is a common neurodevelopmental disorder characterised by developmentally inappropriate levels of inattention, hyperactivity and impulsivity that interfere with functioning across a range of social, academic and/or occupational settings (American Psychiatric Association, 2013). With an estimated worldwide prevalence of 3-5% (Faraone et al., 2015, Polanczyk et al., 2007, 2014), ADHD is one of the mental health disorders most likely to be managed by paediatric and child mental health services (Ford et al., 2007). Although historically viewed as a childhood disorder, for several decades it has been recognised that ADHD can be a lifelong condition, with evidence that 15% of children with ADHD will retain full diagnostic criteria at age 25, while 65% continue to struggle with associated symptoms even though they may no longer meet full formal criteria (Faraone et al., 2006). A recent systematic review found persistence rates into adulthood of 40-50% if age appropriate diagnostic symptom thresholds were applied (Sibley et al., 2016). Despite evidence of considerable impairment among adults, several studies demonstrate that treatment of ADHD drops at a higher than expected rate among teenagers and young adults with ADHD (Johansen et al., 2015, Newlove-Delgado et al., 2018a, Wong et al., 2009, Zetterqvist et al., 2013). There is also qualitative evidence of similarly premature cessation of treatment for young people with ADHD as they transition into adulthood (Swift et al., 2013, Young et al., 2011).

Young people with ADHD represent a vulnerable population at risk of a range of negative health, social, occupation and educational outcomes, which are likely to be worse if untreated (Faraone and Glatt, 2010, Shaw et al., 2012). People with ADHD are overrepresented in the prison population, with an estimated prevalence using diagnostic interview data of 25%, and are at high risk of substance abuse (Molina et al., 2018, Young et al., 2015). They are at a lower risk of illegal activities and contact with the law if ADHD medication is continued (Lichtenstein et al., 2012). There is a strong evidence base for effective drug and behavioural treatments for ADHD (Asherson, 2005, Bolea-Alamanac et al., 2014). Lower than expected rates of continuation of treatment for ADHD into

adulthood are concerning given the availability of effective treatments and high risks of failure to treat. Therefore, the exploration of possible reasons for children and young adults' early disengagement from treatment, such as lack of information, or availability of adult services for ADHD, is a priority.

### **1.2.2 Transition**

As described in the recent UK National Institute for Health and Care Excellence (NICE) (2016) guidelines, transition should be a purposeful, planned process of transferring an adolescent between services which address medical, psychosocial and educational/vocational needs (Blum et al., 1993, NICE, 2016, Paul et al., 2015). Getting mental health service transition right for young people is important as it occurs when multiple other transitions such as changing educational setting, starting a job for the first time, and leaving home are likely to occur (Schulenberg et al., 2004). However, evidence shows that mental health service transitions are often not well supported, leading to disruption of care and premature disengagement from services (Paul et al., 2015, Singh, 2009).

Identified barriers to mental health transitions include lack of clarity on service availability, and different eligibility criteria between child and adult services (Belling et al., 2014, McLaren et al., 2013). Transition outcomes appear to be particularly poor for young people with neurodevelopmental conditions, such as ADHD (Singh et al., 2010a, Tatlow-Golden et al., 2018). Barriers specific to ADHD include variable service provision and the poor availability of adult services (Belling et al., 2014, Hall et al., 2015, Hall et al., 2013). Transitions may also be particularly difficult for young people with ADHD as combined symptoms of impulsivity, inattention and hyperactivity are likely to make organising and managing change difficult (Baric et al., 2017, Gotlieb and Gotlieb, 2009). Young people with neurodevelopmental conditions may also be relatively immature compared to their peers, which can make transition into adult services difficult (Gotlieb and Gotlieb, 2009). Despite clear evidence of unsuccessful transition, barriers and facilitators to successful transition for this vulnerable group are not well understood.

### **Information in transition**

Information is an important aspect of healthcare engagement and self-management for people with long term conditions (Adams, 2010, Wagner et al., 2001). Communication of information about health needs and available care can help young people anticipate future events, reduce their uncertainty, and help them take control, to engage in appropriate action (Smets et al., 2016).

The crucial role of information in transition is encapsulated in NICE (2016) guidance on transition, on patient experience in adult National Health Service (NHS) services, and in guidance on diagnosis and management of ADHD (NICE, 2018b). Recommendations are that information is provided in a developmentally appropriate format to young people and their parents/carers about what support is available and what to expect in adult services; also that information about the young person is communicated between services (NICE, 2016, NICE, 2018b).

Despite its important role in healthcare engagement, little is known about the role of information in transitions for ADHD. Parents of young people with mental health difficulties perceive that a lack of understanding of mental health problems, and knowledge about the help-seeking process, is a barrier to accessing psychological treatment (Reardon et al., 2017). Parents, young people, health workers and teachers have reported that 'feeling knowledgeable' about ADHD increased the likelihood of young people with ADHD engaging in pharmacological and psychological treatments (Bussing et al., 2012a). Research has been carried out into the ways information can support self-care and continued engagement with treatment for other long term conditions, such as diabetes (Misono et al., 2010). Similarly, research suggests that the availability of healthcare information has a potential role in addressing inequity of access to services (Alam et al., 2012).

Due to delays in brain maturation and difficulties with the regulation of attention, which can affect the processing of information (Gotlieb and Gotlieb, 2009), young people with ADHD are likely to have specific informational needs at transition. Given the highly heritable nature of ADHD (Khan and Faraone, 2006), these difficulties may also affect a parent or other family member's ability to interpret

information and support the young person. It is therefore important to better understand the role of information in transition for ADHD, as these difficulties may mean that particular care and attention is required in the delivery of information to make sure that it is received and understood.

### **1.2.3 Availability of adult services**

Adult services for treatment of ADHD need to be available and accessible in order for transition to take place. Treatment and management of ADHD in adulthood have been formalised in the UK through guidance from NICE since 2008 (NICE, 2008, 2018b). UK health services are publicly funded through the NHS and are intended to be free at point of use and accessible to all. NICE was established in 1999 by the Department of Health (NICE, 2008, 2018b), to improve standards of health and social care, by reducing variation in quality and availability of NHS treatments (Culyer, 2005). However, despite NHS organisations using the framework of NICE guidance to improve the quality of care and standards of services, ultimately decisions by local commissioners on how budgets are spent will influence what is provided (NHS England, 2014b, Wolfe et al., 2016). While the intention is to provide equity of access to care, in reality access to care for long term mental health conditions, such as ADHD, is variable and can be poor, especially for vulnerable groups (NHS England, 2014a).

Improving provision for those with long term conditions, such as ADHD, is a priority. This is because of the high personal, social and economic costs to individuals, and communities, of failing to treat. The UK government's Five Year Forward View for mental health identified a need for national data on mental health services to help raise awareness of, and provide the information needed to address, inequalities in service provision (Marmot and Bell, 2012, NHS England, 2014a, NHS England, 2016, NHS England, 2017). A national index of adult ADHD services could support targeted service development, inform commissioning decisions, and increase regional accountability.

There is no consensus on precisely how services for adults with ADHD should be organised (Coghill, 2017). The most recent NICE (2018b) guidelines for the

diagnosis and management of ADHD state that services should be provided for adults by dedicated teams with expertise in ADHD, within specialist or generic services, with the size and capacity of teams determined by local level of need. A multi-agency approach is also recommended, facilitated by close collaboration between services, and with shared care agreements in place with primary care providers (NICE, 2018b). Shared care is defined as the planned joint participation of consultants and GPs in the delivery of care for patients with a chronic condition (Hickman et al., 1994). However, with both primary and secondary care under pressure GPs face multiple challenges in adhering to shared care arrangements for specialist drugs, including uncertainty and concern over a lack of specialist support (Crowe et al., 2010). In the four countries that make up the UK, the limited available data indicate considerable variation in service organisation, with specialist services in some locations, generic services treating ADHD in others, and potentially no services accepting young people with ADHD in some areas (Coghill and Seth, 2015, Hall et al., 2015, Hall et al., 2013, Zaman et al., 2012).

Although a network of generic AMHS is in place across the UK, these are designed to provide episodic care, rather than support long term conditions, and staff are often not trained in treatment of ADHD, meaning these may not be well placed to provide treatment (Hall et al., 2015). Specialist services have been set up to treat adult ADHD, however it was not clear how many services there were, or the extent to which they offered the full range of services as recommended by NICE (2018b). It appears that specialist ADHD services or clinics may be most likely to be established in areas where a clinician has a specific interest in ADHD (Coghill and Seth, 2015, Zaman et al., 2012). This 'ad-hoc' approach to UK provision increases the risks of geographic health inequalities. The current service context and lack of national data makes it difficult to judge whether or not services are being provided in line with guidance, and for policy makers to audit provision. One way of assessing provision is to review available quantitative evidence on regional differences in treatments for young people with ADHD through the transition period. Findings from this analysis will be used as a proxy measure that is indicative of provision of care.

#### **1.2.4 Regional differences in treatment cessation**

The provision of medication to young people with ADHD through the transition period, as well as referral rates into adult services, will be used as proxy measures of treatment provision in the UK. Analysis of these indicators will be used to gain a picture of access to healthcare resources for this group by geographic region of the UK. Research has established that prescriptions of ADHD medication decrease through transition at a higher than expected rate in young adults given the population-based estimates of the prevalence of ADHD into adulthood (Newlove-Delgado et al., 2018a, Wong et al., 2009). This drop implies loss of access to treatment and support for adults with ADHD and suggests unsuccessful transitions are common.

Higher rates of ADHD prescribing in children and young people have recently been identified in more disadvantaged areas (Prasad et al., 2018). Given the strong association between low socioeconomic status and ADHD (Russell et al., 2018), this is to be expected as there is likely to be a higher prevalence and hence need for services in areas of higher levels of deprivation. Prior to this research, geographic variations in the decrease of prescribing of ADHD medication during the transition period had not been assessed. An analysis of differences in service provision, represented by prescribing of ADHD medication and rates of referral into AMHS will help to identify areas where service configurations are supportive of continued treatment engagement. If compared against a national map of adult ADHD service provision, these data could help identify areas with successful continuity of treatment, as well as areas that require increased provision.

#### **1.3 Research objectives**

In order to fulfil the overarching objectives of enhancing wellbeing and reducing suffering by facilitating optimum care for young people with ADHD as they transition into adulthood, this thesis had the following objectives:

- to gain an overview of current research into experiences of transition for young people with ADHD, with a focus on identifying barriers and facilitators to continued service engagement

- to explore views and experiences of young people and their parents/carers on the role of information in transition, to facilitate future improvements in information provision
- to provide national data on adult ADHD services in the UK by creating a map of services, highlighting differences in provision by geographic location and providing a national audit of existing services
- to learn about differences in awareness of adult ADHD service provision, through a comparison of differences in services identified by service users, health workers and commissioners, with the aim of better understanding differences in service knowledge and accessibility
- to explore geographic variations in the prescriptions of ADHD medication to young people over the health service transition period (age 16-19 years), as well as rates of referral to AMHS for young people with ADHD, using these measures as a proxy for accessibility of care

#### **1.4 Study design and rationale**

I used four main research methods in order to answer the research objectives; a systematic review, a qualitative study, a mapping study informed by a national survey of key stakeholders, and a quantitative analysis of a dataset of electronic patient records. These methods were chosen as the research objectives required both quantitative and qualitative approaches. A novel mapping methodology approach was developed and refined in order to create a national map of service informed by multiple stakeholders. Figure 1 illustrates the structure of the thesis.

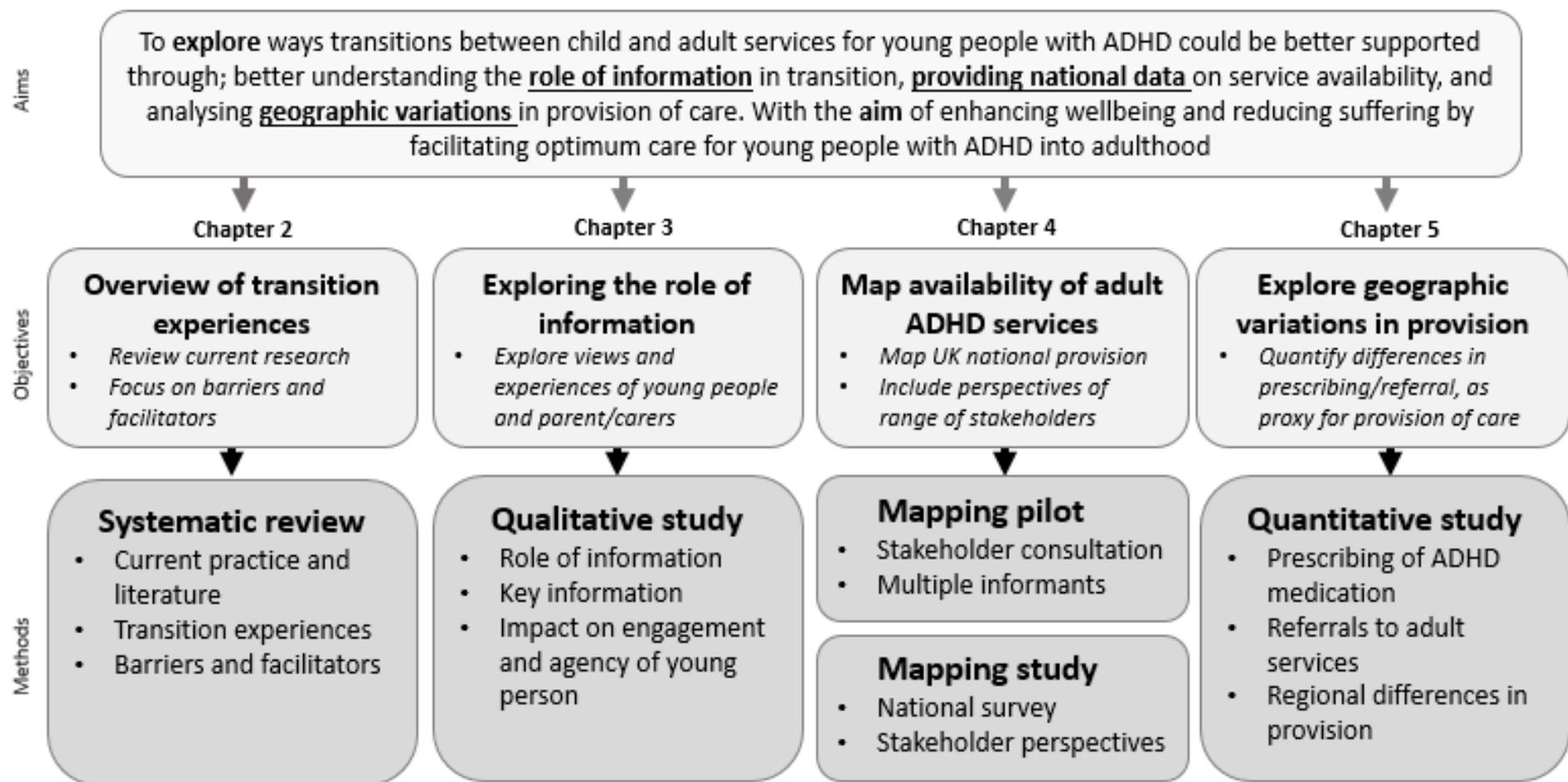


Figure 1. Overview of thesis chapters

## 1.5 Overview of thesis chapters

Each of the chapters presented contributed to the overall aim and research objectives of the thesis.

The systematic review (chapter two) aimed to provide an overview of the background literature relating to experiences of transition for young people with ADHD. The review identified existing literature on difficulties experienced at transition, and recommendations for improvement of the process. The review has been published in *Child and Adolescent Mental Health* (Price et al., 2019).

The qualitative study (chapter three) explored the role of information in young people's transition into adult ADHD services using interviews with young people and their parents/carers from across England. A research paper from this study has been submitted for publication to the journal *BMC Psychiatry* (Price et al., In submission-c).

The mapping study (chapter four) aimed to collect national data on the availability of UK adult services for ADHD. The first stage (part one; 2016-17), involved the development and piloting of a novel research methodology, designed to include reports from a range of key stakeholders, including service users, health workers and commissioners. Lessons learned from this pilot were described in a research paper submitted for publication to the journal *BMC Health Services Research* (Price et al., In submission-b). Following piloting, a definitive survey was conducted in 2018. Findings from this study are reported in full in the second part of chapter four.

The quantitative study (chapter five) explored regional differences in ADHD prescribing and referrals to adult services in the UK. Secondary data from the Clinical Practice Research Datalink (CPRD) was analysed to determine the mean age at which prescription of ADHD medication stopped as well as the rate of referrals into AMHS for young people with ADHD, by UK region. Findings were

mapped against locations of dedicated adult ADHD services, as identified in the mapping study. A research paper from this study has been submitted for publication to the journal *BMC Psychiatry* (Price et al., In submission-a).

The findings of all studies are brought together in a final discussion chapter to summarise my conclusions on the role of information in ADHD transitions, the current availability of UK adult ADHD services, and geographic variation in service provision for young adults with ADHD. The findings are placed in the context of research, policy and practice, and methodological issues and future research questions are discussed.

## **Chapter two: systematic review**

### **2.1 Introduction and overview of chapter**

This chapter consists of a systematic review of studies that describe the experiences of healthcare transitions for young people with ADHD. The aim was to provide an overview of the challenges faced by young people with ADHD when they reach the age boundary for children's services, and the potential impact of these difficulties. The literature synthesised in this chapter was then used to inform the focus of the rest of the thesis, which explores the two major challenges to transition that were identified in the review: the need for better provision of information, and the limitations of adult service provision.

The general principles for systematic reviews, as recommended by the University of York (CRD, 2009), were used. Five databases were searched, quality appraisal was conducted using the Wallace criteria (Wallace et al., 2004), and findings from included studies were synthesised using thematic analysis (Braun and Clarke, 2006).

The rest of this chapter comprises the published manuscript of the systematic review. I led the design, data collection, data analysis and the write up of this paper. It has been published in the journal of *Child and Adolescent Mental Health*, accepted for publication on the 23<sup>rd</sup> July 2018, and first published on the 27<sup>th</sup> August 2018 (Price et al., 2019).

## **2.2 Systematic review: manuscript published online 27<sup>th</sup> August 2018**

### Experiences of healthcare transitions for young people with ADHD: a systematic review of qualitative research

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## 2.2.1 Abstract

**Background:** Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by hyperactivity, inattention and impulsivity. Up to two thirds of young people with ADHD may experience symptoms into adulthood, yet the limited literature available suggests that many young people with ongoing needs do not transfer from child to adult healthcare services. Although worldwide and National Institute for Health and Care Excellence (NICE) guidelines recognise the importance of supported transition, evidence suggests for ADHD this is poorly managed and variable. Little is known about how transition is experienced by those involved. We aimed to synthesise existing peer reviewed literature to understand views and experiences of young people, carers and clinicians on transitioning between child and adult ADHD services.

**Methods:** Five databases were searched and all articles published between 2000 and up until January 2017 considered. Four key search areas were targeted; ADHD, Transition, Age and Qualitative Research. Quality appraisal was conducted using Wallace criteria. Findings from included studies were synthesised using thematic analysis.

**Results:** Eight papers, six from the United Kingdom (UK), and one each from Hong Kong and Italy, were included. Emerging themes centred on difficulties transitioning; hurdles that had to be negotiated, limitations of adult mental health services, inadequate care and the impact of transition difficulties.

**Conclusions:** Healthcare transition for this group is difficult in the UK, because of multiple challenges in service provision. In addition to recommendations in NICE guidelines, respondents identified a need for better provision of information to young people about adult services and what to expect, greater flexibility around age boundaries and the value of support from specialist adult ADHD services. More research is needed into ADHD healthcare transition experiences, especially in countries outside the UK, including accounts from carers and clinicians.

**Keywords:** ADHD, Transition, Systematic Review, Qualitative Methods, Health, Experiences, Adolescence

***Key practitioner message***

- Lack of healthcare provision in the UK results in inadequate care, such as keeping young people on at CAMHS, weaning off medication prematurely and discharging to GP without specialist management, which can leave young people feeling abandoned, under intense distress and unable to cope.
- In addition to the information transfer between healthcare services recommended in the NICE guidelines, clinicians, carers and young people want accurate and sufficient information before and during transition, which should include information about where adult services are and how to access them.
- Differences in thresholds between child and adult mental health services in the UK leave some young people unable to access adult ADHD services.
- Parents and carers want to continue to be involved when the young person transitions, which is often outside the normal patterns of adult mental health service provision.
- There was no consensus about the necessity of age boundaries or the ideal age / stage for transition to adult health services.

## 2.2.2 Introduction

Attention deficit hyperactivity disorder (ADHD) is a lifespan neurodevelopmental disorder characterised by hyperactivity, inattention and impulsivity (Gibbins and Weiss, 2007, Kooij et al., 2010). Reviews of prevalence suggest ADHD affects 5.9-7.1% of children (Willcutt, 2012). Up to two-thirds of affected young people continue to experience symptoms into adulthood (Agnew-Blais et al., 2016, Faraone et al., 2006). The proportion of young people who access treatment declines at a greater rate than age related decrease in symptoms, implying some young people with ADHD do not receive the care they need as adults (Coghill, 2017, Newlove-Delgado et al., 2018a).

Getting healthcare transitions right for young people with ADHD is crucial. Transitional healthcare is defined as “the purposeful, planned movement of adolescents with chronic physical and mental conditions from child-centred to adult-orientated health care systems”(Blum et al., 1993). This review defines transitional healthcare for young people with ADHD broadly, to include transfer to adult mental health services (AMHS), referral to General Practitioner (GP) and ceasing to access health services (Paul et al., 2015). For all young people with mental health needs the move into adult health services occurs at a very vulnerable stage in their lives, with potentially many other challenging transitions; such as changing school, moving out of home, or starting work (Schulenberg et al., 2004). This stage of development is particularly challenging for young people with ADHD because the combination of impulsivity, inattention and hyperactivity make organising and managing change difficult (Baric et al., 2017, Gotlieb and Gotlieb, 2009, Wolraich et al., 2005).

National and international guidelines on ADHD recognise the importance of this healthcare transition (Seixas et al., 2012). In the United Kingdom (UK), the National Institute for Health and Care Excellence (NICE) guidelines (2018b) recommend the move from CAMHS to AMHS for young people with ADHD takes place as a managed transition. Current quantitative and qualitative evidence suggests that healthcare transitions for young people with ADHD are poorly

managed, highly variable and little is known about the experience of those involved (Coghill, 2017, Hall et al., 2015, Hall et al., 2013). Consequently, levels of drop out from services are high (McCarthy et al., 2009, Ogundele, 2013, Wong et al., 2009). Without adequate ongoing treatment, long term consequences can include disrupted social relationships, education, and work, as well as increased high risk behaviours such as drug taking and criminal activity (Montano and Young, 2012). Knowing more about how young people, their parents/carers and clinicians experience transition may help identify barriers and facilitators, and could help inform future transition protocols and service development. Considering that there are effective treatments for ADHD (Banaschewski et al., 2006, Bolea-Alamanac et al., 2014, Sonuga-Barke et al., 2013), reducing drop out and improving transitions into adult health services are key aims to reduce costs to society and to improve the wellbeing of young people with ADHD.

Existing literature on healthcare transitions for young people with mental health disorders includes three recent systematic reviews (Embrett et al., 2016, Mulvale et al., 2015, Paul et al., 2015). Conclusions are limited by scarcity of data but indicate patchy provision, a need for accessible and age-appropriate services, need to tackle stigma, unhelpful cultural differences between CAMHS and AMHS, and parents wanting more involvement (Mulvale et al., 2015, Paul et al., 2015). Literature specific to ADHD healthcare transition is even more limited. It includes a scoping review published in 2013 (Swift et al.) confirming the lack of research and a literature review that described a number of barriers to continuity of care (Montano and Young, 2012). To our knowledge no systematic review has been conducted on ADHD healthcare transitions since NICE guidelines were published in 2008. Findings of previous reviews have been useful but mainly descriptive in nature. This systematic review synthesises existing peer reviewed qualitative literature to answer the following research question: What are the experiences and perceptions of young people with ADHD, their parents/carers, and treating clinicians related to the transition between CAMHS and AMHS?

### 2.2.3 Methods

Methods followed University of York guidance for undertaking reviews in health care (Tacconelli, 2010). As we aimed to synthesise the experiences of key stakeholders to inform future service design, we used thematic analysis, inductive methods and an iterative approach in line with critical realist perspectives (Braun and Clarke, 2006).

#### *Inclusion and exclusion criteria*

The search was limited to peer-reviewed publications written in English, due to language limitations. Articles were included if they reported qualitative data about young people with a diagnosis of ADHD aged 14-25 years before, during or after a transition to adult healthcare services. Data could be collected from young people, their parents/carers, clinicians, educational support workers, or service providers. Study design included primary qualitative research with a recognised methodology (such as interviews or focus groups), mixed methods including a qualitative element (such as questionnaires with free text comments) or consensus statements from stakeholders.

Studies were excluded if they did not report on young people with ADHD or if findings were not reported separately for young people with ADHD.

#### *Search strategy*

Five databases were searched (Medline, Embase, PsychINFO, Global Health and Cinahl) from 2000 (given older studies are less generalisable to current healthcare systems) to 19<sup>th</sup> Jan 2017. Areas targeted were: *Attention Deficit Hyperactivity Disorder, Transition, Age, and Qualitative Research*. A supplementary search looked for reviews of '*mental health*' or '*neuro-disability*' healthcare transitions which were screened for research including an ADHD population. For detailed search strategy and syntax see appendix 1. Experts in the field were consulted and a one-stage forward and backward citation search was carried out for included articles.

### *Study selection*

Title and abstract of all unique citations were screened against the eligibility criteria by two reviewers (AP and AW or MA). The same procedure was followed for the full text screening. Disagreements were resolved through discussion or adjudicated by AJ.

### *Quality assessment*

Quality was appraised using the Wallace criteria to determine the appropriateness of the method and quality of reporting (Wallace et al., 2004), see table 1. This has been used in previous qualitative reviews (Greaves et al., 2017, Husk et al., 2016, Moore et al., 2016), and covers research question, theoretical perspective, study design, context, sampling, data collection, data analysis, reflexivity, generalisability and ethics. Studies were assigned 'yes', 'no' or 'can't tell' for desirable and essential criteria which generates an overall score of 'good', 'moderate' or 'poor' (Husk et al., 2016). Quality appraisal was not used to determine eligibility for inclusion, but to inform judgements about the strength of the evidence. Themes/sub-themes were only included if they emerged from at least one paper rated 'good'. Evidence stemming from 'moderate' or 'poor' quality papers was clearly marked in results and used to support/extend existing themes. Quality appraisal was completed by AP and MA; discrepancies were resolved by discussion with AJ.

### *Data extraction*

Data on sample, study details, research methods and findings were extracted using a checklist adapted from a recent systematic review (Gwernan-Jones et al., 2016) by AP and checked by MA.

### *Data analysis and synthesis*

Thematic analysis was used to synthesise findings (Braun and Clarke, 2006), as other qualitative systematic reviews have applied it to produce findings to inform policy and practice (Orr et al., 2016); it is suitable for data that is mainly

descriptive (Thomas and Harden, 2008). AP and AJ independently familiarised themselves with all papers. AP indexed all included papers and AJ indexed two (also called, open coding) (Gale et al., 2013). Papers were purposefully selected to include comprehensive coverage of the subject (Swift et al., 2013) and a study with wide research aims (Wong et al., 2009). Qualitative data (in the form of quotes, themes and concepts) were identified by the authors and extracted from the results and discussion sections of included articles. The extracted data was coded using NVivo version 11. Codes were compared and discussed before creating a working analytical framework to be applied to all papers. Aptness of the framework and reliability of its application was checked by comparing and discussing coding. A framework matrix was produced and data were summarized by code for each paper (AP); cells also included references to interesting or illustrative quotes and researcher's comments. Finally, a summary was produced by AP for each code, based on the cell summaries, which was reviewed by AJ and led to the development of the conceptual model and decision on final themes.

#### **2.2.4 Results**

The PRISMA flow chart (see figure 2) (Moher et al., 2009) shows the eight included papers selected from 2134 initial records identified. Three further papers almost met inclusion criteria (Marcer et al., 2008, Montano and Young, 2012, Syverson et al., 2016) however the methodology was not clear enough to identify where qualitative research findings came from, so were excluded.

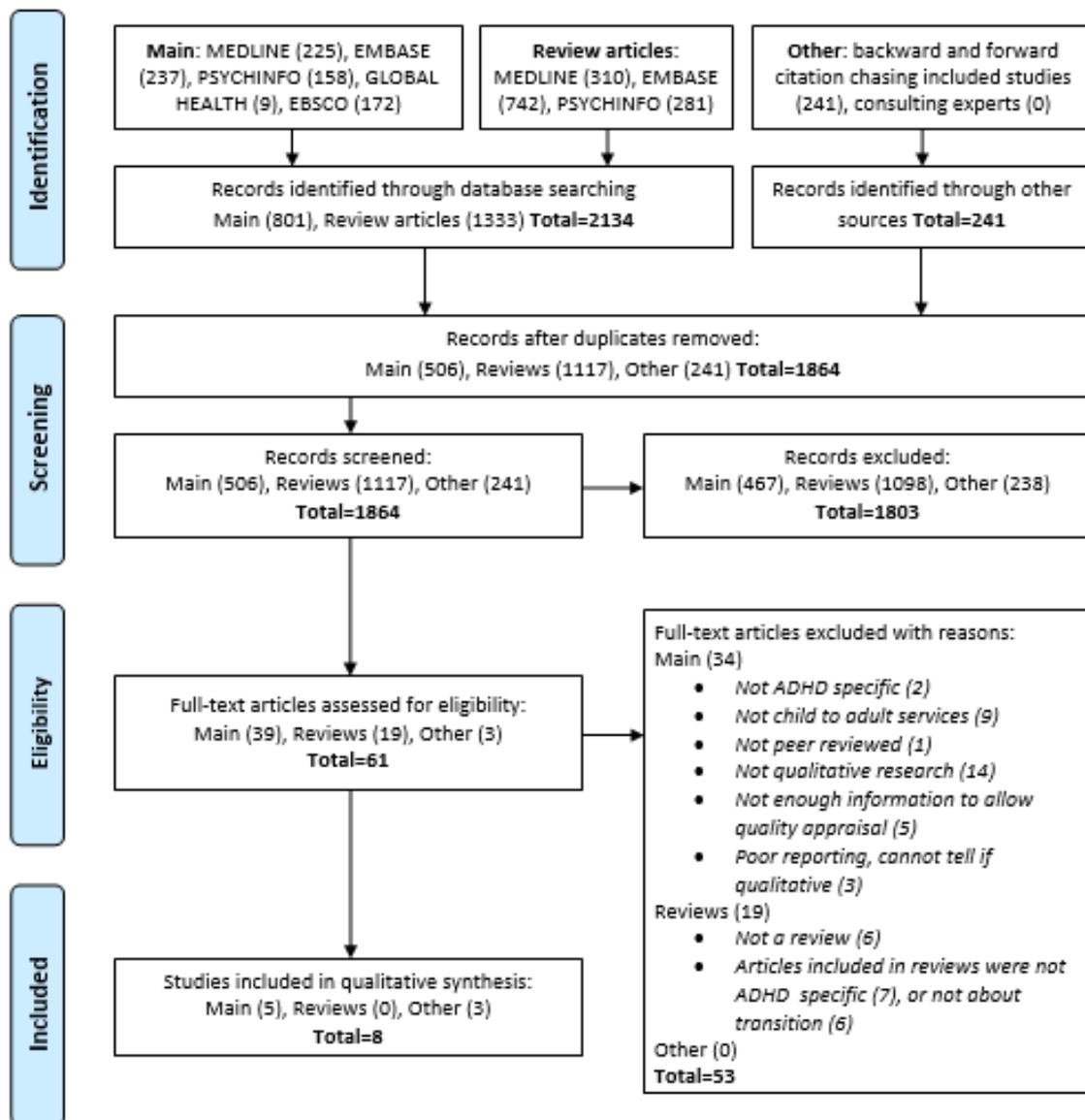


Figure 2. Flow chart of retrieved studies

### Study characteristics

The majority of studies were based in the UK. For an overview of included studies and their quality, see table 1. All studies explored experiences of ADHD specific mental health populations, except Belling et al. (2014). The aims of two studies (Belling et al., 2014, Wong et al., 2009) differed from those of this review, so only relevant aspects were extracted.

Table 1. Study characteristics

Study	Aims	Methods	Sample	Participant type (n)			Quality Score
				YP	P/C	CI	
<b>Belling et al. 2014</b>	Investigate organisational factors that impede/facilitate transition.	Semi-structured Telephone interviews, TA.	Description, Location (Total = N) Clinicians: England (34)	34	0	0	Good
<b>Cheung et al. 2015</b>	Explore experiences of YP with ADHD accessing treatment, coping with impairment, and expectations of future treatment.	Semi-structured interviews, TA.	F2F Patients aged 16-23 receiving pharmacological treatment for ADHD: Hong Kong, China (40)	40	0	0	Good
<b>Ginsberg et al. 2014</b>	Review to discuss unmet adult ADHD needs in Europe.	Systematic analysis of data from web forum, TA.	All postings in two threads in an adult ADHD web forum: United Kingdom				Poor*
<b>Matheson et al. 2013</b>	Explore experiences of adults with ADHD and compare between patients diagnosed during adulthood and childhood.	Semi-structured interviews, TA.	F2F Adults with ADHD recruited through ADHD charity or hospital outpatient clinics: United Kingdom (30)	30	0	0	Good
<b>Reale et al. 2014</b>	Describe experiences of parents and clinicians in relation to transition.	Postal qualitative questionnaires, TA.	Parents/carers of YP aged 18+; Child Clinicians: Lombardy, Italy (51)	0	24	27	Poor*
<b>Swift et al. 2013</b>	Explore experiences of YP with ADHD during transition.	Semi-structured interviews, TA.	F2F YP with ADHD aged 17+; Some parents/carers present at interview: England (10)	10	0	0	Good
<b>Wong et al. 2009</b>	Explore process and outcomes of ADHD medication cessation.	Semi-structured interviews, TA.	F2F YP aged 15-24; Clinicians from London, Liverpool, Nottingham and Dundee: United Kingdom (25)	15	0	10	Good
<b>Young et al. 2016</b>	Consensus statement to discuss transition of ADHD patients. Formulate recommendations for successful transition.	Presentations followed by discussion.	"Multidisciplinary team of mental health professionals, allied professionals and patients": United Kingdom				Poor*

YP = Young people with ADHD; P/C = Parent or carer of young person with ADHD; CI = Clinicians; F2F = Face to face; CAMHS = Child and Adolescent Mental Health Services; AMHS = Adult Mental Health Services; TA = Thematic Analysis. \*NB. Although qualitative evidence was rated poor for purposes of review, research was appropriate for articles' intended purposes

### *Study quality*

Methodological quality of included papers was moderate; five scored 'Good' and three scored 'Poor' (see table 1). Studies scoring poorly were not primarily qualitative. They included a literature review supported by evidence from a web forum (Ginsberg et al., 2014), a consensus statement drawn from an expert workshop (Young et al., 2016) and a study using paper questionnaires (Reale and Bonati, 2015). For detailed quality appraisal information see appendix 2.

### *Synthesis results*

For a summary of themes emerging, see table 2. The five main themes are described below.

Table 2. Themes and sub-themes identified

Main Theme	Papers contributing to theme	Sub-theme	Description
<b>Transitioning</b>	1,2,3,4,6*,7*,8*	Information	Multiple difficulties with transition process. Wide gap between guidelines and practice. Uncertainty about processes caused distress. More information wanted on how to access services, what would happen, differences between child and adult services and experiences of living with ADHD as an adult.
	1,4,6*,7*,8*	Preparation	Quality of preparation was key. Poor preparation led to feeling let down and in the dark. Requests made to meet adult clinicians in advance or see a photo and for written information to be provided.
	2,4,7*,8*	Transition age	Some patients felt transition was unnecessary and wanted to stay with familiar services. Some clinicians found 18 a logical age, others emphasised the need for flexibility, saying transition should be a process not an event.
	2,4,7*,8*	Parent/carer involvement	Parent/carer input seen as essential in transition process. The fact adult services not set up for family involvement was experienced as a barrier.
<b>Hurdles</b>	2, 3, 4, 5, 6, 7*	No adult service	Many hurdles had to be negotiated to get into adult services. Participants spoke of no adult services, which was an insurmountable obstacle to transitioning.
	2,4,5	Patient-clinician relationship	This relationship supported or hindered transition. When a doctor ' <i>went the extra mile</i> ' and listened, this supported transition, but frequent staff changes and too many routine questions made it difficult for the patient to maintain engagement.
	3, 5, 6*, 8*	Gaining referrals	Getting a referral to transition into or enter adult services was difficult. This often related to GPs' limited understanding of ADHD.
	1, 4, 5, 6*, 7*, 8*	Meeting thresholds	High rates of unaccepted referrals were a barrier. Some adult services only accept cases of 'severe' mental health, and didn't include ADHD in that definition.
	1, 3, 4, 6*	Accessibility	Long waiting lists and significant distances to travel were a barrier to access. Young people worried about feeling comfortable in generic adult mental health settings.

Main Theme	Papers contributing to theme	Sub-theme	Description
<b>Limitations of adult services</b>	1,2,3,4,5,6*,7*,8*	Competencies	Once in adult services, young people found support patchy and insufficient. Negative attitudes and lack of understanding led to difficulties gaining appropriate treatment and support. A need for specialist ADHD training and skills development in clinicians treating adults.
		Resources	High demand coupled with inadequate funding led to limited services. Trusts commissioned very limited services.
		Getting prescriptions	Some clinicians were reluctant to prescribe medication.
		Treatment	Treatments available were primarily medication alone, which was thought insufficient. Psychological therapies desired but not available.
<b>Inadequate Care</b>	2, 5	Kept at CAMHS	When transition was not supported, inadequate care arrangements were made that failed to meet patient needs. Child clinicians hold onto patients beyond age boundary.
		Weaned off medication	Clinicians wean patients off medication then discharge.
<b>Impact</b>	1, 2, 3,4,5, 8*	3 Discharged to GP	Patients discharged to GP care. Lack of treatment management and specialist supervision. Combined with challenges ADHD patients already face, poor transition experiences were associated with intense distress, uncertainty and feeling abandoned. Some were unable to cope.

Key: 1 = Belling, 2 = Cheung, 3 = Matheson, 4 = Swift, 5 = Wong, 6 = Ginsberg, 7 = Reale, 8 = Young, \* = Poor quality paper

### Transitioning

Multiple struggles with healthcare transition processes were reported, which, combined with difficulties ADHD patients face with self-organisation and managing change, left some unable to cope. Key sub-themes were lack of appropriate information, importance of preparation, relationship with clinician, transition age, and parental role.

Lack of appropriate *information* on what to expect during healthcare transitions was an extensive and consistent theme across studies. This included uncertainty about which services AMHS provides, where services are, and living with ADHD as an adult. In several studies CAMHS clinicians reported lack of clarity on availability, while difficulties in identifying appropriate AMHS made it difficult to support patients. Several respondents discussed negative impacts of not knowing what to expect,

“...bit vague to me what’s available.” (Nurse, CAMHS) (Belling et al., 2014)

“When she gets to 18 is there gonna be somebody there that can talk to us and talk to her? ... We just don’t know. And it worries you” (Parent) (Swift et al., 2013)

Importance of *preparation* emerged as a key factor. Some reported feeling ill-prepared and let down, while those receiving joint working felt prepared and typically reported more positive transition experiences. Parents and clinicians identified lack of shared transition planning between services and a lack of parallel care as a barrier (Reale and Bonati, 2015). Requests included introductions to new clinicians, seeing a photo and being given written information about next steps. Authors recommended formal protocols, jointly developed with service users, commissioners, paediatricians, AMHS providers and primary care clinicians.

*Parent/Carer involvement* was acknowledged as a highly significant factor in young people accessing adult services (Cheung et al., 2015, Swift et al., 2014). Most clinicians found parental input was important and some parents reported

lack of support for families in adult services as a barrier to transition (Reale and Bonati, 2015).

*“I can see where they’re coming from ‘cos he’s an adult, but ...they know he won’t go out the house and won’t do certain things on his own yet he’s got to go all the way up there and that’s the point he won’t do that”* (Parent) (Swift et al., 2014)

Most young people accepted the need for continued parental support (Swift et al., 2014). The expert consensus statement described parental involvement as essential but noted the tension with the young person’s need for increasing autonomy (Young et al., 2016).

The question of *transition age* for young people was the only theme where there was significant variation between and within studies. Several young people expressed ambivalence about healthcare transitions, preferring to stay with familiar services (Cheung et al., 2015). They found transition unsettling and an annoying inconvenience.

*“I don’t see what age has got to do with who you’re seeing and where you see ‘em. ..., we’re used to coming here, but now we’ve got to change ... so that’s a bit annoying”* (Patient) (Swift et al., 2013)

Italian clinicians said 18 years made sense for transition (Reale and Bonati, 2015). Many clinicians described transition as a process not an event, while others mentioned lifespan clinics that avoid transition at 18 (Young et al., 2016). Flexibility may be the key to the accommodation of young people’s needs.

### Hurdles

Respondents across studies shared experiences of ‘hurdles’ that they had to overcome in order to transition. Difficulties were experienced in accessing adult services, obtaining referrals and meeting acceptance thresholds. The most insurmountable and common was when no services were available.

Lack of *adult services* was reported in most studies; it was viewed negatively and often had traumatic effects.

*“There are places you can go as a kid, but not as an adult, it’s kind of swept under the carpet as soon as you reach 18”* (Young Person (YP)) (Matheson et al., 2013)

*“A common experience of our patients is that once they reach 17, 18, they finish with Child Psychiatry and GPs stop prescribing without any preparation, ... for some of them they experience that as quite traumatic because suddenly they couldn’t take medication”* (Clinician) (Wong et al., 2009)

Authors recommended adult services should provide care consistent with child services and in line with NICE guidelines (Matheson et al., 2013, Swift et al., 2013, Young et al., 2016).

*Patient-clinician relationship* could support or hinder transition, either directly through levels of practical support or indirectly by making the young person more or less likely to engage. Patients liked clinicians who listened and went beyond their job role to support them, but reported negatively on staff changes and brief consultations focussed on routine questions.

*“No relationship with doctor at all...and he has not followed the case regularly so he just asks those routine questions”* (Patient) (Cheung et al., 2015)

*Gaining referrals* was another difficulty according to young people and clinicians. This was attributed to lack of belief in, understanding of, or knowledge about adult ADHD.

*“The GP may or may not have detailed knowledge of ADHD. I don’t think the majority of GPs will have ADHD [as a possible diagnosis] in mind”* (Clinician) (Wong et al., 2009)

*"She [GP] basically said that because I got really good grades in school and am at university doing pretty well that I do not have ADHD."* (Web forum) (Ginsberg et al., 2014)

The ability to re-enter services was considered important.

Difficulty *meeting thresholds* for adult services was a barrier in most studies, with some adult services only accepting referrals for 'severe' conditions, a definition which didn't include ADHD. Stakeholder experiences were that more 'complex' problems made transition smoother.

*"...of course they think he, he's got autism/ADHD but he's not self-harming or anything so he can go to his own doctor if he's got no problems"* (Parent) (Swift et al., 2013)

Clinicians said differing eligibility criteria between child and adult health services, exacerbated by a perceived lack of resources, aggravated this, with some reporting that patients were 're-labelled' at transition:

*"most of them are given a different label, taken off their medication and sent out into the community and goodbye"* (Clinician) (Wong et al., 2009)

These findings were consistent across all studies including parents or clinicians. Notably, they were not mentioned in the two papers that only interviewed young people (Cheung et al., 2015, Matheson et al., 2013).

*Accessibility* of adult services concerned some young people, including distances to travel and feeling comfortable in the environment.

*"Yeah, will there be like people with the same disability, or people with like schizophrenia or any other serious illnesses - Yeah, and will it be a one-on-one as well"* (YP) (Swift et al., 2013)

### Limitations of adult services

Once in services, barriers to treatment included attitudes and experience of adult clinicians, issues with funding and resources, difficulty in getting prescriptions and limitations on available treatments.

*Competencies*: the need for more education, training and skill development in clinicians supporting adults with ADHD emerged in every paper. Many patients experienced negative attitudes and scepticism about adult ADHD from health professionals, making accessing services and getting medication ‘*an uphill struggle*’ (Ginsberg et al., 2014, Matheson et al., 2013). Participants recalled doctors refusing to prescribe, which was often attributed to presumed negative attitudes towards ADHD and/or medication or uncertainty over licensing.

*"Colleagues in General Psychiatry are usually not too keen on diagnosing ADHD because if you diagnose it you need to treat it and the treatment is unlicensed."* (Clinician) (Wong et al., 2009)

Trusts recognised a need to develop skills and confidence in ADHD diagnosis and treatment in adult mental health professionals (Belling et al., 2014). Encountering negative attitudes sometimes led to severe emotional distress and functional impairment in patients (Matheson et al., 2013).

Contrastingly, experiences with specialist ADHD care were associated with provision of more informative advice on medications and coping strategies. This helped patients feel informed about treatment and led to greater patient involvement in decision making (Matheson et al., 2013). Authors suggested fostering engagement in clinical providers through discussion and psychoeducation (Ginsberg et al., 2014) and recommended training clinicians to provide relevant information to service users (Young et al., 2016); several recommended providing specialist consultation or services.

Some UK forum users (Ginsberg et al., 2014) said ADHD was still seen as solely a childhood condition, leaving many adults untreated, while patients from Hong Kong reflected on needs to raise public awareness and prevent stigma:

*“If there is more public awareness, less people will delay their treatment”*  
(YP) (Cheung et al., 2015)

*Resources:* problems of high demand combined with restrictive or non-existent funding emerged across most studies.

*“...commissioners do not commission services for adults, so that is another fall off point”* (Clinician) (Wong et al., 2009)

*“We have ... between 350 and 400 cases of ADHD and with that population 50% of them will have had ADHD after the age of 16 ... it would be good if there was a service to be provided.”* (Psychiatrist, CAMHS) (Belling et al., 2014)

Staff shortages and high work-loads in AMHS, including reported losses of transition workers, explained some barriers (Belling et al., 2014). Young people said more investment was needed to reduce waiting times (Cheung et al., 2015) and reported health trusts refusing to fund medication (Matheson et al., 2013).

Reluctance to prescribe led to difficulties *getting prescriptions:*

*“the psychiatrists but often mostly pharmacists act as if [ADHD drug] is plutonium and it’s, like, ridiculous”* (Patient) (Matheson et al., 2013)

*“...colleagues say it is not recognised, the products aren’t licensed, so why should we? We are prescribing something that isn’t licensed.”* (Clinician) (Wong et al., 2009)

*Treatment* was usually limited to medication, which many saw as insufficient (Cheung et al., 2015, Matheson et al., 2013).

*“beyond medication I am not getting any interactive care [CBT] which I have always found is as important as the medication”* (YP) (Matheson et al., 2013)

Some respondents valued psychological therapies less than medication, but several authors recommended wider access to psychological treatment

(Matheson et al., 2013, Young et al., 2016) as some saw this as essential to meet needs of adults with ADHD (Cheung et al., 2015).

### Inadequate care

Many stakeholders reported inadequate care when transition was not possible. Some patients were *kept at CAMHS*, often unofficially, while others were *discharged to GP care*, with some *'weaned off' medication*.

*The doctor said my case is special so she will continue to follow"* (YP)  
(Cheung et al., 2015)

*"There isn't a service for them. I don't know what will happen if we get caught."* (Clinicians) (Wong et al., 2009)

*"You sometimes find yourself in a position of having to cut back on medication and see if a child can do without."* (Clinician) (Wong et al., 2009)

Some patients were placed in primary care, without monitoring or support, leading to feelings of abandonment, lower self-efficacy and poorer self-management of their condition. This contrasted with valued specialist service support.

*"Participants whose primary interaction was with a GP strongly desired support with adjusting their medication type and dosage, or advice regarding coping with side effects, but did not receive it."*(Author Comment) (Matheson et al., 2013)

### Impact

The majority of studies included reports of significant negative *impacts* on wellbeing associated with lack of access to treatment and support. One author observed, *"exacerbated...feelings of disempowerment, distress and helplessness...led to a downward spiral in functioning"* (Matheson et al., 2013). Unsupported transition experiences for those already living with the accumulated psycho-social burdens associated with ADHD were extreme. Some dropped out of treatment, others went through *"seven years of hell"* (Wong et al., 2009) trying

to access services, or described feeling left out and like no-one cared. One young person said,

*"Putting somebody with ADHD through a bureaucracy is torture.... it's like treating a diabetic in a bakery"* (YP) (Matheson et al., 2013)

Authors commented delays accessing treatment left young people unable to cope (Ginsberg et al., 2014, Matheson et al., 2013).

Data from the six UK based studies contributed to all themes. The two other studies, from Italy and Hong Kong, contributed to themes of; transition difficulties, hurdles experienced, the need to develop ADHD specific competencies in adult clinicians and experiences that medication was the primary treatment available. However, challenges gaining referrals, discharge to primary care and poor accessibility of adult services were reported on only in UK papers (see table 2).

### **2.2.5 Discussion**

This systematic review explores the experiences and perceptions of key stakeholders involved in healthcare transitions for young people with ADHD. As six of eight included studies were based in the UK, findings cannot be generalised beyond this context. Of the five main themes emerging from the synthesis, three allude to the transition pathway: experiences of the transition process, structural steps needed in order to transition and the inadequate adult services that are currently available. The fourth relates to inadequate care provided when the pathway is blocked. The fifth reflects impact on the young person. All draw on patient, parent and clinician reports and highlight barriers and facilitators to successful and appropriate transitional care for these young people. Experiences of distress and inadequate support were shared across all themes.

Included studies revealed patchy provision, unmet need for accessible and age appropriate services, parents wanting more involvement with adult services and a need to tackle stigma, all of which echo findings from a recent systematic review of mental health transitions (Paul et al., 2015). When compared with mental

health transitions across mental health conditions (Paul et al., 2015), ADHD specific experiences appeared to emphasise the essential nature of parent/carer involvement and reveal difficulties caused by a serious lack of appropriate adult services and reluctance of clinicians to prescribe ADHD medication. There is some indication that specialist adult services were seen as more acceptable and less stigmatizing to young people with ADHD than generic provision.

Previously described differences between care philosophies of children's services (emphasising family) and adult services (focussing on autonomy) (Mulvale et al., 2015) explain the importance of preparation and the provision of information about adult services to facilitate transition. These cultural differences may also explain why parents report lack of involvement in adult services as a barrier to continuity of care.

Healthcare transition experiences specific to ADHD included lack of training and resources in AMHS, rejected referrals for ADHD patients without comorbidity, and premature discharge (Hall et al., 2015, Hall et al., 2013). When added to inherent difficulties young people with ADHD face around organisation and managing change, these help explain lower than expected transition rates and high levels of drop out from services (Young et al., 2011). Implementation of existing NICE (2018b) guidelines would address many barriers to transition identified in this systematic review.

For improved organisation and planning of ADHD services, NICE (2018b) recommends greater integration of CAMHS, Paediatric and AMHS with specialist ADHD teams. Mixed opinions of the optimal age for transition indicate a need to evaluate the different service models such as transitional ADHD services or extending CAMHS to treat 0-25 year olds (Singh and Tuomainen, 2015). A flexible approach to age boundaries that is developmentally appropriate should be adopted (NICE, 2018a).

### *Strengths and limitations*

This review was conducted with a clear protocol following established guidelines (Tacconelli, 2010) with double data extraction. Analysis and synthesis were developed iteratively. The supplementary search, expert consultation and citation chasing aimed to detect studies missed by our literature search, yet we only detected eight studies.

To fully explore healthcare transition experiences of this group, evidence from different settings, locations and from a range of countries, similar to that being gathered in the European Union Funded MILESTONE study would be needed (Singh and Tuomainen, 2015). Generalisation of these findings beyond the UK is not possible due to the limited number of studies elsewhere. Nevertheless, evidence included views from a range of stakeholders. We were able to report on clinician, parent and patient perspectives. Future research needs to address limited research involving clinicians and absence of studies involving educators.

Themes tie in with existing quantitative research indicating lack of healthcare provision for adults with ADHD, (Coghill, 2017, Hall et al., 2015) and poor awareness of or adherence to transition protocols (Hall et al., 2013). Further qualitative and quantitative research is needed to assess levels of need and to map provision of adult ADHD services.

There is a potential limitation of mixing study types in the synthesis of evidence as individual study aims may have been quite different. However the consistency of themes across different respondent groups and studies builds confidence in generalisability of findings even from this small selection of studies. The only sub-theme with mixed opinions between respondents was *transition age*. No clear consensus emerged. Some clinicians supported age 18, many respondents and authors recommended flexibility and a few patients questioned the need for any transition.

### **2.2.6 Conclusion**

The qualitative evidence included in this systematic review ties in with existing quantitative evidence, indicating that UK guidelines are not being implemented. The importance of providing service users with information about adult services is a novel finding that could easily be provided and evaluated. Positive experiences of specialist adult ADHD services should also be noted.



## **Chapter three: qualitative study**

### **3.1 Introduction and overview of chapter**

In the previous chapter, a systematic review provided a summary of the literature on the experiences of young people with ADHD requiring transition from child to adult services. It highlighted that many individuals reported difficult healthcare transitions that are more widely relevant to the limitations of UK health service provision. The review found that respondents had identified, among other factors, a need for better provision of information to young people about adult services and what to expect. This chapter presents the findings of a focussed qualitative analysis of data from the CATCh-uS study, exploring the role of information in young people's transition between child and adult services for ADHD.

The wider CATCh-uS qualitative study was developed as part of the project protocol and funded by the National Institute for Health Research (NIHR) (HS&DR Programme Funding: 14/21/52) (Ford et al., 2015). The young people and their parents/carers that were interviewed for this study were recruited from 10 NHS Trusts located across England. I jointly led the recruitment of young people and parents/carers for interview, and conducted 43 of the 92 included interviews. In order to enable a broad overview of pathways of transition, young people were purposively recruited at three different stages relative to transition, and from trusts with different types of service provision. Interviews took place in 2016 and 2017 and were conducted using a variety of methods, including face-to-face, video and telephone interviews, according to the preference of participants. Each interview was voice recorded, transcribed verbatim, and analysed using a thematic and framework approach (Braun and Clarke, 2006, Ritchie et al., 2003). I was part of a team of researchers that analysed the interview data, working with QSR International's NVivo10 qualitative data analysis software. For this thesis chapter I selected interview data relevant to the role of information and carried out a focussed thematic analysis by participant group (young people, and parents/carers). Emergent themes were then reviewed and synthesised across groups. Copies of the interview topic guides used in the

interviews with young people and their parents/carers can be found in appendix 3.

This chapter consists of a submitted manuscript that shares the findings of this qualitative study of the role of information in ADHD transitions. This manuscript has been submitted for publication to the journal *BMC Psychiatry*, and is currently under review (Price et al., In submission-c).

### **3.2 The role of information in health transitions for young people with ADHD: manuscript submitted for publication**

In transition with ADHD: a qualitative analysis of the role of information, in facilitating or impeding young people's transition into adult services

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### 3.2.1 Abstract

**Background:** United Kingdom (UK) National Institute for Health and Care Excellence (NICE) guidelines emphasise the need for good communication of information to young people and their parents/carers about what to expect during transition into adult services. Recent research indicates only a minority of young people in need of transition for Attention Deficit Hyperactivity Disorder (ADHD) experience continuity of care into adulthood, with additional concerns about quality of transition. This qualitative study explored the role that information plays in experiences of transition from the perspectives of parents/carers and young people.

**Methods:** Participants were recruited from 10 National Health Service Trusts, located across England, with varying service configurations. Ninety two qualitative interviews were conducted: 64 with young people with ADHD at different stages relative to transition, and 28 with parents/carers. Thematic analysis of data was completed using the Framework approach.

**Results:** Interviewees reported a range of experiences; however reliance on parents/carers to gather and translate key information, and negative experiences associated with poor communication of information, were universal. Three themes emerged: Navigating information with help from parents; Information on ADHD into adulthood; Information about the transition process. The first revealed the essential role of parents in the translation and application of information, the other two explored distinct types of information necessary for a smooth transition. Interviewees made recommendations for clinical practice similar to UK NICE guidelines. It was important to interviewees that General Practitioners had a basic understanding of adult ADHD and also had access to information about service provision.

**Conclusions:** Our findings illustrate that the availability and communication of information to young people and their parents/carers is an essential component of the transition process between child and adult ADHD services. How and when it is provided may support or impede transition. This study constitutes a substantial contribution to the evidence base, drawing on interviews from a range of participants across England and from Trusts offering different types of services.

**Keywords:** ADHD, Transition, Information, Qualitative, Adolescent, Mental Health

### 3.2.2 Background

Attention deficit hyperactivity disorder (ADHD), is increasingly recognised as a condition which can persist into adulthood (Faraone et al., 2006). Historically, services for ADHD were only provided for children, but as more studies demonstrated impairment into adulthood for some young people (Mannuzza et al., 1993, Wilens et al., 2002), the need for services that could support them became evident. The 2008 National Institute for Health and Care Excellence (NICE) guidelines were the first in the United Kingdom (UK) to recommend treatment for adults (NICE, 2008). Despite these recommendations, recent research indicates that only a minority of young people with ADHD in need of transition experience continuity of care into adulthood, with concerns about the quality of the transition (Eke et al., In submission-a, Singh, 2009, Tatlow-Golden et al., 2018).

Young people with ADHD may be particularly vulnerable to experiencing a disruptive transition due to a number of inter-related factors, which include the core symptoms of ADHD and the associated difficulties in organisation, variation in provision of adult ADHD services, negative and sceptical attitudes of professionals, and a lack of knowledge and training about ADHD in adulthood (Belling et al., 2014, Eke et al., In submission-a, Hall et al., 2015, Hall et al., 2013, Matheson et al., 2013, Tatlow-Golden et al., 2016). For young people who need ongoing support for their ADHD, a move to adult services may be experienced as disruptive and distressing, while the failure to complete transition into an adult service is likely to leave them without treatment. The resulting impaired functioning increases the associated adverse health, social, educational and occupational outcomes (Chang et al., 2014, Lichtenstein et al., 2012, Singh and Tuomainen, 2015, Young et al., 2011).

The sharing of information with patients has long been recognised as a crucial component of health care; Coulter and Ellins (2007) reported that information sharing has an impact on patients' knowledge, understanding and experience of their condition, their use of services, and their general health behaviours. Active

self-management of chronic conditions both for young people and adults often relies heavily on high quality information and communication practices (Adams, 2010, Wagner et al., 2001), yet concerns over the availability and accuracy of information are often raised in studies of ADHD (Ahmed et al., 2014). Misperceptions about the nature of the condition and its management are common both in wider society, and amongst young people with ADHD and their parents and carers (Ahmed et al., 2018, Bussing et al., 2012b, Partridge et al., 2014, Richardson et al., 2015). This 'misinformation' can have significant consequences, for example, when examining adolescents' decision making processes around medication, inaccurate information and beliefs were related to non-adherence (Schaefer et al., 2017). A lack of knowledge about ADHD as a condition that can persist into adulthood and the management of adult ADHD has also been reported amongst clinicians, which could translate into poorer provision of relevant and accurate information for young patients about what to expect from 'living with ADHD' (Ahmed et al., 2018, Matheson et al., 2013, Newlove-Delgado et al., 2018b).

Information and communication play a prominent role in the recommendations from both the NICE (2016) guidance on transition in general and the guidance on ADHD (2018b). NICE recommends that young people and their parents and carers are given information about what to expect from adult services and what support is available to them; and that information about the young person is effectively communicated between child and adult services (NICE, 2016, NICE, 2018b).

The aim of this paper is to explore from the perspectives of parents/carers and young people, the role that information plays in experiences of transition into adult ADHD services, how this impacts on transition outcomes and how it affects engagement and agency of the young person. It is based on an analysis of the qualitative data gathered during the 'Young people with ADHD in transition from children's services to adult services' (CATCh-uS) study. CATCh-uS is a multi-strand research project on ADHD transitions, which included a qualitative study

interviewing young people, their parents/carers, and clinicians (Janssens et al., In preparation), from which information arose as an important theme.

### 3.2.3 Methods

NIHR funded the CATCh-uS project which applied mixed methods to investigate transition from child to adult services for young people with ADHD (Ford et al., 2015). CATCh-uS included a large qualitative exploration of stakeholders' experiences of the transition process, which involved interviews with young people, parents, and clinicians. Ethical approval for this element of the study was granted by NRES South Yorkshire Ethics Committee: Yorkshire & the Humber (REC Reference: 15/YH/0426) and the University of Exeter Medical School Research Ethics Committee (REC Application Number: 15/07/070). For full details of recruitment strategy please see the CATCh-uS report (Janssens et al., In preparation).

This paper focuses on two of these stakeholder groups: young people, and parents of young people with ADHD. To explore differences at each phase of the transition process, we recruited three groups of young people:

- in children's services (*pre transition*)
- just transitioned directly from child to adult services (*at transition*)
- young adults diagnosed with ADHD in childhood who disengaged with services for at least a year before re-entering adult services (*no transition*)

A fourth group was comprised of parents of young people from each of the above groups.

#### *Sampling and recruitment*

Both young people and parents were recruited via 10 participating National Health Service (NHS) provider organisations (Trusts). Five trusts were purposefully selected to capture regional variation as well as a range of service models for the provision for adults with ADHD (South London and Maudsley NHS

Foundation Trust, Berkshire Healthcare Foundation NHS Trust, Devon Partnership NHS Trust, Coventry & Warwickshire Partnership Trust, Nottinghamshire Healthcare NHS Foundation Trust). Participants were also recruited from five other NHS Trusts that subsequently volunteered to recruit towards the study via the NIHR Clinical Research Network: South Staffordshire & Shropshire Foundation Trust, Leicestershire Partnership NHS Trust, Lincolnshire Partnership NHS Foundation Trust, Somerset Partnership NHS Foundation Trust, and Sussex Community NHS Foundation Trust.

We aimed to recruit 20 to 25 young people for each of the three groups, as well as a similar number of parents/carers, henceforth referred to as parents. All parents had a child in services; dyads of parent and young person were accepted. We recruited for all four groups using a sampling matrix to ensure variety in: location and type of service provision (with or without follow-up adult services for ADHD), gender, comorbidity, and residence of participant (with parents or elsewhere), and occupation (school; higher education; employment; or not in education, employment or training). We also aimed to recruit parents of children who were still with children's services, had transitioned directly or had experienced some time without services.

Recruitment of young people and parents was continuously monitored to ensure that the sampling frame was being evenly populated, with a focus on harder to reach groups, such as young women. Eligible participants were approached by staff from the NHS Trust that they attended. Once participants had agreed for their details to be shared with the research team, they were contacted by a researcher to arrange an interview. Participants could choose how (face-to-face or via a telephone) and where they were interviewed (home, hospital, public place or over Skype) and whether or not a companion attended the interview.

Informed consent was gained from all participants aged 16 years and above. For participants under 16, their assent and the consent of a person with Parental Responsibility (as defined by the Children Act 1989) was gained. For all

participants, written consent was documented prior to the interview and all young people were offered a £10 voucher as an incentive.

Decisions about sample size drew on our experiences of previous studies on transition and wider methodological findings regarding the anticipated stage in data collection when data saturation is likely to occur (Mitchell, 2014; Beresford, 2014).

#### *Interview procedure*

AP, AJ and HE conducted semi-structured interviews using a topic guide (see appendix 3), informed by existing literature on transition and the project's parent advisory group and covered the following topics:

- current and future medication use
- current and future contact with services
- preparation for and/or experiences of the transition process
- views on key elements of optimal transition

All interviews were digitally voice-recorded and transcribed verbatim.

#### *Data management and analysis*

Data collection and analysis of young people and parent interviews were split into two phases to allow for an interim analysis to assess data saturation, refine the topic guide to reflect unanticipated emerging themes, and adjustment of the sampling frame to reflect all important stakeholder groups (phase 1: 1 April 2016 until 30 November 2016, Phase 2: 1 March 2017 until 31 May 2017).

Each recruited participant was assigned a unique identifier code; descriptive data on the participants were stored in an encrypted spreadsheet. Interview recordings and transcriptions were stored on an encrypted hard drive. Once transcribed, interview data were managed using QSR International's NVivo12 qualitative data analysis software (2012) and were stored securely and password protected. The interviews were analysed by the research team using thematic analysis with

framework (Gale et al., 2013). This method facilitates systematic and transparent data analysis, and enables researchers to identify patterns or commonalities, as well as contradictions in and between participants' accounts, so they can explore and test explanations for those patterns (Ritchie et al., 2003, Ritchie et al., 2013).

The first stage of analysis 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, used to code all remaining interviews. The next stage involved writing summaries per interview for each of the codes, resulting in a separate summary matrix for each of the three groups of young people and parents' group. This allowed for comparison, exploration and explanation of patterns emerging (Braun and Clarke, 2006, Ritchie et al., 2013). For the purpose of this paper, themes related to information during the transition process were extracted from each of the summary matrices. Themes and subthemes were then synthesised across the four groups of participants.

#### **3.2.4 Results**

A total of 64 young people at three different stages relative to transition, and 28 parents were interviewed from 10 NHS Trusts across England, see table 3. Table 3 illustrates that we successfully recruited some young women with ADHD of each age group, but only three fathers. For further participant details, see the CATCh-uS report (Janssens et al., In preparation).

Table 3. Transition stage, gender and age-range of participants

Stage	Gender			Age-range	Total
	M	F	F&M		
Pre transition	16	5	-	14-17	21
At transition	13	9	-	17-21	22
No transition (re-entered as adult)	15	6	-	19-29	21
P=parent	1	25	2*	N/A	28
Total	45	45	2*	14-29	92

*M=male, F=female, F&M=female and male, \*both parents present, and interviewed together*

Three themes emerged illustrating the impact of information on young people's experiences of transition into adult ADHD services, their transition outcomes, and their confidence in their ability to self-manage their condition:

1. navigating information with help from parents
2. information on ADHD into adulthood
3. information about the transition process

The first referred to the essential role of the parent in navigating information, and the two others exposed two distinct types of information necessary for a smooth transition. Interviewees reported a range of experiences, however a reliance on parents to gather and translate key information, and difficulties and negative emotional experiences associated with poor quality communication of information, were universally reported. These are detailed below, for a summary see table 4.

Table 4. Descriptive themes and sub-themes, with stages relative to transition at which they emerge

Theme	Stage *	Sub-theme
Navigating information with help from parents		<i>Parent</i>
	0,1,P	Translates treatment experiences; interpreting clinical advice for young person.
	0,1,X,P	Retains informed overview of ADHD as a condition; holds understanding of young person's potential long term treatment needs often when young person cannot; can guide treatment decision.
	0,1,X,P	Persistently seeks service information necessary to continue access to care.
	0,1,P	Navigates and manages administrative information on behalf of young person; for example helping record appointment dates, and locate service addresses.
	X,P	Attempts to access information and signposting to services through General Practitioner (GP); often without success.
	1,X,P	Coaches/supports young person in navigation of administrative information; helping them practice information management strategies.
	0,P	Role effectiveness limited by parent's understanding of ADHD and knowledge of service provision.
		<i>Young person</i>
	X	Seeking information necessary to access care is impossibly difficult.
X	When asked GPs do not provide appropriate information.	
X	Communicating with adult services is difficult and distressing.	
Information on ADHD into adulthood	0,1,P	Informed will definitely grow out of ADHD; unhelpful and inaccurate.
	0	Limited information provided about condition; good start but many want to know more.
	0,1,P	No information given.
	1,X	Told might/might not grow out of ADHD; starts process of self-reflection.
	1,P	Understands long term support may be needed; thinks about future care.
	1,P	Sufficient information provided; develops a nuanced understanding of long term care needs.
	0,X,P	Wants information about ADHD as a condition to come from experts (clinicians); relying on parent not sufficient.
Information about the transition process	0,1,X,P	No transition information provided; one young person did not mind, many felt left 'in the dark'.
	0	Basic information provided, that transition may happen.
	0,1,X,P	Insufficiently detailed information provided to enable young person to prepare for transition.
	1	Sufficient information provided; emotional comfort and confidence in transition process.
	0,1,X,P	
	1,X	Relies on information from informal sources; often worrying, which causes distress.
	X,P	No contact point for information during transition, or when out of services; highly distressing.
	1,X,P	No information on how to re-enter services as adult; a barrier to accessing care. GPs are key point of contact; but inconsistent and confusing sources of information, leading to difficulties accessing care and emotional distress.

\*Stage at which theme present

0=pre-transition; 1=at-transition; X=no-transition (re-entered as adult). P=parent. F=female, M=male

Recommendations for clinical practice were made by interviewees, these are presented in figure 3 with supporting material in appendix 4. They included:

- *when* to start communicating about transition
- *what* information to share, and
- *ways* of communicating relevant information

### **Recommendations for clinical practice, as reported by participants**

1. *Equip GPs so that they understand ADHD as a condition and can signpost to services.* As gatekeepers of services, GPs need to have a basic understanding of ADHD and knowledge of appropriate services.
2. *Start sharing key information more than a year in advance.* Make this a staged process, with time for the young person to reflect and discuss options.
3. *STAGE 1: Provide an initial overview of ADHD as a condition* including the fact that it could potentially be lifelong, and of the transition process. Let the young person know they may or may not continue to be affected by ADHD. Explain the transition process. Include a discussion of options for re-entry into services.
4. *STAGE 2: Provide nuanced information about the young person's ADHD needs,* combined with detailed information about the transition process. This is important for the young person to be able to start engaging in managing their own condition and planning their engagement with adult services.
5. *Take ADHD into account when providing information and include parents/carers or other advocates.* People with ADHD may struggle to focus on administrative detail and can be overwhelmed by too much information. Parents/carers play a crucial role in translating and navigating key information for young person.
6. *Provide information about being in adult services,* including:
  - a. Letting them know if they are likely to be able to access adult services.
  - b. Explaining differences between child and adult services.
  - c. Sharing information about the new clinician/team.
  - d. Communicating the physical location of adult services.
7. *Share information between child and adult services.* If adult services know about the young person in advance it reduces burden on young adult to communicate, and helps ensure appropriate care.
8. *Provide a point of contact during transition.* Ideally a named person who knows young person. At the least a way to access information in an emergency and updates on waiting times.

Figure 3. Recommendations for clinical practice (for supporting quotes see appendix 4)

### *Navigating information with help from parent*

*Parent essential:* Having a parent to seek, navigate and translate information about *ADHD into adulthood*, and *transition between services* was a crucial aspect of service engagement for the majority of young people. The term 'navigate' encapsulates the way parents steer the young person through transition, by finding and helping them process the information they need. Without such advocacy, many would not have transitioned.

*"If I didn't have the parents that I did, I'm scared to imagine where I would've ended up because it's not good. It's not good at all."* F-1

*"[Without mum] I'd have no clue. I wouldn't have known about the medication types, I wouldn't have known that there was an adult services I could go to and I wouldn't have done it myself"* M-1

The reliance on a parent for support was not defined by chronological age. Young adults also reported needing the support of a parent to find and manage information needed to re-access care as adults.

*"We had to do all the research. When I decided that I wanted to try again we had to do the research and start from scratch basically."* F-X

*"All I can remember is my support worker from my hostel taking me there... I didn't know where to go and I think she helped me, pushed me in the right direction, yes she did that."* M-X

*Persistently seeking information:* In the majority of cases, the information on *ADHD into adulthood* and *on transition processes* needed for a young person to transition into adult services was not readily available, and parents demonstrated incredible persistence in their attempts to access it.

*"From the age of 17 I was on the paediatrician's back saying, "Look, what happens next? Can you refer us to adult ADHD?" ...So I found all the information out, I went to my paediatrician with that and said, "Look, can you refer us to this?"* F-P

Many parents approached GPs for information, but for the majority this was not a successful strategy.

*"I think mental health services are one of the areas that possibly GPs don't know enough about."* F-P

"It should be easier for parents with their GPs, so there should be more information for GPs and an easier referral system...so that there's a degree of support there from the beginning before the actual disillusionment and the stress and all the rest of it and the isolation," F&M-P

*Teaching information management:* A few parents described coaching young people in the development of administration and information management skills needed to gradually increase self-management.

*"I do what I can. I sit and help him fill in the application forms, I talk to him about it."* F-P

*"I am helping X become an adult... I'm moving him secretly into his life."*  
M-P

*No information support; no transition:* Those young adults that had not transitioned appeared not to have received sufficient information pre transition, and reported multiple failed attempts to access information about treatment in adult services.

*"I don't think there's really a straightforward route people can go and find out for ADHD."* M-X

*"I've been begging for help for absolute f\*\*\*ing years."* M-X

Some reported chaotic service structures that made maintaining contact or finding out what was happening incredibly difficult, leading to a sense of failure and experiences of emotional distress.

*"Every time I ring I never get through to anyone. ...it seems to go around loads of different offices. I ring up someone and I say, 'Oh, can you check?'"*

*and they say, 'You're not part of our department. We'll put you through to another one...It's getting me down because I want to know where I'm going, what direction I'm going in and I'm getting mixed signals from both different professionals....It got me worried.'* M-X

Without support from a parent, these young people were confused by complex systems, could not stay engaged with services, and were therefore unable to access treatment.

*"I rang them up to tell them that I've moved ... and just got voicemail after voicemail. I left a voicemail and I still haven't heard back."* F-X

#### *Information on ADHD as a lifelong condition*

*Pre transition:* Before transition, although registered with a health service and receiving treatment for their ADHD, young people and their parents reported very little understanding of ADHD as a lifelong condition and a distinct lack of information on what this might mean for the young person as they entered adulthood.

*"Don't know what to expect, haven't thought about it."* M-0

*"I don't know. It just remains to be seen."* F-P

In some cases they had been given the misleading message that ADHD would definitely not be an issue into adulthood.

*"We've been under the impression that ADHD is not recognised as an adult problem in this area. Like they're supposed to grow out of it at 18."*

M-0-(P)

In the context of being interviewed about transition, some young people and parents expressed a desire to understand more about *ADHD into adulthood*. They believed this would help them to prepare for the future.

*"I think it would be useful if ... they were spoken to by someone ... saying, 'You are 16 now, there's lots of options that you can do... to have someone who knows about ADHD to say, 'these are your options.'" F-0-(P)*

Some young people wanted to know more about ADHD to help them to develop more insight into their condition.

*"For me it's all about finding out why I have it, what it actually is and what can be done to change it in the future." "It's nice to almost have that... insight." F-0*

*"I feel like if I was briefed on what knowledge people have about ADHD and why I have it ... I'd feel a lot more comfortable." M-0*

They wished to learn from people with expert knowledge.

*"He would like a relationship with someone who he can ask these questions of ...consistency with a knowledgeable, qualified person that can actually help him move into adulthood." M-0-(P)*

*At transition:* For those young people at transition whose clinicians had not discussed *ADHD into adulthood*, this uncertainty was linked to significant distress and confusion about how they would manage without treatment.

*"I said because I'm going to uni hopefully, I probably want to stay on the medication. So yeah but then in the Child's place they were talking about taking me off it. ...I don't know how it's going to happen? I'm just like going to be taken off of it at some point and then expected to be able to move forward without doing anything else? I don't really know. But no they haven't really said anything about that." F-1*

By contrast, those that had been provided with the basic information by their clinician that their ADHD might continue to affect them into adulthood, had some limited understanding about potential future treatment needs.

*“So it could get worse or it can ease off and you tend to grow out of it. But I don’t think I’m going to grow out of mine. I can’t see it happening.” M-1*

The more detailed information young people had about their ADHD and ways it might change, the more self-reflective and nuanced their discussion of future needs appeared to be, including consideration of ways they might self-manage their condition.

*“I know that it’s not going to be a quick fix... I want them to give me the tools and I’ll build the house. I don’t expect them to do it for me, but...” F-1*

*“She assessed me before I finished and just said my ADHD has calmed down from when I was little and it will probably calm down a bit more when I get older, but I will still always be that hyperactive child... she [clinician] said as you get older I will start to recognise signs more and learn how to control it.” F-1*

Developing a nuanced understanding of ADHD as a condition, including the fact that symptoms may change over time; that environments such as jobs or studying may interact with their symptoms; and that use of self-management strategies can improve with maturity, may promote positive attitudes to self-management as well as help seeking in the young person and parent.

*“I’d say information for empowerment, definitely, is what adults need around ADHD, and teenagers especially so they can know their condition.” M-X*

*No transition:* The majority of young adults who had not transitioned had received inaccurate or no information about *ADHD into adulthood*.

*“I thought you just grew out of it. And so there was no information about being an adult with ADHD, like jobs might be hard sometimes and stuff like that.” M-X*

Looking back, they expressed anger, regret and distress that they had not been informed properly as teenagers.

*“I feel bad speaking ill of my psychiatrist there because he did help me ... but he did leave me under the impression that I wouldn't have any more issues with ADHD and it's not something that I'd need to be... I'd need to see in the service anymore....I felt there was misinformation, yes.” M-X*

*“Even medical professionals, they all told me, ‘It will go away when you're about 17 or 18 and you'll be a normal person.’...It's the biggest crock I have ever heard.” M-X*

Several parents reported that their GPs' lack of understanding about ADHD was a barrier to accessing treatment or support.

*“I think that's critical. That's your first point-of-call, I would have thought... She just said, ‘Tough love.’ I'll never forget that.” F-P*

*“My GP has absolutely no idea about anything. He's been telling me and X his whole life there's nothing wrong with him. So I don't know how I would re-access those services.” F-P*

For all young people and parents' a basic understanding that ADHD might continue into adulthood appeared to be related to understanding the need to remain engaged with services. Developing a more nuanced understanding of ways ADHD symptoms might change with age appeared to be related to a reflective approach to self-management of symptoms into future, for example through learning and applying strategies.

#### *Information about the transition process*

*Pre transition:* The majority of young people approaching transition reported that they had been provided either with very limited or no information about the process. They did not know if or when transition might occur, what processes were involved or what to expect of adult services. While some of the youngest in this group were not concerned at this lack of detail:

*"It won't affect me, I'd probably still carry on."* M-0

By age 16 the majority wished to know about the transition process in advance so that they had time to plan and prepare themselves for change.

*"I'd have to know what they'd even do to be able to ask questions."* F-0

*"I'd rather have time to plan...I don't like sudden changes."* F-0

*"Instead of just being left in the dark after you've left the child stuff."* M-0

*"I'd rather it sooner than later because then I know what to expect ...because it's my future and I don't really know what's going to happen."*

M-0

Some of the eldest pre-transition interviewees' expressed anxiety about the lack of information on services for adults, fearing their symptoms might become worse if they did not have health service support.

*"I kind of worry that it's going to get to a point where I won't know where to go...it will just get worse and the cycle will start."* F-0

Parents of young people pre-transition stated a need for clear information about available services, which was not met.

*"A list of all the services and how to access some would be really good. Also not just services to do with his medical needs but also the wider things."* F-P

*"It would be nice if there was more information about the adult service. It ought to be almost a seamless transition...I don't really understand why there seems to be such a barrier."* F-P

In their role supporting young people, parents explained that they needed to know about transition in advance to make plans, prepare the young person for change, and help them manage their anxiety.

*“Having someone say before he got to 18, saying 'Look you know it's going to end when he's 18, the services here, you'll then need to go to...' I could have had something in place or you know but I weren't actually given that opportunity.” F-P*

*“Yeah it's being informed. If you're informed then you've got like ahead of the game if you know what I mean? You feel like you can prepare the ground ready for them to come into it. But as I am now...I'm like, I don't know nothing X, and that obviously with anxiety kicking in that's not good.” F-P*

Faced with a lack of information about the transition process, some parents relied on informal sources of information. In these cases, reports of poor adult services and transition failures tended to increase their concerns.

*“I am dreading him going, changing over services, because I know what mental health services in X are and I know how awful they are at the moment and I know there is hardly any.” F-P*

*“It scares me from people that I've known...it makes me nervous as to what will happen when he comes out of Children's Services.” F-P*

*At transition:* Several young people already in the process of transition still had no information about where they were going after reaching the age boundary for child services, or what would happen.

*“[I] kept ringing the numbers to see where I was going, but no one would ever answer.” F-1*

*“Not a clue. I don't know even if there is a building.” F-1*

Having no point of contact or named person to advise them on simple procedural matters, such as the address of a service, or time remaining to wait for an appointment, caused intense distress. For many this also had an impact on concurrent life events such as exams.

*“...panic stations and not coping with the thought of being 18... As it is now, I don't even know where it is. I don't even know the name of it. So I know nothing.” F-P*

*“When I called they juggled me round departments for ages and then realised that they hadn't even sent the letter out, so after two weeks in exam season of not having any clue, I was then told that they hadn't done anything...” M-1*

The majority of young people at transition reported not knowing what to expect from adult services which meant they felt unable to prepare themselves. This affected their first experiences of adult services.

*“It was a bit intimidating...having the information first we would have understood what the place was, but when we first walked in we had no idea” M-1*

*“It doesn't help because I get mega anxious and nervous about new places and not knowing anything about a new place in the first place is...” M-1*

Some reported that their child clinician did not appear to know enough about local adult services to be able to answer their queries.

*“I wanted to know how adults was but she didn't know, that's the truth. No one in CAMHS seems to know what adults is actually like.” F-1*

Not knowing what to expect of adult services was a major cause of distress, so that even if there was a 'successful' transition, the anticipated experience was emotionally stressful and negative. One young person explained how their ADHD affected the way they experience new environments, and why not knowing anything about adult services in advance was so stressful.

*“I describe ADHD as trying to pay attention to everything at the same time. And if you're doing that in a completely new place where you don't know anything, that's exceptionally overwhelming, I completely shut down, I feel incapable... I don't know what their job title is let alone what they look like,*

*let alone their name, let alone what they're like and it terrifies me. When I go in it's going to be awful.” F-1*

A few young people in transition reported receiving sufficiently detailed information in advance and described the transition experience positively, in clear contrast to the majority of interviewees.

*“They gave me some booklets on talking about ADHD and how the adult services will deal with it now and what it’s going to mean for me.” M-1*

*“Yeah, good. They prepared me. They told me all the information, what I needed to know, told me I was moving. They informed me quite a lot.” M-1*

Information about the expected transition from the child clinician, provided early, and repeated over a period of time, appeared to provide a sense of stability at transition stage.

*“She’s always told me about the adult clinic. From a young age she’d tell me that once I get to a certain age I’ll have to leave her and I’m going to have to go to the adult clinic...amazing doctor.” F-1*

Even if the information was that there was no service, it seemed that knowing in advance was better than finding out when they had already left child services.

*“My consultant told me that I probably wouldn’t qualify for the adult psychiatry...at the moment I’m kind of like okay, but I think... when it was first mentioned I was completely distraught.” F-1*

*No transition:* Young adults who did not transition reported having received no information in advance about the transition process.

*“There was no discussion about that. I didn't get told about anything, I didn't know there was any support for adults.” M-X*

*“No paediatrics are aware of it being an adult thing...they are not referring people on to the ADHD adult services for help.” F-X*

*“They didn't say how I could access any services when I get to an adult. They never said nothing really. I've had to find out from other people that I know.” M-X*

Those that had not transitioned, reported that finding out how to re-enter services was particularly difficult. Several believed that it would have been helpful to receive this information before they left children's services.

*“What might have helped because we decided to drop out, if they gave us some information for later on in life in adulthood.” F-X*

*“There was never any discussion about if you do need post 16 care this is where to go, this is how to apply. Nothing like that.” M-X*

For many young adults who had lost contact with child services, one strategy for information seeking involved asking GPs for support. When GPs were well informed, or searched for information on the young person's behalf, this was helpful.

*“Some of them, they really know their stuff but then ... two GPs four streets away don't have a clue. So its consistency, I think.” F-P*

However, many reported that their GP did not understand ADHD as a condition or know about suitable adult services, and therefore provided no support and/or inaccurate information.

*“It would be better if the GP actually knew who to refer you to.” F-X*

*“You should at least go to your GP and be like 'Could I go back on this?' they say 'Of course' you know like I need support well here you go...But I didn't even know about that at all. I wasn't given that information.” M-X*

For many of these young adults, the gap in care they experienced was seen by their parents as linked to serious life issues they had faced, such as problems with the police.

*“If we’d have accessed it when he was 18 I still believe to this day he wouldn’t have been in the trouble he was in.” F-P*

*“So at the point of discharge he was just coming up to his 18th birthday ...from then is when everything started unravelling for him.” F-P*

*[Note: F=female, M=male. 0=pre-transition; 1=at-transition; X=no-transition (re-entered as adult). P=parent. (P) = Parent commenting within young person’s interview.]*

### **3.2.5 Discussion**

Our findings demonstrate that communication of key information on *ADHD into adulthood* and *transition processes*, well in advance of transition in a manner that takes account of the *essential role of parents*, is important for a successful and positive transition experience. These findings support recommendations made in the NICE guidelines for treatment and management of young people with ADHD since 2008 (NICE, 2018b) and are encapsulated in the more recent guidelines on supporting transition from child to adult services (NICE, 2016). However, the majority of participants reported experiences of poor information communication across these areas, associated with emotional distress and difficulties in the transfer of care. Recent research has highlighted how few young people with ongoing treatment needs related to their ADHD successfully transition, as well as low quality transition experiences that fail to adhere to the NICE guidelines for young adults with ADHD (Eke et al., In submission-a, Eke et al., In submission-b) with poor provision of information about adult services identified as a barrier (Price et al., 2019).

#### *Navigating information with help from parent*

Participants with ADHD reported needing help from a parent to gather, navigate and manage the information necessary to access services; a need that continued

into adulthood for all participants. This ties in with the key symptoms of ADHD that have implications for processing and managing information and evidence of delays in brain maturation associated with ADHD (Curatolo et al., 2010, Shaw et al., 2007). At transition, the information processing load is likely to be higher, due to the need to take on new information, manage changing processes and prepare for new experiences, therefore provision of key information in simple clear formats and via several methods, to both the young person and their parent becomes even more crucial.

Not including parents in communication of information, was reported as a barrier to young people's engagement with services in our study, as well as in previous work (Swift et al., 2013, Young et al., 2011). In contrast to the family orientated approach of child services, AMHS tend to adopt an individual patient centred approach which can lead to parents feeling or being 'cut out' (McLaren et al., 2013). This cultural emphasis is in conflict with the reality that many young adults with complex conditions report needing a degree of parental involvement in adult services (Beresford and Stuttard, 2014). In line with the NICE guidelines on transition (NICE, 2016) adult services need to offer an appropriate level of care for young people with ADHD, taking into account developmental maturity. Findings from this study indicate that, planned inclusion of parents in communication of key information, with consent from the young adult, is likely to be required for continuation of care.

#### *Information about ADHD into adulthood.*

In order to engage with adult services, the young person needs to understand that ADHD can be a long term condition (Turgay et al., 2012). For many participants this information was either not being communicated or was not understood. In line with previous research, young adults that had not transitioned reported being 'misinformed' that adult ADHD did not exist (Bussing et al., 2012b, Partridge et al., 2014, Richardson et al., 2015, Young et al., 2016). Many younger participants 'at' or 'pre' transition, had not received information about ADHD as a potentially lifelong condition. ADHD is often diagnosed in early to mid-childhood, and it is important that clinicians revisit diagnosis and prognosis with the young

person and their carer as they mature. However, most child mental health services are structured around episodes of care rather than long term conditions (York and Kingsbury, 2009). Lack of communication about the potential persistence of ADHD into adulthood, more than a decade since the knowledge has been written into clinical guidelines (Greenhill et al., 2002, NICE, 2008) is a service delivery issue that could be addressed at relatively little cost.

As self-management of chronic conditions often relies on effective communication of high quality information (Adams, 2010, Coulter and Ellins, 2007), the development of a nuanced understanding of ADHD into adulthood appears to be related to starting to reflect on self-management of the condition. Several participants wanted more information on ADHD to be provided by 'experts'. While clinicians working in child services have a role in such provision, alternative 'expert' sources such as adult ADHD service clinicians and/or specialist ADHD nurses, should be considered (Taylor et al., 2010).

#### *Information about the transition process*

NICE guidelines recommend provision of practical information about transition processes and adult services as young people approach transition (NICE, 2016, NICE, 2018b). The majority of participants received insufficiently detailed information; lack of information was thought to contribute to failure to transition, and was a cause of emotional distress, which replicates existing evidence that poor information provision may be a barrier to continued access to services (Price et al., 2019).

It is possible that transition information is not provided because clinicians do not know what is available, or are not familiar with eligibility criteria in adult services (Belling et al., 2014, Price et al., 2019, Wong et al., 2009). In the 'Transition from Child to Adolescent Mental Health Services to Adult Mental Health Services' project, failure to transition was more often related to failure to refer, as rejection was assumed, rather than because adult services declined referrals made (Singh et al., 2010a). Transition preparation might also be neglected due to workload and resource limitations (Eke et al., In submission-b).

### *Strengths and limitations*

These data were an analysis from a large qualitative sample, recruited from 10 NHS trusts in different areas, and with different levels of adult ADHD service provisions. We used a sampling grid with an interim analysis to ensure that as broad range of experiences were represented and interviews were conducted using a topic guide that was revised and refocused at the interim analysis. Therefore, we are confident that our data reflects a broad range of lived experience of ADHD into early adulthood. However, only young people currently registered with a service were included in this study. We know little about the experiences of adults with childhood treatment of ADHD who fail to transition and remain out of contact with services, which could be addressed by future research.

### *Implications*

Evaluation is required to establish the most effective methods for information provision to young people with ADHD and their families, without adding to the workload of already overburdened health professionals. Future research also needs to explore ethical issues faced by adult services in balancing patient confidentiality against a need for long term advocacy for young adults who are developmentally predisposed to struggle with managing their long term condition (Bogossian et al., 2018, Young et al., 2011).

As gatekeepers of services, GPs play an essential part in communicating key information to young people with ADHD and enabling to access continued care. However, GPs may feel insufficiently equipped to do this, both in terms of knowledge about ADHD, and in terms of being able to signpost to appropriate services (Newlove-Delgado et al., In submission, Tatlow-Golden et al., 2016). There is consequently a need for evaluation of the best ways to support primary care practitioners in this role, and how shared care arrangements can optimise communication between all providers involved in transition (Coghill, 2017, Goodman et al., 2011). Commissioners and providers also need to produce clear information about local services for adults with ADHD, their remit, and referral criteria, to enable GPs to effectively signpost and refer young people for support.

Currently, there is a great deal of variation in configuration of services for adult ADHD, with some controversy around optimum models of care (Coghill, 2017). Consistent national implementation of NICE transition guidelines with a clear clinical pathway into adult care for young people with ADHD would facilitate the information transfer for clinicians (Eke et al., In submission-b). It would also allow for universal resources such as leaflets and short videos to be produced nationally (and made available via websites and apps), forming a cost effective resource for both patients and health care providers.

### **3.2.6 Conclusion**

This study provides insight into how the appropriate communication of information can contribute to a successful transition and support a young person in their journey towards self-management. Due to developmental delays and processing difficulties associated with ADHD, many young people continue to rely on support from advocates, often parents, into adulthood, so their involvement in the provision of information optimizes the chances of continuity of care. Some instances of poor communication could be addressed with relatively simple measures such as repeated discussions about ADHD as a condition and adult services over their time attending children's services. Improving information provision is likely to have a positive impact on transition outcomes. Understanding and, where possible, addressing barriers to appropriate communication of information to this group will be an important step in facilitating transition.

### **3.2.7 Acknowledgements**

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## Chapter four: mapping study

### 4.1 Introduction and overview of chapter

The systematic review in chapter two demonstrated that service availability is an important factor in the success or otherwise of young people's transitions out of children's services. Findings from the qualitative study, in chapter three, emphasised the importance of sharing information about adult services in advance of transition, and reflected current experiences of the poor availability of such information, and also a lack of service provision. Building on these findings, the aim of the mapping study presented in this chapter was therefore to provide a national overview of current service provision for adults with ADHD in the UK.

The mapping study was developed as part of the CATCh-uS project protocol (Ford et al., 2015) and aimed to build on previous work that surveyed directors of mental health Trusts (Hall et al., 2015) by surveying all key stakeholders, including health workers, service users and clinical commissioners. I led and managed the mapping study throughout, including methodology development, data collection, data management, data analysis and the write-up. Because the study was using novel methods, it was run in two phases. Phase one, the development phase, involved a process of stakeholder consultation and iterative development, to test and refine the survey methodology and culminated in a pilot study, run in 2016. Phase two built on lessons learned from the pilot and involved preparing and running a definitive survey in 2018. In addition to data from this national survey, the 2018 mapping study incorporated data from the CATCh-uS surveillance and qualitative studies (Eke et al., In submission-a, Janssens et al., In preparation).

This chapter is organised in two parts. Part one describes the novel mapping methodology that was developed, and communicates the lessons learned. This section consists of a manuscript that is in submission (currently under review) with the *BMC Health Services Research Journal* (Price et al., In submission-b).

Part two describes the definitive 2018 mapping study, including the methodology used, the results, and a discussion of the data collected. Much of the content of part two also forms part of the full NIHR report for CATCh-uS, which will be published in 2019 (Janssens et al., In preparation).

### *Impact*

This work has already made a significant impact for stakeholders. The pilot map of services [http://bit.ly/AdultADHD\\_2016](http://bit.ly/AdultADHD_2016), was shared online via the CATCh-uS study website, and through research partners, resulting in over 34,000 views (University of Exeter, 2016). The definitive map of services was published online in December 2018 (available here <http://bit.ly/adultADHDmap>), with over 2,200 views of the definitive map, at 24<sup>th</sup> April 2019, see appendix 5 (University of Exeter, 2018). I have had multiple requests from service users and health workers, via Twitter (see appendix 6), and through professional and service user networks, to conduct similar mapping exercises to provide data on UK GP surgeries offering ADHD medication through shared care, and to map UK services for people with autistic spectrum disorder (ASD). I am currently working with the UK Adult ADHD Network (UK-AAN) (a professional body that aims to support practitioners) to support them to host and update the map of adult ADHD services into the future. UK-AAN hosting is due to go live by the end of April 2019.

## 4.2 Part one – methodology paper: manuscript submitted for publication

### Seven steps to mapping health service provision: lessons learned from mapping services for adults with ADHD in the UK

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### 4.2.1 Abstract

**Background:** Attention deficit hyperactivity disorder (ADHD) affects some individuals throughout their lifespan, yet service provision for adults in the United Kingdom (UK) is patchy. Current methods for mapping health service provision are resource intensive, do not map specialist ADHD teams separately from generic mental health services, and often fail to triangulate government data with accounts from service users and clinicians. Without a national audit that maps adult ADHD provision, it is difficult to quantify current gaps in provision and make the case for change. This paper describes the development of a seven step approach to map adult ADHD service provision in the UK.

**Methods:** A mapping method was piloted in 2016 and run definitively in 2018. A seven step method was developed: 1. Defining the target service 2. Identifying key informants 3. Designing the survey 4. Data collection 5. Data analysis 6. Communicating findings 7. Hosting/updating the service map. Patients and members of the public (including clinicians and commissioners) were involved with design, data collection and dissemination of findings.

**Results:** Using a broad definition of adult ADHD services resulted in an inclusive list of identified services, and allowed the definition to be narrowed to National Health Service funded specialist ADHD services at data analysis, with confidence that few relevant services would be missed. Key informants included patients, carers, a range of health workers, and commissioners. A brief online survey, written using lay terms, appeared acceptable to informants. Emails sent using national organisations' mailing lists were the most effective way to access informants on a large scale. Adaptations to the methodology in 2018 were associated with 64% more responses (2371 vs 1446) collected in 83% less time (5 vs 30 weeks) than the pilot. The 2016 map of adult ADHD services was viewed 13,688 times in 17 weeks, indicating effective communication of findings.

**Conclusion:** This seven step pragmatic method was effective for collating and communicating national service data about UK adult ADHD service provision. Patient and public involvement and engagement from partner organisations was crucial throughout. Lessons learned may be transferable to mapping service provision for other health conditions and in other locations.

**Keywords:** Mapping, Survey, ADHD, Transition, Health Service Provision

### **Steps identified in running a mapping study**

1. *Engage with patients and the public throughout*, to learn about the target service, test survey designs, request support with data collection and help with sharing findings.
2. *Define what you are trying to map*: be clear and make it understandable for all.
3. *Determine who your informants are*: who are the stakeholders with regards to the services you are trying to map?
4. *Design your survey*: keep questions to a minimum and focus on necessary data. Check acceptability with representatives of each informant group.
5. *Carrying out data collection*: work in partnership with relevant organisations, design a strategy to reach informants. Consider direct email, freedom of information requests and sharing links on social media.
6. *Data analysis*: Design your survey to keep this to a minimum. Check identified services with online records. Then confirm service details with those meeting your target service definition.
7. *Communicate findings*: use visual media and interactive online maps to share findings. Involve research partners in sharing maps with their members.

## 4.2.2 Background

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder that affects a significant proportion of individuals across their lifespan, for which there are effective, evidence based treatments (Bolea-Alamanac et al., 2014). Mental health service provision in higher income countries is separate for children and adults, and the transition often occurs at a key developmental stage (Singh et al., 2010a, Singh and Tuomainen, 2015). Provision for adults with ADHD remains relatively scarce across the world (Coghill, 2017) and is known to be patchy and difficult to access in the UK (Singh, 2009).

Atlases of Health, which map international health service provision using government and expert sources, are well-established tools designed to provide objective and reliable information on healthcare service provision (Fernandez et al., 2015, World Health Organization, 2000, World Health Organization, 2008). The European Service Mapping Schedule (Johnson and Kuhlmann, 2000) is a survey instrument for the description and classification of mental health services. It was adapted by Signorini et al. (2017), and used to survey child psychiatry representatives on the characteristics of child and adolescent mental health services (CAMHS) across the European Union (EU). While valuable, these tools often fail to triangulate government and expert reports of service provision with the experience of service users and clinicians in practice. The general focus also means that they may not capture condition specific information.

The Atlas of Variation series (Public Health England, 2015) uses routinely available data and consultation with clinical experts, to provide government reports (with maps, charts and time-series data) on provision and patient outcomes for a selection of health topics (NHS England, 2018). However, to date, ADHD services and outcomes have not been mapped. The information provided is also highly complex, difficult for lay readers to understand and does not include accounts from service users and clinicians. Independent regulators such as the Care Quality Commission use inspection methodology including consultations with staff and service users and observing clinical practice to provide detailed

reports on the state of care (Care Quality Commission, 2017). Findings are reported in a format that is accessible to a range of stakeholders. However, this is a resource intensive process, and most specialisms are not identified separately from community mental health, which makes it impossible to learn about adult ADHD service provision from these reports (Care Quality Commission, 2017). Without a national audit aimed specifically at mapping adult ADHD provision, drawing on a range of stakeholder sources, it is difficult to quantify and address current gaps in healthcare and make the case for appropriate change.

In a recent survey of every NHS mental health trust in England, senior health professionals were asked to provide information on transition protocols, pathways and commissioned services for ADHD (Hall et al., 2015). Over two thirds of NHS Trusts responded (68%). The survey was designed to be completed by a senior healthcare professional within the trust and it is unknown whether non-response from 17 trusts is simply a gap in data or reflects reluctance to report on gaps in services or other reasons for non-response such a lack of time or personnel. Less than half of the responding mental health trusts in England offered specialist provision for adults with ADHD and less than a third had specific commissioning arrangements for this group (Hall et al., 2015). In a separate survey, all healthcare professionals working in child and adult health services in the East Midlands region of England, were asked about transitional health services for young people with ADHD (Hall et al., 2013). The overwhelming majority of respondents reported a lack of provision (Hall et al., 2013). Despite a relatively low response rate (19%), surveying all staff resulted in responses from a variety of professionals working with people with ADHD including psychiatrists, managers, nurses and paediatricians. This method, although more resource intensive and limited to a smaller geographic area, included perspectives of clinicians working daily with patients. There are risks of bias if only senior healthcare professionals are surveyed. It is possible they will not have daily experience of service provision in practice. It is possible their responsibilities as directors of service may conflict with straightforward reporting.

Our recent systematic review of qualitative research about transition into adult ADHD services found that a lack of available information about adult ADHD services created difficulties in accessing treatment (Price et al., 2019). People with ADHD reported they did not know where to access treatment (Matheson et al., 2013), while some clinicians reported difficulties in finding an adult service to refer patients on to (Wong et al., 2009). This work indicates the importance of information about where services for ADHD are, what they offer and how to access them. Methods used to map ADHD services need to collect data that is relevant and accessible to patients and clinicians as well as service providers and commissioners. Different stakeholders are likely to have different perspectives on what is as well as what needs to be available and it would be interesting to explore differences between provider's reports on service availability and patient experiences of provision.

To extend and expand the findings from previous research (Hall et al., 2015, Hall et al., 2013, Signorini et al., 2017), we piloted and refined a multi-informant, multi-source methodology to map adult ADHD provision in the UK. This paper describes the seven step approach that we developed. The methods used are intended to meet current needs for national service data specific to ADHD and to enable a comparison of differences in reported information by different stakeholder groups.

#### **4.2.3 Methods**

The mapping methodology was piloted in 2016, followed by a definitive study in 2018: the mapping findings are reported in full elsewhere (Janssens et al., In preparation). An iterative process of trialling and reviewing methods (figure 4), led to development of the seven step mapping method described in the current paper (figure 5).

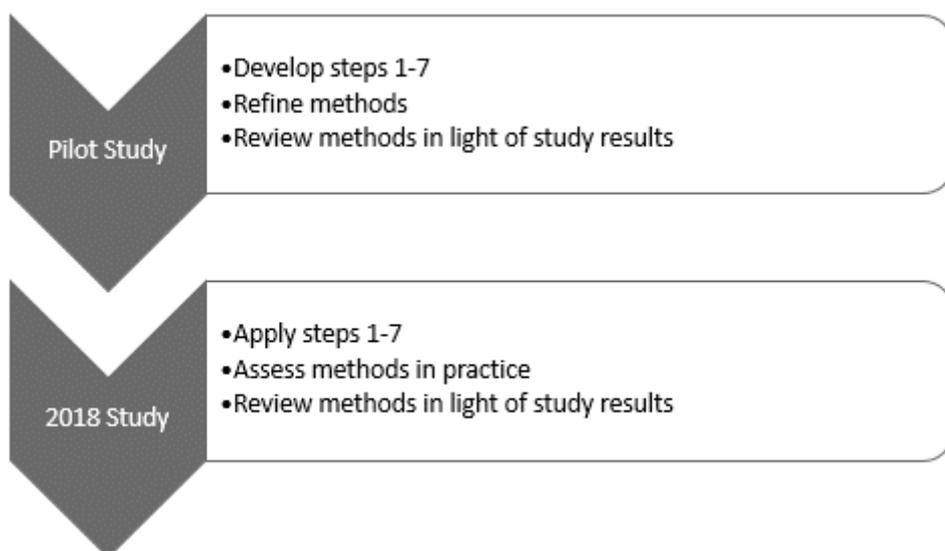


Figure 4. Process of refining methods

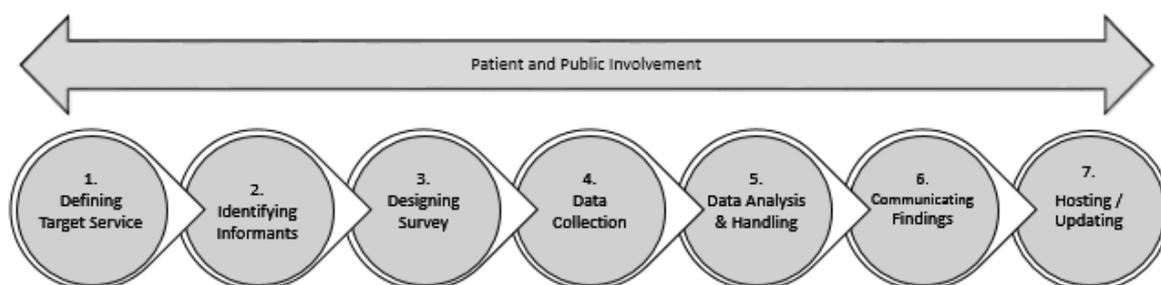


Figure 5. Seven steps to mapping a health service

*Patient and public involvement:* Patients and members of the public (including clinicians and commissioners) were involved with design, data collection and dissemination of research findings. We worked with an advisory group consisting of parents of young people with mental health difficulties including ADHD; consulting with them before the survey launch about who appropriate informants might be; checking language was accessible; testing early survey designs; requesting feedback on how to improve geographic spread and balance of responses; and sharing results from the pilot. Early survey designs were shared with representatives from each informant group and adjusted in line with feedback. Clinical and ADHD focussed organisations were contacted at various

stages and asked to support distribution of the survey, communicate findings and to consider hosting/updating the service list after the research study finished.

### *Step 1. Defining target service*

The UK National Institute for Health and Care Excellence guidelines state the following services should be available for adults with ADHD: transitional care, assessment and diagnostic services, drug titration, monitoring and review, and psychoeducation (NICE, 2008, NICE, 2018b). The most recent guidance is that treatment should be holistic and provided by specialist teams with expertise in ADHD. After titration and dose stabilisation, care may be carried out under shared care protocol arrangements with primary care (NICE, 2018b). In addition, research indicates that due to gaps in services, adults with ADHD may either cease to access treatment or seek help at an extended range of services, including those not commissioned to treat adult ADHD (Wong et al., 2009).

*Pilot:* In light of the complex nature of the provision being mapped, two levels of service definition were employed. Firstly, a broad definition of “*any mental health service for people with ADHD aged 18 and above*” was used in the survey in order to record all services currently accessed by adults with ADHD. Secondly, during data analysis, the definition was narrowed so that only adult NHS specialist, private and charitable services with a focus on treating ADHD or neurodevelopmental conditions were checked to see if they supported/treated adults with ADHD. Applying a broad initial definition allowed us to later narrow the focus while remaining confident that we would be unlikely to miss any relevant services specialising in treating/supporting adults with ADHD.

*2018 Study:* Two levels of service definition were repeated and refined. The first-stage broad definition was kept, with notes added to the survey to make it explicit that a service could be a “*specialist doctor or team, mental health team, clinic, charity or support group that treats or supports adults with ADHD*”. At the second stage, in line with the aims of this research, the definition was narrowed to specialist adult ADHD services funded by the NHS. All services identified by informants were indexed, but only adult ADHD, ADHD and autism spectrum

disorder (ASD), Transition and Neurodevelopmental services were checked during data analysis to see if they offered services as recommended in the NICE guidelines (NICE, 2008, 2018b).

### *Step 2. Identifying informants*

The aim was to survey those receiving treatment/support (service users), those providing services (clinicians) and those funding services (commissioners). As NHS provision is underdeveloped and frequently seems not to adhere to NICE guidelines since 2008 (NICE), it was not immediately clear who those delivering care might be. Without a specialist service, treatment might be sought at a variety of services, including non-specialist NHS services, private and voluntary providers, and appropriate informants might provide treatment or funding for adults with ADHD at any of those services.

*Pilot.* Informants were initially identified by considering those in contact with young people with ADHD as they approach the age where they need to transition to adult services. This highlighted child and adolescent psychiatrists, adult psychiatrists and paediatricians, as well as young adults and their parents/carers. Clinical Commissioning Groups (CCGs) in England, Health Boards in Scotland and Wales and Health and Social Care Trusts in Northern Ireland are, to varying degrees, responsible for planning and commissioning health care services for their local area and therefore hold a key role in funding adult ADHD services. Different informants in different areas held varied knowledge and understanding of services, which emphasised the need to consult the widest range of stakeholders possible in order to be confident that all relevant services were identified. *2018 Survey.* In addition to informants identified for the pilot, general practitioners (GPs), nurses, practice managers and administrators were included, as it had become clear from pilot responses that individuals in these roles also played a significant part in service provision. Pilot responses revealed that many informants identified with more than one role. Therefore, respondents were given the opportunity to indicate additional roles. Respondents might, for example, indicate '*Parent of child with ADHD*' was their main role while also being a

'*Psychiatrist*' and '*Adult with ADHD*'. Health commissioners across the UK were also identified.

### *Step 3. Designing the survey*

An online survey method, Survey Monkey, was used as a pragmatic way of gathering data from a wide range of UK stakeholders, with the aim of covering a wide geographic area and minimising gaps in the data. Surveys were designed using lay terms to be accessible to all informants.

*Pilot.* The survey was made up of 9-15 questions, dependent on responses given, and collected demographic and location specific information about respondents. Survey respondents were asked to identify themselves as a: young person, young adult, parent/carer, clinician or other. If the response was 'other', details could be provided using free text. Five core questions asked whether respondents knew of any services for adults with ADHD in their area, and if they did, to provide details. Wording and content were developed iteratively in consultation with parents/carers, clinicians and commissioners to ensure relevance and acceptability. Separate versions were created for each stakeholder group to enable collection of detailed demographics (see appendix 7).

*2018 Survey.* The survey was brief, with 5-9 questions, and was merged into a single version for all respondents (see appendix 8). Basic demographic information was collected and questions about informant location were limited to a predefined list of UK regions and postcodes to simplify data collection. The same core question was asked about knowledge of services, but without requesting treatment details as responses to these questions in the pilot had been varied and unreliable. Respondents were shown a list of services identified in the pilot and given the opportunity to indicate which of these they knew of, before being asked to provide details of any other services. After identifying a service, informants were asked to indicate if they or anyone they knew had experience of using that service for treatment/support of adult ADHD. This question meant

services that were 'known of' could be separated from those that informants had 'experience with' in relation to adult ADHD support.

#### *Step 4. Data collection*

*Pilot.* Survey links were distributed to informants via three main methods: direct email from mailing lists of national organisations; in newsletters; and on websites. Awareness of the research was raised through university press releases, conference presentations and social media (Twitter). Initially, the survey was emailed to CCGs in England. Following review this strategy was changed to use of freedom of information (FOI) requests. FOIs give individuals the right to access recorded information held by public sector organisations (Information Commissioners Office, 2016).

*2018 Survey.* Data collection was planned in advance with research partners such as AADD-UK, the ADHD Foundation and the Royal Colleges of Psychiatrists (see appendix 9). Where possible, emails were sent out via research partners' mailing lists and used to share a link to the survey. The NIHR-funded Clinical Research Network (CRN) South West arranged to distribute emails via all regional CRNs, specifically targeting nurses, GPs, managers and clinical psychologists. The Twitter strategy focussed on sharing the survey link (possible because of the single survey design) and tagging appropriate organisations.

In preparation for the 2018 survey, a UK-wide dissemination strategy was planned, including contacting health boards in Scotland and Wales and trusts in Northern Ireland, as the pilot survey had not contacted funders/commissioners from these areas. Part-way through data collection, we checked responses to identify under-represented locations/informant groups. This allowed subsequent targeting of ADHD focussed and clinical organisations in those locations, with the aim of improving the balance of responses.

### *Step 5. Data analysis and handling*

*Pilot:* Survey responses were uploaded into Excel, reviewed by two researchers and checked against the limited information available online to create a list of identified services. Those potentially offering support/treatment to adults with ADHD, were contacted by a research nurse via phone or email to confirm the type of service (for example, private, NHS, voluntary, specialist or generic) and details of treatments available. Child services were excluded from service checking.

*2018 Survey:* During data collection, response balance was assessed using Survey Monkey. Then data was uploaded into Excel and analysed using STATA SE15 (StataCorp., 2017). Responses were checked against online information to create a list of identified services. Online information was often out of date or didn't specify whether adult ADHD was treated, but checking allowed researchers to link identified services with the relevant organisational provider. Services potentially meeting the definition of specialist adult ADHD services funded by the NHS were checked by sending FOI requests to the relevant health trust, to confirm details of provision (see appendix 10). Child and adolescent, generic adult mental health, privately funded and voluntary services were excluded from service checking.

### *Step 6. Communicating findings*

Response numbers were presented by informant group and location using a geographic information system, QGIS 2.18 (2018), to analyse and display the data. Shapefiles for UK counties and regions were imported (McGarva, 2017, Office for National Statistics, 2016). Checked services, with details, were listed in Excel and uploaded to an interactive Google My Map.

*Pilot:* A Google map of checked services was posted onto the project website (University of Exeter, 2018). The map included a disclaimer stating it was 'a *work in progress...and not definitive*' (University of Exeter, 2018). Services were categorised as NHS specialist, charity or private. Partner organisations

embedded links to the map on their websites. Findings were shared via social media.

*2018 Survey.* Results were communicated using the same methods as for the pilot. These are reported elsewhere in full (Janssens et al., In preparation).

#### *Step 7. Hosting/updating service map*

The pilot service map was updated in 2018, following the definitive survey. Two partner organisations, AADD-UK and UK Adult ADHD Network, were invited to host (and potentially update) the map of adult ADHD services once the research ends.

### **4.2.4 Results**

#### *Defining target service*

Use of two levels of service definition led to two lists of services. The first was a comprehensive and inclusive index of the wide range of public, private and voluntary services in the UK reported by informants, where adults with ADHD could access treatment/support. The second was a map of NHS funded specialist ADHD services, with details about treatments available.

In the pilot study, respondent provided information on treatment/support available at services was unreliable as conflicting details were given for the same service, and these questions were removed in the 2018 study. Checking specifications of provision via the service/relevant NHS trust at the service checking stage provided more consistent data. The inclusion of a question in 2018, asking informants if they knew of someone who had used the service, made it possible to distinguish services which informants had direct knowledge of from those they had just heard of.

### Identifying Informants

Targeting a range of key stakeholders made it possible to investigate differences in service knowledge between groups. During the pilot, ongoing qualitative research (Ford et al., 2015) highlighted the important role of primary care clinicians as gatekeepers of specialist services, and data collection was adjusted part-way through the pilot to include GPs.

Free text responses of ‘*other*’ to the identity question in the pilot provided data which was used to populate the list of stakeholder identity options in 2018 (see table 5). The pilot received 224 (15%) responses of ‘*other*’, compared with 86 (4%) in 2018, indicating this was a more acceptable list of pre-populated options.

Table 5. ‘Identity’ categories used in the pilot and adapted/added to for the 2018 survey

Pilot	2018
Young person (from 14 up to 17 years old)	Young person with ADHD (up to 17 years old)
Young adult (18 or older)	Adult with ADHD (aged 18+)
A parent/carer of a person with ADHD	Parent/carer/partner of someone with ADHD
A clinician working with young people and/or adults with ADHD	In an ADHD support role (e.g. voluntary, support work or training)
Paediatrician	Paediatrician
Psychiatrist	Psychiatrist
GP	GP
Other (please specify)	Clinical Psychologist
	Educational Practitioner (e.g. Support worker, Teacher, Behavioural Support, Ed Psych, EWO)
	Nurse
	Manager
	Allied health professional
	Researcher or academic
	Administrator
	Clinical commissioner
Other (please specify)	

*Ed Psych* = educational psychologist, *EWO* = education welfare officer

In 2018, the addition of a question giving informants the opportunity to specify additional roles they identified with worked well as 1,010 (47%) of informants identified themselves as having two or more roles.

### *Designing the Survey*

Use of online survey methodology and a short questionnaire format appeared acceptable. The 2018 survey took respondents a median of three minutes to complete, and achieved 2,371 responses with 79% completing all relevant questions.

Designing a single questionnaire for all informant groups in 2018 simplified data collection, as stakeholders could be sent a single link. It reduced subsequent data cleaning and enabled use of analytic tools built into the hosting software to rapidly identify areas/key groups where responses were low. Use of a pre-populated list of identified services in 2018 appeared acceptable, and reduced data cleaning.

### *Data Collection*

The 2018 strategy of planning data collection in advance with research partners, with the primary focus on emails, was associated with 64% more responses (1,446 compared with 2,371) in 83% less time (5 weeks compared with 30) when compared with the pilot.

Distributing links via emails sent from national organisations' mailing lists appeared to be the most effective dissemination tool, with high response numbers for stakeholders where this strategy was used (see table 6). Response numbers were relatively low when direct email was not possible, despite survey promotion via organisational newsletters and social media.

Table 6. Pilot and 2018 survey data collection strategies used; response numbers by stakeholder group

Stakeholders	Pilot		2018 Survey	
	Strategies	Responses	Strategies	Responses
Psychiatrists	1*,4,5	380	1*,4,5	530
Paediatricians	3,5	104	3,5	74
GPs	2,5	200	1*,5	387
Health Professionals	2	116	1*	306
Service Users	3,5	477	3,5	455

1=Email via national organisation's mailing list; 2=Email via regional organisation; 3=Promotion via organisation's newsletter/website; 4=Promotion via conference; 5=Promotion via social media; \*=Strategy associated with high response numbers

Use of social media, in particular Twitter, appeared to raise awareness of the survey. During the 2018 survey, linking with relevant organisations resulted in high levels of engagement on Twitter, with 44,000 tweet impressions, and 101 survey link clicks. It is unknown how tweet impressions relate to survey response numbers.

The first approach to contacting commissioning organisations, via direct email, resulted in a low response rate of 9%. Subsequent use of FOI requests resulted in excellent response rates of 80-90% (see table 7).

*Table 7. Response rates from commissioning organisations, with data collection strategies used*

Commissioning organisations	Strategy	Response numbers (response rate)	
		Pilot	2018 Survey
CCGs (England)	Email <sup>1</sup>	19 (9%)	N/A
CCGs (England)	FOI <sup>2</sup>	169 (80%)	190 (89%)
Health Boards (Scotland)	FOI <sup>2</sup>	N/A	12 (86%)
Health Boards (Wales)	FOI <sup>2</sup>	N/A	6 (86%)
Health and Social Care Trust (Northern Ireland)	FOI <sup>2</sup>	N/A	5 (100%)
Total		169 (80%)	213 (90%)

*1 = An email was sent with a survey link or, if requested, with the questionnaire attached*

*2 = An official Freedom of Information (FOI) request sent with the questionnaire attached*

*Balance of Responses:* Use of regional organisations' mailing lists was an effective tool for data collection but tended to result in a higher number of responses from that geographic area. During the pilot, the survey was emailed to GPs via the CRN South West, resulting in 200 responses. However 61% of these came from the South West. In 2018, emails via a spread of English CRNs led to a 94% increase in GP responses (387) and also resulted in less skew towards the South West (38% of responses). This was an improvement in geographic spread compared with the pilot (see figure 6).

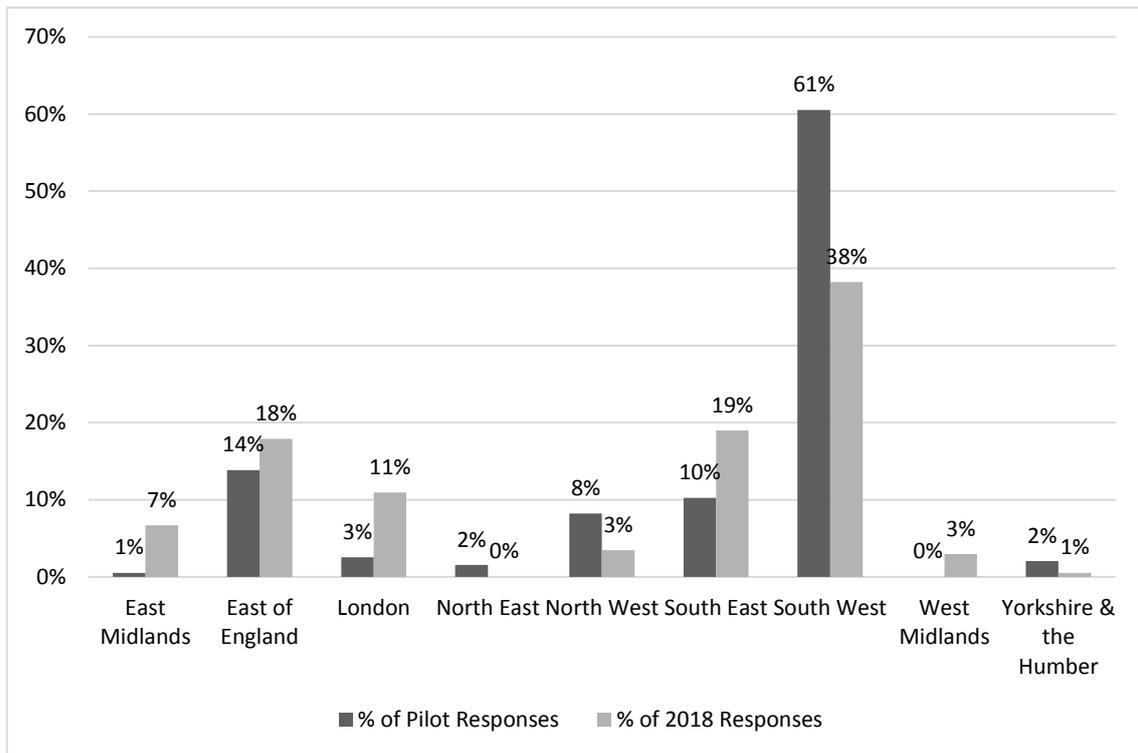


Figure 6. Graph showing percentage of total GP response numbers per region of England and by survey

By contrast, emails distributed by organisations with a national reach, such as the Royal College of Psychiatrists, were associated with a relatively even spread of responses by geographic region (see figure 7).

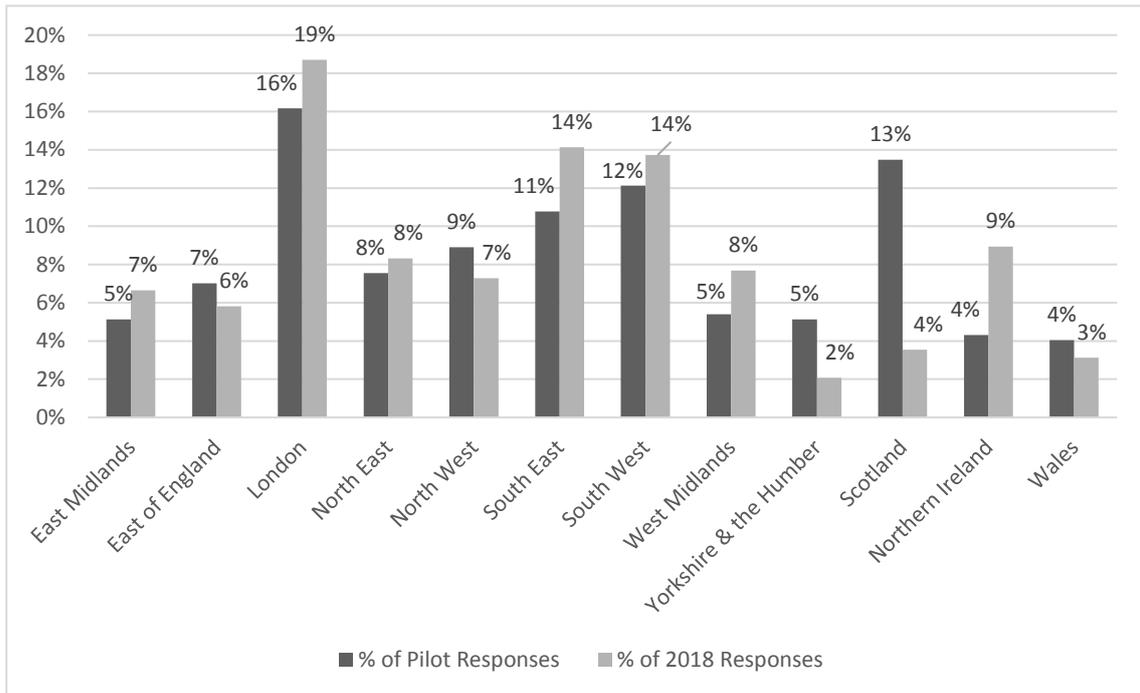


Figure 7. Graph showing percentage of psychiatrist responses by UK region and by survey

*Minimum Responses:* Strategies aimed at increasing response numbers in 2018, combined with targeting of under-represented regions (and stakeholder groups) part way through data collection, led to an increase in regions with 51 or more informants (see figures 8 and 9). However, responses for Yorkshire and the Humber dropped from 85 to 42, and for Wales response numbers remained low at 33.

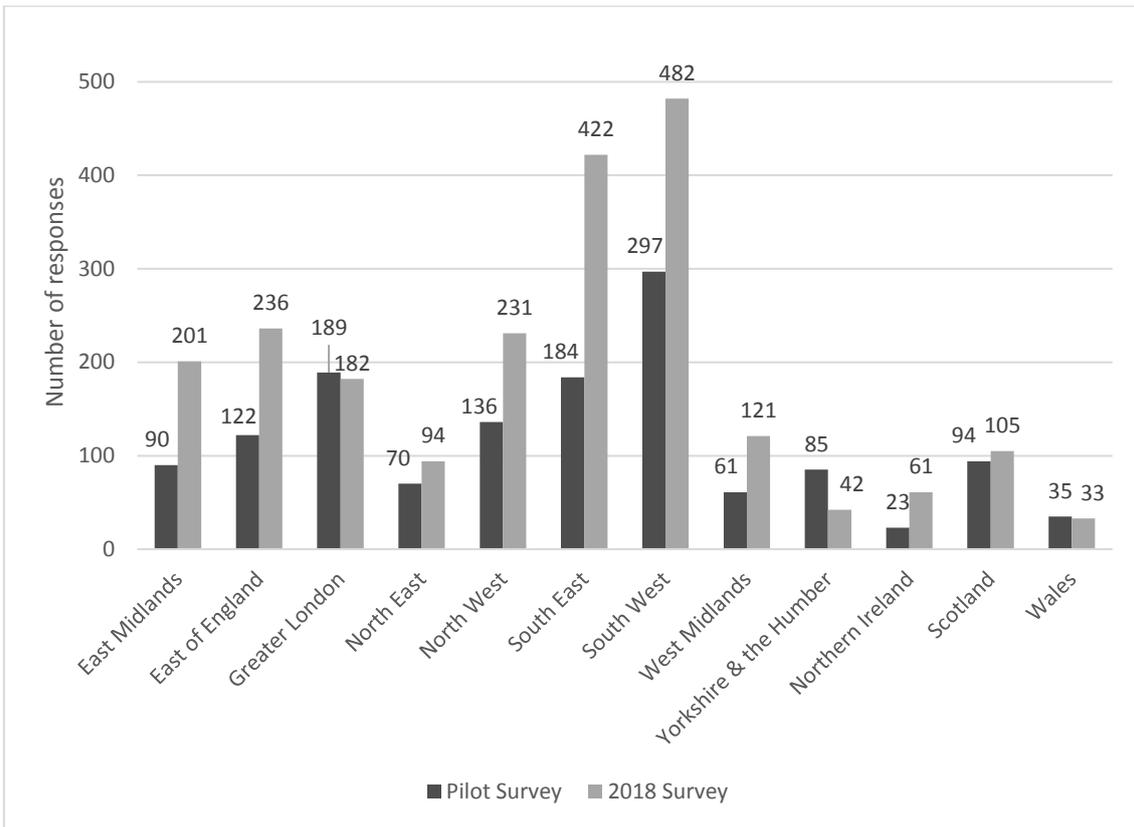


Figure 8. Number of responses by region of UK and by survey

### *Data Analysis and Handling*

*Data Handling:* Analysing pilot data was challenging. Data from multiple surveys required merging, and different questions by informant group made comparison difficult. Findings were checked three times by researchers to reduce risks of data processing errors. Use of a single survey in 2018 made comparison of data provided by different informant groups' straightforward and reduced the risk of data processing errors.

*Identifying services:* Service identification was faster in 2018 as the pre-populated list of services reduced the instances of services being identified by informants using free text (and thus needing hand matching to online information) from 100% to 16% of total instances (see table 8).

*Table 8. Numbers of unique services identified, and reports of services being identified, by survey*

Survey	Pilot	2018 Survey
Reports <sup>1</sup> of services being identified via free text	789	543
Reports <sup>1</sup> of services being identified via pre-populated list	-	3119
Total reports <sup>1</sup> of service identification	789	3662

*1=number of times any respondent indicated they knew of a service*

*Checking services:* Narrowing the focus of service checking in 2018, combined with use of FOIs to NHS Trusts reduced the data processing burden. In the pilot, 83% of identified services (172 out of 208) met criteria of the second service definition, meaning they needed to be checked by researchers. Following 26 weeks spent contacting these services, 132 services had responded with data of mixed quality: a 77% response rate. By contrast, in 2018, only 23% of identified services (66 out of 292) met the narrower service checking criteria. These were checked via FOIs to 56 NHS trusts, with 49 responding within 10 weeks (an 88% response rate).

### *Communicating findings*

The QGIS software allowed us to analyse the sample geographically and by stakeholder group, producing clear visual representations of response numbers by location (see figure 9).

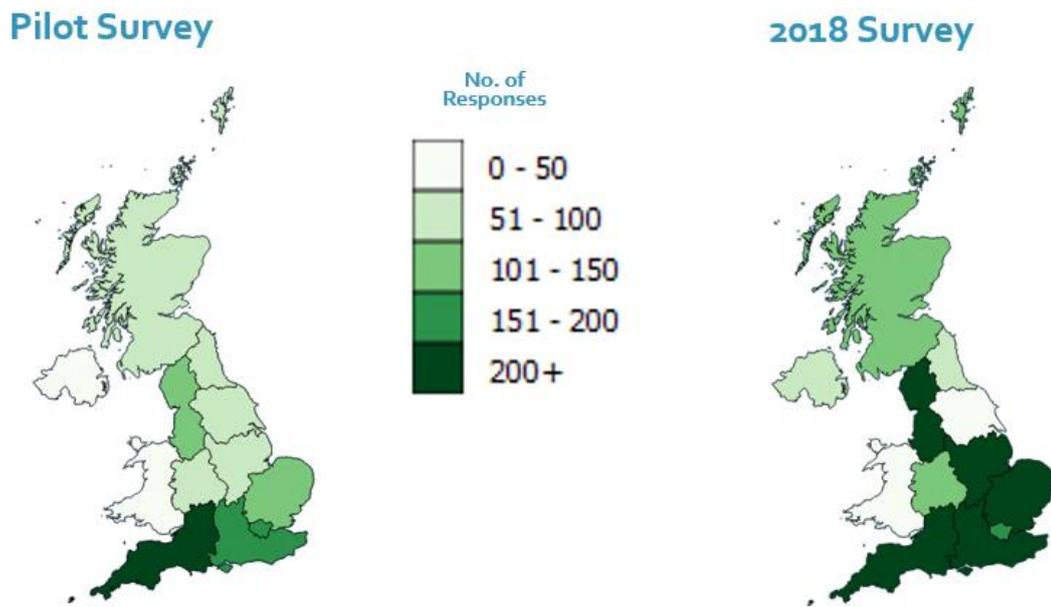


Figure 9. Response numbers by UK region and by survey

Google My Maps, an interactive tool on which the service list could be uploaded for sharing, was an appropriate platform to communicate service locations. Presenting the final list of services (from the pilot) as a map, available via a research webpage, resulted in 13,688 views within 4 months, indicating it was accessible and of interest to a large number of stakeholders (University of Exeter, 2018) (see figure 10).



Figure 10. Interactive Google map of adult ADHD services identified in pilot

#### *Hosting/updating service map*

As services change and develop, service maps need active maintenance to remain accurate. The 2018 map was uploaded with clear information about when data collection took place.

#### **4.2.5 Discussion**

To expand and extend the findings from existing research (Hall et al., 2015, Hall et al., 2013, Signorini et al., 2017), we piloted and refined methods for mapping adult ADHD services in the UK, with the aim of meeting current needs for national data about adult ADHD service provision. We developed seven steps to map services rapidly, using available technology, and including the perspectives of a range of stakeholders.

Patient and public involvement (PPI) work with the parent advisory group, clinicians and commissioners, helped clarify aims and design an accessible survey. Research partnerships with clinical and ADHD support organisations made it possible to reach large numbers of informants across the UK and share findings. Piloting was instructive and important, as was a careful study of previous literature in order to produce a definitive map quickly and efficiently. Future research should aim to; gather background information on the range of services accessed by patients; develop a working definition of target services; and identify all key stakeholders, in advance of data collection.

A two-stage approach to the definition of the target service meant a wide range of services were indexed during data collection, with a narrower focus on NHS funded specialist ADHD services during analysis. The narrower focus on NHS funded specialist ADHD services, meant provision could be checked against government guidelines (NICE, 2008, NICE, 2016, NICE, 2018b). A balance needs to be struck between surveying all services relevant to stakeholders, which is time-consuming, but may reveal the sometimes hidden role of generic, voluntary and private services, and focussing on NHS specialist services. The first stage results in 'messier' data, but reflects stakeholders' experiences of the complex nature of health service provision, providing validity.

Deciding on an appropriate way to narrow the focus when checking services was challenging due to high levels of heterogeneity in configuration of adult ADHD services in the UK (Coghill, 2017), but the detailed pilot allowed us to make decisions about the narrower definitions that were based on empirical data. One recommended model of care, that of adult ADHD specialists working within general NHS mental health services (Coghill, 2017), was not included in service checking, which is a limitation. However, all generic NHS services identified by respondents as providing treatment/support were indexed. Limiting the 2018 map to specialist services for adults with ADHD funded by the NHS, produced a serviceable map in line with the study aims.

Surveying an inclusive range of informants served several functions. It helped reduce this risk of missing services (Hall et al., 2015) because multiple respondent types were asked about services in their area. It also allowed for comparisons between provider reports on service availability and patient experiences of provision. Findings are reported in full elsewhere (Price et al., In submission-b). Interestingly, over 40% of study informants identified themselves with two or more ADHD-related roles, a reminder that survey respondents often occupy multiple identities (Gee, 2016). Inclusion of a range of informants is a strength when compared with mapping methods which rely on expert or government sources alone (Signorini et al., 2017, World Health Organization, 2008). However, the identification of key informants was more complex than expected; responses to the pilot, PPI work and previous literature all provided data that informed the final list.

During data collection, different dissemination methods appeared to work better for different stakeholders. Direct emails from trusted organisations gained high numbers of responses from busy clinicians. FOIs were effective when contacting commissioners, as they ensured someone with allocated time and resources received and responded to the query. FOIs can be a powerful tool for improving the transparency of mental health provision; which is known to be critical to delivering good outcomes and ensuring consistency of services (NHS England, 2014a, NHS England, 2017). However care needs to be taken to ensure appropriate and responsible use, as FOIs have resource implications for the relevant public body (Savage and Hyde, 2012). Social media appeared to be a powerful and suitable resource for raising the profile of the survey (Moorhead et al., 2013). Our use was mainly limited to Twitter, but this was an effective method of linking with ADHD focussed and appropriate clinical organisations. More proactive use of other social media formats, might have increased response numbers from young adults with ADHD. A recent study looking at patterns of instant messaging use in students in the South West of England found 96% used Facebook and 59% used Instagram, compared with 58% using Twitter (Piwek and Joinson, 2016). More work needs to be done to contact a range of young adults including students, those in and out of employment, and those with mental health difficulties.

### *Strengths and limitations*

This methodology provides a blueprint for producing a definitive map quickly and efficiently. However, services are dynamic and service maps will need maintenance and clear information on the limitations of data accuracy.

The aim of the survey was to gain a balance of responses, by geographic area and by stakeholder group, in order to achieve an accurate picture of service provision. This was achieved, although there were low response numbers from some regions.

The online survey and data collection methods used were pragmatic and 'fit for purpose' (Baker et al., 2013), making use of technological advances to reach a wide audience rapidly and at relatively low cost. The non-probabilistic sampling methods allowed organisations to share the survey via their mailing lists without compromising data protection. It also facilitated link sharing across a variety of open forums. Respondents were not selected randomly and, except for commissioners, response rates could not be assessed, however this was not important as the aim was to gain an accurate and nuanced picture of service provision, not to generalise findings.

### **4.2.6 Conclusion**

This seven step process appears to be a pragmatic and efficient method for collating and communicating national service data about adult ADHD service provision in the UK. The inclusion of data from a range of stakeholders minimises the risk of missing information about services and allows comparison of perceptions of provision between commissioners, health workers and service users. We found information learned through PPI, and support from partner organisations both during the development of the surveys, data collection and for dissemination of results was crucial. Lessons learned here may be transferable to mapping service provision for other health conditions and in different contexts.

For adult ADHD services, this method is an effective tool for quantifying provision and revealing gaps in service, so that, where indicated, an informed case can be made for change.

### **4.3 Part two – mapping health service provision for young people with ADHD: a chapter of the CATCh-uS NIHR report (in preparation)**

#### **4.3.1 Introduction**

Service provision for adults with ADHD remains relatively scarce and difficult to access in the UK because service configuration and workforce development are lagging behind recent medical recognition that ADHD is a long term condition that typically persists beyond adolescence into adult life (Asherson et al., 2007, Kooij et al., 2019, McCarthy et al., 2009). Previous studies revealed patchy transitional care provision (Paul et al., 2015) and identified reasons for poor or failed transition such as a lack of clarity on service availability and the operation of different eligibility criteria between child and adult mental health services, with variable service provision for young people with ADHD (Belling et al., 2014). In many areas, this is compounded by a lack of services for onward referral, and limited information about what is available (Singh, 2009). Previous research is either restricted to a certain region of England, or explores specific aspects of provision, rather than systematically mapping available services for those with ADHD in adult mental health services (AMHS) (Edwin and McDonald, 2018, Hall et al., 2015, Hall et al., 2013, Taylor et al., 2010, Zaman et al., 2012). These authors concluded their work by stating that “the next step is to map the provision of ADHD services nationally” (Hall et al., 2013).

The UK NICE guidelines state the following services should be available for adults with ADHD: transitional care, assessment and diagnostic services, drug titration, monitoring and review, and psychoeducation (NICE, 2008, NICE, 2018b). Treatment should be holistic, addressing psychological, behavioural, occupational, and educational needs, while services should be provided by multidisciplinary teams with expertise in ADHD (NICE, 2018b). Medication should be offered as the first line of treatment after environmental modifications have been implemented and reviewed. After titration and dose stabilisation, care may be carried out under shared care protocol arrangements with primary care (NICE, 2018b). However, controversy remains over organisation of services for

managing ADHD in adults (Coghill, 2017), with wide variation in treatment approaches across the UK. In addition, research indicates that, partly due to existing gaps in services, adults with ADHD may either cease to access treatment or seek help at an extended range of services, including those not commissioned to treat adult ADHD (Wong et al., 2009). Even after the NICE guidance in 2008 stressed the need for adults who required medication to access it, there remained a much more rapid decline in prescriptions for ADHD medication than the epidemiology would lead us to anticipate (Newlove-Delgado et al., 2018a). As nearly 8% resumed their prescriptions of ADHD medication after the age of 20, this suggests that some young people are stopping treatment prematurely (Newlove-Delgado et al., 2019a).

To date studies that have mapped services for adults with ADHD have tended to draw on the perspectives of one stakeholder group, such as senior service managers (Hall et al., 2015), or practitioners (Hall et al., 2013). A recent systematic review of qualitative research about transition into adult ADHD services found that a lack of available information about adult ADHD services created difficulties in accessing treatment (Price et al., 2019). Service users are unsure where to access treatment (Matheson et al., 2013), while some clinicians reported difficulties in finding an adult service to refer patients on to (Wong et al., 2009). This implies that even if commissioners hold knowledge of an appropriate service, service users and practitioners may not. The inclusion of a range of stakeholders minimises the risk of incomplete knowledge and may reveal previously hidden discrepancies in awareness.

A problem with asking respondents to identify services lies in the complexity of health service provision in the UK and the fact that there is no definitive way to ensure that the same 'unit' of 'service' is identified. For example, in England, respondents might report a locality base, which organisationally falls under a community mental health team (CMHT), or an AMHS, which in turn may be a directorate within an NHS Trust that also provides learning disability (LD), liaison and in-patient mental health care. Respondents might report a private service or dedicated (ADHD-specific) service of which they are aware, or other service more

orientated towards delivering care for people with other mental health problems. All of these issues can lead to variation in respondent-defined adult ADHD-clinical care provision 'services'. This complexity has been taken into account in the data handling section below.

The mapping study reported in this chapter aimed to identify service provision for adults with ADHD across the UK. By surveying multiple stakeholders, the study aimed to include services relevant to all groups and to analyse differences in the perspectives of commissioners, health workers and services users on service availability. This study was designed to provide national level data on existing services that could be used to identify gaps in provision and knowledge as well as to optimise transition and service provision for this vulnerable group.

This mapping stream aimed to provide:

- a geographical overview of services for young adults with ADHD
- details of support/treatment provided (transition, diagnosis, medication or psychological) by dedicated NHS adult ADHD services
- an exploration of the awareness of services by different stakeholder groups (commissioners, health workers and service users)

#### **4.3.2 Methods**

The mapping methodology was piloted and refined in 2016. An iterative process of trial and review led to the development of the protocol used in the definitive study, which ran between 8<sup>th</sup> January and 11<sup>th</sup> February 2018. An overview of the methodology is presented below, while a more detailed description of the development process and a detailed description of the different steps is published elsewhere (Price et al., In submission-b).

We collected information on UK services for adults with ADHD from the following essential stakeholders in the transition process:

- those receiving treatment / support (service users)
- those providing services (clinicians, health care practitioners), and
- those funding services (commissioners)

A wide range of stakeholders were approached from across the UK in order to gather local knowledge and ensure as many relevant services were identified as possible. To collect information on service provision from these different sources, we used several different techniques to optimise data capture.

- *Online survey*: an online survey (on the Survey Monkey platform) distributed using different techniques to a wide range of stakeholders
- *FOI requests*: (based on the same survey questions) sent to UK health service commissioners
- *Surveillance study*: selected data from the surveillance study. Information on services was extracted from questionnaires completed by consultant psychiatrists and paediatricians (Eke et al., In submission-a)

We particularly targeted child and adolescent psychiatrists, adult psychiatrists and paediatricians, general practitioners (GPs), nurses, practice managers, and administrators, as well as young adults and their parents/carers. Commissioning bodies within the NHS were identified as they hold a key role in service provision. They differ slightly across the UK with CCGs in England, Health Boards in Scotland and Wales, and Health and Social Care Trusts in Northern Ireland. The resulting service list was cross-checked against services described in the CATCh-uS qualitative study interviews with young adults and parents (Price et al., In submission-c). Services not already included on the list were added, with the interviewee listed as the informant.

#### *Definition of services*

In light of the complex nature of the provision being mapped, we asked stakeholders to respond to an inclusive service definition of “*any mental health service for people with ADHD aged 18 and above*”. The categorisation of responses is described in the analysis section below.

### *The online survey*

The survey was designed using Survey Monkey and in collaboration with the Parent Advisory Group and local clinicians. We used lay terms to be accessible to all informants and limited the length to between five and nine questions (see appendix 8). The same version was used for all respondents. Basic demographic information was collected, including region (from a pre-defined list) and postcode. Respondents were provided with a check-list of services identified in a 2016 pilot survey and given the opportunity to indicate which of these they knew of, and asked to provide details of any other services not already listed. After identifying a service, informants were asked to indicate if they or anyone they knew had experience of using that service for treatment/support of adult ADHD.

Respondents were also asked to indicate their primary role, with the opportunity to identify up to seven non-primary roles; for example '*Parent of child with ADHD*' as their primary role, but also a '*Psychiatrist*' or an '*Adult with ADHD*'. The categories applied and their definitions are included in appendix 11.

### *Freedom of Information*

All commissioning bodies within the NHS were sent FOI requests, which give individuals the right to access recorded information held by public sector organisations (Information Commissioners Office, 2016). The survey was sent via FOI email addresses, published online. In total, 209 English CCGs, 21 Health Boards (14 in Scotland, 7 in Wales) and 7 Northern Ireland Health and Social Care Trusts were contacted.

These FOI requests asked the same five core questions as the online survey. In addition, details were requested about service type (Adult, Specialist, Child and Adolescent Mental Health or Other), and interventions available (Treatment with Medication, Other Treatment, Assessment, Diagnosis or Other). Respondents were automatically identified as commissioners, and were not given the opportunity to indicate additional roles, see appendix 10.

### *Surveillance study*

Responses to two questions about service provision were included in mapping data analysis. The first, included in the baseline questionnaire, asked for the young person's intended destination, (Specialist adult ADHD, Other AMHS, Primary Care or Other), with identifying details, such as service name. The second, at follow up nine months later, confirmed where the young person had been referred to, for details see Eke et al. (In submission-a)

### *Qualitative study*

Identified services were checked against services described in the CATCh-uS study qualitative interviews of groups 1 to 3 (64 young adults) and 4 (28 parents/carers) (Price et al., In submission-c). In the case of other services being mentioned in these interviews, they would be added to the list of services, with the interviewee listed as the informant.

### *On-line survey data collection*

Survey links were distributed to potential informants via multiple methods, with the aim of maximising the responses.

The survey-link was distributed through the following channels:

- direct e-mails via the mailing lists of: AADD-UK, ADHD Foundation and Royal College of Psychiatrists (Faculty of Child and Adolescent Psychiatry as well as the Faculty of General Adult Psychiatry) (see appendix 12)
- e-mails via all regional Clinical Research Networks, with a request to target nurses, GPs, managers and clinical psychologists, as these groups had not been targeted via their professional organisation mailing lists
- Twitter: sharing the survey link via accounts of the various team members, tagging appropriate organisations
- publication of the link and an explanation in the British Association of Community Child Health, the Royal College of General Practitioners and the George Still Forum

In addition, awareness of the research was raised through university press releases, organisational newsletters, conference presentations and social media. The survey was open for 34 days from 8<sup>th</sup> January, 2018. An interim analysis of responses was conducted to identify under-represented locations or informant groups. Subsequently, ADHD and clinical organisations in those locations and working with those groups were targeted, with the aim of improving the balance of responses.

#### *Data handling*

Data was uploaded into Excel and analysed using STATA SE15 (StataCorp., 2017). Response data was validated against online information, using free text responses as key search terms and searching for details of the named services online, to create a list of identified and verified services. This process allowed researchers to index all identified services and link services with the relevant organisational provider.

Services were categorised into four groups according to how ADHD-specific the provision was (see figure 11). As online information was often quite dated or did not specify whether or not adult ADHD could be treated at that service, FOI requests were sent to check service provision of the dedicated ADHD services.

This generated a nested model of service specificity, with four layers of service provision for adults with ADHD where layers also relate to the degree of certainty about the data. Layer 1 included the greatest degree of certainty as well as specificity.

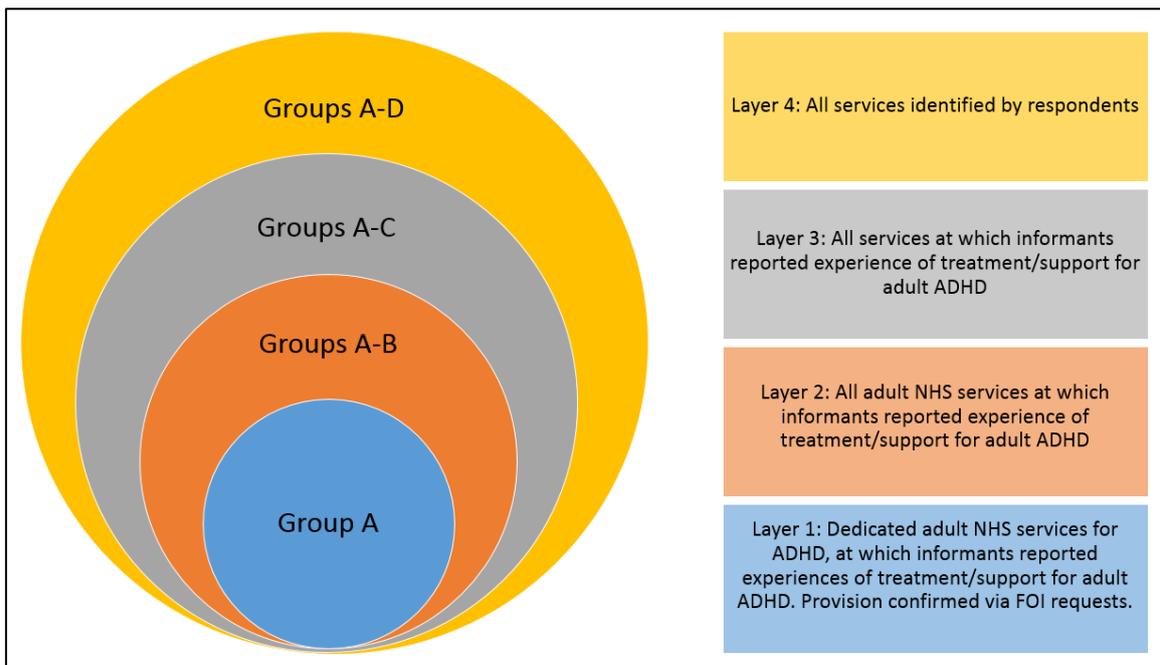


Figure 11. Stacked Venn diagram showing layers of service identification, decreasing in specificity of service type and reliability of information

Made up of groups A to D

**Service groupings:** services are organised in four nested layers of service (1-4), comprised of differing combinations of four discrete groups of services (Groups A-D) as described below and illustrated in figure 11.

- **Layer 1 (group A)** dedicated provision for adult ADHD within NHS services, verified by FOI request
- **Layer 2 (groups A&B)** was made up of all other NHS services *for adults experienced* by respondents as providing treatment/support. **Group B** comprised generic NHS services for adults. LD services were categorised as group B, however, due to the high number identified, providers of these services were also contacted to verify details of provision
- **Layer 3 (groups A,B&C)** comprised all services *experienced* by respondents as providing treatment/support for adult ADHD. **Group C** included services at which stakeholders reported experience of receiving treatment/support for adult ADHD which were either not NHS services, or not commissioned to provide services for adults. Examples include NHS services for under 18's, as well as private and third sector services

- **Layer 4 (groups A, B, C & D)** comprised all services identified by respondents, including those reported but without any *confirmed* experience of access for adults (**group D**)

*Counting the number of services:* For every service identified in group A (dedicated services), every uniquely named service was counted separately. For example, Oxleas NHS Foundation Trust had a '*Bromley adult ADHD service*' and a '*Bexley adult ADHD service*', which were counted as two services. For all other services (groups B-D), due to constraints on study resources, each service type was treated as a single service for each area. For example, all the community mental health teams provided by Somerset Partnership Foundation Trust, were listed as one service although these are delivered at multiple locations across the county. In the same way, private or voluntary/charity providers, such as AADD-UK, with multiple locations or national reach, were listed as a single service.

#### *Data analysis*

*Descriptive Statistics:* Responses were presented by informant group (service user, health worker or commissioner) and location (UK NHS region), using a geographic information system, QGIS 2.18, to analyse and display the data. Shapefiles for UK counties and regions were imported (McGarva, 2017, Office for National Statistics, 2016, QGIS Development Team, 2018).

*Services identified:* Descriptive summaries were created of identified services. These were sorted into groups and layers (see above), and by NHS region. Due to difficulties in differentiating specialist services from specialist clinics operating within a generic adult mental health service, services were described as 'dedicated' if they had 'ADHD' or 'neurodevelopmental' in the service name. Findings were presented using maps, to explore geographic variation in service availability.

*Stakeholder perspectives:* Differences in service identification were explored by creating descriptive summaries of the numbers of services identified by each

informant group. Venn diagrams were used to display group differences and overlap in service identification. The percentages of services identified by each respondent type (commissioner, health worker and service user) and for each service group where there was direct experience of care (A to C) were summarised and tabulated, with Pearson Chi-squared tests used to investigate statistically significant differences in stakeholder reporting. Categories ranged from 'all stakeholders' to a single stakeholder group. Results were summarised and Pearson Chi-squared tests were used to explore statistically significant differences between categories. Group D was not included in this analysis, as these were services at which no stakeholder had reported experiences of treatment/support.

### 4.3.3 Results

#### *Descriptive statistics, by data source*

In total 2,686 different reports were included in the study, with most data (80%) coming from the online survey; 12% of reports came from the clinicians in the surveillance study and 8% from commissioners in response to freedom of information requests (see figure 12).

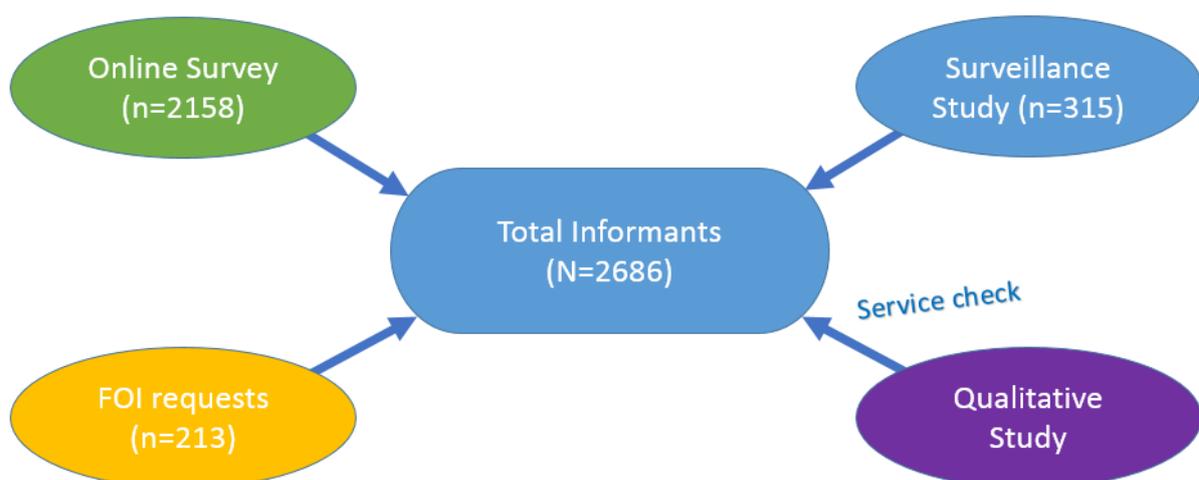


Figure 12. Graphic showing mapping study data sources

Table 9 describes how informants varied in their method of reporting. Health workers contributed the most responses in the on-line survey, with a further contribution via the surveillance study, but we were pleased that 17% of the responses overall were from service users.

*Table 9. All reports by data source and informant group*

	Data Source						
	Online Survey				Surveillance Study	FOI Requests	All
Informant group	Service users	Health workers	Commissioners	Other	Health workers	Commissioners	
Number of responses (n)	461	1631	3	63	315	213	2686
Percentage of reports (%)	17%	61%	0%	2%	12%	8%	100%

No new services were identified through checking qualitative study interviews, therefore the qualitative study is not mentioned any further in this chapter.

*Online survey:* online survey respondents identified with between 1 and 4 roles ( $M = 1.3$ ,  $SD = .49$ ); 23% identified with at least one additional role. Table 10 summarises online survey contributors by informant groups and primary role identified. It also summarises the overlap between primary and non-primary roles, and indicates an overlap between being a service user and parent/carer, as well as the both of these, and being a health worker in primary care and a commissioner.

Table 10. Heatmap showing overlap between primary and non-primary roles identified by online survey respondents

Informant group	Primary role identified*	Total	% all roles	Code	Non-primary role**															
					S1	S2	S3	H1	H2	H3	H4	H5	H6	H7	H8	H9	C1	O1	O2	O3
Service User	Adult with ADHD; age 18+	262	12	S1	-	45	<6	<6	<6	0	0	25	<6	7	0	<6	0	16	<6	9
	Parent/carer, someone with ADHD	193	9	S2	18	-	<6	<6	7	0	0	15	7	8	0	<6	0	18	0	<6
	Young person with ADHD; age <18	6	0	S3	<6	<6	-	0	0	0	0	0	0	0	0	0	0	0	0	0
Health worker	Administrator	93	4	H1	<6	<6	<6	-	0	0	0	0	<6	<6	0	0	<6	<6	0	<6
	Allied Health Professional	101	5	H2	<6	<6	<6	0	-	0	0	<6	<6	<6	0	0	0	<6	<6	<6
	Clinical Psychologist	84	4	H3	<6	<6	0	<6	<6	-	0	0	8	0	0	0	0	0	0	<6
	GP	387	18	H4	0	10	0	0	0	0	-	0	<6	0	<6	<6	18	<6	<6	25
	In an ADHD support role <sup>1</sup>	29	1	H5	<6	12	0	<6	0	0	0	-	<6	0	0	0	0	0	0	0
	Manager	116	5	H6	0	0	<6	7	6	0	0	<6	-	10	0	0	0	0	0	0
	Nurse	217	10	H7	<6	8	<6	<6	<6	0	0	<6	17	-	0	0	0	<6	0	17
	Paediatrician	75	3	H8	<6	<6	0	0	0	0	0	0	<6	0	-	<6	0	0	<6	<6
	Psychiatrist	529	25	H9	<6	21	<6	0	0	0	<6	7	20	0	0	-	0	<6	<6	29
Commissioner	Clinical Commissioner	3	0	C1	0	0	0	0	0	0	0	0	<6	0	0	-	0	0	0	
Other	Educational Practitioner <sup>2</sup>	16	1	O1	<6	0	<6	0	0	0	0	<6	0	0	0	0	0	-	0	<6
	Researcher or Academic	43	2	O3	<6	0	0	0	0	0	0	0	<6	0	0	0	0	<6	-	0
	Other (please specify)	4	0	O2	0	<6	0	<6	<6	0	<6	0	<6	<6	0	<6	0	0	0	-
<b>Total</b>		<b>2158</b>	<b>100</b>		<b>39</b>	<b>111</b>	<b>21</b>	<b>17</b>	<b>26</b>	<b>0</b>	<b>5</b>	<b>54</b>	<b>74</b>	<b>36</b>	<b>1</b>	<b>7</b>	<b>19</b>	<b>42</b>	<b>9</b>	<b>97</b>

<sup>1</sup>e.g. voluntary, support work, social work or training; <sup>2</sup>e.g. Support worker, teacher, behavioural support, educational psychiatrist, education welfare officer

\*Respondents indicating this role fitted them best; \*\*respondents indicating this role also applied to them; S1-S3 = service user; H1-H9 = health worker; C1 = commissioners; O1-O3 = other

<6 = a number greater than zero but smaller than 6. Darker colours indicated a greater overlap between roles

There were some interesting overlaps between stakeholder groupings in terms of their identified roles. Of the 461 respondents primarily identifying as service users, 84 (18%) also identified as health workers. Of the 1,631 respondents primarily identifying themselves as health workers, 92 (6%) also identified as service users. In total, 176 survey respondents (8% of those identifying as health workers or service users) identified with both roles.

*Surveillance study:* from the baseline surveillance study questionnaires, 315 contained information potentially relevant for the mapping study (Eke et al., In submission-a); 203 were from paediatricians, and 112 from psychiatrists. Some clinicians listed multiple services on the questionnaires for cases reported to the study; they either listed the same service as referral service for all reported cases while others reported different services for different cases.

*FOI requests:* all 236 organisations responsible for commissioning/providing NHS mental health services in the UK (HSC Northern Ireland, 2018, NHS Scotland, 2018, NHS Wales, 2018, Office for National Statistics, 2017) were contacted via FOI requests as part of the mapping study, and 213 (90%) responded (see table 11). So while this method contributed a relatively small proportion of the overall information, the data was nearly complete.

Table 11. Response rates to FOI requests from commissioning organisations

Country	Organisation Type *	Number**	Responses (n)	Response Rate (%)
England	Clinical Commissioning Groups	209	190	91
Northern Ireland	Health and Social Care Trusts	6	5	83
Scotland	Health Boards	14	12	86
Wales	Local Health Boards	7	6	86

\*Organisations responsible for commissioning NHS mental health services in UK

\*\*Accurate April 2017 (Office for National Statistics, 2017)

#### *Descriptive statistics, all data sources*

*Respondent type:* for a summary of the roles of contributors from all sources informing the mapping study, see figure 13 below, which represents roles from all sources combined. The online survey is reported from the primary role identified and surveillance study respondents were categorised as health worker but no additional roles could be attributed as this was not asked by the surveillance questionnaires.

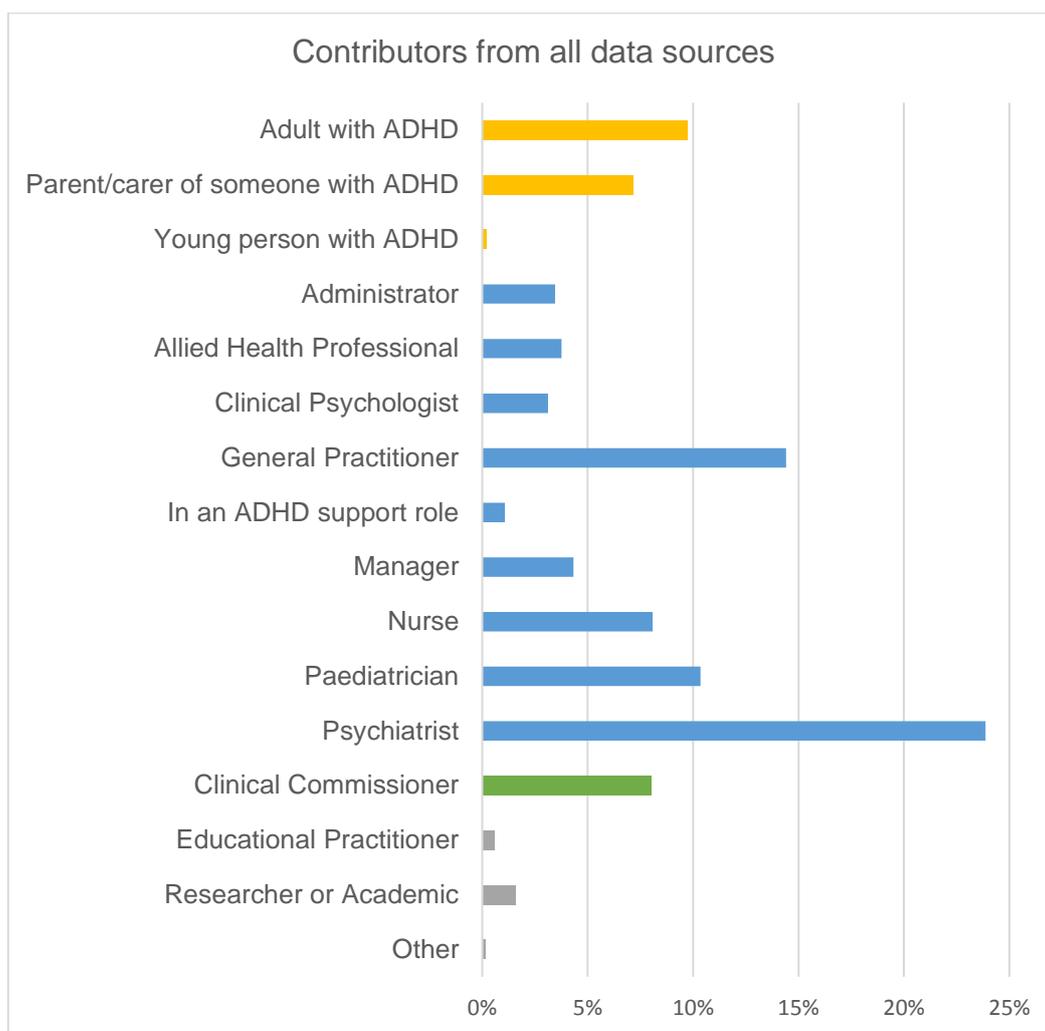


Figure 13. The balance of roles from all sources, n=2686

Orange=service users, blue=health worker, green=commissioners, grey=other

Psychiatrists were the most represented group, and provided nearly a quarter of the responses at (24%, n=641), followed by GPs (14%, n=387) and paediatricians (10%, n=278). High numbers of responses from medical doctors are not surprising given the central role of medication in the management of ADHD and the direct emails that the Royal College of Psychiatrists were willing to send to their members. The least represented respondents were young people with ADHD aged under 18, with 6 reports comprising less than 1% of all respondents.

*Location of contributors:* contributors to all data sources indicated the region of the UK where they lived, or if a health worker, the location of their workplace.



Table 12. Number of mapping study informants by NHS region; with percentage of UK population

Data source and informant group	Online Survey				Surveillance Study	FOI Requests	All Sources	% of all contributions	% of UK population*
	Service users	Health workers	Commissioners	Other	Health workers	Commissioners			
London	40	163	0	8	20	31	262	10	13
Midlands & East of England	70	362	0	8	107	54	601	22	26
North of England	127	166	1	15	76	57	442	16	20
South East England	64	306	0	11	36	36	453	17	14
South West England	34	425	1	10	42	12	524	20	9
Northern Ireland	32	23	0	1	12	5	73	3	3
Scotland	37	53	0	2	15	12	119	4	9
Wales	11	16	0	0	7	6	40	1	5
Missing Data**	46	117	1	8	0	0	172	6	-
<b>Total</b>	<b>461</b>	<b>1631</b>	<b>3</b>	<b>63</b>	<b>315</b>	<b>213</b>	<b>2686</b>	<b>100</b>	<b>100</b>

\*2011 Census (Office for National Statistics, 2013); \*\*Missing Data = No information received

As can be seen from the data displayed in table 12, the informant response approximated to the distribution of the UK population by NHS region, except in South West England (study location) which had relatively higher numbers of reports, and in Scotland and Wales, which had relatively lower numbers.

*Service identification:* table 13, summarises the number of respondents from each data source identifying at least one service; there were 3,829 unique instances of service identification from across all sources. Just over half the informants (57%) identified one or more services. The high numbers of services identified by some respondents reflects the online survey methodology, which provided a pre-populated list of possible services derived from pilot data as well as asking respondents to identify other new services. Respondents to the surveillance study, could only report one service, while commissioners could report between 0 and 4 services. In the online survey, health workers (44%) were significantly more likely than were service users (32%) to identify at least one service at which they had experience of someone accessing support for adult ADHD ( $\chi^2 (1, N=2092) = 8.65, p = 0.003$ ). A similar proportion of psychiatrists and paediatricians (61%) mentioned at least one service in the surveillance study. Over 90% of commissioners, who were responding to FOIs and therefore legally bound to provide information, formally identified at least one service. Respondents to the online survey each identified experiences of treatment/support at between 0 and 10 services, which left 32 services identified as known (with or without experience) by a single respondent.

Table 13. The number respondents identifying at least one service, and the number of services identified by any single respondent; by data source and informant group

Source	Informant group	Total (n)	Type of service identification	Respondents identifying services			Number of times any service was identified (n)	Number of services identified by any single respondent		
				1 or more (n)	None (n)	Percentage 1 or more		Range	Mean	S.D.
Online Survey	Service users	461	Known*	188	273	41%	555	0-32	1.20	2.61
			Experienced**	149	312	32%	254	0-9	0.55	1.10
	Health workers	1631	Known*	929	702	57%	2720	0-28	1.67	2.89
			Experienced**	716	915	44%	1139	0-10	0.70	1.06
	Commissioners	3	Known*	2	1	67%	2	0-2	0.67	0.58
			Experienced**	2	1	67%	2	0-2	0.67	0.58
	Other	63	Known*	28	35	44%	132	0-15	2.10	3.59
			Experienced**	11	52	17%	23	0-15	0.37	0.97
Surveillance Study	Health workers	315	Baseline*	191	124	61%	191	0-1	-	-
			Follow Up**	152	163	48%	152	0-1	-	-
FOI Requests	Commissioners	213	Formally identified***	197	16	92%	229	0-4	1.08	0.53
<b>All Sources<sup>1</sup></b>	<b>All</b>		<b>Known*</b>	<b>1537</b>	<b>1149</b>	<b>57%</b>	<b>3829</b>	<b>0-32</b>	<b>-</b>	<b>-</b>
			<b>Experienced**</b>	<b>1030</b>	<b>1656</b>	<b>38%</b>	<b>1570</b>	<b>0-10</b>	<b>-</b>	<b>-</b>

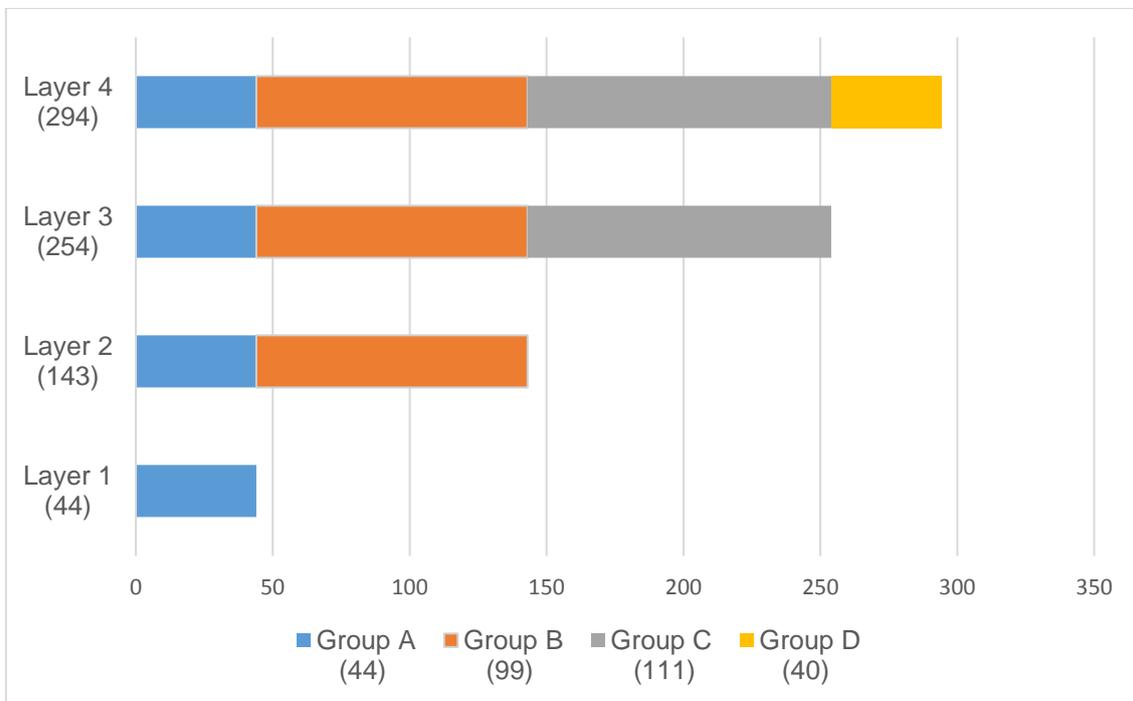
Note: <sup>1</sup>For purposes of this summary, under 'All Sources', known and experienced are defined in the following ways: \*Known = online survey known services, surveillance study 'baseline' services; \*\*Experienced = online survey experienced services, and surveillance study 'follow up' services; \*\*\*Formally identified = identified via commissioners FOI responses. FOI = Freedom of information

## Services identified

### Overview

Respondents identified 294 unique services, with relatively few dedicated to adults with ADHD (group A, n=44). There were approximately equal numbers of reports of service provision in generic NHS AMHS (group B, n=99) and non-NHS or NHS services that were not for adults (group C, n=111). Relatively few were identified which were not supported by respondent experience (group D, n=40).

For a summary of numbers of services at each layer and by group, see figure 15.



*Figure 15. Stacked bar chart showing the number of identified services by layer of service specificity*

*Layer 1=dedicated NHS services for adults with ADHD (group A); layer 2=all NHS adult services experience by informants (groups A+B); layer 3=all services experienced by informants (groups A+B+C); layer 4=all identified services*

Table 14 provides further details of the different types of services reported for each layer and illustrates the huge range of service models in which adults with ADHD may access support. While dedicated services and arguably those for ASD

and LD, which are common comorbidities, would be expected to provide services for this group, other types of service may also provide services. In some areas CMHTs may be commissioned to provide care, while other services may relate to comorbidities (drug and alcohol services) or be pragmatic responses (prison and primary care).

Table 14. Services identified by informants; by group and type of service

Layers	Service Type	Number of Services	Cumulative Total
1. Dedicated NHS service for adults with ADHD (Group A)	NHS Adult ADHD	29	<b>44</b>
	NHS Adult ADHD & ASD	7	
	NHS Adult Neurodevelopmental	8	
2. All NHS adult services experienced* by informants (Groups A+B)	<i>Group A (see above)</i>	44	<b>143</b>
	NHS 0-25 Service	2	
	NHS Adult ASD	2	
	NHS Adult Drug & Alcohol	1	
	NHS AMH CMHT	70	
	NHS Health & Social Care	1	
	NHS Adult Learning Disability	17	
	NHS AMH & Learning Disability	2	
	NHS AMH Primary Care	2	
NHS AMH Prison & Custody	2		
3. All services experienced* by informants (Groups A+B+C)	<i>Groups A and B (see above)</i>	143	<b>254</b>
	Charity/Voluntary	15	
	Charity/Voluntary (Support Group)	24	
	NHS Child ADHD Specialist	3	
	NHS Child Neurodevelopmental	3	
	NHS Generic Child	26	
	Private	36	
	Private (Social Enterprise)	4	
4. All identified** services (Groups A+B+C+D)	<i>Groups A-C (see above)</i>	254	<b>294</b>
	Charity/Voluntary	6	
	Charity/Voluntary (Support Group)	2	
	NHS Child Neurodevelopmental	2	
	NHS Generic Child	7	
	NHS Generic AMH	6	
	NHS Adult Learning Disability	6	
	Private	10	
	Private (Social Enterprise)	1	

\*Experienced = At least one informant reported knowing of someone receiving treatment/support for adult ADHD at that service and/or the service was formally identified by a commissioner. \*\*Identified = at least one informant identified service as a potential place to access treatment/support for adult ADHD. NHS = National Health Service; AMH = adult mental health; ADHD = attention deficit hyperactivity disorder; ASD = autistic spectrum disorder; Child = child & adolescent mental health or paediatric service (for under 18 years); CMHT = community mental health team

Layer 1 (group A): dedicated adult ADHD services (see tables 14 and 15)

Group A, comprised of 44 dedicated services for adults with ADHD; provided by 35 organisations. Services were either dedicated to working with adults with ADHD (29), ADHD and ASD (7) or Neurodevelopmental disorders (8). Five provider organisations provided more than one service. The most extensive geographic spread of services was offered by South London and Maudsley NHS Foundation Trust with 1 national service and 4 satellite clinics that offered treatment in several locations and across several counties.

Table 15. NHS Specialist ADHD Services checked with relevant provider organisations, using FOI requests

Location		Service Details				FOI Responses from NHS Trust/Organisation confirming the treatment/support available for ADHD in adults										
NHS Region	NHS Trust/Organisation Name	No. of Services	Main Service Name	Service Type	Location/s	Provide Services	Lower/Upper Age Limit		Transition	Diagnoses	Medication Management	Ongoing Prescribing	Shared Care	Psychological	Other*	Funding Access**
London	Barnet, Enfield & Haringey MH NHS Trust	1	Adult ADHD Service	ADHD	Single	1										
London	Central & NW London NHS FT	1	CNWL ADHD Service	ADHD	Multiple	1	18	N/A	0	1	1	0	1	0	0	1
London	Camden & Islington NHS FT	1	Adult ADHD Clinic	ADHD	Single											
London	East London NHS FT	1	City & Hackney Adult ADHD Service	ADHD	Single	1	18	N/A	0	0	1	1	1	1	0	0
London	Oxleas NHS FT	3	Bexley, Oxleas & Greenwich Adult ADHD Service	ADHD	Multiple	3	18	N/A	0	3	3	0	3	3	0	2
London	South London & Maudsley NHS FT	5	National & Satellite Adult ADHD & ASD Services	ADHD & ASD	Multiple	5	18	N/A	3	5	5	1	4	2	0	2
London	SW London & St George's Mental Health NHS Trust	1	Richmond ADHD Services	ADHD	Single	1	18	N/A	0	1	1	1	1	0	0	0
Midlands & East of England	Birmingham & Solihull MH NHS FT	1	25+ Adult ADHD Service	Neurodevelopmental	Multiple	1	25	N/A	1	1	1	1	0	1	1	0
Midlands & East of England	Cambridgeshire & Peterborough NHS FT	1	Adult ADHD Clinic	ADHD	Multiple											
Midlands & East of England	Coventry & Warwickshire Partnership NHS Trust	2	Adult Neurodevelopmental & Transitions Service	Neurodevelopmental	Multiple	2	17	N/A	2	1	2	2	2	1	1	0
Midlands & East of England	Dudley & Walsall MH Partnership NHS Trust	1	Adult Neurodevelopmental Service	Neurodevelopmental	Multiple											
Midlands & East of England	Leicestershire Partnership NHS Trust	1	Adult ADHD Service	ADHD	Single	1	18	N/A	1	1	1	1	1	0	0	0
Midlands & East of England	Norfolk & Suffolk NHS FT	1	Norfolk & Waveney Adult ADHD service	ADHD	Single	1	18	65	1	1	1	1	1	0	0	1
Midlands & East of England	Northamptonshire Healthcare NHS FT	1	Adult ADHD & Asperger's team	ADHD & ASD	Multiple	1	18	N/A	1	1	1	1	1	1	1	1
Midlands & East of England	Nottinghamshire Healthcare NHS FT	1	Adult ADHD Clinic	ADHD	Single	1	18	N/A	0	1	1	1	0	1	1	0
North of England	Blackpool Teaching Hospitals NHS FT	1	Adult ADHD Clinic	ADHD	Single	1	16	N/A	1	1	1	1	1	0	0	0
North of England	Cheshire & Wirral Partnership NHS FT	1	Wirral Adult ADHD Service	ADHD	Multiple	1	16	N/A	1	1	1	1	1	0	1	1

Location		Service Details				FOI Responses from NHS Trust/Organisation confirming the treatment/support available for ADHD in adults										
NHS Region	NHS Trust/Organisation Name	No. of Services	Main Service Name	Service Type	Location/s	Provide Services	Lower/Upper Age Limit		Transition	Diagnosis	Medication Management	Ongoing Prescribing	Shared Care	Psychological	Other*	Funding Access**
North of England	Greater Manchester West MH NHS FT	1	Trafford Extended service	ADHD & ASD	Single	1	18	N/A	1	1	1	1	1	0	0	0
North of England	Lancashire Care NHS FT	1	Adult ADHD Assessment Team	ADHD	Multiple	1	16	N/A	1	1	1	1	1	0	0	0
North of England	Leeds & York Partnership NHS FT	1	Adult ADHD Service	ADHD	Single	1			1	1	1	1	1	1	1	1
North of England	Mersey Care NHS FT	1	Adult ADHD Service	ADHD	Multiple	1	16	65	1	1	1	1	1	0	0	0
North of England	North West Boroughs NHS FT	1	Adult ADHD Service	ADHD	Multiple	1	18	N/A	1	1	1	1	1	0	0	0
North of England	Northumberland, Tyne & Wear NHS FT	1	Adult ADHD Service	ADHD	Multiple	1	18	N/A	1	1	1	0	1	0	0	0
North of England	Rotherham Doncaster & South Humber NHS FT	1	Doncaster ADHD clinic	ADHD	Single	1			1	1	1	1	1	1		0
North of England	Sheffield Health & Social Care NHS FT	1	Sheffield Adult Autism & Neurodevelopmental Service	Neurodevelopmental	Single											
North of England	SW Yorkshire Partnership NHS FT	1	Service for Adults with ADHD & Autism	ADHD & ASD	Multiple	1	18	N/A	1	1	1	1	1	1	1	1
North of England	Tees, Esk & Wear Valleys NHS FT	1	TEVV Adult ADHD Service	ADHD	Single	1	18	N/A	1	1	1	1	1	0	0	1
South East England	Berkshire Healthcare NHS FT	1	Neuropsychology Service	Neurodevelopmental	Single	1	18	N/A	1	1	1	1	1	1	1	0
South East England	Isle Of Wight NHS Trust	1	ADHD Assessment & Treatment Service	ADHD	Multiple	1	18	N/A	1	1	1	1	1	1	1	0
South East England	Surrey & Borders Partnership NHS FT	2	Hampshire, Surrey & Borders Autism & ADHD Services	ADHD & ASD	Multiple	2	18	N/A	0	2	2	2	2	2	0	1
South East England	Sussex Partnership NHS FT	2	East Sussex, Brighton & Hove Neurobehavioural Services	Neurodevelopmental	Multiple	2	18	N/A	2	2	2	0	2	2	2	0
South West England	Avon & Wiltshire MH Partnership NHS Trust	1	Adult ADHD Service	ADHD	Multiple	1	18	N/A	1	1	1	1	1	1	1	1
South West England	Devon Partnership NHS Trust	1	Devon Autism & ADHD service	ADHD & ASD	Single	1	17.5	N/A	1	1	1	1	1	1	0	0
Scotland	NHS Lothian	1	Adult ADHD Resource Team	ADHD	Multiple	1	18	N/A	0	1	1	1	0	1	1	0
Wales	Hywel Dda University Health Board	1	Adult ADHD Assessment Service	ADHD	Single	1	18	N/A	0	0	0	0	1	0	0	NA
<b>Total</b>	<b>35 Trusts/Boards</b>	<b>44</b>				<b>39</b>			<b>26</b>	<b>36</b>	<b>38</b>	<b>27</b>	<b>35</b>	<b>22</b>	<b>13</b>	<b>13</b>

Blank cell = no response; \*other = any other service, for example patient support groups; \*\*funding access = patients from outside commissioned/funded locations may be able to access the service

In England a total of 42 dedicated ADHD services for adults were identified, provided by 33 trusts. Wales and Scotland each had one identified service. No dedicated services were identified for Northern Ireland. However, freedom of information responses from some health board/trusts, (particularly in Scotland, Wales and Northern Ireland) implied generic services (see group B) were more likely to be configured to treat adult ADHD in these countries.

As table 15 indicates, only 12 (27%) of these dedicated adult ADHD services offered the range of interventions specified by NICE (2018b). They were most likely to provide medication management, ongoing prescribing or shared care (89%) and diagnosis (82%). But transitional care (59%), and psychological treatment (50%) were less frequently offered. Two reported an upper age limit of 65 years, which may present problems in the future as increasing numbers of adults with persistent ADHD reach the boundary for old age psychiatry services. Nearly a third (30%) indicated patients from outside their commissioned/funded location might be able to access treatments.

As figure 16 illustrates, the provision of NHS dedicated adult ADHD services are not evenly distributed across the country.

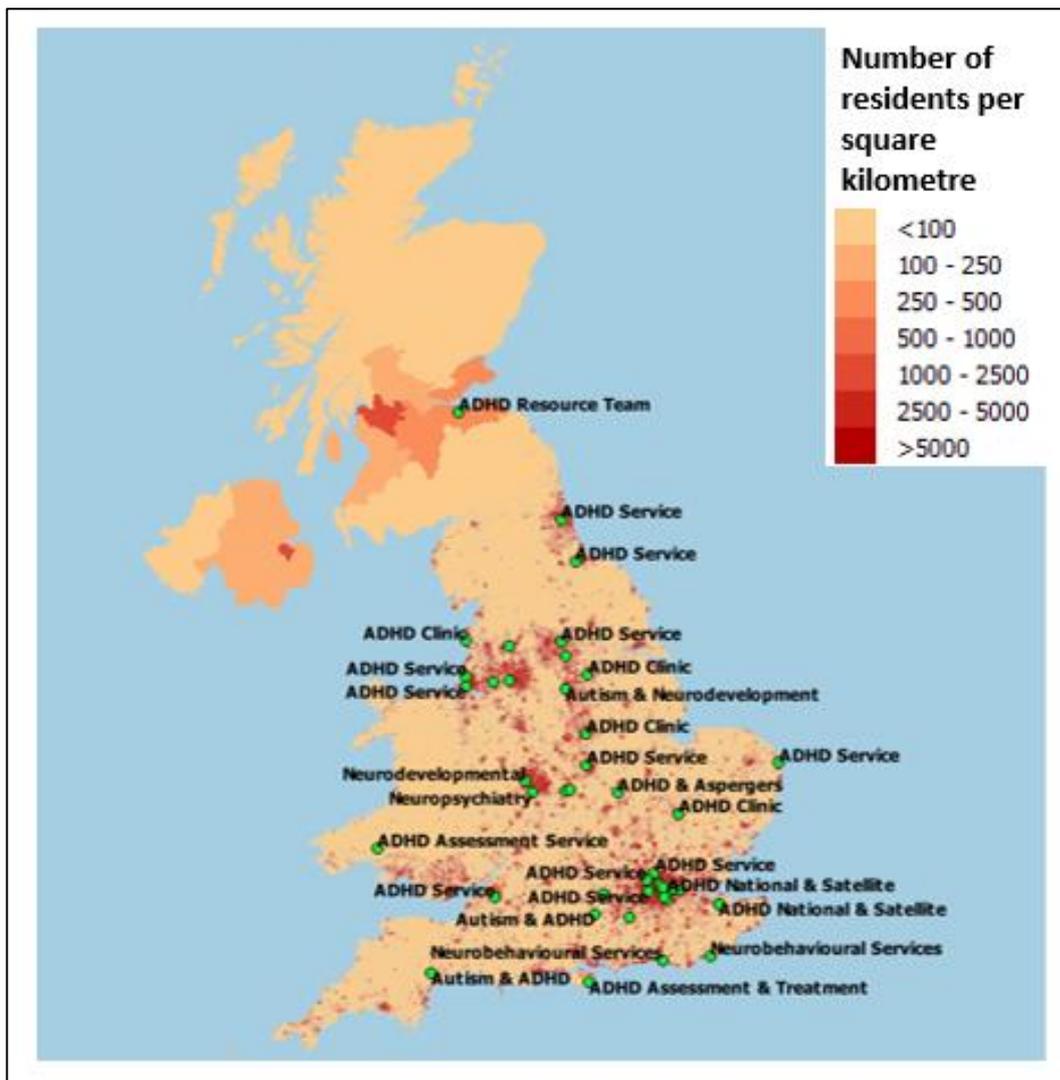


Figure 16. Map showing locations of dedicated NHS services for adults with ADHD in the UK, against number of residents per square kilometre

Population density displayed by: lower super output area for England and Wales; Health and Social Care Board for Northern Ireland; and Health Board for Scotland (National Records of Scotland, 2018, Office for National Statistics, 2016, Office for National Statistics, 2018, OpenDataNI, 2016, UK Data Service, 2017)

Layer 2 (groups A and B): adult NHS services (see table 16 and figure 17)

Group B, comprised of 99 adult NHS services; provided by 71 organisations.

Layer 2 (n=143) was made up of:

- 111 English services, provided by 58 organisations (57 Mental Health NHS Trusts and 1 London Council). *Note: England has approximately 60 Mental Health trusts, although mental health service provision by NHS trusts varies and is difficult to track.*

- 6 Northern Ireland services, provided by each of the 5 NHS Health and Social Care trusts.
- 17 Scottish services, provided by each of the 14 NHS Health Boards, and
- 9 Welsh services, provided by each of the 7 Local Health Boards.

Table 16 summarises the types of adult NHS adult services identified in layer 2, by region.

Table 16. Adult NHS services identified by respondents as ones at which someone had experienced treatment or support for adult ADHD; by service type and UK NHS region

NHS Service Type		Number of Services by UK NHS Region							
Primary	Detailed	London	Midlands & East of England	North of England	South East England	South West England	Northern Ireland	Scotland	Wales
Dedicated ADHD Services for Adults	ADHD	9	5	10	2	1	0	1	1
	ADHD & ASD	2	1	1	2	1	0	0	0
	Neurodevelopmental	0	3	1	4	0	0	0	0
Total group A	44	11	9	12	8	2	0	1	1
Percentage group A	100%	25%	20%	27%	18%	5%	0%	2%	2%
Services for Adults	ASD	0	1	0	1	0	0	0	0
	Drug & Alcohol	0	0	0	1	0	0	0	0
	Generic Adult MH	8	14	11	5	8	5	13	6
	Health & Social Care	1	0	0	0	0	0	0	0
	Mental Health & LD	0	0	0	0	0	0	1	1
	Primary Care MH	0	1	0	0	0	1	0	0
	Prison & Custody MH	0	0	0	0	2	0	0	0
0-25 Service	0-25	0	2	0	0	0	0	0	0
Adult LD Services	LD	1	5	3	3	2	0	2	1
Total group B	99	11	23	14	9	12	6	16	8
Percentage group B	100%	11%	23%	14%	9%	12%	6%	16%	8%
% of UK NHS Region Population*	100%	13%	26%	24%	8%	13%	3%	8%	5%

Note: NHS = National Health Service, ASD = autistic spectrum disorder, MH = mental health, LD = learning disability. Number of services for group A = every service with a unique name. Number of services for group B = one service per type, per providing trust/health board. For example, adult community MH teams in one region may have multiple locations but only be counted as a single service. \*2015 ONS mid-year population estimates (Office for National Statistics, 2018)

*Learning disability services:* the most commonly identified type of service unique to layer 2 after generic AMHS, were LD services. These were sent FOI requests about the nature of their provision; of 17 providers contacted 13 (76%) responded. One provider, NHS Fife in Scotland, confirmed that their LD service provided treatment for adults with ADHD. The remainder were either unclear (3), confirmed they did not provide adult ADHD treatment within LD services (5) or mentioned other services in their trust at which treatment was provided (4).

Figure 17 illustrates the geographic locations of services at layer 2, which suggests that some gaps in dedicated service provision may be explained by access to services within generic mental health services.

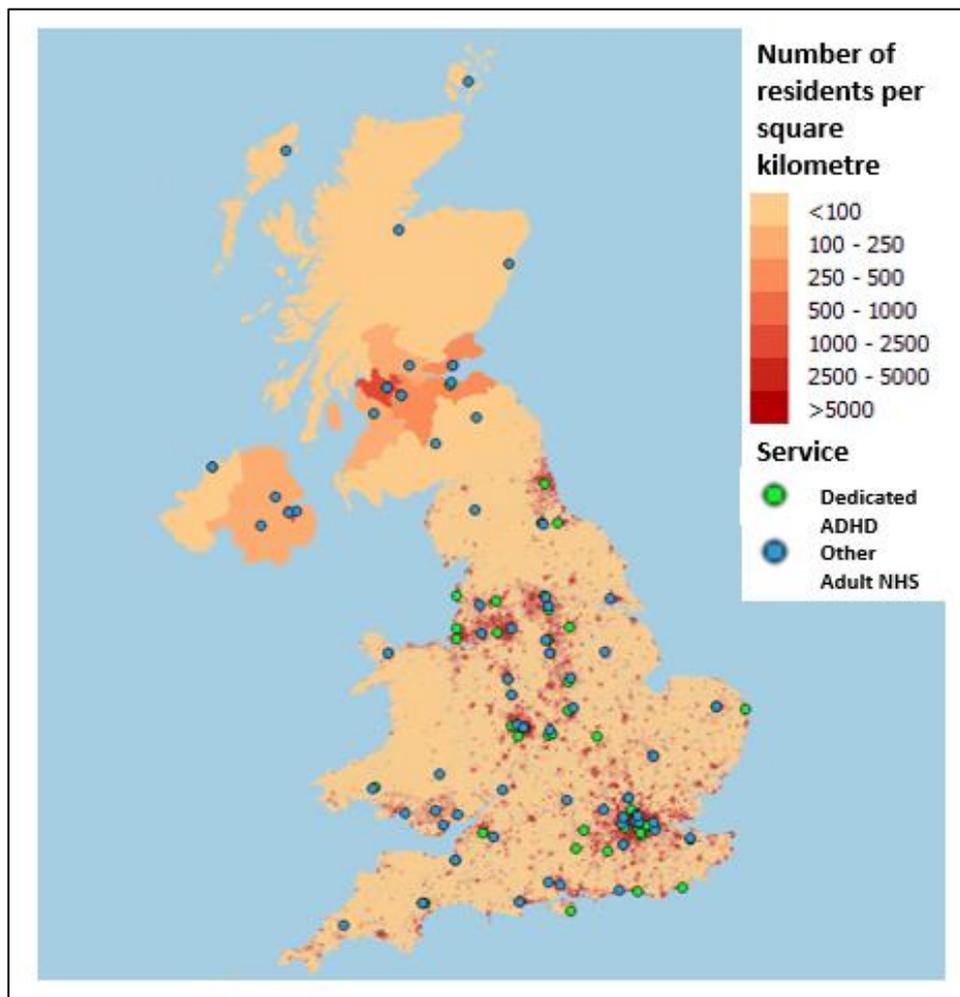


Figure 17. Map showing adult NHS services at which respondents reported experience of treatment for adult ADHD

Set against map showing number of residents per square kilometre (population density)

Layer 3 (groups A, B and C): all services at which support experienced

Group C, comprised of 32 NHS children's services, (which officially only treat up to age 18 years but at which respondents' reported experiences of post 18 support), as well as 40 private organisations and 39 voluntary services/charities (111 services in total). Layer 3 (n=254) was made up of all services experienced as providing treatment/support for adults with ADHD. This included NHS services for children and adults as well as private and charity/voluntary services.

Layer 4 (groups A, B, C and D): all services

Group D, comprised an additional 40 services (9 NHS child, 12 NHS adult, 11 private, and 8 charity/voluntary services) that were reported but without confirmation of experience. Layer 4 (n=294) was made up of all the unique services identified by contributors to the study.

Sharing service data

Services in groups A, B and C, were uploaded to an interactive Google My Map, and posted onto the project website, see figure 18, and <http://bit.ly/AdultADHD2018> (University of Exeter, 2018). The map included a disclaimer stating it was '*a work in progress and not definitive*' (University of Exeter, 2018). Partner organisations embedded links to the map on their websites. Findings were also shared via social media.

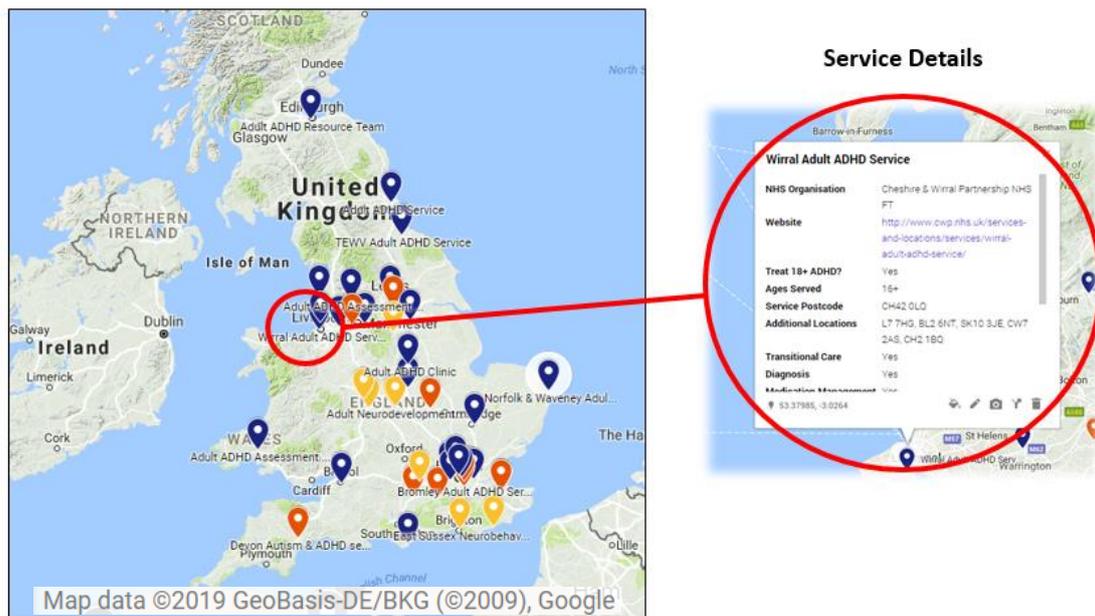


Figure 18. Illustration of the interactive Google my map of NHS dedicated adult services

### Stakeholder perspectives

*Informants reporting types of service experienced:* the figures displayed in table 17 should be viewed in the context of the distribution of survey responses; 73% of respondents identified themselves primarily as health workers, 17% as service users, 8% commissioners and 2% as other.

Table 17. Differences in service identification by informant group and service type

Service layer	Number of services	Experienced by Service Users		Experienced by Health Workers		Identified via FOI by Commissioners	
		Number of services	% Services in that layer	Number of services	% Services in that layer	Number of services	% Services in that layer
Group A	44	25	57	38	86	41	93
<b>Layer 1</b>	<b>44</b>	<b>25</b>	<b>57</b>	<b>38</b>	<b>86</b>	<b>41</b>	<b>93</b>
Group B	99	23	23	89	90	34	34
<b>Layer 2</b>	<b>143</b>	<b>48</b>	<b>34</b>	<b>127</b>	<b>89</b>	<b>75</b>	<b>52</b>
Group C	111	42	38	90	81	17	15
<b>Layer 3</b>	<b>254</b>	<b>90</b>	<b>35</b>	<b>217</b>	<b>85</b>	<b>92</b>	<b>36</b>

Groups: A=dedicated adult ADHD, NHS; B=other adult NHS; C=non-adult NHS, private and voluntary. Layers: 1=dedicated adult NHS; 2=all adult NHS; 3=all services experienced

There were significant differences between informants (commissioners, service users and health workers) in the proportion of services reported in groups A, B and C ( $X^2$  (4, N=399) = 34.29,  $p < 0.001$ ). Commissioners were more likely to report dedicated NHS adult services, ( $X^2$  (2, N=346) = 32.09,  $p < 0.001$ ), than other NHS adult or child NHS, private or voluntary/charity services. Service users were marginally more likely to report dedicated NHS adult or child NHS, private or voluntary/charity services, ( $X^2$  (2, N=344) = 7.13,  $p = 0.028$ ), and less likely to report other NHS adult services. In contrast, health workers reported similar proportions of all services, ( $X^2$  (2, N=471) = 0.26,  $p = 0.88$ ).

*Combinations of informants reporting service experience:* every service was categorised by the combination of informant groups for which at least one contributor had reported experience of treatment/support for adult ADHD at that service. Categories were: all three informant groups, (commissioners, health workers and service users), a combination of two, or only one informant group. For a descriptive summary, see table 18.

Table 18. The combinations of stakeholder groups identifying experience of services in groups A, B and C.

Service grouping	Total	Combination of informant groups identifying service experience*							
		Co, HW + SU	Co + HW	Co + SU	HW + SU	Co	HW	SU	Other
Group A (n)	44 <b>100%</b>	24 <b>55%</b>	11 <b>24%</b>	0 <b>0%</b>	1 <b>2%</b>	6 <b>14%</b>	2 <b>5%</b>	0 <b>0%</b>	0 <b>0%</b>
Group B (n)	99 <b>100%</b>	7 <b>7%</b>	18 <b>18%</b>	0 <b>0%</b>	15 <b>15%</b>	9 <b>9%</b>	49 <b>50%</b>	1 <b>1%</b>	0 <b>0%</b>
Group C (n)	111 <b>100%</b>	7 <b>6%</b>	4 <b>4%</b>	0 <b>0%</b>	22 <b>20%</b>	6 <b>5%</b>	57 <b>51%</b>	13 <b>12%</b>	2 <b>2%</b>

Co = Commissioners; HW = Health workers; SU = Service users. \*Experience = online survey 'experienced' services, surveillance study 'follow up' services, and FOI formally 'identified' services. Groups: A = dedicated adult ADHD, NHS; B = other adult NHS; C = non-adult NHS, private and voluntary

The overlap between informants reporting services is interesting in terms of what it may indicate about information needs and flows. The majority of dedicated NHS adult services (group A) were reported by all stakeholder groups, while the majority of other NHS adult and child NHS, private and voluntary/charity services (groups B and C), were reported by health workers alone. There was a statistically significant difference in proportion of group A (55%) services experienced by all informant groups, compared with group B (7%) and group C (6%) services, ( $p < 0.001$ , Fisher's exact test; see figure 19). The implication from this data is that dedicated NHS adult services were generally known about by all three informant groups, while there were differences in respondent knowledge held about other services experienced.

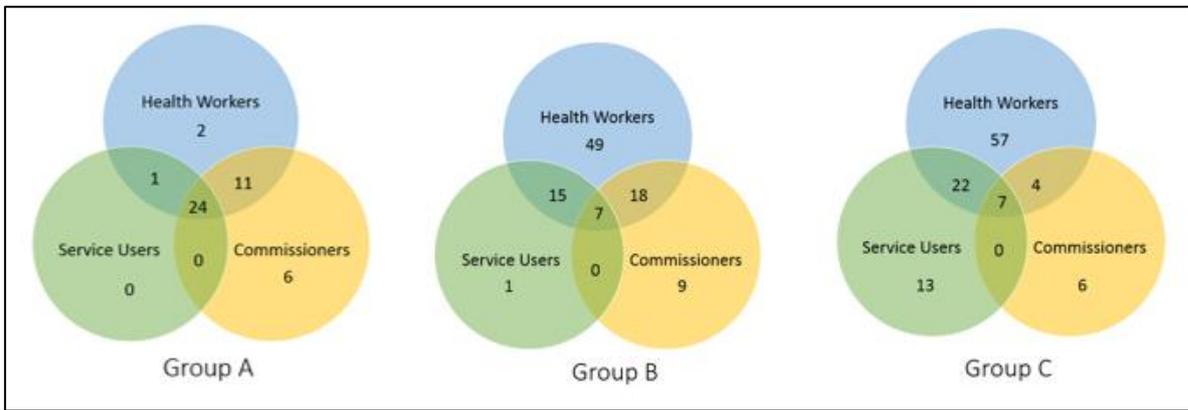


Figure 19. Venn diagrams illustrating overlap of service identification for groups A, B and C

Two services identified by 'other' are excluded, so the total number of services is not equal to the sum of services in each group

Learning disability services: the reporting of adult NHS LD services is of interest, as they comprised the largest proportion of group B service type identified, see figure 20.

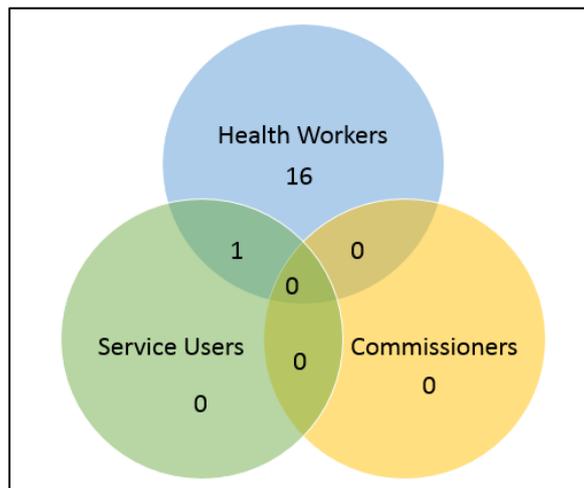


Figure 20. Venn diagram illustrating identification of learning disability services, by informant group

Of the LD services identified, all were named by health workers, only one by a service user and none by commissioners as providing treatment/support for adult ADHD. Although 17 LD services were identified in group B, in responses to FOI requests only one provider confirmed that their LD service provided treatment/support for adult ADHD.

#### **4.3.4 Discussion**

Gathering data on service provision from a range of stakeholder perspectives is an important part of improving healthcare and identifying barriers to transition (Colver et al., 2018, Love et al., 2014). Mapping services is particularly relevant for conditions such as adult ADHD, for which gaps in care have been identified (Hall et al., 2013, Marcer et al., 2008). Therefore, in line with recommendations from the Five Year Forward View for Mental Health (NHS England, 2016) our findings may meet multiple needs, including service users in need of more accessible and better quality information, health workers wanting to know where to refer to, and commissioners and service providers making decisions about future service design, coordination and delivery.

This study was designed to provide national level data on existing services for young adults with ADHD, which could be used to optimise transition and service provision (Hall et al., 2013, NHS England, 2016). The methods used build on existing surveys of adult ADHD service provision which have focussed on indexing and describing services in specific UK regions or surveying a single stakeholder group, by seeking multiple informants on a national scale (Edwin and McDonald, 2018, Hall et al., 2013, Wong et al., 2009). The significantly different pictures of service availability provided by stakeholder groups, emphasises the importance of combining information from multiple informants and raises questions about the validity of mapping methodologies that rely on input from a single source. The methodology used was relatively quick and focused, which suggests that it may be appropriate for ongoing updating, and for indexing health service provision for other health conditions.

### *Defining dedicated services*

The complexity of health service provision and commissioning in the UK meant there was no way to ensure that health service workers, service users, and commissioners identified the same 'unit' of 'service' when responding to the survey. In addition, like many specialist services in the NHS such as specialist services for older people and eating disorder services (Petrovici and Ritson, 2006, Reed et al., 2006), specialist adult ADHD services are not clearly defined, which made categorising services in a way that reflected experiences of multiple stakeholders challenging.

Within UK healthcare, a 'team' of clinicians may identify themselves (or be identified by service users) as a 'service' when they work across the whole or parts of provider organisations or their constituent units and localities. A 'specialist service' may be labelled through the individual perspective of a service user, a clinician, a manager or a commissioner without it necessarily being a bona fide unit in the organisation of the provider organisation. Highly specialist services may be regional or even national in terms of the "catchment area" from which they are willing to accept referrals. But equally, as commissioning arrangements are complex and varied, local areas may commission their own specialist teams, which may include dedicated time for practitioners working in generic services to focus on adults with ADHD. This complex picture, paired with the aim of including multiple stakeholder perspectives, made the task of categorising adult ADHD services challenging. The methodological decision to label services with ADHD in the title as 'dedicated' means dedicated services will comprise a range; from the highly specialist national and regional, to the ADHD consultant who has one or two days per month within an AMHS.

### *Service types*

Identified adult NHS services (groups A and B) were of most interest as they had scope to provide the range of treatments recommended by NICE via a 'multidisciplinary specialist team/clinic with expertise in ADHD' (2018b). However, findings showed that many dedicated services (group A) did not offer the full range of recommended provision. It is possible that other adult NHS services

(group B), offered treatments in line with UK clinical guidelines, but we lacked the resources to check these details. There seemed to be an interesting disagreement between health workers reports of adults accessing adult LD services for ADHD, perhaps for comorbid LD, and FOI request responses that stated few of them provided services to adults with ADHD. The range of Group C services identified, (NHS services for under 18s, private and charity/voluntary services) provided a snapshot of 'alternative' ways stakeholders currently access treatment or support for adult ADHD, and were surprisingly commonly reported, particularly by health workers.

### *Geographic variations in provision*

The maps that we generated clearly illustrate geographic inequalities in dedicated provision, with areas where services appear to be currently lacking. However it is possible that treatment is being provided through non-dedicated (group B) services in some of these areas, for example in Scotland, Wales and Northern Ireland, as indicated by FOI responses. The findings tie in with existing evidence of variable specialist service provision for adults with ADHD in the UK, with high levels of geographic variation and identified gaps in care (Belling et al., 2014, Coghill, 2015, Hall et al., 2015, Healthcare Improvement Scotland, 2012, Leavey et al., 2018, Zaman et al., 2012). Healthcare Improvement Scotland (2012), identified an urgent need to develop capacity and capability for treatment of adult ADHD, as did (Leavey et al., 2018) for Northern Ireland. The current study, with data collected in 2018, identified one dedicated service in Scotland and none in Northern Ireland, but some generic provision.

Various service models are currently employed in the treatment of adult ADHD (Coghill, 2017). One region, which initially integrated ADHD services into CMHTs (Crimlisk, 2011) now has a dedicated service, implying a move towards specialist provision. By contrast, in one Scottish region, where work was carried out to treat ADHD within generic children's services (Coghill and Seth, 2015), an adult CMHT was identified by service users and health workers, implying support for adult ADHD may be being successfully accessed within this generic service. Indeed, responses from some commissioners in Wales, Scotland and Northern Ireland

suggest their service models are configured to treat adult ADHD within generic services, which may explain some of the regional differences in provision of dedicated services. If there was sufficient expertise in generic services, the need for specialist provision would lessen.

#### *Changes in service provision over time*

Zaman et al. (2012) described seven UK services for adults with ADHD, which if an exhaustive list, indicates numbers of dedicated services have increased rapidly over the last decade. The 33 English organisations identified here as providing dedicated services, when compared with 16 mental health trusts identified by Hall et al. (2015), also suggest an increase. However, due to changing NHS structures the number of English NHS trusts responsible for providing mental health services has almost doubled since 2013 (NHS England, 2018). Examined with proportionality in mind, the 55% of English NHS mental health trusts found to provide dedicated adult ADHD services in 2018 represents only a marginal increase on the 44% found in 2014, (Hall et al., 2015).

#### *Organisation of services*

Some controversy remains over how to organise adult ADHD services (Coghill and Seth, 2015), and there is as yet no established, evidence based service model. Some NHS organisations may treat adult ADHD within non-dedicated AMHS. NICE (2018b) guidelines specify services should include a team of clinicians with expertise in diagnosis and treatment of adult ADHD. Generic adult NHS services' capacity and availability for treating adults with ADHD represents a grey area that needs urgent further investigation (Coghill, 2017). It is worrying that fewer than 30% of identified dedicated services provided the full range of NICE recommended treatments, but equally it can be difficult to provide transitional or psychological care to those who live a considerable distance away. Some recommended treatments, particularly transitional care and psychological treatment could be provided by other services.

### *Stakeholder perspectives*

Analysis of stakeholder perspectives showed a significantly lower proportion of other adult NHS services (group B) were identified by all stakeholders, compared with the proportion of dedicated NHS adult ADHD services (group A) identified. This raises questions over which, if any, generic adult NHS services, provide accessible treatment for adult ADHD in practice and in line with guidelines (Crimlisk, 2011, NICE, 2018b). The significant differences in stakeholder identification of other NHS adult (group B) services, the majority of which were identified by health workers alone, implies service users may not be accessing these services. This could be because service users do not know about them, did not report access in the survey, or because only a 'lucky' few patients received care from clinicians going beyond the remit of their service to meet clients' needs. It could also mean that although health workers believe general adult NHS services offer treatment to adults with ADHD, in practice, referrals to that service are not accepted. This barrier to transition was identified in a recent surveillance study, in which only a fifth of ADHD referrals to adult services were accepted (Eke et al., In submission-a). The last possibility is particularly concerning, as high rates of unaccepted referrals into adult services is an identified barrier to transition into adult ADHD services, which can cause significant emotional distress to young people and older adults with ADHD (Belling et al., 2014, Price et al., 2019, Swift et al., 2013, Wong et al., 2009).

### *Non-NHS, and child NHS services*

Of the services identified by respondents at group C (child NHS, private and voluntary/charity), the high number of NHS services for under 18s, gives weight to research findings that when transition fails and/or adult ADHD services are not available, child services may keep young people beyond the age boundary of their service (Cheung et al., 2015, Leavey et al., 2018, Price et al., 2019, Wong et al., 2009). This represents a pragmatic short-term solution to gaps in adult ADHD provision, but one which may lead to sub-optimal care (Bailey et al., 2003), and reduce the capacity for CAMHS to work with other younger people. The high number of private and charity/voluntary services experienced, point to a significant role of private providers and third sector organisations in adult ADHD treatment and support. The high number of private providers raises the question

of whether patients are being pushed into paying for care due to lack of NHS services.

### *Methodological issues*

This study was the first national ADHD service survey in the UK to triangulate perspectives from a wide range of service users, health workers and commissioners and apply multiple methods to optimise responses. Checking provision offered by generic adult NHS services was challenging due to a lack of up to date information available online, so we have to rely on informant reports and lack detail about what is provided. Study resource limitations meant that we were only able to send FOIs to verify provision to LD and dedicated services. Of LD services, only 6% were confirmed by their providers as treating adult ADHD, which implies that for this sub-section of group B at least, not all identified services provided treatment as part of their official remit.

Although high response numbers and a reasonable balance of responses was attained, the majority of responses came from the online survey, which necessarily accessed a sample of interested and computer literate responders. As it was not obtained via a known sample frame, this approach potentially introduced information bias, but we would argue contributes towards knowledge of and reporting of services. For this reason, analysis of service identification by stakeholder group should be treated with caution, as those who may be struggling to access services may be particularly likely to be in contact with the support organisations who supported us to disseminate the survey. In addition, we had differential access to stakeholders, with direct email contact from the Royal College of Psychiatrists and ADHD support organisations, who clearly are likely to be more concerned than other health disciplines.

Service capacity of dedicated services, in terms of staffing levels, size of service and catchment area, was not evaluated and we lacked resources to confirm the status of other adult NHS (group B) services. The pragmatic definition of 'dedicated' ADHD services, adopted when grouping services, was in line with study aims. A more robust definition of 'dedicated' or 'specialist' ADHD adult NHS services could enhance the clarity of the service map, but would take

considerable additional resources to complete with a high level of accuracy. Alternative approaches to mapping provision, such as contacting all providing NHS organisations and asking them to confirm which ADHD treatments are provided, by which type of service, could potentially help clarify complexities in service organisation. However reporting by health providers alone would not capture service user experience of availability in practice. UK adult ADHD services continue to change and evolve, and this data only provides a snapshot in time of provision. Thus, any map will need regularly updating if it is to provide accurate information. In addition, a key problem for adults with ADHD is registration with a GP who is willing to prescribe medication if they require it, which further mapping could usefully address.

#### *Future work*

Developing optimum and economic service models for treating adults with ADHD remains an urgent priority. The Department of Health NHS mandate (2012), highlighted areas for NHS improvement, with one focus being on providing better care for long term conditions through improved integration of primary and secondary care services. There is a need to better understand barriers to management of ADHD within primary care and explore ways of supporting this integration. Future research could map availability of primary care practices to support adults with ADHD either through a shared care model or as standalone practices.

Findings from the CATCh-uS qualitative study have indicated that having a dedicated service, and confirmation from a provider of treatments offered, does not necessarily mean services are provided in practice (Janssens et al., In preparation). Therefore, research is needed to assess the capacity of dedicated services for ADHD, providing an overview of staff numbers and backgrounds, and the time and resources available for them to support their work with adults who have ADHD, as well as waiting lists.

#### **4.3.5 Conclusion**

Ensuring adequate provision of adult services, both across geographic locations and providing services in line with NICE guidelines, is an important factor in removing structural barriers to successful transition for young people with long term conditions (Gray et al., 2018, Singh et al., 2010a). This applies for young people with ADHD, whose associated difficulties with organisation and managing change can make health care transitions especially challenging (Hall et al., 2013, Singh et al., 2008, Singh et al., 2010a). Mapping the availability of adult ADHD services is an important step towards increasing the transparency of current services and structures (Belling et al., 2014, NHS England, 2016), with the aim of providing information to help optimise service design, and preventing premature disengagement from treatment and the associated negative life outcomes for this vulnerable group. Given that services change with time, we are delighted that the work we have started will be continued and developed by the UK Adult ADHD Network.

#### **4.3.6 Acknowledgements**

The authors would like to thank the following people: Abigail Woodley, Andi Stanescu and Tom Reed for data cleaning; Kate Powell and Rachel Califano for service checking. Kerry Pearn and Dr Sean Manzi from the PenChord team (<http://clahrc-peninsula.nihr.ac.uk/penchord>) for support with QGIS Mapping Software. The CATCh-uS parent advisory group for survey development. All the organisations and individuals that supported this work, including the Royal College of Psychiatrists, the UK Adult ADHD Network, the ADHD Foundation and the Clinical Research Network South West.

## **Chapter five: quantitative study**

### **5.1 Introduction and overview of chapter**

Previous chapters, in line with existing research, have highlighted that limited provision of services for adult ADHD in the UK is a barrier to transition for young people with ADHD. The systematic review, in chapter two, found that reported transition difficulties were linked to poor availability of adult services for ADHD. The qualitative study, in chapter three, revealed confusion and a lack of clarity on the part of young people about where adult services were, and what services were provided, with parents/carers having to fight hard to obtain such information. The mapping study in chapter four provided the first national map of services, as reported by service users, health workers and commissioners. The map found limited numbers of dedicated NHS adult ADHD services, with many offering only a restricted range of treatment options and this study highlighted variation in service provision by geographic region, and high levels of heterogeneity of NHS services for adults with ADHD. However, despite clear evidence of patchy service provision and the high associated personal and emotional costs for people with ADHD and their families when they cannot access care, due to complex service configurations and differences in reports of service availability, it was difficult to conclude with certainty where inequities in accessing adult ADHD services existed in practice.

One method for assessing availability of healthcare services in practice is to find a proxy indicator for provision of care. Many questions were raised by the map of services. Despite what was clearly an uneven distribution of dedicated ADHD services, with extensive geographic gaps, it was not possible to tell to what extent existing AMHS (in areas where dedicated services were not available) met adult ADHD needs. In practice meeting need often means prescribing medication for ADHD, which is the first line of treatment for adults with ADHD in UK guidelines (NICE, 2018b). Therefore, a measure of treatment in practice of young people with ADHD through transition was needed. Previous research, using UK primary care data from the CPRD, has found that young people with ADHD are at high

risk of cessation of medication during transition from child to adult services (Newlove-Delgado et al., 2018a). This study also reported that decreases in UK primary care prescribing of ADHD medication through the transition period (ages 16-18) was higher than expected, given estimates of population prevalence of ADHD (Newlove-Delgado et al., 2019b). These data, drawn from an analysis of primary care records, suggest that at least some young people with ADHD are stopping medication prematurely, which may be related to transition difficulties due to patchy service provision. However, to date, these data have not been analysed by geographic region.

The aim of the quantitative study presented in this chapter was to build on previous work using data from primary care records in the UK, to explore changes in prescribing rates and the numbers of referrals into adult services for young people with ADHD, by geographic region of the UK. This was achieved through an analysis of existing CPRD data. The rates of change in prescribing of ADHD medication and percentage of referrals into adult services were used as a proxy measure for provision of care. From this analysis inferences could be made about equity of access by region of the UK. Identified regional variations were plotted onto visual maps and compared against locations of dedicated adult ADHD services identified in my 2018 mapping study, to check for any visually identifiable relationship. Despite clear limitations due to the large size of UK NHS regions, which meant that it was not possible to identify factors underlying differences found, and the fact that the CPRD only captures primary care prescribing and is limited by data processes such as a reliance on GPs recording referrals and censoring of prescribing data, this analysis provided concrete evidence of geographic variations in prescribing and referrals for young adults with ADHD. The following study builds on the results of the mapping study by beginning to address questions about provision of care in practice and establishing a clear line of future research - investigating adult ADHD health service provision in practice through the use of proxy measures of medication provision and referral rates.

The current chapter consists of a research paper that shares the findings of the quantitative analysis of the CPRD data set, which has been submitted for publication to the *British Journal of Psychiatry*, and is currently under review (Price et al., In submission-a).

## **5.2 ADHD prescribing and referrals by UK region: manuscript submitted for publication**

Regional analysis of UK primary care prescribing and adult service referrals for young people with ADHD

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### 5.2.1 Abstract

**Background:** Attention deficit hyperactivity disorder (ADHD) often persists into adulthood. In the United Kingdom (UK) there is a sharp reduction in ADHD drug prescribing over the period of transition from child to adult services. The decrease is higher than expected given estimates of ADHD persistence, and may be linked to difficulties in accessing adult services. However, little is currently known about geographical variations in prescribing and how this may relate to service access.

**Aims:** To analyse geographic variations in primary care prescribing of ADHD medications over the transition period (age 16-19 years) and adult mental health service (AMHS) referrals, and illustrate their relationship with UK adult ADHD service locations.

**Method:** Using a Clinical Practice Research Datalink cohort of people with an ADHD diagnosis aged 10-20 in 2005 (study period 2005-2013; n=9,390), regional data on ADHD prescribing over the transition period, and AMHS referrals, were mapped against adult ADHD services identified in a linked mapping study.

**Results:** Differences were found by region in the mean age at cessation of ADHD prescribing, range 15.8-17.4 years,  $F(12, 3463)=6.18$ ,  $p<0.001$ , as well as in referral rates to AMHS, range 4-21%,  $\chi^2(12, N = 9,390) = 121.60$ ,  $p<0.001$ . There was no obvious visual relationship between service provision and prescribing variation.

**Conclusions:** Clear regional differences were found in primary care prescribing over the transition period and in referrals to AMHS. Taken together with service mapping, this suggests inequitable provision and is important information for those who commission and deliver services for adults with ADHD.

**Keywords:** CPRD, ADHD, Transition, Prescribing

## 5.2.2 Introduction

Rates of primary care prescribing of attention deficit hyperactivity disorder (ADHD) medication for young people with ADHD in the United Kingdom (UK) appear to decline more steeply than expected given the rate of symptom reduction from follow-up studies (Newlove-Delgado et al., 2018a). The timing coincides with the age at which children's services end, usually between 16 and 18 years, and transition into adult services occurs if continuation of medication is recommended. This is a key developmental stage when multiple other transitions are likely, such as changing educational setting or leaving home for the first time. The National Institute for Health and Care Excellence (NICE) guidelines recommend that prescribing of ADHD medication for adults should happen via shared care agreements between primary and secondary care (NICE, 2018b). The principle of shared care assumes that the young person will be in the care of an adult mental health service (AMHS) with the General Practitioner (GP) continuing to prescribe (Taylor et al., 2010). However problems could arise, due to lack of adult ADHD services, because there is no shared care agreement, or because GPs are not prepared, trained or supported to prescribe (French et al., 2018, Tatlow-Golden et al., 2016).

Evidence is increasingly emerging of low rates of successful transition and poor quality transition experiences for people with ADHD (Eklund et al., 2016, Price et al., 2019). Disruption of care during transition adversely affects young people with mental health conditions (Singh et al., 2010a) whilst untreated ADHD can worsen health, education and occupational outcomes (Faraone and Glatt, 2010, Shaw et al., 2012). For those young people who continue to require medication, cessation of prescribing could be related to lack of service provision. Studies have suggested that there are gaps in provision of adult ADHD services and a shortage of specialist services (Hall et al., 2015, Hall et al., 2013). Population prescribing studies suggest higher incidences of ADHD diagnosis and prescribing in young people in areas of socioeconomic deprivation (Prasad et al., 2018), however this is unsurprising given the strong link between deprivation and the prevalence of ADHD (Russell et al., 2018).

Recent research has evidenced geographic gaps in the availability of dedicated NHS services for adults with ADHD in the UK (Price et al., In submission-b), but due to the complex organisation of health services and the fact that some general AMHS will provide treatment for adult ADHD where there is no dedicated service, it is unclear whether this affects equity of access to treatment. The current model of ADHD prescribing is that primary care services prescribe for ADHD under shared-care agreements with dedicated or general AMHS (NICE, 2018b), therefore examining primary care prescribing through transition is likely to provide the most complete data. In this study we used the prescribing of ADHD medication through transition, and rates of referral into any AMHS as a proxy for access to services.

To our knowledge, no study has examined regional differences in prescribing for young people with ADHD in the UK during the transition period. Knowledge and understanding of any regional variations in prescribing rates through transition, and potential links to availability of dedicated adult ADHD services may allow commissioners and practitioners to address inequalities of provision. The current study aimed to analyse regional variation in prescribing patterns of ADHD medication and rates of referrals into AMHS for young people with ADHD aged between 16 and 20 years from 2005 to 2013, using the Clinical Practice Research Datalink (CPRD). It also aims to explore relationships between prescribing patterns, referral rates and service locations.

### **5.2.3 Methods**

#### *Data source*

The CPRD is a large database of anonymised patient records including diagnoses, prescribed drugs and referrals to secondary care services. The primary care section is contributed to by over 670 GP practices across the UK and contains the records of over 11 million patients. It covers up to 6% of the UK population and is broadly representative in terms of age, sex, ethnicity, and geographical location of practices (Herrett et al., 2015).

The data source for service locations was the 2018 UK mapping study, a national survey of adult ADHD services, run as part of the 'Children and Adolescents with ADHD in Transition from Child to Adult services' (CATCh-uS) study of transition in ADHD (Ford et al., 2015). Data on services were gathered from over 2,600 informants from across the UK; service users, health workers and National Health Service (NHS) commissioners. Data were collected via an online survey, freedom of information requests to commissioners (90% response rate) and surveillance reports. A total of 44 NHS dedicated adult ADHD services were identified; consisting of 29 ADHD, 7 ADHD and ASD, and 8 Neurodevelopmental services (University of Exeter, 2018).

#### *Study design and population*

We used a cohort from the CPRD of young people aged between 10 and 20 years in 2005, for the study period which ran from 1<sup>st</sup> Jan 2005 until 31<sup>st</sup> Dec 2013 (Newlove-Delgado et al., 2018a). This allowed us to study prescribing over the transition period (see below). To be included, cases had to have a diagnosis of ADHD coded in their primary care record. ADHD diagnoses were defined as any of the 22 CPRD medical codes and primary care read terms (based on ICD-10 F90 categories) that relate to an ADHD diagnosis (see Newlove-Delgado et al. (2018a) for details on case identification and supplementary material). Cases were defined as having an ADHD prescription if any prescription record had an ADHD-related medication code, including categories of stimulants and non-stimulants for ADHD (Newlove-Delgado et al., 2018a). Rare cases of narcolepsy, for which ADHD medication may be prescribed ( $n < 20$ ) were excluded from the analysis.

Regions were defined by the NHS strategic health authority (SHA) boundaries, in which reporting GP practices were situated during the study period.

### *Statistical analysis*

The first phase of analysis used STATA version 15.0 (StataCorp., 2017) and focussed on changes in prescribing of ADHD medication through transition and incidences of referral to AMHS services. The CPRD did not supply dates of birth, therefore age bands were assigned with, for example age-band 14/15 indicating the year of 15<sup>th</sup> birthday. This analysis focusses on changes in prescribing over the transition period. We defined this period as being between the year of 16<sup>th</sup> birthday, which often marks the end of children's services, and the year of 19<sup>th</sup> birthday, which is when the transition to adult services should be completed, according to NICE guidance (NICE, 2016).

Firstly, analyses were carried out to examine differences in prescribing prevalence by region. The proportion of cases with an ADHD prescription at any point was calculated, followed by the proportion of cases with a prescription in each age band from 14/15 years to 19/20 years, to cover the transition period and one year either side. For each region, the difference in the proportion of cases with an ADHD prescription between the beginning and end of the transition period was then reported. The denominator for each age band only included cases who had records for the full year in question.

Age at cessation of medication by region was then examined, with cessation being defined as a gap of more than six months in prescriptions. This was chosen to allow for uncertainty in estimating prescription length as ADHD prescriptions are typically provided for between a one or two month duration, and to account for any medication 'breaks' which may occur. When calculating age at cessation, cases that were censored, as they still had a prescription at the time of leaving the database (i.e. lost to follow up or at the age boundary of the cohort) were excluded from the analysis. As full details of date of birth are not provided by CPRD, to calculate the age of cessation date of birth was designated as 1st July for each case, minimising error each way to a maximum of 6 months. Mean age of cessation was calculated with confidence intervals, and a one-way ANOVA run to explore differences in means by region.

Cases were defined as having a referral to an AMHS if they were coded with a referral to adult psychiatry, a community psychiatric nurse or clinical psychology. The proportion of cases referred by region was calculated, examining differences in proportions using the Chi squared test. Given that referral might have been for non-ADHD-related treatment, we also described the proportion excluding cases potentially referred for a psychiatric co-morbidity. The first definition used was '*cases without any other psychiatric diagnoses*'. However as diagnoses are not coded as reliably as prescription data in the CPRD (Herrett et al., 2010), and common co-morbidities such as ASD are not consistently treated in AMHS, a second definition was also used of '*cases without a prescription for any other psychotropic medication*'.

Linear regression was used to examine the association between region (independent variable) and the age of cessation (dependent variable) and subsequently adjusted for referral to an AMHS as a covariate.

The second phase of analysis used a geographic information system, QGIS 2.18 (2018), to analyse and display the service mapping data alongside the prescribing data. Shapefiles for UK countries and SHA regions were imported (McGarva, 2017) and maps created to illustrate changes in patterns of prescribing and rates of referral to AMHS by region. Locations of dedicated NHS services for adults, as identified in the 2018 CATCh-uS study (University of Exeter, 2018) were plotted on the same maps.

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects/patients were approved by the following: for the CPRD dataset, the Independent Scientific Advisory Committee on behalf of the National Research Ethics Service Committee (protocol number 13\_213); for the 2018 CATCh-uS mapping study, the University of Exeter Medical School Ethics Committee (REC Application Number: 15/07/070).

### 5.2.3 Results

There were 9,390 eligible cases: 84% (7,876) were male, 25% (2,335) had a recorded diagnosis of a psychiatric co-morbidity, 62% (5,780) had at least one recorded prescription for an ADHD medication, and 25% (2,336) had a prescription for any other (non ADHD) psychotropic medication.

From a cohort of 5780 who were prescribed ADHD medication, 415 cases were ineligible for reasons such as their last year of medication being before the start of the study period. In total 1889 (32.7%) were censored, as they still had a prescription at the time of leaving the database. In total, 3,476 cases, had complete data that allowed us to calculate age of cessation of ADHD medication. Censored cases (those that still had a prescription at the time of leaving the database) were similar to uncensored cases with respect to medication duration and year of birth. However there were differences according to gender, with a higher proportion of females (41.7%) censored than males (31.0%). There were also some differences by region, with a higher proportion censored in some regions than others (overall  $p < 0.001$ ).

#### *Percentage of ADHD cases with an ADHD prescription*

Scotland was the region with the highest percentage of cases (75%) with at least one ADHD prescription *at any point*, while Yorkshire and the Humber had the lowest (48%). There were differences by region in the proportion of cases that had an ADHD medication prescribed for every age band (see figure 21), but a similar pattern of rapidly reducing prescriptions with age from the mid-teens to the early 20s was seen in all regions.

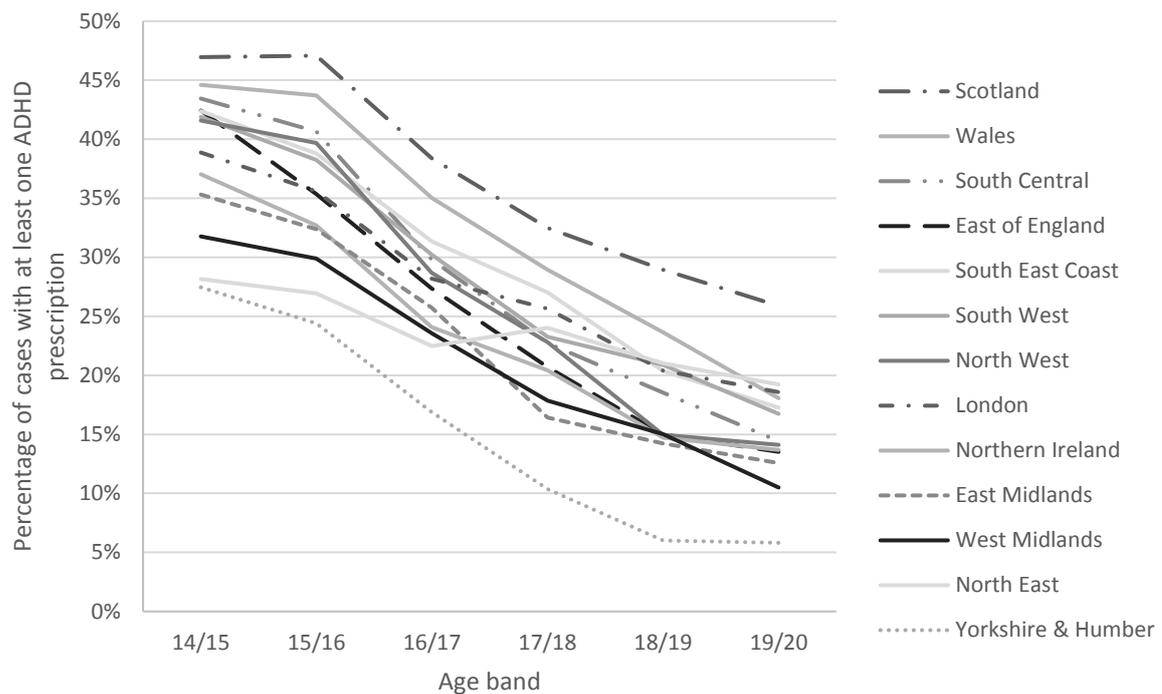


Figure 21. Percentage of ADHD cases with an ADHD prescription, by age band and region

*Difference in proportion of cases with ADHD prescription before and after transition*

The drop in the proportion of cases with an ADHD prescription between the year of 16<sup>th</sup> birthday and the year of 19<sup>th</sup> birthday (age bands 15/16 and 18/19) was 19% for all cases; but varied by region from 6% in the North East to 25% in the North West, (see table 19 and figure 21).

*Mean age of cessation of ADHD medication prescription (table 19)*

The mean age of termination of medication prescription was 16.6 years, SD=2.63, (95% CI 16.5-16.7). A one-way ANOVA determined that differences in the mean age of end of ADHD medication prescription were statistically significant by region; mean ages ranged from 15.8 to 17.4 years,  $F(12,3463)=6.18, p<0.001$ .

*Proportion of cases referred to AMHS (table 19)*

The percentage of cases with ADHD referred to any AMHS was 11%, but varied by region from 4% to 21%,  $\chi^2 (12, N = 9390) = 121.60, p < 0.001$ . When cases with any other non-ADHD psychiatric diagnosis were excluded from the dataset, the overall proportion dropped to 9%, and varied by region from 3% to 15% ( $\chi^2 (12, N = 7055) = 49.12, p < 0.001$ ). When cases with prescription for any other psychotropic medication were excluded, the percentage of those referred was even lower (7%), and also varied by region from 3% to 11% ( $\chi^2 (12, N = 7052) = 27.73, p < 0.001$ ).

Table 19. Difference in ADHD prescriptions, mean age of cessation of ADHD medication, and instances of referral to adult mental health services; by sub-group and region

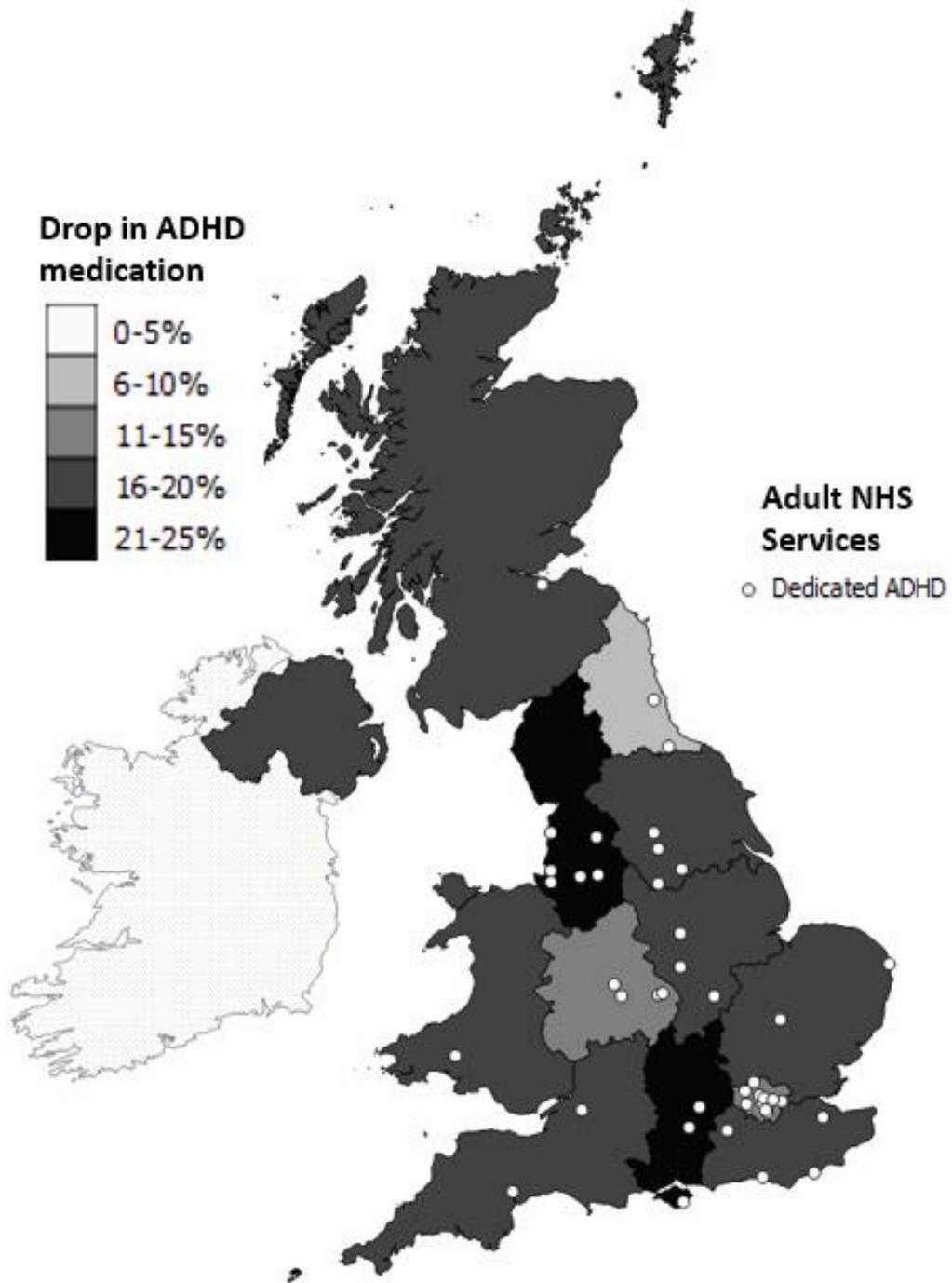
Region	Difference in percentage (%) with ADHD prescription pre and post transition (15/16-18/19)	Mean age of prescription cessation (95% confidence intervals)	Percentage referred to an AMHS (%)		
			All cases	Cases without any other psychiatric diagnosis	Cases without prescription for any other psychotropic medication
North East	6	17.4 (16.5-18.2)	5	3	3
North West	25	16.6 (16.4-16.9)	11	10	8
Yorkshire & Humber	18	15.8 (15.4-16.3)	8	8	6
East Midlands	18	16.5 (16.1-17.0)	4	3	4
West Midlands	15	16.1 (15.7-16.4)	11	10	8
East of England	20	16.2 (15.9-16.4)	8	7	6
South West	17	16.9 (16.6-17.2)	7	7	6
South Central	22	16.6 (16.3-16.8)	11	9	6
London	15	17.4 (17.0-17.8)	11	8	6
South East Coast	18	16.6 (16.3-16.8)	13	11	9
Northern Ireland	18	15.9 (15.4-16.4)	13	10	8
Scotland	18	16.9 (16.7-17.2)	10	8	7
Wales	20	16.6 (16.3-16.9)	21	15	11
Total	19	16.6 (16.5-16.7)	11	9	7

There was a marginal association between region and the age of cessation of ADHD medication prescription in the unadjusted model ( $R^2=.0013$ ,  $F(1, 3474) = 4.56$ ,  $p=0.03$ ). However, when referral to any AMHS was added to the model, ( $R^2=.0046$ ,  $F(2, 3473) = 83.55$ ,  $p<0.001$ ), region was no longer a predictor and

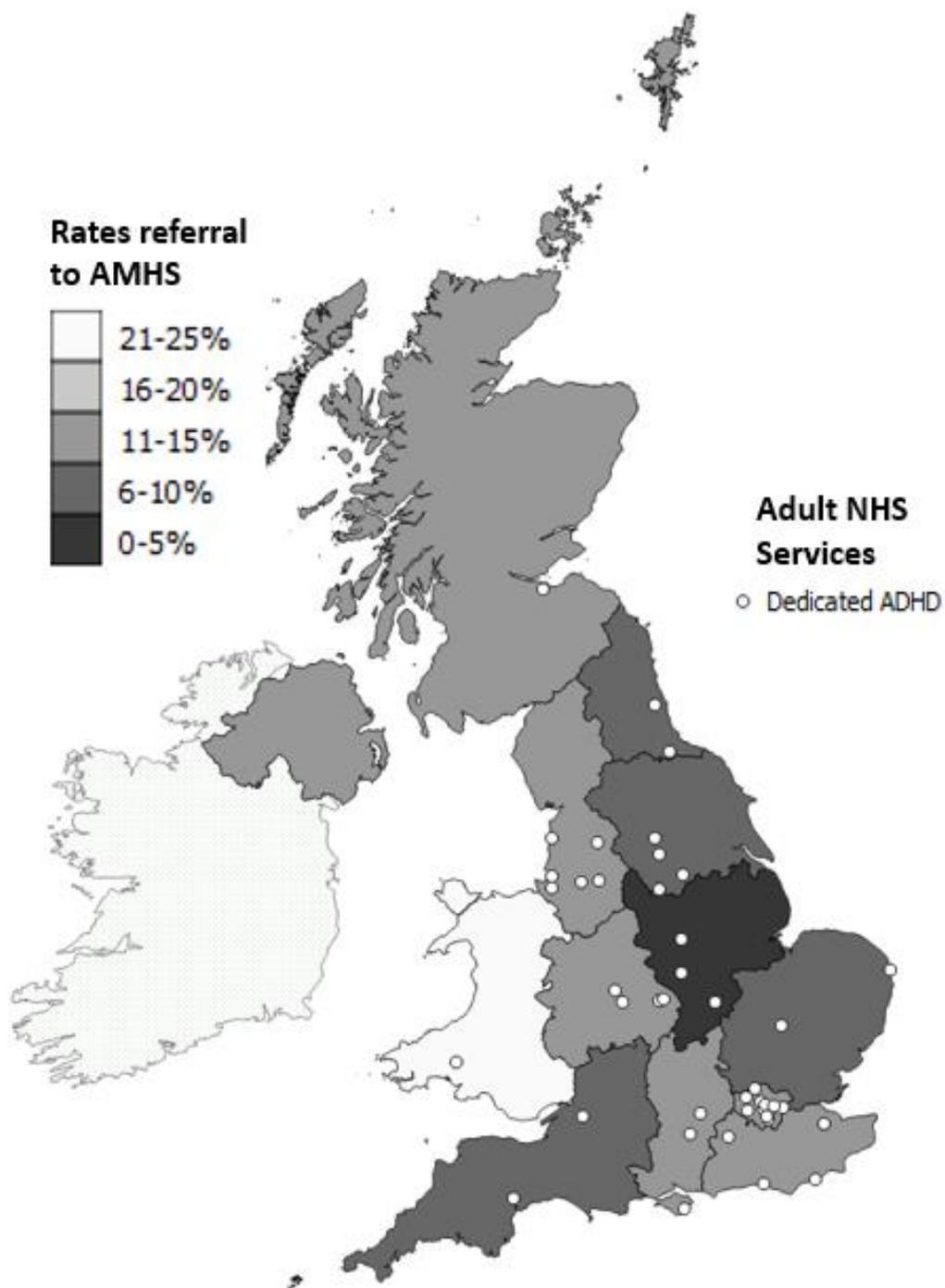
only referral to any AMHS was a significant predictor of age of prescription cessation.

*Regional variations, mapped against service locations*

Figures 22 and 23 clearly illustrate the regional variations in prescribing patterns, referral rates and service locations. On visual inspection however, there were no clearly identifiable relationships between levels of prescriptions, referral rates or identified locations of dedicated adult ADHD services.



*Figure 22. Drop in prescribing rates for ADHD medication for young people with ADHD Between the age bands of 15/16 and 18/19: plotted against locations of dedicated adult ADHD services*



*Figure 23. Referral rates to AMHS for young people with ADHD  
Plotted against identified locations of dedicated adult ADHD services*

## 5.2.4 Discussion

We detected regional variations in primary care prescribing of ADHD medication for young people with ADHD through the transition period, and in the proportions of young people with ADHD being referred to an AMHS. The creation of visual maps showed clear variation by region for prescribing, referrals and the location of dedicated services, but no discernible relationships between these three measures. Distribution of services was patchy and uneven across the UK and there were many areas without a dedicated service nearby. These findings are novel, evidencing potential inequalities in healthcare provision across the UK for this patient group, which are likely to have an impact on continuation of care and treatment into adulthood.

### *Organisation and availability of adult ADHD services*

All young people included in this study had a diagnosis of ADHD in their primary care record; therefore, the findings of significant variation are unlikely to be due to regionally-patterned differences in prevalence. Variations in prescribing and in referrals found by region are therefore likely to be related to differences in the organisation and availability of services for ADHD. There is currently no established or consistent approach to the configuration of health services for adult ADHD. Management in secondary care may be undertaken in generic AMHS or within a specialist service (Coghill, 2017), consequently variations found in primary care prescribing through transition may reflect a mixture of service models. Whether or not a young person has psychiatric co-morbidities can also affect whether they are eligible for AMHS, or directed to specialist or generic services (Belling et al., 2014). This may contribute to our findings of differences in referral rates for cases without a co-morbidity, or other psychotropic medication.

The service mapping we present also demonstrates a patchy geographical spread of specialist adult ADHD services. NICE recommends diagnosis and treatment for adults via separate teams or clinics with expertise in ADHD, but with no guidance on the size and time commitment (NICE, 2018b). The NHS is

structured differently in the four countries that comprise the UK, including different commissioning arrangements (Paul et al., 2013). There is an argument that treatment within generic services, which are not identified on the map, is potentially a cost-effective and practical solution to long term treatment of ADHD, however issues still need to be addressed, such as a lack of training of AMHS professionals and the fact that services are often set up to provide episodic care, rather than to treat long-term conditions (Belling et al., 2014).

#### *Variation in primary care practice*

Our findings on variation in prescribing may also reflect regional differences in primary care practice and culture to some extent, however we were unable to examine variation by Clinical Commissioning Group (see limitations below). Although medication has been recommended by NICE for management of adult ADHD since the 2008 guidance, evidence suggests that GPs may feel unsupported to prescribe ADHD medications to adults, with issues such as lack of training or lack of available support from a specialist service identified as barriers to prescribing (Newlove-Delgado et al., In submission, Tatlow-Golden et al., 2016). For example, a study in Northern Ireland reported reluctance from GPs to prescribe under a shared care partnership, which may bear some relation to our finding that Northern Ireland had the earliest mean age of medication cessation in our analysis (Carrington and McAloon, 2018).

#### *Transitions into adult ADHD services*

Regardless of local prescribing and secondary care arrangements, if a young person does not transition into adult services, they are unlikely to continue to receive treatment into adulthood. Young people with ADHD are already at a higher risk of a range of negative health, educational and occupational outcomes compared with the general population, and without treatment, these risks are increased (Faraone and Glatt, 2010, Shaw et al., 2012). The regional differences in prescribing and referrals found in this study support available qualitative evidence of unsupported transitions and findings of limited adherence to and inconsistencies in implementation of the NICE guidelines on transition (Hall et al., 2015, Hall et al., 2013, Price et al., 2019).

### *Strengths and limitations*

Strengths of this study include a large population based sample of primary care records. To our knowledge this is the first time primary care ADHD medication prescribing in this age group and referrals to AMHS have been analysed by region. It is also the first time regional quantitative data on primary care prescribing and referral rates have been explored in comparison with national UK data on the locations of adult ADHD services. A key limitation of this was the time lapse between the study period for CPRD data (2005-2013) and the date of the service mapping study (2018). The provision and organisation of mental health services are constantly evolving, and some services identified in 2018, may only have been recently commissioned. In addition, while the CPRD dataset automatically includes all primary care prescriptions, those issued through a secondary mental health service may be missing (Herrett et al., 2015). NICE (2018b) guidance states that once a young person is stable on ADHD medication, prescribing should be through shared care, however in some complex cases secondary services may have prescribed for longer than the 6 month time period defined as medication cessation in this study. If this prescribing is not recorded in CPRD these cases may have been inaccurately recorded as having stopped medication. In addition, we may have underestimated referral rates, as although CPRD records referrals from primary care into AMHS, if referrals are made using free text letters these can only be captured by scanning the free text, to which we did not have access. Similarly, free text references to referrals between child services and AMHS would not be included. However, this limitation is likely to apply across all regions, and is unlikely to have influenced the significant variation in referral rates found in our analysis.

When calculating age at cessation, a moderately high proportion of cases were censored. However censoring is a common limitation in this type of database study and this loss-to-follow-up is in line with other studies in the CPRD (Strongman, 2018, Leung et al., 1997). Although no differences were found between censored and uncensored cases with respect to medication duration and year of birth, there were differences by gender, with more female cases censored than male, and by region. It is unclear why females might be more likely

to be censored than males, or why censoring would differ by region. It is possible that this censoring was informative (which occurs where what causes a case to be censored is related to what would cause them to experience or not experience an event of interest, in this case, stopping medication) e.g. if girls were more likely to be censored due to moving away for higher education and therefore more likely to stay on medication, being unable to follow-up these cases would result in an underestimate of the age of cessation (Leung et al., 1997). However, whilst there are various potential explanations, it is not possible to determine the impact of this censoring on the findings based on the data available.

A further study weakness is the size of regions analysed. While SHA reflected the structure by which health care was organised during the CPRD study time-period, their large size means they include multiple NHS Trusts and many GP practices, which may vary in their arrangements for adults with ADHD. The size of defined regions also made it difficult to incorporate geographic deprivation measures into the analysis, as deprivation varies at much smaller geographies than this. Future research would benefit from using smaller geographic areas.

### **5.2.5 Conclusion**

These findings, combined with evidence that more than one in ten commissioners are failing to meet expected Mental Health Investment Standards, point to unequal provision of resources for mental health (NHS England, 2017). Large and unchanging regional health inequalities in England point to the need for targeted interventions to improve the equity of access to care more generally (Kontopantelis et al., 2018). Studies of variation can help to increase accountability for mental health service provision, and indexing regional differences in prescribing and referral rates is one way of highlighting inequity. This data can contribute to planning regional service development and provision and, ultimately, to addressing health inequalities in people with ADHD.

### **5.2.6 Declarations**

The CPRD research was funded as part of a Doctoral Research Fellowship from the NIHR held by Tamsin Newlove-Delgado (Reference: DRF-2012-05-221). Tamsin Newlove-Delgado is currently funded by an NIHR Academic Clinical Lectureship.

*Author Contribution:* AP led the analysis of CPRD data with support from TND. TND obtained and prepared the CPRD data and ethical approvals. AP led the CATCh-uS mapping study design, data collection and analysis, with support from AJ and TF. This study was designed by AP and TND in collaboration with TF and AJ. All other authors contributed to the writing of the paper.

### **5.2.7 Acknowledgements**

The authors would like to thank the CATCh-uS study team, members of the study steering committee, and all the mapping study research partners.

## **Chapter six: discussion of conclusions**

### **6.1 Introduction and overview of chapter**

In this thesis I presented a study of the transition between child and adult services for young people with attention deficit hyperactivity disorder (ADHD). In it, I explored the role of information in transition, the identification of available adult services, and regional differences in health service provision and medication prescription. I used a multi-method approach, including a systematic review to build an overview of current literature, qualitative research to explore stakeholder experiences, a novel mapping methodology to assess current service provision, and a quantitative analysis which used existing data on medication and referral rates as a proxy for treatment availability. This chapter is an overarching discussion of the programme of work, building on discussions at the end of each individual chapter.

Key findings of the thesis will be discussed in relation to each of the research objectives set out in the introductory chapter, see pages 24-25. The individual studies have a number of strengths and limitations, however where these have already been covered in the discussion sections of the relevant chapters these will not be repeated. In the following, findings of the programme of work as a whole will be considered in the context of existing research evidence, current policy and practice, and the combined methodological strengths and weaknesses of the included studies. Implications for future research will be highlighted. For a visual representation of the studies that make up this thesis, methods used and key findings, see figure 24.

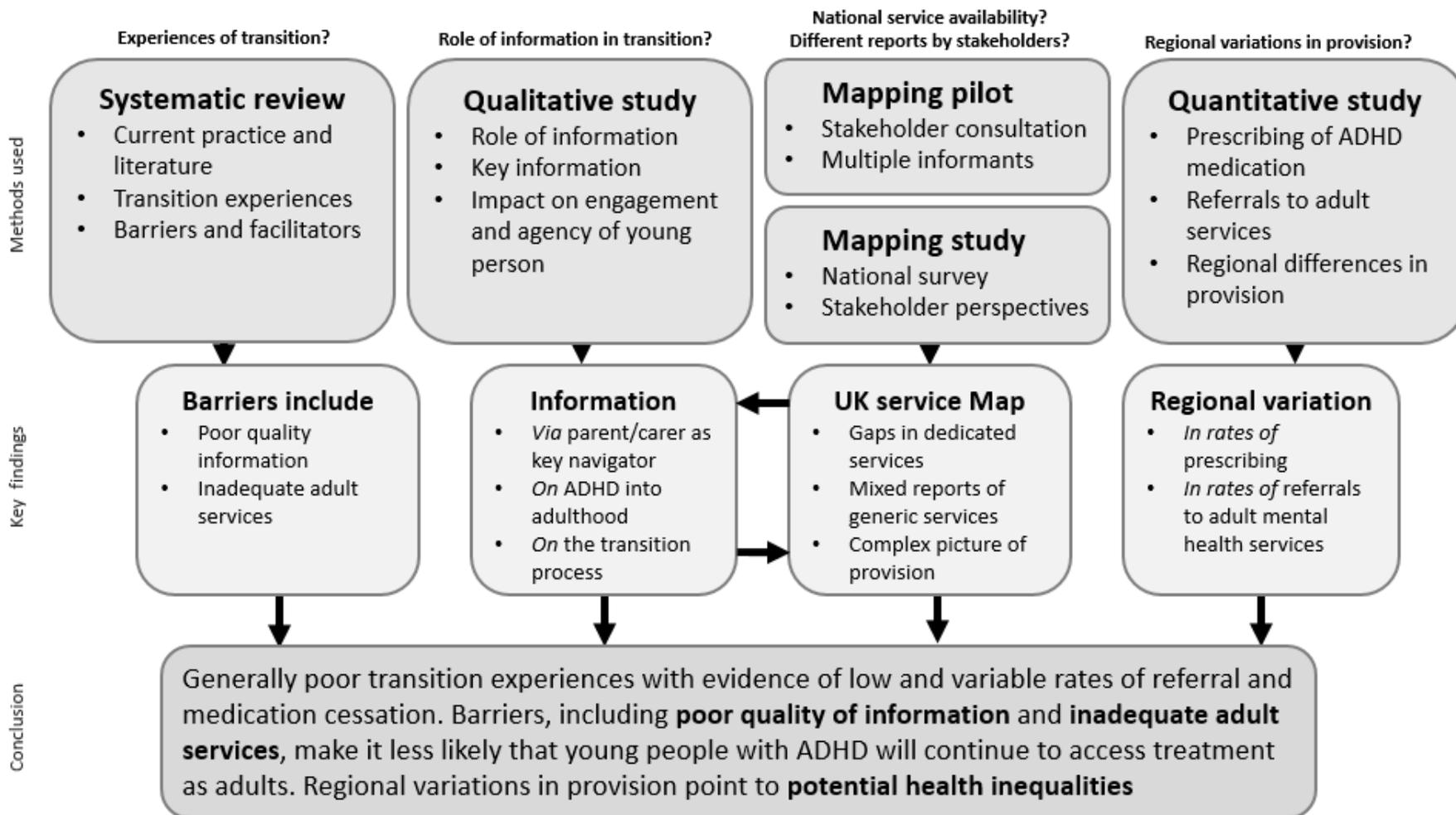


Figure 24. Graphic overview of thesis

Summarising included studies, their key findings, and an overall conclusion

## **6.2 Discussion of thesis findings related to research objectives**

### **6.2.1 Providing an overview of current findings on experiences of ADHD transition**

I will discuss the extent to which this thesis fulfilled the objective of gaining an overview on current research into experiences of transition for young people with ADHD, with a focus on identifying barriers and facilitators to continued service engagement. I will then briefly discuss findings in the light of existing literature, with a consideration of methodological issues.

The systematic review (chapter two), a systematic method of obtaining an overview of existing research related to a topic using quality assessment and including a synthesis of qualitative evidence, was conducted to meet this aim, and provided a strong basis for my subsequent studies. Findings of poor quality experiences of the transition process for young people with ADHD, as reported by service users, parents/carers and health workers, were in line with existing quantitative evidence of particularly poor transition outcomes for people with neurodevelopmental disorders, such as ADHD (Singh et al., 2010a). Identified barriers to continuity of care, such as inadequate provision of services, reflected existing quantitative evidence suggesting limited services for adults with ADHD (Hall et al., 2015, Hall et al., 2013). The emergent sub-theme, which was present across included studies, was that more information was wanted on transition. This included information on how to access services, details about adult services, and details on living with ADHD as an adult. This suggested a need to explore further the role of information in ADHD transitions and provided a clear avenue of enquiry for the qualitative study in chapter two.

#### *Strengths and limitations*

Included studies were qualitative and only covered the time period from 2000 to 2017, limiting generalisability of the findings. Only a limited number of studies were included in the systematic review, indicating a need for more qualitative research into transition experiences. Included studies were primarily from the UK,

which could limit the generalisability of the findings, as experiences of health transitions for this group were not explored from studies located in a range of countries. Only limited conclusions could be drawn about the role of information in transition, due to gaps in the literature. Findings from this review echoed findings from existing quantitative research, providing confidence in the findings. For the purposes of this thesis, the inclusion of relatively recent, mainly UK-based studies, meant that findings would be relevant to the organisation of services in the UK.

### **6.2.2 Exploring the role of information in the transition process**

I will discuss the extent to which the second research objective, exploring views and experiences of young people and their parents/carers related to the role of information in transition, was fulfilled. I will then discuss findings in the light of existing literature and current UK guidelines. Emergent issues with poor quality provision of information will be considered in the light of the additional burden this places on parents/carers as information navigators. The ways that inclusion of parents/carers can be affected by barriers such as the cultural differences between child and adult mental health services are discussed. Finally, implications for policy and practice, methodological limitations, and potential avenues for future research are considered.

The qualitative study, which used a broad and systematic sampling frame for recruitment, explored experiences of many young people and their parents from locations across England. Participants interviewed reported a range of experiences related to the role of information, which varied slightly by their stage relative to transition, but added up to tell a coherent story about three important themes: *the role of parent carer as navigator, the importance of information on ADHD as a condition, and of information about the transition process*. Identified themes were consistently reported by young people who were at the stages of pre-transition, at transition, or re-entering services without having transitioned. Similar themes also emerged from interviews with parents and carers. In addition to the qualitative study, the mapping study (chapter four), although not intended

to directly address this research question, provided data about the complexity of service provision and limited availability of dedicated services. The different types of services reported by stakeholder groups pointed to mismatches of information held. These findings may in part explain why young people with ADHD, their parents/carers and clinicians, struggle to access clear information about the transition process, and on what to expect in adult services.

NICE (2016) guidelines on transition emphasise this need for developmentally appropriate communication of information. For the majority of young people with ADHD, this is still not being provided. Previous research into ADHD demonstrates possible delays in brain maturation and difficulties with attention and associated processing (Curatolo et al., 2010, Shaw et al., 2007). NICE (2016) transition guidelines recommend that a 'named person' should be provided by services in order to provide support in a number of ways, including helping young people to source appropriate information and signposting them to appropriate services. However, findings from the qualitative study show that in many cases parents/carers of young people with ADHD who needed to transition into an adult service were required to carry out this role themselves, as the young person received little or no informational support from services.

This failure of services to meet young people's informational needs through the transition process puts additional pressure on parents/carers as well as young people, which is concerning given evidence that bringing up a child with ADHD can be demanding and cause high levels of emotional and physical exhaustion (Ghosh et al., 2016, Goodwillie, 2014, Hallberg et al., 2009, NICE, 2018a). In addition, ADHD has strongly heritable components (Freitag et al., 2010, Khan and Faraone, 2006), so parents may struggle in similar ways to their children with accessing and processing information, making it even more difficult for them to provide this type of support at transition. Findings from the qualitative study made it clear that without support by a parent/carer, young people felt they would not have been able to access healthcare into adulthood. Therefore, children from families where parents do not have the resources to provide informational support may be at an increased risk of losing access to care. As there is a strong

association between low socioeconomic status and ADHD (Prasad et al., 2018, Russell et al., 2018), this failure may feed into a cycle of increasing health inequalities for this group. In contrast, identifying the importance of informational support, and working to improve transition nationally, has the potential to help to reduce health inequalities. Providing information appropriately could increase the chances of a successful service transition, leading to continued treatment into adulthood. This could improve educational or occupational outcomes for the young person, (Faraone and Glatt, 2010, Shaw et al., 2012) and reduce the risks of adverse outcomes, such as contact with criminal justice services (Lichtenstein et al., 2012).

#### *Cultural difficulties with AMHS including parents*

There is an important cultural difference between AMHS, where practitioners expect to work mainly with individuals, and children's services, which are often family focused and expect to involve parents (Mulvale et al., 2015). This cultural difference, combined with concerns over confidentiality and protecting the rights of young adults with ADHD (Bogossian et al., 2018, Young et al., 2011), may underlie the reluctance of some adult services to routinely include parents/carers in the exchange of information. NICE (2016) transition guidelines state that services should consult with young people about the extent to which they would like family and carers to be involved in their care. However, findings from the qualitative study imply that, with ADHD, proactive strategies are likely to be needed to ensure that, where desired by the young person, parents/carers can be automatically included in the communication of key information. Many young people interviewed indicated that without information related support from a parent or carer, they believed they would have been unable to access care as adults.

#### *Recommendations for policy and practice*

Young people and their parents/carers need information about ADHD as a potentially lifelong condition while still in child services, so that they can make informed decisions about ongoing care as they approach transition age. If they believe (or are told) that ADHD is something that they will definitely grow out of,

as several participants of the qualitative study reported, then they will not have the essential facts that they need when considering the transition process. They may assume that they will not need treatment once they have left school and therefore not prepare for transition or pay attention to relevant information. The importance of communication and provision of appropriate information in enabling patients to actively participate in their care is clearly described in the NICE (2012) guidelines on *patient experience in adult NHS services*. The NICE (2008) guidelines on ADHD were updated in 2018, introducing a new section on *information and support* (NICE, 2018b). This includes a recommendation that following diagnosis clinicians should conduct structured discussions that are tailored to meet individual needs and circumstances including age, gender and stage of life, on how ADHD may affect a patient's life. Findings from the qualitative study imply that due to changing developmental needs, these discussions should be conducted on a regular basis, at least annually, to ensure that patients' understanding of their condition develops with age and is up to date at the point of transition. Therefore child (and adult services) for ADHD should implement annual reviews for patients, including their parents/carers where appropriate, to discuss how ADHD is currently affecting key areas of the patient's life, and provide information on the potential impact of their condition on their life into the future.

Interestingly, the review of evidence informing the 2018 update to the NICE guidelines on ADHD (NICE, 2018a), reported that much of the supporting evidence was limited, due to most studies being from outside the UK, or being of insufficient depth or quality. This means that findings from my qualitative study, which are in accordance with the updated guidelines, comprise a timely and useful addition to the UK evidence base.

In the current economic climate, and with constraints on NHS provision, potential areas for service development could include; supporting services in the communication of key information on transition and ADHD into adulthood; and highlighting the locations of current adult services so that information about these is readily available. Developing a national information resource on ADHD as a

condition in adulthood and what this may mean, in a format that is developmentally and cognitively appropriate for young people with ADHD and their parents/carers could provide a tool for service managers to use to support transitions, and help meet current NICE guidelines. My mapping study has to some extent addressed the lack of information on locations of current services for adults with ADHD. This may impact positively on young people with ADHD who are trying to find an adult service to transition into, help clinicians to access the information they need to advise young people on where to go for an adult service, and support commissioners to make informed decisions about where investment is needed.

### *Strengths and limitations*

Due to the design of my qualitative study, those young people who had re-entered services as an adult were reporting on transition experiences from up to 10 years previously. Therefore, in the context that services change and develop over time, some participants were reporting on experiences that might have been out of sync with current provision. However, the accounts of those 'at' or 'pre' transition did reflect current service provision at the time of the study, and their reports were similar, giving confidence in the findings, and meaning that the implications are relevant to current policy and practice. The wide range of participants interviewed has provided an in-depth insight into the role of information during transition for young people with ADHD in different services in England. These data are timely, given the low quality of much of the research supporting the 2018 update to the NICE guidelines (NICE, 2018a).

### *Potential for future research*

To build my findings it would be important to investigate how services could be supported to provide key information to young people and their parents/carers. Many of the young people interviewed in the qualitative study expressed a desire to learn from 'experts', while many young adults interviewed had inspiring and relevant stories of their own transition to share. Developing a mechanism to share stories of similar 'experts' with lived experience of an ADHD transition, in a way that was accessible to those just starting the transition process is one method

through which information could be shared. One possible approach could build on research carried out by Coyne et al. (2016) with adolescents and young adults with long term illnesses such as heart disease and diabetes. In this project, participatory methods were used to co-design information and a website, in order to support young people in their transition to adult healthcare (Coyne et al., 2016). Young people expressed preferences for information that was trustworthy, empowering and available online. They also desired video testimonials of experiences from young adults who had already transitioned (Coyne et al., 2016). Given that stories can increase the quality of medical decisions, and improve health judgements (Shaffer et al., 2018), future research could use a structured framework of participatory design to develop informational resources designed to meet ADHD specific needs (Moore et al., 2019).

There is a need to develop targeted information resources based on research with service users, health workers and commissioners, and make use of available technology to share them with people who use and deliver services. Providing information digitally could be a scalable and economically viable way of supporting stretched services to provide relevant information about transition. Technology based interventions, which involve the use of equipment such as mobile phones to enhance care through improved communication and enhanced ability to process information, have been used to support patients with other long term health conditions such as heart disease and diabetes, but there is only mixed evidence on their effectiveness (Carpenter et al., 2019). However the use of narrative stories, including stories of peer experiences, has been successful in improving a range of health outcomes related to self-management of long term conditions such as hypertension and diabetes (Bokhour et al., 2016, Campbell et al., 2015, Hinyard and Kreuter, 2007). These strategies may be transferable to patients with ADHD.

Finally, the aims of the current qualitative study could be expanded to include experiences of other stakeholders in relation to the role of information, so that the perspectives of health workers in child and adult services could be explored. For example, Wong et al. (2009) found that clinicians who work with children often

reported they did not know where to refer patients with ADHD on to, due to a lack of awareness of appropriate adult services. Difficulty gaining referrals, and high rates of unaccepted referrals, which were both identified as barriers to transition in my systematic review (Price et al., 2019) may be linked with health workers not having the information they need to refer appropriately. An in-depth study of health workers' experiences of information in relation to transition, using available data from CATCh-uS study interviews (Janssens et al., In preparation), was beyond the scope of my thesis, but could clarify the potential impact on information provision on ADHD transitions from the perspective of this stakeholder group. Exploring the perspectives of commissioners would also be of interest, to establish the types of information they need, use and have available to them, when making decisions about funding services for adults with ADHD.

### **6.2.3 Providing national data on UK adult ADHD services**

This section discusses the extent to which the research objective of providing national data on UK adult ADHD services by creating a map of services, was fulfilled. The definitive mapping study, conducted in 2018, met this objective by creating a national map of adult ADHD services designed to be relevant for, and to reflect the experiences of, service users, health workers and commissioners. In order to conduct this study, a pilot was successfully conducted in 2016, resulting in the development of a seven-step methodology, which has the potential to be used to provide national data on other health services in the future. The piloting phase was conducted because the ambitious undertaking of mapping health services from the perspectives of multiple stakeholders presented novel challenges, including defining 'adult ADHD services' in a way that was meaningful to service users, health workers and commissioners, and the need to gain survey responses from a balance of informants, located across the UK.

#### *Services identified*

The map revealed multiple types of service, as reported by stakeholders, with services from NHS, private, and charitable providers. Services potentially

meeting NICE (2018b) guidelines for management of adult ADHD included a mixture of 44 dedicated and 99 'other' NHS adult mental health services. Services were categorised as 'dedicated' if they had ADHD or neurodevelopmental in the service name, and it was within their remit to treat adults. During analysis, differences in service organisation by country and region of the UK made it difficult to detect whether an area without a dedicated service was also therefore an area without a commissioned statutory service for adults with ADHD. The picture was not straightforward, because evidence suggested regional variation in whether or not generic adult services offered treatment of ADHD. In some areas, such as Wales, responses from health providers implied that treatment was available within generic services, while in other areas in England, responses from commissioners did not identify generic services as offering treatment. Existing evidence, including my systematic review in chapter two, has found that treatment of adult ADHD within generic services is often poor, with transitional problems such as young people not meeting referral criteria for adult services, and difficulties in accessing treatment related to a lack of training and specialist knowledge in staff (Belling et al., 2014, Coghill, 2017, Price et al., 2019, Swift et al., 2013). Therefore, it could be said that, from the perspectives of some stakeholders, those UK regions with no 'dedicated' services, represent a gap in provision of care for adults with ADHD.

In addition to multiple types of adult services, several other models of statutory provision were identified, including services for ADHD that focused on supporting transition, and services for young people aged between 0 to 25 years, which avoided the cut off from CAMHS and paediatric services between the ages of 16 and 18 years. Reports from qualitative interviews with adults with ADHD in England found that those with access to private healthcare reported more positive experiences of using ADHD services in adulthood (Matheson et al., 2013). The identification of high numbers of private services could be taken as an indication that, in the absence of an accessible NHS service, some young adults may have sought privately funded healthcare in order to continue to access treatment for their ADHD into adulthood.

### *Impact of the research*

The high level of engagement from a range of stakeholders in the surveys (with 1,446 pilot responses and 2,686 responses in 2018) and a high number of views of our published maps of services (with more than 34,000 views of pilot map and over 2,200 views of the definitive map, at 24<sup>th</sup> April 2019, see appendix 5), indicate a need for better quality information on adult services, as identified in my systematic review and qualitative study. Although it was not possible to collect information on those who viewed the published maps, messages received on Twitter and by email showed active engagement in the information provided, from young people with ADHD, parents/carers, and health workers (see appendix 6). The high proportion of responses from health workers to the 2018 survey, (73%), may reflect my sampling methodologies, but also indicates a strong need to address service issues from the perspective of clinicians. I found it remarkable that over 900 busy psychiatrists, paediatricians and GPs volunteered their time to complete the 2018 survey. I believe this was a reflection of the fact that difficulties around service provision for young adults with ADHD are a current cause for concern among clinicians, as indicated by qualitative research identified in my systematic review (Belling et al., 2014, Price et al., 2019, Wong et al., 2009). In part, the success of the mapping study was likely to have been related to the real appetite for national information on adult ADHD services, from those who use and from those who provide them, as well as those who are unable to access them.

### *Strengths and limitations*

The mapping study has provided the most extensive national data to date on adult ADHD services in the UK, extending existing research which was region specific or which relied on information from a single source (Hall et al., 2015, Hall et al., 2013), by surveying health workers, service users and commissioners from across the UK. Use of FOI requests was an effective method of contacting commissioners, demonstrated by the 90% response rate, and ensured that someone with time and resources received and responded to the query. The novel mapping methodology, developed and piloted in consultation with stakeholders, is an effective and rapid method for mapping adult ADHD services.

The use of non-probabilistic sampling methods in the survey was a cost effective method of gathering data which allowed organisations to share the survey via their contacts without compromising data protection. An acceptable number of responses was achieved for all UK regions, although there were low response numbers from some stakeholder groups (young people with ADHD), and in some areas. However, this sampling methodology meant that respondents were not selected randomly and, except for commissioners, response rates could not be assessed. This was not a key concern, as the aim of the study was to build a picture of services from perspectives of a range of stakeholders, and the more widely the survey was distributed, the more confident we can be that all relevant services were identified.

It would have been possible to learn more from the map if we had had the resources to check whether providers of generic AMHS provided treatment and support for adults with ADHD. In addition, I was unable to reliably confirm the capacity of identified services. The extent to which non-dedicated adult services filled service needs in the regions where no dedicated services were identified was unclear, and therefore only limited conclusions could be drawn from the data.

#### *Potential for future research*

The mapping methodology developed within this thesis could be used to identify other UK mental health services and therefore meet recommendations for national data on mental health services (NHS England, 2017). There has been positive feedback on the map of adult ADHD services, with comments from young people with ADHD and clinicians on its usefulness. There have been requests for a similar map showing which GP surgeries provide adult ADHD prescribing under shared care (appendix 6). There has also been considerable interest in using this stakeholder informed method to map services for young people with autism. ADHD and ASD commonly co-occur (Jensen and Steinhausen, 2015), and there may therefore be some overlap in service needs between these two neurodevelopmental disorders (Antshel et al., 2016). Seven of the dedicated ADHD services identified were joint ADHD and ASD services, and in my patient and public involvement work for the mapping, and interviews for the qualitative

study, several young people and their parent/carers mentioned difficulties they experienced trying to access ASD services.

Following completion of the 2018 mapping study, I met with Autistica, a leading UK research charity, to explore options for using this methodology to map autism services. A brief rationale for the proposed work follows. Since the Autism Act (HM Government, 2009), successive policies on provision of services for people with autism have been published for England, Scotland, Wales and Northern Ireland, including statutory requirements for local governments to provide needed services for diagnosing and supporting people with autism (Department of Health, 2010, HM Government, 2014). The NICE quality standard on autism (2014) recommends that people with autism are offered a named key worker, provided with diagnostic assessment within three months and have a personalised plan implemented if appropriate with an autism team. The 'Think Autism' strategy (HM Government, 2014) sets an expectation that the NHS should have a clear framework for assessing care and support needs of adults with autism in every local area. However, there are identified barriers to transition for young people with autism, including a lack of comprehensive and integrated adult services (Anderson et al., 2018, McConachie et al., 2011). In addition, the national availability of services for young people with autism remains unclear (Parkin, 2016). Using the mapping methodology to create a map of NHS, voluntary and private services in the UK for adults with autism, from the perspectives of a range of key stakeholders, could help to audit provision and provide information to support service development and inform commissioning decisions for this group (NHS England, 2017).

#### **6.2.4 Exploring differences in information reported on adult ADHD services, by service users, health workers and commissioners**

This section will discuss the extent to which the research objective of learning about differences in awareness of adult ADHD service provision, through a comparison of differences in services identified by service users, health workers

and commissioners, was met. I will then briefly discuss methodological limitations and the potential for future research.

The inclusion of responses from key stakeholder groups allowed for an analysis of differences in reports of services. Given the complexity of provision identified in the mapping study, this additional level of data provided valuable insight into services identified. Respondents to the survey were identified by a primary role, which was then categorised as being one of three key stakeholder groups; service user, health worker or commissioner. Analysis of service identification by stakeholder group revealed fascinating differences in the identification of 'dedicated' services, in comparison to other NHS adult services, shedding some additional light on the question of which service types were known about by stakeholders. The majority, 55%, of dedicated services were identified by informants from all stakeholder groups, while only 7% of 'other' mental health services were identified by all groups. This finding implies that dedicated services were the most known about and therefore potentially the most accessible NHS adult services.

The inequality in reported information about non-dedicated NHS, private and voluntary services, with multiple services identified by health workers that were not identified by commissioners or service users, suggests that, in keeping with findings from my systematic review and qualitative study, that there may be gaps in information held on services by particular stakeholder groups. Differences in service reporting highlight the need for accessible national data, as provided by the mapping study, and may explain the high levels of engagement in the survey. The differences in service reports between health workers, commissioner and service users are perhaps unsurprising given that the UK government identified a need for more national data on mental health service provision (NHS England, 2016), and that earlier work surveying adult ADHD provision concluded that the next step was to map ADHD services nationally (Hall et al., 2013).

### *Strengths and limitations*

Surveying multiple informants to map adult ADHD services was a uniquely inclusive methodology when compared with current established methods which often only survey clinicians, government providers or experts (Signorini et al., 2017, World Health Organization, 2008). Including reports from more than one respondent type reduced the risk of missing data and also enabled the analysis of differences in reporting between groups, which provided information on potential difference in knowledge held by service users, health workers and commissioners. However, we cannot be sure that data collected on which stakeholder groups reported each service represented the knowledge respondents held. We can only know that these were services they told us about. In addition, due to the lack of a sampling frame for the mapping survey, response bias may have crept in. It is possible, for example, that those responding to the online survey were the most concerned about the lack of a service, and that those who were satisfied with provision may have been less likely to respond.

The analysis of service identification by stakeholder group was also limited by the fact that 'stakeholder group' was assigned from the primary role that respondents identified themselves with, or in the case of surveillance study data and commissioner responses, the respondents' professional role. This is a limitation, as we know from the analysis of multiple roles reported by respondents to the online survey, that there were some cases of an overlap between roles from different key stakeholder groups, such as being a health worker *and* a commissioner.

### *Potential for future research*

The inclusion of reports from multiple perspectives should be built into future mapping studies, to reduce chances of missing data and allow comparison of reports by stakeholder groups. Engaging stakeholders throughout service development and auditing is a way of helping to ensure that health policies are implemented effectively (World Health Organization, 2000). The UK Health and Social Care Act (2012) states that the NHS has a duty to involve stakeholders and patients in decisions about their healthcare. It would be interesting to conduct

future mapping exercises, perhaps with a smaller geographic reach, with a controlled sample from each stakeholder group. In this way, response bias could be reduced and significant differences between stakeholder reports found in this study could be checked against a findings from a different methodology.

### **6.2.5 Exploring regional variations in prescribing and referrals for young people with ADHD**

The quantitative analysis of an existing dataset of UK primary care records (Herrett et al., 2015), enabled an exploration of regional variations in prescribing and referrals for young people with ADHD during the time period of the study (from 2005 to 2013), which were used as proxy for equity of access to healthcare services. This was important in the context of the findings from the mapping study, which despite clear evidence of patchy provision of dedicated services, were inconclusive about access to services for adults with ADHD in practice. Regional differences in prescribing and AMHS referrals for young people with ADHD in the years 2005 to 2013 were found. This is of concern, especially given studies that have attempted to quantify national estimates for transition for neurodevelopmental disorders or ADHD in the UK have found discontinuity of care provision for some patients who pass the age threshold for children's services but are not accepted by adult services (Singh et al., 2010a, Tatlow-Golden et al., 2018). A recent surveillance exercise found that only a fifth of cases identified as needing a transition completed transition and were seen in adult services (Eke et al., In submission-a). It is possible that variations in the changes in rates of prescribing of ADHD medications for young people with ADHD between the ages of 16 and 19 are related to adult service provision and/or poor provision of information in services in some areas. Heterogeneity and gaps in adult service provision, as demonstrated by the map of services, could lie behind regional differences in referrals to AMHS. The variations found could reflect the multiple models of service provision identified by respondents to the mapping survey. The comparison of regional differences in prescribing and referral rates against dedicated services location, showed no visible relationship. This could be linked to the large size of regions used, and time gap between studies.

### *Strengths and limitations*

The size of regions analysed in this study, as defined by the CPRD data, meant that each region was likely to include multiple adult service providers and GP practices, which were likely to vary in their arrangements for adult ADHD. Therefore, variations in provision by health provider, or type of service, could not be explored. A detailed comparison of CPRD data against locations of existing dedicated ADHD services would have been possible if smaller regions and a more recent CPRD dataset was available. However, findings have important implications about health inequalities for young people with ADHD, given the regional differences found in prescribing and AMHS referrals for young people with ADHD, which demonstrate that provision varies nationally.

### *Potential for future research*

Future research should aim to repeat this analysis, using smaller regions and a more recent CPRD dataset. Use of smaller regions could enable the incorporation of data on areas of deprivation. Triangulation of this data with other routine NHS datasets which might, for example, include prescription data on patients seen in secondary care, should also be considered (McIntosh et al., 2016). It would also be interesting to link future studies with national surveillance data on ADHD transitions, (Eke et al., In submission-a) analysed by UK region. Another avenue to explore could involve selecting regions with the highest and lowest drops in prescribing rates for ADHD medication in young people aged between 16 and 19, and conducting a more focussed analysis of service provision in those areas.

## **6.3 Discussion of thesis findings**

In summary, the studies that make up this thesis have answered the research questions set out in the introduction and listed above. My systematic review used an established and effective methodology to provide an overview of current research, which formed a basis for subsequent studies. The qualitative study made use of a wealth of detailed data from participants across England to add to the evidence base around the role of information in ADHD transitions, with

important findings that have informed subsequent studies. The mapping study, the largest of its kind in the UK, has provided extensive national data on adult ADHD services in the UK, while piloting work has established a new methodology that could be used to map other services. However, in some ways the map of services raised more questions than it answered, with the lack of clarity on the accessibility of generic AMHS for adults with ADHD making it difficult to analyse where gaps in services exist. The exploration of differences in services reported by stakeholder group revealed interesting differences between health worker, commissioner and service user opinions, highlighting the need for a national map, but findings must be viewed in the context of methodological factors which limit any conclusions that can be drawn. Finally, the aim of exploring regional variations was effectively addressed through use of an existing dataset. My analysis found clear evidence of variation, with future work needed to investigate variations on a smaller scale, so that a clearer picture can be gained on how local health service configurations may affect variations in prescribing and referrals into AMHS.

It is clear that better quality provision and communication of information is needed, in line with the *information and support* section of the newly updated NICE (2018b) guidelines. In addition to the need for quality information, taken together, the findings from the studies that make up this thesis point to significant issues underlying poor transitions for young people with ADHD in the UK. The current lack of consistency and functionality in health service organisation for adults with ADHD is a barrier to providing transitional care (Eke, In submission, Price et al., 2019), and makes a national audit of provision difficult. There is no consensus on optimum ways of organising care for adults with ADHD (Coghill, 2017). However, it is clear that co-ordination between providers and a multi-agency approach is important (NICE, 2018b). Evidence from America suggests that integrated care models for ADHD in children and adolescents can lead to better clinical outcomes (Shahidullah et al., 2018). However, as American health systems, which are based on health insurance, differ considerably from the NHS in the UK, it is unclear whether these findings would translate to the UK.

As recent research into the impact of the structural divide between child and adult mental health services in Europe has shown, providing continuity of care for young people with mental health conditions, and especially neurodevelopmental conditions, may require reformed service models that are based on needs and preferences rather than chronological age boundaries (Singh and Tuomainen, 2015). In my systematic review, the question of transition age was the only sub-theme where there was variability within studies. Some young people with ADHD felt transition into another adult service was unnecessary, and wanted to stay with a familiar service (Cheung et al., 2015), and there were conflicting reports from clinicians, with some saying 18 years was a logical age to change service, while others emphasised the need for more flexibility (Wong et al., 2009). The high levels of distress expressed in my qualitative study by young people with ADHD and their parents/carers, due to difficulties accessing the information they needed to transition into an adult healthcare service, starkly illustrate the detrimental impact of the current organisational split. There have been several initiatives to develop youth mental health services which treat young people into their mid-twenties in Australia, Ireland and the UK (McGorry et al., 2013, McGorry et al., 2014). The mapping study identified one transition specific ADHD service, and two generic adult mental health services that provided treatment and support for people aged 0-25 (University of Exeter, 2018), which indicates that these models have not yet been widely adopted in the UK. There is no evidence of the effectiveness of any particular health service model for supporting transition (Paul et al., 2015).

My thesis adds to the growing evidence of poor continuity of care for young adults with ADHD (Buitelaar, 2017), which suggests that services need to be developmentally appropriate for adolescents and young adults, and include teams with expertise in ADHD, in order to meet the healthcare needs of young people with ADHD.

Rather than just trying to bridge the gap between child and adult services, an adoption of treatment strategies tailored to the needs of this vulnerable group which also improve continuity of care are needed (Buitelaar, 2017). Currently,

most treatment strategies for adolescents are copied from treatments offered to children, but findings from my qualitative study, in line with the updated NICE (2018b) guidelines, have shown that treatment and accompanying information need to be appropriate to stage of life, and focussed on ADHD-related vulnerabilities, such as difficulties with processing information, and the impact these are likely to have on the young person as they negotiate the demands of adolescence and young adulthood. Adolescents with ADHD, and their parents/carers, need guidance and information to help them make informed choices about whether or not to continue to access treatment. Both child and adult services need to be configured to include key individuals, such as parents, carers or spouses in communications, if agreed with the young person. In my qualitative study, young people with ADHD and their parents/carers asked for more detailed and nuanced information about service availability and about what ADHD might mean for them as they develop and change. Adult services should also provide treatment and information that is developmentally appropriate for young adults.

In the UK, the integration of GPs as providers of shared care is seen by many as a priority to cope with the high demand for services and achieve affordable service provision for all young adults with ADHD (Coghill, 2017, Goodman et al., 2011). A recent qualitative study exploring GPs experiences of transition for young people with ADHD (Newlove-Delgado et al., In submission), found that currently many GPs become involved in ADHD transitions by default, due to the absence of a smooth transition into adult services. This ties in with findings identified in my systematic review that, in the absence of mental health services, some patients were placed in primary care without monitoring or support (Price et al., 2019). This led some young people to experience feelings of abandonment as well as to poorer self-management of their condition (Matheson et al., 2013). Findings from my qualitative study show that the role of GPs in providing information necessary for an ADHD transition (or otherwise), was experienced as highly varied, and that in several cases, a GP's lack of basic understanding about ADHD and available services added to difficulties accessing care and emotional distress for young people and their parents/carers. Once a young person with ADHD leaves children's services, and especially if transition is not supported, the

GP's role as a universal point of contact and patient advocate becomes very important (Rashid et al., 2018). For GPs to provide effective information and support to patients with ADHD, information strategies are needed to ensure GPs have access to information both on ADHD as a condition, and on available adult ADHD services (as provided by the mapping study).

The NICE (2018b) guidelines outline the important role of primary care in providing treatment and support for ADHD, with GPs identified as being ideally placed to provide monitoring and prescribing for people with ADHD under shared care arrangements. These arrangements depend on specialist support being available from mental health services. However, GPs have warned that, contrary to guidance, they are being pressurised to prescribe ADHD medication without specialist input (Iacobucci, 2017). These reports tally with evidence of the patchy provision of specialist ADHD services (2015, Hall et al., 2013), and the limited availability of dedicated services reported in the 2018 mapping study. A recent qualitative study of GP experiences in relation to ADHD transitions found that decisions on whether to prescribe or not were influenced by concerns over responsibility, in particular where specialist services were lacking, and highlighted tensions over how shared care worked in practice (Newlove-Delgado et al., In submission). Given the limited number of dedicated services identified by my mapping study in 2018, this could be a barrier to the provision of shared care prescribing by GPs to adults with ADHD.

## Summary of findings

- **Current experiences of young people with ADHD who need to transition into adult ADHD services in the UK are poor.** Multiple barriers to transition exist including unaccepted referrals, a shortage of adult ADHD services, and unsupported transition processes. This causes unnecessary suffering for people who already face multiple challenges, and often results in inadequate care
- **The poor quality of information provided to young people with ADHD and their families about transition into adult ADHD services is a significant barrier to continuing care.** In order to support continued healthcare into adulthood it is essential that health services
  - communicate that ADHD can continue into adulthood,
  - provide information on how to transition, what to expect, who to contact and where adult ADHD services are located,
  - routinely provide the option to include parents/carers in the communication of key information
- **The UK national map of services for adults with ADHD shows geographic gaps in the availability of dedicated NHS services.** Taken together with evidence of multiple difficulties faced by adults with ADHD trying to access healthcare it suggests that where someone lives will impact on whether or not appropriate treatment is available to them. It is contrary to the stated aim of the NHS of providing equity of access to appropriate healthcare for people with long term conditions, and should be addressed as a matter of urgency.
- The supplementary quantitative study of primary care data found variations in ADHD prescribing and in referrals by region, which is in line with mapping study evidence that appropriate NHS healthcare for young adults with ADHD is not consistently available across the UK.

### *Future work*

Future work urgently needs to establish optimum models of care for adults with ADHD in the UK and explore the role of primary care provision in helping to meet current gaps in care. This could include case studies of different service configurations and evaluations of their effectiveness from the perspectives of key stakeholders, using outcome measures such as the proportion of completed transitions and numbers of young people remaining engaged in treatment through the transition process. Economic evaluations using a societal approach could explore the costs of providing dedicated vs generic services, including costs of failure to treat (Byford and Raftery, 1998). Economic modelling to assess the

costs of untreated adult ADHD should use a broad perspective such as that used in the Danish Psychiatric Central Register which has demonstrated the extent to which the economic burden of ADHD falls both on the individual and the state (Daley et al., 2015). Health service modelling, such as that provided by the Peninsula Collaboration for Health Operational Research and Development to evaluate the impact of changes to existing systems (Monks et al., 2015), and social system design techniques (Proctor et al., 2011) could potentially be used to develop optimum service structures for managing ADHD across the lifespan (Turgay et al., 2012). Another key priority would be to explore ways of addressing current barriers to GPs providing shared care for young people with ADHD (Thapar and Thapar, 2002).

Evidence from the studies in this thesis suggest that a relatively low-cost intervention to support ADHD transitions would be development of an information strategy. To be effective, this would need include information on ADHD as a condition (with a focus on developmental changes in early adulthood) and on available services for adults, including a national map of services. Separate components conveying information in appropriate formats and using accessible forms of media, should be designed to share with service users, health workers in child and adult services, GPs, and commissioners. It is likely that mapping surveys would need updating periodically, as happened in the national child and adolescent mental health service mapping exercise (Barnes et al., 2006). Inviting a partner organisation to update and host the service map, as we have with UK-AAN, helping them to use the mapping methodology to provide updated national data on service provision, should help to raise awareness of gaps in services, inform stakeholders, and drive service development forward.

## Recommendations

- **Provide health services for adults with ADHD throughout the UK.** The highest priority is to provide basic healthcare for adults with ADHD across the UK. Taken together, the findings from this thesis evidence unacceptable gaps in care. When services for adults with ADHD are not available it is not possible to provide supported health service transitions.
- **Communicate the costs of failure to provide care into adulthood.** In a time of competition for limited NHS resources the argument needs to be clearly made that failing to provide existing evidence-based treatments for a condition with high social and economic costs for both the individual, their community and society as a whole, is a short-term and ultimately costly strategy.
- **Use national data to evidence need.** National data on the availability of services from the perspectives of different stakeholder groups, such as that provided in this thesis, serves to highlight the problem and put pressure on government to address failures of provision. Use of quantitative data to analyse access to care in practice, especially when there is a lack of clarity about where services exist, is another way of providing evidence to support calls for change.
- **Provide information to support transition.** Information on ADHD as a condition and possible healthcare needs into adulthood should be made available to young people with ADHD for several years pre-transition, with gradually increasing levels of detail. Where adult services exist, information on where and how to find them, on transition processes, and on what to expect, should be made available to young people with ADHD and their parents/carers in formats that are accessible to them. There are many opportunities to provide this information at a local level when young people are in children's services, and as they approach transition.

### *Next steps*

Despite clear practical recommendations arising from this work, many of the highlighted difficulties around healthcare transitions for young people with ADHD point to deeper structural issues in health service provision. Research is needed to inform solutions that are evidence-based and workable in practice. Although one would think that relatively low-cost strategies such as providing information on the transition process and on understanding ADHD as a condition should be straightforward to implement, it is important to understand the influence of the service context. Proposed next steps arising from this work are summarised below, with a focus on information provision and improving service organisation.

### Information provision

- **Future work should develop national information resources for young people with ADHD.** These should be multi-media, making use of video and apps, and need to be informed by and tested through the involvement of people with lived experience and clinicians with expertise in ADHD. The resulting resources could be made available to every service in the UK. These would reduce the burden on health workers to inform patients, and provide a cost-effective way of sharing key information to support transition.
- **Research should be conducted into how information technology can be harnessed to provide information ‘at the point of need’ to health workers supporting young people with ADHD.** Given underlying issues with lack of training for clinicians who work with people with ADHD, and in the context of high levels of demand on health workers and clinicians such as GPs, paediatricians, psychiatrists and specialist nurses, research is needed into how information technology can be used to provide appropriate and helpful information at the point of need. Examples could include apps to provide essential data on diagnosis and management of ADHD to GPs; digital resources for health workers with links to maps showing local adult ADHD services; online transition guides; and other information resources that can be shared with patients, such as video stories about *living with ADHD as an adult*.

## Organisation of services

- **Research involving key stakeholders should be undertaken to learn from instances where service provision is working well in practice and inform a national strategy for service design.** The variable design and delivery of health services for adults with ADHD makes it difficult to audit services and reflects the fact that there is currently no consensus on the best model of care. Although service users often report better experiences of care within dedicated services, (with generic adult mental health services often not accepting referrals or without staff with appropriate training in the treatment and management of adult ADHD), economic constraints make nationwide provision of dedicated services unlikely. Case-studies should be undertaken to explore the strengths and weaknesses of different models of care in different settings. They should include economic evaluations, and detailed data on waiting lists, staffing levels, and patient satisfaction. The quantitative work using prescribing rates as a proxy for access to care needs to be refined and repeated to provide high quality data to inform these case studies, and highlight areas of inequity of access.
- **Research is needed into the most cost-effective and acceptable model of providing care for adults with ADHD; and how primary care can be supported to treat adults with ADHD within shared-care agreements.** With increasing numbers of young people with ADHD reaching the age of transition, pressure on services is going to increase. A more integrated approach which included involving GPs in care is needed. However, as with adult ADHD services, current involvement of primary care services in managing adult ADHD appears to be ad-hoc and highly variable from practice to practice. Research is needed to find examples of best practice and highlight barriers and facilitators to effective shared-care from the perspectives of GPs.

## 6.4 Conclusion

The findings from the studies included in my thesis are that experiences of health service transition in the UK for young people with ADHD are generally poor, with multiple barriers to continuation of care including inadequate provision of information and limited availability of adult health services. Evidence also points to some geographic health inequalities for young people with ADHD in the UK, with regional variation of dedicated NHS adult ADHD services, in rates of referrals

to adult services, and the prescribing of ADHD medication during the period of transition. Findings highlight the clear need to develop an information strategy to accompany the transition process and provide accessible adult UK ADHD services, to support transition for young people with ADHD and reduce health inequalities. The low number of dedicated NHS adult ADHD services reported in the mapping study appears to represent a significant barrier to transition, however clarity is needed on optimum service configurations and the role of primary care. Future research should explore low cost, scalable interventions to improve the communication of key information, as well as clarifying optimum models of care for adults with ADHD.

# Appendices

## Appendix 1: systematic review - search strategy

### Main Search\*

19/01/2017

Ovid: Search Results

Database(s): Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

Search Strategy:

#	Searches	Results	Annotations
1	"attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/ or conduct disorder/	31185	ADHD 1
2	ADHD.t,ab.	21759	ADHD 2
3	ADHS.t,ab.	514	ADHD 3
4	ADDH.t,ab.	113	ADHD 4
5	attention deficit.t,ab.	25233	ADHD 5
6	hyperactiv*.t,ab.	54200	ADHD 6
7	(hyper adj1 activ*).t,ab.	835	ADHD 7
8	(Attention adj3 (problem* or difficult* or disorder* or issue*)).t,ab.	31817	ADHD 8
9	hyperk*.t,ab.	19646	ADHD 9
10	inattent*.t,ab.	6565	ADHD 10
11	impulsiv*.t,ab.	18365	ADHD 11
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11	112431	ADHD search string - all options joined with 'or'
13	transition.mp. or Health Transition/ or Transition to Adult Care.mp. or exp "Continuity of Patient Care"/ [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	334360	Transition 1
14	transition*.t,ab.	354233	Transition 2
15	(child adj2 adult).t,ab.	3603	Transition 3
16	(continu* adj2 care).t,ab.	14854	Transition 4
17	adolescent to adult.t,ab.	3804	Transition 5
18	transfer of care.t,ab.	383	Transition 6
19	13 or 14 or 15 or 16 or 17 or 18	430665	Transition search string - all options joined with 'or'
20	Adolescent/ or Adolescent Health/ or adolescent.mp.	2026739	Adolescents 1
21	young adult.mp. or Young Adult/	688816	Adolescents - 2
22	adolescen*.t,ab.	247178	Adolescents - 3
23	youth*.t,ab.	64903	Adolescents - 4
24	teen*.t,ab.	28610	Adolescents - 5
25	young adult*.t,ab.	84414	Adolescents - 6
26	young person.t,ab.	882	Adolescents - 7
27	young people.t,ab.	23002	Adolescents - 8
28	(transition* adj2 adult).t,ab.	1041	Adolescent - 9
29	(transition adj2 (paediat* or child) adj2 (adult or adolescen*)).t,ab.	216	Adolescents - 10

30	20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29	2424424	Adolescents - options all combined with 'or'
31	qualitative research.mp. or Qualitative Research/	46004	Qual - 1
32	experience.ti,ab.	586589	Qualitative - 2
33	experiences.ti,ab.	167328	Qual - 3
34	understanding.ti,ab.	721497	Qual - 4
35	Interview*.ti,ab.	316746	Qual - 5
36	qualitative.ti,ab.	182405	Qual - 6
37	perceive*.ti,ab.	181102	Qual - 7
38	Perception*.ti,ab.	211907	Qual - 8
39	(views or view or viewpoint*).ti,ab.	365260	Qual - 9
40	focus group*.ti,ab.	36669	Qual - 10
41	attitude*.ti,ab.	129887	Qual - 11
42	beliefs.ti,ab.	48420	Qual - 12

43	feelings.ti,ab.	28800	Qual - 13
44	(meaning or meanings).ti,ab.	54101	Qual - 14
45	observation*.ti,ab.	787250	Qual - 15
46	(workshop adj5 (ADHD or transition)).ti,ab.	28	
47	31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46	3100572	
48	12 and 19 and 30 and 47	238	
49	limit 48 to yr="2000 -Current"	225	

\*Note: although the example shown is for a search of Ovid, search strategies were identical for each database.

## Additional Search\*

25/01/2017

Ovid: Search Results

Database(s): Epub Ahead of Print, In-Process & Other Non-indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

Search Strategy:

#	Searches	Results
1	exp "Review"/ or review.mp. or consensus development conference/	3020681
2	review.t,ab.	1346022
3	1 or 2	3020681
4	exp Neurodevelopmental Disorders/ or neurodisability.mp. or Mental Health/ or mental health condition.mp.	205206
5	neurodisability.t,ab.	168
6	neurodevelopmental disorders.t,ab.	4069
7	mental health.t,ab.	115989
8	4 or 5 or 6 or 7	301331
9	transition.mp. or Health Transition/ or Transition to Adult Care.mp. or exp "Continuity of Patient Care"/ [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	334864
10	transition*.t,ab.	354738
11	(child adj2 adult).t,ab.	3607
12	(continuu* adj2 care).t,ab.	14878
13	adolescent to adult.t,ab.	3811
14	transfer of care.t,ab.	385
15	9 or 10 or 11 or 12 or 13 or 14	431280
16	Adolescent/ or Adolescent Health/ or adolescent.mp.	2028589
17	young people.mp. or Young Adult/	687555
18	adolescen*.t,ab.	247540
19	youth*.t,ab.	65012
20	teen*.t,ab.	28633
21	young adult*.t,ab.	84531
22	young person.t,ab.	883
23	young people.t,ab.	23042
24	(transition* adj2 adult).t,ab.	1046
25	(transition adj2 (paediat* or child) adj2 (adult or adolescen*)),t,ab.	216
26	16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25	2427248
27	3 and 8 and 15 and 26	417
28	limit 27 to yr="2006 -Current"	310

\*Note: although the example shown is for a search of Ovid, search strategies were identical for each database.

## Appendix 2: systematic review - quality appraisal

Quality Ratings for Included Articles: Wallace Criteria								
Assessment Item (E/D)	Article							
	Wong 2009	Swift 2013	Matheson 2013	Belling 2014	Reale 2014	Ginsberg 2014	Cheung 2015	Young 2016
Is the research question clear? (E)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is the theoretical or ideological perspective of the author (or funder) explicit? (D)	Yes	Yes	Yes	Yes	No	Yes	Yes	No
Has this influenced the study design, methods or research findings?	Yes	Yes	Yes	Yes	No	Yes	Yes	Can't tell
Is the study design appropriate to answer the question? (E)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell
Is the context or setting adequately described?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Is the sample adequate to explore the range of subjects and settings, and has it been drawn from an appropriate population? (E)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell
Was the data collection adequately described? (E)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Was data collection rigorously conducted to ensure confidence in the findings? (E)	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Can't tell
Was there evidence that the data analysis was rigorously conducted to ensure confidence in the findings? (E)	Yes	Yes	Yes	Yes	No	Can't tell	Yes	No
Are findings substantiated by the data? (D)	Yes	Yes	Yes	Yes	No	Yes	Yes	No
Has consideration been given to any limitations of the methods or data that may have affected the results?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Do any claims to generalisability follow logically and theoretically from the data? (D)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell
Quality Ratings for Included Articles: Wallace Criteria								

	<b>Article</b>							
Assessment Item (E/D)	Wong 2009	Swift 2013	Matheson 2013	Belling 2014	Reale 2014	Ginsberg 2014	Cheung 2015	Young 2016
Have ethical issues been addressed and confidentiality respected? (D)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
Score on Essential and Desirable Items	5E, 4D	5E, 4D	5E, 4D	5E, 4D	3E, 2D	2E, 3D	5E, 4D	1E, 1D
<b>Total Score</b>	13Y	13Y	13Y	13Y	8Y,4N,1CT	9Y,1N,3CT	13Y	2Y,6N,5CT
<b>Quality Rating</b>	<b>Good</b>	<b>Good</b>	<b>Good</b>	<b>Good</b>	<b>Poor</b>	<b>Poor</b>	<b>Good</b>	<b>Poor</b>

*E=essential, D=desirable*

## **Appendix 3: qualitative study - interview topic guides**

### **Topic guide 1: young people pre-transition**

#### **1. Current contact with services**

- Do you remember when you had your last appointment at CAMHS? And can you tell us a bit about how that went?
  - Who was present? (who was there – parent, clinician, nurse)
  - What was the appointment for? (Prescription, talking about transition, medical review, discuss other problems, did you discuss other problems, such as anxiety, depression...)
  - Where you asked questions? Could you answer for yourself?
  - Did you have questions for your clinician / nurse? Did you get to ask them? (Why not?)
  - When you left the doctor's consultation room, did you understand why you had attended the appointment, where any decisions made, was anything going to happen / change as a result of the appointment? (ATTENTION: we want to know what the YP perceives! Not what actually happened, no point mum adding to the conversation now)
  - Looking back, and what you have just told me, do you feel like you were a part of what has been said and or decided?
    - Did you feel your contribution made a difference?
    - Did you discuss what happened at the appointment with your mum on the way back?
    - Did you feel like it was worth going? (Why not?)

#### **2. Managing your care**

- How much would you say, your mum helps you with managing your ADHD? (remind you to take medication, order prescriptions, make new appointment, attend the appointment, drive there, asks questions at the appointment about your medication ...)

- Which of these things do you think you will soon be able to do yourself?
  - What do you think would help you to be more confident to do these things yourself?
  - Has anyone suggested you do these things yourself (and if so, did you try and what happened?)

### **3. ADHD as long-term condition**

- What is the main reason that you still attend CAMHS? (What is currently the main reason to continue your treatment?)
- Do you see yourself going to CAMHS or any other services for your ADHD in the future? (Suggestion: at 16/18, when leaving school ...)? Do you think you will still need help or support for your ADHD after you leave school?
  - Why (not)?
  - What would be a reason for you to stop attending CAMHS or receiving help for managing your ADHD? Could you see a reason at the moment to stop going to CAMHS?
  - What do you think would happen if you stopped going (do you think you could go back after a few years?) would you want someone to keep contacting you to see how you are doing? Would you want someone to encourage / persuade you to stay / attend appointments? How do you think your family / mum would react?
- Do you think ADHD may still be a problem at 18, 20?  
 Do you think at some point some of the symptoms might be more difficult to deal with and you might need support again? (hence, you would return to services)  
 Who would you turn to for help if you found out you were still struggling with things related to your ADHD?
  - GP – do you ever see your GP? Do you get any help from them with your ADHD?
  - If you ever go to your GP for something, do you get to talk about your ADHD as well? / does the GP ask about your ADHD?

#### **4. Transition**

- So, has anyone talked to you about that? (That you might have difficulties later on in life; or that you might need support after you have stopped going to CAMHS)
  - Has transition been discussed at one of your CAMHS appointments?
    - Do you know until what age you can attend your current CAMHS?
    - Do you know where they will refer you after 18?
    - Has anyone talked to you how this service might be different from your current CAMHS?
  - Is there anything specific that you would want to know and how would this help you? Is there anything specific that you are worried about (related to your ADHD when you get too old for CAMHS services)?
  - Is there anything you have been asked to do to prepare yourself for the next step, or for going to this new service?

#### **5. Closing question**

If you could ask your clinician just one question about the next step after leaving CAMHS / reaching 18 (might be adult services, might be dealing with life without any support), what would it be?

If you could ask your mum just one question about the next step after leaving CAMHS / reaching 18 (might be adult services, might be dealing with life without any support), what would it be?

#### ***Add-ons for Young person in residential school / care***

Who helps you with managing your care?

Who goes with you when you meet your clinician?

## Topic guide 2: young people at transition

### 1. AMHS

- When was your last appointment with AMHS?
- Can you tell me a bit about what was that like?
- Do you have any co-existing mental health conditions alongside your ADHD?
  - If so, were these discussed in your appointment with AMHS?
  - Do you any support or treatment elsewhere for these?
- Was your appointment with AMHS different from CAMHS?
  - If so, in what way?

### 2. Transition

- When did you first realise you might need support after leaving CAMHS/turning 18?
  - (If they realised it themselves, did they ask their clinician/anyone else about this? If not, why not?)
  - What sort of support did you think you needed?
  - How did you feel about still needing support?
- When was transfer to AMHS first discussed during a consultation/with CAMHS?
  - What was discussed with you?
  - Were there things you wanted to ask but didn't ask? (Unanswered questions?)
- What happened next?
  - Was there a planning meeting? (Who was there?)
  - Did you meet anyone from AMHS before your first appointment there?
  - Can you give a few details about how the adult service was in contact with you?
    - Did you get a letter? Who got it, when, did you see it?

- How long did you have to wait to be seen by AMHS?
  - Whilst waiting, what did you know about what would happen next?
  - Whilst waiting, what happened to your medication in that time?
  - Was it clear who you could contact for help throughout the process?
  - Could you still contact your old CAMHS service? Did you have a named contact or transition worker at CAMHS?
  - Did you have a named contact or transition worker at AMHS?
  - Were there any gaps in your care when you moved from CAMHS to the service for adults, or times when you could not get the help you needed?
    - If so, what happened during that time?
    - Did you know what was happening or who to contact?
    - Did you contact or try to contact anyone?
  - At your first appointment with AMHS, did you know who you were going to see?
  - At your first appointment with AMHS, did you know where to go?
- What did you think about how CAMHS and the service for adults worked together?

### **3. Role of the GP**

- How has your GP been involved in your ADHD care so far?
- Would you get in touch with them if you needed help? (Why/ why not?)
- Do you think that there is anything that your GP could help you with?

### **4. Managing as an adult**

- Now that you have taken the next step into AMHS, do you feel confident managing your care? (e.g. making appointments, ordering prescriptions, getting to appointments)

- *(If they mention their mum does all of this - if it wasn't your mum doing this for you, would you be able to do it yourself? Would you know what to do?)*
- Do you think you'll become more confident managing your care in future?
  - What do you think would help you get more confident/manage better?
  - What do you think your CAMHS team could have done to prepare you for managing your own care as an adult?
- Is there anything specific that you find difficult about managing as an adult with ADHD?
  - Do you think there is support out there to help you?
  - What sort of support do you think would help?

## **5. Giving advice and closing interview**

- If you spoke to a younger person who is still in CAMHS with ADHD, what would you tell them to expect as they get older?
  - What advice would you give them about treatment, symptoms and medication?
  - What advice would you give them about moving to adult services?

## Topic guide 3: young adults no transition

### 1. Returning to services

- What triggered you to go back into services?
  - What influenced this decision to go back at this point?
  - Did you discuss this with anyone?
  - Was this the decisive moment?
  - Whose idea was it to go back into services?
  
- What happened next?
  - Can you describe the steps you took?
  - Who did you go to first?
  - Did you still contact your old/previous doctor? What happened?
  - How did you get referred to the service you are attending now?
  - Were there any difficulties in getting seen by adult services?
  - Did you get a letter? Who got it, when, did you see it?
  - Did you have a contact number or a named person?
  - Did you/your parent ring them?
  - How long did you have to wait?
  - If you were waiting, what did you know at that point about AMHS?
  - How did you feel about this process?
  
- **Do you have any co-existing mental health problems?**
  - Did you get a chance to discuss your mental health more widely with the person who referred you to AMHS?
  - When you got to AMHS, did you discuss your mental health in general?

### 2. Leaving services

- Can you tell me a bit about when you stopped going to CAMHS and why that happened?
  - Did you discuss this with anyone?

- *(if they stopped taking medication)* - Did anyone discuss what might happen when you stopped medication?
  - Did anyone discuss how that might affect you?
- *(If they disengaged)* – did anyone ask you why?
  - Did anyone try to stop you?
- *(if was their choice to stop going)* Was there anything that would have made you change your mind? (E.g. decide to keep taking medication / stay at that service / transfer to adult services?)
- When you left, did you feel you could come back?

### **3. Current care**

- Has your GP been involved since you left CAMHS services?
  - If not, why was that?
  - If yes, when were they involved? What did they do?
- Now you're in AMHS, do you feel confident managing your care?
  - Is there anything specific that you find difficult about managing as an adult with ADHD?
  - How are you coping with these difficulties?

### **4. Reflection/Close**

- If you spoke to a young person who was about to leave CAMHS, what advice would you give to them?
  - What advice would you give them about medication?
  - What advice would you give them about moving to adult services?
  - If they want to leave services, would you encourage them to stay? Why/or why not?

## Topic guide 4: parents/carers

### 1. Current situation

- How old is your child?
- Could you tell us a little bit about any help your child receives for their ADHD?
- How you involved in the treatment of your child's ADHD?
- Does your child have any (comorbid) conditions as well as ADHD?

### 2. **“Were you/your child discharged from services if you missed appointments, even though you/they still had an ongoing need for support?” “What happened then?”**

### 3. **What would happen/has happened if you chose not to use medication but still want to be in touch with services? Can you do this?**

### 4. Future (Transition)

- If currently, your child takes medication for their ADHD. Do you see this continued in the future?
- How do you see this future support?
- What are your thoughts on ADHD and growing up (how this may present into teenage and adulthood)?
- What are your thoughts on medication for ADHD, what about medication into adulthood?

### 5. Planning and preparation for transition

- When did your child's therapist/doctor at the children's service first talk about a transition to adult services?
  - Has this been addressed yet?
  - How did you feel about this?

- What was discussed prior to the transfer? What made you continue medication/treatment for your child's ADHD?
- If transition has not yet been addressed, when do you think would be a good time for your child's doctor to first talk about transition?
  - Have you thought about discussing transition and needs into adulthood with your clinician?
  - What kind of information have you had from your clinician (other sources) about ADHD and growing up (how it may change, needs, treatment)?
  - Do you know how ADHD will progress during adolescence and into adulthood? Has your clinician talked to you about this?
- When did you first have contact with professionals from the adult service?
  - If you have not yet had contact, when do you think would be a good time to first have contact?
- How were you, as a parent, involved in this process?
  - How, as a parent would you like to be involved in this process?
- How well prepared did you feel for your child's transfer?
  - What would make you feel well prepared for your child's transfer?
- Is there anything that could have helped you and your child prepare for leaving CAMHS/Paediatrics?
  - Is there anything that would help you and your child prepare for leaving CAMHS?

## **6. The transition process**

- Is it clear who you can contact for help throughout the process?
  - If so, who is this, and how did you find out about them?
  - If not, who would you ask to find out?
- Did you have a named contact or transition worker at CAMHS? At the service for adults?
  - If still in CAMHS, do you have a named contact in CAMHS, how do you get in touch with them?

- Were there any gaps in your care when you moved from CAMHS to the service for adults, or times when you could not get the help you needed?
  - Do you think there may be any gaps in your child's care when they move from CAMHS to adult services?
  - What would do you both do if you could not get the help you needed?
- What did you think about how CAMHS and the service for adults worked together?
  - Or if not yet transitioning, how do you think the CAMHS and adult services are likely to work together?
  - How would you like them to work together?

## **7. Improving transition**

In your opinion, how could transition be improved for young people moving from CAMHS to services for adults?

- What might the best designed service look like?
- What would your child in particular most benefit from during transition?

#### **Appendix 4: qualitative study - recommendations for clinical practice**

*Equip General Practitioners (GPs) so that they understand ADHD as a condition and can signpost to services*

GPs are often a first point of contact for young people and may be an essential link to help access services. Therefore they need to be aware of ADHD as a condition and be able to access service information.

The information a GP holds can be a crucial factor in parent/carer and young people's access to services, medication if required and their well-being. A GPs lack of understanding of ADHD as condition and/or inability to access information about appropriate adult services can be a significant barrier to transition and contribute to young people and parents/carers' isolation and distress.

*Start sharing key information at least a year in advance*

Preparation should be timed so that it can be a staged process with a basic overview of ADHD as a condition plus the need to transition into adult services, followed by more detail. Give young people time to get used to the idea and a chance to discuss options before they reach 18. This enables the young person to increase their understanding of ADHD as a condition, reflect on their own needs and make informed choices about continued engagement with services.

*"I think they need 12 months just to get the idea... to explain everything...we need to forward plan and we need to know what's going to happen before it happens otherwise the anxiety will just kick in." F-P*

*"I think it would be useful if ... they were spoken to by someone who does a transition type package saying, 'You are 16 now, there's lots of options that you can do.' ... to have someone who knows about ADHD to say, 'These are your options'." F-0-(P)*

Young people with ADHD often said that they did not like sudden changes and wanted time to plan and think about their own futures.

*“I’d rather have time to plan...I don’t like sudden changes.” F-0*

*“I’d rather it sooner than later because then I know what to expect in the future...because it’s my future and I don’t really know what’s going to happen.” M-0*

Preparation needs to be flexible enough to take into account the young person’s developing maturity and how this is interacting with their ADHD.

*“Within that year you’ll either see a maturity where they’re not growing out of it but learning to live with it shall we say? Or it will be panic stations...let’s get them booked in ready and have it all sorted.” M-0-(P)*

*Stage 1. Provide an initial overview of ADHD as a condition and of the transition process*

Let the young person know they may or may not continue to be affected by ADHD into adulthood. Let them know transition is a possibility with an overview of how and when it might happen.

*“I’d definitely like to know when and what happens [at transition]” and when children’s services end.” M-0*

*“Could I carry on, if I needed it or something? Would I have to pay for it?”  
M-0*

Young adults who did not transition recommend that the choice to stop treatment is discussed early, in a way that involves the young person. The clinicians from children’s services should explain that ADHD may cause the young person difficulties into adult life and provide information that they might need to make informed choices about treatment and transition. They recommended a sensible discussion about impact of stopping. They also emphasise the importance of providing young people with the information necessary for re-entry into services if they do lose contact. If someone leaves, they need to know how to access help later.

*Stage 2. Provide nuanced information about the young person's ADHD needs, combined with detailed information about the transition process*

Information about ADHD as a condition is a necessary part of preparation for transition – this might not have been discussed for some years if the young person was diagnosed in childhood. Understanding the way that their ADHD needs may continue, change and develop, the potential impact of study or work environments, and possible use of strategies to deal with this is an important part of empowering young people to engage manage their own condition and will affect their decisions about continuing into adult services. Most young people and carers would like this information from expert clinicians.

*“I want him to have some help to understand how he can sort himself out and how he can control it himself. There's only so much I can tell him or he can find out himself.” F-P*

*“He would like a relationship with someone who he can ask these questions of.” F-P “Consistency with a knowledgeable, qualified person that can actually help him move into adulthood.” F-P*

Providing detailed information about the transition process, laid out in clear steps may diminish or even avoid uncertainty that can causes high levels of distress in young people. Clear information allows parents/carers to better support young people in navigating organisational information in a way that will allow them to get to their appointments.

Through being provided with detailed information, young people are given an opportunity to reflect and ask questions.

*“I'd have to know what they'd even do to be able to ask questions.” F-0*

*Take ADHD into account when providing information and include parents/carers*

People with ADHD struggle with the regulation of attention and organisation. This means they can find it difficult to focus on specific details and may be overwhelmed by too much information. Therefore, information needs to be communicated in simple, clear formats and via several methods. Give the young person time to process new data and avoid discussing lots of things at once.

*“They should take into account the nature of the condition, [for transition planning]...I think they understand that you might be slow in your response or that you might not want to sit down all of the time. So they take that into account but they don't when they're giving you loads of information all at once without really repeating it.” F-P*

*“Information leaflets, stuff like that to help you with it and to understand what's happening or what will happen so it just makes it a lot smoother for you.” M-1*

*“A video would be ideal. Clips would be ideal. Or a picture book, or even just re-enacting. Literally seeing it and re-enacting it out. It needs to be hands-on with people with ADHD.” M-X*

Include and facilitate the parent/carer in their role as information interpreter for the young person. Young people need the option for parents/carers support to continue after leaving child services, given the effect of ADHD on many young people's ability to organise themselves. The parent/carer is likely to continue to play a crucial role in navigating practical/administrative information to enable the young person to access treatment, as well as supporting them in developing understanding of ADHD as condition and how it may continue to affect them.

#### *Provide information about being in adult services*

Having information about what to expect in the adult service, where it is, who they will be meeting and how treatment may differ from child services is very important to young people. Knowing this in advance helps them manage the process of change and to feel they are ready to engage with the adult service when the time comes.

- **Let them know about access into adult services:** whether they will qualify for treatment. That there is a service. If there is no service, or they may not meet referral criteria, that is likely to cause distress. However, knowing in advance is better than finding out when they have already left child services.

*“My consultant told me that I probably wouldn’t qualify for the adult psychiatry...at the moment I’m kind of like okay, but...when it was first mentioned I was completely distraught.” F-1*

- **Explain differences between child and adult services:** Not knowing this can cause anxiety, while understanding the differences and similarities can help the young person think about how they will be able to manage their condition as an adult, what help will be available and be ready to engage in adult services in a suitable way.

*“I’d like to know how different things would be and how they do things compared to the way that the children services do things.” F-0*

- **Share information about the new clinician:** If possible provide joint meetings, most young people ask for this, to help them to get to know their new clinician and reduce anxiety around the unknown and meeting new people. If this is not possible, provide as much information about the person as you can.

*“You are integrating into it [adult service] it might make things easier rather than it just being a sudden sort of change from this person to this person, if you just slowly met up with them and built a relationship up with them a bit.” F-0*

*“Yeah. I’m not really great around new people.” M-0*

- **Share information about the physical location:** for young people knowing where they will be going to as an adult, perhaps visiting this place in advance, is a way of managing the process of change.

*“So then you know where you are going and you feel comfortable and you feel acquainted already.” M-0*

## 1. Share information between child and adult services

Young people with ADHD can struggle with information processing and communication. Making sure the adult clinician and services is already briefed about the young person, which reduces the burden on them to repeat their story.

*“Someone to know a bit more about my past in detail than what I have just said, it would be much better.” M-0*

*“I’d prefer it if a doctor just spoke to the other doctor and actually told her all about it [me] and what...the other doctor needs to do...how to handle [my ADHD].” M-0*

### *Provide a point of contact*

A point of contact when between services is very important both practically and emotionally. Ideally this would be a named person who can update the young person on where they are in the transition process, answer administrative questions and signpost to other services in an emergency. However, even an informed administrator or a drop in centre where they can go to ask questions would make a big difference. This could provide a sense of still being ‘in’ services, rather than left alone. This would help to reduce the stress associated with waiting for adult services which can be very difficult. Hearing nothing at all leads to frustration.

*“Just knowing someone is there if anything was to happen, touch wood it doesn’t but if something was to happen I could actually speak to someone.” M-0*

*“Nothing complicated, just if you were to find websites that would be in your face that ‘hey this is the number that you can call anytime’ that would make it easier.” M-0*

*[Note: F=female, M=male. 0=pre-transition; 1=at-transition; X=no-transition (re-entered as adult). P=parent. (P) = Parent commenting within young person’s interview.]*

## Appendix 5: mapping study – impact and map views

### 1. Pilot map

2016 pilot map of adult ADHD services, released December 2017, informed by 1446 service users, clinicians and commissioners.

Available

here:

<https://www.google.com/maps/d/u/1/edit?mid=1cRvjh3Vq4XqsLsWPJ2dqy3a3ltl&ll=52.720680980025264%2C-1.06391974999999682&z=7>

**Number of map views at 24<sup>th</sup> April 2019 = 32,564**, see figure 1. Indicating high levels of interest and engagement in the research.

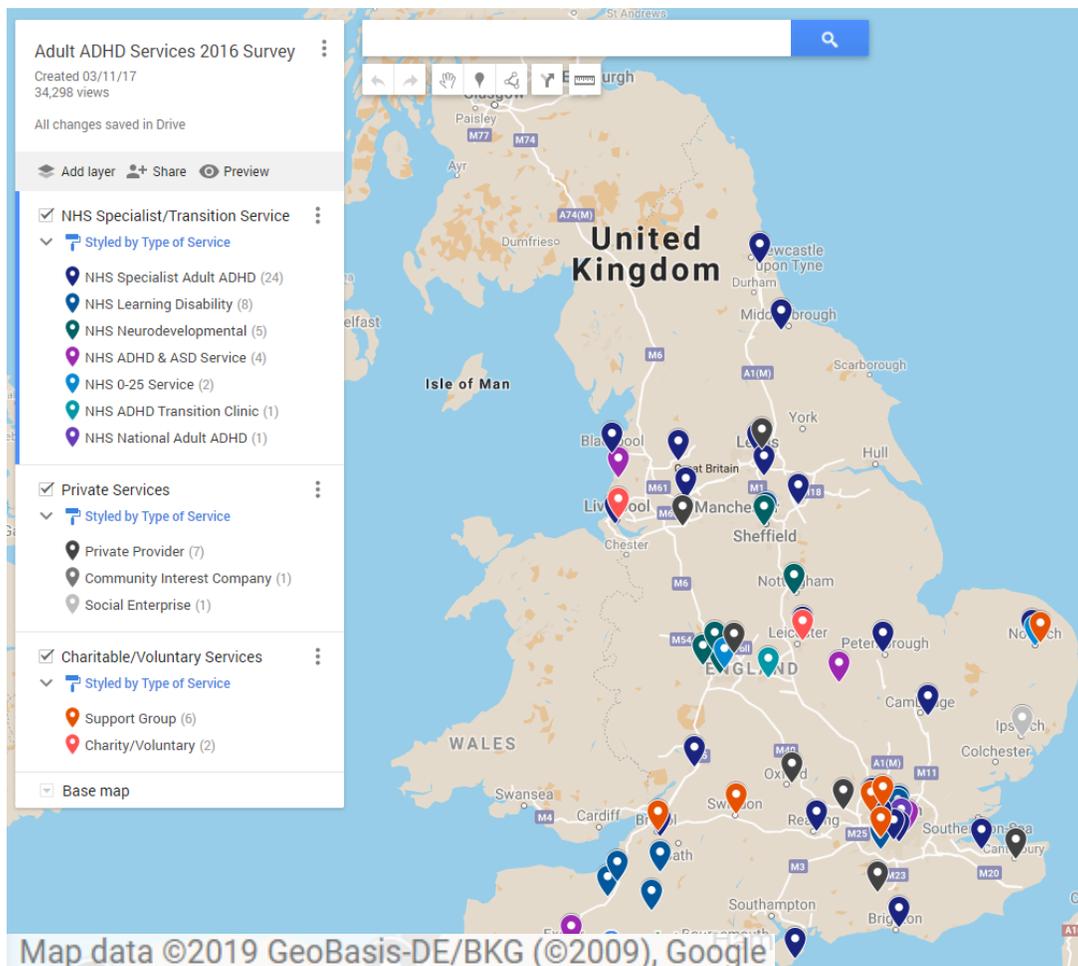


Figure 25. 2016 pilot map of adult ADHD services in the UK

## 2. 2018 map

2018 map of services, released on 21<sup>st</sup> November 2018, as informed by 2686 service users, clinicians and commissioners.

Available here: <http://medicine.exeter.ac.uk/catchus/mapping/adhdservices/>

**Number of map views at 24<sup>th</sup> April 2019 = 2,226**, see figure 2. Indicating high levels of interest and engagement in the research. High engagement on twitter with over 17,000 impressions.

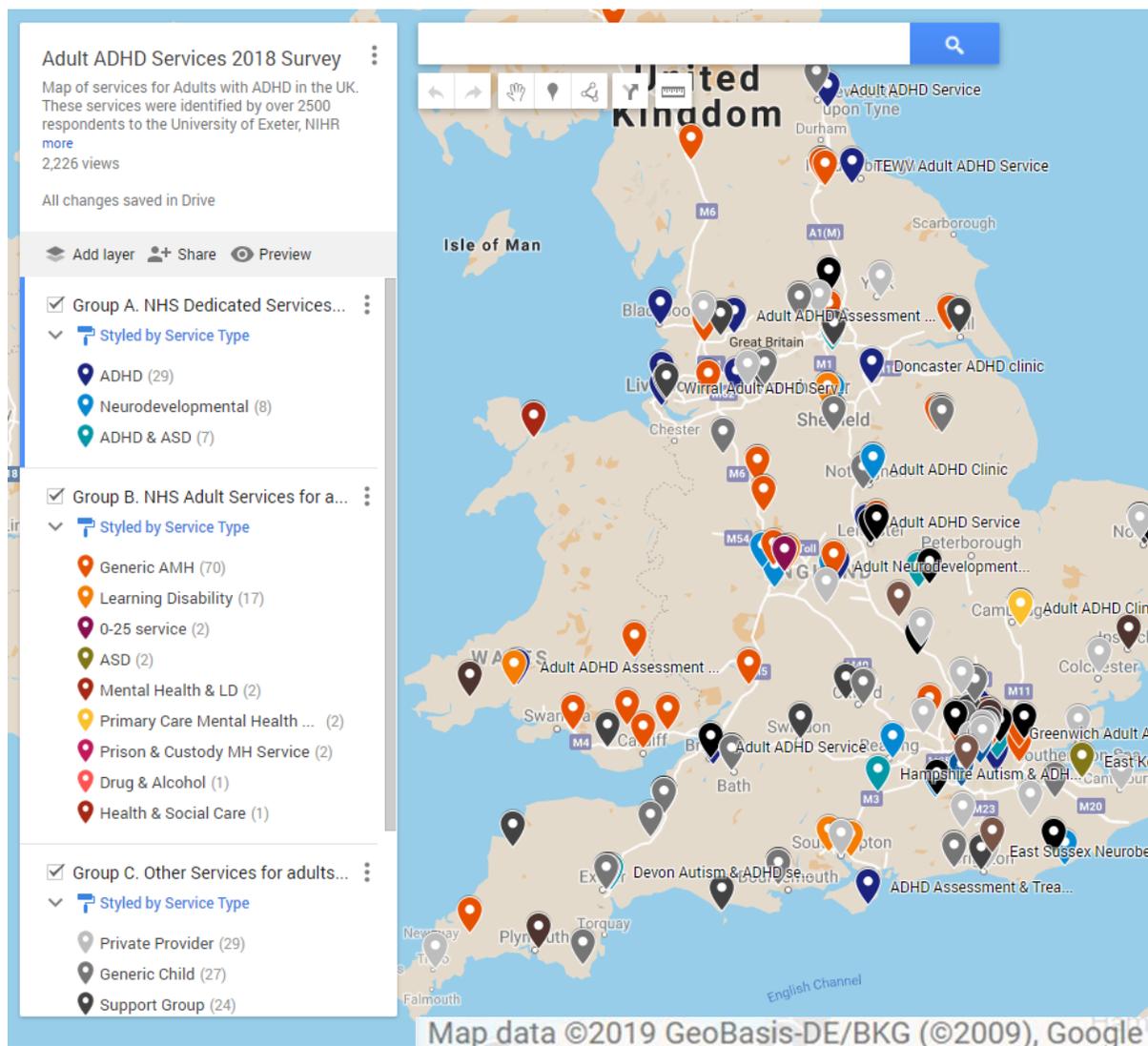


Figure 2. 2018 map of adult ADHD services in the UK

### 3. 2018 promotional material, examples

ACAMH: <https://www.acamh.org/blog/adhd-service-map/>

PenCru: [http://www.pencru.org/aboutus/news/title\\_694553\\_en.php](http://www.pencru.org/aboutus/news/title_694553_en.php)

University of Exeter: [http://www.exeter.ac.uk/news/research/title\\_693739\\_en.html](http://www.exeter.ac.uk/news/research/title_693739_en.html)

### Appendix 6: mapping study – Twitter comments

**Bookmarks**  
@Anna\_M\_Price

**Chris RW** @C\_RWright - 20 Nov 2018  
Replying to @Tamsin\_J\_Ford, @Anna\_M\_Price and 2 others  
Will certainly feed back once the 2018 map is released. Couple of off-the-cuff ideas. Often a big discrepancy between GP surgeries, even within trusts that will treat adult ADHD. Could the data drill down to that level in future?

**Chris RW** @C\_RWright - 4 Dec 2018  
Replying to @C\_RWright, @Anna\_M\_Price and @AvaJanssens  
This was the first 5 GPs I had to register then deregister with post-private diagnosis to get an NHS prescription. I only succeeded by going to the trust and literally begging a GP over the phone for support.

**OnLineTraining** @Team\_OLT - 18 Dec 2018  
ADHD does not just effect children and some great work has been completed by @Anna\_M\_Price and @ExeterMed highlighting what support and services are out there for young adults with #ADHD. Please share this map to help raise awareness. #catchusADHD

**ADHD Foundation** @ADHDFoundation - 21 Nov 2018  
Excellent work by Exeter University and ADHD Patient Services & Organisations in making ADHD services in the U.K. @AvaJanssens @Anna\_M\_Price @UniofExeter [twitter.com/Anna\\_M\\_Price/s...](https://twitter.com/Anna_M_Price/s...)

**Karen Scorer** @KarenScorerOT - 14 Dec 2018  
Replying to @Anna\_M\_Price, @ADHDFoundation and 7 others  
[@emilylinka](#) here is a list of all ADHD services. NHS services do exist but tend to have long waiting lists, if no service in your area ask to be referred to one nearby.

**Melanie || ADHD & Mental Health Blogger** @itsnotmel... - 3 Dec 2018  
Disappointing gap in services where I live so if you're ever wondering why I moan so much about getting no help? This is why. #ADHD

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**Rachel Hayes** @rahayesuk · 30 Nov 2018  
Fabulous resource for families and practitioners

**Association for Child & Adolescent Mental Health** ... · 29 Nov 2018  
An online #ADHD service map aims to stop young people slipping through net.  
From @Anna\_M\_Price @ExeterMed

**ADDvanced Solutions** @ADDvancedSol · 29 Nov 2018  
Replying to @Anna\_M\_Price, and @NorthDevonForum  
This is really interesting @Anna\_M\_Price - we wondered if you're planning anything focusing on children and young people's services?

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**Poppy Ellis Logan** @poppyellislogan · 19 Nov 2018  
Replying to @Anna\_M\_Price  
Cannot wait to get my hands on this - will it be ok to share with patients (eg those moving to different areas of UK or thinking of doing so?)

1         

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**Poppy Ellis Logan** @poppyellislogan · 20 Nov 2018  
Replying to @Anna\_M\_Price, @OfficialNIHR and 3 others  
Excellent excellent excellent. @shannoncutting we should get a copy for everyone in the team

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**Chris RW** @C\_RWright · 20 Nov 2018  
Replying to @PenCLAHRC, @Anna\_M\_Price and 2 others  
Find me a better example of genuine public service through research. Thank

**AADD-UK #ADHD #StopBrexit** @AADDUK · 21 Nov 2018  
Replying to @Anna\_M\_Price, @ADHDFoundation and 7 others  
And thank you Anna for all your hard work!

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*Tweets highlighted within red oval, show example of stakeholder requests for similar maps of children and young people's services, or of GP surgeries that will treat adult ADHD*

## Appendix 7: mapping study - pilot surveys

### All stakeholders



#### **CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

The CATCH-uS study is funded by the National Institute for Health Research and has ethical approval. Details can be found on our [website](#). The aim of this survey is to map available services for young people with Attention Deficit Hyperactivity Disorder (ADHD) who are aged 18 and over. We only want to know about services in your area and will not share any of your personal information. The survey is anonymous and confidential. Answers will help to create a list of existing services. This is to support the overall study aims of informing and improving service provision for young adults with ADHD.

Please answer the following questions to help us map available ADHD services in the UK. The survey should take no longer than 5 minutes to complete.



1. Are you a...?

- Young person (from 14 up to 17 years old)
- Young adult (18 or older)
- A parent/carer of a young person
- A clinician working with young people and/or adults with ADHD
- Other (please specify)



**CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD



2. Where do you live in the UK?

3. Which County or London Borough do you live in?



**CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

4. Do you or does a person you care for have a clinical diagnosis of ADHD?

- Yes
- No
- Awaiting a diagnosis / Undiagnosed
- Don't know
- Comments:

5. Do you know about any NHS provided or other mental health services\* for people with ADHD aged 18 +?

\*in your area or available to you

- Yes
- No
- Don't know
- Other (give details)



**CATCh-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

**Mapping the availability of services for young people with ADHD**

6. Which of the following sectors do you work in? (Tick all that apply)

- Private Sector
- Private Provider for NHS
- Community Interest Company (or equivalent) for NHS
- NHS
- Other (please specify)

7. Please provide details of your job:

Job Title

Details

8. Which region of the UK do you work in?

9. Which County or London Borough do you work in?

**CATCh-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

**Mapping the availability of services for young people with ADHD**

6. Which of the following sectors do you work in? (Tick all that apply)

- Private Sector
- Private Provider for NHS
- Community Interest Company (or equivalent) for NHS
- NHS
- Other (please specify)

7. Please provide details of your job:

Job Title

Details

8. Which region of the UK do you work in?

9. Which County or London Borough do you work in?

10. For this study we would like to interview a small number of clinicians from different areas **If you are a GP or clinician and you see/treat patients 18 years old or older with ADHD** would you be willing to be contacted about taking part in a short telephone \*interview? If so please provide contact details below:

\*If selected, this would be about your experiences in general of transition and/or referral of young adults with ADHD into adult services.

Name	<input type="text"/>
Job Role	<input type="text"/>
Contact Telephone Number	<input type="text"/>
Email Address	<input type="text"/>

11. Where you work are there NHS provided mental health services for people aged 18 years and above with ADHD?

- Yes
- No
- Don't know



**CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

12. Please provide as many details as you can about the service\* or services (either the name, the postcode or the town).

\*A service could be your specialist doctor, a hospital, a clinic or a support group

Service 1	<input type="text"/>
Service 2	<input type="text"/>
Service 3	<input type="text"/>

### 13. Details of the service\*

\*This question is optional. If you don't know how to answer it then move on to the next question

	Is this service provided by	Is this service a part of
Service 1	<input type="text"/>	<input type="text"/>
Service 2	<input type="text"/>	<input type="text"/>
Service 3	<input type="text"/>	<input type="text"/>

If you have other details please add them here:

### 14. Do these services offer (answer all that apply):\*

\*This question is optional. If you don't know how to answer it then move on to the next question

	Assessment	Diagnosis
Service 1	<input type="text"/>	<input type="text"/>
Service 2	<input type="text"/>	<input type="text"/>
Service 3	<input type="text"/>	<input type="text"/>

Other (please specify)

### 15. Do these services offer (answer all that apply):\*

\*This question is optional. If you don't know how to answer it then move on to the next question

	Treatment (Medication)	Treatment (Other Intervention)
Service 1	<input type="text"/>	<input type="text"/>
Service 2	<input type="text"/>	<input type="text"/>
Service 3	<input type="text"/>	<input type="text"/>

Other (please specify)



**CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Thank you!

16. If you would like to add anything to your answers, please comment below:

Thank you for your help. A report on this study is expected in 2019 and full details will be available on the website. If you have any queries about the CATCH-uS study, please visit our website: <http://medicine.exeter.ac.uk/catchus/>

# Psychiatrists



CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services

Mapping the availability of services for young people with ADHD

**IF YOU ARE A PSYCHIATRIST PLEASE CONTINUE. IF YOU ARE NOT PLEASE FOLLOW THIS OTHER SURVEY LINK: [https://www.surveymonkey.co.uk/r/CATCH-uS\\_SU](https://www.surveymonkey.co.uk/r/CATCH-uS_SU).**

The CATCH-uS study is funded by the National Institute for Health Research and has ethical approval. Details can be found on our [website](#). The aim of this survey is to map available services for young people with Attention Deficit Hyperactivity Disorder (ADHD) who are aged 18 and over. The focus is on service provision and no personal or identifiable data will be shared. Data gathered will be used to create a map of current services and will feed into the overall CATCH-uS study aims of informing and improving service provision for this vulnerable group.

Please answer the following questions to help us map available ADHD services in the UK. The survey should take no longer than 5 minutes to complete.

1. Are you

- Child and Adolescent Psychiatrist
- General Adult Psychiatrist
- Trainee Registrar in Psychiatry
- Other (please specify)

2. Please indicate your grade

- Trainee
- Staff Grade / Associate Specialist / Trust Doctor
- Consultant
- Other (please specify)

3. In which of the following sectors do you work? (Tick all that apply)

- Private Sector
- Private Provider for NHS
- Community Interest Company (or equivalent) for NHS
- NHS
- Other (please specify)

4. Which region of the UK do you work in?

5. Which County or London Borough do you work in?

6. Where you work, are there NHS provided mental health services for people aged 18 years and above with ADHD?

- Yes
- No
- Don't know



**CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

**Mapping the availability of services for young people with ADHD**

7. Please provide as many details of the service or services as possible (postcode, town, website):

Service 1

Service 2

Service 3

8. Details of the service

	Is the service provided by staff	Is this service a part of
Service 1	<input type="text"/>	<input type="text"/>
Service 2	<input type="text"/>	<input type="text"/>
Service 3	<input type="text"/>	<input type="text"/>

9. Do these services offer (answer all that apply)

	Assessment	Diagnosis	Treatment (Medication)	Treatment (Other Intervention)
Service 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Service 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Service 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>



CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services

Thank you!

10. For this study we would like to interview a small number of clinicians from different areas. If you see/treat patients 18 years old or older with ADHD and would be willing to take part in a short telephone \*interview, please could you provide your contact details below:

\*If selected, this would be about your experiences in general of transition and/or referral of young adults with ADHD into adult services.

Name

Contact Telephone Number

Email Address

11. If you would like to elaborate on any of your answers, please provide comments below:

Thank you for your help. A report on this study is expected in 2019 and full details will be available on the website. If you have any queries about the CATCH-uS study, please visit our website: <http://medicine.exeter.ac.uk/catchus/>.

# Paediatricians



## Paediatrics - CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services

Mapping the availability of services for young people with ADHD

**IF YOU ARE A PAEDIATRICIAN PLEASE CONTINUE. IF YOU ARE NOT PLEASE FOLLOW THIS OTHER SURVEY LINK: [https://www.surveymonkey.co.uk/r/CATCH-uS\\_SU](https://www.surveymonkey.co.uk/r/CATCH-uS_SU).**

The CATCH-uS study is funded by the National Institute for Health Research and has ethical approval. Details can be found on our [website](#). The aim of this survey is to map available services for young people with Attention Deficit Hyperactivity Disorder (ADHD) who are aged 18 and over. The focus is on service provision and no personal or identifiable data will be shared. Data gathered will be used to create a map of current services and will feed into the overall CATCH-uS study aims of informing and improving service provision for this vulnerable group.

Please answer the following questions to help us map available ADHD services in the UK. The survey should take no longer than 5 minutes to complete.

1. Are you

- Community Child Health Paediatrician
- General Paediatrician
- Registrar / Speciality Trainee in Paediatrics
- Paediatric Neurologist
- Paediatrician in Neurodisability
- Different Paediatric Specialist or Other (please specify)

2. Please indicate your grade

- Consultant
- Staff Grade / Associate Specialist / Trust Doctor
- Trainee
- Other (please specify)

3. In which of the following sectors do you work? (Tick all that apply)

- Private Sector
- Private Provider for NHS
- Community Interest Company (or equivalent) for NHS
- NHS
- Academia
- Other (please specify)

4. Which region of the UK do you work in?

5. Which County or London Borough do you work in?

6. Do you see children/adolescents with ADHD?

- Yes
- No
- Other (please specify)



**Paediatrics - CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

7. Where do you refer children with ADHD (with or without co-morbidities) who reach the age boundary for paediatric services on to? (tick all that apply)

- Adult Mental Health Services
- Specialist ADHD clinic or service
- Learning Disability Service
- Youth or Young People Mental Health Service
- GP
- Don't know
- No service

Other (please specify)

8. Do you have any additional comments on the question above?



**Paediatrics - CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

9. Are there NHS provided mental health services for people aged 18 years and above with ADHD in your area?

- Yes
- No
- Don't know



**Paediatrics - CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

10. Please provide as many details of the service or services as possible (postcode, town, website):

Service 1	<input type="text"/>
Service 2	<input type="text"/>
Service 3	<input type="text"/>

11. Details of the service

	Is the service provided by staff	Is this service a part of
Service 1	<input type="text"/>	<input type="text"/>
Service 2	<input type="text"/>	<input type="text"/>
Service 3	<input type="text"/>	<input type="text"/>

12. Do these services offer (answer all that apply)

	Assessment	Diagnosis	Treatment (Medication)	Treatment (Other Intervention)
Service 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Service 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Service 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>



**Paediatrics - CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Thank you!

13. If you would like to elaborate on any of your answers, please provide comments below:

Thank you for your help. A report on this study is expected in 2019 and full details will be available on the website. If you have any queries about the CATCH-uS study, please visit our website: <http://medicine.exeter.ac.uk/catchus/>

## General practitioners



### CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services

Mapping the availability of services for young people with ADHD

**IF YOU ARE A GP PLEASE CONTINUE. IF YOU ARE NOT PLEASE FOLLOW THIS OTHER SURVEY LINK: [https://www.surveymonkey.co.uk/r/CATCH-uS\\_SU](https://www.surveymonkey.co.uk/r/CATCH-uS_SU).**

The CATCH-uS study is funded by the National Institute for Health Research and has ethical approval. Details can be found on our [website](#). The aim of this survey is to map available services for young people with Attention Deficit Hyperactivity Disorder (ADHD) who are aged 18 and over. The focus is on service provision and no personal or identifiable data will be shared. Data gathered will be used to create a map of current services and will feed into the overall CATCH-uS study aims of informing and improving service provision for this vulnerable group.

Please answer the following questions to help us map available ADHD services in the UK. The survey should take no longer than 5 minutes to complete.

1. Are you

- General Practitioner
- General Practitioner Registrar
- Other (please specify)

2. Do you have a special interest or extended role in mental health?

- Yes
- No

Comments

3. Do you have a role in commissioning NHS services?

- Yes
- No



### CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services

Mapping the availability of services for young people with ADHD

4. If yes, please provide

Name of Clinical Commissioning Group

Your job role/title within the CCG

5. In which of the following sectors do you work? (tick all that apply)

- Private Sector
- Private Provider for NHS
- Community Interest Company (or equivalent) for NHS
- NHS
- Academia
- Other (please specify)

6. Which region of the UK do you work in?

7. Which County or London Borough do you work in?

8. Are you actively involved in the management of ADHD in any of your patients (child and/or adult) (for example by prescribing)?

- Yes
- No

Comments



**CATCh-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

9. How do you manage the ADHD symptoms of children and adolescents with ADHD? (tick all that apply)

- In collaboration with Paediatric Services
- In collaboration with Child and Adolescent Mental Health Services
- In collaboration with Learning Disability Services
- In collaboration with Specialist ADHD Services
- I manage their ADHD symptoms myself, without specialist support
- I don't manage their ADHD symptoms as there is not a specialist service to collaborate with
- Other (please specify)

10. How do you manage the ADHD symptoms of young adults with ADHD who are aged 18 and above? (tick all that apply)

- In collaboration with Adult Mental Health Services
- In collaboration with a Specialist ADHD clinic or service
- In collaboration with a Learning Disability Service
- In collaboration with a Youth or Young People Mental Health Service
- I manage their ADHD symptoms myself, without specialist support
- I don't manage their ADHD symptoms as there is not a specialist service to collaborate with
- Don't know

Other (please specify)

11. Do you have any additional comments on the question above?



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Mapping the availability of services for young people with ADHD

12. Are there NHS provided mental health services for people aged 18 years and above with ADHD in your area?

- Yes
- No
- Don't know



**CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

13. Please provide as many details of the service or services as possible (postcode, town, website):

Service 1	<input type="text"/>
Service 2	<input type="text"/>
Service 3	<input type="text"/>

14. Details of the service

	Is the service provided by staff	Is this service a part of
Service 1	<input type="text"/>	<input type="text"/>
Service 2	<input type="text"/>	<input type="text"/>
Service 3	<input type="text"/>	<input type="text"/>

15. Do these services offer (answer all that apply)

	Assessment	Diagnosis	Treatment (Medication)	Treatment (Other Intervention)
Service 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Service 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Service 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>



**CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

16. For this study we would like to interview a small number of clinicians from different areas. If selected, would you be willing to be contacted about taking part in a short telephone interview?

\*This would be about your experiences in general of transition and/or referral of young adults with ADHD into adult services.

- Yes  
 No



**CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Mapping the availability of services for young people with ADHD

17. Please provide your contact details

Name   
Contact Telephone Number

18. Please provide your email address:

Email Address



**CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services**

Thank you!

19. If you would like to elaborate on any of your answers, please provide comments below:

Thank you for your help. A report on this study is expected in 2019 and full details will be available on the website. If you have any queries about the CATCH-uS study, please visit our website: <http://medicine.exeter.ac.uk/catchus/>.

## Appendix 8: mapping study – 2018 survey

1



2018 CATCH-uS: Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children's services and adult services

Mapping the availability of services for people aged 18 and above with ADHD

The CATCH-uS study is funded by the National Institute for Health Research and has ethical approval. Details can be found on our [website](#). The aim of this survey is to map available services for people with Attention Deficit Hyperactivity Disorder (ADHD) who are aged 18 and over. This is to inform and improve service provision for young adults with ADHD. We only want to know about services you are aware of and/or have used for the management of ADHD. We will not share any of your personal information. The survey is anonymous and confidential. Answers will help to update a list of existing services, available [here](#).

The survey should take no longer than 5 minutes to complete.

Example of website with service details...



\* Are you...?

(Please choose whichever describes you best)

- Young person with ADHD (up to 17 years old)
- Adult with ADHD (aged 18+)
- Parent/carer/partner of someone with ADHD
- In an ADHD support role (e.g. voluntary, support work or training)
- Paediatrician
- Psychiatrist
- Clinical Psychologist
- Educational Practitioner (e.g. Support worker, Teacher, Behavioural Support, Ed Psych, EWO)

- Nurse
- GP
- Manager
- Allied Health Professional
- Researcher or Academic
- Administrator
- Clinical Commissioner
- Other (please specify)

Are you also...?

(If any of the options below also describe you, please tick all that apply)

- Young person with ADHD (up to 17 years old)
- Adult with ADHD (aged 18+)
- Parent/carer/partner of someone with ADHD
- In an ADHD support role (e.g. voluntary, support work or training)
- Paediatrician
- Psychiatrist
- Clinical Psychologist
- Educational Practitioner (e.g. Support worker, Teacher, Behavioural Support, Ed Psych, EWO)
- Nurse
- GP
- Manager
- Allied Health Professional
- Researcher or Academic
- Administrator
- Clinical Commissioner
- Other (please specify)

If you work with people with ADHD please answer the following question i(f not, please skip).

Which of the following sectors do you work in?

(Tick all that apply)

- Academia or Research
- Community Interest Company (or equivalent) providing for NHS
- NHS
- Private Provider for NHS
- Private Sector
- Voluntary Sector
- Education
- Other (please specify)

\* Do you know of any mental health services\* (provided by NHS or other organisations) for people with ADHD aged 18+?

- Yes
- No

\*A service could be NHS, private, a transition team, a charity or support group.

UK regions...



We want to know who is responding to our survey, so please let us know where you live\*. All information will be treated confidentially, with data stored securely and only used for the purpose of mapping areas responses come from.

\* What is your postcode?

(For example EX1 2LU)

\* Which region of the UK are you based in?

\*If you are a clinician or working with people with ADHD, please choose the postcode and region of your workplace.

### Northern Ireland: Mapping the availability of services for people aged 18 and above with ADHD

Here is a list of services that were identified in our 2016 survey. Please tick the services that you believe treat or support adults with ADHD.

(NOTE: not all of these have confirmed that they treat adult ADHD)

- ADHD Foundation; National Charity, L2 2AH
- Belfast Health & Social Care Trust; 'CAMHS', BT97AB
- MIND; National Charity, E15 4BQ
- NHS England; National Service 'Improving Access to Psychological Therapies (IAPT)', Mental Health Trlage, LS2 7UE
- Northern Health & Social Care Trust; 'CAMHS', BT41 2QB
- Northern Health & Social Care Trust; 'Community Mental Health', BT41 4AB
- Northern Health & Social Care Trust; Learning Disability, BT38 8AZ
- Northern Ireland & Southern Health & Social Care Trust; 'Outpatient Psychiatry Centre', BT61 7QG
- South Eastern Health & Social Care Trust; 'Adult services', BT28 1JP
- South London & Maudsley NHS FT; National Adult ADHD Service, SE5 8AZ
- Western Health & Social Care Trust; 'Primary Care Liaison Service', BT47 6SB
- Western Health & Social Care Trust; 'Recovery Mental Health Team', Adult Service, BT47 6AU

If none of the above, please click next.

**Are there any services\* missing from the previous list that you know treat or support adults with ADHD? If YES, please complete as many details as possible below.**

**\*A service could be NHS, private, a transition team, a charity or support group.**

Service 1

Name	<input type="text"/>
Postcode	<input type="text"/>
Town/City	<input type="text"/>
Website Link	<input type="text"/>
Other identifying information	<input type="text"/>

Have you, or do you know someone aged 18+ who has received treatment or support at this service for their ADHD?

Yes

No

Service 2

Name

Postcode

Town/City

Website Link

Other Identifying Information

Have you, or do you know someone aged 18+ who has received treatment or support at this service for their ADHD?

Yes

No

Service 3

Name

Postcode

Town/City

Website Link

Other Identifying Information

Have you, or do you know someone aged 18+ who has received treatment or support at this service for their ADHD?

Yes

No

UK regions...



We want to know who is responding to our survey, so please let us know where you live\*. All information will be treated confidentially, with data stored securely and only used for the purpose of mapping areas responses come from.

\* What is your postcode?  
(For example EX1 2LU)

\* Which region of the UK are you based in?

\*if you are a clinician or working with people with ADHD, please choose the postcode and region of your workplace.

# Thank you!

If you would like to add anything to your answers, please comment below:

Do you want to hear about findings from this study? If so, please enter your email address below and we will send you a link to the final report (expected early 2019). We will only use your email address to share our findings with you.

Full details, including the list of ADHD services can be found on the mapping page of our website <http://medicine.exeter.ac.uk/catchus/>. Twitter: [#catchusADHD](https://twitter.com/catchusADHD).

Thank you for completing this survey.

## Appendix 9: mapping study – key research partners

<b>Name</b>	<b>Abbreviation</b>	<b>Website</b>
AADD-UK The site for and by adults with ADHD	AADD-UK	<a href="https://aadduk.org/">https://aadduk.org/</a>
ADHD Foundation		<a href="https://www.adhdfoundation.org.uk/">https://www.adhdfoundation.org.uk/</a>
Association for Child and Adolescent Mental Health	ACAMH	<a href="https://www.acamh.org/">https://www.acamh.org/</a>
British Association for Community Child Health	BACCH	<a href="http://www.bacch.org.uk/index.php">http://www.bacch.org.uk/index.php</a>
Collaboration for Leadership in Applied Health Research and Care South West Peninsula	PenCLAHRC	<a href="http://clahrc-peninsula.nihr.ac.uk/">http://clahrc-peninsula.nihr.ac.uk/</a>
PenCRU: CATCh-uS Parent Advisory Group		<a href="http://www.pencru.org/getinvolved/ourfamilyfaculty/">http://www.pencru.org/getinvolved/ourfamilyfaculty/</a>
Clinical Research Network, England	CRN	<a href="https://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/crn/">https://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/crn/</a>
Clinical Research Network South West Peninsula	CRN SW	<a href="https://www.nihr.ac.uk/nihr-in-your-area/south-west-peninsula/">https://www.nihr.ac.uk/nihr-in-your-area/south-west-peninsula/</a>
Mental Health Commissioners Network	MHCN	<a href="https://www.nhsc.org/networks/mental-health-commissioners/">https://www.nhsc.org/networks/mental-health-commissioners/</a>
Royal College of General Practitioners	RCGPs	<a href="http://www.rcgp.org.uk/">http://www.rcgp.org.uk/</a>
Royal College of Psychiatrists	RCPsych	<a href="https://www.rcpsych.ac.uk/">https://www.rcpsych.ac.uk/</a>
UK Adult ADHD Network	UK-AAN	<a href="https://www.ukaan.org/">https://www.ukaan.org/</a>

## Appendix 10: mapping study – FOI requests to service providers

Dear Sir/Madam

Please provide the following information about services provided by your Trust\* for adults (people aged 18 and above) with Attention Deficit Hyperactivity Disorder (ADHD).

\*If you provide FOI for more than one MHT, please answer questions separately for **every** MHT you represent. This is a national survey so we want to know about all MHTs in England and we have only contacted FOI email addresses once, to avoid duplication of workload.

### **2018 Survey for the ‘Children and adolescents with Attention Deficit Hyperactivity Disorder in transition between children’s services and adult services’ (CATCh-uS) study.**

The CATCh-uS study is funded by the National Institute for Health Research and has ethical approval. Details can be found on our [website \(http://medicine.exeter.ac.uk/catchus/\)](http://medicine.exeter.ac.uk/catchus/). Answers will help to update a list of existing services, available [here \(http://medicine.exeter.ac.uk/catchus/mapping/adhdservices/\)](http://medicine.exeter.ac.uk/catchus/mapping/adhdservices/).

Thank you in advance for your support.

<b>Part 1: Overview</b>
Which Health Trust (MHT) do you represent? a. Name: b. Postcode:
Who is responsible for provision of adult ADHD mental health services in your trust? (e.g. lead for mental health services or head of department) c. Name: d. Email Address: e. Job Role:
Which NHS England region is your Trust part of? f. London g. Midlands and East of England h. North of England i. South West England j. South East England
Which region of England is your trust in? k. East Midlands l. Eastern m. London n. North East o. North West

<ul style="list-style-type: none"> <li>p. South East</li> <li>q. South West</li> <li>r. West Midlands</li> <li>s. Yorkshire and the Humber</li> </ul>
<p>Does your Trust provide services for people with ADHD aged 18 years and above?</p> <ul style="list-style-type: none"> <li>t. Yes</li> <li>u. No</li> <li>Other (please specify)</li> </ul> <p>If yes, please provide details below for each service.</p>
<p>In practice, does your Trust accept patients aged 18 and above for treatment for their ADHD?</p> <ul style="list-style-type: none"> <li>v. Yes</li> <li>w. No</li> <li>x. Other (please specify):</li> </ul>

<p><b>Part 2: Service details - Service 1</b></p>
<p>Service 1</p>
<ul style="list-style-type: none"> <li>a. Name:</li> <li>b. Town:</li> <li>c. Website:</li> <li>d. Service Main/Administrative Postcode:</li> <li>e. Postcode/s of <b>all</b> locations where patients can access treatment:</li> </ul>
<p>Service type (<i>please indicate which and details if a specialist service</i>):</p> <ul style="list-style-type: none"> <li>a. Generic Adult Mental Health Service</li> <li>b. Specialist Mental Health Service <ul style="list-style-type: none"> <li>a. ADHD</li> <li>b. ADHD &amp; ASD</li> <li>c. ASD</li> <li>d. Neurodevelopmental</li> <li>e. Learning Disability</li> <li>f. Other (<i>please provide details</i>):</li> </ul> </li> <li>c. Other (<i>please provide details</i>):</li> </ul> <p>Ages served:</p> <ul style="list-style-type: none"> <li>d. Upper age boundary?</li> <li>e. Lower age boundary?</li> </ul>
<p>Adult ADHD Services (<i>please indicate</i>):</p> <ul style="list-style-type: none"> <li>a. Transitional Care (<i>arrangements for transition of care from child to adult services</i>)</li> <li>b. Diagnosis</li> <li>c. Medication management</li> </ul>

<p><i>(initial prescription, titration and/or monitoring &amp; oversight)</i></p> <p>d. Ongoing prescribing of ADHD medication <i>(provided directly by this service)</i></p> <p>e. Shared care <i>(agreement with local physicians to prescribe, with monitoring by this service)</i></p> <p>f. Psychological treatment</p> <p>g. Other, such as support groups... <i>(please provide details)</i></p>
<p>Commissioning:</p> <p>a. Which Clinical Commissioning Groups (CCGs) commission this service? <i>(names in full)</i></p> <p>b. Are patients from other CCGs or regions also able to access this service? <i>Y/N? (If yes, please provide details)</i></p>

<p><b>Part 2: Service details - Service 2</b></p>
<p>Service 2</p>
<p>f. Name:</p> <p>g. Town:</p> <p>h. Website:</p> <p>i. Service Main/Administrative Postcode:</p> <p>j. Postcode/s of <b>all</b> locations where patients can access treatment:</p>
<p>Service type <i>(please indicate which and details if a specialist service):</i></p> <p>f. Generic Adult Mental Health Service</p> <p>g. Specialist Mental Health Service</p> <p>    a. ADHD</p> <p>    b. ADHD &amp; ASD</p> <p>    c. ASD</p> <p>    d. Neurodevelopmental</p> <p>    e. Learning Disability</p> <p>    f. Other <i>(please provide details):</i></p> <p>h. Other <i>(please provide details):</i></p> <p>Ages served:</p> <p>    i. Upper age boundary?</p> <p>    j. Lower age boundary?</p>
<p>Adult ADHD Services <i>(please indicate):</i></p> <p>h. Transitional Care <i>(arrangements for transition of care from child to adult services)</i></p> <p>i. Diagnosis</p>

- j. Medication management  
*(initial prescription, titration and/or monitoring & oversight)*
- k. Ongoing prescribing of ADHD medication  
*(provided directly by this service)*
- l. Shared care  
*(agreement with local physicians to prescribe, with monitoring by this service)*
- m. Psychological treatment
- n. Other, such as support groups...  
*(please provide details)*

Commissioning:

- c. Which Clinical Commissioning Groups (CCGs) commission this service?  
*(names in full)*
- d. Are patients from other CCGs or regions also able to access this service?  
*Y/N? (If yes, please provide details)*

**Part 2: Service details - Service 3**

Service 3

- k. Name:
- l. Town:
- m. Website:
- n. Service Main/Administrative Postcode:
- o. Postcode/s of **all** locations where patients can access treatment:

Service type *(please indicate which and details if a specialist service):*

- k. Generic Adult Mental Health Service
  - l. Specialist Mental Health Service
    - a. ADHD
    - b. ADHD & ASD
    - c. ASD
    - d. Neurodevelopmental
    - e. Learning Disability
    - f. Other *(please provide details):*
  - m. Other *(please provide details):*
- Ages served:

- n. Upper age boundary?
- o. Lower age boundary?

Adult ADHD Services *(please indicate):*

- o. Transitional Care  
*(arrangements for transition of care from child to adult services)*

- p. Diagnosis
- q. Medication management  
*(initial prescription, titration and/or monitoring & oversight)*
- r. Ongoing prescribing of ADHD medication  
*(provided directly by this service)*
- s. Shared care  
*(agreement with local physicians to prescribe, with monitoring by this service)*
- t. Psychological treatment
- u. Other, such as support groups...  
*(please provide details)*

Commissioning:

- e. Which Clinical Commissioning Groups (CCGs) commission this service?  
*(names in full)*
  
- f. Are patients from other CCGs or regions also able to access this service?  
*Y/N? (If yes, please provide details)*

**Part 2: Service details - Service 4 onwards...**

Please duplicate the forms above to provide details for as many mental health services as your trust/board provides for people with ADHD aged 18 years and above...

## Appendix 11: mapping study – categorisation of informants

<b>Stakeholder Group</b>	<b>Role</b>
Commissioner	Clinical Commissioner
Health Worker	Administrator (e.g. of clinic or health practice)
Health Worker	Allied Health Professional
Health Worker	Clinical Psychologist
Health Worker	General Practitioner
Health Worker	In an ADHD support role (e.g. voluntary, support work or training)
Health Worker	Manager (e.g. of clinic or health practice)
Health Worker	Nurse
Health Worker	Paediatrician
Health Worker	Psychiatrist
Other	Educational Practitioner (e.g. Support Worker, Teacher, Behavioural Support, Educational Psychologist, Education Welfare Officer)
Other	Other (please specify)
Other	Researcher or Academic
Service User	Adult with ADHD (aged 18 and above)
Service User	Parent/carer/partner of someone with ADHD
Service User	Young person with ADHD (up to 17 years old)

## Appendix 12: mapping study – email sent via organisational mailing lists

**Subject:** CATCh-uS: 5 minute NIHR Survey to map adult ADHD services

Dear Doctor,

Please help us to map the services currently available to people with Attention Deficit Hyperactivity Disorder (ADHD) who are aged 18+. This national survey should take less than 5 minutes of your time.

<https://www.surveymonkey.co.uk/r/adultADHDservices2018>

Please open the survey even if you are not aware of any services in your area. Then forward to any relevant colleagues. The survey is anonymous and forms a part of the '*Children and Adolescents with ADHD in Transition between Children's services and adult Services*' (CATCh-uS) study which is funded by the National Institute for Health Research and has been approved by NHS REC (Reference: 15/YH/0426). Thank you very much for your help. Visit the research's team website, <http://medicine.exeter.ac.uk/catchus/mapping/> or the Royal College of Psychiatrists' website, <http://www.rcpsych.ac.uk/quality/research/capss/currentstudies.aspx> for more information.

Twitter: #catchusADHD

Yours sincerely

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