# Service use and unmet mental health need in children and young adults: analysis of three years of follow up from the 2004 British Child and Adolescent Mental Health Survey & description of primary care psychotropic prescribing & transition in young adults with Attention Deficit Hyperactivity Disorder

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I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature: Tamsin Newlove-Delgado

# Abstract

This thesis aimed to examine service contact among children and young people with mental health problems, and has three complementary parts. The first is a secondary analysis of data from the British Child and Adolescent Mental Health Survey (BCAMHS) 2004, which explored mental health related service contact in relation to psychopathology over three years. The second and third parts focussed on young people with ADHD in transition from child services, which is a particularly challenging time. This involved a qualitative interview study of young peoples' experiences, and an analysis of primary care prescribing of ADHD medication over the transition period using a cohort from the Clinical Practice Research Datalink from 2005-2013.

Less than a third of children with a psychiatric disorder in BCAMHS reported contact with child mental health services. Instead, teachers were the most frequently used service, with two-thirds reporting mental health related contact. Interviews with young people with ADHD highlighted themes including concerns around medication management post transition and need for information. The prescribing analysis found that the majority of adolescents on ADHD medication at age 16 stopped during the transition period. This continuing disparity between estimates of symptom persistence and medication persistence suggests that many may be stopping medication from which they could still benefit; as various barriers have been identified to ongoing prescribing.

In summary, the findings of these three linked studies suggest common themes in terms of unmet needs and gaps between policy and practice in mental health services for children and young people. One of the chief implications is the need for oversight and policy levers to ensure the implementation of best practice, accompanied by complementary efforts to better understand and overcome other barriers to providing optimal care, including research into knowledge and attitudes of different groups and the provision of targeted training.

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# List of common abbreviations and definitions

| | |
|---|---|
| ADHD | Attention Deficit Hyperactivity Disorder |
| AMHS | Adult Mental Health Services |
| ASD | Autism Spectrum Disorders |
| BCAMHS | British Child and Adolescent Mental Health Survey |
| BNF | British National Formulary |
| CADDY study | Cessation of Attention Deficit Hyperactivity Disorder Drugs in the Young study (Wong *et al.* 2009) |
| CAMHS | Child and Adolescent Mental Health Services |
| CBT | Cognitive Behavioural Therapy |
| CCG | Clinical Commissioning Group |
| CD | Conduct Disorder |
| CI | Confidence Interval |
| CMO | Chief Medical Officer |
| CPRD | Clinical Practice Research Datalink |
| DAWBA | Development and Wellbeing Assessment |
| DSM-IV | Diagnostic and Statistical Manual of Mental Disorders version 4 (American Psychiatric Association, 2000) |
| GHQ | General Health Questionnaire |
| GP | General Practitioner |
| IAPT | Improving Access to Psychological Therapies |
| ICD-10 | International Classification of Diseases version 10 (World Health Organisation, 1992 ) |
| LD | Learning Disability |
| NICE | National Institute for Health and Care Excellence |
| NIHR | National Institute for Health Research |
| NS-SEC | National Statistics Socio-economic Classification |
| ODD | Oppositional Defiant Disorder |

| | |
|---|---|
| OR | Odds Ratio |
| PDD | Pervasive Developmental Disorder |
| SD | Standard Deviation |
| SDQ | Strengths and Difficulties Questionnaire |
| TRACK study | Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services study (Singh *et al.* 2010) |

# Chapter One: Introduction

My thesis focusses on two aspects of service provision for children and young people with psychiatric disorders in the UK. The first is mental health related service contact in school aged children and the trajectories of psychopathology over time of children in contact with services. The second is transition from child to adult services in young people with Attention Deficit Hyperactivity Disorder (ADHD). The following chapter briefly introduces the context and background necessary to understand both and presents the main aims and justification for the three constituent studies. The policy and research background to the topics is then reviewed and discussed in further detail in Chapter Two.

## 1.1 Context

### 1.1.1 Psychiatric disorders in children and adolescents: prevalence and impact

According to the first and second British Child and Adolescent Mental Health Surveys in 1999 and 2004, approximately one in ten children aged 5-16 in the UK has a psychiatric disorder (Meltzer *et al.* 2000, Green *et al.* 2005), a figure which is in line with global estimates of prevalence (Costello *et al.* 2005). The most common disorders reported in the 2004 British survey were conduct disorders (5.8%) and anxiety disorders (3.3 %); with approximately a quarter of those with a disorder experiencing comorbidity (Green *et al.* 2005). Prospective analysis of children with psychiatric disorders in the Great Smoky Mountains Study by Copeland *et al.* (2009) also found childhood disorders to be predictive of adult disorders. This prediction occurred both homotypically, e.g. depression predicting later depression, and heterotypically, where childhood disorder predicted different adult disorders (Copeland *et al.* 2009). In retrospective analysis of the Dunedin cohort, approximately half of adults with a psychiatric disorder aged 26 had first met diagnostic criteria between the ages of 11-15 years, and almost three-quarters had symptoms by the age of 18 (Kim-Cohen *et al.* 2003). Adolescence is therefore a key time for the emergence of psychiatric disorders, which emphasises the importance of early identification and management as part of a life course approach.

In addition to the risk of psychiatric disorder in adulthood, young people with mental health problems are more likely to experience a range of other adverse outcomes, which are not only confined to those meeting criteria for a diagnosis but may also affect those with sub-threshold symptoms (Copeland *et al.* 2015). These include: exclusion from school, educational and occupational underachievement, relationship difficulties and poorer physical health (Fergusson and Woodward 2002, Fergusson *et al.* 2009, Richards and Abbott 2009, Gibb *et al.* 2010, Klein *et al.* 2012, Costello and Maughan 2015, Parker *et al.* 2015). The association between socio-economic disadvantage and poorer mental health also means that these adverse impacts are more likely to affect children who are already vulnerable (Davis *et al.* 2010, Boe *et al.* 2012, Reiss 2013). The costs to society in terms of perpetuated inequality and lost potential are substantial. In economic terms the costs of childhood psychiatric disorder to health, social care and education are estimated to reach over one billion pounds per year in the UK, with the majority of the cost falling on frontline education and special education services (Snell *et al.* 2013).

### 1.1.2 Need for healthcare

This thesis is concerned with the unmet mental healthcare needs of children and young people with psychiatric disorders. Acheson (1978) discusses two early definitions of needs for healthcare: firstly as being any ‘disturbance of health and wellbeing’ (the ‘humanitarian model’ first proposed by Donabedian); or secondly as existing only where there is some capacity to benefit from medical intervention ‘*at reasonable cost’*. The latter definition is one that is more commonly used, with or without the ‘reasonable cost’ caveat, which represents an entire field of health economic study and therefore may be highly subject to the context of resources and prioritisation. The World Health Organisation (2016) also uses three further definitions. Firstly, perceived healthcare needs, defined as: ‘the need for health services as experienced by the individual and which he/she is prepared to acknowledge’. Secondly, professionally defined health needs, defined as: ‘the need for health services as recognized by health professionals from the point of view of the benefit obtainable from advice, preventive measures, management or specific therapy’. Thirdly, scientific need, which was defined as need ‘considered to correspond to those conditions that can be classified in accordance with the International Classification of Diseases’.

Demand exists where needs are felt and expressed by the patient – i.e. where patients ask for or attend services (Wright *et al.* 1998). Demand is strongly influenced by individual and group illness behaviour, media attention, knowledge of services, and indeed the supply of services, and hence is not a proxy for need. The supply of services is dependent on professional interests, historical configurations, national and local resources and prioritisation, and is also affected by demand. Consequently, need, supply and demand are interdependent and overlapping concepts.

The prevalence and impact of psychiatric disorders in childhood and the existence of effective interventions (see 1.1.4 below) indicates that there is a need for child mental healthcare in both a humanitarian sense and in terms of children's capacity to benefit. Healthcare is of course delivered by services, which will provide 'service equivalents' to meet a need where available such as therapy for an anxiety disorder (Acheson 1978). Unmet need in this case could therefore be simply defined as occurring where children who could benefit from a service providing healthcare do not receive such a service. This definition is complicated somewhat by the question of whether the service provided is also effective. Contact with services does not necessarily imply that all needs are met, depending on whether coming into contact with this service is *beneficial* for the patient, and in what way. This question is introduced briefly below, and discussed in more depth in Chapter Two.

### 1.1.3 Services for children with mental health problems

Services for children with mental health problems have traditionally been conceptualised as existing in four 'tiers' (NHS Health Advisory Service 1995) (see Figure 1.1 below). The first consists of 'universal services' provided by GPs and teachers, and by other statutory or third sector practitioners such as youth workers, who to varying degrees will promote mental health and identify and manage less severe problems. Second-tier services involve 'targeted services' provided by single discipline teams and professionals such as primary mental health workers, school counsellors, or educational psychologists. Third-tier services are defined as specialist child mental health teams, which are community based and multidisciplinary (referred to as Tier 3 Child and Adolescent Mental Health Services or CAMHS). Finally, inpatient services and highly specialist teams, such as child eating disorders teams, constitute fourth tier CAMHS.

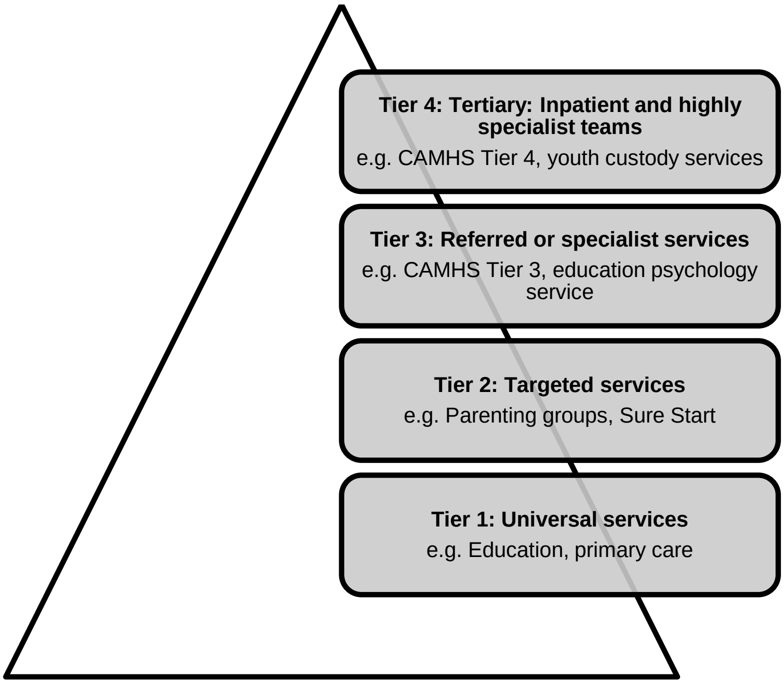


**Figure 1.1: The tiered model of services for children with mental health problems**

### 1.1.4 Mental health related contact with services

There has been a recent expansion in the collection of data regarding mental health service contacts in children, such as the CAMHS Benchmarking Reports introduced in 2011, and the forthcoming CAMHS Minimum Dataset, which will provide data on activity, evidence based interventions and outcomes in CAMHS from early 2016 (Health and Social Care Information Centre 2016a). However, there remain as yet no integrated routine administrative datasets to describe and collate mental health related contacts across the breadth of services that children use such as schools, primary care, paediatrics and CAMHS. Estimates of the prevalence of contact with services have therefore historically come from parent reports of contact using population survey methods. The 1999 British Child and Adolescent Mental Health Survey (BCAMHS) found that a large minority (42%) of children meeting criteria for a psychiatric disorder had no contact with any services regarding their mental health over the three year follow up period (Ford *et al.* 2007b). These figures imply a considerable degree of unmet need which has been increasingly acknowledged by reports including the Child and Adolescent Mental Health Review in 2008

(Department of Health 2008a). More recently, the House of Commons Health Select Committee (2014) report continued to highlight problems in access to services, high referral thresholds and considerable variations in service quality and delivery across England. The recommendations of these reports are considered further in Section 2.1.8: Current policy and recommendations, alongside other recent policy.

### 1.1.5 Effectiveness of services

Even for children who do come into contact with services, the effectiveness of the care they receive is yet to be conclusively demonstrated. There is evidence of effectiveness from trials of certain specific interventions targeting child psychiatric disorders such as parent training programmes for conduct disorder, Cognitive Behavioural Therapy (CBT) for anxiety, and medication for children with ADHD, amongst others (Faraone and Buitelaar 2010, Furlong *et al.* 2013, James *et al.* 2015). The Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme, introduced in 2011, aims to increase the delivery of evidence based interventions (NHS England 2016). However, data are currently lacking on whether evidence based interventions are being widely offered within services, and of their quality and outcomes (Davies 2013). The fidelity of adoption of interventions is likely to be highly variable, with a number of barriers to full implementation being identified including training, attitudes, resources, and the increasingly complex caseload in clinical practice (Novins *et al.* 2013). Studies of local datasets from child mental health services suggest that children receiving 'usual care' experience some improvement over the shorter term (Hurst *et al.* 2014, Deighton *et al.* 2015) but without a control group findings are likely to be affected to some extent by measurement phenomena such as attenuation and regression to the mean (see Chapter Two). To interpret data on the effectiveness of services and consider what 'optimal outcomes' might be, it is also necessary to understand the natural trajectories of childhood psychiatric disorders (Costello and Maughan 2015). Longitudinal research demonstrates that children with psychopathology follow a variety of trajectories over time; some experience chronic and severe difficulties, whilst others have more transient problems (Angold *et al.* 2000, Dekker *et al.* 2007, Pingault *et al.* 2011, Chaiton *et al.* 2013). Surveys such as BCAMHS can help to describe the trajectories of psychopathology over time in children using services in a naturalistic setting.

### 1.1.6 Transition from child to adult services

The term ‘transition’ is used to refer to the process of moving from child to adult services. This stage is characterised by multiple transitions within health and social care and education, against the backdrop of social and psychological change taking place in late adolescence. Indeed, the brain is still developing and carrying out activities such as pruning and myelination until the mid-twenties, leading to the introduction of the phase ‘emerging adulthood’ by Arnett (2000) to describe those between 18 and 25 years old. The difficulties of transition for young people with mental health conditions can be compounded by having to contend with multiple significant transitions during the emergence of new psychiatric disorders, for which adolescence is the peak time (Copeland *et al.* 2011), and by a marked cultural divide between child and adult mental health services (McLaren *et al.* 2013).

### 1.1.7 Attention Deficit Hyperactivity Disorder and transition

The second part of this thesis focusses on the needs of young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition, for whom this period may be particularly challenging. ADHD has a multifactorial aetiology, with genetic and environmental risk factors, and is one of the most common childhood psychiatric disorders, with worldwide estimates of prevalence in children at 3.4% (Thapar *et al.* 2012, Polanczyk *et al.* 2015). ADHD has previously been considered a condition affecting only children and younger adolescents, yet follow-up studies estimate that 40-60% of those with the condition experience persistence of symptoms at age 25 (Faraone *et al.* 2006). Simon *et al.* (2009) in their meta-analysis of prevalence studies suggest that approximately 2.5% of adults may meet criteria for ADHD; but the accuracy and applicability of such estimates in adults are likely to be affected by questions about the validity of the diagnostic criteria for adults as well as the known decline in prevalence with increasing age. The latest fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines ADHD as a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development (American Psychiatric Association 2013). In the International Classification of Diseases (ICD-10) the term ‘hyperkinetic disorder’ is used to refer to a more restrictive and severe definition of the equivalent condition; although often this is still referred to as ADHD (World Health Organisation 1992). ADHD also has significant adverse impacts on a wide range of health, social and economic domains

(Hoare and Beattie 2003, Biederman and Faraone 2006, Barkley and Brown 2008, Groenman *et al.* 2013, Kang *et al.* 2013, Chang *et al.* 2014, Dalsgaard *et al.* 2015, Uchida *et al.* 2015, Cortese *et al.* 2016). There are effective treatments for ADHD; with the National Institute for Health and Care Excellence (NICE, 2008b) recommending non-pharmacological management as a first line treatment for children with moderate impairment, and pharmacological treatment as a second line, and for those with more severe impairment. Medication is also effective in adults with ADHD, and is recommended by NICE as a first-line treatment for those affected (NICE 2008b, Faraone and Glatt 2010). A systematic review by Shaw *et al.* (2012) of long term outcomes suggested that wider outcomes ranging from academic attainment to obesity and social functioning were worse in people with untreated ADHD compared to those on treatment, although such outcomes were still poorer than for people without ADHD.

The historical perception of ADHD as a condition confined to children has meant that older adolescents and adults continue to face obstacles to support and treatment after the age of 16 or 18 years. Identified barriers include a lack of services for adults with ADHD where medication may be monitored (Marcer *et al.* 2008, Young *et al.* 2011, Hall *et al.* 2015), and attitudes amongst clinicians; recent research indicates that prescribing for adults with ADHD is still not well established and accepted amongst many professionals (Hall *et al. 2013*, Matheson *et al.* 2013). Previous UK studies of primary care prescribing found that the majority of young people with ADHD stopped medication before the age of 18 (Wong *et al.* 2009, McCarthy *et al.* 2012a), and that the rates of cessation reported were greater than the estimated rate of persistence of ADHD according to Faraone *et al.*'s (2006) meta-analysis of follow-up studies. The TRACK study of transition also concluded that those with neurodevelopmental disorders were a group who were particularly likely to experience ongoing need but did not experience optimal transition (Singh *et al.* 2010a). The impact of stopping treatment and/or disengaging from services may be increased by the vulnerability of adolescents during this crucial developmental stage, and little is known about how this transition is experienced by the young people themselves.

# 1.2 Aims and Justification

## 1.2.1 Aims

This PhD consists of three complementary studies, with the overarching aim of studying service provision and contact amongst children and young people with mental health problems. The second and third parts focus in particular on adolescents with ADHD who are in transition from child to adult services.

The main aims of the three constituent studies are as follows:

1. To analyse mental health related service contact and trajectories of psychopathology over three years in a cohort of school-aged children
2. To examine primary care prescribing of ADHD medication and other psychotropic medication in people with ADHD over the transition period, and report on the time to cessation of medication from age 16
3. To explore the experiences of young people with ADHD in transition from child to adult services

## 1.2.2 Constituent studies and justification

### Study 1: Mental health related service contact and trajectories of psychopathology over three years in the British Child and Adolescent Mental Health Survey 2004 (Chapter Three)

The first study is a secondary analysis of the British Child and Adolescent Mental Health Survey (BCAMHS) 2004 and its follow-up in 2007. It describes mental health related contact with services amongst children who did and did not meet criteria for a psychiatric disorder as well as exploring the predictors of contact. The study also examines the trajectories of psychopathology over time, including at interim points between the surveys, among children who did and did not use services, and analyses the association between service contact and outcome in terms of psychopathology at follow-up. The study design offers the opportunity to examine children’s trajectories in relation to ‘real-world’ service contacts in a community setting; a question not previously explored in the 2004-2007 survey data, and one which may inform the future collection and interpretation of service outcomes data. It will also enable comparison with the previous BCAMHS 1999-2002, which used very similar methodology, adding to prior findings about which children do and do not use services and may be under served (see Chapter Two: Background).

### Study 2: Primary care prescribing of ADHD and psychotropic medication in young people with ADHD in the Clinical Practice Research Database 2005-2013 (Chapter Four)

Chapter Four presents the second study, which is an analysis of primary care prescribing of ADHD and other psychotropic medications in people with ADHD over the transition period up to the age of 27, using a cohort from the Clinical Practice Research Datalink (CPRD) from 2005-2013. The study also includes a survival analysis of the time to cessation of ADHD medication from age 16. As explored in more detail in Chapter Two, earlier studies of ADHD prescribing using general practice databases in the UK have covered the periods 1999-2006 in the CPRD (Wong *et al.* 2009) and 2003-2008 in the Health Improvement Network (McCarthy *et al.* 2012a & 2012b). Past research has concentrated on the prescribing of ADHD drugs rather than also examining other psychotropic medication, which is particularly relevant in ADHD due to the high prevalence of comorbidity that may be under-treated or obscure the ADHD symptoms(Asherson *et al.* 2007). New guidance on prescribing in transition and in adults was released by the British Association for Psychopharmacology in 2007 (Nutt *et al.* 2007), and later by NICE in 2008 (NICE 2008b). No UK study has therefore to date examined prescribing and time to cessation using data collected since the introduction of the NICE guidance. Understanding more recent patterns both of prescribing of ADHD medication and of other psychotropic medications will therefore allow greater understanding of current practice in treating ADHD and its comorbidities in adolescents and adults, and contribute to recommendations for treatment and training.

### Study 3: Young people’s experiences of transition from child to adult services with ADHD (Chapter Five)

The final study is a qualitative interview study of the experiences of transition of young people with ADHD recruited from CAMHS, paediatrics and Adult ADHD services. Transition for this group is acknowledged to be especially challenging, with a number of barriers identified by professionals (Wong *et al.* 2009, Belling *et al.* 2011, Hall *et al.* 2013). Consequently, keeping young people engaged with existing services, and involved in developing appropriate care is crucial. However, the perspectives of this ‘hard-to-reach’ population have not been well studied, with only one recent UK qualitative study by Swift *et al.* (2013) directly seeking their experiences. A clear gap in understanding therefore exists in understanding their vision of what services would help them and why might they disengage, which is directly relevant in creating functional and acceptable transition pathways.

This chapter has provided a brief introduction to the research problem, and outlined the aims and justification for the constituent studies. In Chapter Two, the research and policy background is examined in more detail, to highlight the existing gaps in knowledge.

# Chapter Two: Background

Chapter Two presents a review of the research and policy background to the three studies in the PhD. This chapter begins with a discussion of current knowledge about service access and contact in children with mental health problems. It then examines the evidence for the effectiveness of services and methodological questions relating to outcome measurement. The chapter finishes by assessing the challenges of the transition period in young people with ADHD and the need to understand current prescribing practice in this group.

## 2.1 Services for children with mental health problems

Increasing recognition of the scale and significance of mental health problems in childhood has led to attempts to improve and expand prevention and provision over the last two decades in the UK. The National Service Framework for Children, Young People and Maternity Services in 2004 included a section on child mental health prioritising a comprehensive CAMH service and emphasising increased accessibility of services (Department of Health, 2004). The final report of the National CAMHS Review in 2008 acknowledged that significant expansion of services had taken place over the intervening time, from 2005 to 2008, but expressed concern about unwarranted variation both in access to services and in the implementation of recommended interventions (Department of Health 2008a). More recent policy developments have included the introduction of the CYP IAPT programme, and the Future in Mind report published by the Department of Health (2015) which are described further in Section 2.1.8 below.

### 2.1.1 Service activity data

In the tiered system of services for children with psychiatric disorders, many children are seen in Universal or Targeted services, such as primary care, youth services, paediatric clinics or education. The diversity of these providers means that there is no aggregated source of activity data. In contrast, CAMHS Benchmarking Reports, recently introduced in 2011 by the NHS Benchmarking Network (2015), provide information about the numbers of children referred to and seen by services by mapping activity within CAMHS, covering 79 provider organisations at last report in

2015. Referral rates to Tier 1-3 averaged 3,051 referrals per 100,000 children aged 0-18 years in this period but rates ranged from less than a hundred to over seven thousand referrals per 100,000 in different providers. The average figure for total contacts with CAMHS was 19,158 per 100,000, and again there was considerable variation from fewer than three thousand to more than 40,000 contacts per 100,000. The report concluded that such variation in referrals and activity were influenced not only by demand reflecting need, but by current and historic capacity levels, local service cultures and configurations, and of course funding (NHS Benchmarking Network 2015). Figures for referrals, waiting times and contacts have all increased since the previous benchmarking in 2013/14; with referrals increasing by 11% and mean waiting time standing at 32 weeks compared to 22 weeks in 2013/14.

### 2.1.2 Population surveys of service contact

Whilst service activity data is essential to examine variation, and in understanding the demands on services, it is limited by being unable to capture data on children who are not referred for help. Comparisons of activity can be made with population estimates of prevalence, but this is a crude measure of unmet need. Furthermore, the tiered system means that the majority of mental health related contacts may take place outside specialist child mental health services, for example in schools, GP surgeries and paediatric clinics. As there is no integrated system that collates such activity together, population surveys therefore still remain key methods in estimating the proportion of those in need (i.e., who have a psychiatric disorder) who have contact with services.

In the UK, the British Child and Adolescent Mental Health Surveys (Meltzer *et al.* 2000, Green *et al.* 2005), which took place in 1999 and 2004, are one of the chief sources of information on a population scale about mental health related contacts with public sector services. The surveys questioned parents about their child's mental health related contact with a variety of public sector services and professionals, with the main categories being: teachers, special education, CAMHS, primary care, paediatrics and social workers. The results of a secondary analysis of the 2004 survey are discussed in the BCAMHS 2004 analysis in Chapter Three. The 1999 survey reported that over a third of children who had a psychiatric diagnosis either at baseline or follow up had no contact with any services regarding mental health over the three year follow-up period (Ford *et al.* 2007b). Almost a quarter of those with a persistent disorder at both baseline and follow-up,  and two-fifths of those with an emerging disorder at follow up also reported no contact at all with services (Ford *et al.* 2007b).

In terms of contact with specific services, a quarter of children with a disorder in BCAMHS 1999 had contact with specialist child mental health services (i.e. CAMHS), 28.9% reported contact with a GP, and 16% with paediatrics (Ford *et al.* 2007b). Estimates of service contact amongst adults with psychiatric disorders from the 2007 Adult Psychiatric Morbidity Survey are not directly comparable due to different timescales, but again suggest a minority in contact with health services; 39% of adults with a common psychiatric disorders had contact with any health service over the previous year; 38% with a GP and 18% with community mental health (National Centre for Social Research 2007).  For children, education professionals appear to be on the ‘front line’, accompanying an increasing focus on the role of schools in mental health promotion and intervention beginning with Every Child Matters in 2003 (HM Treasury 2003).Teachers were the most commonly contacted professional group regarding child mental health by parents of children with a psychiatric disorder in the 1999 BCAMHS – 41% reported contact (Ford *et al.* 2007b). Contacts with education also constituted over 80% of all mental health related service activity in the US Great Smoky Mountains Study and often represented the common starting point for receiving other mental health services (Farmer 2003).

Recent studies from the US, Australia and Europe report a minority of children and adolescents with mental health problems seeking help from or using any services, Whilst such estimates are not directly comparable to BCAMHS, due to varying service structures and definitions, the results imply that low levels of contact are not unique to the UK. For example, the 2012-2013 US National Comorbidity Survey found that fewer than half of adolescents with any mental health disorder had been in contact with any service during the twelve month period (Costello *et al.* 2014). In Australia, contact levels with primary care and with mental health services amongst young people aged 16-24 with a psychiatric disorder were lower than 25% in the national Survey of Mental Health and Wellbeing (Reavley *et al.* 2010). Similar estimates are reported by population surveys in European nations (Essau 2005, Zachrisson *et al.* 2006).

### 2.1.3 Predictors of service contact

The majority of observational studies across Europe and the US report a higher proportion of children with ‘externalizing’ disorders in contact with services than children with ‘internalizing’ disorders (Zwaanswijk *et al.* 2003, Heiervang *et al.* 2007, Ford *et al.* 2008b, Costello *et al.* 2014). In the 1999 BCAMHS, 64% of children with hyperkinetic disorder and 49% of children with conduct disorders had mental health related contact with specialist services, in contrast with just 33% of those with anxiety disorders(Ford *et al.* 2008b). Findings on gender and service contact have been mixed. A number of studies have found boys to be more likely to have mental health related contact with various services than girls, even after adjusting for diagnosis or problem scores (Burns *et al.* 1995, Ford *et al.* 2008b, Merikangas *et al.* 2010, Posserud and Lundervold 2013, Costello *et al.* 2014), whereas others report no association (Simpson *et al.* 2009, Wolfle *et al.* 2014). Interactions of age and gender have been reported whereby girls were reported to be less likely to use services in childhood and early adolescence but more likely to have contact than boys during the later adolescent years ( Young *et al.* 2011, Reijneveld *et al.* 2014)

Severity and impact of psychopathology consistently predict mental health related contact with a variety of specialist and non-specialist services (Ford *et al.* 2008b, Reijneveld *et al.* 2014, Langer *et al.* 2015). Specific predictors of contact with specialist mental health services in previous studies include impact of psychopathology, stressful life events, neurodevelopmental disorders, parental socio-economic status, contact with primary care and ‘reconstituted’ or other non-traditional family types (Zwaanswijk *et al.* 2003, Ford *et al.* 2008b, Amone-P'Olak *et al.* 2010, Young *et al.* 2011).

### 2.1.4 Service contact and unmet need

Understanding how many children with disorders are not in contact with services provides an indication of the scale of unmet need. It cannot be assumed, however, that all children who do come into contact with services will have their needs met. Data remain lacking on exactly which psychological and pharmacological interventions children seen in services actually receive. This gap was highlighted in the recent Chief Medical Officer’s report, and may be addressed to some extent by the new CAMHS Minimum Dataset (Davies 2014). Furthermore, a variety of factors will influence children’s needs and outcomes including: the existence of effective treatment strategies in the first place, service variation in implementing evidence based practice, fidelity of adoption of such interventions, and the complexity and trajectory of any individual's psychopathology and psychosocial context.

### 2.1.5 Evidence based interventions in child mental health

According to Hoagwood *et al.* (2001, p.1180) the term 'evidence based' is used to "differentiate therapies… that have been studied with varying degrees of rigor from therapies that are used but have not been studied or have not been studied well". The authors argue that the multiple variables inherent in psychosocial interventions in particular create challenges in studying these therapies, which may be intensified by the nature of the changing stages of child development. Nonetheless, there has been increasing focus on developing appropriate methods to trial interventions such as parenting programmes, cognitive behavioural therapy and family therapy amongst others. In the UK, the CYP IAPT programme represents an initial attempt to widen the delivery of psychotherapies for which there is such an evidence base. According to the programme, CYP IAPT now works with CAMH services covering 68% of the child population (NHS England 2016).

There are well-recognised barriers and facilitators to the introduction and full implementation of evidence based interventions, which relate to clinicians, services, and individual patients (Garland *et al.* 2013, Novins *et al.* 2013). Clinician factors include differing attitudes towards interventions, preferences for delivery and skills to correctly provide the treatment. The perception from services may be that resources are too scarce to deliver the intervention at the required frequency and intensity, or to provide staff with time for training, although this might prove a false economy. The child and family constitute another variable in this process. Engagement with services can be challenging and linked to myriad socio-cultural influences; consequently children and their families may be unable or unwilling to complete a full course of treatment. Children seen in clinical practice often have more comorbidities, more severe disorders and face greater psycho-social adversities than those who take part in trials to establish the evidence base (Garland *et al.* 2013, Weisz *et al.* 2013).These differences have implications not only for the successful implementation of interventions, but for the applicability of the results of clinical trials.

Consequently, the innate superiority of evidence based interventions to 'usual care' has been called into question (Kazdin 2013, Weisz *et al.* 2013). Weisz *et al*. (2013)

in their meta-analysis of psychotherapies found that the advantages of evidence-based psychotherapies compared to usual care were statistically and clinically non-significant in samples of clinically referred and diagnosed young people. Deighton *et al.* (2015), using naturalistic service collected data similarly reported no significant difference in outcome between evidence based practice and non-evidence based practice in children with conduct disorders, but a significantly greater improvement according to child self report in children with emotional disorders. In contrast, Hurst *et al.* (2014) did report differences in pre- and post- intervention parent reported SDQ scores when using routine outcome measurements to examine evidence-based parenting programmes in children with conduct disorders. The increased use of such routine outcome measurements in UK CAMHS (see section 2.1.8 below) is likely to provide more clarity about the benefits of implementing evidence based practices in clinical settings, and is an evolving field.

### 2.1.6 The effectiveness of 'usual care'

Whilst individual evidence based interventions exist, the effectiveness of usual care in child mental health services has not been conclusively demonstrated. Evaluating usual care is an area fraught with difficulty in terms of measuring and interpreting outcome data. Usual care (sometimes referred to as 'treatment as usual' in trials) can be defined as the routine care as opposed to an intervention delivered in a trial setting  and may not consist of a single or specific intervention, but encompass a broad range of management as delivered by each individual clinical team and service configuration (Freedland *et al.* 2011).  Consequently, usual care is highly diverse and context specific, meaning trials using a usual care control group must be interpreted with care, as argued by Freedland *et al.* (2011). Similarly, statistical and measurement phenomena complicate attempts to measure change, and to attribute change to service use, particularly where there is no comparison group.  Regression to the mean occurs due to random error, so that large or small scores tend to be followed by measurements closer to the mean (Barnett *et al.* 2005). This can result in difficulty distinguishing change that is due to an intervention such as service use, from random change. Another phenomenon in repeated measurements is attenuation, whereby respondents in studies tend to report more problems in the first questionnaire or interview, and fewer thereafter, potentially due to respondent fatigue. This may result in an improvement in scores without an accompanying improvement in symptoms (Jensen 1995, Ford *et al.* 2009).

Some studies using datasets of children seen in community mental health care have reported improvement in behavioural and emotional symptoms and goal based outcomes over the shorter term (4-6 months), although symptom improvement effect sizes were small to medium (Trask and Garland 2012, Edbrooke-Childs *et al.* 2015a). These studies suggest that children receiving ‘usual care’ experience some improvement, yet this cannot be directly attributed to the care itself without a control group, and can clearly be affected by attenuation as described above. Other studies of children and adolescents in receipt of usual care services report variable outcomes, with some cases deteriorating over the course of treatment and others experiencing no change (Manteuffel *et al.* 2008, Warren *et al.* 2010). A number of longitudinal observational studies, which analysed the association between reported contact with  mental health services and outcomes failed to detect any association between contact with usual care and improved outcomes (Zwaanswijk *et al.* 2006, Jörg *et al.* 2012). The TRAILS study in the Netherlands reported problem scores for those who had and had not had contact with mental health services, adjusted for baseline problem scores and common confounding factors. The authors found poorer outcomes in terms of problem scores in those in contact with services compared to those without contact; and outcomes were poorest in those who were in contact over a longer period (Jörg *et al.* 2012).

There are a number of considerations in the interpretation of these results, which do not necessarily imply that services are not effective. Observational studies are complicated by inherent limitations such as residual confounding and confounding by indication when attempting to compare groups. Interpretation should be influenced by what ‘optimal outcomes’ might be for children with disorders and how outcomes will be influenced by the natural trajectories of childhood psychiatric disorders (Costello and Maughan 2015). Children with the same disorder and symptom severity when measured at one or two time points may still be on different trajectories. Subsets of children that meet the same diagnostic criteria have been shown to experience chronic and severe difficulties, whilst others have more transient problems (Pingault *et al.* 2011, Chaiton *et al.* 2013). For example, depressive and anxiety symptoms have been shown to follow stable high trajectories in subgroups of adolescents (Van Oort *et al.* 2009, Broeren *et al.* 2013). Angold *et al.* (2000) in their analysis of specialist mental health service use in the multi-wave Great Smoky Mountains Study observed a positive effect of service use on symptoms only after controlling for pre-treatment trajectory. They also noted that children who would later receive treatment exhibited higher levels of psychopathology than those with untreated need and that these children demonstrated deterioration before using services. This underlines the importance of understanding trajectories in interpreting data on symptom change.

### 2.1.7 Outcome measurement

Despite the challenges discussed above, there is a clear move towards the routine collection of outcome data in CAMHS in England, which is already embedded within the CYP IAPT programme and supported by the work of the CAMHS Outcome Research Consortium.  The latest Benchmarking report found that outcomes data was routinely collected in 95% of participating CAMHS services in 2012/2013, increased from 88% in the previous year (NHS Benchmarking Network 2015). Whilst some initial datasets drawn from this routinely collected data have been analysed, such work is at an early stage, but has considerable potential (Edbrooke-Childs *et al.* 2015a).

There remains debate over the choice of appropriate outcome measures. Broad measures such as the well validated Strengths and Difficulties Questionnaire (SDQ) developed by Goodman (1997) have the benefit of allowing aggregation and comparison across teams and services (Lee *et al.* 2005, Edbrooke-Childs *et al.* 2015a). Capturing a wide range of emotional and behavioural difficulties and measuring impact, the SDQ can also be applied throughout services including CAMHS, social services and education. On the other hand, it has been argued that the SDQ may underestimate the effectiveness of services, particularly in specialist services where specific, more focused outcome measures might be more relevant and where the SDQ has detected a smaller effect size than more specialist questionnaires (Lee *et al.* 2005). A case has also been made for the use of idiographic instruments such as the Goal Based Outcome tool, which aims to measure progress towards goals identified jointly by patient and clinician (Edbrooke-Childs *et al.* 2015a). A clear advantage of such idiographic measures is their relevance to individual children and their families, but by the same token comparison across groups may be less valid than for broader measures; and the question of subjectivity and vulnerability to manipulation when meeting targets should not be dismissed (Edbrooke-Childs *et al.* 2015a).

### 2.1.8 Current policy and recommendations

This section briefly summarises current policy and recommendations in three areas: service commissioning, service transformation and CAMHS data.

**Commissioning of Child Mental Health care**

The Health and Social Care Act of 2012 is the most recent reorganisation of the commissioning and delivery of care (HM Government 2012). Whereas previously Primary Care Trusts under the oversight of Strategic Health Authorities would be the primary commissioners of child mental health services, under the Act such responsibilities were largely devolved to Clinical Commissioning Groups (CCGs). In contrast to the top-down approach to implementation of the Act, one of the stated aims was to liberate clinicians to make decisions about the needs of their local population(Department of Health 2010a).  However, concerns were raised about a lack of expert public health and commissioning support to CCGs to assist the new bodies in this role (West 2012). There is some evidence to suggest that children with mental health problems may not be well served by the new system. Barely two years down the line in 2014 the House of Commons Health Select Committee report on CAMHS delivered this assessment of the situation: “demand for mental health services for children and adolescents appears to be rising, many CCGs report having frozen or cut their budgets. CCGs have the power to determine their own local priorities, but we are concerned that insufficient priority is being given to children and young people’s mental health” (House of Commons Health Select Committee 2014, p.4). Some of the most recent figures on budgets and waiting times are discussed in the context of the findings of the thesis in the final Overarching Conclusions chapter.

The Select Committee report recommended national oversight of CAMHS; an increase in monitoring by NHS England and the Department of Health of spending levels on CAMHS by CCGs, and further support in order to address service variation and standards. There is  nonetheless likely to be tension between a commissioning structure set up to encourage local decision making and responsibility and increased central oversight and intervention to ensure that mental health services do not remain overlooked and underfunded.

**Service transformation**

The Future in Mind report was published in 2015, and is based on the themes identified by the Child Mental Health and Wellbeing Taskforce (Department of Health 2015). Although CAMH services were described in the previous section of this thesis as being largely conceptualised in tiers, the Future in Mind report advocates moving from a ‘tiered’ service to a pathway based service in order to remove artificial barriers to care. Linking with the Select Committee report, Future in Mind also envisages joint commissioning by CCGs and local authorities, as well as local transformation plans to act as a driver. However, at this early stage, the effects of planned service transformation on outcomes are yet to be seen.

**Data and outcomes measurement**

There has been an increasing policy consensus on the importance of data in improving child services. The 2013 Chief Medical Officer (CMO) report noted a lack of information on interventions currently offered to children and their outcomes (Davies 2014); and the need for more and better evaluations of interventions, whilst the Select Committee’s opinion was that: “those planning and running CAMHS services have been operating in a “fog”” (House of Commons Health Select Committee 2014, p4). More specifically, both the CMO and the Children and Young People's Health Outcomes Forum identified outcome measurement in services and the need for a regular prevalence survey as key priorities for the future (Department of Health 2012, Davies 2014).

### 2.1.9 Summary

The first study in this thesis uses the British Child Mental Health Survey 2004 to examine some of the questions discussed above, including mental health related contact with services, the trajectories of psychopathology over time among children using and not using services and the association between service contact and outcome in terms of psychopathology at follow-up. The second and third studies focus on ADHD, and specifically, young people with the disorder who are in transition from child to adult services. The second part of this Background chapter examines this topic in more detail.

## 2.2 Transition from child to adult services in young people with ADHD

### 2.2.1 The importance of transition

Young people in late adolescence and early adulthood constitute a distinct group with distinct needs, which may not be easily met by services catering to the wider 18 to 65 year old ‘adult’ age range. The term ‘emerging adulthood’ has been used to describe this developmental stage (Arnett 2000). Whilst 18 years is considered the age of legal maturity, the brain is still developing and carrying out activities such as pruning and myelination until the mid-twenties (Johnson *et al.* 2009). Furthermore, factors such as increasing time in education and the disproportionate impact of the global recession on the young mean that this age group also have different social and economic experiences to older adults (Arnett *et al.* 2014).

There has been increasing recognition of the challenges involved in moving from child to adult services. The UK Department of Health Good Practice Guide ‘Getting it right for children and young people’ was one of the first to focus on transitions in health care. The report used the definition of transition as “a purposeful, planned process” of moving from child to adult services, as opposed to a single event of ‘transfer’ of care (Department of Health 2006, p14). However, the 2010 Kennedy review of children’s services suggested that adolescents were still seen as a: “forgotten group, caught between services for children and adults and therefore also between bureaucratic barriers and professional spheres of influence” (Department of Health 2010b, p38). The report considered that transition in reality often therefore amounted to no more than a disruptive ‘transfer’ of care.

Each condition presents its own challenges in negotiating this developmental stage, for example, taking increased responsibility for injections and glycaemic control in diabetes. Adolescence is also the peak time for new psychiatric disorders to develop (Copeland *et al.* 2011), and the difficulties for these young people may be compounded by cultural divides between child and adult mental health services and by the extent of persisting stigma surrounding mental ill-health. People with ADHD may be particularly affected by historical perceptions of the disorder as being a childhood condition, which are still likely to shape their experience of transition in terms of attitudes, understanding and services provided. Two of the three studies in this thesis focus on transition in young people with ADHD; and the rationale and background to this research is therefore discussed further below.

### 2.2.2 The impact and importance of ADHD and the effectiveness of treatment

An extensive literature base describes adverse outcomes for children, adolescents and adults with ADHD over a wide spectrum of interlinked domains of function, including: education, occupation, comorbid psychiatric disorder, relationships, substance misuse, general health, obesity, criminality and accidents and injuries (Hoare and Beattie 2003, Biederman and Faraone 2006, Barkley and Brown 2008, Groenman *et al.* 2013, Kang *et al.* 2013, Chang *et al.* 2014, Dalsgaard *et al.* 2015, Uchida *et al.* 2015, Cortese *et al.* 2016). Associated with this is the high cost to health, social and education services, estimated at over £5000 per adolescent in a 12 month period in one UK study (Telford *et al.* 2013).

There is evidence for the effectiveness of pharmacological interventions in children and adults in terms of short term symptom reduction, but also across a wider range of outcomes including quality of life (Coghill 2010, Faraone and Buitelaar 2010, Faraone and Glatt 2010). A review of outcome studies suggested that people with treated ADHD experienced better outcomes than those with untreated ADHD in the categories of academic and occupational achievement, self-esteem, obesity, drug use and addictive behaviour and antisocial behaviour (Shaw *et al.* 2012). Pharmacological treatment has also been associated with a reduced risk of serious road traffic accidents and criminal convictions in males with ADHD and with reduced emergency department attendance and accidents and injuries in children (Dalsgaard *et al.* 2015, Lichtenstein *et al.* 2012, Chang *et al.* 2014). There is also evidence to suggest benefits from non-pharmacological management including parent training and school-based interventions (Fabiano *et al.* 2015, Richardson *et al.* 2015).

In 2008 NICE recommended medication for adults with ADHD for the first time as a first line treatment, as well as psychological support such as Cognitive Behavioural Therapy (CBT) and also recommended re-assessment at the time of transition to ensure appropriate management could be provided (NICE 2008b). NICE estimated in their guidance that only 1-2% of adults with ADHD were receiving treatment implying that at the time few young people continued their medication into adulthood (NICE 2008a).

### 2.2.3 Persistence of ADHD into adulthood

ADHD was previously considered to be a developmental condition, and therefore to affect only children and younger adolescents. Historically, services have reflected this and stopped working with young people at 16 or 18 years of age in the UK (Young *et al.* 2011). The findings of follow-up studies have naturally been influenced by how persistence of ADHD is defined: as meeting full, usually Diagnostic and Statistical Manual IV (American Psychiatric Association 2000) criteria, or as still experiencing symptoms or impairment of functioning. Similarly, the changing nature of ADHD symptoms into adulthood has also meant that persisting symptoms might go unrecognised, as earlier diagnostic criteria such as those in the DSM-IV were written for application to children (Kooij *et al.* 2010).   The 2006 meta-analysis by Faraone *et al.* (2006) attempted to analyse data from multiple follow-up studies and reported both persistence of meeting full diagnostic criteria and persistence of ‘partial remission’, where cases still experienced residual symptoms and impairment. Persistence of full symptoms at age 25 years stood at only 15%, but more strikingly the percentage experiencing partial remission was estimated at between 40% and 60% (Faraone *et al.* 2006).

More recent studies have yielded comparable results; an analysis of girls with ADHD in the US with a mean age of 22 years at follow-up found that two –thirds still met full or subthreshold diagnostic criteria (Biederman *et al.* 2010). Cheung *et al.*’s (2015) UK study had a lower mean age at follow-up (18.7 years) and reported that almost eight in ten participants continued to meet clinical criteria. There still remain relatively few studies which have followed participants into their thirties and beyond, and research into persistence in older adulthood has relied on retrospective self reports which is problematic in terms of recall bias and sample selection (Guldberg-Kjar *et al.* 2013, Semeijn *et al.* 2015). The Dunedin cohort study was able to administer adult ADHD diagnostic interviews to participants at the age of 38 and conduct both follow-forward and follow-back analyses (Moffitt *et al.* 2015). Surprisingly, they found little overlap between those meeting criteria at this age, and those who had earlier met DSM criteria as children, the authors concluding that, in this cohort, ‘the adult syndrome did not represent a continuation from a childhood-onset neurodevelopmental disorder' (Moffitt *et al.* 2015, p.6). This finding warrants interest and replication, however for the purposes of studying ADHD over the transition period its applicability is limited by the lack of ADHD assessments during the participants' twenties.

Arguably, research into the outcomes of clinically referred samples may not be representative of all children with ADHD, but on balance the evidence is supportive of persistence of ADHD symptoms over the transition period and beyond in a significant proportion of cases studied. Factors such as higher parent rated symptoms in childhood, lower IQ, lower socio-economic status, psychiatric comorbidity, family history of psychopathology, and school functioning at baseline have been linked with persistence of ADHD symptoms and poorer outcomes, adding to the vulnerability experienced by this group (Cheung *et al.* 2015, Uchida *et al.* 2015).

### 2.2.4 ADHD as a controversial diagnosis

Transition may be a particularly difficult time for young people with ADHD, given past and present controversies surrounding the condition. Much debate has been provoked by questions regarding the validity of the ADHD diagnosis, and to what extent it represents the creeping 'medicalisation' of childhood (Moncrieff and Timimi 2010, Singh and Wessely 2015). The existence of ADHD in adults has been even more controversial. It has been argued by Moncrieff and Timimi (2010, p.547) that adult ADHD represents little more than 'aggressive marketing' by pharmaceutical interests, and that medication represents 'cosmetic psychopharmacology'. Key aspects of this case revolve around the dimensional nature of ADHD, the 'subjectivity' of a diagnosis and the multifactorial aetiology of the condition. None of these characteristics are exclusive to ADHD and apply to many other disorders; nonetheless the fact that ADHD medications are the most commonly prescribed psychotropic drugs in children (Steinhausen 2014) means that this is a sensitive subject that arouses concerns about over-diagnosis and over-treatment.

Such anxieties are prominent in the minds of the public and parents, with surveys suggesting that many members of the public thought that ADHD was diagnosed and children treated too frequently (Bussing *et al.* 2012, Partridge *et al.* 2014). Concerns have been raised by clinicians about the lack of a holistic approach and limited access to the non-pharmacological support recommended as first line treatment for mild and moderate ADHD (Bowers 2014). The potential subjectivity of classifying the disorder as mild, moderate or severe may further contribute to fears about over-reliance on medical treatment and to calls for conservative management (Thomas *et al.* 2013, Batstra *et al.* 2014) On the other hand, although the numbers of children treated with medication for ADHD has undoubtedly risen over time in the UK, estimates of rates of treated ADHD remain lower than estimates of prevalence(McCarthy *et al.* 2012b). Clinic and case note based studies have similarly found no evidence of over-diagnosis or inappropriately prescribed treatment within the CAMH services examined (Foreman and Ford 2008, Foreman 2010).

Perhaps influenced by the media attention and controversy, attitudes from professionals towards ADHD are consequently also more variable than they might be for many other mental or physical disorders. A recent review of ADHD in schools suggested that many teachers held ‘polarised’ views on ADHD, believing it to be either of social or biological origin; and those attributing a social cause to ADHD widely believed that symptoms originated in the home with poor parenting (Richardson *et al.* 2015). This had a consequent effect on their views on whether assessment or interventions would be necessary or helpful. Research into attitudes and knowledge amongst health professionals so far has largely consisted of surveys of small (n<50) samples, which are likely to be prone to bias in terms of self-selection of respondents.  A recent UK survey of professionals working in adult mental health services reported that 73% thought ADHD was a valid diagnosis, although only 41% thought that treatment for ADHD was effective(Hall *et al.* 2013).  In terms of knowledge and confidence, Ahmed *et al.* found  that 50% of 38 adult psychiatrists surveyed were ‘confident’ in diagnosing ADHD  in adults and only 63% felt confident to prescribe medication, with most identifying a need for further training (Ahmed *et al.* 2009).

### 2.2.5 Transition pathways in ADHD

This section of the review concentrates on transition in the UK. The majority of children with ADHD in the UK are seen in Child and Adolescent Mental Health services although a significant minority are instead treated in paediatric medical services, depending on local service configurations (NHS Benchmarking Network 2015). Young people with ADHD then undergo transition from child services to adult services at around the age of 18 in most parts of the country.  Their destination will be influenced by multiple factors including their wishes, the persistence and severity of their symptoms, their comorbidities and the available services locally.  Possible pathways are illustrated in Figure 2.1 below and may involve referral to Adult Mental Health Services (AMHS), referral to a specialist Adult ADHD clinic, or transfer of all care back to the GP. Some may disengage or have their referrals to services rejected, but ultimately return to mental health services further down the line, for example, if they develop psychiatric co-morbidities or are assessed in the criminal justice system. Simultaneously, adolescents might be moving away for work or higher education, meaning there may also be a geographical shift in where their care is delivered. Maintaining continuity of treatment and engagement with services at this time is important, but often young people leaving CAMHS enter what has been described by Young *et al.* (2011) as a ‘twilight zone' gap in care. The factors contributing to this are explored in further detail below.

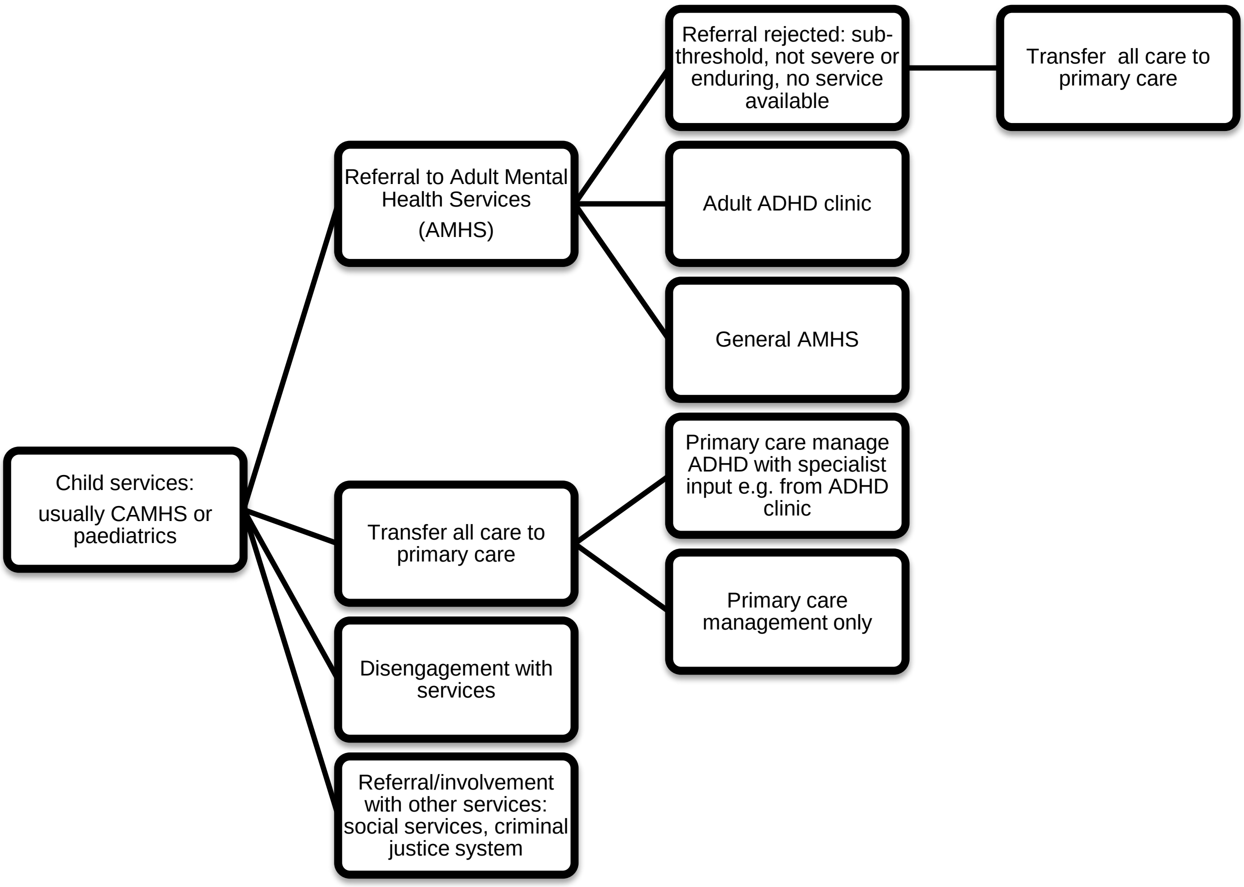


**Figure 2.1: Formal and informal transition pathways for young people with ADHD**

### 2.2.6: Transition from a professional perspective

At an organisational and professional level, several key and inter-related barriers to transition between child and adult services for young people with ADHD emerge in the literature. One of these is resources, or lack of services to meet need. Belling *et al*. (2014) interviewed CAMHS and AMHS professionals about difficulties in transition for all mental health conditions, and found resources were a central theme. Workloads in AMHS were thought to contribute to an overly rigid interpretation of eligibility and age criteria for services, and to an emphasis on meeting the needs only of those with 'severe and enduring' mental disorders. A gap repeatedly identified was for provision for young people with Autism Spectrum Disorders (ASD) and ADHD. Findings from a recent national survey of mental health trusts also suggested that a high proportion of young people with ADHD were discharged prematurely from CAMHS due to a lack of suitable adult services (Hall *et al.* 2015); surveys of paediatricians have similarly identified ongoing needs for care in their patients with ADHD, but a gap in service provision (Marcer *et al.* 2008, Taylor *et al.* 2010).

Another, related difficulty in transition in mental health is the acknowledged organizational and cultural differences which exist between CAMHS and AMHS (McLaren *et al.* 2013). CAMHS and AMHS professionals interviewed by Belling *et al*. (2014) also cited differences including a lack of clarity on service eligibility and different thresholds between CAMHS and AMHS, with AMHS seen as prioritising only 'serious' psychosis and forensic risks. Hall *et al.* (2013), in their survey of East Midlands mental health professionals found a lack of consensus between child and adult services in their view of what should be provided post-transition for people with ADHD. Only 65% of AMHS respondents agreed that AMHS should provide services for this group, and furthermore, just 54% felt they possessed the skills to manage adult ADHD (Hall *et al.* 2013). Ambivalence amongst AMHS and even CAMHS professionals regarding the validity of adult ADHD as a diagnosis, and about the effectiveness of medication is also likely to influence organisational culture and practice (Ahmed *et al.* 2009, Hall *et al.* 2013, Belling *et al.* 2014).

### 2.2.7 Perspectives of young people in transition

CAMHS and AMHS professionals also suggested that transition might be sub-optimal where young people themselves did not engage with services over this period(Hall *et al.* 2013). The perspective of service users themselves is less studied than that of professionals, possibly because this group is generally understood to be ‘hard to reach’, with difficulties in recruitment cited by various researchers (Wong *et al.* 2009, Hovish *et al.* 2012, Swift *et al.* 2013) (see also Chapter Four). The TRACK study included qualitative interviews with 11 service users undergoing transition from CAMHS (Hovish *et al.* 2012). Participants reported varying experiences of transition, but highlighted a number of helpful (preparation, consistency, parallel processes) and unhelpful (key worker changes, waiting lists) practices. The simultaneous changes they were dealing with alongside CAMHS transition were described as being powerful influences on their experience. However, the TRACK study did not include any young people with ADHD diagnoses. The particular challenges faced by those with ADHD over the transition period mean that their experiences may be different.

Swift *et al.* (2013) carried out qualitative interviews with ten young people with ADHD based in the Midlands on their experience of transition from CAMHS to AMHS. A number of findings resonated with those reported in the TRACK study, for example, the importance of clinician qualities and relationships. There were other themes which may have been more specific to this group, such as the importance of service thresholds and concerns about not being accepted by services if they ‘only’ had ADHD without co-morbid mental health problems. Responsibility for care and the role of the parent (who may be providing considerable practical support in terms of planning appointments and medication) were also reported as emerging themes which might be of particular relevance to adolescents with ADHD. Thus far, this is the only published study of the experiences of young people with ADHD in transition in the UK, and the findings will necessarily be influenced by the specific local service configurations. Clearly, the perspectives of this vulnerable group merit further study in various service settings and constitute a gap in research. Despite the challenges, understanding young peoples’ vision of what services would help them and why they engage or disengage is key to creating functional and acceptable transition pathways.

### 2.2.8 Prescribing in young people with ADHD over the transition period

On leaving CAMHS or other child health services at the age of 16-18 years, young people may be referred to specialist services, return to primary care, or lose contact altogether with sources of help and support. Some may already have stopped medication and this may be entirely appropriate for a variety of reasons: personal preference, side effects, symptom reduction, using alternative coping strategies or a change in their daily environment e.g. from school to work (McCarthy 2014).

However, for those preferring to remain on medication, arrangements for continuation of prescribing may be less clear, particularly where there is no specialist clinician in adult services willing to oversee or review primary care prescribing (Young *et al.* 2011). Despite the publication of NICE guidance in 2008, in many localities prescribing for adults with ADHD may not be widely established and accepted (Hall *et al.* 2013, Matheson *et al.* 2013). A recent qualitative study of the experiences of adults with ADHD described participants' perceptions of 'overwhelmingly negative and sceptical attitudes towards ADHD by health professionals', including experiences where GPs or pharmacists were unwilling to prescribe or stock medication, causing problems with access and continuation of medication (Matheson *et al.* 2013) .

Interviews with adolescents have highlighted some central themes regarding their perspectives on continuation of ADHD medication. Choosing to stop was interpreted as an exertion of autonomy by young people in a number of US and UK qualitative studies (Travell and Visser 2006, Wong *et al.* 2009, Brinkman *et al.* 2012). Participants interviewed by Brinkman *et al.* (2012) expressed doubt and uncertainty about their future use of medication; some saw academic success as the primary purpose of treatment and therefore saw no need to continue their medication after school. Another prominent theme was trade-offs, weighing up positive effects against diverse negative effects including loss of an 'authentic self', side-effects, and embarrassment at taking medication. The role of services in cessation was little mentioned, with the exception of three participants in one UK study who reported stopping their medication as they no longer had access to treatment (Wong *et al.* 2009).

Young adults in the UK are most likely to stop treatment around the time of leaving CAMHS, according to database studies of primary care prescribing. The CADDY study (Cessation of Attention Deficit Hyperactivity Disorder Drugs in the Young) used survival analysis to examine rates of cessation of ADHD medication in 15-21 year olds over the period 1999 to 2006 in the General Practice Research Database, which is now known as the Clinical Practice Research Datalink or CPRD (Wong *et al.* 2009). The steepest reduction in prescribing was between the ages of 16 and 17, and was a decrease far greater than the estimated rate of remission of ADHD related difficulties (Faraone *et al.* 2006). A study of persistence using the Health Improvement Network, another primary care database found 38.5% of those starting treatment before the age of 12 remained on treatment beyond the age of 18 (McCarthy *et al.* 2012a). Of those starting between 13 and 17, the rate of persistence was 42.8%. Again, the rate of cessation reported exceeded the estimated rate of persistence of ADHD.

Rates of prescribing in adults have historically been low. An increase in the prevalence of prescribing in adults was reported over the period 2003-2008 in one UK primary care database, potentially due to increasing awareness of adult ADHD (McCarthy *et al.* 2012b). However, by 2008 total prescribing in 18-24 year olds stood at 1.122 per 1000, and at 0.079 per 1000 in 25-45 year olds; even allowing for a preference for non-pharmacological management amongst adults, and the decline in ADHD symptoms with age, these figures are markedly lower than the expected prevalence of adult ADHD, which is in the region of 2.5% or 25 per 1000 (Boe *et al.* 2012).

### 2.2.9 Prescribing and psychiatric comorbidities in ADHD

There are two ways in which the identification and treatment of psychiatric comorbidities in ADHD are particularly relevant over the transition period. Firstly, comorbidities in ADHD are common, affecting over half of people with ADHD (Kraut *et al.* 2013, Jensen and Steinhausen 2015). Furthermore, the peak age of emergence for many of these disorders is in adolescence and early adulthood (Kessler *et al.* 2007, Copeland *et al.* 2011). Comorbidities may contribute to overall impairment and adverse outcomes, necessitating identification and appropriate management (Kooij *et al.* 2010, Bolea-Alamanac *et al.* 2014).

Secondly, moving from adolescence to adulthood, the clinical presentation of ADHD may also lead to under-treatment if the symptoms are mistaken for the signs of other common psychiatric disorders. For example, mood instability may lead to diagnoses of mood or personality disorders, when this may instead be due to the patient's ADHD (Asherson *et al.* 2007). Women and girls may be particularly affected by misdiagnosis due to the higher preponderance of inattentive-type ADHD which may be harder to identify(Quinn and Madhoo 2014). It could be theorised that other psychotropic medications might then become substituted for ADHD prescriptions when the young person moves into adult services, as clinicians may be more familiar with prescribing for depression or anxiety, or treat other conditions in preference to ADHD (Ginsberg *et al.* 2014). The result may be missed opportunities to treat ADHD and the use of ineffective management strategies (Asherson *et al.* 2007).

Despite the significance of psychiatric comorbidities in ADHD, prescribing for such conditions has been little studied using large databases. The CADDY study did not report on the prevalence of comorbidity prescribing in ADHD, but did examine prescription of another psychotropic medication as a predictor of cessation of ADHD medication (Wong *et al.* 2009). In the Cox regression model such prescriptions were not associated with stopping medication for ADHD. Using the Health Improvement Network to identify cases, McCarthy *et al.* (2013) surveyed the GPs of three random samples of adult cases with ADHD who had either discontinued treatment before adulthood, continued treatment into adulthood, or newly started treatment as adults. Of those who continued treatment into adulthood, a quarter were receiving or had received treatment for comorbid psychiatric disorders. In contrast, the majority (18 of 31) cases who had newly started treatment as adults had been treated with medication for other psychiatric disorders before being diagnosed with ADHD; and 11 continued to be prescribed such medication alongside treatment for their ADHD. Such findings, albeit from a small sample of cases, suggest that professionals may look to identify and treat other psychiatric disorders first in newly-diagnosed adults with ADHD, but also raises the question of whether those diagnosed with ADHD as children might be under-treated for their comorbidities.

### 2.2.10 Current policy and recommendations

The importance of transition has been well-recognised in policy for over two decades, yet progress has been limited. A Health Select Committee report as recently as 2014 still referred to transition from CAMHS to adult services as a ‘cliff edge’(Health Select Committee 2014, p.51). Although the report of the Children and Young Peoples Outcome Forum (Department of Health, 2012) proposed the inclusion of age appropriate services and effective transition as new outcomes indicators, these have not so far been adopted into either the NHS or CCG Outcomes Frameworks. Objective national methods to monitor progress therefore remain lacking.

More positively, NHS England (2015) recently produced a service model specification for transition, identifying young people with ADHD and Autism Spectrum Disorders as a particularly vulnerable group. The model incorporates many good practice points ranging from transition care pathways to transparent criteria for gaining access to adult services.  There is nonetheless acknowledgement from NHS England that there will be places: “where commissioned adult services are not equipped or/ appropriate to provide NICE evidence -based care”, for example in ADHD, and where this is the case “this should be brought to the attention of the commissioners of services”(NHS England 2015, p.13).  Consequently, clear mechanisms do not appear to exist to hold commissioners to account for these gaps, or to ensure the provision of new or extended ADHD services. Furthermore, planned savings within social care and competing crisis pressures within mental health services will influence the implementation of recommendations, particularly where they are perceived to carry extra costs. Research into service user experiences and prescribing practice is therefore especially relevant in ensuring that any investment is meeting clearly identified healthcare needs.

### 2.2.11 Summary

This second part of the Background Chapter has sought to describe the context for the second and third studies in this thesis, and to introduce the gaps in knowledge which they aim to fill.  The analysis of prescribing in young people with ADHD will be the first to use the Clinical Practice Research Datalink to examine prescribing and time to cessation of ADHD medication since the introduction of the NICE guidance on ADHD in 2008. It will be complemented by the third qualitative study, which will seek to address some of the gaps in understanding of the experiences of young people with ADHD in transition using services and their needs and concerns.

Chapter Three next presents and discusses the results of Study 1: Mental health related service contact and trajectories of psychopathology over three years in the British Child and Adolescent Mental Health Survey 2004

# Chapter Three: Mental health related service contact and trajectories of psychopathology over three years in the British Child and Adolescent Mental Health Survey 2004

## 3.1 Introduction

This chapter presents and discusses the results of a secondary analysis of data from the 2004 British Child and Adolescent Mental Health Survey (BCAMHS) (Green *et al.* 2005). It begins by briefly revisiting some of the background from Chapter Two in order to introduce the analysis, followed by the aims and research questions. The methods section starts by describing BCAMHS 2004 and subsequently details the procedure for the secondary analysis. The results for each research question are then presented. Finally, the discussion reviews the key findings in the context of existing literature and policy, as well as outlining the strengths and limitations of both the dataset and the secondary analysis.

As described in Chapters One and Two, approximately one in ten children meet criteria for a psychiatric diagnosis at any point in time (Costello *et al.* 2005); and such disorders also predict the development of psychiatric disorders in adulthood (Kim-Cohen *et al.* 2003, Copeland *et al.* 2009). Children with disorders are also at higher risk for other adverse social, psychological and educational outcomes (Fergusson and Woodward 2002, Fergusson *et al.* 2009, Gibb *et al.* 2010, Klein *et al.* 2012, Copeland *et al.* 2015, Parker *et al.* 2015). Survey data from across the US, UK, Australia and Europe suggest significant unmet need in that many children and adolescents who meet criteria for disorders or score highly in terms of psychopathology rating scales do not come into contact with services (Essau 2005, Zachrisson *et al.* 2006, Reavley *et al.* 2010, Costello *et al.* 2014). In the UK, analysis of the earlier 1999 BCAMHS by Ford *et al.* (2007b) found that a large minority (42%) of children who met criteria for a psychiatric diagnosis either at baseline or follow up reported no contact with services regarding mental health over the three year follow up period. Three-quarters had no contact with specialist child mental health services.

However, even where children with disorders do come into contact with services, there are questions about the degree of effectiveness of routine care in child mental health services. The extent to which evidence based interventions are incorporated into routine care is largely unknown, and there are acknowledged challenges to delivery in terms of skill mix, resources, and complexity of caseloads (Garland *et al.* 2013, Novins *et al.* 2013, Davies 2014). Studies of outcome data from child mental health service local datasets suggest that children receiving ‘usual care’ experience some improvement, (Trask and Garland 2012, Deighton *et al.* 2015, Edbrooke-Childs *et al.* 2015a); and some also report greater improvements in those receiving evidence based interventions compared to those in receipt of usual care, although this is an emerging field (Deighton *et al.* 2015). However, such designs do not include a control group who were not in contact with services. In contrast, a number of observational longitudinal studies of service contact have failed to find an association between mental health service contact and improved outcomes in terms of psychopathology at follow-up (Zwaanswijk *et al.* 2006, Jörg *et al.* 2012) although the influence of residual confounding cannot be discounted. The measurement and comparison of outcomes is a complex field, and influenced by multiple factors including choice and interpretation of measure and by phenomena such as regression to the mean and attenuation (Ford *et al.* 2009, Edbrooke-Childs *et al.* 2015a). Furthermore, symptoms of psychiatric disorders often fluctuate over time, and subsets of children may follow different trajectories; i.e. some demonstrate chronic and severe difficulties, and others have more transient problems (Zwaanswijk *et al.* 2006, Van Oort *et al.* 2009, Pingault *et al.* 2011, Chaiton *et al.* 2013). With the growth of outcomes monitoring within child mental health services, an understanding of the trajectories of children using services is highly relevant in the measurement and interpretation of such data.

This secondary analysis examines mental health related contact with a broad range of services over three years in children in BCAMHS 2004, as well as exploring the predictors of contact. It will enable comparison with BCAMHS 1999, which used very similar methodology. The study also explores the trajectories of psychopathology over three years in children who did and did not have contact with services, and examines the association between service contact and outcome in terms of psychopathology at follow-up. Based on previous work, such as that by Angold *et al*. (2000) it was anticipated that children who would later access services would demonstrate deteriorating mental health. When taken in conjunction with the diversity of what real world service contacts represent, as well as the observational methodology, it was not predicted that a clear improvement over time would be observed amongst children in contact with services.

## 3.2 Aims

The overarching aim of this study was to analyse mental health related service contact in relation to psychopathology over three years in a community sample of children aged 5 to 16 years.

There are three main questions which this secondary analysis addressed:

1. What services do children with psychopathology have contact with over a three-year period (2004-2007)?
2. Which factors predict contact with services over the study period?
3. What are the trajectories of psychopathology over time in children who do and do not have service contact; and are there differences in outcome in 2007 between children who have or have not been in contact with services?

## 3.3 Methods

### 3.3.1 Overview of BCAMHS

The survey used a multi-informant model, involving a face-to-face interview with a parent (and with the child if aged 11-16), plus a teacher questionnaire. The key mental health measures completed were the Development and Wellbeing Assessment (DAWBA) and the Strengths and Difficulties Questionnaire (SDQ) (Goodman 1997, Goodman *et al.* 2000).

The 2004 BCAMHS was extended by follow-up waves at 6 months, 12 months and 24 months that involved parental completion of the SDQ. In 2007, the three year follow up survey repeated interviews with informants, collecting information on mental health and contact with services (Parry-Langdon 2008). The 2004 survey is detailed in Green *et al.'s* report (2005), and the 2007 follow-up in Parry-Langdon's report (2008); procedures for both taken from the reports are described below.

## 3.3.2 Subjects and recruitment

### Sample selection

Children aged 5-16 living in private households in England, Scotland and Wales were included in the 2004 survey. The sample of 12,294 was drawn from the Child Benefit Register from 426 postal sectors selected by the Office for National Statistics (ONS). According to the Department for Work and Pensions, virtually all eligible families claimed Child Benefit, which at that time was a universal benefit, so that the register covered almost all children except for those in foster or residential care, or other non-private households (Green *et al.* 2005). These sectors were selected by stratifying by Government Office Region and then by socio-economic group. In each sector, 29 children were randomly selected except for in five sectors where all children were sampled due to the very small numbers in the sample frame.

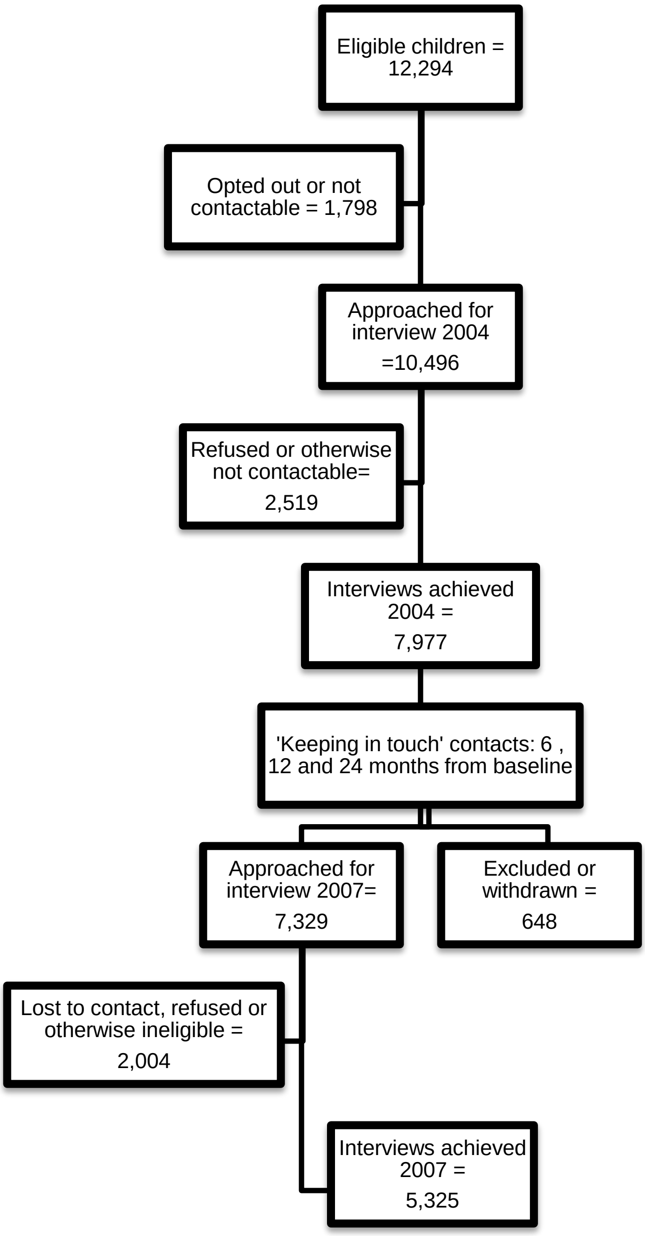
Parents were then sent invitations by the Child Benefit Centre on behalf of the ONS, to preserve confidentiality. Fifteen per cent of those selected in this way opted out or were not contactable. This left 10,496 families who were approached for interview. In all, 7,977 interviews with parents were achieved, constituting 76% of all cases approached. Teachers were asked to complete a questionnaire only if the child's parents consented, which 96% did. Of those teachers contacted, 83% returned a questionnaire, meaning that teacher information was available for almost 80% of all children assessed.

### Follow-up contacts

Parents were asked to consent at baseline to taking part in the six month follow up study involving a questionnaire only, which aimed to examine  the persistence of psychopathology, and therefore all children with a disorder at baseline whose parents consented (n=705) were included, along with a sample of those with no baseline disorder (n=926). Two-thirds of parents of children with a disorder returned the questionnaire, compared to 77% of those without, making a total follow-up sample of 1,174. Parent questionnaires were also collected on the whole sample at

12 months (n= 6,375) and 24 months from baseline (n= 5,794). 7329 children of the original 7977 were approached for interview in 2007, the remainder excluded as they had moved abroad, died, or withdrawn from the study. Almost three-quarters of this sample took part in the interview, resulting in a final number of 5,325 cases. Please see Figure 3.1 below for an overview of recruitment to the 2004 survey and 2007 follow-up.

**Figure 3.1: Flow chart of recruitment to 2004 BCAMHS and 2007 follow-up**



### 3.3.3 Measures

#### Socio-demographic measures

Socio-demographic data collected included: age, ethnicity, gender, housing status, family type, parental education and employment and household income. The McMaster Family Assessment Device (Miller *et al.* 1985) was used to assess family functioning and the General Health Questionnaire (GHQ) (Goldberg *et al.* 1997) to assess parental mental health. Parents were asked whether the child suffered from a list of physical and neurodevelopmental disorders and how many stressful life events (out of 10 potential events) the child had experienced. Parental interviews also covered the child's friendships and social aptitudes.

#### Measures used to assess psychopathology

*The Strengths and Difficulties Questionnaire*

Parents, teachers and children (if aged over 11) were asked to complete the one page Strengths and Difficulties Questionnaire (SDQ), a screening tool which covers emotional and behavioural difficulties and their impact on the child and family(Goodman 1997). The SDQ has versions for completion by parents, teachers and 11-16 year olds, and asks about 25 positive and negative attributes over 5 subscales: emotional symptoms, conduct problems, hyperactivity/inattention, peer problems and prosocial behaviour. The items are scored 0 (not true), 1 (somewhat true) or 2 (certainly true) or the reverse for positive items so that higher scores indicate greater difficulty. Items in the first four subscales are then added together to give the total difficulties score (possible range 0 to 40). In addition, there is a brief impact supplement, which asks the respondent whether they consider the child (or themselves if a self-rated questionnaire) to have a problem in terms of emotions, behaviour, concentration or relationships with others, and if so to rate the level of distress and impairment caused. The impact supplement is scored 0 (normal range), 1 (borderline) or 2 or more (abnormal).

The SDQ has been validated across various populations (Rothenberger *et al.* 2008, Stone *et al.* 2010, Gómez-Beneyto *et al.* 2013). The first BCAMHS (Meltzer *et al.* 2000) also served to provide norms for SDQ scores for a community sample, shown in Table 3.1 below.

**Table 3.1: Normative scores for British community population in 1999 and ranges for 'caseness' (taken from www.sdqinfo.com (Youth in Mind, 2016))**

| Informant and SDQ score | Mean (SD) | Normal range | Borderline range | Abnormal range |
|---|---|---|---|---|
| **Parent** | | | | |
| Total difficulty score | 8.4 (5.8) | 0-13 | 14-16 | 17-40 |
| Impact score | 0.4 (1.1) | 0 | 1 | 2 |
| **Teacher** | | | | |
| Total difficulty score | 6.6 (6.0) | 0-11 | 12-15 | 16-40 |
| Impact score | 0.4 (1.0) | 0 | 1 | 2 |
| **Self** | | | | |
| Total difficulty score | 10.3 (5.2) | n/a | n/a | n/a |
| Impact score | 0.2 (0.8) | n/a | n/a | n/a |

### *The Development and Wellbeing Assessment (DAWBA)*

The Development and Wellbeing Assessment (DAWBA) was used to determine psychiatric diagnostic status (Goodman *et al.* 2000). It has demonstrated high levels of agreement (93% for any disorder) between case notes and DAWBA diagnosis in clinic samples and differentiated clearly between the level of difficulty reported by those recruited from clinics and the community(Goodman *et al.* 2000). The DAWBA takes the form of a structured interview based on DSM-IV and ICD-10 criteria (World Health Organisation 1992, American Psychiatric Association, 2000), which can be administered by non-clinical researchers. Where the structured questions identify problem areas, open ended questions and prompts follow to allow the informant to describe the problem more fully – their words are then transcribed verbatim. There are also 'skip rules', allowing some sections to be missed out if initial screening questions indicate there is unlikely to be a problem, and if the relevant SDQ subscale score is within the normal range. Computer generated diagnoses arising from the interviews are then reviewed by a clinical rater who has access to all the data plus the verbatim transcripts. The clinician is subsequently able to either confirm or discard the computer generated diagnosis depending on their interpretation and clinical judgement. In the validation study by Goodman *et al.* (2000) clinical raters judged 2.2% of those given a computer generated diagnosis not to have a psychiatric disorder and assigned 4.1% additional diagnoses. Transcripts also allow them to recognise confusion arising from erroneous reporting by any informant, to assign 'not otherwise specified diagnoses' to children who are clinically impaired yet do not fit a precise diagnostic category and to deal with disagreement between informants using complex and individually tailored clinical judgments as would occur in the clinic.

**Measures of service contact**

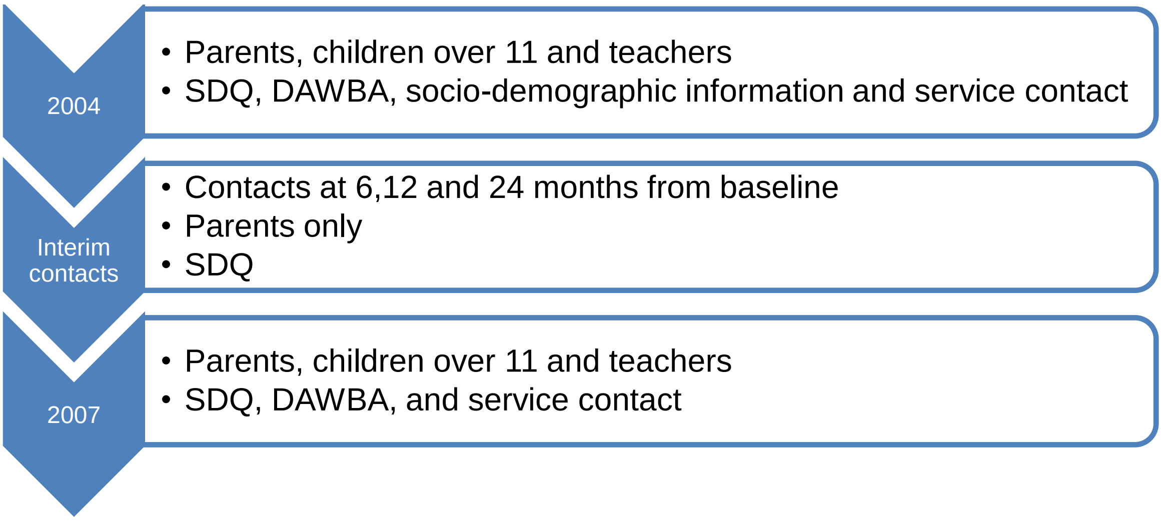
Parents were asked in 2004 and at the three-year follow up in 2007 whether they or their child had contact with a range of public sector services specifically in relation to concerns about the child's mental health in terms of emotions, behaviour or concentration difficulties within the past 12 months. These reported contacts could involve the child or parent and encompass telephone advice, meetings, assessment, or interventions received by the child and family. Throughout the analysis the term 'service contact' is therefore used to refer to contact with services in relation to their child's mental health reported by a parent. The services and professionals included were:

- Teacher
- Primary care/GP
- Specialist services
    - Educational psychology/special education
    - Paediatrics
    - Child mental health services (CAMHS)
    - Adult mental health services (AMHS)
    - Social workers/social services

### 3.3.4 Collection of data in BCAMHS

The key data from each group of informants collected at each stage is illustrated in the diagram below.

**Figure 3.2: Data collection and informants in 2004-2007 BCAMHS**



### 3.3.5 Secondary analysis

**Ethical approval**

The Multicentre Research Ethics Committee provided the ethical approval for the survey, for which all participants including parents, teachers and children over 11 gave informed consent. The Institute of Psychiatry Research Ethics committee then approved the initial secondary analysis (REC reference 103/00). The Chair of the Peninsula College of Medicine and Dentistry ethics committee subsequently made the decision that separate ethical permission for subsequent secondary analysis within the Medical School was not required.

**Variables used in the secondary analysis**

The key measures from BCAMHS 2004 that were used in the secondary analysis are presented in Table 3.2 below

*Socio-demographic variables*

Variables relating to the child and family were selected to describe their association with service contact, and as covariates in the regression models. These key variables were pre-determined in the analysis plan and chosen due to the existing literature suggesting their association with both service use and mental health problems (see Chapter Two). All of these were baseline variables, measured in 2004.

**Table 3.2: Baseline socio-demographic variables measured in 2004**

| **Variable** | **Type** | **Values** |
|---|---|---|
| Age | Continuous | |
| Gender | Binary | Male |
| | | Female |
| Ethnicity | Binary | White |
| | | Black and minority ethnic |
| Child learning disability | Categorical | None |
| | | Borderline |
| | | Moderate |
| | | Severe |
| Child neurodevelopmental disorder (including epilepsy and cerebral palsy) | Binary | Yes |
| | | No |
| Child general health | Binary | Very good or good |
| | | Fair, poor, very poor |
| Life events | Binary | Three or more |
| | | Two or fewer |
| At least one parent in employment | Binary | Yes |
| | | No |
| Housing status | Binary | Rented |
| | | Non-rented |

| | | |
|---|---|---|
| Maternal age at birth | Continuous | |
| Parental education level | Categorical | No qualifications |
| | | Poor GCSE |
| | | Good GCSE or A-Level |
| | | Degree or diploma |
| Household income | Binary | £200 or more per week |
| | | Less than £200 per week |
| Socio-economic status of household reference person (five category National Statistics Socio-economic Classification, referred to as NS-SEC) | Categorical | Higher/lower managerial |
| | | Intermediate/small employer |
| | | Lower supervisory/ semi-routine |
| | | Never worked/ long-term unemployed |
| | | Full Time students/not stated |
| Family size | Categorical | Two or fewer children |
| | | Three or more children |
| Family type | Categorical | Traditional ( 2 parent) |
| | | Single parent |
| | | Reconstituted |
| | | Grandparent care/other |
| Family functioning<br>(using McMasters score) | Binary | Unhealthy (score <2) |
| | | Healthy (score 2 or more) |
| Parental General Health Questionnaire score | Binary | Case (score of 3 or more) |
| | | Non case (score of 2 or fewer) |

*Diagnostic and psychopathology variables*

DSM-IV DAWBA diagnoses are presented throughout, as using ICD-10 criteria resulted in almost identical disorder prevalence; the only exception being hyperkinetic disorder/ADHD. The ICD-10 criteria for hyperkinetic disorder identify a slightly narrower group than the DSM-IV ADHD criteria, although there is substantial overlap in terms of clinical characteristics in validity studies (Tripp *et al.* 1999, Lee *et al.* 2008). Therefore, in order to capture a broader range of psychopathology, DAWBA diagnoses using DSM-IV were used throughout the secondary analysis. The main diagnostic groups were conduct disorder/Oppositional Defiant Disorder (ODD), (referred to throughout as conduct disorder), ADHD, anxiety disorder, depressive disorder and pervasive developmental disorder (PDD).

Children' characteristics and service contact were analysed according to their DAWBA diagnosis status, which was assessed in 2004 and 2007. Diagnostic status was categorised as follows:  any DAWBA diagnosis 2004 or 2007 (referred to as: "any disorder"), or no DAWBA diagnosis in 2004 or 2007. Disorder status was also examined according to the diagnostic status in 2004 and 2007; categorised as no disorder, resolving disorder, emerging disorder and persisting disorder. Table 3.3 defines these diagnostic variables which were created for the secondary analysis, in more detail.

The key SDQ scales selected for the secondary analysis were the total difficulty and total impact scores. The total difficulty score is a dimensional measure that represents a broad range of psychological difficulty, and so was particularly appropriate for capturing psychopathology across different psychiatric disorders. Impact as rated by the SDQ has been studied in BCAMHS 2004 by Stringaris and Goodman (2013) who found it to have stability and consistency as well as predicting future disorder. The impact supplement also asks whether respondents are concerned that the child has a problem in terms of emotions, behaviour, concentration or relationships with others; this binary variable was also selected for the analysis. The prosocial subscale score was included in the secondary analysis although was not included as an outcome in the linear and logistic regression models. Finally, although parent, teacher and self-rated SDQ scores are presented, only parent and teacher rated scores were included in the regression models as self-rated scores were not captured for under-11s. Parent rated scores were used as the outcome measure when analysing the relationship between service contact and outcome, as data from parents was available on more of the sample than scores from the other two informants (see Missing Data section).

### *Service contact variables*

Service contact was categorised in various ways (see Table 3.3 for details). Firstly, as any service contact, reported in 2004 and/or 2007, with any of the main service types: teachers, special education, primary care, paediatrics, CAMHS, AMHS and social work. Secondly, a specialist service contact variable was created, defined as any contact in 2004 and/or 2007 with a specialist service – i.e. special education, paediatrics, CAMHS, AMHS or social work. Thirdly, service contact was also reported as contact in 2004 and/or 2007 by individual service type. Finally, variables were also created to describe both “any service contact” or CAMHS contact over time, defined as: no service contact, contact in 2004 only, contact in 2007, and contact at both time points (2004 and 2007).

### *Variable management*

A number of new categorical and binary variables were created for the secondary analysis. This process is described in the table below.

**Table 3.3: New variables created for the secondary analysis of BCAMHS 2004-2007**

| New variable | Description | Values of new variable |
|---|---|---|
| **Socio-demographic** | | |
| Child’s general health | Recoded from 5 categories (‘very good, good, fair, bad, or very bad’) to 2 | Very good or good |
| | | Fair, bad or very bad |
| Child’s ethnicity | Recoded from 5 categories (‘white, black, Indian, Pakistani/Bangladeshi, other’) to 2 | White |
| | | Non-white/Black and Minority Ethnic |
| Household income | Recoded from categorical to binary | £200 and above per week |
| | | Less than £200 per week |
| Family size | Recoded from categorical to binary | 2 or fewer children |
| | | 3 or more children |
| **Diagnosis and psychopathology** | | |
| Any disorder 2004 or 2007 according to DAWBA | New binary variable | Any disorder 2004 or 2007 |
| | | No disorder 2004 or 2007 |
| Disorder status according to the DAWBA over the follow-up period | New categorical variable | No disorder |
| | | Resolving disorder (2004 only) |
| | | Emerging disorder (2007 only) |
| | | Persisting disorder (2004 & 2007) |
| Abnormal SDQ parental total difficulty score | Continuous variable of parental total difficulty score in 04 and 07 was recoded into a binary variable for each year, using the score of 17 which is the cut-off point for an abnormal score | Parental total difficulty score below 17 |
| | | Parental total difficulty score of 17 and above |

| **Service contact** | | |
|---|---|---|
| Any service contact 2004 or 2007 | New binary variable | No service contact 2004 or 2007 |
| | | Any service contact 2004 or 2007 |
| Any specialist service contact 2004 or 2007 | New binary variable. Specialist service contact was defined as reported contact with any of the following: CAMHS, AMHS, special education, social work and paediatrics | No specialist service contact 2004 or 2007 |
| | | Any specialist service contact 2004 or 2007 |
| Contact with services 2004-2007 | New categorical variable | No contact |
| | | Contact 2004 only |
| | | Contact 2007 only |
| | | Contact 2004 & 2007 |
| Contact with specialist services 2004-2007 | New categorical variable | No contact |
| | | Contact 2004 only |
| | | Contact 2007 only |
| | | Contact 2004 & 2007 |
| Type of service contact | New categorical variable | Teacher |
| | | CAMHS |
| | | GP |
| | | Paediatrics |
| | | Special education |
| | | Social work |
| | | AMHS |
| | | Other |

## Application of weights in the secondary analysis

### *Weighting procedures used in BCAMHS*

The selection procedure described above for BCAMHS should have resulted in equal sampling probability for each child. However, there was some inequality due to a delay in sampling and the withdrawal of a very small number of children considered sensitive cases by the Child Benefit Centre. The second stage involved accounting for the regional variation in response rate, which ranged from 69% in London to 81% in the South West (Green *et al.* 2005). The BCAMHS team applied weights to correct for this so that the sample represented the total population age/sex/region structure. The BCAMHS 2004 report consequently used weighted bases when presenting figures from the survey.

In the 2007 follow up, weighting was a three stage procedure involving firstly weighting the 2007 sample using the 2004 survey population weights. Subsequently, it was necessary to account for differential non-response at follow-up based on variables associated with non-response. These included region, age, sex, diagnosis, family type and SDQ score. The third stage was to weight to match the age, sex and region population structure according to the ONS figures (Parry-Langdon 2008).

### *Weights in the secondary analysis*

As the current secondary analysis used the sample of children who were followed up in 2007, the 2007 weighting derived by the BCAMHS authors was used where appropriate. Descriptive analysis of sample characteristics was unweighted. Where prevalence of diagnoses and contact with services was analysed, as well as throughout the regression models, 2007 weights were applied.

## Missing data

### *Completeness of dataset*

Missing data in 2004 and 2007 are shown in Table 3.4a & b below. Of the 2007 follow-up sample used for the descriptive analysis, there were missing data for fewer than 4% of participants on all of the socio-demographic variables. As a completed interview was a prerequisite for inclusion in the sample, all participants had a completed DAWBA in 2004 and 2007, meaning that the disorder status was known for all participants. Similarly, over 99% had no missing data on parental rating of concern or parental SDQ. The exception was self-rated and teacher-rated scores on the SDQ (Table 3.4). Teachers were only contacted when parents gave permission to do so; where teachers were contacted, 83% in 2004 and 74% in 2007 returned a completed questionnaire (1, 159). Approximately a fifth of cases in the study sample had teacher SDQ ratings missing in 2004, and approximately two-fifths had these variables missing in 2007. There was also a high proportion of missing data on self-rating scores, even amongst the over-11s who were eligible to complete the SDQ.

**Table 3.4a Missing data in the 2004 and 2007 samples: Percentage with missing data on socio-economic and demographic variables**

| **Variable** | **2004 sample (n=7,977) %** | **2007 sample (n=5,326) %** |
|---|---|---|
| **Age** | 0 | 0 |
| **Gender** | 0 | 0 |
| **Ethnicity** | 0.05 | 0.1 |
| **Neurodevelopmental disorder** | 1.4 | 0 |
| **Life events** | 2.5 | 0.7 |
| **Learning Disability** | 0.6 | 0.1 |
| **Parental unemployment** | 2.2 | 0.6 |
| **Maternal age at birth** | 3.1 | 2.1 |
| **Rented accommodation** | 0.1 | 0.04 |
| **Parental education** | 2.7 | 0.7 |
| **Family size** | 0 | 0 |
| **Family type** | 0 | 0 |
| **Household income** | 4.6 | 4.0 |
| **Child general health** | 1.4 | 0 |
| **Family functioning score** | 3.6 | 1.2 |
| **GHQ score** | 3.0 | 1.0 |
| **Social class (NS-SEC)** | 0 | 0 |

**Table 3.4b Missing data in the 2004 and 2007 samples: Percentage with missing data on diagnosis and psychopathology variables**

| **Variable** | **2004 sample (n=7,977) %** | **2007 sample (n=5,326) %** |
|---|---|---|
| **DAWBA diagnosis** | 0 | 0 |
| **Concern at baseline** | 1.4 | 0 |
| **SDQ Parental total difficulty score 2004** | 0.7 | 0.1 |
| **SDQ Parental impact score 2004** | 0.6 | 0.04 |
| **SDQ Parental prosocial score 2004** | 0.5 | 0.02 |
| **SDQ Teacher total difficulty score 2004** | 25.0 | 22.3 |
| **SDQ Teacher impact score 2004** | 25.2 | 22.6 |
| **SDQ Teacher prosocial score 2004** | 25.0 | 22.3 |
| **SDQ Self total difficulty score 2004** | 57.0 | 57.2 |
| **SDQ Self- impact score 2004** | 82.8 | 57.4 |
| **SDQ Self prosocial score 2004** | 57.0 | 57.2 |
| **SDQ Parental total difficulty score 12 months** | 20.1 | 8.2 |
| **SDQ Parental total difficulty score 24 months** | 27.4 | 12.3 |
| **SDQ Parental total difficulty score 2007** | 33.8 | 0.9 |
| **SDQ Parental impact score 2007** | 33.8 | 0.8 |
| **SDQ Parental prosocial score 2007** | 33.8 | 0.8 |
| **SDQ Teacher impact score 2007** | 60.8 | 41.3 |
| **SDQ Teacher total difficulty score 2007** | 61.3 | 42.0 |
| **SDQ Teacher prosocial score 2007** | 60.8 | 41.2 |
| **SDQ Self total difficulty score 2007** | 57.2 | 35.9 |
| **SDQ Self impact score 2007** | 57.4 | 36.3 |
| **SDQ Self prosocial score 2007** | 57.2 | 35.9 |

*Distribution of missing data in the study sample*

The distribution of the missing data by diagnostic status was examined for the study sample for all variables where more than 2% of the data were missing. This is not presented for the self- rated scores as they were only used in the descriptive analysis. The table below (Table 3.5) displays the distribution of missing data by DAWBA disorder status in 2004 and 2007. Data were missing for a slightly higher proportion of children with disorders in 2004 and/or 2007 than without disorders on the teacher SDQ ratings in 2007 in particular; however 2007 scores were used only in descriptive analysis and were not included in the regression models. There was also a less marked difference in missing data on household income at baseline, parental age at birth and service contact in 2007.

**Table 3.5: Distribution of missing data by DAWBA disorder status in the 2007 follow-up sample**

| **Variable** | **Percentage with missing data (%) (n=5,326)** | | | |
|---|---|---|---|---|
| | **DAWBA diagnosis at baseline (2004)** | | **DAWBA diagnosis at follow-up (2007)** | |
| | **Yes** | **No** | **Yes** | **No** |
| **SDQ Teacher total difficulty score 2004** | 20.9 | 22.4 | 24.1 | 22.1 |
| **SDQ Teacher impact score 2004** | 21.2 | 22.8 | 24.5 | 22.4 |
| **SDQ Teacher prosocial score 2004** | 20.9 | 22.4 | 24.5 | 22.1 |
| **SDQ Teacher total difficulty score 2007** | 49.0 | 41.4 | 43.0 | 41.9 |
| **SDQ Teacher impact score 2007** | 48.3 | 40.7 | 42.3 | 41.2 |
| **SDQ Teacher prosocial score 2007** | 48.6 | 40.6 | 41.7 | 41.2 |
| **Household income** | 5.1 | 3.9 | 4.4 | 4.0 |
| **Parental age at birth** | 2.9 | 2.0 | 2.5 | 2.2 |
| **Service contact 2007** | 1.4 | 2.5 | 2.7 | 1.2 |

### Data analysis

Analyses were carried out using Stata SE version 14 (Statacorp 2015).For the initial descriptive analysis, the characteristics of the children in the sample were described in terms of socio-demographics, prevalence of disorders and contact with services, presented with percentages and 95% confidence intervals, or with means and standard deviations for continuous variables. SDQ total difficulty scores were summarised as means with standard deviations, and SDQ impact scores were examined using the median and interquartile range, as the distribution of impact scores is more skewed than total difficulty scores. Throughout, the term ‘statistically significant’ is used in the text as a shorthand to refer to a result with a p value lower than 0.05. However, in tables, more exact p values are given i.e. <0.05 or <0.001, and 95% confidence intervals are also given to indicate the precision of the result.

For the three main research questions, the analysis procedure is described below.

### *Question 1: What services do children with psychiatric diagnoses have contact with over a three-year period (2004-2007)?*

Contact with any service was examined according to children's DAWBA diagnosis, firstly, as the percentage of those with any disorder who had any service contact, and subsequently by disorder status over time (none, resolving, emerging, persisting) and by the type of diagnosis. The analysis was then repeated for contact by service type and by service contact over time. Contact with any service was also examined by psychopathology according to whether the child had a parental total difficulty SDQ score in the abnormal range. In order to explore patterns of service contact, the percentage of those in contact with one service type with any disorder who also reported contact with another service type was tabulated.

As these were categorical and binary variables, they were presented as percentages using cross-tabulation. The Chi-squared test for association between categorical variables was also performed where appropriate and p values were reported. To examine the odds of service contact in different disorder groups, odds ratios and confidence intervals were derived using logistic regression. Contact with services was also described in the two age groups: children aged 5-10 at baseline and children aged 11-15 at baseline. Association between service contact and gender was explored further using logistic regression. Age as an effect modifier in the relationship between gender and service contact was initially examined by tabulating the percentages in contact and the odds of contact for each gender, with and without a diagnosis, for the 5-10 age group and the 11-15 age group. Tests for interaction were also performed using likelihood ratios.

Finally, to examine the level of difficulty experienced by children who did have contact with services, the mean parent, teacher and self-rated SDQ total difficulty scores in 2007 were calculated for children by contact with any service, and by service type.

### ***Question 2: What factors predict contact with services over the study period?***

*Any service contact*

Logistic regression was used to firstly examine the association between contact with any service in 2004 and /or 2007 (binary outcome) and potential predictor variables. The baseline predictor variables fell into four groups: characteristics of the child, the family, disorder type at baseline on DAWBA and baseline parent and teacher SDQ total difficulty, impact and prosocial scores. Child SDQ scores were not included in the predictor variables as these were only completed by over 11s and over half had missing data. Consideration was given as to whether to include the teacher ratings of psychopathology on the SDQ as predictors in the models, due to the fact almost a fifth of participants had missing data for this variable (see Missing Data). Regression models were run with and without the variable and there was no significant difference in the results or the fit of the model as tested using Hosmer and Lemeshow's (1980) goodness-of-fit F-adjusted mean. However, given that teachers were often contacted regarding mental health problems, in this analysis and in the previous BCAMHS 1999-2002, teacher rating of difficulty appeared to be an important variable to include.

The child and family variables entered into each model were: age, gender, ethnicity, child learning disability, child neurodevelopmental disorder, child general health, life events, parental employment, housing status, parental age at birth, parental education level, household income, socio-economic status of household reference person, family size, family type, family functioning and parental GHQ in the case range. Details of these variables are given earlier under *Socio-demographic variables*.

Models were fitted in three stages. First, each potential predictor was entered singly in separate models. Secondly, factors that were associated with contact at the 5% level of significance were then included in a multivariable model for each grouping of variables. Lastly, all factors that were still significant predictors at this stage were entered into a final multivariable model.

Age (aged 10 or under versus aged 11 or over at baseline) was initially examined as a potential modifier of the relationship between gender and service contact, as this has been previously reported (Ford *et al.* 2008b, Young *et al.* 2011, Reijneveld *et al.*

2014) and likelihood ratios were therefore used to test for interaction between age and gender. In consideration of this interaction, and due to the differences between primary and secondary school aged children (e.g. many emotional disorders are more common in older children (Ford *et al.* 2003)), the predictors of contact were examined separately for children aged 5-10 at baseline and children aged 11-15 at baseline.

### *Contact by service type*

Using the logistic regression methods described above, the analysis was repeated with any specialist service contact as the outcome variable; and subsequently for the four most commonly contacted services: teacher, GP, CAMHS and special education. Again, the predictors of contact were examined separately for children aged 5-10 at baseline and children aged 11-15 at baseline.

### *Testing the models*

The fit of each final model was tested using the survey-adjusted version of Hosmer and Lemeshow's goodness-of-fit F-adjusted mean.

## ***Question 3: What are the trajectories of psychopathology over time in children who do and do not have service contact, and are there differences in outcome in 2007 between children who have been in contact with services and those who have not?***

### *Analysis of trajectories*

The parent rated total difficulty score of the SDQ was selected as the main measure for the analysis of trajectories and of outcomes, as it represents a validated dimensional measure of a broad range of psychological difficulty (Goodman and Goodman 2009). It is approximately normally distributed with a positive skew. Service contact was analysed as any service contact, or contact with CAMHS in particular, as this would capture both general mental health-related contact and contact with specific child mental health services.

To analyse trajectories of psychopathology over time, tables were produced of mean parental total difficulty SDQ score at baseline, 12 and 24 months and in 2007, by service contact group; firstly for contact with any service, and then for contact with

CAMHS. Mean parental total difficulty scores were then plotted using line graphs to display the trajectories of psychopathology in groups with different levels of service contact. Parent rated SDQ impact scores over time were also examined in order to determine whether they would show similar trends. As the distribution of the impact score is skewed, tables were produced to show the median and interquartile range as the summary measure; and the impact scores were also displayed in box and whisker charts.

*Regression analysis of association between service contact and outcome*

Linear regression was used to examine the association between service contact and parental SDQ total difficulty score in 2007. This was done separately for children with and without a DAWBA diagnosis at baseline in 2004. The outcomes of children without a diagnosis at baseline were examined as, due to the categorical nature of assigning psychiatric diagnoses, it is possible for children to be developing or experiencing clinical levels of psychopathology, yet not meet criteria for a single diagnosis on the DAWBA, and similarly, symptoms may fluctuate over time. Separate models were fitted for any service contact and CAMHS contact. Contact was examined using the categories: no contact, contact 2004 only, contact 2007 only, contact 2004 and 2007. This contact variable was firstly entered into an unadjusted linear regression model with 2007 parent SDQ total difficulty score as the outcome. Secondly, it was entered into an adjusted model with covariates which might act as confounders due to their association with service contact and outcome. These were: age, gender, ethnicity, child learning disability, child neurodevelopmental disorder, child general health, life events, parental employment, housing status, parental education level, household income, parental socio-economic status, family size, family type, family functioning and parental GHQ in the case range, as well as concern about child mental health, parent and teacher SDQ total difficulty and impact scores at baseline. The fit of the linear regression models were tested by examining the distribution of the standardised residuals and plotting them against the fitted values to check for heteroscedasticity.

# 3.4 Results

The results are presented in two parts: firstly, there is a description of the sample and its characteristics, and secondly, the findings in relation to each of the research questions are described.

## 3.4.1 Description of sample

In this section, the basic characteristics of the whole sample are first described in terms of socio-demographic variables, disorder status and psychopathology. This is followed by a brief analysis of children’s characteristics firstly by DAWBA disorder status and then by service contact status. Finally, the prevalence of disorders and psychopathology in children reporting contact with services is presented.

### Whole sample characteristics

The sample for the secondary analysis consisted of all the 5,326 children who were followed up in 2007. The mean age was 13. 44 (SD = 3.32). Ages of the children and young people in the sample ranged from 7 to 20; 51.5% were boys and 48.5% girls. Almost 90% were white, with the largest ethnic groups being children of mixed or other races (3.8%), and children of Pakistani/Bangladeshi origin (2.6%).  Just under 2% were of Indian origin (1.9%) and black children made up the smallest group (1.8%). Other characteristics of the child and family are displayed in Table 3.6 below.

### Table 3.6: Child and family characteristics of sample (unweighted)

| **Characteristic at baseline in 2004** | **Percentage of sample (n=5,326)** |
|---|---|
| **Parental unemployment (neither parent working) %** | 15.4 |
| **Living in rented accommodation %** | 38.9 |
| **Single parent family %** | 24.5 |
| **Family size** | |
| 2 or fewer children | 64.2 |
| 3 or more children | 35.8 |
| **Parental education** | |
| No qualifications % | 18.3 |
| Poor GCSE or equivalent % | 13.7 |
| Good GCSE or A-Level % | 41.4 |
| Degree or diploma % | 26.7 |
| **Household income under £200 per week %** | 13.8 |
| **Maternal age at birth, mean (SD)** | 28.3 (5.3) |
| **Parental GHQ score in clinical range %** | 22.6 |
| **Unhealthy family functioning score %** | 17.5 |
| **Child's general health: fair, bad or very bad %** | 5.1 |
| **Child has a neurodevelopmental disorder (e.g. epilepsy, cerebral palsy etc.) %** | 3.0 |
| **Child general learning disability** | |
| None % | 92.5 |
| Borderline % | 5.8 |
| Moderate % | 1.3 |
| Severe % | 0.39 |
| **Socio-economic status (NS-SEC) of household reference person:** | |
| Higher/lower managerial % | 39.8 |
| Intermediate,small employer % | 21.7 |
| Lower supervisory/ semi-routine % | 35.2 |
| Never worked/ long-term unemployed % | 2.1 |
| Full time students/not stated % | 1.3 |

### *Prevalence of psychiatric disorders*

Almost one in ten children met criteria for a DSM-IV diagnosis for a psychiatric disorder on the DAWBA at baseline and in 2007. The prevalence of the main diagnostic groups is presented in Table 3.7. Fewer than 0.4% met criteria for rarer disorders such as mutism, tics and eating disorders and therefore data on these groups was considered to be too small for further analysis(Green *et al.* 2005).The most common disorder at both time points was conduct disorder and the least common was pervasive developmental disorder. One in five of those with a disorder had more than one disorder in 2004(Green *et al.* 2005).

**Table 3.7: Prevalence of DAWBA – identified disorders in 2004 and 2007**

| **Development and Wellbeing Assessment diagnosis (DSM-IV)** | **Percentage with the disorder in 2004* (weighted)** | **Percentage with the disorder in 2007 (weighted)** |
|---|---|---|
| **Any disorder** | 9.6 | 9.1 |
| **Any ADHD/hyperkinetic disorder** | 1.5 | 1.3 |
| **Any conduct disorder or Oppositional Defiant Disorder** | 5.8 | 4.4 |
| **Any depressive disorder** | 0.9 | 1.1 |
| **Any anxiety disorder** | 3.3 | 3.4 |
| **Pervasive developmental disorder** | 0.9 | 0.8 |

*Taken from 2004 survey report (Green *et al.* 2005)

### *Disorder status 2004-2007*

Over 200 of the 5,326 children had at least one disorder in both 2004 and 2007, comprising four per cent of the total follow-up sample. This encompassed both homotypic and heterotypic persisting disorders – i.e. children who had the same disorder at both points and children who had different diagnoses in 2004 and 2007. Two hundred and seventy children developed a new disorder between 2004 and 2007.

**Table 3.8: DAWBA disorder status 2004-2007**

| Disorder status | N | Percentage |
|---|---|---|
| **No disorder** | 4,640 | 87.1 |
| **Resolving disorder (04 only)** | 204 | 3.8 |
| **Emerging disorder (07 only)** | 270 | 5.1 |
| **Persisting disorder (04 and 07)** | 212 | 4.0 |
| **Total** | 5,326 | 100 |

***Psychopathology according to the SDQ***

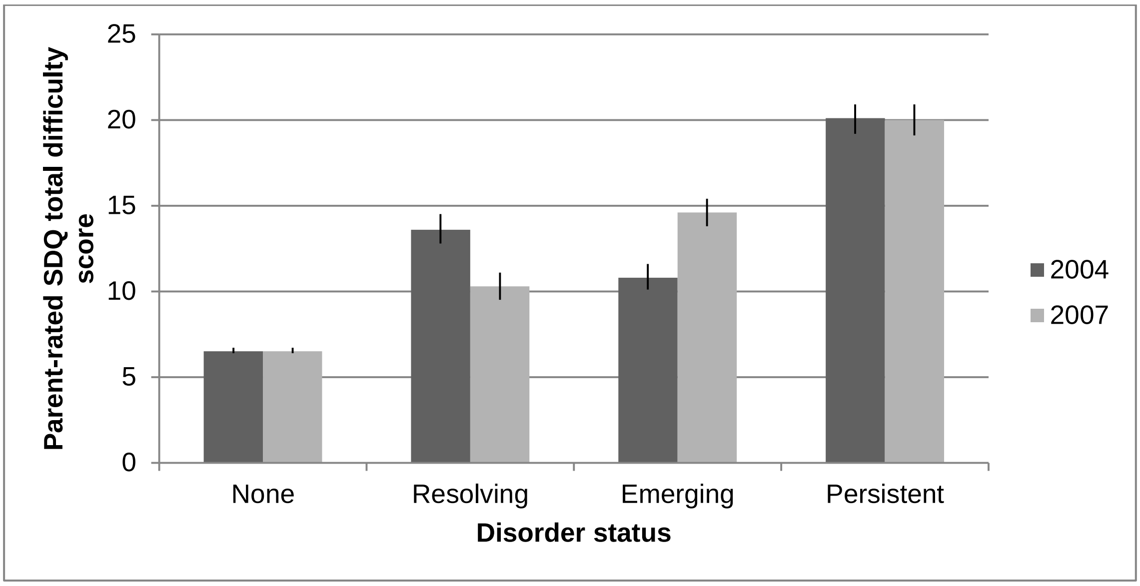
The mean parent, teacher and self-rated total difficulty scores for the whole sample in 2004 and 2007 are presented in Table 3.9. At both time points the mean scores were within the normal range.

**Table 3.9: Mean SDQ total difficulty scores in 2004 and 2007**

| SDQ rater | SDQ Total difficulty score Mean (SD) | |
|---|---|---|
| | **2004** | **2007** |
| **Parent rated** | 7.97 (5.92) | 7.56 (5.84) |
| **Teacher rated** | 6.48 (6.00) | 5.67 (5.77) |
| **Child rated** | 10.01 (5.19) | 9.68 (5.12) |

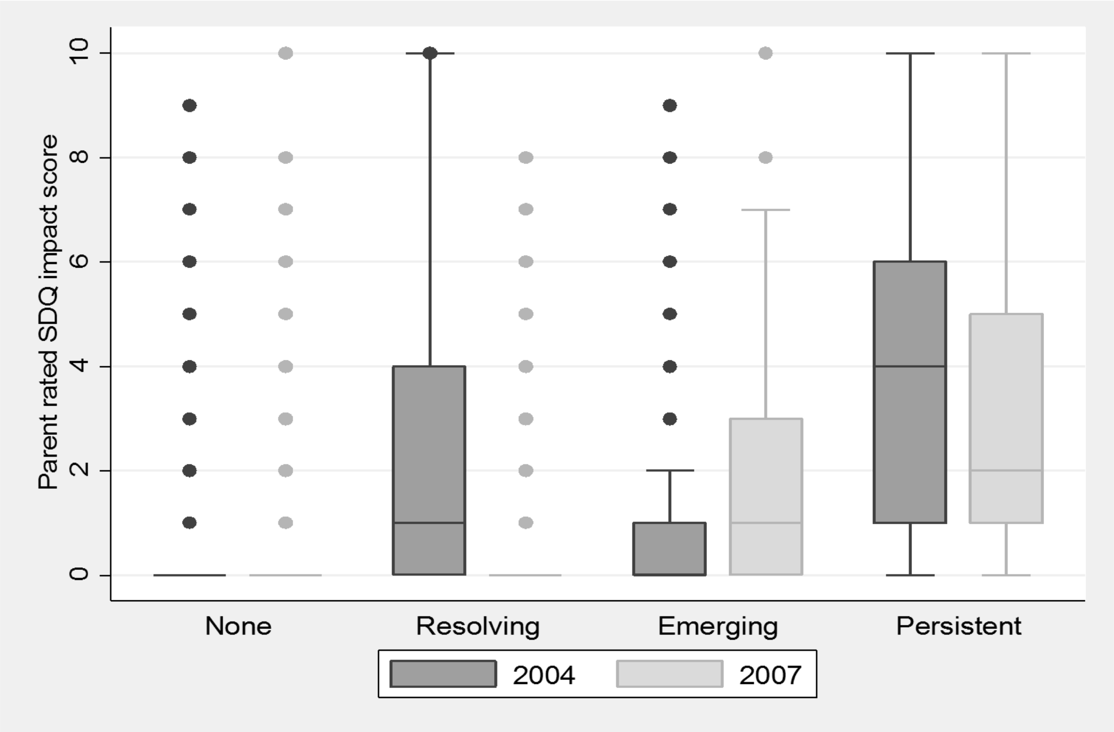
SDQ scores were then examined by DAWBA disorder status. These scores corresponded closely to disorder status, as demonstrated in Figure 3.3 below. Children with resolving, emerging and persisting disorders over the study period had significantly higher parental total difficulty scores in 2004 and 2007 than children who did not meet criteria for a DAWBA diagnosis at either point. Children with a persistent disorder had a mean score of 20 points at both time points, a score well into the abnormal range. Those who had a disorder in 2004 but not in 2007 (the resolving group) had a higher mean total difficulty score in 2004 than in 2007, whereas the emerging group who had a disorder in 2007 but not in 2004 had a higher score in 2007 than 2004.

**Figure 3.3: Mean parental total difficulty score in 2004 and 2007 by disorder status, with 95% confidence intervals**



A similar pattern is seen in relation to the parent-rated SDQ impact scores (Figure 3.4), although in contrast to the total difficulty score, for children with persisting disorders the median impact score is lower in 2007 than 2004, possibly a result of attenuation, or adaptation to the disorder.

**Figure 3.4: Box and whiskers plot of median parental impact scores in 2004 and 2007 by diagnostic status, showing median score and interquartile range**



## Characteristics by disorder status

Boys made up nearly three-quarters (71.2%) of those with a persistent disorder (see Table 3.10 below). Almost one fifth of this group also had a neurodevelopmental disorder. The persisting disorders group also had the highest proportion of parental unemployment and were more likely to be living in rented accommodation. Just under one-third had experienced three or more stressful life events, in comparison to fewer than one in ten of the no disorder group, and 45% of the parents of these children scored in the ‘case’ range on the GHQ.

The resolving disorders group had the highest proportion of children living in a single parent headed family (35.8%). In this group, a fifth had a household income lower than £200 per week and over a quarter had mothers with no qualifications.

There were also significant differences between disorder groups in terms of family size, family functioning, and socio-economic status. Children without any disorder had healthier family functioning, better general health and came from families in higher socio-economic groups.

## Table 3.10: Child and family characteristics by disorder status 2004-2007 (unweighted)

| **Characteristics** | **No disorder (n=4,640)** | **Resolving disorder (n=204)** | **Emerging disorder (n=270)** | **Persistent Disorder (n=212)** | **p value** |
|---|---|---|---|---|---|
| **Age, mean (SD)** | 10.3 (3.3) | 11.3 (3.4) | 10.6 (3.3) | 10.5 (3.1) | NS* |
| **Male gender %** | 50.5 | 57.8 | 49.3 | 71.2 | p <0.001 |
| **White ethnicity %** | 89.6 | 94.1 | 90.7 | 92.9 | NS* |
| **Neurodevelopmental disorder %** | 2.1 | 3.9 | 5.9 | 18.9 | p<0.001 |
| **Any Learning Disability %** | 5.6 | 18.4 | 13.0 | 33.5 | p <0.001 |
| **Three or more life events %** | 7.7 | 25.1 | 18.8 | 32.7 | p <0.001 |
| **Parental unemployment % (neither parent working)** | 10.1 | 22.7 | 20.5 | 27.8 | p <0.001 |
| **Living in rented accommodation %** | 21.5 | 38.2 | 35.3 | 44.3 | p <0.001 |
| **Single parent family %** | 19.0 | 35.8 | 25.6 | 31.1 | p <0.001 |
| **Family size: 3 or more children** | 35.1 | 37.3 | 40.7 | 43.4 | p<0.05 |
| **No parental qualifications** | 14.3 | 26.2 | 17.2 | 25.4 | p <0.001 |
| **Household income under £200 per week %** | 10.8 | 20.0 | 16.9 | 12.0 | p<0.001 |
| **Parental age at birth, mean (SD)** | 29.0 (5.2) | 27.7 (5.4) | 28.1 (5.4) | 27.8 (5.6) | NS* |
| **Parental GHQ score in clinical range %** | 19.2 | 41.1 | 30.1 | 45.4 | p <0.001 |
| **Unhealthy family functioning score %** | 14.6 | 23.8 | 17.8 | 34.6 | p <0.001 |
| **Child general health: Fair, bad or very bad %** | 4.0 | 11.3 | 10.0 | 17.5 | p <0.001 |
| **Socio-economic status (NS-SEC)** | | | | | |
| Higher/lower managerial % | 41.6 | 27.9 | 31.1 | 21.2 | p <0.001 |
| Intermediate,small employer % | 21.9 | 17.2 | 21.5 | 23.1 | |
| Lower supervisory/ semi-routine % | 33.5 | 49.5 | 42.6 | 47.6 | |
| Never worked/ long-term unemployed % | 1.9 | 3.4 | 2.2 | 4.3 | |
| Students/not stated % | 1.1 | 2.0 | 2.6 | 3.8 | |

*NS = not significant at the p<0.05 level

## Contact with services

Almost 40% of all children in the sample had contact with any service regarding their mental health in 2004 or 2007. This included contact with a teacher or primary care, or with a specialist service such as CAMHS, AMHS, special education, social worker or paediatrics.  In contrast, only 15% had any contact with a specialist service, and only 3.6% had contact with a specialist service at both time points.

**Table 3.11: Contact with services 2004 and 2007: all children (unweighted)**

| Contact status | Any service | | Specialist services | |
|---|---|---|---|---|
| | N | Percentage | N | Percentage |
| **No contact** | 3,187 | 60.6 | 4,554 | 85.3 |
| **Contact 04 only** | 489 | 9.3 | 175 | 3.3 |
| **Contact 07 only** | 915 | 17.4 | 340 | 6.4 |
| **Contact 04 and 07** | 666 | 12.7 | 188 | 3.6 |
| **Total** | 5, 257 | 100 | 5,257 | 100 |

### *Characteristics by service contact status*

There were significant differences in most characteristics examined between children in different service contact groups (see Table 3.12). Children who reported service contact at both time points were younger, and the majority were male (65%). In general this group also experienced more adverse circumstances, with 33% living in rented accommodation and 19% having no parent working, whereas only 9% of those with no service contact had neither parent employed. A fifth had experienced more than three life events, and over one in ten had a neurodevelopmental disorder, in contrast to one per cent of those who reported no contact. Just under a quarter had some degree of learning disability. Parental mental health was also poorer in this group – 38% scored in the ‘case’ range in the GHQ.

## Table 3.12: Characteristics of children by service contact group 2004-2007

| Characteristics | No service contact (n= 3,187) | Service contact 04 only (n=489) | Service contact 07 only (n=915) | Service contact 04 and 07 (n=666) | p value |
|---|---|---|---|---|---|
| **Age, mean (SD)** | 10.4 (3.4) | 10.6 (3.3) | 10.1 (3.3) | 10.0 (3.2) | p<0.05 |
| **Male gender %** | 48.0 | 56.7 | 51.8 | 65.0 | p<0.001 |
| **White ethnicity %** | 88.5 | 92.6 | 93.3 | 93.8 | p<0.001 |
| **More than 3 life events %** | 6.4 | 14.5 | 11.8 | 20.1 | p<0.001 |
| **Neurodevelopmental disorder %** | 0.97 | 4.7 | 3.1 | 11.3 | p<0.001 |
| **Any learning disability %** | 3.9 | 11.7 | 7.4 | 21.3 | |
| **Parental unemployment %** | 9.3 | 11.0 | 14.3 | 19.1 | p<0.001 |
| **Living in rented accommodation %** | 20.8 | 27.4 | 23.5 | 33.2 | p<0.001 |
| **Single parent family %** | 17.2 | 25.8 | 23.8 | 26.9 | p<0.001 |
| **Family size: 3 or more children %** | 35.6 | 31.3 | 35.6 | 38.3 | NS* |
| **No parental qualifications %** | 15.0 | 15.8 | 13.1 | 17.7 | p<0.05 |
| **Household income under £200 per week %** | 10.8 | 12.5 | 11.9 | 13.8 | NS* |
| **Parental age at birth, mean (SD)** | 29.1(5.1) | 28.5 (5.3) | 28.7 (5.4) | 28.4(5.3) | p<0.05 |
| **Parental GHQ score in clinical range %** | 17.0 | 25.2 | 24.0 | 37.8 | p<0.001 |
| **Unhealthy family functioning score %** | 14.4 | 17.3 | 14.9 | 22.7 | p<0.001 |
| **Child general health:Fair, bad or very bad %** | 3.4 | 5.3 | 5.5 | 12.8 | p<0.001 |
| **Socio-economic status (NS-SEC)** | | | | | p<0.05 |
| Higher/lower managerial % | 41.4 | 38.7 | 40.2 | 35.0 | |
| Intermediate,small employer % | 22.7 | 20.7 | 20.0 | 20.0 | |
| Lower supervisory/ semi-routine % | 32.7 | 38.5 | 36.7 | 41.4 | |
| Never worked/ long-term unemployed % | 2.1 | 1.8 | 1.6 | 2.0 | |
| Students/not stated % | 1.1 | 0.4 | 1.4 | 1.7 | |

*NS = not significant at p<0.05 level

### *Contact with different service types*

Over the course of the survey, teachers were the most contacted service, with over a fifth of respondents reported having had mental health related contact with a teacher when questioned in 2004 and/or 2007 (Table 3.13). The next most contacted service was primary care. The least commonly used service was adult mental health services, although as the majority of children in the sample were under 16 in 2007 this would be expected. Consequently, when considering individual service types, the analysis focusses on contact with the five most commonly contacted health and education service types: teacher, GP/primary care, special education, CAMHS and paediatrics.

**Table 3.13: Contact with different service types, 2004 and/or 2007 (unweighted)**

| **Service type** | **Contact with service, 2004 and/or 2007** | |
|---|---|---|
| | N ( total n=5,257) | Percentage |
| **Teacher** | 1,523 | 29.0 |
| **GP** | 590 | 11.2 |
| **Special education** | 388 | 7.4 |
| **CAMHS** | 293 | 5.6 |
| **Paediatrics** | 214 | 4.1 |
| **Social work** | 128 | 2.4 |
| **AMHS** | 63 | 1.2 |

### *Characteristics of children in contact with different service types*

The characteristics of children who reported contact with the most common health and education service types in 2004 and/or 2007 is reported in Table 3.14 below. Overall, children in contact with teachers and paediatrics had a lower mean age at baseline than those in contact with primary care and CAMHS. There was also a male preponderance amongst users of every service. This was especially marked for CAMHS (65% male) paediatrics (67%) and special education (64%). Almost one in four children in contact with paediatrics had a neurodevelopmental disorder, and 16% reported fair, bad or very bad general health. Those in contact with CAMHS and special education services generally experienced the most adverse socio-economic circumstances – just under a fifth of children had no parent in employment. Children in contact with CAMHS and special education also had the highest proportion of parents with poor mental health according to the GHQ, and those in contact with primary care the lowest.

Table 3.14 Characteristics of children by contact with service type in 2004 and/or 2007 (unweighted)

| **Characteristics** | **No service contact (n= 3,187)** | **Teacher (n=1523)** | **GP (n=590)** | **CAMHS (n=293)** | **Special education (n=388)** | **Paediatrics (n=214)** |
|---|---|---|---|---|---|---|
| **Age, mean (SD)** | 10.4 (3.36) | 9.9 (3.2) | 10.4 (3.3) | 10.4 (3.2) | 10.2 (3.2) | 9.5 (3.1) |
| **Male gender %** | 48.0 | 60.5 | 55.9 | 65.2 | 63.7 | 66.8 |
| **White ethnicity %** | 88.5 | 93.6 | 93.2 | 94.2 | 93.8 | 92.5 |
| **More than 3 life events %** | 6.4 | 15.2 | 22.5 | 28.8 | 22.3 | 15.1 |
| **Neurodevelopmental disorder %** | 0.97 | 6.9 | 10.2 | 13.7 | 15.2 | 24.8 |
| **Any Learning disability %** | 3.9 | 14.3 | 17.1 | 19.5 | 26.3 | 27.1 |
| **Parental unemployment %** | 9.3 | 14.2 | 17.3 | 19.5 | 18.3 | 13.6 |
| **Living in rented accommodation %** | 20.1 | 27.1 | 30.5 | 32.8 | 32.5 | 26.2 |
| **Single parent family %** | 17.2 | 24.9 | 27.5 | 25.6 | 26.8 | 19.2 |
| **Family size: 3 or more children %** | 35.6 | 35.8 | 37.5 | 38.9 | 39.2 | 41.1 |
| **No parental qualifications %** | 15.0 | 14.8 | 18.4 | 18.9 | 23.1 | 18.9 |
| **Household income under £200 per week %** | 10.8 | 11.5 | 14.7 | 13.8 | 12.6 | 12.4 |
| **Parental age at birth, mean (SD)** | 29.1(5.1) | 28.7 (5.3) | 28.0 (5.3) | 28.4 (5.4) | 28.4 (5.1) | 28.8 (5.5) |
| **Parent GHQ score in clinical range** | 17.0 | 29.0 | 34.6 | 40.2 | 36.9 | 33.8 |
| **Unhealthy family functioning score %** | 14.4 | 18.1 | 22.3 | 22.6 | 21.1 | 20.7 |
| **Child general health: Fair, bad or very bad %** | 3.4 | 8.3 | 14.6 | 14.0 | 12.6 | 16.8 |
| **Socio-economic status (NS-SEC)** | | | | | | |
| Higher/lower managerial % | 41.4 | 38.9 | 32.0 | 36.5 | 33.5 | 35.1 |
| Intermediate,small employer % | 22.7 | 20.0 | 21.2 | 19.8 | 16.5 | 19.2 |
| Lower supervisory/ semi-routine % | 32.7 | 38.2 | 43.2 | 40.3 | 45.1 | 42.1 |
| Never worked/ long-term unemployed % | 2.1 | 1.7 | 1.5 | 1.4 | 2.8 | 2.8 |
| Students/not stated % | 1.1 | 1.2 | 2.0 | 2.1 | 2.1 | 0.9 |

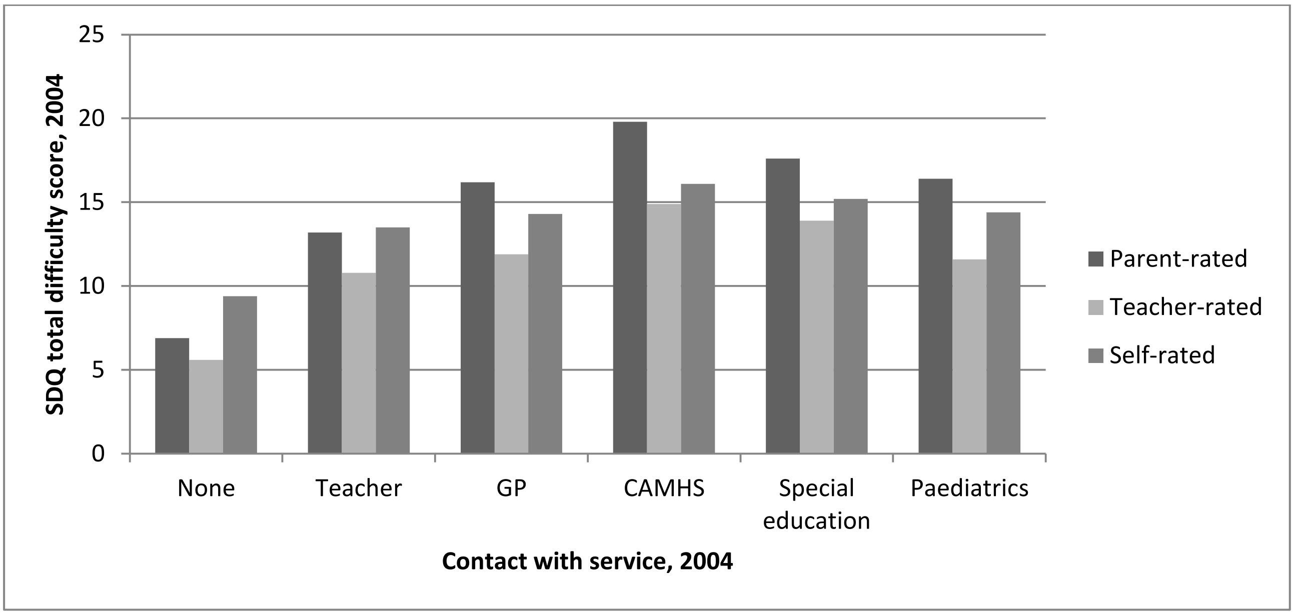
### *Psychopathology and psychiatric diagnoses amongst children in contact with services*

The prevalence of disorders was highest amongst children reporting CAMHS contact (69.2%) and lowest amongst children reporting teacher contact (32.1%)(Table 3.15). The most common disorders amongst children reporting contact with each service were conduct disorders, with anxiety disorders and then ADHD being the next most prevalent. This pattern was less marked in children in contact with paediatrics and special education. Figure 3.5 displays the mean SDQ total difficulty scores as rated by parents, teachers and children of those in contact with services at baseline. Again, these are highest for CAMHS (into the borderline and abnormal ranges) and lowest for teacher contact. The mean parent rated SDQ score was in the abnormal range for each type of service.

**Table 3.15: Prevalence of psychiatric disorders in children reporting mental health related service contact at any point (unweighted)**

| **Service contact 2004 and/or 2007** | **Percentage in contact with service with disorder at any time point (2004 and/or 2007)** | | | | | |
|---|---|---|---|---|---|---|
| | **Any disorder %** | **Conduct disorder %** | **ADHD %** | **Anxiety disorders %** | **Depressive disorders %** | **PDD %** |
| **Teacher** | 32.1 | 19.7 | 8.6 | 11.8 | 3.9 | 2.8 |
| **GP** | 49.8 | 28.7 | 13.6 | 22.5 | 7.6 | 4.7 |
| **CAMHS** | 69.2 | 43.4 | 25.3 | 30.5 | 10.0 | 9.4 |
| **Special education** | 55.1 | 35.4 | 21.4 | 21.2 | 7.9 | 7.4 |
| **Paediatrics** | 43.4 | 24.2 | 16.7 | 16.4 | 2.9 | 8.8 |

**Figure 3.5: Mean SDQ total difficulty scores of children in contact with services at baseline**



## 3.4.2 Research questions

### Question 1: What services do children with psychopathology have contact with over a three-year period (2004-2007)?

In order to answer this research question, the results are presented in three sections:

- Service contact in children with any psychiatric disorder
- Service contact according to psychiatric diagnosis
- Service contact by age and gender

### Service contact in children with any psychiatric disorder

#### *Any disorder and any service contact*

Of children with any disorder at baseline in 2004, 87.7% (95% CI 84.1-90.5%) had contact with any service at any time point (2004 and/or 2007). Having a disorder according to the DAWBA at any time point was associated with service contact ($p<0.001$). As displayed in Table 3.16 below, the vast majority (85%) of parents of children with a disorder at any time point reported contact with a service regarding their child's mental health. A third of those who did not meet criteria for a diagnosis at either time point still reported mental health related contact with services. Such children may have difficulties despite not meeting criteria for a DAWBA diagnosis at either time point, which was borne out by the SDQ scores. On examination of SDQ scores of children without a DAWBA diagnosis but with mental health-related service contact, these children had higher mean parental total difficulty scores than children who had neither a disorder nor any mental health related contact with services (mean score at baseline 8.62 versus 5.84, p<0.001, in 2007, 8.82 vs 5.51, p <0.001). A third also had parents who reported concern about their child's mental health at baseline (33.8%), compared to only 10.7% of children with neither diagnosis nor service contact.

**Table 3.16: Any service contact in children with a psychiatric disorder 2004 and/or 2007**

| **Any DAWBA disorder, 2004 or 2007** | **Any contact with any service, 2004 or 2007** | | |
|---|---|---|---|
| | **No contact % (95% CI)** | **Any contact % (95% CI)** | **Total** |
| **No disorder** | 66.5<br>(65.1-68.0) | 33.5<br>(32.1-34.9) | 100% |
| **Any disorder** | 15.5<br>(12.7-18.3) | 84.5<br>(81.7-87.3) | 100% |
| **Total** | 59.1<br>(57.7-60.5) | 40.9<br>(40.0-42.3) | 100% |

### *Disorder status and any service contact*

Almost all children with persistent disorders (96%) reported mental health related contact with services in 2004 and/or 2007 (see Table 3.17 below). Relative to children with no disorder, the odds ratio of being in contact for this group was 43.70 (95% CI 22.04-86.68). Service contact was also significantly more common among children with a resolving disorder (OR 7.73, 95% CI 5.45-10.96) or an emerging disorder (OR 7.63, 95% CI 5.6-10.41) than children without a disorder. Just over a fifth of children with a resolving or emerging disorder reported no contact with services in either 2004 or 2007.

**Table 3.17: any service contact 2004 or 2007 by disorder status, with odds ratio for service contact**

| Disorder status 2004-2007 | Percentage not in contact with any service (95% CI) | Percentage with any service contact 2004 or 2007 (95% CI) | Odds ratio for any service contact, adjusted for age and sex (95% CI) |
|---|---|---|---|
| **None** | 66.5<br>(65.1-67.9) | 33.5<br>(32.1-34.9) | Reference |
| **Resolving** | 21.1<br>(16.0-27.3) | 78.9<br>(72.7-84.0) | 7.7<br>(5.5-11.0) |
| **Emerging** | 21.1<br>(16.5-26.7) | 78.9<br>(73.3-83.5) | 7.6<br>(5.6-10.4) |
| **Persistent** | 4.2<br>(2.2-7.8) | 95.8<br>(92.0-97.8) | 43.7<br>(22.0-86.7) |

Service contact corresponded to the timing of disorder; (Table 3.18); children with a resolving disorder had higher levels of contact with services in 2004 than children with an emerging disorder, and vice versa for contact in 2007. Almost three-quarters of children with a persisting disorder reported service contact in both 2004 and 2007, in contrast to 28% of those with an emerging disorder and 39% of those with a resolving disorder.

**Table 3.18: Timing of service contact by disorder status 2004-2007**

| Disorder status | Percentage with service contact (95% confidence interval) | | | | |
|---|---|---|---|---|---|
| | No service contact | 2004 only | 2007 only | 2004 and 2007 | Total |
| **None** | 66.5<br>(65.1-67.9) | 9.1<br>(8.2-9.9) | 16.2<br>(15.1-17.3) | 8.2<br>(7.4-9.1) | 100% |
| **Resolving** | 21.1<br>(16.0-27.3) | 27.1<br>(21.3-33.9) | 13.3<br>(9.2-18.7) | 38.5<br>(32.0-45.5) | 100% |
| **Emerging** | 21.1<br>(16.5-26.7) | 6.9<br>(4.4-10.8) | 43.5<br>(37.5-49.7) | 28.4<br>(23.2-34.4) | 100% |
| **Persistent** | 4.2<br>(2.2-8.0) | 6.3<br>(3.6-10.6) | 16.5<br>(11.9-22.5) | 73.0<br>(66.4-78.8) | 100% |

***Contact with services by psychopathology on the total difficulty score***

Examining service contact by psychopathology as measured by the SDQ total difficulty score produces a similar pattern to the previous analysis of disorder (Table 3.19). A lower proportion of those with a persisting abnormal score were in contact with services at both time points than those with a persisting disorder; 64% reported both 2004 and 2007 contact as opposed to 73% of the persisting disorder group.

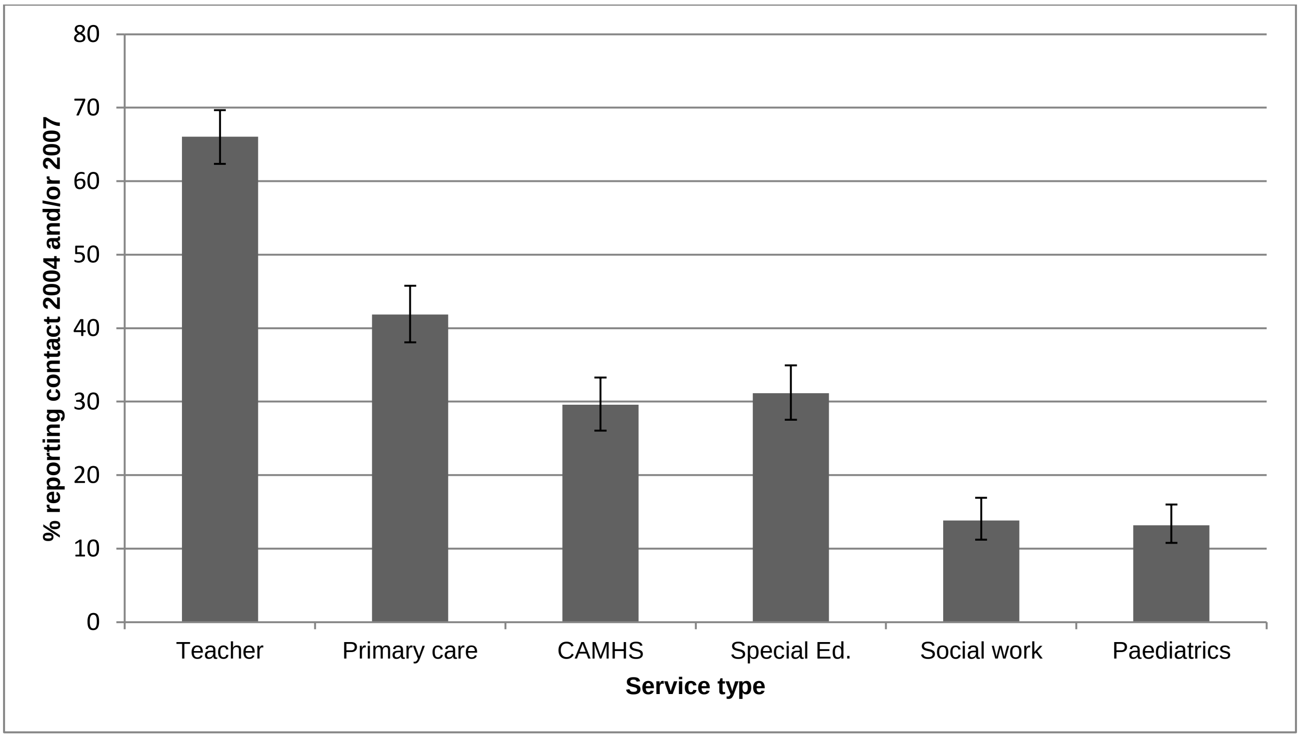
**Table 3.19: Contact with any service by abnormal parental SDQ total difficulty score (17 or above): 2004-2007**

| Abnormal parental total difficulty score | Percentage reporting contact with any service (95%CI) | | | | |
|---|---|---|---|---|---|
| | No service use | 2004 only | 2007 only | 2004 and 2007 | Total |
| **None** | 66.2<br>(64.7-67.5) | 9.1<br>(8.3-10.0) | 16.4<br>(15.3-17.5) | 8.3<br>(7.6-9.2) | 100% |
| **2004 only** | 20.7<br>(15.7-26.9) | 24.3<br>(18.7-30.9) | 14.3<br>(10.0-20.0) | 40.8<br>(34.1-47.8) | 100% |
| **2007 only** | 18.5<br>(13.9-24.3) | 6.1<br>(3.5-10.4) | 42.0<br>(35.6-8.6) | 33.4<br>(27.5-40.0) | 100% |
| **2004 & 2007** | 11.2<br>(7.6-16.1) | 7.6<br>(4.6-12.1) | 17.5<br>(12.7-23.5) | 63.8<br>(56.9 -70.1) | 100% |

### *Contact with individual services amongst children with a disorder*

Amongst children who had a DAWBA disorder at any point, teachers were the most frequently contacted service, with 66.1% of respondents reporting having approached them regarding their child's mental health. Just under half (41.9%) had contact with primary care. Specialist services were less commonly accessed; less than a third reported CAMHS contact (29.6%) or contact with special education (31.1%). The least frequently contacted health and education service as reported by participants with a disorder was paediatrics (13.1%). Contact with these services is presented in Figure 3.6 below. More detailed description of contact with individual health and education services by disorder and diagnostic status follows later.

**Figure 3.6: Contact with services amongst those with a disorder: percentage of children with any disorder reporting contact with individual services at any time point (with 95% confidence intervals)**



### *Contact with more than one service*

Table 3.20 below presents figures describing contact with more than one service amongst children with any disorder. If children were only in contact with one service, this was most likely to be a teacher. Only 38.1% of those with a disorder who reported teacher contact also reported contact with CAMHS. In contrast, 51.7% of those who had seen their GP reported CAMHS contact too. Of those seen by teachers, 48.9% reported also having contact with a GP; and of those seen in primary care, 77.2% reported mental health related contact with a teacher, which was the lowest figure for all service types. Unsurprisingly, as CAMHS is a specialist service, almost three-quarters of children seen by CAMHS also reported GP contact, and over half had also had contact with special education.

**Table 3.20: Contact with more than one service amongst those with a disorder: percentage of those in contact with one service at any point that also reported contact with another service**

| Children with a disorder in contact with: | Percentage reporting any contact with another service, 2004 or 2007 (95% confidence intervals) | | | | |
|---|---|---|---|---|---|
| | **Teacher** | **Primary care** | **Special education** | **CAMHS** | **Paediatrics** |
| **Teacher** | n/a | 48.9<br>(44.2-53.7) | 40.0<br>(35.4-44.8) | 38.1<br>(33.5-42.9) | 16.9<br>(13.6-20.9) |
| **Primary care** | 77.2<br>(71.8-81.8.) | n/a | 46.6<br>(40.7-52.7) | 51.7<br>(45.7-57.7) | 21.3<br>(16.8-26.7) |
| **Special education** | 84.9<br>(79.1-89.3) | 62.7<br>(55.7-69.3) | n/a | 55.7<br>(48.7-62.6) | 26.1<br>(20.4-32.7) |
| **CAMHS** | 85.1<br>(79.3-89.4) | 73.2<br>(66.4-79.1) | 58.7<br>(51.4-65.6) | n/a | 24.2<br>(18.6-30.9) |
| **Paediatrics** | 84.9<br>(75.4-91.2) | 67.7<br>(56.7-77.1) | 61.5<br>(50.6-71.5) | 54.3<br>(43.4-64.8) | n/a |

### *Any disorder and specialist service contact*

Specialist services were defined as CAMHS, AMHS, special education, paediatrics and social services for the purposes of this analysis. There was a significant association between psychiatric disorder and contact with specialist services (p <0.001). A smaller proportion of children were in contact with these services; just over half of those with a disorder and fewer than one in ten of those without a disorder reported contact at either time point (Table 3.21).

**Table 3.21: Specialist service contact in children with any disorder 2004 and/or 2007**

| Disorder status | Percentage reporting contact with any specialist service, 2004 or 2007 (95% confidence interval) | | |
|---|---|---|---|
| **Any disorder, 2004 or 2007** | **No contact** | **Any contact** | **Total** |
| **No disorder** | 91.5 (90.7-92.4) | 8.5 (7.6-9.3) | 100 |
| **Any disorder** | 48.6 (44.7-52.4) | 51.4 (47.6-55.3) | 100 |
| **Total** | 85.3 (84.2-86.3) | 14.7 (13.7-15.8) | 100 |

### *Any disorder and CAMHS contact*

Fewer than 30% of children with a disorder reported any contact with CAMHS. Children without a disorder were very unlikely to be seen by CAMHS; only 2.2% reported such contact (Table 3.22).

**Table 3.22: CAMHS contact in children with any disorder 2004 and/or 2007**

| Disorder status | Percentage reporting contact with CAMHS, 2004 and/or 2007 (95% confidence interval) | | |
|---|---|---|---|
| **Any disorder, 2004 or 2007** | **No contact** | **Any contact** | **Total** |
| **No disorder** | 97.8 (97.3-98.2) | 2.2 (1.8-2.7) | 100 |
| **Any disorder** | 70.4 (66.9-74.0) | 29.6 (26.0-33.1) | 100 |
| **Total** | 93.7 (93.1-94.5) | 6.2 (5.5-6.9) | 100 |

### *Type of service contact by disorder status*

Exploring contact in more detail, Table 3.23 displays contact with each individual service by disorder status over the 2004-2007 period. Teachers were again the most-contacted service. Almost 80% of those with a persisting disorder and over half of those with emerging or resolving disorders reported contact. Even amongst those who did not meet criteria for a disorder, over 20% of parents reported contact with a teacher at some point regarding their child’s mental health. Amongst children with a persisting disorder, the next most frequently used service was primary care (55% in contact) followed by special education (52%) and CAMHS (51%).

**Table 3.23: Type of service contact by disorder status 2004-2007**

| **Disorder status 2004-2007** | **Percentage of children reporting contact with each individual service over the 2004-2007 period (95% CI)** | | | | |
|---|---|---|---|---|---|
| | **Teacher** | **GP** | **CAMHS** | **Special education** | **Paediatrics** |
| **None** | 23.8<br>(22.6-25.1) | 7.2<br>(6.5-8.0) | 2.2<br>(1.8-2.7) | 4.3<br>(3.7-5.0) | 2.9<br>(2.5-3.5) |
| **Resolving** | 60.9<br>(53.9-67.5) | 34.1<br>(27.7-41.1) | 18.7<br>(13.8-24.9) | 19.6<br>(14.6-25.8) | 8.9<br>(5.5-14.0) |
| **Emerging** | 58.4<br>(52.2-64.4) | 36.1<br>(30.4-42.2) | 18.7<br>(14.4-23.9) | 22.2<br>(17.4-27.8) | 8.1<br>(5.3-12.4) |
| **Persisting** | 79.1<br>(72.7-84.4) | 55.3<br>(48.2-62.2) | 51.4<br>(44.3-58.4) | 51.5<br>(44.4-58.5) | 22.6<br>(17.4-28.8) |

### Service contact by psychiatric diagnosis

Figure 3.7 displays contact with different health and education services amongst children who had DAWBA diagnoses at any point. The majority of children within all disorder categories (anxiety disorders, depressive disorders, ADHD, CD and PDD) had contact with a teacher about their mental health; with the highest levels of contact amongst those with ADHD (86.1%), CD (74.4%) and PDD (79.6%) and the lowest amongst children with anxiety disorders (58.4%). Children with anxiety disorders had a markedly higher level of contact with primary care than with CAMHS (see Table 3.24 overleaf for estimates with confidence intervals); the same was not true for those with ADHD and PDD, who had the highest levels of CAMHS contact at over 50%. Children with more than one disorder at any time point formed 4.3% (n=184) of the sample, with almost all (95.0%, 95% CI 90.5 to 97.4%) reporting service contact in 2004 and/or 2007.

**Figure 3.7: Service contact amongst children with psychiatric disorders at any point**

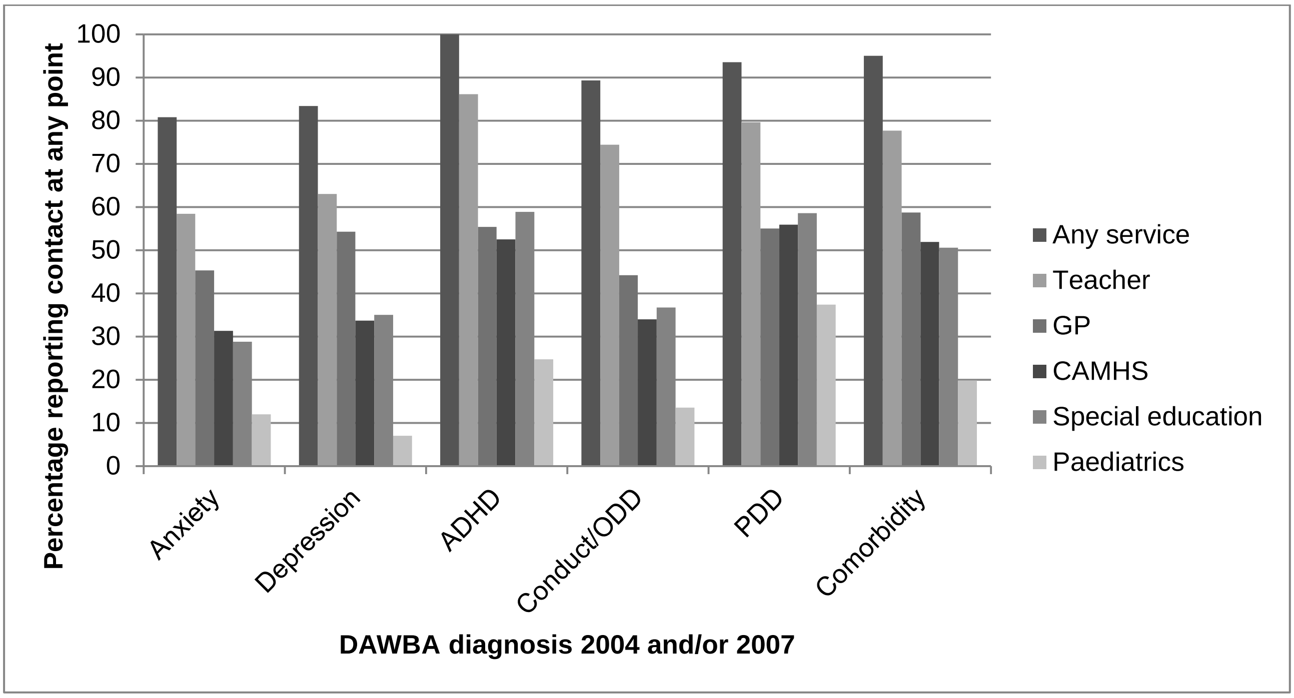


Table 3.24 below displays service contact by whether the child had a diagnosis at any time point or at both time points (persisting disorder). Over nine in ten children with a persisting diagnosis of any disorder reported mental health related contact with services. Children who met ADHD criteria at both time points had the highest levels of contact with every service except paediatrics, where contact was most frequent amongst those with a PDD.

**Table 3.24: Contact with individual services by diagnosis and diagnostic status**

| Disorder on DAWBA 2004/2007 | Timing of disorder | Percentage in contact with each service at any time point (2004 and/or 2007)(95% confidence interval) | | | | | |
|---|---|---|---|---|---|---|---|
| | | **Any service** | **Teacher** | **GP** | **CAMHS** | **Special education** | **Paediatrics** |
| **Anxiety disorders** | **Any time point (n=279)** | 80.8 (75.6-85.1) | 58.4 (52.3-64.3) | 45.3 (39.3-51.4) | 31.3 (25.9-37.3) | 28.8 (23.6-34.6) | 12.0 (8.6-16.4) |
| | **Persistent (n=39)** | 93.4 (80.5-98.0) | 69.7 (53.5-82.7) | 50.8 (34.5-66.9) | 52.1 (35.7-68.0) | 39.5 (24.7-56.5) | 16.0 (7.4-31.2) |
| **Depression** | **Any time point (n=83)** | 83.4 (73.1-90.3) | 63.0 (51.8-73) | 54.2 (43.0-65.0) | 33.7 (23.9-45.1) | 35.0 (25.2-46.3) | 7.0 (3.0-15.3) |
| | **Persistent (n=4)** | n/a | n/a | n/a | n/a | n/a | n/a |
| **ADHD** | **Any time point (n=129)** | 100 | 86.1 (78.5-91.4) | 55.4 (46.3-64.2) | 52.5 (43.5-61.4) | 58.9 (49.7-67.5) | 24.7 (17.9-33.0) |
| | **Persistent (n=53)** | 100 | 85.5 (73.6-92.6) | 59.9 (45.4-72.9) | 66 51.4-78.1) | 68.7 (53.8-80.5) | 23.8 (13.9-37.7) |
| **Conduct disorders** | **Any time point (n=354)** | 89.3 (85.6-92.1) | 74.4 (69.4-78.8) | 44.2 (38.9-49.6) | 34.0 (29.1-39.3) | 36.7 (31.6-42.0) | 13.5 (10.2-17.7) |
| | **Persistent (n=91)** | 97.7 (91.0-99.5) | 80.6 (70.1-88.0) | 54.3 (43.5-64.7) | 56.4 (45.5-66.6) | 55.9 (45.1-66.2) | 18.3 (11.6-27.6) |
| **Persistent Developmental Disorder** | **Any time point (n=46)** | 93.5 (80.6-98.0) | 79.6 (62.7-90.1) | 55.0 (39.4-69.6) | 55.9 (40.3-70.5) | 58.6 (42.8-72.9) | 37.4 (24.2-52.8) |
| | **Persistent (n=35)** | 91.7 (75.8-97.5) | 82.4 (61.7-93.2) | 50.0 (32.6-67.3) | 51.2 (33.6-68.4) | 57.7 (39.3-74.1) | 38.4 (23.2-56.3) |

## Service contact, age and gender

### *Analysis by age group*

Service contact was analysed by age group at baseline in 2004, split into primary school- aged children and secondary school-aged children. Overall, 42.2% (95% CI 40.3-44.1%) of children aged 5-10 at baseline, and 39.7% (95% CI 37.7-41.7%) of children aged 11-15 reported any mental health-related service contact. Service contact in children with a DAWBA disorder at any time point is displayed in Table 3.25 below. Fewer children in the older age group reported contact with CAMHS, special education and paediatrics, although 95% confidence intervals overlapped for all these estimates. However, the main difference in patterns of contact was in mental health-related contact with teachers; reported by 58.6% of older children and 76.0% of younger ones.

**Table 3.25: Service contact amongst children with psychiatric disorders at any point, by age group**

| **Children with a DAWBA disorder** | **Percentage in contact with each service at any time point (2004 and/or 2007)**<br>**(95% confidence interval)** | | | | | |
|---|---|---|---|---|---|---|
| | **Any service** | **Teacher** | **GP** | **CAMHS** | **Special education** | **Paediatrics** |
| **Children aged 5-10 at baseline**<br>**(n=305)** | 87.6<br>(83.4-90.8) | 76.0<br>(70.8-80.5) | 41.7<br>(36.1-47.5) | 34.1<br>(28.8-39.8) | 33.6<br>(28.3-39.3) | 17.2<br>(13.2-22.0) |
| **Children aged 11-15 at baseline**<br>**(n=367)** | 82.2<br>(77.9-85.8) | 58.6<br>(53.4-63.7) | 42.0<br>(36.9-47.2) | 26.2<br>(21.8-31.1) | 29.3<br>(24.7-34.2) | 10.2<br>(7.4-13.8) |

### *Analysis by age group and gender*

Amongst all children aged 5-10, only 35% of girls had service contact compared to 48.9% of boys (see Table 3.26). When analysis was confined only to those with a disorder, this pattern was still evident, with 77.2% of girls in contact versus 92.4% of boys. The gender difference was still present when including only those with a persisting disorder (i.e. a disorder in 2004 and 2007) although the gap was narrower with more imprecise estimates related to the smaller numbers in this group. Unadjusted odds ratios were calculated for contact in females, with males being the reference group, which illustrate the pattern that girls were overall less likely to have contact with services in comparison with boys in this age group.

**Table 3.26: Contact with services by gender and disorder, weighted: children aged 5-10 at baseline**

| | Gender | Percentage in contact with any service (95% CI) | OR for contact (95% CI) | p value for OR |
|---|---|---|---|---|
| **All children aged 5-10 at baseline** | **Boys (n=1383)** | 48.9<br>(46.2-51.6) | Reference | p<0.001 |
| | **Girls (n=1324)** | 35.0<br>(32.4-37.8) | 0.56<br>(0.48-0.66) | |
| **Children aged 5-10 at baseline with any disorder** | **Boys (n=204)** | 92.4<br>(88.1-95.3) | Reference | p<0.001 |
| | **Girls (n=101)** | 77.2<br>(67.8-84.5) | 0.28<br>(0.14-0.55) | |
| **Children aged 5-10 at baseline with any persisting disorder** | **Boys (n=85)** | 97.9<br>(91.7-99.5) | Reference | p =0.13 |
| | **Girls (n=19)** | 90.5<br>(65.4-98.0) | 0.21<br>(0.26-1.64) | |

In older children aged 11-15 at baseline (Table 3.27), the difference between genders was much smaller. Whilst 36.9% of girls aged 11-15 at baseline had service contact compared to 42.2% of boys, when examining only those with a disorder the corresponding figures were 80.6% and 83.6%. Among those with a persisting disorder, more girls than boys reported service contact. There was no statistically significant difference (at the p<0.05 level) in the odds of service contact between the genders in the disorder and persisting disorder groups, in contrast to the younger 5-10 age group.

**Table 3.27: Contact with services by gender and diagnosis (any diagnosis 2004 or 2007), weighted: children aged 11-15 at baseline**

| | Gender | Percentage in contact with any service (95% CI) | OR for contact (95% CI) | p value for OR |
|---|---|---|---|---|
| **All children aged 11-15 at baseline** | **Boys (n=1332)** | 42.2<br>(39.5-45.0) | Reference | p<0.01 |
| | **Girls (n=1218)** | 36.9<br>(34.2-39.8) | 0.80<br>(0.68-0.95) | |
| **Children aged 11-15 at baseline with any disorder** | **Boys (n=193)** | 83.6<br>(77.6-88.2) | Reference | p=0.47 |
| | **Girls (n=174)** | 80.6<br>(73.8-86.0) | 0.82<br>(0.48-1.47) | |
| **Children aged 11-15 at baseline with any persisting disorder** | **Boys (n=63)** | 94.7<br>(84.3-98.3) | Reference | p =0.79 |
| | **Girls (n=40)** | 95.8<br>(83.7-99.0) | 1.28<br>(0.20-8.31) | |

This analysis suggests that in younger children, boys are more likely to be in contact with services than girls, even when both boys and girls have a disorder. It is possible that this reflects differences in the gender distribution of disorders, particularly the male preponderance of externalizing disorders. Analysis by disorder group was limited by the small numbers involved in each category. For example, when examining only the children with conduct and oppositional disorders aged under 11, girls were half as likely to report any service contact as boys (OR 0.51), but the confidence interval was very wide and crossed unity (95% CI 0.23 - 1.10). This effect is not seen in older children, which may indicate an interaction between age group and gender on service contact. This is supported by the results of the likelihood-ratio test for interaction, where p value for the Chi-squared test was 0.0019.

## Question 2: What factors predict contact with services over the study period?

This section presents the results of logistic regression models examining the predictors of service contact. Predictor variables and the procedure for analysis are described in the Methods section. Outcomes in the models were: contact with any service, contact with specialist services, and contact with the most common individual service types. In each table, only the predictors which were significant at the p<0.05 level in the fully adjusted model are displayed. The p value for the Hosmer and Lemeshow's goodness-of-fit F-adjusted mean (Hosmer and Lemeshow 1980) was non-significant for each model, suggesting that the models fitted the data.

### Contact with any service over the study period

In this analysis, the dependent variable was contact with any service over the study period – i.e. contact in 2004, or 2007, or both. The model is displayed in Table 3.28 below, where the unadjusted odds ratios are also displayed.

Increasing age, female gender, non-white ethnicity and lower socio-economic class all lowered the odds of service contact. However, the unadjusted association between lower socio-economic classes and service contact was in the opposite direction to the adjusted model. Other groups had increased or equal odds of contact in the unadjusted model compared to the highest baseline group, those in managerial or professional jobs. Having a neurodevelopmental disorder, experiencing three or more life events and coming from a non-traditional family structure were all associated with increased odds of contact, as was parental GHQ score in the case range. Parental ratings of psychopathology at baseline on the total difficulty score and the impact score were also predictors of contact, as was teacher rating of total difficulty, which was associated with contact even after adjusting for parental ratings. Overall, the strongest predictors were neurodevelopmental disorder (OR 2.46) and concern about mental health at baseline (OR 2.50).

**Table 3.28: Final adjusted model predicting any service contact: all children (n=2,138)**

| **Variable at baseline** | **Unadjusted OR (95% CI)** | **Fully adjusted OR (95% CI)** | **p value for adjusted OR** |
|---|---|---|---|
| **Age** | 0.98 (0.96-1.00) | 0.96 (0.94-0.98) | p<0.001 |
| **Female gender** | 0.67 (0.60-0.76) | 0.85 (0.73-0.99) | p<0.05 |
| **Non- white ethnicity** | 0.55 (0.45-0.68) | 0.54 (0.41-0.72) | p<0.001 |
| **3 or more life events** | 2.71 (2.24-3.28) | 1.63 (1.23-2.16) | p<0.001 |
| **Neurodevelopmental disorder** | 7.23 (4.82- 10.85) | 2.46 (1.33-4.53) | p<0.05 |
| **Family type:** traditional | Reference | Reference | p<0.05 |
| Single parent | 1.79 (1.55-2.06) | 1.30 (1.07-1.59) | |
| Reconstituted | 1.54 (1.28-1.85) | 1.23 (0.96-1.58) | |
| Other | 2.65 (0.44-15.97) | 0.59 (0.11-3.36) | |
| **Parent GHQ score in case range** | 1.98 (1.73-2.27) | 1.25 (1.04-1.51) | p<0.05 |
| **Socio-economic class:** Higher/lower managerial | Reference | Reference | p<0.05 |
| Intermediate,small employer | 0.99 (0.85-1.15) | 0.75 (0.62-0.92) | |
| Lower sup/ semi-routine | 1.35 (1.18-1.53) | 0.78 (0.65-0.93 | |
| Never worked/ long-term unemployed | 0.87 (0.64-1.48) | 0.42 (0.22-0.80) | |
| Students/not stated % | 1.48 (0.87-2.52) | 0.62 (0.26-1.49) | |
| **Concern about mental health** | 6.39 (5.54-7.38) | 2.50 (2.03-3.07) | p<0.001 |
| **Parental SDQ total difficulty score** | 1.18 (1.16-1.19) | 1.08 (1.06-1.99) | p<0.001 |
| **Parental SDQ impact score** | 2.03 (1.82-2.28) | 1.23 (1.09-1.39) | p<0.05 |
| **Teacher SDQ total difficulty score** | 1.12 (1.11-1.13) | 1.04 (1.02-1.06) | p<0.001 |

Given the previous evidence discussed for an interaction between age group and gender, and the possible differences between primary and secondary school age children, models were also produced for the separate age groups, shown in Table 3.29 below. Corresponding to the findings in the descriptive analysis, gender was only associated with service contact in the younger age group, with an odds ratio for contact in girls aged 5-10 of 0.74 (95% CI 0.61-0.91). In older children, gender was not a significant predictor. Socio-economic class and parental GHQ score were predictors of contact in younger children but not in the older age group. General learning disability was associated with contact in 5-10 year olds but not in 11-15 year olds and vice versa for neurodevelopmental disorder. Concern about mental health at baseline remained a strong predictor of any service contact in both age groups, and odds ratios for parental and teacher total difficulty and parent impact scores remained very similar in both models, and very close to the initial all-children model above (Table 3.28).

**Table 3.29: Model predicting any service contact 2004-2007, by age group at baseline***

| **Variable** | **Children aged 5-10 at baseline (n=2,138)** | | | **Children aged 11-15 at baseline (n=1,797)** | | |
|---|---|---|---|---|---|---|
| | **Unadjusted OR (95% CI)** | **Fully adjusted OR (95% CI)** | **p value for adjusted OR** | **Unadjusted OR (95% CI)** | **Fully adjusted OR (95% CI)** | **p value for adjusted OR** |
| **Age** | | | | 0.94 (0.89-0.98) | 0.91 (0.84-0.97) | p<0.01 |
| **Female gender** | 0.56 (0.48-0.66) | 0.74 (0.61-0.91) | p<0.001 | | | |
| **Non- white ethnicity** | 0.49 (0.37-0.65) | 0.52 (0.35-0.74) | p<0.001 | 0.61 (0.46-0.87) | 0.61 (0.38-0.97) | p<0.05 |
| **More than 3 life events** | 2.73 (2.01-3.71) | 1.65 (1.08-2.52) | p<0.05 | 2.81 (2.20-3.60) | 1.56 (1.06-2.30) | p<0.05 |
| **Neurodevelopmental disorder** | | | | 7.47 (4.24-13.17) | 3.34 (1.43-7.81) | p<0.01 |
| **General Learning Disability**:<br>None<br>Borderline<br>Moderate<br>Severe | <br>Reference<br>3.30 (2.45-4.44)<br>7.91 (3.43-18.23)<br>0.23 (0.03-1.82) | <br>Reference<br>1.24 (0.84-1.82)<br>2.73 (0.84-8.90)<br>0.20 (0.05-0.77) | <br>p<0.05 | | | |
| **Parental GHQ score in the case range** | 1.98 (1.62-2.41) | 1.32 (1.01-1.71) | p<0.05 | | | |
| **Socio-economic class:**<br>Higher/lower managerial<br>Intermediate,small employer<br>Lower sup/ semi-routine<br>Never worked/ long-term unemployed<br>Students/not stated | <br>Reference<br>0.89 (0.72-1.10)<br>1.20 (1.00-1.44)<br>0.86 (0.47-2.23)<br>1.02 (0.47-2.23) | <br>Reference<br>0.68 (0.52-0.89)<br>0.68 (0.54-0.95)<br>0.43 (0.20-0.95)<br>0.28 (0.08-0.99) | <br>p<0.001 | | | |
| **Concern about mental health** | 6.10 (4.97-7.50) | 2.51 (1.90-3.32) | p<0.001 | 6.84 (5.59-8.36) | 2.58 (1.88-3.53) | p<0.001 |
| **Parental SDQ total difficulty score** | 1.17 (1.15-1.19) | 1.09 (1.06-1.12) | p<0.001 | 1.18 (1.16-1.20) | 1.06 (1.03-1.10) | p<0.001 |
| **Parental SDQ impact score** | 2.01 (1.67-2.42) | 1.24 (1.01-1.51) | p<0.05 | 2.08 (1.80-2.41) | 1.25 (1.07-1.46) | p<0.01 |
| **Teacher SDQ total difficulty score** | 1.11 (1.09-1.13) | 1.04 (1.01-1.07 | p<0.01 | 1.13 (1.11-1.15) | 1.04 (1.01-1.07) | p<0.05 |

*Grey shading indicates that this variable was not significant at the p<0.05 level in this age group

### Contact with specialist services over the study period

In the final model (Table 3.30), again, female gender was associated with lower odds of contact with specialist services (OR 0.69, 95% CI 0.50-0.94) in the younger age group. Life events and parental GHQ score were associated with service contact in younger children but not in older children, whilst neurodevelopmental disorder predicted specialist contact in both groups. Having an ADHD or PDD diagnosis at baseline was associated with specialist contact in younger and older children respectively. For both age groups, parent and teacher rated measures of psychopathology and concern again were predictive of contact.

**Table 3.30: Model predicting any specialist service contact 2004-2007, by age group***

| Variable | Children aged 5-10 at baseline (n=2,187) | | | Children aged 11-15 at baseline (n=1,850) | | |
|---|---|---|---|---|---|---|
| | Unadjusted OR (95% CI) | Adjusted OR (95% CI) | p value for adjusted OR | Unadjusted OR (95% CI) | Adjusted OR (95% CI) | p value for adjusted OR |
| **Female gender** | 0.45 (0.35-0.57) | 0.69 (0.50-0.94) | p<0.05 | | | |
| **More than three life events** | 3.54 (2.55-4.92) | 2.33 (1.47-3.70) | p<0.001 | | | |
| **Neurodevelopmental disorder** | 10.93 (6.78-17.63) | 2.60 (1.24-5.47) | p<0.05 | 8.91 (5.53-14.33) | 4.49 (2.22-9.08) | p<0.001 |
| **Parental GHQ score in case range** | 2.66 (2.10-3.41) | 1.60 (1.14-2.23) | p<0.01 | | | |
| **ADHD at baseline** | 56.30 (26.39-120.14) | 5.16 (1.95-13.65) | p<0.01 | | | |
| **PDD at baseline** | | | | 30.14 (10.1-90.1) | 10.9 (1.45-81.9) | p<0.05 |
| **Concern about mental health** | 8.22 (6.46-10.47) | 2.46 (1.72-3.51) | p<0.001 | 9.04 (7.0-11.71) | 2.18 (1.38-3.46) | p<0.01 |
| **Parent SDQ total difficulty score** | | | | 1.19 (1.17-1.22) | 1.04 (1.01-1.09) | p<0.05 |
| **Parent SDQ impact score** | 1.95 (1.74-2.19) | 1.23 (1.08-1.42) | p<0.01 | 1.79 (1.65-1.94) | 1.26 (1.10-1.45) | p<0.01 |
| **Teacher SDQ impact score** | 2.01 (1.80-2.24) | 1.27 (1.07-1.51) | p<0.01 | 2.00 (1.76-2.27) | 1.20 (1.01-1.45) | p<0.05 |

*****Grey shading indicates that this variable was not significant at the p<0.05 level in this age group

### Contact with individual services,

Models for contact with the most commonly contacted front line (teacher and GP) and specialist (CAMHS and special education) services are displayed in Tables 3.31 to 3.34 in the following pages, by age group.

*Teacher contact (Table 3.31)*

Age, gender and ethnicity were associated with teacher contact regarding mental health. Among children aged 5-10 at baseline, parents of girls and children from non-white ethnic backgrounds were less likely to have approached a teacher for help and support. Being from a lower socio-economic group was also associated with lower odds of teacher contact in younger children. For older children, increasing age was also associated with reduced odds of teacher contact, whilst having a neurodevelopmental disorder was predictive of contact in the model. Again, parent and teacher rated psychopathology predicted service contact for both age groups.

*GP contact (Table 3.32)*

In contrast to other services, female gender in older children was associated with an increased odds ratio for contact with a GP (OR 1.82, 95% CI 1.30-2.57). Being in poor health or coming from a non-traditional family background also predicted GP contact in older children in this model, whilst experiencing more than three life events and having neurodevelopmental disorders were associated with contact in younger children. For both groups, parent rated psychopathology was associated with GP contact, but teacher rated psychopathology in the adjusted model was not.

*CAMHS contact (Table 3.33)*

As for teacher and specialist service contact, younger girls were less likely to be in contact with CAMHS than younger boys (OR 0.61, 95% 0.37-0.99). With increasing age, adolescents also had reduced odds of CAMHS contact. Experiencing three or more life events was associated with contact in both groups, as was parent rated psychopathology. In older children, anxiety disorders at baseline were also predictive of CAMHS contact in this model (OR 3.53, 95% CI 1.66-7.54).

*Special education contact (Table 3.34)*

Once again, female gender was associated with lower odds of special education contact in younger children (OR 0.65, 95% CI 0.42-0.99) but not in older children. Neurodevelopmental disorder and learning disability predicted contact in older and younger age groups respectively. Unsurprisingly, given that teachers are key referrers into special education services, teacher ratings of impact were also associated with contact with this service.

## Table 3.31: Model predicting any teacher contact 2004-2007, by age group*

| Variable | Children aged 5-10 at baseline (n=2,184) | | | Children aged 11-15 at baseline(n=1,839) | | |
|---|---|---|---|---|---|---|
| | Unadjusted OR (95% CI) | Adjusted OR (95% CI) | p value for adjusted OR | Unadjusted OR (95% CI) | Adjusted OR (95% CI) | p value for adjusted OR |
| **Age** | | | | 0.87<br>(0.82-0.92) | 0.85<br>(0.78-0.92) | p<0.001 |
| **Female gender** | 0.50<br>(0.42-0.59) | 0.66<br>(0.53-0.81) | p<0.001 | | | |
| **Non white ethnicity** | 0.51<br>(0.36-0.69) | 0.53<br>(0.37-0.77) | p<0.01 | | | |
| **More than three life events** | 2.60<br>(1.92-3.51) | 1.64<br>(1.07-2.53) | p<0.05 | | | |
| **Neurodevelopmental disorder** | | | | 4.88<br>(2.99-7.94) | 2.51<br>(1.20-5.24) | p<0.05 |
| **Socio-economic class:** | | | | | | |
| Higher/lower managerial | Reference | Reference | p<0.05 | | | |
| Intermediate,small employer | 0.86<br>(0.69-1.08) | 0.73<br>(0.56-0.97) | | | | |
| Lower sup/ semi-routine | 1.18<br>(0.97-1.43) | 0.70<br>(0.54-0.90) | | | | |
| Never worked/ long-term unemployed | 0.90<br>(0.50-1.64) | 0.52<br>(0.21-1.28) | | | | |
| Students/not stated | 1.08<br>(0.48-2.45) | 0.37<br>(0.11-1.45) | | | | |
| **Concern about mental health** | 5.23<br>(4.29-6.36) | 2.23<br>(1.69-2.95) | p<0.001 | 5.11<br>(4.19-6.24) | 2.19<br>(1.57-3.04) | p<0.001 |
| **Parent SDQ total difficulty score** | 1.16<br>(1.15-1.18) | 1.07<br>(1.05-1.10) | p<0.001 | | | |
| **Parent SDQ impact score** | 1.79<br>(1.56-2.05) | 1.22<br>(1.04-1.45) | p<0.05 | 1.64<br>(1.49-1.80) | 1.23<br>(1.07-1.41) | p<0.01 |
| **Teacher SDQ total difficulty score** | 1.12<br>(1.10-1.14) | 1.05<br>(1.02-1.08) | p<0.001 | 1.92<br>(1.68-2.20) | 1.04<br>(1.01-1.07) | p<0.05 |

*Grey shading indicates that this variable was not significant at the p<0.05 level in this age group

**Table 3.32: Model predicting any GP contact 2004-2007, by age group***

| **Variable** | **Children aged 5-10 at baseline (n=2,681)** | | | **Children aged 11-15 at baseline (n= 2,524)** | | |
|---|---|---|---|---|---|---|
| | **Unadjusted OR (95% CI)** | **Adjusted OR (95% CI)** | **p value for adjusted OR** | **Unadjusted OR (95% CI)** | **Adjusted OR (95% CI)** | **p value for adjusted OR** |
| **Female gender** | | | | 1.14 (0.90-1.47) | 1.82 (1.30-2.57) | p<0.01 |
| **General health: fair, bad or very bad** | | | | 4.96 (3.22-7.62) | 1.94 (1.01-3.73) | p<0.05 |
| **More than three life events** | 3.64 (2.56-5.16) | 1.95 (1.24-3.05) | p<0.01 | | | |
| **Neurodevelopmental disorder** | 6.88 (4.27-11.1) | 2.37 (1.20-4.70) | p<0.05 | | | |
| **Family type:** | | | | | | |
| Traditional | | | | Reference | Reference | p<0.05 |
| Single parent | | | | 1.98 (1.49-2.63) | 1.64 (1.09-2.46) | |
| Reconstituted | | | | 1.83 (1.29-2.60) | 1.54 (0.95-2.50) | |
| **Concern about mental health** | 6.73 (5.16-8.78) | 2.35 (1.59-3.47) | p<0.001 | 7.25 (5.57-9.45) | 2.75 (1.76-4.30) | p<0.001 |
| **Parent SDQ total difficulty score** | 1.17 (1.14-1.19) | 1.05 (1.01-1.10) | p<0.01 | 1.15 (1.12-1.17) | 1.05 (1.01-1.10) | p<0.05 |
| **Parent SDQ impact score** | | | | 1.55 (1.45-1.67) | 1.20 (1.01-1.26) | p<0.05 |

*Grey shading indicates that this variable was not significant at the p<0.05 level in this age group

## Table 3.33: Model predicting any CAMHS contact 2004-2007, by age group*

| Variable | Children aged 5-10 at baseline (n=2,184) | | | Children aged 11-15 at baseline (n=1,850) | | |
|---|---|---|---|---|---|---|
| | **Unadjusted OR (95% CI)** | **Adjusted OR (95% CI)** | **p value for adjusted OR** | **Unadjusted OR (95% CI)** | **Adjusted OR (95% CI)** | **p value for adjusted OR** |
| **Age** | | | | 0.88<br>(0.79-0.97) | 0.80<br>(0.69-0.94) | p<0.01 |
| **Female gender** | 0.33<br>(0.23-0.49) | 0.61<br>(0.37-0.99) | p<0.05 | | | |
| **More than three life events** | 4.37<br>(2.85-6.68) | 2.12<br>(1.09-4.17) | p<0.05 | 4.10<br>(2.83-5.97) | 2.05<br>(1.17-3.60) | p<0.05 |
| **Neurodevelopmental disorder** | 10.69<br>(6.38-17.91) | 3.10<br>(1.36-7.11) | p<0.01 | | | |
| **Any anxiety disorder at baseline** | | | | 8.88<br>(5.42-14.56) | 3.53<br>(1.66-7.54) | p<0.01 |
| **Concern about mental health** | 15.68<br>(10.43-23.56) | 3.98<br>(2.20-7.20) | p<0.001 | 10.57<br>(7.20-15.54) | 2.42<br>(1.28-4.59) | p<0.01 |
| **Parent SDQ impact score** | 1.81<br>(1.63-2.00) | 1.17<br>(1.01-1.36) | p<0.05 | 1.61<br>(1.49-1.73) | 1.18<br>(1.03-1.34) | p<0.05 |

*Grey shading indicates that this variable was not significant at the p<0.05 level in this age group

### Table 3.34: Model predicting any special education contact 2004-2007, by age group*

| Variable | Children aged 5-10 at baseline (n=2,176) | | | Children aged 11-15 at baseline (n=1,845) | | |
|---|---|---|---|---|---|---|
| | **Unadjusted OR (95% CI)** | **Adjusted OR (95% CI)** | **p value for adjusted OR** | **Unadjusted OR (95% CI)** | **Adjusted OR (95% CI)** | **p value for adjusted OR** |
| **Age** | | | | 0.87 (0.80-0.95) | 0.84 (0.74-0.95) | p<0.01 |
| **Female gender** | 0.40 (0.29-0.55) | 0.65 (0.42-0.99) | p<0.05 | | | |
| **Neurodevelopmental disorder** | | | | 6.38 (3.74-10.87) | 3.67 (1.53-7.42) | p<0.01 |
| **Generalised Learning disability**: None | Reference | Reference | p<0.01 | | | |
| Borderline | 4.48 (3.07-6.53) | 2.16 (1.21-3.87) | | | | |
| Moderate | 14.47 (7.30-28.69) | 4.48 (1.33-15.1) | | | | |
| Severe | 2.23 (0.28-18.03) | 4.69 (0.97-22.62) | | | | |
| **Concern about mental health** | 9.37 (6.78-12.95) | 2.77 (1.71-4.47) | p<0.001 | 10.35 (7.28-14.72) | 2.74 (1.49-5.01) | p<0.01 |
| **Parent SDQ impact score** | 1.76 (1.60-1.94) | 1.24 (1.07-1.44) | p<0.01 | 1.62 (1.51-1.74) | 1.25 (1.09-1.44) | p<0.01 |
| **Teacher SDQ impact score** | 2.14 (1.89-2.42) | 1.29 (1.06-1.58) | p<0.05 | 1.91 (1.67-2.18) | 1.29 (1.06-1.57) | p<0.05 |

*Grey shading indicates that this variable was not significant at the p<0.05 level in this age group

### Question 3: Are there differences in the trajectories of psychopathology over time and in the outcome in 2007 between children who have been in contact with services and those who have not?

This section first presents the findings of the analysis of children's trajectories over time by service contact status. This is followed by the results of the regression models examining the association between service contact and outcome in terms of psychopathology in 2007.

### Trajectories of psychopathology over time by service contact

#### *Trajectories of children in contact with any service, 2004-2007*

*Trajectories of children with disorders*

Figure 3.8 illustrates that those with a disorder who had any contact with services had consistently higher total difficulty scores over the three year study period than those with a disorder who reported no contact. In both groups, the mean score did not change significantly over time, suggesting that as a group their levels of difficulty as measured by the total difficulty score were largely sustained.

**Figure 3.8: Parent rated SDQ total difficulty scores over time by service contact status in children who had a disorder at any point (with 95% confidence intervals shown by error bars)**

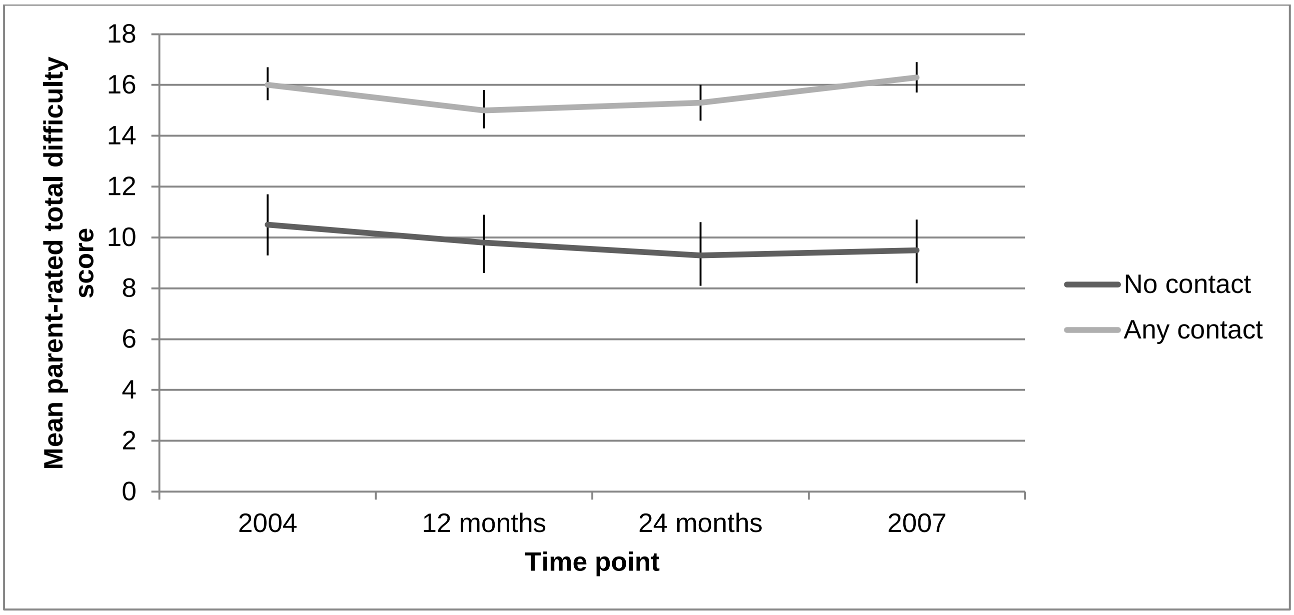
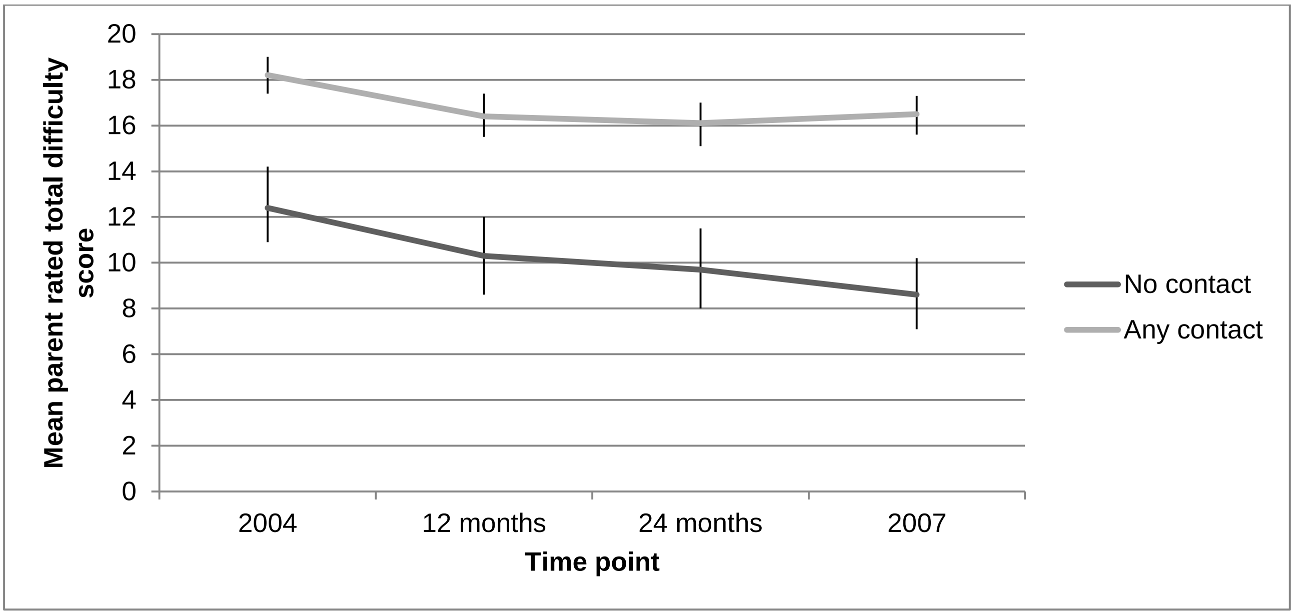


Figure 3.9 shows that a similar pattern was detected for those with a disorder at baseline; those in contact with services had significantly higher mean total difficulty

scores than those who did not, suggesting that they experienced higher levels of psychopathology despite all meeting criteria for a diagnosis in 2004. The mean score of the service contact group was 18.2 (95% CI 17.4-19.0) at baseline, which is in the abnormal range of the SDQ, whereas the mean score of the no service contact group was only 12.4 (95% CI 10.5-14.2). Finally, whilst the mean scores of both groups decreased between 2004 and 2007, the score of those with service contact remained within the abnormal range in 2007 with a mean of 16.5 (95% CI 15.6-17.3) points on the total difficulty scale.

**Figure 3.9: Parent rated SDQ total difficulty scores over time by service contact status in children who had a disorder at baseline (with 95% confidence intervals shown by error bars)**



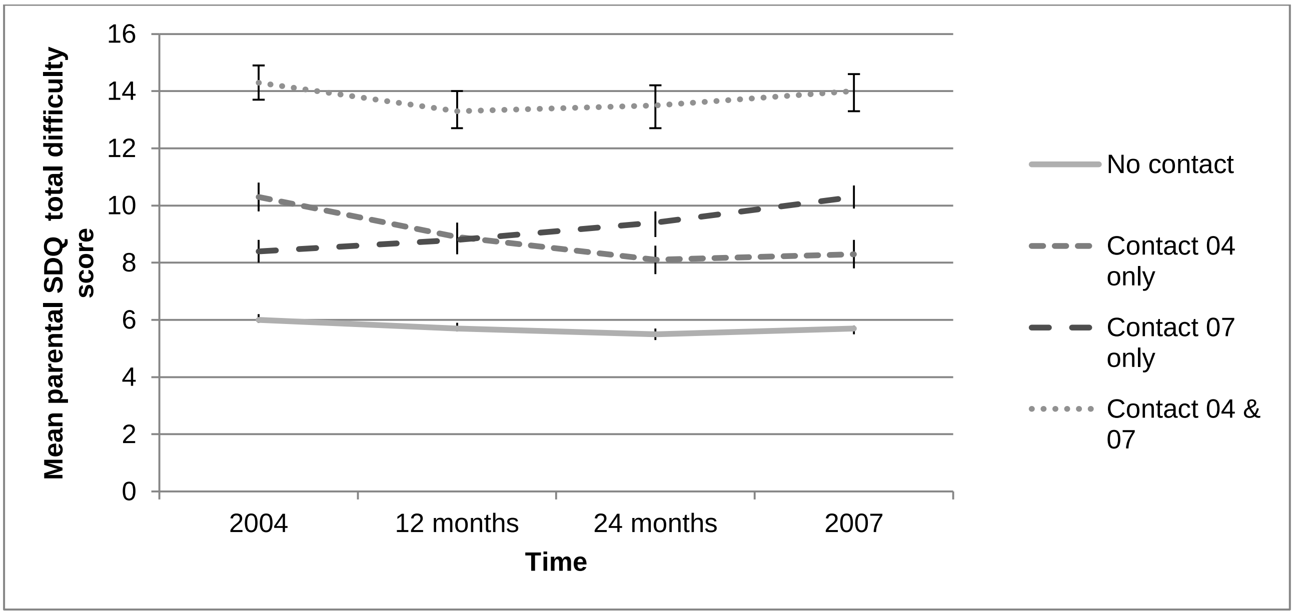
*Trajectories in all children*

The mean parental SDQ total difficulty scores are presented by service contact groups over the study period, in Figure 3.10 and Table 3.35 below.  Children with reported service contact at both time points (2004 and 2007) consistently demonstrated the highest scores over time, with no overall change for this group in the parental rating of difficulty between 2004 and 2007. Among children with service contact only in 2004, there was a decrease in mean score between 2004 and 2007, suggesting improvement. Similarly, the group who had contact with services only in 2007 had a greater level of difficulty than those not using services at all, even at baseline ‘pre-contact’ in 2004 and their scores clearly display an upward trajectory until follow-up in 2007 .

**Table 3.35: Mean parental SDQ total difficulty scores 2004-2007 by contact with any service, with 95% confidence intervals**

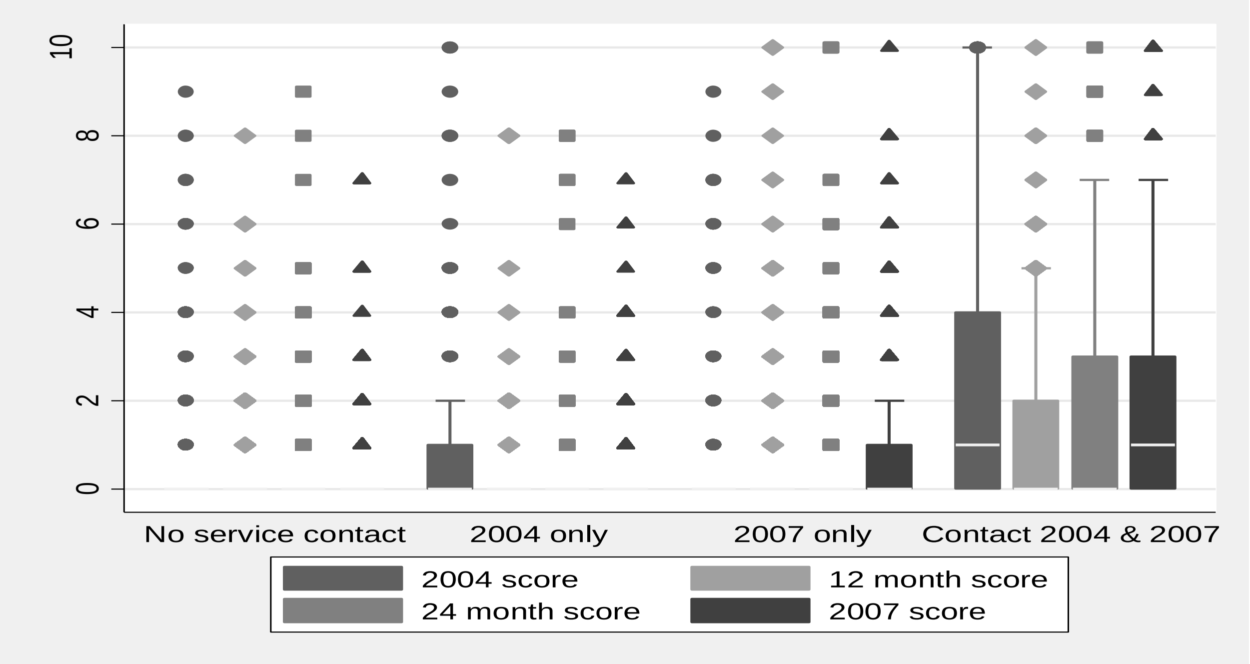
| **Service contact status** | **Parental mean SDQ total difficulty scores (95% confidence interval)** | | | | |
|---|---|---|---|---|---|
| | **2004** | **12 months** | **24 months** | **2007** | **Mean change 2004-2007** |
| **No service contact** | 6.0<br>(5.9-6.2) | 5.7<br>(5.6-5.9) | 5.5<br>(5.3-5.7) | 5.7<br>(5.5-5.8) | -0.4<br>(-0.5, -0.2) |
| **Contact in 2004 only** | 10.3<br>(9.8-10.8) | 8.9<br>(8.3-9.4) | 8.1<br>(7.6-8.6) | 8.3<br>(7.8-8.8) | -2.0<br>(-2.4, -1.5) |
| **Contact in 2007 only** | 8.4<br>(8.0-8.8) | 8.8<br>(8.4-9.2) | 9.4<br>(8.9-9.8) | 10.3<br>(9.9-10.7) | 1.8<br>(1.5, 2.2) |
| **Contact in 2004 & 2007** | 14.3<br>(13.7-14.9) | 13.3<br>(12.7-14.0) | 13.51<br>(12.8-14.2) | 14.0<br>(13.4-14.6) | -0.23<br>(-0.8, 0.2) |

**Figure 3.10: Trajectory of mean parental SDQ total difficulty scores 2004-2007 by contact with any service, with 95% confidence intervals**



The median and interquartile ranges of parent impact scores over time by contact with any service are shown below in a box and whiskers plot in Figure 3.11. The total impact scores can be seen to follow a similar pattern to the total difficulty scores over time.

**Figure 3.11: Box and whiskers plot of median and interquartile range of parent SDQ impact score over time by service contact**



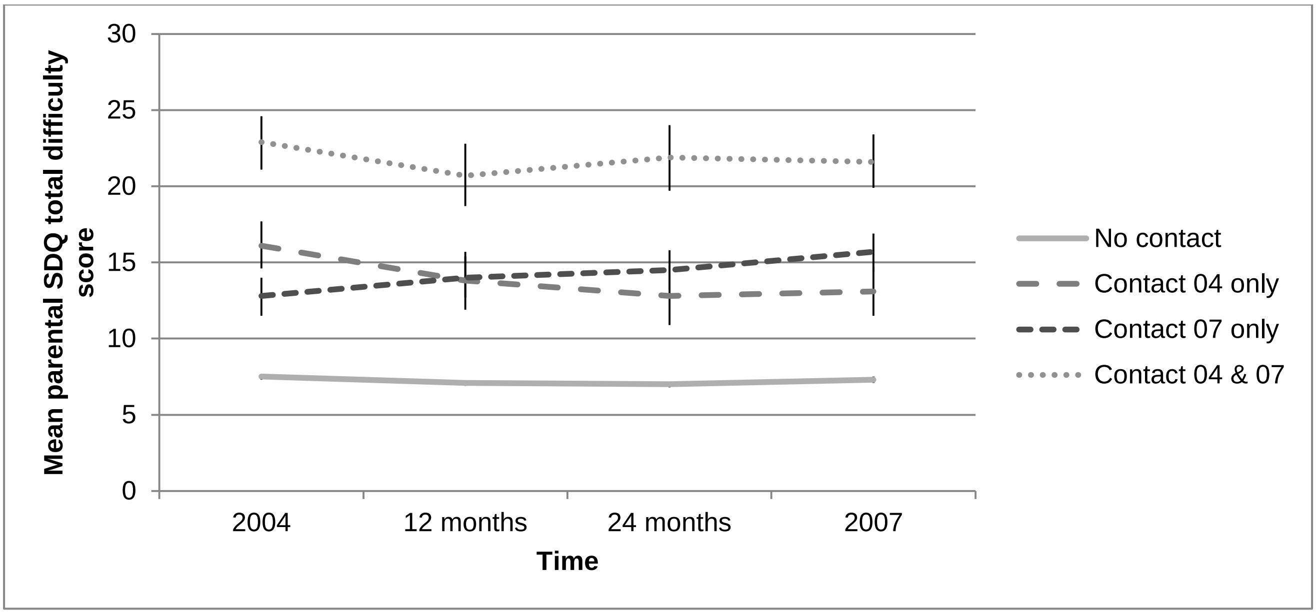
*Trajectories of children in contact with CAMHS, 2004-2007*

Repeating the analysis of trajectories over time for children in contact with CAMHS revealed a similar pattern, shown in Table 3.36 and Figure 3.12 below. However, the mean levels of difficulty were much greater among children who had access to CAMHS compared to those who had contact with any services, as might be expected. Children reporting contact with mental health services both in 04 and 07 in particular had mean scores well into the abnormal range for the total difficulty score of the SDQ (17 and above) at each time point.

**Table 3.36: Mean parental SDQ total difficulty scores 2004-2007 by contact with any service, with 95% confidence intervals**

| Contact with CAMHS | Parental mean total difficulty scores (95% confidence interval) | | | | |
|---|---|---|---|---|---|
| | **2004** | **12 months** | **24 months** | **2007** | **Mean change 2004-2007** |
| **No CAMHS contact** | 7.46<br>(7.30-7.62) | 7.06<br>(6.90-7.23) | 6.96<br>(6.79-7.13) | 7.31<br>(7.14-7.47) | -0.15<br>(-0.28, -0.06) |
| **Contact in 2004 only** | 16.12<br>(14.57-17.68) | 13.79<br>(11.92-15.66) | 12.75<br>(10.73-14.76) | 13.1<br>(11.51-14.68) | -2.97<br>(-4.34, -1.60) |
| **Contact in 2007 only** | 12.77<br>(11.53-14.02) | 14.03<br>(12.65-15.40) | 14.49<br>(13.16-15.82) | 15.66<br>(14.39-16.93) | 2.89<br>(1.90, 3.88) |
| **Contact in 2004 & 2007** | 22.86<br>(21.07-24.64) | 20.73<br>(18.69-22.78) | 21.86<br>(19.70-24.01) | 21.63<br>(19.87-23.38) | -1.23<br>(-2.85, 0.39) |

**Figure 3.12: Trajectory of mean parental total difficulty scores 2004-2007 by contact with mental health services, with 95% confidence intervals**



## Association of service contact with outcome in 2007

### *Contact with any service*

Table 3.37 displays the model for contact with any service as a predictor of parental total difficulty score in 2007 for two groups of children: children who did not have a DAWBA diagnosis at baseline (on the left of the Table) and children who did have a diagnosis on the DAWBA at baseline in 2004 (on the right of the Table). The reference group was children who had had no reported mental health related service contact. For both groups service contact at any point was associated with an increased unadjusted total difficulty score in 2007. Following adjustment for baseline covariates including socio-demographics, initial SDQ ratings of difficulty and impact, and DAWBA diagnoses, the coefficients became much smaller. However, the association between service contact as a categorical variable, and total difficulty score in 2007 remained ($p<0.001$). For children in both groups who had service contact in 2004 only, the 95% confidence interval for the coefficient crossed zero, indicating no significant improvement or deterioration at the $p<0.05$ level compared to those who did not have any service contact. For both groups, contact with services in 2007 only and at both time points, was associated with a higher total difficulty score in 2007. On checking both models by examining the distribution of the standardised residuals and plotting them against the fitted values, there was no evidence of significant heteroscedasticity.

**Table 3.37: Association of any service contact 2004-2007 and parental total difficulty score in 2007 - results of linear regression analysis**

| **Predictor:** **Contact with any service** | **Outcome: Parental SDQ total difficulty score in 2007, with 95% confidence intervals** | | | | | |
|---|---|---|---|---|---|---|
| | **Children without a DAWBA diagnosis at baseline (n=3636 in adjusted model)** | | | **Children with a DAWBA diagnosis at baseline (n=304 in adjusted model)** | | |
| | **Mean SDQ total difficulty score at follow-up (unadjusted)** | **Unadjusted mean difference/ coefficient** | **Fully adjusted mean difference/ coefficient** | **Mean SDQ total difficulty score at follow-up (unadjusted)** | **Unadjusted mean difference/ coefficient** | **Fully adjusted mean difference/ coefficient** |
| **No contact** | 5.6<br>(5.4 to 5.8) | Reference | **Reference** | 8.6<br>(7.1 to 10.2) | Reference | **Reference** |
| **Contact 2004 only** | 7.6<br>(7.2 to 8.1) | 2.6<br>(2.1 to 3.1) | **-0.1**<br>**(-0.5 to 0.5)** | 11.7<br>(10.3 to 13.0) | 3.0<br>(1.0 to 5.0) | **0.9**<br>**(-0.9 to 2.8)** |
| **Contact 2007 only** | 9.8<br>(9.4 to 10.2) | 4.6<br>(4.2 to 5.1) | **2.7**<br>**(2.3 to 3.1)** | 15.7<br>(13.8 to 17.6) | 7.0<br>(4.6 to 9.5) | **5.9**<br>**(3.5 to 8.3)** |
| **Contact 2004 and 2007** | 11.5<br>(10.9 to 12.1) | 8.4<br>(7.8 to 9.0) | **2.6**<br>**(2.0 to 3.2)** | 18.1<br>(17.0 to 19.2) | 9.5<br>(7.6 to 11.3) | **4.3**<br>**(2.5 to 6.1)** |
| **p value for association between service contact and outcome** | | p<0.001 | **p<0.001** | | p<0.001 | **p<0.001** |

*Contact with CAMHS*

Table 3.38 displays the model for CAMHS contact as a predictor of parental total difficulty score in 2007, for children who did not have a DAWBA diagnosis at baseline (on the left) and children who did have a diagnosis on the DAWBA at baseline (on the right). For both groups of children, there was an association between CAMHS contact as a categorical variable, and total difficulty score in 2007 (p<0.001) in the unadjusted and the fully adjusted models. Unlike in the any-service model, both for children with a diagnosis at baseline and for children without a diagnosis, service contact in 2004 only was associated with a reduction in total difficulty score in 2007. However, the 95% confidence interval for the coefficient included zero. For children without a diagnosis at baseline, being in contact only in 2007 with CAMHS was associated with the greatest increase in the total difficulty score in 2007, compared to children who had contact at both time points, which might be related to their upward trajectory of difficulty. On checking both models by examining the distribution of the standardised residuals and plotting them against the fitted values, there was no evidence of significant heteroscedasticity.

**Table 3.38: Association of child mental health service contact 2004-2007 and parental total difficulty score in 2007 - results of linear regression analysis**

| **Predictor:**<br>**Contact with CAMHS** | **Outcome: Parental SDQ total difficulty score in 2007, (with 95% confidence intervals)** | | | | | |
|---|---|---|---|---|---|---|
| | **Children without a DAWBA diagnosis at baseline (n=3636 in adjusted model)** | | | **Children with a DAWBA diagnosis at baseline (n=291 in adjusted model)** | | |
| | **Mean SDQ total difficulty score at follow-up (unadjusted)** | **Unadjusted mean difference/ coefficient** | **Fully adjusted mean difference /coefficient** | **Mean SDQ total difficulty score at follow-up (unadjusted)** | **Unadjusted mean difference/ coefficient** | **Fully adjusted mean difference/ coefficient** |
| **No contact** | 6.9<br>(6.7 to 7.0) | Reference | **Reference** | 13.5<br>(12.6 to 14.5) | Reference | **Reference** |
| **Contact 2004 only** | 11.0<br>(9.2 to 12.7) | 4.1<br>(2.4 to 5.9) | **-0.1**<br>**(-1.9 to 1.7)** | 14.7<br>(12.4 to 17.1) | 1.2<br>(-1.4 to 3.8) | **-1.5**<br>**(-3.4 to 0.5)** |
| **Contact 2007 only** | 13.8<br>(12.5 to 15.2) | 6.9<br>(5.6 to 8.3) | **4.8**<br>**(3.5 to 6.2)** | 19.0<br>(16.8 to 21.1) | 5.4<br>(3.1 to 7.8) | **3.1**<br>**(1.3 to 4.8)** |
| **Contact 2004 and 2007** | 15.0<br>(11.2 to 18.8) | 8.1<br>(6.7 to 7.1) | **1.9**<br>**(-2.9 to 6.7)** | 22.6<br>(20.8 to 23.4) | 9.0<br>(7.0 to 11.1) | **4.3**<br>**(1.9 to 6.7)** |
| **p value for association between service contact and outcome** | | p<0.001 | **p<0.001** | | p<0.001 | **p<0.001** |

## 3.5 Discussion

This section places the findings of the secondary analysis of BCAMHS in the context of the literature, policy and practice. The findings from each of the three research questions are first considered individually, followed by a discussion of the strengths and limitations of the analysis, and a summary of key implications for research and practice.

### ***Mental health related contact with services***

The first question in this study was: 'What services do children with psychopathology have contact with over a three-year period?' The analysis of data on service contact demonstrates that a high proportion of children with difficulties had contact with any service over the study period. Overall, levels of service contact in BCAMHS 2004-2007 appeared higher than in the previous BCAMH Survey 1999-2002; 85% of children with a disorder at baseline in 2004 reported service contact in this analysis, compared to 57% in the earlier survey (Ford *et al.* 2007b).

Nonetheless, half of children with disorders still did not report being seen by a specialist service in this latest survey, and levels of contact with CAMHS were not markedly higher; 30% had contact with CAMHS in 2004-2007 compared to 23% in 1999-2002 (Ford *et al.* 2005). Just under half (49%) of those with a persisting disorder in 2004 and 2007 had not been in touch with CAMHS at all; the corresponding figure in the 1999 survey was 62%, suggesting a small increase in contact amongst children with more enduring psychopathology (Ford *et al.* 2005). There are no directly comparable surveys examining service contact amongst adults with psychiatric disorders; although the findings of the 2007 Adult Psychiatric Morbidity Survey (National Centre for Social Research, 2007) imply that specialist services are also used by a minority of adults with common mental disorders (CMDs). In the survey, 38% of those with a CMD reported GP contact within the past year, but only 18% reported using a specialist or community service.

Levels of service contact in children with emerging diagnoses are also important to track as they may provide an indication of how quickly new disorders are recognised, which may have a bearing on the possibilities for early intervention. Again, reported contacts were higher in this group than in the previous BCAMHS. Just 23% of those with an emerging disorder reported not being in touch with any service over the study period in 2004 – 2007, compared to 40% in 1999-2002 (Ford *et al.* 2005). This increase in contact with any service however did not translate into a rise in contact with specialist CAMHS; the percentages not in contact in 1999-2002 and 2004-2007 were 79% and 81% respectively (Ford *et al.* 2005). These findings about contact with CAMHS may be influenced by the timescale of referral from frontline to specialist services, especially in the emerging disorder group. Whilst there are no data on waiting times from the period when BCAMHS was carried out, the most recent CAMHS Benchmarking Survey in 2014/15 reported an mean average wait of 32 weeks (2014/15), with considerable variation around the country (NHS Benchmarking Network 2015).

Children who had an emotional disorder at any time point reported lower levels of contact with services than those with externalizing disorders, and those with ADHD in particular. When interpreting these results it is important to consider the different courses of these disorders. Emotional disorders more typically follow an episodic or relapsing and remitting course, although some children may experience chronic difficulties (Chaiton *et al.* 2013, Legerstee *et al.* 2013). In contrast, ADHD and PDD are neurodevelopmental disorders and by definition these children would be expected to have persistent problems. Examining only those with persisting disorders partially addressed this issue, and suggested that the difference in contact was not as marked as unstratified analysis initially suggested. Children with ADHD remained more likely than those with anxiety disorders to have been in touch with every individual service except social services, although this was not statistically significant, possibly due to the small numbers of those with persisting disorders. This is in keeping with other studies reporting lower levels of contact amongst children with anxiety disorders (Zachrisson *et al.* 2006, Ford *et al.* 2007b, Costello *et al.* 2014), and may reflect barriers to the identification and referral of emotional disorders. Front line professionals such as GPs have reported feeling uncomfortable with recognising and managing emotional disorders and highlighted the need for more training (Roberts *et al.* 2013). Teachers cite similar concerns, and also report competing pressures to manage more disruptive behaviours in the classroom; finally young people themselves may be more reluctant to initiate help-seeking for such disorders (Gulliver *et al.* 2010, Kidger *et al.* 2010, Papandrea and Winefield 2011).

When involvement with more than one service amongst children with a disorder was examined, those reporting teacher contact were found to be the least likely to be involved with other services. In particular, just over a third reported CAMHS contact as well, compared to over half of those seen by GPs. These findings are in line with work from the previous 1999 BCAMHS where the biggest overlaps in service use between front line and specialist services reported were between GPs and CAMHS and paediatrics, and separately between teachers and specialist education(Ford *et al.* 2007b). There was less overlap in service use between the health and education systems. In the US Great Smoky Mountain Study of service use, education was the point of entry 'least likely to be followed by involvement by other sectors'(Farmer 2003). It is possible that many of these children with disorders who had mental health related contacts only within the education sector may have received entirely appropriate education-focussed assessment and intervention, and the involvement of other sectors may not have been indicated. Similarly, although all children examined had a disorder according to the DAWBA, children reporting teacher contact on average had lower mean parent rated total difficulty scores, which were not adjusted for at this point. However, these findings may also be influenced by reported teacher preference for exploring educational resources for help rather than refer to health, and uncertainty about what support from health might be required (Ford 2000, Moor *et al.* 2007, Papandrea and Winefield 2011). This is likely to be perpetuated by a perceived mismatch between the expectation that schools will address and refer these problems, and the availability of mental health consultation and services as discussed further in the Overarching Conclusions chapter (Rothì *et al.* 2008, Taggart and McDonald 2014).

Overall, findings suggest that levels of contact with all services may have grown over time, without a corresponding increase in the prevalence of mental health problems (Green *et al.* 2005). There are various explanations for this possible increase and it is necessary to consider whether this is likely to be broadly representative of service contact in the wider population. The similarity in methods and measures between the two BCAMH surveys do enable comparisons to be made, although analyses were slightly different, as many of the secondary analyses of BCAMHS 1999 focussed on children who had a disorder at baseline (Ford *et al.* 2005, Ford *et al.* 2007b). Both were weighted to be representative of the British child population at the time each respective survey was carried out. In such a large sample it is also unlikely that the overall levels of service contact were a chance finding, although there were very small numbers  and wide confidence intervals in some categories e.g. children with depressive disorders.

The figures on service contact were also dependent on parental recall and as BCAMHS 2004 asked about service contact over a whole year, this is an important factor which could contribute to under- or over-estimation. Parents appear to recall their previous health concerns about their children with a high degree of accuracy over long time periods, for example, recalling concerns from ten years ago in one study by Russell *et al*. (2014).  Studies validating service use instruments suggest that parents are likely to accurately recall that they used a service, but that their memory of the exact service type may be less reliable. Bean *et al.* used the Services Assessment for Children & Adolescents (SACA) to interview parents about mental health service contact over the period of a year, and found overall agreement with case notes was high at 91%, but that recall of type of service was much more variable(Bean *et al.* 2000). Validation of the Children’s Services Interview (CSI) also suggested that parental recall was moderately reliable over a three month period, although their recall of which professional/service was seen was less so, particularly for teachers and the voluntary sector (Ford *et al.* 2007a). Another consideration is of course that parents may be unaware of service contacts by their child, for instance if these occur at school. Older teenagers may also attend services on their own or without informing their parents which could lead to underestimation or misattribution of service contact (Ford *et al.* 2007b).

If this represents a true increase in contact to some extent, it is likely to be due to a combination of changes in demand for help with mental health problems, and changes in supply such as expanded availability and accessibility of services. Activity levels overall in the NHS have increased in terms of GP appointments and also referrals and appointments in CAMHS (NHS Benchmarking Network 2015, King's Fund 2016). These findings would also be in keeping with international trends, such as reports from the US national comorbidity surveys which found an increase in the proportion of children with disorders in contact with services from 2003 to 2012

(Merikangas *et al.* 2011, Costello *et al.* 2014). Policy changes may reflect growing awareness of mental health problems, leading to increased recognition and demand; they are also likely to have widened the availability of services since 2002. The National Service Framework in 2004 prioritised a comprehensive CAMH service and emphasised increased accessibility of services (Department of Health 2004). The 2008 CAMHS Review also reported a number of improvements in provision since 2005, which overlaps with the time period of the second BCAMHS survey (Department of Health 2008a). However, since 2010, austerity is likely to have had an impact on services, and the possible implications of this as they relate to the findings of this thesis are discussed further in the Overarching Conclusions chapter (Young Minds 2015).

### ***Predictors of service contact***

The second study question focussed on the factors that predict contact with services. Here the results were generally in line with other studies, including the previous BCAMHS. An exception to this was the finding that those in the younger age group of lower socioeconomic status had reduced odds of any service contact, and of teacher contact relative to the reference higher managerial and professional group, something not reported in the previous BCAMH Survey in 1999 (Ford *et al.* 2008b). However, in the unadjusted models these groups had equal odds of contact compared to the baseline group. This would suggest that children from lower socio-economic groups are as likely to contact services as those in higher groups, but that once psychopathology and other factors are adjusted for the effect is reversed – i.e. they may be less likely to be in contact relative to markers of need. This is known as the inverse care law (Tudor Hart 1971) and is not a new phenomenon in mental health; reduced access to mental health services relative to need in lower-income groups has been reported elsewhere, particularly in the United States (Newacheck *et al.* 2003).

Non-white ethnicity was also found to be negatively associated with service contact in this analysis, for any service in all age groups and with teacher contact in younger children. Under-representation of children from ethnic minorities in child mental health services has been previously observed in the UK, by Bradby *et al.* (2007) and Messent and Murrell (2003) amongst others, who propose that this may result from the influence of more traditional community structures or from different views on the role of services in mental health. Referral patterns also seem to reflect ethnic differences; recent examination of referral pathways to CAMHS in England found that children from ethnic minorities were less likely to be referred to child mental health from primary care than white children; instead the more frequent referral route was via education or social services (Edbrooke-Childs *et al.* 2015b).

These results also indicated an interaction between age group and gender on service contact, which is in line with other population studies of service contact reviewed in Chapter Two (Young *et al.* 2011, Reijneveld *et al.* 2014). In the adjusted analyses, younger boys were more likely than younger girls to report contact with any service overall, and with special education, teachers and CAMHS specifically. In the older age group, those aged 11 to 15 at baseline, girls were more likely to report contact with a GP than boys. As these analyses were adjusted for DAWBA diagnosis at baseline and SDQ, these differences are not likely to relate to major differences in psychopathology, but may be influenced by gender differences in symptom recognition and referral patterns. For example, a number of studies have suggested that girls with ADHD and autism may be less likely to be referred to services than boys with the same conditions (Novik *et al.* 2006, Ford *et al.* 2008a, Bussing *et al.* 2012, Lai *et al.* 2015).

### ***Trajectories and outcomes***

Question Three related to examining the trajectories of psychopathology and outcomes in terms of psychopathology in 2007 of children in contact and not in contact with services. Analysis demonstrated that children in contact with services had consistently higher levels of difficulty over time than children without service contact, even when only children who met criteria for psychiatric diagnoses were included. Correspondingly, those who were in contact with services at both time points had on average more severe difficulties as measured by parental SDQ total difficulty and impact scores than any of the other three groups. Such children had sustained high total difficulty scores over the four time points of the study, although a small decrease in impact score was observed. Those who were in contact with services only in 2004 on average improved, whereas children who were in contact only in 2007 displayed a trajectory of increasing difficulty prior to their contact with services. However, as service contact was only measured at two time points, this study was unable to collect data post service contact for this group, which would help to determine whether this upward trajectory was maintained, or arrested by service contact, as suggested by Angold *et al.* (2000). In keeping with the examination of trajectories, in the regression analysis service contact only at follow-up in 2007 or at both time points (2004 & 2007) was associated with worse psychopathology than no reported service contact, even after adjusting for psychopathology at baseline.

The explanation for these findings is probably multifactorial, as the relationship between service contact and psychopathology is complex. Costello and Maughan's review (2015) discusses optimal outcomes for children with disorders and acknowledges that there is likely to be great individual variability in what might constitute the best possible outcome for any given child. In BCAMHS, children in contact with services experienced higher levels of psychosocial adversity in the baseline survey, some of which have been associated with greater persistence of difficulties and poorer outcomes (Costello and Maughan 2015). However, the association between service contact and outcome remained even after adjusting for such covariates.

One contributing factor to this finding is likely to be that children with poor mental health are on different trajectories in terms of their psychopathology, which is supported by many of the studies quoted in Chapter Two (Zwaanswijk *et al.* 2006, Dekker *et al.* 2007, Pingault *et al.* 2011, Chaiton *et al.* 2013) . Children with a persisting disorder are likely to experience more enduring and chronic problems that may have worsened even further without contact with services, consequently, avoiding deterioration in this group may in fact represent a 'gain'. Conversely, children with more transient difficulties, who were not seen at all or only seen in 2004, may have improved without service contact. The 2007 only contact group demonstrated an upward trajectory of worsening problems before they came in contact with services. This may have explained the adjusted association with poorer outcomes in 2007 in these children and also replicates previous findings by Angold *et al*. who reported deterioration in symptoms before children used specialist services in the multi-wave Great Smoky Mountains Study (Angold *et al.* 2000). Angold *et al*. (2000) also observed a positive effect of service use on symptoms only after controlling for pre-treatment trajectory. This was unfortunately which not possible in BCAMHS where service contact was measured at two points only.

The results of this trajectories analysis are similar to those of the TRAILS study which reported poorer outcomes in terms of psychopathology at follow-up in those in contact with mental health services and in particular among those who were in contact over a longer period (Jörg *et al.* 2012). TRAILS were able to adjust for service contact in the past, a potential predictor of poorer outcomes (Visser *et al.* 2003) which was not possible in BCAMHS. A number of other observational studies of ‘real world’ services have also reported no change in psychopathology over time (Zwaanswijk *et al.* 2006). In Warren *et al*.’s (2010) retrospective study of community mental health settings, 24% of children even experienced an increase in symptoms by the end of their treatment episode. Deterioration on various measures in up to 30% of transition-aged young people receiving general mental health services was also reported by Manteuffel *et al.* (2008). Some of these studies were set in specialist mental health services and most of the included samples experienced an intervention of either therapy or medication. In contrast in BCAMHS, there was no available data on whether interventions were offered and if so, what they were.

In BCAMHS, parents were asked about contact with services rather than whether their child had been assessed or treated, and what management they received. The information on service contact is therefore not fine grained. Children who reported contact with services may still have been on a waiting list, have received only a brief assessment or not yet completed an intervention. Others may have been offered short or prematurely terminated therapies, which some have argued could be detrimental (Angold *et al.* 2000). Some children may have been offered evidence based interventions and completed courses of therapy. This heterogeneity is of course more likely to obscure any influence of effective intervention, whereas this model found the association to be statistically significant. Repeating the analysis for individual groups, for example examining CAMHS contact in children with ADHD, may have produced different results, but small numbers meant that these analyses were inappropriate due to a lack of power.

As BCAMHS is an observational study rather than a randomised trial set up to examine service contact, the findings are likely to have been influenced to some extent by confounding by indication. That is, that there were factors not measured which influenced both the final outcome in 2007 and the probability of service contact. Jörg *et al.* (2012) proposed that the clinical opinion of service gatekeepers could constitute such a factor. Another might be educational achievement, as whilst estimates of IQ or learning disability were included as covariates both in the TRAILS study and this secondary analysis, neither study included a specific measure of school progress. Furthermore, resilience is increasingly recognised as playing a role in the development and response to mental disorders (Rutter 2013), although it is also a complex and dynamic concept which would not be captured by our measures, with possibly the most relevant being the prosocial rating on the SDQ. All could act as confounding factors. However, it is unlikely that confounding by indication would explain the entire association that persisted after adjustment for multiple characteristics.

### *Strengths and limitations*

BCAMHS 2004-2007 had a number of strengths that made it appropriate for answering the research questions. It reported naturalistic patterns of contact with a wide variety of public sector services and is representative of the British population of school age children. The range of services included was not limited just to specialist mental health but also included education and social work, reflecting the wider range of contacts which families have and their broader needs. BCAMHS also employed well-validated measures of psychopathology, which are increasingly used in services today, such as the Strengths and Difficulties Questionnaire (Goodman and Goodman 2009). In addition, the multi-informant methodology increased the validity of ratings of children’s difficulty, as did the use of total difficulty and impact scores on the SDQ.

The follow-up period of three years with the interim contact points also allowed the trajectory of children to be followed over time, rather than just as a ‘snapshot’ of psychopathology at two time points. This was valuable in examining the differences between service contact groups and also added context to the regression models. Overall the size and level of detail in the dataset was sufficient to explore the broad research questions.

There are various limitations, both to the dataset and the methods of analysis used. A number of these have already been outlined above, such as the lack of detail on the nature of service contact which precluded more detailed analysis of aspects such as duration which may be associated with outcome. In addition, although the sample size was large enough that analysis of the most common diagnostic groups was feasible, the small numbers of those with less common disorders such as depression meant that results for these children were reported with low precision. Due to tiny numbers, analyses of data on children with rarer diagnoses such as eating disorders were not appropriate. There was also a high proportion of missing data on teacher SDQ ratings and accordingly the extent to which multi-informant data could be used was restricted.

The naturalistic community sample of BCAMHS made it very appropriate for an examination of ‘real world’ service contact but as this was an observational study, there were attendant limitations. Considerable heterogeneity was introduced by the timing of follow-up. Whilst trials and routine outcome studies measure psychopathology pre and post intervention, BCAMHS measured difficulties at a variety of points, depending on when parents were surveyed in relation to the service contact. The time points when parents were surveyed were therefore unlikely to relate directly to before or after experiencing an intervention. Some children may have accessed effective interventions and experienced reduced psychopathology that was not detected by the study as data collection did not correspond with the end of their treatment.

Furthermore, as discussed above, the effects of residual confounding in the logistic and linear regression models cannot be excluded, despite the use of multivariable models. The analysis also adjusted only for baseline circumstances, so changes in socio-demographic variables occurring after 2004 will have influenced the outcome in 2007 but would not be accounted for in the regression model. Consequently, the results of the service contact and outcomes analysis should be interpreted with caution as representing an association between service contact and outcome that has been adjusted for common measured confounding factors at baseline.

The decision to use parent rated SDQ scores as outcomes in this analysis may also have restricted the extent of change that was detected. Whilst the SDQ total difficulty score and impact score are broad and well validated measures that can be aggregated across groups, the SDQ may underestimate the effectiveness of services. Recent analysis of outcome measurement in a small cohort of children attending child mental health services in the UK found that although the SDQ showed change over time, this was to a lesser extent than more individualised measures such as goal based progress (Edbrooke-Childs *et al.* 2015a). These findings replicate an earlier study in a specialist service for Obsessive Compulsive Disorder, where the SDQ detected a smaller effect size than more specialist questionnaires (Lee *et al.* 2005). Combining more specific measures such as SDQ subscales may have increased the sensitivity of the analysis and detected improvements that the total difficulty and impact scores did not. On the other hand, this would have involved multiple analyses or the development of a latent score which would have been more methodologically complicated and potentially created a lack of clarity.

Finally, this BCAMHS dataset now dates from the previous decade. Changes in service supply and demand may mean that these results under- or over-estimate the extent of service contacts or the association between contact and outcome. Some changes, such as the introduction of Improving Access to Psychological Therapies (NHS England, 2016) for children and young people in 2011 may have increased the availability and effectiveness of services.  The Targeted Mental Health in Schools programme (TaMHS) which took place between 2008-2011 was also shown to have increased mental health input into schools during this time period (Wolpert *et al.* 2013). Conversely, concerns continue to be raised over high barriers for entry to CAMH services and over the impacts of austerity. Recent figures from a Freedom of Information request by the charity Young Minds (2015) reported that the majority of NHS Clinical Commissioning Groups and local authorities had cut or frozen their budgets. Nonetheless, whilst the broad configuration of services remains the same these results may also serve as a useful benchmark for assessing the impact of changes between 2007 and the future 2016 BCAMHS.

### ***Summary***

The results of the secondary analysis suggest that a high proportion of children with difficulties were in contact with services during the period between 2004 and 2007. Nonetheless, there remained a significant number who were missing out on opportunities to have their problems assessed and managed, who might feel and function better with support and who may accrue secondary difficulties without it Findings on the association of contact and outcomes are broadly in line with other studies, but raise a number of questions which require more detailed study designs to address, and which link with an emerging emphasis on measuring outcomes in mental health services. The final Overarching Conclusions chapter aims to consider and integrate the findings of all three studies together, and will discuss in more detail the clinical and research implications. The next chapter, Chapter Four, focusses on young people with ADHD and examines primary care prescribing over the transition period.

# Chapter Four: Primary care prescribing of ADHD and psychotropic medication in young people with ADHD in the Clinical Practice Research Database 2005-2013

## 4.1 Introduction

This chapter explores primary care prescribing of medications for ADHD and other psychotropic medications in young people with ADHD. It focusses in particular on cessation of ADHD medication from the age of 16 onwards, in order to study what happens to prescribing as young people move on from child to adult services. The study uses a dataset from the Clinical Practice Research Datalink, a large UK database containing primary care records.

ADHD was once considered to be a condition only of children and younger adolescents. It is increasingly accepted that this is not the case, with follow-up studies estimating that 40-60% of those with ADHD experience persistence of symptoms at age 25 (Faraone *et al.* 2006). However, it was only in 2008 that NICE first recommended appropriate assessment and management services, including medication, for adults affected by ADHD (NICE 2008b). NICE guidance reflected increasing evidence that stimulants are effective in reducing symptoms in adults as well as children, and that outcomes for treated ADHD are likely to be better across a spectrum of health, occupational and educational domains, although poorer than for those without ADHD at all (Faraone and Glatt 2010, Shaw *et al.* 2012). Furthermore, pharmacological treatment has also been associated with a reduced risk of serious road traffic accidents and criminal convictions in males with ADHD (Lichtenstein *et al.* 2012, Chang *et al.* 2014).

Previous UK studies of primary care prescribing have reported that the majority of young people with ADHD stop medication before the age of 18 (Wong *et al.* 2009, McCarthy *et al.* 2012a). In the 1999-2006 CADDY study, the peak age for discontinuation of medication in young people with ADHD was 16-17 years, which coincides with the period of transition from child to adult services (Wong *et al.* 2009). The rate of cessation reported by the CADDY study up to 2006 was far greater than the estimated rate of persistence of ADHD in Faraone *et al.*'s (2006) meta-analysis of follow-up studies. Consequently, persisting symptoms may affect a young person's functioning; and the impact of stopping medication at the time of transition may be intensified by the vulnerability of adolescents during this crucial developmental stage (Young *et al.* 2011, McGorry *et al.* 2013). In addition to the multiple challenges of leaving school, starting employment or further education and moving away from the family home, this transition from adolescence to early adulthood is also the time when substance misuse, personality disorders and severe mental illnesses may emerge (Singh *et al.* 2010, Copeland *et al.* 2011).

Young people may themselves choose to stop taking medication as they move on from school or college, having assessed the trade- off between benefits and adverse effects and taking the opportunity to exert their autonomy (McCarthy 2014). It is nonetheless the case that there are a number of external barriers to continuation of medication during this vulnerable transition period. These include the acknowledged lack of services for adults with ADHD where medication may be monitored and attitudes amongst clinicians, who may not yet be fully accepting or knowledgeable about ADHD in adults as a valid diagnosis (Young *et al.* 2011, Hall *et al.* 2013, Matheson *et al.* 2013, Coghill 2015, Hall *et al.* 2015).

During the transition from adolescence to adulthood, the clinical presentation of ADHD may also lead to under-treatment, or to substitution of other psychotropic medication for ADHD medication if the symptoms are mistaken for the signs of other common psychiatric disorders (Asherson *et al.* 2007). Conversely, failure to recognise and treat existing psychiatric comorbidities, which are common in ADHD can also lead to sub-optimal management and increased impairment (Sobanski 2006, Kooij *et al.* 2010, Jensen and Steinhausen 2015).

Given the considerable impact of ADHD, discussed in Chapter Two, improving the availability and accessibility of appropriate management is central to improving the outcomes of people with the condition. The examination of recent patterns in both the prescription of medications for ADHD and of other psychotropic medications will facilitate greater understanding of current practice in treating ADHD and its comorbidities, and enable exploration of the hypothesis that medication substitution may be taking place. Earlier studies of ADHD prescribing using primary care databases in the UK have covered the periods 1999-2006 (Wong *et al.* 2009) and 2003-2008 (McCarthy *et al.* 2012a & 2012b), and concentrated on the prescribing of ADHD drugs rather than also examining other psychotropic medication. New guidance on prescribing in transition and in adults was released by the British Association for Psychopharmacology in 2007 (Nutt *et al.* 2007) and later by NICE in 2008 (NICE 2008b). Exploring recent trends in a time period covering the changes in guidance will both complement and add to previous studies, as well as directing future research. In terms of wider benefit, better understanding of primary care prescribing in ADHD should feed into recommendations for practice and training, leading to improved assessment and treatment of this condition.

## 4.2 Aims & Research Questions

This was a study of primary care prescribing of ADHD medication and other psychotropic medications between 2005 and 2013 in a cohort of people with ADHD aged 10-20 at baseline in 2005.

The objective of this study was to examine trends in prescribing of ADHD and psychotropic medications in this cohort as they cross the transition boundary, describing prescribing from early adolescence into the mid-twenties in order to capture prescribing over the transition period and beyond. Specifically, it aimed to answer the following main questions:

1. What is the prevalence and incidence of prescribing of ADHD medication amongst people with ADHD aged 10-27?
2. What is the prevalence and incidence of prescribing of other psychotropic medications in people with ADHD between the ages of 10 -27?
3. What is the prevalence of comorbid psychiatric diagnoses and referrals to mental health services in people with ADHD between the ages of 10-27?
4. What is the prevalence of ADHD medication cessation within each age band?
5. What is the time to cessation of medication amongst young people aged 16 with a prescription, and what factors (including prescription of other psychotropic medications) are associated with cessation?

# 4.3 Methods

## 4.3.1 Study design

### Description of the Clinical Practice Research Datalink

The Clinical Practice Research Datalink (CPRD) is a large UK clinical database run by the Medicines and Healthcare products Regulatory Agency (MHRA)(Herrett *et al.* 2015). The primary care section of the database contains the records of over 11 million patients and is contributed to by more than 670 GP practices across the UK, covering over 6% of the population. CPRD uses software to extract anonymised data from participating practices' IT systems. Records of each patient are coded by GPs and practice staff according to NHS coding schemes; chiefly Read codes (NHS Health and Social Care Information Centre 2016b). Read codes are a hierarchical clinical classification system containing over 96, 000 codes based on a system of standard clinical terminology and mapping to the International Classification of Diseases (World Health Organisation 1992). Records include information on the following:

- Patient registration details, including status, dates and gaps
- Consultations
- Clinical events including diagnoses and symptoms (coded using Read medical codes, referred to as medical codes)
- Referrals e.g. to secondary or specialist care
- Prescriptions issued in primary care (coded using CPRD product codes and British National Formulary (BNF) (Joint Formulary Committee 2015) codes
- Records of immunisations and vaccinations

### Ethical approval

All protocols using patient level data from the CPRD are reviewed for scientific quality and approved by the Independent Scientific Advisory Committee (ISAC) on behalf of the National Research Ethics Service Committee. This study protocol

(13_213) was granted ISAC approval in January 2013 (please see Appendix One for protocol).

## Overview of study design and research population

### *Study design*

The study design was a cohort study, including cross-sectional and yearly analysis of prescribing prevalence of ADHD and other psychotropic medication in people aged between 10 and 27 during the study period (2005-2013). These age ranges allowed the study of patterns of prescribing before and during the transition period as well as into early adulthood. Analysis of referrals to mental health services and of recorded psychiatric diagnoses was also included, to give context to the prescribing and to examine the influence of recorded comorbidities. Prescribing was also explored by gender.

In addition, the design included a brief descriptive analysis of age at cessation of medication. This was followed by a survival analysis of time to cessation in a subsection of the cohort who were prescribed ADHD medication at the age of 16. This age was chosen as it marks the beginning of the formal transition period from education and from children's health services, including CAMHS, and would capture the period where cessation rates were highest in older studies (Wong *et al.* 2009, McCarthy *et al.* 2012a). Early estimates from CPRD obtained in 2012 suggested that there would be approximately 1100 cases meeting the study criteria, with follow-up data available for 8 or more years on 80% of these. Power calculations suggested this sample size would be large enough to allow inclusion of up to 13 predictors in multivariable Cox regression models without concerns about stability of the estimated confidence intervals and p-values.

### *Study period*

The study period was defined as running from the 1st January 2005 until 1st January 2014. This covered a nine year period encompassing the changes to prescribing guidance by NICE in 2008 and also including the most recently available data.

### *Study population*

In order to answer the research question, two populations were identified

1. **Cases who had ADHD and were aged between 10 and 20 at baseline in 2005, in order to study the prevalence & incidence of prescribing of ADHD medication and psychotropic medications, psychiatric diagnoses and referrals over the study period (research questions 1,2, 3 & 4 above).**

Cases were therefore selected for the dataset if they had a medical code in their Clinical record at any point during the study period that was ADHD-related (see Appendix One for list of codes). This population would be refined further prior to analysis but a wide definition was used initially, as once received the dataset could not be changed.

2. **Cases that were prescribed ADHD medication and were aged between 10 and 20 at baseline in 2005. This population would allow the identification of people aged 16 with a prescription at any point for the survival analysis (research question 5)**

To initially identify this population, cases were selected who had at least one prescription for an ADHD medication (defined as medication licensed for ADHD i.e. stimulants such as methylphenidate or non-stimulants included in Section 4.4. of the BNF, see Appendix One for list of codes) in their prescription records during the study period. Figure 4.1 below illustrates the age range of participants during the study period and those who would be eligible for the survival analysis.

**Figure 4.1: Cohort of patients in dataset: age of cases in each year of the cohort***

| Year | **Age of cases** | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **2005** | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 |
| **2006** | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 |
| **2007** | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 |
| **2008** | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 |
| **2009** | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 |
| **2010** | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 |
| **2011** | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 |
| **2012** | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 |
| **2013** | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 |

***Grey shading indicates subset of participants eligible for survival analysis**

## Dataset specification

Following approval of the research protocol by ISAC, the dataset specification was agreed in conjunction with MHRA staff. All patients included needed to have Up-to-Standard (UTS) data within the study period, which is a CPRD term to define ‘research-quality’ data and is identified by computer algorithm (Herrett *et al.* 2015). Dataset specifications were as follows:

**Table 4.1: Dataset specification**

| Specification | CPRD definition |
|---|---|
| Study period | 01/Jan/2005 to 31/Mar/2014 |
| Source Population | The extraction population will comprise of all acceptable patients in CPRD (from the most recent snapshot available; May 2014) |
| Cohort definition | • Patients have had a record of an ADHD diagnosis found in the clinical, referral or test files recorded at any point before the end of the study. ADHD will be found using the medical codes specified in Appendix<br>• Or who have a record of any ADHD prescription as specified in Appendix, found in therapy files, and who have at least one record during the study period<br>• Patients have above events within their up-to-standard follow-up period<br>• Patients will have at least one day of up to standard follow-up following their index date (either the ADHD diagnosis or the ADHD prescription)<br>• Patients will have a minimum age of 10 years at the study start<br>• Patients will have a maximum age of 20 years at the study start |
| Follow-up period | Follow-up will be defined as the latest of the patient registration date, the practice UTS date and 01/01/2005. The end of follow-up will be defined as the earliest of the patient transfer out date, the practice last collection date and 1/1/2014 |

Applying these criteria in CPRD resulted in a total number of 27,502 eligible patients in dataset, whose records were supplied and constituted the initial dataset for the study.

## 4.3.2 Data Analysis

### Dataset preparation and checking

Stata SE13(Statacorp 2015) was used for all data analysis. The initial dataset supplied by CPRD was checked and read into Stata, and two new datasets were prepared from this original source:

- Dataset for the descriptive analysis, addressing questions 1,2 3 & 4 ***(the descriptive dataset)***
- Dataset for the survival analysis ***(the survival dataset)***

### *Checking patient registration*

Patient registration dates and status were checked in the Patient file, and cases were excluded from the new datasets if their registration end date was before 1st January 2005 or their registration start date after 1st January 2014.

### *Identifying cases with ADHD*

Using the Clinical file, a new variable termed ‘ADHD’ was created whereby any record with an ADHD related medical code had a value of 1, and any without a value of 0. Of codes identified this way, 99% were classified as a ‘Diagnosis’ consultation type, indicating that they related to a diagnosis rather than symptom or presentation. The codes used to create this variable included all 22 CPRD medical codes/ GP Read terms (based on ICD-10 categories) which related to an ADHD diagnosis e.g. ‘Attention Deficit Hyperactivity Disorder’, ‘Child Attention Deficit Disorder’ ‘Attention Deficit Disorder’ etc. These codes are listed in Appendix One. Terms related to general behaviour problems and disorders, such as ‘Behavioural Disorder’ and ‘Reduced concentration’ were coded as 0. This was done to avoid an over-inclusive definition of ‘ADHD’ which could result in an artificially low estimation of prevalence of medication use. However, as explored in greater depth in the Discussion, this definition of an ADHD related medical code has a number of limitations, including a reliance on the GP to enter a diagnosis code if the child is assessed and diagnosed elsewhere, for example in CAMHS.

### Identifying cases with an ADHD prescription during the study period

Using the Therapy file, a new variable termed ‘ADHD medication’ was created whereby any prescription record which had an ADHD related medical code within the study period had a value of 1, and any without a value of 0. The codes used to create this variable included all 74 CPRD product codes referring to BNF categories of stimulants and non-stimulants for ADHD such as Atomoxetine.

### Assigning age band

The CPRD did not supply dates of birth for most cases, for 96% of the sample only year of birth was available. Therefore, for the descriptive analysis, age bands were assigned. For example, those born in 1990 would be in the age band 15/16 in 2006. For the survival analysis, where it was necessary to designate a fixed point as the case’s 16th birthday, the date of birth was therefore assumed to be 1st July for each case, which minimised the error each way to a maximum of 6 months, and as transition is a process rather than a single event happening on the 16th, 17th or 18th birthday, this assumption did not affect the ability of the study to encompass the relevant time period of transition.

### Excluding narcolepsy

A very small number of cases (n<20) had a prescription for ADHD medication, no ADHD related medical code but instead a narcolepsy diagnosis code. As stimulant medication is on occasion prescribed for narcolepsy, a very rare condition, these cases were excluded from the analysis.

### Creating new variables

A number of new variables were created for the analyses. The key variables and their definition are listed in Appendix One.

### Missing data

Data from the CPRD undergoes quality checks and cases included in a research dataset are required to have at least a day of ‘up-to-standard’ data, which is defined by a metric examining continuity of recording by a practice and recording of events in a patient record (Herrett *et al.* 2015). However, the recording of variables, especially over time, may still be incomplete and therefore require further checking by the researcher. Checks were therefore carried on the key variables required for the proposed analysis. There were no missing data on basic demographics such as gender or year of birth, or on records of registration status. Prescriptions issued by the GP are automatically recorded with a product name and British National Formulary code, alongside the dosage instructions and quantity, so data on the type of prescription issued were complete. However, one field that was not always completed by the GP were the number of treatment days prescribed for a specific therapy event (e.g. the number of days that each ADHD prescription was meant to cover). This required making some assumptions about prescription length for the purposes of the survival analysis, explained further below.

## Descriptive analysis

The descriptive analysis aimed to answer the first four research questions:

1. What is the prevalence and incidence of prescribing of ADHD medication amongst people with ADHD aged 10-27?
2. What is the prevalence and incidence of psychotropic medications in people with ADHD between the ages of 10 -27?
3. What is the prevalence of comorbid psychiatric diagnoses and referrals to mental health services in people with ADHD between the ages of 10-27?
4. What is the prevalence of ADHD medication cessation within each age band?

This was based on the descriptive dataset, which included only those cases who had an ADHD medical code within the study period.

### ***Question 1: What is the prevalence and incidence of prescribing of ADHD medication amongst people with ADHD aged 10-27?***

#### *1a Prescribing prevalence*

The percentage of all cases that had a prescription for ADHD medication over the study period was calculated, with 95% confidence intervals. Pearson's Chi-squared test was used to examine whether an association existed between prescription and gender. More detailed analysis of prevalence of prescribing was performed in two ways:

1. By age e.g. for all patients in the age band 15/16 at any point. This was calculated by summing all the patients aged 15/16 with a prescription for ADHD medication in the year they were aged 15/16, with the denominator being all patients who had data for the year they were 15/16. This was expressed as a percentage with the attendant 95% confidence interval.
2. By age and year e.g. patients aged 15/16 in 2005 that had at least one prescription record during the period 1st January 2005 to 31st December 2005, with the denominator being all patients whose assigned age band in 2005 is 15/16. This was expressed as a percentage with the attendant 95% confidence interval.

In order to produce an accurate denominator, only cases who had data within the CPRD for the study period in question, e.g. the year 2005, were included in the calculation. If the case transferred out before the end of a year - i.e. before 31st December 2005, then that was counted as an incomplete year and the case was not included in numerator or denominator.

### *1b Prescribing incidence*

Incidence was calculated by age band and defined as the number of cases within each age band that began their first spell of medication in that age band, i.e. had their first ADHD prescription. Re-initiation of medication, such as second and third spells of medication with gaps of over a year was not examined in this analysis.

## ***Question 2: What is the prevalence and incidence of prescribing of other psychotropic medications in people with ADHD between the ages of 10-28?***

### *2a Psychotropic prescribing prevalence*

The percentage of all cases with a prescription for other psychotropic medications (i.e. not medication for ADHD) at any point over the study period was calculated, with 95% confidence intervals. Prescribing prevalence was also presented by psychotropic type according to the main BNF categories: antidepressants (BNF section 4.3), anxiolytics (section 4.2.1) and antipsychotics (section 4.2), and by gender, using the Chi-squared test.

Prevalence of prescribing was then examined by age e.g. for all patients in the age band 15/16 at any point. This was calculated by summing all the patients aged 15/16 with a prescription for a psychotropic medication in the year they were aged 15/16, with the denominator being all patients who had data for the year they were 15/16. This was expressed as a percentage with the attendant 95% confidence interval.

As with ADHD medication prescribing, in order to produce an accurate denominator, only cases who had data within the CPRD for the study period in question, e.g. the year 2005, were included in the denominator. If the case transferred out before the end of a year, i.e. before 31st December 2005, then that was counted as an incomplete year and the case was not included in numerator or denominator.

### *2b Psychotropic prescribing incidence*

Incidence was defined as the number of those in an age band who had their first prescription for other psychotropic medication, with the denominator being all of those in that age band, at any point.

## ***Question 3: What is the prevalence of psychiatric diagnoses and referrals to mental health services in people with ADHD between the ages of 10-27?***

### *3a Prevalence of comorbid psychiatric diagnoses*

The prevalence of comorbid psychiatric diagnoses was calculated for all cases with an ADHD medical code by diagnostic category and for any diagnosis, as a percentage with 95% confidence intervals. The numerator was those who had the diagnostic code at any point, the denominator all cases with an ADHD code, i.e. all study participants. The diagnostic categories included were based on ICD-10 classification and groups of READ codes and were:  Autism spectrum disorder (ASD), Anxiety or depression related disorder, Conduct/oppositional defiant disorder, Substance/alcohol misuse related disorder, Any tic disorder, Any personality disorder, and Bipolar affective disorder or psychoses. Prevalence was also compared by gender, with the Chi-squared test.

The prevalence of learning disability (mild, moderate and severe) was also calculated as a percentage with 95% confidence intervals.

### *3b Psychiatric diagnoses and prescribing*

The percentage of those with any comorbid psychiatric diagnosis who had an ADHD medication prescription at any point or a psychotropic prescription at any point was reported for all cases and by gender, with 95% confidence intervals. The percentage of all cases and of cases with a comorbid diagnosis that had a concurrent prescription (in the same year) for a psychotropic and an ADHD medication was calculated, over the study period and by age band.

### *3c Prevalence of referrals to mental health services*

The percentage of all cases with a code for a new referral to a mental health service was calculated for all cases as a percentage with 95% confidence intervals, for all mental health referrals and by specific service (e.g., adult mental health). This percentage was also calculated separately for cases with and without a psychiatric comorbidity.

### ***Question 4: What is the prevalence of ADHD medication cessation within each age band?***

Prior to the survival analysis of time to cessation, a brief descriptive analysis of cessation was carried out. For this purpose, cessation was defined as taking place in the last year of recorded prescription in the database. Age at cessation was therefore the age band of the case in the year in which cessation occurred. However, where the last year of prescription was also the last year of the study period, or the case's last year in the CPRD due to transferring out of the practice, the case was regarded as censored rather than having stopped medication (and therefore not categorised as having experienced cessation), because the case was not followed up to determine whether or not medication was stopped or continued (see also section on Censoring below).

Cessation was described in two ways:

i. First, as the percentage of those stopping medication in each band (i.e. who had their last prescription in that age band) as a percentage of all cases prescribed ADHD medication during the study period.
ii. Second, as a percentage of those who had a prescription for an ADHD medication in each age band for whom this was their last prescription

Cessation over the transition period from age 16 onwards was then explored more fully in the Survival Analysis.

## Survival analysis

The survival analysis was set up to analyse the time to cessation of ADHD medication, from the subject's 16th birthday. It aimed to answer the following research question:

***Question 5: What is the time to cessation of ADHD medication amongst young people aged 16 with a prescription, and what factors (including prescription of new psychotropic medications) are associated with cessation?***

*Criteria for entry into survival analysis*

In order to be eligible to be entered in the survival analysis, each case had to meet certain criteria. Cases needed to:

- Have data within the study period 2005-2013
- Have at least six months of consecutive prescriptions for an ADHD medication for the time period up to and including the 1st July of the year of their 16th birthday. A gap of up to 6 months between prescriptions was allowed.
- Have at least one day of follow up following 16th birthday

Cases were excluded if:

- They had a gap in their registration with the practice for more than 6 months after their 16th birthday, meaning that data was not available for analysis
- They had less than 6 months of consecutive prescriptions for ADHD at the time of their 16th birthday

*Defining cessation*

Cessation was defined as a gap of more than six months in prescriptions for ADHD medication. This was chosen to allow for error or uncertainty in estimating prescription length, as well as to allow for medication 'breaks' which may occur during school holidays, or, for example, due to delays in obtaining new prescriptions due to administrative or other reasons such as starting University. The intention was for the definition of cessation to represent stopping medication, rather than a brief interruption. Data were not recorded on the length of a prescription in 98% of cases; where it was recorded the most common values were 28 or 30 days. Consequently, where data were missing as to the length of a prescription it was assumed to last 30 days. This was also chosen as methylphenidate preparations are controlled drugs, and in many localities may only be prescribed for a month at a time (Bolea-Alamanac *et al.* 2014).

*Setting up the survival analysis*

Cases meeting the survival criteria detailed above were transferred into a survival dataset. The survival analysis was set up using the Stata command *stset* and was based on the following definitions shown in Table 4.2 below.

**Table 4.2: Definitions used in survival analysis**

| | Entry point/start | Observation period/time at risk | Failure |
|---|---|---|---|
| Definition | 16th birthday - assigned as 1st July | From 16th birthday until cessation or censoring occurs or study period ends (1st Jan 2014) | The first period of cessation of medication for more than six months following the case's 16th birthday |

*Censoring*

Censoring occurred in the dataset where there were no further prescribing records for a case within the study period, and the outcome – i.e. whether and at what point cessation occurred, is unknown. This would be the case where a person was transferred out of the CPRD, e.g. moved or otherwise left the practice but had not yet experienced cessation. Cases that were censored therefore are those who still had a prescription at the time of transferring out and being lost to follow-up. This was defined as having a prescription dated within 40 days of the date of transfer out of the CPRD. A sensitivity analysis was also carried where this definition was changed to 90 days (i.e. approximately three months).

*Analysing time to cessation*

The initial survival analysis involved several steps:

- Calculating the number of events and total number remaining in the survival analysis at each time point and the consequent survival function – the probability of remaining on medication at each time point. This was displayed in years rather than months/days to simplify reporting.
- Calculating the median time to cessation and the interquartile range, with 95% confidence intervals
- Calculating the rate of cessation per year, with 95% confidence interval
- Producing a Kaplan-Meier curve of time to cessation using years as the timescale

### ***Explanatory variables***

The next stage was to explore the variables which might be associated with cessation of ADHD medication, including year of birth, which was chosen to examine secular trends. Most of these were pre-specified in the protocol (see Appendix One) but a number were revised in light of the dataset which was received, such as the comorbid psychiatric diagnoses, as this depended partially on their prevalence within the survival analysis dataset.

These categorical variables were:

- Gender
- Prescription for another psychotropic medication in the age 15/16 age band or older
- Referral to adult psychiatry at any point
- Anxiety or depression related diagnosis at any point
- Conduct or ODD diagnosis at any point
- Autism spectrum disorder diagnosis at any point
- Learning disability
- Year of birth – binary variable (1989, 1990, 1991 & 1992 vs 1993, 1994, 1995)
- Smoking
- Time on ADHD medication before 16th birthday  (Less than 2 years, 2-3 years,3 or more years)

### *Univariate analysis*

Each of the predictor variables above was initially explored by producing a Kaplan-Meier curve to examine the shape of the survival function for each group. In order to determine whether an association existed with cessation, the log rank test for equality of survivor functions was performed. Finally, each variable was also entered alone as a predictor in a Cox regression model, in order to produce a hazard ratio and 95% confidence interval

Two methods were used to test for non-proportional hazards (a key assumption of the Cox regression model) for each predictor:

- A Nelson-Aalen plot of cumulative hazard estimates to graphically examine the proportionality of hazards over time in the groups
- Using Schoenfeld (1982) residuals saved in each Cox regression to test proportionality

### *Multivariable analysis using Cox proportional hazards regression*

All predictors with a p value of 0.05 or under were then entered into the multivariable Cox regression analysis. Schoenfeld residuals were saved and used to test for non-proportionality of hazards in the final model. Testing for interactions was theory driven. For example, an interaction between adult psychiatry referral and comorbid psychiatric diagnosis might be present on cessation, if a comorbid diagnosis had a different effect in those referred to adult psychiatry than in those not referred. This situation might occur if different prescribing practices occur in primary and secondary care. Interactions were therefore tested where considered feasible using likelihood ratio tests. The fit of the final model was then tested by producing a graph of Nelson-Aalen cumulative hazard function against Cox-Snell residuals.

### *Sensitivity analyses*

Sensitivity analyses were also carried out to assess the effect of excluding the cases censored before the end of the study, and of extending the definition of censoring to include cases that had a prescription within 90 days of transferring out of CPRD.

# 4.4 Results

## 4.4.1 Descriptive analysis

### Sample characteristics

There were 9,390 cases with an ADHD medical code at any point and data within the study period. Of these, 83.9% were male. Cases were born between 1985 and 1995, and their ages ranged from 9-10 to 19-20 in the start year of 2005 (see Table 4.3 below). The majority of the cohort was born from 1993-1995. The age bands included in the analysis were from 9/10 to 26/27; this is due to the small numbers for whom there were data in the 27/28 age band (only those born in 1985), as well as the stated aim to examine prescribing up to the mid-twenties.

**Table 4.3: Year of birth and age band at start and end of cohort in descriptive analysis**

| Year of birth | Age band at start (2005) | Age band at end (2013) | Frequency (n) | Percent |
|---|---|---|---|---|
| 1985 | 19/20 | 27/28 | 235 | 2.5 |
| 1986 | 18/19 | 26/27 | 306 | 3.3 |
| 1987 | 17/18 | 25/26 | 385 | 4.1 |
| 1988 | 16/17 | 24/25 | 590 | 6.3 |
| 1989 | 15/16 | 23/24 | 707 | 7.5 |
| 1990 | 14/15 | 22/23 | 840 | 9.0 |
| 1991 | 13/14 | 21/22 | 1,108 | 11.8 |
| 1992 | 12/13 | 20/21 | 1,148 | 12.2 |
| 1993 | 11/12 | 19/20 | 1,359 | 14.5 |
| 1994 | 10/11 | 18/19 | 1,389 | 14.8 |
| 1995 | 9/10 | 17/18 | 1,323 | 14.1 |
| Total | | | 9,390 | 100 |

Cases were required to have had an ADHD diagnosis coded at any point in order to be included. More than three-quarters of cases included had their first medical code for ADHD recorded before the age of 15 (n=7,167, 77.2%).

In the descriptive dataset, two-thirds of cases had data for 5 or more years of the study period (Table 4.4). Only 8.7% had follow-up data for less than a year.

**Table 4.4: Time in study**

| Study time | Frequency (n) | Percent |
|---|---:|---:|
| 0-1 yrs | 813 | 8.7 |
| 1-2 yrs | 774 | 8.2 |
| 2-5 yrs | 1,595 | 17.0 |
| 5-8 years | 6208 | 66.1 |
| Total | 9,390 | 100 |

## Findings

***Question 1: What is the prevalence and incidence of prescribing of ADHD medication amongst people with ADHD aged 10-27?***

### Prevalence of prescribing of ADHD medication

*For all cases over the study period*

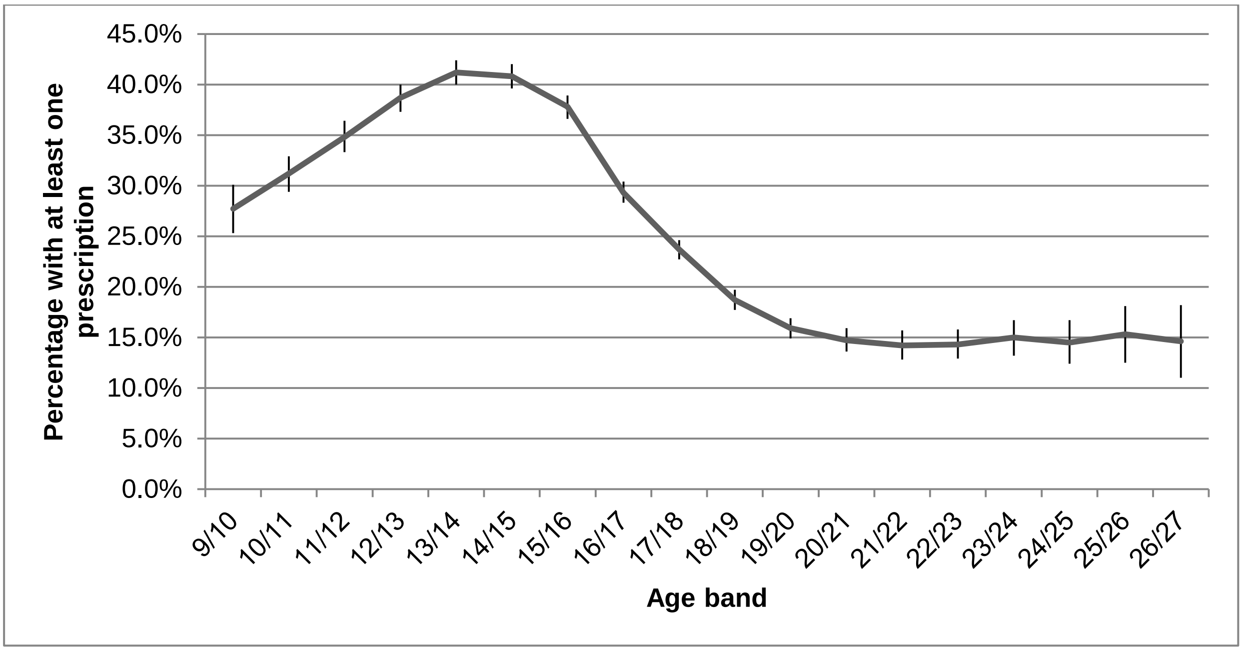
61.6% (n=5780/9390) had at least one ADHD prescription at any point during the study period (95%CI: 60.6% to 62.5%). Prescribing prevalence was 61.8% (n=4866/7876, 95% CI 60.7 to 62.9%) amongst males and 60.4% (n= 914/1514, 95% CI 57.9 to 62.8%) amongst females, with no significant difference (p=0.301) between the genders. Fewer than half of those with a prescription at any point (45.3% n=2618/5780, 95% CI 44.0-46.6%) had a prescription at the age of 17/18 or over.

The most commonly prescribed drugs were all methylphenidate preparations. Concerta XL 36mg was the most commonly prescribed, with 39.5% of all patients with a prescription having received the drug at any point, this was followed by 37.8% who had been prescribed Methylphenidate 10mg, and 35.3% who had been prescribed Concerta XL 18mg.

*By age band (all years pooled)*

Prescribing by age band is displayed in Figure 4.2 with 95% confidence intervals. The highest prevalence of ADHD prescribing in the sample was amongst the 13/14 age band, where 41.2% (95% CI 40.0 to 42.4%) had at least one prescription. Over the transition period there was evidence of falling prevalence. Amongst 15/16 year olds, the prevalence of prescriptions for ADHD medication was 37.8% (95% CI: 36.6-38.9%) whereas in the 17/18 age band less than a quarter had a prescription (23.7%, 95% CI: 22.7-24.6%). The lowest prevalence of prescriptions was in the 21/22 age band (14.2%, 95% CI: 12.9-15.4%). The decline in prescribing appeared to tail off after this, but the small numbers in the older age bands meant that there were wider confidence intervals around these estimates.

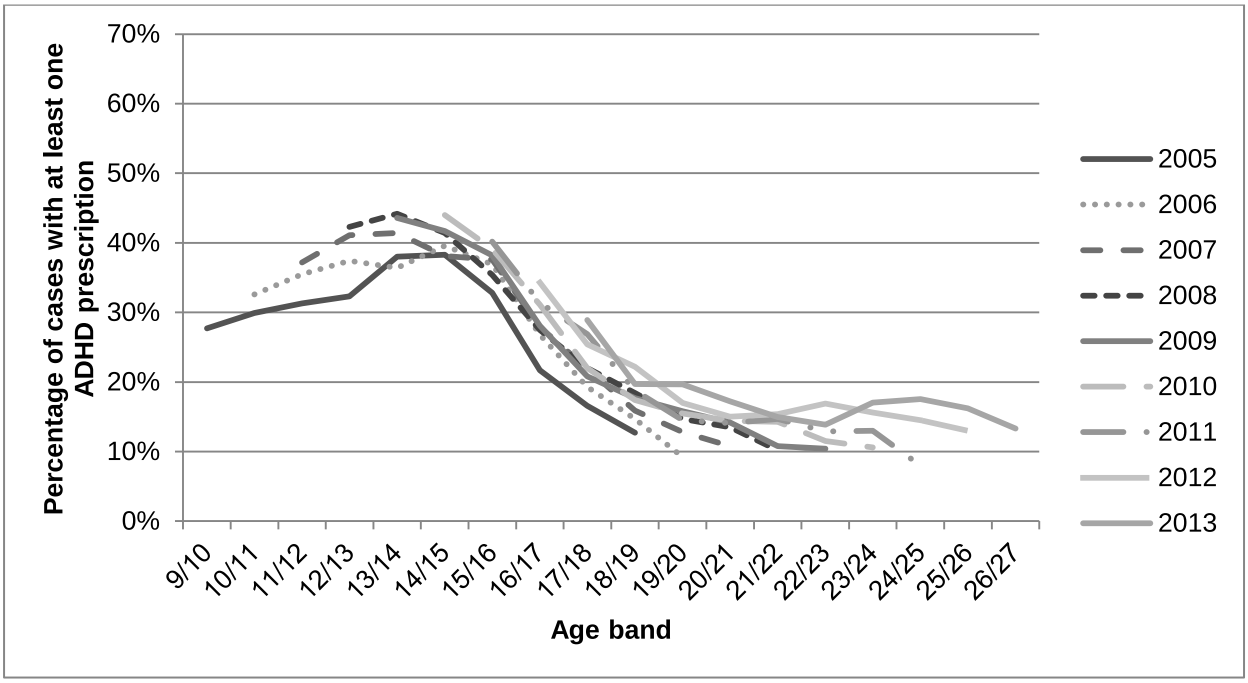
**Figure 4.2: Percentage of cases with ADHD at each age with an ADHD medication prescription (all years 2005-2013, with 95% confidence intervals)**



*By age band and study year*

As Figure 4.3 below demonstrates, patterns of prescribing followed a similar pattern in each year of the study period, with the sharpest drop in prescribing consistently seen between16 and 18 years of age. However, there did appear to be a possible trend over time for increasing prevalence of prescribing for people in their mid-twenties, although small numbers of those in the older age bands in each individual year meant that there were very wide confidence intervals around these estimates (not shown in Figure for clarity).

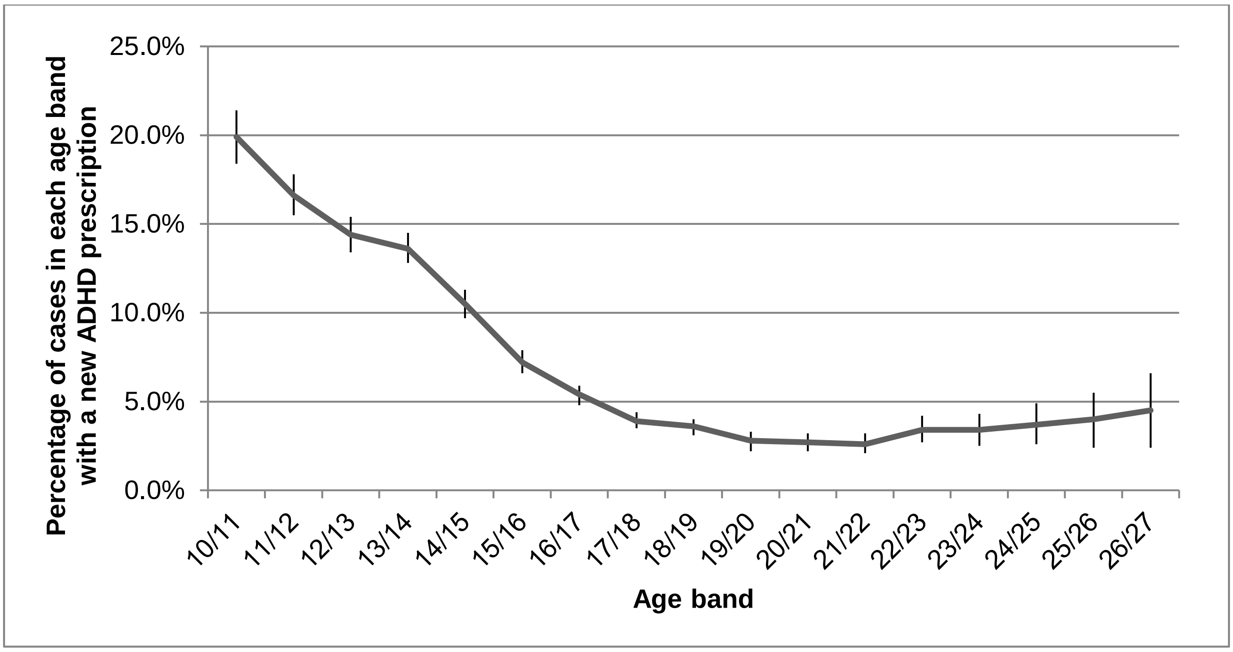
**Figure 4.3: Percentage of cases with an ADHD prescription, by age band and study year.**



**Incidence of new prescriptions of ADHD medication, by age band**

Figure 4.4 below displays the percentage of cases in each age band that had their first prescription of ADHD medication within the study period during that year. The highest incidence of medication initiation was among the younger age bands, with almost a fifth of those aged 10/11 with ADHD beginning medication. Incidence then drops quite sharply from 10.5% in the 14/15 age band to 5.4% in the 16/17 age band. The lowest rates of initiation were in the early twenties from 19/20 to 21/22. Re-initiation (i.e. stopping and re-starting months or years later) was not explored in this analysis but is likely to have occurred in some cases, particularly amongst older participants.

**Figure 4.4: Percentage of cases with ADHD at each age with a first ADHD medication prescription (all years 2005-2013)**



***Question 2: What is the prevalence and incidence of prescribing of other psychotropic medications in people with ADHD between the ages of 10-27?***

### Prescribing prevalence

*All cases*

A quarter of all cases (n=2336/9390, 24.9%, 95% CI 24.0 to 25.8%) had at least one prescription for another psychotropic medication at some point during the study period, with the most commonly prescribed category being antidepressants (Table 4.5). Females had a markedly higher level of antidepressant and anxiolytic prescriptions. In total, over a third of females had a psychotropic prescription at any point (36.4%, 95% CI 34.0 to 38.9%) compared to just over a fifth of males (22.7%, 95% CI: 21.7 to 23.6).

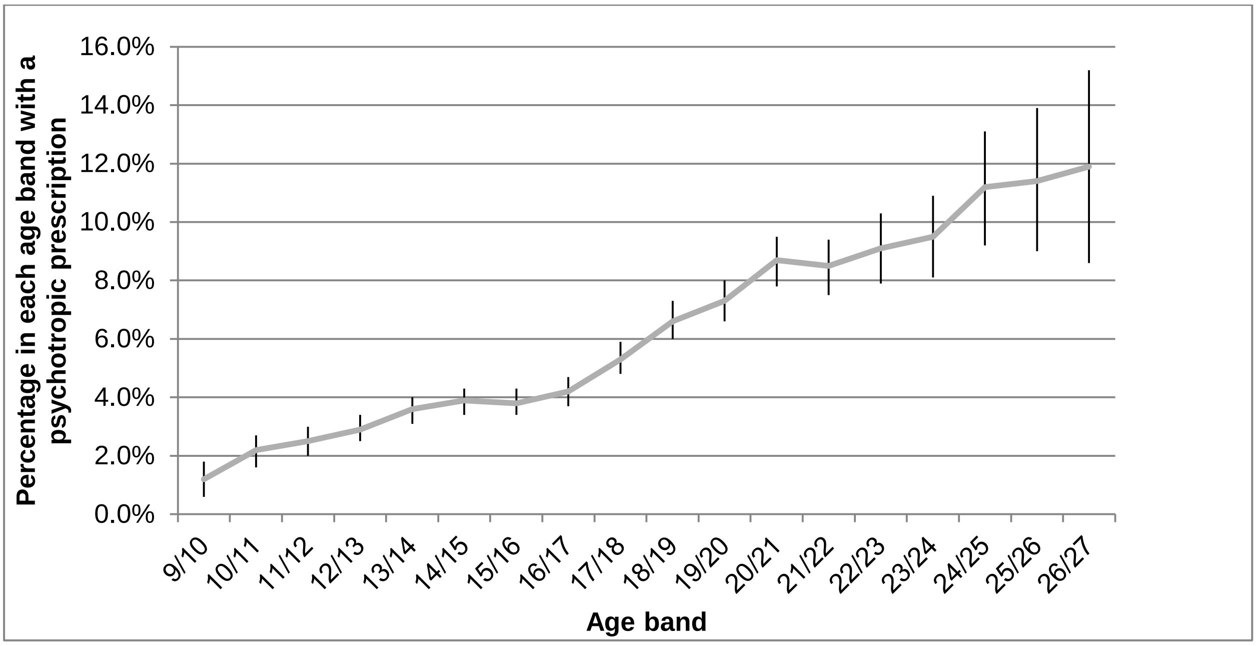
**Table 4.5: Psychotropic prescribing (excluding ADHD medication) 2005-2013, for all cases, and by gender**

| **Medication category (according to BNF category)** | **Percentage (95% confidence intervals) with at least one prescription during study period** | | | |
|---|---|---|---|---|
| | **% All cases (n=9390)** | **% By gender** | | |
| | | **% Males (n=7,876)** | **% Females (n=1,514)** | **p value for Chi-squared test** |
| **Antidepressants** | 16.0 (15.3-16.8) | 13.6 (12.8-14.4) | 28.7 (26.5-31.0) | p<0.001 |
| **Anxiolytics** | 5.8 (5.3-6.2) | 5.1 (4.6-5.6) | 9.2 (7.7-10.6) | p<0.001 |
| **Antipsychotics** | 10.7 (10.1-11.3) | 10.5 (9.7-11.2) | 11.4 (9.8-13.0) | p=0.31 |
| **Any psychotropic medication** | 24.9 (24.0-25.8) | 22.7 (21.7-23.6) | 36.4 (34.0-38.9) | p<0.001 |

*By age band*

When calculated by age band, less than 1 in 20 of those aged 16 and under had a non-ADHD psychotropic prescription. From the ages of 16/17 onwards there was a clear rise in the prevalence of psychotropic prescribing (see Figure 4.5 for illustration) so that at the age of 23/24 almost 1 in 10 (9.5%, 95% CI 8.1 to 10.9%) had a prescription. The prevalence of prescriptions for other psychotropics continued to rise with age, however due to small numbers in the older age groups, there was more uncertainty around these estimates.

**Figure 4.5: Percentage of cases with ADHD at each age with a psychotropic medication (non-ADHD) prescription, with 95% confidence intervals (all years 2005-2013)**



## Prescribing incidence, by age band

Overall, the incidence of new psychotropic prescriptions was low for all age bands (Table 4.6). Incidence rose from under 2% in the under-17s to 2.7% in 17/18 year olds and then to a peak of 4.0% amongst the 20/21 age band. Again, wider confidence intervals were found around point estimates for incidence in older cases, making interpretation of trends more uncertain.

**Table 4.6**: **Percentage of cases with ADHD at each age with a new psychotropic medication prescription (all years 2005-2013)**

| Age Band | Frequency n/total n | Percentage (95% CI) |
|---|---|---|
| 10/11 | 46/2647 | 1.7 (1.2-2.2) |
| 11/12 | 56/3931 | 1.4 (1.1-1.8) |
| 12/13 | 74/4954 | 1.5 (1.2-1.8) |
| 13/14 | 99/5903 | 1.7 (1.3-2.0) |
| 14/15 | 103/6528 | 1.6 (1.3-1.9) |
| 15/16 | 100/6981 | 1.4 (1.2-1.7) |
| 16/17 | 134/7263 | 1.8 (1.5-2.2) |
| 17/18 | 197/7308 | 2.7 (2.3-3.1) |
| 18/19 | 212/6307 | 3.4 (2.9-3.8) |
| 19/20 | 179/5235 | 3.4 (2.9-3.9) |
| 20/21 | 160/4048 | 4.0 (3.4-4.6) |
| 21/22 | 96/3130 | 3.1 (2.5-3.7) |
| 22/23 | 71/2249 | 3.2 (2.4-3.9) |
| 23/24 | 39/1610 | 2.4 (1.7-3.2) |
| 24/25 | 41/1073 | 3.8 (2.7-5.0) |
| 25/26 | 21/648 | 3.2 (1.9-4.6) |
| 26/27 | 10/377 | 2.7 (1.0-4.3) |

### Prescribing summary: *Comparison of ADHD and psychotropic prescribing*

Figure 4.6 plots the prescribing prevalence of both psychotropic and ADHD medications together by age band.

Key points to note include:

- There was a higher prevalence of ADHD prescribing than other psychotropic prescribing until age 24/25 onwards
- Psychotropic prescribing increases continually over time from a very low base
- ADHD prescribing prevalence peaks in the early teenage years, then declines steeply from age 15/16 onwards to 20/21,

- The two lines begin to converge in the mid- twenties, although the smaller numbers in the higher age bands mean there is more uncertainty around these estimates

**Figure 4.6: Percentage of cases with ADHD at each age with an ADHD or other psychotropic medication prescription (all years 2005-2013)**

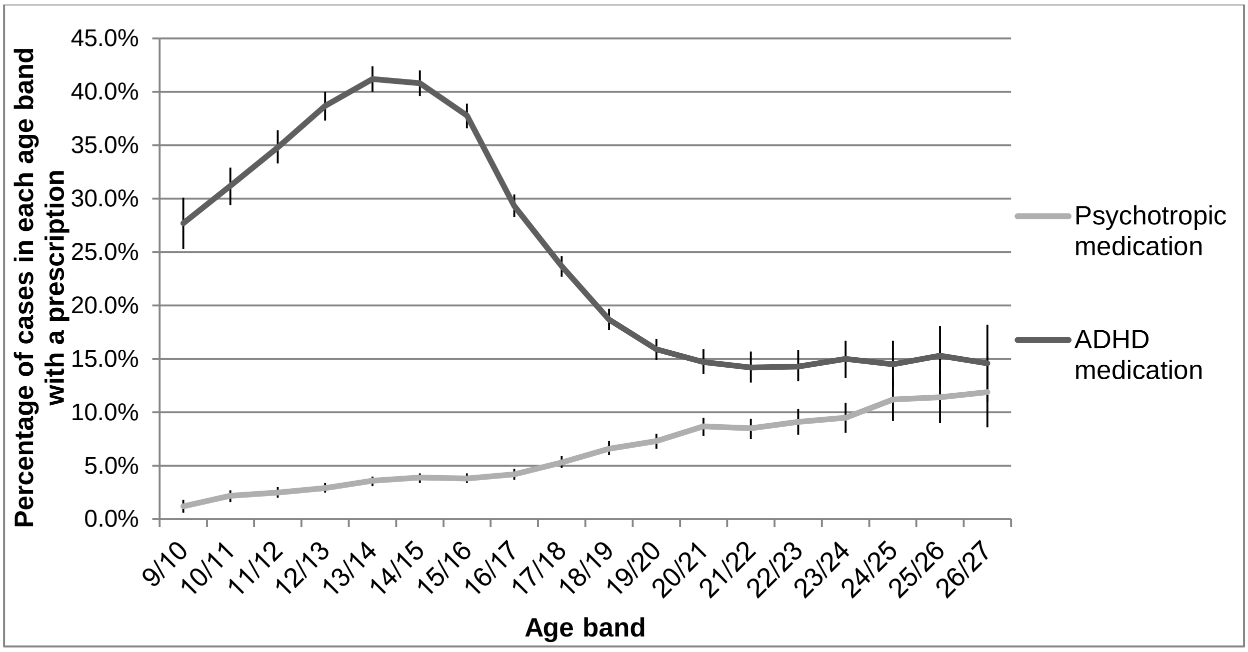
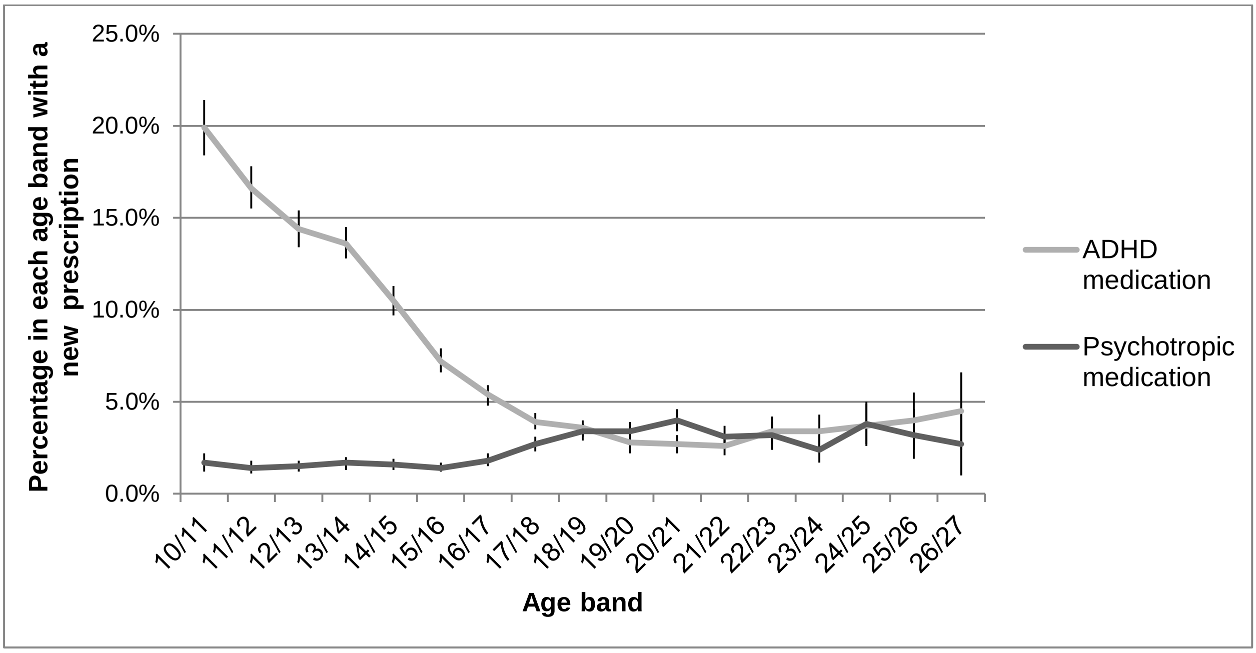


**Figure 4.7** below plots the incidence of new prescriptions of both psychotropic and ADHD medications together by age band.

Key points to note include:

- The highest incidence of ADHD prescribing is in the youngest age bands, and until the age of 17/18 years, is far higher than the incidence of psychotropic prescribing
- Prescribing incidence of other psychotropic medication rises continually over time from a very low base, peaking in the early twenties
- In the 18/19 age band, the lines converge; and in the 19/20, 20/21 and 21/22 age bands, a higher percentage of the sample have new psychotropic prescriptions than ADHD prescriptions. However, confidence intervals overlap for most of these data points.

**Figure 4.7: Percentage of cases with ADHD at each age with a first ADHD or other psychotropic medication prescription (all years 2005-2013)**



*Concurrent prescribing of ADHD and psychotropic medication*

Less than 1 in 10 cases (8.8%, 95% CI 8.3 to 9.4%) had a prescription for an ADHD medication and another psychotropic medication within the same calendar year. This figure was higher among females (11.1%, 95% CI 9.5 to 12.7%) and rose to 17.8% (16.3 to 19.4%) in cases with a comorbid psychiatric disorder. In cases who ever had a psychotropic prescription at any point, over a third had a concurrent prescription with ADHD medication at any point (35.5%, 95% CI 33.5 to 37.4%). The prevalence of concurrent prescribing rose slightly by age.

### *Question 3: What is the prevalence of psychiatric diagnoses and referrals to mental health services in people with ADHD aged 10-27?*

### Psychiatric diagnoses

*All cases*

Over a quarter of cases in the sample had a psychiatric diagnosis at any point (26.0%, n=2440/9390), see Table 4.7 below. The most common categories of psychiatric disorder in the sample were autism spectrum disorders (ASD) (9.9%) and anxiety or depressive disorders (9.3%), followed by conduct and oppositional defiant disorders (5.2%). Fewer than 3% of the sample had diagnoses coded for tic disorders (2.1%), substance or alcohol disorders (2.1%), or personality disorders (1.9%). The least common diagnostic category was bipolar affective disorders and psychoses (0.46%).

Psychiatric comorbidity was more prevalent in females with almost 30% having any disorder at any point, and 15.9% having an anxiety or depressive diagnosis. Personality disorders were also more common in females, whereas ASD, conduct disorders and tics were significantly more common in males.

**Table 4.7: Prevalence of comorbid psychiatric disorders coded at any point, for all cases and by gender**

| **Disorder category** | **N in dataset** | **Percentage (95% confidence intervals) of cases with the disorder recorded at any point** | | | |
|---|---|---|---|---|---|
| | | **All cases % (n=9390)** | **By gender** | | |
| | | | **Males % (n=7876)** | **Females % (n=1154)** | **p value for Chi-squared test** |
| **Any comorbid psychiatric disorder** | 2,335 | 26.0<br>(25.1-26.9) | 25.3<br>(24.4-26.3) | 29.4<br>(27.1-31.7) | p<0.01 |
| **Autism spectrum disorder (ASD)** | 927 | 9.9<br>(9.3-10.5) | 10.3<br>(9.6-11.0) | 7.7<br>(6.3-9.0) | p<0.01 |
| **Anxiety or depression related disorder** | 876 | 9.3<br>(8.7-9.9) | 8.1<br>(7.3-8.7) | 15.9<br>(14.1-17.7) | p<0.001 |
| **Conduct/oppositional defiant disorder** | 490 | 5.2<br>(4.8-5.7) | 5.5<br>(5.0-6.0) | 3.8<br>(2.9-4.8) | p<0.01 |
| **Substance/alcohol misuse related disorder** | 199 | 2.1<br>(1.8-2.4) | 2.0<br>(1.7-2.3) | 2.6<br>(1.8-3.5) | p=0.12 |
| **Any tic disorder** | 198 | 2.1<br>(1.8-2.4) | 2.3<br>(2.0-2.7) | 1.0<br>(0.5-1.5) | p<0.01 |
| **Any personality disorder** | 179 | 1.9<br>(1.6-2.2) | 1.5<br>(1.2-1.8) | 4.0<br>(3.0-5.0) | p<0.001 |
| **Bipolar affective disorder or psychosis** | 43 | 0.46<br>(0.32-0.59) | 0.50<br>(0.34-0.65) | 0.26<br>(0.01-0.52) | p=0.22 |

### Prescribing and psychiatric comorbidity

Table 4.8 presents the prevalence of prescribing of ADHD and other psychotropic medication at any point in those who did and did not have a psychiatric comorbidity (i.e. another psychiatric disorder in addition to ADHD). Of all cases with comorbidity, 49.1% had a prescription for a psychotropic medication at any point, versus 16.8% of those without recorded comorbidity.  The prescribing prevalence of psychotropic medication was significantly higher ($p<0.01$) among females with a comorbid disorder than in males with such a disorder; almost two-thirds (64.5%, 95% CI 59.8 to 68.9%) had a prescription compared to under half of males (45.8%, 95% CI 43.5 to 48.0%). When including only those with a diagnosis of anxiety or depressive disorders, this pattern remained, with 67.8% (95% CI: 64.0 to 71.3%) of males having a psychotropic prescription versus 76.3% (95% CI: 70.4 to 81.2%) of females (not shown in Table 4.8), although the difference was not significant at the $p<0.05$ level.

In contrast to the findings on psychotropic prescribing, females with a comorbid psychiatric disorder had a lower prevalence of ADHD medication prescribing than males (60.7% vs. 63.5%, see Table 4.8), although again this difference was not significant at the $p<0.05$ level ($p=0.3$).

**Table 4.8: Prescribing of ADHD and psychotropic medication in those with and without psychiatric comorbidities**

| | **Cases without recorded psychiatric comorbidity** | **Cases with any psychiatric comorbidity** | | |
|---|---|---|---|---|
| | All | All | Males | Females |
| **Percentage prescribed psychotropic medication (95% confidence interval)** | 16.8%<br>(16.0-17.7%) | 49.1%<br>(47.1-51.1%) | 45.7%<br>(43.5- 47.9%) | 64.4%<br>(60.0-68.9%) |
| **Percentage prescribed ADHD medication (95% confidence interval)** | 61.0%<br>(60.0-62.2%) | 63.1%<br>(61.0-64.9%) | 63.5%<br>(61.3-65.6%) | 60.7%<br>(56.2-65.2%) |

## Learning disability and ADHD: prevalence and prescribing

### *Prevalence*

513 cases (5.5%, 95% CI 5.0 to 5.9%) had a code for a learning disability (including mild, moderate and severe categories). The prevalence was similar amongst females (5.7%, 95% CI 4.7 to 7.0%) and males (5.4%, 95% CI 4.9 to 5.9%, p=0.6).

### *ADHD Prescribing*

68.6% (95% CI 64.5 to 72.5%) of cases with a learning disability (LD) had an ADHD prescription, compared to 61.2% (95% CI 60.1 to 62.2%) of those without (p=0.01). Prescribing prevalence was higher amongst girls with LD; 72.4% (95% CI 61.9 to 80.9%) were prescribed an ADHD medication compared with 67.8% (95% CI: 63.2 to 72.1%) of males. However, this analysis may have lacked power due to small numbers and the confidence intervals overlapped (p=0.4)

*Psychotropic prescribing*

Almost half of cases with LD had a psychotropic prescription at some point during the study period (44.6%, 95% CI 40.4 to 50.0%). Again, females with LD had a higher prevalence (p=0.02) of psychotropic prescribing than males; 56.3% (95% CI 45.6 to 66.5%) had a prescription versus 42.3% (95% CI 37.6 to 47.0%) of males.

### Psychiatric referrals

Over the study period, only a fifth of cases had a recorded new referral to mental health services for any reason, which included CAMHS, adult psychiatry, clinical psychology and community psychiatric nurses (n= 1,894, 20.2%, 95% CI 19.3 to 21.0%). A higher percentage of females had referrals recorded (24.1%, 95% CI 22.0 to 26.3%) than males (19.4%, 95% CI 18.5 to 20.3%, p<0.001). This figure rose to 26.4% (95% CI 24.6 to 28.2%) amongst cases with a comorbid psychiatric disorder, and fell to 16.6% amongst those with a learning disability (95% CI 13.6 to 20.1%).

The most common service that young people were referred to was CAMHS. Approximately, 1 in 10 had a referral recorded (see Table 4.9). Very small numbers were specifically coded as being referred to clinical psychology or to community psychiatry nurses.

**Table 4.9: Psychiatric referrals by type over study period in cases with an ADHD code**

| **Referral** | **Frequency n/total n** | **Percentage (95% CI)** |
|---|---:|---|
| **No recorded referral** | 7,496/9390 | 79.8 (19.4-21.0) |
| **CAMHS** | 1,017/9390 | 10.8 (10.2-11.3) |
| **Adult psychiatry** | 816/9390 | 8.7 (8.1-9.3) |
| **Clinical psychology** | 168/9390 | 1.8 (1.5-2.1) |
| **Community Psychiatric Nurse** | 76/9390 | 0.81 (0.63-1.0) |

### *Question 4: What is the prevalence of ADHD medication cessation within each age band?*

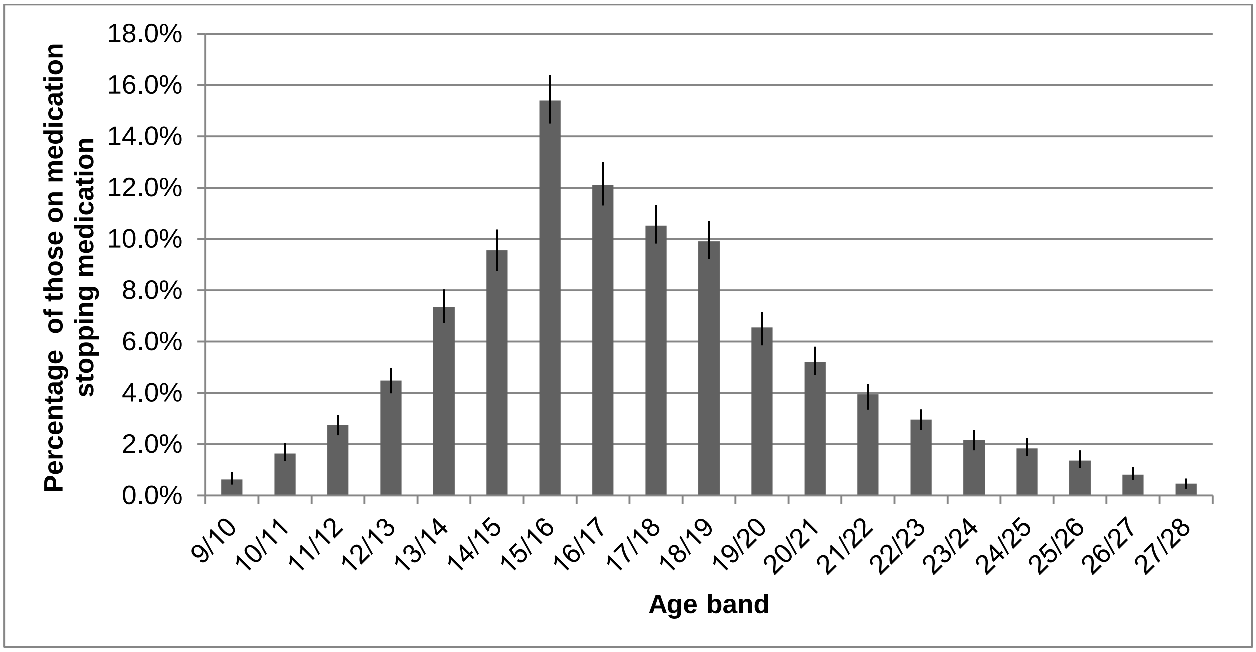
*Time on medication and cessation*

The median number of years between first and last prescription for ADHD medication for all cases was 3 (interquartile range 1.0 to 6.0). Of the 5,780 cases who had an ADHD prescription at any point, 60.1% (n=3476, 95% CI 58.9 to 61.4%) had their last prescription recorded before the end of the study period (i.e. between 2005 and 2012). Only 22.8% (n=1316, 95% CI 21.7 to 23.9%) were still on medication at the end of the study period in 2013. The remaining 17.1% (n=988, 95% CI 16.1 to 18.1%) transferred out of the CPRD whilst still with a prescription for medication before the end of the study, hence their outcome was unknown.

*Age at cessation*

Figure 4.8 below shows the percentage of those stopping medication in each band (i.e. who had their last prescription in that age band) as a percentage of all cases prescribed ADHD medication during the study period. The highest frequency of cessation was at 15/16 years (15.4%) followed by 16/17 years (12.2%). Cessation over the transition period from age 16 onwards is explored more fully in the following section on Survival Analysis.

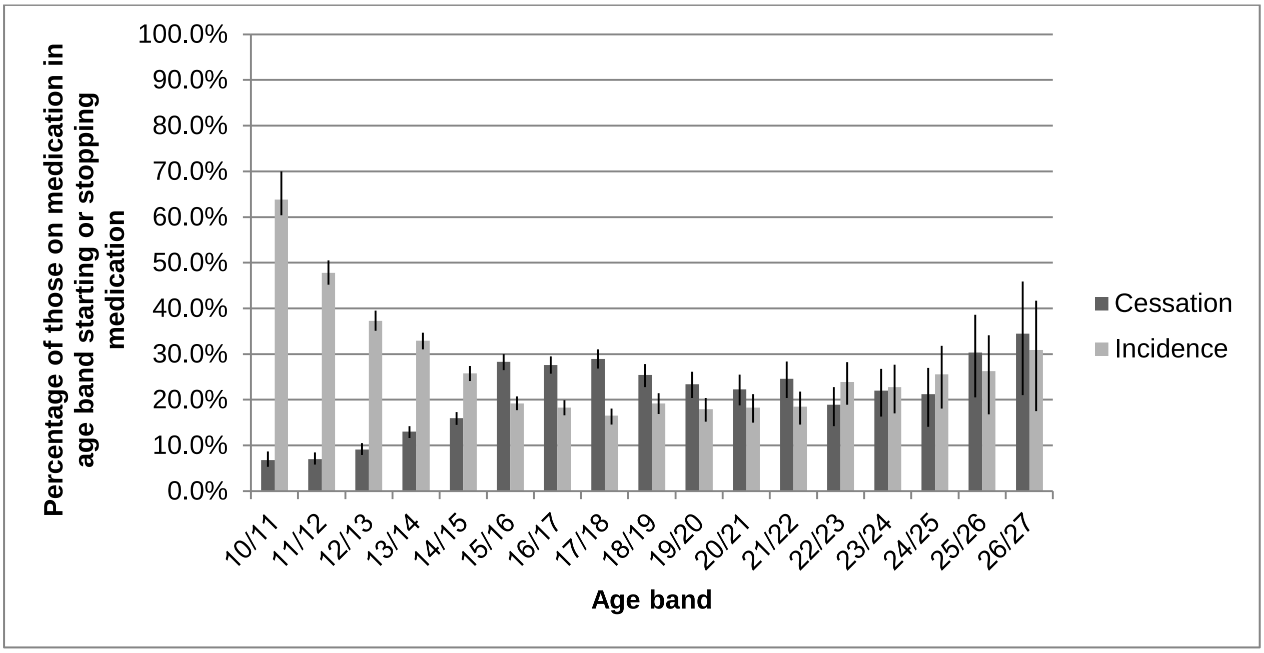
**Figure 4.8: Percentage of cases with an ADHD medication prescription stopping medication in each age band**



*Cessation as a proportion of prevalence*

Figure 4.9 displays the percentage of those who had a prescription for an ADHD medication in each age band for whom this was their first prescription (incidence) or last prescription (cessation) recorded in the database. Pre-transition, incident prescriptions are more frequent than cessation, but from the 15/16 age band onwards this pattern is reversed, 28.3% of prescriptions were stopped, compared to 19.2% of prescriptions being new. For cases in their twenties trends in cessation and incidence are more unclear due to smaller numbers introducing more uncertainty (e.g. there were only 99 cases with a prescription in the 25/26 age band, and only 55 in the 26/27 age band).

**Figure 4.9: Cessation* and incidence as a proportion of prevalence: percentage of cases in each age band on ADHD medication for who this was their first or last recorded prescription**



*Cessation is defined as the last year of recorded prescription, not counting cases in the numerator who were censored – i.e. for whom this was their last year in study – (see Methods)

### 4.4.2 Survival analysis

***Question 5: What is the time to cessation of ADHD medication amongst young people aged 16 with a prescription, and what factors (including prescription of new non-ADHD psychotropic medications) are associated with cessation?***

*The survival analysis dataset*

1,620 cases met the criteria for entry into the survival analysis. Of these cases, 87.6% (n=1419) were male.

The total amount of time at risk (i.e. time from 16th birthday to censoring or cessation) for cases in the dataset was 3099.1 years. The minimum time at risk was 0.08 years and the maximum 8.7 years, with the mean being 1.9 years. It is important to note that cases had their 16th birthdays from 2005 to 2011, meaning that for those turning 16 in 2011, there was less than 3 years of follow-up until the study end on 1st Jan 2014.

390 cases, or 24.1% of the dataset did not experience cessation by the end of the study period. 302 were still on medication at the end of the study, 1st Jan 2014. 88 were censored during the study period; i.e. they were lost to follow-up whilst still on medication before the end of the study. These cases were not significantly different to uncensored cases with respect to starting time, duration of medication, or year of birth.

**Time to cessation**

*Time to cessation*

The median time to cessation was 1.5 years (95% CI 1.4 to 1.7), with the interquartile range being 0.67 years to 3.4 years.

*Rate of cessation*

75.9% (n=1230/1610, 95% CI 72.8 to 78.0%) of cases experienced cessation during the follow-up period. The rate of cessation per year was 0.40 (95% CI 0.38 to 0.42), or 396.9 per 1000.

*Survival function/probability of remaining on medication*

The survival function, which is the cumulative proportion of cases surviving up to the respective time interval at each year of follow up, is presented in Table 4.10 below. It represents the probability of remaining on medication up to a given time point. The survival function at 1 year (i.e. at the age of 17) was 0.63, but by two years, the probability of remaining on medication had fallen to 0.41. By 3 years this had fallen further to 0.30. At 6 years, only 39 cases remained on medication in the study, the rest having been censored by reaching the end of the study period or being transferred out; or having experienced cessation. Figure 4.10 displays the accompanying Kaplan-Meier plot of survival function over time.

**Table 4.10: Survival function at each year of follow-up**

| **Time post 16th birthday in years (age)** | **N in the analysis** | **N experiencing cessation** | **Survival function/probability of remaining on medication* (95% CI)** |
|---|---|---|---|
| 0 (16) | 0 | 0 | 1 |
| 1 (17) | 1016 | 590 | 0.63 (0.61-0.65) |
| 2 (18) | 646 | 343 | 0.41 (0.39-0.43) |
| 3 (19) | 337 | 159 | 0.30 (0.28-0.32) |
| 4 (20) | 165 | 91 | 0.21 (0.19-0.23) |
| 5 (21) | 75 | 30 | 0.16 (0.14-0.19) |
| 6 (22) | 39 | 11 | 0.13 (0.1 -0.16) |
| 7(23) | 11 | 6 | 0.11 (0.08-0.14) |
| 8 (24) | 11 | 0 | 0.11 (0.08-0.14) |

*Note, the survivor function is calculated over days and evaluated at indicated times; it is not calculated from aggregates shown at left of the table – therefore numbers censored are not shown

**Figure 4.10: Kaplan Meier plot of survival function over time from age 16 years**

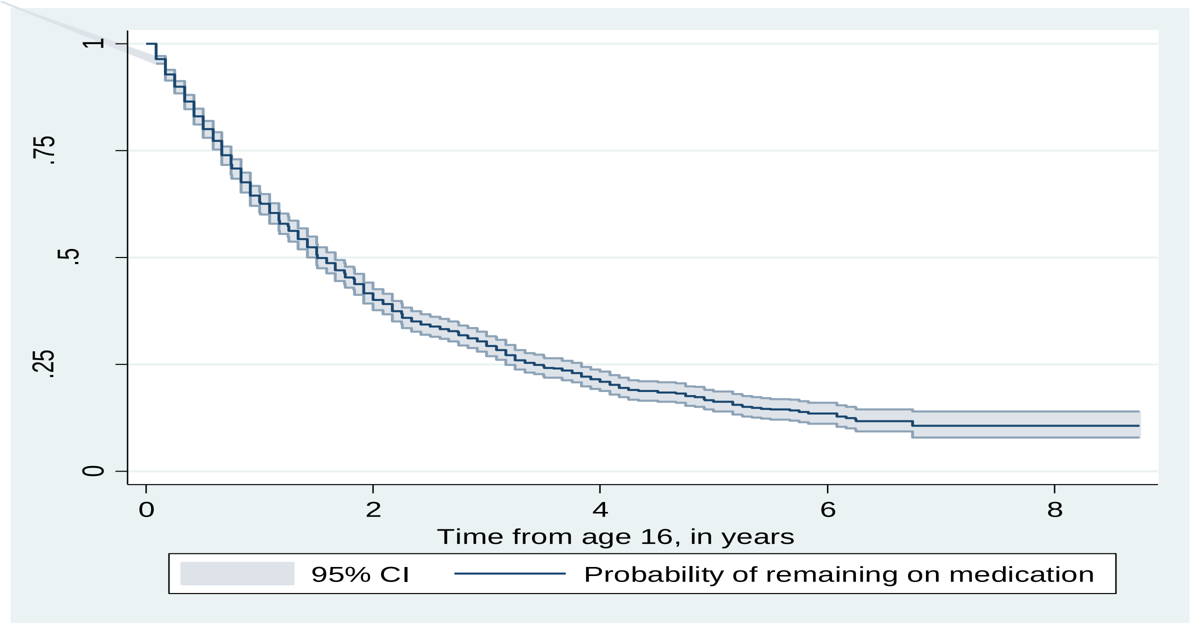
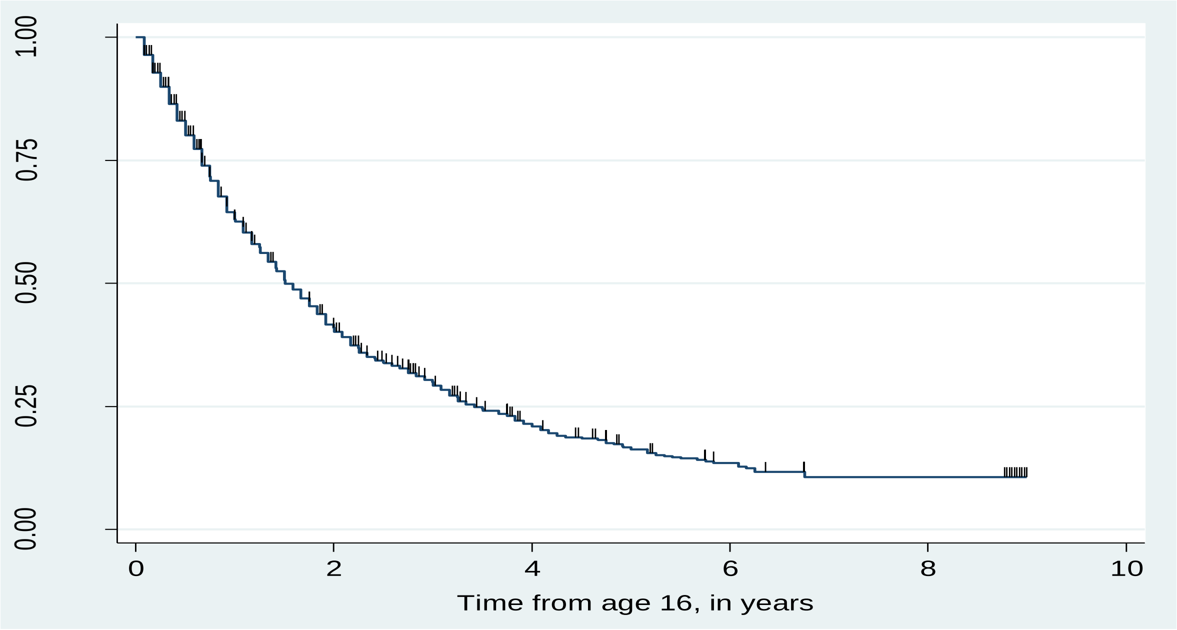


Figure 4.11 displays the Kaplan-Meier curve with censoring, with vertical marks representing multiple censored cases; note that there are fewer censored cases after 6 years as only 39 cases remained on medication after this point.

**Figure 4.11: Kaplan Meier plot of survival function over time, showing censored cases**



**Factors associated with cessation/Explanatory variables**

The results for this question are presented in two parts; firstly the findings of the univariate analysis, and secondly the model for the multivariable analysis.

*Univariate analysis*

The findings displayed below in Table 4.11 suggest that there is an association at the $p<0.05$ level between a number of variables and cessation of medication. Having a prescription for another psychotropic medication at the age of 16 or over, being born later in the cohort, referral to adult psychiatry, comorbid ASD / LD and being on medication for 3 or more years prior to 16th birthday all appear to be associated with a reduced hazard of cessation. Smoking at any point was associated with an increased hazard. There was no strong evidence of non-proportionality of hazards over time, the test suggested weak evidence for non-proportionality of hazards for ASD ($p=0.08$) but on further examination of the graphed Nelson-Aalen estimates this was more marked at extremes of time where the model was more unstable.

**Table 4.11: Predictors of cessation of ADHD medication: univariate analysis**

| **Variable** | **Univariate Cox regression** | | | **Test for non-proportionality of hazards P value** | **p value (derived from log-rank test)** |
|---|---|---|---|---|---|
| | **Hazard ratio** | **95% CI** | **P value** | | |
| **Female gender** | 0.93 | 0.78 to 1.10 | 0.38 | 0.58 | p=0.38 |
| **Psychotropic prescription post 16** | 0.77 | 0.66 to 0.90 | <0.001 | 0.75 | p<0.001 |
| **Anxiety or depression diagnosis** | 0.94 | 0.75 to 1.18 | 0.60 | 0.59 | p=0.60 |
| **Conduct/ODD diagnosis** | 1.04 | 0.81 to 1.32 | 0.77 | 0.61 | p=0.77 |
| **Autism spectrum disorder (ASD)** | 0.62 | 0.51 to 0.76 | <0.001 | 0.08 | p<0.001 |
| **Learning disability** | 0.56 | 0.43-0.71 | <0.001 | 0.30 | p<0.001 |
| **Adult psychiatry referral** | 0.68 | 0.55 to 0.83 | <0.001 | 0.82 | p<0.001 |
| **Year of birth 1993-1995 (vs 1989-1992)** | 0.79 | 0.71 to 0.89 | <0.001 | 0.84 | p<0.001 |
| **Smoking at any point** | 1.17 | 1.05 to 1.31 | 0.005 | 0.38 | p=0.005 |
| **Time on medication prior to 16th birthday:** | | | | | |
| *Less than 2 years* | *Reference* | *Reference* | <0.001 | 0.27 | p<0.001 |
| *2-3 years* | 1.03 | 0.89 to1.20 | | | |
| *3 or more years* | 0.76 | 0.67 to 0.97 | | | |

*Multivariable analysis*

Factors associated with cessation were entered into a multivariable Cox regression analysis. The results are presented in Table 4.12 below. Having a learning disability, an ASD diagnosis and being referred to adult psychiatry at any point were the strongest predictors of remaining on medication, with a hazard ratio for cessation of 0.60, 0.68 and 0.67 respectively. Having a prescription of psychotropic medication at the age of 16 or over was also an independent predictor of remaining on medication

(HR 0.79). Those born later in the cohort, between 1993 and 1995, had a reduced hazard of cessation compared with those born earlier (HR 0.88), even after adjusting for all other variables, but the association was (just) not significant at the p<0.05 level (p=0.05). Having an ADHD prescription for 3 or more years prior to the age of 16 was also associated with remaining on medication. Smoking, coded at any point during the study period, was associated with an increased hazard of cessation (HR 1.10), although the 95% confidence interval included unity.

**Table 4.12: Fully adjusted multivariate Cox regression model of factors associated with cessation (n=1620)**

| **Variable** | **Hazard ratio** | **95% confidence interval** | **p value** |
|---|---|---|---|
| **Psychotropic prescription aged 16 or over** | 0.79 | 0.67 to 0.91 | p<0.01 |
| **Autistic Spectrum Disorder** | 0.68 | 0.55 to 0.83 | p<0.001 |
| **Learning disability** | 0.60 | 0.47 to 0.77 | p<0.001 |
| **Referral to adult psychiatry** | 0.67 | 0.54-0.83 | p<0.001 |
| **Smoking** | 1.10 | 0.98-1.24 | p=0.1 |
| **Birth year 1993-1995**<br>**(vs 1989-1992)** | 0.88 | 0.77-1.00 | p=0.05 |
| **Time on medication prior to 16th birthday:** | | | |
| *Less than 2 years* | *Reference* | *Reference* | p<0.01 |
| *2-3 years* | 1.04 | 0.89 to 1.21 | |
| *3 or more years* | 0.81 | 0.70 to 0.94 | |

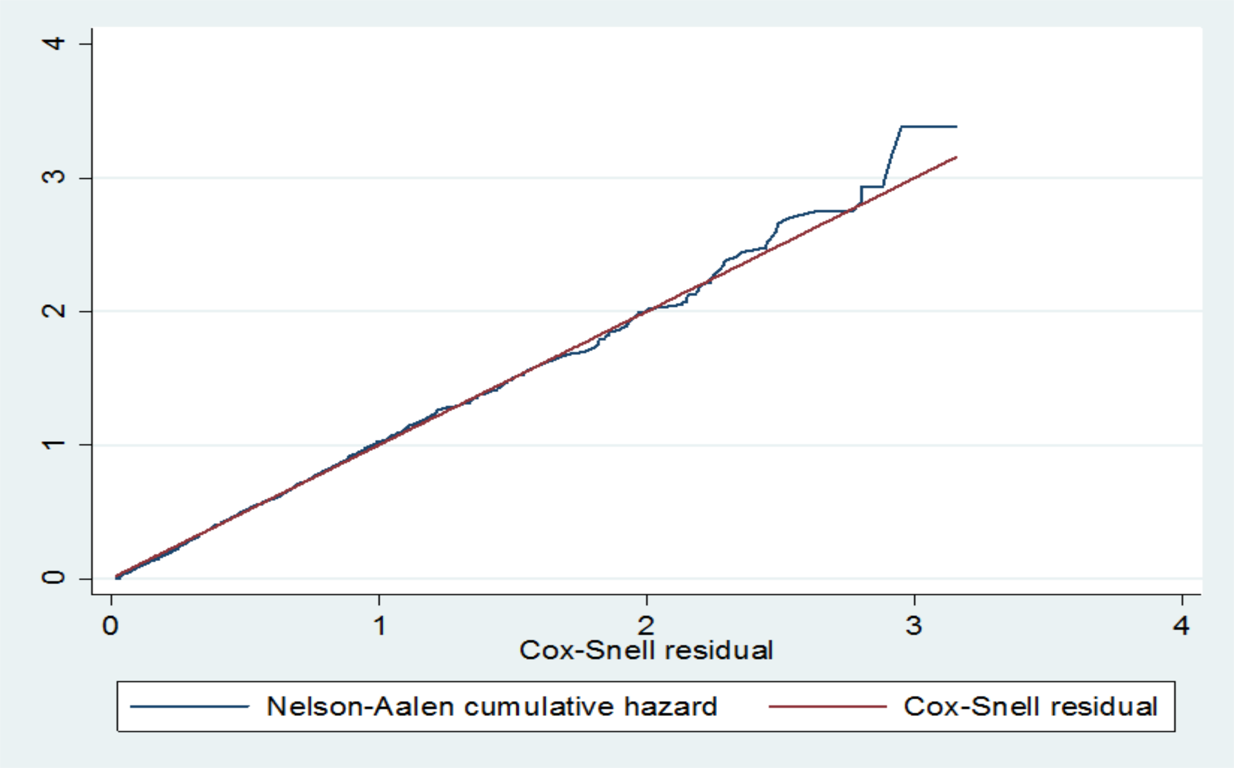
*Interactions*

There was no strong evidence of any interaction between the variables included in this model. There was weak evidence of an interaction between ASD diagnosis and psychotropic prescription over 16 (p=0.06); in people with a diagnosis of ASD, a psychotropic prescription over the age of 16 did not significantly change the hazard of cessation, and vice versa. Similarly, there was weak evidence of an interaction between ASD diagnosis and LD (p=0.08).

*Testing the model*

The p value for the global test of non-proportionality was 0.55, which suggested that the assumption of proportional hazards was reasonable. Testing the fit of the model by plotting Nelson-Aalen cumulative hazard function against Cox-Snell residuals (Figure 4.12) indicated that the model was a good fit overall with the hazard function following the 45 degree line. For larger values of time there was some deviation from the line, which is likely to be due to the increasing amount of censored data.

**Figure 4.12: Testing fit of multivariable model tested by plotting Nelson-Aalen cumulative hazard function against Cox-Snell residuals**



*Sensitivity analysis*

The planned sensitivity analyses to assess the effect of excluding the cases censored before the end of the study, and of extending the definition of censoring, did not appreciably alter the estimates obtained, and did not improve the fit of the model.

## 4.5 Discussion

### ADHD and other psychotropic prescribing

The first aim of this study was to examine prescribing of ADHD medication in cases with ADHD aged between 10 and 27.  Overall, 61.6% of cases had an ADHD prescription at any point during the study period. NICE guidelines (2008b) state that medication is a second-line treatment for children with moderate ADHD (following interventions such as referral to parent training groups) and a first line intervention for those with severe ADHD. Approximately 40% of children with ADHD have the severe form, and a further 35% have the moderate form (Kessler *et al.* 2005). We might therefore expect between 40% and 75% of those with ADHD to be treated with medication at some point.

In this sample, the highest prescribing prevalence in any age band was at 13/14, where two-fifths had a prescription.  When examining prescribing by year, even for 2012 and 2013, prevalence of prescribing never exceeded 44%. Although concerns have been raised about the rising number of ADHD prescriptions in the UK (Thomas *et al.* 2013), these findings do not suggest that children diagnosed with ADHD in this sample were being over-treated with medication, and are in keeping with UK population estimates of pharmacologically treated ADHD being lower than population estimates of prevalence (Ford *et al.* 2003, McCarthy *et al.* 2012b). The figures from this analysis are also lower than the reported prescribing prevalence in CAMHS samples described by Ford *et al.* (2008a) (up to 93% of those with ADHD reporting ever having had medication), although these would represent a more severely affected and complex population.

### Fall in prescribing over the transition period

Results clearly demonstrated a decline in prescribing from the age of 15/16 to 20/21 years, with a fall of 23.1% over the study period. Despite the secular trend for slowly increasing prescribing in all age bands, this fall was still evident in more recent years (2012 and 2013) within the study period. Incidence of new prescriptions mirrored prevalence in this age group - dropping from 10.5% in the 14/15 age band to 5.4% in the 16/17 age band, with the lowest rates of initiation from 19 to 22.

As expected, parallel to the decline in ADHD prescribing, there was an increase in prevalence of psychotropic prescribing with increasing age, particularly over the transition period. This is of course the peak age for emergence of new mental health diagnoses whilst ADHD symptoms decline with age (Faraone *et al.* 2006, Kessler *et al.* 2007), however it does not contradict the hypothesis that these prescribing trends might equally represent substitution of one medication by the other in some cases.

### Prescribing in early adulthood

Fewer than one in five of those aged 21/22 or over had an ADHD prescription. In the 24/25 age band, 14.5% were on medication. Such figures are markedly lower than the estimates of persistence of symptoms at the age of 25 (40-60%), even for the most recent years in the study period, and add to the body of findings suggesting adults remain under-treated for their ADHD (Faraone *et al.* 2006, McCarthy *et al.* 2012b, Ginsberg *et al.* 2014).

Interestingly, there was a suggestion of a slight rise in incident and prevalent prescribing of ADHD medication from the mid-twenties onwards, although estimates had wide confidence intervals. This would require replication and further exploration, but may imply a trend for people with ADHD finding their way back to services and onto medication to manage their ADHD in the context of professional and family life as an adult. Such help-seeking may be facilitated by increasing awareness and by an expansion in shared care prescribing arrangements and new services for adult ADHD in England and Scotland (Crimlisk 2011, Health Improvement Scotland 2012, Magon *at al.* 2015).

Pharmacologically treated adult ADHD appears to have risen over time. In 2008, NICE estimated that only 1.24% of adults with ADHD were currently receiving medication (NICE 2008a), in contrast, the current study found that 14-15% of adults in in each age band between 20 and 27 had an ADHD prescription. Prescribing in all age bands gradually rose over the course of the study, with prevalence in the older age bands (24/25, 25/26, 26/27) increasing from 2010 to 2013. This trend has been found in previous studies covering earlier and overlapping time periods, such as. McCarthy *et al.*'s (2012b) research using the Health Improvement Network (covering 2003-2008) in the UK, as well as a number of European studies ( Zetterqvist *et al.* 2013, Geirs *et al.* 2014)

### Comorbid psychiatric disorders and psychotropic prescribing

Just over a quarter of all cases had an additional psychiatric diagnosis coded at any point. Approximately one in ten had a code for ASD and a nine per cent had anxiety or depressive disorders diagnosed. Overall the prevalence of other disorders in this sample was lower than estimates from comorbidity studies, although these estimates will not be directly comparable as comorbidity studies screen for psychiatric diagnoses using diagnostic instruments and clinical interviews, and in this study diagnoses were recorded by GPs. A review of comorbidity studies (Sobanski 2006) suggests that approximately 16-26% of children with ADHD will have a comorbid depressive syndrome and 15% will have an anxiety disorder. Lifetime prevalence of depressive episodes in adults with ADHD stands at 35-50%, with 40-60% for anxiety disorders, however comparison is more difficult as people in this study were followed up only until age 28. Whilst a quarter of the whole sample had a prescription for another psychotropic (i.e. non-ADHD medication) at any point, this rose to half of those who had a psychiatric comorbidity, with the most commonly prescribed class being antidepressants.

### The relationship between gender, comorbidity and prescribing

There was a clear gender difference both in the prevalence of other psychiatric diagnoses and of other psychotropic prescribing. Lifetime prevalence rates of anxiety and depression are higher amongst females with ADHD than with males, although externalizing disorders are more common amongst males (Levy *et al.* 2005, Elkins *et al.* 2011). This pattern was evident in the results of the current study; anxiety and depression were more commonly coded in relation to females and conduct and oppositional defiant disorders amongst males.

Females were more likely to be prescribed a psychotropic than males. This is not fully explained by the higher prevalence of emotional disorders amongst females, as even amongst those with a coded disorder of anxiety or depression, prescribing prevalence was higher amongst females (76%) than males (65%). The findings imply that females are more likely to be pharmacologically treated in primary care for comorbidities with ADHD, although without other information such as severity or details of other management, it is not possible to say whether this represents under- or over-treatment for either gender.

Although females were more likely to be prescribed medication for comorbidities in this study, it has been suggested that they are less likely to receive medication for their ADHD itself (Coles *et al.* 2012, Garbe *et al.* 2012, Quinn and Madhoo 2014). This analysis found that women and girls with comorbidities were possibly less likely to be prescribed ADHD medication than males, although the difference was not significant at the $p<0.05$ level. This finding may still imply pharmacological under-treatment of females,  as they may face higher barriers to receiving a diagnosis which are documented in the literature, including attitudes amongst teachers and parents (Maniadaki *et al.* 2006, Groenewald *et al.* 2009, Ohan and Visser 2009). Referral rates for girls have been found to be disproportionately lower than boys across Europe, even given the estimates of the gender ratio in ADHD (Novik *et al.* 2006). Barriers to identification may be even higher where ADHD exists alongside comorbid depression and anxiety, which may be diagnosed and treated in preference to ADHD (Quinn and Wigal 2004, Quinn and Madhoo 2014). As all cases in this dataset had diagnosed ADHD, the females may have represented a more severely affected group than the males in order for their ADHD to have been clinically recognised and referred. Consequently, even this non-significant difference might represent under-treatment, although there were no data on severity and impairment to explore this hypothesis further.

### Cessation of ADHD medication

In this sample, the majority of participants had stopped medication by their 18th birthday; the probability of still being on ADHD medication by then was 0.41, and 0.30 by 19 years. These estimates are in line with McCarthy *et al.*'s (2012a) findings using the THIN database that approximately 40% of those starting medication in childhood or adolescence remained on medication at 18 or over. Whilst a direct comparison should not be made with the earlier CADDY study due to slightly different methods, the populations are similar enough to note that the estimates of persistence on medication from this analysis are higher than those reported in the previous study, (54% at age 17, 36% at age 18, 24% at age 19) (Wong *et al.* 2009). The probability of remaining on treatment after the age of 19 was comparable in both studies (0.21 by age 20 versus 22% in CADDY), although the small numbers remaining after censoring by this time point meant that these estimates were more unstable and less reliable. Cases born later in this cohort, between 1993 and 1995, who turned 16 between 2009 and 2011 had a reduced hazard of cessation compared with those born earlier even after adjusting for all other variables, and the probability of remaining on medication at one year was highest amongst those born in 1995 (0.72). These findings may reflect changing prescribing practice over the transition period, the development of adult services and an increasing acceptance that ADHD continues to merit pharmacological intervention after the age of 16, possibly influenced by the new NICE guidelines in 2008 (NICE 2008b, Crimlisk 2011, Magon *et al.* 2015).

Less positively, the rate of cessation remains greater than the estimated persistence of symptoms. Faraone *et al.*'s (2006) meta-analysis of follow-up studies found the persistence of ADHD meeting the full criteria for the condition 1 year later to be 83%, whereas the probability of medication persistence in our study was 0.63. The authors also place the persistence of symptomatic ADHD at age 20 at 69%, and a more conservative estimate of persistence of the full ADHD syndrome at 28%; both in excess of the probability of remaining on medication by 20 in this study (0.21).

### Predictors of cessation

In contrast to the CADDY study, this analysis found associations between both referral to adult psychiatry and psychotropic prescribing, and cessation (Wong *et al.* 2009). Being referred to adult psychiatry at any point was the strongest predictor of remaining on medication (probability 0.73 versus 0.62 for those with no referral). This may reflect a greater willingness of GPs to continue prescribing ADHD medication if the patient is being seen or referred to a psychiatrist, as guidelines recommend specialist oversight of prescribing (NICE 2008b, Bolea-Alamanac *et al.* 2014). It may also be due to these patients having more severe or persistent ADHD symptoms for which we were unable to adjust, which would mean they were both more likely to be referred and to continue medication.

The prescription of psychotropic medication at the age of 16 or over predicted remaining on medication. The association remained even after adjusting for possible confounders in the Cox regression including having a psychiatric diagnosis, and being referred to adult psychiatry. These findings do not support the original hypothesis for exploration, that psychotropic medications may be substituted for ADHD medication in patients transitioning into adulthood. It is possible that the relationship between psychotropic prescription and ADHD medication cessation may be confounded by other factors. For example, other psychotropic medication prescription may be a marker for severity of ADHD (Simon *et al.* 2013), or for variables such as social class or other patient factors influencing help seeking behaviour and engagement with services. The substitution hypothesis would require a more detailed analysis including these potential confounding variables to examine this further, and/or could be explored using qualitative methods such as interviews with GPs.

Smoking at any point was associated with a small (but non- significant at the p=0.05 level) increased risk of cessation, which may be explained by young people using smoking to self-medicate post cessation, as there is some evidence for an association between consistent ADHD medication and reduced risk of tobacco smoking (Schoenfelder *et al.* 2014). However, this analysis examined smoking only as a binary variable as ever-smokers and non-smokers and relied on primary care coding at consultation. This meant that it was not possible to define the order in which cessation and smoking occurred, or to conclude that any kind of causal relationship exists.

This analysis did not find an association between cessation and gender, in contrast to the CADDY study, which reported a 27% lower hazard of cessation in females after 6 months(Wong *et al.* 2009). In this study the hazard ratio in females compared to males was less markedly reduced (0.93), with the 95% confidence interval spanning unity. The difference is unlikely to be due to power; 12.1% (201/1620) of the sample were female, compared to 9% (74/983) in CADDY, but may have been influenced by the younger starting age in CADDY, or be due to secular changes.

The only comorbid psychiatric diagnosis significantly associated with remaining on medication was ASD. Explanations for this finding are varied; people with ASD may be more likely to adhere to medication, or to have more severe ADHD and experience greater impairment increasing their desire to continue with treatment(Leitner 2014). Due to their dual neurodevelopmental disorders they may also be managed and monitored in different services from young people without ASD, such as paediatrics or learning disability, where transition may occur later or where there may be a greater acceptance of the use of medication. A similar explanation is likely to apply to the association between learning disability and remaining on ADHD medication.

### Strengths and limitations

The chief strength of this analysis is the use of high quality and recent data from a national database capturing primary care prescribing until the end of 2013. The dataset covered a period following the introduction of the NICE guidance on prescribing for adults and an expansion in awareness of adult ADHD. The cohort design of the sample enabled both secular trends and trends by age to be examined. The size of the sample eventually eligible for analysis exceeded that required from the initial power calculation allowing multiple predictors of cessation to be examined, in contrast to previous studies with smaller numbers.

#### *Identification of prescriptions*

Increasing use of shared care means that primary care prescriptions are likely to provide the fullest available picture of prescribing without using data linkages, or dispensing records which may offer limited details. A 2008 study of young people seen in CAMHS found that GPs were prescribing for 82% of the sample (Ford *et al.* 2008a). Some Mental Health Trusts also have shared care prescribing protocols for ADHD in adults; a 2013 audit found 35% of the 68% of Trusts that responded had such a protocol (Hall *et al.* 2015). Nonetheless primary care records will fail to capture prescribing taking place in specialist services, which might relate to shorter-term trials of medication, or be for more severe and complex cases.

Medication in most cases will be initiated by CAMHS, paediatrics or adult mental health services, according to NICE guidance (NICE 2008b). However, once a patient is established on medication, prescribing is often transferred to primary care. Short-term trials of medication may therefore not appear in the CPRD if the prescriptions were only issued in specialist care. Where prescriptions are initiated outside primary care then transfer over to the GP, the length of time that a case has been on medication may be underestimated, although the date of cessation which was central to this analysis would be unaffected. As Adult ADHD services may not provide ongoing prescribing for the condition but pass this responsibility to primary care (Magon *et al.* 2015), it is reasonable to assume that the proportion of prescriptions not captured in primary care for over 18s would have been minimal.

Findings from other studies in Europe and the US also suggest that the decline in prescribing over the transition period found in the current study is unlikely to be artefactual. A European study by Zetterqvist *et al.* (2013) using data on all dispensed (i.e. from all prescribers) medication also reported the highest rate of treatment discontinuation amongst 15 to 21 year olds, suggesting that the pattern of discontinuation exists regardless of where medication is prescribed. A recent study from the US of self-reported ADHD medication use from the Medical Expenditure Panel Survey revealed a more gradual decline in prescribing between the age of 12 and 23 years, although there were considerable geographical, ethnicity and gender related variations in prevalence rates amongst adolescents and young adults (Johansen *et al.* 2015). It is possible that the sharper decline in the UK and European studies might be a function of different health systems, service configurations and attitudes towards ADHD within between countries, although it may also be influenced by the self-report design of the US study.

### *Identification of patients*

Cases were included if they had a Read code for ADHD at any point during their records. These Read codes map to ICD-10 chapters. This might contribute to overestimation of prescribing prevalence if cases with diagnosed ADHD received only a general code of behavioural disorder or concentration problems without an ADHD diagnosis recorded. However, estimates of validity of diagnoses in the CPRD are generally high (Herrett *et al.* 2010, Khan *et al.* 2010), particularly for non-acute conditions. Diagnoses made in specialist care (which would include all ADHD diagnoses) would usually be recorded and coded from letters sent to the patient's GP. There is a possibility that occasional diagnoses may be missed due to poor communication between primary and specialist care, or through being coded as free text (Herrett *et al.* 2010) . Furthermore, relying on coded diagnoses of ADHD to select cases might also contribute to overestimation of prescribing prevalence if recording of diagnosis was more complete among those who were prescribed drugs than those who were not.

### *Assumptions*

There were two main areas which necessitated assumptions to be made. As the day and month of birth were not included in the dataset, it was necessary to assume a July birthdate (see Methods). Participants therefore entered the survival analysis on their 'assumed' 16th birthday, resulting in a potential variation of up to 6 months between the actual and the assumed date. Time to cessation from 16th birthday therefore includes a margin of error, but one which is unlikely to have affected the overall estimation, or its implications as transition is a period rather than a specific event happening on a 16th or 18th birthday. Secondly, where data was missing as to the length of a prescription it was assumed to last 30 days, as this was the most common prescription duration. This may have underestimated the time to cessation in a minority of cases, but as six months without a prescription was required for cessation to be declared, such an assumption would not have led to error in assigning the outcome.

### *Confounding*

The dataset did not contain information on socio-economic status and severity of ADHD related symptoms, which would have been of interest both as variables related to prescription or cessation and as potential confounders. The potential effect of these variables in particular should be considered in interpreting the findings of the Cox regression analysis, as discussed above.  For example, it is probable that young people with more severe ADHD are also more likely to continue medication, and to be referred to adult psychiatry services, meaning that the true effect of adult psychiatry referral alone on cessation may not be as marked as in this analysis.

### *Censoring*

There were fewer than 200 cases remaining after 4 years of follow-up in the survival analysis. Those cases turning 16 in 2010 and 2011 had less than 4 years of follow-up until the study end on 1st Jan 2014, and a small proportion of all cases (5.5%) were censored during the study period. The result was greater uncertainty around the probability of remaining on medication beyond the age of 20. Cases censored during the study period may also have affected the results if the censoring was informative; that is, if what causes a case to be censored is related to what would cause them to experience an event (Leung *et al.* 1997). This could apply to cases that were still on medication but had transferred out of the CPRD before the study end. Transferring out could be related to moving away, which feasibly could be related to stopping medication, if it is not continued in another area. Alternatively, such a transfer might relate to moving to higher education and indicate a higher propensity to continue medication for the purpose of studying. Nonetheless, when these cases were removed in a sensitivity analysis, there was no significant effect on the findings, suggesting that the influence of informative censoring was minimal.

### Implications

Young people with ADHD remain at high risk of cessation of medication over the transition period, despite the publication of guidance on prescribing in over-18s (NICE 2008b, Bolea-Alamanac *et al.* 2014). The decision to stop medication may be appropriate and reflect patient choice for reasons of adverse effects, personal preference or use of other management strategies (McCarthy 2014), but the continuing disparity between symptom persistence as reported by follow-up studies and medication persistence suggests that many are stopping medication that they could still benefit from (Faraone *et al.* 2006). Relating to providing optimal care, a study of ADHD medication doses in a cohort of transitional patients in the North of England found that patients appeared to be prescribed much less than the recommended dose despite experiencing severe symptoms (Adamou and Bowers 2011). Whilst this is a single small study, the findings suggest that a larger scale analysis of ADHD medication dosage may be warranted; and although such analysis was outside the scope of this thesis, the CPRD dataset would be a potential resource to explore this further, alongside service audits.

The findings must also be considered in the context of reports of inadequate provision of services for people with ADHD in transition, and an identified need for training for professionals in both primary and specialist care (Marcer *et al.* 2008, Ahmed *et al.* 2009, Hall *et al.* 2013, Hall *et al.* 2015). No evidence was found of a direct substitution of psychotropic medication for ADHD medication, but the high levels of comorbidity in ADHD make this a complex question. The potential gender differences in prescribing suggested by this analysis also strengthen the case for further training not only on ADHD in adolescents and adults, but on the identification and management of comorbidities in the context of ADHD in both genders. Clinicians' beliefs and knowledge regarding their prescribing practices in young people and adults with ADHD could also be better understood (and the substitution hypothesis explored) by methods such as qualitative interviews and structured questionnaires with GPs.

Furthermore, results also suggest that a higher proportion of adults with ADHD are now being pharmacologically treated, and that some who have previously stopped medication or never taken it may be presenting to services in their mid-twenties. This could be initially explored by using this CPRD dataset to examine the pattern and prevalence of re-initiations of medication amongst adults. Sustainable service models are therefore needed both to optimise management of ADHD over the transition period, and to support adults who continue to experience impairing symptoms. Services should also not be confined to providing pharmacological oversight, but also take a holistic approach to assist people to manage their condition, considering complementary psychological or behavioural strategies appropriate for this age group, such as Cognitive Behavioural Therapy (NICE 2008b, Bolea-Alamanac *et al.* 2014, Coghill 2015). Different approaches to delivering care for older adolescents and adults with ADHD include youth services models and specific adult ADHD services; but investment by commissioners should be made on the basis of robust evaluation of the cost-effectiveness, outcomes and acceptability of such configurations.

As many common themes are identified from the findings of this prescribing analysis which also relate to the findings of the following qualitative analysis in particular, more specific implications for policy, practice and research are discussed further in the final Overarching Conclusions Chapter.

## Summary

This analysis found a sharp decline in the prescribing of ADHD medication in young people with ADHD over the transition period, which exceeded estimates from follow-up studies of the expected decline of symptoms. The majority of young people with ADHD on medication at the age of 16 years had stopped medication by the age of

18 years. In contrast, the prescribing of other psychotropic medication increased over the same time period, although no evidence was found from the survival analysis that other psychotropics were associated with cessation of ADHD medication.

The next chapter presents a qualitative interview study of young people with ADHD about their experiences of service use and transition.

# Chapter Five: The experiences of young people with ADHD in transition from child to adult services

Chapter Four focussed on psychotropic prescribing in primary care over the transition period among young people with ADHD. This chapter presents the third study in the thesis, which complements the previous analysis of ADHD prescribing by using qualitative methods to examine the experiences of young people with ADHD in transition.

## 5.1 Introduction

The importance of the transition period in people with ADHD has been discussed previously in Chapters Two and Four, and is therefore summarised only briefly here to avoid excessive repetition. In the UK, most services for children with ADHD will stop at the age of 18 (Young *et al.* 2011). Possible pathways from child services may involve referral to Adult Mental Health Services, referral to a specialist Adult ADHD clinic, or the transfer of all care back to the GP. This ultimate destination will be influenced by multiple factors including the young person's wishes, whether they continue to need medication, the persistence and severity of their symptoms, their comorbidities and the available services locally. A number of factors have been identified by professionals that may also adversely affect transition in this group, such as gaps in services, different organisational cultures in child and adult services, and a lack of knowledge and training regarding adult ADHD (Ahmed *et al.* 2009, Hovish *et al.* 2012, Hall *et al.* 2013, McLaren *et al.* 2013, Belling *et al.* 2014, Coghill 2015).

However, there has been a paucity of studies exploring the perspectives of young people with ADHD in the UK on the transition period, with only one recent qualitative study directly seeking their experiences (Swift *et al.* 2013). This may be influenced by a perception of young people in general, and those with ADHD in particular, as groups which may be ‘hard to reach’ in terms both of services and of recruitment for research (Wong *et al.* 2009, Flanagan and Hancock 2010, Singh *et al.* 2010). A clear gap therefore exists in understanding young people's vision of what services would help them and why might they disengage, which is directly relevant in creating functional and acceptable transition pathways. Greater understanding of the personal experiences of service users also assists in interpreting the findings of population studies. For example, whilst the primary care dataset analysis in the previous chapter illustrated trends in prescribing over the transition period, this qualitative interview study was designed in order to explore transition from the viewpoint of young people themselves.

Qualitative methods are a particularly appropriate way to examine the perspectives of these service users, as the methods lend themselves to exploring experiences and meaning(Strauss and Corbin 1990). As this is a little-studied field, qualitative methods also allow for an inductive approach to the data, rather than presupposing what concerns and experiences young people may have. The semi-structured interview format was specifically chosen as it allows the interview to be structured around the areas of service use and transition whilst enabling participants to volunteer their views and perspectives.

## 5.2 Aims and Methods

### 5.2.1 Aim

The aim of this study was to explore the experiences of young people with ADHD in transition from child to adult services in the South West Peninsula using qualitative interviews. This included their experience of using child services, their experiences of transition, and their perception of unmet needs and what services might help them in future.

### 5.2.2 Study design and setting

The study used qualitative semi-structured interviews to seek the experiences of young people with ADHD in transition regarding the services they were using. Service users going through transition were recruited from Child and Adolescent Mental Health Services (CAMHS), Child Health, and Adult ADHD services in Devon and Cornwall. Services for young people with ADHD in the Peninsula are provided by a variety of NHS Trusts and social and private enterprises. Due to time and resource constraints, including the need to engage clinicians in person at geographically distant sites and to seek approvals from many separate providers, it was not possible to include all such services in the study. Settings were therefore chosen to encompass urban and rural populations across the Peninsula with different service configurations, and where links could be established with clinicians.

Table 5.1 below displays the services which agreed to assist in recruitment. These include five children's services providing care for children with ADHD, and the only specialist Adult ADHD service in the Peninsula, which takes referrals from both CAMHS and Child Health in the Devon area. In the other areas of the Peninsula, there is no specialist Adult ADHD service, meaning that young people may return either to GP care, or potentially be referred to a general Adult Mental Health Service if they met local service thresholds. The aim was to recruit participants currently in the process of transition, including both those making the transfer to an adult ADHD service and those who were not transferring to any adult service, to gather young peoples' experiences of these different transition processes.

**Table 5.1: Services involved in recruiting participants**

| **Area** | **Name of service (provider)** | **Type of service** | **Notes** |
|---|---|---|---|
| **Cornwall** | Cornwall CAMHS (Cornwall Partnership Foundation Trust) | Child and Adolescent Mental Health Service | No Adult ADHD service in area |
| **Torbay** | Torbay CAMHS (Torbay and South Devon NHS Foundation Trust | Child and Adolescent Mental Health Service | No Adult ADHD service in area |
| | Torbay Child Health Services (Torbay and South Devon NHS Foundation Trust) | Child Health/paediatrics | No Adult ADHD service in area |
| **Devon** | Devon CAMHS (Virgin Care) | Child and Adolescent Mental Health Service | Can refer to DANA (below) |
| | Devon Adult ADHD and Autism Service (DANA) (Devon Partnership NHS Trust) | Specialist Adult ADHD and Autism service | Accepts referrals from Devon CAMHS and from Child Health/paediatric services in Devon |
| **Plymouth** | Plymouth CAMHS (Plymouth Community Healthcare) | Child and Adolescent Mental Health Service | No Adult ADHD service in area |

### 5.2.3 Sample and sampling strategy

The sample frame for this study included young people aged between 17 and 19 years with a clinical diagnosis of ADHD. The gender ratio in ADHD is estimated at between 1:3 and 1:6 in epidemiological studies depending on subtype, although girls appear to be less likely to be referred for treatment (Novik *et al.* 2006). Consequently, the aim was for the sample to include males and females, although it was planned that fewer females would be recruited due to these ratios. In order to gain a variety of perspectives, the sampling strategy was therefore to recruit young people both from the Transition Pathway of the local Adult ADHD service and from CAMHS and Child Health services locally that did not have access to this service (i.e. from Cornwall, Plymouth and/or Torbay).

#### Inclusion and exclusion criteria

For inclusion, participants were required either to be on the caseloads of CAMHS or Child Health Services (see Table 5.1 above for list of Trusts) and be due to leave the service within the following six months; or to be on the Transition Pathway of an Adult ADHD service and have left child services within the previous six months. This timescale was chosen for two reasons; firstly to gain the perspectives of people going through different stages of transition, and secondly, to increase flexibility by allowing for the fact that participants were often seen by clinicians and identified for the study at different time points in the process.

The study did not exclude service users who might have other psychiatric comorbidities, as these are common amongst those with ADHD and their exclusion would lead to a sample that did not share characteristics with others in this situation. The chief exclusion criteria related to exclusions on the grounds of significant vulnerability or difficulties in communication which might make participation challenging. The clinicians identifying patients for the study were responsible for judging whether an otherwise eligible patient should be excluded on these criteria. Inclusion and exclusion criteria are presented in Box 5.1 and Box 5.2 below.

**Box 5.1: Inclusion criteria**

- Young people aged 17 to 19 years with a clinical diagnosis of ADHD, including those in partial remission
- On the caseloads of CAMHS or Child Health services (Tier 2 or 3), or the transition pathway of the Adult ADHD service
- Currently in active treatment (with or without ADHD medication)
- May be in education, work, training or other
- Participants may have other psychiatric co-morbidities, but must have the capacity to consent to take part in the study
- Either:
    - Due to leave CAMHS or Child Health within the next six months and cross the transition boundary regardless of whether referral made or accepted to Adult Mental Health Services (AMHS)

  Or:
    - Currently on the transition pathway of the Adult ADHD service and having left CAMHS or Child Health within the previous 6 months

**Box 5.2: Exclusion criteria**

- Young people were excluded if there was a significant language barrier which meant that the interview could not be completed without an interpreter
- Young people were excluded from the study if their care co-ordinator or other clinician felt that taking part will be detrimental to their mental health, or if they were otherwise considered to be particularly vulnerable
- Young people with moderate or severe learning disability. This group were excluded as they represented a somewhat different population from those with mild or no learning disability in terms of their needs and the services they use. They are also more likely to be using specialist learning difficulty services rather than mainstream CAMHS.

### 5.2.4 Recruitment strategy and procedure

#### Identification of participants

I visited clinicians and managers within the included services to discuss and seek feedback on the study protocol and identification of participants. Clinicians, including doctors, specialist nurses and clinical psychologists were provided with information sheets detailing the inclusion and exclusion criteria for the study. They were then asked to identify eligible patients from their caseloads. The majority of services did not have a central list of ADHD patients, and therefore most participants were identified by clinicians only when attending clinics. Clinicians were asked to verbally introduce the study to eligible patients, and to give out a pack containing the Participant Information Sheet (see Appendix Two), and a contact details form with a stamped addressed envelope for returning the form which indicated that the patient consented to being contacted regarding the study. Full consent for taking part in the study was obtained following supply of further information, and a consent form being completed (see below). The forms supplied by the clinician also included my telephone number and email address in case the young person preferred to make contact directly.

#### Making contact and seeking informed consent

Once the young person agreed to be contacted by me, they received a telephone call, text message, email or letter depending on their indicated preferred contact method. Several attempts were made to contact potential participants, but if they then indicated that they were no longer interested, their contact details were destroyed. On making contact, I offered to discuss the research further and answer any questions in person or by phone or email. The potential participant was also encouraged to discuss taking part with family members or close friends if appropriate.

Where the young person was then interested in participating, I reviewed the Consent form (in Appendix Two) with them in person or over the phone, and took informed consent. The participant was required to read and sign all sections of the form to ensure they were aware of aspects such as the need to audio-record the interview, and how their data would be stored.

### 5.2.5 Interview procedure and contents

Participants were interviewed using a semi-structured topic guide (see Table 5.2 below). I carried out all interviews, which took place either on University premises, or at the participant's home if requested, and were digitally audio-recorded. Parents were present if the young person wished them to be, although it was made clear that this was intended primarily to be an interview with the young person about their personal experience. The length of interviews ranged between 15 and 45 minutes, with an average length of 25 minutes. The duration of the interview was influenced by engagement and rapport with the participant, and by their ability to concentrate, as well as by the home environment. Questions covered the participant's past and present experience of using services for their ADHD, including how the transition process could be improved, as well as asking about what their ‘ideal service’ would look like. Due to the nature of qualitative research the exact questions varied and evolved as the first interviews were analysed, and the questions were modified slightly depending on how far along the process of transition participants were; however the structure and question areas remained the same. The key questions (shown in Table 5.2 below) covered experiences of services in the past, the present, and asked participants what ‘ideal services’ would look like in the future.

**Table 5.2: Key question areas from the interview Topic Guide**

| Topic Area | | |
|---|---|---|
| **Past** | **Present** | **Future** |
| Could you tell me a bit about your experience of Child and Adolescent Mental Health Services/Child Health services in the past? | Could you tell me a bit about the services you are using now (if any)? | How do you see your ADHD affecting you in the future (if at all)? |
| Could you tell me what it was like leaving CAMHS/Child Health? | Is there anything you find helpful at the moment about services?<br>Is there anything you find unhelpful? | In an ideal world, what tools, services or support do you think would be available for you in the future to help you manage with your ADHD? |
| How did / do you feel about moving on into adult services? | In an ideal world, what services or support do you think would be available for you now to help you manage with your ADHD? | |
| Was there anything that could have made this process easier/better? | | |

### Amendments to procedure

A number of amendments were made to these procedures during the study due to slow recruitment of participants. In the first six months of the study, only two participants were recruited, one of whom subsequently dropped out prior to completing the interview. Initially, it was intended to complement the qualitative interviews with supplementary parallel quantitative data collection about service use pre-transition and post-transition from questionnaires. However, this slow start indicated that there would be considerable challenges both in recruiting participants in the first place, and in retaining them in the study long enough to complete both questionnaires alongside the qualitative interview. The decision was therefore taken to focus on the qualitative interviews alone. Feedback was also sought from clinicians identifying patients, who thought that one problem was likely to be the reliance on young people to take the initiative in terms of returning the contact details form to me or emailing or telephoning me themselves if interested. The procedure was therefore amended so that clinicians briefly introduced the research in clinic and sought consent at the same time to pass on the details of eligible patients to me directly. In order to avoid the study information being lost or overlooked by patients or clinicians, brightly coloured study materials and envelopes were also introduced.

Clinicians involved with the project also suggested that young people and their parents might want to discuss the research with me in person after their clinic appointment if they were interested in hearing more, and that this might improve recruitment. Unfortunately, this was not possible for CAMHS clinics, as there was not a system to alert me in advance when an eligible case might be attending. However, in the Adult ADHD service, one new patient was seen in the transition pathway clinic on most weeks, and on several occasions I was able to be available in person in case interested service users wanted to discuss the project once it had been introduced to them by their clinician.

### 5.2.6 Ethical and risk considerations

Ethical approval for the study was granted by the South West Research Ethics Committee (reference: 13/SW/0162, see Appendix Two for copy of letter), and approval was also sought and obtained for substantial amendments to the protocol. Research and Development (R & D) permissions were also obtained for all sites involved in the study. Specific considerations related to this study involved informed consent, data protection, impact on participants and safeguarding.

**Informed consent**

Each young person involved in the study received the Participant Information Sheet and was given the opportunity to discuss the study with me before deciding whether they would like to take part. All participants were also made aware that they could withdraw from the interview or study at any time without needing to give a reason and without affecting their care in any way. Written, informed consent was obtained from each participant.

### Data protection and confidentiality

All interview recordings and transcripts were kept separated from contact details and personal information, and unique codes were assigned as identifiers for participants. All hard copies of contact details and consent forms, recordings of qualitative interviews and data analysis were kept in a locked drawer in a locked university office in accordance with the Data Protection Act and Good Clinical Practice in research (HM Government 1998, European Medicines Agency 2002). Research data was kept on the university server which is automatically backed up and protected by secure password. Data will only be kept for as long as required by the data protection policy of the funder (NIHR) and the University of Exeter, which is currently a period of five years and subsequently completely destroyed according to the policy using the prescribed IT procedures.

### Risk management

Clinicians were responsible for identifying eligible young people. If they considered any patients as being particularly vulnerable in terms of their mental health or other circumstances then they were not approached to take part in the study. Those taking part had the contact details of the researcher in case they should experience any aspect of the interview as distressing (this did not occur in any of the interviews). The researcher had a prepared list of local sources of support which were also detailed on the Participant Information Sheet, which also included appropriate contacts in case the participant wished to complain either about the study or about aspects of care that they received.

As the research involved direct contact with young people, some under 18 years, the study followed the Child Mental Health Research Group’s Child and Vulnerable Adult Safeguarding Policy. The study protocol also incorporated actions to be taken in the event that participants disclosed other information about risk to themselves, for example, ideas about self harm or suicidal ideation, although this situation did not arise during any interview. These actions were adapted from the Mood Disorders

Centre at the University of Exeter's Risk Protocol, which has been used for various trials involving participants with mental health difficulties (for example the Mindfulness Based Cognitive Behavioural Therapy for Parents trial). A statement was included in the information sheets to make participants aware that their details might be disclosed if the researcher had concerns either regarding safeguarding or about risk to the participant or other people. Finally, in order to address any potential risks due to interviewing participants at their home, the study protocol followed the Child Mental Health Research Group's Safe Conduct of Fieldwork Policy.

## 5.2.7 Data analysis

### Approach to analysis

Digital copies of recorded interviews were kept separated from contact details and personal information, and uploaded onto the secure university server. Each interview was anonymised and assigned a number, and each participant was given a pseudonym. Interviews were then transcribed by me or by another member of staff with transcribing experience, and then checked against the recording for meaning and accuracy. NVIVO software, version 10 (QSR Software Ltd 2012) was used as a tool to manage and catalogue the data.

The qualitative method used in this study was thematic analysis, which is described by Braun and Clarke (2006, p.6) as: "a method for identifying, analysing and reporting patterns (themes) within data".  Thematic analysis was chosen as it represents a clear and sequential method for analysing qualitative interviews where there is no intention to generate new theory, but instead to describe participant experiences relating to a defined area – i.e., going through transition. The approach taken to the analysis was a realist one, meaning that the study aimed to "report experiences, meanings and the reality of participants" (Braun and Clarke 2006, p.9). I also took a predominantly inductive approach to the data; although the interview was structured around transition, the actual coding and development of themes was guided by the content.

### Initial coding

The interview transcripts were read repeatedly in order to become familiar with the material. I then carried out initial coding of all transcripts, generating descriptive labels for sentences, paragraphs or sections to produce a first iteration of a coding frame. Material from the parent, where present at the interview, was marked out clearly as being parental material in order to distinguish them from data from the young person themselves. Extracts were coded more than once if they fitted several code definitions. Next, extracts from all interviews with the same code were collated together and compared to determine whether re-coding or merging of codes was required. In this way, a coding frame was produced describing and defining all the codes used across all transcripts. To enhance quality, coded examples of text were discussed with a supervisor, who was asked to code sections independently and compare. These discussions informed subsequent coding.

### Generation of themes and development of narrative

The relationships between the different codes were mapped, in order to create categories arising from the coding frame (see Appendix Two for mapped Coding Frame). Extracts of interviews in each category were reviewed and analysed in order to develop overarching themes relating to the research questions. A description was written of each 'candidate' theme, all of which were then judged by Patton's (1990) criteria of external heterogeneity and internal homogeneity to determine whether they were sufficiently different from each other, and whether data within each theme was coherent and/or sufficiently demonstrated the theme. If this was not the case, themes were discarded or created, or extracts were moved between themes. This process resulted in four final overarching themes.

Finally, each theme was written up as a narrative to tell the 'story' of transition. Quotes from the data were selected to demonstrate meaning and provide examples of the theme under discussion. In writing up this narrative, care was taken to include extracts which might contradict one another and to 'deviant cases' where one participant might hold a completely different view to the others, in order to illustrate and account for differences in experience.

### Consideration of reflexivity

Mays and Pope (2000, p.51) define reflexivity as: "sensitivity to the ways in which the researcher and the research process have shaped the collected data, including the role of prior assumptions and experience". They also highlight the impact that the researcher's personal and professional characteristics can have on the interview and on the interpretation of the data. During the process of the interviews and of the analysis it was therefore important for me personally to be aware of how my experience might influence this research.

I have previously trained in child psychiatry and worked in some of the services from which participants were recruited. I did not however make reference to any clinical background when introducing myself to young people in order to prevent replicating a doctor-patient relationship, which might affect the young person’s willingness to volunteer their views, and also place me in a position of already ‘knowing’ about ADHD and transition. I attempted to be conscious of other ways in which this clinical background might affect the interview or my response to the data, for example, if I were to feel defensive about criticism of former professional colleagues.

On the other hand, this previous clinical experience was in contrast to the position of being a ‘new’ qualitative researcher and a PhD student.  My status as a student allowed me to be curious and ask questions without my clinical advice being sought by participants, and therefore facilitated interviews. It was more difficult to avoid the temptation to use familiar methods of conducting a more directive ‘clinical’ interview instead of a qualitative interview. This challenge is also discussed by McNair *et al.* (2008), in their paper on clinician researchers, who suggest that those trained initially in medical interviewing are more prone to pitfalls such as excessive control over time, inappropriate paraphrasing and inadequate probing for feelings and meanings. Slow recruitment meant I also felt considerable pressure for early interviews to be detailed and ‘rich’, which heightened anxieties about technique. As proposed in McNair *et al.*’s (2008) paper, my supervisor and I reviewed the first interview transcripts closely in order to identify any of the pitfalls described above, and to consider how to take a more open approach to the interview. I also attempted to remain aware of these potential influences on interviewing and analysis by using memos attached to the data, and through the discussion of transcripts and interpretations with my primary qualitative supervisor as part of the analysis process.

# 5.3 Results

## 5.3.1 Description of sample

Recruitment took place from December 2013 to September 2015. Over this time period, a total of 22 young people were identified by clinicians as being eligible to take part in the study, who also consented to being contacted regarding the research. Of these, only 12 responded to repeated attempts to contact them by email, text message, phone and post. Four of the young people who were successfully contacted decided that they did not wish to take part in the interview, citing lack of interest and lack of time as reasons. One agreed to take part but subsequently stopped responding to contact, and therefore no interview was carried out. Qualitative interviews were therefore carried out with seven participants.

### Characteristics of participants

The characteristics of the participants are presented in Table 5.3 below. Five of the seven participants were male, and all were aged 17 or 18. There was some success in interviewing young people from across the Peninsula, with interviews being achieved with service users from Devon (n=4), Plymouth (n=1) and Cornwall (n=2). Five participants had already left child services, with the remaining two still being seen by CAMHS. Three young people had Autism Spectrum Disorder as well as ADHD, and one had borderline and specific learning difficulties. In four cases, interviews took place with a parent present.

For the purposes of the analysis, participants were given a pseudonym and number, shown in Table 5.3. Throughout the Results section, participants are referred to by these pseudonyms and participant numbers (e.g. David, P1), in order to show the gender of the participant.

**Table 5.3: Characteristics of participants**

| Participant number and pseudonym | Age and gender | On ADHD medication? | Psychiatric co-morbidities | Transition stage | Parent present at interview |
|---|---|---|---|---|---|
| P1 David | 18 M | Yes | None reported | Care transferred to GP from CAMHS | No |
| P2 Joe | 18 M | Yes | Borderline and specific learning difficulties | Leaving CAMHS | No |
| P3 Rebecca | 17 F | Yes | None reported | Leaving CAMHS | Yes – mother |
| P4 Sam | 18 M | Yes | ASD | Care transferred to Adult ADHD service, from Paediatrics | Yes – mother |
| P5 Lauren | 18 F | Yes | ASD | Care transferred to GP from CAMHS | Yes – mother |
| P6 Patrick | 18 M | Yes | None reported | Care transferred to GP from CAMHS | Yes – mother |
| P7 Owen | 17M | Yes | ASD | Care transferred from Adult ADHD service from CAMHS | No |

### 5.3.2 Themes

Four key themes pertinent to the perceptions of transition emerged from analysis of these seven interviews: professionals' roles and relationships with young people; the role of ADHD medication, uncertainties around transition, and identified needs and increasing independence. The first two themes describe more general experiences regarding professionals and medication, but which were highly relevant to the process of transition, whereas the second two themes relate to specific aspects of transition. All are presented in turn below, and then discussed in further detail and in the context of current policy and literature in the final Discussion section of this Chapter.

### Theme: Professionals' roles and relationships with young people

When asked about their experience of using services for their ADHD, participants volunteered their thoughts about a number of professional groups that they had had contact with. The main groups referred to were teachers, GPs, and specialists, including psychiatrists, paediatricians and mental health workers. They discussed these professionals and services in terms of the role they considered them to have, their perceived attitudes towards and knowledge of ADHD, and the relationships that they, the participant, experienced with the professional. Participants' experiences with each group are described in turn below.

#### *Teachers and other education professionals*

Interactions with schools and teachers were discussed as a core part of young peoples' experience of ADHD. Experiences appeared to be framed more in terms of the attitudes and attributes of staff rather than the academic role of the school:

> *They* [are] *just understanding and they just say the right things and… they're just all really nice people there, all seem happy and that cheers you up as well* (Sam, P4)

This shows that the relationship with and personal characteristics of members of staff were important to young people. Positive attitudes were valued, particularly when accompanied by an understanding of the person and their ADHD. Consequently, participants also identified situations where they did not feel they or their ADHD were accepted or understood:

> *…they would say that you're a trouble-maker… what quite a lot of teachers think…I find that most mainstream schools don't get educated in ADHD and things like that…so I think all the teachers should like go on a course about it* (Rebecca, P3)

Rebecca’s experience was that attitudes towards ADHD varied from school to school, and where there was a lack of knowledge about the condition, teachers might quickly assign the child the status of ‘naughty’ or ‘trouble-maker’, sometimes without reading any notes about the child and their condition first.

Other interviewees had a mixed reaction to the help on offer at their schools. One participant (Patrick) had been offered extra time for his exams, but a greater concern for him was the crowds at school, which he found harder to cope with. Another had been given one-on-one support in school and access to separate learning areas, but his perception of this was that it served to differentiate him and hindered his ability to make friends:

> *…what that meant was that for the entirety of my lunches and breaks I had to go to this room, secluded from everyone else, which was embarrassing…Whereas I would’ve liked rather than to do that to go out and make friends without one to one support, that was rubbish* (Owen, P7)

Such comments perhaps indicate that although support was available it was not necessarily tailored to what students with ADHD felt they wanted or needed, illustrating differences in the perception of needs between the school and the pupil. Whilst schools appeared to concentrate on accommodating academic requirements, the less obvious social aspects of the school experience were similarly important to the young people interviewed.

Participants’ experiences of primary and secondary education highlighted occasions where their needs were perceived to be unmet, or had to be fought for; for example by moving schools. Consequently the move to further education and training alongside the transition taking place in health services was also associated with anxieties regarding the availability of support and getting to know the new system. This is discussed further under the final theme of ‘Identified needs and increasing independence’.

### ***GPs***

All participants discussed their experiences with primary care, past and present. For the young people interviewed, the GP's role was often very limited, and primarily seen as to provide prescriptions for medication.

> *…we* [just] *go to the GP to order the repeat and then collect it* (Sam, P4)

This distant relationship that participants felt they had with their GP was sometimes contrasted with the more personal and developed relationship with CAMHS or Child Health (see section below). Such limited contact informed concerns about a transfer of care from CAMHS to primary care:

> *It's a bit iffy …..cos doctors* [the GP]… *just don't really know …if I've got CAMHS I know they know what I'm not like and what I'm like… Doctors don't really know…. I've seen them…in the last two years, like twice no more*" (Joe, P2)

Interviewees perceived contact with their GP to be an infrequent event, meaning that their GP did not know them, or and indeed perhaps had not so far needed to know them as CAMHS dealt with their ADHD management.  Consequently, young people did not necessarily feel they had a relationship with the GP that could be built on after transition.

Two of the young people interviewed had recently made the transfer from CAMHS back to the care of their GP at the age of 18. In both cases, the GP agreed to continue providing a prescription, but the participants still had concerns. One young woman felt that her GP did not know her at all, and had been told that he would see her only once or twice a year for standard medication checks:

> *I've only seen him once…just walked in and* [he] *changed my prescription* (Lauren, P5)

This described encounter was experienced as being perfunctory and functional, focussing only on medication. The implication is that there was no time for discussion, which might represent an abrupt change from the style of appointments participants were used to in CAMHS, and leave the young person feeling cast adrift and let down; these feelings are discussed further under the theme ‘Uncertainties around transition’.

Another participant who had also recently left CAMHS was particularly concerned that the GP would not provide help in managing medication, such as tailoring the dose, or being available to answer questions in the same way as CAMHS were. He described an appointment where he had discussed medication with his GP:

> *He’s not really qualified, he wouldn’t, he didn’t want to change it because he doesn’t really know what he’s doing as much as the specialists did, so he wouldn’t change it* (Patrick, P6)

This encounter appears to reflect a similar feeling from the participant of lack of engagement from primary care with their specific case. In addition, perhaps because the participants have had so little contact with the GP to date, the GP is not seen as being informed about ADHD, and this led to doubts about whether the GP was ‘qualified’ to manage their medication.

The experiences of participants suggest that where the GP’s role has been limited (both in terms of time and input into care), naturally the relationship between the doctors and the young person and their family is not one of mutual trust and understanding. There was a lack of trust from participants that their GP would be knowledgeable about their ADHD and to manage it appropriately. Meanwhile, from the other side, the GP may be suddenly faced with a patient at the age of 18 that they do not know well enough to feel able to tailor prescription requirements to their needs. This is a difficult context for transition, setting the scene for the later theme ‘Uncertainties around transition’.

### ***CAMHS and Child Health/paediatrics***

Overall, most of those interviewed appeared to value a number of aspects of their relationships with specialists from CAMHS and Paediatrics. Appointments were often seen as being the opportunity to see clinicians who understood ADHD and who knew them, with whom they could build a relationship:

> *I was on good terms with doctor* [name]*. She said just drop her an email if I wanted to talk about anything* (David, P1)
>
> *The fact how nice they were and everything, it was just really good* (Sam, P4)
>
> *It was nice to talk to someone….it was always the same guy… Yeah, it was cool, we always had like a quiz session at the end about things we liked…* (Owen, P7)

The positive aspects of the encounters with CAMHS therefore were about availability, approachability, responsiveness and time to talk through any issues required, which also seemed to contribute to building a bond and even a sharing of interests.

Participants also discussed how, unlike primary care, specialist care helped them to manage their medication and to change the dosage to suit them. Young people saw drug doses as something that might need to be reviewed quite frequently, and that this medication change might be a tool to help them cope with daily activities or academic schedules:

> *I'd say to them like… I need more medication and they'd give it to me and if they say you need less medication I say yeah, they give me less…but if I ever needed medication I'd just ring up saying I need more medication, I need more dosage...they'd give it to me* (Joe, P2)
>
> *She* [the paediatrician] *was really good… 'cos I was saying that the tablets don't last the whole day, they kind of wear off in the evenings and sometimes for example when during exams it can be… quite important for me… to be able to concentrate throughout the evening and she came up with the idea of*

> *top up once in the evening like… a lower dose, and that's been quite useful to just be able to do more work in the evenings when I need to* (Sam, P4)

In these quotes young people describe an interactive system that is flexible and responsive to their requests. There is also a sense of partnership whereby either the young person or the professional could initiate changes in medication in response to a perceived need, showing trust in the reality of the patient's experience in recognising and managing their symptoms.

Nonetheless, not all clinicians were seen as being equally helpful in this regard. One of the same participants quoted above contrasted one paediatrician with another that he had seen who was reluctant to add an extra dose, and who was therefore perceived as "not supportive" (Sam, P4). Other interviewees also recounted occasions where they had not been able to see their regular clinician, due to rotations, sickness or the staff member leaving:

> *Been difficult, cos like I thought I'd be seeing the same one, but then I go there, there's a different one… so it's difficult, difficult to say to one person, then to another person, then to another person* (Joe, P2)

This disrupted their positive view of services and made it harder for them to build up trust and good relationships. The turnover of staff was also seen as having a negative effect on transition, as discussed in more detail under 'Uncertainties around transition'.

There was also a feeling that gaps between appointments were often long, or did not correspond with expectations:

> *Erm when they say they'll… review in a couple of months it takes 6-7 months to even get the letter through* (Owen, P7)

This implies that service users were aware of a gap between the expected or promised care and what was actually delivered. This might be heightened by an expectation of more frequent or intensive review in specialist care compared to primary care.

***Summary of theme***

This theme describes the experiences young people had with professionals involved in the care of their ADHD, in relation to their roles, attitudes and relationships, which form the backdrop for their transition from child to adult services. In particular, participants discussed perceived differences in roles, understanding, knowledge and relationships between primary care and CAMHS/paediatrics. Given that participants were all leaving these child services, either for an Adult ADHD clinic or for primary care, such narratives are highly relevant to their expectations and experiences of this transition.

### Theme: The role of ADHD medication

Medication was mentioned far more often than non-pharmacological ADHD management by the young people interviewed, and was largely discussed in terms of medication effects, and medication purpose. To illustrate this, participants gave examples of what happened when they did not take their medication:

> *I have a note not to forget… to take them when going to school and it was in physics lesson I remember… normally I can get it quite quickly and I understand it and I'm able to concentrate and I just wasn't able to … well concentrate and… I started thinking 'What! well normally I get this' and it was a lot harder than it was normally and I realised I forgot to take them and that was when I realised… made me think about how difficult it actually is sometimes when I don't take them* (Sam, P4)

> *well we had a trial* [of stopping medication], *and within the first couple of days I was on the steps outside* [school] *and I was just in tears because I was just felt like everyone was having a go at me, it just felt all of a sudden everyone was just shouting at me, do this, do that, that's not how you do it, that's not how you do this, and I was just… I felt almost suicidal… I just felt everyone was having a go at me* (Patrick P6)

Occasions where medication was stopped accidentally or deliberately had a marked impact on some participants, and they were able to remember and describe these events in some detail as shown above. In Sam's quote, the impact of a forgotten dose was felt in a marked deterioration in concentration and understanding at school, but in Patrick's case a trial of cessation was actually a highly distressing experience. The role of ADHD medication was therefore seen not only in terms of concentration and focus in the academic environment, but also in terms of emotional impact and ability to function. For some, just the thought of stopping medication was anxiety-provoking. One interviewee had been very concerned that when he moved to adult services they would stop his medication. However, on further thought he reassured himself that professionals would be unlikely to do this whilst he was still attending school:

> *I felt kind of protected if you will… by the fact that I was* [still] *going to school next year* (Sam, P4)

The use of the word 'protected' suggests that medication may be seen as both a literal, and a symbolic, safety net for some participants, and that being still at school would provide protection against enforced cessation. Most of the young people interviewed made this link between medication and education:

> *I don't usually stay medicated when I'm not doing academic work …I see it as an aid in situations when I need to concentrate 'cos I'm not that bad. I'm not awful without it. But I do find it hard to get on with things when I'm not medicated* (David, P1)
>
> *I know people who like have taken Ritalin like that, they often, when they finish the exams, they stop taking it, and then some people carry on taking it, but then they don't know how long they can take it for and whether they can carry on taking it while in college or they have to stop it when eighteen…* (Rebecca, P3)

The first quote from David frames medication as being a specific tool that he chooses to use for academic work, whereas the second quote from Rebecca also links medication and education but voices more uncertainty about the exact purpose of the drugs. She suggests that medication might be for taking exams, although possibly only for those at school and not those at college. This implies that in her mind the appropriateness of taking ADHD medication might be directly related to age or stage of the education system instead of whether or not the treatment is needed to function academically. The uncertainties that she talks about also relate to the third theme of ‘Uncertainties around transition’.

Although education was seen as being the most important purpose of medication, participants also discussed other positive effects. One interviewee reported that medication was essential for him to safely ride his motorbike. However, the most highly valued and commonly cited ‘non-educational’ effect of medication was experienced by young people as the benefit to social and family relationships:

> *It* [the medication] *does help for other things – I’m normally giving my mum, like, attitude all the time if I don’t take it, if she p** me off I just tell her to shut up, but if I do take them I just walk out of the room … like to calm myself down* (Joe, P2)

> *And…I’m able to kind of have more of a conversation with people than…just being set on speed and just telling them what I think all the time…I’m able to help out a bit more* [at home] *…and yeah… I’m able to be a lot more switched on …, when I need to focus to help out* (Sam, P4)

Interviewees therefore valued the effects of medication on relationships; both in the home environment in terms of reducing conflict and being able to play a ‘helpful’ role; and in the wider sense of improving social skills and interactions with other people.

Negative aspects of medication mentioned included a dislike of swallowing large tablets, or decreased appetite. Only one interviewee suggested that he would prefer not to take the drugs. For this young person, the decision to take medication appeared from his point of view to be heavily influenced by his parents’ perceptions. He felt they were looking for specific behaviour changes from him:

> *Erm being, normal, blending in with people…Not jumping off roofs, things like that…I didn’t feel the need to take it* [the medication]*. Like, I thought I could just be myself* (Owen, P7)

For Owen, his idea was that his parents wanted him to be ‘normal’ and conform, the implication being perhaps that he was in some way abnormal, although he also refers to engaging in risky behaviour which indicates that he might recognise legitimate concerns on their part. Owen also reported that taking medication made him feel more tired and depressed. His words suggest he felt that he was not himself on medication, and that it affected his feelings of identity. His motive for taking ADHD drugs seemed therefore to be at least partially to show his parents that he could be responsible, and go out without getting into trouble, rather than because he valued the benefits of the treatment. This was one of the only occasions in the interviews where there appeared to be tension between the views about treatment between parents and children; although it was one of three interviews where no parent was present.

#### *Summary of theme*

This theme represented young peoples' experiences of the role and effects of ADHD medication, past and present. The majority of participants reported pharmacological therapy as being central to their ability to manage ADHD in an academic environment, and for some this appeared to be the primary and possibly only purpose of medication.  However, despite saying that they took medication 'for school', the positive effects on social interactions and daily life at home and with other people were also highly valued by most interviewees, which suggests that motivation to use medication is likely to be more complex. These perceptions about the purpose and value of pharmacological therapy are relevant as they directly informed their views on needs over the transition period and beyond, which are discussed in detail in the next two themes.

### Theme:   Uncertainties around transition

All the young people interviewed voiced a number of uncertainties and concerns around the process of transition. This included both those who had already left CAMHS or paediatrics, and those who were still being seen by child services. As described in the previous theme, for many participants, medication played an important role in helping them manage daily life at home and at school or college. Consequently, for those who were only just leaving CAMHS, a central area of uncertainty was how their medication would be continued, and who would prescribe it. One young woman had had previous difficulties with her GP refusing to prescribe

ADHD medication, and did not think they might prescribe it after the age of 18 even though she wanted to continue. This was because:

> *I would think ‘cos it’s for kids more than anything* (Rebecca, P3)

This suggested a clear link between age and medication, rather than functioning and medication, as discussed under the previous theme. It was unclear though whether this idea about medication being ‘for kids’ had come from other young people with ADHD that she knew, or from professionals.

Another participant was more confident that his medication would be continued somehow:

> *Now I’m headed off to university and switching GPs and everything and I’m not entirely sure where to go from there…I think I need to have an appointment, I’ve been told I need an appointment with the GP when I get there just to make sure the prescription’s fine to stay on* (David, P1)

David’s quote above mentions the added complication of going to University and changing his GP, but although he appears to expect that his medication will continue to be prescribed there is still an element of doubt present.

Most of the young people interviewed specifically wished to continue medication beyond the age of 18, and they linked this to their ongoing education and training at college or University. Those who had not yet left child services talked about their anxieties about the impact of stopping medication on their plans:

> *If I don’t take them it’d be …I… don’t get on with work I’ll be clumsy , if I do take them, I’ll be concentrating all the time. I know if I stop taking them and I’ll just be kicked out of college, just won’t be able to handle myself…* (Joe, P2)

For participants who had found medication crucial to functioning in an academic environment, concerns about whether they would be “allowed” to stay on medication were evident.  To them, the potential consequences of stopping were envisaged as being potentially severe, including being “kicked out” of their course, and being unable to continue with education and training.

The account of one interviewee, who had recently made the transfer to an Adult ADHD service, of his last appointment with paediatrics suggested he found this final appointment an anxiety-provoking experience. He had seen a different doctor than usual, who had implied that his medication might be stopped. Prior to his first appointment with the Adult ADHD service he then became worried that the fact he was doing well at school might mean that the adult clinic would decide he did not need his medication:

> *I was kind of worried that they* [the adult ADHD service] *were going to say ‘Ok, I think you’re doing well and so I think that, you know, you can probably do without* [the medication]*’* (Sam, P4)

This first appointment with adult services was therefore framed almost as a ‘judgement’, with his medication, and consequently his success at school, hanging in the balance. In particular, Sam thought that his educational success so far might count against him in that adult services might decide he could cope without the drugs.

The sense of uncertainty experienced by some participants was further heightened by what they perceived as a lack of preparation for leaving child services, with no or little notice given or much idea of what to expect. The last appointment at child services did not always appear to be part of a planned transition, but often an afterthought:

> *It just felt like any other meeting. Apart from towards the end she said ‘oh um, er we won’t be having any more meetings’. I mean, I was surprised at the time because I didn’t realise that was coming up, um cos I’ve had it since I was young, I just got used to them… it was just so sudden….’Oh you’re 18 now, goodbye’* (Patrick, P6)

> *Yeah, you get dropped when you’re 18…* [They said] ‘*you go to your GP now…Fill some forms in and we’re leaving you*’ (Lauren,P5)

The language used by Patrick and Lauren above suggests that this final appointment was experienced as dismissal, or even abandonment: ‘we’re leaving you’ ‘goodbye’; leaving a sudden gap. Furthermore, their accounts imply that young people found the approach to the encounter rather rushed and lacking in care, with the issue of leaving addressed suddenly, or only at the end of the appointment.

Only one of those who had left child services appeared to have been notified well in advance:

> *Yeah, they sent me a letter about 6 months before, so I knew it was coming* (Owen, P7)

This participant appeared to experience less concern and uncertainty over leaving CAMHS than many over the other participants, which might relate to his more ambivalent attitudes towards medication which were discussed under the previous theme. He was satisfied with being notified about transition by letter and not during a meeting. The letter also informed him about the option to be assessed by the Adult ADHD service, which he thought was something useful to do, ‘in case’ he did need help later on.

### *Summary of theme*

In this theme the participants’ narratives highlighted the uncertainties around transition that most experienced to some degree. These uncertainties aroused anxieties; in particular regarding the continuation of medication post-transition. Their accounts of leaving child services also suggested that sometimes this was perceived as a sudden event for which they were unprepared.  Consequently, this theme of uncertainty leads into the final theme which elaborates on the needs identified by the young people interviewed.

## Theme Four: Identified needs and increasing independence

Participants’ responses highlighted several areas where they felt services did not meet their needs over the transition period. These subthemes included: information about transition, timing of transition, and specific needs post transition such as medication management and support in higher education. In conversations around transition, there was also a common theme of independence and responsibility, both in terms of growing independence of child from parent, and, to a lesser extent, in terms of increased self-management of ADHD and less reliance on services. These aspects are discussed and illustrated further below.

***Information about transition***

As described in the previous theme, leaving CAMHS or paediatrics was often perceived to be a sudden event, rather than part of a process of moving between child and adult services. Consequently, most of the interviewees therefore expressed a desire for more information further in advance in order to prepare:

> *I would've just liked to know a bit more about what it was going to be like* [the Adult ADHD service] *and everything 'cos I didn't really have a clear idea and the way we kind of left the last session…I just kind of, I didn't know what to, I just didn't know what to expect. But yeah, if I would've known what it was going to be like I would've been so much more relaxed* (Sam, P4)

> *Like if they said it last year before I was chucked off…this time next year, this would be the last appointment, I'd be like 'OK I can prepare myself in whatever ways'* (Patrick, P6)

> *Just, I suppose that at this age you would be expected to get on with it, see your GP and ask for advice but some kind of informative thing, a pamphlet or something to tell you the steps to take before moving away, would have been helpful* (David, P1)

These quotes do not appear to suggest that participants required detailed or complex information, but instead a clear indication of what happens next, where they are expected to go and contact points. This lack of information led to considerable anxiety, which young people thought could have been avoided in some cases by better communication. The extracts from Patrick and David also imply that they were willing to take on some responsibility for preparation and finding information themselves (which also relates to the next sub-theme below on increasing independence), but that they perhaps needed some advance help or encouragement to do so.

### *Timing of transition and increasing independence*

The timing of transition was discussed by participants and parents in relation to increasing independence and responsibility. It was suggested that transition might occur too early, and might be better in the early twenties, for example at the age of 21:

> *…like CAMHS up to age of twenty-one and then change …'cos you're an adult but you're not adult adult* (Rebecca, P3)

> *I think it may be nice to extend to 21 'cos… if I've still got any questions I can ask* [CAMHS] (Patrick, P6)

These quotes came from young people who were not moving into an Adult ADHD service. The first quote suggests that it is the young person's age, or maturity that dictates the timing of transition, i.e. when they are an 'adult adult'; whereas the second quote implies that it should be decided by needs. Patrick's quote also suggests that he feels most confident in CAMHS to meet those needs, in this case, by answering questions.

Parents still appeared to be accompanying their children to ADHD-related appointments in many cases, but the degree to which young people took control of ADHD management also varied:

> *They* [parents] *make sure that I take them 'cos after, the whole month and a half thing of me not taking them, they wanted to make sure I was. So they make sure I take them every morning…I think I'll take it…as long as people see a problem with me not taking it. But if people start not seeing a problem with me not taking it I'll stop taking it* (Owen, P7)

> *I mean I'm getting better at determining whether or not I need medication, if I feel… sort of really out of it and I can't concentrate on something, or I think hang on a minute I would not normally do this, like metaphorically climbing up the walls, just things out of character, then I'd say right I'm going to have one of my meds now* (Patrick, P6)

> *I'm trying to get into the habit of also thinking 'Ok, I've got a week left, I need to order them [the tablets] in again and pick them up in time' otherwise I'll go on without them for a bit and that's not really good* (Sam, P4)

Owen makes reference here to a time where he did not take the ADHD medication which he had been prescribed, which meant that his parents took over the responsibility of monitoring his adherence. This seems to be related to the fact that he himself did not greatly value the effects of the medication. Therefore, because others viewed him as a 'problem' when he did not take medication the onus was on them to oversee the drugs. Even though Owen is shortly to have his 18th birthday, he also appears to feel that the decision whether or not to even continue medication does not rest with him, but rather with others and is externally controlled. Patrick on the other hand discussed becoming more aware of his symptoms, recognising when he might benefit from taking a dose, and therefore making his own decisions about his treatment schedule. The third quote is from a participant who was shortly leaving for University. He was already thinking about the need to start preparing for taking control of his condition when away from home, but this responsibility appeared very practical in terms of taking on tasks such as ordering and collecting prescriptions.

These quotes therefore illustrate varying levels of independence and responsibility as young people and their families undergo the process of transition. Such differences seem naturally to closely relate to participants' own beliefs about the benefits and purpose of pharmacological therapy, as discussed in an earlier theme, but are also likely to be influenced by family dynamics, symptom severity and general functioning. All these accounts nonetheless supported a general narrative in which independence was seen by participants to refer to managing their own ADHD medication, rather than in a wider sense of taking charge of their interactions with services, but might represent the first step on this journey.

### *Needs post transition*

Two participants who had made the transfer to an Adult ADHD service locally had already had their first appointments. These appointments with specialist nurses and psychologists were perceived as being helpful experiences:

> *It was a surprise it was really nice… when I went there… I didn't know what it was going to be like but if I'd known beforehand how kind of nice they would've been and how relaxed it would have been I would've been maybe… a little bit better* (Sam, P4)

Therefore, in contrast to his anxieties about adult services, this participant was actually pleasantly surprised. He may have been expecting staff in adult services to be more judgemental and unfriendly, compared to the atmosphere in child services, but found that this was not the case.

He and his mother also valued the advice given by Adult ADHD services regarding the support available in higher education, as it seems that the clinic had experience in managing patients who were away at university. The importance of support for ADHD in further and higher education was mentioned by other participants too:

> *It seems they've* [the University] *got a good department in place that will offer support if you need it. They've got counsellors, both very central to the university and within your accommodations and colleges. So I think that's quite nice and you'll have someone to go to that, you know, who's just there* (David, P1)

In this case support was perceived not necessarily to be ADHD-specific, but also to relate to counselling and advice generally for any issues that might arise.

The predominant focus of need identified by young people was active management and monitoring of medication post-transition. This seemed to be more of a preoccupation for those who had left CAMHS, and returned to the care of their GP, without any specialist ADHD input. These participants often perceived people with ADHD as having particular needs which might not be served by 'routine' primary care check-ups. One of these young people explicitly felt this arrangement did not meet his needs:

> *…I used to look forward to the meetings 'cos they used to be able to change my dosage and see what the doctor recommends, but I can't really go and see her anymore to ask questions,* [like] *If I lower my meds down by 5 or 10*

> [what will happen]? *but I don't know, well then… just stay on the same dosage then. So, I can't… I've got no one to ask anymore…and it feels a bit… awkward really* (Patrick, P6)

Patrick's concern seems particularly to relate to having no-one to consult regarding his medication, in contrast to the highly valued specialist appointments he had in CAMHS. By saying that he has no-one to ask, Patrick implies that he cannot approach his GP with questions, which is linked to his earlier statement where he perceived GPs as not being qualified to help with ADHD. The result in this case is that he feels quite lost, and unable to test out changing his dosage as he would like to do.

Another participant, David, was also not transferring into an Adult ADHD service and was planning to continue medication for the present:

> *Well, I still need a height weight blood pressure review at least annually if I stayed…on medication* (David, P1)

However, in contrast to Patrick above, David did not appear to want closer oversight of his medication. Instead, he identified his needs as being annual reviews of the physical health aspects of his treatment, perhaps seeing this as being within the GP's remit.

**Summary of theme**

This final theme describes participants' perceptions of their needs over the transition period and beyond.  Young people identified a number of elements which would help them manage their ADHD, including better information and preparation for transition, ongoing specialist medication management, and advice and support with further and higher education options. The narratives present in this theme related to young people's increasing independence over the period of transition, but also indicated the complex negotiations between child and parent which formed part of the process.

# 5.4 Discussion

This study directly explored the experiences of young people with ADHD who are undergoing transition from child services. The findings add to the very limited body of research in this area, despite considerable difficulties in recruitment. There is only one published UK study which has previously interviewed service users with ADHD in transition, which was set in Nottinghamshire and included young people making the transition from CAMHS to Adult Mental Health Services (Swift *et al.* 2013). In the current study described in this chapter, participants came from different areas of the South West Peninsula with varying service configurations. Consequently, the research was able to include the experiences of transition both of those who made the transfer to an Adult ADHD service, as well as of those who were returning to primary care management of their ADHD.  As there is known to be considerable variation in the services commissioned for adult ADHD across the country, particularly in whether an adult ADHD service is provided, this research may therefore serve to illustrate themes which have a wider relevance to services outside the Peninsula (Hall *et al.* 2015, Coghill 2015).

The four themes which arose from the analysis were: professionals' roles and relationships, role of medication, uncertainties around transition and finally identified needs and increasing independence.  These findings chime in many respects with other qualitative literature, but also highlight aspects of young peoples' experiences which have not been previously explored or reported.

## Discussion of themes

### *Professional roles and relationships*

The importance of relationships with professionals is a theme commonly arising from qualitative research with people using mental health services ( Jones *et al.* 2009,Swift *et al.* 2013, Plaistow *et al.* 2014), which was also the case in this study. Positive qualities such as understanding, being 'nice' and non-judgemental were frequently identified when discussing experiences with professionals. On the other hand, despite these attributes of individual staff members, young people referred frequently to a lack of continuity in medical and other staff within child services (as opposed to continuity of staff between services over the transition period). This was seen as having a negative effect on relationships and also consequently on their experience of transition, for example, seeing a new clinician on their last appointment with child services. In Swift *et al*.'s (2013) interviews with young people with ADHD in transition, both service users and parents also viewed these relationships with CAMHS as having a 'pivotal impact' on transition. Lack of continuity and depersonalised transition between teams is also reported as undermining patient satisfaction and wellbeing in research with adult service users by Jones *et al.* (2009).

However, one of the most highly valued roles professionals in CAMHS and paediatrics were perceived to have was that of an expert in ADHD who would help them manage and optimise their medication; this was sometimes contrasted with the role of primary care (discussed further below). Professionals from CAMHS and paediatrics were generally considered by participants to understand ADHD. This was not the case with all professional groups. Whilst some young people had a positive experience of ADHD support in schools, other interviewees reported encountering negative attitudes, such as an assumption that children with ADHD would be 'trouble makers'. These quotes are mirrored on a much larger scale by a recent systematic review which suggested that many teachers held polarised views about ADHD (Richardson *et al.* 2015). The review found some teachers tended to perceive the disorder as being of a wholly sociological origin rather than being of multifactorial aetiology, relating it to 'naughtiness' and to the environment in the home. In the review, attitudes towards ADHD were also found to influence classroom management of ADHD. Similarly, the help offered to some participants in this study was perceived as not being tailored to their needs, and even as being stigmatising; experiences which were also reported in the review. Such findings are concerning given the increasing policy emphasis placed on school-based mental health and on the role of teachers in identifying and managing disorders (see Chapters Two and Three for policy details).

The GP's role in managing ADHD, both pre- and post-transition was discussed across the majority of interviews, and extracts relating to primary care were relevant to all the key themes. This was unsurprising as much prescribing for children with ADHD takes place under shared care arrangements with primary care (Ford *et al.* 2008a). Primary care also takes on care for adults with ADHD, either under shared care arrangements with specialist services or even without specialist oversight (although this is not recommended under NICE guidelines) (NICE 2008b, Bolea-Alamanac *et al.* 2014). The contrast between primary care and specialist services was explicitly made by young people in this study. Understandably, some young people compared the closer relationship they had with their psychiatrist or paediatrician with the fact that they 'never saw' their GP, and felt that they did not know, or perhaps trust them. Indeed, their only ADHD-related encounters with primary care may have been in the process of referral for their initial diagnosis (which may also have represented a 'fight' or 'battle' for the parent), and when collecting repeat prescriptions, encounters which would not build a trusting and understanding base for the therapeutic relationship in adulthood.

Participants expressed little confidence in their GP's ability to help them manage their medication post transition, again in contrast to this specific support that they valued from specialists. This lack of confidence may be influenced by various factors such as the absence of a longstanding therapeutic relationship with the GP, and real and practical constraints such as limited GP time. Furthermore, interviews also suggested that many young people and parents naturally took on the role of 'expert patients', having built up years of experience of managing their condition, similarly to young people with other chronic health conditions. They may therefore have been more critical of primary care, and the knowledge or qualifications of GPs relating to ADHD. Potentially, the perceptions of participants might also reflect wider misunderstandings about primary care; other research amongst young adults has found that this group report issues with trust and communication in primary care, with some believing that GPs dealt exclusively with physical disorders and lacked training in or understanding of psychiatry (Biddle *et al.* 2006, Davey *et al.* 2013).

Misunderstandings and stigma surrounding ADHD itself as a condition, as well as controversies around ADHD medication (see Introduction and Background) might further contribute to difficulties in the therapeutic relationship with primary care, where participants encountered 'unsupportive' attitudes or refusals to prescribe. This attitude towards prescribing chimes with the reports of adults with ADHD interviewed by Matheson *et al*. (2013) who described GPs being reluctant to prescribe, and pharmacists being unwilling to dispense, treating the medication like 'plutonium'; with periods of enforced cessation being the result.

From the perspective of professionals themselves, comments made by paediatricians in a survey of those treating ADHD cases suggested that some also felt that GPs might not have the time, skills or interest to manage young people with ADHD (Marcer *et al.* 2008); something that was also raised by the small number of psychiatrists and paediatricians interviewed in the qualitative part of the CADDY study (Wong *et al.* 2009). Perhaps surprisingly, given their key role, to date in the UK there have been no published studies of GP attitudes towards ADHD in this age group. Evidence does suggest that many may feel uncomfortable and unprepared in taking responsibility for the management of young people with mental health problems. For example, GPs interviewed by Roberts *et al*. (2013) expressed anxiety in communicating with young people. They reported finding the mental health presentations of young adults highly variable and unpredictable, and felt they lacked the training to deal with them. Furthermore, GPs considered that their practice was hampered by guidelines limiting what they could do without specialist support or access to psychotherapies; and at the same time were frustrated by problems in gaining access to such specialist services for their patients.

The question of guidelines is of course very salient to ADHD; as NICE guidance (2008b) currently recommends that ADHD medication requires occasional review by a specialist, and where such services are not available (see section below on Transition) this will limit the GP's ability to prescribe, or to offer non-pharmacological interventions even where they might wish to do so. In addition, relationships with the patient may affect the GP's own confidence and willingness to prescribe, given that they themselves may be suddenly faced with a patient at the age of 18 who has always previously been seen by specialist services. GPs may therefore be cautious in taking on prescribing responsibilities in ADHD after patients reach 18 years, especially given that stimulants are controlled drugs (Bolea-Alamanac *et al.* 2014).

### The role of medication

A commonly expressed idea by the young people interviewed was a strong link between medication and education. They described the purpose of medication in various ways: as helping them to be calm in the classroom, to concentrate, to complete homework, and to take exams. This, of course, is possibly the most common reason for taking medication cited across the literature (Travell and Visser 2006, Wong *et al.* 2009, Brinkman *et al.* 2012). Young people interviewed by

Brinkman *et al.* (2013, p.57) in the US “recalled that medication was recommended by teachers and/or physicians in order to achieve academic success” . There was also the suggestion from Travell and Visser’s (2006) study of medication that many adolescents thought that the end of school (i.e. age 16 or 18 years) was the time to stop medication, which might relate to the comment from one participant in this current study that ‘medication is for kids’; although it is not known whether this was their own idea or something heard from clinicians or teachers. If it is a commonly held belief amongst professionals, both clinicians and teachers, that medication is just for children, or just for school, this is a view that may need exploring or addressing in future research. Although education appeared to be considered to be the ‘purpose’ of medication, the benefits of medication on social relationships were also prominent in young peoples’ accounts. Indeed, in Singh *et al.’s* (2010) qualitative study with young adolescents with ADHD, participants reported that medication had more of a beneficial effect on their social relationships than on their academic work. Interestingly, although the interviewees in the current study seemed to value these effects on social relationships, no participant gave them as the main reason for wanting to continue medication. It is possible that education was seen by young people and parents as being the most worthy or acceptable purpose for medication; and one that would be harder for professionals to argue with, especially given their uncertainties regarding whether their medication would be continued after leaving child services.

### Transition

Two of the themes focussed on experiences and needs around transition and beyond: ‘uncertainties around transition’ and 'identified needs and increasing independence’. Participants’ views on medication, discussed above, contributed to the uncertainties around transition that they faced. A major anxiety expressed by some participants appeared to be the fear that if their medication was stopped, their training and education might consequently suffer, even to the extent of being expelled from college, or having to leave University. Most interviewees (although not all) also appeared keen to continue to take their medication after the age of 18. This contrasts to some degree with other qualitative studies with adolescents about ADHD medication where a significant number of participants perceived that the negatives of medication outweighed the positive, and where many reported making their own decision to stop medication (Wong *et al.* 2009, Brinkman *et al.* 2012, Charach *et al.* 2014). The findings may differ due to the sample interviewed; the young people interviewed in this current study were all still on medication; which suggests both that these participants recognised the need for medication and remained engaged with healthcare services. The majority also planned to remain in some form of education or training after the age of 18. This is important to acknowledge when considering all the study findings and is discussed further under Limitations below.

The need to prepare young people for transition is well recognised from previous research and forms a key part of the guidance on optimal transition across physical and mental health services (Department of Health 2008b). Consequently, one of the more striking findings was how important information was to participants; and that this remained a central unmet need identified by interviewees in this study. Even young people who were otherwise satisfied with the service they received felt that extra attention and information around the time of transition in terms of what to expect and next steps to take would have helped them. The feeling of being unprepared, being suddenly ‘dropped’ and the experience of not being kept informed suggest guidance may not have been followed (see Implications below). Being informed was linked with the concept of becoming an adult and taking increased responsibility. The negotiation of a transfer of responsibility from parent to child appeared to be a stage that families were undergoing alongside transition. The extent of the transfer and the type of parent involvement naturally varied between participants who had differing levels of functioning, family structure and comorbidities, a finding also reported amongst young people with life-limiting health problems interviewed by Beresford *et al*. (2014).

The second major unmet need identified relating to care over the transition period and beyond was for support in managing ADHD medication. In particular, participants who were not transferring to an Adult ADHD service to appeared to have concerns about lack of specialist advice and review. They felt that they required regular review of dosage and type of drug in order to optimise the management of their symptoms. Similarly, in Matheson *et al.*’s (2013) study of adults with ADHD, those that received only repeat prescriptions from their GP wanted extra support with adjusting their medication and dealing with adverse effects, suggesting this might not be a role that primary care is always able to fulfil.

In contrast to the anxieties voiced regarding medication, needs for non-pharmacological management were less prominently expressed during interviews. Non-pharmacological interventions were generally referred to in more vague terms such as ‘someone to talk to’ or ‘support’ with further or higher education. Given that those interviewed had only just left child services, the issue of medication may have been a more urgent concern; but the relative lack of emphasis placed on other interventions might also reflect uncertainty about the role of non-pharmacological management. Adolescents interviewed by Singh *et al.* (2010) reported the view that medication was the most efficacious treatment for ADHD; and many also could not recall memorable or helpful non-pharmacological interventions. Such perceptions may indicate both a lack of awareness and a lack of availability of non-pharmacological options for young people with ADHD, leaving medication as their only ‘safety net’ over the transition period.

### Strengths and limitations

One of the strengths of this study was that the design involved interviewing young people using a variety of services across the South West Peninsula, encompassing four different service providers and configurations. It therefore describes the perspectives of service users from both CAMHS and paediatrics that transferred to Adult ADHD services as well as those for whom no such service was available and who were returning to GP care. Their experiences may therefore be applicable to young people in other areas of the country where similar arrangements are in place. The sample was also quite diverse. Although no young people from black or minority ethnic backgrounds were identified as being eligible, the sample included young men and women, with different co-morbidities, and who had varying destinations following transition such as vocational training, further education and higher education. The inclusion of young people with comorbidities (in particular Autism Spectrum Disorder) is likely to have meant that these wider needs would also have influenced their responses and experiences of service use; nonetheless this inclusion also resulted in a sample that reflected the ‘real-life’ complexities of clinic populations to a greater extent.

There were also potential strengths and limitations relating to the interview. Firstly, as a first time qualitative researcher, there were challenges in adapting a clinical interview technique to a more open technique suitable for qualitative interviewing, meaning that early interviews could potentially have been deeper and richer in data. On the other hand, as considered under Reflexivity earlier in the chapter, there were also advantages of having previous interviewing experience, and regular supervisory meetings allowed the discussion of transcripts and the development of techniques.

One of the requirements of ethical approval was to explain to the participant that a parent or carer could be present at the interview if they wished. Accordingly, four of the seven participants were also interviewed with parents present. This may have carried the potential to inhibit the participant, but on the other hand may also have allowed them to feel more comfortable in being interviewed by a stranger. Although data from the parent where present forms part of the ‘contextual’ information given in the analysis, data from the parent was not reported as part of the thematic analysis. This decision was taken because the original intention was for this study to concentrate on the perspectives of the young people themselves. There were of course varying levels of parental involvement in the interview itself; in some cases this was only at the level of factual information given to remind the child, in others parents wanted to contribute to the narrative, for example, discussion of how they had fought or battled to get into the ‘system’. On analysis there appeared to be no major differences in how the themes were represented across the data from young people in interviews with and without parents present. Nonetheless, it is important to acknowledge the influence that parents may have had, and consider that the findings of the study may not ‘purely’ represent the views of young people alone.

One of the key limitations was the difficulty in recruiting this hard-to-reach group, despite adapting the study design on several occasions (described in Section 5.2 Aims and Methods). Although qualitative studies are not predicated on reaching a specific sample size (Mays and Pope 2000) the small number of young people interviewed means that the data may not reflect the full range of experiences of transition, and therefore should be generalised with some caution. Nonetheless, few studies have successfully managed to recruit to plan when carrying out research with this population. For example, both the large TRACK and CADDY studies reported very low response rates (Wong *et al.* 2009, Hovish *et al.* 2012); in TRACK, only 11 service users out of a planned 20 were interviewed. Problems with a low response rate and a high drop-out rate prior to interview were also noted by Swift *et al.* (2013) (who identified initially over 80 cases but could interview only 10) and Matheson *et al.* (2013), both studies involving adolescents and adults with ADHD.

Young people in general can be hard to engage with, and the nature of ADHD involved added challenges in recruitment and retention. Those with the disorder generally experience problems with organisation and attention, both issues which would make it harder for them to respond to invitations and reminders. Indeed, most of those who eventually took part required repeated contacts, sometimes over the course of weeks or even months. Young people with ADHD may also have comorbid ASD or associated difficulties with social skills, meaning that telephone contact, for instance, may have been anxiety provoking (the reason given by one non-participant), as may taking part in an actual interview.  Engaging young people often required repeated attempts at contact, and many seemed nervous or reluctant to speak on the telephone. Online ‘chat-room’ style discussions have previously been used with ‘hard to reach’ groups’ (Wilkerson *et al.* 2014) and might represent an alternative acceptable option for some participants, especially given the high prevalence of autism or social skills difficulties in those with ADHD (Murray 2010, Green *et al.* 2015). The fact that the study design involved making contact with service users at the disruptive and potentially chaotic time of transition is likely to have been yet another barrier to recruitment.

Another point for consideration is that the young people interviewed in this current study were all still being seen in specialist services at the age of 17-18 years and were all on medication; which suggests that these participants both recognised the need for medication and were engaged with healthcare services.  The study is therefore unable to reflect the experiences of young people who might disengage from services earlier in adolescence; a group who may face different challenges and report different priorities and needs.

### Implications

Although this study presents the experiences of a small number of young people at a specific point in time, their stories suggest that best practice around transition is not always being followed. Transition planning should begin at least six months in advance of leaving child services, and, in order to provide as much continuity as possible should include joint working and meetings between child and adult services (Department of Health 2008b, NHS England 2015). The NICE guidance on ADHD (2008b) recommends that the patient be given ‘full information’ about adult services, and that they should be involved in the planning of transition. Similarly, the NHS England Service Specification (2015) for transition from CAMHS places emphasis on keeping the young person and family informed throughout the process, with access to multi-media information resources, copies of care pathways, and regular meetings. Furthermore, arrangements for the continuation of medication described by participants in this study did not always appear to be optimal, or accord with current guidelines.  A number of young people seemed to be continuing medication after leaving CAMHS under the sole care of their GP. This is in contrast to guidance from NICE (2008b) and the British Association for Psychopharmacology which suggests that, if continuation of treatment is required this should take place with the oversight of specialist clinicians (Bolea-Alamanac *et al.* 2014).

Whilst this research does not in any way represent an audit of care, a gap nonetheless appears to be present between the guidance on transition, and what is experienced by the young people themselves. This relates not only to potentially more complex and resource-intensive provision (such as access to adult ADHD specialists) but to what would seem initially to be simple and cheap measures such as providing information, which was highly valued by young people.  Such a gap does not seem likely to be a local problem, but instead to reflect national shortcomings in delivering services for those in transition. The findings are in keeping with those of the 2010 TRACK evaluation of transition from CAMHS to AMHS, which found that ‘basic principles of good practice identified in transition protocols’ were not implemented, and that only 5% of cases experienced ‘good transition’ (Singh *et al.* 2010a). This gap between policy and practice is also evident in recent mapping surveys of healthcare professionals and mental health trusts in England, which highlighted a lack of transition protocols and care pathways for young people with ADHD (Hall *et al.* 2013, Hall *et al.* 2015).

### *Implications for research*

The findings suggest a number of priorities for future research; in particular regarding knowledge and attitudes of professional groups towards managing young people with ADHD in transition. The potential gap between policy and service user experience is another area requiring further exploration. Mapping transitions on a national scale is also likely to assist in service planning and provision by defining the scale of potential unmet need. The experience of conducting this study helped gain insight into the challenges of engaging this ‘hard-to-reach’ group.  Key points of learning included the need to allow sufficient time for recruitment and to build relationships with clinicians, as well as flexibility in the methods of contacting young people to take account of their anxieties and preferences. Some of the experiences from this study have therefore contributed to the protocol for a mixed methods project using surveillance, qualitative and mapping studies entitled “Children and Adolescents with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children’s services to adult services (CATCh-uS)” (Ford *et al.* 2015) on which the author is a co-applicant, and which takes forward some of the work from this thesis. The CATCh-uS study and other recommendations for research are considered further in more detail in the Overarching Conclusions chapter as they are also relevant to the overall findings of the thesis.

## Summary

This chapter described a qualitative interview study with young people with ADHD recruited from various service configurations across the South West Peninsula, who discussed their experiences and concerns about the transition process, such as anxieties about managing medication, and the need for better preparation. The key themes from the data were professional roles and relationships, the role of medication, uncertainties around transition, and identified needs and increasing independence.

Many of the implications for research and practice arising from these interviews are common to one or both of the other studies in this thesis, and in particular the study of primary care prescribing in Chapter Four. Further implications are therefore discussed in greater depth in the final Overarching Discussion and Conclusions chapter.

# Chapter Six: Overarching discussion and conclusions

## 6.1 Introduction

This final chapter aims to draw together the findings of the three studies which form the thesis. While the strengths and limitations, issues and implications which are specific to each study have been discussed in the relevant section of the chapter devoted to that study, this over-arching discussion will draw out the common themes and points of agreement or contrast.  This chapter will then consider what the overall implications might be for further research, for policy and for practice.

All the studies in this thesis examined contact with services and/or treatment for children and young people with psychiatric disorders from different perspectives and using different methodologies. The first study (in Chapter Three) analysed mental health related service contacts in school aged children across the range of disorders. The second and third both focused on the transition from child to adult services in young people with ADHD.  The large dataset analysis (in Chapter Four) described changes in primary care prescribing of ADHD and other psychotropic medication during the ages in which transition from child to adult services occurs, and the complementary qualitative study (in Chapter Five) explored the experience of service users going through this transition.

## 6.2 Common themes and findings

Findings from all three studies suggested gaps between the need for healthcare and the provision of services.  Whilst the majority of children with a disorder in BCAMHS 2004 reported some contact with at least one service regarding their mental health, only a minority had contact with a specialist mental health service. In line with the previous 1999 BCAMHS, this work found that teachers were the most commonly approached source of help and support for children with mental health problems (Ford *et al.* 2007b). However, there was an increase from the earlier survey in the proportion of children reporting contact with education professionals, which might relate to the expansion of school based mental health initiatives and overall awareness of mental health over the intervening period. In contrast, the proportion of children reporting CAMHS contact did not show such a marked increase, with little change amongst children with more enduring psychopathology; only half of those with persisting disorders reported CAMHS contact in 2004-2007. Such findings may indicate reliance on less specialist services to provide assessment and management of psychiatric disorders, which may not meet the more complex needs of these children; as discussed further under Implications below.

Similarly, the analysis of primary care prescribing in young people with ADHD also suggests unmet needs. This study is to date the first survival analysis of persistence of ADHD medication in the UK which includes a significant period of time after the introduction of the NICE guidelines on ADHD in 2008. The survival analysis revealed ongoing discrepancy between estimates of symptom persistence from taken from follow-up studies, such as the meta-analysis by Faraone *et al.* (2006) and medication persistence. Although there are caveats, such as the inclusion of only primary care prescriptions, the implication remains that many adolescents with ADHD may not be continuing treatment that they could potentially benefit from. Analysis of recorded psychiatric comorbidities against prescribing of psychotropic medication also suggested some gender differences in prescribing patterns which would warrant further investigation (see Chapter Four). Associations with gender were also evident in the BCAMHS analysis; where younger boys were more likely than younger girls to have mental health related contact with special education, teachers and CAMHS, and older girls more likely to have GP contact. Gender differences in service contact and referral patterns, particularly for ADHD and ASD, have been reported in other studies and might represent unmet need in both males and females (Novik *et al.* 2006, Staller and Faraone 2006, Ford *et al.* 2008a, Bussing *et al.* 2012).

Finally, in the qualitative interviews with young people that complemented this large dataset analysis, participants expressed needs for support and information that were not always being met by current services. Two inter-related themes emerging from the data were of particular relevance: concerns regarding stopping medication, and the role of and relationship with GPs. Participants discussed the importance of medication for education, with an attached assumption from some young people that as the purpose of medication was to concentrate at school or college, there might be no need to continue once leaving, or after having finished exams. This might indicate a considered choice by young people in the wider population to stop their medication at 16 or 18 years and may be relevant to the steep decline in prescribing at this age found in the prescribing analysis using the CPRD. However, those interviewees that planned for college or apprenticeships expressed uncertainty about who would prescribe their medication after the age of 18 and had concerns about what cessation might mean for them in terms of continuing their education and training and performing at their best. This related to participants' experiences of problems with prescriptions such as the reluctance of GPs to prescribe; and a feeling that GPs did not know them as well as CAMHS or were 'not supportive' of ADHD. Such perceptions may well reflect external influences on cessation and might constitute another explanation for our findings of 'premature' cessation in the second study. In this respect these findings also resonate with the experiences of adults with ADHD interviewed by Matheson *et al.* (2013) who recalled experiencing 'enforced cessation' and described problems gaining access to prescriptions for medication, with psychiatrists and pharmacists treating it like 'plutonium'.

## 6.3 Implications for further research

Whilst the specific limitations of this work and implications for research are discussed in the individual chapters, the overall findings of the thesis suggest key general and more focussed areas for development, including evaluation of interventions, use of large datasets and data linkages; and the need for complementary research into knowledge, attitudes and policy implementation.

In discussing the findings of this thesis, reference has often been made to uncertainties and controversies surrounding interventions in child mental health and their efficacy. Accordingly, as recognised by recent reports from the Chief Medical Officer (Davies 2014) and the CAMHS Taskforce (Department of Health 2015), good-quality trials and evaluations of interventions and services continue to be a central priority in order to improve outcomes. However, an associated implication is the corresponding need for balanced reporting of research, as care for those with ADHD in particular may be adversely affected by controversy surrounding the condition and its treatment. Media reporting of the results of a recent systematic review of methylphenidate (Storebo *et al.* 2015) was highly variable, with some newspaper headlines implying that methylphenidate may not help with ADHD or be unsafe (Rhodes 2015). Media portrayal of such uncertainties may contribute to stigma felt by parents of children with ADHD (DosReis *et al.* 2010). It is even possible that the polarised media presentations of ADHD medication as discussed by Clarke (2011) might contribute to reluctance to fully treat ADHD with medication by professionals (Wang *et al.* 2015), although this is not a well- studied area. Consequently, well designed research needs to be accompanied by dissemination of the results that is balanced and informative.

Linking back to the qualitative work done for this thesis, it was also notable that participants gave little emphasis to non-pharmacological treatments for ADHD, in line with other qualitative studies suggesting that adolescents may have little knowledge of or confidence in such interventions (Singh *et al.* 2010b). Similarly, the effects of non-pharmacological interventions in ADHD could also be better understood. Systematic reviews suggest beneficial effects, but again restate the importance of rigorous evaluation that takes into account the context in which interventions happen, as well as the mapping of intervention components and approaches to outcomes(Fabiano *et al.* 2015, Richardson *et al.* 2015).

### ‘Big Data’ and data linkages

The large dataset analyses examining service contact (in BCAMHS) and prescribing (in CPRD) were able to answer the research questions, but were limited by using single sources of routinely collected and survey data. Further context and understanding could be gained by using ‘Big Data’, a term used to describe data that is high volume and uses a variety of data types, which may involve large dataset linkages or data mining (Belle *et al.* 2015). For example, the Clinical Record Interactive Search (CRIS) programme at the South London and Maudsley NHS Foundation Trust allows access to pseudonymised clinical records with free text available. Programmes are being developed to extract and analyse such free text, which could be highly valuable in adding detail and nuance that is not coded (Downs *et al.* 2015a). CRIS is also being linked with the National Pupil Database, a longitudinal dataset containing educational and census information, which will allow examination of education outcomes using individual level longitudinal data (Downs *et al.* 2015b).

Therefore, developing linkages with existing administrative datasets across health and education would provide even greater opportunities to study access to services, interventions and outcomes for children with psychiatric disorders; and ideally to study access and outcomes in individual disorders. Correspondingly, focussing on young people with ADHD, data linkages with CAMHS and AMHS records and with routine outcome collection would allow exploration of the relationship between ADHD severity, functioning and prescribing. This would provide more detail on where and consequently, how the management of those with ADHD and associated comorbidities could be optimised over the transition period and beyond.

### Research with primary care

A number of findings suggested the need for further research in primary care. GPs were the second most commonly contacted service in BCAMHS 2004; as well as playing a key role in the management of young people with ADHD in transition. Whilst research has examined GP attitudes towards some psychiatric disorders (Roberts *et al.* 2013, Roberts *et al.* 2014); the knowledge and attitudes of UK GPs regarding ADHD in older adolescents and adults has not been well studied. This is surprising given that GPs may take over the management of ADHD patients leaving child health services, and that the NICE guidance on ADHD recommends that GPs can prescribe for adults with ADHD under shared care arrangements with specialists(NICE 2008b). The British Association for Psychopharmacology suggests a number of components which should be included under such an arrangement; including defining the role of the specialist as being available for medication reviews, and trigger points for referral back to specialist care (Bolea-Alamanac *et al.* 2014). However, as reviewed in Chapters Four and Five, fewer than half of English Trusts surveyed by Hall *et al.*(2015) in 2013 had a shared care protocol, and the majority had no specialist service. Given that this qualitative study also suggests that young people prefer their ADHD medication to be actively managed and regularly reviewed, primary care professionals are likely to experience tensions between the needs of their patients, best practice guidance, and what they are able to deliver and are trained to provide. Therefore, as part of examining potential barriers to the implementation of guidance and policy (see also section on Policy below) it is important to understand how GPs make prescribing decisions in treating patients with ADHD, their attitudes towards the disorder, and their training needs. Both primary care questionnaires and qualitative interview studies could address these questions, and identify priorities to support GPs in caring for their patients with ADHD.

### Further research into transition

The research described in this thesis illustrates recent prescribing patterns for ADHD over the transition period on a national level; and also presents the direct experiences of young people with ADHD using local services. The themes arising from these qualitative interviews may reflect aspects of the experiences of service users across the country, and will also serve to inform local commissioning. However, this work also highlights the need for better understanding of the national picture of demand and supply. Surveys by Hall *et al.*(2013, 2015) of mental health Trusts and professionals, have begun to fill in some of this gap, but there remains no comprehensive national map of transition in ADHD which might help commissioners identify the likely numbers using and/or needing services.

The forthcoming CATCh-uS (Children and adolescents with ADHD in transition between children's services and adult services) study of transition in ADHD may assist in quantifying the scale of ongoing need in young people with ADHD leaving both CAMHS and paediatric services, as well as describing the provision of adult ADHD services nationwide(Ford *et al.* 2015). The study will also aim to complete qualitative interviews with various groups of professionals and people with ADHD, including two groups not included in the qualitative study for this thesis: young people attending CAMHS or paediatric services prior to the age when maximal drop-out from services is thought to occur (14-16 years old), and young adults who return to services in their mid-twenties after a period without secondary health care. Research by Matheson *et al*. (2013) also suggests that some adults with ADHD may re-initiate medication after a break in early adulthood or adolescence, but little is known about this group or about the potential scale of this population's needs. Exploring the perspectives of those returning to services would therefore be complemented by future study of re-initiation of medication following cessation using sources such as the CPRD.

Furthermore, there are likely to be other specific groups of young people with psychiatric disorders who may be especially vulnerable to the disruptions of transition. According to the TRACK study, those with other neurodevelopmental disorders such as ASD and those with emotional disorders were also less likely to experience ‘optimal transition’ (Singh *et al.* 2010a). There is consequently the potential to use similar methods, e.g. mapping and surveillance, complemented by interview studies, to examine their experience of transition and identify barriers and facilitators.

Tracking young people in transition and mapping provision is an important first step in understanding the need for services, yet questions remain regarding the evidence on the best service models of transition. A systematic review in 2015 by Paul *et al.* (2015) examined 19 studies, mostly surveys and semi-structured interviews, intervention studies and case notes reviews, and concluded that there was currently no ‘high quality’ evidence to support the use of any particular transition care models. Evaluation of transition models should be embedded in services and involve the use of standardised measures of outcomes such as transfer rates, service satisfaction and functioning to allow more meaningful comparison and conclusions. The Europe-wide Milestone study, which will randomise CAMHS teams to control groups or managed transition intervention groups, may also provide evidence on the outcomes and cost-effectiveness of transition models, as well as identifying and validating potential outcome measures (Milestone 2015).

## 6.4 Implications for policy

Chapters One and Two of the thesis discussed the policy background in terms of child mental health and transition. Consideration of the overall findings of the thesis in the light of current policy suggests that another theme of this research may be the gap between policy and practice, resulting from complex factors including conflicting policies, lack of oversight, attitudes and beliefs, and possibly deteriorating access to services. As recognised by Tudor-Hart’s inverse care law, problems in gaining access to services may particularly affect the most vulnerable (Tudor Hart 1971, Goddard 2008).

For children and for young people making the transition to adult services, the model of local commissioning by Clinical Commissioning Groups (CCGs) in a climate of resource scarcity is likely to have influenced service delivery. The change in economic climate since the 2007 BCAMHS follow-up means that the impact of austerity will not have been captured in the analysis presented by this thesis, and equity of access for those from lower socio-economic groups may have further deteriorated. Child mental health policy has placed considerable emphasis on the roles and responsibilities of the education system; however devolved budgets and more fragmented oversight of schools have led to concern about variation in the service delivered, and the potential impact on children with special educational needs in particular(Muir and Clifton 2014). At the same time there has been a lack of investment in specialist CAMHS for front line services to refer on to.   Indeed, a recent Freedom of Information request from the charity Young Minds (2015) found that 75% of Mental Health Trusts, 67% of CCGs and 65% of Local Authorities had frozen or cut their CAMHS budgets between 2013/14 and 2014/15. Waiting times for CAMHS have also increased, with a mean maximum wait standing at 32 weeks in 2015 compared to 22 weeks in 2013/14 (NHS Benchmarking Network 2015). Whilst extra investment has been promised for CAMHS, it needs to be carefully channelled into services that can demonstrate benefit. Unfortunately, the levers to monitor and enforce service provision are weak. This situation is compounded by complex commissioning arrangements for child mental health with multiple budgets and systems, and therefore a lack of clear leadership and accountability (Department of Health 2015). This fact has also been acknowledged by the Health Select Committee (2014) who suggested an increase in monitoring of service variation and standards in their recent review of CAMHS, and a return to a greater degree of national oversight from NHS England and the Department of Health.

More positively, the findings of the CPRD study in this thesis suggested that the 2008 NICE guidance had some impact on practice. Analysis suggested a rise in prescribing for adolescents and adults over time,  consistent with research using the Health Improvement Network in the UK, as well as a number of European studies (McCarthy *et al.* 2012b, Zetterqvist *et al.* 2013, Geirs *et al.* 2014). In this more recent analysis, young people appeared to remain on medication for longer than in the older CADDY study, although the studies are not directly comparable (Wong *et al.* 2009). This was particularly the case for those in the later age cohort, suggesting that practice may have gradually changed. However, both the continuing gap between symptoms and medication persistence and the experiences of the young people interviewed imply that guidance from NICE and the British Association for Psychopharmacology on ADHD is not being fully implemented (NICE 2008b, Bolea-Alamanac *et al.* 2014). Hall *et al.'s* (2015) 2013 survey of a number of mental health trusts confirmed that many Trusts did not have a transition protocol that clinicians were aware of, and that half had no commissioned service for adults with ADHD. The recently introduced NHS England (2015) transition service specification sets out best practice, which is welcome but suggests only that clinicians take up matters with commissioners if suitable post-18 services are not provided. As well as studying barriers to policy implementation, as discussed above, the inclusion of 'good transition' as an outcome in the NHS Outcomes Framework might serve to encourage and monitor the implementation of transition best practices.

## 6.5 Implications for professionals and services

### Implications for primary care

Primary care plays a crucial role in caring for children and young people with mental health problems, and GPs were the second most frequently contacted professional group in BCAMHS. Qualitative research with GPs suggests that they themselves identify opportunities to improve their management of mental health conditions and often feel especially unprepared to address their patients' emerging emotional disorders, a target area for professional development (Roberts *et al.* 2013). A study of GPs referring to a CAMH service by Hinrichs *et al.* (2012) also found that they were more likely to have a referral rejected than other agencies, and that GPs experienced care pathways and referral criteria to be unclear; suggesting a need for more 'GP-friendly' systems and interfaces. The findings of the qualitative study and of the prescribing analysis in this thesis also suggest that GPs may experience specific training needs in relation to ADHD (as discussed in Implications for research above), and on the identification and management of comorbidities in the context of ADHD in both genders. Opportunities should be explored to integrate teaching on specific aspects of child mental health, including ADHD, but also on other under-served conditions such as emotional disorders, in the training scheme for GP registrars.

There are also implications for the interface between primary care and specialist care in the case of ADHD. As reported in surveys of Trusts and GPs, there appears to be little consistency in local policy on the role of GPs in managing adult ADHD (McCarthy *et al.* 2013, Hall *et al.* 2015). The British Association for Psychopharmacology also identify added complications in terms of the prescribing regulations on controlled ADHD drugs, which may be implemented differently across localities and create further complexity in commissioning and in shared care arrangements (Bolea-Alamanac *et al.* 2014). Therefore, GPs are also likely to require further clarification of their remit in ADHD, along with appropriate support from specialist services where indicated.

### Implications for education

Teachers were the professional group most contacted regarding mental health in the BCAMHS analysis, and children that reported teacher contact had a high prevalence of psychiatric disorder and difficulties. Education was also a central theme for young people with ADHD interviewed in the qualitative study, some of whom felt strongly about teacher misconceptions about their condition. A recent Health Technology Assessment review of ADHD in schools found that levels of conflict relating to ADHD between teachers, pupils and parents were often high (Richardson *et al.* 2015). Both the classroom environment and stigma related to ADHD were seen as having a role in aggravating symptoms, and a number of training needs were identified. Another key concern of participants in the interviews was the potential impact of medication cessation on their studies and future educational achievements, which highlights their feelings of vulnerability and might suggest they lacked other forms of support. A number of young people also indicated that they valued advice from schools about managing their ADHD in further and higher education, including how to choose supportive Universities. Therefore, teachers and lecturers have the potential to play a major part in helping students through these multiple simultaneous transitions.

However, educational professionals face a number of potential obstacles to fulfilling their role on the front line of mental health in schools and colleges. These challenges are not confined to ADHD. More generally, teachers also report feeling ill-equipped to deal with the responsibility of recognising mental health problems, with emotional disorders being a particular area of concern (Connelly *et al.* 2008, Rothì *et al.* 2008, Kidger *et al.* 2010). The various competing demands on teachers' time are acknowledged to be a barrier to their ability to recognise problems and intervene; a recent survey of head teachers in England reported that workload was a key factor preventing early identification of mental health problems in schools (Taggart *et al.* 2014). The emotional wellbeing of professionals themselves can also be affected by working with children and young people in distress without proper time or training to do so, and in turn have an impact on their response  to their pupils' needs (Kidger *et al.* 2010).

Despite more than a decade of policy focus on the role of schools in mental health, beginning with Every Child Matters in 2003, teachers surveyed by the National Foundation for Educational Research in 2015 still reported gaps in support and training (Harland  *et al.* 2015). Whilst a small majority (62%) felt equipped to identify potential mental health problems in pupils, a minority (32%) thought that they had received appropriate training in schools in this area, and just over half (52%) reported feeling confident in assisting their students to access appropriate support (Harland *et al.* 2015). This is especially concerning, as in line with previous research, the BCAMHS analysis also found that education may be the first or only point of contact for many children with clinical and diagnosable levels of difficulty.  Evaluation of the Targeted Mental Health in Schools (TaMHS) programme, which took place between 2008 and 2011, also reported that much of the increase in mental health support in schools resulting from the initiative was provided by teachers rather than specialists (Vostanis *et al.* 2013). Consequently, in line with the concerns raised by these surveys, training for teachers across the range of psychiatric disorders, including ADHD should remain a priority. Teachers and lecturers should also be aware of the needs that their students might have for support over the transition from school to college or university; and in particular the fact that symptoms of disorders such as ADHD may not necessarily stop at the age of 16 years. E-learning programmes such as MindEd (Street and Mainey 2015) may represent useful starting points for education professionals, but training also needs to be accompanied by adequate support, time and resources for schools and teachers to effectively carry out their mental health role.

Nonetheless, even with improved training, schools should not be relied upon to deal alone with complex mental health problems. With concerns raised repeatedly about access to child mental health services by front line professionals as well as in national policy reviews (Department of Health 2008a, Kidger *et al.* 2010, Health Select Committee 2014), timely access to specialist help is essential.

## Implications for mental health services

### *Child mental health services*

A significant proportion of children with emerging and persisting psychiatric disorders reported no contact with CAMHS in the 2004 survey. Concerns have been repeatedly raised over high barriers for access to CAMHS, not least by those in education who may seek to refer on children with problems that they have identified (Kidger *et al.* 2010, Taggart *et al.* 2014). Aside from the problems of investment discussed above, recommendations by the recent Mental Health Taskforce include dissolving the tiered system and greater integration of services to remove artificial barriers and enable earlier intervention (Department of Health 2015).

In the analysis of data from BCAMHS, children that did come into contact with CAMHS had high levels of disorder and difficulty, and did not experience on average a significant improvement as measured by the SDQ after three years. For optimal outcomes, further focus is needed not just on access to CAMHS, but on the effective implementation of appropriate interventions once children are seen in services, as recommended by the Chief Medical Officer report (Davies 2013). At present, the extent to which children are receiving evidence based interventions remains unknown, and there is still uncertainty about which interventions are effective for which groups of children, and to what extent (Hoagwood *et al.* 2001, Davies 2013). Linking to the theme of data discussed above, outcomes monitoring therefore has an important part to play in gathering data on the implementation of evidence based practice, and in allowing 'real-world' outcomes of interventions to be measured. The forthcoming CAMHS Minimum Dataset is likely to have a major role in this, as it will contain indicators on outcomes and on the use of evidence based interventions. However, outcome data needs to be used and interpreted with caution. Costello and Maughan's review (2015) discusses optimal outcomes for children with disorders and acknowledges that there is likely to be great individual variability in what might constitute the best possible outcome for any given child. Services and commissioners will also need to consider the gathering and interpretation of outcomes data carefully, perhaps using the 'MINDFUL' framework outlined by

Wolpert *et al.* (2014) for examining outcome data; which emphasises the use of multiple perspectives, triangulation of data, the consideration of outliers, and the appreciation of uncertainty.

### ***Transition***

As discussed in the sections on research and policy above, the provision of services over the transition period has been identified as sub-optimal for young people with a variety of psychiatric diagnoses, such as for young people with ADHD, ASD and emotional disorders (Singh *et al.* 2010a).The findings from this PhD and from other studies such as TRACK support the implementation of best practice guidance relevant to all conditions, such as transition planning and the importance of providing timely and appropriate information to young people approaching transition(Department of Health 2008b, NHS England 2015). Transition pathways also need to be appropriate and accessible for young people moving on from both CAMHS and paediatrics; as some paediatricians will routinely see children with ADHD but perhaps have less well established links with adult mental health(Marcer *et al.* 2008).

Nonetheless, although improving transition in existing service structures is an important step forward, there are strong arguments for investing in changing the structures themselves to suit the needs of the young people using them. Participants in this PhD qualitative study also questioned the current leaving age for child services of 18 years, suggesting that “you’re an adult, but not adult adult”. For those moving to further or higher education, transition at the ages of 21 or older was considered to better suit their needs and allow continuity whilst they established themselves in adult life. Furthermore, the majority of people with ADHD are likely to still meet full syndrome criteria at 18, but this is estimated to fall to under 40% by the age of 20 (Faraone *et al.* 2006). Consequently, an extended service to the age of 21 or 25 would provide support for those who continue to experience impairing symptoms, allow improved identification of any emerging comorbidities, and potentially address the sharp drop in medication prescribing between the ages of 16 and 19.

The potential benefits of youth or ‘extended’ service are likely to be applicable across the range of psychiatric disorders; McGorry *et al.* (2013, p.s30) in their review of youth services suggest that the current age boundary may be one of the worst possible times in which to transfer between services, arguing that “the system is weakest where it needs to be strongest”, given the instabilities inherent in this developmental phase, the emergence of risk-taking behaviours such as substance misuse, and the high incidence of new disorders which all together have lasting functional impacts on young peoples’ life chances (Gibb *et al.* 2010). Youth services up to the age of 25 could provide more acceptable and integrated mental health care, as well as social and vocational support for young people during this time when they are more likely to disengage from sources of help (Green *et al.* 2012, Ogundele and Omenaka 2012, Cappelli *et al.* 2014). The emergence of youth services might also allow for the concentration and continuity of expertise in neurodevelopmental conditions that participants in this qualitative study valued highly. For example, in Birmingham the new 0-25 community mental health service includes streams for 0-14 and 15-25 year olds; with the aim of providing ‘seamless’ care, enabling continuation of medication, and early intervention in emerging disorders (Forward Thinking Birmingham 2016). In Australia, the Headspace programme goes a step further to integrate mental and physical healthcare provision for this age group. The evaluation suggested that co-locating physical health services served to minimise stigma associated with attending a specific mental health service, as well as addressing co-morbidities such as substance misuse(Muir *et al.* 2009). Both local authorities and child and adult clinical commissioners should therefore review the results of evaluations of such service models; and consider which configurations might best meet the local needs identified in their Joint Strategic Needs Assessments (Department of Health 2013).

### *Adult mental health services*

Focussing specifically on adults with ADHD, these findings implied that more adults are now continuing to take medication into their mid-twenties and beyond than was previously the case, yet there is still likely to be a gap between prescribing and prevalence of adult ADHD. This should not necessarily be interpreted as representing under-treatment, as people with ADHD may prefer to find their own management strategies and not to use medication. Nonetheless, a sustainable model for assisting adults with ADHD to manage their condition is needed, in terms both of medication (the first line in NICE guidance) and of other psychological or behavioural strategies. Any model is likely to involve a role for AMHS in providing specialist oversight and advice and supporting and liaising with primary care, depending on the severity and complexity of the case. Specialist input may involve specialist nurse prescribers as well as psychiatrists and psychologists(Mangle *et al.* 2014). The service provided by AMHS may involve an integrated model whereby ADHD management forms part of general adult psychiatry, or may constitute a separate specialist service. Both have advantages and disadvantages, for example in terms of the benefits of specialist care versus splitting off ADHD into a 'silo' which may further distance the condition from the rest of psychiatry (Bolea-Alamanac *et al.* 2014, Coghill 2015). Furthermore, the existence of a specialist adult clinic does not necessarily mean that all the patients' needs are met; audit of adult ADHD clinics in East Anglia found that the service lacked a rounded programme to provide psychological, behavioural and educational support, although compliance with NICE standards on assessment and pharmacological treatment was good (Magon *et al.* 2015). In order for commissioners to invest in improving ADHD management, the various models of delivering services for people with ADHD from transition onwards must consequently be evaluated in terms of cost-effectiveness, acceptability and sustainability.

## 6.6 Conclusions

In summary, the findings of these three linked studies suggest common themes in terms of unmet needs and gaps between policy and practice in the care of children with psychiatric disorders, and for those with ADHD making the transition between child and adult services. Given the impact of psychiatric disorders in childhood on multiple domains including education, relationships and general health, there are considerable public health gains to be made by optimising the identification and management of these conditions and the transition to adulthood. One of the chief implications of this research is the need for oversight and policy levers to ensure the implementation of best practice and that resources are allocated to meet unmet needs, especially in the most vulnerable. This should be accompanied by complementary efforts to better understand and overcome other barriers to providing optimal care, including research into knowledge and attitudes of different groups and the provision of targeted training.

# APPENDIX ONE:

### Documents relating to Study Two in Chapter Four: Primary care prescribing of ADHD and psychotropic medication in young people with ADHD in the Clinical Practice Research Datalink 2005-2013

## List of contents

1. Protocol 13_213 for Study Two approved by ISAC: version 4 10/12/13
2. Table A1.1 List of ADHD codes included in the dataset
3. Table A1.2List of ADHD medication codes included in the analysis
4. Table A1.3 List of ADHD medication codes eligible for inclusion in the analysis
5. New variables created for the analysis

# Protocol 13_213 for Study Two approved by ISAC: version 4 10/12/13

**PROTOCOL: version 4 10/12/13**

**With minor amendments dated 7/4/14, 11/4/14 and 17/4/14**

## Psychotropic prescribing for young people with ADHD in the Clinical Practice Research Datalink: a cohort study

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## 1. Lay Summary

Attention Deficit Hyperactivity Disorder (ADHD) is not only a condition of children, but can also persist into adulthood. Previous research suggests that although those over 18 could benefit from medication, many stop receiving prescriptions for their treatment at the age of 16/17, which is also the time when most young people will stop having contact with Child and Adolescent Mental Health Services (CAMHS). This study aims to describe what happens to prescribing of ADHD medication and of medication for other mental health problems in primary care over time in a group of young people with ADHD in the Clinical Practice Research Datalink (CPRD), from the age of 16/17 to 23/24. The study will report on how many of these young people stop being prescribed their medication after the age of 16 or 17, as well as on factors such as gender which might affect how likely they are to stop. It will also look at how many are prescribed other medications for different mental health disorders over this time period. Understanding recent trends in prescribing in this group will help in identifying where health needs might not be met and in planning and improving services for people with ADHD.

## 2. Background

This study addresses primary care prescribing in young people with Attention Deficit Hyperactivity Disorder (ADHD) aged between 16 and 24. This age range has been chosen in order to study what happens to prescribing as young people move on from CAMHS into adult services, which historically has happened between the ages of 16-18. ADHD is often thought of as just a condition of children and younger adolescents – however, evidence suggests that this is not the case. A meta-analysis of data from follow-up studies of ADHD reported the persistence of symptoms in 40-60% (Faraone, Biederman, & Mick, 2006), although persistence of the disorder meeting the full diagnostic criteria at age 25 was only 15%. It is estimated that there are over 400,000 adults in the UK with ADHD. (NICE, 2012). Over a lifetime, over three-quarters of those with ADHD are likely to experience psychiatric co-morbidity, with depression and anxiety being most common(Sobanski, 2006). Smoking, substance misuse and criminal behaviour are also increased in this population, who underachieve educationally and occupationally(Shaw et al., 2012).

### 2.1 Medication in adult ADHD

The role of medication in adults has historically been controversial. However, there is now evidence that stimulants are effective in reducing symptoms in adults as well as children and in 2008 the National Institute for Health and Clinical Excellence (NICE) first recommended appropriate assessment and management services, including medication, for adults affected by ADHD(NICE, 2012). A systematic review of long term outcomes found that without treatment, outcomes ranging from academic attainment to social functioning were worse in people with ADHD compared to those without(Shaw et al., 2012). Outcomes were better in treated as opposed to untreated ADHD, although still poorer than for people without the diagnosis. However, despite the potential benefits of treatment, NICE estimated that in 2008 only 1-2% of adults were receiving medication. Recent qualitative research indicates that prescribing for adults with ADHD is still not well established and accepted amongst many professionals.(Matheson et al., 2013).

### 2.2 Existing UK studies of prescribing

Young adults are most at risk of premature discontinuation of treatment as they leave Child and Adolescent Mental Health Services (CAMHS) or shortly afterwards. This is the case even with GP prescribing of ADHD medication, as treatment prescribed in primary care is often monitored by CAMHS teams. The CADDY study (Cessation of Attention Deficit Hyperactivity Disorder Drugs in the Young) specifically looked at 15-21 year olds over the period 1999 to 2006 using the General Practice Research Database (Wong et al., 2009). This study used survival analysis to examine rates of cessation of ADHD medication, finding the most noticeable reduction between the ages of 16 and 17. The rate of cessation was greater than the estimated rate of persistence of ADHD, suggesting that medication may be being prematurely terminated. Whilst young people may themselves choose to stop taking medication as they move on from school or college, the inappropriate cessation of medication during this time may contribute to the psychological, social and personal difficulties experienced by this age group. The Health Improvement Network database has also been used to examine the persistence of ADHD medication prescribing into adulthood for patients who started the drugs in childhood or adolescence (McCarthy et al., 2012a). Of those starting treatment before the age of 12, 38.5% remained on treatment beyond their 18th birthday. Of those starting between 13 and 17, the rate of persistence was 42.8%.

Prescribing in older adults with ADHD in the UK has been an under-examined area until recently. Another 2012 study using the Health Improvement Network database examined the prevalence and persistence of ADHD prescribing in over-18s over the period 2003-2008(McCarthy et al., 2012b). An increase in the prevalence of prescribing in adults was reported over this period, potentially due to increasing awareness of adult ADHD. However, total prescribing in 2008 in 18-24 year olds in this database stood at 1.122 per 1000, and at 0.079 per 1000 in 25-45 year olds. Despite the fact that many adults may prefer not to use medication or may be prescribed medication by specialist services outside of primary care, these figures are markedly lower than even the most conservative estimates of adult ADHD prevalence, ranging from 0.4% to 4% (Simon, Czobor, Bálint, Mészáros, & Bitter, 2009), suggesting a considerable unmet need.

### 2.3 Prescribing and comorbidities

Psychiatric disorders which have higher rates of prevalence in ADHD include depression, anxiety, substance misuse, sleep disorders and personality disorder(Sobanski, 2006). In addition to true co-morbidity, in clinical practice there may also be an element of misdiagnosis, whereby the symptoms of ADHD, particularly in adults, are mistaken for the signs of another disorder. For example, mood instability may lead to diagnoses of mood or personality disorders, when this may be actually be a feature of the patient's ADHD (Asherson, Chen, Craddock, & Taylor, 2007). Whilst this may occur with any medical diagnosis, historical stigma and misconceptions relating to ADHD increase the likelihood of such misdiagnoses.

It is therefore feasible to suggest, as clinicians may be more familiar with prescribing for depression or anxiety and see these conditions as more 'acceptable', other psychotropic medications may be inappropriately substituted for ADHD treatment. The result may be missed opportunities to treat ADHD, as well as the use of other ineffective management strategies(Asherson et al., 2007).

## 3. Rationale

Given the considerable impact of ADHD, improving the availability and accessibility of appropriate management is central to improving the outcomes of people with the condition. Part of addressing this should involve understanding recent patterns in prescribing and diagnosis. Earlier studies of ADHD prescribing using general practice databases have covered the periods 1999-2006 (Wong et al., 2009) and 2003-2008(McCarthy et al., 2012a), and largely concentrated on the prescribing of ADHD drugs rather than also examining other psychotropics . New guidance on prescribing in transition and in adults was released by the British Association for Psychopharmacology in 2006(Nutt et al., 2007), and later by NICE in 2008 (NICE, 2008). Capturing a picture of recent trends in a time period covering the changes in guidance will both complement and add to previous studies. In terms of wider benefit, better understanding of primary care prescribing and comorbidities in ADHD should feed into recommendations for practice and training, leading to improved assessment and treatment of this condition.

## 4. Study design

This is an observational study using a retrospective cohort design.

## 5. Research objective

To estimate the use of ADHD and other psychotropic medications over time in young adults aged 16-24

## 6. Specific aims

The three specific aims of the study are to:

- Describe the how the percentage of young people prescribed ADHD medication in primary care in this cohort changes between the ages of 16/17 and 23/24
- Describe the prescribing of other psychotropic medications in primary care over the same time period and analyse the relationship between the prescription of ADHD medication and other psychotropics
- Describe the new psychiatric diagnoses and psychiatric service referrals that occur

The study will collect the following data on the cohort:

- Prescription of ADHD medication
- Prescription of other psychotropic medication to include antidepressants, antipsychotics and anxiolytics
- New mental health diagnoses
- New mental health service referrals

## 7. Study population

The cohort will be defined as follows. It will include all cases with primary care records in the CPRD in 2005 who:

- Are aged 16 or 17 years of age as of 1st January 2005
- Have a recorded prescription for an ADHD medication (Methylphenidate, Dexamphetamine or Atomoxetine), and have been prescribed this medication for at least 6 months as of 31st January 2005
- Have had at any point a diagnosis of ADHD coded
- Are not classed as ‘temporary residents’

All cases meeting these criteria will be included.

The time period of the study will be from 1st January 2005 until 31st December 2012 (availability of CPRD data permitting).

## 8. Sample size

Early estimates from GPRD obtained in 2012 suggested that there would be approximately 1100 cases meeting the study criteria, with follow-up data available for 8 or more years on 80% of these – i.e., around 900 participants. This sample size is large enough to estimate the percentage of the cohort that remains on medication in adulthood with a margin of error no greater than +/-3.3 percentage points based on the width of the 95% confidence intervals. The sample size for the regression analyses is most easily considered by treating the outcome as binary (whether remains on medication versus ceases medication) rather than time to event (i.e., time until cessation of medication). If 15% remain on medication to the age of 24/25 then around 135 will continue using medication and 765 will cease. This is large enough to allow inclusion of up to13 predictors (135 divided by 10) in multivariable Cox regression models without concerns about stability of the estimated confidence intervals and p-values. The sample size is also large enough to detect a difference of a third of a standard deviation unit on a continuous predictor between those who remain on medication and those who cease medication in adulthood with 85% at the 5% level of significance, assuming that 90 remain on medication and 810 cease medication

## 9. Exposures, outcomes and covariates

### 9.1 Outcomes:

- Cessation of ADHD medication from the study start date (primary outcome) – defined as greater than a 6 month gap in prescriptions
- Percentage of participants who receive a new prescription of other psychotropic medication since the study start date
- Percentage of participants who receive a new psychiatric diagnosis recorded in the CPRD since the study start date
- Percentage of participants who have a new mental health service referral recorded in the CPRD since the study start date

### 9.2 Covariates:

A number of covariates will be examined using Cox proportional hazards regression to determine their effect on the primary outcome (cessation of ADHD medication). These are likely to include:

- Age (i.e. whether aged 16 or 17 at start of the study)
- Gender
- Comorbidity with other psychiatric disorders
- Referral to mental health services
- Prescription of other psychotropic medication

## 10. Data analysis plan

Data will be analysed using Stata SE version 12 (Statacorp, 2011). The extent of missing data will be described. The method of addressing significant missing data will depend on how missing data are associated with key variables and the likelihood of introducing bias, but any assumptions made and methods used (such as multiple imputation) will be justified and fully described.

### 10.1 Cessation of medication

All participants will be prescribed ADHD medication in 2005 (as this is one of the inclusion criteria for the study). Kaplan-Meier curves will be used to examine the time until cessation of ADHD medication in this cohort over the following time period to 2012. The median (inter-quartile range) time until cessation will be reported assuming a sufficiently large number cease medication in order for these statistics to be calculated. Cessation will be defined as a minimum of 6 month's gap in prescriptions from the last medication prescription. Factors potentially associated with cessation will be examined using Cox proportional hazards regression. These will include: age, prescription of new psychotropic medication, new psychiatric diagnosis, mental health services referral and gender.

As with the CADDY study, informative censoring (where loss of the patient from the database is associated with the outcomes of interest) is likely to occur. This will be taken into account when interpreting the data. However, recent correspondence from the CPRD suggests that over 8 years of follow-up data is available for almost 80% of eligible cases in the database.

### 10.2 Prescription of new psychotropic medications, psychiatric diagnoses and mental health service referrals.

The incidence and prevalence of the above will be described for each year of the study period:

1. Prescription of new medication:

The percentage of participants that have been prescribed a new psychotropic medication (since 1st January 2005) will be reported as below:

- The percentage who have been prescribed a new psychotropic over the whole of the study period
- In each year of the study, the percentage that are prescribed a new psychotropic medication since 1st January of that year
- The above will be presented for any psychotropic medication, and by medication groups e.g. antidepressants, antipsychotics etc.

2. New diagnoses:

We will report the percentage of participants that have received a new psychiatric diagnosis (since 1st January 2005).

- The percentage who received a new psychiatric diagnosis over the whole of the study period
- The percentage receiving a new diagnosis in each year of the study period (since 1st January of each year)
- The above will be presented for any psychiatric diagnosis and for individual diagnostic groups.

3. New referrals:

We will report the percentage of participants that have been newly referred to mental health services since 1st January 2005. We will report:

- The percentage who were newly referred over the whole of the study period
- The percentage referred in each year of the study period (since 1st January of each year)

## 11. Limitations

As with other studies using primary care databases, this study will not capture prescriptions issued in specialist services or other secondary care, which is likely to result in some under-estimation of the prescription of ADHD medication and other psychotropics. Where ADHD or other comorbidities are more severe, this increases the likelihood of prescriptions being issued outside primary care. In particular, some psychotropic medications are more likely to be initiated and monitored in specialist care than others, e.g. Lithium or certain antipsychotics. However, over time where medication is to be prescribed over a longer period and the patient is to be maintained on it, then in the majority of cases prescribing will be transferred to primary care. This is increasingly likely to happen under shared care arrangements and as specialist appointments become used more for assessment than more lengthy follow-up care. This will need to be taken into account when considering the interpretation of the planned analysis.

Information on severity and impairment is also not recorded in CPRD records, meaning that the association between these factors and cessation and other outcomes of interest cannot be examined. Similarly, there is also the potential for limited available data on new psychiatric diagnoses and mental health service referrals, which may result in lower statistical power for these analyses.

Finally, as reasons for cessation of ADHD medication or prescriptions of new psychotropics will not be recorded, it will not be possible to confirm whether these prescribing decisions were appropriate. However, it will be possible to comment on whether rates of cessation or new prescriptions exceed what we would expect to see from epidemiological studies of ADHD and comorbidities, and to comment on changes from previous research covering earlier time periods.

## 12. PPI

This study, along with 2 others which form part of an NIHR Doctoral Research Fellowship held by the Chief Investigator, has a small budget for PPI and has recruited advisors who have personal experience of having ADHD or being a carer for someone with the condition. Advisors will be invited to attend meetings or contribute by telephone or email throughout the Fellowship and will be reimbursed for their time. Specific areas where PPI advice and input will be sought include identification of important research questions and how best to present and disseminate the results.

## 13. Dissemination/communication

This study forms part of a PhD which is funded by a NIHR Doctoral Research Fellowship. There is a small budget for presentation of the research through conferences as well as through open access publication as required by NIHR. In addition to dissemination through conferences, publication etc., the results will also be communicated through NIHR networks and via the production of the completed PhD thesis. As described above, the input of PPI advisors will be used to determine how best to communicate relevant findings to the public, service users and carers – this is likely to involve presentations to support group networks, newsletters and the use of social media.

## 14. Amendments

In order to study the most recent trends in prescribing the study period will be extended from 01/01/2005 to 31/12/12 to cover a longer period of 01/01/2005 to 31/3/2014.

### Widening of study cohort definition

We will include all those aged 10-20 at the start in 2005 who have a recorded diagnosis of ADHD or a prescription event during the study period. This will enable us to study prevalence of ADHD medication prescribing and other psychotropic medication prescribing from the age of 16/17 onwards as originally envisaged, and will allow examination of the prevalence of prescribing of ADHD medication and other psychotropic medications into the mid-twenties. The restriction on having at least 6 months of prescriptions of ADHD medication will therefore be removed. All those from within this cohort with a current prescription at the age of 17 will be entered into the survival analysis to study medication cessation.

This wider definition will require the identification of genuine ADHD patients from those who are only given a prescription (but no diagnosis). For this group of drugs the major indication is ADHD. Much rarer indications include narcolepsy, or epilepsy (to counter toxic effects of anticonvulsants). The initial plan to deal with this would be to check each patient record where there was a prescription but no diagnosis coded for codes related to these much rarer indications – if they had another recorded indication and no codes relating to ADHD problems they would therefore be excluded. It is not anticipated that there would be many such cases which would make this feasible to carry out.

## 15. References

Asherson, P., Chen, W., Craddock, B., & Taylor, E. (2007). Adult attention-deficit hyperactivity disorder: recognition and treatment in general adult psychiatry. *The British journal of psychiatry : the journal of mental science*, *190*(1), 4–5. doi:10.1192/bjp.bp.106.026484

Faraone, S. V., Biederman, J., & Mick, E. (2006). The age-dependent decline of attention deficit hyperactivity disorder: a meta-analysis of follow-up studies. *Psychological Medicine*, *36*(02), 159–165. Retrieved from http://journals.cambridge.org/abstract_S003329170500471X

Matheson, L., Asherson, P., Wong, I. C. K., Hodgkins, P., Setyawan, J., Sasane, R., & Clifford, S. (2013). Adult ADHD patient experiences of impairment, service provision and clinical management in England: a qualitative study. *BMC health services research*, *13*, 184. doi:10.1186/1472-6963-13-184

McCarthy, S., Wilton, L., Murray, M. L., Hodgkins, P., Asherson, P., & Wong, I. C. (2012a). Persistence of pharmacological treatment into adulthood, in UK primary care, for ADHD patients who started treatment in childhood or adolescence. *BMC psychiatry*, *12*(1), 219. doi:10.1186/1471-244X-12-219

McCarthy, S., Wilton, L., Murray, M. L., Hodgkins, P., Asherson, P., & Wong, I. C. K. (2012b). The epidemiology of pharmacologically treated attention deficit hyperactivity disorder (ADHD) in children, adolescents and adults in UK primary care. *BMC pediatrics*, *12*, 78. doi:10.1186/1471-2431-12-78

NICE. (2008). CG72 Attention deficit hyperactivity disorder (ADHD): NICE guideline. NICE. Retrieved from http://publications.nice.org.uk/attention-deficit-hyperactivity-disorder-cg72

NICE. (2012). *Service for the diagnosis and management of attention deficit hyperactivity disorder in adults and young people in transition*. London: NICE. Retrieved from http://www.nice.org.uk/usingguidance/commissioningguides/adhd/adhdmainpage.jsp?domedia=1&mid=AEA5D678-19B9-E0B5-D4A25BE255FBBA69

Nutt, D. J., Fone, K., Asherson, P., Bramble, D., Hill, P., Matthews, K., … Young, S. (2007). Evidence-based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology. *Journal of psychopharmacology (Oxford, England)*, *21*(1), 10–41. doi:10.1177/0269881106073219

Shaw, M., Hodgkins, P., Caci, H., Young, S., Kahle, J., Woods, A. G., & Arnold, L. E. (2012). A systematic review and analysis of long-term outcomes in attention deficit hyperactivity disorder: effects of treatment and non-treatment. *BMC medicine*, *10*(1), 99. doi:10.1186/1741-7015-10-99

Simon, V., Czobor, P., Bálint, S., Mészáros, A., & Bitter, I. (2009). Prevalence and correlates of adult attention-deficit hyperactivity disorder: meta-analysis. *The British journal of psychiatry : the journal of mental science*, *194*(3), 204–11. doi:10.1192/bjp.bp.107.048827

Sobanski, E. (2006). Psychiatric comorbidity in adults with attention-deficit/hyperactivity disorder (ADHD). *European archives of psychiatry and clinical neuroscience*, *256 Suppl* , i26–31. doi:10.1007/s00406-006-1004-4

Statacorp. (2011). Stata Statistical Software: Release 12. College Station Texas: StataCorp LP.

Wong, I. C. K., Asherson, P., Bilbow, A., Clifford, S., Coghill, D., DeSoysa, R., … Taylor, E. (2009). Cessation of attention deficit hyperactivity disorder drugs in the young (CADDY)--a pharmacoepidemiological and qualitative study. *Health technology assessment (Winchester, England)*, *13*(50), iii–iv, ix–xi, 1–120. doi:10.3310/hta13490

## 16. APPENDIX: CPRD Codes

### 15.1 Proposed CPRD medical codes to identify ADHD diagnosis

| | |
|---|---|
| Eu90011 | [X]Attention deficit hyperactivity disorder |
| E2E0.00 | Child attention deficit disorder |
| 1BR..00 | Reduced concentration |
| E2E..00 | Childhood hyperkinetic syndrome |
| Eu9y700 | [X]Attention deficit disorder |
| E2E0100 | Attention deficit with hyperactivity |
| ZS91.11 | ADD - Attention deficit disorder |
| 1BR0.11 | Short attention span |
| ZS91.00 | Attention deficit disorder |
| Eu90.00 | [X]Hyperkinetic disorders |
| E2E0z00 | Child attention deficit disorder NOS |
| Z7C5312 | Short attention span |
| E2E2.00 | Hyperkinetic conduct disorder |
| ZS91.12 | [X]Attention deficit disorder |
| Eu90100 | [X]Hyperkinetic conduct disorder |
| E2E0000 | Attention deficit without hyperactivity |
| Eu90z00 | [X]Hyperkinetic disorder, unspecified |
| E2Ez.00 | Hyperkinetic syndrome NOS |
| Eu90111 | [X]Hyperkinetic disorder associated with conduct disorder |

| | |
|---|---|
| Eu90y00 | [X]Other hyperkinetic disorders |
| Eu90z12 | [X]Hyperkinetic syndrome NOS |

## 16.2 Proposed CPRD product codes to identify ADHD medication

| Product code | Product name |
|---|---|
| 5811 | Concerta XL 36mg tablets (Janssen-Cilag Ltd) |
| 576 | Methylphenidate 10mg tablets |
| 5810 | Concerta XL 18mg tablets (Janssen-Cilag Ltd) |
| 2679 | Ritalin 10mg tablets (Novartis Pharmaceuticals UK Ltd) |
| 7101 | Methylphenidate 5mg tablets |
| 9738 | Dexamfetamine 5mg tablets |
| 6169 | Methylphenidate 36mg modified-release tablets |
| 35159 | Concerta XL 27mg tablets (Janssen-Cilag Ltd) |
| 6868 | Equasym XL 20mg capsules (Shire Pharmaceuticals Ltd) |
| 6107 | Methylphenidate 18mg modified-release tablets |
| 14331 | Equasym XL 30mg capsules (Shire Pharmaceuticals Ltd) |
| 14512 | Dexedrine 5mg tablets (Auden McKenzie (Pharma Division) Ltd) |
| 14346 | Equasym XL 10mg capsules (Shire Pharmaceuticals Ltd) |
| 6643 | Atomoxetine 40mg capsules |
| 11733 | Methylphenidate 20mg tablets |
| 6644 | Atomoxetine 60mg capsules |

| | |
|---|---|
| 6645 | Atomoxetine 25mg capsules |
| 7100 | Atomoxetine 10mg capsules |
| 13914 | Equasym 5mg tablets (Shire Pharmaceuticals Ltd) |
| 13946 | Equasym 10mg tablets (Shire Pharmaceuticals Ltd) |
| 11536 | Methylphenidate 20mg modified-release capsules |
| 35658 | Medikinet XL 30mg capsules (Flynn Pharma Ltd) |
| 35659 | Medikinet XL 20mg capsules (Flynn Pharma Ltd) |
| 13212 | Methylphenidate 10mg modified-release capsules |
| 37658 | Medikinet XL 40mg capsules (Flynn Pharma Ltd) |
| 14848 | Methylphenidate 30mg modified-release capsules |
| 35469 | Methylphenidate 27mg modified-release tablets |
| 14129 | Atomoxetine 18mg capsules |
| 36628 | Medikinet XL 10mg capsules (Flynn Pharma Ltd) |
| 17014 | Strattera 40mg capsules (Eli Lilly and Company Ltd) |
| 16949 | Strattera 25mg capsules (Eli Lilly and Company Ltd) |
| 40279 | Atomoxetine 80mg capsules |
| 17588 | Strattera 60mg capsules (Eli Lilly and Company Ltd) |
| 37237 | Medikinet 10mg tablets (Flynn Pharma Ltd) |
| 14119 | Strattera 10mg capsules (Eli Lilly and Company Ltd) |
| 37097 | Medikinet 5mg tablets (Flynn Pharma Ltd) |
| 6804 | Equasym 20mg tablets (Shire Pharmaceuticals Ltd) |

| | |
|---|---|
| 35515 | Methylphenidate 40mg modified-release capsules |
| 18832 | Strattera 18mg capsules (Eli Lilly and Company Ltd) |
| 13238 | Dexamfetamine 1mg/ml oral liquid |
| 46593 | Medikinet XL 5mg capsules (Flynn Pharma Ltd) |
| 36910 | Medikinet 20mg tablets (Flynn Pharma Ltd) |
| 46607 | Methylphenidate 5mg modified-release capsules |
| 41492 | Strattera 80mg capsules (Eli Lilly and Company Ltd) |
| 21399 | Equasym xl 20mg Capsule (Celltech Pharma Europe Ltd) |
| 54504 | Methylphenidate 20mg modified-release tablets |
| 24116 | Durophet 12.5mg Capsule (3M Health Care Ltd) |
| 47609 | Dexamfetamine 5mg modified-release capsules |
| 56336 | Elvanse 50mg capsules (Shire Pharmaceuticals Ltd) |
| 55987 | Lisdexamfetamine 30mg capsules |
| 31623 | Dexedrine 15mg Spansules (Imported (United States)) |
| 16185 | Dexamfetamine 15mg modified-release capsules |
| 51453 | Dexamfetamine 5mg/5ml oral solution |
| 55635 | Atomoxetine 100mg capsules |
| 18998 | Durophet 7.5mg Capsule (3M Health Care Ltd) |
| 55495 | Dexamfetamine with amfetamine 10mg with 10mg capsules |
| 55747 | Elvanse 30mg capsules (Shire Pharmaceuticals Ltd) |
| 47481 | Dexamfetamine 10mg modified-release capsules |

| | |
|---|---|
| 52233 | Methylphenidate 54mg modified-release tablets |
| 56742 | Elvanse 70mg capsules (Shire Pharmaceuticals Ltd) |
| 18996 | Durophet 20mg Capsule (3M Health Care Ltd) |
| 23173 | Tranquilyn 10mg tablets (Genesis Pharmaceuticals Ltd) |
| 47099 | Dexamfetamine with amfetamine 10mg with 10mg modified-release capsules |
| 49392 | Amfetamine 10mg / Dexamfetamine 10mg modified-release capsules |
| 55169 | Lisdexamfetamine 50mg capsules |
| 56576 | Elvanse 30mg capsules (Shire Pharmaceuticals Ltd) |
| 47679 | Dexamfetamine 15mg modified-release capsules |
| 23161 | Tranquilyn 5mg tablets (Genesis Pharmaceuticals Ltd) |
| 52461 | Equasym XL 10mg capsules (Waymade Healthcare Plc) |
| 54804 | Equasym XL 10mg capsules (Doncaster Pharmaceuticals Ltd) |
| 53527 | Equasym XL 30mg capsules (Waymade Healthcare Plc) |
| 56713 | Ritalin-SR 20mg tablets (Imported (United States)) |

# Table A1.1 List of ADHD codes included in the dataset

| CPRD medical code | Read code | Read term |
|---:|---|---|
| 1363 | E2C..11 | Behaviour disorder |
| 11054 | 1B1X.00 | Behavioural problem |
| 6519 | Eu90011 | [X]Attention deficit hyperactivity disorder |
| 5565 | E2E0.00 | Child attention deficit disorder |
| 10741 | 1BR..00 | Reduced concentration |
| 14650 | 13Z4C00 | Behavioural problems at school |
| 3775 | E2E..00 | Childhood hyperkinetic syndrome |
| 10918 | 1P00.00 | Hyperactive behaviour |
| 10378 | 1BW..00 | Poor concentration |
| 26285 | Eu9y700 | [X]Attention deficit disorder |
| 9715 | E2E0100 | Attention deficit with hyperactivity |
| 101067 | 6A61.00 | Attention deficit hyperactivity disorder annual review |
| 24808 | ZS91.11 | ADD - Attention deficit disorder |
| 28543 | ZS91.00 | Attention deficit disorder |
| 1458 | Eu90.00 | [X]Hyperkinetic disorders |
| 24546 | Ry13.00 | [D]Overactivity |
| 20467 | E2E0z00 | Child attention deficit disorder NOS |
| 45263 | E2E2.00 | Hyperkinetic conduct disorder |
| 24753 | ZS91.12 | [X]Attention deficit disorder |
| 42988 | 1BR0.00 | Reduced concentration span |
| 33505 | Eu90100 | [X]Hyperkinetic conduct disorder |
| 37994 | ZS9..00 | Disorders of attention and motor control |
| 34199 | E2E0000 | Attention deficit without hyperactivity |
| 50015 | Eu90z00 | [X]Hyperkinetic disorder, unspecified |
| 41769 | E2Ez.00 | Hyperkinetic syndrome NOS |
| 37894 | ZS94.00 | Minimal brain dysfunction |
| 46551 | Z7C5313 | Short concentration span |
| 58069 | E2E1.00 | Hyperkinesis with developmental delay |
| 45799 | Eu90111 | [X]Hyperkinetic disorder associated with conduct disorder |
| 6510 | Eu90y00 | [X]Other hyperkinetic disorders |
| 96770 | Eu90z12 | [X]Hyperkinetic syndrome NOS |

| | | |
|---|---|---|
| 28394 | 1BR0.11 | Short attention span |
| 22789 | Z7C5312 | Short attention span |

## Table A1.2 List of ADHD medication codes eligible for inclusion in the analysis

| | |
|---|---|
| 5811 | Concerta XL 36mg tablets (Janssen-Cilag Ltd) |
| 576 | Methylphenidate 10mg tablets |
| 5810 | Concerta XL 18mg tablets (Janssen-Cilag Ltd) |
| 2679 | Ritalin 10mg tablets (Novartis Pharmaceuticals UK Ltd) |
| 7101 | Methylphenidate 5mg tablets |
| 9738 | Dexamfetamine 5mg tablets |
| 6169 | Methylphenidate 36mg modified-release tablets |
| 35159 | Concerta XL 27mg tablets (Janssen-Cilag Ltd) |
| 6868 | Equasym XL 20mg capsules (Shire Pharmaceuticals Ltd) |
| 6107 | Methylphenidate 18mg modified-release tablets |
| 14331 | Equasym XL 30mg capsules (Shire Pharmaceuticals Ltd) |
| 14512 | Dexedrine 5mg tablets (Auden McKenzie (Pharma Division) Ltd) |
| 14346 | Equasym XL 10mg capsules (Shire Pharmaceuticals Ltd) |
| 6643 | Atomoxetine 40mg capsules |
| 11733 | Methylphenidate 20mg tablets |
| 6644 | Atomoxetine 60mg capsules |
| 6645 | Atomoxetine 25mg capsules |
| 7100 | Atomoxetine 10mg capsules |
| 13914 | Equasym 5mg tablets (Shire Pharmaceuticals Ltd) |
| 13946 | Equasym 10mg tablets (Shire Pharmaceuticals Ltd) |
| 11536 | Methylphenidate 20mg modified-release capsules |
| 35658 | Medikinet XL 30mg capsules (Flynn Pharma Ltd) |

|  |  |
|---|---|
| 35659 | Medikinet XL 20mg capsules (Flynn Pharma Ltd) |
| 13212 | Methylphenidate 10mg modified-release capsules |
| 37658 | Medikinet XL 40mg capsules (Flynn Pharma Ltd) |
| 14848 | Methylphenidate 30mg modified-release capsules |
| 35469 | Methylphenidate 27mg modified-release tablets |
| 14129 | Atomoxetine 18mg capsules |
| 36628 | Medikinet XL 10mg capsules (Flynn Pharma Ltd) |
| 17014 | Strattera 40mg capsules (Eli Lilly and Company Ltd) |
| 16949 | Strattera 25mg capsules (Eli Lilly and Company Ltd) |
| 40279 | Atomoxetine 80mg capsules |
| 17588 | Strattera 60mg capsules (Eli Lilly and Company Ltd) |
| 37237 | Medikinet 10mg tablets (Flynn Pharma Ltd) |
| 14119 | Strattera 10mg capsules (Eli Lilly and Company Ltd) |
| 37097 | Medikinet 5mg tablets (Flynn Pharma Ltd) |
| 6804 | Equasym 20mg tablets (Shire Pharmaceuticals Ltd) |
| 35515 | Methylphenidate 40mg modified-release capsules |
| 18832 | Strattera 18mg capsules (Eli Lilly and Company Ltd) |
| 13238 | Dexamfetamine 1mg/ml oral liquid |
| 46593 | Medikinet XL 5mg capsules (Flynn Pharma Ltd) |
| 36910 | Medikinet 20mg tablets (Flynn Pharma Ltd) |
| 46607 | Methylphenidate 5mg modified-release capsules |
| 41492 | Strattera 80mg capsules (Eli Lilly and Company Ltd) |
| 21399 | Equasym xl 20mg Capsule (Celltech Pharma Europe Ltd) |
| 54504 | Methylphenidate 20mg modified-release tablets |
| 24116 | Durophet 12.5mg Capsule (3M Health Care Ltd) |
| 47609 | Dexamfetamine 5mg modified-release capsules |

| | |
|---|---|
| 56336 | Elvanse 50mg capsules (Shire Pharmaceuticals Ltd) |
| 55987 | Lisdexamfetamine 30mg capsules |
| 31623 | Dexedrine 15mg Spansules (Imported (United States)) |
| 16185 | Dexamfetamine 15mg modified-release capsules |
| 51453 | Dexamfetamine 5mg/5ml oral solution |
| 55635 | Atomoxetine 100mg capsules |
| 18998 | Durophet 7.5mg Capsule (3M Health Care Ltd) |
| 55495 | Dexamfetamine with amfetamine 10mg with 10mg capsules |
| 55747 | Elvanse 30mg capsules (Shire Pharmaceuticals Ltd) |
| 47481 | Dexamfetamine 10mg modified-release capsules |
| 52233 | Methylphenidate 54mg modified-release tablets |
| 56742 | Elvanse 70mg capsules (Shire Pharmaceuticals Ltd) |
| 18996 | Durophet 20mg Capsule (3M Health Care Ltd) |
| 23173 | Tranquilyn 10mg tablets (Genesis Pharmaceuticals Ltd) |
| 47099 | Dexamfetamine with amfetamine 10mg with 10mg modified-release capsules |
| 49392 | Amfetamine 10mg / Dexamfetamine 10mg modified-release capsules |
| 55169 | Lisdexamfetamine 50mg capsules |
| 56576 | Elvanse 30mg capsules (Shire Pharmaceuticals Ltd) |
| 47679 | Dexamfetamine 15mg modified-release capsules |
| 23161 | Tranquilyn 5mg tablets (Genesis Pharmaceuticals Ltd) |
| 52461 | Equasym XL 10mg capsules (Waymade Healthcare Plc) |
| 54804 | Equasym XL 10mg capsules (Doncaster Pharmaceuticals Ltd) |
| 53527 | Equasym XL 30mg capsules (Waymade Healthcare Plc) |
| 56713 | Ritalin-SR 20mg tablets (Imported (United States)) |

# Table A1.3 List of ADHD codes eligible for inclusion in the analysis

| **CPRD medical code** | **Read code** | **Read term** |
|---|---|---|
| 6519 | Eu90011 | [X]Attention deficit hyperactivity disorder |
| 5565 | E2E0.00 | Child attention deficit disorder |
| 26285 | Eu9y700 | [X]Attention deficit disorder |
| 9715 | E2E0100 | Attention deficit with hyperactivity |
| 101067 | 6A61.00 | Attention deficit hyperactivity disorder annual review |
| 24808 | ZS91.11 | ADD - Attention deficit disorder |
| 28543 | ZS91.00 | Attention deficit disorder |
| 1458 | Eu90.00 | [X]Hyperkinetic disorders |
| 24546 | Ry13.00 | [D]Overactivity |
| 20467 | E2E0z00 | Child attention deficit disorder NOS |
| 45263 | E2E2.00 | Hyperkinetic conduct disorder |
| 24753 | ZS91.12 | [X]Attention deficit disorder |
| 33505 | Eu90100 | [X]Hyperkinetic conduct disorder |
| 37994 | ZS9..00 | Disorders of attention and motor control |
| 34199 | E2E0000 | Attention deficit without hyperactivity |
| 50015 | Eu90z00 | [X]Hyperkinetic disorder, unspecified |
| 41769 | E2Ez.00 | Hyperkinetic syndrome NOS |
| 37894 | ZS94.00 | Minimal brain dysfunction |
| 58069 | E2E1.00 | Hyperkinesis with developmental delay |
| 45799 | Eu90111 | [X]Hyperkinetic disorder associated with conduct disorder |
| 6510 | Eu90y00 | [X]Other hyperkinetic disorders |
| 96770 | Eu90z12 | [X]Hyperkinetic syndrome NOS |

# Table A1.4 List of new variables created for analysis

| Variable | Definition | Values |
|---|---|---|
| Study psychotropic | At least one recorded prescription for a psychotropic medication (anxiolytic, antidepressant, antipsychotic etc )during the study period | 0 –None prescribed<br>1 – one or more prescriptions |
| Psychotropic in X year | At least one recorded prescription in a given calendar year | 0 –None prescribed<br>1 – one or more prescriptions |
| Psychotropic aged X | At least one recorded prescription in the year that case was in that age band (e.g. 15/16) | 0 –None prescribed<br>1 – one or more prescriptions |
| ADHD medication in X year | At least one recorded prescription for ADHD medication in a given calendar year | 0 –None prescribed<br>1 – one or more prescriptions |
| ADHD medication at X age | At least one recorded prescription in the year that case was in that age band (e.g. 15/16) | 0 –None prescribed<br>1 – one or more prescriptions |
| Concurrent medication | At least one prescription for ADHD medication and psychotropic medication in the same calendar year during the study period | 0 – No concurrent prescriptions<br>1 – one or more years with concurrent medication during the study period |
| Referral to any mental health service | Recorded referral at any point during the study period to any mental health services (defined as:<br>Adult psychiatry<br>CAMHS<br>Clinical psychologist<br>Forensic psychiatry<br>Community Psychiatric Nurse, psychotherapy) | 0 –No referral<br>1 – one or more referrals |
| Referral to adult psychiatry | Recorded referral at any point during the study period to adult psychiatry | 0 –No referral<br>1 – one or more referrals |
| Transfer out | Case transferred out/left the practice before the end of the study period. | 0 – Not transferred out<br>1 – transferred out |
| Study time category | Number of years of data that | 0-1 year |

| | | |
|---|---|---|
| | case has in the study period | 1-2 years<br>2-5 years<br>5-8 years |
| Depression or anxiety related diagnosis | Depression or anxiety related code<br>coded in clinical file | 0 – No code<br>1 – Coded at least once |
| Bipolar affective disorder or psychosis related diagnosis | Bipolar affective disorder or psychosis code<br>coded in clinical file | 0 – No code<br>1 – Coded at least once |
| Substance or alcohol misuse diagnosis | Any code relating to substance or alcohol misuse coded in the clinical file at any point | 0 -No code<br>1– Coded at least once |
| Any personality disorder diagnosis | Any code relating to a personality disorder coded in the clinical file at any point | 0 – No code<br>1 – Coded at least once |
| Autism spectrum disorder diagnosis<br>(ASD) | Any code relating to Autism, Asperger's or another pervasive developmental disorder coded in the clinical file at any point | 0 – No code<br>1 – Coded at least once |
| Conduct or oppositional defiant disorder (ODD) diagnosis | Any code relating to a conduct or oppositional defiant disorder coded in the clinical file at any point | 0 – No code<br>1 – Coded at least once |
| Learning disability | Any code relating to learning disability; mild, moderate, severe or profound | 0 – No code<br>1 – coded at least once |
| Tic disorder | Any code relating to a tic disorder coded in the clinical file at any point | 0 – No code<br>1 – Coded at least once |
| Smoking | Smoking related medical code coded in clinical file at any point. | 0 - No code<br>1 - Coded at least once |
| Time on medication prior to 16th birthday | Number of years where an ADHD prescription was coded prior to the year of 16th birthday<br>(for survival analysis dataset only) | 0 - Less than 2 years<br>1 - 2-3 years<br>2 - 3 or more years |

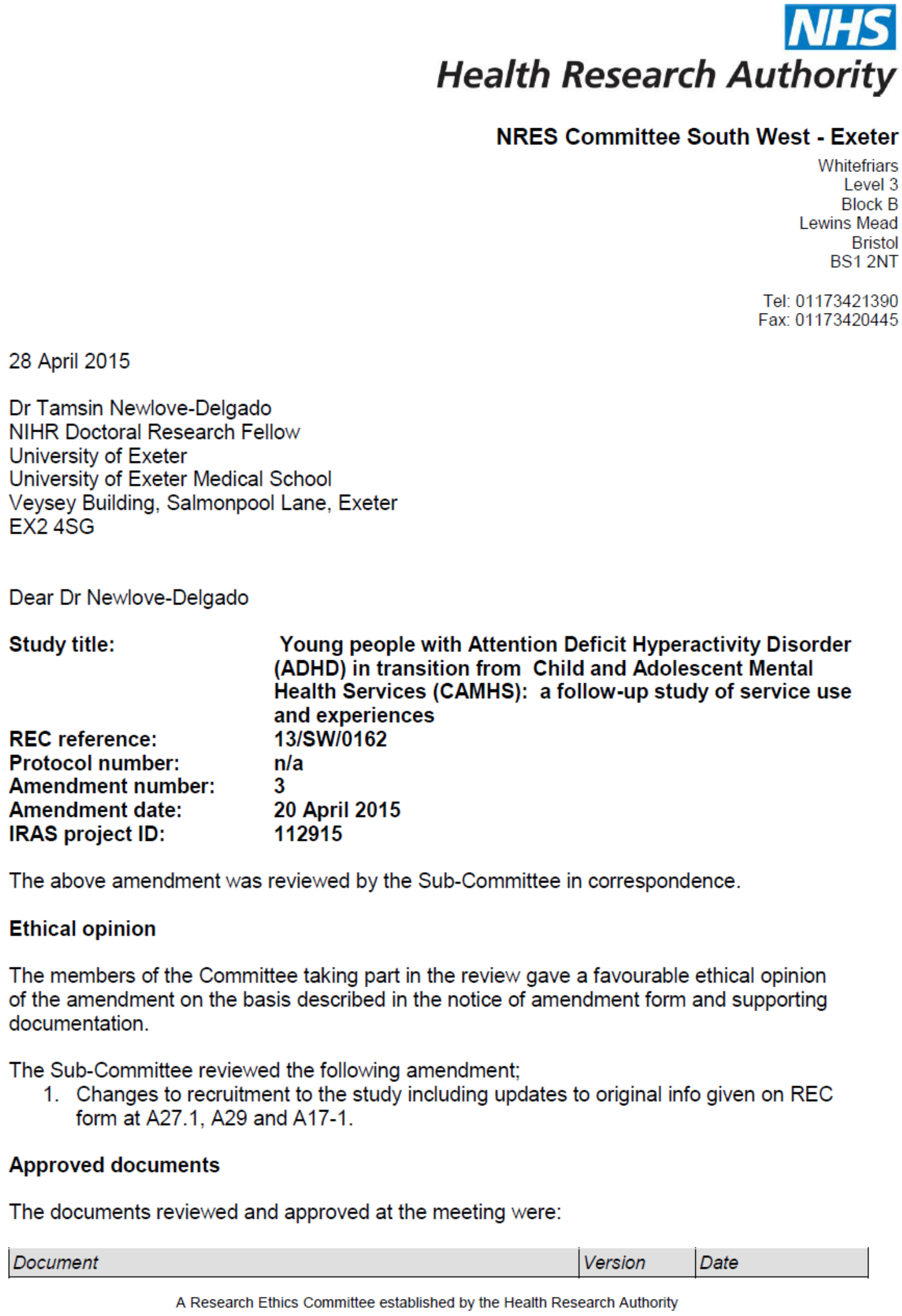
# APPENDIX TWO

**Documents relating to Study Three in Chapter Five: The experiences of young people with ADHD in transition from child to adult services**

## List of contents

1. Latest letter of ethical approval for study and amendments
2. Sample Participant Information Sheet for participants from Adult ADHD Clinic (v3)
3. Sample Participant Information Sheet for participants from CAMHS (v2)
4. Sample Consent form
5. Coding frame for qualitative analysis

# Latest letter of ethical approval for study and amendments



NHS
Health Research Authority

**NRES Committee South West - Exeter**
Whitefriars
Level 3
Block B
Lewins Mead
Bristol
BS1 2NT

Tel: 01173421390
Fax: 01173420445

28 April 2015

Dr Tamsin Newlove-Delgado
NIHR Doctoral Research Fellow
University of Exeter
University of Exeter Medical School
Veysey Building, Salmonpool Lane, Exeter
EX2 4SG

Dear Dr Newlove-Delgado

| | |
|---|---|
| **Study title:** | **Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from Child and Adolescent Mental Health Services (CAMHS): a follow-up study of service use and experiences** |
| **REC reference:** | **13/SW/0162** |
| **Protocol number:** | **n/a** |
| **Amendment number:** | **3** |
| **Amendment date:** | **20 April 2015** |
| **IRAS project ID:** | **112915** |

The above amendment was reviewed by the Sub-Committee in correspondence.

**Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee reviewed the following amendment;

1. Changes to recruitment to the study including updates to original info given on REC form at A27.1, A29 and A17-1.

**Approved documents**

The documents reviewed and approved at the meeting were:

| *Document* | *Version* | *Date* |
|---|---|---|

A Research Ethics Committee established by the Health Research Authority

| | | |
|---|---|---|
| Notice of Substantial Amendment (non-CTIMP) | 3 | 20 April 2015 |
| Participant information sheet (PIS) | 3 - Clean | 17 April 2015 |
| Participant information sheet (PIS) | 8 - Clean | 17 April 2015 |
| Research protocol or project proposal | 8 - Clean | 14 April 2015 |
| Research protocol or project proposal | 8 - Tracked | 14 April 2015 |

**Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

**R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

**13/SW/0162: Please quote this number on all correspondence**

Yours sincerely

PP.

**Dr Denise Sheehan**
**Chair**

E-mail: nrescommittee.southwest-exeter@nhs.net

| | |
|---|---|
| *Enclosures:* | *List of names and professions of members who took part in the review* |
| *Copy to:* | *Mrs Sue Crampton, Royal Devon and Exeter NHS Foundation Trust*<br>*Ms Gail Seymour* |

# Sample Participant Information Sheet for participants from Adult ADHD Clinic (v3)

## Young people with ADHD in transition:

## Participant information sheet for qualitative interview

## Version 3 (17/04/15) – For use with participants from Adult ADHD services

**We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please read this information sheet carefully. If you are interested in finding out more or taking part, one of our researchers will go through the sheet with you and answer any questions that you might have. Thank you!**

### What is the purpose of this study?

This study is about people with ADHD moving on from Child and Adolescent Mental Health Services (CAMHS) or other children and young people's services. This period is often referred to as 'transition', and can be a difficult or challenging time. We are interested in hearing about the experiences of people who have been through transition.

We are asking if you would be willing to take part in an interview with the researcher to tell us about your experiences. There is more information about this below.

### Why have I been chosen?

We are looking to interview people aged 17-19 who have ADHD and have been through transition and left CAMHS or other child services, and who are now being seen in Adult ADHD services. We are trying to interview a wide range of people to understand and learn from their experiences.

### Do I have to take part?

It is entirely up to YOU whether you would like to take part. Taking part is voluntary and you can withdraw from the study at any time without any disadvantage. We would encourage you to discuss taking part in the study with your parents, carers or other close family or friends. The researcher is not a part of CAMHS, Devon Autism & ADHD (DANA) Service or any other clinical services and the decision to participate in or withdraw from the study will NOT influence how you are treated.

### What do I have to do if I take part in the study?

If you decide that you would like to take part in the researcher will talk through what will happen, and you will need to sign a consent form if you are willing to join the study.  If you agree to take part, we will arrange a convenient time and place to come and talk to you. If you need to travel in order to take part in the interview, we will refund you for any reasonable travel costs.
We will want to ask you about your experiences of transition in a one-to-one interview somewhere private, lasting up to 30 minutes. To help us remember what you say we would like to make an audio-recording during the interview. This would only be used as a record of the conversation to help the researcher write about what you have said, and the recording would be kept securely. We might also want to use direct quotes from what you have said in published work, but these quotes would be anonymous and no-one would be able to identify you from them.
<u>If you would like to bring someone along to the interview with the researcher for support (such as a family member), you would be very welcome to do so.</u>

### What are the possible risks or disadvantages of taking part?

It will take approximately 20-30 minutes of your time. We don't expect that taking part in the interview will be upsetting, but you would be able to stop at any time if you do find it distressing or for any other reason. You would not be disadvantaged in any way in deciding not to go ahead with the interview. You will also be able to contact the researcher at any point if you have concerns, and if necessary they will link you up with sources of help and support (please see What is there is a problem? at the end of this sheet)

### What are the advantages of taking part?

The aim of this research is to improve services for people with ADHD, in particular for those aged 17-19. The information that you have given may help other young people in future, although we don't expect that there will be any direct advantages to you as a result of taking part.

### What will happen to the results of this study?

This study is a student study. The results will be published as part of a PhD thesis and in academic journals. We will produce a summary for young people in the study and for ADHD support groups, and share what we find with services working with people with ADHD to discuss how services can be improved. You will not be identified in any publication from this work.

### Will my taking part be kept confidential?

Everything that you say will be kept private unless what you say suggests that you or anyone else may be at risk. If this happens, we have a legal duty to discuss what has been reported with professionals who know you to see how we can help you and reduce any risk to you or anyone else. No one will be identified in any reports that come out of this research. Both the recording of the interview and any other information about you will be kept securely. Only the research team will have access to the data and it will be stored securely in accordance with the relevant guidelines, and destroyed after 5 years**. <u>We will ask for your permission to inform your GP that you are taking part in this project,</u> but will only share information about you with professionals with your written permission.**

## Who has reviewed this study and who is funding it?

All research within the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NRES Committee South West-Exeter. The study is being funded by the National Institute for Health Research (NIHR) as part of a Doctoral Research Fellowship, and is being carried out by the University of Exeter Medical School.

## What if there is a problem?

If you have any complaints about the way in which this study has been carried out please contact the Patient Advice and Liaison Service on 0800 0730741

If you become distressed at any point in the study and need support, please do get in touch with your adult mental health team if you are in contact with them, or with any other keyworker if you have one. If you are not currently in contact with any services you may want to speak to your GP or to NHS Direct on 0845 4647 for advice.
Childline also offer confidential telephone or webchat advice and counselling for people under 19 and can be contacted on 0800 1111 or at
http://www.childline.org.uk
Young Minds is a charity which offers information to young people about emotional health and wellbeing, and has useful information available on its website including how to look after yourself, get support and find out about your rights or complain.
http://www.youngminds.org.uk/for_children_young_people

**If you have any questions or need any further information, please feel free to contact:**

**Tamsin Newlove-Delgado**
**Doctoral Research Fellow**
**University of Exeter Medical School**
**Email : t.newlove-delgado@exeter.ac.uk**
**Telephone : 01392 726083**

# Sample Participant Information Sheet for participants from CAMHS (v2)

## Young people with ADHD in transition:

## Participant information sheet for qualitative interview

### Version 2 (17/7/13)

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please read this information sheet carefully. If you are interested in finding out more or taking part, one of our researchers will go through the sheet with you and answer any questions that you might have. Thank you!

**What is the purpose of this study?**
This study is about young people with ADHD moving on from Child and Adolescent Mental Health Services (CAMHS) or other children and young people's services. This period is often referred to as 'transition', and can be a difficult or challenging time. We are interested in hearing about the experiences of people who have been through transition.

We are asking if you would be willing to take part in an interview with the researcher to tell us about your experiences. There is more information about this below.

**Why have I been chosen?**
We are looking to interview people aged 17-19 who have ADHD and have been through transition and left CAMHS or other child services. We are trying to interview a wide range of people to understand and learn from their experiences.

**Do I have to take part?**
It is entirely up to YOU whether you would like to take part. Taking part is voluntary and you can withdraw from the study at any time without any disadvantage. <u>We would encourage you to discuss taking part in the study with your parents, carers or other close family or friends</u>. The researcher is not a part of CAMHS or any other clinical services and the decision to participate in or withdraw from the study will NOT influence how you are treated.

**What do I have to do if I take part in the study?**
If you decide that you would like to take part in the researcher will talk through what will happen, and you will need to sign a consent form if you are willing to join the study. If you agree to take part, we will arrange a convenient time and place to come

and talk to you. If you need to travel in order to take part in the interview, we will refund you for any reasonable travel costs.

We will want to ask you about your experiences of transition in a one-to-one interview somewhere private, lasting up to 30 minutes. To help us remember what you say we would like to make an audio-recording during the interview. This would only be used as a record of the conversation to help the researcher write about what you have said, and the recording would be kept securely. We might also want to use direct quotes from what you have said in published work, but these quotes would be anonymous and no-one would be able to identify you from them.

We would encourage you to let your parents or carers know that you are taking part, and if you would like to bring someone along to the interview with the researcher for support (such as a family member), you would be very welcome to do so.

**What are the possible risks or disadvantages of taking part?**

It will take approximately 20-30 minutes of your time. We don't expect that taking part in the interview will be upsetting, but you would be able to stop at any time if you do find it distressing or for any other reason. You would not be disadvantaged in any way in deciding not to go ahead with the interview. You will also be able to contact the researcher at any point if you have concerns, and if necessary they will link you up with sources of help and support (please see What is there is a problem? at the end of this sheet)

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This study is a student study. The results will be published as part of a PhD thesis and in academic journals. We will produce a summary for young people in the study and for ADHD support groups, and share what we find with services working with people with ADHD to discuss how services can be improved. You will not be identified in any publication from this work.

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**Who has reviewed this study and who is funding it?**

All research within the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NRES Committee South West-Exeter. The study is being funded by the National Institute for Health Research (NIHR) as part of a Doctoral Research Fellowship, and is being carried out by the University of Exeter Medical School.

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Childline also offer confidential telephone or webchat advice and counselling for people under 19 and can be contacted on 0800 1111 or at
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Young Minds is a charity which offers information to young people about emotional health and wellbeing, and has useful information available on its website including how to look after yourself, get support and find out about your rights or complain.
http://www.youngminds.org.uk/for_children_young_people

**If you have any questions or need any further information, please feel free to contact:**

**Tamsin Newlove-Delgado**
**Doctoral Research Fellow**
**University of Exeter Medical School**
**Email : t.newlove-delgado@exeter.ac.uk**
**Telephone : 01392 726083**

# Sample Consent form

UNIVERSITY OF EXETER | MEDICAL SCHOOL

**Young people with ADHD in transition:**
Participant consent form for qualitative interview
Version 3 (26/7/13)

**I understand/agree that: (*please read each statement fully and ask the researcher if you have any questions or concerns. Please sign with your initials in each box and sign in full at the bottom of the sheet*)**

| | | Please initial each box |
|---|---|---|
| 1. | I confirm that I have read the Participant Information Sheet (version 3: 17/4/15) concerning this study and understand what it is about. All my questions have been answered to my satisfaction. I understand that I can request any further information at any stage or contact the researcher with any other questions or concerns. | |
| 2. | I am aware that taking part is entirely voluntary and I am free to leave the study or stop the interview at any time without any disadvantage; | |
| 3 | I agree to the interview being audio/tape recorded | |
| 4 | I agree to the use of quotes from my interview being used in papers or other publications – these will be anonymous and I will not be identifiable from them | |
| 5 | All the information collected about me for the study will be kept in secure storage, including audio recordings, and destroyed after 5 years. | |
| 6 | I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from NHS Trusts, where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records. | |
| 7 | My GP will be informed that I am taking part in this study and I consent to this | |
| 8. | The results of the study may be published, but my anonymity will be preserved. | |
| 9. | Everything I say will be kept confidential, but I understand that confidentiality may be broken if anything indicates that I or other people may be at risk. | |

| | | |
|---|---|---|
| 10 | I agree to taking part in this study | |

Please give your telephone number if you are happy to be contacted by telephone call or text message: ______________________________

Please give your email address if you are happy to be contacted by email:

_________________________________

Printed name of participant ______________ Signature ______________ Date ______________

Printed name of Researcher ______________ Signature ______________ Date ______________

Ethical Approval: All research within the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NRES Committee South West-Exeter

# Coding Frame of Themes, Categories and Codes

| **ROLE OF ADHD MEDICATION: Categories** | |
|---|---|
| **Effects of medication :Codes** | **Purpose of medication: Codes** |
| Education | For kids |
| Relationships | College/school |
| Driving | Daily activities |
| Going out | So I can go out/ Difference of perception between child and parent |
| Effects on emotions e.g. calmer | Being normal |
| Stops me being myself | |
| Physical effects | Exams |
| Helping out at home | |

| **PROFESSIONALS: ROLES AND RELATIONSHIPS: Categories** | | | |
|---|---|---|---|
| **Attitudes and ideas: Codes** | **Professional knowledge/lack of : Codes** | **Relationships: Codes** | **Role: Codes** |
| Child with ADHD as trouble-maker | Managing medication | Knowing the patient | Managing medication inc changing dose |
| Naughty families/broken families | Qualifications | Temporary staff/staff leaving | Medication review |
| Assumptions about ADHD | Parent/YP as expert | Understanding and judgement | Prescribing vs problems with prescribing |
| Understanding and judgement | Doing own research | Asking questions | Physical monitoring |

| **UNCERTAINTIES AROUND TRANSITION: Categories** | | |
|---|---|---|
| **Preparation by services: Codes** | **Concerns: Codes** | **Feelings: Codes** |
| Lack of information | Who will prescribe? | Getting ‘dropped’ at 18 |
| Expectations | Who will manage? | |
| Timing of preparation | Asking questions | |
| | Impact of cessation/consequences of cessation | |

| **IDENTIFIED NEEDS AND INCREASING INDEPENDENCE: Categories** | | | |
|---|---|---|---|
| **Need for information: Codes** | **Need for support with medication : Codes** | **Becoming an adult/becoming independent: Codes** | **Other needs/support:Codes** |
| Lack of information | Who will prescribe? | Preparation – handover between parent and child | Support in further/ Higher education |
| Expectations | Who will manage? | Parent management/parent expectations | Choosing further/higher education |
| Timing of preparation | Asking questions | Timing of transition – relates to ideal service | |
| | Impact of cessation/consequences of cessation | Changing needs vs too much/unwanted support | |

# Bibliography

Acheson, R. M. (1978) The definition and identification of need for health care. *Journal of epidemiology and community health*. 32(1), pp.10-15.

Adamou, M. and Bowers, S. (2011) Dose of methylphenidate during service transition for adults with ADHD. *Therapeutic advances in psychopharmacology*. 1, pp. 71-5.

Ahmed, A. A., Cress, S. and Lovett, L. (2009) Adult ADHD: the new kid on the block has grown up. *Psychiatric Bulletin.* 33, pp. 37-37.

American Psychiatric Association (2000) *Diagnostic and statistical manual of mental disorders (4th ed., Text Revision).* Washington, DC: American Psychiatric Association.

American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders (5th ed.).* Washington, DC: American Psychiatric Association.

Amone-P'Olak, K., Ormel, J., Oldehinkel, A. J., Reijneveld, S. A., Verhulst, F. C. and Burger, H. (2010) Socioeconomic position predicts specialty mental health service use independent of clinical severity: the TRAILS study. *Journal of the American Academy of Child and Adolescent Psychiatry*. 49(7), pp. 647-55.

Angold, A., Costello, E. J., Burns, B. J., Erkanli, A. and Farmer, E. M. (2000) Effectiveness of nonresidential specialty mental health services for children and adolescents in the "real world". *Journal of the American Academy of Child and Adolescent Psychiatry*. 39(2), pp.154-60.

Arnett, J. J. (2000) Emerging adulthood. A theory of development from the late teens through the twenties. *American Psychologist*. 55(5), pp. 469-80.

Arnett, J. J., Žukauskienė, R. and Sugimura, K. (2014) The new life stage of emerging adulthood at ages 18–29 years: implications for mental health. *The Lancet Psychiatry*. 1(7), pp. 569-576.

Asherson, P., Chen, W., Craddock, B. and Taylor, E. (2007) Adult attention-deficit hyperactivity disorder: recognition and treatment in general adult psychiatry. *The British Journal of Psychiatry*. 190(1), pp. 4-5.

Barkley, R. A. and Brown, T. E. (2008) Unrecognized attention-deficit/hyperactivity disorder in adults presenting with other psychiatric disorders. *CNS Spectrums*. 13(11), pp. 977-84.

Barnett, A. G., van der Pols, J. C. and Dobson, A. J. (2005) Regression to the mean: what it is and how to deal with it. *International Journal of Epidemiology*. 34(1), pp. 215-20.

Batstra, L., Nieweg, E. H. and Hadders-Algra, M. (2014) Exploring five common assumptions on Attention Deficit Hyperactivity Disorder. *Acta Paediatrica*. 103(7), pp. 696-700.

Bean, D., Leibowitz, A., Rotheram-Borus, M., Horwitz, S., Jordan, D. and Hoagwood, K. (2000) False-negative reporting and mental health services utilization: parents' reports about child and adolescent services. *Mental Health Services Research*. 2(4), pp. 239-249.

Belle, A., Thiagarajan, R., Soroushmehr, S. M. R., Navidi, F., Beard, D. A. and Najarian, K. (2015) Big Data analytics in healthcare. *BioMed Research International* [online]. doi:10.1155/2015/370194. [Accessed 12 January 2016].

Belling, R., McLaren, S., Paul, M., Ford, T., Kramer, T., Weaver, T., Hovish, K., Islam, Z., White, S. and Singh, S. P. (2014) The effect of organisational resources and eligibility issues on transition from child and adolescent to adult mental health services. *Journal of Health Services Research and Policy*. 19(3), pp. 169-176.

Biddle, L., Donovan, J. L., Gunnell, D. and Sharp, D. (2006) Young adults' perceptions of GPs as a help source for mental distress: a qualitative study. *The British Journal of General Practice*. 56(533), pp. 924-931.

Biederman, J. and Faraone, S. V. (2006) The effects of attention-deficit/hyperactivity disorder on employment and household income. *Medscape General Medicine*. 8(3), pp. 12-12.

Biederman, J., Petty, C. R., Monuteaux, M. C., Fried, R., Byrne, D., Mirto, T., Spencer, T., Wilens, T. E. and Faraone, S. V. (2010) Adult psychiatric outcomes of girls with attention deficit hyperactivity disorder: 11-year follow-up in a longitudinal case-control study. *American Journal of Psychiatry.* 167(4), pp. 409-17.

Boe, T., Overland, S., Lundervold, A. J. and Hysing, M. (2012) Socioeconomic status and children's mental health: results from the Bergen Child Study. *Social Psychiatry and Psychiatric Epidemiology,* 47(10), pp. 1557-66.

Bolea-Alamanac, B., Nutt, D. J., Adamou, M., Asherson, P., Bazire, S., Coghill, D., Heal, D., Muller, U., Nash, J., Santosh, P., Sayal, K., Sonuga-Barke, E. and Young, S. J. (2014) Evidence-based guidelines for the pharmacological management of attention deficit hyperactivity disorder: update on recommendations from the *British Association for Psychopharmacology. Journal of Psychopharmacology.* 28(3), pp. 179-203.

Bowers, S. (2014) Why are we failing young patients with ADHD? BMJ (Clinical research ed.). 349, p. 6082.

Bradby, H., Varyani, M., Oglethorpe, R., Raine, W., White, I. and Helen, M. (2007) British Asian families and the use of child and adolescent mental health services: a qualitative study of a hard to reach group. *Social Science & Medicine*. 65(12),pp. 2413-24.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3(2),pp. 77-101.

Brinkman, W. B., Sherman, S. N., Zmitrovich, A. R., Visscher, M. O., Crosby, L. E., Phelan, K. J. and Donovan, E. F. (2012) In their own words: adolescent views on ADHD and their evolving role managing medication. *Academic Pediatrics.* 12(1), pp. 53-61.

Broeren, S., Muris, P., Diamantopoulou, S. and Baker, J. R. (2013) The course of childhood anxiety symptoms: developmental trajectories and child-related factors in normal children. *Journal of Abnormal Child Psychology*, 41(1), pp.81–95.

Burns, B. J., Costello, E. J., Angold, A., Tweed, D., Stangl, D., Farmer, E. M. and Erkanli, A. (1995) Children’s mental health service use across service sectors. *Health Affairs (Project Hope)*, 14(3), pp.147–59.

Bussing, R., Koro-Ljungberg, M., Noguchi, K., Mason, D., Mayerson, G. and Garvan, C. W. (2012) Willingness to use ADHD treatments: a mixed methods study of perceptions by adolescents, parents, health professionals and teachers. *Social science & medicine (1982)*, 74(1), pp.92–100.

Bussing, R., Zima, B. T., Mason, D. M., Meyer, J. M., White, K. and Garvan, C. W. (2012) ADHD knowledge, perceptions, and information sources: perspectives from a community sample of adolescents and their parents. *Journal of Adolescent Health*,. 51(6), pp. 593-600.

Cappelli, M., Davidson, S., Racek, J., Leon, S., Vloet, M., Tataryn, K., Gillis, K., Freeland, A., Carver, J., Thatte, S. and Lowe, J. (2014) Transitioning youth into adult mental health and addiction services: an outcomes evaluation of the youth transition project. *Journal of Behavioural Health Services Research.* 47(10) pp. 1557-66.

Chaiton, M., Contreras, G., Brunet, J., Sabiston, C. M., O'Loughlin, E., Low, N. C. P., Karp, I., Barnett, T. A. and O'Loughlin, J. (2013) Heterogeneity of depressive symptom trajectories through adolescence: predicting outcomes in young adulthood. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*. 22(2), pp. 96-105.

Chang, Z., Lichtenstein, P., D'Onofrio, B. M., Sjolander, A. and Larsson, H. (2014) Serious transport accidents in adults with attention-deficit/hyperactivity disorder and the effect of medication: a population-based study. *JAMA Psychiatry*. 71(3), pp. 319-25.

Charach, A., Yeung, E., Volpe, T., Goodale, T. and Dosreis, S. (2014) Exploring stimulant treatment in ADHD: narratives of young adolescents and their parents. *BMC psychiatry*. 14, p.110.

Cheung, C. H., Rijdijk, F., McLoughlin, G., Faraone, S. V., Asherson, P. and Kuntsi, J. (2015) Childhood predictors of adolescent and young adult outcome in ADHD. *Journal of Psychiatric Research.* 62, pp. 92-100.

Clarke, J. N. (2011) Magazine portrayal of attention deficit/hyperactivity disorder (ADD/ADHD): A post-modern epidemic in a post-trust society. *Health, Risk & Society*. 13(7-8), pp. 621-636.

Coghill, D. (2010) The impact of medications on quality of life in attention-deficit hyperactivity disorder: a systematic review. *CNS Drugs.* 24(10), pp. 843-66.

Coghill, D. (2015) Services for adults with ADHD: work in progress: Commentary on . . . Specialist adult ADHD clinics in East Anglia. *BJPsych Bulletin*. 39(3),pp. 140-143.

Coles, E. K., Slavec, J., Bernstein, M. and Baroni, E. (2012) Exploring the gender gap in referrals for children with ADHD and other disruptive behavior disorders. *Journal of Attention Disorders*. 16(2),pp. 101-8.

Connelly, G., Lockhart, E., Wilson, P., Furnivall, J., Bryce, G., Barbour, R. and Phin, L. (2008) Teachers' responses to the emotional needs of children and young people. Results from the Scottish Needs Assessment Programme. *Emotional and Behavioural Difficulties.* 13(1), pp.7-19.

Copeland, W., Shanahan, L., Costello, E. J. and Angold, A. (2011) Cumulative prevalence of psychiatric disorders by young adulthood: a prospective cohort analysis from the Great Smoky Mountains Study. *Journal of the American Academy of Child and Adolescent Psychiatry*.50(3), pp.252-61.

Copeland, W. E., Shanahan, L., Costello, E. J. and Angold, A. (2009) Childhood and adolescent psychiatric disorders as predictors of young adult disorders. *Archives of General Psychiatry.* 66(7), pp. 764-72.

Copeland, W. E., Wolke, D., Shanahan, L. and Costello, E. J. (2015) Adult functional outcomes of common childhood psychiatric problems: a prospective, longitudinal study. *JAMA Psychiatry.* 72(9), pp.892-9.

Cortese, S., Moreira-Maia, C. R., St Fleur, D., Morcillo-Penalver, C., Rohde, L. A. and Faraone, S. V. (2016) Association between ADHD and obesity: a systematic review and meta-analysis. *American Journal of Psychiatry.* 173(1), pp.34-43.

Costello, E. J., Egger, H. and Angold, A. (2005) 10-year research update review: the epidemiology of child and adolescent psychiatric disorders: I. Methods and public health burden. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44(10), pp.972–86.

Costello, E. J., He, J.-P., Sampson, N. A., Kessler, R. C. and Merikangas, K. R. (2014) Services for adolescents with psychiatric disorders: 12-month data from the national comorbidity survey. *Psychiatric services*. 65(3), pp.359–366.

Costello, E. J. and Maughan, B. (2015) Annual Research Review: Optimal outcomes of child and adolescent mental illness. *Journal of Child Psychology and Psychiatry*. 56(3), pp.324-341.

Crimlisk, H. (2011) Developing integrated mental health services for adults with ADHD. *Advances in Psychiatric Treatment.*17(6), pp.461-469.

Dalsgaard, S., Leckman, J. F., Mortensen, P. B., Nielsen, H. S. and Simonsen, M. Effect of drugs on the risk of injuries in children with attention deficit hyperactivity disorder: a prospective cohort study. *The Lancet Psychiatry*. 2(8), pp.702–709.

Dalsgaard, S., Ostergaard, S. D., Leckman, J. F., Mortensen, P. B. and Pedersen, M. G. (2015) Mortality in children, adolescents, and adults with attention deficit hyperactivity disorder: a nationwide cohort study. *Lancet*, 385(9983), pp. 2190-6.

Davey, A., Asprey, A., Carter, M. and Campbell, J. L. (2013) Trust, negotiation, and communication: young adults' experiences of primary care services. *BMC Family Practice*. 14(1), p.202.

Davies, S. C. (2013) *Chief Medical Officer's annual report 2012: Our Children Deserve Better: Prevention Pays.* London: Department of Health.

Davies, S. C. (2014) *Annual Report of the Chief Medical Officer 2013, Public Mental Health Priorities: Investing in the Evidence*. London: Department of Health.

Davis, E., Sawyer, M. G., Lo, S. K., Priest, N. and Wake, M. (2010) Socioeconomic risk factors for mental health problems in 4-5-year-old children: Australian population study. *Academic Pediatrics.* 10(1), pp.41-7.

Deighton, J., Argent, R., De Francesco, D., Edbrooke-Childs, J., Jacob, J., Fleming, I., Ford, T. and Wolpert, M. (2015) Associations between evidence-based practice and mental health outcomes in child and adolescent mental health services. *Clinical child psychology and psychiatry*. 21(2), pp.287-96.

Dekker, M. C., Ferdinand, R. F., van Lang, N. D. J., Bongers, I. L., van der Ende, J. and Verhulst, F. C. (2007) Developmental trajectories of depressive symptoms from early childhood to late adolescence: gender differences and adult outcome. *Journal of child psychology and psychiatry, and allied disciplines*, 48(7), pp.657–66.

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: the mental health and psychological well-being of children and young people: standard 9*. London: Department of Health

Department of Health (2006) *Transition: getting it right for young people: Improving the transition of young people with long term conditions from children's to adult health service*s. London: Department of Health.

Department of Health (2008a) *Children and young people in mind: the final report of the National CAMHS Review*. London: Department of Health.

Department of Health (2008b) *Transition: moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*.London: Department of Health.

Department of Health (2010a) *Equity and Excellence: Liberating the NHS.* London: Department of Health.

Department of Health (2010b) *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs.* London: Department of Health.

Department of Health (2012) *Report of the Children and Young Peoples' Health Outcomes Forum.* London: Department of Health.

Department of Health (2015) *Future in mind: Promoting, protecting and improving our children and young people's mental health and wellbeing*. London: Department of Health.

DosReis, S., Barksdale, C. L., Sherman, A., Maloney, K. and Charach, A. (2010) .Stigmatizing experiences of parents of children with a new diagnosis of ADHD. *Psychiatric Services.* 61(8), pp. 811-6.

Downs, J., Hotopf, M., Ford, T., Simonoff, E., Jackson, R., Shetty, H., Stewart, R. and Hayes, R. (2015) Clinical predictors of antipsychotic use in children and adolescents with autism spectrum disorders: a historical open cohort study using electronic health records. *European child & adolescent psychiatry*. DOI: 10.1007/s00787-015-0780-7 [Accessed January 6, 2016].

Downs, J., Newlove-Delgado, T. and Kolliakou, A.(2015) *Big data in CAMHS: what is it, and can it improve mental health care?* Presented at the Royal College of Psychiatrists Faculty of Child and Adolescent Psychiatry Annual Scientific Meeting, Brighton, UK September 15-19 2015.

Edbrooke-Childs, J., Jacob, J., Law, D., Deighton, J. and Wolpert, M. (2015a) Interpreting standardized and idiographic outcome measures in CAMHS: what does change mean and how does it relate to functioning and experience? *Child and Adolescent Mental Health.* 20: pp.142–148.

Edbrooke-Childs, J., Newman, R., Fleming, I., Deighton, J. and Wolpert, M. (2015b) The association between ethnicity and care pathway for children with emotional problems in routinely collected child and adolescent mental health services data. *European Child & Adolescent Psychiatry.* DOI:10.1007/s00787-015-0767-4 [Accessed October 30, 2015].

Elkins, I. J., Malone, S., Keyes, M., Iacono, W. G. and McGue, M. (2011) The impact of attention-deficit/hyperactivity disorder on preadolescent adjustment may be greater for girls than for boys *Journal Of Clinical Child And Adolescent Psychology.* 40(4), pp.532-45.

Essau, C. A. (2005) Frequency and patterns of mental health services utilization among adolescents with anxiety and depressive disorders. *Depression and anxiety*, 22(3), pp.130–7.

Fabiano, G., Schatz, N., Aloe, A., Chacko, A. and Chronis-Tuscano, A. (2015) A systematic review of meta-analyses of psychosocial treatment for attention-deficit/hyperactivity disorder. *Clinical Child and Family Psychology Review*. 18(1), pp. 77-97.

Faraone, S. V., Biederman, J. and Mick, E. (2006) The age-dependent decline of attention deficit hyperactivity disorder: a meta-analysis of follow-up studies. *Psychological Medicine*. 36(02),pp. 159-165.

Faraone, S. V. and Buitelaar, J. (2010) Comparing the efficacy of stimulants for ADHD in children and adolescents using meta-analysis. *European Child and Adolescent Psychiatry*. 19(4), pp. 353-64.

Faraone, S. V. and Glatt, S. J. (2010) A comparison of the efficacy of medications for adult attention-deficit/hyperactivity disorder using meta-analysis of effect sizes. *Journal of Clinical Psychiatry.* 71(6), pp. 754-63.

Farmer, E. M. Z. (2003) Pathways into and through mental health services for children and adolescents. *Psychiatric Services.* 54(1),pp. 60-66.

Fergusson, D. M., Boden, J. M. and Horwood, L. J. (2009) Situational and generalised conduct problems and later life outcomes: evidence from a New Zealand birth cohort. *Journal of Child Psychology and Psychiatry.* 50(9), pp. 1084-92.

Fergusson, D. M. and Woodward, L. J. (2002) Mental Health, Educational, and Social Role Outcomes of Adolescents With Depression. *Archives of General Psychiatry*, 59(3), p.225.

Flanagan, S. M. and Hancock, B. (2010) 'Reaching the hard to reach' - lessons learned from the VCS (voluntary and community sector). A qualitative study. *BMC Health Services Research*.10, pp. 92-92.

Ford, T. (2000) Teachers' attitudes towards child mental health services. *Psychiatric Bulletin.* 24(12), pp. 457-461.

Ford, T., Fowler, T., Langley, K., Whittinger, N. and Thapar, A. (2008a) Five years on: public sector service use related to mental health in young people with ADHD or hyperkinetic disorder five years after diagnosis. *Child and Adolescent Mental Health*, 13(3), pp.122–129.

Ford, T., Goodman, R. and Meltzer, H. (2003) The British Child and Adolescent Mental Health Survey 1999: the prevalence of DSM-IV disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*. 42(10), pp.1203–11.

Ford, T., Goodman, R. and Meltzer, H. (2003) Service use over 18 months among a nationally representative sample of British children with psychiatric disorder. *Clinical Child Psychology and Psychiatry*, 8(1), pp.37–51.

Ford, T., Hamilton, H., Goodman, R. and Meltzer, H. (2005) Service contacts among the children participating in the British Child And Adolescent Mental Health surveys. *Child and Adolescent Mental Health*. 10(1), pp.2–9.

Ford, T., Hamilton, H., Dosani, S., Burke, L. and Goodman, R. (2007a) The children’s services interview: validity and reliability. *Social Psychiatry and Psychiatric Epidemiology.* 42(1), pp.36-49.

Ford, T., Hamilton, H., Meltzer, H. and Goodman, R. (2007b) Child mental health is everybody’s business: the prevalence of contact with public sector services by type of disorder among British school children in a three-year period. *Child and Adolescent Mental Health*. 12(1), pp.13–20.

Ford, T., Hamilton, H., Meltzer, H. and Goodman, R. (2008b). Predictors of service use for mental health problems among British schoolchildren. *Child and Adolescent Mental Health*. 13(1), pp.32–40

Ford, T., Hutchings, J., Bywater, T., Goodman, A. and Goodman, R. (2009) Strengths and Difficulties Questionnaire Added Value Scores: evaluating effectiveness in child mental health interventions. *The British Journal Of Psychiatry.* 194(6), pp.552–8.

Ford T, J. A., Asherson, P., Beresford, B., Paul, M., Ani, C., Sayal, K., Hollis, C., Elliott, T., Young, S., Newlove-Delgado, T., Shotton, C., and Logan, S. (2015) HS&DR - 14/21/52: *Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (Catch-uS): a mixed methods project using national surveillance, qualitative and mapping studies (protocol).* NIHR [online]. Available at: http://www.nets.nihr.ac.uk/projects/hsdr/142152 [Accessed 10 January 2016]

Foreman, D. M. (2010) The impact of governmental guidance on the time taken to receive a prescription for medication for ADHD in England. *Child and Adolescent Mental Health.* 15(1), pp.12-17.

Foreman, D. M. and Ford, T. (2008) Assessing the diagnostic accuracy of the identification of hyperkinetic disorders following the introduction of government guidelines in England. *Child And Adolescent Psychiatry And Mental Health*. 2(1), pp. 32-32.

Forward Thinking Birmingham (2016) *Forward Thinking Birmingham* [online]. Available at: https://forwardthinkingbirmingham.org.uk/ [Accessed 12 January 2016].

Freedland, K. E., Mohr, D. C., Davidson, K. W. and Schwartz, J. E. (2011) Usual and unusual care: existing practice control groups in randomized controlled trials of behavioural interventions. *Psychosomatic Medicine*. 73(4), pp. 323-335.

Furlong, M., McGilloway, S., Bywater, T., Hutchings, J., Smith, S. M. and Donnelly, M. (2013) Cochrane Review: Behavioural and cognitive-behavioural group-based parenting programmes for early-onset conduct problems in children aged 3 to 12 years (Review). *Evidence-Based Child Health: A Cochrane Review Journal*. 8(2), pp. 318-692.

Garbe, E., Mikolajczyk, R. T., Banaschewski, T., Petermann, U., Petermann, F., Kraut, A. A. and Langner, I. (2012) Drug treatment patterns of attention-deficit/hyperactivity disorder in children and adolescents in Germany: results from a large population-based cohort study. *Journal Of Child And Adolescent Psychopharmacolog*y. 22, pp. 452-8.

Garland, A. F., Haine-Schlagel, R., Brookman-Frazee, L., Baker-Ericzen, M., Trask, E. and Fawley-King, K. (2013) Improving community-based mental health care for children: translating knowledge into action. *Administration And Policy In Mental Health*. 40(1), pp. 6-22.

Geirs, D. P., Pottegård, A., Halldórsson, M. and Zoëga, H. (2014) A nationwide study of Attention-Deficit/Hyperactivity Disorder drug use among adults in Iceland 2003-2012. *Basic & Clinical Pharmacology & Toxicology.* 115: pp. 417–422.

Gibb, S. J., Fergusson, D. M. and Horwood, L. J. (2010) Burden of psychiatric disorder in young adulthood and life outcomes at age 30. *British Journal of Psychiatry*, 197(2), pp. 122-7.

Ginsberg, Y., Quintero, J., Anand, E., Casillas, M. and Upadhyaya, H. P. (2014) Underdiagnosis of attention-deficit/hyperactivity disorder in adult patients: a review of the literature. *The Primary Care Companion For CNS Disorders*, 16(3). DOI: 10.4088/PCC.13r01600 [Accessed January 28, 2015].

Goddard, M. K. (2008) *Quality in and Equality of Access to Healthcare Services in England*. York: Centre for Health Economics.

Goldberg, D. P., Gater, R., Sartorius, N., Ustun, T. B., Piccinelli, M., Gureje, O. and Rutter, C. (1997) The validity of two versions of the GHQ in the WHO study of mental illness in general health care. *Psychological Medicine.* 27(1),pp. 191-7.

Gómez-Beneyto, M., Nolasco, A., Moncho, J., Pereyra-Zamora, P., Tamayo-Fonseca, N., Munarriz, M., Salazar, J., Tabarés-Seisdedos, R. and Girón, M. (2013) Psychometric behaviour of the strengths and difficulties questionnaire (SDQ) in the Spanish national health survey 2006. *BMC Psychiatry*. 13, pp.95-95.

Goodman, A. and Goodman, R. (2009) Strengths and difficulties questionnaire as a dimensional measure of child mental health. *Journal of the American Academy of Child and Adolescent Psychiatry.* 48(4), pp. 400-3.

Goodman, R. (1997) The Strengths and Difficulties Questionnaire: A Research Note. *Journal of Child Psychology and Psychiatry*. 38(5), pp. 581-586.

Goodman, R., Ford, T., Richards, H., Gatward, R. and Meltzer, H. (2000) The Development and Well-Being Assessment: description and initial validation of an integrated assessment of child and adolescent psychopathology. *Journal Of Child Psychology and Psychiatry.* 41(5),pp. 645-55.

Green, C. A., Wisdom, J. P., Wolfe, L. and Firemark, A. (2012) Engaging youths with serious mental illnesses in treatment: STARS study consumer recommendations. *Psychiatric Rehabilitation Journal*. 35(5), 360-8.

Green, H., McGinnity, A., Meltzer, H., Ford, T. and Goodman, R (2005) *Mental health of children and young people in Great Britain, 2004. A survey carried out by the Office for National Statistics on behalf of the Department of Health and the Scottish Executiv*e. Basingstoke: Palgrave Macmillan.

Green, J.L, Rinehart, N., Anderson, V., Nicholson,  J.M., Jongeling, B. and Sciberras E (2015). Autism spectrum disorder symptoms in children with ADHD: A community-based study. *Research in Developmental Disabilities.* 47, pp.175–184.

Groenewald, C., Emond, A. and Sayal, K. (2009) Recognition and referral of girls with Attention Deficit Hyperactivity Disorder: case vignette study. *Child: care, health and development*, 35(6), pp.767–72.

Groenman, A. P., Oosterlaan, J., Rommelse, N., Franke, B., Roeyers, H., Oades, R. D., Sergeant, J. A., Buitelaar, J. K. and Faraone, S. V. (2013) Substance use disorders in adolescents with attention deficit hyperactivity disorder: a 4-year follow-up study. *Addiction*. 108(8), pp.1503-11.

Guldberg-Kjar, T., Sehlin, S. and Johansson, B. (2013) ADHD symptoms across the lifespan in a population-based Swedish sample aged 65 to 80. *International Psychogeriatrics*. 25(4), pp.667-75.

Gulliver, A., Griffiths, K. M. and Christensen, H. (2010) Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry*.10, p.113.

Hall, C. L., Newell, K., Taylor, J., Sayal, K. and Hollis, C. (2015) Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: A national survey of mental health trusts in England. *Journal of Psychopharmacology.* 29(1), pp.39–42.

Hall, C. L., Newell, K., Taylor, J., Sayal, K., Swift, K. D. and Hollis, C. (2013) “Mind the gap”--mapping services for young people with ADHD transitioning from child to adult mental health services. *BMC Psychiatry*, 13, p.186

Harland, J., Dawson, A., Rabiasz, A. and Sims, D. (2015) *NFER Teacher Voice Omnibus: Questions for the Department for Education – June 2015.* London: Department for Education.

Health Improvement Scotland (2012). *ADHD services over Scotland: Stage 3 Final Report* [online]. Available at: http://www.healthcareimprovementscotland.org/our_work/mental_health/adhd_services_over_scotland/stage_3_adhd_final_report.aspx [Accessed 6 January 2016].

Health and Social Care Information Centre (2016a) *Child and Adolescent Mental Health Services Data Set* [online]. Available at: http://www.hscic.gov.uk/CAMHS. [Accessed 6 January 2016].

Health and Social Care Information Centre (2016b) *Read codes* [online], Available at: http://systems.hscic.gov.uk/data/uktc/readcodes [Accessed 7 January 2016].

Heiervang, E., Stormark, K. M., Lundervold, A. J., Heimann, M., Goodman, R., Posserud, M. B., Ullebo, A. K., Plessen, K. J., Bjelland, I., Lie, S. A. and Gillberg, C. (2007) Psychiatric Disorders in Norwegian 8- to 10-Year-Olds. *Journal of the American Academy of Child & Adolescent Psychiatry*. 46(4), pp.438–447.

Herrett, E., Gallagher, A. M., Bhaskaran, K., Forbes, H., Mathur, R., van Staa, T. and Smeeth, L. (2015) Data Resource Profile: Clinical Practice Research Datalink (CPRD). *International Journal of Epidemiology*. 44(3):827-836. doi:10.1093/ije/dyv098.

Herrett, E., Thomas, S. L., Schoonen, W. M., Smeeth, L. and Hall, A. J. (2010) Validation and validity of diagnoses in the General Practice Research Database: a systematic review. *British Journal Of Clinical Pharmacology*. 69(1), pp.4–14.

Hinrichs, S., Owens, M., Dunn, V., & Goodyer, I. (2012). General practitioner experience and perception of Child and Adolescent Mental Health Services (CAMHS) care pathways: a multimethod research study. *BMJ Open*, *2*(6), e001573.

HM Government (2012) *Health and Social Care Act 2012.* London: The Stationery Office

HM Treasury (2003) *Every Child Matters.* London: The Stationery Office

Hoagwood, K., Burns, B. J., Kiser, L., Ringeisen, H. and Schoenwald, S. K. (2001) Evidence-Based Practice in Child and Adolescent Mental Health Services. *Psychiatric Services*. 52(9),pp. 1179-1189.

Hoare, P. and Beattie, T. (2003) Children with attention deficit hyperactivity disorder and attendance at hospital. *European Journal Of Emergency Medicine.* 10(2), pp.98–100.

Hosmer, D. W. and Lemeshow, S. (1980) Goodness of fit tests for the multiple logistic regression model. *Communications in Statistics - Theory and Methods*. 9(10), pp. 1043-1069.

House of Commons Health Select Committee: (2014) *Children's and adolescents' mental health and CAMHS: Third Report of Session 2014–15 (HC 342*). London: House of Commons.

Hovish, K., Weaver, T., Islam, Z., Paul, M. and Singh, S. P. (2012) Transition experiences of mental health service users, parents, and professionals in the United Kingdom: a qualitative study. *Psychiatric Rehabilitation Journal*. 35(3), pp.251–7

Hurst, A., Price, A., Walesby, R., Doolan, M., Lanham, W. and Ford, T. (2014) Routine outcome monitoring of evidence-based parenting programmes: indications of effectiveness in a community context. *Journal of Children's Services*, 9(1), pp.58–74.

James, A. C., James, G., Cowdrey, F. A., Soler, A. and Choke, A. (2015) Cognitive behavioural therapy for anxiety disorders in children and adolescents. *The Cochrane database of systematic reviews*, 6, p.CD004690. Available at: http://www.ncbi.nlm.nih.gov/pubmed/23733328 [Accessed January 27, 2014].

Jensen, C. and Steinhausen, H.-C. (2015) Comorbid mental disorders in children and adolescents with attention-deficit/hyperactivity disorder in a large nationwide study. *Attention Deficit and Hyperactivity Disorders*, 7(1), pp.27–38.

Jensen, P. (1995) Test-Retest Reliability of the Diagnostic Interview Schedule for Children (DISC 2.1). *Archives of General Psychiatry*. 52(1),pp. 61-61.

Johansen, M. E., Matic, K. and McAlearney, A. S. (2015) Attention Deficit Hyperactivity Disorder Medication Use Among Teens and Young Adults. *Journal of Adolescent Health.* 57(2), pp.192-7.

Johnson, S. B., Blum, R. W. and Giedd, J. N. (2009) Adolescent maturity and the brain: the promise and pitfalls of neuroscience research in adolescent health policy. *Journal of Adolescent Health.* 45(3), pp. 216-221.

Joint Commissioning Panel for Mental Health (2013) *Guidance for commissioners of mental health services for young people making the transition from child and adolescent to adult services: Volume Two: Practical mental health commissioning*. London: Joint Commissioning Panel for Mental Health.

Joint Formulary Committee (2015) *British National Formulary, 60th ed.*. London: BMJ Group and Pharmaceutical Press.

Jones IR., Ahmed N., Catty J., McLaren S., Rose D., Wykes T., Burns T., Echo Grp (2009) Illness careers and continuity of care in mental health services: a qualitative study of service users and carers. *Social Science & Medicine.*69(4), pp.632–9.

Jörg, F., Ormel, J., Reijneveld, S. A., Jansen, D. E. M. C., Verhulst, F. C. and Oldehinkel, A. J. (2012) Puzzling findings in studying the outcome of "real world" adolescent mental health services: the TRAILS study. *Plos One*. 7(9), pp. e44704-e44704.

Kang, J.-H., Lin, H.-C. and Chung, S.-D. (2013) Attention-deficit/hyperactivity disorder increased the risk of injury: a population-based follow-up study. *Acta paediatrica*. 102(6), pp.640–3.

Kazdin, A. E. (2013) Evidence-based treatment and usual care: Cautions and qualifications. *JAMA Psychiatry*. 70(7), pp. 666-667.

Kessler, R. C., Amminger, G. P., Aguilar-Gaxiola, S., Alonso, J., Lee, S. and Ustun, T. B. (2007) Age of onset of mental disorders: a review of recent literature. *Current Opinion in Psychiatry.* 20(4), pp. 359-64.

Kessler, R. C., Chiu, W. T., Demler, O., Merikangas, K. R. and Walters, E. E. (2005) Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*. 62(6), pp. 617-27.

Khan, N. F., Harrison, S. E. and Rose, P. W. (2010) Validity of diagnostic coding within the General Practice Research Database: a systematic review. *The British Journal Of General Practice.* 60(572), pp.e128–36.

Kidger, J., Gunnell, D., Biddle, L., Campbell, R. and Donovan, J. (2010) Part and parcel of teaching? Secondary school staff's views on supporting student emotional health and well-being. *British Educational Research Journal*. 36(6),pp. 919-935.

Kim-Cohen, J., Caspi, A., Moffitt, T. E., Harrington, H., Milne, B. J. and Poulton, R. (2003) Prior juvenile diagnoses in adults with mental disorder: developmental follow-back of a prospective-longitudinal cohort. *Archives of General Psychiatry*. 60(7), pp.709-17.

Klein, R. G., Mannuzza, S., Olazagasti, M. A. R., Roizen, E., Hutchison, J. A., Lashua, E. C. and Castellanos, F. X. (2012) Clinical and Functional Outcome of Childhood Attention-Deficit/Hyperactivity Disorder 33 Years Later. *Archives Of General Psychiatry*. 69(12) pp. 1295-303.

Kooij, S. J. J., Bejerot, S., Blackwell, A., Caci, H., Casas-Brugué, M., Carpentier, P. J., Edvinsson, D., Fayyad, J., Foeken, K., Fitzgerald, M., Gaillac, V., Ginsberg, Y., Henry, C., Krause, J., Lensing, M. B., Manor, I., Niederhofer, H., Nunes-Filipe, C., Ohlmeier, M. D., Oswald, P., Pallanti, S., Pehlivanidis, A., Ramos-Quiroga, J. A., Rastam, M., Ryffel-Rawak, D., Stes, S. and Asherson, P. (2010). European consensus statement on diagnosis and treatment of adult ADHD: The European Network Adult ADHD. *BMC Psychiatry*. 10(1), p.67

Kraut, A. A., Langner, I., Lindemann, C., Banaschewski, T., Petermann, U., Petermann, F., Mikolajczyk, R. T. and Garbe, E. (2013) Comorbidities in ADHD children treated with methylphenidate: a database study. *BMC Psychiatry*. 13, p.11.

Lai, M.-C., Lombardo, M. V., Auyeung, B., Chakrabarti, B. and Baron-Cohen, S. (2015) Sex/gender differences and autism: setting the scene for future research. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(1), pp.11–24.

Langer, D. A., Wood, J. J., Wood, P. A., Garland, A. F., Landsverk, J. and Hough, R. L. (2015) Mental Health Service Use in Schools and Non-School-Based Outpatient Settings: Comparing Predictors of Service Use. *School Mental Health*. 7(3), pp.161–173.

Lee, S. I., Schachar, R. J., Chen, S. X., Ornstein, T. J., Charach, A., Barr, C. and Ickowicz, A. (2008) Predictive validity of DSM-IV and ICD-10 criteria for ADHD and hyperkinetic disorder. *Journal Of Child Psychology And Psychiatry*. 49(1), pp.70–8.

Lee, W., Jones, L., Goodman, R. and Heyman, I. (2005) Broad Outcome Measures May Underestimate Effectiveness: An Instrument Comparison Study. *Child and Adolescent Mental Health*. 10(3), pp.143–144.

Legerstee, J. S., Verhulst, F. C., Robbers, S. C. C., Ormel, J., Oldehinkel, A. J. and van Oort, F. V. A. (2013) Gender-specific developmental trajectories of anxiety during adolescence: determinants and outcomes. The TRAILS Study. *Journal of the Canadian Academy of Child and Adolescent Psychiatry.* 22(1), pp.26–34.

Leitner, Y. (2014) The co-occurrence of autism and attention deficit hyperactivity disorder in children - what do we know? *Frontiers in human neuroscience*. 8, p.268.

Leung, K. M., Elashoff, R. M. and Afifi, A. A. (1997) Censoring issues in survival analysis. *Annual Review of Public Health*. 18, pp. 83-104.

Levy, F., Hay, D. A., Bennett, K. S. and McStephen, M. (2005) Gender differences in ADHD subtype comorbidity. *Journal of the American Academy of Child and Adolescent Psychiatry*. 44(4), pp.368–76.

Lichtenstein, P., Halldner, L., Zetterqvist, J., Sjölander, A., Serlachius, E., Fazel, S., Långström, N. and Larsson, H. (2012) Medication for attention deficit-hyperactivity disorder and criminality. *The New England Journal Of Medicine*. 367(21), pp.2006–14.

Magon, R. K., Latheesh, B. and Muller, U. (2015) Specialist adult ADHD clinics in East Anglia: service evaluation and audit of NICE guideline compliance. *BJPsych Bulletin*. 39(3), pp.136–40.

Mangle, L., Phillips, P., Pitts, M. and Laver-Bradbury, C. (2014) Implementation of independent nurse prescribing in UK mental health settings: focus on attention-deficit/hyperactivity disorder. *Attention Deficit And Hyperactivity Disorders*. 6(4), pp.269–79.

Maniadaki, K., Sonuga-Barke, E. and Kakouros, E. (2006) Adults' self-efficacy beliefs and referral attitudes for boys and girls with AD/HD. *European Child & Adolescent Psychiatry*.15(3), 132-140.

Manteuffel, B., Stephens, R. L., Sondheimer, D. L. and Fisher, S. K. (2008) Characteristics, service experiences, and outcomes of transition-aged youth in systems of care: programmatic and policy implications. *The Journal Of Behavioral Health Services & Research*. 35(4), pp.469–87.

Marcer, H., Finlay, F. and Baverstock, A. (2008) ADHD and transition to adult services--the experience of community paediatricians. *Child: Care, Health and Development*. 34(5), pp.564–6.

Matheson, L., Asherson, P., Wong, I. C. K., Hodgkins, P., Setyawan, J., Sasane, R. and Clifford, S. (2013) Adult ADHD patient experiences of impairment, service provision and clinical management in England: a qualitative study. *BMC Health Services Research*. 13, p.184.

McCarthy, S. (2014) Pharmacological interventions for ADHD: how do adolescent and adult patient beliefs and attitudes impact treatment adherence? *Patient Preference and Adherence*. 8, pp.1317–27.

McCarthy, S., Wilton, L., Murray, M., Hodgkins, P., Asherson, P. and Wong, I. C. K. (2013) Management of adult attention deficit hyperactivity disorder in UK primary care: a survey of general practitioners. *Health and Quality Of Life Outcomes*, 11, p.22.

McCarthy, S., Wilton, L., Murray, M. L., Hodgkins, P., Asherson, P. and Wong, I. C. (2012a) Persistence of pharmacological treatment into adulthood, in UK primary care, for ADHD patients who started treatment in childhood or adolescence. *BMC Psychiatry.*12(1), pp.219-219.

McCarthy, S., Wilton, L., Murray, M. L., Hodgkins, P., Asherson, P. and Wong, I. C. K. (2012b) The epidemiology of pharmacologically treated attention deficit hyperactivity disorder (ADHD) in children, adolescents and adults in UK primary care. *BMC Pediatrics*.12, pp. 78-78.

McGorry, P., Bates, T. and Birchwood, M. (2013). Designing youth mental health services for the 21st century: examples from Australia, Ireland and the UK. *The British Journal of Psychiatry*. Supplement, 54, pp. s30-5.

McLaren, S., Belling, R., Paul, M., Ford, T., Kramer, T., Weaver, T., Hovish, K., Islam, Z., White, S. and Singh, S. P. (2013) 'Talking a different language': an exploration of the influence of organizational cultures and working practices on transition from child to adult mental health services. *BMC Health Services Research*. 13, pp. 254-254.

McNair, R., Taft, A. and Hegarty, K. (2008) Using reflexivity to enhance in-depth interviewing skills for the clinician researcher. *BMC Medical Research Methodology.* 8, pp. 73-73.

Meltzer , R. , Gatward., R., Goodman, R. and Ford, T. (2000) *The mental health of children and adolescents in Great Britain. The report of a survey carried out in 1999 by Social Survey Division of the Office for National Statistics on behalf of the Department of Health, the Scottish Health Executive and the National Assembly for Wales*. London: Office for National Statistics.

Merikangas, K. R., He, J.-P., Brody, D., Fisher, P. W., Bourdon, K. and Koretz, D. S. (2010) Prevalence and treatment of mental disorders among US children in the 2001–2004 NHANES. *Pediatrics* 125(1), pp. 75-81.

Merikangas, K.R., He, J.-P., Burstein, M., Swendsen, J. ,Avenevoli, S., Case, B., Georgiades, K., Heaton, L., Swanson, S. and Olfson M.(2011) Service utilization for lifetime mental disorders in U.S. adolescents: Results of the national comorbidity survey Adolescent supplement (NCS-A).. *Journal of the American Academy of Child and Adolescent Psychiatry*. 50(1): pp.32–45.

Messent, P. and Murrell, M. (2003) .Research leading to action: a study of accessibility of a CAMH service to ethnic minority families. *Child and Adolescent Mental Health.* 8(3), pp. 118-124.

Milestone (2016) *Milestone: Managing the link and strengthening transition from child to adult mental healthcare* [online]. Available at: http://www.milestone-transitionstudy.eu/ [Accessed 14 January 2016].

Miller, I. W., Epstein, N. B., Bishop, D. S. and Keitner, G. I. (1985) The McMaster Family Assessment Device: reliability and validity. *Journal of Marital and Family Therapy.* 11(4), pp. 345-356.

Moffitt, T. E., Houts, R., Asherson, P., Belsky, D. W., Corcoran, D. L., Hammerle, M., Harrington, H., Hogan, S., Meier, M. H., Polanczyk, G. V., Poulton, R., Ramrakha, S., Sugden, K., Williams, B., Rohde, L. A. and Caspi, A. (2015) Is adult ADHD a childhood-onset neurodevelopmental disorder? Evidence from a four-decade longitudinal cohort study. *American Journal of Psychiatry*. 172(10), pp.967–977

Moncrieff, J. and Timimi, S. (2010) Is ADHD a valid diagnosis in adults? No. *BMJ*, 340, c547.

Moor, S., Maguire, A., McQueen, H., Hester, M., Wells, E. J., Elton, R., Wrate, R. and Blair, C. (2007) Improving the recognition of depression in adolescence: can we teach the teachers? *Journal Of Adolescence*. 30(1), pp. 81-95.

Muir, K., Powell, A., Patulny, R., Flaxman, S., McDermott, S., Oprea, I., Gendera, S., and Vespignani, J., Sitek, T., Abello, D., Katz, I. (2009) *Independent Evaluation of headspace: the National Youth Mental Health Foundation*. Sydney: Social Policy Research Centre, University of New South Wales.

Muir, R. and Clifton, J. (2014) *Whole System Reform: England's Schools and the Middle Tier*. London: Institute for Public Policy Research.

National Centre for Social Research (2007) *Adult psychiatric morbidity in England, 2007: Results of a household survey*. Leeds: The NHS Information Centre for Health and Social Care.

National Health Advisory Service (1995) *Together We Stand: Thematic review of the commissioning, role and management of Child and Adolescent Mental Health Services*. London: Department of Health.

Newacheck, P. W., Hung, Y. Y., Park, M. J., Brindis, C. D. and Irwin, C. E. (2003) Disparities in adolescent health and health care: does socioeconomic status matter? *Health Services Research.* 38(5), pp. 1235-52.

NHS Benchmarking Network (2015) *CAMHS Benchmarking Report*. NHS Benchmarking Network.

NHS England (2015) *Model Specification for Transitions from Child and Adolescent Mental Health Services*. London: NHS England.

NHS England (2016) *Children and Young People's Improving Access to Psychological Therapies Programme* [online]. Available at : https://www.england.nhs.uk/mentalhealth/cyp/iapt/ [Accessed 10 January 2016].

NICE (2008a) *Attention deficit hyperactivity disorder. Costing report: Implementing NICE guidance.* London:NICE.

NICE (2008b) *CG72 Attention deficit hyperactivity disorder (ADHD): NICE guideline.* London:NICE.

Novik, T. S., Hervas, A., Ralston, S. J., Dalsgaard, S., Rodrigues Pereira, R. and Lorenzo, M. J. (2006) Influence of gender on attention-deficit/hyperactivity disorder in Europe--ADORE. *European Child and Adolescent Psychiatry*. 15 (Suppl) (1), pp. 15-24.

Novins, D. K., Green, A. E., Legha, R. K. and Aarons, G. A. (2013) Dissemination and implementation of evidence-based practices for child and adolescent mental health: a systematic review. *Journal of the American Academy of Child and Adolescent Psychiatry*. 52(10), pp.1009–1025.

Nutt, D. J., Fone, K., Asherson, P., Bramble, D., Hill, P., Matthews, K., Morris, K. A., Santosh, P., Sonuga-Barke, E., Taylor, E., Weiss, M. and Young, S. (2007) Evidence-based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology. *Journal of Psychopharmacology*.21(1), pp.10–41.

Ogundele, M. and Omenaka, I. (2012) An audit of transitional care for adolescents with ADHD in a North West England district. *Archives of disease in childhood*. 97(Suppl 1), p. A129.

Ohan, J. L. and Visser, T. A. W. (2009) Why Is There a Gender Gap in Children Presenting for Attention Deficit/Hyperactivity Disorder Services? *Journal of Clinical Child & Adolescent Psychology.* 38(5), pp. 650-660.

QSR International Pty Ltd (2016) *QSR International's NVivo 10 qualitative data analysis Software.* QSR International Pty Ltd.

Papandrea, K. and Winefield, H. (2011) It's not just the squeaky wheels that need the oil: examining teachers' views on the disparity between referral rates for students with internalizing versus externalizing problems. *School Mental Health*. 3(4),pp. 222-235.

Parker, C., Whear, R., Ukoumunne, O. C., Bethel, A., Thompson-Coon, J., Stein, K. and Ford, T. (2015) School exclusion in children with psychiatric disorder or impairing psychopathology: a systematic review. *Emotional and Behavioural Difficulties.* 20(3), pp. 229-251.

Parry-Langdon, N. (2008) *Three years on: Survey of the development and emotional well-being of children and young people*. London: Office for National Statistics.

Partridge, B., Lucke, J. and Hall, W. (2014) Over-diagnosed and over-treated: a survey of Australian public attitudes towards the acceptability of drug treatment for depression and ADHD. *BMC Psychiatry.* 14, p. 74.

Patton, M.Q. (2002). *Qualitative Research and Evaluation Methods*. Thousand Oaks, California: Sage Publications.

Paul, M., Street, C., Wheeler, N. and Singh, S. P. (2015) Transition to adult services for young people with mental health needs: A systematic review. *Clinical Child Psychology and Psychiatry.*20(3), pp. 436-457.

Pingault, J. B., Tremblay, R. E., Vitaro, F., Carbonneau, R., Genolini, C., Falissard, B. and Cote, S. M. (2011) Childhood trajectories of inattention and hyperactivity and prediction of educational attainment in early adulthood: a 16-year longitudinal population-based study. *American Journal of Psychiatry*. 168(11), pp. 1164-70.

Plaistow, J., Masson, K., Koch, D., Wilson, J., Stark, R. M., Jones, P. B. and Lennox, B. R. (2014) Young people's views of UK mental health services. *Early Intervention In Psychiatry*. 8(1), pp.12–23.

Polanczyk, G. V., Salum, G. A., Sugaya, L. S., Caye, A. and Rohde, L. A. (2015) Annual Research Review: A meta-analysis of the worldwide prevalence of mental disorders in children and adolescents. *Journal of Child Psychology and Psychiatry*. 56: pp. 345–365.

Posserud, M.-B. and Lundervold, A. J. (2013) Mental health services use predicted by number of mental health problems and gender in a total population study. *The Scientific World Journal*, 2013, p.247283.

Quinn, P. and Wigal, S. (2004) Perceptions of girls and ADHD: results from a national survey. *Medscape General Medicine*. 6(2), p.2.

Quinn, P. O. and Madhoo, M. (2014) A review of attention-deficit/hyperactivity disorder in women and girls: uncovering this hidden diagnosis. *The Primary Care Companion For CNS Disorders*. 16(3).

Reavley, N. J., Cvetkovski, S., Jorm, A. F. and Lubman, D. I. (2010) Help-seeking for substance use, anxiety and affective disorders among young people: results from the 2007 Australian National Survey of Mental Health and Wellbeing. *The Australian And New Zealand Journal Of Psychiatry*. 44(8), pp.729–35.

Reijneveld, S. A., Wiegersma, P. A., Ormel, J., Verhulst, F. C., Vollebergh, W. A. M. and Jansen, D. E. M. C. (2014) Adolescents' use of care for behavioural and emotional problems: types, trends, and determinants. *PloS One*. 9(4), e93526.

Reiss, F. (2013) Socioeconomic inequalities and mental health problems in children and adolescents: a systematic review. *Social Science & Medicine.* 90, pp. 24-31.

Richards, M. and Abbott, R. (2009) *Childhood mental health and adult life chances in post-war Britain: insights from three national birth cohort studies.* London: Centre for Mental Health.

Richardson, M., Moore, D. A., Gwernan-Jones, R., Thompson-Coon, J., Ukoumunne, O., Rogers, M., Whear, R., Newlove-Delgado, T. V., Logan, S., Morris, C., Taylor, E., Cooper, P., Stein, K., Garside, R. and Ford, T. J. (2015) Non-pharmacological interventions for attention-deficit/hyperactivity disorder (ADHD) delivered in school settings: systematic reviews of quantitative and qualitative research. Health Technology Assessment. 19(45), pp. 1-470.

Roberts, J., Crosland, A. and Fulton, J. (2014) Patterns of engagement between GPs and adolescents presenting with psychological difficulties: a qualitative study. *The British Journal of General Practice.* 64(622), pp.e246–54.

Roberts, J. H., Crosland, A. and Fulton, J. (2013) “I think this is maybe our Achilles heel...” exploring GPs’ responses to young people presenting with emotional distress in general practice: a qualitative study. *BMJ Open*. 3(9), p.e002927.

Rothenberger, A., Becker, A., Erhart, M., Wille, N. and Ravens-Sieberer, U. (2008) Psychometric properties of the parent strengths and difficulties questionnaire in the general population of German children and adolescents: results of the BELLA study. *European Child & Adolescent Psychiatr*y. 17 (Suppl 1), pp. 99-105.

Rothì, D. M., Leavey, G. and Best, R. (2008) On the front-line: Teachers as active observers of pupils’ mental health. *Teaching and Teacher Education*. 24(5), pp.1217-1231.

Russell, G., Miller, L., Ford, T. and Golding, J. (2014) Assessing recall in mothers’ retrospective reports: concerns over children’s speech and language development. *Journal Of Abnormal Child Psychology.* 42(5), pp. 825-830.

Rutter, M. (2013) Annual Research Review: Resilience-clinical implications. *Journal of Child Psychology And Psychiatry*. 54, pp. 474-87.

Rhodes, S. (2015) Stimulant medication for children with Attention Deficit Hyperactivity Disorder (ADHD). *Research the Headline*s [online], Available at: http://researchtheheadlines.org/2015/12/01/stimulant-medication-for-children-with-attention-deficit-hyperactivity-disorder-adhd/ [Accessed 9 January 2016].

Schoenfeld, D. (1982) Residuals for the proportional hazards regression model. *Biometrika* 69(1), pp. 239-241.

Schoenfelder, E. N., Faraone, S. V. and Kollins, S. H. (2014) Stimulant treatment of adhd and cigarette smoking: a meta-analysis. *Pediatrics*. 133(6),pp.  1070-1080.

Semeijn, E. J., Comijs, H. C., de Vet, H. C., Kooij, J. J., Michielsen, M., Beekman, A. T. and Deeg, D. J. (2015) Lifetime stability of ADHD symptoms in older adults. *Attention deficit and hyperactivity disorders*. 8(1), pp.13-20.

Shaw, M., Hodgkins, P., Caci, H., Young, S., Kahle, J., Woods, A. G. and Arnold, L. E. (2012) A systematic review and analysis of long-term outcomes in attention deficit hyperactivity disorder: effects of treatment and non-treatment. *BMC Medicine*, 10(1), p.99.

Simon, V., Czobor, P., Balint, S., Meszaros, A. and Bitter, I.  (2009) Prevalence and correlates of adult attention-deficit hyperactivity disorder: meta-analysis. *The British Journal of Psychiatry.* 194(3), pp.204–11.

Simpson, G. A., Cohen, R. A., Bloom, B. and Blumberg, S. J. (2009) The impact of children’s emotional and behavioural difficulties on their lives and their use of mental health services. *Paediatric and Perinatal Epidemiology*. 23(5), pp.472–81.

Singh, I. and Wessely, S. (2015) Childhood: a suitable case for treatment? *The Lancet Psychiatry*. 2(7), pp. 661-666.

Singh, S. P., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S., Hovish, K., Islam, Z., Belling, R. and White, S. (2010a) Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study.*The British Journal of Psychiatry.* 197(4), pp. 305-12.

Singh, I., Kendall, T., Taylor, C., Mears, A., Hollis, C., Batty, M. and Keenan, S. (2010b) Young people’s experience of ADHD and stimulant medication: a qualitative study for the NICE guideline. *Child and Adolescent Mental Health*. 15(4), pp.186–192.

Snell, T., Knapp, M., Healey, A., Guglani, S., Evans-Lacko, S., Fernandez, J.-L., Meltzer, H. and Ford, T. (2013) Economic impact of childhood psychiatric disorder on public sector services in Britain: estimates from national survey data. *Journal Of Child Psychology And Psychiatry.* 54(9), pp.977–85

Sobanski, E. (2006) Psychiatric comorbidity in adults with attention-deficit/hyperactivity disorder (ADHD). *European archives of psychiatry and clinical neuroscience*. 256 (Suppl) pp.i26–31.

Staller, J. and Faraone, S. V. (2006) Attention-deficit hyperactivity disorder in girls: epidemiology and management. *CNS Drugs.* 20(2), pp. 107-23.

StataCorp (2015) *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP.

Steinhausen, H.-C. (2014) Recent international trends in psychotropic medication prescriptions for children and adolescents. *European Child & Adolescent Psychiatry.* 24(6), pp. 635-640.

Stone, L. L., Otten, R., Engels, R. C. M. E., Vermulst, A. A. and Janssens, J. M. A. M. (2010) Psychometric Properties of the Parent and Teacher Versions of the Strengths and Difficulties Questionnaire for 4- to 12-Year-Olds: A Review. *Clinical Child and Family Psychology Review*, 13(3), pp.254–274.

Storebo, O. J., Krogh, H. B., Ramstad, E., Moreira-Maia, C. R., Holmskov, M., Skoog, M., Nilausen, T. D., Magnusson, F. L., Zwi, M., Gillies, D., Rosendal, S., Groth, C., Rasmussen, K. B., Gauci, D., Kirubakaran, R., Forsbol, B., Simonsen, E. and Gluud, C. (2015) Methylphenidate for attention-deficit/hyperactivity disorder in children and adolescents: Cochrane systematic review with meta-analyses and trial sequential analyses of randomised clinical trials. *BMJ*. 2015, 351, h5203.

Strauss, A. L. and Corbin, J. M. (1990) *Basics of qualitative research: grounded theory procedures and techniques.* Newbury Park, California: Sage Publications.

Street, C. and Mainey, A. (2015) *The MindEd e-Portal for children and young people's emotional health and well-being: Final evaluation report.* London: National Children's Bureau

Stringaris, A. and Goodman, R. (2013) The value of measuring impact alongside symptoms in children and adolescents: a longitudinal assessment in a community sample. *Journal Of Abnormal Child Psychology*. 41(7), pp.1109–20.

Swift, K. D., Hall, C. L., Marimuttu, V., Redstone, L., Sayal, K. and Hollis, C. (2013) Transition to adult mental health services for young people with attention deficit/hyperactivity disorder (ADHD): a qualitative analysis of their experiences. *BMC Psychiatry*, 13, p.74.

Taggart, H., Lee. S., McDonald, L. (2014) *Perceptions of wellbeing and mental health in English secondary schools: a cross sectional study.* London: Centre Forum.

Taylor, N., Fauset, A. and Harpin, V. (2010) Young adults with ADHD: an analysis of their service needs on transfer to adult services. *Archives Of Disease In Childhood*. 95(7), pp. 513-7.

Telford, C., Green, C., Logan, S., Langley, K., Thapar, A. and Ford, T. (2013) Estimating the costs of ongoing care for adolescents with attention-deficit hyperactivity disorder. *Social Psychiatry And Psychiatric Epidemiology*. 48(2),pp. 337-44.

Thapar, A., Cooper, M., Jefferies, R. and Stergiakouli E. 2012. What causes attention deficit hyperactivity disorder? A*rchives Of Disease In Childhood*,.97(3), pp.260–5.

The King's Fund (2016) *The NHS in a nutshell* [online]. Available at: http://www.kingsfund.org.uk/projects/nhs-in-a-nutshell/hospital-activity [Accessed 12 January 2016].

Thomas, R., Mitchell, G. K. and Batstra, L. (2013) Attention-deficit/hyperactivity disorder: are we helping or harming? *BMJ (Clinical research ed.)*. 347, p.f6172.

Trask, E. V. and Garland, A. F. (2012) Are children improving? Results from outcome measurement in a large mental health system. *Administration And Policy In Mental Health*. 39(3), pp. 210-20.

Travell, C. and Visser, J. (2006) ‘ADHD does bad stuff to you’: young people's and parents' experiences and perceptions of Attention Deficit Hyperactivity Disorder (ADHD). *Emotional and Behavioural Difficultie*s. 11(3), pp. 205-216.

Tripp, G., Luk, S. L., Schaughency, E. A. and Singh, R. (1999) DSM-IV and ICD-10: a comparison of the correlates of ADHD and hyperkinetic disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*. 38(2),pp.  156-64.

Tudor Hart, J. (1971) The Inverse Care Law. *The Lancet*,.297(7696), pp.405-412.

Uchida, M., Spencer, T. J., Faraone, S. V. and Biederman, J. (2015) Adult outcome of ADHD: an overview of results from the MGH Longitudinal Family Studies of pediatrically and psychiatrically referred youth with and without ADHD of both sexes. *Journal of Attention Disorders*. doi:10.1177/1087054715604360.

Van Oort, F. V. A., Greaves-Lord, K., Verhulst, F. C., Ormel, J. and Huizink, A. C. (2009) The developmental course of anxiety symptoms during adolescence: the TRAILS study. *Journal of Child Psychology and Psychiatry*. 50(10), pp. 1209-1217.

Visser, J. H., van der Ende, J., Koot, H. M. and Verhulst, F. C. (2003) Predicting change in psychopathology in youth referred to mental health services in childhood or adolescence. *Journal Of Child Psychology and Psychiatry*. 44(4),pp.  509-19.

Vostanis, P., Humphrey, N., Fitzgerald, N., Deighton, J. and Wolpert, M. (2013) How do schools promote emotional well-being among their pupils? Findings from a national scoping survey of mental health provision in English schools. *Child and Adolescent Mental Health.* 18(3),pp. 151-157.

Wang, L. J., Lee, S. Y., Yuan, S. S., Yang, C. J., Yang, K. C., Lee, T. L. and Shyu, Y. C. (2015) Impact of negative media publicity on attention-deficit/hyperactivity disorder medication in Taiwan. *Pharmacoepidemiology and Drug Safety*. 25(1), pp.45–53.

Warren, J. S., Nelson, P. L., Mondragon, S. A., Baldwin, S. A. and Burlingame, G. M. (2010) Youth psychotherapy change trajectories and outcomes in usual care: Community mental health versus managed care settings. *Journal Of Consulting And Clinical Psychology*. 78(2), pp. 144-55.

Weisz, J. R., Kuppens, S., Eckshtain, D., Ugueto, A. M., Hawley, K. M. and Jensen-Doss, A. (2013) Performance of evidence-based youth psychotherapies compared with usual clinical care: a multilevel meta-analysis. *JAMA Psychiatry*. 70(7), pp. 750-61.

West, D. (2012) *CCG Barometer: 'Weak support' a major concern for clinical commissioners* [online], Available at : http://www.hsj.co.uk/ccg-barometer-weak-support-a-major-concern-for-clinical-commissioners/5051514.fullarticle [Accessed 10 January 2016].

Wilkerson, J. M., Iantaffi, A., Grey, J. A., Bockting, W. O., &  Rosser,S. B. R. (2014) Recommendations for internet-based qualitative health research with hard-to-reach populations. *Qualitative Health Research*. 24(4),pp.  561–574.

Wolfle, S., Jost, D., Oades, R., Schlack, R., Holling, H. and Hebebrand, J. (2014) Somatic and mental health service use of children and adolescents in Germany (KiGGS-study). *European Child and Adolescent Psychiatry.* 23(9), pp. 753-64.

Wolpert, M., Deighton, J., De Francesco, D., Martin, P., Fonagy, P. and Ford, T. (2014) From “reckless” to “mindful” in the use of outcome data to inform service-level performance management: perspectives from child mental health. *BMJ quality & safety*, 23(4), pp.272–6.

Wolpert, M., Humphrey, N., Belsky, J. and Deighton, J. (2013) Embedding mental health support in schools: learning from the Targeted Mental Health in Schools (TaMHS) national evaluation. *Emotional and Behavioural Difficultie*s. 18(3),pp. 270-283.

Wong, I. C. K., Asherson, P., Bilbow, A., Clifford, S., Coghill, D., DeSoysa, R., Hollis, C., McCarthy, S., Murray, M., Planner, C., Potts, L., Sayal, K. and Taylor, E. (2009) Cessation of attention deficit hyperactivity disorder drugs in the young (CADDY)--a pharmacoepidemiological and qualitative study. *Health Technology Assessment*. 13(50), pp. iii-iv, ix-xi, 1-120.

World Health Organisation (2016) *Health Systems Strengthening Glossary* [online]. Available at: http://www.who.int/healthsystems/hss_glossary/en/index5.html [Accessed 21 December 2015]

World Health Organisation (1992) *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10*). Geneva: World Health Organisation.

Wright, J., Williams, R. and Wilkinson, J. R. (1998) Development and importance of health needs assessment. *BMJ.* 316(7140), pp. 1310-1313.

Young Minds (2015) *Widespread cuts in last year from children and young people’s mental health services* [online]. Available at: http://www.youngminds.org.uk/news/blog/2942_widespread_cuts_in_children_and_young_people_s_mental_health_services [Accessed 12 January 2016].

Young, R., Riordan, V. and Stark, C. (2011) Perinatal and psychosocial circumstances associated with risk of attempted suicide, non-suicidal self-injury and psychiatric service use. A longitudinal study of young people. *BMC Public Health*. 11, pp. 875-875.

Young, S., Murphy, C. M. and Coghill, D. (2011) Avoiding the “twilight zone”: recommendations for the transition of services from adolescence to adulthood for young people with ADHD. *BMC Psychiatry*. 11(1), p.174.

Youth in Mind (2016) *SDQ: Normative School-Age SDQ Data from Britain* [online] .Available at: http://www.sdqinfo.com/norms/UKSchoolNorm.html [Accessed 12 January 2016].

Zachrisson, H. D., Rödje, K. and Mykletun, A. (2006) Utilization of health services in relation to mental health problems in adolescents: a population based survey. *BMC Public Health*. 6, pp. 34-34.

Zetterqvist, J., Asherson, P., Halldner, L., Långström, N. and Larsson, H. (2013) Stimulant and non-stimulant attention deficit/hyperactivity disorder drug use: total population study of trends and discontinuation patterns 2006-2009. *Acta Psychiatrica Scandinavica* 128(1), pp. 70-7.

Zwaanswijk, M., Van der Ende, J., Verhaak, P. F. M., Bensing, J. M. and Verhulst, F. C. (2003) Factors associated with adolescent mental health service need and utilization. *Journal of the American Academy of Child and Adolescent Psychiatry*. 42(6). pp.692–700.

Zwaanswijk, M., Verhaak, P. F. M., van der Ende, J., Bensing, J. M. and Verhulst, F. C. (2006) Change in children’s emotional and behavioural problems over a one-year period: Associations with parental problem recognition and service use. *European Child & Adolescent Psychiatry*.15(3), pp.127–31.