

## **Portfolio 1: Major Research Project**

**Clinician experiences of the pathways to adult ADHD diagnosis**

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## Abstract

Adult ADHD care in the UK remains fragmented, inconsistent and often under-resourced, despite rising demand and increasing public awareness (Asherson et al., 2022; Smith et al., 2023). While national guidance outlines a clear framework for healthcare provision (NICE, 2018), implementation across services and regions remains highly variable. A qualitative Systematic Literature Review (Chapter 2) explores healthcare professionals (HCPs) perspectives on barriers to accessing care for adults with ADHD or Autism Spectrum Disorder (ASD) in the UK. The results emphasise widespread concerns about under-diagnosis, limited training, diagnostic overshadowing and inadequate support post-diagnosis. Using qualitative methodology, the empirical study presented (Chapters 1; 3-5) begins to address the identified gap in research on HCP perspectives specific to adult ADHD pathways.

Twelve UK-based HCPs specialising in ADHD were interviewed and analysed using Reflexive Thematic Analysis (Braun & Clarke, 2019) within a critical realist framework (Bhaskar, 1979; Fryer, 2022). Five main themes were identified: (1) A strained system, (2) Referral, primary care and General Practitioner (GP) barriers, (3) Diagnostic mismatch, (4) A pariah diagnosis? (5) Solutions and facilitators. Participants described systemic issues, including lack of training, gatekeeping, fragmented commissioning, and the neurotypical design of assessment tools. Post-diagnostic care was widely described as absent or tokenistic, with many professionals questioning the ethics of delivering a diagnosis with no follow-up support. The final theme highlighted examples of good practice and offered reflections on how adult ADHD care might be improved through greater integration, flexibility, and investment in existing models of care. The study contributes new insight into how adult ADHD care is experienced by practicing professionals, and how clinical and structural change might be enabled through more a national ADHD strategy, and relational, joined up, and inclusive approaches to care.

**Keywords:** Adult ADHD, healthcare professionals, qualitative research, diagnostic pathways, systematic literature review, Reflexive Thematic Analysis, critical realism, GP barriers,

diagnostic overshadowing, post-diagnostic care, service provision, UK healthcare system, neurodiversity, integrated care, ADHD policy.

## Chapter 1: Introduction

### 1.1 Chapter Overview

This Chapter introduces the research area, starting with why the project matters, followed by an outline of the researcher's perspective, both personally and theoretically. The research is then situated in context, covering history, current policy, service provision, and theoretical foundations. The Chapter ends with the rationale for the Systematic Literature Review (SLR) in Chapter 2.

### 1.2 Why This Research Matters

Adult Attention Deficit Hyperactivity Disorder (ADHD) care in the UK remains inconsistent and under-resourced, despite clear national guidance and growing public awareness (NICE, 2018; Smith et al., 2023). Recent analyses highlight major regional disparities in service provision, affecting timely diagnosis and treatment (Price et al., 2020). Since the COVID-19 pandemic, referrals for adult ADHD assessments have risen sharply, placing further strain on already stretched services (Asherson et al., 2022). This surge has worsened long-standing issues, including extended waiting times and limited access to specialist care (Price et al., 2019). These pressures raise critical questions about how services are designed, delivered, and experienced by both service-users and professionals.

### 1.3 Theoretical and Personal Positioning

#### 1.3.1 Personal Positionality and reflexivity

**A personal perspective.** This project stems from both personal experience and clinical interest. I come to it as a past and present user of services, son, partner, and advocate, as well as a healthcare professional (HCP). I often reflect on my younger self navigating mental health services during a difficult time, feeling vulnerable and unsupported. That experience shaped my hopes for a clinician who would listen, advocate, and not give up, which is the type of clinician that I strive to be. It felt important to focus my thesis on a group still excluded from services, and to centre voices of HCPs whose insights are often missing from the literature, despite being the very people with the power to push for change.

**An outside researcher.** Being an ‘insider researcher’ involves a shared identity or lived experience with the population being studied (Ross, 2017). By that definition, I am not an insider and cannot speak from lived experience. However, I feel I hold an adjacent position. I work as a HCP in the NHS, which is also the setting under study. I have spent nearly a decade navigating National Health Service (NHS) systems professionally, and for my whole life as a patient. I have experienced what it can mean to receive a mental health diagnosis and also to live and manage a long-term health condition, which has shaped how I personally engage with healthcare systems. While I do not share the same clinical roles as many of my participants, I am part of the broader professional community, and these experiences influence how I understand the systems and challenges under discussion.

These influences cannot be separated from the research, nor are they intended to. I chose Reflexive Thematic Analysis (RTA) because it supports reflexivity and recognises the researcher’s active role in meaning-making (Braun & Clarke, 2006). I aim to stay alert to my own biases and assumptions throughout, using strategies like reflective journaling (Byrne, 2022) to support this process and maintain analytical integrity.

### ***1.3.2 Theoretical Perspective, Ontology and Epistemology***

This research adopts a critical realist stance (Bhaskar, 1979; Fryer, 2022), which assumes there is reality independent of human perception, but that our understanding of it is shaped by context, interpretation, and social position (Cruickshank, 2012). This framework informed the design, data collection and analysis stages of the project, and is explored further in Chapter 3. Appendix A outlines key extracts from my own reflective journalling in which theoretical perspectives are reflected on.

### **1.4 Defining Language and Key Terms**

The language used to describe ADHD shapes how it is understood. Terminology continues to evolve, with individuals choosing different terms for themselves and others. This research adopts language identified by Experts by Experience (EBEs) as respectful and inclusive. Words carry power such that inclusive language can foster dignity, while harmful terms can reinforce stigma (Walter, 2018). Appendix B outlines key terms used in this thesis to ensure clarity, reduce ambiguity, and reflect EBE preferences.

## 1.5 Situating the Research in Context

### 1.5.1 A brief history of ADHD

Table 1 outlines key milestones in how ADHD has been understood from the 1950s to the present. It shows a shift from early focus on childhood hyperactivity to broader recognition of attention, impulsivity, and adult presentations. These changes have shaped diagnostic practices and recognition patterns. The table also reflects ADHD's Western framing, with limited recognition in non-Western contexts due to cultural norms, mental health infrastructure, and stigma. Rather than covering every development in depth, the table is intended to give a clear snapshot of how thinking around ADHD has evolved over time and set the scene for understanding current challenges in assessment and care. From its early medicalisation in post-war North America, ADHD has become a globally recognised, though still contested, diagnosis, shaped by changing clinical, cultural, and political influences (Smith, 2017; Timimi & Taylor, 2004).

**Table 1**

*History of conceptualising ADHD: 1952-present*

Year	Milestone	Implication
Late 1700s – 1844	Weikard, Crichton and Hoffman describe early ADHD-like traits.	First recorded accounts of ADHD in Western literature, though framed morally rather than medically.
1902	Still identifies 'incapacity for sustained attention'.	Marks the start of formal medical recognition of attention difficulties.
1920s	Goldstein links symptoms to brain injuries in soldiers.	Introduces neurological explanations for ADHD-like traits.
1930s	Kramer and Pollnow describe 'hyperkinetic disease of infancy'.	Early conceptualisation of hyperactivity in children.

	Amphetamines introduced as treatment.	First pharmacological intervention for attention-related conditions.
1940s	Methylphenidate	Key ADHD medication enters clinical use.
1952	DSM-I published	ADHD excluded
1968	DSM-II introduced as ' <i>Hyperkinetic Reaction of Childhood</i> '	First formal mention of ADHD characteristics focusing on hyperactivity
1970s	Research by Pontius (1973)	Helped shift understanding toward attention and impulse control, not just hyperactivity
	Borland & Heckman (1976) highlight adult ADHD	This work began to challenge the view that ADHD was a presentation of childhood
1980s	DSM-III introduced <i>Attention Deficit Disorder (ADD)</i> , with or without hyperactivity; research by Douglas (1984) supported focus on attention and impulse control	Marked shift in terminology; focus expanded beyond hyperactivity
1994	DSM-IV formalized ADHD and introduced subtypes	Inattentive, hyperactive-impulsive, and combined types recognised (Lahey et al., 1994)
2000	NICE recognised ADHD in childhood	Marked the start of UK policy alignment with diagnostic frameworks

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2008	NICE formally acknowledged adult ADHD in the UK (NICE, 2008; Taylor et al., 2009)	Key policy step toward developing services for adults
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### ***1.5.2 Historical Theoretical Models of ADHD***

Theoretical models of ADHD have traditionally been developed by biomedically-informed theories, such as Executive Dysfunction Theory and the Dual Pathway Model (Barkley, 1997; Sonuga-Barke et al., 1994). Although now largely considered outdated, they were important in shaping early ideas about ADHD. A short summary below shows how thinking developed:

Executive Dysfunction Theory suggests ADHD comes from executive dysfunction, including response inhibition, working memory, or general control (Barkley, 1997; Castellanos & Tannock, 2002; Pennington & Ozonoff, 1996). Pennington & Ozonoff's review found ADHD was linked to weaknesses in some areas, but the studies were small. Later research showed people with ADHD often did worse on executive tasks, but not all areas were equally affected (Willcutt et al., 2005). Some studies didn't find much difference, especially around spatial memory and inhibition, which might depend more on how hard the task is (Brocki et al., 2008).

The Dual Pathway Model adds to this by suggesting ADHD is linked to both executive difficulties and 'delay aversion', whereby people struggle to tolerate impulses and are motivated by instant rewards (Sonuga-Barke, 1994; Willcutt et al., 2005). However, this is criticised for being an overly complex theory and hard to falsify, and has a limited evidence base (Johnson et al., 2009).

More recent biomedical views focus on dopamine differences in the brain and tend to view medication as the main treatment (Faraone & Bonvicini, 2024). While this has helped push research and diagnosis forward, it often ignores an individual's wider needs, such as their mental health and context-based distress (Watson et al., 2014).

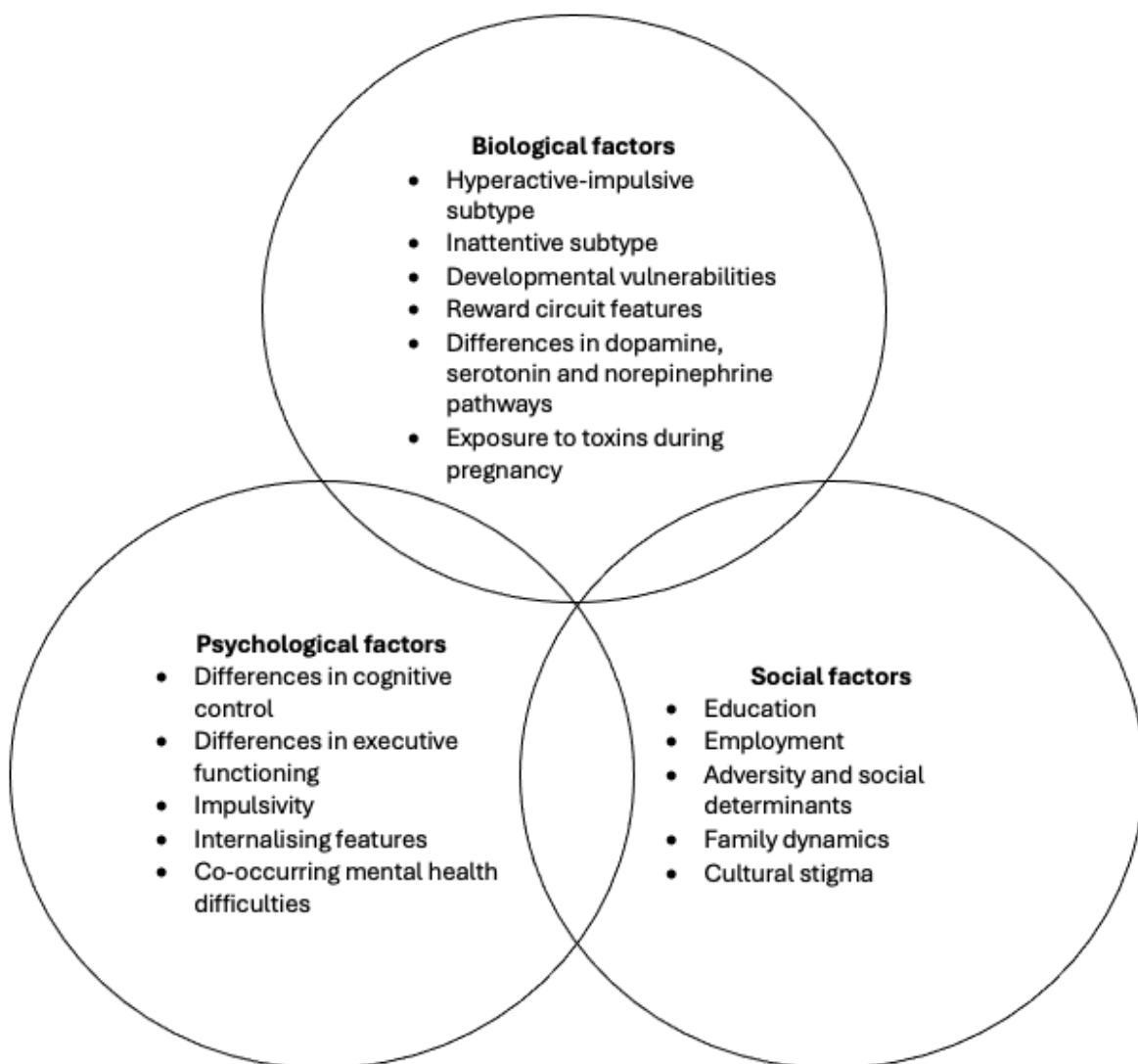
### ***1.5.3 Contemporary theoretical models of ADHD***

The biopsychosocial model, originally developed by Engel (1977), offers a more integrative framework that moves beyond reductive biomedical accounts by considering

interactions between biological, psychological, and social factors. This approach challenges binary debates such as 'nature versus nurture' and 'individual versus context' in understanding ADHD (Cao et al., 2025). Recent research has drawn on this model to conceptualise ADHD in more systemic terms, as illustrated in Figure 1 (Cao et al., 2025; Richards, 2013; Salamanca, 2014).

**Figure 1**

*The biopsychosocial model of ADHD*



This model considers specifically considers the complex interaction between the psychological, biological and contextual factors of the environment an individual inhabits, and has also been applied to all persons across ages, cultures and gender (Card, 2023). More

recent uses of this model have extended it further and added a ‘cultural’ part to it too, thus becoming the biopsychosocial-cultural model (Pham, 2015).

Biological factors refer to genetic influence, apparent differences in brain structure and function, and neurochemical imbalances that can affect attention, impulse control, and emotional regulation (Cortese et al., 2021; Faraone et al., 2015). To date, no biomarkers for ADHD have been found, undermining biological explanations of ADHD (Abi-Dargham et al., 2024; Ryan et al., 2023).

Psychological factors refer to individual cognitive profiles, such as executive functioning, coping styles, emotional regulation, and internalised experiences like low self-esteem (Knouse et al., 2013; Ramsay & Rostain, 2006). Social factors refer to environmental influences such as family dynamics, work demands, access to and knowledge about services and societal stigma (Bussing et al., 2012; Mueller et al., 2012). Cultural differences include variations in how ADHD is conceptualised, recognised, and responded to across communities, influencing both help-seeking and diagnosis.

To date, there has been an overt focus on biological factors, meaning psychosocial factors have been less regarded. This explains why the predominant focus of existing research is on a medical explanation of neurobiological differences in the brain, which ignores influences of an individual’s personality, sense of self, family history and functioning, and context (such as socioeconomic status).

#### **1.5.4 Policy and Strategy**

This section outlines the key frameworks shaping the recognition and support available for adults with ADHD in the UK. These policies guide clinical practice, legal protections, education, employment, and healthcare access.

The National Institute for Health and Care Excellence (2018) guidelines recommend training across child and adult services, including primary care, mental health, and forensic settings. Medication is advised as a first line intervention when characteristics impact daily life. Psychological interventions like Cognitive Behavioural Therapy (CBT) should be available for those who prefer them, or who continue to struggle despite medication. Specialist ADHD teams are expected to support diagnosis, treatment, and transitions into adult care, while shared care agreements allow GPs to manage prescriptions once stable.

Table 2 summarises key UK policies and strategies relevant to ADHD. While some offer legal protections or targeted support, most focus on children and young people. Adult ADHD is often overlooked, particularly in wider mental health and social care frameworks, highlighting a disconnect between policy and lived experience.

**Table 2**

*UK policies and strategies relevant to ADHD*

<b>Policy / Strategy</b>	<b>Focus Area</b>	<b>Relevance to ADHD</b>
Equality Act (2010)	Employment and education	Recognises ADHD as a disability if difficulties are substantial and long term.  Allows for reasonable adjustments such as flexible hours or assistive technology.
Care Act (2014)	Social care	Provides needs assessments and support with independent living for adults experiencing daily difficulties due to ADHD.
SEND Code of Practice (2015)	Education and training	Covers adjustments in education for individuals with ADHD up to age 25.  Includes access to Disabled Students Allowance (DSA) and extended Education, Health, and Care (EHC) plans in higher education.
	Employment	Offers tailored employment support for

Work and Health Programme (2017-2018)	people with disabilities, including those with ADHD, to help them find and keep work.
NHS Long Term Plan (2019)   Healthcare	Promotes early ADHD identification and intervention in children and young people.  However, lacks attention to adult ADHD, especially in service planning.
Community Mental Health   Adult mental health Framework (2019)	Broader strategy that fails to specifically address adult ADHD, reflecting a wider systemic gap.

While these frameworks exist, they rarely reflect the perspectives of healthcare professionals who act as gatekeepers to care. Policy decisions often appear targeted towards improving access or investing in staffing and training, however, long wait times and under-resourced services suggest neither has been prioritised at the commissioning level.

### **1.5.5 Service Provision**

Typically, the first route to gaining an ADHD diagnosis in the UK is through primary care by General Practitioners (GPs). While referral eligibility can vary across different service providers, GPs act as gatekeepers in that, following screening<sup>1</sup>, they should refer an individual on to secondary care services - Paediatric or Child and Adolescent Mental Health Services (CAMHS) for children, or Adult Mental Health Services (AMHS) - where individuals should be able to access an assessment, diagnosis and access to treatment if needed (French et al., 2020). GPs are also often responsible for handling prescriptions of medication once treatment is initiated via a shared care agreement (Wilkinson, 2024).

<sup>1</sup> Adult ADHD Self-Report Scale, version 1.1 (Kessler et al., 2005)

Despite the recommended policy, strategy and service provision outlined, adult ADHD service provision in the UK is in crisis (Smith et al., 2024). A recent UK-wide mapping survey indicated that provision remains inconsistent, with patchy coverage of services, and some areas lacking specialist provision entirely (Price et al., 2019; Price et al., 2020).

For example, the CATCh-uS mapping study found widespread gaps in service provision, with only 12 out of 294 services meeting NICE guidelines and significant regional differences found across referrals, treatment access, and prescribing practices (Price et al., 2019; Price et al., 2020). Where there is a lack of provision, individuals should be able to access services elsewhere under the NHS Constitution (Department of Health & Social Care [DHCS], 2015), but this is often not the case in practice (Price et al., 2019).

Limited service provision is further reflected in national data. An NHS survey on health and wellbeing described adult ADHD services as either uncommon or significantly under-resourced (Russell, 2024). This is further reiterated by an audit published on Freedom of Information requests, which revealed stark differences in waiting times for adult ADHD assessments, with assessment waits of up to 3.8 years (Takeda, 2021). These waiting times have also been widely reported in the national media. Prolonged waits for assessment contribute to increased distress and reduce the ability to function day-to-day, which further increases risk of presentations to crisis and emergency mental health services, placing further strain on the healthcare system (Rethink Mental Illness, 2024).

### **1.5.6 Barriers to care**

Another major challenge is misdiagnosis and inconsistent clinical recognition of adult ADHD. Many HCPs receive limited formal ADHD training, leading to frequent misdiagnoses including anxiety, depression, or so-called ‘personality disorders’ (Blanco & Surman, 2024). Some help-seeking individuals are dismissed entirely, reinforcing the misconception that ADHD is primarily a presentation of childhood (Asherson et al., 2022). The diagnostic overlap between ADHD and autism further complicates assessments, with some individuals misdiagnosed with the wrong label (Rommelse et al., 2011). These challenges result in delayed interventions, leaving individuals without appropriate support and increasing their risk of adverse outcomes such as unemployment, relationship difficulties, and poorer mental health (du Randt, 2024). Additionally, the co-occurrence of other neurodiverse

differences such as dyslexia and dyspraxia leads to some people identifying more with the label of 'neurodiversity'<sup>2</sup> rather than a particular label (Dwyer et al., 2025).

As well as limited access to services, there may also be a lack of clinicians that recognise and support neurodivergent ways of experiencing the world, since most view these characteristics through a purely medical, deficit-based lens, of 'symptoms' that need 'treating' (Fletcher-Watson & Happé, 2019; Kapp, 2020).

### **1.5.7 Prevalence rates**

Prevalence estimates for ADHD vary, but global figures suggest that around 5% of children and 2–4% of adults are affected (Polanczyk et al., 2007; Song et al., 2021). While it was long assumed that ADHD was primarily a childhood condition, research now shows that many people experience persistent difficulties into adulthood. Gender and cultural biases in diagnostic practices contribute to under-recognition, particularly among women and individuals from global majority groups. Many adults report being misdiagnosed with anxiety or depression, particularly females who have often presented with anxiety or depression before being diagnosed (Morgan, 2024 ), delaying appropriate care.

### **1.5.8 Characteristics of ADHD**

According to the Diagnostic Statistical Manual (5<sup>th</sup> ed.; DSM-5), ADHD is characterised by persistent inattention and/or hyperactivity-impulsivity that interferes with daily functioning or development. It is divided into three presentations: predominantly inattentive, predominantly hyperactive-impulsive, and combined type (American Psychological Association [APA], 2013).

The DSM-5 provides diagnostic criteria for both children and adults. For children aged 4 to 16, a diagnosis requires at least six characteristics of inattention and/or hyperactivity-impulsivity persisting for at least six months across multiple settings, significantly impairing daily life. For adults, five or more characteristics must be present for at least five months, with a significant impact on functioning. The DSM-5 also includes severity specifiers (mild, moderate, or severe) to indicate the level of impairment (APA, 2022).

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<sup>2</sup> A perspective recognising neurological differences like ADHD and autism as natural variations in cognitive profiles rather than deficits (Catala, 2023)

In adults, ADHD characteristics fall into two main domains: inattention and hyperactivity-impulsivity. Inattention often manifests as difficulty maintaining focus, organising tasks, managing time effectively, and remembering commitments (such as health appointments). Many adults with ADHD struggle with distractions, careless mistakes, and incomplete projects (Onandia-Hinchado, 2021). Hyperactivity and impulsivity may present as internal restlessness rather than overt physical movement in adulthood (Centers for Disease Control and Prevention [CDC], 2024). This can include difficulty remaining still, a constant need for activity, impulsive decision-making, excessive talking, or impatience in situations requiring waiting. A recent cohort study of 4000 young American adults showed a prevalence of ADHD in 3.55% of young adults. Of those meeting threshold for ADHD, 46.5% were inattentive subtype, 12.7% were hyperactive/impulsive subtype and 40.8% were combined subtype (Matte et al., 2014).

Both the DSM-5 and International Classification of Diseases (11<sup>th</sup> ed.; ICD-11) require ADHD characteristics to be persistent, present since childhood, and significantly impair functioning across multiple domains such as work, education, relationships, and emotional well-being (APA, 2022; WHO, 2019). While individuals may develop coping strategies over time, these often mask underlying difficulties. The ICD-11 situates ADHD within a broader neurodevelopmental framework, acknowledging overlap with other neurodevelopmental conditions. In contrast, the DSM-5 categorises ADHD according to three presentation subtypes. A further distinction is that the ICD-11 lists eleven core features both for inattention and hyperactivity/impulsivity, compared to nine in the DSM-5.

### **1.5.9 Demographic characteristics in ADHD**

Certain demographic characteristics believed to drive disparities in diagnosis of ADHD include age, gender and cultural difference (Shalaby et al., 2024).

**Age Differences.** In childhood, ADHD has an estimated prevalence of 5-7% (Polanczyk et al., 2007, Polanczyk et al., 2014). During adolescence, inattention characteristics and in particular hyperactivity-impulsivity characteristics become milder for a subset of children diagnosed with ADHD (Vos & Hartman, 2022). However, some evidence suggests the full clinical onset only presents in adolescence (Breda et al., 2020).

Prevalence estimates of adult ADHD are typically lower than in childhood, ranging between 3-5% (Polanczyk et al., 2007; Fayyad et al., 2007). However, adult ADHD has

historically received less research attention, with wide variation in definitions across studies and a lack of large population-based datasets encompassing the full adult lifespan (Dobrosavljevic et al., 2020; Franke et al., 2018; Balint et al., 2009). This variation may partly reflect diagnostic biases, such as women being more frequently misdiagnosed with anxiety or depression (du Randt, 2024). A recent systematic review and meta-analysis by Song et al. (2021) examined 40 datasets and distinguished between 'characteristic' and 'persistent' adult ADHD. Characteristic adult ADHD referred to adults who met full diagnostic criteria of ADHD at assessment, regardless of whether it was present in childhood, whereas persistent adult ADHD referred to adults who both meet current diagnostic criteria and had showed evidence of ADHD features in childhood. Prevalence estimates were 6.8% for characteristic ADHD and 2.6% for persistent adult ADHD, highlighting the impact of definitional criteria on reported rates.

**Gender differences.** ADHD has historically been considered a male dominant presentation due to a low number of identified cases of ADHD in females, perhaps due to the subtler, inattentive nature of female presentations and the frequent co-occurrence of internalising characteristics such as anxiety and mood related challenges (Young et al., 2020; du Randt, 2024). Despite this previously accepted view, in a recent meta-analysis, nearly half of the studies showed an equal ratio of prevalence in females. In the remaining meta-analysis studies, the ratios of male to female were comparable (Faheem et al., 2022). These results also shared similarity to another study on gender differences (Kessler et al., 2006).

However, the fact that females with ADHD are still more likely to be unrecognised or misdiagnosed may perpetuate the lower-than-expected rates of referral, assessment and treatment for ADHD (Young et al., 2020). While lower referral rates are often explained by the inattentive and the internalising way ADHD can present in women, they remain surprising given that the predominantly inattentive subtype has been formally recognised in the DSM-5 for many years. This suggests that outdated stereotypes and limited training continue to shape clinical recognition, with hyperactivity and impulsivity still seen as the default presentation (Antoniou et al., 2021).

**Cultural and ethnic differences.** The literature shows a clear pattern of underdiagnosis among global majority groups. In the US, African-American boys are more likely to be labelled as antisocial, even when their behaviours are similar to those of white peers (Gomez-Benito et al., 2019; Lewczuk et al., 2024). In Evans (2004) describes the

“mad/bad” paradox, where white children with ADHD traits are viewed as clinical cases, but Black children are more often seen as ‘bad’, which remains an issue today (Slobodin & Masalha, 2020). A common critique of the literature is its focus on white males, leaving women and global majority groups to fall through diagnostic gaps (Waite and Ivey, 2009). One study found that individuals from global majority backgrounds and older adults were less informed about ADHD (McLeod et al., 2007). If people do not recognise ADHD features in themselves or others, this can delay diagnosis and access to support, reinforcing existing inequalities (Martin, 2024).

### **1.5.10 Co-occurring challenges**

**Physical health.** Adults with ADHD experience co-occurring physical health conditions, including obesity, diabetes, and hypertension, which contribute to a reduced life expectancy. One large cohort study found that men with ADHD live an average of 6.78 years less, and women 8.64 years less, than peers without ADHD, largely due to higher rates of these health conditions (O’Nions et al., 2025).

Alongside these long-term health risks, adults with ADHD also face a greater likelihood of unintentional injuries and accidents across the lifespan (Brunkhorst-Kanaane et al., 2021). In childhood, this may include burns, falls, fractures or poisonings, while in adulthood, risks often relate to traffic collisions, workplace accidents, and sports injuries. These patterns appear to reflect a combination of core ADHD features such as impulsivity and inattention. As a result of falls and other injuries, ADHD is also linked with a higher incidence of traumatic brain injury (TBI), with one study finding that 6.6% of adults with a history of TBI screened positive for ADHD, and 5.9% reported a prior ADHD diagnosis, rates notably higher than in the general population (Kirsop, 2019).

**Mental health.** Studies indicate that between 65-89% of adults with ADHD experience at least one co-occurring mental health problem over their lifetime, including issues relating to mood, anxiety, substance use, problematic eating (Kessler 2004; Biederman et al. 1993; Kooij et al. 2010; Spencer et al. 2005) and so-called personality disorder (Manuzza et al. 1993; Vermeiren et al. 2000; Rösler et al. 2004). These patterns of co-occurrence are not limited to mental health problems; ADHD frequently overlaps with other neurodevelopmental differences, most notably autism.

**Autism.** ADHD and autism are both common neurodevelopmental differences, affecting around 6-14% of the population combined (Frances et al., 2022). While they can share certain features, such as sensory sensitivities or difficulties with attention, they are fundamentally different developmental presentations, each with distinct cognitive profiles and support needs.

Despite these differences, co-occurrence is common. Research suggests that 50 to 70% of adults with ADHD may also meet criteria for autism (Hours et al., 2022), and many autistic individuals show characteristics typically associated with ADHD, particularly around focus and impulsivity (Rommelse et al., 2011). However, this co-occurrence does not imply that ADHD and autism are variations of the same presentation. Rather, they can co-exist in complex and nuanced ways, with both shared and distinct features. For example, what might be described as an “attentional deficit” in an autistic person could in some cases reflect heightened attentional sensitivity, rather than a feature of co-occurring ADHD.

Some groups are at higher risk of underdiagnosis. For instance, people with intellectual disability (ID) may experience diagnostic overshadowing, where ADHD characteristics may be wrongly attributed to their ID (Perera et al., 2021). The medical model’s tendency to categorise differences in intellectual ability into separate, fixed boxes can also lead to underestimating how often ADHD and autism (often referred to together as AuDHD) occur in the same individual. This narrow view can delay recognition or lead to misdiagnosis. More recent research highlights the complexity of distinguishing and accurately identifying co-occurring presentation, underlining the need for more integrated and nuanced diagnostic approaches (Jaiswal et al., 2024).

People with intellectual disability (ID) also risk remaining underdiagnosed due to diagnostic overshadowing, whereby ADHD characteristics are misattributed to their ID (Perera et al., 2021)

However, the medical model’s tendency to categorise conditions into discrete boxes can lead to an underestimation of the frequency and complexity of co-occurring ADHD and autism (AuDHD). This narrow focus often overlooks the nuanced ways these conditions can intersect, resulting in misdiagnoses or delayed recognition. Recent research highlights the challenges in differentiating and accurately identifying co-occurring presentations, emphasising the need for more integrated diagnostic approaches (Jaiswal et al., 2024).

**The underrepresentation of Professional Perspectives.** Although research and policy have progressed, our understanding around adult ADHD still lags behind. The number of adults identifying with ADHD has risen sharply (NIHCR, 2023), yet services have not kept pace. NHS waiting lists often exceed three years, and even private routes involve delays in accessing medication or establishing shared care. For adults who were not considered for ADHD in childhood, navigating the system can be especially difficult (McQueenie et al., 2024). Similarly, autistic adults face lengthy waits, inconsistent access to assessments, and a lack of post-diagnostic support, reflecting systemic gaps that parallel those seen in ADHD services (Crane et al., 2018; Gellini & Marczak, 2024).

Despite growing pressure on services, little research has explored the views of healthcare professionals (HCPs), who are working within increasingly stretched systems (Blanco et al., 2024). Their voices remain largely absent from the literature, despite being well placed to highlight what is working, what is not, and what needs to change (Price et al., 2019). This gap forms the basis for the current SLR, for which the full rationale is outlined below.

### 1.6 Rationale for SLR

Despite NICE guidelines (NICE, 2018) and the NHS Long Term Plan (2019), services for adults with ADHD and autism remain fragmented and underfunded. Clinicians report feeling underprepared, and service users experience long waits and inconsistent care. Though much has been written about systemic problems, there is little research focusing directly on the experiences of healthcare professionals (HCPs) who work within these settings. Their perspectives are key to understanding how services function in practice.

The SLR was originally intended to focus solely on ADHD. However, as the review planning progressed, two issues became clear: first, there was insufficient published research on adult ADHD alone to support a full literature review; and second, autistic adults encounter many of the same systemic and pathway barriers to healthcare as adults with ADHD, including long waiting times, service gaps, and limited clinician training (Crane et al., 2018; Gellini & Marczak, 2024).

As a result, the scope of the review expanded to include autism alongside ADHD, while treating them as distinct neurodevelopmental differences with different cognitive profiles and support needs. This review, therefore, addresses a dual gap: the lack of

research capturing HCP perspectives on adult ADHD and on adult autism, to inform effective, contextually grounded healthcare for both populations.

## Chapter 2: Systematic Literature Review

### 2.1 Chapter Overview

This Chapter outlines the SLR, which explores HCP perspectives on barriers to accessing care<sup>3</sup> for adults with ADHD or ASD, and describes the methodology used, focusing on the development of the research question, the search strategy, and the search process, before presenting the results of a thematic synthesis (Thomas & Harden, 2008). The Chapter concludes with a brief discussion, including its clinical implications, and provides actionable recommendations for future practice. This systematic literature review aims to address the following research question:

*What are healthcare professionals (HCPs') perspectives on the diagnosis and treatment of adult ADHD and ASDS within the UK healthcare system?"*

### 2.2 Methodology: Development Stage

The Cochrane guidelines were followed throughout the SLR (Higgins & Green, 2011). A comprehensive literature search was performed in adherence to PRISMA<sup>4</sup> guidelines (Page et al., 2021). The review protocol<sup>5</sup> was registered with PROSPERO on 22/10/2024, *protocol number: CRD42024601298*. Registration minimises the risk of bias by establishing strict eligibility criteria and promotes transparency to support replication, thereby ensuring the reliability of reproduced findings (Open Science Collaboration, 2015).

#### 2.2.1 Defining the question

The SPIDER tool was used for question configuration. Cooke et al., (2012) developed the SPIDER search tool to help develop qualitative research questions that focus on searching for qualitative and mixed-method studies (see Table 3).

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<sup>3</sup> 'Care' refers to the full pathway of support, including assessment, diagnosis, treatment, and post-diagnostic services

<sup>4</sup> Preferred Reporting Items for Systematic Reviews and Meta-Analyses

<sup>5</sup> [https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=601298](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=601298)

**Table 3**

*SPIDER question configuration*

Acronym	Question configuration
<b>S:</b> Sample	HCPs such as doctors, psychiatrists, nurses, social workers, psychologists, counsellors, physicians, paediatricians
<b>P:</b> Phenomenon: Of Interest:	ADHD and ASD Adults, late diagnosis, delayed diagnosis
<b>D:</b> Design	Interview, Focus group, observations, surveys, qualitative questionnaires
<b>E:</b> Evaluation	Perspectives
<b>R:</b> Research Type	Qualitative studies, mixed-method studies

### **2.2.2 Scoping Exercises**

Google Scholar and Scopus were used to test the validity of the research question. Two filters were used: (1) to search only for UK-wide studies, due to the review's specific interest in UK healthcare systems, and (2) for studies that were published from 2013 onwards to ensure that perspectives reflected conceptual changes to ADHD and autism characteristics as outlined in the DSM-5 (APA, 2013).

The original research question only focused on HCP perspectives regarding adult ADHD. However, during the scoping exercise, the lack of sufficient UK-based studies on adult ADHD published since 2013 to comprise a systematic review became apparent. Consequently, adult autism was also included in the question, as this population face similar challenges in accessing care in the UK today (Malik-Soni et al., 2022; Young et al., 2021). PROSPERO was checked to confirm that there were no registered ongoing reviews investigating the same question.

## 2.3 Methodology: Search Strategy

Following PRISMA guidelines (Page et al., 2021), the search strategy was developed in consultation with the supervisory team and a psychology librarian at the University of Hertfordshire. Terms were selected based on preliminary scoping and key elements of the research question. The SPIDER framework was utilised (Cooke et al., 2012), incorporating MeSH terms and Boolean operators (see Appendices C, D and E).

The following six databases were searched: Scopus, Medline, CINAHL, Cochrane Library, PsycINFO, and Google Scholar<sup>6</sup>. Potential studies were identified via searches performed in October 2024. Search alerts were set up after conducting the initial database searches to track any new studies. Backward and forward snowballing searches were also conducted on relevant studies<sup>7</sup>. Any relevant studies identified after the completion of the search process were not considered for inclusion. Grey literature<sup>8</sup> was also included in this review. The Cochrane Handbook and the Institute of Medicine Standards recommend including grey literature in systematic reviews both as review items and as a tool for identifying relevant studies and publications (Higgins & Green, 2011). The following grey literature databases were searched: BASE, King's Fund Library and EThOS.

### 2.3.1 Eligibility Criteria

Searches were screened using inclusion/exclusion criteria, detailed with justification in Table 4.

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<sup>6</sup> The first 200 results were recorded.

<sup>7</sup> Forward snowballing involves checking which papers have cited a given study, while backward snowballing involves reviewing the references cited within that study

<sup>8</sup> Grey literature refers to research and information procured outside of academic publishing, such as reports, theses, policy documents, or conference papers, which are not controlled by commercial publishers.

**Table 4***Study characteristics: inclusion and exclusion Criteria*

	<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>	<b>Justification</b>
Study Characteristics	Language: English Design: Qualitative or mixed-methods studies with a qualitative component Full-text available	Language: Non-English Design: Quantitative-only studies Abstract only (e.g. conference, workshop, poster, keynote)	Only studies published in the English language are accessible to the researcher.
	Published in 2013 and later	Published prior to 2013	To reflect changes to ADHD and ASD criteria in the release of the DSM-5
	Peer reviewed studies and grey literature studies	Published prior to 2013 (2012 and earlier)	To ensure inclusion of high-quality, credible, and rigorously evaluated research
			Groups such as charities and local councils publish important research

Condition of Interest	ADHD, ASD	Studies about other neurodevelopmental differences such as dyslexia and dyscalculia	Services offering support for these disorders are over-subscribed and under-resourced
Participant	<p>HCPs of any discipline in any setting</p> <p>Studies involving other stakeholders (e.g. service users, carers, commissioners) were included if HCP perspectives could be separately identified</p>	<p>Studies where the main participants are not HCPs. For example, services that only include individuals with ADHD/ASD</p>	<p>No reviews exist to date specifically focusing on UK HCPs working with this client group</p>
Outcome of Interest	<p>HCPs knowledge of ADHD and ASD pathways</p> <p>HCPs experiences, such as diagnosing and treating, ADHD and ASD</p>	<p>Studies not reporting on HCPs knowledge or experiences with ADHD or ASD</p>	<p>To understand crucial barriers and facilitators of care for this client group</p>
Geographical location	UK based studies only. No restriction on geographical location within the UK.	Non-UK studies	<p>The review focused on UK-specific healthcare contexts, so non-UK studies were excluded.</p>

## 2.4 Methodology: Search process

Database searches were downloaded into Covidence<sup>9</sup>. In total, 16321 studies were downloaded. 8971 duplicates were removed, 7350 studies were left. Following backward and forward snowballing and grey database searching, 137 studies were downloaded, and 62 duplicates were removed, leaving 75 studies from this process. See Figure 2. In total, 7425 studies remained for screening via a two-phase screening process.

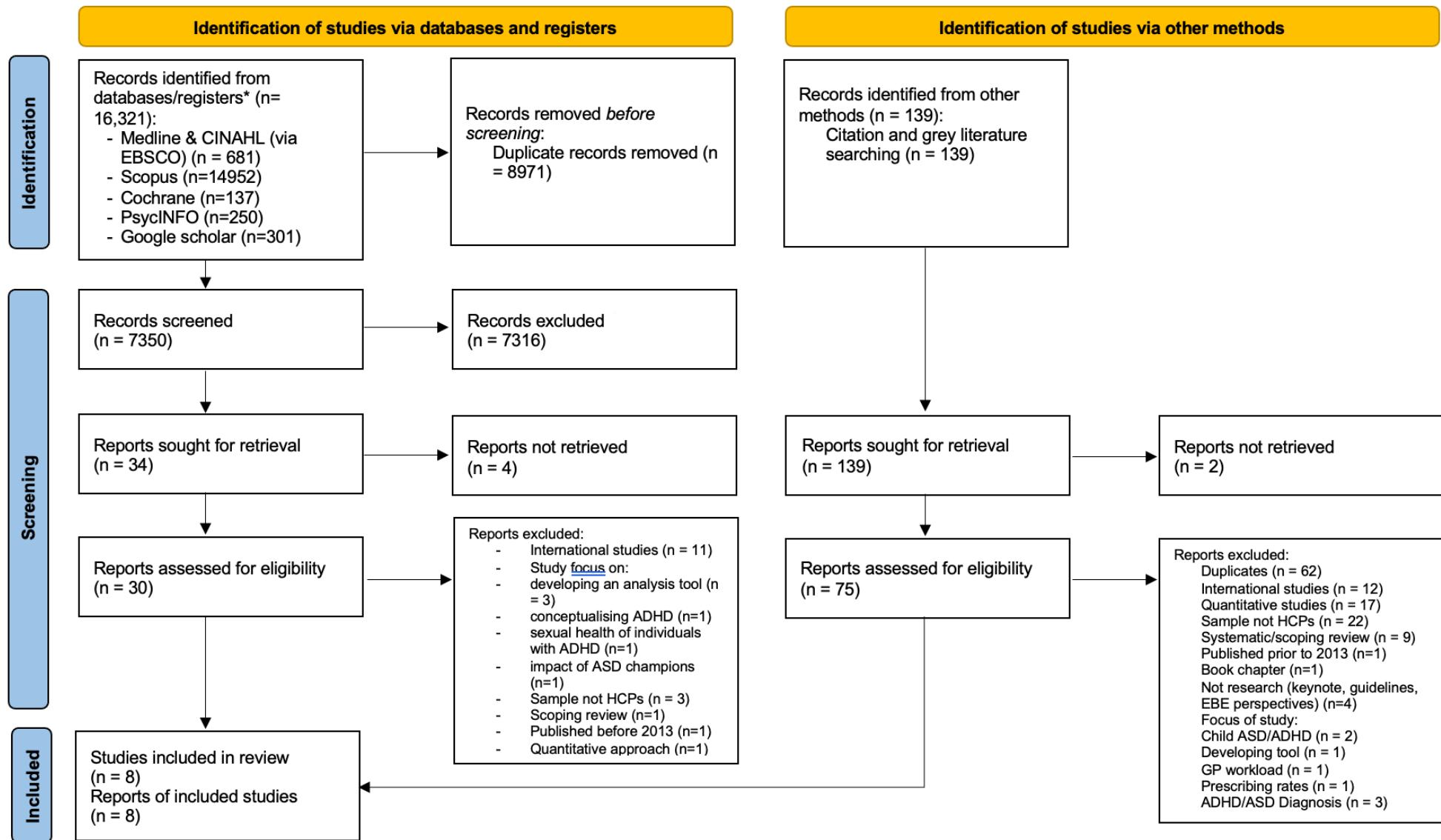
**Phase one.** In phase one, the title and abstract of all 7425 studies were independently screened against the inclusion/exclusion criteria by the primary researcher. Of the studies, 10% were independently reviewed by a colleague (now referred to as the 'secondary researcher'). The screening process revealed 5 conflicts, equating to 99.33% agreement between researchers, and a Cohen's Kappa<sup>10</sup> of 0.93 (almost perfect agreement). The conflicts related to a different interpretation of the inclusion criteria, but were able to be resolved following guidance from the main supervisor. 30 articles were initially progressed into phase two from the initial database search and 77 from the other search strategies.

**Phase Two.** From both search strategies, a total of 105 studies progressed to phase 2 for independent full-text screening against the eligibility criteria by the primary researcher. The secondary researcher then independently screened 50% of the full-text studies against the eligibility criteria to determine the reliability of the included studies. The screening process revealed 4 conflicts, equating to 92% agreement between researchers, and a Cohen's kappa of 0.84 (almost perfect agreement). Conflicts were discussed with rationales for decisions made. Any cases that could not be agreed upon were discussed with the primary researcher's principal supervisor. 97 studies were removed in this phase. Eight articles were included in the final stage of the SLR, which consisted of data extraction and quality appraisal. The reference lists of the final 8 articles were reviewed, and relevant articles were checked against Covidence; all were duplicates. Figure 2 presents the search process in a PRISMA diagram (Page et al., 2021).

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<sup>9</sup> Covidence is an online software platform designed to streamline the systematic review process, including study screening, data extraction, and quality assessment.

<sup>10</sup> A measure of inter-rater reliability.

**Figure 2***PRISMA flowchart showing study selection process*

## 2.5 Methodology: Quality assessment

Included published studies were critically appraised using the Critical Appraisal Tool Programme (CASP) tool for qualitative research to evaluate methodological rigour, data relevance and ethical considerations (CASP, 2023). The CASP tool is supported by the Cochrane Collaboration and the World Health Organisation (WHO) as an effective tool to critically appraise qualitative research (Hannes & Bennett, 2017; Hannes & Macaitis, 2012). The tool consists of 10 questions, each answered as 'Yes,' 'Can't Tell,' or 'No,' with responses assigned the following weights: 'Yes' = 1 point, 'Can't Tell' or 'No' = 0 points, following the scoring method set out by Boeije et al., (2011). Each study received a score out of 10, with scores 8-10 considered high quality, 5-7 moderate, and below 5 low quality. These classifications were characterised as A, B and C, respectively. No studies were excluded based on quality, as none returned a score of concern and there are no standardised methods for excluding qualitative studies (Thomas et al., 2012). The results are summarised in Table 5.

The included grey literature study was quality assessed using the AACODS<sup>11</sup> checklist (Tyndall, 2010), selected for its comprehensive nature and domain-based approach; the scoring of which is provided in Table 6 (for a full summary see Appendix F). For this SLR, a scoring system (Garavito et al., 2024) was slightly adapted to classify studies as high, moderate or low quality, providing as much consistency in evaluation with the CASP checklist as possible (CASP, 2023). Each criterion was assessed using a 2-point scale: 'No' or 'Can't tell' = 0 points, and 'Yes' = 2 points. This scoring system yielded a total possible score ranging from 0 to 12. Scores were categorised into three quality levels: low quality (0–4 points), moderate quality (5–8 points), and high quality (9–12 points).

The primary and secondary researcher conducted the quality appraisal of the eight included studies. This process revealed 2 conflicts<sup>12</sup>. Each conflict was discussed, and a final decision was made in collaboration with supervisors. A table with a sample outlining the specifics of how each question was answered can be found in Appendix G. There is a full written summary in Appendix H.

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<sup>11</sup> Authority, Accuracy, Coverage, Objectivity, Date Significance

<sup>12</sup> Cohen's kappa was not calculated as the number were so low that it would be too volatile to calculate (Bujang & Baharum, 2017)

**Table 5**

*Quality assessment of included published studies*

<b>CASP Criterion</b>	<b>Included Studies</b>						
	Asherson et al., (2022)	Crane et al., (2019)	French et al., (2020)	Hayes et al., (2022)	Spain et al., (2022)	Ward et al., (2024)	Young et al., (2021)
1. Was there a clear statement of the aims of the research?	1	1	1	1	1	1	1
2. Is the qualitative methodology appropriate?	1	1	1	1	1	1	1
3. Was the research design appropriate to address the aims of the research?	1	1	1	1	1	1	0
4. Was the recruitment strategy appropriate to the aims of the research?	0	1	1	1	1	1	0

5. Was the data collected in a way that addressed the research issue?	0	1	1	0	1	1	0
6. Has the relationship between researcher and participants been adequately considered?	0	0	1	0	0	0	0
7. Have ethical issues been taken into consideration?	1	1	1	1	1	1	0
8. Was the data analysis sufficiently rigorous?	0	0	1	0	0	1	0
9. Is there a clear statement of findings?	1	1	1	1	1	1	1
10. How valuable is the research?	1	1	1	1	1	1	1
Total score	6	8	10	7	8	9	4

**Table 6***AACODS Checklist*

<b>AACODS Criterion</b>	<b>Included Studies</b>
	Westminster Commission on Autism, (2016)
1. Authority	2
2. Accuracy	2
3. Coverage	2
4. Objectivity	0
5. Date	2
6. Significance	2
Total score	10

**2.6 Methodology: Data Extraction**

Cochrane guidelines (Higgins et al., 2019) recommend that each study have the following data extracted: (a) details relating to the publication: first author, year of publication; (b) aims and objectives; (c) study design/methodology, (d) sample, (e) results, (f) strengths and limitations, (g) clinical and practical implications (see Table 7). The extracted data was cross-verified by the secondary researcher. The Cochrane Handbook directs that any information which involves *subjective interpretation* should be extracted by two researchers (Moore et al., 2023).

**Table 7***Summary of extracted data*

	Reference	Setting	Aims and objectives	Study Design / Methodology	Sample and Participant Demographics	Results	Strengths and Limitations	Clinical and Practical Implications	CASP/AACO DS rating
1	Asherson et al., (2022)	<i>Focus:</i> <ul style="list-style-type: none"><li>• ADHD</li></ul> <i>Country:</i> <ul style="list-style-type: none"><li>• UK</li></ul> <i>Setting:</i> <ul style="list-style-type: none"><li>• Primary, secondary and tertiary care</li></ul>	To investigate service constraints and assess care models that improve access and delivery for adult ADHD, focusing on the role of primary care in diagnosis, management, and integrating ADHD care into primary and secondary systems.	This research employs a qualitative methodology. Participants were recruited from primary, secondary, and tertiary healthcare sectors using a purposive sampling method. Data was collected through a discussion group meeting held at the Royal College of Physicians in London. The meeting was transcribed and synthesised, then reviewed by co-authors. Data was analysed using thematic analysis.	<i>Sample size:</i> <ul style="list-style-type: none"><li>• Not stated</li></ul> <i>Demographics:</i> <ul style="list-style-type: none"><li>• Not stated</li></ul> <i>Participants:</i> <ul style="list-style-type: none"><li>• Primary Care Practitioners (PCPs):<ul style="list-style-type: none"><li>• 3 GPs</li><li>• 1 nurse consultant</li><li>• 2 professionals from health commissioning</li></ul></li><li>• Professionals specialising in ADHD across secondary care (psychiatry, nursing, psychology)</li></ul> <i>Work context:</i> <ul style="list-style-type: none"><li>• Primary and secondary care</li></ul> <i>Years of experience:</i> <ul style="list-style-type: none"><li>• Not stated</li></ul>	<i>Nine themes were identified:</i> <ul style="list-style-type: none"><li>• Ambiguity of 'ADHD specialist' role</li><li>• Organisational pressures</li><li>• Limited funding</li><li>• Managing routine adult ADHD cases in primary care</li><li>• Formal training and accreditation for ADHD specialists</li><li>• Joint working across university disability services, diagnostic assessors, and clinical teams</li><li>• Aligning ADHD care pathways with those used for other common mental health conditions</li><li>• Increased mental health funding in primary care</li></ul>	<i>Strengths</i> <ul style="list-style-type: none"><li>• Not discussed</li></ul> <i>Limitations</i> <ul style="list-style-type: none"><li>• A limitation is the studies focus on English only services.</li></ul>	The results summarise how the current healthcare systems could be improved to increase access to care and reduce 'bottlenecks' in services. They offer solutions to improve continuity of care across the lifespan. They advocate for training programme providers of health professions incorporate specialist ADHD training to upskill professionals. They consider how developing services can be cost-effective, and incorporated into primary care as common mental health problems have been in recent years.	6 (B)

2	Crane et al., (2019)	<p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• Autism</li> </ul> <p><b>Country:</b></p> <ul style="list-style-type: none"> <li>• UK</li> </ul> <p><b>Setting:</b></p> <ul style="list-style-type: none"> <li>• Psychiatry, autism healthcare</li> </ul>	<p>To explore psychiatrists' experiences of working with autistic people, including their confidence in making diagnostic and management decisions, and the factors influencing those decisions.</p>	<p>This study used a mixed-methods design. Participants were initially recruited through the Royal College of Psychiatrists via convenience sampling, with additional recruitment through social media using snowballing techniques. Data were collected through an online survey and analysed using thematic analysis within an essentialist framework, aiming to reflect participants' lived experiences and perspectives.</p>	<p><b>Sample size:</b> 172</p> <p><b>Demographics:</b></p> <p><b>Gender:</b></p> <ul style="list-style-type: none"> <li>• 52.3% female</li> </ul> <p><b>Age:</b></p> <ul style="list-style-type: none"> <li>• Mean age: 48.56 years</li> <li>• Range: 31 to 73 years</li> </ul> <p><b>Ethnicity:</b></p> <ul style="list-style-type: none"> <li>• 69.98% white</li> <li>• 2.3% black</li> <li>• 19.2% Asian</li> <li>• 3.5% mixed heritage</li> <li>• 4.1% preferred not to say</li> </ul> <p><b>HCP role:</b></p> <ul style="list-style-type: none"> <li>• Psychiatrists, 159 consultants</li> </ul> <p><b>Work Context:</b></p> <ul style="list-style-type: none"> <li>• Child &amp; Young Persons</li> <li>• Adult</li> <li>• Older adult</li> <li>• Learning Disability</li> <li>• Inpatient</li> <li>• Community services</li> <li>• 89% in public healthcare</li> </ul> <p><b>Years of experience:</b></p> <ul style="list-style-type: none"> <li>• Mean years: 19y</li> </ul>	<p><b>Seven themes were identified:</b></p> <ul style="list-style-type: none"> <li>• Long waiting times result in delayed support for service-users</li> <li>• Demand exceeds the capacity of persistently underfunded services</li> <li>• Unclear diagnostic and support pathways, with poor cross-agency coordination</li> <li>• Commissioning gaps for autistic adults without mental health needs or learning disabilities</li> <li>• very limited post-diagnostic support for individuals and families</li> <li>• Greater autism awareness needed among professionals beyond psychiatry</li> <li>• Ongoing tensions around how autism is understood and positioned in society</li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• First survey-based study to focus specifically on psychiatrists' knowledge, experience, and confidence in working with autistic individuals.</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>• The majority of respondents had autistic adults as their service users, likely impacting survey findings. E.g. regarding lack of confidence in supporting children with autism.</li> <li>• The response rate to the survey was low.</li> <li>• Nearly half the sample had personal connection to ASD, suggesting potential bias in their sample.</li> </ul>	<p>The authors emphasised steps already taken by the NHS, such as making autism more visible in the Mental Health Minimum Data Set for England. They highlighted that sharing the findings could boost practitioners' confidence in working with autistic clients and ensure autism is not seen as a diagnosis of exclusion. They advocated for both specialist service development and greater access to existing mental health services, incorporating autistic voices into service planning. They also recommended psychiatrists contribute to strategies addressing waiting time disparities.</p>	8 (A)
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3	French et al., (2020)	<p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• ADHD</li> </ul> <p><b>Country:</b></p> <ul style="list-style-type: none"> <li>• UK</li> </ul> <p><b>Setting:</b></p> <ul style="list-style-type: none"> <li>• Primary and secondary care</li> </ul>	<p>To explore individual stakeholder experiences of ADHD assessment, diagnosis and treatment</p> <p>This study adopted a qualitative design. Participants were recruited via the local Clinical Research Network and through direct contact with practices, using convenience sampling. Data were gathered through semi-structured interviews and analysed using inductive thematic analysis, informed by grounded theory principles. The interview schedule was designed to encourage the emergence of new topics, allowing participants' experiences to guide the discussion. 3 males, 2 females.</p>	<p><b>Sample size:</b></p> <ul style="list-style-type: none"> <li>• 19 (10 HCPs)</li> </ul> <p><b>Demographics:</b></p> <p><b>Gender:</b></p> <ul style="list-style-type: none"> <li>• 6 male</li> <li>• 4 female</li> </ul> <p><b>Age:</b></p> <p>GPs:</p> <ul style="list-style-type: none"> <li>• Mean age: 33y.4m</li> <li>• Range 29y.4m- 44y.7m</li> </ul> <p>Secondary care professionals:</p> <ul style="list-style-type: none"> <li>• Mean age: 41y.2m</li> <li>• Range: 36y.6m – 63y.5m</li> </ul> <p><b>Ethnicity:</b></p> <ul style="list-style-type: none"> <li>• Not stated</li> </ul> <p><b>HCP roles:</b></p> <ul style="list-style-type: none"> <li>• 5 GPs</li> <li>• 5 secondary care professionals</li> </ul> <p><b>Context of work:</b></p> <ul style="list-style-type: none"> <li>• Secondary care</li> <li>• CAMHS, community paediatric team</li> </ul> <p><b>Years of experience:</b></p> <ul style="list-style-type: none"> <li>• Not stated</li> </ul>	<p><b>Five themes were identified:</b></p> <ul style="list-style-type: none"> <li>• ADHD often goes unrecognised in primary care</li> <li>• Lack of clear diagnostic pathways and service provision</li> <li>• Limited GP knowledge and common misconceptions about ADHD</li> <li>• Consequences of diagnosis, and risks of being undiagnosed</li> <li>• Poor communication across services and stakeholders</li> </ul>	<p><b>Strength:</b></p> <ul style="list-style-type: none"> <li>• Four stakeholder groups used, overarching themes expressed by most groups overlapped, indicating a strong relevance of issues presented.</li> <li>• Findings have international relevance.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>• Individual experiences might not map onto others. Self-selected GP sample mostly younger, and older GPs views not represented.</li> <li>• Younger GPs more likely to have ADHD training.</li> <li>• No Fathers of participants represented.</li> </ul>	<p>Future research should address the highlighted issues, particularly gaps in knowledge and understanding of ADHD among GPs. This can be achieved by enhancing accurate information, dispelling misconceptions, and validating tailored psychoeducational interventions. Additionally, improving ADHD management requires targeted training, streamlined care pathways, better integration with secondary care, and effective support strategies during the diagnostic process.</p>	10 (A)
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4	<p>Hayes et al., (2022)</p> <p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• Autism</li> </ul> <p><b>Country:</b></p> <ul style="list-style-type: none"> <li>• UK</li> </ul> <p><b>Context:</b></p> <ul style="list-style-type: none"> <li>• Specialist autism assessment teams</li> </ul>	<p>To explore the experiences and challenges faced by clinicians involved in autism assessments within specialist teams across adult and children's services in England.</p> <p>This study adopted a qualitative design. Participants were purposively recruited online and through the NIHR Clinical Research Network. Data collection involved both structured and semi-structured interviews, incorporating Tape-Assisted Recall (TAR) to explore participants' reflections on real case examples. Thematic analysis was used to analyse the data. The interview guide focused on diagnostic tools and processes, with TAR used to prompt discussion of specific clinical cases.</p>	<p><b>Sample size:</b></p> <ul style="list-style-type: none"> <li>• 16</li> </ul> <p><b>Demographics:</b></p> <p><b>Gender:</b></p> <ul style="list-style-type: none"> <li>• 3 male</li> <li>• 13 female</li> </ul> <p><b>Age:</b></p> <ul style="list-style-type: none"> <li>• Range: 30-60y</li> </ul> <p><b>Ethnicity:</b></p> <ul style="list-style-type: none"> <li>• Not stated</li> </ul> <p><b>HCP roles:</b></p> <ul style="list-style-type: none"> <li>• 4 Consultant Psychiatrists</li> <li>• 6 Clinical Psychologists (CP)</li> <li>• 1 Educational Psychologist</li> <li>• 1 Speech &amp; Language Therapist (SLT)</li> <li>• 1 Occupational Therapist (OT)</li> <li>• 3 senior managers with specialist autism or social work background</li> </ul> <p><b>Context of work:</b></p> <ul style="list-style-type: none"> <li>• 7 in adult assessment</li> <li>• 9 in child &amp; adolescent assessment</li> </ul> <p><b>Years of experience:</b></p> <ul style="list-style-type: none"> <li>• 2-30y</li> </ul>	<p><b>Four themes were identified:</b></p> <ul style="list-style-type: none"> <li>• Institutional pressure</li> <li>• Making diagnosis make sense</li> <li>• Seeing through an autism lens</li> <li>• 'Just tools'</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• TAR methodology allowed rich and free-flowing discussion in interviews, resulting in rich data collection.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>• Researchers picked the studies to focus on in interviews potentially introducing bias</li> <li>• The self-selecting nature of the sample may have introduced selection bias.</li> <li>• The study did not capture the full range of professional roles, age groups, or ethnic and geographic diversity.</li> </ul>	<p>Additional resources are needed to meet autism assessment requirements in clinical guidelines. A specialist autism pathway is opposed, as it risks a narrow focus, overlooking broader needs. They propose evaluating the benefits and resource demands of autism-specific assessment services and their integration into broader healthcare.</p>	7 (A)
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5	Spain et al., (2022)	<p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• Autism</li> </ul> <p><b>Country:</b></p> <ul style="list-style-type: none"> <li>• UK</li> </ul> <p><b>Context:</b></p> <ul style="list-style-type: none"> <li>• Telehealth autism assessment</li> </ul>	<p>This study aimed to investigate HCPs' experiences of conducting autism assessments remotely. It focused on the challenges and enablers of telehealth delivery, their training and supervision needs, suggestions for improving service quality, and their experiences of offering support following diagnosis.</p> <p>.</p>	<p>This research employs a qualitative methodology following phenomenological principles.</p> <p>Participants were recruited via the authors' existing England-wide collaborations and network, gatekeepers at health organisations and universities, word of mouth, and social media. Convenience and snowball sampling methods were used.</p> <p>Data was collected through semi-structured interviews. Data was analysed using thematic analysis.</p>	<p><b>Sample size:</b></p> <ul style="list-style-type: none"> <li>• 45</li> </ul> <p><b>Demographics:</b></p> <ul style="list-style-type: none"> <li>• Not state</li> </ul> <p><b>HCP roles:</b></p> <ul style="list-style-type: none"> <li>• 13 CPs</li> <li>• 6 SLTs</li> <li>• 6 OTs</li> <li>• 5 Psychiatrists,</li> <li>• 5 Neurodevelopment Workers,</li> <li>• 3 Social Workers,</li> <li>• 2 Paediatricians,</li> <li>• 2 Nurses,</li> <li>• 2 Medical Physicians</li> <li>• 1 Counselling Psychologist</li> </ul> <p><b>Context of work:</b></p> <ul style="list-style-type: none"> <li>• 32 worked in the NHS</li> <li>• 13 privately</li> <li>• 13 worked with children</li> <li>• 17 with adults</li> <li>• 5 across the lifespan</li> </ul> <p><b>Years of experience</b></p> <ul style="list-style-type: none"> <li>• Average experience was 12.14 years (range 0.5 to 30).</li> </ul>	<p><b>Seven themes were identified:</b></p> <ul style="list-style-type: none"> <li>• Practicalities of telehealth</li> <li>• Telehealth autism diagnostic assessments</li> <li>• Diagnostic conclusions</li> <li>• Clinical considerations</li> <li>• Post-diagnostic support</li> <li>• Future ways of working</li> <li>• Healthcare professionals' experiences and needs</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• Recruited from a wide sampling frame</li> <li>• Seven professional disciplines represented</li> <li>• Participants worked across different settings and services</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>• The reach of recruitment materials could not be assessed.</li> <li>• Participants' motivations for taking part were not explored.</li> <li>• There was limited representation from medically trained professionals.</li> <li>• Participants were not purposively sampled to reflect all relevant services</li> <li>• All participants English</li> </ul>	<p>Professionals need ongoing training in telehealth for autism services, focusing on clinical, autism-specific, and practical skills.</p> <p>Systemic factors that could improve service provision also included blended care models, streamlining processes, supervision and team cohesion.</p> <p>Integrating skills-based training into core and post-qualification programs is essential.</p> <p>Service users and families should also be supported to access telehealth, and digital poverty should be assessed to improve access to care.</p>	8 (A)
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6	<p><b>Ward et al., (2024)</b></p> <p><b>Focus:</b> • ADHD</p> <p><b>Country:</b> • UK</p> <p><b>Context:</b> • Primary care</p> <p>To examine the views of individuals with ADHD, their supporters, and primary care professionals regarding the broader physical and mental health needs associated with ADHD, as well as the support currently provided.</p> <p>This research employs a qualitative methodology. Participants were recruited from five GP practices in Southwest England using a purposive sampling method. Data was collected through semi-structured interviews. Data was analysed using reflexive thematic analysis. Researchers used research advisory group including multiple stakeholders to help develop interview guide.</p> <p><b>Sample size:</b> • 11</p> <p><b>Demographics:</b></p> <p><b>Gender:</b> • 3 male • 8 female</p> <p><b>Age:</b> • Not stated</p> <p><b>Ethnicity:</b> • 8 White • 2 Asian • 1 Mixed heritage</p> <p><b>HCP roles:</b> • 5 GPs • 5 practice managers • 1 well-being worker</p> <p><b>Context of work:</b> • Primary care</p> <p><b>Years of experience:</b> • Not stated</p> <p><b>Three themes were identified:</b></p> <ul style="list-style-type: none"> <li>• Understanding health in ADHD</li> <li>• Barriers to health in ADHD</li> <li>• Addressing health in ADHD</li> </ul> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• Captures a wide range of lived experiences</li> <li>• Adopts a broad understanding of health beyond standard medical or therapeutic interventions</li> <li>• Demonstrates that health inequalities vary by context</li> <li>• Identifies structural, service, and knowledge gaps as central to the challenges highlighted</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>• Treats ADHD as a singular entity</li> <li>• Only includes health data from NHS England, limiting generalisability to other UK countries</li> </ul> <p>Providing both practical and instructional support may assist individuals with ADHD in managing daily tasks. Improving healthcare professionals' understanding of neurodiversity is also essential. Flexible approaches to appointments and service delivery were seen as helpful. While there is support for a more structured, holistic approach to managing ADHD-related health needs, current provision remains inconsistent. Tackling structural, service-level, and knowledge-related gaps is vital to reducing the health inequalities identified.</p> <p>9 (A)</p>
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7	Young et al., (2021)	<p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• ADHD</li> </ul> <p><b>Country:</b></p> <ul style="list-style-type: none"> <li>• UK</li> </ul> <p><b>Context:</b></p> <ul style="list-style-type: none"> <li>• NHS-wide &amp; private practice</li> </ul>	<p>The paper sought to raise awareness of the gaps in diagnosis, treatment, and support for individuals with ADHD and to advocate for improved services through a consensus of expert opinion.</p>	<p>This study used a qualitative design. Recruitment and sampling methods were not specified. Data were collected through discussion groups. The authors synthesised findings by examining points of agreement and disagreement across the expert panel, combining quantitative consensus scores with qualitative insights from the Delphi process to develop a comprehensive set of conclusions and recommendations regarding ADHD service provision in the UK.</p>	<p><b>Sample size:</b></p> <ul style="list-style-type: none"> <li>• 53</li> </ul> <p><b>Demographics:</b></p> <ul style="list-style-type: none"> <li>• Not stated.</li> </ul> <p><b>HCP roles:</b></p> <ul style="list-style-type: none"> <li>• Academics</li> <li>• Mental health professionals</li> <li>• Educational and occupational specialists</li> <li>• Charity workers</li> <li>• Quantities of HCPs not stated</li> </ul> <p><b>Context of work:</b></p> <ul style="list-style-type: none"> <li>• Private practice</li> <li>• NHS</li> </ul> <p><b>Years of experience:</b></p> <ul style="list-style-type: none"> <li>• Not stated</li> </ul>	<p><b>Five themes were identified:</b></p> <ul style="list-style-type: none"> <li>• Detection of ADHD and associated problems</li> <li>• Gatekeepers of ADHD assessment and diagnosis</li> <li>• ADHD Healthcare Organisation in the UK</li> <li>• Barriers to treatment</li> <li>• Plugging the gaps</li> </ul>	<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• Not discussed.</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>• Not discussed.</li> </ul>	<p>Authors state that there is a need for improved ADHD healthcare services in the UK, emphasizing the importance of enhancing training, support, and resources for healthcare professionals, and advocating for system-wide changes to address current gaps in diagnosis, treatment, and long-term care</p>	4 (B)
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8 Westminster Commission on Autism, (2016)	<p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• Autism</li> </ul> <p><b>Country:</b></p> <ul style="list-style-type: none"> <li>• UK</li> </ul> <p><b>Context:</b></p> <ul style="list-style-type: none"> <li>• NHS-wide</li> </ul> <p>To explore barriers autistic individuals face when accessing healthcare, the role of training for both healthcare staff and service users, and the importance of data collection, regulation, and inspection in improving healthcare quality. How to better implement existing resources like NICE guidelines to address these barriers.</p> <p>This study used a mixed-methods design. Participants were recruited via social media through convenience and snowball sampling. No details were provided regarding the data analysis process.</p>	<p><b>Sample size:</b></p> <ul style="list-style-type: none"> <li>• 244</li> </ul> <p><b>Demographics:</b></p> <ul style="list-style-type: none"> <li>• Not stated.</li> </ul> <p><b>HCP roles:</b></p> <ul style="list-style-type: none"> <li>• Not stated.</li> </ul> <p><b>Context of work:</b></p> <ul style="list-style-type: none"> <li>• Not stated.</li> </ul> <p><b>Years of experience:</b></p> <ul style="list-style-type: none"> <li>• Not stated.</li> </ul> <p><b>Seven themes were identified:</b></p> <ul style="list-style-type: none"> <li>• Lack of Understanding</li> <li>• Autism and co-occurring conditions</li> <li>• Co-occurring mental health issues</li> <li>• Diagnostic overshadowing</li> <li>• Sensory processing and communication</li> <li>• Leadership of autism in the health system</li> <li>• Isolation, avoidance, inertia and neglect</li> </ul> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• The survey provided insight into the views and experiences of autistic individuals.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>• Participants were recruited via convenience and snowball sampling through social media, resulting in a self-selecting sample and limitations in the generalisability of findings.</li> <li>• The results may not reflect the wider autistic population.</li> </ul> <p>Doctors should highlight autistic service users in their record system.</p> <p>All autistic people should be offered an annual health check.</p> <p>All HCPs should have autism training. NHS England need to do more to make this possible.</p> <p>NHS England should have an Autism Champion to lead on making changes for autistic people. We think that this would improve services for autistic people.</p>
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### **2.6.1 Summary of extracted data**

**Year, location and study setting.** Eight UK-based studies published between 2016 and 2024 were included. Six studies recruited a nationally representative sample (Asherson et al., 2022; Crane et al., 2019; French et al., 2020; Hayes et al., 2022; Spain et al., 2022; Ward et al., 2024). Two did not specify recruitment methods (Westminster Commission on Autism, 2016; Young et al., 2021). Four studies focused on ADHD (Asherson et al., 2022; French et al., 2022; Ward et al., 2024; Young et al., 2021), and four on ASD (Crane et al., 2019; Hayes et al., 2022; Spain et al., 2022; Westminster Commission on Autism, 2016). One focused on primary care (Ward et al., 2024), whilst two spanned primary and secondary care settings (Asherson et al., 2022; French et al., 2020). Others addressed broader ADHD and ASD healthcare settings across the NHS, public and private sectors (Crane et al., 2019; Hayes et al., 2022; Spain et al., 2022; Westminster Commission on Autism, 2016; Young et al., 2021).

**Aims and objectives.** The studies explored HCPs' roles and experiences in assessing, diagnosing, and managing ADHD and ASD, with a focus on barriers and service improvement. Collectively, they examined systemic issues such as delays, diagnostic overshadowing, inconsistent pathways, and the need for greater training; while highlighting opportunities to enhance access, collaboration, and the quality of post-diagnostic care.

**Study design.** Six studies employed qualitative methods (Asherson et al., 2022; French et al., 2020; Hayes et al., 2022; Spain et al., 2022; Ward et al., 2024; Young et al., 2021), whilst two employed a mixed-methods research design (Crane et al., 2019; Westminster Commission on Autism, 2016).

**Sample and participant demographics.** Half of the studies included multiple stakeholders<sup>13</sup> (French et al., 2020; Ward et al., 2024; Westminster Commission on Autism, 2016; Young et al., 2021), and half focused exclusively on HCPs (Asherson et al., 2022; Crane et al., 2019; Hayes et al., 2022; Spain et al., 2022). Across the studies, HCPs were represented from a range of backgrounds, including medicine, psychology, speech and language therapy, nursing, and social work. Three studies reported years of professional experience (Crane et al., 2019; Hayes et al., 2022; Spain et al., 2022).

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<sup>13</sup> Stakeholders refer to individuals with a direct interest in ADHD or ASD care, including HCPs, service users, family members, and policymakers

Sample sizes (including stakeholders) ranged from 16 (Hayes et al., 2022) to 1047 (Westminster Commission on Autism, 2016); the mean was 196. For HCPs specifically, sample sizes ranged from 10 to 244, with a mean of 83. Four studies reported gender distribution (Crane et al., 2019; French et al., 2020; Hayes et al., 2022; Ward et al., 2024), with an overall balance of 93 male (44.7%) and 115 female (55.3%) HCPs. Ethnicity was reported by three studies (Crane et al., 2019; Hayes et al., 2022; Ward et al., 2024).

**Results.** All studies highlighted barriers to care provided for adult ADHD and ASD. Thematic synthesis revealed systemic and logistical challenges in diagnosis and management. Section 2.9.2 provides a detailed summary of how the results answered the research question.

**Strengths and limitations.** A strength of all studies was in addressing the unexplored topic of HCP perspectives on barriers to care for adult ADHD and autism. Additionally, several studies included diverse samples of different professions, which helped to enhance the quality of depth, and transferability of the findings across professions and healthcare settings (French et al., 2020; Hayes et al., 2022; Spain et al., 2022; Ward et al., 2024).

Three studies either failed to specify (Westminster Commission on Autism, 2016; Young et al., 2021), or only partially specified (Asherson et al., 2022; French et al., 2020), the represented professions, the frequency of each profession represented and the level of experience. A lack of transparency around recruitment was also a common issue. For example, Crane et al. (2019) reported that many of their participants had a personal connection to ASD, which may have shaped how they engaged with and interpreted the study topic. This does not necessarily introduce bias, but it is important to acknowledge how lived experience can influence perspectives. Similarly, Hayes et al. (2022) relied on self-selecting participants, which can limit the extent to which findings represent the wider HCP population. Two studies provided limited detail about participants' motivations for taking part, making it more difficult to assess how representative their views might be (Spain et al., 2022; Westminster Commission on Autism, 2016).

Additionally, both Westminster Commission on Autism (2016) and Young et al. (2021) did not specify how their data were analysed, which limits the transparency and

replicability of their findings, both of which are important when evaluating the trustworthiness of qualitative research (Tong et al., 2007).

**Clinical and practical implications.** All eight studies identified a range of barriers that hinder effective care for adults with ADHD (Asherson et al., 2022; French et al., 2020; Ward et al., 2024; Young et al., 2021) and ASD (Crane et al., 2019; Hayes et al., 2022; Spain et al., 2022; Westminster Commission on Autism, 2016). Commonly cited barriers included gaps in training and confidence among HCPs, unclear or fragmented care pathways, and wider systemic problems such as underfunding and service variability.

Six studies emphasised that improving ADHD and ASD-specific training for HCPs was essential to address some of the barriers highlighted. Four studies also emphasised the need for broader structural changes at the service level to improve timely access and appropriate care (Asherson et al., 2022; Crane et al., 2019; French et al., 2020; Ward et al., 2024).

## **2.7 Methodology: Synthesis strategy**

The method of data synthesis for this SLR was thematic synthesis (Thomas & Harden, 2008). This method was selected because it allows the analysis to remain grounded in the data, building descriptive and analytic themes in a way that mirrors the original analytic approach taken in most included studies. Other methods of synthesis were considered, including narrative synthesis (Popay et al., 2006) and meta-ethnography (Sattar et al., 2021). Narrative synthesis is typically used for reviews that include both quantitative and qualitative data, making it less suitable for the present review, which focused exclusively on qualitative studies. Meta-ethnography, while offering a higher level of theoretical abstraction through conceptual reinterpretation, was not considered appropriate due to the largely descriptive nature of the included studies, most of which employed thematic analysis and lacked abstract theoretical frameworks. Thematic synthesis was therefore deemed the most appropriate approach for staying close to the original data and ensuring consistency with the analytic style of the included studies.

The synthesis process followed the techniques outlined by Thomas and Harden (2008), which involved: 1) coding each text line-by-line, 2) developing descriptive themes, and 3) generating analytic themes. To begin this process, all eight included studies were

reviewed in full to enable the primary author to become thoroughly familiar with their content (Braun & Clarke, 2006, 2013, 2019). Becoming thoroughly familiar with each study was essential to ensure that the coding process was grounded in a comprehensive understanding of the findings and context. The resulting analytic themes were then discussed with the supervisory team to ensure they were appropriately aligned with the SLR research questions and to minimise the risk of bias by ensuring validity and transparency of the data (Cargo et al., 2018; Thomas & Harden, 2008).

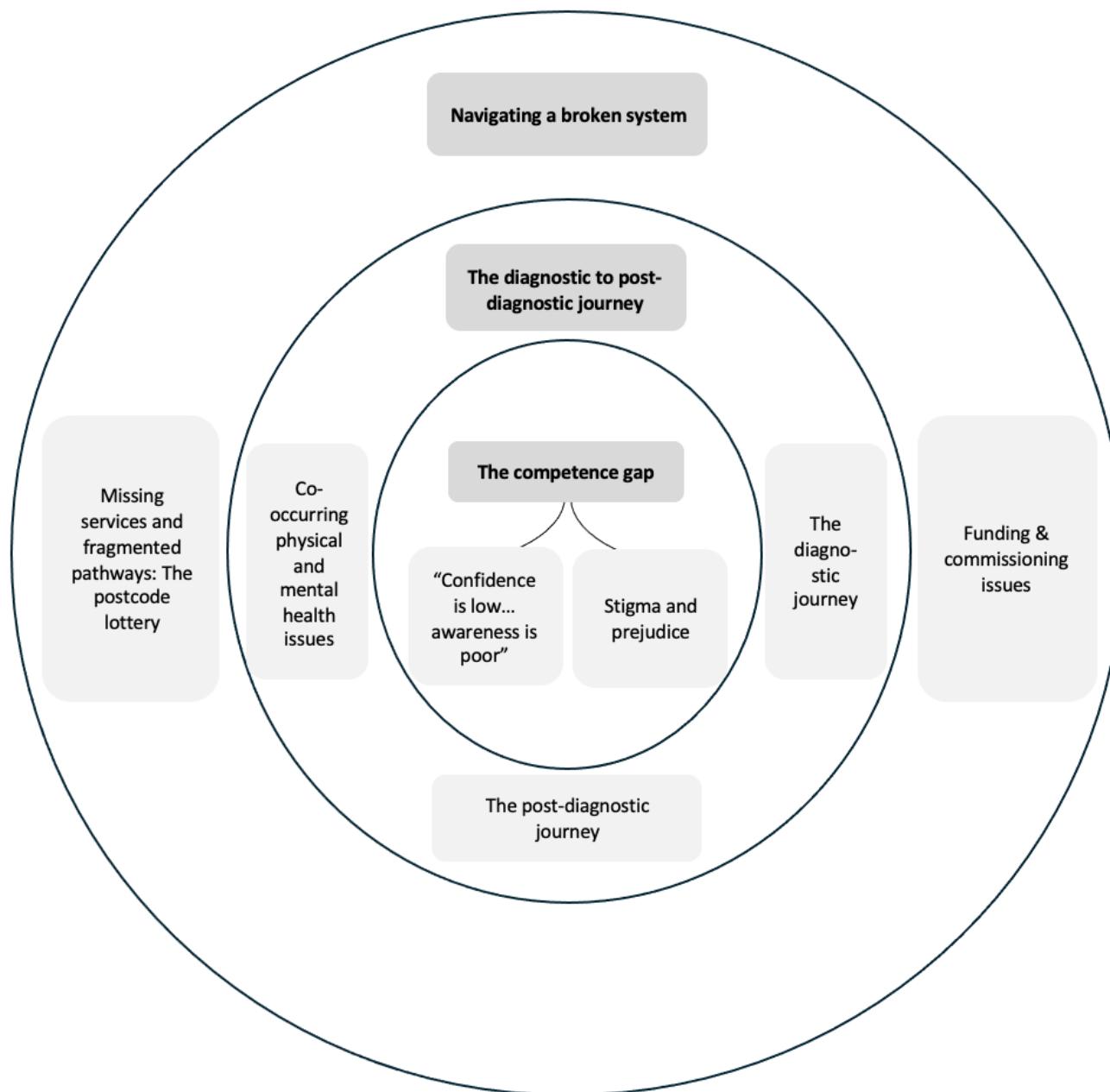
This approach synthesised findings across the included studies to construct a coherent and meaningful picture of what is currently known about the research topic (Gough et al., 2012). Direct quotes from study participants were used to illustrate both descriptive and analytic themes where available. In studies where participant quotations were not reported (Asherson et al., 2022; Young et al., 2021), author-reported findings were used instead, in line with the principles of thematic synthesis (Thomas & Harden, 2008).

## **2.8 Findings: Thematic Synthesis of Results**

Three themes and seven subthemes were revealed using thematic synthesis (see Figure 3). Further tabulation was completed to depict the source of each theme (Appendix I).

**Figure 3**

*SLR findings, themes and subthemes*



### 2.8.1 Theme 1: The competence gap

All included studies addressed professional competency in supporting adults with ADHD and autism. This theme was shaped by the recurrence of HCPs expressing inadequate training, limited knowledge and experience, and their resulting assumptions, stigma, and discriminatory practices toward adults with ADHD and autism.

***“Confidence is low... awareness is poor”***. All but one study (Hayes et al., 2022) highlighted the need for formal training. Despite recommendations from NICE (2018), ADHD is rarely included in formal training programmes. Within the NHS, for example, there is an urgent need for this training across primary and secondary care settings and across professions (Asherson et al., 2022). Due to demand and provision issues, providers external to the NHS, such as third-sector and private providers, are frequently relied upon. However, such providers often lack the training to manage the complexity that ADHD can involve, with a consensus that training is required across all professions:

*“Access to evidence-based training will address the issue of awareness and attitudes of key professional groups in the public sector and improve recognition and support for individuals with ADHD”* (Young et al., 2021, p. 10).

Building on this, the synthesis suggests that a stepped care model of training would better equip HCPs to support adults with ADHD or ASD. At a minimum, all HCPs should receive basic awareness training, regardless of role or setting. This could be delivered as a short half-day or one-day online course, aimed at improving recognition of ADHD or ASD in challenging outdated stereotypes.

For HCPs working in adult contexts where they are likely to encounter or support adults with ADHD or ASD, an intermediate level of training is essential. A minimum of two days of structured training should cover recognising diverse presentations, understanding diagnostic criteria and co-occurring problems, knowing when and how to refer for assessment, and supporting individuals through diagnostic pathways and beyond.

For those specialising in assessment or treatment, advanced, role-specific training would be beneficial. This should include administering and interpreting diagnostic tools, delivering psychoeducation, and coordinating multidisciplinary care. Embedding this stepped-care model would promote greater consistency, reduce diagnostic overshadowing, and ensure adults receive appropriate, timely support. These recommendations align with

NICE (2018), which emphasises the importance of workforce training to improve recognition, referral, and access to assessment and treatment.

Autism studies similarly emphasised the need for adequate training and experience, including differential diagnosis and referral pathway knowledge, as lack of clarity around referral options can delay: “... *referring people on for follow-up assessments and follow-up treatment*” (Spain et al., 2022, p. 11).

There were shortages of trained HCPs, such as neuro-affirmative<sup>14</sup> therapists, who could support autistic clients with co-occurring mental health problems (Crane et al., 2019). 70% of participants prioritised improving healthcare access through better training for HCPs (Westminster Commission on Autism, 2016).

In ADHD care, secondary care services often misunderstood the diagnosis, leading to misdiagnosis and offering ineffective support, which negatively affected health outcomes (Asherson et al., 2022). GPs reported limited knowledge, with few GPs identifying cases and: “*No mention of any kind of support except for private support*” (French et al., 2020, p. 6).

Structural factors also contributed: rigid attendance policies for appointments failed to accommodate the organisational challenges common in ADHD, leading to exclusion (Ward et al 2024). PCPs were hesitant to manage ADHD due to lack of “*buy-in*” (Young et al., 2021, p. 5).

Autism studies highlighted tensions between clinicians’ training and experiences and, the perspectives of the families of service users (Hayes et al., 2022). Two studies emphasised the value of experiential learning alongside formal training (Crane et al., 2019; Spain et al., 2022):

“... *You can ... go on as [many] training courses that you can, but you never quite get it until you've been working with individuals for a long period of time*” (Spain et al., 2022, p. 9).

Participants also called for “*greater specialist training for all multidisciplinary team staff [as] generally confidence is low with autism cases*” and “*better general awareness*” across professional groups (Crane et al., 2019, p. 6). The Westminster Commission on Autism

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<sup>14</sup> Neuro-affirmative refers to an approach that recognises neurodiversity as a natural and valuable form of human variation. Instead of pathologising and seeing neurological differences like ADHD or autism through the medical lens, as deficits or disorders, neuro-affirmative practice seeks to respect, validate, and support individuals’ unique ways of thinking, their experiences, and ways of interacting with the world.

(2016) reiterated the importance of training, noting that autism was often ignored or misinterpreted as a primary mental health condition in services.

**Stigma and prejudice.** Six studies referenced this theme (Asherson et al., 2022; Crane et al., 2019; French et al., 2020; Ward et al., 2024; Westminster Commission on Autism, 2016; Young et al., 2021). Unhelpful attitudes toward ADHD were evident, particularly toward families from lower socioeconomic backgrounds:

*“A lot of parents who are saying ‘I think my kid has ADHD’ are generally of a lower socio-economic class... maybe asking for an explanation or an excuse in poorer families.”* (French et al., 2020, p. 7).

Negative perceptions extended to individuals with ADHD:

*“They tend to be a bit impulsive at times, so it is more of a challenge... to take on board broader health messages.”* (Ward et al., 2024, p. 5). Despite broader diagnostic criteria, some HCPs remain unaware of the full range of ADHD presentations, leading to underdiagnosis of certain ADHD presentations, particularly in inattentive and adult presentations (French et al., 2020; Young et al., 2021). This could be one explanation for the stigmatising stereotype that ADHD only refers to extroverted young males:

*“GPs, professionals, even teachers will say, actually they’re a quiet inattentive young girl rather than loud noisy boy... if you’re not extreme, you don’t warrant a psychiatric assessment.”* (French et al., 2020, p. 8).

Stigma and misinformation restrict funding and resources for ADHD. Unhelpful beliefs such as ADHD being a behavioural problem (with emphasis on disruptive behaviour), or due to environmental factors (for example adverse childhood environments), lead to a reluctance to accept ADHD as a valid difference in neurodevelopment, and it is thus deprioritised in the competition for limited funding (Young et al., 2021). These unhelpful views that question the legitimacy of ADHD can also undermine shared care agreements, of which HCPs, especially GPs, are reluctant to take on due to poor communication with ADHD services, lack of protocols and inadequate means to monitor treatment (Asherson et al., 2022). Similarly, stigma against autistic individuals with mental health problems was evident:

*“Colleagues both medical and non-medical [are] relatively unsympathetic to patients with the condition.”* (Crane et al., 2019, p. 6). Discrimination was also apparent in mental and physical health services:

*“Mental health services openly, and unashamedly, tell me that they know very little about autism... emphasis has been on encouraging general socialising without knowing ASD limitations.”* (Westminster Commission on Autism, 2016, p. 31).

In physical healthcare, authors reported experiences of HCPs withholding medical treatment such as kidney transplants and dental braces due to the individual’s ASD, due to poor understanding and awareness of how to manage the needs and behaviours of autistic individuals (Westminster Commission on Autism, 2016).

Discriminatory practices in healthcare are evident at multiple levels of the system, including in Care Quality Commissions (CQC) inspections, which consider other vulnerable groups such as those with dementia but not ASD (Westminster Commission on Autism, 2016).

### ***2.8.2 Theme 2: The diagnostic to post-diagnostic journey***

This theme explores the disconnected, inconsistent journey that individuals face from referral through to diagnosis and post-diagnostic support, highlighting systemic barriers, service limitations, and the often unidentified and unmet complexity of co-occurring needs.

***The diagnostic journey.*** Only one study (Ward et al., 2024) did not discuss issues with the diagnostic process. As many HCPs in primary and secondary care professionals questioned the legitimacy of ADHD, and saw parental help-seeking as an attempt to “*shift blame*” or find a “*quick fix*” for behavioural problems (Young et al., 2021, p. 5), there was often resistance reported in completing referrals. Health settings were found to only support the most severe presentations, resulting in care being delayed until the point of crisis:

*“So I think there’s still that thought that if you’re not extreme, you don’t have difficulties warranting a psychiatric assessment”* (French et al., 2020, p. 8).

Long waiting lists further risk the vulnerable reaching crisis point before receiving care they should be entitled to:

*“So then people wait for 18 months to two years... it’s very hard for them and for us... it may lead to lots of life problems [...] at times it can be life-threatening, if people do stupid things or feel suicidal and so on”* (French et al., 2020, p. 8).

Individuals with high intellectual functioning may not meet stringent referral thresholds (Young et al., 2021), so many turn to unregulated private providers, that may be

associated with concerns about poor quality evaluations and inappropriate diagnoses (Asherson et al., 2022; Young et al., 2021).

The autism diagnostic process involved similar challenges due to under-resourced services:

*“Services for general adult psychiatry are woefully underprovided – autism is low on the pecking order. There is no plan for service provision in general, never mind autism support.”* (Crane et al., 2019, p. 5).

The process is often lengthy, with a psychiatrist noting: *“We are getting three referrals specifically for autism diagnosis or management per week... it’s all chaos.”* (Crane et al., 2019, p. 5). Telehealth assessments have also created issues, including digital poverty: *“Privileged people can access a lot better and get a much more robust kind of assessment...”* (Spain et al., 2022, p. 6).

Westminster Commission on Autism (2016) highlighted diagnostic overshadowing in autism, where co-occurring physical or mental health-related problems were misattributed to autism, hindering appropriate treatment. Diagnosing women and girls is particularly difficult as they often mask their difficulties:

*“...when you do the ADOS, they don’t score, because they mask their difficulties and they’ve learnt how to behave and how to interact and what you should do.”* (Hayes et al., 2022, p. 494).

This can make autistic characteristics less visible, meaning many girls do not meet diagnostic thresholds even though they experience significant difficulties in everyday life. Clinicians also voiced concerns about pressure from increasing referrals and long waiting lists impacting the quality of assessments (Hayes et al., 2022).

***The post-diagnostic journey.*** All but one study highlighted issues with the management and treatment of ADHD or autism following diagnosis (Hayes et al., 2022).

In ADHD studies, shared care protocols, which are optional for GPs, were a central concern. Some GPs declined responsibility due to poor communication with secondary care, lack of training, or unclear guidance (Asherson et al., 2022). These protocols varied widely across regions, and, without them, service users were left to navigate complex and fragmented secondary care pathways (French et al., 2020; Ward et al., 2024), as one participant noted:

*“Because there’s conflict between the GPs and secondary care about who takes on the prescribing, so the area prescribing have not managed to reach agreement to develop a shared care protocol”* (French et al., 2020, p. 5).

Even when shared care agreements were in place, they often broke down, harming service users and wasting resources (Young et al., 2021). Access to psychological support was very limited (Asherson et al., 2022; Ward et al., 2024), and GPs highlighted their own failure of ADHD identification in practice (French et al., 2020).

Care pathways were described as overly narrow, with GPs often focusing solely on medication and lacking awareness of other useful supports such as psychological therapies and peer support groups (Ward et al., 2024). HCPs also noted challenges in engaging service users in ongoing health management, and that misdiagnosis often led to poor health outcomes (Young et al., 2021).

In autism care, participants called for better support for co-occurring mental health challenges (Crane et al., 2019). Psychiatrists expressed frustration about the lack of structured post-diagnostic services:

*“At the moment, people can be assessed for autism, but that’s where the road ends... there are not enough (capacity or range) options available”* (Crane et al., 2019, p. 5).

In the absence of post-diagnostic follow-up, clinicians relied on charities, though limited funding restricted clinicians’ capacity (Crane et al., 2019). Post-diagnostic support varied, from no intervention to psychoeducation workshops or occasional therapy sessions (Spain et al., 2022), leading to unacceptable outcomes in some cases:

*“The lack of access to specific services for people with autism has caused repeated readmissions in many of my patients. They do not have the right support in the community”* (Crane et al., 2019, p. 6).

This aligns with those who do not meet diagnostic thresholds for co-occurring health issues, and were consequently “dump[ed]” by services due to commissioning structures (Spain et al., 2022, p. 11).

**Co-occurring physical and mental health issues.** People with ADHD faced various physical and mental health challenges, including substance use, road traffic accidents, and

communicable diseases<sup>15</sup> (Asherson et al., 2022 French et al., 2020; Ward et al., 2024; Young et al., 2021):

*“If you are constantly told when you are little that you are naughty, that you are failing at things, that is an adverse childhood experience that you will carry through your life. You will grow up with poor self-esteem and anxiety.”* (Ward et al., 2024, p. 4).

Services with limited provision result in long wait times for assessments, which further exacerbated mental ill health:

*“We know they aren’t going to improve in that time … and at times it can be life threatening, if people do stupid things or feel suicidal and so on”* (French et al., 2020, p. 8).

Misattributing ADHD characteristics to other mental health presentations led to incorrect treatment pathways (Asherson et al., 2022; Young et al., 2021). Untreated symptoms worsened functioning, while meaningful support reduced long-term risks (Asherson et al., 2022). Conflicting guidance across care levels complicated service commissioning, and long waiting lists increased risks of academic failure and co-occurring challenges (Asherson et al., 2022). The societal cost of neglecting adult ADHD outweighed that of providing effective care (Asherson et al., 2022).

Autistic individuals struggled to access appropriate care, with individuals that mask well often left without support and those with mental health needs facing a lack of coordinated services (Crane et al., 2019). For example, HCPs reported increasingly “*complex cases*” (Spain et al., 2022, p. 10), yet many lacked autism-specific training, potentially risking discriminatory practice against those with autism:

*“… certainly, the services they offer are tarnished by this inability to recognise autism.”* (Westminster Commission on Autism, 2016, p. 10)

Autism assessments failed to “*differentiate between autism and learning disability or anxiety*” (Hayes et al., 2022), increasing the risk of misdiagnosis.

### **2.8.3 Theme 3: Navigating a broken system**

In all but one study (Young et al., 2021), participants described ADHD and autism services as inaccessible, unclear, and exclusionary. Individuals seeking support faced

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<sup>15</sup> Illnesses by infectious agents such as bacteria, viruses, or parasites, and can be transmitted from person to person, either directly or indirectly.

challenges from services such as being sent out of area due to limited local service provision, and being actively and unfairly excluded by services (French et al., 2020; Westminster Commission on Autism 2016), similarly the fragmented, siloed structure of health services meant many adults with ADHD and autism fell through the gaps (Crane et al., 2019; Young et al., 2021).

**Funding and commissioning issues.** Six studies discussed this subtheme (Asherson et al., 2022; French et al., 2020, Hayes et al., 2022; Spain et al., 2022; Ward et al., 2024; Westminster Commission on Autism 2016).

Pathways for an ADHD assessment and diagnosis varied due to differing priorities across NHS Trusts, impacting availability of ADHD services (French et al., 2020). Ambiguities in professional roles and funding further complicated access (Asherson et al., 2022). One professional highlighted conflicts between services such as tertiary and secondary care:

*“Because we’re a tertiary service and we don’t have the resource[s] ... case holding needs to take place in secondary care, not adult mental health services... there’s conflict between the GPs and secondary care about who takes on the prescribing.”* (French et al., 2020, p. 5).

Service design for adults with ASD remains disputed, with some advocating for specialist services and others pushing for integration into mainstream care (Ward et al., 2024). A significant gap also existed for autistic adults without ID or mental health issues:

*“Some see [individuals without a learning disability or co-occurring mental health problem] as not the remit of psychiatrists... those without significant social care needs or psychiatric co-morbidity [were] left without any support.”* (Crane et al., 2019, p. 5).

Mental health care for autistic individuals was fragmented, due to both a lack of consensus around professional responsibility of care and limited staff competence in autism (Crane et al., 2019; Westminster Commission on Autism, 2016). Commissioning constraints also limited access:

*“We’re commissioned to look at the assessment of autism and that’s it. Every young person we do an additional assessment<sup>16</sup> for is another one waiting a bit longer.”* (Hayes et al., 2022, p. 492).

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<sup>16</sup> such as a cognitive assessment

Services users who were lucky enough to get an assessment often found that many services lacked post-diagnostic support:

*“Lots and lots of children and adults... are being diagnosed with autism. But then, [they ask], what now? Where do I go with this?”* (Spain et al., 2022, p. 11).

This begged the question of why there were issues at so many systemic levels.

Narrow commissioning priorities offered a plausible explanation:

*“They [commissioners, managers] sometimes lack the understanding that it is much more than a diagnosis or not... it’s about... being able to do something helpful for families.”* (Spain et al., 2022, p. 11).

There was broad agreement that more resources were needed to improve post-diagnostic support, aligning with NHS policy, and to reduce health inequalities (Westminster Commission on Autism, 2016).

***Missing services and fragmented pathways: the postcode lottery.*** Only one study (Spain et al., 2022) did not mention this theme.

Access to ADHD-specific support, such as psychological interventions, was severely limited across the UK, with many regions lacking dedicated services (Asherson et al., 2022; Young et al., 2021). Differences in service provision were shaped by commissioning and funding allocation (Asherson et al., 2022), leaving many adults without clinical and social support or legal recognition of their diagnosis, depending on where they live (Young et al., 2021). In many areas, the absence of commissioned services acted as a gatekeeper to care, often forcing people to seek support elsewhere:

*“It can be difficult to get somebody assessed for ADHD [...] So in my experience, I have had to send somebody out of area in the past in order that they can get a diagnosis or get some ... support for it.”* (French et al., 2020, p. 8).

Even where services were commissioned, long waiting times and unclear referral pathways added to frustration for those trying to access services (Young et al., 2021). One HCP explained that the lack of a clear pathway itself is due to the complete absence of a commissioned service in their area:

*“There isn’t a pathway because it’s not a commissioned service.”* (French et al., 2020, p. 8)

The failure of some Clinical Commissioning Groups (CCGs) to fund or adequately staff ADHD services ignores clinical evidence, national guidelines, and legal duties to prevent

health inequalities (Young et al., 2021). Even where services do exist, they were often so poorly advertised and restructured that HCPs were unaware of their existence (French et al., 2020). Poor coordination between mental and physical health providers deepened the divide, as well as between child and adult services, leaving service users unable to either access or maintain support (Young et al., 2021).

A lack of understanding between services worsens these issues, with GPs describing a mismatch between what they can do in their role and what secondary care services believe they can do (French et al., 2020).

Current service design often isolates ADHD, treating it as an “*ultra-specified*” (Ward et al., 2024, p. 7) presentation with little regard for its broader health implications. Without a cohesive system, adults with ADHD will continue to face fragmented care.

*“The one healthcare issue per visit set up of GP practices” limits discussion of the broader impact of ADHD on an individual’s physical and mental health (Ward et al., 2024, p. 7).*

Autism services were also fragmented, with tensions between specialised and general services. A combined approach, involving specialised assessments alongside equal access to primary and other health services was suggested (Crane et al., 2019). Authors were critical of the present healthcare system where only specialist services offer care, highlighting that it narrowed perspectives and responsibilities:

*“You come along with this concept of what autism is and everything that you look at becomes filtered through that lens... a search for things that fit in... that does sometimes close down thinking.” (Hayes et al., 2022, p. 8)*

The Westminster Commission on Autism (2016) highlighted barriers autistic individuals faced in primary care, including communication issues and lack of provider understanding. It called for better training, sensory-friendly environments, continuity of care, consistent diagnostic codes, a National Primary Care Register, and an Autism Indicator in Quilty Outcome Frameworks<sup>17</sup> (QOFs).

## 2.9 Discussion

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<sup>17</sup> A UK system for rewarding GP practices financially for providing high-quality care. It includes indicators for clinical care, public health, and patient experience, and aims to improve standards and consistency across primary care services.

### **2.9.1 Summary of Findings**

This SLR explored HCP perspectives on barriers to accessing care for adults with ADHD or ASD. The thematic synthesis identified three key themes: (1) The competence gap, (2) The diagnostic to post-diagnostic journey and (3) Navigating a broken system. These themes discussed the professionals and systemic challenges HCPs faced when working with adults with ADHD and ASD.

### **2.9.2 Linking findings to existing literature**

*'The training gap'* amongst HCPs was a major issue. The data highlighted that many HCPs step into clinical roles with inadequate training on ADHD and autism, especially in adulthood. The training gap extended beyond a significant knowledge gap, as the findings seemed to be the perpetuation of unhelpful biases and outdated assumptions (such as ADHD stemming from environmental factors). In the current review, HCPs repeatedly explained that diagnostic inaccuracy and overshadowing led to the reinforcement of harmful perceptions.

Calls for training aligned with previous research, which has long advocated for, and shown the benefits of, incorporating training into healthcare education (Clarke & Fung 2022; Boufin Tebeu, 2023). Although promising that autism training is now incorporated into mandatory training (The Health & Care Act 2022), the need for specific training for those supporting people with ADHD still lags behind. It is also a possibility that HCPs simply do not have capacity to attend additional training given the systemic challenges in their workplace, such as poor working conditions (Cooksley et al., 2023) and high staff turnover (Buchan et al., 2019). The recurrence of this theme across seven of the eight eligible studies, mostly of high quality (see Table 8), demonstrated the reliability of the theme and the validity of the conclusions drawn.

*'Navigating a broken system'* highlighted systemic challenges that were deeply entrenched within the healthcare infrastructure and even acknowledged by the UK Health Secretary<sup>18</sup> (Streeting, 2024). Issues lead to fragmented service provision (Smith et al., 2024), and were associated with funding, commissioning, and regional disparities, often described as a “postcode lottery” (Redhead & Lynch, 2024). At a service level, poor communication and

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<sup>18</sup> Wes Streeting at the time of writing

coordination between services caused significant delays to diagnosis and support (Shady et al., 2024; Veale 2018). This pattern mirrored wider concerns raised across the literature, emphasising that such inefficiencies compromise health outcomes (Matheson et al., 2013). The NHS and successive governments have yet to adopt a coordinated strategy to address the ongoing mismatch between service provision and demand, resulting in long wait lists and failures in healthcare delivery. This can have a particularly damaging impact on adults with ADHD and autism, who often face additional barriers to accessing appropriate care. Seven studies mentioned this theme, six of which were high quality, reflecting its relevance and significance across diverse healthcare contexts (see Table 7).

The third theme described the '*Diagnostic to post-diagnostic journey*'. The process of securing a diagnosis is consistently fraught with delays, misdiagnoses, and conflicting practices across HCP and services (Maciver et al., 2024; Smith et al., 2024).

Post-diagnostic support, according to NICE guidelines (2018), should include collaborative formulation, psychoeducation, medication, psychological therapy, practical strategies and environmental adjustments, signposting and peer support, as well as employment support. However, HCPs noted that once a diagnosis is made, many are essentially "*dumped*" (Spain et al., 2022, *p. 11*) by the system, which can lead to repeated crises, re-referrals, disengagement from services, and worsening mental health (Huang et al., 2024). Only one study did not include this theme (Ward et al., 2024). The five studies that did were of high quality, highlighting the unfortunate consistency of a fragmented and unsupported journey across contexts and stages of care (see Table 7).

Receiving a diagnosis without any meaningful follow-up raises serious concerns about the value of the process and risks exposing individuals to increased stigma and prejudice from wider society (Craddock et al., 2014).

### **2.9.3 Strengths and Limitations**

**Strengths.** This SLR was the first of its kind to look at HCP perspectives on the barriers to care for adults with ADHD and autism in the UK and therefore filled a significant gap in the literature. A rigorous methodology was utilised in the search process and data extraction and quality appraisal were completed by two researchers with knowledge in the field, boosting the validity of decision-making about which studies and information were included. Cohen's Kappa was calculated to check inter-rater reliability, and consistently showed high

levels of agreement, and disagreements were resolved through discussion and use of the principal supervisor. Through the lens of CR, variations in study ratings and inter-rater reliability are expected as it is accepted that each researcher will engage with the information presented to them differently (Fletcher, 2017). This reflects the view that knowledge is always partial and situated, shaped by the researcher's position, context, and interpretive lens.

All included studies were conducted in the UK, which strengthens the applicability and relevance of the findings to UK healthcare contexts. This shared setting allows the synthesis to reflect consistent systemic, policy and service-level challenges faced by HCPs working within NHS and relate systems.

**Limitations.** One limitation of this literature review is that several included studies sampled multiple stakeholder groups, introducing heterogeneity into the findings and subsequent conclusions. While incorporating the views of families and EBEs is valuable, their priorities and perspectives can differ significantly from those of healthcare professionals. As a result, conclusions drawn specifically about the clinical challenges and training needs of HCPs may be less precise than if the sample had focused exclusively on professionals.

Another limitation is the risk of bias in the samples of the included studies. Many of the included studies had self-selecting recruitment methods. Therefore, HCPs may have had particular motivations for engaging with the research, such as personal connections to ADHD and ASD, causing differing perspectives from less interested HCPs. As a result, conclusions drawn on factors such as knowledge and awareness may be skewed to a more favourable view. The findings may not truly reflect the views of the wide professional community. The review may risk underplaying the genuine scepticism and stigma among HCPs less engaged with issues concerning those with neurodevelopmental differences like ADHD and ASD.

A further limitation of this review is that not all available databases were searched due to time limitations of the project as a whole, meaning that it is possible some relevant studies were not retrieved.

A final limitation of the included studies lies in their research design and sampling transparency. Several relied on self-selecting participants or failed to outline how they recruited their sample. These issues negatively impact their transparency and therefore limits transferability. It also raises concerns about potential bias in the reported findings.

#### **2.9.4 Critical Appraisal of SLR**

The CASP tool for systematic reviews (CASP, 2023) was used to quality appraise this SLR. The appraisal was conducted independently, then reviewed by the secondary researcher to reduce the risk of bias. Each response was scored using the system described in Appendix J.

#### **2.9.5 Implications for Clinical Practice and Future Research**

**Implications for Clinical practice.** The findings of this review highlight several clinical implications. First, there is a clear need to enhance HCPs knowledge and confidence in working with adults with ADHD and ASD. Consistent with previous research, many of the studies reviewed described gaps in training that compromise diagnostic accuracy and the quality of care provided. Encouragingly, the Autism Act (2009) and subsequent developments, such as the rollout of the Oliver McGowan mandatory training represent steps in the right direction. However, similar progress has not yet been made in ADHD education, despite comparable need and prevalence.

The review highlights the importance of moving beyond a purely medicalised diagnostic approach to one that includes collaborative formulation and person-centred care planning. Following a diagnosis, service users should be supported to understand their neurodevelopmental profile, formulate their experiences, and co-create a treatment plan that reflects their needs, goals, strengths, and interests (NICE, 2012, 2018). This may involve psychoeducation, therapy, medication where appropriate, practical strategies, and signposting to social and employment support services. Without this, there is a risk that diagnosis becomes a stigmatising label rather than a gateway to understanding and support.

Furthermore, the findings highlight the value of multidisciplinary, integrated models of care (Pellicano et al., 2022). Such models should involve collaboration across general practice, psychiatry, psychology, occupational therapy, and other relevant HCPs, alongside stronger integration between services more broadly. Greater coordination has the potential to improve communication, support clinicians, and strengthen service delivery systems (French et al., 2020), ultimately increasing the likelihood of meeting the long-term, complex, and heterogeneous needs of adults with ADHD and autism. Without such systemic change, services risk perpetuating the fragmented and overly medicalised “diagnose and discharge” model described by participants across multiple studies.

Investment in healthcare for ADHD and autism is not only ethically necessary but also economically justified. For example, unmet needs result in repeated crises, re-referrals, and greater long-term costs to the NHS (Furukawa et al., 2021; Newlove-Delgado et al., 2023). The current system not only fails those it seeks to support but also contributes to clinician burnout and service overload (Kinman et al, 2023). There is, therefore, an urgent need to develop consistent, funded, and long-term post-diagnostic pathways that centre the person, not just the diagnosis (NHS England, 2024).

**Future Research.** Future research could build on these findings by exploring the perspectives of specific healthcare professional groups. Many existing studies use mixed samples, which can obscure profession-specific insights. Qualitative research focused on distinct professional roles is therefore needed to better understand the barriers to improving ADHD care. Further studies should also examine how improved training on neurodiversity, particularly ADHD, affects clinical outcomes, including diagnostic accuracy, treatment planning, and patient experience.

In addition, investigating system-level factors such as commissioning arrangements, shared care protocols, and digital accessibility could offer valuable insights into how service structures shape continuity of care. Finally, intersectional research is needed to explore how individual characteristics such as gender, ethnicity, and socioeconomic status influence access to ADHD and autism diagnosis and ongoing support. This evidence could help inform the development of more inclusive, equitable, and neurodiversity-affirming services.

## 2.10: Conclusion

This SLR sought to synthesise the literature on HCP perspectives on barriers to accessing care for adults with ADHD or ASD by consolidating and critically examining the research. In doing so, it amplified the voices of frontline HCPs underrepresented in research, and provided valuable insights that seek to inform targeted changes to existing service provision as well as the development of new care models. The findings indicate that HCPs face challenges in offering effective care to adults with ADHD and autism, due to limited training opportunities, navigating a systemically flawed healthcare system, and insufficient complex care pathways. Recommendations have been made to improve access to training, promote integrated care models, and develop evidence-based post-diagnostic support.

These insights point to key avenues for future research, emphasising the need for further investigation into systemic reforms and innovative support mechanisms to ultimately enhance outcomes for adults with ADHD and ASD.

The findings from this review highlighted significant gaps in the literature and informed the design of the empirical study presented in Chapter 3.

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**A personal reflection...**

I did not collect full demographic data, including ethnicity, as part of the Qualtrics survey, which limits the extent to which I can comment on the diversity of the sample. However, based on participants' responses to the data I did collect, I was aware that the sample lacked diversity in characteristics such as gender, which mirrors the workforce demographic make-up of many NHS mental health services. While their insights were extremely valuable, I was mindful that this relative homogeneity may have limited the range of perspectives captured, particularly around cultural and structural issues in ADHD diagnosis.

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## Chapter 3: Methodology

### 3.1 Chapter overview

This study explored the perspectives of HCP specialists in ADHD, on the challenges adults face in accessing diagnosis and support. The Chapter begins with a brief positionality statement to clarify the researcher's lens, followed by an overview of the research process. This includes the study design, ethical considerations, stakeholder consultation, recruitment strategy, and participant characteristics. It then outlines how the data were collected and analysed, concluding with a quality appraisal and a short section on researcher reflexivity.

#### 3.1.1 *Rationale for Current Study*

The current study was developed in response to the Future Research recommendations outlined in Section 2.9.5, as well as the significant gaps in the literature identified in Section 2.9.2. While the SLR provided valuable insight into systemic and clinical barriers, it also revealed how the perspectives of frontline HCPs working directly with adult ADHD remain underrepresented. Building on these findings, this study focuses on understanding pathway issues in adult ADHD care from the viewpoint of HCPs with specialist knowledge and lived professional experience.

Particular attention was paid to barriers that have been underreported in the literature, such as cultural and intersectional factors contributing to underdiagnosis and misdiagnosis. These areas are crucial for addressing known inequalities in ADHD recognition and access to support. By capturing these nuanced professional perspectives, this study seeks to generate new insight into how services can better reflect the realities of practice, inform policy, and ultimately support the development of more inclusive and sustainable models of care.

The findings will not only address current gaps in research but are also intended to inform future service design, workforce training, and commissioning priorities. In doing so, this study lays the groundwork for further applied research into the implementation of neurodiversity-affirming, equitable care pathways for adults with ADHD.

**Aims and Research question.** This study aims to explore the following questions:

***Primary research questions:***

1. According to HCPs specialising in ADHD, what pathway issues exist for adults who are seeking ADHD diagnosis and support?

***Secondary research questions:***

2. How do HCPs conceptualise the presentation of ADHD in adults, considering its heterogeneous presentation?
3. What are HCPs perceptions of cultural issues in adult ADHD that may contribute to under-diagnosis and misdiagnosis, and what if any, specific cultural factors do they identify as potential contributions?
4. How can access to diagnosis and support for adult ADHD be facilitated and improved?

### **3.2 Theoretical perspective, ontology and epistemology**

This research was carried out from a critical realist (CR) perspective, which recognises an independent reality while also acknowledging that our access to that reality is always partial and shaped by interpretation (Bhaskar, 1979; Cruickshank, 2012). Unlike positivism, which sees reality as objective and measurable, or constructivism, which views reality as entirely socially constructed, critical realism (CR) navigates a middle ground. It adopts a realist ontology, that a world exists beyond our perceptions, and a relativist epistemology, recognising that all knowledge is theory-laden, socially influenced, and context-dependent (Fryer, 2022; Fletcher, 2017; Wynn & Williams, 2012).

This ontological and epistemological stance underpinned both the design and analysis of the project. It enabled a nuanced exploration of HCP narratives while also allowing for critical consideration of the systems and structures shaping those accounts. RTA was chosen specifically because it aligns with this position. RTA acknowledges the researcher's subjectivity and avoids claims of neutrality and objectivity. Instead, it sees the researcher as an active participant in meaning-making (Braun & Clarke, 2006, 2022).

This stance also aligns with a neuro-affirmative approach, which recognises the role of language in shaping how neurodivergence is understood and responded to. A neuro-affirmative lens avoids deficit-based or pathologising terms and instead uses language that respects ADHD and autism as forms of neurocognitive diversity. It positions distress not as a

symptom of disorder, but as a potential consequence of environmental mismatch, unmet needs, or social invalidation. This perspective informed the way participants' accounts were interpreted and underpinned efforts to produce findings that challenge reductive narratives around ADHD and autism (Hartman et al., 2024).

### ***3.2.1 Positionality***

Whilst I class myself as an outsider researcher, I also hold an adjacent position that places me close to the context under study. I do not have lived experience of ADHD, nor do I have close relational experience with it, but I am a HCP who has worked in the NHS for nearly a decade. I have been fortunate to work with many who have identified as 'neurodiverse' or as 'ADHD'.

My status as a HCP was made clear to participants through the participant information sheet, where my job title was stated, although it was not discussed further during interviews. I hoped that having some shared ground, particularly in relation to professional roles and experience of NHS systems, might help participants feel more at ease when speaking with me. Shared experiences between researcher and participant can build rapport and trust in qualitative interviews (Reeves et al., 2008). However, this positioning can also present challenges. It can lead to assumptions, missed opportunities to explore participants' meanings in more depth, or moments where I unintentionally slipped into a clinical or collegial role (Asselin, 2003). Being aware of these risks was important to how I approached both data collection and analysis.

I am under no illusion that my clinical practice has informed my research, and my research has informed my practice. I approached this project not as a detached observer but as someone personally and professionally invested in improving healthcare experiences for a clinical group that has long been overlooked. For these reasons, engaging in ongoing reflexivity, including critical examination of my own views, assumptions, and professional positioning, was essential to enhancing the trustworthiness and credibility of the findings in this study.

### ***3.2.2 Reflexivity***

Different strategies were employed to support reflexivity throughout the project:

**Supervision.** Regular supervisory meetings gave me a space to talk openly about the decisions I was making and what was influencing them. These conversations helped me think critically about my interpretations and added depth to both the methodology and the analysis.

**Reflective diary.** I kept a diary during the research process, which helped me track how my clinical work and research thinking were interacting. It gave me a space to notice when personal assumptions or emotional reactions might be shaping the way I understood what participants were saying. Extracts from this diary can be found in Appendix A.

**Input from others:** I had the opportunity to consult with a range of people across the span of the project, including Experts by Experience and HCPs. Their perspectives often helped me challenge my own thinking and highlighted aspects of the data I might have overlooked. These conversations helped me to build a fuller understanding of the topic.

**Professional communities:** I committed to staying involved in wider conversations about ADHD care through specialist training<sup>19</sup> and professional forums. This helped me stay up to date with current issues and broadened my understanding of how the issues discussed in this research play out in real-world practice. It also helped strengthen my sense of investment in the relevance and impact of the findings.

### 3.3 Design

#### 3.3.1 Qualitative Methodology

This study used a qualitative, RTA methodology to address the research question (Braun & Clarke, 2006). Semi-structured interviews were conducted to support reliable and comparable data collection across participants while allowing for the exploration of additional topics emerging during interviews (Kallio & Hanna, 2015). As outlined in Section 3.2, the epistemological stance of this study adopted a CR position (Braun & Clarke, 2022a; Fryer, 2022).

#### 3.3.2 Rationale for Qualitative Design

In healthcare, qualitative research helps to understand how people make sense of the environments in which they live, work, give, and receive care (Atkinson et al., 2001; Holloway & Galvin, 2023). A qualitative design was therefore selected, as the research

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<sup>19</sup> 'Understanding ADHD' (Open University, 2 days)

question explores the perspectives of HCPs working within the systems that shape ADHD care, rather than seeking a quantifiable outcome (Gunter, 2002). RTA was chosen for its flexibility, focus on meanings made, and its relevance for exploring experiential accounts in applied settings (Braun & Clarke, 2022b), making it well-suited to this study.

It was felt that RTA was a good fit for the underlying theoretical and philosophical assumptions of this project. It allowed the data to be approached in a way that valued the subjectivity of participants' accounts, while also recognising that the author's own interpretations as the researcher would inevitably shape the analysis.

### ***3.3.3 Reflexive Thematic Analysis***

RTA was chosen as the method of analysis (Braun & Clarke, 2006, 2013, 2019). RTA offers a structured yet flexible way of identifying and developing themes across a dataset using a six-step process (Braun & Clarke, 2006). This approach recognises the central role of the researcher in the analytic process. Rather than treating subjectivity as something to be minimised, RTA encourages researchers to be reflexive and to actively engage with their own perspectives, experiences, and assumptions (Devine, 2021).

Reflexivity involves being aware of the lens we bring to the research and how this may shape interpretation (Haynes, 2023). Braun and Clarke (2006, 2013, 2019) highlight the importance of critically interrogating how our own position may be influencing the way we engage with and make sense of the data (Devine, 2021). Given the researcher's position as an outsider to participants' specific experiences within their roles, but with adjacent experience through both professional and personal engagement with NHS systems, reflexivity was essential for ensuring transparency and maintaining analytic integrity throughout the research process.

As with any method, RTA carries both strengths and limitations, which are acknowledged in relation to the aims and context of the study. Table 8 provides a summary of the strengths and limitations of RTA, specifically considered in a healthcare context.

**Table 8***Strengths and limitations of reflexive thematic analysis in healthcare contexts*

	<b>Strengths (opportunities)</b>		<b>Limitations (challenges)</b>
Capturing complexity	<ul style="list-style-type: none"> <li>• Respects the complexity of human experiences</li> <li>• Captures nuanced, lived experiences of service users and professionals</li> <li>• Aligns with the realities of complex health systems</li> <li>• Encourages rich, contextualised interpretations</li> </ul>	Need for clarity	<ul style="list-style-type: none"> <li>• May lack analytic clarity if poorly executed</li> <li>• Without clear focus, themes can become vague or descriptive</li> <li>• Risk losing coherence when flexibility is not carefully managed</li> </ul>
Reflexivity	<ul style="list-style-type: none"> <li>• Values researcher's insight, reflexivity and role in shaping meaning</li> <li>• Encourages critical engagement with positionality and assumptions</li> <li>• Promotes depth and thoughtfulness in interpretation</li> </ul>	Risks of subjectivity	<ul style="list-style-type: none"> <li>• Relies heavily on research skill</li> <li>• Analysis quality depends on the researcher's ability to be reflexive</li> <li>• Can lead to shallow or biased findings if reflexivity is superficial</li> </ul>
Flexibility	<ul style="list-style-type: none"> <li>• Adaptable across settings and frameworks</li> <li>• Can be used within different paradigms e.g. critical realism, constructionism</li> <li>• Suits exploratory or under-explored areas of</li> </ul>	Lack of standardisation	<ul style="list-style-type: none"> <li>• No formal coding framework makes it harder to compare across studies</li> <li>• May be questioned in more positivist or medically-oriented teams (Renjith et al., 2021)</li> </ul>

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health research

- Does not require rigid coding structure, themes can emerge organically (Braun & Clarke, 2019)
-

**Alternative qualitative methods.** Other qualitative analytic approaches were considered, but reflexive thematic analysis was judged the best fit for this study. Appendix K outlines the rationale for not selecting alternative methods.

### 3.4 Ethical considerations

This research received ethical approval from the University of Hertfordshire Research Ethics Committee (protocol number: 0676-2025-FebHSET, Appendix L), and approved by the Health Research Authority (HRA) (protocol number: 24/HRA/4796, IRAS Project ID: 347235, Appendix M). The research was conducted in line with the British Psychology Society's Code of Human Research Ethics (British Psychological Society [BPS], 2021a) which supplements the general ethical principles outlined in the Society's Code of Ethics and Conduct (BPS, 2021b). The following ethical considerations were outlined in the participant information sheet and were also discussed at the beginning of each interview.

**Informed consent.** A brief description of the research project was sent to the participants initially through the advertisement poster (Appendix N) at the point of recruitment, and then via the participant information form (Appendix O) that was on the initial page of the Qualtrics screening survey (See section 3.8.3 below: Appendix P). Participants were asked to sign the consent form via Qualtrics (Appendix Q) prior to being contacted via email for interview.

**Confidentiality.** Participants were assured that any information they shared would be kept confidential. They were reminded of their right to decline answering any questions they felt were too personal. Every effort was made to ensure that the data collected respected participants' dignity and autonomy and did not compromise their interests (Bos, 2020). Participants were also informed about the limits of confidentiality and were advised that, if necessary, confidentiality would only be broken in line with the BPS Code of Conduct (BPS, 2021a). Confidentiality in research is protected under the European General Data Protection Regulation (Data Protection Act, 2018). All consent forms, interview recordings, and transcripts were securely stored on the University of Hertfordshire's encrypted OneDrive system.

**Anonymity.** Participants were informed that their data would be stored anonymously. Personal information, such as demographic details, was saved electronically on the University of Hertfordshire's encrypted OneDrive under a unique participant number, kept separate from the interview files. Quotes from interview transcripts were anonymised

by removing any identifying details (such as names and locations) before being shared with the research team, which was made up supervisors.

**Right to Withdraw.** Participants were advised that they could withdraw from the research at any point before their interview took place. After taking part, they were reminded they could withdraw their data without giving a reason, up to two weeks after their interview date. If a participant chose to withdraw, any data collected would be securely destroyed.

**Psychological distress and protecting participants.** Participants were informed that some of the topics discussed might be emotive or personally challenging. To ensure appropriate support, a full list of resources was included in the debrief form provided after the interview, including details of where to seek help if any feelings of distress or moral injury were triggered (Appendix R).

### 3.5 Consultation

Consultation was welcomed throughout the research process (Table 9). Three consultants formed an advisory panel<sup>20</sup>, which took place via Microsoft (MS) Teams.

**Table 9**

*Engagement with Consultation*

Research Stage	Task	Who?
Engagement with EBE	To advise on: Recruitment	Informal network meeting with advisory panel and EBE
Methodology	To review the consent form To review the participant information form	'Advisory Panel' (three consultants, one EBE)
	To review the interview schedule	

<sup>20</sup> Mental health nurse, SLT, and clinical psychologist

	To review the advertisement poster	
Data collection	Pilot Interviews	One EBE, one colleague
Data Analysis	To discuss/review codes To discuss/review themes	Advisory panel, supervision team
Discussion	To discuss themes in relation to existing literature	Advisory panel, supervision team
Dissemination	To advise in effective methods of dissemination  To advise on any challenges that might arise in relation to dissemination, and accessing the population of interest	Advisory panel, supervision team

In planning stages, I reached out to several organisations with a vested interest in adult ADHD healthcare, including ADHD UK, UKAAN and the ADHD Foundation. This was done to explore opportunities for consultation, build relationships with relevant networks, and ensure that the study remained grounded in current issues faced by both professionals and those seeking support. These organisations were supportive of the research and helped to share the study through their networks, aiding with participant recruitment.

### 3.6 Recruitment

#### 3.6.1 Recruitment Strategy

It was hypothesised that recruitment may be challenging, given that barriers to involving HCPs in research include time constraints, heavy clinical workloads, competing priorities, and a lack of protected time for research involvement (Maguire et al., 2022; Spratling, 2013). To address this, a clear recruitment strategy was developed to ensure enough participants were reached (Negrin et al., 2022). This involved two main routes: NHS and non-NHS.

Non-NHS recruitment began first. Three national ADHD charities were contacted: ADHD UK, UKAAN, and the ADHD Foundation. An initial email was sent outlining the study and the recruitment process, along with the recruitment poster, and all three charities

agreed to share the study through their networks. The study was also shared via the lead researchers own social media accounts and through several professional networks they were part of, where research opportunities are regularly advertised. Recruitment via this channel started in January 2025.

The study attracted interest from several HCPs with lived experience of ADHD (EBE), one of whom later became an EBE for the project. In addition, three professionals outside of the supervisory team who got in touch became members of the advisory panel.

NHS recruitment took place through Hertfordshire Partnership University NHS Foundation Trust (HPFT). I worked with their Research and Development Team, who shared the study through internal email lists and relevant professional networks. This required research sponsorship approval (Appendix L). Recruitment via this channel started in February 2025.

Following this, the advisory panel was invited to review early drafts of key study materials, including the recruitment poster, consent form, participant information sheet, debrief document, and interview schedule. Their input led to a number of revisions. One key change was clarifying in the advert that the study was aimed at healthcare professionals who work with adults with ADHD, rather than those with a diagnosis themselves. An invitation email was then distributed to prospective participants (see Appendix S).

### **3.7 Participants**

#### ***3.7.1 Sampling***

Purposive sampling was used to recruit HCPs with relevant experience of working with adults with ADHD. This approach involves targeting individuals who are likely to have insight into the topic under study (Palinkas et al., 2015). Recruitment was carried out through professional email networks and social media platforms, where the study was advertised to reach potential participants. This was supported by convenience and snowball sampling. Participants self-selected into the study based on interest and availability, and some went on to share the advert with colleagues. In addition, senior clinical leads were contacted directly and asked to circulate the study within their teams and networks. A brief email was sent to them with details of the study and a copy of the recruitment poster attached.

#### ***3.7.2 Participation Criteria***

The inclusion and exclusion criteria for participation are shown in Table 10.

**Table 10***Recruitment: Inclusion and Exclusion Criteria*

<b>Participant Inclusion Criteria</b>	<b>Participant Exclusion Criteria</b>
<ul style="list-style-type: none"> <li>Qualified HCPs with experience of supporting service user with ADHD processes (such as diagnostic assessment, support such as therapy and coaching)</li> <li>HCPs who have worked in the NHS within the last five years, in a service where ADHD diagnostic assessments are provided</li> </ul>	<ul style="list-style-type: none"> <li>HCPs who are actively seeking a personal ADHD diagnosis</li> <li>HCPs working exclusively in private practice</li> <li>HCPs who have not worked in the NHS in the last five years</li> </ul>

**3.7.3 Participant Demographics**

Participants expressed interest in taking part by completing a Qualtrics survey (appendix P), accessed via the QR code on the research poster. The survey included the participant information sheet, consent form, and a short screening form to confirm inclusion and exclusion criteria.

As part of the survey, participants were asked to confirm their eligibility (Table 10) and to indicate whether they were willing to attend a follow-up interview via Microsoft Teams. Basic demographic information was also collected, including profession, age range, and clinical context (such as NHS or non-NHS). This information was used to confirm eligibility and helps contextualise the sample. Details are summarised in Table 11.

A total of 58 people completed the survey. Of these, 15 met inclusion criteria and were invited to interview. Two participants did not respond, and one participant did not attend or respond to a follow-up email offering a new time. Twelve participants were interviewed, making up the final sample.

Twelve HCPs took part in the study. 5 identified as male (42%), and 7 identified as female (58%). In order to protect anonymity, it was decided by the lead researcher and supervisory team not to report ethnicity.

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### A personal reflection...

My sample lacked cultural diversity, which mirrored the workforce demographic make-up of many NHS mental health services. While their insights were valuable, I was aware that this homogeneity may limit the range of perspectives captured, particularly around cultural and structural issues in ADHD diagnosis.

Navigating the ethics process was one of the more challenging aspects of this project. At times it felt unnecessarily complex involving unclear forms, long waits for response, and frequent follow-up emails. What stood out to me was how much this echoed the themes explored in my research. It offered a small but meaningful insight into what many people describe when seeking support for ADHD: navigating a system that feels unresponsive and not built with you in mind.

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**Table 11***Participant demographic information*

Pseudonym	Age Range	Gender	Profession	Context
Harriet	40-49	Female	Mental Health Nurse	Primary care network, GP practices
Rachel	18-29	Female	Clinical Psychologist	ADHD & ASD service
Joanna	40-49	Female	Speech and language therapist	ADHD service
Colin	60+	Male	Consultant Psychiatrist	LD service
Sophie	30-39	Female	Clinical Psychologist	ADHD service
Nadia	40-49	Female	Consultant Forensic Psychologist	Forensic service
Thomas	30-39	Male	Consultant Psychiatrist	LD service
Louise	40-49	Female	Occupational Therapist	ADHD service
David	30-39	Male	Clinical Psychologist	Family safeguarding
Enya	40-49	Female	Clinical Psychologist	Early intervention in psychosis
Anna	30-49	Female	Clinical Psychologist	Social services
Monica	50-59	Female	Counselling Psychologist	AMHT

### 3.8 Data Collection

#### 3.8.1 Resources

All 12 interviews were scheduled to take place online and recorded via Microsoft Teams. All recordings were saved on the University of Hertfordshire OneDrive and encrypted for data protection purposes. The interviews were transcribed via Microsoft Teams, then exported to Microsoft Word and checked through with the recording of the interview to correct any transcription errors (transcript extract, Appendix T). Microsoft Excel was used in the analysis of the transcripts.

#### 3.8.2 Interview Schedule

**Interview schedule development.** The lead researcher developed a semi-structured interview schedule in collaboration with the principal investigator, following best-practice recommendations for qualitative interview design (Bearman, 2019). The schedule was guided by a general interview guide approach (Turner, 2010), combining predetermined open-ended questions with flexibility to follow the participant's lead. This method supports the generation of rich, experiential data that is grounded in the perspectives of the participants (DiCicco-Bloom & Crabtree, 2006).

The schedule was shaped by a review of relevant literature and policy document, which informed both the focus and wording of the questions (Kallio et al., 2016). Topics were selected to reflect key issues highlighted in the existing evidence base and areas of ongoing debate in adult ADHD care. The draft schedule was reviewed by an EBE with lived experience of ADHD and navigating NHS and private pathways. Their feedback helped ensure the questions were appropriately framed and sensitive to the perspectives of those with ADHD. The EBE did not participate in the study itself.

The interview schedule was structured around five sections: (1) warm-up and background information, (2) referral and diagnostic pathways, (3) service provision and barriers, (4) characteristics of the client group, and (5) experiences of work during the Covid-19 pandemic. This structure was designed to build rapport and ease participants in (Bearman, 2019; Mann et al., 2019), followed by system-level questions around referral and access. Questions about client characteristics and ADHD were placed later in the interview to allow participants to draw on reflection and context, with Covid-19 questions used to close the interview on a broader, less personal note. The draft schedule was reviewed by

the research supervisors, who provided feedback on the sequencing and clarity of questions. Revisions were made to improve flow and ensure sensitivity to participant roles and experiences (see Appendix U).

**Pilot interview.** As part of the pilot phase, feedback was sought from an EBE associate and an external colleague not involved in the project. In addition to reviewing the interview schedule, both also participated in a pilot interview highlighted potential weaknesses, limitations, and areas that might be unclear to participants. In line with Kvale's (2007) recommendations, this formative feedback informed key revisions ahead of the study's full rollout. Changes included simplifying the language to reduce jargon, clarifying the structure and timing of the interviews, and refining some of the prompts to better support participant understanding.

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#### **A personal reflection...**

During consultation, my EBE challenged me on my use of the word “*symptom*” when describing ADHD. He explained that the term implies illness and pathology, reinforcing a deficit-based model that stigmatises neurodivergence. This made me reflect deeply on how medicalised language shapes perception, and how much of it I had internalised through training. He reminded me that ADHD is a difference, not a disease. As a result, I revised the interview schedule to remove clinical terms and became more mindful of how my language and assumptions needed to shift if I was to be truly neuro-affirmative. It was a pivotal moment where I reflected on how I wanted to approach this project and the concept of ADHD more widely.

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#### **3.8.3 Interview Procedure**

The researcher joined the Microsoft Teams call shortly before the scheduled start. After brief introductions, the participant was given the chance to ask questions. The consent form was reviewed, and anonymity, confidentiality, and the right to withdraw were reiterated. Recording began once consent was confirmed, and basic demographic details were collected before starting the interview. At the end, participants were invited to add

anything further, thanked for their time, and sent a debrief form. All participants chose to be kept updated and consented to secure storage of their email addresses for this purpose. An update will be sent once dissemination plans are confirmed. An email will be sent to participants once plans for dissemination have been confirmed, such as publication details.

### 3.9 Data Analysis

Anonymised transcripts were analysed using RTA (Braun & Clarke, 2006, 2013, 2019), supported by Microsoft Excel. Analysis followed the six-phase framework outlined by Braun and Clarke for conducting effective RTA (2006, 2013). A breakdown of each phase is shown in Table 12.

**Table 12**

*Six-Steps to RTA (Braun & Clarke, 2006, 2013, 2019)*

RTA Phase	Researcher Role
<b>Phase 1:</b> Data Familiarisation	Each interview recording was listened to, and transcripts were read through multiple times to become immersed in the data. Transcripts were printed, and initial thoughts, ideas, and patterns were noted down for each interview. These annotations were developed into familiarisation doodles, as described by Braun & Clarke (2013). A sample of these can be found in Appendix V.
<b>Phase 2:</b> Generating Initial Codes	Each transcript was coded using Microsoft Excel. Transcripts were read verbatim and initial codes and code labels were developed (Appendix W). Effort was made to code all words and phrases relevant to the research questions. Following this period of coding and recoding, 158 initial codes had been developed.
<b>Phase 3:</b> Generating Themes	The 158 code names were written out on post-it notes. As each one was written, the associated quote was revisited to check how it related to the research question. Any codes or quotes that did not seem relevant were removed. Following

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this process, 51 codes remained. These post-it notes were then grouped in ways that reflected shared meaning across the dataset. Thematic maps were developed (Appendix X), which supported generation of the 5 themes, with 13 accompanying subthemes. These were shared with thesis supervisors for consultation.

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<b>Phase 4:</b>	Over time, distinct themes were developed from the data.
Reviewing Potential Themes	Each theme and subtheme was reviewed carefully in relation to the research question, the internal coherence of the theme, and whether it meaningfully captured something important within the data.
<b>Phase 5:</b>	Themes were refined, named, and defined. Each theme was linked back to the dataset by revisiting relevant quotes, ensuring a clear and coherent narrative was present. Themes were reviewed again with thesis supervisors. At this stage, the six initial themes described in Phase 3 had been refined into five final themes. Not all of these contained sub-themes.
<b>Phase 6:</b>	I gave a lot of thought to how the themes could be represented visually, as it did not feel right to show them as a simply linear process. In the end, I decided to use a metaphor shared by one of the participants. It felt like a genuine way to reflect the themes in a way that was both meaningful and true to the experiences they described.
Write-Up	

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### 3.10 Quality Appraisal, Rigour and Self-Reflexivity

#### 3.10.1 Quality Appraisal

Qualitative research is often critiqued for a perceived lack of rigour, limited generalisability, and subjectivity in interpretation (Leung, 2015). Concerns have also been raised about transparency in data analysis and potential researcher bias (Galdas, 2017). Furthermore, RTA is critiqued for methodological incongruence, misunderstanding

the concept of 'themes', using overly positive leaning language and practices<sup>21</sup>. A full quality appraisal of this research, addressing the common critiques can be found in Appendix Y.

### **3.10.2 Rigour and Quality**

To support the quality of the research, Elliot et al.'s (1999) seven-criteria framework was applied alongside RTA. Although developed independently, the framework complements RTA's principles by emphasising researcher reflexivity, grounding interpretations in data extracts, and promoting overall coherence and transparency. A summary of how each criterion was addressed is presented in Table 13.

**Table 13**

*Seven-Step Quality Framework (Elliot et al., 1999)*

<b>Quality Framework</b>	<b>Researcher Role</b>
<b>Step 1:</b> Owning one's perspective	The researcher's theoretical positioning was made explicit at the outset of the study. A reflexive journal was kept throughout to document personal values, assumptions, and reflections, supporting ongoing awareness of how these may have shaped the research process.
<b>Step 2:</b> Situating the sample	Demographic information was collected from participants to help situate the sample and to understand how context may have influenced the findings and their wider applicability.
<b>Step 3:</b> Grounding in examples	The results section presents participant quotations for each theme. This approach allowed readers to appraise how well the data fitted the researcher's interpretation. A transparent example of how codes were developed from the raw data is provided in Appendix T.
<b>Step 4:</b> Reviewing Potential Themes	Initial codes generated from the transcripts were discussed with the research supervisor, who has significant experience in the field. This helped ensure that the chosen themes and subthemes were firmly grounded in the data.

<sup>21</sup> Such as utilising concepts from quantitative research methods such as 'data saturation' and 'inter-rater reliability'.

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<b>Step 5:</b> Refining, Defining and Naming Themes	A thematic map was developed to show the visual relationship between the themes and subthemes. Alongside the narrative account, this helped to illustrate the broader connections between different parts of the dataset.
<b>Step 6:</b> Write-Up	Efforts were made to present the analysis in a way that felt authentic, compelling, and recognisable to readers familiar with the topic. Themes were illustrated with rich, illustrative quotes and grounded in participants' language to enhance relatability. The narrative aimed to communicate findings clearly without oversimplifying complexity, allowing readers to engage critically with the interpretations and assess their relevance to practice.
<b>Step 7:</b> Resonating with readers	The study findings were written up using an accessible narrative style and avoiding jargon where possible, aiming to make the interpretation and clinical relevance clear to a wide range of readers.

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### **3.10.3 Self-Reflexivity**

Within Reflexive Thematic Analysis (RTA), reflexivity involves recognising the researcher as actively involved in the construction of meaning, with subjectivity regarded as an asset rather than a bias to be eliminated (Gough & Madill, 2012). The researcher's background, beliefs, and prior experiences are understood to influence all aspects of the analytic process, from noticing patterns to generating codes and shaping themes. Rather than attempting to bracket these influences, RTA encourages researchers to acknowledge and critically engage with them as part of the interpretive work (Braun & Clarke, 2019).

Braun and Clarke (2022) stress that meaningful reflexivity involves interrogating the role of the researcher in shaping the research, requiring insight and transparency about one's values and assumptions. In this study, the researcher continually reflected on how their own identity, including being a white, British, thirty-one-year-old, middle-class, cisgender man, may have shaped interpretations. A reflexive journal was kept throughout all stages of the project, from ethical approval through to final analysis and write-up. This

included reflections on emotional responses, theoretical positions, social identity, and intersecting positionalities. Keeping this journal was a key strategy to support transparency and critical reflection, aligning with the RTA emphasis on researcher positionality as central to the analytic process (Braun & Clarke, 2019). Selected entries are included in Appendix A.

## Chapter 4: Results

### 4.1 Chapter overview

This Chapter presents the qualitative analysis of twelve semi-structured interviews, using RTA (Braun & Clarke, 2006, 2013, 2019). Five themes and thirteen subthemes were developed from the data and are discussed throughout this Chapter.

### 4.2 Presentation of the findings

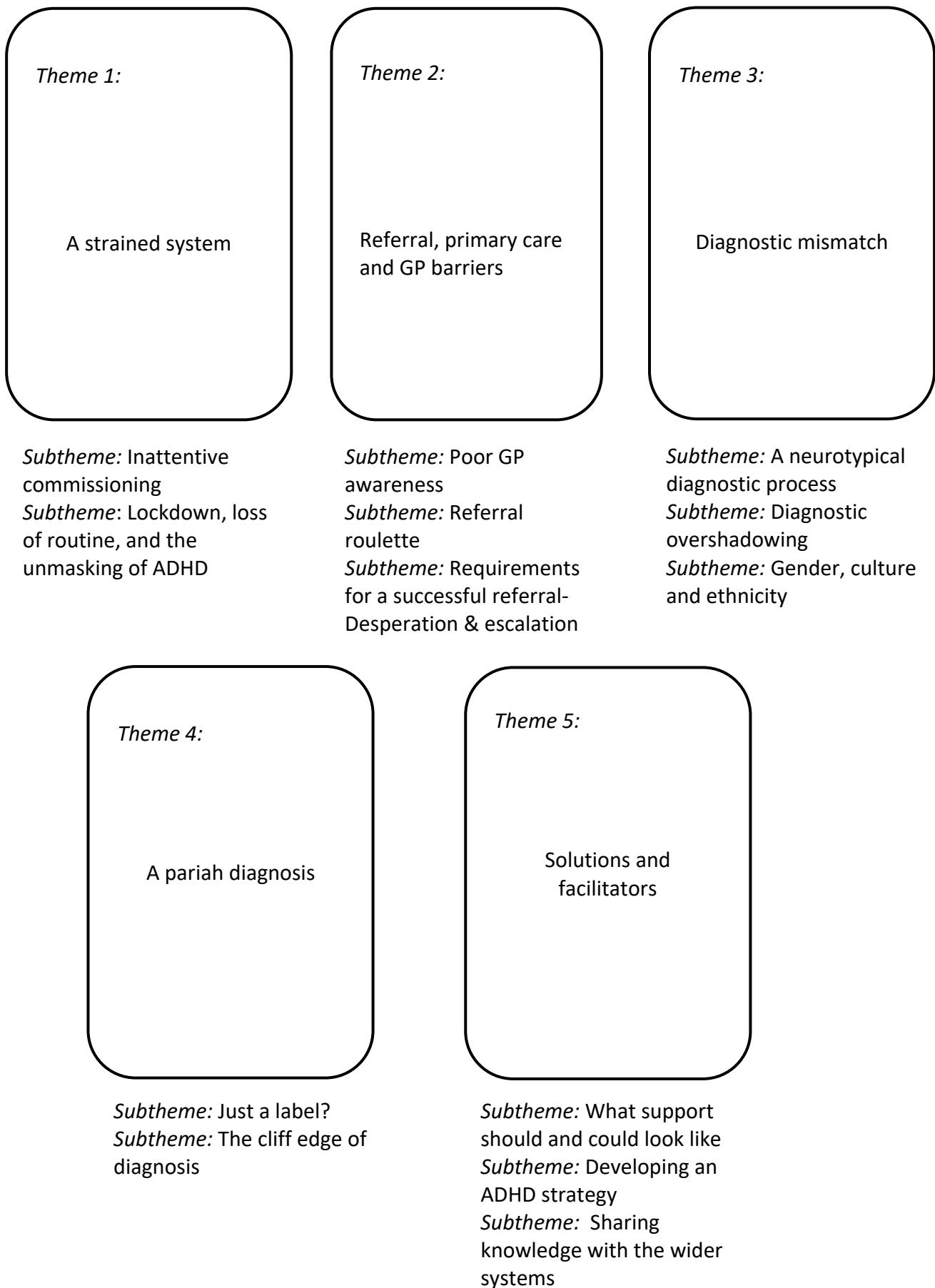
There is no explicit guideline on how the results of RTA should be presented, allowing researchers to be creative with how findings are presented (Braun & Clarke, 2006, 2013, 2019). While thematic tables are often used in theses, they can suggest a false sense of neat, linear theme development. Similar to how researchers tend to move back and forth between the stages of RTA (Braun & Clarke, 2006, 2013, 2019), adults newly recognising that they may be struggling with ADHD often find themselves moving in similarly non-linear ways, through unclear and fragmented care pathways. In place of a thematic table, this Chapter draws on a metaphor shared by one participant on the failure to acknowledge ADHD:

*“You’re not working with a full deck of cards. I mean, this is the thing that I don’t understand, and I guess it’s a psychological thing with formulation, right? You need to have a full deck of cards. You need to know what is going on with the person to be able to formulate what might be affecting their difficulties.”* (Enya)

Enya described a common experience in seeking support for ADHD; individuals were frequently met by clinicians with limited understanding of ADHD, leading to invalidation and dismissal by HCPs. Without a full picture, including developmental history, cultural context, and intersecting physical and mental health needs, HCPs were left to formulate based on guesswork. Meaningful understanding requires time, an understanding of context, and a willingness to view people holistically, both of which can be omitted in a strained and under-resourced health system.

Further developing the metaphor used by Enya, this Chapter navigates the barriers to ADHD care, moving from individual and relational challenges through to wider systemic and societal obstacles. Each theme and sub-theme is represented by a playing card. Together, the hand reveals how care is navigated, blocked, or denied. Only by gathering enough cards can we begin to understand the rules of the game, and only then can we begin

to challenge them (see Figure 4). The Chapter explores the intersecting barriers present across every stage of the ADHD care pathway. It considers how disjointed commissioning, outsourcing to private providers, unaddressed wait lists, and rigid diagnostic criteria contribute to confusion and delay. It also follows what happens beyond diagnosis, where many are met with a cliff edge in care, left without post-diagnostic support and forced to battle for treatment and recognition.

**Figure 4***Diagram of RTA themes and subthemes*

#### **4.2.1 Theme 1: A strained system**

This theme was developed during a time of significant political and structural change, both within the NHS and more widely in society. The gutting of NHS England (Public Accounts Committee, 2025) and restricting Right to Choose (Tickell, 2025), were signs of a return to austerity (Triggle, 2025). In ADHD care, a national working taskforce was formed, whilst services remained under-resourced (Cardiff University, 2024). Understanding the context was important for uncovering: uncovering a system under strain with structural barriers deeply entrenched:

*“They've set up some group now. Some reference group. I don't know what they do. They said they're doing something... So it's like a relatively neglected policy area, you know.” (Colin).*

Colin represents a wider scepticism from participants regarding whether the recently announced strategies, such as the National ADHD Taskforce (Cardiff University, 2024), will lead to a meaningful national policy direction and systemic change, or whether it is merely a tokenistic policy gesture.

***Inattentive commissioning.*** This sub-theme explored how the absence of national and local strategies to manage ADHD, particularly at commissioning level, leads to instability and sparse service provision. The absence of clear plans or funding structures often results in shifting responsibility, creating uncertainty for both staff and service users.

*“I just don't feel the [participant's local] ICB has a very clear plan on ADHD. It is incredibly ad hoc. It's interpreted in different ways in different areas. And it's not helpful for anybody. They just don't want to take on the problem because of the money involved, I suppose”. (Harriet).*

This omission of a strategy for ADHD healthcare at the level of commissioning resulted in a burdensome situation for clinicians, including underfunding and resulting staff recruitment issues. The result of high staff burnout and turnover was cited by participants, not as the exception, but as the familiar norm:

*“We're seeing burnout everywhere- people holding three roles and still not getting through the wait lists” (Rachel).*

The increasing burnout reported among staff reflects systemic stressors within the ADHD care pathway. The notion of services “*not being commissioned*” (Colin) was routinely

used by services to justify rejecting referrals and disengaging from ADHD-related support, regardless of clinical need. Rather than implementing adaptations to their clinical approach, services often used commissioning boundaries to justify inaction. This response was not framed as reluctance or incapacity, but as a contractual limitation, effectively depersonalising the decision and displacing responsibility.

*"One dreaded sentence we hear about ADHD is, 'We are not commissioned to provide that service'... Mental health services are notorious for saying that about ADHD... There's still a kind of, 'No, no, you've got ADHD, you go to the Neuro service and get your service there', and then the Neuro service is sitting and saying, 'Oh my God, we've got all these people to diagnose and manage, and why? Why are you shoving patients our way when you could jolly well manage them yourself with a bit of training?" (Colin)*

Colin's account cuts to the core of systemic neglect within ADHD care. Narrow commissioning frameworks leave services shifting the blame, each insisting ADHD is not within their remit. His frustration captures how these structures not only reflect service gaps but actively produce them. Another indication of the system deflecting responsibility was the decision to outsource assessments to private companies, which signals a move away from NHS accountability and commissioning duties. This reinforces its status as a two-tier health system (McCann & Ford, 2025), where continuity of care is undermined in favour of short-term fixes.

Poor structural planning was also mirrored in how ADHD was positioned by clinicians on the ground, as many described ADHD being absent from formal and ongoing clinical training. None of the participants received formal ADHD teaching during their core training:

*"So... It's going to sound awful now, but not... not a huge amount [of training]. Formally, there were a couple of days on the [clinical] doctorate... but mine has been more picked up from just kind of clinical experience, supervision, and probably my own CPD, yeah. Nothing... nothing formal." (Sophie)*

Even among this group, participants described how ADHD continues to be treated as a lower priority, often viewed as less serious or less deserving of resources than other diagnoses. Nadia reflected on this dynamic:

*"There are some conditions that they think are more valid than others... schizophrenia, bipolar... things like trauma or autism or ADHD, these are kind of less valid... I*

*don't know if that's because those conditions are less treatable psychiatrically... but then ADHD doesn't fit that either, because ADHD is a really obviously treatable condition." (Nadia)*

Thomas explained how some HCPs are reluctant to give an ADHD diagnosis:

*"This may be a potential barrier because there may be potential for people to... It's easier for some people to prescribe an antipsychotic medication that the GP will prescribe, than to diagnose as ADHD and then accept you're going to have to do a script every month". (Thomas).*

Thomas's reflection was particularly troubling, as he worked in contexts where some people were non-verbal. If clinicians misdiagnose because it makes their job easier, it risks pushing an already vulnerable group onto the wrong treatment paths. One participant framed this reluctance as a moral decision:

*"It's the recognition. So the problem is that the lack of understanding in the system, and then how the help is implemented... if it's implemented... And what you find is that it relies on people like me or whoever to make a noise. And I understand why people don't, because we're all tired, quite frankly. And it's just a job, right? But for me? Ethically and morally, I, you know, I can't not. It's not right. So it's patchy, it's uneven, OK? Depending on who's getting in the ring with it and who's not." (Enya).*

Together, Thomas and Enya paint a picture of a system that fails to plan for ADHD at every level, from underfunding and poor strategy resulting in unclear pathways, to diagnostic hesitation and a reluctance of services to engage. ADHD is repeatedly positioned as another service's problem. Without structures that recognise and prioritise the neurodiverse differences that ADHD brings, the responsibility is instead pushed onto individual professionals. And for those seeking support, that difference in whether a clinician *"gets in the ring"* (Enya) can mean the difference between receiving appropriate care, or falling through the cracks altogether.

***Lockdown, loss of routine, and the unmasking of ADHD.*** Participants described how the COVID-19 pandemic added a layer of complexity to already disjointed ADHD pathways. A surge in public awareness and adult self-identification, partly driven by ADHD content on social media platforms, was not matched by service capacity. Several participants noted many adults had previously coped through structured routines and external accountability, such as having a job, but this was lost during lockdown. The absence

of routine, hobbies, social contact, and work-based structure left many struggling in ways that were newly emergent or visible:

*“[COVID] increased so much stress and anxiety and uncertainty around jobs and everything... Adult ADHD relies on routine, structure to manage their symptoms... like work schedules, social commitments, activities, being outside and all those things. The pandemic took every one of those away... they’re not feeling motivated and they don’t like it and they can’t concentrate.” (Anna)*

Social media platforms were understood as the catalyst for ADHD becoming a “*diagnosis de jour*” (Enya) during the pandemic, broadening societal narratives about what constitutes ADHD. This phenomenon may have contributed to an increase in inappropriate self-referrals, adding pressure to already stretched services.

#### **4.2.2 Theme 2: Referral, primary care and GP barriers**

In primary care, a GP is often the first point of contact for individuals who feel they need support for ADHD, and their onward referral is an essential step in accessing assessments and support. It is therefore necessary to interrogate why many referrals are blocked at this entry stage of the system. This theme aims to explore what narratives, structures and constraints shape GP decision-making. It explores what conditions may need to shift within the wider system to enable GPs to respond differently, in ways that centre ADHD voices and improve access to care.

**Poor GP awareness of ADHD.** Across interviews, it was remarked that GPs often lacked the knowledge and confidence to recognise ADHD in adults. Participants acknowledged wider systemic gaps, such as little to no ADHD training for GPs, and also reflected that societal narratives of adult ADHD has on the care that GPs provide. Participants described seeing first-hand how people were dismissed by GPs, often due to unhelpful or outdated perspectives, such as ADHD only affecting “*little boys who can’t sit still*” (David).

*“A lot of people... really took a lot to convince the GP to send the referral... Some saying they had to push for almost a year.” (Rachel)*

Others highlighted how assumptions about what ADHD ‘looks like’, such as being visibly chaotic or underachieving, led to being dismissed. Louise recalled:

*“I’ve had people being told they can’t have ADHD. They’ve got a PhD, they can’t have ADHD, they’ve got a job. You can’t have ADHD. You’re married...” (Louise)*

This raised questions not just about the lack of training, but about whose knowledge is considered valid. As Enya stated, people often come to their GP with a strong sense that something is wrong, that their difficulties might be explained by ADHD, but too often have their stories overruled:

*“Do we privilege the lived experience of people who are saying there is something spicy with me, or do we take the clinical judgement of the GPs, who’ve got 10 minutes [to see them]?” (Enya).*

Clinical judgement, shaped by limited training and a pressured system, took precedence over lived experience. Participants again pointed to the structures that position GPs as gatekeepers, without giving them the tools, the time, or the clinical will to recognise what they are being asked to help with. This could result in the perpetuation of ignorance through institutional training pathways and diagnostic hierarchies, leading to persistent marginalisation with ADHD.

The implications of these issues are far-reaching. When people are not heard and validated at the first point of contact, they often internalise the idea that they are not struggling enough. Some give up, others turn to private care, paying to be seen in a system that should have recognised them from the start. What emerges is a wider pattern of dismissal and diagnostic gatekeeping that leaves people feeling unheard and left without support.

**Referral roulette.** Even when GPs did acknowledge ADHD as a valid diagnosis in adulthood, getting a referral was not always straightforward: *“They can’t even get in the door if their GP doesn’t believe in ADHD” (Nadia).* For many, the path to assessment was blocked by a series of small barriers requiring persistence, resilience, and time. The system is set up in a way in which people have to keep asking, proving, and returning to their GP practice, often long before being seen by a specialist. Participants described a role reversal, where those seeking help had to act as educators, bring evidence, correct misconceptions, and justify their distress. As Sophie reflected, people felt that they had to: *“bring NHS guidelines to their GP just to get taken seriously”*.

Several examples were given of people being turned away from their GP on the basis that they were functioning *“too well”* (Monica), or because ADHD characteristics were

wrongly assumed to be the result of common mental health problems such as anxiety or depression. A picture emerged that only those with the right words, level of confidence, and energy to keep returning got referred. For most service-users already navigating distress, holding down a job, as well as other responsibilities such as childcare, battling with their GP was simply not feasible. Rachel offered a particularly stark example of this dismissal, recalling that:

*“A lot of people... especially women... would say that it really took a lot to convince the GP to send the referral on. And that they were usually fobbed off – a lot of like, ‘it’s just your hormones’” (Rachel)*

This also speaks to how the system demands significant evidence before it listens and positions the GP as the sole gatekeeper of care too often. Even then, access may depend on whether the person is stabilised *“on the right antidepressant”* (David) or has deteriorated enough to meet the referral threshold. But even when referrals are made, the process is rarely smooth. Participants working in neurodevelopmental services described how referrals often arrived from primary care with little or no context: *“They’ll literally just write one line this, you know, this person thinks they’ve got ADHD. Can you, can you see them?”* (Joanna). This left teams being expected to triage based on vague information, despite being expected to make careful assessments of lifelong neurodevelopmental needs. Referrals often simply requested an ADHD assessment, with no developmental history or rationale, leaving specialist services in a difficult position. The knock-on effect is clear: when GPs lack the time or training to provide adequate referral detail, it compromises the quality of care further down the line.

It becomes apparent how the NHS becomes ‘a revolving door’ where referrals, and therefore people, become lost in the system. Those who make it through often do so because they are persistent, resourced, or lucky. Those who do not may never appear in the system at all. The referral process becomes a site of loss, where people fall out of the system before their needs are recognised. This raises serious concerns about who gets left behind; those without the language, confidence or capacity to advocate for themselves, including people with intellectual disabilities, communication needs, or who are navigating deprivation without support.

***Requirements for a successful referral - desperation and escalation.*** This subtheme captures the extremity of the paths people have travelled before arriving at an ADHD

diagnosis. Whether through the justice system, health crisis, or financial sacrifice, desperation and escalation were prerequisites for being heard.

This theme of crisis-at-entry-point came up again in relation to forensic services. Anna reflected on the disturbing reality that psychiatric care can be more available inside prison than outside of it:

*"You go into a prison and you've got psychiatry and diagnostic support on hand. And it's- do you have to commit a crime now to make sure you get the assessment and diagnosis and post-diagnostic support?... Does it need to get to that level in order for us to intervene?"* (Anna).

This starkly implies that some people may only be eligible for support should they break the law. Others pointed to the growing reliance on private or semi-private options, such as Right to Choose, as another form of escalation. While these routes were never presented as ideal, they were often described as the only realistic option for people who could not afford to wait for a diagnosis:

*"It's not that they want to go private, it's that they feel they have no other option. They can't wait three years."* (Louise)

While some participants saw Right to Choose as a necessary workaround, offering quicker access in an otherwise blocked system, others raised concerns about quality, consistency, and the ethics of relying on private providers to fill gaps in ADHD healthcare. This drew out a conflict in the data: while some participants valued the flexibility and speed of private provision, others questioned its clinical robustness, variable assessment standards, and the longer-term implications for NHS responsibility.

This reflected a wider concern raised across interviews, that access to care is increasingly dependent on financial or emotional desperation. Those with money, knowledge, or time can bypass delays and get seen, while those without remain stuck: waiting, deteriorating, or giving up altogether. Many people were unaware of their rights to alternative pathways, while others were actively blocked from them.

Several participants also reflected on the damaging effects of long waiting lists, particularly for those who are already vulnerable but not yet in visible crisis.

*"We closed our waiting list because of the amount of referrals... there were up to like 1200 people in what was called 'the vault'"* (Rachel).

The use of 'vault' evokes imagery of people being locked away, hidden from view and forgotten, which seemed apt for the malfunctioning system in question. ADHD, by nature, can make the experience of waiting especially difficult, and for some, being in this state of limbo becomes the tipping point into crisis.

*"They're almost at a point where they're kind of nearing... not crisis, but they're struggling. And then for them to have to wait five years... We see people's mental health really deteriorating whilst they're on our waiting list."* (Joanna)

The accounts in this sub-theme reflect a system where legitimacy is granted too late, and often only to those who can pay. These patterns arguably reflect a wider environment shaped by austerity, risk aversion, and marketised approaches to ADHD healthcare. A concerning consensus emerges that even for those who make it through disbelief, blocked referrals, and long waits, what follows is rarely the structured, supportive care outlined in national guidelines (NICE, 2018).

#### **4.2.3 Theme 3: Diagnostic mismatch**

This theme explores the tension, inconsistencies, and clinical blind spots surrounding ADHD assessment and diagnosis, exposing how the needs of individuals with ADHD are often misunderstood and mislabelled within systems not built with them in mind.

***A neurotypical diagnostic process.*** A clear thread woven through participants' accounts was the mismatch between the way ADHD assessments are set up, and the way those with ADHD experience the world. Even before someone gets seen by a clinician, there is substantial paperwork expected of the individual requesting an assessment: self-report questionnaires, observer forms, school records, and developmental history, ideally from a parent or carer. The burden often falls squarely on the individual, who's already trying to navigate a difficult system.

For some, this was made even harder by background and life history. Several participants spoke about clients who had grown up in care, or who were estranged from their families, making developmental histories almost impossible to retrieve. Thomas pointed out just how tricky this can make things:

*"Sometimes it's difficult to get a developmental history. Particularly if they've grown up in a care system, or not assessed until they're in their 40s... and by which time parents may be elderly or not involved..."* (Thomas)

Then there is the glaring irony of asking someone with attention, memory, processing and organisational challenges to sit down and fill out extensive, clinical forms. Several participants highlighted how counterintuitive it is to require those with executive functioning difficulties to navigate such administrative demands to access support.

Participants reflected on the assessment tools themselves too. The Diagnostic Interview for ADHD in Adults (DIVA), widely viewed as the gold-standard structured interview for adult ADHD (Adamou et al., 2024), was seen as thorough but narrow. While it ticks the boxes for diagnostic criteria, it does not always capture the wider context. It was felt to lean too heavily into framing differences as deficits and painting them as pathologies. This framing was unsettling for some, as it echoed broader concerns about how ADHD is conceptualised within services, still steeped in the medical model. In this model, ADHD is turned into a pathologised diagnosis like anxiety and depression, and cognitive differences become a 'disorder', with medication seen as the main 'cure'. Sophie reflected on this tension:

*"The DIVA is great in terms of making sure that you can kind of tick off that diagnostic criteria, but for me it's just it's an added extra... It's the understanding of the person that's the main part of our assessment."* (Sophie)

Together, these accounts paint a picture of an assessment process that demands clarity, history, and executive functioning from people whose very challenges often lie in those areas. It reflects a broader issue- that while ADHD is beginning to be recognised more widely, the systems set up to manage it are yet to catch up.

**Diagnostic overshadowing.** This subtheme captures how ADHD is routinely missed, misunderstood, or deprioritised when other difficulties are present. Diagnostic overshadowing refers to the negative bias that distorts clinical judgment regarding co-occurring difficulties and differences in individuals who have intellectual disabilities or other mental health challenges (Mazza et al., 2020).

By the time many adults make it onto a waiting list or finally get assessed, it is rarely just ADHD they are dealing with. Co-occurring challenges were the norm, not the exception. Participants described working with people who have multiple diagnoses, including anxiety, depression, bipolar, psychosis, autism, personality disorders, addiction and trauma. Physical health issues like chronic fatigue and pain were also common. Shame and self-doubt underscored a lot of these experiences:

*"It's rare to see somebody without a coexisting mental health challenge... Either people have received a diagnosis of unstable or antisocial personality disorder, when actually what's underneath that is ADHD, and trauma as a result..." (Joanna)*

Diagnostic overshadowing was especially common when gatekeeping clinicians relied on a single explanatory framework, missing broader or overlapping presentations. Within the medical model, and because of how services are commissioned, services are often pushed to focus on one diagnosis, further risking misinterpretation of ADHD characteristics. Emotional dysregulation gets labelled as borderline personality disorder or rapid cycling bipolar, impulsivity as psychosis, and attention problems as anxiety or trauma. As a result, people were frequently placed on inappropriate treatment pathways, in the wrong services, or left without support altogether.

ADHD often does not slot neatly into existing service structures. In what appears to be a one-service, one-problem health system, specialist ADHD services are expected to manage ADHD independently. Primary care services (such as Talking Therapies<sup>22</sup> services) focus on anxiety and depression, while secondary care manages severe and enduring mental health problems<sup>23</sup>. But ADHD rarely exists in isolation, with co-occurring trauma and relational challenges common, as well as overlapping needs that do not fit neatly into one category:

*"The whole system's just not geared around ADHD... You've got primary care saying it's too complex, secondary care saying it's not complex enough. People just fall through the gaps". (David)*

As a result, people are bounced around services or dropped altogether. In areas with dedicated ADHD services, other services often disengage, rejecting ADHD as their problem rather than liaising collaboratively. Yet ADHD specialist teams, were overstretched and without the funding to manage the wider mental health difficulties that many people face. This left individuals caught in a bind: too complex for primary care, but not severe enough for secondary services.

In many of the participants' regions, the absence of any ADHD services made the situation even worse, as there was no clear referral route, designated team, or service

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<sup>22</sup> Formerly known as IAPT

<sup>23</sup> Such as bipolar, personality disorders and psychosis

willing to take ownership. Without a clear pathway or service, people with ADHD were left in limbo, unsupported, systematically excluded from care or offered the wrong treatment.

*“People get diagnosed with BPD or anxiety and depression, particularly women... And actually, what's going on is that they've got ADHD that's never been picked up. If you're not curious and just go, 'oh well, it's psychosis.' That is diagnostic overshadowing.”* (Enya)

For most, not being offered support meant they did not have the opportunity to understand what their diagnosis meant. Most were left to carry years of internalised shame, often believing they were flawed or unstable. Yet participants also described people surviving in systems not built for them, by masking, adapting and coping in a world that rarely recognises their needs. This highlights not just individual resilience, but the quiet cost of being repeatedly misunderstood or unseen by the very systems meant to offer support.

***Gender, culture and ethnicity.*** This subtheme explores how ADHD was rendered invisible through the intersecting influences of gender, culture, and disability. Participants described how dominant narratives of who can have ADHD continue to exclude those who do not fit the expected mould, particularly women, those with intellectual disabilities and those from the global majority.

Participants spoke repeatedly about how ADHD in women was often overlooked or misunderstood, as it rarely fit the damaging stereotype of disruptive, hyperactive boys running around classrooms. Rather, women presented with internalised masking, succeeding in education, then quietly burning out. As a result, many women did not get recognised until much later in life, and were often misdiagnosed with mood and personality disorders. They were told they were too smart, too competent, or simply too old to have ADHD - being female and adult excluded them twice over. Unsurprisingly, this contributed to shame and low self-esteem, which were often only questioned during a health crisis.

*“ADHD still has this really fixed image, you know? So if you don't look like the young hyperactive boy... you just don't get thought about. Women, people from other backgrounds, anyone who doesn't fit that mould, they just get missed.”* (David)

ADHD was also described by participants as disproportionately under-recognised in global majority groups. Several clinicians drew attention to how cultural stigma around mental health often limited individuals' ability to articulate what was happening for them to even conceptualise ADHD as a valid explanation. For a lot of cultures, the idea of having any mental health difficulties at all was still taboo:

*“These conditions were discovered in Western Europe and North America. And when you go to other parts of the world, in other ethnicities and cultures... There’s no words for it... You know. I tell you, today, they don’t know what ADHD is in Hindi, for example. And how do you talk about it?” (Colin)*

The absence of language reflects deeper issues of epistemic exclusion. When experiences like impulsivity or restlessness are only understood as naughtiness or laziness, they are unlikely to be recognised as a neurodevelopmental difference. People from global majority backgrounds often encountered services after years of distress, or had reached a crisis point. Even then, ADHD was less likely to be considered as an explanation, and people were more likely to be viewed through more familiar or stigmatised categories such as psychosis, conduct problems, or challenging behaviour.

Similar patterns and challenges emerged for individuals with intellectual disabilities. Participants working in community and forensic settings explained how individuals’ internal experiences were often inaccessible through standard assessments due to communication difficulties. Clinicians had to rely on observation, staff reports, and contextual clues, an approach that many services were not resourced to offer.

Too often, a co-occurring learning disability acted as a stop sign, with clinicians assuming all difficulties were already explained. ADHD was overlooked unless someone explicitly raised it, which few were equipped to do:

*“If the intellectual disability is mild and they’ve got reasonable communication, they may be able to tell me about, you know, being unable to concentrate, racing thoughts... but more often than not, it’s me identifying [ADHD]... It’s very easily missed.” (Thomas)*

#### **4.3.4: Theme 4: A pariah diagnosis?**

This theme explores what support, if any, adults with ADHD receive after diagnosis. The overwhelming narrative was of a system falling silent. Just as sense-making would be expected to begin, where service users are offered space, tools, or even a therapeutic conversation, in reality, care ends. Participants described that once diagnosed, people were often left with no support, scaffolding, or treatment plan. In a medicalised system that leans heavily on diagnosis, what happens when that diagnosis brings nothing?

*“You know you’re not really listened to, you’re not believed, so you feel like a bit of a pariah. You’re not part of the system, you’re excluded from it.” (Colin)*

**Just a label?** What came through across the interviews was that arguably the most crucial part of the pathway rarely happened. Beyond the assessment, the consensus was that little else was offered, if at all:

*“There is no support. There is no pre-diagnostic support. There is no post-diagnostic support. There is no support. Full stop.”* (Enya)

Where post-diagnostic support did exist, it was described as patchy, tokenistic, and only reaching a minority:

*“It’s great that we offer it, but equally I think it’s reserved for a very, very small proportion of the population...”* (Sophie)

Some participants talked about how services and HCPs tried to offer something at the point of diagnosis, knowing there was nothing else coming. There was a shared frustration that ADHD is treated like a medical condition that should lead to support following diagnosis, yet people were mostly blocked from the first-line option that services are set up to provide: medication (NICE, 2018). This was particularly stark in forensic settings, where participants described additional suspicion and stigma around medication access:

*“There’s such stigma associated with getting any kind of medication for ADHD... but the perception is that they’re drug seeking.”* (Nadia)

Private and Right to Choose routes, set up to manage access to treatment, came with their own problems. People would pay for a diagnosis but still could not get medication, as GPs often refused to take on shared care agreements, leaving people stuck.

*“They come out with a diagnosis and they’re not able to get medication. So they’re left with nothing.”* (Harriet)

Alternative options to medication, like therapy and coaching, were described as almost non-existent, even though NICE (2018) recommends them. If anything was offered, it was usually brief and dependent on a clinician going out of their way to provide psychoeducation or equivalent.

When clinicians signposted service-users to coaching, this was usually private and unregulated, making it a less ideal option. ADHD is framed as a medical condition (diagnosis-to-treat), but the care offered rarely matches this conception. Medication, which can be life-changing, is made inaccessible through unhelpful beliefs, gatekeeping and paperwork. This

was especially hard to accept when participants knew earlier access could have made a huge difference:

*“I had this guy who was about maybe 16/17 at the time... long history of aggression... we had a casual look at his history, but we carried on treating him with other stuff, you know, for depression, psychosis, this, that, anxiety. And then it struck me that we hadn’t taken the full developmental history with a focus on ADHD... I just put him on ADHD [medication]... And pretty much suddenly, everything just stopped... And I think he’s been out [in the community] for the last 12/15 years...” (Colin)*

There was a strong sense of frustration amongst participants about the post-diagnostic support. One participant shared a particularly distressing case that captured how severe the consequences can be when a diagnosis is given, with no follow-up support. This described how an individual was left unsupported despite going into a mental health crisis, and their behaviour was reframed as attention-seeking, and care was withdrawn as punishment, despite serious risks and ethical violations:

*“‘She’s tantruming’, ‘She’s manipulating...’ the most horrendously shaming words for someone... what the ward staff had written... she had been absolutely stuck in this injustice cycle” (Monica)*

Several described how people were given a label, then left to figure it out alone, with no time or support to process what the diagnosis meant. Even when participants tried to refer someone for psychological support, such as CBT, services often dismissed it as outside their remit and sent referrals back. And even when participants tried to push further at a commissioning level, the answer was still no:

*“There is supposed to be some ADHD support, but I wasn’t able to commission it for some reason... or, when I was trying for this woman and the senior social worker was trying on my behalf, we couldn’t get the funding. And it was like... access denied.” (Monica)*

The system gives the impression of help, but in reality, people are redirected, blocked, or dropped. These patterns point to more than underfunding. They expose how adult ADHD is still seen as a “pariah” (Colin), outside the boundaries of what services view as deserving of proper investment.

***The cliff edge of diagnosis.*** Participants described how the ADHD care pathway often drops off immediately after diagnosis, leaving adults without follow-up, clarity, or tailored support. There was a shared sense that the system was not designed to

accommodate ongoing ADHD needs, especially for those with intellectual disabilities. Support was often reduced to one-off appointments, information signposting, or inconsistent follow-up, if any at all.

*“We haven’t got any kind of team or programme to offer post-diagnostic support... I then signpost them to... the NHS website on ADHD. And that’s pretty much it.” (Thomas)*

There was frustration about services lacking the infrastructure to offer more than a diagnostic label. David expressed concern that:

*“Services think their job is done when they give someone a diagnosis- and it’s not. That’s just the start of the work.”*

These accounts challenge assumptions that diagnosis alone is enough, highlighting the need for sustainable, relational post-diagnostic support that helps individuals beyond the point of recognition.

#### **4.3.5 Theme 5: Solutions and facilitators**

While the data so far have pointed to many barriers to care, participants also shared rare but valuable examples of thoughtful, joined-up ADHD care, as well as reflections on what needs to change. These accounts did not call for radical reinvention but for space, training, and investment in what already works. In doing so, they challenge the idea that poor care is inevitable.

**What good ADHD care looks like.** While most participants described a stark absence of post-diagnostic support, some offered glimpses into what good ADHD care might look like. These examples, though rare, challenged the assumption that support must be minimal, medicalised, or non-existent. Sophie spoke about the importance of moving away from tick-box tools toward a more thoughtful, compassionate formulation:

*“We’re very formulation-led... using a compassion-focused formulation... a power threat meaning framework... We use the PINCH<sup>24</sup> acronym to understand the function of behaviour.” (Sophie)*

Others echoed the importance of staying curious and working flexibly. Assessments were described not just as diagnostic procedures, but as opportunities to begin helping someone make sense of their story. Louise spoke about drawing strengths into the

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<sup>24</sup> Play, Interest, Novelty, Competition, Hurry up (urgency)

formulation, "There's a lot of creativity, spontaneity, you know, energy and hyperfocus... it can be a real asset."

One participant described a more comprehensive model of support that included occupational therapists (OTs) and speech and language therapists (SLTs), embedded within a post-diagnostic team. They were able to offer practical and therapeutic input, including webinars, strategy groups and onward referrals:

*"We've got occupational therapists and speech and language therapists in a post-diagnostic team... an 'Understanding ADHD' webinar, communication style, sensory needs... also a SPARKS group, an 8-week group around strategies... direct referrals to OT or SLT."*  
(Louise).

These examples were, unfortunately, not the norm. Sophie was clear that this kind of input had to be tightly ringfenced because demand was so high. A few participants mentioned assistant psychologists offering short-term support, often in creative ways, but this was almost always down to individual initiative rather than anything formally commissioned.

Participants consistently linked the rarity of good care to wider structural gaps. Many called for a national, joined-up strategy to address the poorly designed or absent ADHD care pathways:

*"It needs a national directive, like the national dementia strategy... because it's just not going to work at a local level." (Harriet)*

Participants stressed the need for integration across primary care, specialists, and support services, arguing it should not fall to individuals to coordinate their care. Professions like pharmacists were described as underused. Without long-term commissioning, several warned services would remain stuck in short-term thinking. Monica called for a more relational, joined-up model that recognised the interconnections between different needs and experiences:

*"Let's listen. You know, what is their experience? Do we have to put people in boxes? When we actually see how so many of these boxes are linked... if services could reflect those links... the population would be so much less in pain." (Monica)*

Some participants described person-centred ADHD care rooted in compassion, contextual understanding, and clinical judgement, which rely on the time and the space to

be delivered properly. Their rarity reflects the strain that the system is under, deprioritising this crucial part of the care pathway.

**Sharing knowledge with wider systems.** The way ADHD is talked about in society has changed rapidly. But within services, professional understanding and training have not kept pace. Several participants reflected on this disconnect, noting that while public awareness has grown, particularly through lived experience and social media, formal training pathways continue to lag:

*“The way society has kind of thought about ADHD has changed so dramatically, but I don’t think the training for psychologists, at least within mental health trusts, keeps up at the pace that society is changing the narrative.” (Anna)*

This mismatch was a consistent theme across interviews. Even brief training sessions were described as powerful in shifting clinical thinking, helping colleagues to notice signs, ask more relevant questions, and take ADHD more seriously. These kinds of training shifts were described as not just helpful, but transformative. When ADHD knowledge became part of everyday team thinking, it changed how people were understood and supported. But in most teams, that kind of training had not been delivered. In many of the services where ADHD routinely presents, it continued to be treated as someone else’s problem.

Training programmes lag behind the societal narrative on ADHD. Participants shared that even a short training session had helped colleagues think differently:

*“I’ve done a few training sessions for my team about ADHD and all things to look out for... I can already see people are identifying it more, having done that training session.”*

(Thomas)

There was a lack of expectation across services that ADHD should be understood, especially in teams where it was more prevalent.

What participants called for was a broader cultural shift. Without adequate training and time, professionals will continue to miss or misinterpret ADHD, leaving people without support until they reach a crisis. Knowledge must be shared beyond specialist teams, embedded into everyday practice across services. Until then, access will remain fragmented, and care will depend more on luck than on need:

*“The reality is that most clinicians... they won’t have generally done specialist ADHD training at any point in their career... a lot of clinicians will have just learned it on the job without having had the specialist training.” (Harriet)*

## Chapter 5: Discussion

### 5.1 Chapter overview

This Chapter begins by summarising the five themes and thirteen subthemes developed from the qualitative data collected in this study. It then discusses each theme in relation to existing theory and literature. The Chapter also presents the strengths and limitations of the research, followed by actionable clinical implications and recommendations for future research.

### 5.2 Summary of findings

The research addressed the main challenges of seeking ADHD diagnosis and treatment as an adult from a HCP perspective. The research findings were explored using RTA (Braun & Clarke, 2006, 2013, 2019), resulting in the development of five themes, which reflected both familiar and less-explored aspects of adult ADHD healthcare from the perspective of specialist HCPs. Participants described fragmented care pathways, difficulties accessing post-diagnostic support, and a diagnostic process that excluded or did not adequately address challenges associated with ADHD.

The findings aligned with existing literature, with themes including delays in receiving diagnosis and poor follow-up support. For example, double-masking in women with ADHD, and the epistemic injustice adults face when their distress is dismissed by HCPs (Fricker, 2007). In line with the CR lens of the study, the findings acknowledge the context-specific accounts shaped by participants' positioning within complex health systems, while offering insights into how professionals themselves interpret and navigate structural barriers, an area that remains underexplored in existing ADHD research.

### 5.3 Relating findings to existing literature

#### 5.3.1 Theme 1: A strained system

Participants reported fragmented, unclear and underfunded ADHD care pathways. Commissioning decisions appeared ad-hoc, with no clear plan, reflective of a non-existent national ADHD strategy, resulting in multiple systemic barriers, long wait times for ADHD assessments, inadequate or no support, and a reliance on outsourced services like Right to Choose that failed to work. As Monica stated, *“People are having to go private or via Right to Choose, but it’s not always ethical or consistent”*.

‘A strained system’ with deep systemic flaws was reflective of adult ADHD services that are in crisis (Smith et al., 2024). Despite fast-growing levels of referrals and prescriptions for ADHD since the pandemic (BMJ Group, 2024), the NHS does not routinely collect detailed national data on adult ADHD service demand, waiting times, diagnostic rates, or post-diagnostic outcomes (NHS England, 2024). Without this data, it is difficult to fully understand or plan for the true scale of unmet need, making it harder to compare current capacity against the rising demand for assessment and support.

Through the pandemic, participants in the present study reported how *‘Lockdown, loss of routine and the unmasking of ADHD’* led many adults to realise for the first time that they may have ADHD. The sudden loss of structure, hobbies, and work schedules appeared to trigger or intensify difficulties. Research has shown that for people with ADHD, routine and external structure play a key role in regulating attention, emotion and motivation, and without them, coping strategies often fall apart, leading to heightened distress (Merzon et al., 2022). Consistent with the biopsychosocial model outlined in Chapter 1, the pandemic highlighted how environmental and social factors can mediate ADHD-related difficulties, particularly when regular sources of scaffolding such as social contact, daily rhythms like getting up for work, or movement were stripped away (Adamou et al., 2020). This reinforces the importance of understanding ADHD distress as contextually shaped, not simply biologically driven.

The drastic rise in ADHD referrals during the pandemic, such as the “70% spike in referrals” reported by Sophie, drew attention to underfunding and the resulting poorly organised care pathways. Participants cited the explosion of ADHD content on platforms like TikTok<sup>25</sup>. Drawing on Cultivation Theory (Gerbner, 1969), repeated exposure to social media content may have had a strong influence on shaping public understanding of what ADHD is and its commonality, often presenting a simplified and relatable version that particularly resonated with many adolescents and younger adults. This likely increased awareness and perhaps self-diagnosis.

In addition, Social Identity Theory (Tajfel & Turner, 1979) could help further understand the increasing rates of self-diagnosing as ADHD. In lockdown, where isolation,

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<sup>25</sup> TikTok was the most downloaded app social media application in 2020 with more than 1 billion active users (BBC News, 2021)

fear and uncertainty became the norm, it is understandable that people sought community and meaning for their difficulties online, through identifying with ADHD, a label that offered not just an explanation for distress, but also a sense of shared experience. What this reflects is less about pathology, and more about the human motivation to make sense of difference, particularly when traditional systems like the NHS were overwhelmed by the national pandemic, and therefore under too much strain to offer much support.

The post-pandemic era has involved significant political change, with the new Labour government proposing structural changes that will directly impact ADHD care, such as the introduction of the national ADHD taskforce (Cardiff University, 2024), and changes to Right to Choose (Tickell, 2025). Participants met these proposed changes with scepticism about whether such initiatives will lead to meaningful change, or if these will be a tokenistic re-attribution of the limited funding. This was felt by Colin, to be at the core of the highlighted systemic issues:

*"There's got to be a commission commitment... not just till the end of March next year."*

Building on this, there is a growing need for Integrated Care Boards (ICBs) and commissioners to take ADHD seriously as part of their core planning responsibilities. NHS England has made clear that ICBs are now responsible for designing and funding services that respond to local population needs (NHS England, 2024), and these findings show that ADHD can no longer be overlooked. With over half a million people in England currently awaiting assessment and demand only increasing, commissioners must start embedding ADHD into everyday service planning, funding decisions, and staff development. This includes building it into community mental health and primary care pathways, not adding it on as an afterthought. Integrated models already exist across physical and mental health; ADHD now needs the same treatment.

The scepticism of participants seemed to come from a deeper sense of frustration, given that many had seen similar announcements before, which amounted to no change at ground level. This corresponds to years of underfunding for ADHD healthcare and policy decisions that have blocked support for this clinical cohort. For many participants, government initiatives seemed like moving around existing resources rather than problem-solving the issues and thus explains the lack of trust in attempts to fix the system. This ongoing strain and lack of meaningful reform led to several participants describing the

emotional and professional pressure of trying to support people within a system falling significantly short of its responsibility.

Lack of trust in reforms coupled with the pressure of working in chronically under-resourced and poorly organised services, affected staff wellbeing. Whilst not always made explicit, the results of this research hinted at early markers of burnout and low morale across participants, who were unable to practice in line with their values. Staff burnout is a chronic, cultural issue in the NHS (Osagyefo et al., 2024; Health & Social Care Committee, 2021; The King's Fund, 2021). Participants gave fresh insight into factors within adult ADHD contexts that may lead to staff burnout and stress, such as "*holding three roles*" (Rachel) at once, becoming overwhelmed by unclear pathways, trying to manage long waiting lists, and the pressures of working in a system not fit for ADHD and difference.

### **5.3.2 Theme 2: Referral, primary care and GP barriers**

Despite GPs being the gatekeepers to ADHD care pathways (Bi & Liu, 2023), participants of this research, alongside existing literature (Young et al., 2021), have highlighted that GPs have poor recognition of ADHD, attributed to limited training on and ongoing stigmatising beliefs. These gaps may contribute to under-referrals and uncertainty around ADHD care, since ADHD is often considered by GPs to be outside their remit (French et al., 2023).

GPs receive little education and formal training on ADHD, leading to '*poor GP awareness of ADHD*', resulting in low confidence in recognising core ADHD characteristics (French et al., 2021). Without training, misconceptions around ADHD persist, such as seeing ADHD as a childhood problem (Powell et al., 2020) and associating causal factors with parental failures (French et al., 2021), which further hinders support (Tatlow-Golden et al., 2016). A high proportion of adults with ADHD experience co-occurring mental health problems (Caye et al., 2019; Choi et al., 2022), which could be partially attributed to being told repeatedly by HCPs that there is nothing wrong with them (Eagle et al., 2023).

Clinicians often gravitate towards more familiar or socially accepted diagnoses, such as anxiety or depression, when faced with presentations of ADHD, particularly when co-occurring difficulties are present (French et al., 2019; Young et al., 2021). This was echoed across participant accounts, where ADHD was routinely deprioritised in favour of presentations viewed as more treatable within current service models. Consequently,

individuals seeking help for ADHD were misdiagnosed and rerouted into mental health services that not only lacked the resources to support neurodevelopmental differences but, in some cases, also rejected ADHD as a valid concern. Once redirected, people were unsurprisingly offered inappropriate interventions or excluded altogether, reinforcing a pattern of dismissal and systemic neglect (Moncrieff et al., 2020; Surman et al., 2023).

In the present study, Sarah highlighted the misconceptions held by GPs about who does and does not "fit" the profile for ADHD. It appeared that those demonstrating conventional markers of success, such as being in work, married, or holding advanced qualifications, were often excluded from consideration. However, many adults with ADHD are employed. While around one in three may be unemployed, this means that approximately two thirds (66%) are in employment (Attention Deficit Disorder Association [ADDA], 2023). Despite this, they are more likely to experience difficulties sustaining employment (Oscarsson et al., 2023).

Nationally, ADHD services are patchy, with many regions lacking service provision (Price et al., 2020)<sup>26</sup>. In the present study, most participants did not have an ADHD service within their borough. Across settings, especially in primary care, there was a culture of shifting the responsibility to specialist services and professionals, yet the development of ADHD pathways remains non-existent in many areas (Asheron et al., 2022), with specialist services sparse. This lack of capacity to understand adult ADHD, or refer correctly, results in inappropriate referrals (Johnson et al., 2020), risking outcomes like misdiagnosis.

The combination of no training, poor commissioning strategy and confusing ADHD pathways reflected not just diagnostic challenges, but structural and epistemic barriers that prevent adults with ADHD from receiving appropriate care (Hall et al., 2021). Furthermore, misdiagnosis can exacerbate self-esteem issues (Waddington et al., 2023), increase psychological distress (National Academies of Sciences, Engineering & Medicine, 2024) and leave unaddressed core ADHD characteristics (Oliva et al., 2021). Adults with undiagnosed or misdiagnosed ADHD report significantly lower self-esteem compared to those with a confirmed diagnosis, highlighting how a lack of diagnostic clarity and limited support lead to internalised blame and feelings of inadequacy (Pedersen et al., 2024).

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<sup>26</sup> Only 44 identified services were ADHD-specific, and only 12 offered a full range of NICE-recommended treatment

In the subtheme '*Requirement for a successful referral – desperation and escalation*', participants described how adults with ADHD often had to reach a crisis point before being taken seriously. Those who got referred were sometimes blocked due to rigid service thresholds, which frequently blocked access. Factors like complex referral forms and narrow inclusion criteria created further barriers, obstructing support at the very first stage of help-seeking.

'*Referral roulette*' captured the inconsistency in who gets through to an ADHD assessment. Diagnostic ambiguity also meant that ADHD is routinely missed in general psychiatric settings, leading to individuals being offered interventions that are not tailored to their needs. Even for those who are prescribed medication rarely receive adequate follow-up. Over half discontinue treatment within months due to poor management and lack of support (Fredriksen et al., 2022).

The Epistemic Injustice Framework (Fricker, 2007) helps explain how adults with ADHD are discredited in healthcare. Testimonial injustice<sup>27</sup> can arise when GPs dismiss their difficulties, not because the distress is unclear, but because it is not recognised and legitimised by them. As one participant put it,

*"They can't even get in the door if their GP doesn't believe in ADHD"* (Nadia), highlighting the structural barrier faced by many at the first step of help-seeking. This kind of injustice often operates implicitly, through systems that undermine help-seeking opportunities. Being disbelieved at the first point of contact is not just frustrating, as many participants reported, but reflects a deeper structural issue in whose knowledge is taken seriously, and whose is not. As Enya asked:

*"Do we privilege the lived experience of people who are saying there is something [neurodivergent] with me, or do we take the clinical judgement of the GPs, who've got 10 minutes...?"*

Overall, the picture painted was one of exclusion at the very first step. Despite GP being the main route into care pathways, participants described a system where ADHD is too often misunderstood, dismissed altogether, or misdiagnosed. Until primary care is adequately resourced, and clinicians are trained properly and accountable for ADHD, many

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<sup>27</sup> Testimonial injustice is where a person's credibility is unfairly downgraded due to social positioning and implicit bias

adults will continue to be blocked from accessing the support that they need.

### **5.3.3 Theme 3: Diagnostic mismatch**

ADHD assessment pathways are based on *neurotypical diagnostic processes*, structured around neurotypical assumptions of how individuals think, communicate and engage with healthcare (Benson, 2023). This study shows how these assumptions can exclude those without close relationships and those needing support with the very skills being assessed. Ironically, the executive function skills needed to complete long pre-assessment forms (attention, planning, and organisation) are the exact skills the person is asking for help with (Turjeman-Levi et al., 2024). Similarly, the use of collateral forms before assessment relies on the presence of a close family member or relationship, like a parent or partner, and reflects a deeper mismatch between standardised tools and how ADHD presents in adulthood. This created difficulties for those from care-experienced or traumatised backgrounds, who are statistically more likely to meet criteria for ADHD but less likely to have someone to validate their experiences for assessment (Ford et al., 2022). These factors highlight how, without considering support, systemic barriers undermine the assessment process.

These examples of a non-inclusive assessment design can be understood via the social model of healthcare, which shows how people are often blocked from accessing healthcare not because of their ADHD features, but because “*systems are not built for difference, right?*” (Enya). The assessment process itself becomes disabling (Shakespeare, 2013). This reflects a wider issue in healthcare: a system built on assumed norms that exclude those who do not fit what is considered ‘normal’ from a neurodevelopmental perspective (Benson, 2023).

*Diagnostic overshadowing* occurs when other diagnoses or presentations are prioritised, leading to ADHD being missed or dismissed (Hallyburton, 2022). This was a recurring pattern in the present study, as Joanna explained, many people:

“*received a diagnosis of unstable or antisocial personality disorder, when actually what's underneath that is ADHD, and trauma as a result.*”

Up to 80% of adults with ADHD have at least one co-occurring mental health issue (Choi et al., 2022), but without training and experience, professionals seldom untangle these overlaps. For example, participants described how ADHD characteristics such as

restlessness, fidgeting and emotional dysregulation were misread as signs of anxiety or mood instability (Grogan et al., 2018). Emotional dysregulation, whilst a recognised characteristic of ADHD, is often mistaken for mood-related problems such as depression or bipolar disorder, increasing the risk of misdiagnosis (Reimherr et al., 2020).

Misdiagnosis risks service-users being on incorrect treatment pathways, without access to the support they need. Diagnostic overshadowing remained across NHS services, particularly where ADHD was not seen as a legitimate concern. Overlapping characteristics between ADHD and other mental health problems often contribute to these patterns when HCPs lack skills to differentially diagnose, reinforcing systemic misdiagnosis and treatment failure (Ohnishi et al., 2019). As David said,

*“You’ve got primary care saying it’s too complex, secondary care saying it’s not complex enough. People just fall through the gaps”.*

The current study shows that diagnostic overshadowing is not just about clinician bias, but also about service structures that seek to avoid complexity. For example, in forensic and ID settings, ADHD was re-formulated in line with unhelpful stereotypes and more favoured diagnoses. In forensic services, help-seeking around medication was often re-formulated as manipulative and “*drug-seeking*” (Nadia), leading to misdiagnosis with substance misuse or behavioural disorders<sup>28</sup>. Risk management was prioritised over understanding the underlying function of seeking medication, such as the fact that it helps individuals with ADHD to regulate emotions and cognitive functioning (Greenfeld et al., 2024; Isfandnia et al., 2024), creating a significant blind spot for ADHD. In ID services, ADHD was frequently overlooked or attributed to the person’s existing diagnosis, with no consideration of further hypothesis testing or re-formulating based on new evidence:

*“People had a previous diagnosis that blocks another diagnosis, and we’ve been told we can’t re-diagnose... but it’s wrong.”* (Thomas).

ADHD often becomes invisible at the intersections of identity, particularly around *gender, culture and ethnicity*. Using the SOCIAL GRACES framework (Burnham, 2018), distress is shaped by race, gender, culture, age and spirituality. Without culturally grounded ways to explain ADHD, distress may be seen as laziness, disobedience, or even

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<sup>28</sup> 25.5% of those in forensic settings would likely meet threshold for an ADHD diagnosis (Young et al., 2014).

spiritual imbalance. In line with existing UK literature, ADHD in women often goes undetected due to clinicians' failure to spot more subtle, inattentive traits that do not match the dominant stereotype of hyperactive boys in school (Attoe et al., 2023), and is therefore frequently misdiagnosed as anxiety or personality-related problems (Claney, 2024). Several participants described how women often mask their difficulties, consciously or not, to meet social expectations, especially when managing work and home roles (Morgan, 2024). Women are often unable to externalise distress in the ways men can, due to patriarchal norms that penalise assertiveness, impulsivity and anger displayed by women (Russell & Rodgers, 2022).

Consequently, HCPs and their clients find themselves in a bind of double-masking: where HCPs' lack of knowledge and individuals' effective masking of their difficulties, intersect to keep female ADHD hidden from view. While female ADHD is known to be under-recognised (Attoe et al., 2023), this study shows how gendered assumptions actively contribute to underdiagnosis rates in women (Russell & Rodgers, 2022). Double-masking offers a new lens on how women with ADHD are not just missed but misunderstood. Instead of ADHD characteristics relating to executive functioning challenges (St John et al., 2022), inattentiveness and emotional dysregulation are seen through the medicalised lens of disordered mood or character flaws (Nussbaum, 2012).

Similar issues came up around cultural differences. Colin described how, in some religious contexts, there is no language to describe ADHD: "*In Hindi, there are no words for it*". This means that for some individuals and their families, ADHD cannot be named or recognised as a valid difficulty without the necessary language for it, and is instead interpreted as disobedience, laziness or even spiritual imbalance. For service-users from global majority groups without the language to frame their experiences, the risk of misinterpretation increases, especially when HCPs lack adequate training (Lekas, 2020; Patel et al., 2023).

This not only delays diagnosis or leads to mislabeling but also points to the importance of culturally aware practices (Abe, 2020; Dong et al., 2020). Individuals from global majority backgrounds risk being viewed through stigmatising lenses, such as being lazy, violent or non-compliant (Zestcott et al., 2016). This potentially leads to structural inequalities in how distress is interpreted and whose experiences are validated.

ADHD was also described as being overlooked in people with difference in

intellectual functioning. Once someone is given an ID label, there is often a false assumption that this explains all distress. Unless ADHD is raised directly, it tends not to be considered. Assessments are rarely offered, and the tools used are often seen as unsuitable for people with limited communication. As a result, ADHD becomes an afterthought, if it is thought about at all (Mellstrom et al., 2023).

Clinician heuristics<sup>29</sup> often shape diagnostic decision-making, relying on problematic stereotyped assumptions such as ADHD being a problem of hyperactive young boys (Young et al., 2021). These assumptions contribute to diagnostic overshadowing, where ADHD is overlooked in favour of more familiar or expected presentations (Hall et al., 2021). This disproportionately affects groups such as women, and individuals from racially minoritised communities (Attoe & Climie, 2023; Ramsay, 2020). As Rachel shared, many women are simply “fobbed off,” and told “*it’s just your hormones*,” reinforcing the role of gendered and stereotyped assumptions in how characteristics are interpreted.

#### **5.3.4 Theme 4: A pariah diagnosis**

This theme explored what typically happens after an adult receives an ADHD diagnosis. Used by Colin, the term *pariah* is defined as a person who is rejected from society or home; an outcast (Oxford Dictionary, 2024). This appeared fitting, given how adults with ADHD were left without support once diagnosed. While diagnosis is supposed to open the door to treatment and support, participants described how services tended to disappear the moment a diagnosis is given. As Enya stated, “*There is no support. Full stop.*”

Guidelines state that once diagnosed, adults should be offered medication, psychoeducation and support (NICE, 2018). But participants reported diagnosis is often followed by none of these. Untreated ADHD has long-term implications, including accidental injury (Doshi et al., 2012), suicide (Chen et al., 2023), poorer health outcomes (Cortese et al., 2020), and issues with substance misuse (Fluyau et al., 2021).

Participants spoke about medication as highly effective, with stimulant medication amongst the most effective interventions in psychiatry (Smith et al., 2024), yet it was increasingly hard to access. Those diagnosed privately or through Right to Choose were often unable to get prescriptions in the NHS. Harriet described the frustration: “*They come*

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<sup>29</sup> Clinician heuristics refer to shortcuts in thinking used to make quick decisions in clinical settings, which can be helpful but also introduce bias or reinforce stereotypes (Croskerry, 2003).

*out with a diagnosis and they're not able to get medication. So they're left with nothing."*

With Right to Choose potentially being restricted (Tickel, 2025), access to medication will likely get narrower.

Whilst medication was recognised as effective, it should not be the only offer. NICE (2018) recommends a shared, holistic treatment plan, yet few participants had observed this in practice. Nurse prescribers and pharmacists were cited as underused resources that could help take pressure off GPs and psychiatrists. Furthermore, recent government policy has utilised prescribers and pharmacists for other health conditions (Price, 2024).

Besides medication, psychological support like therapy was inconsistent, and mostly offered informally rather than commissioned as part of a well-established treatment pathway. This directly contradicts guidelines, which recommend that adults with ADHD receive a holistic, shared plan that includes psychological, behavioural, and occupational support (NICE, 2018). Evidence suggests that CBT can reduce behavioural characteristics (Nimmo-Smith et al., 2020), and that third-wave therapies like Dialectical Behavioural Therapy (DBT) and Mindfulness-Based Cognitive Therapy (MBCT) can improve attention, emotional regulation and co-occurring difficulties (Haynes and Hoffman, 2019). Moreover, psychoeducation also plays a key role, particularly in helping people make sense of their diagnosis and build practical coping strategies (Donker et al., 2009) and can significantly improve functioning, particularly when combined with self-management support (Honkasilta et al., 2022)

These accounts reflected the subtheme '*Just a label*', where diagnosis brought no meaningful follow-up. Craddock et al., (2014) argued that diagnosis should validate distress and offer shared understanding. Yet most were left without any tools to process and understand their diagnosis. People may, as a result, experience internal and external stigma, leading to shame and reduced self-worth (Yanos et al., 2015). Becker's (1963) labelling theory helps to explain how a label is internalised; if the system offers no help, the message is interpreted that the problem is the individual themselves. People can begin to see themselves as broken, unfixable or beyond support.

Another issue is that current diagnostic models are deficit-based, framing ADHD in terms of impairment, with the system preventing explorations of strengths, goals or environmental factors (Hall et al., 2021). Without formulation, diagnosis can feel hollow. Moreover, with medication delays and shortages now widespread, people are often left

with neither tools to manage their ADHD nor treatment (Gudka et al., 2023). This was unsurprising, as ADHD is still seen by some teams as not their problem: “*There’s still a kind of, ‘No, no, you got ADHD, you go to the Neuro service and get your service there’*”. (Colin) Participants agreed that medication should not be the only offer. It may help reduce core features, but cannot teach skills or foster understanding. People typically need support to build self-efficacy and manage ADHD. This includes psychoeducation, environmental adaptations, and therapies that help people connect their diagnosis to their life in a meaningful way. Psychoeducation can significantly improve functioning, particularly when combined with self-management support (Honkasilta et al., 2022; Hennissen et al., 2024).

This theme adds a nuanced picture of post-diagnostic support that goes beyond availability. It highlights how diagnosis, when unsupported, can cause harm, intensifying stigma, reinforcing hopelessness, and entrenching systemic exclusion. The theme points toward the urgent need for a re-evaluation of ADHD pathways where diagnosis is not treated as the endpoint, but the start of a collaborative, meaningful care journey. Emerging evidence links post-diagnostic neglect to worsening psychological well-being and increased perceived stigma in adults with ADHD (Hansson Halleröd et al., 2015; Young et al., 2022).

### **5.3.5 Theme 5: *Solutions and facilitators***

While earlier themes focused on barriers, this theme turns to what participants believed should be happening in ADHD healthcare. Despite working in underfunded systems with rigid structures, participants in the current study provided examples of flexible, thoughtful and compassionate practice that offer a model for what ‘*support should, and could, look like*’.

Participants used “*formulation-led*” approaches (Sophie) such as CFT (Gilbert, 2009) and the power-threat meaning framework (PTMF; Johnstone & Boyle, 2018), which are both useful frameworks designed to support individuals experiencing high levels of shame and criticism (CFT), as well as systemic disadvantage (PTMF). Others described multidisciplinary approaches, involving psychologists, occupational therapists and speech and language therapists within their team, offering webinars, practical interventions and ongoing support (NICE, 2018).

These examples reflected the application of neurodiversity-affirming practice<sup>30</sup> in situ: curious, collaborative ways of working that build on people's strengths. But participants were clear that these examples were rare, reliant on individual staff values or one-off commissioning (such as individual ADHD services in a borough with no alternatives). Sadly, this kind of provision had to be tightly ringfenced due to demand, with only a minority of ADHD services offering evidence-based support (NICE, 2018; Price et al., 2020).

There was a shared understanding that an ADHD strategy at a national level is required. Harriet explained, *"It needs a national directive, like the national dementia strategy... because it's just not going to work at a local level."* This mirrors the literature, which signifies how current systems are not keeping pace with need, and change must be structural. (The National Taskforce, 2024).

Comparisons were drawn with health conditions that have gained policy traction. For example, diabetes is embedded within the Quality and Outcomes Framework (QOF), meaning GPs are incentivised to offer regular care, follow-ups and accurate data collection (McHugh et al., 2011). Autism has its own legal framework through the Autism Act (2009), as well as mandatory training through the Oliver McGowan initiative (DHSC, 2022). Participants suggested ADHD should follow a similar route, with national guidance, cross-sector planning, and workforce training that is meaningful and compulsory. This would help ensure consistency, reduce diagnostic gatekeeping, and begin to address the systemic neglect by embedding ADHD within the same legal and commissioning frameworks that have improved outcomes in other chronic health problems.

In '*Sharing knowledge with the wider systems*', non-specialist teams were described as lacking in confidence and understanding when working with ADHD. Several participants advocated for embedding EBEs into training and service development, so the system learns from those living in it. Others emphasised the need for cultural humility and a shift away from rigid, deficit-focused thinking (Chapman & Botha, 2023).

Monica reflected on the bigger picture, arguing that, *"if services could reflect how all these boxes are linked, the population would be so much less in pain."* ADHD, in her

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<sup>30</sup> Neurodiversity affirming practice recognises neurological differences like ADHD as valid variations of human experience, and focuses on adapting environments and supports rather than changing the individual to fit neurotypical norms (Chapman & Botha, 2023).

view, is not a standalone issue, but something that cuts across education, social care, and mental health services. This study found that services that worked well took time to listen, avoided rushing to conclusions and left space for people to tell their story in full.

This project was completed as NHS structures are being reshaped, and the National ADHD Taskforce has promised an update for Summer 2025. This study offers timely insight into the solutions already in practice by a motivated few. If acted upon, the findings could help shape a system that does not just diagnose ADHD, but actually supports people to live well.

#### **5.4 Strengths and limitations:**

A key strength of this study was its qualitative design that allowed for rich, grounded accounts from specialist clinicians who work directly in ADHD contexts, shedding light on how adult ADHD care is experienced in practice. The complexity and fragmentation of current systems meant that a qualitative approach was well suited, as it gave space for participants to speak to the nuance, messiness and contradictions in their day-to-day work. RTA aligned with the study's critical realist position, supporting exploration of meaning while recognising the role of discourse, context and researcher influence in shaping what was said and how it was interpreted.

The interview schedule was co-developed with EBE input, helping to shape a more accessible and inclusive schedule. Clinical or overly service-focused wording was softened, and prompts were added to help draw out more detailed examples. This helped ground the interviews in the realities of those using services.

Another strength was the range of professionals involved. Unlike other studies that focused narrowly on GPs (Gudka et al., 2024) or did not clearly state who was involved (Young et al., 2021), this project included clinicians from psychiatry, psychology, nursing, OT and SLT. Voices that have often been left out of ADHD research were therefore included, which felt important given how these roles are becoming more central to ADHD care. The data therefore provided more depth and helped capture important barriers to address across the care pathway.

The timing of the study also added value. ADHD care is changing fast, with a new taskforce in place and national reforms being proposed. Participants reflected on these shifts in real time, including changes to Right to Choose and medication shortages. This

gave the findings immediate relevance, especially as many participants had worked through key changes that followed the pandemic. These frontline perspectives help offer a grounded evidence base for those shaping what comes next. Rather than just pointing to problems, the findings show where systems are falling short and where practice is already working well.

Despite these strengths, several limitations need to be acknowledged. The interview guide was broad, so not every participant commented on all parts of the ADHD pathway. This is a feature of qualitative work, but it meant that themes like intersectionality or post-diagnostic support were stronger in some interviews than others. RTA is a co-constructed method, so the data reflects not only what participants chose to share, but also the questions asked, what was followed up, and how the researcher interpreted it. Reflexive journaling helped attend to these dynamics, but the subjectivity of the process should be kept in mind.

Although the study followed good practice in terms of reflexivity and transparency, it did not include independent coding. While not essential for RTA, having a second person read and code part of the dataset could have added another layer of integrity, adding to the overall depth and credibility of the analysis.

Recruitment also likely introduced some bias. Participants were recruited via professional networks, social media and word of mouth, meaning they may already have had an interest in ADHD or aligned with neuro-affirmative views. This was useful for depth, but means the study might under-represent clinicians who hold stigmatising beliefs or are less informed, exactly the kind of barriers the research sought to understand. This could mean the findings risk underestimating how widespread some of the problems are. Furthermore, the inclusion/exclusion criteria of specialists working within ADHD may have excluded GPs who feel that this is not within their remit, one of the key issues highlighted in this study.

Another limitation is that participant ethnicity was not reported due to concerns about preserving anonymity within a small, specialised sample. While this decision was made ethically, it limits the transparency of the sample's representativeness. The NHS workforce is predominantly White (NHS England, 2023), and there is evidence that racial and cultural dynamics can influence how global majority groups engage with services (Edge, 2010; Memon et al., 2016). Without reporting on ethnicity, it is difficult to consider

how these dynamics may have shaped participants' perspectives or been overlooked in the findings.

An additional limitation was that although an EBE was consulted during the development of the interview schedule and also participated in a pilot interview, wider consultation with EBEs, wide Patient and Public Involvement (PPI) was limited. This reduced opportunities for co-production, for example, in shaping the research aims, informing data collection, and contributing to the interpretation of findings. As a result, the study may have missed insights that could have improved the accessibility, relevance, and impact of the research.

Finally, there was limited input from certain contexts. While NHS mental health settings were well represented, areas like probation, housing and social care were not. These settings matter, especially for adults facing multiple disadvantages, where ADHD is often missed or misread. Including these voices in future research would offer a more complete picture of how ADHD is interpreted across systems.

## **5.5 Clinical implications and recommendations for future research**

### ***5.5.1 Clinical implications***

This study offers timely, practice-informed insights into how adult ADHD is currently understood and supported, based on the views of UK-based specialists. With NHS pressures mounting and policy reform underway, these findings highlight key areas for change.

**Meaningful post-diagnostic support:** Post-diagnostic care must be part of the pathway. Participants were clear that a diagnosis without follow-up is harmful. As shown in '*Just a label*', many adults received no explanation or support plan, contradicting recommended guidance. While stimulant medication was often viewed as effective, participants stressed the need for a broader, better-commissioned offer. Psychological therapies such as CBT, DBT, MBCT and CFT (Fleming et al., 2015; Gilbert, 2009; Zylowska et al., 2008) were seen as vital for supporting emotion regulation, reducing shame and building self-understanding. Psychoeducation and strengths-based formulation were also valued, but must not rely on informal goodwill. GPs should be supported to take on shared-care agreements through structural incentives such as inclusion in the QOF, and where prescribing capacity is limited, non-pharmacological options should be prioritised as a first-

line offer.

***Services must integrate, not isolate, ADHD.*** Participants described how ADHD is often siloed in under-resourced clinics. Findings from Themes 1 and 2 highlight the need for integration across primary, secondary and tertiary care. Embedding ADHD support within wider services would better reflect its intersection with trauma, mental health, and social inequality. This would also align with the agenda of NHS ICBs, to operate through a 'neighbourhood model<sup>31</sup>.' While NICE (2018) calls for multi-agency planning, this requires funding and oversight to be meaningful.

***Training should be mandatory across settings.*** Gaps in ADHD knowledge were seen across non-specialist settings, leading to misdiagnosis and missed support (Themes 2 and 5). A national training strategy, similar to the Oliver McGowan framework, should include neurodiversity-affirming practice, trauma-informed care, and cultural humility. It must address how ADHD presents across gender, ethnicity, and intellectual functioning.

***Align ADHD care with existing successful models.*** Participants advocated for a joined-up strategy, akin to the Autism Act (2009) or incentive-based frameworks (such as QOF) for long-term conditions. ADHD currently lacks legal protections, mandatory training and standardised pathways. As the National ADHD Taskforce advances, this study highlights calls for cross-sector coordination, greater use of nurse prescribers and pharmacists, outcome monitoring, and accountability. These measures should enhance, not replace, specialist services, ensuring support is consistent and continues beyond diagnosis.

### ***5.5.2 Recommendations for future research***

Future studies should explore what the needs are for adults with ADHD, in order for them to be supported after diagnosis. Additionally, exploration is needed into which interventions, structures, or supports actually help and why. Future research should also examine the experiences of groups who are often missed or misdiagnosed, such as women, people from global majority backgrounds, and those with learning disabilities. Better understanding of how ADHD presents across diverse populations will lead to more inclusive and effective assessment and support processes.

Further research should include perspectives from non-specialist settings, such as

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<sup>31</sup> The neighbourhood model of integrated care focuses on providing care closer to home, often within local communities, by integrating various healthcare services, including health, social care, and the voluntary sector

GPs, social workers and carers, to understand where knowledge gaps and structural barriers arise. In addition, learning from services already delivering effective ADHD care is vital. Exploring what makes these services work well can offer practical guidance for improving existing good practice. Finally, future research should centre the voices of people with lived experience. Embedding EBEs into service development, training, and evaluation via co-production is key to building neurodiversity-affirming, inclusive care pathways.

### **5.6 Critical Appraisal**

For consistency with the SLR in Chapter 2, the CASP tool (CASP, 2023) was used to quality appraise this study, and can be found in Appendix Y. The CASP was completed in conjunction with the secondary researcher and reviewed by a researcher external to the research team to reduce the risk of bias.

### **5.7 Conclusion**

This study explored the perspectives of UK-based HCPs specialising in adult ADHD, to better understand the barriers and facilitators that shape access to care. In doing so, it adds a focused clinical lens to the growing research base on adult ADHD, drawing attention to the realities of those working within overstretched, fragmented, and at times stigmatising systems. Thematic analysis revealed five key themes. First, many adults still face significant delays before reaching diagnosis, often having to push repeatedly to be heard. Then, once in services, the diagnostic process itself can feel out of sync with the presentation and needs of adults. Next, experiences post-diagnosis were especially troubling: while a diagnosis should lead to support, participants described a cliff edge where care suddenly dropped off, leaving people with a diagnostic label and little else. Finally, despite this, participants shared examples of creative, neurodiversity-affirming practices that are already being used, which can serve as a blueprint for wider change.

This study builds on existing work by offering a more diverse, multi-disciplinary sample of professionals than previous research. It also moves beyond identifying problems to include examples of what good care can look like. In doing so, it captures not just the gaps, but the opportunities. The findings come at a pivotal moment. ADHD services are under intense scrutiny, and national strategies are in development. By centring the voices of those delivering care on the ground, this research can help to ensure those strategies are

informed by lived clinical realities, not just policy ideals. There is still much to do. Systemic barriers remain, and access to support continues to be shaped by geography, funding and who shouts the loudest. But the insights gathered here offer a clear message: the tools for change already exist, but the challenge is now empowering HCPs to implement them consistently and confidently, with the backing of commissioning and strategy to sustain good care. This will ensure that the compassionate, life changing support that clinicians can offer are available to those who desperately need it.

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## Appendices

### Appendix A:

#### Journal entries

##### **Reflective extracts: SLR**

Date	Title and Extract
14/10/2024	<p><b>The search process and Covidence</b></p> <p>I'm really in the swing of Covidence and this week reconnected with a colleague from my first placement on the doctoral course who is going to act as my second researcher. I met with her on Teams and went through the research process. It was really nice to recruit someone, as this process can feel pretty isolating at times. She was really keen and has done a lot of research before. In one working day she's already screened 200 papers in Covidence, so I'd best get a move on!</p> <p>What I'm learning on this project is that the speed of everything fluctuates so much – there will be difficult days and good days. This was definitely a good week, as I've felt like I'm really making progress on my SLR. I've been getting into the habit of going to silent study every day, Monday to Friday, and getting through the tough stuff (finishing off searches, reading, Covidence).</p>
01/12/2024	<p><b>Data extraction</b></p> <p>Extracting my data for the table of all my study summaries has genuinely taken nearly 3 weeks of full days going through each paper. What I initially assumed would take a few concentrated days ended up being much more time-consuming, partly because I wanted to be thorough, and partly because I kept needing to revisit sections to cross-check decisions I'd made earlier. It's been a lesson in realistic time planning and the hidden labour of synthesis.</p> <p>That said, this process has forced me to really slow down and engage deeply with each study. I feel like I now know the literature inside out, not just in terms of findings, but methods, sample characteristics, quality, and scope. In a way, it's become a kind of revision tool for the entire systematic review. I'm coming away from it feeling tired, but also more confident in how well I understand my evidence base.</p>
	<p><b>Write up: Discussion</b></p> <p>I am now at the stage of writing up my discussion Chapter, which I have been putting off for a while. I know I tend to avoid finishing projects when it comes to drawing things together. There is something about trying to conclude that feels quite exposing. I worry about getting it wrong or not doing the findings justice.</p>

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	<p>That said, I have already created a solid plan for how I want to structure the discussion, which has helped reduce some of the avoidance. Breaking it down into clear sections such as key findings, links to the literature, implications, and limitations has made it feel more manageable. Now I just need to stick to the plan and start writing.</p> <p>A recent supervision meeting gave me a real boost. It reminded me that I know this study inside out and that I am not expected to write a perfect version straight away. The feedback helped me reframe this Chapter as a space to bring my ideas together and show what I have taken from the process, rather than treat it like a test. I feel more grounded now and ready to move forward.</p>
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*Reflective extracts: Empirical Study*

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	<b>Title and extract</b>
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*Networking/Scoping exercises*

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<b>02/02/2024</b>	<p><b>Initial responses from third sector organisations (recruitment)</b></p> <p>I spoke with three leading ADHD charities who have agreed to help me with my project. This is so exciting! One of them is a leading research publisher for adult ADHD and I couldn't be more grateful. They have all asked me to send information on my project, which is not only terrifying but really promising. They are yet to confirm how they can support but I'm hoping they can all promote my recruitment as they all have a big presence on social media. Definitely one of those days that I'll remember when I complete this project!</p>
<b>30/01/2025</b>	<p><b>Ethics</b></p> <p><b>Advisory panel</b></p> <p>Due to time constraints I only ended up having time for one meeting with my advisory panel which was a shame but gosh it was so helpful. Today's meeting gave me a completely new perspective on how ADHD services are situated within much broader systems. The discussion ranged from frontline frustration to macro-level mechanisms like Integrated Care Boards (ICBs), funding flow, and political decisions shaping what services are commissioned. One member emphasised how little time professionals have to engage in strategic planning because they're firefighting demand pressures. I realised that while I've been focusing on frontline HCP perspectives, there's an entire system above that, shaping their options. Action: Request if I can join placement supervisor in management meetings to see these high-level decisions in action.</p>
<b>13/01/2025</b>	<p><b>Pilot interview</b></p> <p>I interviewed my EBE and a colleague today with my draft interview schedule. It's all starting to feel very real. The interviews both went really</p>

	<p>well. I recorded them both and am looking forward to listening back. Lots of feedback to follow up on like some of the phrasings of the questions, what flowed and what didn't. It also made me reflect on how I actually put a lot of time into researching interview schedules and the theory behind them, and I think it has paid off. My EBE gave really supportive feedback which was really nice. It's starting to chip away at my imposter syndrome as I feel more and more like a researcher each day!</p>
05/03/2025	<p><b>Ethics</b></p> <p>Complete frustration with recruitment processes via the NHS. It seems every time I think I can start recruiting fully, I'm hit with another barrier. Today I've learnt that I need to submit an additional amendment to my sponsor, in addition to the amendment I already have approved by university, all so that I can email the comms team from the NHS trust to add my study to their newsletter. It feels as if these institutions that are supposed to be sponsoring and supporting the project create so many barriers that people give up. I have decided to focus on non-NHS recruitment which seems to be much quicker and less 'red tape' than NHS routes, which was supposed to be 'quick and easy'.</p>
28/02/2025	<p><b>Interviews</b></p> <p>I had 3 interviews today. The final interview went really well and I felt like a genuine researcher, perhaps due to the level of insight the participant had. They had so much knowledge about my research topic. It's amazing how a successful interview can boost motivation and replenish researcher burnout that I frequently am noticing given the size of this project. It's given my an urge to keep promoting and emailing out requests for advertising, something which I'm not the best at.</p>

### Data analysis

	<p><b>Transcribing</b></p> <p><i>'The great transcription'</i> is what I'll call the past weekend. I sat through all 8 interviews. Pause. Rewind. Pause again. Rewind again. I thought I would come to write in my reflective diary about how cringy it was to look back on my interviews, but I actually loved it. It made me reflect on how much I valued my participants time and hearing their insights. Anyway, I have finished transcribing – GET IN! I began making familiarisation doodles as I went through and noting down key ideas that popped up. It really sent my imagination into overdrive. Today I am feeling most pleased and happy.</p>
02/05/2025	<p><b>Data Familiarisation</b></p> <p>I am about 75% through familiarizing myself with the data. Slightly disconcerting to know when I'll be happy with being familiar enough, but these are the calls one must make as a lead researcher! I'm thoroughly enjoying the process so far. So much rich data! I have so many stories from my participants and one participant used a metaphor that I'm considering using in my results somehow, hope this works. I re-read Braun &amp; Clarke's 'bible' as my seminar tutor refers to it as, and have been thinking about my</p>

	<p>critical realist stance.</p> <p>I have been reflecting on power differences and when I notice myself getting drawn towards certain participants. Perhaps I get drawn towards the psychologists as they speak my language so to speak, whereas with psychiatrists I felt quite cold initially. One thing I have reflected on is this anti-psychiatry bias from the course, as it was quite 'cool' to be critical of psychiatry. I've reflected on this actually couldn't disagree more. This has led to reflecting on my beliefs about the different health professions before continuing.</p>
<b>08/05/2025</b>	<p><b>Generating Codes</b></p> <p>I found this process thrilling and it was very much in line with how my busy mind works. Despite feeling tired from being so immersed in my data and struggling to switch off from my ideas, I also wonder if this is something other researchers experience. When I have done thematic analysis before I made way to many codes, so have reflected that I need to be more careful with the codes I develop this time round. Probably should take a break from research when this process ends as I feel I may start to feel a bit manic if not. Finding balance can be tricky.</p>
<b>12/05/2025</b>	<p><b>Generating themes</b></p> <p>I have started generating my themes today. I am working slow purposefully, which takes a bit of work for me. I'm used to working rather gung-ho but themes require slow thinking, and deep reflection. My approach is to get the latent meanings down, then come back to think more about the semantic wording of them. This approach works for me. I am in uncharted territory. I have found a deeper level of meaning from participant accounts, but I know the own which quotes which hopefully shows I am fully immersed in it all. Onwards!</p>
<b>29/05/2025</b>	<p><b>Reviewing themes</b></p> <p>I had a supervisory meeting today having finally shared my themes with my supervisor. It was so helpful to get feedback on my results. I've been sitting with thoughts like "is this all a load of sh*t?" I got really nice feedback and it's pushed me to move on to refining them for final write up.</p>
<b>01/06/2025</b>	<p><b>Refining and finalising themes</b></p> <p>I have spent the past few days sitting with the themes, re-reading extracts, and pulling together mind maps for each one. It feels like things have started to settle. Each theme has a clear narrative arc, and I can see how the data hangs together. There's enough depth in each one, and they feel distinct but connected. I think they are ready to be written up.</p> <p>That said, there's definitely a bit of anxiety creeping in. Locking the themes in feels final, and part of me worries I've missed something or that they won't hold up under scrutiny. But the process of refining them has been careful and grounded in the data. I've also been revisiting literature and theory to strengthen the framing, so it doesn't feel rushed.</p>

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It's bloody brilliant to be at this stage. The groundwork is there, and it finally feels like I can move forward. Now it's about trusting the process and getting on with writing them up. It's mile 26, and I can see the finish line.

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## Appendix B

### Table of language and key terms

Language and/or key term	Definition
Approach (not intervention)	'Approach' is more appropriate than 'intervention', which implies pathology and a need to correct.
Care pathway	The structured route through which a person receives care, from initial referral to diagnosis and ongoing support. In ADHD services, these are often fragmented or unclear.
Discrimination	The unfair or unequal treatment of individuals based on characteristics such as neurodivergence, often resulting in reduced access to services or opportunities.
Neuro-affirmative care	An approach that respects neurodivergent ways of being and avoids deficit-based language. It recognises ADHD and autism as forms of neurocognitive diversity and sees distress as linked to environmental mismatch rather than disorder.
Neurodiversity	A concept that recognises and values natural variation in human cognition, including conditions like ADHD and autism.
Service user / client	Preferred over 'patient' to reflect agency and reduce medicalised framing.

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Shared care pathway	A formal arrangement between primary care (e.g. GPs) and secondary or specialist services, where responsibility for prescribing and monitoring is shared to ensure continuity and accessibility of care.
Stigma	Negative stereotypes or assumptions that lead to social rejection, marginalisation, or internalised shame for being neurodivergent.
Support / tools (not treatment)	Terms like 'support' or 'tools' avoid implying that ADHD is something to be fixed or cured.
Traits / characteristics (not symptoms)	Describes experiences without framing them as illness, aligning with neurodevelopmental perspectives.

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## Appendix C

### SPIDER search terms

Acronym	Searches
<b>S:</b>	"Health Personnel" OR Clinician* OR "Healthcare provider*" OR "Healthcare professional*" OR Therapist* OR psychiatrist* OR Psychologist* OR Paediatrician* OR physician* OR Counsellor OR Nurs*
Sample	
	AND
<b>P</b>	ADHD OR "Attention Deficit Hyperactivity Disorder" OR
Phenomenon:	"Attention Deficit With Hyperactivity"
	OR
	ASD OR "Autism Spectrum Disorder" OR "Autism"
Of Interest:	
	"Adult" OR "Late diagnosis" OR "Delayed diagnosis"
	AND
<b>D:</b>	Interview* OR "Focus group*" OR Observ* OR Survey* OR
Design	Questionnaire*
	AND
<b>E:</b>	Attitude of Health Personnel+ OR View* OR Experience* OR
Evaluation	Attitude* OR Opinion* OR Perception OR Perspective* OR
	Belie* OR Know* OR Understand* OR Barrier* OR Facilitator
<b>R:</b>	AND
Research Type	Qualitative OR Mixed Methods

## Appendix D

### MESH terms / Boolean operators

*Database search example: Medline & CINAHL (via EBSCO)*

Condition 1	Condition 2	Professional	Design	Outcome
1. Keyword: (MH "Autistic Disorder")	1. Keyword: (MH "Attention Deficit Disorder With Hyperactivity")	1. Keyword: (MH "Health Personnel") 2. Clinician*	1. Keyword: Qualitative research 2. Interview*	1. Keyword: (MH Attitude of Health Personnel+)
2. Autism	2. ADHD	3. "Healthcare provider"	3. "Focus group"	2. View*
3. ASD	3. ADDH		4. Observ*	3. Experience*
4. Autistic	4. Attention Deficit Disorder	4. "Healthcare professional"	5. Survey*	4. Attitude*
	5. Attention Deficit Hyperactivity Disorder	5. Therapist*		5. Opinion*
	6. Attention Deficit Hyperactivity Disorders	6. Psychiatrist*		6. Perception
		7. Psychologist*		7. Perspective*
		8. Paediatrician*		8. Belie*
				9. Know*
				10. Understand*
				11. Barrier*
				12. Facilitator*
				13. Challenge*
				14. Obstacle*
	7. Hyperkinetic Syndrome	9. Physician*		
		10. Counsellor*		
		11. Nurs*		

Search term date: 23/11/2024

## Appendix E

### Full search strategy

“Attention Deficit Disorder With Hyperactivity” or ADHD or Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder

OR

“Autistic Disorder” OR Autism OR ASD OR Autistic

AND

“Health Personnel” OR Clinician\* OR “Healthcare provider\*” OR “Healthcare professional\*” OR Therapist\* OR Psychiatrist\* OR Psychologist\* OR Paediatrician\* OR Physician\* OR Counsellor\* OR Nurs\*

AND

ADULT\*

AND

Interview\* OR “Focus group\*” OR Observ\* OR Survey\*

AND

(MH Attitude of Health Personnel+) or View\* OR Experience\* OR Attitude\* OR Opinion\* OR Perception OR Perspective\* OR Belie\* OR Know\* OR Understand\* OR Barrier\* OR Facilitator\* OR Challenge\* OR Obstacle\*

AND

Research: qualitative research OR qualitative study OR qualitative methods OR interview

**Filter:** Since 2013, English language only

## Appendix F

### Quality Assessment Outcomes of Included Grey Literature Study using AACODS Scoring.

#### *Scoring for Westminster Commission on Autism, 2016.*

AACODS Criterion	Included Studies
7. Authority	8
Identifying who is responsible for the intellectual content.	
<b>Individual author:</b>	
<ul style="list-style-type: none"> <li>• Associated with a reputable organization?</li> <li>• Professional qualifications or considerable experience?</li> <li>• Produced/published other work (grey/black) in the field?</li> <li>• Recognised expert, identified in other sources?</li> <li>• Cited by others? (use Google Scholar as a quick check)</li> <li>• Higher degree student under “expert” supervision?</li> </ul>	2
<b>For organisation and groups:</b>	
<ul style="list-style-type: none"> <li>• Is the organisation reputable? (e.g. W.H.O)</li> <li>• Is the organisation an authority in the field?</li> </ul>	
<b>For all studies:</b>	
<ul style="list-style-type: none"> <li>• Does the item have a detailed reference list or bibliography?</li> </ul>	
8. Accuracy	
<ul style="list-style-type: none"> <li>• Does the item have a clearly stated aim or brief?</li> <li>• Is so, is this met?</li> <li>• Does it have a stated methodology?</li> <li>• If so, is it adhered to?</li> <li>• Has it been peer-reviewed?</li> <li>• Has it been edited by a reputable authority?</li> <li>• Supported by authoritative, documented references or credible sources?</li> <li>• Is it representative of work in the field?</li> <li>• If No, is it a valid counterbalance?</li> <li>• Is any data collection explicit and appropriate for the research?</li> <li>• If item is secondary material (e.g. a policy brief of a technical report) refer to the</li> </ul>	2

---

original. Is it an accurate, unbiased interpretation or analysis?

---

9. Coverage

- All items have parameters which define their content coverage. These limits might mean that a work refers to a particular population group, or that it excluded certain types of publication. A report could be designed to answer a particular question, or be based on statistics from a particular survey.
- Are any limits clearly stated?

2

---

10. Objectivity

- It is important to identify bias, particularly if it is unstated or unacknowledged.
- Opinion, expert or otherwise, is still opinion: is the author's standpoint clear?
- Does the work seem to be balanced in presentation?

0

---

11. Date

For the item to inform your research, it needs to have a date that confirms relevance

- Does the item have a clearly stated date related to content? No easily discernible date is a strong concern.
- If no date is given, but can be closely ascertained, is there a valid reason for its absence?

2

Check the bibliography: have key contemporary material been included?

---

12. Significance

This is a value judgment of the item, in the context of the relevant research area

- Is the item meaningful? (this incorporates feasibility, utility and relevance)
- Does it add context?
- Does it enrich or add something unique to the research?

2

- 
- Does it strengthen or refute a current position?
  - Would the research area be lesser without it?
  - Is it integral, representative, typical?
- Does it have impact? (in the sense of influencing the work or behaviour of others)
- 

<b>Total score</b>	<b>10</b>
--------------------	-----------

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## Appendix G

### CASP criterion example



### CASP Checklist: For Qualitative Research

<b>Reviewer Name:</b>	Jamie Armstrong
<b>Paper Title:</b>	Mainstreaming adult ADHD into primary care in the UK: guidance, practice, and best practice recommendations
<b>Author:</b>	Philip Asherson, Laurence Leaver, Marios Adamou, Muhammad Arif, Gemma Askey, Margi Butler, Sally Cubbin, Tamsin Newlove-Delgado, James Kustow, Jonathan Lanham-Cook, James Findlay, Judith Maxwell, Peter Mason, Helen Read, Kobus van Rensburg, Ulrich Müller-Sedgwick, Jane Sedgwick-Müller, and Caroline Skirrow.
<b>Web Link:</b>	<a href="https://pubmed.ncbi.nlm.nih.gov/36221085/">https://pubmed.ncbi.nlm.nih.gov/36221085/</a>
<b>Appraisal Date:</b>	04/12/2024

During critical appraisal, never make assumptions about what the researchers have done. If it is not possible to tell, use the "Can't tell" response box. If you can't tell, at best it means the researchers

have not been explicit or transparent, but at worst it could mean the researchers have not undertaken a particular task or process. Once you've finished the critical appraisal, if there are a large number of "Can't tell" responses, consider whether the findings of the study are trustworthy and interpret the results with caution.

Section A Are the results valid?		Rating 5 (B)
1. Was there a clear statement of the aims of the research?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell <b>Goal:</b> Outlined in 'background' section, that researchers aimed to identify constraints in service provision, and service delivery models with potential to improve healthcare access and delivery. <b>Importance:</b> sought solutions for widespread gap in care delivery within adult ADHD <b>Relevance:</b> Tackles misconceptions of adult ADHD, and advocates for systemic changes to healthcare systems to improve access to care.	1
<b>CONSIDER:</b>		
<ul style="list-style-type: none"> <li>• <i>what was the goal of the research?</i></li> <li>• <i>why was it thought important?</i></li> <li>• <i>its relevance</i></li> </ul>		
2. Is a qualitative methodology appropriate?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell It allows for a detailed exploration of healthcare professionals' (HCPs) subjective experiences and beliefs regarding the diagnosis and treatment of ADHD in adults. It is well-suited to capture the nuances of HCPs' perspectives, providing insights that go beyond numerical data. As noted by Braun and Clarke (2006) and Green and Thorogood (2018), qualitative methods, particularly interviews and thematic analysis (TA), are effective for understanding the complex, personal, and often hidden aspects of healthcare delivery, such as clinician challenges, practices, and decision-making processes.	1
<b>CONSIDER:</b>		
<ul style="list-style-type: none"> <li>• <i>If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants</i></li> <li>• <i>Is qualitative research the right methodology for addressing the research goal?</i></li> </ul>		
3. Was the research design appropriate to address the aims of the research?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell TA allowed for in-depth exploration of HCP perspectives on ADHD diagnosis and treatment. TA is effective in identifying recurring themes in the data, therefore providing rich understanding of challenges faced by both HCPs and service users. This approach aligns with study's goal to explore both systemic issues within the healthcare system and the personal experiences of individuals working in clinical settings.	1
<b>CONSIDER:</b>		
<ul style="list-style-type: none"> <li>• <i>if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)</i></li> </ul>		
4. Was the recruitment strategy appropriate to the aims of the research?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/> Can't Tell Researchers did not explain how participants were selected. There was no discussion around recruitment.	0

	No explanation was provided for certain professions were included or excluded.	
<b>CONSIDER:</b>		
<ul style="list-style-type: none"> <li>• If the researcher has explained how the participants were selected</li> <li>• If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study</li> <li>• If there are any discussions around recruitment (e.g. why some people chose not to take part)</li> </ul>		
5. Was the <b>data collected</b> in a way that addressed the research issue?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell <p>Data collection was justified as HCPs were recruited from settings that ADHD is managed (e.g. primary, secondary, and tertiary care). Data was collected via a focus group, but this method was not justified. The authors provided a summary of the stages of data collection including the group meeting, discussion topics, transcription, synthesis, arriving at a consensus, review and publication. The form of data included recordings and transcription.</p>	0
<b>CONSIDER:</b>		
<ul style="list-style-type: none"> <li>• If the setting for the data collection was justified:</li> <li>• If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)</li> <li>• If the researcher has justified the methods chosen</li> <li>• If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)</li> <li>• If methods were modified during the study. If so, has the researcher explained how and why</li> <li>• If the form of data is clear (e.g. tape recordings, video material, notes etc.):</li> <li>• If the researcher has discussed saturation of data:</li> </ul>		
6. Has the relationship between researcher and participants been adequately considered?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell <p>No information is provided throughout the study</p>	0
<b>CONSIDER:</b>		
<ul style="list-style-type: none"> <li>• If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location</li> <li>• How the researcher responded to events during the study and whether they considered the implications of any changes in the research design</li> </ul>		
<b>Section B: What are the results?</b>		

7. Have ethical issues been taken into consideration?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell Ethical approval was not deemed relevant for this study. Participants gave verbal consent to participate in the study. Assumed that ethics were addressed	1
<b>CONSIDER:</b>		
8. Was the data analysis sufficiently rigorous?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell	0
	There is a brief description of the analysis process. The approach used for analysis is not stated. No explanation provided on how data was selected from the original sample to demonstrate analysis process. Links to literature were provided to support findings. No evidence that the researcher has critically examined their role in data analysis.	
<b>CONSIDER:</b>		
9. Is there a clear statement of findings?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell	1
	The findings are explicit. There is clear evidence of consideration both for and against the researchers' arguments. The credibility of findings is discussed when they describe how data analysis was completed, such as stating that 2 analysts were used.	
<b>CONSIDER:</b>		
	<ul style="list-style-type: none"> <li>• If the findings are explicit <b>the findings are explicit</b></li> <li>• If there is adequate discussion of the evidence both <b>for and against the researcher's arguments</b></li> <li>• If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst). <b>2 analysts were used.</b></li> <li>• If the findings are discussed in relation to the original research question <b>yes</b></li> </ul>	
<b>Section C: Will the results help locally?</b>		

## Appendix H

### Full written summary of included studies

**Consistent Areas of Strength.** All seven published studies received a 'yes' for Item 1 (Was there a clear statement of the aims of the research?) and Item 9 (Is there a clear statement of findings?). Clarity in aims ensures that the purpose and focus of the research are transparent, guiding both the research process and the reader's understanding. Similarly, clearly stated findings are crucial for interpreting the outcomes and assessing their relevance, particularly in fields like ADHD and autism research, where actionable insights can directly inform clinical practice and policy. This outcome aligns with expectations, as articles failing to clearly outline their aims and findings are unlikely to pass the peer-review process.

Similarly, the 'grey' paper also received a 'yes' in the sections relating to Aims (Accuracy) and Findings (Significance) in the AACODS checklist, which is particularly noteworthy given that grey literature is not always subjected to the same rigorous peer-review standards as published studies. Achieving high scores in these areas highlights the paper's credibility and ensures its findings are both reliable and valuable for informing practice and research. All studies also used appropriate qualitative methodology, with CASP studies all receiving a score of 1 on item 2 (Is the qualitative methodology appropriate?) (CASP, 2023), and the 'grey' paper scoring 1 (out of a possible 2) on the AACODS checklist section of 'accuracy' (Tyndall, 2010).

With regards to the *research impact* (clear statement, value and significance of the findings), all studies scored consistently high on both the CASP (item 9 'Is there a clear statement of findings?' and item 10 'How valuable is the research?') and AACODS checklist (item 6 'Significance'). High impact scores reflect the studies' ability to advance understanding of ADHD and autism in adulthood and highlight their practical value for healthcare professionals. By capturing the perspectives of disciplines such as psychiatry, clinical psychology, and nursing, these studies contribute to improving service delivery, informing evidence-based interventions, and shaping policy to better support this population.

This is unsurprising, as all the studies provided valuable insights into the perspectives of healthcare professionals across the UK on ADHD and autism in adulthood. These were among the first studies to gather the experiences and views of professionals from disciplines such as psychiatry, clinical psychology, and nursing, making a significant contribution to the literature. Their findings provide numerous implications for enhancing healthcare services and outcomes for this population.

**Consistent Areas of Challenge.** Question 6 of the CASP Checklist addresses researcher reflexivity, asking, 'Has the relationship between researcher and participants been adequately considered?' Similarly, the topic of 'Objectivity' in the AACODS checklist addresses the question, 'Is the researcher's standpoint clear?' Addressing researcher reflexivity enhances the credibility and depth of research findings by acknowledging and managing potential biases. This transparency allows readers to understand how the researchers' positions, assumptions, or relationships with participants might influence the study's interpretation and outcomes, ultimately strengthening the trustworthiness of the research. This area was poorly addressed across studies, with only one study adequately addressing it (French et al., 2020). The lack of reflexivity and transparency in researcher positioning limits the ability to fully assess potential biases, which may undermine the trustworthiness and credibility of the findings.

**Discrepancies.** Three studies performed poorly in both sampling (recruitment strategy) and data collection. (Asherson et al., 2022; Westminster Commission on Autism, 2016; Young et al., 2021). Failing to discuss the recruitment strategy results in the studies lacking transparency and undermining credibility. Without clarity on how participants were recruited, it becomes difficult to assess the representativeness of the sample, which can affect the generalisability of the findings. Additionally, a lack of transparency raises concerns about potential selection bias, ultimately reducing the validity and reliability of the study's conclusions. Recruitment is addressed by CASP (Item 4) and AACODS (item 2 'Accuracy'). Data collection is addressed in CASP (item 5) and also incorporated into AACODS (item 2).

Most studies addressed ethical considerations (CASP Item 7); however, two studies (Young et al., 2021; Westminster Commission on Autism, 2016) did not outline their approach to addressing ethical issues. Young et al., (2021) and Westminster Commission on Autism (2016) also both failed to address the aims of the research (CASP item 3; AACODS item 2). We cannot, therefore, fully understand what the researchers in these studies wanted to discover, or if they went about it ethically.

Concerning data analysis and rigour (CASP Question 8, 'Was the data analysis sufficiently rigorous?' and the AACODS 'Accuracy' section), only two studies adequately addressed this aspect (French et al., 2020; Ward et al., 2024). Consequently, six of the included studies employed inadequate analysis methods, making them susceptible to issues such as limited transparency, potential bias, and low replicability.

## Appendix I

### Tabulation of thematic synthesis

Author(s) and Date of Publication	Main Themes and Subthemes						
	The competence gap		The diagnostic to post-diagnostic journey			Navigating a broken system	
	“Confidence is low... awareness is poor”	Stigma and prejudice	The diagnostic journey	The post-diagnostic journey	Co-occurring physical and mental health issues	Funding and commissioning issues	Missing services and fragmented pathways: the postcode lottery
Asherson et al., (2022)	✓	✓	✓	✓	✓	✓	✓
Crane et al., (2019)	✓	✓	✓	✓	✓		✓
French et al., (2020)	✓	✓	✓	✓	✓	✓	✓
Hayes et al., (2022)			✓		✓	✓	✓
Spain et al., (2022)	✓		✓	✓	✓	✓	
Ward et al., (2024)	✓	✓		✓	✓	✓	✓
Westminster Commission Autism (2016)	✓	✓	✓	✓	✓	✓	✓
Young et al., (2021)	✓	✓	✓	✓	✓		✓
<b>Total</b>	<b>7/8</b>	<b>6/8</b>	<b>7/8</b>	<b>7/8</b>	<b>8/8</b>	<b>6/8</b>	<b>7/8</b>

## Appendix J

### Critical appraisal of SLR

Scoring method: 'Yes': 1 point, 'Can't Tell': 0 points, 'No': 0 points. The SLR could therefore be rated as low (0–3), moderate (4–6), or high quality (7–10) (Boeije et al., 2011).

CASP Criteria	Quality Appraisal	Rating
<b>Section A: Are the Results of the Review Valid?</b>		
Did the review address a clearly focused question?	✓ The SLR addressed a specific question, information on how question was developed (incl. breakdown of population, intervention, and outcome) can be found in Chapter 2 (Section 3.2.1)	1
<p><b><i>Consider: 1) The population studied, 2) The intervention given,</i></b></p> <p><b><i>3) The outcome considered</i></b></p>		
Did the authors look for the right type of papers?	✓ The SLR aimed to understand the perspectives of HCPs, thus qualitative studies were included (and mixed-methods studies, looking at qualitative section only)	1
<p><b><i>'The best sort of studies' would:</i></b></p> <p><b><i>1) Address the review's question,</i></b></p> <p><b><i>2) Have an appropriate study design (usually RCTs for papers evaluating interventions)</i></b></p>		
	✓ The results of this SLR appropriately answer the research question	
	✗ It is possible that there are HCP perspective surveys using quantitative data which could have deepened the understanding of the carer experience if included in this SLR	
<b>Is it Worth Continuing?</b>		

Do you think all the important, relevant studies were included?	✓ The author has outlined all databases included in this study Chapter 2 (Section 3.2.1) ✓ The author has included detail around searching references lists in Chapter 2 (Section 3.2.5)	0
<b><i>Consider: 1) Which bibliographic databases were used, 2) Follow up from reference lists, 3) Personal contact with experts, 4) Unpublished as well as published studies, 5) Non-English language studies</i></b>	X The author outlined the time-frame for checking papers and a rationale for this, but did not check for up-to-date papers following this discovery phase. ✓ The researcher had contact with experts in the field as part of this SLR ✓ Unpublished studies were included in this SLR x Non-English language studies were not included in this SLR however, rationale was given as to why this was Chapter 2 (Section 3.2.4)	
Did the review's authors do enough to assess quality of the included studies?	✓ All studies included in the SLR were quality appraised using the CASP or AACODS tool for qualitative research	1
<b><i>Consider: The authors need to consider the rigour of the studies they have identified</i></b>		

---

If the results of the review have been combined, was it reasonable to do so?	✓ The results are similar from study to study, this has been explained through the thematic synthesis	1
<i>Consider: 1) Whether results were similar from study to study, 2) Whether results of all the included studies are clearly displayed, 3) Whether results of different studies are similar, 4) Whether reasons for any variations in results are discussed</i>	✓ The results of each study are clearly outlined in the data extraction (see Table 7)	
	✓ Variations are discussed by outlining how many studies supported with each subtheme in the thematic synthesis, expected variations are also discussed (e.g., with reference to the different health contexts)	

---

### Section B: What are the Results?

---

What are the overall results of the review?	✓ The results are clearly presented, as is typical for a qualitative review, and they are reiterated in the discussion section.	1
<i>Consider: 1) If you are clear about the review's 'bottom line' results, 2) What these are (numerically if appropriate), 3) How were the results expressed (NNT, odds ratio etc.)</i>		

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How precise are the results?	✓	The results are presented with the utmost precision possible for qualitative data, acknowledging the inherent subjectivity that arises from interpretation biases; the researcher has incorporated reflective commentary throughout the SLR to demonstrate the steps taken to manage these biases.	1
<b>Consider: 1)</b> <i>Confidence intervals, if given</i>			

---

### Section C: Will the results help locally?

Can the results be applied to the local population?	✓	The results can be applied to the local population, as it covers samples from across the UK. Despite potential recruitments bias, the samples of studies included are still very likely to be representative of UK based HCPs.	1
<b>Consider: 1) Whether the participants covered by the review could be sufficiently different to your population to cause concern your local setting is likely to differ much from that of the review</b>			
Were all important outcomes considered?	✓	All important outcomes were considered	1

---

**Consider: 1) Whether there is other information you would like to have seen**

---

Are the benefits worth the harms and costs?	✓	There are significant benefits to this review and little to no harms/costs, as there is such little research in the area, this SLR shows a plethora of avenues for change	1
--	---	---	---

***Consider: 1) Even if this is not addressed by the review, what do you think?***

	<b>Total</b>
	<b>Rating</b>

---

	9/10
--	------

## Appendix K

### Rationale for choosing RTA

Qualitative Analytic Method	Description	Reason for Rejection
Interpretative Phenomenological Analysis (IPA); (Smith & Osborn, 2003)	<ul style="list-style-type: none"> <li>This approach is grounded in theory, with roots in phenomenology and hermeneutic inquiry (Breakwell et al., 2012).</li> <li>It sees individuals as 'self-interpreting beings' (Taylor, 1985) and focuses on exploring the human lived experience.</li> </ul>	IPA typically requires a small, homogeneous sample and is more commonly used with 4–6 participants. This study involved a broader, more diverse sample of healthcare professionals, making IPA less appropriate.
Narrative Analysis (Bamberg, 2012)	<ul style="list-style-type: none"> <li>This approach focuses on the stories people tell and the accounts they give of their experiences, and how those stories are shaped and structured as a way of making sense of what they've lived through (Riessman, 2007).</li> <li>It also considers which stories get heard and valued, and which ones are overlooked (Wells, 2011).</li> <li>Participants are encouraged to be fully reflexive in how they share their experiences (Breakwell et al., 2012).</li> </ul>	The focus of this study was on shared experiences across participants rather than the structure or content of individual stories. The aim was to explore common themes in how HCPs understand barriers to ADHD care, rather than how each person personally narrates their experience.
Discourse Analysis (Gill, 2000)	<ul style="list-style-type: none"> <li>A research approach in which language material, such as talk or written texts, and sometimes other material altogether, is examined as evidence of phenomena beyond the individual person (Taylor, 2013)</li> <li>Participants are seen less as individuals sharing personal experience, and more as speakers drawing on broader social discourses that shape how things are talked about and understood (Willig, 2013).</li> </ul>	This approach was not chosen as the aim of this study was to explore healthcare professionals' shared experiences and perspectives, rather than how language constructs those experiences. While discourse analysis offers valuable insight into how meaning is shaped through language, it places less emphasis on the content of what is said, which was central to answering the research question.

## Appendix L

### University of Hertfordshire ethical approval



**University of Hertfordshire**  
Higher Education Corporation  
Hatfield, Hertfordshire  
AL10 9AB

Telephone +44 (0) 1707 284000  
Fax +44 (0) 1707 284115  
Website [www.herts.ac.uk](http://www.herts.ac.uk)

Professor Wendy Wills  
Pro Vice-Chancellor (Research and Enterprise)

Dr Amanda Ludlow (James Armstrong – student)  
Department of Psychology, Sports and Geography  
School of Life and Medical Sciences

20 February 2025

Dear Dr Ludlow,

**Re: UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN FULL for the following:**  
**RESEARCH STUDY TITLE:** Adult Attention-Deficit Hyperactivity Disorder: Clinician experiences of the pathways to adult ADHD diagnosis and treatment  
**NAME OF CHIEF INVESTIGATOR (Supervisor):** Dr Amanda Ludlow  
**NAME OF INVESTIGATOR (Student):** James Armstrong  
**UNIVERSITY OF HERTFORDSHIRE ETHICS PROTOCOL NUMBER:** 0676-2025-Feb-HSET  
**HEALTH RESEARCH AUTHORITY REFERENCE:** 347235

This letter is to confirm your research study detailed above has been reviewed and accepted and I agree to give full University of Hertfordshire sponsorship, so you may now commence your research.

As a condition of receiving full sponsorship, please note that it is the responsibility of the Chief Investigator to inform the Sponsor at any time of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments, or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements.

Permission to seek changes as outlined above should be requested from myself before submission and notification to the Health Research Authority (HRA) or University of Hertfordshire Ethics Committee with Delegated Authority (ECDA) as relevant, and I must also be notified of the outcome. It is essential that evidence of any further relevant external permissions is provided as they are received. Copies of annual reports and the end of study report as submitted to the HRA also need to be provided. Please do this via email to [research-sponsorship@herts.ac.uk](mailto:research-sponsorship@herts.ac.uk)

**Please note that University Sponsorship of your study is invalidated if this process is not followed.**

In the meantime, I wish you well in pursuing this interesting research study.

Yours sincerely,

Professor Wendy Wills  
Pro Vice-Chancellor (Research and Enterprise)



University of Hertfordshire Higher Education Corporation is an exempt charity

## Appendix M

### HRA ethical approval



Ymchwil lechyd  
a Gofal Cymru  
Health and Care  
Research Wales



Health Research  
Authority

Dr A Ludlow  
Head of Psychology and NeuroDiversity applied  
research unit  
Hertfordshire University  
University of Hertfordshire  
College Lane  
Hatfield  
AL10 9AB

Email: [approvals@hra.nhs.uk](mailto:approvals@hra.nhs.uk)  
[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

15 January 2025

Dear Dr Ludlow

**HRA and Health and Care  
Research Wales (HCRW)  
Approval Letter**

**Study title:** Adult Attention-Deficit Hyperactivity Disorder: Clinician  
experiences of the pathways to adult ADHD diagnosis  
and treatment

**IRAS project ID:** 347235  
**Protocol number:** LMS/PGR/UH/05712  
**REC reference:** 24/HRA/4796  
**Sponsor** University of Hertfordshire

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#)  
has been given for the above referenced study, on the basis described in the application form,  
protocol, supporting documentation and any clarifications received. You should not expect to  
receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in  
line with the instructions provided in the "Information to support study set up" section towards  
the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and  
Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland  
and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of  
these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

**What are my notification responsibilities during the study?**

The "[After HRA Approval – guidance for sponsors and investigators](#)" document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **347235**. Please quote this on all correspondence.

Yours sincerely,  
Chelsea Phillips

Approvals Specialist

Email: [INSERT for nation of sender approvals@hra.nhs.uk](mailto:INSERT for nation of sender approvals@hra.nhs.uk)  
[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

Copy to: *Ms Leire Caselles Vajelo*

Appendix N  
Research poster

# Adult Attention-Deficit Hyperactivity Disorder: Clinician experiences of pathways to adult ADHD diagnosis

**Participants needed!**

To participate in a study exploring health professionals experiences of supporting adults seeking an ADHD diagnosis.

**You can participate if you**

- Are a qualified health professional
- Have worked with adults in the last 5 years
- Have been involved with an adult ADHD referral or assessment

**Get in touch!**

Email me:  
[j.armstrong4@herts.ac.uk](mailto:j.armstrong4@herts.ac.uk)

**What does it involve?**

Participating in an interview via Zoom on your experiences of referring or assessing adult ADHD

**Interested in participating?**



**Jamie Armstrong**  
Trainee Clinical Psychologist

**University of Hertfordshire UH** Ethics Committee

University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority  
Protocol number:



## Appendix O

### Participant information sheet

#### PARTICIPANT INFORMATION SHEET

##### 1. Title of study:

Attention-Deficit Hyperactivity Disorder: Clinician experiences of the pathways to adult ADHD diagnosis

##### 2. Introduction

My name is Jamie Armstrong and I am a Trainee Clinical Psychologist at the University of Hertfordshire. I would like to invite you to participate in a research project exploring the experiences of health professionals who have worked, or work, with adults with ADHD, and the experiences of this client group in seeking assessment and treatment. You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link: <https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs> (after accessing this website, scroll down to Letter S where you will find the regulation)

##### 3. What is the purpose of this study?

Previous research and media reports highlight a variety of issues in access to assessment and treatment in ADHD for adults. Organisational and financial pressures are frequently cited, as well as a shortage of professionals who are trained specifically in ADHD in adult settings. This causes demand to consistently outweigh capacity in healthcare services, leading to long wait times, under-diagnosis and a higher financial and health burden on this client group. This study is seeking clinicians who have been a part of an ADHD referral process (such as diagnostics), and clinicians with a core profession who have worked in the NHS within the last 5 years working in a service where ADHD diagnostics provided. They will also need to have received some formal training on ADHD.

##### 4. Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. To withdraw please email [j.armstrong4@herts.ac.uk](mailto:j.armstrong4@herts.ac.uk) with your six-digit identity number.

##### 5. Are there any age or other restrictions that may prevent me from participating?

Participants need to be adults (over 18 years of age). Professionals without specific ADHD

training will not be able to participate, or professionals who are seeking ADHD diagnoses themselves at the time of the study. To take part we will need you to provide your informed consent. This will be asked for after this information sheet.

#### 6. How long will my part in the study take?

You will be asked to complete a short demographic survey prior to the interview taking place. If you decide to take part in this study, you will be involved in an interview via Zoom for approximately 90 minutes.

#### 7. What will happen to me if I take part?

The study will involve the following:

##### *1. Survey questions*

You will be asked to complete a survey that includes questions about you: your age, gender identity, professional qualifications, ADHD-specific training and job roles held in the last 5 years. You will also be asked to confirm you are over the age of 18.

##### **2. Interview**

After you have completed the survey, if the study is appropriate for you, you will be asked to attend an interview via Zoom. This should not take longer than 90 minutes in duration. You will be provided with a booking link at the end of the survey where you can book in the interview at a suitable time for you.

Email communication:

At the start of the survey, we will ask you to provide us with an email address that you are happy for us to contact you on. We will only contact you about this research. The first email all participants will receive will contain this information sheet. You will also be emailed the link to book your interview. If you complete the survey but not the interview, we will send one reminder email. If you do not book the interview, you will be withdrawn from the study. We will not contact you beyond withdrawal. This will be outlined in the initial email.

#### 8. What are the possible disadvantages, risks or side effects of taking part?

The interview carries minimal risk to cause distress. Breaks can be scheduled in the interview. All information will be confidential so there is not risks to confidentiality.

#### 9. What are the possible benefits of taking part?

The information that we gather in this research will help us to contribute to the current gaps in research and possibly have clinical implications on how adult ADHD pathways can be improved. We also hope that it will add to the literature on how specialists conceptualize ADHD in adulthood, which is understood to be heterogeneous in nature. This could also

have implications for criteria of adult ADHD in the future. We also hope to understand more about cultural influences on presentations of adult ADHD.

#### 10. How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Age
- Gender identity
- Professional background
- Work experience within the last 5 years
- ADHD training information
- Date you submitted your survey answer
- Date of interview
- Whether you would like to know the results of the study
- Whether you would like to receive a £10 love-to-shop voucher for your participation

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead of your name (see below).

We will keep all information about you safe and secure by:

- Any data gathered as part of this study will only be published in an anonymised form, so responses cannot be traced back to individual participants.
- We will ask you to assign yourself a random six-digit identity number. This identity number will allow us to store your data and letters under this number as opposed to any identifiable information. The email address you provide us will be kept on the survey platform Qualtrics, which is a secure and password protected platform.
- Other information that you provide us in the survey will be kept anonymously using your six-digit identity number. It will be stored on a password protected Microsoft Excel Spreadsheet.

International transfers

- Your data will not be shared outside the UK.
- Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study.
- We will keep your study data for a maximum of 5 years. The study data will then be fully anonymised and securely archived or destroyed. Personal data will be destroyed following project completion.

#### 11. What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have
- You have the right to ask us to remove, change or delete data we hold about you for the

purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this

**12. Where can you find out more about how your information is used?**

You can find out more about how we use your information, including the specific mechanism used by us when transferring your personal data out of the UK:

- by sending an email to either researchers (see below)

**13. Audio-visual material**

The session will be audio and visually recorded. The recordings will be stored securely in a password protected University OneDrive. This data may be revisited for further analysis by the same researcher but no third party will have access to it.

Zoom recordings will be saved on the Onedrive, password protected, at the University of Hertfordshire. They will be transcribed by the lead researcher who will remove any identifiable information. The transcriptions will be stored on a password protected Microsoft word document, stored on the OneDrive system at the University of Hertfordshire.

**14. Who has reviewed this study?**

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is: 0676 2025 Jan HSET

**15 Who can I contact if I any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with either or both of the following:

Jamie Armstrong  
Lead researcher for this project.  
Trainee Clinical Psychologist, University of Hertfordshire  
Email: [j.armstrong4@herts.ac.uk](mailto:j.armstrong4@herts.ac.uk).

Dr Amanda Ludlow  
Clinical Psychologist and Senior Lecturer at the University of Hertfordshire  
Principal Supervisor of this research project

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address: Secretary and Registrar University of Hertfordshire College Lane Hatfield St Albans AL10 9AB Thank

you very much for reading this information and giving consideration to taking part in this study.

## Appendix P

### Qualtrics screening survey

Please confirm you can read, write and speak English?

- Yes
- No

Are you based in the UK?

- Yes
- No

Are you over the age of 18?

- Yes
- No

Do you work exclusively privately?

- Yes
- No

Are you currently seeking an ADHD diagnosis yourself, or are you planning to do so in the future? Are any of your close relatives seeking an ADHD diagnosis?

- Yes
- No

How old are you?

- 18-29
- 30-39
- 40-49
- 50-59
- 60+

Please give yourself a six-digit identity number.

-----

Please note down this number as you will require this throughout the study. You will also need to provide it should you wish to withdraw from the study at any point.

Please provide an email address that you are happy for us to contact you on in the textbox below. Once you have finished this survey, and this study is suitable for you, this email address will be used to send you

- The participant information sheet
- Debrief information sheet
- The results of this study (if you would like them)

---

What is your identified gender?

- Male
- Female
- Non-binary
- Prefer not to say

Please describe any ADHD training that you have had

---

What is your health profession?

---

How long have you been qualified as a health professional?

- Less than 5 years
- More than 5 years

Would you like to know the results of this study?

- Yes
- No

Are you willing to attend a remote interview regarding your experiences in working with adults with ADHD?

- Yes
- No

By selecting 'Yes' you are consenting to us contacting you by email within 6 weeks to organise an interview. The interview will last for a maximum of 90 minutes.

- Yes
- No

Thank you for completing this survey. If you consented to attend an interview and are selected, you will receive a booking link via email within six weeks.

## Appendix Q

### Consent form

The next question will ask you to provide your informed consent to participate. Before providing your informed consent, please ensure you have read the previous participant information sheet closely.

By providing your consent it means that you are agreeing with the following:

- I confirm that I have read and understood the Participant Information Sheet for this study. I have had the opportunity to consider the information and ask questions if I have needed to, which have been answered satisfactorily.
- I understand that my participation is voluntary and that I can withdraw my information up to 14 days after submitting it. I do not need to provide a reason why I would like to withdraw, but I do need to provide the lead researcher with the six-digit identity number I will give myself following this consent form.
- I confirm that I have been told how my data will be handled, and stored confidentially, who will have access to it and what it will be used for.
- I confirm that I have been told how long my data will be stored for and how it will be deleted.
- I understand that my letters will be typed up and anonymised by the lead researcher and stored confidentially on a secure University of Hertfordshire One Drive.
- I understand the potential risks of participating in this study and that it is my responsibility to keep myself safe during and after the study.
- I understand that when a report is written about this study, which could potentially be published in a peer-reviewed journal, that quotes/sentences from my interview, but all identifying information will be removed or changed.
- I understand that the information that I provide for this research project could be used in various anonymised outputs such as conference presentations

I understand that my anonymised number will be stored until the completion of this project agree to the above and provide my consent to take part in this study:

I consent:

I do not consent:

## Appendix R

### Psychological distress and debrief protocol

#### Research Debrief and Support Resources Email

Dear XXXXX,

Thank you for participating in our research study, which explores clinician's experiences of supporting adults with ADHD, including facilitators and barriers to treatment. Your insights have been invaluable in contributing to our understanding of these complex issues.

During this study, you may have reflected on situations that could potentially trigger or bring awareness to *moral injury*. Moral injury is defined as the psychological distress that results from actions, or the lack of them, which violate one's moral or ethical code. In the context of healthcare, this may arise from situations where professionals are unable to uphold their personal or professional values due to external constraints, leading to feelings of guilt, shame, or betrayal (Williamson et al., 2020).

We understand that such reflections may have been distressing, and we encourage you to reach out if you would like to discuss any concerns. Below is a list of professional resources that may provide support:

- **British Psychological Society (BPS):** The BPS offers resources, events, and a network of psychologists who may help you process complex emotions tied to moral injury. More information is available at [www.bps.org.uk](http://www.bps.org.uk).
- **British Medical Association (BMA):** BMA provides support and resources for medical professionals dealing with occupational stress and ethical dilemmas. You can reach out to them at [www.bma.org.uk](http://www.bma.org.uk).
- **Health and Care Professions Council (HCPC):** HCPC supports registered health professionals, offering guidance on professional standards and well-being resources. Visit [www.hcpc-uk.org](http://www.hcpc-uk.org) for details.
- **Social Work England:** For social workers, Social Work England provides guidance and support tailored to managing ethical challenges in practice. More information can be found at [www.socialworkengland.org.uk](http://www.socialworkengland.org.uk).
- **Nursing and Midwifery Council (NMC):** NMC offers resources specifically for nursing and midwifery professionals. They can be reached at [www.nmc.org.uk](http://www.nmc.org.uk).
- **British Association for Behavioural and Cognitive Psychotherapies (BABCP):** BABCP offers support and training for those interested in cognitive-behavioural approaches to processing moral injury and other occupational stressors. Visit [www.babcp.com](http://www.babcp.com) for resources.
- **British Association for Counselling and Psychotherapy (BACP):** BACP provides counselling resources and a directory of therapists experienced in

dealing with moral and ethical distress in healthcare settings. Their website is [www.bacp.co.uk](http://www.bacp.co.uk).

If you feel the need for additional support, please don't hesitate to contact these organizations. Your well-being is a priority, and help is available should you require it. If you have any questions about this study or need further guidance, please feel free to reach out to us directly at [j.armstrong4@herts.ac.uk](mailto:j.armstrong4@herts.ac.uk)

Once again, thank you for your valuable contribution to our research.

Best wishes,

Jamie

Jamie Armstrong  
Trainee Clinical Psychologist  
University of Hertfordshire  
[j.armstrong4@herts.ac.uk](mailto:j.armstrong4@herts.ac.uk)

## Appendix S

### Recruitment email sent to participants

Good morning (insert name),

Thank you for taking the time to complete my survey on adult ADHD.

I would like to invite you to participate in a 60-minute interview via Microsoft Teams on your experiences.

If you are happy to participate, please let me know your best availability Monday to Friday over the next (insert) weeks.

I am hoping to interview weeks commencing (insert dates)

I look forward to hearing from you.

Once we have agreed on a time/date I'll send you a Teams link (or Zoom if easier).

Best wishes,

Jamie Armstrong (He/Him)

*Trainee Clinical Psychologist  
University of Hertfordshire,  
Hatfield,  
Hertfordshire,  
AL10 9AB*

## Appendix T

### Transcript extract

**Anna:**

Whereas actually someone that doesn't work, that's been on benefits hasn't had contact with many systems or other medical professionals like their GP and they don't have any family around. Where does that collateral information come from? So that can be a huge challenge and often people can't meet diagnosis threshold at that point, which why should that be a barrier? Because almost the diagnosis or the undiagnosed difficulty has led to that as a consequence of that.

**Interviewer:**

Yeah, yeah, would you like to say more?

**Anna:**

Yeah. And actually... Yeah. And actually, if people have been to followed what we call a typical route of ADHD that their school records, they've been excluded and all things like that, and it doesn't exist. Which yeah, creates a... Yeah, the biggest barrier. Erm.. Yeah. And they get excluded from getting this meaningful diagnosis that opens up support to them.

**Interviewer:**

Thank you. Yeah, my next question was around covid, and what your experiences were of support people with ADHD throughout this period?

**Anna:**

Good question. It's funny because I just think we don't think about that enough in a way. Because when I'm sat here thinking about how covid's impact children and young people, it's really easy, isn't it? So, for example, it's really easy to say that they weren't going into school and things like that. But then when you think about adults, I don't think we've thought about that as much. But, for example, when you think about it was huge life event. For a lot of people, increased so much stress and anxiety and uncertainty around jobs and everything.

But when we think about the access to resources.

Let me frame my thinking because there's kind of two answers here.

So like for example, adult ADHD relies on routine structure, to help manage their symptoms like work schedules, social commitments, activities, being outside ...

## Appendix U

### Interview schedule

**Warm-up questions:**

How did you get into your current role?

How long have you been in the role?

What kind of experiences have you had in working with adults with ADHD?

Have you had an ADHD specific training?

What kind of contexts have you worked in with this client group?

What are generally the most common ADHD characteristics you notice in adults?

Co-occurring issues?

---

Can you tell me about the referral pathways for an assessment in the area you cover?

What are the main barriers to getting an assessment?

Where are people usually referred from?

Do you notice any issues in referral?

What do you tend to find are person's experiences of the referral process for an ADHD assessment?

What is provision like for prescribing medication? Do they get timely medication reviews?

Once assessed, is there any post-identification-related support? What does this look like?

Service provision: Where do you feel are the main issues in the provision of services?

Probe: funding/commissioning issues?

Do you notice any issues adults in particular may experience in getting a diagnosis?

Probe: getting collateral information from parents?

do you find that any demographic factors can impact assessment /diagnosis?

Probe: can they influence the diagnostic process?

Cultural factors?

Tell me about your experiences of working in your role throughout the covid-19 pandemic

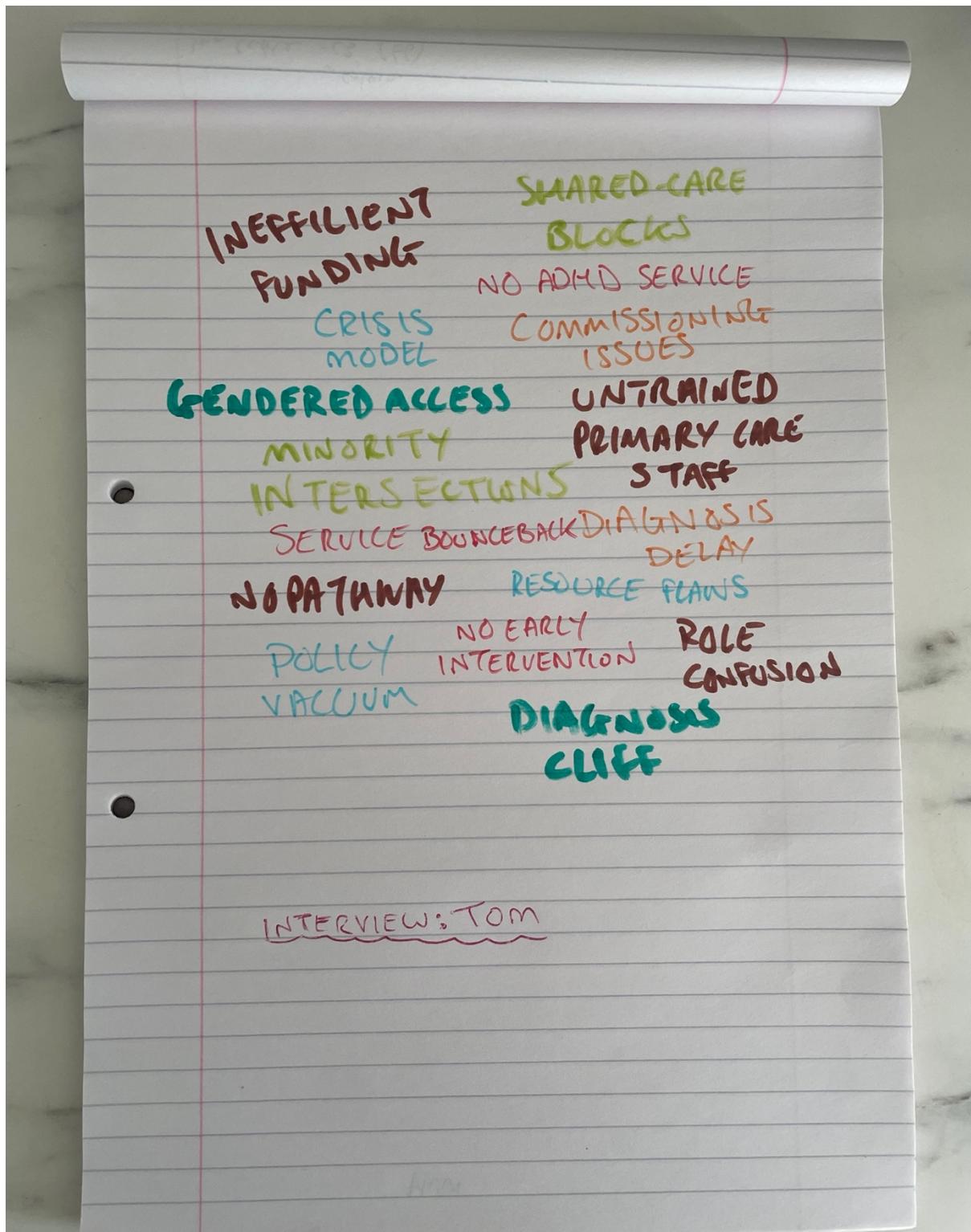
Probe: what do you think about the increase in demand coming out of the pandemic ?

We have about 5 to 10 minutes left of the interview

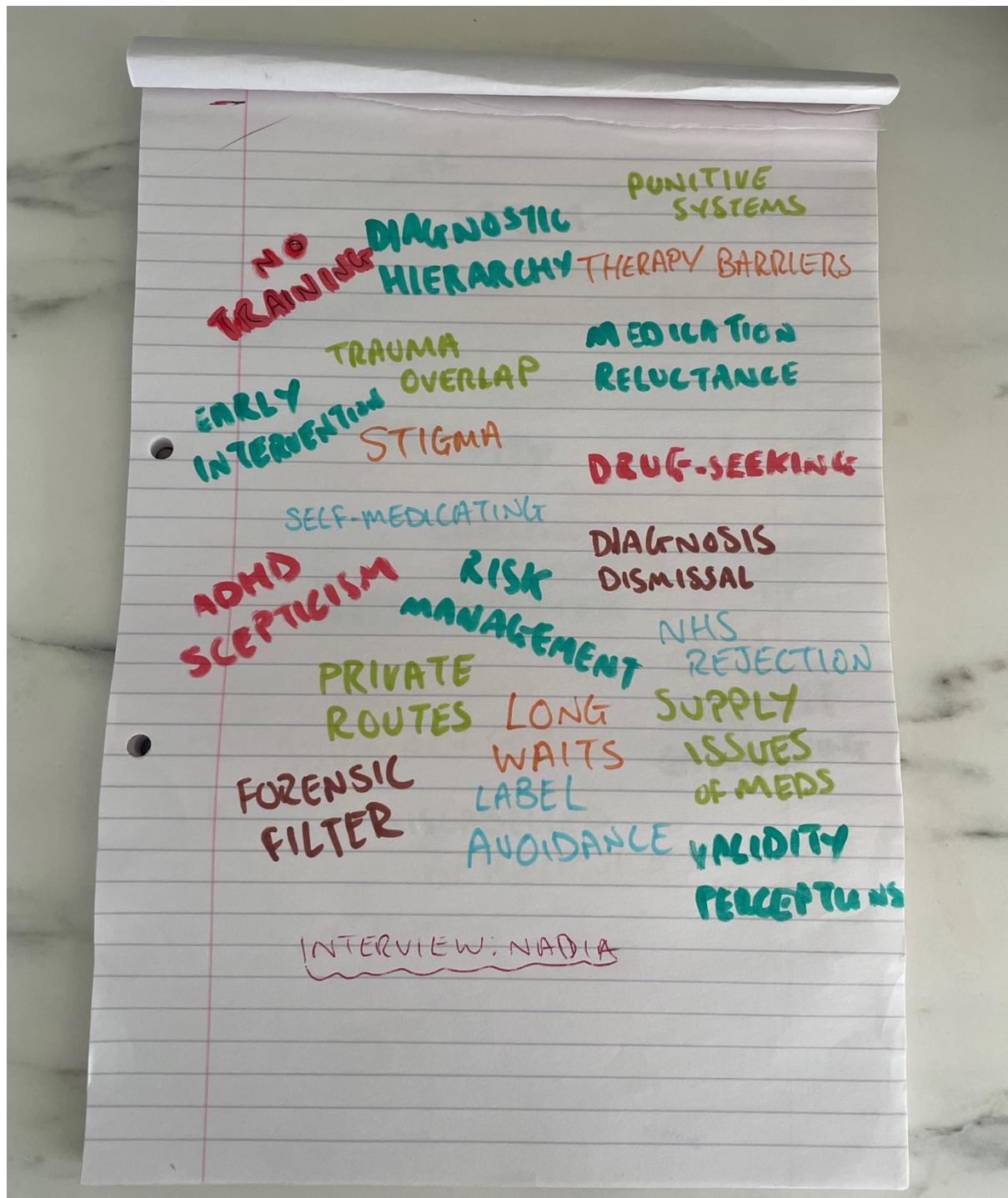
Is there anything else that you would like to add that we haven't discussed?

## Appendix V

## Data familiarisation doodle

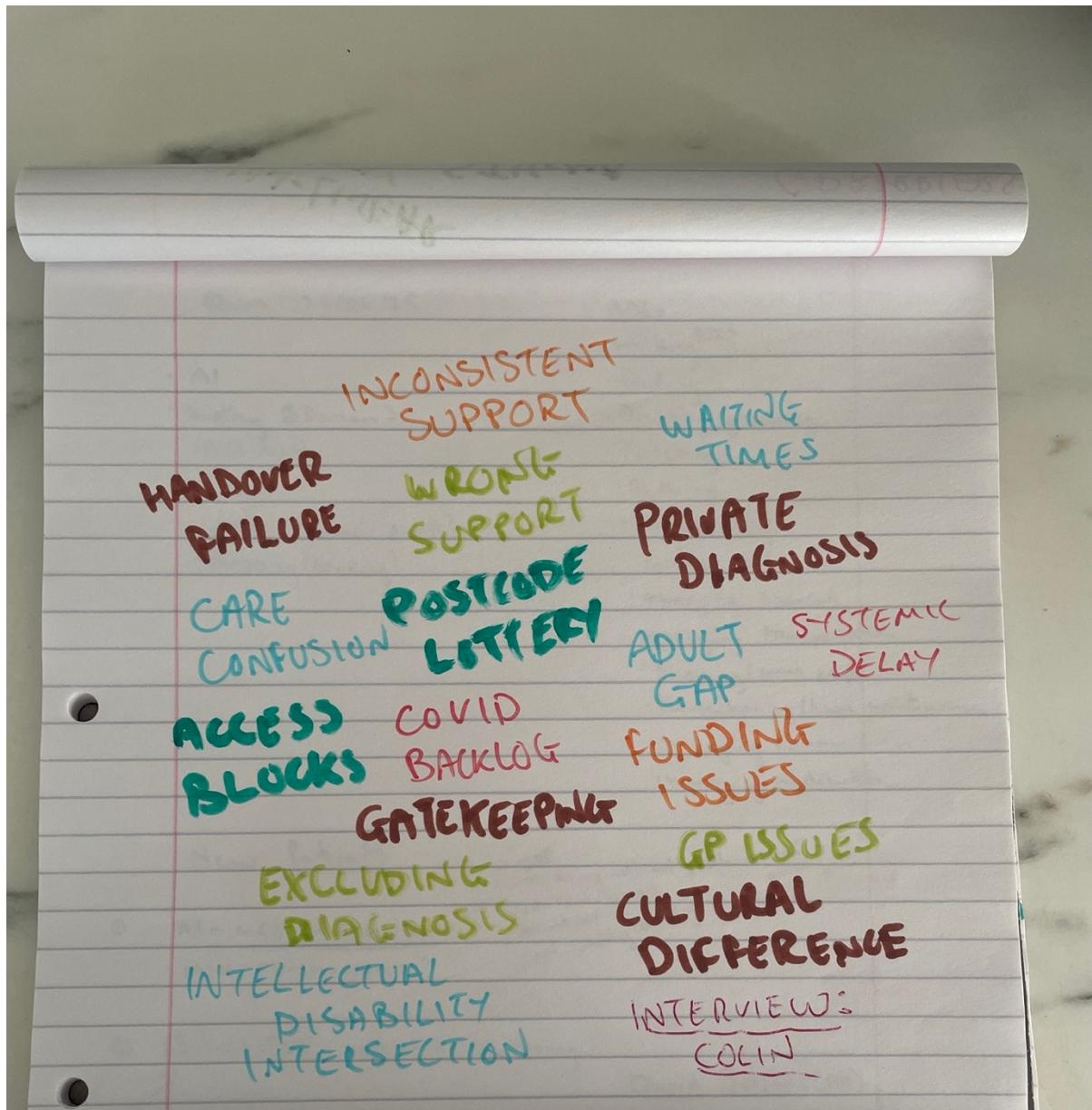
*Data familiarisation: Thomas*

## Data familiarisation: Nadia



*Data familiarisation: Rachel*

Non-linear pathway  
 INATTENTIVE STIGMA GP BARRIERS  
 FEMALE DELAYED DIAGNOSIS COVID ROUTINE LOSS  
 - ADD  
 IMPULSIVITY TIKTOK MISINFORMATION  
 DEPRESSION MOTOR MIND  
 AUTISM OVERLAP CHALLENGES IN DIAGNOSIS SCHOOL MASKING  
 SELF-CRITICISM INTERSECTIONAL CHALLENGES LATE DIAGNOSIS  
 ADVOCACY FATIGUE SPECIALIST GATEKEEPING  
 MISLABELLED BEHAVIOURS  
INTERVIEW: RACHEL

**Data familiarisation: Colin**

## Appendix W

### Coded transcript sample

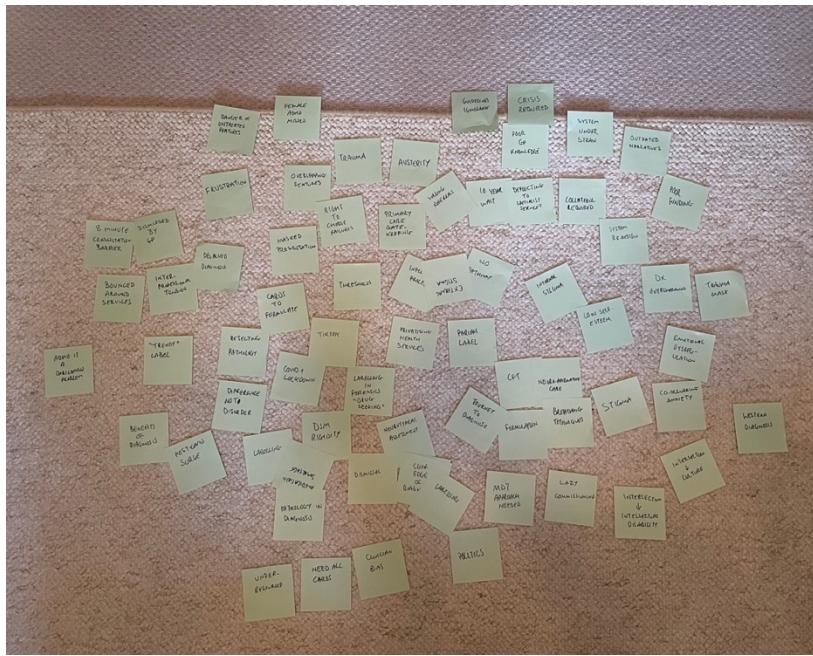
Transcript	Theme	Subtheme
<p>Can you tell me about the referral pathways for an assessment in the area you cover?</p> <p><b>Interviewer:</b></p> <p><b>Sophie:</b></p> <p>Mm hmm. Yeah. Yeah.</p> <p>I think in our service it's... it's about the... the level of impact that we need to see to accept somebody onto the waiting list. So we are we are very I think previously we're probably much more lax and now we have very stringent triaging criteria, so We have to see obviously clear features of ADHD in the referral, but we're also looking for that lifelong presentation and we're looking for two or more functional areas of impact because we're a health service. We need to make sure that there's impact, and people are often at crisis point by the time they come to us, to be sure for an ADHD diagnosis, you shouldn't be diagnosing unless there's impact.</p>	<b>Referral, primary care and GP barriers</b>	<b>Requirements for a successful referral: desperation and escalation</b>
<p><b>Interviewer</b></p> <p>Yeah. Yeah. What do you find people's experiences are like in their journey to getting an assessment?</p> <p><b>Sophie</b></p> <p>Yeah. And I think I think GPs often create the biggest barrier and that's... I know that's not a slight on GPs. They have a million and one different jobs that they have to do. But actually I do think there's still a lot of stigma around adult ADHD from GPs. We we hear the narrative that adults grow up like, "you grow out of ADHD". "Adults don't have ADHD". That is still very prevalent thing that we hear.</p> <p>So people really having to fight the GPs to to get referred because all of our assessments are GP referral only. We</p>	<b>Referral, primary care and GP barriers</b>	<b>Poor GP awareness</b>
		<b>Referral roulette</b>

<p>sometimes see really desperate situations, people going private and begging for help. They just give up.</p>		
<p><b>Interviewer:</b> Yeah.</p>		
<p><b>Sophie:</b> Saying that... I also think that because GPs are so pushed for time when it comes to the right to choose pathways... erm.. People are kind of taking in the, but I think it's great that right to choose make it so accessible. You can just take in your letter. This is what I want and but I'm not sure that GPs are triaging those referrals. So I think then everyone is going through right to choose and I'd be really curious actually about what the diagnostic rates are.</p>	<p><b>A strained system</b></p>	<p><b>Inattentive commissioning</b></p>
<p>In right to choose I've I've heard from kind of colleagues, friends that have gone through the right to choose pathway that it's a 45 minute assessment and you come out with an ADHD diagnosis. I just feels like the bar is very different to what we do. There's no mdt input, no collateral. There's not a lot of "no's", that's very anecdotal. There's no scientific basis to that whatsoever. There's no research, but that's just what... you know... I'm hearing "oh it must be something else" extensive assessment process or triage process. So I do worry that there's almost an invalidation then for those that are really are struggling with having ADHD and it gets that really horrible label of oh, it's just a bit popular at the moment. "Everyone's got ADHD. That's not true". But I do think the system kind of feeds into that narrative sometimes, like if it looks too easy, people start questioning how real it is. And that's hard for the people we see, because they've often been struggling in silence for years, and feel not believed.</p>	<p><b>Diagnostic overshadowing</b></p>	
	<p><b>A pariah diagnosis</b></p>	

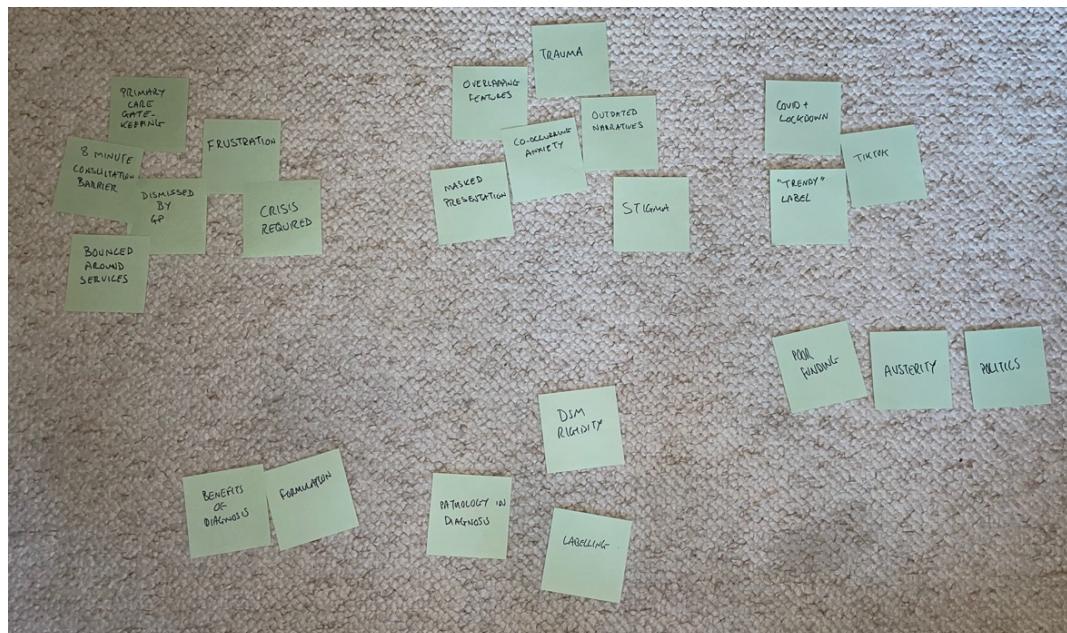
## Appendix X

## Thematic maps

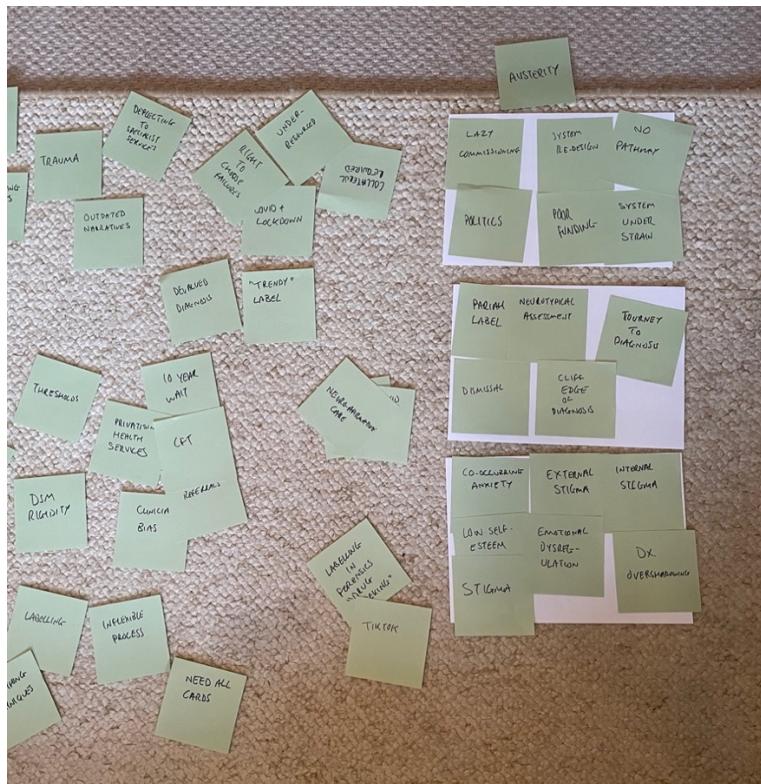
## *Placing initial codes*



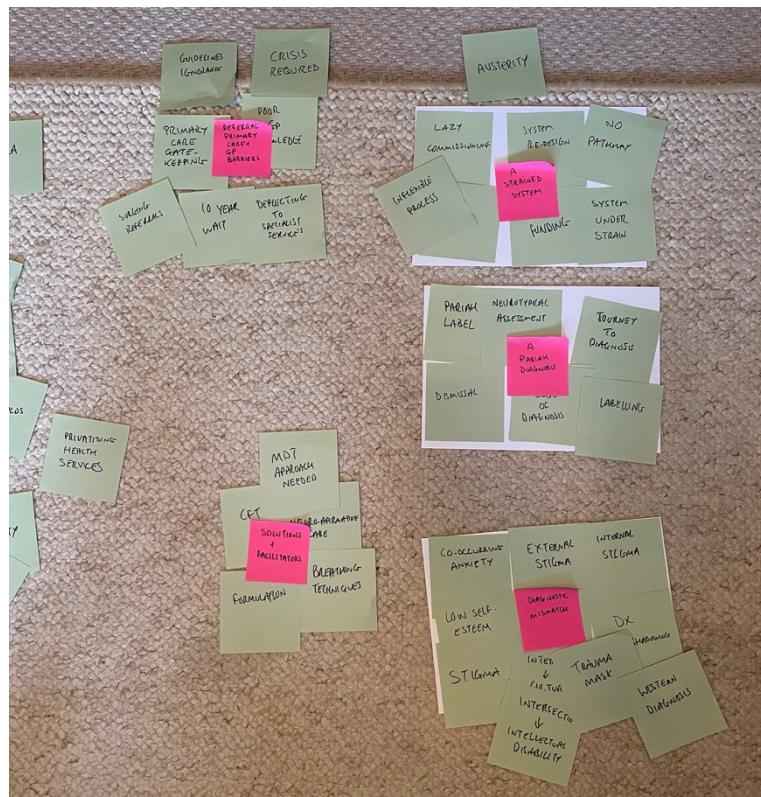
## *Placing more codes*



## ***Grouping codes into initial patterns***



## ***Grouped codes become thematic map***



**Appendix Y**  
**Quality appraisal of full study**

<b>CASP Criteria (incl. description)</b>	<b>Quality Appraisal</b>	<b>Rating</b>
<b>Section A: Are the Results Valid?</b>		
Was there a clear statement of the aims of the research?  <i>Consider: 1) what was the goal of the research? 2) why it was thought important?, 3) its relevance.</i>	✓ The research aims are outlined at the end of Chapter 2 (Section 2.10.1)	1
<b>Is it worth continuing?</b>		
Was the research design appropriate to address the aims of the research?  <i>Consider: 1) If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)</i>	✓ The research design was appropriate to address the aims of the research; an overview of how the research design was determined can be found in Chapter 3 (Section 3.3.3)	1
Was the recruitment strategy appropriate to the aims of the research?  <i>Consider: 1) If the researcher has explained how the participants were selected, 2) If they explained why the participants, they selected were the most appropriate to provide access to the type of knowledge sought by the study, 3) If there are any discussions around recruitment</i>	✓ A detailed recruitment strategy was developed and is described in Chapter 3 (Section 3.6.1)  ✓ The recruitment strategy was robust and ensured that those who came forward fitted the specific participant criteria / had specific knowledge of the area of interest	1

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<p><i>(e.g., why some people chose not to take part)</i></p> <p>Was the data collected in a way that addressed the research issue?</p> <p><b>Consider:</b> 1) If the setting for the data collection was justified, 2) If it is clear how data were collected (e.g., focus group, semi- structured interview etc.), 3) If the researcher has justified the methods chosen, 4) If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews are conducted, or did they use a topic guide), 5) If methods were modified during the study. If so, has the researcher explained how and why, 6) If the form of data is clear (e.g., tape recordings, video material, notes etc.), 7) If the researcher has discussed saturation of data</p>	<p>✓ It is clear how data was collected, and the method of collection was justified in Chapter 3 (Section 3.8)</p> <p>✓ The researcher has provided a clear description of how the interview schedule was developed, and how consultation was used in this process; the interview schedule is also located in the Appendix V.</p> <p>✓ The form of data is clear (audio tapes from MTeams, and subsequent transcriptions)</p> <p>✗ The researcher has not discussed data saturation as it is not in line with the RTA approach</p>	1
<p>Has the relationship between researcher and participants been adequately considered?</p> <p><b>Consider:</b> 1) If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location, 2) How the researcher responded to events during the study and whether they considered the implications of any changes in the research design</p>	<p>✓ The relationship between researcher and participants was constantly considered, please see extracts from reflective journal in Appendix A; these extracts along with the reflection boxes throughout demonstrate how the researcher attended to events throughout the research</p> <p>✓ The researcher discussed positionality as an outsider researcher, but with some personal experiences and qualifications similar to the sample used, throughout the research to demonstrate how this position was constantly considered</p>	1

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<b>Section B: What are the results?</b>		
Have ethical issues been taken into consideration?  <i>Consider: 1) If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained, 2) If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study), 3) If approval has been sought from the ethics committee</i>	<ul style="list-style-type: none"> <li>✓ The researcher has explained how ethical considerations were discussed with participants prior to taking part (participant information form), and when taking part (discussion at beginning of each interview)</li> <li>✓ The researcher has referenced the relevant ethical standards which the research was conducted in alignment with (BPS, 2021a, 2021b)</li> <li>✓ The researcher included a debrief form which was provided to participants post-interview, and there is a discussion around how this was developed in Chapter 3 (Section 3.4)</li> <li>✓ This research received favourable opinion from the University of Hertfordshire ethics committee, protocol number: 0676-2025-FebHSET as well as HRA approval (24/HRA/4796).</li> </ul>	1
Was the data analysis sufficiently rigorous?  <i>Consider: 1) If there is an in-depth description of the analysis process, 2) If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data, 3) Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process, 4) If sufficient data are presented to support the findings, 5) To what extent contradictory data are taken into account, 6) Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of</i>	<ul style="list-style-type: none"> <li>✓ There is a description of the data-analysis process found in Table 12</li> <li>✓ There is evidence of a thematic map which shows how the themes were derived from the data (Appendix Y)</li> <li>✗ It is not clear how the data presented was selected from the original sample</li> <li>✓ There are sufficient quotations to support each point in the data analysis process</li> <li>✓ There is some reference to contradictory data in the results section, (Subtheme 5)</li> <li>✓ An examination of researcher bias is shown throughout- see appendix A, and the reflection boxes throughout the write up</li> </ul>	1

Is there a clear statement of findings?	✓ The findings are explicit, themes are named and discussed under specific headings ✓ Each finding is discussed in relation to existing literature, this includes a discussion of where findings support existing literature and where findings do not support existing literature ✓ Credibility of findings are discussed when it is described how data analysis was completed ✓ Findings are discussed in relation to the original research question, and conclusions are made in this way also	1
<b>Section C: Will the Results help Locally?</b>		
How valuable is the research?	✓ The researcher discusses how valued the research is when looking at clinical implications and making recommendations for future research (Chapter 5, Section 5.6.1)	1
<p><i>Consider: 1) If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature If they identify new areas where research is necessary If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used)</i></p>		
		<b>Total rating</b> <u>10/10</u>