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## Improving healthcare information for young people with ADHD: perspectives from general practice

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## Title

**Improving healthcare information for young people with ADHD: perspectives from general practice.**

Max 12 words

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## Abstract

250 words

**Background:** Attention deficit hyperactivity disorder (ADHD) is a common neurodevelopmental disorder which can have poor long-term outcomes when unmanaged. Young people aged 16-25 with ADHD are often unable to access specialist healthcare as recommended by UK guidelines, due to gaps in services, poor transitional support between child and adult services, and long waiting lists. Healthcare information, which is important for condition management, may help mitigate service gaps and support thriving in people with ADHD, however little is known about provision via primary care.

**Aim:** To investigate experiences of information provision supporting management of young people with ADHD in general practice and explore the potential of digital resources.

**Design and Setting:** This qualitative research comprised interviews with young people with ADHD, their supporters, and primary healthcare professionals from sites across England.

**Method:** Participants were recruited from five purposively sampled general practices, varying by local area characteristics. Semi-structured interviews included questions about information provision, healthcare information needs, and digital resources. Themes were generated using reflexive thematic analysis, within a critical realist framework.

**Results:** 20 participants were recruited (11 healthcare professionals and nine people with lived experience). Four themes were generated: *lack of ADHD-specific resources*, *supporting patients with condition management*, *dedicated resources for clinicians*, and *digital resources enhancing care*.

**Conclusion:** People with lived experience and healthcare professionals want better healthcare information about ADHD in general practice, including co-produced resources to support understanding and self-management. Digital resources represent a potentially cost-effective and accessible solution that is currently under-utilised.

## Keywords

ADHD, Primary Health Care, Digital Resources, Healthcare Information, Qualitative.

## How this fits in

Healthcare information can inform clinical practice and support patients to positively manage long-term conditions, however accessing curated and trustworthy information on ADHD can be challenging for patients, especially given ongoing controversies around the diagnosis. This qualitative study investigates lived experience and clinical perspectives on provision of healthcare information via primary care for people with ADHD and explores the potential for digital resources to address existing gaps. Our findings indicate there are insufficient ADHD-specific, evidence-based resources available via primary care and demonstrate enthusiasm for accessible digital resources to inform and support management of ADHD. Healthcare professionals and people with ADHD recommended digital resources should be co-developed, to ensure they are engaging and accessible.

## Main text

4250 words

### Introduction

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by hyperactivity, impulsivity and/or inattention (1), with an estimated prevalence of 2%-7% in children and adolescents (2-5), and 3% in adults (6, 7). Untreated ADHD can lead to many adverse outcomes and negatively impact multiple life domains (8-11). Young people (YP) aged 16-25 with ADHD are particularly vulnerable, facing multiple transitions such as leaving home, or starting work, and increased risks of developing comorbid mental and physical health conditions (6, 11-13). ADHD can be effectively treated with medication (10, 14-17), and non-medical interventions such as tailored behavioural and cognitive therapies are important for positive condition management (18). However, in the UK, access to ADHD healthcare is limited due to stretched services, long waiting lists, unsupported transitions between child and adult services, and complex care pathways (19-21). These systemic problems often leave primary healthcare professionals (HCP) supporting patients without adequate ADHD-specific resources, support or guidance (22-24).

Provision of evidence-based healthcare information in accessible formats, can help YP with ADHD to navigate care pathways, understand their condition, anticipate changes in symptoms as they age, and manage health risks (25-28). It can also inform clinical practice (29). UK guidelines recommend that people with ADHD and their supporters receive structured discussions to improve understanding of ADHD, and signposting to sources of information, such as charities and websites (30, 31). However, most YP with ADHD experience limited or no access to this element of healthcare, with less than a third of specialist services providing the recommended range of treatments (31, 32). When accessible, treatments typically focus on medication, without providing adjunctive psycho-education or key healthcare information (20). For YP this gap can be especially damaging due to the varied ways ADHD presents at different life-stages, which makes understanding symptoms challenging, and high levels of misinformation online (18, 25, 28, 33, 34).

Digital technologies, including interventions delivered via primary care, represent a potentially cost-effective and accessible way of providing healthcare information about ADHD to YP and their supporters, whilst placing minimal demands on HCPs (26, 35). In the context of increasing and competing demands on the NHS, digital interventions including apps are providing scalable ways of enhancing mental health care (36-38). Similar interventions could help address unmet need in YP with ADHD (21). Primary HCPs are often the first and most consistent point of contact for YP with ADHD (19, 23), so are well placed to provide access to trusted, curated and evidence-based resources. However, little is known about provision of ADHD healthcare information and digital resources in this setting. This study aimed to explore the perspectives of patients, supporters and HCPs on current delivery of healthcare information for young people (aged 16-25) with ADHD via primary care, and on the potential role of digital interventions.

### Methods

#### Participants and recruitment

The Managing ADHD in Primary care (MAP) study used mixed methods to explore primary care provision for young people with ADHD in England (24, 39). Delivery was guided throughout by regular meetings with two research advisory groups (RAGs). One made up of people with lived experience (LE) of ADHD, and another of healthcare professionals (HCPs). The aim was to recruit 10-

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15 young people with ADHD and their supporters, and 10-15 primary care professionals, located across a range of locations (three to six) to reflect diverse experiences. Potential study sites were identified via responses to the MAP national survey where participants had expressed an interest in further research engagement (19), and purposively sampled to reflect varied local area characteristics (rural/urban setting, ethnicity, deprivation). Participants were recruited through sites, or via survey respondents located near sites. Participants had to be people with LE of ADHD (YP aged 16-25 with ADHD or a supporter), or primary healthcare professionals. All participants lived or worked in England. The MAP protocol provides further details of the recruitment strategy and public and patient involvement and engagement (PPIE) (39).

### Data collection

Data were collected via semi-structured interviews (~60 minutes) using topic guides, see Supplementary Material S1. This research focussed on data exploring *information resource use and the potential for digital solutions to support management of ADHD in primary care* (see Box 1). Findings from other topics are reported elsewhere (24). Topics reflected LE priorities highlighted during engagement work (25, 28). Question wording was developed with MAP study research advisory groups, made up of people with LE and HCPs.

#### Box 1. Summary of topics used to generate data, by participant group

Healthcare information, resource use, and exploring digital solutions to help manage attention deficit hyperactivity disorder (ADHD).	
<p><b>Young people and supporters</b>  <i>This section asks about resources to provide information to help manage and self-manage the health of people with ADHD.</i></p>	<p><b>Healthcare professionals and commissioners</b>  <i>This section asks about information resources to help manage the healthcare of patients with ADHD.</i>  <i>The focus is on resources you use to aid your practice, and resources you share with patients to help them understand and self-manage their condition.</i></p>
1. Please tell us about ADHD healthcare resources you have been given by your practice	1. Please tell us about resources you use to help manage the needs of patients with ADHD
2. What other resources do you use to help manage health and wellbeing with ADHD?	2. Please tell us about resources you signpost patients with ADHD to.
3. In an ideal world, what resources would be available from your GP to help manage ADHD?	3. In an ideal world, what kind of resources would you like to be available in primary care to help manage ADHD patient needs?
4. If someone told you about a fab digital tool for people with ADHD, what would it be like and what would it do?	4. If someone told you about a fab digital tool to aid treating patients with ADHD, what would it be like and what would it do?
5. Please tell us about tools for managing other health conditions which could be adapted for ADHD	5. Please tell us about tools for managing other conditions that could be adapted for use with ADHD
6. Do you have anything to add?	6. Do you have anything to add?

Interviews were conducted flexibly to suit participant engagement needs and completed via Microsoft Teams or telephone between March and June 2023, with informed consent. Recordings were transcribed verbatim, with data anonymised and stored on a regulation-compliant secure server.

### Data analysis

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A reflexive thematic analysis of data related to *information provision and digital solutions* was conducted to generate themes, following methodology as described by Braun and Clarke (40), and operationalised by Byrne (41). Analyses were underpinned by a critical realist perspective, which is appropriate for research aiming to address identified gaps in knowledge about healthcare in practice, and how it could be improved (42). This theoretical stance incorporated consideration of the context of the data, and the influence of researcher and stakeholder perspectives, providing a nuanced interpretation of meaning. Data was managed using NVivo (version 14).

Researchers AP and KB immersed themselves in the data by reading all transcripts. Line-by-line coding was undertaken. An initial inductive framework was created from sections of the topic guides, then refined deductively from the data, and in consultation with the study team (TND, BG, JW). Themes and sub-themes were generated. Coders documented and reflected on personal perspectives throughout via group discussions and journals. Column summaries were created for a framework matrix, then organised into themes and sub-themes. Generated themes were iteratively refined in consultation with RAG members and co-authors. Data relevant to improving practice was collated and transformed into an infographic sharing recommendations for practice. See the MAP protocol for further detail (39).

## Results

### Sample

Following RAG consultation, five primary care practice sites were chosen to reflect varied local area characteristics, and a variety of reported care contexts (share-care prescribing, specialist service availability). These included a university-linked practice, practices with specialisms in substance misuse and homelessness, and those without. In total, 20 participants (eleven HCPs and nine people with LE) were recruited from five diverse primary care practice sites located across five NHS England regions. See Supplementary Material S2 for detailed site characteristics. Table 1 details participant characteristics.

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*Table 1. Participants: unique identifier, role and other characteristics*

Site	Unique identifier	Role (age range in years)	Gender, Ethnicity (self-described)	Additional Information (provided at interview)
1	PracticeManager-1	Practice manager	Female, White British	Managing partner
1	YoungPerson-1	A young adult with ADHD (18-25) <sup>a</sup>	Male, White British	Student
1	YoungPerson-2	A young adult with ADHD (18-25) <sup>a</sup>	Female, White British	Graduate
2	GP-1	GP <sup>a</sup>	Female, White British	Commissioning experience, ADHD in family
2	GP-2	GP	Male, White British	ADHD in family
2	PracticeManager-2	Practice manager	Female, White British	Possible undiagnosed ADHD, ADHD in family
2	YoungPerson-3	A young adult with ADHD (18-25)	Female, White	Mother
2	Supporter-1	A supporter of a young adult with ADHD (18-25)	Male, White British	Grandfather
3	YoungPerson-4	A young person with ADHD (16 or 17) <sup>a</sup>	Male, White British	Apprentice
3	Supporter-2	A supporter of a young person with ADHD (16 or 17) <sup>a</sup>	Female, White British	Mother
3	GP-3	GP	Female, British Mixed	Commissioning experience, ADHD in family
3	PracticeManager-3	Practice Manager	Female, White British	-
4	PracticeManager-4	Practice Manager	Female, White	-
4	WellbeingWorker	Wellbeing Worker	Female, White other	Neurodiverse
4	GP-4	GP	Male, Irish	-
4	YoungPerson-5	A young adult with ADHD (18-25)	Female, White British	Student
5	Supporter-3	A supporter of a young adult with ADHD (18-25) <sup>a</sup>	Female, White British	Mother
5	YoungPerson-6	A young adult with ADHD (18-25) <sup>a</sup>	Female, White British	On a break from university
5	PracticeManager-5	Practice manager	Female, British Pakistani	-
5	GP-5	GP	Male, British Pakistani	Commissioning experience

<sup>a</sup> Participant recruited via Managing young people with ADHD in Primary care study (instead of via site) from location within same local area as practice research site. ADHD = attention deficit hyperactivity disorder. GP = General Practitioner

## Findings

Four themes were generated regarding provision of healthcare information for YP with ADHD via primary care: *lack of ADHD-specific resources, supporting patients with condition management, dedicated resources for clinicians, and digital resources enhancing care*. These are summarized in Table 2 and described below.

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Table 2. Summary of themes, with illustrative quotes

Themes • sub-themes	Summary	Illustrative Quotes
<p><b>Lack of ADHD-specific resources</b></p> <ul style="list-style-type: none"> <li>Lack of ADHD-specific healthcare information</li> <li>Variable signposting to resources</li> </ul>	<p>ADHD-specific healthcare information is not usually shared with patients by GPs.</p> <p>While a few GPs are aware of ADHD-specific resources, most signpost to generic websites.</p> <p>Patients are often left to seek information via informal routes, which can be unhelpful.</p>	<p><i>"I am not sure. I know they have some resources on the website...Mostly, I don't have much engagement with my GP about neurodiversity in general."</i> <b>YoungPerson-6</b></p> <p><i>"So, we use the NHS website...we use patient.co.uk...so they will have some ADHD advice and guidance. And it's fairly robust, but there is an opportunity for people to go away and trawl the internet to find information that they find useful"</i> <b>GP-5</b></p>
<p><b>Supporting patients with condition management</b></p> <ul style="list-style-type: none"> <li>Information increasing understanding of ADHD and care pathways</li> <li>Resources and tools to aid self-management</li> <li>Accessible resources, co-developed with people with ADHD</li> </ul>	<p>Information for people with ADHD needs to increase patient and supporter understanding of ADHD and inform navigation of care pathways.</p> <p>Resources and tools to support positive condition management would be helpful.</p> <p>Content needs to be developed alongside people with lived experience and include relatable stories.</p>	<p><i>"Information about things like how to sleep well; how to make sure that you can keep habits. Because with ADHD, you have to take a very specific approach... Because I feel like, if you have ADHD, it's a lot harder to manage your health."</i> <b>YoungPerson-1</b></p> <p><i>"I think sometimes good quality narrative accounts can often be very helpful ...saying here are the issues I grappled with, and this is what I found helpful. ...because sometimes these documents can be very, very dry and it can be very difficult to actually know what something means to a patient's experience."</i> <b>GP-4</b></p> <p><i>"And I think it would have to be co-produced with people with ADHD so that it looked right in terms of the chunking of the information... making that document as accessible as possible"</i> <b>GP-3</b></p>
<p><b>Dedicated resources for clinicians</b></p> <ul style="list-style-type: none"> <li>Improving understanding of ADHD</li> </ul>	<p>Primary care professionals need resources to help them understand care pathways, and how to support the needs of young people with ADHD.</p>	<p><i>"If they don't know anything about ADHD, and they have to go look it up, it's less helpful. ...if they knew just the basics, and they were like, "Okay, so first things first, you refer to this, and then you do this." Or "Okay, you need to talk to that person, who specialises." ...Because when I ring them up about anything, you hear that hesitation on</i></p>

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<ul style="list-style-type: none"> <li>• <i>Guiding clinical practice</i></li> </ul>	<p>When supporting patients with ADHD, primary care professionals want and need better quality resources to guide their clinical practice.</p>	<p><i>the other end of the line, where they're like, "I'm going to have to go talk to someone about where to send you." <b>YoungPerson-2</b></i></p> <p><i>"So yes, number one I guess is the understanding as a GP. My training in ADHD, my access to resources that explain to me how to diagnose and provide initial treatment and management is limited. It's improving ...but it's still got a long way to go." <b>GP-2</b></i></p>
<p><b>Digital resources enhancing care</b></p> <ul style="list-style-type: none"> <li>• <i>Advantages, including improving access</i></li> <li>• <i>Trusted digital content</i></li> <li>• <i>Risks of exclusion</i></li> <li>• <i>Importance of non-digital</i></li> </ul>	<p>Digital resources could improve care by providing tailored healthcare information and condition management support via primary care.</p> <p>Providing trustworthy digital resources would reduce risks of online misinformation.</p> <p>Some people may struggle to access digital resources, and non-digital options remain important.</p>	<p><i>"I think ideal would be, basically, imagine you had a web page, that just had a bunch of links on it. And it was like, "Here's everything. This is the link to the support group; this is the link to the online resources; this is a web page that's all about ADHD, or something." Just one place, basically, where they're like, "Here's the ADHD things. So, you don't have to search so many different places to get it." <b>YoungPerson-2</b></i></p> <p><i>"I'm obviously not clued up on the technology side of things ...I can access an iPad...but I'm very, very limited." <b>Supporter-1</b></i></p>
<p><i>ADHD = Attention deficit hyperactivity disorder. GP = General practitioner. Supporter = Person supporting a young person with ADHD (e.g. parent, partner)</i></p>		

## Themes and sub-themes

### 1. Lack of ADHD-specific resources

#### 1.1 Lack of ADHD-specific healthcare information

Many LE participants reported a lack of health information resources designed with YP with ADHD in mind. Most LE participants reported receiving “*not a dot*” (**Supporter-2**) of ADHD-specific healthcare information from their primary care providers:

*“They had the more generic mental health, but nothing ADHD-specific.”* **YoungPerson-2**

This lack of information was compared against other long-term conditions by one LE participant, where trusted healthcare resources were perceived as being readily accessible:

*“When you get diagnosed with asthma, there’s all sorts of resources available. You get leaflets and all sorts of things ... I have never seen any information at all in the surgery that we go to...about ADHD, nothing.”* **Supporter-3**

#### 1.2 Variable signposting to resources

When asked about experiences of signposting to trusted resources via primary care, most LE participants reported that they had not received any, and several stated their “*understanding of ADHD has come from [their] own research.*” (**YoungPerson-5**). Frustrations about this lack of signposting, and implications in relation to health inequalities, were summarised by a young person:

*“If I want to find out something about ADHD, I primarily use either medical webpages that I trust, or I read research. But I’m also aware that that’s not an accessible option for most people. ... it’s kind of annoying that I have to do that, because there isn’t anything else that I trust.”*

**YoungPerson-1**

Despite reported frustrations, several participants shared details of resources that they had identified independently and found useful, including “*YouTube channels*” (**YoungPerson-5**), “*podcasts*” (**YoungPerson-6**), and the “*ADHD Foundation*” (**Supporter-2**).

By contrast, many HCP participants reported routine signposting practices. However, approaches used, and specificity of resources shared varied. As one HCP stated, “*Different clinicians are aware of [different] things*” (**PracticeManager-1**). Several GPs mentioned signposting to websites such as “*nhs.uk*” (**GP-5**) or relying on clinic letters:

*“In terms of online resources for patients, I tend to find that the clinic letters that come with patients tend to have a long list at the end of those online resources. So, I personally don’t feel I need to point them in those directions because...I think most students will be aware of what is available.”* **GP-4**

Meanwhile, some described ADHD-specific resources including podcasts, videos and books:

*“I direct them towards the ADHD Foundation to see if any of that is of additional support to them, I will print off or text them information from NHS sources on ADHD.”* **GP-1**

### 2. Supporting patients with condition management

#### 2.1 Information increasing understanding of ADHD and care pathways

Many patients and supporters said having information to increase understanding of living with ADHD would have helped them recognise when they needed help, and better understand ADHD needs:

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*“When I first got diagnosed with ADHD, it was sort of just “Oh, right, you’ve got ADHD,” sent you on your way. ...it would have been nice to have something to look at where it tells me about it. And I know everyone with ADHD is different, but just some understanding of what’s going on in my head.”* **YoungPerson-4**

Participants said resources to help supporters understand ADHD were also crucial as *“parents understanding has also a massive impact”* (**PracticeManager-3**). One supporter explained why clearer information on care pathways was needed:

*“from a family perspective as well, more information would be really, really helpful because...we end up scrabbling around...and often it will be me that picks meds up etc., so support materials would actually be really helpful”* **Supporter-3**

## *2.2 Resources and tools to aid self-management*

Many YP mentioned wanting more knowledge and understanding about topics important to them, such as living with *“comorbidities”* (**YoungPerson-6**), *“female presentations”* (**YoungPerson-5**), and *“how ADHD can impact your mental health, and your relationships”* (**YoungPerson-1**), implying a need for psychoeducation to support long-term condition management.

Participants across stakeholder groups, highlighted a need for condition management resources. Suggestions included *“guided self-help, CBT”* (**GP-3**), *“planners, reminders”* (**YoungPerson-3**), and information to *“enable you to figure out the best way for you to go about tasks”* (**Supporter-3**). Participants consistently emphasised the need for tailored self-management tools that would *“work for ADHD, rather than being very general”* (**YoungPerson-1**):

*“To have more specific support relating how those symptoms might manifest in different situations and how you might want to manage it would probably be quite useful. ...It is quite difficult to do without anyone else helping you.”* **YoungPerson-6**

A wellbeing worker from a university practice said tools for managing procrastination were a priority:

*“And most of the time, even people who may have had that [ADHD] diagnosis for a while, would still be coming in with the same question, “How do I work with procrastination?””*  
**WellbeingWorker**

## *2.3 Accessible resources, co-developed with people with ADHD*

Several HCPs and LE participants emphasised that resources needed to be engaging and accessible to people with ADHD. One HCP suggested resources should *“be co-produced with people with ADHD so that it looked right in terms of the chunking of the information.”* (**GP-3**). Several young people reported finding peer stories and neurodiverse-led resources helpful:

*“If there was something where it’s stories from people with ADHD, it will help ...I was talking to one of the other lads with ADHD, and when we started talking, he went through a lot of the same stuff I did when I was growing up with it, so it’s a lot more relatable if you hear about it from somebody with ADHD.”* **YoungPerson-4**

*“The best ones, honestly, are...led by people who have ADHD themselves. There’s nothing that can beat that.”* **YoungPerson-2**

One young person suggested advice on self-management should not come from an *“outside perspective”* (**YoungPerson-5**).

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### 3. Dedicated resources for clinicians

#### 3.1 Improving understanding of ADHD

Participants across stakeholder groups outlined the need for resources to improve ADHD-awareness in general practice, including what it is like living with this condition:

*“more training on neurodiversity is absolutely crucial, and I think it is coming...Everybody needs to know about it so I think it’s disingenuous having just one person knowing about it.”* **GP-3**

*“One thing I think could be really useful is if there were videos or information with metaphors or analogies about what the internal experience of ADHD is like for neurotypical people.”*

**YoungPerson-5**

#### 3.2 Guiding clinical practice

Some GPs expressed confidence in available resources for informing their management of ADHD:

*“Yes. I mean, I would personally make use of that shared care protocol that I mentioned because it gives, I think fairly clear advice from a GP point of view.”* **GP-4**

However, others said protocols could be unclear, and observed that when specific questions arose, for example around managing ADHD medication, they *“don’t really have anybody who [they] can go and talk to, to ask those questions”* (**GP-2**).

*“Perhaps we don’t have adequate training in understanding how to use the medication effectively. Not that we’d necessarily expect to be changing doses but understanding the significant side effects that some of these medications have and the way that people learn to use them to the best effect...things like that.”* **GP-2**

### 4. Digital resources enhancing care

#### 4.1 Advantages, including improving access

Many stakeholders saw advantages in using digital resources to communicate healthcare information about ADHD, including making information easier to access and update:

*“I think...a digital tool is always helpful because then it’s very easily accessible...it can be updated, or the information can be nested, and you can follow more complex pathways...whereas the paper one is a bit unidimensional”* **GP-4**

Many discussed the importance of tailoring healthcare information to be accessible and relevant for YP with ADHD. Noted advantages were that digital resources could be available 24/7, and via multiple formats (e.g. video, text, games) which is important for people with difficulties regulating attention:

*“If there is a tool that does assist somebody with ADHD, a quick response. I think the most frustrating thing for people is needing help and not being able to get it quickly.”*

**PracticeManager-3**

*“I think videos are a great way because a lot of kids don’t want to sit and read, but they’ll listen to somebody, say, like, or somebody that has lived [experience]... would make a massive difference”* **Supporter-2**

Participants outlined other ways in which digital technology could improve care, including through delivering *“virtual clinics”* (**GP-1**), and supporting ordering of medication and booking appointments. One discussed how digital assessments might support clinical conversations:

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*“I think the digital platform could be a really useful way forward, because if there were one health professionals accepted as a recognised and appropriate tool where a person could come in and say ‘I’ve done this assessment on this tool, here’s my assessment, scores’, that would be a helpful introduction, wouldn’t it?”* **PracticeManager-4**

#### 4.4 Trusted digital content

Both HCP and LE participants emphasised the importance of curated and trustworthy digital content. Several HCPs said digital resources needed to be “evidence-based” (PracticeManager-1), and easily available:

*“I mean it would be useful to have something [digital] somewhere that is reliable and well curated so the information that we are looking at is as trustworthy as it can get and that contains information that’s more hard clinical”* **GP-4**

Participants with LE said they would value access to digital resources provided via a trusted source such as their GP. They discussed risks of misinformation, and reflected on challenges faced by patients left to navigate online information without support:

*“social media...sometimes isn’t the best place to go. I mean, that’s me personally, but I think there’s a lot of misinformation on the Internet. ...Because social media is mostly young people. And if they get the wrong information, they’re not old enough to understand it and it’s not the right information.”* **YoungPerson-4**

#### 4.2 Risk of exclusion

However, it was noted that digital resources could create inequalities. One grandparent explained that digital help might not be accessible to him:

*“I’m obviously not clued up on the technology side of things...I can access an iPad and things like that but I’m very, very limited.”* **Supporter-1**

A young person with ADHD discussed how reliance on digital support could unintentionally exclude people from disadvantaged backgrounds:

*“Now, if you’re from a poverty family who can’t travel, and haven’t always got access to the internet, there’s nothing for the parent or the child, face to face or even trying to get onto a laptop in a library or whatever, there’s nothing.”* **YoungPerson-4**

Some participants outlined problems with existing digital resources. One noted they can be poorly designed and costly:

*“I had to do an assignment for uni, that was evaluating a bunch of apps to help with stress...They were alright, but they were all badly designed, in terms of their actual useability. They tended to be quite laggy. And if they weren’t laggy, they were behind a massive paywall”* **YoungPerson-1**

#### 4.3 Importance of non-digital

Several participants noted the importance of providing non-digital options, so that digital resources became part of “a multitude of resources in different forms...so that people who focus better on different things have an option that works for them” (**YoungPerson-5**). Key examples included conversations with staff with expertise in neurodiversity, and printed materials:

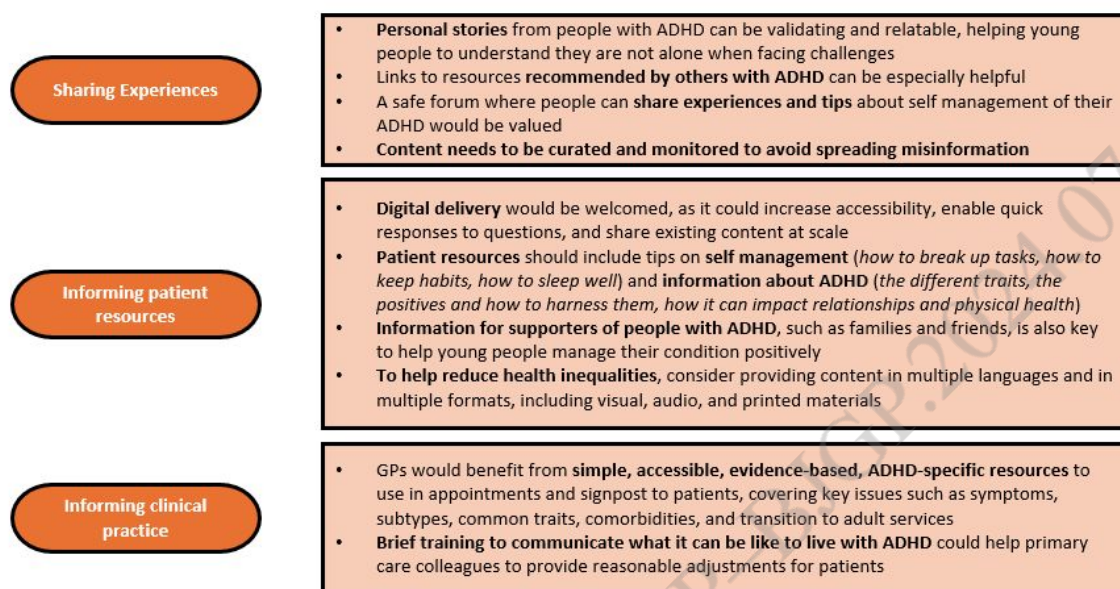
*“...what is the most helpful thing is the actual coaching, and also the opportunity for people to say what it’s like”* **WellbeingWorker**

Healthcare information for young people with ADHD: multiple perspectives from general practice.

*“Obviously, GP services have got a lot to do, which is why I think, a leaflet, if it was like just on the reception and... [they say] “Can you have a look through this while you are waiting?” I think that could be really cool.”* **YoungPerson-5**

## Practice recommendations

Practice recommendations are presented in Figure 1.



*Figure 1. Key recommendations for providing healthcare information to support management of ADHD via primary care.*

## Discussion

### Summary

This research builds on findings about information provision for YP with ADHD in secondary services (25, 28), providing novel data about the primary care context. Our findings tie in with cross-sectional survey and qualitative research, further evidencing geographic variations in NHS support for young people with ADHD (19, 20, 25, 28, 43). The data highlights a lack of accessible healthcare information about ADHD and care pathways, despite UK guidance recommending provision (44, 45). These gaps are negatively impacting healthcare transitions and management of ADHD in YP. Our research also provides a nuanced exploration from multiple perspectives, of the potential for digital technology to address unmet needs in ADHD healthcare, including through tools that support self-management. Findings highlight an opportunity for trusted and curated digital resources, delivered via primary care, to guide clinical practice and support positive management of ADHD. Our recent systematic review provides preliminary evidence of the feasibility and acceptability of digital healthcare information interventions for YP with ADHD, especially those that are co-produced (46). However, no such tools currently meet NHS England standards. This novel research highlights opportunities for stakeholders to work together to co-design and evaluate digital healthcare information interventions, designed for implementation within primary care pathways. Such tools would have the potential to reduce GP burden, whilst better meeting the needs of patients with ADHD.

## Strengths and limitations

This study benefits from a diverse range of perspectives, including practice managers, GPs, and YP with ADHD. However, given service pressures, the HCPs we recruited may have been more likely to have existing knowledge of ADHD and we may underrepresent perspectives of HCPs without an interest in ADHD. People with lived experience may have been more likely to engage if they had experienced challenges accessing healthcare, meaning some positive experiences may not be reflected in these findings. Although every lived experience participant self-described as White British, two RAG members with ADHD (who are from different ethnic backgrounds) contributed to team discussions about ethnicity. This informed data syntheses and has influenced future research plans. Purposive sampling of study sites to include rural and urban practices, and those situated in areas of high and low deprivation, helped the study reflect local variations. However, given the thousands of practices in England, and heterogeneity of communities, data from participants at five sites is unlikely to have reached saturation in relation to the breadth of experiences and perspectives.

## Comparison with existing literature

This research highlights the poor availability of resources to inform and support management of ADHD in YP, especially compared to other long-term conditions such as asthma (47). Failures to provide high-quality healthcare information can leave patients relying on alternative informal sources, making them vulnerable to misinformation, and potentially causing unintended harm (33, 34). HCPs reported signposting as part of routine care, but in line with previous findings, few reported providing ADHD-specific information (25, 28). Some also observed that standard practices, such as adding links to referral letters or sharing verbal recommendations might not represent optimal communication for a group who struggle with memory and focus (18). Prior research emphasises the importance of communicating via varied and accessible formats when supporting YP with ADHD (48). Based on these findings, we recommend collating existing resources (49, 50), and co-developing a digital suite of evidence-based ADHD-specific resources, tailored for YP, and suitable for delivery via primary care (51, 52).

This research raises and answers some questions about optimising resources for primary HCPs (22, 53). GPs need improved guidance on care pathways and resources to better understand ADHD in YP (23). It is possible that improved shared-care protocols, with advice covering topics such as medication and monitoring, might help, especially given difficulties GPs face seeking specialist clinical advice (21, 23). Web-based training has been shown to positively impact practice (54, 55), however given time-constraints, curated digital resources delivered to GPs at the point of need, (e.g., before/during a consultation) may be more practical for implementation at scale.

Digital technologies, including interventions for patients, and clinical guidance integrated into existing IT systems for HCPs, are potentially powerful tools for providing healthcare information and self-management tools within stretched primary care services (56, 57). Digital resources to support YP's mental health are already being recommended for use in the NHS (36). However further research is needed to develop similar interventions for YP with ADHD (49). Some aspects of digitally enhanced usual care for ADHD have been explored, including tools aiming to improve attention and increase medication adherence (50), and smartphone apps delivering self-management tools and psychoeducation (58). However, most interventions lack a robust evidence-base, fail to include lived experience stories, or are only available locally (58-60), which means they do not meet many desired characteristics highlighted in this research. Our findings show that stakeholders want curated digital resources, shared via a trustworthy source such as the NHS (61). Further work is needed to develop such resources and explore system-wide implementation.

### Implications for research and/or practice

There is an urgent need to improve primary care management of ADHD by providing trusted healthcare information and condition management resources to HCPs and patients. Patient resources need to be co-developed, provide ADHD and life-stage specific information, incorporate self-management tools and psychoeducational content, include patients' stories, and be available via multiple formats that are accessible to 'ADHD-brains'. Digital technologies, including healthcare apps for patients, and treatment guidance for clinicians, have the potential to deliver such resources cost-effectively and at scale. Future research needs to integrate the perspectives of multiple stakeholders, and address risks of digital exclusion (62). Co-developing and delivering such resources could reduce health inequalities, enhance the health and wellbeing of YP with ADHD, and improve job satisfaction within general practice. A national strategy, with a coordinated approach to implementation would be important to ensure comparable levels of care and information nationally. The newly formed NHS England ADHD Taskforce represents a unique opportunity to deliver in this area (63).

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## Supplementary Materials

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### S1. Topic Guides



#### Interview Topic Guide - WP2 (Health professionals and providers)

**Study title:** Managing young people with ADHD in primary care (MAP) study

**Chief Investigator:** Dr Anna Price [a.price@exeter.ac.uk](mailto:a.price@exeter.ac.uk). Telephone 01392 726026

*Please note this topic guide is for researchers only. This will be used to prompt questions during the interview. This is not a questionnaire. This topic guide will be adapted and refined following findings from WP1, and in consultation with MAP study research advisory groups.*

This interview aims to explore your perspectives and experiences in relation to providing services and support for young people (aged 16-25) and adults with attention deficit hyperactivity disorder (ADHD) in primary care (e.g., GP practice or local surgery). There will be a particular focus on factors that have made it easier and those that have made it harder to provide accessible and appropriate care. Also, on any recommendations you may have to improve access to primary care for people with ADHD in the future.

#### Demographics

This section asks for brief background information about your role and experience.

- Please tell us briefly about your primary care role? (GP, specialist nurse, PCN manager, pharmacist. Any other roles such as commissioning. How long in role?)
- What is the postcode of your workplace? (GP practice)
- What is your sex (gender)? (Male, Female, Non-binary / third gender, prefer not to say)
- Which ethnic group best describes you?
  - a. Asian, Asian British, Asian Welsh
  - b. Black, Black British, Black Welsh, Caribbean or African
  - c. Mixed or Multiple
  - d. White
  - e. Other ethnic group
  - f. Prefer not to say
- Do you have any professional/personal interests in neurodevelopmental disorders/mental health that inform your work?

## Research topic guide

### 1. How people with ADHD access primary care

This section asks about your experiences of the ways young people and adults with ADHD access primary healthcare.

- a. How do patients with ADHD **make and attend appointments** with your practice? What are the barriers? What makes it easier? (*Supporters/ Moving home/ University/ Covid-19/ Face-to-face/online/phone*)
- b. Is there anything that your service does to make it easier for patients with ADHD to **access** care and support?
- c. Are you aware of any barriers for particular groups of patients, and do you have anything in place to mitigate these?
- d. When patients with ADHD move GP practice (e.g., moving to university, moving home) what usually happens in terms of their access to primary care?
- e. In general, what can primary care providers do to make it easier for young people with ADHD to attend appointments and get the help they need when they need it?

### 2. Support for primary care providers working with young people and adults with ADHD.

This section asks for your perspective on how local providers and the wider healthcare system can support primary care professionals to provide healthcare for patients with ADHD.

- a. What current challenges do you face in providing primary care to patients with ADHD within the existing system? Are there any measures that could be implemented to make this easier? (*at a practice, PCN or national level*)
- b. In general, what systems/structural changes could be made to help you and your service to provide better care for people with ADHD? (*Financial incentives, training, staffing, information resources, decision making tools, care pathways, technology, digital resources*)

### 3. Providing care and support for people with ADHD through primary care

This section asks about your experiences of providing healthcare and support for young people and adults with ADHD, including barriers faced and what makes it easier. Also about differences in experience/process when providing care for patients via NHS, right to choose, or private diagnosis routes.

#### Patients

- a. Please tell us about patients with ADHD at your practice/in your primary care network (PCN)? (*How many there are/ Roughly how many might you see in a year/ How often do you see them*).
- b. Can you describe their characteristics? (*gender, life circumstances, age range*)

#### Prescribing

- c. Do staff at your practice have access to an 'advice and guidance' service from AMHS professionals with specialist knowledge of adult ADHD? *What sort of support would you find useful from AMHS?*
- d. Does your practice have shared care protocols/agreements in place with an AMHS to enable prescribing of adult ADHD medications through primary care for patients? (**NHS/Private diagnosis**)
- e. If relevant, how does your practice manage prescribing adult ADHD medications for patients? (**NHS/Private diagnosis**)

- f. What do you or your practice undertake to do as part of shared care, to enable safe prescribing of ADHD medication?
- g. Please tell us about differences in your experiences of providing ADHD care for patients with different circumstances (*NHS/ right to choose/ private. Diagnosis from another country. Transition. Moving house*)

#### **Other ADHD healthcare (non-pharmacological)**

- h. Please tell us about any non-pharmacological support your practice provides for patients with ADHD (*Social prescribing/ mental health/ support groups*)
- i. Please tell us about your experiences of managing treatment for ADHD when patients go through change. (*transition to AMHS, moving house, going to university. How does this impact continuity of care? Do you have any recommendations for managing/improving this process*)
- j. Does your practice have a protocol for supporting **transition** to AMHS for people with ADHD? (*Do you have experiences of supporting transitions for other LTC that could inform ADHD transitions?*)
- k. What are your experiences of communicating with the patient's **parent/carer** when providing support for ADHD? (*transition, involving in care, contacting, help attending appointments, privacy*)
- l. Do you have anything to add?

#### **4. Providing care and support for wider mental and physical health through primary care to people with ADHD.**

This section asks about your experiences of providing for the wider neurodevelopmental, mental, and physical healthcare needs of young people and adults with ADHD.

- a. Is there anyone at your practice or in the primary care network (PCN) with a special interest in mental health or neurodevelopmental difference that can provide psychological or social support to someone with ADHD?
- b. Please tell us about any additional roles that are in place at your practice or in the PCN that could provide support to a patient with ADHD. (*social prescriber/ pharmacist/mental health worker... What are your experiences in relation to this?*)
- c. Are there any things you consider when providing for the wider healthcare needs of patients with ADHD? (*neurodevelopmental difference/ wider mental & physical health*)
- d. What do you think are the most important increased health risks associated with having ADHD? (*How relate to ADHD?*) *Do you or staff at your practice give targeted advice/support on any of these as part of your approach? If so, please describe.*
- e. Do you have anything to add?

#### **5. Information resources and digital solutions**

This section asks about information resources to help manage the healthcare of patients with ADHD. The focus is on resources you use to aid your practice, and resources you share with patients to help them understand and self-manage their condition.

- a. Please tell us about resources you use to help manage the needs of patients with ADHD (*Recognise possible symptoms; make appropriate referrals; prescribe through shared care; support through transition; provide appropriate advice. Printed material/ audio or video clips/ online training/ digital apps/ conversations with colleagues – which useful and why?*)

- b. Please tell us about resources you signpost patients with ADHD to. (*Which useful and why? Consider self-management, accessing healthcare for ADHD & wider health needs*)
- c. In an ideal world, what kind of resources would you like to be available in primary care to help manage ADHD patient needs? (*For patient /clinician use. Local/ national/ digital/ formats. NHS website, video stories, clinical decision-making tools, apps*)  
If someone told you about a fab digital tool to aid treating patients with ADHD, what would it be like and what would it do?
- d. Please tell us about tools for managing other conditions that could be adapted for use with ADHD (*e.g., clinical decision apps. For clinician/patient use*)
- e. Do you have anything to add?

## 6. Reflection/Close

This section is asking about the advice you would give people who either **provide** or who **need** healthcare for ADHD about how to access care in the current system.

- a. What advice would you give to someone working primary care about how to support a young person with ADHD? (*effective treatment & support/ information & resources/ questions to ask & ways of listening*)
- b. What advice would you give to a young person with ADHD and their family about how to get help and support for their ADHD through primary care? (*how to access/ ADHD medication/ who to talk to/ what to say / questions to ask*)
- c. Is there anything you would like to add?

## Interview Topic Guide – WP2

(Young people and parents/carers)

**Study title:** Managing young people with ADHD in primary care (MAP) study

**Chief Investigator:** Dr Anna Price [a.price@exeter.ac.uk](mailto:a.price@exeter.ac.uk). Telephone 01392 726026

*Please note this topic guide is for researchers only. This will be used to prompt questions during the interview. This is not a questionnaire. This topic guide will be adapted and refined following findings from WP1, and in consultation with MAP study research advisory groups.*

This interview aims to explore your perspectives and experiences in relation to accessing services and support for young people (aged 16-25) and adults with attention deficit hyperactivity disorder (ADHD) through a primary care provider (e.g., GP practice or local surgery). There will be a particular focus on factors that have made it easier and those that have made it harder to access care. Also, on any recommendations you may have to improve access to primary care for people with ADHD in the future.

### Demographics

This section asks for background information about your lived experience of ADHD.

- What is your age (or the age of the person you support)?
- What is the name of your *GP practice?* (or *postcode*)
- Please tell us briefly about your ADHD diagnosis (or that of the person you support) and any other diagnoses. (e.g., *NHS/Private, age diagnosed, any other diagnoses*)
- What do you (or does the person you support) do? (*training, student, job role; not in education, employment, or training (NEET), prefer not to say*)
- What is your sex (gender)? (*male, female, non-binary / third gender, prefer not to say*)
- Which ethnic group best describes you?
  - a. *Asian, Asian British, Asian Welsh*
  - b. *Black, Black British, Black Welsh, Caribbean or African*
  - c. *Mixed or Multiple*
  - d. *Whiteethnic group*
  - e. *Prefer not to say*

### Research topic guide

#### 7. How people with ADHD access primary care

This section asks about your experiences of the ways young people and adults with ADHD make and attend healthcare appointments at their GP practice.

- a. How do you (or does the person you support) **make and attend appointments** with your GP practice? What are the barriers? What makes it easier? (*Moving home/ University/ Covid-19/ Face-to-face/online/phone*)
- b. What role does your parent/carer have in helping you to access care and support? (Or what role do you have as a parent/carer, and what role does the young person take)
- c. Is there anything your practice could do to make it easier?

## 8. Healthcare and support for ADHD through primary care

This section asks about your experiences of healthcare and support for ADHD from your GP, including barriers faced and what makes it easier. We are also interested in differences of experience between NHS and private healthcare routes.

- a. What are your experiences of **referral** for a diagnosis of ADHD via your GP? (*private/NHS. How well AMHS & GP communicate*)
- b. Please tell us briefly about your **diagnosis** of ADHD (or that of the person you support) and about how this was received. (*NHS/right to choose/private. If private, why?*)

### Prescribing

- c. Do you (or does the person you support) need medication for your ADHD? (*if not skip questions d & e*)
- d. What are your experiences of getting **prescriptions** for ADHD medication from your GP? (*Private/NHS routes. What works/does not work. How AMHS & GP communicate*)
- e. Please tell us about your experiences of any **regular checks/review** your GP carries out as part of prescribing ADHD medications. (*Private/NHS*)

### Other ADHD healthcare (not medications)

- a. Which health professionals have you received ADHD support for at your practice? (*GP/ community worker/ pharmacist/ mental health support worker*)
- b. Other than medication, please tell us about **any healthcare** for ADHD you (or the person you support) have received from your local GP practice (*Social prescribing/mental health/support groups*). *What other healthcare would you find useful?*
- c. What are your expectations and needs from a consultation, or other support in primary care for ADHD?
- d. What have been your experiences of ADHD healthcare from your GP at times of change in your life? (*transition to AMHS, moving house, going to university. How did this impact continuity of care? Do you have any recommendations for managing/improving this process*)
- e. What are your experiences of your practice working together with your supporter (family/friend/partner) to help you get healthcare for ADHD? (*transition, involving in care, contacting, help attending appointments, privacy*)
- f. Do you have anything to add?

## 9. Healthcare and support for wider health needs through primary care

This section asks about your experiences of healthcare and support from your GP for wider physical and mental health needs (when you have ADHD).

- a. Do you (or does the person your support) have any co-existing **health** challenges? (*mental health/neurodevelopmental difference/physical*)
- b. Have you had a chance to discuss your health more widely with your primary care provider? (*mental health/neurodevelopmental difference/physical*)
- c. Are you aware of any **health risks** faced by people with ADHD? (*Have you had a chance to discuss this /received advice? Awareness re substance use, smoking, other risk-taking behaviours; any signposting to support; harm reduction strategies etc.*)
- d. What do you feel your practice could do to help you to get your **wider health needs** met when you have ADHD?

- e. Do you have anything to add?

#### 10. Information and resources and digital solutions to help manage ADHD.

This section asks about resources to provide information to help manage and self-manage the health of people with ADHD.

- a. Please tell us about ADHD healthcare resources you have been given by your practice (*printed/ audio or video clips/ online training/ digital apps/ support groups – which useful and why?*)
- b. What other resources do you use to help manage health and wellbeing with ADHD? (*which useful, why*)
- c. In an ideal world, what resources would be available from your GP to help manage ADHD? (*local, national, digital... What is your preferred method for gaining information about treatment and support for adult ADHD and why?*)
- f. If someone told you about a fab digital tool for people with ADHD, what would it be like and what would it do?
- d. Please tell us about tools for managing other health conditions which could be adapted for ADHD (*e.g., diabetes or depression health apps, alarms, exercise programmes*)
- e. Do you have anything to add?

#### 11. Reflection/Close

This section is asking about the advice you would give people who either **provide** or who **need** healthcare for ADHD about how to access care in the current system.

- a. What advice would you give to someone working primary care about how to support a young person with ADHD? (*treatment & support/ information & resources /questions to ask /ways of listening*)
- b. What advice would you give to a young person with ADHD and their family about how to get help and support for their ADHD through primary care? (*how to access/ ADHD medication/ who to talk to/ what to say / questions to ask*)
- c. Is there anything you would like to add?

## S2: Table with summary of research site characteristics

Table S2. Sample: overview of research sites, participants, local area profiles, and site descriptions.

Practice research site (number of participants)	Profile of local authority			Profile of practice, including characteristics of local area as described by participants	
	% 'White' <sup>1</sup>	Rural/Urban classification <sup>2</sup>	IMD rank <sup>3</sup>	Summary	Quotes
S1 (n=3)	94	Urban with City and Town	50	~12,500 patients. High deprivation area. Specialists in substance misuse. Contract for homeless outreach. Social prescriber, Mental Health (MH) worker	<p><i>"most deprived practice in the city...top 10% of most deprived practices in the country. We see a huge amount of mental health, substance misuse. We're specialists in substance misuse ... We hold the contract for the Outreach to the Homeless Service, and we take our care out to hostels."</i></p> <p><i>"...we have a social prescriber through the Additional Role Reimbursement Scheme, with the PCNs...that works in our practice.... We've got a mental health worker"</i> <b>Practice manager</b></p>
S2 (n=5)	84	Urban with Major Conurbation	1	~3,500 patients. High deprivation area. Provide drug misuse services and SAS services. Counsellor.	<p><i>"...one of the areas of England with the highest index of multiple deprivation..."</i></p> <p><i>"inequalities ... massive... lack of job opportunities, education, housing, you name it. ... high asylum seeker community ... a really, really, diverse area."</i></p> <p><i>"We provide a drug misuse service... SAS service...for patients who have been removed from their practice having behaved in a way that warranted the police being called."</i></p> <p><i>"We have an onsite counsellor who's available for brief interventions"</i> <b>General practitioner (GP)</b></p>
S3 (n=4)	97.6	Largely Rural	75	~7,000 patients. Link workers, MH workers.	<i>"we have link workers, and ... primary mental health workers"</i> . <b>GP</b>
S4 (n=4)	70.7	Urban with City and Town	180	~7,000 patients. University linked practice. High numbers of students and patients from overseas. Wellbeing worker.	<p><i>"... we have a young population... We also have a lot of overseas families and students."</i></p> <p><i>Practice manager</i></p> <p><i>"We have a ...[wellbeing] worker who comes to the practice who doesn't provide therapy as such but is very good for exploring complex issues and kind of way finding and thinking about other resources that may be needed or accessible to a particular patient."</i> <b>GP</b></p>
S5 (n=4)	48.6	Urban with Major Conurbation	7	~5,500 patients. High deprivation area. MH worker, social prescriber.	<p><i>"high deprivation area, ...one of the most deprived communities in ... in England, so lowest 10%."</i> <b>GP</b></p> <p><i>"...we have a mental health worker... social prescribers"</i> <b>Practice manager</b></p>

<sup>1</sup>Census 2021, % of people classing themselves as 'White', with average in England being 81.7% (1); <sup>2</sup>Census 2011 (2); <sup>3</sup>Indices of Multiple Deprivation (IMD) summaries for Local Authority Districts (3), Rank of proportion of LSOAs in most deprived 10% nationally with 1 being highest rank for deprivation and 195 being lowest.

\*Published in linked paper (4)

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