Provision of digital health interventions for young people with ADHD in primary care: findings from a survey and scoping review

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Abstract

Background People with attention-deficit hyperactivity disorder (ADHD) are at risk of negative health outcomes, with risks reduced through evidence-based treatments. Therefore, ensuring continued access to treatment for young people with ADHD, especially as they transition from child to adult services, is a priority. Currently many young people with ADHD are unable to access adequate care, with negative consequences for patients and their communities. Preliminary evidence suggests digital health interventions (DHIs) may act as an effective adjunct to usual care, helping overcome barriers to access, and improving outcomes by increasing understanding of ADHD as a long-term condition. The aim of this mixed methods study is to explore the healthcare information preferences of people with lived experience of ADHD in the primary care context and considers these in the light of the emerging body of literature on DHIs for ADHD. To explore this, a descriptive summary of cross-sectional survey responses was compared and discussed in the context of DHIs identified in a scoping review.

Results Digital apps, followed by support groups, were deemed the most useful information resource types by survey respondents, but were the least currently used/provided. Over 40% participants indicated a preference for signposting to all resource types by their general practitioner (GP), suggesting that GPs are credible sources for ADHD healthcare information. The scoping review identified nine studies of DHI for ADHD, consisting of games, symptom monitoring, psychoeducation, and medication reminders, with limited evidence of effectiveness/implementation.

Conclusions People with ADHD state a preference for digital apps as an adjunct to usual care. However, these are currently the least provided information resource in primary care, indicating a key area for future development. The limited evidence base on DHIs for ADHD suggests combining digital apps and support networks, and utilising multimodal delivery methods may also enhance the delivery of healthcare information.

Keywords ADHD, Young people, Primary Health Care, Digital mental health interventions, Health information provision, Mixed methods study

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Introduction

Attention deficit hyperactivity disorder (ADHD) has an estimated worldwide prevalence of 5% and is one of the most common paediatric neurodevelopmental disorders [1]. Approximately 40% people diagnosed with ADHD in childhood/adolescence will experience symptoms that

persist into adulthood, which also predisposes them to the development of other psychiatric disorders such as anxiety and depression [2]. Experiencing ADHD symptoms can have a negative influence on many long-term outcomes for young people, such as their physical and mental health, academic and employment opportunities, services use, financial position, engagement in criminal activity and mortality [3].

Treatment options for ADHD include pharmacological and non-pharmacological interventions, which have both been shown to have short-term efficacy [4, 5]. Long-term outcomes for people with ADHD can also be improved when they receive treatment, compared to when people with ADHD do not receive treatment [3]. The management of ADHD is most effective when pharmacological and non-pharmacological support is delivered in combination; medications are properly trialled and titrated; and patients have adequate access to specialist support [6–8]. However, there are many common barriers to managing ADHD including side effects and poor tolerability of medication, difficulty adhering to treatment, caregiver/professional misconceptions and stigma surrounding medication, and limited availability and accessibility of ADHD services in the UK [4, 9–11]. Research shows that less than a quarter of people who required ADHD medication in the UK transferred successfully from child to adult mental health services, leaving them without easy access to specialist treatment [12]. This is of concern as the transition from adolescence into adulthood is a period where young people need access to services most [13].

With recent research indicating a failure of healthcare for young people with ADHD, there is a clear need for improvements to existing provision [14]. An increased role for primary care in the management of ADHD, may increase access to healthcare for currently underserved groups [6]. In addition, non-pharmacological treatments as an adjunct to existing practice may help to improve access to care by being used instead of or to support medication; while people wait for diagnosis, referral, or prescriptions; to support access; or to support psychoeducation. Recent changes to healthcare delivery in England, such as the formation of Primary Care Networks and Integrated Care Boards (ICB) which organise the provisions of care for local communities [15, 16], present new opportunities to investigate innovative types of treatment/support which may be more accessible to patients via their general practitioner (GP). Digital health interventions (DHIs) offer remote access and the ability to be used repeatedly, which may provide cost effective support and enhance the delivery of healthcare for young people with ADHD via primary care, acting as an adjunct to mental health provisions.

Digital resources and interventions

Evidence suggests that DHIs for ADHD can be a beneficial adjunct to usual care and improve attention and social function for people with ADHD [17, 18]. They may also help people with ADHD to understand and self-manage their ADHD by providing information to help make informed decisions about healthcare or acting as reminders and aids to perform self-management activities such as medication adherence. Types of DHIs include websites and online resources, mobile apps, computer software, Internet-delivered therapies, or gamified interventions. DHIs have advantages such as access in rural areas, at times of day which suit users, fewer side effects and less potential for misuse [18]. Shou et al. found that the reach of DHIs is broad in developed countries that have the infrastructure and hardware to participate [17]. Their systematic review found that both children and adults benefitted equally from DHIs, but there were no studies pertaining to adolescents and young adults (ages 16–25) [17].

Rationale

There is growing interest in the value of DHIs to supplement the delivery of mental health support. However, ADHD is neglected in the evidence base of DHIs [19]. In particular, there is limited evidence for interventions which provide support for young people with ADHD, aged 16–25 [17, 19]. This is of importance because of the transitions that young people often experience at this age, such as the transition from child to adolescent mental health services, within the education system, and leaving home/parental-care. This research has been designed to address these gaps in the literature, investigating the experiences of, and interventions for, 16–25-year-olds with ADHD.

The aim of this study is to compare the current availability of DHIs which could support the delivery of healthcare for young people with ADHD with the needs and expectations of people with lived experience of ADHD. This will provide evidence for future co-production of guidelines and efficacy studies which will improve primary care for young people with ADHD. The research questions are:

1. What current DHIs exist to support the delivery of healthcare for young people with ADHD?
2. What are the reported needs and expectations of people with lived experience with regards to information resources to support the delivery of healthcare for young people with ADHD in primary care?
3. What comparisons can be made between currently available DHIs and the needs and expectations of people with lived experience?

Methods

This work is part of a broader programme of work, the "Mapping ADHD services in Primary care" (MAP) study [20]. All methods involving human participants have been approved by the Yorkshire and the Humber – Bradford Leeds Research Ethics Committee (Reference: 22/YH/0132). All survey participants gave informed consent for their data to be used in this study. This is a mixed-methods study, with results presented from a scoping review and a subset of data from the online MAP survey.

Online survey

The survey methodology is described in more detail elsewhere [20] but is briefly summarised here. The survey was developed in response to a previous study – the Children and Adolescents with ADHD in Transition between Children's and adult Services study [12] – which informed us on the priorities of young people with ADHD with regards to their experiences of primary care. These priorities guided the development of the survey questions. The survey was piloted with research advisory groups and revised to simplify the wording and ensure it was accessible and engaging for all participants. The final version of the survey was tested to ensure that they could be completed within ten minutes. The survey was hosted on Qualtrics, a General Data Protection Regulation compliant online survey tool, and the core team tested it to ensure there were no technical problems before disseminating the survey link.

Questions explored current primary care practice in relation to the National Institute for Health and Clinical Excellence guidelines for diagnosis and management of ADHD. Questions asked participants to reflect on their experiences when they were between the ages of 16 and 25 years old. This project uses data from a subset of questions described in Table 1 focussed on information resources that help to self-manage ADHD.

Participants

The population of interest included young people with ADHD and their supporters (e.g., parents, carers, guardians) over the age of 16 and living or working in England. Anyone over the age of 16 was eligible to take part, but participants were informed that the context of the study was centred around experiences of people aged 16–25 accessing primary care. The target sample size was 210, to allow for a minimum of six respondents from each ICB to ensure adequate coverage of each NHS ICB in England.

Dissemination and sampling

A convenience sample were recruited through various methods. A link to an online survey was shared with participants via emails. Snowball sampling was employed by asking the lead researcher's relevant professional contacts to forward emails with the survey link to their networks. Additionally, research partners, the ADHD Foundation and UK Adult ADHD Network, shared the study via social media and their mailing lists. Finally, researchers shared the survey link on Facebook, Twitter and Instagram accounts associated with the study.

Halfway through dissemination, as per protocol, a geographic analysis of responses identified London as an underrepresented NHS region. Subsequently, dissemination was targeted to London using local ADHD groups and emails to contacts in relevant areas. A paid Facebook advertisement was created in the final week of dissemination to target underrepresented geographic regions. The survey was open for six weeks.

Data analysis

Descriptive data analyses were performed in Microsoft Excel. Respondents were categorised as either a young person with ADHD or a supporter of a young person with ADHD, depending on which they reported as their main role. There were four questions from the survey relevant to the aims of this report, described in Table 1.

Table 1 Survey questions and response rates

Question #	Survey question	# respondents
	Information resources	254
1	Which of the following do you (or the person you support) use to get information to help with understanding and self-managing living with ADHD?	242
2	Which of the following would you (or the person you support) find useful to get information to help with understanding and self-managing living with ADHD?	174
3	Which of the following types of resources have staff at your GP** practice signposted or shared with you (or the person you support) to help with understanding and self-managing ADHD?	182
4	Which of the following types of resources would it be useful for staff at your GP practice to signpost or share with you (or the person you support) to help with understanding and self-managing ADHD?	155

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Participants were able to opt out of answering the information resource questions. Therefore, where participants did not answer a question on information resources, they were excluded from the analysis for that question and treated as "missing data." These non-continuing participants have been recorded but were not included in the analysis. Due to the nature of the non-probability sample and the fact that missing data cannot be treated as random, multiple imputation of missing data has not been conducted.

For each question, the percentages of participants who indicated "yes" to each information resource type were summarised and tabulated, with 95% confidence intervals (CI) for proportions. These summaries were presented visually using bar graphs.

Scoping review

A literature search was conducted by RG in the following electronic databases: Medline, EMBASE and the Cochrane Library. The searches were conducted on 9th December 2022. Search terms were developed with the support of information specialists at the University of Exeter and included terms synonymous with "young people," "people with ADHD," and "digital/online interventions." No date limit was applied to the search results because DHIs have only been available in recent years and thus we did not anticipate finding studies older than ten years. Texts were limited to English language and human participants only. The full search strategies are detailed in Additional File 1.

Studies were included if they measured effectiveness, acceptability, engagement with or experience of a DHI from a sample of young people with ADHD. The intervention had to be delivered online or use a digital technology and had to be self-administered in any country or healthcare setting. Neuro/bio-feedback interventions were excluded because the authors deemed them unable to be replicated in an a self-administered, at-home setting without clinician intervention. Studies of parent, parent–child or family interventions were also excluded. After discussion, the authors decided that any study which included some participants within the desired age range could have valuable results to help answer the research questions, but studies which were aimed specifically at age ranges outside of the specified range (e.g., 5–12-year-olds) would be less relevant and therefore not included. Therefore, after title and abstract screening, the inclusion criteria were narrowed to only include studies where at least one participant was within the target age range (16–25 years old). Full inclusion and exclusion criteria are listed in Additional File 1.

The records found were imported to Mendeley and duplicates were removed. All remaining titles and abstracts were dual screened by RG, AP, and KB. RG reviewed all the included titles and abstracts to apply the updated criterion regarding age of participants. Full-text articles were then screened by the same team of independent reviewers. Any disagreement between reviewers was discussed until agreement was reached. Where no agreement could be reached, the third reviewer was consulted.

RG charted data regarding details of the publication (author, year, country of origin), study design, type and delivery mode of interventions, characteristic of ADHD targeted by the intervention, and any described facilitators and barriers to implementing interventions. Results were synthesised using a narrative approach.

Results
Online survey

In total, there were 254 unique respondents to questions about information resources, reaching the target number of responses. Of these responses, 96 were a supporter of a young person with ADHD and 158 were a young person with ADHD aged 16 or over. Additionally, responses were received from all NHS ICBs in England. Table 1 provides the number of unique respondents and non-continuing respondents for each survey question.

Responses are described below. Tables 2 and 3 show the numbers and proportions of respondents who answered "yes" to information resource types for each question, represented visually in Figs. 1 and 2.

Use of information resources

With regards to which resources respondents currently use, websites were reported by the most respondents (90.9%), followed by a conversation with a friend (65.3%). Digital apps were the least reported in current use of information resources (19.8%). The order of current use of information materials versus which would be useful were exactly opposite. Digital apps (76.4%) followed by support groups (62.1%) were reported by the most participants as "would be useful," with the least reported resource being websites (19.5%).

Signposting of information resources by GPs

Most respondents indicated they had not been signposted to any resources (81.9%), whereas 14.3% reported being signposted to printed materials, and 14.3% to websites. There is little distinction between information resource type with regards to how many respondents reported that they would be useful to hear about from their GPs, with only 11% difference between the most and least reported information resource, websites (54.2%) and video clips (43.2%) respectively.

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Table 2 Information use reported by people with lived experience of ADHD

Question 1: Which resource do you currently use?

Information resource type	Current use reported		95% CI	
	n	%	Lower	Upper
Website	220	90.9	86.6	94.2
Conversation with friend	158	65.3	58.9	71.3
Video clips	142	58.7	52.2	64.9
Audio clips/podcasts	127	52.5	46.0	58.9
Printed material	100	41.3	35.1	47.8
Support groups	91	37.6	31.5	44.0
Digital app	48	19.8	15.0	25.4
Do not know	4	1.7	0.5	4.2

Question 2: Which resource would you find useful?

Information resource type	Would be useful reported		95% CI	
	n	%	Lower	Upper
Digital app	133	76.4	69.4	82.5
Support group	108	62.1	54.4	69.3
Printed material	70	40.2	32.9	47.9
Audio clips/podcast	66	37.9	30.7	45.6
Video clips	52	29.9	23.2	37.3
Conversation with friend	47	27.0	20.6	34.2
Website	30	19.5	13.9	26.2
Do not know	4	1.7	0.5	4.2

95% confidence interval for proportion (95% CI) calculated using the proportion of respondents of respondents indicating "yes" to each resource type

Scoping review

The database searches identified 2498 records (Medline, Embase and Cochrane Library yielded 915, 1356, and 227 records respectively). From these, a total of nine records were identified for inclusion [21–29], see the PRISMA flow diagram for details (Additional File 1). The included studies have publication dates ranging from 2010 to 2022. Five studies were conducted in the USA, with Denmark, Sweden, Israel, and Australia also being home to one study each. Details related to the samples, intervention types and mode of delivery are provided in Table 4. Only two RCTs were identified [23, 25], and four pilot studies [22, 25, 26, 29]. Intervention types included three gamified interventions [22, 23, 28], two wearable symptom monitoring devices [26, 29], one psychoeducation programme [27], one medication reminder service [21], one symptom monitoring survey [24] and one background sound [25]. Three interventions were delivered using a digital app [26, 27, 29], two using an online portal [24, 27], two via computer programmes [22, 23], one via SMS text messaging [21], and one via compact disc [25]. The intervention type and mode of delivery for each identified intervention are visualised in Fig. 3. The Fitbit Flex intervention evaluated by Schoenfelder et al., was delivered primarily via a digital app, but combined delivery methods by also using an invite only Facebook group which allowed participants to interact with facilitators and other participants to receive encouragement, social support, and rewards for meeting goals. This DHI aimed to promote physical activity and reduce ADHD symptoms. Participants wore a wearable activity tracker (Fitbit Flex), which collected data about energy and movement, and then synced to a mobile app that provided participants with visualisations of the data and feedback towards goals.

Of the nine interventions identified, six measured ADHD symptoms as the target for their intervention [22, 24, 26–29]. The remaining three were designed to target different outcomes which may be negatively affected by ADHD: hazard perception while driving, homework problems, and medication engagement [21, 23, 25].

All studies provided interim results which showed improvements in ADHD outcomes, although two studies found no significant group differences between the intervention and control groups: one tested a computerised brain training exercise against a control of Tetris, and one used binaural auditory beats against a placebo sound [22, 25]. Four studies did not use a control group, due to being feasibility or pilot studies focussed on intervention acceptability, hence it is difficult to determine whether the outcomes of these studies are a result of the intervention or another variable [24, 26, 28, 29].

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Table 3 Information signposting by GPs reported by people with lived experience of ADHD

Question 3: Which resources have staff at your GP practice signposted or shared with you?

Information resource type	Current signposting reported		95% CI	
	n	%	Lower	Upper
None	149	81.9	75.5	87.2
Printed material	26	14.3	9.5	20.2
Website	26	14.3	9.5	20.2
Support group	16	8.8	5.1	13.9
Digital app	14	7.7	4.3	12.6
Video clip	13	7.1	3.9	11.9
Audio clip/podcast	11	6.0	3.1	10.6
Do not know	10	5.5	2.7	9.9

Question 4: Which resources would it be useful for staff at your GP practice to signpost or share with you?

Information resource type	Signposting would be useful reported		95% CI	
	n	%	Lower	Upper
Website	84	54.2	46.0	62.2
Digital app	83	53.5	45.4	61.6
Support group	82	52.9	44.7	61.0
Audio clip/podcast	79	51.0	42.8	59.1
None	72	46.5	38.4	54.6
Printed material	71	45.8	37.8	53.9
Video clips	67	43.2	35.3	51.4
Do not know	16	10.3	6.0	16.2

95% confidence interval for proportion (95% CI) calculated using the proportion of respondents of respondents indicating "yes" to each resource type

Some common barriers to implementing interventions were reported, with suggestions for addressing these. These included having a lack of sustained attention whilst trying to do the intervention and forgetting to do it [22, 28]. Interventions which offered reminders were deemed as useful by participants, but participants recommended increasing the number of reminders [22, 28, 29]. Another recommendation was ensuring that images are interesting to the relevant age group and modernised, as some of the interventions were initially developed for different age groups or developed years prior to the studies being conducted [22, 23, 26, 28].

Discussion

This mixed methods study aimed to find out about the needs and expectations of people with lived experience with regards to information resources, and the current availability of DHIs, to inform the future development and implementation of DHIs for young people with ADHD. The findings from our survey show that digital apps would be deemed the most useful by young people with ADHD and their supporters, followed by support groups. Interestingly, results also show that respondents stated a preference for printed materials over websites. Results from questions about signposting of resources show that young people with ADHD and their supporters would find signposting to any information resource from GPs useful, with little difference between resource types.

The scoping review identified literature relating to nine DHIs relevant to young people with ADHD. The review identified some common factors which influence acceptability and implementation of ADHD interventions, including difficulty engaging in interventions due to a lack of sustained attention; increasing engagement and participation using more reminders and up-to-date visuals; and ensuring interventions are tailored to the target age group.

From the results, three key implications for the future development of DHIs have been identified and are discussed below.
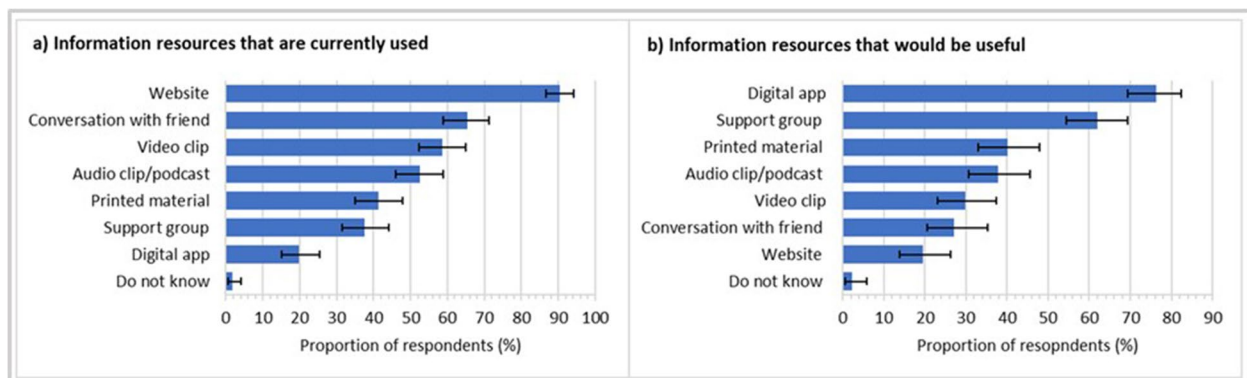
Fig. 1 Information use reported by people with lived experience of ADHD. Bar graphs which show the proportion of respondents with lived experience of ADHD who reported that they **a)** currently use and **b)** would find it useful to use each information resource type to help self-manage their ADHD. 95% confidence intervals are indicated

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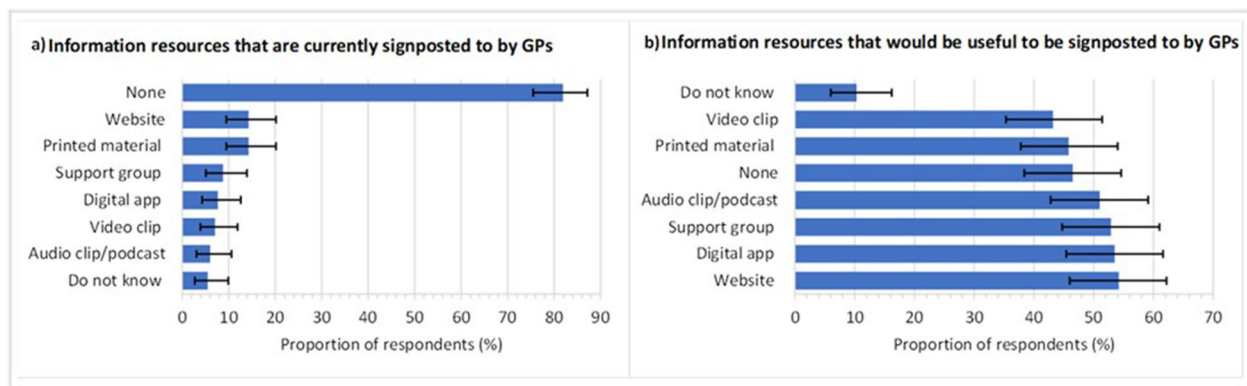
Fig. 2 Information signposting by GPs reported by people with lived experience of ADHD. Bar graphs which show the proportion of respondents with lived experience of ADHD who reported that they **a)** are currently signposted to and **b)** would find it useful to be signposted to each information resource type by their general practitioner (GP) to help self-manage their ADHD. 95% confidence intervals are indicated

Table 4 Characteristics of studies included in scoping review

Study	Study design	Sample size intervention:control	Mean age	Age range	Primary ADHD outcome	Intervention	
						Name	Mode and Type
J Biederman et al. [21]—USA	Non-randomised open-label study	112:336	35.9	18–55	Medication engagement	SMS	SMS text reminders
A Bikic et al. (2017)—Denmark	Double-blind randomised pilot study	9:8	15.6	14–17	Cognition, ADHD symptoms	Scientific Brain Training programme	Computer programme – game
C.R Bruce et al. (2017)—Australia	Exploratory randomised controlled trial	12:13	20.64	16–25	Driving—Mean hazard perception reaction time	Drive Smart	Computer programme – game
T.M Kennedy et al. (2022)—USA	Non-randomised observational study	90:0	14.7	12–18	ADHD symptoms	Ecological Momentary Assessment	Online portal – symptom assessment surveys
S. Kennel et al. (2010)—USA	Randomized, double-blind, exploratory pilot study	20[b]	14.25	8–21	Attention and impulses, Homework problems	Binaural auditory beats	CD
J.E Leikauf et al. (2021)—USA	Open-label pilot study	32:0	11[c]	8–17	ADHD symptoms	StopWatch	Digital App – wearable symptom assessment
L Rachamim et al. (2022)—Israel	Reanalysis of randomised controlled trial	16:22	11.29	7–18	ADHD symptoms	[d] Internet-based self-help comprehensive behavioural intervention for tics	Online portal – psychoeducation
V Ruchkin et al. (2022)—Sweden	Non-randomised feasibility study	12:0	13.75	9–17	Memory	Method of Loci	Digital app – game
E Schoenfelder et al. (2017)—USA	Non-randomised pilot study	11:0	15.5	14–18	ADHD symptoms	Fitbit Flex	Digital App – wearable symptom assessment

[a] Mean age for intervention group, age of whole sample or control group not reported

[b] Total number of participants – allocation to intervention/control not reported

[c] Median age

Enhance digital delivery using social support

Based on the finding that a digital app followed by a support group would be considered the most useful intervention for people with lived experience, the Fitbit Flex intervention which combines these two elements identified in the scoping review is noteworthy [29].

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Fig. 3 Visual representation of types of digital health intervention identified in the scoping review. Interventions identified were binaural auditory beats (BAB) [25], SMS text reminders [21], Fitbit Flex movement tracking [29], StopWatch movement tracking [26], Ecological momentary assessment (EMA) [24], Internet-based self-help comprehensive behavioural intervention for tics (ICBIT) [27], Method of Loci (MoL) [28], Scientific brain training programme (SBTP) [22], and Drive Smart [23]

Evidence shows that support groups and peer support, including closed Facebook groups, can improve mental health outcomes and symptom self-management in adolescents [30–33]. They provide users with social connectedness, empowerment, and the ability to learn from others [30, 33]. However, this research is limited to few empirical studies, especially with regards to the use for support groups for ADHD. The Fitbit Flex study by Schoenfelder et al. was a feasibility trial [29]. Although the results show that there was a significant increase in physical activity, and a decrease in self- and parent-reported ADHD symptoms, it requires more testing and development to determine efficacy and an investigation into the active components that may be leading to an improvement in symptoms. Conversely, an open-label pilot study also identified in the scoping review, which aimed to test the ability of a wearable activity tracker device to treat hyperactivity, also observed an improvement in ADHD symptoms despite not utilising a social support element [26]. Overall, the evidence shows promise in improving ADHD symptoms using wearable monitoring devices and combined with results from the survey shows that enhancing the delivery of digital apps with online social support may be effective and meet the needs of people with lived experience.

Increase engagement using up-to-date, multimodal communication methods

Respondents reported that they most frequently access information from websites, despite websites being regarded as the least useful information resource. Printed materials were reported as useful by more respondents than websites. This is in line with previous research, which shows that printed patient education information is deemed more acceptable to patients than digital print [34]. Online information is perceived as more difficult to read than the equivalent information in printed format [34]. Additionally, for people with ADHD comprehension of written information is worse when the information is delivered digitally rather than in print [35]. Another study of how people prefer to receive healthcare information found that participants value a combination of written, audio and video materials, suggesting that the most useful source of information would utilise multimodal communication methods [36]. It is important to consider some limitations of these studies – the samples were small, and from limited populations, such as a single clinic, university, or level of education, which limits the generalisability of the results. Nonetheless, these findings are of interest for the development of DHIs for young people with ADHD, because they suggest that DHIs may not be useful as sources of written information about ADHD. If used as information resources, DHIs should use multimodal methods of communication.

DHIs may also be more useful when they involve active participation and/or gamified tasks, rather than being designed as information sources. However, one of the common barriers of implementing some gamified DHIs identified in the scoping review was that difficulties with sustained attention limits the use of certain apps [22, 28,

29]. Ensuring that graphics and user interfaces are modern and visually appealing; interventions are tailored to the target age range; and having adequate reminder messages/systems in place were suggestions from participants. This may attract more attention from young people with ADHD, enabling them to stay engaged and complete the intervention.

Ensure interventions are acceptable to GPs and other health practitioners

Finally, when asked what would be useful to be signposted to from GPs, people with lived experience had little preference for information resource type, but each resource was identified as "would be useful" to hear about by over 40% of respondents. A previous study of information resource preference found that health professionals are viewed by parents as a trusted source of information about ADHD [37]. These results imply that resource type is less important to people so long as the recommendation comes from a credible source. The implementation of information provided by a credible source is a recognised behaviour change technique, which increases uptake of behaviours [38]. Similarly, to Sciberras et al. we asked participants about information sources and modes of information, but Sciberras et al. also asked participants about the quality and content of information [37]. This enabled data to be collected regarding the reasons why certain sources are deemed as preferential over others, whereas our study does not allow these inferences to be drawn. Data from a future qualitative study would be beneficial, to provide a rich and in-depth understanding of the preferences of people with lived experience concerning information resources.

Nevertheless, this finding is of interest because it shows that interventions should not only be deemed acceptable by young people, but also by GPs. Research shows that where GPs have a lack of knowledge about a treatment for ADHD, they are left unwilling to prescribe it to young people [39]. This is supported by a systematic review of GPs as gatekeepers to diagnosis and treatment for people with ADHD, which found that there was a general reluctance by GPs to become involved in the treatment of ADHD – oftentimes due to a lack of time and knowledge [11]. Thus, if an intervention is viewed as being time-saving and easy for GPs to understand and operate, it may be more acceptable to them, and so they may be more likely to engage and prescribe it or signpost patients towards it.

Outstanding questions for future research

The survey we have reported on here was also shared with health practitioners with questions tailored to them regarding which information resources they currently signpost young people with ADHD to, and what information resources they would find useful to help them make clinical decisions about the care of young people with ADHD. During the screening phase of the scoping review, the researchers observed multiple texts about DHIs which could be useful to health practitioners for the management of ADHD in primary care, which suggests there is a body of evidence for tools that might assist with clinical decision making. Thus, it may be beneficial to conduct a similar study with the target population of health practitioners in primary care who are involved in the management of ADHD.

A key finding from the scoping review is that relatively few studies focus on the development of interventions for adolescents and young people with ADHD. Other systematic reviews in this area of research find interventions aimed at younger populations, but the evidence for people aged 16–25 is limited [17, 19]. This was the first review to exclusively focus on this age range, and only nine papers were yielded. Given the importance of transition into adulthood for people with ADHD, developing interventions for this age group should be of high priority. In addition, while many of the results from the included studies were promising, they were generally limited to open-label, non-randomised or pilot and feasibility trials, which demonstrates the need for robust randomised controlled trials (RCTs) which have adequate statistical power to measure the true efficacy of currently available DHIs.

Strengths and limitations

This analysis provides the first overview of stakeholder reported views on the provision of information resources to help young people self-manage their ADHD in England. Additionally, the scoping review is the first to scope out the development of resources specifically for young people with ADHD in the target age range, 16–25 years old, identifying facilitators and barriers for use of resources in primary care. The methods of disseminating the survey link, including utilising the mailing lists of partner organisations and charities enabled us to reach more than the target number of responses and resulted in a good geographic spread of data with at least six respondents from each ICB in England. However, despite reaching a high number of respondents in each ICB, the survey may not be nationally representative due to the low number of responses relative to the number of people in England with ADHD. Furthermore, participants were not randomly selected due to the use of non-probabilistic sampling strategies.

The survey also did not collect demographic information, such as gender, ethnic origin, or age because our priority was keeping the survey short and accessible for people with ADHD, who often have attentional

difficulties. Our lack of detailed demographic information limits the generalisability of this sample. It is also possible that the non-probabilistic methods used to sample respondents introduced responder bias. Respondents may have been more likely to complete the survey if they have had extremely negative or positive experiences with their GPs that they wanted to share, so the views presented here may not be reflective of the rest of the population. In addition, most of the advertising for the survey was done online, so respondents had to have access to a computer or mobile device and be computer literate. Furthermore, since participants could be any age over 16, it is difficult to tell whether results exclusively pertain to the experiences of young people aged 16–25, despite framing the context of the research as such prior to the survey and in the wording of survey questions. Results are also susceptible to recall bias should participants over the age of 25 be reflecting on experiences from when they were aged between 16–25.

In addition to limitations regarding the age-range of participants in our survey sample, we also acknowledge the broad age range of participants in included studies in the scoping review which may limit the relevance of findings to people aged 16–25. Due to an underdeveloped body of literature regarding young people with ADHD between the ages of 16–25, this research took an inclusive approach to eligibility of studies which included participants outside of our population of interest. While this enabled us to identify interventions which are being developed/evaluated that may be relevant to this age range, the inclusion of studies which have a mean participant age outside of our population of interest may skew results and impede the ability to draw conclusions for individuals aged 16–25. Quality assessments of the records included in the scoping review were also not performed because this study aimed to identify the scope of the available evidence. The results were synthesised narratively, with some general shortcomings of the evidence highlighted. However, it would be beneficial to conduct a full systematic review which maintains a narrower inclusion criteria regarding age of participants and includes rigorous quality evaluation to fully assess the state of the evidence base regarding current development and provision of DHIs for the management of ADHD symptoms for young people with ADHD. A future systematic review on the same topic is planned [40].

Conclusion

This study investigates the current availability of peer reviewed research on DHIs for young people and ADHD with the preferences of people with lived experience. The scoping review findings highlight that people aged 16–25 with ADHD are an underrepresented population in research into DHIs. By enhancing DHIs using social support groups, we may be able to develop more acceptable DHIs which meet the unique needs of this population. In addition, DHIs as information resources may be optimised by avoiding written text and by using multimodal communication methods. Lastly, people with lived experience may value more signposting from their GPs to information resources, as GPs act as a credible source of information. Thus, interventions also need to be acceptable to GPs to ensure they are willing to prescribe or signpost patients towards them. Further research is required to evaluate and understand the preferences of stakeholders with regards to information resources, and RCTs are necessary to improve the robustness of the evidence base for using DHIs to help people aged 16–25 self-manage their ADHD.

Abbreviations

ADHD   Attention deficit hyperactivity disorder
DHI   Digital health intervention
NHS   National Health Service
GP   General practitioner
ICB   Integrated care board
MAP   Mapping ADHD services in primary care
CI   Confidence interval
RCT   Randomised controlled trial

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s44247-024-00129-1.

Additional file 1. Additional scoping review methods A – Scoping review full search strategy, B – Full inclusion and exclusion criteria for identified studies, C – PRISMA flow diagram of search and screening results.

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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Declarations

Ethics approval and consent to participate
The project was given ethical approval by the Yorkshire and the Humber – Bradford Leeds Research Ethics Committee (Reference: 22/YH/0132). All survey participants gave informed consent to participate and informed consent for their data to be used in this study. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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