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Title

Support for primary care prescribing for adult ADHD in England: national survey

Authors

Anna Price¹, Kieran Becker¹, John Ward^{1,2}, Obioha C. Ukoumunne³, Rebecca Gudka¹, Anita Salimi¹, Faraz Mughal⁴, G.J. Melendez-Torres¹, Jane R Smith¹, Tamsin Newlove-Delgado¹,

Affiliations

¹University of Exeter Medical School, Exeter, EX1 2LU, UK

²Department of Psychiatry, University of Oxford

³NIHR Applied Research Collaboration South West Peninsula, University of Exeter, Exeter, EX1 2LU, UK.

⁴School of Medicine, Keele University, Staffordshire, ST5 5BG

Corresponding author

Dr Anna Price, NIHR Three Research Schools Mental Health Career Development Fellow & Senior Research Fellow (PhD)

ORCID: <https://orcid.org/0000-0001-9147-1876>

Co-authors qualifications, job titles & ORCID IDs:

Kieran Becker, Research Assistant (<https://orcid.org/0009-0002-8813-0258>)

Dr John Ward, Clinical Research Fellow (MBBS) (<https://orcid.org/0000-0002-9108-7900>)

Dr Obioha Ukoumunne, Professor in Medical Statistics (PhD) (ORCID ID: <https://orcid.org/0000-0002-0551-9157>)

Rebecca Gudka, Graduate Research Assistant (BSc) (ORCID ID: <https://orcid.org/0009-0008-6761-0950>)

Anita Salimi, Research Advisory Group member (BSc) (No ORCID ID available)

Dr Faraz Mughal, NIHR Doctoral Fellow & GP (MBChB DCH MPhil FRCGP) (<https://orcid.org/0000-0002-5437-5962>)

Professor G.J. Melendez-Torres, Professor of Clinical and Social Epidemiology (DPhil MPH RN PFHEA NTF FFPH FAAN) (<https://orcid.org/0000-0002-9823-4790>)

Dr Jane Smith, Senior Lecturer in Primary Care (PhD) (<https://orcid.org/0000-0001-5658-9334>)

Dr Tamsin Newlove-Delgado, Associate Professor and Honorary Consultant in Public Health (PhD) (<https://orcid.org/0000-0002-5192-3724>)

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Abstract

Background: Attention deficit hyperactivity disorder (ADHD) is a common neurodevelopmental disorder with effective pharmacological treatments that improve symptoms and reduce complications. NICE guidelines recommend primary care practitioners prescribe medication for adult ADHD under shared care agreements with adult mental health services (AMHS). However, provision remains uneven, with some practitioners reporting a lack of support.

Aim: This study aimed to describe supportive elements (prescribing, shared care, AMHS availability) of primary care prescribing for adult ADHD medication in England, to inform service improvement and improve access for this underserved population.

Design and Setting: Three interlinked cross-sectional surveys asked every integrated care board (ICB) in England (Commissioners), and convenience samples of healthcare professionals (HP) and people with lived experience (LE), about elements supporting pharmacological treatment of ADHD in primary care.

Method: Descriptive analyses used percentages and confidence intervals to summarise responses by stakeholder group. Variations in reported provision and practice were explored and displayed visually using mapping software.

Results: Data from 782 respondents (42 Commissioners; 331 HP; 409 LE) revealed differences in reported provision by stakeholder group, including for prescribing (94.6% of HP vs 62.6% of LE). Over 40% of respondents reported extended AMHS waiting times of two years or more. There was some variability by NHS region, for example London had highest rates of HP reported prescribing (100%), and lowest reported extended waiting times (25.0%).

Conclusion: Elements supporting appropriate shared care prescribing of ADHD medication via primary care are not universally available in England. Co-ordinated approaches are needed to address these gaps.

Keywords

ADHD, Primary Health Care, GPs, Survey, Prescribing, Shared care.

How this fits in

Improved management of ADHD in primary care has been proposed as part of the solution to the current 'failure of healthcare' for people with ADHD in England. However, general practitioners (GPs) and other primary care professionals need better support from mental health specialists to be able to provide shared care prescribing of ADHD medication in line with UK guidelines. This research summarises stakeholder reported availability of the elements necessary for supported and appropriate shared care prescribing via primary care. Any reorganisation of healthcare needs to ensure GPs are properly supported to prescribe for patients with ADHD, especially in areas of the country with high levels of unmet need.

Introduction

ADHD and Prescribing

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder that affects 5-7% of children and adolescents (1, 2) and 2-5% of adults (3, 4). It is defined by patterns of hyperactivity, impulsivity and/or inattention which interfere with functioning in daily life, adversely impacting multiple life domains including physical and mental health, relationships, work, and education (5, 6). Higher ADHD prevalence is associated with economic disadvantage and may lead to greater demands on services in some areas (7). Despite pharmacological treatments with substantial evidence of reductions in risks of depression, suicidality, aggression, criminality, and substance use disorders (8-12), services for ADHD remain insufficient in many regions of the UK. Insufficient services for ADHD are associated with high long-term social, health, personal and economic costs (13). Failure to access pharmacological treatment for those that need it, can have severe impacts for families struggling to manage ADHD, with high emotional and financial costs (13). Understanding (and ultimately improving) prescribing practices has the potential to benefit the lives of patients and their communities across multiple domains (14).

Shared Care Challenges

The National Institute for Health and Care Excellence (NICE) guidelines for treatment and management of ADHD state that after titration by a mental health 'specialist', prescribing, and monitoring of ADHD medication should be carried out under 'shared care' protocol arrangements with primary care (15). Shared care, a formal local agreement between the specialist and general practitioner (GP), enables GPs to share responsibility for safe prescribing and monitoring of specialist medicines. However, evidence suggests GPs may not feel supported to prescribe under shared care, with challenges including inadequate adult mental health services (AMHS) provisions and insufficient prescribing guidance (16-18). GPs may refuse a shared care agreement if they are not happy with the burden of responsibility and perceived risk (17, 18). Perhaps unsurprisingly, patients report multiple challenges accessing prescriptions for ADHD medication, with access dependent on local service contexts, whether their GP facilitates shared care, and the patient's ability to advocate for their care (19, 20). Recent UK guidance recommends development of ADHD specialisms in primary care to help address these issues (21).

Integrating Care

The organisation of UK healthcare, including structural barriers between primary and secondary care, and children's and adult services, can exacerbate existing health inequalities for people living with ADHD (13, 22-24). Barriers include difficulties securing a referral for diagnosis, associated waitlists, challenges in transitioning to adult services, difficulties in re-accessing care after dropping-out, and variability in whether GPs will prescribe (13, 24, 25). The establishment of 42 integrated care systems (ICSs) responsible for jointly planning and delivering health and care services in England (26), represents an opportunity to improve outcomes and tackle barriers that exacerbate healthcare inequalities for underserved groups, such as people with ADHD. Integrated care boards (ICBs) are now responsible for commissioning primary care services through approximately 1250 Primary Care Networks (PCNs), each covering populations of 30-50,000 patients (27). Despite some primary care data evidencing inconsistent prescribing of ADHD medication (7, 28), to date, no study has focussed

on exploring geographic variation in prescribing practice for ADHD, or factors which support successful prescribing.

Aim

This study aimed to describe the presence of elements that support primary care prescribing of adult ADHD medication across England, incorporating the perspectives of multiple stakeholders.

Method

Design

Three linked cross-sectional electronic surveys of primary care provision for people with ADHD were developed following the seven-step method for mapping services (29) to capture experiences of key stakeholders: commissioners, HP, LE. Surveys asked about prescribing, shared care, AMHS, and waiting times: see supplementary material Box S1. Content was co-designed and iteratively reviewed by MAP study research advisory groups (RAGs), to ensure stakeholder priorities were incorporated. Revisions were undertaken to reduce length (<10 minutes) and ensure accessibility. This study is linked to a wider programme of work (30).

Participants

Participants were: commissioners from every ICB in England who responded in relation to provision of NHS services in their geographic area; healthcare professionals (HP) working in primary care (e.g., GPs, practice managers, and mental health workers) who reported on provision and practice at local levels; and people with lived experience (LE) (e.g., people with ADHD, and their supporters) who responded in relation to personal experience, see Table 1. Participants had to be over 16 years old and living/working in England.

Recruitment

The commissioner survey was sent via freedom of information (FOI) requests to every ICB in England in Oct 2022. The anonymous HP and LE surveys (open for six weeks from Oct 2022) were shared via a secure online survey tool, Qualtrics (31), using a variety of convenience sampling techniques. Links were shared on the study website, via social media (Twitter and Facebook), and with research partners (The UK adult ADHD Network (UKAAN) and ADHD Foundation), NIHR clinical research networks (CRNs), professional contacts, and other organisations, who distributed them via their networks. Midway through data collection, underrepresented regions were identified and subsequent dissemination focussed on these areas (by targeting local CRNs and ADHD support groups) with the aim of achieving adequate representation across England. Data collection and storage was conducted in line with UK GDPR.

Table 1. Participants, with sampling method, reporting perspective, and elements of prescribing in primary care reported on.

Stakeholder group	Sampling method	Reporting perspective ¹	Elements reported on	Respondents (n)
Commissioners	Population	Across Integrated Care Board (ICB)	Adult Mental Health Services (AMHS), Waiting times, Shared care	42 (FOI team 20; Commissioning lead/manager 17; Programme lead/manager 5) ²
Healthcare professionals (HP)	Convenience	Practice level	Prescribing, AMHS, Waiting times, Shared care	331 (GPs 198; Nurses 51; Manager/Admin 34; Other ³ 44)
Patients and supporters (LE)	Convenience	Personal experience at local practice	Prescribing, AMHS, Waiting times	409 (LE_P 234; LE_S 149) ⁴

¹ Commissioners responded in relation to provision in their ICB (average patient population ~1.5 million); HP reported on provision in their practice (average number of patients ~9400); and LE reported on individual experiences (population ~1).

²FOI = Freedom of Information respondents, in commissioning roles focussed on general health, mental health, learning disability, and/or autism/neurodevelopment.

³Other' includes social prescribers, pharmacists, care co-ordinators, and health and wellbeing coaches.

⁴LE_P = people with ADHD, LE_S = supporters (parents/carers) of people with ADHD

Data analysis

Data, which comprised responses to questions on prescribing (P), availability of adult mental health services (AMHS), waiting times (WT), and shared care (SC) for people with ADHD from a range of reporting perspectives, were cleaned and analysed in Microsoft Excel and STATA (32) by KB and RG, and checked for accuracy by AP. Respondents were included in the analysis if respondents answered the first two survey questions, providing a postcode, and identifying their role. Where participants answered 'do not know' or missed a response this was treated as missing data and removed for that outcome. Percentages of respondents that reported availability of elements of prescribing practice were presented with 95% confidence intervals, allowing a comparison of reported provision between stakeholders, and by location (ICB or NHS region).

Geographic analyses were carried out using an open source Quantum Geographic Information System, (QGIS), version 3.26.3 (33) and visual maps were created to display findings. Relevant location data, such as NHS region, and longitude/latitude were obtained from postcodes, using a variety of lookup tools/files (34-36).

Results

Sample

In total, 782 responses were received from commissioners (N=42); healthcare professionals working in primary care (N=331), and people with lived experience of ADHD (N=409), located across England, see Table 1 and Figure 2.

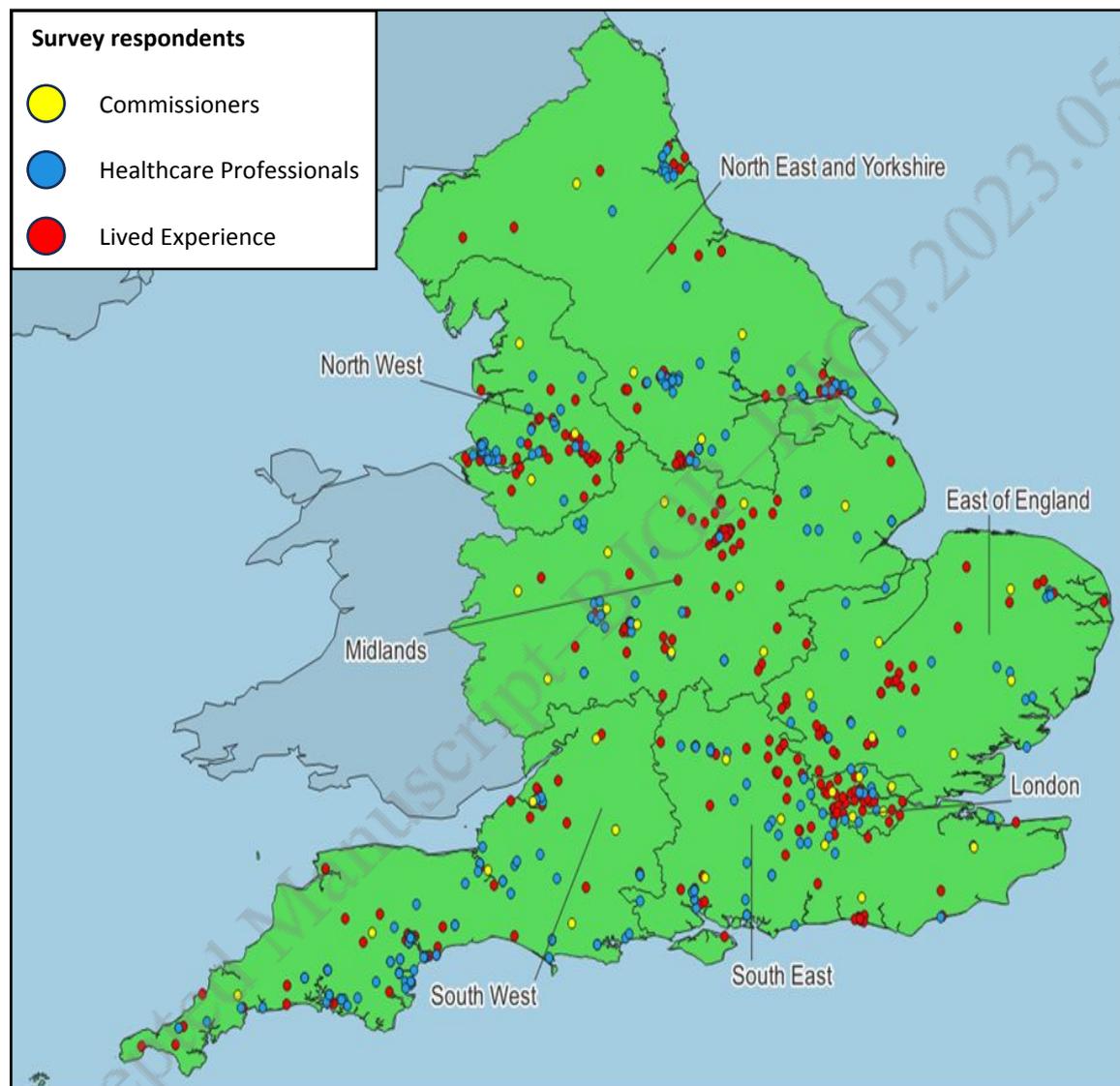


Figure 1. Map showing geographic distribution of survey respondents, by NHS region and stakeholder group.

Provision

Stakeholder reports indicate deficits in some elements necessary for appropriate and supported shared care prescribing of adult ADHD medication in primary care, with variation by stakeholder group and by NHS region (see Table 2, supplementary Table S1, and Figures 2 and 3).

Table 2. Reported availability of elements supporting shared care prescribing of ADHD medication in primary care, by stakeholder group.

Elements supporting primary care prescribing for adult ADHD	Stakeholder group	Yes % (n/d)	95% confidence interval
Prescribing of adult ADHD medication for patients with an NHS diagnosis	HP ¹	89.9 (204/227)	85.2 to 93.5
	LE ²	38.1 (74/194)	31.3 to 45.4
Prescribing of adult ADHD medication for patients with a private diagnosis	HP	49.2 (90/183)	41.7 to 56.7
	LE	39.5 (68/172)	32.2 to 47.3
Adult Mental Health Services (AMHS) available for patients with ADHD ⁴	Commissioners ³	100 (42/42)	91.6 to 100
	HP	79.2 (179/226)	73.3 to 84.3
	LE	55.5 (132/238)	48.9 to 61.9
Waiting lists for AMHS of 2 years or more	Commissioners	45.2 (14/31)	27.3 to 64.0
	HP	42.2 (65/154)	34.3 to 50.4
	LE	37.4 (43/115)	28.6 to 46.9
Shared care agreement/protocol in place to enable prescribing	Commissioners	90.2 (37/41)	76.9 to 97.3
	HP	79.4 (162/204)	73.2 to 84.7

¹HP = healthcare professionals working in primary care (N=331). ²LE = patients and their supporters (N=409).

³Commissioners of primary care (N=42). ⁴Commissioners & HP reported availability of an AMHS for ADHD in their area, LE reported experiences of a referral for ADHD.

Commissioners: Commissioners in every NHS region reported available AMHS for ADHD in their ICB, with no geographic variation. However, 45% confirmed extended waiting times for these services of two years or more. Rates of extended waiting times varied by NHS region, with the lowest in the Midlands (14.3%) and London (24%), and highest in the North West (100%). While 90% of commissioners reported at least some shared care protocols were in place, 10% (located in the Midlands, East of England, and the South East), stated they were not.

Healthcare Professionals: Prescribing for patients (with an NHS or private diagnosis) was reported by most HP, with 95% confirming any prescribing, and little observable difference by NHS region. Interestingly, HPs reported much higher rates for patients with NHS diagnoses (90%) as opposed to private (49%). AMHS for patients with ADHD were only reported by 79% of HPs, with highest rates in London (100%), and lowest in the South East (69%). Extended waiting times (two years or more) were reported by 42% of HPs, with lowest rates in London (25%), and highest in the East of England (55%). Similarly, shared care agreements/protocols were only reported by 79% of HPs, with highest rates in London (100%), and lowest in the South East (72%). See Figure 2.

Healthcare Professional Reported 'Elements of Support' for Primary Care Prescribing by NHS Region, with 95% CIs

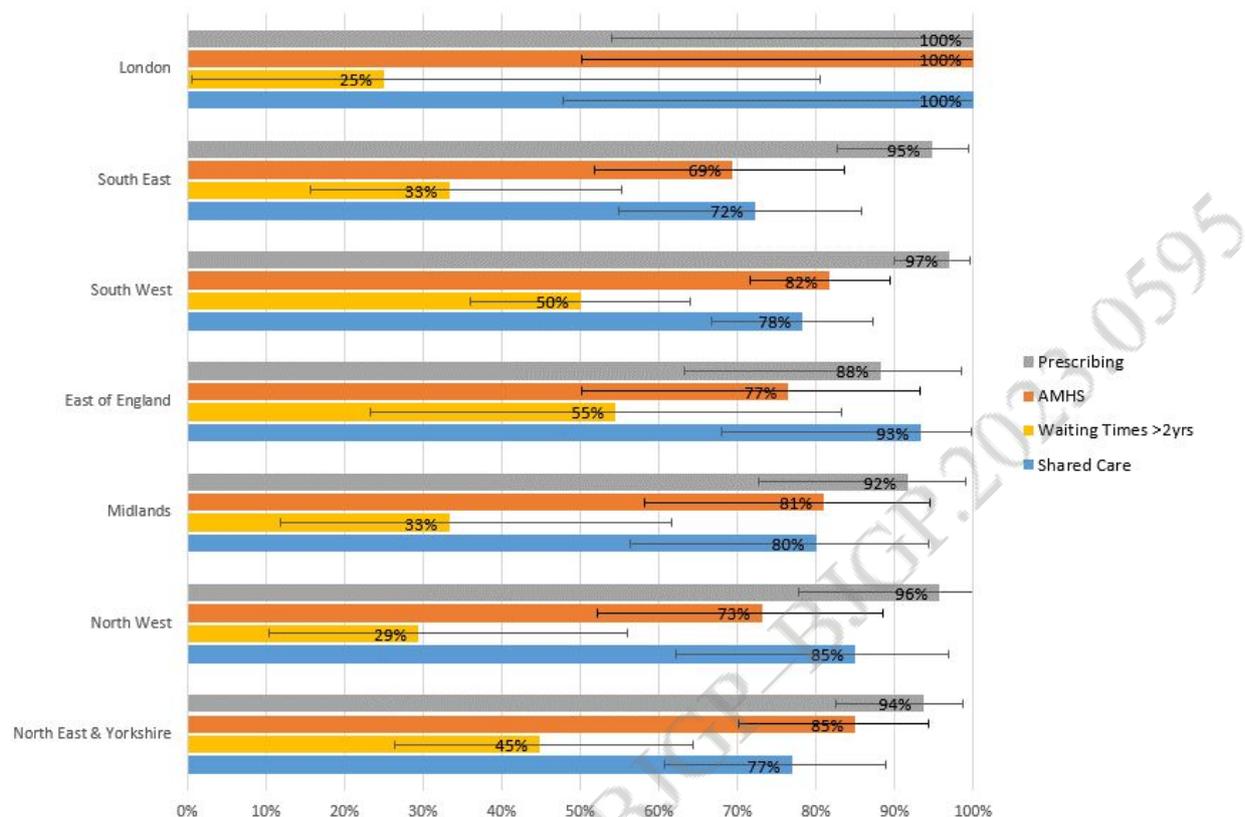


Figure 2. Proportions of healthcare professionals [N=331] reporting 'elements of support' for primary care prescribing of adult ADHD medication by NHS region, with 95% CIs.

Lived Experience: Experience of receiving prescriptions for adult ADHD medication was only reported by 54% of people with lived experience, and rates were similar for patients with NHS (38%) or private (40%) diagnoses. Proportions of LE respondents reporting prescribing were highest in London (83%), and lowest in the Midlands (56%) and South West (55%). AMHS referral for ADHD was only confirmed by 56% of LE respondents, with rates highest in London (81%), and lowest in the South West (43%) and North East and Yorkshire (39%). Extended waiting times were reported by 37% of people with LE, with lowest rates in the East of England (14%), and the highest in North East and Yorkshire (55%) and the South East (53%). See Figure 3.

Lived Experience reported 'elements of support' for primary care prescribing by NHS region, with 95% CIs

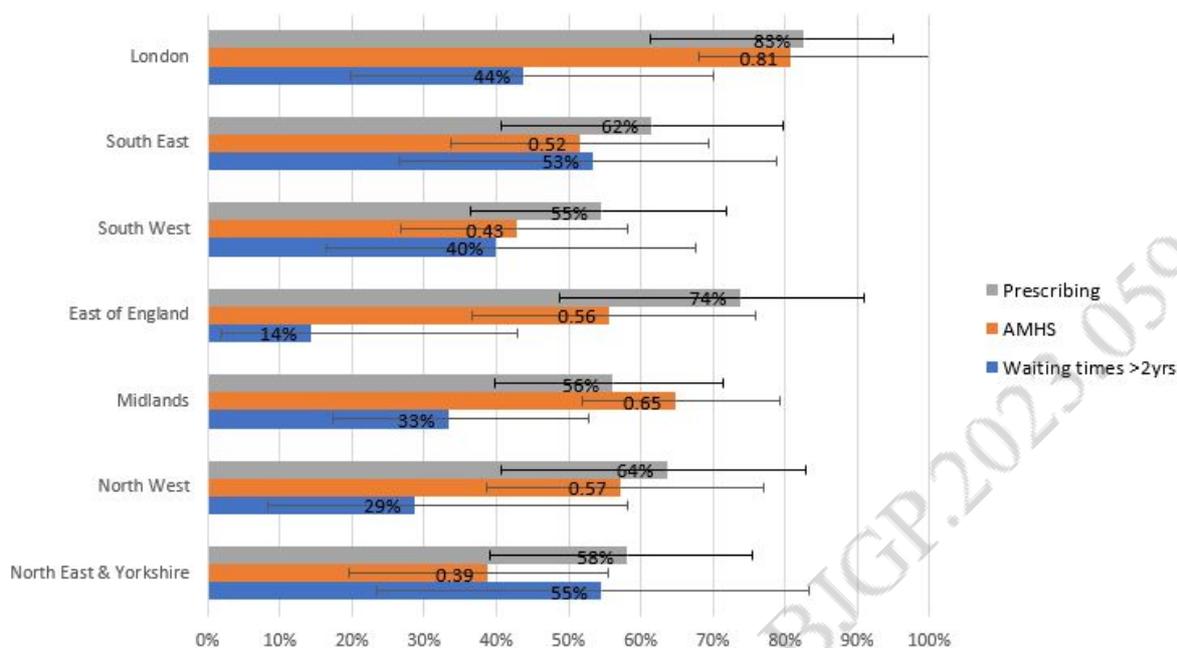


Figure 3. Proportions of patients and supporters with lived experience of ADHD [N=409] reporting 'elements of support' for primary care prescribing of adult ADHD medication by NHS region, with 95% CIs.

Stakeholder variation: There was variation between stakeholder groups in several reported elements of support, with for example, higher rates of HPs reporting prescribing of adult ADHD medication (95%), compared with LE respondents (63%). However, there was little observable difference between stakeholder reports of extended waiting times for AMHS, which were reported by 45% of commissioners, 42% of HP, and 56% of LE respondents respectively. For illustrative maps see Figure 4, and supplementary material Figures S1-S3).

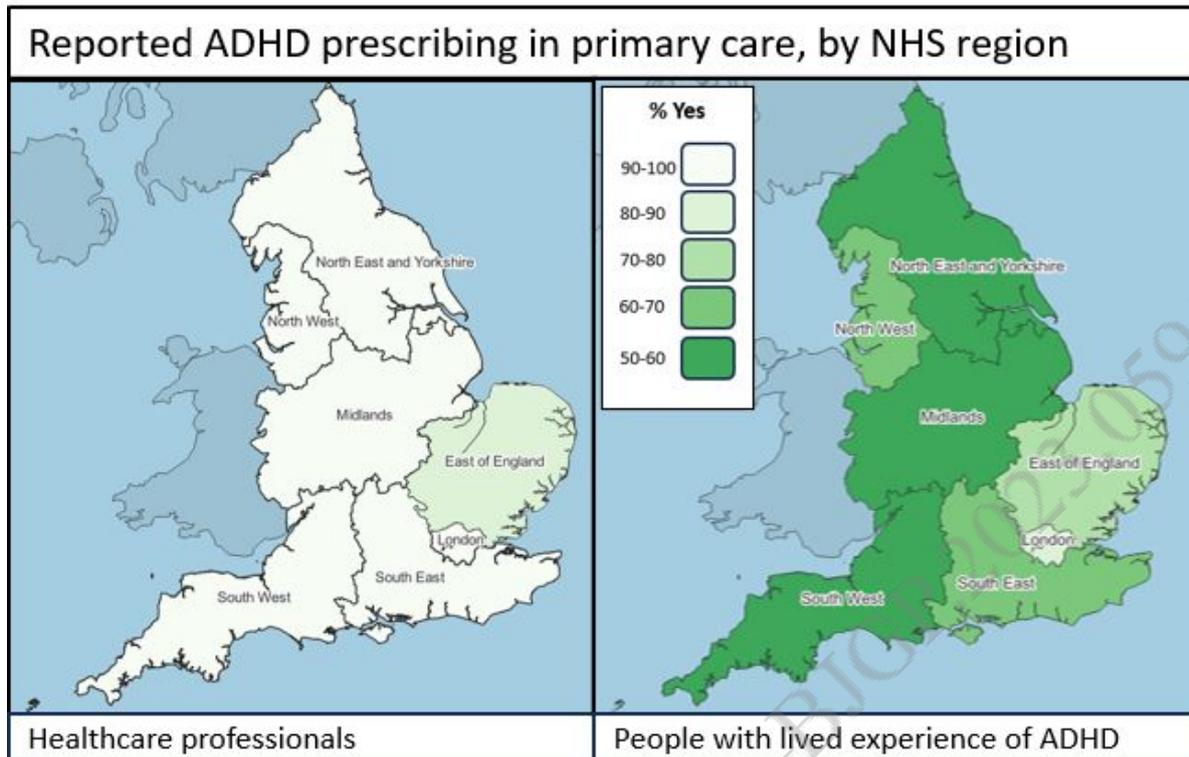


Figure 4. Maps showing proportions of respondents reporting the practice of prescribing of adult ADHD medication in primary care, by NHS region and stakeholder group (healthcare professionals N=331; people with lived experience N=409).

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Discussion

Summary

This overview of stakeholder perspectives on elements of support for primary care prescribing of ADHD medication provides a useful baseline from which to track the impact of the establishment of ICBs on delivery of the NHS equity agenda (37, 38). In relation to the NICE recommendation for shared care agreements, our findings indicate concerning gaps in provision. It is perhaps reassuring that 95% of HP reported their practices prescribed adult ADHD medication. Regional variations emphasise the importance of the mandated work of newly established ICBs to identify and address unmet need in their areas, especially given the higher rates of ADHD in more deprived populations (23, 39). While every commissioner reported an AMHS for patients with ADHD in their ICB, over 40% of respondents (across stakeholder groups) reported waiting lists of two years or more, indicating that timely support for shared care prescribing is limited.

Strengths and limitations

This study has numerous strengths, including the use of stakeholder informed mapping methodology (29), with survey design guided by stakeholder advisory groups. Use of online self-reported measures was cost effective and enabled a wide geographic spread of responses. The 100% response rate from ICB commissioners provides an authoritative overview of provision, while the convenience sample of HP and LE reflects experiences of key stakeholders (such as GPs, nurses, people with ADHD, and their supporters).

We recognise that this study has several limitations. Online data collection may exclude respondents with communication difficulties and/or without internet access. Surveys can be subject to recall bias. The convenience sample is likely to have been biased towards respondents with high levels of interest in ADHD and/or those experiencing challenges. Additionally, we did not collect detailed demographic data from participants because our priority was keeping the survey short and engaging for people with ADHD. This may prevent us from generalising the results to the wider population. Future research is planned to gain a better understanding of the barriers to healthcare for underserved groups. Finally, our data only represent a snapshot of provision at the 6,000 plus GP practices in England, and relatively low response numbers by region mean any geographical comparison needs careful interpretation.

Comparison with existing literature

These data, presented through the lens of primary care, support, extend, and update existing research evidencing limited availability of AMHS health services for ADHD in the UK (16, 40), and lower than expected rates of prescribing in children, at transition, and throughout the lifespan (28, 41, 42). Reports on availability of AMHS from ICB commissioners imply provision of AMHS for ADHD in England may have improved slightly, especially when compared with just over 90% of clinical commissioning groups reporting AMHS for ADHD in 2018 (19). However, as ICBs cover a wider geographic area than CCGs, these data are not directly comparable. In addition, long waiting lists mean many AMHS are not accessible regardless of a potential improvement in provision.

Variations in reported provision accord with research using routinely collected data evidencing regional variations in prescribing of ADHD medication (28). Given that in 2012, ADHD prevalence for young people was found to be double in the most deprived compared with the least deprived areas

(7), the ICB mandate to tackle inequalities is particularly relevant for this population (38). Where services are limited or unavailable, it is often the patients without family support or resources to enable private healthcare that are most negatively impacted.

Supporting primary care providers to prescribe

Primary care plays a key role in prescribing and helping to ensure continuity of care for people with ADHD (19, 20, 43-45). However, GPs need support to feel confident to prescribe (46). Even where shared care protocols are available, GPs may be unwilling to prescribe due to concerns around robustness of diagnosis or a perception that secondary care monitoring is inconsistent or insufficient (13, 18). Qualitative studies have highlighted concerns over the balance of risk and responsibilities in prescribing for ADHD, which are particularly marked where specialist services were lacking (17).

Implications

Our findings suggest that addressing systems issues such as availability of AMHS and standardisation of shared care nationally could reduce NHS variation, and associated barriers to accessing primary care support for patients with ADHD. It is overly simplistic to conclude that GPs need to be better trained, more aware, and more willing to prescribe. One solution to reducing the burden on GPs is providing relevant information in quick, accessible formats which can be integrated seamlessly into systems which are already used in general practice. Information about individual patients needs and pathways to care should be available at the point of need, in a filtered format, placing minimal demand on GP time and energy. Future research needs to explore solutions from the perspectives of primary care professionals and people with lived experience. Digital innovations to support shared care, such as links to shared care templates and answers to frequently asked questions, might be a cost-effective solution to help primary care providers feel more supported in prescribing for patients with ADHD.

We need to support equitable healthcare provision for adults with ADHD by improving communications across the primary-secondary care interface and providing access to specialist colleagues (21, 44). This could be aided by creating standardised share care templates, and digital information resources suitable for use by providers and patients.

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Ethics: The project was given ethical approval by the Yorkshire and the Humber – Bradford Leeds Research Ethics Committee (Reference: 22/YH/0132). Informed consent was gained from all participants in line with Health Research Authority ethics.

Competing interests:

None

Data: Data is stored securely at the University of Exeter and will be made available from the lead author upon reasonable request.

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