Mapping UK mental health services for adults with Attention-Deficit/ Hyperactivity Disorder; survey findings, with an analysis of differences in reporting between stakeholder groups

Running head: Mapping UK services for adults with ADHD

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Abstract

Background: UK clinical guidelines recommend treatment of Attention-Deficit/Hyperactivity Disorder (ADHD) in adults by suitably qualified clinical teams. However, young people with ADHD attempting to transition from children's services experience considerable difficulties in accessing care.

Aims: To map the mental health services in the UK for adults who have ADHD and compare the reports of key stakeholders (people with ADHD and their carers, health workers, service commissioners).

Method: A survey about the existence and extent of service provision for adults with ADHD was distributed online and via national organisations (e.g. Royal College of Psychiatrists, the ADHD Foundation). Freedom of information requests were sent to commissioners. Descriptive analysis was used to compare reports from the different stakeholders.

Results: A total of 294 unique services were identified by 2686 respondents. Of these, 44 (15%) were dedicated adult ADHD services and 99 (34%) were generic adult mental health services. Only 12 dedicated services (27%) provided the full range of treatments recommended by the National Institute for Health and Care Excellence. Only half of the dedicated services (55%) and a minority of other services (7%) were reported by all stakeholder groups, ($p<0.001$, Fisher's exact test).

Conclusions: There is geographical variation in the provision of NHS services for adults with ADHD across the UK, as well as limited availability of treatments in the available services. Differences between stakeholder reports raise questions about equitable access. With increasing numbers of young people with ADHD graduating from children's services, developing evidence-based accessible models of care for adults with ADHD remains an urgent policy and commissioning priority.

Keywords: ADHD, Survey, Health Services, Stakeholders, UK

Introduction

The United Kingdom (UK) National Institute for Health and Care Excellence (NICE) guidelines state that the following services should be available for adults with Attention-Deficit/Hyperactivity Disorder (ADHD): transitional care, assessment and diagnostic services, drug titration, monitoring and review, and psychological treatments (1). NICE also recommends that treatment should be holistic and provided by multidisciplinary teams or clinicians with expertise in ADHD, with shared care protocols with primary care in place after titration and dose stabilisation (1). Shared care is defined as the planned joint participation of consultants and general practitioners (GPs) in the delivery of care for patients with a chronic condition (2). While there are effective, evidence-based treatments for adults who have ADHD (3), there is no consensus about the optimum organisation of health services to provide them (4). Mounting evidence suggests that despite evidence-based treatments, guideline recommendations are frequently ignored, so that adults with ADHD struggle to access appropriate healthcare (5). A recent systematic review found that a lack of available information about services for adults with ADHD, created difficulties for both referring clinicians and service users accessing treatment (6). People with ADHD are already at increased risk of poor health, social, educational and occupational outcomes, and without access to appropriate healthcare, face higher risks of negative outcomes, including substance misuse, criminality, and road traffic accidents (5, 7-9). As increasing numbers of young people with ADHD graduate from children's services, providing national information about adult services, and investigating access to care is a priority.

At the time we undertook this study, there was limited research and grey literature about the provision of services for adults with ADHD across the UK. Studies reported in the literature either covered a specific region, or described young people's experiences of transition, rather than mapping the services available for people with ADHD transitioning to mental health services for adults (10-14). In addition, studies of service availability have tended to

draw on the perspectives of one type of stakeholder, such as senior health professionals (not working in frontline services) (14), or healthcare professionals working in child or adult health services (10), rather than including perspectives of senior health-care staff, frontline staff, commissioners and service users. Surveying a range of key stakeholders minimises the likelihood that a service will be overlooked, while comparison of their reports provides important information about gaps in awareness among different groups.

As recommended by Hall et al. 2013, the study reported in this paper aimed to provide national level data on UK mental health service provision for adults with ADHD (10). We aimed to provide a geographical overview of services; details of treatment provided by dedicated National Health Service (NHS) adult ADHD services; and an exploration of differences in reports of services by key stakeholder group (commissioners, health workers and service users).

Methods

This work formed part of the '*Children and Adolescents with ADHD in Transition from Child to Adult services*' (CATCh-uS) study of transition in ADHD (15). The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects/patients were approved by the University of Exeter Medical School Ethics Committee (REC Application Number: 15/07/070). Following consultation with the research ethics committee, a statement on confidentiality and data usage was included at the beginning of the survey, with the understanding that by continuing with the survey, participants were providing informed consent for the planned anonymous use of their data.

The novel mapping methodology was developed iteratively, with extensive patient and public involvement and is reported in full elsewhere. The definitive study is described below (16).

Participants

Our sample frame was all stakeholders involved in the care process for young people needing transition from child to adult services, as well as those involved in allocating and financing local services. This included young adults and their parents/carers, members of clinical teams (such as psychiatrists, paediatricians, psychologists, GPs, nurses, practice managers, administrators) and service commissioners (Clinical Commissioning Groups in England, Health Boards in Scotland and Wales, and Health and Social Care Trusts in Northern Ireland).

Sampling strategy

Informants were purposively sampled from key stakeholder groups (service users, health workers, and commissioners) via multiple methods. Three data sources informed the service map.

- *Anonymous national online survey (convenience sample)*: links to an online survey were shared with stakeholders via emails from organisational mailing lists, newsletters, websites, and through social media. A snowballing technique was used to recruit additional stakeholders, and their organisations. The survey was open for five weeks from January 2018.
- Freedom of information (FOI) requests *(total population):* organisations responsible for commissioning, or planning and funding, NHS mental health services in the UK were sent survey questions via FOI requests in January 2018. These are legal processes that support the rights of people to gain access to information that is recorded and held by public sector organisations (17). A copy of the survey, examples of FOI requests made, and a list of key supporting organisations, are available as supplementary material.
- *Surveillance (purposive sample)*: reports of transition in ADHD services were collated from paediatricians and psychiatrists who responded to a national surveillance study on young people in need of a transition into adult services. This was run via the British Paediatric Surveillance Unit and the Child and Adolescent Psychiatry Surveillance

System from December 2016 for 12 months. Reported cases were followed up after nine months (August 2017 to August 2018).

Data collection

Survey. The brief online survey, hosted by Survey Monkey, consisted of 5 to 9 questions, dependent on user response. It collected basic demographic information, including respondents' locations (postcode or region in the UK) and respondents' links with ADHD (e.g. 'adult with ADHD' or 'Psychiatrist'), then asked for details of services they had knowledge of for adults with ADHD. Services were broadly defined as "*any mental health service for people with ADHD aged 18 and above*", with notes clarifying that this could include any "*specialist doctor or team, mental health team, clinic, charity or support group that treats or supports adults with ADHD*". Respondents identified services from a pre-populated list and could identify services that were not already listed. For every service they identified, respondents were asked to confirm whether it was somewhere that they, or someone they knew of, had "*received treatment or support …for their adult ADHD*".

FOI requests collected basic demographic information on the commissioning organisation and asked whether they commissioned "*mental health services that treat/support people with ADHD aged 18 years and above*". If yes, they were asked to provide details of services that were similar to the details requested in the survey, as well as to specify the type of service and which treatments were available.

For all NHS-provided dedicated adult ADHD services (group A; see definition below), details of provision were also checked via FOI requests to the provider (details in Supplementary information).

Surveillance study. The CATCh-uS national surveillance study collected data from child and adolescent psychiatrists and paediatricians on transition outcomes of young adults with ADHD (18). Reports of services from this study were triangulated with services already mapped with the intention of incorporating additional services, if any were reported.

Data Analysis

Sample. Informants were categorised into three main stakeholder groups, depending on their strongest link with ADHD. For example, a '*parent/carer/partner of someone with ADHD*' was categorised as a service user, while *psychiatrists* were categorised as health workers. Descriptive statistics summarised respondents' characteristics by data source, geographic location, and stakeholder group (service user, commissioner or health worker). Given the non-probabilistic sampling frame, a pragmatic minimum target of 50 informants per UK NHS region was identified to ensure adequate coverage.

Data cleaning. Raw data on services were matched against existing online information by AP, and checked at least once by other members of the research team. Where details could not be matched to an existing service, they were independently checked a minimum of three times before being categorised as unidentifiable.

Services identified. All of the identified services were recorded. Services for which at least one respondent had confirmed experience of treatment for their ADHD as an adult, were categorised into the following three groups:

A. NHS dedicated services for adults with ADHD
B. Non-dedicated NHS services for adults with ADHD
C. Other services that work with adults with ADHD (including NHS provision for children, charity/voluntary and private)

Services were defined as dedicated if they had 'ADHD' or 'neurodevelopmental' in the service name. The term 'dedicated' was used rather than 'specialist' so that generic NHS services with named clinics with dedicated time for adults with ADHD would be included. Service locations were plotted onto a map of the UK, using QGIS 2.18 (19) and uploaded onto a Google 'My Map' to provide a visual summary of service availability and to communicate findings with stakeholders. The balance of responses by UK region and stakeholder group was similarly mapped.

Stakeholder perspectives. For each service, a descriptive summary was created of the stakeholder groups, and combinations of stakeholder groups, that had identified that service. The percentages of services identified by stakeholder group, and for each service type, were summarised and tabulated. The association between stakeholder type and service reporting was tested using Pearson's Chi-Squared. Differences between combinations of stakeholders reporting services were tested using Fisher's exact test, and overlap was displayed using Venn diagrams.

Results

Informants

In total, 2,686 reports of services were included in the study: 73% (n=1946) were from health workers, 17% (n=461) from service users, 8% (n=216) from commissioners, and 2% (n=63) from others such as educational practitioners or researchers.

Most reports of services (n=2158, 80%) were obtained from the online survey, compared with commissioners responding to FOI requests (n=213, 8%) and the surveillance study (n=315, 12%). Of the 236 organisations sent FOI requests, 213 (90%) responded. Response rates to questionnaires for the surveillance study were also high (79% at baseline, 82% at follow-up). The minimum of 50 informants per UK NHS region reports was reached for every region except Wales, where 40 reports were received. For a geographic overview of the locations of informants, see Figure 1. A more detailed breakdown of the sample by data source and stakeholder identity is available in the CATCh-uS study report (20).

Services

In total, 294 unique services were identified, with 254 services for which informants confirmed experience of treatment or support for an adult with ADHD (see table 1.)

Table 1. Services for adults with ADHD; by group and service type

Services for adults with ADHD, by group	Service type	Number of services	Total
A. Dedicated NHS services for adults	NHS Adult ADHD	29	
	NHS Adult ADHD & ASD	7	
	NHS Adult Neurodevelopmental	8	44 (17%)
B. Non-dedicated NHS services for adults	NHS 0-25 Service	2	
	NHS Adult ASD	2	
	NHS Adult Drug & Alcohol	1	
	NHS AMH CMHT	70	
	NHS Health & Social Care	1	
	NHS Adult Learning Disability	17	
	NHS AMH & Learning Disability	2	
	NHS AMH Primary Care	2	
	NHS AMH Prison & Custody	2	99 (39%)
C. Other services for adults with ADHD	Charity/Voluntary	15	
	Charity/Voluntary (Support Group)	24	
	NHS Child ADHD Specialist	3	
	NHS Child Neurodevelopmental	3	
	NHS Generic Child	26	
	Private	36	
	Private (Social Enterprise)	4	111(44%)

NHS = National Health Service; AMH = adult mental health; ADHD = attention-deficit/ hyperactivity disorder; ASD = autistic spectrum disorder; Child = child & adolescent mental health or paediatric service (for under 18 years); CMHT = community mental health team

Dedicated services. Responses to FOI requests checking details of provision at the 44 dedicated NHS services for adults with ADHD (group A), were received from 89% (31/35) of providing organisations. Responses indicated that only 12 services (27%) offered the range of interventions specified by NICE (1). Services were most likely to offer medication management, shared care or ongoing prescribing (n =39, 89%) and diagnostic assessment (n=36, 82%); while psychological treatment (n=22, 50%) and transitional care (n=26, 59%) were less frequently reported. Two services (5%) reported an upper age limit of 65 years, and almost a third (n=13, 30%) reported that patients from outside their commissioned area

might be able to access treatments in that service. Figure 1 illustrates the uneven distribution of NHS dedicated services for adults with ADHD across the UK.

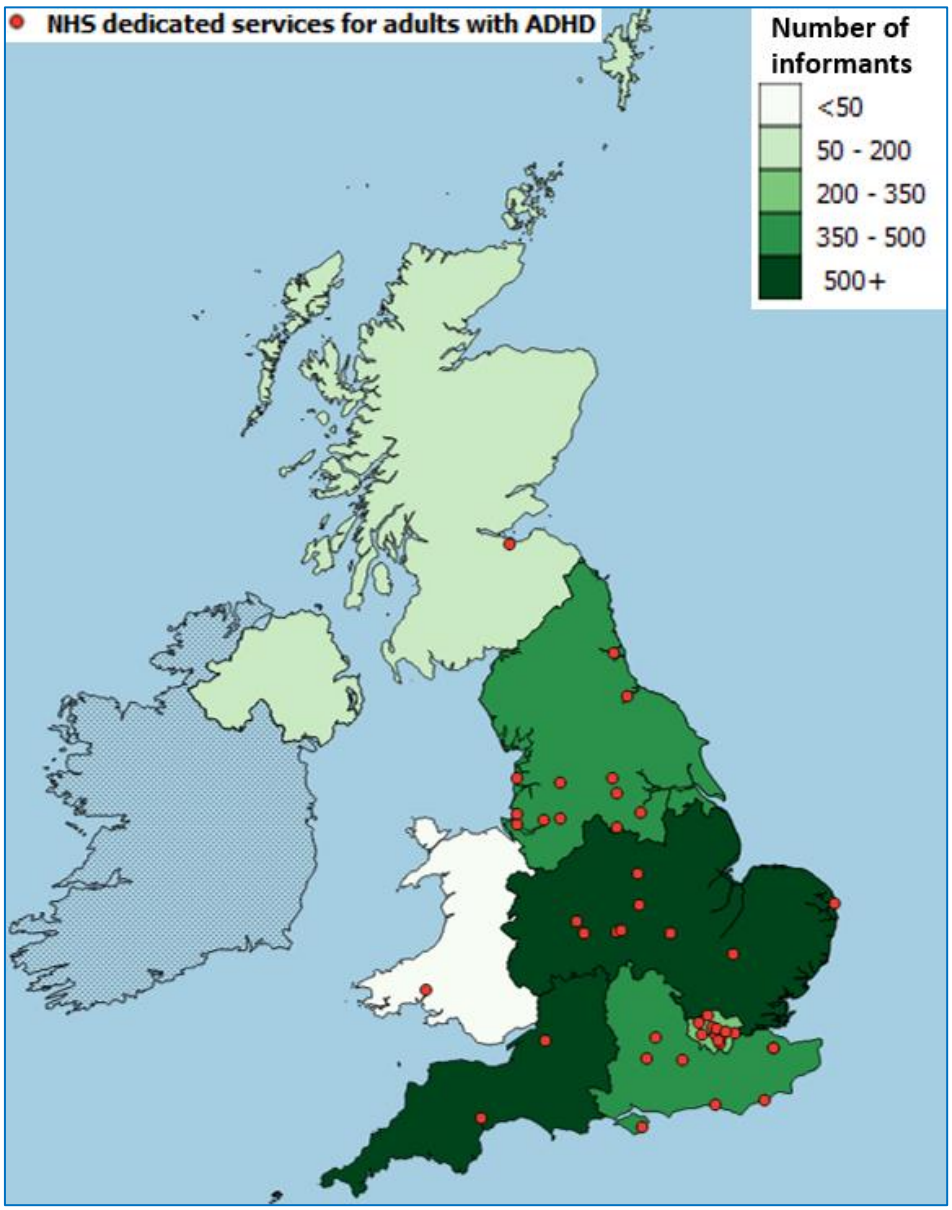

Figure 1. Numbers of mapping study informants per NHS region; and locations of 44 *NHS dedicated services for adults with ADHD* in the UK (group A), as identified by study informants.

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227 *Stakeholder perspectives*

228 Table 2 provides a descriptive summary of service reporting by stakeholder group and
229 combination of stakeholder groups, while Figure 2 indicates the overlap, or lack thereof,
230 between their reports of different levels of service provision.

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Table 2. Numbers of services identified by service users, health workers and commissioners; and combinations of stakeholder groups identifying services: by service group

Service group	Number of services	Total number of services identified by each stakeholder group (%)			Number of services, as identified by different combinations of stakeholder groups (%)							
		SU	HW	Co	SU, HW+Co	SU+HW	SU + Co	HW+Co	SU	HW	Co	Other
Group A	44	25 (57%)	38 (86%)	41 (93%)	24 (55%)	1 (2%)	0 (0%)	11 (24%)	0 (0%)	2 (5%)	6 (14%)	0 (0%)
Group B	99	23 (23%)	89 (90%)	34 (34%)	7 (7%)	15 (15%)	0 (0%)	18 (18%)	1 (1%)	49 (50%)	9 (9%)	0 (0%)
Group C	111	42 (38%)	90 (81%)	17 (15%)	7 (6%)	22 (20%)	0 (0%)	4 (4%)	13 (12%)	57 (51%)	6 (5%)	2 (2%)

Groups: A = dedicated NHS adult; B=non-dedicated adult NHS; C=non-adult NHS, private and voluntary. Stakeholders: SU = Service users, Co = Commissioners, HW = Health workers

There were significant differences in the proportions of dedicated NHS adult (group A), non-dedicated adult NHS (group B) and other (group C) services reported by each stakeholder group; X^2 (4, N=399) = 34.29, p<0.001. Service users were marginally more likely to report group A or group C services, and less likely to report group B services; X^2 (2, N=344) = 7.13, p=0.03. Health workers reported similar proportions of group A, B and C services; X^2 (2, N=471) = 0.26, p=0.88. Commissioners were more likely to report group A services than group B or C; X^2 (4, N=399) = 34.29, p<0.001

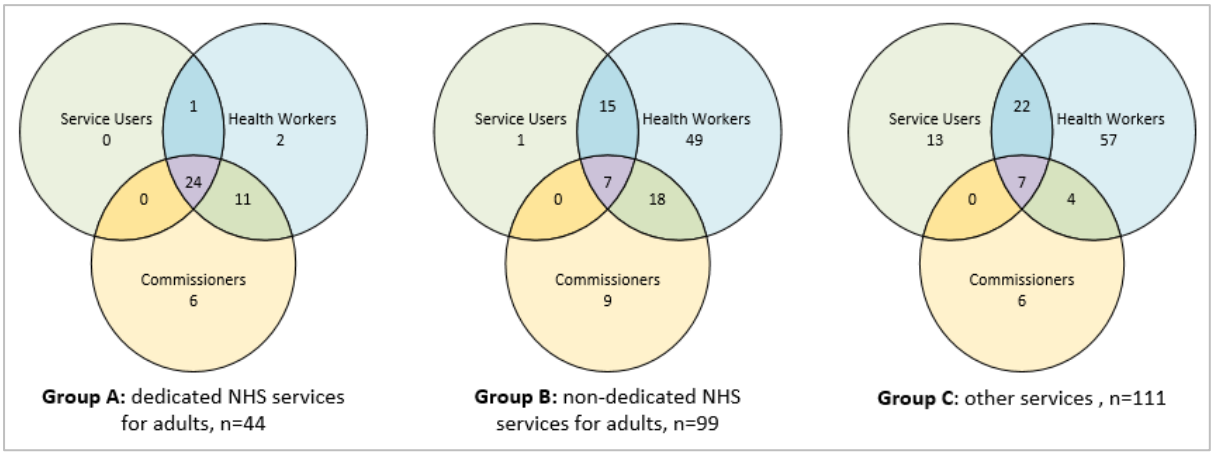

Figure 2. Venn diagrams illustrating the combinations of stakeholder groups identifying services for adults with ADHD by group

As figure 2 illustrates, a higher proportion of dedicated NHS adult (group A) services was reported by all stakeholder groups, n=24, 55%, compared with non-dedicated adult NHS (group B), n=7, 7%, and other (group C) services, n=7, 6%, (p<0.001, Fisher's exact test). The majority of non-dedicated adult NHS (group B) and other (group C) services were reported by health workers alone.

Discussion

The study reported in this paper makes a unique contribution to the research literature by presenting national-level data about the services that were available for adults who have ADHD. It highlights geographical gaps in NHS services in the UK for adults who have ADHD, shows that service provision is limited, and documents major differences in different groups of stakeholders' awareness of the services that are available. In doing so, it updates, supports and extends the existing evidence of patchy provision (10, 11, 13, 14). The significant differences in the types of services identified by stakeholders raise questions about equitable access to care for adults with ADHD, particularly in areas without dedicated services.

Service types

Gaining a clear picture of provision was not straightforward due to differences in NHS service organisation by country and region of the UK. For example, while many health services in England are funded via commissioning bodies, in other countries such as Wales, the commissioning process is often described instead as planning and financing, with the agencies responsible the same as those responsible for service delivery. Differences in the structures of the National Health Services, and how they function across the four jurisdictions, may have influenced the number of responses we had, as well as the way that services were reported.

Informants reported experiences of treatment for adults with ADHD at a range of service types. However, only 44 were 'dedicated' NHS services for adults (those with ADHD or neurodevelopmental in their name) and, of these, less than a third offered the full range of treatments recommended by the NICE guidelines (1). While treatment with medication was available at more than 80% of dedicated services, psychological treatment was only available at half. It is possible that the treatments recommended by NICE, but which were

not available at some dedicated services, were provided by other local NHS services. This seems to us to be unlikely on the basis of previous research, which suggests that patients struggle to access the full range of recommended services, including support for young people who are transitioning between services, and psychological treatments (6, 18, 21). Dedicated services did not indicate to us that they sourced these treatments for patients elsewhere, however further research could explore this explicitly.

Due to the current complexity of the organisation of services for adults with ADHD in the UK, it was difficult to assess whether a lack of a dedicated service equated to the lack of any commissioned service for adults with ADHD in that area. Existing evidence suggests that young people with ADHD may not meet referral criteria for generic adult mental health services, and there can be difficulties in accessing treatment related to a lack of training and specialist knowledge among staff (4, 6). Some stakeholders would argue that UK regions with no 'dedicated' services, represent a gap in provision of care for adults with ADHD. Although an additional 99 "non-dedicated" UK adult NHS services were identified, their existence was most commonly only reported by health workers, rather than service users or commissioners. This suggests that these services may be less accessible, with possible implications for resourcing. Existing qualitative research suggests that service users may be more satisfied with care for adults who have ADHD that they received at dedicated or 'specialist' services (22).

A surprisingly high number of "other services" were identified at which support had been experienced, including child NHS services, private and charitable services. These may represent additional choice and a richer variety of healthcare options, although this needs consideration in the context of difficulties faced by patients trying to access appropriate NHS care for adult ADHD (23). Previous research suggests that clinicians who work in NHS-provided services for children may continue to deliver treatment beyond the upper age specified for their service in locations where no service for adults is available. This may impact on the capacity to respond to younger children in need (21). There are also reports of

adults seeking privately funded healthcare when no other route to treatment is available (24) and 40 such services were reported in the present study, highlighting potentially significant out-of-pocket expenses incurred by people with ADHD. This raises concerns for the wellbeing of the most vulnerable members of the population for whom private healthcare is not an option, and who lack advocates to negotiate or navigate services on their behalf.

There is still no clear consensus on optimal models for the provision of care for adults with ADHD (4); the NICE guidelines only state that service should be provided by teams of "*healthcare professionals with training and expertise in diagnosing and managing ADHD*" (1). Future research should explore different models of service provision within primary and secondary health care services, including evaluations of their effectiveness and cost effectiveness. There is also scope for further mapping to explore the uptake and availability of shared care for ADHD, as qualitative research suggests that some young adults are treated exclusively by their GPs while others experience difficulties finding a GP willing to prescribe medication even under shared care arrangements (20). This suggests that the implementation of shared care arrangements may be highly variable.

Strengths and limitations

This research has provided the most extensive data to date about the availability of services for adults in the UK who have ADHD, and it extends existing region-specific and single source information (10, 14), by triangulating reports from a range of stakeholders. The use of FOI requests to contact commissioners ensured that staff with time and resources responded to enquiries, and proved effective, with a 90% response rate. The novel survey methodology, including collaboration with partner organisations, was a rapid and effective method of gathering reports from a range of stakeholders across the UK (16). However, while a target minimum number of responses was received from all but one UK region, the use of non-probabilistic sampling methods meant that respondents were not selected randomly. Necessarily informants would have been computer literate and interested in ADHD. It is possible that this introduced bias, with survey informants more likely to be those

who had struggled to access healthcare. The use of multiple informants and methods combined with the high number of responses mitigated the risk of bias and made it likely that the vast majority of relevant services were identified.

A clearer definition of 'dedicated' services would have improved the quality of the service map. However, given the complexity of health service provision in the UK, which made it difficult to be sure that health workers, service users and commissioners were identifying the same unit of 'service' when responding to the survey, we chose our definition to ensure that specialist teams and those generic services with practitioners with dedicated time to focus on adults with ADHD could be included on the map. The methodological decision to label services as dedicated meant that identified services comprised a range from highly specialist national and regional services, to clinicians with only a few days a month dedicated to ADHD-related work within their generic adult mental health service. Resource limitations meant that service details were only checked with providers of dedicated services, and their capacity, in terms of staffing levels, and key indicators such as waiting list times were not evaluated. During analysis, differences in service organisation by country and region of the UK made it difficult to ascertain whether an area without a dedicated service was also therefore an area without a commissioned service for adults with ADHD. Findings from the analysis of differences in reporting should be considered in the context of the balance of survey responses, with the majority of responses coming from health workers. As UK health services for adults with ADHD are continually evolving, this research provides only a snapshot in time, however this baseline map of services has been hosted by the UK Adult ADHD Network (see https://www.ukaan.org/adult-adhd-service-map), who will maintain and update it over time, so that it is a useful resource for all stakeholders.

Implications

Given the importance of continuing treatment for ADHD into adulthood where needed (5, 7, 8), the increasing numbers of young people with ADHD graduating from child services, and the existence of effective evidence based treatments (3), these data highlight the urgent

need to improve provision and access for this vulnerable population. Clearly defined, accessible and equitable services for adults with ADHD are needed, combined with better information about what is available for public and professionals. The map of services is a tangible resource to provide better quality and accessible information to all stakeholders, the lack of which has been identified as a barrier when patients need to transition into adult services (6).

Conclusions

There are geographic gaps in the availability of dedicated NHS services for adults with ADHD, as well as limited availability of the treatment options recommended in the NICE guidelines. This suggests that where someone lives will impact on whether or not appropriate treatment is available to them, which is contrary to the stated aim of the NHS of equitable access to appropriate healthcare for people with long-term conditions, and should be addressed as a matter of urgency.

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Data Availability: Data is currently stored securely by the University of Exeter Medical School, under embargo until the end of the CATCh-uS project.

References

1. NICE. Attention deficit hyperactivity disorder: diagnosis and management (NG87) 2018 [cited 2019 29th March]. Available from: https://www.nice.org.uk/guidance/ng87/chapter/Recommendations.
2. Hickman H, Drummond N, Grimshaw J. The operation of shared care for chronic disease. Health bulletin-Scottish home and health department. 1994;52:118-.
3. Bolea-Alamanac B, Nutt DJ, Adamou M, Asherson P, Bazire S, Coghill D, et al. Evidence-based guidelines for the pharmacological management of attention deficit hyperactivity disorder: update on recommendations from the British Association for Psychopharmacology. J Psychopharmacol. 2014;28(3):179-203.
4. Coghill D. Organisation of services for managing ADHD. Epidemiol Psych Sci. 2017;26(5):453-8.
5. Kooij JJS, Bijlenga D, Salerno L, Jaeschke R, Bitter I, Balazs J, et al. Updated European Consensus Statement on diagnosis and treatment of adult ADHD. Eur Psychiatry. 2019;56:14-34.
6. Price A, Janssens A, Woodley AL, Allwood M, Ford T. Review: experiences of healthcare transitions for young people with attention deficit hyperactivity disorder: a systematic review of qualitative research. Child Adolesc Ment Health. 2019;24(2):113-22.
7. Lichtenstein P, Halldner L, Zetterqvist J, Sjolander A, Serlachius E, Fazel S, et al. Medication for attention deficit-hyperactivity disorder and criminality. N Engl J Med. 2012;367(21):2006-14.
8. Chang Z, Lichtenstein P, D'Onofrio BM, Sjolander A, Larsson H. Serious transport accidents in adults with attention-deficit/hyperactivity disorder and the effect of medication: a population-based study. JAMA Psychiatry. 2014;71(3):319-25.
9. Young S, Gudjonsson G, Chitsabesan P, Colley B, Farrag E, Forrester A, et al. Identification and treatment of offenders with attention-deficit/hyperactivity disorder in the prison population: a practical approach based upon expert consensus. BMC Psychiatry. 2018;18(1):281.
10. Hall CL, Newell K, Taylor J, Sayal K, Swift KD, Hollis C. 'Mind the gap'--mapping services for young people with ADHD transitioning from child to adult mental health services. BMC Psychiatry. 2013;13:186.
11. Edwin F, McDonald J. Services for adults with attention-deficit hyperactivity disorder: national survey. Psychiatric Bulletin. 2018;31(8):286-8.
12. Taylor N, Fauset A, Harpin V. Young adults with ADHD: an analysis of their service needs on transfer to adult services. Arch Dis Child. 2010;95(7):513-7.
13. Zaman R, Arif M, Vaze A, Müller U. Setting up adult ADHD service in the United Kingdom. Cutting Edge Pschychiatry in Practice. 2012;1:170-5.
14. Hall CL, Newell K, Taylor J, Sayal K, Hollis C. Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: a national survey of mental health trusts in England. J Psychopharmacol. 2015;29(1):39-42.
15. Ford T, Janssens A, Paul M, Ani C, Young S, Newlove-Delgado T. Study Protocol: Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (Catch-uS): a mixed methods project using national surveillance, qualitative and mapping studies: NIHR; 2015 [Available from: https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/142152/#/documentation.
16. Price A, Janssens A, Dunn-Morua S, Eke H, Asherson P, Lloyd T, et al. Seven steps to mapping health service provision: lessons learned from mapping services for adults with Attention-Deficit/Hyperactivity Disorder (ADHD) in the UK. BMC Health Serv Res. 2019;19.
17. Information Commissioners Office. The Guide to Freedom of Information 2016 [Available from: http://www.legislation.gov.uk/ukpga/2000/36/contents.
18. Eke H, Ford T, Newlove-Delgado T, Price A, Young S, Ani C, et al. Transition between child and adult services for young people with attention-deficit hyperactivity disorder (ADHD): findings from a British national surveillance study. The British Journal of Psychiatry. 2019:1-7.

19. QGIS Development Team. QGIS Geographic information system, version 2.18. Open Source Geospatial Foundation Project. http://qgis.osgeo.org2018.
20. Janssens A, Eke H, Price A, Newlove-Delgado T, Blake S, Ani C, et al. Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (Catch-uS): a mixed methods project using national surveillance, qualitative and mapping studies Health Services and Delivery ResearchIn preparation [cited 2019 29th March]. Available from: https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/142152/#/.
21. Young S, Adamou M, Asherson P, Coghill D, Colley B, Gudjonsson G, et al. Recommendations for the transition of patients with ADHD from child to adult healthcare services: a consensus statement from the UK adult ADHD network. BMC Psychiatry. 2016;16:301.
22. Matheson L, Asherson P, Wong IC, Hodgkins P, Setyawan J, Sasane R, et al. Adult ADHD patient experiences of impairment, service provision and clinical management in England: a qualitative study. BMC Health Serv Res. 2013;13:184.
23. Belling R, McLaren S, Paul M, Ford T, Kramer T, Weaver T, et al. The effect of organisational resources and eligibility issues on transition from child and adolescent to adult mental health services. J Health Serv Res Policy. 2014;19(3):169-76.
24. Wong IC, Asherson P, Bilbow A, Clifford S, Coghill D, DeSoysa R, et al. Cessation of attention deficit hyperactivity disorder drugs in the young (CADDY)--a pharmacoepidemiological and qualitative study. Health Technol Assess. 2009;13(50):iii-iv, ix-xi, 1-120.