

# Involvement of community paediatricians in the care of children and young people with mental health difficulties in the UK: implications for case ascertainment by child and adolescent psychiatric, and paediatric surveillance systems

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## ABSTRACT

**Objective** To ascertain the extent to which community paediatricians are involved in the care of children with mental health conditions in order to determine which difficulties are appropriate for single or joint surveillance by the British Paediatric Surveillance Unit (BPSU) and Child and Adolescent Psychiatry Surveillance System (CAPSS).

**Design** An online survey of the 1120 members of the British Association of Community Child Health (BACCH) working in 169 Community Child Health (CCH) services in the UK.

**Results** A total of 245 community paediatricians responded to the survey. This represents 22% of members of BACCH but likely to have covered many of the 169 CCH units because participants could respond on behalf of other members in their unit. The survey showed that children and young people (CYP) with neurodevelopmental conditions presented more frequently to paediatricians than to Child and Adolescent Mental Health Services (CAMHS). In addition, a sizeable proportion of CYP with emotional difficulties presented to paediatricians (eg, 29.5% for anxiety/obsessive compulsive disorder (OCD), and 12.8% for depression)—mainly due to difficulty with accessing CAMHS. More than half of the community paediatricians are involved in the care of CYP with anxiety and OCD, while 32.3% are involved in the care of those with depression.

**Conclusion** There is significant involvement of community paediatricians in the care of CYP with mental health conditions. Involvement is highest for neurodevelopmental conditions, but also significant for CYP with emotional difficulties. The implication of the findings for surveillance case ascertainment is that joint BPSU and CAPSS is recommended for surveillance studies of neurodevelopmental conditions. However, for emotional disorders, single or joint surveillance should be made based on the specific research question and the relative trade-offs between case ascertainment, and the additional cost and reporting burden of joint surveillance. Single

## What is known about the subject?

- The British Paediatric Surveillance Unit (BPSU) and Child and Adolescent Psychiatric Surveillance System (CAPSS) study uncommon childhood conditions.
- BPSU and CAPSS conduct single or joint studies based on assumptions about whether the conditions overlap, but these assumptions have not been formally tested.
- Understanding the involvement of community paediatricians in caring for children with mental illnesses can improve decisions about joint or single BPSU and CAPSS surveillance.

## What this study adds?

- Community paediatricians are highly involved in caring for children with neurodevelopmental conditions, and to some degree those with emotional difficulties, but minimally for psychosis.
- Joint BPSU and CAPSS surveillance of neurodevelopmental conditions is required to maximise case ascertainment but CAPSS-only surveillance is appropriate for psychosis and bipolar disorder.
- Surveillance studies of emotional disorders could be joint BPSU and CAPSS or CAPSS-only depending on the specific research question.

CAPSS studies remain appropriate for psychosis and bipolar disorder.

## INTRODUCTION

Epidemiological studies are important for understanding disease trends and planning services.<sup>1</sup> Large scale epidemiological studies

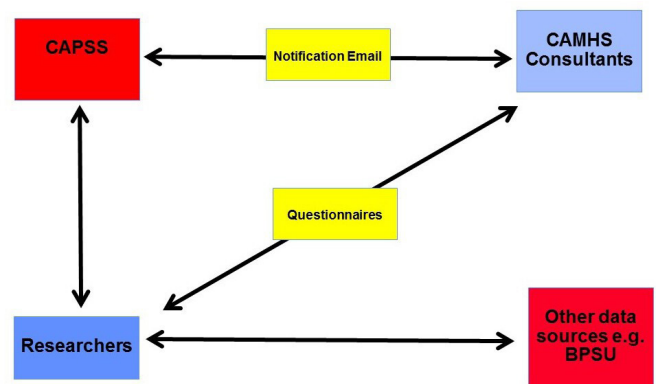
help to determine reliable population estimates of common health conditions. However, for less common disorders, large epidemiological studies may not identify enough cases to enable the required analyses. For example, despite a very large representative sample size of 9117 children, the 'Mental Health of Children and Young People in England Survey' stated that the 'sample was too small to reliably detect change in a low prevalence condition.'<sup>2</sup> Therefore, using typical epidemiological surveys to study uncommon conditions may require prohibitively large sample sizes that would render such studies unaffordable and impractical.

On the other hand, surveillance methodology provides a cheaper and more efficient alternative epidemiological approach to studying uncommon conditions.<sup>1</sup> This methodology was pioneered by the British Paediatric Surveillance Unit (BPSU) in 1986.<sup>3</sup> The BPSU has so far conducted 120 surveillance studies,<sup>3</sup> many of which have had important policy impact.<sup>4</sup> Indeed, this surveillance strategy developed by the BPSU has been referred to as a success story of modern paediatrics.<sup>4</sup> The success has led to its replication for paediatric research in many countries (Lynn and Reading). Also, similar methodology has been developed in the UK for obstetrics and gynaecology, ophthalmology, and child and adolescent mental health.<sup>3</sup> The latter is referred to as the Child and Adolescent Psychiatric Surveillance System (CAPSS) ([https://www.rcpsych.ac.uk/docs/default-source/default-document-library/capss-10-year-report-final.pdf?sfvrsn=e3402268\\_2](https://www.rcpsych.ac.uk/docs/default-source/default-document-library/capss-10-year-report-final.pdf?sfvrsn=e3402268_2)).

Although surveillance methodology is typically applied to uncommon disorders, the strategy can equally be used to study aspects of common conditions. Examples include rare events associated with common conditions or practices such as the incidence of neuroleptic malignant syndrome associated with use of antipsychotic medications. Surveillance strategy can also apply to studies of uncommon subtypes of common conditions such as obsessive compulsive disorder (OCD) related to paediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS).

The principle of surveillance methodology is described in detail elsewhere<sup>5 6</sup> and illustrated in [figure 1](#). Using CAPSS as example, every month, the surveillance team based at the Royal College of Psychiatrists send emails to all consultant child and adolescent psychiatrists in the UK and Ireland requesting them to report whether they have seen a new case of the condition being studied. Consultants who report that they have seen cases are contacted by the researchers (who are independent of CAPSS) to obtain the relevant research data about the case. BPSU and CAPSS operate active case surveillance, which means that consultants are also requested to report if they have not seen a case. This approach helps to monitor response rate and compliance.<sup>3</sup>

Given that incidence rate is one of the main outcomes of surveillance studies,<sup>3</sup> it is essential that the estimation of this parameter is reliable in order to have policy



**Figure 1** CAPSS surveillance research methodology. BPSU, British Paediatric Surveillance Unit; CAMHS, Child and Adolescent Mental Health Services; CAPSS, Child and Adolescent Psychiatric Surveillance System.

impact. The reliability of incidence estimates requires that case ascertainment is as complete as possible.<sup>3</sup> This is particularly crucial for less common conditions because missing a few cases can significantly skew the calculated incidence.

One of the surveillance strategies to improve case ascertainment is multiple data sourcing<sup>17</sup> such as among different professional groups who are likely to see or know of cases of the conditions being studied.<sup>3</sup> Thus, for conditions commonly seen by both paediatricians and child psychiatrists, ascertainment is improved by concurrent surveillance through BPSU and CAPSS. A joint Royal College of Paediatrics and Child Health/British Association of Community Child Health (BACCH) workforce guide identifies child mental health conditions such as attention deficit and hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) as within the roles and expertise of community paediatricians.<sup>8</sup> It is also well recognised that other mental health conditions such as eating disorders and conversion disorder require paediatric support for optimum assessment and treatment. This understanding has informed joint BPSU/CAPSS surveillance studies of eating disorders,<sup>9</sup> conversion disorder<sup>10</sup> and ADHD transition.<sup>11</sup>

The importance of joint BPSU/CAPSS surveillance is well illustrated in the conversion disorder study whereby cases reported by paediatricians and child psychiatrists had only a very small overlap of 4.2%.<sup>12</sup> This study found that surveillance of either professional group alone would have reduced case ascertainment by 59% or 36%, respectively.<sup>12</sup> This strongly underlines the importance of joint BPSU and CAPSS surveillance for better case ascertainment of conditions that commonly interface between Paediatric and Child and Adolescent Mental Health Services (CAMHS).

In addition to joint studies, both BPSU and CAPSS conduct single-unit studies for conditions that are considered to be seen almost exclusively by paediatricians (for BPSU) or child psychiatrists (for CAPSS). CAPSS has conducted single-unit studies of non-affective

psychosis,<sup>13</sup> paediatric bipolar disorder<sup>14</sup> and early onset depression. These CAPSS-only studies ran on the assumption that adequate case ascertainment is achievable for these conditions through surveillance of only child psychiatrists. It was considered that for such conditions, joint CAPSS and BPSU surveillance would achieve little additional case ascertainment at huge extra costs and increased reporting burden on paediatricians who are unlikely to see affected children.

However, while the assumption that paediatricians are not seeing children with the aforementioned types of mental health conditions appears to have face validity, this hypothesis would benefit from empirical evaluation. Although community paediatrics workforce guide<sup>8</sup> states that community paediatricians are not usually trained to assess and treat these types of mental health conditions, the document acknowledged that the underfunding of CAMHS may lead to increased pressure on community paediatricians to become involved in the management of more mental health difficulties. The latter point is hinted at by the increase in the proportion of community paediatric services that manage ADHD from 15% in 2006 to 63% in 2016.<sup>8</sup>

Thus, the first objective of this study is to ascertain the extent to which community paediatricians may be involved in the care of children with mental health conditions, the types of mental health conditions they are involved in providing care for and the reasons for their involvement. These findings could help to determine with more clarity which child and adolescent mental health conditions are appropriate for CAPSS-only surveillance and which ones justify the additional cost and effort of dual BPSU–CAPSS surveillance to maximise case ascertainment. The second objective of this study is to explore the challenges and opportunities in joint working between community paediatricians and CAMHS. However, due to space limitation, data from this second objective are not included in the current paper, but will be the subject of a separate publication. The study focused on community paediatricians because the structure of health services for children in the UK indicates that these are the paediatricians who are more likely to interface with CAMHS.<sup>8</sup> Furthermore, community paediatricians often work with children who are likely to have experienced childhood adversities that increase the risk of mental health difficulties.<sup>15</sup> Examples of such young people include children looked after by the state and those involved in adoption and fostering, and or safeguarding procedures.<sup>16</sup>

## METHODS

### Survey methods

This survey adapted questions and methodology used by an earlier CAPSS survey of consultant child and adolescent psychiatrists.<sup>17</sup> Two experienced community paediatricians and a specialist in surveillance methodology reviewed the earlier survey questions and adapted them for completion by community paediatricians. The final

version of the questionnaire was agreed by consensus. The survey included structured questions with multiple response options and one Likert rating scale. The structured questions sought information on the community paediatricians' special areas of interest, experience of joint working with CAMHS, and presentation of children and young people (CYP) with mental health conditions to their services. The community paediatricians used the Likert scale to rate the likelihood of their involvement in the assessment or care of CYP with specific mental health conditions. The response options were 'Always/mostly' (>75%), 'Sometimes' (25%–75%), 'Rarely/never' (<25%), 'Don't know' and 'Not applicable'. The structured responses are presented in the results as frequencies and percentages. Provision was made for free text comments to help to further understand the context for answers to the structured questions. Thematic content analysis was used to identify common themes within the participants' free text comments. The survey was discussed by the executive committee members of CAPSS as well as by members of the BPSU. The survey has been provided as an online supplemental appendix.

### Survey administration

The survey was distributed through the BACCH newsletters and direct mass-emailing to members via a link to the web-based tool Survey Monkey ([www.surveymonkey.com](http://www.surveymonkey.com)). Responses were obtained between December 2015 and August 2016. BACCH had a total membership of 1120 in 2015. However, in order to reduce response burden and still achieve national coverage, respondents were advised that they could choose to complete one questionnaire on behalf of their service, unit or department. There were 169 distinctly managed Community Child Health Services in the UK in 2015.<sup>8</sup>

### Patient and public involvement

This survey was carried out among clinicians and no direct patient data were required. The BPSU has a permanent patient and public involvement representative on the executive board, who provided support for the study. This is acknowledged in the paper.

## RESULTS

### Respondents' characteristics

A total of 245 community paediatricians responded to the survey. Although this represents 22% of the 1120 members of BACCH in 2015 (excluding retired, affiliate and overseas members), we believe that the responses provide a good coverage of the 169 Community Child Health (CCH) units in the UK because respondents were advised that they could choose to complete one questionnaire on behalf of their unit/service. All the respondents stated that they worked clinically in community paediatrics.

Most respondents were consultants, 177 (75.3%) but responses were also received from associated specialists,

**Table 1** Respondents' main areas of special interest

Main areas of special interest	N	%
Neurodevelopmental (including ADHD and ASD)	160	70.5
Neurodisability	114	50.2
Safeguarding/child protection	97	42.7
Behavioural paediatrics	74	32.6
Look after children	68	29.9
Fetal alcohol syndrome	40	17.6

ADHD, attention deficit and hyperactivity disorder; ASD, autism spectrum disorder.

37 (15.7%); staff grades, 9 (3.8%) and other grades of doctors such as trainees, 12 (5.1%). **Table 1** shows that the respondents' most common areas of special interests are in neurodevelopmental conditions, 160 (70.5%); neurodisability, 114 (50%); child safeguarding, 97 (42.7%) and behavioural paediatrics, 74 (32.6%).

### Joint working with CAMHS

The community paediatricians were asked about joint working with CAMHS in order to gain an understanding of how their organisation's structures might moderate their involvement in the care of CYP with mental health conditions. Less than half of the respondents (42.7%) reported that their paediatric services are part of a multi-disciplinary team or joint service with CAMHS. Thematic analysis of free text comments showed that the most common area of joint work is in the assessment and treatment of CYP with ADHD and ASD, more so for the younger age groups. This theme was mentioned 35 times. An example of a related comment is "I work closely with

CAMHS regarding children with ASD and do joint assessments for children 2½–5 years old."

### Local pathways for new presentations of child and adolescent mental health conditions

In order to explore the community paediatricians' contact with CYP with mental health difficulties at the initial part of the patient's care journey, they were asked which service(s) would a child or adolescent attend for assessment and or treatment if they present in the paediatrician's catchment area with the specific mental health conditions listed in **table 2**.

Their responses showed that, on the whole, CYP with neurodevelopmental conditions such as ASD, ADHD and Tourette syndrome present more frequently to paediatrics than to CAMHS. The difference is particularly striking for ASD whereby 93% would present to paediatrics compared with CAMHS (46.7%). The proportion for ADHD and Tourette syndrome is evenly split between paediatrics and CAMHS. Also, there is limited presentation to 'joint services' for all conditions including neurodevelopmental disorders.

The above trend is different in relation to emotional difficulties, in that, most CYP with self-harm and suicidal behaviour, depression, anxiety and OCD would present to CAMHS ( $\approx 98\%$ ). However, a sizeable proportion of CYP with these emotional difficulties may also present to paediatricians (eg, 29.5% for anxiety/OCD and 12.8% for depression). Even cases of psychosis and bipolar were reported to present to paediatricians although at very low frequencies (1.8%).

Given that the workforce guide for community paediatricians<sup>8</sup> does not recommend working with CYP presenting with the types of emotional difficulties

**Table 2** Local pathways for new presentations of child and adolescent mental health conditions\*

Child or adolescent's mental health condition	Type of service the child or adolescent would attend for assessment and or treatment		
	Paediatrics N (%)	CAMHS N (%)	A joint paediatric and CAMHS service N (%)
ASD	211 (93)	103 (46.7)	47 (20.7)
ADHD	154 (67.8)	138 (60.8)	24 (10.6)
Tourette syndrome	142 (62.6)	149 (65.6)	3 (1.3)
Learning disability	209 (92.1)	84 (37.0)	13 (5.73)
Attachment disorder	84 (37.0)	144 (63.4)	9 (4.0)
Fetal alcohol syndrome	205 (90.3)	32 (14.1)	1 (0.4)
Eating/feeding disorders	127 (56.0)	167 (73.6)	18 (7.9)
Self-harm/suicidality	34 (15.0)	223 (98.2)	3 (1.3)
Anxiety including obsessive compulsive disorder	67 (29.5)	223 (98.2)	3 (1.3)
Depression	29 (12.8)	224 (98.7)	3 (1.3)
Psychosis and bipolar disorder	4 (1.8)	223 (98.2)	3 (1.3)

\*Multiple answers allowed.

ADHD, attention deficit and hyperactivity disorder; ASD, autism spectrum disorder; CAMHS, Child and Adolescent Mental Health Services.

### Box 1 Showing some examples of comments explaining the involvement of community paediatricians in the assessment or care of children with mental health conditions

- ▶ 'It is extremely difficult to access CAMHS and so many patients with mental/emotional health concerns end up being seen by paediatricians.'
- ▶ 'Threshold for referral acceptance by CAMHS is very high so we tend to see a lot of children that would ideally be seen by CAMHS.'
- ▶ 'The Community Paediatric team is holding responsibility for a large number of children who actually require psychological or psychiatric input which is not provided.'
- ▶ 'CAMHS have very strict entry criteria and reject a lot of patients meaning that they sometimes come to paediatricians even though we don't necessarily have the appropriate skills to assess them and no support services to work with them but if CAMHS won't accept then we are seen as 'better than nothing' which is adding additional strain to our already overstretched services.'

Footnotes: CAMHS, Child and Adolescent Mental Health Services.

that would typically be seen in CAMHS, the community paediatricians' free text comments were analysed thematically to understand the reasons why such CYP are presenting to paediatric services. The overwhelming reason identified is 'difficulty with accessing CAMHS'. This concern was mentioned 59 times (which represents 24% of the participating community paediatricians). Four examples of related comments are reported in [box 1](#).

#### Involvement of community paediatricians in the assessment or care of children with mental health conditions

In order to gain further understanding about how much community paediatricians are likely to have some involvement with the care of children with mental health

conditions attending their paediatric services, they were asked to rate the likelihood of them being 'aware of' a child attending their service with the mental health conditions in [table 3](#). 'Awareness' of such cases was defined broadly to include direct clinical care for the child or involvement in multidisciplinary team discussion or supervision about the child. This broad definition is in keeping with the level of involvement required for consultants to be able to report a case for BPSU or CAPSS surveillance studies.<sup>3</sup> A consultant only needs to know enough about the case to judge whether the child meets the inclusion criteria for reporting. BPSU and CAPSS encourage consultants to report cases they 'know of', even if they believe that someone else might report the case. This practice helps to improve surveillance case ascertainment. The potential for double reporting is preferred to non-reporting because surveillance researchers are able to prevent double-counting of reported cases through a process of de-duplication.

By combining the response options of 'always' and 'sometimes', [table 3](#) shows that the vast majority of the community paediatricians (above 75%) have some involvement in the assessment or care of children with ASD, ADHD, Tourette syndrome, intellectual disability and fetal alcohol syndrome. Between 50% and 75% have some involvement in the assessment or care of children with attachment disorder, eating disorder and anxiety including OCD. About one-third (32.3%) are involved in assessment or care of children with depression, and a small proportion (8.2%) in the care of those with psychosis and bipolar disorder.

**Table 3** Respondents' involvement in the assessment or care of children with mental health conditions

Child or adolescent's mental health condition	Level of respondent's involvement*		
	Always/mostly N (%)†	Sometimes N (%)	Rarely/never N (%)
ASD	168 (76.4)	35 (15.9)	12 (5.5)
Intellectual disability	137 (62.3)	67 (30.5)	8 (3.6)
Fetal alcohol syndrome	122 (55.5)	71 (32.3)	20 (9.1)
ADHD	113 (51.4)	52 (23.6)	45 (20.5)
Tourette syndrome	69 (31.4)	74 (33.6)	59 (26.8)
Eating/feeding disorders	43 (19.6)	81 (36.8)	80 (36.4)
Anxiety including obsessive compulsive disorder	34 (15.5)	87 (39.6)	87 (39.6)
Attachment disorder	33 (15.0)	117 (53.2)	54 (24.6)
Depression	6 (2.7)	65 (29.6)	130 (59.1)
Psychosis and bipolar disorder	5 (2.3)	13 (5.9)	166 (75.5)

\*Involvement defined as 'awareness' of such as case from direct clinical care for the child or involvement in multidisciplinary team discussion or supervision about the child.

†Arranged in order of prevalence for paediatricians' involvement.

ADHD, attention deficit and hyperactivity disorder; ASD, autism spectrum disorder.



## DISCUSSION

The main objectives of this study were to ascertain the extent to which community paediatricians are involved in the care of children with mental health conditions, the types of mental health conditions they are involved in providing care for, reasons for their involvement, and the implications for case ascertainment for surveillance studies by CAPSS and BPSU. The survey found high levels of community paediatricians' involvement in the assessment and treatment of neurodevelopmental conditions, more so for ASD. The study also found a significant level of presentation of CYP with emotional difficulties to community paediatric services.

The high level of community paediatricians' involvement in the assessment and treatment of CYP with neurodevelopmental conditions like ASD and ADHD is consistent with their expertise, workforce recommendations<sup>8</sup> and established practice in the UK.<sup>18</sup> The community paediatricians appeared positive about this area of work. There was no free text comment to suggest that any of the paediatricians had concerns about supporting CYP with neurodevelopmental difficulties. Concerns were expressed only when the CYP developed comorbid emotional difficulties which required CAMHS support but this was difficult to access. This concern is consistent with the view that CYP with neurodevelopmental conditions like ADHD and ASD are best managed holistically within an integrated service model involving both paediatrics and CAMHS.<sup>19</sup>

The surveillance implication of the high presentation of neurodevelopmental conditions to community paediatrics supports the current practice of joint BPSU and CAPSS surveillance for such conditions.<sup>20</sup> This practice is exemplified by a recent joint study on ADHD transition which showed that 64% of the cases were reported by paediatricians, while 36% were by child and adolescent psychiatrists with no cases dually reported through both BPSU and CAPSS.<sup>11</sup> The high losses of case ascertainment if the study had been a single BPSU or CAPSS study is self-evident.

The community paediatricians reported a significant level of presentation of CYP with emotional difficulties to their services (eg, 29% for anxiety and OCD). The primary reason for this situation is difficulty with access to CAMHS. The survey found that unlike neurodevelopmental conditions, the community paediatricians expressed concerns that their involvement in the care of CYP with emotional difficulties is beyond their training and expertise. Many suggested that they had to offer help, because the affected CYP would otherwise have no support. The service implications of these concerns are discussed later. However, for purposes of surveillance studies, the significant presentation of CYP with emotional difficulties to community paediatric services could have implications for case ascertainment. The surveillance implication is even more significant if account is taken of the high proportion of community paediatricians who were 'aware' of CYP with emotional

difficulties in their service. The latter point is based on the fact that a consultant being 'aware of' or 'knowing of' a case is sufficient for them to make a surveillance report on the case.

The surveillance implication of the significant presentation of CYP with emotional difficulties to community paediatric services requires some nuancing. Joint BPSU and CAPSS surveillance is two times as expensive. It also tasks the goodwill of consultants in both specialties who make voluntary monthly reports about having seen or not seen cases. Maintaining the goodwill of consultants is a crucial factor in sustaining surveillance platforms. This requires careful management of the number of studies in order to prevent excessive reporting burden on consultants. These points indicate that a strong justification should be required to support joint BPSU and CAPSS studies in order to optimally balance the trade-offs between case ascertainment, cost and increased reporting burden on consultants. We recommend that in relation to emotional difficulties, the justification should depend on the specific research question. For example, while OCD is an emotional difficulty, a surveillance study of OCD presentation in the context of PANDAS would require joint BPSU and CAPSS strategy. The separate executive committees of BPSU and CAPSS can advise researchers early in the planning of a study regarding whether the research question is likely to require a single or joint surveillance.

BPSU surveillance covers all consultant paediatricians in the UK and Ireland. However, for some surveillance studies of child and adolescent mental health difficulties where the interface is more likely with community paediatricians (rather than the general body of paediatricians), a case could be made to limit the cost and reporting burden by running a joint CAPSS and BACCH study (instead of joint CAPSS and BPSU). However, there is currently no surveillance infrastructure for only BACCH members.

The very low levels of presentation of CYP with psychosis and bipolar disorder to community paediatrics support the current practice of CAPSS-only surveillance for such conditions. The additional expense and reporting burden of joint surveillance is unlikely to be justifiable for such cases. However, there could still be circumstances whereby a surveillance study of patients with psychosis may require joint BPSU and CAPSS strategy. A potential example would be a study of the incidence of neuroleptic malignant syndrome in CYP treated with antipsychotic medications.

The concern about access to CAMHS, which was raised by almost a quarter of the paediatricians, requires some brief exploration even though it is less central to the study objective covered in this paper (which is focused on the implication for surveillance case ascertainment). This challenge with CAMHS access appeared to be pervasive and it generated a lot of frustration among the community paediatricians. Some of the paediatricians indicated that they were reluctantly over-reaching their expertise

to help CYP with mental health difficulties that would normally be seen by CAMHS. Many paediatricians formulated the reason for the problem with CAMHS access as underfunding of CAMHS, leading to short staffing, long waiting times and raised referral threshold to focus on CYP with the most severe mental illnesses. Therefore, several community paediatricians suggested that the main solution is to expand CAMHS capacity. Some of the paediatricians cautioned against the type of token measures that occurred in their own catchment which involved the commissioners rebranding CAMHS without extra resources which resulted in no improvement in access. We hope that the National Health Service Long Term Plan (<https://www.longtermplan.nhs.uk/>) which has specific commitment of extra resources for CAMHS as well as commitment to closer integration of services would bring about genuine and sustained improvement in access to CAMHS.

### Strengths and limitations of the study

One of the strengths of this study is its nationwide scope and presentation of a representative sample of CCH paediatricians' workload and experience of working with CAMHS practitioners in the UK. There are however potential weaknesses of the study that require caution when interpreting the results.

The main limitation of this paper relates to uncertainty about the representativeness of the survey sample. We surveyed members of BACCH as this group of paediatricians are more likely to interface with CAMHS. However, they consisted of just over a quarter of the total UK paediatric consultant workforce of 3996 in 2015 (<https://www.rcpch.ac.uk/resources/paediatric-workforce-data-policy-briefing-2017>). Although we believe that the 245 respondents provided a good coverage of the 169 CCH units around the UK, concerns about confidentiality meant that we did not invite data that could link respondents to CCH units. Thus, the absence of information on the regional spread of the respondents as well as the age and gender distribution means that there is some uncertainty about the degree to which the findings are generalisable.

### CONCLUSION

This survey identified a significant involvement of community paediatricians in the assessment and treatment of CYP with mental health conditions. The involvement is highest in relation to neurodevelopmental conditions, and this is in keeping with the expectation and expertise of community paediatricians. However, there is also significant involvement in the care of CYP with emotional difficulties which is mainly due to lack of access to CAMHS. The implication of the findings for surveillance case ascertainment is that joint BPSU and CAPSS continues to be recommended for surveillance studies of neurodevelopmental conditions. For surveillance studies of emotional disorders, a nuanced decision about single or joint surveillance should be made based on

the specific research question and the relative trade-offs between case ascertainment, cost and reporting burden. Single CAPSS studies remain appropriate for surveillance studies of psychosis and bipolar disorder. There is urgent need to expand access to CAMHS. This would reduce the need for community paediatricians to over-reach their expertise to support CYP with mental health difficulties whose needs would be better met by CAMHS.

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**Collaborators** Michael Morton; Simon Lenton; Oana Mitrofan.

**Contributors** HFA conceived the idea. HFA, RML and TS designed the survey material, HFA, MOO and CA analysed the data and prepared the manuscript draft, HFA and RML liaised with BACCH and RML critically reviewed the manuscript. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

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**Patient and public involvement statement** This survey was carried out among clinicians and no direct patient data was required. The BPSU has a permanent PPI Representative on the Executive board, who provided support for the study. This is acknowledged in the paper.

**Patient consent for publication** Not required.

**Ethics approval** In line with current UK research governance framework, ethical approval was not required as this was a completely anonymous survey with entirely voluntary participation by persons not classified as 'vulnerable'.

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**Data availability statement** All data relevant to the study are included in the article or uploaded as supplemental information. All data relevant to the study are included in the article.

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#### REFERENCES

- Eke H, Janssens A, Downs J, *et al*. How to measure the need for transition to adult services among young people with attention deficit hyperactivity disorder (ADHD): a comparison of surveillance versus case note review methods. *BMC Med Res Methodol* 2019a;19:179.
- NHS Digital. Mental health of children and young people in England, 2017 autism spectrum, eating and other less common disorders, 2017. Available: <https://files.digital.nhs.uk/FB/8EA993/MHCYP%202017%20Less%20Common%20Disorders.pdf> [Accessed 12 Dec 2020].
- Lynn RM, Reading R, BPSU Ascertainment Group. Case ascertainment in active paediatric surveillance systems: a report from the British paediatric surveillance unit ascertainment group. *Arch Dis Child* 2020;105:62–8.
- Lynn RM, Avis JL, Reading R. *British paediatric surveillance unit 30th anniversary report: facilitating childhood rare disease research for over 30 years*. London: British Paediatric Surveillance Unit, 2016.
- Verity C, Preece M. Surveillance for rare disorders by the BPSU. *Arch Dis Child* 2002;87:269–71.
- Knowles RL, Smith A, Lynn R, *et al*. Using multiple sources to improve and measure case ascertainment in surveillance studies: 20 years of the British paediatric surveillance unit. *J Public Health* 2006;28:157–65.
- Salotti JA, Nanduri V, Pearce MS, *et al*. Incidence and clinical features of Langerhans cell histiocytosis in the UK and Ireland. *Arch Dis Child* 2009;94:376–80.
- BACCH/RCPC. Covering all bases community child health: a paediatric workforce guide. RCPC Sept 2017, London. Available: [https://www.rcpch.ac.uk/sites/default/files/2018-03/covering\\_all\\_bases\\_community\\_child\\_health\\_-\\_a\\_paediatric\\_workforce\\_guide.pdf](https://www.rcpch.ac.uk/sites/default/files/2018-03/covering_all_bases_community_child_health_-_a_paediatric_workforce_guide.pdf)
- Nicholls DE, Lynn R, Viner RM. Childhood eating disorders: British National surveillance study. *Br J Psychiatry* 2011;198:295–301.
- Ani C, Reading R, Lynn R, *et al*. Incidence and 12-month outcome of non-transient childhood conversion disorder in the U.K. and Ireland. *Br J Psychiatry* 2013;202:413–8.
- Eke H, Ford T, Newlove-Delgado T, *et al*. Transition between child and adult services for young people with attention-deficit hyperactivity disorder (ADHD): findings from a British National surveillance study. *Br J Psychiatry* 2020;217:616–22.
- Ani C, Reading R, Lynn R, *et al*. Child and adolescent psychiatry surveillance system (CAPSS): epidemiology of childhood conversion disorder in UK and Ireland. paper presented at the Royal College of paediatrics and child health conference: BPSU symposium 5th April 2011, Warwick University, UK 2011.
- Tiffin PA, Kitchen CEW. Incidence and 12-month outcome of childhood non-affective psychoses: British National surveillance study. *Br J Psychiatry* 2015;206:517–8.
- Sharma A, Neely J, Camilleri N, *et al*. Incidence, characteristics and course of narrow phenotype paediatric bipolar I disorder in the British Isles. *Acta Psychiatr Scand* 2016;134:522–32.
- Bick J, Nelson CA. Early adverse experiences and the developing brain. *Neuropsychopharmacology* 2016;41:177–96.
- Ogundele M. Profile of neurodevelopmental and behavioural problems and associated psychosocial factors among a cohort of newly looked after children in an English local authority. *Adopt Foster* 2020;44:255–71.
- Schumm TS, Morton MJS. National survey of child and adolescent psychiatrists' clinical activity using the child and adolescent psychiatry surveillance system (CAPSS). *Archives of Disease in Childhood* 2017;102.
- Male I, Farr W, Reddy V. Should clinical services for children with possible ADHD, autism or related conditions be delivered in an integrated neurodevelopmental pathway? *Integrated Healthcare Journal* 2020;2:e000037.
- Ogundele MO, Ayyash HF, Ani C. Integrated services for children and young people with neurodevelopmental and co-morbid mental health disorders: review of the evidence. *J Psychiatry Mental Disord* 2020;5:1027.
- Ayyash HF, Ford TJ, Janssens A, *et al*. Impact of CAPSS and BPSU in identifying the imminent needs of ADHD patients in transition from children's to adults services across the United Kingdom. *Archives of Disease in Childhood* 2018;103:A 191–3.