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Extended Research Article

Enhancing referrals to Child and Adolescent Mental Health Services: the EN-CAMHS mixed-methods study

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This article

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Abstract

Background: National Health Service Child and Adolescent Mental Health Services are specialist teams that assess and treat children and young people with mental health problems. Overall, 497,502 children were referred to National Health Service Child and Adolescent Mental Health Services between 2020 and 2021, and almost one-quarter of these referrals were not successful. Unsuccessful referrals are often distressing for children and families who are turned away usually after a long waiting period and without necessarily being redirected to alternative services. The process is also costly to services because time is wasted reviewing documents about children who should have been referred for alternative help and may prevent young people who need specialist help receiving it in a timely way. The overarching aim of this study was to understand what the problems are with Child and Adolescent Mental Health Services referrals and identify solutions that could improve referral success. A key objective was to talk widely with young people and families, people working in Child and Adolescent Mental Health Services and mental health professionals so that we could understand fully what the problems were and how we might develop their solutions. We gathered individual pseudonymised patient data from nine Child and Adolescent Mental Health Services, and referral data from four National Health Service Trusts to look at what data are available and how complete it is. We report wide variation in the numbers of referrals between and within Trusts and in the proportions not being successful for treatment. Data on factors such as age and gender of children and young people referred into Child and Adolescent Mental Health Services and who made the referral are routinely collected, but ethnicity of the children and young people's reason for referral are not as well collected across all Trusts. We also conducted focus groups with over 100 individuals with differing perspectives on the Child and Adolescent Mental Health Services referral process (children and young people, parents and carers, key referrers, and Child and Adolescent Mental Health Services professionals) and asked about current difficulties within the referral process, as well as potential solutions to these.

Conclusions: Problems identified included: confusion about what Child and Adolescent Mental Health Services is for, that is what it does and does not provide; and lack of support provided during the referral process. Possible solutions included: streamlining the referral pathways through digital technologies with accompanying standardisation of referral forms for National Health Service Child and Adolescent Mental Health Services; and early ongoing communication throughout the referral 'journey' for the referrer/family.

Future work: Should consider the standardisation of and improvement to the Child and Adolescent Mental Health Services referral process following the recommendations outlined in this project.

Study registration: This study is registered on ClinicalTrials.gov with the identifier: NCT05412368. https://clinicaltrials.gov/study/NCT05412368.

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Report Supplementary Material 1 Enhancing referrals to Child and Adolescent Mental Health Services Steering Group Terms of Reference

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/GYDW4507).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

Glossary

Throughout the project, there were regular discussions with all stakeholders about the terminology used when discussing whether referrals were accepted or not accepted by Child and Adolescent Mental Health Services. The terms included:

- Rejected referral
- Failed referral
- Inappropriate referral
- Ineligible referral

Unsuccessful referral – throughout the report, referrals will be termed 'successful' that is accepted for treatment by Child and Adolescent Mental Health Services, or 'not successful' that is not accepted for treatment by Child and Adolescent Mental Health Services.

List of abbreviations

CAMHS	Child and Adolescent Mental Health Services
CYP	children and young people
GP	general practitioner
ICB	integrated care board
LD	learning disability
NASSS	Non-adoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies
NDD	neurodevelopmental disorder
NIHR	National Institute for Health and Care Research
PMG	Project Management Group
PPAG	Parents and Professionals Advisory Group
PPI	patient and public involvement
SES	socioeconomic status
SSC	Study Steering Committee
YP	young people
YPAG	Young Peoples Advisory Group

Plain language summary

National Health Service Child and Adolescent Mental Health Services are specialist teams that assess and treat children and young people with mental health problems. Overall, 497,502 children were referred between 2020 and 2021, almost one quarter of these were unsuccessful. Reasons for unsuccessful referrals include: not following the correct referral process, or because the child is not deemed to meet referral criteria. This is often distressing for children and families who are turned away, and costly to services because time is wasted reviewing referrals which should have been referred for alternative help.

The overarching aim of this study is to understand fully what the problems are and how we can develop solutions that can improve the success of Child and Adolescent Mental Health Services referrals. We analysed patient data from nine Child and Adolescent Mental Health Services, and referral data from four National Health Service Trusts to look at factors, such as age, gender and ethnicity of children and young people referred to Child and Adolescent Mental Health Services. There was wide variation in the numbers of referrals between and within Trusts and in the proportions not being successful for treatment. Problems identified included: confusion about what Child and Adolescent Mental Health Services do and do not provide; and lack of support provided during the referral process.

We also talked to over 60 individuals who have different perspectives on the Child and Adolescent Mental Health Services referral process (children and young people, parents and carers, key referrers, and Child and Adolescent Mental Health Services professionals) and asked about the current difficulties within the referral process. Next, we talked to 45 children and young people, people working in Child and Adolescent Mental Health Services and health professionals about potential solutions to improve the referral process. We shared our findings with professionals who influence policy, and at an event with young people, parents/carers, key referrers and Child and Adolescent Mental Health Services professionals to determine what we should do next. Patient and public involvement was an important aspect of this project and we had extensive input across all stages to ensure findings reflected the views of children and young people, parents and professionals.

Scientific summary

Background

In 2017, 12.1% of children and young people (CYP) aged 7–16 years had a probable mental disorder, this rose to 16.7% in 2020 and rose again to 18.0% in 2022. Almost one-quarter of referrals to Child and Adolescent Mental Health Services (CAMHS), whether referred by general practitioners (GPs), schools or parents/carers, are unsuccessful. This may be for reasons which include: not following the correct referral process, or because the child is not deemed appropriate for secondary care services within the CAMHS provision. For many children and families, who may have waited a long time for such an assessment, this may be both disappointing and distressing; particularly if they are not signposted to alternative sources of support. This is often the case, even if assessment suggests the young person is less unwell than previously thought. Unsuccessful referral into CAMHS is not without a cost: for example, services' time assessing documents for children who could have been referred for alternative help; and delays in children accessing the care they do need. We know that children are referred inappropriately to CAMHS for a variety of reasons including, but not restricted to: lack of awareness by referrers, such as GPs and schools about what CAMHS does and does not provide; lack of knowledge by referrers about other support services; referrers not completing the correct documentation.

Aim

The overarching aim of this study was to understand better the current problems with CAMHS referrals; and to identify tractable solutions that could improve referral success.

Objectives

Our objectives were to:

- Map and describe CAMHS service configurations (including service eligibility criteria).
- Map and analyse referral and inappropriate referral rates against possible Explanatory variables (e.g. age, sex, ethnicity, Index of Multiple Deprivation).
- Extensively engage CAMHS stakeholders across different sites and CAMHS providers.
- Explore what does and does not work in the current referral processes.
- Identify sustainable solutions to support more successful and appropriate Referrals in collaboration with CAMHS stakeholders.
- Identify complexities of implementing sustainable solutions across CAMHS settings.

Method

The study took parallel quantitative and qualitative approaches to examine the extent of the problem in local and Northwest regional CAMHS services, and to determine how this translated into people's experiences; and to identify realistic and implementable solutions.

Quantitative

Child and Adolescent Mental Health Services referral data between 2016 and 2020 were obtained from four NHS Trusts across the north of England. Collected data included information on the outcome of the referral (whether it was

successful or not), demographic information and clinical characteristics of the CYP and the source of the referral. These data were summarised by Trust and by locality within Trust, and then compared against national data. Referral outcome was explored over time descriptively and using logistic regression on the monthly aggregate data. The association between CYP characteristics and referral source with referral outcome was investigated by Trust using logistic regression where individual patient data was available.

Qualitative

We consulted extensively with over 100 key stakeholders from across England through a series of 20 focus groups (12 problem-focused and 8 solution-focused). The stakeholders involved in these discussions were young people, parents/carers, key referrers, for example, GPs/education professionals and CAMHS professionals themselves. Discussions in the problem-focused groups explored the pain points and difficulties which stakeholders experience throughout the referral process. These shaped the solution-focused discussions which explored potential ways to overcome some of the problems. Because we specifically wanted to explore the role of digital solutions within other possible solutions, we used category areas of the Non-adoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies framework evaluation to guide discussions with stakeholders.

Results

Child and Adolescent Mental Health Services referral data analysis:

- Generally increasing number of referrals into CAMHS since 2016.
- There is such variation between Trusts that a single number (and indeed this and the previous statement) is not reflective of the situation. There was an increase of around 10% points in Trust D and Trust B between 2016 and 2020, but a non-linear change in Trust A, so comparing 2020 with 2016 the proportion actually decreased by about 2.5% points. Differences were observed in CAMHS referral success rates between different Trusts as well as within the same Trust. This could be the result of: different referrer/patient characteristics, demographics within a location which may influence the success of CAMHS referral; or CAMHS referral processes may differ between Trusts/regions.
- GPs were the largest contributor of referrals in three out of the four trusts, on average accounting for approximately 43% of referrals.
- CAMHS is being transformed, in part through the digital transformation agenda and the introduction of the new integrated care boards (ICBs).
- Consistent data collection and reporting of CAMHS referral data are required to establish monitoring and benchmarking for future improvements and quality assessment.

Framework analysis of the focus group transcripts suggests problems within the CAMHS referral process related to: all stakeholders having different expectations of what CAMHS is and what CAMHS does, that is can/cannot provide; variability in referral processes, referral forms, and support available across CAMHS both between and within Trusts; inconsistent (and often poor) communication between stakeholders; long waiting times between referral and subsequent contact; and lack of signposting to alternative support both if a referral is unsuccessful, and while waiting for support from CAMHS.

In the solution-focused workshops, stakeholders highlighted aspects of the referral process which people feel should be changed. These included: greater transparency of stages within the referral process and what to expect at each stage; better signposting pre-referral, especially if an alternative service to CAMHS may be more appropriate for a CYP; improved communication both during the referral process and if referral is unsuccessful into CAMHS.

Conclusions

The findings from the quantitative and qualitative analyses, patient and public involvement and senior stakeholder consultations during dissemination activities identified the following as important aspects of solutions to the current problems within the referral process:

Must haves:

- Increased understanding about what CAMHS can/cannot provide.
- A nationally standardised referral process for all CAMHS.
- A mechanism for updating people during the referral process.
- Early signposting to alternatives for all referrers.
- Add in-person aspects where this is achievable at low cost (or can provide clear cost savings).

Like to haves:

- Develop a referral process that can adapt to local/regional variation in CAMHS/alternatives.
- Achieve this at low cost.
- Sustainable model of delivery.
- Co-ordination with existing systems, for example triage.
- Intelligent system – learning from data.
- Collect accurate referral data at every service to support monitoring.

A future piece of funded work aims to:

- develop a simple, clear way for children to get the right support for their mental health problems when they need it;
- explore barriers and enablers to widespread implementation of the new CAMHS referral mechanism across different referrers and CAMHS with various configurations;
- understand how it can become widely successful and therefore embedded in services nationally; and
- evaluate its potential to reduce unsuccessful referrals and the potential cost benefits to services, CYP and families.

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Chapter 1 Background

In 2022, approximately one in six young people (YP) was reported to have a probable mental disorder – a considerable increase from one in nine YP in 2017.[1] In addition, there have been steadily increasing numbers of children and young people (CYP) presenting to services with mental health symptoms, with these trends observed since before the pandemic.[2,3] In 2021–2, there was a 47% increase in the number of CYP referred to Child and Adolescent Mental Health Services (CAMHS) from 2020 to 2021; this is an 84% increase from 2018 to 2019. It is important to note that during 2020–1, referral data for CYP stopped being submitted by CAMHS as part of their monthly data set submissions.[4] On average, in 2021–2 32% of CAMHS referrals were not accepted for treatment in CAMHS.[4] However, as referral data collection varies both between and within NHS Trusts, the true number of referrals into CAMHS that were deemed unsuccessful might have been higher.

YoungMinds is the UK's leading charity for CYP's mental health. Their 'Agenda' identified a need to create 'accessible local and national online resources to make it much easier for young people and professionals to find further information, resources, apps and services in their area'.[5] Locally, there have been various piecemeal initiatives to improve referrals with different professional groups. Initiatives have not been strategic, joined-up or comprehensive. Concerns relate to: what happens to the CYP whose referral is not successful, and how this process may prevent those who do need CAMHS from being treated in a timely manner.[6] Frith identified some key problems with the referral process and aspects of the service: gathering data in this area is difficult because there is a lack of reliable and consistent reporting of mental health demand and service access; service specifications vary, are regionally determined, based on clinician expertise and/or Trust configurations; different regions have broadly different unmet CAMHS needs; and referrers are confused by a lack of clarity about local referral criteria and referrals come from across health, education and social care.[7]

This project addresses the main findings from two important reports 'Rejected referrals to child and adolescent mental health services: audit' and 'Are we listening? A review of CYP's mental health services'.[8,9] The Scottish audit was the first report that combined qualitative data using accounts from individuals who had lived experience of the CAMHS referral process including CYP, their parents/carers and referrers.[10] Both reports highlighted how the referral routes are unclear, making it difficult to find the right support at the right time. They also identified some of the barriers that exist for referrers which cause delays in accessing help. In 2018–9, we consulted four CAMHS localities within Greater Manchester as preliminary pilot exploration and identified a series of problems which we outlined below:

- There is considerable variation in the proportion of inappropriate referrals across localities.
- Reasons for such disparities are unknown; however, there are examples of services where referral appropriateness is less likely to be an issue, for example, learning disability (LD) services. This may be because of more standardised referral pathways in LD services.

Early-stage discovery research conducted by NHSX identified 'pain points' and 'opportunities' in the CAMHS referral process. The report and the NHSX account highlighted similar problems. Therefore, Enhancing Child and Adolescent Mental Health Services (EN-CAMHS) set out to explore this in depth, through multiple stakeholder perspectives, using robust mixed-methods evaluation of quantitative and qualitative data across multiple NHS CAMHS providers and Trusts. We sought to extend previous research on challenges and collaboratively to seek solutions with stakeholders.

To the best of our knowledge, there are no current or recently published studies which specifically aim to improve the rates of successful referral into CAMHS.

We envisage that: (1) having accurate, accessible information about what local provision is and does; (2) having greater clarity about the referral process and standardised electronic (and alternative) forms with input from general practitioners (GPs) required and (3) providing CAMHS with complete clinical information prior to their initial assessment would reduce significantly the number of unsuccessful referrals. Clinicians would be freed from chasing further information to supplement their assessment and formulation and this would improve efficiency, releasing their time for clinical duties. We also suggest this may reduce numbers of inappropriate referrals and lead to improved throughput and reduced waiting times leading to better patient and clinician satisfaction and earlier interventions/diagnosis as appropriate.

Chapter 2 Aims and objectives

The overarching aim of this study was to understand key current problems in the CAMHS referral process and to identify tractable solutions which would improve the CAMHS referral success.

In order to achieve this, our objectives were to:

- Map and examine the various configurations of CAMHS services (including service eligibility criteria).
- Map and analyse referral and inappropriate referral rates against possible; explanatory variables (e.g. age, sex, ethnicity, Index of Multiple Deprivations).
- Engage broadly with CAMHS stakeholders.
- Explore what does and does not work in the current referral processes across different sites and CAMHS providers.
- Identify possible sustainable solutions to support more successful and appropriate referrals in collaboration with key CAMHS stakeholders.
- Identify the complexities/what would be needed to implement sustainable solutions across CAMHS settings.

Patient and public involvement

Patient and public involvement (PPI) was at the heart of this project, and it will be discussed throughout this report following the Guidance for Reporting Involvement of Patients and the Public 2 short form headings within each subsection, in line with National Institute for Health and Care Research (NIHR) guidance. We built on our established collaborations with CYP and their parents/carers/families. Regular consultations with CAMHS stakeholders ensured the study remained relevant and meaningful. The initial design of this project was informed by our advisory groups comprising CYP, parents/carers and relevant practitioners/professionals, and broader PPI consultations indicated the urgent need for improvements to the CAMHS referrals processes. EN-CAMHS aimed to involve CAMHS stakeholders (CYP, parents/carers, plus key referrers and CAMHS professionals) extensively and in all stages of the EN-CAMHS project, from development through to dissemination activities. Specifically, there were three areas in which we wanted to focus our PPI: designing recruitment materials, strategies and topic guides for the stakeholder focus groups; exploring both the problems and solutions that emerged from the focus groups to enhance referrals into CAMHS; and supporting dissemination to ensure findings were shared in a way that was informative and accessible.

Chapter 3 Literature review

Previously identified problems within the CAMHS referral process:

1. **Increased demand for CAMHS** – more CYP are seeking support for their mental health; services are unable to meet this demand.
2. **Families accessing services** – parents/carers feeling as though they have to 'fight' to be seen by CAMHS; unsuccessful referrals cause distress in families.
3. **Reasons for referral** – varying reasons CYP are referred to CAMHS, often families wait a long time before trying to access support.
4. **Who refers into CAMHS (with a focus on GP referrals).**
5. **The likelihood of the referral being successful** – who refers into CAMHS, can impact the likelihood of a successful referral.

A contemporary summary of the literature relevant to pain points and difficulties within the referral process can be found in *Appendix 1*. As the landscape of CAMHS is varied and regularly changes, EN-CAMHS explored whether the identified pain points and conclusions from the previous literature remained relevant; and, if so, explored these in more detail through focus group discussion. Suggested solutions to some of the problems identified within the literature are shown in *Appendix 1*. These have been categorised into those with the potential to be digitised alongside alternative, non-digital solutions. Findings from EN-CAMHS are compared to current literature in the report discussion.

Chapter 4 Methods

This project was granted ethical approval (2021-12126-20663) by The University of Manchester's Research Ethics Committee. The phases of EN-CAMHS are shown in *Figure 1*.

Within Phase 1 (months 1–3) the following management groups for the project were established:

- **Study Steering Committee (SSC):** The SSC provided supervision for the project on behalf of the Project Sponsor and Project Funder and ensured the project was conducted to rigorous standards set out in the Department of Health's Research Governance Framework for Health and Social Care and the Guidelines for Good Clinical Practice (for Steering Group Terms of Reference, see *Report Supplementary Material 1*).
- **Project Management Group (PMG):** The PMG consisted of the co-Principal Investigators, the Project Manager, and the Key Protocol Contributors. The group held monthly meetings throughout the study period to review progress against the Project Management Plan.
- **PPI groups:** There were two PPI groups during this study, a Young Persons Advisory Group (YPAG) and a Parents/carers and Professionals Advisory Group (PPAG). These groups met bimonthly and quarterly, respectively, to review and feedback on the study and ensure young people and their parents/carers/families influenced decision-making.

Phase 2 (months 4–16) included three complementary phases:

1. Identifying referral rates and analysing referral patterns – (quantitative data collection and analysis).
2. Extensive stakeholder consultation – (qualitative data collection and analysis).
3. Triangulation – bringing information together from 1 and 2.

Child and Adolescent Mental Health Services referral data for the last 5 years (2016–20) were collected via our collaborators at four CAMHS providers which cover individual CAMHS sites. National-level CAMHS data published by NHS England were obtained via the NHS Benchmarking reports. Specifically, the following pseudonymised individual patient data were requested from each Trust: CYP socio-demographics (e.g. age, sex, ethnicity); clinical characteristics of the referred CYP (reason for referral), source of referral, referral outcome for the CYP (successful or unsuccessful), and time to first contact with a mental health professional where a referral is judged appropriate and successful by CAMHS.

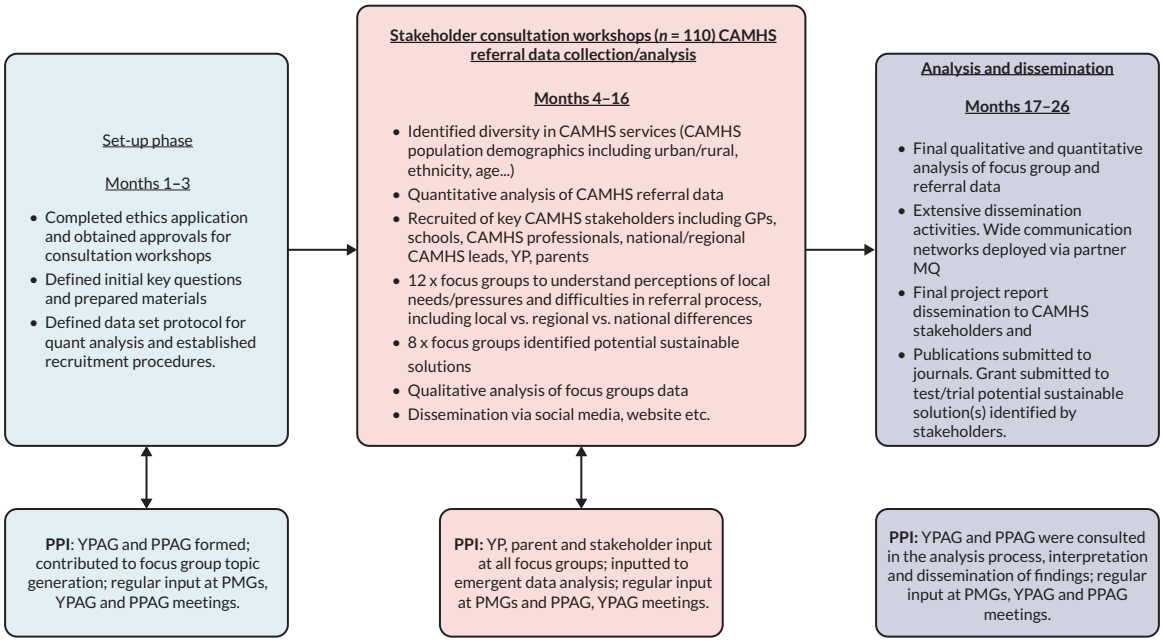

FIGURE 1 Flow chart to show the phases of EN-CAMHS. PMG, Project Management Group; PPAG, Parents and Professionals Advisory Group; YPAG, Young Peoples Advisory Group.

National-level CAMHS data focuses on: number of referrals, number of successful referrals, and sociodemographic and clinical characteristics of CYP where these are available.

Data sources

From January 2016 to December 2020, referral data were requested from four NHS Trusts, covering nine CAMH services. These data were requested directly from the Trusts.

Analysis

Analysis of referral data aimed to understand the rates of unsuccessful referrals. Referral data were explored, summarising: total number of referrals (averaged over 5 years, summarised by year, summarised by CAMHS site) and proportion of inappropriate referrals (averaged over 5 years, summarised by year, summarised by CAMHS site). Trends in unsuccessful referrals over the last 5 years were reported. Quadratic models were fitted using logistic regression on the monthly aggregate data for referrals. Results were expressed graphically, plotting the predicted probability of an unsuccessful referral against time, describing the proportion of unsuccessful referrals over time for each Trust and service within each Trust.

A second key outcome of the quantitative analysis was to understand what data are routinely collected by services, and investigate the quality of these data to use in future analyses. Descriptive statistics including amount of missing data for each of the CAMHS providers were produced to report: sociodemographic characteristics (age, sex, ethnicity) and clinical characteristics of CYP referred; referrer type; and for those with a successful referral, time to first contact with mental health team.

To explore potential factors relating to inequality of service use, and whether any child or referrer characteristics were associated with, whether or not a referral is successful these demographic and referral data were summarised by referral outcome (unsuccessful vs. successful). Additionally, exploratory analyses were undertaken with referral outcome regressed on sociodemographic data, clinical characteristics and referrer type using logistic regression. Separate models were fitted for each Trust and each model adjusted for locality and year. We know that there are often gender and ethnic differences in mental health conditions, and so as we are observing at the point of referral outcome, referral reason may be operating as a selection mechanism. As such, we additionally controlled for reason for referral in the models exploring the relationships of gender and ethnicity in case this confounded the relationship with referral outcome.

Qualitative stakeholder consultation (qualitative data collection and analysis)

This was divided into two parts. Part one focused on the identification of problems within the CAMHS referral process and had the following objectives:

- To clarify the referral criteria to CAMHS.
- Understand localised referral criteria, pain points in the referral pathways.
- Identify reasons for inappropriate referrals.
- Describe the impact of inappropriate referrals on CYP and their families.

Part two focused on solutions and had the following objectives:

- To explore possible ways to solve the problems identified.
- Discuss the practicalities of embedding proposed solutions in busy, real-world referral environments.

Extending work already completed by NHSX and NHS England, we drew on the stakeholder consultations to process map the CAMHS referral pathway across our sites.[11–13] Process mapping helped us to clarify similarities, variations and to identify 'pain points' in the referral process that can be addressed (see *Appendix 2*).

Because we specifically wanted to explore the role of digital solutions within other possible solutions, we used category areas of the Non-adoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies (NASSS) framework evaluation to guide discussions with stakeholders.[14] The NASSS framework has been widely used in evaluations of digital mental health implementation projects.[15]

Participant recruitment and sampling

Information sheets and contact details for the research associate were shared, alongside standardised information about the project. If individuals were interested in participating, they were asked to contact the research associate for consenting, or if they had any questions. Recruitment of CAMHS stakeholders was supported by our extensive network of CAMHS collaborators and our four collaborating sites. Recruitment of key referrers was supported by our school and primary care collaborators, as well as links to key referrers provided by our CAMHS sites. Recruitment of CYP and their families was supported by our CAMHS networks, social media recruitment and our third-sector collaborators (MQ Mental Health Research, 42nd Street, Anna Freud Centre). COVID-19 restrictions meant focus groups were all conducted online via Zoom (Zoom Video Communications, San Jose, CA, USA).

Collaborating sites were chosen to: target the areas of high need for CYP mental health across England; reflect diversity in terms of urban/rural locations; ethnicity of service user population; diversity in configuration of CAMHS services/CAMHS offer. We extended our focus group invitations beyond our collaborating sites to ensure we capture a wide diversity of CAMHS stakeholder perspectives.

Participants were included if they were aged 16 +, able to provide informed consent and, if they were a CAMHS stakeholder who had experience with the CAMHS referral process during or after 2015. Additional inclusion criteria for each stakeholder group were as follows:

- CYP included those who had been referred to CAMHS regardless of whether they were successful into the service or not.
- Parents/carers: included individuals who had experience of their child/a child in their care having been referred to CAMHS, regardless of the outcome of the referral.
- CAMHS staff: included any staff who currently worked in CAMHS.
- Key referrers: included individuals who had experience referring CYP to CAMHS, regardless of how many times, for example, GPs.
- CAMHS Commissioners: included Commissioners who understood the current CAMHS referral processes locally or nationally, and who were involved in the funding process.
- Mental Health Professionals included people with a strategic overview of the CAMHS referral process locally or nationally, who shared their experiences of the referral process.

Sampling drew on the quantitative data analysis to ensure we included particular outlying referrers (i.e. those with very high or very low rates of in/appropriate referrals) and included a range and diversity of referrers for inclusion in our stakeholder consultations. Every effort was made to represent a diversity of views at these focus groups, particularly considering underserved communities (e.g. ethnic minorities CYP). The number of different stakeholders who participated in problem-focused, and solution-focused focus groups are displayed below in *Tables 1* and *2*.

Data collection

The target recruitment number of stakeholders across all focus groups was 120. One hundred and ten CAMHS stakeholders including CAMHS staff, collaborators, CYP, key referrers (e.g. GPs, teachers) and parents/professionals

TABLE 1 Number of stakeholders who participated in problem-focused focus groups

Problem-focused groups	CYP	Parents/carers	Key referrers	CAMHS professionals (individuals currently working within NHS CAMHS)
Number of participants (*n* = 65)	14	21	18 (6 GPs, 6 education professionals, 4 CYP mental health professionals, 2 speech and language therapists)	12

TABLE 2 Number of stakeholders who participated in solution-focused focus groups

Solution-focused groups	CYP	Parents/carers	Key referrers	CAMHS professionals (individuals currently working within NHS CAMHS)
Number of participants (*n* = 45)	13	8	9 (2 GPs, 4 education professionals, 2 CYP mental health professionals, 1 speech and language therapist)	15

were recruited to 20 focus groups before data saturation was reached. The selection method also used a purposive sampling framework to ensure optimal variation in the views, roles and relevant personal and professional characteristics of stakeholders, which included GPs, Special Educational Needs Coordinator, head teachers, CAMHS staff, CYP, parents/carers. The focus group discussions were structured by topic guides developed by the research team in collaboration with our PPI advisory groups, see *Appendix 3*, for an example topic guide). Topic guides provided flexibility to allow themes to emerge and be discussed and were designed to address experiences of the CAMHS referral process, problems which were experienced, and how some of these problems might be resolved.

Twelve qualitative focus groups were conducted with 65 CAMHS stakeholders (CYP, parents and carers, key referrers and CAMHS professionals), focus groups mainly consisted of individual stakeholder groups, that is CYP only, or key referrers only; however, there were two mixed stakeholder focus groups. The aims of the focus groups were to discuss and collaboratively define: the referral process; the barriers to making appropriate referrals for referrers (including GPs, schools, parents/families). The focus groups were focused on identifying the challenges of making appropriate referrals, working with a wide CAMHS stakeholder group, including YP and their families. Focus group facilitators described local CAMHS criteria (identified by staff at collaborating sites) and local service configurations ahead of each discussion.

Eight mixed stakeholder focus groups were conducted with 45 CAMHS stakeholders (CYP, parents and carers, key referrers and CAMHS professionals) to identify and discuss potential solutions to the problems identified from the previous focus groups, particularly aiming to understand stakeholder requirements for solutions developed. We discussed with stakeholders how proposed solutions should be measured (e.g. speed through referral pathway; patient satisfaction).

Analysis

All qualitative focus groups were audio- and video-recorded with consent, transcribed and analysed using the National Centre for Social Research (NatCen) Framework Analysis methodology set out by Ritchie and Spencer, and using NVivo 12, as this has a Framework Matrices Tool.[16,17] Framework analysis is widely used in mental health research. To ensure the quality and credibility of the framework analysis conducted on the qualitative data, the qualitative lead on the project and the research associate used a combination of the following approaches: (1) triangulation of the data (qualitative and quantitative), (2) transparency and reflexivity, (3) generating and discussing alternative explanations and (4) identifying negative and discrepant information. The analysis process followed the below stages and was completed by two researchers (KG and HT):

Following familiarisation with the data, we constructed an initial thematic framework.

This involved the researchers logging initial thoughts on the data as they occurred and preliminary coding. The preliminary codes were reviewed and grouped to construct an initial thematic framework. We then indexed the data, completing line-by-line coding and indexing data under each theme/sub theme. After indexing was complete, framework matrices were created in Excel by merging together problem-focused matrices from each researcher and merging together solution-focused matrices from each researcher. Finally, the data were interpreted which involved reading though each theme and subtheme, summarising what was said by each stakeholder groups, and relating this to problems/solutions within the CAMHS referral process. Regular discussions were held throughout the analysis/interpretation phase with the YPAG, PPAG, Steering Group, Roundtable discussions and PMG meetings.

Triangulation: bringing information together from 1 and 2

Following the production of the qualitative matrix, each row of the matrix was reviewed to identify the following: different perceptions, views, experiences and behaviours which were present in each theme and how they addressed the research questions. The qualitative lead and research associate then considered linkages within the data – for example, linkages between categories and between the quantitative and qualitative data. Explanations were then looked for; for example, why was there a link between an experience in one category and a belief in another? Explanations of the data were provided by the participants themselves and were inferred by the analysts based on close interrogation of the data and also links to existing knowledge or theory. There was some overlap between the quantitative and qualitative analyses, especially in terms of who refers into CAMHS. Both analyses found GPs refer into CAMHS most frequently; however, GPs also have a high number of unsuccessful referrals when compared to schools or self-referrals. There were also differences in reasons for referral depending on the care pathways present within CAMHS, that is some services had neurodevelopmental pathways, others did not.

Changes to protocol

- Socioeconomic status (SES) was not provided by most Trusts and, therefore, a detailed investigation of SES was not possible.
- Information on the clinical configuration of the CAMHS providers at the site level (i.e. what are the clinical thresholds for acceptance to CAMHS) was collected; however, due to the variation across sites and differences in care pathways it was difficult to clearly map these data to enable us to explore if/how these may influence the referral acceptance rate.

Chapter 5 Patient and public involvement methods

Over 50 CYP, parents and carers were involved as part of this project. These individuals were selected because of their first-hand experience of (and often problems with) the CAMHS referral process, so were able to reflect on the effect that these had both for YP and their families; and were able to use that insight to inform the design of our research.

We established separate YPAG (*n* = 12, 9 females, 3 males) and PPAG (*n* = 9, all female) groups, with individuals from across the country. Members of the YPAG and PPAG were provided with an information sheet ahead of joining and were advised not to participate in the advisory groups if they felt it would be distressing. Members were also provided with a mental health support sheet upon joining should they have needed to access additional support. However, the nature of this project and the discussions in the groups were not anticipated by the project team to cause distress. YPAG and PPAG groups were held separately as it was felt this would encourage greater openness and participation from young people. Both groups met six times online throughout the course of the project via Microsoft Teams (Microsoft Corporation, Redmond, WA 98052-7329 USA) (approximately 1 hour per meeting). Meetings were arranged via polls to accommodate as many members' availability as possible. CYP were paid £25.00 per 1-hour meeting, and parents/carers and professionals were paid £50.00 per one and a half-hour meeting.

The advisory groups addressed an agenda for each meeting focused on getting feedback about different stages of the project, for example, recruitment, analysis and dissemination. Groups were led by the project research associate with back-up support from a second facilitator where needed from the Senior Project Managed and/or the patient and public involvement and engagement lead. Materials were circulated in advance using slides and multimedia formats (e.g. videos) to allow 'thinking time'. During meetings, an informal style was used to encourage members to participate including use of interactive tools [e.g. Google Jamboard (Google Inc., Mountain View, CA, USA)], ice breakers and the use of the chat function. Key feedback from the group was circulated to the team at PMG meetings and informally, as needed.

An impact log was kept using the Patient Experience Research Centre (PERC) Impact Log throughout to record attendance, impacts and support critical reflection as we went along.[18] An eight-item online questionnaire with a mix of closed and open questions was circulated at the end of the project to gather feedback from YPAG and PPAG members on their experiences of involvement.

Chapter 6 Results

Quantitative

Data were requested from each Trust for the 5-year period covering January 2016–December 2020. Data for Trust A were not available for the full period, and so to maximise available data, one service within Trust A provided referral data on individuals between April 2018 and October 2021 and the other service between April and December 2021. Individual patient data were available from Trust A, Trust B and Trust D. However, Trust C was only able to export aggregate data. Additionally, outcome of referral was unclear from the Trust C data export, and so descriptions and analysis of unsuccessful referrals was not possible for this Trust.

Table 3 describes the number of referrals received per year for each locality within each Trust, and the proportion of these referrals (%) that were not successful. Whole Trusts are anonymised by letter, that is Trust A, CAMHS within each Trust are anonymised by a number, that is A(1) would reflect one CAMH service within Trust A.

Where the outcome of referral was possible to obtain, all Trusts had complete data apart from Trust B which was missing referral outcome on 63 individuals (0.24%).

TABLE 3 Number of referrals per year and proportion not successful, by locality

Trust A			*A(1)*		*A(2)*					*Total*	
	2018	1689	24.3%	–						1689	24.3%
	2019	2367	20.0%	–						2367	20.0%
	2020	1916	18.4%	–						1916	18.4%
	2021	1929	24.9%	320	2.8%					2249	21.8%
Trust B			*B(1)*		*B(2)*		*B(3)*			*Total*	
	2016	1050	25.6%	1160	32.2%	1722	24.4%			3932	27.1%
	2017	1131	21.8%	1401	29.3%	1808	24.8%			4340	25.5%
	2018	1047	14.1%	1619	37.4%	1869	23.9%			4535	26.4%
	2019	1073	39.9%	1828	46.9%	2397	28.1%			5298	37.0%
	2020	1138	42.6%	1494	46.6%	1774	25.7%			4406	37.1%
Trust C			*C(1)*		*C(2)*		*C(3)*		*C(4)*	*Total*	
	2016	1639		1520		1961		2484		9104	
	2017	1867		1050		1921		2490		9095	
	2018	2231		1149		2811		2865		11,139	
	2019	2456		1126		1726		2910		10,587	
	2020	2637		874		999		2472		8811	
Trust D			*D(1)*		*D(2)*		*D(3)*		*D(4)*	*Total*	
	2016	95	1.1%	1	0.0%	152	0.0%	48	0.0%	296	0.3%
	2017	990	0.1%	4	0.0%	451	0.2%	858	0.5%	2303	0.3%
	2018	870	0.3%	18	16.7%	165	0.6%	1044	0.4%	2097	0.5%
	2019	1025	0.2%	121	18.2%	297	19.2%	1102	0.5%	2545	3.4%
	2020	866	0.3%	923	19.3%	744	27.2%	805	0.6%	3338	11.6%

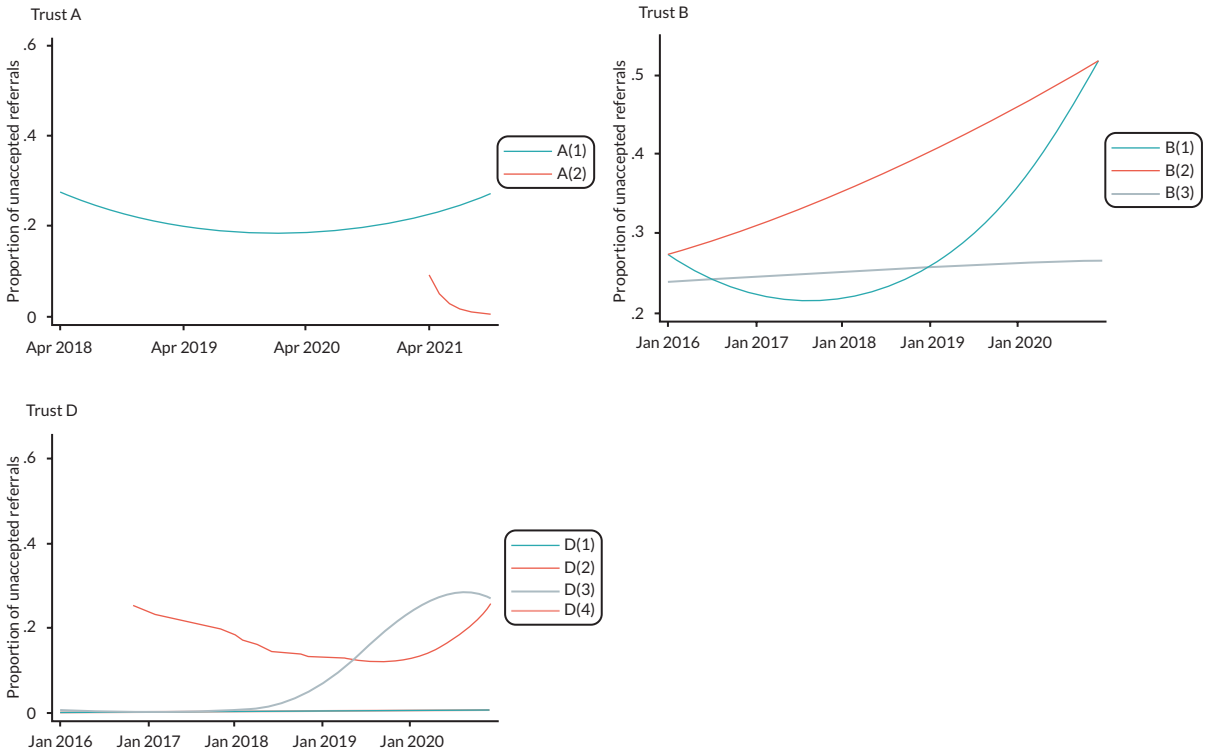

FIGURE 2 Proportion of unsuccessful referrals over time modelled with trends within each Trust.

The proportion of unsuccessful referrals over time was modelled, with trends within each Trust, where data were available, depicted in *Figure 2*.

Across all years from each Trust, 21% of referrals from Trust A, 30.8% of referrals from Trust B and 4.7% of referrals from Trust D were unsuccessful. Overall, there were a greater proportion of unsuccessful referrals in 2019 and 2020 for Trust B and Trust D compared to earlier years. This is at odds with national trends which have seen an increase in the number of referrals per 100,000 CYP year on year, but a reduction in the proportion of unsuccessful referrals (unsuccessful referrals: 2016 27.5%; 2017 26.7%; 2018 25.8%; 2019 23.4%; 2020 22.6%).

There was considerable variation between localities in the proportion of unsuccessful referrals over time

In Trust D, D(1) and D(4) localities have close to 0% unsuccessful referrals, while D(2) and D(3) localities have seen an increasing trend over time, to around 30%. In Trust B, B(1) has experienced a curvilinear trend in unsuccessful referrals, increasing to meet B(2)'s year-on-year increase in the proportion of unsuccessful referrals to over 40%. B(3)'s referrals, however, remain much lower at around 25%, with very little change over time. Although there is monthly variation in Trust A's proportion of unsuccessful referrals, the overall trend shows a slight curvilinear trend in A(1), with the proportion of unsuccessful referrals dropping off, but increasing again from 2020. A(2) has only recently been included and so there are too little data to comment on variation.

Demographic data are summarised as the total number of referrals for the whole sample at each Trust in *Table 4*. Although there was some variation in demographics over time, proportions of female and white CYP did not vary by more than 10% points in any Trust and average age remains relatively stable over time, with only a slight increase in overtime in Trust D. A breakdown by Trust can be found in *Appendix 4*. Demographics split by the outcome of referral (successful or unsuccessful) are available in *Appendix 5* and broken down at the locality within Trust in *Appendices 6–8*.

There is a roughly equal split of female and male referrals across all Trusts, with Trust B and Trust A having a small number of referrals by people who define their gender another way (< 1%). Referrals are majority white, with ethnic minority individuals making up 5.4%, 14.9% and 10.7% of referrals for Trust D, Trust B and Trust A, respectively.

TABLE 4 Demographic summary of referrals across all years, by Trust

		Trust A (*n* = 8221)	Trust B (*n* = 22,511)	Trust C (*n* = 48,736)	Trust D (*n* = 10,579)
Age	Median (IQR)	13 (9–15)	11 (7–13)	–	14 (11–15)
	Missing	0	0	–	0
Gender	Female	50.6%	43.7%	46.6%	55.5%
	Male	49.1%	56.2%	53.2%	44.5%
	Other	0.3%	0%	0.2%	0%
	Missing	≤ 0.1%	≤ 0.1%	0%	0.2%
Ethnicity	White	87.3%	76.8%	89.1%	93.8%
	Black	1.7%	6.1%	0.8%	0.6%
	Asian	6.9%	7.1%	5.9%	1.6%
	Mixed	2.7%	7.7%	3.5%	3.3%
	Other	1.4%	2.2%	0.6%	0.7%
	Missing	5.6%	29.0%	37.4%	2.3%
Clinical characteristics	Anxiety disorder	24.1%	17.4%	9.6%	17.6%
	Assessment and advice	2.7%	0.2%	50.6%	0.2%
	Drug and alcohol difficulties	0.3%	0%	0%	0%
	Eating disorders	1.0%	0.4%	0.5%	0%
	Emotional and behavioural difficulties	13.0%	18.0%	0.1%	67.4%
	Gender discomfort issues	0.4%	0.2%	≤ 0.1%	0.2%
	In crisis	9.4%	0%	≤ 0.1%	0.8%
	Mood disorder	17.3%	13.2%	5.7%	5.2%
	NDD/LD	17.3%	35.4%	16.7%	0%
	Perinatal mental health	0%	0%	≤ 0.1%	0%
	Physical health	0.3%	0.3%	≤ 0.1%	4.1%
	Self-harm/suicidal ideation	14.2%	9.9%	6.4%	4.6%
	Other	0%	5.0%	0%	0%
	Missing	0.5%	67.0%	3.6%	0%
Referrer type	Community healthcare professional	6.0%	13.4%	≤ 0.1%	0.3%
	Crisis team	2.3%	7.3%	6.6%	1.6%
	Eating disorder service	0.2%	0%	0%	0%
	Education	11.5%	14.8%	19.2%	7.4%
	GP	56.8%	47.5%	44.8%	23.8%
	Healthcare professional	1.9%	4.1%	11.2%	7.7%
	Internal referral	4.8%	2.8%	6.5%	5.8%
	NDD service	0.2%	0%	0%	≤ 0.1%

TABLE 4 Demographic summary of referrals across all years, by Trust (*continued*)

		Trust A (*n* = 8221)	Trust B (*n* = 22,511)	Trust C (*n* = 48,736)	Trust D (*n* = 10,579)
	Non-CAMHS mental health service	8.4%	0%	0.4%	6.1%
	Parent/carer	≤ 0.1%	≤ 0.1%	0%	6.5%
	Self-referral	0.4%	7.3%	0%	0.4%
	Single point of access	≤ 0.1%	0%	0%	29.1%
	Social care	4.9%	2.5%	6.9%	7.7%
	Substance use team	0%	0%	0%	≤ 0.1%
	Voluntary and Community Sector	≤ 0.1%	0%	0.3%	0.4%
	Youth justice services	≤ 0.1%	≤ 0.1%	0.2%	1.1%
	Other	2.5%	0%	4.0%	2.2%
	Missing	0.2%	7.7%	0%	0%
Time to first contact (days)	Median (IQR)	28 (6–56)	35 (6–67)	–	58 (24–141)
	Missing	983 (15%)	3028 (20%)	–	1924 (19%)

IQR, interquartile range; NDD, neurodevelopmental disorder.

Note
For categorical data, percentages are expressed out of total number of observed values (i.e. missing removed). Data on age and time to first contact were not available for Trust C.

'Clinical characteristics' are here defined as the documented reason for referral for each individual, rather than a full description of each child's particular needs. Clinical reasons for referral were not standardised across Trusts and were very specific, making for difficulties when summarising. As such, relevant terms were grouped into the summarised categories. For example, emotional and behavioural difficulties grouped verbatim terms such as 'behaviour management', 'attachment difficulties' and 'conduct disorders'. Anxiety disorders contain those referred for anxiety specifically, but also panic attacks, phobias and obsessive–compulsive disorder. In some cases, specific details were not provided in the description, resulting in verbatim terms such as 'in crisis' and simply 'other'. These were categorised as 'other'.

Data were readily available for Trust D and Trust A; however, Trust B were missing referral reasons for 67% of their referrals. Though proportions range across Trusts, several referral categories were consistently high, such as anxiety disorders, which includes obsessive–compulsive disorder, post-traumatic stress disorder and phobias. Neurodevelopmental disorders (NDDs) and LDs were a common referral reason in Trust A, Trust B and Trust C (17.2%, 11.7% and 16.7%), but not at all in Trust D (0%). Though common across all Trusts, the majority of Trust D's referrals were for emotional and behavioural difficulties (67.4%). This includes a range of problems including attachment difficulties, behavioural dysregulation and conduct disorders.

Type of referrer was categorised into broad groups prior to analysis.

For example, **healthcare professionals** include paediatricians, speech and language therapists; and verbatim terms referencing hospital-based referrals.

Education includes school health advisors, special educational needs co-ordinators, education service and teacher/learning mentors.

These data were more complete than the referral reason, with Trust B missing only 7.7% of observations. GP referrals (including practice nurses) account for the majority of referrals overall (Trust D 23.8%, Trust B 43.9%, Trust A 56.7%, Trust C 44.8%), though referrals from educational settings were common across all Trusts (Trust D 7.4%, Trust B 13.7%, Trust A 11.5%, Trust C 19.2%). For Trust D, however, the highest proportion of referrals came through single point of access services (29.1%). The community healthcare professional referrals (including community paediatricians, community nurses and community mental health teams) and self-referrals were more common in Trust B than in other Trusts.

To investigate associations with referral outcome, because of the larger number of categories and a small number of observations in some cells, certain categories were collapsed in the sociodemographic variables to improve interpretation. Specifically, we define the following:

Gender is categorised as female versus male (and other, where given) and ethnicity as white versus non-white, given the low numbers in each of the black, Asian, mixed and other categories. For clinical characteristics, categories created were defined for the more prominent reasons for referrals: anxiety disorders; emotional and behavioural difficulties; mood disorders; NDDs/LDs; self-harm; and other (including assessments and advice, drug and alcohol disorders, eating disorders, physical health conditions, gender identity, in crisis and those just listed as 'other'). Similarly, referrer type is reduced into key referrer categories: education and social care; GP and Practice nurse; Parent/Carer and Self-referral; and Other [which includes community healthcare teams, healthcare professionals, non-CAMHS mental health services, crisis teams, eating disorder services, NDD services, voluntary and community sectors, youth justice services, internal CAMHS referrals, single point of access (Trust D) and those just listed as 'other'].

The collection of referral data in a non-standardised way across CAMH services may account for some of the variation seen with regard to clinical characteristics or reason for referral, for example, how services define 'emotional and behavioural difficulties'. Other differences in how data are recorded depends on the services offered within each CAMHS, for example, Trust D also had no referrals for NDD, as this is not a service provided by CAMHS in this area.

Table 5 and *Figure 3* display the adjusted risk ratios describing the association between each characteristic and unsuccessful referral.

Age
Across all Trusts, the younger a child is, the more likely they are to have an unsuccessful referral.

Gender
Although the proportion of girls experiencing unsuccessful referrals in Trust A and Trust B is lower than other genders (see *Appendix 6*), there is no significant association between gender and referral outcome after controlling for referral reason as a confounder.

Ethnicity (see *Appendix 10* for comparisons of ethnicities of children and young people within each Trust compared to local area)
There are differences in the proportion of unsuccessful referrals across ethnic groups [in *Appendices 6–8*]; however, as with gender, we observe no significant associations after controlling for referral reason.

Referrer
Across all Trusts, referrals from GPs are more likely to result in an unsuccessful referral compared to those from educational or social care settings. Parent/carer and self-referrals are more likely to be successful than those from education and social care, as are referrals from other sources (e.g. non-GP medical professionals, youth justice services, voluntary sector, and single point of access in Trust D).

Clinical characteristic or reason for referral is also associated with referral outcomes, although the specific drivers of an unsuccessful referral differ across Trusts. In Trust D, compared with anxiety disorders, referrals for emotional and behavioural difficulties, mood disorders and self-harm/suicidal ideation are more likely to be successful, with all other referral reasons (physical health problems, gender identity, crisis and assessments/advice) are far more likely to not

TABLE 5 Adjusted risk ratios – risk of unsuccessful referrals, controlling for year and locality within Trust for all models and confounder referral reason for models for gender and ethnicity

	Trust A (21% unsuccessful referrals)						Trust B (31% unsuccessful referrals)						Trust D (5% unsuccessful referrals)					
Scale	**RR**	**95% CI**		***p*-value**	**R0**	**R1**	**RR**	**95% CI**		***p*-value**	**R0**	**R1**	**RR**	**95% CI**		***p*-value**	**R0**	**R1**
Age	0.94	0.94	0.95	< 0.001	26%	22%	0.96	0.95	0.96	< 0.001	31%	29%	0.91	0.89	0.93	< 0.001	6%	5%
Female vs. other (male/ other R0)	0.96	0.88	1.04	0.326	21%	20%	1.01	0.95	1.07	0.758	35%	35%	0.90	0.76	1.06	0.194	5%	4%
White vs. other (non-white R0)	0.90	0.81	1.01	0.078	22%	20%	0.92	0.85	1.01	0.073	32%	30%	1.45	0.91	2.30	0.115	3%	5%
Clinical characteristics																		
Anxiety					9%						31%						7%	
Emotional and behavioural difficulties	5.61	4.81	6.54	< 0.001		50%	1.52	1.38	1.68	< 0.001		48%	0.20	0.14	0.27	< 0.001		1%
Mood disorders	0.80	0.64	1.02	0.068		7%	0.74	0.64	0.85	< 0.001		23%	0.60	0.43	0.84	0.003		4%
NDD/LD	4.64	3.98	5.41	< 0.001		41%	1.20	1.09	1.33	< 0.001		37%	–	–	–	–		–
Self-harm/ suicidal ideation	0.56	0.42	0.75	< 0.001		5%	0.24	0.18	0.31	< 0.001		7%	0.61	0.43	0.86	0.004		4%
Other	2.41	2.01	2.89	< 0.001		21%	1.94	1.74	2.16	< 0.001		60%	2.60	2.15	3.14	< 0.001		18%
Referrer type																		
Education					19%						26%						7%	
GP	1.31	1.14	1.49	< 0.001		25%	1.39	1.31	1.47	< 0.001		38%	1.68	1.37	2.05	< 0.001		12%
Parent/carer or self	1.45	0.85	2.49	0.174		28%	0.64	0.57	0.72	< 0.001		17%	0.23	0.12	0.42	< 0.001		2%
All others	0.68	0.57	0.79	< 0.001		13%	0.64	0.60	0.69	< 0.001		17%	0.17	0.13	0.23	< 0.001		1%

CI, confidence interval; R0, absolute risk of unsuccessful referral in base category; R1, absolute risk of unsuccessful referral in comparator categories; RR, risk ratio.

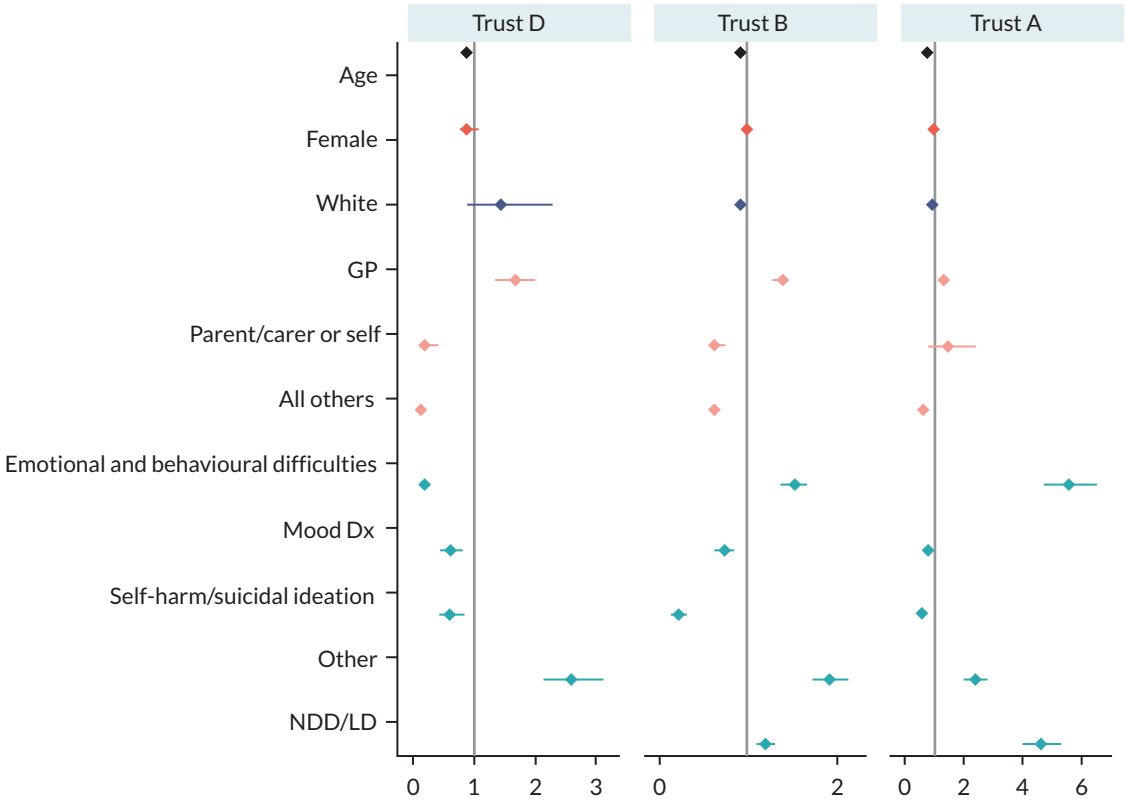

FIGURE 3 Adjusted risk ratios with 95% confidence intervals – risk of unsuccessful referrals, controlling for year and locality within Trust for all models and confounder referral reason for models for gender and ethnicity. Note: mood Dx: mood disorders. The red line represents unity (no association); factors to the right of the line have an increased risk of an unsuccessful referral while factors to the left of the line have a reduced risk of an unsuccessful referral.

be successful. In Trust B, only mood disorders and self-harm/suicidal ideation are less likely to result in unsuccessful referrals than anxiety disorders, with all other reasons more likely to result in an unsuccessful referral. Trust A has a similar trend to Trust B but with stronger associations given the relatively low rate of unsuccessful anxiety referrals. *Emotional and behavioural difficulties, for example, are over five times more likely to end in an unsuccessful referral* compared with a referral for anxiety: while 9 in 100 children referred for anxiety will be unsuccessful, 50 in 100 referrals for emotional and behavioural difficulties will not be successful.

Qualitative

Findings are discussed by theme across stakeholder groups. One hundred and ten stakeholders participated across both the problem and solutions-focused focus groups. Over 60 CAMHS stakeholders (CYP, parents and carers, key referrers and CAMHS professionals) were consulted through a series of focus groups to explore the problems and experiences within the referral process in greater depth.

Problems within the referral process

Our findings echoed and extended the problems identified in the literature:

- Confusion about what CAMHS is for, that is what it does and does not provide.

  There is also a wider question around CAMHS not having agreement on referral criteria. or what they do, who they work with.

- Lack of 'transparency' about the referral process.

  . . . there has to be a lot more transparency and even if it is refer you to a website, but this is stage one decision referral this is how long it may take, this is what happens next, it just needs to be really, really clear I feel.

- Lack of support provided during the referral process.

  . . . we've no idea how long that's going to be and there's no support while we're waiting.

- Poor communication during the referral process.

  . . . your referral goes off, it's almost like it goes into an abyss and you're not sure who's coming back when they're coming back, how they're coming back ...

- Lack of knowledge about alternatives to NHS CAMHS, and lack of confidence in these services.

  I will say that there is a view that CAMHS is the gold standard service and that there is nothing else available . . .

- Unsuccessful referral can increase distress.

  . . . if you can't make the threshold for CAMHS often a rejection just means you're rejected and there's nothing else offered . . .

- Alternative methods being used to get referred into CAMHS – for example, 'other services say people need to go to A&E to get a referral and support'.

  . . . told his parents. Take them to A&E, you'll get seen then . . .

Problems identified within the CAMHS referral process tended to overlap between stakeholder groups, for example, difficulties with the referral form. CYP felt their voice was often not heard in CAMHS referrals; parents/carers expressed concerns with some services accepting self-referrals, whereas others did not; key referrers had mixed views on the ease of completing referral forms, while professionals working within education generally found referral forms straightforward. GPs said that CAMHS referrals were time-consuming and required considerable amounts of information. Finally, CAMHS professionals felt that referral forms were too focused on seeking diagnoses instead of providing a holistic view of the difficulties experienced by the child or young person who was being referred. CAMHS professionals also said the advice to access accident and emergency in order to get referred put undue pressure on the whole system, that is both emergency services and CAMHS professionals.

One of the main problems for all stakeholder groups was the referral process itself.

This theme included:

- Lack of transparency in the stages of the referral process and what to expect at each stage; long-waiting times.
- Poor signposting while waiting for CAMHS.
- Not knowing if a referral was unsuccessful.
- High thresholds for CAMHS, that is moderate to severe mental health difficulties.
- Repeating information to different mental health professionals.
- Having to go back to the beginning if referrals were not successful.

All stakeholders recognised the difficulties associated with the degree of variation in what CAMHS services that are provided across the country, for example, care pathways offered, and thresholds for acceptance. Parents/carers, key referrers and CAMHS professionals all recognised that this was because of differences in local authority funding and commissioning. All stakeholder groups, apart from key referrers, said there was a need for parents/carers to feel

listened to more in the referral process, and to have their thoughts and understanding about the difficulties their child was experiencing validated; and they felt this would go some way to alleviate their anxieties associated with the referral process.

Below are illustrations of the key 'pain points' in the referral process by stakeholder group (see *Appendix 9* for additional information):

Children and young people

- **Lack of awareness about CAMHS**, CYP often did not understand what CAMHS was for or who CAMHS could help, even after a referral into the service had been made.

  . . . I had no clue what it was, I don't even think I knew the acronym until maybe I was halfway through it . . .
  I was just going to say when I got referred, there was so much of the unknown. I think when you're waiting for the initial assessment there's so much anxiety.

- **Referral process not child-focused**, general feeling amongst CYP that they were not involved in the referral process as much as they should have been. Some participants referred to feeling as though decisions were being made for them by parents/carers or other professionals.

  I wasn't very involved either with the process …
  . . . I make those decisions now, rather than when I was younger, people would decide where the best place was to put me . . .
  I had no involvement in the referral I wasn't even aware it was a referral. . .

  High threshold*s for CAMHS were acknowledged byCYP, especially in relation to eating disorders. Some CYP felt that this could make them more ill to meet the threshold; CYP also discussed how the high threshold made them feel as though they had to convince professionals and/or parents/carers that they were 'unwell enough' to need CAMHS.*
  Without going into too much detail about what I was being referred for, very much felt I had to meet a threshold before being taken seriously . . .
  ... you're not in the threshold and then your BMI isn't low enough.

- **Long waiting times for CAMHS and alternatives** occurred widely unless they were in crisis or had been referred for support with psychosis. Participants often felt that longer waiting times led to a deterioration in their mental health difficulties; therefore, at the point of accessing support from CAMHS, they were significantly more unwell than when they were originally referred. CYP also highlighted the long waiting times for alternatives to NHS CAMHS. This meant that if they were signposted to another service for mental health support, they still had to wait for a lengthy period before they were provided with that support.

  I waited about 3 months for an assessment and then a further 9 months for therapy sessions . . .
  . . . there's a high chance that 'you'll get worse while' you're on the waiting list.
  The waiting part was the most overwhelming part for me as well.

Parents/carers

- **Poor communication and signposting** to alternative sources of support, especially if referral is unsuccessful. Lack of communication from CAMHS during the referral process left them feeling in a state of limbo, and isolated from the process. Some CAMHS professionals advised that letters were the preferred form of communication; however, parents/carers felt that more phone calls and being able to speak with CAMHS professionals would be more helpful

and reassuring. Improved communication was seen as especially important if a referral was unsuccessful in being accepted by CAMHS. Participants felt that this should be communicated via a face-to-face appointment or phone call and followed up with a letter. If a referral is not successful, parents/carers felt it would be helpful consistently to receive appropriate signposting advice for support.

> *. . . like me I was just left for months I had no help, and there was no communication.*
> *The services are not joined up as we've all said they don't speak to each other you're having multiple conversations, as we've said with multiple services.*
> *. . . then just wait and then you have a phone call and then you just wait again, so there was nothing keeping me in touch with what was going on in the background . . .*

- **Variability of CAMHS and referral process within and between Trusts**. Parents and carers as well as other stakeholders all reported that the variability in CAMHS both between, and within Trusts was a key problem. Variability refers to a range of aspects including: who can refer, for example, self-referrals, just GPs or school, anyone; pathways within CAMHS, for example, neurodevelopmental support, forensic CAMHS. Parents/carers felt variability was a problem especially as some CAMHS would be able to support children with neurodevelopment disorders and learning difficulties, whereas others could not.

> *. . . that's the thing, isn't it? I think every Trust is doing things slightly differently.*
> *I would love to see a standard practice across the board, you could move house from [West Midlands] to Manchester and get the same standard of practice as a GP or hospital you expect it to be so, why have CAMHS not under the same bracket?*

> *. . . they're not equipped to support [neurodiverse] young people, then they just say no, and leave them out there and that's, that that's what's truly heart-breaking.*

- **Repeating information**, needing to repeat the same information multiple times to different professionals within CAMHS left parents/carers feeling distressed and frustrated.

> *. . . our path when we got to CAMHS was, I would say, sadly really inappropriate and she spoke to lots of different professionals, same story there wasn't a tell it once scenario . . .*
> *. . . tell it once thing, so you don't have to tell your child's story to every single a professional there's a page to tell it once and they know everything . . .*

- **Needing to 'fight' to be seen by CAMHS**, the language used, especially by parents/carers throughout the problem-focused focus groups, reflected a desperation for their child to be seen by CAMHS. One parent/carer referred to CAMHS as the 'gold standard'; another described CAMHS as the 'holy grail' of mental health support. Interpretation of the language used by parents/carers suggested that any other service, outside of NHS CAMHS, may be perceived as unable to support their child or deemed second rate. This seemed inconsistent with the definition usually ascribed to CAMHS as serving CYP with moderate to severe mental illness. If a CYP does not meet the threshold for CAMHS, it suggests their mental health difficulties are less severe which should be positive for parents/carers. It suggests there may be a lack of willingness amongst parents and carers to accept that CAMHS has a clinical threshold. This also can lead to parents/carers having unrealistic expectations of CAMHS, which can then lead to increased distress and feelings of blame.

> *It shouldn't have taken that much fighting to actually get her seen and to stop the pass the parcelling.*
> *I self-referred to social services. I self-referred to early help. I self-referred to absolutely everything else that was out there to try and get CAMHS to respond and to do something.*
> *. . . now it's time to fight your way through it, you're told no we're not going down that path we're going down a different one.*
> *. . . parents are automatically made to feel that, a lot of the time it's just their fault.*

Referrers

- **Poor communication** between and among services was identified as a problem for all referrers, especially educational professionals. This echoed parents/carers' feeling that there was an urgent need for better communication between CAMHS and referrers throughout the referral process. This was especially important relating to feedback if a referral was unsuccessful, so referrers understand how to improve their referrals into CAMHS in future.

  . . . from my point of view, you did a referral and then you got no communication back . . .
  . . . you complete the referral you send it off and then you'll just get a letter back in a few weeks' time saying yes, it's met the threshold or no it hasn't . . .
  . . . not getting the basic confirmation that referrals are received or any explanation, rationale as to why they're not being received it's just this doesn't meet threshold.

- **GPs** generally felt that they were not always aware of alternatives to CAMHS and, therefore, **would see CAMHS as the first port of call**. Some GPs felt they were put off referring young people because of the lengthy waiting times for CAMHS.

  The only information I'd want is what other services are out there for mental health because I do struggle to find it.
  The other thing that sometimes makes me refer is I don't know what the diagnosis is . . .
  . . . you did a referral and then you got no communication back and then you still have the family on the phone a few weeks later saying nothing's happened nobody's helping us . . .
  I know CAMHS diagnose ADHD . . .

- **Social workers and speech and language therapists** felt there was a high threshold for CAMHS and that it was difficult when referrals were unsuccessful, as often they thought CAMHS was the appropriate next step.

  They've practically got to have attempted suicide in some situations before they are actually seen.
  I think the information we need is actually what is the CAMHS threshold.

- **Schools,** poor communication from CAMHS, echoed feelings of parents/carers.

  . . . as a school we do everything we can, and I'm sure there's plenty of other schools, listening to this who are doing everything they can as well. But we're stuck with a system at the moment . . .
  . . . a lot of duplication and repeated information, which again is very time-consuming, and frustrating, I think, for the health professionals, the parents and the pupils.
  . . . there's no indication of where else we can go, there's no support with the signposting.

Child and Adolescent Mental Health Services professionals

- **Referrals not holistic (often diagnosis-seeking)**, see previous point.

  . . . GPs not even weighing children or finding out how much weight loss there is and saying they've got things like anorexia nervosa . . .
  I've noticed certainly, over the past decade or so there is, I've noticed a very definite shift towards diagnosis, equals access to resource in school and other areas. If you've got a diagnosis, it opens wallets, as well as minds to people.
  . . . after the fourth referral coming in, the young person's like well, I think I'm psychotic, I think I have schizophrenia, and you turn around and say, no, actually you don't, but they've been told this by so many other professionals . . .

- There is a prevalent view that **CAMHS can 'fix' everything**. CAMHS professionals felt there was a general perception that CAMHS could support any mental health difficulties a CYP was experiencing and resolve these. This resulted in difficulties signposting to other services, as often families saw these as not being good enough when

compared to CAMHS, links to point below. This can also lead to feelings of 'blame' and frustration between non-CAMHS stakeholders.

. . . I think that there are some stories and myths, going around, maybe legends as well about what CAMHS does and doesn't do . . .
. . . it's what support can CAMHS provide. That's a big question because a lot of people don't know what we do. They have an expectation that can come directly to our service and actually that isn't the process and I don't know if that's a communication thing or an expectation . . .
. . . just lots of frustration all round from parents and GPs and everybody really.

- **Difficult to refer to alternatives as high expectations from families**. This links to language used by parents and carers.

. . . there is an expectation from everyone that they'll come to us and then within 6 weeks we'll have sorted it all out . . .
. . . the language around mental health certainly we had a period where we found with certain schools because they felt their referrals weren't coming through, they started putting words like anxiety and depression so that it would pass the screening stage . . .
. . . there is this understanding of what our process is, and the idea that we look for these key words and that they are then put in . . .

- **Poor standard of completion of referral forms** by referrers. It was felt that the standard of referral forms completed by GPs was generally the poorest. This could be because GPs have limited time to gather information and complete a referral with CYP and their families. The referrals from education professionals and self-referrals often contained sufficient information for the referral to be triaged effectively.

. . . is the information, for us, the minimum information that other people share. It's mandatory fields within the referral form not being completed, first and foremost. So, it's the real information that enables us to triage.
. . . an inappropriate referral for myself would be the one that is just describing a child's behaviour without any context or mental health link at all so it just looks like behaviour which could be poor parenting.
I think that should be standard in my viewpoint, again the systems that we've all got are quite different across the country, I think.

Solutions to some of the problems identified

The subsequent stage of EN-CAMHS was to **consult with CAMHS stakeholders on potential solutions**/aspects to overcome problems within the referral process. A series of focus group discussions with 45 CAMHS stakeholders identified the following potential solutions (see *Appendix 9* for additional information).

- **Standardise referral forms for NHS CAMHS and alternatives to NHS CAMHS.**

. . . you keep calling different people, and you have to re-explain yourself, and your situation . . .
. . . by that point they're like, how many times have I got to share my story, or how many times have I got to say the same thing over and over?
. . . a website, or app, where all the information is at, I think it would be helpful that that account is something that can also be accessed by the person who is referring you, or someone else you're talking to.

- **Provide clear information about the CAMHS process to potential referrers.**

. . . it's a process, so transparency about what that process is would be beneficial, from my point of view . . .
. . . we should be laying out what we have to offer and how we try to meet the need when it arises.
. . . maybe like a flowchart explaining the process, and having descriptions of each step, as well as illustrations.

- **Campaigns of communication, education and online information accessible 24/7 (e.g. an NHS 111 for CAMHS).**

  . . . that there is some awareness and training need for people that are making referrals into CAMHS . . .
  . . . and clear distinction around common mental health problems, what that means and what professionals and parents can be looking out for . . .
  Parents should receive psychoeducation . . .

- **Conversations with CAMHS team pre-referral, and training for referrers and services**.

  . . . re-educate people about that and how there are other services, but I think that's something that can either be done online or it's a training need for those people who are making those referrals.
  Educating referrers about the process to give that information to families or a process map on the website of the service.
  . . . working in each local authority, so the GPs within that area, the schools, everything, understand what that specific service can offer.

- **Early communication for referrer/family**.

  . . . when we're looking at that communication, there wouldn't be … You're managing that level of expectation very early on . . .
  You could get some information you've been accepted onto the waiting list for this service, here are some useful websites, some top tips, some resources.
  . . . a neighbouring CAMHS in the same Trust works very differently and they communicate all the time. They tell you timescales, they tell you what to expect, they tell you other avenues you can go down in the interim. They tell you what's available if they're not available.

- **Seamlessness for referrer and services**.

  . . . communication in multiagency between the GP, between the CAMHS, between early help, social services, CSC, all of these people together, it's the key.
  . . . you may be sent from one place to another, and how would all the information be transferred?
  . . . all digital referrals and using a big system for that, it has made life so much easier.

- **In-person add-ons alongside digital processes**, for example, accessible phone triage.

  Obviously, there needs to be a phone call or some kind of face-to-face or like telehealth appointment so you can talk it through.

Summary of themes and references

Table 6 lists themes identified, stages of referral process to which they relate; and the numbers represent each time a theme was referenced in a transcript. To explore how the themes identified from this project map onto an NHS England process map, see *Appendix 10*.

TABLE 6 Themes identified from framework analysis and the number of times each theme was referenced in a transcript

Problem themes identified	CYP	Parents/carers	Key referrers	CAMHS professionals
Alternatives to CAMHS	4	**49**	38	4
Awareness of services	**27**	40	17	4
Referral form	3	32	**102**	**70**
Pathways within CAMHS	8	29	8	14
Perceptions of CAMHS	15	24	12	35
Who refers into CAMHS?	26	46	**42**	34
Triage process	5	5	7	12
Emotions linked to CAMHS referral process	16	3	5	0
Expectations of CAMHS during referral process	5	11	1	13
Signposting	10	8	7	5
Communication	**23**	**68**	42	28
Processes within CAMHS	8	34	41	**39**
Waiting times	**29**	28	16	23
Referral process itself	**85**	**141**	**97**	**75**
Unsuccessful referrals into CAMHS	6	5	8	24
Demands on CAMHS	6	12	20	20
Solution themes identified			***Mix of stakeholders***	
Repeating background information			14	
Area-specific information			19	
Local CAMHS website			11	
CAMHS reputation			14	
Social media			8	
Understanding progress through the system			**74**	
Throughout the whole process				
Aspects of the referral process which need to be clearer (including waiting times, stages of process, preparation needed at each stage)			**103**	
Communication			**148**	
Trust			**81**	
Accessibility			28	
Non-digital/in-person solutions (including additional funding, GP placements in CAMHS, leaflets and posters, parenting workshops, mental health lessons in schools, CAMHS drop-in sessions)			**109**	
Solutions which could be digital (including applications, infographics, signposting, support while waiting, education and training for referrers, web portal, webinars and videos)			**353**	
Support for developing a website			**81**	
Website features			27	

Note
The bold numbers represent the three most prevalent problem themes identified by each stakeholder group.

Chapter 7 Patient and public involvement results

Our YPAG and PPAG have been very important throughout the project and have allowed us to make timely adaptations to ensure that the project reflects the needs of service users and carers and their experiences of the CAMHS referral process.

Results are grouped into: (a) YPAG and PPAG attendance, participation and experience, (b) influence on project design and outcomes and (c) external recognition.

(a) attendance, participation and experience

The YPAG and PPAG each met six times over the course of the project, with an average attendance of seven and five people, respectively. Members also attended other events as required (see *Table 7* for advisory group attendance).

Based on the feedback received from the final evaluation questionnaires, it was found that the members of both advisory groups had generally no or very little prior experience of public involvement in research. Most indicated that their experience of being involved in the project had met their expectations, although one YPAG attendee commented that they had expected to gain some hands-on research skills too. The frequency of meetings was generally seen as 'about right', although a few respondents commented that opportunities to connect in person, work in smaller groups and/or get more regular project updates in between meetings would have been welcome.

When asked about what they valued and had learnt as a result of being involved, responses included the following comments:

- *'Liked being involved from the start to finish and gaining a bit more insight in how a research project works'* (YPAG member).
- *'Seeing the progress the project made and feeling a part of this/included in it'* (YPAG member).
- *'There is a lot of information needed for the subject matter we talked about and that it opens up other avenues of discussion which hadn't been thought about before'* (PPAG member).
- *'That there is even more misunderstanding between stakeholders than I ever could have imagined, but not intentional'* (PPAG member).

(b) influence on project design and outcomes

Some general themes emerged throughout the project that influenced design and outcomes. The priorities of parents/carers included reducing waiting times, gaining clarity about CAMHS thresholds for acceptance onto caseloads and improving transparency of the process after a referral has been made. CYP emphasised the importance of their voices

TABLE 7 Advisory group attendance

	Mean attendance per meeting	Hours of input	Attendance at other events
YPAG	7	6 × 1-hour meetings over the duration of the project	One member joined the project team at the NIHR Clinical Research Network MQ Mental Health Research Mental Health and McPin Foundation Mental Health Research Service User and Carer Involvement Award event in London. One member presented at the EN-CAMHS dissemination event at HOME.
PPAG	5	6 × 1.5-hour meetings over the duration of the project	One member presented at the EN-CAMHS dissemination event at HOME.

being heard during the referral process; therefore, it is vital that their needs influence the solutions proposed, as well as the priorities of parents/carers.

The team felt PPI had made a number of important changes which had significant effects on the project. The most important included how the YPAG helped adapt the focus group questions: they suggested the focus group facilitators needed to be mindful about not asking two questions at once, and they changed the order of questions and phrasing so these could be understood by CYP. Additional questions were also added to the schedule, which included, 'Was the young person listened to in the referral process?', 'What support, if any, was offered to you while you were waiting?'

The PPAG provided suggestions to help us recruit more CAMHS professionals to the focus groups, which included attending CAMHS team meetings and placing physical flyers in GP surgeries. We followed through on some of these suggestions and subsequently met the focus group recruitment target.

During one of the final PPAG meetings, we discussed the problems within CAMHS, for example, variability, collaboration on referral forms, capacity within CAMHS, and inconsistent signposting. This validated the data we had obtained from the focus groups and offered a different perspective on how to interpret the data.

Members of both the YPAG and PPAG presented at the EN-CAMHS dissemination event at HOME, Manchester. The two members spoke so eloquently, ensuring attendees had service users in mind and setting the scene for subsequent discussions. *Figure 4* shows the discussion captured during this event.

(c) external recognition

The EN-CAMHS project was awarded Runner-Up for the NIHR Clinical Research Network MQ Mental Health Research and McPin Foundation Mental Health Research Service User and Carer Involvement Award 2022 (*Figure 5*). This award recognises the achievements of study teams who actively seek to involve carers and service users at each stage of the research process. The YPAG member invited to attend the awards commented, *'I really enjoyed having the opportunity to go up to London to attend the awards ceremony. It gave me the opportunity to see how research is recognised and considered in the mental health sector'.*

FIGURE 4 Scribe artwork EN-CAMHS dissemination event.

FIGURE 5 The EN-CAMHS team attending the NIHR Clinical Research Network MQ Mental Health Research and McPin Foundation Mental Health Research Service User and Carer Involvement Awards. Lea Milligan (right) sadly passed away in April following a sudden illness. You can read more about his work at MQ and his legacy here: https://www.mqmentalhealth.org/lea-milligan-memorial-fund/.

Chapter 8 Discussion

The EN-CAMHS project sought to understand whether there were tractable problems associated with the steady rise in numbers of children unsuccessfully referred to CAMHS in English NHS services; and to determine what possible solutions might be developed. Furthermore, once we had identified the key problems and their magnitude, we wanted to identify tractable problems and solutions which could be digital or non-digital/in-person. Nine CAMHS providers across four northern Trusts provided data on CAMHS referrals and their outcomes between January 2016 and December 2020.

Nationally, the main reasons cited for unsuccessful referrals are: not meeting the (clinical) threshold, having no mental health condition, having incomplete information, CYP being more suitable for a different service, CYP being over the age of 18 or out of area.[7] Given the wide variation in the success of referrals into CAMHS reported here, far more information from Trusts is required to understand potential patterns of, and reasons behind referral rejections. However, consistent with national figures, we also report that most referrals came from GPs; and that GP referrals were most likely to be unsuccessful, but referral patterns in England are changing. In 2017–8, 34,757 referrals to CAMHS came from schools: this represents 183 referrals every school day.[19] Between 2020 and 2021, local authority services were the second highest referrer to CYP mental health services, with the highest referrer remaining GPs/primary care.[20] Education and advice are essential to ensure that CYP are referred to the most appropriate service and get the timely support they need.[21–23] This chimes with our finding that most of those who were unsuccessful were deemed to have not met the clinical threshold for CAMHS; and suggests that greater mental health support and training for education staff to support CYP within schools could mean fewer CYP are referred into secondary mental health services in the future.[24,25] This may be particularly pertinent following the COVID-19 pandemic when CYP no longer attended their GPs but continued to report psychological distress and symptoms.[26]

Quantitative

Consistent with the literature, we report that the rate of unsuccessful referrals ranged from 5% to 31% across three Trusts. GPs were most likely to refer CYP to CAMHS. However, the outcome of the referral was more likely to be unsuccessful from GPs than from other referrers which mirrors findings from the literature (30–32), although one paper suggested referrals from educational settings were more likely to be unsuccessful compared to GPs (29). We also report that although all Trusts collected some form of information about the characteristics of CAMHS referrals, data collected by Trusts were not standardised (7, 29). Across the four Trusts and nine CAMHS services, individual patient-level data, referrer characteristics, reason for referral and referral source were not consistent either between or within Trusts. However, we report wide variation in the numbers of referrals between and within Trusts and in the proportions not being successful for treatment. Predictors of unsuccessful referral included: younger CYP; if the referral is made by the GP; if the referral reason is anxiety disorders in one Trust; however, in other Trusts, referrals for emotional and behavioural difficulties are more likely to be unsuccessful. It is important to note that though there appear to be imbalances in referral outcomes between genders and different ethnic groups in some Trusts, there is no apparent association after adjusting for referral reason, that is some clinical characteristics driving the referral are likely to be more common in some genders or ethnicities.

Given the data that were available, we are only able to fit quite simplistic models to this incredibly complex system, so we make claims regarding causal processes here. However, as referral reason has been highlighted as a potential factor contributing to the referral outcome, it is important services collect these data for all CYP as accurately and consistently as possible.

Qualitative

Problems

Our focus groups identified a series of key problems with the referral process. These included lack of transparency in the stages of the referral process and what to expect at each stage; long waiting times; poor signposting while waiting

for CAMHS and if a referral was unsuccessful; high thresholds for CAMHS, that is moderate to severe mental health difficulties; a need to repeat information to different mental health professionals and having to go back to the beginning if referrals were not successful.

These findings are notable for their consistency with the existing literature which reports people experiencing that there is a lack of information about where to seek help as one of the main barriers to help-seeking from families.[27,28] However, the focus group discussions extend these findings in several important ways. For example, we found evidence of some non-CAMHS stakeholders 'blaming' CAMHS, and some CAMHS professionals 'blaming' non-CAMHS referrers. Solutions to this may need to be addressed by policy-makers to foster dialogue and improve collaboration between CAMHS and non-CAMHS, in line with results from Smith *et al.*[29]

In addition, for key referrers and CAMHS professionals, one of the main problems was the referral form itself. Some referrers did not fully complete the documentation finding it unwieldy and unclear. Specifically, stakeholders reported the forms were time-consuming to complete, and that it was unclear what was needed in some sections; this resulted in families needing to repeat information which added to their distress. This had not been identified as a 'pain point' in previous literature, but it is seen as an important problem for our stakeholder groups.

Children and young people, parents and carers also reported that the poor communication throughout the referral process was a major problem; and that an improved process meant better communication was critical. This is consistent with previous literature: a lack of contact with professionals and not feeling 'listened to' by professionals have both been identified as barriers to accessing support.[27,28] We have extended these findings and report that CYP in our stakeholder groups felt the entire referrals process needed to become more 'child-centred' and focused on their needs, in order to avoid them feeling side-lined by parents and professionals.

Solutions

We divided potential solutions into those that would be best delivered through nondigital/in-person mechanisms and those that would best suit digital solutions. Nondigital/in-person solutions included the ability for families (and potentially referrers) to have conversations with CAMHS professionals pre referral or pre assessment. In parallel, so-called 'in-person add-ons' to digital solutions that were suggested might include phone or online triage by CAMHS professionals; GPs having placements within CAMHS teams; and widespread public health messaging including broadly available and accessible leaflets and posters about what CAMHS is, what it does and what it does not provide. Solutions such as these need careful consideration as they could put further strain on services, as indicated by McNicholas *et al.*[30] In addition, some stakeholders suggested the need for more central funding for, and expansion of CAMHS provision, as opposed to community-based supports. Such resource diversion would have significant opportunity costs for the NHS and require rigorous evaluation for any additional potential benefit if they were to be sustainable long term.

Digital solutions were considered by many stakeholders as likely to have cost and clinical benefits. These included the potential future ability to standardise a referral form (with legacy paper version remaining); to facilitate more successful referrals because forms would include guidance at each step; alongside this, forms would include signposting where appropriate to alternative resources and services locally; they could also provide clear information about what is required for potential referrers;[23] and make forms accessible to all with minimum input from GPs; online training in CAMHS referral could become available, for referrers;[19] and regular, high-quality communication could be provided digitally about the referral for referrer/family with the opportunity to provide feedback.

Equality, diversity and inclusion

Enhancing Child and Adolescent Mental Health Services endeavoured to incorporate the views, perspectives and contributions of people from diverse backgrounds and at different points during the study, as seen through the PPI input at each stage of the project.

Chapter 9 Limitations

There was a high proportion of missing data from Trusts and services in the quantitative data, as well as inconsistencies with the labelling of variables from each service. To overcome this, the statistician consulted with CAMHS leads and CAMHS professionals to categorise the variables into broader groups. In the focus groups, there were 'imposter' participants in some groups.[31] 'Imposter participants' are defined as those who are dishonest, fraudulent or have fake identities to participate in focus groups or other qualitative research.[32] These individuals were identified on the basis of them not providing their job role/perspective during the discussion nor inputting into discussions, whether that be in the chat or using their microphone. The data from these participants was removed from the analysis. Although we strive to make our participants as inclusive and diverse as possible, we are aware that relatively small numbers of individuals represent large and very diverse populations of CYP, families CAMHS and other professionals. Future work should address the need for any solutions to be aware of cultural and other diversities.

Implications for services

Reducing the substantial number of inappropriate referrals to CAMHS offers the potential for high cost and resource savings that can be freed up for CYP and families already within CAMHS. In our view, the measures suggested by our findings to standardise referral forms and systems could positively affect waiting times for first CAMHS appointments by: reducing the high referral rates, reducing the length of referral meetings, increasing the quality of the referral information; reducing delays in decision-making and improving access to information about alternative services or self-help.[33] More efficient and effective referrals would facilitate success in referral rates and improve patient experience and relationships with referrers.[8] When freed from time constraints and tasks relating to incomplete and insufficient referrals, CAMHS specialists may also have more time for face-to-face appointments. In services where dedicated time to discuss referrals is not routine, greater availability can be carved out for direct contact (phone, e-mail) to prevent inappropriate and unsuccessful referrals, and to ensure those CYP who need to be seen do so.

We scoped feasible, scalable and acceptable solutions to help referrers make decisions about when, where and whom to refer. Taking account of the complexity of current systems and the high potential cost-benefits, an innovative, multidisciplinary approach with stakeholder co-designed solutions would provide a step-change in current referral mechanisms.

Recommendations

The following set of recommendations have been made based on the findings from EN-CAMHS:

1. CYP should be at the centre of the referral process and should properly take account of their needs rather than their possible diagnosis. More work is needed to understand how to achieve this in an age-, gender- and culturally appropriate way.
2. Clearer communication is needed about what CAMHS both is and does, and who CAMHS is for. Public health messaging around psychological distress in CYP needs to be better managed to reduce fear in parents and carers. Understandably the risk of suicide needs to be recognised; however, this also needs to be realistic as this is causing further distress for families making it difficult to reassure them. Throughout our focus groups, different stakeholders described 'gaming' of the system, whereby CYP were deemed at a greater risk of self-harm and suicide on referral forms to increase the likelihood of accessing CAMHS. Improved public health messaging around psychological distress could promote alternatives to CAMHS and reassure families when accessing CAMHS alternatives for support.
3. Rationalise current referral variation across CAMHS and reduce complexity by supporting Trusts to customise the referral process to signpost to available CAMHS and non-CAMHS resources in the local area.
4. Standardise the referral process and referral form across CAMHS. The referral form could be initiated by parents and carers or schools with minimal standard information and required, minimal input from GPs. The form could be

facilitated by drop-downs and links to information for alternative support specific to local resources available. The referral form should be accessible for those with English not as their first language and voice-assisted if needed.

5. Redirect children early on to more appropriate and available services. Signposting should occur as early as possible either before or within the referral form to ensure that CYP access the most appropriate service.
6. Improved communication throughout the referral process to allow families and referrers to be updated regularly about progress and available relevant alternative support/help. Our qualitative findings suggest better information would enable families and referrers to have a greater understanding of what constitutes an appropriate referral, when; and whether they have the information needed to make such a decision – optimising chances of a successful referral. A check-in with CAMHS either in-person (when necessary) or via online notifications to provide an update on the referral form. The check-in in-person would be with a member of staff involved in the screening and triage of referrals, for example. This would form part of staged, progressive sets of information which allows families to understand where they are in the referral pathway. For example, (1) a notification initially to inform the family and referrer that the referral has been logged; (2) information entered into the CAMHS system; (3) referral information has been prepared for triage etc.

Implications for decision-makers

- Current CAMHS referral processes are often distressing for CYP, parents, families and carers. They do not fulfil the needs of key referrers (GPs, CAMHS and school staff).
- Revisions to the CAMHS referral process are urgently needed.
- Implementing a nationally standardised and locally configurable digital platform could address many of the current problems.
- Such a solution needs to be developed with sustainability in mind.
- Trusts and providers must be supported to retain autonomy to customise the referral process to match their local and regional need.

Chapter 10 Patient and public involvement discussion

The involvement of service users and carers in the EN-CAMHS project has helped to ensure that the findings of this research are as relevant as possible to the needs of CYP and parents/carers/families. By regularly consulting our advisory groups, we have ensured that elements of the project, for example, research questions and recruitment strategies have been improved to allow us to address key areas and recruit the target number of participants, which has been absolutely essential because of the scale of this project. By gaining the insight of CYP, parents/carers and professionals throughout the course of the project, we ensured that research questions were presented in a way that participants were able to understand. As a result, the quality of data obtained from the focus groups was more meaningful. Furthermore, the opportunity to review key findings from focus groups with the YPAG and PPAG during the analysis phase helped as a 'sense check' to validate our initial interpretations of key themes and introduce new perspectives.

The YPAG and PPAG faced a few challenges during their operation. Firstly, we noticed CYP in the YPAG discussions often required some prompting to engage in discussions. Secondly, the PPAG faced the challenge of balancing dynamics; managing input from both parents and professionals during meetings while ensuring that members did not experience any distress was a delicate balancing act that required careful management of the discussion topics and the input provided by each member. Thirdly, there were delays in reimbursing all members for their time due to organisational finance processes, which could have caused frustration and inconvenience to the members involved. These issues would need attention in future groups to improve engagement and participation, ensure a balanced dynamic in the group, and ensure members feel valued.

Some of the discussions during the advisory group meetings identified solutions to the difficulties within the CAMHS referral process which were not realistic given the time and budget constraints of the project, for example, more staff and funding for CAMHS, or establishing neurodevelopmental pathways across all CAMHS. When advisory group members suggested solutions such as these, the project team were able to manage expectations of group members in terms of what could be changed and influence in terms of the project objectives. Overall, PPI input positively influenced EN-CAMHS throughout all stages of the project, the negative influences in relation to advisory group members' engagement and expectations were managed as they arose by members of the project team.

Overall, feedback from both PPAG and YPAG members about their experiences of being involved was positive, which was especially important given that for almost all members it was their first time contributing in this type of role, members who had previous experience felt that this was very little. Nonetheless, we did experience some challenges; for example, despite trying strategies to improve interactivity and participation, we noted difficulties at times with maintaining regular engagement, particularly among YPAG members. This could have been due to the fully online format of the meetings, as evaluation responses indicated. For example, feedback from both the YPAG and PPAG about what we could improve upon indicated that more regular project updates would have been helpful in between meetings, and more opportunities to contribute to the project outside of the advisory group meetings including in person.

On reflection, for future PPI activities as part of follow-on projects, we would include a combination of face-to-face and online meetings. More regular project updates will also be shared with group members via e-mail. In projects following on from EN-CAMHS, we shall also endeavour to include a more equal number of female and male participants in future advisory groups to ensure project adaptations and outputs are as relevant as possible.

Chapter 11 Conclusions

We envisaged that: (1) having accurate, accessible information about what local provision is and does; (2) having greater clarity about the referral process and standardised electronic (and alternative) forms with input from GPs required; and (3) providing CAMHS with complete clinical information prior to their initial assessment would reduce significantly the numbers of unsuccessful referral. Clinicians would be freed from chasing further information to supplement their assessment and formulation and this would improve efficiency, releasing their time for clinical duties. We also suggested this may reduce the number of inappropriate referrals and lead to improved throughput and reduced waiting times leading to better patient and clinician satisfaction and earlier interventions/diagnosis as appropriate. EN-CAMHS has furthered our understanding of current problems within the CAMHS referral process, both in terms of referral data collected by services and by providing a greater depth of understanding into the difficulties faced by stakeholders. EN-CAMHS has identified tractable solutions which could improve CAMHS referral success.

While we acknowledge this project has identified both digital and non-digital solutions to the current problems within the CAMHS referral process, implementing non-digital solutions can be costly, resource-dependent and less sustainable. In response to the EN-CAMHS findings, future work will co-design and evaluate a digital referral form linked to stakeholder resources in order to:

- Provide clarity around information requirements for successful referral.
- Provide clear accessible guidance to referrers from health and lay backgrounds.
- Take account of diversity and cultural differences.
- Provide specific tasks for GPs but focus on information gathered by CYP and families.
- Localise CAMHS and adjunct non-CAMHS support geographically and link to the referral form.
- Provide transparency in traffic lighting the progress through the referral.
- Understand how to link with in-person telephone triage.
- Signpost alternative pathways if thresholds for CAMHS are not met.

It can offer a range of benefits by providing a simple, clear way for children to get the right support for their mental health when they need it. By standardising the information collected on the referral form, referral data available from each Trust and service shall also be improved, for example, SES of those referred.

Future work will also include the need to:

- Identify enablers to widespread implementation of a standardised CAMHS referral mechanism across different referrers; and across CAMHS with various configurations.
- Understand how it can become widely successful and therefore embedded in services nationally.
- Evaluate its potential to reduce unsuccessful referrals and the potential cost-benefits to services, CYP and families.

Chapter 12 Dissemination activities

A project web page on the GM.Digital Research Unit's website was established and updated throughout the project (https://camhs.digital/enhancing-camhs-child-and-adolescent-mental-health-service-referrals-en-camhs/; accessed November 2024). The web page contained a link to the GM. Digital Research Unit's Twitter Profile (@GM_DigitalRU) which provided information about the project in engaging formats, accessible for lay audiences. Social media support was also obtained through the social media networks of the project team and collaborators including: MQ Mental Health Research, Anna Freud Centre, McPin Foundation, CAMHS.Digital, CAMHS.Network, NIHR GM ARC, PLACE, Calm Connections, GMMH media team.

Our collaborator MQ Mental Health Research, the leading charity for mental health research in the UK, worked with the project team to develop a dissemination strategy as outlined below:

1. MQ Mental Health Research Science Festival Presentation – October 2022.
2. Roundtable in London – January 2023.
3. Wider Dissemination Event, and Roundtable in Manchester – January 2023.
4. Podcast – after dissemination events as a culmination of the project. The podcast will be recorded by MQ Mental Health Research with PI, KMA.

The MQ Mental Health Research Science Festival presentation in October 2022 involved a 5-minute presentation and a 20-minute panel discussion. This was a virtual event with an audience of over 200 attendees, consisting of academics, practitioners and those with lived experience. This was the first occasion which presented preliminary findings of EN-CAMHS to a wider audience. During this presentation, some audience members felt that the aim of EN-CAMHS was to deter professionals or families referring CYP to CAMHS. This was helpful learning for the project team, as from their perspective, one of the main aims of EN-CAMHS was to streamline referrals into CAMHS to ensure that CYP were able to access the service in a timelier manner at the point of need. Addressing this point was then integrated into all future dissemination events so audiences have a clearer understanding of the aims of EN-CAMHS.

The Roundtable Discussion held in London in January 2023 involved the project team, MQ Mental Health Research, and 10 invitees from NHS England, Mental Health Foundations, NHS Trusts and those in a position to influence policy decisions. The session presented the preliminary findings of referral data and focus groups. Invitees were then asked to share their thoughts about the findings, and about future improvements to the CAMHS referral process. The aims of the roundtable discussion were to achieve a clearer understanding about:

- How this information could feed into a new model of CAMHS referral.
- What this might look like from a digital perspective.
- What other elements should a new model referral process include.
- How CAMHS transformation is likely to influence future standardisation of CAMHS referral processes.

Discussions aimed to answer the following questions:

1. To what degree can referral into CAMHS be standardised nationally?

Responses included:

- Difficult to standardise as multiple services could be involved, and different Trusts require different information.
- Important to be aware of shared identifiers and risk data.
- Referral forms need to be concise and integrated with existing systems or have an option to auto-populate fields.
- Referrals should include:
    - Service user/child/carer/family perspective.
    - Description of the problem.

- Description of the duration of need.
- Description of past support – social, criminal justice system, what has been successful/helpful and unsuccessful/unhelpful.
- Some description of what is hoped for from the CAMHS/referral.
- Assent from child.

2. What elements cannot be standardised?

Responses included:

- Supply and demand mismatch.
- Characteristics such as diagnostic categories, age, ethnicity and social class.
- Acceptance of referrals.
- Informing the public health response – integrated care systems have responsibility/mapping issues.

3. What is the ideal process – mode of delivery for each solution/step?

Responses included:

- Shared care model – like oncology, Hub and Spoke Model, in equilibrium.
- Integrated care boards (ICB) responsible for quality/standards.
- Single review of discharge.
- Model – entry point for complex, hub comes together, discharges hub comes together again to prevent escalation and provide support.
- Sustainability – embedded in commissioning.

4. Where are the digital and non-digital aspects likely to be best placed?

Responses included:

- GPs wanting a digital solution.
- Triage checking point of the journey to referral (Hampshire), but also signpost at each point – human/digital.
- Awareness of training all resources (including non-clinical).
- Peer supporters/human accompaniment.

A wider dissemination event was held **in January 2023** in Manchester. This presented key findings from the quantitative and qualitative data to an audience of over 60 people with a broad mix of experience in this area. Attendees included parents/carers/guardians and CYP, education professionals, CAMHS professionals and other interested parties. A scribe captured discussions from the day via a piece of artwork shown in *Figure 4*.

Feedback from attendees included:

- One hundred per cent of attendees who completed the evaluation felt that research was important (either quite or very).
- Eighty-three per cent of attendees who completed the evaluation were satisfied with the direction of research.
- Attendees learnt …
    - *'That this research has been done and now hopeful it can provide a national conversation about the current crisis for the NHS and its responses'.*
    - *'[About] the importance of the referral process and who is there at the single point of access that will determine the outcome of a CYP'.*

- *'There is a lot of confusion from young people and parents about what CAMHS entails and what services it provides'.*
- *'[About] the complexity of the issue'.*

Following the main dissemination event, there was a roundtable discussion with the project team, MQ Mental Health Research and eight invitees. This discussion focused on the following questions:

- What are the key requirements for an improved referral process?
  - CAMHS professionals used to be in all locations, families saw the highest-level professionals at the front door – now less experienced professionals are at the front door. There is a need to unblock and rationalise the system better.
  - Involve stakeholders in the design process as then more likely to use the system/solution.
  - A need to consider digital poverty and accessibility, as some cultures/communities will not use digital.
  - Define who the solution is for, that is GPs, families?
  - Need the right information any the right time.
  - Interoperability of the system is key.
- Where should we test this? That is what kind of variation do we need to capture in terms of trial sites if we are to test a solution?
  - Possibly repeat EN-CAMHS-type focus groups, also look at quant data on referral success/rates/wait times etc.
  - Trial in one locality to begin with.
  - Percentage of effect change would depend on what the outcome of the solution is.
- Who are our key collaborators that we need to involve in the next phase?
  - Integrated care systems, ICB, integrated care partnership (partnerships, multiple).
  - NHS England.
  - To develop a platform across the whole of England – need to adopt a top-down approach from organisations.
- What are we missing?/what problems do you foresee?
  - Development costs.
  - Who owns the system?
  - Who maintains the system?
  - Needs to be updated and sustained by local boroughs, if we build something that can be standardised nationally needs to be adapted to each local area.

Findings from the EN-CAMHS project were presented internationally at:

- The European Mental Health Conference, September 2023.
- The National Institutes of Health, Washington DC, Temple University, Philadelphia and The New York State Psychiatric Institute alongside other presentations relating to CYP mental health, October 2023.

The VoiceIn PPI app was used in these dissemination activities for the project and to gain direction on next steps.

Additional information

CRediT contribution statement

Kathryn M Abel (https://orcid.org/0000-0003-3538-8896): Conceptualisation (equal), Funding acquisition (equal), Investigation (equal), Methodology (equal), Supervision (equal), Writing – reviewing and editing (equal).

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Other contributions

Professor Kathryn Abel, University of Manchester, led and took responsibility across all work packages, she provided academic and clinical expertise throughout and is a NIHR Senior Investigator.

Dr Pauline Whelan, University of Manchester, had shared overall responsibility for the project and led on all digital elements.

Charlotte Stockton-Powdrell, University of Manchester, was the Senior Project Manager for EN-CAMHS and oversaw the work completed by the research associate.

Dr Lesley-Anne Carter, University of Manchester, is a statistician and led on the quantitative aspects including data collection and evaluation.

Heidi Tranter, Greater Manchester Mental Health NHS Foundation Trust, is a Research Associate who was involved in facilitating focus groups, analysis qualitative data and ensuring the project ran in a timely manner.

Dr Kerry Gutridge, University of Manchester, is qualitative research lead and led on collection and analysis of stakeholder consultation data and interview data.

Dr Lamiece Hassan, University of Manchester, was the PPIE lead on the project.

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Patient data statement

This work uses data collected by the NHS as part of their care and support. Using patient data is vital to improve health and care for everyone. There is huge potential to make better use of information from people's patient records, to understand more about disease, develop new treatments, monitor safety and plan NHS services. Patient data should be kept safe and secure, to protect everyone's privacy, and it is important that there are safeguards to make sure that they

are stored and used responsibly. Everyone should be able to find out about how patient data are used. #datasaveslives You can find out more about the background to this citation here: https://understandingpatientdata.org.uk/data-citation

Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

Ethics statement

This project was granted ethical approval (2021-12126-20663) by The University of Manchester's Research Ethics Committee on 19 October 2021.

Information governance statement

The Greater Manchester Mental Health NHS Foundation Trust and University of Manchester are committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, the University of Manchester is the Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here (www.manchester.ac.uk/discover/privacy-information/data-protection/).

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/GYDW4507.

Primary conflicts of interest: Professor Kathryn M Abel is co-Chair of the NIHR and Office for Life Sciences Mental Health Mission, the NIHR National Lead for Mental Health, the Greater Manchester Clinical Research Network Equality, Diversity and Inclusion Lead and an NIHR Senior Investigator.

Dr Pauline Whelan is a director and shareholder of CareLoop Health Ltd, a for-profit company that develops and markets digital therapeutics for mental health conditions, and a director of Prism Life Ltd, a small consultancy company.

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Appendix 1 Literature review: problems within the Child and Adolescent Mental Health Services referral process

Increased demand on Child and Adolescent Mental Health Services

- Crouch – high demand on services alongside parents' uncertainty about how to find the help they needed presented key hurdles for families.[27]
- Grant *et al.* – increasing school counselling provision did not increase referrals to CAMHS. Other factors within school settings, including higher proportion of White-British pupils, and poorer Ofsted inspection results were associated with increased referrals to CAMHS.[34]
- McNicholas *et al.* – in Ireland there was a significant drop in CAMHS referrals in 2020 from March to August during the pandemic, and this was also reflected in UK data. From September, routine and urgent referrals increased by 50%, and continued to rise. This unprecedented increase in referrals put further strain on already under resourced and underfunded services.[30]

Families accessing services

- Crouch
  - Factors that helped and/or hindered families accessing treatment were associated with parental recognition, contact with professionals, reaching CAMHS, parental effort, and parental knowledge and concerns.
  - Parental persistence and support from general practitioners and education professionals were critical roles in the referral process.[27]
- Hansen, Telléus, Mohr-Jensen and Lauritsen
  - Parents reported median 6-year duration of mental health difficulties prior to CAMHS referral in NDDs and 2.8 years for emotional disorders.
  - Barriers to accessing mental health support perceived by parents include lack of information about where to seek help, perception that professionals did not listen, and professionals refusing to initiate interventions or provide referral to service. Other barriers to help-seeking were a lack of knowledge, stigmatisation and unavailability. Long symptom duration and parent-rated impairment were associated with increased risk of reporting several barriers to help-seeking. Seeking help and encountering barriers could explain the treatment gap and long duration of mental health prior to referral.[28]
- Hansen, Christoffersen, Telléus and Lauritsen – most CYP referred to CAMHS have mental health problems years before referral.[35]
- Iskra *et al.* – help being too expensive was the highest ranked barrier, this included unknown cost factors, that is some services charged fees, and parents/carers having to take time off work for appointments.[36]
- Smith *et al.* – referral characteristics that is source, reason, and sociodemographic characteristics of CYP are not routinely collected. Hence, associations between these factors and other variables, for example wait times, likelihood of successful referral cannot be drawn.[29]

Reasons for referral

- Evans and Huws-Thomas – almost 40% of referrals to CAMHS were for support with self-harm, suicidal intent, thoughts or overdose. Nearly 20% of referrals were for support with depression, low mood and sadness represented the next highest figure, while just over 10% of reasons for referral were anxiety and depression. Overall, approximately 70% of referrals were for support with low mood.[37]

- Lambert *et al.* – most GPs saw their role as signposting and referring CYP with mental health difficulties to support services, rather than offering care directly.[38]
- Smith *et al.* – almost one-third of CAMHS referrals were for 'emotional and behavioural difficulties'.[29]

Who refers, and likelihood of a successful referral

- Evans and Huws-Thomas – GPs referred most frequently, and out of cases examined over 30% were referred back to the GP and no specific intervention was given.[37]
- Hansen *et al.* – educational services were generally the first contact for help-seeking, especially with regard to NDDs; however, referrals to CAMHS predominately came from GPs.[35]
- Hinrichs *et al.* – GPs felt identifying and detecting symptoms of mental health difficulties in CYP were challenging. They would refer to CAMHS based on mental health presentation and perceived likelihood of a successful referral. Referrals from GPs were three times more likely to be unsuccessful compared to other referrers. Communication between referrers varies depending on service relationships.[39]
- NSPCC – a key finding from a study of referrals to specialist CAMHS found that CYP referred by teachers were more likely to be unsuccessful than those referred by medical professionals.[6]
- Rocks *et al.* – similar to GP referrals, those self-referring to CAMHS via the single point of access were mainly from the least deprived areas.[40]
- Smith *et al.*
  - Most referrals to CAMHS were made by GPs.
  - Contrary to previous findings, referrals were more likely to be unsuccessful if referred by teachers and for emotional and behavioural difficulties.[29]

Possible digital solutions

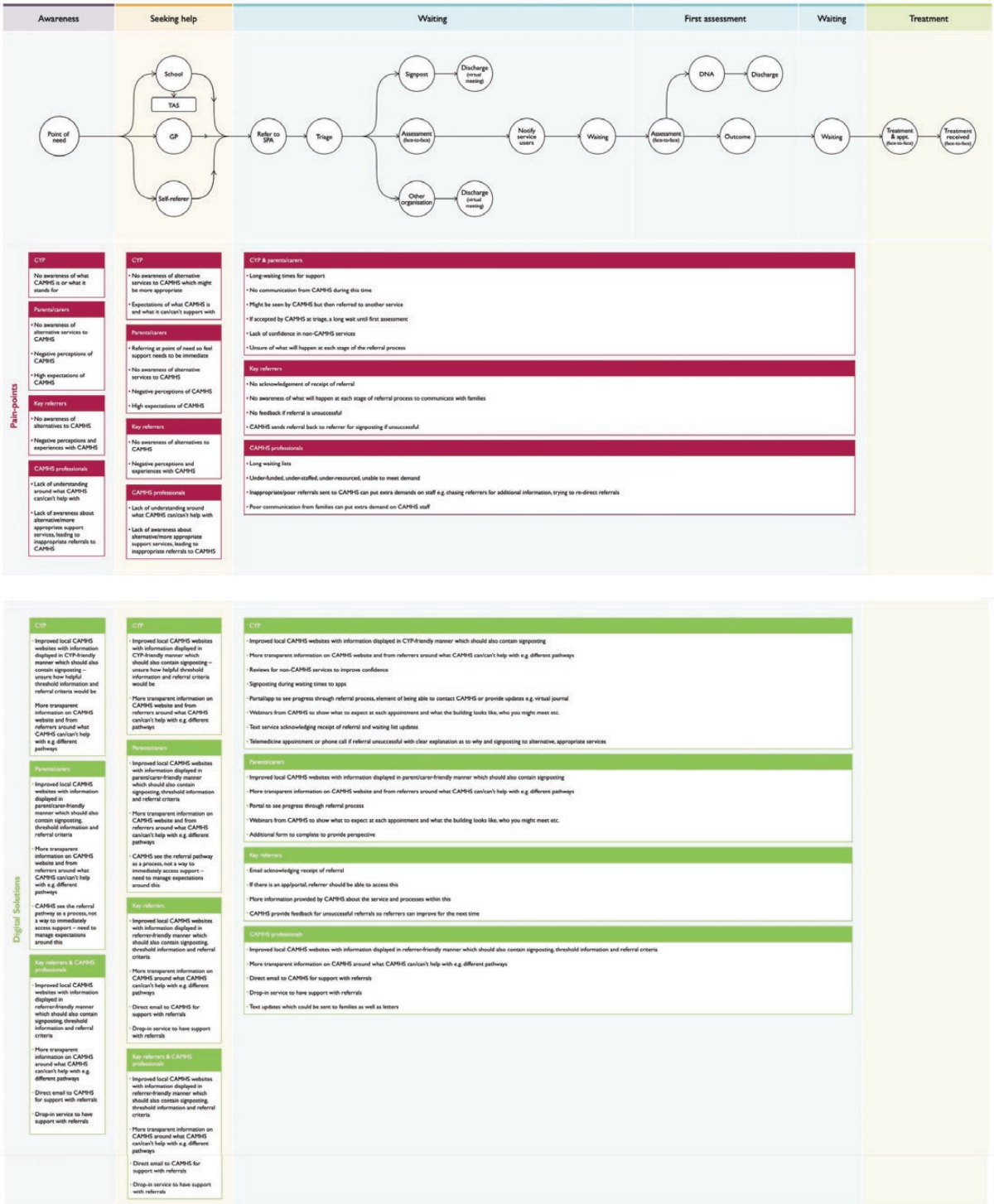
- Frith – understanding the referral journey and the reasons referral will help contextualise national data, and both inform and monitor service changes over time.[22]
- Hinrichs *et al.* – guidelines for referrers, especially GPs are needed to aid decision-making and improve understanding of the referral process.[39]
- Iskra *et al.* – more service-related information is needed to provide greater clarity of services not charging fees.[36]
- Lambert *et al.*
  - Greater clarity on CAMHS criteria and alternative support services available needed for referrers, especially GPs.
  - Increased training for GPs to support CYP with mental health difficulties.
  - Greater collaboration needed between referrers, for example GPs and school staff.[38]
- Royal College of Paediatrics and Child Health – information and guidance on mental health presentations in CYP is needed to ensure families access appropriate support provisions.[21]

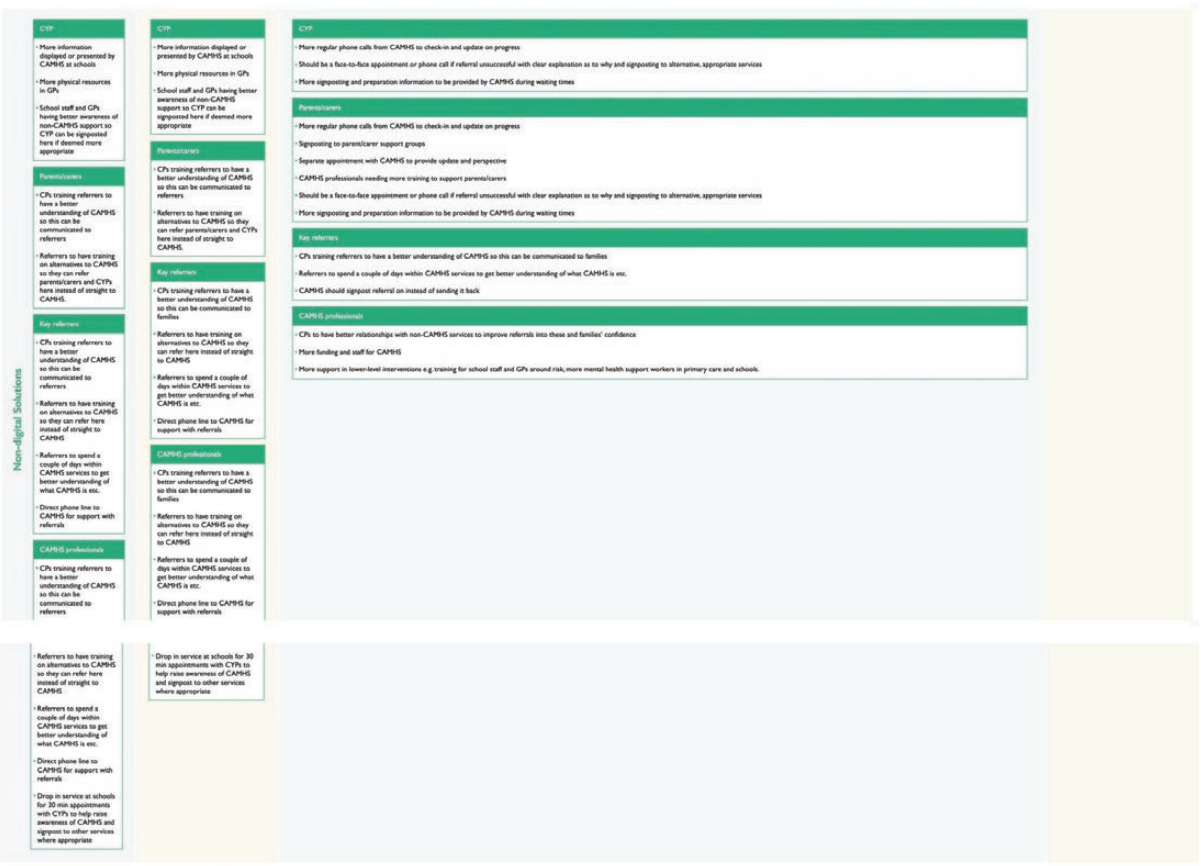
Alternative solutions

- The Children and Young People's Mental Health Taskforce – more clarity needed of processes within CAMHS and what to expect for CYP and families. Professionals need a greater awareness and understanding of listening to and building up a professional rapport with CYP and families. Services needs to be both appropriate and accessible.[23]
- Education and Health Select Committees
  - Training strategy and resource allocation needed, as well as clearly defined roles within services.
  - Majority of referrals were successful in rural CAMHS. Services were developed to focus more on supporting CYP with low mood.[19]
- Fazel *et al.* – single point of access in CAMHS aims to improve access to services for CYP to access to services. Introduction of this role has increased rates of self-referral in services which accept these. Other organisation changes including CYP being seen according to expected degree of psychopathology, and a greater prevalence of early intervention from voluntary and community sector organisations led to a 19% increase in new patients accessing CAMHS. Note these changes took time to implement.[41]

- Lambert *et al.* – primary mental health workers in GP settings could provide timely and accessible mental health advice which could improve access to specialist CAMHS.[38]
- McNicholas *et al.* – CAMHS requires additional funding which needs to be ring-fenced.[30]
- Rocks *et al.* – single point of access roles within CAMHS allows for greater access to CAMHS and awareness of what the services offers. Online referrals into CAMHS became more regularly used than telephone referrals. However, increased access to CAMHS brings challenges such as resources, appropriate staff to triage referrals, and consistent triage decisions.[40]
- Smith *et al.* – policy-makers should consider ways to improve collaboration and dialogue between referrers and CAMHS to improve timely access to support services for CYP. Research is needed to investigate the experiences of CYP who are unsuccessful following a referral to CAMHS.[29]

Appendix 2 Child and Adolescent Mental Health Services process map building on National Health Service England mapping





Appendix 3 Example topic guide for Child and Adolescent Mental Health Services Professionals

Research questions

- Do you refer many people to CAMHS services?
- How do you decide when to make a referral to CAMHS? What other options are there?
- How long does a referral usually take you? What information do you usually include?
- What information is available to you about referring to CAMHS?
- What, if any, difficulties have you experienced in the CAMHS referral process?
- Is there anything that works well in the referral process? If yes, please describe
- Is there more information that could be provided to help you with the referral process? What information would help?
- What specific local needs/pressures are there in your referral process?
- What challenges are there in the referral process?
- Are there any 'paint points' in the referral process that need to be addressed?
- How confident are you that your referral is needed?
- Do you have many referrals returned as inappropriate? If yes/no, why do you think that is?
- What would you consider an inappropriate referral?
- What happens when a referral is returned as inappropriate? Do you offer any other types of support or services?
- What is the impact of inappropriate referrals?

Appendix 4 Variation in children and young people demographics over time, by Trust

Year	Proportion female			Proportion white			Median age (years)		
	Trust D (%)	Trust B (%)	Trust A (%)	Trust D (%)	Trust B (%)	Trust A (%)	Trust D	Trust B	Trust A
2016	59		42	97		78	12		10
2017	53		42	94		77	13		10
2018	55	47	43	93	86	74	13	13	11
2019	55	50	44	93	87	74	14	13	11
2020	58	51	47	94	87	72	14	13	11
2021		54			90			13	

Appendix 5 Demographics presented by referral outcome – all localities summarised at Trust level

		Trust A (*n* = 8221)		Trust B (*n* = 22,511)		Trust D (*n* = 10,579)	
		Accept	Reject	Accept	Reject	Accept	Reject
Total referrals		79.0%	21.0%	68.9%	30.8%	95.4%	4.7%
Age	Median (IQR)	13 (10–15)	10 (7–13)	11 (8–14)	9 (6–13)	14 (11–15)	13 (9–15)
	Missing	0	0	0	0	0	0
Gender	Female	54.4%	36.2%	45.9%	39.0%	55.4%	54.9%
	Male	45.3%	63.7%	54.1%	61.0%	44.4%	44.9%
	Other	0.3%	≤ 0.2%	0%	≤ 0.1%	0.2%	≤ 0.6%
	Missing	≤ 0.1%	≤ 0.2%	≤ 0.1%	0%	55.4%	54.9%
Ethnicity	White	87.5%	86.5%	78.0%	73.6%	93.7%	96.4%
	Black	1.6%	1.9%	5.6%	7.5%	0.6%	≤ 0.6%
	Asian	7.0%	6.9%	6.7%	8.1%	1.6%	0.9%
	Mixed	2.7%	2.8%	7.5%	8.6%	3.4%	2.3%
	Other	1.2%	1.9%	2.2%	2.2%	0.7%	≤ 0.6%
	Missing	4.5%	9.7%	24.5%	39.0%	2.2%	4.5%
Clinical characteristics	Anxiety disorder	27.6%	10.3%	18.6%	15.2%	16.4%	42.7%
	Assessment and advice	3.4%	0.8%	0.2%	0.2%	0.2%	≤ 0.6%
	Drug and alcohol difficulties	≤ 0.1%	1.0%	≤ 0.1%	0%	0%	0%
	Eating disorders	0.3%	3.5%	0.2%	0.7%	0%	0%
	Emotional and behavioural difficulties	8.8%	30.8%	14.3%	25.0%	70.1%	12.4%
	Gender discomfort issues	0.5%	≤ 0.2%	0.3%	≤ 0.1%	0.1%	≤ 0.6%
	In crisis	10.3%	7.6%	0%	0%	0.8%	≤ 0.6%
	Mood disorder	21.2%	6.1%	15.5%	8.7%	5.0%	7.7%
	NDD/LD	13.0%	35.7%	33.8%	38.2%	0%	0%
	Physical health	0.3%	0.5%	0.4%	0.2%	2.9%	28.5%
	Self-harm/suicidal ideation	17.8%	3.5%	14.0%	2.1%	4.4%	7.1%
	Other	0%	0%	2.7%	9.7%	0%	0%
	Missing	≤ 0.1%	2.0%	69.0%	63.2%	0%	0%

		Trust A (*n* = 8221)		Trust B (*n* = 22,511)		Trust D (*n* = 10,579)	
		Accept	Reject	Accept	Reject	Accept	Reject
Referrer type	Community healthcare professional	6.4%	4.1%	14.2%	11.1%	0.3%	≤ 0.6%
	Crisis team	1.6%	4.6%	9.7%	1.2%	1.7%	0.8%
	Eating disorder service	0.2%	≤ 0.2%	0%	0%	0%	0%
	Education	11.8%	10.2%	14.9%	14.7%	7.0%	14.8%
	GP	53.2%	70.1%	42.0%	61.6%	21.9%	61.8%
	Healthcare professional	1.9%	2.0%	4.4%	3.3%	7.7%	6.5%
	Internal referral	5.9%	0.7%	3.5%	1.1%	6.0%	≤ 0.6%
	NDD service	0.2%	≤ 0.2%	≤ 0.1%	0%	0%	≤ 0.6%
	Non-CAMHS mental health service	9.8%	2.8%	0%	0%	6.4%	0%
	Parent/carer	≤ 0.1%	≤ 0.2%	≤ 0.1%	≤ 0.1%	6.7%	2.2%
	Self-referral	0.3%	0.5%	8.4%	4.4%	0.4%	0%
	Single point of access	≤ 0.1%	≤ 0.2%	0%	0%	30.3%	3.3%
	Social care	5.6%	2.3%	2.6%	2.5%	7.7%	7.1%
	Substance use team	0%	0%	0%	0%	0.1%	≤ 0.6%
	Voluntary and Community Sector	≤ 0.1%	0%	0%	≤ 0.1%	0.4%	0%
	Youth justice services	≤ 0.1%	≤ 0.2%	0.2%	0%	1.1%	≤ 0.6%
	Other	2.6%	2.1%	0%	0%	2.2%	1.8%
	Missing	≤ 0.1%	0.3%	4.2%	15.4%	0%	0%
Time to first contact (days)	Median (IQR)	28 (6–56)		35 (6–67)		58 (24–141)	
	Missing	983 (15%)		3028 (20%)		1924 (19%)	

IQR, interquartile range.

Appendix 6 Demographics presented by referral outcome – localities within Trust D

Trust data summarised by locality

		D(1) (*n* = 3846)		D(2) (*n* = 1067)		D(3) (*n* = 1809)		D(4) (*n* = 3857)	
		Accept	Reject	Accept	Reject	Accept	Reject	Accept	Reject
Total referrals		99.7%	0.3%	81.0%	19.0%	85.6%	14.4%	99.5%	0.5%
Age	Median (IQR)	14 (11–15)	12 (8–15)	14 (12–16)	12 (9–15)	14 (11–15)	13 (9–15)	13 (9–15)	8 (4–14)
	Missing	0	0	0	0	0	0	0	0
Gender	Female	99.7%	0.3%	81.0%	19.0%	85.6%	14.4%	99.5%	0.5%
	Male	56.1%	≤ 30%	60.3%	60.6%	56.0%	52.3%	53.6%	44.4%
	Other	43.9%	70%	39.7%	39.4%	44.0%	47.7%	46.4%	55.6%
	Missing	0%	0%	0%	0%	0%	0%	0%	0%
Ethnicity	White	≤ 0.1%	0%	≤ 0.4%	0%	0.4%	≤ 1.2%	0.3%	0%
	Asian	91.6%	80%	97.0%	98.9%	97.2%	96.1%	98.5%	82.4%
	Black	1.0%	≤ 30%	≤ 0.4%	0%	0.5%	0%	0.4%	0%
	Mixed	2.9%	≤ 30%	≤ 0.4%	0%	0.5%	≤ 1.2%	1.1%	0%
	Other	3.2%	0%	1.9%	≤ 1.5%	1.5%	2.4%	4.5%	≤ 17.6%
	Missing	1.4%	0%	0.5%	0%	0.3%	≤ 1.2%	0.4%	0%
Clinical characteristics	Anxiety disorder	1.9%	0%	10.7%	6.9%	0.8%	2.7%	1.2%	≤ 17.6%
	Assessment and advice	7.2%	≤ 30%	66.0%	62.6%	16.2%	30.7%	14.5%	≤ 17.6%
	Drug and alcohol difficulties	≤ 0.1%	0%	≤ 0.4%	≤ 1.5%	≤ 0.2%	0%	0.4%	0%
	Eating disorders	0%	0%	0%	0%	0%	0%	0%	0%
	Emotional and behavioural difficulties	0%	0%	0%	0%	0%	0%	0%	0%
	Gender discomfort issues	85.0%	80%	8.7%	15.8%	51.1%	2.7%	76.7%	77.8%
	In crisis	≤ 0.1%	0%	0.6%	≤ 1.5%	≤ 0.2%	≤ 1.2%	≤ 0.1%	0%
	Mood disorder	0.4%	0%	4.5%	≤ 1.5%	1.3%	0%	0.2%	≤ 17.6%
	NDD/LD	4.4%	0%	8.6%	8.4%	6.7%	7.3%	4.2%	≤ 17.6%
	Physical health		0%	0%	0%	0%	0%	0%	0%
	Self-harm/suicidal ideation	≤ 0.1%	0%	≤ 0.4%	≤ 1.5%	18.4%	52.5%	0.3%	0%

		D(1) (*n* = 3846)		D(2) (*n* = 1067)		D(3) (*n* = 1809)		D(4) (*n* = 3857)	
		Accept	Reject	Accept	Reject	Accept	Reject	Accept	Reject
	Other	2.8%	0%	11.3%	8.9%	6.2%	6.5%	3.8%	0%
	Missing	0%	0%	0%	0%	0%	0%	0%	0%
Referrer type	Community health-care professional	0%	0%	0%	0%	0%	0%	0%	0%
	Crisis team	≤ 0.1%	0%	≤ 0.4%	0%	0.5%	≤ 1.2%	0.5%	≤ 17.6%
	Eating disorder service	1.2%	0%	5.6%	2.0%	2.2%	0%	1.1%	0%
	Education	0%	0%	0%	0%	0%	0%	0%	0%
	GP	3.6%	0%	10.3%	10.8%	16.7%	19.5%	5.9%	
	Healthcare professional	20.7%	0%	60.8%	75.9%	20%	55.9%	15.2%	22.2%
	Internal referral	2.6%	≤ 30%	5.8%	7.4%	16.0%	5.4%	9.9%	≤ 17.6%
	NDD service	7.7%	0%	5.4%	≤ 1.5%	8.5%	≤ 1.2%	3.5%	0%
	Non-CAMHS mental health service	0%	0%	0%	≤ 1.5%	0%	0%	0%	0%
	Parent/carer	9.5%	0%	4.6%	0%	8.1%	0%	3.1%	0%
	Self-referral	2.4%	0%	0%	0%	11.2%	3.8%	10.7%	≤ 17.6%
	Single point of access	0.2%	0%	0%	0%	0.6%	0%	0.5%	0%
	Social care	42.7%	70%	0%	0%	≤ 0.2%	0%	37.0%	50%
	Substance use team	7.0%	≤ 30%	3.8%	2.5%	10.8%	10.3%	7.9%	≤ 17.6%
	Voluntary and Community Sector		0%	0%	0%	0.5%	≤ 1.2%	0%	0%
	Youth justice services	≤ 0.1%	0%	0%	0%	0.4%	0%	0.8%	0%
	Other	1.5%	0%	0.6%	0%	1.2%	≤ 1.2%	0.8%	0%
	Missing	0.9%	0%	3.0%	0%	3.2%	3.5%	3.0%	0%
Time to first contact (days)	Median (IQR)	64 (32–115)		30 (14–48)		25 (14–60)		115 (32–222)	
	Missing	728 (19%)		469 (54%)		100 (6%)		627 (16%)	

IQR, interquartile range.

Appendix 7 Demographics presented by referral outcome – localities within Trust B

Trust data summarised by locality

		B(3) (*n* = 9570)		B(1) (*n* = 5439)		B(2) (*n* = 7502)	
		Accept	Reject	Accept	Reject	Accept	Reject
Total referrals		74.3%	25.5%	70.6%	28.7%	60.7%	39.2%
Age	Median (IQR)	11 (8–14)	10 (6–13)	11 (7–14)	8 (5–12)	11 (8–14)	9 (7–13)
	Missing	0	0	0	0	0	0
Gender	Female	46.4%	41.8%	45.6%	33.7%	45.1%	39.5%
	Male	53.5%	58.1%	54.3%	66.3%	54.8%	60.5%
	Other	≤ 0.1%	≤ 0.3%	≤ 0.3%	0%	≤ 0.1%	≤ 1.0%
	Missing	0%	0%	≤ 0.3%	0%	≤ 0.1%	0%
Ethnicity	White	92.6%	91.4%	51.5%	44.1%	73.7%	73.4%
	Black	1.5%	2.2%	12.4%	15.9%	7.5%	7.9%
	Asian	1.2%	1.1%	18.3%	21.1%	7.1%	7.3%
	Mixed	3.8%	4.3%	13.4%	15.0%	9.3%	8.9%
	Other	1.0%	0.9%	4.4%	4.0%	2.4%	2.5%
	Missing	17.1%	35.7%	29.2%	40.2%	32.1%	41.2%
Clinical characteristics	Anxiety disorders	92.6%	18.8%	13.8%	9.9%	20%	61.7%
	Assessment and advice	1.5%	≤ 0.3%	0%	0%	≤ 0.1%	≤ 1.0%
	Drug and alcohol difficulties	≤ 0.1%	0%	0%	0%	0%	3.3%
	Eating disorders	3.8%	0.8%	≤ 0.3%	≤ 0.4%	≤ 0.1%	34.0%
	Emotional and behavioural difficulties	1.0%	30.8%	17.7%	34.8%	5.4%	0%
	Gender discomfort issues	17.1%	≤ 0.3%	≤ 0.3%	0%	≤ 0.1%	0%
	In crisis	0%	0%	0%	0%	0%	0%
	Mood disorders	0.4%	11.3%	19.6%	7.2%	9.4%	7.0%
	NDD/LD	30.6%	31.4%	31.7%	43.9%	44.0%	41.1%
	Physical health	0.3%	0.5%	0%	0%	0%	≤ 1.0%
	Self-harm/suicidal ideation	92.6%	3.6%	15.6%	0.8%	13.1%	1.5%
	Other	1.5%	2.4%	1.4%	3.0%	7.8%	24.7%
	Missing	62.7%	60.1%	71.1%	50.8%	77.0%	72.3%

		B(3) (*n* = 9570)		B(1) (*n* = 5439)		B(2) (*n* = 7502)	
		Accept	Reject	Accept	Reject	Accept	Reject
Referrer type (categories)	Community healthcare professional	12.9%	8.4%	14.1%	16.9%	16.6%	10.1%
	Crisis team	7.9%	1.0%	14.1%	0.7%	8.8%	1.7%
	Eating disorder service	0%	0%	0%	0%	0%	0%
	Education	11.7%	7.2%	19.2%	20.5%	16.4%	19.5%
	GP	46.9%	72.9%	39.9%	51.5%	35.5%	55.4%
	Healthcare professional	2.8%	2.0%	2.3%	4.8%	9.0%	3.7%
	Internal referral	3.2%	0.9%	4.2%	1.1%	3.2%	1.3%
	NDD service	≤ 0.1%	0%	≤ 0.3%	0%	≤ 0.1%	0%
	Non-CAMHS mental health service	≤ 0.1%	0%	≤ 0.3%	0%	0%	0%
	Parent/carer	≤ 0.1%	≤ 0.3%	≤ 0.3%	0%	≤ 0.1%	≤ 1.0%
	Self-referral	12.0%	6.5%	3.1%	1.5%	6.9%	4.1%
	Single point of access	0%	0%	0%	0%	0%	0%
	Social care	2.0%	1.1%	2.8%	3.0%	3.3%	4.0%
	Substance use team	0%	0%	0%	0%	0%	0%
	Voluntary and Community Sector	≤ 0.1%	0%	≤ 0.3%	0%	≤ 0.1%	≤ 1.0%
	Youth justice services	0.3%	0%	0.2%	0%	≤ 0.1%	0%
	Other	0%	0%	0%	0%	0%	0%
	Missing	0.8%	1.4%	4.7%	4.7%	9.2%	32.6%
Time to first contact (days)	Median (IQR)	31 (6–72)		29 (4–68)		41 (9–63)	
	Missing	1261 (18%)		798 (21%)		969 (21%)	

IQR, interquartile range.

Appendix 8 Demographics presented by referral outcome – localities within Trust A

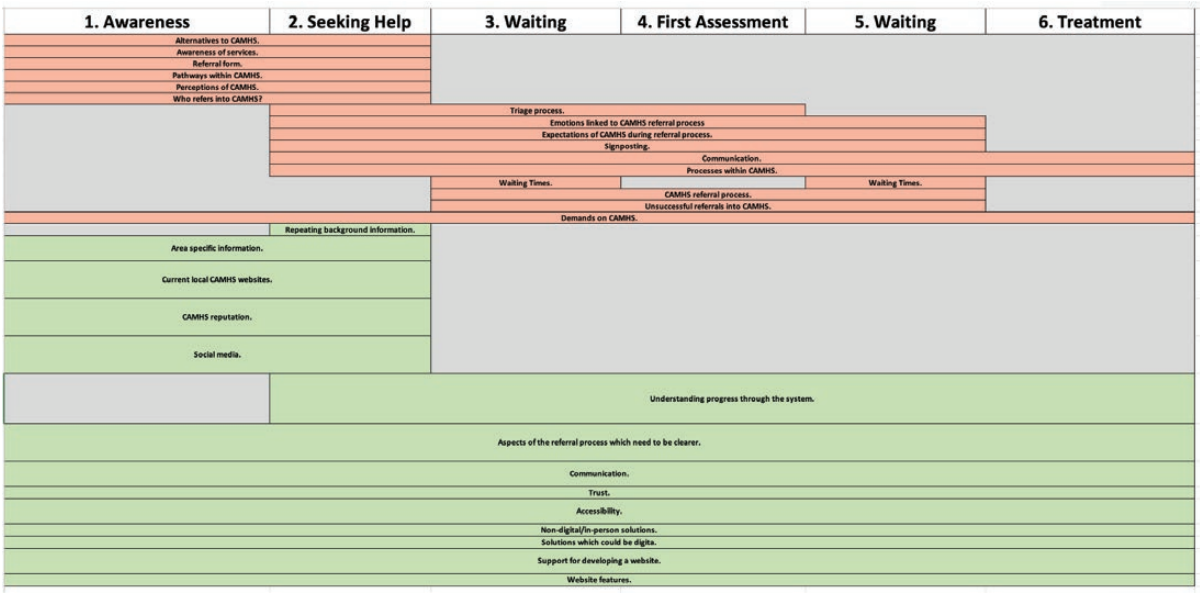
Trust data summarised by locality

		A(1) (*n* = 7901)		A(2) (*n* = 320)	
		Accept	**Reject**	**Accept**	**Reject**
Total referrals		78.3%	21.7%	97.2%	2.8%
Age	Median (IQR)	13 (10–15)	10 (7–13)	13 (10–15)	11 (8–12)
	Missing	0	0	0	0
Gender	Female	54.3%	36.1%	56.9%	66.7%
	Male	45.4%	63.9%	43.1%	≤ 33.3%
	Other	0.3%	≤ 0.2%	0%	0%
	Missing	≤ 0.1%	≤ 0.2%	0%	0%
Ethnicity	White	87.3%	86.5%	96.4%	80%
	Black	1.7%	1.9%	≤ 1.0%	0%
	Asian	7.2%	6.9%	0%	0%
	Mixed	2.7%	2.8%	2.6%	0%
	Other	1.2%	1.9%	≤ 1.0%	≤ 33.3%
	Missing	2.8%	9.5%	38.3%	44.4%
Clinical characteristics	Anxiety disorders	27.7%	10.4%	26.7%	0%
	Assessment and advice	1.0%	0.6%	46.3%	55.6%
	Drug and alcohol difficulties	≤ 0.1%	1.0%	≤ 1.0%	0%
	Eating disorders	0.3%	3.5%	17.4%	0%
	Emotional and behavioural difficulties	7.9%	30.6%	0%	0%
	Gender discomfort issues	0.5%	≤ 0.2%	≤ 1.0%	0%
	In crisis	10.4%	7.6%	0%	0%
	Mood disorders	20.8%	6.1%	8.7%	0%
	NDD/LD	13.1%	35.9%	0%	0%
	Physical health	0.3%	0.5%	0%	0%
	Self-harm/suicidal ideation	17.9%	3.6%	≤ 1.0%	0%
	Other	0%	0%	0%	0%
	Missing	≤ 0.1%	2.0%	0%	44.4%
Referrer type (Categories)	Community healthcare professional	6.6%	4.1%	3.5%	0%
	Crisis team	1.7%	4.6%	0%	0%
	Eating disorder service	0.2%	≤ 0.2%	0%	0%

		A(1) (*n* = 7901)		A(2) (*n* = 320)	
		Accept	Reject	Accept	Reject
	Education	9.4%	9.9%	59.8%	66.7%
	GP	55.9%	70.5%	0%	0%
	Healthcare professional	2.0%	1.9%	0%	≤ 33.3%
	Internal referral	6.2%	0.7%	0%	0%
	NDD service	0.2%	≤ 0.2%	0%	0%
	Non-CAMHS mental health service	10.3%	2.9%	0%	0%
	Parent/carer	≤ 0.1%	≤ 0.2%	≤ 1.0%	0%
	Self-referral	0.3%	0.5%	0%	0%
	Single point of access	≤ 0.1%	≤ 0.2%	0%	0%
	Social care	4.1%	2.2%	35.7%	≤ 33.3%
	Substance use team	0%	0%	0%	0%
	Voluntary and Community Sector	≤ 0.1%	0%	0%	0%
	Youth justice services	≤ 0.1%	≤ 0.2%	0%	0%
	Other	2.7%	2.2%	≤ 1.0%	0%
	Missing	≤ 0.1%	0.3%	0%	0%
Time to first contact (days)	Median (IQR)	29 (5–56)		25 (8–49)	
	Missing	863 (14%)		120 (39%)	

IQR, interquartile range.

Appendix 9 Problem and solution themes across the stages of the referral process from National Health Service England



Red is problem, green solution.

Appendix 10 Trust ethnicity data and how these map onto local areas

Ethnicity		Local area
Trusts A and B		
White	87.3%	56.8%
Black	1.7%	11.9%
Asian	6.9%	20.1%
Mixed	2.7%	5.3%
Other	1.4%	5.1%
Trust C		
White	87.3%	75.4%
Black	1.7%	< 2.0%
Asian	6.9%	20.5%
Mixed	2.7%	< 2.0%
Other	1.4%	< 2.0%
Trust D		
White	87.3%	97.6%
Black	1.7%	0.2%
Asian	6.9%	1.1%
Mixed	2.7%	0.8%
Other	1.4%	0.3%

EME
HSDR
HTA
PGfAR
PHR

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