

Enhancing CAMHS Referrals (En-CAMHS) Protocol

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EN-CAMHS

RESEARCH REFERENCE NUMBERS

UREC Number: *To be added when approval granted*

SPONSORS Number: *To be added when provided by sponsor*

FUNDERS Number: NIHR131379

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: --Protocol still under review--

Date:

...../...../.....

Name (please print):

Sarah Leo.....

Position: Head of Research & Innovation Office.....

Chief Investigator:



Date:

28/05/2021

Signature:

Name: (please print):

Prof Kathryn Abel.....

Statistician:



Date:

01/06/2021

Signature:

Name: (please print):

Dr Lesley Anne Carter

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LIST OF ABBREVIATIONS

CAMHS	Child and Adolescent Mental Health Services
CYP	Children and Young People
GM	Greater Manchester
PIS	Participant Information Sheet
PPAG	Parent and Professional Advisory Group
SMG	Study Management Group
SSC	Study Steering Committee
YPAG	Young Person's Advisory Group

KEY STUDY CONTACTS

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Committees	<p>Project Steering Committee: <i>Subject to NIHR Approval</i></p> <p>Chair: TBC</p> <p>Statistician: TBC</p> <p>Dr Nicola Preston Faculty of Health, Education and Society University of Northampton, University Drive, Northampton, NN1 5PH Nicola.Preston2@northampton.ac.uk</p> <p>Jessica Streeting Central London Community Healthcare NHS Trust 5 Parsons Green Fulham, London SW6 4UU jessicastreeting@nhs.net</p> <p>Mark Brown Social Spider CIC The Mill, 7-11 Coppermill Lane, Walthamstow, London E17 7HA markbrown1977@gmail.com</p> <p>Sarah Brooke brookesarah1@gmail.com</p> <p>Dr. Pooky Knightsmith pooky@inourhands.com</p> <p>Myrvete Gashi (PPI) Contact via Zara Bernard</p> <p>Dawn Allen (PPI) Contact via Zara Bernard</p>

STUDY SUMMARY

Study Title	Enhancing CAMHS Referrals
Internal ref. no. (or short title)	En-CAMHS
Study Design	Mixed methods: Qualitative (key stakeholder focus groups) and quantitative (CAMHS referral data)
Study Participants	<p>CAMHS Stakeholders who have had experience with the CAMHS referral process, including:</p> <ul style="list-style-type: none"> • CAMHS staff • Collaborators • Children and young people (CYP) • Key referrers (e.g., GPs, teachers, SENCOs, community paediatricians, social workers) • Parents/carers • CAMHS commissioners • Mental Health Leads
Planned Size of Sample (if applicable)	We aim to recruit 120 CAMHS stakeholders to take part in 12 focus groups
Follow up duration (if applicable)	N/A
Planned Study Period	20 months (1 st May 2021 – 31 st December 2022)
Research Aims	<p>The aims of this research are to:</p> <ol style="list-style-type: none"> 1. Examine current challenges within the CAMHS referrals process and 2. Identify low-cost, accessible, sustainable solutions to help referrers, designed to reduce the number of unsuccessful/inappropriate referrals
Objectives	<ol style="list-style-type: none"> i. extensively engage key CAMHS stakeholders to explore what does and does not work in the current referral processes across different sites and CAMHS providers ii. map and examine the various configurations of CAMHS services (including service eligibility criteria) iii. map and analyse referral and inappropriate referral rates against possible explanatory variables (e.g., age, sex, ethnicity, index of multiple deprivation) iv. identify possible sustainable solutions to support more successful and appropriate referrals in collaboration with key CAMHS stakeholders v. identify the complexities of implementing sustainable solutions across CAMHS settings

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	FINANCIAL AND NON FINANCIAL SUPPORT GIVEN
National Institute for Health Research Health Services and Delivery Research Programme	£320,417.80

ROLE OF STUDY SPONSOR AND FUNDER

Department of Health definition of a sponsor: An individual, organisation or group taking on responsibility for securing the arrangements to initiate, manage and finance a study. A group of individuals and/or organisations may take on sponsorship responsibilities and distribute them, by agreement, amongst the members of the group, provided that, collectively, they make arrangements to allocate all the responsibilities that are relevant to the study.

Summary of Sponsor Responsibilities:

- taking responsibility for putting and keeping in place arrangements to initiate, manage and fund the study
- confirming that everything is ready for the research to begin
- satisfying itself the research protocol, research team and research environment have met the appropriate scientific quality assurance standards
- satisfying itself the study has ethical approval before relevant activity begins
- allocating responsibilities for the management, monitoring and reporting of the research
- ensuring that appropriate arrangements are in place to approve any modifications to the design, obtaining any regulatory authority required, implementing such modifications and making them known
- satisfying itself that arrangements are kept in place for good practice in conducting the study and for monitoring and reporting, including prompt reporting of suspected unexpected serious adverse events or reactions.

For full details of sponsor definitions and responsibilities please refer to the Department of Health's Governance Framework for Health & Social Care (2nd Edition 2005).

Sponsor: Greater Manchester Mental Health NHS Foundation Trust (GMMH) will assume overall responsibility for the project. GMMH sponsorship regulations are outlined in RD SOP14 Trust Sponsorship of Research (GMMH) <https://www.gmmh.nhs.uk/search/text-content/ri-standard-operating-procedures-sops-and-guidance-documents--1739>

Funder: National Institute for Health Research Health Services and Delivery Research Programme. The role and responsibilities of the funder are outlined in the contract between the Secretary of State for Health and Greater Manchester Mental Health NHS Foundation Trust Version number: 2/18 NHS Feb 18

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITTEES/GROUPS & INDIVIDUALS

Study Steering Committee (SSC): The role of the SSC is to provide overall supervision for a project on behalf of the Project Sponsor and Project Funder and to ensure that the project is conducted to the

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.

The main features of the SSC are as follows:

- To provide advice, through its Chair, to the Project Funder, the Project Sponsor, the Principal Investigator, the Host Institution and the Contractor on all appropriate aspects of the project
- To concentrate on progress of the trial/project, adherence to the protocol, patient safety (where appropriate) and the consideration of new information of relevance to the research question
- The rights, safety and well-being of the participants are the most important considerations and should prevail over the interests of science and society
- To ensure appropriate ethical and other approvals are obtained in line with the project plan
- To agree proposals for substantial protocol amendments and provide advice to the sponsor and funder regarding approvals of such amendments
- To provide advice to the investigators on all aspects of the project.

Project Management Group (PMG): The Project Management Group will consist of the co-Principal Investigators, the Project Manager, and the Key Protocol Contributors. The group will hold monthly meetings throughout the study to review progress against the Project Management Plan.

Patient and Public Involvement Groups: There will be two Patient and Public Involvement (PPI) groups during this study, a Young Persons Advisory Group (YPAG) and a Parents/carers and Professionals Advisory Group (PPAG). These groups will meet bimonthly and quarterly, respectively, to review and feedback on the study and ensure young people and their parents/carers/families influence decision making.

PROTOCOL CONTRIBUTORS

Professor Kathryn Abel, (KMA) is Professor of Psychological Medicine and Director of the Centre for Women's Mental Health at the University of Manchester. She is Honorary Consultant Psychiatrist and Co-Director of the CAMHS.Digital Research Unit at Greater Manchester Mental Health.

CAMHS.Digital has the specific scope of working with CYP to develop scalable and valued digital solutions to improve CYP mental health and wellbeing. She is NIHR National Specialty Lead for Mental Health, an NIHR Senior Investigator and European Research Council Fellow. She has many years' experience leading and successfully completing large scale mental health research trials. KMA will have overall responsibility for the project and oversee all work packages of the project.

Dr Pauline Whelan (PW), is Co-Director of the GMMH CAMHS.Digital Research Unit which aims to develop and evaluate evidence-based technologies to improve the mental health and wellbeing of YP. She is also a Digital Health Technical Lead and the co-lead for the Connected Health academic theme at the Centre for Health Informatics, University of Manchester. She has 20+ years' experience developing and deploying digital solutions across a range of research, healthcare and industry projects and is also an experienced PPI facilitator and mixed methods researcher. PW will have joint lead-applicant responsibilities, attend all PMG meetings, and advise on the potential for digital health technologies to support the range of potential solutions in WP1.

Dr Julian Edbrooke-Childs (JEC), is Head of Digital Development and Evaluation at Anna Freud National Centre for Children and Families, Associate Professor of Evidence Based Child and Adolescent Mental Health at University College London, and Deputy Director of the Evidence based Practice Unit. His research covers three main areas: empowering young people, implementation science, and digital innovations. He has extensive experience of developing and evaluating digital mental health interventions for young people, publishing in leading journals in this field (e.g., the

Journal of Medical Internet Research) and computer science conferences. JEC will attend all PMG meetings and advise on YP inequalities across the project.

Dr Rachel Elvins, (RE), MD, FRCPsych is a Consultant Child and Adolescent Psychiatrist working in central Manchester. Clinically she has worked in a wide range of CAMH settings from community outreach to specialist inpatient facilities. Her research interests focus on eating and mood disorders in adolescents, treatment of autistic spectrum conditions, digital treatments in mental health and process measures in treatment trials, particularly the therapeutic alliance. Rachel co-leads the CAMHS research hub in MFT Trust which produces a range of high-quality research, and in collaboration with other research and clinical institutions. RE will attend all PMG meetings, provide clinical input into all work packages and coordinate local trial site in MFT.

Dr Kerry Gutridge (KG), is a Research Fellow, based at the University of Manchester. She is an experienced qualitative researcher who will lead the qualitative aspects of the research. She is the PI for a digital feasibility and acceptability grant to develop an app for women in prison who self-harm.

Rachel Green (RG), is the Head of Operations for CAMHS at Greater Manchester Mental Health and has been in this role for 4 years. Rachel is a Registered Mental Health Nurse who has been qualified for 25+ years and has a range of experience working in different roles, both clinical and managerial, within the Trust's Specialist Services Network. She provides senior operational leadership across all GMMH CAMHS services, which include both community and in-patient settings.

Dr Lesley-Anne Carter (LAC), is a Lecturer in Biostatistics at the University of Manchester, specialising in clinical trials methodology. She has a particular focus on the design and analysis of cluster trials and has expertise in multilevel modelling. In addition, she has experience with feasibility studies and is a member of the North West RfPB Regional Advisory Committee. LAC will attend all PMG meetings and lead on the analysis of the referral data.

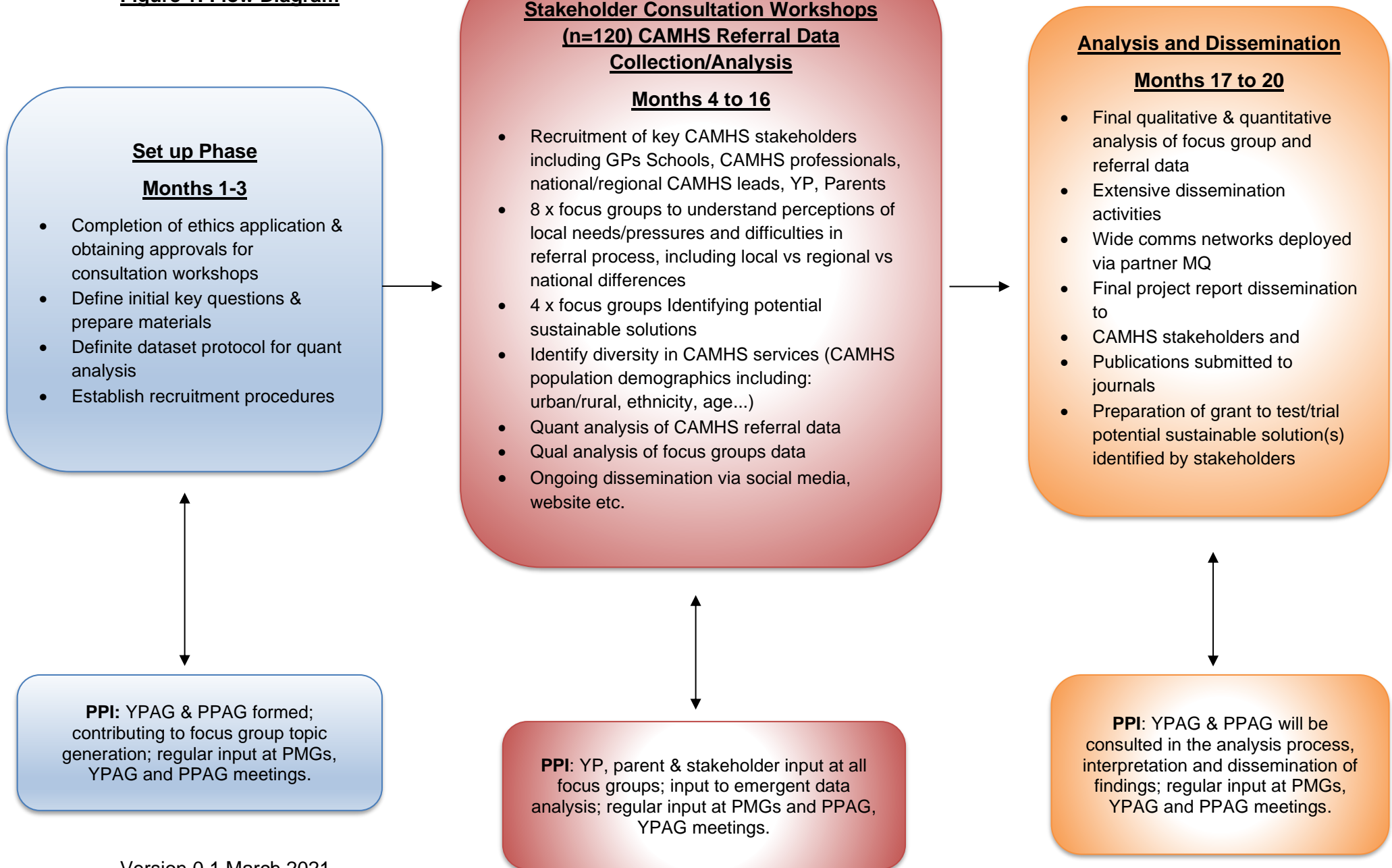
Dr Lamiece Hassan (LH), is a Health Data Research UK Research Fellow, based at University of Manchester. She specialises in using participatory approaches from the social sciences, health informatics and computer science to explore user experiences, acceptability, preferences and ethical issues relevant to digital and data-driven health interventions. She is public involvement and engagement lead for the Division of Informatics, Imaging and Data Sciences. LH will attend all PMG meetings and lead on all PPI activities.

Zara Bernard (ZB), the Project Manager, is a Research Associate at Greater Manchester Mental Health NHS Trust (GMMH). She will be responsible to the day-to-day project management and oversight. She is an experienced research associate who has conducted research with healthy and vulnerable populations, including research on sensitive topics.

KEY WORDS:

CAMHS, referral, children and young people, care pathway, service configurations

Figure 1: Flow Diagram



Enhancing CAMHS referrals (EN-CAMHS)

1 BACKGROUND

Three quarters of mental health problems emerge in childhood and adolescence. Recent reports suggest that around 1 in 8 children and young people (CYP) has a mental disorder, with overall rates continuing to rise [1-3]. In this context, the recent Education Policy Institute (EPI) report makes for salutary reading: 54 of the 60 providers responding to the Freedom of Information requests reported a total of 264,733 referrals in 2017/18, on average 21.1% were deemed inappropriate. This rapid rise in overall number of referrals to Child and Adolescent Mental Health Services (CAMHS), increasing by 26 per cent over the last five years, equates to at least 55,800 children referred being rejected; the true number will be higher given that 10% of providers did not respond [4]. The number of referrals deemed inappropriate is a significant problem for CYP and mental health services alike [5, 6, 7]. Notwithstanding the costs in time and resource for services, and the distress and time-wasting for patients, there is growing concern about this significant number of rejected referrals to CAMHS [5,6] and about what happens to the children and young people whose referral is not accepted [8]. The EPI authors identify some key problems: 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 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.

Data we gained from 4 CAMHS localities within Manchester NHS Foundation Trust (18/19) highlight the concerns. There is considerable variation in the proportion of inappropriate referrals across localities. Reasons for such disparity are unknown; however, there are clear examples of services where referral appropriateness is not an issue, e.g., Learning Disability Services. This highlights the essential need to understand locally what/where the difficulties are. This project will address the main findings from two key reports [9,10]. The Scottish audit was the first-time qualitative data have been brought together by CAMHS with lived experience from CYP, their parents/carers and referrers [11]. Both reports highlighted how the referral routes are often unclear, making it difficult to find the right support at the right time. They also identified the barriers that exist for referrers which cause delays to accessing help. As identified by CYP within the YoungMinds Agenda, there is 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” [12]. Locally there have been various initiatives to improve referrals with different professional groups. However, they have not been strategic, joined-up or comprehensive. On a larger scale, this project will contribute to reducing the substantial variation in the quality of information provided by CAMHS nationally [13] (referral criteria, referral processes and referral training).

A key finding from a study of referrals to specialist CAMHS found that CYP referred by teachers were more likely to get rejected than those referred by medical professionals [7]. A further report found that since 2014/15, referrals made by schools seeking mental health treatment for their pupils increased by over a third in the last 3 years in the UK [14,15]. In 2017/18, there were 34,757 referrals made by schools to CAMHS, which represents 183 referrals every school day [14]. These figures demonstrate that appropriate education and advice is essential to ensure CYP are being referred to the most appropriate service and get timely support [16-19]. The main cited reasons for rejected referrals nationally are: not

meeting threshold, no mental health condition, have incomplete information, are more suitable for a different service, are over the age of 18 or out of area [4]. This is consistent with local data from a sample of 50 rejected referrals. Overall, 35/50 were deemed unsuitable for CAMHS across Manchester with 19 of those being referred to another more appropriate service, and 13 having insufficient information. However, increased understanding is required to understand potential patterns of and reasons behind referral rejections (e.g., to explore whether referrals from GPs are rejected more than from schools).

With such complexity and with high cost-savings in mind, we propose an innovative, multi-disciplinary approach to identifying the challenges and co-designing new solutions to these problems; one which represents a true step-change in current processes. We also recognise difficulties which extend further into the system; where CYP and families get redirected, having waited for their initial assessment [20]. This is alarming, given these reasons could have been identified at a much earlier stage. Given that the impact of being rejected includes: worsening health, distress, stress on family relationships and financial stressors when some families have to seek help privately [9], our project aims to prevent CYP and families going through this unnecessary, significant distress with appropriate re-diversion and help from the outset of a referral being contemplated. We aim to direct CYP to the appropriate referral pathway (CAMHS or alternative support service) at the earliest opportunity.

This study aspires to reduce the considerable individual and family distress of inappropriate/unsuccessful referral by redirecting children to more appropriate and available services at the time of need [19,21]. By talking with young people and families, referrers e.g., schools and GPs, people working in CAMHS and mental health leads, we shall seek to understand fully what the problems are and find solutions that can be used by referrers to help them make decisions about when and whom to refer. We shall aim to understand how we can enable referrers to have a greater understanding of what constitutes an appropriate referral, and whether they have enough information to make such a decision/referral (thus maximising the chance of acceptance if appropriate).

We shall consult extensively with key stakeholders across 8 focus groups to clarify the criteria for referrals to CAMHS and to understand the barriers to making appropriate referrals including referrals to other services more suited/better aligned to the CYP need. We shall analyse the CAMHS referral data to understand problems in the CAMHS referral process. We shall explore problems at a local CAMHS site level and also at regional and national levels, supported by our mental health partners on the project. With key stakeholders across 4 additional focus groups, we shall aim to identify potential sustainable solutions to the current problems and examine the challenges to the adoption and sustainability of proposed solutions.

2 RATIONALE

Our consultations with key stakeholders (including young people, parents/carers, CAMHS professionals across more than 14 CAMHS sites, national CAMHS strategic leads, school staff and GPs) have highlighted the urgent need for a flexible and locally relevant mechanism that can support referrers better to understand the local referral process and provide them with alternative signposting for young people (YP) when CAMHS is not an appropriate referral path. The mechanism must incorporate the diversity of local CAMHS configurations; enable a standardised approach to CAMHS referrals across localities and referrers; be able seamlessly and quickly to update signposting materials for cases when

CAMHS is not an appropriate source of help; and be readily scalable to support children and young people (CYP) and CAMHS across England.

This study aims to identify a unique, valuable and sustainable way to develop and support a standardised, informative and useful approach to CAMHS referrals through consultations with key stakeholders. We aim to identify new ways to improve the success of referrals to CAMHS which not only can be seamlessly integrated into routine practice but also can be standardised, informative and useful to referrers. It must also be flexible enough to support a range of service configurations and to be responsive to change. Importantly, we aim to: ensure that CYP receive appropriate help as early as possible in the care pathway; prevent challenging wait times to receive help; support referrers to understand the local referral processes and enable them to provide locally relevant alternatives while receiving updates to signposted materials in a timely manner.

Reducing the substantial number of inappropriate referrals to CAMHS offers the potential for high cost and resource savings that can be freed up for use for CYP and families already within CAMHS. It will help to reduce waiting times for first appointments by reducing some of the main factors that contribute to these: “high referral rates, long referrals meeting, poor quality referral information, delays in decision making and insufficient information about alternative services or self-help” [20]. With swifter processes, it will help reduce the number of young people who get to assessment stages and then get rejected for becoming eligible for adult services [9]. Given reports that CYP often do not know what has happened to their referral, a more responsive service will improve overall patient experience and relationships with referrers. When freed up from time constraints and tasks relating to incomplete and insufficient referrals it may allow for more face-to-face appointments being offered. In services where dedicated time to discuss referrals are not routine, greater availability can be carved out for direct contact (phone, email) to prevent inappropriate and rejected referrals, and to ensure those CYP who need to be seen do so. This remains an essential clinical activity to ensure patient safety. It would reduce the need for lengthy, and weekly referral meetings freeing up resource internally [20].

Research by the PI, KMA, has demonstrated that young people’s mental health has deteriorated the most during the COVID19 pandemic [22]. Our collaborating CAMHS sites are now urgently preparing for an anticipated surge in demand for already-overstretched CYP mental health services, reflecting UK-wide concern across CAMH services about the increasing rates of CYP needing help post (/in the ongoing) lockdown and ever-increasing demands on the service. The support and commitment of CAMHS services (4 CAMHS providers encompassing 9 CAMHS sites are our confirmed partners), at a time when services are anticipating unprecedented demand, signals the urgency and importance of addressing this problem from a service perspective. This project offers huge potential benefit to CAMH services by improving client care while reducing costs, improving patient satisfaction, increasing speed through care pathways, reducing time wasted on triaging inappropriate referrals and enabling CAMHS to focus on delivering the care they have been designed to provide.

3 RESEARCH QUESTION/AIM(S)

The overarching aim of this study is to improve the success of referrals made to CAMHS.

Research questions:

1. What are the current challenges in making referrals to CAMHS services?

2. What low-cost, accessible, sustainable solutions should be developed for referrers to use to make decisions about when and whom to refer?

3.1 Objectives

Our key objectives are to:

- i. extensively engage key CAMHS stakeholders to explore what does and does not work in the current referral processes across different sites and CAMHS providers
- ii. map and examine the various configurations of CAMHS services (including service eligibility criteria)
- iii. map and analyse referral and inappropriate referral rates against possible explanatory variables (e.g., age, sex, ethnicity, index of multiple deprivation)
- iv. identify possible sustainable solutions to support more successful and appropriate referrals in collaboration with key CAMHS stakeholders
- v. identify the complexities of implementing sustainable solutions across CAMHS settings

3.2 Outcomes

This will be the first in-depth study specifically designed to improve the quality and success of referrals to CAMHS. The study will define challenges within CAMHS referral pathways and offer solutions that have been extensively co-designed with key CAMHS stakeholders. Solutions will be low-cost, accessible and sustainable, and be designed to guide referrers through the process and reduce the numbers of children turned away following referral/inappropriate referral, meaning more successful referrals are made to CAMHS services.

We shall publish our consultation work with referrers in academic journals, on our project website and share widely through social media, mental health charities and other organisations. We will use innovative and accessible techniques such as animation to reach children and young people as well as professionals. We shall work with our collaborators and CAMHS stakeholders to ensure knowledge which ensues from the project is shared widely.

We anticipate that improving the quality of CAMHS referrals will

- i) reduce the distress caused to children and families by inappropriate referrals and lengthy waiting times for help
- ii) create confidence in referrers to CAMHS that the referrals they make are appropriate and will enable the young people to receive timely help
- iii) benefit CAMH services hugely through the reduction in time spent triaging and following up inappropriate referrals and signposting young people to other sources of help
- iv) will support the timely delivery of care from appropriate sources and alleviate significant distress by signposting young people to appropriate help at the earliest opportunity
- v) increase skill and knowledge in referrers about CAMH service availability and purpose
- vi) foster collaboration and partnership working between stakeholders (GPs, teachers, parents, local non-CAMH providers and CAMHS) by suggesting what local alternative resources and supports are available to children in need

4 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYSIS

The study uses a mixed method design with two key complementary phases:

- Identifying referral rates and analysing referral patterns (Quantitative)
- Extensive stakeholder consultation (Qualitative)

4.1.1 Data Collection:

Identifying Referral Rates and Analysing Referral Patterns to CAMHS (Months 4-12)

Site Level Data

Quantitative CAMHS referral data will be collected from 9 participating CAMHS sites across the North of England from a 5-year period (2015-2020) to identify referral rates and analyse referral patterns to CAMHS. Referral data are routinely captured by all CAMHS sites and easily accessible. This data collection process will be supported by our 4 collaborating CAMHS providers in which the 9 sites are based (Greater Manchester Mental Health NHS Foundation Trust; Pennine Care NHS Foundation Trust; Manchester University NHS Foundation Trust; Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust). Site level data will be received in aggregate, anonymous format, however, if it is possible to do so, anonymised patient level data will be collected from each site. Initial consultations with sites will determine whether data is collected at site or patient level.

Specifically, at the CAMHS site level, we shall request:

- The overall number of referrals
- Number of un/successful referrals and reasons why they were unsuccessful/deemed inappropriate
- Referral data by type of refer (e.g., Self-referral, GP, School) including date
- Referral success and 'appropriateness' by type of referrer (where this is available)
- Routinely collected socio-demographic data on the referred CYP (including e.g., age, sex, ethnicity)
- Clinical characteristics of the referred CYP (e.g., reason they were referred, any mental health diagnosis)
- Referral outcome for the CYP (e.g., what services were accessed) and decision date
- Time to first contact with a mental health professional where a referral is accepted by CAMHS
- Drop of rates for successful referrals
- Reasons for drop out of successful referrals

We will also ask staff at the 9 CAMHS sites to provide us with information about any significant changes in service delivery, referral processes or pathways. For example, this may be changes due to alterations in national or service level policies or changes as a result of external events that have happened over time (e.g., impact of COVID-19). Dates or time periods for the changes will be recorded so they can be entered into the analysis.

We shall also collect information on the clinical configuration of the CAMHS providers at the site level (i.e., what are the clinical thresholds for acceptance to CAMHS). This will enable us to explore if/how

clinical configurations may influence the referral acceptance rate and will also inform the discuss with stakeholders to understand the referral challenges and to map the referral process.

National Level Data

Additionally, national level CAMHS data from NHS England & NHS Improvement will be collected and analysed to compare with the regional and provider level CAMHS data. These data will be collected with help of our collaborator, Dr Chitsabesan, who is the Co-National Lead for CAMHS. All data will be received in aggregate, anonymous format. We will collect national level CAMHS data on:

- overall number of referrals
- % un/successful referrals
- socio-demographics for the CYP referred, where available
- clinical characteristics of CYP, where available

Stakeholder Consultation (Months 5-13)

We aim to recruit 120 CAMHS stakeholders nationally to take part in 12 focus groups.

The topic guides for the focus groups will be informed by the available literature and evidence on CAMHS referrals, our background/preliminary consultations and data analysis, and the preliminary data analysis of referrals to our collaborating CAMHS sites. They will be reviewed by the advisory groups. Topic guides will provide flexibility to allow themes to emerge and be discussed.

Eight focus groups will be held to identify challenges in making successful CAMHS referrals (months 5-12), then four focus groups will be held to identify and discuss potential solutions to the problems identified (months 9-13). Informed by the information we have gathered on local service configurations, the first eight focus groups will be designed to identify and examine the challenges key stakeholders have experienced through their involvement in the current CAMHS referral process. Groups will be convened with the following stakeholders: CAMHS staff, collaborators, children and young people, key referrers (e.g., GPs, teachers, SENCOs, community paediatricians, social workers), parents/carers, CAMHS commissioners, mental health leads.

The aims of the groups are to understand localised referral processes, challenges which lead to 'pain points' in the referral pathways, reasons for unsuccessful/inappropriate referrals and the impact of unsuccessful/inappropriate referrals on CYP and their families.

We shall ensure that stakeholders have an opportunity to describe the problems of CAMHS referrals freely and openly, and that all difficulties in the CAMHS referrals pathways are explored as fully as possible in the focus groups.

Extending work already completed by NHSX, NHS England and NHS Improvement [23-24], we shall draw on the stakeholder consultations to process map the CAMHS referral pathway. Process mapping will help us clarify similarities and variations between sites and to identify 'pain points' in the referral process which need to be addressed in any proposed solutions. Process maps developed from discussion at the focus groups will be taken to our advisory boards for consideration and review, to ensure the breadth and variation in referral processes across CAMHS in England has been adequately captured by our local groups.

The last 4 focus groups will aim to identify and discuss potential solutions to the problems identified, particularly aiming to understand stakeholder requirements for solutions developed. We shall discuss with stakeholders how proposed solutions should be measured (e.g., speed through referral pathway; patient satisfaction). We shall also discuss the practicalities of embedding proposed solutions in busy real-world referral environments.

These groups will be used to examine stakeholder perceptions about:

- 1) potential sustainable solutions to the current challenges of making successful/appropriate referrals
- 2) suggestions for how to improve signposting to alternative sources of support for CYP who are deemed ineligible for CAMHS
- 3) barriers and enablers (and any unintended consequences) to integrating proposed solutions into routine practice
- 4) strategic perceptions about the wider use and scalability of proposed solutions (i.e., how could a proposed solution be scaled up and integrated across multiple services in England)
- 5) the sustainability and adoption potential of suggested solutions longer term

If digital tools are proposed as potential solutions, a Non-adoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies (NASSS) framework evaluation [25] will be used to guide discussion with stakeholders. The NASSS framework has been widely used in evaluations of digital mental health implementation projects (see e.g. [26]). This will help identify any barriers to success of suggested solutions, so that these can be considered and addressed in the focus group discussions.

During months 9-13, stakeholder consultation will also be completed using the NIHR-funded GM ARC PPI app. Short survey/queries can be placed on the app, which is then shared with a large PPI mental health community. Respondents can easily and safely respond to questions, capturing views and opinions of a wide CAMHS stakeholder audience for rapid feedback on specific, simple questions. Questions/surveys will be developed alongside the focus groups and the rapid responses will feed back into the focus group discussions.

4.2 Data Analysis

4.2.1 Quantitative Data Analysis:

Analysis of referral data will aim to understand the rates of appropriate/inappropriate referrals both across individual CAMHS and on a national level.

Referral data will be explored, summarising:

- i. Total number of referrals: averaged over 5 years, summarised by year, summarised by CAMHS site
- ii. Proportion of inappropriate referrals: averaged over 5 years, summarised by year, summarised by CAMHS site

Important factors relating to inequality of service use will be explored, for example ethnicity and socio-economic background. Initial work found that fewer young people from minoritized ethnic groups were referred into CAMHS services in greater Manchester, but young people from minoritized ethnic groups also had fewer inappropriate referrals than white young people. We will investigate this in all sites, summarising the following:

- i. Number of YP from minoritized ethnic groups accessing services as a proportion of the population of YP from minoritized ethnic groups in the geographical area. Broken down by CAMHS site area if data is available
- ii. Number of YP from minoritized ethnic groups with inappropriate referrals as a proportion of the population of YP from minoritized ethnic groups in the geographical area. Broken down by CAMHS site area if data is available

CAMHS referral data for the last 5 years will be explored graphically and using linear mixed models to investigate trends in number of referrals and proportion of inappropriate referrals over time. These models will include important reported changes in service delivery and external events (e.g. COVID-19) where possible. Variation over time in the characteristics of the CYP referred into services will also be explored.

Descriptive statistics for each of the 9 CAMHS sites will be produced, split by 'appropriateness' of referral: referrals by referrer type; referrals by sociodemographic characteristics of CYP (e.g. age, sex, ethnicity, socio-economic background); clinical characteristics of CYP referred. Where referrals are judged to be appropriate, descriptive statistics will be provided for time to first contact with a mental health professional. These descriptive statistics will also be produced at a national level, supported by NHS England & NHS Improvement data. Inferential statistics will be used to analyse the relationships between, for example: age and referral outcome; sex and referral outcome; ethnicity and referral outcome; socio-economic background and referral outcome; referrer type and outcome; clinical characteristics and outcome.

4.2.2 Qualitative Data Analysis

We shall use a qualitative framework approach to analyse the focus group data. All qualitative focus groups will be audio and video recorded with consent, transcribed and thematically analysed using a Framework approach as set out by Gale et al [27] and using Nvivo 12. Framework analysis is widely used in mental health research [28]. We shall use the Framework Method to take an inductive approach to theme generation and then refine the emerging themes using a deductive approach. The Framework Method will enable us to answer our key research questions but also allow new themes to be iteratively and collaboratively generated. The coding framework we develop will then be applied to the analysis of subsequent focus group/consultation transcripts, and we will ensure ongoing adaptation to these as new themes emerge during the analysis. Thematic data will then be charted into a matrix and refined through discussion at regular analysis meetings with relevant members of the research team, led by the funded Research Associate. We shall engage our research team, advisory groups and wider stakeholder collaborators in the analysis of thematic data. To ensure the quality and credibility of the qualitative analysis we shall use a combination of the following approaches: i) triangulation of the data (qualitative and quantitative data triangulation) ii) respondent validation (reviewing summaries of emerging findings) iii) transparency and reflexivity iv) generating and discussing alternative explanations v) identifying

negative and discrepant information. Data analysis will be led by Co-I KG; conducted primarily by the funded RA; and supervised by the PI and Co-PI. Regular analysis updates will be presented at the regular weekly research meetings and monthly PMGs.

5 STUDY SETTING

This is a multi-site study. The referral data collection will involve 9 CAMHS sites from 4 regional providers. The four providers are Greater Manchester Mental Health NHS Foundation Trust, Pennine Care NHS Foundation Trust, Cumbria, Northumberland Tyne and Wear NHS Foundation Trust, and Manchester University NHS Foundation Trust. The collaborating sites have been chosen to: target the areas of high need for CYP mental health; reflect diversity in terms of urban/rural locations; ethnicity of service user population; diversity in configuration of CAMHS services/CAMHS offer.

National level CAMHS data will be collected remotely from NHS England & NHS Improvement, and the GM ARC PPI app will reach CAMHS stakeholders nationally. For the focus groups, CAMHS stakeholders will be included from many more sites and regions across the UK. Local data will then be able to be compared to national data to reflect diversity.

All referral data will be obtained remotely.

The stakeholder consultations will be held virtually for the time being, however, dependent on COVID-19 related regulations, these may eventually be held in person. Virtual focus groups will be facilitated via a video link platform, such as zoom. If any sessions are held in person, these will be held at different locations across England to optimise diversity across key criteria – e.g., rural/urban locations; underlying populations; areas of high unmet need for CAMHS. The choice of location for these focus groups will be informed by the quantitative data mapping and analysis.

6 SAMPLE AND RECRUITMENT

6.1 Eligibility Criteria

6.1.1 Inclusion criteria

- A CAMHS stakeholder who has had experience with the CAMHS referral process:
 - CAMHS staff
 - Collaborators
 - Children and young people
 - Key referrers (e.g., GPs, teachers, SENCOs, community paediatricians, social workers)
 - Parents/carers
 - CAMHS commissioners
 - Mental health leads
- Able to provide informed consent or parental consent (for children under the age of 16)

6.1.2 Exclusion criteria

- Participants must be able to speak English at a basic level
- Participants must have good internet access to take part in the online focus groups
- Participants have not had experience with the CAMHS referral process.

6.2 Sampling

6.2.1 Size of sample

We will recruit 120 CAMHS stakeholders. We will hold 12 stakeholder consultation focus groups with 10 stakeholders per focus group. Based on the research teams experience holding focus groups, a maximum of ten people per focus group is preferred.

6.2.2 Sampling technique

Sampling for the focus groups will draw on some early quantitative data analysis to ensure we include any particular outlying referrers (i.e., those with very high or very low rates of un/successful referrals) and include a range and diversity of type of referrers for inclusion in our stakeholder consultations.

Underserved communities (e.g., Black, Asian and Minority Ethnic CYP) will be targeted for inclusion, to represent a diversity of views at these focus groups.

6.3 Recruitment

6.3.1 Sample identification

Identification and recruitment of CAMHS professional stakeholders will be supported by our extensive network of CAMHS collaborators and our 9 collaborating sites. Recruitment of key referrers is 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 will be supported by our CAMHS networks, adverts on social media and websites, and our third sector collaborators (MQ, 42nd Street, Anna Freud Centre). We will also recruit children and young people, parents and carers via a recruitment agency (Taylor McKenzie, <https://www.taylormckenzie.co.uk/market-research-recruitment/>). Recruitment of CYP and their families may be recruited via CAMHS sites and staff, however this will only occur if an IRAS application is submitted to the NHS REC and approved.

We shall extend our focus group invitations beyond our collaborating sites to ensure we capture a wide diversity of CAMHS stakeholder perspectives.

6.3.2 Consent

All potential participants will be asked to provide informed consent to participate in the focus groups. They will be provided with a Participant Information Sheet and Consent Form.

Once a potential participant has expressed interest in taking part in the focus group the research team will send the Participant Information Sheet and Consent Form via email. The Information Sheet will detail the nature and objectives of the study and has been developed in accordance with University guidance. The information sheet and the consent form will be developed in consultation with both our YPAG and PPAG.

Participants will be given sufficient time to understand the information they are given and to weigh up the information in order to make an informed decision. They will be given the opportunity to ask any questions about the research if they want to. The Consent form will be collected prior to the focus group

via email or post. Participation is voluntary and participants will be informed that they have the right to withdraw at any time without giving a reason. As per the consent form, any previous information collected from focus group participation before withdrawal will still be used in the study.

For children and young people under the age of 16, we will ask for their parents/carers to sign a parental consent form on their behalf.

6.3.3 Payment

PPI Payment will follow the NIHR INVOLVE recommended rates. CYP and parents/carers will be paid for their involvement in the focus groups, at a rate of £75 per participant for roughly half a day's activity. Professional CAMHS stakeholders will not be offered payment, unless agreed otherwise.

7 ETHICAL AND REGULATORY CONSIDERATIONS

7.1 Assessment and management of risk

Safeguarding:

At the beginning of the focus groups, participants will be reminded that they can leave the group at any time, without giving an explanation. The focus groups will be facilitated by experienced researchers who will ensure that a friendly and positive environment is created.

Participants will be asked about their experiences with the CAMHS referral system, either as professionals, referrers, parents/carers or CYP themselves.

We do not envisage that the focus groups will be distressing for professional participants. For parents/carers or CYP who have had difficult experiences with the referral process, discussing their experiences may be distressing. For this reason, we have developed a distress protocol which will be shared with participants prior to the focus group. The distress protocol will include information on access to mental health services in case people are affected by the topics within the focus groups and want to seek help.

Confidentiality:

All participants will be reminded at the start of the group of the importance of respecting each other and it will be made clear that they should not talk about what other people have said outside of the focus group. Participants will not be asked to share specific personally identifiable information during the focus group, but they may spontaneously share information. The focus groups will be recorded and transcribed. During transcription, all identifiable information will be removed, and the recording deleted permanently.

7.2 Research Ethics Committee (REC) and other Regulatory review & reports

Before the start of the study, a favourable opinion will be sought from the UREC for the study protocol, informed consent forms and other relevant documents e.g., advertisements. All correspondence with the UREC will be retained.

The Principal Investigator's and Project Manager will produce progress reports as required and the Principal Investigator will notify the UREC of the end of the study. If the study is ended prematurely, the Chief Investigator will notify the UREC, including the reasons for the premature termination.

If we are recruiting children and young people via the NHS and IRAS application completed and submitted for consideration by an NHS REC.

7.2.1 Amendments

Amendments will be handled in line with the University of Manchester's policy. Substantial amendments that require review by UREC will not be implemented until the UREC grants a favourable opinion for the study. Any substantial change to an approved project should be submitted for approval as a project amendment. This will be done by the Project Manager via the ERM system and will be reviewed by the PI. Guidance for how to submit an amendment can be found on the Research Governance, Ethics and Integrity website under the heading of Revising an Application.

Substantial changes can be defined as (but not limited to):

- Data collection extensions
- Changes in researchers
- Change of data collection procedures
- Change of recruitment procedures
- Change of inclusion/exclusion criteria
- Change of location of where data is collected
- Changes which increase the risk to researchers
- Changes which increase the risk to participants
- Changes in data management procedures (including change in transcription procedures for interviews)
- Changes in numbers of participants

In making a decision about more complicated amendment requests the following guidelines will be used: <https://documents.manchester.ac.uk/protected/display.aspx?DocID=36448>

A log of all amendments will be tracked in the protocol to identify the most recent protocol version.

7.3 Peer review

The study underwent independent peer review by research experts in the area by the National Institute for Health Research prior to the Principal Investigator receiving funding for this project.

7.4 Patient and Public Involvement

We will hold bimonthly meetings with our Young Persons Advisory Group (YPAG, n=6-10) and quarterly meetings with our Parents/Carers and Professionals Advisory Group (PPAG; n=6-10). We will establish mechanisms for incorporating feedback from these groups into our work, ensuring young people and their parents/carers/families influence decision making.

We will work with our YPAG and PPAG to develop the topic guide for the stakeholder focus groups. We will feed back the discussions of the advisory groups for consideration at the focus groups in an iterative manner to allow the topic content to evolve. Process/pathway mapping outcomes and data analysis will be discussed at the YPAG/PPAG meetings. This will a) ensure the advisory groups are informed about emerging findings b) identify any gaps/problems in the data and analysis c) ensure the direction of the research remains aligned with their priorities. Our PPI groups and activities will be fully supported throughout the project.

7.5 Protocol compliance

Accidental protocol deviations can happen at any time. They must be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

Deviations from the protocol which are found to frequently recur are not acceptable, will require immediate action and could potentially be classified as a serious breach.

7.6 Data protection and patient confidentiality

All investigators and study site staff must comply with the requirements of the Data Protection Act 1998 with regards to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles.

Throughout the project, data security, data protection and confidentiality will be addressed as follows:

- i. All data will be hosted on secure servers hosted at the University of Manchester
- ii. Information and research governance and data protection/GDPR compliance will be closely overseen by the University of Manchester Information Governance team, supplemented by specialist health informatics data security and confidentiality guidance from the Centre for Health Informatics, University of Manchester
- iii. No identifiable data will be collected.
- iv. All data access will be restricted to the research team as per GCP guidelines.
- v. Data sharing agreements will be established between organisations and sites as required. This will be overseen the University of Manchester Information Governance and Contracts team.
- vi. In line with GCP, confidentiality will only be broken when there is a concern of immediate risk of harm to self / others. It is not anticipated that this will be required in this study.

7.7 Indemnity

This study is sponsored by the GMMH Trust and standard NHS insurance and indemnity will apply.

7.8 Access to the final study dataset

The co-PIs, the Project Manager, the statistician, and the qualitative analyst will have access to the final study dataset. Other members of the research team will be allowed access if a formal request describing their plans is approved by the steering group.

8 DISSEMINATION POLICY

8.1 Dissemination policy

The datasets arising from the study will be protected by know-how, copyright and database rights (which are automatic rights and do not need to be registered). The copyright for the foreground IP will be held by GMMH.

The draft final report will be due to the NIHR two weeks after the end of the contract. The NIHR will contact the team at least three months before this time with more specific advice. Further guidance on writing the draft final report can be found on the Information for Authors webpage. This guidance is regularly updated and will change during the lifespan of the project. We must make sure to use the most up to date guidance when drafting the report.

The process from receipt of the draft final report to its final publication typically takes around a year, during which time the report will be subjected to external review and editorial scrutiny. It is advised to make the appropriate plans and/or arrangements for this period, particularly in the light of the fact that a substantial part of the funding award is withheld pending final publication.

Frequent causes of delays for publications are from delivery of incomplete reports resulting in additional revisions, delays in acquiring permissions for reproduced work or errors within the referencing. For further information or guidance regarding the report please contact the NIHR Journals Library team at journals.library@nihr.ac.uk

Overdue reports: It should be noted that contractual penalties may be applied for any report that becomes overdue.

8.1.1 Additional Information from the NIHR related to the draft final report:

A group of scientists and editors have formed the STARD (Standards for Reporting of Diagnostic Accuracy) Initiative, to provide a method for improving reporting quality and accuracy of diagnostic studies. Information on this initiative and the documents involved can be down loaded from the STARD website. The NIHR request that the research team include the checklist (available from <http://ibooked.no/stard-statement.html>) as a separate appendix to the final report.

The National Screening Committee (NSC) is enthusiastic to discuss the report when it is published. The committee has requested that the NIHR should ask the research team (and all other authors of reports initiated by the Population Screening Panel) to address a number of key criteria/questions. Information regarding the criteria/questions which they would like the research team to respond to and then include as an appendix to the final report can be found at <http://www.screening.nhs.uk/criteria>

8.2 Outputs

The focus group and referral data will be drawn together to produce key project findings which will be presented in a final report for the NIHR HS&DR Programme. The findings will define challenges within CAMHS referrals pathways and offer sustainable and implementable solutions that have been extensively co-designed with key CAMHS stakeholders. These outputs will:

- clarify, in a regionally specific, responsive and sensitive manner, CAMHS criteria and challenges in making appropriate referrals to CAMHS
- identify how the high number of unsuccessful/inappropriate referrals to increasingly stretched CAMHS can be reduced
- identify how best to sign post to alternative local resources and social prescribing
- capture contemporary referral patterns and behaviours by different types of referrers
- identify how family and individual distress associated with unsuccessful/inappropriate referral can be alleviated
- identify how improvements to the care pathway and patient experience/satisfaction can be achieved

These results will enable a feasibility study of the proposed solutions to be implemented as the next step.

Finally, we aim to produce 4 peer-reviewed academic publications during the project.

8.3 Dissemination Strategy

Policy Input: We shall influence policy and practice through direct contact with NHS partners and governments and by feeding information about referral over time and different regions. Many of our project team and collaborators are influencers at national and regional policy level (e.g., Abel; Chitsabesan; Ranote; Jiva). We shall also input directly to professional groups (e.g., Faculty of Child and Adolescent Psychiatry).

Website: A project website will be established and updated regularly throughout the project. It will link to social media feeds which will keep the content fresh and will include project updates in engaging formats accessible for lay audiences. Our collaborator network (particularly the CAMHS.Digital Research Advisory Group) and advisory groups (YPAG and PPAG) will contribute materials (blogs, vlogs, podcasts) which can be shared widely with lay audiences.

Social media: We will not set up a specific media (Twitter, Facebook) account for the project but instead leverage the combined extensive social media networks of our project team and collaborators including: MQ, Anna Freud Centre, McPin Foundation, CAMHS.Digital, CAMHS.Network, NIHR GM ARC, PLACE, Calm Connections, GMMH media team. All partners have agreed to help with social media dissemination. We shall also mobilise our collaborator YP and digital collaborators to share project findings through their multimedia channels and networks (e.g., the CAMHS.Digital podcast series).

Dissemination via MQ: Our collaborator MQ, the leading charity for mental health research in the UK, are fully committed partners in this project and costed to develop a communications strategy for this work; including content development relating to the project; and performing public/supporter outreach. This will include podcast/webinar/blog contributions and wide dissemination from MQ. Head of Research at MQ, Sarah Shenow, will join the project as a collaborator. MQ will provide communications training to the research team, which will focus on developing an effective communications strategy for project dissemination, as well as content development and public/supporter outreach. The MQ Director of Strategy, Communications and Engagement and the MQ Content Producer will develop this strategy. Materials will be discussed and developed in consultation with the YPAG, PPAG and PPIE leads and

will likely include a podcasts/webinars/blogs and extensive social media dissemination. MQ collaboration will be coordinated by the project PM and the funded RA.

Conference/Webinars/Events: We shall host a series of conferences, webinars and events throughout the duration of the project. We shall host a PPI engagement conference in partnership with our YPAG and PPAG to convey our findings to a public and lay audience. We shall host a stakeholder workshop to present and discuss the findings of this research. We shall exploit our longstanding and extensive connections with national-level NHS representatives (Public Health Leads, DoH Directors of Mental Health, NHS England CAMHS Leads, MQ and Wellcome MH Lead) to convene a round table discussion about how our findings present new avenues for service improvements. Depending on COVID19, we shall carry out these events virtually, as required.

Guidance on disseminating research can be found here: <https://www.nihr.ac.uk/funding-and-support/documents/funding-for-research-studies/manage-my-study/How-to-disseminate-your-research/dissemination-guidance.pdf>

8.3 Authorship eligibility guidelines and any intended use of professional writers

All study team members who make a substantive contribution to reading and writing the final report will be granted authorship on the final study report

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10. APPENDICIES

10.1 Appendix 1 – Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made

List details of all protocol amendments here whenever a new version of the protocol is produced.

Protocol amendments must be submitted to the Sponsor for approval prior to submission to the UREC.