



**MAPS: Mental Health Admissions to Paediatric Wards Study
Project Protocol V2**

IRAS: WP1: 322013 and WP2&3:322271

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Study investigator(s)

Principal Investigator: Dr Lee D Hudson,¹
l.hudson@ucl.ac.uk

Co-Investigator (A): Prof Russell Viner¹
Co-Investigator (B): Prof Helen Roberts¹
Co-Investigator (C): Dr Francesca Cornaglia²
Co-Investigator (D): Dr Dasha Nicholls³
Co-Investigator (E): Prof Faith Gibson^{4,5}
Co-Investigator (F): Dr Damien Roland⁶
Co-Investigator (G): Ms Gabrielle Mathews⁷

1. Population, Policy and Practice Research Programme, UCL Great Ormond Street Institute of Child Health, London, UK.
2. Queen Mary University of London, London, UK.
3. Imperial College Health Partners, London, UK.
4. Great Ormond Street Hospital for Children NHS Trust, London, UK.
5. University of Surrey, Guildford, UK.
6. University Hospitals of Leicester NHS Trust, Leicester, UK.
7. CYP Transformation Team, NHS England and NHS Improvement London, London, UK.

1. Research Summary

1.1. Background

Children and young people (CYP) presenting with a mental health (MH) crisis are frequently admitted to general acute paediatric wards as a place of safety. Prior to the pandemic, a survey in England showed that 6% of general paediatric inpatient beds were occupied by CYP due to MH crisis, and there have been longstanding concerns about quality of care to support these patients in this setting.¹ Since the pandemic there is evidence that both numbers of paediatric admissions and severity of CYP in MH crisis have increased, and paediatric teams are experiencing challenges delivering safe care.² There is a general paucity of published data on CYP with MH crisis admissions to general paediatric wards including total numbers, factors associated with admissions, outcomes for CYP admitted and the impact of admissions on CYP, parents and professionals caring for them.

1.2. Aims and objectives

We aim to generate a Theory of Change (ToC) model^{3,4} to positively impact upon quality of care for CYP admitted to acute paediatric services after presenting in a MH crisis. To reach this aim, our objectives are to investigate: 1) national trends in admissions; 2) characteristics of admissions in terms of sociodemographic factors, diagnoses and reasons admitted 3) factors influencing decisions to admit CYP to paediatric wards for primary MH problems; 4) views and experiences of CYP, families and health professionals during admissions to paediatric wards.

1.3. Research methods

We will conduct a mixed methods study combining qualitative and quantitative data collection and analysis to inform a Theory of Change (ToC) framework, this alongside a stakeholder group (consisting of patients, families, key professionals from health and social care, professional groupings such as royal colleges and commissioners). To achieve this, we will undertake several work packages (WP) over 30 months (Jun 2022-Nov 2024). WP1 will analyse national service level data (health episode statistics) of MH admissions to paediatric wards. WP2a we will undertake a rapid review, and will bring together the research team and stakeholder group, using a modified Delphi process, to develop our data collection instrument for WP2b. WP2b will be a prospective reporting system of MH crisis admissions from 15 paediatric wards in England over 6 months (planned sample size 720 cases). WP3 will be a qualitative study of the experiences of CYP admitted in MH crisis at 5 paediatric wards, as well as their families and staff members caring for them (planned sample size 36 CYP, 15 families and 36 professionals across a range of disciplines). Findings from the WPs will be brought together in WP4 (at 24 months) with the stakeholder group, so a final ToC can be developed with outputs agreed to achieve impact.

1.4. Outputs, dissemination

We will publish papers from our findings for WP1, 2B and 3 to provide much needed additions to the published literature. We will also publish the overall synthesis of data in WP4 and the final ToC to improve care of CYP with MH crisis admitted to general acute paediatric settings. As co-producers of the ToC, we will work with our stakeholder group and collaborators to ensure wide dissemination of findings to effect change. Potential impacts will be upon service development, new models of care, training, and workforce planning.

2. Background and Rationale

The rise in mental health (MH) problems amongst children and young people (CYP) during the COVID-19 pandemic is well described.^{5,6} Recent national data report that being at high risk of problems rose from 1 in 9 in 2017 to 1 in 6 by February 2021, with a doubling of the proportion of CYP at risk of eating problems over that same time period.⁷ Early in the pandemic access to inpatient and outpatient child and adolescent mental health services (CAMHS) was reduced.⁸ This mismatch of greater distress and reduced access led to increases in already unmet need.⁹ Acute hospital children's services saw a marked increase in admissions for MH problems in 2020-2. During the first pandemic wave, acute services became 'default providers' where community or inpatient CAMHS services were not accessible. MH admissions to acute paediatric wards appeared to peak during the third pandemic wave (winter 2020/21: data from NHS England; RCPCH and survey by Hudson et al (see below)).²

Although amplified by the pandemic, increasing MH admissions to acute paediatric wards is a long-standing issue. Acute children's services have always provided a vital place of safety for CYP in mental health crisis, especially where medical treatments are also needed (e.g. for self-poisoning), despite not always having the resources or training.^{10,11} MH admissions to paediatric wards have been identified as a leading safety and quality concern for acute paediatric providers for some years.¹ A survey in 2019 of 60% of acute paediatric services in England found that 6% of general paediatric beds were occupied by CYP with mental health problems,¹⁰ and pre pandemic data from London suggest that management of CYP with mental health problems was one of the main challenges for acute children's services.¹ During the pandemic, despite early problems with access, referrals to CAMHS services increased by 70% in late 2020 compared to 2019.¹² Eating disorders services saw a doubling of urgent referrals¹³ many of whom needed acute admissions. Increases appear to have occurred in other disorders too, such as self-harm. Increased demand has surpassed the capacity of already stretched CAMHS resources. Although access to community services has been limited, acute children's services and paediatric wards remain an open door of 'last resort' for distressed CYP and families. Additional resources have been allocated to uplift CAMHS services¹⁴ but not acute paediatric services. Two of us (Hudson and Viner) have published a systematic review of interventions to avoid inpatient admissions for CYP presenting in MH crisis¹⁵ – evidence was poor and limited, meaning that CYP are likely to continue to need to be admitted in crisis, with paediatric wards a common place whilst waiting assessment given the lack of direct access to specialist mental health ward for most children.

Little is known about trends in MH admissions to acute paediatric wards. In a review of top-line Hospital Episode Statistics (HES), mental health admissions in children's wards increased around 25% over the 4 years prior to the pandemic (unpublished data, Viner). Anecdotal reports from within the paediatric community confirm that numbers of such admissions have increased, as has acuity. Teams are increasingly caring for CYP under the Mental Health Act, using restrictive practices sometimes without mental health liaison support. A literature search using Pubmed on 17th September 2021 (search terms: (mental health) AND (children or adolescent) AND (paediatric OR pediatric) AND (ward OR inpatient OR admission) found only 2 published papers studying CYP who are admitted to paediatric wards (excluding specialist inpatient mental health wards) – the first a published letter of our survey² (see below) and a study from Ireland of nursing experiences also described below.¹⁶

Because of the lack of data, to quantify the problem urgently and to prepare for this study, we undertook a brief survey of consultants from 60 paediatric centres with an acute paediatric ward in England regarding MH admissions to acute paediatric wards in England for the first 3 months of 2021(now published).² Thirty-six responded, representing 22% of all acute wards in England. 88% reported increases in numbers of admissions of CYP with a primary mental health diagnosis versus last year, with more than half reporting that at least a quarter of all

admissions were for a primarily mental health reason. Median reported admission rate across centres was 13 per month, with a median of 0.5-1 patient per month requiring care under the Mental Health Act. 50% felt that access to mental health professional support was inadequate or poor. Additional work by Viner with NHS England (NHSE, Dr. Simon Kenny, National Clinical Director for Children and Young people, a collaborator) during the pandemic identified that in winter 2020/21, admissions for mental health problems were the most common group of admissions to acute children's wards and paediatricians and nurses frequently expressed concerns about training to deal with their needs.

No data have been published on the outcomes for CYP, patient experience, or whether such admissions may be avoidable or better managed in other settings. In a recent published systematic review, we found no evidence evaluating the use of acute children's wards as an alternative to mental health admission.¹⁵ The impact on those caring for CYP with MH problems in acute ward settings has also been little studied. We found only one study from Ireland of paediatric nurses, which highlighted concerns around the appropriateness of ward environments and the training and skills to manage CYP with mental health problems.¹⁶ This is important not only for quality of care, but also because managing patients outside of professional competence and training can be stressful for professionals, and affect retention.¹⁷ There is a lack of data relating to patient experience and no systematic exploration of the views and experiences of CYP and families in paediatric ward settings.

Responses by government and the health services have predominantly focused on prevention, particularly through investment in school mental health services,¹⁸ and bolstering CAMHS provision. Until recently, the increases in presentations of CYP with primary MH problems to emergency departments (ED) and acute children's services has been largely overlooked and under-studied. The NHS England Children's Program has recently instituted a joint program on overlaps between physical and mental health with the NHSE Mental Health Program, and mental health presentations to acute paediatric wards are now seen as an urgent problem within NHS England. However, the burden on acute services, the appropriateness and quality of care received by CYP, barriers to alternative care routes and the potential for different models of care to address these problems are largely unknown. Such information is vital and urgently needed to inform national and local approaches to service development, training and advocacy for patients, families, and staff groups.

3. Why this research is needed now

As outlined above, there is a striking lack of information available to guide care and service delivery for the rapidly growing issue of CYP with MH health problems being admitted and managed on acute paediatric wards. Large numbers of CYP are being managed in acute settings not designed for purpose, where training is limited and access to specialist CAMHS advice is inadequate. Research is urgently required to understand the extent of the problem and identify optimal ways to improve outcomes and experiences.

Concern about the mental health of CYP –and improved services and experiences of care– are important priorities for CYP and carers.^{19,20} There have been calls to improve MH care for the broader population via research since the pandemic²¹ but earlier, there were calls for research to improve services for CYP and families,²² and of acute children's services e.g. the NHS Youth Forum.²³ For our study, we have consulted CYP and families with experience of paediatric admissions for mental health reasons to ensure that our study addresses key areas that are important to them. One young person told us: "Sometimes when young people are in crisis, they can become violent or aggressive at times which can be quite scary for other young children who are unwell and in times like this I do not feel it is appropriate for them to be on the same ward." Another told us: "often nurses will tell you they do not have the training to be able to help you and sometimes struggle to know how to support you." Increasing numbers of

CYP with MH problems on acute paediatric wards has also become a priority concern for professional bodies such as the Royal College of Paediatrics & Child Health (RCPCH),¹⁰ Royal College of Psychiatry (RCPsych) and Royal College of Nursing (RCN).

We have consulted with a network of paediatricians across England who highlighted a range of concerns:

1. Composition of acute paediatric wards. Paediatric wards are not designed to safely manage CYP with high self-harm risk, for example ligature points and areas for nursing. Traditional paediatric settings are designed for younger children (whereas most MH admissions are teenagers), and staffing skill mix is designed for a medical and surgical cases.
2. Competencies, confidence and training. Paediatric medical and nursing training both have limited formal training on managing primary mental health diagnoses, especially those who are highly distressed and need supportive care and use of interventions such as restraint.
3. Variation in pathways and models of care. Described was significant variation across England in care models and pathways. Professionals are keen to explore new models of care and joint working.

4. Aims and objectives

Our overall aim is to improve care of CYP presenting in a MH crisis admitted to acute paediatric settings by producing a Theory of Change approach (ToC)^{3,4} combining data and stakeholder perspectives (see below). During this process, in the context of a paucity of data on this topic, we also aim to characterise admissions for primary MH problems to acute children's wards to inform health system responses to improve outcomes and experiences for CYP, families and professionals.

Objectives:

1. Identify trends in admissions for primary MH reasons to acute paediatric wards in England 2015- 2021: to characterise admissions in terms of sociodemographic factors, reasons admitted, characteristic of admissions (e.g. duration, site, recurrent admissions) and outcomes of admission including subsequent health service use (Workpackage (WP)1).
2. Investigate factors influencing decisions to admit CYP to paediatric wards for primary MH problems, including why possible alternative services were not used and characterise the care given, treatment outcomes and subsequent service use (WP2).
3. Explore views and experiences of CYP, families and health professionals during admissions to paediatric wards (WP3).
4. Synthesise data with a stakeholder group to create a ToC model for agreed impacts (with the stakeholder group) to inform service provision, potentially including the development of new pathways or models of care needed to improve the care of CYP admitted to acute wards (WP4).

5. Research Plan / Methods

We will undertake a national (England), sequential, mixed methods study combining qualitative and quantitative strands of data collection and analysis using an improvement science framework. Our study consists of 4 work packages (WP) undertaken over 30 months (Apr 2022-Mar 2024) (see flow chart and individual descriptions below). Central to the study will be the collaboration between the research team and a stakeholder group comprising a representative mix of CYP and parents with lived experience, a broad range of health, social

care, and criminal justice professionals, and professional bodies and patient representative groups. We will use a Theory of Change (ToC) approach^{3,4} as our framework, which uses activities and as logic (quantitative) data and co-production (qualitative) data to map change and has been applied to a range areas of health and social care improvement settings.²⁴⁻²⁶ ToC defines long-term impact (e.g. impact optimise delivery of care for CYP in MH crisis) and then maps backward to identify short/medium rapid outcomes. Using the steps of ToC will provide a solid improvement framework to enable us to map and synthesise datasets to meet aims, draw conclusions and deepen our understanding of key issues, facilitating also focused work with our stakeholder group to achieve impacts. Though in essence, consideration of the ToC will run throughout the study, three WPs will deliver types of evidence needed to inform our ToC: (including evidence of need, evidence of context and evidence of effectiveness) gathered from national data (WP1); published and stakeholder perspectives (modified delphi: WP2a); more granular detail about admissions from a prospective reporting system within a sample of hospitals (WP2); and qualitative data collected from staff, patients and carers from that sample (WP3). Overall, these data will bring together a range of perspectives from national trends through detailed data on a representative sample of sites to individual patient, family and staff perspectives (see figure 1) so that in WP4 4 will involve our stakeholders as we synthesize data across perspectives and disseminate findings to finalise the ToC model with outputs to deliver impact (see detail on ToC in WP4 below).

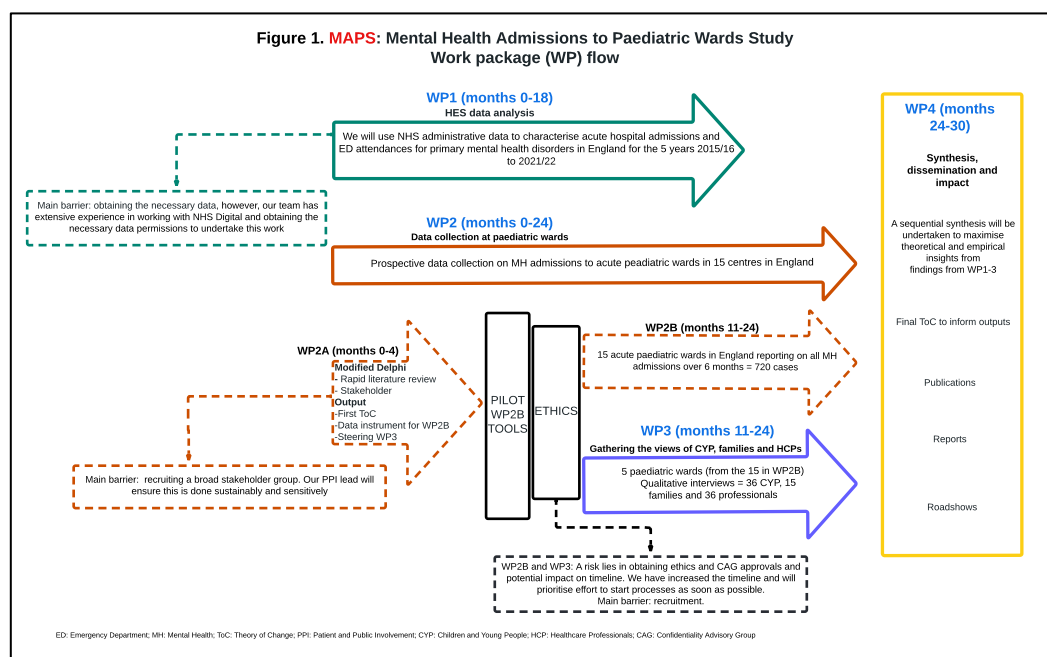


Figure 1: Research components which will be combined to form a Theory of Change (ToC) to meet the aims of the MAPS study

Here, we outline each work package in detail. The stakeholder group is described in detail under work package 2a (please note here that the stakeholder group is distinct from the independent advisory group – see under project management below – whose purpose will be to a council of reference and provide independent advice and oversight of the study).

6. WP1: Using national routine administrative data to identify and characterise trends in MH admissions in acute paediatric wards

(Months 0-24)

Lead: Viner.

Researchers: post-doctoral researcher, supported and trained by Viner

The overall aim of the MAPS study is to improve care of CYP presenting in a MH crisis admitted to acute paediatric settings by producing a Theory of Change approach (ToC) combining data and stakeholder perspectives. During this process, in the context of a paucity of data on this topic, we also aim to characterise admissions for primary MH problems to acute children's wards to inform health system responses to improve outcomes and experiences for CYP, families and professionals.

The analysis of routine administrative data in WP1 (Figure 1) will be highly informative regarding national trends and characteristics of CYP admitted. The aim for this work package is to identify trends in admissions for primary MH.

6.1. WP1 Research Objectives

1. Describe trends in MH admissions to acute inpatient services, attendances to accident & emergency (A&E), and outpatient appointments related to MH within England 2015-2022 (or latest available data) in children and young people aged 5-18.
2. Understand the financial burden of MH admissions to acute paediatric wards among CYP aged 5-18 in England.
3. Examine the role of primary and community health care services both.

6.2. Study design

We will use NHS administrative data to characterise acute hospital admissions and Emergency Dept (ED) attendances for primary MH disorders in England for the 5 years 2015/16 to 2021/22 (or latest available data).

6.3. Inclusion criteria

The data subjects for this project are all children and young people aged 5-18 who have been admitted to hospital, attended accident and emergency, or had planned outpatient activity for any cause (physical or mental health complaints), in England between 2017 to 2022 (or latest available data).

6.4. Methods

We will purchase pseudo-anonymised individual level data from the following datasets: HES Admitted Patient Care (APC), HES Outpatient Care (OPC), HES Accident and Emergency (A&E), HES Emergency Care Dataset (ECDS) and Mental Health Dataset (MHDS).

These data will allow the objectives described above to be achieved as follows:

Objective 1 of this project is to describe trends in healthcare activity related to MH problems in secondary care in England between 2017-2022 (or latest available data). To do this, we will need to analyse secondary inpatient and outpatient mental health care activity (held within MHDS and HES OPC), attendances to A+E due to MH concerns (data held within ECDS) and mental health care activity within acute inpatient services (held within HES

APC). We will describe trends over time, by age group, sex, markers of deprivation, prior MH healthcare activity and comorbid physical health problems, and analyse geographic variation in MH healthcare activity within England.

In addition to sociodemographic characteristics of CYP attending secondary healthcare due to MH concerns, we will describe prior attendance to accident and emergency (data held within HEE ECDS and HES A+E), prior admissions to acute paediatric services (data held within HES APC), prior outpatient MH activity (data held within MHDS and HES OPC) and prior MH inpatient activity (data held within MHDS).

We will identify healthcare activity (inpatient, outpatient, A+E) related to mental health and physical disorders as follows:

1. Primary diagnostic ICD-10 codes (DIAG_1) relating to mental and physical health disorders and provider codes for treating consultant (TREATSPEF and MAINSPEF) within finished consultant episodes within HES Admitted Patient Care
2. Provider codes for treating consultant (TREATSPEF and MAINSPEF) for planned outpatient activity relating to Mental and physical Health specialty within HES Outpatient Care
3. ECDS codes for mental health presentations linked to a same-day acute admission with a primary diagnosis consistent with a Mental or physical health presentation. This approach is only possible for 2018 onwards and cannot be done for pre-2018 ED data as reasons for presentation are not available.
4. Diagnostic coding within Mental Health Dataset (MHDS) to identify Mental Health outpatient activity not identified within HES Outpatient Care

We will link, clean and collapse data using established protocols we have developed for HES analyses. We will then describe:

1. Burden and trends in healthcare activity related to mental health disorders by sex, ethnicity, level of deprivation and geographic region, and examine variation at Trust level where numbers allow.
2. Burden and trends in acuity of mental health-related inpatient admissions. This will be examined by examining repeat admissions and readmissions and the numbers of admissions under the mental health act.
3. Burden and trends in admission source and discharge destination of healthcare activity related to mental health disorders (i.e., mental health “tier 4” inpatients unit, criminal justice system, etc).
4. Burden and trends in healthcare activity related to mental health disorders by mental health diagnosis (note diagnostic coding within outpatients is limited). This will be limited to large groups, e.g., eating disorder admissions, anxiety and depression, psychotic disorders – grouping to be determined.
5. Burden and trends in healthcare activity related to mental health disorders associated with other medical conditions and comorbidities, identified through primary and secondary diagnostic coding within HES. We will particularly examine the common chronic conditions (diabetes, asthma, epilepsy) as well as use broader definitions of medical comorbidity.
6. Burden and trends in healthcare activity related to non-mental health disorders within CYP identified as having healthcare activity related to mental health disorders including eating disorders, anxiety, depression, and psychotic disorders – grouping used to define mental health disorder to be determined.

Objective 2 of this project seeks to understand the financial impact of admissions to acute inpatient services due to MH problems. To do this, we need to first identify and group all

hospitalisations in England in CYP due to MH concerns in acute inpatient services (objective 1). We will then use data within the National Cost Collection for NHS to estimate the financial burden associated with admitting CYP to an acute hospital inpatient unit for all causes, and those related to mental health admissions. We will then extrapolate this cost to a national estimate and describe changes in the financial burden of MH admission to acute inpatient paediatric services over time, and this varies by different parts of England.

Objective 3 of this project seeks to examine the role of primary and community health care services both before and after admission of children and young people with mental health conditions to and from paediatric wards. We will seek to use quality of community mental health provision as a predictor for regional variation in the numbers of CYP admitted to acute inpatient units related to mental health crises. We will do this by establishing the quality of community mental health service provision using publicly available data including staffing levels within general practice, and quality outcome framework indicators related to mental health. We will also use data within the MHDS to assess community provision of mental health services, including proxy indicators including wait time from referral to the first appointment. For this indicator, we require data held within MHDS.

6.3. Ethical considerations

We have applied for this study to be reviewed by an NHS Research Ethics Committee, and for review by the Confidential Advisory Group (CAG). The main ethical issues arising from this project pertain to the use of sensitive data without consent, and the risk of individuals being identified in the data. Because of these risks, the data will be stored and analysed entirely within the UCL data safe haven, which has been certified to the ISO27001 information security standard and conforms to the NHS Information Governance Toolkit. Only authorised UCL staff members will have access to the data, and it will not be accessible by any third parties, nor can it be accessed outside the UK. Subsequently, the risk to data security will be very low.

We will not be explicitly seeking the consent of participants to use these data for analysis and so there is a risk that participants may be included in the study when they do not wish to be. As a result, we will seek support from the CAG as part of this application. We have provided a transparency statement describing this analysis to the public which includes details of how to opt-out of personal confidential data being shared by NHS England for purposes other than direct care. We have carefully considered the process of using data without consent and have taken the opinion of both, our stakeholder group and several CYP and their families. This is outlined in our next section.

Finally, we set up a Study Advisory Group (SAG) of independent academics and practitioners who are independently supported by the National Institute for Health and Care Research (NIHR). We also invited to this group parent members of the stakeholder group for reference through the study. The group is monitoring the study and providing independent advice. Our first meeting was held virtually on October 31st, 2022, to discuss the proposal and methodology of the study. SAG members were fully supportive of the methodology and process of using data without consent.

6.4. The views of young people and families

The research proposal and dissemination plan were presented to members of the Think4Brum (T4B), which is the youth advisory group for Forward Thinking Birmingham (FTB), and the GOSH Young Persons' Advisory Group for research (YPAG) in October and November 2022, respectively, as part of a Patient and Public Involvement and Engagement initiative. The T4B and GOSH-YPAG are a diverse group of CYP recruited from across the

country who have received training in research methods and policy. Focus groups of 40 young people (32 from GOSH and 8 from T4B) aged <18 (and parents) were held to discuss the acceptability of the research methods (including the use of data without consent).

The groups were overwhelmingly supportive of the importance of this research and the necessity of analysing data without consent (see Appendix 1). The young people did raise the issue of data usage and security, but our explanations for how we will use and store the data were acceptable to the young people who attended. For both young people's groups, we followed up to see if there were any comments after the meetings. For the GOSH group, there was not, but for T4B the group had gone away and discussed it with a larger group than had attended. We were told by the leader of the group that on further discussion with a broader group initially: "we did have some concerns about usage of data but that was allayed when we feedback your input from our session."

6.5. Data protection

We will require pseudo-anonymised individual level data on inpatient admissions and outpatient and A&E presentations amongst CYP < 18 years from Hospital Episode Statistics (HES Admitted Patient Care APC, HES Outpatient Care (OPC), HES Accident and Emergency (A&E), HES Emergency Care Dataset (ECDS) and Mental Health Dataset (MHDS)). All datasets will be linked and provided through NHS England.

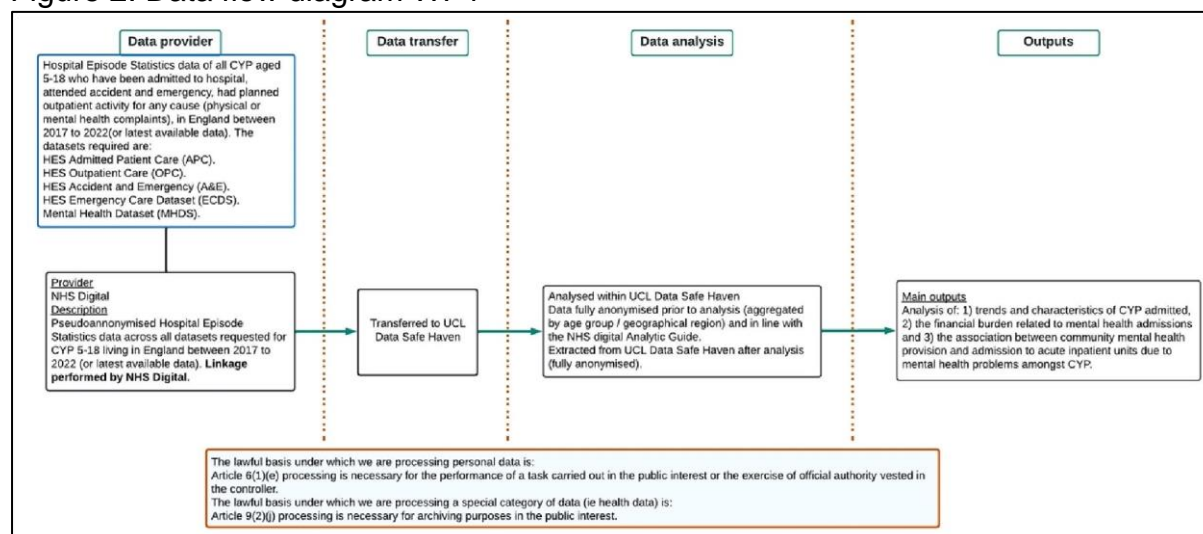
The NHS England data will be stored and analysed entirely within the UCL data safe haven, which has been certified to the ISO27001 information security standard and conforms to the NHS Information Governance Toolkit. Access to these data will be limited to those UCL employees contributing to this project. Data will be kept within the EEA. The data will be encrypted for transfer, and information compliance training for information security, freedom of information, and data protection will be completed by all staff who have access to the data. All data outputs will be aggregated in line with the HES analytic guide prior to being exported from the UCL data safe haven.

Data will be fully anonymised prior to the analysis and the anonymised data will then be extracted from UCL Data Safe Haven after analysis.

All outputs will contain only data that is aggregated with small numbers suppressed in line with the HES analysis guide. Data will only be accessed by individuals within UCL who have authorization to access the data for the purpose described, all of whom are substantive employees of UCL.

The data will not be linked with any record level data. There will be no requirement nor attempt to reidentify individuals from the data. The data will not be made available to any third parties other than those specified except in the form of aggregated outputs with small numbers suppressed in line with the HES analysis guide.

Figure 2. Data flow diagram WP1



A summary of our study procedure for WP1 and lawful basis under which we are processing the data can be seen in Figure 2.

6.6. Study management

This WP will be led by Viner. The study management group will consist of Viner, Hudson, the postdoctoral researcher, and the project manager, who will meet weekly. The management group will also include collaborator Ward, a data scientist and clinical lecturer in paediatrics with extensive experience in HES analyses of child and adolescent data, and Cornaglia the health economist investigator. Other investigators will input through monthly project management meetings.

Moreover, we set up a SAG of independent academics and practitioners who are independently supported by the National Institute for Health and Care Research (NIHR). We also invited to this group parent members of the stakeholder group for reference through the study. The group is monitoring the study and providing independent advice. We plan to hold regular (every 5-6 months) SAG meetings to review the progress of the study. Our first meeting was carried about in October 2022 and the next one will be in March 2023 (the meeting has been scheduled).

6.7. Processing activities

This study will require NHS administrative data to characterise acute hospital admissions and Emergency Dept (ED) attendances for primary mental health disorders in England for the 5 years 2017/18 to 2021/22 (or latest available data) (Figure 2).

The NHS England data will be transferred to UCL Data Safe Haven, and the NHS England data will only be analysed within the UCL Data Safe Haven. Data will be fully anonymised prior to the analysis. The anonymised data will then be extracted from UCL Data Safe Haven after analysis. After data from NHS England have been transferred to UCL, these data will only be processed by UCL (Figure 2). UCL data safe haven has been certified to the ISO27001 information security standard and conforms to the NHS Information Governance Toolkit.

All outputs will contain only data that is aggregated with small numbers suppressed in line with the HES analysis guide. The data will not be linked with any record level data. There will be no requirement nor attempt to re-identify individuals from the data.

We will use publicly available data on quality of community mental health provision for CYP as described above. We will use this to analyse the number of admissions for MH reasons to acute paediatric wards amongst CYP by local authority, with area level “quality” of community mental health provision. Number of admissions to acute paediatric units will be aggregated at local authority level, and we will only analyse these data in accordance with the HES analytic guide, i.e., where small numbers prohibit analysis at local authority level we will seek to analyse at larger geographic units (e.g., government region).

Data will only be accessed by individuals within UCL who have authorisation to access the data for the purpose described, all of whom are substantive employees of UCL. Information compliance training for information security, freedom of information, and data protection will be completed by all staff who have access to the data.

6.8. Deliverables and outcomes

Research findings will be summarised in a briefing paper for policy and practice colleagues, accompanied by seminars and infographics. Findings will be published in academic papers in international peer reviewed journals. Each objective within this workstream will form a separate publication. The primary targets for publication will be peer-reviewed journals. The estimated publication date for these analyses will be Sept 2023 – Jan 2024.

6.9. Outcomes and significance

Our overall aim is to improve care of CYP presenting in MH crisis admitted to acute paediatric settings. For this WP, primary outputs will be:

- 1) Analysis of trends and characteristics of CYP admitted to acute inpatient services due to mental health problems, attendances to accident & emergency (A&E), and outpatient appointments related to mental health within England 2015- 2022 (or latest available data) in children and young people aged 5-18
- 2) Analysis of the financial burden related to mental health admissions to acute paediatric wards among CYP aged 5-18 in England
- 3) Analysis of the association between community mental health provision and admission to acute inpatient units due to mental health problems amongst CYP.

6.10. Secondary outputs

In addition to the specific outputs outlined above, this workstream will inform the other work streams of the MAPS project and contribute to an overall report which will describe a summary of findings for each WP. This will outline the Theory of Change model, which will include contributions from our collaborators of the RCPCH, RCPsych, NHSE and others. We envisage this being a set of standards for admissions based on our findings aimed at policy and practice audiences, but we will also publish this in a peerreviewed journal.

All outputs will contain only data that is aggregated with small numbers suppressed in line with the HES analysis guide.

7. WP2: Detailed prospective data collection on mental health admissions to acute paediatric wards in 15 centres in England (consisting of WP2a and 2b).

(Months: 0-24)

Lead: Hudson

7.1. WP2 Research Objectives

Investigate factors influencing decisions to admit CYP to paediatric wards for primary MH problems, including why possible alternative services were not used and characterise the care given, treatment outcomes and subsequent service use.

7.2. Study design

Detailed prospective data collection on mental health admissions to acute paediatric wards in 15 centres in England (consisting of WP2A and 2B).

7.3. WP2A: Development of data collection instrument

We worked with a stakeholder group to co-create the instrument for collecting data to fulfil the aims of WP2. The following members comprised the stakeholder group:

- a. Parents representatives
- b. CYP representatives
- c. Mental health nurses
- d. Registered paediatricians
- e. The Challenging Behaviour Foundation
- f. Research Lead Autistica
- g. Nuffield Trust, Healthcare Safety Investigation Branch
- h. NHS England & NHS Improvement
- i. East Sussex Healthcare NHS Trust
- j. NHS England, Royal College of Nursing
- k. Roald Dahl CNS for teenagers and young adults Barts Health NHS Trust
- l. Great Ormond Street Hospital
- m. Representative for mental health for association of directors of children's services
- n. Sandwell Children's Trust
- o. Royal College of Psychiatrists
- p. Devon Partnership Trust
- q. Beat eating disorders charity
- r. CAMHS Community Eating Disorders Service
- s. Children's Commissioner's Office
- t. Hempsons
- u. What Works for Children's Social Care
- v. Basingstoke Hospital - Hampshire Hospitals NHS Foundation Trust
- w. University College London Hospitals NHS Foundation Trust
- x. Association for Young People's Health
- y. Consultant Psychiatrists and academic experts on the mental health act

The instrument was informed by:

1) A rapid review of the literature. We began with a rapid review of the literature (see 'MAPS Study background' section). The software Covidence (<https://www.covidence.org/>) was used to manage the review process. The review protocol was registered on PROSPERO (CRD42022350655).

2) A modified Delphi process with the stakeholder group. Findings from the review contributed to the development of an initial data collection instrument which was refined using a modified Delphi approach. Members of our stakeholder group and Patient and Public Involvement and Engagement (PPIE) group were the experts in our Delphi.

The purpose of the modified Delphi process was to agree on key areas for data collection in WP2B. We anticipated that these will include reasons for admission, repeat admissions, decision-making processes around admissions (e.g. alternatives considered, professionals involved or approached, perceptions of support or lack of support from community services), interventions on wards (for example assessment and observation only; refeeding (oral or nasogastric); restrictive practices (section under the Mental Health Act, restraint); involvement of mental health professionals (e.g. liaison teams), discharge plan and treatment. We were also interested in whether admissions could have been avoided or shortened and what barriers were present. The stakeholder group was asked to define avoidable admissions and help to operationalise an algorithm to identify avoidable admissions. We worked with our health economics investigator to examine what data could be collected to inform outline health economic analyses.

The modified Delphi process was undertaken in two rapid rounds, using available online software within a hybrid format (in-person/online model). First, the rapid literature review informed an initial set of key domains which were modified after consultation with the stakeholder group. After consultation, we developed the tool and then, sent it for comments/suggestions from the stakeholder group. We incorporate the changes, and we built an online web form to enable data entry by clinicians. We used the secure and well-tested RedCap system in which data are directly imported into the secure UCL Data Safe Haven.

For round two, we tested the instrument and online webform (month 6) in three sites using a series of 'dummy' or fictitious patients. Feedback from this piloting was incorporated into the final instrument.

7.3.1. WP2A outcomes and deliverables

- a. Identification of key areas for data collection. Some of the areas highlighted by the stakeholder group can be seen in Appendix 2.
- b. Finalised instrument for WP2B. The instrument consists of the following sections: a) Key facts about admissions, b) Further detail about management during admission, c) Mental health assessment/support during admission, d) Social care aspects of the admission, e) Information about the lead-up/prior to admission, f) Discharge and g) Overall perceptions of the admissions. For more detail about the questions included in the instrument, see Appendix 1.
- c. Academic publication from the rapid systematic review. The results of the rapid review, mentioned in the 'MAPS study background' section, were presented at the RCPCH and YPHSIG Adolescent Health conference: Re-coming of age. Re-calibrating and moving forward the global health agenda for young people (9–10 November 2022, Birmingham). The manuscript will be submitted for review to an international peer-reviewed journal by the end of January 2023.

Key outcomes will be reported back to the stakeholder group and working with them to bring together all the work packages (WP4; see Figure 1) and to produce a ToC model.

7.4. WP2B: Data collection at paediatric wards

We will prospectively collect data on all primary MH admissions to 15 acute paediatric sites in England over 6 months. For this, we will use the tool developed in WP2A (Appendix 1).

The end of the study will be the date of final data collection from a site. We will ask centres to give us any interim details on current admissions at end.

7.4.1. Study setting/centres

We will purposively select 15 acute paediatric centres from children's hospitals and district general hospitals across different geographical regions, urban and rural in England. We will also ensure that the selected sites have a range of local inpatient MH bed provision to enhance generalisability. Sites will be recruited through existing networks of paediatric wards maintained by the RCPCH and through strong personal networks maintained by the investigators.

7.4.2. Eligibility Criteria

We have already obtained outline agreement from approximately 30 centres who would welcome participation in this project and that our proposed data collection is feasible and welcome. The selected 15 acute paediatric sites will come from the 30 who have already signalled interest. We will enlist the support of the CRN to support local centres and have costed into the grant necessary costs with our CRN for local team time, admin support and training. We will begin the process of recruiting sites and local R&D processes from the beginning of the study (led by Hudson and the project manager) so that sites are ready as soon as ethical approval is granted.

7.4.3. Study Procedures

7.4.3.1. Recruitment of participants and procedures

A nominated paediatrician from each study centre will report data on all CYP admitted meeting the case definition over 6-months. Reporting will be enhanced through the provision of administrative support to all reporting sites and the offer of inclusion of reporting paediatricians in study outputs.

Cases of interest will essentially be any CYP admitted to the acute paediatric ward for a primary MH admission during the data collection period. Data will be entered using our webform (developed in WP2A) through a simple, secure online platform (RedCap), with data transferred automatically and securely into the UCL Data Safe Haven.

The specific data that will be collected from each participant site can be seen in Appendix 1. We will collect additional general information outside of the online questionnaire relating to what is the case during the study. This additional information includes the total number of admissions during the time of the study to the ward, the number of admissions over time of the study, if they have a restraint policy and a refeeding protocol, if they have access to mental health support on the ward by mental health professionals and training resources centres for these admissions. Moreover, we will ask for the price of an admission tariff, what is the flow from A&E to the ward and the local CAMHS set-up and link with the ward – e.g., number of FTE of professionals available as liaisons.

We have 30 centres willing to take part, and we will work early on with the 15 selected centres in training on the reporting system. We have also costed for research costs to be paid to centres to ensure appropriate administrative support for reporting, and clinician time at

centres. We will also work via our PPI lead with our advisory and stakeholder groups to inform approaches to maximise recruitment of young people and families.

7.4.3.2. Safety considerations/Patient safety

With specific regard to WP2B, this package will be prospective data collection by centres, with no direct involvement with patients by the research team, and safeguarding will be managed by teams through local pathways and policies. We will be asking for data on safeguarding issues about these patients.

In addition, the MAPS study has a safeguarding protocol. This protocol is to guide the research team around safeguarding of children, young people and adults during the MAPS project. It includes safeguarding, but also risks identified about safety or mental health of participants throughout the study (Appendix 3).

7.4.3.3. Data monitoring

Data will be entered using our webform (developed in WP2A) through a simple, secure online platform (RedCap), with data transferred automatically and securely into the UCL Data Safe Haven (DSH). Members of the research team involved with data collection and storage will be appropriately trained to have access to the DSH. Data collected will be stored on a secure, password protected database held on a non-networked laptop.

Data collected will not include names or patient identifiers. All data will be destroyed after 10 years or at a point earlier requested by the patient and/or family.

7.4.4. Statistical considerations and data analysis

7.4.4.1. Sample size

Our survey of 36 sites in Jan-March 2021 showed a median number of primary MH admissions per centre of 13 per month. We anticipate there will be a lower number post-pandemic of 8 patients per month across 15 sites, totalling 720 patients. We estimate that data will be collected on 90% of these, providing a sample of 650 for the study. We have not formally undertaken a formal power calculation but note that 650 patients provide a precision (95% CI) of +/- 2.3% for a proportion of 10% and +/- 3.5% for a proportion of 30% for the primary outcomes noted above (given school-age population approximately 8 million).

7.4.4.2. Statistical methods

Reporting of outcomes will be primarily descriptive, and we will minimise formal statistical testing. Note that much of the data (e.g., on factors related to causes of admissions, barriers to alternative treatments etc) will be semi-quantitative and only descriptive analyses will be undertaken. We will use simple linear or logistic regression to examine associations of various sociodemographic factors (e.g., age, ethnicity, sex, deprivation) with admissions for different MH problems and with experience of different barriers to accessing alternative treatments and with patterns of discharge care. Analyses will be undertaken by the post-doctoral researcher supervised by Hudson and Viner (an experienced data scientist). Health economic analysis will be carried out by Cornaglia.

7.4.5. Risks to research

There are no direct risks to research participant. However, we will not be asking for consent as the need to obtain consent would bias the sample and reduce generalisability and would potentially burden those admitted in distress. We will have information posters in hospitals and information on our website describing the research and providing patients with contact details so they can opt-out (Appendix 4).

7.4.6. Ethical considerations

For WP2B, we will set up a prospective reporting system (akin to a surveillance study) by a lead clinician at each site without consent as the need to obtain consent would bias the sample and reduce generalisability. It would also potentially burden those admitted in distress.

Moreover, we will follow additional steps to deal with not asking for consent: a) Minimizing personal identifiable data; b) Rely on local NHS services opt-out processes (we will only select sites where this is active, but should be in all NHS trusts); c) Put up signs around units on wards easily accessible to patients and families explaining what we are doing, with a QR link to further information on the study, and encourage CYP and families to notify local teams that they do not want their data used; d) Local paediatric teams have been working with us on the process and will be central to data collection but also local assurances and education (the grant includes money to support the education of data and time taken to do so). We have had a large amount of support from paediatric units in the project, methodology and the use of data without consent - like how paediatricians report to the British Paediatric Surveillance Unit; e) Reiterate the use of the data safety haven and the limited amount of access to the data set other than researchers.

For opt-out processes, we also going to ask reporting paediatricians to record the unique identifier for an admission in patient notes. That way an admission could be identified locally from clinical notes through the specific identifier, which could be relayed to the research team, so that we could delete that data point.

Worth to mention that we involved CYP and parents in the original design and grant application of the project, which was reviewed by the NIHR when submitting the proposal of the study. Therefore, all the previous steps have been explained to the young people's groups and PPI consultation.

Moreover, we have carefully considered the process of collecting data without consent and have taken the opinion of both, our stakeholder group and several CYP and their families. This is outlined in our next section.

Finally, we set up a Study Advisory Group (SAG) of independent academics and practitioners who are independently supported by NIHR. We also invited to this group parent members of the stakeholder group for reference through the study. The group is monitoring the study and providing independent advice. Our first meeting was held virtually on October 31st, 2022, to discuss the proposal and methodology of the study. SAG members were fully supportive of the methodology and process of collecting data without consent.

7.4.6.1. The views of young people and families

The research proposal and dissemination plan were presented to members of the Think4Brum (T4B), which is the youth advisory group for Forward Thinking Birmingham (FTB), and the GOSH Young Persons' Advisory Group for research (YPAG) in October and November 2022, respectively, as part of a Patient and Public Involvement and Engagement initiative. The T4B and GOSH-YPAG are a diverse group of CYP recruited from across the country who have received training in research methods and policy. Focus groups of 40 young people (32 from

GOSH and 8 from T4B) aged <18 (and parents) was held to discuss the acceptability of the research methods (including the use of data without consent).

The groups were overwhelmingly supportive of the importance of this research and the necessity of analysing data without consent (see Appendix 5). The young people did raise the issue of data usage and security, but our explanations for how we will use and store the data were acceptable to the young people who attended. For both young people's groups, we followed up to see if there were any comments after the meetings. For the GOSH group, there was not, but for T4B the group had gone away and discussed it with a larger group than had attended. We were told by the leader of the group that on further discussion with a broader group initially: "we did have some concern about usage of data but that was allayed when we feedback your input from our session." Specific feedback regarding strategies to inform CYP and their families of the research were incorporated into the project as well as recommendations about what questions to ask.

7.4.7. Outcomes and significance

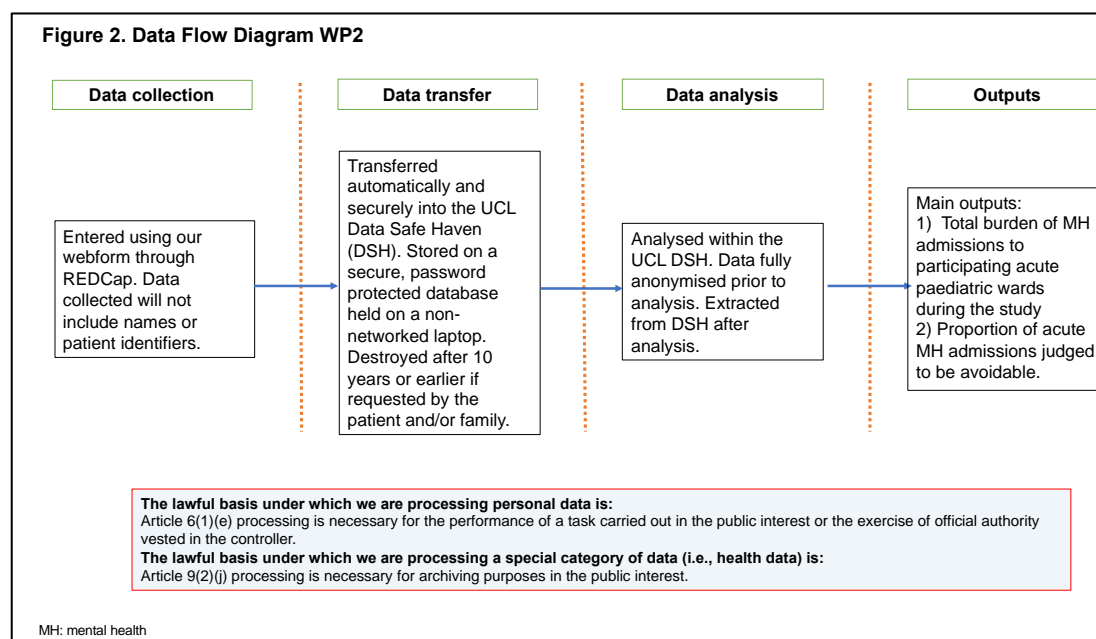
At the outset of the study our overall aim is to improve care of CYP presenting in a MH crisis admitted to acute paediatric settings, with this being the primary aimed impact of the study. However, by producing a Theory of Change approach as described above, desired impacts will be augmented and developed through the process of combining data with stakeholder views.

With specific regard to WP2B, nominated paediatrician from each service will report data on all CYP admitted meeting the case definition over 6-months. Reporting will be enhanced through the provision of administrative support to all reporting sites and the offer of inclusion of reporting paediatricians in study outputs.

We anticipate that our primary outcomes will be:

- i. The total burden of MH admissions to participating acute paediatric wards during the study period, as 1) a proportion of total acute admissions and 2) as a proportion of total bed-days occupied during the period.
- ii. Proportion of acute MH admissions judged to be avoidable (using the algorithm identified by the stakeholder group in WP2A).

A summary of our study procedure for WP2 and lawful basis under which we are processing the data can be seen in Figure 2.



8. Work Package 3 (WP3): Gathering the views of CYP, families and HCPs

Months 11-24

Lead Gibson

8.1. Rationale

Understanding the experiences of CYP and their families is fundamental to examine the context of care. The NHS England funded Amplified programme is providing evidence on the importance of and approaches to engaging with CYP, such as, supporting and building participation to ensure CYP are involved in decision making about their own care and providing feedback on their experience (26). For CYP and families experiencing vulnerabilities, we need to find ways of designing and promoting mental health support that works for them. This requires understanding their experiences of care and service provision, especially how 'good mental health support' would look through their eyes and then co-designing how we work to deliver this. The views of CYP, their families and those who care for them, will best illuminate the narrative of care, revealing values and attitudes that shape services.

8.2. Theoretical framework

Theory of Change (ToC) is essentially a comprehensive description of how and why a desired change is expected to happen in a particular context (27). In our study, it will assist in defining long-term impact (e.g., impact optimising delivery of care for CYP in MH crisis) and will then map backward to identify short/medium rapid outcomes. Using the steps of ToC will provide a solid improvement framework to enable us to map and synthesise datasets to meet aims, draw conclusions and deepen our understanding of key issues, facilitating also focused work with our stakeholder group to achieve impacts. Though in essence, consideration of the ToC will run throughout the study, three WPs will deliver types of evidence needed to inform our ToC: (including evidence of need, evidence of context and evidence of effectiveness) gathered from national data (WP1); published and stakeholder perspectives (modified Delphi: WP2A); more granular detail about admissions from a prospective reporting system within a sample of hospitals (WP2); and qualitative data collected from staff, patients and carers from that sample (WP3).

8.3. WP3 Research aim

To explore the views and experiences of CYP admitted to paediatric wards for primary MH problems, and the views and experiences of their families and HCPs, with concern to admission, care and treatment.

8.4. WP3 Research objectives

1. To explore CYP's and their families experience of their admission to a paediatric ward, including an understanding of the reasons for admission, the care and treatment received prior to and during this admission.
2. To explore HCPs experience of caring for CYP with primary MH problems, and their families, to understand more fully their preparation for this role, as well as enablers and barriers to delivery of individualised patient-centred care.
3. To determine recommendations for the improvement of care, treatment and outcomes of CYP and their families admitted to paediatric wards for primary MH problems.

8.5. Outcomes

- A. Description of the experiences, care and treatment of CYP admitted to paediatric wards for primary MH problems
- B. Description of the treatment and care CYP and their families want to receive in paediatric wards and recommendations for the improvement of care, treatment and outcomes of CYP
- C. A theory of how treatment and care for CYP admitted to acute paediatric wards with primary MH diagnosis can be improved

8.6. WP3 study design

A multiple-case study will be our focus. Case studies seek to investigate phenomena within a context or series of contexts ('collective' or 'multiple-case' studies), and it is a methodology that is uniquely suitable when studying complex settings where several interrelating variables exist (28-29). It is an intensive "study of the particularity and complexity of a single case, coming to understand its activity within important circumstances" (30p. xi). By collecting qualitative data about a phenomenon, we will gather rich in-depth insights about that phenomenon: in this study, the case, is the paediatric ward, where CYP are admitted with primary MH problems.

8.7. Study Setting

For WP3, five acute paediatric wards will be selected from the 15 anonymised sites involved with WP2B, with each paediatric ward representing a case. As stressed by Gerring & Cojocar (31), transparency in our approach to case selection is essential if others (for example policy makers) are to assess the nature of evidence presented in our multiple-case study. As we aim to conduct intensive analysis on a small number of units (cases), to understand a larger group of similar units (the wider population of cases), it is essential our case-selection approach maximises the representativeness of the sample of cases selected (32). We will therefore apply a 'Diverse' case selection approach, which aims to ensure maximum variance of cases along relevant dimensions or criteria (31; 33). Using available data from WP1, our rapid review, and expert knowledge of the study team and stakeholder group, a list of selection criteria will be described a priori by the project team. The stakeholder group will then ensure transparent and unbiased selection of cases through applying selection criteria to the

anonymised 15 sites recruited as part of WP2B. A consensus will be reached by the stakeholder group on cases to be included as based on the maximum variation of values for described selection criteria. Such selection criteria may include number of paediatric in-patient beds, geography and deprivation score, size of children's service, and ethnic diversity of the population. The five paediatric wards selected will provide a rich and diverse sample of CYP experiencing MH problems, related family, carers or friends, and HCPs from varying disciplines. All selected sites will be sent a standardised email (Appendix 6) and can say if they are able to participate or not. For any site that is unable to participate, we will select and approach the next site on our list that met the inclusion criteria.

8.8. Study procedures and methods

8.8.1. Sampling

Our PPI group and HCP members from our study stakeholder group will support the study team in outlining a sampling matrix for CYP a priori, to be used by staff leads identified at each site. A named staff lead for each of the five paediatric wards will be identified and asked to support with purposeful sampling and identification of CYP to be approached. Our sampling matrix will describe a representative and diverse sample CYP, varied, for example, in sex at birth, gender identity, sexuality, age, ethnicity, socio-economic background, learning disability, and MH diagnosis. This approach to sampling will ensure that at least 25% of recruited participants are from minority groups (ethnic minorities). Note that gender recruitment issues are complex as only 20% of adolescents with eating disorders are male, however we will purposively target males for recruitment.

During data collection, CYP will be asked to identify 1 or 2 family members, carers/guardians or friends, as well as 1 or 2 HCPs from their paediatric centre to participate in data collection. To assist them in making that choice, they will be asked to base their choice on those who have played an important role in their care and admission. The research team will oversee and monitor HCP sampling and recruitment as data collection progresses, with the aim of ensuring the sample recruited represent the breadth and diversity of multi-disciplinary care teams.

For each case (centre), we aim to recruit up to 7-8 CYP (total n=35-40), and 8-9 family members (total n=40-45), and 4-5 HCPs (total n=20-25); however, data collection will continue until a theory has emerged and the data set provides sufficient similarities and contrasts to the emerging theory (34).

8.8.2. Inclusion criteria

- CYP aged 10 to 17 years (up to 18th birthday) who live in England.
- CYP admitted to one of the five paediatric wards with a primary MH diagnosis.
- Family members, carers/guardians or friends of CYP who are 16 years and above, live in England, and have been identified by CYP as having played an important role in their care and admission.
- HCPs who are a member of the treating team for CYP working on one of the five selected paediatric wards.
- HCPs self-identified by CYP as having played an important role in their care during their admission.

Note, that CYP can be included without identifying any family members, carers/guardians or friends for recruitment to the study.

8.8.3. Exclusion criteria

As the project is focusing on care on the general paediatric ward, we will exclude HCPs who work exclusively in the accident and emergency department.

8.8.4. Recruitment and consent with CYP

A named staff lead for each of the five sites will support with identification of CYP to be approached. With guidance from our local CRN, we budgeted appropriately to cover costs associated with identification of participants to be conducted by the sites.

Figure 3 illustrates the flow of steps which will be taken to identify and recruit CYP. The recruitment process is tailored to the needs of CYP who are under 16 years, and those over 16 years, and is as follows:

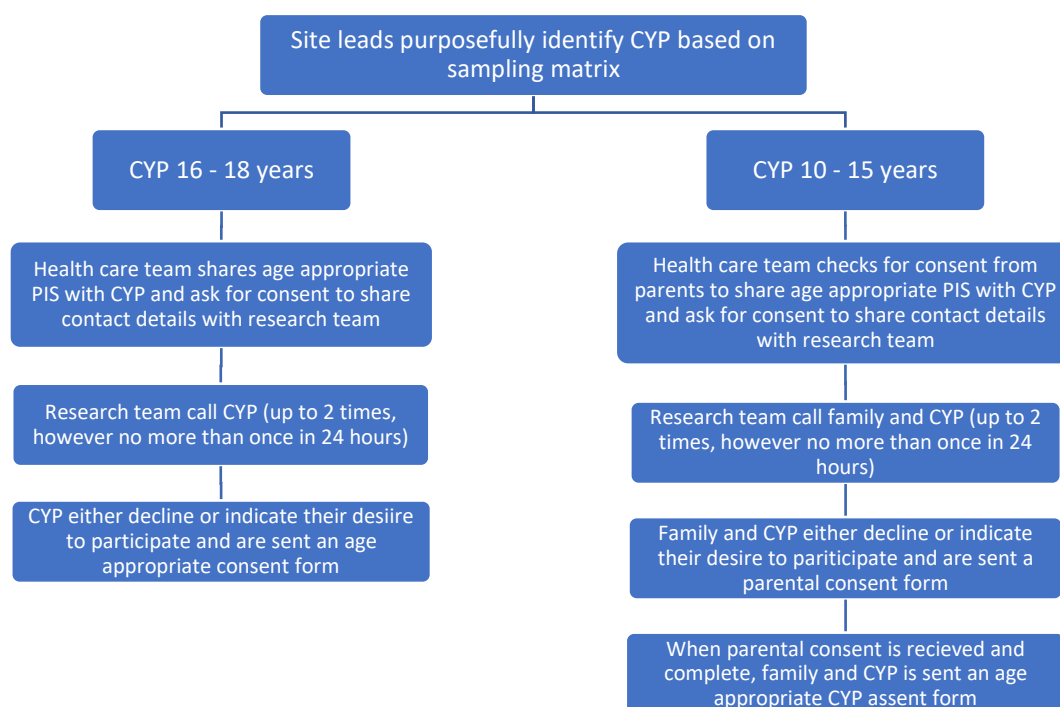
- The lead at each paediatric ward will purposefully identify CYP in accordance with the sampling matrix.
- The lead will request a member of the respective health care team to approach the CYP (and their parents/carers if CYP is under 16 years).
- For CYP under 16 years, parents/carers will be approached first to give permission for the CYP to hear about the study.
- If a CYP expresses interest, they will be given an age-appropriate printed PIS.
- If under 16 years, parents/guardians will also be given a printed PIS.
- If CYP still interested, they (or their parents/carers if aged 10-15 years) will be asked to provide written consent (Appendix 7) for their contact details to be passed onto a researcher at UCL.
- The researcher at UCL will then contact the CYP to discuss the study, answer any questions they might have, gauge their interest in their participation.

Three versions of the CYP PIS will be made available (Appendix 8-10) – one tailored to young people who are 16 years and over; another tailored to CYP who are 10-15 years; and a third tailored to parents/carers of CYP who are 10-15 years.

If consent to be contacted is given, a member of the research team would contact the CYP (who are over 16 years) and parents/guardians of CYP (who are under 16 years) by phone to provide more information and gauge interest in the study. The research team will only speak to CYP who are under 16 years, after having spoken with their parents/carers, and will ensure the CYP have received an age-appropriate PIS. The research team is permitted to contact them by phone a maximum of two times, and not contact them for at least 24 hours after the initial approach. CYP and families can contact the research team if they wish to speak with someone and/or ask questions about the research. Contact details for the research team will be included on all PISs.

Three versions of CYP consent/assent form have been developed (Appendix 11-13); these include a consent form for CYP aged 16 years and over; a parental/carer consent form for CYP aged 10-15 years, and an assent form for CYP aged 10-15 years. Consent/assent forms will be shared with those CYP and parents/carers who indicate a desire to participate and must be completed by CYP and parents/carers of CYP age 10-15 years prior to participation in the study. CYP aged 16 years and over, as well as parents of CYP age 10-15 years will be asked if they consent to a letter being sent to their GP (Appendix 14) informing them of the CYP's involvement in the study.

Figure 3. Recruitment flow chart for CYP



8.8.5. Recruitment and consent with family members, carers and/or friends

CYP will be asked to self-identify family members, carers and/or friends who are aged 16 years and over during the data collection process who have been involved in their treatment, care and admission. The research team will have already obtained contact details and consent to contact parents or carers of CYP aged 10 to 15 years and will therefore contact them by phone a maximum of two times to gauge their interest in participating in the study and will share a family, carer and friend PIS (Appendix 15) with them. For family, carers and/or friends of CYP age 16 years and over, and for those family and/or friends who the research team does not have consent to contact, a family, carer and friend PIS will be shared with the relevant CYP, and it will be their responsibility to share the information with the family members, carers and friends, and the potential participants' responsibility to get in touch with the research team. A family, carer and friend consent form has been developed (Appendix 16). All family members, carers and friends interested in the study will be required to complete the consent form prior to participating in the study.

8.8.6. Recruitment and consent for HCPs

The staff lead for each of the five sites will be asked to facilitate the recruitment of HCPs identified by CYP. A list of HCPs nominated by CYP will be shared with the respective leads, who will then share printed invitation cards to respective HCPs. The HCP invitation card (Appendix 17) provides a brief overview of the study, states that a CYP who received their care has nominated them to participate, includes the research team contact details, and asks the HCP to contact the research team to receive more information about their potential participation. The research team will explain about the study when contacted by HCPs and share a HCP PIS (Appendix 18) with them by email. If we do not hear from nominated HCPs, the research team will ask the lead to follow-up with the respective HCP and ascertain if they are intending to contact the research team.

A HCP consent form has been developed (Appendix 19). The HCP consent form will be shared with those participants who indicate a desire to participate and must be completed by HCPs prior to participation in the study. The site will not know who has agreed to participate, unless the participant themselves chooses to tell their teams.

All participants will have two weeks to decide whether to participate in the study. All non-responders will be re-contacted once via phone call, two weeks after the last contact.

8.8.7. Data collection

Data collection will aim to understand patient and family, carer and friend experiences of admission to paediatric wards with a primary MH diagnosis using interpretive and participatory approaches. Qualitative data will be collected, as this will provide more detailed information on the experiences of CYP and that of their family, carers and friends. Data collected will aim to explore participant experiences of the lead-up to admission, as well as causal factors in this process, and experiences of services, treatment, and care and quality of outcomes for CYP admitted to paediatric wards with a primary MH diagnosis.

Data collection methods with CYP will be participatory, flexible and adaptable to their needs. As much as possible, we will aim to be guided by the professionals who work with these CYP as to determine the best ways of involving and facilitating data collection with them. With the intention of supporting more effective recruitment of participants and access to the study, we will aim to collect the majority of CYP data via semi-structured interviews held virtually (via MS Teams or Zoom). However, the research team will make clear to CYP that there is the option of holding in-person interviews at an appropriate private, local location of their choice should they wish. For CYP aged 10-15 years, decisions concerning location of data collection and whether to hold the interview virtually or in person will be determined via consultation with the participant and their parent and/or guardian/carer. Similarly, researchers will be sensitive to the needs of 'looked after children' in identifying suitable interview locations should participants prefer to hold the interviews in-person.

The use of semi-structured interviews will allow for key question topic areas to be explored with participants, however also for more in-depth exploration of CYP and family/friend experiences of care and service provision, adapting questioning to participant narrative and discussion where necessary. PPI members will also be consulted on selection of and approach to integrating more creative and participatory techniques of data collection in interviews to support increased participation of CYP who are less receptive to more traditional interview techniques. Participatory techniques such as body mapping, timelines, and photo elicitation will all be explored as potential 'tools'. CYP and parents and guardians of CYP aged 10-15 years will be required to complete a photo reproduction rights form (Appendix 20) to consent for photographs to be used in data collection and subsequent study outputs. For younger CYP involved in data collection, we will also consult with them prior to interview to ascertain if they would find specific participatory methods helpful, and whether (or not) they would like their parent or guardian present during data collection to act as an aide-mémoire.

Semi-structured interviews will be conducted with family members, carer and friends who have been identified by CYP as having been involved in their treatment, care and admission. We will aim to conduct most of these interviews virtually, however where advantageous, will conduct these interviews in-person at a similar time/location of their related CYP should they also wish to conduct their interview in-person.

Data collected with HCPs will aim to explore their experiences of caring for CYP admitted to paediatric wards with primary MH diagnosis. As with other study participants recruited under WP3, qualitative data will be collected. Semi-structured interviews held virtually (via MS

Teams or Zoom), or by telephone, will be used to collect data with HCPs. The use of semi-structured interviews will allow for key question topic areas to be explored with participants, however also for more in-depth exploration of HCP experiences of care and service provision. More specifically, data collected will aim to explore HCPs preparation for their role, enablers and barriers to delivery of quality individualised patient care, and their recommendations for improvement of care and quality of outcomes of CYP admitted to paediatric wards with a primary MH diagnosis.

When conducting data collection with participants virtually, participants will be advised to utilise a room where they have privacy to conduct their interview, thereby allowing them to express views freely and feel as comfortable as possible whilst discussing sensitive, and potentially upsetting topics.

Proposed interview schedules for CYP, family, carers and friends of CYP, and HCPs are included in Appendix 21, however these will be reviewed and updated prior to data collection via consultation with PPI and study stakeholder group members.

Interviews will be conducted by members of researcher team with skills and experience in qualitative research with child and adult populations. Interpreters will be used as required to support with interviews and discussion with participants who do not have English as their first language. Gibson has extensive expertise in qualitative research with CYP (See Appendix 22 for Gibson's CV), including management and supervision of other researchers. Both research assistants also have considerable qualitative research experience, however, will receive training on best practice in conducting research with CYP. Supporting safe participation of CYP in our study will be a priority – and we will take guidance from our PPI lead and advisory group on safeguarding and related data collection processes, as well as training for researchers leading on collection of qualitative data.

The end of the study will be when the last interview has been conducted.

8.8.8. Safety and safeguarding

Any safeguarding concerns, including any disclosures of significant harm experienced by a young person or relating to another young person made during data collection, will be escalated in-line with the study Safeguarding protocol (Appendix 3). All researchers will have undertaken level 3 safeguarding training prior to commencing participant recruitment and data collection. Safety of researchers will be supported, and risks minimised via all researchers following UCL's 'Lone Working' and 'Off-site Working' guidance. A risk assessment will be developed to manage and mitigate risks associated with conducting data collection face to face with participants and 'off-site'.

8.9. Promoting inclusion

We are aware of potential barriers some CYP and their parents/carers may face in restricting their ability to participate. Barriers may include not having English as a first language, or having physical, sensory or intellectual difficulties or disabilities. All efforts will be made to overcome potential barriers to participation, including:

- Provision of age-appropriate PIS and online consent forms
- Paper copies of study materials can be sent to potential participants upon request.
- Translation of study materials will be provided, as required.
- The provision of interpreters will be provided for interviews and other qualitative data collection activities, as required.
- Individualising our approach to data collection with CYP

8.10. Data entry and analysis

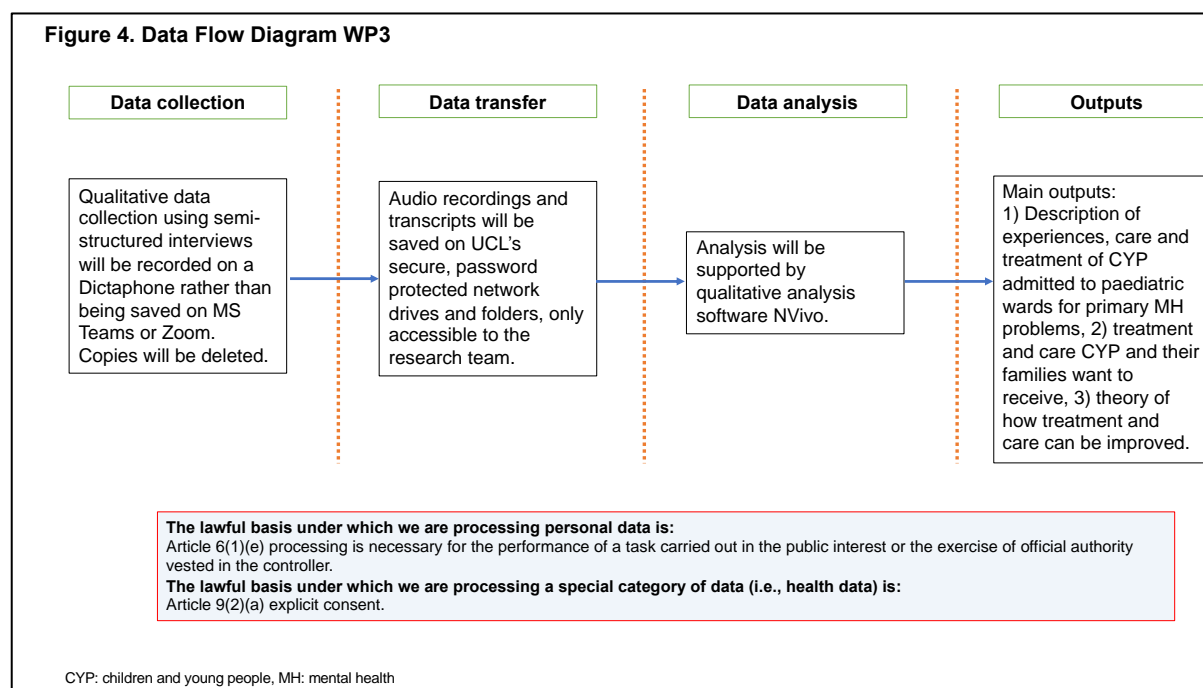
All interviews will be recorded on a Dictaphone rather than being saved via MS Teams or Zoom applications. All audio recordings and transcripts will be saved on UCL's secure, password protected network drives and folders, which are only accessible to the research team. Copies of audio files on the Dictaphone will be deleted. Recordings will be transcribed verbatim by a UCL approved professional transcription company in parallel with ongoing data collection. Transcripts will be checked by the research team to ensure validity and completeness of data. All recordings will be destroyed after the transcription has been made.

Our approach will be iterative-inductive analysis as there will be simultaneous sampling with collection and analysis of data, each informing the other. This will allow for structured and defensible flexibility in our study and maximise our ability to respond to theoretical sensitivity. Initially each data source will be analysed separately, and then aggregated together for each case, and further aggregated when bringing the cases together. The analysis will involve an interpretative approach including memoing, coding and constant comparison in the development of categories that will seek to reveal internal patterns in the data. This will continue until there is an emergent framework, that adds to our emerging ToC. External patterning is the final stage where analysis will be explored in relation to external knowledge base. As with all approaches to qualitative research our analysis will involve four key cognitive processes: comprehending, synthesizing, theorizing, and contextualizing (34). This will be supported by qualitative analysis software, NVivo.

8.11. Risks to research

Risks to the research for WP3 include selected cases not agreeing to be research sites. Other risk includes not recruiting enough HCPs and CYP, as well as not recruiting CYP of sufficient diversity to meet the prescribed sampling frame. The research team will aim to harness existing relationships with sites established during delivery of WP2B in recruitment of selected cases for WP3. To support with recruitment, the MAPS study information poster (Appendix 23) will be placed in appropriate locations in paediatric wards at selected sites, informing the study population of the aims, intended outputs, outcomes and benefits of the research. HCP invitation cards (Appendix 17) will support with HCP recruitment, with them including an overview of the study and stating that one of their CYP patients has nominated them to participate. Effective and regular communication with site leads will be maintained throughout sampling, recruitment and data collection to ensure challenges and issues are detected early and resolved. Sampling and recruitment will be monitored and reviewed weekly by the research team to ensure gaps in sampling are identified and addressed.

A summary of our study procedure for WP3 and lawful basis under which we are processing the data can be seen in Figure 4.



9. WP 4: Synthesis, dissemination and impact

Months 24-30 (synthesis 24-27 and dissemination 28-30)

Lead: Hudson

In this section we describe WP4 but also refer to overall expected outputs, dissemination and impacts in the section below. It is in this WP that the final ToC will be agreed, bringing together the initial stakeholder inputs and data collected from WP1,2b and 3. In essence, consideration of a ToC by the research team and the stakeholder group (in particular through early engagement in WP 2a) will run throughout the study alongside other WPs, as all of the study will inform the ToC. However, it is in WP4 that this will be brought together for the final model.

9.1. Aim

To synthesise data across WPs, to contribute and finalise our ToC with new evidence, around context, need and effectiveness to inform service provision, including staff development and new pathways or models of care needed to improve the care of CYP admitted to acute wards and then deliver impact.

9.2. Background

In this work package, we will bring together all of the work packages, and here describe anticipated outputs and impacts to finalise a ToC.

9.3. Methods and Deliverables

A sequential synthesis will be undertaken to maximise theoretical and empirical insights from findings from WP1-3. Key to this will be reporting back to the stakeholder group and working with them to produce a ToC with agreed outputs and pathways to them to achieve impacts (which were first agreed in WP2a but can be developed at this last stage). We expect outputs in the ToC to include generating a systems map to identify recommendations and transformation plans to share with policy makers, commissioners, service leads, and

professionals. We will refresh the systematic review undertaken in WP2A and work with our Stakeholder group to identify potential alternative models for service provision, both international models and emerging UK models, and examine whether some of these may be potentially feasible and effective in the UK setting to meet some of the likely needs identified in this study.

The process of drawing up the ToC will be participatory between the research team and stakeholder group, and is crucial to inform what becomes the final “output” around service provision and new models of care. There will be a full-day workshop to bring this together in WP4, and then a further smaller workshop where the research team will bring back the model for final discussion and amendment with the stakeholder group.

Beginning in WP2a, we will begin the process of formulating the ToC using the following 5 steps. This consists of 5 steps, undertaken with our stakeholder group, using workshops, we will use the 5 steps illustrated in figure 2 below to build our model. The first 2 steps of identifying aims and outcomes will be particularly examined earlier on in the study. It will be important that the final ToC is credible, achievable, consensus driven and measurable at a later stage (and the bringing together of the research from WP 1-3, research team and stakeholder group will be central to ensuring these criteria are met through the final steps of Figure 2.

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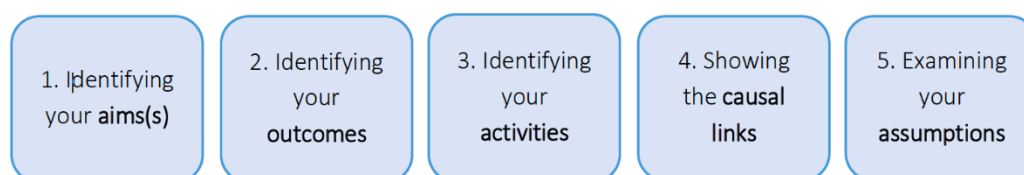


Figure 2: Steps for developing the final ToC.

A proposed format and content for initial and final stakeholder workshops to bring together the ToC is shown as an appendix (Appendix 1).

9.4. Dissemination, outputs and anticipated Impact

At the outset of the study our overall aim is to improve care of CYP presenting in a MH crisis admitted to acute paediatric settings, with this being the primary aimed impact of the study. However, by producing a Theory of Change approach as described above, desired impacts will be augmented and developed through the process of combining data with stakeholder views.

Our collaborator and stakeholder networks also provide immediate routes for impact, given involvement of the key national commissioners and professional bodies, and we have costed for open access in the grant to maximise visibility and reuse. Each of the co-investigators, collaborators have large networks in order to reach a large audience with our data. Influence and outputs are not restricted until the end of the study. As ideas and data emerge (including very early on from the modified delphi and stakeholder meetings) we will use them to inform projects ongoing at senior levels of the NHS.

Outputs will include:

- Individual papers from each work package described above to add to the published literature on this topic (which as we have stressed is currently poor).
- An overall report which will describe a summary of findings for each WP, but most importantly outline the ToC model derived from WP4, which will include our collaborators of the RCPCH, RCPsych and NHSE – we envisage this being a set of standards for admissions based on our findings at ToC. This will be aimed at policy and practice audiences, but we will also publish this in a peer reviewed journal.
- Dissemination events specifically for centres who have been involved, policy and practice communities. as well as publish 3+ papers in peer-reviewed open access journals (1-2 per WP). Each of the co-investigators, collaborators have large networks in order to reach a large audience with our data.

Broader impact is not limited to the duration of WP4 and might include:

1. Influencing professional training and workforce planning – we expect specific recommendations about training to feature in WP4 outputs. Improvements achieved as an impact from our study could also improve working conditions and retention for Staff within the NHS (given anecdotal reports of the toll of this work at the outset). Our current understanding is that in particular nursing and medical professionals are struggling with the issues of MH admissions. We would work with the RCN and colleges to produce guidance on training and in future developments of curricula.
2. Influencing developments of current and new models of care. We expect our study to produce important information for example on service user needs, safety/ quality issues and economic implications which will be helpful and persuasive within the NHS and further afield. We are aware of at least one London trust which is currently planning the redesign of its mental and physical health care for CYP and through one of our co-I associated with that trust, we can directly feed into this from our findings even at an early stage through our stakeholders.
3. Providing data and outputs which will enable advocating for and improving cultural views on CYP with MH crises as part of the acute paediatric system (a problem which as we have outlined frequently gets little attention).
4. Further research and development questions for future work by ourselves and others identified in the study, as well as forging new collaborations via stakeholder groups

Barriers to the impact of our findings could include:

- 1) Mindsets – before setting out, anecdotally we know that some centres and service deliverers are not convinced that mental health admissions in paediatric settings are appropriate. It seems likely that these admissions will continue to happen, but by producing outputs describing positive and negative factors to work with, we can persuade and develop mindsets to improve care.
- 2) Economic barriers –attempts to change health care frequently faces economic barriers due to available funding. One of our objectives is to understand the social and economic implications of admissions and our outputs will look at how developments could make things more cost efficient.

10. Equality, Diversity and Inclusion

WP1 will include the entire English population and we will examine the impact of sex, deprivation and ethnicity on outcomes. In WP2, we again will collect data on all acute MH admissions regardless of protected characteristics although we will collect data on sex, ethnicity, deprivation and comorbid conditions including disabilities. We will use purposive sampling to ensure we include sites representative of England in terms of deprivation, geography and rurality.

In qualitative work in WP3, We will use a purposive recruitment matrix to ensure that at least 25% of recruited participants are from minority groups (ethnic minorities). Note that gender recruitment issues are complex as only 20% of adolescent eating disorders patients are male, however we will purposively target males for recruitment.

Published guidance and perspectives to increase inclusivity of people from minority groups in research consistently highlight the importance of including advocates from minority groups to advise and partner in research. We will therefore ensure the stakeholder group are diverse. We will ensure advocates from different minority groups (e.g. ethnic minority groups and LGBTQ+) participate in stakeholder groups. Where possible we will also link with any local minority advocacy groups to better understand local issues to encourage representative sampling and involvement with the study. We will ensure that one member of our advisory group is expert on diversity to advise and hold the researchers to account on this issue.

We have costed for interpreters and translation of information sheets for WP3 We will ask participating 5 centres for WP3 at the beginning of the study to inform us of the most common languages spoken by service users and ensure patient information sheets are available in these. We will also have the capacity to produce information sheets in other languages as required.

We will ensure that research team members have taken equality and diversity training – not only at institute level, but also link up with training opportunities through national groups which our PPI lead has experience of and can facilitate for us.

11. Project timetable

Prior to commencing

Seek ethics for WP1, and recruitment for research assistant (to start month 0) and post-doctoral fellow (to commence month 6).

Begin to recruit to stakeholder group through networks.

Month 1-4:

Work will begin on WP1

WP2a will commence, commencing the literature review and stakeholder group in place.

Organisation of the data safe haven, redcap reporting system will also be put in place for WP2b and preparation of ethics permission/CAG process.

Commence final recruitment of paediatric centres.

WP3 preparation of ethics permission.

Month 5:

Trial of the research tool and system using dummy cases with 3 centres in England, with feedback and any final alterations.

Submission for ethics approvals and CAG approval for study WP2b sought when tool finalised.

Commence training of paediatricians for data collection tools and begin local R&D agreements for WP2b and 3.

Write up of WP2a.

Commence work (including with stakeholder group members) on final details for WP3 sites and selection of 5 sites.

Submission for ethics approvals for WP3.

Month 14:

Start data collection for WP 2B for centres (up until month 24 : it is expected that some centres will start at different times, but each for a total of 6 months)

Start data collection for WP3

Month 24 –27:

WP4: data synthesis.

Begin write ups WPs and final report.

Month 28-30

WP4 dissemination including events.

Complete write-ups.

Meet stakeholder group to present findings and develop outputs

12. Project management

The study will be led jointly by Hudson and Viner as Co-PIs, with Hudson responsible for day-to-day leadership of the study and Viner having responsibility for finance and deliverables.

Hudson will meet weekly with the study researchers and the project manager, with specific management details for each WP detailed in the section above. The project manager will have specific responsibility for planning the sequencing of each element, keeping the risk register and advising the investigators when timing is at risk.

The Study Management Group will consist of all named investigators and will meet every two months throughout the project.

We will set up an Advisory Group of independent academics and practitioners, separate to the Stakeholder Group, to provide robust independent advice. Dr Pradmanabhan Ramnarayan, a consultant paediatric intensivist and lead investigator for the DEPICT study (NIHR funded study following PICU admissions nationally and thus similar set-up to our study)²⁹ has agreed to chair this group. We will invite a smaller component of CYP and parent members of the stakeholder group to join an advisory group for reference through the study (we would do this in pairs of CYP/parents to support each other). This group will meet virtually approximately 3 times during the project. We will invite a smaller component of CYP and parent members of the stakeholder group to join an advisory group for reference through the study (we would do this in pairs of CYP/parents to support each other).

Within the tasks outlined throughout the WP above, an important part of the management and governance of the project will include the creation of important standard operating procedures for safeguarding (see below) and involvement of vulnerable PPI (in particular CYP with mental health problems) in the study. These will be developed jointly by the co-investigators (e.g PPI lead, psychiatry, paediatrics) bringing their individual expertise to them.

13. Safeguarding

As PI, and a paediatrician with experience and current work clinically in safeguarding children, young people and vulnerable adults, Hudson will be the study lead for safeguarding. We will create a safeguarding SOP for the study. In general, safeguarding policy will be aligned with UCL's policies for staff working with children, young people and vulnerable adults. It should be noted that several of the co-investigators work in safeguarding as part of their work and are Level 3 trained with the NHS.

With specific regard to WPs:

- As WP1 is using anonymised national data already collected there are unlikely to be any specific safeguarding issues
- WP2a and 4 will involve stakeholder groups and there may be safeguarding issues raised (see below)
- WP2b will be prospective data collection by centres, with no direct involvement with patients by the research team, and safeguarding will be managed by teams through local pathways and policies. We will be asking for data on safeguarding issues about these patients.
- WP3 will involve contact with patients, the majority through virtual appointments, but some in person so the research team's SOP for safeguarding will apply.

Key elements of safeguarding SOP will be:

- All research team members will receive safeguarding training
- A network of local institute social work and safeguarding team can be called upon for advice and to talk through any issues confidentially.
- In the case of safeguarding issues raised regarding participants recruited from centres for WP3, concerns will be discussed and handed to local paediatric teams and pathways. All NHS hospital centres in the study will have mandatory safeguarding pathways.
- Where safeguarding issues are identified with children, young people or vulnerable adults who may be part of the stakeholder group, local policies for safeguarding will apply.
- We will ensure that stakeholders have information about sharing safeguarding issues with the team, and providing safety and safety nets for CYP who take part in stakeholder groups will be a key part of the PPI involvement process (e.g. groups of young people with mental health problems will be invited through their known clinicians who will still have responsibility for them).

14. Ethics and regulatory approvals

Ethics approvals have been outlined within each work package above. In summary, we will apply for HRA and NHS ethics approval for all WP 1, 2B and 3. We will also seek CAG approval for 2B. We will commence the approvals needed for WP 1 before the study starts so that we can begin work on this immediately as the project begins.

For WP2B, we will set up a prospective reporting system (akin to a surveillance study) by a lead clinician at each site without consent as the need to obtain consent would bias the sample and reduce generalisability. It would also potentially burden those admitted in distress. We will obtain the appropriate regulatory approval for this through the CAG and ethics.

For WP3 we will obtain informed consent (in the case of under 16 year olds obtain assent and parental consent; participants over 16 – including parents and staff – will consent themselves). All participants will be provided with information sheets, and be introduced to the research team by local teams. We will provide all participants with information on the results of the study.

15. Project / research expertise

Member of the research team Expertise
(Investigator)

Lee Hudson (co-PI) Hudson is a practicing clinical academic general paediatrician. He has had experience being a principal investigator and managing clinical research studies. He is a paediatrician with particular expertise in mental health, and leads a network of general paediatricians across England looking after CYP with eating disorders to be involved in the study. Hudson has extensive clinical experience of admitting CYP with mental health problems to paediatric settings. He is published in quality improvement and advocacy for care for CYP with mental health problems in paediatric settings. He is chief officer for mental health at Great Ormond Street Hospital.

Russell Viner (co-PI) Viner is professor of Adolescent Health, a paediatrician, and is a clinical academic data scientist with very extensive experience of leading large multi-institution projects that deliver on-time and on-budget. Viner brings expertise in the links between physical and mental health in adolescence, in policy research and the translation of findings into policy and practice. He has extensive experience of using routine administrative data such as HES.

Faith Gibson (Co-I) Gibson is a clinical academic nurse and brings clinical background knowledge of issues for nursing, including expertise in the experiences of CYP in inpatient settings. She has extensive expertise in qualitative research, including supervision of other researchers and working with CYP in research. Gibson has large experience of working with service users to study health care improvement including bringing together qualitative and quantitative data.

Gabrielle Mathews (CO-I and PPI lead) Mathews is a multi-award winning children and young people's advocate with extensive experience representing patients and their carers in clinical and research projects. Her experience of participatory methods will be utilised in working with the stakeholder group and linking in VCSE organisations.

Dasha Nicholls (Co-I) Nicholls is a practicing clinical academic child and adolescent psychiatrist. She will bring the expertise of liaison psychiatry issues for admissions, and the underlying

mental health issues for CYP who are admitted. Nicholls is also an experienced researcher in quantitative and qualitative measures, and experienced data scientist.

Damien Roland (Co-I)

Roland is a practicing clinical academic with a background in paediatric emergency medicine. Via previous NIHR funded studies he has experience in interpreting population level data for emergency admissions and undertaking qualitative research in understanding parental attitudes to care. He will bring clinical and research experience of the interface between emergency medicine and clinical wards, as well as understanding of the factors around admitting CYP with mental health problems.

Helen Roberts (Co-I)

Roberts is an academic social scientist with expertise in health, education and social care. She has research interests in the translation of research evidence into policy and practice, inequalities in health and the voice of the patient, service user and citizen. Roberts has researched and written on the lay expertise of users of services (including child users); the synthesis of different kinds of research evidence, and implementation issues. Robert's input will be important for the social care aspects of the study throughout as well as the stakeholder engagement and bringing the evidence together.

Francesca Cornaglia (Co-I)

Cornaglia is a health economist who specialises in mental health aspects of health economics. She will bring health economic expertise to study and analyse economic aspects of admissions, as well as broader economic issues for families and society from our data.

In addition to the expertise of individuals, each investigator brings a team base expertise for reference and support at various points across all work packages, and our collaborators will bring key expertise and input (described in the next section).

16. Collaborators

The project benefits from a number of named collaborators:

Dr. Simon Kenny is National Clinical Director for Children and Young People at NHS England/Improvement, and Honorary Professor at Liverpool University.

Dr. Prathiba Chitabesan is Consultant Child and Adolescent Psychiatrist who is National Speciality Advisor and Co-chair of the Clinical Reference Group for the Children and Young People's Mental Health Team at NHS England and NHS Improvement).

Dr Terry Segal is a consultant paediatrician and Convenor of the RCPCH's Young People's Special Interest Group (YPHSIG).

Dr Jon Goldin is a child and adolescent psychiatrist who until recently has been Vice-Chair of the child and adolescent faculty of the RCPsych and has established formal support for the

study within the RCPsych. He is currently the RCPsych lead for parliamentary engagement in mental health.

Dr Karen Street is a consultant paediatrician and Mental Health Officer for the RCPCH and has established formal support for the study within the RCPCH.

Goldin, Street and Segal will support stakeholder membership, as well as provide access to clinical teams across England to support recruitment.

Kenny and Chitabesan will ensure this research is linked to and directly informs evolving work within the NHS England children's and mental health teams and will play important roles in our dissemination and impact strategy.

17. PPI Lead

Gabrielle Mathews will lead the PPI component of the study. She will play an important role in ensuring the research is co-designed with CYP and families. She is an award winning young people's representative, and has extensive experience of public and patient involvement in health research, service and policy development. She will bring access to an extensive network of other young people's forums e.g. Young Minds, the National Network of Hospital Youth Forums and NHS Youth Forums for the stakeholder group and in general development and management of the project. Her experience of participatory methods will be utilised in working with the stakeholder group and linking in VCSE organisations. Faith Gibson is also very experienced in PPI involvement in research and will support Gabrielle Mathews in her role. We will ensure that there are appropriate safeguards and sensitivity around involvement for patients and parents with experience of mental health problems (We will have a specific policy on this for the study). Matthews and Gibson are very experienced in this area, and our research team includes Nicholls who is a clinical academic psychiatrist.

We have costed to pay for the time of PPI representatives in the grant, and Gabrielle Mathews will be employed by UCL from the grant in her role as PPI lead for the whole of the study. Gabrielle Mathews will have support from Faith Gibson, the research leadership (Hudson and Viner) and the broader research team, plus access to a range of additional training and pastoral support through UCL as needed.

17.1. Stakeholder and advisory group meetings

Meetings of both the stakeholder and advisory group (see detailed research plan) will be a hybrid mixture of virtual and in person to suit availability – in particular the first and last meetings. Funding is therefore needed to support travel, venue and refreshment costs. Funds are needed to reimburse for PPI time.

Appendix One: A Proposed format and content for stakeholder meetings to formulate the ToC (using steps in Figure 2).

- 1st workshop (Month 1-4), possible plan for the workshop

Activities	Plan	People
Using these 6 exercises we will develop an initial theory of change	In broad terms this is what the exercises will do	This will involve our stakeholder group, this will be their 1st meeting
Exercise 1: Elevator pitch (5 minutes)	Turn to your neighbour and take one minute each to describe who you are and what you Report back to the group. Scribe in one colour for inputs/activities/outputs and another for outcomes.	Patient and public members
Exercise 2: Situation analysis (20 minutes)	In groups of 3-4 work through the following questions; 1. The main problem our project addresses 2. Causes and characteristics and needs of service users 3. Contributing factors/barriers to progress 4. Opportunities Report back to group: Scribe and group together. 5. Looking at the things we have listed in 2-4, which are “in scope” for our project and which are not. I.e. what can we do something about?	Professionals from a range of relevant occupations Representatives from key professional groups
Exercise 3: Developing a theory of change (1 hour)	Facilitated in groups of 3-4 using post-it notes. 1) Pose 3 key questions in sequence. - What long-term outcomes are you aiming for (ultimate goal)? - What are the intermediate outcomes? -What are the early outcomes? - What needs to happen to achieve these outcomes? 2) Cluster outcomes – summarise themes on post-its 3) Organise in a chain of “if-then” statements (if you can) 4) Present to other groups (if applicable) 4) Critical review: Is every link properly explained? Does it seem plausible/logical that one link will lead to the next. If not, what else needs to be included? 7) What evidence is there that each element leads to the next (if there is no evidence then the link is an ‘assumption’)	
Exercise 4: What does our project do to activate the	Consider the following questions in sequence. Depending on how many people are involved get people to shout out answers or break them up into groups and	

theory of change? (30 minutes)	ask them to write ideas down on post-it notes. 1) Look at the sequence of intermediate outcomes in the draft theory of change. What activities or processes do we need to make these outcomes happen? 2) How do you want service users to engage with these activities and processes – what does good look like ‘on the day’? 3) What elements of good practice and principles do we need to apply to make sure this happens? 4) In a few words how would you describe the key features of what makes your programme work, what are the critical factors, active ingredients, what makes it special/distinctive?	
Exercise 5: Enabling factors (10 minutes)	Consider factors outside your control that might influence the theory of change. It may be useful to think in terms of; a) structural factors; b) institutions and; c) other circumstances. In particular, what other stakeholders or partners are important to our success?	
Exercise 6: Evidence (10 minutes)	What evidence are we aware of, any evidence that supports the ideas in the theory of change? (Any element not supported by evidence is referred to as an ‘assumption’)	
Conclusion (5 minutes)	Outline next steps: Explain that you will write up the notes and invite further comments from everyone at that stage. Get feedback on the session: Ask, “what went well? and “even better if?”	

- Diagram and narrative of our theory of change will be developed (Months 5-6). The checklist below will be used after the 1st workshop with the core research team, then with our stakeholder group via email, once complete, map our theory of change to a logframe, to express
 - Activities
 - Outputs
 - Outcomes
 - Impact

<input type="checkbox"/>	Does your Theory of Change have a title which includes the name of the project?
<input type="checkbox"/>	Does your Theory of Change include activities, outcomes, causal links, assumptions and one or more aims?
<input type="checkbox"/>	Are each of those elements colour-coded and labelled?
<input type="checkbox"/>	Does your Theory of Change make it clear who the target population is?
<input type="checkbox"/>	Does your Theory of Change avoid referring to the scale of your programme?
<input type="checkbox"/>	Does your Theory of Change describe the 'dosage' of the activities i.e. how much of the activities each beneficiary receives?
<input type="checkbox"/>	Does your Theory of Change avoid referring to training, referral routes, marketing, programme setup or any other operational activities?

<input type="checkbox"/>	Are all of your outcomes and aims measureable?
<input type="checkbox"/>	Are some of your outcomes connected to each other by causal links? (i.e. all of the outcomes don't lead directly to the aim)
<input type="checkbox"/>	Are all of your causal links visually clear and easy to follow on the page? (top tip – square arrows are much easier to follow!)
<input type="checkbox"/>	Is every item connected to at least one of your aims?
<input type="checkbox"/>	Do all of the causal pathways make sense?
<input type="checkbox"/>	Are all of your assumptions sitting on specific causal links? Each assumption should relate to a specific causal pathway: there should not be general project assumptions floating around.

- 2nd workshop (Month 24-25)

This would include using a range of participatory and consensus methods with our stakeholder group to:

1. Revisit our theory of change, populate with new evidence.
2. Detail outputs and impacts.
3. Describe alternate models of service provision, through recommendations and transformation plans.
4. Finalise our theory of change, detail approaches to inform evaluation.