Protocol for project: What CAMHS interventions predict positive outcomes for which young people with a social worker: A mixed-methods study of clinical support and cost-effectiveness utilising linked operational data

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Sponsor: Cambridgeshire & Peterborough ICB

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1.Aims/ Objectives

Many children and young people with social work involvement (CYPwSW) experience mental health difficulties. Yet we know too little about the mental health care they receive from Child and Adolescent Mental Health Services (CAMHS). We do not know which young

people get accepted or rejected for treatment. We do not know what treatments lead to positive change for these young people. We also do not know how much these treatments cost.

To address these knowledge gaps we will combine quantitative analysis of linked administrative health and education records, and co-produced qualitative analysis of case notes and semi-structured interviews.

The research questions for our quantitative studies are:

1. What are the socioeconomic and demographic factors, clinical needs, and long-term outcomes of CYPwSW whose referral is accepted or rejected by CAMHS?
2. What CAMHS interventions predict better outcomes for which CYP?
3. What demographic factors and service factors at intake predict better outcomes for which CYP?
4. What are the cost effectiveness and cost consequences of these forms of intervention?

The objectives for our quantitative studies are to:

1. Characterise the socioeconomic and demographic factors, clinical needs, and educational outcomes and use of emergency care services for
    1. CYPwSW referred to CAMHS and accepted
    2. CYPwSW accepted on re-referral after 6 months
    3. CYPwSW referred but never accepted by CAMHS
2. Develop a taxonomy of forms of CAMHS interventions
3. Identify which forms of CAMHS intervention predict positive outcomes for CYPwSW
4. Investigate covariates and moderators of treatment effectiveness
5. Analyse the cost-effectiveness and cost-consequences of different forms of intervention

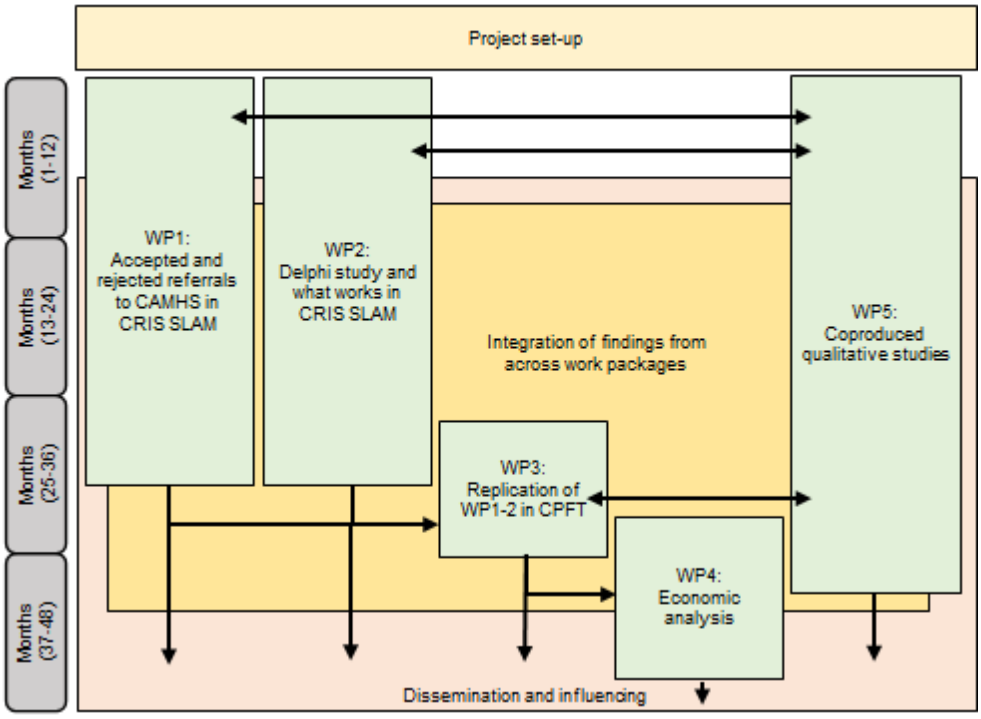
Our co-produced qualitative studies have two exploratory research questions:

1. How are CYPwSW and their social care needs characterised in CAMHS case notes?
2. What is the experience of CAMHS among CYPwSW?

This exploratory work will:

1. Examine the characterisation of CYPwSW and their care needs in CAMHS case notes
2. Interview CYPwSW to understand their experiences of CAMHS

Timeline of the project



2. Background and Rationale

There are three main statutory categories of children and young people (CYP) who have social work involvement (CYPwSW): children in need (CIN); those on a child protection plan (CP); and those looked after by local authorities (CLA). According to DfE data[1] in England in March 2020 there were:

- 389,260 CIN, with approximately 19% identified by social care as having mental health needs.
- 51,510 CP. We know of no domestic population level reports on their mental health.
- 80,080 CLA, with 38% having Strengths and Difficulties Questionnaire (SDQ) scores at clinically relevant levels.[2] Several studies, including our own, have reported highly elevated rates of mental-ill health in CLA, including higher rates of suicide and suicidal thoughts.[3] When asked in open-ended interviews, "mental health difficulties were reported for practically all CLA".[4]

The cost of mental health services for CYPwSW is unknown, and we know of no direct health economic evaluation.

Our study will add knowledge relevant to improving health and social care policy and practice by producing rigorous and relevant evidence about what CAMHS interventions predict positive outcomes for CYPwSW; and the health economic implications of these interventions. We will also provide evidence of the differential socioeconomic and demographic context, clinical needs, and long-term educational and health outcomes for CYPwSW referred to CAMHS and accepted; those accepted on re-referral after 6 months; and those whose referral was rejected by CAMHS.

Decades of research have pursued the question of what interventions predict positive outcomes (e.g. improvement in psychological health, educational attainment) for different CYP experiencing mental health needs.[5] Research has identified various evidence gaps and three continue to loom large:

1. Whereas there is evidence of differences in educational attainment of CIN and CLA[4, 6] we know little about mental health provision for CYPwSW, and especially CIN and CP. One of the few studies was conducted by the Croydon Safeguarding Children's Board, and so has particular relevance to the CRIS SLaM sample.[7] In their small sample, they found that CYPwSW often had a distinctive combination of mental health needs but no clear diagnosis. They also reported that CAMHS treatments were not generally well adapted to this population, and appeared comparatively less effective in reducing symptoms for CYPwSW.
2. It is currently unclear what routine CAMHS practice looks like for CYPwSW, its strengths and weaknesses, its similarities or differences with provision for peers. Lack of knowledge of routine practice with CYPwSW is a critical obstacle to the use of trials methodology to improve interventions: with treatment-as-usual not well understood, this undermines efforts to isolate causality and interpret trial findings. We also do not know how poverty, ethnicity, gender, physical disability and other personal and contextual factors for CYPwSW may be linked to acceptance or rejection of referrals to CAMHS in the first place. US studies have documented ethnicity as a potent predictor of barriers to mental health treatment for CYPwSW[8] but we know of no UK study. The interim report of the Independent Review of Children's Social Care has called for further research, highlighting that "we heard from many parents and carers at our engagement workshops that access to CAMHS support was a serious issue for children in their care".[9]
3. We know little about how poverty, ethnicity, physical disability and other personal and contextual factors alter CAMHS intervention effectiveness, especially for CYPwSW who more frequently face multiple socioeconomic and demographic adversities than other CAMHS attendees. An obstacle has been statistical power: 506 participants are needed (80% power) to detect a main effect of d=0.25 and examination of interaction effects requires at least four times that.

Linked administrative datasets are a major development for addressing these limitations. Clinical Record Interactive Search (CRIS) was commissioned by the NIHR to permit research on anonymised CAMHS records from the South London & Maudsley Foundation Trust (SLaM) (2007-present)[10] and Cambridge and Peterborough Foundation Trust (CPFT) (2012-present).[11] Data linkage is available for SLaM and CPFT with Hospital Episode Statistics, the Office for National Statistics, and the National Pupil Database.

A unique feature of CRIS SLaM is the availability of unstructured fields, including referral documents, assessments, correspondence, and progress notes. Though redacted for potentially identifying details, this unstructured data can be studied both qualitatively and quantitatively. CRIS offers opportunities for characterising and understanding inequalities in access and what works for CYPwSW within CAMHS. Findings from service-level data from two Trusts permits replication. This knowledge will have direct implications for the organisation and delivery of health and social care services.

3.Why our research is needed now

The number of CYPwSW has been rapidly increasing.[12] Mental health is implicated here: for instance the proportion of children where serious mental health difficulties was identified

as the primary reason for 'in need' status increased by 36% between 2018/2019 and 2019/2020.[1] This trend may have been exacerbated by Covid. We need to understand what mental health provision helps this population, as well as the role of personal and contextual factors and inequalities in shaping access to provision and the effectiveness of provision.

1. Clinicians, policy-makers and experts by experience (EbyE) have placed the question of what works for CYP as a top priority mental health research goal.[13, 14] The Child Safeguarding Practice Review Panel and the Care Leavers Association have urged the need for studies on how to improve services for CYPwSW specifically. CYPwSW may have distinct mental health needs. They may receive distinct potential benefits from CAMHS. They may also have particular worries about mental health services.[15, 16, 17]. Understanding what interventions work and for which CYP is an imperative for ensuring a safe, effective and equitable service.

2. We have documented dramatic increases in rates of long-standing mental illness among CYP in the UK.[18] The Children's Commissioner reports a 35% increase in referrals last year, but only a 4% increase in the number of CYP seen by CAMHS.[19] Little is known about the socioeconomic and demographic profile and longer term outcomes for CYP who are referred to CAMHS but do not get seen, or who are accepted only after re-referral.

3. 12.9 times more was spent on adult mental health than CYP in England in 2019/20, despite 59% of adult mental health conditions commencing by adolescence.[19] In order to best meet population and individual need, evidence of what works for CYPwSW and its cost effectiveness will be exceptionally important for justifying resources to policy-makers and commissioners.

4.Methods

4.1 Setting

South London & Maudsley NHS Foundation Trust (SLaM) provides services to a catchment area of approximately 1.2 million people, making it one of the largest mental health services in Europe. Patients are typically resident in Croydon, Lambeth, Lewisham and Southwark. In 2007, funding from the NIHR supported anonymisation of CAMHS electronic healthcare records and their availability in the CRIS dataset for use by authorised researchers. Recent estimates suggest that over 300,000 CAMHS patient records are accessible using CRIS, with approximately 20,000 new records added each year.[10] CRIS SLaM includes 46,973 CYP with at least one risk assessment conducted by CAMHS. Of these, over 10,000 have a parent with a mental health difficulty, nearly 5,500 have experienced some form of domestic or family violence, and there are safeguarding concerns in over 10,000 cases. For instance, around 7,000 of the sample have ever been on a child protection plan.

However limitations and idiosyncrasies of findings can arise from analysis of administrative data from only one site, driving the need for replication. Cambridgeshire & Peterborough NHS Foundation Trust (CPFT) provides services to a catchment area of approximately 860,000. CRIS CPFT was developed in 2012 following the example of SLaM, again with NIHR funding. At present, there are about 215,000 CAMHS records in the CRIS CPFT. In contrast to SLaM, CPFT provides services to both an urban and rural population, thus facilitating comparisons on the impact of rural and urban living. This means that not only will CRIS CPFT offer important opportunities for validation through replication, but also permit further scrutiny of factors that may influence service provision or effectiveness.

4.3 Design

Data Collection

Data will be analysed from two large administrative datasets: Clinical Record Interactive Search (CRIS) at South London and Maudsley NHS Foundation Trust (SLaM) and Cambridgeshire and Peterborough NHS Foundation Trust (CPFT). We will utilise existing data linkages between each of these datasets and data held by the Office for National Statistics (ONS), Hospital Episode Statistics (HES) and the National Pupil Database (NPD). Participants for the Delphi study will be recruited using professional networks in the UK.

Research Participants

WP1-WP4 and the case notes study in WP5 pursue secondary analysis of administrative data, routinely collected by services, and anonymised for use by authorised researchers. We will use social care involvement/status (CIN, CPP, CLA, no social care involvement) as the defining factor for groups. Not all CYPwSW who are experiencing mental ill-health will have access to CAMHS support. However, the focus of this project is to understand the provision of CAMHS services to CYPwSW, rather than to understand mental ill-health in general.

Preliminary to WP2, we will conduct an online Delphi survey to develop a typology of CAMHS interventions. Participants to the survey will be: CAMHS clinicians (n=20), social workers whose practice entails close links with CAMHS (n=20), academics (n=20), and EbyE (n=20) recruited through purposive sampling, and with equality, diversity and inclusion a central concern. The Association of Child and Adolescent Mental Health (ACAMH), the British Association of Social Workers (BASW) and our practitioner advisory group will support recruitment of professionals; our academic advisory group will support recruitment of academics; and the Care Leavers Association and NCB will support recruitment of EbyE.

For the case notes analysis in WP5 participants will be children and young people aged 12-18 who are involved in the CAMHS service. The case notes analysis (n=80 cases) will compare children and young people with a social worker to those in the CAMHS service who have high safeguarding concerns but no social work involvement. Participants for the qualitative interviews (n=60) will all have social work involvement; around a quarter of participants will have had their referral to CAMHS rejected, whilst the other participants will have had their referral to CAMHS accepted immediately or on re-referral. The inclusion and exclusion criteria are as follows:

Inclusion Criteria

For WP1-4

- Children and young people referred to SLaM CAMHS since 2007 who have social work involvement and a matched sample of CYP without social care involvement recorded in their records
- All CYP must be aged 17 years or younger at time of referral

For WP5 (qualitative interview study):

- Been referred to SLaM CAMHS
- Experienced involvement with children's social care
- Between the ages of 12-18 at the time of recruitment

Exclusion Criteria
For WP1-4

- Missing data for truncated date of birth
- Over 18 at time of referral

For WP5 (qualitative interview study):

- Any person under 12 and over 18 years old.
- Any person 12-15 years old who has been identified by a parent/ guardian as unable to take part.
- Anyone 16-18 who cannot consent - which may be due to aspects of their mental health condition, or disruptive side-effects of their medication.
- Any case where there are doubts that the legal guardian lacks capacity to give consent for the participation of the child.
- Anyone who is currently hospitalised.
- Though English language is not a requirement as we have provision for translators, exclusion may occur where we are not able to find an appropriate translator.

Proposed sample size

Quantitative research
CRIS-SLAM and CRIS-CPFT contain records for all children and young people referred to and attending CAMHS in their respective catchment areas. Previous work with CRIS-SLaM indicates that there are over 10,000 in the dataset with safeguarding needs. The final sample size for this study will be determined during extraction and matching with NPD and HES.

Regarding work package 1, there is accumulating evidence to suggest that there are inequalities in CAMHS referral pathways.[15] However, to our knowledge no previous work in the UK has explored the association between sociodemographic and referral characteristics and acceptance to CAMHS. Nevertheless we anticipate this study will be adequately powered to detect a significant association even in the context of a relatively weak effect. For instance, a sample of N=1340 would provide 80% power at a 5% significance level to identify an effect of r=0.10 between ethnicity and referral acceptance.

Regarding work packages 2-3, one of the main outcomes for work packages 2-3 is scores on mental health measures such as the SDQ. Again, the exact sample size for this study will be determined during extraction and matching with NPD and HES. Assuming a relatively weak effect size (r=0.10), a sample of N=1629 would provide 80% power at a 5% significance level to detect an effect between social care status (i.e. CIN,. CPP, CLA) and mental health outcomes controlling for form of intervention.

Qualitative research

Due to the broad aims of our study, and the high diversity we anticipate in our sample, a medium-to-large sample size may be needed for obtaining adequate *information power*.[20] This informs our sample size in both our case notes and qualitative interviews.

Case notes
Our analysis will draw on a selection of: i) 40 case notes of young people with both children's social care and CAMHS involvement; ii) 40 case notes of young people for whom CAMHS have a high level of safeguarding concern identified in their first risk assessment but without involvement of children's social care. These groups will be distinguished based on

responses to social work involvement in the referral information, CAMHS risk assessments, and CAMHS information.

The study will use a conditional random sampling plan, i.e. subject to constraints to ensure minimum proportions of diversity characteristics in the sample, each set of 40 case notes will be selected at random. These constraints will be to ensure sufficient diversity of: child age; gender; socioeconomic status; ethnicity. or young people with social care involvement, we will aim to include diversity of extent of social care escalation (i.e. child in need; child protection; looked after child).

Qualitative interviews
have planned to interview 60 children and young people who have experienced i) social work involvement and who have been referred for mental health provision at CAMHS. During the research process, we will review this particular sample size through appraising information power continuously, as well as critically ascertaining whether the sample size is adequate for analysis and final publication at the end.

5.Plan of Investigation and Analysis
Work Package 1: Examining accepted and rejected referrals - CRIS SLaM (Months 1-30).

Addressing research question 1, in WP1 we will establish which factors distinguish CYPwSW whose referral to CAMHS is accepted or rejected, or who are accepted only on re-referral. We will also explore long-term outcomes of these groups.

Some CYPwSW who experience mental-ill health will be referred to CAMHS, but will have their referral rejected. Other young people had their initial referral rejected, only to be accepted at a later date. Other young people will be referred to CAMHS but have their referral rejected. Exploring differences between these groups is important on several grounds: understanding access to CAMHS for CYPwSW; discerning inequalities in service provision; and identifying limits on the generalisability of findings from subsequent work packages which focus on the sample who received treatment.

For CYPwSW accepted for treatment by CAMHS, CRIS contains information on their mental health, including the SDQ and standardised and bespoke measures of suicidal ideation at various timepoints including exit. For all three groups we have access to relevant fields such as referral source, perceived urgency by the referer, perceived urgency of referral by CAMHS, as well as rich information on personal and contextual factors including socioeconomic status, ethnicity, gender, physical disability, and whether the young person has dependent children. Despite considerable information within CRIS about CYPwSW with rejected referrals, it does not contain their long-term mental health outcomes. Based on consultation with EbyE, we have therefore selected education and emergency health service use as long-term outcomes for comparing the trajectories of CYPwSW with accepted and rejected referrals. For this, we will use linked data from the National Pupil Database and Hospital Episode Statistics, and look at young people's education (e.g. Key Stage results; school attendance; fixed-term exclusion) and use of emergency healthcare (e.g. A&E visits due to self-harm).

Using regression modelling, we will examine factors that distinguish these groups at initial referral. We will scrutinise re-referrals, looking to understand predictors of mental health

needs escalation among CYPwSW, and what forms of escalation lead to CAMHS acceptance. We will also examine differences in education outcomes and use of emergency care services of the three groups. We will compare CYPwSW accepted within 6 months to those accepted only on re-referral on the SDQ and suicidal ideation using CAMHS data.

Work Package 2: Assessing interventions - CRIS SLaM (Months 1-30).

In WP2 a Delphi consensus study will be used to generate a typology of forms of intervention within CAMHS. Addressing research questions 2 and 3, we will then use data from CRIS to examine the contribution of these forms of intervention to 4 outcomes for CYPwSW and peers.

Typology development: With such a variety of forms of CAMHS intervention, a preliminary step will be to develop categories that are amenable to analysis. An online Delphi study will be conducted to develop a typology of CAMHS interventions. We anticipate that three phases of data collection will be necessary to reach consensus on this typology.

In Phase I, we will ask experts to agree on a narrow set of criteria or dimensions that they think are needed for distinguishing mental health interventions in CAMHS. In Phase II, we will ask experts to rate a list of interventions administered in CAMHS with the criteria identified in Phase I. The responses of experts will be analysed with Latent Profile Analysis in order to obtain data-driven categories from experts' responses. In Phase III, experts will be surveyed about the typology thus obtained. The Delphi process will be administered online.

Approval of for the Delphi study was granted by the University of Cambridge Department of Psychology Ethics Committee on the 6th February 2023, Ref: PRE.2022.085. HRA advised that approval was not required.

Descriptive statistics: Data from CRIS will be used to provide a descriptive account of socioeconomic and demographic factors, service activity (e.g. onward referrals, attendance, nature of the appointment), and interventions for all CYP (e.g. medication, CBT) in SLaM. We will examine correlates of CIN, CP and CLA status, and of social care escalation and deescalation.

Information regarding social care involvement will be drawn from CAMHS patient information, CAMHS risk assessments and National Pupil Database linkage. This will be used to create a data frame of CYPwSW. We will conduct subgroup analyses for:

- CIN, CP and CLA
- Prior and concluded social work involvement compared to involvement at the time of admission to CAMHS
- Children of pre-primary school age, primary school age, and secondary school age.

Development of quasi-control group: Propensity score matching will be used to create a quasi-control group of CYP without social work involvement. A list of potential i) covariates and ii) moderators will be co-developed with EbyE. For instance, these might include both socioeconomic and demographic factors and service activity (e.g. referral reason, time on the waiting list, attendance, and adherence). Regression analysis will be conducted to explore the extent to which covariates predict subgroup status. This will be used to calculate a propensity score. We will then use matching procedures to define groups.

Analysis of outcomes: Then we will explore how different types of intervention predict 4 outcome indices. The selection of these outcomes stems from EbyE input:
1) Data from SDQ assessments in CAMHS will be used to estimate a general psychopathology factor.
2) Educational outcomes (e.g. Key Stage 3-4; school attendance; exclusion) using data from the National Pupil Database.
3) Self-harm, suicidal ideation and suicide - using both standardised and bespoke measures and at various timepoints including exit from CAMHS.
4) An index of wellbeing codesigned with EbyE, including physical (e.g. A&E visits) and mental and social outcomes (e.g. Mood & Feelings Questionnaire).

Work Package 3: Replication of WP1 and WP2 - CRIS CPFT (Months 26-36).

Addressing research questions 1-3, in WP3 we will pursue a replication of WP1 and WP2 using data from Cambridgeshire & Peterborough NHS Trust (CPFT).

One of the potential challenges associated with conducting research using administrative dataset is transferability, given the risk that some findings may be attributable to some local coding practice or service configuration and are not applicable to other contexts. Here we address this threat through replication of WP1 and WP2 in CPFT, supporting confidence in the conclusions, recommendations and uptake from our work. Use of CPFT data also allows assessment of whether rural or urban residence impacts findings from WP1 and WP2.

Work Package 4: Economic analysis (Months 34-44).

Addressing research question 4, in WP4 we will evaluate the economic impact of interventions found to be effective in terms of one or more of the four outcomes in WP2-3, including both the costs of the interventions themselves, their impact on downstream public costs. We will also evaluate their incremental cost-effectiveness.

An economic analysis is warranted given that interventions will likely have impacts on outcomes and public sector costs. Our analysis will conform to accepted NICE economic evaluation methods, focusing on the reference case for 'Interventions funded by the public sector with health and non-health outcomes'.[21] A cost-utility analysis is not possible given the lack of preference-based health-related quality of life data suitable for measuring quality-adjusted life years (QALYs). We will undertake cost-effectiveness analyses and cost-consequences analyses of the interventions comparing costs and outcomes associated with each intervention among intervention recipients with a matched group of participants who had similar characteristics but who received other interventions within CAMHS. Given the nature of the available cost data we will take a public sector perspective on costs, and outcomes will include health and non-health effects from the main analysis in WP2-3: general psychopathology based on the SDQ; educational outcomes; self-harm, suicidal ideation and suicide; and wellbeing.

The time horizon will be a minimum of one year for each intervention, to be determined by the length of follow-up after intervention start in the CRIS datasets. Assuming a one-year time horizon discounting will be unnecessary, but with a longer time horizon costs and effects will be discounted at the recommended rate of 3.5% (with other rates explored in sensitivity analysis).

Measuring costs: We will undertake detailed micro-costing analyses of all interventions found to be effective in one of more of our outcome measures in WP2-3. To do this we will:
1) Delineate the treatment pathways for each intervention over a one-year period from initiation of the intervention. Woolgar and Humphrey will coordinate their clinical colleagues from intervention providers at SLAM and CPFT respectively to help with this, including identifying differences between the two providers where appropriate.
2) Using data from CRIS and with input from intervention providers at SLAM and CPFT we will plot the movement of intervention recipients through each of the pathways, focusing in particular on the number and type of service contacts.
3) We will identify the unit costs associated with the main cost components of the identified pathways for each intervention. These will be obtained from the finance departments at SLAM and CPFT, as well as published and other routinely available sources
4) We will calculate the costs associated with each intervention, by applying the unit costs associated with each item in the pathway from stage 3 to the numbers of service users incurring that cost based on the data at stage 2.

We will also account for the impact of the interventions on downstream costs. We will create a dataset of resource use associated with CAMHS, other NHS and social services, taking service use data from the CRIS datasets, which includes a rich range of contacts with services, including: hospital services (e.g., A&E contacts, outpatient attendances, day cases, inpatient stays); community services (e.g., contacts with the Community Mental Health Team); primary care contacts (e.g., contacts with the GP, practice nurse, pharmacist, and dentist); public sector residential stays; justice system contacts (e.g., contacts with the police, young offenders institution, prison); and, education system contacts. The resource use data will be multiplied by local (SLAM, CPFT) and national published unit costs for each type of contact.[22] We will itemise costs separately for each sector (NHS, social services, justice system, education). We will then investigate how the different types of intervention for CYPwSW predict these costs using similar econometric methods to those described in WP2-3 above, using regression methods suitable for analysing cost data (e.g. generalised linear models with log link and gamma family).[23]

These two cost analyses will allow us to calculate the net costs of each intervention, accounting for the intervention costs and impact on downstream costs to public sector services.

Analysis: We will undertake cost-effectiveness analyses and cost-consequences analyses of each intervention. Cost-effectiveness will be calculated as the mean cost difference per CYPwSW with the intervention compared with other interventions within CAMHS divided by the mean difference in outcomes (as described) to give the incremental cost-effectiveness ratio (ICER). We will subject the results to extensive deterministic (one-, two- and multi-way) and probabilistic sensitivity analysis (PSA); for the latter, assigning distributions to unit costs, probabilities, outcomes and resource use measures to calculate confidence intervals around the ICERs.[24] The simulations in the PSA will also be used to construct cost-effectiveness acceptability curves, which will show the probability that each strategy is cost-effective for different values of the public sector's willingness to pay for an additional unit of outcome. We judge these analyses will be valuable given the lack of a formal cost-effectiveness threshold for each of the outcome measures used. We will also undertake cost-consequences analyses, drawing up balance sheets of the incremental costs and benefits of each intervention.

We will conduct analyses separately for SLAM and CPFT patients. We will also undertake subgroup analyses to evaluate the cost and cost-effectiveness of the interventions for the same subgroups identified in WP2 (CIN, CP and CLA; those with concluded social work involvement compared to involvement at the time of admission to CAMHS; by school age). We will combine data on incremental public sector costs with epidemiological data on projected numbers of CYPwSW intervention users and undertake a budget impact analysis to evaluate what the total cost impact of rolling out each intervention would be nationally were it to be scaled up. We will also use the probabilistic sensitivity analyses combined with the epidemiological information on projected numbers to undertake a value of information analysis to evaluate the potential economic value of future research on each intervention.[25]

Work Package 5: Co-produced qualitative studies (Months 1-40).

In WP5 we will work with EbyE to design and conduct analysis of case notes and undertake interviews, with the goal of deepening our understanding of how CYPwSW are depicted within CAMHS and their experiences of the service.

Informed by available best practice,[26] and based on our experience of co-produced research, Crozier-Roche, Smith and Drayak will receive support and training in relevant research methods to take a leading role in study design, data collection, analysis, and dissemination. Though running concurrently, the scope and priorities of WP5 will be shaped by emergent findings from WP1-3.

Case notes are available for the whole sample of consenting participants in CRIS SLaM, including referral documents, assessments, correspondence and progress notes. This will include correspondence with social workers or social care teams, as well as any referrals made from or to social services.

Participants for interviews will be purposively recruited using the CRIS SLaM 'consent for contact' for further research register. Interviews will be co-delivered by an EbyE and a researcher. Interview participants will include those whose referral to CAMHS was rejected, facilitating dialogue with WP1. Participants will be offered the personal choice of virtual or in-person interviews.

It is anticipated that WP5 will address topics including: the characterisation of CYPwSW and their social care needs and provision in CAMHS case notes; the perceived contribution of social work involvement to mental health or illness among patients and in CAMHS case notes; and the extent to which CAMHS interventions received resembled those characterised in the typology from WP2.

Findings across the work packages will be placed in dialogue using the Moran-Ellis 'following a thread' method for data integration and juxtaposition.[28] For instance, findings from our qualitative research may identify threads that prompt *post hoc* analyses of data from our quantitative studies, and vice versa.

Additional analyses funded by the NIHR's mental health research initiative

We will also examine: how do homelessness/insecure housing and or family debt shape clinical provision for young people in contact with mental health services?

Using data from CRIS SLaM, we will first conduct descriptive analysis to learn more about these young people. We will compare these young people to i) the general CAMHS cohort; ii) young people in the lowest socioeconomic quintile for neighbourhood deprivation. This will help articulate where and how these young people's situations and needs differ or are the same. Our descriptive analysis will consider the following factors - all at intake:

1. Source of initial referral
2. Demographic differences (age, sex, ethnicity);
3. Self-reported mental health (strengths and difficulties questionnaire);
4. Parent-reported mental health (strengths and difficulties questionnaire);
5. Clinician-reported child general functioning (Children's Global Assessment Scale);
6. CAMHS risk assessment;
7. Social care involvement, and extent;

We will then conduct inferential statistics to examine whether homelessness/insecure housing and acute family debt make a contribution to key aspects of care, over and above socioeconomic status and other demographic differences. Predictors will be added sequentially in random intercept models. The aspects of care we will examine will be:

1. Number of face-to-face appointments
2. Number of risk assessments
3. Non-attendance at clinical sessions
4. Final diagnosis;
5. Psychosocial treatments provided by CAMHS

6. Study Management

COACHES will be managed by a core research team who will meet regularly to monitor, collect and analyse data (depending on the stage of the research project). There will be three main management committees:

Project Board
The project board is composed of representation from each of the collaborating organisations on the study, and is chaired by Duschinsky. The project board will meet every 6 months.

Steering Committee (SC)
The Steering Committee is chaired by Rachel Hiller, with Dougal Hargreaves as deputy chair. The steering group will meet at least yearly, and oversee study activities, as well as report to the funders if there are problems with the study.

Data Monitoring and Ethics Committee (DMEC)
The DMEC is chaired by Nick Midgley, with Doug Simkiss and Melissa Nolas also on the committee. All three are independent from the current research project. The purpose of this group is to ensure safeguard procedures are in place and to handle ethical issues as they arise on the project. They are also in place to support the research team, including to ensure that they are supported when collecting and analysing this sensitive research material. This group will meet every 6 months. It may meet more frequently during periods of data collection and analysis.

7. User Advisory Group

This research has been and will continue to be deeply informed by experts by experience through every stage of the work package. David Graham, CEO of the Care Leavers Association, is costed for 12%FTE to facilitate EbyE involvement, drawing on his previous experience of supporting EbyE involvement in research. The present application was co-designed with Crozier-Roche, Smith and Drayak; Graham and the PIs will support their ongoing leadership role within the project, ensuring their expertise is felt throughout for the research and the research team.

We will also continue to have input from the three EbyE groups from Duschinsky and Hutchinson's Wellcome Collaborative Award on thresholds in children's social care (Living Assessments): care experienced adults; young people with Child in Need status; and parents who have experienced CP investigations. These groups are coordinated by the National Children's Bureau.

8. Ethical Arrangements

CRIS SLaM has been approved for secondary data analysis by the University of Oxford (Ref: 08/H0606/71+5). CRIS gleans anonymised data from electronic health records. To analyse anonymised CRIS data, authorised researchers submit a project proposal to the CRIS oversight committee at Kings College, London giving full details of their study. This project proposal is reviewed by a panel including researchers and EbyE. Searches are audited regularly and every 3-6 months researchers submit a report outlining their activities.
The research team will use a Virtual Private Network (VPN) to access and work with the data unless on site in SLaM. Following the CRIS security model, all data for WP1 and WP2 will be analysed and stored within the SLaM firewall. Within the firewall, data will be stored on a T:Drive for researchers authorised to use CRIS and all files will be password protected. In line with the CRIS security model, to avoid threats to patient anonymity, cell sizes of n=9 or fewer will not be presented. In line with current regulations, linked data will be accessed from a secure ONS research location. All members of the study team who are engaged in data analysis will attend ONS safe researcher training sessions prior to accessing linked data.

For the analysis of the case notes in CRIS SLaM in WP5, it is envisaged that any qualitative data will be stored in an encrypted file in a separate drive within the SLaM firewall. Unless there is good justification, to avoid proliferation the only researchers able to access these will be the EbyE co-Is, Graham, Duschinsky and the mixed methods research associate and students supervised by them. The CRIS oversight committee will review any direct quotations from the clinical notes before they are used in publications/presentations.

CRIS CPFT has been approved for secondary data analysis by NHS East of England Cambridge Central Research Committee (17/EE/0442). Authorised researchers submit an application for approval by an oversight committee. Like CRIS SLAM, data is required to stay within the CPFT firewall and linked data will be analysed at ONS research facility.

We received ethical approval from the University of Cambridge for the Delphi study in WP2.

Ethical and governance approvals for the interview component of WP5 has been obtained from: the NHS Health Research Authority; the SLaM Research and Development team; and the CRIS oversight committee. Recruitment of participants from the 'consent to contact' register will be undertaken by the project administrator and mixed methods research associate, with steps taken to minimise risks of participant deanonymisation (e.g. anonymisation of interview transcripts). HRA and Health and Care Research Wales (HCRW)

gave approval for the study on 27/7/23: IRAS project ID: 325983; Protocol number: researchregistry134922 ; REC reference: 23/WM/0107

Permission to participate in qualitative interviews

This study is also based on international ethical standards. The literature argues that minors have the right to be heard and to give their opinion, which should be taken into consideration progressively, according to their age, degree of maturity and discernment and have the capacity to make decisions about their ability to participate in research.[29] We acknowledge that different ethical standards relate to those aged 12-15 to those aged 16 and over. We have outlined these below.

Assent with children and young people 12-15 years old

Age appropriate information sheets have been developed with input from young people on the specific wording used in this form. As above - for participants who are aged under 16, parental or legal guardian consent will be obtained. The child will give their assent on a separate age appropriate Participant Information sheet and assent form. In the event of any conflict between the parent and child, the child will not enter the study.

Assent will also be monitored during the interview process in an ongoing fashion, in line with best practice.[30] The study will be explained to the participant before we begin the interview. Particular mention will be made of the risks and benefits of involvement. Alternatives to participants will be offered (including the option to just have a talk and not to have anything recorded). We will restate that participation in the study is voluntary and that they may stop the interview and/or withdraw from the study at any time. Participants will have the opportunity to remove their data at any point until we have deleted the coding list. Participants will be instructed to contact the interviewer either by the phone, email or post to do so. They do not need to provide a justification. This will be made clear to them when we go through the consent and/or assent process before the interview begins.

Consent with young people 16-18 years old

According to the HRA guidelines, a young person over 16 is presumed to be capable of giving consent on their own behalf to participate in research. We recognise however that a young person's right to give consent is dependent upon their capacity to understand the specific circumstances and details of the research being proposed, which in turn will relate to the complexity of the research itself. Detailed and age-appropriate information about what the study involves will be shared with prospective participants in written and verbal ways to ensure that they have enough information to consent to the study.

Even where participants have consented over phone we will make sure that everyone in the study provides written consent before any interview takes place. During this interview process, consent will be monitored in an "on-going" way to ensure capacity to consent.[31]This will include touching base with participants during the interview about their desire to participate (especially if it is clear they are growing bored or irritated etc). We will also offer breaks during the interview if this would help, including the option to conduct interviews over multiple sittings.

Assessment of harms and adverse effects

Safeguarding issues

This research may involve some risks for the children and young people (CYP) including important safeguarding issues. We know that interviews about mental health and social care needs and provision can sometimes lead CYP to recall potentially distressing experiences. However, we aim for the interviews to be a safe space for CYP to speak about their experiences of accessing mental health services. Time will be set aside at the start of each interview for questions and clarifications, and there will be a debriefing period at the end of the study where participants are provided a space to reflect on their interview off-tape.

Young people will be asked how they prefer the interview to take place in order to make them as comfortable as possible. For example, participants will be told they can bring a friend or family member with them to the interview if it would help make them feel more comfortable. For participants with disabilities, they are welcome to invite their carer to attend or we can provide a specialist support worker, to help facilitate their participation. Participants will be offered the option of being interviewed whilst going for a walk, or to use drawing materials (for example for mapping out a timeline) rather than solely offering verbal descriptions. They will be asked in advance whether they will be happy to take the interview in one long session, or if they prefer to break the interview into two shorter sessions.

We will put a number of steps in place to ensure that participants are sufficiently supported through the interview process. Before we begin the interview we will clarify which Local Authority that the child or young person is attached to, and if possible the name and contact details of their social worker so that we can contact them in the circumstances of disclosure of harm or a crime that their social worker is not already aware about. It will be made clear to the young person why we are asking about this.

If young people wish to discuss issues that have arisen from the interview we will direct them to discuss with their social worker or to contact their care coordinator or the team they are under in CAMHS in the first instance. If their problems are severe and acute (say in the context of immediate self-harm or suicide) we will direct participants to A&E. For participants 12-15 years old, their guardian will always be the first suggested point of contact.

If an interview reveals that a participant or another person is in significant danger or discloses a crime, the pair of interviewers will be obliged to take action in response to that disclosure. This will breach confidentiality. We propose that in instances where confidentiality must be broken, the pair of interviewers will first consult Robbie Duschinsky, the co-PI on the project. The purpose of this will be to ensure that where we do need to breach confidentiality of a participant, we are doing so in a way that minimizes disclosure. We will aim to contact a person who is best placed to take appropriate action. This will most likely be the guardian or a social worker but will depend on the context (living arrangement, family dynamics) and nature of the disclosure. Our procedures around the limits on confidentiality will be outlined in the participant information sheet, and will be discussed again before the start of the interview.

In each of the four boroughs from which the sample will be drawn there are different confidential, non-statutory services, and the interviewer will be aware of those locally

available services, and be able to speak to the young person about what is on offer in their borough, should they need further help.

An additional concern participants may have is that critical comments about services might impact their access to services in the future. We will clarify that participants in the study will be anonymous and will have no impact on their care.

Version control table

Version	Author	Date	Changes
0.1	Robbie Duschinsky	19/09/2022	First draft
0.2	Tessa Morgan	23/11/2022	Update to methodology of Delphi study and qualitative studies based on stakeholder discussions
1.0	Robbie Duschinsky	02/12/2022	Approved original protocol, with updated project number
1.1	Robbie Duschinsky	15/2/2023	Updated with Delphi ethics approval
1.2	Robbie Duschinsky	02/8/2023	Updated with ethics approval for interview study
1.3	Robbie Duschinsky	03/6/24	Updated with additional analyses funded by the NIHR's mental health research initiative

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Terms of Reference:

ACAMH = Child and Adolescent Mental Health
BASW = British Association of Social Workers
CYPwSW = Children and young people with social work involvement
CAMHS = Child and Adolescent Mental Health Services
CIN = Child in Need
CLA = Child looked after by local authorities
CP = Child with Child Protection plan
CPFT = Cambridge and Peterborough NHS Foundation Trust
CRIS = Clinical Record Interactive Search
EbyE = Experts by experience
HES = Hospital Episode Statistics
NIHR = National Institute for Health and Care Research
NPD = National Pupil Database
ONS = Office for National Statistics
SLaM = South London & Maudsley NHS Foundation Trust
SDQ = Strengths and Difficulties Questionnaire