FULL TITLE OF PROJECT

Investigating How Dedicated Youth Worker Services for Young People with Physical and/or Mental Health Conditions are Organised, Provided and Experienced

SHORT STUDY TITLE/ACRONYM

Health and Youth Work

PROTOCOL VERSION

4.0

PROTOCOL VERSION CONTROL

PROTOCOL VERSION	Date Issued	Details of Changes Made
1.0 (Original)	11-06-24	N/A
2.0	26-07-24	Information about participant vouchers added. NIHR disclaimer included.
3.0	10-02-25	Ethics exemption obtained for WP1. Aim to obtain HRA approval for WP2 by the end of March 2025
4.0	29-05-25	Short study title added. Research registration added. Sponsor reference number added. Date of HRA approval added. Changes made following HRA review: (1) Further detail added about how notes taken during interviews will be kept safe. (2) Further detail added about how information about any safeguarding issues will be passed on, how disclosure risk will be assessed and what steps will be taken if the risk is urgent. (3) Inclusion of an end of study definition

RESEARCH REFERENCE NUMBERS

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KEY STUDY CONTACTS

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END OF STUDY DATE: 31st March 2027. This is defined as the end of data collection.

CONTENTS

SCIENTIFIC SUMMARY

Background

Recent data suggests that around a quarter of young people (YP) aged 11–25 have a long-term physical or mental health condition (LTC) and that the number of YP with mental health problems has increased significantly. These YP experience poorer psycho-social and educational outcomes than their healthy peers and are at increased risk of engaging in risky behaviours. The years between 11 and 25 are recognised as a time of sub-optimal self-management, service disengagement and deteriorating health outcomes. However, health services struggle to provide the support that YP want and need at this stage of their lives. YP experience them as being overly clinical and non-holistic and do not feel involved in decision-making. Many healthcare professionals feel unprepared to support and communicate with YP. In response to this problem, youth workers (YW) have been introduced into healthcare and other settings to improve the support of YP with LTCs. However, there is a lack of robust evidence to support this introduction, and little is known about these targeted YW services. This study aims to fill this evidence gap and inform service commissioning, organisation and delivery.

Aims and objectives

The overall aim of the study is to explore how YW services for young people with LTCs between 11 and 25 years old in the UK are organised, provided and experienced to inform service commissioning and delivery.

1. To describe current youth work services for young people with LTCs in the UK.
    a) To generate a typology of different models of youth work services.
    b) To identify variation in organisation and delivery of youth work services.
    c) To develop a sampling frame for work package 2.
2. To investigate six contrasting case studies of youth work services to examine their organisation, delivery and integration:
    a) Explore young people, parents, youth workers and other service providers experiences of youth work services and their perceived influence on young people’s engagement and wellbeing.
    b) Identify facilitators/barriers to the organisation, provision and sustainability of youth work services and contextual factors influencing these.
    c) Investigate how youth work services are integrated with the multi-disciplinary team and wider service system.
3. To compare and contrast six case study services in relation to their acceptability, integration, sustainability and young people’s engagement and co-design a service development framework to guide the commissioning, organisation and provision of youth work services for young people with LTCs.

Methods

We will use a sequential exploratory mixed-methods design comprising two stages. (1) To meet aim one we will map current YW services in the UK that focus on YP with LTCs aged 11 to 25 years old provided by the NHS and other organisations using an online survey. (2) To meet aims two and three we will purposefully sample six contrasting YW services (case studies) from this service map. At each site we will conduct interviews with young people and parents who have used the service. We will also interview service providers, managers and commissioners in the local service system and observe a range of YW

activities. We will conduct a within-case analysis prior to a cross-case analysis to co-develop a service development framework to guide the commissioning, organisation and delivery of YW services.

Timelines for delivery
The project will last 30 months. In the first six months we will conduct the mapping survey. In months 7 to 26 we will carry out the case study stage. The final four months are dedicated to completing the analysis, dissemination and impact activities.

Anticipated impact and dissemination
New knowledge generated by this study will be used to co-develop an evidence-based service development framework. This aims to improve the commissioning and delivery of YW services to benefit YP health and wellbeing. Findings will be tailored for different audiences and disseminated to stakeholder groups in different ways to promote impact. Engagement of stakeholder groups has already commenced and will be intensified at study outset.

PLAIN ENGLISH SUMMARY

What is the problem?
About a quarter of young people now have a physical or mental health condition (LTC) (e.g. diabetes, depression). Young people who live with a LTC are more likely to have problems than their peers regarding their emotional well-being, their day to day living and how well they do at school. Becoming an adult can be difficult for these young people and they can find it difficult to take their treatments, work with health care professionals and attend appointments. This can negatively affect their health and wellbeing. Services struggle to provide the right support that young people need and want as they move into adulthood. Young people see them as overly clinical and don't feel involved in decision-making. Many health care professionals feel unprepared to support adolescents. In response to this problem, youth workers have been employed to work to support young people with LTCs. However, we don't know very much about their role or the best way of providing youth work services to improve the health of young people.

What will this study aim to do?
Overall, we want to find out what is the best way of providing youth work services to improve the health and wellbeing of young people with LTCs. To do this we want to know: (1) what types of youth work services are available in the United Kingdom; (2) what young people like and don't like about these services, what helps them and what they would prefer; (3) what parents and professionals think about youth work services; (4) how youth work services work with other services.

At the end of the study we will use the information we gather to develop guidance on the best way of providing youth work services. We hope that this will be used by the NHS and other organisations to design and provide youth work services for young people with LTCs.

How will we do this?
The study has two stages. In stage one we will carry out a survey to find out what types of youth work services there are for young people with LTCs in the UK. In stage two we will choose six youth work services from the survey to compare different ways of providing youth work. We will study these services in detail and talk to young people, parents, professionals and managers about their views on the services. We will also look at documents about services and observe youth work sessions. We will use

the findings from stage two to work with young people, parents, youth workers and other key people to develop guidance for services.

Benefits to young people

The study findings will help services develop and provide youth work services that improve young people's health, confidence, social relationships and resilience. This could support young people living with LTCs to have a better quality of life both now and in adulthood.

Patient and public involvement

We will work with 12 young advisors who have a LTC across both stages of the study to make sure this work is relevant, and matters, to young people. They will help us to develop the study materials, understand the best way to carry out the research, help us to understand the findings and co-develop the guidance for developing youth work services. Parents will also be involved in this.

Sharing our findings

We will work with our young advisors and project advisory group to create messages about our research to share through online and social media so that people hear about what we find.

BACKGROUND AND RATIONALE

Recent data suggest that 23% of 11–15-year-olds and 29-34% of 16-24 years olds have a long-term physical or mental health condition (LTC)[1]. The number of young people (YP) with mental health problems has increased significantly since 2017 to 20% of 8–16-year-olds, 23% of 17–19-year-olds and 22% of 20-25-year-olds in 2023[2]. Furthermore, there is evidence that the Covid-19 pandemic negatively impacted on YP mental health and substantially increased referrals to mental health services[3-7]. It is well established that YP with LTC experience poorer psycho-social and educational outcomes than their healthy peers and are at increased risk of engaging in risky behaviours[8-14]. Furthermore, mental health difficulties can persist into adulthood (three quarters of adult mental health problems emerge before the age of 18) and YP with physical LTCs will need to engage in life-long self-management[15].

The years between 11 and 25 mark a time when YP experience a range of significant emotional and social changes as they transition into adulthood[16,17]. Adolescence is a life stage when patterns of health behaviour are established that continue into adult life - it is therefore a key time to intervene to improve health, social and educational outcomes in adulthood. However, for YP with LTCs it is recognised as a time of sub-optimal self-management, service disengagement and deteriorating health outcomes[18-20].

Services struggle to provide the appropriate support YP want and require at this stage[21,22]. It has been recommended that services should be developmentally appropriate, holistic, YP-centred, coordinated, respectful and involve YP in decision-making[23-26]. Instead, services are experienced as having an overly clinical, non-holistic approach. YP feel uninvolved in decision-making and lack trust in healthcare professionals (HCPs), with poor communication leading to missed appointments and poorer clinical outcomes[27-29]. Many HCPs are inadequately prepared to support YP and find communicating with them challenging[27]. In response to this problem, youth workers (YW) have been introduced in increasing numbers into UK healthcare settings to support YP and HCPs in delivering developmentally appropriate care; help YP navigate a complex healthcare system; learn how to live with and self-manage their health condition; promote service engagement before and after their transfer to adult services; and work in partnership with HCPs[30.31].

The literature on YW services targeted at YP experiencing long-term health conditions (LTCs) is overwhelmingly comprised of service descriptions and evaluations[30]. A recent literature review and additional literature searching conducted in 2023 for the application has identified only three (qualitative) empirical studies relating to YW in health settings - none of these were conducted in the UK[30]. Hence what is known about UK services is derived from service descriptions. From this literature it appears that YW interventions with YP experiencing LTCs aim to promote their physical/emotional wellbeing and their personal/social development[32-40]. The YW approach is characterised as holistic, flexible and individualised; focussed on YP engagement and advocacy; and built on a trusting, non-hierarchical relationship[33-35, 39-40]. This relationship has been positioned as different to the more formal, clinically orientated relationships developed between YP and HCP[35,37,38]. Research-based evidence and a service evaluation directly reporting the views of YP, parents and HCPs suggests that the informal, non-judgemental relationships YW develop with YP and their individualised, 'non-medical' and holistic approach may be important in developing YP self-confidence and motivating them to engage with treatment[41-44]. YW may be seen as providing a safe, supportive space for YP to discuss their concerns and YP value the opportunities YW provide to develop their social connections and receive peer support[41-44]. Participants in a service evaluation described the advocacy role of YW and how they provide a link between YP and other services[43]. Participants perceived that YW possessed a unique perspective and different skill set to other members of the multidisciplinary team. However, it has been noted that HCPs can lack understanding of YW role in health settings and YW themselves can feel that their skills and role are not valued by HCPs which can negatively influence inter-professional relationships[37,45].

Currently the evidence-base consists of three small-scale qualitative studies conducted outside the UK[41,43,44]. It is unknown how YW services for YP with LTC are organised and delivered in the UK; if different service models are perceived to work 'better' than others or are more sustainable (and if so why); or what barriers and disbenefits are encountered when they are introduced to support YP with LTC. Therefore, there is no robust evidence base for YW services targeted at YP experiencing LTC. This study aims to fill this evidence gap and inform service commissioning, organisation and delivery by investigating how UK YW services in health and non-health settings who support YP with LTC between 11 and 25 are currently organised, provided and experienced.

AIMS AND OBJECTIVES

The overall aim of this exploratory study is to explore how YW services for YP with physical/mental health conditions (LTCs) between 11 and 25 years old in the UK are organised, provided and experienced to inform service commissioning and delivery.

1. To describe current YW services for YP with LTCs in the UK.
    a) To generate a typology of different models of YW services.
    b) To identify variation in organisation and delivery of YW services.
    c) To develop a sampling frame for work package 2.
2. To investigate six contrasting case studies of YW services to examine their organisation, delivery and integration:

   a) Explore YP, parents, YW and other service providers experiences of YW services and their perceived influence on YP engagement and wellbeing.
   b) Identify facilitators/barriers to the organisation, provision and sustainability of YW services and contextual factors influencing these.
   c) Investigate how YW services are integrated with the multi-disciplinary team and wider service system.
3. To compare and contrast six case study services in relation to their acceptability, integration, sustainability and YP engagement and co-design a service development framework to guide the commissioning, organisation and provision of YW services for YP with LTCs.

RESEARCH PLAN/METHODS

Design

We will use a sequential exploratory mixed-methods design. The study will involve two work packages (WP): a mapping of current YW services operating in both health and non-health settings followed by comparative case studies of six YW services for YP with LTC in the UK. Our Young Person's Advisory Group (YPAG) and study Advisory Group (AG) will be involved in both WPs. We will use a youth empowerment theory, Transactional Partnering (TP)[46,47] to inform WP2. This theory conceptualises empowerment as a mutual process of transactional partnering between adults and YP to promote and support YP engagement in assessing their own quality of life, developing action plans and implementing solutions within the context of an empowering environment.

Work Package One (WP1): Mapping Youth Worker Services (Months 1-6)

WP1 is designed to meet aim one of the study:

- To describe current YW services for YP with LTCs in the UK.
    a) To generate a typology of different models of YW services.
    b) To identify variation in organisation and delivery of YW services.
    c) To develop a sampling frame for WP 2.

Sampling and Recruitment

We will map current YW services that focus on YP with long-term physical/mental health conditions (LTCs) aged 11 to 25 years old provided by the NHS and other organisations (e.g. schools and charities) across the UK using an online survey. The database of YW services held by the Health-Based *Youth Worker's* Group will be the main sampling frame for the mapping survey. One of the co-applicants (DH) is the Chair of this group and permission has been given for the mailing list to be used for this purpose. As the completeness of this database is unknown, this will be supplemented by circulating information about the survey: (1) to appropriate NHS/Local Authority providers, CAMHS, voluntary sector organisations; (2) to the relevant networks of the research team and study advisory group (AG) (3) to services identified through internet searching; (4) via social media (e.g. 'X'). Services will be included in the map if they are *UK YW services that (1) focus on YP with long-term physical and/or mental health conditions aged 11 to 25 years old (2) are provided by the NHS, schools, Local Authorities, Voluntary Sector and other organisations.*

Data collection

We will develop an online mapping survey using Qualtrics for completion by the lead of each YW service. The survey will build on versions used in previous studies and will be co-developed with our YPAG and AG. It will be piloted and refined before circulating for completion. The survey will collect information about YW services on areas such as: focus of the service (eligibility criteria); service roles/functions; type of commissioning/funding arrangements (e.g. health commissioning); staffing profile; referral routes; service locations; provider organisation; length of operation; activities/interventions; integration with other professionals/services. No personal data will be collected other than the lead's work email address.

Data analysis

After data cleaning and the removal of any duplicate services, the data will be analysed using SPSS to produce descriptive statistics. This will produce a detailed description of the characteristics of YW services operating in the UK. This data will then be used to develop a typology of YW services i.e. a means of classifying services according to their characteristics. Typology building will start with identifying differentiating characteristics and then organising these into dimensions. On the basis of these dimensions, we will explore whether it is possible to discern particular service models. Our YPAG and AG will be involved in this analysis and in the development of the typology. The services that have been identified through the mapping exercise will then be coded against the typology dimensions and if possible, a service model. The mapping exercise will provide a sampling frame for WP 2 for selecting six YW services for in-depth study.

Work Package Two (WP2): Case Studies of Youth Worker Services (Months 7-26)

WP 2 will use case study methods[48] to meet aims two and three of the study.

- To investigate six contrasting case studies of YW services to examine their organisation, delivery and integration:
  a) Explore YP, parents, YW and other service providers experiences of YW services and their perceived influence on YP engagement and wellbeing.
  b) Identify facilitators/barriers to the organisation, provision and sustainability of YW services and contextual factors influencing these.
  c) Investigate how YW services are integrated with the multi-disciplinary team and wider service system.

- To compare and contrast six case study services in relation to their acceptability, integration, sustainability and YP engagement and co-design a service development framework to guide the commissioning, organisation and provision of YW services for YP with LTCs.

Sampling of case study sites

Using the typology developed in WP1 we will purposefully sample six YW services (case studies) to (1) reflect different dimensions of the typology and (2) different geographical locations (including those experiencing socio-economic disadvantage, rural locations and those with diverse communities). We will also consider the different contexts and policies of the different UK nations in selecting case study sites. Our YPAG and AG will work with us in selecting case study sites to approach to participate in the study.

Sampling and recruitment of study participants

At each site a purposeful sample of YP (8-10), parents (3-5) and YW/clinicians/managers/commissioners (5-8) will be recruited. In total the sample will include up to 60 YP, 30 parents (who may or may not be related to YP participants) and 48 YWs/clinicians/managers (n=138). This sample size is consistent with multiple case study research, our previous case study research and recommendations for achieving data saturation[49,50]. In relation to our purposeful sampling, we will aim to recruit a sample that reflects the particular service characteristics as well as including diversity in terms of characteristics such as age, gender identity, ethnicity, health condition. At all sites we will work with service providers to recruit YP from seldom-heard groups and those who have disengaged from the YW service.

We will work with our YPAG and AG to ensure that we develop participant information that is appropriate, accessible and provided in different forms (i.e., written and video). We have requested funding for translation and interpreters to enable the participation of YP and parents who do not have English as their first language. Participants meeting the inclusion criteria (Table 1) will be approached by staff at the YW service about study participation and provided with appropriate participant information. Adverts will also be placed in relevant locations. Where feasible the project researchers will be present to informally discuss study participation with YP and parents. Parental permission will be obtained to provide YP under 16 years old with study information and to contact them regarding study participation. The lead of the YW service will approach service providers/managers and commissioners with information about participation in the study. After receiving information about the study, potential participants (or their parents) will contact the research team directly about taking part in the research. The researchers will then discuss the study further with potential participants (and their parents for those under 16) and make arrangements for an interview. Informed consent/assent will be obtained at the time of the interview.

Table 1: Eligibility Criteria

Participant Group	*Inclusion Criteria*	*Exclusion Criteria*
Young People	Young people aged from 11 to 25 who have accessed the YW service	Young people who have not accessed the YW service
Parents	Parent or guardian or foster parent of a child who has accessed the YW service.	Child has not accessed YW service
Service providers/managers and commissioners	Service providers/managers and commissioners who are involved in providing, working with or commissioning the YW service	Service providers/managers and commissioners who have had no role in providing, working with or commissioning the YW service

Data collection

Data will be collected by interviewing, documentary analysis and observation. At each site we will request service-related documents to provide contextual information about the service. These could include operational policies and service specifications; local audits/evaluations; annual service reports. We will also collect data about service costs in order to conduct an initial cost analysis. Semi-structured interviews will be conducted with YP who have current or previous experience of the service; with parents whose children have accessed the service and with YWs, clinicians/practitioners and managers/commissioners. Participants will be given the choice over whether interviews are conducted in-person, by telephone or using videoconferencing. Those preferring in-person interviews will be given choice over their location. Interpretation and translation costs have been included in the budget to promote the inclusion of YP/parents who do not have English as their first language. Young people and parents will be offered a £20 voucher. With the participant's permission interviews will be audio-recorded. If participants do not wish their interviews to be recorded then the researcher will take notes. These may be made directly into an encrypted lap-top or they may be hand-written. In both cases no identifying information will be included in the notes and the notes will be given an identifying number once uploaded to the University of Manchester research data service (RDS) Hand-written notes will be scanned and uploaded to the RDS as soon as possible and then securely destroyed once transfer has been checked.

Bespoke topic guides for each participant group will be co-developed with our YPAG and AG and will be informed by the aims of the WP and our underpinning theory. Areas to incorporate include: experiences of using/providing/commissioning YW services (both positives and negatives of YW services and the barriers/facilitators encountered); perceptions of the influence of the service on YP engagement and wellbeing; how cultural sensitivity is ensured; actions taken to embed and sustain the service; how the service relates to and works with the wider service system. For YP, we will incorporate arts-based, creative approaches into the interviewing process. This includes offering YP the opportunity to take photographs, use drawings or write poems/narratives as a way of communicating their experiences and views. Visual activities will be discussed by the researcher with YP during recruitment as these will be undertaken prior to the interview. However, participation in the study will not be dependent on engaging in these activities. We have found the use of arts-based approaches empowers YP over how they choose to communicate their experiences; increases participation; enables them to communicate sensitive, complicated and abstract ideas; and makes the research process fun[51]. We will conduct observations of YW 'in action' looking at the practices and approaches used by YW with YP (e.g. peer support groups) and other workers (e.g. multi-disciplinary team meetings). Field notes will record these observations. Interviews and fieldnotes will be fully transcribed.

Data Analysis

Data from the interviews and observations will be imported into NVivo for analysis using the Framework Approach[52] of deductive and inductive coding. Analysis will be conducted in two stages: a within-case analysis and a cross-case analysis and will focus on understanding the service characteristics that promote acceptability, integration, sustainability and YP engagement. Members of our YPAG and AG will be involved in the analysis process. Following the familiarisation stage, data will be deductively coded using a set of *a priori* codes developed from the study aims and the study's theoretical framework (Transactional Partnering). This within-case analysis will generate six charts (one per case study) for the later cross-case comparative analysis. Data collection and analysis in each case study site will be conducted concurrently to ensure that analysis can inform subsequent interviews. For the initial cost analysis, the total cost of each service will be estimated by totalling the costs of the component resources required to deliver the service. For the cross-case analysis, the six charts developed from the within-case analysis charts will be examined to inductively identify both cross-cutting themes and themes specific to a particular case study site informed by Transactional Partnering as an analytical lens. These data will then be analysed inductively to identify cross-cutting themes using a matrix approach to enable the comparative display of summary data. Themes will be developed by examining their dimensions, exploring relationships between them, and searching for potential explanations. The cross-case analysis will focus on comparing and contrasting services in relation to acceptability, integration, sustainability and YP engagement and identifying contextual influencing factors. We will also consider the different contexts and policies of the different UK nations in the cross-case analysis. The cross-case analysis will be used as the basis for co-developing, with our YPAG, AG and other stakeholders, a service development framework of 'best practice' principles to guide the commissioning, organisation and delivery of YW services.

PPI

PPI work with YP with LTC (who had experience of Youth Work services) and parents was carried out to develop the application. They were prepared for this by engaging in a range of interactive activities to help them understand the research process. YP and parents thought that YW services should be accessible to all YP with a LTC. They felt that it was important that research was conducted to find out how YW services can be best provided. YP provided guidance on the study recruitment plans and on data collection methods. They emphasised that it was important that the study included a range of perspectives i.e. YP living with different LTCs and YP from seldom-heard groups. They felt that it was important that YP could choose whether they were interviewed in-person, by telephone or using videoconferencing. If they chose to be interviewed then they felt that they should be offered a choice of location for this (e.g., at home, in a private room at the hospital) and have the opportunity to have someone with them during the interview (e.g. a friend). During the development of the application, we also engaged with voluntary sector organisations about the study.

During the study NR will co-lead PPI activities with RN (PPI co-applicant). RN will be prepared and supported to actively contribute to the team meetings and to co-lead PPI activities. At the start of the project a group of 12 young advisors (YA) will be recruited and involved in all study stages. Some members of this group will comprise YP who were involved in application development. Our Young Person's Advisory Group (YPAG) will be recruited to ensure it includes YP from seldom heard groups with lived experience of physical and/or mental health conditions. We will recruit YA from the Youth Forum at the Royal Manchester Children's Hospital and from other PPI groups outside Greater Manchester. We plan to recruit two parents via the Youth Forum to join the study advisory group (AG) and work with us throughout the study. Two YA from the YPAG will also join the AG to ensure a YP voice is represented. YP and parents will be prepared for their PPI role. We will provide accessible, developmentally appropriate training to help them understand the research methods being used in the study and promote their involvement. NR will support YA and parents throughout the study.

DISSEMINATION

Our YPAG and AG will work with us in co-developing accessible materials and media tailored for dissemination to different audiences. We will promote the study and disseminate our outputs throughout the project using our social media channels, project website and, if appropriate, email/post. The key output from the study will be a co-developed, evidence-based *service development framework* to guide the commissioning, organisation and provision of YW services in relation to their (1) development and implementation (2) organisation and integration; (3) engagement of YP. This framework will comprise actionable evidence-based principles and practices and will be co-developed with our YPAG, AG and a wider group of stakeholders to ensure it is produced in an accessible and usable format. We will hold a *webinar* to launch the framework to a range of organisations and stakeholders across sectors and geographical areas. We will report the findings from the mapping survey in the form of a *targeted briefing* for commissioners, managers and YW services. We will co-design accessible *summaries* of the study findings in different formats for research participants and other stakeholders. This will include short written *reports/briefings, an animation and an infographic*. We will publish *papers* in open access health and social care journals. We will work with NIHR to use NIHR Open Research and NIHR Alerts to publish and promote our research findings with a broad range of evidence users. At the end of the study a synopsis of the study findings will be disseminated by the NIHR Journal Library. We will approach the Local Government Association about writing a 'Think Piece'. We will present the research findings at local/national/international conferences and meetings. We will seek opportunities to present the study at events which would enable us to promote the study and engage with research gatekeepers and evidence users.

ETHICS

An exemption to ethical approval was obtained from University of Manchester's ethics committee for WP1. We obtained ethics approval for WP2 from the Health Research Authority (HRA) for WP2 on May 28th 2025. The study will adhere to the research governance principles/regulations of the HRA and the University of Manchester (research sponsor)[58]. Key ethical issues for this project are assent/consent; confidentiality; anonymity and distress/disclosure.

Consent/assent: A range of information materials and assent/consent forms will be developed for different participant groups and for different ages of YP. Informed consent or assent (for children under 16 years) will be obtained from participants at the time of the interview. For YP under 16 years of age, parental consent for their child's participation will also be obtained. We will ensure that the final decision on participating rests with the YP themselves. Consent/assent will be regarded as a process throughout the interview with the researcher observing for any verbal/non-verbal cues that might indicate the interviewee no longer wishes to participate. Informed consent/assent will be obtained prior to observations of YW activities/events.

Confidentiality and anonymity: All data will be stored securely and comply with University of Manchester and NHS data protection and information governance regulations. All identifiable data will be anonymised prior to analysis. Interview notes will not contain any identifiable information.

Distress/disclosure: It will be emphasised to participants that they do not have to answer questions that might cause discomfort and that they can terminate the interview at any point. YP will be equipped with tools to support the expression of this right, e.g., flashcards (for in-person interviews) or taught how to use emoji (on Zoom/Teams platforms) to indicate that they do not wish to answer a question or wish to stop the interview. If distress occurs, a comprehensive distress protocol will be followed that identifies the researcher's actions in accordance with the level of distress. At the end of each interview, the researcher will assess the participant's wellbeing and, if necessary, help the participant contact a key contact at the service. In the case of YP, the researcher would discuss the need to contact their parents (if not present in the interview). In addition, a debrief form will be developed and given to all participants at the end of each interview with appropriate contact details of support available at the site or through other services. While we consider the risk of safeguarding disclosures to be low in this study, there is the potential for a participant to disclose a safeguarding risk to themselves or others. These may relate to disclosures of physical, sexual or emotional abuse made by child participants or a parent (who may disclose information that suggests they themselves pose a risk to a child or allege that another adult does so) or they may relate to the disclosure of suicidal thinking/behaviours/plans. In either case if someone was assessed to be at risk of immediate harm then the researcher would phone 999 and remain with them until an ambulance or the police arrive. In the case of remote interviews (telephone/video conferencing), then the researcher will stay on the phone or video call until a family member or friend comes to be with the participant.

In relation to the disclosure of physical, sexual or emotional abuse, then the researchers will follow both the local site and University of Manchester safeguarding policies. This will be discussed with each service prior to the start of data collection so that these are fully understood. Information about the limitations to confidentiality and that the researchers have a duty to report any safeguarding concerns is included in the participant information sheets. An overarching principle is that a researcher's role in responding to disclosures of abuse is not to investigate or to determine if abuse has taken place but to report the disclosure in line with the safeguarding policies that govern their work. If a child (or other person) makes a disclosure, then researchers would: (1) Take seriously what the child is telling them. (2) Ask the child if they have told them everything they want to. (3) Tell the child that they will need to talk to someone else about this (4) Check that the child understands the actions that are going to be taken. (5) Make contemporaneous notes about what has been said. If the child or other person is not in immediate danger, then the researcher will discuss the disclosure with the Principal Investigator and/or local site lead. Local site safeguarding policies will be instigated in the first place. The University of Manchester Safeguarding Policy (version 3, 19/7/25) will then be followed which includes reporting sites for child-specific concerns and adult-specific concerns.

If a child/adult made a disclosure of suicidal thinking/behaviours/plans and were considered to be at risk of immediate harm then the researcher would phone 999 and stay with the participant until help arrived. In the case of remote interviews (telephone/video conferencing), then the researcher will stay on the phone or video call until a family member or friend comes to be with the participant. If the risk of harm is not immediate then steps 1 to 5 above would be taken and a parent/trusted adult as well as the lead at the study site contacted. The researcher would again stay with the participant (or stay on the call in the case of remote interviews) until a family member or friend arrived. We also have a distress management protocol as discussed above.

The team are very experienced in conducting research with YP and families and approaching issues such as obtaining assent/consent and managing distress and disclosure.

PROJECT MANAGEMENT

The study will be managed by Susan Kirk (SK) and Marie Marshall (MM) as joint project leads. Both are experienced project managers and they will lead each WP. The full research team will meet quarterly with a core team meeting every two to four weeks to plan and progress each WP. The project research associates will be managed and supervised by SK and MM.

A study advisory group (AG) of key stakeholders (parents, YP, NHS managers, health and social care commissioners, Youth Workers, NHS clinicians, education representatives, voluntary sector providers, Social Workers) will meet on six occasions (in-person or virtually) over the course of the study. Care will be taken to ensure that the AG is composed of individuals that will bring both a physical and mental health perspective. Between meetings advice may be sought from the group (or individuals within the group) via email and/or videoconferencing. Recruitment to this group will commence prior to the start of the project.

Prior to the start of the project a group of 12 young advisors (YA) will be recruited and involved in all study stages. Some members of the Young Person's Advisory Group (YPAG) will comprise YP who were involved in developing the application with others recruited via other PPI groups in Greater Manchester and nationally. Two members of the YPAG will join the AG.

In line with NIHR guidance, project oversight will be managed through an independently chaired study steering committee (SSC) who will meet three times virtually.

PROJECT/RESEARCH EXPERTISE

The research team possess the necessary methodological, clinical/practitioner, managerial/commissioner and PPI experience for successful project delivery.

Susan Kirk: Professor of Family & Child Health. Leading child/young people's health researcher with a track record of leading, managing & disseminating NIHR/DHSC research. Expertise: qualitative research, mixed method research, case study research, CYP LTC. Role: Joint lead, shared project management responsibility with Dr Marshall; mentorship of Dr Marshall; project planning; supervision of data collection; lead data analysis/interpretation across all project stages; dissemination activities.
Marie Marshall: Consultant Children's Nurse and leading clinical academic researcher. Expertise: qualitative research, case study research, CYP LTC, youth work service development. Role: Joint lead, shared project management responsibilities with Professor Kirk, project planning; supervision of data collection; data analysis/interpretation across project stages; lead dissemination activities.
Nicola Evans: Reader in Mental Health Nursing. Leading CYP mental health researcher with a track record of leading, managing & disseminating NIHR research. Expertise: qualitative research, case study research. Role: Study planning; data analysis and interpretation across the study; advise on CYP mental health.
Albert Farre: Lecturer. Social psychologist & applied health researcher (YP health). Expertise: implementation science, health care improvement research, mixed method research, young people's health. Role: Study planning; statistical analysis (WP1); data analysis and interpretation across both WPs; implementation science advice.
Rajesh Patel: Youth Work educator and researcher. Youth Focus Northwest Board Member. Expertise: youth work practice and organisation, qualitative research. Role: Study planning; data analysis and interpretation across the study; advise on youth work practice and organisation, voluntary sector youth work.
Nicola Rigby: Senior YW in a hospital setting. Expertise: youth work practice across statutory and third sectors; engaging YP from seldom heard groups. Role: PPI co-lead, advise on youth work practice and engagement of YP from seldom heard groups in the study.
Rosie Naylor: Young person with lived experience of LTC, experienced youth forum member. Role: Co-lead PPI activities; study planning; data interpretation across the study; dissemination activities.
Donna Hilton: Youth Work Service Manager, Chair of the UK Health Based Youth Worker Group; national leader in the development of YW in health settings. Expertise: youth work practice and organisation. Role: Study planning; support dissemination of WP1 survey; data interpretation across the study; advise on youth work practice and organisation.
Michael Devine: Children's Services Commissioner. Expertise: Commissioning children's services. Role: Advise on service commissioning. Link to commissioning networks.

Ruth Marshall: Consultant Child and Adolescent Psychiatrist. Expertise: Adolescent mental health Role: Advise on adolescent mental health. Link to CAMHS networks.
Suzanne Coney: Consultant Paediatrician. Expertise: Adolescent health. Role: Advise on adolescent health. Link to Paediatrician networks.

DISCLAIMER

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PROJECT/RESEARCH TIMETABLE

	Year 1 (1/10/24-30/9/25)												Year 2 (1/10/25-30/9/26)												Year 3 (1/10/26-31/03/27)											
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36
PROJECT MANAGEMENT																																				
RA induction	■						■																													
PPI Training [1]	■									■																										
Website/Social Media development	■	■																																		
Ethics & governance			■	■	■	■																														
Advisory group meetings		1					2									3						4						5	6							
NIHR Steering Group Mtg (1 x year)						1												2										3								
WORK PACKAGE 1 (MAPPING)	**1/10/24-1/4/25**																																			
Survey development and piloting	■	■																																		
Online Survey & Internet search		■	■	■																																
Data analysis/typology development				■	■																															
Write up						■																														
WORK PACKAGE 2 (CASE STUDIES)	**1/4/25 - 31/03/27**																																			
Sampling of sites							■	■																												
Recruitment of sites								■	■	■																										
Data collection											■	■	■	■	■	■	■	■	■	■	■	■	■													
Data analysis																		■	■	■	■	■	■	■	■	■										
Co-design of framework																											■	■	■	■						
Write up																									■	■	■	■	■	■						
DISSEMINATION																																				
Website/Social Media/Digital	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Interim/Final Reports to NIHR						I						I						I						I						F						
Lay short reports/animation																													■	■						
Conferences/papers													■																					■		

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[1] PPI activities are embedded throughout the project.