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Crisis care for children and young people with mental health problems: national mapping, models of delivery, sustainability and experience (CAMH-Crisis2). A study protocol.

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STUDY PROTOCOL

REVISED **Crisis care for children and young people with mental health problems: national mapping, models of delivery, sustainability and experience (CAMH-Crisis2). A study protocol. [version 2; peer review: 3 approved]**

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Abstract

Background

One in six five 16-year-olds have a probable mental health difficulty. Of these, almost half of older teenagers and a quarter of 11–16-year-olds report having self-harmed or attempted suicide. Currently, there is little research into mental health crisis services for young people, with little understanding of what services exist, who uses them, or what works best.

Question





'How are mental health crisis responses for children and young people up to the age of 25 sustained, experienced and integrated within their local systems of services?'



Objectives

1. To describe National Health Service (NHS), local authority, education and third sector approaches to the implementation and organisation of crisis care for children and young people across England and Wales.
2. To identify eight contrasting case studies in which to evaluate how crisis services have developed and are currently organised, sustained, experienced and integrated within the

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1. **Kimberly Hoagwood**, New York University, New York, USA
2. **Kristin Cleverley** , University of Toronto, Toronto, Canada
3. **Emma Ashworth** , Liverpool John Moores University, Liverpool, UK

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context of their local systems of services.

3. To compare and contrast these services in the context of the available international evidence, drawing out and disseminating clear implications for the design and delivery of future crisis responses for children and young people and their families.

Methods

A sequential mixed methods approach, underpinned by normalisation process theory will be employed. A survey will create a detailed record of how crisis responses across England and Wales are organised, implemented and used. Subsequently, eight contrasting services in relation to geographic and socioeconomic setting, populations served, and service configuration will be identified as case studies. Interviews will be conducted with children, young people and parents/carers who have used the service, as well as commissioners, managers and practitioners. Operational policies and service usage data will also be examined. Analysis of how each service is provided, experienced, implemented and sustained will be conducted both inductively and deductively, reflecting normalisation process theory constructs.

Keywords

Mental health crisis; children and young people; crisis services; service models; normalisation process theory; sequential mixed methods; case study; qualitative research

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REVISED Amendments from Version 1

This protocol has been amended in response to the reviewers' suggestions. In the 'Aims and Objectives' we provide a working definition of crisis services, drawing on our earlier evidence synthesis (Edwards *et al.*, 2023), in response to Reviewer Two's feedback. Likewise, in the 'Theoretical Framework' section we provide some further detail regarding normalisation process theory (NPT). In response to Reviewer One's point about giving consideration to the system features of each case, in the section outlining 'Work package two', we have added details of how we will consider the systems characteristics of each candidate case. In this section we have also explicitly referred to sustainability; this is in response to Reviewer Two's question on how this will be explored. At the end of the 'Work package three' section we refer to our underpinning, completed, evidence synthesis (Edwards *et al.*, 2023), in response to the first reviewer's query concerning what source of information we will use to compare our findings with the international evidence. Under 'Dissemination' we have outlined how we will work with members of the Study Advisory Group and young people working with us as advisors; this is in response to the second reviewer's question regarding dissemination.

Any further responses from the reviewers can be found at the end of the article

Plain english summary**Background**

There has been a sharp increase in children and young people experiencing extreme emotional distress and/or self-harm, which is also known as 'crisis'. Services for young people in crisis are a priority in the UK but little is currently known about what crisis services exist, who uses them, or what type of service works best.

Aim and objectives

This project aims to explore the types of mental health crisis services currently available to children and young people up to the age of 25 in England and Wales, and to examine how they are organised, perceived and integrated within other local care systems. The objectives are to:

1. Find out what NHS, local authority, education and charity sector crisis services exist for children and young people across England and Wales, to describe the services and to create a database of them.
2. Identify eight contrasting services from the database and evaluate how these services are organised, perceived and integrated within local care systems.
3. Compare and contrast these services with the available international evidence, drawing out clear implications for the design and delivery of future crisis responses for children and young people and their families.

Methods

We will use a survey to create a database of crisis response services across England and Wales. From the database we

will identify eight contrasting services and we will conduct interviews with children, young people and parents/carers who have used the service as well as managers and staff. We will look at how the services work and explore how they are used and by whom. We will compare and contrast each case study and consider findings of other research studies from around the world to draw clear, actionable, lessons for the future provision of high-quality crisis services for children and young people.

Introduction

This study protocol summarises the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme funded CAMH-Crisis2 study protocol (Ref: NIHR151811). Our recent evidence synthesis, which set out to identify, appraise and synthesise international research and non-research evidence on crisis care for children and young people (CYP) (Edwards *et al.*, 2023; Evans *et al.*, 2019) identified a significant paucity of research studies originating from the UK. However, the mental health of CYP is an area of sustained and expressed need (World Health Organization, 2013) with one in six five-16 year olds in England in 2020 having a probable mental health disorder (Vizard *et al.*, 2020), a rise from one in eight five-19 year olds in 2017 (Sadler *et al.*, 2018). In those with a mental health problem, a quarter of 11–16 year olds and almost half of 17–19 year olds are reported to have self-harmed or attempted suicide (Sadler *et al.*, 2018). It is also known that 9% of 16–24 year olds have attempted suicide in their lifetime (McManus *et al.*, 2016). CYP in poverty (Gutman *et al.*, 2015) are over-represented amongst CYP with mental health problems, as are CYP with lesbian, gay, bisexual or other non-heterosexual identities (Sadler *et al.*, 2018). CYP from black, Asian and minority ethnic (BAME) groups (Pople & Rees, 2017) and in rural communities (Allwood, 2020) face additional challenges, with the Covid-19 pandemic further exacerbating these inequalities (Welsh Parliament Health and Social Care Committee, 2022). A further concern is the mental health of looked-after CYP (also known as CYP in out-of-home care), of whom up to half have a recognisable mental health disorder (Department for Education and Department of Health, 2015) and for whom effective cross-agency coordination is particularly important (House of Commons Education Committee, 2016).

Help for most CYP with mental health difficulties is, ideally, provided through primary care and early years services, with some referred to specialist child and adolescent mental health services (CAMHS) (Garratt *et al.*, 2022). An important goal is the provision of safe, accessible and effective care for CYP who need urgent help during periods of mental health crisis, with investments being made in dedicated crisis services in many parts of the UK (Quality Network for Community CAMHS, undated). In England, out of hours and crisis services for CYP are expanding to include provision in the National Health Service (NHS), social care and in educational settings (NHS England, 2019). In Wales, both crisis care and mental health care for CYP remain priorities

(Welsh Government, 2020). Responding appropriately to CYP in crisis has also featured in recent national Crisis Care Concordats (HM Government, 2014; Welsh Government and Partners, 2016). However, despite the prioritisation of crisis care for CYP very little information is available in the UK on the organisation, delivery and sustainability of services or the experiences of CYP and families. National standards suggest that responses to crises experienced by CYP should be immediately accessible and provided by the right professional; clearly understood by CYP and families; provided in settings which are acceptable and not in hospital whenever possible; and characterised by continuity (Quality Network for Community CAMHS, undated). Reflecting the paucity of relevant UK research, it is not known how far these standards are being met in England and Wales. In addition, the characteristics of CYP using crisis services, how services are organised, delivered, sustained and experienced, and how far they reflect the best available international evidence remain unknown.

Protocol

Aims and objectives

This project aims to explore the types of mental health crisis response currently provided to CYP up to the age of 25 in England and Wales, and to examine how crisis responses are organised, sustained, experienced and integrated within their local systems of services. Reflecting the lack of a single, agreed, definition, of ‘crisis’ we are using the approach used in our underpinning evidence synthesis by including in this project all ‘services which are provided in response to extreme psychosocial distress, which for CYP may be in any location such as an ED, a specialist or non-specialist community service, a school, a college, a university, a youth group, or via a crisis support line’ (Edwards *et al.*, 2023).

The project has three objectives, each linked to a work package (WP):

- To describe and map NHS, local authority, education and third sector approaches to the implementation and organisation of crisis care for children and young people across England and Wales.
- To identify eight contrasting case studies in which to evaluate how crisis services have developed and are currently organised, sustained, experienced and integrated within the context of their local systems of services.
- To compare and contrast these services in the context of the available international evidence, drawing out and disseminating clear implications for the design and delivery of future crisis responses for children and young people and their families.

Theoretical/conceptual framework

Throughout this project, organised responses to CYP in mental health crisis will be considered to be examples of

complex interventions introduced into complex systems (Hawe *et al.*, 2009; Moore *et al.*, 2019). To better understand the development, organisation, sustainability and experience of crisis responses for CYP as exemplars of complex interventions introduced into complex systems, normalisation process theory (NPT) will be employed throughout (May & Finch, 2009). NPT helps frame understanding of the implementation of new practices and approaches through an emphasis on four generative mechanisms: *coherence, cognitive participation, collective action and reflexive monitoring*.

Methods

Patient and public involvement

Patient and public involvement (PPI) is central to this study. Young people and family members directly contributing to our underpinning evidence synthesis (Edwards *et al.*, 2023; Evans *et al.*, 2019) helped identify the need for this new project. Co-investigators include a young person mental health activist and research advisor, and a carer. The proposal also builds on the ‘Blueprint study’, in which CYP played a major part (Fraser *et al.*, 2022; Prymachuk *et al.*, 2018). Ongoing involvement of CYP in this project will be supported by CASCADE Voices, which is run in partnership with Voices from Care Cymru. CASCADE Voices members, and representatives from other organisations supporting care-experienced young people, such as *Become*, will be approached and supported to advise on the design of the survey, participant information sheets, interview schedules and dissemination as outlined below.

Work packages

This sequential mixed methods (Creswell & Plano Clark, 2018) research will comprise a detailed description and mapping of service models developed in England and Wales to meet the needs of CYP in mental health crisis with a comparative case study (Yin, 2013) examination of the experiences and implementation of contrasting approaches. It is made up of three work packages (WP) which correspond with the study objectives:

Work package 1: Describing and mapping approaches to the implementation and organisation of crisis care for CYP across England and Wales

A comprehensive database of organisations commissioning and providing dedicated responses to CYP (up to the age of 25) in crisis across England and Wales will be created. This will be achieved by drawing on the database created in the ‘Blueprint study’ (Fraser *et al.*, 2022; Prymachuk *et al.*, 2018), the expertise and contacts of members of our stakeholder advisory group (SAG) and snowball sampling. Our proposed unit of analysis in the context of database creation and survey distribution will initially be health commissioning bodies, NHS provider trusts in England, health boards in Wales, local authorities, academy chains in England, national third sector providers and universities.

A bespoke survey instrument for direct completion by a key informant in each of the crisis services we identify has been co-created with the help of members of our SAG and by CYP who are members of *CASCADE Voices* a group of young people who are care-experienced (some of whom also have experience of using CAMHS and crisis services) who advise on research involving CYP. The design and content will be informed by the 'Blueprint study' (Fraser *et al.*, 2022; Prymachuk *et al.*, 2018), the findings from our recent evidence synthesis (Edwards *et al.*, 2023; Evans *et al.*, 2019) and from the direct incorporation of NPT ideas through the use of questions derived from the *Normalisation Measure Development (NoMAD)* tool (Finch *et al.*, 2015). It will be designed, piloted and refined with the purpose of gathering information on the commissioning, provision and normalisation of service approaches to CYP in crisis provided through the NHS, local authorities and third sector organisations in England and Wales.

Data collected from key respondents will be supplemented by desk-based research using publicly available information from service commissioner and provider websites, and data on indices of deprivation in the areas served by each crisis service available online through National Statistics (Ministry of Housing Communities & Local Government, 2020). Desk-based research will also be undertaken to gather information on service approaches in the case of non-response.

Data will be analysed descriptively, outlining the features of each locale and population served and the key components of the services provided. This descriptive analysis will also draw on data derived from the NoMAD tool to produce a summary of how each service has been normalised. Using findings on the range of approaches to crisis care available from our previous evidence synthesis (Edwards *et al.*, 2023; Evans *et al.*, 2019) as a starting point, we will create a typology of service responses using the information gathered in this WP, bringing this forward to inform our case study sampling frame in WP2.

Work package 2: Evaluating crisis responses within the context of their local systems of services

Using our description and typology of crisis care responses created in WP1, we will purposively identify eight contrasting organised responses to crisis. These will include exemplars which collectively have as many of the following features as possible: from both England and Wales; provided by (or involve) social care practitioners; serve CYP who are socioeconomically disadvantaged, and/or are from diverse ethnic backgrounds, and/or are in remote locations, and/or are looked-after or in touch with youth offending services. In our selections we will also play close attention to the system characteristics of each candidate case, including its organisational structure, the services provided, and staffing. We will work particularly closely with members of the SAG in determining our case study selection, in order that our sampling reflects not only variety of services but also the knowledge needs of stakeholders. The sex and gender of participants will not

inform inclusion or exclusion criteria since these considerations are beyond the scope of this study.

With the purpose of contextualising each case study, in the first phase of data generation we will supplement and expand the information already gathered in WP1 by accessing local documents (such as operational policies and service specifications), along with additional information on service use, completed local audits and/or evaluations, and related grey literature. All additional new data in this WP will then be generated using in-depth qualitative interviews, again underpinned by commitments to the use of NPT ideas. At each of the eight sites we aim to interview five CYP, five parents or carers (who may or may not be associated with the CYP) and ten practitioners/managers and commissioners.

The purpose of interviewing CYP and family members/carers is to inform the case-by-case evaluation of each approach to crisis care in addition to helping inform our parallel, implementation-focused, interviews with managers and practitioners in each case study. This will be achieved by using CYP and family members'/carers' 'views and experiences' data to inform the ongoing refinement of the case study-specific components of our semi-structured, implementation-focused, interview schedules for use with staff.

In each case study, practitioners/managers and commissioners will be purposively sampled from within the crisis response service and from elsewhere in the local system. The specific purpose is to explore the development, organisation, normalisation and sustainability of each case study approach to crisis care. Individuals fulfilling a variety of roles will therefore be recruited, including people leading and providing crisis services for CYP along with individuals located in other parts of the local health, social care and education system.

Interviews will be conducted using videoconferencing and audio-recording technology, and CYP and parents/carers will be given the option of in-person interviews. All interview schedules will be developed in consultation with our SAG and with members of *CASCADE Voices*, with practitioner/manager and commissioners' interviews including the application of NPT ideas (May *et al.*, 2021).

All interview data will be transcribed in full, with data derived from interviews subjected to reflexive thematic analysis (Braun & Clarke, 2019). We will also use a deductive (or directed content) analytic approach to our CYP and family members'/carers' interview data (Hsieh & Shannon, 2005). Analysis of the practitioner/manager and commissioner data will be conducted using both *a priori* codes reflecting NPT constructs and codes developed in inductive, data-driven, style to fully surface participants' experiences. Data generation and analysis in each case study will be conducted concurrently in order that, in iterative fashion, analysis of documents and of completed interviews is available to inform subsequent interviews.

All data will be managed and analysed using the software programme NVivo (QSR International Pty Ltd, 2020), with analysis confined to a series of within-case examinations of experiences, implementation and sustainability centred on each of the eight discrete case studies. A comparative, cross-case, synthesis will follow in WP3.

Work package 3: Comparing and contrasting services, and drawing out and disseminating clear implications for future design and delivery of crisis responses

In this final work package, we will compare and contrast the development, organisation and implementation of each case study depicted in WP2 using a matrix approach (Miles *et al.*, 2020). This will support the comparative display of summary data addressing macro-level comparisons and contrasts reflecting the generation of data in England and Wales; the type of crisis service provided in each case study; the populations served; staff, CYP and family/carer experiences; and the implementation, normalisation and sustaining of the crisis care model. This comparative, cross-case, analytic approach will allow us to display how each contrasting crisis approach is organised, implemented, embedded and experienced and how far it both reflects and extends current best available international evidence as brought together in our underpinning, completed, evidence synthesis (Edwards *et al.*, 2023). It will also allow us to show how each approach serves, or does not serve, diverse sets of needs in particular ways.

Ethics

Throughout this study we will follow the principles of good practice set out in the UK Policy Framework for Health and Social Care Research (Health Research Authority *et al.*, 2021). Ethical issues in this project arise in WP1 (mapping) and WP2 (case studies). The primary ethical and research governance issues here are consent, anonymity, confidentiality, data protection and the safety of participants and researchers. Of particular importance to this study is the involvement of CYP as research participants.

Regarding consent, we will follow standard ethical procedures for gaining informed consent from participants which will include CYP, parents/carers, commissioners, managers and service provider staff. In the case of CYP we will obtain ‘assent’ from those who are aged seven -15 years and children under seven years will be given appropriate information and asked for their views.

In relation to data protection, all data we collect will be confidential to the project and stored securely in line with current University and NHS research governance and general data protection regulations. Any identifiable data will be

anonymised prior to analysis in line with good research practice.

In the context of participant safety and wellbeing, researchers will be trained in good interview practice as well as the use of distress protocols (including immediately ceasing the interview if participants become upset and providing avenues for support) and a disclosure protocol. All researchers accessing participants will be DBS checked. Regarding researcher safety, we will develop a fieldwork protocol with due regard to University and NHS guidance on lone working and safety and adhere to the Code of Practice for the Safety of Social Researchers (Social Research Association, 2001).

Ethical review and approval will be required for WP1 and WP2. WP1 involves the completion of a survey by a key respondent associated with service commissioning and/or provision. We have worked through the Health Research Authority’s Decision Tool, which determines this WP as not meeting the criteria for NHS ethics review. We have, therefore, obtained a proportionate review from the School of Healthcare Sciences Research Ethics Committee in Cardiff University as part of our commitment to good research practice, and to facilitate the publishing of our WP1 findings. WP2 involves the collection of data from staff, service users and carers. For this we will apply for NHS research ethics and governance approval via the Health Research Authority.

Dissemination

We will share findings from each WP as they emerge and engage with national stakeholders throughout each stage of the project. Working with members of our SAG, and with young people helping us as advisors, we will tailor our findings in different ways for different audiences, adhering to NIHR guidance on both dissemination (National Institute for Health Research, 2019) and impact (National Institute for Health Research, undated).

Data availability

No data are associated with this article.

Reporting guidelines

COREQ guidelines (Tong *et al.*, 2007) have been adhered to in developing this protocol.

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Emma Ashworth 

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This is a very interesting and much needed piece of research, looking at the provision of crisis care for CYP in the UK. It is detailed and well-written, and the methodology appears sound. Previous reviewer comments appear to have been adequately addressed. I only have a few very minor points:

- There is a missing hyphen in the first line of the abstract – it should be ‘one in six five-16 year olds’
- I think it would be helpful if the authors could briefly explain the ‘Blueprint study’ and how it links to this proposed work
- There is a typo in work package 2 – ‘play close attention’
- In work package 2, it would be useful to have an explanation as to why the analysis of the parents/CYP interviews will be deductive, and what this will include
- I note that a previous reviewer has asked for more information on how CYP will be involved in dissemination, and I still feel this could be more detailed. It would also be good to see the ways in which findings will be disseminated to ensure they are accessible, and so that they can be directly relevant to policy and practice.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Yes

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Researcher in children's mental health - specifically school interventions, CAMHS, and suicidal crisis.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 18 July 2023

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**Kimberly Hoagwood**

Grossman School of Medicine, New York University, New York, New York, USA

The authors were highly responsive and the manuscript is stronger. It will make an important contribution to work on crisis services for young people

Is the rationale for, and objectives of, the study clearly described?

Not applicable

Is the study design appropriate for the research question?

Not applicable

Are sufficient details of the methods provided to allow replication by others?

Not applicable

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Dissemination and implementation science; child, youth and family mental health services; system and policy research and analysis

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 22 June 2023

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**Kristin Cleverley** 

Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, Ontario, Canada

This is an interesting project that aims to explore how child and youth crisis services are organised in the UK. The use of mixed methods was advantageous and fit responding to the project's overall research aim.

A few minor points for clarification to strengthen the protocol.

1. Is there a definition of 'crisis services' that can be provided? I understand that this is part of the project, but it was not clear what the typical reason for use of crisis services is. Is this akin to emergency psychiatric services?
2. How will the sustainability of the crisis service be mapped/described? It is part of the overall research question, but is not clear in the work packages and methods.
3. The integration of young people's voices into the project is very well done. It is not clear how (or if) caregivers will be engaged in the co-design.
4. In the introduction, a short (1-2 sentence) description of Normalisation Process Theory would be beneficial, especially since it will be used for the direct analysis.
5. How will young people be involved in the project's dissemination strategy?

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Yes

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.**Reviewer Expertise:** Child and youth mental health access, service organisation, and transitions in care; mixed methods research design; patient-oriented research

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 23 May 2023

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Kimberly Hoagwood

Grossman School of Medicine, New York University, New York, New York, USA

This protocol is timely, well written, and thorough. It addresses an important public health issue young people face globally--i.e., accessing crisis care services in the array of services. There are three issues that if described more thoroughly would strengthen the disseminability of findings when the study is complete.

First, the methods state that one aim is to compare and contrast services in the context of available evidence. However, it is not clear the sources from which those data will be derived. As there are many sources of evidence about child and youth mental health services, as well as summaries thereof, it is important to know from where and how this evidence will be mapped against the qualitative findings.

Second, the protocol mentions the use of purposeful sampling for practitioners and commissioners, but given the goal of disseminating findings widely, it would be helpful to know if the authors considered the use of purposeful sampling of system-level characteristics, such as setting, organizational structure, staffing, etc. For ultimate disseminability, especially internationally, it is helpful to be able to compare system characteristics.

Third, because the position of crisis services within the continuum of services varies across settings, systems, and countries, it would be helpful to have more description of the referral networks within which the crisis services are made available. In other words, before or after a crisis, what kinds of referral networks exist already (how do children get to these services and how do they exit from them) and are there system differences?

Again, this is an interesting and important protocol and the findings from it are likely to generate great interest and hopefully applicability in improving care for child, youth and families.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

No

Are the datasets clearly presented in a useable and accessible format?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Dissemination and implementation science; child, youth and family mental health services; system and policy research and analysis

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 23 May 2023

Clare Bennett

Thank you for this detailed review.

With regards to comparing and contrasting services and situating these within the evidence, we are referring to our recent evidence synthesis, which set out to identify, appraise and synthesise international research and non-research evidence on crisis care for children and young people (Edwards et al., 2023; Evans et al., 2019), as well as the 'Blueprint study' which underpins this research (Fraser et al., 2022; Pryjmachuk et al., 2018).

Your second point, concerning our sampling frame for work package two is helpful, thank you. For this we will draw from our description and typology of crisis care responses created in work package one, which will indeed consider the system-level characteristics that you outline, in addition to the features that we describe in the protocol.

And yes, we agree with your third point regarding the importance of exploring the interconnectedness of services. This is explored to some degree in the survey (work package one) but will be explored in more detail as part of the eight case studies, in work package two.

Once again, thank you for taking the time to provide this constructive review.

Competing Interests: Nil to declare