NHS Bedfordshire, Luton and Milton Keynes Integrated Care Board

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Health Innovation East

PRIORITIES FOR CHILDREN & YOUNG PEOPLE'S MENTAL HEALTH RESEARCH ENGAGEMENT

Proceedings of a human-centred design workshop at the Luton Irish Forum January 20th, 2025

SHOBHANA NAGRAJ, KATE EMOND, SADDAF SHAHEEN, EMMA BROWN, SANHITA CHAKRABARTI, DONNA COE, MARC VAN ROOSMALEN, DEBBIE ROBSON, MARIA GAME, SOPHIE KNIGHT, JOHN BATEMAN

NHS England

The Bedfordshire, Luton and Milton Keynes Research Engagement Network

Children & Young People's wellbeing

At a national level, there are over three times as many Children & Young People (CYP) in contact with mental health services as there were seven years ago [1]. Latest evidence suggests that rates of mental illness in CYP may be growing at a faster rate than amongst adults. Between 2017 and 2022, rates of probable mental health disorder increased from around 1 in 8 young people aged 7-16 to more than 1 in 6 [2]. For those aged 17-19, rates increased from 1 in 10 to 1 in 4.

In 2023, the report of mental health of CYP in England, identified that one in five CYP in England aged 8 to 25 had a probable mental disorder [2]. It found that 20.3% of 8 to 16-year-olds had a probable mental disorder in 2023. Among 17 to 19-year-olds, the proportion was 23.3%, while in 20 to 25-year-olds it was 21.7% [2]. After a rise in rates of probable mental disorders between 2017 and 2020, prevalence continued at similar levels in all age groups between 2022 and 2023.

Participants of the survey were also questioned about eating disorders for the first time since the 2017 survey. In 2023, 12.5% of 17 to 19-year-olds had an eating disorder, an increase from 0.8% in 2017. Between 2017 and 2023, rates rose both in young women (from 1.6% to 20.8%) and young men (from 0.0% to 5.1%) in this age group [2]. The 2023 survey also found 5.9% of 20 to 25-year-olds had an eating disorder, while eating disorders were identified in 2.6% of 11 to 16-year-olds, compared with 0.5% in 2017 – with rates in 2023 four times higher in girls (4.3%) than boys (1.0%) [2].

The recent Darzi report outlined a surge in mental health needs amongst CYP, with increased in waiting times for mental health support [3]. Referrals for mental health services for CYP have tripled from 40,000 in 2016, to almost 120,000 in 2024 [3]. These findings have coincided with an increased cost of living and worsening child poverty, signalling the impact of wider social determinants on the mental health of CYP and their families. An emphasis has been placed on improving community-based care with early recognition and prevention.

With thanks to NHS England.

The NHS Long Term Plan outlines priorities in relation to CYP Mental health

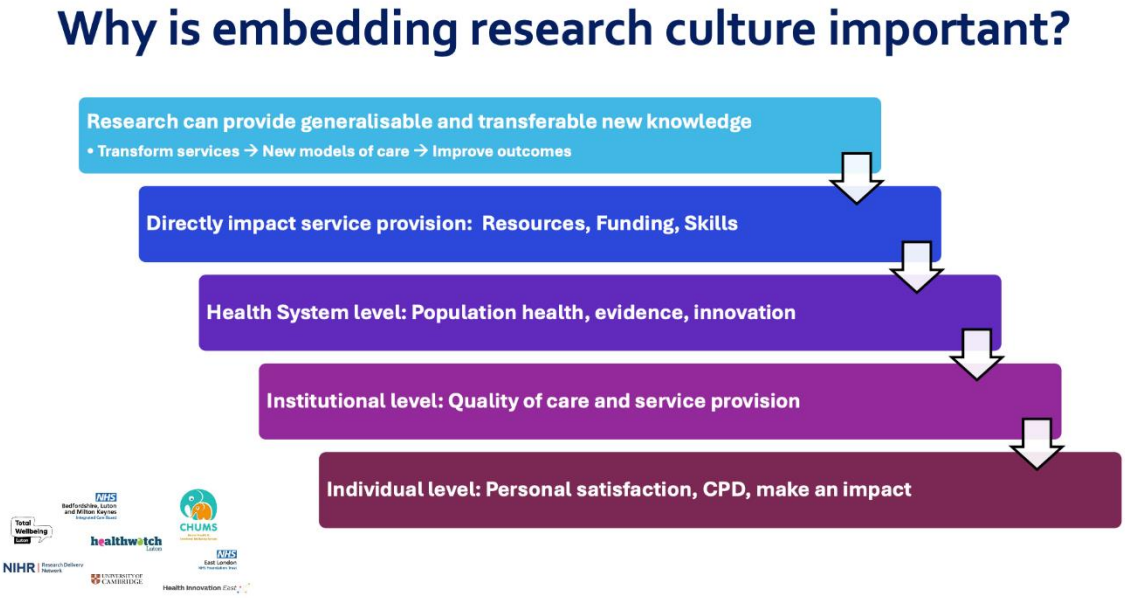
The context of CYP wellbeing in Luton

Luton has a young, ethnically diverse population, and many live in areas of multiple deprivation with widespread health challenges. Luton has 24% of neighbourhoods in the 20% most deprived areas in England [4]. These groups are typically underserved by research [5]. It is the most ethnically diverse area in the Bedfordshire, Luton, Milton Keynes (BLMK) region, with over a third (37%) of the population being South Asian. South Asian communities are consistently underrepresented in mental health research due to stigma, and systemic and cultural barriers.

Importance of research engagement for Children & Young People and their families

Research can often be viewed as removed from service delivery and the day-to-day practicalities impacting the wellbeing of CYP. However, promoting a collaborative, vibrant and safe research environment for CYP and their families, clinicians, academics, voluntary sector, local authorities and policymakers, has multiple benefits for clinical services, with potential to improve access, quality and outcomes of care, as well as providing individual impact and contributing transformative knowledge.

With thanks to NHS England.



Creating a sustainable model of research engagement for Children & Young People

We co-created a new model of research engagement for CYP, by developing Research Champions (RCs) and providing targeted training in CYP Mental Health. Our RCs included social prescription link workers, people participation workers and child welfare practitioners embedded within existing community organisations including Active Luton (https://www.activeluton.co.uk/) and CHUMs (https://chums.uk.com/), and East London NHS Foundation Trust (ELFT).

Bespoke mental health training was delivered by the ELFT People Participation and Psychotherapies teams. The two-day, face-to-face training course was co-designed with CYP and built upon a model of community resilience, providing an overview of the mental health needs of CYP as well as their families. The aim of the training was to help RCs to effectively support CYP in their daily roles as well as to engage with future research in Luton.

In addition, we provided National Institute for Healthcare Research (NIHR) Research Ready Communities training to the RCs, to introduce the importance of embedding an active research culture within communities, and the benefits of participating in research. We ensured that the RCs understood the safeguarding implications of engaging with CYP and their families. We maintained a focus on the wider social context in which CYP mental health occurs, including the home and school environments.

With thanks to NHS England.

Co-creating a research engagement plan

On Monday 20th January 2025, we held a human-centred design workshop, to bring together key stakeholders working with CYP in Luton and involved in CYP research, recognising that CYP mental health occurs within the wider context of family, peer, and community systems. The workshop was part of a larger programme of work to improve research engagement with CYP mental health in Luton, Bedfordshire.

The workshop was divided into three sessions:

1. Understanding the context of CYP mental health in Luton & Bedfordshire
2. Exploring the opportunities for CYP & Families to engage with research
3. Co-designing a vision and engagement plan for CYP wellbeing research

With thanks to NHS England.

Aims & Objectives

To bring together key stakeholders to ensure future CYP research is locally-driven, embedded within communities, meets local needs, and improves population health.

- To *listen* to the perspectives of key stakeholders involved with CYP
- To *understand* the needs and priorities of communities in relation to CYP health.
- To *co-design* a CYP research strategy with key collaborators, to enact local change
- To *create* a community of practice for future CYP research in Luton & Bedfordshire

Overview of Speakers

Introduction to Human Centred Design workshop	Shobhana Nagraj
Workshop evaluation	Kate Emond
Overview of CYP Mental Health in East of England	Kelly Dowling
ICB Priorities for Luton	Emma Brown & Bridget Moffat
CYP Voices: Priorities for research engagement	
Rapid presentations: 1. CHUMS Luton: Debbie Robson 2. Active Luton: Maria Game 3. CAMHS Luton: Vicky Taylor 4. Community Resilience: Marc van Roosmalen 5. BLMK Research Champions: All 6. Primary Care & CYP: Nina Pearson	
CYP Research in Luton & Beds	
NIHR East of England Regional Research Delivery Network	Donna Coe
Research engagement with library services: Beth Thompson	Beth Thompson
Transitions to adulthood, University of Bedfordshire	Seana Friel
Flying Start Luton, University of Bedfordshire	Rosemary Davidson
Children & social care (COACHES study), University of Cambridge	Dihini Pilimatalawwe
Designing complex interventions, University of Cambridge	Shobhana Nagraj
Children and Neurotrauma, University of Cambridge	Sara Venturini, Laura Hobbs

With thanks to NHS England.

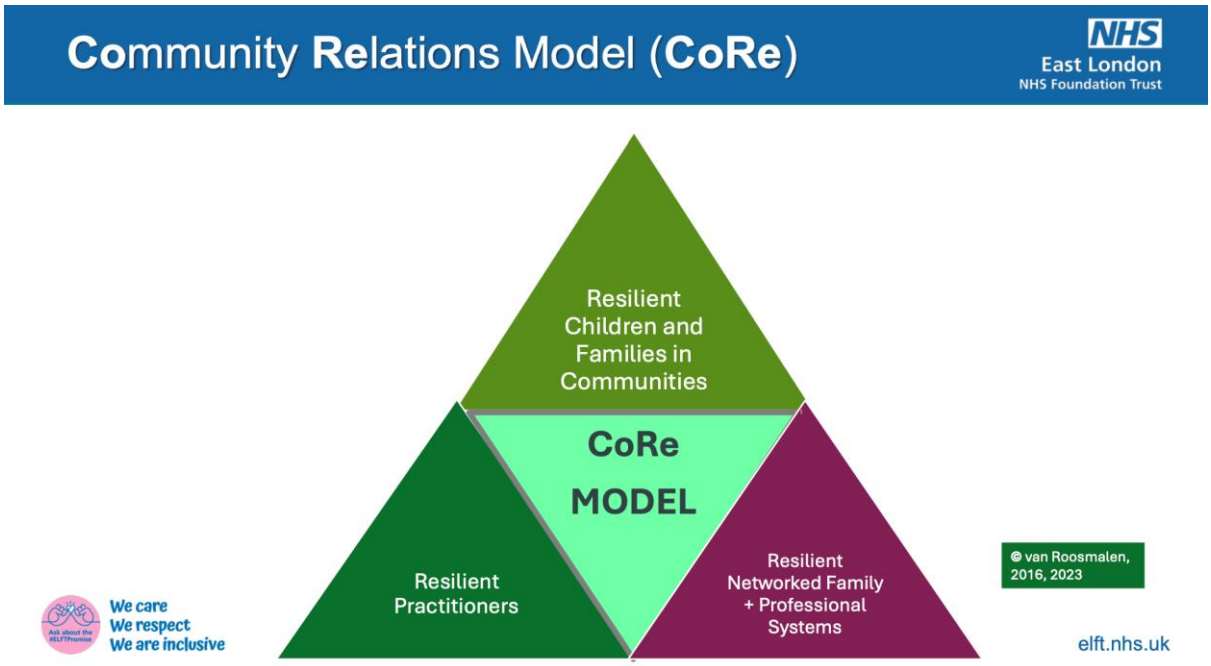
Key messages from workshop

1. A paradigm shift in the way we view mental health is needed

The mental health needs of local CYP is increasing year upon year. Services are not able to meet the demand. While CYP and their families wait for referral, there is much that can be done in communities. Firstly, early recognition of changes in CYP wellbeing through repeated observations over time is key to prevention, timely intervention, and management. Secondly, a fundamental shift in the way we conceptualise mental health is needed, in order to remove stigma.

We heard from Debbie Robson (CHUMS) and Maria Game (Active Luton), and our RCs about the challenges facing CYP locally, the impact of social media, the Covid-19 pandemic and funding cuts to the voluntary sector. We heard of the need to move towards a social model for improving community cohesion, rather than 'sticky plaster' fixes for CYP mental health.

Dr Marc van Roosmalen highlighted the need to move away from a purely medical model of CYP wellbeing, towards one of community resilience - from "I Thrive" to "We Thrive". The **Co**mmunity **Re**silience (**CoRe**) model focuses on the interpersonal interactions between CYP, families and communities, practitioners and their relationships with one another. It recognises that mental health of individuals operates within a wider social context and family environment, and there are no quick fixes; through enabling effective coping mechanisms and the practice of resilience, we can better relate with those experiencing emotional distress and provide a safe space for them to heal.



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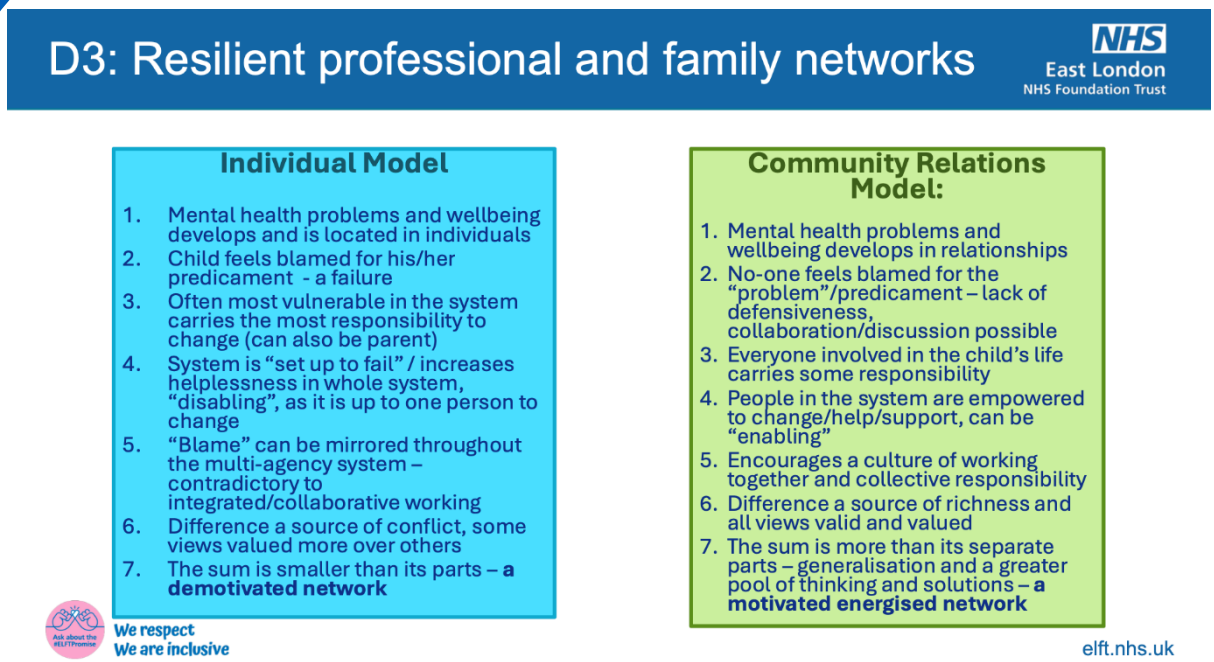

2. CYP wellbeing occurs in a social context

A local GP, Dr Nina Pearson outlined the important role of primary care and GPs as a first point of contact in noticing changes in CYP wellbeing over time. When CYP and families can't express distress, observation over time is key to noticing early changes for prevention. Dr Pearson outlined the importance of observation and being curious about life circumstances when seeing CYP and their families. The structural inequalities that exist in funding primary care health services were also highlighted. These inequalities directly impact on health outcomes for CYP that are most in need.

Recent changes in the cost of living, have contributed to increasing levels of food and income insecurity. Dr Shobhana Nagraj emphasised the need to consider the underlying social determinants of health alongside presentations of CYP mental health: '*how can we talk about CYP mental health, when many CYP and their families struggle with hunger, poverty and inability to meet their daily needs?*'. Our discussions highlighted that mental illness is not isolated from social circumstances, nor separate from physical health problems, which co-exist and are intricately connected. Mental illness can also exist alongside neurodiversity, making the current distinctions between mental and physical health services for CYP challenging.

3. We require high quality, contextually relevant research

RCs are uniquely placed as brokers between the community and health services and academics as they know local CYP priorities, understand cultural barriers, and are rooted in communities. The RCs have developed Trust with CYP and families and understand needs. Future research would benefit from involving RCs, CYP, and local communities more meaningfully in designing research questions and research studies that are meaningful and relevant to local communities.

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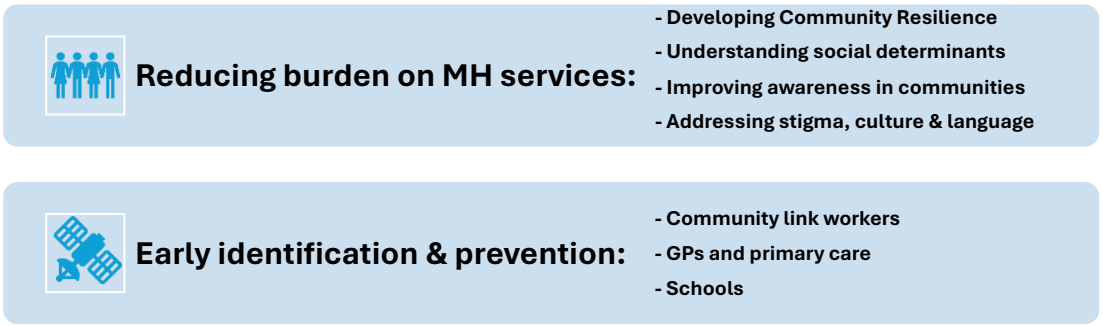
Key areas for research impact are in understanding the barriers to early recognition of mental health issues

Findings from workshop: Areas for impact



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Challenges in engaging CYP and families in research

Some of the major challenges in conducting meaningful research identified during the workshop included the stigma associated with CYP having mental health conditions, varying cultural conceptions of mental health, and significant language barriers. Lack of skilled interpreters and inherent distrust of researchers were also identified as barriers to effective engagement with CYP and their families. These personal and interpersonal factors, in addition to emotional and social circumstances, and significant stigma, might not enable CYP to engage with research.

Other barriers to research engagement included the needs of parents, who might require childcare to engage with research studies, and a lack of awareness of practical value of research to health services. Discussions revealed the need for intersectoral working & effective communication between different stakeholders to communicate changes in CYP wellbeing.

Current priorities in relation to research engagement

There is a research gap to understand why CYP mental health has increased so much and so rapidly in recent years. The workshop discussions revealed a disconnect between the CYP research being conducted nationally and locally, and what is needed locally. RCs are trusted members of the community that have strong local knowledge of CYP and families. They are facilitators who bridge the gap between researchers and community members, and can advocate for CYP mental health – by ensuring that community voices shape our

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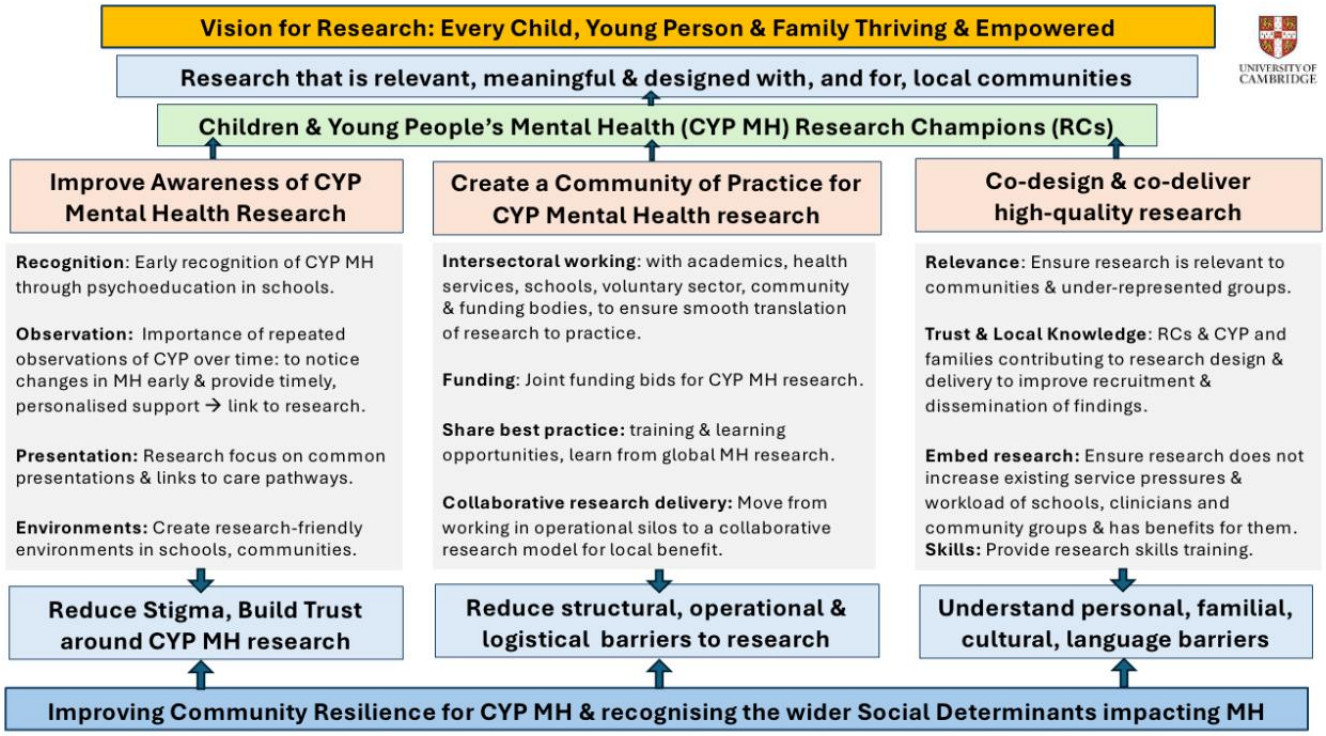
research. However, RCs require sustainable funding. They also provide further understanding of the cultural and language barriers faced by CYP in expressing their distress, and in de-stigmatising mental health. The workshop discussions resulted in a vision for research Engagement & Plan to overcome some of these barriers.

Research Engagement plan for CYP Mental Health Research



Summary of the Research Engagement Plan for Research Champions

The objectives of the research engagement plan are:

- To equip RCs with the knowledge and skills to engage meaningfully with CYP and families.
- To co-design research questions and methodologies that reflect real-world priorities for the communities in Luton & Bedfordshire.
- To foster trust and collaboration between academics, the RCs, health services, funders and the community.
- To promote and share research findings to improve CYP mental health services.

We also identified the need for co-designing of community-led research priorities, develop engagement strategies and provide a means of feedback loops to the community, to enable

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community ownership and involvement with research. We acknowledged the need to measure impact and sustainability of local research.

Outputs of workshop

Based on the findings of the workshop, we took steps in line with our research engagement plan to build capacity for sustainable local research.

As a result of the workshop, we have:

1. Developed a **Community of Practice for CYP Mental Health** with key local stakeholders to work collaboratively and develop sustainable funding models for research that is locally relevant.

2. Created a network of **RCs trained in CYP mental health** to engage with CYP & families. By embedding RCs within community organisations, and providing training in research-ready communities, child and adolescent mental health, and safeguarding and confidentiality, we aimed for RCs to feed into future research design and delivery.

3. Conducted a **Research Co-Design workshop** with RCs to design research questions that are locally driven and impactful for future research.

4. Presented our findings at **Regional and National meetings** to showcase our work for engaging CYP and their families with mental health research

Acknowledgments

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With thanks to NHS England.