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Strategy for Public Involvement and Engagement in Addiction and Mental Health Research 2025 – 2030

Version: 1.0

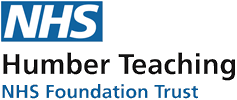
Date: April 2025

**Our partners:**

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**In collaboration with:**

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## Introduction

This strategy outlines our guiding principles, approach and goals for Patient and Public Involvement and Engagement at the Centre for Addiction and Mental Health Research. It details our desired outcomes, how we will deliver these, and how we will assess our impact and development.

The Centre for Addiction and Mental Health Research (CAMHR) sits within the Institute for Clinical and Applied Health Research (ICAHR) which is a hub for collaborative health research in the fields of medicine, nursing, midwifery, sport and exercise, psychology, sociology and social work and includes the Hull Health Trials Unit and Methods Hub. Working within this infrastructure, our strategy for public involvement follows the framework set out by ICAHR.

This strategy was developed in collaboration with our Public Co-applicant and the ICAHR Patient and Public Involvement Network, Involve Hull.

It is the role of the CAMHR Patient and Public Involvement & Engagement Co-ordinators (PPIE) to ensure appropriate actions are followed to achieve the outcomes set out in this strategy. The CAMHR PPIE Co-ordinators are:

**Ayisja Moss, PPIE Co-ordinator for Young People**

Ayisja is qualified in Youth Work and Community Development and Social Research and has over 10 years of experience working with underrepresented, disadvantaged young people with unmet needs. Ayisja’s expertise and passion is supporting youth participation to embed views and experiences of young people in decisions that affect them.

**Sarah Capes, PPIE Co-ordinator for Adults**

With a Psychology background, Sarah has more than 10 years of experience working within drug and alcohol support services across York and Hull. Most recently working within Social Prescribing for NHS Primary Care taking a holistic approach supporting patients focusing on what matters to the individual. Sarah is passionate about making sure underrepresented groups have the opportunity to be included and their voices are heard throughout the research process

## 1 Executive summary

This document sets out the Public Involvement and Engagement Strategy for the Centre for Addiction and Mental Health Research (CAMHR) at the University of Hull. The strategy has been developed in collaboration with researchers and members of our Patient and Public Involvement Network, Involve Hull.

## 2 Introduction and background

[2.1 Centre for Addiction and Mental Health Research](https://www.hull.ac.uk/work-with-us/research/groups/centre-for-addiction-and-mental-health-research)  
  
The Centre for Addiction and Mental Health Research was launched in November 2024. The centre combines expertise from the University of Hull with those of our partners King’s College London, University of York and our collaborators University of Kent, Humber Teaching NHS Foundation Trust and Hull University Teaching Hospitals NHS Trust to increase capacity of research across the region and nationally.

Our target area covers a population of 1.7 million people from cities, market towns, rural villages and coastal communities across the Humber and North Yorkshire Integrated Care Board (ICB) area. It includes areas that experience high levels of unemployment, housing problems and wider health difficulties who have poor access to effective mental health and substance use treatment. We have discussed our project with people who plan and commission services, who agree that addiction and mental health is a major priority across the region.

The aim of this new centre is to develop and deliver addiction and mental health research at the University of Hull so services, communities and individual benefit. We will target national priorities and the mental health needs of our local population, resulting in better access to care and treatment that works. The Centre for Addiction and Mental Health Research at the University of Hull is supported by the University of York and King’s College London, who already have similar centres. The funding will help the new centre grow so it can continue for years to come.

Our plan involves individuals with lived experience of addiction and mental health problems as well as local groups. Patients and the public will be involved in the development of our research, helping us to understand the results of our projects, and how to effectively communicate research findings with target audiences. The plan will include several projects across three areas:

A heart and hands with black background

AI-generated content may be incorrect. [**Improving care pathways and outcomes for young people with substance use and mental health problems.**](https://www.hull.ac.uk/work-with-us/research/groups/improving-care-pathways-and-outcomes-for-young-people-with-substance-use-and-mental-health-problems)We aim to improve care pathways for young people (i.e. 10-18 years) with substance use and mental health problems who often miss out in getting the help they need.

A pink tree with a black background

AI-generated content may be incorrect. [**Improving care pathways for adults with substance use and mental health problems presenting to 'Places of Safety' and emergency departments.**](https://www.hull.ac.uk/work-with-us/research/groups/improving-care-pathways-for-adults-with-substance-use-disorders-and-mental-health-problems-presenting-to-places-of-safety-and-emergency-departments)We aim to improve care for adults who have substance use disorder and urgent mental health problems when they ask for urgent help.

A blue and black brain

AI-generated content may be incorrect. [**Theme 3: Defining the needs of adults with alcohol-related cognitive impairment.**](https://www.hull.ac.uk/work-with-us/research/groups/defining-the-needs-of-adults-with-alcohol-related-cognitive-impairment)We aim to understand more about those adults who have early memory problems caused by alcohol. The research will help services to identify and care for these people earlier so that longer term problems can be avoided.

CAMHR will deliver benefits to people with addiction and mental health problems in our local area in the following ways:

* More people with addiction and mental health problems will be able to get involved in health research that will change services and improve outcomes.
* Involve the voices of people with lived experience of addiction and mental health care, and those of their family and carers.
* Explore best practice for increasing access and improving outcomes for those experiencing addiction and mental health problems. Our research will also assess the value for money and impact of new service models across a variety of settings.

[**What is PPIE?**](https://www.nihr.ac.uk/glossary?letter=P#letter-p)

## 3 Our vision and values

## 3.1 Our vision for public involvement and engagement

Our vision is to foster a research partnership that is inspiring, inclusive, promotes collaboration and transforms the lives of patients and families. We aim to do this by addressing gaps in the care system and finding practice-based solutions resulting in greater access to care and treatment that works.

We will involve people with lived experience, carers, families and local communities as active partners in our health and care research. We envision that, together we can make a positive difference to health and care in our region and beyond.

## 3.2 Our values

Our commitment to public involvement and engagement springs from our values as a university.

**We are inclusive:**

* We believe that everyone counts, and this includes the people who are the focus of our research. We welcome and encourage people from all walks of life to get involved in research.

**We are empowering:**

* We work in a respectful and collaborative way that enables people to share their knowledge and experiences and have a meaningful voice in our research.

**We are progressive:**

* We involve people to help us focus on the benefits of our research for our communities, and carry out our research in an open, transparent, and ethical way.

## 4 Purpose of public involvement and engagement

The purpose of involving people with lived experience, carers, families and the wider public is to make sure that our research focuses on what really matters to people with lived experience of mental health, addictions and services. We want our research to meet the needs of our communities and address the inequalities that exist in health and care outcomes and access to services and treatments across our region.

Public involvement and engagement will help us to:

* improve the quality of our research
* hear the voices of those who are often under-represented in or excluded from research, and
* learn from each other and value different kinds of knowledge

Our approach will be relevant and important to the public and carried out in ways that are sensitive and acceptable. We want to create clear and meaningful research materials and share our findings with the wider public in ways that make sense to them. Public involvement can help us to do all these things more effectively.

## 5 Aims and objectives

This strategy describes how we will embed active public involvement and engagement throughout the research process, from the early development of research ideas to the dissemination of research findings. We want people with lived experience, carers, families and users of services to have a voice in shaping our research from the earliest stage. This will include all types of research, from PhD studies, to fellowships, to grant-funded research projects and programmes, across all the research groups, centres and clusters within our centre. We want this to become a simple, normal, universal part of the way that we do research in the Centre for Addiction and Mental Health Research at the University of Hull.

Below describes the PPI support we will provide to different research studies:

* For studies, including PhDs, carried out under CAMHR, all stages of the application will be supported.
* Studies outside of CAMHR will be supported at the second stage of application and beyond, dependent on budget and capacity.
* PhD students will be supported at the second stage of application.
* We will support facilitation of all PPI groups, however funding outside of CAMHR, will need to cover payment for participants time and expenses, e.g. travel, refreshments.

Our objectives are set within the framework of the [UK Standards for Public Involvement](https://sites.google.com/nihr.ac.uk/pi-standards/home). The standards cover: inclusive opportunities; working together; support and learning; communication; impact; and governance. Our approach to public involvement will follow the [NIHR Guiding Principles](https://www.nihr.ac.uk/research-funding/global-health/community-engagement-and-involvement).

## 5.1 Inclusive opportunities

We will ensure that opportunities for involvement and engagement are accessible and meaningful to the people and groups that are affected by our research and who we need to involve. We will be proactive and flexible in our approach and aim to work with the right people for each research project. We will not simply work with people that we already know just because this is easier to do. We will take practical steps to address the barriers people face to getting involved in research, reaching out to community groups and networks to help us do so. As part of this commitment, we will.

* reimburse people’s expenses and offer fees to thank them for their research activities with us,
* recruit young people and adults with lived experience of substance use/addiction and mental health,
* engage with underrepresented communities within our research and public involvement,
* meet with the public in their own communities to prevent barriers to participation,
* offer a range of methods/venues for the public to engage with the research so that this is accessible for all who choose to take part,
* engage with professionals working with lived experience groups to understand the needs for engagement and prevent potential barriers, and
* host events to promote all research engagement opportunities.

## 5.1.1 Young Internships

As part of our patient and public involvement, we will recruit paid Young Interns with lived experience throughout different periods of the award. This will enrich the public involvement within the research by having young people with real life experience working alongside the team and providing first-hand perspectives. The Internships will offer opportunities for young people to gain skills and experience that will equip them as they move forward in life.

We will ensure that the recruitment process is carried out openly and transparently, removing any potential barriers that may exist to employment for young people with lived experience. Throughout these Internships, the Young People’s PPIE Co-ordinator will provide a high level of support and supervision and ensure that a thorough training and development plan is in place for each Intern.

The Interns will utilise their lived experience in supporting the PPIE Co-ordinators to work with the Lived Experience Advisory Groups. They will additionally support the continuous review and development of this strategy to ensure young people’s experiences are embedded within our PPIE approach.

## 5.2 Working Together

We will work together in a collaborative and open way, respecting the contribution that people with lived experience, families and stakeholders bring to research. This approach will underpin how we manage and undertake public involvement and engagement. We will challenge each other where we feel there is a tick box approach to public involvement and engagement. We will encourage the development of ongoing dialogue and working relationships between researchers and public contributors to build long term, reciprocal relationships. This is a shared responsibility.

* We will work with the Lived Experience Advisory Groups to develop a Terms of Reference around what group involvement entails
* We will create a welcome pack and ‘induction’ to be completed with all new group members
* We will involve Lived Experience Advisory Groups in the annual review of the PPIE strategy
* We will develop shared communication channels to bridge the gap between the public and researchers, and ensure the public are aware of all involvement opportunities
* We will liaise with stakeholder groups on public involvement processes and activities to ensure meaningful engagement with lived experience groups

## 5.3 Support and learning

We will approach public involvement and engagement as a process of mutual learning in the development of better research. We will offer a clear point of contact for support, advice and information, both for public contributors and researchers, making sure that support and learning is tailored to the needs of each individual. We will use diverse methods to support people and help them learn, and our approach will be informed by continuous feedback and reflection.

* We will assess learning and training needs for each individual taking part in public involvement and offer relevant development opportunities
* We will offer introductory workshops/training around public involvement and research based on a needs-led assessment
* We will allocate time at the end of each PPI session to support the wellbeing of the public as needed
* The PPIE Co-ordinators will have personalised training and development plans to ensure they are carrying out their role effectively
* We will engage with PPIE Network’s regionally and nationally to implement peer learning and reflection
* Regular supervision for PPIE Co-ordinators, including debriefing opportunities in distressing situations
* We will develop and integrate public involvement training for new research staff as part of their induction
* We will produce a clear list of available services that can offer support for public involvement groups. We will include this in the induction and provide a copy at all sessions. PPIE Co-ordinators will debrief individuals at the start of all sessions.

## 5.4 Communication

We will use respectful, inclusive and everyday language to communicate with the public, when we are involving them as public contributors, encouraging them to take part in research as participants, and explaining the findings of our research. We will make it our responsibility to improve public understanding and engagement with research. If involving the public is difficult, we will reflect on our approach and our communication and change our practice. We will follow the guidance outlined in the University of Hull Research Inclusion Strategy.

* We will offer various methods of contact for the public to reach the PPIE Co-ordinators and liaise with researchers through all stages of involvement
* All our forms of communication will be written in accessible formats
* We will ensure there are allocated funds for translation services so that there are no barriers to participation
* We will ensure that researchers are using accessible language and formats when working with the public and that Plain English Summaries are easy follow
* PPIE Co-ordinators will bridge any gaps between communication with the public and research
* We will allocate set time for reflecting after all public involvement communications to determine effectiveness and needs for future development

## 5.5 Impact

We will develop simple ways for public contributors to share feedback about their experiences of being involved in our research. Alongside this we will expect all researchers to evaluate their public involvement and engagement, including both positive and challenging aspects, and reflect on its contribution to their development as researchers and to knowledge exchange. We will periodically collate and assess this evidence and share our learning across the research institute.

* We will offer the opportunity for the public to evaluate and give feedback on their experiences of each session
* Upon the end of the research, we will co-create a piece of work that demonstrates the impact that public involvement has had on the groups
* We will produce annual reports for PPIE including case studies to demonstrate impact
* We will share best practice at events with other PPIE Co-ordinators and take on board learning from others
* We will support groups to co-produce ways of interpreting and presenting research findings in a way that is accessible to the public

## 5.6 Governance

We will establish clear accountability and resources for public involvement and engagement within our research institute and work towards placing this on a sustainable basis. We will include public representatives on the CAMHR independent steering group and study management groups for research projects and programmes. We will also work towards including public representatives on the CAMHR Strategy Board and the CAMHR Patient and Public Involvement Group.

* Development of Standard Operating Procedures (SOPs), including onboarding, database management, demographics, progress monitoring
* Development of policies, including safeguarding, confidentiality, risk management, payment, complaints, lone working
* Monitor and track PPI budget and report to Team Leader

## 6 Delivering our objectives

The following principles will guide the way we work and deliver our objectives:

* We will respect the experience, knowledge, and opinions of others, regardless of their role or status
* We will approach public involvement and engagement as a dialogue where researchers and public contributors share knowledge and expertise
* We will work collaboratively with a range of university, public and community partners
* We will communicate clearly and openly, using a range of methods and channels
* We will build trust in our working relationships by saying what we mean and doing what we say
* We will be proactive, creative, questioning, and constructive
* We will learn by doing and reflecting on our practice
* We will aspire to progress from consulting the public to working in partnership with them

## 7 Action Plan

|  |  |  |
| --- | --- | --- |
| **Objectives** | **Activity** | **Timing** |
| **Inclusive** | Develop Lived Experience Advisory Groups (LEAG) | 2024/2025 |
| **Opportunities** | Develop EDI checklist for carrying out PPI activities | 2024/2025 |
|  | Identify barriers to engagement to ensure opportunities are inclusive for all | 2024/2025 |
|  | Engage with stakeholders and existing Lived Experience Groups to explore barriers to engagement | 2024/2025 |
|  | Engage with communities to build relationships with existing groups before developing the LEAGs | 2024/2025 |
|  | Recruit two Young Interns with lived experience | 2024/2025 |
| **Working Together** | Co-produce LEAG documents e.g. Terms of Reference, Welcome Pack and Induction, Annual Review of Strategy | 2024/2025 |
|  | PPIE Co-ordinators to work in partnership with stakeholders, e.g. attending events to keep up to date with current support services and presenting issues | 2024/2025 |
| **Support and** | PPIE Co-ordinators to seek out peer support networks for best practice | 2024/2025 |
| **Learning** | Develop training needs analysis to identify training and developmental needs for PPI Groups | 2024/2025 |
|  | Deliver public involvement training as part of the induction for new research staff as required | 2024/2025 |
| **Communication** | We will provide monthly updates in Theme and PMG meetings, and quarterly updates to the Strategic Advisory Group | 2024/2025 |
|  | Provide feedback to lived experience groups about the impact of their involvement in the research. | Ongoing |
|  | We will support the Young Interns to develop a monthly newsletter for the CAMHR website and LEAGs | 2024/2025 |
| **Impact** | Develop impact and evaluation forms to be completed by LEAGs | 2024/2025 |
|  | Produce annual reports and case studies to demonstrate impact, co-produced with LEAGs | Ongoing |
|  | Share best practice at events with other PPIE Co-ordinators and stakeholders | Ongoing |
| **Governance** | PPIE Representative appointed to the CAMHR Independent Steering Committee | 2024/2025 |
| Develop Standard Operating Procedures (SOPs) for PPI processes, e.g. privacy statements, members database, onboarding new members, consent (YP) | 2024/2025 |
| Establish annual review and evaluation to drive improvements, monitor goals and progress, and address areas of development | 2024/2025 |
| Develop policies for PPI including safeguarding, confidentiality, risk management, payment, complaints, lone working | 2024/2025 |

## 8 Accountability and reporting

All research theme groups have PPIE co-ordinator representation, with the PPIE Action Plan being reviewed 6 monthly within the overarching Project Management Group. Reports will also be received by the Centre for Addiction and Mental Health Research Independent Steering Committee. Additionally, CAMHR PPIE Co-ordinators will provide updates to the ICAHR PPIE Committee. We will provide a range of opportunities for the public to be involved in feedback sessions, such as teatime talks, webinars, and attending community groups. This will ensure those who have taken part in PPI activities understand what has been done with the information they have provided and the impact of this. It will also allow those involved to provide any additional feedback on their public involvement experiences.

To ensure that the PPIE activities are sustained, we have a separate budget within CAMHR that is monitored by PPIE Co-ordinators and feeds into the finance reporting structure for the centre.

## 9 Further information

For more information about this strategy, please contact:

* Ayisja Moss (Young People) or Sarah Capes (Adults) on [CAMHR\_PPI@hull.ac.uk](mailto:CAMHR_PPI@hull.ac.uk)

## 9.1 Contributors

* Lead Authors – Ayisja Moss and Sarah Capes, PPIE Co-ordinators, Centre for Addiction and Mental Health Research

The following individuals contributed to the development of this strategy:

* Helen Roberts, PPI Co-ordinator, Involve Hull
* Professor Thomas Phillips, Director of the Centre for Addiction and Mental Health Research and Professor of Nursing
* Dr Philippa Case, Senior Research Fellow
* Dr Rachel Coleman and Dr Tyler Mills, Research Fellows
* Professor Judith Cohen, Co-director of the Centre for Addiction and Mental Health Research, Director of Hull Health Trials Unit
* Alison Sharpe, Public Co-Applicant
* Members of Involve Hull, Patient and Public Involvement Network
* Document was reviewed by CAMHR Programme Management Group and NIHR Mental Health Research Group oversight team

## Target Organisations

* Humber & North Yorkshire Integrated Care Board
* Addiction Services
* Mental Health Services
* Commissioners
* NHS Humber & North Yorkshire Trust
* Local Authority Youth and Adult Services
* Voluntary, Community & Social Enterprise Services
* Schools
* Memory Services
* Emergency Department Services
* Police
* Primary Care
* Youth & Criminal Justice Services

This list is not exhaustive, but details organisations we aim to target for patient and public involvement.