



# Strategy for public involvement in health and care research 2022 - 2024

## 1 Executive summary

This document sets out the Public Involvement Strategy for the Institute for Clinical and Applied Health Research (ICAHR) at the University of Hull, including for the Transforming Cancer Outcomes in Yorkshire research programme (TRANSFORM). The strategy has been developed in collaboration with researchers, and members of our public involvement network, Involve Hull.

## 2 Introduction and background

### 2.1 Institute for Clinical and Applied Health Research

Our research institute was launched in March 2019 to bring together experts from the University of Hull's Faculty of Health Sciences and Hull York Medical School. We are a hub for collaborative health research in the fields of medicine, nursing, midwifery, sport and exercise, psychology, sociology and social work.

We carry out clinical research into the causes of human illness, and how it can be prevented, treated or managed. We also carry out applied research so that we can solve real world health problems and create direct benefits for patients.

We carry out research in four main areas:

- Living with long term conditions
- Palliative care
- Primary care
- Women's public health

We work closely with researchers in the Centre for Clinical Sciences at Hull University Teaching Hospitals (HUTH) who specialise in:

- Cancer
- Cardiology
- Diabetes and endocrinology
- Respiratory conditions
- Vascular conditions

You can find out more about our research groups on our website here:

<https://www.hull.ac.uk/work-with-us/research/institutes/institute-for-clinical-and-applied-health-research/our-work>

## 2.2 Transforming cancer outcomes in Yorkshire (TRANSFORM) programme

Our largest research programme is about transforming outcomes for people living with cancer across Yorkshire and the Humber. The TRANSFORM programme began in 2018 and is funded by Yorkshire Cancer Research. You can find out more about this on our website here: <https://www.hyms.ac.uk/research/transform>

## 3 Our values and vision

### 3.1 Our values

Our commitment to public involvement 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.

### 3.2 Our vision for public involvement

We want to involve patients, carers, families and local communities as active partners in our healthcare research, so that together we can make a positive difference to health and wellbeing in our region and beyond.

## 4 Purpose of public involvement

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

Public involvement helps 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

We want our work to 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 of these things more effectively.

## 5 Aim and objectives

This strategy describes how we will embed active public involvement throughout the research process, from the early development of research ideas to the dissemination of research findings. We want patients, carers and users of health and care 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 of the research groups, centres and clusters within our research institute. We want this to become a simple, normal, universal part of the way that we do research in Health Sciences at the University of Hull.

Our objectives are set within the framework of the UK Standards for Public Involvement. The standards cover: inclusive opportunities; working together; support and learning; communication; impact; and governance. You can find more information about the standards on this website: <https://sites.google.com/nihr.ac.uk/pi-standards/home>.

### 5.1 Inclusive opportunities

We will ensure that opportunities for involvement 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.

### 5.2 Working together

We will work together in a collaborative and open way, respecting the contribution that patients, carers and users of services bring to research. This approach will underpin how we manage Involve Hull, as well as how we undertake public involvement in individual projects. We will challenge each other where we feel there is a tick box approach to public involvement, and we will encourage the development of ongoing dialogue and working relationships between researchers and public contributors. This is a shared responsibility.

### 5.3 Support and learning

We will approach public involvement 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.

### 5.4 Communication

We will use everyday language and accessible formats 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.

## 5.5 Impact

We will develop simple ways for public contributors to share feedback about their experiences of being involved in our research, both as members of Involve Hull, and in individual projects. Alongside this we will expect all researchers to evaluate their public involvement, 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 and Involve Hull.

## 5.6 Governance

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

# 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 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

Yorkshire Cancer Research currently funds the full-time role of Patient and Public Involvement Coordinator through the TRANSFORM research programme, as well as our budget for pre-award patient and public involvement in cancer related research within our research institute. This funding will end in 2024.

We also have a fund for pre-award public involvement in developing research grant applications, available to researchers in the wider Faculty of Health Sciences. This makes small grants throughout the year.

Public involvement in PhD studies is funded for those with university or other scholarships.

Post-award public involvement is funded directly from research grants.

We work in partnership with colleagues across the University, the Medical School, and Hull University Teaching Hospitals, as well as Humber and North Yorkshire Cancer Alliance, the

local clinical commissioning groups, Healthwatch, Hull CVS, Forum, Humber All Nations Alliance and a range of other voluntary sector and community groups, and health charities.

## 7 Action plan

We will focus on these core elements of the UK Standards for Public Involvement during 2022 to 2024 as these are the areas in which we have the most work to do:

- impact,
- working together and
- governance.

We will assess our progress against the UK Standards as a whole on an annual basis from the 2022/2023 academic year onwards.

	Activity	Completion
<b>1 Impact</b>		
<b>1</b>	Agree a set of standard metrics for use across all research projects, including for measuring the extent of equality, diversity and inclusion in public involvement	2022
<b>2</b>	Develop a report template and set of reflective questions for evaluating public involvement at regular points throughout a research project	2022
<b>3</b>	Create two model feedback surveys, one for researchers and one for public contributors	2022
<b>4</b>	Gather feedback from funding body review panels about public involvement plans in research grant applications	2022
<b>5</b>	Establish reporting routes and frequency for evaluation reports	2022
<b>6</b>	Develop and implement an evaluation form for doctoral students within the TRANSFORM programme	2023
<b>7</b>	Publish illustrated case studies of public involvement on the Involve Hull webpages	2023
<b>8</b>	Create a podcast series of conversations with researchers and public contributors	2023
<b>9</b>	Set up an interview study to capture the learning from researchers and public contributors who have collaborated on the TRANSFORM programme	2024
<b>2 Working together</b>		
<b>1</b>	Set up a regular events programme for Involve Hull, to include talks by researchers and informal drop in sessions for members and researchers to get to know each other	2022
<b>2</b>	Include public involvement themed seminars within the ICAHR lunchtime seminar series, so that researchers can share their learning with each other	2022
<b>3</b>	Develop a grant application in response to the funding call from the NIHR Programme Development Grants Scheme: developing innovative, inclusive and diverse public partnerships	2022

	Activity	Completion
4	Offer training in Plain English for researchers outside the TRANSFORM programme, and training in collaborative working for researchers and public contributors	2023
<b>3 Governance</b>		
1	Develop a model plan for public involvement in the governance of research studies and trials	2022
2	Develop a model role description, criteria and selection process for public members of study steering committees and study management groups	2022
3	Include public / community representation on the ICAHR Strategy Board	2023
4	Develop a way for members of Involve Hull to have a voice on the ICAHR Patient and Public Involvement Group	2023
5	Develop ways to involve the local community in setting our research agenda and priorities, with a view to reaching those who are normally under-represented in health and care research	2024

## 8 Accountability and reporting

The Patient and Public Involvement Coordinator is responsible for delivering, monitoring, and reporting on the strategy in collaboration with colleagues on the ICAHR Patient and Public Involvement Group. The Patient and Public Involvement Coordinator reports to the ICAHR Operational Group. The ICAHR Academic Lead reports on public involvement to the Faculty of Health Sciences Research Committee and the ICAHR Strategy Board. Progress is reported annually in respect of the action plan.

Responsibility for delivering, monitoring, and reporting on public involvement in research programmes, projects and PhD clusters is devolved to the principal investigator, PPI lead, supervisors, or other member of the research team.

## 9 Further information

For more information about this strategy, please contact:

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Information about our patient and public involvement network Involve Hull is available on [our website](#). Follow us on Twitter at @HullInvolve.