



Leicester Biomedical  
Research Centre

National Institute for  
Health Research

# Public and Patient Involvement in Research for the NIHR Leicester Biomedical Research Centre



We turn scientific discoveries into better healthcare for patients

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# DEFINITIONS

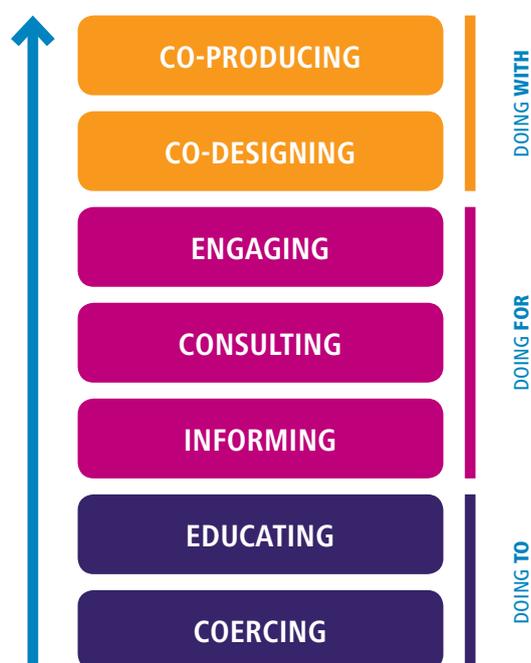
This strategy is about public awareness of research and public involvement and engagement in research. The terms used throughout the strategy are based on the definitions by INVOLVE, the National Advisory Group funded by the National Institute for Health Research that seeks to advance public involvement as an essential part of research:

**Awareness:** Where we make people aware of the role and importance of research, and of the research taking place locally. Awareness underpins all aspects of research but most importantly recruitment, engagement and involvement.

**Engagement:** Where information and knowledge about research is provided and disseminated, for example, at science festivals or open days, or through media coverage.

**Involvement:** Involvement in research refers to active involvement between people who use services (for example, patients and carers) and researchers, rather than the use of people as participants in research (or as research 'subjects').

Many people describe involvement as doing research **with** or **by** people who use services (rather than **to**, **about** or **for** them). This takes place on a spectrum; from consultation, where we ask people what they think about our research plans, to co-production, where the public actively participates in the development and delivery of the research. Co-production may be limited to parts of the research. For example, when developing a new lifestyle intervention, co-production might involve members of the public helping to make the decision on the subject of research (often called a 'priority setting exercise'), or becoming co-investigators on the research project.



Source: New Economic Foundation

**Recruitment:** Where people take part in research projects as research participants.

**NOTE:** When using the term 'public', we include patients, potential patients, carers, members of the general public and people who use health and social care services. While all of us are actual, former or potential users of health and social care services, an important distinction needs to be made between the perspectives of the public and the perspectives of people who have a professional role in research or healthcare.

# CONTEXT

## THE LEICESTER AND LOUGHBOROUGH RESEARCH FAMILY



Leicester and Loughborough have a long-standing commitment to research that has led to the development of a number of research units in the area. These generally comprise a variety of partnerships between:

**The University Hospitals of Leicester NHS Trust:** Leicester is a world leader in many specialty areas with many prominent researchers. Research and innovation is identified as an area of importance in the Trust's strategy. The Trust continues to create new state-of-the-art facilities (such as a Children's Research Space), to develop its existing capabilities, and to enhance its research portfolio. The Trust is fortunate to host several National Institute for Health Research bodies along with its academic partners, the Universities of Leicester and Loughborough: the NIHR Leicester Biomedical Research Centre, the Clinical Research Network, and East Midlands and Collaboration in Leadership for Applied Health Research and Care (CLAHRC) East Midlands. The Trust also has Experimental Cancer Medicine Research Centre status and as the result of Leicester achieving Cancer Research UK Centre status, the HOPE Unit is vital in the delivery of its research.

**The University of Leicester:** An academic partner with a long standing relationship with the University Hospitals of Leicester NHS Trust, specialising in health science, the University of Leicester is particularly famous for its work in genetics and precision medicine.

**Loughborough University:** An academic partner specialising in sports, preventative medicine and engineering, and notably hosting the National Centre for Sports and Exercise Medicine, Loughborough University is a key partner in prevention and education research.

The research groups and partnerships include:

**The NIHR Leicester Biomedical Research Centre:** The NIHR Leicester Biomedical Research Centre is a partnership between the University Hospital of Leicester NHS Trust, Loughborough University and the University of Leicester. It creates a clear pathway from bench to bedside so lab research can reach patients quickly and easily. The Leicester Biomedical Research Centre provides labs, offices, equipment, staff and expertise so research can happen. It helps researchers build partnerships with lots of different types of experts including scientists, clinicians, health economists, statisticians, the IT team, and importantly with people who are experts by experience.

The NIHR Leicester Biomedical Research Centre evolved out of the three NIHR Biomedical Research Units. All three units invested heavily in facilities, computer systems, equipment and staff to support research.

- **The NIHR Leicester-Loughborough Diet, Lifestyle and Physical Activity Biomedical Research Unit** was funded in 2012, to explore and develop innovative lifestyle interventions to help prevent and treat chronic disease. It was a collaboration between both local universities (Loughborough and Leicester) and University Hospitals of Leicester.
- **The NIHR Leicester Cardiovascular Biomedical Research Unit** did research to improve the diagnosis, prognosis and treatment of cardiovascular diseases. It was initially funded in 2009 and received a further five years' funding in 2012. The unit is shared with the new BHF-funded Cardiovascular Research Centre.
- **The NIHR Leicester Respiratory Biomedical Research Unit**, funded in 2012, focuses on promoting the development of new and effective therapies for the treatment of respiratory diseases, including severe asthma and chronic obstructive pulmonary disease (COPD).

**The NIHR Clinical Research Facility:** The Clinical Research Facility provides facilities, technical staff and nursing staff to work in clinical trials.

**The Leicester Precision Medicine Institute:** The Leicester Precision Medicine Institute is a partnership between the University of Leicester, University Hospitals of Leicester NHS Trust and industry. It does research about: genetics, how the body works chemically, using technology to measure health, using medical imaging and especially new types of imaging in research, and using data from medical records in research.

**The Centre for Black and Minority Ethnic Health:** The Centre for Black and Minority Ethnic Health does research to help reduce health inequalities, shares research findings with communities, puts research into practice and improves representation of communities in research.

**The NIHR Collaboration for Leadership in Applied Health Research and Care:** There are thirteen Collaborations for Leadership in Applied Health Research and Care across the UK. The East Midlands Collaboration does research about preventing long-term health problems, managing long-term health problems, care for older people and those who have had stroke, improving mental health, and using research to improve healthcare.

# SCOPE

Whilst the NIHR Leicester Biomedical Research Centre works with all the local research groups and partnerships this strategy applies to the NIHR Leicester Biomedical Research Centre between April 2017 and March 2022.

Revision Record:

There are no revisions to detail at this time.

# LINKING TO BRC STRATEGY

This strategy covers involvement and engagement for the NIHR Leicester Biomedical Research Centre. It is important to consider the role of public involvement and engagement in the context of the strategic goals of the Biomedical Research Centre.

Goal	Public Involvement
Getting healthcare and research to work together	<p>We will work to make people aware that research leads to, and is an important part of developing quality healthcare. We will support people accessing healthcare to take part in research.</p> <p>We will work with the public to develop approaches that bring healthcare and research together, ensuring that research is quickly turned into better care and that people accessing healthcare can take part in research easily.</p>
Making sure we have the facilities and equipment to do good research.	<p>We will work with the public to develop research facilities in which people feel comfortable and welcome. We will involve the public to ensure that we are using our funding in an acceptable way. By ensuring the public are our partners and have an equal voice in our research priorities we will be able to direct investment in line with their priorities. We will also work to ensure we hear all voices and especially those which are under-represented, including those with rare diseases.</p>
Making sure we have the people, information and resources we need to do good research.	<p>People with lived experience are as important to research as scientists, nurses and doctors. With their help and support:</p> <ol style="list-style-type: none"> <li>1. our research is more accessible to participants</li> <li>2. research is done in ways that make it as easy as possible to take part</li> <li>3. the treatments we research are more likely to be effective in the real world.</li> </ol>
Developing the skills and leadership for future research.	<p>The active role of people with lived experience in our research groups will prepare the researchers of the future to do great research in partnership with the public. This will make sure their research meets the public's needs and that they develop treatments people will use.</p>
Working with charities, businesses and groups to get the most out of our research.	<p>In many cases, the charities and groups we need to work with include large numbers of members of the public, for example, Take Heart Leicester and Diabetes UK. These groups help us get a broad range of opinions and advice about our research, and allow us to find people who would like to get more involved in planning, producing and doing research. These groups often play an important role in identifying research priorities using priority-setting exercises, like that recently done by Diabetes UK and those done by The James Lind Alliance.</p>

# DEVELOPING OUR STRATEGY FOR PUBLIC INVOLVEMENT AND ENGAGEMENT

This strategy builds on the previous work of the three Biomedical Research Units. That strategy was developed in partnership with INVOLVE and was endorsed by them in 2012.

This strategy was initially drafted in August 2017. It was circulated to the involvement groups that have been built up by the research groups over the last decade and the final version was produced in February 2018.

The strategy was notably guided by NIHR Policy, including Going the Extra Mile and the (draft) guidelines for coproduction. The NIHR key priorities for delivery in 2018-19 are:

- **Standards:** To define what good public involvement and engagement looks like.
- **Impact / Getting Results:** To understand and show the value of public involvement and engagement.
- **Invention:** To test new ideas in public involvement and engagement and share the learning.
- **Voice:** To ensure patients, carers and the public have a voice in how the NIHR works.
- **Feedback:** To ensure patients, carers and the public get feedback on how they have made a difference.

# RESOURCES

The NIHR Biomedical Research Centre has a half-time Public Involvement Manager. There is an annual budget of £8775 for public involvement. The Public Involvement Manager is supported by the research teams who take an active role in delivering their own public involvement. The Public Involvement Manager is also supported by PR and Communication colleagues in the Trust and the Leicester Diabetes Centre.

# PRINCIPLES, AIMS AND OBJECTIVES

The NIHR Leicester Biomedical Research Centre is committed to raising awareness of research and to public engagement and involvement that ensures people have an opportunity to contribute to the research agenda strategically and operationally. Our work is based on a series of principles and delivered through objective-based workstreams. Workstreams may overlap between awareness raising, involvement and engagement.

## Principles:

Research is valuable and it contributes to health and wealth. We will continue to communicate about our research in diverse and accessible ways, particularly to those in our healthcare facilities, to promote the role of the hospitals as research centres. We will publicise our work, including where we discover that interventions do NOT work, through press releases, media and social media, and routine production of research findings in plain English.

We are a research hospital. We embrace and support research, and people using our facilities are encouraged to find out about the research happening here. We work with the NIHR to deliver national campaigns like 'I am Research', and we encourage clinicians to talk to their patients about research.

Research is for everyone. We build good relationships with the communities of Leicester to ensure that everyone receives equally good healthcare. We recognise that health inequality and research inequality are linked, and we actively seek to ensure this ends. This means investing in reaching seldom-heard communities.

Research is accountable to the public through diverse involvement opportunities. We hold our professionalism to account and our research and research processes are transparent. Lay representatives are involved in our research throughout the governance structure from study-specific activity to the Biomedical Research Centre Board. Their concerns, ideas, support and input are documented and our responses recorded and available to the public and the NIHR.

Research has real impact. We recognise that healthcare research impacts people's lives in real ways. We will develop our public involvement to ensure we don't just involve people who are easily available but actively reach out to the people who will be affected by our work. We recognise this can be low-yield, challenging work and will assess involvement in terms of quality and relevance.

Public involvement and engagement, and raising awareness about research are based on a limited evidence base that needs to be developed. We will ensure that activity is evaluated for quality, impact and relevance. We will contribute to sharing good practice in the wider NIHR family and building the evidence base by developing an academic contribution to the field.

Objective-based workstreams:

1. Raise awareness of research and the work of local research groups, and increase participation in research.
2. All non-commercial research will have a simple study-specific public involvement and engagement plan (recommended based on PIIAF), and will deliver on public involvement throughout the study lifecycle. Where possible, this will also apply to commercial research and we will encourage commercial partners to recognise the value and importance of meaningful public involvement.
3. Develop co-production in research.
4. Develop the roles of Co-Investigators and Public Representatives.
5. Seek improvements in involvement and engagement and contribute to the evidence base.

These are mapped the NIHR key priorities for 2018-19, as follows:

BRC Workstream	Related NIHR Priorities
Raise awareness of research and the work of local research groups and increase participation in research	Transparency ensures that people are aware of our work and can therefore have a <b>voice</b> and influence our work.
All non-commercial research will have a simple, study-specific public involvement and engagement plan (recommended based on PIIAF), and deliver on public involvement throughout the study lifecycle. Where possible, this will also apply to commercial research and we will encourage commercial partners to recognise the value and importance of meaningful public involvement.	These processes will continue to adapt to the recognised <b>standards</b> of NIHR involvement. They measures <b>impact</b> to help inform these standards and local practice and allows us to test <b>inventive</b> approaches to involving the public. This is essential to ensuring that the public <b>voices</b> are not just heard but responded to meaningfully. Activity in this workstream includes providing <b>feedback</b> .
Develop co-production in research.	
Develop the roles of Co-Investigators and Public Representatives.	
Seek improvements in involvement and engagement and contribute to the evidence base.	The key focus of this workstream is assessing <b>inventive</b> approaches to public involvement and measuring the effectiveness and <b>impact</b> of these. This is fundamental to the development and updating of <b>standards</b> in public involvement.

# OBJECTIVE 1: RAISING AWARENESS

Raise awareness of research and the work of local research groups and increase participation in research.

We recognise that most people do not know that the NHS does research or why research is important, and that there is a need for greater transparency to avoid any recurrence of problematic situations like that of the care.data scheme. This will be beneficial to research in many ways; encouraging young people to train for careers in science, encouraging people to adopt healthy lifestyles based on scientific insight, and encouraging people to take part in research.

In respect of raising awareness, our Public and Patient Involvement Group has identified several key audiences with whom we need to engage, and key messages we need to communicate.

BRC Workstream	Related NIHR Priorities
Seldom heard communities	<p>We want to learn more about your community and its relationship with health and science.</p> <p>We want to build community and start new conversations.</p> <p>People like you perform and take part in research.</p> <p>Research is culturally relevant to you.</p>
People using our clinical provision	<p>Your healthcare today was brought to you by research participants (Research Changed My Life).</p> <p>You can help without doing anything (much), for example, giving us consent to access your medical records or to use leftovers from your blood tests.</p> <p>You can help by <i>taking part</i> in research as a research participant or by getting <i>involved</i> in research (e.g. joining our Public and Patient Involvement Group or attending a focus group to help design a piece of research).</p>
The person on the street	<p>Research leads to better healthcare.</p> <p>Research can save the NHS money.</p> <p>Research has led to these advances...</p> <p>You can take part in research.</p>

## OBJECTIVE 2: DELIVERING STUDY-SPECIFIC PUBLIC INVOLVEMENT

All non-commercial research will have a simple, study-specific public involvement and engagement plan (recommended based on PIIAF), and will deliver on public involvement throughout the study lifecycle. Where possible, this will also apply to commercial research and we will encourage commercial partners to recognise the value and importance of meaningful public involvement. .

Activity	Purpose	How do we know we're getting it right?
Complete a simple plan of study-specific need for public involvement with a focus on finding the 'right' people, not just the 'available' people.	This will ensure that we talk to the people affected by our research and that public involvement is purposeful and can be evaluated in light of the study-specific aims.	All non-commercial research projects will have an involvement plan identifying who they need to talk to, and about what (PIIAF is the recommended format).  All non-commercial research projects will have an assessment plan so we can work out how well we're doing in terms of public involvement and how we can improve.
Support a range of Public Involvement Groups to help meet study-specific needs. These currently include: <ul style="list-style-type: none"> <li>• Diabetes Education.</li> <li>• AAA.</li> <li>• Cardiovascular.</li> <li>• Respiratory.</li> <li>• Young Adults with Type 2 Diabetes.</li> </ul>	This enables people with an interest in a particular area of research to find out more about it and also help researchers develop their study-specific involvement plans. It supports us to build community and relationships beyond specific research projects.	Each of the groups listed will meet at least twice a year (some considerably more often).  The membership of the groups will increase in both number and diversity.  Focus group activity will not be duplicated as these groups hold our organisational memory.
Develop a large pool of volunteers who help with study-specific focus groups according to their particular experiences and interests.	Researchers often need to speak to people affected by the most common disease areas we research. Having a large pool of 'in-demand' people who are willing to help with focus groups is cost effective.	Where appropriate to study-specific need, focus groups can be held to address the topics on which researchers want advice.  Information from focus groups can be used to inform outreach and 'armchair' involvement.
Reach out to the people affected by our research to gain a deeper understanding of the public perspective on our research and access more diverse opinions. This might be through micro-interviews at a village fete or going to a special interest or community group to ask questions and hear their thoughts and experiences.	Involvement Groups and the pool of focus group volunteers offer the perspective of a limited number of people on our research and often the people who take part in these activities are not representative of the general population or the specific people affected by our research. We can gain a greater depth of insight by using outreach as well.	Ideas from focus groups or the Public Involvement Groups are checked against a wider, disengaged group where appropriate.  Community is built as we develop a presence in the diverse communities of Leicester.

Activity	Purpose	How do we know we're getting it right?
<p>Share our research findings according to the ethical approval for the research project, the needs of the study-specific assessment, and public interest, and in order to raise awareness of research generally and our research in particular.</p>	<p>It is important that people know what we discover because we are accountable to the public for the use of public funds. Sharing our discoveries also help get people excited about science, research and health.</p>	<p>Research findings are shared in plain English. As a minimum, findings are shared with research participants, sometimes through a feedback event.</p> <p>Findings are shared with the public, e.g. with the communities affected, mailed out to patients with a particular condition, or made available in clinical areas.</p> <p>Press releases are produced and both these and plain English summaries are shared via our media/social media and that of our colleagues and stakeholders.</p> <p>Researchers engage with the media with the support of the hospital and university communication teams.</p>

## OBJECTIVE 3: DEVELOPING CO-PRODUCTION IN RESEARCH

The Biomedical Research Centre will continue to work with Co-Investigators who are experts by experience, where this is meaningful. We will work to develop the role and individuals in these roles fully. Co-production is already quite common in the Lifestyle Theme of the Biomedical Research Centre and will be developed and supported. Adoption in the Cardiovascular and Respiratory Themes will be supported. We will work with local stakeholders to develop partnership working and build links to seldom-heard communities, and we will work with patients and the public to deliver the research they want.

Activity	Purpose	How do we know we're getting it right?
<p>Engage with the diverse communities of Leicester and Leicestershire through a range of projects and activities. Assess and evaluate the ability of these activities to challenge existing power dynamics, level the playing field, build relationships and community, and develop mutual cultural insight.</p>	<p>We will invest in building community, including with under-represented communities, simply for the sake of building community, creating relationships and levelling the playing field. This is not a recruitment exercise.</p>	<p>Researchers will engage in community building activities. Engagement will not focus on recruitment and involvement but simply on raising cultural awareness and building community.</p> <p>Members of the public will engage in community building activities and also raise their cultural awareness of health and science.</p> <p>Evaluation and feedback will indicate where there was shared learning and new knowledge created.</p> <p>Stakeholders not usually associated with health and science will engage with us, e.g. community arts groups.</p>
<p>Build networks of individuals, community groups and community leaders to reach out to the diverse communities of Leicester. This includes attending community events, running community events, maintaining communications, and developing partnerships.</p>	<p>This helps us to correct health inequalities that can be linked to research inequalities. Part of this does include work that supports recruitment in under-represented groups.</p>	<p>We will attend at least five community events every year.</p> <p>We will deliver at least one community engagement project every year.</p> <p>We will host at least one open day or public event each year.</p> <p>We will enable community groups to visit our facilities.</p> <p>We will deliver a series of public lectures.</p> <p>We will support the University Hospitals of Leicester public lectures.</p> <p>We will provide speakers for community and special interest groups.</p>

Activity	Purpose	How do we know we're getting it right?
<p>In the initial study-specific needs assessment, the opportunities for co-production will be explored and considered in the context of potential funding opportunities.</p>	<p>This ensures we continue to move public involvement forward into a more meaningful exercise.</p>	<p>The study-specific involvement plan will document the opportunities for co-production.</p> <p>Increasing numbers of research projects will incorporate co-production methods.</p>
<p>Co-production, involvement and engagement are incorporated early on in the bid stage of research.</p>	<p>This ensures that research is increasingly done in meaningful partnership with the people it affects. It helps correct the power imbalance between health and science, communities and individuals.</p>	<p>Study documentation will indicate that these have taken place.</p> <p>There is routine public involvement pre-bid.</p> <p>Increasingly, research projects feature co-production, Co-Investigators with lived experience, and Public Representatives.</p>

## OBJECTIVE 4: DEVELOP THE ROLES OF CO-INVESTIGATORS AND PUBLIC REPRESENTATIVES

We have a strong track record of working with Co-Investigators with lived experience and Public Representatives. We will continue to encourage research teams to work with experts by experience in this way and we will explore how to make the most out of these partnerships.

Activity	Purpose	How do we know we're getting it right?
<p>Studies large enough to have a Trial Steering Committee will include representatives from the public. These could be from a charity or special interest group, a Public Involvement Group, or simply a person with relevant experience.</p>	<p>This ensures transparency and accountability throughout the governance structure of the Biomedical Research Centre.</p> <p>We recognise the imbalance of power in this scenario and will work to understand this through research and subsequent action.</p>	<p>Trial Steering Committees will routinely include a member of the public.</p> <p>Consideration will be given to how this actively enhances the process of the Trial Steering Committee and who would be well-placed to deliver.</p> <p>The role of Public Representatives will be explored through research and findings shared through publication.</p>
<p>Co-Investigator roles will be properly resourced with study-specific funding for expenses, time, materials and training. Such will not usually be provided through the core budgets for the Biomedical Research Centre.</p>	<p>This will ensure that Co-Investigator Roles are not tokenistic and that public involvement is properly costed in bids.</p>	<p>Co-Investigators are paid (unless they specifically do not want to be) for their time and their expenses.</p>
<p>Co-Investigators and Public Representatives will have meaningful roles, specifically including tasks and decisions.</p>	<p>Co-Investigators and Public Representatives are genuine partners in the research process.</p>	<p>Study documentation will indicate where the Co-Investigator or Public Representative has led on a task or decision.</p> <p>Increasingly, role descriptions will be developed when we ask people to work with us in these roles</p> <p>Co-Investigators and Public Representatives will have a form of annual appraisal to identify their needs and explore how to grow their roles. This should be led by a senior member of the research team, but should be supported by the Public Involvement Manager.</p>

## OBJECTIVE 5: SEEK IMPROVEMENT IN INVOLVEMENT AND ENGAGEMENT AND CONTRIBUTE TO THE EVIDENCE BASE

The evidence base for public involvement and engagement offers some insights but there is a need to more fully investigate how we create meaningful and fulfilling involvement and high-quality engagement. Some of this can be achieved through systematic evaluation and some through targeted research into public involvement and engagement, co-production processes, and Co-Investigator and Public Representative roles.

Activity	Purpose	How do we know we're getting it right?
All study-specific involvement will be evaluated and an annual summary report will be provided to the Biomedical Research Centre Board with recommendations for improvement.	This will ensure continuous improvement and maintain a focus on quality.	<p>We produce publications about public involvement and engagement.</p> <p>We support staff to develop their skills to do research into public involvement and engagement.</p> <p>We support PhD students in exploring involvement and engagement.</p>
Public involvement, engagement and associated roles are researched by qualified staff, independently or as part of the research project they are taking part in.	This will ensure a growing body of evidence that informs national guidelines and good practice, and that involvement and engagement practices are considered critically.	<p>We produce publications about public involvement and engagement.</p> <p>We support staff to develop their skills to do research into public involvement and engagement.</p> <p>We support PhD students in exploring involvement and engagement.</p>
Our publications meet the GRIPP2 criteria and detail the public involvement and engagement that took place as part of the research.	By using the GRIPP2 criteria, we support the national standard for reporting the public involvement in research.	Researchers use GRIPP2 criteria in their publications.