

Leicester Cardiovascular Biomedical Research Unit

Leicester-Loughborough  
Diet, Lifestyle and Physical Activity  
Biomedical Research Unit

Leicester Respiratory Biomedical Research Unit

# Public and Patient Involvement in Research for the Leicester-Loughborough Biomedical Research Units



## Vision

To deliver research that changes healthcare in a way that ensures maximum impact and meaningfulness through the engagement and involvement of patients and the public.

## Definitions

This strategy is about both patient and public involvement (PPI), and patient and public engagement (PPE), in research.

## Involvement

INVOLVE defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This can include, for example, patients/the public working with research funders to prioritise research areas, sitting on project steering groups, commenting on and developing research materials, and undertaking interviews with research participants.

## Engagement

INVOLVE define engagement as the process by which information and knowledge about research is provided and disseminated. Examples of engagement are:

1. Science festivals open to the public, with debates and discussions on research
2. Open days at research centres, where members of the public are invited to find out about research
3. Raising awareness of research through various media, such as television programmes, newspapers and social media

Dissemination to research participants, colleagues or members of the public of the findings of a study  
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 health and social care services.



## The Leicester and Loughborough Biomedical Research Units

The University Hospitals of Leicester and both Leicester and Loughborough Universities host three Biomedical Research Units (BRUs) funded by the National Institute for Health Research (NIHR):

1. The Leicester-Loughborough Diet, Lifestyle and Physical Activity Biomedical Research Unit
2. The Leicester Cardiovascular Biomedical Research Unit
3. The Leicester Respiratory Biomedical Research Unit

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. The Unit is based at Leicester General Hospital and benefits from state of the art facilities, including consulting rooms, an exercise laboratory, and the use of facilities at the world renowned Loughborough University, a centre of excellence in Sports Science.

The NIHR Leicester Cardiovascular Biomedical Research Unit (LCBRU) aims to improve the diagnosis, prognosis and treatment of cardiovascular diseases. The Unit, which was initially funded in 2009 and received a further 5 years' funding in 2012, is based at Glenfield Hospital. Since its inception, the Unit has developed an outstanding infrastructure for research, including a translational medicine facility (TMF), a clinical research facility (CRF), a 3T-MRI research scanner, an informatics platform - the Biomedical Research Informatics Centre for Cardiovascular Science (BRICCS) and the Leicester Cardiovascular Bioresource (LCB).

More recently, these facilities have been augmented by the addition of a BHF funded Cardiovascular Research Centre. The Unit has 15 Principle Investigators and directly funds over 30 specialist staff, fellows and students and has a large pool of research nurses and support staff.

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). This funding has enabled the construction of a new specially designed unit at Glenfield Hospital, Leicester, including clinical space and a specialist team allowing world class investigations into lung disease.

The BRU hosts an impressive 11 individual clinical rooms, exercise laboratory, 4 bedded ward, and specialist laboratory space including an immunohistochemistry laboratory. The BRU has 10 Principal Investigators, several of whom are Chief Investigator to multi-national, multi-centre studies. The BRU comprises over 100 staff, including research nurses, researchers, doctors, scientists, administrators and students.



## Linking to the BRU Strategies

Effective involvement of patients and the public across the 3 BRUs will be crucial in delivering research that is acceptable and accessible to participants and meets their needs. In doing so, their involvement will safeguard the public's interest and the BRUs will develop a reputation for excellence in PPI/E.

The goals of Leicester's BRUs are to:

1. Deliver a programme of innovative research outlined in the NIHR BRU applications – measured deliverables will include high impact publications, increased grant income, increased patient participation in research, increased number of patents and increased outputs, with demonstrable patient benefit.
3. Consolidate our reputation as natural partners with industry for collaborative experimental studies – measured deliverables will include increased numbers of industry-sponsored studies and increased grant income.

Involvement plays a key role in ensuring that our research translates into healthcare that meets public and patient need and is designed and delivered in a way that is acceptable and accessible to patients, maximising recruitment to studies. Increasingly, it is also a requirement of funding bodies too.

2. Establish ourselves as the regional hub for translational cardiovascular, respiratory and lifestyle research – measured deliverables will include evidence of increased collaborations with other local and regional NIHR structures and with other University/ NHS partners (Loughborough and Nottingham), and a rising citation factor and H-index.

There is a strong drive from the PPI Groups to continue to make best use of research through collaboration with healthcare and academic partners. The involvement of patients and the public is vital in ensuring our research has maximum impact in translation to healthcare by meeting patient and public need, and will be a fundamental and integrated part of the development of the BRUs into regional hubs for cardiovascular, respiratory and lifestyle research.

The challenges of getting commercial partners to engage with PPI are well recognised. The BRUs will demonstrate the tangible benefits of involving patients and the public to commercial partners to encourage them to benefit from our expertise and experience of working with patients and the public to achieve maximum impact in translation to healthcare.

4. Further strengthen our national and international academic partnerships – measured deliverables will include increased number of collaborative programme grants, engagement with NIHR infrastructure and participation in relevant experimental therapeutic clusters.

The PPI Group is keen for research data and samples to be used in a way that ensures maximum benefit for participant effort through partnership working with healthcare and academic partners. The Leicester Cardiovascular BRU patient lead basic science project into Spontaneous Coronary Artery Dissection (SCAD) is a key example of an international collaboration developed in response to patient demand, which arose out of transatlantic and international conversation between SCAD patients on social media. The Lifestyle BRU supported a service user designed study (STOP diabetes) investigating Type 2 diabetes prevention strategies for people with learning disabilities.



5. Continue to enrich and broaden our research portfolio by engagement with other disciplines – measured deliverables include collaborative research and cross-thematic studentships with engineering and physical sciences.

Within the Leicester Cardiovascular BRU and Leicester-Loughborough Lifestyle BRU, this includes collaborations with mathematicians and colleagues in engineering. The Lifestyle BRU and Cardiovascular BRU also collaborate on novel imaging technologies across a number of studies involving young people with type 2 diabetes.

Involving patients and the public to achieve maximum impact in translation to healthcare by meeting patient and public need with research that is acceptable and accessible to participants will help create a research culture that is attractive to potential research partners in the statutory and commercial sector across a range of disciplines. This is particularly helped by a PPI Group with several members from engineering backgrounds and an enthusiasm and passion for engineering and the physical sciences.

There is scope to further enrich the research portfolio by engaging staff and lay representatives in the BRU teams in research into effective public and patient involvement.

6. Ensure sustainability and progress towards renewal of funding– measured deliverables include success in training and nurturing the next cadre of clinician scientists.

Public and patient involvement will play a vital role in the next funding application, supporting partnership working between the BRUs, and creating opportunities to collaborate on involvement, through the joint BRU PPI Strategy building on shared working between 2012 and 2015, notably the joint BRU open days/roadshows. The role of involvement in supporting the units to deliver maximum impact in translation to healthcare by meeting patient and public need is fundamental to their sustainability.



## Development of Public and Patient Involvement in Research Strategy

### Public and Patient Involvement in the Biomedical Research Units

Development of Public and Patient Involvement in Research Strategy Public and Patient Involvement in the Biomedical Research Units There are many reason for involving the public and patients in the work of Leicester's Biomedical Research Units, and several ways in which people can be involved.

#### Reasons for involving the public and patients include:

- Research is geared towards what matters for patients and the public, so healthcare subsequently meets their needs better
- Gaining constructive advice on study materials and design
- Improving recruitment rates into research studies
- Improving the quality of the research and making the research more relevant
- Public awareness of the units is an opportunity to communicate preventative health messages
- Research is often funded by public money, so researchers should be accountable to patients and the public

Involvement activities are very varied and differ from one piece of research to the next. People can be involved in the BRUs at a number of different levels, which are explored in more detail in the 5 year action plan. Raising awareness of research (engagement) generally underpins patient and public involvement in the units. This is facilitated by attendance at events, newsletters, social media, news stories and the websites. An occasional level of involvement appeals to some patients and members of the public, for example, through our open days, roadshows, surveys, occasional diagnosis or study specific meetings, and public lectures or talks to special interest groups.

#### Process of Developing the Strategy

This strategy is based on the Leicester Cardiovascular BRU 2011-2016 Strategy, revised in 2014 in partnership with INVOLVE and the Leicester Cardiovascular BRU Patient and Public Involvement Group and subsequently revised in October 2014 into an overarching strategy between the three BRUs. The strategy is informed by substantial work developing genuine public and patient involvement, started in 2010 with the inauguration of the Leicester Cardiovascular BRU Public and Patient Involvement Group. The strategy was updated in September 2015 to reflect more ambitious NIHR aspirations for PPI.

#### Stakeholders

A range of people have an interest in the work of units related to their employment, third sector involvement, or through personal experience. This wider group of people can influence the BRUs' joint strategy and support activity in raising awareness. Stakeholders include partners in local government, health, sport, special interest groups, and the third sector.

At the heart of patient and public involvement are the Patient and Public Groups. These groups meet periodically to steer patient and public involvement in the units, contribute to their strategic direction, and review specific research projects.

#### Development of Involvement and Engagement

The Cardiovascular BRU has been actively implementing and promoting patient and public involvement and engagement since 2010, when the 0.5 WTE PPI Officer came into post. The newer Respiratory BRU and Lifestyle BRUs similarly have established PPI groups since their set up in 2012, and have a record of attending public events and running open days and roadshows, often in collaboration with research partners in the other BRUs and other research and clinical stakeholders.

## Lifestyle BRU

The Lifestyle BRU presents unique opportunities for PPI. Much of the unit's research is about what patients can do to treat their disease, rather than what can be done to them. As such, the research naturally entails PPI. Since its inception in 2012, the Lifestyle BRU has worked jointly with the former Diabetes Research Network and benefited from a PPI group comprising over 300 members.

Following the creation of the East Midlands Comprehensive Research Network (EM-CRN), the Lifestyle BRU now supports the PPI group and continues to benefit from their collective input into studies run through the BRU, meeting for opt-in focus groups monthly or as studies require. Since 2012, the Lifestyle BRU has also assembled a large cohort of people geographically based around the Loughborough campus. This group has a different demographic to 'typical' PPI groups, being predominantly of working age, female and/or students in higher education, and thus, brings a complimentary perspective. The Loughborough cohort meets monthly at a Lifestyle public lecture series hosted at Loughborough.

As the Lifestyle BRU did not initially have dedicated PPI support, their working patterns are different to those of Leicester's other BRUs and all personnel undertake involvement which is now coordinated by a 1.0 WTE PPI Manager.

## Respiratory BRU

The Leicester Respiratory BRU has been embedding PPI activity through the core of its work since 2012 with the appointment of a 0.5 FTE PPI Lead. The PPI group within the unit currently has 40 members, consisting of men and women of all ages and life experiences and who have a keen interest in lung research. The PPI group meet periodically and review specific projects and applications. One investigator has trialled an online survey for a study to increase participation, particularly for those who are unable to attend a face to face meeting. This was undertaken in collaboration with Asthma UK and proved very successful. The PPI group have been directly involved with researchers and investigators in a range of activities from reviewing grant applications and helping design the research, reviewing specific studies and study literature, through to dissemination of results. An online password protected 'members' area' of the website is now available for PPI members to access PPI materials, view event calendars and gain study specific information. The 'members' area' was a concept originally thought of by a PPI representative and the area was built to the requirements of the group by passing the design via the members at several meetings. A PPI representative also sits on the BRU Executive Committee. The Unit has close links with local charitable groups and stakeholders including Breathe Easy (British Lung Foundation) and has close working relationships with the other BRUs and CLAHRC.

## Cardiovascular BRU

During 2010 and 2011 the Cardiovascular PPI Group was established, supported by the University Hospitals of Leicester NHS Trust Patient Advisors. Terms of reference were agreed and the group was resourced appropriately to fund expenses, parking and training costs. By October 2010 a wider group of patients and the public were welcomed, many as representatives of stakeholder organisations including HealthWatch (then LINKS), the British Heart Foundation support group, Patient Advisors and local charity and support group Take Heart Leicester. The group decided they wanted to be volunteers and that they would like the meetings to be facilitated (rather than chaired) and administrated by the PPI Officer. Immediately researchers began presenting their projects to the group. The current membership comprises a mix of men and women, many of whom are retired, with a wide range of life experiences.



## PPI Group Member Profiles

### Anthony Locke

I suppose it must have grown from my interest in research generally. I became alerted to the growing cardiovascular team when I was undergoing investigations. I volunteered for research projects in respiratory, exercise and cardiovascular experiments.



These things soon get you involved in other groups. The process still goes on - now being involved in Prof Gavin Murphy's research projects and those in other universities and hospitals where I'm a patient. I've taken part in projects in other hospitals and universities too, so I've been able to use the experience gained in different contexts to inform the others and my own understanding.

I consider the cross referencing of data and findings, not just for one medical condition, but across disciplines vital to extending understanding of conditions and potential treatments the BRUs and the relationships between them, not just in Leicester University, Loughborough University, UHL, but nationally and internationally vital.

### Phil Caldwell

I joined the group having spent two years on the Cardiac and Pulmonary PPI group, of which I am still a member. In that group I was fortunate enough to be part of a team working on the 'Activate Your Heart' project and through that experienced the benefit of past patients (I had a heart attack in 2010 and subsequently went through rehab) working closely with the professionals and inputting our own experience to bring about a really successful outcome, in this case a system which is already being seen to increase cardiac rehab uptake in our region.



Seeking further involvement of a similar in-depth nature, I joined the cardiac PPI group in the summer of 2013 and have enjoyed both learning about the range of projects currently being undertaken and participating in giving feedback on some of these projects. I hope to become involved in specific projects in the near future, and with this in mind have joined Gavin Murphy's recently established steering group.

There is so much ground breaking work going on in this and related fields, and ample scope to draw on the resource and experience of PPI members, so I am happy to be a part of this partnership and bring to the table whatever assistance I can.

### Ballu Patel



I have CVD and the effects have been life changing and lasting. The support that has been given to me by the clinicians and other staff has been outstanding and so in return I wanted to offer something back, even if it is limited in terms of experience or knowledge. The Patient and Public Involvement Group (PPI) offer me the opportunity to hear about the latest research being undertaken within the Trust and allow reflections from the patient perspective.

The presentations and discussions with the researchers and consultants are in a language that allows lay members to understand medical developments and also has room for meaningful discussions to take place. I look forward to each meeting to hear about these developments and also to be able to engage with other lay members.

During 2011 the PPI Officer was actively involved in designing and delivering training for people involved as patient and public representatives, with colleagues from the local involvement collaboration LNR REPP (now East Midlands Research Engaging with Patients and the Public).

The BRU have built partnerships with stakeholders in healthcare, research, sport, local government and the community. Partnership working with these organisations is evident through BRU involvement in community events like SkyRide, community health fairs, council led events, sport events and local groups and clubs.

The British Heart Foundation have invited the LCBRU to have a presence at some of their national events, so people can find out about our BHF funded research. A number of key resources have been developed since 2010 in partnership with PPI Group, including newsletters, poster display materials, expression of interest forms for the PPI group, newsletter mailing list postcards, patient produced information (leaflets, posters, fliers and bookmarks) on Spontaneous Coronary Artery Dissection, a short film about the BRU, our website and social media sites.



## BRU Together

Since 2012, with the renewal of the Leicester Cardiovascular BRU and the founding of the Leicester Respiratory BRU and Leicester-Loughborough Lifestyle BRU, informal joint working on events, social media and open days has developed from grassroots shared opportunities.

The units annually host joint 'roadshows' in partnership, and with other research groups, though no longer at the units themselves, as the success of these events has necessitated a move to larger venues to support the level of interest from patients, the public and research personnel.

In 2014 the Cardiovascular PPI Strategy was updated to formalise joint working practices between the BRUs and in 2015 the Joint PPI Strategy was updated to reflect more ambitious PPI/E aspirations.

The BRUs have cohesively produced quarterly newsletters and cross-populated each other's social media streams. Most engagement activity is now undertaken jointly, maximising cost effectiveness and soft-outcome benefits of partnership working between the units. Joint display materials have been developed and joint projects undertaken, notably including a community arts project undertaken with the Leicester People's Photographic Gallery.



## Aims and Objectives

The three BRUs are committed to public and patient involvement to ensure patients and the public have an opportunity to contribute to the research agenda of the Units, strategically and operationally.

### Aims:

1. Facilitate discrete PPI Groups of patients and the public to review all new non-commercial research projects, and be made aware of and where possible, review all commercial research projects supported through the respective units.
2. Raise and maintain awareness of the units and research more generally in the community.
3. Support patients and the public to contribute to the strategic research agenda.
4. Work with local stakeholders to develop partnership working.
5. Work with patients and the public to deliver the research they want.
6. Disseminate results of research to research participants and make results publicly accessible.
7. Increase participation in research.
8. Seek improvement and develop quality PPI approaches

## Resources

Achieving the aims and objectives of this strategy is made possible by comprehensive resourcing of the associated projects and processes.

Each BRU has an allocated annual budget to pay for PPI/E related expenses like room hire, catering, refreshments, mileage and parking, display materials, newsletters and other media, training and conference attendance for PPI Group members. The cost of shared resources including newsletters, materials and project costs has been shared since the formalisation of joint working arrangements in 2014.

Each unit employs a PPI Lead/Manager (Cardiovascular 0.5 WTE, Respiratory 0.5 WTE and Lifestyle 1.0 WTE). These posts create synergy between the internal and external governance processes.

The PPI Managers are supported by access to University and Hospital teams specialising in communications, media, information technology and graphic design. The University Hospitals of Leicester NHS Trust employ a Communications Manager for research who works closely with the PPI Managers on engagement activity.

A range of stakeholders from the statutory, not-for-profit, and independent sectors, service users and carer groups support the PPI Managers, particularly around access to events, stakeholder media and through opportunities to give talks and demonstrations at various events. Funds are available to support the PPI Managers to attend relevant national conferences and training events.





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