



**National Institute for  
Health Research**

Leicester Cardiovascular Biomedical Research Unit

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

Leicester Respiratory Biomedical Research Unit

# PPI Strategic Action Plan Lay Review How are we doing?



## Action Plan: Delivering a PPI Group

Each Unit will facilitate a PPI Group 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 units.

### Activity, Outputs & How are we doing?

#### 1. Provide regular opportunities for researchers to access patients and the public in respect of their studies at all stages of research projects.

- Meet periodically, host 10 meetings per unit annually
- Support all BRU researchers to access patient / public perspective
- Maintain attendance of at least 5 people at involvement meetings

**How are we doing Updated April 2016:** The units host PPI Groups in Cardiovascular, Respiratory, 18-30 Diabetes, Bariatric Patients, AAA, Kidney Patients, Cardiac Surgery. The groups meet between 4-10 times annually. Occasionally attendance has been below 5 but this is rare.

All new BRU studies since 2014 have had some kind of PPI.

#### 2. Grow the group into a larger body

- Through the awareness workstream, recruit new people to join the committees.

**How are we doing Updated April 2016:** The awareness workstream continues to recruit new people into involvement, and has meant we can set up new PPI groups for bariatric patients, kidney patients and young adults with diabetes.

The PPI groups are actively involved in recruiting members by attending engagement activities and helping to design and implement advertisements.

#### 3. Dissemination of research findings

- Provide twice annual updates on the progress of all reviewed studies
- Provide a lay summary of research findings for all reviewed studies and the PI (or delegate) to report back in person for major studies
- Make lay summaries of all reviewed studies accessible to the public on the internet
- Present findings of major research projects to the public through public lectures

**How are we doing Updated April 2016:** This has proved challenging because our PPI groups are in such demand. We manage to share an update of progress by email every 6 months and researchers commonly come to the PPI group repeatedly and update the group then. Study updates are uploaded to the PPI members' area of the website (in Respiratory). Shifting to study specific PPI Plans and PIIAF evaluation has meant we have more ongoing involvement in studies throughout the life cycle of the project rather than just before approval.

An archive of lay summaries is starting to build up online. The findings of major research projects are routinely shared through press release, media stories and social media as well as our websites and the Public Lecture Series has proved a popular forum for Lifestyle studies and even some Cardiac Surgery ones.



# Action Plan: Delivering Research Awareness

The three Units will raise and maintain awareness of their research in the community.  
What we want to achieve, How we can achieve it & How are we doing?

## 1. Produce 4 shared newsletters per year

- Produce 4 accessible joint newsletters per year and distribute these in the community and make available for download from websites
- Develop a growing shared mailing list of patients and the public who want to receive the newsletter and other updates about the BRU

**How are we doing Updated April 2016:** Newsletters are produced every quarter with input from all three BRUs and CLAHRC and shared with the UHL Trust Membership, the BRU email contact lists (nearly 1000 people and organisations) and through our social media and websites. Paper copies of the newsletter are widely distributed whenever the BRU's attend events (approximately 500 copies are taken per quarter based on printing receipts).

## 2. Maintain BRU Social Media

- Continue to announce all BRU public events on the social media and announce up to date news
- Grow social media accounts followers/likers
- Engage with social media accounts of other BRUs, by re-tweeting/reposting and discussing

**Updated April 2016:** Our social media accounts engage over 5000 people and the main accounts are updated daily. All current news, press releases and events are shared on social media. There is considerable interaction between the accounts.



## 3. Attend and organise events for the public, patients and the research community to attend. Share staffing and media production

- Engage in a minimum of 12 events per year in the public forum providing information and opportunities to get involved to patients and the public. This will support the growth of the mailing list and PPI groups. for events

**How are we doing Updated April 2016:** In 2015 we attended 42 public events, reaching an estimated 4800 people. At these events we shared the newsletter, information about our research and recruited people to the mailing list, studies and involvement opportunities. Many of these events presented an opportunity to access seldom heard groups using micro-interview techniques.

## 4. Host shared BRU open days/roadshows

- Facilitate an annual opportunity for patients and the public to meet researchers, and find out what they have been up to locally in the format of the research roadshow.

**How are we doing? Updated April 2016:** Annually, a public event has been hosted by the 3 BRU's together, though not always as a Research Roadshow. In 2015 the Photographic Exhibition Preview and the Research Fair served as our large scale public event. Individual units also commonly host at least one Open Day annually, where the units open their doors to members of the public.

## 5. Maintain PPI webpages on the BRU webpages Include links to local NIHR infrastructure on webpages

- Continue to maintain and regularly update the BRU websites.

**How are we doing? Updated April 2016:** The BRU websites are maintained and up to date and serve as a platform for sharing our stories directly to the public and also as a linked-platform for our social media activity e.g. we locate the newsletter on the website and share the link to it on social media. Cardiovascular also benefit from a specific website for SCAD patients taking part in the SCAD study, which was designed by the patients themselves. Here they can opt in to the study but also share their experiences and stories. Respiratory host a specific password protected area of the website dedicated for PPI members.

## Action Plan: Delivering Involvement in the BRU PPI Strategy and Internal Governance

The units will support patients and the public to contribute to the strategic research agenda.  
What we want to achieve, How we can achieve it & How are we doing?

### 1. Provide information about BRU strategy to patients and the public

- Share information about the research strategy in the BRU in the newsletter, webpages and facebook page and source comments

**How we are doing Updated April 2016:** We are good at sharing strategic information on our social media accounts and with our mailing lists, although the newsletter tends to focus on studies. We regularly use survey monkey to enable comments on relevant policy and strategic issues (roughly once a month). All new BRU studies since 2014 have had some kind of PPI.

### 2. Support representations of patients and the public

- Ensure representation of patients and the public at the BRU Board and Management meetings
- Report annually to the BRU Management Meeting

**How we are doing Updated April 2016:** There is lay representation on the BRU Board and Management meetings and further lay representation is facilitated for larger study's steering committees, where a study depends particularly on the community e.g. the Feasting and Fasting study looking at management of Diabetes during Ramadan, or where a major piece of strategic work is underway e.g. the BRC application 2016.



## Action Plan: Delivering Partnership Working and Stakeholder Involvement

The units will work with local stakeholders and develop partnership working.

What we want to achieve, How we can achieve it & How are we doing?

### 1. Work with special interest and support groups locally.

- Distribute newsletters to local support and interest groups
- Support local groups by providing stories for their newsletters
- Use local groups to access a wider population of patients and the public
- Invite local groups to open days and events

**How we are doing Updated April 2016:** The newsletter is provided to the local Diabetes UK, Breathe Easy and Take Heart Leicester special interest groups. The PPI Leads provide content for their own newsletters on request, usually annually to coincide with a visit to the group. The local special interest groups are key partners in our work and are always invited to our events.

### 2. Engage with the UHL Foundation Trust Membership

- Circulate the BRU newsletter to the membership via the PPI lead for the Trust
- Support Trust events like the health fair at the AGMs

#### **How we are doing Updated April 2016:**

The BRU newsletter is shared with the UHL membership via the membership lead for the Trust.

The BRU's are always represented at the Trust AGM and health fairs.

### 3. Engage with UHL Patient Advisors

- Representatives from amongst the Trust Patient Advisors will sit on the PPI Committees and feedback our work to the Patient Advisors, and feedback any comments to us.

**How we are doing Updated April 2016:** Patient Advisors sit on the Cardiovascular and Respiratory PPI Group.



## Action Plan: Delivering Patient Led Research

The units will work with patients and the public to deliver the research they want.  
What we want to achieve, How we can achieve it & How are we doing?

### 1. Engage patients, the public and stakeholders in priority setting partnerships (PSPs)

- Seek funding through the Wellcome Trust to deliver a PPI Fellowship with a focus on PSP and improving PSP methodology to engage with diversity and enhance democracy through new media, arts and traditional methodologies.

**How we are doing Updated April 2016:** This work has not yet been started but forms a key part of our application to become one big research unit in 2017 (a Biomedical Research Centre or BRC). A mini-priority setting activity was conducted in early 2016 to assess the relative importance of the research projects some of the Lifestyle researcher wanted to explore with funding from the NIHR Fellowship Awards.

- Engage patients, the public and stakeholders in Priority Setting Partnerships either with the James Lind Alliance or independently

**How we are doing Updated April 2016:** This work has not yet been started but forms a key part of our application to become one big research unit in 2017 (a Biomedical Research Centre or BRC).

- Disseminate findings of Priority Setting Partnerships

**How we are doing Updated April 2016:** This work has not yet been started but forms a key part of our application to become one big research unit in 2017 (a Biomedical Research Centre or BRC).

- Demonstrate synergy with findings of PSP OR action plan refocusing research objectives to meet identified priorities

**How we are doing Updated April 2016:** This work has not yet been started but forms a key part of our application to become one big research unit in 2017 (a Biomedical Research Centre or BRC).

### 2. Create opportunities for patients and the public to communicate their research questions to us

- A list of potential research projects from patients and the public, particularly including seldom heard communities, will be drawn up with a view to identifying and delivering some of these in partnership with the relevant stakeholders.

**How we are doing Updated April 2016:** Through PPI focus groups and PPI groups we have identified several ideas for patient led projects and have notably successfully had one such study funded. The SCAD study is an example of a patient initiated study, but is also unusual because patients recruit each other and because it's a basic science project (most patient led research is about treatments not basic science).



### 3. Maintain patient leadership of the SCAD project (Cardiovascular Only)

- Draw up a BID and REC application in partnership with patients

**How we are doing Updated April 2016:** The SCAD study protocol and particularly the method for recruiting people with SCAD to take part, has been designed with the SCAD patients, funded by the BHF (NIHR initially) and approved to run in the UK. It has recruited nearly 300 patients.

- Explore how to have patients named as researchers on the application in terms of approval requirements

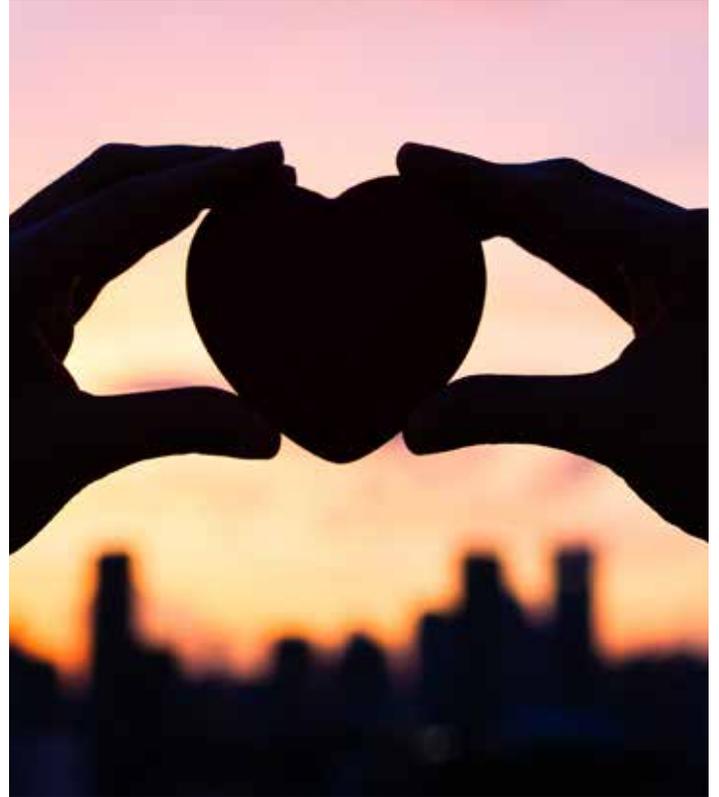
**How we are doing Updated April 2016:** Produce SCAD research website requested by patients.

- Patients were named as co-investigators

**How we are doing Updated April 2016:** The SCAD website has been live and operating since 2014.

- Maintain patient involvement in the project supporting recruitment / publicising the SCAD recruitment portal, developing SCAD information and materials and helping out at public events

**How we are doing Updated April 2016:** The SCAD patients remain integral to the study, not just by helping steer it but by raising awareness of it and directing people to the website and recruitment portal as part of their peer-support activities. The patients have formed a charity and hosted an annual conference on SCAD in partnership with the research team.



### 4. Facilitate patient initiated/led research projects arising from PPI Groups and actively create and pursue opportunities for Citizen Science.

- Patient initiated projects will be funded and delivered

**How we are doing Updated April 2016:** We continue to raise awareness of opportunities for citizen science projects and have hosted a number of short one-day projects with school. We hope to deliver larger scale community projects in the future. Facilitate patient initiated/led research projects arising from PPI Groups and actively create and pursue opportunities for Citizen Science.

- Patient initiated projects will be funded and delivered

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## Action Plan: Dissemination and Public Accessibility of Results

The units will share study findings in accessible and appropriate forums.

What we want to achieve, How we can achieve it & How are we doing?

### 1. Create an online archive of lay summaries for all major research projects on which we lead

- An online resource is available
- The resource is accessed and used
- BRU studies routinely produce a lay summary of their findings and the archive is kept up to date
- Additions to archive are flagged on social media and newsfeeds

**How we are doing Updated April 2016:** The online archive of lay summaries is slowly building up and remains a priority action for PPI Leads with support from Senior Management.

### 2. Outreach/inreach to disseminate findings

- Feedback findings of reviewed research projects to the PPI Groups
- Present findings at public events and lectures, engaging with appropriate stakeholders

**How we are doing Updated April 2016:** The Research Roadshow includes presentations from at least one researcher per unit and posters about research findings are displayed at public events. For larger studies all units host presentation evenings to share their findings with participants e.g. PhARaoH Study and the ACUTE Study.

The PPI Groups and PPI Focus Group Pool in Lifestyle are regularly updated with information from finished studies although there is a slow turnaround in this because a reviewed study can take a year to even start recruiting people to take part in the research.

The Public Lecture Series has delivered 17 lectures from Lifestyle and Cardiac Surgery researchers.



Respiratory actively engage the research participants and PPI members in providing feedback of research findings via events and lectures, such as the recent PhARaoH study results meeting that provided study results to 75 research participants.

Publicly available lay summaries are something that the units are striving to improve upon.

## Action Plan: Increase Participation in Research

The units will work with patients and the public to develop effective recruitment strategies and seek novel approaches.

What we want to achieve, How we can achieve it & How are we doing?

### 1. Involve the public in supporting recruitment.

- Seek advice through PPI and stakeholder groups on strategies and sources of recruitment
- Involve stakeholders and community leaders in supporting recruitment
- Get patients and the public actively recruiting to studies, as part of protocol, where appropriate e.g. familial genetics studies, SCAD

**How we are doing Updated April 2016:** PPI Groups regularly advise on the challenges of recruitment and this is particularly a focus when studies target seldom heard groups like the South Asian Communities of Leicester. Recently, a range of community groups with Muslim members and the Federation of Muslim Organisations worked with us to help us access information on how best to engage people in our research about managing diabetes during Ramadan.

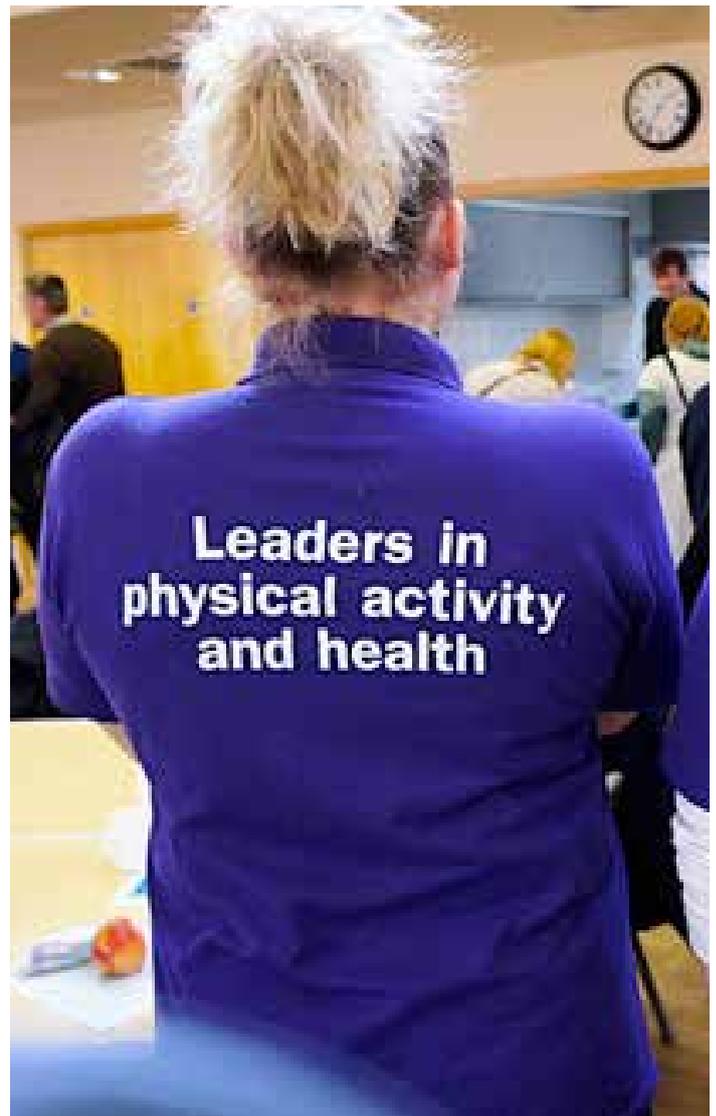
SCAD patients actively recruit fellow patients into the study through their peer support activity online and the Cardiovascular BRU study in familial hypercholesterolaemia (high levels of cholesterol that runs in families) has patients with the condition recruiting their relatives to participate.

PPI groups regularly advise researchers and shape protocols on recruitment strategies. PPI members are involved in engagement activities where they help with recruitment to research and PPI.

### 2. Publicise research generally and specifically (reference the 'raising awareness' workstream)

- Provide opportunities for patients and the public to join a shared potential participant database, through events, newsletters, and media
- Provide appropriate, protocol-compliant opportunities to opt-in to studies through events, newsletters and media

**How we are doing Updated April 2016:** The recruitment databases currently operate within each separate BRU. People are recruited to these primarily through events and social media and the PPI Lead attending the event recruits to ALL databases not just that of their own unit. Many studies recruit through events and social media, particularly those seeking healthy volunteers for lifestyle research though not exclusively.



## Action Plan: Seek Improvement and Develop Quality PPI Approaches

The units will commit to developing systems and processes that develop meaningful opportunities to contribute through involvement.

What we want to achieve, How we can achieve it & How are we doing?

### 1. Implement systems and processes that avoid tokenism and foster an approach to taking PPI seriously

- Researchers will act on public and patient advice and the audit trail will document how this was done or justify not doing so

**How we are doing Updated April 2016:** Use of PIIAF (the NIHR tool for evaluating PPI) has significantly developed the focus on purposeful involvement and shifted involvement from consultation into collaboration. This tool documents recommendations and the research team response to them. All new studies have had PIIAF evaluation since Jan 2015.

### 2. Drive cultural change to ensure that patient and public views are heard and acted on, that the patient is at the heart of all BRU work and promote understanding of the value and usefulness of PPI

- Researchers will consistently engage in PPI
- Quality and benefits of PPI are well documented using PiiAF
- Top level commitment to and enthusiasm for PPI

**How we are doing Updated April 2016:** Use of PIIAF (the NIHR tool for evaluating PPI) has significantly developed the focus on purposeful involvement and shifted involvement from consultation into collaboration. This tool documents recommendations and the research team response to them. All new studies have had PIIAF evaluation since Jan 2015.

### 3. Develop knowledge about PPI

- PPI activity is evaluated, ideally using PiiAF
- Evaluation influences practice
- Demonstrate trying novel and creative approaches to PPI and evaluate success
- Engage in research into PPI approaches

**How we are doing Updated April 2016:** Use of PIIAF (the NIHR tool for evaluating PPI) has significantly developed the focus on purposeful involvement and shifted involvement from consultation into collaboration. This tool documents recommendations and the research team response to them. All new studies have had PIIAF evaluation since Jan 2015. The PIIAF findings have been used to develop an informal tool for researchers called "How do I PPI?" as well as guidelines for seeking review by patients and the public and a proforma of possible questions to ask at review.

### 4. Ensure adequate funding is available for PPI/E activities so patients and members of the public are properly remunerated for their contributions.

- Agree a joint reimbursement policy for PPI in partnership with the PPI Groups
- Resource fulfilment of the policy

**How we are doing Updated April 2016:** A draft reimbursement policy has been developed and is being worked on by all the PPI Leads. Pragmatically, mileage and expenses are consistently paid for all PPI activity and in some cases voucher payments are also made as an additional incentive.

## 5. Ensure training about PPI/E is available to researchers, personnel and lay representatives

- A minimum of one lay representative and one staff representative will be trained as a trainer.
- A minimum of two sessions per year will be delivered between the research units

**How we are doing Updated April 2016:** We have committed to the NIHR 'Building Better Partnerships' training programme and will engage when it is rolled out. We have also opted in to the regional 'training share bank' to enable delivery of this project.

In Jan 2015 several PPI members undertook lay assessor training.

## 6. Enhance PPI/E resources

- Sources of PPI/E funding for discrete PPI/E projects will be identified
- Bids will be made to PPI/E funding streams
- Research projects will routinely budget for PPI/E activity

**How we are doing Updated April 2016:** The PPI Leads work together with the Regional CRN (comprehensive research network) PPI Leads to identify funding opportunities. A bid for funds has been successfully made for the 18-30 diabetes PPI Group. Research projects and grant applications are routinely including costings for PPI.

## 7. Raise the profile of PPI/E across the region and share good practice

- The research units will be represented at good practice events and conferences

**How we are doing Updated April 2016:** The BRU's have presented at all annual R&D conferences and all INVOLVE conferences to date and continue to lead and pioneer involvement nationally.





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