

NIHR Sheffield Biomedical Research Centre Patient and Public Involvement in research (PPI) Strategy 2017 - 2019

Over-arching aim:

To bring patients and researchers together to benefit the translational neuroscience research for chronic neurological disorders that we do.

Summary of Objectives

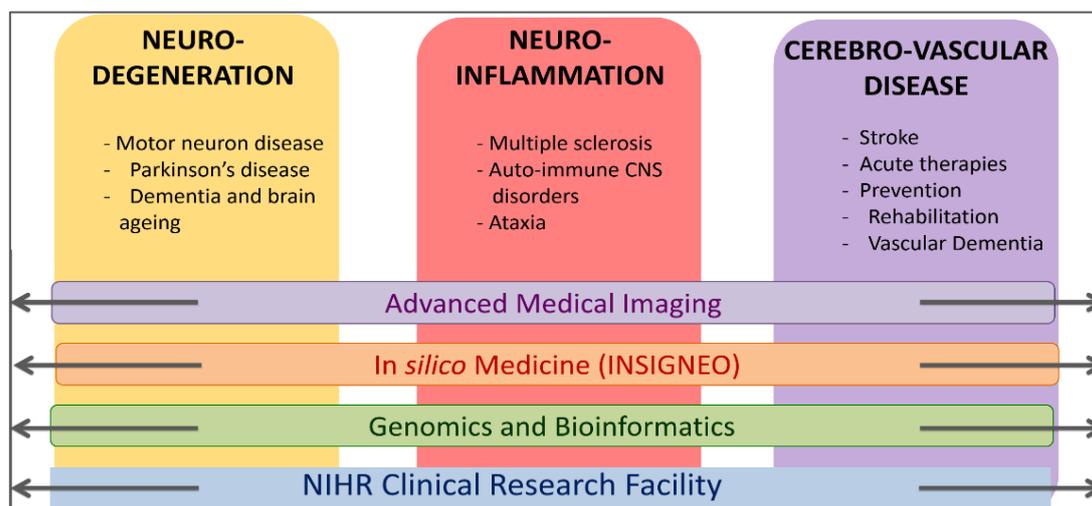
- 1. Get the word out**
Initiate a programme of engagement activities to raise awareness of the Sheffield BRC as a new organization and the role and opportunities for Patient and Public Involvement so we can recruit volunteers to help shape our research.
- 2. Build capacity for PPI**
Facilitate equal opportunities for PPI across all our research themes, in particular making longer-term collaborations possible in all disease areas, by setting up new PPI groups e.g. a multiple sclerosis group meeting quarterly, as well as supporting flexible involvement through focus groups and meeting training needs for researchers and volunteers.
- 3. Collaborate with a variety of partners**
Learn from other groups, share best practice, keep up to date with useful tools and thinking on how PPI is best practiced, how its impact can be assessed and contribute to the development of the growing field.
- 4. Integrate PPI training into the training strategy**
Promote the long-term adoption of PPI in all aspects of clinical and translational research by delivering basic training for PPI to all our PhD students and Clinical Research Fellows and giving them opportunities to put that into practice.
- 5. Collect data for impact assessment**
Record a log of PPI activities, together with their aims and outcomes so that the impact of PPI can be tracked.
- 6. Embed PPI into the Governance structure of the BRC**
Invite patient and public representatives to help steer the PPI strategy and add value for research prioritisation at the Executive board level.

Background

The Sheffield BRC begins as a new infrastructure in a varied landscape of PPI activities, resources and researcher experience across the subtheme and cross-cutting theme areas.

A number of similarly organized, separately funded PPI groups that align with subtheme areas of neurology, and the cross-cutting theme of Genomic Medicine were already established at the start of the Sheffield BRC in April 2017 (Table 1). The [Sheffield MND Research Advisory Group \(SMNDRAG\)](#), [South Yorkshire Dementia Research Advisory Group \(SYDEM-RAG\)](#), [The Yorkshire and Humber NHS Genomic Medicine Centre PPI Panel](#), and [Parkinson’s UK Sheffield Branch](#) all have local quarterly meetings that present opportunities for regular interactions with BRC researchers. Additionally, further PPI volunteers that do not attend regular meetings can be contacted on an *ad hoc* basis for consultation (surveys and focus groups) through databases organised by Sheffield Teaching Hospitals NHS Foundation Trust and University of Sheffield, and the Sheffield [Clinical Research and Innovation Office](#), for example for Stroke research and a ‘neurologically neutral’ online panel.

Fig 1. Structure of the Sheffield BRC



A number of researchers in the BRC have long-standing relationships with PPI volunteers and come with a portfolio of PPI experience and activities including co-designed projects and joint grant applications that they bring forward into their BRC research. Other researchers are naïve to PPI in practice and to the [NIHR-INVOLVE](#) definitions of Involvement, Engagement and Participation in research.

The PPI strategy will therefore focus initial efforts on encouraging researchers new to PPI to meet with appropriate groups and begin a discourse. Support will be offered to existing groups to ensure they can be maintained and expand their operation, and new groups will be established where needed.

Initial consultation with existing local PPI groups with specific neurological themes (Motor Neuron Disease, Parkinson’s Disease, Dementia) indicated that opportunities for PPI in the cross-cutting areas of *in silico* medicine and Advanced Medical Imaging should be also be developed. We aim to facilitate the practice of PPI throughout the Sheffield BRC.

Table 1. Existing PPI panels with permanent membership as of April 2017

Neurology Subtheme Areas	Dedicated Patient and Public Involvement Panel
Motor Neuron Disease	Sheffield MND Research Advisory Group (SMNDRAG)
Parkinson's Disease	Parkinson's UK Yorkshire and Humber Research Interest Group
Dementia	South Yorkshire Dementia Research Advisory Group (SYDEMRA G)
Multiple Sclerosis	none
Gluten-Related Neurological Disorders and Ataxia	none
Cerebrovascular Disease and Stroke	none
Cross-Cutting themes	
Advanced Medical Imaging	none
In Silico Medicine	none
Genomics and Bioinformatics	Yorkshire and Humber NHS Genomic Medicine Centre PPI panel
NIHR Clinical Research Facility	none

Long-term Vision

Our goal is to have patient and public involvement play a key role in shaping research across all our main areas of investigation: Neurodegeneration, Neuroinflammation and Cerebrovascular Disease. We will extend the practice of PPI to build on success from our partners at The University of Sheffield and Sheffield Teaching Hospitals NHS Foundation Trust and aligning with delivering the objectives of the BRC and the [National Standards for Public Involvement in Research](#).

NIHR Standards for PPI	Summary
Inclusive Opportunities	Make a broad range of involvement opportunities accessible and known about to gain diverse involvement
Working Together	Sustaining respectful relationships
Support & Learning	To build confidence and skills for involvement in research
Communications	Using plain language to develop shared understanding
Impact	Capture and share the impact of public involvement in research to drive improvement in practice
Governance	Involve the public in research governance and leadership

We will promote the practice of PPI for BRC projects and raise awareness of the benefits of PPI with our researchers, including trainees, to encourage the long-term adoption of planning for PPI by investigators. We will use PPI training modules offered by charity partners such as Parkinson's UK and the Alzheimer's society for researchers to learn how to start planning involvement in their research. We will signpost interested PPI volunteers and researchers to the general PPI training courses delivered by the Sheffield Clinical Research and Innovation Office (CRIO) and work with the CRIO to adapt their training package for a BRC trainees half day induction.

Development of this Strategy

This document sets out a strategy that has been developed over the first year of operation of the Sheffield BRC and which has undergone several iterations before being finalized. Advice was sought from three established PPI panels in the area of Neurodegeneration, and the BRC Executive board including all the research theme leads and two PPI representatives who joined the board in February 2018 were consulted on strategy development. Wider patient and public opinion on elements of the strategy were surveyed via a live polling event at the [Sheffield BRC PPI launch event](#) in December 2017. The results of this poll reinforced the importance of having knowledgeable PPI representatives join the Executive board to help research prioritisation. Enabling longer-term patient-researcher collaborations was seen as equally as important as surveying a larger range of volunteers in shaping research.

The strategy will be reviewed after a full year of implementation (in 2019).

Implementation Plans for Strategy Objectives

1. Get the word out

Hello World: Engagement activities in the first year

We aim to kick-start discourse with the public by:

- Introducing the BRC to existing PPI groups.
- Establishing a Sheffield BRC website and Twitter presence.
- Hosting a BRC public launch event with a PPI theme including activities and short presentations.
- Having a presence at the Sheffield International Clinical Trials Day event.
- Having a presence at an NHS70 public event outdoors in the city centre planned in collaboration with Sheffield Teaching Hospitals NHS Foundation Trust and the University of Sheffield.

These activities will help to raise awareness of the BRC and associated PPI opportunities and resources both among people who are already PPI volunteers, as well as among people who may have no knowledge of the research landscape in Sheffield. The website will signpost information allowing people to find out more about research and opportunities for involvement and participation. We are collaborating with the Sheffield NIHR Clinical Research Facility (CRF) and the STH Clinical Research and Innovation Office (CRIO) to link our engagement channels and join up how participation and involvement opportunities are advertised.

The [website](#) was trialled by the [Online Patient and Public Advisory Panel](#) several months before the Go Live date, via a focus group meeting. Laptops were made available to the focus group participants and navigational, visual and comprehension issues were raised freely by the group and discussed during the session. A brief questionnaire and general feedback and comments were collected and fed into the development of site.

The website hosts news updates semi-informed by a calendar for features to make sure all research sub-themes are covered throughout the year and aligned with awareness weeks, such as Parkinson's and Dementia awareness weeks, wherever possible.

Lay summaries of Sheffield BRC research will be posted to the BRC website and these can be disseminated through PPI groups and made available in the Sheffield Clinical

Research Facility and elsewhere. The Sheffield Clinical Research and Innovation Office is a [test-bed site for trialling the NIHR Public Involvement Standard for Communication](#) and in collaboration we are developing ways to make research results and activities more accessible for patients through both digital and physical means of dissemination.

2. Build capacity for PPI

Facilitate equal opportunities for PPI across all our research themes

Meaningful PPI requires the commitment of time on the part of both the researchers and volunteers, therefore equal PPI across all research areas cannot be guaranteed. However, funds, administrative help, raising awareness by promoting good case studies, and providing meeting spaces and signposting to training courses can be offered by the BRC to help researchers incorporate PPI into their work, pull focus groups together, sustain PPI panels and establish new ones.

We are in the process of setting up a first meeting ‘taster session’ for a [new PPI panel for multiple sclerosis](#) (MS). We are advertising for volunteers for the panel through the Sheffield Teaching Hospitals NHS Foundation Trust Clinical Service for MS. The MS Society and the Sheffield Clinical Research and Innovation Office are providing templates for terms of reference and membership application forms as well as hosting information about the group on their website. The venue for the meetings is provided by the University of Sheffield Institute for Translational Neuroscience (SITraN). We plan to initiate another new panel for stroke research later in 2018.

A reporting spreadsheet for projects aligned with BRC deliverables has been developed with a section for PPI where any current activity can be recorded and any resources required to carry out an activity can be documented. This will help to embed the consideration of PPI in new research projects, to link existing resources with projects, or highlight gaps where resources need to be developed. Suggestions for particular PPI activities can be made at the monthly BRC operational and executive meetings where PPI is a standing item on the agenda. Researchers who have less experience in PPI can benefit from discussion with those more experienced and the PPI lead can help to put researchers in touch with coordinators for recommended groups.

We are discussing the [Voice North](#) platform with the NIHR Newcastle Biomedical Research Centre as a forum where PPI activities can be listed as ‘wanted’ by researchers and conducted via webcast so that focus groups and other interactions can take place remotely with volunteers registered to the forum.

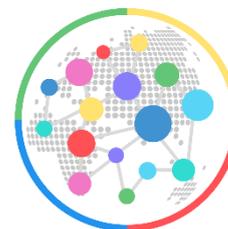
3. Collaborate with a variety of partners to take priorities forward

To learn from other groups, share best practice, keep up to date with useful tools and thinking on how PPI is best practiced, on how its impact can be assessed and contribute to the development of the growing field, we are collaborating with a wide variety of partners.

A joint strategy for the NIHR and other clinical research infrastructures in Sheffield ([CRF](#), [CRIO](#), [D4D](#), [ECMC](#), [CLAHRC](#)) is being developed. A single online landing page is planned to present a cohesive picture of PPI across the research structures and throughout the research cycle. The collaboration offers the chance to join up and feedback on PPI from the design phase of studies (for example at the BRC) to the patient experience at the point of delivery of experimental medicine and clinical trials at the Clinical Research Facility. The collaboration is already helping to share knowledge of PPI and incur savings by sharing facilities and resources.

The Sheffield BRC has joined the BRC PPI leads steering group, which is focusing on the topic of evaluating the impact of PPI in its first year of collaboration.

The Sheffield BRC has applied for membership to [Patient Focused Medicines Development \(PFMD\)](#); an international coalition of academic, pharmaceutical industry, charity, regulatory body and other stakeholders gathering case studies, producing online tools and resources, and producing guidelines for PPI in the drug development process. We are using the online tool provided by PFMD to log our own PPI activities and contribute to the data collection on PPI and shared learning.



PATIENT FOCUSED MEDICINES DEVELOPMENT

4. Integrate PPI training into the training strategy

In order to promote the long-term adoption of PPI in all aspects of clinical and translational research we are delivering a basic training package for PPI to all our PhD students and Clinical Research Fellows and giving them opportunities to put that into practice. PPI training is not part of the University Doctoral Development Programme for post-graduate students so formalising its inclusion for BRC trainees gives them added value for their professional development. We are working with the Sheffield Clinical Research and Innovation Office to adapt and deliver the training module they offer to PPI volunteers and researchers to a maximum of 12 post-graduate students, clinical research fellows and post-doctoral researchers in May 2018. PhD students will record the details of the training and subsequent PPI into their PebblePad Personal Learning Space.

5. Collect data for impact assessment

Record the aims, details and outcomes of PPI activities so their impact can be tracked

The Sheffield BRC PPI lead is co-chairing the BRC leads steering group for PPI, which is focusing on the topic of evaluating the impact of PPI in its first year of collaboration. The steering group has developed an impact evaluation mapping spreadsheet and is asking all the BRCs to input into it to capture knowledge and experience across the BRCs so as to provide a shared learning resource to support the broader group. The annual BRC PPI leads meeting being organised by the steering group is themed around impact this year, with interactive workshop sessions on defining impact and overcoming challenges planned.

- Sheffield BRC [is using Patient Focused Medicines Development](#) (PFMD) as a tool to record PPI activities.
- The Sheffield BRC PPI lead is engaging with researchers and our Clinical Trials Manager to log PPI activities as initiatives on the online tool.
- The tool gives a report on the impact of initiatives on seven quality criteria for PPI that have been determined in a framework co-created by 70 representatives from organisations including INVOLVE, charities such as Parkinson's UK, pharmaceutical companies regulatory agencies, scientists and patients.

- Sheffield BRC PPI Lead presenting our interim experience of using PFMD to collect data and assess the impact of PPI activities at the BRC PPI leads meeting 31 May.
- Applied for membership to PFMD which will enable us to download an aggregate report off all our logged PPI activities and to see their overall impact.

6. Embed PPI in the Governance structure of the BRC

This factor was voted as being the most important in achieving Patient & Public Involvement in prioritising research as compared to conducting a wider public survey (18:2) by the attendees of our PPI launch event in December 2017. Patient and public involvement in research prioritisation within the Sheffield BRC is encouraged by the invitation of PPI volunteers to join the BRC Executive meetings (where PPI is a standing item), and to the External Scientific Advisory Group. As of February 2018, we are pleased to have appointed two PPI representatives for the BRC Executive board: [Jacqui Gath](#), a member of the Yorkshire and Humber Genomic Medicine PPI panel, and Colette Beecher, a patient co-applicant on a major grant for the multiple sclerosis theme. In future, forming an overarching PPI group for the BRC with evenly mixed representation from different neurological perspectives might help to give peer support to Executive PPI members and provide representation for the range of research themes and disease specialities covered by the BRC.