NIHR Maudsley Biomedical Research Centre
at South London and Maudsley NHS Foundation Trust
and the Institute of Psychiatry, Psychology & Neuroscience
at King's College London

NHS
National Institute for
Health Research

A strategy for Patient and Public Involvement (PPI)

Part I – Overview

Vision

The Biomedical Research Centre (BRC) at South London and Maudsley NHS Foundation Trust (SLaM) and King's College London (KCL) develops and supports infrastructure to improve research in mental health and neurological conditions. We involve patients/service users[1] and the public in our research at all stages. This means service users and the public are involved in setting research agendas, overseeing projects and programmes, and disseminating research. This includes supporting research by expert researchers with experience of using mental health services. We want to ensure that our research is relevant to stakeholders, including patients, their supporters, and clinical staff. Patients and the public are embedded into the management and governance of our work. We have a commitment to plain language and attempt to be jargon free, if you find something on this page which you find hard to understand, please let us know.

Scope

This strategy outlines how we approach **public involvement**. We want to involve people in shaping the direction of our research and which infrastructure we need to develop. For the purposes of this document, the INVOLVE definition of public involvement in research will be used, which is, "research being carried out **with** or **by** members of the public rather than **to**, **about** or **for** them." We are not talking about public engagement, although elements of public engagement (and research participation) will cross over with some of the work in this document, and are included where necessary. We believe that sometimes engagement can lead into involvement, since people often need to be aware of research before becoming involved.

Development of this strategy

Our strategy is the result of a number of discussions with other BRCs and has had the support of the Central Commissioning Facility, the National Institute of Health Research (NIHR) and INVOLVE. We also consulted with academics and clinicians within our BRC, and with service users and carers/supporters who have been involved with the BRC. We also completed a priority setting exercise with service users and carers/supporters to influence the future direction of research in our BRC; this exercise itself was run by service users and researchers. The Service User Research Enterprise in KCL oversaw the development of this strategy. We have written this document with reference to the '4PI' framework, adhering to the Principles, Purpose, Presence, Process, and Impact (National Survivor User Network) of involvement activity on our BRC. We have highlighted where our activities adhere to this framework.

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[1] Regarding terminology, we have chosen to use the term 'service user' throughout this document as an alternative to 'patient'. Our BRC predominantly has a mental health focus. The term 'service user' is often preferred to 'patient' in this context. However, we acknowledge the limitations of using either term. Our BRC includes research into neurological conditions (outside of mental health), where the term 'patient' might be more appropriate.

Part II – Practice

The Service User and Carer Participation theme works across the BRC to provide input in five main ways. Our approach to Patient and Public Involvement (PPI) runs through each of these strands. In addition to public involvement in research and strategy, our reflection and evaluation activities are led and conducted by people with lived experience of mental health problems.

1. **Strategic oversight**
   Service users have been involved in developing BRC strategy and future direction. This has occurred in the following ways:
   - Setting priorities for future research through a service user led (and conducted) consultation. This involved consulting with 83 service users and carers across South London. The results are used to shape future research proposals.
   - Redevelopment of the BRC website and development of clinical trials portal within the website. Service users provided input on how they would like to read the site as well as its content.
   - Service user representatives are full members of all strategy meetings and workshops.
   - Leadership of the CRIS system (Clinical Records Interactive Search), via the chair of the oversight committee.
   - Providing feedback into BRC funding applications; for example, training and preparatory fellowships.
   - Judging award schemes for patient and public involvement
   - Building relationships with local service user-led organisations and providing assistance with the development of their evaluation strategies.

2. **Assisting researchers**
   A panel of approximately 30 service users and carers are available to comment on research proposals. We have capacity to assist on approximately 60 research proposals per year.
   - The BRC Service User Advisory Group (SUAG) has six meetings a year and can be consulted on research design, scope and methodology.
   - The BRC Young People's Research Group meets approximately every eight weeks and can be consulted for similar purposes, with a focus on issues affecting young people.
   - The BRC Addiction Services User Research Group (SURG) is run at the Aurora Project, a local user-led organisation for people with experience of substance misuse. The group have been involved in research projects, teaching and public engagement activities, including film making and media contributions.
   - The BRC 'Fast-R' service allows researchers to gain feedback on proposals, information sheets and consent forms. Researchers can submit their work virtually and receive feedback within seven days.
   - Researchers from the Service User Research Enterprise are available to provide 1:1 advice for researchers on all aspects of research, including helping them with involvement.
   - Guidance (written in collaboration with service users) to help researchers in how to involve lay members in steering committees for clinical trials and other projects.
   - Lectures and training on service user involvement to postgraduate students as part of their Research Methods course.

3. **Conducting research**
   We conduct our own research which is published as open-access (see Appendix 1). Examples of service user-led research include:
   - Testing the feasibility and usability of an electronic Patient Health Record for monitoring physical and mental health.
   - Developing a research register based upon the information in the NHS clinical record, and conducting research on its acceptability and governance.

4. **Public engagement**

The Service User and Carer Participation theme contributes to public engagement within the BRC as do all the themes. We have conducted several public engagement activities.

- Showcasing research in collaboration with local service user organisations, such as the Dragon Café in Southwark.
- An annual NIHR 'OK to ask' campaign on International Clinical Trials Day with events in each of the four main hospital sites.
- A BRC Youth Takeover Challenge, in which young people devised a plan for running the BRC for one day, and interviewed academics and clinicians about their work.
- #MeSearch event for children and young people's mental health, held at Pop Brixton in February 2016
- Reporting on BRC events through reports from the perspectives of service users (published on the BRC website)

5. **Improving PPI practice through reflection and evaluation**

It is essential to have continuous improvement of our PPI practices to ensure close involvement of service users in governance and research. Our programme of work includes:

- A service user led ethnographic evaluation of service user involvement within our own BRC. This is carried out independently of the BRC and involves observations and interviews. The results will inform present and future strategy.
- An annual online survey of our support infrastructure services (i.e., Fast-R, the SUAG and the Young Persons group). For example in April 2016 we ran a follow-up survey with researchers who had used out service user research support services over the past two years. The results of the most recent exercise are available in Appendix 2. The annual survey results will be available in advance of International Clinical Trials Day.
- We will run an equivalent survey with service users and carers who have been involved in BRC projects and programmes, to map the benefits which people may get from being involved. Some of this data is available in 'case study' form in Appendix 3.
- Collaborating with PPI leads within other BRCs to share ideas, information and good practice.

Part III – The Future

In addition to monitoring the effectiveness of service user involvement in governance we will also ensure that all BRC projects keep PPI in mind for the choice of project, its design and implementation. We will also facilitate service user-led research and develop infrastructure to increase recruitment, involvement and engagement with research amongst service users, carers, clinicians and the general public. We are currently developing a clear plan for future research, with clear statements of outputs, timelines, and success indicators.

Research outputs

Consenting for contact? Linking electronic health records to a research register within psychosis services, a mixed method study. Robotham, D., Riches, S., Perdue, I., Callard, F., Craig, T., Rose, D. & Wykes, T. 14 May 2015 In : BMC HEALTH SERVICES RESEARCH. 15, 1, 199

Linking a research register to clinical records in older adults' mental health services: a mixed-methods study. Robotham, D., Evans, J., Watson, A., Perdue, I., Craig, T., Rose, D. & Wykes, T. 1 Apr 2015 In : Alzheimer's research & therapy. 7, 15

Electronic personal health records for people with severe mental illness; a feasibility study. Robotham, D., Mayhew, M., Rose, D. & Wykes, T. 2015 In : BMC Psychiatry. 15, 192

Staff and service users' views on a 'Consent for Contact' research register within psychosis services: a qualitative study. Papoulias, C., Robotham, D., Drake, G., Rose, D. & Wykes, T. 24 Dec 2014 In : BMC Psychiatry. 14, , 377

Collaborative development of an electronic Personal Health Record for people with severe and enduring mental health problems. Ennis, L., Robotham, D., Denis, M., Pandit, N., Newton, D., Rose, D. & Wykes, T. 18 Nov 2014 In : BMC Psychiatry. 14, 305

Selecting outcome measures in mental health: the views of service users. Crawford, M. J., Robotham, D., Thana, L., Patterson, S., Weaver, T., Barber, R., Wykes, T. & Rose, D. Aug 2011 In : Journal of Mental Health. 20, 4, p. 336 – 346

Close to the bench as well as at the bedside: involving service users in all phases of translational research. Callard, F., Rose, D. & Wykes, T. Dec 2012 In : Health Expectations. 15, 4, p. 389-400

Development and evaluation of a de-identification procedure for a case register sourced from mental health electronic records. Fernandes, A., Cloete, D., Broadbent, M., Hayes, R., Chang, C-K., Jackson, R., Roberts, A., Tsang, J., Soncul, M., Liebscher, J., Stewart, R. & Callard, F. 11 Jul 2013 In : BMC medical informatics and decision making. 13, 71

Rapid progress or lengthy process? electronic personal health records in mental health. Ennis, L., Rose, D., Callard, F., Denis, M. & Wykes, T. 26 Jul 2011 In : Bmc Psychiatry. 11, 117

Emerging consensus on measuring addiction recovery: Findings from a multi-stakeholder consultation exercise. Neale, J., Panebianco, D., Finch, E., Marsden, J., Mitcheson, L., Rose, D., Strang, J. & Wykes, T. 22 Oct 2015 In : Drugs: Education, Prevention and Policy.

"You're all going to hate the word 'recovery' by the end of this": Service users' views of measuring addiction recovery. Neale, J., Tompkins, C., Wheeler, C., Finch, E., Marsden, J., Mitcheson, L., Rose, D., Wykes, T. & Strang, J. 1 Jan 2015 In : Drugs: Education, Prevention and Policy. 22, 1, p. 26-34

Blending qualitative and quantitative research methods to optimize patient reported outcome measures (PROMs). Neale, J. & Strang, J. 2015 In : Addiction.

How should we measure addiction recovery? Analysis of service provider perspectives using online Delphi groups. Neale, J., Finch, E., Marsden, J., Mitcheson, L., Rose, D., Strang, J., Tompkins, C., Wheeler, C. & Wykes, T. 1 Jan 2014 In : Drugs: Education, Prevention and Policy. 21, 4, p. 310-323

Outputs of BRC consultation groups

An online survey was sent to 60 researchers in April 2016, there were 28 completed surveys. We have collated the following information:

- 27 researchers said that consultation was helpful (19 said 'very helpful')
- 28 would use the service again
- 25 researchers made changes to their study after receiving input
- Ten made funding applications after consulting
- Six of these applications were successful (resulting in a known £4.5 million income from major research funders, e.g., MRC, NIHR)

Feedback from researchers:

"I received really astute, thoughtful feedback from the group. Their perspectives on the research was really invaluable" (YP group)

"I was successful in receiving funding for my PhD fellowship through NIHR. The BRC Service User Group, and my consultation with it, formed a substantial part of my application and justification for the study. I am certain that this materially led to a stronger application and contributed to my award being granted." (SUAG)

"We changed the structure of the Participant Information Sheet, included information on data storage, changed some wording throughout the documents, and described how we will include carers in the study." (FAST-R)

"I used the BRC SUAG to present a qualitative study proposal to gain service users perspectives on the use of anonymised mental health patient records linked to other non NHS government held databases (e.g school data, employment records) for research. The SUAG gave some very well considered ideas on what questions may be important to ask when canvassing service user perspectives on use of their mental health records, and how these questions could be framed. They also gave me important pointers on how to better engage service users and improve the terminology within the information material I provide on research programmes using mental health patient records. The SUAG has helped me refine the key aims of my proposal for applications to charitable funders. It has also helped me establish links with research active service users, who are providing further advice over the project design." (SUAG)

Impact of involvement on service users/carers

"Involvement in research has given me the confidence to feel and believe that I and my experiences have value and can make a positive contribution to mental health research. I cannot over-emphasize how positive my experience of involvement in research has been. Not only is it a very exciting and interesting area, but the people I have met through this; academics, clinicians and fellow service users, have all been so open and friendly and eager to exchange ideas and experiences." (SUAG member)

"Involvement in research has given me a strong sense of purpose and opened up many opportunities for me. I can honestly say it has made the most significant and sustained contribution to my recovery. I would recommend it to everyone. Don't under-estimate the sense of meaning and motivation it can give you." (SUAG member)