Oxford Biomedical Research Centre
Enabling translational research through partnership

NHS
National Institute for Health Research

National Institute for Health Research (NIHR) Oxford Biomedical Research Centre

National Institute for Health Research (NIHR) Oxford Biomedical Research Unit

Patient and public involvement in research strategy 2014-2017

August 2014
Version: 1.0
Author: Sophie Petit-Zeman

A patient and public involvement (PPI) in research strategy for the Oxford Biomedical Research Centre (BRC) & Oxford Biomedical Research Unit (BRU)

2014-2017

This document sets out a new PPI strategy for the second phase of the current Oxford BRC and BRU. The aim of this revision is to build on PPI success to date and address suggestions for improvement. Key among these is that we better align the PPI strategy to assist in delivering the aims and objectives of the two organisations.

This plan has been developed with our patient/professional strategic committee, Patients Active in Research (PAIR), with the Directors, theme, and working group leads of the BRC and BRU and in consultation with other partners as noted below.

As this revision is launched mid-way through the current terms of the BRC/U, its content includes ongoing and new activities; the aim is to launch or complete all by 2017.

Contents:

Detailed work is described in the main document **(see page 7>).**

Three documents follow here:

Summary of the new BRC/BRU Patient and public involvement (PPI) strategy 2014-2017

This strategy builds on PPI success to date and is aligned with delivering the aims and objectives of the BRC and BRU. It complements rather than replicates others' work, is focused on patient benefit and underpinned by openness, transparency, collaboration, communication and learning from experience. It has been developed with members of our Patients Active in Research (PAIR) Group and numerous internal and external partners. We will:

Build strategic partnerships: setting up joint projects to promote effectiveness of our PPI strategy, including better understanding and integration of patients' wishes in our work with the drug and biotechnology industries.

Develop PPI across the research cycle: we are promoting the James Lind Alliance (JLA) method to enable patients/carers/clinicians to decide what research matters across disease areas, disseminating results and helping secure research funding while working with Healthtalkonline to increase knowledge of patient experience. We also support BRC/U themes to use PPI at other stages of the cycle, in research design, identification of outputs and dissemination.

Work at the junction of involvement and engagement: engagement is part of our PPI strategy, to increase understanding and awareness of, and involvement and participation in, medical research. We will support Y Touring Theatre Company to take medical topics to young audiences, expand links with lay and professional media and develop our website with and for patients showcasing PPI opportunities across the Thames Valley.

Embed PPI in governance: PAIR, with patient/professional members and a lay co-chair, leads our PPI work. We will also strengthen links with BRC/U theme leads, the BRC steering committee and the Trust's Executive Board by: regularly updating BRC/U theme leads; having PPI as a standing item for the Strategic Partnership Board/BRC Steering Committee; having a non-executive member of the Trust Executive Board act as "PPI Champion;" inviting a patient to sit on all appointment committees for staff at band 7 or above.

Share good practice, knowledge, skills, resources: through our dedicated PPI website, while also working to define and assess good practice. PAIR members have identified training needs and we will similarly work with professionals engaged in PPI and at new staff induction. We will work to the principles of the AllTrials campaign, calling for greater openness and transparency in clinical trials and launch two parallel activities: analysis of trials within the BRC/U since they began and ascertaining how best to ensure full publication of all current and future research; work with researchers and patients to ensure registered trials are accompanied by good lay summaries.

Grow the evidence base for PPI: the work of our PPI research fellow in impact assessment is crucial to help us identify what works in PPI. She has a steering group of professional and lay members, reports regularly to PAIR and is supervised within the Oxford Health Experiences Institute. We are also conducting the first pilot of the MRC-funded Public Involvement Impact Assessment Framework (PiiAF) within our JLA work on kidney transplant.

Alongside the above, we will continue and grow activities that contribute to wider PPI for patient benefit with external partners.

Summary of the strategy in table form

ACTIVITY	DETAILS	MAIN COLLABORATORS
Strategic partnerships		
	Other research/related organisations	Oxford Academic Health Science Network (AHSN) Oxford Academic Health Science Centre (AHSC) Collaboration for Applied Health Research and Care (CLAHRC) Oxford NIHR Clinical Research Network (CRN): Thames Valley and South Midlands NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) Health Experiences Research Group (HERG); Health Experiences Institute (HEXI) & Healthtalkonline (HTO) Trusts and research charities
	Drug & biotech industries	BRC Business Development team/AHSN
	Creative/engagement	Y Touring Theatre Company (YTTC); Wellcome Trust
PPI in research priority setting	Enabling patients/carers and clinicians to agree research priorities	James Lind Alliance (JLA)/NETSCC/multiple external partners
Involvement and engagement	Through drama	YTTC/Wellcome Trust/schools
	Professional and lay media	BRC comms team
	Website – PPI opportunities across the Thames Valley	AHSC/AHSN/CLAHRC/CRN
Review, monitoring & governance	With Strategic Partnership Board	Presentations from PPI Director
	With OUH NHS Trust Board	Non-exec Director as PPI Champion
	All BRC/U jobs Band 7 and above	Patient on interview panel
Sharing good practice/skills/resources		
	Training patients as they require	Internal and external partners as appropriate
	Training researchers in PPI/inducting new staff via HR	OUH NHS Trust HR dept
	Retrospective review of trials in BRC/U	Centre for Evidence Based Medicine; BRC Director of Operations
	Ensuring appropriate lay summaries of all BRC/U trials	With patient support
Growing the evidence base for best PPI practice		
	Assessment of impact of PPI in trials	BRC PPI Impact Research Fellow; HEXI; HTO
	Patient involvement impact Assessment (PiiAF) evaluation	JLA kidney transplant Priority Setting Partnership; University of Lancaster

All activities involve patients/public, BRC & U themes/working groups/staff and are overseen by the Director of Patient Involvement and PAIR. **Funding:** The total PPI budget of the BRC/U is ~£500k/pa; approx 2.5% of the total BRC annual expenditure. The activities and staff above are funded in part or whole by the PPI BRC budget. Further details on request.

What does the strategy offer to and ask of the BRC/U themes, staff and the patients and public with whom we work?

BRC/U themes and staff: offer & ask

- We will help you integrate PPI across the research cycle, with a focus on research priority setting
- We will help you engage with patients and the public to raise awareness of, involvement and participation in research in general, and your work in particular, and to support patients' roles in governance and appointments
- We will support your PPI through a new website showcasing PPI opportunities
- We will work with you and our Business Development team to ensure that PPI is aligned with development of work with the drug and biotech industries
- Where relevant we will ask you to help us with retrospective analysis of publications of past BRC/U trials and to ensure all such studies are published
- We will work with you to develop and adapt this strategy to make it fit for purpose beyond 2017

Patients and the public: offer & ask

- With the patient members of our Patients Active in Research (PAIR) Group we will promote the overarching principles and specific activities of this strategy
- We will arrange training in areas requested by you, such as better understanding of and involvement in joint work with industry
- We will work with you to develop active roles in governance, including contributing to Board level activity and appointments above NHS Band 7
- We will ask for your help to ensure that lay summaries of clinical trials are lay and hence that information on trial registries is meaningful to patients
- We will encourage you to share experiences of research and care and work through our collaborations with the Health Experience Institute and Healthtalkonline to feed this back into better research
- We will seek to ensure that our strategy increases your involvement in research in the Thames Valley

A new patient and public involvement (PPI) in research strategy for the Oxford Biomedical Research Centre (BRC) & Oxford Biomedical Research Unit (BRU)

2014-2017

Note: a glossary of terms covering the BRC/U, other organisations named in this document and the links between them is at appendix a.

What do we want to achieve?

By 2017 we hope to have embedded a PPI programme that helps deliver the OxBRC/U aims while complementing activity in other organisations locally and further afield. Our efforts set out here focus on unique activities: the PPI world is fast-growing and we want to develop areas not covered by others while building partnerships where joint working is beneficial.

This document thus details plans for:

- Strategic Partnerships
- Developing PPI across the research cycle
- The meeting point of involvement, engagement and participation
- Review, monitoring and governance of PPI
- Sharing good practice, knowledge, skills, resources
- Growing the evidence base for what works in PPI

Contents **Page**

Background to this document

The organisations and structures within which medical research is carried out in Oxford have changed since the applications for the BRC/U 2012-17 were made. This document reflects this, presenting a PPI strategy focused on delivery of BRC/U aims and the partnerships that can facilitate this. It has been drawn up with:

- Our Patients Active in Research (PAIR) group – a committee of patients and health/research professionals working together on an equal footing that guides our activity at a strategic level (see below and appendix b)
- The BRC/U Directors and leaders of the 14 research themes and 7 working groups of the BRC and the 6 themes of the BRU (see appendix c).

The BRC/U themes and working groups are at different stages of developing their PPI, but all recognise the need to ensure strong commitment to this strategy in helping to deliver their aims and objectives.

Also consulted were staff from (see appendix a for details):

- The Oxford Academic Health Science Network (AHSN)
- The Oxford Academic Health Science Centre (AHSC)
- The Collaboration for Applied Health Research and Care (CLAHRC) Oxford
- The NIHR Clinical Research Network (CRN): Thames Valley and South Midlands
- Oxford University Hospitals NHS Trust. As the host for the BRC, BRU and CRN, this strategy is also adopted as a set of best practice PPI principles for the Trust.

The AHSN/AHSC/CLAHRC and CRN are also creating their own PPI strategies and we are working closely with them.

This strategy builds on favourable feedback from the NIHR on the first year of PPI activity for the BRC/U (2012-2013) where we set out three main activities. These are explained in detail below and are: Growing the evidence base for best practice in PPI; Developing the work of the James Lind Alliance (JLA)/a JLA "satellite;" Setting up a website with and for patients, highlighting PPI opportunities.

As noted above, we also address suggestions for improvements made to all BRC/Us in 2012-13. NIHR stated:

- We would encourage BRCs to develop processes for regular monitoring, review and governance of their strategies. This could then usefully feed in to future annual reports.
- We would encourage BRCs/BRUs to develop effective, sustainable mechanisms for sharing good practice, knowledge, skills and resources on topics of mutual interest such as training, developing policies and processes, monitoring and evaluation etc.

These are covered in sections 4 & 5, and also woven through several other activities.

How does this strategy support the work of the BRC/U?

In their bids for funding, the BRC and U set out detailed plans for 5 years' research covering a range of clinical areas and approaches, such as: "personalised/ genetic" medicine (tailoring treatment to patients' genetic make-up), new ways for researchers to "image" – or "see" - into the body, and better use of information technology to join up research and care. The BRC and U cover all areas of ill health (see Appendix c).

We will promote PPI to all theme leads, support them in doing it, and adapt to support them as their and our work develops. This strategy does not set out detailed thematic work, but activities to support this, addressing the aims and objectives of the BRC/U initial applications and subsequent activities. Three general principles about the BRC/U are:

- their work is aimed at "translating" research into patient benefit
- their work is underpinned by partnerships, such as those between the BRC/U themselves, with other relevant partners and – a major priority addressed in this strategy - with industry
- PPI needs to be part of deciding what research is done, how it is done and what happens to the results and outcomes

The first of these is common to all BRC/Us.

The second – strategic partnerships - are again important across all BRC/Us. The focus of PPI to support this in Oxford will be in two areas:

- collaborations with partners noted in this document. They have been involved in creating this strategy and we will set up joint projects where practical

- developing the BRC/U commitment to working with the drug and biotechnology industries, with and for patients. Much has been done to explore the relationship between patients and industry, yet we believe we are are the first BRC/U to be working to (a) find out what patients know/feel about these relationships and (b) develop the relationships with and for them.

See section 1 **"Strategic Partnerships"** for full details on these two strands.

The third element above – making PPI a key factor in deciding what research is done, how it is done and outcomes – will be addressed by:

- Growing the work of the James Lind Alliance

- Working with all BRC/U themes to help them better understand where and how they can use PPI in the research cycle

See section 2 **"Developing PPI across the research cycle"** for full details.

The above activities will be underpinned and overseen by PAIR and supported and enhanced by strong communication and engagement activities. See section 3.

1. Strategic partnerships

1a. Other research/research-related organisations

Working with partners that have helped develop this strategy (appendix a) we will set up joint projects where practical/where this can promote effectiveness of our PPI strategy.

Examples of such work include:

With the AHSN, AHSC, CLAHRC and CRN to develop our PPI website (see section 3c)

With the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) to develop the Oxford JLA hub (see section 2)

With charitable and other funders to identify research priorities through JLA partnerships

With Y Touring Theatre Company/Wellcome Trust to promote engagement through drama (see section 3a)

With the Health Experiences Research Group to inform our work deciding what research is done (see section 2)

With Leeds and York Partnership NHS Foundation Trust to work with patients to identify research in bipolar and with major mental health charity MQ to do the same for depression

1b. The drug and biotechnology industries

Building partnerships with industry is a key BRC/U aim, yet as far as we know no BRC/U has sought to understand what patients know about these partnerships and develop them with and for patients.

We held a workshop to explore:

- What are the relationships between the BRC/U and industry?
- Is the national health and well-being agenda compatible with the “wealth agenda”?
- Does the relationship between the BRC/U and industry affect patients’ desire to work with us?
- If yes, how can we find a way ahead?
- Do special issues arise where industry wants to pursue possible joint work in confidence?

These points and more were discussed with PAIR members and with speakers: Simon Denegri, NIHR National Director for Public Participation and Engagement

in Research, Nick Scott-Ram, Director of Commercial Development at the Oxford AHSN & Alex Prior, Oxford Business Development Manager.

As part of our commitment to learning from patient experience, the event was informed by patients' views of links with industry from the Healthtalkonline module on clinical trials: http://healthtalkonline.org/peoples-experiences/medical-research/clinical-trials/funding-and-publishing-trials

The workshop's findings have been reported (http://oxfordbrc.nihr.ac.uk/wp-content/uploads/2013/11/OxBRCPPIIndustryReport.pdf) and we are now developing activities that link PPI with the BRC/Us relationships with industry as requested by our patients.

2. Developing PPI across the research cycle

We want to involve patients in deciding what research is done, how it is done and defining and assessing its outcomes.

On the first of these, we work with NETSCC (the NIHR Evaluation, Trials and Studies Coordinating Centre), which manages the James Lind Alliance (JLA). The JLA enables research priorities to be set by patients, carers and clinicians, rather than researchers who may never see patients or the drug industry.

This work was described in our 2012-13 Annual Report and cited by NIHR as "Particularly encouraging in delivery of [BRC's] PPI strategy."

The BRC directly funds JLA Priority Setting Partnerships (PSPs), works with those wanting to do them to gain external funding, has appointed an Oxford JLA Project Manager and now has a "hub" providing streamlined admin/co-ordination support for Oxford PSPs and is working with NETSCC to develop the method. Current PSPs are: hip and knee replacement (two PSPs, one in early stage and one in late stage disease); spinal cord injury; common shoulder problems; renal transplant; and in partnership - bipolar disorder and depression. The topics where we support PSPs have been and will always be selected with NETSCC to ensure local activity reflects national priorities.

We will refine and grow JLA activity/team to meet high demand for PSPs in Oxford. We will provide admin support for PSPs across all disease areas, while encouraging them to secure funding from other organisations (successful to date in 4 of those above) and we will explore other avenues to extend the reach of JLA principles, including:

- determining how best to ensure JLA-identified research is broad by working with the UK Database of Uncertainties about the Effects of Treatments (UK DUETs, part of the NICE Evidence Series) to see whether there is need to develop a database for priorities beyond the usual scope of UK DUETs – i.e. diagnosis or prognosis

- identifying how best to ensure that where research questions are suggested by patients/carers/clinicians to which the answers are known, this knowledge is shared
- working with drug/biotech companies to fund research into and/or research JLA-identified questions
- checking patient interviews gathered by Healthtalkonline (HTO), where patients share their experiences, for uncertainties to feed into JLA PSPs. This work is informed by a current BRC-commissioned research project comparing the value of gathering uncertainties through this route versus other sources. This extends impact of the work of BRC Health Experience Fellow Louise Locock.

We encourage the growing interest in PSPs across BRC/U themes and are working with other organisations that may replicate the JLA hub model.

Priority setting is only one stage in the research cycle where patients can play a role: there is growing evidence of the value of PPI throughout the cycle and we will support BRC/U themes to develop their PPI work such as in research design, identification of outputs and dissemination, and will showcase PPI opportunities on our website (see 3c).

3. Where involvement, engagement and participation meet

The focus of this strategy is on how the BRC/U work with patients to ensure research addresses their wishes, is done in ways right for them and helps the BRC/U deliver on their aims. Through achieving this, the evidence suggests we will increase research participation–the numbers of patients who join trials and studies.

Much engagement work–interesting patients in research and what it means for their care–is done by our communications colleagues. However, we are making engagement part of our involvement strategy such that it leads to better understanding and awareness of medical research, and, in turn, greater participation. As set out in a recent blog, we are also linking engagement, involvement and patient experience: http://oxfordbrc.nihr.ac.uk/blog/the-best-medicine/.

Below are three engagement activities that are integral to our PPI strategy

3a. Engaging through drama

Y Touring is an award-winning theatre company supported until 2017 by a Wellcome Trust Strategic Award. It produces quality theatre and associated activities to enable audiences to explore difficult and sensitive issues in medicine and health through “Theatre of Debate” where a play is followed by live debate supported by electronic voting. All projects are backed-up by online resources, development of each begins with a workshop bringing playwrights, experts and

members of the target audience together to explore the chosen subject and productions are also filmed.

We will explore joint working with Y Touring on projects including:

- “Starfish” a play about the nature of and need for clinical trials and ethical issues that surround them. As PPI is often concerned with finding ways to ensure clinical trials are acceptable to patients, and hence that they recruit well, we believe
Starfish is an important tool to enhance involvement, engagement and participation and has demonstrable learning impacts (independent evaluation), has attracted media interest and support at senior levels from the Department of Health and other partners.

- “Hungry” - created under the Wellcome Trust Award, about nutrition and diabetes. Susan Jebb, Professor of Diet and Population Health at the University of Oxford is on the Advisory Group for the project and we will explore ways to work with this project and evaluate its impact through behaviour change.

3b. Engaging through professional and lay media

In 2012/13 we showcased the PPI work of OxBRC in a public talk, several guest lectures at professional events, Nature magazine, the Oxford Times, The Daily Telegraph, the JLA newsletter and a weekly blog written by the Director of PPI. This was selected by The Participation Agency as “Top of the Blogs” and tweeted by Simon Denegri, NIHR National Director for Public Participation and Engagement in Research as “wonderful.”

We will continue to find ways to ensure our PPI reaches wide audiences and encourage and support our patients to themselves become speakers, writers and bloggers.

3c. Engaging and involving through a website with and for patients

We want to make it easier for patients to find PPI opportunities and for researchers to find patients. The national “People in Research” (PIR) website, run by INVOLVE, has similar aims, and we are working with them to see at what stage and how we may collaborate. INVOLVE has told us that revision of the PIR site may lead to it being used as a portal for local sites such as ours.

Our site may thus become a model for others seeking to grow regional PPI. It is provisionally called “Patients in Thames Valley Research” and we will work with patients to refine this to reflect the site’s purpose: enabling patients to find local opportunities for PPI and links to trials or others studies to enable participation.

The site will be set up, run (and funded at least initially) by the BRC, but incorporate the AHSN Thames Valley geography and that of the new Clinical

Research Network (CRN). We are keen to collaborate in this way as the AHSN/CRN unite local research partners.

Information-gathering about who is doing what in PPI is crucial to the website and a survey of those whose work we want to include is underway.

4. Review, monitoring and governance of PPI

Simon Denegri, NIHR National Director for Public Participation and Engagement in Research cited his top priority for PPI locally as involvement in governance "No organisation can genuinely say it is working in the public interest unless it can demonstrate public involvement in how it makes decisions." Our Patient involvement Working Group (PIWG) is now led by PAIR, with patient/professional members and a lay co-chair.

We will also ensure that constructive links are made with BRC/U theme leads, the BRC steering committee and the Trust's Executive Board as follows:
- The Director of Patient Involvement will provide regular updates for the BRC/U theme leads via written reports and attendance at meetings

- PPI will be a standing item for the Strategic Partnership Board (SPB), which supports all major Partnership initiatives via the BRC Steering Committee and the Director will attend some meetings

- A non-executive member of the NHS Trust Executive Board will act as a "PPI Champion" and point of contact between this Board and BRC/U PPI activity

- A patient member of PAIR will be invited to sit on all appointment committees for BRC/U staff at band 7 or above

5. Sharing good practice, knowledge, skills, resources

We acknowledge NIHR's call to "share good practice," but need to define good practice and refine methods to assess what this is, in light of :

- the lack of evidence for good practice (see section 6)
- the breadth of PPI work underway in Oxford both within individual BRC/U themes, across the organisations and by our partners

In order to pool knowledge, skills and resources, we need to find out what they are. We are thus working with patients and others to develop our Patients in Research website.

On training needs, we have identified these with PAIR members and they focus primarily on helping them to engage in specific activities:

a. A list of abbreviations/acronyms (to be provided whenever needed)
b. Specific training on research areas that PAIR is required to inform on
c. Clinical trial methodologies
d. The relationship of industry with the BRC/U, current and future

Over time we may also train professionals engaged in PPI and work with communication/HR colleagues to ensure new staff receive induction in research and PPI.

As part of our best practice activities, we have worked with the Oxford University Hospitals NHS Trust to secure their signing of the AllTrials campaign, calling for greater openness and transparency in clinical trials. Other signatories to date have made it clear that patients want all research results to be published, and this is reflected locally in our discussions with patients.

Alongside the Trust signing AllTrials, the BRC/U are launching two activities: (1) a study of what has happened to trials carried out within the BRC/U since they began in Oxford and identifying how best to ensure full publication of all current and future research. We hope this may set a trend for other research organisations. (2) Work with our researchers and patients to ensure that when trials are registered they are accompanied by lay summaries truly understandable to non-specialist audiences. This will better enable patients to find out about trials for which they are eligible as well as ask about outcomes of those that are finished.

6. Growing the evidence base for best practice in PPI

We have appointed a BRC postdoctoral research fellow in patient involvement impact assessment, her work led by a steering group including external experts and patients, chaired by the Director of Patient Involvement. The academic supervisor is the Director of the Health Experiences Institute who is also the lead on PPI and Experience for the AHSN and CLAHRC.

This research role is crucial to help us identify what works in PPI. Dissemination of findings will be key to the BRC's knowledge and best practice-sharing role and the researcher links with and reports regularly to PAIR.

As set out in the application to the NIHR for the BRC, "the Partnership will work to develop a new Oxford Health Experiences Institute (HEXI) as an international centre of excellence for health experience research. This initiative will work to improve understanding of how healthcare impacts on patients and test how the research findings can make clinical care and clinical research more patient-centred, and represents innovative translational research."

Joint work with HEXI/AHSN is important for our commitment to gathering and sharing evidence/experience-based best practice. As part of this we are also conducting the first pilot of the MRC-funded Public Involvement Impact

Assessment Framework (PiiAF) within our Priority Setting Partnership on kidney transplant, to assess both PiiAf itself as an impact measurement tool, and to assess the impact of PPI within a JLA PSP.

Wider influence

Alongside the activities described we will also to contribute to wider PPI work for patient benefit. Examples include:

- with the steering group of UK DUETs, as above, and at a strategic level through the Director of Patient Involvement's membership of this group
- working with NIHR and INVOLVE to resolve confusion and contradiction around paying patients for PPI if they also receive state benefits or pension
- advising other organisations as they devise and develop their PPI strategies
- growing links between Oxford and medical research charities and patient groups, such as close joint working on JLA PSPs. A key outcome is the planned adoption by Arthritis Research UK of the priorities set by patients, carers and clinicians for treatment of osteoarthritis of the knees and hips as its research strategy.

Looking ahead

The OxBRC/U's current funding runs until 2017. This PPI strategy will thus deliver and/or complete activities set out here during that time as well as develop longer-term work. The BRC/U host Trust is committed to adopting this strategy for its own PPI and we will grow existing links with patient experience colleagues to ensure PPI is informed by and responsive to patient need.

This responsiveness is at the heart of our strategy: it has been devised not for but with patients and we are committed to addressing their priorities, wishes and concerns.

Appendix a: Glossary of terms

All the below are supported by the National Institute for Health Research (NIHR), the route through which the Department of Health funds medical research, and are key partners in devising and delivering this strategy

Collaboration for Applied Health Research and Care (CLAHRC) Oxford: The Collaboration for Applied Health Research and Care (CLAHRC) Oxford is a collaboration of leading applied health researchers across Oxford and the Thames Valley. Led from within Oxford University's Department of Primary Care Health Sciences it involves colleagues from the university's Medical Sciences Division, in particular researchers at the Department of Psychiatry, and in partnership with the Oxford Health NHS Foundation Trust (mental health) and other local trusts and related structures. 50% of its total funding of £18million is from NIHR, additional matched funding is from a combination of the university, local Health Trusts, Authorities, charities and business.

Oxford Academic Health Science Centre (AHSC): The Oxford AHSC sits within the AHSN (see below), and has just four partners: Oxford University, Oxford Health NHS Foundation Trust (the mental health trust), Oxford University Hospitals NHS Trust, and Oxford Brookes University. AHSCs are said to represent partnerships between "world-class" universities and leading NHS organisations, will work to research new treatments and improve health education and patient care, bringing scientific discoveries "from the lab to the ward", as well as drive economic growth through partnerships with industry.

Oxford Academic Health Science Network (AHSN): The Oxford AHSN covers a population of 3.3 million living in Berkshire, Buckinghamshire, Milton Keynes, Oxfordshire and Bedfordshire. It includes a large number of partners, among them the BRC, the University of oxford (and 8 other universities) and the OUH NHS Trust (and 10 other trusts). The AHSN's four core objectives are to: focus on the needs of patients and local populations; speed up adoption of innovation into practice; build a culture of partnership and collaboration; create wealth.

Oxford Biomedical Research Centre (BRC): The NIHR Biomedical Research Centre, Oxford (OxBRC) is based at the Oxford University Hospitals NHS Trust and run in partnership with the University of Oxford. It was one of five centres funded by the NIHR in 2007 through a competitively awarded grant of £57m over five years. In April 2012, as a recognition for its outstanding contribution to healthcare research it was awarded a further 5 years funding of £97m.

Oxford Biomedical Research Unit (BRU): Smaller than the BRC, and focusing its work on illnesses of the joints, bones and muscles (musculoskeletal disease) the BRU is also a partnership of Oxford University Hospitals NHS Trust and the University of Oxford.

The NIHR Clinical Research Network (CRN): Thames Valley and South Midlands:
The CRN: Thames Valley and South Midlands is part of the NIHR Clinical Research Network, which helps to enable clinical research to take place in the NHS. Following the restructure of the Clinical Research Network, from April 1 2014, the CRN: Thames Valley and South Midlands is one of 15 regional networks responsible for ensuring the effective delivery of research in trusts, primary care organisations and other qualified NHS providers throughout the Thames Valley and South Midlands area. It is hosted by the Oxford University Hospitals Trust and covers Oxfordshire, Berkshire, Buckinghamshire and Milton Keynes.

Appendix b – PAIR members list & brief biographies where available

PAIR is comprised of 11 patient and 7 professional members. Some have also identified as both. Those who have consented to be named to date/provided biographies are listed below:

PAIR co-chairs:

Louise Locock: BRC Health Experiences Research Fellow and Director of Applied Research at the Health Experiences Research Group

Gwyn Weatherburn: Gwyn has wide experience of issues relating to close family members and friends with chronic, acute and malignant diseases. She has experience of research studies as a patient and also as a researcher. She is particularly interested in the effect that the introduction of new technologies has on patients of all ages, their carers and staff and how they can affect the patient and carer journey.

Other PAIR members:

Iain Chalmers: Iain practised as a clinician for seven years in the UK and the Gaza Strip, before becoming a full time health services researcher. Between 1978 and 1992 he was founding director of the National Perinatal Epidemiology Unit (www.npeu.ox.ac.uk). Between 1992 and 2002, he was founding director of the UK Cochrane Centre, which convened the meeting at which the Cochrane Collaboration (www.cochrane.org) was inaugurated. Since 2003, he has coordinated the James Lind Initiative to promote public and professional acknowledgement of the need to address uncertainties about the effects of treatments. He is now coordinator of the James Lind Initiative, coordinating editor of *The James Lind Library* (www.jameslindlibrary.org) and *Testing Treatments Interactive* (www.testingtreatments.org). He was knighted in 2000 for services to health care.

Philip Edge: Philip lives in Oxford. His work started in biological research followed by 25 years experience in academic publishing. The last 10 years or so has focused on working with information management projects in developing countries, including internet and mobile phone networks for both research and rural community environments. His particular interests now cover communication of scientific and medical research, and understanding the effects of this.

Jeremy Fairbank: Consultant orthopaedic surgeon, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences

Karen Melham: Senior Researcher in Ethics at the Centre for Health Law and Emerging Technologies (HeLEX) at the University of Oxford,

Alison Monk: Alison is Communications and Public Involvement Officer with the Clinical Research Network: Thames Valley and South Midlands. The Network supports the delivery of clinical research in primary and secondary care, across a range of disease areas. It is hosted by Oxford University Hospitals NHS Trust and covers Berkshire, Buckinghamshire, Milton Keynes and Oxfordshire. Alison works with patient groups, NHS Staff and health professionals on activities to help raise awareness of research.

She works closely with the Network's Patient and Public Involvement Reference Panel and Online Review Group (diabetes specialty). She facilitates meetings and communications between the two groups and researchers, to help provide a patient opinion on different aspects of research studies, in line with the Network's Patient, Carer and Public Involvement and Engagement (PCPIE) strategy and annual plan. Before joining the Network she worked at the Multiple Sclerosis Society in London where she was seconded to the Research Team as Public Involvement Officer.

Fraser Old: I spent my working life as a research scientist/engineer and became interested in medical research when my wife developed orthopaedic problems in our retirement. This led to my membership of the Nuffield Patient and Public Involvement Network where I am a patient/carer representative on various research topics in orthopaedics. I also have an interest in memory loss and am a member of DeNDRoN, the Dementia and Neurological Diseases Research Network as well as being a lay member of the Healthtalkonline Advisory Panel. More recently I have developed a more personal interest in joint replacement when I was diagnosed with an arthritic hip so expect to be able to offer an "insider view" over the coming year.

Sophie Petit-Zeman: Director of Patient Involvement, Oxford BRC/Director of SPZ Associates, specialising in medicine and social care communications and strategy. Scientific advisor to Y Touring Theatre Company and chair of the Steering Group for their Wellcome Trust strategic award. Sophie writes for lay and professional publications, is a member of the UK DUETs steering group for NICE/NHS Evidence and a Trustee of the Brain and Spine Foundation. From 2004-2012 she was Head of External Relations/Adviser for Public Involvement & Engagement at the Association of Medical Research Charities. Sophie has written two books: *Doctor, What's Wrong? Making the NHS human again* (Routledge, 2005) and *How to be an Even Better Chair* (Pearson, 2006).

Mark Sheehan: BRC Ethics Fellow at the Ethox Centre and a James Martin Research Fellow in the Institute for Science and Ethics.

Jean Simmonds: After retiring from a career in teaching, I became a magistrate for ten years. My husband's treatment and wholly positive experiences at the Churchill, NOC and JR led to an interest in the degree to which effective two way communications was at the heart of a positive patient experience. My main interest is to enable patients to participate effectively in all aspects of the hospital experience - from discussions with clinicians to negotiating admin structures. I participate in a patient support and information group, in staff nurse training panels and have worked on patient information leaflets. I also write for a charity raising funds for research into urological cancers.

Peter Walter: Peter has experience as a patient (prostate cancer and Parkinson's) and of research. He is currently investigating the breeding of mute swans at Abbotsbury in Dorset – this work follows on from an MSc he has completed in Applied Statistics. Peter is a retired school teacher.

Sandie Wellman: Consultant Nurse, OUH NHS Trust

Appendix c BRC and BRU themes and working groups

BRC themes

Biomedical Informatics and Technology – improving care by using information technology
Blood
Cancer
Cardiovascular – conditions that affect the heart and blood vessels
Dementia and Cerebrovascular Disease – conditions such as stroke and its outcomes, such as confusion
Diabetes
Functional Neurosciences and Imaging – using advances in brain science to better understand how the brain works, and to help patients
Genomic Medicine – using genetic technology to understand and treat disease
Immunity and Inflammation - developing ways to measure the course and treatment of diseases of the immune system
Infection
Prevention and Population Care – improving public health through disease prevention, earlier diagnosis and better management
Surgical Innovation and Evaluation – establishing ways to develop and test new and less traumatic surgical techniques
Translational Physiology – improving healthcare by using computers, telephones and other information technology
Vaccines

BRC working groups

Molecular Diagnostic – blood diseases and cancer
Clinical Trials Units
Research Education and Training
Transplantation
Patients Active in Research (PAIR)
Clinical Informatics – information technology & data management in research & care
Cognitive Health – promoting the healthy brain

BRU themes

Epidemiology and sports injuries
Orthopaedics – issues with skeleton and muscle
Rare bone diseases
Rehabilitation
Rheumatology – diagnosis/management of arthritis & other disorders of joints, bones, muscles etc
Sarcoma – cancers in muscle, bone, nerve, cartilage, tendons, blood vessels & fatty/fibrous tissues

Appendix d: The current and future PPI team

Director of Patient Involvement - Sophie Petit-Zeman. This appointment was a first for any BRC/U and has enabled thorough review of the PPI strategy and creation of this new plan.

Louise Locock, Ann-Marie Boylan & Romola Coope – PPI & Health Experiences research
Joanna Crocker – Impact of PPI research fellow (supervised by **Sian Rees**)
Rosamund Snow - PiiAF pilot
Sandra Regan – Oxford JLA Project Manager

Further staff recruitment will follow to enable implementation of this strategy, potentially to include: Assistant to Director; JLA admin hub administrator; Website development & support officer.

ENDS