

# Research & Development Patient and Public Involvement in Research Strategy

Version 1

**2014-2015**



## Contents

<b>Foreword</b>	<b>3</b>
<b>1.0 Overview</b>	<b>3</b>
<b>2.0 Vision</b>	<b>3</b>
<b>3.0 Mission Statement</b>	<b>3</b>
<b>4.0 Goals</b>	<b>4</b>
<b>5.0 Links to Other Strategies, Policies and Procedures</b>	<b>4</b>
<b>6.0 Background</b>	<b>4</b>
<b>7.0 Levels of Involvement</b>	<b>5</b>
<b>8.0 BDCT Services and Stakeholders</b>	<b>6</b>
<b>9.0 Current PPI in Research Activity</b>	<b>6</b>
<b>10.0 Service User stories</b>	<b>7</b>
<b>11.0 Resources</b>	<b>7</b>
<b>12.0 Action Plan</b>	<b>8</b>
<b>13.0 Links</b>	<b>12</b>
<b>14.0 Appendices</b>	<b>13</b>
<i>Appendix A – Glossary</i>	<i>13</i>
<i>Appendix B – BDCT Internal Services</i>	<i>17</i>
<i>Appendix C – Current PPI Opportunities</i>	<i>18</i>
<i>Appendix D – Resources, training and support for patients and the public to be involved in research</i>	<i>19</i>

## Foreword

This Research and Development Patient and Public Involvement (R&D PPI) in Research Strategy has been developed to provide clarity and guidance on how Bradford District Care Trust (BDCT) plans to increase public and patient involvement in research for the period 2014 – 2015. It builds on previous work that the Trust has undertaken in this area e.g., XPLORE, a service user led research project and other existing involvement activities as part of the wider Trust strategy. The accompanying action plan will be used to deliver the PPI in Research Strategy. BDCT is committed to genuine involvement in research by implementing this strategy which will be overseen by an implementation group with adequate representation from carers, patients and the public. It has been ratified and approved by the Research Forum and the Service Governance Committee, which is a committee of the Executive Board.

## 1.0 Overview

The goal of research is to improve health and wellbeing. This is achieved by developing the evidence base about effective treatments and care and implementing evidence into practice. Public involvement in research is founded on the core principle that people who are affected by research have a right to have a say in what and how research is undertaken.<sup>1</sup> Recent evidence has suggested that it is essential to include patients and the public in research to ensure quality.<sup>234</sup> Public, patients, service users and carers are 'experts by experience' of their own health problems and can enable us to produce research that is relevant to our communities.

## 2.0 Vision

People at the Heart of Research

## 3.0 Mission Statement

To inspire patients, carers and the public to be involved in research, now and in the future.

---

<sup>1</sup> Staley K. (2009) Exploring Impact: Public involvement in NHS, public health and social care research. INVOLVE, Eastleigh, p12

<sup>2</sup> Oliver S., Clarke-Jones L., Rees R., Milne R., Buchanan P., Gabbay J., Gyte G., Oakley A. and Stein K. (2004) 'Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach.' *Health Technology Assessment*, Vol. 8: No. 15

<sup>3</sup> Department of Health (2013) The NHS Constitution for England. DH 1-16

<https://www.gov.uk/government/publications/the-nhs-constitution-for-england>

<sup>4</sup> INVOLVE (2012) Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh

## 4.0 Goals

The Research Strategy, v.2 (section 7.4) confirms BDCT's commitment to increasing public, service user and carer involvement and in particular:

1. To broaden service user and carer involvement at all stages of the research cycle, from design to dissemination, across all sections of the communities we serve.
2. To be an active partner within the Yorkshire & Humber Local Clinical Research Network hub initiatives including service user representation at the regional meetings.
3. To offer training opportunities for the public, service users and carers who have expressed an interest in active involvement in research.
4. To actively develop partnerships with Clinical Commissioning Groups (CCGs) and Commissioning Support Units (CSUs).
5. To ensure our research has an impact outside of academia and is transferred into practice across hospitals, health centres, community mental health teams and community services.

## 5.0 Links to Other Strategies, Policies and Procedures

This R&D PPI in Research Strategy has been compiled to support and complement the overarching BDCT Research Strategy (v.2) and Involving You (3) – From Involvement to Empowerment Strategy<sup>5</sup>. It also supports a number of key national strategic healthcare documents including Liberating the NHS, High Quality Care for All, the Francis Report and The NHS Constitution. Further documents which are helpful for supporting PPI in research at BDCT are:

- Policy on payment and reimbursement for service user and carer involvement
- Volunteering policy
- Nursing Strategy

## 6.0 Background

INVOLVE<sup>6</sup> defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

The term 'public' includes patients, carers, service users and people from organisations that represent people who use services. Involvement, engagement and participation are often linked and though they are distinct, they complement each other. PPI is increasingly recognised as a leading driver of quality research in the NHS

*'No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. (Dame Sally Davies, the Chief Medical Officer in England).*

---

<sup>5</sup> The Involving You Strategy and Action Plan has been in place since July 2008 and provides a framework for developing BDCT's involvement activities

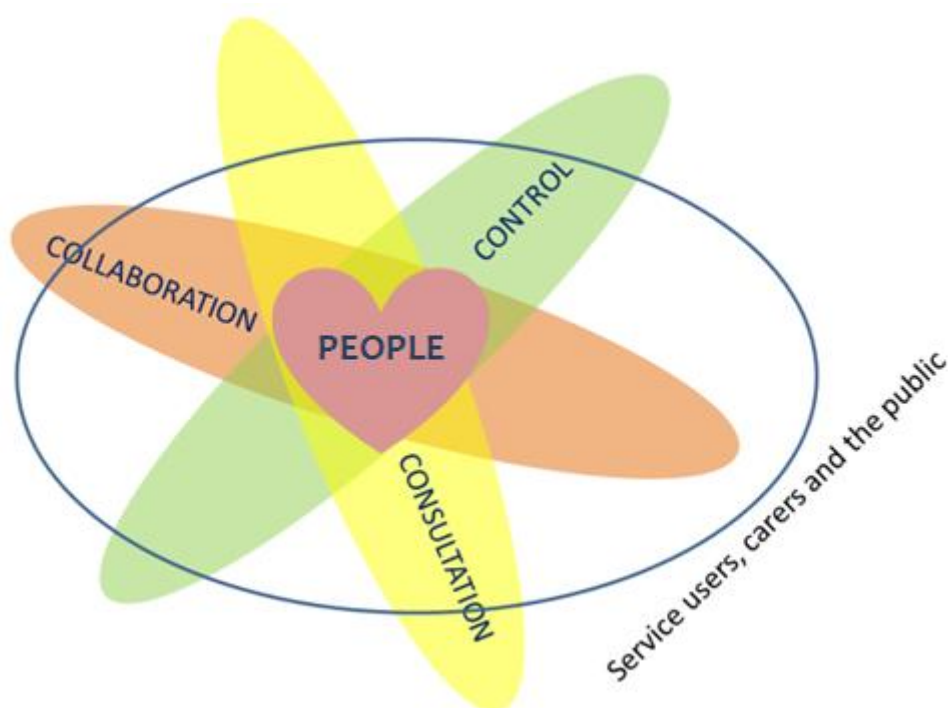
<sup>6</sup> INVOLVE is a national advisory group that supports greater public involvement in NHS, public health and social care research. INVOLVE is funded by and part of the [National Institute of Health Research](#) (NIHR).

## 7.0 Levels of Involvement

Traditionally levels of involvement were viewed as hierarchical i.e. some were perceived as being more worthwhile or genuine than others. At the top of the hierarchy was full 'citizen control' where every decision is made by those that would be affected. At the bottom of the hierarchy those affected by decisions are, at worst, ignored or, at best, informed after the fact. INVOLVE, the national advisory group that supports greater public involvement in NHS, public health and social care research suggests that engagement is a continuum typified by consultation, collaboration and control.

Bradford District Care Trust believes that all involvement has value if the motivation is genuine and the process transparent. Furthermore, BDCT recognises that all involvement is inter-related and importantly that not all individuals would wish to be involved. The following diagram illustrates how the key typologies of involvement overlap where service users, carers and the public may encounter some of these or none at all.

Figure 1: The BDCT model of Inter-relational Involvement



The table below shows some examples of involvement activities and how they might fit within the typologies.

Involvement typology	Example of involvement activity
Control	Joint applicant or co-applicants on grant proposals Identifying research priorities
Collaboration	Undertaking fieldwork, analysis, report/paper writing
Consultation	Advisory/steering group members Steering Reviewing materials e.g. participant information sheets

The activities within this table may be carried out in greater or lesser depth and with more or less autonomy thus blurring the definitions of 'control', 'collaboration' and 'consultation'.

## 8.0 BDCT Services and Stakeholders

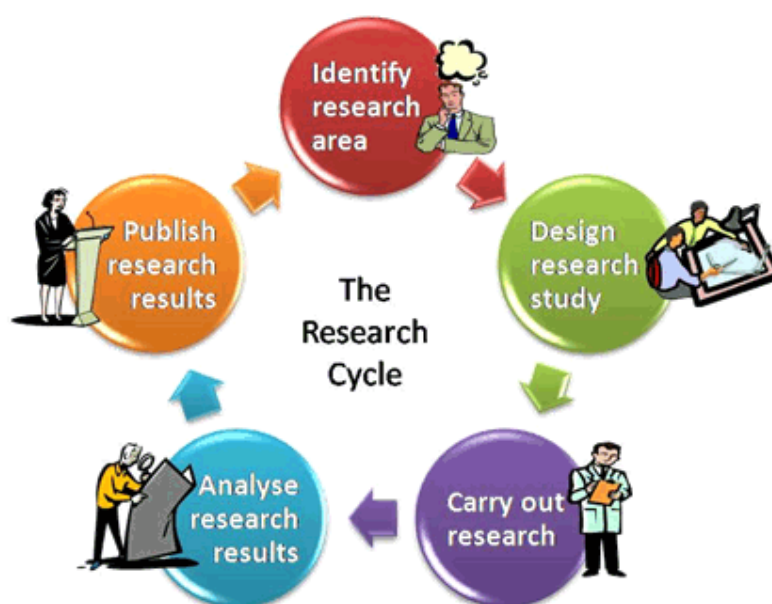
The expansion of the BDCT remit beyond mental health and learning disabilities into a range of community services means that BDCT now provides a diverse range of services across Bradford and Airedale. This means that scope for research activity, and therefore PPI in research can be found across a wide range of services, full details of which can be found in [Appendix B](#).

The R&D team also has strong working relationships with a number of universities, including Leeds, Bradford and Huddersfield, as well as the Bradford Institute for Health Research. In addition, it has strong links with Sheffield and York through the Collaboration for Leadership in Applied Health Research and Care (CLAHRC).

## 9.0 Current PPI in Research Activity

BDCT aims to ensure patients, carers and the public are involved at all stages of the research cycle. Details of existing service user involvement groups at BDCT can be found in [Appendix C](#) and a list of our existing research projects can be found in [Appendix D](#).

Figure 2: The Research Cycle



At the current time we do not include patients and the public in all aspects of the research cycle. A new management and implementation group for the delivery of this strategy will be convened and will address this (see Action Plan, objective (b)). The new group will be comprised of senior members of the R&D team who are experienced in the delivery of PPI as well as a number of service user representatives who will receive a high level of training and support.

## 10.0 Service User stories

People often find that taking part in research activity can be very helpful, even where there is no direct benefit to them personally. The quote below is from a service user who took part in a clinical trial of anti-depression medication at BDCT.

***“Just to have done the study makes me feel useful and helpful instead of useless and pathetic, I pray by taking part in research studies such as this one I may start to learn how to live and love again before it is too late –thanks for helping me”***

***ADD Study Research participant***

As well as taking part in research as participants, BDCT encourages patients, carers and the public to become actively involved in research. The quote below is from a service user who took part in a service user led research project looking at the effect of long journey times on the mental health of service users.

***The key element I enjoy is being involved with a group of researchers from different backgrounds, which include other “Service Users”. Doing research is a challenge, and the support given, whether it is through training, regular group “XPLORE” meetings, or learning new skills, makes the whole process enjoyable.***

***XPLORE service user researcher***

## 11.0 Resources

A range of resources, training and support to help develop skills and knowledge in research is available and details can be found in [Appendix D](#).

Our research team can also provide details of available funding sources and can help with applications for grants, bursaries and charitable funding. For example, most grant applications now require a PPI plan which should generally be around 10 – 20% of the total cost, depending on the type of study and we can help with drawing up these plans where required.

## 12.0 Action Plan

Goal	Objective	Action	Lead	Timeframe
1.	(a) To develop a new management and implementation group to deliver the PPI in Research strategy.	<ul style="list-style-type: none"> <li>Decide what the group will be called.</li> <li>Elect a rolling Chair and Co-Chair at first meeting of the management group (preference for at least one lay member to be co-chair)</li> <li>Develop and increase membership from strategy development steering group</li> <li>Develop Terms of Reference, including aims &amp; objectives, chair, membership, quoracy, meeting frequency and reporting arrangements</li> <li>Establish guidelines for ensuring that standard operating procedures for research are assessed by patients and the public</li> <li>Agree research and PPI definitions, principles and terminology to establish common reference point for all members</li> </ul>	<p>Janine Bestall (<b>JB</b>, Chair of Strategy Development Group)</p> <p><b>JB</b></p> <p><b>JB</b></p> <p><b>New Chair</b> (and members) of implementation group, to be decided</p> <p>Angela Ross (<b>AR</b>, Manager of R&amp;D department)</p> <p><b>Service User rep lead</b>, to be confirmed</p>	<p>Mar 2014</p> <p>Mar 2014</p> <p>Mar 2014</p> <p>April 2014</p> <p>April 2014</p> <p>To be agreed</p>
1. and 5.	(b) To engage service users, carers and the public in the BDCT area in research	<ul style="list-style-type: none"> <li>Create opportunities for PPI in the research cycle via the governance office by: (1) Identifying on-going and proposed projects, (2) Training PPI lay advisors and (3) Linking PPI opportunities (see <a href="#">Appendix C</a>) and trained individuals</li> <li>Create and lead a PPI forum for developing a research proposal into severe mental illness (SMI) and diabetes. This is part of BDCT's</li> </ul>	<p>Sarah Kirkland (<b>SK</b>, Research Governance Lead) + <b>Service User Rep</b>, to be confirmed</p> <p><b>SK</b></p>	<p>To be agreed</p> <p>June 2014</p>



Goal	Objective	Action	Lead	Timeframe
		contribution to the SMI theme of CLAHRC2 (Collaborations for Leadership and Applied Health Research and Care) 2014 – 2018.		
1.	(c) To improve public confidence in, and understanding of, clinical research through greater patient and public involvement	<ul style="list-style-type: none"> <li>Continue to raise the profile of research through active involvement in NIHR campaigns such as 'OK to ask' and other NIHR initiatives</li> <li>Ensure the research statement is added to all patient/service user letters and is suitably evaluated</li> <li>Promote PPI in the foundation Trust newsletter</li> <li>Promote PPI in the Trust at induction stands supported by trained individuals.</li> </ul>	<p>Alison Barraclough (AB, Clinical Studies Officer)</p> <p><b>AB/AR</b></p> <p><b>AB</b></p> <p><b>SK</b></p>	<p>Ongoing</p> <p>To be agreed</p> <p>Ongoing</p> <p>Ongoing</p>
1.	(d) Develop online and paper-based materials for communicating with patients and the public about involvement opportunities in research.	<ul style="list-style-type: none"> <li>Develop a database of service users, carers and members of the public who would like to participate in research at BDCT</li> <li>Develop a web portal for PPI to also link in with regional portal for Y&amp;H</li> <li>Develop a 'Research Information Manual' to go in all outpatient/clinic receptions co-produced with service users.</li> <li>Provide quarterly updates of 'PPI opportunities' to all staff and outpatient/clinic receptions</li> <li>Place campaign screen savers on Trust and University TV screens</li> </ul>	<p><b>AR</b> with support from IT officer</p> <p><b>AR</b> with support from IT officer</p> <p><b>AR + Service User Rep</b> to be decided</p> <p><b>SK</b> with support from admin</p> <p><b>AB</b></p>	<p>To be agreed</p> <p>To be agreed</p> <p>To be agreed</p> <p>Ongoing</p> <p>Ongoing</p>

Goal	Objective	Action	Lead	Timeframe
		<ul style="list-style-type: none"> <li>• Add our details to council booklet of services.</li> <li>• Use examples of good practice of PPI in research including the impact of this on portal and to support promotional activities</li> </ul>	<b>AB</b>  <b>AR</b>	April 2015  Ongoing
2. and 4.	(e) To develop and support alliances with key stakeholders, i.e., service user and carers group, the public, researchers, government, appropriate interest groups, funders and sponsors, CCGs, CSUs. In particular to increase involvement in research amongst hard to reach groups	<ul style="list-style-type: none"> <li>• Identify, support and develop key partnerships by visible representation at key events and fora</li> <li>• Develop and maintain a register of internal and external links with a named contact e.g. BME, LGBT internal networks and Voluntary, Faith &amp; Community Services (VCFS), Healthwatch, BAMHAG etc.</li> <li>• Develop an online information source for researchers on how to access PPI in research, e.g., to access a reviewer for participant information sheets (PIS) and consent forms</li> <li>• Run a development day/workshop to identify and prioritise research questions from (i) a service user and carer perspective (ii) joint stakeholder, service user, carer and professional perspective.</li> </ul>	<b>AR/SK/AB</b>  <b>SK</b> with support from admin/IT officer  <b>AR</b> with support from IT Officer  <b>All</b>	Ongoing  June 2015  Ongoing  To be agreed
3.	(f) To ensure that carers, patients and the public have access to appropriate resources and training to support them in being involved in research.	<ul style="list-style-type: none"> <li>• Review resources, training and support in the table in <a href="#">Appendix D</a> annually</li> <li>• Ensure all staff are aware of the resources, training and support available</li> <li>• Link with regional and</li> </ul>	<b>AB</b>  <b>All</b>  <b>Shahid Islam (SI, Patient</b>	Feb 2015  Feb 2015  Ongoing, to be

Goal	Objective	Action	Lead	Timeframe
		<p>national opportunities for training e.g. EPAP</p> <ul style="list-style-type: none"> <li>• Work with Involvement team and existing strategies to assess the training needs of patients, carers and the public in being involved in research.</li> <li>• Monitor training process and outcomes including collection of feedback about satisfaction with resources and effectiveness of these.</li> </ul>	<p>Improvement Manager)</p> <p><b>SK</b></p>	<p>reviewed Oct 2014</p> <p>Ongoing with quarterly reports to group</p>
5.	(g) To monitor and evaluate the effectiveness and impact of patient and public involvement in research and disseminate to all stakeholders. To ensure appropriate levels of recognition and reward for involvement are maintained.	<ul style="list-style-type: none"> <li>• Embed PPI activity in all BDCT Research Governance, Approvals and Monitoring and Audit Standard Operating Procedures</li> <li>• Survey researchers to determine added value from PPI</li> <li>• Survey patients and members of the public involved in research to find out their experiences and how they might be improved</li> <li>• Disseminate findings to key local and national stakeholders</li> <li>• Develop advice on how to demonstrate the impact of PPI activity in research.</li> <li>• Review activity across all areas of the research cycle and prioritise activity for 2015/16</li> <li>• To ensure an adequate mechanism is in place for capturing and rewarding PPI endeavours across the Trust</li> </ul>	<p><b>SK</b></p> <p><b>SK</b></p> <p><b>SK</b></p> <p><b>SK</b></p> <p><b>SK</b></p> <p><b>SK</b></p> <p><b>SK</b></p>	<p>July 2014</p> <p>Jan 2015</p> <p>Jan 2015</p> <p>Mar 2015</p> <p>Dec 2015</p> <p>Jan 2015</p> <p>Jan 2015</p>

### **13.0 Links**

[www.bdct.nhs.uk](http://www.bdct.nhs.uk)

[www.invo.org.uk/](http://www.invo.org.uk/) (INVOLVE)

[www.rds-yh.nihr.ac.uk/](http://www.rds-yh.nihr.ac.uk/) (Research Design Service, Y&H)

[www.bamhag.org.uk](http://www.bamhag.org.uk) (Bradford & Airedale Mental Health Advocacy Group)

## 14.0 Appendices

### Appendix A – Glossary<sup>7</sup>

<b>Abstract:</b> This is a brief summary of a research study and its results. It should tell you why the study was done, how the researchers went about it and what they found.
<b>Analysis:</b> Data Analysis involves examining and processing research data, in order to answer the questions that the project is trying to address. It involves identifying patterns and drawing out the main themes and is often done with specialist computer software.
<b>BAMHAG:</b> Bradford and Airedale Mental Health Advocacy Group
<b>BME:</b> Black, minority, ethnic
<b>Clinical Research:</b> Clinical research aims to find out the causes of human illness and how it can be treated or prevented. This type of research is based on examining and observing people with different conditions and sometimes comparing them with healthy people. It can also involve research on samples of blood or other tissues, or tests such as scans or X-rays. Clinical researchers will also sometimes analyse the information in patient records or the data from health and lifestyle surveys.
<b>CCG:</b> Clinical Commissioning Groups are groups of GP practices that are responsible for commissioning the majority of health and care services for patients.
<b>CSU:</b> Clinical Support Units provide a range of support services to CCG's, including supporting research in primary care.
<b>Clinical Trial:</b> Clinical trials are research studies involving people who use services, which compare a new or different type of treatment with the best treatment currently available. They test whether the new or different treatment is safe, effective and any better than what already exists. No matter how promising a new treatment may appear during tests in a laboratory, it must go through clinical trials before its benefits and risks can really be known.
<b>Consent:</b> (often referred to as 'informed consent'). A process by which a person voluntarily confirms his or her willingness to participate in a particular study, after having been informed of all aspects of the study that are relevant to that person's decision to participate. Informed consent is documented by means of a written, signed and dated informed consent form.
<b>Data:</b> Data is the information collected through research. It can include written information, numbers, sounds and pictures. It is usually stored on computer, so that it can be analysed, interpreted and then communicated to others e.g. in reports, graphs or diagrams.
<b>Dissemination:</b> Dissemination involves communicating the findings of a research project to a wide range of people who might find it useful. This can be done through: <ul style="list-style-type: none"><li>• Producing reports (often these are made available on the Internet)</li><li>• Publishing articles in journals or newsletters</li><li>• Issuing press releases</li><li>• Giving talks at conferences.</li></ul> It is also important to feedback the findings of research to research participants.

<sup>7</sup> Staley K. (2009) Exploring Impact: Public involvement in NHS, public health and social care research. INVOLVE, Eastleigh, p98 (Adapted from)

<p><b>Focus Group:</b> A focus group is a small group of people brought together to talk. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions to problems.</p>
<p><b>‘Grey literature’:</b> Grey literature is material that is less formal than an article in a peer review journal or a chapter in a book – so it’s not easily tracked down. It includes internal reports, committee minutes, conference papers, factsheets, newsletters and campaigning material. However, ‘grey literature’ may be made available on request and is increasingly available on the Internet.</p>
<p><b>Involvement Typology:</b> The level or degree of involvement, e.g. ‘consultation’ is when someone is invited to give their views on a proposed scheme or idea, whereas ‘control’ would indicate a far greater level of involvement e.g. advising on research priorities.</p>
<p><b>LGBT:</b> Lesbian, gay, bi-sexual, trans-gender</p>
<p><b>Outcome measures:</b> Outcome measures are measurements of the effects of a treatment or service. They might include physical measurements – for example measuring blood pressure or psychological measurements – for example measuring people’s sense of well-being. So if someone takes part in research, they may be asked questions, or may be asked to have extra tests to assess how well the treatment or service has worked.</p>
<p><b>Participant:</b> A participant is someone who takes part in a research project. Sometimes research participants are referred to as research ‘subjects’.</p>
<p><b>Patient information sheet (PIS):</b> Researchers must provide a patient information leaflet to everyone they invite to take part in a research study, to ensure people can make an informed decision about this. The leaflet explains what taking part will involve and should include details about:</p> <ul style="list-style-type: none"> <li>• Why the research is being done, how long it will last and what methods will be used</li> <li>• The possible risks and benefits</li> <li>• What taking part will practically involve e.g. extra visits to a hospital or a researcher coming to interview someone at home</li> <li>• What interventions are being tested or what topics an interview will cover</li> <li>• How the researchers will keep participants information confidential</li> <li>• What compensation is available to people if they are harmed as a result of taking part in the research</li> <li>• Who to contact for further information</li> <li>• How the results will be shared with others</li> </ul>
<p><b>Peer interviewers:</b> In peer interviews the participants are interviewed by people who have a similar experience to them – their peers. For example, in a project to find out about children’s experiences of after school care, children with experience of using after school care may act as peer interviewers, asking other children for their views.</p>
<p><b>Peer review:</b> Peer reviewing is where a research proposal or a report of research is read and commented on by people with similar interests and expertise to those who wrote the proposal or report. Peer reviewers might be members of the public, researchers or other professionals. Peer review helps to check the quality of a report or research proposal. Members of the public who act as peer reviewers may choose to comment on:</p> <ul style="list-style-type: none"> <li>• Whether the research addresses an important and relevant question</li> <li>• The methods used by researchers</li> <li>• The quality of public involvement in the research.</li> </ul>

<p><b>Placebo:</b> A placebo is a fake or dummy treatment that is designed to be harmless and to have no effect. It allows researchers to test for the 'placebo effect'. The placebo effect is a psychological response where people feel better because they have received a treatment, and not because the treatment has a specific effect on their condition. By comparing people's responses to the placebo and to the treatment being tested, researchers can tell whether the treatment is having any real benefit.</p>
<p><b>Proposal:</b> see <b>Research Proposal</b></p>
<p><b>Protocol:</b> A protocol is the plan for a piece of research. It usually includes information about:</p> <ul style="list-style-type: none"> <li>• What question the research is asking and its importance/relevance</li> <li>• The background and context of the research, including what other research has been done before</li> <li>• How many people will be involved</li> <li>• Who can take part</li> <li>• The research method</li> <li>• What will happen to the results and how they will be publicised.</li> </ul> <p>A protocol describes in great detail what the researchers will do during the research. Usually, it cannot be changed without going back to a research ethics committee for approval.</p>
<p><b>Qualitative research:</b> Qualitative research is used to explore and understand people's beliefs, experiences, attitudes or behaviours. It asks questions about how and why. Qualitative research might ask questions about why people want to stop smoking. It won't ask how many people have tried to stop smoking. It does not collect data in the form of numbers. Qualitative researchers use methods like focus groups and interviews (telephone and face-to-face interviews).</p>
<p><b>Quantitative research:</b> In quantitative research, researchers collect data in the form of numbers. So they measure things or count things. Quantitative research might ask a question like how many people visit their GP each year or what proportion of children have an MMR vaccine, or whether a new drug lowers blood pressure more than the drugs that are usually used. Quantitative researchers use methods like surveys and clinical trials.</p>
<p><b>Randomised controlled trial:</b> A controlled trial compares two groups of people: an experimental group who receive the new treatment and a control group who receive the usual treatment or a placebo. The control group allows the researchers to see whether the treatment they are testing is any more or less effective than the usual or standard treatment. In a randomised controlled trial (RCT) the decision about which group a person joins is random (i.e. based on chance). A computer will decide rather than the researcher or the participant. Randomisation ensures that the two groups are as similar as possible except for the treatment they receive. This is important because it means that the researcher can be sure that any differences between the groups are only due to the treatment.</p>
<p><b>Research Proposal:</b> This is usually an application form or set of papers that researchers have to complete to say what research they want to do and how they want to do it. It will also cover the aim of the research, what the research questions are, who will be involved (both as participants and in carrying out the research), the timescale and the cost.</p>
<p><b>Stakeholder:</b> A stakeholder is anyone who has an interest in a research project. It includes the people and organisations who are actively involved, as well as the people who might be affected by the outcomes.</p>

**Systematic review:**

Systematic reviews aim to bring together the results of all studies addressing a particular research question that have been carried out around the world. They provide a comprehensive and unbiased summary of the research. For example one clinical trial may not give a clear answer about the effectiveness of a treatment. This might be because the difference between the treatments being tested was very small, or because only a small number of people took part in the trial. So systematic reviews are used to bring the results of a number of similar trials together, to piece together and assess the quality of all of the evidence. Combining the results from a number of trials may give a clearer picture.

**User researcher:**

A user researcher is someone who uses or has used health and/or social care services because of illness or disability, who is also a researcher. Not all researchers who use health or social care services call themselves user researchers. Calling yourself a user researcher is making a statement about your identity as a service user as well as a researcher.

**XPLORE:**

A service-user led research project running within BDCT.

**Web Portal:**

A specially designed Web page within a larger website which brings together information from a range of diverse sources in a uniform way.



## Appendix B – BDCT Services

Mental Health	Community Health	Learning Disability
<b>Adult Mental Health:</b> <ul style="list-style-type: none"> <li>• In-patient Wards</li> <li>• Urgent Response</li> <li>• Intensive Home Treatment Team</li> <li>• Housing Related Support</li> <li>• Day Services</li> </ul>	<b>Adult Services:</b> <ul style="list-style-type: none"> <li>• District Nurses</li> <li>• Community Matrons</li> </ul>	<b>Specialist Services:</b> <ul style="list-style-type: none"> <li>• Behavioural outreach team</li> <li>• Community matrons</li> <li>• Clinical team</li> <li>• Health facilitation team</li> <li>• Learning disability psychiatric team</li> </ul>
<b>Child &amp; Adolescent Mental Health:</b> <ul style="list-style-type: none"> <li>• ADHD</li> <li>• Looked After Children (LAC)</li> <li>• Severe Learning Disability (SLD)/Autistic spectrum conditions (ASC)</li> <li>• Substance misuse</li> <li>• Youth offending</li> <li>• Eating disorders</li> <li>• Family therapy</li> </ul>	<b>Allied Professionals and Planned Care:</b> <ul style="list-style-type: none"> <li>• Speech and Language therapy</li> <li>• Foot health</li> <li>• Homeless &amp; New Arrivals team</li> <li>• Carers connection</li> <li>• Tissue viability</li> <li>• Hospice at Home</li> <li>• Palliative care</li> <li>• Continence</li> <li>• Nursing support</li> <li>• COPD</li> <li>• Pulmonary rehab</li> </ul>	<b>In-patient Services:</b>
<b>Low Secure Services:</b> <ul style="list-style-type: none"> <li>• Occupational therapy</li> <li>• Psychology</li> </ul>	<b>Children &amp; Family:</b> <ul style="list-style-type: none"> <li>• Health visiting</li> <li>• School nursing</li> <li>• Safeguarding children</li> <li>• Family nurse partnership</li> </ul>	
<b>Older People's Mental Health:</b> <ul style="list-style-type: none"> <li>• Dietetics</li> <li>• Memory Assessment</li> <li>• Occupational therapy</li> <li>• Physiotherapy</li> <li>• Psychological therapies</li> <li>• Speech &amp; Language</li> </ul>	<b>Dental Services:</b> <ul style="list-style-type: none"> <li>• Salaried services</li> <li>• Emergency services</li> </ul>	
<b>Substance Misuse:</b> <ul style="list-style-type: none"> <li>• Alcohol care team</li> <li>• Multi agency ante natal services</li> <li>• Physical health</li> <li>• Substance misuse</li> </ul>	<b>Specialist:</b> <ul style="list-style-type: none"> <li>• Health on the street</li> <li>• Working women's support</li> <li>• Health trainers</li> <li>• Social prescribing</li> <li>• Champion's Show the Way</li> <li>• Health of Men</li> </ul>	

## Appendix C – Current PPI Opportunities

Research activity	Description	Progress	Level of PPI
“OK to ask” campaign	National campaign to raise awareness	annual	
XPLORE Research Study	Project to assess the impact of long journey times on mental health service users		
PiTSTOP!	Pilot Trial of Stop Delirium! A complex intervention to reduce delirium in care home settings	18/24 months complete	Lay representation on the Implementation Team and Advisory Board.
<p><i>Current and forthcoming BDCT research studies to be added here (see action for Objective b. in the Action Plan)</i></p>			

## Appendix D – Resources, training and support for patients and the public to be involved in research

Name	Type	Description	Access at
PPI in the research process	Online leaflet	This leaflet from the NIHR research design service provides a brief overview of how patients and the public can become involved in all parts of the research process (cycle).	To be embedded into BDCT website for ease of access at a later stage.
The patient and public involvement toolkit Cartwright & Crowe	Book	A short handbook with all the key issues you need to consider about PPI in research, service development, commissioning or provision.  A good short handbook.	Library, bookshop, amazon.  Publisher: Wiley-Blackwell Chichester 2011
Experienced based co-design (EBCD) toolkit	Online co-design toolkit with case examples	EBCD enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership. It is a different service improvement approach.. EBCD involves gathering experiences from patients and staff via in-depth interviewing, observations & group discussions, identifying key 'touch points' (emotionally significant and assigning positive or negative feelings). A short edited film is created from the patient interviews. This is shown to staff and patients, conveying in an impactful way how patients experience the service. Staff and patients are then brought together to explore findings and work in small groups to identify and implement activities that will improve the service or the care pathway.	<a href="http://www.kin.gsfund.org.uk/projects/ebcd">http://www.kin.gsfund.org.uk/projects/ebcd</a>
Good practice guidance for involving carers, family members and close friends of service users in research	Online report	A good practice guide for including carers, patients and the public in research aimed at professionals and users of research.	To be embedded into BDCT website for ease of access at a later stage.

Name	Type	Description	Access at
Mental Health Service User Toolkit	Online toolkit	A toolkit for involving service users in the research process	
NHS networks SMART guides to engagement	Online series of booklets (CCG focus)	The Smart Guides to Engagement series is for everyone working in or with clinical commissioning groups (CCGs). The guides have been written by experts to provide straightforward advice on all aspects of patient and public engagement in an easily digested format.	<a href="http://www.networks.nhs.uk/nhs-networks/smart-guides/">http://www.networks.nhs.uk/nhs-networks/smart-guides/</a>
INVOLVE train the trainer PPI package	Online resource	There is a resource on the INVOLVE website for assessing training needs and delivering training to patients and the public who are in a range of roles. There is no “off the shelf” training package from this site because there are few public training programmes. They usually need to be tailored to the needs of your target audience.	<a href="http://www.invo.org.uk/resource-centre/training-resource/">http://www.invo.org.uk/resource-centre/training-resource/</a>