Brain Health Centre
Patient and Public Involvement and Engagement
Objectives

Thanks to the members of the BHC Advisory Group for their support in developing these objectives.

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1. Introduction and background

1.1 The OH BRC Brain Health Centre

The Brain Health Centre (BHC) is a joint research and clinical assessment centre that aims to combine research into a clinical service to improve diagnosis and management for disorders of mental and cognitive health.

Establishing the BHC is a key objective of NIHR Oxford Health Biomedical Research Centre (OH BRC), which is a partnership between Oxford Health NHS Foundation Trust and the University of Oxford. In 2016, the OH BRC was awarded £12.8 million by the NIHR to focus on adult mental health, older adults and dementia, and precision psychological treatments research. The OH BRC aims to bring the best science to the complex problems of mental disorders and dementia, to transform scientific discoveries into new treatments.

The BHC will provide patients with access to high-quality assessments not commonly available in clinical practice, and increase opportunities for patients and carers to participate in research studies and trials. The BHC will empower clinicians to give more confident, timely diagnoses, and enable researchers to test novel diagnostic, treatment and prevention strategies, which can be rapidly put in place to provide better care for patients.

Whilst the overall ambition of the BHC is to serve all of mental health, the initial focus of the BHC is memory clinic services run by Oxford Health NHS Foundation Trust. A pilot of the BHC will run for six months from June 2019. If successful, the BHC pilot will be extended and expanded.

1.2 Patient and Public Involvement and Engagement (PPIE) in the BHC

The OH BRC has developed a PPIE strategy that provides processes to support researchers and the public to work together towards the ultimate aim of tailoring personalised treatment for people with mental disorders and dementia (https://oxfordhealthbrc.nihr.ac.uk/patient-and-public-involvement/ppi-strategy/). The OH BRC PPIE strategy has informed the BHC’s PPIE objectives and planned activities.

The BHC is a new entity, providing the opportunity for Patient and Public Involvement to influence the design and development of the BHC from the start. The BHC also aims to develop and expand over time, and therefore the PPIE objectives reflect the different phases of the project.

The BHC recognises the importance of working together with people with lived experience of health conditions (i.e. patients/service users, and family/friends who care for them), and members of the public.

The BHC recognises that Patient and Public Involvement and Engagement (PPIE) helps develop research that better serves the needs and interests of patients, carers and researchers, than that developed by researchers alone. PPIE is fundamental to achieving the aims of the BHC, and will improve the quality of the clinical service we provide and the research we carry out.
1.3 Developing the objectives

In 2018, the BHC Advisory Group was set up, to bring together patient, carer, public and staff members to guide the PPIE activities for the BHC. The BHC Advisory Group advised on the development of the BHC’s PPIE objectives.

In early 2019, the draft objectives were sent out for consultation to:

- The BHC Advisory Group
- The BHC Working Group
- The OH BRC PPI Manager

Feedback was incorporated and the objectives were published in July 2019.

2. Vision and purpose for PPIE at the BHC

The BHC’s vision is for PPIE activities to be embedded in the decisions, activities and future directions of the BHC. Embedding PPIE activities in the BHC will make sure that the first-hand insights and experiences of patients and carers will help identify and fully consider what is important for the project.

To achieve this, the BHC PPIE objectives will provide targets and actions that will support researchers and public members to work together, to the ultimate benefit of the BHC and its public contributors.

3. Objectives

We have identified 6 objectives to help us to achieve our vision and purpose. See Appendix 1 for our framework of activities to deliver these objectives.

3.1 Objective 1: Establish the infrastructure to embed public participation in the set-up and running of the Brain Health Centre

As part of this objective, we will focus on setting up the infrastructure necessary to make ongoing PPIE a core feature of the BHC. This will include: setting up a PPI Advisory Panel, recruiting a PPI member to the BHC Working Group and developing BHC PPIE objectives in collaboration with the BHC PPI Advisory Group. We will communicate major actions and decisions of the BHC Working Group to the BHC PPI Advisory Group, and vice versa, to ensure a two-way dialogue.

We will also document and share PPIE training resources to ensure public contributors benefit from involvement in the BHC, including regular circulation of training opportunities, sharing experiences to learn from each other, and development of learning opportunities for other PPI contributors, in collaboration with the OH BRC PPI manager.
3.2 Objective 2: Incorporate patients, family and public views into the design of the clinical service provided at the Brain Health Centre

We will work with the BHC Advisory Group and the BHC PPI Working Group representative to ensure that patient and carer experience of the clinical service provided by the BHC is as good as or better than expected.

In delivering this objective, we will review clinic letters and documents to make sure information is clear and easy to read and understand, ensure the timing and nature of communication with the BHC before, during and after the appointment is acceptable, and invite members of the BHC Advisory Group to participate in a trial run of BHC assessments.

By working with the BHC Advisory Group, and wider public groups, we aim to create a positive experience of the clinical service and maximise attendance to the clinical service.

3.3 Objective 3: Incorporate patient, family and public views in the research carried out at the Brain Health Centre

We will incorporate feedback from the BHC Advisory Group, and wider public groups, in to the way BHC research is conducted (e.g. the number and duration of tests), to ensure the nature and duration of research activities are acceptable for patients and their families.

With the BHC Advisory Group, we will review research documents to make sure information is clear and easy to understand, and review the BHC research data sharing policies to ensure these are acceptable.

Public contributors will continue to have input to the BHC research through the data access committee, which will also include the BHC Administrator. This group will review and monitor applications to the BHC Research Database, particularly those from industry applicants, and will prioritise research study applications to minimise burden to potential research volunteers.

We will also work with the BHC Advisory Group to identify further opportunity for PPI to influence our research across the research cycle, including identifying which research questions are important to patients and carers.

By incorporating patient, family and public feedback, we aim to create a positive experience of the research offered at the BHC and maximise participation in research at the BHC.

3.4 Objective 4: Involve patients, family and the public in the monitoring and evaluation of the Brain Health Centre

We will involve the BHC Advisory Group, as well as patients and family members that have used the BHC service, in the evaluation of the success of the BHC pilot. This will include:

- Reviewing the anonymous feedback from BHC attendees, to provide ideas for addressing areas that may require improvement
• Evaluating the success of public involvement in the BHC, by reviewing whether the PPI activities have achieved their intended aims
• Evaluating the public contributors’ experiences of involvement in the BHC project, to inform how PPI is done within the BHC after the pilot

The BHC Project Manager and PPI Working Group representative will raise the public feedback for discussion by the BHC Working Group to make sure public feedback is included in the future plans of the BHC.

After the BHC pilot, we will also review the membership of the BHC Advisory Group to ensure we have the best representation on the panel for the next phase of the project.

3.5 Objective 5: Involve patients, family and the public in outreach and public engagement to promote the Brain Health Centre and its research findings

As part of this objective, we will tap into the networks of BHC public contributors to ensure public input to the BHC is representative of the population that the service will serve.

We will also involve public contributors when communicating the benefits of the BHC to key stakeholders, including:

• Researchers - to maximise the use of the research data collected by the BHC
• Commissioners - to help ensure the continued running of the BHC
• Clinicians - to encourage BHC practices and research advances to be incorporated into clinical practice.

To improve public knowledge and understanding of the BHC and the research carried out there, we will involve public contributors in the promotion of the BHC and its research findings to the wider public as well as the media. In particular, we aim to consult the BHC Advisory Group on press releases and other public scientific communication to ensure BHC research findings are shared in a way that the public can read and understand them.

3.6 Objective 6: Incorporate patient, family and public feedback into the future directions of the Brain Health Centre

To ensure future priorities and directions of the BHC are right for patients, family members and the public, we will present proposed changes to the BHC’s clinical and research activities to the BHC Advisory Group, and wider public groups where appropriate to the proposed change. The BHC staff will aim to address feedback from the BHC Advisory Group before changes are put into practice at the BHC.

Any future funding applications to support the continued running of the BHC will include PPI contributors as named applicant(s).
4. Delivering our objectives

To guide the way we work and achieve our objectives, we will use the relevant principles set out in the OH BRC PPIE strategy guidance (https://oxfordhealthbrc.nihr.ac.uk/patient-and-public-involvement/ppi-strategy):

- We will work collaboratively, where sensible and practical to do so, with a range of internal and external partners
- We will be pragmatic, recognising that the scope of the BHC will change over time
- We will use existing tools and processes, where it is sensible and practical for us to do so
- We will foster a culture of respect and equality, that allows for the empowerment of all concerned
- We will be transparent, striving for communications that are easily accessible
- We will learn by doing, recognising this is an iterative process, and will review progress and consider learning outcomes on an annual basis
- We will aim to understand what impact our strategy is having, and will adjust our approach to assessing impact in line with evolving NIHR guidance and in collaboration with local partners
- We will aim to deliver PPIE in keeping with the NIHR standards

We will annually review the BHC PPIE objectives and progress made towards achieving our objectives. We will also develop an annual work plan, by identifying specific activities for each objective, and specifying timeframes for activities and measures of success.

5. Accountability and reporting

The BHC Project Manager is responsible for delivering the BHC PPIE objectives and work plans, including reporting, and will work with the BHC Advisory Group to monitor progress and review objectives.

The BHC Project Manager works closely with the OH BRC PPI Manager and reports to the BHC Principal Investigator.

Progress on PPIE is regularly reported at BHC Working Group meetings and is included in the annual reporting to the NIHR. A summary of the annual reporting for PPI activities across the OH BRC will be published on the OH BRC PPI website (https://oxfordhealthbrc.nihr.ac.uk/patient-and-public-involvement/).
6. Further information

For more information about the Brain Health Centre, please contact:

- Brain Health Centre Administrator
  - Karen Lindsay
  - karen.lindsay@psych.ox.ac.uk
  - 01865 618184

- Brain Health Centre Project Manager
  - Gary Gibbs
  - gary.gibbs@psych.ox.ac.uk
  - 01865 618267

For more information about PPIE and how you can get involved, please contact:

- Public and Patient Involvement Manager
  - Claire Murray
  - claire.murray@oxfordhealth.ox.ac.uk
# Appendix 1 – Activities to Deliver the BHC PPIE objectives 2018-2022

## Objective 1: Public involvement

Establish the infrastructure to embed PPIE in the set-up and running of the Brain Health Centre

<table>
<thead>
<tr>
<th>Activities</th>
<th>Measures of success:</th>
<th>Timeframe:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establish a BHC PPI advisory group</td>
<td>Diverse group of people living with dementia, family members and public members recruited</td>
<td>2018/19</td>
</tr>
<tr>
<td>Recruit a PPI member to the BHC working group</td>
<td>Working group meeting regularly attended by PPI representative</td>
<td>2018 and ongoing</td>
</tr>
<tr>
<td>Develop PPIE objectives for the BHC</td>
<td>Objectives drafted; objectives document reviewed and agreed by working group and OH BRC PPI manager; objective document published on OH BRC website</td>
<td>2019</td>
</tr>
<tr>
<td>Document and share training opportunities and resources to develop the knowledge/skills of the BHC advisory group</td>
<td>Satisfactory list of PPIE resources compiled and shared with advisory group; list of resources regularly reviewed and updated</td>
<td>2019 and ongoing</td>
</tr>
<tr>
<td>Establish and maintain regular discussions of PPIE activities at BHC working group meetings</td>
<td>PPIE added as standing item on BHC working group agenda; PPIE updates provided at each working group meeting</td>
<td>2018 and ongoing</td>
</tr>
<tr>
<td>Set up regularly communication of project progress to the Advisory group</td>
<td>Relevant minutes and actions from working group circulated to advisory group after each meeting</td>
<td>2019 and ongoing</td>
</tr>
</tbody>
</table>

## Objective 2: Design of clinical service

Incorporate patients, carers and public views into the design of the clinical service provided at the Brain Health Centre

<table>
<thead>
<tr>
<th>Activities</th>
<th>Measures of success:</th>
<th>Timeframe:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide feedback on letters and documents related to clinical service</td>
<td>Documents reviewed; feedback incorporated.</td>
<td>mid 2019</td>
</tr>
<tr>
<td>Provide feedback waiting room material</td>
<td>Potential material identified; material revised; suggestions considered and actioned by working group</td>
<td>mid 2019</td>
</tr>
<tr>
<td>Provide feedback on timings of patient journey (before, during and after BHC appointment)</td>
<td>Timings reviewed; feedback incorporated</td>
<td>mid 2019</td>
</tr>
<tr>
<td>---</td>
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</tr>
<tr>
<td>Provide feedback on communication with patients/family member before, during and after BHC appointment</td>
<td>Communication methods/procedures reviewed; feedback recorded and incorporated</td>
<td>mid 2019</td>
</tr>
<tr>
<td>Provide feedback on procedures undertaken by patients and their carer during the patient journey (during the BHC appointment)</td>
<td>BHC clinical procedures reviewed; feedback recorded and incorporated</td>
<td>mid 2019</td>
</tr>
<tr>
<td>Provide feedback from perspective of patient/family member on the BHC clinic day</td>
<td>Advisory group participated in trial run; comments and feedback recorded; feedback incorporated</td>
<td>mid 2019</td>
</tr>
</tbody>
</table>

**Objective 3: Design and conduct of BHC research**

Incorporate patient, family and public views in the research carried out at the Brain Health Centre

<table>
<thead>
<tr>
<th>Activities:</th>
<th>Measures of success:</th>
<th>Timeframe:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide feedback on public research documents</td>
<td>Information sheets and consent forms reviewed; feedback recorded and incorporated</td>
<td>early 2019</td>
</tr>
<tr>
<td>Provide feedback on the number, duration and format (e.g. computerised or pen/paper) of research assessments</td>
<td>Research assessment procedures reviewed; feedback recorded and incorporated</td>
<td>mid 2019</td>
</tr>
<tr>
<td>Provide feedback on the methodology of research activities (e.g. type of questions asked, when to ask questions), where appropriate</td>
<td>Research assessment methodology reviewed; feedback recorded and incorporated</td>
<td>mid 2019</td>
</tr>
<tr>
<td>Provide feedback on BHC data sharing policies</td>
<td>Data sharing policies reviewed; feedback recorded and incorporated</td>
<td>mid 2019</td>
</tr>
<tr>
<td>Establish a BHC data access group</td>
<td>Group including PPI contributors and BHC administrator formed and convening on a monthly basis</td>
<td>late 2019 onwards</td>
</tr>
<tr>
<td>Provide suggestions for future research questions to be</td>
<td>Research suggestions complied and discussed by the BHC research team</td>
<td>2020 and ongoing</td>
</tr>
</tbody>
</table>
addressed by the BHC

Identify further opportunities for PPI to influence BHC research across the research cycle | Opportunities for further PPI identified, recorded and incorporated | 2020 and ongoing

**Objective 4: Evaluation**

Involve patients, family members and public in the monitoring and evaluation of the Brain Health Centre

<table>
<thead>
<tr>
<th>Activities:</th>
<th>Measures of success:</th>
<th>Timeframe:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify BHC service users to join the PPI advisory panel</td>
<td>Service users recruited to advisory group; regular attendance at meetings</td>
<td>late 2019</td>
</tr>
<tr>
<td>Identify areas of improvement based on anonymous feedback from BHC attendees</td>
<td>Pilot feedback reviewed by the advisory group; feedback summarised and improvements suggested to the working group; suggestions implemented where appropriate</td>
<td>late 2019, ongoing until early 2020</td>
</tr>
<tr>
<td>Explore the success of PPI involvement in the BHC</td>
<td>Progress against set objectives reviewed annually</td>
<td>mid 2019 and ongoing</td>
</tr>
<tr>
<td>Evaluate the experience of public contributors’ involvement in the BHC</td>
<td>Experience of public contributors captured annually; identified improvements implemented and good practices continued</td>
<td>mid 2019 and ongoing</td>
</tr>
</tbody>
</table>

**Objective 5: Outreach**

Involve patients, family members and public in outreach and public engagement to promote the Brain Health Centre and its research findings

<table>
<thead>
<tr>
<th>Activities:</th>
<th>Measures of success:</th>
<th>Timeframe:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify wider public groups and organisations for PPI consultations</td>
<td>Key relationships with community groups identified and developed; public groups/organisation collaborators reviewed regularly</td>
<td>2019 and ongoing</td>
</tr>
<tr>
<td>Promote BHC and its benefits to clinicians</td>
<td>Plan of events/activities developed, delivered and recorded</td>
<td>late 2019 and ongoing</td>
</tr>
<tr>
<td>Promote BHC and its benefits to researchers</td>
<td>Plan of events/activities developed, delivered and recorded</td>
<td>late 2019 and ongoing</td>
</tr>
<tr>
<td>Support the BHC to promote</td>
<td>Plan of events/activities developed, delivered and recorded</td>
<td>late 2019 and ongoing</td>
</tr>
<tr>
<td>the BHC and its benefits to commissioners</td>
<td>delivered and recorded</td>
<td>ongoing</td>
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<td>----------------------------------------</td>
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<tr>
<td>Promote BHC and its benefits to wider public</td>
<td>Opportunities to promote the BHC identified and addressed</td>
<td>late 2019 and ongoing</td>
</tr>
<tr>
<td>Support the BHC to promote BHC and its benefits to the media</td>
<td>BHC communications plan supported; media output regularly reviewed and recorded</td>
<td>late 2019 and ongoing</td>
</tr>
<tr>
<td>Support sharing of research findings with the public</td>
<td>Lay friendly research summarises drafted and promoted via the BHC website</td>
<td>2020 and ongoing</td>
</tr>
</tbody>
</table>

**Objective 6: Future directions**

Incorporate patients, family members and public feedback into the future directions of the Brain Health Centre

<table>
<thead>
<tr>
<th>Activities:</th>
<th>Measures of success:</th>
<th>Timeframe:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide feedback on future changes to BHC protocols to PPI panel</td>
<td>Proposed changes to BHC protocols presented to the advisory group; feedback recorded and implemented.</td>
<td>2019 and ongoing</td>
</tr>
<tr>
<td>Provide a PPI perspective for future grant applications</td>
<td>PPI representative(s) included as co-applicant(s) on future grant applications</td>
<td>2020 and ongoing</td>
</tr>
</tbody>
</table>