Patient and Public Involvement / Public Engagement Strategy

NIHR Cambridge Biomedical Research Centre, 2019-2020

Overview

Cambridge University Health Partners (CUHP) is an Academic Health Science Centre formed of a partnership between three leading NHS Trusts and the University of Cambridge, which together host the National Institute for Health Research (NIHR) Cambridge Biomedical Research Centre (BRC). Together, they combine world-leading expertise, high quality health care facilities, outstanding research infrastructure and established, productive links with industry. The dynamic interaction between academia, industry and the NHS results in ground-breaking research that will lead to better outcomes for patients and their families, improve the efficiency and quality of the NHS, and benefit the local and national economy.

Patients and the public are central to our strategic aims and their experience and expertise are essential to ensure that our research goals and outputs are relevant, value for money and achieve maximum beneficial impact, driving our research discoveries from basic research to improved treatments and service delivery.

Strategy

Our strategy has been developed in consultation with the Patient and Public Involvement/Engagement (PPI/E) in Research Oversight Committee, campus research professionals and members of our CUH PPI/E panel. Our vision is to actively involve patients and the public in all aspects of our research, and to produce a range of engagement activities to showcase our findings. We aim to empower researchers and the public with the training that they need to maximize the impact from involvement collaborations and to provide appropriate support to researchers to develop and execute their PPI plans. Finally, we will carefully evaluate all aspects of our public involvement to ensure maximum positive impact for all stakeholders and to track its influence on research outcomes. We will incorporate feedback into our training programs for researchers and contributors and work to share best practice, locally and with our external collaborators and partners.

Aims

Increasing the range of opportunities to be involved and diversity of participants

A variety of PPI activity is already operating on campus, with many research groups establishing their own patient/carer advisory groups. We also have a panel of public volunteers (CUH PPI/E panel) who are interested in research and are available to provide feedback and advice to campus researchers. We aim to build on this to be able to connect interested members of the public with a variety of opportunities to get involved, in ways that suit their circumstances, skills and interests and that are best suited to the research in question. Working with patient support groups, charities and community leaders, we will also look for ways to increase involvement from under-served groups to ensure that as many voices as possible are heard. Encouraging young people to become more
involved in research and to consider research as a potential career is also a major focus and we will work to build upon our successful work with the Young People in Research Program to widen young person participation and involvement in research.

*Improved communication of campus research activity and Involvement / Engagement opportunities*

Our vision is to ensure that every patient is aware of our research activity and we will encourage our research and clinical staff to engage with patients about their research and encourage them to be involved. As part of this, we will work with our clinical staff to increase awareness and to promote the research taking place on campus. Effective engagement and communication of our research can inspire greater involvement, and we will aim to include an invitation to become involved in all our communication and engagement activities. Likewise, all patients and public contributors who become involved in campus research will be invited to engagement opportunities and kept informed of research progress and outcomes. We will also seek feedback from our patient and public contributors on our communications to ensure that they are as accessible and effective as possible.

*Embed PPI in research cycle and governance*

Quality patient and public involvement has the potential to positively impact all patient-focused research, and research can benefit from public expertise at all stages of the research cycle. Our goal is to embed PPI into our research governance framework to encourage researchers to view public involvement as integral to research initiation as ethics and regulatory approval. Furthermore, we aim to facilitate researchers to extend their PPI activities beyond the earliest stages of their research, to include oversight and goal setting during data collection, and, most importantly, to encourage appropriate, effective dissemination of their results to relevant stakeholders.

*Training for researchers and contributors*

We provide tailored training for researchers to support their PPI activities, including general introductory training for students and new researchers and more targeted training on specific aspects of PPI, such as writing lay summaries, facilitating focus groups and forming patient advisory groups. We will also develop further training materials as requested by researchers and in response to feedback from patient and public contributors. We will provide training and support for our public contributors to equip them with the skills and confidence they need to maximize their involvement, and support researchers in providing training to their advisory groups as required.

*Valuing honest evaluation and feedback to maximise Impact*

We recognize that effective collaboration between the public and researchers takes significant time, energy and enthusiasm from all involved, and, mindful of this investment, we will carefully evaluate our PPI activities for their impact on the public, the researchers and the research itself.

We encourage and invite feedback from all participants in public/researcher partnerships, and will encourage the sharing of best practice across the campus. We will support the adoption of the National Standards for Public Involvement as a benchmarking tool for evaluating PPI activities and use them to track progress in improving involvement across campus.
Partnerships and Collaborations

On campus and regionally there are several NIHR organisations that we work with to deliver PPI strategy, including the BRC, RDS, CCTU, BioResource, CRF and PLRH. We will consult and collaborate with our partners to deliver complimentary involvement strategies and share training and other resources to avoid duplication. Additionally, we will work with other campus and local research institutes, such as CRUK, the Wellcome Trust, Cambridge University and the Sanger Institute, and with the biomedical industries based on campus, such as AstraZeneca and Abcam, to share best practice and raise awareness of further involvement opportunities.

Evaluation and Governance

PPI activity on campus is governed at multiple levels, led by the PPI in Research Oversight Committee, formed of CUHP Governors and senior research leaders. Other campus-wide PPI committees meet throughout the year, and further oversight is provided by the Strategy Lead for Patient and Public Involvement for Cambridge BRC and the PPI team. We will undertake an annual evaluation of our PPI/E activity, to assess its impact on public contributors, researchers and the research that is generated. PPI/E activities and improvements will be assessed by formal and informal feedback from researchers and involved members of the public, in addition to objective measures such as the proportion of research applications featuring quality PPI/E plans and the number of researchers accessing PPI/E advice.