

NIHR UCLH Biomedical Research Centre Strategy for Patient and public involvement, engagement and communications

March 2018

Context

We are excited about the future possibilities for public involvement, engagement and communications at the UCLH Biomedical Research Centre.

Our expanded BRC now encompassing 13 themes, the deliberate steps now being taken by UCLH to become a research hospital, and the unfolding new agenda for the NIHR provides us with a real opportunity to make a step change in our public-facing work, building on our strengths and successes of the last 5 years.

This strategy aims to set out how we intend to take full advantage of this context and to remain a leading organisation in involving patients, carers and the public in all that we do to improve our research and its impact.

Strategy development

This strategy was developed by our PPI Strategy Committee, which also continues to monitor the strategy and revise the plans as necessary. The Committee is made up of 2 lay people, 2 researchers and our theme lead and PPI Manager. It was also developed after working closely with the directors of the BRC's 13 themes and to meet the needs of our Clinical Research Facility. The strategy has also been presented and discussed at the BRC nucleus board which brings together the directors of the BRC's four main themes.

Our aims for the active involvement of patients, carers and the public (PPI) in research at UCLH/UCL are:

- to improve our research by making it more relevant to patient and public need and better able to improve patient care and outcomes
- to involve our communities more fully and effectively in our work
- for UCL/UCLH to become a centre for excellence for PPI
- to conduct our work in accordance with the new UK-wide public involvement standards

Vision for the future

We will work together with patients, the public and the research community to make UCL/UCLH a place where:

- patients are at the heart of our research and are our partners and co-producers
- a diverse and rich representation of patients and the public are involved in our biomedical research – we want the people we involve to be truly representative of our local communities

- PPI is embedded as an essential part of the culture, infrastructure, support and expectations of the broad range of biomedical research –we want the UCL/UCLH research community to be one where all researchers, regardless of their research area or seniority, know how to confidently and effectively involve patients and the public
- PPI is a positive experience for and helpful to researchers, and beneficial and rewarding for the patients and public who work with us
- UCL/UCLH are innovators in PPI, breaking new ground so that the culture of public involvement moves forward
- We are contributing actively to the evidence-base for public involvement and engagement in the UK and abroad
- PPI impact is evaluated and monitored and reported to the public
- We actively seek feedback from our public community and demonstrate how this is leading to continuous improvement in what we do.

Priorities moving forward

The BRC's PPI team of 4 has considerable expertise and track record in PPI, engagement and communications. Our work has been recognised by awards and over the last 3 years has attracted an average of over £70,000 in external funding each year.

By making its PPI/E work into a cross-cutting theme in its 3rd funding term, the BRC will ensure the development of PPI/E across all themes, and as such will provide value for money.

Most importantly, the status of BRC theme will bring the authority and potential partnerships needed to instigate a step change in PPI/E. Our aim is to make use of the status of theme to develop the BRC's PPI/E work to a greater depth and reach than hitherto possible and drive forward a comprehensive, far-reaching programme falling into 4 key areas:

1. Building capacity and capability

Training for researchers

The BRC will continue to provide its training for researchers to give them the skills and confidence to actively and effectively involve patients and the public.

The BRC has established a highly successful programme of PPI training workshops, with over £120,000 funding from HENCEL. The workshops won an award for their contribution to patient-centred training and we have worked with our partners to provide training across the UCLPartners group of organisations. The workshops, developed in consultation with patients and so far delivered to nearly 600 researchers with

PPISUPPORT



640 researchers trained



Impact

X3

Confidence levels of PPI skills tripled after workshops

80%

rated workshops excellent

After 6 months

over **50%**

involved lay people to identify research topics

86%

understood PPI after session, compared to 22% before

64%

respondees carried out PPI

>75%

agreed workshops had helped

Annual PPI Bursary Fund established to offer:

4X £2,000

for innovative PPI

16X £500

PPI starter grants

excellent feedback, provide targeted training, with 'beginners' and 'experienced' grades, focusing on practical advice.

The training is rigorously monitored through immediate evaluation and again six months after the training. Evaluation has shown the support the BRC already provides is highly effective in enabling researchers to carry out PPI.

We will develop this programme to:

- reach a minimum of 200 researchers a year across a wider spread of UCLPartner organisations and including a greater range of career stages and specialties
- train new trainers to increase our access to trainers by at least 100% and in partnership with other BRCs and UCLP partner organisations build up a body of expertise as a foundation for establishing an 'academy' to train trainers.
- publish our evaluation of the training and how it impacts on research
- produce a self-financing programme, with partner organisations contributing financially and increased ability to attract external funds, as well as working with organisations outside the NIHR family to build mutually beneficial partnerships
- extend its rigorous evaluation of training workshops to provide extensive body of data, rather than just narrative documentation of case studies. The theme towards the end of this funding term will commission a full academic study of the impact of

support on the practice of PPI and its ultimate impact on experimental research at UCL/UCLH.

- set up a joint initiative with the UCL Medical School to train and involve medical students in PPI in research, in order to embed a culture of PPI in the next generation of clinical researchers.
- work with UCL's School of Life and Medical Sciences and our BRC Education theme to get PPI training accredited as a part of the continuing professional development and appraisal of UCL researchers

Supporting researchers on a day-to-day basis

- The BRC has established a permanent support service for researchers at grant application stage. This is based on a successful 3-month pilot helping researchers to access patients and the public, and to set up and run a preliminary focus group. Feedback indicated the service is highly effective in developing researchers' skills, as well as contributing to successful grant applications.
- The BRC will continue to run its PPI Bursary Fund. So far, with support from the Wellcome Trust, £37,000 has been awarded to 20 PPI projects. Each year we will be providing 16 PPI start-up grants of £500 and 4 £2,000 grants for innovative PPI projects. We anticipate securing further funds to increase the innovation grants to larger sums in order to be more realistic about the cost of large PPI projects and support some of the more innovative PPI happening in our themes
- The BRC will continue to expand its network of patients and the public interested in research. This network has helped researchers run focus groups on issues such as hospital acquired infection, use of identifiable data, and the ethics of early access to medicines. We will be focusing our work on ensuring the network is fully engaged with, and actively participates in our PPI. We will expand the diversity of people involved (See below for more details).

This year the BRC reviewed the range of researchers accessing its PPI support services. The BRC concluded much of its support service, especially training in PPI, was probably only reaching about 10% of the research community and with a disproportionate focus on young early career researchers.

The BRC will seek to proactively redress this imbalance that reflects the fact that PPI has as yet to be embedded in biomedical research at UCL. Our strategy will be to identify areas where PPI training and support are needed and to tailor support to meet the particular needs of specific research teams and departments:

- The BRC will commission its PPI trainers to work with teams and produce bespoke training.
- The BRC is currently working with its CRF to identify the PPI training needs of administrative and nursing staff.
- The BRC is developing its support for senior researchers with PPI. This is a key area for embedding the practice of PPI at institutional level. The BRC will be working with trainers and NIHR Senior Investigators to design training to meet the needs of researchers applying for senior investigator status.

- The BRC will be running seminars for senior personnel on embedding and supporting and encouraging PPI in their institutions and departments.

The theme is already working to extend the BRC's support into an annual programme in order to provide:

- twice-monthly PPI training workshops, across different locations in partnership with UCLPartner organisations including BRCs, CRNs and the CLAHRC
- online PPI training resources
- monthly sessions for lay people on research methodologies, with modules on areas patients have asked for such as biostatistics
- all-year round PPI service for researchers making grant applications
- quarterly round of PPI bursaries
- diversified pool of people available to work with researchers and a library of their skill sets and interest areas
- a PPI awards scheme.

2. Involving people in the BRC's work

Expanded panels

The BRC has a lay panel of 6-8 people for each of its current themes. Panels review applications to the BRC, are available to researchers to provide advice and input into the BRC's strategy. The BRC will expand the panels to work with the new research themes. Recent work with the panels on the BRC's overall strategy has revealed the need for more engagement at board level, cross-cutting panel work and regular communications. The BRC will be addressing all these issues with an expectation of themes to hold at least 2 lay panel meetings a year with representation at board level.

Embedded PPI Champions

The BRC will fund researcher time to establish PPI champions in each theme cluster. By funding time, the BRC aims to ensure that PPI is taken seriously within each theme; and that the PPI/comms team is able to work more closely with the research community. This kind of funding should mean PPI becomes a recognised part of career development.

Diversity and inclusion

A central plank of our strategy is to develop the active involvement in our research of the full diversity of UCL and UCLH's local communities.

Evidence from our work shows the need to involve a greater range of people in research. For example, a large portion of applicants to the BRC's PPI bursary

fund are seeking help to involve communities they have found hard to reach. Our recent engagement activity with local 'A' level students and lay panel members revealed the need to find new ways of communicating.

Although Camden, Islington and nearby boroughs are some of the most diverse in the world in terms of ethnicity and income, it has proved challenging engaging diverse communities in the research of the UCLH BRC.

A PPI manager has been appointed to carry forward a comprehensive, strategically planned programme of work to address this issue. Instead of inviting people to visit UCL/UCLH, this long-term initiative will proactively 'go out' into and involve and engage with the BRC's local communities, with the aim of setting up a life-long partnership with them.

The PPI manager has already begun work in partnership with local Healthwatch groups, GP patient participation groups, commissioning groups, and local authorities to carry out a comprehensive mapping of communities. The PPI manager will then enlist a group of researchers and together they will:

- work with community leaders and groups to identify barriers to involvement and the best way of engaging with different communities - for instance, by identifying particular health issues of interest or health needs
- develop resources for outreach engagement and work with the UCL Public Engagement Unit to provide training for researchers to provide events and input which address these health interests and needs
- carry out an outreach programme including
 - profile raising - getting people interested in research happening
 - actively involving people in specific research studies; building up the BRC's database of interested people
 - setting up the mechanisms for ongoing dialogue including an online medium for the public to suggest research priorities
 - building on our work with schools and the UCL Public Engagement Unit to establish a programme of partnerships with schools

We have already established a system for monitoring impact on the range and representativeness of people involved in our research and surveyed the people currently working with us. Our aim is for the range of people working with us to progressively become more representative of our local communities.

3. Innovation

The BRC has identified the goal of becoming innovative leaders in the field of PPI. Our original strategy identified innovative areas to be developed such as PPI in lab-based research and PPI in strategy and priority setting:

- The BRC has already begun working with 4 research charities to pilot and evaluate different forms of PPI in lab-based research, with a view to providing guidance and models of good practice. We anticipate publishing our findings at the end of 2019.
- A review by the BRC has identified many areas of innovative PPI already happening in different areas of research and it will be funding the study and evaluation of this in the form of funding of PhD students.
- The BRC also aims to be an innovator and expert in the promotion and development of PPI in large institutions, and this forms a key part of our training and PPI support strategy.
- The BRC aims to publish results of our evaluation exercises and our experience of developing PPI at this level
- The BRC has been working closely with researchers on the About Me project to ensure patient input into and leadership of this pioneering UCLH initiative that will transform the way research is conducted in the NHS and mean patients will drive research. Patients attending UCLH will be invited to donate information from their hospital health records and a sample of their blood they will receive feedback on personal genetic and other biological information. The BRC PPI team has been working on ensuring UCLH patients decide what information they should receive and mandate this project from the start. Ultimately, this will enable 'personalised medicine' where clinicians decide what is the best care for a patient based on their personal information.
- The BRC will also be breaking new ground in the development and establishment of co-production as a central way of working with patients and the public. The BRC will be working with the new UCL Centre for Co-Production as a space where researchers and patients, carers, health professionals and colleagues are involved together in the crowdsourcing of project ideas which address the health and social care needs of seldom heard voices/communities. Our aspiration is for a BRC project to be among one of the first early-adopter projects to use the Centre.
- Co-production is seen as a key approach in the BRC's communications strategy as well and, for instance, the BRC will be commissioning film production companies to partner with patients and students to produce films about research at UCL and UCLH.

4. Continuous improvement

The BRC aims to build monitoring and evaluation into all its PPI work, and in particular to gather evidence as to the impact on patient care and treatment. We will aim to publish at least two journal papers per year which report on the BRC's experiences as well as reporting impact data more regularly on our website. This will include feedback from out-patient and public involvement community on how well they think we are doing.

In keeping with our aim to be a learning organisation we will be signing up as a PPI standards 'freestyle' organisation and will develop our work to meet these new standards and, if possible, exceed the expectations they set.

5. Engagement and communications and participation

ENGAGEMENT & COMMUNICATIONS



Main funder of in2scienceUK

A level students going on to university

83%

in2scienceUK students compared to **44%** free school meal students

A level students going on to Russell Group universities

58%

in2scienceUK students compared to **5%** free school meal students

The BRC's aim is to stimulate patient and public interest in biomedical research at UCLH/UCL in interactive and exciting ways, in particular reaching people not normally engaged with the research community. We not only want to raise people's interest in our particular institution, but also to excite and capture people's imagination with biomedical research in general.

In keeping with the UCLH strategy of becoming a 'Research Hospital,' the BRC aims to work to ensure every patient using UCLH services is aware of relevant research taking place at the Trust and of the opportunity to participate. We also think the learning we gain from engaging and building trust with the public in a research hospital setting will be of value to other health organisations in the UK and around the world.

Highlights of our engagement and communications work include:

- The BRC runs a very large annual research open day in the UCLH main hospital, attracting over 40 research stalls, interactive activities, prizes, high throughput of public visitors, school tours and talks. The day has been adopted as UCLH's main open day. The BRC will be working towards greater input from the local community at the event. This year, we will be working with the hospital to make the day a celebration of the NHS 70 birthday
- The BRC prioritises work with schools and is the main funder of the in2science UK scheme which provides lab placements for bright 'A'level students from disadvantaged backgrounds. The BRC's support for 25 students each year is a key way the BRC seeks to develop the next generation of researchers as well as engaging with the local community. 83% of students taking part go onto university and 58% to Russell Group universities (compared with 44% and 5% respectively of students on free school meals).
- The BRC will be exploring new ways of engaging with patients through the hospital radio, web chats, lectures, annual meetings and patient leaflets, as part of the work to establish UCLH as a research hospital.

- The BRC will be establishing a quarterly magazine on research for distribution around the hospital sites.

Communications including social media

The BRC will continue raising the profile of its work by promoting accessible news and information on websites and newsletters and will continue working with partner organisations, the media and the NIHR on press releases. The BRC currently produces 7 news stories a month, 45% of which are also covered by the media. We continue to increase our Twitter followers with a ratio of 1:10 of followees to followers and have increased impressions from 14,000 a month to 31,000 a month, and we increased unique page visits to our website by 1,000 to over 3,600 a month. The BRC aims to make better use of these outlets, with more targeted material, and is re-designing the website in the light of a search engine optimisation review.

Areas the BRC will be developing include:

- the use of short films using computer graphics and mobile friendly formats to communicate groundbreaking concepts in biomedical research to the public –our aim is to be an educator, communicator and entertainer and we will be commissioning a science communication production company to enable the BRC to exploit social media to circulate and highlight our output. Over the 3rd term we will be producing 10 short films.
- greater use of social media - in particular developing the use of images, Facebook and LinkedIn and increasing the level of engagement and exchange we achieve. We will be setting up a social media steering group to guide us in this work and have set a target of doubling our followers over the next year
- promotion of debates on issues such as the sharing of data, the concept of precision medicine and genetic information.
- increasing its support of the in2science initiative.
- use of short interview videos in news stories.
- pitching of news stories to the press.

Promoting opportunities to participate in research

IN 2019 UCLH will be implementing a new electronic health record system called EPIC and this will significantly improve our ability to offer our patients the opportunity to take part in research. The BRC is currently working with the EPIC implementation team and R&D database providers to identify opportunities for linking project activities with the clinical records.

The BRC will be working with software developers to increase the accessibility and usability of our local database - UCLH Research Gateway – which provides the public with searchable and accessible information on research studies currently recruiting at UCLH. The BRC will utilise future improvements to the UK Clinical Trials Gateway.

The BRC will be developing kiosks at each hospital site so members of the public can search the database. The BRC will work with clinical services to ensure Trust badged information is available across the trust in the form of leaflets, screen messages and short films.

Conclusion

The BRC continues to make strides in its plans to develop PPI and communications and as it progresses we look forward to working in partnership and collaboration with a range of organisations, community groups, industry, and charities. We believe we have a vital role to play in bringing them together on health research.