Sharing Our Practice: Successes and challenges of public engagement in the Wellcome Trust's UK Centres

14 May 2013

wellcome trust

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Report of a one-day workshop held at the Wellcome Trust, London, 14 May 2013

Executive summary

Public engagement is one of the Wellcome Trust's key objectives, and its major UK biomedical science and medical humanities centres are expected to deliver programmes of public-facing work alongside their research. Several centres have established extensive and varied programmes of outreach work.

Sharing experiences can encourage good practice and stimulate discussion on issues that are common to different centres. The choice of audience remains fundamental to successful public engagement, and a wide variety of audiences are currently being engaged by our centres. Many activities focus on engaging with schools, although several centres are attempting to increase their engagement with adult audiences.

Understanding audiences, for example through consultation and dialogue, can shape the nature of an engagement project and the formats used. Consultation can also provide the basis of an integrated evaluation, which would ideally be developed at the beginning of a project. Addressing topical issues can be a powerful way to engage with audiences, but dealing with controversial topics requires careful preparation. In particular, the way to address the use of animals in research needs to be considered carefully.

Patient groups are an attractive potential audience because they are likely to have a strong intrinsic interest in research. Connecting with patients offers opportunities for dialogue that benefits research, as well as patients.

A range of formats are now available for public engagement, but the most appropriate format will depend on the target audience. Aligning activities with an audience's existing interests – such as art or comedy – can lead to stronger engagement. Broadcast media and online activities provide opportunities for engagement with many individuals, but it is important to understand how such industries operate and work with suitable partners. The internet provides multiple opportunities for engagement, from online community building to games development. Some activities can be undertaken at low cost, but more sophisticated offerings (e.g. high-quality apps or interactive websites) require investment.

Funding agencies have established policies to promote public engagement. However, many people feel that public engagement work is not as well recognised as it might be, which might discourage some people from participating.

Providing a range of opportunities in addition to training, encouraging staff to take ownership of public engagement activities and lowering hurdles to participation can all increase the number of researchers taking part in high-quality public engagement projects. It is also helpful to stress the personal development benefits of participation. In addition, centres can establish a culture supportive of public engagement. Seeing directors and senior researchers promote public engagement and recognising researchers' commitment to it sends an important messages to staff.

Introduction

In May 2013, the Wellcome Trust held a one-day public engagement workshop for public engagement and outreach staff, researchers, and directors of its major UK biomedical science and medical humanities centres. The aim of the workshop was to provide participants with a chance to exchange ideas, share good practice and discuss challenges, and forge links with fellow practitioners from the wider public engagement community and Trust staff (a delegate list is provided at the end of the report). The first part of the day explored the practical challenges of public engagement, with a focus on audiences and formats and with input from external public engagement professionals. In the afternoon, participants considered the challenges of embedding public engagement within academic institutions and how these might be overcome.

The workshop highlighted many successful public engagement activities being carried out at Wellcome Trust centres, from science festivals and workshops in schools to book clubs and online games. Sharing this diversity of experience enabled delegates to consider how they might engage with new groups or adopt new formats.

All sessions involved reflecting on practice and the lessons centres had learned from their experiences. Even projects that do not turn out as hoped still provide valuable learning and can lead to more successful projects in the future. For the greatest benefit, monitoring and evaluation should be embedded within a project from the start. Evaluation should also address the quality and depth of the engagement experience, not just basic information such as the number and demographics of attendees, and should aim to capture information about process.

A graphic facilitator, Eleanor Beer, produced visual maps of some workshop sessions, and these have been embedded within this report. In addition, seven case studies summarising projects and other work presented at the workshop are included at the end of the report.

Audiences

Defining a target audience is crucial for any public engagement project and will ultimately depend on the purpose of the project. Goals might include inspiring young people by communicating the results of research, or building mutual trust and empowering communities with health problems by collaborating on a research project. The purpose of engagement will determine which groups to work with and the methods that are likely to be most effective.

The public is heterogeneous, so work should be tailored by considering the nature of target audiences. Categories such as age, gender, ethnicity, location and interests can be helpful starting points and might indicate suitable target groups (e.g. schools and colleges, families, adults, and patient groups). It is important to understand the needs and concerns of target audiences and to consider the suitability of different methods of engagement, ideally as part of a formative evaluation. Specifically, consulting with target audiences early in projects can provide invaluable knowledge about their needs, questions and concerns and feed into the development of a project.

Working with schools
To generate interest in biomedical science and STEM careers, many centres target young people. An obvious way to reach this audience is through schools, as illustrated by outreach at the Diamond synchrotron facility (see case study, page 14). A recent report commissioned by the Wellcome Trust (*Working with Schools in STEM Public Engagement: Approaches taken by Wellcome Trust-funded research centres*) documented work being undertaken in this area. Guidelines for research centres aiming to enhance their work with schools are available on the Trust's website).

The Wellcome Trust's work with schools includes the *Big Picture* educational resource. Among the findings from a recent evaluation of *Big Picture* was that teachers preferred paper copies of the publication and that YouTube was the only form of social media used by many teachers. The *Big Picture* evaluation is available on the Trust's website.

Individual centres often generate their own resources to support public engagement. It would be helpful to create more links between the Trust and the centres so that such material could be shared more widely.

Engaging with adults
Centres typically have well-established schools programmes but are keen to extend their outreach to adult audiences. Clarity about the rationale for engagement will suggest which audiences to engage with and how they might best be engaged.

Adult audiences are diverse, and the centres have targeted many different communities. A good approach in adult engagement is to match topics to the areas of interest of groups – examples include work with the over-75s, looking at the impact of medical advances, stand-up comedy aimed at people aged 18–40 (UCL's Bright Club; see case study, page 10), and work with book clubs organised by the Wellcome Trust Centre for Cell Biology in Edinburgh (see case study, page 11).

Accessibility may be an issue, particularly for institutes that are not based near large population centres, such as Diamond. One solution is to take activities out into the community, as Bright Club does at various comedy venues. Reaching target audiences may also be a challenge. It might be possible to work with charities or other 'gatekeepers', such as the Women's Institute, that can provide access to particular communities.

Working with patients and healthcare professionals
Patients have an obvious vested interest in particular areas of science and medicine and are an attractive target audience for public engagement projects. The aims of projects might range from providing updates on new areas of research or the development of therapeutics to consulting on research priorities or the design of research projects.

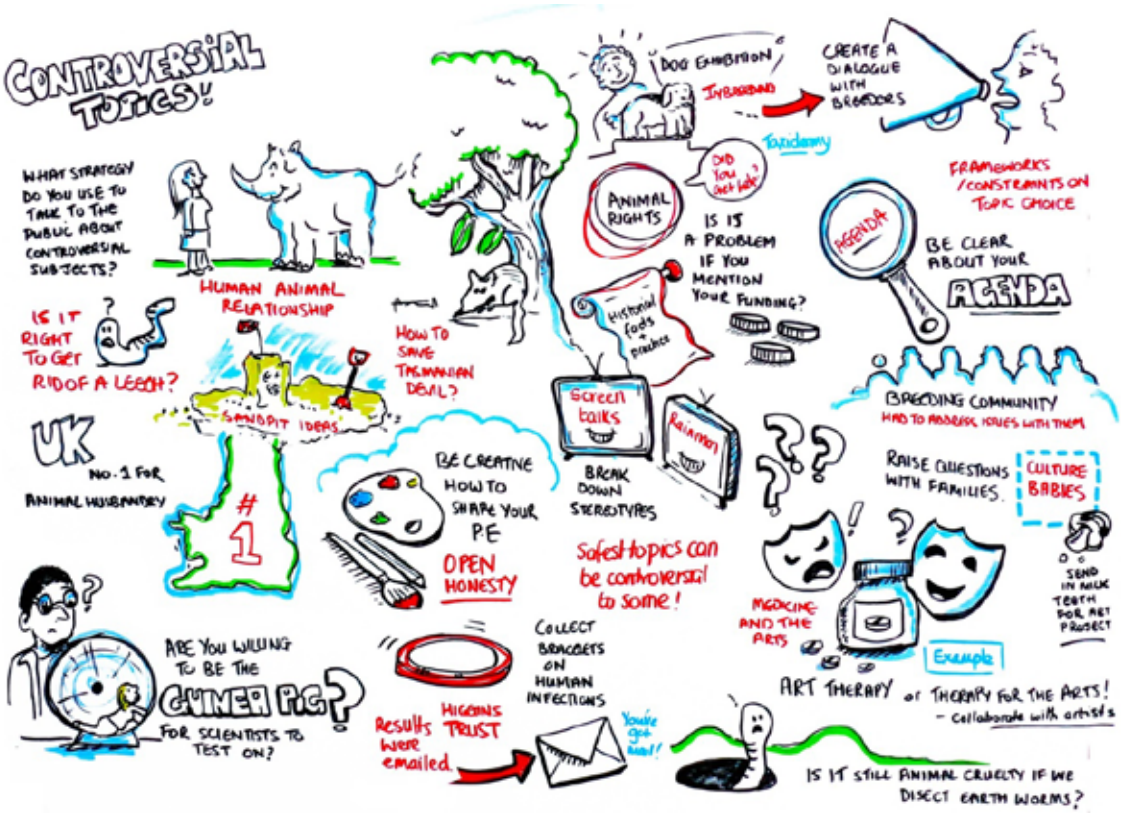
It is important to remember that patients are not defined solely by their conditions and have many other skills and interests. Recruitment may be challenging, so methods of recruitment (and associated ethical issues) need to be considered carefully (see Nowgen case study, page 13). It might be helpful to draw upon clinical contacts and networks or existing patient and public involvement infrastructure. Charities and patient organisations may also provide valuable entry points to patient populations.

Engaging with family audiences and addressing controversy
Several centres intend to enhance their engagement with family audiences. The Science Museum is aiming to boost its number of family visitors through a range of activities such as storytelling, workshops, live shows and interactive tours. Special events are organised for new exhibition openings, for national and international celebrations, and to mark prominent science anniversaries. Events are held every weekend, on all holidays and public holidays, and during half-terms.

Another example is the 'Culturebabies' public engagement initiative developed by Manchester Museums and Galleries Partnership, which highlighted innovative cultural practice with the under-twos.

Tackling topical issues can be an effective way to engage with family audiences and enable the public to contribute to discussion and debate. However, topical issues are often controversial; this may raise challenges for researchers, who might not be confident managing debates or dealing with the ethical and social consequences of research. Projects that include animal research can be particularly problematic. Researchers may feel wary of talking to the public about animal research because of possible activist responses, and they might also feel obliged to support the positions adopted by their major funders.

Organisations have successfully tackled 'difficult' topics. The Science Museum in London, for example, has run events about bioterrorism and sexually transmitted infections, as well as climate change. When addressing controversial topics, it is important to respect alternative viewpoints, even when they are in conflict with those of researchers. It is also helpful to keep communication channels open during and after activity for public audiences, to encourage further exchange and discussion. If third party organisations are involved, it is important to be fully aware of their positions to ensure that the project can be run effectively and without reputational risk.



Formats

Public engagement encompasses many diverse activities, from participating in festivals and working with museums to online discussion forums and public debates. In addition, media such as film, TV and games can provide useful platforms to entertain mass audiences with content inspired by science, and collaborations with artists can explore novel perspectives on biomedical issues.

Creative arts
The Wellcome Trust has supported many experimental art collaborations in biomedical science. Their aim is to stimulate interest and debate, and to explore the ethical, social and cultural context of biomedical science, rather than just explain or visualise scientific concepts.

Centres have run a range of art projects, including life drawing classes, knitted portraits and jelly cells. One advantage of such projects is that they are highly engaging – participants actually undertake activities themselves. Furthermore, when participants are doing activities they are skilled at, they can contribute as equal partners and may feel less conscious of not being science 'experts'. More ambitious projects such as performance theatre can be particularly effective but are very challenging to organise and run, especially when working with young people.

Working with the broadcast industry
The Wellcome Trust works strategically with mass media to increase the quality, quantity and visibility of biomedical content in TV programmes, films and games. Work spans all genres, from documentaries to comedies, with the aim of providing entertainment inspired by biomedical science. One example is the documentary *The Great Sperm Race*, an imaginative look at the journey of conception with the sperm cells played by real people. The programme was part-funded by the Wellcome Trust and broadcast on Channel 4 in 2009.

Ideas for TV programmes are usually generated in independent production companies (although networks may also identify topics they are interested in). Companies may obtain seed funding to develop their concept internally or from external bodies such as the Wellcome Trust. Once they have a concept, they pitch to a broadcaster and, if they are successful, the programme is commissioned. After this, the script is developed and the programme is filmed and edited.

Scientists are often approached to contribute to programme ideas or to provide comment ('factoids'). This can help to build connections with production companies and can lead to more opportunities to provide background and/or context. Unless a programme has already been commissioned, a fee is unlikely. Fees are usually given for filming documentaries, location use and script review, but not development.

For researchers keen to be involved in broadcast projects, there are many ways to get noticed. Establishing a strong online presence (e.g. by blogging, tweeting and/or setting up a YouTube channel) can raise a scientist's profile. Anyone raising their visibility through routes such as YouTube, however, will need to be prepared for abrasive reviews. Sending expressions of interest to production companies or responding to requests for input may help to establish contacts. Opportunities to be a presenter are limited and require an obvious interest and passion for a subject.

Engaging communities online

Online media can be a tool for engagement rather than just one-way communication, as illustrated by the Shift.ms (see case study, page 15) and Great Brain Experiment (see case study, page 12) projects.

Shift.ms has developed as an online community for people with multiple sclerosis. It provides a way for patients to feed into the development of research, as well as a tool for recruitment into research projects. It is also being used to pair up researchers with young patients acting as 'citizen journalists'.

The Great Brain Experiment, developed by researchers at the Wellcome Trust Centre for Neuroimaging at UCL, is based on a fun app and provides an opportunity for mass participation in research. Such projects involve substantial upfront investment but have the potential to reach large numbers of people. People need little motivation to go online or download apps, so recruitment can be straightforward if projects offer an engaging experience.

Exhibitions
Exhibitions can range from posters at science festivals or libraries to objects displayed in museums or science and discovery centres. All have a level of interactivity – with explainers or curators, or through interactive objects, exhibits or information displays.

Museums, science and discovery centres, libraries, and other cultural venues make excellent partners. Many are well established within their communities and have the infrastructure, access and experience to engage public audiences effectively.

Establishing new exhibitions in physical spaces can be costly and labour intensive, but alternative approaches are possible. Researchers from the Centre for the History of Science, Technology and Medicine at Manchester invite the public to handle objects at the Museum of Medicine and Health and give talks inspired by the objects, as well as lectures to museum visitors. Similarly, the Wellcome Trust Strategic Programme on the Human Body developed a self-guided museum trail on the future of the body at Manchester Museum, along with guided tours (see the case study on the Wellcome Trust website at **www.wellcome.ac.uk/Education-resources/Engagement-with-your-research/Case-studies/WTP051845.htm**).

Drivers and challenges

Public engagement and the impact agenda
The Research Excellence Framework and 'Pathways to Impact' policies (established by the Higher Education Funding Council for England and Research Councils UK to encourage researchers to maximise the potential benefits of their research) have important implications for public engagement within the UK higher education sector. Both mechanisms recognise that public engagement activities have the potential to generate economic and societal impacts.

Although this is an opportunity for public engagement to be recognised and valued, particularly engagement that tailors research to deliver benefits to the public as well as the scientific community, the models imposed by some Research Excellence Framework panels and funding bodies could limit the types of public engagement that are undertaken. A lack of institutional support for public engagement and researchers' time constraints are also important barriers to engagement.

Motivating the research community
Public engagement can involve large numbers of researchers. Of Diamond's 500 researchers, for example, around 80 scientists regularly participate in public engagement activities. One challenge for scaling up is that the same people tend to be involved in multiple activities, so there is a need to increase the number of researchers participating.

Researchers often feel that they receive little or no recognition for the public engagement work they carry out, so it is important to develop a nurturing environment in which such activities are valued. Public engagement could become a formal part of an academic's role and incorporated into criteria for promotion, as is the case at UCL.

Funders are encouraging universities to recognise researchers carrying out public engagement (e.g. through the Beacons for Public Engagement and Concordat for Engaging the Public with Research). However, there is a general feeling that such policies are not always implemented effectively; for example, public engagement may not be taken into account by heads of departments when considering promotions.

Awards for public engagement – such as the Society of Biology's science communication award, MRC science writing awards, FameLab or institutional schemes like the one run by UCL – can be motivating and contribute to a researcher's chances of promotion. However, even simple measures such as a personal email sent by a Centre Director can send powerful messages. Indeed, senior management can be important champions for public engagement, and the sight of leading researchers and heads of department engaging with the public sets a good example for others to follow.

The push for greater public engagement needs to recognise that it is a specialist activity and requires a particular skillset. Training and mentoring can support those new to engagement. The Centre for Cell-Matrix Research in Manchester has run a scheme whereby researchers are offered training and mentoring, and can apply for funds to run their own activity (see case study, page 16). Potentially, public engagement could also contribute to the personal development credits acquired by PhD students.

Fostering a supportive culture
Centre directors have a crucial part to play in establishing a culture that supports public engagement. Several factors can contribute to this supportive culture:

- Specialised professional support is extremely valuable. Universities can provide support centrally, but it is beneficial for centres to have their own dedicated staff.

- Funding for public engagement can be a challenge. Funding to be able to respond to opportunities or for innovative projects within a centre would make a big difference.

- Researchers need to be rewarded for their public engagement activities, although there is no clear guidance on how this can be achieved.

- Including sessions on public engagement in academic conferences for early-career researchers could create a positive culture for public engagement in academia. Funders such as the Trust could include a question about past public engagement activities on funding applications, to signal the importance attached to such work.

Conclusions

In recent years, public engagement has gone from being an 'add-on' to being an integral part of research centres' work, supported by specialist professional staff. To help institutions plan public engagement programmes, the National Coordinating Centre for Public Engagement has developed **a self-assessment tool** (Appendix 1). This tool encourages centres to consider the challenges they will need to address if a programme is to be successful.

Diverse, imaginative and effective work is now carried out locally and nationally. Opportunities exist for centres to widen the scope of their activities, and to consider new audiences and innovative formats to reach these audiences.

The examples discussed at the workshop (and summarised in the attached case studies) provide inspiration for those considering new avenues of engagement, and the network of centres and other institutions funded by the Trust provide an excellent forum for the exchange of ideas and good practice. As interest in science and medicine remains high among the general public, and new technologies open up additional opportunities for imaginative engagement, current work provides an excellent foundation for the development of extensive public engagement programmes across the UK.

Appendix I. A self-assessment tool for developing public engagement programmes[1]

Clarify your PURPOSE for engaging with the public	
	**Mission** Create a shared understanding of the purpose, value, meaning and role of public engagement to staff and students, and embed this in your strategy and mission.
	**Leadership** Support champions across the organisation who embrace public engagement.
	**Communication** Communicate consistent, clear messages to validate, support and celebrate it, and ensure open and two-way communication with members of the public and community organisations.
Invest in PROCESSES that support good quality engagement	
	**Support** Co-ordinate the delivery of engagement to maximise efficiency, target support, improve quality, foster innovation, join up thinking and monitor involvement and impact.
	**Learning** Provide opportunities for learning and reflection, and provide support for continuing professional development and training.
	**Recognition** Recognise and reward staff involvement within recruitment, promotion, workload plans and performance reviews, and celebrate success with awards or prizes.
Focus on how effectively PEOPLE are involved and supported	
	**Staff** Ensure that all staff – in academic and support roles – have opportunities to get involved in informal and formal ways.
	**Students** Proactively include and involve students in shaping the mission and in the delivery of the strategy, and maximise opportunities for their involvement.
	**Public** Invest in people, processes and infrastructure to support and nurture the involvement of individuals and organisations external to the HEI.

[1] National Co-ordinating Centre for Public Engagement. Available from **www.publicengagement.ac.uk/support**.

Appendix II. Case studies

Bright Club: Public engagement comedy night

Organisers: UCL Public Engagement Unit.
Summary: Research-based comedy events.
Purpose: To bring research to adult audiences in an entertaining format and to provide opportunities for staff and scientists to gain early experience of public engagement.
Audience: People aged 18–40 and not associated with a university.

Background
Bright Club is an innovative model for public engagement in the form of stand-up comedy. It takes place every month in a comedy club in Clerkenwell, London, with occasional larger gigs at the 500-seat Bloomsbury Theatre. A professional comedian comperes the evening, and researchers perform eight-minute sets about aspects of their work, all with a single unifying theme. It was launched in May 2009, and more than 60 Bright Club events have been held in London alone.

Performers are trained in the skills that underlie live comedy and in how to rethink their research with the needs of a comedy audience in mind. In addition to audience engagement, the project provides an entry point for staff and students interested in public engagement. Participants receive advice and feedback throughout their training, rehearsal and gigs, which helps develop their presentation skills and ability to think creatively.

Regular monthly events usually attract 90 attendees, most of whom do not engage with higher education (they are midweek comedy-goers). All events are labelled as 'comedy', to attract a different audience to science events. The format has been adopted widely, with regular gigs in 11 UK cities and Melbourne and appearances at science, comedy and music festivals. It has featured prominently on the BBC, New York Times and Guardian websites, and on Radio 4. The Edinburgh chapter ran a gig every day of the 2013 Fringe.

The project is largely self-funding, with initial stages supported by the Science and Technology Facilities Council and the Wellcome Trust. UCL supports the project with staff time and resources (e.g. use of the Bloomsbury Theatre).

Tips to ensure success
Prepare performers. The project uses a largely self-directed training programme. Speakers are briefed on Bright Club and comedy performance. They then develop their material, before taking part in a rehearsal, with other speakers providing peer feedback and advice.
Generate media. Photographs, flyers, podcasts, case study reports, audio recordings, newspapers and websites can all help spread the word.
Make it fun. Enjoying the performance is a major incentive to participation.
Reach out to new audiences. Make good use of project partners and their networks. Bright Club deliberately avoids advertising within UCL and science event circles, to attract non-academic audiences.
Get to know the community. It helps to know the local comedy circuit, how a comedy venue operates and how to use tools such as social marketing to create a buzz at low cost or no cost.

Impact
Considerable positive feedback has been obtained from both audiences and participants. The continuing good attendance reflects Bright Club's popularity, as does the spread of the concept to other cities.

Many participants have graduated to other public projects, including high-profile media and speaking opportunities. Some have gone on to become teachers, professional communicators or champions for public engagement in their departments.

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Science with reading groups and book clubs

Organisers: Wellcome Trust Centre for Cell Biology, University of Edinburgh
Summary: Introducing science-based books to book clubs.
Purpose: To encourage discussion of scientific issues among lay audiences with an interest in literature.
Audience: Members of reading clubs.

Background
The project grew out of an internal book club set up at the Wellcome Trust Centre for Cell Biology in Edinburgh to discuss books from Wellcome Trust Book Prize shortlists.

The first book chosen was the highly acclaimed *The Immortal Life of Henrietta Lacks*, by Rebecca Skloot, and it was immediately apparent that the book could also be used for outreach activities with non-scientific audiences. As part of the Midlothian Science Festival, Sarah Keer-Keer took two sets of the book to established book groups. The groups borrowed the books free for a month, and when they met for discussion, they were joined by Sara and a suitably knowledgeable scientist (who had also read the book).

Many books that are read by the general public contain elements of science in their story. How well the science is depicted varies considerably, but it can provide an entry point for lay audiences. The project provides book groups with free access to books, and a chance to discuss scientific aspects of stories as part of wider discussions.

The project provides a deep engagement experience. Book club members will have spent many hours reading the books and are likely to come loaded with insight and questions – and sometimes ready for a good argument.

Tips to ensure success
Consider your location. It is best to meet in the book club's usual meeting place.
Choose the book carefully. The best books have a strong storyline and the potential to spark discussion and debate, particularly with an ethical dimension. Read a range of books beforehand and choose those that best fit your area of interest.
Be informal. The meeting should be informal, with an opportunity for discussion rather than a prepared talk.
Be prepared. When reading a book, identify the passages that are most scientifically relevant and encourage discussion of these in the meeting; it can be helpful to prepare additional material, such as images or even a video.
Widen your scope. Be prepared for questions and discussions on a wide range of scientific issues, not just those specifically raised in a book.
Fast beforehand. Book clubs are highly hospitable, and you are likely to be plied with cake and other treats.

Impact
Feedback from the book clubs has been highly positive. Some 78 per cent of participants said they would not normally have read Skloot's book, but 96 per cent said they would be keen to repeat the experience. The average score for overall experience was 4.5 out of 5, while the average score for valuing or enjoying the scientists' input was 4.8 out of 5.

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The Great Brain Experiment

Organisers: Wellcome Trust Centre for Neuroimaging, UCL
Summary: A mobile app-based game promoting engagement with psychological science.
Purpose: To interest a general audience in psychological science while collecting scientifically valid experimental data.
Audience: Smartphone users.

Background
The Great Brain Experiment was developed by a team of early-career researchers at the Wellcome Trust Centre for Neuroimaging, UCL (Dr Rick Adams, Harriet Brown, Dr Fiona McNab, Dr Robb Rutledge, Peter Smittenaar and Peter Zeidman, overseen by Professor Ray Dolan). The team's motivation was to develop a form of outreach compatible with busy contemporary lifestyles. With the near-ubiquity of smartphones, an app seemed to be the ideal solution.

A secondary aim was to use the app to involve participants directly in research, as a form of 'citizen science'. The app was therefore also designed to collect scientifically valid data – participants could keep their results to themselves, compare their results with others or submit them for anonymised analysis.

The project was funded through a Wellcome Trust Engaging Science grant as part of the Trust's Wonder collaboration with the Barbican, which enabled the centre team to work with a professional app development company, White Bat Games.

The app is based on four standard psychological experiments examining aspects of memory, impulsivity, risk-taking and attention, which are traditionally used in a laboratory setting. The project therefore provided an innovative opportunity to explore the value of app-based 'gamified' tests in public engagement, as well as the validity of laboratory psychological findings in less artificial situations. The team is now developing a suite of games exploring other aspects of brain function, in collaboration with other researchers who want to crowd source data.

Tips to ensure success
Work with professional partners. The app benefited from design and development input from White Bat Games, ensuring that the final product was of a professional standard and could compete with traditional apps.
Compromise. A middle path has to be steered between the desire to include scientific detail, or capture more information, and the need to provide an engaging experience.
Commit time. The development and testing of apps is not an activity to be undertaken lightly; be prepared to commit time and resources to the project. After this initial upfront investment, however, there is great potential to reach large numbers of people.

Impact
The app has been highly successful, achieving more than 75 000 downloads. Data were collected from more than 40 000 users – sufficient to allow scientific analysis and to confirm that the psychological findings from laboratory studies also apply to real-world situations. An initial paper has been written describing the scientific findings, and others are planned as data accumulate.

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Changing Futures

Summary: Engaging with teenagers with cystic fibrosis.
Purpose: To enable young people with cystic fibrosis to use creative methods to explore gene therapy, and to co-create an online resource for patients and students.
Audience: Young people with cystic fibrosis; school students learning about genetic health conditions.

Background
Nowgen, a centre of excellence in public engagement, education and professional training, was keen to work with young people with cystic fibrosis (CF), to explore how research affected them. Young people with CF are encouraged not to mix, because of the risk of cross-infection, which makes it hard for teenagers to share their views about living with CF and the latest research. Discussions with young people with CF (aged 11–17) revealed that bodies such as the CF Trust already provided ways for patients to stay in touch online, and there was little interest in additional social media resources such as discussion forums, Facebook pages or Google groups.

Young people were, however, very interested in gene therapy as a potential treatment for cystic fibrosis, but felt they had limited understanding of what it involved and what progress was actually being made. Consequently, Nowgen decided to work with young people to develop an online resource geared towards the needs of young people.

Teenagers with cystic fibrosis, who were recruited through the Royal Manchester Children's Hospital, were given the opportunity to work with a range of artists to communicate the experience of living with cystic fibrosis and their thoughts on gene therapy. In addition to keeping their own video diaries, they interviewed researchers working on cystic fibrosis and gene therapy.

Some 16 films were worked up and reviewed by patients, teachers and health professionals. They range from interviews with researchers to animations illustrating scientific principles of gene therapy, and they form the heart of the Changing Futures web resource (**www.changing-futures.org**).

Tips to ensure success
Co-create. The young people were involved from the start, helping to define the scope of the project and helping to develop content at each stage of website development. The site therefore closely reflects their needs and represents an authentic portrayal of their lives.
Be interdisciplinary. The multidisciplinary project team ensured that scientific, medical, patient and educational perspectives were all integrated during the development of the resource. Involving representatives from Science Learning Centres, for example, ensured that teachers' needs were recognised.
Communicate. With a multicentre, multidisciplinary team, it was important to maintain channels of communication, particularly at the beginning of the project.
Consider ethical issues. To work with patients, the project had to obtain permission from the hospital's research ethics committee.

Impact
An independent evaluation found that the young people directly involved in the project found it a highly rewarding and enjoyable experience, and one they would gladly repeat.

The website produced has been well used and, notably, engages visitors for extended periods (it has an average visit time of more than ten minutes). The website was also positively received by a review panel of teachers, 93 per cent of whom said they would be likely to use it in lesson time.

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Engaging with school audiences

Organisers: Diamond Light Source
Summary: Developing public engagement activities for schools audiences.
Purpose: To excite and inspire young people and encourage students to consider a career in science or engineering.
Audience: School students, particularly post-16.

Background
The Diamond Light Source, the UK national synchrotron facility, runs an extensive public engagement programme. Alongside work with adults and family audiences, Diamond places a great emphasis on engagement with schools, hosting visits by more than 2000 students each year.

As Diamond is an impressive physical facility, visits naturally lie at the heart of its educational outreach. It aims to provide insight into the nature of research carried out at Diamond and its relevance to everyday life, and to communicate what life is like as a practising scientist. Diamond also provides extensive online materials for those unable to visit, including simulations, films, animations and podcasts.

With potentially very high levels of demand, work with schools has been prioritised within Diamond's formal public engagement strategy. Within this strategy, post-16 students are a priority audience, followed by younger secondary school groups and primary schools.

Although the key aims are to inspire and enthuse students, and to provide information about careers in science and engineering, visits and materials are tailored to the curriculum to ensure visits have educational value. This draws on extensive discussions with teachers to identify relevant areas of their curriculum and to ensure that activities complement those taking place in schools. For younger groups and those less likely to go into scientific or technical careers, Diamond has been developing alternative activities, such as writing competitions based on an aspect of Diamond, its facilities or its staff.

With such an extensive programme of activities, staff commitment to public engagement is essential. Diamond staff are generally positive about public engagement: around 100 out of 450 regularly contribute to outreach (e.g. by showing small groups of students around the facility). Seeing public engagement be firmly embedded in Diamond's work encourages staff to contribute. Staff are provided with training, and mechanisms are being developed to ensure that participation in public engagement is recognised and can enhance their CVs.

Tips to ensure success
Develop a strategy. Consider whether schools should be a priority and, if so, which age groups and for what purpose, so activities can be tailored accordingly.
Understand an audience's needs. Work with teachers and schools to identify what they want to gain from visits and resources, and to link topics to curricula.
Embed public engagement. Ensure public engagement is seen as a core activity of a centre, not an add-on or an activity carried out by an isolated department.
Encourage and recognise participation. Stimulate interest, provide training and resources to support outreach, and consider ways to ensure staff can gain benefits from participation.

Impact
There is a strong demand for visits to Diamond, which have to be accommodated within its operating schedule. In addition to regular visits from local schools, Diamond hosts trips from further afield, and more than 2000 students visit each year. Students and teachers typically find the experience both useful and enjoyable.

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Shift.ms: an online community for young people with multiple sclerosis

Organisers: Shift.ms
Summary: Social networking and other online tools to build bridges between patients and researchers.
Purpose: To establish closer links between young MS patients and researchers.
Audience: Young people (20–40) diagnosed with MS; researchers working on MS.

Background
The Shift.ms website was developed by friends of George Pepper, who was diagnosed with MS aged 22. George felt isolated and unable to share his experiences with people in a similar situation – most support activities targeted older patients with more advanced disease.

To address this situation, George and Freddie Yauner developed Shift.ms, a social networking website for young people with MS. Their aim was to provide a platform for people to share experiences, but also to promote positive attitudes – to encourage young patients to continue striving to achieve their goals. The site was designed to be user-driven, with minimal central oversight.

An encounter with MS researcher Professor Gavin Giovannoni at Barts and The London School of Medicine and Dentistry inspired a new, ongoing partnership that has greatly strengthened links between patient and research communities. Professor Giovannoni is a committed public communicator and has a highly regarded blog (**multiple-sclerosis-research.blogspot.co.uk/**).

A Wellcome Trust People Award to Professor Giovannoni and Shift.ms enabled young people with MS to suggest 'hot topics' in MS research, with scientists filmed while providing replies. A follow-up grant has shifted the focus to the 'MSers' themselves. After a training session, a group of MSers are given a lapel microphone and a tripod, and use their smartphones to interview researchers directly. These films are then edited for use on the Shift.ms website. In addition, an online resource is being developed to encourage more MS researchers to participate in public engagement.

Tips to ensure success
Use inherent interest. Engaging with patient communities is a special case, as audiences will have a strong existing interest. Patients are also well-placed to drive the process, identifying the issues most important to a community.
Take a patient's-eye view. Social networking approaches are flexible and highly responsive to a community's needs. Organisers establish a framework and ground rules but can be hands-off as a site develops.
Patients lead the process. The interviewing approach places minimal demands on busy researchers, who simply need to talk about their research and MS more generally. Even without formal training, most researchers naturally adjust their tone and delivery when talking to a patient interviewer, or can be prompted to explain jargon or difficult concepts.
Encourage participation. The value of participation (and risks of non-participation) needs to be emphasised to researchers, and hurdles to participation need to be lowered.

Impact
The Shift.ms site is popular among MSers, and the films are widely accessed. It has reached 126 000 people affected by MS and receives 15 000 unique visitors monthly. The site now has more than 5000 registered users, a 50 per cent increase within a year.

Closer ties with the MS community have also been beneficial to Professor Giovannoni – through dialogue with the community, he was able to convince funders that a project was feasible despite concerns that patients would not be willing to undergo an invasive procedure. In the longer term, research will depend on the participation of patients and, hence, good relations with the MS community. Informed, well-organised patient communities can also have a significant impact on political decision-making.

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Motivating researchers to participate in public engagement

Organisers: Wellcome Trust Centre for Cell-Matrix Research
Summary: How to persuade researchers to take part in public engagement activities.
Purpose: To increase the number and diversity of researchers participating in public engagement.
Audience: Mixed, but with a strong focus on young people.

Background
The Wellcome Trust Centre for Cell-Matrix Research is based at the University of Manchester and carries out fundamental and medically oriented research linked to the extracellular matrix. It organises a programme of public engagement activities, coordinated by Ceri Harrop, ranging from school and A-level study days to one-off lunchtime and evening events, as well as book clubs and art programmes. It faces a particular challenge as the subject matter of its research – the extracellular matrix – is not necessarily familiar to lay audiences.

An important aspect of Ceri's role is to encourage staff to take part in public engagement activities. Researchers have many other demands on their time and often feel they receive little recognition for their public engagement work. Ceri aims to lower the obstacles to participation, but she also stresses the personal benefits that researchers can gain from public engagement, including developing new skills and networking opportunities. She ensures that staff have a strong sense of ownership of a project: researchers are involved early and help to shape the planning and delivery of a project, so they do not feel they are simply 'helping out' with the public programme. By having a range of possible opportunities, from work with young children to arts projects, the Centre can also match projects to staff members' own areas of interest.

Public engagement is also given high status, so it is seen as an integral part of the Centre's work. Ceri sits on and reports directly to the Centre's Management Committee, and public engagement is featured in all the Centre's internal communications. Public engagement is promoted by the Centre's director; even if senior team leaders do not take part in public engagement activities themselves, they encourage and support the work done by their junior staff.

The Centre also runs an annual competition in which researchers can receive training and mentoring and develop ideas for public engagement. These are pitched to a *Dragon's Den*-like group and funding is awarded to develop successful projects.

Tips to ensure success
Promote ownership. Ensure that researchers feel involved in the development of projects.
Stress benefits. Convince researchers of the range of benefits they will gain from participation.
Lower hurdles. Make it as easy as possible for researchers to take part.
Create a positive culture. Embed public engagement fully and send positive messages from the top.
Maximise opportunities. Develop a programme of activities so researchers can find a project that suits them.

Impact
The amount of public engagement carried out at the Centre has been growing, and more of the Centre's researchers are taking part in public engagement activities. Overall, almost half the researchers in the Centre now take part, compared to just 10 per cent three years ago.

Contact
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Appendix III. Delegate list

Delegates attending the Public Engagement Workshop for UK Wellcome Trust Centres, 14 May 2013

Rick Adams	UCL
Sian Aggett	Wellcome Trust
Helen Atkinson	Wellcome Trust Centre for Mitochondrial Research
Victoria Bates	University of Exeter
Eleanor Beer	Visual facilitator
Isabelle Boscaro-Clarke	Diamond Light Source
Molly Crockett	Wellcome Trust Centre for Neuroimaging
Steve Cross	UCL
Angela Davis	University of Warwick
Laura Dawes	University of Cambridge
Iain Dodgeon	Wellcome Trust
Helene Doerflinger	Wellcome Trust Gurdon Institute
Peter Donnelly	University of Oxford
Bruce Etherington	Cardiff University
Martyn Evans	University of Durham
Georgina Ferry	Wellcome Trust Centre for Human Genetics
Robin Franklin	Wellcome Trust-MRC Cambridge Stem Cell Institute
Stefan Galander	Wellcome Trust Centre for Cell Biology
Tudor Georgescu	Oxford Brookes University
Gillian Griffiths	Cambridge Institute for Medical Research
Richard Harris	3KQ – facilitator
Ceri Harrop	Wellcome Trust Centre for Cell Matrix Research
Laura Holland	Diamond Light Source
Brian Hurwitz	King's College London
Lauren Kassell	University of Cambridge
Sarah Keer-Keer	Wellcome Trust Centre for Cell Biology
Nicos Kefalas	University of Leicester
Steven King	University of Leicester
David Kirby	University of Manchester
Robert Kirk	University of Manchester
Sevinc Kisacik	Science Museum
Mun-Keat Looi	Wellcome Trust
Jane Macnaughton	University of Durham
Nora Maddock	Wellcome Trust
Jenny Nelder	Wellcome Trust-MRC Cambridge Stem Cell Institute
Allan Pacey	University of Sheffield
Neil Pemberton	University of Manchester
Robb Rutledge	Wellcome Trust Centre for Neuroimaging
Amy Sanders	Wellcome Trust
Chloe Sheppard	Wellcome Trust
Stephanie Sinclair	Wellcome Trust
Austin Smith	Wellcome Trust-MRC Cambridge Stem Cell Institute
Bella Starling	Central Manchester University Hospital
Mhairi Stewart	Wellcome Trust Centre for Molecular Parasitology

Charles Streuli	Wellcome Trust Centre for Cell Matrix Research
Tilli Tansey	Queen Mary, University of London
Sonya Taylor	Wellcome Trust Centre for Molecular Parasitology
William Viney	University of Durham
Katherine Watson	Oxford Brookes University
Paul Weindling	Oxford Brookes University
Julia Willingale-Theune	Wellcome Trust Sanger Institute
Miriam Wood	University of Oxford
Angela Woods	University of Durham
Alan Yabsley	Queen Mary, University of London
Freddie Yauner	Shift.ms

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