

Developing a Strategic Approach to Public Engagement in the Wellcome Trust's UK Centres

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I Introduction

In May 2014, the Wellcome Trust held the second annual workshop for the public engagement and outreach staff, researchers and directors of its major UK biomedical science and medical humanities Centres. The aims of the workshop were to reflect on the strategic direction for public engagement within the Centres, to consider how best to embed public engagement within the Centres so it is better recognised and rewarded, and to determine how the Trust can support these aims.

These themes emerged from discussions about the challenges of public engagement at the last meeting in May 2013. Delegates had talked about how public engagement takes time and requires skills and expertise, which require adequate funding. The Wellcome Trust has since been able to secure ring-fenced funding for public engagement within our research grants through the Provision for Public Engagement. One of the main aims of this funding is to strengthen capacity for public engagement and provide opportunities for researchers; it can be used to support public engagement activities directly, but it can also be used for training and/or dedicated post salaries. The Centres are now beginning to use this opportunity to create a step change in their public engagement. Centres are now developing strategies for embedding public engagement and seeking to improve how they recognise and reward researchers for their involvement.

Sophie Duncan from the National Coordinating Centre for Public Engagement (NCCPE) delivered a session about developing a public engagement strategy, focused on the importance of knowing your audience. She presented the example of the National Trust: the National Trust has segmented their visitors based on the visitors' values and what they want to get from their visit. In doing this, National Trust properties are more able to target their approach and their activities to their visitors' needs. In the afternoon, participants considered the challenges of making sure researchers are recognised and rewarded for their engagement activities, sharing examples of formal and informal approaches.

The workshop was preceded by a meeting for just the public engagement practitioners, giving them the chance to network and share their practical experiences and successful public engagement activities (case studies of eight of these are included at the end of the report). Building on the discussions from last year, delegates discussed how else public engagement can be best supported – both within the Centres and externally by the Wellcome Trust.

Since the first workshop the Trust has supported public engagement in several ways. The Provision for Public Engagement was launched in October 2013; so far, 60 applications have been considered, resulting in 18 awards totalling £1 755 218. The Trust ran a series of regional workshops bringing researchers, public engagement practitioners and local community partners together to help build relationships and inspire new collaborations. In addition, the Trust's Researchers' Engagement team provide advice and guidance on public engagement activities and training for Wellcome Trust Researchers and Centres both in the UK and internationally.

Guidance on applying for the Provision for Public Engagement can be found on the Wellcome Trust website at www.wellcome.ac.uk/stellent/groups/corporatesite/@msh_peda/documents/web_document/wtp054220.pdf.

2 Developing a public engagement strategy

The question of ‘what does a useful public engagement strategy contain?’ became a popular topic of discussion. A public engagement strategy should, broadly speaking, include:

- priorities for engaging the public (e.g. target audience, topics, aims and so on)
- dedicated public engagement staff with adequate logistical and financial support
- rewards and recognition for researchers taking part in public engagement
- effective training, tailored to different researcher levels
- the embedded evaluation of public engagement activities and programmes.

These topics are explored further in section 3.

Centres can help to embed public engagement by establishing a coherent strategy that has support throughout the Centre and complements the overall public engagement plan of the university. These are ideas that have been previously addressed in the Concordat for Public Engagement (www.publicengagement.ac.uk/sites/default/files/publication/concordat_-_an_introduction_and_overview.pdf), which provides practical guidance for how to embed public engagement within a university.

For any strategy to work, there is a need for an aligned vision of public engagement within individual institutions and Centres. This vision should be generated collaboratively, not only to ensure all stakeholders feel ownership of the strategy but also to make sure its objectives are realistic, adequately prioritised and SMART (specific, measureable, achievable, relevant and time-bound). It was felt that a suitable public engagement strategy could only be established with genuine commitment and endorsement from “the very top” (i.e. Vice-Chancellor, Principle Investigators and Centre Directors). This ‘buy in’ from senior staff would be an important step in establishing the support, reward and recognition needed to encourage researchers to participate in public engagement without feeling they “weren’t allowed” or fearing it would hurt their career by taking time away from research.

In addition, strategies need to be sustainable, going beyond the terms of individual grants. As mentioned above, this could include establishing dedicated public engagement staff that are employed long term and not on a project-by-project basis. These members of staff would then be able to help embed public engagement within the Centre by building relationships and trust with the researchers and forging useful partnerships with communities outside of academia.

Further reading

- Resources to help establish support for embedding public engagement on the NCCPE website: www.publicengagement.ac.uk/explore-it/what-are-policy-drivers/concordat-engaging-public-with-research
- A discussion of the economic value of public engagement: www.britishecienceassociation.org/people-science-magazine/june-2012/economic-case-public-engagement
- Making a business case for public engagement in monetary terms: www.involve.org.uk/wp-content/uploads/2011/07/Making-the-Case-for-Public-Engagement.pdf
- A report on the social value of universities: www.publicengagement.ac.uk/sites/default/files/publication/80096_nccpe_social_value_report.pdf
- Planning for Change – Embedding Public Engagement Guidance: www.publicengagement.ac.uk/support-it/planning-change

3 Support, reward and recognition

Ideas surrounding adequate support for public engagement as well as reward and recognition were often discussed. The perception is that there is a general lack of suitable support, reward and recognition for researchers wishing to participate in public engagement in the Centres. Many felt that public engagement is often seen as a non-essential, 'do-good' activity with no perceived benefit to the researcher or the research group. This can come from a misunderstanding and underrepresentation of the value of public engagement. There was a view that currently too few researchers in the Centres are engaging the public – raising questions about the burden on those involved, as well as issues of equity, which were similar to those raised by Heads of Departments in the NCCPE's national action research programme (NCCPE, 2011).

It is the responsibility of universities, Centres and funders such as the Trust to encourage public engagement, so researchers feel that taking part is supported by their employer and funder.

Further reading

- Embedding Public Engagement in Higher Education: Final Report of the National Action Research Programme, NCCPE, 2011:
www.publicengagement.ac.uk/sites/default/files/publication/action_research_report_o.pdf

3.1 What are the personal and career-related benefits of public engagement?

The personal benefits of doing public engagement are not always recognised and can be difficult to measure. The Wellcome Trust has highlighted some of the benefits that researchers have told us they gain from public engagement in the film 'Connecting your research with society' (www.wellcome.ac.uk/Education-resources/Engagement-with-your-research/Funding-within-research-grants/index.htm).

As the RCUK booklet 'What's in it for me?' (www.rcuk.ac.uk/RCUK-prod/assets/documents/scisoc/RCUKBenefitsofPE.pdf) identifies, taking part in public engagement provides a wealth of transferable skills that are valuable to careers both within and outside research. Communication, presentation, media, project management, collaboration and connection building are some of the potential skills that can be developed with public engagement. In addition, researchers get the chance to network with their peers and with others within the university, potentially leading to new ideas and collaborations that will benefit everyone. Thinking about a problem from a different angle can give new insights: the public often challenge research assumptions and introduce fresh perspectives, so working with them can be inspiring and bring new energy and ideas back into the lab. Many of these benefits, along with others, have also been outlined in the Vitae booklet 'The engaging researcher' (www.vitae.ac.uk/vitae-publications/guides-briefings-and-information/vitae-researcher-booklets), which was written in collaboration with the NCCPE.

Centres are increasingly recognising the benefits of public engagement by offering rewards for good public engagement (discussed in the next section).

3.2 How do we recognise and reward public engagement?

Public engagement staff organise engagement activities for their Centre, but they often find it challenging to recruit researchers. One of the factors affecting this is the visibility of the public engagement teams and activities available to researchers: often, researchers are unaware of the public engagement activities that are available, and they sometimes do not realise their Centres have dedicated public engagement staff. The Centres gave examples of activities that have helped make their public engagement staff more visible:

- having a presence at researcher inductions
- attending Principle Investigator meetings

- promoting previous public engagement activities using newsletters or noticeboards
- highlighting ‘champions’ of public engagement in internal communications
- using dedicated articles in university newspapers and on front pages of websites
- inviting researchers and their families to events as guests, not just as participants.

As identified in the Concordat for Public Engagement, having champions of public engagement is a great way to highlight it within the Centre. Learning from the Beacons for Public Engagement showed that these champions should be at all levels, including Principal Investigators who can show support and thought leadership. If new PhDs and postdocs see that their peers and superiors are taking part in public engagement, and see it as a part of lab culture, they are likely to be more inclined to get involved themselves.

Internal competitions and awards within universities can help to promote the recognition and visibility of public engagement activities. It was suggested that competitions and awards such as the recently established National Public Engagement Competition from the NCCPE could also be given by funders.

Further reading

- NCCPE’s Beacons for public engagement: www.publicengagement.ac.uk/work-with-us/completed-projects/beacons
- The NCCPE’s Catalysts project, which is taking the lessons learned from the Beacons to help embed public engagement in a further eight universities: www.publicengagement.ac.uk/work-with-us/current-projects/catalysts-project

3.3 Recognising high-level skills and training

One of the issues that public engagement practitioners face is that their professional skills are not recognised as high-level skills at many universities. This is perhaps a cultural problem within academia, where there can be a lack of appreciation for professional services or skills, points of view and knowledge outside research siloes. Obviously, this view is not held by all: there are universities and research groups who appreciate well-rounded, multi-skilled researchers and have experienced and well-respected public engagement staff. Vitae’s Researcher Development Framework is often used for researcher training, and their public engagement ‘lens’ (www.vitae.ac.uk/researchers-professional-development/about-the-vitae-researcher-development-framework/lenses-on-the-vitae-researcher-development-framework) shows the breadth of research skills that can be gained from public engagement activities.

To change the cultural view of public engagement skills it could be useful for training to be recognised with certificates to make it something that researchers could add to their CV, so contributions to public engagement were considered as part of a research career. It was suggested that training could be accredited and linked to a personal development plan, in a similar way to teaching. Funders could help by recognising public engagement skills and past experience in their application forms.

Delegates emphasised the importance of giving support and training early in the research career to enable public engagement to become a normal research activity. Training should be tailored and given at all levels of the research hierarchy, from principal investigators to postdocs, PhDs and even undergraduates. Each new intake of students or staff could be given a short introduction to public engagement, which would explain the university’s stance on public engagement, its usefulness to research and the wider community, and the opportunities available to take part in activities. This would also ensure the next generation of researchers have some awareness of their public engagement responsibilities as they move through their career. Training can therefore help to change the culture of research to embrace and encourage public engagement.

Training can also build confidence in public engagement skills. It provides a good opportunity to prepare researchers who may face difficult questions when dealing with the public because of their research area (e.g. research into mitochondrial disease or animal research). Empowering researchers to talk about

sensitive subjects improves the transparency of the research process and builds trust between research institutions and the public.

Several resources are available for people who would like to develop public engagement training.

- Training available from the National Coordinating Centre for Public Engagement (NCCPE): www.publicengagement.ac.uk/work-with-us/continued-professional-development-cpd-training
- The Engaging researcher information booklet from Vitae: www.vitae.ac.uk/vitae-publications/guides-briefings-and-information/the-engaging-researcher-vitae-2010.pdf (requires login)

3.4 Supporting public engagement

To provide the right support for good public engagement, dedicated public engagement staff are needed. Researchers new to public engagement like well-defined projects in which their commitment expectations are explained upfront and that they can engage with easily, without taking too much time out of research. Experienced members of staff would be able to use, demonstrate and impart the skills needed to run good public engagement activities and long-term programmes with opportunities that researchers could easily contribute to or collaborate in.

For research groups or individual researchers with their own ideas for public engagement activities and programmes, public engagement staff can give guidance and help deliver projects. Public engagement staff are often able to assist with logistics, project management, building partnerships with communities outside the university and communications about the activity. Public engagement staff also tend to be very knowledgeable about the money that is available for projects and initiatives. Seed funds to kick-start researchers' own public engagement activity ideas in universities such as UCL have worked well, and it would be beneficial if Centres could have similar pots of money available.

Currently, public engagement support is variable across the universities our Centres are in. In some institutions public engagement capacity is good, with several dedicated public engagement staff. In others, however, a single member of staff is under pressure to deliver all the public engagement training, researcher support and public engagement activities. To properly maintain a fully embedded and sustainable public engagement programme, universities need to think about coordination between departments and make sure there is enough capacity and administrative support for the full range of public engagement activity. Several directors have recognised the value of having dedicated staff to support public engagement within the Centre and are beginning to strengthen their public engagement capacity using the Provision for Public Engagement.

4 Evaluation

Evaluation is an extremely important part of public engagement and should be planned into any project from the start. Ideally, evaluation should also play a key part in strategy planning, feeding into priorities and continually improving the programme of public engagement at a Centre.

The research impact agenda and the recognition of public engagement as a ‘pathway to impact’ has been a driver for improving monitoring and evaluation within universities. For example, impact case studies submitted to REF 2014 needed to demonstrate ‘reach’ (how widely the impact has been felt) and ‘significance’ (how much difference was made to the beneficiaries). Qualitative data, as well as quantitative information, should be gathered to show a fuller picture of activities’ reach and impact. Measuring the impact of an activity is not always easy, but that doesn’t necessarily mean the activity is not valuable. Delegates questioned whether it would be helpful to have a standard set of measurements for assessing public engagement activities and their impact. The consensus was that the wide variety of activities covered by public engagement may not be appropriately evaluated by a standard measurement.

It was suggested that examples of more effective and less effective public engagement should be collected; these can then be used as bench marks. It is also worth thinking about and implementing longer-term evaluation, if possible, as the impact of an activity may accumulate over the course of a programme or become clear at a later date.

There are many tools, techniques and resources available on evaluation and evaluation strategies. The NCCPE has listed some at www.publicengagement.ac.uk/plan-it/evaluation/evaluation-resources.

Several evaluation guides are also available for anyone thinking about evaluating their public engagement activities. They include:

- the NCCPE’s Public Engagement Evaluation Guide (www.manchesterbeacon.org/files/manchester-beacon-pe-evaluation-guide.pdf)
- JISC’s ‘Embedding impact analysis in research’ (www.publicengagement.ac.uk/sites/default/files/publication/nccpe_jisc_booklet_proof_07.05.13.pdf)
- the Wellcome Trust’s guide for successfully evaluating science engagement events (www.wellcome.ac.uk/stellent/groups/corporatesite/@msh_publishing_group/documents/web_document/wtx032701.pdf).

5 Concluding remarks

Discussion at this workshop focused on tackling the challenges of public engagement with research. It was agreed that the first and most important step to accomplishing this goal is for Centres to develop a strategy for public engagement, with input from all levels of the Centre, aligned with their long-term goals.

Discussions about the benefits of public engagement brought up many points covered in the Concordat for Public Engagement. The consensus was that Centres could build on these intrinsic benefits by offering participating researchers some form of reward.

Promoting public engagement was of interest to many of the delegates, and the idea of having ‘champions’ of public engagement was popular. In addition, delegates thought implementing interventions to make sure public engagement activities were more visible, particularly to researchers, was important.

The importance of training also came across as a strong theme in the workshop. The need to establish the understanding that good public engagement requires ‘high level’ skills is a cultural change that could be supported by well-devised training schemes. The Wellcome Trust, in collaboration with the Sanger Institute, is currently developing a new training programme to be added to the programme of Advanced Courses at the Institute. These courses will be developed with experts in public engagement, and it is hoped they will form the basis of a new framework for public engagement training.

Delegates believed that dedicated public engagement staff are necessary to provide adequate recognition and training for public engagement. It was highlighted that public engagement should be a normal research activity, but without proper staff support it is in danger of falling by the wayside. The Wellcome Trust’s new Provision for Public Engagement, ring-fenced public engagement funding within research grants, is intended to cover the costs of supporting quality public engagement activities, including funds for dedicated public engagement staff. It is enabling the Centres to be more strategic in their public engagement plans, rather than thinking on a project-by-project or ‘response mode’ basis. The Trust hopes these funds will be used wisely to create a step change in research culture, resulting in quality public engagement becoming a standard part of research.

Delegates had the chance to voice their questions and concerns directly to Clare Matterson, the Director of the Trust’s Culture & Society division, on the final day of the workshop. Suggestions were made to highlight and promote good public engagement across the UK Centres, and the Trust was asked to collect examples of less effective public engagement to feed back lessons learned and evaluation strategies across the Centres. It was suggested that Centres could take responsibility for doing this themselves, by making sure their evaluation was thorough and shared openly. Delegates asked for funding committees to take into account public engagement activities when deciding whom to fund. Through the discussion it was found that some committees do discuss public engagement, particularly in the humanities and social sciences, but many do not. This is something the Trust is exploring (although, ultimately, the committee members choose what is talked about, so the research community from which the panels are drawn must take some responsibility).

Following the discussions from the workshop, the Centres agreed that their priorities over the next year will be:

- to develop a strategy for public engagement at the Centre
- to consider employing dedicated public engagement staff to help implement the strategy
- to consider implementing ideas for providing rewards and recognition to researchers that engage with the public.

In response, the Wellcome Trust has agreed to:

- explore ways to give the Centres further support for evaluation
- continue to run the Public Engagement Annual Workshop and provide outlets for sharing case studies, good practice and learning
- encourage funding committees to consider how public engagement is taken into account.

6 Case studies

6.1 IDEA Collaboration: From Research to Action

Organisers: Centre for the History of Medicine, University of Warwick.

Summary: A multidisciplinary network for highlighting issues relating to ethnicity and health in Britain.

Purpose: To improve the delivery of ethnically appropriate healthcare research, services and policy.

Audience: Policy makers, service providers and users, researchers and minority ethnic communities.

Background

The Collaboration for Improving the Delivery of Ethnically Appropriate Research, Services and Policy (IDEA) was founded by Roberta Bivins and a group of researchers (based at the University of Warwick, Cardiff University and De Montfort University) with experience in studying the impact of ethnicity on healthcare and health outcomes from a range of disciplinary perspectives. Its aim is to make sure the best research is widely and immediately accessible to research users: practitioners, policy makers, publishers, funding bodies and affected communities. As a first step towards achieving this goal, in 2011–12 IDEA hosted a series of three workshops for researchers and practitioners with experience with issues related to ethnicity and health. Videocasts of the workshops were made; these have attracted a high number of external pageviews, suggesting they are useful for researchers and research users in the field. In 2013, IDEA hosted their first symposium, 'From Research to Action', to explore strategies and tools for translating research into action through collaboration with the media, policy makers, the third sector and communities themselves.

'From Research to Action' began with a presentation from Baroness Masham of Ilton. This was followed by a series of short presentations from research users from the healthcare industry, the third sector and the media. These demonstrated the benefits of close collaboration between researchers and research users, and stimulated discussion of strategies to overcome the barriers to such collaborations. All participants were encouraged to bring posters and other materials reflecting their own research and/or practice, which were displayed in key event spaces. The day ended with a general discussion of the points considered, the action points, translational strategies and examples of best practice that emerged.

Tips for success

Start planning early. Working across disciplines and sectors means working with over-scheduled people and a range of calendars, from the Parliamentary calendar to the academic and financial years.

Maintain flexibility. Again, you are working with a complex set of constraints, and many very willing and enthusiastic participants may have last-minute changes in their commitments.

Build in lots of extra time for discussions, networking and one-to-one conversations on the day itself and into the post-event weeks.

Impact

'From Research to Action' proved highly successful, bringing new members (especially from the third sector) into the IDEA fold and spreading the word about the expanding resources available on the IDEA website. Not only did the presentations filmed on the day itself generate more than 12 000 website visits in the months immediately following the event, but video clips from the preceding three IDEA workshops gained new popularity. Since the symposium, IDEA has organised an additional workshop with the Industry and Parliament Trust, and is now working with the Birmingham Health Exchange and researchers at Kaiser Permanente on issues relating to diabetes and the health impacts of housing, etc. IDEA Convenor Roberta Bivins was also invited to present the keynote address to the NHS Research and Development Forum 2014 to share her approach to fostering engagement between researchers, policy makers and the public.

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www2.warwick.ac.uk/fac/arts/history/chm/research_teaching/research/idea/ideasymposium2013/

6.2 London Interdisciplinary Discussion Group

Organisers: Centre for the Humanities and Health, King's College London.

Summary: Bringing together speakers from across science, medicine, the arts and humanities to explore a shared topic from multiple perspectives.

Purpose: To attain a better and broader understanding of the topic in question (e.g. 'Transplantation', 'Images', 'Order/Disorder' and 'Blindness') by considering it from varying and seemingly disparate disciplinary approaches.

Audience: A mixture of academics and the general public.

Background

Susie Christensen (English/Centre for the Humanities and Health, King's College London) founded the London Interdisciplinary Discussion Group in 2010 with Helen Barron (Neuroscience, UCL). They held a series of four popular events at King's College London. After gaining funding from the CHH and the Wellcome Trust, Susie worked alone to put on three events at the Science Museum (two in the Dana Centre and one in the Director's Suite).

Each event consisted of a panel discussion in which each panel member gave a short presentation, which was followed by a discussion on the topic in question with the speakers and audience. This was then followed by a drinks reception to allow for further, informal conversation. The events were titled 'Vision and Images', 'Order/Disorder' and 'Blindness'. From the outset, the activity was designed to suit a public-facing audience and was intended to generate conversation, not only across the disciplines but also between the speakers and the audience. The speakers were briefed on this and their talks were tailored accordingly.

As with any interdisciplinary activity, there was a risk that there would be no coherence or that people would be talking at cross-purposes. Meetings were arranged in advance of the event so the speakers could be briefed on the event and discuss what they planned to speak about. This ensured there was coherence but no overlap.

Tips for success

Plan as much as you can.

Always get the speakers on a panel to talk in advance.

Impact

Discussions with attendees showed that the events brought academic research and thinking about the idea of interdisciplinary research to a public audience. Many valued the opportunity for conversations between academics and professionals from a range of areas, who would not usually have been able to talk to each other about their work.

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6.3 The 'Asylum Trilogy': *Trade in Lunacy*

Organisers: Centre for the History of Medicine, University of Warwick (with Talking Birds Theatre Company).

Summary: Three theatrical performances exploring topics in the history of mental health and illness.

Purpose: To explore historical responses to mental illness; to start conversations with the general public and mental health service users/providers about perceptions of – and responses to – mental health and illness in contemporary Britain.

Audience: The general public (largely adults), mental health service providers and service users.

Background

Trade in Lunacy was an exciting collaboration between the Centre for the History of Medicine and Talking Birds theatre company. This chamber piece explored the cure, containment and corruption associated with the 18th-century private asylum trade. It was the first of three planned productions, the 'Asylum Trilogy', which explore the history of mental illness and confinement through performance. They use theatre and history to open up conversations concerning our current attitudes to mental illness and its treatment. Nine performances of *Trade in Lunacy* took place at the Shop Front Theatre in Coventry City Centre between 27 and 29 June 2013.

The theme was inspired by the practice of setting up private houses specialising in treating 'diseases of the mind', which took hold in Britain during the 18th century. These usually small-scale institutions were established by individual entrepreneurs or families – some medically trained, many not – who claimed expertise in treating and curing mental disorder. Many of them genuinely attempted to improve the lot of the mentally disturbed. Treatment included a variety of approaches, from careful management and control of patients and their daily routines to drugging, bleeding, cold baths and the spinning chair.

The event built on Hilary Marland's research into the history of mental disorder and its institutions; she acted as advisor on the script and provided a range of historical material for scriptwriter Peter Cann to work with. Peter's script brought to light the tensions between caring for (and curing) the mentally ill and the need to make a medical living. The actors produced fine recreations of the 'typologies' of mental disorder during this period, as well as the plights of the sufferers.

The first evening's performance was followed by a lively panel discussion that provided the opportunity to discuss the themes of the play, as well as the production process itself. Alongside this, Hilary and the three PhD students produced a series of short historical essays on *Trade in Lunacy*, which are available on the Centre for the History of Medicine website.

Tips for success

It is crucial to be genuinely collaborative when producing work like this. We found it invaluable to engage with the Talking Birds team as early as possible and to incorporate their ideas alongside our own to produce an engaging and accessible piece of theatre.

Impact

The performances attracted excellent and useful feedback. Much of it commented on the ways in which theatre based on historical records, patient casenotes, memoirs and testimonies can provide us with a unique way of exploring attempts to cure mental illness in the past and can urge us to reflect on our current attitudes towards mental illness:

This performance has, more than anything else, amazed me with its humorously, sensitively and carefully researched transformation of what is in many ways a highly emotive subject. Before the performance I couldn't imagine how the material I presumed would be used could be turned into a performance; after it I'm very impressed by the ingenuity.

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6.4 Centre for Medical Humanities blog

Organisers: Dr Angela Woods, Dr Will Viney, Mr Ben Kasstan and Dr Felicity Callard, Centre for Medical Humanities, Durham University.

Summary: The UK's leading medical humanities blog.

Purpose: To support and develop the medical humanities community.

Audience: The medical humanities community, including established and emerging scholars from a range of disciplines, clinicians, arts in health practitioners, artists and the wider health-interested public.

Background

In 2008, the Centre for Medical Humanities (CMH) at Durham University received a five-year Strategic Award to "further the public understanding of both scientific and humanities enquiries into health, medicine and well-being." CMH identified the need for an online forum to help the emerging interdisciplinary and inter-professional medical humanities community to share news and ideas, and to engage a wider public in its research. The CMH blog was launched in September 2010 to address this need.

Posts: The blog publishes three main kinds of post: (i) information about upcoming events, publications and research opportunities; (ii) essays and 'ideas' pieces from scholars, clinicians and artists; and (iii) reviews of books, conferences and exhibitions. More than 1500 posts have now been published, including more than 100 invited and commissioned guest posts and reviews.

Visitors: More than 3000 people subscribe to or follow the blog. Annual traffic grew by 58 per cent in 2013 to reach between 10 000 and 12 500 total pageviews per month. Visitors come from 174 countries; most are from the UK, the USA, Canada, Australia and India.

Awards: In 2011, the blog was named 'One of the 50 Best Blogs for Humanities Scholars' by the Online Education Database. In 2014, the blog was highly commended in the UK Blog Awards and judged to be among the top three health organisation blogs.

Risks and challenges: The key challenges for the ongoing development of the blog are sourcing new and dynamic content and ensuring that staff working on the blog are supported in their roles. We have addressed these issues by expanding our editorial team (from one to four) and by prioritising the commissioning of guest posts and reviews from diverse members of the medical humanities community.

Tips for success

What's the best way to connect with your audience? Think carefully about whether a standalone blog or guest contributions to existing sites will be the most efficient way of reaching readers.

Running a blog is deceptively time-intensive! Ensure you have the technological capacity and resources within your team before you take the plunge. There is nothing less engaging than a blog that looks neglected and is updated only sporadically.

Invite people to write for your blog to bring in fresh voices and increase the profile of the site as a whole within different disciplines, institutions and communities. Remember that although some people are natural bloggers, others will not have written for this medium before and may appreciate some guidance and/or a template.

Impact

The CMH blog is an ongoing initiative that engages an ever-expanding audience. We monitor growth through data collected automatically by Wordpress (including visitor numbers, post views and so on) and Twitter (including followers, retweets and followed links). It is more difficult to measure engagement with the blog as a whole, but a survey conducted in 2013 gave us valuable feedback from readers on the content, format and structure of the blog, and informed our redesign and editorial expansion in early 2014. We routinely receive positive informal feedback from blog authors and readers and are widely regarded as the leading medical humanities blog nationally and internationally.

Editing the blog has been a rewarding experience for those involved and key to developing skills and a profile within public engagement. The blog's success at the UK Blog Awards was celebrated by CMH staff

and recognised by the Durham Media Office and Pro Vice-Chancellor for Research. The founding editor, Dr Angela Woods, was awarded the Faculty of Social Sciences and Health award for Media in 2012.

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6.5 Engaging with the voice-hearing community

Organisers: Hearing the Voice, Durham University.

Summary: Developing a series of networking events and public engagement activities for voice-hearers and their families and carers.

Purpose: To share research findings, increase awareness of local sources of support, and gain feedback and input from voice-hearers on questions for future research.

Audience: Mental health service users, mental health professionals, people with lived experience of psychosis, and voice-hearers and their families and carers.

Background

Engagement with voice-hearers and their families and carers is a key priority for Hearing the Voice, yet fear of mental health stigma and discrimination means that people are often wary of publicly admitting that they hear voices or have other unusual experiences. As a result, there is a certain sense in which the voice-hearing community is a hidden one that can be difficult for academic researchers to identify and reach.

The Hearing Voices Network (HVN) is the leading peer-support and advocacy network for people who hear voices in the UK. Founded in 1988, it supports more than 180 Hearing Voices Groups across the country and has extensive networks in England, Wales, Scotland and Northern Ireland. A collaboration with HVN therefore seemed like a natural solution to the problem of how to establish contact with voice-hearers and their families and carers and involve them in Hearing the Voice research.

The collaboration began in 2011 during the planning phase of Hearing the Voice, when Jacqui Dillon, the Chair of the Hearing Voices Network in England, was invited to join our advisory board and share her expertise in the development of the project. Her advice on how to engage members of the voice-hearing community resulted in a series of mutually beneficial engagement events that enabled our team to identify new research areas and priorities and also allowed HVN to expand its presence in the North-East.

The events were hosted by Hearing the Voice at Durham University and included a three-day Hearing Voices Group Facilitation and Network Development Training workshop delivered by Jacqui Dillon (February 2013); two HVN North-East Networking events in February and May 2013; and a series of interactive research showcases attended by 40–50 mental health professionals, group facilitators, mental health service users, and voice-hearers and their families and carers from Durham and surrounding areas (May 2013 and January 2014).

The knowledge exchange made possible by these events has been beneficial both to members of the voice-hearing community and to Hearing the Voice researchers. For example, the HVN networking meetings enabled people to meet other voice-hearers and HVN members, share ideas and experiences, and discuss the ways in which support can be made more widely available for people who hear voices in the region. The interactive research showcases provided an opportunity for academics to share the findings of their research with voice-hearers and their families and carers, and talk to them in informal groups about their needs, questions and concerns. The results of these conversations have, in turn, fed into the design of future collaborations and engagement activities, and have led to the identification of new issues and questions for research into voice-hearing and other unusual experiences.

Tips for success

Get to know your audience early. Consulting members of the voice-hearing community during the development phase of Hearing the Voice shaped the nature of the engagement activities and the formats that were used.

Build trust. Invest time and energy into building relationships, respect expertise, and empower members of marginalised groups by giving them key roles on the project.

Use social media effectively. Peer support and advocacy groups are often active on social media. Online communication tools such as Twitter and blogs provide an effective means of advertising events, strengthening relationships and reaching these audiences.

Respect alternative viewpoints. Voices often have important meanings for an individual, and it was important for our researchers to respect and acknowledge this – even when the voice-hearer’s interpretation of their experiences was in conflict with their own.

Impact

The Hearing Voices Group Facilitation and Network Development Training delivered by Jacqui Dillon resulted in the development of six much-needed Hearing Voices peer-support groups in the North-east of England at considerable benefit to local communities. The knowledge and contacts gleaned from the HVN Networking Events enabled the formulation of an interactive map of peer-support groups in the region, which is hosted on the Hearing the Voice website and helps to increase the availability of information about local sources of support for people who find their voices distressing.

The collaboration with key members of the Hearing Voices Network has also resulted in significant academic outputs, including a special issue of the journal *Psychosis* edited by Angela Woods, Simon McCarthy-Jones, Jacqui Dillon, Marius Romme and Sandra Escher.

Jacqui Dillon's contribution to Hearing the Voice and to mental health research at Durham University was formally recognised through her appointment as an honorary fellow of the School of Medicine, Pharmacy and Health.

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6.6 *Adam Plus One*

Organisers: Hearing the Voice, Durham University.

Summary: A three-minute film about one individual's experience of psychosis and hearing voices.

Purpose: To raise public awareness, reduce stigma and discrimination, and challenge preconceived opinions about hearing voices and other hallucinatory experiences.

Audience: General adult audiences, mental health service users, mental health professionals, and voice-hearers and their families and carers.

Background

Improving public understanding of voice-hearing and reducing mental health stigma and discrimination is a key priority for Hearing the Voice. As part of our activities in this area, the project supported the making of *Adam Plus One* – a short film about personal experience of hearing voices.

The film was screened for the first time at Cinema and Psychosis at the Barbican in March 2013, to an audience of more than 200 people. The screening was accompanied by a short talk by project director Charles Fernyhough on the need for interdisciplinary research into voice-hearing and the way in which the biomedical model of auditory verbal hallucinations fails to understand the heterogeneity of voices and the many different contexts in which they can occur. After the screening the film-maker, Adam, gave a short talk about the making of the film. The film was subsequently shown in *Lionel: The spaceship of our imagination* (a cinema in a campervan) as part of the Wellcome Trust Wonder Season in April 2013, and at the North-east Mental Health Day in Newcastle in October 2013, which was sponsored by the national Time to Change campaign.

As a result of the film, Adam appeared on BBC Radio 4's *Saturday Live* in March 2013 to talk about his experiences with the interviewer Sian Williams. The broadcast reached an audience of 2.3 million and was praised by listeners for its sensitive and sympathetic portrayal of voice-hearing and mental health issues.

Tips for success

Develop a dissemination strategy. Be selective about where the film is screened and formulate a dissemination strategy that maximises impact and helps to get your message across to the target audience.

Work with professional partners. The film benefitted from the expertise of the production crew, who had previous experience of working with vulnerable individuals and ensured that the subject matter was handled sensitively.

Build trust and co-create. Invest time and energy into building relationships, provide sources of support, and involve the subject of the film in each stage of the production process so they feel a sense of ownership over the final product.

Consider ethical issues. If the film deals with sensitive or controversial issues, consider whether the participants' anonymity needs to be protected and how this should be ensured.

Impact

Feedback from audiences who have viewed the film indicates that *Adam Plus One* provides a deeply engaging experience and is successful as a means of increasing understanding of voice-hearing, reducing stigma and combating the notion that hearing voices is exclusively a symptom of severe mental illness.

Hearing the Voice is now supporting a further series of films featuring voice-hearers from diverse social groups and backgrounds (e.g. young people, the elderly, and people from different cultural and religious communities), which will explore the different ways in which these people interpret and make sense of their experiences. One of these films focuses specifically on Adam; it explores his reflections on the initial film and the way in which his voice-hearing experiences have changed over time.

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6.7 Mitochondrial patient day

Organisers: Julie Murphy, Catherine Feeney, Bernadette Caygill, Sue Callender, Robert McFarland and Doug Turnbull.

Summary: On 18 October 2013 we held a patient information day, which included a series of talks and workshops run by medical and scientific professionals.

Purpose: The talks and workshops aimed to inform people with mitochondrial disease of current developments within research, diagnostics and the care of people with mitochondrial disease and to gain feedback from patients about issues that are important to them.

Audience: The audience was primarily people affected by mitochondrial disease and their families.

Background

The mitochondrial patient day is an annual event that aims to engage those who are affected by mitochondrial disease. The topics of talks at the event included advances in diagnosing mitochondrial disease and current research at the Wellcome Trust Centre for Mitochondrial Research. These topics were intended to address some common issues and questions raised by the patients during clinic visits and following questionnaires after previous patient days. The smaller workshops and focus groups included discussions on hearing loss, fertility issues and social networking among patients. The addition of smaller workshops to the formal talks allowed the patients and families to provide feedback on the research currently being undertaken and issues they find important. This helps us to shape future research within the Centre. The workshops and focus groups also helped to promote the interaction between patients, clinicians and scientists for the Wellcome Trust Centre. The whole day was videoed, and the video is available via the Wellcome Trust Centre for Mitochondrial Research's website for people who were unable to attend owing to cost or health issues.

The mitochondrial patient day is held where there is easy accessibility and parking to ensure even those with severe disabilities are able to attend. Patients travel from all over the UK, and careful consideration is given to the timing of the event. Anyone presenting or holding a focus group was encouraged to remove any complex scientific jargon or abbreviations to make their content clear and informative. Researchers were given time to work together on their presentations and to make sure patients' needs were being addressed by working together with science, medical and nursing staff.

Tips for success

Always get patient involvement when planning talks and focus groups, so you address real questions and real issues that the patients face or want to discuss.

Include smaller, more informal sessions so patients do not feel intimidated and feel free to contribute to group discussions.

Listen and observe the group so you can ensure everyone feels comfortable and has their views represented.

Work as part of a team to ensure that all the patients' needs are met, including access, timing of the event and contact numbers if there are any problems.

Make sure all speakers are free and available during coffee breaks to encourage interaction and an open dialogue between the speakers, researchers and patients.

Impact

100 per cent of the patients rated the day good to excellent in our evaluation questionnaires, with most of these attendees feeling they had learned something new and found the day beneficial. Researchers who took part in the day were able to improve their communication skills and were also able to see the human side of the often-anonymised research going on within the Centre by interacting directly with patients, patient groups and their families.

The success of the activity was shared with the patients via our newsletter *Mitonews* and online on our website, and formally with the researchers during our research in progress meetings.

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6.8 People of the British Isles: Genetic Maps

Organisers: Wellcome Trust Centre for Human Genetics and Department of Oncology, University of Oxford; Centre for Vision, Speech and Signal Processing, University of Surrey; Department of Geography, UCL; Department of Twin Research and Genetic Epidemiology, King's College, London.

Summary: Presentation stand to explain the genetic study of the people of the British Isles and the light it sheds on British history and – more broadly – to introduce people to key ideas in genetics.

Purpose: To show how collecting genetic information can shed light on the history of the people of the British Isles and help medical research.

Audience: Adult members of the general public and secondary school children.

Background

Where did British people come from, and how have they changed since modern humans first came to the British Isles? Why are people different from each other, and what determines the differences? Led by Sir Walter Bodmer, in 2004 the People of the British Isles project began to collect blood samples from 4500 people from rural populations throughout the British Isles. The main criterion for participation was that all four grandparents should have been born locally. Researchers at the Centre led by its director, Peter Donnelly, analysed more than 500 000 genetic markers in each sample to map genetic variation across the British Isles.

In 2012 we presented the results of the study in an exhibit at the Royal Society Summer Exhibition entitled 'Genetic Maps'. It featured a map showing genetic clusters in different regions of the British Isles, an interactive terminal where visitors could find out where their surname most commonly occurred in 1881 and in 1998, and the opportunity to sit for a 3D photograph. 'Hands-on' activities included PTC (phenylthiocarbamide) tasting and tongue curling, and wristbands and leaflets were available. The exhibit was designed to be accessible to visitors of all ages and was staffed by scientists who could explain the map and answer wider questions about genetics, genes and disease.

The same exhibit was shown in 2013 at the national Big Bang Fair at ExCeL in London, at the Natural History Museum's Science Uncovered event and in the Discovery Zone at Cheltenham Science Festival in 2014.

Tips for success

Invest resources in professional design and production for the stand and its display items.

Provide a clear and careful briefing for scientists presenting on the stand.

Impact

Our experience is that there is very wide interest in the People of the British Isles project and its results from members of the public, many of whom have a general curiosity about the science and what it can tell us about the history of the UK.

The Royal Society recorded 11 120 visitors to the exhibition. A total of 623 3D photos were taken at the People of the British Isles stand, 1700 people participated in PTC tasting and tongue curling, and 2400 wristbands were given away.

Researchers enjoyed taking part in the activity and learning how to match the level of their conversation to the needs of the visitor.

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