



Patients Participate! Workshop Report



***Bridging the Gap between Information Access and
Understanding in Health Research***



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More information on the project is available at:
<http://blogs.ukoln.ac.uk/patientsparticipate/about/>

Report Overview

This report is a summary of a workshop organised as part of the JISC-funded '**Patients Participate! project**' held in June 2011 and represents the project team's interpretation of the key issues raised on the day. The project brings The British Library, UKOLN and the Association of Medical Research Charities together in partnership. This 7-month feasibility study aims to explore the potential for developing a useful body of literature for patients and the public interested in biomedical and health research.



Patients Participate! Project partners from right to left: Liz Lyon (UKOLN and DCC), Lee-Ann Coleman (British Library), Sara Ellis (AMRC) and Melanie Welham (University of Bath). For detailed biographies see Appendix 2.

This workshop aimed to:

- Bring together people from different communities - patients, carers, researchers, charities, and technologists – to explore the motivations, challenges and barriers to biomedical information access, comprehension, and wider use.

- Produce a set of recommendations on how best to leverage different communities and/or tools to enhance the communication of biomedical research.
- Identify individuals for follow up interviews to serve as case studies documenting existing approaches to online engagement, access and community evaluation for biomedical information.

The recommendations identified by workshop participants indicated their enthusiasm for enabling and enhancing access to biomedical information, but highlighted the continued need for further action in this area.

Workshop participants valued the event, especially the opportunity to share ideas and meet those from different communities and learn from each other (see Participant Feedback).

This report includes the following:

1. Background information - setting the context for the Patients Participate Workshop
2. A summary of what happened at the workshop
3. A summary set of recommendations delivered by workshop groups
4. Appendices provide additional information including the workshop programme and a long list of recommendations from individual groups.

Defining Terms

Citizen Science is a term used for projects in which volunteers, including the general public and enthusiasts, engage in research-related tasks to collect information or participate in research in other ways. As well as increasing the resources available to collect or analyse research data, thereby accomplishing tasks that otherwise might not have been feasible, citizen science makes a positive contribution to the public's engagement with science.

Crowdsourcing is the act of outsourcing tasks, traditionally performed by a professional, to an undefined, large group of people or community (a "crowd"), through an open call, typically using internet technologies.

Patient is used in this report to describe any individual who has an interest in a disease-condition from a personal perspective; they may also be carers, parents, advocates, survivors etc. This is to differentiate them from the general public who may have an awareness of a given condition, but not personal experience of it and its impact. Definition from Natural Ground Report: http://www.amrc.org.uk/our-members_natural-ground:-patient-and-public-involvement-project_ppi:-natural-ground.

Patient and Public Involvement 'An active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Active involvement may take the form of consultation, collaboration or

user control. Many people define public involvement in research as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public.' Definition from the national advisory group, INVOLVE.

Project background

Every year the UK contributes billions of pounds of public funding to scientific research, much of it aimed at investigating human health and disease. With an ageing population, an increasing number of people living with chronic health conditions and with many members of the public indicating an interest in medical research, there is a need for access to easy-to-understand information about conditions, treatments and the latest scientific research findings. However, researchers often struggle, to describe their work in ways that the general public can understand.

Through initiatives such as UK PubMed Central (UKPMC), a free-to-access archive of biomedical research papers, some of the barriers to accessing biomedical information are being addressed. Thanks to UKPMC anyone with a computer and an internet connection can read much of the latest biomedical research results. Having access to the information does not always help patients or the public make sense of scientific research.

A number of organisations, such as charities and patient groups, acknowledge this situation and already produce lay summaries of some biomedical research. There are over 100 medical research charities in the UK which are members of the Association of Medical Research Charities and they vary hugely in size and cover a broad range of conditions. Unsurprisingly therefore, the way in which charities approach this area - from the way the information is produced to the level of involvement of patients in the process - is highly variable. Some examples of the range of approaches are outlined in the AMRC Natural Ground report <http://www.amrc.org.uk/our-members-natural-ground:-patient-and-public-involvement-project-ppi:-natural-ground>. Despite these efforts, there is evidence suggesting that more can be done to enhance patient and the public understanding of and engagement with science, by providing information that caters for a variety of audiences.

The Patients Participate! Project aims to build on existing work and best practice and will explore how to transition from access to understanding of the biomedical research literature. We want to explore the possibility of further recognising and harnessing the untapped knowledge, skills and capabilities of patients, their families, charities and communities; combining this with the knowledge and expertise of researchers. Working together across these groups could allow a richer body of lay information relating to biomedical research to be developed.

We would also like to examine novel ways in which new technologies, social media and web tools might be used to best effect in facilitating access, understanding and

collaborative working, to ultimately help people to make sense of the biomedical information.

Some relatively new technologies have helped to bring down walls between disciplines and between researchers and the general public. Examples of new approaches such as 'citizen science' include members of the public in the research process. One example, [Galaxy Zoo](#), a project where astronomers use 'crowdsourcing' to classify galaxies, has proven very successful in harnessing the power of crowds. Wikipedia represents an obvious example of crowdsourcing information, relying on collaborative contribution by the community to produce an online free-to-access encyclopaedia. These types of approaches have not had an impact in biomedical/health related areas to date.

It is an open question, and one we would like to address through this project whether 'crowd sourcing' and/or 'citizen science' type approaches could work in the biomedical/health information area.

The Patients Participate! Project concludes in September 2011 and will aim to produce guidelines for researchers and patients, based on feedback from the workshops and follow-up interviews, on ways to access, contribute to and make biomedical research more participatory.

Workshop Outline

The Patients Participate! Workshop, which was hosted at the British Library Conference Centre on 17 June 2011, had four main parts:

1. An opening plenary session to set the scene with presentations by the project partners.
2. Workshop sessions where participants explored the motivations, challenges and barriers to biomedical information access.
3. Demonstrations of the UKPMC (ukpmc.ac.uk) literature resource and Hyperwords (hyperwords.net) tool
4. A final plenary where;
 - Prioritised recommendations were presented from each group and discuss what was required to take these priorities forward.
 - Two speakers rounded up the day from the patient and charity sector perspectives.

The programme for the day is provided in Appendix 1.

Plenary Session

In the opening plenary session, the project partners set the scene for the workshop:

Liz Lyon (UKOLN) – *Patients Participate: Origins and Overview;*

- Introduced the idea of ‘citizen science’ with examples
- Raised the issue of technical language barriers to understanding
- Highlighted potential impact of open- and citizen- science approaches
- Gave an overview of aims of the project

Lee-Ann Coleman (British Library) - *Accessing Biomedical and Health Information;*

- Overviewed the scholarly communication process and evolution of scientific publishing
- Explored the issue of who ‘should’ have access to biomedical information
- Highlighted the difference between ‘available’ and ‘accessible’
- Looked to the future of ‘community content’ and what that could mean

Sara Ellis (AMRC) - *Patient Perspectives on Research Findings;*

- Presented an overview of AMRC and its member charities
- Explained why lay summaries matter to AMRC
- Gave some background on what AMRC has done already - the Natural Ground report
- Highlighted a couple of case studies of patient involvement

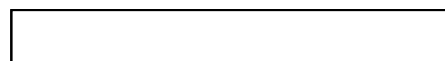
Melanie Welham (University of Bath) - ‘Communicating research beyond Academia’ (A researcher’s perspective);

- Explained historical changes taking place in academic research – impact agenda means there is much greater emphasis on academics engaging with beneficiaries
- Suggested some benefits of engagement – communication leads to a public that is better informed about advances in science, more equipped to judge what it means to them and more likely to participate
- Explored the barriers to patients accessing information
- Highlighted potential routes to facilitation – academics need to know what sort of information patients need and want in order to develop innovative solutions.

Group Sessions

After the plenary session, there were three facilitated group sessions which took place concurrently. These sessions were structured to allow participants to consider a range of questions, to help understand:

1. **Different perspectives and motivations** - What motivates different types of users to look for biomedical information?
2. **What does 'good' look like and how do we get there?**
 - What are the barriers to online access to biomedical information?
 - What are the key factors for the way biomedical information is presented that enable easy comprehension by a range of people?
 - How could the different communities work together e.g. patients, charities and researchers in enabling access to and facilitating translation of biomedical information?



Workshop Findings

Exploring perspectives and motivations

Participants were first asked to consider different perspectives of potential users of biomedical information and came up with a long list of suggestions, which were then clustered into groups with similar motivations. These included: Patients, General Public, Health Professionals, Charities, Communicators, Funders and Policy Professionals. Participants then explored, in more detail, the motivations and requirements of particular groups in accessing and understanding biomedical information.

'The patient with a disease has an acute need for information - your motivation is survival and you want information, yet you face many barriers.'

'Right at the start I simply wanted to know; How can I access research information?'

What should 'good' look like?

Some common themes emerged from group discussions on perspectives and motivations across the different workshop groups.

- Biomedical/health information should be open and easy to access and understand - Lay summaries should be available for every biomedical article
- Presentation needs to be concise, uncluttered and attractive
- Language should be plain English but not patronising in any way
- Need to consider formats - something that can easily be printed so users can take it away with them and can be shared easily online and also need to account for disabilities
- It would be useful to provide context – i.e. not just facts - how does this fit into current understanding and knowledge in the field and presentation of negative results could also be considered
- Users will have different motivations and needs and these may vary at different times - health professionals generally need greater depth than those looking for general interest, but the time poor and cross-disciplinary reader may also just skim read headlines. Stratified layers or different levels of information that allow users to drill down to more complex and comprehensive information could help cater for variations in levels of understanding and different requirements.
- Need to consider independent, impartial and trusted sources to provide information and how this might be validated and monitored and by whom (Government, not-for-profit or independent companies) particularly if crowd sourcing was utilised.

'I like the NHS choices website - there is lots of information for people interested about health and it provides links out to greater depth of information relating to research. It brings this type of information into the public domain really well.'

'There is a BHF leaflet which explains in a very understandable way why it is important to have Centres of Excellence to carry out specialist surgeries/treatments. This was really useful because lots of people couldn't understand why their treatment couldn't be closer to home. Researchers and health professionals should be made more aware of examples that work well.'

'Macmillan voices an excellent example of how an organisation can disseminate information to patients.'

In considering what 'good' should look like for a variety of audiences workshop participants then set out a number of goals and recognised the challenges to achieving these and any other issues that might need to be addressed.

Goal 1: Clear lay summaries with every research article

Considerations:

Who should produce these? Professional communicators or translators will already possess the required specialist skills; however finding the necessary resource to support this activity may be an issue. It would be really useful to collect and collate existing information on lay summaries, such as guidance on writing lay summaries, in order to learn from existing best practice. It will also be really important to develop methods to evaluate how useful they are to patients and the public.

'A lot of existing information is already out there about getting involved, and learning about the researchers' perspectives and patients perspectives, although not all of it is published. Is there a way this could be collected? Is there a role for the AMRC in co-ordinating this?'

'A high level group is needed to join things up at a strategic level.'

A second possibility is that researchers themselves could produce lay summaries of their research but training, support and guidelines would be needed to ensure they produce something clear and understandable. Patient and public involvement in research could help to bridge the gap and make researchers more aware of patient' needs. This would require increased networking between patients and researchers and could be facilitated by forums where they could meet on an equal footing. Workshop participants felt that while patients should be involved in the process and could provide useful feedback and guidance on what they would find useful, they should not be the primary authors. While lay summaries were universally considered to be very useful, alternative media and formats will also be needed – they would not provide the whole solution.

'Another important element is to ensure that non-published research (for example on-going trials) is described in lay friendly terms.'

Goal 2: Information set in context

Considerations:

Placing research findings in context of the given knowledge (published and unpublished) in a field and including information on researchers involved would be useful. Also need to consider linking to related information and correct accreditation of sources. Published research tends to be skewed in favour of positive results and sometimes negative results are not published. This practice, along with explanations about the inherent uncertainty of research results, also needs to be communicated. Professional guidance may therefore be required on how best to communicate this inherent uncertainty of research information. Misinformation or overselling research outputs should be avoided, as patient choices can be influenced by this information.

Goal 3: Open access to all biomedical information

Considerations:

Increasing transparency and access to research outputs was highlighted as a major benefit of open access. The argument for open access often hinges on a democratic right to research information originated from the public purse, however at the workshop there was a call for increased openness within private companies and industry. This is particularly relevant for clinical trials that are privately funded, where not releasing the information, can mean that patients only have a partial view of the current findings in a particular area.

Although open access means that specialist information is increasingly accessible to all but it can create issues around relevance and quality, which calls for third parties to help patients navigate this complex landscape. Patients/public and charities may also have difficulty accessing the latest research outputs because of embargoes placed upon open or free-to-access publications.

Goal 4: Crowd Sourcing Information

Considerations:

Information overload was a recurrent theme throughout the day, as were issues of resource and scalability. The possibility of creating something similar to Wikipedia where lots of people could contribute was a suggested solution, although it could create issues around ownership and quality control. It was suggested that an unbiased third party, such as the British Library, could play an important role (as opposed to a university which may wish to push their own research).

Final Plenary

The final plenary session participants from all groups fed back key recommendations. Following on from these recommendations we had two final speakers wrap up the day, giving their take on the day's discussion from two different perspectives; Patient Advocate Graham Steel and Simon Denegri, Chief Executive of Ovarian Cancer Action (and formerly CE of AMRC) and Chair of INVOLVE – the national advisory group for the promotion and support of public involvement.

Graham Steel

Graham covered the patient advocate perspective on why the Open Access and Open Science movements are so important to the public. He suggested that the outputs of scientific research should be 'Everyone's knowledge and nobody's property. He gave examples of how communities of patients and their carers use online forums to share personal experiences. He then suggested that STM publishers might have a role to play in the production of lay information on biomedical research for the public.

Simon Denegri

Simon suggested that science is switching on to the fact that patients and the public are essential partners in innovation and adoption, which raises the questions of how

these new relationships, might work. He went on to highlight that social media provides opportunities to take partnerships to a new level which can improve science and improve lives. He then concluded by proposed that the lay summary could be a focus for this greater connectivity and transformative in its impact - a building block of innovation.

Key Recommendations

In the final session, participants from all groups fed back recommendations from each group (these are provided verbatim in Appendix 4). The following key recommendations summarise the main points:

1. **A lay summary for every UKPMC article**, which includes discussion about uncertainty of the information and the context in which it has been created. Should consider layers of complexity to allow users the ability to 'drill down'.
2. **Guidelines, structures, templates and standards** for producing lay summaries are needed to ensure consistency and that all relevant information is included. Many organisations (e.g. charities) have their own guidelines and style guides – enhancing sharing of resources, expertise and knowledge across the sector would be very useful.
3. **Need to develop a method to evaluate** lay summaries to continually check they are fit-for-purpose and adequately answer the questions patients have.
4. There is a **need for a perception shift amongst researchers**, so that plain language and the associated writing skills are valued. Increasing opportunities for patient-researcher interaction and involving patients in producing lay information, as well as improving networking and sharing of ideas, including communications training for researchers and considering the role of the patient as teacher, could contribute to this change.
5. Could **consider new media to disseminate research more widely** for example online forums, learning modules and social networking (e.g. Twitter). This could also help to facilitate patient interaction with researchers. Every paper could be summarised in 140 words and every new paper should be accompanied by a tweet and a hash tag for relevant subject to navigate - allowing people to search for research in a particular area e.g. # stem cells etc. This approach could also help with information overload, given succinct format.
6. A combination of approaches would be needed to encourage best practice and **to ensure compliance - mandates, incentives and awards**. This would be particularly important if researchers produce lay summaries and funders' support would be required.

Participant Feedback

At the end of the day participants were asked to complete a feedback form. Overall, attendees found the workshop very valuable and thought the structure of the day allowed them to engage with the issues.

Some of the things people said they enjoyed most about the day were:

- *'The diversity of perspectives represented at the workshop made for interesting discussions'*
- *'The sessions were well structured and a lot came out of them – it will be good to see how the information is used'*
- *'It was great to have the opportunity to network and share experiences with other participants'*

Some of the things they would have changed:

- *'Given the time and vastness of the subject some felt we may have achieved a little more by focusing down a bit more'*
- *'Would have liked to see more researchers there'*

Views from the organisers

The Patients Participate! Project team were very pleased with the high level of interest and enthusiasm from the workshop participants. We recognised that given the broad topic and the structure of the day, limited time was available to explore initial suggestions in more detail. Having more time would have been valuable given the range of perspectives represented during the workshop. We are also very thankful that following on from the event everyone we approached agreed to participate in interviews which will contribute to more detailed case studies.

Next Steps

Liz Lyon (UKOLN) concluded the day by thanking participants for attending. She confirmed that all documents generated through the 'Patients Participate! Project' would be shared with participants. These would include:

- Workshop report
- Guideline document for Academics on how best to produce lay summaries
- Resource guide for Patients on how to make sense of biomedical information
- Case studies of organisations producing lay summaries of biomedical research

She also encouraged people who had taken part in the workshop to attend the TalkScience event with Tracey Brown (Sense about Science) at the British Library in October 2011. This event aims to explore some of the wider issues raised throughout the project and serve as a launch for the 'Patients Participate! Project report.

Appendices

Appendix 1: Workshop Programme

11:00 Welcome to the workshop

Liz Lyon (UKOLN, University of Bath) - *Patients Participate: Origins and Overview*

11:15 Introduction to the project from the project partners

- Lee-Ann Coleman (British Library) – *Accessing Biomedical and Health Information*
- Sara Ellis (Association of Medical Research Charities) – *Patient Perspectives on Research Findings*
- Professor Melanie Welham (Centre for Regenerative Medicine, University of Bath) – *Communicating Research Beyond Academia*

11:45 Assigning workshop groups, brief introductions and setting questions

12:15 Lunch

13:00-15:20 Workshop groups (including afternoon tea break from 14:30)

15:20 Feedback from workshop groups and Summary Recommendations (Liz Lyon)

Reporting from each workshop group on discussions aligned to 5 questions/recommendations under the broad themes of:

- Motivations and Barriers
- Good and Bad Examples
- Potential for Improving and Collaborating

15:50 Final guest speakers & Q&A

- Graham Steel – Patient Advocate
- Simon Denegri – Chief Executive, Ovarian Cancer Action & Chair Involve.

16:30 Close

Appendix 2: Speaker Biographies

Dr Liz Lyon is Director of UKOLN, University of Bath, and Associate Director, Digital Curation Centre. She is author of major direction-setting Reports: *Open Science at Web-Scale: Optimising Participation and Predictive Potential* (2009), *Scaling Up* (2008) and *Dealing with Data* (2007), and has led pioneering research data

management projects: eBank, eCrystals Federation, Infrastructure for Integration in Structural Sciences (I2S2) and SageCite. She has a PhD in cellular biochemistry.

Dr Lee-Ann Coleman joined the British Library in 2007 to take up the post of Head of Scientific, Technical and Medical Information. For ten years prior to that, she worked in science policy and administration, and gained experience in the funding, university and medical research charity sectors. She has a PhD from the University of Western Australia where she studied the development of the visual system and completed postdoctoral research in the United States and at Oxford before moving into scientific administration.

Dr Sara Ellis is communications manager at the Association of Medical Research Charities (AMRC) where she supports the team on print, online and media communications. Sara has a PhD in biochemistry from the University of Bristol and spent seven years in the lab as a researcher before crossing over into the charity sector. Sara hates jargon, although sometimes is guilty of it, loves clear communication and is particularly interested in social media.

Professor Melanie Welham started her scientific career as an undergraduate in Biochemistry at Imperial College, London and moved to the Imperial Cancer Research Fund for her PhD. After several years of post-doctoral research at The Biomedical Research Centre, University of British Columbia, in Vancouver, Canada, Melanie was appointed to a Lectureship in the Department of Pharmacy and Pharmacology, University of Bath, where she is now Professor of Molecular Signalling and co-Director of the University's Centre for Regenerative Medicine. She leads a team of researchers whose focus is on investigating the behaviour and biology of stem cells, work initiated during her time as a BBSRC Research Development Fellowship (2003-2006). In her alternate career, Melanie cares for two daughters, a husband and three guinea pigs!

Graham Steel has been actively involved in Patient Advocacy work in his spare time since 2001. Graham acted as Vice-Chairman for a UK Charity, the Human BSE Foundation 2001 – 2005 and then as Information Resource Manager for the CJD International Support Alliance (CJDISA) 2005 – 2007. More recently, his activities have been focused mainly on Neurodegenerative conditions such as Motor Neurone Disease. He is also involved in advocating for Open Access/Science/Data and acts in advisory capacities to the Open Knowledge Foundation, the Public Library of Science (PLOS) and most recently, Digital Science.

Simon Denegri is chief executive of Ovarian Cancer Action. Before taking up this appointment in June 2011, he spent five years as chief executive of the Association of Medical Research Priorities (AMRC). Simon was appointed chair of INVOLVE – the national advisory group for the promotion and support of public involvement – in May 2011. He is also a member of the National Institute for Health Research (NIHR) Advisory Board, the NIHR Strategy Board and the UK Clinical Research Collaboration (UKCRC) Board. He has written and spoken extensively on issues concerning medical

and health research policy and practice and writes a popular blog on the world of medical research, charities, public engagement and involvement:
<http://simondenegri.com/>

Appendix 3: Workshop Group Recommendations

Workshop Group 1 Recommendations :

1. Clear lay summary which includes discussion about uncertainty of the information and the context in which it has been created
2. Open access produced in different layers of detail
3. Present these layers of information but not in electronic form
4. Lay involvement: to include networking and sharing of ideas including communications training for researchers

Workshop Group 2 Recommendations:

1. Look at and evaluate research summaries to check they are usable and answer the questions people searching them have
2. Perception shift - plain language is critical- involve lay people in producing it. Patient as teacher.
3. Structured lay summary based on best practice - Tweeted summary with relevant hash tag
4. Lay summary for every article
5. Guidelines for producing summaries
6. Funders to mandate summaries - incentives/awards to encourage best practice

Workshop Group 3 Recommendations:

1. Collect and collate existing information such as guidance on writing lay summaries
2. Develop a forum where patients, researchers and funders regularly meet on an equal footing
3. Improve the process around the provision of lay summaries

4. Establish an online module that helps lay people access information and research