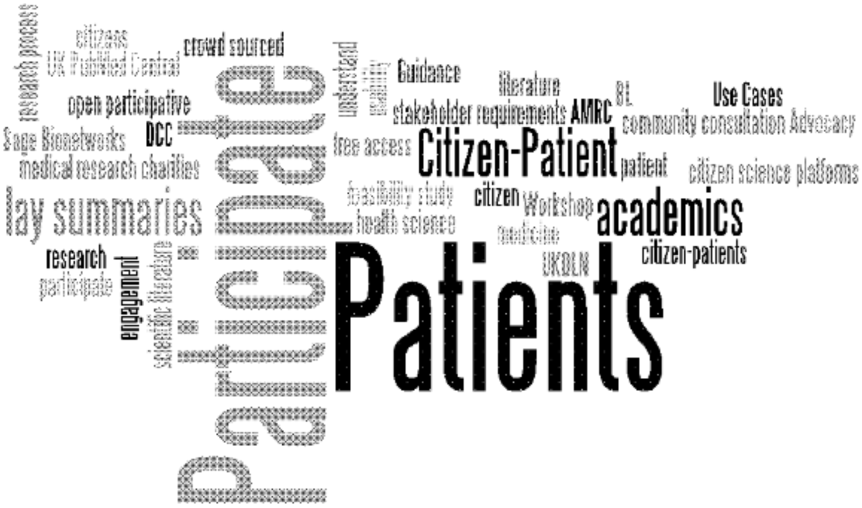
Patients Participate!
Position Paper



Bridging the Gap between Information Access and Understanding in Health Research

Introduction

This position paper describes the background to the Patients Participate! project, helping to set the scene and explain the project's ideas, for those generally interested in engaging with the project and taking up its outcomes. It describes the organisations behind the Patients Participate! Project, explains some of the terms that will be used during the course of the project, provides examples of related work that the project can build on, and finally outlines some of the potential benefits and questions that the project wishes to explore. The paper was particularly useful in preparing for the Patients Participate! workshop which took place on June 17, 2011.

The Patients Participate! Project

The Patients Participate! project is a partnership between UKOLN, based at the University of Bath, the British Library and the Association of Medical Research Charities, with the support of the Digital Curation Centre and Sage Bionetworks. All the organizations have an interest in bringing the results of research activity to a wider audience.

- UKOLN works with researchers to understand how information technology and the principles of digital information management can be applied to increase the effectiveness of the work that researchers do. UKOLN is part of the Digital Curation Centre, which is a major channel of data advocacy, training and dissemination to the higher education sector.
- The British Library (BL), as the UK's national library, is well-placed to be a hub of activity for engaging with a wide audience, given its position and public reach. One of the British Library's strategic priorities is to 'Enable access to everyone who wants to do research'. It has also been involved in delivering UK PubMed Central (UKPMC), a discovery service for biomedical and health publications, supported by the eight major UK biomedical and health research funders. All of these funding bodies have mandated that the outputs of the research that they fund must be freely accessible by being placed in UKPMC.
- The Association of Medical Research Charities (AMRC) is a membership organisation of the leading medical and health research charities in the UK. AMRC works with member charities and partners to support the sector's effectiveness and to develop best practice in areas relevant to medical research charities. The AMRC has expertise in helping charities involve

patients in the process of making strategic decisions about the research that they fund. The charities that the AMRC represents have a natural and unique relationship with patients.

The partnership wants to explore how we can involve the public and researchers in making sense of the scientific literature. With the barriers to access being gradually removed as a result of open access initiatives, particularly in the biomedical and health fields, the public can now see scientific publications that were once just the preserve of academics. However, truly accessing the knowledge contained in the publications requires more than a computer and an internet connection. Even those working in the field struggle to keep up with the volume of new information and if the research area is outside one's expertise, it can often take significant time and effort to understand the context and the key messages contained within a research article.

Specifically, the partners in this project want to explore the potential for developing a body of useful literature for patients interested in biomedical and health research. Although we hope that the principles will apply to all areas of biomedical and health research, we have chosen to focus on stem cell research for this project, since it has a high profile in the media, with promises of cures for a range of diseases and the possibility of regenerating or replacing tissues and even whole organs.

By working with patients, charities and researchers we aim to better understand the barriers to extracting information that is useful to them from scientific papers and assessing the feasibility of building a corpus of quality content that is truly open to all. We will consider how patients currently access this type of information, the role of researchers and medical research charities in interpreting the science and whether new technologies can be applied to aid the transition from access to understanding.

Citizen Science and PPI

An interesting convergence has emerged between two approaches that involve the public in areas normally dominated by specialists – Citizen Science and Public and Patient Involvement.

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 analyze 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.

While there are a number of models for involving the public in science, the concept of collecting contributions from many individuals to achieve a goal is more generally called crowdsourcing. Crowdsourcing has been used to good effect in the environmental sciences and astronomy, but less commonly in biomedical research. It is also popular in other spheres, for example, a New York Times blog post by Tina Rosenberg (Crowdsourcing a Better World) describes instances where crowdsourcing has been applied with a particular emphasis on contributions that help to bring about social change. At Innocentive.com, companies can offer a cash prize for solutions to problems that they wish to solve, with the result that an outsider often contributes to finding a solution. Rosenberg argues that crowdsourcing helps people to connect to a cause in ways other than financial donations, including aggregating and organising knowledge.

Where people have been involved in the delivery of healthcare, a different approach has arisen. Patient and Public Involvement (PPI) is the term used to describe the process by which non-professionals are included in the medical decision-making processes that affect them as consumers of health care.

The Natural Ground Report, published by the AMRC in 2010, notes that the terms 'patient' and 'public' describe a wide range of roles taken by people who may become involved, such as advocates, consumers, survivors, carers and charity members. The term 'patient' can therefore be applied to '*an individual who has an interest in a disease-condition from a personal perspective*', including those who may not have the condition but are carers, parents etc. Many medical research charities already use or are developing models of patient and public involvement. Patients are involved in setting research strategies and priorities, evaluating research grant applications and communicating the results of research more widely.

INVOLVE, a national advisory group that supports and promotes public involvement in the NHS, defines involvement as '*An active partnership between public and researchers in the research process, rather than use of people as the subjects of research*'. The distinction is made between involvement in research as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public. Active involvement takes the form of consultation, collaboration or user control.

The partners of the Patients Participate! project propose that the developments in web infrastructure which have led to successful citizen science initiatives, coupled with the interest of patients and charities in medical research, alongside the growing demand for scientists to make their research more accessible not only through removing the barriers to accessing the original article, but by ensuring that the outcomes can be understood more widely, make this a timely project.

We plan to explore the potential for using lay summaries of research as a starting point in developing a body of information that can be used by the public and researchers. Lay summaries of both research projects and published research articles are being produced by researchers and medical research charities but this activity is not uniform and, to our knowledge, when lay summaries are developed they are not linked to the original articles nor available in an easily accessible way at the moment. Some publishers also produce summaries of research articles – the Public Library of Science journals for example, use a variety of formats. PLoS Medicine provides an editor's summary of an article, while PLoS Biology has an author's summary.

Lay summaries are defined as '*a brief summary of a research project or a research proposal that has been written for members of the public, rather than researchers or professionals. It should be written in plain English, avoid the use of jargon and explain any technical terms that have to be included*'

Building on existing examples of participation.

Participation in science by members of the public can take different forms, illustrated by the following successful examples:

GalaxyZoo is a mature open science example which has developed a community of amateur astronomers who collectively help to classify galaxies via customised user interfaces, combining human observational and pattern recognition capacity with categorisation capability. The public work alongside disciplinary experts in a truly global initiative to help to collaboratively map the universe.

The interactive Foldit game allows contributors to 'solve puzzles for science' by taking advantage of human puzzle-solving ability with people playing competitively to fold the best proteins. Foldit attempts to predict protein structures; future developments will add functionality to the game to allow users to design new proteins that could help prevent or treat important diseases.

Whilst patients have participated in medical research in other ways, for example by participating in trials, donating tissue, being part of the UK BioBank, analysing their genes through services like 23andme and rating hospitals, medical research charities provide examples of patient involvement in research which is characterised as being more influential than passive (being a subject):

Developing a research strategy for the charity: to develop a research strategy that is responsive to patients needs and doesn't simply focus on research that is considered scientifically exciting.

Making research funding decisions: Patients involved in the peer review process of assessing research, alongside scientific experts.

Taking part in the full research cycle: Patients becoming involved in all stages of research projects, including design (for example by helping researchers gain deeper understanding of a condition), helping to draft patient information leaflets for clinical trials.

Making information about research more accessible to patients and the public: Cancer Research UK has a specialist team who develop lay summaries of clinical research; Arthiritis Research Campaign and The Stroke Association require researchers to write plain English/lay accessible summaries of their research in order to help lay reviewers make funding decisions.

Potential Benefits and Practical Implications

A number of benefits that result from a crowd-sourced approach to making research accessible can be articulated for the different stakeholders:

Empowerment: One study on urban participatory work found that citizen patient activities can 'enable individuals to become active participants and stakeholders as they publically collect, share and remix'.

Improved Understanding: A graduate-level class project on editing chemistry-related concepts in Wikipedia reported that the project enabled students to 'work collaboratively, explore advanced concepts in chemistry, and learn how to communicate science to a diverse audience'. Participants may also improve their understanding of how other stakeholders view research.

Social contact: citizen science platforms provide a virtual meeting place, which could bring researchers and patients into contact with each other to discuss research and communicate. Social networking features could

also help to form communities and connect people who share interests, for example in disease areas or treatments.
Inclusivity: the Internet can provide a level playing field where differences, including physical or social ones, may be hidden or surpassed, so that all participants start out equal.
Skill development: The process of participating in a citizen science initiative can present opportunities for personal development, spanning both specific training and knowledge acquisition in a particular field, as well as confidence with technology and acquiring communication skills.

The Patients Participate! project aims to explore questions around the feasibility of a service that provides lay summaries to patients to enable them to better understand and participate in research. The following questions have so far been identified:

How will the collaborative model between researchers and patients for summary writing develop? What skills, training and tools are needed? How will recruitment of lay summary writers be managed?

There are design issues in making systems usable. What current features of citizen science tools are desirable? Is the practice of using reputation and ratings to motivate contributions suitable in this context? Would existing software platforms for citizen science work well for lay summary services, what modifications would they need, or do we need to build new ones? What documentation and guidance is needed? What special needs have to be met in order to be inclusive?

What concerns do different stakeholders have about the quality of lay summaries, and how can quality assurance be implemented? What evaluation methods could be applied?

Researchers may want to reflect on the implications for the research process. What are the risks? What are the implications for shorter and longer term policy, for example around researcher training? Would lay summaries affect the research agendas of funders, including charities? How would engaging in citizen science activities with patients affect the researcher-patient relationship?

Charities need to ask questions about the models and experiences that would help inform how to take the idea forward. Where could lay summaries make the greatest difference to their current activities? What will other internal and external stakeholders think? What are the resource implications? Can sensible next steps be identified and where does the leadership come from?

Conclusion

The Patients Participate! Project will be exploring these questions in a workshop with the various stakeholders, and will be publishing resources and findings from the project.

Links

Patients Participate Website
http://blogs.ukoln.ac.uk/patientsparticipate/
UKOLN
http://www.ukoln.ac.uk/
The British Library Science team
http://www.bl.uk/science/
The Association of Medical Research Charities
http://www.amrac.org.uk/
The Digital Curation Centre
http://www.dcc.ac.uk/
Sage Bionetworks
http://www.sagebase.org/
UK PubMed Central
http://ukpmc.ac.uk/
AMRC. (2009) Natural Ground Paths to patient and public involvement for medical research charities.
http://www.amrc.org.uk/our-members_natural-ground:-patient-and-public-involvement-project_ppi:-natural-ground
INVOLVE
http://www.involve.org.uk/
Galaxy Zoo
http://www.galaxyzoo.org/
Foldit
http://fold.it/portal/

Buckland, S. et al (2007) Public Information Pack. How to get actively involved in NHS, public health and social care research. INVOLVE Public Information Pack 4 http://www.invo.org.uk/pdfs/pip44jargonbuster.pdf

Acknowledgments

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http://www.jisc.ac.uk/whatwedo/programmes/digitisation/econtent11.aspx