

Contents

SUMMARY & BACKGROUND	3
CHARITIES' PERSPECTIVES	3
SHARING GOOD PRACTICE	3
ACTION ON HEARING LOSS	4
BREAKTHROUGH BREAST CANCER	4
BUPA FOUNDATION	4
KIDS KIDNEY RESEARCH	4
ROYAL COLLEGE OF SURGEONS	4
TENOVUS	4
MUSCULAR DYSTROPHY CAMPAIGN	4
ABOUT US	5

Summary & Background

The JISC-funded **Patients Participate!** project brings The British Library, UKOLN and the Association of Medical Research Charities (AMRC) together in partnership for a 7-month feasibility study which aims to explore the potential for developing a useful body of literature for patients and those interested in biomedical and health research. A report on the Patients Participate! Workshop is available here: <http://blogs.ukoln.ac.uk/patientsparticipate/files/2011/10/PP-Workshop-Report-final.pdf>

Medical research charities need to tell patients, supporters and other interested parties about medical research. In addition to the examples contributed to the case studies, charities told us about how they are doing this. We talked to 35 AMRC member charities to find out who was responsible for writing about medical research in lay terms, asked them about their processes and to share any guidance.

This document summarises the perspectives of the charities we talked to and identifies innovative examples of good practice.

Charities' perspectives

Communicating often highly complex scientific information in an engaging way to people with very little scientific knowledge is challenging. Patients, families and the public who support medical research charities want to know about the research they fund.

What do charities want?

- To be able to find out about and access publications that result from the research they fund – many find it difficult to get timely information on published research.
- Most charities that fund research would like better lay summaries – many employ people to write about research in lay terms.
- A way to get feedback on the information they provide for lay audiences – is it useful, interesting and pitched at the right level?
- Charities feel researchers need better training in communicating with lay audiences.

Almost all charities ask researchers to summarise their research in lay terms when applying for funding and in end of project reports. Yet one in three told us they have difficulties using the summaries for their intended purposes, and often have to rewrite them. Two charities told us they have now abandoned the practice of asking for written lay summaries. In an effort to improve the information quality for lay audiences, they now ask their researcher to submit social media-friendly video content instead.

Sharing good practice

Charities work hard to make their writing about research understandable and engaging to lay audiences. Here we have captured some innovative ways charities involve patients and the public to talk about research.

Action on Hearing Loss

Action on Hearing Loss has held two live Twitter events focusing on specific research topics. One of these was stem cell research. These ran for 30 minutes and the biomedical research team at the charity answered questions live from people online. The charity also has several online forums where research questions often come up. The biomedical research team join the forum discussions to comment and answer questions about research.

Breakthrough Breast Cancer

Breakthrough Breast Cancer-funded researchers host laboratory visits so the charity's supporters can see how their money is being used. The charity recently began offering communications training to those scientists involved in the visits to help their interaction with the lay supporters.

Bupa Foundation

The Bupa Foundation uses face to face communication to reach patients and the public. Rather than write about research on their website, they invite patient groups to participate in research seminars.

Kids Kidney Research

Young people working towards their Duke of Edinburgh's Award are helping Kids Kidney Research pilot a new way to tell supporters about some of the charity's research. The fourteen-year olds are making YouTube videos to describe some of the research projects funded by the charity. The pilot will involve the teenagers interviewing researchers at Great Ormond Street Hospital and will challenge the researchers to explain their research in terms that a young people can understand.

Royal College of Surgeons

The Royal College of Surgeons holds research evenings where researchers present their research in lay language to donors and potential donors.

Tenovus

Instead of a written final report, Tenovus now asks researchers to provide a social media-friendly communication about their research at the end of the project. This requirement has been incorporated into their terms and conditions of funding.

Tenovus hosted a workshop for their PhD students to help them gain skills in communicating with lay audiences. This was run in collaboration with Science Made Simple (<http://www.sciencemadesimple.co.uk/>) – the resulting videos can be seen on the Tenovus website (<http://www.tenovus.com/research/in-the-laboratory/phd-studentship-projects-laboratory.aspx>).

Muscular Dystrophy Campaign

Accessing journal articles when you don't have a subscription is a problem for many charities. PatientINFORM is a US-based initiative to help patients and the public access the latest health research articles through health organisations that they trust. In this scheme, voluntary health organisations get access to peer-reviewed journal articles from

participating publishers. They use these to write lay-friendly summaries and news articles that can be published on the health organisations' websites, along with a link to the full text of the original research article.

PatientINFORM started out with a focus on cancer, heart disease and diabetes and many of the patient organisations that have joined so far are American ones. It's now expanding to cover rarer conditions and UK-based Muscular Dystrophy Campaign has signed up.
<http://www.patientinform.org/>

About us

Patients Participate! was a collaborative project between UKOLN, based at the University of Bath, the British Library and the Association of Medical Research Charities. We wanted to find out about involving the public and researchers in making sense of scientific literature for patients interested in medical and health research. The Patients Participate! project has been funded through the JISC eContent programme 2011:
<http://www.jisc.ac.uk/whatwedo/programmes/digitisation/econtent11.aspx>