Panel discussion: Quality and Responsibility in Patient Engagement with Scientific Research Outputs

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Context

There is a growing body of evidence that suggests that quality patient engagement improves the health outcomes of individuals, improving both patient knowledge and experience, including a better appreciation of treatments and their outcomes (Coulter and Ellins, 2007; Coulter 2012). One aspect of this engagement is the communication of current research developments from basic science to translational work. Patients Participate explored with various stakeholders the form this type of communication should take to best serve the needs of patients. The recommendations from this project and the underlying drive for more patient-centred health research information raises several questions for those science communicators and/or public engagement practitioners working in research institutions. It was with these practical considerations in mind that we put together this panel discussion; maybe if we opened up these questions to the wider community we could see ways forward.

Federica Balzani: A patient’s perspective

Federica’s talk can be read in full in Appendix A.

Research is about the patient more than any other person as it affects their life and health in a very personal way. We want to know where the research that affects us is at and how it has evolved, explained in terms we understand. Including:

- The differences in research in the US and Europe and why they exist.
- How medicines are developed, tested and monitored and the motives of development for pharmaceutical companies.
- The process of research – How funding works, what is funded and why.

For most young patients, the preferred mode of communication is the internet, but it is important that this information is reliable. Real-time information, especially when taking part in clinical trials would be preferable. Face-to-face meetings and conferences with researchers also have an important role, especially when the programme is designed by the patients. Overall, we’d like to be more at the centre; to be able to ask questions and express opinions, so that our experience of the condition can contribute to and direct research.
Gianvito Martino: A scientist’s perspective

As a scientist and clinician I’m confronted with questions every time I interact with patients (see appendix B for example questions). The consequence of this for scientists is that: (1) I have to be constantly updated on news about stem cells (this is not always the case among physicians) in order to judge the robustness of such news; (2) I have to try to explain to patients as much as possible about what is going on in the field using simple but precise wording; (3) Solid relationships need to be built between scientists, patients and patients’ associations in order to be consistent with each other when providing information. All of this needs time to dedicate to patients which is to me, in these days, as important as curing them appropriately.

Karen Walshe: Multi-stakeholder’s view – ‘Patients Participate!’

The British Library’s Science team worked in partnership with the Association of Medical Research Charities and University of Bath on a JISC-funded project called Patients Participate. The project looked at ways to make sense of scientific literature for patients, the public and anyone interested in biomedical and health research.

We held a workshop in June 2011 and invited representatives from patient groups, funders, researchers, publishers and libraries and asked: ‘How can we work together in making sense of the scientific literature, to truly open up research findings for everyone who is interested?’ Patients told us they want easy-to-understand, evidence-based information relating to biomedical and health research, in the form of plain-English summaries. Meanwhile, scientific researchers often find it challenging to communicate complex scientific information to the public in an accessible and engaging way. To explore how researchers could be supported, we interviewed representatives of organisations who currently produce easy-to-understand information on biomedical research for the public, and asked how they do it.

The project produced a set of reports and case studies which give insights into best practice in producing plain English summaries of research and guidance for those starting out, all available at http://www.bl.uk/science-patients-participate

Emma Kemp: A science communicator’s view

EuroStemCell is an EU-funded project focused on engagement of a wide range of European publics with stem cell and regenerative medicine research. Patients are amongst our key stakeholder groups and we consider provision of reliable, accurate, up-to-date and trustworthy information on the latest science as a major part of our role. Our website, www.eurostemcell.org, is at the heart of this effort. Putting together the content for the site in a responsible and effective way means involving both the scientific experts and the patients we hope to reach. As science communicators, our role is to facilitate that process. Responsibility also means being transparent about the sources of our information. One of the important strengths of our project is the direct involvement of many leading scientists, each of whom is named and associated visibly with information they help to produce. We have confidence in the quality of our information and we know it is being used. However, production of carefully thought out and reviewed content takes time. A challenge we face and would like to discuss
Cathy Southworth

Optistem (http://www.optistem.org/) is a pan-European research consortium, funded by the European Commission, focused on the use of stem cells in muscle and epithelial disease. As a consortium we have a commitment to quality public engagement. One of our main stakeholders is patients. Having reflected on the Patients Participate’ project we felt that producing ‘lay summaries’ of our main research papers would be an effective and practical way of making our research more accessible to a wider audience. Setting out on this task presented several questions: Who would write the lay summaries? Which papers should we choose? What should the structure and layout be? And, how will the summaries be disseminated? The issues that these questions raised centred around five considerations: accuracy, accessibility, relevance and credibility of the summaries and available time and resources. The approach we took was:

1. Written by a scientist using guidelines, edited by a science communicator, checked by the paper author.
2. The project co-ordinator (scientific lead) selects the most significant paper releases.
3. A structure and layout developed and evaluated by a patient organisation.
4. Disseminated via our websites Optistem and Eurostemcell but also through relevant patient group websites.

On reflection we still have questions about the best means of disseminating the summaries to patients to ensure a wide reach and also distributing guidelines and examples of our work to the wider science communication community. The time needed to produce summaries is quite intensive and so sustainability beyond the end of the consortium will need to be considered.

Discussions

The panellists agreed on four requirements of quality patient engagement with research outputs:

1. Accurate, accessible and consistent material
2. Solid scientist-patient-patient group relationships
3. Both web and face-to-face interaction
4. Patient-centred

Discussions with the audience focused on experiences of patient engagement and ways science communicators could support the communication of research. (See appendix C for the list of questions used to provoke discussion). The question of whether research papers represented ‘accuracy’ was asked, in relation to the way in which scientific papers
are published. The writing of accessible ‘consensus papers’ by several scientists in the field was suggested, which could prove more valuable than summaries of many individual papers. It was also considered that in addition to communicating the research, it was imperative to communicate about the research process. It was felt that doing this would empower individuals to interpret and assess research information themselves. The question also arose about the communication of unpublished data, particularly that data which may have shown that a particular method or approach didn’t work. The use of ‘consensus papers’ could arguably include such unpublished work. But the difficulty of accessing this information even within the scientific field was noted. There was a general consensus that the best funding model for the production of ‘lay summaries’ was through the dissemination part of individual research grants.

Development of face-to-face relationships was agreed to be important not just in the communication of research information but in the building of trust. Whilst research clinicians often developed patient and patient-group relationships through their work, it was felt that science communicators and public engagement practitioners within institutions had a role to play in forging links between these groups and basic scientists. On this theme, it was also suggested that general practitioners and other healthcare practitioners were important target groups for the communication of research outputs, as these people were often the first contact for patients, many of whom will have research-related questions instigated by searches on the World Wide Web.

A suggestion was made that information about research outputs aimed at patients and provided on the web could be rated by readers, in order to get direct feedback from target groups. This question of evaluating quality led to discussions on the availability of guidance for scientists and public engagement practitioners on how to write material for patients. We agreed that it would be useful for guidelines, developed alongside the evaluation of material, to be more widely disseminated amongst science communicators and public engagement practitioners to prevent duplication of work. The Patients Participate project website was recommended for accessing resources to support such writing.

References


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