The public in peer review

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Public involvement in scientific research is not new, particularly with respect to clinically relevant research. In the 1900s, for example, Mary Lasker pushed for a disease eradication model of health, while the activism of patients with HIV/AIDS in the 1980s and 1990s helped to shape research agendas in the early part of the HIV epidemic [1]. Today, crowd-sourced funding for research is becoming more common, with patients directly funding the work of scientists. Individuals still make a difference: Bill Gates, for example, has been supporting and shaping research in malaria and HIV vaccines for years through the Bill and Melinda Gates Foundation.

In fact, the idea that patients or even the extended public should be routinely involved in science, specifically in the review of grant proposals, is already well described, for example, in the review of the US Department of Defense's Congressionally Directed Medical Research Programs (<http://cdmrp.army.mil>). Individual citizens, still called 'consumers' in DOD parlance, not only evaluate research based on whether it might be beneficial for patients, but also sit with scientists to evaluate individual projects for grant approval.

Most of the extant guidance for including non-technical experts in proposal review makes it fairly clear that the intent is not to have members of the public judge the science *per se* (in these cases, mostly clinical research), but rather acknowledge that even clinicians may not be able to fully evaluate the clinical experiences of patients. Yet, reviewing grant proposals is only one part of the scientific ecosystem. Research agendas and projects are very broad and may include everything from basic molecular biology to large clinical trials, and from grant proposal to the analysis of results and eventually publication.

One current iteration of involving the public in peer review is apparent in new journals that specifically seek to understand and exemplify public or patient involvement, such as *Research Involvement and Engagement*, and in established ones, such as the *British Medical Journal*, which engages patients in the peer review of a subset of submissions (<http://www.bmj.com/about-bmj/resources-reviewers/guidance-patient-reviewers>; [2]). Peer review in BMJ in particular goes a step beyond the question of whether the research being evaluated is generally a good idea to the more specific question of whether the particular research is relevant and good for patients.

To date, most of the questions that patient reviewers have been asked to look at seem reasonable. The potential for problems is rather with the timing of patient or public review. For example, one of the questions in the BMJ guidelines, 'Do you think this will really work in practice', is a critical one that patients seem perfectly placed to answer. It is also a reasonable question to ask of many primary research papers submitted to journals. However, the BMJ also asks its patient reviewers 'Is this an issue that matters to you?' It is certainly a critical question to ask of a research project, but here the timing is important. This is a question that seems ideally suited to ask of a grant proposal for a clinical trial, but asking it at the publication stage seems disconnected from the point of peer review of scientific papers. Reviewers evaluate the scientific value of a paper—and in many cases its novelty—but they do not evaluate whether the research should have been done at all, which the question seems to imply. If the concern is that the work is not useful for patients, the time to ask that question would have been during the review of the project or proposal.

If there is general acceptance of inclusion of patients or family members early in the review of projects, should this be extended to other groups? 'Is this an issue that matters to you?' would seem to be an applicable question for a wide range of consumers, notably patients' groups or advocates. But the implications of the difference between patients and the general public, with respect to the review of research, have not yet been sorted out.

Further, should this be extended to evaluating the early stages of foundational research that might eventually lead to clinical trials? Particularly for publicly funded research, could there be a role for including patients, or any member of the public, in asking whether this research addresses problems important to the public? Again, this would not be a case of asking a non-expert to evaluate technical details, but there might be an argument to be made for considering how, for instance, research in molecular biology might fit in with desired societal outcomes.

Some of these issues will likely be discussed through the European Commission's Responsible Research & Innovation (RRI) action, with the intent of implementing it across all Horizon 2020 research programmes. Public engagement is clearly an aspect of RRI, and through these mechanisms, the public could become more involved in defining and evaluating research. The problem here is not necessarily that scientists ignore the public or that researchers are concerned about an uninformed public preventing certain projects from going forward. Rather, the questions are about the roles of all of the stakeholders in the process—from basic to clinical research to actual treatments—and how everyone might be involved in evaluating these steps. As with the review of science itself, we should not make assumptions

about any participant's role, be that a researcher or patient, and instead work as a community to understand and integrate the knowledge that parties can contribute.

References

1. Epstein S (1993) *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Oakland, CA: University of California Press
2. Chawla DS (2014) The rise of patient peer review. ScienceInsider 10 December. <http://news.sciencemag.org/health/2014/12/rise-patient-peer-review>