COMMENT

METRICS Patients, farmers and more must co-create tools to evaluate and incentivize **p.32**

INTERNET The rise of Reddit — social software or social malware? **p.34**

MATERIALS The interplay of minerals security and US foreign policy **p.36**

OPEN ACCESS *Paywall* documentary hits screens as Plan S lands **p.37**

STARWORKS NETWORK

Children with artificial limbs and their carers talk to researchers and industry representatives about improving prosthetics.

Co-production from proposal to paper

Three examples show how public participation in research can be extended at every step of the process to generate useful knowledge.

GARY HICKEY

Share power in five ways

Senior public-involvement manager at INVOLVE, a UK health-research advisory group

A project that is co-produced is one in which researchers, practitioners and the public together share power and responsibility for the work throughout. The 'whys' of this process are self-evident: patients and the public have the right to be more than just participants in research, and their involvement can lead to better outcomes.

Take, for example, the Child Prosthetics Research Collaboration. This project brought together children and their families with the National Health Service, industry and academia, and was funded by the UK National Institute for Health Research (NIHR). It led to inventions and optimizations that reflected what children and families need. The experts and academics who develop prosthetics would probably never have heard from families and children how a poor-fitting or unattractive limb can limit a child at home, in the classroom and in the playground.

The 'how' of co-production is less obvious. For the past two-and-a-half years, I have worked with colleagues from the NIHR and beyond to develop guidance ▶

CO-PRODUCTION OF RESEARCH
A *Nature* special issue
nature.com/collections/coproduction

on co-production and to establish an international network for patient and public involvement in health research. It is the main part of my role at INVOLVE, the national advisory group in England's NIHR to foster public involvement in health and social-care research.

Our team held workshops, iterative round-table discussions, consultations and a literature review to characterize co-production. Public members felt that many researchers and practitioners claim their work is co-produced, but still do not respect patient knowledge as equally valuable or put in the effort to ensure that the patient voice has true power.

We identified a handful of principles that define co-production. The crucial one is power sharing — no longer do researchers or practitioners make all the key decisions or take on all the responsibilities.

Sharing power depends on building and maintaining relationships across researchers, practitioners and public members of a research group. That means constant reflection on power differentials, and managing these to build trust. For example, the project team for a study to improve online responses to patient feedback baked cakes and communicated using social media to take people away from the work environment. Everyone could engage in these informal activities, giving people a chance to chat and to reduce anxieties. Space for team-building should be explicitly scheduled into the research cycle. Holding meetings in a neutral setting, such as the local library, and providing opportunities for regular feedback, also helped to build open and trusting relationships between team members.

All relevant perspectives and skills must be included. At the beginning of a research project, the team should consider which knowledge, views, experiences and skills are required, and how to ensure diversity and inclusion. Members should collectively ask: which voices are not around the table?

The knowledge of all team members should be respected and valued. For instance, in a project to update a systematic review of stroke physiotherapy (undertaken by the Nursing, Midwifery and Allied Health Professions Research Unit at Glasgow Caledonian University, UK), the working group of stroke survivors, carers, physiotherapists and educators developed a set of rules. To make it easier for everyone to get their voice heard, no one would be allowed to jump into the group discussion without first raising their hand. To avoid individuals dominating discussions, no one was allowed to speak for more than two minutes at a stretch.

Reciprocity is imperative. Everyone should feel that they get something back from working on a project. For patients, this might be bigger and better social networks, access to training, co-publication and co-presentation, more self-confidence, a sense of contributing to the greater good, or even payment. For example, a project by Newcastle University set out to develop ways to help young people with neurodisabilities to participate in leisure activities. Researchers, affected children and artists co-produced an animated film to share the results. The film-makers, 'AniMates', continue to make artwork about research projects, and are now collaborating with other researchers and advisory groups.

It can be difficult for researchers to truly share power when universities are often the main recipients of research grants and academics are ultimately accountable for how the money is spent. New sorts of partnership help. For example, the charity Alcohol Research UK funded its own joint project with the University of Bedfordshire in Luton to explore the experiences of older adults in residential alcohol-rehabilitation services, rather than handing the reins entirely to a grant recipient.

Co-production won't just happen because it is a good thing. The way in which research is currently funded and organized is an obstacle to meeting these principles. Policymakers, funding bodies, institutions, journals, patient advocates and others need to change their practices and cultures to enable the necessary relationships and facilitate the sharing of power.

TESSA RICHARDS

Get patients to review papers

Senior editor at The BMJ *and leader of its patient–partnership initiative*

At the clinical journal *The BMJ*, patients and patient advocates have an influential role in our day-to-day decision-making. The journal has long championed partnership with patients in health care and, five years ago, we stepped up our advocacy for it. We were stimulated to do so by mounting concern about wasteful and inequitable Western health systems that fail to serve patients well.

We set up an international panel of patients and patient advocates, and asked them what we needed to do to 'walk the talk' on patient partnership in our editorial processes. I was asked to work with the panel and my editorial colleagues to develop and implement a BMJ patient-partnership strategy.

It has attracted much interest. Every week, we hear from patients, health professionals and policymakers from around the world who share our passion for partnership. They are keen to draw attention to their work and to learn more about what we do.

Incorporating patient and public review alongside our conventional peer-review processes was the first change we introduced: initially for research papers, then for educational and scholarly comment articles, too. We have an open invitation for people to join our database of patient and public reviewers, and around 700 are registered. Editors invite comments from the reviewers whose lived experience matches as closely as possible to the papers under consideration.

A formal study of the initiative is planned, but informal feedback has been encouraging. Editors report that patient and public reviewers provide valuable perspectives that complement those provided by academic reviewers. These include insights into the wider impact of illness — biological, psychological and social — the 'burden' of treatment, how people self-manage conditions, and whether interventions are practicable. Some patient reviewers have asked authors to modify statements that are not backed by strong evidence, to avoid arousing unjustified hope in the patient community. They also flag inadvertent use of perjorative language, such as 'the patient failed treatment'. Authors have told us that they now think about how their research might be seen through the eyes of patient reviewers.

A survey of our patient and public reviewers found that they greatly appreciate the opportunity to comment on *The BMJ*'s papers and to be involved in our work (S. Schroter *et al. BMJ Open* **8**, e023357; 2018). Many see it as a way to use their experience of illness to help others. We also learnt that we need to explain editorial processes more clearly and communicate with reviewers more often. Our guidance now addresses reviewers' concerns (for example, explaining that it is OK to decline an invitation to review) and we send out regular newsletters thanking reviewers for their support and updating them on developments.

Patient editors and the continued lively dialogue we have with our patient panel help to implement all aspects of our strategy. Foremost is the requirement that authors submitting a manuscript specify whether and how patients were involved in setting the research question, the design and implementation of the study and its dissemination. Patients and patient advocates also write for us, sit on our editorial board, are members of the advisory committees for our conferences, and are involved in the panels that judge our annual awards.

The changes we have introduced are gradually spreading across the BMJ portfolio of journals, and a few other journals have taken similar steps, such as the obstetrics and gynaecology journal *BJOG*. Patients have responded by drawing up a charter calling for patients to be included in the processes of medical journals (see https://patientsincluded.org). We believe that their inclusion will help to improve the quality of health research.

CHILDREN'S INN AT NIH STAFF

Anne Klein (second from right) is a patient advocate on a clinical-trial panel for her son Everett Schmitt (far right), who has severe combined immunodeficiency.

JEFF SHEEHY

Ask patients what to fund

Board member, California Institute for Regenerative Medicine, USA

In 2004, voters in California allocated US$3 billion in bonds to create the California Institute for Regenerative Medicine (CIRM), which funds research to produce therapies from stem cells. Unusually, patient advocates such as myself wield formal power at CIRM. Of the 29 board members, 12 slots are designated for patient advocates, including the chair and vice-chair. Board members participate in peer review of all grants, including clinical-stage grant applications. Once formal reviews are in, we vote on the final approval of all grants. A patient advocate is also required on each of the 68 clinical advisory panels that guide late-stage projects, such as a CIRM-funded trial for severe combined immunodeficiency.

I was diagnosed with HIV in 1997. For the past three decades, I've been an activist for the rights of people from sexual and gender minorities (LGBT+), and have even coordinated acts of civil disobedience. I have held legislative office in San Francisco and been the communications director of the AIDS Research Institute at the University of California, San Francisco. When I was appointed to the CIRM board, I had no interest in merely being a cheerleader or in rubber-stamping decisions that could affect people's lives.

I knew to expect pushback. The legislation that created CIRM gave a voice to patient advocates, but scientists had no experience of having to listen. Many researchers doubted that patient advocates could truly participate in decision-making. Over time, however, relationships between advocates and scientist reviewers developed and scepticism abated.

Time and familiarity were key. The grant-review process at CIRM often lasts for a couple of days, with people being brought together over meetings and meals. We got to know each other through robust debates over different approaches to what research to fund; for example, extremely prevalent diseases versus rare ones neglected by pharmaceutical companies. After 12 years of such gatherings, many of the reviewers have become friends and they listen to, and even welcome, input from me and other patient advocates.

> ***"Patient advocates are more willing to champion outlier science."***

These discussions are not academic to us. Expert scientific reviewers often focus on the high risk of failure. Patient advocates are more willing to champion outlier science. We can make informed decisions to accept high risk if it is balanced by the potential for great reward. For instance, I pay special attention to grant applications that receive highly varied scores from reviewers. Our influence has sometimes meant that a risky grant has been funded over a safer one with higher median scores.

For clinical applications, experts might be less enthusiastic when the best possible outcome is only a partial result — such as a person with a spinal cord injury regaining the use of their arms but not the ability to walk. Yet that partial improvement lets people move themselves in and out of their wheelchair to use a car; to type and text; and to lead an independent life instead of requiring round-the-clock care. I believe that, when it comes to discussions on funding, we bring a clearer understanding of the impact on patients.

Patient advocates can also be more sceptical of strategies that consider human physiology but neglect behaviour. Such strategies include 'kick and kill' HIV therapies, commonly supported among scientists, which eliminate the virus but do nothing to prevent reinfection.

Patient advocacy was pioneered in many ways by AIDS activists, and is now formally referred to in Europe as co-production. People living with conditions, and those who care for them, provide context and counterpoints to unchallenged scientific wisdom.

During its tenure, CIRM has awarded almost 1,000 grants and funded 49 clinical trials, as well as trials of gene therapies that saved the lives of ten people who have different, rare diseases of the immune system. The institute has certainly encountered plenty of controversy, but I think that patient advocates helped it to weather those storms and to steer the best course. ■