



# Trish Greenhalgh: Towards an institute for patient-led research

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*“More powerful than the march of mighty armies is an idea whose time has come”*

– Victor Hugo

## **The intellectual legacy of Rosamund Snow**

Rosamund Snow was a social scientist with type 1 diabetes; she was an academic at the University of Oxford and a Patient Editor for *The BMJ*. She led the field in questioning conventional approaches to patient and public involvement in research and in mainstreaming a patient-*led* way of doing research.

Rosamund’s PhD was entitled “*The role of patient expertise inside and outside the health system.*” She addressed, from the patient’s perspective and using critical social science methodology, what it was like to attend a diabetes clinic. [1] This work led to a widely-cited academic paper “What happens when patients know more than their doctor?” which addressed knowledge imbalances between educated patients and non-specialist GPs. [2] She was critical of “partnership” approaches to research priority-setting, which she viewed as both tokenistic and paternalistic (she claimed that patients had been accused, for example, of proposing the “wrong kind of research questions”). [3] At *The BMJ*, she led a radical re-engineering of processes for including the patient voice in the journal. She co-authored (with me) another highly-cited paper addressing the question of whether evidence-based medicine is “biased” against the patient. [4]

Tragically, [Rosamund died on 2nd February 2017](#). Her parents made a significant financial donation to help create an institute in her memory; this funding is being used to pump-prime the initiative with some doctoral fellowships. [The applications are still open until January 2020](#). [5]

## **Patient involvement in research—a brief history**

There is a well-described mismatch between the research that is done on a particular condition and the research that patients themselves would like to see done. [4,6] Formal research priority-setting partnerships aim to reduce this mismatch by involving patients in the selection of topics for research. [7, 8] The National Institute for Health Research (NIHR) has strongly supported patient and public involvement (PPI) in research, produced national benchmarks for PPI, funded INVOLVE ([www.invo.org.uk](http://www.invo.org.uk)) which promotes patient involvement in all aspects of biomedical research, and written up some exemplar case studies.[9, 10, 11] Co-design and co-delivery of research with patients and communities using “partnership” models is increasingly popular. [12,13]

While these and similar approaches have merits, all are designed and run by researchers (with greater or lesser efforts to achieve democratic governance); they are not *led* by patients. [14] Sarah White distinguishes *nominal* involvement of patients and the public (undertaken to confer legitimacy on a project), *instrumental* involvement (to improve its delivery and/or efficiency), *representative* involvement (to avoid creating dependency) and *transformative* involvement (to enable citizens to influence their own destiny). [15] Arguably, most of what is called “patient involvement” in medical research is nominal or instrumental in nature.

## **Transformative involvement of patients: a question of power**

Social scientists have highlighted the persistence of power imbalances when well-meaning clinicians and scientists seek to “involve” patients in research. [16] In a paper called “Beware Zombies and Unicorns,” Mary Madden and Ewen Speed cautioned against aligning with an uncritical (instrumental) agenda for PPI and called for models of patient-led research that address fundamental questions about who holds the power and sets the agenda in research. [17] Helga Nowotny,

past President of the European Research Council, has highlighted the need to “democratise expertise” when undertaking science with citizens (everyone is an expert—in different aspects of the problem). [18] Such partnerships, run democratically and with careful attention to the processes of governance and power-sharing, would align well with Simon Lock’s call for a People’s Research Council. [19]

### **A different kind of knowledge**

Researchers in all fields become patients (and vice versa). Patient-led research may therefore include conventional forms of objective knowledge such as randomised controlled trials or bench science in the researcher’s own illness. More uniquely, patients bring experiential knowledge—the subjective, lived-body knowledge of *what it is like to live with* a particular illness or condition.

Experiential knowledge can be systematically explored through phenomenology (the study of what we can discern through our consciousness and senses [20]) and auto-ethnography (the study of one’s own experience in an unfamiliar world [21]). Experiential knowledge is complementary to knowledge generated in the laboratory or the clinical trial, potentially producing “multiple realities” as accounts of the patient experience clash with textbook descriptions of disease or the unsurfaced assumptions of clinicians and researchers. [22]

Another kind of knowledge that is unique to the patient experience (and ripe for research) is the collective knowledge generated by online communities. The growth of the “social web” has enabled the emergence of large (and increasingly research-aware) communities of individuals with a particular disease. Some of these communities share ideas for research and self-organise to undertake self-experimentation, self-surveillance and even analysis of their own genomic data. [23, 24]

### **Governing patient-led research: scientific rigour and ethics**

If patient groups are to undertake and/or commission research, academic input (to match patients’ priorities and questions with appropriate theories and methodologies, and to support analysis and writing up) and capacity-building

(training patients in research methods and techniques) are surely essential to ensure that patient-led research is scientifically defensible (and hence has credibility with clinicians and policymakers). [25,26]

The question of what counts as scientific rigour may itself be contested if the term is defined narrowly using the traditional scientific criteria of objectivity and distance. Martha Nussbaum, for example, has vigorously challenged the (arguably, flawed and gendered) view of science as necessarily dispassionate, uninvolved and emotionless; she considers emotion to be a dimension of scholarship without which science is impoverished and uncreative. [27]

Patient-led research raises both similar and different ethical challenges to conventional research. A comparison of patient-led research with standard research, for example, revealed six areas that are of potential relevance to ethical oversight: institutionalization, state recognition and support, incentive structures, openness, bottom-up approach, and self-experimentation. [23]

### **The productive role of conflict**

In the best research programmes, the (productive) conflicts generated when patients' experiential knowledge meets conventional research paradigms not only *informs* the wider research agenda, but *transforms* conventional researchers into more creative scientists who prioritise different questions and study them in imaginative and flexible ways. Vololona Rabearisoa distinguishes between conventional "researchers in the lab" and patient groups, which she calls "researchers in the wild". [22] Citing her own empirical work on the research interactions in rare diseases, she comments:

*"We witnessed the trajectory of scientists who had started on the bench as biologists, then, as they exchanged with patient organizations, oriented themselves towards the clinic, and then returned to the bench with new research questions stemming from their observations, enriched by patients' observations."*

Notwithstanding the potential for such creative conflict, a significant challenge for patient-led research is that it is often (understandably) underpinned by "cognitive passions"—that is, deeply-held, emotionally-charged perspectives on

a condition. While such passions give energy and focus to a patient-led research agenda, they may mean that patients find it difficult to approach research into their own condition with the equipoise expected in science. However, while one high-profile patient-scientist conflict seemed to generate negative tension (chronic fatigue syndrome [28]); there are many counter-examples of conflicts that were highly productive, including in rare diseases, HIV/AIDS, mental health, and breast cancer. [22,29,30,31]

In short, there are many questions—both scientific (in the broad sense) and philosophical—that could be taken forward by an institute for patient-led research.

Whilst substantial additional funds will need to be raised to create a full-blown institute, a preliminary vision for such an institute is set out in Box 1.

### **A vision for an institute for patient-led research**

Such an institute would:

1. Support research that is
  - defined by patients as needed and wanted
  - undertaken wholly or primarily by patients (usually in settings other than healthcare organisations)
  - underpinned by rigorous academic standards and approaches
  - disseminated to the audiences that patients wish to reach in language and formats that are understandable to all
  - independent of commercial interests and priorities
2. Build capacity among patients and patient organisations to plan, undertake and disseminate high-quality research.
3. Advocate for patient-led research (as opposed to patient ‘involvement in’ research).
4. Develop and address a research agenda on patient-led research, including issues of credibility, funding, institutionalisation and governance.

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