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Cite this as: *BMJ* 2022;376:o451

<http://dx.doi.org/10.1136/bmj.o451>

Published: 22 February 2022

Thanking patients for their role in research is part of creating wider cultural change

Acknowledging the participants who make research possible recognises their humanity and contributions to medical care, say Michael H Kanter and Suzanne Schrandt

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Our ability to rapidly create new knowledge about covid-19 was only possible because of the many patients whose medical data were mined for research purposes and others who lined up to participate in clinical trials. Medical science cannot advance without such patients, but they are rarely even acknowledged in publications. These omissions are indicators of a medical and research culture that does not always solicit or consider patients' experiences as much as it should. We believe, however, that a greater recognition of patients' contribution to research would help to create a cultural shift in how patients are involved in research, leading to benefits for all.

A thankless experience

In 1973, one of us (MHK) was diagnosed with metastatic testicular carcinoma. His medical data contributed to at least five peer reviewed publications from 1973 to 1980. As was the custom, he did not receive any official acknowledgment for his role in the research. His physician received well deserved recognition for his work, subsequently becoming a leader in urologic cancer treatment. After treatment, MHK completed medical school and went on to author more than 100 articles in peer reviewed medical journals.

With firsthand experience of both carrying out research and receiving intensive medical care, he knows how much more arduous his experience was when he was a patient participating in a study, instead of a physician carrying one out. Patients can often be going through some of their most difficult moments in life when they participate in medical research, experiencing the pain, discomfort, and uncertainty that accompanies illness and treatment. Yet researchers rarely acknowledge the patients without whose involvement their work is impossible. We distinguish here between two types of involvement: patient engagement refers to patients serving as advisers or consultants on research teams and patient participation refers to those whose data are used or who take part in research activities. In the former, patient partners are publicly recognised as valuable team members in such endeavours; in the latter, patients are almost never acknowledged for their role.

Depending on the type of research being conducted, patient participants may not even be consented. They bear the risks, however, of potentially unsafe or ineffective care practices or treatments and of their personal health information being identified. More recently, interest has grown in research that applies

artificial intelligence and big data analytics to retrospective data.¹ Although this trend has raised substantial concerns and discussion about patient privacy, possible exploitation, and ways for patients to directly benefit from the use of their data, acknowledging patient contributions in any resulting publications has received less attention.

Researchers usually receive compensation for the time they've spent conducting studies and credit for their publications as listed authors, which can advance their careers. Patient participants in studies receive none of these benefits. Indeed, for patients included in medical records research, for example, they are often unaware of its existence or their participation and thus unable to even take pleasure in knowing they have helped others or contributed to scientific knowledge.

A changing landscape

In many areas of research, we are making progress towards a patient engagement revolution. Patients have increasingly sophisticated roles and influence on research as partners, advisers, and principal investigators or co-investigators. They join research teams in varying capacities, from helping design recruitment protocols and materials to data collection and interpretation, with some serving on data safety and monitoring boards and committees. The Patient-Centered Outcomes Research Institute, the first funder to require partnerships with patients and other stakeholders in research planning, conduct, and dissemination,² has been joined by many others. These engaged patients often do receive some sort of official acknowledgment for their roles.³ However, despite their expanding engagement in research, patient participants (those who have their data used or who are research participants) still remain largely unacknowledged.

Recommendations from the International Council of Medical Journal Editors (ICMJE) on the conduct, reporting, editing, and publishing of scholarly work recognise the importance of acknowledging group contributions that fall short of authorship criteria, but do not mention patient participants.⁴ Expanding examples of group contributions to include patient participants may prompt the hundreds of medical journals adhering to ICMJE recommendations to encourage authors to do so.

At a time when there is growing recognition of the input of patients to research and when many are stepping forward as active partners, this silence in papers on the contribution of participants is a jarring

anachronism. All patients deserve acknowledgment for any part they play in knowledge generation. Since patient participants will understandably be anonymous as individuals, it can take the form of a simple note of gratitude and recognition. For several years, for example, the Southern California Region of Kaiser Permanente has included the following acknowledgment in research publications based on patient data: “The authors thank the patients of Kaiser Permanente for helping us improve care through the use of information collected through our electronic health record systems.”

Thanking patients in publications is more than a tickbox exercise: it acknowledges that they are human beings and partners in research and medical care, not merely datapoints or passive recipients.

Over time, acknowledging patients in publications could also help to change the culture of research in medicine. It may sensitise researchers to ethical concerns when technology companies or health systems stand to profit financially from the use of patient data. It can also increase patient centredness among researchers and institutions, keeping the participation of these individuals in research at the forefront of researchers’ minds, and spurring them on to increase engagement and involve patients and families as active partners in research. It can also prompt researchers to think of the more substantial ways in which they can thank patients for their participation—for example, by finding ways to send all participants the study results where possible. Although a simple thank you or acknowledgment may seem like a small gesture, we think it is part of creating wider cultural change that will usher in more engagement of patients and more patient centred research.

Competing interests: None declared.

Provenance and peer review: Not commissioned; peer reviewed.

- 1 Copeland R, Mattioli D, Evans M. Inside Google’s quest for millions of medical records. *Wall Street Journal*. January 11, 2020;B1.
- 2 Patient-Centered Outcomes Research Institute (PCORI). Authorizing legislation. Available at: <https://www.pcori.org/about-us/governance/authorizing-legislation>
- 3 Price A, Schroter S, Snow R, et al. Frequency of reporting on patient and public involvement (PPI) in research studies published in a general medical journal: a descriptive study. *BMJ Open* 2018;8:e020452. doi: 10.1136/bmjopen-2017-020452 pmid: 29572398
- 4 International Council of Medical Journal Editors. Defining the role of authors and contributors. Available at: <http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html#three>