EDITORIAL

Patient partnerships for research

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The reputed response of Deng Xiaoping when asked what he thought of the French revolution was 'too early to tell'. The response of the *British Medical Journal* to the 'patient revolution' in health care can be summed up as 'time to get moving'.¹ What is the patient revolution, and why is it important to the readers of *Public Health Action*?

The patient revolution in health care refers to the role of patients in improving health care delivery. The idea is to enlist the help of those whom the health system is supposed to serve, i.e., patients who, even more than clinicians, 'understand the realities of their condition, the impact of disease and its treatment on their lives, and how services could be better designed to help them'.² The role of patients (and the public) in health research is an important and so far often underplayed aspect of the patient revolution. Yet patients may well contribute to a range of research activities, including prioritisation, proposal development, ethics, implementation, review and results dissemination.

An opportunity for patient research partnership arises, for example, in conducting operational research, given the close contact between the researchers and the programme and general health service staff involved, and the patients whose interests they serve. At the point of collecting information about patients served by a health programme, staff could advise patients of the likely use of that information for research purposes aimed at improving programme performance and the patients' health. This step could pave the way for establishing or enhancing patient research partnership. There is increasing recognition of the need to consider the extent of ownership by patients of the uses not only of biological samples but also of data obtained from and about them. So this step could also serve as an op-

portunity to enable patients to understand what is done with their data.

As a journal that 'actively encourages, communicates and reports new knowledge, dialogue and controversy in health systems and services for vulnerable groups', PHA can play a role in exploring and encouraging the involvement of patients throughout the research process. Key questions arise of relevance to the community of researchers served by PHA. Are researchers also ready to respond to the patient revolution with 'time to get moving'? Or is it still necessary to build the groundswell of support? Which activities in the research process should we consider first for patient involvement? How can 'vulnerable' groups, who may be disempowered through poverty, enter into a meaningful partnership in research? What can researchers do to help patients in vulnerable groups overcome the barriers posed by disempowerment and poverty? Will we be able to assess the proposed benefits for research and improvements in health care delivery arising from the patient revolution?

Who knows where the revolution ends? What may be in prospect is 'a patient centred revolution that goes even deeper and has profounder implications since it challenges the dichotomy of patient versus researcher, providing further impetus for disrupting hierarchical relations in healthcare'.³ But that is at the end of the journey ahead, and vulnerable groups may only be at the start.

References

- 1 Richards T, Godlee F. The BMJ's own patient journey. *BMJ* 2014; 348: g3726
- 2 Richards T, Montori V M, Godlee F, Lapsley P, Paul D. Let the patient revolution begin. *BMJ* 2013; 346: f2614.
- 3 Vayena E. The next step in the patient revolution: patients initiating and leading research. *BMJ* 2014; 349: g4318.

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