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TECHNICAL REPORT

Participatory Health Research

International Observatory on
Health Research Systems

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Summary

- The language of participatory research is now prevalent within the health research field and beyond, even though this approach emerged in the very late 20th century.
- Initially stimulated by long-term processes of historical and social change in developed countries, participatory research has been driven lately by the emergence of powerful new actors in civil society—some of them social movements (including the feminist movement), others formal organisations (i.e. AIDS campaigning organisations), and, in a small number of cases, individual activists (e.g. Brown et al., 2004). It has been associated with parallel changes in the status of patients, who are increasingly regarded as active participants in defining the care they receive, rather than passive recipients.
- But participatory research has also been underpinned by powerful arguments grounded in moral and political philosophy. Some simply assert the ethical importance of involving lay participants in the governance of health research projects, rather than as mere subjects. Others envisage a much more holistic approach, advocating the democratisation of a scientific research establishment that they argue has come to be viewed with an increasing level of distrust by the general public.
- This complex range of drivers and precipitating factors has helped to bring about quite varied approaches to participatory research. There is no consensus on who may be included within the broad term of “patient and service-user”; participatory research may involve anyone from patients through to representatives (activists, carers, etc.), and even civil society organisations acting on the behalf of patients. Involvement may also be of varying degrees: at a minimal level, lay participants may simply be approached through the standard route of consultations, but there are also instances in which they have directly controlled or even led research projects.
- Although there are important practical arguments for participatory research (but also some notable ones against), our understanding of the strengths and weaknesses of this approach is hampered by ongoing disagreement over the terms on which they should be judged, and a lack of clear evidence. On the one hand, anecdotal reports suggest that participatory methods may improve both the quality of research and the quality of the health interventions that are developed

as a result. Some contend that these methods help to improve relations between researchers and ordinary citizens, particularly by building an understanding of the technical issues relating to research among members of the community. Others suggest that participatory approaches have helped to overcome long-term problems of under-representation for marginalised groups, and promoted greater understanding of the proper ethical conduct of health research. On the other hand, detractors accuse it of reducing the effectiveness of research by pretending to be representative of wider communities when this is in fact impossible, thus damaging the quality of research by introducing into the process participants with little understanding of the underlying science and by introducing systematic biases that may skew research findings. Ultimately, however, participatory research should be acknowledged as an exercise in trade-offs, and costs resulting from skewing effects must be balanced against the benefits of improved validity and research question definition, among others.

- We find evidence of a range of experiences internationally, most of which are focused on issues in mental health and social medicine. Importantly, the evolution of participatory research has varied from country to country, sometimes reflecting particular institutional histories (e.g. strong centralisation of health-care provision in the United Kingdom), or growing concern for the rights of marginalised or disenfranchised communities (e.g. aboriginals in Australia and Canada). The Netherlands is an unusual case. Here, participatory approaches seem to have been entrenched since the early 1970s through science shops, linking universities with their surrounding communities in a bottom-up way; this is a model that is now winning wider support with financial backing from the European Union.
- Although there seems to be no question that participatory research is here to stay, getting the most out of this approach to health research in future will require further attention in a number of areas. We need a better understanding of how to evaluate participatory research, and measure outcomes relating to it. We can nevertheless draw some conclusions about strengthening it; there is, for example, some evidence that participatory research is more successful when researchers and lay participants are trained in preparation, before projects begin; training procedures are stronger in some areas than others. Finally, there is a clear need for further evidence on what works with respect to participatory research. Much of what is known about the success or otherwise of patient and service-user involvement derives from one-off case studies or anecdotal evidence, and greater clarity will be needed if we are to ensure successful outcomes in future.