

TESTING TREATMENTS

Chapter 11, 11.1

11 Getting the right research done is everybody's business

In the preceding chapters we have shown how much time, money, and effort can be wasted in doing bad or unnecessary research into the effects of treatments – research that does not, and never will, answer questions that matter to patients. We hope we have convinced you that better testing of treatments in the future should come from productive partnerships between patients, clinicians, the public, and researchers.

HOW CAN PATIENTS AND THE PUBLIC HELP TO IMPROVE RESEARCH?

The formerly closed world of medicine is increasingly opening its doors to admit fresh ideas and former ‘outsiders’, and paternalism is steadily diminishing. As a result, patients and the public are contributing more and more to the conduct of healthcare research – both what is researched and how studies are undertaken.¹ Worldwide, there is growing support for collaborating with patients as partners in the research process, and useful guidance is now available for professionals who wish to involve patients and the public.^{2,3,4}

Patients have experience that can enhance deliberations and provide insights. Their first-hand knowledge can shed valuable light on the way in which people react to illness and how this affects choice of treatments. Accumulating evidence from questionnaire surveys;⁵ systematic reviews of research reports;¹

PATIENTS' CHOICE: DAVID AND GOLIATH

'Who has the power to see that research questions actually address the greatest needs of patients in all their misery and diversity? Why aren't the most relevant questions being asked? Who is currently setting the questions? Who should be? Who shall direct this prioritisation? Patients are best able to identify the health topics most relevant to them and to inform their comfort, care, and quality of life, as well as its quantity. The patients are the David, who must load their slings against the Goliaths of the pharmaceutical companies who need evidence to market goods and make profits, and trialists who are driven by curiosity, the need to secure research money, professional acclaim, and career development. Profit, scientific inquiry, grant money, and research papers are acceptable only if the central motivation is the good of patients. Independent patients and organisations that advocate good quality research should ready their sling, carefully choose their stone, take aim, and conquer.'

Refractor. Patients' choice: David and Goliath. *Lancet* 2001;358:768.

reports of individual trials;⁶ and impact assessments⁷ shows that involvement of patients and the public can contribute to improving tests of treatments.

Among many initiatives, the Cochrane Collaboration (www.cochrane.org), an international network of people who review, systematically, the best available evidence about treatments, has embraced the input of patients from its inception in 1993. The James Lind Alliance (www.lindalliance.org), established in 2004, brings together patients, carers, and clinicians to identify and prioritize those unanswered questions about the effects of treatments that they agree are most important. This information about treatment uncertainties helps to ensure that those who fund healthcare research know what matters most to patients and clinicians.⁸ Beginning in 2008, the European Commission

A KEY PARTNERSHIP

'People-focused research in the NHS simply cannot be delivered without the involvement of patients and the public.

No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost effective as well.'

Professor Dame Sally Davies. Foreword to Staley K. *Exploring impact: public involvement in NHS, public health and social care research*.

Eastleigh: INVOLVE, 2009. Available from: www.invo.org.uk.

funded a project to promote the role of patient organizations in clinical trials with the aim of pooling experience among European countries through workshops, reports, and other exchanges.⁹ In other countries, too, there is active public representation in research activities generally.

Roles are continually evolving¹⁰ in various ways, enabling patients and the public to work together with health professionals, and new methods of doing so are being developed (see below *Bridging the gap between patients and researchers*, and Chapter 13, point 2, *Design and conduct research properly*).¹¹ This is happening across the whole spectrum of research activities:

- formulation of questions to be addressed
- design of projects, including selecting which outcomes are important
- project management
- development of patient information leaflets
- analysis and interpretation of results, and
- dissemination and implementation of findings to inform treatment choices.