To see whether a proposed trial might be feasible and acceptable, exploratory work involving groups of patients can be useful. This may highlight shortcomings in the design plans; or help to define outcomes that are more relevant; or even suggest that the concept is a non-starter.[5, 6]

This can save a lot of time, money, and frustration. The clinical trial in men with localized prostate cancer that we described in Chapter 11 (p140-141) showed how the research design was improved by careful consideration of the terms used by clinicians to describe the trial's purpose and the treatment options. Exploration of patients' views led to an acceptable study because the concerns and information needs of the men being invited to participate had been identified, and the information provided to potential participants took account of these findings.[7]

3. **Publish all the results and make them accessible** Selective reporting of the results of research can lead to serious biases. Some 'negative' studies are never published when the results do not match the expectations of the investigators or funders. Without a published report to tell the tale, these trials disappear without trace.[8] Furthermore, results within published trials may be selectively reported – that is, some of the results are excluded because they are not so 'positive' for the treatment being tested.[9] Patients have suffered and died because of biased reporting of research on the effects of treatments. This practice is unethical as well as unscientific.

4. **Produce unbiased and useful research reports**
Even when studies are published, they often omit important elements that enable readers to assess and apply the findings. One review of 519 randomized trials published in reputable journals during December 2000 found that 82% did not describe the process of allocation concealment and 52% did not provide details of measures to reduce observer biases – both features that we suggested in Chapter 6 were crucial to good studies.[10] This poor reporting of details extends even to the description of the treatments used. A trial showing that giving a specific booklet (compared with no booklet) helped patients with irritable bowel

syndrome, omitted to describe the contents of the booklet or how to obtain it; the 'treatment' could therefore not be used by any other patients or doctors. This was just one example in an analysis of trials in major journals that found about a third omit such crucial details.[11]

Finally, most published trials do not set their results in the context of previous similar trials. Without this key step, as we explained in Chapter 8, it is impossible to know what the results actually mean. Four-yearly checks of randomized trials reported in five major medical journals over a period of 12 years – 1997-2009 – illustrate the extent of the problem. Overall, only 25 of 94 (27%) reports made any reference at all to systematic reviews of similar trials. Only 3 of 94 reports actually contained updated reviews integrating the new results, and so showing what difference the new results had made to the totality of evidence. Sadly, there was no evidence of improvement in reporting practice with the passage of time.[12] This failure can lead to clinicians using different treatments depending on which journals they happen to read.

BLUEPRINT FOR A BETTER FUTURE

Medical research *could* be done for the right reasons and could be done and reported well. Taken individually, none of the suggestions that follows is novel. Taken together and promoted jointly by patients and clinicians, our eight action points constitute a blueprint for a better future in the testing and use of treatments.

1. Increase general knowledge about how to judge whether claims about treatment effects are trustworthy A condition for change is greater public awareness of the ways in which bias and the play of chance can seriously distort evidence about the effects of treatments. One of the most important features of scientific investigation – recognizing and minimizing bias – can hardly be regarded as 'general knowledge' at present. We need more determined efforts to reduce these important gaps in understanding, and to make these concepts a routine part of education, from school age onwards.