

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.

2. Increase the capacity for preparing, maintaining, and disseminating systematic reviews of research evidence about the effects of treatments

Many of the answers to questions about the effects of treatments can be readily addressed by systematically reviewing evidence that already exists, by keeping such reviews up to date, and by disseminating the results efficiently to professionals and patients. There is a long way to go before the messages from existing evidence are readily available in systematic reviews. Addressing this deficiency should be one of the prime goals of health systems, so that reliable information about the effects of treatments is synthesized and made readily accessible.

3. Encourage honesty when there are uncertainties about the effects of treatments

Admitting uncertainty is often hard for health professionals, and it is sometimes not welcomed by patients. As a result, patients are sometimes given a false sense of security and are not informed about the uncertainties in the evidence. If clinicians and patients are to work together successfully for more efficient assessment of treatment effects, both must be more ready to acknowledge that inadequately evaluated treatments can do substantial harm; they must become more familiar with the methods needed to obtain reliable evidence. We need to find the best ways of making this happen.

4. Identify and prioritize research addressing questions deemed important by patients and clinicians

The portfolios of research funders and academic institutions are dominated by basic research that is unlikely to benefit patients in the foreseeable future, and by research directed at maximizing profits for industry. Applied research into questions that offer no potential to make money, yet matter to patients, has to fight for resources, even when it is publicly supported. We should see to it that more is done to identify what questions patients and clinicians are asking about the effects of treatments, and that research funders take account of them in prioritizing research to reduce these uncertainties.

5. Confront double standards on consent to treatment

Clinicians who are prepared to admit uncertainties about the effects of treatments and address them in formal treatment comparisons are subject to more stringent rules for interacting with patients than are their colleagues who are not. This perverse double standard is illogical and indefensible. When there are uncertainties about treatment effects, participation in randomized trials or other methods of unbiased evaluation should be the norm. We should ensure that participation in research on treatment effects is not presented as a necessarily risky endeavour, implying that 'standard' practice is always effective and safe.

6. Tackle inefficiencies within the research community

Many people are astonished to find that researchers are not required to assess systematically what is known already when they seek funding and ethical approval for new research. The consequence is inevitable – poorly designed and frankly unnecessary research continues on a scale that is unacceptable on ethical as well as scientific grounds. We should press research funders and research ethics committees to ensure that researchers do not embark on new research of any kind without referring to systematic reviews of existing relevant evidence. Reports of new research should begin by referring to systematic reviews showing why the additional research is needed, and end by showing what difference the new results have made to the totality of evidence.

7. Outlaw biased publication practices

To help stamp out biased publication practices steps are needed both when trials begin and when they end. When trials begin they should be registered and the protocols made publicly available for scrutiny. On completion, the results of all trials should be published and the raw data made accessible for scrutiny and further analysis.

8. Demand transparency of information about commercial and other conflicts of interests

There is now substantial evidence that vested financial and other interests sometimes take precedence over the interests of

patients in the design, conduct, analysis, interpretation and use of research. This jeopardizes the mutual trust required to ensure that research serves the interests of patients more effectively. Everyone involved, from commercial companies to patient pressure groups, should be required to be transparent about any vested interests other than the well-being of patients.

Action is needed now

A revolution in testing treatments is long overdue. If professionals and patients act together, the steps that we advocate are eminently practicable. You, the readers, should demand change – now.

AN ACTION PLAN – THINGS YOU CAN DO

Identify questions about the effects of treatment that are important to you.

Learn to recognize uncertainty; speak up; ask questions; seek honest answers.

Don't be afraid to ask your doctor what treatments are available; what may happen if you choose a particular treatment; AND what might happen if you don't.

When thinking about possible treatments, you may find the information on decision aids at www.ohri.ca/DecisionAid helpful. See also: Additional Resources (Do you want to know more about shared decision-making?)

Use reliable websites such as NHS Choices (www.nhs.uk). See: Chapter 12 and the *Additional Resources* section in this book.

Be a healthy sceptic about unfounded claims and media reports of treatment 'breakthroughs'; about the way that 'numbers' are reported in the media – especially large numbers in headline claims!

Challenge treatments offered to you or your family on the basis of beliefs and dogmas, but unsubstantiated by reliable evidence.

Be wary of unnecessary disease 'labelling' and over-investigation (see Chapters 2 and 4) – find out if the disease in question is considered high risk or low risk for you. Ask what would happen if nothing immediate is done.

Agree to participate in a clinical trial only on condition (i) that the study protocol has been registered and made publicly available (ii) that the protocol refers to systematic reviews of existing evidence showing that the trial is justified; and (iii) that you receive a written assurance that the full study results will be published, and sent to all participants who indicate that they wish to receive them.

Encourage and work with health professionals, researchers, research funders, and others who are trying to promote research addressing inadequately answered questions about the effects of treatment which you regard as important.

Encourage wider education about the effects of biases and the play of chance, and lobby your elected political representative and others about doing more to emphasize this in school curricula, beginning in primary schools.