Patients’ expectations of the benefits and harms of treatments and tests

A systematic review found that for many treatments and diagnostic or screening tests, the majority of people overestimated the likely benefits and underestimated the likely harms.

Overview: People are offered a wide range of interventions as part of their care: medicines; surgery or other treatments; and diagnostic or screening tests. The chances of benefiting from an intervention or being harmed by it are likely to be important when a person is deciding whether or not to have the intervention.

A person needs to weigh up how likely a treatment is to prevent an undesirable outcome or provide relief from unpleasant symptoms compared with the risk of adverse effects or complications. The implications for them if an outcome they hope to avoid were to happen should also be considered. For diagnostic and screening tests, a person needs to consider the reliability of the results: given a positive or negative result, how likely it is that they truly do or do not have the condition being tested for, and the implications for them of that result. Patients may also need to consider if and how the results of a diagnostic test might change their treatment, and whether their outcome would be likely to improve.

Other questions are also important in a person’s decision about their care, such as how unpleasant or inconvenient the intervention is. However, if someone overestimates or underestimates the benefits or harms of an intervention, they may come to a different decision from the one they would have made if they had had a better appreciation of these factors.

Current advice: The NICE guideline on patient experience in adult NHS services recommends giving people information, and the support they need to make use of it, to promote their active participation in care and self-management. This includes discussing the risks, benefits and consequences of the investigation or treatment options, clarifying what the person hopes these will achieve, and discussing any misconceptions with them.

The NICE Pathway on patient experience in adult NHS services brings together all related NICE guidance and associated products on this topic in a set of interactive topic-based diagrams.

New evidence: A systematic review has assessed the evidence from studies that quantitatively measured patient or public expectations of the benefit or harm of treatments, diagnostic tests or screening tests (Hoffman et al. 2015). The authors included data from 35 studies from 16 different
countries (about half from the United States) involving 27,323 participants. Examples of the study topics included infliximab for inflammatory bowel disease, hormone replacement therapy (HRT), statin therapy, cataract surgery, cardiopulmonary resuscitation, mammography, prostate-specific antigen testing, bowel cancer screening and scans for fetal abnormalities.

For 34 treatment, diagnostic test or screening test outcomes, quantitative data were available about overestimation of benefits by study participants compared with the primary study authors’ estimates of the ‘correct’ answers. The likely benefits of 22 (65%) of these outcomes, such as the number of breast cancer deaths prevented by mammography, were overestimated by the majority (50% or more) of study participants. The majority of participants correctly estimated the likely benefits for 2 outcomes (improved vision after cataract surgery and accuracy of cervical smear tests) and underestimated the benefits for 1 outcome (improved lower back pain after back surgery). There was not a majority overestimation or underestimation for the remaining 9 outcomes.

For 17 other beneficial outcomes, the authors of the systematic review could not calculate the proportion of participants who overestimated or underestimated benefit. However, for 15 (88%) of these outcomes, the primary study authors concluded that participants had overestimated benefits.

Conversely, the majority of study participants underestimated likely harms for 10 (67%) of the 15 outcomes for which data about underestimation of harms were available (for example, the risk of death or adverse events with infliximab). The likely harms were correctly estimated by the majority of people for 2 outcomes (the proportion of people who need glasses after cataract surgery and the risk of miscarriage from amniocentesis) and overestimated for 1 intervention (the risk of breast cancer with HRT).

Strengths of this systematic review include the diversity of interventions studied and countries included. However, this diversity made it difficult for the authors to compare individual studies. Some studies had small or selective samples. There is likely to have been variation in methods of assessing participants’ expectations (which were largely untested), criteria for deciding whether an expectation was an underestimate or overestimate (such as how close a participant had to be to the ‘correct’ answer), and participants’ backgrounds.

Commentary: “The authors claim that this is the first systematic review to pull together evidence on patient and public expectations of the benefits and harms of medical interventions, and I believe they are right. They have usefully focused attention on an issue of major importance – the public are over-optimistic about the benefits of treatment, screening and diagnostic tests. We will have no hope of ensuring that medical care delivers best value until people have a more balanced understanding of its limitations.

“The over-optimism probably derives from various sources, including difficulties in accessing reliable information, commercial influences, media distortions, advice from over-optimistic clinicians and a general tendency to want good news rather than bad. These influences lead to distortions in medical decision-making, making patients unaware of the risks and trade-offs involved and seriously undermining the principle of informed consent.

“One way to deal with the problem is to ensure that people receive clear, unbiased, evidence-based information at the point of decision-making. A Cochrane review by Stacey et al. (2014) found that use of patient decision aids led to significant improvements in people’s understanding of their options and more informed decisions. There is plenty of evidence that patients want this type of information, but many don’t receive it. Demand for ineffective or unproven treatments will continue to rise unless we make a more concerted effort to help people make informed decisions.” – Dr Angela Coulter, Senior Research Scientist, Nuffield Department of Population Health, University of Oxford

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