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Informed choice for screening: Implications for evaluation

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Abstract
Evaluation of screening should reflect consumer priorities. We need to make more effort to find out what they really are.

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Analysis and comment

Screening and choice

Informed choice for screening: implications for evaluation

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Evaluation of screening should reflect consumer priorities. We need to make more effort to find out what they really are

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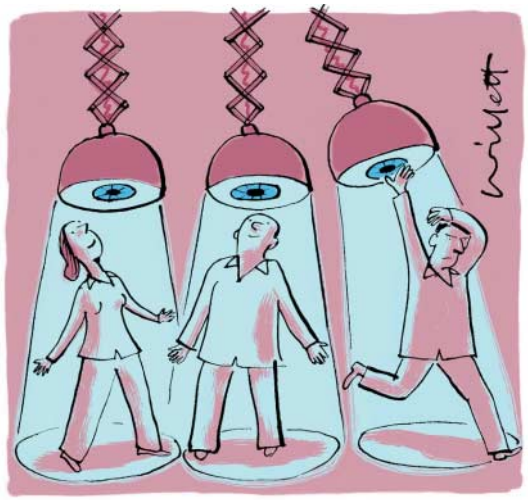
Most evaluations of screening do not include the full range of benefits and harms.[1 2] The United Kingdom and World Health Organization's latest guidelines on screening accentuate the need for more rigorous evidence of effectiveness and greater concern about the adverse effects of subsequent investigation and management.[3 4] The UK guidelines now state that the benefit from the screening programme should outweigh the physical and psychological harm caused by the test, diagnostic procedures, and treatment.[3] In the updated WHO guidelines for medical screening, Strong et al state that "Identification of either trivial or untreatable conditions can cause anxiety and waste resources with no practical outcome."[4] They also argue that the acceptability of screening is an important issue to consider. We outline three principles concerned with how consumers' views can be ascertained and used to enable value based decisions about screening programmes.



Value all benefits and harms

Evidence from randomised trials that screening reduces mortality is necessary but not sufficient to justify screening. Decisions should be based on an assessment of all the benefits and harms, not only of the screening test but also of follow up tests and treatments. As the UK criteria state, the screening programme must be clinically, socially, and ethically acceptable to the public and the benefits outweigh the harm.[3]

A holistic approach to evaluation requires studies to identify the benefits and harms perceived by consumers and clinicians. Harms include:

- Complications of investigation of screen detected abnormalities
- Unexpected effects, such as increased morbidity and mortality from side effects of screening or subsequent management
- Overdetection—the identification of disease that would not have presented during the person's lifetime, and
- Psychosocial effects.

Some harms or downsides may seem trivial, but, unlike the benefits, occur soon after screening and are common. For example, biennial mammographic screening has been estimated to avert only two deaths in 1000 women aged 50-59 over 10 years but requires 5000 screens, 242 recalls, and 64 women to have at least one biopsy.[5] Moreover, five women will have a ductal carcinoma in situ detected, some of which may never have progressed if left untreated. This information may lead some people to decide that the downsides of screening outweigh avoidance of longer term serious but rare outcomes.[6]

Consultation about screening policy between policy makers and an informed public is essential. The public can be involved through methods such as citizen juries, deliberative panels, and round table discussions with community members.[7] Community surveys among representative samples can provide policy makers with useful information about how benefits are valued against harms in the population.[6 8 9] Preferences can be measured directly: "Given the benefits and harms, would you prefer to be screened or not screened?" or through utility measurement techniques that assess individuals' preferences through specific trades or gambles (choices) associated with the benefits and harms of screening.

Enable participation in informed choice

High quality evidence that a reasonable proportion of consumers would see the benefits as outweighing the harms may be sufficient to decide to offer screening. However, some consumers may still not want to be screened.[6 9]

Patient autonomy requires that people should be able to choose, free from coercion, whether they wish to participate in screening. To make a decision participants require unbiased information on both the benefits as well as the harms of screening.[10] However, although there have been some encouraging moves in this direction,[11 12] much current information overemphasises the benefits of screening, minimises the harms, and does not clarify to the reader that there is a choice to be made about whether screening is worthwhile for them.[13 14] Consequently, informed choice is difficult to achieve and screening has overwhelming uncritical public support.[15]

Consumers, and their practitioners, should therefore receive balanced information about the benefits and harms of screening. Including information about how similar people weigh the benefits and harms—for example, data from surveys of community preferences—may also be helpful. Individuals then have different ways of exercising informed choice about screening. They may follow screening guidelines provided by an authoritative health body or their doctor's advice, or they may weigh up the benefits and harms for their personal situation. People who want to make an individual decision may require more detailed information than initially given.

Tools to support consumers in making informed decisions about their health care, such as decision aids, have been shown to improve knowledge, clarify preferences, and reduce uncertainty around decision making, with high levels of acceptability among consumers.[10 16] Further development and research is needed to ensure that these tools are easy to understand and use by all sectors of the community and do not create barriers that contribute to social inequity.

Measure concordance between preferences and actions

Providers need to select performance indicators for screening that fit with the consumer choice model.[17] Participation rates, often used as one of the markers of success of screening programmes, are not an adequate marker of appropriate participation. Indeed, when they are accompanied by incentive payments to practitioners (such as in the UK and Australian cervical screening programmes) they may undermine the provision of genuine choice to consumers.[18 19]

Some providers have been reluctant to allow consumer choice. This may partly derive from the common misconception that a high participation rate is necessary to ensure community benefit and cost effectiveness. But in most cases community benefit is no more than the sum of the individual benefits, the main exception being screening for infectious diseases such as tuberculosis. If the screening programmes do not have large set-up costs, benefits are usually proportional to costs.[20] For colorectal cancer screening, cost effectiveness has been shown to worsen only at extremely low levels of participation.[21]

The measurement of appropriate participation in screening is challenging.[17 22] Marteau and colleagues have developed a measure of informed choice for use in prenatal testing based on the constructs knowledge, attitudes, and behaviour.[22] Jepson proposes a more complex set of factors to indicate informed choice in cancer screening programmes.[17] Dowie also outlines a model based on decision responsibility, information provision and value clarification.[23]

We propose a simple three stage model for use in screening that assesses the consistency between an individual's preference for decision making and their subsequent screening behaviour. This approach recognises that not all consumers will want to make an individually based choice and highlights the relation between the decision about screening (intentions) and subsequent screening behaviour. The model proposes that all those eligible for screening should be aware of the screening programme and have received and understood an agreed minimum of information about benefits and harms of the procedure so that they can decide whether to follow the advice of an authoritative health body or make an individual choice. Secondly, everyone should know how to access the information and support to make a personal decision about screening. Thirdly, there should be an assessment of the extent to which an individual's screening intentions and behaviour agree with his or her preferred method of decision making. For consumers who prefer to follow advice, we would expect that their decisions and behaviour are consistent with the recommendation. For consumers who prefer to make an individual choice, we would expect the consumer who chooses to be screened to perceive the benefits of screening as outweighing the harms and vice versa for those who choose not to be screened.

Tools need to be developed to measure both intentions and behaviour. The match between them provides valuable feedback to indicate whether genuine choice is on offer. If consumers intend to be screened but are not, this suggests that there are obstacles to participation. On the other hand, if consumers do not intend to be screened but are, this may indicate lack of choice. Evaluation needs to include assessment of whether the provision of understandable information and access to choice and decision support is equal to all, irrespective of social, economic, or cultural factors. In this way, fairness is achieved not by maximising participation but by ensuring that everyone has an equal opportunity to make an informed choice.

Conclusion

The three principles described above have implications for decisions about whether screening should be introduced and, once introduced, how it should be evaluated. The consumer should be at the centre of the value based principles. Health professionals and policy makers need to provide the means to enable this. A

Summary points

All benefits and harms of screening must be fully ascertained and undergo community valuation before screening is offered

Service providers should respect patient autonomy and ensure that participation in screening is an informed choice

Concordance between consumer preferences and screening behaviour should replace participation as one of the measures of success for screening programmes

more holistic approach to evaluation, respect for consumer autonomy in decision making, and pursuit of informed choice in screening should lead to better benefit:harm ratios and improve the framework for assessing the worth of population screening programmes.

Contributors and sources: LI is a medical epidemiologist who has researched issues in screening for several decades. KMcC is a behavioural scientist with expertise in decision making and the psychosocial outcomes of screening. GS has published widely on consumer preferences for screening and has a long-standing interest in the application of economic methods for the evaluation of screening. PB is a clinical epidemiologist who studies methods to evaluate medical tests and to obtain patient trade-offs of benefit and harm. This article arose from concerns about how the incentive to achieve high participation in screening often runs counter to principles of informed choice. All authors contributed to the development of ideas and the writing of the manuscript. LI is the guarantor.

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Cancer genetics

Common susceptibility genes for cancer: search for the end of the rainbow

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The human genome map has started a hunt to find common genes that are associated with cancer. But new research questions the likelihood of success.

Huge resources are being invested in the search for common inherited genetic variants that increase susceptibility to cancer. However, these studies are expensive because they require large sample sizes to rule out false positive results (table).[1 2] The US cancer genetic markers of susceptibility project (http://cgems.cancer.gov), for example, will cost $14m (£7.9m; €11m). In addition, large replication studies may still be necessary to confirm generalisability to other populations. For these studies to eventually lead to a clinical therapeutic benefit, common genetic variants that increase susceptibility to cancer must exist and it must be feasible to rigorously evaluate the clinical benefit of targeting these common genetic variants. Both these requirements require formal consideration.

P+ *An explanation of sample size calculations for gene-cancer association studies is on bmj.com*