

# Public expectations about screening still don't match what screening programs can deliver

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Misconceptions about how screening works, its limitations and possible harms are still being perpetuated by media stories and high profile cases, such as Angelina Jolie's double mastectomy and emotive tabloid case studies of women under 25 dying from cervical cancer. Campaigners and celebrities still call for more screening: for more diseases, in more people and for longer. In the last few months alone, Taylor Swift encouraged fans' parents to get earlier breast screening following her mother's cancer diagnosis, campaigners have called for all women over 70 to be screened for breast cancer and researchers have been developing screening tests for Alzheimer's, as well as discussing screening babies from birth. There's also a widespread misconception that screening programmes are only offered to certain age groups due to financial considerations.

We have released a new edition of our guide *Making Sense of Screening* today to address the unrealistic expectations of what [screening](#) can deliver.

In the guide, scientists, clinicians and medics explain that screening:

- rarely benefits all sections of the population.
- can have negative effects, so it needs to be targeted at those most likely to benefit.
- can identify some of the people who have a disease but it cannot prevent disease.
- cannot give you a 'yes' or 'no' answer and an 'all clear' does not mean you will not go on to develop the disease.
- [screening tests](#) differ from [diagnostic tests](#).

## Comments:

Dr Anne Mackie, director of programmes for the UK National Screening Committee: "Screening is very different from asking your GP for a test. It is offered to a large number of people who are apparently healthy and not showing symptoms, which means that most people will be tested with no possibility of benefit.

"In addition, some people, rarely, will be given a result that suggests they have a problem when they don't, or even told they don't have a problem, when they do. That is why it is important that people make their own decision whether to attend for screening when offered - understanding there may be risks as well as benefits.

"We need to help people see that although screening is beneficial at the population level, they need to consider the implications for themselves as an individual. It is therefore so important that people, when invited, are given the full information before making a decision on whether to have a screening test."

Andrew Miller, former chair, House of Commons Science and Technology Select Committee: "This is an important piece of work against a background of confusion and misconceptions surrounding some screening programmes. I hope this public guide will be widely available as it could help to improve engagement between clinicians and the public."

Dr Danielle Freedman, chair, LabTestsOnLine, UK Board: "As professionals, we need to prevent overdiagnosis in healthy individuals causing 'pseudo disease' through 'unnecessary screening'. It leads to wasting of resources on unnecessary care, instead of using these precious resources for treating and preventing genuine illness."

Dr Suzy Lishman, president, The Royal College of

Pathologists: "Screening plays an important role in keeping people healthy, but there are many misconceptions about its purpose and accuracy. The more people are aware of its benefits and limitations, the better equipped they will be to make decisions about whether to be tested and to understand the results they receive. Making Sense of Screening explains what screening aims to do, what the results mean and why there are screening programmes for some conditions but not others. I would recommend it to anyone to help them make informed decisions about their health care."

Sarah May, deputy chief executive, Institute of Biomedical Science: "A screening test in effect predicts risk; it does not give an absolute guarantee of disease absence or disease presence. A positive result means that further investigation is required. Some of those with positive results will be found to be at risk of developing a particular disease and others will be found to be clear. However, there will always be some false positives which should be offset by the benefit of detecting the low numbers of genuine 'at risk' individuals. A negative result means that no evidence of a particular disease or condition was found but it does not mean that the person will remain disease free in the future."

Emily Jesper, assistant director, Sense About Science: "Since Sense About Science first launched this guide in 2009, confusion, misconceptions and misinformation about screening have not gone away. The influence of celebrities and campaigners in the media and public discussion often amplifies this, which needs to stop. Continual calls for more screening ignores the risk of harm, which always need to be weighed against the benefits when making decisions about screening, both for national programmes and for individuals."

Joe O'Meara, government affairs officer, Association for Clinical Biochemistry and Laboratory Medicine: "I'm delighted to see the publication of the new edition of "Making Sense of Screening". There are many who do not understand, or have serious misconceptions about, screening. I hope that all involved in establishing screening programmes will take note so that our limited resources are deployed effectively and to

the benefit of the whole population"

Dr Clare McKenzie, vice president for education, The Royal College of Obstetricians and Gynaecologists (RCOG): "People often get confused between screening and diagnostic tests. Screening is for women without symptoms. Cervical cancer screening can detect pre-cancer abnormalities, which can then be treated before it develops into cancer. As most women do not experience any symptoms at this stage, screening is the only way to find these abnormal cells."

"If women have any symptoms, such as abnormal bleeding, they should not wait for their next screening but instead be seen by their GP and referred for diagnostic tests and treatment if necessary. In the majority of cases a simple reason is found."

Sarah Williams health information manager, Cancer Research UK: "Cancer screening plays an important role in helping us beat cancer, through detecting the disease early and in some cases preventing it from starting in the first place, but as Sense About Science's useful report highlights the story isn't as straightforward as people often think. It's important that people have a sense of perspective about the benefits that screening can offer them - the most likely outcome from taking part in screening is that the test correctly finds you don't have cancer. And screening has potential harms too, so people should have clear and accurate information about both sides of the equation to help them decide whether they want to take part."

Robert Music, chief executive, Jo's Cervical Cancer Trust: "There has been much press coverage and petitions launched to lower the screening age following the diagnosis of [cervical cancer](#) in women under 25. It is tragic to see these young women going through a [cancer diagnosis](#) but expert opinion, which we like other charities have to be guided by, says that reducing the age at which a woman is first screened is unlikely to diagnose more cancers in those under 25 or prevent more deaths. There is also evidence that [cervical screening](#) is less effective in younger women and can cause more harm than good with unnecessary

treatment.

Susan Bewley, professor of complex obstetrics, Kings College London: "Even in the old well-established screening programmes such as mammography, there is debate about the risks of screening and how often they occur. Women should be as well informed as possible about the potential risks, as well as the benefits, before starting on the screening journey. Fewer attend when they are fully and properly informed and understand it is not an unmitigated boon. I am saddened when I hear non-medical contemporaries discuss their distress about their own or their wife's "cancer" diagnosis when it was DCIS discovered on a mammogram. DCIS looks like cancer down a microscope but doesn't behave like [cancer](#). It might never have developed into a problem. Women do not realise that the life-changing mastectomy, or even bilateral mastectomy, for DCIS was an adverse consequence of being screened. They should be told about the real risks and benefits to make their own, informed decisions."

**More information:** [www.senseaboutscience.org/](http://www.senseaboutscience.org/)

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