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### Communicating about screening

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## Communicating about screening

### Abstract

Informed choice is important for screening, but not everyone wants or is able to analyse research data. Vikki Entwistle and colleagues propose a new approach to communication.

### Keywords

communicating, about, screening

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# Communicating about screening

Informed choice is important for screening, but not everyone wants or is able to analyse research data. **Vikki Entwistle and colleagues** propose a new approach to communication

People are offered a wide range of screening tests by diverse providers. For example: maternal and child health services screen for genetic conditions and developmental problems; general practitioners screen for cardiovascular risk factors; NHS programmes screen for bowel, breast, and cervical cancer; and commercial providers offer various health assessments, including body and gene scans. Provision of tests is not well regulated, and there is a bewildering amount of information of variable accuracy in the public domain.<sup>1</sup>

It is unclear how healthcare providers should communicate about screening in order to support appropriate uptake. And what constitutes appropriate uptake is also contested because of disagreements about the merits of particular tests and tensions between concerns to promote health and to respect autonomy.<sup>2-4</sup> Debates about communication have tended to consider two types of approach, which we call “be screened” and “analyse and choose.” We consider their problems and propose a third approach, “consider an offer.”

## Be screened

The be screened approach aims to persuade people to have screening, usually with a view to promoting health gain, cost effective service provision, or profit.<sup>2-4</sup> Its key features are encouragement to be screened; an emphasis on the benefits of screening and de-emphasis of potential harms; and a lack of recognition that it might be reasonable not to be screened.

This approach is found in commercial advertisements and some invitations to participate in government funded screening programmes. For example, the leaflet *Breast Cancer: the Facts*, from the NHS Breast Cancer Screening Programme presents screening as necessary for women aged over 50.<sup>5</sup> It asks, “Should all women have breast screening?” and gives no hint of any scope for a negative answer. The leaflet highlights the benefits of mammography and describes the main processes but plays down potential harms. It does not mention that screening may lead to overtreatment or that clinicians and epidemiologists seriously dispute the value of breast screening. It gives no indication that women might reasonably choose not to be screened,

and includes a breast awareness code that instructs women to “Go for breast screening every 3 years if you are over 50.”

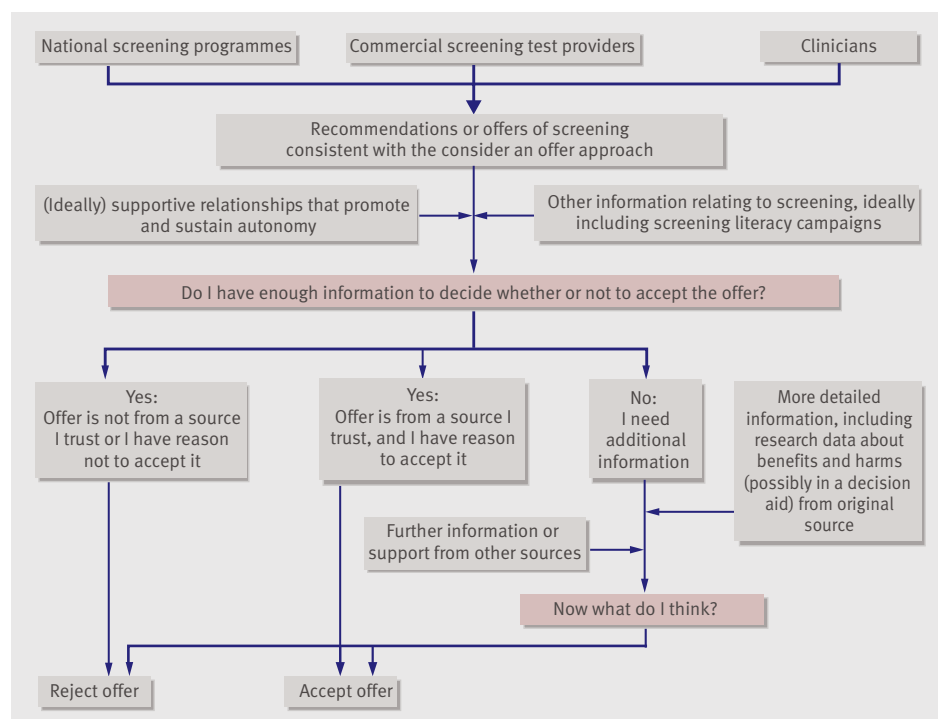
The main criticisms of the be screened approach are that it inadequately reflects the benefit-harm profile of screening tests and fails to respect autonomy because it does not facilitate informed decision making by individuals.<sup>6-8</sup> Some communications with features typical of this approach purport to facilitate informed choice, but they present only one option: to be screened.

## Analyse and choose

The analyse and choose approach is one response to criticisms of the be screened approach. It emphasises respect for autonomy and treats this as a matter of ensuring that competent individuals have sufficient understanding of their options and can make intentional, sufficiently independent choices.<sup>9</sup> It assumes that sufficient understanding requires comprehension of detailed research based information about benefits and harms and promotes informed individual decision making based on this.

The key features of this approach are an emphasis on the importance of individual (sometimes independent) choice and the provision of comparative data about the various outcomes of screening and no screening. The approach is exemplified by decision aids, which seek to present the data in accessible ways.

There are three main criticisms of the analyse and choose approach. Firstly, the implication that everyone eligible for screening should consider detailed effectiveness data may be unnecessarily burdensome. This criticism is particularly strong when expert committees acting in the public interest have reviewed the available research, judged the tests to be broadly effective and acceptable, and supported the introduction of government endorsed screening programmes. Secondly, there are concerns that encouraging detailed decision analysis by individuals might not lead to good choices (it might disrupt people’s usual effective decision making processes) or deter uptake of effective, appropriate screening.<sup>4 7 10 11</sup> Thirdly, some critics think this approach overemphasises rational and



Overview of the consider an offer approach

independent decision making—reflecting an inappropriately narrow understanding of autonomy.

**New considerations**

Recent research into decision making has highlighted some potential downsides of detailed decision analysis and maximising (aiming to make the best possible choice). It suggests that heuristics and “satisficing” (aiming to make good enough choices) can be less burdensome and yield better decisions and outcomes.<sup>12 13</sup>

The understanding of autonomy that prevails in health care has been criticised for focusing too narrowly on discrete decisions, over-idealising rationalism, and inappropriately assuming that interpersonal collaboration and trust will compromise rather than promote autonomy.<sup>14-16</sup> Although autonomy relates to individuals, it is both developed and exercised in the context of social relationships.<sup>16-18</sup> People who use “intellectual outsourcing” to help shape their opinions, and who do not process detailed data for themselves before they choose or act, do not necessarily fail to exercise autonomy,<sup>18</sup>

although others who try to impose their views and discourage competent consideration of alternatives do tend to undermine it.

Neither of the two approaches above considers the importance of the interests and trustworthiness of those who offer and advise about screening. This failing, together with recent evidence about what patients value about communication with health professionals<sup>19</sup> and involvement in decision making,<sup>20</sup> leads us to suggest a third approach to communication about screening.

**Consider an offer**

The consider an offer approach is designed to respect personal autonomy without overburdening people with unwanted information and decision making tasks and without deterring uptake of effective and personally appropriate screening. Within this approach, communicators either recommend or offer screening or help people to consider recommendations or offers from others. They openly explain and discuss the basis for the recommendation or offer; encourage and facilitate an individual assessment of the recommendation or offer (including consideration of the potential bias

and trustworthiness of those making it and of its personal relevance); provide or facilitate access to further information if that is required; and acknowledge that the recommendation or offer might reasonably be refused.

Just what information and how much detail are required will vary across screening tests, contexts, and individuals, but will usually include a summary of the potential benefits and harms of the test considered, consideration of any known objections to it, information about test providers, and factors that might affect the appropriateness of the test for particular individuals (table). The optional extra information might include detailed data on outcomes and, more controversially, other people’s experiences and preferences, especially in value laden contexts such as screening for fetal abnormality.<sup>7</sup>

When presented with a screening offer, people might reasonably respond in various ways. Some might judge the trustworthiness and personal relevance of a screening offer on the basis of the initial communication; others might habitually seek and follow the advice of a trusted health professional; and others might want to evaluate research evidence for

**Illustration of communication by general practitioner consistent with consider an offer approach to screening**

Key communication topics	Rationale	Response to a healthy 45 year old’s query about prostate cancer screening	Recommendation of cardiovascular risk assessment
Who made the recommendation or offer?	Being able to depend on others appropriately is essential for autonomy. <sup>16</sup> Information about the individuals, committees, and organisations that recommend or offer screening can help people assess their trustworthiness and identify potential concerns about their recommendations or offers	Although several men’s groups are campaigning for screening, the National Screening Committee, which is required to review the evidence very carefully, does not think that routine screening for prostate cancer is justified	The National Institute for Health and Clinical Excellence and all the major professional and patient groups have worked together and now recommend that we carry out a cardiovascular risk assessment for most people aged 45 and over
What is the basis of the recommendation, and what are the main benefits and harms of screening?	An explanation of how a recommendation was reached may help people to assess its trustworthiness. Information about consequences is an important component of practical reasoning, and people usually want to know (or at least not be misled about) the main reasons for or against healthcare interventions	Although prostate cancer kills many men, a lot of men have prostate cancer but do not die from it . . . Prostate specific antigen (PSA) testing will pick up some prostate cancers but will also miss some. And we can’t tell which of the prostate cancers that it does pick up would be life threatening. When a man is found to have prostate cancer after being screened, no one can be sure if current treatments will leave him better off than if he had not been screened. Research is ongoing, but at the moment we really don’t know the overall effects of PSA testing	Studies following thousands of people over several decades have allowed experts to develop accurate estimates of how likely individuals are to have a heart attack or stroke, based on their age, sex, family history, blood pressure, blood cholesterol, and whether they smoke. Many things can be done to reduce the risk and screening would allow us to discuss options appropriate for your level of risk
Are there any factors that make the screening test more appropriate for some people than others?	Beyond a clear statement about who a recommendation or offer applies to, it may be useful to highlight circumstances that can make screening more or less appropriate for particular individuals—eg, age and risk exposures that modify the likelihood of benefit and values that can give people reason to accept or decline screening tests	Prostate cancer is rare in men under 50 and you have no family history of prostate cancer, so the chances of you having it are relatively low. But if you are particularly anxious about it and concerned to find out, then we should take that into account—but still bearing in mind that the test is not 100% accurate and may lead to unnecessary treatment	You’re a heavy smoker, which increases your risk of heart disease and stroke. If you’re worried about having a stroke like your uncle, screening might help us think again about the smoking and look at other ways you can reduce that risk
Who might gain from screening and how are people protected?	Information about the financial and other significant interests of the organisations and individuals that recommend, offer, and provide screening are relevant in some contexts	Although I wouldn’t really recommend it, I can arrange for a PSA test for you on the NHS... You’ll find private health care providers more enthusiastic about the test—but then they can make money from it in a way that I can’t	The income we get from government to help run the practice depends in part on us doing some of these checks, but we recommend it because we think it can help patients. The practice would still care for you if you chose not to be screened
Is more information needed?	People’s information needs vary. Initial communications can usefully encourage people to consider whether they have enough information and enable those who want more to access other potentially useful sources	Has that given you enough information, or would you like more detail or more time to think about it? I have a leaflet here that summarises the information we’ve talked about, and it lists a few other sources of information	Does that give you enough to go on? I can give you more information, or point you towards a website that explains the assessment in more detail



**Patients offered screening can be helped to consider whether a test is appropriate**

themselves—at least for some tests. It should be feasible to respond to these varied preferences even when communications are necessarily standardised to some extent. For example, mailed invitations from national screening programmes can encourage people to consider whether they would like more information and tell them where to find additional resources and personal support.

This approach respects autonomy because it encourages and enables people to consider screening offers carefully. Although it can incorporate strong recommendations, it does not close down opportunities for thoughtful refusals of screening. For example, practitioners will avoid presenting screening as routine<sup>16</sup> or necessary and will ensure people feel they can safely say they do not think a test is right for them. The consider an offer approach can facilitate informed decision making about screening, providing summary information about the benefits and harms of screening to all and decision aids with more detailed epidemiological information to those who want them (figure), but it does not assume that autonomous choice or informed decision making will always require every individual to work through detailed statistics for themselves.

Because it accepts the reality of intellectual outsourcing<sup>18</sup> and the importance of trust, the consider an offer approach makes people vulnerable to manipulation: trust can be both inappropriately placed and abused.<sup>21</sup> However, this vulnerability is arguably no greater than with the be screened approach. Consider an offer provides some protection by discussing the basis of recommendations or offers, facilitating assessment of the trustworthiness of those who make them, and raising questions

about the adequacy of the information supplied. The further protection that the analyse and choose approach offers by encouraging rational personal decisions based on detailed data on outcomes is not practical for many.

For screening programmes backed by agencies such as the National Screening Committee, the consider an offer approach should not adversely affect uptake of broadly effective tests. Communication consistent with this approach should help people to recognise when providers are trustworthy. In contrast, the be screened approach might lead to mistrust over time if people come to realise practitioners have underplayed the downsides of screening.

The consider an offer approach is less demanding on those eligible for screening than the analyse and choose approach, but it puts more onus on providers to communicate in a range of ways to meet diverse information needs. Some programmes already use features of consider an offer—for example, information about newborn bloodspot tests presents recommendations and explanations and points out that tests are not compulsory.<sup>22</sup> But if the approach is found to be successful, health service agencies will need to develop more resources to support adoption by front line health professionals.

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