

# CLINICAL REVIEW

## Communicating risk

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The communication of risk is an important and often difficult aspect of clinical practice. This clinical review aims to provide practising clinicians with a comprehensive and up to date overview of current evidence in this developing area.

### What is risk communication?

Risk is the probability that a hazard will give rise to harm.<sup>1</sup> Risk communication is defined as the open two way exchange of information and opinion about harms and benefits, with the aim of improving the understanding of risk and of promoting better decisions about clinical management.<sup>2</sup> Risk communication should therefore cover the probability of the risk occurring, the importance of the adverse event being described, and the effect of the event on the patient.<sup>3</sup>

Risk messages are common. We hear that “there is a risk of flooding” or “the terrorism threat level is orange.” In medicine, we may tell people that their “risk of a heart attack is 15%” or “stopping smoking will reduce their risk of lung cancer,” but what do clinicians hope to achieve by providing this information? Box 1 outlines a clinical scenario that requires effective risk communication.

Communicating risk involves providing the patient with a balanced evidence based summary of the risks and harms associated with a service, test, or treatment.<sup>3</sup> In Ms Jones’s case, it would be important to deal with her personal risk of breast cancer (based on her risk factors) and how this risk compares with the general population. To make an informed decision, she would also need to know whether screening would reduce the risk of an adverse outcome should she develop breast cancer and how this reduction in risk compares with no screening. She would also need to know the harms of screening. The clinician should present this information to her in the most transparent and understandable (rather than persuasive) way and accept that her informed decision on her own care may not necessarily be the one that reduces her risk. This highlights the complexities of risk communication. People perceive risk differently depending on their awareness and understanding of the risk in question and also depending on the way the risk information is

presented to them.<sup>1</sup> Therefore, effective risk communication should involve the sharing of information that improves risk perception and understanding and that allows shared decision making. Sometimes this may be at odds with apparent “public health” messages that may, for example, promote uptake of screening tests to achieve programme effectiveness at population levels. However, the clinician should accept that the final decision depends as much on the patient’s own values as it does on the risk information presented.

The literature on risk communication is diverse and some areas of risk communication are still without strong evidence.<sup>4</sup> This review discusses the importance of effective risk communication and summarises the evidence behind the various methods of presenting risk information.

### Why is risk communication important?

Where there is good evidence of the benefits of an intervention, risk communication should aim to go beyond simply sharing information and endeavour to change beliefs or promote behavioural change.<sup>4</sup> This is achievable, because theories of behavioural change highlight the association between risk perception (belief about the likelihood of personal harm from any given “risk”) and health related behaviour.<sup>5</sup> For example, adults who think that they are at high risk of an illness (such as influenza) are more likely than others to take up vaccination.<sup>6</sup> However, many healthcare decisions have no single “best treatment” and require trade-offs between harms and benefits.<sup>7</sup> The provision of risk information in these scenarios should therefore promote patient involvement, informed decision making, and shared management plans.

How risk information is presented (for example, graphically, visually, verbally) is important and influences the degree to which perceived risk will affect behavioural change, such as with cardiovascular risk information.<sup>8,9</sup> Attention is needed not just on accurately predicting cardiovascular risk but also on how best to present that risk, stimulate changes in health behaviour, and reduce risk levels. Risk communication is important because it is something that most clinicians do every day. If done

### Summary points

- Risk communication is the open two way exchange of information and opinion about harms and benefits; it aims to improve understanding of risk and promote better decisions about clinical management
- Strong evidence suggests that the format in which risk information is presented affects patients' understanding and perception of risk
- There is emerging evidence that effective risk communication can lead to more informed decision making in screening
- Decision aids can be an effective adjunct to risk communication and can improve knowledge, awareness, and decision making
- The presentation of data uncertainty is one of the most difficult aspects of risk communication

### Box 1 Ms Jones's dilemma

Ms Jones has just celebrated her 50th birthday. She is fit and well and takes no regular drugs. She comes to the surgery to discuss mammography screening. Ms Jones has no family history of cancer, had her first period aged 14 years, and her first child aged 26. Her sister has told her that a mammogram will detect a cancer before she feels a lump, so that any cancer will be diagnosed earlier, which "can only be a good thing." Ms Jones is more sceptical, having read stories in the press of women who had mammograms and biopsies and were then told it was a "false alarm." She wishes to know more about the benefits and harms of mammography screening before making a final decision.

### Sources and selection criteria

We are updating a Cochrane systematic review on risk communication in screening. Published studies and review papers identified during the search period for this review (2008-2011) were consulted for this article. We also searched PubMed and the Cochrane library for primary research articles, systematic reviews, and commentaries by authoritative authors in the field of risk communication published in the past 12 months.

effectively it can trigger changes in beliefs or behaviour, but for this to occur the risk has to be communicated effectively.

## How good (or bad) are clinicians at communicating risk?

Risk communication research has focused more on what we are doing rather than on how well we are doing it. An observational study of 70 consultations in primary care reported that cardiovascular risk was mainly communicated using verbal qualifiers (telling patients that their risk is "high," "medium," or "low"), but that patients' subjective understanding was significantly higher when visual formats were used.<sup>10</sup> Qualitative research reported that a sample of gynaecologists in Germany often did not correctly explain the benefits and harms of mammography screening to women.<sup>11</sup> Further work by Gigerenzer and colleagues highlights doctors' difficulties with explaining positive predictive values of mammography, interpreting risks associated with the use of the contraceptive pill, and understanding survival rates for cancer.<sup>12 13</sup>

## Barriers to effective risk communication

Effective risk communication can be difficult to achieve for many reasons. The most commonly reported reason is the difficulty that patients and doctors have understanding numbers.<sup>12-15</sup> Gigerenzer coined the term "collective statistical illiteracy" to describe how doctors, patients, journalists, politicians, and society at large have trouble understanding and interpreting health statistics.<sup>12</sup> Basic numeracy is also a problem—for example, only 21% of a sample of highly educated American adults could correctly identify one in 1000 as being equivalent to 0.1%.<sup>14</sup> Clinicians need to be adept at understanding numbers and explaining them in a way that patients can comprehend.

## Methods available to communicate risk

Risk information can be communicated using several different methods and formats. Here we summarise these methods, provide examples, and discuss recent advances in the evidence base for their use.

## Framing

"Framing manipulation" is the presentation of logically equivalent information in different ways.<sup>16</sup> It can be further subdivided into "attribute framing" and "goal framing."

Attribute framing is the positive versus negative description of a specific attribute of a single item or state. For example, Ms Jones could be told that there is an 82% chance that she will survive for five years after a diagnosis of breast cancer (positive attribute framing), or that she has an 18% chance of dying within five years of such a diagnosis (negative attribute framing). Akl and colleagues systematically reviewed 35 trials of positive versus negative attribute framing for their effects on cognitive and behavioural outcomes.<sup>17</sup> Interventions were perceived as more beneficial when presented using positive framing messages, but there was little evidence that framing affected patients' understanding or behaviour.

Goal framing describes the consequences of performing or not performing an act, presented as a gain versus a loss. For example, "screening will improve your chance of survival from cancer" versus "not participating in screening will reduce your chance of survival from cancer." Patients perceived screening as more effective when presented with a loss message, but again there was no evidence of an effect on patients' understanding or behaviour.<sup>17</sup>

## Presenting risk reduction

Risk reduction can be presented using relative risk reduction (RRR), absolute risk reduction (ARR), or numbers needed to treat (NNT).

The RRR is the reduction of risk in the intervention group relative to the risk in the control group. For a risk of 20% in the control group and a risk of 10% in the intervention group, the RRR would be 50%. The ARR is the difference in risks between two groups, which for these same figures would be 10%. The NNT is the number of patients who need to be treated (or screened) to prevent one additional adverse outcome (NNT=10 for the above figures).

Ms Jones could be presented with the following statements<sup>18 19</sup>:

- RRR: Early detection with mammography reduces the risk of dying from breast cancer by 15%
- ARR: Early detection with mammography reduces the risk of dying from breast cancer by 0.05%
- NNT: 2000 women need to have regular mammograms for more than 10 years to prolong one life.

A recent review of evidence suggested that using RRR makes treatment benefits and changes in risk seem larger than they are and recommended that information on risk reduction be consistently presented using ARR.<sup>20</sup> A Cochrane systematic review compared the use of ARR, RRR, and NNT in 35 trials.<sup>21</sup> No studies reported effects of using these risk reduction formats on patients' decision making or behaviour. The review did assess effects on patients' objective understanding, perception of benefit, and persuasiveness. It concluded that:

- RRR and ARR are equally well understood and both formats are better understood by patients and clinicians than is NNT
- RRR is perceived to be larger and is more persuasive than ARR and NNT
- ARR is perceived to indicate a larger effect than when the same information is expressed using NNT but is no more persuasive.

### Personalising risk information

The risk of breast cancer can be presented as a general population based risk estimate (generalised risk information) or on the basis of the individual's own risk factors (personalised risk information). Personalised risk information can be presented as an absolute risk or as a numerical estimate of risk; it can categorise the individual as belonging to high, medium, or low risk groups; or it may simply list the individual's risk factors. Because personalised risk information is based on the individual's own characteristics, it is thought to provide a more accurate picture of risk and to improve decision making.<sup>22</sup> A risk tool (such as [www.cancer.gov/bcrisktool](http://www.cancer.gov/bcrisktool); fig 1) could be used to provide Ms Jones with her personalised risk of developing invasive breast cancer. Several tools are also available for calculating cardiovascular risk, such as QRISK (<http://qrisk.org>).

A Cochrane review of 22 randomised controlled trials suggests that, compared with general risk information, personalised risk communication (whether written, spoken, or visually presented) in the context of screening tests can lead to more accurate risk perception, improved knowledge, and increased uptake of screening tests.<sup>22</sup> Since the publication of that review, three randomised controlled trials have shown that providing personalised risk information leads to more informed decision making about participation in colorectal cancer and prenatal screening.<sup>23-25</sup>

### Natural frequencies

A natural frequency is a joint frequency of two events, such as the number of women with breast cancer who have a positive mammogram.<sup>26</sup>

The use of natural frequencies, rather than percentages or probabilities, probably improves understanding of risks and benefits.<sup>26, 27</sup> Akl and colleagues showed that clinicians and patients find natural frequencies easier to understand than probabilities, suggesting that decisions based on frequencies are more informed than those based on probabilities.<sup>21</sup> There is also growing evidence to support the use of pictographs (fig

2) to present natural frequencies, with evidence suggesting that these are well understood and that they effectively support communication about individual statistics.<sup>8, 20</sup>

### Decision aids

Decision aids aim to help patients participate in healthcare decisions by providing clear evidence based information on the choices available. They should communicate the benefit and harm of each option and promote informed decision making. A systematic review of 86 randomised controlled trials found that the use of decision aids improves patient knowledge and risk perception and increases patients' participation in decision making, promoting informed decision making that is consistent with patient values.<sup>28</sup> This review also suggested that although decision aids can improve patient-doctor communication, they have not been shown to improve actual health outcomes. Another systematic review of randomised controlled trials showed that decision aids can also increase the clinician's adoption of shared decision making.<sup>29</sup>

Although there is good evidence to support the cognitive benefits of decision aids, evidence for behavioural change is weaker. One systematic review suggested that decision aids have variable effects on patient behaviour.<sup>28</sup> For certain decisions, patients exposed to a decision aid behaved differently from those who did not use a decision aid. For example, patients exposed to a decision aid were less likely to opt for prostate specific antigen screening (risk ratio 0.85, 95% confidence interval 0.74 to 0.98). However, for other decisions (such as participating in colorectal screening), there was no evidence to suggest that patients exposed to the decision aid behaved any differently from those who were not.

An increasing number of online decision aids include risk communication elements, such as for decisions about screening (for example, prostate specific antigen testing; [www.prosdex.com](http://www.prosdex.com)), surgical treatment (for example, choosing between breast conserving surgery or mastectomy for breast cancer; [www.bresdex.com](http://www.bresdex.com); fig 3), or medication (for example, choosing to take a statin; [www.npc.nhs.uk](http://www.npc.nhs.uk)). Clinicians' use of these aids during consultations could increase shared decision making and improve patients' knowledge and understanding. Furthermore, patients who use decision aids are consistently more ready to make a decision than those receiving usual care.<sup>28</sup> In the case of Ms Jones, she could be directed to the breast screening decision aid above to help her reach an informed decision about whether to participate in mammography screening (box 2).

### Uncertainty

Other areas of risk communication remain inconclusive, including the quantity of information that should be presented, the order in which to present information, the use of summary tables, and best practice on presenting risk information when the evidence base is unclear. The presentation of uncertainty about data has been highlighted as one of the most difficult elements of risk communication,<sup>30</sup> and empirical research studies are still needed in this area. Politi and colleagues report the problems of communicating uncertainty in a narrative review.<sup>30</sup> They highlight the conceptual differences in the definition of uncertainty and in its measurement. The available research suggests that the response to uncertainty depends very much on the clinician's and patient's personal characteristics and values. Cross sectional surveys suggest that the communication of scientific uncertainty about medical tests and treatments depends on doctors' perceptions of their patients' reaction to uncertainty.<sup>31</sup> Further research also suggests that patients are

**Box 2 Helping Ms Jones to make an informed decision**

The NHS National Prescribing Centre ([www.npc.nhs.uk](http://www.npc.nhs.uk)) provides a breast screening decision aid. This explains that if 1000 women aged 50-70 years attend regular mammography screening for 10 years, 970 women will not have breast cancer, although 130 of these women will have undergone unnecessary extra investigations. Thirty women will have breast cancer diagnosed. Of these 30 women:

- In four, the breast cancers would have been clinically inconsequential
- In 23 of these women, the fact that the breast cancer was picked up by screening will have no effect on their outcome
- Three women will live longer because their breast cancer was detected early through screening

unclear about the degree of uncertainty in medical decisions, with 39% of 2944 American adults believing that the Food and Drug Administration approves only “extremely effective” drugs.<sup>32</sup> Communicating uncertainty may also lead to lower decision satisfaction among patients.<sup>33</sup>

The degree of scientific uncertainty that complicates medical decision making can be highlighted using the example of Ms Jones. Is it appropriate to present Ms Jones with the risk of breast cancer in the UK using a prevalence estimate? Should we provide her with confidence limits for the prevalence estimate so that she can see the uncertainty associated with the estimate? When we informed Ms Jones that “mammography would reduce her risk of breast cancer by 15%,” should we also have discussed the strength and validity of the research that the review was based on? For example, when the review looked only at adequately randomised trials, outcome did not differ between patients who underwent screening and controls.<sup>18</sup> Numerical literacy and understanding are even more important when communicating data uncertainty, and the clinician needs to balance information provision with the understanding and knowledge needed to make a decision. In an attempt to achieve this aim, several methods have been adopted, but there is little evidence for their effectiveness.<sup>30</sup> The most commonly used method is to summarise the quality of evidence pertaining to a given health intervention using a rating system and simple descriptive terms to describe the degree of uncertainty (fig 4).

In summary, evidence suggests that ARR is a more balanced and understandable representation of risk reduction for patients and clinicians than RRR or NNT. Natural frequencies are easier to understand and interpret than percentages or probabilities. Emerging evidence supports the use of personalised risk communication for promoting informed decision making in screening. There is also good evidence to support decision aids as a practical support to risk communication. Finally, it is difficult to communicate data uncertainty; there is little clear guidance on best practice approaches, and this area needs further empirical research.

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Competing interests: All authors have completed the ICMJE uniform disclosure form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, AGKE has been involved in the development of the decision aids cited (Prosdex and Bresdex), which are hosted by Cardiff University on a not for profit basis and are publicly available.

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**Questions for future research**

Can effective risk communication lead to behavioural change when the evidence supports specific outcomes?

Are there methods of presenting data uncertainty that can improve understanding, knowledge, and decision making?

**Tips for non-specialists**

Become familiar with tools that provide decision support for common consultations and use them as adjuncts to normal consulting

Consider using absolute risks when discussing risk reduction with patients

Direct patients to decision aids for interventions where more than one option is available and informed decision making depends on patients' personal preferences and values

**Additional educational resources***Resources for healthcare professionals*

NHS National Prescribing Centre ([www.npc.nhs.uk/patient\\_decision\\_aids/](http://www.npc.nhs.uk/patient_decision_aids/))—Large number of freely available patient decision aids that can be downloaded, printed, and used during consultations

*Resources for patients*

Option Grids ([www.optiongrid.co.uk/](http://www.optiongrid.co.uk/))—"Option grids" are brief tools that describe options for several commonly encountered healthcare decisions

Patient UK ([www.patient.co.uk/search.asp?searchterm=brief+decision+aid&searchcoll=All&x=0&y=0](http://www.patient.co.uk/search.asp?searchterm=brief+decision+aid&searchcoll=All&x=0&y=0))—Brief decision aids for a variety of conditions

## Figures

**The breast cancer risk assessment tool (www.cancer.gov/bcrisktool)**

**Risk factors**  
 Does the woman have a medical history of any breast cancer, ductal carcinoma in situ (DCIS), or lobular carcinoma in situ (LCIS)? NO  
 What is the woman's age? 50 years  
 What was the woman's age at the time of her first menstrual period? 14 years  
 What was the woman's age at the time of her first live birth of a child? 25-29 years  
 How many of the woman's first degree relatives (mother, sisters, or daughters) have had breast cancer? 0  
 Has the woman ever had a breast biopsy? NO  
 What is the woman's race/ethnicity? WHITE

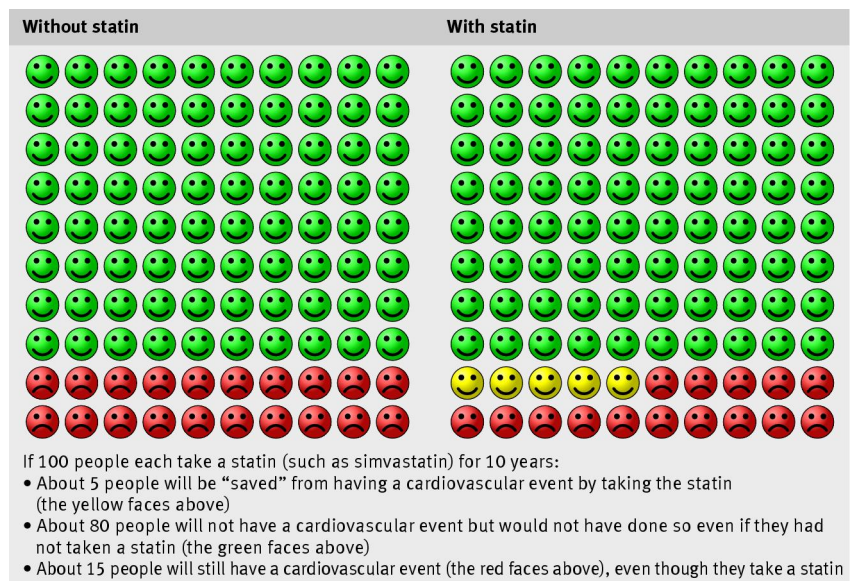
**Risk estimates**  
**Five year risk**  
 This woman (age 50): 1%  
 Average woman (age 50): 1.3%

**Explanation**  
 On the basis of the information provided, the woman's estimated risk for developing invasive breast cancer over the next 5 years is 1% compared with a risk of 1.3% for a woman of the same age and ethnicity from the general population. This calculation also means that the woman's risk of NOT getting breast cancer over the next 5 years is 99%

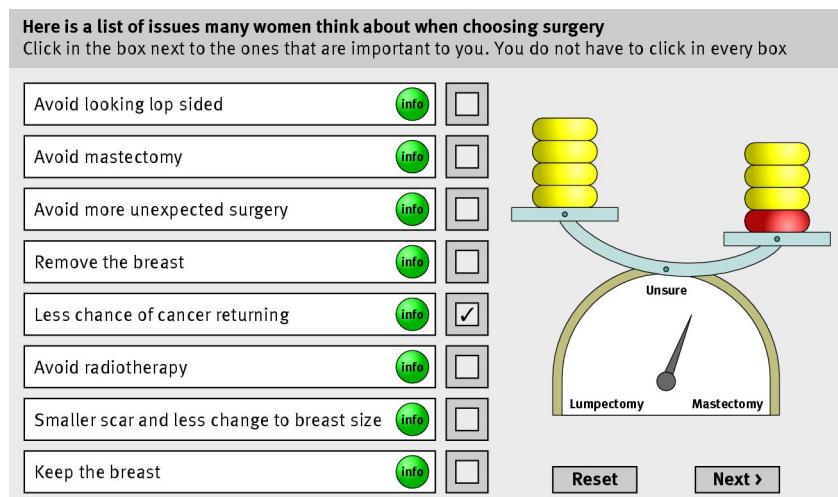
**Lifetime risk**  
 This woman (to age 90): 9.1%  
 Average woman (to age 90): 11.2%

**Explanation**  
 The woman's estimated risk for developing invasive breast cancer over her lifetime (to age 90) is 9.1% compared with a risk of 11.2% for a woman of the same age and ethnicity from the general population

**Fig 1** Calculating Ms Jones's risk of invasive breast cancer using her personal risk factors



**Fig 2** The NHS National Prescribing Centre provides pictographs to help explain the reduction in cardiovascular risk from taking statins in people with a moderate risk of a cardiovascular event (20% over 10 years). For more details see [www.npc.nhs.uk](http://www.npc.nhs.uk)



**Fig 3** Breast Cancer Decision Explorer (BresDex; www.bresdex.com). A decision aid to help women with breast cancer choose between mastectomy and breast conserving surgery

Intervention	Icon	Description
Beneficial	↑ ↑	For which effectiveness has been demonstrated by clear evidence from systematic reviews, randomised controlled trials, or the best alternative source of information, and for which expectation of harms is small compared with the benefits
Likely to be beneficial	↑ ?	For which effectiveness is less well established than for those listed under “beneficial”
Trade-off between benefits and harms	↑ ↓	For which clinicians and patients should weigh up the beneficial and harmful effects according to individual circumstances and priorities
Unknown effectiveness	? ?	For which there are currently insufficient data or data of inadequate quality
Unlikely to be beneficial	? ↓	For which lack of effectiveness is less well established than for those listed under “likely to be ineffective or harmful”
Likely to be ineffective or harmful	↓ ↓	For which ineffectiveness or associated harm has been demonstrated by clear evidence

**Fig 4** Presenting data uncertainty. Categories of evidence: an approach used by the *BMJ Clinical Evidence* series<sup>7</sup>