# Risk communication: Why, what and how?

Hermione Price

**One of the key roles of the GP with a special interest in diabetes is effective communication of the risks and benefits of a particular treatment or course of action (Rothman and Kiviniemi, 1999; Edwards et al, 2003). The aim of risk communication is to reduce uncertainty and confusion and to help people to choose a course of action, preferably one that will reduce risk (Edwards and Elwyn, 1999). If done well, risk communication provides an ideal opportunity to involve the individual in making decisions about their care, particularly when the healthcare professional has no clear preference regarding the choice made (Edwards, 2000). This article discusses the currently available evidence concerning risk communication to assist primary healthcare professionals with deciding how best to communicate risk to people in their care.**

**Article points**

1. Risk communication becomes ever more important in primary care where healthcare professionals are increasingly asked to identify individuals at risk of developing disease in the future.
2. In many circumstances the effect of risk on the individual may be quite different from that which the healthcare professional would expect or want.
3. The optimal method of conveying risk information is not known but the provision of personalised risk information is the only intervention to have been found to work consistently and to have been evaluated in primary and secondary care.

**Key words**

- Communication
- Psychological impact
- Risk assessment

Hermione Price is Clinical Research Fellow at the Diabetes Trials Unit, Oxford Centre for Diabetes, Endocrinology and Metabolism, University of Oxford, Headington.

Healthcare professionals need to translate raw data from clinical trials or risk calculators into information that an individual can understand and use to make an informed choice (Atkins, 1997; Edwards et al, 2002). Undoubtedly, there are challenges in translating scientific data into an acceptable form (Nic Gabhainn et al, 1999), but if this information is not communicated properly, the healthcare professional risks providing information that is misleading or inaccurate (Hollnagel, 1999).

Risk communication becomes ever more important in primary care where healthcare professionals are increasingly asked to identify individuals at risk of developing disease in the future. Often these individuals will have no symptoms and will not be aware that they are at increased risk of future ill health. One current example of this is the Government's recently launched vascular risk assessment programme (Davies et al, 2008), which recommends that all adults aged between 40 and 70 years undergo vascular risk assessment and estimation. Many individuals are likely to be identified as being at increased risk of vascular disease and it will fall to those working in primary care to explain to people what this means and what can be done about it.

The area of risk communication is vague and remains poorly researched, and even the government has acknowledged that at the moment there is no clear agreement on how best to communicate risk information (Davies et al, 2008). In addition, risk, in general, poorly understood.

## What is risk communication?

### What is a risk estimate?

A risk estimate is the probability that an individual without any current symptoms will develop a disease at some point in the future, or that an event will occur in relation to an existing condition.

### Certainty and uncertainty

Epidemiology is able to tell us the rates of disease in a population and also factors associated with increasing or decreasing likelihood of developing a condition or its complications. Epidemiology is not, however,

able to give us any indication if the person in front of us is the one in a hundred who develops a certain condition or outcome. This holds true even when the individual has been identified as being at increased risk (Hollnagel, 1999).

Communicating the concepts of probability and uncertainty that a particular behaviour or treatment will cause an effect are crucial to effective risk communication (Calman, 2002). Risks range from the hypothetical, where the risk is possible but there is no evidence of certainty, to the clearly identified, where certainty has been established and the level of risk is known. However, even when the level of risk is known the chance of an individual experiencing this risk remains a probability (Calman, 2002). For example, a healthcare professional discusses the need for statin therapy with a person with type 2 diabetes. The healthcare professional states that if 100 similar people take a statin for 1 year then 0.94 of them will have an acute coronary heart disease event. However, if all 100 decide not to take a statin, 1.47 of them will have an acute coronary event (Colhoun et al, 2004).

In addition, 1 in 1000 people taking a statin will experience myopathy and there is a hypothetical risk of death from rhabdomyolisis. It is not known if the person sitting in front of us will be one of the people that will be protected from an acute coronary heart disease event by statin therapy or if they will be one of the minority of people to develop myopathy, or the very rare person who develops rhabdomyolisis. Communicating this uncertainty is a difficult but key element of risk communication.

### Level of risk

The level of risk must be known for an individual in relation to the rest of the population. Are they at higher or lower risk than average?

## The effect of risk on the individual

The way in which people respond to risk information will differ and may not be the same as the healthcare professional. Individuals perceive and react to risk in different ways (Price et al, 2009).

In many circumstances the effect of risk on the individual may be quite different from that which the healthcare professional would expect or want. When this is the case, the risk communication consultation must attempt to address this with the aim of helping an individual to make an informed decision. If a particular behaviour (for example, continuing to smoke cigarettes) is clearly associated with a hazard (for example, lung cancer) an individual may choose to continue to smoke despite the evidence presented. In this case they should be made aware of the consequences of their decision (Calman, 2002). In addition, it needs to be made clear that in most cases, even with optimal lifestyle or therapy, the individual will still remain at some degree of risk.

The healthcare professional needs to explain clearly what is achievable (how much of their risk is reducible). For example, in the case of cardiovascular disease, age (Stamler et al, 1993) and sex (Goldacre et al, 2006) are major risk factors, and these cannot be altered. The risk, however, can be reduced by treating modifiable risk factors including lowering cholesterol levels and treating high blood pressure. In the case of quitting smoking, however, an individual can return to the usual risk of lung cancer for a person of their age and sex after 10 years (Peto et al, 2000).

### Adverse psychological effects of communicating risk

Studies have been conducted in a range of future conditions, including cardiovascular disease and Huntington's disease, and have looked at different psychological aspects over the short- (<1 month) and long-term in individuals receiving both positive and negative risk assessment results.

The results of a total of 54 studies have been pooled in an attempt to shed light on these questions (Shaw et al, 1999). Unfortunately, the quality of the studies included varied, making it difficult to draw clear conclusions. For example, only two studies randomised their participants and each study measured psychological distress in a different way (Shaw et al, 1999). However, the authors concluded that when an asymptomatic individual receives adverse information about the

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1. The idea that psychological distress is short-lived is supported by a study that investigated anxiety in people 3 years after them being told if they carried the defective gene for cystic fibrosis or not. Levels of anxiety were no different in those informed they had the gene compared with those informed that they did not.
2. Evidence suggests that people prefer risk to be expressed in terms of words rather than numbers, but that there is wide variation in how verbal expressions of risk are interpreted.
3. A review investigating how best to use graphics to display risk information has concluded that the graphical features that increased understanding were not the same as those that altered behaviour or intentions.

future risk of developing a disease, some anxiety and distress is inevitable. This does not appear to persist long-term and can be reduced by interventions aimed at minimising these effects (Shaw et al, 1999).

Interestingly, disease type and severity did not seem to make a difference to the psychological distress experienced, with similar results seen for preventable and treatable conditions, such as type 2 diabetes and cardiovascular disease, as for certain and more debilitating conditions, such as Huntington's disease (Shaw et al, 1999).

The idea that psychological distress is short-lived is supported by a study that investigated anxiety in people 3 years after them being told if they carried the defective gene for cystic fibrosis or not (Axworthy et al, 1996). Levels of anxiety were no different in those informed they had the gene compared with those informed that they did not. However, those who were told they did carry the gene reported lower levels of current health even though they had been told that carrying the gene did not have any implications for their own health.

## Methods of communicating risk

### Can we communicate risk using words instead of numbers?

Evidence suggests that people prefer risk to be expressed in terms of words rather than numbers, but that there is wide variation in how verbal expressions of risk are interpreted (Misselbrook and Armstrong, 2002; Ohnishi et al, 2002). In one study, researchers investigated how 22 different expressions of risk were interpreted by patients and doctors. These included words such as "infrequent", "sometimes", "often", "common" and "typical". For 17 of these phrases, the ways in which they were interpreted varied so much so that they could not be used to communicate risk (Nakao and Axelrod, 1983).

The European Union has also tried to develop a standardised risk vocabulary ("very common", "common", "uncommon", "rare" and "very rare"), but again patient interpretation did not correspond with the risks they were intended to convey (Paling, 2003). At present, there is no satisfactory way of communicating risk to people using words instead of numbers.

### Numeracy

Numeracy, or the ability to do basic mathematics, is another important consideration. People can find interpreting decimals and fractions difficult. One study found that participants interpreted 1286/10 000 as more risky than 24.14/100 (Edwards et al, 2002). While numbers cannot be replaced with words for the reasons outlined above, healthcare professionals can present risks in different ways to try and aid understanding.

For example, a risk of 20% could be described as a one in five chance, or odds of four to one. However, the way in which risk information is presented has been shown to influence decision-making (Misselbrook and Armstrong, 2001). People with diabetes are more likely to accept a treatment when risk is presented as a relative risk reduction rather than as a number needed to treat, personal probability of benefit or absolute risk (Misselbrook and Armstrong, 2001).

It is tempting to use relative risks to try and emphasise the need for a treatment. For example, a treatment that reduced the risk of a stroke from 2% to 1% would result in a 50% relative risk reduction. However, the initial absolute risk (2%) is so small that an individual may decide it is not worth taking a tablet every day to achieve a 1% absolute risk reduction. The use of relative risks is controversial as some people feel they overinflate numbers and are meaningless unless the underlying rate (absolute risk) is known (Atkins, 1997, Hollnagel, 1999), and suggest the risk of developing a disease (2%) should be compared with the risk of not developing a disease (98%) (Hollnagel, 1999).

### What about using graphs and charts?

A review investigating how best to use graphics to display risk information concluded that the graphical features that increased understanding were not the same as those that altered behaviour or intentions (Ancker et al, 2006). In general, people preferred simple graphs, even if this was at the expense of accuracy. However, crowd-charts (a proportion of shaded-in stick-men or faces) have been found to be disliked by patients for being confusing, unconvincing and busy, and bar charts were similarly unpopular

for lacking impact, being too dry, too statistical and too scientific (Edwards et al, 2002). Most graphical representations of risk have been found to require a degree of expertise or instruction to aid understanding (Ancker et al, 2006).

## Recall of risk information

Telling a person once that they are at increased risk of disease may not be adequate. It appears that few people are able to remember their risk when asked at a later date. In the study by Axworthy (1996), only 43% of individuals negative for carrying the cystic fibrosis gene and 80% of those carrying it could correctly recall their cystic fibrosis gene status 3 years later.

Recall of risk information has also been found to be poor in individuals with type 2 diabetes who were told their personal risk of future coronary heart disease (Asimakopoulou et al, 2007). This apparent failure to retain personalised risk information could harm an individual's ability to make informed decisions. Healthcare professionals should be alert to the need to repeat risk information periodically to account for this.

## Tailored risk information

Individually tailored risk information has shown modest success in increasing the uptake of mammography by women. In one study, women were sent a questionnaire asking them about risk factors for breast cancer (Curry et al, 1993). Once a questionnaire had been returned, the information it contained was used to tailor a mammography invitation letter according to their own level of risk.

This tailored information only increased mammography attendance in those with a family history of breast cancer and not in those identified as being at increased risk for other reasons. The design of this study did, however, have some problems, and this may have affected the results.

Women who did not return their questionnaire were included in the study and a proportion of women who did return the questionnaire did not actually meet the inclusion criteria for the study (for example, because of a personal past history of breast cancer). Personalised information regarding cholesterol levels, however, has been shown to be successful at changing behaviours designed to reduce cholesterol levels, and was described by participants as engaging and memorable – a wake-up call and frightening but important (Goldman et al, 2006).

The Department of Health commissioned a review of risk communication and concluded that the provision of personalised risk information was the only risk communication intervention to have been found to work consistently and to have been evaluated in primary and secondary care (Edwards, 2007).

## Risk factors without symptoms

Talking to people about cardiovascular disease risk can be particularly difficult because many of the risk factors rarely cause symptoms, for example high blood pressure or high cholesterol.

A study has shown that risk factors without symptoms are not considered to be a disease and that people rarely associate high cholesterol with risk of cardiovascular disease (Durack-Bown et al, 2003). This is supported by a survey which found that cholesterol levels were viewed as unstable and unpredictable and not perceived as a disease (Durack-Bown et al, 2003).

The risk communication consultation should attempt to address the fact that although an individual may not have any symptoms and feel well at present, they may still be at risk of future ill health.

## Knowledge gaps

Despite the many studies that have been conducted to investigate risk communication, it still remains unclear which individuals are most likely to experience distress as a result of risk information and under what circumstances (Shaw et al, 1999). It also remains inconclusive how best to frame risk information, the setting in which it should be given and the clinical topics in which it is most effective. Many of the trials that have been conducted are of poor quality and as yet, efficacy has not been shown in routine clinical practice.

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## Conclusion

The optimal method of conveying risk information is not known, but the provision of personalised risk information is the only intervention to have been found to work consistently and to have been evaluated in primary and secondary care. At present this appears to be the most useful method for communicating risk to individuals and should be used wherever possible. ■

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