

# Risk communication in type 2 diabetes

Koula Asimakopoulou

## Article points

1. Communication of cardiovascular disease risk is central to patients understanding the complications of type 2 diabetes.
2. Despite the substantial literature on risk understanding and communication, the risk of CVD in diabetes has attracted little attention.
3. The UKPDS risk engine was used to assess people's risk perceptions compared with their actual risk, and their mood was also monitored.
4. Many risk factors were found to affect people's risk perception, including age, gender, education, self efficacy, anxiety, social trust and personality.
5. Presenting people with individualised risk information may be a reliable method of correcting their pessimistic beliefs and may lead to subsequent decisions about lifestyle changes in order to self-manage the condition.

## Key words

- Risk communication
- Health cognition models
- Risk perception

Koula Asimakopoulou is a Chartered Health Psychologist and Lecturer in Health Psychology at King's College, London. For correspondence, please email koula.asimakopoulou@kcl.ac.uk.

Communication of cardiovascular disease risk is central to patient understanding of the complications of type 2 diabetes and subsequent decisions about lifestyle changes in order to self-manage the illness. The present article discusses current research on the importance of discussing risk information, the factors that might impinge on successful risk communication and the limited research on risk communication in people with type 2 diabetes. It concludes with practical suggestions on how cardiovascular risk might be best communicated to people with diabetes.

Risk was defined by the British Medical Association (BMA) as 'the probability that something unpleasant will happen' (BMA, 1990). This definition conveys two major points; one is that there is a degree of uncertainty surrounding the event under discussion and secondly that, if the event happens, it is unlikely to have pleasant consequences.

Risk of complications is an important area that normally features in the education programmes of people newly diagnosed with diabetes. One major complication of diabetes is cardiovascular disease (CVD). CVD is well known to be the major cause of mortality in people with diabetes (Wannamethee et al, 2004). Data from a UK prospective study (Roper et al, 2002) showed that middle-aged people with diabetes were five times more likely than their diabetes-free counterparts to experience cardiovascular morbidity and mortality. Such findings have led experts in the field to go as far as to describe diabetes as 'a state of premature cardiovascular death' (Fisher, 2003). It follows that communicating cardiovascular risk to

people with type 2 diabetes should be an issue central to disease management.

## Why is risk information important?

In a broad sense, risk communication is the social process of informing people about hazards, with the aim of enabling them to make decisions about risk issues, and influencing them towards behavioural change (Rohrmann, 2000). In health settings, the importance of risk communication rests on concepts such as informed choice and patient empowerment; the current NHS agenda is clearly in favour of patient choice (DoH, 2004) with people being encouraged to make more, and better, informed choices about their health. This emphasis on choice is closely related to the ethics and morals of modern medicine; as Thomson and colleagues (2005) argue, there is an ethical and moral need to engage people in decisions to do with their health and to do so in line with their values, preferences and expectations.

Furthermore, and related to this argument, the now well-established National Service Framework (NSF) for

**Page points**

1. The idea behind some health cognition models is that higher-risk perceptions may be associated with greater intentions to adopt precautionary health behaviours.
2. The health belief model proposes that health-related behaviour is a function of a person's perceptions of likelihood and severity of a health threat combined with an assessment of the ease of taking steps to avoid the health threat.
3. Amongst numerous factors ranging from age, gender and education to self efficacy, anxiety and social trust, personality has been shown to predict people's perceptions of a range of risks.

diabetes (DoH, 2001) advocates patient empowerment. Empowerment is about giving people the necessary tools and information to take on full responsibility for their illness and be in a position to make well-informed and rational decisions about their diabetes self care (Funnel et al, 1991). Clearly, understanding of cardiovascular risk as a result of diabetes has to be an important tool, which may help people shape their lifestyle change efforts in self managing the illness.

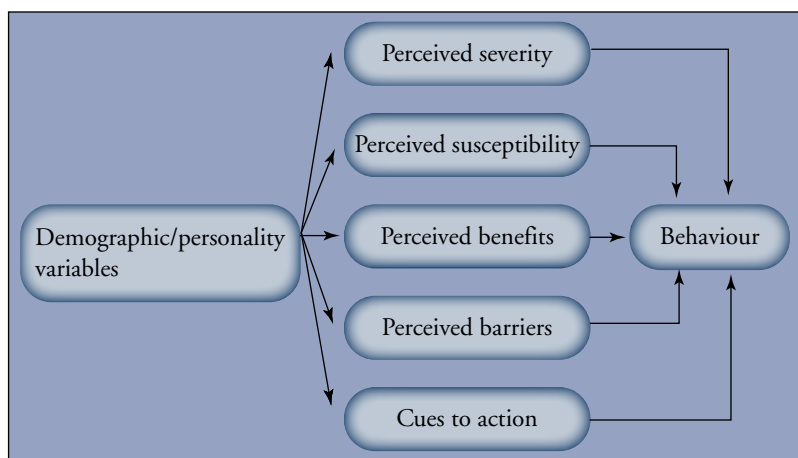
Such a view is supported by health psychology theory, as summed up in health cognition models. These models seek to propose factors that may play a role in understanding the choices people make in the uptake and maintenance of healthy behaviours. The idea behind some of these models is that higher-risk perceptions may be associated with greater intentions to adopt precautionary health behaviours (Klein, 2002). Becker and Rosenstock's (1984) health belief model (HBM) is one such example (*Figure 1*). This HBM proposes that health-related behaviour is a function of a person's perceptions of likelihood and severity of a health threat combined with an assessment of the ease of taking steps to avoid the health threat. For example, if a person with diabetes thought that: the consequences of stroke are extremely unpleasant (high severity); their risk of having a stroke as a result of

diabetes was elevated (high susceptibility); and reducing salt in their diet was an easy and effective strategy in minimising risk (high benefits/low barriers), it is suggested that they would be more motivated to try and reduce salt in their diet than someone who thought that: their cardiovascular risk and consequences were, respectively, low and modest; reducing salt in their diet was difficult; and the benefits of such a reduction would be negligible. Coupled with demographic and personality influences, as well as factors such as social influence, peer pressure and education campaigns (cues to action, *Figure 1*), the model provides a reasonable framework for predicting health behaviours and gives risk appraisal a central role in it.

**What factors may affect patient risk perception?**

It is becoming clear that understanding of risk is not a straightforward process; this is because it involves the amalgamation of objective (the actual risk) and subjective information (How do I feel about it? Do I think this particular risk is important? Do I have the resources to deal with it?). Risk perception is therefore likely to vary from one individual to another. An optimistic person who tends to see the glass as 'half full' is likely to differ in their attitudes to risk compared with a person who sees the glass as 'half empty'. Amongst numerous factors ranging from age, gender and education to self efficacy, anxiety and social trust (Chauvin et al, 2007), personality has been shown to predict people's perceptions of a range of risks (Bouyer et al, 2001; Chauvin et al, 2007).

At the same time, it has been well demonstrated (Weinstein, 1980; 1982) that people can hold substantially inaccurate beliefs about their risks; in a phenomenon termed 'unrealistic optimism', it has been shown that people reliably believe that their risk of experiencing adverse events is much lower than that of 'the average person'. There are several reasons behind



*Figure 1. Becker and Rosenstock's health belief model (1984).*

this phenomenon and they include lack of experience with the risk event, the belief that if something bad hasn't happened yet it is unlikely to happen in the future and inaccurate beliefs relating to the person's ability to control events in an attempt to enhance their current self esteem (Weinstein 1987, Weinstein and Klein, 1996).

Work on people's beliefs about risks surrounding major illnesses has further produced very interesting results. We know that diseases that are dreaded, whose mechanisms are not well understood and that are thought not to be under people's personal control, such as cancer, are rated as riskier and worry people more than illnesses that are perceived as less dramatic (Covello, 1991). Women, for example, rate their chances of dying from breast cancer higher than heart disease (Covello and Peters, 2002), although the mortality rate for heart disease in women is nine times greater than that of breast cancer (Murphy, 2000). On the other hand, health risks relating to illnesses that are less dreaded, whose mechanisms are better understood and that are perceived to have controllable causes are underestimated (Covello and Peters, 2002).

### Risk communication in diabetes

Despite the substantial literature on risk understanding and communication, both in general and health settings, the perception and communication of CVD risk in diabetes has attracted little attention. To the best of the author's knowledge, there is little work that has systematically explored people with diabetes' perceptions of cardiovascular risk. Nevertheless, Frijling and colleagues (2004) examined absolute risk perceptions surrounding myocardial infarction and stroke in a sample of people with hypertension or diabetes, and compared these estimates with actual risk perceptions using baseline data from the Framingham study. The study produced some very interesting results; a quarter of their sample of 1557 individuals was unable to provide any cardiovascular risk estimate. Of those

who did, most tended to overestimate their risk by more than 20%. The authors concluded that people's perception of their cardiovascular risk is inadequate and advised that healthcare professionals ought to routinely provide more, and better, risk information to their patients.

A study considering how risk information could be disseminated in patient-friendly ways was recently undertaken by Edwards and colleagues (2006). The authors used a web interface to provide people with diabetes information on the risks and benefits associated with either tight or usual glycaemic control. In a randomised controlled trial, the amount and type of information made available to patients was manipulated and data on their preferences were recorded. The overall findings were that people found the provision of risk information using bar charts helpful, but the use of anchoring (a technique whereby risk data are related to everyday life events that the individual may be familiar with, such as the risk of a road accident) confusing and unhelpful. They also reported a preference for a modest (rather than large) amount of overall information and found the combination of several different ways of presenting the same information overwhelming. The authors concluded that 'the challenge is to provide more information, in appropriate and clear formats, but without risking information overload' (Edwards et al, 2006).

### UKPDS risk engine

The previous study did not adjust the risk information provided to take into account the actual individualised risk profiles, although individualised risk presentation is known to be an advantageous strategy (Roach and Marrero, 2005; Thomson et al, 2005). By contrast, our group has recently undertaken work examining individualised risk communication in people with type 2 diabetes using the UKPDS risk engine (Asimakopoulou et al, 2007a; Asimakopoulou et al, 2007b),

### Page points

1. Diseases that are dreaded, whose mechanisms are not well understood and that are thought not to be under people's personal control, such as cancer, are rated as riskier and worry people more than illnesses that are perceived as less dramatic.
2. Despite the substantial literature on risk understanding and communication, the risk of CVD in diabetes has attracted little attention.
3. In a sample of people with hypertension or diabetes most tended to overestimate their risk of myocardial infarction and stroke by more than 20%.
4. People found the provision of risk information using bar charts helpful. They also have a preference for a modest amount of overall information and find the combination of several different ways of presenting the same information overwhelming.

### Page points

1. The author used the UKPDS risk engine to calculate individualised risk information and also to present people with graphs reflecting their actual risks.
2. Participants were hugely pessimistic in their cardiovascular risk estimates and this was the case more for stroke than CHD.
3. Interestingly, the greater the discrepancy between their perceived and actual risk (the more inaccurate their perception), the better their mood.
4. The implications of this work on risk communication rest on the need for the provision of accurate, individualised risk information in an attempt to correct people's unduly pessimistic views of their cardiovascular risks and any impact such views might have on their motivation to self manage.

a software program specifically designed for use with people with type 2 diabetes (available at <http://www.dtu.ox.ac.uk/index.php?maindoc=/riskengine/>). The engine was developed on the basis of data collected from 53 000 people with type 2 diabetes recruited into the UKPDS, the UK's largest prospective study of people with type 2 diabetes to date (UKPDS, 1998). Although not routinely used in clinical practice, its ease of use and reliability of measurement make it a sound tool for individualised risk prediction in uncomplicated diabetes (Roach and Marrero, 2005). We used the software to calculate individualised risk information and also to present people with graphs reflecting their actual risks. In addition to individualised cardiovascular risks, we also assessed people's perceptions and feelings about these risks. Therefore, we initially measured people's self-reported perception of their risk of coronary heart disease and stroke as well as their mood surrounding these risks. We then compared these perceptions with actual risks presented in one of three time frames: 1, 5 or 10 years. Having explained to each person what their actual risk was separately for CHD and stroke, and having checked that they understood actual risks, we re-assessed their mood. We contacted participants again 6 weeks later and asked them to recall what their actual risks were. We found that as in Frijling's study, participants were hugely pessimistic in their cardiovascular risk estimates and this was the case more for stroke than CHD. Unsurprisingly, their mood was also negative; again more so for stroke. Interestingly, we also found that the greater the discrepancy between their perceived and actual risk (the more inaccurate their perception), the better their mood. In all time frames, we succeeded in reducing participants' originally inflated perceptions of CHD and stroke, but the degree of success differed according to time frame. Time frame also affected participants' recall of risk of CHD and stroke at 6 weeks post consultation, with

risk recall in the 10-year time frame regressing back to original, inflated estimates for both CHD and stroke. A paper including statistical analyses of these data is in preparation. The implications of this work on risk communication between healthcare professionals and people with diabetes rest on the need for the provision of accurate, individualised risk information in an attempt to correct people's unduly pessimistic views of their cardiovascular risks and any impact such views might have on their motivation to self manage.

It would appear that the limited research on risk communication in diabetes calls for routine individualised risk information using software such as the UKPDS risk engine (Roach and Marrero, 2005; Asimakopoulou et al, 2007a; Asimakopoulou et al, 2007b). So how feasible would the routine communication of cardiovascular risk be to people with type 2 diabetes in the primary care setting?

### Communicating cardiovascular risk to people with diabetes in primary care settings: A practical guide

The general principles governing successful communication of risk information in health settings, discussed in detail by Edwards and colleagues (2001; 2002) Paling (2003) and, more recently, Thomson and colleagues (2005), apply here.

First, given that risk communication very much relies on the skills of the clinician, it has been suggested that 'the most powerful preliminary move is for the clinician to display competence, a caring approach and a willingness to discuss the patient's own expectations and fears... [this] enables people to ask questions and discuss risks fully, providing the greatest opportunity to enhance understanding' (Thomson et al, 2005).

Second, and in line with the results of empirical research on the matter (Edwards et al, 2000; Roach and Marrero 2005; Asimakopoulou et al, 2007a), it is suggested that people are presented with

individualised rather than general risks. To this end, software such as the UKPDS risk engine is a quick and efficient means of obtaining such individualised risk estimates as the data it requires to produce these individualised estimates should normally be readily available within primary care settings (Figure 2).

The language of risk (for instance, how risks are presented to individuals) has attracted considerable attention (see volume 327 of the BMJ [2003] for numerous papers on the subject). It has been suggested that people probably find numerical risks; for example: 'your risk of stroke is 2%' is easier to conceptualise than qualitative ones, such as: 'your risk of stroke is low' (Hallowell et al, 1997; Bogardus et al, 1999). It has also been argued that comprehension is probably better if the risk is presented in absolute terms, such as: 'your risk of having a stroke in the next year is 2%', rather than relative terms; for instance, 'taking up exercise will reduce your cardiovascular risk by 25%' (Edwards et al, 2002; Gigerenzer and Edwards, 2003). Graphical ways of presenting risks have also been explored (Edwards et al, 2002) leading to the suggestions that simple bar charts are probably understood more easily than any other graphical presentation method (Edwards et al, 2006). Presenting risks in more than one way in order to meet the needs of different individuals has also been advocated (Thomson et al, 2005), although the presentation of risks in more than a couple of ways has been found to be problematic (Edwards et al, 2006).

Communicating risks can be a complex task to perform. Even if such information is communicated effectively by clinicians, evidence suggests that patients (and, surprisingly, clinicians) may have distorted views as to what went on in a diabetes consultation (Parkin and Skinner, 2003; Skinner et al, in press). For this reason, it has been suggested (Asimakopoulou, 2007; in press) that healthcare professionals should consider routinely checking patient

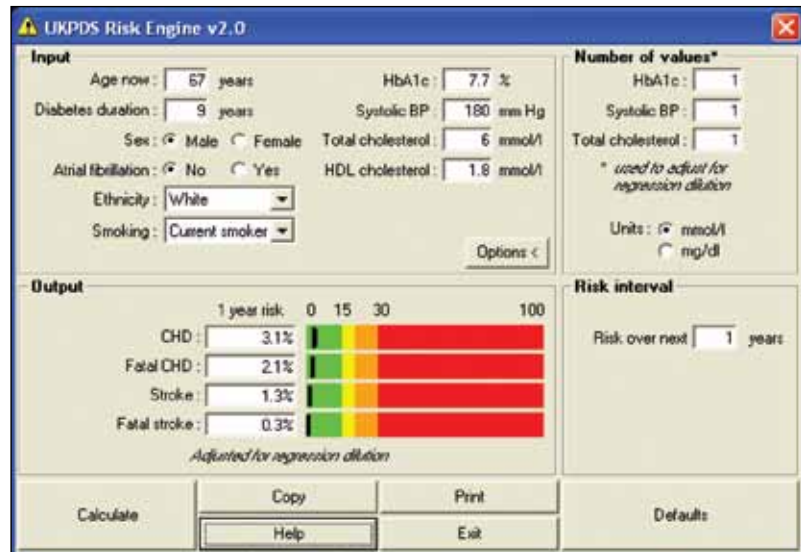


Figure 2. The UKPDS risk engine (adapted with permission from Stevens et al, 2001).

understanding of the consultation key points to ensure that important information, such as one's risk, has been understood and is likely to be remembered.

### Conclusion

Informing people with diabetes about their cardiovascular risk is an important task that is central to enhancing patient understanding and, hence, the chance of making empowered informed choices about their diabetes self management. People have been found to hold erroneous, pessimistic views about their diabetes-related risks that may have adverse effects on motivation to self care. Presenting people with individualised risk information along the lines discussed may be a reliable method of correcting such pessimistic beliefs. ■

- Asimakopoulou K (2007) Empowerment: are we ready to test assumptions? *European Diabetes Nursing (In press)*
- Asimakopoulou K et al (2007a) *Diabetic Medicine* 24(S1): 96
- Asimakopoulou K et al (2007b) *Diabetic Medicine* 24(S1): 97
- Becker MH, Rosenstock IM (1984) Compliance with medical advice. In: Steptoe A and Mathews A (Eds) *Healthcare and Human Behaviour*. London: Academic Press
- Bogardus ST et al (1999) *JAMA* 281: 1037–41
- Bouyer M et al (2001) *Risk Analysis* 21: 457–65

### Page points

1. Simple bar charts are probably understood more easily than any other graphical presentation method.
2. Presenting risks in more than one way in order to meet the needs of different individuals has also been advocated.
3. Healthcare professionals should be routinely checking patient understanding of the main points of the consultation, rather than assuming that they have understood and will remember the information conveyed.
4. Presenting people with individualised risk information along the lines discussed may be a reliable method of correcting such pessimistic beliefs.

- British Medical Association (BMA; 1990) *Guide to Living With Risk*. Penguin, London
- Chauvin B et al (2007) *Risk Analysis* 27: 171–85
- Covello V (1991) Risk comparison and risk communication: Issues and problems in comparing health and environmental risks. In: Kasperson R, Stallen P (Eds). *Communicating risks to the public*. Kluwer, New York
- Covello VT, Peters RG (2002) *Health Communication* 14: 377–95
- DoH (2001) *National Service Framework (NSF) for Diabetes: Standards*. DoH, London
- DoH (2004) *Better information, better choices, better health is a programme of action: Putting information at the centre of health*. DoH, London
- Edwards A et al (2000) *Medical Decision Making* 20: 290–7
- Edwards A et al (2001) *Journal of Health Communication* 6: 61–82
- Edwards A et al (2002) *BMJ* 324: 827–30
- Edwards A et al (2006) *Patient Education and Counseling* 63: 336–49
- Fisher M (2003) *Heart* 89: 28–30
- Frijling BD et al (2004) *Patient Education and Counseling* 52: 47–53
- Funnell MM et al (2001) *Diabetes Educator* 17: 37–41
- Gigerenzer G, Edwards A (2003) *BMJ* 327: 741–4
- Hallowell N et al (1997) *Journal of Genetic Counseling* 6: 269–86
- Klein WM (2002) *Risk, Decision and Policy* 7: 193–202
- Murphy SL (2000) *National Vital Statistics Reports* 48: 1–105
- Paling J (2003) *BMJ* 327: 745–8
- Parkin T, Skinner TC (2003) *Diabetic Medicine* 20: 909–14
- Roach P, Marrero D (2005) *Vascular Health Risk Management* 1: 301–7
- Rohrmann B (2000) *The Australasian Journal of Disaster and Trauma Studies*. Available from: <http://www.massey.ac.nz/~trauma/issues/2000-2/rohrmann.htm> (accessed 25.01.03)
- Roper NA et al (2002) *Diabetes Care* 25: 43–8
- Skinner TC et al (2007) *Diabetic Medicine* (in press)
- Stevens RJ et al (2001) *Clinical Science* 101: 671–9
- Thomson R et al (2005) *Clinical Medicine* 5: 465–9
- UK Prospective Diabetes Study (UKPDS) group (1998) *Lancet* 352: 854–65
- Wannamethee SG et al (2004) *Heart* 90: 1398–403
- Weinstein ND (1980) *Journal of Personality and Social Psychology* 39: 806–20
- Weinstein ND (1982) *Journal of Behavioral Medicine* 5: 441–60
- Weinstein ND (1987) *Journal of Behavioral Medicine* 10: 481–500
- Weinstein ND, Klein WMP (1996) *Journal of Social and Clinical Psychology* 15: 1–8