

## I. Communicating and understanding risk

# Understanding risk and lessons for clinical risk communication about treatment preferences

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### Abstract

**This paper defines risk and its component elements and describes where clinical practice may be starting from in terms of what is reported in the literature about understanding risks and the information requirements of consumers. It notes briefly how theoretical models in the literature contribute to our understanding by providing a basis from which to summarise current evidence about the effects of healthcare interventions which address risks and risk behaviour. The situations or types of interventions in which risk related interventions are most effective are described, but a significant caveat is noted about the types of outcomes which have been reported in the literature and which are most appropriate to evaluate. The effects of “framing” variations in the information given to consumers and the ethical dilemmas these raise for a debate about “informed choice” in healthcare programmes are discussed. In response to both the practical and ethical dilemmas that arise from the current evidence, some of the areas where attention should be focused in the future are outlined so that both health gain and informed choice might be achieved. These include the use of decision aids, although their implementation is not widespread at present. Lessons from the current literature on how further progress can be made towards improved communication, discussion between professionals and consumers, and enhancing informed choice are discussed.**

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### Defining risk

Risk is the probability that a hazard will give rise to harm.<sup>1</sup> Naturally, therefore, when thinking about how risks are interpreted, two elements must be addressed. The first is the probability of it happening. How the language or statistics are perceived by the individual may vary, and some of the contributory factors to this variation will be discussed below. The term “subjective probability” describes this component of risk interpretation.<sup>2</sup> The second

### Key messages

- Greater flexibility is required in matching information about treatments or care to the needs of individual consumers.
- The potential to manipulate consumer decisions by framing manipulations is great and should be minimised.
- Clinicians, researchers, and policy makers should note the potential for more informed choices by individual consumers to result in lesser or greater use of services; in some situations this may be less likely to maximise health gain in the population.
- Decision aids are being developed widely and offer scope to help achieve informed decision making and greater involvement of consumers in their health care. Continuing evaluations are required, assessing their effects on health outcomes, resource use, and whether informed choices and satisfaction with decision making have been achieved.

component concerns the actual harm, and its severity for that individual. The importance or value placed on the adverse event, such as developing breast cancer, may also vary from one individual to another according to their knowledge and personal experiences, and these values may be termed “outcome utilities”.<sup>3</sup> Other terms used for the concept of severity include “adversity” and “burden”.<sup>3,4</sup> From this abstract angle, it appears that discussion of risks and provision of information to healthcare users should address both the probabilistic aspects and the importance and nature of the adverse events being described. However, putting this into practice is rather more complex, and we will examine what is currently reported in the literature about consumers’ information needs and the content of risk related discussions in clinical practice as they seek to express their treatment preferences.

### The starting point

Some healthcare professionals spend much of their time discussing the harms and benefits of treatments with their “consumers”,<sup>5</sup> which can take the form of describing the broad advantages or disadvantages of different options.

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Alternatively, it may involve the specific use of numerical data about the potential outcomes of choosing one treatment or another.<sup>9</sup> In reality, data are rarely available to professionals when needed,<sup>7</sup> so the relevant information is often not being used to maximum effect. Even when the information is available, professionals are unclear about how best to discuss the harms and benefits of treatment most effectively with users.<sup>7</sup> There are certainly great risks of misleading users which depend on how the information is presented.<sup>8</sup> Addressing these difficulties is crucial if quality in healthcare consultations is to be enhanced.

#### INFLUENCE OF RISK INFORMATION ON CONSUMERS

There is relatively little theoretical work specifically relating to communication about risks in the healthcare setting, although some practical work has been done. The interpretation of risks varies greatly,<sup>9</sup> with wide ranges in the meanings or numerical values attributed to verbal descriptions of risks (“rarely”, “sometimes”, “often”, and so on). For example, the term “frequent” was expressed on average as equivalent to nearly 70% in one study looking at information about the probabilities of harm and benefit from treatments, but with a wide range around this figure of 30–90%.<sup>10</sup> Wide variations in the interpretation of numerical data among physicians have also been described.<sup>11</sup>

Studies in the literature suggest that most people usually prefer numerical presentation of information, but approximately one third of consumers prefer verbal descriptions.<sup>12–15</sup> The type of information preferred and how people understand numerical information is affected by several factors, including the severity of the illness or other outcome concerned, and characteristics such as age, educational level, health status, and recent experience of illness.<sup>14</sup> Single figures presented in isolation—for example, one in 10 000—may be interpreted differently from when presented in a list of sequential risks. Presenting single figures without others with which to compare them may lead to over-weighting of low probabilities and under-weighting of high probabilities.<sup>15</sup>

Furthermore, people differ not just in their interpretation of the language of risk (different evaluation of the same terms), but also in the meaning or significance they attach to different outcomes.<sup>16</sup> The “utilities” or values that people place on different outcomes are likely to affect their use of the risk information in modifying or not modifying their own risks. For example, people’s understanding of the term “breast cancer” and the significance they attach to it may affect the degree to which they are motivated to choose to enter screening programmes, even if the same information is presented to all such consumers.

#### THEORETICAL MODELS IN THE LITERATURE

There is a considerable theoretical base in the literature for understanding risk (see also paper by Lloyd in this supplement<sup>17</sup>). The usual conceptual framework for this derives from two

main strands—cognitive psychology and decision making theory. In general, the models seek to provide an understanding of how individuals perceive risk and how this influences behaviour. These models frequently attribute consequences in behaviour change to two underlying dimensions: an individual’s perception of the *value* of an outcome presented in a health recommendation and the perceived *threat* presented by the outcomes in the recommendation.

The Health Belief Model (HBM), the Theory of Reasoned Action, the Theory of Social Behaviour, and the Prospect Theory all emphasise the perceived value of a presented consequence.<sup>18–19</sup> The Transtheoretical Model (“stages of change”) is another model in which interpretation of the likelihood of behaviour change is understood in terms of an individual’s readiness to change, and interventions may be targeted accordingly.<sup>20</sup> Many of these models are indeed the basis for planning several risk communication interventions.

#### Effects of interventions

To summarise the effects of interventions addressing risk and risk behaviour, we refer to a systematic review of the literature.<sup>21</sup> This review sought to identify effective risk communication interventions and then to identify the characteristics of the most effective interventions—the “effect modifiers”. Ninety seven studies were included in the review. Modest beneficial effects of the interventions were seen across a range of clinical topics (mean effect size 0.3; funnel plot midline of effect sizes approximately 0.15). This is equivalent, for example, to a study demonstrating that adherence to a screening programme increased from 70% to 83% with the introduction of a risk communication intervention.

#### MOST EFFECTIVE RISK COMMUNICATION

Two key “effect modifiers” were identified—namely, “treatment choice” clinical topics and the use of individualised (calculated) risk estimates in the risk communication process. The treatment choices included topics such as cholesterol lowering therapy, blood pressure therapy, and hormone replacement therapy. Risk communication interventions were more effective in these situations, where consumers were making decisions or expressing treatment preferences, than in studies which attempted to modify risk behaviour such as uptake of screening tests or smoking cessation.

#### GOALS OF CLINICAL INTERVENTIONS

In the treatment choices studied, professionals may often be close to “equipoise”—that is, not having a clear preference about which treatment (or no treatment) the consumer chooses. In risk behaviour modification programmes, professionals often have a clear aim—namely, to enhance uptake of tests or reduce risk exposure. This does not sit comfortably with the notion of enhancing “informed choice”<sup>22</sup> but it is an important dilemma that should be resolved. To date, studies commonly report changes in perhaps more objective outcomes such as behavioural or health outcome measures.<sup>23</sup> In

general, the studies have not evaluated whether risk communication has achieved improvements in understanding among consumers.

In keeping with the spirit of partnership and “evidence based patient choice” now emerging,<sup>24 25</sup> perhaps the professional goals of communication should be to enable “informed choices” by consumers rather than simply to modify behaviour. This may be in spite of the fact that conventional public health gains from these newer approaches could be smaller in some situations. There is a potential conflict between allowing greater choice for consumers and some healthcare policy that is directed more towards standardised healthcare provision. Resolving this conflict will require explicit debate between the stakeholders with recognition of the implications. Wider consumer involvement may result in greater variations in treatment or care provided/used, but variations in care have also been associated with health care that is not evidence based. Attempts to make healthcare provision more standard may need to be afforded a lower priority if wider consumer involvement is to be promoted.

In the literature review referred to above,<sup>21</sup> individually calculated risk estimates (based on personal risk factors) were most effective in achieving improved patient outcomes. However, the studies only addressed a narrow range of clinical topics including calculating individual breast cancer risks from the Gail formula<sup>26</sup> or cardiovascular risks, usually from the Framingham study data.<sup>27</sup> Further research should examine the generalisability of these findings for other clinical topics. If they do appear to be generalisable, attention should then be paid to the ways in which information is used and presented in health care practice.

#### FRAMING

For any method of risk communication, different ways of “framing” the information have varying effects.<sup>8 22 28</sup> Framing itself is defined as presenting “logically equivalent” information in different ways.<sup>18</sup> For example, the risk of major osteoporotic fractures is 12% in women who take hormone replacement therapy (HRT) for over 5 years and 15% in those who do not. This can be framed as a 3% reduction in (absolute) risk or that fractures are 20% less common in women who take treatment (relative risk reduction). Other framing variations include expressing the figures as “3% more people remaining free of fractures with HRT” (positive framing) or “3% more people suffering fractures if not taking HRT” (negative framing), or converting absolute risk reductions into the “number needed to screen”.<sup>29</sup> These different expressions have different motivational effects and substantially influence whether individuals choose treatment options or adhere to chosen plans.<sup>22 30</sup> There are clear risks of manipulating consumer decisions by the way information is presented,<sup>28</sup> thus restricting opportunities for informed choice. Care is therefore crucial in deciding whether to use such formats in discussions with consumers, whether it is truly helpful, or

whether the formats should only be used in research and policy settings.

People have different preferences for the way they wish information to be presented and discussed with them. For example, some people may not be comfortable with the use of numerical terms and may prefer the same facts to be conveyed descriptively, such as “fractures are slightly less common in those who take HRT”. These issues are examined further by Dudley elsewhere in this supplement.<sup>31</sup>

#### The future

The way facts and figures are expressed ought to vary according to the needs of the individual consumer. As mentioned above, some may prefer more descriptive terms, building up scenarios to illustrate what the professionals mean to convey.<sup>32</sup> Others may prefer numerical data, and others still may prefer graphical formats. From the professional’s perspective, one such approach alone is also likely to be insufficient for clinical practice.<sup>33</sup> Professionals usually wish to be able to choose the method or presentation format for information being used in a consultation to meet the needs of the individual consumer.<sup>7</sup>

Having identified substantial differences in treatment choices made by consumers when presented with absolute or relative risk information, Hux and Naylor concluded that “multiple complementary formats may be most appropriate”<sup>30</sup> and this is supported by other workers.<sup>34</sup> A range of complementary formats—for example, descriptive, absolute and relative risk, “numbers needed to treat”, and graphical presentations—may be more valued by professionals and patients.<sup>33</sup> Having such information available may facilitate partnerships between professionals and consumers in the consultation, in which both are able to make an informed contribution. Whatever data are available, it is important to maintain a sense of perspective.<sup>35</sup> Thus, some have suggested that absolute risk should be the preferred format for presentation of data.<sup>8</sup> This may be a balanced perspective of results, but both relative and absolute risk information in isolation can be criticised as only giving part of the picture. People often make decisions on the basis of making comparisons,<sup>36</sup> and this requires relative risk as well as absolute risk data. Others have advocated using “everyday risks” with which people are familiar (such as car driving or others as appropriate) to maintain an accurate perspective of the size of a risk and to provide data from which people are able to make an informed comparison of the risk.<sup>1 37</sup>

#### ETHICAL PRINCIPLES

Such approaches may enable patients to make informed choices based on the “whole truth” rather than the “truth”. In terms of ethical principles, this appears to be closer to the “relationality” principle proposed by Bottorff *et al.*<sup>38</sup> It complements other ethical principles such as (consumer) autonomy, beneficence, non-maleficence, and justice. Relationality promotes the provision of accurate honest

information in the context of the individual situation. It examines the ethics of care in terms of such factors as response, interpretation, accountability, and social solidarity, often counterbalanced against other values such as truth and confidentiality. If the relevant information is made available in this context, then perhaps some strides are being made towards “informed choice” and thus achievement of quality in healthcare consultations. Further discussion of the ethics of informed and shared decision making is covered elsewhere in this supplement.<sup>39</sup>

#### EVIDENCE OF INFORMED CHOICE AND UNDERSTANDING

Such informed choice may not be evident in the conventional cognitive and behavioural outcomes<sup>40</sup> frequently reported in the literature. It is perhaps more likely to be evident in the affective outcomes which are increasingly reported.<sup>21</sup> These include satisfaction with the communication process, understanding of the risks and benefits of the different options, and certainty that the best treatment choice has been made.<sup>23</sup> Many of these outcomes are now the focus of attention for current work in this field<sup>41</sup> and may be of greater importance to consumers. How much consumers understand of the disclosed information is also an important issue, and ethicists have argued that consumers must “substantially understand” information when giving consent to treatment or tests.<sup>42</sup> The ethical debate has perhaps not progressed to a point where the notion of “substantial understanding” has been clarified.<sup>42</sup> Others have explored in practice, though, what can be learnt about the value of the “reasonable person’s standard” in comparison with the “professional standard”.<sup>43</sup> Whatever the level of understanding, adhering to the chosen treatment is likely to be a very different prospect for those who are satisfied and “certain” compared with those who are not and who are still in a position of “decisional conflict”.<sup>44</sup>

We therefore suggest that future strategies to enhance informed choice should be based on methods which portray the decision issues in more depth and which use individual risk estimates. The information should be presented (framed) in as fair and balanced a way as reasonably possible, set in the context where appropriate of everyday risks with which the consumer is familiar. From the discussion about framing effects, it seems that a range of complementary data formats should be available to professionals.<sup>30</sup> This could be referred to as a “shopping basket” of options with enough flexibility to address the needs of a great range in requirements of consumers. This idea is starting to be operationalised in some of the “decision aids” now available,<sup>41</sup> including booklets, tapes, videodiscs, interactive computer programmes, and paper based charts. Some decision aids are provided for consumers to work through on their own (outside the consultation or at home),<sup>34 45–47</sup> some are specifically intended to provide a platform for discussions in a further consultation,<sup>48–50</sup> while

others form the basis for discussions within consultations, prompting consumer questions and so on.<sup>51 52</sup> Each is likely to have its place according to the situation, but where decision aids are discussed in consultations, this is perhaps more likely to ensure that both patient and professional contribute to the process of making an informed decision (“shared decision making”<sup>53</sup>). Additional components of decision aids include structured counselling approaches for the professional,<sup>54</sup> exploration of the consumer’s preferred level of involvement in the decision making itself,<sup>49 55</sup> and the use of specific approaches to clarify or quantify consumer values—for example, “weigh scales”<sup>49</sup> or formal utility assessment methods.<sup>56</sup> Value clarification exercises may be highly relevant to attempts to achieve and demonstrate that informed choice has occurred.

It is noteworthy that, when provided with information and opportunity for greater involvement in decisions, consumers generally become more wary of the treatments offered and make more conservative choices. In their review of this specific area of the literature, O’Connor *et al*.<sup>57 57</sup> found that, on average, consumers were 26% less likely to choose treatment or tests in studies where information was provided and choices offered (relative risk of choosing treatment 0.74, 95% CI 0.6 to 0.9). Such findings are not direct evidence of understanding the risk and other information provided, but where the direction of effects is contrary to the simplistic goals of interventions (for example, greater uptake of tests), this is at least suggestive that consumers have grasped onto certain key elements of the information and that this has affected the choices made. These effects are likely to be of great interest not just to consumer representative groups, but also to purchasers of care; decision aids may be highly cost effective interventions. Such findings may change, however, as further trials address a broader range of healthcare choices, particularly those in which apparent “overutilisation” of health care is less clear cut.

#### IMPLEMENTATION

Many professionals are reluctant to use some of the decision aids and other tools now becoming available.<sup>58 59</sup> Wider implementation is likely to depend on greater promotion of the principles of “shared decision making” so that professional attitudinal barriers may be diminished.<sup>33 58</sup> This stimulus may be most effective if it comes from consumers or their representatives, rather than professional opinion leaders. Professionals will also need to be sufficiently familiar with the content of decision aids to use them to maximum benefit. Interactive media may be required to enable individually calculated risks to be used in consultations. This presents practical difficulties of using technological innovations across a range of clinical settings, and suggests that interventions must remain simple if they are to be broadly implemented.

For both simple and complex decision aids, professionals will require training, not least to

feel confident in their own understanding and ability to use risk information.<sup>7</sup> It is also important for any training to address the ethical issues raised (see above), particularly relating to the risk of manipulating consumer decisions or behaviour. Raising awareness of these issues should be the first step at least towards reducing the risks of professionals manipulating individual consumers with data. In this context, there will be a platform from which to discuss risks, to enhance understanding of the risks and potential risk reductions, and to facilitate informed choices by consumers.

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