

## Personalised risk communication for informed decision making about taking screening tests

### Review question

Does personalised risk communication improve informed decision making for people taking screening tests?

### What is personalised risk communication?

Personalised risk communication is the provision of screening information that is tailored to the individual, based on their personal risk factors for a condition (such as age or family history). See “Related Resources” on page 2 for examples of personalised risk communication formats.

### Key findings

Based on the results of 41 studies, involving 28,700 participants, the authors concluded that there is:

- Strong evidence that personalised risk communication enhances informed decision making
- Weak evidence showing a small increase in screening uptake
- Moderate evidence that personalised risk communication increases knowledge
- Weak evidence indicating a trend towards more accurate risk perception
- Very weak evidence showing a trend towards reduced anxiety

#### Full citation for this review:

Edwards AGK, Naik G, Ahmed H, Elwyn GJ, Pickles T, Hood K, Playle R. [Personalised risk communication for informed decision making about taking screening tests](#). *Cochrane Database of Systematic Reviews* 2013, Issue 2. Art. No.: CD001865. DOI:10.1002/14651851.CD001865.pub3.

#### This summary is relevant for:

This evidence bulletin can be used by decision makers and clinicians (e.g. general practitioners, nurses) involved in discussing screening with patients.

#### This summary includes:

- Key findings from research based on a systematic review (p 1)
- Considerations about the relevance of this research to policy makers and clinicians (p 2)
- A more detailed description of the research (p 3)

#### Not included:

- Additional evidence
- Detailed descriptions of personalised risk communication or how to implement the intervention in practice
- Recommendations

#### What is a systematic review?

A systematic review aims to locate, appraise and synthesise all of the available evidence related to a specific research question. Authors adopt rigorous methods to minimise bias as a way of producing reliable findings with the ultimate goal of making the evidence more useful for practice. See [navigatingeffectivetreatments.org.au](#) for more information.

## Relevance to the health care context in Victoria, Australia

<p>The broader policy and clinical context</p>	<p>By improving an individual's capacity to make an informed screening decision, personalised risk communication supports their health literacy. Improving Australians' health literacy by providing an adequate 'health literacy environment' is a key focus for the <a href="#">Australian Commission for Safety and Quality in Health Care</a> (see also the <a href="#">National Safety and Quality Health Service Standards</a>). Improving health literacy is also a central plank of the Victorian Government's <a href="#">Health Priorities Framework 2012-2022</a>. In addition, many Australian screening guidelines for clinicians (see Related Resources, below) advocate a personalised risk communication approach.</p>
<p>The populations and settings in which this relevant</p>	<p>The results of this review are highly relevant to the Australian health care context; all studies were conducted in high-income countries, including four in Australia. It is important to note that the majority of studies (34/41) involved participants making decisions about mammography or colorectal cancer screening. Caution is required when applying these results other clinical areas.</p> <p>Only a small number of studies (5/41) specified that they included participants with low health literacy or from disadvantaged backgrounds. As a result it is unclear how applicable the findings are to people with low health literacy and those from culturally and linguistically diverse communities or disadvantaged backgrounds.</p> <p>There was no information on the health status (chronic diseases, multi-morbidity) of participants, therefore it is unclear how applicable the findings of this review are to people with multi-morbidity or complex health conditions.</p>
<p>Implications for decision makers</p>	<p>Decision makers could consider promoting personalised risk communication in the development of policies, guidelines and other frameworks for use by health professionals and others.</p>
<p>Implications for clinicians</p>	<p>Clinicians could consider a personalised risk communication approach when discussing screening risks with patients, in particular for breast and colorectal cancer screening. A number of health care organisations have developed personalised risk pathways/tools to assist clinicians incorporate personalised risk communication into practice (see Related Resources, below). Although it was not measured in this review, clinicians may consider the effect of pathway tools for personalised risk communication on the length of the clinical consultation.</p>

### Related Resources

#### Examples of personalised risk communication

- Risk score Australian [absolute cardiovascular risk score](#), National Vascular Disease Prevention Alliance
- Risk category [diabetes risk assessment category](#), Department of Health and Ageing.
- Risk factor list [breast cancer risk factors](#), Breast Cancer Care WA

#### Systematic reviews

- Gøtzsche et al (2013) [Screening for breast cancer with mammography](#)
- Hewitson et al, (2008) [Screening for colorectal cancer using faecal occult blood test, hemoccult](#)
- Stacey et al, (2011) [Decision aids for people facing health treatment or screening decisions](#)

#### Evidence bulletins

- Framing of health information messages (2014)
- Using alternative statistical formats for presenting risks and risk reductions (2014)
- Decision aids for people facing health treatment or screening decisions (2014)

#### Screening resources

- National Breast and Ovarian Cancer Centre, [Advice about family aspects of breast and epithelial ovarian cancer, a guide for health professionals](#)
- National Health and Medical Research Council, [Clinical Guidelines for the Prevention, Early detection and management of Colorectal Cancer](#)
- Royal College of General Practitioners [Red Book, 8<sup>th</sup> Edition](#).
- National Health and Medical Research Council, Victorian Cytology Service, [Management of Asymptomatic Women with Screen-Detected Abnormalities Guidelines](#)

## Background

Like any treatment in health there are risks and benefits associated with screening for health conditions. Fully informing consumers of these risks and benefits is an integral component of the consent process for any screening procedure. Personalised risk communication allows consumers to decide what is appropriate for them, taking into account personal circumstances, risks, benefits and alternative healthcare options. However, the best strategy for presenting and/or discussing this information about screening is unclear.

## Information about this review

The authors of this systematic review conducted a detailed search of studies published up to March 2012. They used the following criteria to determine which studies to include:

### *Types of studies*

- Randomised controlled trials

### *Participants*

- People making real life decisions about whether to undergo screening for themselves or on another's behalf (individuals, couples or guardians)

### *Types of intervention*

Three different types of personalised risk communication were included. These included communication that used:

- Risk score (i.e. an individualised risk score or actual risk information such as relative or absolute risk rates) (see example in Related Resources, p2)
- Risk category (i.e. a categorised risk information such as 'high', 'medium', or 'low risk') (see example in Related Resources, p2).
- Risk factor list (i.e. a discussion of personal risk factors such as an individual's own risk compared to the general public) (see example in Related Resources, p2).

The risk discussion had to be delivered in a primary health care service or hospital outpatient clinic by an appropriately skilled health professional. It could be delivered face-to-face (i.e. written or verbal) or electronically (i.e. internet).

### *Comparison*

Personalised risk information interventions were compared to generalised risk communication interventions, including population risk estimates and information on risk factors in general

### *Outcomes*

The following outcomes were examined:

- Informed decision
- Cognitive outcomes (knowledge of risk, accurate risk perception)
- Affective outcomes (e.g. anxiety)
- Behavioural outcomes (uptake of tests)

## Main results

This review included 28,700 participants in 41 studies.

### *About the studies*

All included studies were from high-income countries, 4 were conducted in Australia. Twenty-three studies focused on breast cancer screening, and 11 focussed on colorectal cancer screening.

### *Effects of personalised risk communication vs general risk communication*

- Strong evidence from three studies showed that personalised risk communication promotes informed decisions (see Results table, line 1).
- Uptake of screening test was measured in 12 studies, showing weak evidence of a small increase in uptake of screening tests (see Results table, line 2).
- The effects on uptake appeared to be higher in participants at higher risk of disease than average, irrespective of the level of risk communication, indicating that 'high risk status' may be a potential effect modifier for personalised risk information.
- Knowledge was measured in nine studies; each of the types of personalised risk communication showed a significant improvement in knowledge (see Results table, lines 3 and 4).
- Risk perception/comprehension was measured in three studies which showed weak evidence of a trend towards more accurate risk perception (see Results table, line 5).
- Anxiety was measured in six studies which showed weak evidence of a small trend that personalised risk communication decreased anxiety scores (see Results table, line 6).

## What this review does not show

It is difficult to draw conclusions about the most effective personalised risk communication approach as the included studies used a variety of strategies. It is unclear how well personalised risk communication works in clinical screening areas outside mammography and colorectal cancer.

**Results table: personalised risk communication versus generalised risk communication**

Outcome		Impact with Generalised Risk Communication	Impact with Personalised Risk Communication (95% CI)*	Relative effect* (95% CI)*	No of Participants (studies)	Evidence quality (GRADE)#
<b>1</b>	<b>Informed decision (risk score and risk category combined)</b>	20 per 100	48 per 100 (35 to 61)	OR 3.65 (2.13 to 6.23)	2444 (3 studies)	High
<b>2</b>	<b>Uptake of screening test (risk score and risk category combined)</b>	53 per 100	56 per 100 (54 to 59)	OR 1.15 (1.02 to 1.29)	6442 (12 studies)	Low
<b>3</b>	<b>Knowledge - continuous data</b>					
	Risk Score	SMD 0.4 (0.23 to 0.56) higher in the intervention group			588 (1 study)	Moderate
	Risk Category	SMD 0.57 (0.32 to 0.82) higher in the intervention group			260 (1 study)	Low
	Risk Factor List	SMD 0.89 (0.75 to 1.04) higher in the intervention group			838 (2 studies)	High
<b>4</b>	<b>Knowledge – dichotomous data</b>					
	Risk Score	24 per 100	46 per 100 (29 to 63)	OR 2.6 (1.27 to 5.34)	1413 (3 studies)	High
	Risk Factor List	17 per 100	59 per 100 (54 to 64)	OR 7.13 (5.79 to 8.79)	2107 (2 studies)	High
<b>5</b>	<b>Accurately perceived risk</b>	23 per 100	32 per 100 (22 to 45)	OR 1.65 (0.96 to 2.81)	1264 (3 studies)	Low
<b>6</b>	<b>Anxiety (all risk groups)</b>	SMD -0.13 (-0.29 to 0.03) lower in the intervention group			1848 (6 studies)	Very Low

\* Relative effect is measured as Odds Ratio (OR) or Standardised Mean Difference (SMD), followed by a 95% confidence interval (95% CI)

# For more information on the GRADE working group's rating of quality of evidence go to [www.gradeworkinggroup.org](http://www.gradeworkinggroup.org)

This evidence bulletin draws on the format developed for SUPPORT summaries (for more information on SUPPORT summaries see [www.supportsummaries.org](http://www.supportsummaries.org)). It replaces the previous version of this bulletin (September 2007) which is based on the previous version of this Cochrane review.

### Health Knowledge Network

The Health Knowledge Network is the knowledge transfer arm of the Centre for Health Communication and Participation. The Centre is funded by the Quality, Safety and Patient Experience Branch, Department of Health, Victoria, Australia.

The Health Knowledge Network summarises reviews published by the Cochrane Consumers and Communication Review Group.

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