Barriers in using cardiometabolic risk information among consumers with low health literacy

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Objectives. To identify the barriers from the perspective of consumers with low health literacy in using risk information as provided in cardiometabolic risk assessments.

Design. A qualitative thematic approach using cognitive interviews was employed.

Methods. We performed interviews with 23 people with low health literacy/health numeracy, who were recruited through (1) several organisations and snowball sampling and (2) an online access panel. Participants completed the risk test of the Dutch national cardiometabolic risk assessment and viewed the personalized information about their risk. They were asked to answer probing questions about different parts of the information. The qualitative data were analysed by identifying main themes related to barriers in using the information, using a descriptive thematic approach.

Results. The four main themes identified were as follows: (1) People did not fully accept the risk message, partly because numerical information had ambiguous meaning; (2) people lacked an adequate framework for understanding their risk; (3) the purpose and setting of the risk assessment was unclear; and (4) current information tells nothing new: A need for more specific risk information.

Conclusions. The main barriers were that the current presentation seemed to provoke undervaluation of the risk number and that texts throughout the test, for example about cardiometabolic diseases, did not match people’s existing knowledge, failing to provide an adequate framework for understanding cardiometabolic risk. Our findings have implications for the design of disease risk information, for example that alternative forms of communication should be explored that provide more intuitive meaning of the risk in terms of good versus bad.

Statement of contribution
What is already known on this subject?
- Online disease risk assessments have become widely available internationally.
- People with low SES and health literacy tend to participate less in health screening.
- Risk information is difficult to understand, yet little research has been carried out among people with low health literacy.

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What does this study add?

- People with low health literacy do not optimally use risk information in an online cardiometabolic risk assessment.
- The texts provided in the cardiometabolic risk assessment do not suit to their existing knowledge.
- The typical risk communication (numbers, bar graph, verbal label) seems to provoke undervaluation of risk.

There is an increasing expectation that people make autonomous health decisions (O’Connor et al., 2007; Woolf et al., 2005). In preventive health care too, such an approach is increasingly embraced (Kirkegaard et al., 2010; Koelewijn-van Loon et al., 2009). Informed decision-making about preventive options could empower people and foster healthy choices (Edwards et al., 2013; Naik, Ahmed, & Edwards, 2012). An important example is online risk assessments that identify people at risk of diseases (Fanaian et al., 2010; Heikes, Eddy, Arondekar, & Schlessinger, 2008; Nielen et al., 2010; Sheridan, Pignone, & Mulrow, 2003; Witterman, Zikmund-Fisher, Waters, Gavaruzzi, & Fagerlin, 2011).

Although the aim of such assessments is not always formally described as facilitating health decisions, most experts involved agree that this is important, besides the more general aim of creating risk awareness (Holmberg, Harttig, Schulze, & Boeijing, 2011; Ruiz et al., 2013; Sheridan et al., 2010), or specific aims focused on health behaviour, for example motivating people to adopt preventive behaviour (Holmberg et al., 2011; Koelewijn-van Loon et al., 2009; Sheridan et al., 2010), and improving population health (Colkesen et al., 2011; Holmberg et al., 2011; Jacobson, Gutkin, & Harper, 2006; Ruiz et al., 2013).

In the Netherlands, the ‘Prevention Consultation for Cardio-metabolic risk’ has been introduced in GP and occupational health care (Dekker et al., 2011; Van der Meer et al., 2013). Cardiometabolic diseases (type 2 diabetes [T2DM], cardiovascular diseases [CVD], and chronic kidney disease [CKD]) contribute heavily to disease burden (Gu et al., 2005), while the risk can be considerably reduced by appropriate medication and a healthy lifestyle (Gaede, Vedel, Parving, & Pedersen, 1999; Norris et al., 2004). The aim of this risk assessment is to increase awareness of one’s cardiometabolic health risk and to guide subsequent decisions and foster better population health. Based on seven questions in an online risk assessment, people’s risk is estimated and communicated. Different risk presentations (percentage, natural frequency, bar chart, verbal label) and an explanation of one’s risk factors are provided. In the case of an elevated risk, people are advised to visit their GP for further screening. In the case of a slightly elevated risk, people receive general lifestyle advice and a link to a detailed lifestyle test.

It is known that people with low socio-economic status and health literacy tend to participate less in screening programmes (Bennett, Chen, Soroui, & White, 2009; Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Dobbins, Simpson, Oldenburg, Owen, & Harris, 1998; Dryden, Williams, McCowan, & Themessl-Hube, 2012; Guerra, Krumholz, & Shea, 2005; Kobayashi, Wardle, & Von Wagner, 2014; White, Chen, & Atchison, 2008). Different reasons have been suggested, such as invitational materials being difficult to understand (Kobayashi et al., 2014). Other more general explanations are that people with lower socio-economic status and/or inadequate health literacy also have lower perceived self-efficacy (Berkman et al., 2011; Norman & Conner, 1993) or lower patient activation (Greene & Hibbard, 2012; Rademakers, Nijman, Brabers, de Jong, & Hendriks, 2014), as well as typical beliefs and values about screening and health behaviours (Wardle, McCaffery, Nadel, & Atkin, 2004), which may all hinder engagement with health screening.
One explanation that has received less attention is that the comprehension of the provided risk information may be difficult for people with low health literacy (McCaffery, Smith, & Wolf, 2010), ultimately resulting in dropout. It is known that risk information is typically abstract, technical, and statistical in nature, while at the same time, many people lack adequate health literacy (which also includes health numeracy; Galesic & Garcia-Retamero, 2011; Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz, & Woloshin, 2007; Likpus & Peters, 2009; Morris, Grant, Repp, Maclean, & Littenberg, 2011; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Reyna, Nelson, Han, & Dieckmann, 2009). Recently, several experimental studies have identified risk formats that support people with low numeracy. For example, natural frequencies as well as visual aids can improve understanding among people with low health numeracy (Gaissmaier et al., 2012; Galesic, Gigerenzer, & Straubinger, 2009; Garcia Retamero & Galesic, 2010). However, such experiments usually focus on people’s comprehension of risk numbers, and not on how consumers generally process information provided in the entire risk assessment. Furthermore, the intuitive or affective meaning that people derive from the provided information typically remains underemphasized (Zikmund-Fisher, Fagerlin, & Ubel, 2010). The problems encountered by people with low health literacy may not only be associated with getting the numbers right, but also with capturing the intuitive meaning of their risk result, as well as with using accompanying educational materials. For example, previous studies found that many people have a rather fuzzy concept of an elevated risk (Damman & Timmermans, 2012; Damman, Van der Beek, & Timmermans, 2014), which may make it difficult to appreciate the risk message. This study aimed to identify the barriers from the perspective of consumers with low health literacy in using risk information provided in cardiometabolic risk assessments.

Methods

Design

This study used a qualitative descriptive thematic approach to understand difficulties from the perspective of consumers with low health literacy. This approach was chosen as it was our aim to explore and identify broad barriers in using disease risk information. The Dutch ‘Prevention Consultation for Cardio-metabolic risk’ (Van der Meer et al., 2013) was used as a case example. Cognitive interviews were conducted (Beatty & Willis, 2007), focusing on people’s thought processes as they went through the risk test. Our interview protocol was focused on participants’ general information processing, information interpretation, evaluation of the information, and (hypothetical) decision-making. The study was exempt from review by a medical research ethics committee in accordance with local regulatory guidelines and standards for human subjects protection in the Netherlands (Medical Research Involving Human Subjects Act (WMO), 2005).

Data collection

Participants were first recruited through several organizations (a home-care organization and occupational physicians employed in our academic hospital) and through snowball sampling, focusing on employees with a lower educational level. Reflecting well-known difficulties in recruiting people with lower SES, this led to the inclusion of just five participants. Next, 806 people were approached through an online access panel (FlyCatcher Internet Research, 20,000 panel members in total, ISO 20252- and ISO 26362-
certified), who filled in three subjective health literacy screening items developed by Chew, Bradley, and Boyko (2004). Of the 495 panel members who responded, 163 had inadequate health literacy and were also willing to participate. We invited 67 of these persons, namely those who had inadequate literacy on item 2 and those who had inadequate literacy on items 1 and 3. Eighteen of these 67 individuals (27%) participated in our study. Together with the five participants recruited through organisations and snowball sampling, we had 23 participants (Table 1).

**Procedure**

Interviews were conducted at our academic hospital or at the participant’s home. First, participants were instructed about the study aim – namely to test a Web-based disease risk

<table>
<thead>
<tr>
<th>Variable</th>
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<tr>
<td>Age, M (range)</td>
<td>52.6  (40–66)</td>
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<td>Gender (%)</td>
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<tr>
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<td>Female</td>
<td>15 (65)</td>
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<td>Educational level (%)</td>
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<tr>
<td>Low (no or primary education)</td>
<td>10 (43)</td>
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<td>Average (secondary education)</td>
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<td>High (tertiary education)</td>
<td>4 (17)</td>
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<tr>
<td>Subjective health literacy (%)*</td>
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<tr>
<td>Inadequate health literacy</td>
<td>19 (83)</td>
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<td>Adequate health literacy</td>
<td>4 (17)</td>
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<td>Health numeracy (%)†</td>
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<tr>
<td>0 Questions correct</td>
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<td>3 Questions correct</td>
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<td>Graph literacy (proxy) (%)‡</td>
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<td>0 Questions correct</td>
<td>2 (9)</td>
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<td>1 Question correct</td>
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<td>2 Questions correct</td>
<td>8 (35)</td>
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<td>3 Questions correct</td>
<td>11 (48)</td>
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**Notes.** *Based on the three subjective health literacy screening items developed by Chew *et al. (2004): (1) ‘How often do you have someone help you read hospital materials?’, (2) ‘How confident are you filling out medical forms by yourself?’, and (3) ‘How often do you have problems learning about your medical condition because of difficulty understanding written information?’. Inadequate health literacy if answers other than ‘never’ on items 1 or 3 and/or answers other than ‘extremely’ or ‘quite a bit’ on item 2.

†Based on the three items developed by Schwartz *et al. (1997). The maximum number of questions correctly answered was 3.

‡Based on the graph literacy instrument developed by Galesic and Garcia-Retamero (2011). We only used the three items related to how people read bar graphs. The correlations of the three items with the total graph literacy score in the original study were satisfactory, namely .52 for question 1 (question 2 in the original instrument), .43 for question 2 (question 3 in the original instrument), and .42 for question 3 (question 13 in the original instrument) (personal communication with Dr. Mirta Galesic). The maximum number of questions correctly answered in our study was 3.
and were provided with a general description of the ‘Prevention Consultation for Cardio-metabolic risk’. It was explained that the test would calculate their risk of cardiometabolic diseases (T2DM, CVD and CKD), based on questions to be filled in. Participants were explicitly told that if they had any objections to filling in these questions about individual risk factors, they were allowed to use fictitious answers. None of the participants expressed such objections. Next, the interviewer informed participants about the interview structure and gave instructions to think aloud throughout completing the risk test. This instruction said: ‘I would like you to think aloud as much as possible while using this website. That means that you say anything that comes to your mind while I remain silent. You may have to get used to thinking aloud; I will perhaps stimulate you by asking a question every now and then’. We asked permission to audiotape the interviews and obtained written consent from participants prior to the start of the interview. Participants were rewarded with a gift token of 15 euros.

Participants were then provided with the online risk assessment on a laptop and asked to think aloud while filling in the questions of the test (age, gender, smoking, family history T2DM and CVD, BMI, waist circumference) and while viewing their results. Each question is posed on a separate webpage; the Web pages contain both textual and visual information and provide information buttons and links to more information on the specific risk factor. The supplementary files display examples of two questions (Figures 1 and 2). The test result comprises two Web pages: One with the risk communication and one with an explanation of personal risk factors that contribute to their risk (Figures 3 and 4). After thinking aloud, probing questions about information considered essential for understanding and using the information were posed, while the interviewer went back and forth through particular information. Additionally, participants were asked about their (hypothetical) decisions.

Finally, participants filled in a short survey with questions about educational level, age, sex, health numeracy, and graph literacy. Health numeracy was measured by the three items developed by Schwartz, Woloshim, Black, and Welch (1997). We considered scores of less than three questions answered correctly as relatively low health numeracy. We
measured graph literacy using a proxy of three items derived from the existing graph literacy scale of Galesic and Garcia-Retamero (2011). These items concerned comprehension of a bar graph, which was considered most relevant for the risk assessment under study. We considered scores of less than three questions answered correctly as relatively low graph literacy. The Appendix provides a summary of the interview protocol and survey.

**Analysis**

All interviews were transcribed verbatim. Before starting the analysis, all transcriptions were given a number linked to the number provided to the survey the participants
completed. Personal data (names and email addresses) and informed consent forms were not stored in the same physical place where the audio files, transcriptions, and completed surveys were stored. We screened the transcriptions for any personal information, anonymizing if necessary. The principal investigator (OD) first coded 10 interviews and, reflecting a descriptive approach, searched for what happened in information processing, interpretation, evaluations, and decisions. Based on that, initial themes were assessed. After discussion about the themes, two researchers coded the remaining interviews and had several consensus meetings, together assessing the final main themes. A total of four interviews were double-coded (both OD and NB).

Results

Table 1 describes the 23 participants’ characteristics. Ultimately, four persons had adequate subjective health literacy as measured by the screening items of Chew et al. (2004), all of whom were recruited in organizations or via snowball sampling. These participants did have relatively low health numeracy and two of them also had relatively low graph literacy. As health numeracy is part of health literacy (Berkman et al., 2011; Fransen, Van Schaik, Twickler, & Essink-Bot, 2011), we decided to include them in the study. Overall, 17 of our 23 participants had relatively low health numeracy and 18 of our participants had relatively low graph literacy.

Most interviews lasted between 30 and 40 min, with some taking relatively shorter or longer. On average, about 20–30% of the interview time was spent on participants’ thinking aloud. However, it should be noted that not all of the resulting data covered what is traditionally seen as thinking aloud (i.e., participants’ verbalizations without interference of the interviewer). It appeared to be difficult to think aloud while completing the risk test.
In most cases, there were long silences, prompting the interviewer to ask questions about what participants were thinking or doing. If that did not work either, the interviewer sometimes asked more explicitly what thoughts the provided information was evoking.

The main themes derived from the interviews are presented in Figure 5 and described below with illustrative quotes from participants. Where differences between people with low versus high health literacy, numeracy, and graph literacy emerged, these are reported.

**Theme 1: People did not fully accept the risk message, partly because numerical information had ambiguous meaning**

We found that many people did not fully accept the risk message. In some cases, they did accept the risk number, but judged it to be not that high (subtheme 1a). In other cases, people doubted the number’s accuracy, because for example, certain lifestyle factors were not taken into account in the risk test (subtheme 1b). Another reason for not...

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**Figure 5.** Main themes derived from the interviews and their relations to each other.
accepting the risk message was that not all risk factors were accepted as valid for one’s personal situation (subtheme 1c).

**Subtheme 1a: Undervaluation of the risk number**
Several participants with relatively high risks thought their risk number was not that high. One aspect that played a role in this ‘risk undervaluation’ was that people thought their risk could ascend to 100%, which is – in reality – an unrealistically high percentage.

(Woman, 56 years old, inadequate health literacy, low health numeracy and low graph literacy, responding to her 42% risk): ‘Oh that’s only half of the risk! Let’s take a look... “Your risk is 42%”. Then it could have been worse’.

The bar graph seemed to contribute to these perceptions, especially among those with low health numeracy. We also noticed that people with high risks used the colours in the graph to play down their risk.

(Woman, 45 years old, inadequate health literacy, low health numeracy and low graph literacy, responding to her 36% risk): ‘Well I’m not above the 50% risk. I’m in the red zone, but in the lower part of it’.

So it seemed that the intuitive meaning people derived from relatively high risk numbers was that it was a low risk, and this implies that they did not fully ‘accept’ the risk message as understood by experts, namely that it was severe enough to warrant further health screening.

**Subtheme 1b: Doubting the accuracy of the risk number**
In other cases, people actually objected to the numbers, because they thought the risk test did not adequately take into account all risk factors or their complete personal situation.

(Man, 55 years old, inadequate health literacy, low health numeracy and low graph literacy): ‘I expected to have to fill in more about myself. About my eating habits, smoking’.

In particular, people who considered their lifestyle to be healthy thought their risk was actually lower than what was communicated. We noticed self-protective reactions among some participants, such as that they did not smoke that much or did not inhale the smoke. People also wondered why other lifestyle factors they considered relevant were not taken into account, such as stress and alcohol use. As a result, the risk number was not always believed or accepted as valid. Several participants explicitly questioned the accuracy of the test, mostly because it was so short.

(Man, 50 years old, inadequate health literacy, high health numeracy and high graph literacy): ‘I don’t know if this is enough... these type of questions that are very short. It’s pretty smart that it can give a result after six or seven questions’.

This also seems to be illustrative of the fact that people’s notions of the test differed from those of experts (for whom a test with as few questions as possible is most desirable given the test’s purpose).
Subtheme 1c: Risk factors not accepted
Several participants did not accept all risk factors contributing to their risk, and we noticed particular problems with waist circumference and BMI. Waist circumference was not always accepted as a risk factor because it was unclear how it related to cardiometabolic risk, or because the test indicated that their BMI was healthy.

(Woman, 55 years old, inadequate health literacy, high health numeracy and high graph literacy): ‘It’s strange that fat on your belly is so bad... for your body...? ’

Furthermore, it was not clear how to weigh the importance of waist circumference, as people had no idea what a healthy waist circumference was, and the test did not provide this information. As a result, waist circumference was not salient in people’s risk perceptions, and the risk numbers were sometimes judged to be too high. BMI was not always accepted as a valid measure of a healthy weight. In addition to BMI and waist circumference, we found that in the case of multiple risk factors, people typically focused on just one. In particular, when people had a family history of diseases, this led to neglecting other relevant risk factors.

(Man, 55 years old, inadequate health literacy, low health numeracy and low graph literacy, both family history of T2DM and BMI and waist circumference as risk factors): ‘I would explain this as... well I did the test and it turned out that because of my family... I already knew that’.

Theme 2: People lacked an adequate framework for understanding their risk
People’s risk interpretations were somewhat inconclusive, partly because the concept of an ‘elevated risk’ was not clear to them. While this concept is probably immediately clear to experts, it was a rather ‘empty’ concept for participants (subtheme 2a: Superficial notion of the elevated risk concept). Furthermore, participants’ risk perceptions often concerned a general health risk, instead of a specific cardiometabolic disease risk (subtheme 2b: No clear picture of cardiometabolic diseases). Both issues led to our interpretation that people lacked an adequate framework for understanding their cardiometabolic risk.

Subtheme 2a: Superficial notion of the elevated risk concept
We questioned people in more detail on the concept of an ‘elevated risk’, mentioned on the home page. It appeared that this concept did not provoke concrete ideas; participants usually had superficial negative associations:

(Woman, 64 years old, adequate health literacy, low health numeracy and low graph literacy): ‘Well, that means that it’s not good. That I should do something about it’.

Some described an elevated risk as ‘a higher chance’. Others explained it by having one or several risk factors, usually lifestyle factors or family history of diseases, or as having complaints associated with cardiometabolic diseases.

(Woman, 66 years old, inadequate health literacy, low health numeracy and low graph literacy): ‘You can collapse, lose consciousness, you can get a hypo, and what else...’
Subtheme 2b: No clear picture of cardiometabolic diseases
Participants appeared to have no clear picture of the diseases central to the risk assessment (T2DM, CVD, and CKD).

(Man, 40 years old, inadequate health literacy, high health numeracy and high graph literacy): ‘OK, I want to find out what diabetes exactly is, because that’s what this test is about, right? So what is type 2 diabetes exactly?’

As a result, people often focused on one single disease (of the three) while filling in the questions and interpreting information, or they had a more general health risk in mind.

(Woman, 61 years old, inadequate health literacy, low health numeracy and high graph literacy, responding to her 20% risk %): ‘Well, my risk is 20%. Could be better but could also be worse. So an elevated risk of developing heart disease’.

We noticed that there was a lot of confusion about T2DM and that information buttons and links were not helpful to people because these did not answer participants’ main question (what is the difference between type 1 and T2DM?). For CVD, it was often unclear which diseases were concerned, for example, only heart attacks and heart failure or also high blood pressure.

Theme 3: Purpose and setting of the risk assessment unclear
In addition to lacking a framework for understanding their risk (Theme 2), participants also lacked a broader framework for understanding the purpose and setting of the risk assessment. For example, questions were raised about when to visit a GP (subtheme 3a), and the usefulness of the provided general lifestyle advice (subtheme 3b); both of which indicate that the test’s general purpose (creating awareness of one’s risk to facilitate further health decisions) was not sufficiently clear. In this respect, it was also striking that people did not feel they had to make a decision (subtheme 3c).

Subtheme 3a: Not clear when to visit a GP
It was insufficiently clear to people when to visit a GP. Some problems were related to the information provided in the risk test. For example, on the home page, it was described that ‘if you have an elevated risk, you will be advised to visit your GP’. For the individuals who had a ‘slightly elevated risk’, it was unclear whether they should visit their GP or not.

(Woman, 40 years old, inadequate health literacy, high health numeracy and high graph literacy, discussing her 3% risk): ‘I mean, a 3% risk is no reason to see your GP is it? But it says I should do so. If you have an elevated risk, visit your GP. And it says I have a slightly elevated risk, so I should also see the doctor. But I wouldn’t go to a doctor with this . . .’

Other problems were more related to people’s own perceptions of when it is appropriate to visit a GP. The risk information did not motivate participants to visit their GP, as was recommended for a risk of 20% and above.
(Woman, 56 years old, inadequate health literacy, low health numeracy and low graph literacy, reading the advice resulting from her 42% risk): ‘It says “visit your GP”. Oh no, that man has more important things to do’.

Subtheme 3b: People thought general advice was useless
The general lifestyle advice provided at the end of the risk test (live more healthily) was perceived as annoying and useless by several participants, especially by those with relatively high health numeracy and graph literacy. In particular, as lifestyle was not assessed in detail, people considered such advice as inappropriate. Furthermore, as it did not become clear to everyone how lifestyle actually related to the diseases, people thought a general advice was useless.

(Woman, 42 years old, inadequate health literacy, high health numeracy and high graph literacy, reading the general lifestyle advice): “By living more healthily...” What is more healthily exactly? They don’t know how I live exactly, do they?”

Subtheme 3c: No real feeling of having to make a decision
Using the information in (hypothetical) decisions appeared to be quite difficult for several participants, as they initially indicated that they would not decide anything in particular. After a few probes, most people said that they considered altering their lifestyle. However, few people experienced these considerations as a process towards a decision to be made. Furthermore, visiting their GP for further screening was not considered as a decision option.

Theme 4: Current information tells nothing new: Need for more specific risk information
Current information told nothing new to many participants (subtheme 4a), and at least some of our participants expressed a need for more specific information about their risk and lifestyle modification (subthemes 4b and 4c). This relates to theme 3, as the current assessment has not been developed as a tool for detailed lifestyle assessment and advice, and participants seemed to be unaware of its actual aim. However, it also illustrates that current risk information might be too succinct, as participants were interested to know more.

Subtheme 4a: Information confirms what people already know
For several participants, the provided information (e.g., BMI, waist circumference, personal risk) was not new, but rather a conformation of what they already knew. It was no trigger to think about (or make decisions about) lifestyle change or visiting their GP (see Theme 3). People who smoked did not consider quitting, overweight people did not consider losing weight.

(Woman, 58 years old, inadequate health literacy, low health numeracy and high graph literacy): ‘This test wouldn’t particularly motivate me, because I already knew everything’.

Such verbalizations were particularly apparent when we asked people what decision they would make based on the information.
Subtheme 4b: People needed clear information about risk reduction

Despite the fact that several participants said they would not consider lifestyle modification, at least some participants seemed to need more information about how to lower their risk. The current way of presenting such information is that it is described per modifiable risk factor – what the size of the risk would be without that risk factor. This information was not noticed by many people, as people usually only scanned the explanation of personal risk factors. However, it appeared that people wanted to know this, because many went back and forth through the test and altered their answers to see how the risk factors affected their risk.

(Man, 55 years old, inadequate health literacy, low health numeracy and low graph literacy): ‘I’m curious to know what happens if I go back... and then click... I’m now back at the waist circumference’.

People also wanted to know how slightly altering lifestyle (such as reducing the number of cigarettes per day) would affect their risk.

Discussion

We aimed to identify the main barriers for consumers with inadequate health literacy in using risk information as provided in cardiometabolic risk assessments. Although our participants indicated they had no problems using the risk information, our analysis showed that they did not use it optimally. The main barriers were that the presentation seemed to induce undervaluation of the risk number and that texts throughout the test, for example about cardiometabolic diseases, did not match people’s existing knowledge and thus failed to provide an adequate framework for risk understanding.

One main finding was that many people ultimately did not ‘accept’ parts of the risk message. Some did accept the risk number, but judged it to be not that high, whereas others doubted its accuracy. The first problem seemed to be related to the fact that risk numbers had ambiguous meaning and that participants might have used cues from the way information was presented to judge whether it was good or bad (Zikmund-Fisher et al., 2010). The bar graph seemed to evoke a false assumption that one’s risk could reach a maximum of 100% and therefore conclude that ‘it could have been worse’, whereas experts would say that it is bad enough. It might be worthwhile to consider other designs of bar charts, to better fit the information processing and needs of (low-literate) consumers (Smith et al., 2013; Zikmund-Fisher, 2013). However, the basic problem seems to be that people have difficulty in judging whether their risk result is good or bad. Another graph might not resolve this, as people will probably just use another cue from the graph in their interpretations. It might be more fruitful to provide an intuitive meaning of good versus bad by displaying comparison information (e.g., the risk of others; Fagerlin, Zikmund-Fisher, & Ubel, 2007; Lipkus, Biradavolu, Penn, Keller, & Rimer, 2009; Timmermans & Oudhoff, 2012) or providing analogies of their risk result (Galesic & Garcia-Retamero, 2013). Such communications seem to better suit how people think and experience things in everyday life and language, and might facilitate more meaningful risk interpretations. It should be kept in mind that these approaches might be somewhat directive or they might nudge people too much towards certain beliefs (Rossi & Yudell, 2012). However, providing people with meaningless risk information seems to serve no purpose at all.
The problem of doubting the risk number’s accuracy has been demonstrated in other studies in the context of colon cancer, breast cancer, and diabetes (Holmberg et al., 2011; Scherer et al., 2013; Weinstein et al., 2004). This tendency might have different underlying reasons, for example motivated scepticism or defensive coping strategies (Scherer et al., 2013). Likpus and Peters (2009) suggested that such strategies are particularly used by the less numerate. In their quantitative study, Scherer et al. (2013) found that many women believed their risk number did not adequately account for family history and personal background. Our qualitative study confirmed these findings for cardiometabolic risk. To counterbalance these doubts, access to background information of the test should be provided. For the test in this study, it could be mentioned why only seven questions are needed for the risk estimation and that dietary habits, physical activity, stress, and alcohol use are not needed in this first screening step. One could also consider the development of a more elaborated risk calculator that does take into account more lifestyle factors.

A flaw in current risk information was the lack of detailed information about risk reduction, which may have contributed to people’s neglect of relevant risk factors. As described in the literature about (cognitive) representations of illnesses, one key dimension of representations concerns the control of the particular illness, for example: What can I do to control the symptoms? (Cameron & Leventhal, 2003). So it seems obvious that risk assessments also provide detailed information about this. In our study, people appeared to be in need of such information, a finding also demonstrated by Holmberg et al. (2011). The lack of information may have influenced people’s feelings of personal vulnerability and their risk number acceptance, as a lack of insight into risk-reducing options may have led to persistent feelings of a non-controllable risk.

Another finding was that much information was not appropriate to people’s existing knowledge about cardiometabolic risk, resulting in their risk interpretations remaining somewhat inconclusive. One important example was the texts about cardiometabolic diseases throughout the test. Because people did not have a clear picture of these diseases, let alone an idea of their interrelatedness, one can question whether the essence of the communicated risk was really understood (a risk of what exactly? What are the consequences of an elevated risk? Zikmund-Fisher et al., 2010). We saw that risk information was often interpreted narrowly, namely in terms of one of the three diseases, and that the term ‘elevated risk’ had superficial meaning. An important question is how a proper framework for understanding disease risk can be provided. Some minimal framework seems needed, in which key physiological processes (e.g., veins that sludge) are emphasized. An explanation of what it means to be at elevated risk should also be given, that is that some physical damage is already apparent more than in healthy individuals, despite the absence of health complaints. However, all these recommendations produce extra information, and we should be wary of information overload. Therefore, one might also think of alternative ways to present information, such as video narratives (Shaffer, Owens, & Zikmund-Fisher, 2013).

We also found that the purpose and the setting of the risk assessment remained unclear to people. The risk test is a first step to potential further screening by the GP, in which the aim is to increase risk awareness and guide health decisions. However, few participants seemed to understand and/or appreciate this, as many with relatively high risks found it unnecessary to visit their GP. It may be that people with low health literacy are reluctant to visit their GP in the case of an elevated risk, because they are unfamiliar with screening and/or think it will burden their physician. It may also be that compared to people with higher health literacy, those with lower health literacy have a low ‘preventive attitude’,
comparable to the differences between lower and higher SES people (Goldstein, 1992; Wardle et al., 2004). This might result in people with lower health literacy having more trouble in understanding the idea of ‘being at risk’. In any case, the provided information did not succeed in altering such perceptions and may even have contributed to uncertainties.

A final finding to reflect on was that people did not actively consider the decision options following from the risk assessment, namely altering one’s lifestyle and/or visiting one’s GP. It seems plausible that the test’s framework, which is not a decision aid but ‘only’ a risk assessment, may have contributed to this. However, our findings suggest that people with low health literacy are in need of more active guidance towards these options, as they indicated a wish for specific advice on risk reduction and lifestyle modification, and also needed more information about the role of the GP.

Limitations and further research
A limitation was that although people were told their personal risk, decisions to be made were only hypothetically discussed. If people are actually invited by their own GP and perform the test at home, they may process information differently and may be more convinced of the need to visit their GP in the case of an elevated risk. This study may also be partly limited by the fact that participants with low health literacy found it hard to say anything that came to their mind and that this interview part did not provide us with rich data. Other researchers also experienced this (Smith et al., 2013). However, the probing questions did work well, and we think that, using these questions, we were able to identify themes reflecting barriers in information use. We found that several themes were more apparent among people with lower levels of health literacy, health numeracy, and graph literacy, most notably the undervaluation of the risk number. Quantitative studies are needed to ascertain how information comprehension and use differs among these different groups.

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References


Appendix: Summary of the interview protocol and accompanying short questionnaire

**Part 1: Saying anything that comes to mind**
This is the Website www.testuwrisico.nl. You can use the Website for about 20 min, just like you would do at home. It is important that you say anything that comes to your mind while using the Website, about what you are doing and why and what you are thinking.

- What comes to your mind when you see this information?
- Where is this information about? What does it say to you?
- You were looking at. What were you thinking?

**Part 2: Probing**
I would like to consider several parts of the information in more detail with you. I will ask you some questions about these parts of the information.

*If you have an elevated risk, you are advised to visit your GP. It can be possible that your GP does not work with the PreventionConsultation yet. But even in that case, he or she will be able to advise you what to do in case of an elevated risk. Take along your test results from this risk test if you will visit your GP.*

- Can you explain in your own words what an ‘elevated risk’ means?

*Men from the age of 60 years and women from the age of 65 years have an elevated risk because of their age, and they don’t need to do this test.*

- Can you explain in your own words what this means?

*(Family history type 2 diabetes) Does your father, mother, brother or sister have diabetes type 2?*

- Can you explain to me what is meant here?
- What does diabetes type 2 mean?
(Question BMI). Your BMI: (underweight, overweight, or normal weight).

- What does this BMI mean to you?

(Page risk communication): Your risk of developing CVD, diabetes or chronic kidney disease is...%. This means that of every 100 men/women having the same score as you, ... will develop CVD, diabetes or chronic kidney disease between now and 7 years. Your risk is thus (slightly elevated, elevated, considerably elevated etc.)

- What does this risk mean to you? Can you explain that to me?
- What do you think if you look at this information?

(Overall)

- If you would explain the test result to your neighbours, how would you do that?

Part 3: Decision-making
I would like you to do as if you were making a decision based on the information that has just been provided to you.

- What would be your decision? What would you do first?
- What would this information mean concerning your decision?

Questionnaire

Demographic variables
Are you male or female?

- Male
- Female

What is your year of birth?

19____

What is your highest education?

- No education
- Primary school
- Lower vocational education
- Medium general continued education
- Medium vocational education
- Higher general continued education
- Higher education
- Academic education (university)
- Other:

Which description suits most to you currently?

- Student
- Employed
- Unemployed
- Disabled
- Housewife/man
- Pensioner

What language do you usually speak at home?

- Dutch
- Fries
How would you describe your general health?
- Excellent
- Very good
- Good
- Moderate
- Bad

Health numeracy
- Imagine that we flip a fair coin 1,000 times. What is your best guess about how many times the coin would come up heads in 1,000 flips? 
  ... times out of 1,000.
- In the BIG BUCKS LOTTERY, the chance of winning a $10 prize is 1%. What is your best guess about how many people would win a $10 prize if 1,000 people each buy a single ticket to BIG BUCKS? 
  ... person(s) out of 1,000.
- In a contest of a large store chain, the chance of winning a car is 1 in 1,000. What per cent of the participants will win a car? 
  ... %

Proxy for graph literacy
Here is some information about cancer therapies

![Bar graph showing percentages of patients recovered after different treatments](image)

- What percentage of patients recovered after chemotherapy?
  ________ %
- What is the difference between the percentage of patients who recovered after a surgery and the percentage of patients who recovered after radiation therapy?
  ________ %
Here is some other information about cancer therapies

- What is the percentage of cancer patients who die after chemotherapy?
  ________ %