Use of focus groups to develop methods to communicate cardiovascular disease risk and potential for risk reduction to people with type 2 diabetes

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Background. People need to perceive a risk in order to build an intention-to-change behaviour yet our ability to interpret information about risk is highly variable.

Objectives. We aimed to use a user-centred design process to develop an animated interface for the UK Prospective Diabetes Study (UKPDS) Risk Engine to illustrate cardiovascular disease (CVD) risk and the potential to reduce this risk. In addition, we sought to use the same approach to develop a brief lifestyle advice intervention.

Methods. Three focus groups were held. Participants were provided with examples of materials used to communicate CVD risk and a leaflet containing a draft brief lifestyle advice intervention and considered their potential to increase motivation-to-change behaviours including diet, physical activity, and smoking in order to reduce CVD risk. Discussions were tape-recorded, transcribed and coded and recurring themes sought.

Results. Sixty-two percent of participants were male, mean age was 66 years (range = 47–76 years) and median age at leaving full-time education was 18 years (range = 15–40 years). Sixteen had type 2 diabetes and none had a prior history of CVD. Recurring themes from focus group discussions included the following: being less numerate is common, CVD risk reduction is important and a clear visual representation aids comprehension.

Conclusion. A simple animated interface of the UKPDS Risk Engine to illustrate CVD risk and the potential for reducing this risk has been developed for use as a motivational tool, along with a brief lifestyle advice intervention. Future work will investigate whether use of this interactive version of the UKPDS Risk Engine and brief lifestyle advice is associated with increased behavioural intentions and changes in health behaviours designed to reduce CVD risk.

Keywords. Cardiovascular disease, risk communication, type 2 diabetes.

Introduction

Perception of risk is an important precursor of intention-to-change behaviour yet research to date is unclear on how to best present information on risk.

Communication of risk
The communication of information concerning risk is gaining increasing prominence in routine clinical practice not least because of government screening initiatives focusing on individuals at increased risk. Despite this, there is no clear consensus on how this is best achieved.

Framing
The way in which risk is presented can influence patient decision making (framing). Patients are more likely to accept a treatment when risk is presented as a relative...
risk reduction rather than as a number needed to treat, personal probability of benefit or absolute risk.\textsuperscript{2}


Visual aids

The use of visual aids has been recommended wherever possible\textsuperscript{3} in order to increase the effectiveness of risk communication.\textsuperscript{4} Computer-generated personalized predictions of cardiovascular risk-adjusted age have been described as engaging and memorable\textsuperscript{5} and have already been used successfully for cardiovascular disease (CVD) risk reduction.\textsuperscript{6} This is despite the difficulties faced in conveying the importance of asymptomatic risk factors.\textsuperscript{7} A need to develop and assess the effectiveness of different formats for communicating risk information has been highlighted.\textsuperscript{4}

Content

Any risk information provided should be relevant but the minimum required to make a decision as the ability to assimilate information varies.\textsuperscript{4} The likelihood of hypertensive patients taking their medication as prescribed increases with increasingly accurate knowledge of the disease\textsuperscript{8} yet, conversely, the provision of information has also been associated with a decreased uptake of treatment.\textsuperscript{4}

Individuals with diabetes

Patients with type 2 diabetes have a 2- to 4-fold increased risk of CVD\textsuperscript{9} but have been shown to be both unaware of and to overestimate their risk of future CVD.\textsuperscript{10,11} Unawareness of risk may mean that risk-reducing behaviours are not adopted and overestimating risk may increase anxiety unnecessarily and hamper informed decision making.\textsuperscript{12} Focus group research carried out in Ireland has shown that awareness of microvascular complications among individuals with diabetes is far greater than that of macrovascular complications.\textsuperscript{13} Hence, the need for an effective CVD risk communication tool for individuals with diabetes to increase awareness of this important complication.

We aimed to use a user-centred design process to develop an animated interface for the UK Prospective Diabetes Study (UKPDS) Risk Engine to illustrate CVD risk and the potential to reduce this risk. In addition, we sought to use the same approach to develop a brief lifestyle advice intervention.

Methods

Study design, participants and data collection

Our approach was designed to identify themes during data collection, rather than test predetermined hypotheses. Three focus groups (group interviews) were held with 21 adults in Oxford in January 2008. Participants were recruited from a database compiled by the Oxford Centre for Diabetes Endocrinology and Metabolism (OCDEM) clinical research unit of individuals expressing interest in taking part in research studies. All participants gave written informed consent and the study received approval from the Milton Keynes Local Research Ethics Committee.

The focus groups were held in seminar rooms at OCDEM. They were audiotaped and transcribed verbatim. Each focus group lasted \~90 minutes. Participants received no financial incentive for taking part but were reimbursed their travelling expenses and were given drinks and light refreshments during the sessions.

The groups were moderated by a clinical research fellow with an interest in using personalized CVD risk information as a motivator of behaviour change (Hermione Price). The assistant moderators (BB and CD) were diabetes specialist research nurses. A question map of open-ended questions was used during the groups (Appendix 1).

To compare participants’ reactions to commonly used visual risk communication material, examples were provided to each participant \~1 week prior to the group meeting. Although some of the examples were interactive computer-based tools, these were not demonstrated during the focus groups but a brief explanation of how each worked was given.

The scenarios provided included a 65-year-old man,\textsuperscript{14} a 60-year-old man\textsuperscript{15} and a 54-year-old woman, all with an estimated 10-year CVD risk of 13% calculated using the Framingham risk equations.\textsuperscript{16,17} Participants were also shown images of The Paling Perspective Scale\textsuperscript{©}, crowd charts depicting 100 faces with colours indicating the proportion of individuals affected,\textsuperscript{4} New Zealand CVD risk charts\textsuperscript{18} and British Hypertension Society risk charts.\textsuperscript{19} They were also shown a simple bar chart shaded from blue to red (through green, yellow and orange) to represent lowest and highest possible risk for an individual of that age and sex with a second bar next to it to represent current personal risk.\textsuperscript{20}

Participants were provided with a draft version of a CVD risk reduction brief lifestyle advice intervention based on self-regulation theory\textsuperscript{21} and their opinions regarding its content and likelihood of motivating behaviour change were sought. The intervention focused on five target behaviours: increasing physical activity, increasing fruit and vegetable intake, reducing alcohol intake, adherence to prescription medication and smoking cessation.

Data analysis

Preliminary analyses began as each focus group transcript was completed. After completion of three focus groups, we recognized that we had reached a level of data saturation as comments were becoming repetitive. In-depth analysis of the transcripts was undertaken once all three focus groups had been completed. The tape recordings were listened to and
the transcripts read repeatedly. Codes were then developed and the transcripts were coded line by line but a qualitative data indexing software package was not used. New codes were generated during this process as required. Following coding, recurring themes, similar patterns and distinctions were sought and supportive quotations were identified. Themes were not predetermined. All the analyses were completed by the lead author. The themes were not referred back to the focus group participants but they were invited to take part in a pilot study using the interventions developed.22

Development of brief lifestyle advice and UKPDS Risk Engine interface
The interpretations of these data were used to refine the brief lifestyle intervention and to design an interactive display version of the UKPDS Risk Engine that could illustrate potential reductions in CVD risk. The UKPDS Risk Engine interface chosen was that which best reflected the most common requirements, including the incorporation of sliders to demonstrate the accumulation of risk and a traffic light colour scheme. The interface was not tested again prior to its incorporation as an intervention into a CVD risk reduction study.22

Results
Mean age of the 21 participants was 66 years (range = 47–76); 62% were male and the median age at leaving full time education was 18 years (range = 15–40). Sixteen had type 2 diabetes and none had a prior history of CVD. All three focus groups were held in the same building and included participants from mixed educational levels.

Three recurring themes emerged. The first is that being less numerate is common and that for many people numbers are incomprehensible (Box 1). This was particularly true of older women focus group participants. The second theme was that CVD risk reduction is important (Box 2). Participants expressed a wish to be at or below average risk and were willing to modify behaviour to achieve this even if it meant only a modest reduction in absolute risk. The idea of personalized risk information was appealing and preferred over more general information but needed to be accompanied by risk reduction strategies. The third theme concerned the visual representation of risk (Box 3). Participants felt a clear visual representation of risk aided comprehension particularly when demonstrating how risk is accumulated. The ability to use sliders and option buttons to demonstrate the impact of changes (for example, reducing blood pressure) on 10-year CVD risk was popular. A traffic light system of colours was considered a universally comprehensible method of conveying risk information. The size of any graphical interface should be such that it fills the entire computer screen on which it is displayed.

Responses to visual representations of risk
New Zealand risk charts. These were disliked by the majority of participants Box 4. Participants explained that although consisting of 16 different boxes only one would be relevant to any one individual. The colour scheme was also unpopular with a strongly held view that the highest risk boxes should be shaded red and not pink.

The heart attack risk calculator. This was viewed more positively. The comparison to other people of the same age was popular.

Crowd chart. This was very unpopular. It did not resonate with any of the participants. It was considered to be confusing and incomprehensible.

The National cholesterol education risk score/The British Hypertension Society charts/healthlink. These visual representations generated few comments.

The Paling Perspective Scale. The Paling Perspective Scale was disliked by all. It was considered confusing and irrelevant.

Your disease risk bar charts. The bar charts used by your disease risk provoked varied responses. Some liked the colour scheme but other preferred the standard traffic light scheme. Many commented on the unnecessary second bar present.

Responses to draft brief lifestyle advice intervention
The participants largely felt more comfortable with the information contained in the brief lifestyle advice intervention than they did with the CVD risk material (Box 5).

Participants felt that the health messages contained within the intervention were well known and considered to be true. They felt that the intervention did not contain any confusing or conflicting health messages. Participants did not, however, like rigid targets for exercise and fruit and vegetable intake. Instead, they wanted an intervention that encouraged them to do as

<table>
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<tr>
<th>Box 1 Supportive quotations for the theme of being less numerate</th>
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<td>Participant 1 ‘Numbers defeat me’</td>
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<td>Participant 2 ‘I prefer words to numbers’</td>
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much as they can. There was also a strong feeling in all
the groups that the intervention should acknowledge
each individual's own circumstances that may make
following the lifestyle advice more difficult, for exam-
ple family commitments limiting time for exercise or
financial constraints restricting fruit and vegetable
intake.

Five participants with diabetes were unaware of the
link between diabetes and heart attacks and wanted
more explanation as to why this is the case.

There was also concern that, in its present state,
the intervention assumed everyone was smoking or
drinking too much alcohol that may not always be
the case.

Box 2  Supportive quotations for the theme of the importance or CVD risk reduction

Participant 3 ‘Yes, but then he could say to me “well look, you’re here if you worked harder on your blood pressure by doing a bit more exer-
cise or blah blah blah then we could bring it down to here, but look if you took the statins then you could bring the risk this way a bit”’ and so
I think . . . it is useful’
Participant 4 ‘I’ve been doing this, that and that it should have come down, it’s giving you something to . . . to aim for’
Moderator ‘If you were 13% and your GP said right, if you drink a little bit less, do that 30 minutes walking a day and come back and see me
in 6 months and you’ll be 9%. You would consider that something worth doing? . . . Even though 4% might not sound very much, that would
be enough to make you do it?’
Participant 5 ‘But it’s not 4% is it, cos, it’s actually nearly 50%.’

Box 3  Supportive quotations for the theme of visual representation of risk

Participant 6 ‘what I’d like to know is, how much does that factor contribute to the risks?’
Participant 3 ‘by putting the sliders up and down . . . people could see . . . how much the risk factors affected their outcome’
Participant 7 ‘That’s the more usual arrangement where red for danger, green for you know, go.’
Participant 7 ‘Green for good and red for bad . . . it’s just that it’s a convention that every body knows and every body understands and you
don’t have to explain’
Participant 6 ‘a traffic light system then, 3 colours’
Participant 8 ‘It’s too small! Can’t even read it. I won’t even bother trying.’
Participant 4 ‘If those are going to be used they’ve got to be larger.’

Box 4  Supportive quotations for the opinions regarding existing representations of risk

New Zealand Risk Charts
Participant 6 ‘you don’t want 16 squares on there when only one applies to you’
Participant 8 ‘I would strongly support the view that red should be the highest’
The Heart Attack Risk Calculator
Participant 2 ‘The heart attack calculator. I thought that was particularly good’
Crowd Chart
Participant 7 ‘I didn’t understand the one with all the faces on’
The Paling Perspective Scale
Participant 4 ‘I thought that was rubbish’
Participant 4 ‘Risk of death from resident being killed by crashing aeroplane, I’ve got a job to even think about that. Risk of being killed by
lightening well, again I can’t really see the relevance’
Participant 9 ‘What is a trillion, how do you get your head around that?’
Your disease risk bar charts
Participant 10 ‘It sort of strikes you as, more accurate, it goes from blue up to red’
Participant 3 ‘Except that the second bar . . . is functionless, why is the second bar there? The first one was fine.’
We have used focus groups to inform the design of a simple graphical method (Fig. 1) for illustrating likely risk reductions and a brief lifestyle intervention for use as motivational tools.

Discussion

Our focus group discussions have shown that among our sample of late middle-aged British public being less numerate is common; CVD risk reduction is considered important and clear visual representations of risk aid comprehension. These findings have allowed us to produce a brief lifestyle advice intervention and develop an interactive UKPDS Risk Engine interface that should have high acceptability and comprehension by their target audience.

Strengths and limitations

The participants in this study were recruited through a database of individuals willing to take part in research and their education level was high. As such, they may not be truly representative of the late middle-aged British population. However, interest in the topic could be considered high given that the response rate to invitations to take part in the focus groups was 30%. In order to confirm our findings, we could repeat the focus groups with individuals from a broader range of educational backgrounds and include individuals from a variety of ethnic groups. Our study is liable to bias and the focus groups were transcribed and analyzed by one person without the aid of a suitable software package. Our results are, however, in keeping with another similar study.23

Some of the risk communication examples discussed were interactive computer-based tools and we assumed a degree of familiarity with computers in our participants. This is not unreasonable as data from the US shows 55% of adults aged 60–64 years have access to a home computer.24 Access to a home computer does decline with advancing age falling to 16% of those aged >90 years.24 A study in the US has also shown that with appropriate training older adults are able to successfully play complex strategic computer games25 suggesting that our interface could be used by our target audience with some instruction.

Risk communication

We have added to the literature that there is interest in knowing your personal risk of having a CVD event in the next 10 years particularly when this is accompanied by information about how to reduce risk. We have also concurred with similar previous findings that any risk communication tool will not be universally acceptable to all patients.26

Development of a brief lifestyle advice intervention

In terms of developing a brief lifestyle advice intervention, we have incorporated the findings from the focus groups that rigid targets are unhelpful but that general guidelines are acceptable and useful. Any reference to government health policy should be avoided and health care professionals are ideally placed to deliver such an intervention as they represent the most trusted source of health care information. An acceptance of individual circumstances should also be included in any lifestyle intervention to acknowledge that lifestyle choices are influenced by many other factors (finances,

Box 5 Supportive quotations for the opinions regarding the draft brief lifestyle advice intervention

Participant 1 ‘This stuff is lovely. I can get to grips with this.’
Participant 11 ‘Do you think that that recommendation to walk for 30 minutes a day. Was that something that you’d heard of before?’
Participant 12 ‘There was a lot of it I think that we have heard.’
Participant 13 ‘Absolutely’
Participant 14 ‘It does make the assumption that everybody is drinking too much alcohol . . . we might not be’
family commitments, etc.), besides a desire to be healthy and protect one against future disease events. As in an earlier study, we have also found that the concepts of luck and fate play a role in individual’s perceptions about future ill health.23 The health messages contained within the lifestyle intervention were well known and it was accepted that following the lifestyle advice would be advantageous to health.

Visual representation of risk and development of an interactive UKPDS Risk Engine interface
To date, there has been a paucity of data regarding differing forms of numerical presentation and it has been noted that visual aids need pilot testing with their target group in order to assess applicability and interpretation.27 It has also been shown that whilst many decision aids are available few have been evaluated.27 Trials indicate that decision aids improve knowledge and realistic expectations, enhance active participation in decision making, lower decisional conflict, decrease the proportion of people remaining undecided and improve agreement between values and choice.27 The effects on persistence with chosen therapies and cost-effectiveness have yet to be evaluated.27 Others have highlighted the benefits of information tailored to the individual patient, for example calculation of stroke risk based on individual patient characteristics rather than quoting an average risk.26 The same authors have promoted the idea of using online or interactive formats allowing real-time presentation of individual risk and an interactive discussion of risk.26

Clear messages emerged from our focus group participants concerning risk communication. Participants felt very strongly about the colour scheme that should be used to communicate risk and clearly felt that deviation from the accepted traffic light colour scheme was unhelpful to patients. The font size of text was also important in order to facilitate understanding. Finally, the use of interactive buttons and sliders that demonstrated the accumulation of risk was viewed favourably. Our findings are likely to be applicable to many clinical situations requiring a discussion of risk and may assist others wishing to design a user-centred risk communication tool. The international patient decision aid standards collaboration have published a checklist that can be used to assist with the production of risk communication materials28 and our findings are in agreement with many of the elements of the checklist. The UKPDS Risk Engine interface we have developed also complies with the majority of the checklist, including the ability to compare outcome probabilities using the same denominator, time period and scale and it allows patients to view probabilities based on their own situation. It also includes multiple methods of viewing probabilities including numbers and graphics and uses a traffic light colour scheme.

Conclusion
We have developed a risk communication tool and a brief lifestyle advice intervention aimed at reducing CVD risk in individuals at high risk. This has been developed with the aid of focus groups and other published evidence. In order to evaluate these further, we plan to undertake a randomized controlled trial with a 2 × 2 factorial design to determine the ability of each intervention to motivate individuals to adopt lifestyle changes aimed at reducing their CVD risk.22 We hope ultimately to produce an evidence-based CVD risk reduction intervention that can be used in routine clinical practice. Finally, our key recommendations for producing a comprehensive risk communication tool: use a traffic light system of colours, use a large font size and make the tool interactive.
Declaration

Funding: Diabetes Trials Unit Fellowship (to H.C.P.).

Ethical approval: Milton Keynes Local Research Ethics Committee.

Conflict of interest: none.

References


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Appendix 1

The Understanding Risk Focus Groups Question Map

Introduction

What the research is about?

The Understanding Risk Pilot Study is a randomized study to investigate the effect of personalized heart disease risk information on physical activity levels in adults at high risk of developing heart disease.

What will be done with the research?

The information collected will be used to design the risk information and develop the lifestyle advice that is given to participants in the Understanding Risk trial. For example, is the advice useful, informative, helpful or are things missing, need expanding or unclear.

Purpose of focus group

Group interview

Confidentiality

All information collected will be confidential and the anonymity of participants preserved in any publications of the research findings.

Opinions

No right or wrong answers

Questions

Some questions may seem obvious but this is to ensure that we are absolutely clear about what is being said.

Opening Circle

Name

Relevant information
Initial view on subject matter

Introductory Questions
Ask if everyone has had the opportunity to read the risk information
Ask if there were any terms that were not understood by participants

Key Questions
Thoughts on each example of risk representation and draft brief lifestyle advice intervention

Is it comprehensible?
Is it acceptable?

Ending Questions
Does anyone have any final comments that they would like to make or feel we have not covered.

Closing circle
How have you found the experience today?
What could we do to improve for subsequent focus groups?