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Supporting national policy development and implementation

Cardiovascular risk communication:
Systematic review of qualitative evidence

DRAFT REPORT

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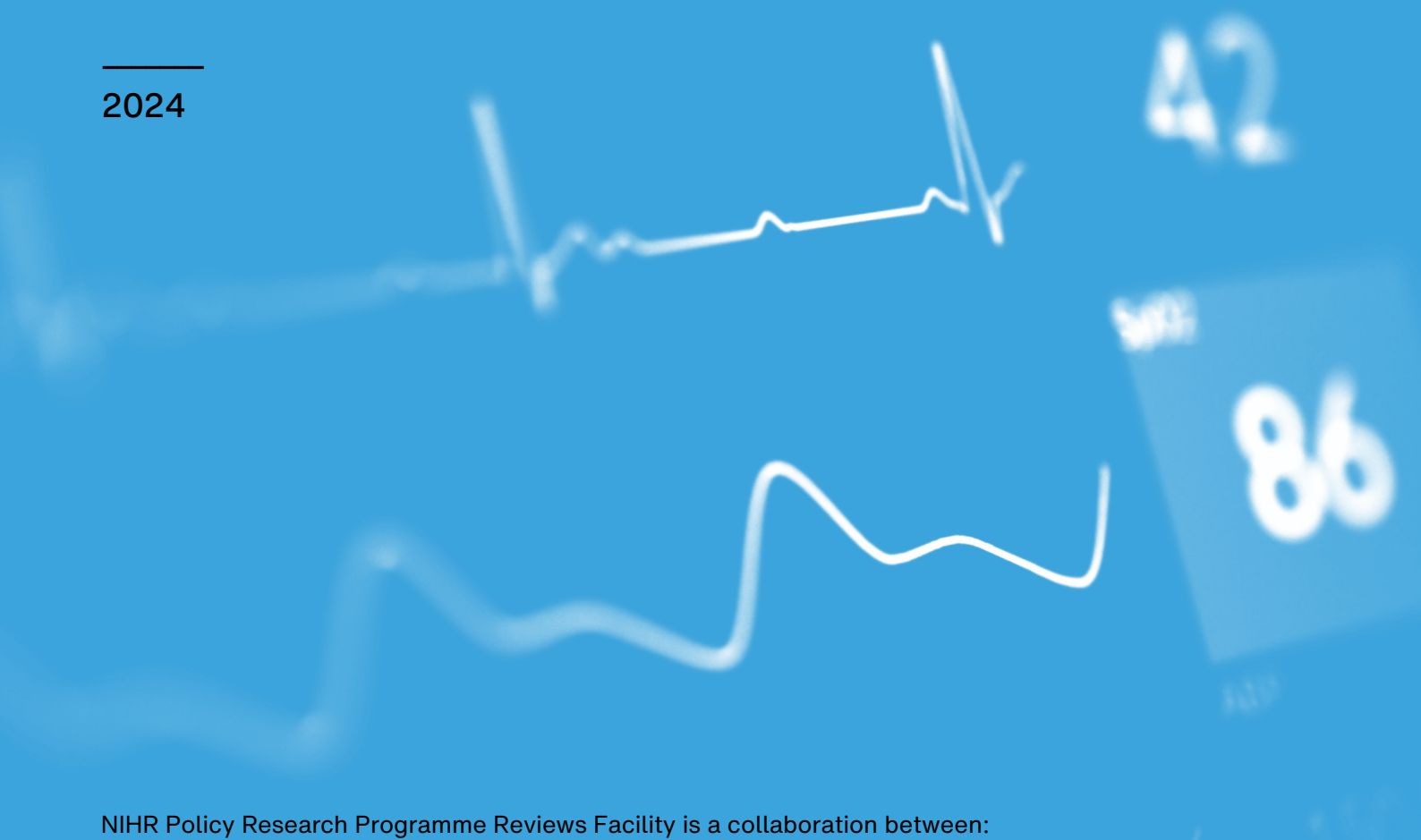

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Contributions

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1 Summary

This report presents the findings of a systematic review of qualitative evidence commissioned to support policy development for the NHS Health Checks programme. The review focuses on views and experiences of cardiovascular risk assessment and risk communication.

We searched four database sources in October 2022 using terms for cardiovascular disease, risk communication, and qualitative research. We included primary qualitative studies focusing on the assessment of cardiovascular risk and the communication of risk scores to individuals conducted in high-income (OECD member) countries.

The review included 37 studies. The findings show that many people do not understand the meaning of risk scores, or do not see them as practically relevant. Some people are sceptical about the validity of risk models, and often see risk scores regarded as moderate or high risk in clinical practice as not a cause for concern. Other sources of information – subjective health status, lifestyle behaviours or family history – feed into informal estimates of risk which may lead people to reject the results of clinical risk assessment when the two conflict. Data on the impact of risk communication is mixed: many people report intentions to change lifestyle as a result of learning their risk score, but others report that it makes little difference.

Clinicians are broadly positive in their views of risk assessment, but identify several barriers at patient level, including: understanding of probability or risk; excessive anxiety about risk, or indifference to future risks; and low risk scores removing motivation for lifestyle change. They find that individuals vary widely in their reactions and understanding, and have a range of strategies for adapting risk communication accordingly.

Both clinicians and individuals have some specific preferences for risk communication, including a preference for: visually engaging formats; heart age rather than absolute risk; and the ability to manipulate data inputs.

The findings suggest that people are more likely to understand ways of communicating risk which provide some comparison or reference point beyond a simple probability score. More generally, the broader communication and signposting around risk assessment may be as important in determining the messages received as the detail of risk scoring itself. The findings also arguably point to some gaps in theoretical models of risk communication: in particular, they indicate that the epistemic value of absolute risk to the individual is under-specified in the theory. Risk communication interventions are based on a rationalistic model of decision-making, but as enacted in practice, may be more about appeals to emotion.

2 Background

Several different tools are available for calculating individuals' risk of cardiovascular disease, such as the Framingham Risk Score (Wilson *et al.*, 1998) and QRISK (Hippisley-Cox *et al.*, 2007, 2008). These tools combine information about individuals' demographics, behaviours and clinical measurements (for example, blood pressure, cholesterol) to estimate their risk of cardiovascular disease, either over a limited timeframe (generally 5 or 10 years) or over their whole lifetime. Risk scoring tools were originally developed to inform clinical decision making, particularly for risk stratification to assist in decisions about treatment for diagnosed cardiovascular disease, or about preventive care for people at high risk. More recently there has been interest in using them more broadly to raise awareness of cardiovascular disease, and to help to motivate behaviour change to reduce risk. The focus of this review is on the latter, i.e. the communication of risk to individuals, with the aim of increasing their understanding of risk and helping them to make decisions about how to reduce risk, rather than on decision-making around treatment.

There is a substantial body of evidence on the effectiveness of incorporating cardiovascular risk assessment into clinical care in reducing cardiovascular risk factors (Collins *et al.*, 2017; Karmali *et al.*, 2017; Studziński *et al.*, 2019) – although it is not always clear from these studies how risk assessments are being utilised – and a smaller number of studies comparing different ways of communicating risk (Bonner *et al.*, 2021; Schulberg *et al.*, 2022). However, there remains considerable uncertainty in the findings of this research (Karmali *et al.*, 2017; Studziński *et al.*, 2019). Qualitative evidence can help to illuminate the complex pathways through which risk communication can lead to positive health outcomes, to understand how clinicians and patients approach risk in practice, and to identify barriers and facilitators of successful communication. One previous systematic review covers some of these studies (Muthee *et al.*, 2020), but that review does not carry out a synthesis of qualitative data. There is thus a need for a more focused review of qualitative evidence.

This review was commissioned to inform policy development for the NHS Health Check programme. The NHS Health Check programme, which has been in place since 2009, aims to promote early identification and management of cardiovascular risk factors among adults aged 40-74 without cardiovascular disease. A key part of this process is the standardised assessment of cardiovascular risk using QRISK3 (Public Health England, 2019). A recent policy review of NHS Health Checks identifies several strategic goals for future development, including more effectively supporting individuals to understand and manage their cardiovascular risk, and launching a new digital pathway for the Health Check (Office for Health Improvement and Disparities, 2021). This research aims to assist this rethinking of the programme by bringing together evidence on individuals' and clinicians' views and experiences of cardiovascular risk assessment, and identifying barriers to effective risk communication.

3 Aims and methods

3.1 Aims

The aim of this review was to synthesise evidence from qualitative research about individuals' and clinicians' views of cardiovascular risk communication.

3.2 Methods

The review was registered on PROSPERO before starting work (registration number CRD42022380742). EPPI-Reviewer Web software was used to manage data.

3.2.1 Searching

The search strategy was designed by an Information Specialist (HF) in consultation with the review team. The strategy uses search terms to represent the following concepts: cardiovascular disease; risk assessment or risk communication; and qualitative studies. These concepts will be combined using the Boolean operator AND. Text word searches for terms appearing in the title or abstract fields of database records were included in the strategy alongside searches of relevant subject headings. The strategy used a geographic filter to limit papers to OECD countries and was also limited to English language papers. No date limits were applied to the search. The search was initially developed in MEDLINE and later adapted with relevant subject headings (controlled vocabularies) and search syntax, appropriate to each resource. The full MEDLINE search strategy is presented in Appendix 1. The following databases were searched in October 2022: MEDLINE(R) ALL (Ovid); Embase (Ovid); PsycINFO (Ovid); and CINAHL (EBSCO).

The reference lists of included studies and relevant systematic reviews were screened for additional studies, and forward citation chasing was performed using Google Scholar.

3.2.2 Screening

The studies were screened against the following criteria:

1. Does the study report primary qualitative data, or a systematic review of qualitative studies?
   (*Exclude* non-research publications (commentaries, editorials etc.). *Exclude* protocols. *Exclude* studies only reporting quantitative views data.)
2. Does the study focus on the assessment or measurement of cardiovascular risk in people without diagnosed cardiovascular disease?
   (*Exclude* views about cardiovascular disease or risk factors in general. *Exclude* studies which include cardiovascular risk as a secondary topic. *Include* studies of NHS Health Checks.)
3. Does the study report substantive data on the views of clinicians or patients about the communication of cardiovascular risk?
   (Exclude studies solely focusing on clinicians' use of cardiovascular risk

assessment to inform decisions about care, where it is unclear that risk was communicated to individuals. *Exclude* studies of patients' views of risk generally, without data on clinician-patient communication. *Include* studies of decision support tools.)

4. Was the study conducted in a high-income country (OECD member)?
5. Is the study available in English?

An initial sample of 10% of titles and abstracts were screened by two reviewers, and differences resolved by discussion. Agreement on these was high (99.7% agreement on inclusion, Cohen's κ=0.908), so the remaining titles and abstracts were screened by one reviewer alone. All full-text references were screened by two reviewers independently (TL and GS, both systematic review methodologists with expertise in public health and qualitative research).

3.2.3 Quality assessment and data extraction

The quality of included studies was assessed using Hawker et al.'s tool (Hawker *et al.*, 2002); see Appendix 2. Contextual data on the studies was extracted using a standardised form including information on the study methods (sampling, data collection etc.), the characteristics of the sample, and so on. Qualitative data were coded line-by-line using the coding tool in EPPI-Reviewer web (only data meeting inclusion criteria were coded). Quality assessment and data extraction were conducted by one reviewer and checked in detail by a second.

3.2.4 Synthesis

A qualitative thematic synthesis was undertaken to identify key themes in the data (Barnett-Page and Thomas, 2009). The initial coding framework divided findings into patient and clinician data, and into the following broad categories: understanding of risk; contexts of risk communication; and impacts of receiving or communicating the risk score. Within this broad framework, we used a grounded-theory methodology to develop codes inductively from the data. Coding was iterative; where new codes emerged during the process of synthesis, all data were re-read to ensure they were captured across the data set.

4 Results

4.1 Flow of literature through the review

The searches returned 7,298 unique results. After screening, a total of 37 studies were included in the review. The flow of literature through the review is shown in figure 1.

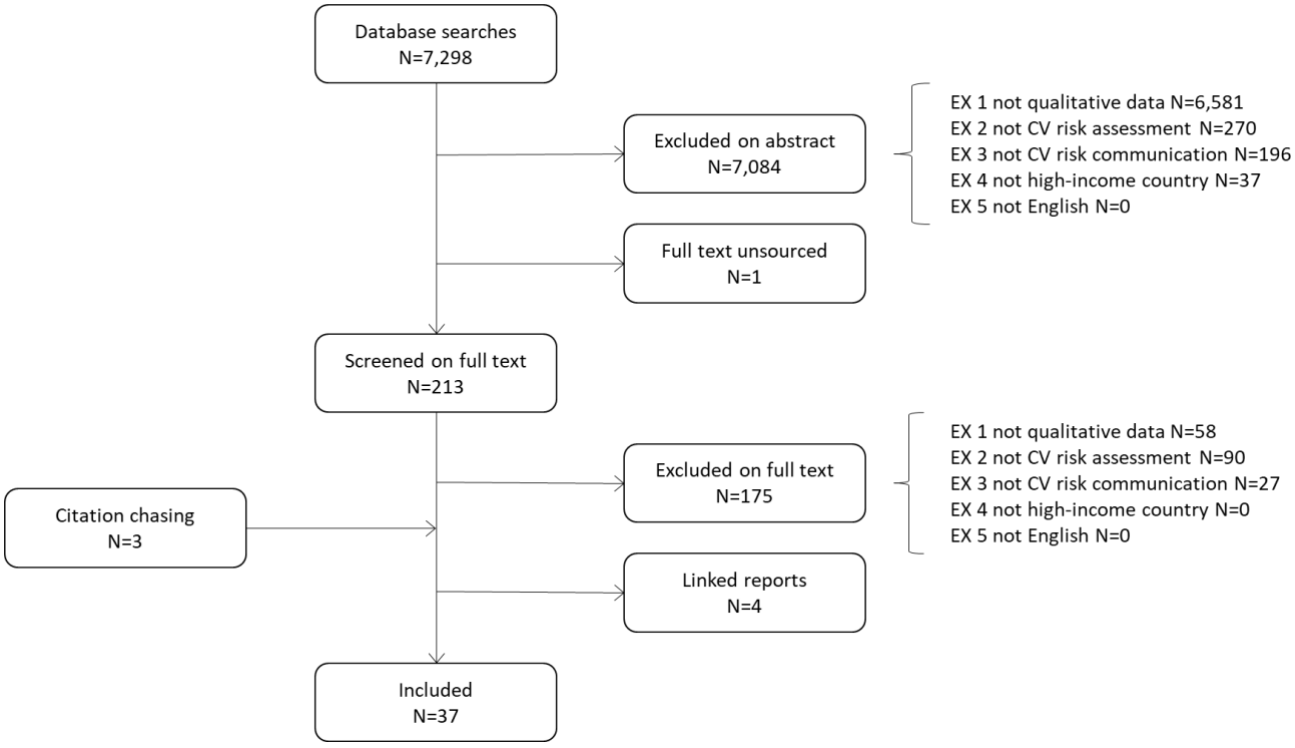

Figure 1. Flow of literature through the review

4.2 Quality assessment

The results of quality assessment are shown in table 1. The quality of the studies was moderate overall; there are some low scores on question 4 (sampling) and question 8 (transferability and generalisability), which may raise questions about the external validity of some of the data.

Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Bengtsson et al. (2021)	G	F	G	F	F	F	G	F	F
Boase et al. (2012)	G	G	F	F	G	F	G	P	F
Bonner et al. (2013; 2014)	G	F	G	G	F	F	F	F	G
Bonner, Jansen, Newell, et al. (2014)	G	G	G	P	F	F	F	P	G
Bonner et al. (2018)	G	G	F	P	F	F	G	P	F
Coorey et al. (2019)	G	F	G	P	F	F	F	P	F
Cupit et al. (2020)	F	G	P	P	P	F	F	P	P
Damman et al. (2016)	G	G	G	G	F	F	G	G	F
Damman et al. (2017)	G	G	G	G	F	F	G	G	P
Farrimond et al. (2010)	F	G	F	F	F	F	G	F	G
Frolund and Primdahl (2015)	G	F	G	G	F	F	F	G	F
Gidlow, Ellis, Cowap et al. (2021); Gidlow, Eliis, Riley et al. (2021); Riley et al. (2020)	G	G	F	G	F	F	G	G	G
Gooding et al. (2016)	G	F	F	F	F	F	F	F	F
Grauman et al. (2019); Grauman (2020)	G	G	G	F	G	G	G	F	G
Hall et al. (2007)	G	F	P	G	F	F	G	F	F
Hawking et al. (2019)	G	F	G	F	F	F	G	F	F
Hill et al. (2010)	G	G	G	F	G	F	G	F	G
Honey et al. (2015)	G	G	G	P	F	F	G	P	G
Kirby and Machen (2009)	G	F	F	F	F	F	F	P	F
Lenz, Kasper and Muhlhauser (2009)	G	F	G	F	F	F	F	P	F
Marshall, Wolfe and McKevitt (2018)	G	G	G	F	F	F	G	F	F
McKinn et al. (2016)	G	F	G	P	F	F	G	P	F
McNaughton (2018)	G	G	G	F	F	G	G	F	G
Middlemass et al. (2014)	G	F	F	P	F	F	G	P	G
Nielsen et al. (2009)	G	F	F	P	F	F	G	P	F
Nolan et al. (2015)	G	F	F	F	F	F	G	P	G
Peiris et al. (2009)	G	F	G	F	F	F	G	P	F
Perry et al. (2016)	F	G	F	F	F	P	G	F	F
Polak and Green (2015)	G	F	F	F	F	F	G	F	G
Riley et al. (2016)	G	G	G	G	F	F	G	G	F
Sheridan et al. (2009)	G	F	G	F	F	F	F	P	G
Snell and Helen (2020)	F	F	G	F	F	F	G	F	P
Taylor et al. (2021)	G	F	G	F	G	G	F	F	G
Usher-Smith et al. (2017)	G	F	F	F	F	P	G	P	F
Vaidya et al. (2012)	P	F	F	P	P	F	P	P	P
van Steenkiste et al. (2004)	P	G	F	V	F	F	F	P	F
Wan et al. (2008)	G	F	G	F	F	F	F	F	F

Table 1. Results of quality assessment

Key: G = good, F = fair, P = poor, V = very poor

4.3 Characteristics of the studies

Table 2 shows some of the general characteristics of the studies. The 'context' column aims to give some sense of the setting within which studies were conducted. This covers a wide range; broadly, there are five types of studies which concern:

1. established health check programmes in clinical settings which include cardiovascular risk assessment (mainly studies of NHS Health Checks, but also similar schemes in other countries), including people receiving health checks and/or clinicians responsible for delivering them;
2. clinicians' views and practices, generally in primary care settings, focusing either on risk assessment in routine practice (or, in one study, on the management of hypothetical cases) or on the introduction of specific new tools or risk models;
3. general population or specific risk groups, eliciting broad views of risk assessment;
4. trials or pilots of specific novel risk assessment tools, most using computer- or web-based interfaces, and one using in-person presentations;
5. general population or specific risk groups, eliciting reactions to the presentation of hypothetical risk data (i.e. where data inputs are not based on individuals' real values).

Reference	Country	Population (age)	Sample size	Context
Bengtsson et al. (2021)	Sweden	GPs	15	HC programme
Boase et al. (2012)	UK	Nurses	28	Primary care
Bonner et al. (2013; 2014)	Australia	GPs	25	Primary care
Bonner, Jansen, Newell, et al. (2014)	Australia	Gen. pop. (40-67)	26	Web-based risk tool
Bonner et al. (2018)	Australia	Gen. pop. (35-74)	25	Web-based risk tool
Coorey et al. (2019)	Australia	GPs + gen. pop. (mean 68)	72	Primary care (trial of web-based e-health intervention)
Cupit et al. (2020)	UK	Clinicians + gen. pop. + stakeholders	47	Primary care incl. NHS HC
Damman et al. (2016)	Nether-lands	Gen. pop. (mean 53) with low health literacy	23	Web-based risk tool
Damman et al .(2017)	Nether-lands	Gen. pop. (45-65)	16	Web-based risk tool
Farrimond et al. (2010)	UK	Gen. pop. (mean 58)	38	Primary care (trial of risk assessment incl. family history)

Frolund and Primdahl (2015)	Denmark	People with rheumatoid arthritis (51-70)	14	Specialist hospital service
Gidlow, Ellis, Cowap et al. (2021); Gidlow, Eliis, Riley et al. (2021); Riley et al. (2020)	UK	Clinicians + gen. pop. (40-74)	183	NHS HC (comparison of JBS3 and QRISK2 risk tools)
Gooding et al. (2016)	USA	Young people (17-21) + parents	72	Hypothetical risk results
Grauman et al. (2019); Grauman (2020)	Sweden	Gen. pop. (52-65)	31	HC programme
Hall et al. (2007)	UK	GPs + nurses + gen. pop. (20-60)	28	Primary care
Hawking et al. (2019)	UK	Gen. pop. (40-64)	18	NHS HC (trial of risk report)
Hill et al. (2010)	Australia	GPs + gen. pop. (mean 50)	37	Hypothetical risk tools
Honey et al. (2015)	UK	People at high CV risk (46-74)	37	NHS HC
Kirby and Machen (2009)	UK	GPs + nurses + gen. pop.	35	Primary care
Lenz, Kasper and Muhlhauser (2009)	Germany	Clinicians + people with type 2 diabetes	32	Hypothetical risk tools
Marshall, Wolfe and McKevitt (2018)	UK	People with hypertension (51-90)	24	Hypothetical risk tools
McKinn et al. (2016)	Australia	GPs	25	Hypothetical patients
McNaughton (2018)	UK	People at high CV risk (57-76)	26	NHS HC
Middlemass et al. (2014)	UK	Gen. pop. (median 59)	29	Primary care (genetic testing for CV risk)
Nielsen et al. (2009)	Denmark	Gen. pop.	22	HC programme
Nolan et al. (2015)	UK	People with diabetes (44-77)	36	Web-based risk tool
Peiris et al. (2009)	Australia	GPs	21	Primary care (pilot risk tool)
Perry et al. (2016)	UK	Gen. pop.	36	NHS HC
Polak and Green (2015)	UK	Gen. pop. (53-87)	34	General views
Riley et al. (2016)	UK	Clinicians + gen. pop. (>40)	43	NHS HC

Sheridan et al. (2009)	USA	People at moderate to high CV risk (52-75)	29	Pilot risk tool
Snell and Helen (2020)	Finland	Gen. pop. (46-65)	40	Hospital (risk assessment incl. genetic testing)
Taylor et al. (2021)	New Zealand	Gen. pop. (61-91)	39	General views
Usher-Smith et al. (2017)	UK	Gen. pop. (40-80)	37	Web-based risk tool
Vaidya et al. (2012)	Australia	GPs + gen. pop. (53-71)	70	Primary care (trial of risk tool)
van Steenkiste et al. (2004)	Nether-lands	GPs	15	Primary care
Wan et al. (2008)	Australia	GPs + gen. pop. (42-81) + stake-holders	57	Primary care

Table 2. Characteristics of the studies

Key: gen. pop. = general population; HC = health check

4.4 Thematic synthesis

The structure of the thematic coding is divided into two parts according to whether views were expressed by patients or clinicians (most studies focused on one or the other), except for views on specific preferences for risk communication, where we have combined the two. Codes were developed inductively in each category (table 2).

Patient data	Understanding of risk scores	General points
		Meaning of probability and credibility of risk scores
		Risk scores vs individual risk factors
		Self-rated health
		Genetics and family history
		Behaviours and lifestyles
	Impacts of risk assessment	Emotional reactions
		Reassurance
		Behaviour change
	Broader context	Perceptions of CVD
		Population subgroups
Clinician data		General attitudes and understanding of risk scores
		Perceptions of patient understanding
		Perceptions of patient behaviour and attitudes
		Strategies for communicating risk
		Impacts on care delivery
Specific preferences for risk communication		Visual representations
		Risk algorithms
		Modifiable inputs

4.4.1 Patient data: understanding of risk scores

General points

Two studies which directly aimed to assess participants' understanding of risk scores (using hypothetical results rather than real risk assessments) generally found that most participants did correctly understand the information presented (Lenz, Kasper and Muhlhauser, 2009; Marshall, Wolfe and McKevitt, 2018). However, other studies report widespread misunderstanding (Damman *et al.*, 2017), and participants in several studies express a lack of understanding of what the risk score referred to (Kirby and Machen, 2009; Bonner, Jansen, Newell, *et al.*, 2014; Nolan *et al.*, 2015; Polak and Green, 2015; Perry *et al.*, 2016; Damman *et al.*, 2017; Bonner *et al.*, 2018; Grauman *et al.*, 2019; Gidlow, Ellis, Cowap, *et al.*, 2021).

> Well, that I have a 2%, so I have 2. Well, what does it mean? Does it mean that 1, 2 days out of 100, I'm at risk of a heart attack. I don't know what that means. I have a 2% chance, I have a ... well, it sounds low but what does it mean? I mean I don't know ... (participant, Bonner, Jansen, Newell, *et al.*, 2014)

> Well, if it's 6.6%, my question is what's the percent out of? Is it a stat like across Australia for my age group that I'm looking at? (participant, Bonner *et al.*, 2018)

> I had a hard time understanding that information; it's a bunch of numbers and ... no, I don't even remember what it said, but it was numbers and letters and I don't know anything about such things. (participant, Grauman *et al.*, 2019)

Several studies found that some participants identified as at high risk were under the impression that they had received a low risk rating (Hill *et al.*, 2010; Damman *et al.*, 2016, 2017; Riley *et al.*, 2016; McNaughton, 2018; Gidlow, Ellis, Cowap, *et al.*, 2021); see further 'reassurance' under 'impacts of receiving the risk score' below. In addition, participants who had received a numerical risk score often could not recall it when interviewed afterwards (Bonner, Jansen, Newell, *et al.*, 2014; Gidlow, Ellis, Cowap, *et al.*, 2021), and some did not remember receiving a risk assessment at all (Kirby and Machen, 2009; Middlemass *et al.*, 2014).

These findings may not all reflect the same underlying issue. It does not seem that most participants literally did not understand the meaning of, say, a 10-year percentage risk, aside from a small number of participants who expressed basic misunderstandings such as interpreting 6% as one in six (Gidlow, Ellis, Cowap, *et al.*, 2021). Rather, the point more commonly seems to be that a numerical score in isolation is not meaningful or actionable without being set in some broader context or compared to a reference class, or at least accompanied by clear guidance on action (see following subsection).

Some of these findings may relate to the format of risk communication, which varied across studies (and often within studies). In particular, the findings suggest a contrast

between an understanding of risk as categorical (for example, as high, medium or low), and the numerical outputs produced by risk scoring algorithms (five- or ten-year probability, event-free survival or heart age). The findings here are to some extent conflicting. Several studies suggest that participants tended to think of risk in binary terms – 'at risk' versus 'not at risk', or 'abnormal' versus 'normal' – so that the concept of percentage risk was seen as irrelevant or confusing (Polak and Green, 2015; Perry *et al.*, 2016; Bonner *et al.*, 2018; Grauman *et al.*, 2019; Hawking *et al.*, 2019). On the other hand, one study of incorporating genetic information into risk assessment found that participants felt that a binary categorisation ('average' versus 'above average') was unsatisfactory (Middlemass *et al.*, 2014). There is also complexity in the implementation of risk scoring in practice, with some participants reporting that clinicians communicated results categorically even when using a tool that produces a numerical output (Honey *et al.*, 2015).

> Participants could not tell whether a percentage result was good or bad unless they linked it to an appropriate reference point, most commonly the risk category label (for example, low risk or high risk). (authors, Bonner *et al.*, 2018)

> Those for whom English was not a first language mostly communicated their CVD risk in general, binary terms when asked, reporting that they were "fine" or "not at risk." Risk for these interviewees was either a state of being 'at risk' or not. Percentage risk and/or heart age were not mentioned or discussed. (authors, Hawking *et al.*, 2019)

Meaning of probability and credibility of risk scores

Issues with participants' understanding and interpretation of risk scores often appear to relate to broader views about the nature of probability or the risk scoring process. There are broadly two issues, both of which are linked with the other themes discussed below. The first has to do with the meaning of the numerical risk scores and the difficulty of deciding without further information whether a given risk score is practically actionable or concerning. The second concerns a broader epistemological scepticism about the reliability of probabilistic reasoning about the future, as compared to other forms of knowledge.

A finding in several studies is that risk scores that are clinically regarded as 'high risk', or as grounds for concern, are often not so regarded by participants. As already noted under 'understanding of risk score' above, some participants express general incomprehension of the risk score taken out of context. It is not always clear from the studies what further information would help to anchor the findings. In some cases it is information about 'normal' or average risk for other comparable individuals, while in others, more implicitly, it may be information about other health risks. As already discussed, there seems to be considerable variation across and within studies as to how far clinicians or researchers attempted to contextualise and interpret risk scores for participants.

> I can't quite understand what like 25% is, what's, what's good and what's bad with 25%? (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

> I think with the percentage unless you have been given the range it should be in for your age and for your, you know, capabilities, then it's kind of a mismatch of information. I don't know which to kind of … they are saying it's high, but I think it's quite low, but I don't know what high is because I haven't been given anything to compare it against. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

> Some participants […] were also interested in knowing their risk in relation to others and wondered about what was "normal" or "common" for their age. (authors, Grauman *et al.*, 2019)

In other cases participants were willing to immediately translate risk scores into practical implications, but appeared to be applying their own tacit thresholds which were higher – often very much higher – than those stated in clinical guidelines (Hill *et al.*, 2010; Vaidya *et al.*, 2012; Damman *et al.*, 2016, 2017; Bonner *et al.*, 2018; McNaughton, 2018; Gidlow, Ellis, Cowap, *et al.*, 2021). Some studies suggested that clinicians may also downplay risk scores at the lower end of the 'high risk' bracket (Honey *et al.*, 2015).

> Well, 13% out of a hundred's pretty low. Anything under 25 is pretty low. (participant, Bonner *et al.*, 2018)

> Well I'm not above the 50% risk. I'm in the red zone, but in the lower part of it. (participant, Damman *et al.*, 2016)

> I thought about it but, 25% that's yeah I thought well err most people walking round now are at, what is it 25%? … You know erm, I, I thought the odds were pretty good myself to be honest with you [laughter] (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

> When 16% was used as the sole presentation of risk, most consumer participants assumed this was safe because it was not 75% or 80%. (authors, Hill *et al.*, 2010)

> When they said that I was 28 out of 100, well I thought that was quite low. If I was 50%, 60%, 70% then I would be quite worried. At 28% I wasn't all that worried, if you know what I mean? (participant, McNaughton, 2018)

The second subtheme relates to the status of probabilistic or risk-based reasoning in general. Some participants suggested that inferences about the probability of future events are inherently questionable, since our knowledge of the future can never be complete; several participants contrast risk scores with more concrete information such as blood pressure or cholesterol readings, or information about family history (Damman *et al.*, 2016; Coorey *et al.*, 2019; Gidlow, Ellis, Cowap, *et al.*, 2021).

> Although the score was personalized, patients spoke of it seeming less relevant in isolation from other risk factors (for example, family history), or an investigative test (for example, negative coronary angiogram) that is not incorporated into the score estimation[.] (authors, Coorey *et al.*, 2019)

> You know, that's pretty ridiculous … I can listen to myself and think err … I've got a 51-year heart or you know … they're gonna know that … But to predict how long I'm gonna, live really that's errr … science fiction ain't it really? (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

> [Interviewer:] So getting your actual cholesterol result, so rather than having kind of your 10-year risk or your heart age, or your survival age, it would be your cholesterol … ?
> [Participant:] Yeah very much so because that is the now, you know all those other things are projections. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

> Because it seems to me it isn't really absolute risk because we all know that even given all that, there's some element of unknown environmental effects, whatever. (participant, Hill *et al.*, 2010)

> I have understood that heart attack risk is caused by various factors. But it is all about chance; it is not certain even if you have all those risk factors. (participant, Lenz, Kasper and Muhlhauser, 2009)

A more nuanced position is that, while probabilistic reasoning may be valid on its own terms, its application to a concrete individual is by definition uncertain. In other words, since probabilities as such can only be directly quantified at a population level, their implications for any given individual are debatable (Lenz, Kasper and Muhlhauser, 2009; Polak and Green, 2015; Marshall, Wolfe and McKevitt, 2018; McNaughton, 2018).

> Although I understand that heart attack risk is nothing individual, my concern is, who of them am I? Am I a lucky white one or one of the yellow figures who will get the attack? (participant, Lenz, Kasper and Muhlhauser, 2009)

> [I]t does say 'imagine a hundred people who are similar to you' but you see, who is? no person is similar to … you know … (participant, Marshall, Wolfe and McKevitt, 2018)

> Well, that's another issue I have with numbers. It's calculated on a total population, which is nonsense, because I am not a total population. (participant, McNaughton, 2018)

Finally, even for participants who regarded the risk score as both credible and applicable, some questioned the practical value of the information.

> Well, not as much as I would like in the sense that, I think what I've been given is in very broad brush kind of terms. And even a bald statement of "You've got a 15 percent chance, or whatever it is, of being admitted in the next five years with heart or a stroke." I mean OK it's a sort of risk and it's worth taking, yeah and I'd rather know that than not know it. But it's not all that helpful in the things that I'm really concerned about. Is what am I doing that can help this and what are the risks of doing that? And is it worth taking some risky thing for some pretty marginal kind of benefit? (participant, Taylor *et al.*, 2021)

There are also issues with other forms of risk scoring such as heart age or event-free survival (see 'Preferences for risk communication' below), although they are not explored in the studies in as much depth. One study of younger people and their parents found that event-free survival ages were sometimes felt to be so far in the future as to be irrelevant (Gooding *et al.*, 2016). One study found widespread confusion (by clinicians as well as patients) between predicted survival and predicted event-free survival (Gidlow, Ellis, Cowap, *et al.*, 2021).

The following themes explore some of the more specific reasons which may contribute to the feeling that risk scores are unhelpful or lack credibility.

Risk scores vs individual risk factors

All risk scoring algorithms, whatever form their output takes, involve aggregating information about a range of distinct individual risk factors. Many participants were aware of the difference between the latter and the summary risk score, and expressed a range of views on the relationship between them. On the one hand, in some studies the summary risk score was felt to be less real or tangible than the data on the basis of which it is calculated, and the diagnosis of 'high cardiovascular risk' to be less real than a defined organic condition (McNaughton, 2018). As noted above, information from laboratory tests or family history was often felt to be more reliable than future-oriented calculations of risk. Some participants felt that they did not learn anything from receiving the risk score, since they were already aware of all the information included in it (Damman *et al.*, 2016, 2017; Usher-Smith *et al.*, 2017; Snell and Helen, 2020; Gidlow, Ellis, Cowap, *et al.*, 2021)

On the other hand, some data suggest that participants did value the summary score over the individual data points which go to make it up (Sheridan *et al.*, 2009; Farrimond *et al.*, 2010). In one study where participants were provided only with data on risk factors individually, and no overall score, participants expressed a preference for a summary score (Grauman *et al.*, 2019).

Participants also felt that the range of factors included in the risk score was inadequate to produce a convincing result, and that the algorithm should take account of family history (see 'genetics and family history' below) or health behaviours and lifestyles (Sheridan *et al.*, 2009; Bonner, Jansen, Newell, *et al.*, 2014; Damman *et al.*, 2016, 2017; Bonner *et al.*, 2018; McNaughton, 2018; Coorey *et al.*, 2019). The latter

criticism was particularly pointed when behavioural recommendations were made on the basis of risk scores which did not take account of those behaviours (Bonner, Jansen, Newell, *et al.*, 2014).

> I'm grumpy with this website already. Because it's asking me to do things that it didn't actually question me about before, like being active or eating. (participant, Bonner, Jansen, Newell, *et al.*, 2014)

> Well, I think, I do take the result seriously, because it's not just made up, but I'd value it more if lots more factors were included. (participant, Damman *et al.*, 2017)

On a practical level, risk scoring was sometimes compromised by issues with the data inputs. For scoring processes which involved participants inputting their own data, missing or inaccurate information on factors such as blood pressure or cholesterol was an issue (Bonner, Jansen, Newell, *et al.*, 2014). Data taken from electronic health records were also sometimes out of date (Coorey *et al.*, 2019).

Self-rated health

Many participants who received high risk scores questioned their validity on the grounds that they conflicted with their own sense of themselves as healthy, either as a subjective perception or on the basis of their lifestyle behaviours or physical capacities (Farrimond *et al.*, 2010; Bonner, Jansen, Newell, *et al.*, 2014; Nolan *et al.*, 2015; Gooding *et al.*, 2016; Damman *et al.*, 2017; Usher-Smith *et al.*, 2017; Marshall, Wolfe and McKevitt, 2018; McNaughton, 2018; Coorey *et al.*, 2019; Grauman *et al.*, 2019; Gidlow, Ellis, Cowap, *et al.*, 2021). Participants in one study explicitly distinguished between their rational acceptance of the risk score and their subjective conviction of being in good health (Farrimond *et al.*, 2010).

> Intellectually I know that, yeah, I'm at risk, because all the indicators will say that I am. But personally, no, I don't. It's illogical, isn't it, really? I think because … I think being on the medication is one thing and also the change in my lifestyle … I honestly don't feel as though I am at risk, no. But that's a feeling, isn't it? That's an emotional thing. (participant, Farrimond *et al.*, 2010)

> That is a bit of a surprise really for that, because I don't feel that you know, and I don't know I still feel quite energetic and still play you know the sports I do, I am never tired, or feeling like I can't go on any … you know, in fact I do the complete opposite. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

Genetics and family history

Participants in several studies pointed to the importance of genetic or family history factors in determining risk, as a reason to be sceptical of risk scores, as additional information which needed to be taken into account, or in some cases as confirming their risk score (Farrimond *et al.*, 2010; Honey *et al.*, 2015; Gooding *et al.*, 2016; Damman *et al.*, 2017; Marshall, Wolfe and McKevitt, 2018; McNaughton, 2018; Coorey

et al., 2019; Gidlow, Ellis, Cowap, *et al.*, 2021; Taylor *et al.*, 2021). This point was particularly raised in studies of participants with high risk scores or diagnosed hypertension (Farrimond *et al.*, 2010; Honey *et al.*, 2015; Marshall, Wolfe and McKevitt, 2018; McNaughton, 2018).

> It was clear that mine was ... driven by my genetics, my family history. It seemed to me that the dial was not going to change anything. (participant, Coorey *et al.*, 2019)

> I wasn't surprised, really, when I got the letter to say I'm kind of high risk, because I've always been told I could be high risk because my mother, so it didn't come as any great surprise to me, really. No. (participant, Farrimond *et al.*, 2010)

> That sort of stuff, heart problems, I believe is family [related] [...] I'm not saying it's all in your genes but I think a lot of it is in your genes. (participant, McNaughton, 2018)

As noted above, these perceptions sometimes undermined the credibility of the risk algorithms applied in the studies, where they did not include genetic or family history information. Some participants suggested that a family history of other illnesses such as cancer meant that they were unlikely to die of cardiovascular disease, regardless of the risk score (McNaughton, 2018; Taylor *et al.*, 2021). For some participants who had been identified as at high risk, a family history of CVD made their risk status clearer (McNaughton, 2018; Gidlow, Ellis, Cowap, *et al.*, 2021); conversely, a lack of family history could be a reason to disregard a high risk score (Honey *et al.*, 2015).

The impact on views about modifiable risk factors is complex (and largely beyond the scope of this review). In some cases awareness of genetic risk supported a fatalistic attitude, leading participants to think that changed lifestyle factors were unlikely to reduce risk (Honey *et al.*, 2015; Gooding *et al.*, 2016; McNaughton, 2018; Gidlow, Ellis, Cowap, *et al.*, 2021). On the other hand, some participants suggested that becoming aware of high genetic risk could be a motivator for lifestyle change, although this finding comes from a study of hypothetical risk assessment (Gooding *et al.*, 2016).

> Well, I mean if you're genetically predisposed to it you're more likely to get it. So you could do more to counteract that in as far as your lifestyle decisions then you're less likely to get a heart attack. (participant, Gooding *et al.*, 2016)

> I think it is something in your genes, it's gonna be, I mean you can prevent it, I suppose you can? You know, help prevent it, but I think it's inevitable if it is in your genes that you're gonna, you know? (participant, McNaughton, 2018)

Three studies focused specifically on including genetic information into the cardiovascular risk assessment process, one on family history (Hall *et al.*, 2007) and two on genetic testing (Middlemass *et al.*, 2014; Snell and Helen, 2020). In one further study family history was assessed for some participants, but this was not the main

focus (Farrimond *et al.*, 2010). Participants often took up the offer of genetic testing because they knew or suspected that there was a family history of CVD and wanted to clarify their risk and that of their children or other family members (Middlemass *et al.*, 2014; Snell and Helen, 2020). Some were surprised by receiving a genetic risk score that diverged from their sense of their family history, while for others the one confirmed the other (Middlemass *et al.*, 2014; Snell and Helen, 2020).

Information about genetics and family history was sometimes challenging to incorporate with information from conventional risk assessments (Hall *et al.*, 2007; Middlemass *et al.*, 2014; Snell and Helen, 2020). Confidence in the validity of the genetic test itself seems to have been fairly high, although some sceptical views were reported. However, some participants thought the information was of limited value in terms of practical consequences (Hall *et al.*, 2007; Middlemass *et al.*, 2014; Snell and Helen, 2020). Hall et al.'s study, using data from video-recorded consultations, found that clinicians often did not integrate family history with other (modifiable) risk factors in discussing risk, leading to a sense of ambiguity among patients (Hall *et al.*, 2007).

> No, I don't feel that anything is written in stone as far as genes are concerned. You know it's just one of those things that can happen and I live with that. (participant, Middlemass *et al.*, 2014)

> In addition, the laboratory results were more concrete to many discussants and already formed a big part of their personal narratives. [...] The discussions tended to turn to more familiar aspects and factors in the participants' lives and to issues the participants thought they could influence. Cholesterol level, blood pressure or level of sugars were, for many, more concrete issues that could be acted on, compared to the genetic risk score. (authors, Snell and Helen, 2020)

Behaviours and lifestyles

Many participants emphasised the role of lifestyle factors – physical activity, diet, smoking, alcohol, stress and so on – in determining their perceptions of risk. As noted above, the fact that risk assessment procedures generally did not include information on these factors, other than smoking, was often a source of scepticism. Participants often interpreted risk scores in the light of their own perceptions of their lifestyle, or were sceptical of the risk scores where they perceived a dissonance (Farrimond *et al.*, 2010; Bonner, Jansen, Newell, *et al.*, 2014; Middlemass *et al.*, 2014; Nolan *et al.*, 2015; Damman *et al.*, 2016, 2017; Perry *et al.*, 2016; Marshall, Wolfe and McKevitt, 2018; McNaughton, 2018; Snell and Helen, 2020). Some study authors suggest that participants held a stereotype of the 'high risk' individual, from which they tried to distance themselves (Farrimond *et al.*, 2010).

> All participants more or less knew which risk factors from the risk calculator would apply to them personally and would thus contribute to their risk. Many participants, both with relatively low and with relatively high risks, relied

> heavily on such own knowledge and beliefs about risk factors, rather than on the numerical risk information provided. (authors, Damman *et al.*, 2017)

> And so, you think, I'm above average, you know, and obviously that concerns me, 'cause I walk round the town, like, and I see all these people, younger than me even, like this, you know, stick, fag in their mouth … you think 'well, if I'm above average, where the hell are they, like? Where's Mr Average?' (participant, Farrimond *et al.*, 2010)

On the other hand, many participants also expressed the opposite view that cardiovascular events were ultimately a matter of chance, and cited examples of people who led healthy lifestyles but still had heart attacks or strokes (Hall *et al.*, 2007; Honey *et al.*, 2015; McNaughton, 2018; Grauman *et al.*, 2019; Gidlow, Ellis, Cowap, *et al.*, 2021). Perhaps paradoxically, this could also be a reason for scepticism about risk assessment, in that it called into question the very idea of quantifying future risks (see also 'meaning of probability' above): "These stories seem to run counter to any coherent argument for risk reduction and management as they point to a more random and fatalistic understanding of CVD" (authors, McNaughton, 2018).

> [Interviewer:] Yeah, so was that information in particular helpful, or unhelpful, the 9%? […]
> [Participant:] To me it didn't mean anything, because to me you know I can change my lifestyle and all that sort of thing, but at the end of the day it is a bit of a sort of like lottery really isn't it? [Laughs] (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

> One of my colleagues, he was so healthy [. . .] he was lean and slim and always running around in the woods. He had two heart infarctions and a stroke within three months. Then I kind of felt like it's a lottery anyway, so it kind of doesn't matter. (participant, Grauman *et al.*, 2019)

4.4.2 Patient data: impacts of risk assessment

Emotional reactions

Many participants expressed emotional reactions to receiving a risk score, including worry and anxiety, shocked surprise, and in some cases guilt or shame (Middlemass *et al.*, 2014; Honey *et al.*, 2015; Nolan *et al.*, 2015; Gooding *et al.*, 2016; Perry *et al.*, 2016; Riley *et al.*, 2016; Usher-Smith *et al.*, 2017; Marshall, Wolfe and McKevitt, 2018; McNaughton, 2018; Coorey *et al.*, 2019; Grauman *et al.*, 2019; Gidlow, Ellis, Cowap, *et al.*, 2021).

> 15% of us will be dead in a few years. I thought right, I've got to change that … it got through to me, that's what bad shape I was in. It sort of sunk in. (participant, Coorey *et al.*, 2019)

> I got a letter from the doctor's saying 'as you are at a high risk of a stroke or heart attack' … well I nearly died, and I thought 'well what have my results come up as?' And so of course I made an appointment and I went on. (participant, Honey *et al.*, 2015)

Receiving unclear or contradictory information, or uncertainty while waiting for test results, was a particular source of concern for some participants (Riley *et al.*, 2016; Grauman *et al.*, 2019).

> It made me think and [I] asked the doctor about these specific blood values, and he told me that they have a different template […] than what, for example, a GP has […] I guess that was really my thought, that you have different interpretations of these results – what is dangerous and what isn't dangerous? […] … Yes, I was very worried, because I wondered whether I could really trust [this]. (participant, Grauman *et al.*, 2019)

Some participants expressed concern about potential mental health impacts, for example that the risk assessment could exacerbate issues with health anxiety or eating disorders (Gooding *et al.*, 2016). However, this point was not raised very often (and mainly concerned hypothetical risk results), and for some participants experiencing shock or anxiety about their results was a "salutary lesson" (participant, Riley *et al.*, 2016) or a "wake-up call" (participant, Perry *et al.*, 2016) and a stimulus to reducing risk (Middlemass *et al.*, 2014; Perry *et al.*, 2016; Riley *et al.*, 2016). This said, some studies suggest that these reactions may sometimes express a more free-floating anxiety which has little to do with the results of risk assessment: "Some participants indicated that they were nervous […] and that they also worried about the score after the event. This view was expressed by those with high- and low-risk scores, suggesting a general level of anxiety that might have clouded understanding of what the score actually meant" (authors, Perry *et al.*, 2016). Several participants also reported not being unduly worried by receiving their risk score (Gooding *et al.*, 2016; Perry *et al.*, 2016; Gidlow, Ellis, Cowap, *et al.*, 2021).

In a few cases participants suggested that they would prefer not to know their risk score (Marshall, Wolfe and McKevitt, 2018; Taylor *et al.*, 2021).

> Many participants expressed a desire to avoid contemplating future risk of disease, including both younger and older participants. Key reasons expressed by participants included: finding the consideration of future serious illness unpleasant or stressful; perceiving that looking at future risk did not make sense due to old age; and having other active health problems that were perceived as more serious making CVD risk less relevant (eg, pain from osteoarthritis). (authors, Marshall, Wolfe and McKevitt, 2018)

> No, I would not want to know from our GP. I just leave my life to our maker, that's the reason I don't want my GP to say to me, "You're going to have a heart

> attack, in two to three years' time." That's like a predicting, my days but it's not him … it's our Lord, that's my belief anyway. (participant, Taylor *et al.*, 2021)

Reassurance

In contrast, many participants felt reassured by the risk assessment, particularly those who had previously had concerns about their health (Nielsen *et al.*, 2009; Bonner, Jansen, Newell, *et al.*, 2014; Middlemass *et al.*, 2014; Frolund and Primdahl, 2015; Gooding *et al.*, 2016; Perry *et al.*, 2016; Riley *et al.*, 2016; McNaughton, 2018; Grauman *et al.*, 2019; Snell and Helen, 2020; Gidlow, Ellis, Cowap, *et al.*, 2021).

> You don't get any healthier with age so it's good to have an idea about your general health, only to see that there is nothing there. (participant, Grauman *et al.*, 2019)

> I just thought it would be terrible, I weigh too much and sit on my backside day in day out. I've never had anything the matter, but people in my family have died of cancer or coronaries. I was at no risk or low risk. I think that was lovely, I wouldn't mind going again … (participant, Nielsen *et al.*, 2009)

> […] probably because it was a clean bill of health … and … 'phew! [Laughs] Thank god for that.' And then I walked out and sort of punched the air … it felt really good. (participant, Riley *et al.*, 2016)

As already suggested, this includes a substantial number who received a high risk score as well as those at low risk (McNaughton, 2018; Gidlow, Ellis, Cowap, *et al.*, 2021). As discussed above, in some cases this may represent misapprehension of the meaning of the risk score. However, one author suggests that a diagnosis of high CV risk may be reassuring insofar as it is not a diagnosis of a 'real' illness.

> In some cases, paradoxically, people found knowledge of their at-risk status comforting. Having a risk confirmed was preferable to having a physiological condition that could be life threatening. Risk in this case was something to aspire to, meaning that there was a lack of condition that needed treatment and could affect quality of life. (authors, McNaughton, 2018)

Behaviour change

Many participants reported intentions to change (or actual changes to) their health behaviours as a result of risk assessment, for example increasing physical activity, eating more healthily, or giving up smoking (Nielsen *et al.*, 2009; Sheridan *et al.*, 2009; Farrimond *et al.*, 2010; Vaidya *et al.*, 2012; Bonner, Jansen, Newell, *et al.*, 2014; Middlemass *et al.*, 2014; Frolund and Primdahl, 2015; Honey *et al.*, 2015; Gooding *et al.*, 2016; Perry *et al.*, 2016; Riley *et al.*, 2016; Usher-Smith *et al.*, 2017; McNaughton, 2018; Grauman *et al.*, 2019; Hawking *et al.*, 2019; Gidlow, Ellis, Cowap, *et al.*, 2021; Taylor *et al.*, 2021). However, some participants reported that they did not intend to change any behaviours (Nielsen *et al.*, 2009; Farrimond *et al.*, 2010; Middlemass *et al.*, 2014; Honey *et al.*, 2015; Damman *et al.*, 2016; Gooding *et al.*, 2016; Perry *et al.*, 2016;

Riley *et al.*, 2016; McNaughton, 2018; Grauman *et al.*, 2019; Hawking *et al.*, 2019; Snell and Helen, 2020; Gidlow, Ellis, Cowap, *et al.*, 2021).

To some extent this theme goes beyond the scope of this review, insofar as the impacts of risk communication, strictly speaking, cannot be disentangled from the wider interventions, such as lifestyle advice, that participants often also received. A few participants did mention specific aspects of risk communication, such as heart age, as a specific stimulus to behaviour change (Bonner, Jansen, Newell, *et al.*, 2014; Honey *et al.*, 2015; Gidlow, Ellis, Cowap, *et al.*, 2021); see 'preferences for risk communication formats' below. In most cases, however, the link is more vague. As with the other themes in this section, it is not easy to say how much of the impact is attributable to the risk score specifically, and how much to broader conversations with clinicians or the 'halo' effect of being prompted to think about risk in general. One study reported that behaviour change intentions were more widely reported by low-risk than high-risk participants (Frolund and Primdahl, 2015), and another that information about genetic risk could prompt behaviour change intentions even though it is recognised to be unmodifiable (Middlemass *et al.*, 2014), which may suggest that it is not always the fact of being identified as high risk that motivates behaviour change.

Participants in several studies also suggested that risk assessment could motivate them to seek medical care, or to increase adherence to prescribed treatments such as statins (Sheridan *et al.*, 2009; Damman *et al.*, 2016; Marshall, Wolfe and McKevitt, 2018; Gidlow, Ellis, Cowap, *et al.*, 2021; Taylor *et al.*, 2021).

4.4.3 Patient data: broader context

This section briefly covers some contextual factors which emerged in the coding. While a full exploration of these themes lies beyond the scope of the review, they are relevant to understanding experiences of cardiovascular risk assessment.

Perceptions of CVD

Participants' perceptions of the likely impacts and seriousness of CVD had an impact on how they felt about their risk scores. There was some unclarity around the definition of the term 'CVD' itself, for example whether it includes hypertension, and more specific terms such as 'heart attack' were better understood (Wan *et al.*, 2008; Nolan *et al.*, 2015; Damman *et al.*, 2016, 2017; Taylor *et al.*, 2021). CVD was sometimes seen as not very serious, particularly in comparison with other diseases such as cancer (Nolan *et al.*, 2015; Damman *et al.*, 2017; McNaughton, 2018; Taylor *et al.*, 2021), or as a natural part of the ageing process (Farrimond *et al.*, 2010) or a more general bodily 'weakness' (Marshall, Wolfe and McKevitt, 2018).

> Yes, cos it's about these diseases and that happen to be diseases that I'm not at all afraid of but if it would be about cancer or something like that, yes, then if this would be the result or 20, then I'd go to the doctor tomorrow, it's just what eh, what frightens you. (participant, Damman *et al.*, 2017)

A few participants expressed the view that a relatively rapid death from a heart attack might be preferable to other causes of death (Honey *et al.*, 2015; Taylor *et al.*, 2021). Several participants in Taylor et al.'s study expressed different attitudes to stroke and heart attack, with the former seen as more threatening due to the possibility of prolonged disability, and as less treatable (Taylor *et al.*, 2021); no other study reported this kind of detailed distinction between different cardiovascular outcomes.

> I am not afraid of death. If I go, I go but I want it to be quick. (participant, Honey *et al.*, 2015)

> I've immediately got some reservation about lumping those two together. Because being hospitalised for a heart attack is different to me from being hospitalised for a stroke. My mental function is important to me in my old age and I don't want a heart attack either, but I'm conscious that a lot of heart attacks these days can be ably managed with stenting and various other things ... but those two that have been lumped together are different risks for me in terms of how they would affect me and what I can do in my old age. (participant, Taylor *et al.*, 2021)

People with other long-term conditions or disabilities were particularly likely to regard CVD as not a major concern. Three studies focused specifically on populations with non-cardiovascular conditions that may increase risk for CVD, two on type 2 diabetes (Lenz, Kasper and Muhlhauser, 2009; Nolan *et al.*, 2015) and one on rheumatoid arthritis (Frolund and Primdahl, 2015). While all these studies found broadly positive attitudes to cardiovascular risk assessment, most participants also felt that cardiovascular risk was a less important concern than the effects of their primary condition. Several other studies also found that people with other long-term conditions (for example, osteoarthritis) or health risks (for example, asbestos exposure in earlier life) saw cardiovascular risk as secondary by comparison (Farrimond *et al.*, 2010; Marshall, Wolfe and McKevitt, 2018; McNaughton, 2018).

Population subgroups

There is little information in the studies on how perceptions may differ between population subgroups. One study reported specifically aiming to recruit an ethnically diverse sample; however, this study was conducted in New Zealand, with European, Maori, Pacific, and South Asian participants, and so may not be transferable to the UK context (Taylor *et al.*, 2021). This study reports that non-white participants were more likely to be unaware that cardiovascular risk could be predicted and managed, but otherwise reports few differences between groups (Taylor *et al.*, 2021). One study mentions gender difference, suggesting that women may downplay their own health risks relative to that of their husbands, but this appears to be based on a single data point (Farrimond *et al.*, 2010). One study focuses on young adults aged 17-21, finding potential barriers from the perception that potential cardiovascular outcomes are many years in the future (Gooding *et al.*, 2016).

4.4.4 Clinician data

General attitudes and understanding of risk scores

Clinicians expressed broadly positive perceptions of risk assessment tools, and a high degree of confidence in using them and communicating the results to patients (Wan *et al.*, 2008; Vaidya *et al.*, 2012; Riley *et al.*, 2016; Gidlow, Ellis, Cowap, *et al.*, 2021). Some studies raised concerns about the accuracy of clinicians' understanding (van Steenkiste *et al.*, 2004; Kirby and Machen, 2009; Lenz, Kasper and Muhlhauser, 2009; Cupit *et al.*, 2020; Gidlow, Ellis, Cowap, *et al.*, 2021). For example, there were some instances of confusion between estimated survival and estimated event-free survival (Gidlow, Ellis, Cowap, *et al.*, 2021), and between absolute and relative risk (Kirby and Machen, 2009).

The range of information required for risk assessment may also pose challenges. Clinicians who were used to managing single risk factors (for example, elevated cholesterol) were sometimes reluctant to move to a risk algorithm which incorporates a wider range of information (van Steenkiste *et al.*, 2004; Vaidya *et al.*, 2012; Bonner *et al.*, 2013), and some participants found it challenging to explain multifactorial risk scores to patients (Cupit *et al.*, 2020; Gidlow, Ellis, Cowap, *et al.*, 2021).

> Several things are taken into account, so age, sex, their BMI [body mass index] ... which does make it, to me, very complicated ... to try and explain it to [patients] is the hardest. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

> If someone's got a known high cholesterol, I will treat that. If someone's got a high blood pressure, I will treat that. I don't need the risk calculator to tell me that I'm meant to treat those risk factors. (participant, Vaidya *et al.*, 2012)

Some participants suggested that the fine detail of the risk assessment process may be less important than simply providing an opportunity to discuss cardiovascular risk factors with patients (Wan *et al.*, 2008; Peiris *et al.*, 2009).

> It's basically like a mini audit. So anything that makes you look a little bit deeper at the person sitting in front of you is always worthwhile ... (participant, Peiris *et al.*, 2009)

> I imagine it acting like a springboard for discussion – the most important thing about people filling in a check list, and it isn't the number that pops out of the box, it's 'oh, I see you're a smoker, I see your father had a heart attack, tell me what happened there' and exploring some of those, and 'why do you keep smoking' – [It is] almost a springboard for discussion rather than a calculator for risk... (participant, Wan *et al.*, 2008)

Some clinicians raised concerns about the data inputs to the risk tools, for example out-of-date laboratory results (Peiris *et al.*, 2009) or potentially unreliable self-reported data on behaviours (Wan *et al.*, 2008). In one or two cases, participants

raised limitations of the risk algorithms themselves, for example whether they were accurate for ethnically diverse populations (Kirby and Machen, 2009).

> It gives information which, as it's blandly presented, you go, "How did you get that? ..." I got a couple of people where I got a 20% number and you go, "Oh that's madness, that's not you," and often because it's based on single digit information ... like a single blood pressure. (participant, Peiris *et al.*, 2009)

Perceptions of patient understanding

Many studies reported a perception that patients had, or would have, difficulties in understanding risk. Several participants expressed a view that many patients simply did not understand numerical probabilities (van Steenkiste *et al.*, 2004; Wan *et al.*, 2008; Kirby and Machen, 2009; Hill *et al.*, 2010; Bonner, Jansen, McKinn, *et al.*, 2014; Gidlow, Ellis, Cowap, *et al.*, 2021), and concerns were also raised about their ability to interpret graphs or other graphical ways of presenting risk (van Steenkiste *et al.*, 2004; Hill *et al.*, 2010; Bonner, Jansen, McKinn, *et al.*, 2014).

> I think people with a higher education level are much more interested in perhaps in absolute figures and like to see the chart or the risk calculator and see how things can change. Whereas if you've got ... someone who is less educated then you need to be a little bit more ... simplistic in your description of risk and changing risk. (participant, Bonner, Jansen, McKinn, *et al.*, 2014)

> Patients are generally not familiar with statistics, so for nine out of ten of them reading a graph is not something they are used to. Let alone interpreting tables with red, yellow and white colours. (participant, van Steenkiste *et al.*, 2004)

Some more specific points were raised and have links with the themes seen in the patient data. One is that even where risk is well understood in the abstract, a given percentage risk may not be meaningful in isolation (Cupit *et al.*, 2020). Another is that even where patients understand individual risk factors they may not grasp the idea of combining them into an overall risk score (Kirby and Machen, 2009; Lenz, Kasper and Muhlhauser, 2009; Peiris *et al.*, 2009; Bonner *et al.*, 2013).

> A lot of patients don't have that idea of overall risk ... they are very much blood pressure, cholesterol, they don't have the concept of putting it all together. (participant, Bonner *et al.*, 2013)

> It's hard to give people these figures because it's a bit of an abstract concept [to tell someone] 'you've got 21% risk of getting a heart problem in the next 10 years'. For some people that might seem very low and others ... (participant, Cupit *et al.*, 2020)

> And from their point of view, I mean it's hard to know, but they seemed to understand that it was a multifactorial thing, rather than just being one of those single disease problems ... (participant, Peiris *et al.*, 2009)

In one study focusing on the use of carotid ultrasound imagery in risk communication, clinicians felt that patients, while well informed in general, may not understand the implications of the findings (Bengtsson *et al.*, 2021).

Perceptions of patient behaviour and attitudes

Some participants also expressed challenges to do with patients' reactions to the risk score, or their willingness to respond (although, again, the latter theme goes beyond the scope of this review). Participants reported that some patients reacted with excessive fear or anxiety (van Steenkiste *et al.*, 2004; Boase *et al.*, 2012; Bonner *et al.*, 2013; Bonner, Jansen, McKinn, *et al.*, 2014; Bengtsson *et al.*, 2021), and that they changed their communication style when dealing with patients they perceived to be anxious in general.

> Ones that have a high cholesterol just about freak out and they don't need anybody more telling them ... their risks of having a heart attack ... I would be a bit dubious about showing them straight off because they would only get themselves into more of a state. (participant, Bonner, Jansen, McKinn, *et al.*, 2014)

Concerns about understanding are also bound up with issues around broader attitudes to cardiovascular risk behaviours. Participants in one study suggested that patients may not want to understand risk where it implies unwelcome lifestyle change (Gidlow, Ellis, Cowap, *et al.*, 2021). Participants were sometimes reluctant to communicate risk where patients had low risk scores but did have risky lifestyles or behaviours, for fear of demotivating them to make changes (van Steenkiste *et al.*, 2004; Bonner *et al.*, 2013); in another study participants suggested that talking about cardiovascular risk may make patients less likely to seek care in the future (Bonner, Jansen, McKinn, *et al.*, 2014).

> Often people come out with a really low risk and then they think they [can] continue with ... their obesity and high blood pressure. (participant, Bonner *et al.*, 2013)

> To be honest if I talk too much then they don't turn up, they go to some other doctor. [laughter] It's very true with male patients they don't really want to find out what's wrong with them unless they feel they need help. (participant, Bonner, Jansen, McKinn, *et al.*, 2014)

> [Interviewer:] Why do you think some don't understand [the percentage risk score]?
> [Participant:] Maybe poor education ... maybe they do understand, but they don't care ... so they don't want to know, they don't want to discuss it. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

> The cardiovascular risk was very frequently overestimated. In some cases this was done on purpose as a strategy to change unhealthy behaviour. (authors, van Steenkiste *et al.*, 2004)

There were varying perceptions as to how far risk assessment was likely to motivate patients to change, with some participants feeling it was largely irrelevant, and others seeing it as potentially a useful tool (Kirby and Machen, 2009; Gidlow, Ellis, Cowap, *et al.*, 2021). Some participants found that different formats (heart age versus risk, or relative risk versus absolute risk) made a difference here; see 'preferences for risk communication' below.

> ... giving them a percentage, doesn't inspire them, doesn't motivate them really ... (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

Some participants felt that patients may have more immediate concerns which make conversations about cardiovascular risk less useful (Boase *et al.*, 2012; Bonner, Jansen, McKinn, *et al.*, 2014).

> ... what they really need is like more money, or able to work less hours or the women need to be more, to feel stronger identity in relation to themselves, more accommodation ... so you know what good is it me [to give lifestyle advice]? (participant, Boase *et al.*, 2012)

> Cardiovascular risk just isn't on their agenda, they are more worried about their day to day social issues or their mental health issues even though technically in the back of my mind they're more likely to die from a heart attack (than) from suicide or violence. (participant, Bonner, Jansen, McKinn, *et al.*, 2014)

Strategies for communicating risk

Partly due to these challenges and the range of patient responses, participants described using different strategies for tailoring risk depending on the individual, based both on their prior knowledge or overall impressions of the patient, and on their moment-by-moment reactions (including non-verbal behaviours as well as verbal responses) in the consultation itself (Wan *et al.*, 2008; Boase *et al.*, 2012; Bonner, Jansen, McKinn, *et al.*, 2014; Gidlow, Ellis, Cowap, *et al.*, 2021).

> ... there's no one uniform way, I don't think of going about it ... it's your own experience, knowing your patients ... personality, social class ... all those kinds of things ... (participant, Boase *et al.*, 2012)

> I try and explain it for the level of the person that is sitting there and adapt it. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

Participants viewed a generic 'box-ticking' approach to communicating risk that did not incorporate these adjustments and situational awareness as inappropriate and potentially harmful (Boase *et al.*, 2012).

> … part of our role is about not causing harm. So … you've also got to be aware … respecting their wishes … I think the danger is if you have a policy … you'll have all the staff who may not be aware of what harm they could be doing … So I think the person would have to have the skill to know this patient doesn't wish to know or 'I can show you your risk factors and I can make you aware of where you fit in the average, how would you feel about that?' (participant, Boase *et al.*, 2012)

A range of factors may come into play in tailoring communication, including: patients' level of understanding of risk; their anxiety around risk and future illness; their current health behaviours; and their willingness to change these behaviours (Wan *et al.*, 2008; Boase *et al.*, 2012; Bonner, Jansen, McKinn, *et al.*, 2014).

The tone or emotional colouring of communication around the risk score may also be adjusted to the individual patient. In particular, participants described using negatively-framed fear appeal strategies, with strong emphasis on the likely harms of cardiovascular disease, where they judged that this was necessary to make an impression on the patient, and more positive framings where this was judged to be counter-productive, for example, for patients who were already anxious (Wan *et al.*, 2008; Boase *et al.*, 2012; Bonner *et al.*, 2013; Bonner, Jansen, McKinn, *et al.*, 2014).

> Nurses […] also discussed how they might 'pitch' their language according to how much they thought patients understood, acknowledging that sometimes they would 'skirt around' the topic to avoid worrying or frightening them. (authors, Boase *et al.*, 2012)

> Reassuring people a bit and helping them to understand that they can control their risk factors either with or without medication and then I think that gives them a sense of empowerment, a bit of control. (participant, Bonner, Jansen, McKinn, *et al.*, 2014)

> I like to … put a little fear into them … if they don't 'pull up your socks' [*sic*] bad things can happen to them … if you don't want that kind of scenario you do what I tell you. (participant, Bonner, Jansen, McKinn, *et al.*, 2014)

Participants in several studies reported sometimes not communicating the risk score at all, if they felt the patient would not understand, or that it would be counter-productive in terms of having a constructive conversation about risk factors and behaviours (Boase *et al.*, 2012; Bonner, Jansen, McKinn, *et al.*, 2014; Gidlow, Ellis, Cowap, *et al.*, 2021).

> One strategy that many described was to concentrate on risk reduction without actually talking to a patient about risk scores explicitly at all. Thus, lifestyle advice and behaviour change were frequently raised not in terms of a patient's cardiovascular risk per se, but in more general terms around the idea of maintaining or improving health – thereby eliminating any language that might

> be interpreted as suggesting an ill or unhealthy status. (authors, Boase *et al.*, 2012)
>
> [If] you think the patient perhaps is not going to pay any attention to you, they are not going to take it in, then no. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

That they just might not have understood, like the complexity of how you explain the QRISK and that maybe where I would then adapt it, and maybe there are times when I might explain it, but not explain the QRISK and the percentage as much, like I did with those patients you know? (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

Impacts on care delivery

The place of risk communication within the broader narrative of the clinician-patient encounter is complex and, of course, depends largely on the context. As already noted, for some participants risk assessment has an inherent value for patient care, while for others its main value appears to be as a stimulus for a broader conversation about risk and lifestyles, such that the specifics of the assessment process are of secondary importance.

Perceptions of the impacts of risk communication on care delivery were mixed. In one study participants valued risk communication as they felt that increasing patients' knowledge enabled clinicians to take a more "consultative" rather than "instructive" view, and helped patients to participate in clinical decision-making on a more equal basis (Bengtsson *et al.*, 2021). More broadly, some participants felt that a formalised, multifactorial risk assessment tool helped to facilitate broader conversations about risk, compared to screening individual risk factors (Peiris *et al.*, 2009). Participants in one study thought that having patients fill out a risk assessment form themselves would help engage them (Wan *et al.*, 2008).

> I think the biggest impact is that it changed the way I talked about what I was doing with patients, in that it made it a much more slick, neat package to describe the normal screening that you do for risk management. And so I felt it was easier to deliver some description of where they're at now. (participant, Peiris *et al.*, 2009)

In contrast, participants in some studies raised concerns about possible negative impacts on care delivery. Participants in one study felt that the standardised nature of the NHS Health Check process could potentially detract from patient-centred care by encouraging a 'box-ticking' approach (Boase *et al.*, 2012). Gidlow et al.'s study, using video-recorded NHS Health Check consultations, suggested that risk assessment was rarely utilised by clinicians as an opportunity to discuss risk more broadly (Gidlow, Ellis, Cowap, *et al.*, 2021).

> One nurse described following rigid guidelines as leading to a feeling that although they cover what was required, by not really engaging with the patient,

> they 'could do it with your eyes closed'. Nurses were therefore aware that, although they may have an obligation to complete data-collecting tasks, this may not always be in the patient's immediate interests. (authors, Boase *et al.*, 2012)

Many participants reported that they had limited time to conduct risk assessment and communication, hence limiting the value, and in some cases the usability, of risk tools (Wan *et al.*, 2008; Kirby and Machen, 2009; Peiris *et al.*, 2009; Boase *et al.*, 2012; Vaidya *et al.*, 2012; Bengtsson *et al.*, 2021). They emphasised that the tools needed to be integrated with existing platforms for data management and decision support, and not unduly time-consuming or complicated, to maximise uptake (van Steenkiste *et al.*, 2004; Wan *et al.*, 2008; Kirby and Machen, 2009; Peiris *et al.*, 2009; Vaidya *et al.*, 2012).

Some concerns were raised about staffing. The role of different professionals varied across the studies, and implementation was often complex. Some doctors felt that nurses could take a more central role (Wan *et al.*, 2008; Kirby and Machen, 2009), and in one study clinical organisations spontaneously developed protocols whereby low-risk results were handled by nurses and high-risk results by doctors (Bengtsson *et al.*, 2021). Some doctors and nurses expressed concern about healthcare assistants participating in risk communication, questioning whether they had the relevant skills and training (van Steenkiste *et al.*, 2004; Riley *et al.*, 2016). More broadly, some general concerns were raised about effective collaboration between different professionals (Wan *et al.*, 2008; Kirby and Machen, 2009), although the data does not allow in-depth exploration of this point.

4.4.5 Specific preferences for risk communication

A substantial amount of data addresses patients' and clinicians' views about specific ways of communicating or representing risk; the two have been combined for this set of themes, as many of the same issues come up across both sets of data. The studies looked at a wide variety of tools and formats; this synthesis mainly draws out high-level general points.

Visual representations

On visual formats generally, views were mixed. Some participants expressed a strong preference for visual tools over purely verbal or numerical information, seeing them as more likely to communicate the seriousness of cardiovascular risk, and appreciated visual formats which made use of colour and design to focus attention (Kirby and Machen, 2009; Peiris *et al.*, 2009; Sheridan *et al.*, 2009; Hill *et al.*, 2010; Bonner, Jansen, Newell, *et al.*, 2014; Nolan *et al.*, 2015; Bonner *et al.*, 2018; Coorey *et al.*, 2019). Some participants felt that imaging such as patients' carotid ultrasound (Bengtsson *et al.*, 2021), or visual tools showing damage from cardiovascular events (Bonner, Jansen, McKinn, *et al.*, 2014), could be useful.

> … because it was on the screen, I think that is such an aid to memory … you know it's just that sort of interactive ability really to be able to see something, rather than just being told information. Because in any situation that is new to you, if there's a lot of things going on and you are not sure what's going on, you don't hear … But if you see it, it is actually much, much clearer to you. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

> I find it all too wordy … I can't read those words while I'm sitting there with a patient. I still have to sit there and think, "What does that sentence actually mean?" …So, it needs to be very graphic, where it says the same thing to you graphically. (participant, Peiris *et al.*, 2009)

On the other hand, some participants suggested that patients may have limited understanding of quantitative risk information in graphs and tables, and that visually cluttered or confusing formats could hamper comprehension (Kirby and Machen, 2009; Hill *et al.*, 2010; Bonner, Jansen, Newell, *et al.*, 2014; Nolan *et al.*, 2015; Damman *et al.*, 2017; Coorey *et al.*, 2019). Specific issues here included inconsistent use of colour (Bonner, Jansen, Newell, *et al.*, 2014), and the use of visual scales from 0%-100% which made even relatively high risks appear visually small (Hill *et al.*, 2010; Damman *et al.*, 2017). The use of smiley faces in graphical risk illustrations was felt to be trivialising (Nolan *et al.*, 2015; Bonner *et al.*, 2018).

Risk algorithms

Several studies found a preference for heart age over other ways of representing risk, with both patients and clinicians seeing it as having more impact than percentage risk (Bonner, Jansen, Newell, *et al.*, 2014; Hawking *et al.*, 2019; Gidlow, Ellis, Cowap, *et al.*, 2021). This may be partly because it can be directly compared to the patient's actual age, and so is more meaningful than a decontextualised probability figure.

> Where it says 'your heart age is' and gives you a heart age, straight away you know whether that is good, or bad, because if your [chronological] heart age is lower than the reading [heart age estimate], then you know straight away that is not so good. Whereas if it is higher you know. So I think that one is a bit more clearer. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

Participants in one study expressed a preference for relative over absolute risk, for similar reasons (Hill *et al.*, 2010).

> I actually prefer relative risk in a way because as you get older your absolute risk gets higher and higher, and I think everyone thinks of themselves as being relative to their peers, not relative to a 35-year-old healthy person. (participant, Hill *et al.*, 2010)

One study found some preference for JBS3 over QRISK, partly because it was easier to generate heart age as an output, and partly because the calculator allowed for modification of inputs (see next section); however, one disadvantage was that JBS3

does not have clear thresholds for high, medium and low risk (Gidlow, Ellis, Cowap, *et al.*, 2021)

Views on the relative merits of five- and ten-year risk were mixed. A ten-year timeframe was seen to be more remote (Wan *et al.*, 2008; Bonner *et al.*, 2018), but calculating ten-year risk produces higher numbers and hence might be more motivating (Bonner *et al.*, 2018).

Modifiable inputs

Several studies found that the ability to modify inputs to the risk algorithm dynamically, and immediately see what difference this made to outputs, was a helpful feature, enabling patients to immediately grasp the potential benefits of behaviour change (Hall *et al.*, 2007; Kirby and Machen, 2009; Peiris *et al.*, 2009; Vaidya *et al.*, 2012; Honey *et al.*, 2015; Nolan *et al.*, 2015; Coorey *et al.*, 2019; Gidlow, Ellis, Cowap, *et al.*, 2021). One study reports that patients spontaneously tried out different values even when not prompted to do so, in order to see the results (Damman *et al.*, 2016).

> Yes, I think it helps, rather than somebody talking to you and saying, 'well it's like this, it's like that', but actually when you can see it and then by altering it, you know and saying, 'if we put this information in you can see how … so if you were much heavier say, for example, or if you smoke, or if you do these sorts of things', so I found that really helpful. (participant, Gidlow, Ellis, Cowap, *et al.*, 2021)

However, a few participants thought this could sometimes be demotivating, since it can suggest that the payoff of behaviour change is actually not very great (Nolan *et al.*, 2015; Coorey *et al.*, 2019).

> When I played with the sliders and moved them down to the lowest level my dial only shifted slightly … I thought well that's not much motivation. (participant, Coorey *et al.*, 2019)

> No, that's the one, that's the one that I can change. If I change that [exercise 4 hours a week] to yes. 1.2 years. It's quite a low return for quite a major effort it seems to me. (participant, Nolan *et al.*, 2015)

5 Discussion

5.1 Summary of findings

This review of qualitative evidence finds several important barriers to the effective communication of cardiovascular risk scores. While most participants do not seem to have difficulty grasping the basic concepts, many report a sense that the risk score in isolation is irrelevant or not practically actionable. Risk scores above the threshold for high risk are often seen as not a major cause for concern. Some also question the credibility of the risk score on a range of grounds, either because other factors not included in the risk models are felt to be important in determining outcomes, or because they are more generally sceptical of the models' ability to predict risk or of the applicability of the outputs to the individual. This is particularly the case where the risk score conflicts with their own subjective sense of being in good health, or their healthy lifestyles and physical capacities.

The findings on the impacts of risk communication are mixed, and hard to disentangle from the broader interventions (for example, lifestyle counselling) that also took place in the studies. However, many participants do report intentions to change behaviour or to seek preventive care because of receiving cardiovascular risk assessment.

Clinicians report broadly positive views of risk assessment, but also some scepticism as to whether patients understand the information presented, and its effectiveness in motivating behaviour. They are concerned about inappropriate reactions in both directions: patients who react with excessive anxiety about risk; and those who take a low risk score as confirming they do not need to change any behaviours. They report considerable variation in how patients respond to and take on risk information, and tailor risk communication in complex ways to individuals' needs. There may be issues integrating standardised risk tools into clinical practice because of a lack of time, limitations in the usability of the tools, or because they are felt not to be appropriate for all patients.

Both patients and clinicians have specific preferences about the delivery of risk information, including a preference for: tools including visually engaging, accessible formats; heart age rather than absolute risk; and tools which allow counterfactual manipulation of data inputs to see the potential impact of changes.

5.1.1 Comparison between patient and clinician data

While data from clinicians and patients seem broadly consistent, there are some tensions on a few points. While none of these are conclusive – in particular, they could result from selection bias in the studies – they are suggestive. First, some clinicians, although certainly not all, suggest that patients struggle to understand risk scores because they lack ability to deal with numbers generally, or are unused to thinking about probability in quantitative terms. The patient data indicate that this is probably rarely the case; our interpretation of the data (which is of course open to debate) suggests that expressions of incomprehension are less to do with an inability to

comprehend risk on a basic level than with a lack of context which would make the score meaningful.

Second, clinicians in several studies emphasise that some patients are excessively anxious about risk (while others are much less concerned than they should be), and that risk communication needs to be handled sensitively to avoid exacerbating this anxiety. With some exceptions, this is a less prominent theme in the patient data: while expressions of shock or worry are widespread, these seem as likely to have a positive valence, in that these emotions are stimuli to action, as a negative one. Few participants report that risk communication, on its own, caused worry sufficient to have mental health impacts, although ambiguity and delay (for example, being identified as potentially at risk, and then waiting for test results) could sometimes cause concern.

Third, as noted, there is considerable scepticism about risk assessment in the patient data, for a range of reasons from the more practical (a narrow range of data inputs) to the more abstract (the applicability of population-level risk estimates to the individual). With very few exceptions, the clinician data do not show this kind of critical attitude to the risk models themselves.

5.2 Strengths and limitations of the review

This review was carried out using a systematic methodology to minimise bias, including highly sensitive searching, screening using robust *a priori* criteria, and clearly defined procedures for data extraction and synthesis. We used a thematic synthesis methodology based on grounded theory principles, rather than a pre-set theoretical framework.

There may have been some limitations to the sensitivity of the search, in particular where studies did not use the vocabulary of cardiovascular disease or cardiovascular risk. We double-screened only a sample of titles and abstracts. However, agreement on these was high, and all full-text references were double-screened. Our synthesis focused on developing coherent narratives across themes, rather than on isolating thematic constructs; as a result, we cannot provide clear assessments of the reliability of data with respect to specific individual findings. Due to the limited timescale of the review, it was not possible to involve patients or the public.

A strength of the review is the clear demarcation of the question, enabling the review to minimise bias in the selection of studies. This does mean that data outside the boundaries of the review question were excluded, including some potentially illuminating topics, for example: patients' broader understanding of cardiovascular disease, risk behaviours and so on (where the data did not concern formal risk assessment tools); clinicians' views of the broader clinical role of risk assessment (where the data did not focus on communication of risk scores to patients); and potentially other topics. In particular, the data in the review, with some exceptions, largely do not address what happens after risk assessment for individuals identified as

being at higher risk. This would include questions such as what support people receive for changing risk behaviours, or how clinicians and patients make decisions about preventive treatment. As discussed below (5.4), there is arguably a gap in the causal models which purport to link risk assessment to health status outcomes, so this is an important set of questions and could be a focus of further research.

There may be some limitations in the primary studies. As described above, while study quality was rated as moderate on average, there are some concerns around sampling and generalisability, and a lack of detailed description of study samples. The studies include a variety of contexts, which may also pose challenges to generalisability, although most do focus either on Health Checks or similar programmes and/or on populations like those targeted by Health Checks (middle-aged and older adults from the general population). There is a lack of data about how perceptions and experiences may differ between different population groups, which means it is unclear how our findings relate to questions about health inequalities.

5.3 Implications for policy and practice

As described in section 2, the context for this project was the recent review of the NHS Health Check programme, which emphasises the importance of supporting individuals to understand and manage their cardiovascular risk, and which launched a new digital pathway for the Health Check (Office for Health Improvement and Disparities, 2021). This rethinking of Health Checks raises two broad questions to which our data may be relevant. First, do the findings suggest any promising strategies for communicating and reporting cardiovascular risk, to make the information more comprehensible and relevant? Second, are there potential issues with communicating risk in a digital workflow where individuals may receive a risk score from an online tool without the involvement of a clinician? This section briefly considers some specific suggestions about risk communication (5.3.1-4) and the likely impact of the context of communication (5.3.5).

5.3.1 Modes of expressing risk

This review suggests that an important barrier to the communication of risk is that assessments of probability, in isolation and without any context, have little meaning to many people. As noted, the issue is not so much that people are unused to thinking about risk quantitatively at all (although this is probably also true in a few cases) as that, without some comparison point, an absolute risk score provides little practically usable information. In the absence of such a comparison to anchor the meaning of the score, there is a tendency to index risk to arbitrary values – 50% or 100% – or to vague estimates of typical risk, both usually implying a tacit threshold much higher than that indicated in clinical guidance. Hence, even when a risk score has been communicated, many people at moderate or high risk draw the conclusion that they have nothing to be concerned about. The findings suggest a few approaches which may merit further exploration as ways to address this issue.

1) Anchoring and comparison. The data suggests a clear need for some form of anchor or reference point against which individuals can compare their numerical risk score. There are various ways this might be expressed – for example, as a relative risk, or more informally with supporting information on typical risk scores for comparable groups. Expressing risk as a heart age would also fit here, in that by anchoring the risk estimate against the individual's chronological age, it gives some practically usable sense of the magnitude of the problem. That said, the effectiveness data do not clearly bear out the suggestions that either heart age (Bonner *et al.*, 2021) or relative risk (Waldron *et al.*, 2011) are preferable to absolute risk, and there may be scope to explore different formats.

2) Categorical thresholds. To some extent, the categorisation of risk as high or low, or more generally as cause for concern or not, may also serve as an anchor for understanding risk (whether in the form of an explicit threshold built into the model, or more informally while discussing risk). However, our findings suggest that where both a categorical expression of risk and a numerical probability score are communicated, this may contribute to confusion, since the thresholds included in the risk tools are seen (not entirely unjustifiably) as basically arbitrary. This leaves scope for patients to interpret the score in terms of intuitive thresholds which tend to underestimate risk. It may be worth thinking in more detail about the relation between numerical and categorical expressions of risk within communication tools.

3) Ability to manipulate inputs. Another feature that is seen to be helpful by both clinicians and patients is the ability to enter different values for model inputs and dynamically see the output in terms of changed risk scores. This can help to make the latter more meaningful by illustrating relative risk reductions because of changes to behaviour, or just by clarifying the contribution of different factors. However, there may be potential negative effects: some data indicate that this can be demotivating for individuals contemplating behaviour change. This could be a productive focus of further work.

5.3.2 Delivery formats

Both clinicians and patients express broadly positive views of graphical interfaces as a means of communicating risk. Visually engaging formats can help to underline messages about behaviour change, and to focus clinician-patient encounters. However, they do not on their own address more fundamental issues with the understanding of risk, and may in some cases exacerbate them (for example, by encouraging people to index risk to a 0%-100% scale). While the broader literature on effectiveness of risk communication is supportive of the use of visual aids (Zipkin *et al.*, 2014), the data on cardiovascular risk specifically are less conclusive (Waldron *et al.*, 2011; Schulberg *et al.*, 2022), and there is scope for further testing of different ways of representing risk. The potential for graphical formats to increase the salience of risk information – or, conversely, to promote misinterpretation of risk – may be magnified in a digital

workflow where they are not being explained and contextualised by a clinician (see further 5.3.5 below).

5.3.3 Data inputs

The credibility of risk scores may be limited by the fact that their data inputs are fairly narrow, and some risk models do not take account of factors regarded as relevant, such as lifestyle (other than smoking) or family history. Where there is such a credibility gap, it tends to be filled by individuals' subjective perception of their health status or lifestyle behaviours, often leading to unrealistically low assessments of risk. While policy and practice obviously need to be based on validated risk models, it may be worth considering how the broader communication around risk addresses factors not included in the models.

Against this, however, the data also point to some scepticism of risk assessment in general, and an overvaluation of the role of chance in determining outcomes. Single data points, particularly test outcomes such as blood pressure and cholesterol, are often regarded as epistemically more secure than the summary risk score. This can lead to confusion where test results are 'good' and risk scores 'bad' or *vice versa*. This may be particularly a concern in a workflow where individuals are responsible for inputting their own test results.

Incorporating information from genetic tests or family history assessment appears to be viewed positively in general. However, it may make limited difference to understanding of risk in practice. Again, if the risk algorithm does not incorporate these factors with those included in conventional risk assessment in a single output, there is the potential for conflicting results to generate confusion.

5.3.4 Understanding of cardiovascular disease

Some people may not clearly understand what cardiovascular disease is, or the likely implications. As found in one study, for those that do, aggregating heart attacks and strokes may itself be problematic (Taylor *et al.*, 2021). Exploring how this information is presented in the context of communicating risk may prove a valuable exercise.

5.3.5 Clinical context

One overarching implication of the findings is that individuals' understanding of the risk score – and the broader impacts of risk communication on understanding or health behaviours – may depend as much on the broader context of the clinician-patient encounter as on anything specifically to do with the risk tool itself. Given the need for further context to make risk information meaningful or actionable, the message received may depend on the nuances of how clinicians report risk and the broader communication that surrounds discussions of risk. Clinicians report a complex process of gauging individuals' likely reactions, and may judge it preferable not to communicate a risk score at all, even where there is clear guidance to this effect.

This raises some concerns about tools which communicate risk without the involvement of a clinician. Face-to-face consultations, including non-verbal cues as well as verbal interaction, may provide important scaffolding which helps individuals make sense of risk, and which would be difficult to replicate within a purely digital workflow. They also usually include broader conversations, for example around lifestyle behaviours, psychosocial factors, or other health issues, which will inevitably influence how risk is interpreted and acted upon. This said, studies using data from video-recorded consultations (Hall *et al.*, 2007; Gidlow, Ellis, Cowap, *et al.*, 2021) raise some doubt as to how well this works in reality. Also, this review only included data on risk communication, and there is a much larger body of evidence on perceptions of cardiovascular risk more broadly, which we excluded. Nonetheless, it is clear that focusing narrowly on risk communication inevitably misses much of the complexity of clinician-patient encounters in real-world settings.

In the context of a potential digital workflow for the NHS Health Check, this point suggests that while the detailed questions raised in the previous subsections are important, they may have less impact than the broader signposting and availability of resources to help individuals take recommended actions. Designing a system optimised purely for risk communication may have unintended consequences in terms of the broader impacts of the whole Health Check process.

5.3.6 Potential harms

The findings indicate that risk communication may have some potential negative effects. Some people may misinterpret their risk score and feel reassured when they are actually at high risk. In other cases people may be discouraged from adopting healthy behaviours by receiving a low risk score. Manipulating data inputs may have a similar effect by suggesting that lifestyle change makes little difference to risk (by comparison with the impacts of unmodifiable risk factors such as age, gender and genetics).

Risk scoring may also cause unnecessary anxiety. However, some data suggests that this has less to do with the actual risk score received than with the process itself, perhaps because some people find it inherently stressful to contemplate future health risks. While, as noted, the data on this point is mixed, clinicians feel that it is a concern for a subset of patients, and modify their communication style accordingly. This may be an issue for digital workflows which are limited in how far they can take account of these personal differences in how people react to risk information. While the data in this review does not allow quantification of these potential harms, or how likely they are, there are some grounds for concern.

5.4 Theoretical implications

The results of this review should be seen in light of ongoing debates about health behaviour change. Broadly speaking, these debates can be seen as setting 'social cognitive' theories such as the Health Belief Model (Janz and Becker, 1984) and the

Theory of Planned Behaviour (Ajzen, 1991), which emphasise the role of cognition within a broadly rationalistic paradigm of individual agency, against theories which emphasise that culture, environment and 'automatic' mental processes play an important role in individuals' decisions about health (Marteau, Hollands and Fletcher, 2012; Michie and Wood, 2015; Kelly and Barker, 2016). More inclusive theories of health behaviour change, such as Michie and colleagues' 'behaviour change wheel', suggest that the pathways between individual risk information and behaviour are complex, and may not be well captured by a narrow focus on cognitive mediators (Michie, van Stralen and West, 2011; Michie *et al.*, 2021). Arguably, the impact of risk communication on behaviour largely relies upon such cognitive pathways, such that giving people accurate information about risk enables them to make more informed decisions. If so, then – while qualitative data cannot directly evaluate the impact of interventions – this review suggests that the potential for risk communication in isolation to facilitate changes in individuals' behaviour may be limited.

Risk scoring can also be used to inform shared decision-making about preventive treatment. This topic is only partially related to this review, since we focused on risk communication and excluded data on the broader contexts of clinical decision-making. This said, there are some potentially relevant findings in the qualitative literature on the latter (Ju *et al.*, 2018; Qadi *et al.*, 2020). In particular, patients' interpretation of quantitative data on risks and benefits reflects a complex mixture of scepticism and trust which resonate with our findings on patients' attitudes to risk models (Ju *et al.*, 2018; Qadi *et al.*, 2020).

More speculatively, these findings may have implications for the theory behind work on cardiovascular risk communication. In particular, they prompt reflection on the expectations which are placed on the individuals receiving risk information, from a clinical or policy perspective. Within the rationalistic model of individuals' decision-making – and leaving aside broader questions about this model – we can ask: what practical use should individuals, behaving rationally, make of information about their absolute risk?

That is, leaving aside the complexity of real individuals' reactions, we could imagine a purely rational utility-maximising agent making a decision about whether to undertake behaviours to reduce cardiovascular risk (whether lifestyle changes or medication). To perform a cost-benefit analysis, such an agent would need to know: the costs of undertaking such behaviours; the relative risk reduction to be expected from them; and the costs of cardiovascular disease. Their absolute risk at baseline would be largely irrelevant, except insofar as it constrains the scope of relative risk reduction. Information on absolute risk is valuable to the healthcare system in making decisions about treatment and allocating resources efficiently, but does not play a substantial role in the individual's decision-making. (Arguably this is as one would expect given that risk algorithms were originally developed to inform clinical decision-making, and subsequently repurposed as tools for patient communication.) One might argue that absolute risk helps to clarify how much attention should be given to cardiovascular

disease in comparison to other health risks, but in the great majority of cases individuals are not being given any information on the latter, and so are not able to make these judgements either.

If this argument holds, there are two broad implications. First, it suggests that the sense which is prominent in the qualitative data that risk scores are without real meaning is not a contingent failure of communication, but embodies a criticism of the project of communicating risk which is basically correct. Without a theoretically consistent narrative linking risk information to action even on an ideal level, abstracted from the complexity of real decision-making, the theory of change behind risk communication interventions remains incomplete. If so, then marginal improvements to these interventions may have limited scope to improve understanding, even aside from the question of whether this is an effective way to facilitate behaviour change.

Second, this argument might explain the data suggesting that the use of risk scores in practice is not premised upon a rationalistic model of decision-making, but has more to do with appeals to emotion. Clinicians try to take patients' emotional reactions into account when communicating risk, and are more likely to emphasise risk scores when they judge that a fear appeal is of value, and to downplay them when the patient is already overly anxious. This underlines that from the clinician's perspective, a large part of the value of risk communication lies in generating emotional reactions by focusing attention on the prospect of death or other serious health impacts from cardiovascular disease. There is thus a tension between the theoretical model discussed above, with its focus on the utilisation of information and a rational assessment of costs and benefits, and the enactment of risk communication in practice, which often focuses more on mobilising clinical and scientific authority to make future health risks emotionally salient.

6 References

Ajzen, I. (1991) 'The theory of planned behavior', *Organizational Behavior and Human Decision Processes*, 50(2), pp. 179–211. Available at: https://doi.org/10.1016/0749-5978(91)90020-T.

Ayiku, L., Levay, P. and Hudson, T. (2021) 'The NICE OECD countries' geographic search filters: Part 1-methodology for developing the draft MEDLINE and Embase (Ovid) filters', *Journal of the Medical Library Association: JMLA*, 109(2), pp. 258–266. Available at: https://doi.org/10.5195/jmla.2021.978.

Barnett-Page, E. and Thomas, J. (2009) 'Methods for the synthesis of qualitative research: a critical review', *BMC Medical Research Methodology*, 9(1), p. 59. Available at: https://doi.org/10.1186/1471-2288-9-59.

Bengtsson, A. *et al.* (2021) 'Increased knowledge makes a difference! - general practitioners' experiences of pictorial information about subclinical atherosclerosis for primary prevention: an interview study from the VIPVIZA trial', *Scandinavian Journal of Primary Health Care*, 39, pp. 77–84. Available at: https://doi.org/10.1080/02813432.2021.1882083.

Boase, S. *et al.* (2012) 'Tinkering and tailoring individual consultations: how practice nurses try to make cardiovascular risk communication meaningful', *Journal of Clinical Nursing*, 21(17–18), pp. 2590–2598. Available at: https://doi.org/10.1111/j.1365-2702.2012.04167.x.

Bonner, C. *et al.* (2013) 'General practitioners' use of different cardiovascular risk assessment strategies: a qualitative study', *Medical Journal of Australia*, 199, pp. 485–9.

Bonner, C., Jansen, J., McKinn, S., *et al.* (2014) 'Communicating cardiovascular disease risk: an interview study of General Practitioners' use of absolute risk within tailored communication strategies', *BMC Family Practice*, 15, p. 106. Available at: https://doi.org/10.1186/1471-2296-15-106.

Bonner, C., Jansen, J., Newell, B.R., *et al.* (2014) 'I don't believe it, but i'd better do something about it: patient experiences of online heart age risk calculators', *Journal of Medical Internet Research*, 16, p. e120. Available at: https://doi.org/10.2196/jmir.3190.

Bonner, C. *et al.* (2018) 'Heuristics and biases in cardiovascular disease prevention: How can we improve communication about risk, benefits and harms?', *Patient Education & Counseling*, 101, pp. 843–853. Available at: https://doi.org/10.1016/j.pec.2017.12.003.

Bonner, C. *et al.* (2021) 'Interventions Using Heart Age for Cardiovascular Disease Risk Communication: Systematic Review of Psychological, Behavioral, and Clinical Effects', *JMIR Cardio*, 5(2), p. e31056. Available at: https://doi.org/10.2196/31056.

Collins, D.R.J. *et al.* (2017) 'Global cardiovascular risk assessment in the primary prevention of cardiovascular disease in adults: systematic review of systematic reviews', *BMJ Open*, 7(3), p. e013650. Available at: https://doi.org/10.1136/bmjopen-2016-013650.

Coorey, G. *et al.* (2019) 'Persuasive design features within a consumer-focused eHealth intervention integrated with the electronic health record: A mixed methods study of effectiveness and acceptability', *PLoS ONE [Electronic Resource]*, 14, p. e0218447. Available at: https://doi.org/10.1371/journal.pone.0218447.

Cupit, C. *et al.* (2020) 'Overruling uncertainty about preventative medications: the social organisation of healthcare professionals' knowledge and practices', *Sociology of Health & Illness*, 42 Suppl 1, pp. 114–129. Available at: https://doi.org/10.1111/1467-9566.12998.

Damman, O.C. *et al.* (2016) 'Barriers in using cardiometabolic risk information among consumers with low health literacy', *British Journal of Health Psychology*, 21, pp. 135–56. Available at: https://doi.org/10.1111/bjhp.12149.

Damman, O.C. *et al.* (2017) 'How lay people understand and make sense of personalized disease risk information', *Health Expectations*, 20, pp. 973–983. Available at: https://doi.org/10.1111/hex.12538.

Farrimond, H. *et al.* (2010) 'Making sense of being at "high risk" of coronary heart disease within primary prevention', *Psychology & Health*, 25, pp. 289–304. Available at: https://doi.org/10.1080/08870440802499382.

Frolund, J.C. and Primdahl, J. (2015) 'Patients' Experiences of Nurse-Led Screening for Cardiovascular Risk in Rheumatoid Arthritis', *Musculoskeletal Care*, 13, pp. 236–47. Available at: https://doi.org/10.1002/msc.1104.

Gidlow, C.J., Ellis, N.J., Riley, V., *et al.* (2021) 'Cardiovascular disease risk communication in NHS Health Checks: a qualitative video-stimulated recall interview study with practitioners', *BJGP Open*, 5(5). Available at: https://doi.org/10.3399/BJGPO.2021.0049.

Gidlow, C.J., Ellis, N.J., Cowap, L., *et al.* (2021) 'Cardiovascular disease risk communication in NHS Health Checks using QRISK®2 and JBS3 risk calculators: the RICO qualitative and quantitative study', *Health Technology Assessment*, 25(50), pp. 1–124. Available at: https://doi.org/10.3310/hta25500.

Gooding, H.C. *et al.* (2016) 'Adolescent Perceptions of Cholesterol Screening Results: "Young Invincibles" or Developing Adults?', *Journal of Adolescent Health*, 59(2), pp. 162–170. Available at: https://doi.org/10.1016/j.jadohealth.2016.03.027.

Grauman, Å. *et al.* (2019) 'Exploring research participants' perceptions of cardiovascular risk information—Room for improvement and empowerment', *Patient Education and Counseling*, 102(8), pp. 1528–1534. Available at: https://doi.org/10.1016/j.pec.2019.03.010.

Grauman, Å. (2020) *The publics' perspective on cardiovascular risk information: Implications for practice*. PhD. Uppsala University. Available at: https://www.diva-portal.org/smash/get/diva2:1509397/FULLTEXT01.pdf.

Hall, R. *et al.* (2007) 'Assessing family history of heart disease in primary care consultations: a qualitative study', *Family Practice*, 24, pp. 435–42.

Hawker, S. *et al.* (2002) 'Appraising the Evidence: Reviewing Disparate Data Systematically', *Qualitative Health Research*, 12(9), pp. 1284–1299. Available at: https://doi.org/10.1177/1049732302238251.

Hawking, M.K.D. *et al.* (2019) 'Improving cardiovascular disease risk communication in NHS Health Checks: a qualitative study', *BMJ Open*, 9, p. e026058. Available at: https://doi.org/10.1136/bmjopen-2018-026058.

Hill, S. *et al.* (2010) 'Absolute risk representation in cardiovascular disease prevention: comprehension and preferences of health care consumers and general practitioners involved in a focus group study', *BMC Public Health*, 10, p. 108. Available at: https://doi.org/10.1186/1471-2458-10-108.

Hippisley-Cox, J. *et al.* (2007) 'Derivation and validation of QRISK, a new cardiovascular disease risk score for the United Kingdom: prospective open cohort study', *BMJ (Clinical research ed.)*, 335(7611), p. 136. Available at: https://doi.org/10.1136/bmj.39261.471806.55.

Hippisley-Cox, J. *et al.* (2008) 'Predicting cardiovascular risk in England and Wales: prospective derivation and validation of QRISK2', *BMJ (Clinical research ed.)*, 336(7659), pp. 1475–1482. Available at: https://doi.org/10.1136/bmj.39609.449676.25.

Honey, S. *et al.* (2015) 'Patients' responses to the communication of vascular risk in primary care: a qualitative study', *Primary Health Care Research & Development*, 16(1), pp. 61–70. Available at: https://doi.org/10.1017/S1463423613000509.

Janz, N.K. and Becker, M.H. (1984) 'The Health Belief Model: a decade later', *Health Education Quarterly*, 11(1), pp. 1–47. Available at: https://doi.org/10.1177/109019818401100101.

Ju, A. *et al.* (2018) 'Patient beliefs and attitudes to taking statins: systematic review of qualitative studies', *British Journal of General Practice*, 68(671), pp. e408–e419. Available at: https://doi.org/10.3399/bjgp18X696365.

Karmali, K.N. *et al.* (2017) 'Risk scoring for the primary prevention of cardiovascular disease', *Cochrane Database of Systematic Reviews* [Preprint]. Edited by Cochrane Heart Group, (6). Available at: https://doi.org/10.1002/14651858.CD006887.pub4.

Kelly, M.P. and Barker, M. (2016) 'Why is changing health-related behaviour so difficult?', *Public Health*, 136, pp. 109–116. Available at: https://doi.org/10.1016/j.puhe.2016.03.030.

Kirby, M. and Machen, I. (2009) 'Impact on clinical practice of the Joint British Societies' cardiovascular risk assessment tools', *International Journal of Clinical Practice*, 63, pp. 1683–92. Available at: https://doi.org/10.1111/j.1742-1241.2009.02201.x.

Lenz, M., Kasper, J. and Muhlhauser, I. (2009) 'Development of a patient decision aid for prevention of myocardial infarction in type 2 diabetes - Rationale, design and pilot testing', *GMS Psycho-Social-Medicine Vol 6 2009, ArtID Doc05*, 6.

Marshall, I.J., Wolfe, C.D.A. and McKevitt, C. (2018) '"People like you?": how people with hypertension make sense of future cardiovascular risk-a qualitative study', *BMJ Open*, 8, p. e023726. Available at: https://doi.org/10.1136/bmjopen-2018-023726.

Marteau, T.M., Hollands, G.J. and Fletcher, P.C. (2012) 'Changing Human Behavior to Prevent Disease: The Importance of Targeting Automatic Processes', *Science*, 337(6101), pp. 1492–1495. Available at: https://doi.org/10.1126/science.1226918.

McKinn, S. *et al.* (2016) 'Factors influencing general practitioners' decisions about cardiovascular disease risk reassessment: findings from experimental and interview studies', *BMC Family Practice*, 17, p. 107. Available at: https://doi.org/10.1186/s12875-016-0499-7.

McNaughton, R.J. (2018) Utilising Normalisation Process Theory to understand the patient journey for high-risk individuals participating in the NHS Health Check programme. Available at: https://research.tees.ac.uk/ws/portalfiles/portal/8058619/Rebekah_McNaughton.

Michie, S. *et al.* (2021) 'Developing an evidence-based online method of linking behaviour change techniques and theoretical mechanisms of action: a multiple methods study', *Health Services and Delivery Research*, 9(1), pp. 1–168.

Michie, S., van Stralen, M.M. and West, R. (2011) 'The behaviour change wheel: A new method for characterising and designing behaviour change interventions', *Implementation Science*, 6(1), p. 42. Available at: https://doi.org/10.1186/1748-5908-6-42.

Michie, S. and Wood, C.E. (2015) 'Health behaviour change techniques', in M. Conner and P. Norman (eds) *Predicting and changing health behaviour. Research and practice with social cognition models*. 3rd edn. Maidenhead: Open University Press, pp. 358–389.

Middlemass, J.B. *et al.* (2014) 'Introducing genetic testing for cardiovascular disease in primary care: a qualitative study', *British Journal of General Practice*, 64, pp. e282-9. Available at: https://doi.org/10.3399/bjgp14X679714.

Muthee, T.B. *et al.* (2020) 'Factors influencing the implementation of cardiovascular risk scoring in primary care: a mixed-method systematic review', *Implementation Science*, 15(1), p. 57. Available at: https://doi.org/10.1186/s13012-020-01022-x.

Nielsen, K.D. *et al.* (2009) '"Couldn't you have done just as well without the screening?". A qualitative study of benefits from screening as perceived by people without a high cardiovascular risk score', *Scandinavian Journal of Primary Health Care*, 27, pp. 111–6. Available at: https://doi.org/10.1080/02813430902808619.

Nolan, T. *et al.* (2015) 'Patient reactions to a web-based cardiovascular risk calculator in type 2 diabetes: a qualitative study in primary care', *British Journal of General Practice*, 65, pp. e152-60. Available at: https://doi.org/10.3399/bjgp15X683953.

Office for Health Improvement and Disparities (2021) *Preventing illness and improving health for all: a review of the NHS Health Check programme and recommendations*, *GOV.UK*. Available at: https://www.gov.uk/government/publications/nhs-health-

check-programme-review/preventing-illness-and-improving-health-for-all-a-review-of-the-nhs-health-check-programme-and-recommendations (Accessed: 22 February 2023).

Peiris, D.P. *et al.* (2009) 'An electronic clinical decision support tool to assist primary care providers in cardiovascular disease risk management: development and mixed methods evaluation', *Journal of Medical Internet Research*, 11, p. e51. Available at: https://doi.org/10.2196/jmir.1258.

Perry, C. *et al.* (2016) 'The NHS health check programme in England: a qualitative study', *Health Promotion International*, 31(1), pp. 106–115. Available at: https://doi.org/10.1093/heapro/dau059.

Polak, L. and Green, J. (2015) 'Using quantitative risk information in decisions about statins: a qualitative study in a community setting', *British Journal of General Practice*, 65(633), pp. e264–e269. Available at: https://doi.org/10.3399/bjgp15X684433.

Public Health England (2019) *NHS Health Check: Best practice guidance for commissioners and providers*. Available at: https://www.healthcheck.nhs.uk/seecmsfile/?id=1480.

Qadi, O. *et al.* (2020) 'Patients' and health professionals' attitudes and perceptions towards the initiation of preventive drugs for primary prevention of cardiovascular disease: a systematic review of qualitative studies', *BJGP open*, 4(5), pp. 1–12. Available at: https://doi.org/10.3399/bjgpopen20X101087.

Riley, R. *et al.* (2016) 'Experiences of patients and healthcare professionals of NHS cardiovascular health checks: a qualitative study', *Journal of Public Health*, 38, pp. 543–551.

Riley, V. *et al.* (2020) 'A qualitative exploration of two risk calculators using video-recorded NHS health check consultations', *BMC Family Practice*, 21(250).

Schulberg, S.D. *et al.* (2022) 'Cardiovascular risk communication strategies in primary prevention. A systematic review with narrative synthesis', *Journal of Advanced Nursing*, 78(10), pp. 3116–3140. Available at: https://doi.org/10.1111/jan.15327.

Sheridan, S.L. *et al.* (2009) 'Individuals' responses to global CHD risk: A focus group study', *Patient Education and Counseling*, 76, pp. 233–239. Available at: https://doi.org/10.1016/j.pec.2009.01.010.

Snell, K. and Helen, I. (2020) ''Well, I knew this already'-Explaining personal genetic risk information through narrative meaning-making', *Sociology of Health & Illness*, 42, pp. 496–509. Available at: https://doi.org/10.1111/1467-9566.13018.

van Steenkiste, B. *et al.* (2004) 'Barriers to implementing cardiovascular risk tables in routine general practice', *Scandinavian Journal of Primary Health Care*, 22, pp. 32–7.

Studziński, K. *et al.* (2019) 'Effect of using cardiovascular risk scoring in routine risk assessment in primary prevention of cardiovascular disease: an overview of systematic reviews', *BMC Cardiovascular Disorders*, 19(1), p. 11. Available at: https://doi.org/10.1186/s12872-018-0990-2.

Taylor, D.A. *et al.* (2021) 'Cardiovascular disease risk prediction in older people: a qualitative study', *British Journal of General Practice*, 71, pp. e772–e779. Available at: https://doi.org/10.3399/BJGP.2020.1038.

Usher-Smith, J.A. *et al.* (2017) 'Factors associated with engagement with a web-based lifestyle intervention following provision of coronary heart disease risk: Mixed methods study', *Journal of Medical Internet Research Vol 19(10), 2017, ArtID e351*, 19. Available at: https://doi.org/10.2196/jmir.7697.

Vaidya, R. *et al.* (2012) 'Sustaining cardiovascular absolute risk management in Australian general practice', *Australian Journal of Primary Health*, 18, pp. 304–7.

Waldron, C.A. *et al.* (2011) 'What are effective strategies to communicate cardiovascular risk information to patients? A systematic review', *Patient education and counseling*, 82(2), pp. 169–81. Available at: https://doi.org/10.1016/j.pec.2010.04.014.

Wan, Q. *et al.* (2008) 'Sharing risk management: an implementation model for cardiovascular absolute risk assessment and management in Australian general practice', *International Journal of Clinical Practice*, 62, pp. 905–11. Available at: https://doi.org/10.1111/j.1742-1241.2008.01769.x.

Wilson, P.W. *et al.* (1998) 'Prediction of coronary heart disease using risk factor categories', *Circulation*, 97(18), pp. 1837–1847. Available at: https://doi.org/10.1161/01.cir.97.18.1837.

Wong, S.S.-L., Wilczynski, N.L. and Haynes, R.B. (2004) 'Developing Optimal Search Strategies for Detecting Clinically Relevant Qualitative Studies in MEDLINE', *Medinfo*, 11(1), pp. 311–316. Available at: https://doi.org/10.3233/978-1-60750-949-3-311.

Zipkin, D.A. *et al.* (2014) 'Evidence-based risk communication: a systematic review', *Annals of Internal Medicine*, 161(4), pp. 270–280. Available at: https://doi.org/10.7326/M14-0295.

Appendix 1: Medline search strategy

Ovid MEDLINE(R) ALL

via Ovid http://ovidsp.ovid.com/

Date range searched: 1946 to October 26, 2022

Date searched: 27 October 2022

Records retrieved: 5050

The MEDLINE strategy below includes the NICE OECD geographic search filter for Ovid Medline (Ayiku, Levay and Hudson, 2021) and an adapted version of McMaster University's qualitative studies filter (sensitivity maximising version) for Ovid Medline (Wong, Wilczynski and Haynes, 2004).

1 Cardiovascular Diseases/ (170779)

2 ((cardiovascular or cardio vascular or cardio-vascular or CVD) adj2 risk*).ti,ab. (123072)

3 ((cardiovascular or cardio vascular or cardio-vascular) adj (disease* or health)).ti,ab. (213162)

4 or/1-3 (352622)

5 Risk Assessment/ (302128)

6 Risk Management/ (19300)

7 "Risk Evaluation and Mitigation"/ (64)

8 (risk* adj (assess* or estimat* or calculat* or evaluat* or classif*)).ti,ab. (106255)

9 (risk* adj (scor* or value* or quantif* or measur* or rating* or grade* or index or indices or chart* or algorithm* or equation* or table* or model* or tool*)).ti,ab. (53133)

10 ((risk* adj (manag* or mitigat* or reduc* or control*)) and (prevent* or barrier* or facilitat*)).ti,ab. (13632)

11 (risk adj2 (absolute or prediction)).ti,ab. (22914)

12 (Framingham* adj (risk* or score*)).ti,ab. (3629)

13 (("European Systematic Coronary Risk Evaluation" or SCORE) adj2 algorithm*).ti,ab. (621)

14 ("German Prospective Cardiovascular M?nster" or PROCAM*).ti,ab. (1888)

15 QRISK*.ti,ab. (288)

16 ((World Health Organization or WHO) adj risk*).ti,ab. (218)

17 (NHS adj2 Health Check*).ti,ab. (164)

18 or/5-17 (443346)

19 4 and 18 (34643)

20 ((cardi* or CVD or vascular) adj2 (risk* adj2 communicat*)).ti,ab. (84)

21 19 or 20 (34671)

22 Qualitative Research/ (77227)

23 (qualitativ* adj2 (research* or data or study or studies or review*)).ti,ab,kw. (112605)

24 interview*.ti,ab. (429656)

25 px.fs. (1163806)

26 exp *Health Services Administration/ (1405859)

27 or/22-26 (2719252)

28 21 and 27 (6319)

29 limit 28 to english language (5954)

30 letter/ (1196956)

31 editorial/ (623847)

32 news/ (214790)

33 exp historical article/ (409040)

34 anecdotes as topic/ (4746)

35 (letter or comment*).ti,pt. (1754626)

36 or/30-35 (2757497)

37 29 not 36 (5544)

38 afghanistan/ or africa/ or africa, northern/ or africa, central/ or africa, eastern/ or "africa south of the sahara"/ or africa, southern/ or africa, western/ or albania/ or algeria/ or andorra/ or angola/ or "antigua and barbuda"/ or argentina/ or armenia/ or azerbaijan/ or bahamas/ or bahrain/ or bangladesh/ or barbados/ or belize/ or

benin/ or bhutan/ or bolivia/ or borneo/ or "bosnia and herzegovina"/ or botswana/ or brazil/ or brunei/ or bulgaria/ or burkina faso/ or burundi/ or cabo verde/ or cambodia/ or cameroon/ or central african republic/ or chad/ or exp china/ or comoros/ or congo/ or cote d'ivoire/ or croatia/ or cuba/ or "democratic republic of the congo"/ or cyprus/ or djibouti/ or dominica/ or dominican republic/ or ecuador/ or egypt/ or el salvador/ or equatorial guinea/ or eritrea/ or eswatini/ or ethiopia/ or fiji/ or gabon/ or gambia/ or "georgia (republic)"/ or ghana/ or grenada/ or guatemala/ or guinea/ or guinea-bissau/ or guyana/ or haiti/ or honduras/ or independent state of samoa/ or exp india/ or indian ocean islands/ or indochina/ or indonesia/ or iran/ or iraq/ or jamaica/ or jordan/ or kazakhstan/ or kenya/ or kosovo/ or kuwait/ or kyrgyzstan/ or laos/ or lebanon/ or liechtenstein/ or lesotho/ or liberia/ or libya/ or madagascar/ or malaysia/ or malawi/ or mali/ or malta/ or mauritania/ or mauritius/ or mekong valley/ or melanesia/ or micronesia/ or monaco/ or mongolia/ or montenegro/ or morocco/ or mozambique/ or myanmar/ or namibia/ or nepal/ or nicaragua/ or niger/ or nigeria/ or oman/ or pakistan/ or palau/ or exp panama/ or papua new guinea/ or paraguay/ or peru/ or philippines/ or qatar/ or "republic of belarus"/ or "republic of north macedonia"/ or romania/ or exp russia/ or rwanda/ or "saint kitts and nevis"/ or saint lucia/ or "saint vincent and the grenadines"/ or "sao tome and principe"/ or saudi arabia/ or serbia/ or sierra leone/ or senegal/ or seychelles/ or singapore/ or somalia/ or south africa/ or south sudan/ or sri lanka/ or sudan/ or suriname/ or syria/ or taiwan/ or tajikistan/ or tanzania/ or thailand/ or timor-leste/ or togo/ or tonga/ or "trinidad and tobago"/ or tunisia/ or turkmenistan/ or uganda/ or ukraine/ or united arab emirates/ or uruguay/ or uzbekistan/ or vanuatu/ or venezuela/ or vietnam/ or west indies/ or yemen/ or zambia/ or zimbabwe/ (1251918)

39 "Organisation for Economic Co-Operation and Development"/ (482)

40 australasia/ or exp australia/ or austria/ or baltic states/ or belgium/ or exp canada/ or chile/ or colombia/ or costa rica/ or czech republic/ or exp denmark/ or estonia/ or europe/ or finland/ or exp france/ or exp germany/ or greece/ or hungary/ or iceland/ or ireland/ or israel/ or exp italy/ or exp japan/ or korea/ or latvia/ or lithuania/ or luxembourg/ or mexico/ or netherlands/ or new zealand/ or north america/ or exp norway/ or poland/ or portugal/ or exp "republic of korea"/ or "scandinavian and nordic countries"/ or slovakia/ or slovenia/ or spain/ or sweden/ or switzerland/ or turkey/ or exp united kingdom/ or exp united states/ (3444485)

41 European Union/ (17407)

42 Developed Countries/ (21236)

43 or/39-42 (3460110)

44 38 not 43 (1163591)

45 37 not 44 (5050)

Key:

/ = indexing term (Medical Subject Heading: MeSH)

fs = floating subheading

* = truncation

ti,ab,kw = terms in either title, abstract, keyword fields

adj2 = terms within two words of each other (any order)

? = optional wild card character for zero or one letters

pt = publication type

Appendix 2: Quality assessment tool

The quality assessment tool is reproduced from Hawker et al. (Hawker *et al.*, 2002).

1. Abstract and title: Did they provide a clear description of the study?

    Good: Structured abstract with full information and clear title.

    Fair: Abstract with most of the information.

    Poor: Inadequate abstract.

    Very Poor: No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?

    Good: Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions.

    Fair: Some background and literature review. Research questions outlined.

    Poor: Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background.

    Very Poor: No mention of aims/objectives. No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?

    Good: Method is appropriate and described clearly (for example, questionnaires included). Clear details of the data collection and recording.

    Fair: Method appropriate, description could be better. Data described.

    Poor: Questionable whether method is appropriate. Method described inadequately. Little description of data.

    Very Poor: No mention of method, AND/OR Method inappropriate, AND/OR No details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?

    Good: Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.

    Fair: Sample size justified. Most information given, but some missing.

    Poor: Sampling mentioned but few descriptive details.

Very Poor: No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?

Good: Clear description of how analysis was done. Description of how themes derived / respondent validation or triangulation.

Fair: Descriptive discussion of analysis.

Poor: Minimal details about analysis.

Very Poor: No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

Good: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Researcher was reflexive and/or aware of own bias.

Fair: Lip service was paid to above (i.e., these issues were acknowledged).

Poor: Brief mention of issues.

Very Poor: No mention of issues.

7. Results: Is there a clear statement of the findings?

Good: Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text.Results relate directly to aims. Sufficient data are presented to support findings.

Fair: Findings mentioned but more explanation could be given. Data presented relate directly to results.

Poor: Findings presented haphazardly, not explained, and do not progress logically from results.

Very Poor: Findings not mentioned or do not relate to aims.

8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?

Good: Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).

Fair: Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.

Poor: Minimal description of context/setting.

Very Poor: No description of context/setting.

9. Implications and usefulness: How important are these findings to policy and practice?

Good: Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.

Fair: Two of the above (state what is missing in comments).

Poor: Only one of the above.

Very Poor: None of the above.

Appendix 3: Evidence tables

Bengtsson et al. (2021)	
Research question / study focus	"[T] to explore how pictorial information of [*sic*] patients' subclinical atherosclerosis provided to patients and physicians, affects GPs' perception of patients' risk, their communication with patients and their attitudes to and treatment of CVD risk factors" p78
Theoretical approach	NR
Sampling and recruitment methods	Sampling within intervention arm of effectiveness study. GPs recruited through letters / calls to health centres (unclear if all GPs in intervention group were contacted). GPs eligible if they had received ultrasound results for ≥3 patients.
Country / location	Västerbotten County, Sweden
Setting / context	Primary care; health check programme where all residents age 40-60 invited for CV screening and counselling, including carotid ultrasound
Sample size	15
Population characteristics	GPs; n=4 female, n=11 male; n=9 urban, n=6 rural; n=6 <5 years' experience, n=9 >5 years
Data collection methods	Semi-structured interview focusing on use of visual information on atherosclerosis
Data analysis methods	Qualitative content analysis, guided by thematic saturation
Limitations identified by author	Sample may not be representative of broader population of GPs
Limitations identified by reviewer	Some unclarity in sampling and recruitment. Study has a specific focus and does not aim to access broader notions of risk

Boase et al. (2012)	
Research question / study focus	"[T]o consider the perspectives of practice nurses in terms of how they approach communicating cardiovascular risk to patients within their clinical practice and the way that might influence how that information is received." p2591
Theoretical approach	NR
Sampling and recruitment methods	"Systematic purposive sampling"; practices within selected trust were listed and senior nurses identified as being involved in discussion of CV risk. Limited information on selection of sampling frame, how many practices / nurses were contacted or response rate.
Country / location	UK, location NR
Setting / context	Primary care. Context of risk communication is not clearly defined in terms of which patients are under discussion; NHS

	Health Checks are mentioned in the discussion, but unclear if the data directly concern the Health Check programme
Sample size	28 (n=12 for focus groups, n=16 for interviews)
Population characteristics	Nurses; n=27 female, n=1 male; age 42-58
Data collection methods	Focus groups using vignettes and visual prompts, focused generally on communication of cardiovascular risk; semi-structured interviews focused more on visual risk communication techniques
Data analysis methods	Iterative thematic analysis; triangulation through use of field notes and reflexive diaries; feedback of main themes to participants for validation
Limitations identified by author	Study only includes nurses and not others involved in communicating risk; data does not cover issues with communicating with English-second-language patients
Limitations identified by reviewer	Some unclarity around sampling / recruitment and practice context

Bonner et al. (2013; 2014)	
Research question / study focus	"[T]o investigate GPs' views and experiences of CVD risk assessment to identify factors that influence the extent to which Australian AR assessment guidelines are used" p1
Theoretical approach	Phenomenology
Sampling and recruitment methods	Invites sent to all members of selected Divisions of General Practice; 55 of 3743 responded; 25 selected based on purposive sampling for variation in characteristics likely to affect risk management
Country / location	New South Wales, Australia
Setting / context	Primary care. Context of CV risk assessment is not fully reported; the study mentions Australian practice guidelines but does not clearly report what these include or which patients are recommended to be assessed
Sample size	25

Population characteristics	GPs; n=15 female, n=10 male; n=6 <40 years, n=8 40-49, n=7 50-59, n=4 ≥60; n=5 <10 years' experience, n=6 10-19 years, n=9 20-29 years, n=5 ≥30 years
Data collection methods	Semi-structured interview focusing on CV risk assessment and management
Data analysis methods	Framework analysis using constant comparison; double coding [but unclear if all data were double coded]
Limitations identified by author	Participants may not be representative of broader population; self-report may differ from actual practice
Limitations identified by reviewer	No major limitations

Bonner, Jansen, Newell, et al. (2014)	
Research question / study focus	"[T]o investigate patient experiences and understanding of online heart age calculators" p2
Theoretical approach	NR
Sampling and recruitment methods	Purposive sampling for variation by age, gender, risk status (with focus on low- and moderate-risk patients) and risk knowledge. Inclusion criteria: 40-70 years old, at least one risk factor, not currently taking medication. Recruitment was by GPs who were provided with some guidance on eligibility, but no further information or response rate reported. Recruitment continued until thematic saturation in data analysis.
Country / location	New South Wales, Australia
Setting / context	Primary care; no further information
Sample size	26
Population characteristics	N=16 female, n=10 male; age 40-67; n=4 not completed high school, n=6 high school, n=7 technical qualification, n=9 university degree; n=23 low CVD risk, n=3 moderate risk.
Data collection methods	Think-aloud methodology: participants completed online heart age calculator tools while talking. Protocol piloted and amended before study. Interviews audio-recorded and website interaction screen-captured.

Data analysis methods	Framework analysis; double-coding of sample of transcripts
Limitations identified by author	Video recording unavailable for some interviews; presence of interviewer may have influenced results so findings are not reflective of interaction with tools in a realistic setting; sample not representative of whole population
Limitations identified by reviewer	Some unclarity around sampling and recruitment

Bonner et al. (2018)	
Research question / study focus	"[H]ow patients make sense of and interpret CVD risk results presented in a variety of numerical, verbal and graphical formats, including both shorter (5 year) and longer (10 year) timeframes." p844
Theoretical approach	NR
Sampling and recruitment methods	Recruitment via GPs (sampling of GPs themselves NR). Inclusion criteria: 35-74 years old, with CV risk factors. Purposive sampling for variation in age, gender, medication use, CV risk status. Limited information on the actual process of sampling and recruitment. Recruitment continued until thematic saturation reached in data analysis.
Country / location	New South Wales, Australia
Setting / context	primary care; no further information
Sample size	25
Population characteristics	n=15 female, n=10 male; n=2 age 35-44, n=1 45-54, n=9 55-64, n=13 65-74; n=21 low risk, n=3 moderate, n=1 high; n=14 taking at least one CVD medication; n=21 no established CVD
Data collection methods	Think-aloud protocol while using web-based risk calculator with graphical interface based on Framingham Risk Equation, giving either 5-year or 10-year risk. Risk calculator piloted and amended.
Data analysis methods	Framework analysis method involving initial development of a thematic framework, followed by charting/mapping of themes

Limitations identified by author	People who agreed to participate may be more aware of CV risk than the general population; findings could be different if a clinician guided patients through the information
Limitations identified by reviewer	Some unclarity around sampling and recruitment

Coorey et al. (2019)	
Research question / study focus	To explore the implementation of a web-based eHealth intervention, as part of a process evaluation linked to a randomised trial
Theoretical approach	NR
Sampling and recruitment methods	Participants and GPs in the intervention arm of the trial were invited. Purposive sampling for variation in demographics (patients) and practice characteristics (GPs). Limited information on the sampling and recruitment process. Response rate NR
Country / location	Sydney and surrounding area, Australia
Setting / context	Primary care. Limited information on setting or context
Sample size	N=55 patients, N=17 clinicians
Population characteristics	Patients: mean age 68; n=35 male; n=23 school only, n=7 degree, n=12 postgraduate qualification, n=13 vocational qualification; n=17 employed, n=38 retired; n=24 existing CVD, n=31 high risk of CVD. GPs: n=11 male; n=11 practices with >=3 GPs.
Data collection methods	Focus groups and semi-structured interviews with patients; questions focused on experiences of the intervention and broader health behaviours. Individual semi-structured interviews with GPs; questions focused on experiences of the intervention, CV risk communication generally, and patients' health behaviours.
Data analysis methods	Inductive thematic coding using framework derived from the intervention logic model; comparison between patient and GP data to understand intervention experiences
Limitations identified by author	Study conducted 12 months after intervention; reliance on self-report data about behaviours; no double-coding of qualitative

	data; possible selection bias leading to over-representation of male and older patients
Limitations identified by reviewer	Some unclarity around sampling and recruitment. The study is focused on a specific intervention, although there are data on risk communication more broadly.

Cupit et al. (2020)	
Research question / study focus	To understand the social and institutional shaping of CVD prevention, including risk assessment and prescribing
Theoretical approach	Institutional ethnography
Sampling and recruitment methods	Purposive sampling for "familiarity with the work processes and texts under investigation" (p118); no further information
Country / location	UK, location NR
Setting / context	Primary care; the context is mostly NHS Health Checks (with a focus on "Part 2" where results are communicated to high-risk individuals), but includes other CVD prevention (not specified)
Sample size	n=24 patients, n=9 clinicians, n=14 other stakeholders; also observation additional to the interview sample
Population characteristics	NR
Data collection methods	Interviews; for clinician interviews, questions focused on 'walking through' sequence of actions in the Health Check consultation (no information beyond this); observations of preventative interactions, especially NHS Health Checks (32 hours); document analysis
Data analysis methods	NR
Limitations identified by author	NR
Limitations identified by reviewer	Generally very limited description of methods or sample

Damman et al. (2016)	
Research question / study focus	"[T]o identify the barriers from the perspective of consumers with low health literacy in using risk information provided in cardiometabolic risk assessments" (p137).
Theoretical approach	NR
Sampling and recruitment methods	Initial sampling through healthcare organisations (process unclear), which recruited only n=5 participants. Subsequently an online access panel was used; participants were invited if they had low health literacy scores and were willing to participate. Response rate 27% (18 / 67). Token incentive paid to participants.
Country / location	Netherlands, location NR
Setting / context	Participants used an online risk communication tool (on a laptop). There is a CV prevention consultation programme in the Netherlands (similar to NHS Health Checks) but it is unclear if participants had undertaken this.
Sample size	23
Population characteristics	All participants had low health literacy. Mean age 53; n=8 male, n=15 female; n=10 no or primary education, n=9 secondary, n=4 tertiary
Data collection methods	Interviews in hospital or participants' homes. Participants were provided with an online risk assessment tool on a laptop and asked to think aloud while completing the tool. Some further questions asked to explore understanding and engagement with the information.
Data analysis methods	Thematic coding; subsample of interviews (n=4) double coded
Limitations identified by author	Findings may not be representative of what happens in a real risk assessment with a clinician. Think-aloud process elicited limited data.
Limitations identified by reviewer	No major limitations

Damman et al. (2017)	
Research question / study focus	To understand how people understand information from a cardiovascular risk calculator
Theoretical approach	NR
Sampling and recruitment methods	Target population; age 45-60, no history of CVD or diabetes. Recruitment through advert in a free local newspaper; n=21 responses, of whom n=16 participated. Small cash incentive paid to participants.
Country / location	Netherlands, location NR
Setting / context	Participants viewed online material
Sample size	16
Population characteristics	n=6 45-50 years, n=6 51-55, n=1 56-60, n=6 60-65; n=3 male, n=13 female; n=1 no or primary education, n=7 secondary, n=8 tertiary; n=4 low risk, n=10 slightly elevated risk, n=2 elevated risk
Data collection methods	Interviews conducted in university laboratory. Participants viewed an online tool on a computer with eye-movement tracking, were then tested on recall, and finally participated in a semi-structured interview with questions focusing on understanding of risk.
Data analysis methods	Thematic coding; double-coding of all interviews; comparison between the three data sets
Limitations identified by author	Self-selected sample; some eye tracking data were not usable; participants were not asked about knowledge or perception of risk before completing the risk calculator
Limitations identified by reviewer	No major limitations

Farrimond et al. (2010)	
Research question / study focus	To explore how people identified as at high risk of CVD understand and respond to this information
Theoretical approach	NR

Sampling and recruitment methods	Sampled from participants identified as 'high risk' in a controlled trial of CVD risk communication and reduction. Sampling for the trial unclear. Purposive sampling for variation in demographic characteristics (the actual choice of invitees is NR). Response rate 77.5% (38 / 49).
Country / location	Lincolnshire, Nottinghamshire, Devon and Cornwall, UK
Setting / context	Primary care. Sampled from participants in a trial of including CV family history in risk assessments using JBS2 CV risk calculator. Not clear whether participants would have received risk assessment in any case (note study predates the NHS Health Check).
Sample size	38
Population characteristics	n=14 female, n=24 male; mean age 58; n=11 managerial/professional occupational status, n=2 intermediate, n=2 lower supervisory, n=18 manual, n=5 disabled/unemployed
Data collection methods	Individual interviews at participants' homes or by telephone. Interviews structured chronologically around participants' experience of the intervention ("discovery interview").
Data analysis methods	Latent thematic analysis; subsample of transcripts coded by four researchers independently
Limitations identified by author	NR
Limitations identified by reviewer	No major limitations. Study focus is broad and includes constructs of 'risk' in a broader sense as well as the risk assessment.

Frolund and Primdahl (2015)	
Research question / study focus	To explore the experiences of patients with rheumatoid arthritis participating in a nurse-led screening programme for CVD
Theoretical approach	Phenomenology
Sampling and recruitment methods	Inclusion criteria: diagnosed rheumatoid arthritis, participation in CV screening in last 6 months, Danish-speaking, no diagnosed CVD, diabetes, kidney disease, severe mental illness. Participants contacted by nurse at the study site (hospital specialising in rheumatic diseases); unclear how invitees were

	selected. Participants sampled purposively for variation in gender, age, arthritis duration and CVD risk. Total participation rate 30% (14 / 46).
Country / location	Graasten, Denmark
Setting / context	Specialist hospital outpatient service for rheumatoid arthritis; hospital had implemented nurse-led CVD screening, carried in parallel to patients' usual appointments, using SCORE risk calculator
Sample size	14
Population characteristics	n=8 female, n=6 male; age range 51-70; n=8 low to moderate CV risk, n=6 high risk; n=8 married, n=6 single; n=4 in work, n=10 retired / sick leave
Data collection methods	Focus groups stratified by CV risk; carried out in hospital; semi-structured format with questions focusing on general experiences as a person with arthritis and experiences of the CV risk assessment
Data analysis methods	"Meaning condensation" process (a form of thematic analysis)
Limitations identified by author	Relatively small sample; low response rate, possibly leading to selection bias
Limitations identified by reviewer	No major limitations. Study focuses on a specific patient group who are at higher risk of CVD.

Gidlow, Ellis, Cowap et al. (2021); Gidlow, Eliis, Riley et al. (2021); Riley et al. (2020)	
Research question / study focus	To explore risk communication in NHS Health Checks and clinicians' and patients' understanding of cardiovascular risk
Theoretical approach	Protection motivation theory
Sampling and recruitment methods	Practices were sampled based on experience delivering NHS Health Checks and willingness to participate, and stratified by area-level deprivation. Inclusion criteria for patients were the same as for NHS Health Checks (40-74 years, no diagnosed CVD, not taking statins, not at high CV risk (≥20% 5-year risk)). Sampling was based on a priori sample size calculations in order

	to achieve variation in patient age, gender and CVD risk. The recruitment process is not clearly described.
Country / location	West Midlands, UK
Setting / context	Primary care; NHS Health Checks; practices in a range of settings (higher- and lower-SES). The study compared risk assessment and communication using two different risk calculators (JBS3 and QRISK2) between two randomly allocated groups.
Sample size	N=128 for recorded Health Checks (qualitative analysis); n=40 for patient interviews; n=15 clinician interviews
Population characteristics	For recorded Health Check sample: n=64 female, n=64 male; n=55 age 40-54, n=37 55-64, n=36 65-74; n=114 White British, n=14 ethnic minority; n=86 low CV risk, n=42 medium-high risk. For patient interview sample: n=21 male, n=19 female; n=14 age 40-54, n=14 55=64, n=12 65-74; n=36 White British, n=4 ethnic minority; n=28 low CV risk, n=12 medium-high. Clinician interviews: n=15 female; n=13 White British, n=2 British Asian; mean 5 years' experience delivering Health Checks
Data collection methods	Video and audio recording of Health Check consultations; "video-stimulated recall" interviews with patients and clinicians following a piloted topic guide which varied depending on group allocation (topic guide NR)
Data analysis methods	For the recorded health checks: deductive thematic analysis, with framework based on protection motivation theory; subsample of transcripts double-coded. For the interviews: inductive thematic analysis.
Limitations identified by author	Low response rate potentially leading to selection bias; low patient recruitment meant that stratified sampling was not possible; issues with application of the framework to data analysis; results may not be generalisable to broader population; possible Hawthorne effect from recording of Health Checks; most interviews conducted in practices, potentially leading to social desirability bias.
Limitations identified by reviewer	No major limitations

Gooding et al. (2016)	
Research question / study focus	To understand young people's perception of cholesterol screening
Theoretical approach	Cognitive Behavioral Emotional Model
Sampling and recruitment methods	Purposive sampling stratified by CV risk factors (familial hypercholesterolemia / obesity / neither). Both young people and their parents were sampled. Inclusion criteria: age 17-21 for young people sample; no cognitive / communication disorders; English-speaking. Participants invited in clinical settings when they accessed routine care (response rate NR). Sampling ended when thematic saturation reached in data analysis.
Country / location	USA, location NR
Setting / context	Primary care, paediatrics, cardiology; cholesterol screening results were hypothetical, not the result of actual risk assessment
Sample size	72
Population characteristics	Mean age 18-19 for young people, 49-50 for parents; n=17 male, n=55 female; n=11 Hispanic/Latino, n=60 not; n=2 Asian, n=24 Black, n=35 White, n=5 multiple races; n=40 private insurance, n=19 public, n=12 other / don't know. [Note totals reported do not always add up]
Data collection methods	In-person semi-structured interviews; questions focused on responses to hypothetical screening results and perceived impact on health. [Study also includes a quantitative component; data not extracted for this review]
Data analysis methods	Thematic coding based on grounded theory; double-coding of all transcripts
Limitations identified by author	Participants may not be representative of the broader population; screening results were hypothetical and most participants had never actually received a cholesterol screening result; self-reported intentions may not translate into actual behaviour change
Limitations identified by reviewer	Some unclarity in recruitment. Study focus is fairly narrow. Unclear how far findings on hypothetical results are transferable to data about real risk assessment.

Grauman et al. (2019); Grauman (2020)	
Research question / study focus	To explore perceptions of receiving cardiovascular risk information
Theoretical approach	NR
Sampling and recruitment methods	Participants were sampled from a larger cohort study of CVD (inclusion criteria for that study: age 50-64 and Swedish-speaking; participants were "randomly selected" from the general population; no further information). Participants were invited by email (NR who was invited; no further inclusion criteria were applied; response rate NR).
Country / location	Uppsala, Sweden
Setting / context	Participants had received a comprehensive health check (including CT angiography and ultrasound as well as blood tests and questionnaires) as part of the cohort study. (The larger population were not otherwise receiving any health check.) Participants were recruited from a "test center", but it is unclear whether this was a special facility or part of the standard healthcare system.
Sample size	31
Population characteristics	Mean age 61, range 52-65; n=15 male, n=16 female; n=1 primary education, n=9 secondary, n=9 university [sic]
Data collection methods	Focus groups carried out in university setting (n=5 groups, 4-8 participants each). Questions focused on experiences of the testing procedure.
Data analysis methods	Qualitative content analysis; all transcripts double-coded
Limitations identified by author	Focus groups may have inhibited some participants; sample not representative of broader population; some participants had medical training and were more confident in interpreting risk
Limitations identified by reviewer	Some unclarity around sampling and recruitment

Hall et al. (2007)	
Research question / study focus	To examine "patient–clinician communication and patients' understandings of family history in the context of CHD risk assessment" (p436)
Theoretical approach	NR
Sampling and recruitment methods	Inclusion criteria: age 18-55 (men) or 18-65 (women); no heart disease, diabetes or familial hypercholesterolaemia; not prescribed statins. Participants recruited either directly by clinicians when requesting a cholesterol test, or by post if they had requested one in the past 3 months. Response rate for direct recruitment 70% (16 / 23), for postal recruitment 25% (5 / 20).
Country / location	Exeter, UK
Setting / context	Primary care; all participants had received a cholesterol test. Clinicians carried out "their usual method of CVD risk calculation" plus family history questionnaire (p436).
Sample size	21 patients, 7 clinicians
Population characteristics	For patients: n=1 age 20-30, n=14 40-50, n=6 50-60; n=12 male, n=9 female; n=10 social class I/II, n=10 III/IV, n=1 V; all White ethnicity
Data collection methods	Video recording of consultations; open-ended interviews focusing on understanding of risk and views of the risk assessment process
Data analysis methods	Thematic analysis using constant comparative method
Limitations identified by author	Findings may not be generalisable to non-white patients or higher-risk patients
Limitations identified by reviewer	No major limitations

Hawking et al. (2019)	
Research question / study focus	"[T]o explore patient perspectives and experiences of a personalised Risk Report designed to improve cardiovascular risk communication in the NHS Health Check" (abstract)
Theoretical approach	NR

Sampling and recruitment methods	Study nested within a randomised trial. Inclusion criteria the same as for Health Checks (age 40-64). Participants were sampled for diversity in age, gender, ethnicity and CV risk; unclear how invitees were selected. Response rate NR
Country / location	Newham (London), UK
Setting / context	Primary care; NHS Health Check
Sample size	18
Population characteristics	n=11 male, n=7 female; n=4 40-50, n=9 51-60, n=5 60-74; n=11 low risk (QRISK <10), n=7 moderate (10-19), n=0 high (>=20); n=2 White, n=8 Black, n=6 South Asian, n=2 other ethnicity
Data collection methods	Individual semi-structured interviews in primary care setting; questions focused on experiences of the Health Check generally and the Risk Report in particular
Data analysis methods	Inductive thematic analysis; double-coding of subsample of transcripts
Limitations identified by author	Findings may not be generalisable to people who do not take up the offer of a Health Check, or non-English-speakers.
Limitations identified by reviewer	No major limitations

Hill et al. (2010)	
Research question / study focus	"[T]o explore consumer and GP views and preferences about the most suitable formats for the representation and discussion of absolute risk for CVD" (p2)
Theoretical approach	NR
Sampling and recruitment methods	Inclusion criteria (for patients): age 40-60, without diagnosed CVD. Sampling for diversity in gender, SES, urban vs rural residence, and GP practice characteristics. Incentive paid to participants. Recruitment " targeted several community-based health organisations" (p3); no further details. Response rate NR.
Country / location	Melbourne and rural Victoria, Australia
Setting / context	Primary care; participants expressed views on hypothetical formats for risk communication and do not appear to have

	undertaken real risk assessment (none of the participants in either sample reported previous use of a risk calculator)
Sample size	N=19 patients, n=18 GPs
Population characteristics	Patients: mean age 50; n=12 female; "a range of different educational levels" not further specified; all "English-speaking backgrounds". GPs: mean age 48; n=4 female; n=5 "non-English-speaking backgrounds".
Data collection methods	Focus groups; questions focused on general perceptions of CVD and risk, and on responses to a range (n=16) of different risk communication formats.
Data analysis methods	Thematic analysis focusing on preferred risk communication formats; draft report circulated to focus group participants
Limitations identified by author	Relatively small and self-selected sample; some participants had limited understanding of risk; risk scenarios were hypothetical.
Limitations identified by reviewer	Some unclarity in recruitment. Unclear if findings on communication of hypothetical risk would generalise to practice.

Honey et al. (2015)	
Research question / study focus	To explore high-risk patients' responses to communication of cardiovascular risk within the NHS Health Check
Theoretical approach	NR
Sampling and recruitment methods	Participants "identified from databases" in practices; no further information
Country / location	"a northern city", UK
Setting / context	Primary care; NHS Health Checks
Sample size	37
Population characteristics	mean age 66 (range 46-74); n=30 male, n=7 female; n=35 white, n=2 black
Data collection methods	Semi-structured in-person interview, most at participants' homes; questions focused on the health check process, understanding of risk, impact on health behaviours

Data analysis methods	Thematic coding
Limitations identified by author	Some participants had limited recall of the health check and retrospective reports may not be reliable; sample may not be representative of population; some groups under-represented (ethnic minorities, younger high-risk patients)
Limitations identified by reviewer	Unclarity in sampling and recruitment

Kirby and Machen (2009)	
Research question / study focus	To evaluate the utility and feasibility of the JBS2 risk calculator tool in general practice
Theoretical approach	NR
Sampling and recruitment methods	Clinicians appear to have been sampled from the larger sample for the quantitative phase of the study; for the latter, all GPs in the study area were invited, as well as a national sample from a market research panel. Sampling for the qualitative phase is unclear, other than aiming for both clinicians who had used the tool and those who had not. Sampling and recruitment for the patient sample is unclear. Inclusion criteria: adults; risk factors for CVD that had been discussed with GP / practice nurse; English speaking; no previous CVD event or other "condition that a GP considered would make participation unlikely/ inappropriate" (p1686)
Country / location	Hertfordshire (?), UK
Setting / context	Primary care; patients and clinicians had undertaken some form of CV risk assessment, but otherwise limited information on context [note study predates NHS Health Checks]
Sample size	n=22 clinicians, n=13 patients
Population characteristics	For clinicians: n=17 GPs, n=4 practice nurses, n=1 nurse practitioner; no further information. No information on patient sample.
Data collection methods	Focus groups (2-7 participants each) and individual interviews (n=2), focusing on responses to the JBS2 risk calculator tool
Data analysis methods	Thematic coding

Limitations identified by author	Difficulty in recruiting patients, so thematic saturation was not reached, and the sample may not be representative
Limitations identified by reviewer	Limited information on methods. The study is mixed-methods and the qualitative data are reported fairly briefly, with no direct quotes from participants.

Lenz, Kasper and Muhlhauser (2009)	
Research question / study focus	To pilot a decision aid about prevention of myocardial infarction for people with type 2 diabetes
Theoretical approach	MRC guidance on complex interventions used as a framework
Sampling and recruitment methods	Clinician sample "recruited from ... clinics", no further information. Patient sample "selected according to age, gender, blood pressure, and status of smoking" (p6); recruitment and response rate NR
Country / location	Hamburg, Germany
Setting / context	Diabetes clinic. The data presented was hypothetical (although "passages according to specific risk factors were allocated according to individual risk profiles" p6) and it is unclear if participants had received any CV risk assessment in reality
Sample size	n=5 clinicians, n=15 first phase with patients, n=12 second phase [very limited data reported from this]
Population characteristics	Clinicians: n=4 female, n=1 male; all >=10 years' experience in diabetes education and counselling. Patients (first phase): median age 57; all completed elementary education (>=8 years); n=5 "of higher educational level"; n=8 male, n=7 female; n=6 with hypertension. Patients (second phase, limited data reported): n=7 female, n=5 male; median age 56; all completed elementary education (>=8 years);
Data collection methods	Individual interviews (n=2 per participant for the clinicians and first phase of patients); 'think-aloud' method while using the pilot tool and test of understanding; interview questions focused on ease of understanding the tool and information needs
Data analysis methods	Thematic coding

Limitations identified by author	Representativeness and transferability of the findings may be limited.
Limitations identified by reviewer	Unclarity around sampling and recruitment. The study is narrowly focused on the particular tool being evaluated and the qualitative data are fairly limited.

Marshall, Wolfe and McKevitt (2018)	
Research question / study focus	To explore how people with hypertension understand cardiovascular risk
Theoretical approach	NR
Sampling and recruitment methods	Inclusion criteria: diagnosed hypertension; no diagnosed CVD or diabetes. Participants sampled from hypertension registers of two general practices. Sampling purposive for variation in age, ethnicity, gender and time since diagnosis. Participants recruited face-to-face or by letter by doctors. Response rate NR
Country / location	South London, UK
Setting / context	Primary care; practices serving "a highly mobile, multiethnic population" with high prevalence of hypertension. The information presented was hypothetical and it is unclear whether participants had undergone real CV risk assessment.
Sample size	24
Population characteristics	"diverse occupations", n=15 retired; age 51-90; 46% male; 54% born in UK, 21% Africa, 13% Caribbean, 12% other; 54% White British ethnicity, 13% White other, 21% Black African, 13% Black Caribbean.
Data collection methods	Semistructured interviews using hypothetical decision aid
Data analysis methods	Thematic analysis
Limitations identified by author	Younger participants not sampled; responses may have been influenced by the interviewer being a clinician; example decision aid may have influenced responses
Limitations identified by reviewer	No major limitations

McKinn et al. (2016)	
Research question / study focus	To understand GPs' decisions on reassessment interval for patients for primary CVD risk
Theoretical approach	NR
Sampling and recruitment methods	"GPs were recruited via a letter of invitation through their Divisions of General Practice" (p3); no further information
Country / location	location NR, Australia
Setting / context	Primary care; participants viewed hypothetical cases
Sample size	25 (for qualitative component)
Population characteristics	GPs. N=10 male, n=15 female; n=6 <40 years, n=8 40-49, n=7 50-59, n=4 >=60; n=5 <10 years' experience, n=6 10-19, n=9 20-29, n=5 >=30
Data collection methods	Individual semi-structured interviews by telephone or in person; questions focused on management of hypothetical patients and reassessment of CVD risk.
Data analysis methods	Thematic coding using framework analysis; subsample of transcripts triple-coded
Limitations identified by author	Sample may not be representative of broader population of GPs; self-reported behaviour may differ from practice; GPs may have been thinking of treatment monitoring rather than risk reassessment
Limitations identified by reviewer	Unclarity around sampling and recruitment. The qualitative component is only part of the study. The study is narrowly focused.

McNaughton (2018)	
Research question / study focus	To understand high-risk individuals' experiences of and engagement with the Health Check programme
Theoretical approach	Normalisation Process Theory
Sampling and recruitment methods	Inclusion criteria: had undergone Health Check; high CV risk (>20% 10-year risk); had been given lifestyle advice and/or preventive medication; had attended annual review. GP practices were initially invited by email. Practices recruited participants at their annual reviews (unclear if all patients

	attending annual review were invited). All who expressed an interest were interviewed (response rate NR as it is unclear how many were invited initially). Participants received token incentive.
Country / location	Hartlepool, Middlesbrough, Stockton-on-Tees, Redcar, UK
Setting / context	Primary care; NHS Health Checks
Sample size	26
Population characteristics	N=17 male, n=9 female; age 57-76; n=22 married, n=2 divorced, n=1 widowed, n=1 single; n=22 retired
Data collection methods	Individual semi-structured interviews at participants' homes or university; interview questions focused broadly on experiences of the Health Check and any behaviour change resulting from it; interview guide piloted before study
Data analysis methods	Thematic analysis informed by Interpretative Phenomenological Analysis
Limitations identified by author	Sample not representative (mostly older, all White, mostly less-deprived areas); small sample size; individuals' recall may have been limited; people who did not attend the Health Check or the annual review were not sampled
Limitations identified by reviewer	No major limitations. Study focus is broad and much of the data are about behaviours rather than risk communication as such.

Middlemass et al. (2014)	
Research question / study focus	To understand responses to genetic testing for CVD risk in addition to conventional cardiovascular risk assessment
Theoretical approach	NR
Sampling and recruitment methods	Inclusion: had received conventional cardiovascular risk assessment; had chosen to have genetic test. Participants sampled from 12 general practices; unclear if all who met criteria were invited to participate (of n=119 who chose to have genetic testing, n=30 were included).
Country / location	Nottinghamshire, UK

Setting / context	Primary care; both urban and rural settings. All participants had received risk assessment, but unclear whether this was routine practice [NHS Health Checks are not mentioned in the study]
Sample size	29
Population characteristics	Median age 59; n=21 male; n=28 White, n=0 Asian, n=1 Mediterranean; n=2 GCSE-level education, n=3 vocational, n=2 A-level, n=10 degree, n=5 other, n=6 no formal qualifications; n=6 average CV risk (<10% 10-year risk), n=18 moderate (10-19%), n=5 high (>=20%).
Data collection methods	Interviews focusing on experiences and understanding of both conventional risk assessment and genetic test
Data analysis methods	Thematic analysis
Limitations identified by author	Sample may not be representative of population (limited younger people, minority ethnic people and areas of higher deprivation); some participants did not recall genetic test results
Limitations identified by reviewer	Generally limited reporting of methods

Nielsen et al. (2009)	
Research question / study focus	To explore how non-high-risk individuals interpret and respond to cardiovascular screening results
Theoretical approach	NR
Sampling and recruitment methods	Participants recruited from a large randomised trial; sample for the trial stated to be "random", no further details. Participants were sampled based on low or moderate CV risk scores, and for variation in age and self-rated health status. No further information on sampling or recruitment.
Country / location	Ebeltoft, Denmark
Setting / context	Participants received extensive health check as part of the trial; unclear if this was routine practice otherwise. Limited information on setting
Sample size	22
Population characteristics	N=7 male, n=15 female

Data collection methods	Interviews focusing on experiences of the screening programme and the results, with the additional question "Couldn't you have done just as well without the screening, since the result turned out to accord with your own sense that everything was normal?"
Data analysis methods	Thematic analysis
Limitations identified by author	NR
Limitations identified by reviewer	Generally limited information on methods or sample

Nolan et al. (2015)	
Research question / study focus	"To explore user reactions to a cardiovascular risk calculator for people with type 2 diabetes" (abstract)
Theoretical approach	NR
Sampling and recruitment methods	Participants recruited through adverts on websites (diabetes organisation, black and minority health forum, local councils) and at GP practices and diabetes groups. Sampling aimed for variation by sex, age, experience using the internet, and diabetes-related characteristics. No further information
Country / location	Location NR, UK
Setting / context	No information on setting. Participants viewed real risk assessments based on data they collected from GPs. NR if participants had previously undertaken cardiovascular risk assessment.
Sample size	36
Population characteristics	People with diabetes. N=20 male, n=16 female; mean age 61, range 44-77; n=29 White British, n=1 White Irish, n=4 Black, n=2 other
Data collection methods	Three distinct phases: focus groups to collect data on overall views of risk assessment; usability testing with a pilot version of the tool; and think-aloud interviews while using the tool, followed by semi-structured interviews exploring participants' experiences.
Data analysis methods	Thematic coding using framework analysis with focus on identifying data useful for development of the tool; comparison

	between the different data sets; aimed to find disconfirming themes
Limitations identified by author	Self-selected sample who may be more engaged or experienced than the general population; some participants had difficulties getting clinical data from their GP
Limitations identified by reviewer	Unclarity around sampling and recruitment

Peiris et al. (2009)	
Research question / study focus	To evaluate the acceptability for GPs of a clinical decision support tool for cardiovascular risk management
Theoretical approach	NR
Sampling and recruitment methods	Purposive sampling for GPs interested in research and training, and for diversity in age, gender and practice size. No other information on sampling or recruitment
Country / location	New South Wales, Australia
Setting / context	Primary care; general practices in urban area and Aboriginal Medical Services. Most GPs (n=16) reported carrying out CV risk assessment more than never, but less than 50% of the time
Sample size	21
Population characteristics	GPs. N=12 male; n=1 20-29 years old, n=3 30-39, n=11 40-49, n=6 >=50
Data collection methods	Semi-structured interview focusing on the pilot tool, experiences of using it and recommendations for its development
Data analysis methods	Thematic analysis
Limitations identified by author	Sample was purposive for GPs who could contribute to development of the tool, so may not be representative.
Limitations identified by reviewer	Unclarity around sampling and recruitment

Perry et al. (2016)	
Research question / study focus	To understand people's experiences of and responses to participating in the NHS Health Check
Theoretical approach	NR
Sampling and recruitment methods	Sampling frame: list of participants who had undergone health check and consented to participate in research (unclear how this list was generated). All participants at high CV risk invited; low-risk participants sampled for diversity in age, gender, risk score. Response rate for the high-risk subsample 32% (12 / 38), NR for the low-risk.
Country / location	Knowsley, UK
Setting / context	NHS Health Checks; community settings including shops and libraries, with health check staff actively approaching members of the public
Sample size	36
Population characteristics	N=17 male, n=19 female; n=12 high-risk (>20% 10-year) and n=24 low-risk
Data collection methods	Focus groups or individual semi-structured interviews (participants were offered the choice). Questions focused on experiences of the health check, behaviour change and referral pathways.
Data analysis methods	Thematic analysis
Limitations identified by author	Small self-selected sample; study could not explore reasons for not engaging with the health check
Limitations identified by reviewer	No major limitations. Study focus is on the health check broadly, and only a subset of the data is relevant for this review

Polak and Green (2015)	
Research question / study focus	"To understand the role of quantitative risk information in patients' accounts of decisions about taking statins" (abstract)
Theoretical approach	NR

Sampling and recruitment methods	Inclusion criteria: >50 years; had been offered statins. Participants recruited through community groups and snowballing. No further information
Country / location	East Anglia, UK
Setting / context	NR
Sample size	34
Population characteristics	Age 53-87; n=22 currently taking statins
Data collection methods	Semi-structured interviews either individually or in couples; questions focused broadly on health, medication and use of statins
Data analysis methods	Thematic analysis based on constant comparative method
Limitations identified by author	Results may not be generalisable to other contexts; the interviewer was a GP and this may have affected results
Limitations identified by reviewer	Unclarity around sampling and recruitment; limited information on sample or context

Riley et al. (2016)	
Research question / study focus	To examine patients' and clinicians' experiences of NHS Health Checks
Theoretical approach	NR
Sampling and recruitment methods	Sampling frame: n=8 practices selected for diversity in SES. Patients sampled from list of people who had undertaken health check in previous 6 months. Response rate 14% (95 / 541). Participants sampled purposively for SES, risk score, gender, ethnicity, age. Clinicians sampled from same practices and recruited by letter: response rate 83% (15 / 18). Sampling guided by data saturation
Country / location	Bristol, UK
Setting / context	NHS Health Checks. Practices representing a range of area-level SES
Sample size	n=28 patients, n=15 clinicians

Population characteristics	Patients: n=2 age 40-49, n=5 50-59, n=15 60-69, n=6 >=70; n=23 White British, n=2 White other, n=2 Black, n=1 Asian; n=16 female, n=12 male; area-level SES n=11 1 (most deprived), n=6 2, n=6 3, n=4 4, n=1 5 (most affluent); n=11 high CV risk, n=11 medium, n=6 low. Clinicians: n=5 GP, n=5 practice nurse, n=3 healthcare assistant, n=2 pharmacists; n=1 age 25-34, n=3 35=44, n=8 45=54, n=3 55-64; n=11 White British, n=3 White other, n=1 Black; n=10 female, n=5 male; area-level SES of practice n=6 1 (most deprived), n=3 2, n=3 3, n=0 4, n=3 5 (most affluent)
Data collection methods	Individual interviews with patients, in participants' homes or by telephone; questions focused on experiences and impacts of the health check. Individual interviews with clinicians in workplaces; questions focused on experiences and general views of the Health Check programme
Map: Data analysis methods	Thematic analysis
Limitations identified by author	Sample from one geographical area; most participants White ethnicity; self-selected sample; study did not include people who did not attend the Health Check
Limitations identified by reviewer	No major limitations. Study focuses broadly on the Health Check in general and only a subset of data is relevant for this review.

Sheridan et al. (2009)	
Research question / study focus	"To explore how individuals respond to global coronary heart disease (CHD) risk and use it in combination with treatment information to make decisions to initiate and maintain risk reducing strategies" (abstract)
Theoretical approach	Protection Motivation Theory, Integrative Theory, Self-Determination Theory
Sampling and recruitment methods	Study aimed to sample people at moderate to high cardiovascular risk but with no history of CVD. Patients recruited by post or email from two sources: a chart review at one general practice; and a decision support registry (limited information on this). Sampling guided by thematic saturation. Participants paid cash incentive.

Country / location	Location NR, USA
Setting / context	No information on context. Participants were provided with real risk asssessment results for the study, but unclear to what extent they had undergone CV risk assessment in the past
Sample size	29
Population characteristics	Mean age 63, range 52-75; n=21 male; n=25 at least some college education; n=25 good/excellent health status; n=9 moderate CV risk (6-9% 10-year), n=15 high (10-20%), n=5 very high (>20%)
Data collection methods	Focus groups including presentation about CV risk and communication of risk assessment results. Discussion guide focused on decision-making about CV risk and role of risk assessment within this.
Data analysis methods	Thematic analysis
Limitations identified by author	Including informational presentation in the focus groups may have influenced responses; having a clinician present may have led to social desirability bias; format of risk information varied; non-representative sample
Limitations identified by reviewer	No major limitations

Snell and Helen (2020)	
Research question / study focus	To explore experiences and interpretations of a cardiovascular risk score combining genetic analysis, lifestyle information and laboratory tests
Theoretical approach	NR specifically; draws on literature on sociology of health and science and technology studies
Sampling and recruitment methods	Participants sampled from larger study of genetic testing (including 45- to 65-year olds). Participants recruited by letter: authors state they sent 20-30 letters "per focus group" (n=9), and included n=40 participants, which would imply a response rate of 7%-11% (20 / 180-270)
Country / location	Kotka, Finland
Setting / context	The setting is "a traditional harbour and industrial town" with an ageing population, high unemployment and poor health status.

	The authors note that all people in Finland can access preventive care and check-ups either through their employer or the public healthcare system, but it is unclear how this relates to the risk assessment carried out for this study (carried out in a hospital).
Sample size	40
Population characteristics	Age 46-65; 65% female, 35% male; "mainly working-class or lower-middle-class"; "almost a quarter" pensioners
Data collection methods	Focus groups (n=3-6 participants each). Carried out in the same hospital where risk assessments were conducted. Questions focused on perceptions and understanding of the risk score and impacts of the risk assessment.
Data analysis methods	Thematic analysis
Limitations identified by author	NR
Limitations identified by reviewer	No major limitations

Taylor et al. (2021)	
Research question / study focus	To explore the views of older people on cardiovascular risk assessment
Theoretical approach	NR
Sampling and recruitment methods	Inclusion criteria: age >75 for European ethnicity and >65 for other groups. Participants recruited via adverts at community sites and clinics and by word of mouth. Sampling aimed for diversity in ethnicity. No further information
Country / location	Location NR, New Zealand
Setting / context	Participants are described as "community-dwelling"; no further information on context. Unclear if participants had received any CV risk assessment
Sample size	39
Population characteristics	Mean age 74, range 61-91; n=19 female; n=9 European, n=7 Maori, n=15 Pacific, n=8 South Asian

Data collection methods	Interviews and focus groups; interview guide was piloted and included questions on understanding of CVD and preferences around CV risk assessment. Data collection methods were adapted to the needs of different ethnic groups (guided by "ethnic-specific researchers") to capture richer data and create a culturally safe environment.
Data analysis methods	Thematic analysis using iterative and inductive method; each ethnic group initially analysed separately with involvement of "ethnic-specific researchers"; double-coding of all data
Limitations identified by author	Small and self-selected sample; study did not aim for thematic saturation
Limitations identified by reviewer	No major limitations

Usher-Smith et al. (2017)	
Research question / study focus	To explore engagement with a web-based risk assessment and behaviour change promotion tool
Theoretical approach	NR
Sampling and recruitment methods	Participants were sampled from participants in a larger intervention study who had given consent to participate in the qualitative component (the trial is described as including "a convenience sample of … blood donors"; no further information). Sampling aimed for diversity in gender and age, and particularly for higher-risk participants. No further details
Country / location	Various locations in England, UK
Setting / context	NR; participants were recruited online
Sample size	37
Population characteristics	N=23 male, n=14 female; n=5 age 40-49, n=14 50-59, n=13 60-69, n=5 70-80; n=26 married, n=3 separated/divorced, n=3 widowed, n=5 single; n=1 no formal education, n=17 secondary, n=19 university; n=1 income <£8000 pa, n=13 £8000-£40000, n=19 >£40000, n=4 don't know / no response; 10-year CVD risk n=11 <5%, n=14 5-10%, n=9 10-20%, n=3 >20%
Data collection methods	Face-to-face interviews with questions covering understanding of CV risk and reactions and responses to risk score

Data analysis methods	Thematic analysis; double-coding of subsample of transcripts (n=4)
Limitations identified by author	Small and unrepresentative sample; participants were mostly high-SES
Limitations identified by reviewer	Unclarity around sampling and recruitment

Vaidya et al. (2012)	
Research question / study focus	To describe GPs' and patients' perceptions of cardiovascular risk assessment in the context of a randomised trial
Theoretical approach	NR
Sampling and recruitment methods	All GPs from intervention arm of the trial contacted (n=19); n=12 participated, although unclear if this is all respondents. Sampling procedures for the trial NR. N=51 patients invited from participating practices, n=15 responded (response rate 29%). Inclusion criteria: moderate or high risk. No further information
Country / location	Australia
Setting / context	Primary care
Sample size	19 GPs, 51 patients
Population characteristics	GPs: n=8 male, n=11 aged 35-64. Patients: n=12 male, age 53-71
Data collection methods	Semi-structured interview; questions focused on cardiovascular risk assessment and its impact on clinicians' practices and patients' behaviour
Data analysis methods	Thematic coding; comparative analyses focusing on GPs who reported sustained use versus those who did not, and for patients who sustained behaviour changes versus those who did not.
Limitations identified by author	Self-selected sample who may be more motivated; sample did not include low-risk patients
Limitations identified by reviewer	Some unclarity around sampling and limited description of sample. Study report is brief and focused on the specific intervention, and themes are not explored in depth.

van Steenkiste et al. (2004)	
Research question / study focus	To examine barriers to GPs' uptake of risk tables in the context of cardiovascular risk management
Theoretical approach	NR
Sampling and recruitment methods	"The first 20 consecutive GPs who responded to the recruitment letter were eligible to take part in the study" (p32); no further information
Country / location	Netherlands
Setting / context	Primary care. GPs appear to have been using a standardised guideline for risk assessment.
Sample size	15
Population characteristics	GPs. N=2 female, age 37-57. Urban and rural areas (Ns NR).
Data collection methods	Researchers first recorded two consultations for each GP in which the risk assessment tool was used [data from these do not appear to be directly reported in the paper]. These recordings informed the development of a guide for semi-structured interviews; questions focused on problems in implementing the guideline and deviations from it.
Data analysis methods	Thematic coding using constant comparative approach, with focus on barriers to implementation of the guideline
Limitations identified by author	Included GPs may be more experienced than the broader population
Limitations identified by reviewer	Very little information on sampling or recruitment, or study context

Wan et al. (2008)	
Research question / study focus	To gather views about cardiovascular risk assessment and management in order to develop an implementation model
Theoretical approach	NR
Sampling and recruitment methods	For GPs: recruited through three Divisions of General Practice, through newsletters. Patients recruited through GPs and group programmes run by the Division. Inclusion criteria: >40 years; at

	least one CV risk factor. Other stakeholders recruited through various organisations (professional bodies, policy bodies, consumer organisations etc.). No information on sampling process or response rate for any of the subsamples.
Country / location	Sydney, Australia
Setting / context	Primary care
Sample size	22 GPs, 26 patients, 9 stakeholders
Population characteristics	GPs: n=7 female, age >30, average experience 25.7 years. Patients: n=15 female, age 42-81 (mean: 63.5); n=12 1-2 CV risk factors, n=14 >2
Data collection methods	Focus groups (n=6) for GPs and patients, individual semi-structured interviews for stakeholders
Data analysis methods	Thematic coding; double-coding of all transcripts; comparative analysis between the three subsamples
Limitations identified by author	NR
Limitations identified by reviewer	Some unclarity around sampling; limited information on sample characteristics

Appendix 4: Table of themes

Study ID			Bengtsson	Boase	Bonner 2013	Bonner 2014	Bonner 2018	Coorey	Cupit	Damman 2016	Damman 2017	Farrimond	Frolund	Gidlow	Gooding	Grauman	Hall	Hawking	Hill	Honey	Kirby	Lenz	Marshall	McKinn	McNaughton	Middlemass	Nielsen	Nolan	Peiris	Perry	Polak	Riley	Sheridan	Snell	Taylor	Usher-Smith	Vaidya	van Steenkiste	Wan
Patient data	Understanding of risk scores	General points				x	x	x			x		x	x	x	x		x	x	x	x	x	x		x	x	x	x		x	x	x	x	x		x		x
		Meaning of probability and credibility of risk scores				x	x	x		x	x	x	x	x	x	x		x	x	x	x	x	x		x	x	x	x			x	x	x	x	x	x	x		
		Risk scores vs individual risk factors				x	x	x		x	x			x								x	x		x									x	x					
		Self-rated health				x		x			x	x		x	x	x		x					x		x	x		x									x			
		Genetics and						x			x	x		x	x		x			x			x		x	x									x	x				

		family history																																						
		Behaviours and lifestyles				x				x	x	x		x		x	x			x			x		x	x		x		x				x	x				x
	Impacts of risk assessment	Emotional reactions						x					x	x	x	x				x			x		x	x		x		x		x				x			
		Reassurance				x							x	x	x	x									x	x	x	x		x		x		x					
		Behaviour change				x				x		x	x	x	x	x		x		x			x		x	x	x			x		x	x	x	x	x	x		
	Broader context	Perceptions of CVD								x	x	x	x		x	x			x	x			x		x			x							x				
		Population subgroups																						x											x				
Clinician data		General attitudes and understanding of risk scores			x				x					x							x	x							x							x	x	x

	Perceptions of patient understanding	x	x	x				x					x					x		x	x																	x	x
	Perceptions of patient behaviour and attitudes	x	x	x									x							x			x															x	x	
	Strategies for communicating risk		x	x				x					x					x					x															x	x	x
	Impacts on care delivery	x	x																	x			x					x			x							x	x	x
Specific preferences for risk communication	Visual representations	x			x	x	x			x	x		x				x	x		x	x							x	x			x					x	x	
	Risk algorithms					x							x				x	x																						x
	Modifiable inputs				x	x	x		x				x			x			x	x							x	x									x		

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