"The medical industry is evolving; they're using information in a positive and constructive way"

- study participant

Receptiveness to risk-based innovations

A multi-methods exploration of the receptiveness of the public to implementation of risk-based innovations within cancer screening and early diagnosis in the UK

March 2024

CANCER RESEARCH UK

Together we are beating cancer

Contents

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Cancer Research UK

Cancer Research UK (CRUK) is the world’s leading cancer charity dedicated to saving lives through research, influence and information. In 2021/22, we spent £443 million on new research. We support research into all aspects of cancer through the work of over 4,000 scientists, doctors and nurses. This pioneering work into the prevention, diagnosis and treatment of cancer has helped save millions of lives. Cancer Research UK wants to accelerate progress so that 3 in 4 people survive their cancer for 10 years or more by 2034. This research was funded by the Evidence and Implementation Department, Cancer Research UK. Cancer Research UK is a registered charity in England and Wales (1089464), Scotland (SC041666) and the Isle of Man (1103). http://www.cancerresearchuk.org/

List of acronyms

1. AI – artificial intelligence
2. CI – confidence interval
3. DCE – discrete choice experiment
4. ErbB2 – epidermal growth factor receptor 2
5. GP – general practitioner
6. HPV – human papillomavirus
7. IQR – interquartile range
8. NHS – National Health Service
9. NPV – negative predictive value
10. PPI – patient and public involvement
11. PPV – positive predictive value
12. PRS – polygenic risk score
13. SES – socioeconomic status
14. TFA – theoretical framework of acceptability
15. UK – United Kingdom
16. US – United States

Executive summary

Background

Cancer Research UK (CRUK) has a long-standing focus on improving early diagnosis of cancer and bridging the gaps in innovation, adoption, and implementation of scientific research. To coordinate such action across the UK, CRUK led the development of the Early Detection and Diagnosis (ED&D) roadmap with extensive consultation from stakeholders across the ED&D ecosystem. The roadmap focused on the required efforts from government, industry, charities, and researchers to deliver more impactful progress towards improving cancer outcomes. In particular, the ED&D roadmap highlighted the importance of advancing the discovery, testing and translation of innovations. A key part of this process is ensuring innovations are acceptable to the public and their development is informed by public preferences regarding ED&D approaches. Innovative risk-based approaches are a key and common feature of the future cancer landscape with implications for both early detection and cancer prevention. Understanding the public's position on new approaches and adjusting implementation and communication strategies accordingly is therefore important. Whilst some evidence exists in this space, further research is required to understand public receptiveness to risk-based innovations, and how this might be influenced by a range of factors.

In response to this research gap, the Public Perceptions to Risk-Based Innovations (RIBBONS) project was commissioned by CRUK's Evidence & Implementation Department. This project aimed to develop a detailed understanding of public attitudes towards new and emerging risk-based cancer screening and diagnostic approaches and associated technologies. The findings of this research provide insight into the key requirements for public acceptability of these approaches which pave the way for future research and recommendations that can guide rapid adoption and implementation.

Research Approach

The RIBBONS project used four different study methodologies to elucidate public views. These were: (1) community juries (2) think-aloud interviews (3) an online survey (4) a discrete choice experiment (Figure A). Six examples of innovations, outlined in Table A below, were explored within the studies.

Figure A: The four linked studies within this research.

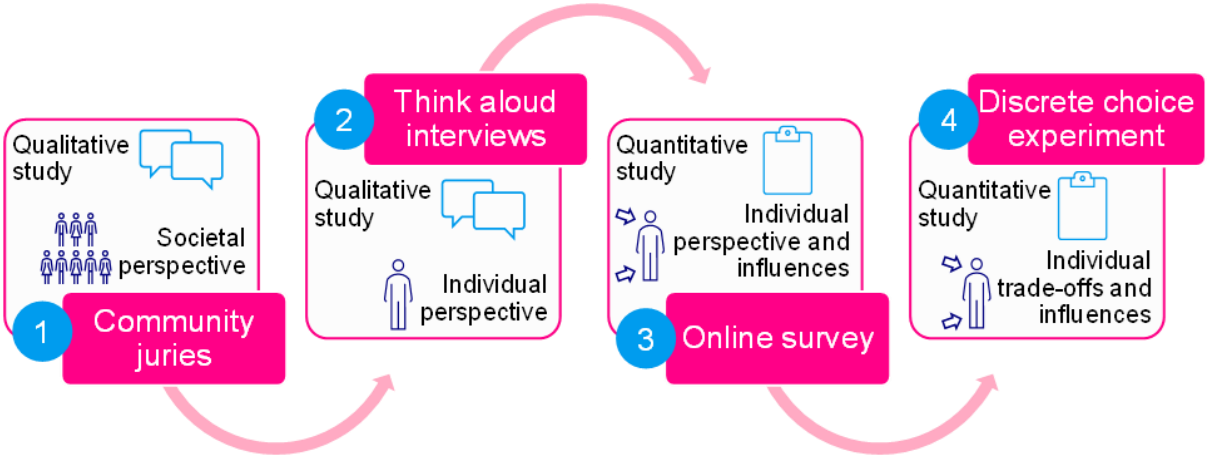


Table A: The six risk-based innovations explored in the RIBBONS studies.

Use of personal data	Testing biomarkers	New technology
Polygenic risk scores (PRS)	Minimally invasive tests (i.e., blood or saliva tests)	Artificial intelligence (AI)
Geodemographic segmentation data	Continuous monitoring of biomarkers (i.e., a patch or sensor)	Wearable devices

The community juries (study 1), aimed to provide a societal perspective on innovative risk-based approaches and to identify particular factors of acceptability in using risk prediction for cancer screening or early detection. Participants were informed about the topic by experts in the field and were then encouraged to deliberate on what would be best for society overall. Researchers posed discussion questions and the group were tasked with seeking a group verdict through discussion that often involved developing an understanding of others' views and thinking beyond one's own interests.

In the think-aloud interviews (study 2) and the online survey (study 3) the research aimed to explore qualitatively (study 2) and quantitatively (study 3) individual perspectives on innovative risk-based approaches for identifying cancer. The questions included both asymptomatic and symptomatic scenarios to determine if this impacted likelihood of taking a risk assessment, acceptability of the innovation, and comfort of wider use of innovative risk-based approaches.

The final study, the discrete choice experiment (study 4), aimed to quantify individuals' preferences to risk-based approaches and innovations by proposing both symptomatic and asymptomatic hypothetical scenarios. The survey utilised different attributes such as method, location, frequency, and accuracy of risk assessments to determine which was the most important in driving people's preferences.

Key findings from each study

Study 1: Community Juries – the societal perspective

- Participants agreed that using novel innovations to estimate cancer risk was acceptable so long as it did not replace clinical expertise or the doctor-patient relationship.
- Participants considered the positive impacts that innovative risk-based approaches would have on the healthcare system, cancer outcomes, behaviour and decision-making, psychological outcomes, and technological advances while also acknowledging ethical considerations.
- There was no clear consensus on whether risk assessments are more acceptable for cancer screening or people with symptoms.
- Participants identified that innovative risk-based approaches should (1) be accurate (2) have a low participant burden (3) not be too intrusive (4) prioritise data security, and (5) be easy to opt-out of.

Study 2: Think-aloud surveys – individual perspective

- Participants perceived all of the six examples of innovations positively.
- Participants often preferred tests that were easier to complete and that involved long-term or continuous measurement as opposed to one-off snapshots.
- Participants preferred innovations that involved biological or medical samples over the use of lifestyle or environmental data (i.e., geodemographic segmentation data).

Study 3: Online survey – individual perspective

- Most respondents reported being likely to take up an offer of risk assessment prior to screening (62 to 85%) or investigations of symptoms (64 to 94%) and most thought that it would be acceptable to use this information to inform screening (66 to 89%, excluding geodemographic segmentation) or symptomatic investigations (69 to 90%, excluding geodemographic segmentation).
- The innovations that were more likely to be taken up were PRS and minimally invasive tests.
- Geodemographic segmentation data was least likely to be considered acceptable as respondents thought it would widen inequalities. Specifically, only 59% of respondents found geodemographic segmentation acceptable in a screening context and 57% found it acceptable in a symptomatic context.
- People of White ethnicity, higher socioeconomic status, and those who often used healthcare apps or technology were more likely to agree to a risk assessment.

Study 4: Discrete choice experiment – individual preferences for particular innovations

- Participants preferred a risk assessment over no risk assessment 80% of the time in an asymptomatic context and 92% of the time in the symptomatic context.
- The most important factor for the public was the accuracy of the risk assessment, with most being more willing for their risk be overestimated as opposed to underestimated.
- PRS and minimally invasive tests were most preferred in both screening and

symptomatic contexts. In comparison, in the screening context, continuous biomarker monitoring and wearable devices were least preferred whereas in the symptomatic context, geodemographic segmentation data and AI were least preferred.

Overall findings

Together the four studies found that members of the UK public were receptive to the concept of using risk-based approaches and innovations to inform both cancer screening and further symptomatic investigations.

Some key themes and considerations were identified. First, risk-based approaches within a symptomatic context were more intuitive for the public compared to the asymptomatic screening context. This was shown particularly in the discrete choice experiment with individuals more likely to opt-in to risk assessment in the symptomatic context compared to the asymptomatic context.

Second, in relation to specific innovations, the public generally preferred minimally invasive tests, PRS and (except for in an asymptomatic context) continuous monitoring of biomarkers. The driver for these being they are perceived as more medical/biological and therefore more accurate. Geodemographic segmentation and AI were consistently least preferred, driven by perception of accuracy and fear of perpetuating inequalities.

Third, particular individual characteristics were associated with lower likelihood of accepting innovations and lower acceptability. These include lower socioeconomic status, those that have lower usage of technology and those from ethnic minority backgrounds. Particular innovations were also more acceptable to some groups compared to others. For example, PRS and minimally invasive tests for screening were more acceptable to older individuals and those worried about cancer, and people over the age of 40 found continuous monitoring of biomarkers more acceptable than younger people. These examples highlight the importance of considering individual characteristics for implementation of innovative approaches to risk assessment.

Taken together the four studies identify general requirements for risk-based innovations to be acceptable to the public, summarised in Figure B.

Figure B: Requirements for acceptable risk-based innovations to the public, according to the TFA.

Conclusion

Overall, findings from the four studies showed that the members of the UK public were receptive to the concept of using novel innovations to estimate risk of cancer and inform cancer screening and/or referral to investigate symptoms. This research has provided valuable understanding from both a societal and individual perspective and has identified preferences and the attributes that support the acceptability of innovations. We hope these findings will inform further research priorities, recommendations for adoption and implementation of innovations, and information provision to the public for innovations currently being implemented in the cancer pathway.

Lay summary

New technologies are being developed to help estimate people's risk of cancer. For a risk assessment, people might need to share information about themselves, provide a blood or saliva sample, wear a device, or similar. The result could be used to inform when someone who doesn't have any symptoms should be invited to cancer screening or help doctors decide what tests to do when someone seeks help for symptoms that could be a sign of cancer.

This approach can help to improve the care provided to patients by making sure that individuals are offered the healthcare that is most likely to benefit them. It can also help reduce the harms experienced by patients by making sure that individuals are not offered screening, investigations or tests when they don't need them.

We wanted to understand public opinions about this idea using four study designs, explained below. In this research, we used six new and different examples of estimating the risk of cancer, which are described in Figure 3.2.

Study 1 Community juries

Twenty-four people (in three groups) met to learn about the subject, then discussed their thoughts with the researchers and each other to make recommendations for using the risk assessments. Overall, the idea of using new technologies to conduct risk assessments and using the result to inform healthcare was acceptable. In order to maximise acceptability, it was important that people could choose not to take part if they didn't want to, and that new technologies would be suitably accurate at assessing risk, people's health data risk would be held securely, the effort to take part would be as small as possible, and people would remain free to make their own choices about their lifestyles.

Study 2 Think aloud interviews

We conducted online interviews with 21 people. They completed a survey while sharing their thoughts with the researcher; for example, why they had given a particular answer. We found that using new cancer risk assessments was viewed as a "proactive" approach that made "absolute sense". Doing the tests required for a risk assessment would not be too much effort, although they preferred options that were easier. For example, ones that could be completed at home over travelling to the hospital. Biological data was seen to be "more sophisticated" than lifestyle or environmental data. Data collection that took place over a long period of time or continuously was also favoured over one-offs that gave a snapshot. Whether the risk assessment would have implications for health insurance, the possibility of invasion of privacy, and impact on inequalities within society were also important considerations to participants.

Study 3 Survey

The same survey as in study 2 was completed by 999 participants. Most participants were likely to indicate that they would take up the offer of the risk assessment: 62% to 85% for screening people without symptoms and 64% to 94% for people with symptoms (depending on the type of risk assessment). People of White ethnicity, higher socioeconomic status and who often used technology like healthcare apps were more likely to take up the risk assessment. Most participants also felt that it would be acceptable to use the risk assessment to help decide when someone is invited to cancer screening or what tests to do if someone has symptoms.

Study 4 Discrete choice experiment

The final survey was completed by 1,200 participants. It showed that participants often wanted to have a risk assessment. They only chose the option not to 20% of the time for screening and 12% of the time for people with symptoms. The most important factor in their decision over which option to select was how accurate the risk assessment was. Participants particularly did not want risk to be underestimated. Whether it was a genetic or non-genetic test, the location and how often they would repeat it were least important.

Summary

Members of the public in the UK were receptive to the idea of estimating risk of cancer using new technologies. It was generally acceptable to use the result to help decide when someone is invited to cancer screening or how someone's symptoms should be investigated. Participants with lower socioeconomic status, from ethnic minority backgrounds and who were less familiar with health technology tended to find it less acceptable. However, which types of tests would be acceptable to use to estimate risk of cancer was also dependent on whether someone had symptoms of cancer or not, and what the test involved.

Overall, new policies will be more acceptable to the public if the recommendations based on these findings are considered by all those developing or considering implementing new technologies in cancer healthcare.

Introduction

Cancer early detection and diagnosis

Improving cancer outcomes through early detection and diagnosis (EDD) is a priority within the NHS Long Term Plan (1), with a key aim being that by 2028 75% of people diagnosed with cancer in England will be diagnosed at an early stage (stage 1 or stage 2). This has the potential to substantially improve survival from cancer as stage at diagnosis is a key factor associated with cancer outcomes: diagnosis with early-stage disease (stage 1 or stage 2) has a better prognosis on average than diagnosis with late-stage disease (stage 3 or stage 4). Improvements in diagnostic timeliness have been achieved in recent years through improvements to screening programmes and the introduction of fast-track diagnostic pathways, cancer waiting time targets, and rapid access diagnostic centres for patients with non-specific symptoms. Nevertheless, large proportions of cancer patients are still diagnosed following an emergency admission and/or with late-stage disease (2). Continuing to explore mechanisms to improve the early detection and diagnosis of cancer is therefore important.

Current cancer pathways

The NHS currently offers routine population-based screening for breast, cervical and bowel cancer. In all three programmes, with the exception of those known to be at very high risk (such as those with high-risk pathogenic variants or a strong family history), members of the public are invited for screening based on their age and sex and then managed according to pre-defined standard regimens. Latest data from the 'Routes to Diagnosis' analysis shows that just over 6% of cancers in England are picked up at screening (2). However, many more are prevented by screening programmes, through the identification and treatment of precancerous lesions (2).

A far greater proportion of cancers are diagnosed symptomatically, with people presenting in primary care and being referred for diagnostic testing. Almost 40% of cancers in England were diagnosed via the 'two week wait' urgent referral pathway in 2018, with a further 21% diagnosed following non-urgent referrals from primary care (2). In England, the National Institute for Health and Care Excellence (NICE) provides guidelines for referrals of those presenting with symptoms. These guidelines are currently based on combinations of the individual's age, sex, 'red flag' symptoms and test results, with the threshold for referral set at a positive predictive value of approximately 3% (3).

These cancer screening and referral pathways are illustrated in

Figure 1.1.

Risk-based healthcare

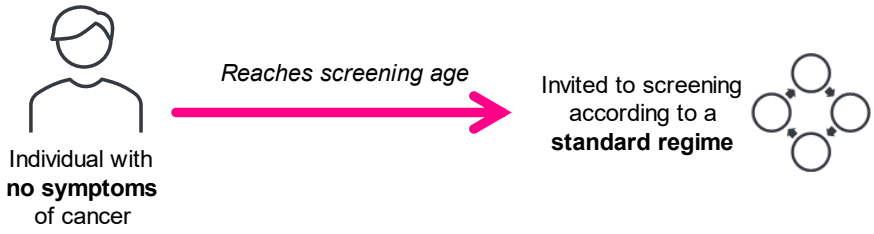
In risk-based or risk-stratified healthcare, access to screening and diagnostic tests varies according to the explicit estimated risk of individuals or groups of individuals. Risk is estimated using a combination of risk factors to enable assignment of individuals to a risk group. Individuals in different risk groups are then differentially offering screening or diagnostic work-up, based on their risk level.

For asymptomatic individuals, risk-stratified screening could mean adjusting the age at which they are first invited to screening, the frequency at which screening is repeated, the screening test used, or the threshold used to define a positive test (Figure 1.2a). For individuals

presenting with possible symptoms of cancer, estimated risk of cancer could contribute to the

Figure 1.1. Current cancer healthcare strategies.

a) Screening for asymptomatic individuals



b) Referral of symptomatic individuals based on symptoms

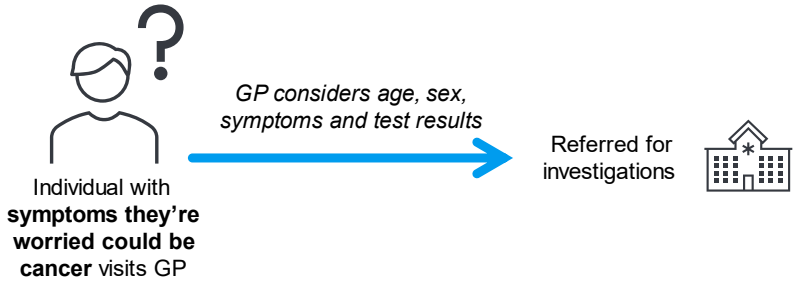
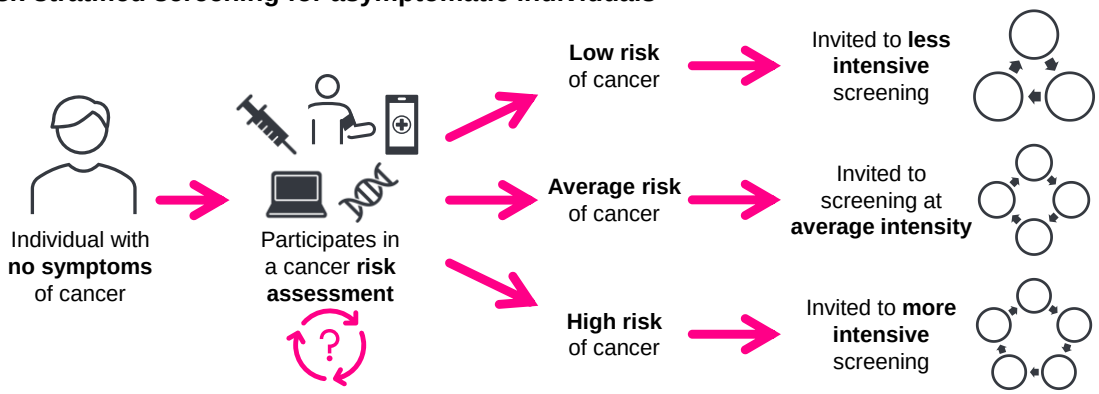
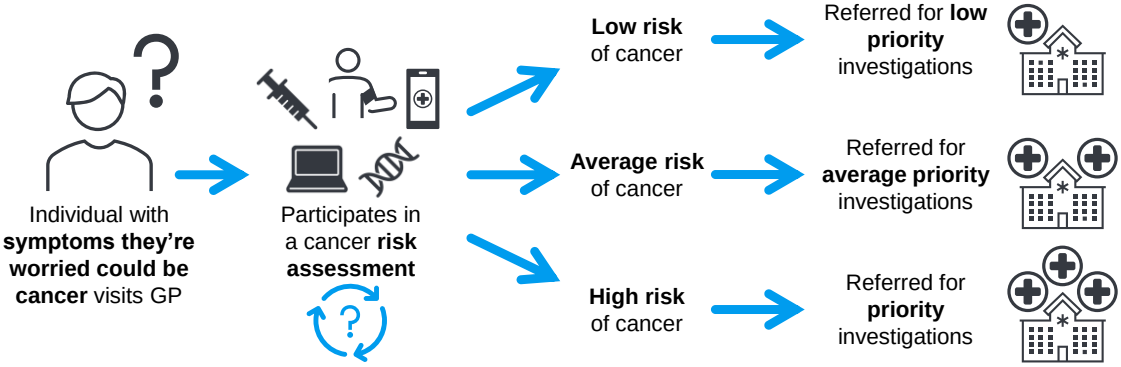


Figure 1.2. Risk-stratified cancer healthcare strategies.

a) Risk-stratified screening for asymptomatic individuals



b) Risk-stratified referral of symptomatic individuals



GP's decision regarding which tests and investigations to conduct (Figure 1.2b). Depending on the nature and purpose of the risk assessment, individuals might have their risk assessed as a one off, repeated whenever necessary, or monitored continuously over time.

In both cases, risk-based care has the potential to optimise the use of limited healthcare resources so that benefits are maximised and harms associated with screening and diagnostic tests are minimised, particularly for those at lowest risk. For example, in breast cancer screening, modelling has shown that targeting screening based on risk could improve the cost-effectiveness of the screening programme and reduce overdiagnosis while maintaining the benefits of screening (4). Similarly, in bowel cancer screening, inviting individuals for screening based on either phenotypic or genomic risk is associated with higher net monetary benefit, reduced overall bowel cancer incidence and mortality, and reduced resource use (5).

Novel innovations in risk-based healthcare

Recent advances in understanding of the evolution of cancer and the development of new screening and diagnostic tests and approaches mean that in the near future there is likely to be a wide range of new innovations that could support risk assessment (6). For example, multi-cancer early detection tests (7) and point-of-care testing technologies mean that analyses of biomarkers within blood, urine, saliva, faecal and other samples may no longer be limited to expensive, time-consuming laboratory-based processes (8,9). Self-testing, minimally invasive testing or continuous monitoring of biomarkers could also be enabled (8–10). For example, high-density silicon microneedle technology is under development to extract and quantify the breast cancer biomarker epidermal growth factor receptor 2 (ErbB2) via a device that would sit on the skin (11) and the capsule sponge test for oesophageal cancer is currently being trialled (12). Furthermore, computational developments have resulted in novel algorithms and machine learning approaches to make use of data from wearable technologies, geodemographic segmentation and within electronic health records (13,14). For example, coupled with a smartphone application, a wearable sensor can detect ultraviolet light exposure that can, in turn, inform an estimate of skin cancer risk (15).

Ethical considerations

The potential introduction of risk-based healthcare brings with it a number of ethical considerations. Following Beauchamp and Childress's principles of medical ethics, any risk-based innovations must promote doing good and avoiding harm (beneficence and non-maleficence) (16). While this means that the expected total benefits of risk assessments and risk-based healthcare should outweigh the expected total harms, how exactly those outcomes are measured, the value that members of the public place on them (since they typically give greater value to the benefits (17,18)), and how benefits and harms are distributed across subpopulations are necessary to take into account (19).

Risk-based healthcare also raises the important issue of justice; that is, whether people have a right to screening and certain investigations, and whether it is unfair to invite different people according to different strategies (16,19). It is important to remember that healthcare intervention can cause physical and psychological harm, therefore it may be most fair to offer it to those most likely to benefit and less likely to be harmed (such as not referring people with a very low risk of cancer for invasive investigations). However, how risk is assessed can also have implications related to justice as people have different abilities to affect their risk of cancer: for example, 'while there may be good epidemiological reasons to segment populations by body mass index, these decisions might reinforce stigmatisation or existing unjust inequalities' (19).

Lastly, risk-based approaches could exasperate the already complex subject of informed consent and individual autonomy by making the interventions harder to understand (which will have a greater impact on those with low health literacy (20)) and creating the issue of how/when to screen or refer people who chose not to take part in a risk assessment (16,19). Research participants have previously suggested that individuals could manipulate the risk assessment in order to get the screening that they want (e.g., not taking part in a risk assessment if they anticipate a low risk of cancer so that they are not eligible for the lower intensity screening schedule (21,22)).

Importance of considering public receptiveness

Implicit in risk-based approaches is that early detection or screening tests may not be offered, or may be offered less frequently, to those at lower cancer risk. Consequently, key challenges are ensuring that the means of estimating risk of cancer are valid and reliable, and that the approaches to risk assessment are understood by and acceptable to those at lower risk and do not lead to greater inequalities in healthcare access. Understanding the perspectives of target populations and society more broadly is, therefore, essential to ensure that promising novel risk-based approaches to accelerate timely cancer detection can be communicated and implemented in a way that optimises acceptability and uptake while minimising potential inequalities.

The importance of understanding public attitudes towards risk-based healthcare was highlighted by the recent public backlash against the extension of cervical screening intervals in Wales for human papillomavirus (HPV)-negative women. The policy change had been recommended by the UK National Screening Committee following the introduction of primary HPV testing and was based on a thorough evidence review. However, almost 1.3 million signatures were collected on a change.org petition protesting against the change (23), which suggests that the rationale had not been adequately communicated to the public. Similar negative responses to changes in screening recommendations in Australia (24) and the US (25) further illustrate the importance of clear communication, and the potential for changes to undermine trust in health systems, especially when they involve de-intensified intervention. There is emerging evidence to suggest that once people understand the rationale, they are more accepting of the idea of de-intensified screening (26,27).

It is likely that many future risk-based innovations will also make use of the collation and assessment of increasing amounts of personal data. A recent study commissioned by the Academy of Medical Sciences to gather public views on ‘awareness, expectations, aspirations and concerns around any future technologies which would require patient data to be accessed, analysed, or linked with innovative types of data and/or analysis’ identified general optimism about the use of new technology in healthcare but also highlighted potential challenges to implementation (28). These include concerns about any use of data that might lead to erosion of choice or delivery in healthcare. There were also concerns that widespread linkage of data might uncover hidden patterns in society and lead to different ways of thinking about healthcare, and about the introduction of two-tier systems or a ‘eugenics’ society with stratification based on genetics.

Many of these concerns are directly relevant to the use of future risk-based innovations for the prevention and early diagnosis of cancer. Understanding these concerns in more detail in this context and any patterns in beliefs across different groups of society will be central to the planning, development, and implementation of future data-driven risk-based innovations. A UK survey on willingness to share different types of data for health research found significant demographic variation with, for example, older people less likely to be willing to share smartphone, wearable device, and social media data than younger groups (29).

Understanding and addressing variations in receptiveness will be essential to maximise uptake, avoid creating or exacerbating social inequalities in healthcare access, and improving the likelihood of successful roll-out.

Research aims and objectives

This project addressed the call for research generating evidence on public receptiveness to risk-based approaches in the context of cancer EDD. This research gap was identified in Cancer Research UK's EDD roadmap (30).

The overall aim of this research was to develop a detailed understanding of public attitudes towards new and emerging risk-based cancer prevention, screening and diagnostic approaches and technologies. This includes attitudes towards both the technologies themselves, including the nature of any test or data source accessed, analysed or linked for the purposes of risk assessment, and how such technologies might be used to determine eligibility for cancer prevention, screening or diagnostic care. The findings of this research provide recommendations to support and guide future rapid adoption and implementation of such innovations.

Across the studies, we explored potential differences in attitudes between the screening compared with the symptomatic context, and used a range of examples to illustrate different ways in which data could be collected and used to assess risk.

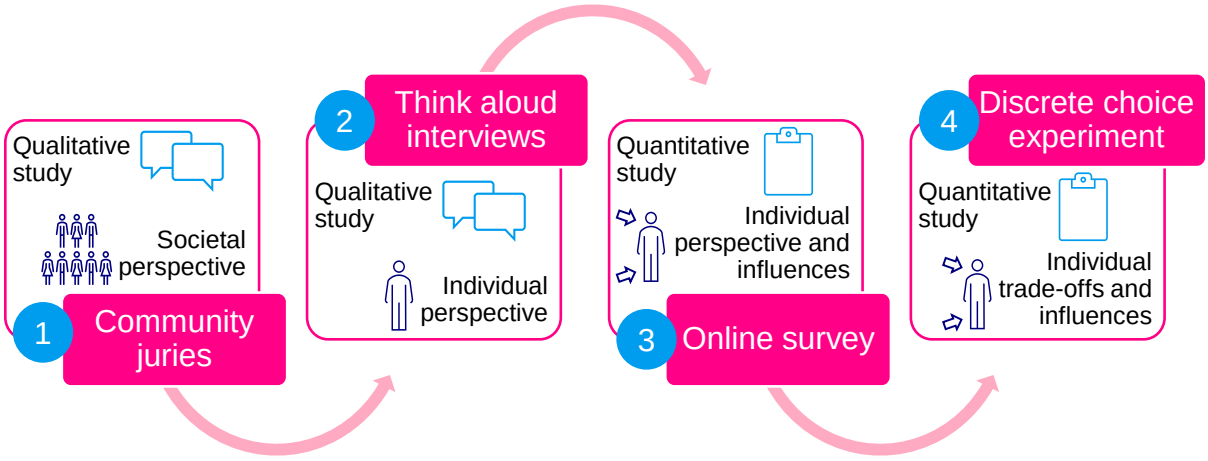
Specifically, the objectives were to:

1) Explore the views of the public on future risk-based technologies and risk-stratified cancer prevention and early diagnosis at a societal level.
2) Explore, in depth, public attitudes and receptiveness to risk-based innovations at an individual level and identify key barriers and enablers towards uptake.
3) Describe and quantify public attitudes and receptiveness to risk-based innovations and how these are influenced by individual level characteristics and attitudes towards risk of cancer.
4) Quantify the relative importance of different attributes of risk-based technologies amongst members of the public and their potential impact on uptake.

Methods overview

We conducted four linked studies to explore the public's views on novel risk-based innovations from both individual- and societal-level perspectives (Figure 3.1). In each, we considered the use of risk-based innovations in asymptomatic individuals for the purpose of cancer screening and symptomatic individuals to support clinical decision making for referral to investigate the symptoms.

Figure 3.1. Four linked studies within this research.



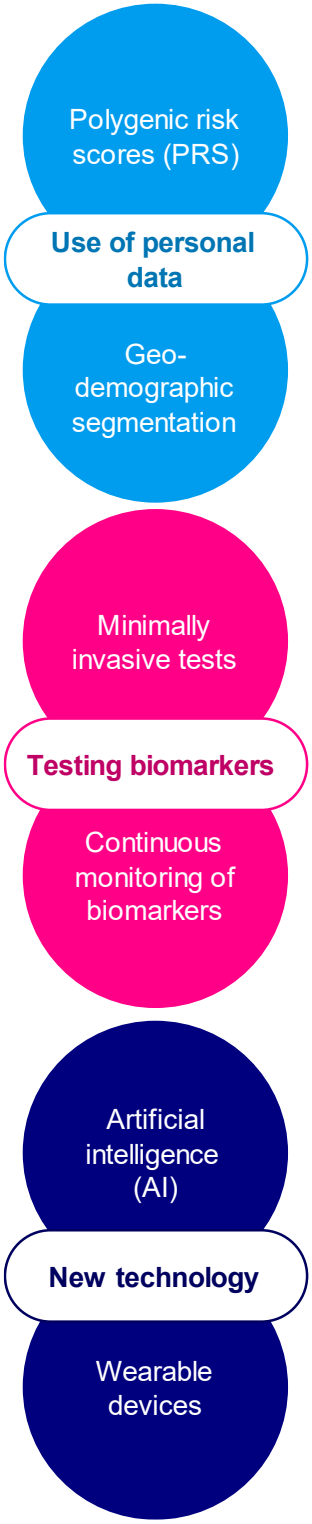
Examples of risk-based innovations

Prior to conducting the research, we identified six novel innovations to use as examples to illustrate the concepts to the participants. These were identified and prioritised using a short survey with 20 experts or academics in the field using a snowballing approach, the majority of whom were based in the UK.

Firstly, we reviewed the literature to identify new innovations and technologies, which had recently emerged or were under development, that could be used to estimate risk of cancer in people without a cancer diagnosis. For each of these, we asked the experts if they thought it was an important category of innovation and how they thought it could be best applied to cancer EDD. After ranking the importance of our suggestions, we asked them to suggest additional ideas. Finally, the research team selected six examples that would both reflect the opinions of the experts collected through the survey as well as representing a variety of approaches.

The final examples of risk-based innovations that we used are summarised in Figure 3.2. They were grouped as using personal data, testing biomarkers and new technologies.

Figure 3.2. Summary of the examples of risk-based innovations used throughout these studies to illustrate estimating risk of cancer.



How can it be used to assess cancer risk?
A PRS accounts for the multiple variations in someone's genes. Some of these increase the risk of certain cancers while others protect against them.
How does someone take part?
By providing a blood or saliva sample for analysis.

How can it be used to assess cancer risk?
By considering geodemographic data, generalisations about cancer risk can be made (e.g. population density or pollution levels).
How does someone take part?
By providing their postcode and additional data such as about their housing or socioeconomic situation.

How can it be used to assess cancer risk?
Biomarkers can be used to understand processes occurring in the body. They may be produced by the cancer cells themselves, or other cells in response to the cancer. A minimally invasive test would provide a snapshot of someone's biomarkers.
How does someone take part?
By providing a blood, saliva, urine, stool or sweat sample for analysis using a non-invasive or minimally invasive test.

How can it be used to assess cancer risk?
Unlike the snapshot generated by a minimally invasive test, continuous monitoring would reveal changes in someone's biomarkers over a period of time.
How does someone take part?
By wearing a patch or other sensor to constantly measure certain biomarkers.

How can it be used to assess cancer risk?
An algorithm produced using machine learning could be applied to someone's medical record (e.g. age, sex, smoking status, medical history, medications, etc.) and generate a cancer risk score.
How does someone take part?
By consenting to their health records being analysed.

How can it be used to assess cancer risk?
A wearable device could continuously track, record and monitor physical health parameters. For example, sleep patterns or temperature of the skin of the breast.
How does someone take part?
By wearing the device and sharing the data with clinicians.

Based on the information provided to participants in the survey used in the survey.

Ethical approval

Ethical approval was obtained for each study by research ethics committees within the University of Cambridge:

1. Community juries: Psychology Research Ethics Committee; reference PRE.2023.002
2. Think aloud interviews and survey: Psychology Research Ethics Committee; reference PRE.2023.064
3. DCE: Humanities and Social Sciences Research Ethics Committee; reference 23.342.

Researchers and PPI

Four PPI representatives supported this research, including providing feedback on the plans for the studies and ensuring that any participant-facing study materials were easy to understand.

Meetings with the wider research team, PPI representatives and representatives from the Cancer Research UK Social and Behavioural Research and Strategic Evidence teams were held regularly to plan the studies and discuss interpretation of the findings.

Community juries

Summary

We explored the views of the public on risk-based innovations using three community juries. This involved informing the participants about the topic and encouraging them to deliberate on what would be best for society overall, not just themselves. Overall, they found the concept of using risk-based innovations in cancer healthcare acceptable. They considered that the benefits would outweigh the drawbacks, in whole and with regards to the healthcare system, cancer outcomes, behaviour and decision making, psychological impacts, technological advances, and ethical considerations. There was no clear distinction between whether it was more acceptable for cancer screening or in people with symptoms. In all cases it was important for people to be able to easily opt-out of risk-based innovations. Acceptable risk-based innovations would be accurate and with least burden, personal liberty would be maintained, and data would be held securely.

Methods

Study design

We conducted three community juries. The community jury method enables participants to be informed about a policy issue, develop an understanding of others' views and think beyond their own interests through discussion, and seek to reach a group verdict on the questions posed (31).

Two community juries took place online using Zoom, with two sessions over two consecutive days. One community jury took place in-person in a University of Cambridge building for individuals who were able to travel to Cambridge. This in-person jury was held over one day.

Research team

The research team consisted of eight researchers including public health researchers, health psychologists and academic clinicians. Several of the researchers had experience of community juries and/or qualitative analysis. Four patient and public involvement (PPI) members supported the researchers in designing and reviewing of the study protocol and participant-facing information. Four members of the research team delivered presentations and question and answer sessions on their area of expertise across the three juries.

Participants and recruitment

Participants were recruited via a market research company. They were purposefully recruited based on age (between 21 and 79 years), sex, socioeconomic background, and screening history to represent a range of demographics. Participants with a personal history of cancer, medical expertise or an experience participating in previous studies conducted by the research team were excluded from this research. The market research company allocated participants to the juries, obtained informed consent, provided relevant organisational and study details, and reimbursed participants at their recommended rate.

Jury procedure

Each jury began with an introductory presentation, where jury members were presented with the aims of the study and the outline of the jury sessions. Participants then watched a series of pre-recorded presentations that detailed the key clinical, ethical and regulatory concepts for integrating future risk-based innovations into cancer healthcare (Table 4.1). After watching each presentation, participants were given the opportunity to engage in a live question and answer session with the expert presenters, via Zoom.

Table 4.1. Overview of expert presentations used to inform the community jury participants.

Session	Content
1. Introduction to concepts	• What is prevention, screening and early detection • Current cancer screening and referral pathways • Current approaches to decision-making
2. Risk prediction	• What is risk prediction • How risk-based innovations might change in practice • Modes of data collection • Data storage • Data access • Why understanding public receptiveness is important
3. Ethical considerations	• Resource-limited setting • Principles for considering the ethical issues
4. Potential impact of risk-based innovations	• Timescales for implementation • Six examples of risk-based innovations • Individual impact at different points on the pathway • Impact on healthcare systems • What we know and don't know

The expert presentations were followed by a focus group facilitated by two members of the research team, who remained impartial by encouraging exploration of a range of perspectives, withholding their own views, and emphasising the need to understand the participants' views. Participants elected a foreman then were left to engage in unfacilitated deliberations regarding their views and attitudes towards the topics discussed and to reach a verdict on the research questions (Table 4.2). They explained their verdicts to a third member of the research team. Finally, jurors were asked to consider the implementation barriers and facilitators during a final facilitated deliberation session that was informed by the theoretical framework of acceptability (TFA) (32).

Table 4.2. Research questions for community jury deliberation and verdict.

Questions
1. Do you think it is acceptable in general to use data from a range of sources to assess cancer risk and use that risk to determine access to healthcare?
2. Does it make a difference whether people have symptoms or not?
3. Does it make a difference what data are used?
4. Do you think people need to have the option to opt out of the use of data being used in this way? If so, how would you handle those individuals?
Please be prepared to explain your answers.

The questions were explained to the participants before the researchers left the deliberation to ensure understanding.

Data collection and analysis

All participant contributions (question and answer sessions, discussions, deliberations and feedback sessions) were videorecorded using Zoom. Research notes regarding the jury's deliberations and subsequent verdict were recorded by the researchers. The transcripts from the deliberation and feedback sessions and research notes were analysed using codebook thematic analysis (33). The coding frame was developed inductively, based on the transcripts and the topic guide and research questions. The analysis was led by the lead facilitator of the juries, and a second researcher coded one of the juries to support development of the coding frame and interpretation. Through discussion with the research team, themes were developed in order to answer each research question.

Participants also completed an online questionnaire both before and after the juries, providing demographic information, as well as their individual attitudes towards risk-based innovations before and after taking part. The questionnaires were analysed using descriptive statistics to summarise participant characteristics and views and identify changes in individual attitudes before and after the juries.

Results

Participant characteristics

A total of 24 participants took part across the three juries. Eight participants took part in jury 1 (online), nine in jury 2 (in-person) and seven in jury 3 (online). A range of demographic characteristics were included in each jury (Appendix Table 4.1). Overall, ten female participants and 14 male participants took part. Two female participants withdrew immediately before jury 3 due to external factors, resulting in an unbalanced representation of male and female participants in this jury. 75% of the participants were of White ethnicity. There was an even distribution of working- and middle-class participants, and one-third had a degree.

Participants' thoughts about cancer and screening are shown in Appendix Table 4.2. Of note, only one participant would not want to know if they had cancer. Approximately half of the participants felt that their risk of developing cancer in the next 10 years was comparable to those of the same age and sex.

Appendix Table 4.3 shows their attitudes towards online privacy. The majority of participants were at least moderately concerned about online privacy (63%) and about how much information they need to provide about themselves were shopping online (63%). Five participants (21%) were extremely or very concerned about who might access their medical

records electronically, 13 participants (54%) were moderately or slightly concerned, and only six participants (25%) were not at all concerned.

Question 1: Acceptability of the principle

All three juries reached the verdict that, in principle, estimating risk of cancer using novel innovations and using the outcome to inform cancer screening and diagnosis policies was acceptable and the approach was perceived favourably.

> We were happy with the in general use of data. It's proven to make a difference but perhaps, not become too over reliant on it because it's one factor, basically.
>
> P1, jury 1, feedback session

> We all agreed that, yes, it is absolutely fine to do that. But saying that, as long as… we're not excluding people who don't necessarily fulfil the criteria but have a genuine cause for concern, to have a screening or a test.
>
> P17, jury 2, feedback session

> So as a group we do believe it is acceptable to use data and use modern techniques, provided the sources are ethical and medical and the data is accurate.
>
> P22, jury 3, feedback session

Each jury's positive verdict was followed by a caveat. This was because the jurors anticipated the potential for both positive and negative impacts of introducing risk-based innovations. They discussed the possible implications on six key domains (detailed in Table 4.3) and considered that the pros of such a change would outweigh the cons in each case (Figure 4.1). For example, they did not want healthcare professionals' clinical expertise, intuition and relationship with their patients to be replaced by risk assessments, but supported the implementation of risk-based innovations overall because of the greater potential benefit of enabling healthcare to become more efficient and prioritise those in greatest need. This is illustrated by jury 1's proposition that the risk assessment is only one of the considerations when making referral decisions or screening policies.

Table 4.3. Impacts anticipated by jury participants of using novel sources of data to identify people's risk of cancer and using this to prioritise them for screening or diagnostic tests.

Domain of impact	Con/disadvantage	Pro/advantage
Healthcare system		
	Conducting a risk assessment could result in more work overall, and innovations could reduce human interaction with healthcare professionals. *"The problem is people will be alarmed because they're losing that personal interaction and maybe because people's fear of automation…"* P25, jury 3, facilitated discussion 1	It has the potential to enable healthcare services to become more efficient and proactive, meaning care could be prioritised to those who need it most. *"…they are now becoming proactive rather than reactive, because the NHS is very reactive at the moment."* P27, jury 3, facilitated discussion 2
Cancer outcomes		
	Delays in diagnoses and treatment could result from incorrect classification of risk, or in people with a low risk who still develop cancer. *"Let's say someone who's not in that risk factor but does turn out to have cancer but was excluded from that process. It could cause a social dilemma… the chances are it'll end up on the news or the Daily Mail and BBC News. That can turn from being a social dilemma to being politically unpopular. That can ruin the reputation of the NHS if it's quite widespread."* P5, jury 1, facilitated discussion 1	This has the potential to facilitate earlier detection and improved outcomes. *"Obviously, everything comes with pros and cons, and if they use the data to narrow the field, you are going to potentially miss more, but you're potentially going to save more as well."* P18, jury 2, facilitated discussion 1
Behavioural/decision-making		
	Knowing more about your cancer risk has the potential to impact life decisions significantly and negatively (such as choosing not to save for retirement if you have a high cancer risk). *"What's the point in paying off my mortgage because I'm going to be dead before…"* P6, jury 1, facilitated discussion 1	Knowing more about your cancer risk could motivate positive action (such as making healthy lifestyle choices). *"Obviously, you can't change genetics and you can't change your age, and you can't change, you know, that sort of thing, but you can change some parts of your lifestyle."* P18, jury 2, facilitated discussion 2
Psychological		

	Discovering your risk or taking part in a risk assessment could result in anxiety (for example, because of the awareness of every aspect of life impacting cancer risk and/or constant monitoring). *"I was quite happy, toddling along as I was and now, "Oh my. What might happen next week? … At the same time, I'd know it was great, but I'd also worry."* P1, jury 1, unfacilitated deliberation	Discovering your risk could result in reassurance (for example, because you are found to have a low risk or, even if you have a high risk, you would be monitored so cancer could be treated early). *"The anxiety is that something's possibly been identified. I'd cooperate and it would either confirm or dispel… it's not just accept, I would be reassured. And actually, I suppose I'd feel valued within the system."* P25, jury 3, facilitated discussion 1
Technological advances		
	Concerns that implementing risk-based innovation is changing the system just for the sake of it. *"It's almost like one's going to replace what is working at the moment, currently working, or appears to be working, shall I say, in my opinion, rather than something that's going to be – change for change's sake, shall we say."* P14, jury 2, facilitated discussion 1	This is an opportunity to utilise technological advances and additional data, and adding another 'layer' in policies is more logical than basing them on age and sex. *"The medical industry is evolving, they're using information in a positive and a constructive way."* P25, jury 3, facilitated discussion 1
Fairness and ethics		
	In some ways, it is unfair to prioritise the health of people who choose to have unhealthy/risky lifestyles (although universal healthcare is inherent to society's wider values). *"I think people can make their own choices and I'm all for being fair and stuff like that. I do feel those more at risk should take priority. Like if somebody smoked all their life and drank all their life and then, gets priority over somebody else that hasn't, I do think that's unfair, and it would cause resentment."* P7, jury 1, facilitated discussion 1	Differential screening/testing is acceptable as long as it is justified, policies change in light of new data, and people are 'taken seriously' if they have symptoms. *"I think I wouldn't have a problem with it if I knew that they were at higher risk. Yes. Like my dad gets screened for bowel cancer but I don't because I'm not that age yet."* P6, jury 1, facilitated discussion 1

They considered that this approach would be a large or radical change to healthcare policy. They anticipated varying levels of public support plus some opposition from the media since "*It's a very, very big undertaking to shift people's attitudes*" [P1, jury 1, facilitated discussion 2]. Additionally, they predicted that some members of the public would want to take part and discover their cancer risk whereas others would not.

Question 2: Differences in acceptability for symptomatic versus asymptomatic people

The verdicts of all juries were that using risk-based innovations was equally acceptable to determine access to screening tests as to diagnostic tests. For example:

> So generally we said no, it doesn't make a difference, symptoms or not, for the risk-based approach… Everybody was on the same page with that one.
>
> P22, jury 3, feedback session

However, analysis of their group discussions and follow-up questioning in the feedback sessions revealed some misunderstanding and several complex viewpoints that are potentially in tension with the overall verdict. In these discussions, the principle of risk stratification appeared to some to be more logical when applied to screening than when applied to referral to investigate symptoms. It was clear that it is not valuable to screen people with a low risk of cancer, whereas "*if you've got symptoms you should get the same test*" [P8, jury 1, unfacilitated deliberation] even with a low cancer risk. On the other hand, the benefits of apparently healthy people completing a medical test or requiring data collection that was invasive or intrusive for the risk assessment were less obvious to some jurors. This was considered from the perspective of both the individual undergoing testing and the healthcare service committing scarce resources.

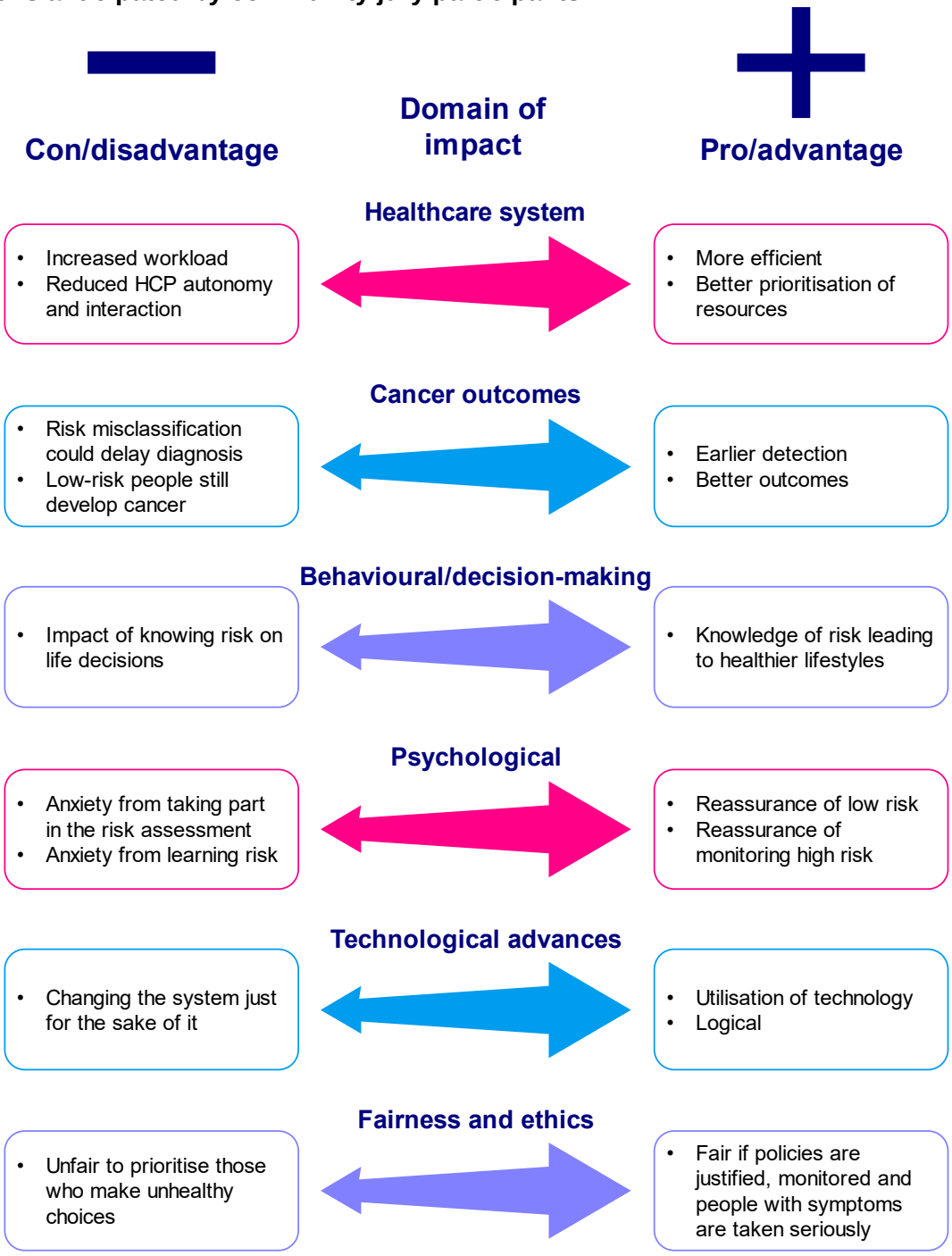
> When it actually comes to the crunch, you can test everyone but symptomatic must lead to better outcomes, early interventions, people actually need something rather than maybe need something.
>
> P8, jury 1, unfacilitated deliberation

> A lady with a lump on her breast is going to want to get ahead of someone who's going to sit there and…
>
> P14, jury 2, unfacilitated deliberation

> We would be conscious if it was a thing that we had to wear it all the time, if we weren't showing symptoms. As opposed to… we just presumed we'd wear it if we were showing symptoms, to further the investigation.
>
> P7, jury 1, feedback session

This suggests that whilst the general principal of including risk assessments was supported, acceptability is nuanced and depends on situation-specific factors. These include the degree of medicalisation and intrusiveness of the risk assessment method, vagueness of symptoms, and availability of resources.

Figure 4.1. The anticipated pros of using novel sources of data to identify people's risk of cancer and using this to prioritise them for screening or diagnostic tests outweighed the cons anticipated by community jury participants.

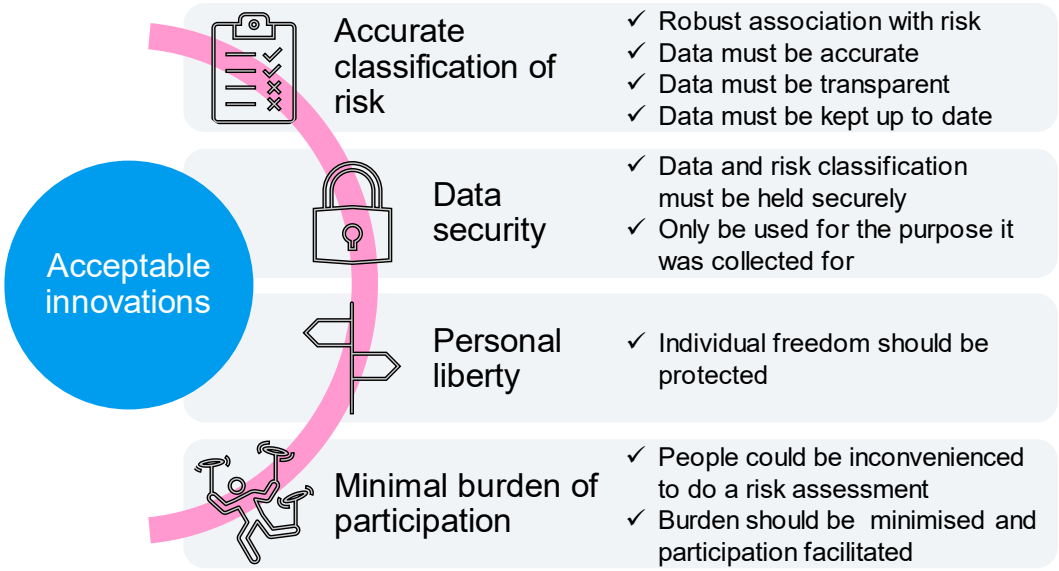


Question 3: Differences in acceptability according to the innovation example

Despite some differing individual views on specific innovations, the jurors were generally positive about all of the examples presented to them. Their priorities were accurate classification of risk, data security, maintaining personal liberty, and minimising the burden of participation (Figure 4.2). If they could be reassured that these conditions were met and that the public would benefit, they largely would be happy for innovations to be implemented.

> P17: We went through all the six ways that you could test, and for all of them, we said, for the pure purpose of accessing healthcare and–
>
> P18: No other reason.
>
> P17: –We agreed to all of them as a yes.
>
> P17 and 18, jury 2, feedback session

Figure 4.2. Jurors' priorities for acceptable risk-based innovations.



Accurate classification of risk

Firstly, the jurors emphasised the need to have confidence that risk of cancer was not misclassified as a result of the risk estimation using novel methods (but did not discuss what degree of misclassification, if any, they would accept). They discussed how misclassification as high-risk could result in anxiety that would otherwise have been avoided, and inappropriate testing. Misclassification as low-risk could delay diagnosis and treatment, which would be detrimental for individuals as well as the reputation of the policy. It was for this reason that many felt that the risk result should be used alongside clinical expertise so that decisions, particularly regarding referrals to investigate symptoms, should not be made solely on risk estimate, especially if someone has a low estimated risk of cancer.

In order to avoid misclassification, the evidence for the association between the data/risk assessment and cancer risk must be robust. For example, they were concerned that using geosegmentation data based on postcode would not be valid due to large differences in environmental risk factors within postcodes. Similarly, whilst some felt it was "*okay to be a little bit grey*" [P17, jury 2, unfacilitated deliberation] to others the 'black box' nature of AI algorithms was viewed with caution because it meant risk assessments cannot be verified, adjusted manually or fully explained:

> …but it could be that there is an unconscious bias in the institution that means that it's not really looking at everything in the best interests of everybody, it's not representative of the entire population.
>
> P23, jury 3, unfacilitated deliberation

Furthermore, the jurors were keenly aware that the data must be accurately collected and recorded in order for the risk assessment to be correct. Several participants told their jury peers that wearable devices can have a wide variability when measuring heartrate, therefore they felt that it was important that any technology is suitably accurate to collect data to estimate risk of cancer. Further inaccuracies could be introduced by intentional manipulation or old or missing data. They suggested that some people's housing data changes frequently and is often not kept up to date. The ability to easily access, check and update risk data was important.

Data security

Secondly, they wanted appropriate safeguards of both the risk data and classification to be in place, as they anticipated a range of unexpected and unintended consequences. Jury 1 felt that a code of conduct was insufficient and that the data should be protected by law. This was particularly the case for genetic data.

Specifically, all juries raised concerns about their data being shared with, sold to or hacked by external agencies. In general, they trusted the NHS to hold personal data but were suspicious about third-party or private companies, including if the NHS outsourced tasks to them.

Moreover, many considered the implications of their risk of cancer becoming known beyond the screening/referral context for which it was estimated and were concerned that "*these tests [could] penalise you from something else […] for years to come*" [P7, jury 1, facilitated deliberation 1]. For example, life, health, travel, etc. insurance companies might charge higher rates for people with higher risk of illness, which will compound the challenges faced by many people in these positions. Importantly, they realised that this would impact everyone, even if they chose not to take part in the risk assessment or not to disclose the result, as the absence of risk information could be used against them.

> …those who are going to be ill are going to bear the burden of it, because they won't get insurance, they won't get all the other things…
>
> P14, jury 2, facilitated deliberation 1

> I think it boils down to we're all happy to participate but the minute that that cooperation is used against us then the cooperation is withdrawn… a situation where just through prudence you had a test done because of what was going on within your family and the test that you had was actually possibly used against you.
>
> P25, jury 3, unfacilitated deliberation

Personal liberty

Some jurors felt that the approach had the potential to be too intrusive on personal freedom or liberty, or that it would be "*the onslaught of Big Brother*" [P25, jury 3, unfacilitated deliberation]. Often, this appeared to result from other contexts in which they had little control and gained minimal benefit, such as targeted online adverts and virtual assistant technologies (e.g. Alexa and Siri) 'listening' to their conversations. This was particularly relevant to risk assessments based on lifestyle such as tracking shopping loyalty cards and wearable devices because they felt that people should be free to make their own lifestyle decisions. Risk assessments such as these could result in "*them saying, 'You buy too much red meat' or 'You buy chocolate every week' […] 'So you've caused this yourself' or something like that*" [P27, jury 3, unfacilitated deliberation].

> I guess it does make me slightly uncomfortable but then, I also think, well, these commercial companies are collecting all of this information anyway. The NHS would put that information to much better use than they would, by trying to sell me stuff I don't want. I feel slightly uncomfortable about it but I can, kind of, see the benefits as well.
>
> P6, jury 1, feedback session

> I'd fully cooperate if it's in my wants and best interest to give as much information…
>
> P25, jury 3, facilitated deliberation 1

Other jurors did not share these concerns. Some felt that they did not have anything to hide. Importantly, others realised that they could benefit personally through more appropriate cancer screening and investigations, therefore it was worth their while.

Burden of participation

Lastly, in general, jurors did not consider that participating in a risk assessment was asking too much of members of the public, particularly if they have the option to opt-out as described below. They compared the tests to vaccinations and existing cancer screening tests that many people already do. However, they did accept that some groups of people would find it easier to complete the tests or be more willing to engage in them than others, and that these could be people who are already disadvantaged in society:

> It could be timewise, I suppose it might be tricky. If you're a mum, juggling a full-time job and caring for your kids, trying to find the time to go to your GP and have the test might be tricky. But if you want to look after your health, you prioritise things, don't you?
>
> P6, jury 1, facilitated deliberation 1

The jurors were more sure about and/or preferred risk assessments that were easy to complete. This included using data that is already available (as for running an AI algorithm on the medical record) and quick and straightforward tests (based on blood tests or minimally invasive tests, which were "*quick wins*" [P1, jury 1, feedback session]). Some were comfortable wearing a patch to continuously monitor biomarkers "*as long as it's not too uncomfortable*" [P6, jury 1, feedback session]. Making these tests as easy as possible to access by providing them in supermarkets, places of work, pharmacies, etc. was valued.

Question 4: Views on opting-in versus opting-out

Finally, it was essential for the jurors that people have the option to choose whether to take part in the risk assessments. All juries took the viewpoint that these policies should be implemented automatically, and people should opt-out if they do not wish to take part. Jury 3 was concerned that certain demographics might miss out on the better approach otherwise:

I think everyone should be in and they opt out if they want to. I think if you do it the other way round there might be people who aren't aware of what's going on and will be opted out without being able to change it, particularly perhaps the elderly and that sort of thing, who are not sort of so in touch with what's going on or tech-savvy.

P27, jury 3, unfacilitated deliberation

It wouldn't bother me at all if everybody in the whole world's seen my data but as long as I've got the option to choose. It's up to me to say, 'Yeah, you can have it' or 'No, you can't'…

P29, jury 3, facilitated deliberation 1

As well as sufficient information about the policy, the consequences of opting out should be clearly communicated so that people can make informed decisions. Furthermore, it should be straightforward for individuals to implement their preferences according to type of data. Respecting individual choices in this way would make it fair.

However, there was no prominent opinion regarding how to screen or refer individuals if they did not have a risk assessment. Many jurors felt that it was important for people who opt out not to be disadvantaged, particularly that they would not "*be treated any different to anybody else at a later date if they present with symptoms; they shouldn't be penalised*" [P8, jury 1, unfacilitated deliberation]. However, they were not clear what it would mean, in practice, to "*treat them fairly*" [P8, jury 1, feedback session] and for them to "*just remain on the standard procedure and follow the usual route*" [P22, jury 3, feedback session]. Participants in juries 1 and 3 felt that those who opt out could be assumed to be and treated as average or low risk; this meant that they should accept less frequent screening or referral for less intensive tests initially.

There have to be consequences to opting out… In a caring, compassionate society, they're still going to get looked after but if it's at a slightly lower level of intensity, if that's the word, then so be it.

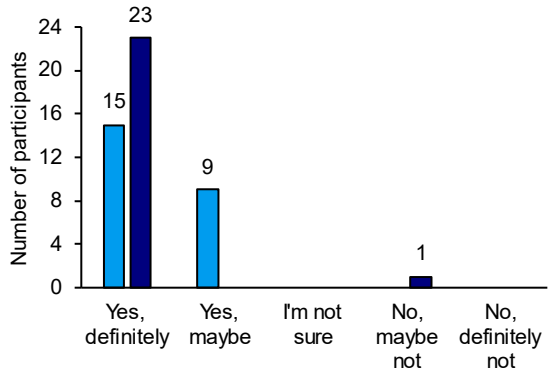
P1, jury 1, feedback session

Individual views

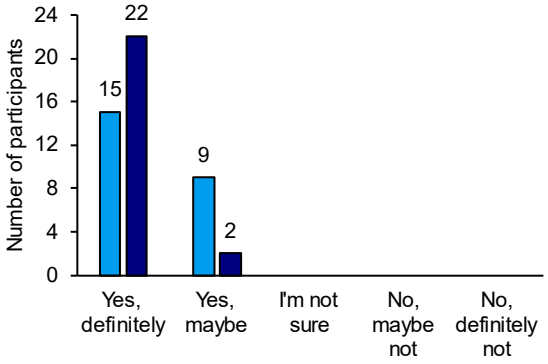
Finally, participants' responses to the individual surveys are presented in Figure 4.3. Across all the questions, they were collectively more positive about the use of data after taking part in the community juries than before. All but one participant thought it was a good idea to use health data, existing or newly collected, to estimate risk of cancer. There were more differences in views towards using data that is not currently connected to healthcare, with some saying that this shouldn't be used. Participants tended to be less sure about using the risk assessment to inform decisions about cancer healthcare, but 17 (71%) thought it was a good idea after the juries.

Figure 4.3. Community jury participants' individual beliefs about using data to estimate risk of cancer before and after the community juries.

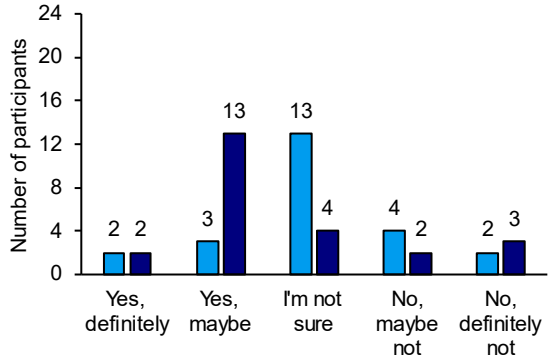
a. Do you think it's a good idea to use **existing health data** to understand people's cancer risk?



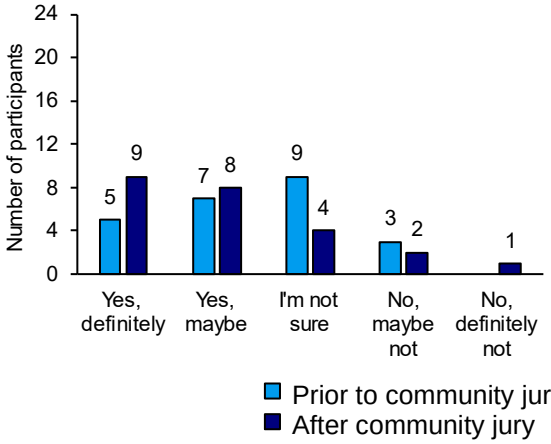
b. Do you think it's a good idea to collect and use **extra health data** to understand people's cancer risk?



c. Do you think it's a good idea to use **data that is not currently connected to healthcare** to understand people's cancer risk?



d. Do you think it's a good idea to use this data to inform decisions about access to healthcare?



N = 24 participants.

Think aloud interviews

Summary

We used interviews to understand 21 participants' attitudes towards each example of a risk-based innovation, and what might help or prevent participation. In general, the risk-based innovations were received positively and tended to be understandable. Although they preferred innovations that seemed easier to complete, the participants considered that taking part would be feasible and not too much effort. Many participants preferred risk-based innovations that utilised biological or medical samples to lifestyle or environmental data, and continuous assessments to one-off snapshots.

Methods

Study design

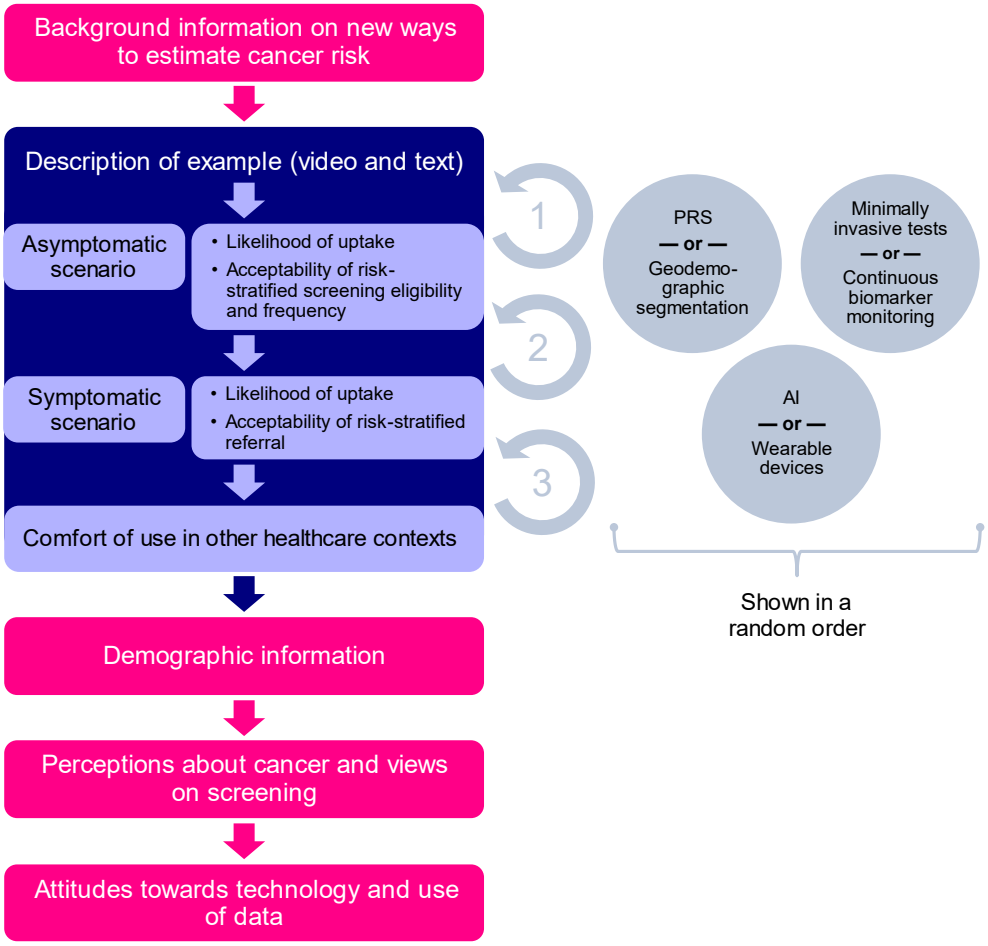
In this study, participants completed a survey whilst thinking out loud. As described below, the same survey was completed quantitatively in the survey study.

By asking participants to verbalise their thoughts and spontaneously report what goes through their minds while completing surveys or tasks, think aloud interviews provide rich data on cognitive processes (34,35). This means that they can be used to explore in-depth how people consider potential new approaches to cancer screening and referral for diagnostic tests, such as the inclusion on innovations.

Survey design

The design of the survey is summarised Figure 5.1 and described in detail below.

Figure 5.1. Summary of the structure of the survey.



In the main part of the survey, participants answered a set of questions on three examples of risk-based innovations. One example from each category was used (use of personal data, testing biomarkers and new technologies), and the categories were displayed in a random order. A similar number of responses were collected on each example.

For each example, participants were provided with a short video clip that described the innovation, how it could be used to assess cancer risk and what providing that data/taking part would involve. If they did not want to watch the video, they had an option to read the transcript, and all participants were provided with the same information in a written text descriptor.

The questions were presented in the form of scenarios. First, participants were asked to imagine that they felt fine (that they had no symptoms of cancer). They were asked how they would feel about taking part in a risk assessment using the innovation and using the risk result to inform cancer screening. Second, they were asked to imagine that they had lost weight without trying (as an example of a vague symptom). They were then asked how they would feel about taking part in a risk assessment using the innovation, and the general practitioner (GP) using the risk result to help decide which tests to use to investigate the symptom. As shown in Table 5.1, outcomes included the likelihood of taking up the risk assessment, the acceptability of risk-stratified healthcare in that context and, lastly, how comfortable they would be with the innovation being used within their healthcare more generally. Likert scales were used throughout.

Table 5.1. Key outcomes and details of survey questions and response options.

	Asymptomatic scenario	Symptomatic scenario
Likelihood of taking up the risk assessment with each example	How likely would you be to take up the offer to have [example]? (5-point Likert scale from 'Extremely likely' to 'Extremely unlikely')	How likely would you be to take up the offer to have [example]? (5-point Likert scale from 'Extremely likely' to 'Extremely unlikely')
Acceptability of incorporating each example within risk-stratified healthcare	How acceptable does it seem to you that [example] would be used alongside your age and sex to decide *when you would first be invited* to have a cancer screening test? How acceptable does it seem to you that [example] would be used alongside the results of any previous screening tests to decide *how often you would be invited* to have a cancer screening test? (5-point Likert scale from 'Extremely acceptable' to 'Extremely unacceptable')	How acceptable does it seem to you that [example] would be used to help decide which tests to use to investigate your symptoms? (5-point Likert scale from 'Extremely acceptable' to 'Extremely unacceptable')
Comfort with each example being kept and used more widely within healthcare	How comfortable would you be with the NHS having the results of [example] on record, and potentially using it to also risk of other health issues (diabetes, heart disease, etc.)? (5-point Likert scale from 'Extremely comfortable' to 'Extremely uncomfortable')	

Before these questions, participants were given a short description of the context for the study. At the end of the survey, participants provided demographic information and completed measures about lifestyle and screening history, thoughts and beliefs about cancer, and attitudes towards online privacy.

Participants and recruitment

A sample of 21 adult participants were recruited using purposeful sampling by a market research company, as for the community juries. Unlike the inclusion criteria for that study, we sought three participants with a previous history of cancer. Those who had taken part in the community juries were not invited to take part.

The market research company provided participants with adequate information about the study, obtained informed consent, and reimbursed them for their time at their recommended rate.

Participants were able to complete the interview in a language of their choice, and non-English interviews utilised an interpreter.

Data collection

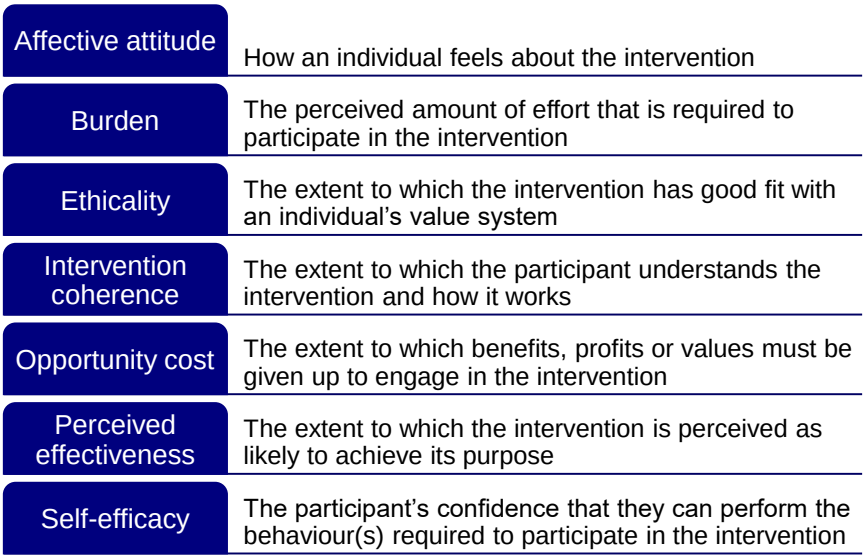
The interviews took place and were recorded using Zoom video conferencing. English-language interviews lasted for up to 1 hour, and non-English-language interviews lasted for 1.5 hours. Participants completed the online survey using the screen sharing function. One or two researchers conducted each interview. After ensuring they understood the purpose of and procedure for the interview, the researchers encouraged the participants to work through the survey whilst verbalising their thoughts on the information provided, reasons for their answers to the questions, etc. If necessitated by time restrictions, participants were able to complete the survey for two rather than three scenarios.

Analysis

Recordings of the interviews were transcribed verbatim and personal identifiers were removed. Data analysis was conducted using codebook thematic analysis (33), using NVivo software. An initial deductive coding frame was developed based on the six examples of risk-based innovations and the structure of the survey, and further codes were added inductively based on participants' responses. After summarising and reviewing each code, we defined themes according to key and repeating concepts. These were guided by the TFA where applicable.

The TFA describes acceptability as 'a multifaceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experiential cognitive and emotional responses to the intervention' (32). The seven domains of the TFA are described in Figure 5.2 (32).

Figure 5.2. The theoretical framework of acceptability (TFA), reproduced from Sekhon et al. 2017 (32).



The analysis was conducted alongside data collection to ensure that identified issues were explored and developed through additional data collection. An initial sample of the transcripts was coded by two researchers to develop and refine the coding frame. The remaining transcripts were coded by one researcher, with regular research meetings to ensure consistency and appropriateness of coding, and to discuss the interpretation of the findings.

Results

Participant characteristics

The think aloud interviews took place between 11th August and 5th September 2023. A total of 21 interviews were conducted: 18 were in English and three were in a non-English language with support from an interpreter (two in Bengali and one in Indian Punjabi).

Participants with a range of demographic characteristics were included (Appendix Table 5.1). Six participants (28.6%) were 39 years or younger, seven participants (33.3%) were aged 40 to 49 years and eight participants (38.1%) were 50 years or older. There was an even split of male and female participants. Nine participants reported White ethnicity and the remaining 12 participants were Asian, Black, Mixed or Other ethnicity. Half of the participants (47.6%) had a degree-level education and half (47.6%) ranked themselves within the lower half of socioeconomic status. All participants had attended cancer or abdominal aortic aneurysm screening to which they had been invited. Appendix Tables 5.2 and 5.3 show participants' thoughts and beliefs about cancer and screening, and attitudes towards technology and use of data.

In the following sections, the findings of the think aloud interviews are described in relation to the seven domains of the TFA, ending with further themes that do not fit within the TFA. Additionally, key points relating to specific examples of risk-based innovations are included in boxes.

Affective attitude

Affective attitude refers to how the participants felt about the risk assessments.

Overall, using innovations to assess cancer risk prior to a healthcare decision was viewed as a "*proactive"* approach that made "*absolute sense"*, with individuals generally being very accepting and welcoming of using them. Additionally, the participants were positive towards each of the specific examples presented.

However, concerns were also expressed that the ease of some of these risk assessment methods may lead some people to undertake them without considering the potential consequences or implications. This was particularly stated in relation to minimally invasive tests, but also applies to other examples.

> I suppose the bit of a trap there is that you could submit a sample without really thinking through the consequences of what you're about to potentially learn and the journey that you might be about to take.
>
> Female, 40-49, white, SES 7

Additionally, as explained in Box 5.1, participants considered the impact of AI on their relationship with healthcare professionals, also described as the "*human versus technology*" trade-off, with mixed emotions.

Box 5.1. Affective attitude towards artificial intelligence (AI).

Positive comparison of AI and healthcare professionals

Some participants felt that AI would be more effective than a GP as it may be "*much more accurate than humans who tend to err".* From a resource perspective, AI was seen to "*utilise data sets efficiently and effectively",* which, in turn, may lead to positive financial implications. Participants also felt that AI would benefits GPs, such by as reducing workload and time pressure.

> It's presumably looking at the most up to date clinical evidence for risk factors, probably at a level that is far superior to what any poor, overworked GP could ever hope to understand… I think it's probably likely to spot things that a GP doesn't have time to.
>
> Female, 40-49, white, SES 7

Negative comparison of AI and healthcare professionals

In contrast, other participants expressed a strong preference for maintaining the traditional GP-patient interaction. They placed value on this "*humanistic*" element. AI was considered to be a tool with "*amazing application potential"* but one that should not "*devolve all of our personal responsibility or turn our backs on attending GP appointments and having conversations".* They felt that GPs should be able to carry out the same role as AI, and more, because GPs could notice external factors that an algorithm may miss. Consequently, the AI algorithm might generate a less accurate risk assessment.

Participants therefore did not want their healthcare to be informed solely by the output of the algorithm. They felt that AI should be used as a *"side by side"* or secondary check to ensure other risk assessments did not miss anything and to confirm the risk categorisation.

> If AI could be used alongside some other measures and it can give you like perfect result to confirm either way… then there is no harm in using AI because it's more effective and it's sort of giving you guarantee there that [there are] less chances of failure.
>
> Male, 18-29, Asian, SES 4

Burden

The perceived level of effort that is required to participate in the risk assessment is described as burden within the TFA.

Key benefits of AI and geodemographic segmentation were that they are low effort because the retrieval of data does not require high levels of involvement by individuals. Wearing a smart device or sensor to continuously monitor biomarkers, or providing a sample for a PRS were also viewed as low effort because they only require one appointment or setting up a device that then works autonomously in the background.

Participants also discussed the potential burden of the different strategies for minimally invasive testing, shown in Box 5.2.

Box 5.2. Burden associated with minimally invasive tests.

The level of burden was dependent on two factors: the type of minimally invasive test that was required, and the test location.

Providing urine and stool samples made some participants feel uncomfortable, therefore they preferred saliva and blood tests.

Tests that could be carried out at home were preferred to those taking place in a clinical setting. They were considered to be "*less stigmatising*" and a "*very natural step*".

I don't like the giving samples, urine and stool, I think they can be uncomfortable, so yes, theyhave to make it really discreet I think the way it's, like saliva, blood tests, it's much easier to do.

Female, 40-49, Asian, SES 5

You can do it comfortably at home in familiar surroundings. It's separated out from a clinical processso I suppose it feels quite easy.

Female, 40-49, white, SES 7

Ethicality

Ethicality describes the extent to which a risk assessment strategy has a good fit with an individual's value system.

This tended not to be mentioned within the interviews, with the exception of geodemographic segmentation. As described in Box 5.3, participants expressed concerns about the impact on people of lower socioeconomic status: firstly, the psychological impact; secondly the implications for inequalities. It is interesting to highlight that many participants intuitively anticipated utilisation of geodemographic segmentation data would disadvantage people of lower socioeconomic status, and needed the interviewer to explain that the opposite case is more likely. Overall, this shows the importance that members of the public place on fair cancer healthcare, particularly for people who may already face disadvantages.

Box 5.3. The ethicality of geodemographic segmentation.

May make people from lower socioeconomic backgrounds feel judged

Participants were uncomfortable about the potential of causing individuals from a lower socioeconomic background to feel that a judgement has been passed on them. Participants acknowledged that geodemographic segmentation may make people feel "*guarded*" and inadvertently cause negative views towards the decisions that people had made such as lifestyle choices, occupation, etc.

I think that it's raising questions for me… a judgement about decisions that I've made about my financial status o my occupational status. I could see that in a way it's making my barriers come up a little bit.

Female, 40-49, white, SES 7

Potential to exacerbate inequalities

Prior to correction, participants were concerned that geodemographic segmentation may disadvantage the poorest in society because they may not have the opportunity to move to areas that have fewer health risks. This idea was viewed as unethical and went against participants' value systems.

Just because I live in an area that may be a lot more wealthieror I am a lot more wealthierthat others doesn't necessarily mean that I should get more than others. Yeah, I think everyone should be treated equally whether they have the money or not.

Male, 30-39, black, SES 7

Intervention coherence

Intervention coherence is the TFA domain that refers to the extent to which the participant understands the risk assessment and how it works.

Overall, intervention coherence was high across all risk assessment methods. Participants had prior knowledge of some of the strategies (such as wearable devices and minimally invasive tests). Other methods were newly introduced during the interviews but were considered to be easily understood (such as continuous monitoring of biomarker levels and PRS).

Conversely, participants objected to the possibility of not being able to understand how their risk was calculated using AI (Box 5.4). This was also a principal that applied more generally: risk assessments were only acceptable if a detailed breakdown of the risk score could be provided. By understanding the components of their risk score, they would treat it in a more serious manner, which could motivate people to engage in behaviour change or "*make important decisions about their health".* This could also "*lead to conversations with healthcare professionals"* and enable people to get support to lower their cancer risk.

Box 5.4. Intervention coherence of artificial intelligence.

Negativity towards the 'black box'

Participants did not want to receive a risk categorisation that could not be explained. They expected to receive, at a minimum, a general explanation as to why they received their risk score. A lack of explanation would make them" *untrust[ing]*" of the NHS. Furthermore, it could be "*dangerous* ", particularly for those at high risk. Overall participants would feel more positive towards the use of AI if a report was produced to explain and justify their result.

Opportunity cost

Opportunity cost refers to the benefits, profits or values that must be given up to engage with the risk assessment.

The different examples of risk assessments were each associated with different opportunity costs. As explained in Box 5.5 to 7, participants considered the cost of giving their medical records for AI, the implications for health insurance associated with geodemographic segmentation, and invasion of privacy if using wearable devices.

Irrespective of risk assessments, participants spontaneously mentioned concerns for data access and storage. Health data is sensitive information, therefore, they were accepting of it being accessed as long as it was for a risk assessment, as intended, and that it was safeguarded appropriately to prevent misuse. Participants generally trusted the NHS with their medical data, and felt it was logical to use it to assess risk of other health conditions, not just cancer. They also expressed an interest in having access to their own personal data.

Box 5.5. Opportunity cost associated with artificial intelligence (AI).

Sharing medical information

Participants valued their medical data and viewed it as private and sensitive. This opportunity cost had the potential to be lessened if it could be guaranteed that the data is used solely for the purpose it is intended for and that it stays in a medical context.

> The only thing that I would obviously want to be careful about is… those health records… are private and can be quite sensitive… so [if] its purely for that purpose then I think it could be fine.
>
> Male, 30-39, mixed ethnicity, SES 6

Box 5.6. Opportunity cost associated with geodemographic segmentation.

Ramifications for health insurance

Individuals worried that if they were deemed as higher risk based on the area that they live in, that this information could be "utilised by other companies and agencies" to charge people higher insurance premiums.

> Might it affect somebody's premium… that their broader socioeconomic, etc., factors might be something that is already affecting their life.
>
> Female, 40-49, white, SES 7

Box 5.7. Opportunity cost associated with wearable devices.

> But it can seem very intrusive, because it's more or less something that's basically checking your health 24/7, without you even knowing it… [but] why not get the help immediately rather than letting it wait till later.
>
> Male, 30-39, black, SES 7

Invasion of privacy

Participants felt that continuous monitoring would inevitably be accompanied by an invasion of their privacy. This was particularly true for wearable or mobile technologies that would show lifestyle factors. However, they also felt that the benefits outweighed the invasion of privacy.

Perceived effectiveness

Perceived effectiveness refers to the extent to which the risk assessment is perceived to be likely to achieve its purpose. In addition to example-specific considerations (Box 5.8 to 11), perceived effectiveness was impacted by the type and frequency of data collection.

Box 5.8. Perceived effectiveness of artificial intelligence (AI).

Out of date records

Participants were concerned that medical records that were not up to date would affect the effectiveness of AI. This could be caused by individuals not attending their GP regularly, health events that have not been reported and therefore are unknown to the algorithm, or individuals that may only attend their GP if they become symptomatic.

> If you ever change surgeriesthen things can get lost…
>
> Male, 30-39, mixed ethnicity, SES 6

> I know some people who in the past have never been to the doctor until they've got signs of cancer.
>
> Male, 40-49, Asian, SES 6

Participants proposed that a standardised check of health records is conducted prior to running AI to ensure that there is a consistent baseline level of information and that no biases are present within the algorithm.

Box 5.9. Perceived effectiveness of geodemographic segmentation.

Too much generalisation

Participants felt that the risk assessment would be ineffective because it *was "too generic"* and lacked the ability to examine specific cancer risk factors such as genetics, family history, lifestyle and environment.

> It's generalisations, whereas I'm more intereste in what is happening to me specifically.
>
> Male, 40-49, other ethnicity, SES 4

Incorrect data

They also worried that individuals may not report their data correctly leading to errors in categorisation.

> Maybe the data should come directly from the council… The results of the surveys are dependent on the honesty of the respondent. And they might genuinely think that they're giving correct answers, but they're not because they don't have a clue.
>
> Male, 40-49, other ethnicity, SES 4

Box 5.10. Perceived effectiveness of wearable devices.

Reliability

Predominantly, concerns were expressed about the reliability of the technologies and the potential for them to fail or be inaccurate. Participants explained they had "doubts and concerns because technology cannot be trusted".

Constant wear

The practicalities associated with constantly wearing a device (such as removing it to shower or charging it) made participants worried that some significant symptoms may not be recorded, affecting the accuracy of their risk score.

Box 5.11. Perceived effectiveness of polygenic risk scores (PRS).

Missing other important factors

While PRS was viewed positively for its objective and biological nature, participants felt that additional factors such as environmental and lifestyle factors need to be taken into consideration. For example, an individual may have a low genetic risk of developing cancer but live in a polluted environment or lead an unhealthy lifestyle, which place them as higher risk.

> So, they could see your genetic scorethat it's in your blood line that you might develop bowel cancer or whatever but.. that won't help if you've been working in industries where you've been exposed to things that could cause cancer.
>
> Male, 40-49, Asian, SES 6

Participants placed a greater value on the collection of biological data as this was seen to be "*more sophisticated"* than lifestyle or environmental data because it examines individualised internal processes. While lifestyle and environmental factors were still considered important in assessing cancer risk, participants generally favoured biological data as it was perceived to also incorporate the effects of lifestyle and environmental factors. Furthermore, its potential extended beyond cancer prediction, such as alerting individuals to biological indicators of other diseases, as well as benefiting society by providing further information on disease processes.

When considering the frequency of data collection, continuous methods were favoured over one-off snapshots. Continuous data collection was viewed as "*comprehensive", "reliable"* and "*accurate"* as it provides "*real time"* data. Although single data collection events required less effort, upon reflection, participants felt that they had more potential for inaccuracies as the results reflect a person's health at just one moment in time. They were also concerned that additional, non-fixed factors may impact the results. For example, the quality of the test conducted, potential for contamination, or additional biological and lifestyle related factors that change regularly (sleep, stress, diet etc).

> When you do a blood test, it's a snapshot of a point in time, when ideally you should be wearing like a sensor on your arm or something that is continuously checking your blood stats, so it's obviously much better.
>
> Male, 40-49, other ethnicity, SES 4

> [Continuous monitoring of biomarkers] seems really reliable and accurate, just because it's on you at all times, for me it's the most personal method. So yes, I think for me, that's the most trustworthy.
>
> Female, 18-29, Asian, SES 8

Self-efficacy

Individuals' confidence that they can perform the behaviour required to participate in the risk assessment is described as self-efficacy.

Self-efficacy was not considered for AI, continuous monitoring of biomarkers, geodemographic segmentation and PRS. These risk assessments tend not to require an individual to perform a behaviour independently for data collection. Conversely, participants showed a lack of confidence that they or others could complete the tests that required more active engagement. As described for the burden of completing certain minimally invasive tests (Box 5.2), some were unsure about providing urine or stool samples at home. Moreover, they worried that a lack of self-efficacy would impact the accuracy of risk assessments based on data collected by wearable devices, as described in Box 5.12.

> Somebody in a white coat has got the sample under a microscope, that gives me greater confidence.
>
> Male, 60-69, black, SES 6

Box 5.12. Self-efficacy considerations relating to wearable devices.

Participants felt that wearable or mobile technologies would be difficult for individuals if they are not *"tech savvy"*. Participants felt that they may not be able to correctly operate the technologies or understand the outputs, which could lead to them feeling *"overwhelmed"* and *"agitated"*. Furthermore, it could lead to an inaccurate risk category.

If you're using a smartwatch it could be [that you didn't use] the correct setting so it might not be giving them the accurate result. It's fine but I can't really trust technology like that

Female, 30-39, black, SES 7

Additional findings

Three themes were not associated with domains of the TFA: the impact of culture on views towards the innovations, communication with the public, and different ways that people might react to the outcome of the risk assessment.

Cultural factors

The female participant who completed the interview in Bengali only gave tentative answers to the questions relating to whether they would take up the invitation for risk assessments to assess cancer risk (specifically in the context of continuous monitoring of biomarkers and AI). They explained that the decision would be taken by, or in conjunction with, their husband and they did not wish to share their personal perspective.

I cannot take any decision on this regard asking my husband. So I think your questions will depend on [my] husband's agreement, consent.

Female, 40-49, Asian, SES 5

Public communication

Communication strategies were viewed as important in terms of the acceptability of cancer risk assessments to the public. Participants suggested that any changes to current practice should be communicated through public campaigns, letters formally stamped with the NHS logo, and conversations with GPs as the point of call.

More specifically, conflicting opinions were expressed regarding the communication of the results from individuals' risk assessments. Numeric scores were viewed as precise but had the potential to be "*morbid"* and it could lead to comparison amongst friends and family. Presenting the risk score categorically (high, medium or low risk) was equally conflicting as although it may be easier for the public to understand, individuals on the lower or higher ends of these scales could get either a false sense of security or anxiety.

Coping style

Lastly, throughout the interviews it became apparent that the level of receptiveness to risk assessment methods varied according to the coping style of individuals, irrespective of the example risk assessment method they reviewed. Some participants demonstrated an avoidant coping style towards health and therefore were not enthusiastic to take up a risk assessment as they "*would rather not know".* In contrast, some participants were proactively "*wanting to keep on top of their health"* and therefore were enthusiastic about taking up the innovations and finding out the results.

Survey

Summary

The aim of the third study was to describe how likely the public would be to take up the offer of risk-based innovations, and how acceptable it would be to use the result to prioritise screening or symptom investigation. Most of the 999 participants indicated that they were likely to take up the offer of the risk assessment: 62 to 85% for screening people without symptoms and 64 to 94% for people with symptoms. PRS and minimally invasive tests were the two innovations most likely to be taken up in each scenario, and geodemographic segmentation was least likely. People of White ethnicity, higher socioeconomic status and who often used healthcare apps were more likely to take up the risk assessment. Most participants also felt that it would be acceptable to use the risk assessment to inform cancer screening (66 to 89%, excluding geodemographic segmentation with just 59% participants considering this acceptable) or what tests to use to investigate symptoms (69 to 90%, excluding geodemographic segmentation with just 57% participants considering this acceptable).

Methods

Study design

We used the same survey as described for the think aloud interviews.

Survey participants were also given the option to explain their reasons for being likely or unlikely to take up the offer of each risk assessment by providing a free text response to the question “In a few words, why?”.

Participants and recruitment

A sample of 1,000 participants was recruited through an online participant recruitment platform for researchers in which individuals volunteer to take part in studies and are compensated for their time at their recommended hourly rate.

Participants were resident in the UK and representative of the UK population in terms of age, sex, ethnicity, and socioeconomic status. The first 600 participants were recruited by age, sex and ethnicity using the recruitment platform’s representative sample feature. The sample was then enriched with 400 participants of lower socioeconomic status (self-reported socioeconomic decile 1-3) using the recruitment platform’s pre-screeners to match the demographics of the UK population.

Data collection

The survey was completed online and hosted by Qualtrics.

Analysis

Quantitative analysis

Descriptive statistics were used to summarise the characteristics of the participants and the participants' responses to each of the three key outcomes for each of the six examples and in both the asymptomatic and symptomatic contexts (Table 5.1, above). For analysis of the acceptability of incorporating each example within risk-stratified screening in the asymptomatic scenario, views on use to decide when individuals would first be invited to screening and how often individuals would be invited to screening were combined into one variable. Differences between asymptomatic and symptomatic scenarios were assessed using the Wilcoxon signed-rank test.

Multivariable logistic regression was used to explore differences between the six examples within asymptomatic and symptomatic contexts and the impact of individual level characteristics (age group, sex (female versus male), smoking status (ever smoker versus never smoker), ethnicity (ethnic minority versus White), education level (university level or equivalent versus below university level), socioeconomic status ladder, prior history of cancer (yes versus no), technology use (at least one of using an app, tracking device or wearable daily versus no use or use of only an electronic device daily), and perceived risk of cancer ('*extremely/somewhat likely*' versus '*neither likely nor unlikely*' versus '*somewhat/extremely unlikely*'). In all these analyses the three key outcomes (likelihood, acceptability and comfort) were dichotomised by combining '*extremely likely/acceptable*' with '*somewhat likely/acceptable*', and '*neither likely nor unlikely/acceptable nor unacceptable*' with '*somewhat unlikely/unacceptable*' and '*extremely unlikely/unacceptable*' for likelihood and acceptability and '*extremely comfortable*' versus all other options for comfort. The order in which examples were presented (Table 6.1) and an interaction between the example and the order were also included.

Table 6.1. Orders in which the participants were presented with the examples in the survey.

	First example	Second example	Third example
Order 1	New technology	Use of personal data	Testing biomarkers
Order 2	Use of personal data	Testing biomarkers	New technology
Order 3	Testing biomarkers	New technology	Use of personal data
Order 4	New technology	Testing biomarkers	Use of personal data
Order 5	Use of personal data	New technology	Testing biomarkers
Order 6	Testing biomarkers	Use of personal data	New technology

Use of personal data: geodemographic segmentation or PRS; testing biomarkers: minimally invasive tests or continuous biomarker monitoring; new technology: AI or wearable devices.

Differences between the six examples are presented as predicted probabilities ± 95% confidence interval using the margins command in Stata. The impact of individual characteristics on likelihood of uptake are presented as odds ratios ± 95% confidence interval.

All quantitative analyses were performed using Stata 14.

Qualitative (free text) analysis

Responses to the free text questions were analysed thematically following an approach used previously (36), utilising Microsoft Excel spreadsheets. The comments were analysed in 12 groups according to whether participants were likely to take up the test or unsure/unlikely, and for each of the six examples of innovations. Comments given in asymptomatic and symptomatic scenarios were combined.

First, any comments that were generic to cancer, screening and/or symptoms, and/or risk assessments (that is, not specific to the innovation such as *I think it will save more lives*) were removed. Comments that were inconsistent with the participant's previous answer (such as if they answered 'very unlikely' to take part but provided a free text answer suggesting they would take up the test) were also removed.

For each group, at least two researchers familiarised themselves with a subset of the comments (20% of each group) and suggested a list of potential codes. The researchers met to agree initial code lists then piloted these on a subset of the comments (20%). After comparing and reviewing the coding decisions, they developed consolidated code lists for each group, repeating the codes across groups where possible. The remaining free text comments were then coded into the consolidated lists. Each comment was coded by two researchers and any discrepancies were discussed to reach an agreement. If a comment contained multiple meanings, it was assigned to as many codes as appropriate to cover the content.

Individual codes were then mapped into overarching themes based on the TFA. The frequency at which each code was used is reported.

Results

Participant characteristics

The survey was live between 8 and 11 August 2023 (approximately 80 hours). 1,052 individuals registered with the recruitment platform accessed the survey. 41 individuals withdrew by returning their submissions, 11 individuals timed-out, and one was excluded because they completed the survey exceptionally quickly (in 3 minutes) and their responses showed that they had not considered their answers. 999 complete responses were included. These participants took a median 18 minutes 45 seconds to complete the survey (IQR 14 minutes 57 seconds to 25 minutes 10 seconds.

The participant demographics are shown in Appendix Table 6.1. Reflecting the sampling strategy, the participants were largely representative of the UK population with respect to age, sex, ethnicity, and self-reported socioeconomic status. Most (82.3%) had completed A levels, further education or equivalent or higher, 29.3% were not currently working, and the majority of those who had been invited to existing cancer screening programmes had taken up that screening. Appendix Tables 6.2 and 6.3 show participants' thoughts and beliefs about cancer and screening, and attitudes towards technology and use of data.

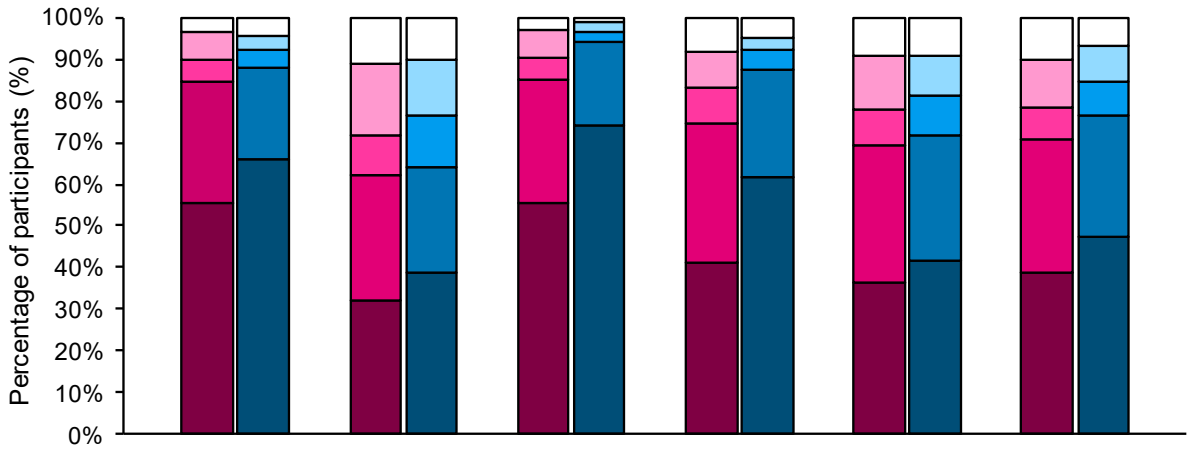
Likelihood of taking up the risk assessment

In unadjusted analyses, the majority of survey participants responded that they would be '*extremely*' or '*somewhat*' likely to take up the offer of risk assessment with each of the examples both in asymptomatic and symptomatic scenarios, as shown in Figure 6.1. Likelihood of taking up the risk assessment ranged from 62.0% for geodemographic segmentation to 85.2% for minimally invasive tests in the asymptomatic scenario and from 64.2% for geodemographic segmentation to 94% for minimally invasive tests in the symptomatic scenario. However, more than one in five participants would be unlikely to take up geodemographic segmentation, AI or wearable devices in the asymptomatic scenario or geodemographic segmentation in the symptomatic scenario. Across all examples, the likelihood to take up the offer of risk assessment was higher in the symptomatic scenario than in the asymptomatic scenario ($p \leq 0.001$).

Figure 6.2 shows the probability of being likely or very likely to take up the risk assessment for each example after adjustment for participant age, sex, smoking status, ethnicity, education level, socioeconomic status, prior history of cancer, technology use and perceived risk of cancer, and accounting for the order in which the examples were presented. Similar to the unadjusted univariable results above, participants were less likely to take up geodemographic segmentation while minimally invasive tests, PRS and continuous biomarker monitoring in the symptomatic scenario were associated with the highest probability of take up. The results for each of the six orders are presented in Appendix Figure 6.1.

The impact of participant characteristics on likelihood of uptake across all examples is shown in Figure 6.3 (with the breakdown for each example in Appendix Table 6.4). Participants from ethnic minority groups were less likely to take up risk assessment in the asymptomatic scenario. Those with higher socioeconomic status and greater technology use were more likely to take up risk assessment in both the asymptomatic and symptomatic scenarios.

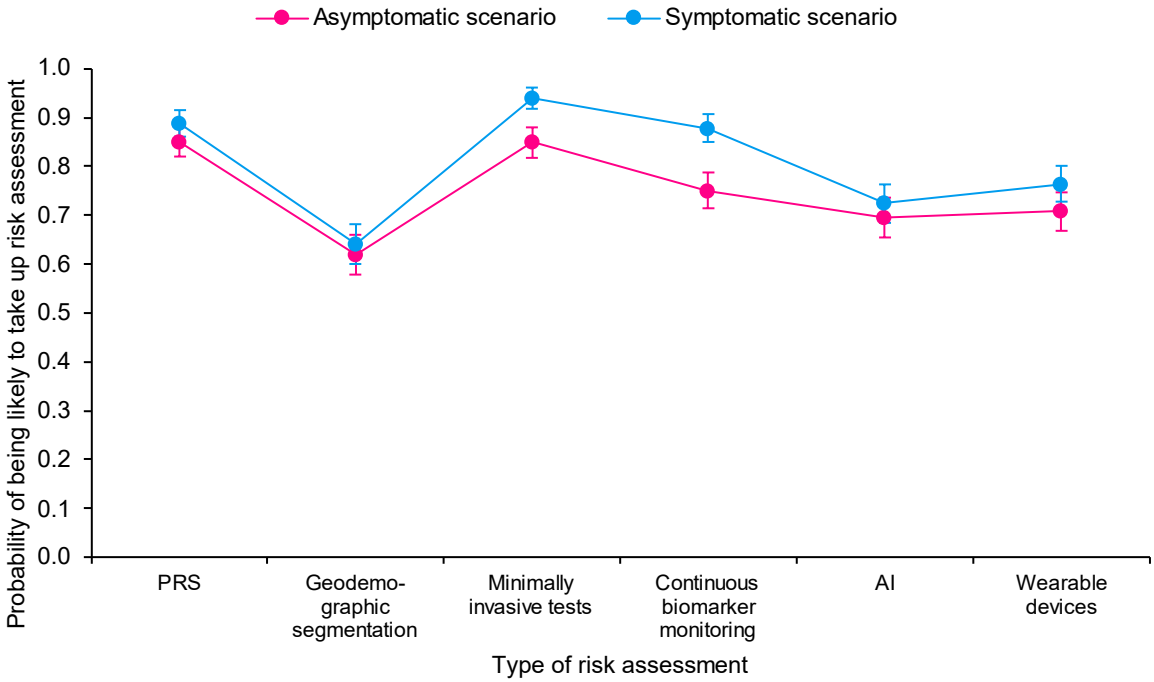
Figure 6.1. Likelihood that survey participants would take up the offer of different risk assessments in asymptomatic and symptomatic scenarios.



	PRS	Geodemo-graphic segmentation	Minimally invasive tests	Continuous biomarker monitoring	AI	Wearable devices
P value for difference*	<0.001	0.001	<0.001	<0.001	0.001	<0.001
Asymptomatic scenario						
Extremely likely	276 (55.5)	161 (32.1)	277 (55.4)	205 (41.1)	182 (36.6)	194 (38.7)
Somewhat likely	145 (29.2)	150 (29.9)	149 (29.8)	168 (33.7)	162 (32.6)	161 (32.1)
Neither	25 (5.0)	50 (10.0)	25 (5.0)	41 (8.2)	44 (8.9)	39 (7.8)
Somewhat unlikely	34 (6.8)	85 (16.9)	35 (7.0)	45 (9.0)	64 (12.9)	56 (11.2)
Extremely unlikely	17 (3.4)	56 (11.2)	14 (2.8)	40 (8.0)	45 (9.1)	52 (10.4)
Symptomatic scenario						
Extremely likely	328 (66.0)	194 (38.7)	370 (74.0)	308 (61.7)	208 (41.9)	239 (47.6)
Somewhat likely	110 (22.1)	128 (25.5)	100 (20.0)	129 (25.9)	149 (30.0)	144 (28.7)
Neither	21 (4.2)	61 (12.2)	12 (2.4)	23 (4.6)	46 (9.3)	42 (8.4)
Somewhat unlikely	16 (3.2)	67 (13.4)	12 (2.4)	14 (2.8)	49 (9.9)	44 (8.8)
Extremely unlikely	22 (4.4)	52 (10.4)	6 (1.2)	25 (5.0)	45 (9.1)	33 (6.6)

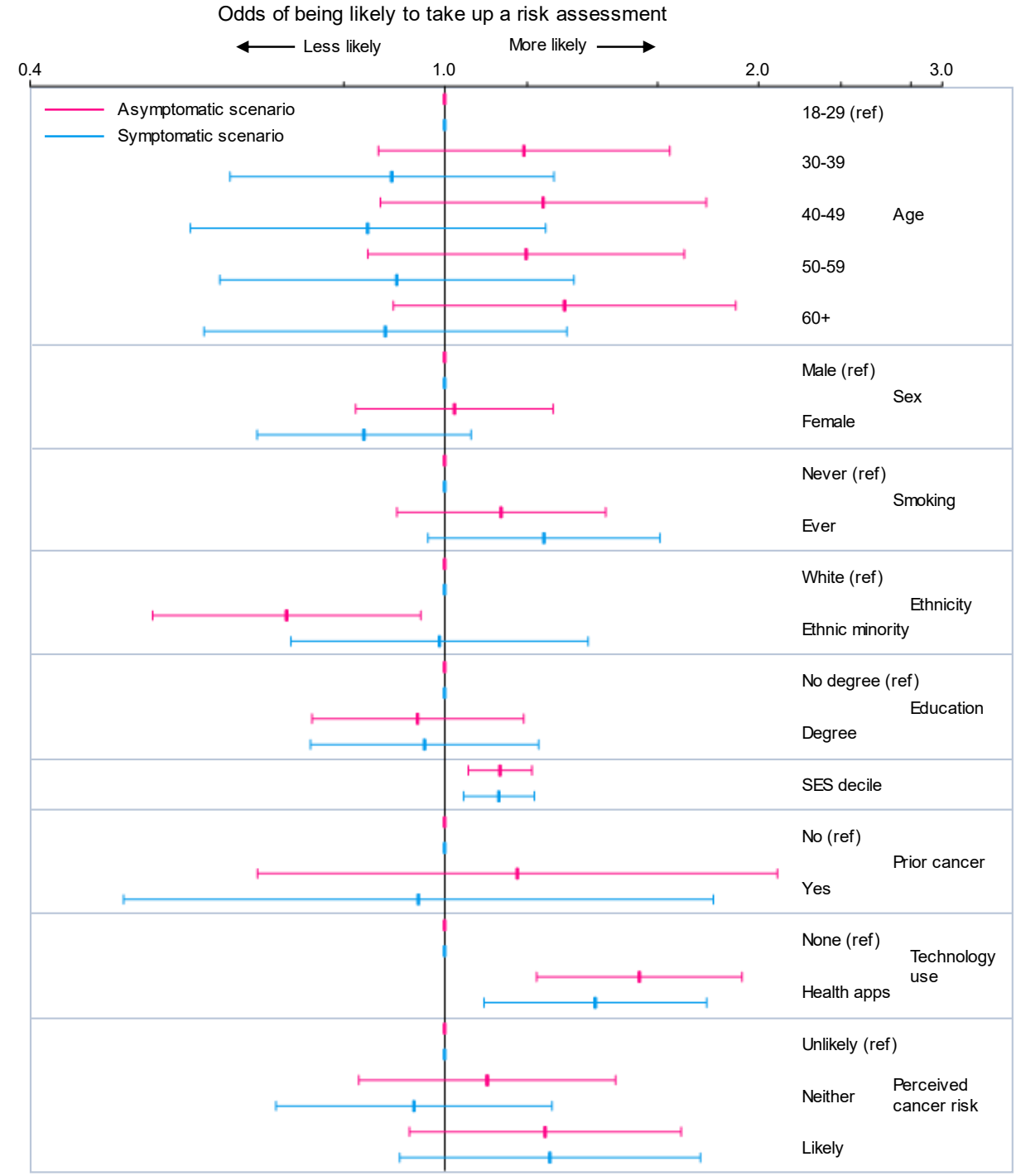
* P value for difference between asymptomatic and symptomatic scenarios.
N (%) participants reported in the table.
N = 999 participants.

Figure 6.2. Probability that survey participants would be likely or very likely to take up the offer of different risk assessments in asymptomatic and symptomatic scenarios, adjusted for individual demographics and the order in which examples were presented.



Error bars represent 95% confidence intervals.
N = 999 participants.

Figure 6.3. Odds ratios of survey participants being more or less likely to take up a risk assessment in asymptomatic and symptomatic scenarios.



N = 999 participants.
Ref: reference; SES: socioeconomic status.

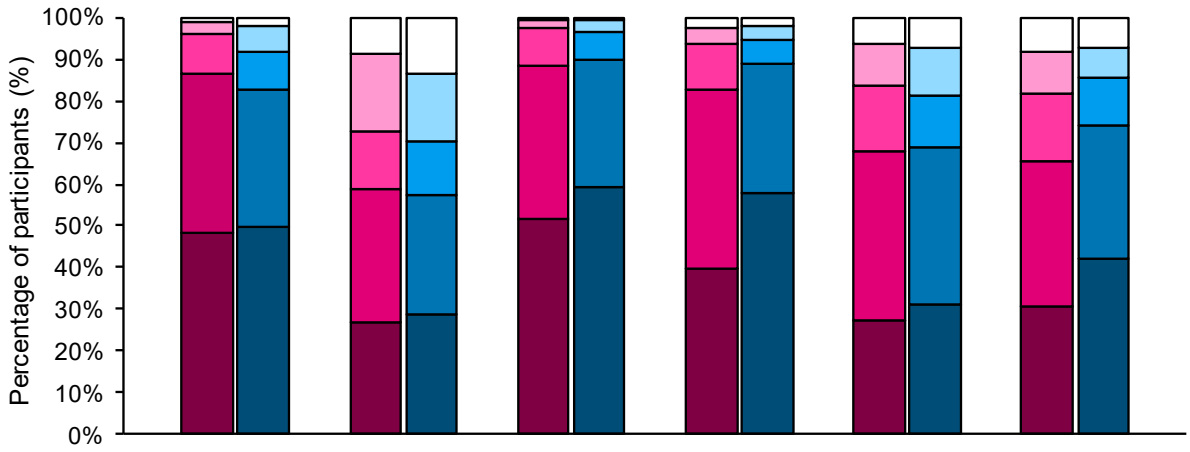
Acceptability of risk-stratified screening or referral

The majority of survey participants also responded that use of the examples within risk-stratified screening or referral pathways would be '*extremely*' or '*somewhat*' acceptable (Figure 6.4). Notably 13.5% of participants, however, considered the use of geodemographic segmentation extremely unacceptable in the symptomatic context and over 10% considered the use of geodemographic segmentation, AI or wearable devices '*extremely*' or '*somewhat*' unacceptable in both asymptomatic and screening contexts. Acceptability was higher in the symptomatic context than in the asymptomatic context ($p \leq 0.001$) for all examples except minimally invasive tests where no difference was seen ($p = 0.224$).

The acceptability of each example after adjustment for participant age, sex, smoking status, ethnicity, education level, socioeconomic status, prior history of cancer, technology use, perceived risk of cancer, and accounting for the order in which the examples were presented in shown in Figure 6.5. The pattern is similar to the uptake of risk assessment for each example (Figure 6.2), with geodemographic segmentation less acceptable, and PRS, minimally invasive tests and continuous biomarker monitoring more acceptable, in both the asymptomatic and symptomatic contexts. The results for each of the six orders are presented in Appendix Figure 6.2.

Female participants were less likely to consider use of any of the examples acceptable and those with greater technology use were more likely to take up risk assessment in both the asymptomatic and symptomatic contexts (Figure 6.6). Participants with higher socioeconomic status were more likely to consider risk assessment acceptable in the asymptomatic context than those with lower socioeconomic status. Associations with sociodemographic characteristics for each example are given in Appendix Table 6.5.

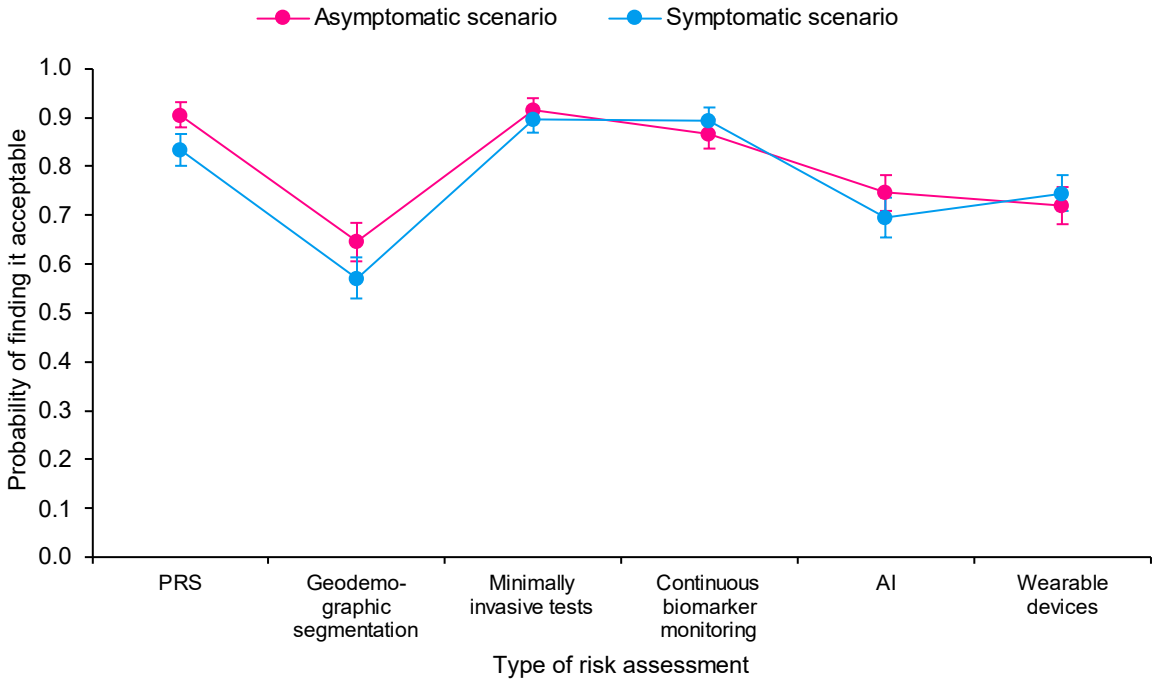
Figure 6.4. Acceptability if the risk assessment was used alongside age and sex to inform screening or referral in the asymptomatic or symptomatic scenarios.



	PRS	Geodemo-graphic segmentation	Minimally invasive tests	Continuous biomarker monitoring	AI	Wearable devices
P value for difference*	0.002	0.001	0.244	<0.001	0.009	<0.001
Asymptomatic scenario						
Extremely acceptable	241 (48.5)	135 (26.9)	258 (51.6)	199 (39.9)	136 (27.4)	155 (30.9)
Somewhat acceptable	188 (37.8)	160 (31.9)	185 (37.0)	213 (42.7)	201 (40.4)	175 (34.9)
Neither	48 (9.7)	71 (14.1)	44 (8.8)	56 (11.2)	80 (16.1)	80 (15.9)
Somewhat unacceptable	15 (3.0)	93 (18.5)	9 (1.8)	18 (3.6)	48 (9.7)	51 (10.2)
Extremely unacceptable	5 (1.0)	43 (8.6)	4 (0.8)	13 (2.6)	32 (6.4)	41 (8.2)
Symptomatic scenario						
Extremely acceptable	248 (49.9)	145 (28.9)	297 (59.4)	289 (57.9)	154 (31.0)	211 (42.0)
Somewhat acceptable	164 (33.0)	142 (28.3)	152 (30.4)	154 (30.9)	189 (38.0)	161 (32.1)
Neither	44 (8.9)	67 (13.3)	34 (6.8)	30 (6.0)	61 (12.3)	58 (11.6)
Somewhat unacceptable	30 (6.0)	80 (15.9)	14 (2.8)	15 (3.0)	56 (11.3)	36 (7.2)
Extremely unacceptable	11 (2.2)	68 (13.5)	3 (0.6)	11 (2.2)	37 (7.4)	36 (7.2)

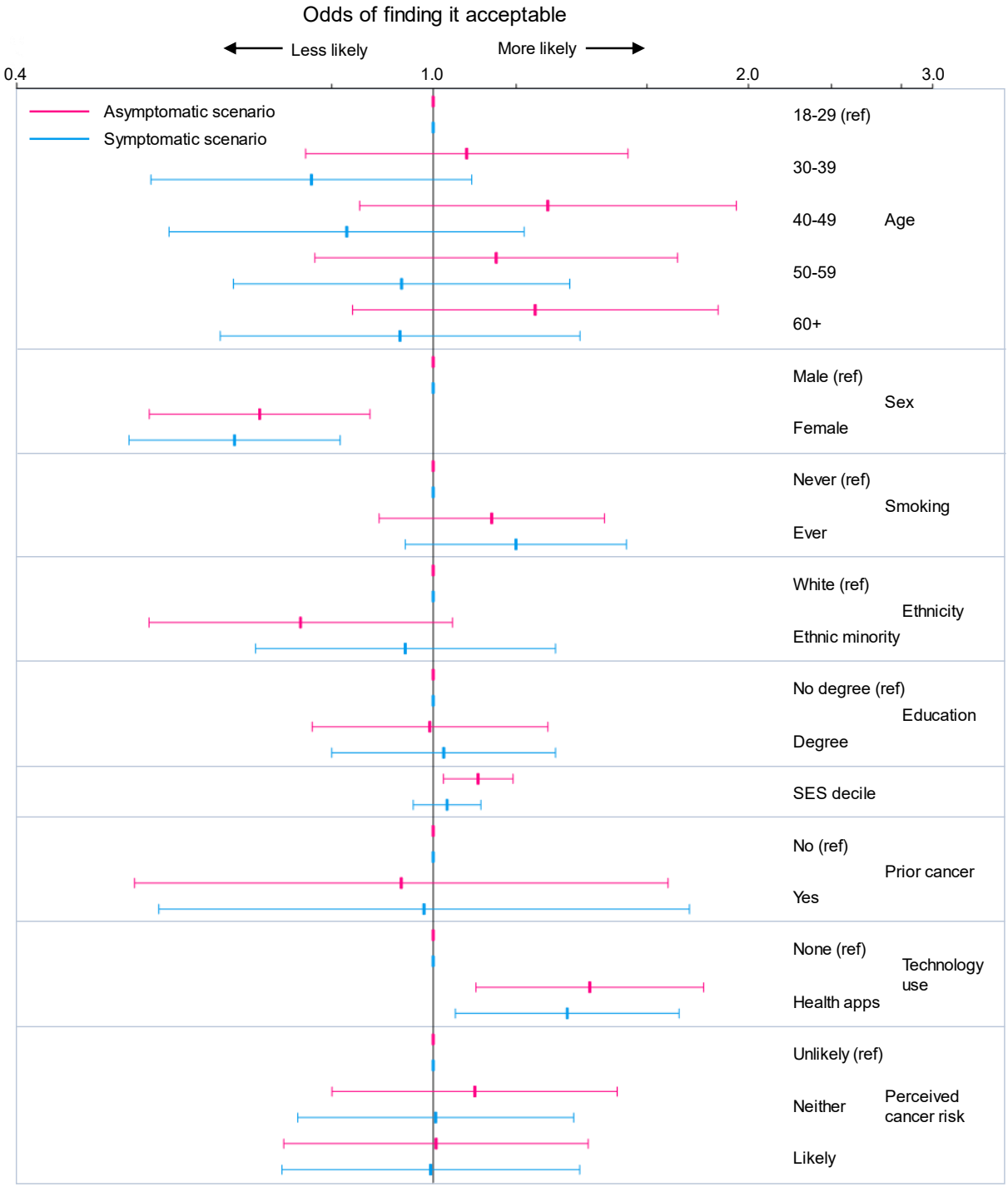
* P value for difference between asymptomatic and symptomatic scenarios.
N (%) participants reported in the table.
N = 999 participants.

Figure 6.5. Acceptability if the risk assessment was used alongside age and sex to inform screening or referral in the asymptomatic or symptomatic scenarios, adjusted for individual demographics and the order in which examples were presented.



Error bars represent 95% confidence intervals.
N = 999 participants.

Figure 6.6. Odds ratios of survey participants being more or less likely to find it acceptable to use the risk assessment alongside age and sex to inform screening or referral in the asymptomatic or symptomatic scenarios.



N = 999 participants.
Ref: reference; SES: socioeconomic status.

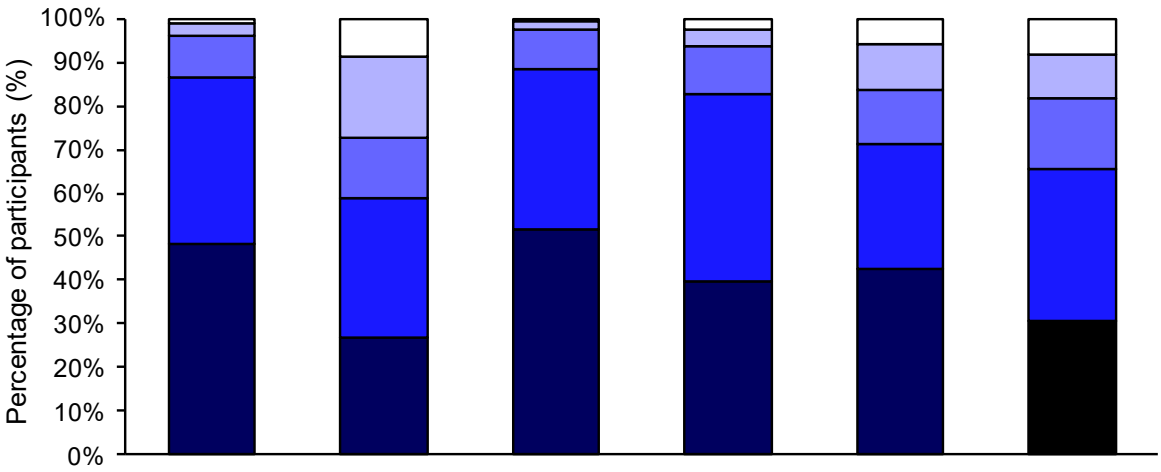
Comfort with results from risk assessments being kept on record

Comfort with the results from risk assessments being kept on record and used within the NHS to assess risk of other health conditions was generally high (Figure 6.7). Over 80% of respondents were comfortable with the NHS holding data on PRS, from minimally invasive tests and continuous biomarker monitoring. Between 58% and 62% were comfortable with data from geodemographic segmentation, AI and wearable devices being held by the NHS.

The pattern of responses was similar after adjustment for participant characteristics and accounting for the order in which the examples were presented, with participants more comfortable with the NHS holding and using data derived from PRS, minimally invasive tests and continuous biomarker monitoring than from geodemographic segmentation, AI and wearable devices (Figure 6.8). The results for each of the six orders are presented in Appendix Figure 6.3.

Participants over 60 years of age, male, White ethnicity and with higher technology use were more likely to be extremely comfortable across all the examples than younger, female, participants from ethnic minority backgrounds with lower technology use. Those with higher education were less likely to be comfortable (Figure 6.9). No association was seen with socioeconomic status. Associations with sociodemographic characteristics for each example are given in Appendix Table 6.6.

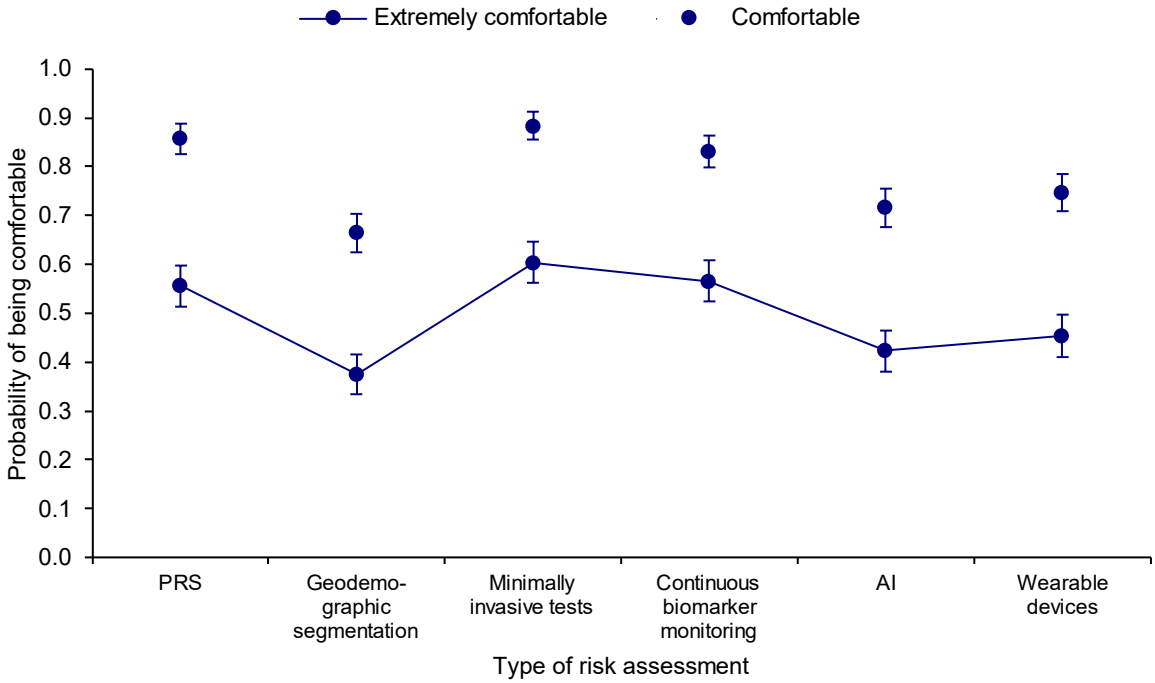
Figure 6.7. Comfort with the NHS having the results from different risk assessments on record, and potentially using the data to assess risk of other health issues.



	PRS	Geodemo-graphic segmentation	Minimally invasive tests	Continuous biomarker monitoring	AI	Wearable devices
Extremely comfortable	277 (48.5)	188 (26.9)	301 (51.6)	282 (39.9)	211 (42.5)	226 (30.9)
Somewhat comfortable	147 (37.8)	145 (31.9)	141 (37.0)	131 (42.7)	143 (28.8)	147 (34.9)
Neither	39 (9.7)	63 (14.1)	38 (8.8)	37 (11.2)	63 (12.7)	43 (15.9)
Somewhat uncomfortable	20 (3.0)	72 (18.5)	15 (1.8)	37 (3.6)	50 (10.1)	57 (10.2)
Extremely uncomfortable	14 (1.0)	34 (8.6)	5 (0.8)	12 (2.6)	30 (6.0)	29 (8.2)

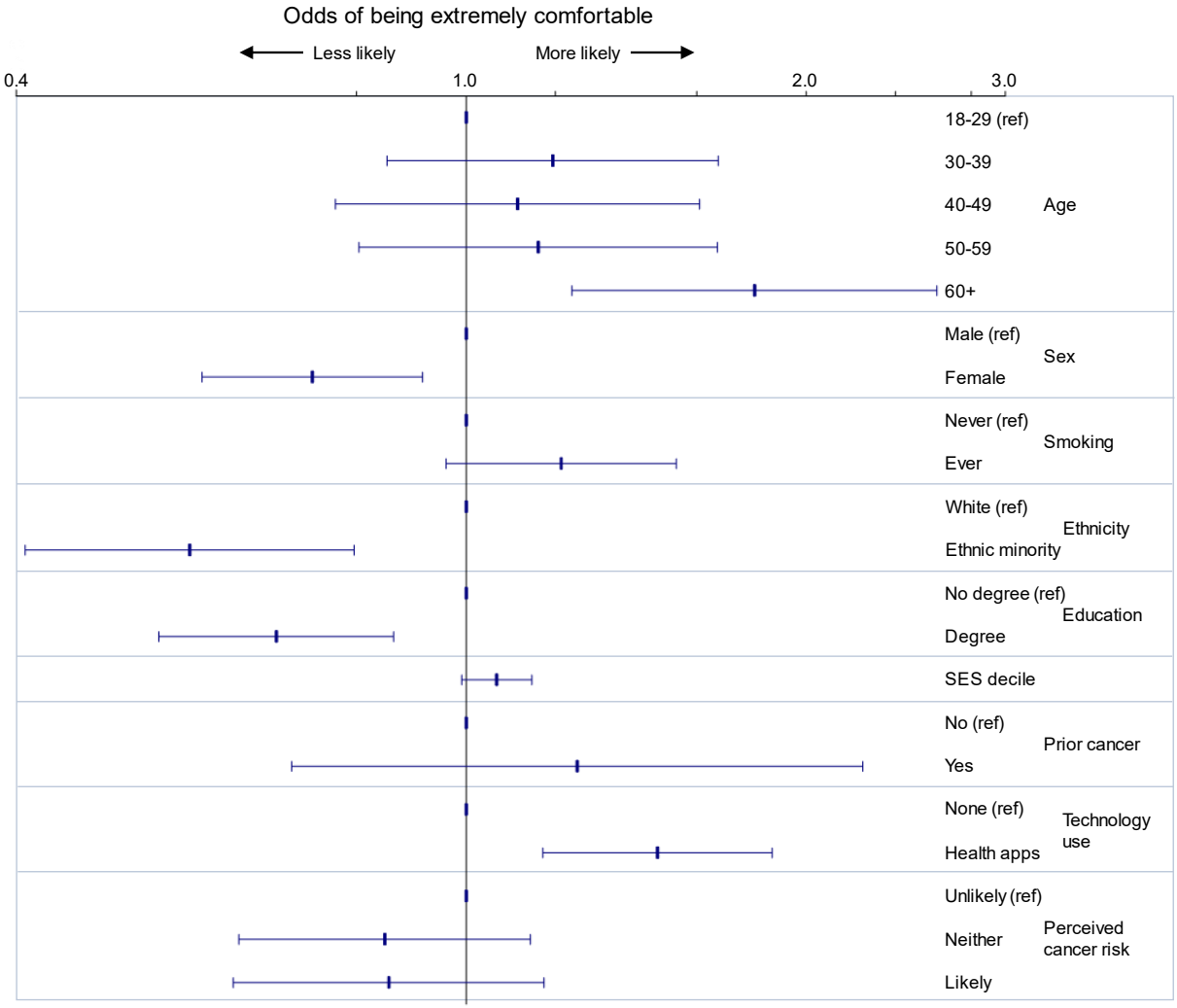
N (%) participants reported in the table.
N = 999 participants.

Figure 6.8. Comfort with the NHS having the results from different risk assessments on record, and potentially using the data to assess risk of other health issues.



Error bars represent 95% confidence intervals.
N = 999 participants.

Figure 6.9. Odds ratios of survey participants being more or less likely to be extremely comfortable with the NHS having the results of different risk assessments on record, and potentially using the data to assess risk of other health issues.



N = 999 participants.
Ref: reference; SES: socioeconomic status.

Self-reported reasons for the likelihood of taking up the risk assessment

All but one participant provided at least one free text comment to explain their likelihood of taking up the risk assessment in both asymptomatic and symptomatic scenarios. Across the six risk-based innovations, a total 4,616 comments were given to explain why someone was likely to take up the risk assessment (positive comments) and 1,342 comments were given to explain why someone was unlikely to take up the risk assessment (negative comments). 3,536 comments were omitted because they were not specific to risk assessment using the innovation in question, were inconsistent with the likelihood of taking up the risk assessment or were too vague to classify their meaning. This included comments that the participant would do anything recommended by their GP to benefit their health, did not want a risk assessment, and stating the aim of EDD.

The codes and the domain of the TFA into which they fit are reported in Table 6.2. Codes mapped onto four of the TFA domains – affective attitude, burden, ethicality and perceived effectiveness, plus a fifth domain, anticipated benefits and costs, which was an adapted domain incorporating both the opportunity costs domain plus anticipated benefits. No comments related to intervention coherence or self-efficacy. Anticipated benefits and costs contained subthemes including the risk assessment helping healthcare professionals' decision-making, contribution to the 'greater good' such as contributing to medical knowledge, opportunities to learn about personal risk of cancer, and the potential for reduced access to tests if their risk of cancer was found to be low. The principle of 'garbage in, garbage out' was a key component of the negative codes of the perceived effectiveness theme.

Notably, several of the concepts applied both positively and negatively. For example, some participants were likely to take up PRS, minimally invasive tests and continuous monitoring of biomarkers because they considered it trustworthy and reliable whereas other participants would not want to take it but because they considered it not trustworthy and reliable enough. Similarly, some participants would take up wearable devices and continuous monitoring of biomarkers because they required low effort (describing them as easy, non-invasive, and convenient) whereas other participants thought they were intrusive and required too much effort (describing them as burdensome and invasive).

The proportion of participants citing each concept in their reason for being likely or unlikely to take up the risk assessment varied between examples though and is presented in Figure 6.10.

Table 6.2. Domains and codes used to describe survey participants' reasons for the likelihood of taking up the risk assessment.

TFA domain	Positive codes	Negative codes
PRS		
Affective attitude	• -	• -
Burden	• Requires minimal effort (e.g. non-invasive and simple)	• -
Ethicality	• -	• Data protection concerns
Anticipated benefits and costs	• For the greater good • To understand cancer risk in light of family history • For reassurance regarding their genetic cancer risk	• Could be penalised for 'good genes'
Perceived effectiveness	• Trust in the reliability and accuracy of PRS	• Garbage out (e.g. mistrust of the interpretation)
Geodemographic segmentation		
Affective attitude	• Willing to share this information	• Considered irrelevant information for risk • Considered too impersonal
Burden	• Requires minimal effort (e.g. easy and simple)	• -
Ethicality	• -	• Privacy concerns • Stigma and sensitivity of financial information
Anticipated benefits and costs	• For the greater good • To help the GP in light of their geodemographics • For reassurance in light of their geodemographics	• Could be penalised (e.g. 'postcode lottery')
Perceived effectiveness	• To give a fuller picture of their health • To help find potential issues early in light of their geodemographics	• Garbage in (e.g. they have lived in multiple places) • Garbage out (e.g. mistrust of the interpretation)
Minimally invasive tests		
Affective attitude	• -	• Considered unnecessary
Burden	• Requires low effort (e.g. simple and non-invasive)	• Too invasive • Takes too much time or effort
Ethicality	• -	• -
Anticipated	• For the greater good	• Could a barrier to further

benefits and costs		investigation
Perceived effectiveness	• To help find potential issues early through biomarkers • Trust in the reliability and accuracy of biomarkers	• Mistrust in the reliability and accuracy of biomarker assessment
Continuous monitoring of biomarkers		
Affective attitude	• -	• Considered too impersonal and generalised • General dislike of the concept
Burden	• Requires low effort (e.g. easy, non-invasive and convenient)	• Requires too much effort (e.g. burdensome, invasive and intrusive) • Continuous monitoring would be anxiety-inducing
Ethicality	• -	• Data protection and privacy concerns
Anticipated benefits and costs	• For the greater good	• Time taken to monitor biomarkers could delay referral
Perceived effectiveness	• Trust in the reliability and accuracy of monitoring biomarkers continuously • To help find potential issues early due to continuous monitoring • To help find potential issues early as its personalised data	• Garbage out (e.g. mistrust of the interpretation)
AI		
Affective attitude	• Trust those who developed and recommend the algorithm	• General mistrust of AI • Considered too impersonal
Burden	• Requires minimal effort (e.g. easy and no action needed)	• -
Ethicality	• -	• Data protection concerns • Had not given consent for their records to be used in this way
Anticipated benefits and costs	• More efficient than doctors (e.g. result in faster tests)	• Would not want AI to impact their healthcare • Unwilling to reduce/lose doctor's input
Perceived effectiveness	• Considered powerful at finding trends • Considered more effective than doctors (e.g. more accurate, reliable or objective)	• Garbage in (e.g. inaccurate or missing data) • Garbage out (e.g. the algorithm could be inaccurate)

Wearable devices		
Affective attitude	• Willing to share this information	• Not considered appropriate or reasonable to inform healthcare
Burden	• Already use a wearable device • Requires low effort (e.g. non-invasive and non-intrusive)	• Find wearable devices uncomfortable, inconvenient or anxiety-inducing
Ethicality	• -	• Concerns about data security and too much surveillance • Could attribute blame to the individual
Anticipated benefits and costs	• For the greater good • Could provide feedback to help improve their lifestyle • To help the GP in light of their lifestyle • Save NHS time and resources	• Cost of the device • Could be penalised for a healthy lifestyle
Perceived effectiveness	• To help find potential issues early in light of their lifestyle	• Garbage in (e.g. anticipate inaccuracy or unreliability) • Garbage out (e.g. mistrust of the algorithm or interpretation) • Too slow to estimate risk

For each group, the code 'other' was also included.
"-" indicates that no codes applied to this TFA domain.

The most common reason for taking up PRS was the low burden of completing the test, being referred to in 61% of the included comments (n = 194). Conversely, the perceived effectiveness (mistrust), ethicality (data protection concerns) and anticipated costs (potential to be penalised for 'good genes') were all suggested reasons for not taking part.

Several different benefits were anticipated with regards to geodemographic segmentation, which amounted to 37% of the included comments (n = 166). Affective attitude was a frequent consideration both for and against geodemographic segmentation: some were simply willing to share geodemographic information (31% comments [n = 166]) versus others who saw geodemographic information as irrelevant or too impersonal (43% comments [n = 311]).

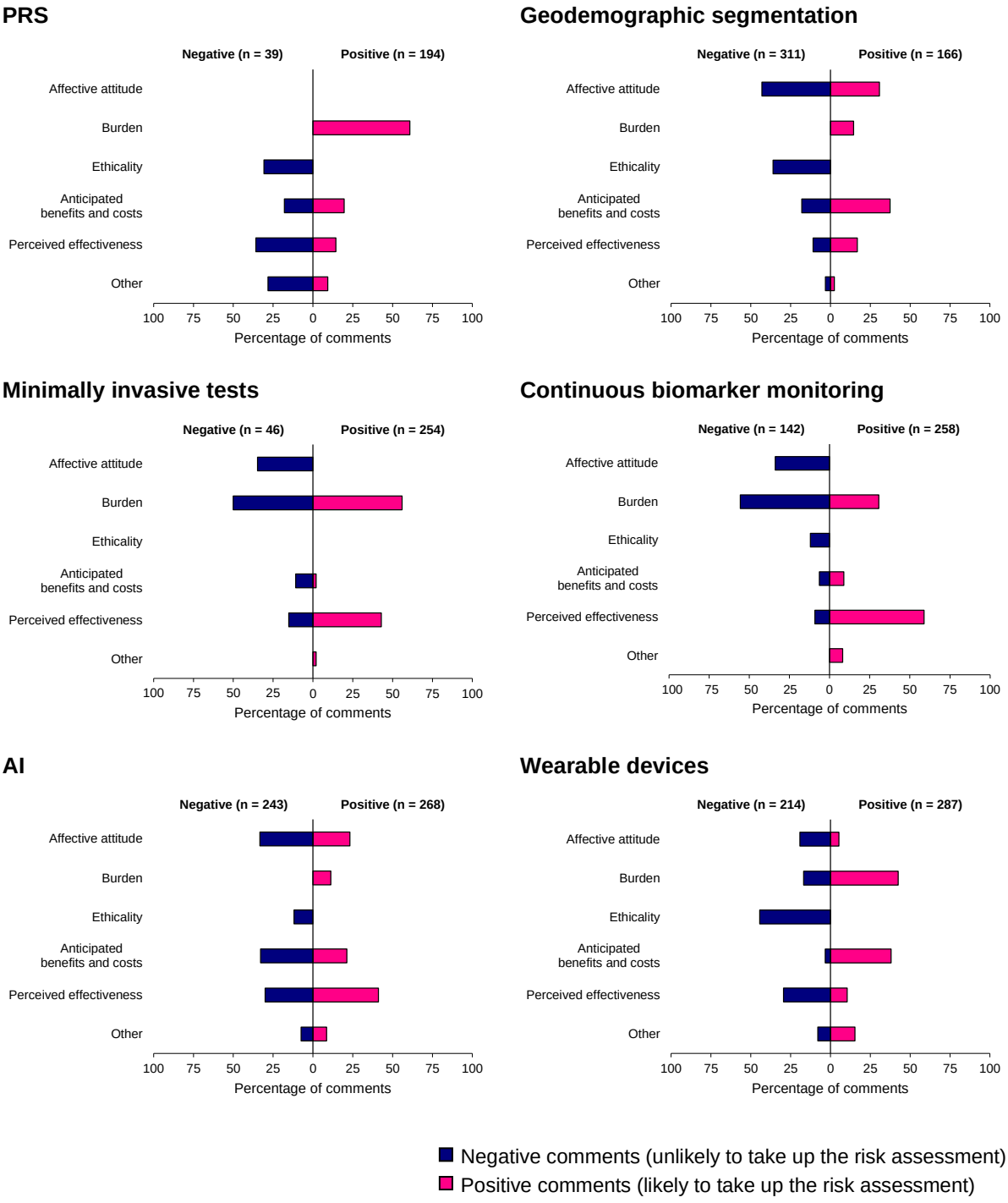
Reasons for taking up minimally invasive tests were either associated with the low burden or perceived effectiveness, although half of the negative comments included that the burden of completing a minimally invasive test was still too great in terms of time or invasiveness (50% comments [n = 46]).

Like minimally invasive tests, burden and perceived effectiveness were the most frequently noted reasons for being willing to take up continuous monitoring of biomarkers, being included in 31% and 59% comments, respectively (n = 258). Again, those who were unwilling to have continuous monitoring described the burden as too great (56% comments [n=142]), or considered it too impersonal or generally disliked the concept (34% comments classified as affective attitude [n=142]).

The most frequently cited reason for being willing for AI to assess cancer risk was its perceived effectiveness, mentioned in 41% included comments (n=268), whereas affective attitude, anticipated costs and perceived effectiveness each covered a third of the negative comments (n = 243).

There were more positive comments on the burden of wearable devices than negative, with participants indicating that it would be easy since they already had a device or anticipated it to be a low effort risk assessment. 44% of the included negative comments (n = 214) were related to ethicality: specifically, participants were concerned about data security, surveillance, and the potential to attribute blame for a high cancer risk to the individual. Perceived ineffectiveness was also an important consideration with 29% comments (n = 214).

Figure 6.10. Percentage of positive and negative free text comments included in each domain of the TFA to describe survey participants' reasons for the likelihood of taking up the risk assessment.

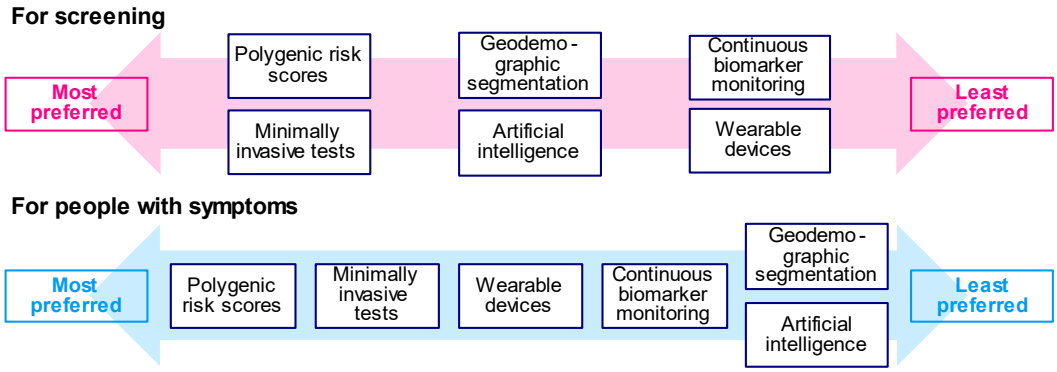


Percentage of comments add up to more than 100% as some comments contained multiple meanings. Responses given in asymptomatic and symptomatic scenarios are combined.

Discrete choice experiment

Summary

This study was a DCE with 1,200 participants. In addition to the finding that participants often wanted to have a risk assessment, only choosing not to in 20% of responses in the asymptomatic cohort and 12% of responses in the symptomatic cohort ($p < 0.001$), the DCE quantified how important different aspects of risk assessments were to the public and their preferences for them. The most important factor was how accurate the risk assessment was, especially not underestimating cancer risk because this may result in less testing than ideal. Whether it was a genetic or non-genetic test, the location and test frequency were least important. We modelled that, compared to no risk assessment for screening, the likelihood of preferring PRS and minimally invasive tests was 84%, preferring geodemographic segmentation was 81%, preferring AI was 80%, preferring continuous biomarker monitoring was 78%, and preferring wearable devices was 77% (assuming the highest modelled levels of accuracy). Compared to no risk assessment for referral, the likelihood of preferring PRS was 95%, preferring minimally invasive tests was 93%, preferring wearable devices was 91%, preferring continuous biomarker monitoring was 88%, and preferring geodemographic segmentation and AI was 86% (assuming the highest modelled levels of accuracy). The following orders of preference were therefore observed:



The differences in preference compared to the survey are likely because the preferences are based on the attributes of the innovations, rather than the innovations themselves.

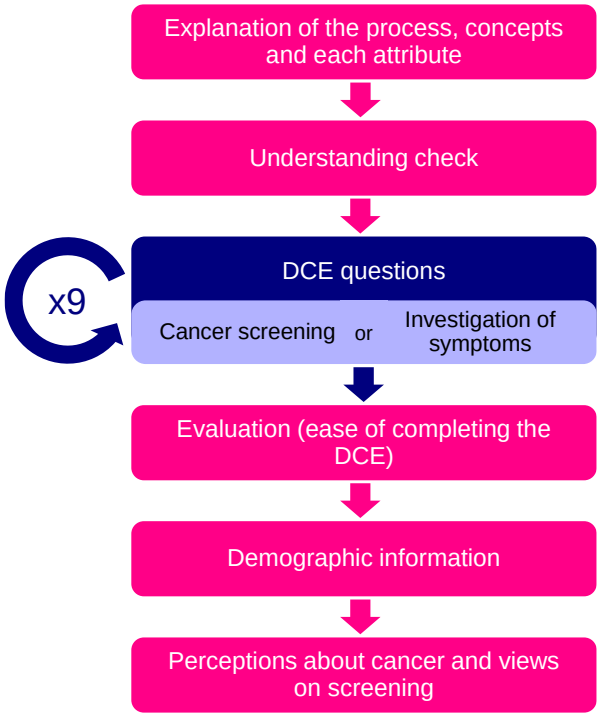
Methods

Survey design

Conjoint analysis methods, such as DCEs, quantify the strength of preference for different aspects of policies by asking respondents to select between hypothetical strategies with different characteristics (attributes) in a series of questions (37). Analysing the choices individuals make allows understanding of which attributes of future risk-based innovations are most important in driving people's preferences.

The structure of the survey is shown in Figure 7.1. Each participant answered nine DCE questions. Half of the participants completed the questions in the context of cancer screening, and half completed the same questions in the context of referral for investigation of symptoms that could be cancer.

Figure 7.1. Summary of the structure of the DCE survey.



The attributes included within the DCE (Table 7.1) were selected to enable us to compare preferences for the six examples of risk-based innovations to assess risk of cancer used throughout these studies (i.e., the six examples could be identified by specific combinations of the levels of these attributes). They were also informed by the findings of the earlier studies and reviews of the literature, and discussion with experts in DCE design and patient and public representatives. The levels reflect a plausible and clinically relevant range while also avoiding extreme values to limit grounding effects. Illogical or nonsense combinations of levels were removed.

Table 7.1. Attributes and levels used in the DCE.

Attribute	Definition	Levels
Method of risk assessment	How the data for the risk assessment is collected.	1. Questionnaire or data access 2. Blood test 3. Non-invasive test 4. Wearable device
Type of risk assessment	Whether the risk is based on genetic data or non-genetic data.	1. Genetic 2. Non-genetic
Location of risk assessment	Where data collection for the risk assessment takes place.	1. Home 2. Community clinic/pharmacy 3. General practice 4. Hospital
Frequency of risk assessment	How often data collection for the risk assessment needs to be repeated.	1. One-off single event 2. Once every 5 years 3. Once every year 4. Continuously for a 2-week period 5. Constantly
Accuracy – risk of cancer is over-estimated	The number of people whose risk of cancer would be over-estimated by this option and are told they are at high risk of cancer when actually they are not. This means that they might be offered more screening or more diagnostic tests than they need, based on their actual cancer risk. The tests may cause more harm than benefit.	1. 5 2. 10 3. 15 4. 20 …out of every 100 people who have a risk assessment
Accuracy – risk of cancer is under-estimated	The number of people whose risk of cancer would be under-estimated by this option and are told they are at low risk of cancer when actually their risk is higher. This means they might be offered less screening or fewer diagnostic tests than they should be, based on their actual cancer risk. This might mean a cancer is diagnosed later than it could have been if they had been offered more tests.	1. 5 2. 10 3. 15 4. 20 …out of every 100 people who have a risk assessment

Each conjoint-analysis task (DCE question) included two options for risk assessments plus an opt-out option (i.e. do not estimate cancer risk), and participants were asked which option they preferred. They were asked one set of nine questions from a possible 18, in a random order. They had to answer every question. An example question is shown in Table 7.2.

Table 7.2. Example of a DCE choice question.

	Option 1	Option 2
Method of risk assessment	**Non-invasive test** This quick and easy test may include providing a sample of urine, stool or saliva. The sample will be analysed for certain biomarkers (which are signals of what is going on in the body).	**Questionnaire or data access** Cancer risk can be estimated using data from the person's existing health records (with their permission), or they could do a questionnaire to provide additional information.
Type of risk assessment	**Genetic** A person's genes or DNA are analysed to estimate their cancer risk.	**Non-genetic** Data other than a person's genes or DNA are analysed to estimate their cancer risk.
Location of risk assessment	**Home** The test is carried out by the person, in their own home.	**Home** The person would do the questionnaire/give permission to access data in their own home.
Frequency of risk assessment	**One-off single event** They would only do the test one time ever.	**Once every 5 years** They would give permission for data access and update the questionnaire once every five years.
Accuracy – risk of cancer is over-estimated	**5 out of every 100 people** who have a risk assessment are **told they are at high risk of cancer when actually they are not**.	**20 out of every 100 people** who have a risk assessment are **told they are at high risk of cancer when actually they are not**.
	This means that they might be offered more screening or more diagnostic tests than they should be, based on their actual cancer risk. The tests may cause more harm than benefit.	
Accuracy – risk of cancer is under-estimated	**5 out of every 100 people** who have a risk assessment are **told they are at low risk of cancer when actually their risk is higher**.	**10 out of every 100 people** who have a risk assessment are **told they are at low risk of cancer when actually their risk is higher**.
	This means they might be offered less screening or fewer diagnostic tests than they should be, based on their actual cancer risk. This might mean a cancer is diagnosed later than it could have been if they had been offered more tests.	

Question posed in the **asymptomatic context**:

Imagine someone has no symptoms of cancer. A decision must be made about the age at which they are first invited to screen for a particular type of cancer, and how often they should be invited.

Which option do you think is most acceptable?

1. Using their risk estimated according to **Option 1**, offer more intensive screening if they have a high risk and less intensive screening if they have a low risk.

2. Using their risk estimated according to **Option 2**, offer more intensive screening if they have a high risk and less intensive screening if they have a low risk.

3. **Neither** – do not estimate their risk and so offer the same screening to everyone (at average intensity).

Question posed in the **symptomatic context**:

Imagine someone has a symptom that could potentially be a cancer. A decision needs to be made about which referral to make to investigate their symptoms. What investigations they should be offered must be decided.

Which option do you think is most acceptable?

1. Using their risk estimated according to **Option 1 alongside the clinical judgement of the GP**, arrange urgent, extensive tests if they have a high risk and refer initially for less urgent, less extensive tests if they have a low risk.

2. Using their risk estimated according to **Option 2 alongside the clinical judgement of the GP**, arrange urgent, extensive tests if they have a high risk and initially refer for a non-urgent test if they have a low risk.

3. **Neither** – do not estimate their risk and refer based on clinical judgment alone.

Participants and recruitment

1,200 individuals resident in the UK were recruited through the same recruitment platform as for the survey. Again, the sample was representative of the UK population, which was achieved by recruiting 750 participants representative with regards to age, sex and ethnicity, and 450 participants of lower self-reported socioeconomic status. People who had completed the survey were not invited to take part.

Data collection

The survey was completed online and hosted by Qualtrics.

Analysis

All analyses were performed using Stata 15. Descriptive statistics were used to summarise the characteristics of the participants and their beliefs about cancer.

The main analysis used conditional logistic regression models (fixed effects logit) to indicate participants' preferences for different aspects of risk assessments (38). We compared the responses of those who completed the DCE in the context of screening with those who completed it for investigation of symptoms using Chi-squared tests.

Three sensitivity analyses were run. Firstly, excluding those who showed poor attention by consistently selecting Option 1 or 2 or who completed the survey in less than 7.5 minutes (the fastest 5%). Secondly, excluding those who showed poor understanding of the DCE by failing to answer the three understanding questions correctly. Thirdly, only including the responses in which participants selected Option 1 or 2 (i.e. excluding "neither" selections).

Subgroup analyses were conducted to investigate differences in preferences according to selected demographics (age older or younger than 50 years, male or female sex, white or ethnic minority, low [≤3] or not low [>3] self-reported socioeconomic decile), screening history (those who had attended screening versus those who had chosen not to take up the offer), cancer worry (worried versus not worried), and ease of completing the DCE (easy versus difficult).

The coefficients generated in the main analysis were used to calculate (39):

- The relative importance of each attribute (percentage contribution to decision-making);
- Trade-offs between attributes (marginal rates of substitution);
- The impact of changing each level of the attributes on the probability that different options would be preferred;
- The probability that the six examples of risk-based innovations would be preferred compared to no risk assessment.

In the final two analyses in which the probability of preferring certain options was calculated, no risk assessment was used as the comparator (reference). We set the categorial variables to zero to indicate no method, type, location or frequency of risk assessment. We fixed the value of the continuous attributes (over- and underestimated risk) at 12.5 out of every 100 people who have a risk assessment. This is the mean of the levels these attributes could take (5 to 20), therefore is closest to cancelling them out since setting them to zero would have implied a perfect risk classification, which is nonsense in the case of no risk assessment. We tried fixing the continuous attributes at different levels and the trends between levels do not change, but the predicted probability does change. The levels used to model each example of risk-based innovation are reported in Table 7.3.

Table 7.3. The levels of each attribute used to model the six examples of risk-based innovations in the DCE, plus the reference.

	Method	Type	Location	Frequency	Accuracy*
PRS	Blood test	Genetic	General practice	One-off single event	5 or as specified
Geodemo-graphic segmentation	Questionnaire or data access	Non-genetic	Home	Once every 5 years	5 or as specified
Minimally invasive tests	Non-invasive test	Non-genetic	Community clinic/ pharmacy	Once every year	5 or as specified
Continuous biomarker monitoring	Wearable device	Non-genetic	Hospital	Continuously for a 2-week period	5 or as specified
AI	Questionnaire or data access	Non-genetic	Home	Once every year	5 or as specified
Wearable devices	Wearable device	Non-genetic	Community clinic/ pharmacy	Constantly	5 or as specified

No risk assessment (reference)	None	None	None	None	12.5

* Over- and underestimated risk; out of every 100 people who have a risk assessment.

Results

Participant characteristics

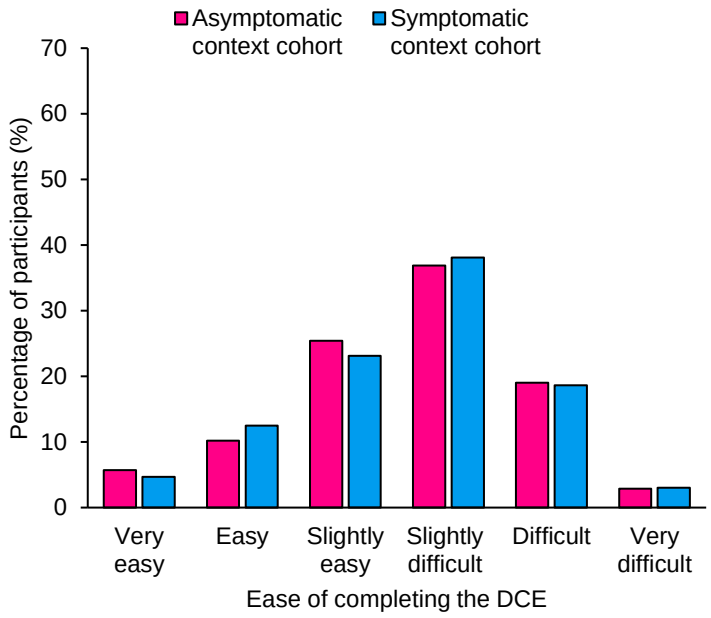
The survey was live between 21st and 24th November 2023 (approximately 70 hours). 1,288 individuals registered with the recruitment platform accessed the survey. 70 individuals withdrew by returning their submissions, 16 individuals timed-out, and 1,202 individuals completed the survey. Two were excluded because they completed the survey exceptionally quickly (in 3 minutes) and their responses showed that they had not considered their answers.

Participants took a median 15 minutes 9 seconds to complete the survey (IQR 11 minutes 22 seconds to 21 minutes 9 seconds), with a median 15 seconds (IQR 9 to 23 seconds) spent reading the instructions and information about cancer screening.

599 participants answered the questions in the context of screening asymptomatic individuals (asymptomatic context cohort) and 601 answered the questions in the context of referral to investigate possible cancer symptoms (symptomatic context cohort). As shown in Appendix Tables 7.1 and 7.2, participants' demographic characteristics and thoughts and beliefs about cancer and screening were similar between cohorts.

Most participants answered all the questions to test their understanding of the table of risk assessment options correctly (74%, 883 participants). Levels of understanding were comparable between participants in the asymptomatic and symptomatic context cohorts. Ease of completing the DCE was also similar for the asymptomatic and symptomatic context cohorts. Most participants found it difficult (59%, 711 participants), as shown in Figure 7.2.

Figure 7.2. Participants' ease of completing the DCE.



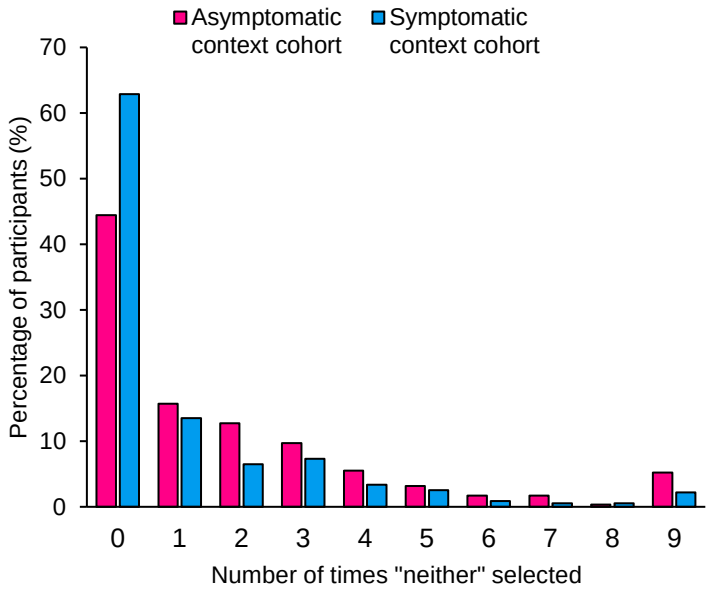
N = 1,200 participants.

Preferences for different aspects of cancer risk assessments

Table 7.4 presents the results of the regression analysis showing participants' preferences for different aspects of cancer risk assessments using novel innovations. To inform screening for asymptomatic individuals, blood tests and non-invasive tests were preferred over questionnaires or data access, and wearable devices were less favoured. Participants thought that all the suggested examples were better than questionnaires or data access for people with symptoms. Whether a test was genetic or non-genetic did not impact preference. Similarly, there were no differences in preference according to location or frequency of repeating the test, except that participants thought asymptomatic people should not have a test done at a hospital. Finally, participants preferred risk assessments that more accurately estimated risk of cancer. The coefficients for overestimated risk were not significantly different between asymptomatic and symptomatic contexts, whereas it was more important that risk was not underestimated in people with symptoms compared to those without symptoms.

Participants chose to assess risk of cancer in most instances. The "neither" option, indicating a preference not to estimate risk of cancer, was selected 20% of the time in the asymptomatic context cohort (1,072 out of the 5,391 responses) and 12% of the time in the symptomatic context cohort (638 out of the 5,409 responses; p for difference < 0.001 [X^2]). 644 (54%) participants never selected the "neither" option while 44 (4%) selected "neither" in response to all questions. Frequency of selecting "neither" is summarised in Figure 7.3.

Figure 7.3. Frequency at which participants opted not to estimate risk of cancer across nine DCE questions.



N = 1,200 participants.

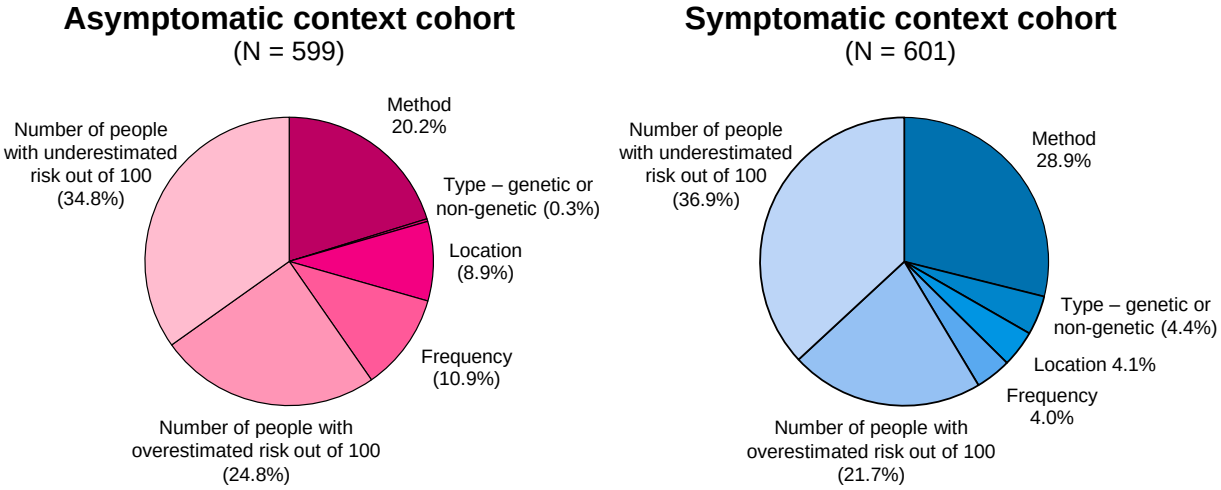
Table 7.4. DCE participants' preferences for risk assessments in screening and referral cohorts (main analysis).

	Asymptomatic context cohort	Symptomatic context cohort	P value for difference
N participants	599	601	**<0.001** for
N observations	16,173	16,227	overall
Pseudo R^2	0.0974	0.2118	difference
Constant (no risk assessment)*	**-0.684 (-0.827 to -0.541)**	**-0.829 (-0.985 to -0.673)**	0.178
Method of risk assessment			
Questionnaire or data access	Ref	Ref	
Blood test	**0.321 (0.194 to 0.448)**	**0.956 (0.820 to 1.091)**	**<0.001**
Non-invasive test	**0.313 (0.204 to 0.423)**	**0.717 (0.603 to 0.832)**	**<0.001**
Wearable device	**-0.193 (-0.362 to -0.023)**	**0.273 (0.105 to 0.440)**	**<0.001**
Type of risk assessment			
Non-genetic	Ref	Ref	
Genetic	-0.008 (-0.154 to 0.138)	0.147 (-0.012 to 0.306)	0.161
Location of risk assessment			
Home	Ref	Ref	
Community clinic/pharmacy	-0.031 (-0.144 to 0.082)	0.106 (-0.012 to 0.224)	0.100
General practice	-0.100 (-0.215 to 0.016)	-0.009 (-0.134 to 0.116)	0.299
Hospital	**-0.227 (-0.335 to -0.118)**	-0.029 (-0.136 to 0.078)	**0.012**
Frequency of risk assessment			
One-off single event	Ref	Ref	
Once every 5 years	0.002 (-0.134 to 0.138)	0.006 (-0.139 to 0.150)	0.972
Once every year	-0.056 (-0.171 to 0.060)	-0.001 (-0.125 to 0.124)	0.526
Continuously for 2 weeks	0.220 (-0.029 to 0.469)	-0.032 (-0.280 to 0.216)	0.161
Constantly	-0.032 (-0.196 to 0.132)	0.099 (-0.071 to 0.268)	0.277
Accuracy – per additional person out of 100 whose risk will be overestimated	**-0.042 (-0.049 to -0.035)**	**-0.048 (-0.055 to -0.040)**	0.271
Accuracy – per additional person out of 100 whose risk will be underestimated	**-0.059 (-0.066 to -0.053)**	**-0.081 (-0.088 to -0.074)**	**<0.001**

* Fixed at 12.5 in the analysis.
Results where p<0.05 are highlighted in bold.
Positive coefficients indicate a preference for the specified level compared to the reference; negative coefficients indicate a preference for the reference compared to the specified level.

The contribution of each attribute to the decision (the relative importance of each attribute to the choice) is illustrated in Figure 7.4. In both cohorts, the primary consideration was the number of people whose risk would be underestimated. The number of people whose risk would be overestimated was more important than the method used in asymptomatic people, whereas this was the other way round in the symptomatic context. Whether it was a genetic or non-genetic test, the location and frequency were always the three least important attributes.

Figure 7.4. Relative importance of each attribute to the choice between risk assessments for DCE participants (main analysis).



Participants' preferences for risk assessments in the three sensitivity analyses are reported in Appendix Tables 7.3 a to c. The sensitivity analyses tended to be statistically different to the main analysis, but any differences between the magnitude of the coefficients were small. One exception was that participants who showed better understanding of the information preferred genetic over non-genetic tests for people with symptoms that could be indicative of cancer. The size of the coefficients of the accuracy attributes were also slightly larger in the sensitivity analyses.

Subgroup analyses (Appendix Tables 7.4 a to g) revealed many statistical differences in the preferences for risk assessments between participants with different characteristics. For example, males had stronger preferences for asymptomatic risk assessments (for screening) at home. There were differences between the views of participants with White ethnicity versus ethnic minority and low versus high socioeconomic status in the symptomatic context cohort. For example, ethnic minority participants and participants with higher socioeconomic status had less concerns about inaccuracies in risk prediction (particularly underestimated risk). There were also differences according to cancer worry, which tended to relate to the method and location of the risk assessment. In particular, people who were less worried about cancer did not want to wear a device to assess cancer risk if they were asymptomatic, whereas people who were more worried about cancer did not mind.

Possible trade-offs between different aspects of cancer risk assessments

Table 7.5 shows that, based on the expressed preferences, participants were more willing to accept inaccuracies in risk assessment results in order to use their preferred test method in people with symptoms than without symptoms. Additionally, they were more willing to give up accuracy in terms of overestimated risk than underestimated risk. For example, they were willing for risk of cancer to be overestimated in 8 more people for a blood test for screening and 20 more people for a blood test for referral rather than having a data-based risk assessment (95% confidence intervals 5 to 11 and 17 to 23 more people, respectively).

Participants required risk of cancer to be overestimated in 1.4 fewer people in order to accept an additional person's risk being underestimated for screening for every 100 people undergoing a risk assessment (95% confidence interview 1.3 to 1.6 fewer people). Participants required risk of cancer to be overestimated in 1.7 fewer people in order to accept an additional person's risk being underestimated in people who had symptoms (95% confidence interview 1.6 to 1.8 fewer people).

Table 7.5. Trade-offs that DCE participants were willing to make between a. over- and b. underestimated risk of cancer and different aspects of cancer risk assessments.

	Asymptomatic context cohort	Symptomatic context cohort	Interpretation note
a. Participants were willing for risk of cancer to be **overestimated** in __ [more] or would need risk of cancer to be **overestimated** in __ [fewer] people out of 100 people undergoing risk assessment in order…			
Method of risk assessment			…to have a blood test, non-invasive test or use a wearable device rather than a questionnaire or data access
Questionnaire or data access	Ref	Ref	
Blood test	8 (5 to 11) more	20 (17 to 23) more	
Non-invasive test	7 (5 to 10) more	15 (13 to 17) more	
Wearable device	5 (1 to 9) fewer	6 (2 to 9) more	
Type of risk assessment			…to have a genetic test rather than a non-genetic test
Non-genetic	Ref	Ref	
Genetic	0 (-3 to 4) fewer	3 (-0 to 6) more	
Location of risk assessment			…to have a risk assessment outside the home rather than at home, as specified
Home	Ref	Ref	
Community clinic/pharmacy	1 (-2 to 3) fewer	2 (-0 to 5) more	
General practice	2 (-0 to 5) fewer	0 (-2 to 3) fewer	
Hospital	5 (3 to 8) fewer	1 (-2 to 3) fewer	
Frequency of risk assessment			…to have a risk assessment more than once, as specified
One-off single event	Ref	Ref	
Once every 5 years	0 (-3 to 3) more	0 (-3 to 3) more	
Once every year	1 (-3 to 4) fewer	0 (-3 to 3) fewer	
Continuously for 2 weeks	5 (-1 to 11) more	1 (-5 to 6) fewer	
Constantly	1 (-3 to 5) fewer	2 (-1 to 6) more	
Accuracy	1.4 (1.3 to 1.6) fewer	1.7 (1.6 to 1.8) fewer	…for an additional person's risk to be underestimated out of 100
b. Participants were willing for risk of cancer to be **underestimated** in __ [more] or would need risk of cancer to be **underestimated** in __ [fewer] people out of 100 people undergoing risk assessment in order…			
Method of risk assessment			…to have a blood test, non-invasive test or use a wearable device rather than a questionnaire or data access
Questionnaire or data access	Ref	Ref	
Blood test	5 (8 to 3) more	12 (10 to 13) more	
Non-invasive test	5 (7 to 3) more	9 (7 to 10) more	
Wearable device	3 (0 to 6) fewer	3 (1 to 5) more	
Type of risk assessment			…to have a

Non-genetic Genetic	Ref 0 (-2 to 3) fewer	Ref 2 (-0 to 4) more	genetic test rather than a non-genetic test
Location of risk assessment			…to have a risk assessment outside the home rather than at home, as specified
Home Community clinic/pharmacy General practice Hospital	Ref 1 (-1 to 2) fewer 2 (-0 to 4) fewer 4 (2 to 6) fewer	Ref 1 (-0 to 3) more 0 (-1 to 2) fewer 0 (-1 to 2) fewer	
Frequency of risk assessment			…to have a risk assessment more than once, as specified
One-off single event Once every 5 years Once every year Continuously for 2 weeks Constantly	Ref 0 (-2 to 2) more 1 (-1 to 3) fewer 4 (0 to 8) more 1 (-2 to 3) fewer	Ref 0 (-2 to 2) more 0 (-2 to 2) fewer 0 (-3 to 3) fewer 1 (-1 to 3) more	
Accuracy	0.7 (0.6 to 0.8) fewer	0.6 (0.5 to 0.7) fewer	…for an additional person's risk to be overestimated out of 100

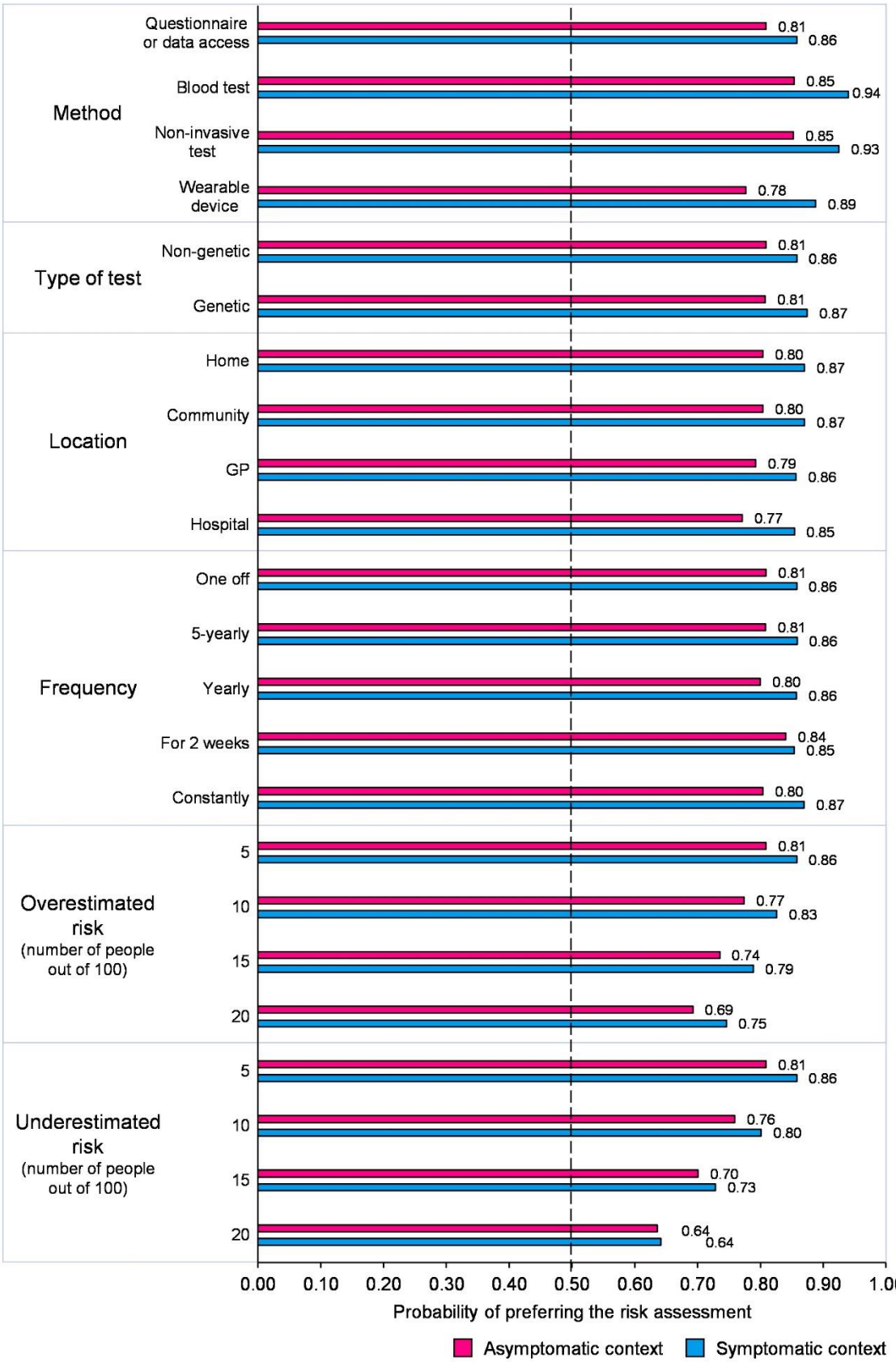
Positive values were described as 'fewer'; negative values were described as 'more'.
Reported as number of people out of 100 (95% confidence interval).

Impact of different aspects of risk assessments on preferences

The impact of each level on the likelihood of preferring a risk assessment is show in Figure 7.5. With the accuracy of no risk assessment arbitrarily set at 12.5 people out of 100 with risk over- or underestimated, risk assessments were always preferred compared to no risk assessments, regardless of the levels used in the models.

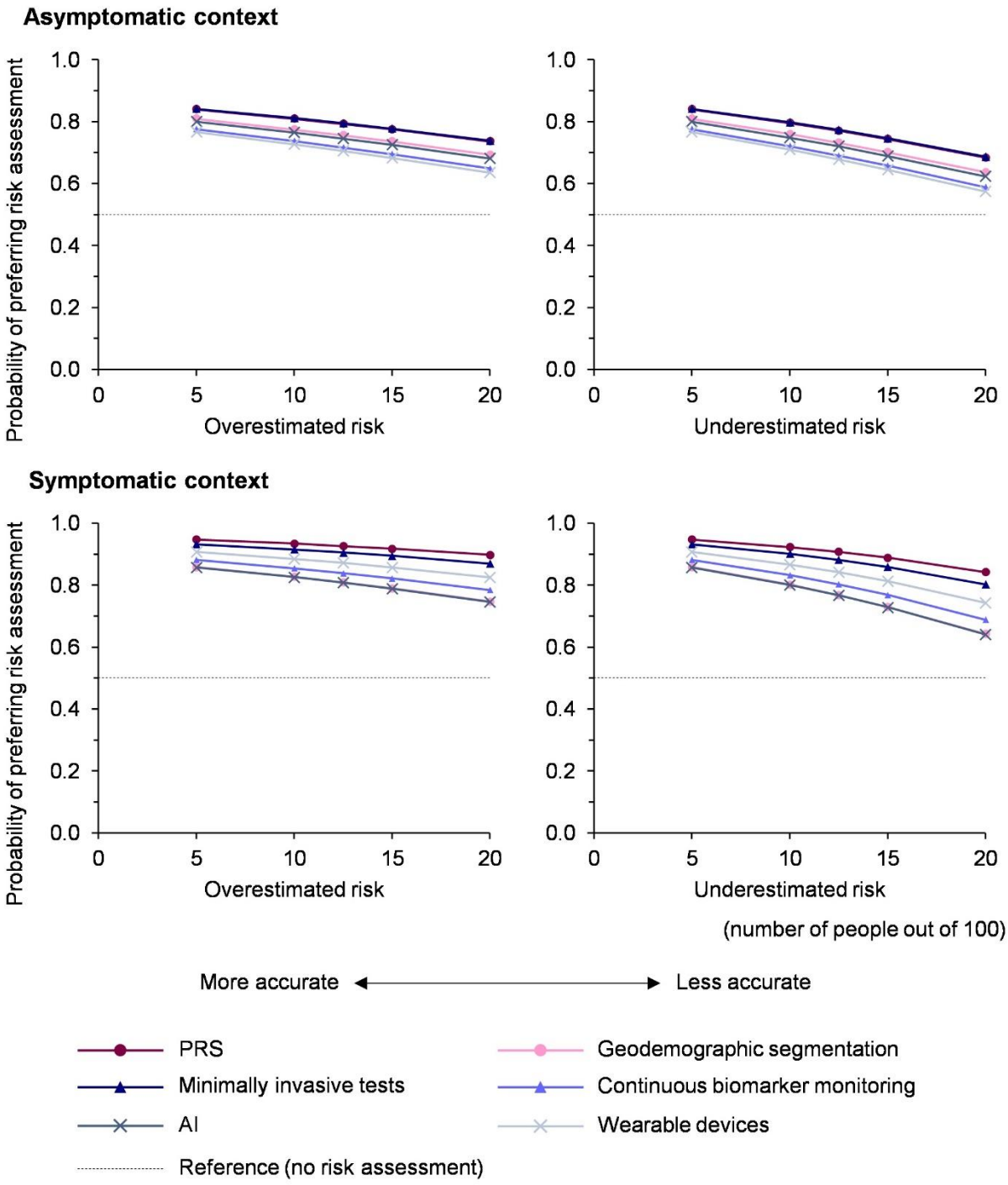
Figure 7.6 illustrates the relative preference for the different examples of risk-based innovations (according to the levels described). All six examples of risk-based innovations were likely to be preferred compared to the option for no risk assessment with the levels of accuracy modelled (i.e., 20 people or fewer with their risk of cancer over- or underestimated out of every 100 people undergoing a risk assessment). Assuming each innovation has the same accuracy, these findings suggest that PRS and minimally invasive tests are equally favoured for screening. They were followed by geodemographic segmentation and AI, then continuous biomarker monitoring and wearable devices. For referral, continuous biomarker monitoring and wearable devices were considered better, with the order of preference: PRS, minimally invasive tests, wearable devices, continuous biomarker monitoring, and then geodemographic segmentation and AI.

Figure 7.5. Effects of changing each aspect of risk assessments on the average predicted probability of preference compared to no risk assessment.



Accuracy of no risk assessment was fixed at 12.5 and set as the reference (0.5 preference).

Figure 7.6. Probability of preferring different risk assessments at differing levels of accuracy.



Accuracy of no risk assessment was fixed at 12.5 people out of 100, and accuracy of over-/underestimated risk was fixed at 5 people out of 100 unless otherwise stated.
Levels for each example of risk-based innovation reported in Table 7.3.

Perceived acceptability of and priorities for cancer risk assessments

After completing the DCE, all participants were asked their views on the acceptability of using cancer risk assessments in screening and symptomatic cohorts, regardless of whether they had completed the DCE in the context of screening or the context of symptoms. As shown in Table 7.6, the findings reflected the analysis from the main DCE. The majority of participants (59%, 706 participants) felt that cancer risk assessments in both contexts were acceptable. Of the remaining participants, more than twice as many felt that it was more acceptable in referral than screening (26%, 317 participants versus 11%, 135 participants). There were no differences between the views of those who had answered the DCE about screening and whose who had answered it about referral to investigate symptoms (p = 0.387).

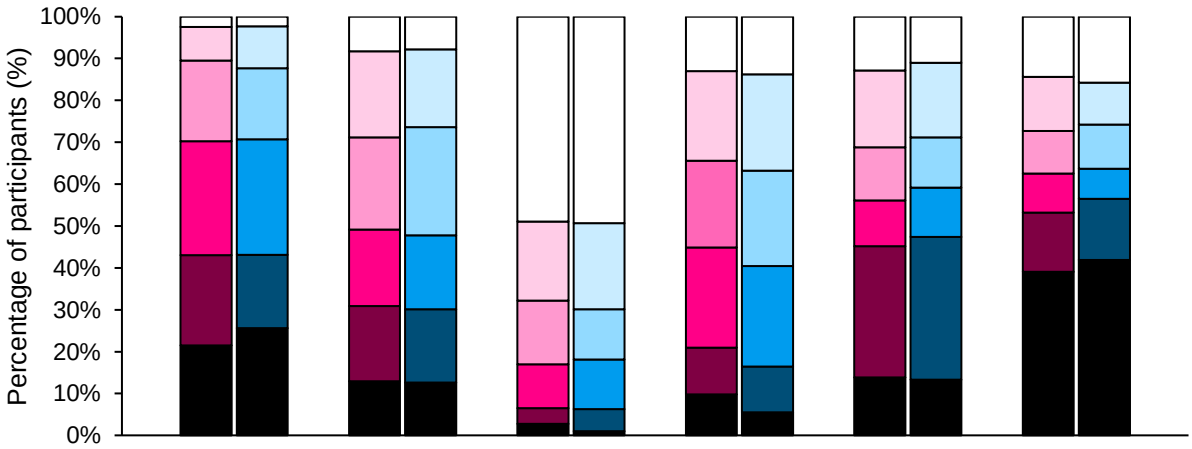
Table 7.6. DCE participants' views on the relative acceptability of using cancer risk assessments in screening and referral contexts.

	Asymptomatic context cohort	Symptomatic context cohort	Total (%)
Total N	599	601	1,200 (100)
It is *more* acceptable to use a cancer risk assessment to decide *how much screening someone is offered*	67	68	135 (11.1)
It is *more* acceptable to use a cancer risk assessment to decide *how urgently and thoroughly someone's symptoms are investigated*	146	171	317 (26.4)
Both are *equally* acceptable	366	340	706 (58.8)
Neither are acceptable	20	22	42 (3.5)

P value for difference = 0.387 (χ^2).

Finally, Figure 7.7 shows the order in which participants ranked the attributes of risk assessments. This largely follows the relative importance of the attributes revealed in the DCE (Figure 7.4): number people in whom risk of cancer is underestimated, number people in whom risk of cancer is overestimated, method of risk assessment, type of risk assessment, frequency of risk assessment, then location of risk assessment. Note that unlike the data presented in Figure 7.4, these rankings do not account for the levels of the attributes.

Figure 7.7. DCE participants' ranking of the attributes of risk assessments.



Rank	Method	Type	Location	Frequency	Over-estimated risk*	Under-estimated risk*
Asymptomatic context cohort (n = 599)						
1 (top)	21.5	12.9	2.8	9.8	13.9	39.1
2	21.5	18.0	3.7	11.2	31.4	14.2
3	27.2	18.2	10.5	23.9	10.9	9.3
4	19.2	22.0	15.2	20.7	12.7	10.2
5	8.0	20.5	18.9	21.4	18.4	12.9
6	2.5	8.3	48.9	13.0	12.9	14.4
Symptomatic context cohort (n = 601)						
1 (top)	25.6	12.6	1.0	5.5	13.3	41.9
2	17.5	17.5	5.3	11.0	34.1	14.6
3	27.6	17.6	11.8	24.0	11.8	7.2
4	17.0	25.8	12.0	22.8	12.0	10.5
5	10.0	18.6	20.6	23.0	17.8	10.0
6	2.3	7.8	49.3	13.8	11.0	15.8

* Accuracy of risk assessment is the number of people with over-/underestimated risk out of 100.
% of participants reported in the table.
N = 1,200 participants.
34 (2.8%) participants did not change the order of attributes from that presented in the question.

Discussion

Overall public receptiveness to risk-based innovations

From both a societal and an individual perspective, the members of the UK public across these four studies were receptive to the concept of using novel innovations to estimate risk of cancer and inform cancer screening and/or referral to investigate symptoms. At a societal level, we found that incorporating a risk assessment was regarded as a logical strategy that made sense across a range of outcomes and was acceptable. Likewise, 70% to 90% of the population reported they were likely to take up a risk assessment (excluding geodemographic segmentation) in the survey and a maximum of 20% selected opt-out responses in the DCE. Together, these findings suggest that engagement with risk assessments is likely to be high if they were offered to the public prior to screening or if they presented with symptoms in primary care. This is consistent with previous studies that have shown public willingness to participate in cancer risk assessments (40). As we observed, many participants in those studies anticipate that gaining knowledge of their personal risk of cancer would be empowering (40), would motivate behaviour change (41,42), and would enable those at high risk to access increased monitoring and/or prophylactic intervention (43–46).

Based on the findings of the four studies, we were able to identify the characteristics of risk-based innovations that matter most to the public and develop a series of general requirements for risk-based innovations to be acceptable to the public (Figure 8.1).

In order to be acceptable, risk-based innovations and the stratified healthcare that follow a risk assessment should be logical and coherent. This means that cancer risk calculations should be intuitive and explainable; for example, that someone's risk classification has arisen due to the presence of certain genetic variations, biomarkers, environmental risk factors, etc. Furthermore, it should make sense to members of the public how this has contributed to their personalised screening policy or referral decision. It is additionally vital that the risk assessment accurately classifies risk, particularly that it does not substantially underestimate risk. While they are willing to put effort into taking part in risk assessment, the burden of completing the test should be minimised through interventions to facilitate participation, such as testing facilities at community locations. Help to complete the test should be available so that no one loses out due to lack of confidence or ability. The burden should also be proportional to the potential gains, meaning that physically or personally invasive tests or those requiring a hospital visit should only be offered to symptomatic individuals. In order to be considered fair and ethical, risk-based innovations should be voluntary, have a neutral or positive impact on inequalities within society, and not take resources that would be better used elsewhere. Data associated with cancer risk assessments should be secure and remain within the context for which it was collected. Personal freedom (e.g. over lifestyle choices) and interactions with healthcare professionals should be maintained.

Figure 8.1. Requirements for acceptable risk-based innovations to the public, according to the TFA.

The influence of the asymptomatic or symptomatic context

Across the studies, our findings suggest that there are small differences in the receptiveness of the public to risk-based innovations in the context of screening asymptomatic people compared with aiding clinical decisions to investigate symptoms.

The most convincing context-specific differences were seen in the DCE, where participants asked to consider the symptomatic context opted for a risk assessment over no risk assessment more frequently than those considering the asymptomatic context (88% versus 80%, $p < 0.001$ for difference between asymptomatic and symptomatic contexts – Figure 7.3). A stronger receptiveness within the symptomatic context was also observed in the community juries where, although the participants were generally positive about implementing risk-based innovations regardless of context, participants were keener to have a risk assessment if they had symptoms. This may have been because they considered the risk assessment as a form of investigation, with the need for investigations more prominent in those with symptoms and previous studies demonstrating an enthusiasm for testing at even very low risks of cancer in patients with symptoms (18,47). Conversely, in the community juries participants were sometimes less positive about the findings of a risk assessment being used to inform a referral decision in individuals with symptoms. In these discussions, the participants noted that the symptoms themselves were an important factor and there were concerns that those with 'red flag' symptoms should not be denied investigations based on other risk factors. These participants were more receptive to implementation of risk stratification if someone had a vague symptom such as a cough than if they had a lump or other 'red flag' symptom. This was also seen in the survey responses, in which slightly more participants would be likely to take

up each innovation if they were symptomatic than asymptomatic ($p \leq 0.001$ for difference between likelihood distribution in asymptomatic and symptomatic scenarios – Figure 6.1). However, participants tended to be more likely to find it acceptable to use the result of the risk assessment to inform risk stratification in asymptomatic screening policies than symptomatic referral policies.

While these differences between asymptomatic and symptomatic contexts are small, together the findings from across the four studies suggest that the introduction of risk-based innovations within the symptomatic context may make more intuitive sense to the public and naturally fit with other investigations in individuals with symptoms more so than in asymptomatic individuals. However, particularly in the context of those with symptoms, how the results of such risk assessment are used to determine subsequent care and how additional risk factors are combined with symptoms will need careful explanation, especially for symptoms that the public already consider to be potentially caused by cancer.

The influence of characteristics of the innovation

Acceptability of the risk-based innovations themselves is likely to be influenced by a number of attributes, particularly the accuracy of the classification of risk and the burden of participation.

As expected (48), it was most important to the public that the innovation was effective in terms of accurately classifying risk of cancer (e.g. whether people were correctly identified as high-, average-, or low-risk). Negative predictive value (NPV) was more important than positive predictive value (PPV), especially in symptomatic populations. On average, participants were willing to accept an additional 1.4 people having their risk overestimated to avoid one person having their risk underestimated for screening. In the symptomatic context, participants would accept 1.7 people having their risk overestimated to avoid one person having their risk underestimated. These findings are similar to our previous research in which cancer-related outcomes or test sensitivity are more important to the public than the nature of the risk assessment (49,50). Similarly, for symptomatic individuals, the public preferred a blood test or non-invasive test to be used over a questionnaire, wearable device, or data analysis as they had more confidence in tests that were intuitively more biological or medical.

Participants also considered the personal burden of taking part in a risk assessment. Whilst they were willing to be inconvenienced by providing data or samples, they felt that burden should be as low as possible and be proportional to the potential gain. For example, they were only willing to complete tests at home or in the community in the asymptomatic context, whereas they would attend a risk assessment at the hospital if they had symptoms. This is likely to be for a number of reasons including the inconvenience of attending a hospital. A second example is that they were more willing to undergo tests that made them feel physically or emotionally uncomfortable if they were symptomatic because the intrusiveness was worthwhile in that case.

Additionally, a range of other key elements were important for the use of the innovation to be acceptable. There needed to be a clear procedure for people to opt-out if they do not want to take part in the risk assessment in order for the policy to maintain the principle of personal choice, which is regarded highly by the public (21,22). Additionally, an ethical policy needed to ensure that data were held securely, the resources for undertaking risk assessments are available and not diverted from more worthy causes, and inequalities do not increase as a result of risk stratification. They also felt that it was important to be able to understand how the risk was calculated so they could understand why they had been given a particular risk classification, which primarily affected receptiveness to AI using medical records. A recent review has suggested reduced patient autonomy in decision making and greater psychological harm caused by misdiagnoses as consequences of inability to understand the AI algorithm (51). Lastly, if risk-based innovations were to be implemented, the public wanted personal liberty or freedom and the relationship with healthcare professionals to be maintained, and

assurance that insurance premiums would not be impacted. This is important as research has shown that concern about insurance discrimination is associated with both deciding not to take up risk assessments and not seeking insurance (52,53).

Overall, this suggests that the public are more receptive to minimally invasive tests, PRS and, with the exception of the asymptomatic context in the DCE, continuous monitoring of biomarkers. Our findings suggest this is likely to be driven by the perception of these as medical or biological tests that are therefore perceived to give a more accurate risk classification. Conversely, geodemographic segmentation and AI were consistently not preferred, despite the low burden of providing these data. These were perceived to give an less accurate risk classification as participants considered numerous ways in which the data might be inaccurate, from there being a too wide a variation in cancer risk factors across geodemographic regions to medical records being outdated. Some of the concerns around geodemographic segmentation may additionally be attributable to misunderstanding that personal financial data would contribute to the risk assessment instead of socioeconomic status of the area.

The influence of characteristics of the target population

In the survey and DCE, we were able to assess the association between individual participant characteristics and several measures of receptiveness to each example of a risk-based innovation.

Likelihood of taking up any of the innovations was lower amongst people from lower socioeconomic backgrounds, those who use less technology within their daily routine, and participants from ethnic minority backgrounds in the context of screening. This is consistent with screening itself, in which people from lower socioeconomic status and ethnic minority backgrounds are known to be less likely to take up screening (54–56). Similar patterns have been found for returning a faecal immunochemical test kit in symptomatic patients (57), help-seeking for possible cancer symptoms (58), and in a study assessing uptake of breast cancer risk assessments based on phenotypic and genetic risk and mammographic density (59). Not discouraging this group further is, therefore, particularly important. We also observed that ethnic minority, non-English speaking women were not willing to comment on the likelihood of them taking up an innovation independently from their husbands which will need to be considered.

There were also some differences between the examples; most notably, PRS and minimally invasive tests were more acceptable to older individuals for screening and people who were less worried about cancer were less willing to wear a device to assess cancer risk if they were asymptomatic. Additionally, people who thought they were likely to have or develop cancer were much more likely to take up a minimally invasive test. Overall, acceptability was also lower amongst women (particularly for innovations based on questionnaires or data access), those using less technology (for wearable devices or biomarker sensors) and people from low socioeconomic backgrounds (particularly in the context of screening). Additionally, people over the age of 40 found continuous monitoring of biomarkers more acceptable than younger people did.

Overall, we found that people were comfortable with the NHS holding their data and using it to assess the risk of other healthcare issues. People who were less comfortable were female (particularly for innovations based on questionnaires or data access), from ethnic minority groups, or had a higher level of education (particularly for continuous monitoring). People over 60 years, or those who used more technology were more likely to be comfortable with use of their data in this way.

These differences according to individual characteristics are important to consider for implementation of risk-based innovations, particularly to ensure that those groups already less likely to engage in screening and present with symptoms are not discouraged further through the prospect of a risk assessment.

Strengths and limitations

The use of a range of qualitative and quantitative methods within this research has enabled us to generate a comprehensive and coherent assessment of the receptiveness of the UK public to the concept of using of risk-based innovations in cancer healthcare. The qualitative methods facilitated an in-depth exploration of a small number of people's views (45 participants). In the community juries, informed members of the public considered the principles that they thought were best for society as a whole, while we gained insight into how people might personally feel if they were offered specific risk assessments in the think aloud interviews. Between the population survey and DCE, we assessed the individual perspectives and influences on these perspectives amongst 2,199 individuals representative of the UK population with respect to age, sex, ethnicity and sociodemographic status. The think aloud interviews helped us to understand the quantitative data collected in the survey. Unlike in the survey, we did not specifically name the examples of risk-based innovations in the DCE (but instead classified them using a range of attributes) and were able to calculate preferences for different types of risk assessment and trade-offs people were willing to make. Furthermore, our analyses were informed by the TFA, meaning we considered recognised domains of acceptability.

Throughout the research, we used a set of six examples of risk-based innovations. This made the complex concepts easier for participants to understand and helped them to engage in the studies despite the theoretical nature of the questions we were asking. Choice of examples was informed by expert consensus to ensure that the findings were relevant and up to date within this quickly advancing field. Although we primarily analysed the findings to identify universal principles of acceptability rather than focusing on the chosen examples themselves and were able to impute the acceptability for other examples using the coefficients generated in the DCE, our examples to do cover all potential innovations.

All of our examples were also presented as hypothetical and we did not have specific data on the examples (such as accuracy or cost of the risk assessment), which some participants wanted to know in order to answer the questions. Due to the wide scope of this project and in order to not to overwhelm the participants, we could only give a short description of innovations. If details akin to what they would receive in practice were provided, the results would be more in-depth and specific. As a result, differences between innovations should be incorporated with caution and the general principles for acceptable innovations arising from this work should be the focus. Furthermore, we observed an order effect in the survey meaning that the participants had been influenced by the other innovations that they had seen. Providing more details on the innovation and/or only asking each participant to consider one innovation could mitigate this.

We recruited participants with a wide range of demographic characteristics from across the UK, including three participants in the think aloud interviews that did not have sufficient competency or confidence in the English language to complete the interviews in English. This means that the findings are more likely to be applicable across the population. However, the participants may not be representative of the UK population according to characteristics that we were not able to measure or recruit according to such as lived experience, and all were registered with survey or qualitative recruitment agencies. Importantly, people who showed an interest in research on this topic when approached to take part may also have different perspectives from people who were not interested.

Conclusion

Our findings show that members of the UK public are receptive, both from a societal and an individual perspective, to the concept of using novel innovations to estimate risk of cancer and inform cancer screening and/or referral to investigate symptoms. Overall receptiveness is influenced by the accuracy and burden associated with the risk assessment. Coherence, perceived fairness and transparency around the risk assessment and subsequent risk-based management also impact receptiveness. In addition, there is a desire for personal freedom and interactions with healthcare professionals to be maintained, and a need for data to be held securely within the context for which it was collected. These general requirements should be considered by all those developing or considering implementing risk-based innovations in the context of cancer EDD.

We additionally identified a range of influences on receptiveness to innovations that will be important to consider. These include whether the innovation would be used to inform asymptomatic screening or referral to investigate symptoms, the characteristics of the innovation, and the characteristics of the recipients. In particular, we found lower receptiveness amongst people from low socioeconomic and ethnic minority backgrounds, women, and those who use less technology. Specific strategies to communicate, promote, and adapt future innovations to these groups may therefore be required. The differences in receptiveness observed between the examples of potential innovations used in these studies further highlights the importance of engaging the public early in the development of individual innovations in the future.

Appendices

List of appendices

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DCE

- Appendix Table 7.1. DCE participants' demographics.
- Appendix Table 7.2. DCE participants' thoughts and beliefs about cancer and screening (collected at the end of the survey).
- Appendix Table 7.3 a to c. DCE participants' preferences for different aspects of risk assessments in screening and referral context cohorts (sensitivity analyses).
- Appendix Table 7.4 a to g. DCE participants' preferences for different aspects of risk assessments in screening and referral context cohorts (subgroup analyses).

Appendix Table 4.1. Community jury participants' demographics.

	Jury 1 (Online)	Jury 2 (In-person)	Jury 3 (Online)	Total (%)
Total *N*	8	9	7	24 (100.0)
Age (years)				
21-29	2	2	0	4 (16.7)
30-39	2	1	1	4 (16.7)
40-49	1	3	1	5 (20.8)
50-59	1	1	2	4 (16.7)
60-69	0	1	2	3 (12.5)
70-79	2	1	1	4 (16.7)
Sex*				
Female	4	4	2	10 (41.7)
Male	4	5	5	14 (58.3)
Ethnicity				
Asian/Asian British	1	1	0	2 (8.3)
Black/African/Caribbean/Black British	1	0	1	2 (8.3)
Mixed/Multiple ethnic group	1	0	1	2 (8.3)
White	5	8	5	18 (75.0)
Social grade				
Middle class (ABC1)	3	5	4	12 (50.0)
Working class (C2DE)	5	4	3	12 (50.0)
Education level				
Not completed A levels, further education or equivalent	3	3	1	7 (29.2)
Competed A levels, further education or equivalent	3	5	2	9 (37.5)
Completed a bachelor's or postgraduate degree	2	2	4	8 (33.3)
Self-perceived health status				
Fair	2	2	3	7 (29.2)
Good	2	4	1	7 (29.2)
Very good	3	2	2	7 (29.2)
Excellent	1	1	1	3 (12.5)
Family history of cancer				
Yes	3	4	3	10 (41.7)
No	5	4	4	13 (54.2)
Don't know/prefer not to say	0	1	0	1 (4.2)

Close friends' history of cancer				
Yes	1	4	6	11 (45.8)
No	7	5	1	13 (54.2)
Attended screening for (yes):				
Abdominal aortic aneurysm	1	2	1	4 (16.7)
Bowel cancer	2	2	3	7 (29.2)
Breast cancer	1	0	1	2 (8.3)
Cervical cancer	4	3	2	9 (37.5)

* For all participants, gender identity corresponded to sex as registered at birth.

Appendix Table 4.2. Community jury participants' thoughts and beliefs about cancer and screening (collected prior to taking part in the study).

	Jury 1 (Online)	Jury 2 (In-person)	Jury 3 (Online)	Total (%)
Total *N*	8	9	7	24 (100.0)
"If I feel well, it is not necessary to have cancer screening"				
Strongly agree	1	0	0	1 (4.2)
Agree	0	0	1	1 (4.2)
Neither disagree nor agree	1	1	0	2 (8.3)
Disagree	1	4	4	9 (37.5)
Strongly disagree	5	4	2	11 (45.8)
"If I follow a healthy lifestyle such as a balanced diet and regular exercise, I don't feel it is necessary to have regular screening"				
Strongly agree	1	0	0	1 (4.2)
Agree	1	0	1	2 (8.3)
Neither disagree nor agree	0	1	0	1 (4.2)
Disagree	1	5	5	11 (45.8)
Strongly disagree	5	3	1	9 (37.5)
"I see a doctor or have cancer screening only when I have a health problem"				
Strongly agree	1	1	0	2 (8.3)
Agree	2	2	3	7 (29.2)
Neither disagree nor agree	1	4	2	7 (29.2)
Disagree	2	2	2	6 (25.0)
Strongly disagree	2	0	0	2 (8.3)
"These days, many people with cancer can expect to continue with normal activities and responsibilities"				
Strongly agree	0	0	1	1 (4.2)
Agree	5	5	3	13 (54.2)
Neither agree nor disagree	2	3	1	6 (25.0)
Disagree	1	1	2	4 (16.7)
Strongly disagree	0	0	0	0 (0.0)
"Most cancer treatment is worse than the cancer itself"				
Strongly agree	0	1	0	1 (4.3)
Agree	2	5	4	11(45.8)
Neither agree nor disagree	4	2	1	7 (29.2)
Disagree	2	1	2	5 (20.8)
Strongly disagree	0	0	0	0 (0.0)
"I would not want to know if I had cancer"				
Strongly agree	0	0	0	0 (0.0)
Agree	1	0	0	1 (4.2)
Neither agree nor disagree	1	1	0	2 (8.3)

Disagree	2	4	3	9 (37.5)
Strongly disagree	4	4	4	12 (50.0)
“Cancer can often be cured”				
Strongly agree	2	0	0	2 (8.3)
Agree	3	7	4	14 (58.3)
Neither agree nor disagree	1	1	0	2 (8.3)
Disagree	1	1	3	5 (20.8)
Strongly disagree	1	0	0	1 (4.2)
“Going to the doctor as quickly as possible after noticing a symptom of cancer could increase the chances of surviving”				
Strongly agree	7	4	4	15 (62.5)
Agree	1	4	3	8 (33.3)
Neither agree nor disagree	0	1	0	1 (4.2)
Disagree	0	0	0	0 (0.0)
Strongly disagree	0	0	0	0 (0.0)
“Some people think that a diagnosis of cancer is a death sentence”				
Strongly agree	1	1	0	2 (8.3)
Agree	2	1	2	5 (20.8)
Neither agree nor disagree	2	5	0	7 (29.2)
Disagree	2	2	3	7 (29.2)
Strongly disagree	1	0	2	3 (12.5)
Compared with other people the same age and sex as you, what do you think your chances of getting cancer in the next 10 years are?				
Much below average	0	0	1	1 (4.2)
Below average	1	0	1	2 (8.3)
Same as average	3	9	2	14 (58.3)
Above average	3	0	3	6 (25.0)
Much above average	1	0	0	1 (4.2)

Appendix Table 4.3. Community jury participants' attitudes towards online privacy (collected prior to taking part in the study).

	Jury 1 (Online)	Jury 2 (In-person)	Jury 3 (Online)	Total (%)
Total *N*	8	9	7	24 (100.0)
"In general, how concerned are you about your privacy while you are using the internet?"				
Extremely	0	1	0	1 (4.2)
Very	2	1	0	3 (12.5)
Moderately	3	4	4	11 (45.8)
Slightly	2	2	1	5 (20.8)
Not at all	1	1	2	4 (16.7)
"Are you concerned that you are asked for too much personal information when you register or make purchases online?"				
Extremely	1	1	0	2 (8.3)
Very	1	1	2	4 (16.7)
Moderately	3	5	1	9 (37.5)
Slightly	2	1	3	6 (25)
Not at all	1	1	1	3 (12.5)
"Do you watch for ways to control what people send you online (such as check boxes that allow you to opt-in or opt-out of certain offers)?"				
Rarely	1	1	1	3 (12.5)
Sometimes	2	4	2	8 (33.3)
Often	3	4	3	10 (41.7)
Always	2	0	1	3 (12.5)
"Are you concerned who might access your medical records electronically?"				
Extremely	1	2	0	3 (12.5)
Very	0	0	2	2 (8.3)
Moderately	1	1	2	4 (16.7)
Slightly	3	5	1	9 (37.5)
Not at all	3	1	2	6 (25)

Appendix Table 5.1. Think aloud participants' characteristics.

	Total (%)
Total *N*	21 (100)
Age (years)	
21-39	6 (28.6)
40-49	7 (33.3)
≥50	8 (38.1)
Sex	
Female	11 (52.4)
Male	10 (47.6)
Ethnicity (simplified)	
Asian	4 (19.0)
Black	3 (14.3)
Mixed	2 (9.5)
White	9 (42.6)
Other	3 (14.3)
Socioeconomic status (self-reported)	
1-3 (lowest deciles)	1 (4.8)
4-5	9 (42.9)
6-7	8 (38.1)
8-10 (highest deciles)	3 (14.3)
Education level	
Not completed A levels, further education or equivalent	4 (19.0)
Competed A levels, further education or equivalent	7 (33.3)
Completed a bachelor's degree	7 (33.3)
Completed a postgraduate degree	3 (14.3)
Employment status	
Employed full time	11 (52.4)
Employed part time	4 (19.0)
Self-employed	1 (4.8)
Not currently working (unemployed, carer, homemaker or retired)	5 (23.8)
Self-reported health status	
Excellent	2 (9.52)
Very good	9 (42.9)
Good	4 (19.0)
Fair or poor	5 (23.8)
Prefer not to say	1 (4.8)
Tobacco smoking status	
Never smoked	13 (61.9)
Used to smoke	6 (28.6)
Currently smoke	2 (9.5)
Self-reported weight	
About right or underweight	12 (57.1)

Overweight	9 (42.9)
Personal history of cancer	
Yes	2 (9.5)
No	18 (85.7)
Prefer not to say	1 (4.8)
Screening history*	
Abdominal aortic aneurysm (ultrasound, men aged ≥65)	4 (21.1)
Bowel (stool sample, all aged 50 (or 60 depending on region) to 74)	5 (26.3)
Breast (mammogram, women aged 50-71)	4 (21.1)
Cervical (smear test, women aged 25-64)	9 (47.4)

* All participants had attended screening to which they had been invited.

Appendix Table 5.2. Think aloud participants' thoughts and beliefs about cancer and screening (collected at the end of the interview).

	Total (%)
Total *N*	18 (100)*
"These days, many people with cancer can expect to continue with normal activities and responsibilities"	
Strongly agree	3 (16.7)
Agree	9 (50.0)
Neither agree nor disagree	3 (16.7)
Disagree	2 (11.1)
Strongly disagree	1 (5.6)
"Most cancer treatment is worse than the cancer itself"	
Strongly agree	2 (11.1)
Agree	5 (27.8)
Neither agree nor disagree	7 (38.9)
Disagree	3 (16.7)
Strongly disagree	1 (5.6)
"I would not want to know if I had cancer"	
Strongly agree	0 (0.0)
Agree	0 (0.0)
Neither agree nor disagree	1 (5.6)
Disagree	3 (16.7)
Strongly disagree	14 (77.8)
"Cancer can often be cured"	
Strongly agree	5 (27.8)
Agree	9 (50.0)
Neither agree nor disagree	2 (11.1)
Disagree	2 (11.1)
Strongly disagree	0 (0.0)
"Going to the doctor as quickly as possible after noticing a symptom of cancer could increase the chances of surviving"	
Strongly agree	16 (88.9)
Agree	2 (11.1)
Neither agree nor disagree	0 (0.0)
Disagree	0 (0.0)
Strongly disagree	0 (0.0)
"Some people think that a diagnosis of cancer is a death sentence"	
Strongly agree	4 (22.2)
Agree	1 (5.6)
Neither agree nor disagree	2 (11.1)
Disagree	8 (44.4)
Strongly disagree	3 (16.7)
How likely do you think is it that you will get cancer at some point in the next 10 years?	
Extremely or somewhat likely	4 (22.2)
Neither likely nor unlikely	5 (27.8)
Extremely or somewhat unlikely	9 (50.0)

During the past month…	
…how often have you thought about your own chances of getting cancer?	
Not at all	3 (16.7)
Rarely	4 (22.2)
Sometimes	7 (38.9)
Often or a lot	4 (22.2)
…how often have thoughts about your chances of getting cancer affected your mood?	
Not at all	6 (33.3)
Rarely	7 (38.9)
Sometimes	3 (16.7)
Often or a lot	2 (11.1)
…how often have thoughts about your chances of getting cancer affected your ability to perform your daily activities?	
Not at all	16 (88.9)
Rarely	2 (11.1)
Sometimes	0 (0.0)
Often or a lot	0 (0.0)

* Three participants did not answer these questions due to time limitations.

Appendix Table 5.3. Think aloud participants' attitudes towards technology and use of data (collected at the end of the interview).

	Total (%)				
Total *N*	18 (100)*				
Frequency of using health or wellness app(s) or wearable device(s)					
Daily	10 (55.6)				
At least once a week, but not daily	5 (27.8)				
Less than once a week	3 (16.7)				
Comfort with continuous monitoring, according to who the data are available to					
	Extremely uncomfortable	Somewhat uncomfortable	Neither	Somewhat comfortable	Extremely comfortable
Heartrate					
You	0 (0.0)	0 (0.0)	0 (0.0)	3 (16.7)	15 (83.3)
NHS	0 (0.0)	0 (0.0)	0 (0.0)	2 (11.1)	16 (88.9)
Temperature					
You	0 (0.0)	0 (0.0)	0 (0.0)	3 (16.7)	15 (83.3)
NHS	0 (0.0)	0 (0.0)	0 (0.0)	3 (16.7)	15 (83.3)
Sleep patterns					
You	0 (0.0)	0 (0.0)	0 (0.0)	4 (22.2)	14 (77.8)
NHS	0 (0.0)	0 (0.0)	0 (0.0)	4 (22.2)	14 (77.8)
Step count					
You	0 (0.0)	0 (0.0)	0 (0.0)	3 (16.7)	15 (83.3)
NHS	0 (0.0)	0 (0.0)	2 (11.1)	1 (5.6)	15 (83.3)
Blood glucose					
You	0 (0.0)	0 (0.0)	0 (0.0)	3 (16.7)	15 (83.3)
NHS	0 (0.0)	0 (0.0)	0 (0.0)	1 (5.6)	17 (94.4)

* Three participants did not answer these questions due to time limitations.

Appendix Table 6.1. Survey participants' demographics.

	Total (%)
Total *N*	999 (100)
Age (years)	
18-29	222 (22.2)
30-39	223 (22.3)
40-49	166 (16.6)
50-59	190 (19.0)
≥60	198 (19.8)
Sex	
Female	512 (51.3)
Male	481 (48.1)
Non-binary or prefer not to say	6 (0.6)
Ethnicity (simplified)	
Asian	80 (8.0)
Black	39 (3.9)
Mixed	25 (2.5)
White	844 (84.5)
Other	11 (1.1)
Socioeconomic status (self-reported)	
1-3 (lowest deciles)	242 (24.2)
4-5	355 (35.5)
6-7	343 (34.3)
8-10 (highest deciles)	59 (5.9)
Education level	
Not completed A levels, further education or equivalent	175 (17.5)
Competed A levels, further education or equivalent	310 (31.0)
Completed a bachelor's degree	361 (36.1)
Completed a postgraduate degree	152 (15.2)
Not reported	1 (0.1)
Employment status	
Employed full time	398 (39.8)
Employed part time	151 (15.1)
Self-employed	110 (11.0)
Studying	47 (4.7)
Not currently working (unemployed, carer, homemaker or retired)	293 (29.3)
Self-reported health status	
Excellent	70 (7.0)
Very good	270 (27.0)
Good	361 (36.1)
Fair	228 (22.8)
Poor	69 (6.9)
Prefer not to say	1 (0.1)
Tobacco smoking status	
Never smoked	601 (60.2)
Used to smoke	302 (30.2)

Currently smoke	96 (9.6)
Self-reported weight	
Underweight	54 (5.4)
About right	509 (51.0)
Overweight	436 (43.6)
Personal history of cancer	
Yes	39 (3.9)
No	955 (95.6)
Prefer not to say	5 (0.5)
Screening history	
Abdominal aortic aneurysm (ultrasound, men aged ≥65)	
Invited	36 (3.6)
Attended	33 (91.7)
Bowel (stool sample, all aged 50 (or 60 depending on region) to 74)	
Invited	263 (26.3)
Attended	225 (85.6)
Breast (mammogram, women aged 50-71)	
Invited	205 (20.5)
Attended	184 (89.8)
Cervical (smear test, women aged 25-64)	
Invited	448 (44.8)
Attended	385 (85.9)

Appendix Table 6.2. Survey participants' thoughts and beliefs about cancer and screening (collected at the end of the survey).

	Total (%)
Total *N*	999 (100)
"These days, many people with cancer can expect to continue with normal activities and responsibilities"	
Strongly agree	77 (7.7)
Agree	544 (54.4)
Neither agree nor disagree	255 (25.5)
Disagree	108 (10.8)
Strongly disagree	15 (1.5)
"Most cancer treatment is worse than the cancer itself"	
Strongly agree	61 (6.1)
Agree	244 (24.4)
Neither agree nor disagree	387 (38.7)
Disagree	242 (24.2)
Strongly disagree	65 (6.5)
"I would not want to know if I had cancer"	
Strongly agree	15 (1.5)
Agree	39 (3.9)
Neither agree nor disagree	119 (11.9)
Disagree	301 (30.1)
Strongly disagree	525 (52.6)
"Cancer can often be cured"	
Strongly agree	121 (12.1)
Agree	498 (49.8)
Neither agree nor disagree	272 (27.2)
Disagree	91 (9.1)
Strongly disagree	17 (1.7)
"Going to the doctor as quickly as possible after noticing a symptom of cancer could increase the chances of surviving"	
Strongly agree	677 (67.8)
Agree	274 (27.4)
Neither agree nor disagree	39 (3.9)
Disagree	9 (0.9)
Strongly disagree	0 (0.0)
"Some people think that a diagnosis of cancer is a death sentence"	
Strongly agree	51 (5.1)
Agree	193 (19.3)
Neither agree nor disagree	325 (32.5)
Disagree	333 (33.3)
Strongly disagree	97 (9.7)
How likely do you think is it that you will get cancer at some point in the next 10 years?	
Extremely or somewhat likely	253 (25.3)
Neither likely nor unlikely	440 (44.0)
Extremely or somewhat unlikely	306 (30.6)

During the past month…	
…how often have you thought about your own chances of getting cancer?	
Not at all	194 (19.4)
Rarely	266 (26.6)
Sometimes	378 (37.8)
Often or a lot	161 (16.1)
…how often have thoughts about your chances of getting cancer affected your mood?	
Not at all	477 (47.7)
Rarely	240 (24.0)
Sometimes	215 (21.5)
Often or a lot	67 (6.7)
…how often have thoughts about your chances of getting cancer affected your ability to perform your daily activities?	
Not at all	753 (75.4)
Rarely	173 (17.3)
Sometimes	56 (5.6)
Often or a lot	17 (1.7)

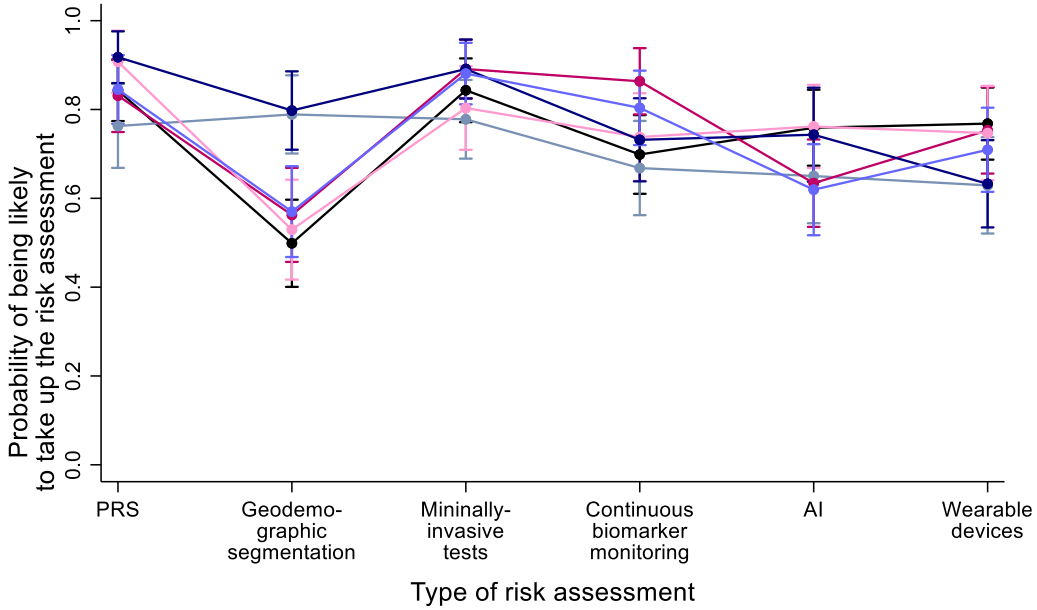
Appendix Table 6.3. Survey participants' attitudes towards technology and use of data (collected at the end of the survey).

	Total (%)				
Total *N*	999 (100)				
Frequency of using health or wellness app(s) or wearable device(s)					
Daily	394 (39.4)				
At least once a week, but not daily	201 (20.1)				
Less than once a week	404 (44.4)				
Comfort with continuous monitoring, according to who the data are available to*					
	Extremely uncomfortable	Somewhat uncomfortable	Neither	Somewhat comfortable	Extremely comfortable
Heartrate					
You	25 (2.5)	32 (3.2)	69 (6.9)	191 (19.1)	682 (68.3)
NHS	52 (5.2)	75 (7.5)	59 (5.9)	295 (29.5)	518 (51.9)
Temperature					
You	23 (2.3)	23 (2.3)	86 (8.6)	186 (18.6)	681 (68.2)
NHS	46 (4.6)	64 (6.4)	84 (8.4)	275 (27.5)	530 (53.1)
Sleep patterns					
You	23 (2.3)	40 (4.0)	87 (8.7)	185 (18.5)	664 (66.5)
NHS	68 (6.8)	119 (11.9)	108 (10.8)	265 (26.5)	439 (43.9)
Step count					
You	27 (2.7)	22 (2.2)	82 (8.2)	172 (17.2)	696 (69.7)
NHS	71 (7.1)	100 (10.0)	112 (11.2)	270 (27.0)	446 (44.6)
Blood glucose					
You	22 (2.2)	28 (2.8)	76 (7.6)	188 (18.8)	685 (68.6)
NHS	48 (4.8)	55 (5.5)	74 (7.4)	260 (26.0)	562 (56.3)

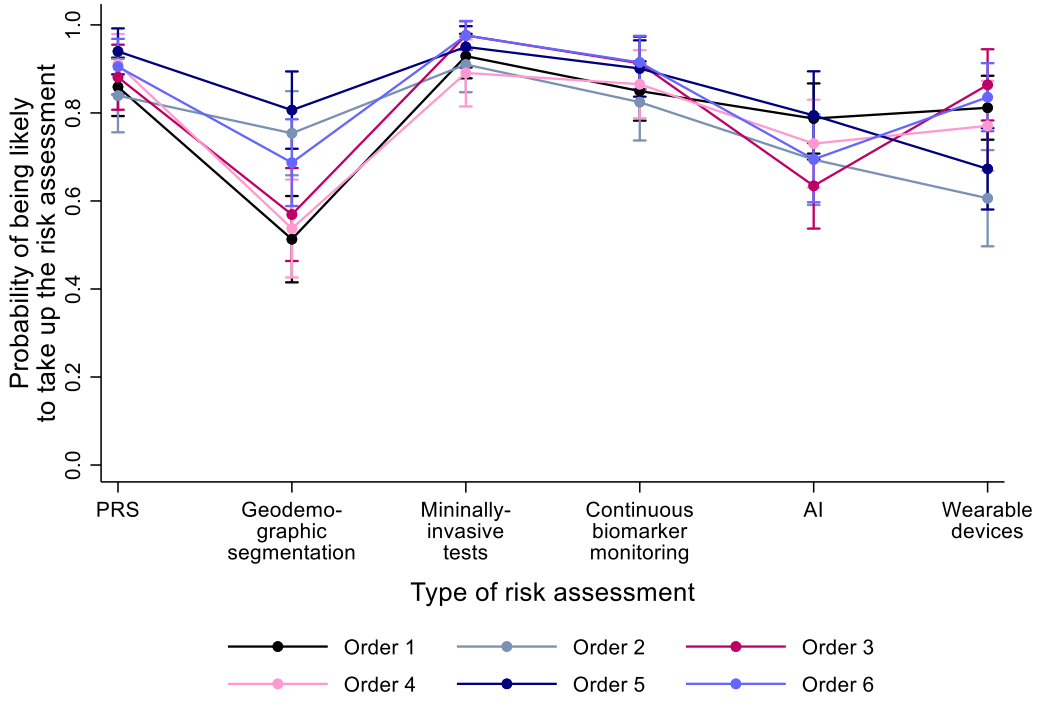
* There was a statistically significant difference in comfort between whether the data are available to you or the NHS for each type of data ($p<0.001$ using sign rank test).

Appendix Figure 6.1. Likelihood that survey participants would take up the offer of different risk assessments in (a) asymptomatic and (b) symptomatic scenarios, according to order of seeing the example.

a. Asymptomatic scenario (N = 999)



b. Symptomatic scenario (N = 999)



Order 1: New technology→Use of personal data→Testing biomarkers
Order 2: Use of personal data→Testing biomarkers→New technology
Order 3: Testing biomarkers→New technology→Use of personal data
Order 4: New technology→Testing biomarkers→Use of personal data
Order 5: Use of personal data→New technology→Testing biomarkers
Order 6: Testing biomarkers→Use of personal data→New technology

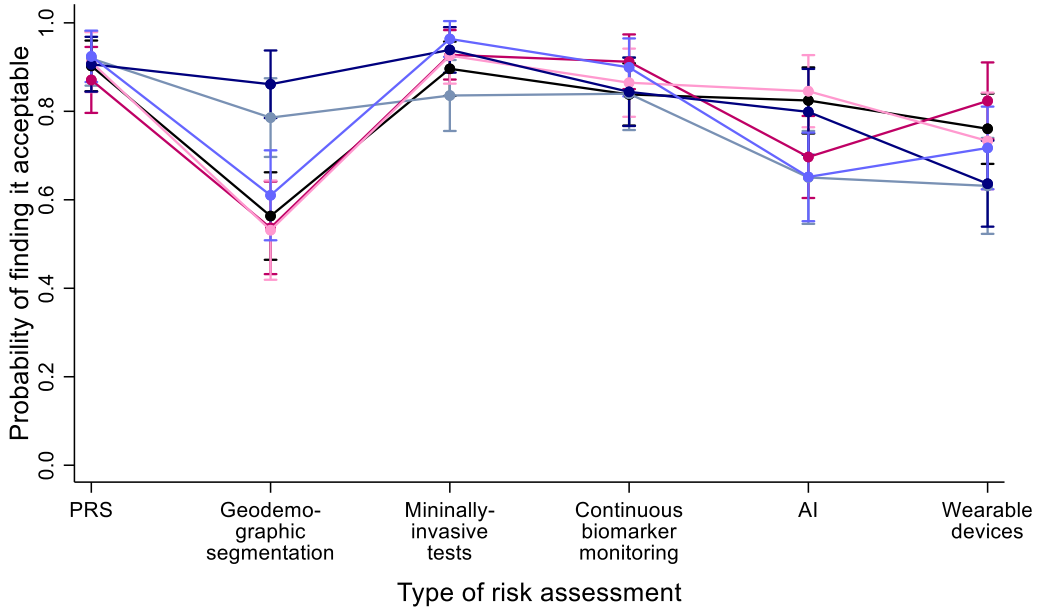
Appendix Table 6.4. Odds that survey participants with different demographics would be likely to take up the offer of a risk assessment in asymptomatic and symptomatic contexts.

	Any type of risk assessment	PRS	Geodemographic segmentation	Minimally invasive tests	Continuous biomarker monitoring	AI	Wearable devices
Asymptomatic							
N observations	2,961	467	498	493	494	491	496
Age							
18-29	Ref	Ref	Ref	Ref	Ref	Ref	Ref
30-39	1.19 (0.86 to 1.64)	1.25 (0.61 to 2.56)	0.99 (0.57 to 1.74)	**2.28 (1.10 to 4.71)**	1.35 (0.73 to 2.49)	1.67 (0.86 to 3.23)	0.66 (0.36 to 1.23)
40-49	1.24 (0.87 to 1.78)	**2.67 (1.17 to 6.10)**	0.90 (0.46 to 1.79)	2.28 (0.99 to 5.25)	2.08 (0.97 to 4.47)	1.17 (0.62 to 2.22)	0.52 (0.26 to 1.03)
50-59	1.20 (0.84 to 1.70)	**3.35 (1.32 to 8.51)**	0.88 (0.48 to 1.61)	**2.41 (1.02 to 5.70)**	1.67 (0.82 to 3.40)	0.74 (0.39 to 1.40)	0.79 (0.39 to 1.58)
60+	1.30 (0.89 to 1.90)	**2.99 (1.21 to 7.41)**	0.94 (0.50 to 1.79)	**2.68 (1.12 to 6.41)**	1.34 (0.67 to 2.66)	1.08 (0.56 to 2.07)	1.06 (0.51 to 2.21)
Sex							
Male	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Female	1.02 (0.82 to 1.27)	1.56 (0.91 to 2.67)	0.84 (0.57 to 1.23)	1.05 (0.63 to 1.75)	**1.88 (1.21 to 2.91)**	**0.60 (0.40 to 0.92)**	1.02 (0.67 to 1.55)
Smoking							
Never	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ever	1.13 (0.90 to 1.43)	0.67 (0.38 to 1.20)	1.20 (0.80 to 1.80)	1.01 (0.58 to 1.77)	1.08 (0.69 to 1.70)	1.40 (0.93 to 2.12)	1.22 (0.77 to 1.93)
Ethnicity							
White ethnicity	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ethnic minority	**0.71 (0.52 to 0.95)**	0.56 (0.28 to 1.10)	**0.56 (0.32 to 0.97)**	**0.50 (0.25 to 0.99)**	0.86 (0.49 to 1.49)	**0.49 (0.27 to 0.88)**	1.64 (0.90 to 3.00)
Education							
No degree	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Degree	0.94 (0.75 to 1.19)	1.28 (0.71 to 2.31)	0.97 (0.65 to 1.47)	1.24 (0.70 to 2.20)	1.03 (0.64 to 1.66)	1.01 (0.66 to 1.54)	**0.60 (0.38 to 0.94)**
SES decile							
	1.13 (1.05 to 1.21)	1.12 (0.95 to 1.33)	**1.15 (1.01 to 1.30)**	1.16 (0.98 to 1.36)	1.08 (0.93 to 1.25)	**1.17 (1.04 to 1.33)**	1.10 (0.96 to 1.26)
Prior cancer							
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes	1.17 (0.66 to 2.08)	NA	1.32 (0.41 to 4.25)	2.09 (0.30 to 14.66)	0.88 (0.26 to 2.92)	1.53 (0.46 to 5.07)	0.76 (0.29 to 1.98)
Tech use							
None	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Health apps	**1.54 (1.22 to 1.93)**	1.08 (0.61 to 1.91)	1.47 (0.98 to 2.21)	1.07 (0.62 to 1.85)	**1.96 (1.21 to 3.15)**	0.94 (0.62 to 1.43)	**3.36 (2.12 to 5.34)**
Perceived risk							
Unlikely	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Neither	1.10 (0.83 to 1.46)	0.85 (0.45 to 1.60)	1.23 (0.73 to 2.08)	0.65 (0.34 to 1.21)	**1.99 (1.14 to 3.46)**	1.11 (0.66 to 1.88)	1.06 (0.63 to 1.81)
Likely	1.25 (0.92 to 1.69)	1.14 (0.57 to 2.28)	1.20 (0.68 to 2.10)	1.96 (0.90 to 4.27)	1.68 (0.93 to 3.05)	1.13 (0.65 to 1.97)	1.24 (0.69 to 2.22)

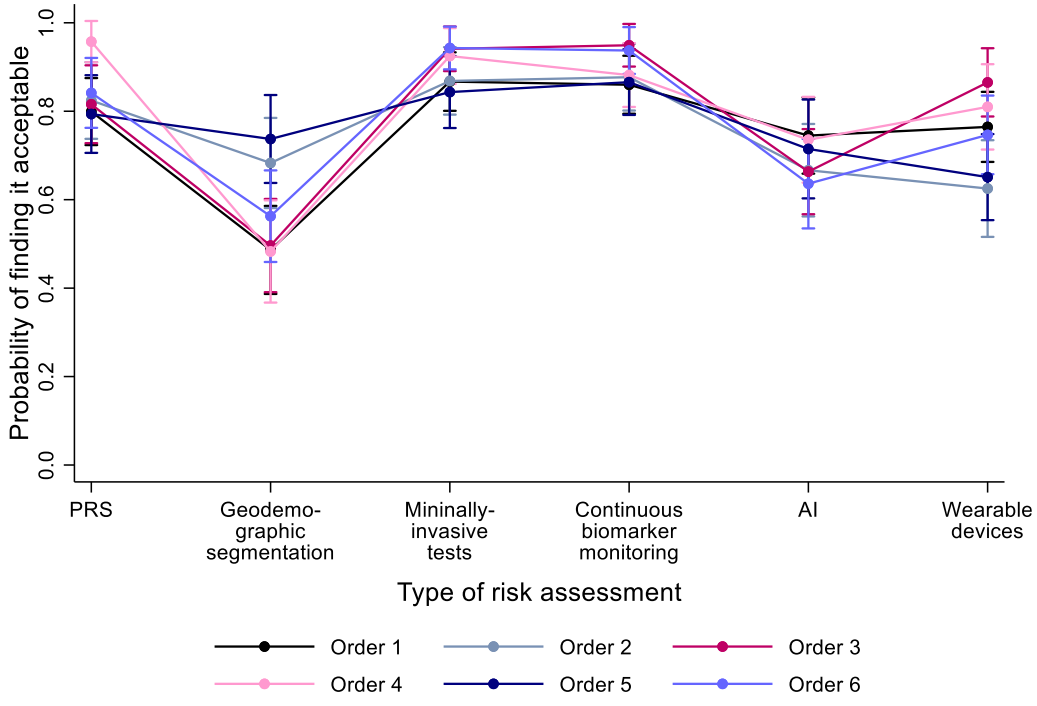
Symptomatic							
N observations	2,961	489	498	473	494	491	496
Age							
18-29	Ref	Ref	Ref	Ref	Ref	Ref	Ref
30-39	0.89 (0.62 to 1.27)	0.60 (0.25 to 1.44)	0.72 (0.41 to 1.28)	3.03 (0.89 to 10.29)	0.73 (0.31 to 1.72)	1.98 (1.00 to 3.94)	0.54 (0.28 to 1.03)
40-49	0.84 (0.57 to 1.25)	1.01 (0.38 to 2.71)	0.52 (0.26 to 1.02)	1.59 (0.49 to 5.20)	0.91 (0.32 to 2.56)	1.54 (0.79 to 2.98)	**0.45 (0.22 to 0.91)**
50-59	0.90 (0.61 to 1.33)	1.23 (0.44 to 3.42)	0.82 (0.43 to 1.57)	2.35 (0.63 to 8.79)	0.84 (0.32 to 2.18)	0.80 (0.42 to 1.51)	0.75 (0.36 to 1.58)
60+	0.88 (0.59 to 1.31)	1.52 (0.56 to 4.10)	0.53 (0.28 to 1.02)	1.21 (0.41 to 3.56)	0.68 (0.27 to 1.70)	1.28 (0.66 to 2.46)	0.83 (0.39 to 1.76)
Sex							
Male	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Female	0.84 (0.66 to 1.06)	**2.57 (1.36 to 4.86)**	0.73 (0.50 to 1.07)	1.36 (0.60 to 3.07)	0.90 (0.50 to 1.62)	**0.56 (0.37 to 0.84)**	0.75 (0.48 to 1.18)
Smoking							
Never	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ever	1.25 (0.96 to 1.61)	0.95 (0.51 to 1.76)	1.25 (0.83 to 1.88)	0.79 (0.36 to 1.74)	1.59 (0.89 to 2.85)	1.33 (0.86 to 2.05)	1.20 (0.73 to 1.97)
Ethnicity							
White ethnicity	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ethnic minority	0.99 (0.71 to 1.37)	1.41 (0.56 to 3.51)	0.75 (0.43 to 1.31)	1.04 (0.36 to 3.00)	0.95 (0.42 to 2.17)	0.92 (0.49 to 1.71)	1.21 (0.67 to 2.17)
Education							
No degree	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Degree	0.96 (0.74 to 1.23)	1.45 (0.76 to 2.77)	0.78 (0.51 to 1.19)	1.65 (0.71 to 3.88)	1.11 (0.60 to 2.04)	0.88 (0.57 to 1.37)	0.92 (0.57 to 1.47)
SES decile							
	1.13 (1.04 to 1.22)	0.97 (0.80 to 1.18)	**1.14 (1.01 to 1.30)**	1.20 (0.96 to 1.49)	**1.26 (1.04 to 1.53)**	1.13 (0.99 to 1.29)	1.09 (0.94 to 1.26)
Prior cancer							
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes	0.94 (0.49 to 1.81)	2.11 (0.25 to 17.67)	0.96 (0.31 to 2.97)	NA	0.43 (0.14 to 1.36)	1.24 (0.39 to 3.96)	0.82 (0.29 to 2.36)
Tech use							
None	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Health apps	1.39 (1.09 to 1.78)	0.70 (0.39 to 1.29)	1.26 (0.84 to 1.88)	1.57 (0.69 to 3.58)	1.51 (0.81 to 2.81)	1.00 (0.65 to 1.55)	**2.93 (1.77 to 4.84)**
Perceived risk							
Unlikely	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Neither	0.93 (0.69 to 1.27)	**0.34 (0.15 to 0.77)**	1.05 (0.62 to 1.78)	1.58 (0.64 to 3.90)	0.95 (0.44 to 2.05)	1.09 (0.64 to 1.86)	1.10 (0.63 to 1.92)
Likely	1.26 (0.91 to 1.76)	0.53 (0.21 to 1.37)	1.27 (0.73 to 2.23)	**4.07 (1.21 to 13.66)**	1.02 (0.43 to 2.42)	1.36 (0.77 to 2.41)	1.89 (0.99 to 3.64)

Appendix Figure 6.2. Acceptability if the risk assessment was used alongside age and sex to inform screening or referral in the (a) asymptomatic or (b) symptomatic scenarios, according to order of seeing the example.

a. Asymptomatic scenario (N = 999)



b. Symptomatic scenario (N = 999)



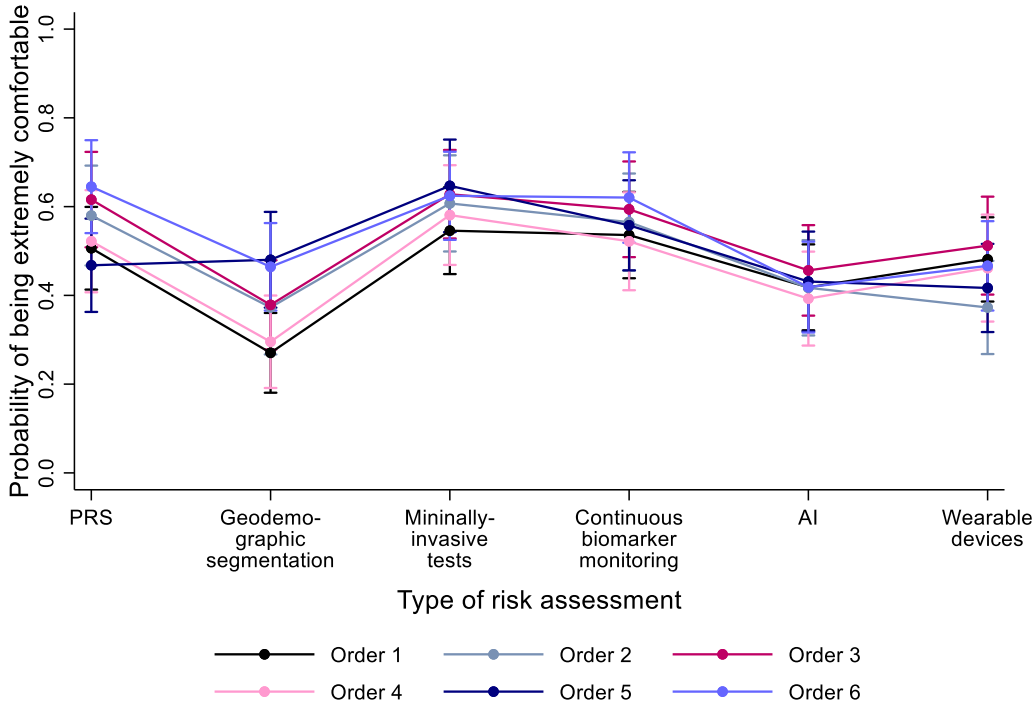
Order 1: New technology→Use of personal data→Testing biomarkers
Order 2: Use of personal data→Testing biomarkers→New technology
Order 3: Testing biomarkers→New technology→Use of personal data
Order 4: New technology→Testing biomarkers→Use of personal data
Order 5: Use of personal data→New technology→Testing biomarkers
Order 6: Testing biomarkers→Use of personal data→New technology

Appendix Table 6.5. Odds that survey participants with different demographics would find it acceptable to use a risk assessment alongside age and sex to inform screening or referral in the asymptomatic or symptomatic scenarios.

	Any type of risk assessment	PRS	Geodemographic segmentation	Minimally invasive tests	Continuous biomarker monitoring	AI	Wearable devices
Asymptomatic							
N observations	2,961	467	498	473	494	491	496
Age							
18-29	Ref	Ref	Ref	Ref	Ref	Ref	Ref
30-39	1.08 (0.76 to 1.53)	1.31 (0.54 to 3.18)	0.84 (0.48 to 1.48)	**3.19 (1.09 to 9.39)**	1.27 (0.60 to 2.69)	1.05 (0.53 to 2.08)	0.82 (0.45 to 1.51)
40-49	1.29 (0.85 to 1.95)	1.81 (0.66 to 5.00)	1.05 (0.52 to 2.09)	1.64 (0.55 to 4.88)	**3.12 (1.19 to 8.19)**	1.30 (0.64 to 2.64)	0.75 (0.38 to 1.47)
50-59	1.15 (0.77 to 1.71)	2.68 (0.85 to 8.48)	0.91 (0.48 to 1.73)	0.94 (0.37 to 2.39)	**2.81 (1.15 to 6.82)**	0.80 (0.40 to 1.58)	0.93 (0.46 to 1.89)
60+	1.25 (0.84 to 1.87)	1.84 (0.68 to 5.00)	0.67 (0.35 to 1.28)	2.46 (0.75 to 8.05)	**2.43 (1.04 to 5.69)**	1.28 (0.64 to 2.57)	1.12 (0.54 to 2.30)
Sex							
Male	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Female	**0.68 (0.54 to 0.87)**	0.77 (0.42 to 1.41)	**0.55 (0.37 to 0.82)**	0.95 (0.49 to 1.83)	1.26 (0.73 to 2.18)	**0.43 (0.27 to 0.67)**	0.77 (0.50 to 1.17)
Smoking							
Never	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ever	1.14 (0.89 to 1.46)	0.86 (0.45 to 1.65)	0.92 (0.61 to 1.39)	1.31 (0.65 to 2.63)	1.10 (0.63 to 1.90)	1.13 (0.72 to 1.77)	1.54 (0.98 to 2.40)
Ethnicity							
White ethnicity	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ethnic minority	0.75 (0.54 to 1.04)	0.87 (0.37 to 2.03)	0.58 (0.33 to 1.02)	0.54 (0.23 to 1.27)	0.63 (0.31 to 1.28)	1.11 (0.57 to 2.14)	0.78 (0.45 to 1.37)
Education							
No degree	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Degree	0.99 (0.77 to 1.29)	1.33 (0.67 to 2.62)	1.16 (0.77 to 1.76)	1.24 (0.59 to 2.60)	0.98 (0.54 to 1.77)	0.87 (0.55 to 1.39)	0.83 (0.53 to 1.29)
SES decile							
	1.10 (1.02 to 1.19)	1.13 (0.90 to 1.41)	1.08 (0.96 to 1.22)	1.09 (0.92 to 1.28)	1.10 (0.90 to 1.33)	1.14 (1.00 to 1.30)	1.09 (0.95 to 1.25)
Prior cancer							
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes	0.93 (0.52 to 1.68)	1.01 (0.51 to 1.98)	1.66 (0.54 to 5.06)	NA	**0.24 (0.08 to 0.71)**	1.01 (0.31 to 3.27)	0.58 (0.23 to 1.49)
Tech use							
None	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Health apps	**1.41 (1.10 to 1.81)**	1.01 (0.51 to 1.98)	1.15 (0.77 to 1.74)	1.11 (0.56 to 2.23)	**2.27 (1.26 to 4.10)**	0.98 (0.63 to 1.52)	**2.33 (1.50 to 3.61)**
Perceived risk							
Unlikely	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Neither	1.10 (0.80 to 1.50)	0.88 (0.39 to 1.99)	1.53 (0.90 to 2.62)	1.03 (0.46 to 2.27)	1.03 (0.50 to 2.09)	1.02 (0.59 to 1.79)	1.05 (0.61 to 1.82)
Likely	1.01 (0.72 to 1.41)	0.89 (0.38 to 2.10)	1.13 (0.64 to 1.97)	1.17 (0.46 to 2.98)	0.76 (0.35 to 1.62)	1.37 (0.74 to 2.51)	0.84 (0.47 to 1.51)

Symptomatic							
N observations	2,961	489	498	493	494	491	496
Age							
18-29	Ref	Ref	Ref	Ref	Ref	Ref	Ref
30-39	0.76 (0.54 to 1.09)	0.83 (0.38 to 1.78)	0.58 (0.34 to 1.01)	1.00 (0.44 to 2.29)	1.15 (0.49 to 2.71)	1.17 (0.61 to 2.22)	**0.49 (0.26 to 0.94)**
40-49	0.83 (0.56 to 1.22)	0.69 (0.32 to 1.50)	0.64 (0.34 to 1.21)	1.47 (0.55 to 3.95)	2.10 (0.72 to 6.10)	1.27 (0.66 to 2.44)	**0.41 (0.20 to 0.84)**
50-59	0.93 (0.64 to 1.35)	1.20 (0.49 to 2.90)	0.68 (0.37 to 1.24)	2.05 (0.76 to 5.53)	1.54 (0.58 to 4.08)	0.79 (0.42 to 1.48)	0.68 (0.33 to 1.40)
60+	0.93 (0.63 to 1.38)	1.36 (0.57 to 3.25)	**0.53 (0.28 to 0.99)**	1.61 (0.58 to 4.44)	1.36 (0.56 to 3.28)	1.15 (0.60 to 2.20)	0.72 (0.34 to 1.52)
Sex							
Male	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Female	**0.65 (0.51 to 0.81)**	0.63 (0.38 to 1.04)	0.70 (0.48 to 1.02)	**0.53 (0.29 to 0.97)**	0.80 (0.44 to 1.43)	**0.49 (0.32 to 0.74)**	0.75 (0.49 to 1.16)
Smoking							
Never	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ever	1.20 (0.94 to 1.53)	1.51 (0.88 to 2.57)	1.01 (0.68 to 1.49)	0.90 (0.48 to 1.69)	1.28 (0.68 to 2.39)	1.19 (0.79 to 1.80)	1.45 (0.91 to 2.30)
Ethnicity							
White ethnicity	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ethnic minority	0.94 (0.68 to 1.31)	1.12 (0.55 to 2.28)	1.10 (0.64 to 1.89)	0.83 (0.37 to 1.89)	0.67 (0.31 to 1.45)	0.82 (0.45 to 1.49)	0.95 (0.53 to 1.70)
Education							
No degree	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Degree	1.02 (0.80 to 1.31)	0.91 (0.52 to 1.60)	1.24 (0.83 to 1.84)	1.17 (0.60 to 2.27)	1.33 (0.70 to 2.51)	1.05 (0.68 to 1.60)	0.82 (0.51 to 1.29)
SES decile							
	1.03 (0.96 to 1.11)	1.02 (0.86 to 1.20)	0.97 (0.86 to 1.09)	0.99 (0.83 to 1.18)	1.06 (0.85 to 1.31)	1.05 (0.93 to 1.18)	1.08 (0.93 to 1.25)
Prior cancer							
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes	0.98 (0.55 to 1.76)	2.12 (0.41 to 10.81)	0.94 (0.32 to 2.76)	2.06 (0.27 to 15.46)	0.32 (0.10 to 1.02)	1.40 (0.44 to 4.42)	0.83 (0.32 to 2.12)
Tech use							
None	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Health apps	**1.34 (1.05 to 1.72)**	0.96 (0.57 to 1.62)	1.20 (0.81 to 1.77)	1.28 (0.67 to 2.44)	**2.12 (1.06 to 4.24)**	0.94 (0.63 to 1.42)	**2.24 (1.41 to 3.54)**
Perceived risk							
Unlikely	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Neither	1.01 (0.74 to 1.36)	0.65 (0.34 to 1.24)	1.34 (0.81 to 2.20)	0.62 (0.29 to 1.35)	1.11 (0.50 to 2.48)	1.23 (0.74 to 2.05)	1.08 (0.62 to 1.87)
Likely	0.99 (0.72 to 1.38)	0.62 (0.30 to 1.27)	1.30 (0.77 to 2.21)	0.60 (0.26 to 1.37)	0.89 (0.39 to 2.06)	1.52 (0.87 to 2.67)	1.01 (0.55 to 1.84)

Appendix Figure 6.3. Comfort with the NHS having the results from different risk assessments on record, and potentially using the data to assess risk of other health issues, according to order of seeing the example.



N = 999.

Order 1: New technology→Use of personal data→Testing biomarkers
Order 2: Use of personal data→Testing biomarkers→New technology
Order 3: Testing biomarkers→New technology→Use of personal data
Order 4: New technology→Testing biomarkers→Use of personal data
Order 5: Use of personal data→New technology→Testing biomarkers
Order 6: Testing biomarkers→Use of personal data→New technology

Appendix Table 6.6. Odds that survey participants with different demographics would be extremely comfortable with the NHS having the results of different risk assessments on record, and potentially using the data to assess risk of other health issues.

	Any type of risk assessment	PRS	Geodemographic segmentation	Minimally invasive tests	Continuous biomarker monitoring	AI	Wearable devices
N observations	2,961	489	498	493	494	491	496
Age							
18-29	Ref	Ref	Ref	Ref	Ref	Ref	Ref
30-39	1.19 (0.85 to 1.67)	1.18 (0.67 to 2.09)	1.19 (0.67 to 2.13)	**2.05 (1.17 to 3.58)**	1.16 (0.66 to 2.04)	0.77 (0.42 to 1.39)	1.17 (0.67 to 2.06)
40-49	1.11 (0.77 to 1.61)	1.33 (0.73 to 2.41)	1.22 (0.63 to 2.35)	1.30 (0.71 to 2.38)	1.44 (0.76 to 2.70)	0.91 (0.48 to 1.70)	0.66 (0.34 to 1.28)
50-59	1.16 (0.80 to 1.67)	1.45 (0.77 to 2.70)	1.16 (0.62 to 2.17)	1.47 (0.83 to 2.62)	1.27 (0.68 to 2.36)	0.72 (0.39 to 1.35)	1.15 (0.63 to 2.10)
60+	**1.80 (1.24 to 2.61)**	**2.51 (1.34 to 4.68)**	1.84 (0.97 to 3.51)	**2.63 (1.40 to 4.94)**	1.59 (0.86 to 2.97)	1.02 (0.55 to 1.91)	**2.07 (1.10 to 3.89)**
Sex							
Male	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Female	**0.73 (0.58 to 0.92)**	1.05 (0.72 to 1.52)	**0.54 (0.37 to 0.79)**	0.89 (0.60 to 1.31)	0.70 (0.48 to 1.03)	**0.47 (0.32 to 0.69)**	0.90 (0.61 to 1.31)
Smoking							
Never	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ever	1.21 (0.96 to 1.53)	1.03 (0.69 to 1.53)	1.39 (0.93 to 2.07)	1.45 (0.96 to 2.19)	0.91 (0.62 to 1.35)	1.02 (0.69 to 1.50)	**1.74 (1.16 to 2.59)**
Ethnicity							
White ethnicity	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Ethnic minority	**0.57 (0.41 to 0.80)**	0.71 (0.42 to 1.20)	0.64 (0.35 to 1.17)	0.64 (0.38 to 1.09)	**0.43 (0.25 to 0.75)**	**0.31 (0.16 to 0.61)**	0.74 (0.44 to 1.27)
Education							
No degree	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Degree	**0.68 (0.54 to 0.86)**	0.78 (0.53 to 1.16)	0.77 (0.51 to 1.15)	0.73 (0.49 to 1.09)	**0.55 (0.37 to 0.83)**	0.67 (0.45 to 1.00)	**0.55 (0.37 to 0.83)**
SES decile							
	1.06 (0.99 to 1.14)	0.97 (0.86 to 1.09)	1.10 (0.97 to 1.24)	1.09 (0.97 to 1.22)	1.09 (0.96 to 1.24)	1.06 (0.94 to 1.19)	**1.13 (1.00 to 1.27)**
Prior cancer							
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes	1.25 (0.70 to 2.24)	1.71 (0.62 to 4.67)	1.14 (0.36 to 3.60)	**5.80 (1.17 to 28.65)**	0.57 (0.24 to 1.37)	0.95 (0.33 to 2.69)	0.90 (0.37 to 2.23)
Tech use							
None	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Health apps	**1.48 (1.17 to 1.87)**	**1.91 (1.29 to 2.83)**	1.26 (0.84 to 1.90)	1.32 (0.89 to 1.94)	**1.54 (1.03 to 2.31)**	**1.60 (1.07 to 2.39)**	1.42 (0.97 to 2.09)
Perceived risk							
Unlikely	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Neither	0.85 (0.63 to 1.14)	0.71 (0.44 to 1.15)	0.88 (0.52 to 1.47)	0.71 (0.44 to 1.16)	0.96 (0.57 to 1.60)	0.98 (0.59 to 1.62)	0.79 (0.49 to 1.30)
Likely	0.85 (0.62 to 1.17)	0.87 (0.51 to 1.48)	0.91 (0.52 to 1.59)	0.94 (0.54 to 1.62)	0.68 (0.39 to 1.17)	1.14 (0.67 to 1.94)	0.69 (0.41 to 1.18)

Appendix Table 7.1. DCE participant's demographics.

	Asymptomatic context cohort	Symptomatic context cohort	Total (%)
Total *N*	599	601	1,200 (100)
Age (years)			
18-29	140	146	286 (23.8)
30-39	141	135	276 (23.0)
40-49	106	111	217 (18.1)
50-59	100	97	197 (16.4)
60-69	86	88	174 (14.5)
≥70	26	24	50 (4.2)
Sex*			
Female	316	295	611 (50.9)
Male	282	305	587 (48.9)
Other	1	1	2 (0.2)
Ethnicity (simplified)			
Asian	43	38	81 (6.8)
Black	24	23	47 (3.9)
Mixed	13	16	29 (2.4)
White	513	516	1,029 (85.8)
Other	6	8	14 (1.2)
Socioeconomic status (self-reported)			
1-3 (lowest deciles)	166	153	319 (26.6)
4-5	195	212	407 (33.9)
6-7	213	198	411 (34.3)
8-10 (highest deciles)	25	38	63 (5.3)
Education level			
Not completed A levels, further education or equivalent	99	94	193 (16.1)
Competed A levels, further education or equivalent	190	188	378 (31.5)
Completed a bachelor's degree	215	212	427 (35.6)
Completed a postgraduate degree	95	107	202 (16.8)
Location			
England	509	498	1,007 (83.9)
Northern Ireland	14	15	29 (2.4)
Scotland	52	60	112 (9.3)
Wales	24	28	52 (4.3)
Smoking status			

Never smoked	358	351	709 (59.1)
Used to smoke	177	195	372 (31.0)
Current smoker	64	55	119 (9.9)
Weight			
Underweight	31	21	52 (4.3)
About the right weight	312	314	626 (52.2)
Overweight	256	266	522 (43.5)
Personal history of cancer			
Yes	35	18	53 (4.4)
No	560	582	1,142 (95.2)
Not reported	4	1	5 (0.4)
Previously have completed cancer screening			
Yes	281	265	546 (45.5)
No (chose not to)	37	38	75 (6.3)
No (have not been invited)	278	295	573 (47.8)
Not reported	3	3	6 (0.5)

* 18 (1.5%) of the total participants reported that their gender was not the same as the sex that they were assigned at birth. Of these, 9 participants identified as non-binary.

Appendix Table 7.2. DCE participants' thoughts and beliefs about cancer and screening (collected at the end of the survey).

	Asymptomatic context cohort	Symptomatic context cohort	Total (%)
Total *N*			
"These days, many people with cancer can expect to continue with normal activities and responsibilities"			
Strongly agree	48	36	84 (7.0)
Agree	323	335	658 (54.8)
Neither agree nor disagree	158	151	309 (25.8)
Disagree	65	73	138 (11.5)
Strongly disagree	5	6	11 (0.9)
"Most cancer treatment is worse than the cancer itself"			
Strongly agree	27	30	57 (4.8)
Agree	138	125	263 (21.9)
Neither agree nor disagree	204	214	418 (34.8)
Disagree	187	181	368 (30.7)
Strongly disagree	43	51	94 (7.8)
"I would not want to know if I had cancer"			
Strongly agree	14	12	26 (2.2)
Agree	24	22	46 (3.8)
Neither agree nor disagree	63	65	128 (10.7)
Disagree	197	181	378 (31.5)
Strongly disagree	301	321	622 (51.8)
"Cancer can often be cured"			
Strongly agree	79	79	158 (13.2)
Agree	302	312	614 (51.2)
Neither agree nor disagree	170	146	316 (26.3)
Disagree	41	58	99 (8.3)
Strongly disagree	7	6	13 (1.1)
"Going to the doctor as quickly as possible after noticing a symptom of cancer could increase the chances of surviving"			
Strongly agree	411	432	843 (70.3)
Agree	169	144	313 (26.1)
Neither agree nor disagree	9	18	27 (2.3)
Disagree	4	5	9 (0.8)
Strongly disagree	6	2	8 (0.7)
"Some people think that a diagnosis of cancer is a death sentence"			
Strongly agree	28	28	56 (4.7)
Agree	137	129	266 (22.2)
Neither agree nor disagree	188	165	353 (29.4)

Disagree	211	223	434 (36.2)
Strongly disagree	35	56	91 (7.6)
How likely do you think is it that you will get cancer at some point in the next 10 years?			
Extremely or moderately likely	114	135	249 (20.8)
Slightly likely	153	157	310 (25.8)
Neither likely nor unlikely	194	148	342 (28.5)
Slightly unlikely	41	57	98 (8.2)
Extremely or moderately unlikely	97	104	201 (16.8)
During the past month, how often have you thought about your own chances of getting cancer?			
Not at all	191	194	385 (32.1)
Rarely	190	177	367 (30.6)
Sometimes	158	159	317 (26.4)
Often or a lot	60	71	131 (10.9)
During the past month, how often have thoughts about your chances of getting cancer affected your mood?			
Not at all	324	339	663 (55.3)
Rarely	159	140	299 (24.9)
Sometimes	82	92	174 (14.5)
Often or a lot	34	30	64 (5.3)
During the past month, how often have thoughts about your chances of getting cancer affected your ability to perform your daily activities?			
Not at all	436	456	892 (74.3)
Rarely	104	95	199 (16.6)
Sometimes	38	37	75 (6.3)
Often or a lot	21	13	34 (2.8)

Appendix Table 7.3. DCE participants' preferences for different aspects of risk assessments in screening and referral context cohorts (sensitivity analyses).

a. Participants who completed the survey in at least 7.5 minutes and not always selecting Option 1 or Option 2.

	Asymptomatic context cohort	Symptomatic context cohort	p value for difference
N participants	564	560	**<0.001** for overall difference
N observations	15,228	15,120	
Pseudo R^2	0.1046	0.2205	
Constant (risk assessment)	**-0.676 (-0.825 to -0.527)**	**-0.802 (-0.966 to -0.638)**	0.260
Method of risk assessment			
Questionnaire or data access	Ref	Ref	Ref
Blood test	**0.339 (0.207 to 0.471)**	**1.024 (0.883 to 1.165)**	**<0.001**
Non-invasive test	**0.339 (0.225 to 0.453)**	**0.765 (0.645 to 0.886)**	**<0.001**
Wearable device	-0.171 (-0.347 to 0.005)	**0.258 (0.079 to 0.437)**	**<0.001**
Type of risk assessment			
Non-genetic	Ref	Ref	Ref
Genetic	0.015 (-0.138 to 0.167)	0.120 (-0.046 to 0.287)	0.364
Location of risk assessment			
Home	Ref	Ref	Ref
Community clinic/pharmacy	-0.046 (-0.163 to 0.071)	0.095 (-0.028 to 0.218)	0.105
General practice	-0.107 (-0.227 to 0.014)	-0.027 (-0.157 to 0.103)	0.382
Hospital	**-0.233 (-0.346 to -0.121)**	-0.039 (-0.151 to 0.072)	**0.017**
Frequency of risk assessment			
One-off single event	Ref	Ref	Ref
Once every 5 years	0.004 (-0.137 to 0.145)	0.001 (-0.151 to 0.153)	0.976
Once every year	-0.041 (-0.161 to 0.079)	-0.007 (-0.134 to 0.120)	0.706
Continuously for 2 weeks	0.190 (-0.069 to 0.448)	-0.016 (-0.278 to 0.246)	0.270
Constantly	-0.039 (-0.209 to 0.132)	0.109 (-0.072 to 0.289)	0.240
Accuracy – per additional person out of 100 whose risk will be overestimated	**-0.045 (-0.053 to -0.038)**	**-0.051 (-0.059 to -0.043)**	0.286
Accuracy – per additional person out of 100 whose risk will be underestimated	**-0.063 (-0.071 to -0.056)**	**-0.086 (-0.093 to -0.078)**	**<0.001**
p value for difference versus main analysis	**0.003**	**<0.001**	

b. Participants who showed understanding of the concepts by answering all understanding questions correctly.

	Asymptomatic context cohort	Symptomatic context cohort	p value for difference
N participants	436	447	**<0.001** for overall difference
N observations	11,772	12,069	
Pseudo R^2	0.1057	0.2256	
Constant (risk assessment)	**-0.611 (-0.781 to -0.440)**	**-0.762 (-0.948 to -0.575)**	0.236
Method of risk assessment			
Questionnaire or data access	Ref	Ref	Ref
Blood test	**0.348 (0.197 to 0.498)**	**0.987 (0.828 to 1.145)**	**<0.001**
Non-invasive test	**0.401 (0.271 to 0.530)**	**0.701 (0.566 to 0.837)**	**0.002**
Wearable device	-0.143 (-0.342 to 0.056)	**0.281 (0.081 to 0.480)**	**0.003**
Type of risk assessment			
Non-genetic	Ref	Ref	Ref
Genetic	0.009 (-0.163 to 0.182)	**0.198 (0.012 to 0.385)**	0.150
Location of risk assessment			
Home	Ref	Ref	Ref
Community clinic/pharmacy	0.060 (-0.073 to 0.192)	0.120 (-0.019 to 0.259)	0.539
General practice	-0.018 (-0.154 to 0.118)	0.018 (-0.129 to 0.166)	0.724
Hospital	**-0.184 (-0.312 to -0.055)**	-0.041 (-0.167 to 0.086)	0.122
Frequency of risk assessment			
One-off single event	Ref	Ref	Ref
Once every 5 years	0.010 (-0.151 to 0.170)	0.035 (-0.135 to 0.204)	0.834
Once every year	-0.058 (-0.195 to 0.078)	0.039 (-0.106 to 0.183)	0.349
Continuously for 2 weeks	0.158 (-0.135 to 0.451)	0.077 (-0.216 to 0.370)	0.699
Constantly	0.017 (-0.178 to 0.212)	0.180 (-0.024 to 0.383)	0.249
Accuracy – per additional person out of 100 whose risk will be overestimated	**-0.045 (-0.053 to -0.037)**	**-0.053 (-0.062 to -0.044)**	0.207
Accuracy – per additional person out of 100 whose risk will be underestimated	**-0.061 (-0.069 to -0.053)**	**-0.090 (-0.098 to -0.081)**	**<0.001**
p value for difference versus main analysis	0.114	**0.025**	

c. Excluding the neither/opt-out responses.

	Asymptomatic context cohort	Symptomatic context cohort	p value for difference
N participants	NA	NA	**<0.001** for overall difference
N observations	8,638	9,542	
Pseudo R^2	0.1073	0.1714	
Constant (risk assessment)	NA	NA	NA
Method of risk assessment			
Questionnaire or data access	Ref	Ref	Ref
Blood test	**0.380 (0.240 to 0.520)**	**1.060 (0.913 to 1.206)**	**<0.001**
Non-invasive test	**0.378 (0.260 to 0.496)**	**0.804 (0.681 to 0.927)**	**<0.001**
Wearable device	-0.121 (-0.305 to 0.063)	**0.352 (0.164 to 0.540)**	**<0.001**
Type of risk assessment			
Non-genetic	Ref	Ref	Ref
Genetic	-0.028 (-0.188 to 0.132)	0.145 (-0.031 to 0.321)	0.167
Location of risk assessment			
Home	Ref	Ref	Ref
Community clinic/pharmacy	0.035 (-0.093 to 0.162)	0.120 (-0.010 to 0.250)	0.363
General practice	-0.022 (-0.151 to 0.106)	0.017 (-0.120 to 0.154)	0.684
Hospital	**-0.185 (-0.298 to -0.071)**	-0.031 (-0.141 to 0.079)	0.057
Frequency of risk assessment			
One-off single event	Ref	Ref	Ref
Once every 5 years	0.074 (-0.078 to 0.226)	0.035 (-0.122 to 0.192)	0.730
Once every year	-0.064 (-0.190 to 0.062)	-0.026 (-0.156 to 0.104)	0.684
Continuously for 2 weeks	0.080 (-0.199 to 0.358)	-0.120 (-0.396 to 0.155)	0.314
Constantly	-0.108 (-0.292 to 0.076)	0.050 (-0.138 to 0.238)	0.239
Accuracy – per additional person out of 100 whose risk will be overestimated	**-0.045 (-0.052 to -0.037)**	**-0.053 (-0.061 to -0.044)**	0.183
Accuracy – per additional person out of 100 whose risk will be underestimated	**-0.062 (-0.070 to -0.055)**	**-0.084 (-0.092 to -0.077)**	**<0.001**
p value for difference versus main analysis	NA	NA	

Appendix Table 7.4. DCE participants' preferences for different aspects of risk assessments in screening and referral context cohorts (subgroup analyses).

a. Age

	Asymptomatic context cohort		Symptomatic context cohort	
	Older people (aged ≥50 years)	**Younger people (aged <50 years)**	**Older people (aged ≥50 years)**	**Younger people (aged <50 years)**
N participants	212	387	209	392
N observations	5,724	10,449	5,643	10,584
Pseudo R^2	0.0598	0.1279	0.1851	0.2314
Constant (risk assessment)	**-0.470 (-0.705 to -0.234)**	**-0.826 (-1.008 to -0.643)**	**-0.429 (-0.697 to -0.161)**	**-1.061 (-1.257 to -0.865)**
Method of risk assessment				
Questionnaire or data access	Ref	Ref	Ref	Ref
Blood test	**0.399 (0.185 to 0.614)**	**0.274 (0.115 to 0.433)**	**1.001 (0.778 to 1.224)**	**0.953 (0.784 to 1.123)**
Non-invasive test	**0.380 (0.196 to 0.565)**	**0.271 (0.134 to 0.408)**	**0.746 (0.549 to 0.944)**	**0.709 (0.567 to 0.851)**
Wearable device	-0.037 (-0.328 to 0.254)	**-0.277 (-0.487 to -0.068)**	**0.458 (0.163 to 0.754)**	0.186 (-0.025 to 0.398)
Type of risk assessment				
Non-genetic	Ref	Ref	Ref	Ref
Genetic	-0.194 (-0.438 to 0.050)	0.094 (-0.090 to 0.278)	**0.366 (0.095 to 0.636)**	0.026 (-0.170 to 0.221)
Location of risk assessment				
Home	Ref	Ref	Ref	Ref
Community clinic/pharmacy	-0.130 (-0.320 to 0.060)	0.027 (-0.115 to 0.168)	0.140 (-0.062 to 0.341)	0.086 (-0.059 to 0.231)
General practice	-0.186 (-0.380 to 0.007)	-0.047 (-0.193 to 0.099)	-0.062 (-0.277 to 0.153)	0.016 (-0.136 to 0.167)
Hospital	**-0.258 (-0.443 to -0.073)**	**-0.207 (-0.342 to -0.072)**	-0.049 (-0.235 to 0.136)	-0.018 (-0.150 to 0.114)
Frequency of risk assessment				
One-off single event	Ref	Ref	Ref	Ref
Once every 5 years	0.033 (-0.194 to 0.260)	-0.011 (-0.180 to 0.159)	0.051 (-0.197 to 0.299)	-0.027 (-0.207 to 0.153)
Once every year	-0.181 (-0.374 to 0.012)	0.015 (-0.131 to 0.160)	0.181 (-0.025 to 0.387)	-0.099 (-0.250 to 0.052)
Continuously for 2 weeks	0.074 (-0.347 to 0.495)	0.297 (-0.013 to 0.607)	-0.018 (-0.449 to 0.413)	-0.042 (-0.353 to 0.268)
Constantly	-0.178 (-0.457 to 0.101)	0.043 (-0.162 to 0.247)	0.086 (-0.215 to 0.386)	0.098 (-0.113 to 0.309)
Overestimated risk*	**-0.031 (-0.043 to -0.019)**	**-0.048 (-0.057 to -0.039)**	**-0.042 (-0.055 to -0.029)**	**-0.052 (-0.061 to -0.042)**
Underestimated risk*	**-0.048 (-0.060 to -0.037)**	**-0.066 (-0.075 to -0.057)**	**-0.082 (-0.094 to -0.070)**	**-0.081 (-0.090 to -0.072)**
$\chi 2$ (older = younger)	**p < 0.001**		**p < 0.001**	

b. Sex

	Asymptomatic context cohort		Symptomatic context cohort	
	Female	**Male**	**Female**	**Male**
N participants	316	282	295	305
N observations	8,532	7,614	7,965	8,235
Pseudo R^2	0.0835	0.1204	0.1795	0.2523
Constant (risk assessment)	**-0.520 (-0.718 to -0.322)**	**-0.895 (-1.105 to -0.685)**	**-0.435 (-0.657 to -0.213)**	**-1.264 (-1.490 to -1.038)**
Method of risk assessment				
Questionnaire or data access	Ref	Ref	Ref	Ref
Blood test	**0.243 (0.070 to 0.417)**	**0.418 (0.229 to 0.607)**	**1.064 (0.874 to 1.255)**	**0.848 (0.658 to 1.039)**
Non-invasive test	**0.266 (0.115 to 0.416)**	**0.374 (0.213 to 0.535)**	**0.829 (0.663 to 0.996)**	**0.610 (0.450 to 0.770)**
Wearable device	-0.189 (-0.423 to 0.045)	-0.191 (-0.439 to 0.056)	**0.277 (0.029 to 0.525)**	**0.260 (0.021 to 0.499)**
Type of risk assessment				
Non-genetic	Ref	Ref	Ref	Ref
Genetic	0.042 (-0.157 to 0.241)	-0.072 (-0.290 to 0.145)	**0.235 (0.010 to 0.460)**	0.057 (-0.165 to 0.280)
Location of risk assessment				
Home	Ref	Ref	Ref	Ref
Community clinic/pharmacy	0.093 (-0.063 to 0.249)	**-0.197 (-0.362 to -0.032)**	0.141 (-0.027 to 0.309)	0.070 (-0.095 to 0.235)
General practice	-0.048 (-0.208 to 0.111)	**-0.172 (-0.342 to -0.002)**	0.030 (-0.147 to 0.208)	-0.048 (-0.221 to 0.125)
Hospital	**-0.192 (-0.343 to -0.041)**	**-0.284 (-0.442 to -0.125)**	-0.032 (-0.187 to 0.124)	-0.032 (-0.181 to 0.118)
Frequency of risk assessment				
One-off single event	Ref	Ref	Ref	Ref
Once every 5 years	0.110 (-0.076 to 0.295)	-0.130 (-0.331 to 0.071)	0.025 (-0.184 to 0.235)	-0.017 (-0.219 to 0.185)
Once every year	-0.011 (-0.170 to 0.147)	-0.119 (-0.289 to 0.051)	0.084 (-0.089 to 0.258)	-0.081 (-0.252 to 0.089)
Continuously for 2 weeks	0.042 (-0.303 to 0.387)	**0.420 (0.054 to 0.785)**	0.119 (-0.243 to 0.480)	-0.165 (-0.516 to 0.186)
Constantly	-0.025 (-0.252 to 0.203)	-0.055 (-0.294 to 0.184)	0.154 (-0.095 to 0.402)	0.047 (-0.193 to 0.287)
Overestimated risk*	**-0.035 (-0.045 to -0.025)**	**-0.052 (-0.062 to -0.041)**	**-0.045 (-0.056 to -0.034)**	**-0.050 (-0.061 to -0.040)**
Underestimated risk*	**-0.058 (-0.068 to -0.048)**	**-0.061 (-0.071 to -0.052)**	**-0.075 (-0.085 to -0.065)**	**-0.088 (-0.098 to -0.078)**
$\chi 2$ (female = male)	**p < 0.001**		**p < 0.001**	

2 (0.2%) participants preferred not to provide their sex and were not included in this analysis.

c. Ethnicity

	Asymptomatic context cohort		Symptomatic context cohort	
	White ethnicity	**Any other ethnicity**	**White ethnicity**	**Any other ethnicity**
N participants	513	86	516	85
N observations	13,851	2,322	13,932	2,295
Pseudo R^2	0.1008	0.0882	0.2175	0.1952
Constant (risk assessment)	**-0.676 (-0.831 to -0.520)**	**-0.726 (-1.095 to -0.357)**	**-0.803 (-0.973 to -0.632)**	**-0.988 (-1.397 to -0.578)**
Method of risk assessment				
Questionnaire or data access	Ref	Ref	Ref	Ref
Blood test	**0.296 (0.158 to 0.434)**	**0.466 (0.134 to 0.799)**	**0.999 (0.853 to 1.146)**	**0.705 (0.367 to 1.042)**
Non-invasive test	**0.323 (0.204 to 0.441)**	0.262 (-0.024 to 0.548)	**0.751 (0.626 to 0.877)**	**0.523 (0.233 to 0.812)**
Wearable device	**-0.264 (-0.447 to -0.081)**	0.209 (-0.241 to 0.660)	**0.370 (0.183 to 0.557)**	-0.279 (-0.718 to 0.161)
Type of risk assessment				
Non-genetic	Ref	Ref	Ref	Ref
Genetic	0.021 (-0.138 to 0.180)	-0.180 (-0.560 to 0.200)	0.150 (-0.023 to 0.323)	0.132 (-0.261 to 0.525)
Location of risk assessment				
Home	Ref	Ref	Ref	Ref
Community clinic/pharmacy	-0.014 (-0.136 to 0.109)	-0.120 (-0.413 to 0.173)	0.100 (-0.028 to 0.227)	0.159 (-0.143 to 0.462)
General practice	-0.114 (-0.240 to 0.012)	-0.024 (-0.320 to 0.273)	-0.018 (-0.153 to 0.117)	0.040 (-0.271 to 0.350)
Hospital	**-0.206 (-0.324 to -0.088)**	**-0.336 (-0.623 to -0.050)**	-0.054 (-0.171 to 0.063)	0.126 (-0.152 to 0.403)
Frequency of risk assessment				
One-off single event	Ref	Ref	Ref	Ref
Once every 5 years	-0.011 (-0.157 to 0.136)	0.070 (-0.292 to 0.431)	-0.042 (-0.200 to 0.116)	0.270 (-0.100 to 0.641)
Once every year	-0.072 (-0.197 to 0.054)	0.022 (-0.278 to 0.323)	-0.005 (-0.137 to 0.127)	0.032 (-0.272 to 0.336)
Continuously for 2 weeks	**0.282 (0.013 to 0.552)**	-0.139 (-0.799 to 0.520)	-0.108 (-0.382 to 0.165)	0.381 (-0.266 to 1.028)
Constantly	0.011 (-0.167 to 0.189)	-0.278 (-0.711 to 0.155)	0.027 (-0.161 to 0.216)	**0.492 (0.062 to 0.921)**
Overestimated risk*	**-0.043 (-0.051 to -0.035)**	**-0.038 (-0.057 to -0.020)**	**-0.050 (-0.058 to -0.042)**	**-0.036 (-0.055 to -0.017)**
Underestimated risk*	**-0.062 (-0.070 to -0.055)**	**-0.043 (-0.061 to -0.026)**	**-0.085 (-0.093 to -0.078)**	**-0.058 (-0.075 to -0.040)**
$\chi 2$ (white = any other ethnicity)	p = 0.470		**p = 0.005**	

d. Socioeconomic status

	Asymptomatic context cohort		Symptomatic context cohort	
	Low socioeconomic status (decile 1-3)	**Higher socioeconomic status (decile 4-10)**	**Low socioeconomic status (decile 1-3)**	**Higher socioeconomic status (decile 4-10)**
N participants	166	433	153	448
N observations	4,482	11,691	4,131	12,096
Pseudo R^2	0.0973	0.0991	0.2021	0.2191
Constant (risk assessment)	**-0.685 (-0.959 to -0.411)**	**-0.682 (-0.851 to -0.513)**	**-0.842 (-1.150 to -0.535)**	**-0.829 (-1.013 to -0.646)**
Method of risk assessment				
Questionnaire or data access	Ref	Ref	Ref	Ref
Blood test	**0.245 (0.006 to 0.483)**	**0.354 (0.203 to 0.505)**	**0.792 (0.522 to 1.063)**	**1.014 (0.859 to 1.168)**
Non-invasive test	0.167 (-0.039 to 0.373)	**0.369 (0.239 to 0.499)**	**0.490 (0.259 to 0.721)**	**0.797 (0.664 to 0.929)**
Wearable device	-0.137 (-0.455 to 0.180)	**-0.214 (-0.416 to -0.013)**	0.198 (-0.149 to 0.545)	**0.297 (0.100 to 0.495)**
Type of risk assessment				
Non-genetic	Ref	Ref	Ref	Ref
Genetic	0.007 (-0.269 to 0.282)	-0.012 (-0.185 to 0.162)	0.264 (-0.068 to 0.596)	0.113 (-0.067 to 0.292)
Location of risk assessment				
Home	Ref	Ref	Ref	Ref
Community clinic/pharmacy	0.010 (-0.208 to 0.228)	-0.048 (-0.180 to 0.084)	-0.068 (-0.307 to 0.171)	**0.163 (0.028 to 0.298)**
General practice	-0.090 (-0.313 to 0.133)	-0.104 (-0.240 to 0.032)	-0.227 (-0.483 to 0.029)	0.061 (-0.080 to 0.203)
Hospital	-0.146 (-0.352 to 0.061)	**-0.261 (-0.390 to -0.132)**	-0.114 (-0.332 to 0.104)	-0.003 (-0.126 to 0.121)
Frequency of risk assessment				
One-off single event	Ref	Ref	Ref	Ref
Once every 5 years	-0.003 (-0.258 to 0.251)	0.002 (-0.159 to 0.163)	0.114 (-0.173 to 0.400)	-0.029 (-0.197 to 0.140)
Once every year	0.096 (-0.123 to 0.315)	-0.107 (-0.244 to 0.029)	-0.037 (-0.284 to 0.210)	0.014 (-0.125 to 0.154)
Continuously for 2 weeks	0.057 (-0.413 to 0.528)	0.287 (-0.007 to 0.582)	-0.222 (-0.730 to 0.285)	0.030 (-0.259 to 0.320)
Constantly	-0.063 (-0.376 to 0.249)	-0.018 (-0.211 to 0.176)	0.012 (-0.333 to 0.357)	0.135 (-0.064 to 0.334)
Overestimated risk*	**-0.041 (-0.054 to -0.028)**	**-0.043 (-0.051 to -0.034)**	**-0.060 (-0.076 to -0.045)**	**-0.044 (-0.052 to -0.035)**
Underestimated risk*	**-0.064 (-0.078 to -0.051)**	**-0.058 (-0.066 to -0.050)**	**-0.097 (-0.112 to -0.083)**	**-0.076 (-0.084 to -0.068)**
$\chi 2$ (low = higher socioeconomic status)	p = 0.786		**p < 0.001**	

e. Screening history

	Asymptomatic context cohort		Symptomatic context cohort	
	Yes (completed screening)	**No (chose no screening)**	**Yes (completed screening)**	**No (chose no screening)**
N participants	281	37	265	38
N observations	7,587	999	7,155	1,026
Pseudo R^2	0.0816	0.0955	0.1914	0.265
Constant (risk assessment)	**-0.522 (-0.730 to -0.314)**	**-1.177 (-1.735 to -0.618)**	**-0.604 (-0.839 to -0.370)**	-0.673 (-1.347 to 0.001)
Method of risk assessment				
Questionnaire or data access	Ref	Ref	Ref	Ref
Blood test	**0.443 (0.258 to 0.628)**	-0.237 (-0.746 to 0.271)	**1.042 (0.843 to 1.242)**	**1.154 (0.592 to 1.716)**
Non-invasive test	**0.420 (0.260 to 0.580)**	-0.014 (-0.448 to 0.421)	**0.735 (0.561 to 0.909)**	**1.175 (0.689 to 1.661)**
Wearable device	-0.126 (-0.378 to 0.126)	-0.631 (-1.339 to 0.078)	**0.305 (0.043 to 0.566)**	0.550 (-0.172 to 1.273)
Type of risk assessment				
Non-genetic	Ref	Ref	Ref	Ref
Genetic	-0.079 (-0.291 to 0.134)	-0.203 (-0.769 to 0.363)	**0.346 (0.105 to 0.587)**	-0.106 (-0.755 to 0.543)
Location of risk assessment				
Home	Ref	Ref	Ref	Ref
Community clinic/pharmacy	-0.067 (-0.232 to 0.099)	-0.099 (-0.544 to 0.347)	0.098 (-0.079 to 0.275)	0.149 (-0.356 to 0.655)
General practice	**-0.191 (-0.360 to -0.022)**	-0.006 (-0.448 to 0.437)	-0.048 (-0.236 to 0.141)	0.020 (-0.503 to 0.542)
Hospital	**-0.306 (-0.466 to -0.146)**	-0.241 (-0.681 to 0.200)	-0.019 (-0.182 to 0.143)	-0.235 (-0.688 to 0.218)
Frequency of risk assessment				
One-off single event	Ref	Ref	Ref	Ref
Once every 5 years	0.079 (-0.119 to 0.277)	-0.008 (-0.550 to 0.533)	0.044 (-0.176 to 0.264)	-0.017 (-0.625 to 0.590)
Once every year	-0.071 (-0.239 to 0.097)	-0.356 (-0.811 to 0.098)	0.050 (-0.132 to 0.232)	0.079 (-0.436 to 0.594)
Continuously for 2 weeks	0.172 (-0.196 to 0.539)	-0.063 (-1.080 to 0.953)	0.008 (-0.373 to 0.388)	-0.242 (-1.324 to 0.841)
Constantly	-0.090 (-0.334 to 0.153)	-0.434 (-1.070 to 0.203)	0.092 (-0.168 to 0.351)	-0.155 (-0.941 to 0.631)
Overestimated risk*	**-0.033 (-0.043 to -0.023)**	-0.004 (-0.032 to 0.025)	**-0.042 (-0.054 to -0.031)**	**-0.058 (-0.088 to -0.028)**
Underestimated risk*	**-0.054 (-0.064 to -0.044)**	**-0.055 (-0.082 to -0.027)**	**-0.078 (-0.088 to -0.067)**	**-0.081 (-0.112 to -0.050)**
$\chi 2$ (screened = not screened)	p = 0.407		p = 0.617	

579 (48.3%) participants had not been invited to screening or preferred not say and were not included in this analysis.

f. Cancer worry

	Asymptomatic context cohort		Symptomatic context cohort	
	Sometimes worry or more	**Not at all or rarely worry**	**Sometimes worry or more**	**Not at all or rarely worry**
N participants	218	381	230	371
N observations	5,886	10,287	6,210	10,017
Pseudo R^2	0.1125	0.0948	0.1125	0.2341
Constant (risk assessment)	**-0.773 (-1.011 to -0.535)**	**-0.636 (-0.817 to -0.455)**	**-0.596 (-0.847 to -0.344)**	**-0.981 (-1.184 to -0.778)**
Method of risk assessment				
Questionnaire or data access	Ref	Ref	Ref	Ref
Blood test	**0.554 (0.347 to 0.761)**	**0.180 (0.018 to 0.342)**	**0.872 (0.657 to 1.087)**	**1.012 (0.840 to 1.184)**
Non-invasive test	**0.450 (0.270 to 0.631)**	**0.231 (0.092 to 0.369)**	**0.532 (0.348 to 0.716)**	**0.838 (0.690 to 0.986)**
Wearable device	0.064 (-0.220 to 0.349)	**-0.340 (-0.552 to -0.128)**	0.211 (-0.069 to 0.491)	**0.319 (0.101 to 0.536)**
Type of risk assessment				
Non-genetic	Ref	Ref	Ref	Ref
Genetic	0.008 (-0.234 to 0.249)	-0.014 (-0.199 to 0.170)	0.139 (-0.109 to 0.388)	0.174 (-0.032 to 0.381)
Location of risk assessment				
Home	Ref	Ref	Ref	Ref
Community clinic/pharmacy	-0.090 (-0.276 to 0.096)	0.006 (-0.137 to 0.149)	**0.265 (0.074 to 0.456)**	0.008 (-0.142 to 0.157)
General practice	**-0.224 (-0.416 to -0.032)**	-0.025 (-0.171 to 0.121)	0.119 (-0.080 to 0.318)	-0.092 (-0.252 to 0.067)
Hospital	**-0.296 (-0.473 to -0.119)**	**-0.189 (-0.328 to -0.050)**	0.132 (-0.046 to 0.310)	-0.125 (-0.260 to 0.010)
Frequency of risk assessment				
One-off single event	Ref	Ref	Ref	Ref
Once every 5 years	-0.004 (-0.231 to 0.223)	0.004 (-0.166 to 0.174)	-0.054 (-0.286 to 0.177)	0.051 (-0.136 to 0.238)
Once every year	0.020 (-0.168 to 0.209)	-0.103 (-0.250 to 0.044)	-0.011 (-0.207 to 0.184)	0.017 (-0.138 to 0.172)
Continuously for 2 weeks	0.062 (-0.351 to 0.476)	0.311 (-0.003 to 0.624)	-0.089 (-0.496 to 0.318)	0.013 (-0.307 to 0.334)
Constantly	-0.220 (-0.496 to 0.056)	0.072 (-0.134 to 0.278)	0.021 (-0.256 to 0.298)	0.156 (-0.064 to 0.376)
Overestimated risk*	**-0.033 (-0.044 to -0.021)**	**-0.048 (-0.057 to -0.039)**	**-0.044 (-0.056 to -0.032)**	**-0.051 (-0.061 to -0.041)**
Underestimated risk*	**-0.055 (-0.067 to -0.044)**	**-0.062 (-0.071 to -0.054)**	**-0.085 (-0.096 to -0.073)**	**-0.080 (-0.089 to -0.071)**
$\chi 2$ (not worried = worried)	**p < 0.001**		**p = 0.002**	

g. Ease of completing the DCE	Asymptomatic context cohort		Symptomatic context cohort	
	Easy	**Difficult**	**Easy**	**Difficult**
N participants	247	352	242	359
N observations	6,669	9,504	6,534	9,693
Pseudo R^2	0.1054	0.0958	0.2345	0.201
Constant (risk assessment)	-0.648 (-0.875 to -0.422)	**-0.708 (-0.893 to -0.522)**	**-0.872 (-1.124 to -0.619)**	**-0.803 (-1.005 to -0.602)**
Method of risk assessment				
Questionnaire or data access	Ref	Ref	Ref	Ref
Blood test	**0.322 (0.122 to 0.522)**	**0.321 (0.156 to 0.486)**	**1.014 (0.796 to 1.231)**	**0.904 (0.733 to 1.075)**
Non-invasive test	**0.305 (0.132 to 0.478)**	**0.320 (0.178 to 0.461)**	**0.811 (0.626 to 0.996)**	**0.654 (0.507 to 0.801)**
Wearable device	**-0.552 (-0.821 to -0.284)**	0.052 (-0.169 to 0.272)	**0.540 (0.266 to 0.813)**	0.076 (-0.146 to 0.298)
Type of risk assessment				
Non-genetic	Ref	Ref	Ref	Ref
Genetic	0.029 (-0.201 to 0.258)	-0.032 (-0.222 to 0.158)	-0.039 (-0.291 to 0.214)	**0.257 (0.053 to 0.460)**
Location of risk assessment				
Home	Ref	Ref	Ref	Ref
Community clinic/pharmacy	0.059 (-0.119 to 0.237)	-0.093 (-0.240 to 0.053)	0.108 (-0.081 to 0.297)	0.114 (-0.036 to 0.265)
General practice	-0.074 (-0.257 to 0.109)	-0.120 (-0.270 to 0.030)	-0.087 (-0.286 to 0.112)	0.043 (-0.116 to 0.202)
Hospital	**-0.220 (-0.391 to -0.048)**	**-0.232 (-0.373 to -0.091)**	-0.142 (-0.315 to 0.031)	0.059 (-0.079 to 0.197)
Frequency of risk assessment				
One-off single event	Ref	Ref	Ref	Ref
Once every 5 years	-0.157 (-0.371 to 0.056)	0.111 (-0.065 to 0.287)	-0.166 (-0.398 to 0.066)	0.103 (-0.084 to 0.290)
Once every year	-0.090 (-0.272 to 0.091)	-0.032 (-0.181 to 0.118)	-0.046 (-0.241 to 0.150)	0.025 (-0.130 to 0.181)
Continuously for 2 weeks	**0.447 (0.053 to 0.841)**	0.066 (-0.257 to 0.390)	-0.351 (-0.755 to 0.053)	0.172 (-0.151 to 0.496)
Constantly	0.134 (-0.123 to 0.391)	-0.147 (-0.362 to 0.067)	-0.009 (-0.292 to 0.275)	0.162 (-0.055 to 0.379)
Overestimated risk*	**-0.043 (-0.054 to -0.032)**	**-0.041 (-0.051 to -0.032)**	**-0.050 (-0.062 to -0.038)**	**-0.046 (-0.056 to -0.036)**
Underestimated risk*	**-0.065 (-0.076 to -0.054)**	**-0.056 (-0.065 to -0.047)**	**-0.091 (-0.102 to -0.080)**	**-0.075 (-0.084 to -0.066)**
$\chi 2$ (easy = difficult)	p = 0.058		**p = 0.003**	

* Accuracy of risk assessment is the number of people with over-/underestimated risk out of 100.

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