“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

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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.

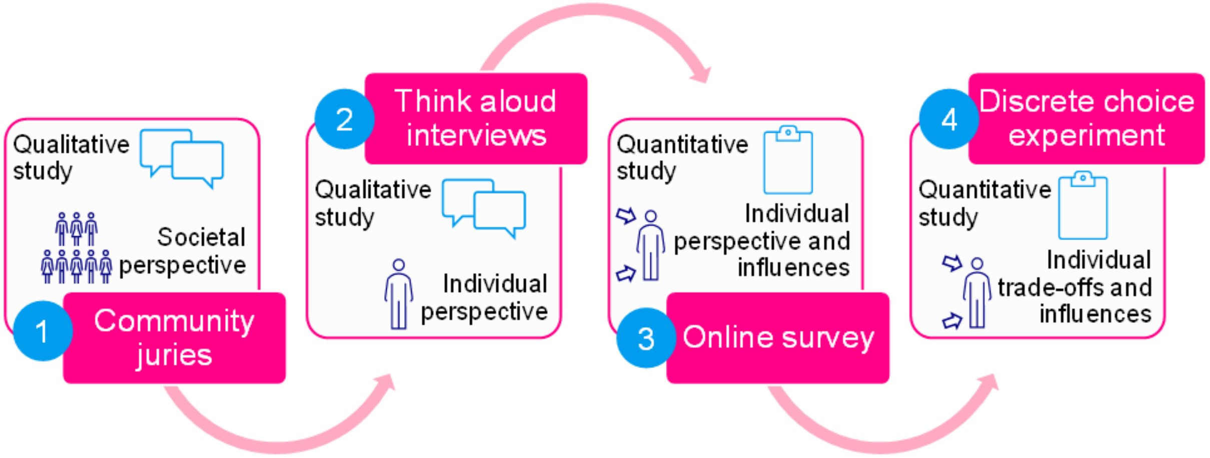

Table A: The six risk-based innovations explored in the RIBBONS studies.

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.

Acceptable risk-based innovations

Affective attitude

Risk assessments and stratification strategies should be logical

Burden

The effort to complete the test should be minimised

People should not have an invasive test or complete it at hospital if they are asymptomatic

Ethicality

Inequalities in society should not increase

Resources for risk assessments should be available

Data need to be held securely

There needs to be the option to opt-out

Intervention coherence

People need to be able to understand how their risk is calculated

The purpose of the risk-based strategy, particularly how it would be used in the context of vague or "red flag" symptoms, needs to be clear

Opportunity cost

Personal freedom should be maintained

Cancer risk should not impact insurance policies

People's relationship with their GP should be maintained

Perceived effectiveness

Risk assessments need to be accurate (and not underestimate risk, in particular)

Self-efficacy

People should have help to complete the test, particularly if they have less capacity or confidence in using technology

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.