

# Views of the Australian public on the delivery of risk-stratified cancer screening in the population: a qualitative study

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## Article history

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## Key points

- Risk-stratified screening has the potential to improve the benefit-to-harm ratio of current population cancer screening approaches
- Little is known about the best way to deliver risk-stratified cancer screening in Australia
- This paper identifies key enablers for successful delivery, including convenience for screening recipients and good communication, clear public information, convincing evidence for change and public engagement
- Health professional education and upskilling across disciplines will be the key to facilitating risk-stratified cancer screening.

## Abstract

**Objective and importance of study:** Risk-stratified approaches to cancer screening aim to provide tailored risk advice to individuals, rather than the mostly one-size-fits-all approach designed for the average person that is currently used in Australia. Stratified cancer screening has the potential to increase the benefits and reduce the harms of screening. Initial risk assessment is a crucial first step for screening programs that use risk stratification. We report findings from a qualitative study exploring the views of the Australian public on how to best deliver risk-stratified cancer screening in the population to help inform future implementation.

**Study type:** Qualitative interview study.

**Methods:** We conducted semistructured interviews with participants from a previous study, half of whom had received personal genomic risk information and half of whom had not. We asked how and where they would like to see risk-stratified screening delivered and how they felt about different health professionals assessing their cancer risk. Data were analysed thematically.

**Results:** Forty interviews were conducted. The age range of participants was 21–68 years; 58% were female. Themes included: 1) Convenience is a priority; 2) General practice is a good fit for some; 3) Web-based technology is part of the process; and 4) “I would want to know why [I was being stratified]”. Similar views were expressed by both groups. Our findings suggest that although health professionals were identified as having an important role, there were mixed preferences for delivery by general practitioners, medical specialists or nurses. Participants were less concerned about who undertook the risk assessment than whether the health professional had the appropriate skill set and availability. Clear communication and evidence of the need for change in screening eligibility

and frequency were key factors in the successful delivery of risk-stratified screening.

**Conclusion:** We identified that convenience and good communication, including clear explanations to the public with convincing evidence for change, will enable the successful delivery of risk-stratified cancer screening in the population, including organised and opportunistic screening approaches. Health professional education and upskilling across disciplines will be key facilitators. Engagement and further consultation with primary care and other key stakeholders will be central.

## Introduction

Cancer screening increases the likelihood of detecting cancer early. In Australia, population-based, organised programs for breast, bowel and cervical cancers are well established and opportunistic screening, such as for prostate cancer and melanoma, is supported in primary and specialist settings for relevant target groups. However, to ensure the benefits outweigh the harms of screening programs, the benefits need to be considered in the context of potential harms, including overdiagnosis<sup>1</sup>, ongoing anxiety related to false-positive test results<sup>2</sup> and financial costs.

Evidence suggests that risk-stratified approaches to giving individuals tailored screening advice, rather than the current mostly one-size-fits-all approach, have potential to increase the benefits of population screening and reduce harms.<sup>3</sup> Risk stratification may use a range of risk factors including lifestyle, environment and personal genomic risk information – in addition to traditional risk factors such as age and family history – to create tailored screening advice. Personal genomic risk information, calculated from a polygenic risk score based on a panel of common gene variants, is increasingly used in research studies.<sup>4,5</sup> However, the use of personal genomic risk information in risk-stratified screening programs raises issues about the privacy of genetic data and reduced accuracy of polygenic risk scores for ethnically diverse populations.<sup>6</sup>

When compared with current approaches, risk-stratified screening has been shown to be cost-effective and to reduce overdiagnosis and deaths in breast cancer<sup>7</sup>; to reduce the false positive rate and harms in colorectal cancer<sup>8</sup>; be more cost-effective for melanoma<sup>9</sup>, and reduce overdiagnosis for prostate cancer.<sup>10</sup> A risk-stratified approach may adjust screening eligibility, frequency and modality to focus on those who are likely to benefit most. Accordingly, it may offer screening less frequently, or perhaps not at all, to those deemed to be at low risk. International<sup>11</sup> and Australian<sup>12,13</sup> studies have demonstrated the acceptability of risk-stratified cancer screening by the general public, including support to increase screening frequency for those at high risk. However, all studies reported some reluctance to reduce frequency or to forgo screening altogether if at low risk.<sup>11,12,13</sup>

The delivery of a risk-stratified cancer screening program will require initial risk assessment and providing tailored screening recommendations based on individual risk.<sup>14</sup> Strategies previously reported include collecting risk information when patients attend the first breast screening episode<sup>15</sup>, a dynamic risk assessment tool to manage the process of updating personalised screening regimens<sup>4</sup> and a risk assessment and decision support tool in a general practice setting.<sup>16</sup> Very little is known about how risk-stratified cancer screening would be most appropriately delivered in the Australian population, and the limited existing research has focused only on breast cancer.<sup>12,17</sup>

This study aimed to explore the views of the Australian public on how best to deliver risk-stratified cancer screening, including organised and opportunistic cancer screening programs for different cancer types, to inform future implementation.

## Methods

This qualitative study was undertaken at the completion of a randomised controlled trial that examined the impact of personal genomic risk information on skin cancer prevention behaviours among the Australian public.<sup>5</sup> The trial's intervention group received personal genomic risk information and the control group did not. The qualitative study included semistructured interviews with participants from the trial to explore the acceptability of risk-stratified cancer screening.<sup>13</sup> This paper reports the findings from these interviews, focusing on participants' views and preferences about the delivery of risk-stratified cancer screening programs.

Participants in the trial (a total of 1025 were randomised: intervention,  $n = 513$ ; control,  $n = 512$ ) were aged 18–69 years and sampled from the population-representative Australian Government Medicare database.<sup>5</sup> Participants in the qualitative study were purposively sampled, ensuring that those with different genders, ages, states and genomic risk (low, average, high) results were included. Interviews were first conducted in the intervention group. Participants for interview from the control group were then matched for gender, age and state only, as genomic risk information was not collected. Interview guides were developed for both groups and piloted with three consumers from a

community health centre. Ethics approval was obtained from the University of Sydney (Protocol no: 2019/941).

## Data collection

Semistructured interviews were conducted (March to September 2019) by one researcher (KD) and continued until data saturation was reached in the intervention arm. The number of interviews was matched in the control group. The concepts of screening, genomic risk information and personalised screening advice were explained in the interview. Questions on participants' views about the delivery of a risk-stratified screening program included:

- To help you with a personalised screening program, how and where would you like to see it delivered? Why?
- How would you feel about different health professionals (probes: GPs, primary care nurses, medical specialists) assessing your risk and giving lifestyle advice?

## Analysis

Interviews were audio-recorded, transcribed and data were analysed thematically using the approach described by Braun and Clarke.<sup>18</sup> All members of the research team initially familiarised themselves with the data by reading four transcripts (two intervention and two control). Broad top-level codes were agreed by comparing across further transcripts to identify common patterns. Coding was applied to the data set by two researchers (KD, ZS) allowing for codes to be collapsed or generated. The research team refined final themes and discussed potential differences between the intervention and control groups.

Reflexivity was ensured by regular research team meetings and the researchers' range of academic backgrounds (epidemiology, bioethics, sociology, implementation science, genetics education). Coding was conducted using NVivo 12 (QSR International, Australia) software.

## Results

Forty interviews were conducted from a sample of 80 people in the trial who were invited to participate; 20 had received personal genomic risk information (10 low risk, 3 average risk, 7 high risk from the intervention group) and 20 had not (control group). The age range of participants was 21–68 years; 58% were female. Participants were from six Australian states. Table 1 summarises participant demographics.

Demographics of nonresponders to the invitation to participate were similar to participants, although fewer nonresponders from the intervention arm had a high genomic risk score (9 low risk, 8 average risk, 3 high risk).

**Table 1.** Demographic characteristics of participants

Characteristic	Intervention n = 20	Control n = 20	Total n = 40
<b>Gender</b>			
Female	11	12	23
Male	9	8	17
<b>Age group</b>			
18–29 years	4	2	6
30–49 years	8	9	17
50–69 years	8	9	17
<b>Socioeconomic index<sup>a</sup></b>			
Mean (SD)	1035.5 (60.6)	1027.8 (70.2)	

<sup>a</sup> Area-based index of relative advantage and disadvantage (SEIFA). The national average SEIFA score = 1000, with standard deviation of 100.

We identified similar themes and views across the intervention and control groups and risk groups and thus report combined results here. The four themes identified were 1) Convenience is a priority; 2) General practice is a good fit for some; 3) Web-based technology is part of the process; and 4) "I would want to know why [I was being stratified]".

### 1. Convenience is a priority

All participants described convenience as a key factor in ensuring people participate in risk-stratified cancer screening and, indeed, any type of screening. Long distances, work and family commitments contributed to the pressure and challenge of attending appointments.

#### a) Travel time to screening

Particular importance was placed on the time needed to travel to screening. Participants were generally not concerned about the kind of location for risk-tailored cancer screening and assessment but focused more on how far they would have to travel (noting that Australia is a large country with a significant population living in regional, rural and remote areas). Many viewed long distances and inconvenience as a deterrent and proposed different testing site options.

*"I'd go anywhere, as long as I didn't have to travel hours to get to it, I would go anywhere, community centre, GP clinic, I wouldn't mind, a school hall, I wouldn't care where I went really, as long as it was fairly private." (Female, 33 years, control)*

One participant suggested mobile screening vans promote participation, based on personal experience.

*"I spent most of my life in a regional place when the trucks pull up, you know the blood van or the breast screening van or the other awareness trucks*

turn up.....everyone turns up.” (Male, 43 years, intervention)

### b) Practicality of receiving reminders

Many participants placed high value on systems that prompted or reminded individuals to attend a screening, such as receiving routine reminders via mail or doctor. One participant said she relied on the reminders sent out every two years by BreastScreen to undertake mammography screening.

*“[I would] probably forget about it) if I didn’t have reminders” (Female, 65 years, intervention)*

The systematic mailout of the National Bowel Cancer Screening home test to all individuals aged 50–74 years was regarded as a practical way of increasing screening participation.

*“I think the bowel screening thing is...really quite good actually, that this thing rocks up in your mailbox and you should do it.” (Female, 47 years, intervention)*

## 2. General practice is a good fit for some

### a) General practice

Some participants nominated general practitioners (GPs) as best placed to conduct individual risk assessment and the risk communication process, although views were mixed. Some expressed trust in GPs, seeing them as a central hub of healthcare and a natural place to go for all health information.

*“If it’s going to be personalised, I think it’s better if your GP ... they end up being a repository of all medical knowledge about you. Seems to me that’s kind of the natural place.” (Male, 57 years, control)*

However, others expressed doubt about the availability and skills of GPs to manage risk-stratified screening, preferring to attend a specialist service.

*“I would try to keep it away from GPs. I think GPs are great at all those other things, but anything to do with cancers, they do send you on to a specialist anyway and I think they’re really overburdened.” (Male, 62 years, control)*

### b) Waiting times

A subset of participants reported frustration with GP waiting room times, including appointments not running to schedule and being double-booked. Some participants from regional areas explained:

*“There’s a waiting list to even get a GP in the area that we’ve moved to.” (Male, 42 years, intervention)*

This was seen as a deterrent to attending a cancer risk assessment with a GP, suggesting health professionals who have more time may be an alternative.

*“It’s better being [for it to be] the nurse because they often have a little bit more time and they deliver some of those things more consistently than the GP does, who has got a million things going on.” (Male, 49 years, intervention)*

### c) The right skills

Some participants felt that if there was an already established relationship with a health professional, for example a GP or practice nurse, then they would most likely be the best person to conduct the risk assessment and risk communication process. However, many participants felt that having the right skill set was more important than who actually delivered the risk assessment, with one participant adding:

*“As long as it’s professional information.” (Male, 54 years, intervention)*

Another participant commented:

*“I would be comfortable wherever, as long as it was qualified people doing it.” (Female, 45 years, control)*

## 3. Web-based technology is part of the process

Participants acknowledged that web-based technology now plays a key role in health communication and would be a logical part of risk assessment, with one participant commenting:

*“It would be a web-based (program) that the GP could look at.” (Female, 53 years, intervention)*

However, it was described as only one component of the broader process, with most participants recognising that full risk assessment and communication may be complex.

*“That’s a good starting point. That’s the kind of first check...do your self-assessment using some online tool, that’s increasingly the way that people like to interact with the world.” (Male, 56 years, control)*

A small number of participants expressed concern about the privacy of their data and a lack of trust in government systems to manage personal genetic data. However, some participants reported a positive experience with completing their questionnaires online during the trial and were in support of web-based technology and having access to their personal screening information.

*“I’d like... a website and be able to log in and have my information where I can actually see it.” (Female, 47 years, intervention)*

#### 4. "I would want to know why [I was being stratified]"

##### a) Explanation and evidence for change

Participants emphasised the need to provide evidence and a clear explanation about the reasons for a change in screening eligibility and/or frequency, such as providing "statistics with information or citations or something to back it up" (male, 25 years, intervention). Some participants were sceptical about who would benefit from risk-stratified screening in the broader sense, pondering whether this was a cost-saving exercise for the government.

*"I probably need more information.... I want it to be explained why you're so sure or that there is no need for screening [in people with a low-risk]."*  
(Female, 25 years, intervention)

##### b) Framing of the message

Participants emphasised the importance of getting the right message to consumers about why screening advice would be changing. Many participants mentioned that advice related to risk-stratified screening would be inconsistent with previous screening advice and public campaigns and that messages would need to be presented logically to be believed. One participant suggested framing it in a positive light as progress towards conquering cancer.

*"That message would sort of give me a sense of we're getting somewhere with it, and things are improving ... those messages where we're working towards eliminating something."* (Female, 47 years, intervention)

## Discussion

To inform future implementation, we explored the general public's views on how risk-stratified cancer screening could best be delivered in the Australian population. Our findings suggest that people are less concerned about who provides the individual risk assessment than they are about appropriate skill sets and availability. Communication was seen as a key factor for the successful delivery of risk-stratified screening. Two factors influencing screening behaviour change were the convenient delivery of a program and being convinced of a reason to change their existing screening pattern and follow new (tailored) screening advice. Although convenience is also relevant to participation in existing cancer screening programs, risk-stratified screening brings additional complexities around the risk assessment process, for example providing consent for access to personal genetic data (if used in the risk assessment), and access to specialised screening technologies for high-risk groups, for example a low-dose CT scan for lung cancer for individuals who smoke or have smoked.

The potential inconvenience of attending risk-stratified screening was described as a key barrier related to travel and waiting times. This hasn't been reported widely and may be particularly relevant to Australia because of its geography.

Communication is well recognised by the general public<sup>19</sup> and health professionals<sup>20</sup> as crucial for the acceptability and successful implementation of risk-stratified cancer screening. At the individual level, effective communication ensures understanding of risk, acceptability of screening eligibility and frequency, and ensures decision-making reflects autonomous choice.<sup>21</sup> At the community level, effective communication avoids community misunderstanding about motives for screening program changes. Woof et al. reported that to implement a low-risk breast screening pathway, health professionals require support to increase confidence in communicating the tailored recommendations to women who have low risk; they recommended clear messaging from screening services and public education campaigns.<sup>20</sup> Focus groups with European women identified that targeting patient information, risk communication format, and the type of risk counselling professional in different healthcare systems, is important for successful communication.<sup>22</sup> Such communication should go beyond mere information provision to encourage screening recipients to engage in dialogue with a health professional about the rationale for change and consider this dialogue in light of their values and attitudes.

Although participants in our study highlighted the importance of involving a health professional in risk-stratified cancer screening (whether in primary or specialist settings or as part of a centralised program), there were mixed views about preferences for the type of health professional, including GPs, medical specialists and nurses. Health professionals having the appropriate skill set and availability was an important determinant of participants' preference. Focus groups with European women found that the preferred professional depends on existing care pathways.<sup>22</sup> In Australia, national population-based screening programs for breast, cervical and bowel cancers are run through partnerships between the Australian Government and state and territory governments. Invitations for screening are sent to the public from central databases to those eligible.<sup>23</sup> Cervical screening is usually conducted by GPs, bowel screening kits for immunochemical faecal occult blood tests are mailed to people in their homes, and breast screening occurs in health settings and mobile vans. For any cancer, personal risk assessment related to age and family history is often undertaken in primary care by a GP or medical specialist in an individual consultation. GPs are recognised as playing a key role in encouraging participation in cancer screening.<sup>24</sup> Thus, despite uncertainty in this study about the suitability of GPs to conduct a personal cancer risk assessment and risk communication, consultation with GPs will be important for future implementation. Primary care nurses have

previously been identified as ideal health professionals for the delivery of a risk prediction tool to increase risk-appropriate colorectal screening in Australia.<sup>16</sup>

Compared with managing an existing health problem, the less urgent nature of screening the asymptomatic population may see the public prioritise other aspects of healthcare over attending screening if it is not easily accessible. Participants offered suggestions to help overcome inconvenience and long waiting times, including providing mobile screening vans or public testing sites. E-health is increasingly recognised as an effective approach to care and was identified by participants in this study. Web-based online information, surveys and access to testing may improve access and convenience. An increase in the adoption of telehealth services during the COVID-19 pandemic that occurred after we conducted these interviews suggests a possible role for telehealth in improving access to risk-stratified cancer screening services.<sup>25</sup> Although risk-stratified cancer screening will involve screening eligibility and frequency tailored to individuals' personal risk, our findings suggest that reminder systems will remain a useful strategy for delivering messages about screening risk assessment and appointments and encouraging appropriate participation.

## Limitations

A strength of this study was the diverse sample recruited from across Australia, including those who have experienced receiving personal genomic cancer risk information and those who have not, with a range of ages and risk levels. There are some limitations to the generalisability of our findings. Although a representative sample of Australians was invited to the study, participants lived in areas with a higher than the average socioeconomic index and may have had a stronger interest in cancer research and screening than in the broader community. Although we identified similar themes across groups, participants had previously participated in a trial about their personal risk of melanoma, which may have influenced their views on preference for health professionals in delivery. In addition, we didn't specifically focus on cancer type, so we appreciate the need for further research in this area.

## Conclusion

Future implementation of risk-stratified cancer screening may present some challenges. This study identified that convenience in attending a risk-stratified screening assessment and good communication are enablers. The community requires clear explanations and convincing evidence for any changes to screening eligibility and frequency. Education and upskilling of health professionals are also key facilitators that will contribute to the successful delivery of risk-stratified cancer screening and associated risk communication processes for both

organised screening and opportunistic early detection programs. Engagement and further consultation with primary care and other key stakeholders will be central.

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Externally peer reviewed, not commissioned.

## Competing interests

None declared.

## Author contributions

The study was planned and designed by AC, AS, KD, NR, LK and AN. KD conducted interviews, and analysis and interpretation of data were performed by AC, KD, NR, LK, AN and AS. KD prepared the first draft of the manuscript under guidance from AC and NR, and all authors read and contributed to subsequent drafts and approved the final manuscript.

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