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# Risk based cancer screening: the role of primary care

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## Background

In Australia in 2022, bowel cancer was estimated to be the second most common cause of death from cancer while breast cancer was the second most diagnosed cancer, with 20 640 cases (Australian Institute of Health and Welfare (AIHW), 2022b). Early detection of bowel cancer greatly increases the survival rate, with a 99% five-year survival rate for stage 1 cancer compared to 13% for stage 4 cancer (National Cancer Control Indicators, 2019). Likewise, around 95% of people survive breast cancer if it is detected early (National Cancer Control Indicators, 2019). However, participation rates in Australia's national bowel and breast cancer screening programs are low; only 40.9% of eligible Australians participate in the National Bowel Cancer Screening Program and 48% of eligible women participate in BreastScreen Australia (AIHW, 2022a; AIHW, 2022c).

Australia's breast and bowel cancer screening programs are population-based and, except for the minority with a family history, do not target patients at higher risk of developing breast and bowel cancer. While the National Bowel Cancer Screening Program invites people aged 50-74 years to participate (Department of Aged Health, 2022), it does not target people below 50 despite an increase in early onset bowel cancer incidence, and 63% of Australians at high risk of bowel cancer do not receive any bowel cancer screening (Akimoto et al., 2020; Dillon et al., 2018; Department of Health and Aged Care, 2022). Similarly, BreastScreen Australia actively invites women aged 50 to 74 for screening and offers women over 40 free

mammograms every 2 years (Department of Health and Aged Care, 2022). However, women in their 40s are not actively invited to screen, and BreastScreen Australia do not offer screening for women aged below 40. This is despite breast cancer being the most prevalent cancer diagnosis in women aged 20-39, and young women having lower survival rates from breast cancer (AIHW, 2022b). These programs do not adhere to Australia's vision of personalised care as screening is not tailored to individual patient's risk (Cancer Australia, 2022; Koczwara et al., 2021).

It has been recommended that risk-stratified cancer screening for breast and bowel cancer should be implemented (Hull et al., 2020; Stephenson, 2021). By targeting interventions for patient groups who will benefit most and reduce screening for those that will benefit least, risk-based cancer screening can increase the early detection of cancer with greater precision (Clift et al., 2021; Emery et al., 2023). This will reduce preventable deaths, unnecessary use of clinical resources and prevent the limited cancer care workforce from being further strained. As of 2023, there are no risk-based cancer screening programs in Australia, apart from a risk-based lung cancer program due to launch in 2025 (Cancer Australia, 2023).

Shifting from Australia's current one-size fits all approach to breast and bowel cancer screening will require greater primary care involvement in early detection. Primary care providers (PCPs) must be supported to play a bigger role in increasing patient acceptability

towards less screening for low-risk individuals; and upskilled to improve risk assessment and communication with patients (Keogh et al., 2019). Australia's limited cancer care

workforce issues need to be addressed before transitioning to a risk-based approach for bowel and breast cancer screening.

## Risk-based breast and bowel cancer screening

Risk-stratified screening programs are tailored based on individual-level risk factors (Dennison et al., 2023), to determine eligibility and how often individuals are screened, and have been shown to minimise overdiagnosis and unnecessary treatment for people with low-risk. Risk stratification can look like using factors such as genetic risk, family history and lifestyle factors (Hull et al., 2020; Phillips et al., 2019) to determine how often patients are screened and appropriate screening tests depending on their risk level (Dennison et al., 2023). This makes risk-based screening programs potentially more cost-effective than population-based screening (Clift et al., 2022; Emery et al., 2023). The benefits of risk-based screening have been recognised by the draft Australian Cancer Plan, as reflected by its priority to provide personalised evidence-based cancer screening for Australians (Cancer Australia, 2022).

Adapting cancer screening practices based on individuals' risk factors will be critical to optimising the delivery of cancer services. As opposed to Australia's current one size fits all approach to breast and bowel cancer screening, risk-based screening uses additional factors such as genetic data to calculate an individual's risk level rather than just age (Clift et al., 2021). Using a range of factors that have been deemed appropriate for breast and bowel cancer respectively ensures that risk-based screening programs are evidence-based,

increasing precision in estimating individual risk (Dennison et al., 2023).

This personalised approach to cancer screening requires a multi-step process, where each step ensures patient expectations are met:

- using risk prediction tools to assess the risk of cancer in individuals,
- assigning individuals to appropriate risk groups and
- delivering tailored interventions to each risk group (Pashayan et al., 2020).

Patient expectations include:

- having access to tailored information about their risk of cancer and
- having their cancer detected early if they have it (Breast Cancer Network Australia (BCNA), 2018).

### Maximising resources

Effective risk stratification ensures that the health system can meet patient needs for tailored guidelines on managing breast and bowel cancer risk, as well as decreasing resource wastage by delivering a more efficient service. Risk-based breast cancer screening generates 38.2% less false positives than age-based breast cancer screening (Burnside et al., 2019). Risk stratification for bowel cancer reduces the rate of unnecessary colonoscopies that people at low or average

risk of bowel cancer undergo (Emery & Saya, 2023). This means that patient groups that benefit most would have increased screenings while screening is reduced for those that benefit least (Hull et al., 2020). Consequently, risk stratification optimises accurate prioritisation of further treatment options for high-risk patients.

### Empowering patients

Risk-based early detection programs for bowel and breast cancer have been advocated by cancer researchers as an effective way to improve risk communication for patients (Hull et al., 2020; Phillips et al., 2019). Risk communication in general practice settings is crucial to improving the likelihood of patients accepting risk-based screening, such as being open to having less frequent screenings when they are determined to be at low risk (Dunlop et al., 2022; Rainey et al., 2018). Inconsistent messaging around the early detection of cancer has resulted in individuals misunderstanding risk management guidelines and scepticism about the purpose of risk-based screening (Dunlop et al., 2022; Keogh et al., 2019).

Risk assessment tools are web-based applications that provide individual risk estimates and tailored management guidelines (Phillips et al., 2019). They are imperative to providing consistent advice and improving patient knowledge about their perception of risk by acting as decision aids (Pashayan et al., 2020). Patients who are exposed to risk assessment tools are more likely to participate in bowel cancer screening (Hull et al., 2020). Likewise, breast cancer risk assessment tools facilitate patient access to tailored information on risk when healthcare providers require

additional support on risk management guidelines (Keogh et al., 2019). As part of a personalised approach to early detection of cancer, risk assessment tools offer valuable information on individualised levels of risk for patients. This is in agreement with national guidelines that champion a person-centred approach to delivering cancer care (Cancer Australia, 2022).

### A coordinated approach

For national risk-based breast and bowel cancer screening programs to be successful, healthcare providers and policymakers must collaborate to ensure that the programs are:

- deemed acceptable by patients (consumers) and healthcare professionals,
- equitably accessible,
- cost-effective and
- feasible.

Healthcare organisation readiness is vital in driving the success of personalised early detection programs (Pashayan et al., 2020). Australia's cancer care workforce needs to be sufficiently equipped with healthcare professionals who understand bowel and breast cancer risk to deliver tailored care to patients.

To achieve this, healthcare organisations should adopt a learning organisational culture where stakeholders (including policymakers) agree on a shared vision of a risk assessment model and screening recommendations (Pashayan et al., 2020).

Although there has been progress in developing risk stratification tools to offer personalised early detection of bowel and breast cancer (Emery & Saya, 2023; Phillips et

al., 2019), Australia still faces significant barriers to implementing robust personalised

early detection programs for bowel and breast cancer.

## Barriers to implementing risk-based cancer screening

Transitioning from a one size fits all approach to a risk-based bowel and breast cancer screening model requires primary care to have the capacity for increased patient consultations and to support patients' concerns and needs around individualised breast and bowel cancer management, such as how screening changes will affect low-risk patients. Applying a risk-based model to Australia's current population-based programs is impeded by the following:

- Limited cancer care workforce that is inadequately prepared to incorporate risk-based practices (Keogh et al., 2019)
- Patients misunderstanding cancer risk, affecting their acceptability towards risk-based screening (Dunlop et al., 2022; Keogh et al., 2019)

### Limited workforce

Australia's cancer care workforce, particularly in primary care, is unable to provide patients with personalised risk information and advice at the beginning of their early detection journey (Keogh et al., 2019). This can be attributed to the sustained lack of general practitioners (GPs), with an estimated 28% shortfall by 2032 (Royal Australian College of General Practitioners (RACGP), 2022a). The expected shortfall of PCPs worsened by reporting that less than 80% of younger GPs intend to remain practicing in 10 years' time (RACGP, 2022b). Challenges faced by primary care, in addition to the strain of an overcrowded hospital system, limit the potential of web-based risk assessment tools in informing risk-based screening practices.

### **Colorectal cancer RiSk Predictor tool (CRISP)**

CRISP is an online risk prediction tool that can be used in general practice settings to determine individuals' bowel cancer risk and the appropriate screening test for them (Emery et al., 2023). CRISP's screening recommendations will reduce colonoscopies in individuals with average risk so that a larger proportion of high-risk patients can undergo necessary colonoscopies. This outcome is in line with the National Cancer Policy's objectives for bowel cancer screening (Cancer Council, 2019).

In primary care, GPs and practice nurses can use CRISP to calculate a patient's individual bowel cancer risk and recommend the most suitable screening for that patient (Emery & Saya, 2023). CRISP differs from population-based screening as it calculates an individual's five year and lifetime risk of bowel cancer based on lifestyle, age and family history factors (Emery & Saya, 2023). With only 40.9% of eligible Australians completing the bowel test kit in the NBCSP (AIHW, 2022), early detection interventions such as CRISP are crucial to ensure individuals start bowel cancer screening at the optimal age with the most suitable test (Emery & Saya, 2023).

CRISP increased the number of patients choosing the most appropriate test for their risk level by 20% when paired with other primary care-based interventions such as SMS reminders and GPs showing patients how to complete the FOBT (Emery et al., 2023). This highlights its capacity to increase uptake in the right screening for bowel cancer patients (Emery & Saya, 2023), with its success hinging on GPs and practice nurses using it accurately.

However, primary care professionals currently lack confidence in managing cancer risk due to their unfamiliarity with online tools and demonstrated lack of knowledge to assess cancer risk (Phillips et al., 2019). Specialist health professionals have also shown distrust towards these online risk prediction tools when its risk estimates conflict with their opinion (Hull et al., 2020).

### **Misunderstanding and acceptability**

Misunderstanding of cancer risk challenges the adoption of risk-based screening due to patients' apprehension toward how risk-based screening will impact low risk individuals (Dunlop et al., 2022; Keogh et al., 2019; Phillips et al., 2019). Patients at low risk specifically are hesitant to accept having fewer screenings or having the starting age for screening pushed back, as highlighted by public opposition to the changes to the National Cervical Cancer Screening Program in 2017 (Keogh et al., 2019; Obermair et al., 2018). This hesitancy persists, despite research showing that not screening women at lower risk of breast cancer improves the cost-effectiveness of breast screening program,

compared to screening women aged 50-69 triennially (Pashayan et al., 2020).

Implementing screening changes based on risk stratification will be impacted by low-risk patients' acceptability towards how the changes affect them.

Patients across Australia have also expressed concern about PCPs' level of expertise in delivering tailored risk assessments, particularly their knowledge in using risk prediction tools (Dunlop et al., 2022). This perception of GPs impacts risk communication between GPs and patients, although this has been partially alleviated by the use of risk prediction tools (Rainey et al., 2018; Phillips et al., 2019) in general practice.

### **iPrevent Breast Cancer Risk Assessment and Management Tool**

iPrevent is an evidence-based breast cancer decision support tool that determines individual breast cancer risk and provides tailored risk management advice based on Australian National Guidelines (Phillips et al., 2019). Unlike BreastScreen that is targeted at women aged 50-74 years old, iPrevent is well-calibrated to predict risk for women younger than 50 years, which is superior to similar risk-prediction tools that underperform for this age group (Phillips et al., 2019).

Patients and clinicians have acknowledged the role of iPrevent as a risk assessment tool in bridging the gap where the current health workforce is unable to provide women with personalised risk information (Keogh et al., 2019). iPrevent encourages collaborative use between women and their clinicians and assesses breast cancer risk through the following process (Phillips et al., 2019):

- Obtains information on risk factors such as lifestyle, medical and family history.
- Provides 10-year and lifetime breast cancer risk estimate.
- Delivers a series of appropriate risk management options for woman depending on her risk level.

As iPrevent automates the selection of breast cancer risk estimation models to be used, patients and primary care professionals can use it themselves (Phillips et al., 2019) without prior expertise in breast cancer. This increases its usability compared to other risk prediction tools (such as Cancer Australia's 'Familial Risk Assessment – Breast and Ovarian Cancer') which PCPs are unfamiliar with using (Keogh et al., 2019).

iPrevent, as an example of a risk assessment and management tool, illustrates the potential for accessible, user-friendly risk prediction tools to:

- enable hospitals to focus on high-risk patients who require more intensive care (Keogh et al., 2019) and
- support PCPs with managing and assessing average and moderate risk patients.

However, while risk assessment tools can streamline cancer screening advice across clinics, primary care professionals' perceived lack of knowledge and low confidence in risk literacy prevents its use from being maximised in primary care settings (Keogh et al., 2019). For example, it has been reported that in

Victoria, women often have a lack of confidence in PCPs, perceiving them as being uninformed about breast cancer risk and risk management options (Keogh et al., 2019).

Supporting primary care, particularly the GP workforce, is crucial in ensuring that the implementation of a risk-based bowel and breast cancer screening approach is feasible and deemed acceptable by both patients and healthcare providers. The importance of primary care engagement with patients and its role in communicating the evidence for risk-based screening to patients has been highlighted by healthcare providers' perspectives on the acceptability of the National Lung Cancer Screening Program (Dodd et al., 2023)



## Recommendations

Given primary care's ability to provide ongoing care for patients and lead coordinated care, PCPs play a significant role in Australia's shift towards a personalised approach to the early detection of breast and bowel cancer.

Australia's healthcare system must better support PCPs before delivering personalised risk-based screening can occur.

### Develop a national roadmap for bowel cancer risk-based screening

A national framework that reviews bowel cancer screening should be developed to

assess risk-based approaches to bowel cancer screening, including in primary care, and create an evidence base of best practices for bowel cancer screening. Such a framework can establish best practice guidelines for the greater involvement of PCPs in delivering personalised care for the early detection of breast and bowel cancer.

A similar Cancer Council project that investigates personalised breast cancer screening is currently underway (Nickson & Tattam, 2021), and is funded by the Department of Health and Aged Care.

### Roadmap for Optimising Screening in Australia (ROSA)

ROSA's objective is to develop a framework for implementing risk-based breast cancer screening in Australia by considering the benefits, harms, and costs of different risk-based approaches (Nickson et al., 2019; Nickson & Tattam, 2021).

The framework is being developed through stakeholder consultations, reviewing BreastScreen Australia data, and international evidence. This includes working with the Australian Institute of Health and Welfare to examine opportunities for improving data collection and reporting of BreastScreen outcomes (Nickson & Tattam, 2021).

The ROSA project aims to answer questions such as appropriate screening technologies and intervals for different risk groups; which health professionals can be involved in risk assessment; which age groups to include in risk-based screening; and how GPs can be involved in risk-based screening (Nickson & Tattam, 2021).

### Establish national cancer risk literacy training programmes

There is a need to educate providers around specialised knowledge of cancer risk and better risk communication with patients.

Training and resources on cancer risk literacy that enable PCPs to offer personalised bowel and breast cancer risk management and screening advice should be introduced. The

delivery of these programs should be funded by the Department of Health and Aged Care under the Australian Cancer Plan.

Training in breast and bowel cancer risk management, including the use of risk assessment tools, will be critical to providing PCPs updated content knowledge and evidence-based responses to communicate with patients. PCPs will be better equipped to

address community concerns and increase support from patients during the transition to risk-based screening. This will increase the role of PCPs in assuring patients as healthcare provider recommendations have been proven to improve screening participation (Obermair et al., 2018).

Consideration could be given to developing public health awareness campaigns that address screening misconceptions that screening is universally beneficial regardless of individual risk levels. These campaigns should work with a range of trusted voices, including

community-based organisations, to reduce public mistrust.

Training programs should be accredited under the Continuing Professional Development (CPD) program for PCPs and reimbursed to ensure PCPs are financially supported in upskilling. The objectives of the proposed training and resources will be in line with the RACGP's key learning outcomes in the Australian General Practice Syllabus, particularly within the communication skills and applied professional knowledge domains (RACGP, 2018).

#### **Risk Communication Lessons from the National Cervical Screening Program Changes in 2017**

In December 2017, the NCSP transitioned from cytology-based screening in women from age 18 every 2 years to primary HPV screening every 5 years in women from age 25. This change sparked community concerns about the longer interval between screenings and pushed back starting age for screening, which culminated in an online petition with more than 70 000 signatures (Smith et al., 2019).

Although there were possible evidence-based responses that could have addressed these concerns (Obermair et al., 2018), not all healthcare providers were aware of such evidence or understood them. This resulted in patients' increased scepticism towards the changes as their healthcare provider also expressed apprehension.

Educating health providers about the rationale behind program changes in advance would equip providers with the relevant information and knowledge to communicate with patients, thereby increasing public acceptance (Obermair et al., 2018).

#### **Reform funding models for integrating shared early detection care**

Federal government funding for integrating shared care between PCPs and specialists should be increased. Integrating a shared care model for early detection of bowel and breast cancer will allow PCPs to be better supported by specialists in managing bowel and breast cancer when PCPs require further advice on

bowel and breast cancer knowledge that is not their area of expertise.

Funding for the general practice workforce should also be reformed to allow PCPs to deliver comprehensive care that is tailored to the individual needs of patients. A new funding model for general practice which will be more sustainable has been proposed during the 2022 General Practice Crisis Summit (RACGP, 2022).

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