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Cancer screening

Pros, cons, choice, and the patient

Background

Cancer is a major cause of disability and death in Australia, with three government funded screening programs now in place nationally. As cancer screening tests are performed on healthy asymptomatic members within the community, one needs to consider whether the potential gains will outweigh possible harms. There are challenges for both practitioners and consumers in communicating about screening in practice.

Objective

This article summarises the pros and cons of cervical, breast and colorectal cancer screening and discusses strategies for implementing informed choice in practice.

Discussion

Cancer screening has often focused on promoting maximum participation. All consumers should have access to balanced information about the pros and cons of screening, and there is now evidence from Australian studies of evidence based decision aids that being informed does not impact on participation rates. For some, this will mean 'accepting the offer' of the screening program and should include an open explanation and discussion of the basis for the recommendation or offer; encourage and facilitate an individual assessment of the recommendation or offer (including consideration of the potential bias and trustworthiness of those making it and of its personal relevance); provide or facilitate access to further information if that is required; and acknowledge that the recommendation or offer might reasonably be refused. Others will prefer to 'analyse and choose' from more detailed information such as decision aids. Tools for practitioners and consumers should mirror this two tiered approach and facilitate a balanced approach to cancer screening in practice.

■ **Cancer, along with cardiovascular disease, remains a major cause of death in Australians, despite considerable gains in cancer control over the past few decades.¹ Cancer is the leading contributor to Australia's total burden of disease and injury. It contributed 19% of total disability adjusted life years (DALYs) followed by cardiovascular disease (17%) and mental disorders (13%). (One DALY is equivalent to 'one healthy year of life lost' and attempts to take into account premature death and disability.)**

The most common overall cause of cancer death in Australia in 2003 was lung cancer, followed by colorectal, non-Hodgkin lymphoma and melanoma. However, the most common cancer diagnosed (excluding nonmelanocytic skin cancer) was prostate (13 526 cases), followed by colorectal (12 536), breast (11 899), melanoma (9524) and lung cancer (8249).² Thus, due to a range of factors including the natural history of some cancers and available diagnostic and treatment options, a person is more likely to die 'with' some cancers than 'from' them.

Screening as a strategy for cancer control

Screening is different to diagnosis. Patients presenting with signs such as a breast lump or rectal bleeding need diagnostic investigation, not screening tests within screening services. It is important to be clear among ourselves and with our patients that:

- screening is performed on people without symptoms
- screening does not provide a diagnosis, rather identifies people at increased risk for follow up diagnostic testing
- screening should identify those at sufficient risk to warrant further investigation (considering follow up may be costly and intrusive and there should be enough potential benefit to warrant this).

The Royal Australian College of General Practitioners (RACGP) *Guidelines for preventive activities in general practice* quotes the United Kingdom definition of screening which states that: 'screening involves asking questions of, or conducting tests on, patients to identify those individuals who are more likely to be helped than



harmful by further tests or treatment to reduce the risk of a disease or its complications'. The RACGP guidelines, however, also take into account the World Health Organization (WHO) definition and have established recommendations for screening in Australian general practice (*Table 1*).³

Cancer screening has been a substantial recipient of health expenditure over recent years. Australia provides publicly funded population screening programs for breast, cervical and colorectal cancer (CRC). Australian health departments in 2006–2007 spent an estimated \$262 million, or 15.3% of all public health expenditure, on screening programs.⁴ This amount is roughly equivalent to public expenditure on communicable disease control and health promotion programs addressing health risk factors. It does not include expenditure on screening that occurs outside population programs, such as prostatic specific antigen (PSA) testing in healthy men, skin cancer checks, colonoscopy in low risk individuals and cancer screening outside recommended age categories. The total health bill for cancer screening in Australia is therefore likely to be much higher.

Screening appropriately for cancer risk

While population based screening programs are based on a benefit-risk ratio for the majority of the population, there is a small but significant group of the population with a higher risk due to genetic or familial factors. It may not be appropriate for them to participate in the same type of cancer screening programs as those of low and average risk (see the article by Emery et al, this issue).

Pros and cons of screening

Mammography screening for breast cancer

Australia has offered screening mammography every 2 years to women aged 50–69 years without symptoms since 1991. The incidence of breast cancer in this age group increased from 269.0 per 100 000 women in 1996 to 288.0 per 100 000 women in 2004, but mortality from breast cancer decreased from 61.5 per 100 000 women in 1996 to 51.8 per 100 000 women in 2005.⁵ It is difficult to know how much of the increase in incidence is due to potentially inconsequential disease such as some forms of ductal carcinoma in situ (DCIS), which were often not diagnosed before screening and are of uncertain clinical significance.

A Cochrane systematic review of seven randomised controlled trials has concluded that there is a likely reduction in breast cancer mortality of approximately 15% as a result of biennial mammographic screening. Based on the risk level of women in the trials, this translates to an absolute risk reduction of 0.05%. The review also concluded that mammography screening leads to over diagnosis and over treatment, with an estimated 30% increase, or an absolute risk increase of 0.5%. The authors estimate that for every 2000 women invited to screening over 10 years, one will have her life prolonged, but 10 healthy women will be treated unnecessarily.⁶ These findings have been the source of much debate and controversy.

Table 1. The RACGP recommendations for screening

- The condition
 - should be an important health problem
 - should have a recognisable latent or early symptomatic stage
 - the natural history of the condition, including development from latent to declared disease, should be adequately understood
- The test
 - should be simple, safe, precise and validated
 - should be acceptable to the population targeted
 - the distribution of test values in the target population should be known and a suitable cutoff level defined and agreed
- Treatment
 - there should be an effective treatment for patients identified, with evidence that early treatment leads to better outcomes
 - there should be an agreed policy on who should be treated and how
- Outcome
 - there should be evidence of improved mortality, morbidity or quality of life as a result of screening and that the benefits of screening outweigh any harm
 - the cost of case finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole
- Consumers
 - should be informed of the evidence so they can make an informed choice about participation

Nevertheless, an important principle is to realise that as a woman's breast cancer risk increases with age, her mortality reduction from screening will potentially be greater in absolute terms because more women in older age groups will get breast cancer and have their cancers detected by screening. In addition, the number of false positives declines slightly with age so the net benefit is greater in women aged 50–69 years compared with women aged 40–49 years⁷ (*Table 2*). Possible additional advantages, such as having the option of breast conserving surgery as a result of earlier detection, are difficult to quantify but will also be important for many women as one considers the overall benefit-harm ratio.

Pap testing for cervical cancer

Australia has the second lowest incidence of cervical cancer in the world and it is the ninth most common cancer in Australian women. Cervical screening became available in the 1960s but was not formally organised until 1991 when the National Cervical Screening Program (NCSP) commenced. Two yearly Pap tests were recommended for women aged 20–69 years and Pap test registers were established. Since then, cervical cancer mortality rates have fallen from 4.0 per 100 000 in 1991 to 1.8 per 100 000 in 2004.⁸

Yet, despite this apparent 'success', some have questioned whether Pap testing results in an unacceptable level of over detection



of potentially inconsequential disease. With new knowledge about human papilloma virus (HPV) and its role in the pathogenesis of cervical cancer and uncertainty about the long term effects of HPV vaccination, it is increasingly difficult to have an informed discussion with women about the likely outcomes of Pap testing for them.

Recent changes in the Australian guidelines for management of abnormal Pap tests reflect new knowledge that the majority of low grade abnormalities will regress spontaneously and even higher grade lesions such as CIN2 (50%) and CIN3 (20%) are likely to regress to normal.⁹ The main factors that increase the chance of progression from high grade intra-epithelial lesions (HSIL) to squamous cell carcinoma are an older age at diagnosis (ie. >50 years), the extent of the HSIL on the cervical epithelium, and the degree of cytological abnormality (CIN2<CIN3).

It has been shown that follow up testing associated with an abnormal Pap result incurs substantial loss of quality of life,¹⁰ negative psychological effects,¹¹ and possibly increased risk of preterm birth for many women.¹² Therefore, it is also important to weigh up the potential benefits and harms of cervical screening.

Faecal occult blood testing for CRC

Biennial faecal occult blood test (FOBT) screening for CRC is the newest population cancer screening program in Australia, the UK and Canada. There is good evidence from a systematic review of three large randomised trials that biennial FOBT reduces CRC mortality by approximately 16% (after adjustment

for participation).¹³ As with other cancer screening tests, there is a chance of false positives which in this case will result in an unnecessary colonoscopy. The principle of weighing up the net potential benefit against harms also applies in this case, with patients at higher baseline risk due to age, male gender or family history being more likely to benefit than those with lower baseline risks. More CRC deaths will be averted in higher risk groups but the risk of false positives remains fairly constant across all categories. In other words, the harms are likely to outweigh the benefits in younger people with no family history, hence the recommendation to start screening in people over the age of 50 years in Australia.

Informed choice for cancer screening: debates and controversies

While these cancer screening programs offer the potential benefit of cancer mortality reduction to their target population groups, there will be a trade off in false positive results and not all cancers will be detected by the recommended screening regimens. Many have argued that healthy 'screenees' have the right to know possible limitations as well as benefits of screening tests. Despite recommendations that consumers who participate in cancer screening should be informed of this evidence, there has been concern that this will lead to a fall in participation rates. Recent Australian randomised trials of evidence based decision aids for mammography screening in women over 70 years of age and in people 50–69 years of age eligible for FOBT screening

Table 2. Model of outcomes of mammography

1000 women aged 50 years who have biennial mammograms for 10 years	1000 women aged 50 years who do NOT have biennial mammograms for 10 years
242.0 recalled for extra tests	0
17.6 invasive breast cancer screen detected	0
10.4 develop interval breast cancer*	0
28.1 diagnosed with invasive breast cancer	19.8 diagnosed with invasive breast cancer
4.9 have DCIS diagnosed**	0.4 have DCIS diagnosed
32.9 breast cancer diagnosis of any type	20.2 breast cancer diagnosis of any type
4.0 die from breast cancer	5.9 die from breast cancer
1000 women aged 40 years who have biennial mammograms for 10 years	1000 women aged 40 years who do NOT have biennial mammograms for 10 years
250.9 recalled for extra tests	0
8.5 invasive breast cancer screen detected	0
9.1 develop interval breast cancer*	0
17.6 diagnosed with invasive breast cancer	13.2 diagnosed with invasive breast cancer
3.4 have DCIS diagnosed**	0.3 have DCIS diagnosed
21.0 breast cancer diagnosis of any type	13.5 breast cancer diagnosis of any type
2.0 die from breast cancer	2.5 die from breast cancer
* Interval breast cancers develop between screens	
** DCIS = ductal carcinoma in situ and is of unknown clinical significance	



showed that people were better informed but no less likely to participate in screening after viewing the decision aids which contained information about both the potential benefits and harms of screening.^{14,15} The exception to this was prostate cancer screening where the evidence of benefit is uncertain and an evidence based decision aid significantly reduced PSA uptake with men being better informed.¹⁶

Consumers can obviously take into account the benefits and risks of screening. In fact, it seems from these studies that some people value cancer screening so highly that they may choose to continue screening even if the potential benefit does not clearly outweigh the harm in their case. The studies also show that the factors most likely to reduce participation are not cognitive, but practical, such as busy lifestyle, the unpleasantness or inconvenience of the test, or other competing health factors. The RACGP recommends informed choice within their guidelines. Better quality information resources with evidence about the benefits and risks of cancer screening need to be more actively disseminated for use by practitioners and consumers.

However, there are some issues that can mitigate against the implementation of this approach. For example, in the UK and Australia, new quality frameworks, performance indicators and incentives are sometimes not well aligned with a patient centred model of informed choice for preventive health care activities. The National Health and Hospital Reforms Commission proposed consideration of a range of indicators within the next Australian Health Care Agreements, including the proportion of women aged 50–69 years having a mammogram in the previous 2 years. The Australian Government's proposed reforms to primary care are likely to promote the incentive payment system which currently includes payments for cervical screening program participation rates and may extend to other forms of cancer screening. This can put general practitioners in a difficult situation and it deserves a more open debate within the community about incentive payments and their potential role on informed choice.

Strategies for communicating about screening in clinical practice

One of the challenges for GPs when communicating about screening is that two of the three cancer screening programs (breast and colorectal) do not involve GPs at the point of invitation to screen. This occurs despite the fact that many consumers consider the GP their preferred source of information about screening, and leaves many to perhaps discuss cancer screening with their GPs during other health consultations. Alternatively, they rely solely on the information provided by screening programs or obtained from the internet, friends or relatives. This is particularly the case for the National Bowel Cancer Screening Program where screening occurs in the absence of a health care provider. Many screening program publications emphasise the potential benefits of screening and de-emphasise or even omit information about the potential

downsides of screening, including the complications of follow up testing and the limitations in accuracy of the test itself. This is not surprising given that they are evaluated on their participation rates.

Evidence based decision aids for cancer screening have been developed to provide balanced information about the pros and cons of screening and to help people weigh this up for themselves. Such tools have been criticised as being overly complex and unnecessary, although some consumers will find them extremely helpful and rate them very highly.

Recently, it has been suggested that a more pragmatic approach to screening discussions be adopted. It acknowledges many people will be happy to accept the expert view of policy makers that on average, the net benefits will outweigh the harms in a particular population group. This has been called the 'consider an offer' approach and it relies on the fact that people feel they have sufficient information to accept or reject the offer and that the information comes from a trustworthy source.¹⁷ This information could be in the form of a balanced leaflet from a screening program or a discussion with their health care provider. The 'consider an offer' approach should include an open explanation and discussion of the basis for the recommendation or offer, encourage and facilitate an individual assessment of the recommendation or offer (including consideration of the potential bias and trustworthiness of those making it and of its personal relevance), provide or facilitate access to further information if required, and acknowledge that the recommendation or offer might reasonably be refused.

This approach leaves more detailed tools such as decision aids as second line for those who want more information in what the same paper describes as the 'analyse and choose' approach. Quantification of screening outcomes can be provided for different risk groups, particularly via online tools and these can allow individuals to weigh up their personal benefits and harms according to baseline risk (*Figure 1, 2*).

Conclusion

Three organised screening programs for cancer screening have been established by the Australian Government. All are effective strategies for reducing cancer deaths by around 15–20%. However,

Figure 1. Online bowel cancer screening decision aid

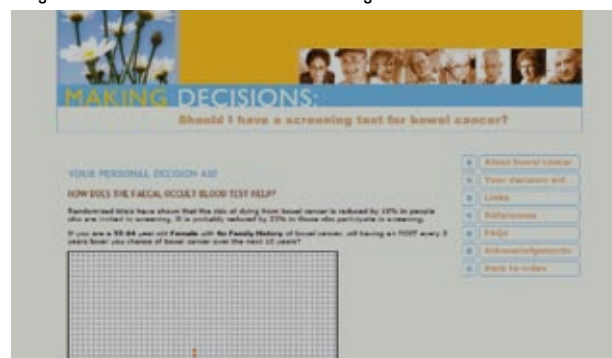
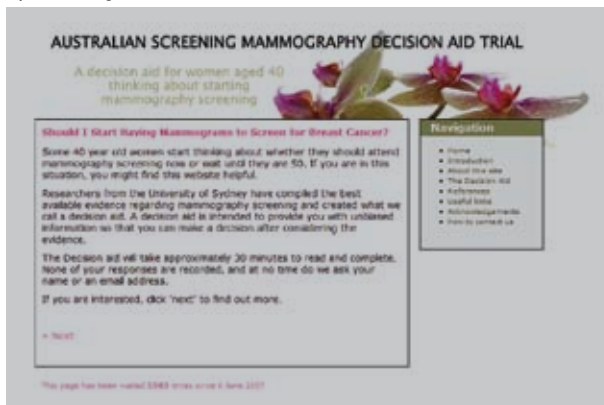


Figure 2. Mammography screening decision aid for women 40–49 years of age



in each case, there are downsides with false positives and follow up testing that have potentially harmful health and psychological outcomes. The higher a patient's baseline risk of the cancer, the more likely the benefit to harm ratio will be positive. Given that screening is offered to healthy individuals, the net benefit should outweigh the harm. Evidence from Australian randomised controlled trials has shown that decision aids can significantly increase consumer understanding about the benefit and harms of cancer screening without reducing participation rates.

All Australians should have the opportunity to access information about the benefit and limitations or harms of cancer screening tests. Although many will likely find the 'consider an offer' approach sufficient, some will prefer to 'analyse and choose'. Whether information is in brochure format or more detailed decision aids, it should be balanced and transparent in informing consumers about benefits and harms arising from screening. Cancer screening tests are limited in their effect and perhaps the future lies in a more holistic approach to cancer prevention that includes primary prevention through lifestyle modification. Such risk factors account for around 33% of the total cancer burden. Compare this with the effect of cancer screening tests and there is perhaps some 'food for thought'.

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References

1. Australian Institute of Health and Welfare. Australia's health 2008. Cat. no. AUS 99. Canberra: AIHW, 2008.
2. Australian Institute of Health and Welfare & Australasian Association of Cancer Registries. Cancer in Australia: an overview, 2006. Cancer series no. 37. Cat. no. CAN 32. Canberra: AIHW, 2007.
3. The Royal Australian College of General Practitioners. Guidelines for preventive activities in general practice. 6th edn. South Melbourne: The RACGP, 2005.
4. Australian Institute of Health and Welfare 2008. Public health expenditure in Australia, 2006–07. Health and welfare expenditure series no. 34. Cat. no. HWE 41. Canberra: AIHW, 2008.
5. Australian Institute of Health and Welfare 2008. BreastScreen Australia monitoring report 2004–2005. Cancer series no. 42. Cat. no. CAN 37. Canberra: AIHW, 2008.
6. Gøtzsche P, Nielsen M. Screening for breast cancer with mammography. Cochrane Database Syst Rev 2006(Issue 4):Art. No.: CD001877. DOI: 10.1002/14651858.CD001877.pub2.

7. Barratt A, Howard K, Irwig L, Salkeld G, Houssami N. Model of outcomes of screening mammography: information to support informed choices. *BMJ* 2005;330:936–40.
8. Australian Institute of Health and Welfare. Cervical screening in Australia 2004–2005. Cancer series no. 38. Cat. no. CAN 33. Canberra: AIHW, 2007.
9. National Health and Medical Research Council. Screening to prevent cervical cancer – Guidelines for the management of asymptomatic women with screen detected abnormalities. Commonwealth of Australia. 2005. Available at www.nhmrc.gov.au/publications/synopses/_files/wh39.pdf [Accessed 22 December 2008].
10. Insinga R, Glass A, Myers E, Rush B. Abnormal outcomes following cervical cancer screening: event duration and health utility loss. *Med Decis Making* 2007;27:414–22.
11. Kahn J, Slap G, Bernstein D, et al. Personal meaning of human papillomavirus and Pap test results in adolescent and young adult women. *Health Psychol* 2007;26:192–200.
12. Samson S-L, Bentley J, Fahey J, McKay D, Gill G. The effect of loop electro-surgical excision procedure on future pregnancy outcomes. *Obstet Gynaecol* 2005;105:325–32.
13. Hewitson P, Glasziou PP, Irwig L, Towler B, Watson E. Screening for colorectal cancer using the faecal occult blood test, hemoccult. *Cochrane Database Syst Rev* 2007, Issue 1. Art. No.: CD001216. DOI: 10.1002/14651858.CD001216.pub2.
14. Mathieu E, Barratt A, Davey H, McGeechan K, Howard K, Houssami N. Informed choice in mammography screening: A randomized trial of a decision aid for 70-year-old women. *Arch Intern Med* 2007;167:2039–46.
15. Trevena L, Irwig L, Barratt A. Randomised trial of a self-administered decision aid for colorectal cancer screening. *J Med Screen* 2008;15:76–82.
16. Gattellari M, Ward J. Does evidence-based information about screening for prostate cancer enhance consumer decision-making? A randomised controlled trial. *J Med Screen* 2003;10:27–39.
17. Entwistle V, Carter S, Trevena L, et al. Communicating about screening. *BMJ* 2008;337:a1591.