Moving forward on bowel cancer screening in Australia

Report of a national discussion forum hosted by The Cancer Council Australia on 20 November 2006 and sponsored by the Australian Department of Health and Ageing.
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Responsibility for content is taken by the Chief Executive Officer of The Cancer Council Australia, Professor Ian Olver. Correspondence to Paul Grogan, c/o paul.grogan@cancer.org.au

Acknowledgement of traditional owners

The Cancer Council Australia acknowledges the Wrundgeri people, the traditional owners of the land on which the forum was held. Special thanks to Wrundgeri tribal elder, Aunty Joy Murphy-Wandin, for providing a Welcome to Country to begin the forum program.
Executive Summary

In 2006 the Australian Government funded The Cancer Council Australia to host a national discussion forum on bowel cancer screening in Australia. The aim was to bring national and international leaders in bowel cancer screening together to share their expertise, examine the latest evidence and invite key stakeholders with a professional or personal interest in bowel cancer screening to participate in the discussion.

This report summarises the presentations, discussions and recommendations from the forum, which was titled 'Moving forward on bowel cancer screening in Australia' and held in Melbourne on 20 November 2006.

While it is a matter for government to determine how the program is to be administered, as Australia’s peak non-government national cancer control agency, The Cancer Council calls on all jurisdictions to ensure the National Bowel Cancer Screening Program is introduced according to the principles of best practice highlighted at the forum.

Evidence

Level one evidence has been available for more than a decade demonstrating the effectiveness of population-based bowel cancer screening in significantly reducing bowel cancer mortality rates among the target population screened.

Data and expert opinion presented at the forum showed that bowel cancer screening effective in clinical terms and that Australia is well-placed to introduce a successful population-based screening program.

Dr Chris Stevenson discussed how the pilot studies in Australia supported international trials showing the effectiveness of bowel cancer screening. The studies indicated that, for the program to be effective nationally, additional effort would be required to:

- understand and overcome barriers to participation among men, Indigenous and non-English speaking population groups and people with a disability to ensure equal opportunity to participate;
- track participants through the screening pathway; and
- improve access to histology data to confirm colonoscopy outcomes (particularly stage of cancer at detection).

The program’s overall effectiveness should also be monitored, including throughout the phase-in period, to facilitate continual improvement based on demonstrated need.

Marissa Otuszewski discussed key elements of the screening program from the Commonwealth perspective, which was of particular interest to administrators and practitioners in the jurisdictions where screening has not commenced. A key to cooperative, multi-jurisdictional support for the program is the endorsement by the Australian Health Ministers’ Conference of a strategy to develop national minimum standards for colonoscopy services.
Quality control

Insights into one of the core challenges of running a national screening program – meeting colonoscopy demand – were provided by Dr Roland Valori from the UK. The principles of best practice employed in the UK are underpinned by a patient-centred, quality assurance framework, built around a range of new tools, techniques, and training designed to ensure clearly articulated and measurable minimum standards are met. Fundamental to the framework was a Global Rating Scale, which Dr Valori believed would be adaptable to the Australian context and useful to underpin best practice.

Mr Andrew Luck expanded on quality issues in an Australian context, concluding that, while colonoscopy in Australia was generally performed at a high level, there were insufficient controls to ensure uniform minimum standards, as formal recognition by the national quality assurance mechanism is voluntary. A NSW Health perspective showed steps that were taken at state level to accommodate increased colonoscopy demand.

Perspectives from general practice and nursing showed how those disciplines could play a significant role in the successful administration of the program.

Screening participation

Additional evidence was presented showing the need for measures to maximise screening participation rates, particularly among population groups with reduced access to screening. Resources are also needed to help ensure eligible people would not drop out of screening programs, and research is required to monitor cost-effectiveness.

Discussion

The panel discussion, along with the forum’s high attendance (120 delegates), reflected the extent of goodwill towards making the National Bowel Screening Program work effectively across jurisdictions. The diversity of views, experience and areas of interest among the group also reflected the complexity of the program and the need for jurisdictions to work in a structured way towards the implementation of bowel cancer screening, according to agreed principles of best practice.

Forum evaluation

Feedback from forum delegates collected through a formal evaluation process indicated that the event was successful in terms of meeting delegate expectations, with 55 of 65 respondents stating that they would recommend a similar event to colleagues, and the same proportion reporting satisfaction with the level of interactivity.
Recommendations

Based on the evidence, information, expert opinion and concerns discussed throughout the forum, The Cancer Council Australia recommends that a detailed framework for the program’s ongoing delivery, articulating the roles and responsibilities of jurisdictions, be funded and endorsed through a robust, rigorous agreement.

Such a framework would be based on the evidence and expert opinion on best practice and incorporate the recommendations following, where appropriate in the context of a federal-state/territory agreement.

- A system for adequate data collection and analysis ensuring that the program’s effectiveness can be measured and that the program can be continually adjusted according to demonstrated need.
- A national approach, agreed to and supported by all jurisdictions, to underpin quality assurance in program delivery, including workforce planning, training and support.
- Inter-jurisdictional agreement on minimum standards and the establishment of a mandatory mechanism to monitor quality controls in colonoscopy provision.
- Forward planning and investment to manage colonoscopy waiting lists.
- Further development of formal measures to support GPs in the performance of their key role in the program.
- Monitoring of participation in the program and investment in targeted communication strategies to reach population groups that are shown to experience lower participation rates, such as men, Indigenous and non-English speaking population groups and people with a disability.
- Further consideration of the role of GE nurses in contributing to the National Bowel Cancer Screening Program.
Introduction

Bowel (colorectal) cancer is the most common potentially fatal cancer in Australia and, after lung cancer, the cause of the most cancer deaths. Around 13,000 new cases are diagnosed and more than 4700 people die of bowel cancer each year.

Evidence shows that population-based bowel cancer screening, using a faecal occult blood test, can reduce bowel cancer deaths through early detection of cancer or precancerous conditions by up to 40% among the screened population. So The Cancer Council Australia emphatically welcomed the Federal Government’s commitment, in the 2005-06 Budget, to phase in a national bowel cancer screening program.

For the screening program to reach its potential to reduce bowel cancer death and disease, numerous sectors and professions will need to coordinate their efforts – federal and state-territory governments, public and private hospitals, non-government organisations; colonoscopy services, general practitioners, nurses, clinical data managers, pathologists, educators and many others.

On behalf of The Cancer Council Australia, I thank the Australian Department of Health and Ageing for sponsoring ‘Moving forward on bowel cancer screening in Australia’. The forum provided an opportunity for key players in bowel cancer screening to share their expertise and discuss the issues.

I also thank the distinguished speakers who comprised an excellent program, particularly Dr Roland Valori, National Clinical Lead – Endoscopy, UK. Dr Valori has worked closely with the UK Bowel Cancer Screening Program, preparing a quality assurance framework and a strategy for a three-year roll-out which began in July 2006. Forum evaluation indicated that Dr Valori’s presentation was particularly useful to attendees.

Finally, I thank The Cancer Council Victoria for doing much of the organisational work for this event, with the support of a national planning committee.

I hope this report of the day’s discussion and outcomes provides valuable information to assist the development of Australia’s National Bowel Cancer Screening Program.

Ian Olver
Chief Executive Officer
The Cancer Council Australia
SESSION 1

Chaired by Professor Ian Olver
Chief Executive Officer
The Cancer Council Australia

Bowel cancer screening – setting the scene
Professor Graeme Young, Flinders University

Abstract

Colorectal cancer (CRC) affects almost one million people worldwide each year. Its incidence is increasing rapidly in westernising countries. In Australia, the actual number of cases is likely to increase by 25% in the next decade and it is the commonest malignancy. The development of CRC is characterised by a long latent pre-cancer period and once cancer has developed it appears to remain curable for some years. Early detection by screening asymptomatic people has been shown in randomised population trials to decrease mortality and incidence, when undertaking two-step screening using an early version faecal occult blood test (FOBT). There is a range of options for screening tests, but the evidence base is weak for some. These options are variably applied around the world but the major ones in use are one step screening by colonoscopy and two-step screening by FOBT. More recently, a technological advance in FOBT termed faecal immunochemical test for haemoglobin (FIT) has proved superior to early FOBT. FIT usage is increasing around the world.

Screening program structure takes two main forms: opportunistic screening supported by test reimbursement and usually implemented in the context of a physician-doctor consultation, and structured population screening where the goal is to maximise population engagement and ensure a cost-effective outcome.

The first national programs were implemented in Japan and Germany but the most comprehensive centrally organised programs are now being undertaken in the UK, France, and Australia. Many other countries are also in the process of planning or implementing large-scale programs that are likely to become national.

Others persist with a model that is ad hoc and based on reimbursement (USA, Germany). The Australian program has several unique features and is likely to be a model for other countries to follow.
Discussion

Professor of Gastroenterology at Flinders University, Graeme Young is a leading international authority on bowel cancer and is an adviser to the Australian Government on bowel cancer screening.

In “setting the scene” in Australia, Professor Young emphasised the following key points:

- The introduction of bowel cancer screening in Australia is one of the most important developments in public health, and has been supported by evidence for 10 years;

- The projected burden of cancer – a 33% increase in incidence between 2002 and 2010, with further expected increases linked to population ageing thereafter – adds to the need for a population-based bowel cancer screening program in Australia;

- Evidence of the effectiveness of bowel cancer screening is “overwhelming”, showing a potential for a 40% decrease in bowel cancer mortality among the screened cohort and a 20% decrease in bowel cancer incidence through the detection of precancerous conditions;

- Bowel cancer screening is clearly cost-effective: the burden of disease caused by later-stage diagnosis would be significantly reduced through screening;

- The World Health Organisation Principles of Screening (see figure 1), which should be adhered to as a matter of course, make a clear case for the introduction of bowel cancer screening in Australia;

- Varied approaches to bowel cancer screening are required across different population groups, in a global and domestic context. For example, research
shows the immunochemical FOBT kit is more suited to the Australian environment predominantly because it generates higher participation rates here;

- Additional measures need to be taken to maximise participation rates among specific population groups;

- Innovative approaches, and ongoing research (including global randomised control trials) will be required to address the increased demand on colonoscopy services associated with bowel cancer screening.

**Conclusion**

Professor Young concluded with a view that Australia is well-placed to achieve high participation rates if the bowel cancer screening program is delivered according to the evidence and the principles of screening.
The national bowel cancer screening program

Dr Chris Stevenson, Australian Institute of Health and Welfare
Marissa Otuszewski, Australian Department of Health and Ageing

This presentation consisted of three parts: a statistical analysis of the pilot studies and an overview of monitoring required to measure the program’s ongoing effectiveness, provided by Dr Stevenson, and administrative information about the Australian Government’s proposed screening program from Ms Otuszewski.

Abstract

The bowel cancer screening pilot and its findings – Dr Chris Stevenson

The Australian Bowel Cancer Screening Pilot Program was conducted in Mackay, Melbourne and Adelaide during 2003 and 2004. The primary aim was to provide information about the feasibility, acceptability and cost effectiveness of bowel cancer screening amongst the Australian population in both rural and urban areas. This presentation will present key results from the analysis of the pilot monitoring data and describe some implications of these results for the National Bowel Screening Program’s design.

Discussion

Dr Stevenson, a distinguished epidemiologist and biostatistician, discussed the Australian bowel cancer screening pilot studies in detail. His presentation emphasised:

- the need for population diversity, hence the different demographic groups targeted by the three pilots;
- that positive FOBT did not mean cancer in the majority of cases (see figure 2);
- the importance of ensuring that the FOBT is packaged and presented in ways that maximise screening participation and the correct use of the test kit;
- that the immunochemical FOBTs used in Australia were more sensitive than the guaiac test used in the United Kingdom, meaning that Australia would detect a higher proportion of cancers along with greater numbers of non-cancerous conditions related to blood in the faeces (see figure 2);
- the value of the large sample size, with 57,000 people receiving FOBT kits;
• the variability of participation rates, depending on a range of issues. For example, as well as the cultural and gender barriers to access (i.e. Indigenous people, people of cultural and linguistically diverse background and men having comparatively lower participation rates), older women were less likely to participate than younger women, while the reverse applied in men.

Figures 3-6 provide participation rates analyses from the pilot studies presented by Dr Stevenson.

Dr Stevenson stressed that while some parallels could be drawn between the established breast and cervical screening programs in Australia and bowel cancer screening, unlike Pap testing and mammography, FOBT was essentially a self-test.

Conclusion

Dr Stevenson concluded that the pilot studies confirmed the feasibility of bowel cancer screening in Australia and the potential for reduced mortality consistent with the evidence. The studies indicated that, for the program to be effective nationally, additional effort would be required to:

• understand and overcome barriers to participation among men, Indigenous and non-English speaking population groups and people with a disability to ensure equal opportunity to participate;
• track participants through the screening pathway;
• improve access to histology data to confirm colonoscopy outcomes (particularly stage of cancer at detection).

<table>
<thead>
<tr>
<th>Test positivity (%)</th>
<th>PPV cancers (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aust. Pilot</td>
<td>7.8</td>
</tr>
<tr>
<td>UK Pilot (Scotland)</td>
<td>2.1</td>
</tr>
<tr>
<td>UK Pilot (England)</td>
<td>1.6</td>
</tr>
<tr>
<td>Nottingham RCT</td>
<td>2.1</td>
</tr>
<tr>
<td>Funen RCT</td>
<td>1.0</td>
</tr>
</tbody>
</table>

*Test positivity = the number of tests requiring further investigation divided by the number of correctly completed tests; “PPV (positive predictive value) cancers” = the proportion of positive tests shown on follow-up to be cancer or adenoma.

The lower ratio of cancer cases to positive FOBT in Australia reflects a more sensitive Australian test that detects a higher rate of non-cancerous conditions linked to faecal blood. Dr Stevenson reported that, if Australia were to reduce the sensitivity of testing to levels comparable with those overseas, we would be at risking of missing up to 40% of cancers and 51% of adenomas.
Figure 3 - Pilot participation by time after mail-out

FOBT Participation (per cent)

Weeks following invitation

Figure 4 - Pilot participation by site

FOBT Participation (per cent)

Weeks following invitation

Mackay
Adelaide
Melbourne
All sites
Abstract

Bowel cancer screening: how do we measure success? – Dr Chris Stevenson

A key part of monitoring and evaluating any health intervention is to define what constitutes success for that intervention and how we would measure whether or not the intervention has achieved this success. This presentation will present an overview of the objectives of the National Bowel Screening Program and what data are needed to monitor the program’s success in meeting these objectives.

Discussion

The second part of Dr Stevenson’s presentation explored the rationale for collecting “monitoring data” to help ensure the bowel cancer screening program was effective and could be adjusted according to changing needs.

He advised that monitoring data were different to the epidemiological data needed to evaluate the clinical effectiveness of a program and to ensure appropriate patient management. Effective monitoring data were less detailed and with fewer indicators than clinical and formal evaluation data, but would usually be collected more frequently. A small, more focused, set of indicators allows clearer and easier interpretation than a larger more detailed monitoring data set.

“Final” outcome measures of the program’s effectiveness might include:

- incidence reduction; and
- mortality and morbidity reduction.

However, because of the time lag between screening and incidence, or mortality and morbidity reduction – and the uncertainty of the link between screening and any subsequent incidence or mortality/morbidity reduction – direct measures of cancer incidence, morbidity and mortality are necessary, but not sufficient, for monitoring the program’s effectiveness.

Intermediate measures

To help ensure the program is continually adjusted according to need in the period between commencement and full evaluation, a number of intermediate outcome measures are required:

- participation:
  o how many people complete an FOBT?
  o do these people represent the diversity in Australia?
• **FOBT outcome:**
  - how many FOBT kits were positive, negative or inconclusive?
  - how many FOBT kits were incorrectly completed (classified by population group)?

• **GP visit (classified by population group):**
  - how many people with a positive FOBT result attended a GP?
  - how many of these were appropriately referred for follow-up?

• **colonoscopy follow-up (classified by population group):**
  - how many people with a positive FOBT result have a colonoscopy?
  - was the colonoscopy ‘adequate’?
  - how many early stage cancers or high-risk polyps were detected?
  - were there any adverse outcomes?

• **participation in subsequent screening rounds (classified by population group):**
  - of the people who are reinvited for screening, how many return a completed FOBT kit? (classified by population group)
  - initially only for people who were part of the pilot.

### Future data collection, ‘interval’ cancers

Dr Stevenson concluded with advice that, as the program gained momentum, new priorities would emerge in the collection of monitoring data, such as recording the number of people with a negative FOBT result who were diagnosed with bowel cancer before their next scheduled test.

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**Abstract**

**The National Bowel Cancer Screening Program**

- Marissa Otuszewski

The National Bowel Cancer Screening Program commenced roll-out on 7 August 2006. This presentation will outline the key elements of the National Bowel Screening Program, as well as activities the Commonwealth [Australian] Government is undertaking to maximise equitable access to the program for the eligible population.
Discussion

Ms Otuszewski, Director of the National Bowel Cancer Screening Program, provided background including the objectives, 2005-08 budget breakdown, eligibility criteria and a plan to evaluate the program throughout the two-year phase-in to 2008. Early milestones were the first invitations to participants in Queensland (7/8/06), NSW (14/8/06) and the ACT (11/9/06), with other states/territories scheduled to follow in early 2007.

Almost 1 million Australians will be invited to participate in the program before 30 June 2008: 531,000 55-year-olds; 331,000 65-year-olds; 57,000 pilot invitees. Expected participation rate is 40%, of whom 7% are expected to test positive and require further investigation.

Ms Otuszewski discussed the key elements of the program, including a national, centralised register that will:

- identify and issue invitations to eligible participants from Medicare data and Department of Veterans Affairs enrolments files;
- track participants through the screening pathway (see figure 7), including collection of data and reminder letters;
- make small information payments to clinicians who return correctly completed forms.

Key differences between the pilots and the phase-in that commenced in 2006 were:

- an end to collection of information on family history or recent symptoms;
- listing of a GP (or practice) is now voluntary;
- fewer and less complex data collection forms;
- age eligibility restrictions;
- only one FOBT kit type.

States and Territories had been given the option of invitations being issued to eligible participants according to birth date or location (geographic).

National service delivery related to the program would be based on the ‘Usual Care’ model.

The Department of Health and Ageing was developing strategies for accessing specific population groups, such as:

- translation of program materials, including web-based information, into multiple languages;
- an interpreting service linked to the national Information Line;
- particular roll out strategies for remote and Aboriginal and Torres Strait Islander communities.
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**Figure 7 – Screening pathway**

**Medical practitioners**

Approaches/resources for GPs include:

- pre-launch letter (one per GP), around one month before invitations commence in their state/territory;
- information pack (one per practice), containing:
Moving forward on bowel cancer screening – report to the Australian Government

- letter from the Commonwealth’s Chief Medical Officer;
- program forms, stickers and reply-paid address labels;
- program information sheet, including screening pathway;
- consultation flipchart;
- participant information booklet;
- Cancer Council Australia/Australian Cancer Network summary of NHMRC Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer and summary of Familial Aspects of Bowel Cancer Guide.

Colonoscopists and histopathologists receive:

- pre-launch letter;
- program commencement letter;
- references GP Information pack materials available on website.

Evaluation

Ms Otuszewski advised that the program would be evaluated prior to the 2008-09 federal budget. If successful on clinical grounds, the aim is to extend screening to all Australians between the ages of 55 and 74 years. Central to the program evaluation framework will be quality issues including workforce, facilities and training needs.

The evaluation will comprise:

1. An analysis of the minimum data items collected by the Register and from other sources, including quality measures and measures of clinical effectiveness;

2. An analysis of workforce, facilities and training needs across the pathway including modelling future need;

3. An economic evaluation of the NBCSP;

4. Review and research into the feasibility, acceptability and cost effectiveness of the program in remote Indigenous communities.

Multi-jurisdictional agreement on colonoscopy

Ms Otuszewski reported that on 20 October 2005, the Australian Health Ministers’ Advisory Council (AHMACV) had agreed to work with relevant stakeholders to develop a strategy aimed at improving, over time, the availability, quality and consistency of colonoscopy services in Australia.

Australia’s federal, state and territory health ministers, via the Australian Health Ministers’ Conference, (AHMC) have endorsed this approach and requested the early formulation of national standards.

‘...AHMC has endorsed a strategy for improving colonoscopy services in Australia and requested national standards...’
Conclusion

Ms Otuszewski concluded by commenting that the program had the potential to deliver significant gains in bowel cancer control and that the key was building capacity over time to ensure it worked to full effect.

SESSION 1 – Q&A’s

Following the formal presentations, speakers from session 1 responded to the following questions from the audience.

Q. Is there a risk that the delayed start to the roll-out of the program will risk data quality in the final evaluation?

A. The quality of data is not expected to be affected by the gradual approach to roll-out. The states and territories have generally demonstrated enthusiasm for the program, and the Commonwealth expects the phase-in to gather sufficient momentum to provide adequate data for thorough evaluation.

Q. Are there concerns about inconsistency of process and data due to the varied budgetary cycles across nine jurisdictions in Australia?

A. No. Screening data will be matched to cancer registry data to ensure quality control.

Q. Why not begin screening people aged under 55 and over 75 now, to reduce the costs of future colorectal cancer burden?

A. The age group for the roll-out has been selected to provide the most efficient and cost-effective cohort for evaluation of the program before 2008-09. Options for expanding the target age group can be considered in the longer term, after the evaluation.

Q. What does the Government plan to do about the sorts of workforce pressures that were generated by the introduction of the BreastScreen program?

A. Baseline data from the evaluation will be used to project longer-term workforce requirements.

Q. Is a centralised registry for program data the most cost-effective option?

A. There will be an analysis and comparison of national and state/territory registration options as part of the evaluation.
Based on the evidence, information, expert opinion and forum concerns discussed in session 1, The Cancer Council Australia’s National Bowel Cancer Screening Committee recommends that the following measures to be built into the National Bowel Cancer Screening Program:

- A detailed framework for the program’s ongoing delivery, based on the evidence and expert opinion on best practice, articulating the roles and responsibilities of jurisdictions.

- A system for adequate data collection and analysis ensuring that the program’s effectiveness can be measured and that the program can be continually adjusted according to demonstrated need.

- A national approach, agreed to and supported by all jurisdictions, to underpin quality assurance in program delivery, including workforce planning, training and support.
SESSION 2

Chaired by Professor Richard Smallwood
Ex-Commonwealth Chief Medical Officer
Former Vice President, WHO Assembly

Keynote presentation:

Improving colonoscopy provision in the UK
Dr Roland Valori

Abstract

This presentation will describe how the endoscopy service in England is responding to the dual challenge of implementing a National Bowel Cancer Screening Program and a maximum wait for routine endoscopy of <6 weeks by March 2009. The key to the approach has been to define what a patient might expect from an excellent endoscopy service and to align the agendas of those who have a stake in the service. These principles have been underpinned by a quality assurance framework that defines standards and the processes with which to monitor them. A variety of tools and techniques have been developed to support the service and a knowledge management system created to facilitate the sharing of best practice. A major component of this support has been a national endoscopy training program designed to improve the standard of endoscopy through better training technique. The presentation will include an overview of the screening program, an explanation of the endoscopy Global Rating Scale (GRS), the results of four national censuses of the GRS, an overview of the national training program, the resources required to reach this stage and some ideas on how to accelerate the adoption of change.

Discussion

Dr Valori has worked closely with the UK Bowel Cancer Screening Program, preparing a quality assurance framework and a strategy for a three-year roll out which began in July 2006. He drew extensively on this experience to explain the establishment of a national endoscopy/colonoscopy service in the UK.
Principles
The UK’s endoscopy service was based on a philosophy designed to:

- align agendas;
- set standards;
- create tools;
- support leadership;
- promote good communication;
- gather data;
- listen carefully.

A benchmark of the UK program is the aim of restricting the waiting time for colonoscopy to six weeks.

The UK approach employs a hub-and-spoke model, bypassing GPs altogether, with regional screening centres funded to manage patients.

Quality
Fundamental to the effective implementation of the program was a quality assurance framework, built around the agreement, achievement and demonstration of standards.

Key mechanisms for the adherence to standards were a “global rating scale” (see figure 8) and the Joint Advisory Group (JAG) on Gastroenterology, the principal body for standards and training in endoscopy in the UK.

The standards aimed to ensure the program was patient-centred as well as assuring quality care in a clinical context.

A purpose-built website, www.grs.nhs.uk, was launched listing the specific requirements underpinning each standard. These included separate procedures to help ensure individual standards were met – for example, the measures to underpin quality aftercare outlined in figures 8 and 9.

Organisations involved in the endoscopy program are required to regularly report against the standards. Feedback mechanisms are also available for patients. Results are compiled and evaluated on a regional and national basis.
Accreditation of colonoscopists is based on:

- assessment of competence, including audit of recent performance and direct observation of procedural skills; and
- a minimum of 150 colonoscopies in the previous year, >90% unadjusted completion rate and an audit of safety; and
- ongoing performance monitoring based on a number of quality and safety indicators.

Resource issues

Dr Valori reported that flexibility was required to address resource limitations. For example, the solution to backfilling lists for annual and study leave undertaken by clinical colonoscopists was to train and employ nurse endoscopists. Dr Valori provided extensive detail about the training of colonoscopists in the UK.

Investing in training was essential. Around $25 million over five years was allocated to training in the UK, less than 1% of government expenditure on endoscopy. Dr Valori recommended that an equivalent investment in training was required in Australia to help build a quality assurance framework.

Figure 9 – measures for after-care quality assurance

<table>
<thead>
<tr>
<th>Levels</th>
<th>Measures</th>
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<tbody>
<tr>
<td><strong>Level C</strong>&lt;br&gt;Patients are discharged with procedure-specific aftercare information and knowing whether there is concern about malignancy. Patients have a 24 hour contact number if they experience problems</td>
<td>There are procedure specific aftercare patient information sheets for all procedures performed in the department&lt;br&gt;There is a 24 hour contact number for patients who have questions and experience problems&lt;br&gt;All patients are told if they are suspected of having a malignancy on the same day as the procedure&lt;br&gt;If it is considered inappropriate to tell the patient malignancy is suspected, a note is made in the file of the reason</td>
</tr>
<tr>
<td><strong>Level B</strong>&lt;br&gt;Patients are discharged knowing the outcome and future plans. Not all patients leave with an appointment when one is required</td>
<td>All patients are discharged with verbal and written information about next steps appropriate for their care&lt;br&gt;All patients are told the outcome of the endoscopic procedure prior to discharge&lt;br&gt;All patients are told if further information from pathological specimens will be available, from whom and when&lt;br&gt;Patients’ views on aftercare processes are sought at least annually</td>
</tr>
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</table>
Australian scenario

Dr Valori noted that differences in government and demographics between the UK and Australia meant that some aspects of an ideal endoscopy/colonoscopy service to support a national bowel cancer screening program may vary across the two nations. However, based on his experience and understanding of the Australian environment, he felt that a number of lessons from the UK experience could apply in Australia, in particular the value of a Global Rating Scale and standards to underpin program quality; commonality in the necessary tools and techniques needed to deliver a quality program; and the importance of national leadership in government.

Conclusion

Dr Valori concluded that Australia was well-placed to deliver an effective national bowel cancer screening program. Essential to the program’s effectiveness was a mechanism to assure colonoscopy quality and adequate investment in colonoscopy training.

Dr Valori’s presentation contains a wealth of useful diagrams and statistics drawn from the phase-in of population-based bowel cancer screening on a national level in the UK.
Quality issues for colonoscopy in Australia

Mr Andrew Luck

Abstract

With the advent of the National Bowel Cancer Screening Program for Australia, the quality of colonoscopy in this country has come under much greater scrutiny than ever before. This presentation will address the current state of colonoscopy training, assessment of training and certification of training in Australia through the Conjoint Committee for the Recognition of Training in Gastrointestinal Endoscopy (CCRTGE). CCRTGE was established in the late 1980s through the efforts of three parent bodies, the Gastroenterology Society of Australia, the Royal Australasian College of Surgeons and the Royal Australasian College of Physicians. There are eight members appointed to this committee from these parent bodies. The committee meets twice a year to assess applications for recognition of training and to discuss issues pertinent to endoscopy in Australia. The issue of quality assurance, including ongoing competence and the possible need for a recertification program, has been discussed at length in recent meetings. An audit process was trialled voluntarily amongst 50 established colonoscopists from April to June 2006. The results of this trial will be presented, as well as other evidence of the current standard of colonoscopy practice in this country.

Discussion

Mr Luck, a colorectal surgeon at Adelaide Hospital, provided high-level insights into issues around colonoscopy quality in Australia, drawing on his experience as a long-standing member of the Conjoint Committee for the Recognition of Training in Gastrointestinal Endoscopy (CCRTGE).

Mr Luck provided the historical background on the CCRTGE, which was jointly established in 1990 by the Gastroenterological Society of Australia, the Royal Australasian College of Surgeons and the Royal Australasian College of Physicians, to:

- develop and monitor guidelines for training in gastro-intestinal endoscopy;
- assess applications for recognition of training; and
- maintain a national registry of those completing satisfactory training in endoscopy.
Recognition of training

Mr Luck described the stringent but voluntary requirements for CCRTGE recognition, which include:

- 100 unassisted, complete examinations to the caecum, in intact colons;
- 30 patients with snare polypectomy(ies);
- 85% caecal intubation rate at completion of training;
- cleaning/disinfection experience;
- detailed supervisor’s report (using a five-point rating scale 1-5).

He then posed the key question:

‘Are these requirements enough to ensure quality colonoscopy?’

Issues for consideration might include professional credentialing and a National Bowel Cancer Screening Program list of providers of ‘quality’ colonoscopy as a component of capsule endoscopy reimbursement through Medicare.

‘Perth series’

Mr Luck summarised the findings of a retrospective review of data from three teaching hospitals in Perth (1989-1999), drawing on the results of 30,463 colonoscopies, including 23,508 outpatient procedures. The review aggregated and analysed complications from colonoscopy (see figure 10).

Pilot colonoscopy data

Mr Luck reflected on the colonoscopy data from the bowel cancer screening pilots. Key findings, based on 2027 colonoscopies, included:

- 96% of procedures reaching caecum;
- cancer detected in 3.5% (71) of patients;
- multiple polyps in 21.1% (427) of patients;
- single polyps in 22.8% (462) of patients; and
- no cancer or polyp in 51.2% of patients.

**Figure 10 – ‘Perth Series’ review of WA colonoscopy services, 1989-99**

<table>
<thead>
<tr>
<th>Complications</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Bleeding</td>
<td>0.21%</td>
</tr>
<tr>
<td>Median time to presentation</td>
<td>6 days</td>
</tr>
<tr>
<td>7 patients (14%) required transfusion</td>
<td></td>
</tr>
<tr>
<td>Perforation</td>
<td>0.10%</td>
</tr>
<tr>
<td>18/23 (78%) with mucosal intervention</td>
<td></td>
</tr>
<tr>
<td>19/23 required laparotomy</td>
<td></td>
</tr>
<tr>
<td>7 laparotomy and oversew</td>
<td></td>
</tr>
<tr>
<td>12 more extensive surgery</td>
<td></td>
</tr>
<tr>
<td>Deaths</td>
<td>0.01% (3 deaths, 1 in outpatients)</td>
</tr>
<tr>
<td>Comparison of consultant v trainees*</td>
<td></td>
</tr>
<tr>
<td>Consultant complications</td>
<td>0.214%</td>
</tr>
<tr>
<td>Unassisted trainee complications</td>
<td>0.202%.</td>
</tr>
</tbody>
</table>

*Unrandomised data; consultants likely to have taken difficult colonoscopies.
Colonoscopy audit pilot

Mr Luck presented the general findings of a CCRTGE pilot audit of colonoscopy services, conducted in Australia from April to June 2006, which demonstrated:

- relatively poor participation response rate (from a self-selected group);
- excellent caecal intubation rate;
- wide variation in withdrawal times;
- minimal morbidity;
- a prevalence of high-volume practitioners.

He recommended that “re-certification” of recognised colonoscopists be considered.

Conclusions

Mr Luck summarised his presentation with the “good news on colonoscopy” in Australia:

- most colonoscopies are performed well;
- there is a (voluntary) system for recognising practitioners (CCRTGE);
- a high proportion of colonoscopists have the experience of high-volume caseloads;
- caecal intubation rates are excellent;
- morbidity is low.

This was offset by the “not-so-good-news”:

- there are a significant number of low-volume practitioners (28.7% of colonoscopists performed fewer than 10 procedures in 2005);
- a significant number of colonoscopists are not CCRTGE-recognised;
- the overall quality of colonoscopy remains to some extent unknown;
- there are inadequate controls on colonoscopy;
- remote nature of practice cannot be an excuse for poor quality.

The roll-out of the national screening program had posed some important questions and raised the need for tough decisions:

- “re-certification” and audit of colonoscopy will facilitate data collection and transparency, and are likely to lead to improved performance;
• if quality, recognised practitioners are to be audited, then others should not be allowed to practice without the same controls and accountability;
• should CCRTGE-certification be mandatory?

Mr Luck ended with the message that the bowel cancer screening program could provide an opportunity to improve quality control in colonoscopy Australia-wide.
Colonoscopy provision in NSW – meeting demand through redesign

Professor Donald MacLellan

Abstract

The Predictable Surgery Program was developed to ensure that the people of NSW have predictable and timely access to appropriate surgical and procedural services. One of the aims of the program is to ensure that no patient waits more than 30 days for an urgent procedure and no more than 12 months for any non-urgent procedure. This includes patients awaiting colonoscopic examinations. Over the past 12 months, the number of NSW patients waiting longer than 12 months for their procedure has been dramatically reduced by over 95% and for urgent procedures by over 80%. These results are expected to reach and remain close to or at zero throughout 2006–07. Waiting times for procedures have significantly decreased as a result of these major achievements. It is recognised that sustaining these improvements in access to treatment remains a major challenge particularly with the growing demand for health services. NSW Health has embarked on patient-focused redesign of medical, mental health and surgical services in order to improve access, efficiency, quality, safety and patient and staff satisfaction. With the commencement of national population screening by FOBT from May 2006, it is estimated that positive FOBT tests may require up to 5000 more colonoscopic examinations in NSW than currently undertaken. Initial surveys of current colonoscopic services in NSW have indicated that this increased demand can be absorbed but not without significant resource reallocation. However, that presumes the current model of care for colonoscopy is optimal. It is considered that the major demand challenge will only be met by colonoscopic service redesign incorporating the principles of supply chain management and lean thinking.

Discussion

Professor MacLellan, Director of Surgery in the NSW Health Department’s Health Service Performance Improvement Branch, explored re-design as a response to increased colonoscopy demand resulting from the bowel cancer screening program.

Professor MacLellan looked at some of the historical drivers of change in the NSW hospital system, such as the increase in life expectancy; the significantly higher proportion of people aged 65 and over; and the comparatively greater use of hospital resources by older people. A capacity to be innovative in responding to changes in the healthcare environment, including treatment advances and heightened patient expectations, was fundamental to meeting population needs.
Professor MacLellan reported that NSW Health were working towards greater capacity to project healthcare demands and plan services better targeted to anticipated need. The approach had helped to effect a major reduction in long (i.e. >1 year) surgical waiting lists, from a peak in February 2005 of 10,587 to a minimum in June 2006 of 49.

A major reduction in the number of overdue colonoscopies, from over 1000 in January 2005 to fewer than 150 in May 2006, was attributed to the ‘Predictable’ model. Long-wait (>1 year) patients had also dropped from almost 350 to none in the same time frame.

**Colonoscopy patient journey redesign**

NSW conducted 30,000 colonoscopies a year, with 10,000 patients awaiting a procedure at any given time. Demand was expected to increase by between 3500 and 5000 colonoscopies a year as a result of bowel cancer screening – with positive FOBT patients given a category 1, high-priority rating requiring colonoscopy within 30 days of referral. This reinforced the need to continue service redesign to meet emerging need.

A new approach to supply chain management is being undertaken, built around demand planning; segmentation; service configuration; new rules of engagement; patient flow planning; and improved capacity planning.
Challenges to accommodating the increased colonoscopy demand, measured in a study of 26 public hospitals in early 2006, included:

- shortage of nursing staff;
- insufficient endoscopy time for some proceduralists; and
- budgetary limitations.

However, a Cancer Institute of NSW study indicated that, among the state’s 88 public and private facilities, 70% of colonoscopists could reprioritise their lists to accommodate screening referrals, and 36 sites could take on extra cases using current staff and equipment.

Drawing on the latest data on system capacity, NSW Health undertook the redesign of colonoscopy service based on the following principles:

- a focus on the patient journey;
- designing the journey to work well for patients, families and staff;
- solutions designed by frontline staff;
- design of IM&T strategy to underpin journeys;
- guarantee implementation across regions;
- skill-up of management; and
- organisational restructure to support the new model.

Improved efficiencies were built into:

- program planning;
- waiting list management (new policy);
- room scheduling and utilisation procedures; and
- discharge planning and communication.

New networks were developed and improvements in referral pathways, infrastructure and information management and technology.
SESSION 2 – Q&A’s

Following the formal presentations, speakers from session 2 responded to the following questions from the audience.

<table>
<thead>
<tr>
<th>Q.</th>
<th>A.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are the 400 colonoscopies performed by practitioners in Australia who do fewer than 10 a year done in the public or private system?</td>
<td>The information is not currently available to determine in which setting those recorded low-volume procedures are undertaken.</td>
</tr>
<tr>
<td>How do we systematically raise and underwrite the national standard of colonoscopy performed throughout Australia?</td>
<td>A difficult issue, as the national Conjoint Committee for the Recognition of Training in Gastrointestinal Endoscopy has no mandated enforcement authority.</td>
</tr>
<tr>
<td>How is the problem of over-servicing managed in the UK?</td>
<td>The Global Rating Scale includes an item on ‘appropriateness’ designed to avoid unnecessary procedures. The high revenues available by providing colonoscopies in the private sector also act as a disincentive for practitioners to overuse the public system.</td>
</tr>
<tr>
<td>How is the problem of low case-load practitioners managed in the UK?</td>
<td>A requirement of 200 colonoscopies per year is built into the Global Rating Scale for individual practitioners.</td>
</tr>
<tr>
<td>What can be done to give the CCRTGE authority to raise minimum standards?</td>
<td>In the UK, the JAG sets and enforces standards across all medical disciplines. A similar approach, involving the professional colleges and government, could be taken to give the CCRTGE a formal mandate.</td>
</tr>
<tr>
<td>How has the UK training program boosted quality?</td>
<td>Training has improved speed and efficiency, raised the overall standard of performance, and facilitated a culture of excellence and a more collegiate professional environment.</td>
</tr>
</tbody>
</table>
Key recommendations from session 2

Based on the evidence, information, expert opinion and forum concerns discussed in session 2, The Cancer Council Australia’s National Bowel Cancer Screening Committee recommends that the following measures to be built into the National Bowel Cancer Screening Program:

- Inter-jurisdictional agreement on minimum standards for ensuring quality colonoscopy provision for all patients.

- The establishment of a mandatory mechanism to set and monitor quality controls in colonoscopy.

- Forward planning and investment to manage colonoscopy waiting lists.
**SESSION 3**

*Chaired by Teri Snowdon*

*National Manager – Quality Care*

*Royal Australian College of General Practitioners*

**GPs – key players in bowel cancer screening**

*Dr Linda Foreman, The Cancer Council South Australia*

**Abstract**

General practitioners (GPs) have an important role in the National Bowel Cancer Screening Program (NBCSP). There is evidence that a GP recommendation can increase participation in bowel cancer screening, and general practice information systems can be used to identify eligible patients and encourage involvement in the NBCSP. There are a number of specific GP involvement points within the program and these include assessing high risk individuals and managing them according to National Health and Medical Research Council (NHMRC) guidelines, receiving FOBT results where the participant has nominated a GP, and assessing and managing participants with a positive FOBT. Another critical role of GPs is in providing information to the NBCSP Register about referral of patients with a positive FOBT, in order to facilitate monitoring and evaluation of Program outcomes.

Particular issues arising from the involvement of GPs in the NBCSP include the provision of information to GPs about their role, issues relating to duty of care and the management of community members for whom bowel cancer screening is appropriate but who are not eligible for the NBCSP.

**Discussion**

Dr Foreman, an experienced GP who was closely involved with the bowel cancer screening pilot, discussed GP feedback from the pilot, interaction with GPs in the current roll-out, and future opportunities and challenges in the optimal longer-term involvement of GPs in bowel cancer screening.

**Pilot feedback**

Comments collated from GPs as part of the pilot evaluation indicated that:

- GP workload and administration associated with the program were “not unduly burdensome”;

The Cancer Council Australia
Moving forward on bowel cancer screening – report to the Australian Government

- duty of care issues were well-defined;
- GPs supported invitations and FOBT kits sent from a national register; and
- GPs supported the use of electronic forms for managing patient information.

GP concerns related to people without fixed address; colonoscopy waiting times; and an excess of poorly targeted GP information.

Quality assurance

Quality assurance benchmarks recommended by GPs included a maximum of nine days between a positive FOBT result and a GP appointment, and a maximum of 30 days between GP referral and completion of colonoscopy if recommended.

While in the pilot 62% of GP appointments to discuss positive FOBT results were recorded on the national patient register, there was concern about the unaccounted 38%, with speculation that some people with positive test results may not have consulted their GP, and that some GPs may not have completed and sent the forms to the register. This raised further concerns about:

- the need for more effective GP education;
- the collection, monitoring and evaluation of data;
- GP’s duty of care;
- the need for a systematic solution to ensure maximum follow-up of positive FOBT results.

GP involvement points in bowel cancer screening

There were a number of areas where GPs could improve the effectiveness of the bowel cancer screening program, such as:

- encouraging people in the target age cohort to participate in the program;
- triaging and managing high-risk patients;
- the management of patients with positive FOBT results;
- notifying the central register.

GP education

GPs are interested in education about the clinical management of bowel cancer and their administrative responsibilities as professional participants in the screening program. Education should be evidence-based, delivered in multiple modalities, readily accessible and tailored to meet GP needs.

‘… GP education should be evidence-based, delivered in multiple modalities, readily accessible and tailored to meet GP needs…’
Duty of care

Following the pilot, there were a number of areas requiring further clarity, such as concerns about the responsibility for tests not ordered by GP; patients nominating a GP who may have no knowledge of the patient; and confusion between the GP’s and the register’s role in managing patient data. Some of these issues were being addressed by the Department of Health and Ageing, which had sought medico-legal advice which was communicated to GP professional groups and incorporated into guidelines in the kits for GPs.

There was also concern about how GPs might manage patients who were interested in FOBT or had a family history of bowel cancer, but were not within the eligible screening cohort.

Conclusion

Dr Foreman concluded the GPs in Australia would be a pivotal part of population-based bowel cancer screening, in both a clinical and administrative capacity. Efforts to work closely with GPs to ensure they are adequately supported to provide their key role should continue.
The role of nurses in bowel cancer screening
Joylene Morcom, Repatriation General Hospital, South Australia
Dianne Jones, Queensland Bowel Cancer Screening Team

Abstract

The role of the nurse in caring for the colorectal cancer patient has, to date, been largely directed toward the patient who has received a cancer diagnosis and focused on pre- and post-operative education, psychological support and stoma care. Now, with the roll-out of the national bowel cancer screening program, it is time for nurses working in appropriate fields to define roles in which they can make a significant contribution. In establishing a bowel cancer screening service in Adelaide, it has become apparent that there are many areas where nurses can become the key facilitator. Nurses are able to facilitate interaction between GPs and screening service providers, provide information on risk and access to genetic counselling and testing, identify and counsel families who are at risk, organise appropriate follow up of patients with previous polyps and cancers, counsel patients with positive FOBTs and organise appropriate follow up. Qld Health has developed the role recommended in the national pilot program report for a bowel cancer nurse coordinator. This advanced nursing role encompasses service coordination and care coordination and will be located in each of the catchment areas across the state.

The national screening program is going to generate a substantial increase in the number of colonoscopy procedures. To ensure patients receive appropriate care, suitably trained endoscopists and endoscopy nurses will be required as well as facilities that can meet the demands that will be placed upon them. Well trained and educated endoscopy nurses are critical to good patient outcomes.

Nurse endoscopist roles are well entrenched in the US and UK and there is ample evidence patient outcomes compare favourably with those of their medical colleagues. Until now in Australia, there have been adequate numbers of medical endoscopists to cope with procedural demand.

With the large numbers of procedures that will be generated not only by screening, but also the ongoing surveillance of participants diagnosed with polyps and cancers, there may well be a role for nurse endoscopists in the future. It is clear that nurses working at all of these levels should be experienced and appropriately trained and educated. Above all, nurses must be empowered to fill these roles. This will require allocation of adequate resources by governments and hospital administrators, supportive medical and nursing directors and motivated nurses who wish to extend their boundaries.
Discussion

Ms Morcom and Ms Jones, with a combined 54 years’ experience in gastroenterological nursing, provided a detailed perspective on key nursing issues in relation to bowel cancer screening.

Ms Morcom opened the discussion with a summary of nurses’ current involvement in bowel cancer care, which was predominantly hospital-based services such as pre and post operative care and education, psychological support and stoma care. The absence of a screening program to date had meant there had been no scope to explore opportunities for nurses to contribute.

Drawing on her experience, Ms Morcom proposed that options for nurses to participate in the bowel cancer screening program could include:

• counselling in response to a positive test;
• assessing patient fitness for colonoscopy:
  o symptoms
  o medical history
  o family history
  o physical assessment
• booking the colonoscopy, assessing the risks of procedure and advising about the bowel preparation;
• minimising wait lists; and
• discussing histopathology results.

Opportunities to add value

The participation of nurses could be particularly important when news of a cancer diagnosis was communicated to patients, as nurses could provide support to family members; help fast-track staging procedures and other appointments; initiate allied health interventions; and liaise with surgical ward staff.

Nurses could also facilitate hospital recall systems, thereby helping to ensure patients are not lost to follow-up and are re-screened at appropriate intervals, reduce colonoscopy waiting times and provide quality patient and GP information.

Gastroenterological nurses could support patients with a strong family history of bowel cancer, by obtaining family histories and developing the family tree, organising pre-symptomatic testing, providing psychological support and liaising with familial cancer centres. They are also well-placed to provide a range of services within the endoscopy unit.

Effective nurse endoscopist roles are well supported by the literature. Nurses have been shown to be as safe and competent as their medical colleagues, with high rates of
patient satisfaction. Appropriately trained and educated nurse endoscopists would be well able to assist in meeting the increased endoscopy workload.

**Nurse coordinator role in Queensland screening program**

Ms Jones reported that in Queensland the GE nurse had been identified as one of the multidisciplinary team members essential to colonoscopy services provided as part of bowel cancer screening.

The importance of a nurse coordinator’s role had been demonstrated in the Mackay component of the bowel cancer screening pilot, with particular value in enhancing the accuracy of patient data and managing colonoscopy referral pathways. A network of GE nurses had been established across each of the 11 designated catchment areas for the program’s roll-out in Queensland.

A nurse coordinator role was defined, with the establishment of a working group that was consulting widely with the profession, and developing advanced competencies and a related training program. The role was set to provide a significant contribution to bowel cancer screening in Queensland, by improving service coordination (e.g. organising assessment of colonoscopy provision within a catchment area; monitoring program quality, data collection and reporting) and supporting other service providers through the provision of information and feedback.

The nurse coordinator would also undertake an advanced clinical role, through:

- pre-procedure assessments via face-to-face or tele-health services;
- information provision;
- initial procedure information for consent (confirmation of final consent by endoscopist on day of procedure);
- instruction on preparation for colonoscopy;
- counselling and support of patients; and
- organisation of subsequent care if required.

Early-stage key deliverables (see figure 12) have been set for the role to ensure some timely measures of effectiveness can be taken as the role gathers momentum.

**Conclusion**

Ms Morcom and Ms Jones concluded with a reiteration that GE nurses could add significant value to the efficient and effective delivery of the National Bowel Cancer Screening Program.
Screening behaviour
Dorothy Reading, The Cancer Council Victoria

Abstract

Australia has two mature population-based cancer screening programs which yield some data on women’s screening behaviour. The bowel cancer screening program will be the first to be offered to men, to be carried out with a self-test kit at home, and to be organised centrally with invitations to participate emanating from the Commonwealth Department of Health and Ageing. Pilot programs conducted in three states and overseas experience are another source of data which could shed light on how men will respond to an invitation to participate in a cancer screening program.

Other areas of interest are:
• the participation of linguistically and culturally diverse groups;
• re-screening behaviour;
• participation of lower socio-economic sections of the community; and
• completion of follow up by participants who test positive.

An examination of available data from Australia and overseas can inform communications and planning for the bowel cancer screening program and help ensure that all eligible members of the public are aware of the program and have the information they need to respond to an invitation to participate.

Discussion

Ms Reading, who has more than 20 years’ experience in cancer prevention and screening policy, explored screening behaviour according to data collected from bowel cancer screening pilots in Australia and the UK. She also referred to programs designed to increase participation in cervical cancer screening in Australia.

Factors influencing screening behaviour

Just over 45% of the Australians invited to participate in the pilot, and 56% of Britons, returned a completed FOBT. In both countries, participation rates were higher among women (4% higher in Australia; 9% in the UK).

There is some research into strategies for increasing participation, and a need for the evidence base to grow. For example, direct mail was shown to be effective, with 38% of respondents indicating that they participated in the Australian pilot program because they received a personalised invitation in the post. Reminder letters were also shown to be effective, with estimates that they increased participation from 30% to 46%.
Cultural issues

In the Australian pilot program participation was lower for Aboriginal and Torres Strait Islander people (25.7%) compared with the general eligible population. This is consistent with established screening programs. While efforts to increase participation by Indigenous people in breast and cervical cancer screening programs have increased take-up rates over a number of years, Aboriginal and Torres Strait Islander women continue to have lower participation rates general population.

People of non-English speaking background also had lower participation rates than the general population. And participation was linked to economic status, with people on higher incomes generally more likely to be involved in the screening program.

Information sources and gaps

Survey data from the Australian pilot show that, after the FOBT kit itself, newspapers and doctors were the most frequently mentioned sources of information, followed by friends, magazines and radio.

Data on non-participants shows they are less likely to:

- be able to identify signs of bowel cancer;
- think they will develop bowel cancer;
- believe in checking if you don’t have symptoms; or
- believe earlier detection increases survival or decreases need for colostomy.

Male non-participants are less likely to know that bowel cancer is common and to have seen or heard information about the pilot.

Trends in cervical cancer screening show that participation rates increase as a result of targeted communication strategies.
Lessons from established programs

Evaluation of PapScreen Victoria/The Cancer Council Victoria's ‘Don’t just sit there...’ campaign showed that targeted communications strategies can boost screening participation, with significant increases in Pap test rates linked to the running of the campaign.

A range of other communications strategies have been shown to improve participation rates in screening programs. Television campaigns are particularly effective, although in their absence, there are many other effective, smaller-scale strategies available. Investment in screening infrastructure must include tailored communications and information to reduce barriers to screening, particularly those faced by specific population groups.

Influencing screening behaviour – key messages

‘It is possible to run a precisely targeted campaign to motivate people to participate in a screening program.

‘Communication strategies need to be targeted to the general population as well as specific groups with low participation rates.

‘Non-participants had significant knowledge gaps.

‘There are many research questions remaining which can be addressed during the roll out of the program.’
The economic aspects of participation in bowel cancer screening

A/Professor Glenn Salkeld, School of Public Health, University of Sydney

Abstract

One of the constant tensions in public health is how to balance respect for the autonomy of individuals against the wider public good. This is reflected in the debate about the right of individuals to make an informed choice about screening for colorectal cancer (CRC) and the wider public good (net of harms) of maximising participation. Setting predetermined participation rates misses the target. There are at least two levels of decision-making that are relevant to screening; one is whether government should fund a population program and the other is whether individuals choose to participate.

The funding decision considers the wider public good against the costs and potential harms. Modelling of CRC screening has shown that high participation in screening is not necessary to achieve cost effectiveness. What matters is who and when people screen. It is more cost-effective for previous non-participants to screen at least once in subsequent rounds than it is to maintain high re-screening rates. That leaves the second level of decision-making – the individual’s right to choose. The challenge here is to provide an affordable decision support system for bowel cancer screening for those people who want a ‘guided choice’. There is no evidence to suggest that the provision of decision support systems lowers demand for screening, but this question should be built into any evaluation of a ‘guided choice’ offered in the context of the Australian bowel cancer screening program.

Discussion

Associate Professor Salkeld, a senior health economist and member of the National Bowel Cancer Screening Monitoring and Evaluation Committee, examined bowel cancer screening in an economic context. The key questions discussed were:

- Is high participation in bowel cancer screening necessary to achieve cost effectiveness?
- Does informed choice decrease participation?
A/Professor Salkeld reported that published opinion and data on whether higher screening participation rates improved cost effectiveness varied markedly. The difference was linked to the way studies looked at participation and non-participation in the second and subsequent rounds of a screening program.

Different studies define participation and non-participation in different ways over time. The key was to examine screening behaviour more closely.

A/Professor Salkeld reported that:

- involvement of even a small percentage of previous non-participants in subsequent screening makes the cost-effectiveness more favourable.
- second-round or subsequent participation must be less than 10% to affect cost-effectiveness; and
- it may be better to spend recruitment dollars on information for non-participants than to ensure high re-screening rates.

**Informed choice**

Principles of informed choice requires that people are free to choose whether they wish to participate in screening or not; and that unbiased information on the benefits, harms and costs are readily available.

Studies produced varying results on the impact of informed choice on screening participation. Further research was needed to produce a conclusive result. However, there was evidence suggestive that decision aids can help ensure the principles of informed choice are applied.

**SESSION 3 – Q&A’s**

Due to time pressures, the group agreed to incorporate questions arising out of session 3 into the panel discussion that followed.
Key recommendations from session 3

Based on the evidence, information, expert opinion and forum concerns discussed in session 3, The Cancer Council Australia’s National Bowel Cancer Screening Committee recommends that the following measures to be built into the National Bowel Cancer Screening Program:

- Further development of formal measures to support GPs in the performance of their key role in the program.

- Monitoring of participation in the program and investment in targeted communication strategies to reach population groups that are shown to experience lower participation rates.

- Further consideration of the role of GE nurses in contributing to the National Bowel Cancer Screening Program.
SESSION 4

Chaired by Terry Slevin
Director – Cancer Education and Research Programs
The Cancer Council Western Australia

Overview

To help ensure the forum provided an opportunity to combine expert insights with extensive dialogue involving stakeholders with an interest in bowel cancer screening, the final session was an open discussion forum.

Panel

The forum called on an expert panel to respond to questions submitted throughout the day and other questions raised during the discussion. Chaired by Terry Slevin, the panel comprised Dr Linda Foreman, general practitioner; Professor Donald Maclellan, Area Performance Manager/State Program Director (Surgery), NSW Health; Professor Finlay Macrae, Consultant Physician & Gastroenterologist Melbourne Hospital; Jennifer Muller, Senior Director, Cancer Screening Services Unit, Queensland Health; Marissa Otuszewski, Director, National Bowel Cancer Screening Program; and Dr Roland Valori, Consultant Gastroenterologist, National Clinical Lead for Endoscopy Services (United Kingdom).

Reporting format

The following summary of the open discussion is based on minutes taken at the time. Where possible, responses are attributed to content experts as documented; due to consent issues and difficulty identifying audience members, the names of non-panel members who posed questions are not listed, except when additional comment has come from listed presenters from elsewhere on the forum program.
PANEL DISCUSSION Q&A’s

Question 1 – Queensland response to screening program: Jennifer Muller opened the discussion in response to a request to describe the model adopted by Queensland to accommodate the bowel cancer screening program at state level. A description of the program is summarised in attachment 1.

Question 2 – referral pathways: A self-identified bowel cancer patient inquired about the UK program redesign process, in particular how future referral pathways in Australia could be streamlined.

Response: Dr Valori cited the UK experience, observing that standards should underpin timeliness and efficiency of referral (see summary of Dr Valori’s presentation, page X). The panel also agreed that GP education could help facilitate more efficient, patient-centred referral.

Question 3 – people outside target group: What can be done for people interested in FOBT but not in the age cohort targeted by the program roll-out?

Response: Ms Otuszewski advised that people in such circumstances should be referred to their GP, especially if they had any symptoms of bowel cancer.

Question 4 – Indigenous participation: What is being done to specifically target Indigenous people as described in the funding announcement for the program?

Response: Ms Otuszewski advised that an Aboriginal working group was being established as part of the program’s administration. Metropolitan and rural/remote regions with relatively high Indigenous populations will act as pilot sites to assess if and how the standard service models need to be tailored to maximise Indigenous participation rates.

Question 5 – Indigenous data in phase 1 evaluation: Will the proposed timelines restrict the collection of program data on Indigenous participation in terms of evaluation?

Response: Ms Otuszewski advised that there were no time-specific targets regarding Aboriginal and Torres Strait Islander populations, as the commitment to maximise participation across all population groups was ongoing; all data gathered in the initial phase would help to refine aspects of the program in future phases.

Question 6 – long-term program expenditure: Has an estimation been made of the program’s recurrent overall cost, up to the point of colonoscopy referral, when it moves to full implementation?
Response: Ms Otuszewski advised that some preliminary costing had been undertaken, but that more accurate projections would be derived from the cost-effectiveness component of the evaluation. Professor Young added that it would be difficult to cost the program when ‘Usual Care’ was the proposed model for managing a positive FOBT.

**Question 7 – nurse colonoscopists:** What are the main barriers preventing nurses from performing colonoscopy?

**Response:** According to Dr Valori, the main barriers were “professional” – i.e. clinicians resisting the advent of nurse colonoscopists, partly to protect their revenue stream – and the investment required to adequately train nurse colonoscopists. He said evidence in Britain showed nurses were as competent as surgeons in performing colonoscopies, and were superior to their clinical colleagues in patient communication.

Professor MacLellan added that there was a shortage of anaesthetists in NSW for colonoscopy procedures that needed to be addressed.

Ms Muller reported that there were concerns about quality of procedures varying according to geographical location. Although flexibility was required to address access issues for more isolated patients, there was the risk of perception of a two-tiered system if non-clinicians predominated in some regions.

Mr Luck commented that the issues of quality and training for colonoscopists needed to be examined, and that the impetus for a coordinated approach to quality assurance would need to come from government, not professional colleges. The Conjoint Committee (CCRTGE) had no mandate to oppose consideration of other disciplines performing colonoscopy.

**Question 8 – colonoscopy capacity:** How can we improve access to colonoscopy services by reducing the volume of unnecessary procedures?

**Response:** Professor Macrae proposed that one option would be for government to regulate the number of colonoscopies performed each year, e.g. set an upper limit of procedures and a minimum interval of three years between colonoscopies through Medicare.

Ms Muller added that by applying the same quality assurance framework in both the public and private systems, availability of colonoscopy in both sectors for those with a demonstrated higher need could be boosted.

**Question 9 – data:** Will data from the screening program be available to non-government interests?

**Response:** The question was referred to Dr Stevenson from the Australian Institute of Health and Welfare, who advised that screening data was technically owned by
Medicare, which operates the screening registry, and subject to stringent confidentiality provisions. Specific requests for data to be used in research projects would be considered, but be unlikely to be approved.

**Question 10 – GP adherence to guidelines:** What can be done to ensure GPs minimise the number of unnecessary colonoscopies?

**Response:** Dr Foreman advised that GPs could help to prevent inappropriate referrals, and act as a ‘gatekeeper’. However, it is difficult for GPs to refuse referring a concerned patient (as a GP herself, Dr Foreman would probably refer a patient who was particularly determined to have a colonoscopy).

Mr Luck added he had observed that patients were more likely to accept advice not to proceed to colonoscopy if the recommendation was provided by a surgeon.

**Question 11 – informed choice:** How can we manage patients who prefer to use colonoscopy, rather than FOBT, as a screening tool?

**Response:** The panel advised that all professionals involved in the program, in particular GPs, need to be consistent with the message that the appropriate screening tool for asymptomatic patients is FOBT. People need to be encouraged to ask themselves, “How can I best manage my bowel cancer risk”, which would mean looking at all the issues including prevention, family history, age, symptoms etc. and understanding that the evidence supports FOBT, not colonoscopy, as the appropriate screening tool.

**Question 12 – screening intervals:** Is the evidence clear that annual is just as effective as biennial (every two years) screening?

**Response:** Professor Macrae advised that, as FOBT was a highly sensitive test and bowel polyps and tumours relatively slow-growing, biennial testing was adequate. However, risks of reduced screening effectiveness on a population basis would arise if people allowed for time lags of more than two years between tests.

**Question 13 – excessive information in booklet:** Is the booklet accompanying the kits too long at 26 pages, and will it be translated into multiple languages?

**Response:** Ms Otuszewski advised that the booklet was developed on the basis of what the pilot studies indicated participants wanted to know. It is already available in the 10 most commonly spoken languages other than English among the screening cohort. Additional multi-lingual information will also be available on the Department of Health and Ageing website and a telephone interpreter service was accessible to the public.
Question 14 – implementation lag and accuracy of data: Will the delays in rolling out the program affect the accuracy of the data required for the program evaluation?

Response: Ms Otuszewski advised that the Government was committed to a strict deadline of finalising phase one of the roll-out, which will be evaluated, by June 2008. The timeline of phasing the program in on a state-by-state basis by early 2007 should not compromise the quality and extent of data necessary for evaluation on a national basis.

Question 15 – research: How will data be collected to ensure the program is continually modified on the basis of new evidence and changes in best practice?

Response: Professor Young commented that the time lag between the pilots and full implementation was too long, demonstrating the need for ongoing research. He added that an up-to-date knowledge base on screening behaviour, for example, would be impossible to build in view of the previous advice about the difficulty in accessing the data for independent research. Ongoing research was also required to ensure that the screening tool could be enhanced over time to increase effectiveness.

Dr Valori reported that there had been a 16-year lag in the UK between the randomised controlled trials showing screening efficacy and program implementation, which had limited the capacity to respond to the emergence of more advanced testing technology.
Forum evaluation results

Forum organisers emailed an online evaluation form to all registered forum delegates, to measure the event’s success in meeting its aims and to inform the development of future events.

Of the 120 forum delegates, 77 responded to the request for feedback, with a total of 62 submitting completed evaluation forms. Delegate profiles, their ratings and comments, are summarised as follows.

Delegate profile

Jurisdictionally, the forum’s audience reflected state-territory population numbers, with a significant over-representation from host state Victoria (26 of 62 respondents).

More than half of respondents were either specialist clinicians or nurses, or healthcare administrators. Only one respondent was a general practitioner. Almost one third were from government departments. The rest were evenly spread across a range of fields.

More than two thirds of the respondents were women.

Of 55 delegates working in healthcare service delivery, 42 were in the public sector.

Expectations

The majority of delegates who described their expectations of the forum said they had registered to gain a general overview of the National Bowel Cancer Screening Program’s progress and a better understanding of the key issues. Involvement in discussion and debate, and insight into the UK program, were also common themes. A small proportion were interested in more specific information, such as the rationale for selecting the immunochemical FOBT kit.

Sixty-five delegates rated the forum’s success in meeting their expectations according to a scale of 1 (expectations not met) to 5 (expectations completely met). More than half (34) rated the forum “4”, followed by 19 who rated it “3”, eight who rated it “2” and four, whose expectations were “completely met”. One delegate’s expectations were not met.

Rating specific modules

All of the individual forum modules attracted a significant number of “useful” ratings, from the lowest – 27 for “The role of nurses in bowel cancer screening” to the highest – 64, for “Improving colonoscopy provision in the UK”. The second and third most popular modules were “Quality issues for colonoscopy in Australia” (56) and Professor Young’s opening scene-setting address (49).

In terms of personal critiques, the majority of text criticism was that the forum focused too much on the pilot studies rather than looking ahead to issues around the program’s administration (as implied in the event’s title).
Interactivity

The event’s promotion as a discussion forum meant the need to gauge the level of interactivity available to delegates. Of 66 respondents, 49 felt the audience was given adequate opportunity to be involved in the discussion. The majority of those dissatisfied with the level of interactivity cited time constraints as the main problem.

Overall success

Of 65 respondents to the question, “Would you recommend a forum like this to someone else”, 55 said yes. Criticisms from others generally focused on the forum’s tendency to look back rather than forward, and lack of information about the program’s administrative arrangements.

Delegate advice

The Cancer Council Australia advised delegates that the forum evaluation process would also be an opportunity to feedback to the Commonwealth their views on how the National Bowel Cancer Screening Program could be improved.

A raw text summary of these comments has been provided to the Department of Health and Ageing.
Attachment 1:

Queensland Bowel Cancer Screening Program – Background Information and Program Model

- Queensland Health has committed resources for the development and implementation of the National Bowel Cancer Screening Program in Queensland. A State Coordination Unit has been established as part of Cancer Screening Services Unit which also coordinates the BreastScreen Queensland and Queensland Cervical Screening Programs.

- The Queensland Program model is based on a staged geographic implementation of the Program in 11 catchments. Each catchment will have a Gastroenterology (GE) Nurse Coordinator for the Program, and a Health Promotion Officer. The GE Nurse Coordinator role has a service coordination and care coordination role, whilst the Health Promotion Officer has a key role informing and educating GPs about the program.

- Detailed planning is occurring at a catchment level in consultation with Area Health Services and Health Service Districts to develop the appropriate service arrangements for the provision of additional assessment colonoscopies generated as a result of the Program.

- State funding has been secured for colonoscopies provided in the public sector, and a process for identifying Preferred Providers (including the use of private proceduralists) for the additional assessment colonoscopies is currently being undertaken via a tender process.

- An Endoscopy Services Information System is being developed to support implementation of the screening program and endoscopy services more generally.
Keep colonoscopy wait to six weeks

THERAPY
by Rada Rouse

Patients should have to wait no more than six weeks for a colonoscopy under the national bowel screening program, a visiting UK expert says.

Gastroenterologist Dr Roland Valori, a consultant to the UK screening program, urged Australian policymakers to “set the bar high” in quality assurance.

He told the Cancer Council Australia’s forum – Moving Forward on Bowel Cancer Screening – last week that the UK program was currently working towards a target of 18 weeks from referral to treatment, including no more than a six-week wait for diagnostic colonoscopy.

“You have a two-tiered system with sometimes spectacular waits in the public system and none in the private system,” Dr Valori said.

“The overall rate of colonoscopy two to three times the rate of the UK. It’s clear people are doing too many repeats.”

Australian gastroenterologists have reported waits of months in some regions for colonoscopy (MO, 4 November 2005).

Dr Valori said the appropriateness of colonoscopies had to be considered with strict adherence to guidelines for the procedure.

Cancer Council Australia CEO Professor Ian Olver said a six-week wait was a “perfectly reasonable” aim, given the graduated roll-out of the program and a willingness to create efficiencies.

But some states might require more resources, he added.

Over-servicing, often driven by patient demand, needed to be addressed.

“If guidelines were more strictly enforced under a screening program then there is the ability to create more capacity without having to find new money,” Professor Olver said.

He said one of the biggest challenges facing the national program would be effective operation of the central registry overseeing referral and follow-up of patients.