AUSTRALIAN MEDICAL ASSOCIATION
ABN 37 008 426 793
T | 61 2 6270 5400
F | 61 2 6270 5499
E | info@ama.com.au
W | www.ama.com.au
42 Macquarie St Barton ACT 2600
PO Box 6090 Kingston ACT 2604

AMA submission to the Department of Health – National Bowel Cancer Screening Program Review

nbcspreview@health.gov.au

Introduction

The AMA supports the National Bowel Cancer Screening Program (NBCSP) as an important, cost-effective, life saving measure and is pleased to see participation rates increase over time[1]. The AMA believes that there are realistically achievable improvements that can be made to increase the participation rate above the current 44%. This includes implementing both regular nation-wide and targeted communication campaigns to promote the NBCSP and raise bowel cancer awareness, and methods to improve general practitioner (GP) endorsement and participation. The AMA regards a lack of timely colonoscopies post-screening as a major barrier in achieving better health outcomes arising from the NBCSP.

Participation levels and equitable access

Challenges for GPs

GPs as a patient's primary carer are crucial to prompt patient participation in the NBCSP and to counsel and advise patients throughout the screening, diagnosis, and treatment process. AMA members report recent improved GP awareness of the NBCSP as a proven preventative strategy, benefitted by several educational meetings. However, GPs could do more for their patients to increase NBCSP participation rates if the system allowed them to. Studies have found that reducing structural barriers, providing screening kits, GP endorsement, and printed educational materials could increase immunochemical faecal occult blood test (iFOBT) participation rates[2,3].

Clinical software systems can be improved to ease barriers GPs face in engaging with the NBCSP such as workflow and time pressures. While some NBCSP clinical information is included in clinical software, full interoperability with the National Cancer Screening Register is needed. Test results

[1] Australian Institute of Health and Welfare (2020) *Cancer screening programs: quarterly data*.
[2] Dodd, N et al (2019) *Testing the effectiveness of a general practice intervention to improve uptake of colorectal cancer screening: a randomised controlled trial.* Australian and New Zealand Journal of Public Health.
[3] National Bowel Cancer Screening Program (2016) *National Bowel Cancer Screening Program – Primary Health Care Engagement Strategy 2016-2020.*

are currently delivered to the GP's software, however the following information should also be available:

- Whether their patients have received their testing kit (or a kit has been sent to them).
- A patient's NBCSP status, particularly whether the patient has opted out. Currently, the GP must manually denote this information in the warnings section and history of their clinical software.
- Pop up notifications in clinical software that the patient has not responded after eight weeks from receiving the invitation letter.
- Pop up notifications in clinical software systems to remind GPs to speak to their eligible patient about the NBCSP.
- The ability for all forms available on the Register to be filled out from clinical software.

Most of the issues above have long been identified as ways to improve GP engagement in the NBCSP[4], however they have not yet been implemented. Interoperability between the Register and clinical software also provides an opportunity to increase reporting data gathered from GPs to more accurately assess the success of the NBCSP. While there are plans for the Register forms to become interoperable with clinical software, the AMA is disappointed that the incentive payments for these will end[5]. GP members considered the incentive to be some recognition of their time spent filling out the forms. The AMA is concerned that reporting data may decrease when the incentive ends.

Providing spare kits for patients who visit a medical practice but have thrown out their kit would provide GPs with the opportunity to counsel their patient on the importance of the screening test, and for the patient to complete the test while that information is fresh in their mind and they feel motivated to act. Providing a demonstrator kit to GPs would also be a useful tool when teaching patients how to use the kit and would provide the opportunity to answer questions. Kits should include short, clear information for GPs on the NBCSP. GP awareness and endorsement may be improved if executive summaries of NBCSP data is provided to each practice.

GP members have also reported receiving their patient's iFOBT results multiple times –through their clinical software and letters. This results in increased administrative burden for general practices without additional gain for the patient. The AMA suggests loading the results into the doctor's clinical software as the most reliable and efficient method, however it would be preferable for the doctor to choose the method in which they receive the results.

The AMA is not mentioned as a key stakeholder in the primary health care engagement strategy[6], which is surprising given its membership base involves all medical specialties involved in bowel cancer diagnosis and treatment. The AMA should be consulted on any future medical practitioner engagement strategies.

[4] National Bowel Cancer Screening Program (2016) *National Bowel Cancer Screening Program – Primary Health Care Engagement Strategy 2016-2020.*
[5] Department of Health (2020) *Reporting participant information to the National Cancer Screening Register.*
[6] National Bowel Cancer Screening Program (2016) *National Bowel Cancer Screening Program – Primary Health Care Engagement Strategy 2016-2020.*

Challenges for patients

The AMA believes that a regular national communication campaign coupled with regular smaller targeted campaigns are required to improve NBCSP participation rates. Currently, communication strategies are largely State-based and fragmented, however they have been successful in increasing participation rates in some jurisdictions[7]. Currently, there is little knowledge around the NBCSP and its benefits, and the public have a low perception of their personal risk of developing bowel cancer and a low awareness of its burden[8].

AMA members report that the level of health literacy needed to understand the information pack is high. Information should be image-based and as short as possible. Further, English only screening kits may be a barrier to culturally and linguistically diverse (CALD) people participating in the program. The AMA understands that information is available in different languages, however this may not be easily understood, and participants may be reluctant to ask an English-speaking individual due to the personal nature of the iFOBT[9]. The AMA suggests investing in methods to identify CALD individuals more easily to send them a CALD-appropriate screening kit. Obtaining CALD data would also improve data on participation rates and screening results for monitoring purposes, which is currently lacking[10]. The NBCSP should also work with CALD leaders to develop better ways of communicating specifically to individual CALD groups on the benefits and processes of the NBCSP. Screening kits should also be more readily available in CALD communities.

Aboriginal and Torres Strait Islander participation is significantly lower than for other Australians and participation rates are lowest in remote areas despite having the highest positivity rates[11]. Particular challenges for an AMA member working in a remote Aboriginal community included patients' low health literacy, and a lack of understanding around the potential benefits. This member advised an educational campaign that is directed to those with low health literacy, is culturally appropriate with minimal writing is needed to increase the rates of NBCSP utilisation in Aboriginal communities.

Stigma also remains a challenge. It is preferable for patients to drop their samples off at the post office to maintain the integrity of the sample. However, AMA members have heard anecdotally that there remains a feeling of embarrassment for some patients to do this. This is also supported by the literature[12]. Further issues to note in rural, remote, and regional areas include the lack of refrigeration and timely postal services. Participants report feeling embarrassed in small

[7] Lofti-Jam, L et al (2019) *Increasing bowel cancer screening participation: integrating population-wide, primary care and more targeted approaches.* Public Health Research and Practice.
[8] Lofti-Jam, L et al (2019) *Increasing bowel cancer screening participation: integrating population-wide, primary care and more targeted approaches.* Public Health Research and Practice.
[9] Javanparast, S (2012) *Barriers to facilitators of colorectal cancer screening in different population subgroups in Adelaide, South Australia.* Medical Journal of Australia
[10] Australian Institute of Health and Welfare (2020) *National Bowel Cancer Screening Program: monitoring report 2020*
[11] Australian Institute of Health and Welfare (2020) *National Bowel Cancer Screening Program: monitoring report 2020*
[12] Javanparast, S (2012) *Barriers to facilitators of colorectal cancer screening in different population subgroups in Adelaide, South Australia.* Medical Journal of Australia

communities where postal service workers are known to them[13]. The NBCSP should explore better ways to collect samples in rural, regional, and remote areas that are more private while maintaining sample integrity. Dropping a sample off at a pathology centre (where available) may provide a more discrete solution.

AMA members report residents of residential aged care facilities (RACFs) receiving the NBCSP kit but not knowing what to do with it. The AMA suggests further guidance around opportunities for substitute decision-makers to opt out of the NBCSP where appropriate. It is also unclear whether the benefits of the NBCSP continue once a patient enters a RACF and this should be reviewed.

There have also been reports from AMA members that patients have been told conflicting results, where an iFOBT was reported to be positive but then the patient was later told it was in fact negative. This can cause patient distress and the extent of this error should be explored.

Diagnostic assessment services post-result

While the NBCSP is managed by the Commonwealth, colonoscopies for iFOBT-positive patients are not. AMA members report that the NBCSP places addition burden on an already inefficient, under-resourced and overcrowded hospital system[14]. The AMA recommends further Commonwealth resourcing to support colonoscopies arising as a result of the NBCSP, which will only increase as participation rates increase[15].

The median time between positive screen and diagnostic assessment services is 51 days[16]. Patients with a positive iFOBT who do not access the private system are added to public colonoscopy waiting lists, however the AMA is not aware of any additional funding provided for these services. The median wait time between a positive iFOBT and a diagnostic assessment is higher for patients who go through the public system than the private system (77 versus 45 days, respectively)[17], although the waiting times could include factors in addition to hospital waiting times.

Aboriginal and Torres Strait Islander Australians have a 47% lower hospitalisation rate for colonoscopies than other Australians, suggesting a huge inequitable gap in care[18]. This is despite the fact that ATSI participants (as well as those living in very remote areas and who have low socioeconomic backgrounds) have higher positive iFOBT rates[19].

[13] Javanparast, S (2012) *Barriers to facilitators of colorectal cancer screening in different population subgroups in Adelaide, South Australia.* Medical Journal of Australia
[14] Australian Medical Association (2020) *AMA Public Hospital Report Card*
[15] Department of Health (2017) *National Bowel Cancer Screening Program: policy framework phase four (2015-2020)*
[16] Australian Institute of Health and Welfare (2020) *National Bowel Cancer Screening Program: monitoring report 2020*
[17] Australian Institute of Health and Welfare (2020) *National Bowel Cancer Screening Program: monitoring report 2020*
[18] Australian Commission on Safety and Quality in Health Care (2018) *The third atlas of healthcare variation.* Page 81
[19] Australian Institute of Health and Welfare (2020) *National Bowel Cancer Screening Program: monitoring report 2020*

As an additional effect of an under-resourced hospital system, AMA members report pressure to undertake additional blood tests and abdomen CTs to assess the severity of the positive iFOBT in lieu of a timely colonoscopy. This creates extra costs and inefficiencies to the patients and the health system.

Early detection of bowel cancer increases the chance of survival, and research has shown that patients diagnosed with bowel cancer up to one year after receiving a NBCSP invitation are on average at an earlier stage than patients diagnosed with cancer who were not invited to the NBCSP[20]. However, Australia's health system does not go far enough post-screening to ensure early detection. The AMA recommends exploring the feasibility of federally funded, dedicated NBCSP colonoscopy clinics or hospital beds.

The NBCSP should work with local governments to clearly communicate colonoscopy and treatment options and accessibility to ensure patient expectations are managed. This would include public options, contacts, and wait times relevant to the patient's area. If the full cascade of investigation and treatment cannot be guaranteed, this causes patient distress and is unethical.

There is some confusion around doctor responsibilities and the timing of follow up colonoscopies. The NBCSP states that "if we have no record of your colonoscopy we will invite you to the program again in 2 years". However, the medico-legal responsibility of follow up lies with the GP. Guidance to GPs should clearly articulate their responsibilities in the follow up process.

Conclusion

The AMA supports the NBCSP as an essential tool to improve health outcomes and survival rates for Australians. However, more can be done to increase participation rates and improve the NBCSP's success. This includes implementing regular nation-wide and targeted communication campaigns to improve NBCSP awareness and understanding of bowel cancer, interoperability between clinical software and the National Cancer Screening Register and increasing capacity for timely colonoscopies. The AMA welcomes further opportunity to comment on any future doctor engagement strategies.

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Contact

Hannah Wigley
Senior Policy Adviser
AMA Policy Department
hwigley@ama.com.au

[20] Cole et al (2013) *Shift to earlier stage at diagnosis as a consequence of the National Bowel Cancer Screening Program.* Medical Journal of Australia