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Tēnā koe Mr Neal

Guidance for best practice management in the National Bowel Screening Programme

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to submit feedback on the Ministry of Health's Guidance for best practice management in the National Bowel Screening Programme (the Guidance).

The RACP works across more than 40 medical specialties to educate, innovate and advocate for excellence in health and medical care. Working with our senior members, the RACP trains the next generation of specialists, while playing a lead role in developing world best practice models of care. We also draw on the skills of our members, to develop policies that promote a healthier society. By working together, our members advance the interest of our profession, our patients and the broader community.

The NZSG works to advance the knowledge of gastroenterology in New Zealand, to promote improved standards in the practice of gastroenterology and to encourage research into gastroenterology and allied subjects. The NZSG connects its members through educational and scientific meetings and fosters links to national and international Societies and Associations relevant to the field of gastroenterology.

Independent Assurance Review for the National Bowel Screening Programme

The Health Quality and Safety Commission (HQSC) published a comprehensive report titled "Independent Assurance Review for the National Bowel Screening Programme (NBSP)" in July 2018¹. This report raised several issues; several appear to not to be covered in this guidance document. NZSG is concerned there may be perceptions these matters have already been discussed and therefore do not need further attention, though they have certainly not been addressed.

¹ Health Quality and Safety Commission. Independent Assurance Review for the National Bowel Screening Programme. [Internet] Wellington: Health Quality and Safety Commission; 2018. Available from <https://www.hqsc.govt.nz/our-programmes/other-topics/publications-and-resources/publication/3430/>. Accessed 14 January 2019.

A significant issue is the workforce challenges faced by clinicians as a result of the demand for colonoscopy. This demand has increased as a direct result of

1. NBSP colonoscopy and subsequent surveillance scopes

The demand has increased as an indirect result of:

2. raised awareness of bowel cancer and lower gastrointestinal symptoms with patients requesting colonoscopy for those reasons; and
3. patients' awareness of positive family history, which has prompted them to come forward.

Potential for an embedded two-tier system to emerge

Given the existing workforce challenges, a number of District Health Boards (DHBs) have outsourced symptomatic and surveillance colonoscopies to the private sector. Although DHBs participating in the NBSP are required to submit data six-monthly to the National Endoscopy Quality Improvement Programme (NEQIP) to demonstrate quality assurance activities, private facilities are under no obligation to meet this expectation. Therefore, those patients having a publicly-funded endoscopy in a private unit are not given the same quality assurance as patients having the same procedure under the same Screening Programme but performed in a public facility.

NZSG finds that a two-tier system is most certainly in place, despite the aims of the NBSP to embed equity. The NBSP is in fact creating inequity by being much more robust with systems for those undergoing a NBSP colonoscopy than those in place for patients undergoing colonoscopy for symptomatic and surveillance purposes in a private unit.

NZSG and RACP recommend that private facilities used for colonoscopies on symptomatic and surveillance procedures on DHB patients should demonstrate the same quality standards as those in the NBSP and participate in NEQIP, or otherwise provide evidence of quality assurance activities of the same standard as those required of DHB units, every six months.

Equity and screening for Māori

The RACP and NZSG recognise that health inequity arises from avoidable health inequalities due to the conditions in which people are born, grow, live, work and age². The system designed to deal with illness – the health system – is predicated on social, political and economic forces which reflect and reinforce dominant political narratives and result in the uneven distribution of resources and access to services. As detailed by several analyses of New Zealand data, a deprivation gradient can be observed in overall cancer risk, given the distribution of and exposure to risk factors (including high body mass index, diet, tobacco use/exposure) and access to health care and services³.

New Zealand has a high incidence of bowel cancer – in 2016, 3152 registrations were recorded for cancers of the colon, rectum and rectosigmoid junction, making it the most

² Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health. Geneva: World Health Organization; 2008. Available from https://www.who.int/social_determinants/thecommission/finalreport/en/. Accessed 7 January 2019.

³ Robson B, Purdie G, Cormack, D. 2010. Unequal Impact II: Māori and Non-Māori Cancer Statistics by Deprivation and Rural–Urban Status, 2002–2006. Wellington: Ministry of Health. Available from <https://www.health.govt.nz/publication/unequal-impact-ii-maori-and-non-maori-cancer-statistics-deprivation-and-rural-urban-status-2002-2006>. Accessed 7 January 2019.

common cancer diagnosis⁴. In 2013, bowel cancer was the second highest cause of cancer mortality in New Zealand (following lung cancer) with 1252 deaths⁵. Although Māori have a slightly lower incidence of bowel cancer than non-Māori (in 2016, the age-standardised rate was 38.0 for Māori compared to 42.1 for non-Māori), Māori are more likely to die from bowel cancer than non-Māori non-Pasifika patients^{3 6}. While some of the disparity can be attributed to late stage of diagnosis, other contributing factors – including access and quality of treatment and care received by Māori – signal entrenched inequities in cancer outcomes^{2 7}.

The Presentation, Investigation, Pathways, Evaluation, Rx (Treatment) (PIPER) Study found that 44 per cent of Māori and 51 per cent of Pasifika patients with colon cancer presented to the Emergency Department as their first symptomatic presentation, compared to and 34 per cent non-Māori, non-Pasifika. This is significantly higher than the United Kingdom, where 21 per cent of patients will present to the Emergency Department. Further, Māori and Pasifika are more likely to be diagnosed with Stage IV (metastatic) disease than non-Māori, non-Pasifika for both colon and rectal cancer, and experience greater delays in accessing treatment⁵.

Affirmative action recommended

Given the existing disparities, greater likelihood severity of disease at diagnosis and the Ministry's prioritisation of equity, we believe the Ministry of Health has an opportunity to proactively address the ongoing health gap between Māori and non-Māori. This could be achieved by screening Māori earlier (from 50 or 55 years).

An affirmative action initiative in the Screening Programme could address ethnic disparities in health gain by recognising the likelihood for Māori to present with end-stage disease; experience poorer health outcomes; and have a lower life expectancy than non-Māori.

Regarding the Bowel Screening Programme specifically, McLeod et al showed Māori will derive half the health gain in quality adjusted life expectancy from the implementation of the Programme compared to non-Māori (11 versus 21 additional health days of life)⁸.

Equality and equity in the Guidance

The Guidance refers to the Ministry's commitment to te Tiriti o Waitangi (the Treaty of Waitangi) and the principles of partnership, participation and protection it guarantees. The recommendations for equity and screening for priority groups are

1. Commitment to equity in health outcomes

⁴ Ministry of Health. New cancer registrations 2016. [Internet] Updated 12 December 2018. Available from <https://www.health.govt.nz/publication/new-cancer-registrations-2016>. Accessed 7 January 2019.

⁵ Ministry of Health. New cancer registrations and deaths 2013. [Internet] Wellington: Ministry of Health; 2016. Available from <https://www.health.govt.nz/publication/cancer-new-registrations-and-deaths-2013>. Accessed 7 January 2019.

⁶ Jackson C, Sharples K, Firth M, Hinder V, Jeffery M et al. The PIPER Project: An internal examination of colorectal cancer management in New Zealand. Auckland: Cancer Research Partnership; 2015. Available from <https://www.cancertrialsnz.ac.nz/piper/>. Accessed 7 January 2019.

⁷ Hill S, Sarfati D, Blakely T, Robson B, Purdie G, et al. Survival disparities in Indigenous and non-Indigenous New Zealanders with colon cancer: the role of patient comorbidity, treatment and health service factors. *J Epidemiol Community Health*. [Internet] 2010; 64:117-23. Available from <https://jech.bmj.com/content/64/2/117>. Accessed 8 January 2019.

⁸ McLeod M, Kvizhinadze G, Boyd M, Barendregt J, Sarfati D et al. Colorectal cancer screening: How health gains and cost effectiveness vary by ethnic group, the impact on health inequalities and the optimal age range to screen. *Cancer Epidemiol Biomarkers Prev* [Internet]. 2017; 26(9):1391-1400. Available from <http://cebp.aacrjournals.org/content/26/9/1391>. Accessed 7 January 2019.

2. Responsiveness to Māori
3. Culturally competent/appropriate services
4. Encouragement for clinicians to advocate for their patients, endorsing the screening pathway while remaining cognisant of the patient's health literacy and additional resources and support that may be available

While we find these Practice Points broadly consistent with the Ministry's guidance on cultural competence, responsiveness, alignment with Treaty principles and the importance of equity as a government priority, we believe these recommendations reflect equality rather than equity.

For example, recommendation R1.01 states "providers are expected to use evidence-based strategies to support equal access and quality for priority group people" – is this equal to the mainstream (in this instance, those not identified by a priority criterion)?

If the recommendation was revised to state "equitable access and quality" this would direct services to work to actively mitigate existing gaps in health outcomes, and strategies could include screening the Māori population earlier than non-Māori population. Earlier screening could identify bowel cancer earlier, enable Māori to obtain the health gains evidence shows that they have missed out on in the existing screening pathway, and contribute to reducing excess mortality from cancer for Māori and their whānau.

We acknowledge the work of the Ministry's Bowel Screening Advisory Group (BSAG) in exploring the equity impacts for Māori in the rollout of the screening programme, particularly in relation to the eligible age range for participation (60-74 years)⁹. The investigation noted that

1. A greater proportion of cancer cases occur in Māori aged under 60 years compared to non-Māori
2. While rates of new bowel cancer registrations have decreased for non-Māori since 2004, the rates for Māori have remained variable, and shown a slight upward trend over the same time period, particularly for Māori males
3. Even if the Māori participation rate was equal to that of non-Māori, health gain inequities would still persist due to the greater likelihood for advanced-stage disease, and shorter life expectancy for Māori compared to non-Māori

Despite the persistent inequities experienced by Māori, the BSAG have recommended the eligible age for entry into the bowel cancer screening programme remain at 60 years. Rationale cited to support this recommendation included the potential for greater risks for Māori including false positive results and psychosocial consequences resulting from this, complications from colonoscopy, and the possibility of overdiagnosis.

The RACP recommends the decision not to implement bowel screening for Māori is reviewed, and a pilot study is undertaken to establish whether screening Māori for bowel cancer from age 50 enables the health gains Māori are currently missing out on.

In line with the RACP's ongoing advocacy campaign #MakeItTheNorm, we call for action on the social determinants of health to move Aotearoa New Zealand towards a more equitable, healthy society¹⁰. We acknowledge that equity-based, affirmative action in bowel cancer

⁹ Ministry of Health. National Bowel Screening Programme: Consideration of the potential equity impacts for Māori of the age range for screening. Wellington: Ministry of Health: 2018. Available from <https://www.health.govt.nz/our-work/preventative-health-wellness/screening/national-bowel-screening-programme/key-documents-national-bowel-screening-programme>. Accessed 7 January 2019.

¹⁰ Royal Australasian College of Physicians. Make it the Norm: Equity through the social determinants of health. [Internet]. Available from <https://www.racp.edu.au/fellows/resources/new-zealand-resources/new-zealand-election-statement-2017>. Accessed 9 January 2019.

screening will be only one component in a suite of initiatives and activities across government, industry and civil society to ensure whānau and community wellbeing. We strongly believe that action must be taken wherever possible to ensure our nation is on track to achieving the highest possible standard of health for all our people, but particularly those that experience entrenched inequity.

Fecal Immunochemical Testing outside the National Bowel Screening Programme

The Ministry has undertaken a gradual roll-out of the Screening Programme, with Hutt Valley and Wairarapa DHBs beginning screening eligible populations in 2017. Given the public discourse around bowel cancer, discussion of the Screening Programme and the high mortality rates in New Zealand, it is unsurprising that alternative tests have been directly marketed to consumers.

NZSG and RACP recommend that clinicians are provided guidance which covers both information about the specificity of the alternative tests (notably the fecal occult blood test (FOBT)) and what clinicians can do if they are referred a person who is asymptomatic but has a positive FOBT result. A starting point could be the statement prepared by Dr Susan Parry and Dr John McMenamin, which can be found on the National Screening Unit's website¹¹.

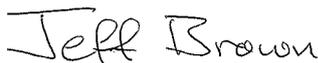
Other comments on the Guidance document

Instances in the document where the macron is absent from Māori: pages 10 and 13.

The Guidance document contains a flowchart at Figure 5 "Cultural and supportive care". It is difficult to ascertain how this flowchart pertains to cultural and/or supportive care, as the flowchart describes treatment pathways for three different presentation types (high-risk groups, population screening and symptomatic presentations) and does not include any references to additional measures to providing cultural and/or supportive care (for example, meeting with whānau, use of translation services, recommendation of the phone support service use of Māori or Pasifika liaison officers). We recommend the title and flowchart are reviewed and amended to ensure it reflects the Ministry's intentions.

The RACP and the NZSG thank the Ministry for the opportunity to provide feedback on this consultation and looks forward to the release of the final version of the Guidance. To discuss this submission further, please contact the NZ Policy and Advocacy Unit at policy@racp.org.nz

Nāku noa, nā



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¹¹ National Screening Unit. Use of self-purchased FOBT kits. [Internet]. Updated 25 October 2018. Available from <https://www.nsu.govt.nz/health-professionals/national-bowel-screening-programme/use-self-purchased-fobt-kits>. Accessed 14 January 2018.