New Zealand House of Representatives
Te Whare Māngai o Aotearoa

Petitions Committee
Komiti Whiriwhiri Take Petihana

54th Parliament
December 2024

Petition of Kristine Hayward: Implement a funded, risk-based, equitable prostate cancer testing regime in NZ

Presented to the House of Representatives
by Greg O'Connor, Chairperson

Contents

Petition of Kristine Hayward

Recommendation

The Petitions Committee has considered the petition of Kristine Hayward—Implement a funded, risk-based, equitable prostate cancer testing regime in NZ—and recommends that the House take note of its report.

Request for a prostate cancer testing regime

The petition was presented to the House on 27 July 2023. It requests:

> That the House of Representatives urge the Government to implement a centrally funded and administered risk-adapted early prostate cancer detection strategy based on prostate-specific antigen (PSA) testing, risk calculators, and MRI imaging, and State-funded support for the psychological and physical effects.

The Petitions Committee of the 53rd Parliament began considering the petition. It invited a submission from the petitioner. We resumed consideration in the 54th Parliament. We received the petitioner's submission, and invited and received written submissions from the Ministry of Health | Manatū Hauora, Health New Zealand | Te Whatu Ora, Te Aho o Te Kahu | the Cancer Control Agency, the Prostate Cancer Foundation of New Zealand, and the Urological Society of Australia and New Zealand.

About cancer screening

Cancer screening is usually carried out on people who do not have any symptoms of a disease. There are two main types of screening:

- population-based screening programmes, which are usually funded and carried out by health authorities
- opportunistic screening, which usually happens when someone asks a doctor for a test or a test is offered by a clinician.

New Zealand currently has population-based screening programmes for breast, cervical, and bowel cancer. New Zealand does not have a national prostate cancer screening programme.

Comments from the petitioner

Mrs Hayward asked that the Government implement a prostate cancer testing regime. She told us her husband and her family were victims of a "broken system" trying to treat prostate cancer. Her husband Bruce was diagnosed with prostate cancer in June 2018 and passed away in November 2019 at the age of 66. Mrs Hayward said he had an aggressive form of cancer because it was diagnosed too late. The cancer had metastasized to his bones, which she described as horrific and painful. She told us that they were married for nearly 50 years, and that losing her soulmate has left a great void in her life.

The experience of prostate cancer diagnosis

Mrs Hayward and her husband were registered nurses who often worked in remote parts of Australia. They sought health checks when they were back in New Zealand. The checks included mammogram and cervical screening for Mrs Hayward, and prostate-specific antigen (PSA) testing for her husband. However, she told us she felt that the last consultation her husband had with his general practitioner (GP) was "extremely deficient" and lacked good advice and information on prostate cancer. She believes this led to his "terrible untimely death".

"Slipping through the system"

The petitioner said that prostate cancer is one of the most commonly diagnosed and deadly cancers in men and that others are also "slipping through the system". She told us that every year over 4,000 people are diagnosed with the disease and over 700 die.[1] Mrs Hayward said that Māori and rural men are disproportionately affected.

Mrs Hayward asked that action be taken to improve screening of men for prostate cancer. She told us, "I don't want any family to go through this hell". She said that using PSA tests is currently dependent on patients asking their GP for a test, or GPs taking the initiative to order a test. She told us neither option is satisfactory, and leads to both over- and under-testing, with many men missing out. Mrs Hayward said that many men have thanked her for starting this petition and for talking about the importance of early detection of prostate cancer. She said the current process for screening for prostate cancer is outdated and haphazard, and she would like to see something more substantial put in place.

The petitioner referred to New Zealand's Cancer Action Plan.[2] She said the plan intends that New Zealanders have better cancer survival rates, and supportive care. Population screening is identified as a priority area to achieve this outcome, but there is currently no regular screening programme for prostate cancer. Mrs Hayward believes this needs to change. She told us, "Surely we can do better".

Comments from the Prostate Cancer Foundation

The Prostate Cancer Foundation of New Zealand expressed strong support for the petition. It said a prostate cancer early detection programme is crucial for the wellbeing of men and would contribute to reducing the burden of prostate cancer.

Around 16,000 New Zealand men have died of prostate cancer in the past 25 years, according to the foundation. It said the most recent information from the Ministry of Health showed there were 762 deaths from prostate cancer in 2021. The foundation described this as being a significant increase on the 706 deaths in 2020, which it said had been the average for several years. The foundation had thought deaths might reduce during the COVID-19 pandemic response, and said the most recent figures were alarming.

1 Prostate Cancer Foundation NZ, Prostate cancer in New Zealand, accessed 22 May 2024.

2 Ministry of Health | Manatū Hauora, New Zealand Cancer Action Plan 2019-2029, p 13.

Experiences of prostate cancer

Thousands of men have shared their experiences of the disease with the foundation. Mr Bedingfield, Chair of the Prostate Cancer Foundation, told us he had been diagnosed with prostate cancer at the age of 37 and "it is not just an old man's disease anymore." He said increasingly men in their 40s and 50s are diagnosed with prostate cancer, and some are still trying to have a family when diagnosed. Mr Bedingfield said a lot of men are reluctant to talk publicly about their experience of having prostate cancer, especially if they have experienced erectile dysfunction or incontinence as a result of the cancer or treatment.

We heard that many wives of men living with prostate cancer and widows of men who have died of prostate cancer are also supporting the petition and the foundation's proposals for screening. Ms Coughlan, a member of the Prostate Cancer Foundation delegation, told us that opportunistic testing alone is not working. She said her husband had requested PSA testing among other medical tests when he turned 50, but his GP had told him it was not necessary. However, four years later he learned that his prostate cancer had spread to his lymph nodes. She said, "A tick in the box at 50 could have saved him a lot of angst".

The foundation said many cases are diagnosed at advanced stages when treatment options are limited and outcomes are poorer. It told us that there are disproportionately poorer outcomes for Māori, Pasifika, and rural men. We asked what other risk factors are relevant for prostate cancer. We were told that family history is an important risk factor, but because many men do not talk about their experience of prostate cancer, often their male relatives are not aware that there may be a family history.

We heard that when prostate cancer symptoms are apparent, it is too late for treatment to save lives. The foundation said that testing men before they have symptoms is the only way to ensure prostate cancer is diagnosed early enough for effective treatment.

Cost-effectiveness of early detection of prostate cancer

The foundation told us it has already provided evidence on the cost-effectiveness of investing in early detection of prostate cancer, including a report commissioned from the New Zealand Institute of Economic Research (NZIER) in 2022.[3] It said that identifying and treating prostate cancer early can prevent costly and more invasive interventions later. When prostate cancer is detected at an early stage, patients have a wider range of treatment options, including less invasive therapies with fewer side effects. It said this not only improves survival rates, but also enhances the overall quality of life for men living with prostate cancer.

According to the foundation, New Zealand's record of screening programmes for other forms of cancer, such as breast and cervical cancer, show that screening programmes detect cancer early and save lives. It told us that in recent years the science behind screening for prostate cancer has improved significantly, and there is a lot of international activity with screening trials and pilots.

[3] New Zealand Institute of Economic Research and Prostate Cancer Foundation NZ, The case for screening: Cost effectiveness of a PSA-based population screening programme for prostate cancer in New Zealand, December 2022.

Proposal for a pilot screening programme

Although the petition requests a national screening programme, the foundation instead proposes a pilot screening programme in two centres. It notes that seven countries are currently piloting screening programmes and trials.[4] It understands that some local decision-makers are waiting to see the outcomes from those pilots. However, the foundation told us it believes New Zealand cannot afford to wait.

In the foundation's view, a New Zealand trial or pilot must start as soon as possible, as the death rate is increasing substantially. It said the European trials will provide important information but will not be able to show local decision makers the likely effect of screening programmes on Māori and Pasifika men in New Zealand. It said a New Zealand pilot would be able to provide that information.

Elements of a pilot screening programme

There is widespread agreement, according to the foundation, that the key components of a pilot screening programme involve progressing through:

- a PSA blood test
- an MRI scan
- a biopsy.

The foundation said that, although each element—such as PSA testing—may continue to develop and improve, it considers that there is no longer any doubt that each of these elements is needed. It told us the question being considered through overseas pilot screening programmes is not whether those screening elements work, but how to ensure that they work effectively in local contexts. A key concern, it said, is how to encourage men to engage with a prostate screening programme.

Regions proposed for a pilot programme

The foundation recognises that the New Zealand health system is under strain. In the long term it recognises that more resources will be needed to roll out a national screening programme. However, it thinks that some regions currently have the capacity to participate in a pilot or trial programme, as they can provide PSA testing, MRI screening, and biopsies.

The regions the foundation recommends as well-suited for a pilot programme are Te Tairāwhiti | Gisborne and Waitemata. It said those two regions would provide information from an urban area and a rural area with a high Māori population. The NZIER research estimated in 2022 that the cost of a 3-year pilot screening programme in these two areas would be $6.5 million. The foundation believes New Zealand could fund this, and it would have a positive impact on the health of New Zealand men.

[4] They include the European Randomized Study of Screening for Prostate Cancer (ERSPC) which involves around 182,000 men in seven countries.

Comments from Health New Zealand and the Cancer Control Agency

Health New Zealand | Te Whatu Ora and Te Aho o Te Kahu | the Cancer Control Agency provided separate written submissions and presented their oral submissions together. The agencies acknowledged that prostate cancer is a major health issue in New Zealand, second to lung cancer as the most common cause of cancer deaths among men.

The Cancer Control Agency said that screening programmes and the treatments that follow an abnormal result often come with their own risks to patients' health. It said the potential benefits of screening must outweigh the potential harms for a screening programme to be viable. Health New Zealand told us that the worst thing to do would be to introduce a population-based screening programme that produces more harm than benefit.

National Screening Advisory Committee assessment

Decisions about screening programmes in New Zealand are made by the National Screening Advisory Committee (NSAC).[5] We heard that the committee includes health professionals, epidemiologists, an ethicist, and Māori and Pasifika consumer representatives. It also invites specialists in particular areas into the committee. The committee assesses proposals for new screening programmes against eight criteria established by the National Health Committee in 2003.

Insufficient evidence for population-based screening

The NSAC reviewed the evidence about prostate cancer screening in July 2018 and April 2019. Those reviews concluded that there was insufficient evidence to introduce population-based prostate cancer screening at that time. We heard that the assessment was that introducing a national screening programme, or even a pilot screening programme, at that time would produce more harm than benefit.

The NSAC most recently considered prostate cancer screening in November 2023. It concluded that the most recent international evidence supported only two of the eight criteria and was inconclusive for the other six. We heard that NSAC intends to review its position on prostate cancer screening again in 2026, or sooner if enough evidence emerges before then.

PSA testing alone not a suitable screening test

We were told that the NSAC noted that the PSA test alone is not a suitable screening test, as it results in higher than desirable numbers of false positive and false negatives.[6] We heard that about 75 percent of men with an abnormal PSA result do not have prostate cancer—a false positive result. About 15 percent of men with no symptoms who have a normal PSA result have prostate cancer, which is a false negative result.

The Health New Zealand written submission included an Appendix summarising the NSAC assessment against its eight criteria. We noted that the second criterion, which asks if there is a suitable test for screening, states: "The latest evidence shows that there are still

5 More information about the National Screening Advisory Committee is available on the website of Health New Zealand | Te Whatu Ora.

6 A false positive test indicates that someone may have prostate cancer when it is not present. A false negative test may clear someone of having prostate cancer when it is present.

limitations with the use of PSA testing as the sole screening tool for prostate cancer screening".

However, the NSAC considered that a prostate cancer screening programme using PSA testing together with other screening tools, such as MRI scans and risk stratification, could have the potential to reduce overdiagnosis and unnecessary treatment. We were told that it believed further evidence was needed. Health New Zealand said that such a screening programme would also require more investment in urology and radiology services and a specialist workforce.

European trials may provide further information

The Cancer Control Agency noted that a three-year European trial that began in April 2023, the Prostate Cancer Awareness and Initiative for Screening in the European Union (PRAISE-U), aims to establish a protocol for a population-based prostate cancer screening programme. It said the outcomes from this trial will address an important data gap.

Responses to the petition request

Health New Zealand told us that it will consider implementing a screening programme for prostate cancer once the evidence supports it. However, it said that the most recent review of the evidence suggests that the harms of screening currently outweigh the benefits.

Need for local data

Both Health New Zealand and the Cancer Control Agency said there is growing international evidence that a prostate cancer screening programme that incorporates MRI screening may be cost-effective. However, more local data is needed to consider whether this would apply in New Zealand. It said there is a need for local research groups to undertake prostate cancer research or modelling to address the gaps in evidence.

Health New Zealand told us that PSA tests do not provide the same level of certainty as screening tests for other forms of cancer, such as cervical cancer. It said high levels of false positives and overdiagnosis have led health authorities in most countries to be hesitant about recommending the test.

Guidance for general practitioners

Health New Zealand pointed to the Prostate Cancer Management and Referral Guidance, published by the Ministry of Health in 2015. It said this provides guidance for GPs to have informed discussions with men.[7]

It can be very difficult for a general practitioner to provide good advice to a man requesting an opportunistic PSA test, according to Health New Zealand. It is concerned that potentially widening the use of PSA testing alone could lead to a lot of men having unnecessary invasive tests, such as biopsies, which have the potential to cause harm.

[7] The Prostate Cancer Management and Referral Guidance is available on the website of the Ministry of Health.

Variation across New Zealand in screening, diagnosis, and treatment

The Cancer Control Agency acknowledged that there is variation in opportunistic prostate screening across New Zealand, and inequities in access to primary health care and subsequent diagnostics following testing. It said the current evidence suggests that the level of opportunistic testing is relatively high, but rates are variable. Māori are significantly less likely to receive PSA testing than non-Māori.

We heard that there is also considerable variation in treatment or diagnosis following an abnormal PSA test. In some parts of New Zealand, a PSA test may be followed by further MRI or ultrasound imaging. This reduces the potential for harm from unnecessary biopsies, which are more invasive. However, in other parts of the country, that is not the case. It depends on the availability of specialist staff and equipment. We were told that access to MRI or ultrasound is "really fraught".

"Too early" for a national screening programme

Health New Zealand and the Cancer Control Agency said they expect that PSA testing will continue to develop and improve. They told us that they do not think prostate cancer screening in New Zealand is far off. However, they emphasised that the NSAC thinks it is too soon to consider a national programme in New Zealand. They also noted that a multi-modality screening programme, such as that recommended by the petitioner, would require substantial investment in MRI equipment and workforce. The agencies told us they believe that improving the quality of current programmes would be preferable to running a pilot screening programme at this stage.

Further comments from the petitioner and Prostate New Zealand

Following our hearing, we offered the petitioner and Prostate New Zealand an opportunity to make further written comment on the health agencies' submissions.

Out-of-date information

The petitioner told us it was "agonising" to hear the agencies refer to screening as unreliable and invasive. She said that the combination of tests proposed in her petition is reliable and non-invasive. She told us she believes the information used by the health agencies is out of date.

The Prostate Cancer Foundation also said that it believes the NSAC's conclusions are based on concerns that are outdated or overstated. It said that arguments that some men currently progress from an abnormal PSA test directly to an invasive biopsy are not relevant to the request made in this petition. The petition asks for a cancer-detection strategy that is based on PSA testing, risk calculators, and MRI imaging. It said that in the petition's proposed approach, the first steps (PSA testing, ultrasound, and MRI scan) are minimally or completely non-invasive.

Screening, diagnosis, and treatment should not depend solely on PSA testing

The foundation agreed with the health agencies that current international research does not point to a screening and diagnosis pathway that relies solely on PSA testing, but said that the petition also does not seek to rely solely on PSA testing. It said the Prostate Cancer Outcomes Registry shows that New Zealand cancer specialists are not rushing to treat low-grade, slow-growing prostate cancer where the harms of treatment outweigh the risk. The foundation said the health agencies, despite expressing concerns of potential harm, did not present evidence that overtreatment follows diagnosis.

MRI availability and workforce

MRI availability in the New Zealand health system must be addressed, according to the foundation, not only for a prostate cancer screening programme, but for the sake of patients across New Zealand who are facing multiple health challenges. However, the foundation does not think this problem needs to be resolved nationwide before a pilot screening programme could be undertaken. It said the former DHB regions of Tairāwhiti | Gisborne and Waitematā already offer a prostate cancer pathway that includes PSA testing, followed by ultrasound and MRI scanning, and then a biopsy for those patients who need it. The foundation restated its belief that these two regions already have the capacity to participate in a potential New Zealand prostate screening pilot or trial.

Comments from the Urological Society of Australia and New Zealand

Following our hearing with the petitioner, the Prostate Cancer Foundation, and the health agencies, we invited written and oral submissions from the Urological Society of Australia and New Zealand (USANZ). USANZ expressed strong support for the petition.

Early detection of prostate cancer

The society said that early detection of prostate cancer currently requires a patient to request screening or a GP to initiate a conversation about it. Information that New Zealand men receive about prostate cancer and access to screening varies hugely across the country, according to USANZ.

We heard that a lot of opportunistic screening occurs, but often at inappropriate intervals or times. USANZ said this can lead to higher rates of diagnosis of low-grade disease and to delays in the diagnosis of high-risk disease. The society told us that prostate cancer has no symptoms in its early stages.

USANZ said that the big international studies on prostate cancer have yet to show an overall survival advantage to screening. However, we heard that the European Randomized Study of Screening for Prostate Cancer (ERSPC) trial in Europe is the largest trial of prostate cancer screening to date. Over 180,000 men have enrolled in this programme, and there is now up to 21 years of follow-up information. The society said this trial has shown a 20 percent reduction in prostate cancer mortality, as well as a 50 percent reduction in the number of cases detected at the advanced disease stage. It has also shown a 60 percent

decrease in secondary treatment, and a 40 percent reduction in the need for palliative treatment.

Equity concerns

USANZ said there are equity concerns in prostate cancer outcomes. It referred us to research undertaken by Professor Kamran Zargar of Auckland University showing that around 61 percent of New Zealand men over the age of 40 will have had a PSA test, but only 41 percent of Māori men.[8]

In New Zealand, opportunistic PSA testing mostly occurs as a result of conversations between patients and GPs. Some of the variability in prostate cancer outcomes in New Zealand results from unequal access to primary health care. The society said at least 10 percent of the population does not have access to a GP, and up to 50 percent face barriers to seeing one, such as cost. USANZ said Professor Zargar's research shows that Māori men have significantly worse outcomes from prostate cancer than the general population primarily because they present later for diagnosis and screening. The society said that, when presentation times match, outcomes are the same for all groups.

Delays in referral

Dr Mike Vincent from USANZ told us that his own research in the southern region showed that delays in referral are a concern. He found that, on average, the majority of men met criteria for referral and investigation two years before they were actually referred. He said this showed that, although testing was being undertaken, it was not necessarily well understood.

USANZ acknowledged that PSA screening alone can result in over-detection and over-treatment. It said this is reduced by pre-biopsy MRI scans and risk algorithms. Additionally, surgical changes have reduced long-term harm.

The society said that New Zealand's prostate cancer guidelines were developed in 2015 and are now out of date. It said that so much has changed in both the diagnosis and treatment of prostate cancer that, in its view, the question is not whether New Zealand should have a screening programme but how one could be implemented.

Our response to the petition

We thank Mrs Hayward for bringing this petition to Parliament. We acknowledge the loss of her husband Bruce, and the work she is undertaking in his memory.

A prostate cancer screening pilot programme

We have considered the petitioner's request for a prostate cancer screening programme, the Prostate Cancer Foundation's recommendation of a pilot programme in two regions, and the feedback from health agencies.

[8] Professor Zargar's research papers and a summary of his findings are provided in supplementary submissions 1-3 of the Urological Society of Australia and New Zealand.

We acknowledge that the National Screening Advisory Committee recommended that a screening programme based on PSA testing alone would not be reliable. However, that is not what the petitioner is asking for. Her request is for a screening programme that includes PSA testing, risk calculators, and MRI imaging.

We heard substantial areas of agreement between all submitters, including:

- A reliable prostate cancer screening programme would require MRI and/or ultrasound imaging following a PSA test.
- There is a lack of MRI workforce and equipment in many regions of New Zealand.
- There are significant equity concerns with the current arrangements.
- There is a need for more New Zealand-based information to complement data and outcomes from international trials and pilots.

We encourage the Government to consider a pilot prostate cancer screening programme in a region with appropriate MRI capacity.

Information about prostate cancer

We noted variation in the written submissions about the number of New Zealanders affected by prostate cancer:

- The petitioner, the Prostate Cancer Foundation, and USANZ told us that more than 4,000 men are diagnosed annually with prostate cancer, and 700 men die from prostate cancer each year.
- Health New Zealand told us that 3,000 new prostate cancer cases are diagnosed each year and that more than 600 men die from prostate cancer annually.
- The Cancer Control Agency's written submission told us that around 4,000 people are diagnosed with prostate cancer and 600–700 die each year.

In its oral submission, the Prostate Cancer Foundation updated us that the most recent information from the Ministry of Health showed an increase from 706 New Zealand deaths in 2020 to 762 deaths in 2021.

The Health New Zealand figures appeared to us to be from the 2015 guidelines. We were surprised that the information they gave us was not based on the most recent figures available from the Ministry of Health.

Need for more MRI imaging equipment

It was clear from the information given by all submitters that proceeding from an abnormal PSA test directly to an invasive biopsy is not considered best practice, and runs the risk of negative side effects. However, it was also clear that, at present, this is all that can be offered to many New Zealand men seeking prostate cancer screening, diagnosis, and treatment.

Separate from the petitioner's request for a national screening programme, we are concerned about the shortage of MRI equipment and a workforce to operate it. Regardless of whether a screening programme or pilot is introduced, many men already in the New Zealand health system are at risk of receiving sub-optimal treatment because MRI imaging is

not available. We would like to see access to MRI imaging improved throughout New Zealand.

Talking about prostate cancer

We appreciate that talking about prostate cancer can be a difficult topic. We know that many men are reluctant to begin a conversation about prostate cancer with their GP.

We were concerned to encounter some reluctance on the part of health agencies to talk clearly about possible negative side effects of prostate cancer screening, diagnosis, and treatment in our committee hearing. We asked the representatives of health agencies five times to explain these possible negative outcomes. We did not receive a clear verbal answer to this question. Instead, in our hearing, we heard general comments that prostate cancer biopsies are “unpleasant”, and “cause a lot of harm”.

We have no doubt that “unpleasant” could be applied to other forms of cancer screening, such as a colonoscopy for bowel cancer, a smear test for cervical cancer, or a mammogram for breast cancer. These procedures may involve some discomfort for patients, but are potentially life-saving. We do not think it is helpful for health agencies to be squeamish about discussing consequences from prostate cancer treatment. We would have appreciated a direct and specific explanation of the agencies’ concerns.

We asked whether there is gender balance on the National Screening Advisory Committee. We were told that there is a balance of men and women on this committee.

We encourage the health agencies who submitted to us to reflect on how their choice of language may persuade or dissuade New Zealand men from talking to health practitioners about prostate cancer. We discourage the description of prostate diagnosis as “unpleasant”. We encourage the use of clear and value-free language.

We think more clarity and openness in talking about prostate cancer would persuade more New Zealand men to have open conversations about prostate cancer with their health professionals. We believe it is important that society becomes more comfortable talking about prostate cancer.

Appendix

Committee procedure

The petition was referred to the Petitions Committee of the 53rd Parliament on 27 July 2023. That committee invited a written submission from the petitioner.

On 6 December 2023, the petition was reinstated with the Petitions Committee of the 54th Parliament. We met between 12 February and 5 December 2024 to consider it. We received written and oral submissions from the petitioner, the Ministry of Health, Health New Zealand | Te Whatu Ora, Te Aho o Te Kahu | the Cancer Control Agency, the Prostate Cancer Foundation of New Zealand, and the Urological Society of Australia and New Zealand.

Committee members

Greg O'Connor (Chairperson)
Carl Bates
Kahurangi Carter (from 6 December 2023 to 8 May 2024)
Greg Fleming
Francisco Hernandez (from 8 May 2024)

Related resources

The documents we received as evidence in relation to this petition are available on the Parliament website.

A recording of our hearing can be on the Parliament website:

- Hearing on the Petition of Kristine Hayward with Kristine Hayward, Prostate Cancer Foundation of New Zealand, Health New Zealand | Te Whatu Ora, and Cancer Control Agency |Te Aho o Te Kahu, Thursday 2 May 2024.
- Hearing on the Petition of Kristine Hayward with the Urological Society of Australia and New Zealand, Thursday 1 August 2024.