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Cancer Services
Population Health
Population Health and Prevention
Ministry of Health
New Zealand

Cancer Society response to the draft cancer action plan for Aotearoa New Zealand

Tena koe

Thank you for the opportunity to feedback on the draft cancer action plan. We believe this is a significant opportunity to provide input into the most comprehensive update of our national cancer strategy since 2003. We wholeheartedly welcome this opportunity and we see an important role for non-government organisations in supporting its delivery and achievements.

The Cancer Society is a non-profit organisation committed to reducing the incidence and impact of cancer in the community. We work across the cancer continuum focusing on prevention, supportive care, provision of information and resources, and the funding of research. The federation consists of a National Office and six Divisions, with 34 offices located around the country. This submission represents the views and input of the whole federation. It includes our submission and a supporting appendix.

Yours Sincerely

Mike Kernaghan

Chief Executive

CANCER SOCIETY RESPONSE TO THE AOTEAROA NEW ZEALAND DRAFT CANCER ACTION PLAN

(11 October 2019)

INTRODUCTION

The Cancer Society is very pleased to see Aotearoa New Zealand's draft Cancer Action Plan. This is a significant opportunity to approach and solve this problem at a national level.

We applaud the government for developing such a comprehensive document that has addressing equity and achieving fewer cancers at its heart. This is the most comprehensive update of our national cancer strategy since 2003. We wholeheartedly welcome the opportunity to work on implementing this plan. We see an important role for non-government organisations in supporting its achievements.

Leadership is a crucial part of addressing the growing gap in cancer outcomes between Aotearoa New Zealand and comparator countries like Australia and the UK. These growing gaps are not reflective of the skill, compassion, and expertise of those working in cancer care, but the diffused responsibility for cancer prevention, early detection, treatment and support in Aotearoa New Zealand. The time has clearly come for strong central leadership, and a nationally joined up approach.

We welcome the new Cancer Control Agency and similar models have worked well abroad. We urge the government to consider defining the authority and functions of an independent agency through an Act of Parliament.

While we have seen many of the existing gaps between Māori and non-Māori close over recent years, the equity gap remains stark. Māori still feel the unfair burden of worse cancer incidence and survival rates in most major cancer types. A key indicator of success for this plan, therefore, is how we address this equity gap for Māori.

SUMMARY POINTS ON THE DRAFT CANCER ACTION PLAN

In general, the plan is a starting point and is much better than what we have now. It identifies key issues that Aotearoa New Zealand faces in cancer control and prevention and has identified high-level aspirational outcomes to address these issues. As an organisation we are very positive about the plan.

However, while we believe the outcomes are good, the actions need to go further to address all the challenges we are facing.

- Leadership is crucial. We embrace the establishment of a National Director of Cancer and see this as critical to achieving the outcomes in the plan. We are unclear however, what the functions, powers, budget, and scope of a permanent National Director will be. We encourage these powers to be broad and funding to be strong.
- We urge the government to consider defining the authority and functions of an independent agency through an Act of Parliament. This independence would ensure that policy and reforms would not be undermined by changes in government and the political cycle.
- We believe more detail is needed and we look forward to feeding back on a detailed implementation plan(s).
- The plan's scope is wide and prioritisation of key activities will be important. At the present time it is unclear which of the plan's actions will occur and at what time. Clear and reportable milestones are needed to measure progress over the plan's duration for achievements in the first two years, five years and 10 years.
- It is not clear how much funding will be allocated to address the goals of the plan. Without the correct funding and resourcing, the plan will not achieve these aspirational high-level outcomes. We request clarity around funding allocations for the projects and goals in the plan
- We want to see people with cancer and their whānau included in this plan, to have their voices heard at all levels, including leadership.
- Achieving equity and improving health outcomes in this plan need to ensure a holistic model of care with people with cancers and their whānau at the centre. Implementation plans need to be developed with equity and Te tiriti o Waitangi considerations at the forefront. The Mātauranga Māori framework should be built into

the co-design, trial and funding of this plan at the outset, and in partnership with Māori.

- It is unclear which actions will be led by DHBs, the Ministry of Health, or the Cancer Control Agency, and which will be developed in conjunction with other groups such as primary health organisations, non-government organisations, or the Health Promotion Agency. Clarity around responsibility for deliverables is critical to achieve the aims of the plan.
- Cancer care and prevention is a collective and collaborative response that includes, primary care and a wealth of non-government and other services providing valuable support outside institutional settings. In many instances, people require considerable and ongoing support post DHB treatment from NGOs such as the Cancer Society. The plan would be greatly enhanced by including the concept of 'inter-sectorial' action for cancer control and prevention.

(1) Leadership and governance

(1.1) The Cancer Society welcome the introduction of the Cancer Control Agency. A system wide view rather than regional responses will deliver better outcomes as we have seen with child cancer in New Zealand. It will also provide an ideal opportunity to develop a holistic model with whanau-centred care and service delivery that best reflects the diversity of our communities within Aotearoa New Zealand.

(1.2) Leadership is dependent on the quality, availability and commitment of the personnel. In this aspect the Cancer Society welcome the appointment of Professor Diana Sarfati into an 'interim' role. However, it is very important that this vital position has the authority and independence to drive the change that is needed. The Cancer Society want to see this position remain viable in the long term, to be funded appropriately and to have a role in monitoring and setting targets for this plan.

(1.3) We recommend that the new Cancer Control Agency Board includes representation by people with cancer and representation from Māori across the country.

(1.4) The leadership structure needs to be independent and have the political distance necessary to achieve the Cancer Action Plan outcomes. We would urge government to consider defining the authority and functions of an independent agency through an Act of

Parliament. This independence would ensure that policy and reforms would not be undermined by changes in government and the political cycle. The Cancer Control Agency must have a transparent budget and responsibilities, and be required to report on demonstrated achievements.

(1.5) The role and function of the new agency is important. Cancer control and prevention arms need to be closely linked. Health promotion activities would sit well in the new agency alongside early detection, supportive care and end-of-life, and treatments.

(1.6) Further information is required on the scope of the Cancer Control Agency and National Cancer Control Network and how they will work together to support the implementation of the national programme and their relationships with District Health Boards, PHARMAC and other stakeholders.

(1.7) International evidence is available that supports a strong, independent cancer agency with national oversight to plan and monitor cancer control efforts:

- No single factor will explain why differences in cancer outcomes persist between high-income countries with universal health coverage. However, the handful of countries that are stand-outs in cancer control share a key characteristic – they all have a strong cancer agency with national oversight to plan and monitor cancer control efforts.
- Modelling indicates that countries with a high performing system of cancer control achieve that by focusing on good governance. Approximately one quarter of differences in cancer survival between OECD countries may be explained by governance arrangements, including the presence of a lead organisation responsible for achieving targets and ensuring co-ordinated services.
- The key features of cancer agencies in countries with the best survival outcomes include:
 - the agency co-ordinates cancer control across the cancer continuum
 - the agency is tasked to oversee a national cancer control plan and is responsible for achieving and monitoring targets and ensuring co-ordinated, consistent services
 - the plan provides the mechanism for the agency to allocate limited resources effectively

- the agency brings together relevant people to co-ordinate an integrated approach
- stable, facilitative leadership and a coherent management strategy
- equity is a key focus
- formalised advisory group structures (comprised of experts and groups most affected by cancer) are in place that support the agency's role and delivery of the plan
- the agency is independent, with public funding and is not undermined by the political cycle.

Please see appendix one – our supporting paper reviewing international examples of effective cancer control agencies.

(2) The funding of the Cancer Action Plan

(2.1) Further information is needed on the funding details associated with the implementation of the proposed Cancer Action Plan and the formation of the Cancer Control Agency.

(2.2) The Minister of Health should ensure that cancer control, from prevention, diagnosis, treatment and post-treatment to palliative care, are adequately funded. Funding for the Cancer Control Agency and its activities should be clear. The Cancer Control Agency should have its own operational and non-operational budget lines. It should be able to outline new investment and the outcomes of this investment, within a clear funding pathway.

(2.3) Both short and long-term outcomes need to be considered when allocating funds. Access to medicines are an important issue along with investing in cancer prevention interventions and other cancer control initiatives to relieve and prevent cancer, now and in the future.

(2.4) To be able to deliver modern cancer care and services we need to equip public hospitals, clinics and treatment centres with more frontline staff, doctors and technicians (radiation, chemotherapy, endoscopies, x-rays and diagnostic medical imaging)) and accompanying machines to help with faster diagnosis, treatment and to alleviate waiting lists. Consideration should be given in the plan towards how the funding of modern cancer care will be included as a priority in guiding new budget allocations in the support of infrastructure development such as the new radiation treatment LINAC machines across the country.

(2.5) The plan does not address how efficiencies could be achieved through government intervention or direction in the investment in resources and systems. Where we have private and public health facilities and services with different subscription levels and capacity utilisation we would like to see government take steps to reduce the distinctions and inequities that this causes. We ask that implementation plans identify ways our country's facilities can be most effectively used to address current demand and shortage.

OUTCOME 1: CONSISTENT & MODERN CANCER CARE

We need to ensure everyone has access to world class cancer care across New Zealand, no matter who they are or where they live.

We believe this will be achieved through strong national leadership, adequate monitoring and a skilled and sustainable workforce with the right information to make the best decisions possible.

(3) Health workforce - A sustainable workforce is required

(3.1) Current capacity of the health workforce is a pressing issue in cancer control and its ability to deal with increased volumes and complexity. We already have a national shortage of radiation therapists and more will be needed to run new LINAC machines.

(3.2) The Health and Disability System Review Report highlighted the importance of population health and prevention. The proposed plan has not mentioned this workforce and this should be included.

(3.3) A culturally competent workforce that reflects our cultural diversity and the inequities experienced by Māori and Pacific peoples is crucial and will need considerable support to achieve.

(3.4) Non-government service providers, including volunteers, have not been mentioned in the plan but are a key component when considering a sustainable workforce.

(3.5) Overcoming the shortage of experienced cancer clinicians and creating a sustainable health workforce is key and the plan should ensure that:

- universities and other education providers are on board and support students to look at cancer care as a specialty

- consistent workforce training and professional development opportunities are provided across the whole sector, including non-governmental organisations, in addition to mainstream health services
- cancer sector jobs are marketed and attractive to Māori and Pacific peoples in particular, and should expand the scope of roles available.

(4) Data and information

(4.1) The Cancer Society continues to advocate for a better health intelligence function that uses up-to-date information to drive cancer planning, monitoring and reporting.

(4.2) There is, and there will always be, a need for a strong voice and mechanism to identify and understand the needs of people with cancer and their whānau, and to use this information to develop and guide service delivery and monitoring.

(4.3) People with cancer and their whānau need to be empowered with comprehensive, accessible and accurate information so they can make the right decisions regarding their health. The plan should strongly ensure collaboration with non-government organisations, including the Cancer Society, that allocate considerable resources to boost health literacy.

(5) Research and innovation

(5.1) The Cancer Society is very supportive of the plan's intention to drive high-quality cancer research and innovative practice through evidence-based improvements across the cancer continuum and the wider health system. The Cancer Society has spent more than \$62 million over the last 10 years on research and we look forward to working closely with the new Cancer Control Agency in this area.

(6) OUTCOME 2: EQUITABLE CANCER OUTCOMES

This section articulates some priority actions to achieve more equitable cancer outcomes and the Cancer Society is whole heartedly in support of this outcome, it aligns with our own priorities as an organisation.

Removing inequities in cancer outcomes by 2030 is an ambitious outcome and we applaud government for prioritising it. We note these actions lack detail and require funding and long-term government commitment to achieve.

- (6.1) We would like to see widespread access to developing and sustaining culturally competent staff across the whole sector, government and non-government. Addressing institutional racism in the sector is of paramount importance.
- (6.2) The attraction of Māori and Pacific people into the health workforce will need innovative and far-reaching measures to achieve. This will include addressing engagement, access and retention issues alongside addressing institutional racism.
- (6.3) We want this plan to be more ambitious for Māori workforce development and include all roles in the sector including policy, data, monitoring, and leadership.
- (6.4) What is not addressed in the plan are some of the other determinants of health such as financial barriers to people accessing health care during the early stages when costs to visit a GP might be a barrier. Earlier access for Māori and Pacific people to diagnosis and treatment needs to be considered carefully. Costs of getting to the GP post treatment can also be a barrier for people with limited income, and so will affect cancer outcomes.
- (6.5) Equitable outcomes need to consider all inequities, including geographic (remote and rural communities) and socioeconomic inequalities which cause big challenges in terms of cancer diagnosis and treatment. Aotearoa New Zealand has an increasing number of refugees and we need to ensure that they will not be disadvantaged or left behind.
- (6.6) The plan should focus on building partnerships with key Māori and community influencers who can make a difference (e.g. Whānau Ora Navigators). Whānau know what many of their solutions are already. There are models available (such as Te Whare Tapu Wha) that can be co-designed, funded and trialled in partnership with Māori to aid in setting up mātauranga Māori pathways.
- (6.7) Cultural safety training should be an ongoing requirement in professional development throughout the sector and we believe that medical specialists must take part in these.
- (6.8) All health professionals should be able to understand and provide a non-judgemental, culturally safe environment where kaupapa Māori practice such as use of karakia, whānau involvement, and use of rongoa etc, are normalised.
- (6.9) We need to do more than we ever have to achieve equitable outcomes in cancer control and prevention. We need to extend our reach, develop strong national and community links, and culturally appropriate standards of care and monitoring

mechanisms to ensure we achieve equitable outcomes by 2030. Targets need to be set and monitored to ensure this is achieved.

(7) OUTCOME 3: FEWER CANCERS

(7.1) Overall, we believe this outcome is very positive but again we would like to see an implementation plan to understand the detail. This section covers the leading risk factors for cancer and could be the biggest contributor to improving overall cancer outcomes and support equity objectives.

(7.2) However, the need for inter-sectoral action is only implied in the plan and the plan would be strengthened if this was clearly identified as underpinning this aspect of the work. Preventing cancer is a challenge of all sectors of society. Government has a key role to provide the leadership in this arena. Action is needed through workplace legislation (exposure to carcinogens), climate change action (prevent increases in skin cancer) and in creating supportive environments in schools for healthy nutrition, physical activity and skin cancer prevention, to name just a few.

(7.2) The Cancer Society note that the focus of this section is on service delivery rather than changing environmental factors to create healthier communities. We believe it would be more helpful to reframe the actions in this section to focus on healthy communities and the policies and environments necessary for that rather than targeting individuals. For example, increasing access to healthy food and reducing access to sugar-sweetened drinks to aid healthy weight achievement.

(7.3) Māori want to see healthy lifestyles in their communities for their mokopuna and tamariki and their engagement in the delivery of health promotion programmes is key.

Many Māori and Hau ora services provided successful health promotion community programmes until funding was withdrawn over 10 years ago. A long-term commitment must be made to see this outcome achieved.

(7.4) The non-government sector already play a significant role in this area of work. There is an opportunity for government to make use of the skills and leadership organisations like the Cancer Society provide through health promotion activities.

(8) Smokefree by 2025

Without seeing the Smokefree action plan it is not easy to comment. However, we are very supportive of the commitment to developing a plan to achieve Smokefree 2025 and we would want to see the following points in the plan.

- Continue to reduce the affordability of tobacco products and prevent industry minimising the impact of measures through increases in tobacco excise, consideration of a minimum price and dedication of additional revenue to support smokers to quit.
- Implement measures to substantially reduce supply by reducing the number of retail outlets that can sell tobacco products.
- Implement measures to reduce the appeal and addictiveness of smoked tobacco products through removal of additives and mandated reduced nicotine content.
- Introduce proportionate regulation and policies for electronic nicotine delivery systems that maximise the degree to which they support smokers to quit or switch whilst minimising any unintended adverse impacts.
- Greatly increase the use of social marketing campaigns to promote reductions in smoking and exposure to second-hand smoke (SHS).
- Expansion of Smokefree settings.
- Support for Smokefree settings to be vape free as well.
- Continue to provide comprehensive cessation services tailored to community needs.
- The issue of smoked cannabis needs exploration, particularly in light of the 2020 referendum.

9) Encourage and support healthy living

(9.1) Supportive food environments

Aotearoa New Zealand's food environment is largely unhealthy and there are inequities in access to healthy food environments. To impact people's food choices and cancer risk we would like to see evidenced-based population-level interventions used to improve availability and access to healthy food based on established models.

- We want to see stronger healthy food (and water) policies in schools, and to see this extended to other environments such as education, sport and recreation, and workplaces.
- A more comprehensive population-based approach is needed to address the rising obesity and cancer burden. Interventions should be based on international best

practice and effective approaches to behaviour change, such as those identified by Gerritsen (cited in National Science Challenges 2019:5). We would like to see:

- The strengthening of the 'Health Star Rating' (HSR) labelling system to help customers identify healthier options. If industry uptake remains poor, the HSR should be made mandatory.
- Setting targets for the voluntary reformulation of foods high in salt, sugar and saturated fats for key food groups to improve their healthiness
- Exploring an excise tax on pre-packaged foods and beverages consistent with WHO guidelines.
- Strategies to address the high density of fast food outlets and improve access to healthy affordable food in lower socioeconomic areas such as establishing fruit and vegetable markets and cooperatives, or food subsidies for healthy food.
- Marketing regulations on unhealthy snacks and sugary drinks to children with independent monitoring and evaluation, especially at times and places frequented by children such as children's sports and events.

(9.2) Physical activity: We agree with the aim to take a coordinated inter-sectoral approach to increase New Zealander's level of physical activity. A partnership with Sport NZ and the Ministry of Education to make school environments active is positive.

- However, to increase population levels of physical activity research shows that multiple intervention strategies are needed. The World Health Organisation provide good advice on strategies to increase population activity levels and these should be considered as part of the plan.
- We suggest that the Cancer Plan acknowledge the work of other Aotearoa New Zealand organisations to progress population physical activity levels. Not everyone participates in 'sport' and we would like to see the plan address the activity needs of harder to reach groups through opportunities to support activity in every-day life.

(9.3) Population approaches for weight: the current Ministry of Health clinical guidelines for weight management are useful for clinicians working with individuals but there have been few resources to support their implementation since they were introduced. These guidelines require people to engage with the health system. People are required to make substantial

changes to achieve them and they are unlikely to have much impact on population obesity rates. Preventative population approaches are needed to make any real impact on obesity and cancer rates as outlined above.

(9.4) Alcohol: the Cancer Society notes that alcohol is a carcinogen and therefore we are very supportive of restrictions on alcohol being included in the plan. We support the proposed actions to reduce accessibility and limit advertising. More specific actions should be included about how this will be achieved that are not solely focused on campaign actions:

- Follow up on the recommendations contained in the Law Commission report *'Alcohol in our Lives- Curbing the Harm'* 2010 e.g. sporting sponsorship bans.
- Raise awareness of alcohols link with cancer e.g. risk labels on products
- Increase excise tax on alcohol.

(10) Prevent cancer related to infection

This is a positive addition to the plan and we strongly support further work on HPV vaccination and a strategy to address H.Pylori infection.

- Consideration needs to be given to H.Pylori as a socio-economic burden impacting on those communities whose living conditions can contribute to increased cancer risk. It can't be isolated from government work on healthy homes and increasing the supply of adequate, affordable housing.
- We look forward to commenting on implementation plans for these areas.

(11) Reduce avoidable skin cancers

(11.1) This action is overly campaign focused and doesn't give the detail we would want to comment on.

- Consideration should be given to environmental changes that can be made such as shade as a priority under this section. This could include requiring shade as a part of new school and public area builds as part of Ministry of Education and Local Government regulation.
- Sun safety needs to have greater detail and emphasis in this plan and government leadership in this area is important.

- Inter-sectoral action is needed in this area e.g. sun safe clothing at school and workplaces.
- Significant impact could be made by government, communities and NGOs working alongside each other to address avoidable skin cancer, as the Cancer Society has already initiated.
- Improving shade in educational settings should feature and we recommend investigating if the Ministry of Education can provide targeted funding for shade as a safety mechanism in schools, as well as a requirement for all new builds.
- We would like to see an action on sunbeds and recommend banning them completely as Australia has.
- We recommend that sunscreen is explicitly regarded as personal protective equipment for outdoor workers, and that sunburn is regarded as an adverse occupational health and safety event.

(11.2) Sunscreen as a therapeutic product is something the Cancer Society has long been seeking to ensure confidence that these products do as they are intended.

(12) Work-related cancers

This is an important area of work and we are pleased to see that Worksafe will be leading it.

- We see an opportunity for the Cancer Society to assist in developing the implementation plan for work-related cancers.
- We would assume that work-related cancer implementation plan would include protection from ultra violet radiation damage.

(13) The inclusion of breastfeeding education in the plan

One of the World Cancer Research Fund's recommendations is for mothers to breastfeed their babies where possible. Lactation protects the mother against breast cancer and having been breastfed, protects children against becoming overweight and obesity. There are lots of initiatives happening for this area of cancer prevention and it could be explored within the plan to reduce cancers.

OUTCOME 4: BETTER CANCER SURVIVAL

This section summarises most of the important activities for improving cancer survival that the Cancer Society are aware of. However, we want to point out the following:

- Outcome 3's focus on prevention policy and environmental actions will have a significant impact on creating better cancer survival.
- This section, and the plan, need to place greater emphasis on the value and place of supportive care and the support required for people living with cancer, or post treatment side effects in the community. This is more than palliative care, and needs to acknowledge the valuable role of non-government service providers, allied health professionals and community health services.

(14) Early detection and population screening

(14.1) Early detection and screening programmes are key to better cancer survival.

- improvements could be made by better access to screening in rural areas
- the roll out of the bowel cancer screening programme needs to be prioritised with a plan to extend the age to 50 year olds included.
- there is strong support for lowering the screening age for bowel cancer to 50, particularly for Māori as a priority.
- The plan needs to factor in the additional resources needed in responding to the demand created by screening and be explicit about funding pathways for this.

(14.2) We would like to see diagnostic and screening services given priority attention to reach comparable international standards diagnostic and to address the huge wait time people with cancer and their whānau are experiencing.

(14.3) We have a poorer one year survival than bench mark countries indicating that early detection remains inadequate, and a priority area for investment. We also know that for most cancers, Māori have later stage at diagnosis than non-Māori. This highlights that access to early diagnosis is an equity issue.

(14.4) For many Māori, detection is coming too late and primary health care has an important role to play in changing this. A clear funded strategy to address this is required.

This needs to include areas such as:

- cultural competency training for health professionals
- funded training for GPs to better understand signs and symptoms of cancer
- improved access to primary care
- rapid access to diagnostics for primary health care providers
- streamlined symptom clinics and health pathways in secondary care
- benchmarking access to critical diagnostics, such as colonoscopy, cystoscopy, and first specialist assessments

(14.5) Primary health care is an important part of the picture. The plan should include all cancer support and prevention with the consumer and their whānau at the centre and not take a secondary and tertiary level system view. GPs are a key support people post-treatment therefore education and standards across primary health care needs to be funded. It also needs to be recognised that NGO's provide psychosocial services post treatment as well.

(15) Better health literacy and awareness promotion in populations help people make decisions about screening, treatment, and advanced care but it is unclear in this plan what this should look like and who should provide it. We would like to see more detail about what campaigns and education programmes are to be implemented. We see non-government organisations having a role to play in this

Cancer care and treatment

(16) Access to medications is low in Aotearoa New Zealand compared with all other OECD countries. This has a profound effect on survivorship and quality of life after a cancer diagnosis.

- We welcome the inclusion of an early access scheme and earlier assessment of medicines from PHARMAC.
- We want to see PHARMAC become more responsive and transparent in their decision-making to understand why they make the decisions they do.
- There should be a clear monitoring mechanism through the new cancer agency.

- We note that PHARMAC have always been able to review medicines without prior MEDSAFE review. Therefore, we do not see this change as substantive. We recommend that PHARMAC are required to have a set time frame for decisions, as is the case with ethics committees, councils, and many other agencies.
- We recommend the benchmarking of access to medicines in Aotearoa New Zealand compared to other comparable countries. This would enable regular and transparent access to medical treatments and would be an indicator of Aotearoa New Zealand's access to medicines against other countries.

(17) Workforce technology and treatment capacity is identified as an action for radiation oncology but providing surgery and diagnostic testing, colonoscopy, dental services, lymphoedema support, skin checks, and psychological counselling are not stated, yet are areas of concern. We would like to see these areas identified and included in the implementation plan.

- Fewer cancers and better cancer survival implies faster cancer treatment timeframes, and we want to see these as targets in the implementation plan.

(18) Living well after treatment

- While this outcome focuses on cancer survival there is little mention of the support many people with cancer and their whānau require after treatment while they are living with a chronic condition. A short mention of palliative care is included which is a separate issue.
- Supporting cancer survivors needs to be given more emphasis in the plan, especially given the increasing number of people who will receive a cancer diagnosis in the future and developments in treatment provision. An additional outcome could be added.
- The Cancer Society provide psychosocial support at all stages of a person's experience and it would be a mistake to assume that supportive care is provided within clinical settings where the focus is firmly on treatment with little capacity for addressing the broader issues impacting patient's lives.
- The cancer plan needs to acknowledge the value added to the sector by nurses, social workers and allied health, particularly within supportive care in the community.

- Cancer has a significant impact on people with cancer and their whānau. Acknowledging the financial cost and the emotional burden cancer places on them needs to be part of this plan. The financial cost includes the costs of GP visits for people living with cancer. We want to see the significant mental health impact acknowledged in the additional support that is needed to address this area.

(19) The National Travel Assistance Review must be given a higher priority to support improved access pathways for people with cancer. This is particularly pertinent as the plan references centralisation of services and this will increase the travel burden for some people. Travel can be a barrier to accessing care and creates inequities.

- Transport is an issue for many people with cancer, in both urban and rural areas. Often there are services in urban areas which are not available in rural areas. The time being taken to improve the national travel assistance scheme is not acceptable and disadvantages many of the people we support. We have examples of whānau having to choose feeding their children over attending chemotherapy treatment.

(20) Access to palliative and end-of-life care is becoming more and more problematic. The Cancer Society supportive care teams report having to provide care for extended periods as palliative care services become further stretched to manage increased demand. We look forward to providing input into any implementation plans on palliative care.

(21) We cautiously welcome care planning for people with cancer as long as the plan belongs to them, can be readily shared and updated amongst all health providers, and be patient driven. We would suggest a trial project and we are keen to participate.

(22) We want to see modern cancer care that:

- Reflects a more holistic approach enabling people with cancer and their whānau to be empowered to make informed decisions, by having access to information at multiple points along the pathway.
- Includes the assistance people require to live well during and beyond cancer treatment with the tools available to make choices about what assistance they need and want. People don't know what they don't know – this has to change.

- Every individual (with their whānau) should have a cancer care plan that they have helped to create, that takes into account not only their physical health, but their mental, spiritual, social / whānau health. Taking Mason Durie's Te Whare Tapa Wha as an example, the approach needs to be inclusive of the whole individual in order to reduce the impact of cancer and to improve long term outcomes.

(23) Separate out traditional Māori medicine from complementary treatments in the plan on p.59. There is a Treaty consideration for the inclusion of Rongoā Māori, traditional Māori medicine should have its own area and focus.

SOME FINAL COMMENTS

This is a positive and ambitious plan providing an opportunity for a comprehensive model of cancer care and prevention to address past system shortfalls.

The Cancer Society looks forward to working with government and other stakeholders to activate this plan as we believe it can only be done with the involvement of the whole sector, including people with cancer and their whānau.

We have received clear feedback though-out the Cancer Society that this plan needs more detail and to sit alongside a clear implementation plan(s) with realistic targets.

The plan needs significant resourcing to be achievable and we would expect this to be beyond current budget commitments.

In order to influence change for future generations we need a plan that will motivate behaviour changes, an approach that recognises that outcomes are not just influenced by clinical treatment but by an inclusive, equitable and holistic health care system where the patient and their whānau can navigate a pathway that works for them.

We are concerned that the plan is heavily focused on the clinical delivery of cancer care forgetting that a significant proportion of cancer care and prevention happens outside of treatment facilities within the community. To achieve these aspirational cancer control goals a collective and collaborative response acknowledging all stakeholders, non-government organisations included, will be necessary.



Thank you for the opportunity to provide feedback on the plan.

Appendix One: Cancer control governance in high performing countries

Cancer incidence is growing rapidly due to population growth, ageing populations and modifiable behaviour risks. Without good control, cancer is expected to be the “leading cause of death and the single most important barrier to increasing life expectancy in every country of the world in the 21st century” [1].

No single factor will explain why differences in cancer outcomes persist between high-income countries with universal health coverage [2]. However, the handful of countries that are stand-outs in cancer control share a key characteristic - they all have a strong **centrally-led, independent cancer agency** that prioritises, plans and monitors national cancer control efforts. Modelling indicates that countries with a high performing system of cancer control achieve that by focusing on good governance. Approximately one quarter of differences in cancer survival between OECD countries may be explained by governance arrangements, including the presence of an independent lead organisation responsible for achieving targets and ensuring co-ordinated services [3]

The Cancer Society supports the governance arrangements outlined by the interim National Director of Cancer Control. However, we also urge a consideration of the establishment of an independent agency with defined authority and functions that are defined by an Act of Parliament. This independence ensures policy and reforms will not be undermined by changes in government and the political cycle.

The following summary outlines the features of the national cancer agencies in Australia, Canada and Norway, the best performing countries in the world in cancer control. We reinforce the importance of building a NZ cancer agency that possesses these features.

These countries all have a national cancer control agency that co-ordinates cancer control along the cancer continuum. It is well documented that countries with strong central planning and co-ordination have yielded better cancer outcomes compared with those who don't [3, 4]. The scope of the Canadian, European and Australian cancer agencies is to govern, facilitate, co-ordinate and fund these essential elements of cancer control:

- (a) Cancer data and information
- (b) Cancer research
- (c) Cancer resources
- (d) Primary prevention and health promotion
- (e) Cancer screening and early detection

- (f) Diagnosis and treatment
- (g) Psychosocial oncology care
- (h) Survivorship and rehabilitation, and
- (i) Palliative and end of life care (only a few govern this area)

These elements are integrated, mutually re-enforcing capabilities that make little sense on their own.

1. **Independence:** the agencies in the best performing countries are independent government agencies with defined authority and functions defined by Acts of Parliament. This independence ensures policy and reforms are not undermined by changes in government, the political cycle and cost shifting. The Agencies role is to **advise the Minister**, make **recommendations** to the government about cancer **policy and priorities** and assist with the implementation of Government policies and programs in cancer control. Policy choices can lead to improved survival rates but careful identification by expert agencies about which policies matter is necessary[3]. In the UK, a country with poorer cancer survival rates, Cancer Research UK is only able to campaign to **influence** the government.
2. Countries with a high performing system of cancer care achieve that by focusing on **good governance**. The following characteristics are most commonly associated with an effective cancer care system and good survival outcome: setting up **cancer-specific targets and timeframes**, **monitoring progress and ensuring that guidelines and quality control are in place**. A **fully implemented national cancer control plan, with an assigned leader and organisation is essential**. In addition, this organisation should be responsible for achieving targets and ensuring coordinated care delivery [3]
3. **A cancer control plan:** countries with very good cancer control have implemented a national plan that the **cancer agency is tasked to oversee, implement and monitor**. The agencies are the stewards of the cancer plan. These plans have three necessary elements that universally contribute to success: (1) the plan focuses on interventions that address the **specific needs** of the population; (2) they provide the necessary **resources** (e.g. infrastructure, tools, personnel), and (3) they are the **collective efforts** of all relevant stakeholders [5]
4. **The cancer control plan** is used as a **planning vehicle** by the cancer agency to allocate limited **resources** most effectively against the specific cancer burden the country faces [5]. The agency strategically considers, integrates and

oversees interventions to best minimise the overall cancer burden and maximise value for money. This expert oversight can limit skewed budget choices free from political influence and reduce costs (i.e. through best practice strategies to prevent cancer, reduce unnecessary use, research to prioritise groups etc).

5. **The cancer control agency brings together relevant stakeholders to co-ordinate an integrated, standardised approach.** Cancer is a complex family of diseases with a wide variety of causes that requires a comprehensive, multi-pronged response from a broad array of health disciplines, sectors, government departments etc. To enhance **integrated, nationally consistent services**, it is well recognised that **national oversight** is required. However, integration between relevant actors is generally somewhat limited and not standardised, with some exceptions. The Australian and Canadian cancer agencies are responsible for drawing stakeholders together to develop best-practice standards, clinical practice guidelines and tools, in addition to performance indicators. Examples include *The NSW Patient Safety and Clinical Quality Program*, *the Canadian Supportive and Palliative Care Best-practice Standards* and the *National Standardised Care Pathway*. The agency has a clear role in leading the development and assessment of standards to avoid a fragmented approach. Collaboration to enhance and facilitate optimal cancer system performance is enabled through the central cancer agency [6]

6. High performing cancer agencies have **formalised advisory group structures** in place to support the Agency's role in national cancer control and delivery of the goals in the national cancer plan. These advisory groups are co-ordinated through the Agency so that relevant experts and those most affected by cancer, including Indigenous peoples, can help to shape cancer control. Cancer Australia's Leadership Group on Aboriginal Cancer Control is a good example of the vital role these groups can play once they are given an opportunity to do so. This Indigenous expert group provides "**strategic advice and guidance** to assist Cancer Australia in Indigenous cancer control; champions **cross-sector collaboration in monitoring the progress of priorities** in the National Aboriginal Cancer Framework; identifies and leverages opportunities to **improve cancer outcomes** at system, service and community levels; identifies **emerging issues** of national importance; and provides input and advice in areas of specialised expertise" <https://canceraustralia.gov.au/about-us/who-we-work/advisory-groups>. Other key advisory groups include tumour-specific expert groups, patient panels, consumer groups and health agency groups.

7. **Governance.** These independent agencies are all controlled by a Board and have appointed CEOs and an executive team. The CEO reports to the Minister for Health. Strategic advisory boards and Scientific Leaders provide relevant advice (e.g. the Cancer Advisory Council, Scientific Advisory Board). In turn, the expert advisory groups (point 6) work with the strategic boards. The Canadian system of governance has a key point of difference - the agency is led by the Cancer Control Council which is composed of leading Cancer Control organisations (including The Cancer Society and National Cancer Institute, provincial Cancer Agency leaders, academics etc). The Board and executives support the Council. As WHO points out, proficient management is needed to integrate these activities into a coherent programme (WHO 2002).
8. **The WHO also notes that** “Key to competent management is the leadership of the programme, who should be facilitative, participatory and empowering in how vision and goals are established and carried out” (WHO 2002).
9. **Equity** is a focus of all high performing agencies. The agency has formalised pathways to engage high priority groups so that they can inform national policy (see point 6). Moreover, the agencies national role enables it to work with stakeholders to address co-ordinated system-level change - essential if real gains are to be made.
10. **Cancer surveillance** is a core component of cancer control. It is fundamental to basic research, intervention, evaluation, awareness raising, planning, monitoring and future planning. It is recognised this data should work in co-ordination and in some countries the cancer agency is responsible for managing cancer registries and databases. However, even in high performing countries co-ordination is difficult. In Australia, for example, lack of integration between state-level registries means, according to Prof Sanchia Aranda, that “We have little capacity to look at how well we are doing,” at a national level in areas such as unwarranted variation in treatment. There is an identified opportunity for the NZ Cancer agency to be stewards of co-ordinated cancer data.

Table 2: Features of cancer agencies in Canada, Australia (Government funded and mandated) and UK (Non-for profit organisation)

		The Canadian Partnership on Cancer	Cancer Australia	Cancer Institute NSW	Cancer Research UK
Scope		National scope to coordinate cancer control	National scope to coordinate cancer control	<ul style="list-style-type: none"> State - provides a strategic direction for cancer control in NSW works within the health system and focuses on health system improvements 	National Research focus
Goals		<ul style="list-style-type: none"> to reduce the number of Canadians diagnosed with cancer to enhance the QOL life of those living with cancer to lessen the likelihood of dying from cancer. 	<ul style="list-style-type: none"> shape national cancer control in Australia improve cancer outcomes inform effective and sustainable cancer care strengthen capability for national cancer control 	<ul style="list-style-type: none"> to lessen the impact of cancer across the State reduce incidence increase the survival rate improve QOL for people with cancer and their carers 	Prevent, diagnose, treat, optimise
Governance/ structure		<ul style="list-style-type: none"> independent, NFP 'The Cancer Control Council' - made up of leading Cancer Control organisations (including The Cancer Society & National Cancer Institute, provincial Cancer Agency leaders, academics etc) executives (CEO, VPs) Board of Directors emphasis on partnering w cancer control sector 	<ul style="list-style-type: none"> government agency the CA Advisory Council & strategic advisory groups provide advice CEO & exec team Co-ordinate/liaise with groups and health care providers with interest in cancer (including Dept of Health, those affected by cancer, experts, health agencies and state governments) 	<ul style="list-style-type: none"> a 'pillar' organisation of NSW Health provides services for the MOH CCO, CEO, COO, board, screening & prevention, Research investment, services & information sets up expert cancer groups, consumer groups, Aboriginal & community panels to work with them facilitates collaboration and co-operation between bodies involved in 	<ul style="list-style-type: none"> charity trustees set strategic direction CEO & Executive Board, CFO, EDs x6, CIOs, Chief clinician, Chief Scientist 100 members (like shareholders) form Council Committees scientific executive Board UK wide research network interest/patient panels cancer ambassadors

				cancer (health orgs, consumers health profs, govt agencies, & others)	
funding		Federal govt Initial funding (2007) \$250 million	Federal govt Funding in (2019-20) \$31.113 million	NSW state govt	<ul style="list-style-type: none"> charity- no govt funding total income 2018/19 £672 million (source: donations; trading; and income from charitable activities) commercial partners
Established		2007	2006	2003	2002
Functions:	Overall function	<ul style="list-style-type: none"> co-ordinates national cancer control (prevention, early detection, tx, care) the steward of <i>the Canadian Strategy for Cancer Control</i> 	<ul style="list-style-type: none"> provide national leadership in cancer control (prevention, early detection, tx, care) assists & co-ordinates the implementation of national government cancer control policies & programs partners across the national health system 	<ul style="list-style-type: none"> fosters and supports best practice in, and an evidence-based approach to, cancer control develops a state cancer plan 	<ul style="list-style-type: none"> research focus (across cancer continuum) supports NHS smoking c programs influence NHS strategies build an international alliance develops new treatments optimises existing treatments
	Advise govt & policy development	Advises Minister	<ul style="list-style-type: none"> advises Minister (and carries out any functions that the Minister directs them to perform) make recommendations to federal govt about cancer policy & priorities works closely with Health Dept assist decisionmakers at all levels 	<ul style="list-style-type: none"> advises/reports to state Minister provides cancer data to the Ministry 	<ul style="list-style-type: none"> advocates & campaigns to influence NHS/govt develop evidence-based policy to inform govt

	Prevention/ health promotion	Monitors and oversees the implementation of primary & secondary prevention practices across Canada	Provides health promotion & communication services	<ul style="list-style-type: none"> develops social marketing/mass media programs manages BreastScreen NSW & NSW Bowel Screening Program 	Focus on prevention research & public prevention communication/social marketing
	Equity	Expressed focus on addressing disparities	Expressed focus on addressing disparities indigenous & CALD, older Australians, rural & remote	'Focus communities' - indigenous & CALD	Yes, especially economic inequities
	Public awareness raising	consumer programs - prevention & support info	consumer programs - prevention & support info	Yes - big focus on developing social marketing campaigns and info e.g. tobacco ads seen on NZ tv	Offer tools and information to the public & media campaigns
	Supportive care	Supportive and palliative care network & resource centre of best-practice standards and performance indicators	Develop clinical practice guidelines, tools, information	Patient reported measures Patient care guidelines	Consumer information Staff tools/guidelines Established patient network/panels to shape their work
	Health workforce	<ul style="list-style-type: none"> provide tools and info resource planning tools address retention health sector studies clinical practice guidelines develops and co-ordinates common cancer care standards performance indicators 	<ul style="list-style-type: none"> service development & clinical practice (CANnet, health prof education, guidance material, models of care clinical practice guidelines to develop a national framework which defines best practice and sustainable models of care across the cancer care continuum. identify areas to optimise safe and effective care, 	<ul style="list-style-type: none"> provides the NSW Patient Safety and Clinical Quality Program disseminates cancer control advice & information 	Works with Health Education England to make sure its workforce plan is fully implemented, and meets the NHS's long-term diagnostic needs (analysis of future needs)

			including through new models of care		
	Research	yes	<ul style="list-style-type: none"> oversees dedicated research budget funding research (priority group focus) clinical trials support partner with orgs/uni's to fund priority research provides financial assistance, out of money appropriated by the Parliament, for research International collaboration on priority cancer research 	<ul style="list-style-type: none"> undertakes, commissions, sponsors cancer-related research and development focus on the translation of research findings into clinical practice runs the NSW Pop & health services ethics committee 	Spent £442m 2018/19 on research Research strategy: https://www.cancerresearchuk.org/sites/default/files/cruk_research_strategy.pdf Collaborates with research sites
	Targets	cancer control targets & analysis	Targets assessed: https://canceraustralia.gov.au/sites/default/files/publications/annual-report-2017-18/pdf/annual-report_2017-18.pdf -	?	Accelerate progress and see $\frac{3}{4}$ of people surviving the disease within the next 20 years Research targets
	Surveillance/monitoring	<ul style="list-style-type: none"> a standardised national cancer surveillance program monitors impacts of cancer control initiatives 	<ul style="list-style-type: none"> national data analyses monitors & reports trends in national cancer control reports on cancer stage and treatments for selected cancers etc leads shared agenda cancer outcomes form the Aboriginal/TI Cancer Framework 	<ul style="list-style-type: none"> progress of the NSW Cancer Plan implementation monitored and evaluated thru 'The Performance Index' manages a number of cancer data registries and data collections NSW obtains and analyses cancer control data 	Monitors cancer plans, NHS reforms, waiting times, care measures, clinical research monitoring

			<ul style="list-style-type: none"> provide national data analyses & evidence review 	<ul style="list-style-type: none"> reviews, monitors, evaluates and recommends improvements to cancer-related programs and proposed initiatives in the public health system in relation to cancer control, facilitates improvements in the effectiveness of cancer control and to develop or endorse strategies to achieve improvements 	
		https://www.partnershipagainstcancer.ca/wp-content/uploads/2017/09/canadian-strategy-for-cancer-control-a-cancer-plan-for-canada.pdf			https://www.cancerresearchuk.org/sites/default/files/ec1060588_cr_uk_ar_2019_interactive.pdf

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Table 1 Characteristics of effective national cancer plans

Gold standard features of national cancer plans	NZ's cancer plan
A defined focus based on NZ needs	✓
Inclusion of stakeholders in plan development	✓
Implementation framework	X
Monitoring and evaluation of plan implementation	X
Setting of realistic priorities	✓
Focus on cancer equity	✓
Evidence based	✓
Specification of programmes for cancer management	
Allocation of appropriate, realistic budgets	X
Details on plan costed and budgeted	X
Promotion of research	X
Strengthening of information systems	X
Leadership	✓
Promotes a multi-pronged approach to cancer control	
Comprehensiveness - Cancer continuum	✓
Focus on health policy	✓
Focus on health systems change	
A clearly accountable body identified	
Coherent management strategy	
Outline to achieve synergies between existing & planned cancer services	

Adapted from Romero, Trapani [5] and Albrecht, Martin-Moreno [4]