Breast Cancer Aotearoa Coalition and Breast Cancer Cure

Joint submission on the Cancer Action Plan 2019-2029

October 2019

Do you agree with the four outcomes proposed in the Plan? (pages 10-11)

Yes or No✓

If not explain why?

Outcome 1. We agree with the concept of future-proofed health and care systems. This needs to include the elements listed: strong governance, accountability and stewardship, strong national leadership, a skilled and sustainable workforce and the right information. However, a key element missing here is access to effective modern, best practice: risk assessment and detection technologies, diagnostics and prognostics, treatments including medicines, radiation and surveillance. Another key element of a successful plan is the inclusion of **empowered and engaged consumers** throughout all processes, including design, implementation and monitoring. This is not achieved through the Ministry-appointed Cancer Consumer NZ group. Strong national leadership should incorporate an ability to respond to issues or inadequacies independent of political influence. We cannot see how this is possible for an Agency housed within the Ministry of Health.

Outcome 2. We agree there needs to be more Māori and Pacific people in the workforce. We also believe the involvement of the Māori consumer voice is essential in system design, implementation and monitoring to ensure delivery of equitable access and outcomes and to meet Treaty of Waitangi obligations.

We also wish to make additional comments relating to equity:

- On page 6 of the plan it is clear from Figure 2 that breast cancer registration is higher for both Māori and non-Māori than any other cancer in New Zealand. In our view breast cancer should be included in the priority group. We are uncertain of the origin of the mortality figures in Figure 3. However, we know that approximately 3,300 are diagnosed annually, 56 people a month die with breast cancer and approximately 1750 live with advanced disease.[1]
- On page 7 we are told “New Zealand does not have statistics indicating poorer outcomes for rural populations although international data suggests this will be the case.” There is data of

this nature for breast cancer. Lawrenson et al, 2016[2] found rural Māori women had inferior breast cancer-specific survival and all-cause survival at 10 years at 72.1% and 55.8% compared to 77.9% and 64.9% for urban Māori. The study shows that rather than being concerned that more needs to be done for rural women in general it is rural Māori women where we need to make extra efforts to ensure early stage at diagnosis and optimum treatment.

- On pages 8 and 9. We agree with the commitment to the Treaty of Waitangi and for Māori rights to be recognised. We also want to see Māori and Pacific people flourish. We are also however concerned about the percentage of Europeans living in deprived conditions as detailed in the Health & Disability System Review Interim report p18. Fig 2.4 9 who endure deprivation. An equity approach needs to consider socio-economic discrepancies, which are often but not always linked to ethnicity.

Outcome 3. We agree with the concept of healthy choices. The concept of impact on risk is broader than lifestyle choices as many cancers will continue to occur despite healthy choices. People need to be made aware that risks are broader than just healthy choices. On page 3 the plan embraces "a commitment and reinvigoration of our approach to preventing and managing the disease."

By way of example, we want to bring the Cancer Control Agency's attention to the updated version of BODICEA (2019)[3] which is relevant to Breast and Ovarian cancer. It is an objective comprehensive risk assessment tool which now recognises a broader range of breast cancer risk factors to identify differing levels of risk in order to influence prevention. Such tools should be adopted across all cancers for which they are available. Factors included within BODICEA, as an example of a state-of-the-art risk tool, are:

- The effects of truncating variants in *BRCA1*, and *BRCA2 (high penetrance variants) and PALB2*, *CHEK2*, and *ATM (rare, intermediate risk variants)*;

- *A Polygenic Risk Score based on 313 single-nucleotide polymorphisms (SNPs) explaining 20% of BC polygenic variance* (conferring lower risks but with substantial levels of stratification in the population)*;* Breast cancer risks associated with SNPs can be conveniently represented as a polygenic risk score (PRS). However, the **known genetic factors explain only about 45%** of the **observed familial aggregation.**

- Known lifestyle/hormonal/reproductive RFs (e.g. age at menarche, age at menopause, parity, and age at first live birth), exogenous hormonal factors (e.g., use of oral contraceptive [OC] and use of postmenopausal hormone replacement therapy [HRT]), anthropometric factors (e.g., height and body mass index [BMI]), and lifestyle factors (e.g., alcohol intake) (collectively referred to as risk factors [RFs] excluding mammographic density are questionnaire-based risk factors [QRFs]. Each of these **RFs** has only a modest effect on cancer risk, but **in combination and with family history and known genetic factors**, they can **improve risk stratification.** Moreover, **as some of these factors can be modified, they can be used in the counseling process to guide at-risk women on possible risk-reducing options through changes in behavior or lifestyle (e.g., reduction in BMI, alcohol intake, or HRT use);**

- Along with mammographic density (MD), and other relevant information.

Among all factors considered, the predicted UK breast cancer risk distribution is widest for the polygenic risk scores, followed by mammographic density. The highest BC risk stratification is achieved

when all genetic and lifestyle/hormonal/reproductive/anthropomorphic factors are **considered jointly.** With all factors, the predicted lifetime risks for women in the UK population vary from 2.8% for the 1st percentile to 30.6% for the 99th percentile. **14.7%** of women are predicted to have a lifetime risk of **≥17–<30%** (moderate risk [NICE] guidelines) and **1.1% a lifetime risk of ≥30% (high risk).** [3]

Until the Ministry of Health (MOH), the Cancer Control Agency, specialists and primary care providers recognise and utilise better risk stratification tools we will continue to fail to identify some critical breast cancers early. How big this group is in our population (10%?) we do not know as that detailed work has not been done. Our statistics suggest we need a sharper knife than the blunt instrument we are currently using. This broader high-risk group needs to be screened appropriately and supported in addition to the better known **familial or BRCA group** (which without testing tends to be under reported by 50%.) Focussing on familial utilising eviQ referral guideline[4] is a start but should not be our eventual destination. **If we are to make significant changes for our population, we need to understand it better and recognise a broader range of risk factors and progressively help all of those at high risk and not just the better-known group.**

As detailed above breast cancer has some modifiable factors which can be used in the counseling process to guide at-risk women on possible risk-reducing options through changes in behavior or lifestyle (e.g., reduction in BMI, alcohol intake, HRT use and prophylactic surgery)[3]. In the September 3, 2019, issue of *JAMA*,[5] the US Preventive Services Task Force (USPSTF) has updated its 2013 recommendation,[6] supported by an updated evidence report and systematic review,[7] for the use of medications to reduce breast cancer risk. For women who are at increased risk for breast cancer but at low risk for adverse events, the USPSTF recommends that clinicians offer to prescribe tamoxifen, raloxifene, or AIs for prevention for those who are at significantly increased risk for breast cancer. They also acknowledge that tools like BODICEA[3] may offer an opportunity to truly personalize benefit and risk estimates for women considering breast cancer chemoprevention. They go on to acknowledge that data on the benefits and risks of all of the available drugs are sparse for African American and Hispanic women (in our case Māori and Pacific) and acknowledge reluctance by some to taking risk-reducing medications which may in part be related to dissatisfaction with and distrust of the medical community. In the new era of precision medicine, there is a realisation that one size no longer fits all for most treatments. The new USPSTF statement mirrors this trend by making a strong case for the need to consider the unique risk profiles of potential chemoprevention candidates and incorporate this complex information into risk models for individualized decision-making. These more efficient and sophisticated tools quantifying each individual's benefit/risk may ultimately translate into precision medicine for breast cancer prevention.

Outcome 4: Surviving cancer is not just about earlier diagnosis. Even those who are diagnosed early and treated well can go on to develop advanced cancer which may already have dispersed micro metastatic disease when early cancer is diagnosed. We agree that the opportunity for survival is certainly enhanced by early detection as well as an overall system that is effectively coordinated, focused on improving outcomes and information-rich, and that can respond in a timely, effective and appropriate way. However, as for Outcome 1, there is no mention here of what a 'timely, effective and appropriate' response involves. **Access to world-class technologies and** treatments needs to be specified here. This includes state of the art detection tools and prognostic tools, medicines, and radiotherapy for early and advanced cancers. Currently the average survival rate for New Zealand

women with advanced breast cancer is only 16 months compared to 2 to 3 years and more in similar countries and this difference is largely attributable to our poor access to medicines.[8] The Agency needs to recognise and face this issue and accept responsibility for actions and reform that will bring New Zealand up to international standards.

Survival is also about timely and effective risk assessment, improved and appropriate surveillance, care and support and as a result earlier diagnosis. High risk groups (BODICEA, 2019)[3] need to be identified and support and information provided to individuals **before** they are diagnosed with cancer. These high-risk groups are not just familial (we know from research that familial cancers are under reported by up to 56%)[3]. At the time of diagnosis, it is also about refining treatment through sound prognostic (molecular/genomics/proteomics) work which helps patients and their clinicians determine the level of treatment required.

This can be achieved in breast cancer as demonstrated in a study completed by Dr Lauren Brown and presented by Reuben Broome at Breast SIG September 2019 (unpublished) and complemented by secondary results from the TAILORx trial presented at ESMO (Soprano, et al, 30 September 2019)[9]. For the local study, analysis was performed on the number of ER positive low risk breast cancer patients who received chemotherapy utilising the Breast Registers. The registers cover 60% of New Zealand patients. They found based on projections from data available and assays performed the number of low risk patients needing to receive chemotherapy each year (380) could be reduced by 70% by using multigene tests. Although there is a cost in providing multigene testing there is a greater saving of time (institutional and personal including travel time), facilities (reduced use of infusion facilities) and for patients reduced toxicity and a reduction in the need to comply with a demanding regimen. Complementary results just published also now confirm through secondary analysis of the TAILORx trial that HR+, ERBB2 negative patients with a high gene score and negative axillary node breast cancer (score 26-100) by gene assay who received adjuvant chemotherapy in addition to endocrine therapy had an estimated proportion free from distant recurrence at 5 years of 93%.[9] These two examples demonstrate that multigene tests bring increased precision to medical oncology. This technology is already being used in New Zealand by those who can afford it.

By using multigene tests, we may see the number of those needing infusions reducing, and the delivery of precisely targeted therapies only to those who will benefit. A sole focus on equity without precision risks simply seeking to provide Māori with the same number of infusions as pākehā now receive, which will help no-one. We are asking here that the Agency and Plan strive for equity at a high standard rather than equity at the lowest common denominator.

In addition, effective prognostic work at the time of diagnosis will also dictate the level of surveillance required to detect metastasis early to guide medical oncology decisions and to optimise overall survival for Advanced Breast Cancer patients.

2. Do you agree with key areas within each outcome? Page 12

Yes or No✓

If not, please explain.

Key elements missing from the infographic on page 12 are:

i. Principles: Add '**Consumer centric approach**' – we would welcome an explicit commitment to a consumer-centric approach in the info graphic. It could be included as a principle: Consumer-centred alongside Equity-led, Knowledge-driven and Outcome focussed. This would ensure that health consumer consultation and input is assured at every step. Involving consumers at all stages will inform models of care so they are patient-centred and responsive to the consumer experience[10].Otherwise it seems to be included purely via the Ministry-appointed National Cancer Network and Cancer Consumer NZ and is missing in other key areas. For example, the detail under **Data and Information** on page 16 refers to partnering "with government, the health sector, academia, and international experts to build collaborative and coordinated information". The Plan is said by those we consulted to have an element of "done to", rather than working with and involving and guided by those with lived knowledge.

ii. Consistent and modern cancer care: Add '**Effective risk assessment**' - It ignores the value of risk assessment (BODICEA, 2019)[3] to ensure that New Zealanders have better cancer survival. A population approach is needed to identify those at high risk to ensure they receive appropriate forms of surveillance, care and screening to achieve earlier diagnosis. Likewise, those at lower risk may not need the frequency of screening currently provided. By researching our population, we would be in a better position to understand the balance between the two.

iii. Consistent and modern cancer care: Add '**Access to state of the art technologies and medicines**.

This should be an explicitly stated aim of the Cancer Action Plan. A critical aspect of modern cancer care is access to modern evidence-based medicines. New Zealand's position as last of 20 OECD countries for access to new medicines is unacceptable. We would like the plan to be aspirational in getting modern treatments to New Zealand patients. Our medicines budget is woefully inadequate – from 2020 New Zealand will spend just $212 per capita on medicines, compared to $466 in Australia (2016) and the OECD average of $951 (2017).[11] We are not a poor country. New Zealanders should not have to put up with severe rationing when it comes to cancer treatment. While everyone agrees that cancer prevention is the ideal, it's just not possible for all, and it does nothing for the thousands of New Zealanders who are already living with advanced cancer. They need access to the proven life-extending medicines that are available in other countries.

iv. New Zealanders have better cancer survival: Amend to '**Improve cancer diagnosis, prognosis, treatment and surveillance to improve** '**outcomes.'** A small but important change that recognises the need to improve diagnosis but this is done alongside a commensurate recognition that we need to become more precise in the nature and level of treatment provided while also ensuring improved access to treatments. As currently stated, it suggests that simply improving diagnosis will improve outcomes.

3. Do you think the actions in the Plan will achieve equitable health outcomes for the priority populations identified (i.e. Māori, Pacific peoples, people living in rural and/or low socioeconomic areas, people with a mental illness and disabled people)?

Yes or No ✓

If not, what suggestions do you have about how we can do this?

Priority Actions, page 13

i. **Leadership and governance**. As mentioned above the establishment of the Agency within the Ministry of Health denies it the necessary transparency and independence needed for effectiveness.

ii. We are concerned a Ministry appointed National Director may support the status quo and be unable to articulate issues and roadblocks to progress and provide challenge where this is needed. We also suggest the Director be selected by a Working Group which includes cancer-related clinical and consumer representatives.

iii. We recommend the Board include at least two consumers preferably nominated by Ministry-independent consumer organisations.

iv. That the National Cancer Control Network and Cancer Consumer representative group be created through a fresh approach which includes co-design by clinicians and consumers.

v. **Health workforce**. There are currently severe shortages in some critical elements of the cancer health workforce. These should be identified and rectified as an urgent priority.

vi. We need additional Māori and Pacific health service providers at all levels, not just cultural competency training.

vii. **Data and information**. Please incorporate the high-quality data now gathered in NZ's Breast Cancer Register. Please refer to Dr Ian Campbell and the Breast Cancer Foundation NZ.

viii. **Research and Innovation**. Please add '**Increase participation in clinical trials'.** If we are to move from where we are today, it is through clinical trials and research that we will get a better understanding of our population and begin to test out new ways of assessing risk, trialling new screening options, understanding the role genomics may play and the costs and benefits of introducing different approaches designed to improve outcomes. This approach will reduce the use of toxic chemotherapy treatments when they are not required and ensure the use of precisely targeted medicines only where they will be effective. The European norms we mainly use today may not be entirely relevant for our diverse population particularly our Māori and Pacific population as demonstrated by the large international studies underway to better understand genetic risk of breast/ovarian cancer in European and non-European populations. The BRIDGES consortium (https://bridges-research.eu/)[12] is building datasets of BRCA1/2 pathogenic variant carriers that include individuals of South American, African and/or Asian descent. Why? Recent research has demonstrated that those who have access to relevant data and precision medicine it guides do better than those who do not.[13] Most recently, the international "Confluence project" is building a genome wide association study which will lead to more powerful modelling of the underlying polygenic risk of breast cancer, and with that a better understanding of breast cancer aetiology. The project will include New Zealand BRCA1/2 pathogenic variants carriers from a Breast Cancer Research Partnership in New Zealand project (Walker et al, 2019)[14] in which Māori and Pacific groups once again remain underrepresented. Walker et al[15] are continuing this work through another Breast

Cancer Research in New Zealand partnership project with a focus on a broader range of breast cancer genes *BARD1, CDH1, CHEK2, PTEN, PALB2* and *TP3*, with work underway on ATM by an ENIGMA colleague. As this research depends on the Christchurch Tissue bank, Māori and Pacific will be under represented and we hope that the Cancer Control Agency and MOH and their respective leaders and the Pacific and Māori communities will see benefit from assisting the partnership and Walker et al to next focus on Māori and Pacific through similar research. As a priority, consideration should be given to central facilitation of clinical trials, funding or coordination, to enable ease of access so that a patient's ability to participate is not dictated by their post code.

ix. **Achieve survival equity by 2030**. Involve Māori and Pacific consumers in the design, implementation and monitoring of cancer services. Co-design will be an essential element of increased engagement and better delivery of services. Different ways of working can be trialled in target groups whether they might be community and whānau initiatives or new advanced treatments or technology.

x. Improve funded access to modern medicines. NZ's failure to provide funded access to targeted medicines that are the standard of care worldwide is impacting more harshly on our people in lower socioeconomic brackets. This bracketing is correlated with ethnicity. Those who have more wealth are currently better able to purchase the unfunded medicines recommended by their oncologists and defined as standard of care in international guidelines. Improved medicines funding will lead to greater equity.

xi. **New Zealanders have better cancer survival. Early detection and population screening.** We welcome the initiative to progressively increase breast screening from 70 to 74, and, our preference is for this to happen immediately rather than progressively. We do have thoughts regarding screening generally and the use of more targeted approaches. In reviewing how and when women should be screened it is important to reflect on four significant trials which have reported in the last two years (PROCAS 1 and 2[16]; MRISC[17], RIscFaM[18] and DENSE[19]).

- Breast cancer stratified screening is seen as ready for implementation if breast density and SNP's (BODICEA. 2019)[3] are included (The PROCAS team, SABCS, December 2018). Annual screening detects breast cancers earlier for women with medium to high risk. Those with a family history and aged 35 to 39 had cancers detected significantly smaller and were less likely to have spread to the lymph nodes. [20]
- Screening with MRI improves survival for women with familial risk of breast cancer (age 35 to 50 years) by 25% at USD$134,932 (€102,164) per LYG compared with 17% mortality reduction at $54,665 (€41,390) per LYG with mammography only (MRISC Trial).[17]
- MRI detects significantly more cancers and at a relevant earlier stage, fewer large and node positive cancers occurred and fewer interval cancers resulted from MRI while clinical breast examination CBE was shown to be so poor it was better discarded, and contrast mammography was less reliable (RIscFaM Trial).[18]
- Supplemental breast MRI screening to measure breast density resulted in an improved cancer detection rate of 16.5/1000 with a significantly reduced interval cancer rate of 0.85 compared to mammogram alone with detection of 5.06/1000 (DENSE, 2019[19]).
- Mortality reduction has been proven for mammography and these trials clearly show that MRI performs better and detects biologically significant cancers earlier.

- Cost effectiveness and feasibility issues are being investigated within the DENSE trial, including reduced need for treatment and improved quality of life through early detection which will be published by year end.
- Use of abbreviated MRI[21] (14 m. vs 42 m.) is demonstrating adequate sensitivity and specificity (85% and 89%) in the differentiation of benign and malignant breast lesions and decreased false positivity in combination with Dynamic Contrast MRI. The basic European breast MRI takes 42 minutes; an abbreviated protocol would take 14 minutes and an unenhanced protocol 6 minutes. 2D and 3D protocols performed similarly with just a 0.1% difference. The results demonstrated benefit across all levels of the breast density scale (A, B, C, D) with critical improvements in C and D.
- A new factor in the BODICEA risk assessment tool, breast density, is neither routinely measured nor reported in New Zealand. According to DenseBreast-Info.org, the law directs the FDA, through the regulatory process to ensure that mammography reports received by patients and their providers include appropriate information about breast density.
- Of note a 2013 study involving 3,000 women showed that Māori women may have greater volumetrically dense tissue in their breasts than Pasifika, Pākehā and Asian women[22]. Greater constructive discussion about breast density among health providers, researchers and consumers would lead to better breast cancer outcomes in New Zealand.
- BSA retrospectively and or prospectively initiate a trial to better understand the potential cumulative risk factors Māori and Pasifika women experience at an earlier age so that potential differences may be identified, and screening timing and modality corrected.
- We often hear the suggestion that women will worry unnecessarily if they are offered supplemental screening and information on breast density. Preliminary results from Western Australia where density has been reported to women for 10 years and a survey by Stone et al, 2018[23] showed that over 70% of the 5000+ women surveyed said that knowing their breast density made them feel informed. Less than 5% did not feel informed. Approximately 20% of women said knowing their breast density made them feel anxious, and around 60% of women said that the information did not make them feel anxious. However, anxiety did not appear to deter women from attending screening, with more than 96% of women who felt anxious about their density indicating they intend to be screened, when next due. Preliminary results also showed that around 17% of women notified they have dense breasts have had an ultrasound due to their breast density, 2/3 of women interviewed were glad to be informed and more likely to be compliant.

vii. **Cancer care and treatment**. Add **'Invest more in medicines to provide better access to effective modern medicines'**. This appears to be the 'elephant in the room'. This issue needs to be dealt with transparently.

It is better to state 'PHARMAC to undertake earlier assessment **and funding** of new medicines. Little is achieved by assessing a medicine rapidly, finding it to be effective and moving it onto an opaque waiting list where it may remain, in some cases, for over 10 years.

Investment is also needed to increase the workforce and treatment capacity for **medical oncology**.

There appears to be no mention of which cancers are intended to be 'priority cancers.' Breast cancer has high prevalence among New Zealanders and high ethnic inequity with outcomes far worse for Māori. We therefore suggest breast should be included as a 'priority cancer'.

We welcome the other initiatives on page 13 but we would recommend adding, **more genomic counsellors and registries for high risk members of our population** as mentioned in relation to Question 1.

4. Are there other Actions in the prioritisation framework which need to be considered?
Yes or No✓
If yes, please explain further.

We need to add as additional bullet points:

- **total cost and societal impact of <u>not</u> intervening** including impact on families
- **benefits** such as **reduction in toxicity, improved length and quality of life.**

If capacity and (**capability**) are constraints the Action Plan should aim to progressively remove that constraint though an increase in capacity and by raising capability through utilisation of new technologies.

The meaning of 'total health impact' is unclear.

We do want those with worse outcomes to benefit as detailed in the plan. We stress for that to happen, leadership "will need to lead" changes across the system to deliver "modern cancer care, fewer cancers and better survival" through new technologies and new ways of working. It is not just a case of doing more of the same, for those with poorer outcomes. In this way all will benefit.

The Plan lacks a sense of aspiration and moving forward. The framework seems to be less enabling and more restrictive or exclusive. It appears to suggest measurement of cost and current capacity without reaching for a world-class standard of care. New Zealanders don't want equity at the lowest common denominator in a system that accepts rationing as its framework. We want this Action Plan to reach higher and drive initiatives that will achieve better outcomes for all.

5. Are there other aspects in the prioritisation framework that need to be considered?

Yes or No

If yes, please explain further

Benchmarking with other countries to determine whether NZ's standard of care is modern and world-class.

Aspiration to achieve equity at a world-class standard for all New Zealanders.

In addition we wish to highlight the following regarding two aspects of the framework not highlighted through subsequent questions.

a. Research and Innovation, page 25

i. National Leadership - It is not just wider use of clinical trials that is important. We need national leadership across multidisciplinary stakeholders to resolve funding and other issues.

ii. Resourcing - We also appear to have as one stakeholder described it, "overworked" clinicians who struggle to lead research alongside their clinical demands. In addition, Research coordinators are described as not well paid and not at a level required for a clinical trial.

iii. Relationships - If we want pharmaceutical companies to work alongside key stakeholders, then we need to be more mature and transparent in how we manage and relate to all stakeholders. Sir Andrew Dillon, Chief Executive of the National Cancer Institute for Health and Care Excellence (NICE) during his visit to New Zealand earlier in 2019, described mature and healthy working relationships, including with pharmaceutical companies with consequent benefits for all from this level of maturity. Coming from a place of fear and distrust does not improve health outcomes.

iv. Another complication is that some pharmaceutical companies appear to have given up on bringing products and clinical trials to New Zealand given the difficulties in interacting with PHARMAC and bringing new medicines to the New Zealand market. The ND and DG need to alter the culture we have in New Zealand which is diminishing the opportunity for clinical trials. We need to be more welcoming and respect each other's roles irrespective of any negotiations that may be ongoing.

v. Page 26. Research into the genetic and molecular profile of cancers – we are very pleased to see this mentioned. It is refreshing and very welcome as we try to understand how we can support such initiatives. Breast Cancer Cure has funded breast cancer research in New Zealand since 1997 and since 2013 alongside The Health Research Council and the Breast Cancer Foundation NZ. This is an area of ongoing focus and we would welcome an opportunity at some point to understand what is intended when mention is made of national processes.

vi. Page 26. The focus and intent of the plan to improve capacity and precision through such initiatives we feel could be stronger. For example, in 2019, **Dr Gavin Harris**, Canterbury District Health Board was a successful recipient of project funding from the Breast Cancer Research Partnership in New Zealand, titled, **Using deep learning and digital pathology to intrinsically subtype breast cancer [15],** 24 months: $249,650. Mention is made on page 27 that in coming years digital technologies and machine learning and AI will provide opportunities to invest. Investment is being made now and we welcome an opportunity to discuss how MOH and the Cancer Control Agency may work alongside us to invest now and not just in the future to ensure ongoing investment. Harris et al.'s project should improve access to high quality data and create additional capacity.

vii. Formalise international research partnerships and connections. The two organisations mentioned, (the New South Wales Cancer Institute and the International Agency for Research on Cancer (IARC) represent a start however there is excellent future focussed work being done in cancer beyond the two mentioned. Other examples are Cancer Research UK, the Institute of Cancer Research London and Peter Macallum

Cancer Centre, and Breast Cancer Trials which would broaden the research focus across the cancer pathway.

viii. Within New Zealand local cancer research is funded by several organisations, there are some partnership models in place, and we would like to others encouraged to reduce the level of replication for funding applications, peer reviews and assessment panels.

ix. Develop advice on how equitable access and wider use of clinical trials can be achieved – see comments above.

6. What three actions across the entire Plan do you think should be progressed first?

Please note the bolded actions in the diagram on P13 are not included in this question as they are already progressed.

We consider that key actions are not included in the Plan.

Action 1.

While options for early access to medicines are being considered and PHARMAC is to undertake earlier assessment of new medicines, neither of these actions will lead directly to better access to medicines or better outcomes for New Zealanders. It is our view that the action that would deliver the greatest benefit to New Zealand cancer patients is:

To establish a responsive, modern cancer service that uses state of the art technologies for risk stratification, detection, diagnosis, prognosis and treatment, including access to medicines established as standard of care in international guidelines such as those developed by ESO-ESMO and ASCO.

This action requires adequate resourcing to allow New Zealand to reach world-class standards.

Action 2. World class cancer care must be supported by trained professionals across the disciplines. We consider this to be the second most important action, i.e.:

To determine the quantity and distribution of workforce required in all cancer detection, treatment and care disciplines to ensure that every New Zealander has access to timely, effective treatment, targeted accurately to their disease, whoever they are and wherever they live in New Zealand.

Action 3.

Development of QPI's and standards that will be regularly monitored and reported in order to:

- Advance consistency
- Increase transparency
- Increase knowledge and gain agreement regarding what will make a difference in achieving modern cancer care and improve overall survival across the cancer pathway

OUTCOME 1: "New Zealanders have a system that delivers consistent and modern cancer care". (page 15-27)

New Zealanders need a high-quality cancer care service now and into the future. To continue to lift our performance in cancer we need to consider how to structure, resource and use the best information to deliver cancer care.

7. Do you agree with the approach for creating a system that delivers consistent and modern cancer control?

Yes or No✓

If no, please explain why not.

We like the concept of consistent and modern cancer care…." We accept this general aim, but key elements are missing.

i. The Cancer Agency will have insufficient independence from the Ministry, Minister and therefore the Government of the day
ii. There is insufficient engagement with consumers or co-design of programmes outlined in the Plan.
iii. The same applies to Māori – there is perception of a top-down view of a system delivering to Māori and Pacific patients without the empowerment and engagement needed to ensure systems are designed with, by and for Māori to make them appropriate and effective
iv. There is limited immediate focus on using state of the art technologies for risk assessment, accurate diagnosis and prognosis, targeted and effective modern treatments including medicines
v. There is insufficient focus on securing the necessary workforce across the disciplines
vi. There is inadequate focus on addressing regional inequities
vii. There is a large focus on prevention and early diagnosis without a complementary focus on world class medicines and treatment at an early cancer stage to decrease the likelihood of recurrence in patients.
viii. Under research and innovation we suggest that you add **formalise local research partnerships** in addition to international partnerships.
ix. Genomics is mentioned in the second to last paragraph; it should read **genomics and proteomics**.

8. Do you think the actions under Health Workforce will address the current issues?

Yes or No✓

If no, please explain why not.

We agree with most of this section. However, there are issues which need to be recognised:

i. Genomic counsellors, pathologists, radiologists, medical oncologists and other specialists in short supply. Issues relating to their shortage and how this problem will be overcome needs to be included in the workforce section. Development of new technologies such as AI and

machine learning for some of these roles will free capacity and capability and ensure we cope with an increase in numbers resulting from immigration and our aging population. See reference to Dr Gavin Harris (5. a. vi) below. The need for additional genomic counsellors will grow although some mainstreaming efforts will reduce some pressure.

ii. Transferring knowledge and capability to Nurse practitioners will also be important if access to the health system is to be improved. Leadership will need to negotiate such a change into national agreements and establishment of training programmes with urgency as this cannot happen at regional level.

iii. Improving the ability of primary care providers to better understand cancer, including detection, referral, monitoring, care and support. Lack of ability to detect and investigate symptoms now leads to late diagnosis, especially for young and Māori and Pacific people. Lack of knowledge of the importance of maintaining treatment regimens such as anti-oestrogen therapy, leads to cancer recurrence and advancement.

iv. Improving the knowledge and learning of all within the system so that we don't just prepare to support family and whānau but also to be ready for new technologies. We cannot ignore the fact that some of these technologies are in our system now and for equity to be achieved this must be recognised. For example, the benefits of a multigene test (see Outcome 4 Dr Lauren Brown and Reuben Broome's work) to determine whether someone needs chemotherapy or not are being enjoyed within the private system along with direction from some tests regarding which treatments will most benefit a patient. Such benefits are not available to all and we would welcome a strengthening of the plan to recognise that investment in such tests and the targeted therapies that would be shown to benefit selected patients will help to reduce inequity.

9. Are there any further actions required to ensure New Zealand has a strong leadership and governance in cancer control?

Yes or No

If yes, pleased explain further.

i. Establish the necessary independence from the Ministry, Minister and hence Government of the day.

ii. The bullet points highlighting what must be delivered refer to Māori leadership and partnership. We note and are encouraged by the comment "encourage consumer leadership, engagement and co-design". This would be extremely welcome, along with details as to how this would be achieved and what mechanisms may be developed for the involvement of patient advocacy groups. The consumer engagement element should be broad and inclusive of those with lived experience of cancer and those who represent New Zealanders with cancer and understand the NZ cancer treatment environment. The Ministry-appointed Cancer Consumer NZ group is not representative of the many engaged consumer stakeholder groups.

iii. We suggest you add **facilitate and encourage research partnerships** (**local and international**) and provide leadership across the sector in association with the Health Research Council of New Zealand and other key stakeholders to facilitate larger clinical trials which will improve cancer outcomes.

iv. Cancer Control Agency – we suggest in addition to the outlined initiatives that a transition plan is developed so that actions not currently prioritised retain transparency and a sense of forward movement and an understanding of way points, when corrective actions may be necessary.

v. National Director (ND) appointment – mention is made of "achieving equity of outcomes across the cancer continuum". Although we don't disagree with this sentiment, we however point out that in addition it is critical in order to achieve modern cancer care that the Director also be tasked with more than just improving health outcomes but also with, **advancing and improving cancer outcomes** in line with future proofing as mentioned in the introduction. One of our challenges is the level of constraint now. It is vital that the Director and the Agency can also find ways to provide leadership across the system through new technologies, modern medicines, new ways of working and access by removing constraints (and raising capability). Both the Agency and its Director need to be aspirational in bringing New Zealand's standard of cancer treatment and outcomes up to a world class standard. We are concerned by recent comments from the Interim Director that suggest a poor understanding of the knowledge gained from clinical trials and the importance of modern medicines in treating cancer. We are also disappointed by comments denigrating the pharmaceutical industry and believe a more positive and conciliatory approach is needed in the role.

vi. Reporting relationships and roles - we note the dual reporting relationship to the Minister by the Director General (DG) and the National Director (ND) roles. We also note the ND is a member of the Cancer Control Agency Board which will be Chaired by the DG. It is more common in New Zealand for all directors to be independent on an organisation like the Cancer Control Agency[24] and for the ND role to report to the Board. We want increased independence and are concerned that confused reporting relationships may not increase independence but ultimately weaken it. A truly independent agency would strengthen leadership authority and influence of the ND role. Will these mixed reporting relationships and roles support the form of independent leadership and governance we in New Zealand deserve? How well equipped will the Minister be to resolve issues of conflict which may develop between the DG and ND when both are to advise him/her?

vii. We support the development of a newly formed, broadly representative National Cancer Network and Cancer Consumer group and would welcome involvement.

OUTCOME 2: New Zealanders experience equitable cancer outcomes (page 28-32)

In Aotearoa New Zealand, people have differences in health outcomes that are not only avoidable but unfair and unjust. This section considers different approaches and providing different resources to achieve equitable health outcomes.

10. Are there any other actions that should be added or removed from Outcome 2 (New Zealanders experience equitable cancer outcomes (p 28 – 32))

Yes or no

If yes, please explain what and why.

We would like to see greater inclusion of Māori in defining the whole equity initiative.

When adopting a robust equity-first prioritisation methodology in cancer investment decision making, we again confirm the need to provide funded access to modern medicines. This is currently a significant source of socio-economic inequity as many effective medicines remain unfunded and therefore out of reach of those who cannot pay for them. This tends to impact more on Māori and results in poorer outcomes such as those experienced for Māori women with advanced breast cancer (BCFNZ, *I'm Still Here* report).[8]

11. Do you think developing and implementing a mātauranga Māori framework and Māori led programmes could achieve equitable health outcomes?

Yes✓ or No

If not, please explain why not.

We agree with a mātauranga Māori framework and we agree that the plan should address all forms of racism and discrimination.

12. Do you think the actions in the section, "achieving equity by design" will ensure equity is at the forefront when developing cancer services?

Yes or no✓

If not, please explain why not.

In keeping with obligations under the Treaty of Waitangi, we believe equity for Maori should be based on Māori-led initiatives and co-design with Māori rather than a top-down approach. We fully support initiatives to achieve equity for Māori but do have a concern that an "Equity by design by 2030" with a sole focus on "equity first prioritisation" may diminish the opportunity for Māori to advance alongside other New Zealanders.

We suggest that to achieve equity by 2030 will not just require a prioritisation and equity focus but also investment in new and modern ways of doing things which will benefit all including Māori and may assist Māori to "leapfrog" some of the barriers currently experienced.

For example, introducing multigene testing for ER+ breast cancer may free up capacity as not all patients need to receive chemotherapy. Although there is a cost in providing multigene testing, as explained earlier there is a greater saving of time (institutional and personal including travel time), facilities (reduced use of infusion facilities) and for patients reduced toxicity and a reduction in the need to comply with a demanding regimen. Through multigene tests, we may see the number of those needing infusions reducing, and the delivery of precisely targeted therapies only to those who will benefit.

A sole focus on equity without precision risks simply seeking to provide Māori with the same number of infusions as pākehā now receive, which will help no-one. We are asking here that the Agency and Plan strive for equity at a high standard rather than equity at the lowest common denominator.

Monitoring framework and data sets – does this include the breast registers? Is there an opportunity to integrate these databases?

We agree with whānau-centred care guidelines.

13. Do you think the Plan will address racism and discrimination in cancer services?

Yes or no?

Please provide details

The plan begins the process for that to happen. QPI's and standards could be used to reinforce this need along with KPI's across the system and effective monitoring. Getting more Māori and Pacific employees into the system will eventually help. Above all it will be important to adhere to the principles of the Treaty of Waitangi, establish strong Māori leadership of initiatives listen to those raising issues and ensure issues raised are recognised and addressed, using co-design.

Leaders across the system have a critical role to play. Include Māori at all steps of leadership, design, implementation and monitoring of the evolving cancer system.

OUTCOME 3: New Zealanders have fewer cancers (page 33-44)

Preventing cancer is without doubt the best strategy for controlling cancer as well as reducing inequities. It is estimated that around 40 percent of health loss from cancers is potentially preventable.

Do you think the actions to support prevention are right?

Yes or No ✓

If not, what suggestions do you have to improve this?

i. Preventing cancer may be a key strategy for controlling particular cancers however for many cancers it is not "without doubt the best". It is important that the Cancer Control Agency remain objective and lead change across the cancer continuum. Prevention needs a focus but not at the exclusion of other vital interventions. Causative factors that can be avoided will certainly never prevent many cancers as they occur as a result of random accumulated damage and copy errors that occur when cells divide. Cancers have been present in all human and animal populations throughout history and it is naïve to suggest otherwise.

ii. We agree with the approach to help New Zealanders to help themselves by managing modifiable risk factors. However, to do so the population needs to understand what their risk is, and which factors are modifiable.
iii. We are concerned that a fervent focus on prevention will give people the impression that they will not be at risk of cancer if they live a healthy lifestyle. In the case of breast cancer, the biggest risks are being female and getting older and these cannot be avoided. An unfortunate side effect of an unrealistic view of prevention is that people who actually have cancer feel stereotyped and suffer societal stigma from those who think they can avoid what is a natural feature of mammalian biology.
iv. We agree with encouragement and support for healthy living and preventing cancers related to infection and reduction of cancers related to UVR and exposure to work related carcinogens.
v. We would like to see an additional factor included of risk assessment relating to not just lifestyle factors as mentioned already but also hormone and reproductive factors, genetic and polygenic risk factors and breast density some of which are not modifiable but earlier and more appropriate and targeted screening can prevent/reduce the number of invasive cancers being detected.

Outcome 4. New Zealanders have better cancer survival (page 45-62)

Surviving cancer is highly dependent on earlier diagnosis and an overall system that can respond in a timely and appropriate way.

15. Are there any other actions that should be added or removed from Outcome 4?

Yes or No

If yes, please explain what and why.

The statement that 'Cancer care will continue to be pressured by the rising number of people with cancer, increasing age and comorbidity, technology and new drugs, increasing specialisation and increasing awareness of and demand for supportive care' is of concern to us. We would prefer to see a patient-centred statement that focuses on people along the lines of 'An increasing number of New Zealanders will be diagnosed with cancer given our growing, ageing population and comorbidities are likely to increase (we're not sure why that is??). However, new technologies and medicines offer opportunities to effectively detect and treat the disease, and patients can also have improved experiences of cancer through supportive care'. The current statement suggests a tired, overburdened system that does not see people at its heart and does not aspire to do better.

We agree with a focus on improving early detection. This needs to be widened to also include earlier detection of advanced cancers.

i. We suggest risk assessment is added in order to develop early detection programmes in line with targeted and appropriate screening. This means for those with poorer prognosis that they also have some form of screening implemented post 5 years in order to detect advanced cancer earlier.

ii. Undertake an epidemiological trial to test a lower breast screening age for Māori and Pacific as well as for a broader high-risk group, to determine the opportunity to detect cancer early in these groups.

iii. Utilise appropriate screening modalities which have a cost in the first instance but bring the benefit of reducing the need to invest in a full range of treatment options (PROCAS 1 and 2[16]; MRISC[17], RIscFaM[18] and DENSE[19]).

iv. For breast cancer there is also a need to improve surveillance for advanced breast cancer – such as through improved prognostic analysis and ctDNA tests.

v. We wholeheartedly support the focus on provision of support for those at risk of cancer and with that, improved monitoring.

   a. Page 46. We agree with raising the age of eligibility for breast screening from 69 to 74, but immediately and not progressively. We would also like to see earlier access to screening particularly for those at risk.

   b. Page 46. The column titled 'Improve cancer diagnosis and treatment outcomes' is limited. We are unsure what 'priority cancers' are. It is good to see improved capacity for radiation oncology specifically mentioned but other capacities such as **pathology and medical oncology** also need to be expanded.

   c. There is also an opportunity to improve the consistency of provision at optimal rates of radiation to free capacity as shown in a case study presented by Dr Melissa James Christchurch Radiation Oncologist, Breast SIG, Friday September 2019 (Unpublished). *Moving the traditional 5 weeks of 50Gy in 25 fractions to hypo fractionated radiotherapy which reduces the number of fractions and therefore the treatment time by using larger doses of radiation per fraction. This frees up patient time and reduces radiation department waiting lists. The Christchurch results after 12.9 years show local recurrence rate is similar or slightly less than international trials and acute toxicity low. The radiation oncology plan 2017-2021 saw the creation of a central depository of detailed radiation oncology information which allows researchers to pull information using NHI level data. The intervention rate for breast cancer varied significantly across regions. The Radiation Oncology Working Group has suggested ratification of Stage one breast cancer recommendations and the South Island group is now looking at advanced breast cancer. Monitoring of variation across the country and visibility of regional differences is an excellent example of how to free up capacity by using national data and new technology while reducing patients' time commitments which may improve access and reduce inequities.*

   d. We agree with earlier assessment of new medicine applications and developing options for earlier access to new medicines along with transparent funding decisions. However, this will achieve nothing unless there is action to increase funding for cancer medicines. To improve cancer survival, treatment of early cancers also needs to improve to include access to world class medicines and to reduce the level and percentage of cancers which will recur. Currently medicines deemed effective by PHARMAC's expert committees can remain on an opaque 'priority list' for over 10 years in some cases. Patients need much faster access to the wide range of cancer medicines that are established as the standard of care in international guidelines such as ESO-ESMO and ASCO and funded in other developed countries. New Zealand must close this gap as a priority.

e. Increased transparency in PHARMAC should include acceptance of well-established evidence and honesty around inability to fund effective medicines because of lack of funding. For too long we have heard the claim that there is insufficient evidence when benefits are well established in rigorous randomised controlled and other clinical trials, and medicines are already the evidence-based global standard of care.
f. We fully support the "living well with and beyond cancer". We do however believe there needs to be easier access to palliative and supportive care for all on a timely basis. We are uncertain that data is being kept of those missing out on palliative care which is shown to improve quality of life for patients and their families.
g. Care for people with advanced cancer involves treatment as well as palliation. This can improve length as well as quality of life. People should not be 'sent home to die' when they have advanced cancer.
h. Provide services to support people with an increased risk of cancer through identification and monitoring, page 49.
i. Clinical trial research in breast cancer has shown that familial cancer is under reported by 50-56% depending upon the trial you follow. There is also recognition that familial cancers alone are not the only high-risk cancers. Other intermediate risk cancers also demonstrate a wide stratification of risk. Some will be low risk while for others high risk. High breast density is also for some a high-risk factor. Monitoring and surveillance targeted at risk has been demonstrated.
j. High quality population screening.
    - The issue for the breast screening programme is not just participation but also the strong suspicion that earlier onset of the disease for some (Pacific) or diagnosis at a later stage (Māori) suggests there may be differences in our population we do not yet fully understand. (Seneviratne,2016)[25]
    - The issue is also not just one of the first screen being successful but also repeat screening.
    - We also need to provide supplemental screening for those at higher risk.
k. Actively monitor evidence for new targeted screening programmes. We shouldn't just monitor new targeted screening programmes for priority populations but retrospectively and prospectively also trial new targeted screening programmes. DENSE 2019[19] and other trials already mentioned demonstrate we are in urgent need of better understanding our own population now and not relying entirely on other countries initiatives as our Māori and Pacific populations will not be well served by such reliance.
l. Implement quality improvement indicators. We look forward to the development of QPIs for breast. Breast SIG at its September meeting agreed to write to MOH in support of the development of QPI's and Standards to ensure consistency across NZ. In addition, we look forward to the development of standards of care for breast and to consistent collection of stage data to help monitor improvements in quality cancer care.
m. We agree with the concept of the need to invest in workforce, technology and treatment capacity for radiation oncology.
n. BCAC's advocacy over the years has made clear our views, including in 2019, regarding earlier assessment of new medicines applications, early access to new medicines and the desire for a more transparency regarding funding decisions by PHARMAC. We welcome recent decisions from PHARMAC and we look forward to the National Director being an

independent voice to support continuing improvements and transparency in access to medicines. It is clear that greater investment is needed in medicines.

o. Living well with and beyond cancer. We agree with the need to develop cancer surveillance guidelines alongside the development of standards of care – which are person centred, focus on risk and are supported by holistic needs assessment and individual care plans

16. Do you think enabling people with the knowledge, skills and confidence to use cancer health information will ensure they have a better understanding of early signs and symptoms of cancer?

Yes or No✓

If not, please explain why not.

This will be helpful for some people. However, we recommended a risk assessment approach because, for example, by the time you find breast cancer yourself, the risk of invasive cancer is very high. This risk is even greater for lung and bowel cancer.

It helps to know signs and symptoms, but primary care providers also need to understand and share this knowledge.

To identify cancer earlier a risk assessment approach initiated at say age 18 would help patients and primary care providers to identify those at high risk and to begin to understand modifiable or non-modifiable aspects of that risk and when screening should begin at age 25 (or earlier), 35, 45 and what modality is best. Some may not wish to participate, others will.

17. To get the best outcome, it may require travelling away from home to access specialist cancer services. What support needs to be considered for someone who receives treatment for cancer away from their home or whānau?

Patients who are required to travel away from home (and whānau) need to have suitable travel and accommodation options to ensure they can access their specialist appointments and treatment and have adequate family support during that time. Ideally, financial support would be available for both patients and family to facilitate this (especially where family members may have to miss or leave work to provide support).

The availability of suitable transport also needs to be considered - and not only for patients required to travel away from home. In large centres, such as Auckland, where specific treatments may be available in only one or two places, access is a real issue, which can result in patients missing appointments or not completing a full course of treatment. This can even include distances generally regarded as very short (e.g. from Domain Lodge to Auckland Hospital). A patient's ability to travel to/from and be supported during treatment should be monitored as part of the booking process and may depend on differing mobility at different times.

An equitable system would ensure that transport and accommodation do not present barriers to accessing specialist cancer services.

18. Does the plan address ways to improve patient experience of cancer services?

Yes or No✓

If no, please explain what and why.

Should our feedback be incorporated we would expect that patient experience of cancer services would improve. It depends whether there is aspiration and action to overcome current constraints within the system and whether there is workforce development, new tools, information systems, technologies, medicines and support mechanisms incorporated which will help to remove some of those constraints. If the approach to services are consumer/patient centred and co-designed with a modern cancer approach where discrimination and racism are absent, then yes.

19. Do care plans need to be developed to meet the holistic needs of patients and families/ whānau?

Yes ✓or no

If no, please explain what and why.

Yes

20. Does the Plan address access to follow-up and surveillance for recurrence, late effects and new cancer post treatment?

Yes or no

If no, please explain what and why.

Only in a very cursory way on page 61.

Anything else?

The Breast Cancer Aotearoa Coalition and Breast Cancer Cure jointly provide the following feedback on the New Zealand Cancer Action Plan. Our feedback also represents views from Sweet Louise.

- We appreciate the development of the New Zealand Cancer Action Plan (CAP) and appreciate the thought and consideration that has been invested into it.
- We were not consulted in its preparation and therefore this represents our first opportunity to provide input.
- We have attempted to digest the plan in detail. We are fully supportive of adhering to the principles of the Treaty of Waitangi and striving for equity for Māori. However, the wording in the introductions by the Minister and Director General and emphasised throughout the plan has

raised concerns for us that the focus on specific populations and specific cancers in the plan's implementation may limit opportunities for wider transformation. We are concerned that this approach could lack aspiration to strive for **system-wide improvements** and could set the Plan's sights on equity at a low common denominator, with minimal change to current standards. No-one, including Māori would benefit from this.

- Please understand, we are fully committed to seeing those with worse outcomes benefit as detailed in the plan. We stress for that to happen, leadership "will need to lead" changes across the system to deliver "modern cancer care, fewer cancers and better survival" as promised in the plan, both through new technologies and treatments and new ways of working. It is not just a case of doing more of the same, for those with poorer outcomes. In this way all will benefit.
- We agree with the sentiment of person centred and compassionate care and wholeheartedly support the values they espouse.
- Page 3 of the plan mentions 5-year survival rates which for breast cancer are 87.3%. This is a misleading statistic. Our thinking may be expressed as follows:

  Breast cancer is the most commonly diagnosed cancer in NZ women[26] It disproportionately affects Māori and Pasifika women (Lawrenson, 2018)[27.] Although many women diagnosed with early breast cancer will survive at least five years, up to 30% of all cancers will eventually advance. depending on subtype. New Zealand's record in treating people with advanced breast cancer is appalling. Our median survival time is just 16 months, compared to 2 to 3 years in European countries and the USA (I'm Still Here, BCFNZ report)[8].

  An international report recently predicted mortality in New Zealand to 2020 would be less favourable than other countries in the Americas, Asia and Oceania, ranking us alongside Argentina, Cuba, Venezuela, Israel, and the Philippines (Caroli et al, 2018)[28]. This highlights how we need to improve how we prevent, detect, diagnose, manage, monitor, treat, care and support those with or at risk of developing breast cancer in New Zealand. Improving population outcomes and eliminating ethnic inequalities in breast cancer stage at diagnosis and mortality can be achieved through concurrent initiatives across the pathway including investment in resource, smart technology, research and improved infrastructure to improve capacity/capability, precision in line with the Māori Health Strategy. Initiatives to improve outcomes should be evidence-based and supported by ongoing research, both overseas and in New Zealand.

Lastly in order to make additional comments about the plan we were forced to respond 'no' to many questions when some of our responses may have tended more toward a 'yes'. We have appreciated the opportunity to provide feedback.

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