Report for Auckland District Health Board

How can ADHB achieve greater equity and improved outcomes for Māori and Pasifika breast cancer patients and how could BCAC assist?

26 November 2018

Background

Pat Snedden (Chair Auckland DHB and Deputy Chair Counties Manukau DHB) proposed to BCAC (Breast Cancer Aotearoa Coalition) members Irene Kereama- Royal (initiator of the meeting and Committee Member), Libby Burgess (Chair), Louise Malone (Treasurer), Fay Sowerby (Secretary) and Emma Crowley (Deputy Chair) that BCAC put their view of how equity issues may be approached in the near and longer term. The initial purpose of the meeting was to discuss use of Counties Manukau infusion facilities to improve outcomes for Māori and Pasifika breast cancer patients. A broad range of issues were traversed by Pat, Richard, Jo and Irene with contributions from other BCAC members.

BCAC was asked to report back in a month with suggestions of how we might assist ADHB with achieving greater equity and improved outcomes for Māori and Pasifika breast cancer patients.

Issue	Comment/ Background	The problem	Proposed approach	BCAC's role
Institutional racism, cultural bias and racial discrimination has been identified as • Leadership/Vision • Policies/Systems • Health service delivery/treatment processes • Way of working/style/culture • Health workforce skills, composition, equity issues • Structural issues.	"The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping	Data available from the Waikato study[2] and BCFNZ ABC Report[3] 2018: Māori and Pasifika early and advanced breast cancer (ABC) patients are not being offered breast cancer care, services, or support in a way/place which encourages them to participate fully in a way that meets their needs – this is impacting on their breast cancer outcomes and	If you view the DHB in its entirety this is a large change process. There may be an opportunity to trial processes with selected teams to evaluate and better understand what is needed to improve service and care while at the same time incorporating fresh thinking into any existing values discussions at leadership level, through recruitment, induction,	Irene, on behalf of BCAC, has a unique contribution to make in this space as a current consumer of Auckland DHB services as a breast cancer (BC) patient. She is willing to lead further engagement between BCAC and Auckland-based DHBs to assist with: - dissemination of evidence-based information from BCAC's networks about

Broad and sustained change will address inequities and build confidence by our affected communities.	which disadvantage minority ethnic peoples." [1] BCAC would like to assist with this work by advising from a consumer advocacy perspective.	has an additional significant social and economic impact on their families and communities.	mentoring, performance management processes and or targeted care pathways. Kaupapa Māori and Pasifika approaches to improve health outcomes, can become a normative part of public health delivery and clinical practice - it is a travesty that it is not and barriers to better health outcomes for these communities will not be removed as a result. Cultural evaluations of service delivery, cultural audits, aggressive HR recruitment programs, Treaty training and partnership policy frameworks, professional development programs and Iwi lead or co-governance arrangements are not only pro-active and innovative initiatives, they are also not preferred as normative health approaches in DHBs.	inequity for Māori and Pasifika and BC outcomes, and - provide description, discussion and information collected about consumer/community experiences of systemic racism within the wider Auckland DHB area. BCAC is supportive of community driven initiatives and engagements that support community led action. The basis of our support is to align and collaborate with agencies to link them with communities that are engagement ready. This focus is evidence based and seeks to align Māori and Pasifika communities which suffer from poorer health outcomes as a result of being domiciled in the wider Auckland DHB area.

				BCAC encourages leadership in improving those poor outcomes for those communities and to support the development and provision of culturally competent care pathways.
Local delivery of chemotherapy, targeted therapies and radiotherapy.	Chemotherapy and radiotherapy are only being delivered at ADHB – not Waitemata or CMDHB - leading to access problems for those in South, West and North Auckland. Lack of resources, standards and coordination, and trained staff, in particular, are factors. Unfortunately, the process of staff training for local delivery has been considerably slower than expected.	Women unable to travel for their infusions/radiotherapy results in poorer outcomes (including worse survival). This is starkly evident in BCFNZ's ABC report[3], and compounds inequities. It is the more deprived who are most significantly impacted.	• Provide additional resources to speed this process up • Have a conversation with us to fully explain the risks that are so important that centralisation must persist • Introduce sub cutaneous (injection, not infusion) Herceptin which can be delivered via a trained medical practitioner in the PHO setting • Continue to move to a stronger local delivery model via DHBs and eventually health centres. Invest adequate resources into this	BCAC would support the DHB in accessing Counties-Manukau patients' feedback / perspectives about how the lack of delivery of chemo infusion services at Middlemore impacts their treatment pathways and their ability to access whānau support, given the travel distance and cost to attend treatment at Auckland hospital. BCAC is supportive of community-based chemo services and could provide assistance with identifying community providers for this purpose (where Māori and Pasifika peoples can feel comfortable attending appointments). More

			process so that it happens more quickly. This is an urgent problem that needs a solution now.	resources are urgently needed to fund Māori and Pasifika BC nurses, navigators and clinical staff.
Women not adhering to therapy regimens	Endocrine therapy non-adherence is a significant factor in high rates of breast cancer recurrence, leading to poor outcomes.	Poorer outcomes for those with hormone-receptor positive breast cancers (the most common type).	More regular follow-up oncology appointments (3 monthly to check on and encourage adherence, deal with side effects). Could these be done by local staff? Training in how to handle side effect problems. Provide more (culturally appropriate) information about risks of non-adherence and ways to alleviate side effects.	BCAC is able to provide information and communication on this issue. DHBs to demand that MOH review the level of support for advanced breast cancer patients so that these issues are effectively managed. BCAC put pressure on MOH to adequately remunerate DHBs for advanced breast cancer patients.
Prevention/Earlier diagnosis	We know that Māori and Pasifika women are diagnosed too late, at a younger age, and with more aggressive cancers.	The Waikato Study[2] makes clear that Māori and Pasifika women should be screened earlier than the current age of 45	DHBs promote the provision of additional resources to BSA to extend breast screening age to 40, targeted initially at Māori and Pasifika women, and to better communicate the need for screening to these women. Waikato/Capital	The opportunity for a retrospective study is already being discussed. Is ADHB interested in a future trial, and what support can the ADHB provide for targeted screening?

			Coast Health (Monica Saini) to do a retrospective study of breast density to eliminate that as an issue using Volpara data. If it is found that density is an issue, then run a prospective trial looking at genomic density date/screening modality to understand how targeted screening methods and age of screening may need to change.	BCAC can provide information and communication on this.
Prevention/Treatment	Lifestyle factors (diet/alcohol/exercise) are now recognised as playing an important role in prevention and treatment of breast cancer. Māori and Pasifika in deprived communities may be more significantly impacted by these issues.	Is there a role that DHBs can play? The Healthier Lives programme seems to focus more on schools, industry led changes and government policy however the Māori/Pasifika community cluster trial could be brought into patients going through treatment?	Local delivery would enable greater possibilities for such a programme but why are we not trialling such initiatives within our hospitals with the necessary support?	BCAC can provide information and communication on this.

Standards of Care	The Northern Network Model of Care for Breast Cancer will integrate with new Standards of Care and tumour standards to be developed by MOH. Breast Cancer Tumour standards were developed in 2013, but not implemented and monitored. MOH hopes to look at the Breast Tumour stream in March/April 2019.	Without adequate resources applied to MOH's Standards development process the invisible hardship and poor outcomes experienced by Māori and Pasifika women, as outlined in the Waikato Study[2] and ABC report[3] will unfortunately continue. This is unacceptable.	Adequate resource needs to be applied to Standards of Care at MOH level to achieve earlier implementation. Without agreed standards it is those in more deprived areas who are most at risk and bear the brunt of a very slow process.	BCAC is pressuring MOH to initiate this work in early 2019. Pressure from Breast Care specialists would be appreciated.
Resourcing - Facilities	Auckland appears to have an issue with: • availability of suitable space in the right location (chemotherapy chairs/day unit space as evidenced in the ABC report[3] • facility maintenance issues • CT imaging.	• ABC patients are being de-prioritised for treatment because of lack of appropriate space • Patients are not able to be treated locally due to maintenance issues with facilities • Poor monitoring of chemotherapy due to limited access to imaging.	Should private facilities be used as an alternative?	BCAC advocate with Ministers and Ministries.

Resourcing - Specialist staff	We are aware that across the country there may be a lack of specialist resource which impacts early and advanced breast cancer patient outcomes including and it seems especially Māori/Pasifika.	Non-referral or lack of referral to medical oncology. Resource to complete ABC biopsies or re-biopsy as disease progresses. Lack of multidisciplinary team meetings for complex cases for advanced breast cancer as there is not enough time/resource e.g. pathology being present with the team. Clinical nurse specialists to help manage symptom response (e.g. endocrine therapy). Lack of staging resource. Trained nursing staff to carry out infusions. More oncology, radiology resource specialists, pathology, medical oncologists (doctors/nurses and nurse specialists, MOSS, pharmacists).	Additional specialist resource is required to provide appropriate levels of service and will be important to support greater equity in provision of services.	BCAC advocate with Ministers and Ministries.

Resourcing - Adequate remuneration to DHBs for treatment and follow-up of cancer patients, both early and advanced. - Inappropriate measures of resource need being applied to cancer patients when their illness is actually chronic.	DHBs are not adequately remunerated for patients with cancer with long term follow up and KPIs have a single or limiting focus.	Response to treatment potentially inadequately monitored given chronicity of the disease in the ABC setting and duration of their care under oncology and the need for multiple lines of therapy, with resultant poorer outcomes than would be expected in a country like New Zealand.	Better remuneration to recognise the reality of advanced breast cancer care as clinics fill with chronic patients and yet measures are for FSAs with no recognition of continuity of care.	BCAC advocate with Ministers and Ministries.
Lack of access to clinical trials and lack of access to new medicines.	Lack of access to clinical trials in advanced breast cancer: (e.g. palbociclib 1st and 2nd line, fulvestrant, erubilin, Kadcyla). We sit at number 19 of 20 compared OECD countries for access to new medicines[4]. Of the 30 OECD countries only, Mexico spends less per capita on medicines[5]. Difficulty recruiting patients for niche clinical trials through difficulty transporting patients across DHBs.	Māori and Pasifika are less likely to crowd fund for access to medicines and (as for all NZ women) cannot gain access via participation in clinical trials, as often these are not run in NZ (sometimes because we lack the standard of care needed for the control arms).	We work together to ensure New Zealand has both better access to clinical trials for ABC patients and together ensure that patients can readily access these trials.	BCAC advocate with Minister, MPs, Health Select Committee, Māori Affairs Select Committee, PHARMAC and raise public awareness of these issues.

Conclusion:

- We can offer specific assistance from our collective voice to bring community and advocacy perspectives about existing service failures, barriers and incompetence to achieve greater equity for Māori and Pasifika communities to improve breast cancer outcomes within Auckland and Counties Manukau DHBs. We appreciate there is institutional resistance that builds from limited specialist/resource/time/appropriate facilities/capacity/capability and eventually has an impact on hospital and associated health service levels.

- Unless adequate resource/remuneration is brought to this issue we are of the view it will take a very long time to bring about change. The information and evidence we have reviewed informs us about the inequities that impact Māori and Pasifika communities. We can offer assistance to connect with these communities, to provide consumer voices in specific health delivery terms (breast cancer treatments within hospitals where affected communities access breast cancer services). We can coordinate several sources of patient contact, advocate voices, direct community engagement and access to research evidence on a range of topical issues, e.g. results of clinical trials, international research re effectiveness of treatments.

Lastly, we reiterate, in the interim, there is an opportunity to assist and advise approaches and service delivery processes with treatment teams and to help evaluate those approaches in order to collaboratively understand what is needed to improve service and care and reduce inequities.

We at BCAC are very willing to work with you to identify innovative approaches and best practice initiatives which may have positive impacts on those affected communities.

Thank you for the opportunity to present our views to you.

References:

[1]The Macpherson Report. 1999. The Stephen Lawrence Inquiry. Report of an inquiry by Sir William MacPherson of Cluny. February 1999. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/277111/4262.pdf

[2]Waikato Research. 2018. Lawrenson, R., et al., Final Report. How to Improve Outcomes for Women with Breast Cancer in New Zealand. Health Research Council Reference: 14-484A, July 2018, Health Research Council of NZ and the University of Waikato.

[3]ABC Report: Breast Cancer Foundation NZ. 2018. “I’m still here” Insights into living – and dying – with Advanced Breast Cancer in New Zealand. September 2018. https://breastcancerfoundation.org.nz/Images/Assets/21894/1/BCFNZ-ABC-Report-2018-Executive-Summary.pdf

[4] Compare 4. Comparison of access and reimbursement environments. A report benchmarking Australia’s access to new medicines. Edition 4. 2018. Medicines Australia. https://medicinesaustralia.com.au/wp-content/uploads/sites/52/2018/10/MA_Compare-final.pdf

[5] PHARMAC. Briefing to the incoming Minister of Health. 8 November 2017. https://www.pharmac.govt.nz/assets/briefing-to-incoming-minister-2017-11.pdf