

## Breast Cancer Foundation NZ's written submission to the Women's Health Strategy

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Breast Cancer Foundation NZ appreciates the opportunity to submit to Aotearoa New Zealand's first Women's Health Strategy. As one of the only OECD countries that doesn't already have a specific strategy to address the unique needs of our diverse female population, our country's health landscape has been missing a critical policy element and a Women's Health Strategy is long overdue. A gender lens applied to our health system's reforms will help to ensure that all New Zealanders can have access to the highest attainable standard of health.

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### 1. About Breast Cancer Foundation NZ (BCFNZ)

- BCFNZ is a not-for-profit charitable trust. We receive no Government funding, and rely entirely on donations from the public and corporate partnerships for our work.
- Our work spans four pillars of activity:
  - education and awareness campaigns to promote the importance of early detection of breast cancer to all women;
  - research, medical grants and training to advance breast cancer detection and treatment;
  - support from our specialist nurses for patients going through treatment and recovery;
  - advocacy to improve access to diagnosis, treatment and care.
- Our programmes are evidence-based and overseen by our Medical Advisory Committee, a group of clinicians who volunteer their time and expertise to give direction on our work.

#### 1.1 Our vision for women's health

Our ultimate vision as an organisation is zero deaths from breast cancer, currently the leading cause of death for women under 65 in Aotearoa New Zealand.<sup>1</sup> We work towards our vision by pushing for new frontiers in early detection, treatment and support.

In the context of how the Women's Health Strategy and the NZ health system should work for breast cancer, our vision includes:

- all women knowing what they can do to reduce their risk of breast cancer, and what steps to take to have breast cancer detected early;
- breast screening available equitably to women aged 45-74 now, with screening practices and technologies to be adapted, in line with emerging evidence, in the future;
- women who are diagnosed with breast cancer having equitable and timely access to best-practice treatment that aligns with international standards of care, optimising the chance of survival and minimising toxicity of treatment;

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<sup>1</sup> Ministry of Health, *Mortality Data 2019*.

- after breast cancer, women having support to regain physical, psychological and emotional wellbeing, management of long-term effects after treatment, and support for prevention of cancer recurrence;
- women with advanced (terminal) breast cancer having access to best treatment and life-extending drugs, with management of symptoms and side effects to enable a good quality of life, giving the ability to continue to work and enjoy time with whānau and friends. Advanced breast cancer would become a chronic condition, to be lived with in the same way that women live with other long-term diseases, such as diabetes or heart disease;
- the public health sector working in partnership with iwi, hauora, fono, NGOs and private providers to achieve this vision effectively for all women.

## 2. Breast cancer and women's wellbeing

### 2.1 Patterns and trends

- Breast cancer has a unique impact on the health and wellbeing of NZ women, with approximately 3,500 women diagnosed with invasive breast cancer every year, and another 450 with DCIS, a pre-cancerous condition treated with the same surgery (and usually radiation therapy) as invasive cancer.
- While men can get breast cancer too, 99.4% of diagnoses are in women.
- It is by far the biggest cancer for women, with an incidence rate four times higher than bowel cancer in Māori and three times higher in non-Māori women. Compared with lung cancer, the incidence of breast cancer is 1.6 times higher in Māori and four times higher in non-Māori women.<sup>2</sup>
- Māori and Pacific women are more likely to develop breast cancer than other ethnicities, with Māori having the highest incidence in the world.<sup>3</sup>
- Breast cancer affects women of all ages: 12% of diagnoses each year occur in women under 45 (including a small number diagnosed in their twenties); more than half are in women aged 45-64, and about a third in women over 65.
- Unlike other cancers, breast cancer is less amenable to prevention strategies. Therefore early detection through screening is key to both the survival and wellbeing of women in Aotearoa NZ.
- Breast cancer survival has improved. The BreastScreen Aotearoa (BSA) screening programme is a major factor; from 1999 to 2011, screening produced a 34% reduction in overall breast cancer mortality in NZ women.<sup>4</sup> New treatments such as Herceptin have also contributed. However, more than 650 women still die of breast cancer each year. It is the leading cause of death for Māori, Pacific and European women under 65 in Aotearoa.

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<sup>2</sup> Ministry of Health, 2019. *New Cancer Registrations 2020*.

<sup>3</sup> Lawrenson, R., et al., 2016. Breast cancer inequities between Māori and non-Māori women in Aotearoa/New Zealand. *European Journal of Cancer Care*, 25(2): 225-230.

<sup>4</sup> Morrell, S., et al., 2015. *Cohort and Case Control Analyses of Breast Cancer Mortality: BreastScreen Aotearoa 1999-2011*. Ministry of Health.

## 2.2 Needs

Breast cancer treatment has a major impact on many aspects of health and life that NZ women might consider essential to their womanhood or femininity. This creates complex physical, emotional and psychosocial challenges.

- Body image – a complex, multi-dimensional concept that affects women at all stages of life – can be significantly impacted by surgery, the primary treatment for most patients. For approximately half of women, surgery involves the removal of at least one breast (mastectomy), which has a negative effect on body image and quality of life.<sup>5 6</sup>
- Breast cancer treatment can cause severe menopausal symptoms, including hot flushes, sexual dysfunction, joint pain, fatigue and cognitive issues at all ages. These can be relatively short-term, in the case of chemotherapy, but are ongoing in the case of the endocrine (hormone) therapies prescribed to most breast cancer patients for five to 10 years after initial treatment. The symptoms of chemical menopause are considered to be more severe than natural menopause.
- Fertility issues are also common with both chemotherapy and endocrine therapy, often requiring urgent decisions around fertility preservation before breast cancer treatment commences. Where fertility is maintained, breast cancer treatment may still cause disruption and delays to a woman’s childbearing hopes and intentions.
- The side effects of breast cancer treatment linger long after treatment ends in a high proportion of patients, resulting in women having poorer quality of life, continued engagement with the healthcare system and a number of unmet needs.

## 3. How the health system performs for breast cancer

### 3.1 Inequities in breast cancer

- Māori and Pacific women have a younger average age of diagnosis, and are more likely to be diagnosed with more aggressive and later stage cancers.<sup>7</sup> But when their cancer is found on a mammogram, their survival is the same as non-Māori or European women.<sup>8</sup>
- BreastScreen Aotearoa (BSA) is working to reduce the gap in screening rates between Māori and non-Māori women, including a patient-centred approach to understanding and addressing the barriers to breast screening for Māori women.<sup>9</sup>
- However, Māori participation in breast screening has worsened over the Covid-19 pandemic, falling from 65% to 57%.<sup>10</sup> Lack of participation can be related to issues in engaging with the

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<sup>5</sup> Spatuzzi, R., et al., 2016. Evaluation of Social Support, Quality of Life, and Body Image in Women with Breast Cancer. *Breast Care*, 11(1):28-32.

<sup>6</sup> Dominici, L, et al., 2021. Association of Local Therapy With Quality of Life in Women With Breast Cancer, *JAMA Surg.* 156(10):e213758

<sup>7</sup> Breast Cancer Foundation NZ, 2022. *30,000 voices: Informing a better future for breast cancer in Aotearoa New Zealand, Te Rēhita Mate Ūtaetae - Breast Cancer Foundation National Register 2003-2020.*

<sup>8</sup> Seneviratne, S., et al., 2015. Impact of mammographic screening on ethnic and socioeconomic inequities in breast cancer stage at diagnosis and survival. *BMC Public Health*, 15(46).

<sup>9</sup> Lawrenson, R., et al., 2016. Breast cancer inequities between Māori and non-Māori women in Aotearoa/New Zealand. *European Journal of Cancer Care*, 25(2): 225-230.

<sup>10</sup> Ministry of Health NZ, 2021. *BreastScreen Aotearoa DHB Coverage Report.*

health system (for example not being registered with a GP), or practicalities such as getting time off work for a mammogram, transportation or childcare, or distance from a screening unit.

- Pacific women experienced the biggest decline in screening participation during Covid-19. Between 2012 and 2019, participation levels for Pacific women were consistently above 70%, but this fell to 59% in September 2021.<sup>10</sup>
- Māori women are more likely to experience delay in the time from diagnosis to treatment, more likely to undergo a mastectomy and less likely to adhere to long-term endocrine therapy (intended to prevent breast cancer recurrence).<sup>11</sup>
- Although breast cancer survival has improved across all ethnicities, Māori and Pacific women still have worse survival than European women. A recent study showed wāhine Māori have a 33% higher chance of dying of breast cancer and Pacific women a 52% higher chance.<sup>12</sup>
- The causes of ethnic disparities in survival are complex, but include inequities in access, timeliness and quality of care. An important contributor of higher breast cancer mortality in Māori and Pacific women is late stage at diagnosis; this could be partly explained by unequal screening coverage.<sup>13</sup>
- Geography also plays a role in breast cancer inequities, with many rural communities having poor access to health services due to their distance from specialist services (potentially limiting or forcing sub-optimal treatment choices) and shortages of GPs. Rural women with breast cancer tend to be older and more likely to be Māori. While there is no difference in all-ethnicity survival for urban and rural New Zealanders, 10-year survival for rural Māori appears lower (72% vs 78% for urban Māori).<sup>14</sup>

### **3.1.2 Priorities for system change to address inequities**

1. All strategies, care and treatment protocols for breast cancer should recognise and acknowledge the principles and obligations underpinned by Te Tiriti o Waitangi (The Treaty of Waitangi). This includes assisting wāhine Māori to access relevant services and support, and where possible incorporating a “by Māori, for Māori” approach to help address ethnic inequities, consulting with iwi and Māori to meet their needs. Health providers should look to restore mauri, enhance mana and recognise and respect the role of whānau.
2. The breast screening eligibility age should be lowered for Māori and Pacific women to 40, in line with their higher incidence of breast cancer at younger ages.
3. Māori and Pacific women reporting a breast lump to a GP should receive priority access to diagnostic centres, reflecting the higher likelihood that their lump is cancer.

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<sup>11</sup> Lawrenson, R., et al., 2016. Breast cancer inequities between Māori and non-Māori women in Aotearoa/New Zealand. *European Journal of Cancer Care*, 25(2): 225-230.

<sup>12</sup> Breast Cancer Foundation NZ, 2022. *30,000 voices: Informing a better future for breast cancer in Aotearoa New Zealand, Te Rēhita Mate Ūtaetae - Breast Cancer Foundation National Register 2003-2020*.

<sup>13</sup> Tin Tin, S., et al., 2018. Ethnic disparities in breast cancer survival in New Zealand: which factors contribute? *BMC Cancer*, 18(1): 58.

<sup>14</sup> Lawrenson, R., et al., 2016. Urban Rural Differences in Breast Cancer in New Zealand. *Int J Environ Res Public Health*, 13(10).

*“I owe my survival to my mammogram. I don’t know how long it would’ve taken to feel a lump; I might have discovered it at a much later stage. Because I caught it on a routine mammogram, it was found early enough to result in a really good outcome for me. I know our stats aren’t as good compared to non-Māori, so it’s important to be self-checking and getting regular mammograms.” – Bidy, a Ngāi Tahu wāhine diagnosed at 49.*

### 3.2 Screening and timely diagnosis

- When breast cancer is found on a mammogram, 10-year survival is 95%, compared to 85% for women who find a lump. Women are three times more likely to die if their cancer is not screen-detected.<sup>15</sup>
- The long-term effect of Covid-19 lockdowns on breast cancer screening and outcomes is yet to be quantified. However, we do know that during Covid-19, BSA participation declined to the lowest it had been in more than 10 years, and that at the time of writing, up to a third of eligible women in central Auckland and Waikato had not had a BSA mammogram in the past two years.<sup>16</sup>
- The 2017 Government coalition committed to extend the free breast screening age to 74. This has not yet been implemented, despite the fact that a NZ woman’s risk of developing breast cancer is higher at 70 than at 50,<sup>17</sup> the World Health Organisation has awarded the evidence for 70-74 screening the same strength rating as the evidence for screening women aged 50-69,<sup>18</sup> and the Ministry of Health’s Cancer Action Plan commits to “Progressively increase the age of eligibility for breast screening from 70 to 74 years”.<sup>19</sup>
- Approximately 350 women aged 70-74 are diagnosed with breast cancer each year in Aotearoa NZ. BSA has acknowledged that extending screening would reduce breast cancer deaths for women aged 70–74 years; deaths for women aged ≥75 might also reduce.<sup>20</sup>
- Extending screening to 74 would bring Aotearoa NZ into line with Australia, Canada, France, Sweden, UK and many other countries.
- A woman aged 70 today will live to 90 at average death rates; a Māori woman aged 70 today will live to 84.<sup>21</sup> Women want to stay healthy, active and contributing into older age.
- BCFNZ has been copied in to more than 300 submissions made by individuals to the Women’s Health Strategy, with the vast majority noting the importance of screening for the early detection and survival of breast cancer. More than half (63%) requested the strategy address widening the current eligibility age of 45-69, to include both younger and older women.
- For women who find a breast lump or other symptom, the diagnosis pathway is through GP referral to a specialist breast clinic. Pressures on hospital breast clinics mean that symptomatic diagnosis can take many months, depending on the urgency with which the GP referred the

<sup>15</sup> Breast Cancer Foundation NZ, 2022. *30,000 voices: Informing a better future for breast cancer in Aotearoa New Zealand, Te Rēhita Mate Ūtaetae - Breast Cancer Foundation National Register 2003-2020*

<sup>16</sup> BreastScreen Aotearoa DHB Coverage Report <https://tewhatauora.shinyapps.io/nsu-bsa-coverage/>

<sup>17</sup> Ministry of Health email, January 24 2018

<sup>18</sup> Lauby-Secretan, B., et al., 2015. Breast-cancer screening--viewpoint of the IARC Working Group. *N Engl J Med.* 372(24):2353-8.

<sup>19</sup> Ministry of Health, 2019. *New Zealand Cancer Action Plan 2019–2029 – Te Mahere mō te Mate Pukupuku o Aotearoa 2019–2029.*

<sup>20</sup> Ministry of Health, 2019. *Impact Analysis: Extending BreastScreen Aotearoa to include women aged 70–74 years.*

<sup>21</sup> Statistics NZ “How long will I live?” calculator [www.statistics.govt.nz](http://www.statistics.govt.nz)

patient. However, the optimal timeframe from referral to diagnosis of breast cancer is within 28 days.<sup>22</sup>

- The existing Faster Cancer Treatment target measures the 20% of patients referred with urgent priority, yet many breast cancers are found in women referred with lower priority (one of the country's largest hospitals told us 30% of diagnoses are from non-urgent referrals).

### 3.2.1 Priorities for system change in screening and diagnosis

1. The breast screening eligibility age should be extended immediately from 69 to 74 for all women, in line with scientific evidence and with Government commitment.
2. Resourcing for breast screening should be prioritised to enable BSA to meet its 70% participation target in all regions, prioritising at-risk groups (Māori and Pacific women).
3. A new target and resources are needed to ensure symptomatic women receive timely diagnosis.

*"I had assumed that your risk diminished in your 70s because that's when the mammogram programme stopped. Cutting women off from free mammograms once they turn 70 makes you feel like you're useless and no longer contributing anymore at all." – Jane, diagnosed at 73.*

### 3.3 Best practice treatment

- The time between a breast cancer diagnosis and treatment is stressful, even traumatic, for women and whānau. Patients view their condition as urgent; timely treatment can reduce uncertainty and anxiety.
- The median time to breast cancer surgery in Aotearoa NZ has increased over time, with the percentage of surgeries performed within 31 days of diagnosis substantially decreasing (from 55.7% to 36.8%). This compares with Australia, where in 2019-2020, 90% of patients were admitted for breast cancer surgery within 29 days of diagnosis (and 50% were admitted within 14 days).<sup>23</sup>
- A recent study concluded that an eight-week delay in breast cancer surgery increased the relative risk of death by 17%, and a 12-week delay by 26%.<sup>24</sup>
- Only 19% of women in Aotearoa NZ have breast reconstruction after mastectomy. Māori and Pacific women are less likely to have reconstruction than other women. Reconstruction rates vary around the country (e.g. only 11% in Christchurch and 13% in Wellington) – this may be related to access to oncoplastic trained breast surgeons or plastic surgery services.<sup>25</sup>
- Research shows that delaying radiation therapy (RT) for more than eight weeks after breast cancer surgery or six weeks after chemotherapy increases the risk of cancer coming back in the breast. Other research shows that the risk escalates 12 weeks after surgery.<sup>26</sup>

<sup>22</sup> Miles A, Asbridge JE. 2019. The NHS Long Term Plan (2019)–is it person-centered? *European Journal for Person Centered Healthcare*, 7(1):1-11.

<sup>23</sup> Australian Institute of Health and Welfare, 2020. *Elective surgery access*.

<sup>24</sup> Hanna, T.P., et al., 2020. Mortality due to cancer treatment delay: systematic review and meta-analysis. *BMJ*, 371:4087.

<sup>25</sup> Breast Cancer Foundation NZ, 2022. *30,000 voices: Informing a better future for breast cancer in Aotearoa New Zealand, Te Rēhita Mate Ūtaetae - Breast Cancer Foundation National Register 2003-2020*.

<sup>26</sup> Huang, J. et al., 2003. Does delay in starting treatment affect the outcomes of radiotherapy? A systematic review. *J Clin Oncol*. 21(3):555-63.

- Breast cancer is one of the biggest consumers of RT, and NZ’s radiation therapy service is under immense pressure. Even with new, shorter treatment protocols in breast cancer, the RT capacity required is far in excess of what is available. As we improve our practice, such as adopting more complex RT techniques and increasing the proportion of breast conserving surgery, more capacity will be required.
- Priority funding of new breast cancer drugs is key to reducing treatment toxicity, extending life for women with advanced breast cancer and removing access inequities.
- There are currently 14 life-saving breast cancer drugs that are widely available in other countries but not funded here. New Zealand women’s lives are impacted by this failure and by the slow Pharmac approval process for new drugs (for example, it took six years for Pharmac to consider the application for funding of Keytruda for lung cancer, approved in March 2023).
- Patients with advanced breast cancer often pay privately for new drugs. Māori and Pacific women are much more likely to develop advanced breast cancer, so when drugs that are international standard of care are only available to those who can afford to pay for them, this is inequitable for those higher-risk groups.
- New cancer medicines are often oral therapies. These are more accessible to rural and deprived populations as they reduce the need to travel for infusions. These wider equity considerations should be given weighting in Pharmac funding decisions.

### **3.3.1 Priorities for system change in treatment**

1. The system should be resourced sufficiently to allow women to commence breast cancer treatment within best practice timeframes.
2. The system should be resourced sufficiently to ensure geographically equitable access to radiation treatment, reconstruction and other treatment around the country.
3. Pharmac should commit to funding an expanded range of advanced cancer drugs to directly address inequities for Māori, Pacific and rural communities. Drugs that have been “recommended for funding” should be funded within a consistent, fairly short timeframe.

*“I was diagnosed with DCIS in the first week of February and given a surgery date of 19 March. I was counting down every single day for my mastectomy, desperate to get this thing out of me. Then Covid happened and five days before my surgery, I was told all operations were cancelled. It ended up being delayed by a month and it was an agonising wait. Afterwards, I learnt they’d found invasive cancer. If I’d been delayed any longer, who knows what the outcome would have been.” – Tarirai, diagnosed at 40.*

### **3.4 Life after treatment**

- As more New Zealanders survive breast cancer thanks to advances in screening and treatment, there is a greater chance they will experience long-term or late side effects of breast cancer treatment. Yet, this is currently an under-researched field and there needs to be more recognition from the health system of how to address this growing issue.
- BCFNZ often hears from patients that they feel adrift after being discharged from their surgical or oncological team and that finishing treatment is not always the end of their breast cancer

journey. Those that do experience ongoing health problems can find it difficult to access specialist care.

- A survey carried out by BCFNZ in February 2023 found patients experienced wide-ranging effects that last or develop long after breast cancer surgery, chemotherapy and radiation therapy have finished. Commonly reported effects included fatigue, concentration and memory problems, osteoporosis and lymphoedema. Respondents described how these effects impacted many areas of their daily lives, from difficulties with getting dressed and doing housework, as well their work, family and ability to socialise.
- These survey findings reflect international evidence on long-term and late effects. For example, between 15% and 50% of patients who have chemotherapy have cognitive issues for a few years afterwards,<sup>27</sup> and 20% of breast cancer patients develop lymphoedema.<sup>28</sup>
- Barriers for patients to receive the right support after breast cancer treatment include an historical focus by the medical community on curing breast cancer, with little attention paid to survivorship; survivorship plans not consistently being offered around the country; and GPs – who are most likely to provide care to patients post-treatment – lacking in specialist knowledge.

### **3.4.1 Priorities for change in long-term support**

1. There should be better recognition by clinicians and health agencies about the impact of long-term and late side effects of breast cancer treatment, so that women feel better supported in the years after completing treatment.

*“There’s an expectation that beating cancer means you’re happy all the time. Yes, I have survived, but it’s taken a lot – there have been things I’ve lost and things I’m still dealing with and people don’t see that. They don’t realise that quality of life post-treatment is also important.” – Jude, diagnosed at 43.*

### **3.5 Advanced breast cancer**

- Around 400 New Zealanders are diagnosed with advanced breast cancer (ABC, also called secondary, Stage 4, or metastatic breast cancer) every year. This is breast cancer that has spread to another part of the body and it is incurable.
- A major BCFNZ report into ABC in Aotearoa NZ found Kiwis are dying of ABC twice as fast as women in comparable countries. Average survival in NZ is just 16 months, compared to two or three years in countries like Australia, Germany and France. Māori five-year survival is just 5% (compared with 15% for non-Māori).<sup>29</sup>
- One significant advancement since the publication of the 2018 report was the ratification of the New Zealand Consensus Guidelines for Advanced Breast Cancer by a group of breast cancer specialists in April 2021. The clinical guidelines provide a framework for everyone involved in the

<sup>27</sup> Vardy, J. and Tannock, I., 2007. Cognitive function after chemotherapy in adults with solid tumours. *Crit Rev Oncol Hematol*, 63(3): 183-202.

<sup>28</sup> Gillespie, T., 2018. Breast cancer-related lymphedema: risk factors, precautionary measures, and treatments, *Gland Surg*, 7(4): 379-403.

<sup>29</sup> Breast Cancer Foundation NZ, 2018. *“I’m still here” Insights into living – and dying – with Advanced Breast Cancer in New Zealand.*



treatment of ABC, including clinicians, patients and government health organisations, to ensure consistency of care to the highest standards.

- With advances in treatment, ABC is increasingly being viewed as a chronic condition that women can live with and manage for many years.

### **3.5.1 Priorities for system change in advanced breast cancer**

1. The system should adopt a chronic disease approach to treatment and survival for women with ABC in Aotearoa NZ, involving a multi-disciplinary approach to care, improved access to guideline-based drug treatments, removal of inequities, and a proactive approach to quality of life issues such as symptom management.

*“It’s a really scary time and not knowing if you are getting gold standard treatment or not is terrifying, it makes the journey all the worse.” - Annemarie, speaking about the importance of the NZ ABC Guidelines, before passing away from ABC in December 2022.*

## **4. Summary of recommendations**

### ***Achieving equity:***

1. Breast cancer care to be underpinned by Te Tiriti o Waitangi.
2. Screening age lowered to 40 for Māori and Pacific women.
3. Priority access to diagnostic centres for Māori and Pacific women.

### ***Improving timely access to screening and diagnosis:***

4. Screening age increased to 74.
5. Screening participation to meet 70% target.
6. Timely diagnosis for symptomatic women.

### ***Improving access to treatment:***

7. Treatment provided within best practice timeframes.
8. Equitable access to treatment.
9. Access to advanced cancer drugs sped up and widened.

### ***Improving long-term support after treatment:***

10. Support for women to get back to full physical and emotional health after breast cancer, stay on endocrine treatment to prevent recurrence, and prevent and/or manage long-term effects.

### ***Improving advanced breast cancer care:***

11. A chronic disease approach for women with advanced breast cancer.

## 5. In conclusion

BCFNZ shares Manatū Hauora – Ministry of Health’s vision of pae ora and fully supports the development Aotearoa’s first Women’s Health Strategy. We strongly believe that as the leading cause of death for New Zealand women under 65, breast cancer must be given due consideration in this strategy, if it is to meaningfully and tangibly improve outcomes for our wāhine.

We would welcome the opportunity to discuss our submission in further detail with you.

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