



Submission to Pae Ora Legislation Committee on Pae Ora (Healthy Futures) Bill

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Submitted by: Brain Tumour Support NZ (Charities Services No. CC56933)

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Declaration of interest

Brain Tumour Support NZ (BTSNZ) works with clinicians, researchers, allied health professionals, academia, government and industry to achieve better outcomes for New Zealand brain tumour patients and their families. Brain tumours are a less common cancer, representing around 1.4% of all cancers diagnosed in New Zealand. Accordingly brain tumour patients face many similar challenges as people with rare disorders including: lack of awareness; delayed or mis-diagnoses; lack of treatments or access to treatments; and a lack of clinical trials.

In this submission, BTSNZ wishes to highlight the inequities in the health system faced by people with brain tumours and other rare disorders. We also wish to address the deficiencies in the Pharmac model and our concerns about New Zealanders' access to modern medicines.

Brain Cancer in New Zealand

- Each year, around 340 people will be diagnosed with brain cancer in New Zealand, and more than 250 will die from the disease. Brain tumours kill more New Zealand children than any other disease and more young people under 40 than any other cancer. Survival rates for brain cancer have barely improved in more than 30 years.
- Glioblastoma multiforme (GBM), the most common and aggressive form of brain cancer, has a median overall survival of 15 months and a 5-year survival rate of around 6 percent (with standard treatments). Tumour recurrence is almost universal, at which point there are limited treatment options. The last medicine to be funded by PHARMAC to treat newly diagnosed GBM was the alkylating agent temozolomide in 2006. More and better treatments are desperately needed.
- Brain cancer is a high impact cancer which has a sudden and devastating effect on the patient and their loved ones. The symptom burden is high, and can include: severe headaches; nausea and vomiting; decline in cognitive function; physical weakness, fatigue and loss of mobility; changes in behaviour and personality; problems with speech, vision and hearing; and seizures.
- Adding to the clinical symptoms are major psychosocial effects. On top of the stress of the diagnosis, there is the immediate loss of independence (eg. losing the ability to drive), changes in the wider family dynamic (changing roles and relationships), changes in employment status, financial hardship, increased stress, anxiety and depression.

- Caregiver burden is a significant and often under-recognised factor for caregivers of brain tumour patients. Compared with other cancer groups (eg. lung, breast, and prostate), caregivers of patients with brain tumours, particularly GBM, report more severe caregiver burden and poorer health-related quality of life (HRQoL)¹.

Pae Ora (Healthy Futures) Bill – Recommended Amendments

Explanatory Note - General Policy Statement

BTSNZ recommends the following amendment:

Successive reviews of, and submissions addressing, the publicly-funded health system in New Zealand, most recently the independent Health and Disability System Review that was released in June 2020, have found consistently poor outcomes for some groups, in particular Māori, Pacific peoples, people living with rare disorders, and people with disabilities, and significant unwarranted variation in service availability, access, and quality between population groups and areas of New Zealand.

Reason for this amendment: Successive reviews of the publicly-funded health system in New Zealand, including the 2020 Health and Disability System Review, the subsequent 2021 White Paper and indeed the Pae Ora (Healthy Futures) Bill itself have repeatedly overlooked the consistently poor outcomes experienced by those diagnosed and living with rare disorders.

Part 1

Section 4: Interpretation

BTSNZ recommends the following amendment:

The Interpretation section of the Bill be amended to include:

“rare disorder means a disease or disorder which affects less than 1 in 2000 people in the New Zealand population”

“population groups means Māori, Pacific, people with a disability, and people with a rare disorder”

Reason for this amendment: BTSNZ believes that the legislation should make explicit reference to rare disorders, which should be defined as per international norms best exemplified by European Union Orphan Drug Regulation 141/2000, which defines a disease or disorder as rare when it affects less than 1 in 2000. This is a population or community of scale with over 300,000 New Zealanders impacted and their whānau.

Furthermore the Bill makes frequent references to the “term population groups” without providing a corresponding interpretation of what this means.

Section 7 (4): Health system principles

BTSNZ recommends the following amendment:

Delete section 7 (4) in its entirety.

¹ Boele FW, Heimans JJ, Aaronson NK, et al. Health-related quality of life of significant others of patients with malignant CNS versus non-CNS tumors: a comparative study. J Neurooncol. 2013;115(1):87–94.

Reason for this amendment: BTSNZ maintains that Pharmac should be bound by clauses 7(1) (b) and (c) in the same way as all other components of the health system. The interim report produced by the Pharmac review panel highlighted several deficiencies in the Pharmac model, including a failure to address inequities among certain sectors of the population. Adequate consultation with patients and patient groups and an over-emphasis on cost savings at the expense of patient outcomes were other factors highlighted in the interim report. The new legislation should ensure that all health entities including Pharmac engage with healthcare consumers sufficiently early in assessment and planning processes to ensure a genuine, non-tokenistic consultation occurs.

Part 2

Section 10 (1) and Section 29 (1)

BTSNZ recommends the following amendments:

Sections 10 (1)(a) “Key roles and health documents” and 29 (1)(b) “Overview of important health documents” be amended by adding:

(v) **Rare Disorders Health Strategy**

The Bill be amended by including an additional Section 41 as follows:

Rare Disorders Health Strategy

- (1) The Minister must prepare and determine a Rare Disorders Health Strategy.
- (2) The purpose of the Rare Disorders Health Strategy is to provide a framework to guide the health system in improving health outcomes for people with rare disorders.
- (3) The Rare Disorders Health Strategy must—
 - (a) contain an assessment of the current state of health outcomes for people with rare disorders and the performance of the health system in relation to people with rare disorders; and
 - (b) contain an assessment of the medium and long-term trends that will affect the health of people with rare disorders and health system performance; and
 - (c) set out priorities for services and health system improvements relating to the health of people with rare disorders, including workforce development.
- (4) **Subsection (3)** does not limit what may be included in the Rare Disorders Health Strategy.

Reason for this amendment: BTSNZ maintains that people with rare disorders, including brain tumours, have long been neglected by the health system. We believe that people with rare disorders have unique issues and challenges which should be recognised through a specific health strategy.

Section 14

BTSNZ recommends the following amendment:

Section 14 (3) be amended to:

“in performing any of its functions in relation to the supply of pharmaceuticals, Health New Zealand may in exceptional circumstances and with the consent of the Minister of Health, act inconsistently with the pharmaceutical schedule where this is warranted by societal costs and benefits”

Reason for this amendment: BTSNZ maintains that there has to be a provision to override Pharmac in exceptional circumstances where a good efficacy and funding case can be made. Health New Zealand should not have to automatically have its mandate to achieve best health outcomes for all held hostage by Pharmac's heavily prescribed decision making processes.

We believe a Medicines Strategy is needed to ensure that Pharmac's objectives, functions, Statement of Intent and operational practice are appropriately aligned with and supportive of, the New Zealand Health Plan, the health strategy documents and the Code of Consumer Participation.

Part 3

Section 61

BTSNZ recommends the following amendment:

Section 61(a) be amended to the objectives of Pharmac are to "secure for eligible people in need of pharmaceuticals, the best health outcomes that are reasonably achievable from pharmaceutical treatment, **either from within the amount of funding provided, or in exceptional circumstances and with the consent of the Minister of Health, as otherwise warranted by societal costs and benefits.**"

Section 62

BTSNZ recommends the following amendment:

Section 62 be amended to include a new subsection 62 (3): "**Pharmac shall be allocated sufficient funds to enable it to carry out its objectives in a way that is consistent with comparable international norms**"

Reason for this amendment: BTSNZ maintains that there should be an exceptional circumstances provision which would allow Pharmac to spend beyond its funding envelope where the costs of investing in a treatment can be justified by the overall benefits to society. BTSNZ further believes that to minimise the need for the proposed "exceptional circumstances" provision there should be a requirement for Pharmac to be sufficiently funded so that New Zealanders receive pharmaceutical treatments in a way that is consistent with what is available to citizens of comparable advanced economies.

Part 4

Section 97

BTSNZ recommends the following amendment:

Section 97(1)(a) be deleted and replaced by

National service arrangements

The Governor-General may, by Order in Council, on the recommendation of the Minister, make regulations...

(a) **specifying national service arrangements**—

(i) through which Health New Zealand and the Māori Health Authority must provide and arrange services; and

(ii) which must be maintained by the Health New Zealand and the Māori Health Authority

Reason for this amendment: BTSNZ notes that the Health and Disability Review report contemplated six to eight DHBs, the subsequent health reforms White Paper proposed four Health New Zealand subregions, and the current Bill leaves the actual number to be determined by the Minister. People with brain tumours and other rare disorders deserve to receive evidence-based services which are consistently available, delivered with consistently high quality in accordance with internationally agreed standards of care for their particular condition, as part of a nationally managed service stream. This is the opposite of the current post-code lottery arrangements which would risk being perpetuated under any future regional arrangements. We believe that the same arguments could be made for other conditions (mental health services, for example), and that rather than have a patchwork quilt where some services are provided regionally and some nationally, it makes best sense for them all to be provided along national service lines. People with brain tumours could come under the umbrella of a dedicated national rare disorders and precision medicine service, or be a discreet sub-service of a broader national service.

Brain Tumour Support NZ appreciates the opportunity to submit our views on the Pae Ora (Healthy Futures) bill and we hope you will consider the points and recommendations made in this submission.

A handwritten signature in black ink, appearing to read "Chris Tse".

Chris Tse
Chair, Brain Tumour Support NZ