

Prof Sanchia Aranda AM
Lead Reviewer
Efficient Funding of Chemotherapy (EFC) Review
EFCReview@health.gov.au

17 July 2021

Dear Professor Aranda

Re: consumer comments on the consultation survey for the EFC review on behalf of people living with blood cancer in Australia

Thank you for the opportunity to provide comments on the EFC review. As the only national organisation that represents all Australians living with blood cancer, we are anxious to ensure the specific needs of people living with blood cancer are represented.

About us

The Leukaemia Foundation is attacking every blood cancer, from every direction, in every way we can. We make sure every Australian with blood cancer gets access to the trusted information, best-practice treatment, and essential care they need.

Thousands of Australian families navigate a blood cancer diagnosis because they have access to trusted information, best practice treatment and essential supportive care through the Leukaemia Foundation.

Through our accommodation and supportive care services, over the last five years more than 4,500 rural and regional families were kept together during treatment and more than 5,500 families received a lifeline through financial support. Our transport services over this period avoided household expenditure of \$6.4 million.

In that same period, we invested \$13.87 million into blood cancer research in Australia. In turn, this investment leveraged an additional \$8.2 million from international NGO and private sector industry investments into Australian blood cancer research.

Support provided by the Leukaemia Foundation reaches the most disadvantaged groups impacted by blood cancer. More than one in three people we support live in Australia's most socio-economically disadvantaged areas and in the absence of our services, 73 per cent would not otherwise have access psychosocial services.

When combined, the Leukaemia Foundation's support services and research investments generate an additional \$853 million for Australia's GDP, resulting from health gains and economic effects. This suggests a return on investment of \$3.35 for every \$1 donated to the Leukaemia Foundation from its support and research services.¹

¹ *The Health, Social and Economic Impacts of the Leukaemia Foundation*, Insight Economics, 2021

Responding to the EFC review

The Leukaemia Foundation would like to respond to the following questions in the consultation survey:

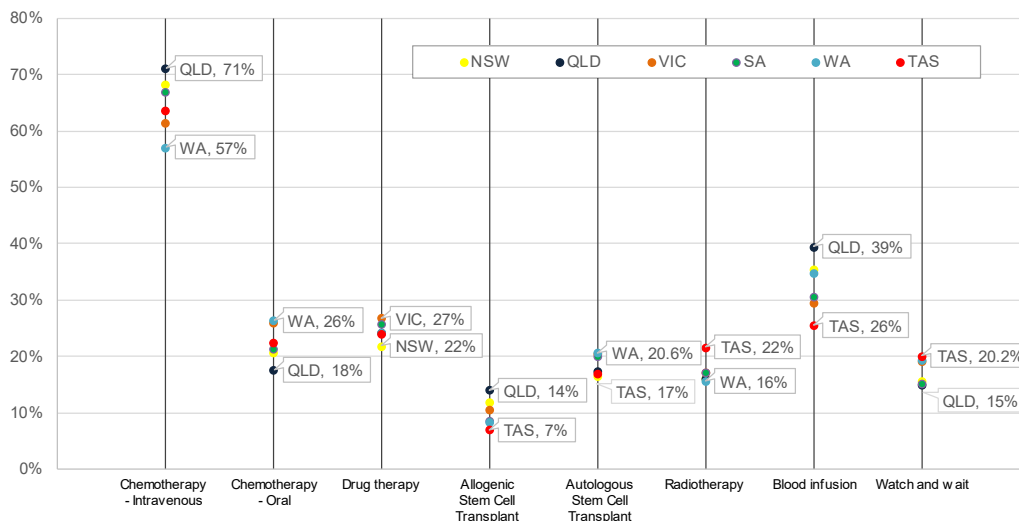
- Does access to chemotherapy services vary in rural and remote areas compared to urban areas? What, if anything, could be changed about current access arrangements? Please provide a case example if possible.
- Are there differences in the costs or processes for receiving chemotherapy services in rural and remote areas? How do access arrangements vary between public and private sectors, States and Territories and what is the effect on accessibility of services? Please provide any details you have to support your position.
- Describe the challenges you have faced with current access arrangements to chemotherapy for Rural and Remote areas, Aboriginal and Torres Strait Islander People, and older Australians. How could these be improved?

The Leukaemia Foundation understands there can be considerable differences in processes for people receiving chemotherapy outside of metropolitan areas, which can also translate into differences in costs. This can be compounded by the state/territory a patient lives in, and whether they are treated in a public or a private hospital setting.

Relevant to both the scope of this Review and to access issues more broadly, the Leukaemia Foundation’s survey of 3,200 blood cancer patients and their families/carers undertaken for the 2019 *State of the Nation: Blood Cancer in Australia* report found considerable variation in service delivery depending on where the patient lived.

For example, people living in Queensland reported receiving intravenous chemotherapy more frequently compared to other jurisdictions, including NSW (68 per cent), Victoria (61 per cent), and Western Australia (57 per cent). Conversely, people living in WA and Victoria reported receiving oral chemotherapy more frequently.

Figure 1: Variation in service delivery by state as reported by people living with blood cancer



Source: Survey of People Living with Blood Cancer from *State of the Nation: Blood Cancer in Australia* report (2019).

There are several potential causes for this variation: clinician expertise and preferences, lack of clinical guidelines for some sub-types, and more relevantly to this Review, variable reimbursement for different types of therapies at the hospital level.

While costs and access arrangements for non-EFC listed cancer treatments (e.g. oral chemotherapy medicines) are considered out of scope for this review, it is important to consider the context of and the role of the EFC Program in determining how chemotherapy services are delivered, which may or may not be to the total benefit of the patient.

Several patients, to whom the Leukaemia Foundation provides support, have not been able to access their intravenous chemotherapy treatments at their closest treating centre, thereby necessitating long travel despite other services being equipped and appropriate to provide care. As an example, one person is currently undergoing a protocol with azacitadine at a treating centre 143 kms away from where they live, despite having two well-resourced oncology centres much closer to their home. This person's situation is not isolated.

Another patient, based in NSW who previously received their combination therapy funded by their private insurer at a private hospital in QLD, has moved to a regional town in NSW with no private cancer care facility. According to the patient, the town's public cancer care centre does not admit any private patients, and its funding will only cover one drug at a time, not in combination. The closest private facility is 281 km away from where the patient lives.

Costs of admitting patients to administer intravenous chemotherapy may be a limiting factor in access decisions, and separately, funding complexities may influence the preference of intravenous chemotherapy (funded via EFC) over oral chemotherapy (not funded via EFC) even where the latter is available and preferred by patients.

Consistency of care across the country is a central theme of the 2020 National Strategic Action Plan for Blood Cancer and is supported by the results of the patient survey undertaken for State of the Nation. In terms of blood cancer mortality, modelling identified that inconsistent treatment is responsible for a 13 per cent variation in survival across the country – an 8 per cent difference between states, and a 5 per cent difference between metro and regional/rural areas. Action 2.1 of the National Action Plan, Develop Optimal Care Pathways and clinical guidelines for all major blood cancer subtypes, under the theme Develop national standards for quality and safety, aims to address this disparity. In 2020, the Federal Government provided funding to the Blood Cancer Taskforce through the Leukaemia Foundation to prepare one component of the framework needed to establish national quality standards in treatment and care, with a project, currently underway, to produce Optimal Care Pathways for six major blood cancer subtypes.

While access to chemotherapy, and the issues within the scope of this Review, are just one piece of the access and best practice puzzle, it is an illuminating example of the range of issues affected by unwarranted clinical variation which is not best practice care. We know patients are having to travel hundreds of kilometres to access chemotherapy where alternative options may be more convenient, affordable and provide the equivalent or better clinical and/or quality of life outcomes. We also know chemotherapy is sometimes unnecessarily delivered

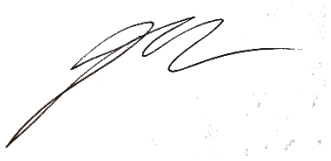
intravenously rather than orally because that is what is funded rather than what is in the interest of the patient.

Noting that the above context is sourced from consumer feedback that formed the basis of the *State of the Nation: Blood Cancer in Australia* and reinforced by ad-hoc feedback from people living with blood cancer to whom the Leukaemia Foundation provides support, we would be interested in participating in future feedback and consultation processes of the Review. This would include participating in roundtables, and directly seeking views from the haematology prescribing community and their patients.

We would also be pleased to forward to our consumers any standardised questions provided by the Review team to assist in refining the scope of the Review and further articulating and quantifying the issues. We would be particularly pleased in assisting in seeking views and experiences of people living in rural and remote areas, and those of First Nations and culturally and linguistically diverse communities – populations we know to be underserved – and haematologists who serve these communities.

Thank you for the opportunity to participate in the initial consultation process of this Review. If you require any further information, please contact Emily Forrest, Head of Policy & Advocacy on eforrest@leukaemia.org.au.

Sincerely,

A handwritten signature in black ink, appearing to read 'Tim Murphy', with a light grey circular stamp or watermark behind it.

Tim Murphy
General Manager
Blood Cancer Partnerships