

Recommendations

Recommendation 1

2.160 The committee recommends that the Chief Executive Officer of the National Health and Medical Research Council considers identifying low survival rate cancers as a National Health Priority Area in the upcoming 2018-19 Corporate Plan.

Recommendation 2

2.164 The committee recommends that the National Health and Medical Research Council introduces the option for extensions to the duration of funding to recipients of research grants, provided that these recipients satisfy certain performance criteria.

Recommendation 3

3.85 The committee recommends that the Australian government improves AustralianClinicalTrials.gov.au so it is more accessible and user-friendly.

Recommendation 4

3.91 The committee recommends that state and territory governments consider:

- allowing low survival rate cancer patients participating in clinical trials to access patient travel subsidy schemes; and
- agreeing on consistent subsidy rates based on the distance and method of travel, and the average cost of accommodation in the city in which the patient is participating in the trial.

Recommendation 5

3.93 The committee recommends that Australian governments improve access to international clinical trials for people with low survival rate cancers, including by:

- exploring ways to reduce the financial barriers to accessing international trials to the extent possible; and
- further developing the existing capacity for international collaboration on trials.

Recommendation 6

3.129 The committee recommends that Australian governments, as a priority, further streamline ethics and governance approval processes for clinical trials, particularly where those processes differ between states and territories, and public and private research institutions.

Recommendation 7

3.132 The committee recommends that the National Health and Medical Research Council develops a standard template and associated guidelines, including timeframes, for ethics and other governance approvals for consideration and possible adoption by each state and territory.

Recommendation 8

4.33 The committee recommends that, through the Council of Australian Governments Health Council, the Australian government leads a process to ensure that arrangements for transitioning children and young people from paediatric to adult oncology services occurs in a consistent and co-ordinated way that preserves continuity and quality of care in the best interests of each individual patient.

Recommendation 9

5.20 The committee recommends that the Australian government undertakes communication activities targeted at the public with the objective of reducing the amount of time taken to detect and diagnose low survival rate cancers.

Recommendation 10

5.25 The committee recommends that the Australian government works in collaboration with the Royal Australian College of General Practitioners and the Australian Medical Association to improve awareness of low survival rate cancers amongst general practitioners, including through continuing professional development.

Recommendation 11

5.59 The committee recommends that the Australian government, in collaboration with state and territory governments:

- considers expanding the Australian Cancer Database to capture all cancers, including benign tumours of the brain and other parts of the central nervous system;
- in so doing, consults with medical researchers to identify what clinical and lifestyle data might be included in order to benefit oncology research; and
- addresses current barriers to data collection and considers ways in which data collection can be improved across Australia, in both public and private health settings.

Recommendation 12

5.62 The committee recommends that the Australian government gives serious consideration to implementing a national network medical and population biobank that includes tumour samples and relevant clinical and lifestyle data associated with each tumour sample.

Recommendation 13

5.98 The committee recommends that the Australian government ensures ongoing funding for genomic research into low survival rate cancers.

Recommendation 14

5.99 The committee recommends that the Australian government implements any recommendation from the Medical Services Advisory Committee to list genetic tests for low survival rate cancer patients on the Medicare Benefits Schedule so that these tests are routinely available to these patients and reimbursed.

Recommendation 15

5.102 The committee recommends that the Therapeutic Goods Administration, if necessary following the medicines and medical devices review, and the Pharmaceutical Benefits Advisory Committee:

- (re-)examine their assessment processes and the appropriateness of those processes for innovative treatments for low survival rate (LSR) cancers, such as immunotherapies; and
- pending that examination, consider adopting more flexible and innovative approaches to approving innovative treatments for LSR cancers and assessing them for listing on the Pharmaceutical Benefits Scheme.

Recommendation 16

5.126 The committee recommends that the Australian government ensures funding is available to researchers investigating whether existing drugs may be suitable for treating low survival rate cancers.

Recommendation 17

5.128 The committee recommends that the Australian government works with industry to consider a mechanism to repurpose drugs.

Recommendation 18

5.131 The committee recommends that the Australian government considers a mechanism to permit access to and properly supervise use of off-label drugs for low survival rate cancer patients without further treatment options, on compassionate grounds.

Recommendation 19

5.133 The committee recommends that the Therapeutic Goods Administration and Pharmaceutical Benefits Advisory Committee examine the appropriateness of their approval and assessment processes for existing drugs repurposed for use in low survival rate cancers.

Recommendation 20

5.136 The committee recommends that the Australian government considers whether the Medical Services Advisory Committee and Pharmaceutical Benefits Advisory Committee processes can be streamlined where a diagnostic test and treatment for a low survival rate cancer are co-dependent.

Recommendation 21

5.176 The committee recommends that the Australian government, in conjunction with its state and territory counterparts, works to improve access to specialist cancer care co-ordinators or nurses for low survival rate cancer patients in every state and territory.

Recommendation 22

5.179 The committee recommends that the Australian government asks the Medical Services Advisory Committee to review the criteria for reimbursement of ongoing diagnostic testing for low survival rate cancer patients.

Recommendation 23

5.181 The committee recommends that the Australian government further simplifies and streamlines the application process for low survival rate cancer patients and their carers when seeking to access the Disability Support Pension, or carer allowance or payment.

Recommendation 24

5.223 The committee recommends that the federal, state and territory governments develop and implement a comprehensive Australia-wide strategy to increase 5-year survival rates for low survival rate cancers to above 50 per cent by 2027:

- taking into account the recommendations in this report;
- consulting with researchers, clinicians, patients and patient groups;
- considering the roles of research, early diagnosis and access to medicines; and
- assessing the applicability of international approaches, such as the *Recalcitrant Cancer Research Act of 2012 (US)*, to the Australian context.

Recommendation 25

5.225 The committee recommends that annual progress reports on the development and implementation of an Australian strategy to improve survival rates for low survival rate cancers are provided to the Council of Australian Governments Health Council and made publicly available.

