

# Chapter 1

## Introduction

### Referral and conduct of the inquiry

1.1 On 29 November 2016, the Senate established the Select Committee into Funding for Research into Cancers with Low Survival Rates (the committee) to inquire and report by 28 November 2017 on:<sup>1</sup>

a. the current National Health and Medical Research Council [(NHMRC)] funding model, which favours funding for types of cancer that attract more non-government funding, and the need to ensure the funding model enables the provision of funding research into brain cancers and other low survival rate cancers;

b. the obstacles to running clinical trials for brain cancers and other cancers with relatively lower rates of incidence, with regard to:

i. funding models that could better support much-needed clinical trials, and

ii. funding support for campaigns designed to raise awareness of the need for further research, including clinical trials;

c. the low survival rate for brain cancers, lack of significant improvement in survival rates, and strategies that could be implemented to improve survival rates and;

d. other relevant matters.<sup>2</sup>

1.2 The committee received and published 326 submissions, listed at Appendix 1.

1.3 The committee took evidence from 117 witnesses over seven days of public hearings in:

- Sydney on 18 and 19 May 2017;
- Brisbane on 6 June 2017;
- Melbourne on 7 June 2017;
- Canberra on 8 June 2017;
- Melbourne on 4 August 2017; and
- Canberra on 29 August 2017.

1.4 The witnesses who appeared at these hearings are listed at Appendix 2.

1.5 The committee also received a number of additional documents, and answers to questions on notice also listed at Appendix 1.

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1 *Journals of the Senate*, No. 21, 29 November 2016, pp 662–663.

2 *Journals of the Senate*, No. 21, 29 November 2016, p. 662.

## Structure and scope of this report

1.6 This report comprises six chapters:

- chapter 1 outlines the conduct of the inquiry, and the definitions for low survival rate (LSR) cancers, distinct from 'rare cancers';
- chapter 2 examines in particular funding for LSR cancers;
- chapter 3 discusses clinical trials for LSR cancers;
- chapter 4 discusses paediatric and youth cancers; and
- chapter 5 considers ways in which survival rates can be increased for LSR cancers.

## Definitions

1.7 In responding to the terms of reference for the inquiry, submitters and witnesses to the committee referred both to LSR cancers and rare cancers.

1.8 For example, the Low Survival Cancers Alliance, comprising 11 organisations including the Cancer Council Victoria and the Leukaemia Foundation, defined LSR cancers as:

...those with five year survival less than or equivalent to 30% and include mesothelioma, pancreas, liver, lung, oesophagus, gallbladder, brain, adult acute myeloid leukaemia, stomach, some neuroendocrine cancers (NETs) and cancer of unknown primary.<sup>3</sup>

1.9 This definition was also put forth by other submitters, including Cancer Voices Australia<sup>4</sup> and the Australasian Gastro-Intestinal Trials Group.<sup>5</sup>

1.10 By contrast, Cancer Australia stated that '[a]s there is no standard definition' of LSR cancers, and focussed in its submission 'on eight cancer types which all have a <50% five-year relative survival rate'.<sup>6</sup> Those cancers identified were ovarian, stomach, acute myeloid leukaemia, brain, oesophageal, lung, pancreatic and mesothelioma cancers.<sup>7</sup>

1.11 The reference to less than 50 per cent survival rate was also identified by the Australian Institute of Health and Welfare (AIHW).<sup>8</sup> In its submission, AIHW identified that in 2009–2013, the following cancers fell into that category:

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3 Low Survival Cancers Alliance, *Submission 90* p. 1. The other members of the alliance are the Asbestos Council of Victoria, AsbestosWise, the Bernie Banton Foundation, Brain Tumour Alliance Australia, the Isabella & Marcus Fund, the Lung Foundation Australia, Pancare, Robert Connor Dawes and the Unicorn Foundation.

4 Cancer Voices Australia, *Submission 61*, p. 1.

5 Australasian Gastro-Intestinal Trials Group, *Submission 85*, p. 1.

6 Cancer Australia, *Submission 129*, p. 1.

7 Cancer Australia, *Submission 129*, p. 1.

8 Australian Institute of Health and Welfare (AIHW), *Submission 83*, p. 2.

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mesothelioma, pancreas, unknown primary site, lung, liver, gallbladder, oesophagus, brain, acute myeloid leukaemia and stomach.<sup>9</sup>

1.12 The committee has accepted this latter definition of LSR cancers for the purpose of this report, that is cancers with less than a 50 per cent survival rate.

1.13 The committee also notes that Rare Cancers Australia identified the distinction between 'less common' and 'rare cancers':

‘**Less common**’ cancers as those with an incidence of between 6 and 12 (inclusive) per 100,000 Australians per annum.

‘**Rare cancers**’ are defined as those with an incidence of less than 6 per 100,000 Australians per annum – a total of 186 cancer types have been defined as rare.<sup>10</sup>

1.14 The committee acknowledges the distinction between LSR, less common and rare cancers. However, the committee will refer only to LSR cancers unless otherwise specified.

### **A note on the NHMRC funding model**

1.15 Since the inquiry was first announced, the NHMRC has made certain changes to its funding structure. Most of the submissions and some of the evidence received at the committee's public hearings were provided in the context of the former NHMRC funding structure.

1.16 Unless specified, the committee believes that the evidence it has included in its report is also reflective of the current funding structure.

1.17 The changes that were announced on 25 May 2017,<sup>11</sup> and the effect of these changes, is discussed in more detail in chapter 2.

### **Recent funding announcements**

#### ***Funding for rare cancers***

1.18 On 24 August 2017, the Australian government announced that Australian children would have access to AIM BRAIN, a four year study with the aim of transforming the brain tumour classification, treatment and survival of children with brain cancer.<sup>12</sup> Further information about this announcement appears in chapter 3.

1.19 The government also announced \$13 million of funding for competitive research grants through the Medical Research Future Fund (MRFF), which is targeted

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9 AIHW, *Submission 83*, p. 2.

10 Rare Cancers Australia, *Submission 50*, p. 1.

11 The Hon. Greg Hunt MP, 'Medical research reforms to improve our future health', *Media Release*, 25 May 2017.

12 The Hon. Greg Hunt MP, 'Major new measures to help combat rare cancers', *Media Release*, 24 August 2017, p. 1.

towards rare cancers and rare diseases.<sup>13</sup> Further information about this announcement appears in chapter 2.

### ***The Australian Brain Cancer Mission***

1.20 On 29 October 2017, the Australian government announced the Australian Brain Cancer Mission, a \$100 million fund to defeat brain cancer.<sup>14</sup> Further information about this fund appears at chapter 5.

### **Acknowledgements**

1.21 The committee thanks individuals and organisations that contributed to the inquiry, and takes this opportunity to express its gratitude to those individuals who took the time to share their personal stories with the committee.

1.22 The committee appreciates that for some, sharing their personal experiences was difficult and upsetting. The committee was deeply moved by these stories and the inquiry has benefitted from their being shared.

### **Notes on references**

1.23 References to the *Committee Hansard* may be references to the proof transcript. Page numbers may differ between proof and official transcripts.

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13 The Hon. Greg Hunt MP, 'Major new measures to help combat rare cancers', *Media Release*, 24 August 2017, p. 1.

14 The Hon. Greg Hunt MP, 'Australian Brain Cancer Mission', *Media Release*, 29 October 2017.