

Chapter 1

Introduction

1.1 On 25 June 2014, the Senate established the Senate Select Committee on Health.¹ The final reporting date for the committee is 20 June 2016. The committee's resolution allows the committee to make interim reports such as this one which focusses on creating new opportunities for public good medical research and policy design from the government's vast holdings of health data.

Public hearings

1.2 The committee has completed 48 public hearings to date. A list of hearings which focused on big linkage is at Appendix 1.²

1.3 Through its extensive program of public hearings, the committee has taken evidence from many health experts, researchers, practitioners, consumers and communities.

1.4 Throughout the committee's inquiry, witnesses and submitters have raised issues with the committee relating to the collection, access, linkage and use of medical data for research purposes. In order to examine these issues in more detail, the committee held three hearings focussing specifically on the use and linkage of medical related data:

- 11 December 2015, Sydney; and
- 2 and 3 February 2016, Canberra.

Submissions

1.5 The committee has received 203 submissions since the beginning of its inquiry. In relation to data linkage issues, the committee has received 29 submissions. A list of submissions relating to data linkage is at Appendix 2.³

1.6 The committee's terms of reference are wide-ranging. It is the committee's intention to explore various issues in depth over the course of its inquiry. While the committee is still accepting general submissions, it is the committee's intention to seek submissions on specific topics as the need arises over the course of the inquiry.

1.7 Additional information, tabled documents, correspondence and answers to questions on notice received by the committee which relate to data linkage are listed at Appendix 3.⁴

1 *Journals of the Senate*, 25 June 2014, pp 996–998.

2 Public hearing details can also be accessed via the committee's website: www.aph.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Public_Hearings.

3 The submissions received by the committee can be accessed via the committee's website: www.aph.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Submissions.

Health Committee's first interim report

1.8 The committee's first interim report was tabled on 2 December 2014.⁵ That report detailed the committee's findings and conclusions at that time, focussing on issues raised during the committee's hearings and through submissions. Key areas of focus in the first report were:

- the government's proposed patient co-payments, cuts to hospital funding and the abolition of Australian National Preventative Health Agency;
- the government's plan to close the 61 Medicare Locals and replace them with 30 Primary Health Networks; and
- the merger of the Organ and Tissue Authority and the National Blood Authority.

Second interim report

1.9 The committee's second interim report was tabled on 24 June 2015.⁶ That report encompassed the committee's findings regarding the government's primary healthcare and general practice policies. In particular the report was a record of the government's frequent changes of policy since the 2014-15 Budget. The second interim report focused specifically on:

- the vital importance of general practice and primary healthcare and the threat posed by the government's numerous policy changes since the 2014-15 Budget;
- the responses of GPs and the primary healthcare sector to the government's various primary healthcare policies; and
- an examination of the 2015-16 Budget's health measures and commentary from stakeholders.

Third interim report

1.10 The committee's third interim report was tabled on 17 September 2015.⁷ That report examined the government's proposed privatisation of Australian Hearing and the National Acoustics Laboratories.

1.11 The report outlined the evidence taken at the 10 July 2015 public hearing and the related written submissions made by witnesses. It also examined:

- the impacts privatisation would have on users of the Australian Hearing services; and

4 The submissions received by the committee can be accessed via the committee's website: www.apf.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Additional_Documents.

5 *Journals of the Senate*, 2 December 2014, p. 1948. The report can be accessed at: www.apf.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/First_Interim_Report.

6 *Journals of the Senate*, 24 June 2015, p. 2809. The report can be accessed at: www.apf.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Second_Interim_Report.

7 *Journals of the Senate*, 17 September 2015, p. 3158. The report can be accessed at: www.apf.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Third_Interim_Report.

-
- the relationship between the National Disability Insurance Scheme (NDIS) and Australian Hearing.

Fourth interim report

1.12 The committee's fourth interim report was presented out of session on 8 October and tabled in the Senate on 12 October 2015.⁸ That report examined mental health issues raised by witnesses and submitters in the context of the National Mental Health Commission's *National Review of Mental Health Programs and Services Report*.

1.13 The fourth interim report specifically focussed on:

- the findings of the Commission's report;
- the Government's response to the Commission's findings;
- the importance of ensuring that there is a smooth transition of mental health programs into the NDIS.

Fifth interim report

1.14 The committee's fifth interim report was presented on 28 April 2016.⁹ That report examined the recent re-emergence of the debilitating lung disease Coal Workers' Pneumoconiosis (also known as black lung disease) in former Queensland coal miners. The report highlighted issues around safe exposure levels, dust monitoring regimes and worker screening practices.

Structure of this report

1.15 This sixth interim report examines the 'big data' and data linkage issues witnesses and submitters have raised with the committee. In addition to this introductory chapter, the report includes three chapters:

- background—setting the broad context of what 'big data' is and how it could be used in Australia (Chapter 2);
- Chapter 3 examines the new opportunities for governments to use big data in health policy development;
- Chapter 4 considers the constraints applying to linking data from the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme; and
- Chapter 5 examines issues relating to access to data including ethics approvals, issues faced by data custodians, the 'linkage logjam' and its relationship to the Australian Government departments.

8 *Journals of the Senate*, 12 October 2015, p. 3175. The report can be accessed at: www.aph.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Fourth_Interim_Report.

9 *Journals of the Senate*, 2 May 2016, p. 4165. The report can be accessed at: www.aph.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Fifth_Interim_Report.

Notes on references

1.16 References to submissions in this report are to individual submissions received by the committee and published on the committee's website. References to the committee Hansards are to the proof transcripts.¹⁰

Acknowledgements

1.17 The committee thanks the many organisations and individuals who participated in the big data and data linkage hearings on 11 December 2015 and 2 and 3 February 2016 as well as those that made written submissions. The committee also acknowledges the contribution of all those who have raised data issues in the committee's previous hearings.

10 Committee Hansards can be accessed via the committee's website:
www.aph.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Public_Hearings.