Research into services and needs for people experiencing complicated grief:

Final report

Prepared for the Palliative Care Section, Cancer and Palliative Care Branch, Population Health and Sport Division, Australian Government Department of Health

Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong

March 2017
Acknowledgements:
The authors acknowledge the 30 stakeholders who offered their time and expertise during the interviews and discussion group, as well as all individuals who responded to the survey and key experts that participated in the facilitated workshop. Their contribution has been critical to the project’s outcomes. We would also like to thank key staff from the funding body, the Australian Government Department of Health, for their assistance. In particular, the ongoing support from Annie Dullow, Cora Shiroyama and Zoë Clews throughout the project is gratefully acknowledged.

Suggestion citation:
Contents

List of abbreviations / acronyms ................................................................. iv
Executive summary .................................................................................. v
1 Introduction ......................................................................................... 1
  1.1 Background and context ................................................................ 2
  1.2 Report structure ........................................................................... 5
2 Methods ............................................................................................... 6
  2.1 Research objectives ........................................................................ 6
  2.2 Research design and data sources .................................................. 7
  2.3 Evidence appraisal ......................................................................... 8
  2.4 Semi-structured interviews .............................................................. 9
  2.5 Survey of service providers ............................................................ 10
  2.6 Secondary data analysis .................................................................. 11
  2.7 Facilitated workshop of key experts .............................................. 11
  2.8 Ethical review and approval ............................................................. 11
3 Evidence appraisal findings ................................................................. 12
  3.1 Defining complicated grief ............................................................. 12
  3.2 Overlap between complicated grief, depression and posttraumatic stress disorder ............................................................. 16
  3.3 Impact of bereavement, including complicated grief ..................... 17
  3.4 Interventions for complicated grief ............................................... 22
  3.5 Predictors of complicated grief ....................................................... 27
  3.6 Screening and assessment tools ....................................................... 29
  3.7 Advance care planning .................................................................. 34
  3.8 Outcome indicators to inform or monitor best practice approaches and service models for complicated grief ............................................................. 38
  3.9 Clinical guidelines ......................................................................... 39
4 Stakeholder consultation findings ...................................................... 42
  4.1 Does complicated grief exist? ......................................................... 43
  4.2 Pathways into services .................................................................... 44
  4.3 Preventing complicated grief ........................................................... 49
  4.4 Identifying complicated grief ......................................................... 57
  4.5 Treating complicated grief ............................................................... 63
  4.6 Unmet needs and barriers to service provision ............................... 70
  4.7 Workforce issues ............................................................................ 79
  4.8 Recovery from complicated grief .................................................... 82

Research into services and needs for people experiencing complicated grief: Final report Page 1
4.9 Outcome indicators ............................................................................................................. 83
4.10 The impact of complicated grief and good practice ....................................................... 86
4.11 Extended case study ......................................................................................................... 92
5 Demand and supply issues ................................................................................................. 95
  5.1 Projecting service demand .............................................................................................. 95
  5.2 Supplying care for persons with complicated grief ....................................................... 101
  5.3 Workforce gaps and issues ............................................................................................ 108
  5.4 Service implications ....................................................................................................... 112
6 Discussion and conclusion ................................................................................................. 113
  6.1 Awareness and Understanding ...................................................................................... 114
  6.2 Appropriateness and Effectiveness ............................................................................... 121
  6.3 Leadership and Governance ......................................................................................... 125
  6.4 Capacity and Capability ............................................................................................... 126
7 Recommendations ............................................................................................................ 130
8 References .......................................................................................................................... 132

List of figures
Figure 1 Sequential exploratory design .................................................................................. 7

List of tables
Table 1  Goals of the 2010 National Palliative Care Strategy .................................................. 4
Table 2  Research requirements ............................................................................................. 6
Table 3  Proposed diagnostic criteria ..................................................................................... 15
Table 4  Prevalence of complicated grief ............................................................................. 19
Table 5  Impact of complicated grief ..................................................................................... 20
Table 6  Reviews of the evidence for complicated grief interventions .................................. 22
Table 7  Strong risk factors for complicated grief ................................................................. 28
Table 8  Measuring complicated grief .................................................................................... 30
Table 9  Literature reviews of advance care planning .......................................................... 34
Table 10 Individual studies investigating the impact of advance care planning on carers ...... 36
Table 11 Quality indicators of end-of-life care .................................................................... 38
Table 12 Bereavement support care pathway – references to complicated grief .................. 39
Table 13 National Palliative Care Standards – Standard 8 ..................................................... 69
Table 14 Number of deaths by PHN in 2013 (AIHW, 2016a) .................................................. 96
Table 15 Number of deaths by remoteness in 2013 (AIHW, 2016a) ........................................ 97
Table 16 Estimated number of bereaved persons at risk of complicated grief in 2013 ....... 99
Table 17 Number of deaths and estimated number of bereaved persons at risk of complicated grief for selected causes of death in Australia, 2013 (ABS, 2016a) ......................... 101
Table 18 Roles providing bereavement support at survey respondents’ services ............... 103
Table 19  Local or regional catchment area by PHN .................................................................103
Table 20  Number of employed psychologists in the workforce by PHN in 2013 (AIHW, 2016b). .................................................................105
Table 21  Number of employed psychologists in the workforce by remoteness in 2013 (AIHW, 2016b) .................................................................................................................................106
Table 22  Number of psychologists and social workers employed in the workforce by State/Territory in 2013 (ABS, 2016b; AIHW, 2016b) .................................................................107
Table 23  Alignment of research questions with National Palliative Care Strategy goals ......113
Table 24  The definition of complicated grief: stakeholder views ........................................114
Table 25  Recommendations .................................................................................................130
Table 26  Search terms ........................................................................................................143
Table 27  Survey invitations .................................................................................................146

List of appendices

Appendix 1  Data matrix....................................................................................................142
Appendix 2  Evidence appraisal search strategy .................................................................143
Appendix 3  Survey methodology ....................................................................................145
Appendix 4  Mapping of complex bereavement activities and services .........................147
Appendix 5  Online case studies.......................................................................................148
## List of abbreviations / acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACP</td>
<td>Advance Care Planning</td>
</tr>
<tr>
<td>ATAPS</td>
<td>Access to Allied Psychological Services</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual</td>
</tr>
<tr>
<td>ICG</td>
<td>Inventory of Complicated Grief</td>
</tr>
<tr>
<td>MeSH</td>
<td>Medical Subject Headings</td>
</tr>
<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
</tr>
<tr>
<td>PCOC</td>
<td>Palliative Care Outcomes Collaboration</td>
</tr>
<tr>
<td>PCBD</td>
<td>Persistent Complex Bereavement Disorder</td>
</tr>
<tr>
<td>PTSD</td>
<td>Posttraumatic Stress Disorder</td>
</tr>
<tr>
<td>REDCap</td>
<td>Research Electronic Data Capture</td>
</tr>
</tbody>
</table>
Executive summary

This report is the result of research into services and needs for people experiencing complicated grief. The project was undertaken by the Centre for Health Service Development, a multidisciplinary research centre based within the Australian Health Services Research Institute at the University of Wollongong, on behalf of the Palliative Care Section, Cancer and Palliative Care Branch, Australian Government Department of Health.

The research objectives are outlined below:

- Review the evidence on the impacts, including productivity impacts (e.g. loss of productivity), of complicated grief on a bereaved individual and those close to that person;
- Undertake a gap analysis of needs and current resources/services/structures for people experiencing complicated grief;
- Map national complex bereavement activities and services;
- Identify workforce gaps and issues;
- Analyse the role and effectiveness of advance care planning in preventing or minimising the onset or effects of complicated grief;
- Identify examples of good practice;
- Identify likely triggers or challenge points for people entering, or staying in, complicated grief;
- Identify potential outcome indicators that could be used by service providers and policy makers to inform and/or monitor best practice approaches and service models;
- Describe examples for service providers and policy makers to inform or monitor best practice approaches and service models; and
- Describe case studies that could function as guidance for clinical practice.

Section 1 of the report is an introduction; it provides background and context to the research, defining complicated grief and describing the policy context, in particular the current National Palliative Care Strategy and related policy framework. The report structure is also outlined.

The methodology used to address the key research questions that reflect the research objectives is detailed in Section 2. The research design and data sources are documented, namely:

- Targeted review of the academic literature
- Semi-structured interviews
- Discussion groups
- Survey of service providers
- Secondary data analysis
- Facilitated workshop of key experts
- Synthesis of data sources and findings.
Findings from the literature review are reported in Section 3. Definitional issues around complicated grief are further explored, and the overlap between complicated grief, depression and posttraumatic stress disorder is also examined. The impact of bereavement and complicated grief is appraised, in particular the adverse outcomes of bereavement, and the prevalence and impact of complicated grief. Evidence about the effectiveness of interventions for complicated grief is also assessed. Predictors of complicated grief are reviewed and related screening and assessment tools are evaluated. Advance care planning and its relation to bereavement and complicated grief are discussed. Potential outcome indicators that may be used to inform or monitor best practice approaches and service models for complicated grief are explored, and finally clinical guidelines related to identification, prevention or treatment of complicated grief are examined.

Section 4 presents the findings from the stakeholder consultation. The prevailing uncertainties and controversies in the field of complicated grief came through strongly in the interviews and focus groups. Some topics were strongly contentious, for example the most appropriate term for “complicated grief”. However there were also many areas of agreement. Analysis of stakeholders’ views on a range of topics is provided, including: whether complicated grief exists; pathways into services for people experiencing complicated grief; prevention, identification and treatment of complicated grief; unmet needs of bereaved people and barriers to service provision; workforce issues; recovery from complicated grief; and the application of outcome indicators for quality improvement purposes. The section concludes with patient vignettes and a case study demonstrating the impact of complicated grief and one approach to treatment.

Section 5 of the report explores issues of service demand and supply, examining the capacity of the health and social care system to respond to the needs of persons experiencing complicated grief. Results in this section are based primarily on analysis of secondary data sources, and are supported by information obtained through the survey of service providers. A range of workforce gaps and issues are outlined that are pertinent to the palliative care sector.

Section 6 aims to respond to the research questions that provided the impetus for this project. The research questions have been aligned with the appropriate goal of the National Palliative Care Strategy 2010 that they primarily address.

In the final section of the report, Section 7, the recommendations for policy, service delivery, workforce/capacity development and further research are provided, as follows. It is recommended that the Department of Health:

Policy
1. Use the term ‘prolonged grief’ consistently in palliative care service policy and planning, and review this term when the International Classification of Diseases (Eleventh Revision) is adopted by the Australian Government.
2. Maintain implementation of the current National Palliative Care Standards and identify opportunities in the forthcoming revision to incorporate initiatives relating to prolonged grief.
3 Develop national standards to guide good practice in assisting people who may be experiencing prolonged grief.

**Service delivery**

4 Recognise that prolonged grief is an identifiable condition and integrate actions to support people with prolonged grief in relevant health and social program service delivery frameworks e.g. primary care, mental health care.

5 Support a range of evidence based models of care for prolonged grief, including those that may increase access for vulnerable populations.

6 Promote public awareness and community education about grief and bereavement.

**Workforce/capacity development**

7 Encourage Primary Health Networks (PHNs) to establish local registries of grief and bereavement support services to improve referral practices and service accessibility (e.g. through utilising the National Health Services Directory or HealthPathways program).

8 Facilitate greater education and understanding of grief and bereavement, including prolonged grief, in undergraduate curricula of health professionals.

9 Support appropriate training about grief, bereavement and prolonged grief for primary care and palliative care health professionals so they are better able to address these issues in practice.

10 Recognise that specialised skills are required to effectively treat persons with prolonged grief and associated co-morbidities. This may require specification of skills and expertise in the future.

**Research**

11 Facilitate knowledge translation by disseminating the findings of this research into prolonged grief to stakeholders particularly in the primary care, aged care and palliative care sectors (e.g. through an issues paper).

12 Document the main pathways that people follow to access prolonged grief services to inform a shared understanding of the trajectories of care among health professionals working in primary care and palliative care sectors.

13 Support research and evaluation about the impact of interventions designed to enhance end-of-life care and prepare and support carers for bereavement (e.g. advance care planning, family meetings etc.).

14 Promote high quality research (including longitudinal studies) aimed at strengthening the evidence base for current and emerging approaches to bereavement support and prolonged grief.

15 Explore the appropriateness of outcome indicators to monitor individual recovery and service provision, following the development of national standards to guide good practice.
1 Introduction

This report is the result of research into services and needs for people experiencing complicated grief and is the major deliverable arising from the Request for Quotation issued by the Australian Government Department of Health using the Deed of Standing Offer SON 2647271.

The Centre for Health Service Development, a multidisciplinary research centre based within the Australian Health Services Research Institute at the University of Wollongong, has undertaken this project on behalf of the Palliative Care Section, Cancer and Palliative Care Branch.

The research objectives of this project necessitated an approach that captured issues related to complicated grief, arising from the death of a relative or meaningful individual in someone’s life, from multiple perspectives including that of:

- The bereaved person, considering different roles and relationship they may have to the patient such as partner, family member, substitute decision maker and/or carer;
- The patient with a life-limiting illness, be they in receipt of palliative care or not; and
- Health professionals assisting with end-of-life care.

The research objectives specified in the Request for Quotation are outlined below:

- Review the evidence on the impacts, including productivity impacts (e.g. loss of productivity), of complicated grief on a bereaved individual and those close to that person;
- Undertake a gap analysis of needs and current resources/services/structures for people experiencing complicated grief;
- Map national complex bereavement activities and services;
- Identify workforce gaps and issues;
- Analyse the role and effectiveness of advance care planning in preventing or minimising the onset or effects of complicated grief;
- Identify examples of good practice;
- Identify likely triggers or challenge points for people entering, or staying in, complicated grief;
- Identify potential outcome indicators that could be used by service providers and policy makers to inform and/or monitor best practice approaches and service models;
- Describe examples for service providers and policy makers to inform or monitor best practice approaches and service models; and
- Describe case studies that could function as guidance for clinical practice.
1.1 Background and context

1.1.1 Defining complicated grief

Bereavement – the loss of a loved one through death – is a normal, common human experience. Although it is associated with a period of acute suffering, most people adapt to their loss over time (Stroebe et al., 2007). For a few people, however, bereavement can lead to extreme and persistent mental and physical ill health, making it an issue of concern for both clinical practice and preventative care (Stroebe et al., 2007). CareSearch, the palliative care knowledge network, provides a definition of complicated grief and a range of useful references about this topic in addition to information and resources about advance care planning and end-of-life care. This definition, based on the work of Prigerson and Jacobs (2001) and Zhang et al. (2006), describes complicated grief as extreme and disturbing grief characterised by a yearning and longing for the deceased which impacts negatively on a person’s relationships, employment and life.

It has been estimated that between 10% and 20% of bereaved people experience complicated grief (Lobb et al., 2010). Shear and colleagues (2011) have stated that while approximately one in ten bereaved people experience complicated grief, rates are higher amongst those bereaved by disaster or violent death, or parents who lose a child.

The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) recognises that bereavement-related grief can become clinically significant, causing prolonged suffering and functional impairment and leading to an increased risk of physical and mental health problems. In the DSM-5, Persistent Complex Bereavement Disorder (PCBD) is listed as a condition requiring further study (i.e. before potential inclusion as a formal diagnosis in a future edition). The criteria for PCBD are based on a large body of work that has explored the risk factors, distinguishing features and consequences of conditions variously known as ‘pathological grief’, ‘prolonged grief disorder’ and ‘complicated grief’ (Kaplow et al., 2014).

The proposal to include PCBD as a formal psychiatric diagnosis has generated much debate among both researchers and the general public. While some fear that normal grief will be seen as ‘pathological’ as a result of this move, others argue that it is an important development that provides an opportunity for focused research (Kaplow et al., 2014) and much-needed recognition and better treatment for sufferers. According to one psychologist, there is a profound difference between normal and complicated grief, and therefore different responses are required:

... complicated grief is characterized by debilitating or prolonged denial, avoidance, anxiety, intrusive thoughts, suicidal ideation, and isolation ... Unlike the ups and downs of normal grief, complicated grief and depression confer a feeling of being stuck, as if trapped in a hollow of the rollercoaster or even in a continued downward spiral. With normal grief, you fall apart but there is respite - periods of time when you can engage with life, get stuff done, or even smile at a joke or appreciate. With complicated grief, you fall apart and remain broken. There is little to no respite (Davis, 2012).
Complicated grief is seen as intense, persistent and disabling. The proposed diagnostic criteria for PCBD require that the person experiences yearning or longing for the deceased, intense sorrow or preoccupation with the deceased or the circumstances of the death, along with at least six other symptoms (from a list of 12) of reactive distress and/or disruption to social behaviour or identity. These symptoms must be present for at least 12 months after the death (six months for bereaved children), cause clinically significant distress or impairment to important areas of functioning, and be considered ‘out of proportion’ to cultural and other norms (American Psychiatric Association, 2013).

Many researchers have acknowledged the challenge of predicting and diagnosing complicated grief. In the lead up to DSM-5, the criteria for prolonged grief disorder were systematically assessed for psychometric validity (Prigerson et al., 2009) while other researchers reviewed the evidence for complicated grief as a distinct disorder and discussed the potential benefits and harms associated with a diagnosis (Shear et al., 2011). A range of tools is available to assess risk, provide a diagnosis and measure treatment outcomes. Although some of these have been in use for many years (e.g. Prigerson et al., 1995), there is continuing debate over their validity. For example, one issue, which requires further exploration, is whether complicated grief has multiple dimensions (e.g. separation distress, disrupted identity) or is a unitary construct (Kaplow et al., 2014; Shear et al., 2011). This has important implications for clinical assessment, diagnosis, treatment and policy (Kaplow et al., 2014). In 2012, while recognising that at the time there was no standardised assessment tool that assessed specifically for complicated grief and bereavement-related conditions, the Australian Government Department of Health and Ageing recommended the ‘Inventory of Complicated Grief – Revised’ as a measure for use in the assessment of the mental health of veterans (Australian Centre for Posttraumatic Mental Health, 2012, p.59). Other scales identified by the Australian Centre for Posttraumatic Mental Health (2012) were the Texas Revised Inventory of Grief, the Hogan Grief Reaction Checklist and the Grief Evaluation Measure.

Complicated grief can be distinguished from psychiatric disorders such as Post Traumatic Stress Disorder and Major Depressive Disorder and has a specific set of risk factors (Nanni et al., 2015). These include gender (female), age (older), low socioeconomic status, lack of social support, history of mental illness and/or previous losses or trauma, and factors connected with the relationship to the deceased (Nanni et al., 2015). Factors associated with the bereavement – including whether it was traumatic and sudden or resulted from a long illness – also affect grieving outcomes. In the case of expected deaths, aspects of carer history are also related to the risk of complicated grief, although this relationship is complex and the evidence is mixed (Nanni et al., 2015; Stroebe et al., 2006). Advance care planning (ACP) may have the potential to alleviate stresses related to caring in life-limiting illness by providing greater clarity about the loved one’s wishes and aiding decision making at the end-of-life but this requires further investigation.

1.1.2 Policy context

The Palliative Care Section is part of the Cancer and Palliative Care Branch within the Population Health and Sport Division in the Australian Government Department of Health. The Department aims to achieve its vision through strengthening evidence-based policy advice, improving program management, research, regulation and partnerships with other government
agencies, consumers and stakeholders. The Palliative Care Section’s primary role is to provide policy advice to Government on issues relating to palliative care and ACP.

The National Palliative Care Strategy 2010 - Supporting Australians to Live Well at the End of Life represents the combined commitments of the Australian, state and territory governments, palliative care service providers and community based organisations to the development and implementation of palliative care policies, strategies and services that are consistent across Australia.

This strategy outlines four goal areas; each has supporting goal statements, objectives and action areas (Department of Health and Ageing, 2011, p.10). These are listed below in Table 1.

Table 1 Goals of the 2010 National Palliative Care Strategy

<table>
<thead>
<tr>
<th>Goal Area</th>
<th>Number</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness and Understanding</td>
<td>Goal 1</td>
<td>To significantly improve the appreciation of dying and death as a normal part of the life continuum.</td>
</tr>
<tr>
<td></td>
<td>Goal 2</td>
<td>To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services.</td>
</tr>
<tr>
<td>Appropriateness and Effectiveness</td>
<td>Goal 3</td>
<td>Appropriate and effective palliative care is available to all Australians based on need.</td>
</tr>
<tr>
<td>Leadership and Governance</td>
<td>Goal 4</td>
<td>To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.</td>
</tr>
<tr>
<td>Capacity and Capability</td>
<td>Goal 5</td>
<td>To build and enhance the capacity of all relevant sections in health and human services to provide quality palliative care.</td>
</tr>
</tbody>
</table>

The goal area of ‘Awareness and Understanding’ includes the following context:

There is a need to significantly enhance the understanding of dying, death, grief, bereavement and loss in Australia, including in health professionals and carers, to support better access to appropriate, timely services across the end of life continuum (Commonwealth of Australia, 2010, p.8).

The Palliative Care Section is responsible for coordinating a response to the report of the Senate Community Affairs Committee Inquiry into Palliative Care in Australia. The report has several references to complicated grief and grief more generally, for example in terms of the need for better support to be provided to families who have experienced the death of a child. The report notes:

The provision of effective palliative care can be expected to directly benefit the child but also has the potential to be a preventive health intervention for the family, with
long term implications for family functioning, mental health, education and employment.¹

The discipline of palliative care has developed expertise and a body of knowledge focused on end-of-life care. The Australian Commission on Safety and Quality in Health Care has published two key documents in relation to end-of-life care: Safety and quality of end-of-life care in acute hospitals: a background paper published in 2013 and the National consensus statement: essential elements for safe and high-quality end-of-life care published in 2015. The National Safety and Quality Health Service Standards are being revised and will be re-issued in 2017 with inclusion of new actions specifically requiring health services to put systems in place for the provision of end-of-life care.

This research project is underpinned by the current National Palliative Care Strategy and related policy framework.

1.2 Report structure

This report has been produced as a strategic resource for officers of the Department of Health and may support future policy development within the context of palliative care and end-of-life care (including advance care planning).

Consequently considerable detail is included about the methods employed (Section 2) with the findings from each major data source discussed in depth and presented in separate sections (Sections 3, 4 and 5). Section 6 presents a discussion and synthesis of these findings and includes a response to each research question, sample case study and best practice examples. The research questions have been clustered under the relevant goal from the National Palliative Care Strategy. In the final section of the report, Section 7, the recommendations for policy, service delivery, workforce/capacity development and further research are provided.

¹ Paediatric Palliative Care Australian and New Zealand Reference Group, Submission 63, p.1, as referenced in the report of The Senate Community Affairs References Committee – Palliative Care in Australia. Commonwealth of Australia, 2012, p.167.
## Methods

The methodology was developed to ensure the research captured multiple perspectives of the key stakeholders affected by the phenomenon of complicated grief.

### 2.1 Research objectives

The research objectives have previously been outlined in Section 1. The methodology was constructed to address the key research questions that reflect the research objectives. These are summarised in Table 2 below.

<table>
<thead>
<tr>
<th>Research Objectives</th>
<th>Research Questions</th>
</tr>
</thead>
</table>
| Review the evidence on the impacts, including productivity impacts (e.g. loss of productivity), of complicated grief on a bereaved individual and those close to that person | ▪ What is the impact of complicated grief on the bereaved individual, their family and significant others?
▪ What are the likely triggers or challenge points for people experiencing complicated grief?
▪ What evidence is there about preventing or minimising the onset or effects of complicated grief? |
| Identify likely triggers or challenge points for people entering, or staying in, complicated grief | |
| Undertake a gap analysis of needs and current resources/services/structures for people experiencing complicated grief | ▪ What are the needs of people experiencing complicated grief?
▪ What resources, services and activities are available to support people experiencing complicated grief?
▪ What is the composition of the workforce that provides bereavement services?
▪ How is the workforce distributed across Australia?
▪ What issues does this workforce face now and in the future? |
| Map national complex bereavement activities and services | |
| Identify workforce gaps and issues | |
| Analyse the role and effectiveness of advance care planning in preventing or minimising the onset or effects of complicated grief | ▪ What is the evidence of the effectiveness of advance care planning in preventing or minimising the onset or effects of complicated grief? |
| Identify examples of good practice | ▪ Where is good practice occurring and what are some evidence based examples of good practice?
▪ What do existing sources of information report about the experience of the bereaved person in relation to their interactions with the broader health system?
▪ What do existing sources of information report about the experience of the patient with a life-limiting illness; their family/carers and treating health professionals in relation to end-of-life care? |
| Describe case studies that could function as guidance for clinical practice | |
| Identify potential outcome indicators that could be used by service providers and policy makers to inform and/or monitor best practice approaches and service models | ▪ Are there any outcome indicators currently monitored by organisations providing services for people experiencing complicated grief?
▪ What is the capacity to build on existing systems e.g. the Palliative Care Outcomes Collaboration (PCOC) and |
Research Objectives | Research Questions
--- | ---
Describe examples for service providers and policy makers to inform or monitor best practice approaches and service models | Integrate appropriate outcome indicators relating to the management of persons experiencing complicated grief and/or the early identification of persons at risk of complicated grief?

2.2 Research design and data sources

The methodology was based on a mixed methods approach that employed a combination of qualitative and quantitative data sources. Triangulation of data was achieved through using multiple sources to capture the required perspectives (the bereaved person, the patient with a life-limiting illness and health professionals assisting with end-of-life care).

A sequential exploratory design was adopted (refer to Figure 1). This research design results in qualitative data being initially collected and informing the subsequent collection and/or review of quantitative data. The first phase of qualitative data collection and analysis is followed by a second quantitative phase that builds on the qualitative results. The synthesis process or integration of data occurs during all phases: data collection, data analysis and interpretation.

Figure 1  Sequential exploratory design²

This research design is particularly useful when exploring a complex phenomenon such as complicated grief, which needs to be understood from different perspectives. The intention behind completing specific qualitative data collection activities early in the project was to gain a rapid understanding of the scope of the topic and to establish boundaries for the project. For example, given the limited evidence of efficacy of preventative interventions the evidence appraisal needed to explore this issue thoroughly but also include treatment interventions. This allowed early identification of several groups with unique risks and requirements that were subsequently excluded from the project because they were deemed to be out of the policy scope of the Palliative Care Section. Examples of these groups included: bereaved children (see, for example, Brent et al., 2012); bereavement associated with Sudden Infant Death Syndrome; bereavement arising from homicide or suicide and bereavement relating to the uncertainty and loss associated with unrecovered ‘missing persons’. Issues related to diversity and the

experience of different cultural groups as well as euthanasia and assisted dying were also specified as out of scope.

The research design comprised the following core components and data sources:

- **Targeted review of the academic literature** to answer several research questions.
- **Semi-structured interviews** with 18 key stakeholders recognised as having highly relevant expertise in the domain of complicated grief and/or related fields to explore a range of issues.
- **Discussion groups**, one with nine NSW-based bereavement counsellors and another with three researchers currently engaged in bereavement studies, to explore a range of issues.
- **Survey of a convenience sample of service providers** to support a gap analysis of needs and current resources/services/structures for people experiencing complicated grief, map national complex bereavement services and identify workforce gaps.
- **Secondary data analysis** of several existing and accessible data sets to explore service demand and supply issues.
- **Facilitated workshop of key experts** to inform the conclusions and recommendations arising from this project.

This comprehensive project report is a result of the synthesis of data sources and findings.

A data matrix is included as Appendix 1 that summarises how the various data sources supported investigation of the research objectives and research questions.

### 2.3 Evidence appraisal

The evidence appraisal focused on answering five specific questions:

1. What is the impact (including impact on productivity) of complicated grief on the bereaved individual, their family and significant others?
2. What are the likely triggers or challenge points for people entering, or staying in, complicated grief?
3. What evidence is there about preventing or minimising the onset or effects of complicated grief?
4. What is the evidence of the effectiveness of advance care planning in preventing or minimising the onset or effects of complicated grief?
5. What outcome indicators have been developed to inform or monitor best practice approaches and service models for complicated grief?

For the purposes of answering these questions, Question 3 was re-worded as two separate questions:

- What evidence is there about preventing the onset of complicated grief?
- What evidence is there about minimising the effects of complicated grief?
The structure of the evidence appraisal consists of outlining the methodology, presenting the findings from the evidence appraisal and then answering each of the research questions. The findings commence with a section which outlines the conceptual and theoretical approaches to complicated grief to provide some context for what follows.

The evidence appraisal had elements of an umbrella review and a rapid review. This approach was adopted because of the time available to conduct the evidence appraisal (which was relatively short) and the target audience for the evidence appraisal (decision makers and policy makers, rather than clinicians). Umbrella reviews involve compiling evidence from existing reviews of the literature, focusing on a broad condition or problem (e.g. complicated grief) for which there are competing interventions and highlights reviews that address those interventions and their results. Rapid reviews involve an assessment of what is already known about a policy or practice issue, using systematic methods to search existing research while using various techniques to shorten the timescale (Grant and Booth, 2009). In practice, this involved conducting a ‘review of reviews’ which constituted the core of the evidence appraisal, supplemented in some instances with searching for studies published since the latest reviews or in situations where no existing reviews of the literature were located. Given the diverse nature of the studies and literature reviews included in the review, no quality appraisal of included papers was undertaken. Further detail about the search strategy used is included in Appendix 2.

2.4 Semi-structured interviews

A purposive, criterion-based sampling approach was adopted for the semi-structured interviews. Criterion sampling involves searching for cases or individuals who meet a certain criterion. In the case of experts, the criterion for inclusion could be peer recognition as leaders in a clinical or academic field relevant to complicated grief and/or bereavement; for consumers, the criterion could be that they have had a particular lived experience of complicated grief and/or bereavement (Palys, 2008). The inclusion criteria for defining the expert groups were developed by the project team in consultation with the Department of Health. The participants’ primary qualification was their specialist knowledge, namely a demonstrated interest in complicated grief and/or bereavement.

Interview participants were identified through several strategies:

- Departmental officers provided the names of experts they were aware of and a list of jurisdictional contacts responsible for advising about palliative care and/or advance care planning.
- Representatives of the Palliative Care Outcomes Collaboration were interviewed and based on their experience and knowledge of the field, suggested a range of clinical experts.
- The research team conducted a Google search for professionals associated with bereavement-related organisations, palliative care services and advance care planning. From the results, websites were scanned to identify individuals responsible for certain publications or initiatives. Websites of other organisations within NSW and Australia likely to have an interest in this area were also scanned.
A snowballing method was used to add to this list by asking already identified experts to nominate others with particularly relevant knowledge and experience in complicated grief.

Initially stakeholders were contacted via email with an invitation to participate in a semi-structured interview (a participant information sheet was included). If a positive response was received via return email a consent form was then sent with a copy of the interview questions. The interview was arranged at a time convenient to the participant and conducted by telephone and with appropriate consent, recorded. The interviews were conducted from 7 October to 14 November 2016. There were 18 interviews completed with an approximate total duration of 14 hours. The mean length of interviews was 47 minutes. The stakeholders came from every state and territory except ACT and Tasmania. There were three jurisdictional representatives, seven researchers and eight clinicians/direct service providers.

In addition, two 1.5 hour discussion groups were held; one with nine NSW-based bereavement counsellors from NSW and another with three researchers currently engaged in bereavement studies.

A specialist transcription company transcribed interviews under a confidentiality agreement and one researcher initially reviewed all transcriptions. A second researcher imported these transcriptions into the NVivo software application to facilitate data analysis. An initial set of codes informed by the literature review was amended and refined as data analysis progressed, with inclusion of additional codes developed inductively.

In this report, direct quotes are presented in italics and indented; quotes from interview participants are in a blue typeface to distinguish them from quotes from other sources (black typeface).

### 2.5 Survey of service providers

A survey was developed that intended to collect information from government, non-government organisations and other service providers about available activities, services and resources and potentially workforce gaps and issues relevant to complicated grief, particularly pertaining to palliative care or end-of-life care.

A service provider list was constructed for the survey based on advice obtained through the expert interviews and via an intensive web-based search for organisations engaged in the provision of bereavement services. The timeframe of this project meant it was unrealistic to compile a complete list of all service providers in Australia and subsequently develop a sampling framework. This resulted in several exclusions. A limitation of this approach is the potential for bias as the group selected for inclusion in the survey may not be representative of all bereavement service providers across Australia, particularly sole private practitioners. Further detail about the administration of the survey is provided in Appendix 3.

The final sample that received the survey was 274. Most invitees were from NSW (78/274, 28%). All states and territories were represented, with Queensland and Victoria being the second and third highest represented states respectively. The survey was distributed on 27 September 2016 and was open for four weeks. Three email reminders were sent to non-
respondents at weekly intervals to increase the response rate. Thirty-two non-respondents were also contacted by telephone to encourage them to complete the survey. Survey results are included in Section 5.2.

2.6 Secondary data analysis

Secondary data analysis was conducted using existing accessible datasets to quantify the demand for complicated grief services and to better understand the workforce available to supply these services. Potential demand for complicated grief services was estimated from mortality statistics and findings from the literature about the proportion of bereaved persons at risk of developing complicated grief and their need for care. The capacity of the health and social care system to supply this care to people experiencing complicated grief was also examined using several available data sources; workforce availability was estimated for psychologists and social workers. The limited availability of some data restricted analysis in certain areas.

2.7 Facilitated workshop of key experts

A facilitated workshop of key experts was conducted on 8 March 2017. The workshop aimed to discuss findings presented in the draft final report and refine policy related issues and recommendations, as well as identify and prioritise practical steps to progress supported recommendations. A range of experts that had participated in stakeholder interviews were invited to attend directly by a representative of the Palliative Care Section, Department of Health. Ten experts in the field of bereavement, grief and complicated grief, with a mix of research and clinical backgrounds, attended the workshop. Four representatives of the Department of Health, one representative of the Australian Institute of Health and Welfare and four members of the project team also attended.

2.8 Ethical review and approval

The study was approved by the University of Wollongong Human Research Ethics Committee on 13 September 2016 (HE2016/329). Amendments were approved on 21 September and 11 October 2016.
3 Evidence appraisal findings

3.1 Defining complicated grief

In their 2006 systematic review of the literature on complicated grief, Kristjanson et al. (2006) reviewed studies designed to investigate the extent to which complicated grief is distinct from other psychological consequences of bereavement such as depression, anxiety and posttraumatic stress disorder (PTSD). Their rationale, which remains current today, is that any such distinction ‘has implications for screening, diagnosis, treatment and health policy decisions’ (Kristjanson et al., 2006, p.37). They concluded that complicated grief can be distinguished from depression and anxiety and that all these potential consequences of bereavement can co-exist.

Over the years there has been a lack of clarity regarding the definition of complicated grief, how complicated grief is conceptualised and how complicated grief is distinguished from normal grief (Guldin, 2014). ‘Complicated’ is only one of many terms which have been used to characterise grief that is ‘not normal’. Examples include ‘prolonged’, ‘pathological’, ‘abnormal’, ‘chronic’, ‘delayed’, ‘inhibited’ and ‘atypical’. Currently, there is no consensus on the criteria for diagnosing complicated grief or even the accepted name for complicated grief (Shear, 2015). Likewise, there is no consensus on a model of complicated grief, with various models proposed:

- A Biobehavioural Model of Bereavement which suggests that complicated grief arises when an attachment figure dies and there is an ‘irreconcilable discord between the reality of the death and the mental representation of the deceased’. This results in ‘disconcerting feelings of continued presence of the loved one and strong urges to search for and unite with the deceased person’ (Shear and Shair, 2005, p.264).

- A Cognitive-Behavioural Model of Complicated Grief which identifies three processes as being key to the development and maintenance of complicated grief: (a) poor elaboration and integration of the loss into the database of autobiographical knowledge, (b) negative global beliefs and misinterpretations of grief reactions, and (c) anxious and depressive avoidance strategies’ (Boelen et al., 2006, p.111).

- A Cognitive Attachment Model of Prolonged Grief which emphasises ‘how one's sense of identity influences yearning, memories of the deceased, appraisals, and coping strategies, to maintain a focus on the loss’ (Maccallum and Bryant, 2013, p.713).

- A proposed framework for bereavement outcomes in late-life which incorporates contextual factors prior to bereavement (Shah and Meeks, 2012).

- The Dual Process Model of Coping with Bereavement – although this is a general model of bereavement, rather than a model of complicated grief, the authors of the model argue that it ‘provides a framework for understanding forms of complicated grief, such as chronic, or absent, delayed, inhibited grief’ (Stroebe and Schut, 2010, p.281).

Currently, the most commonly used terms are ‘complicated grief’ and ‘prolonged grief’, with each term reflecting differences in the way the condition is conceptualised. The former suggests a condition that is qualitatively different from what may be described as ‘normal’ grief; whereas ‘prolonged grief’ implies that the (normal) acute grief response persists for too long; that is, the bereaved person becomes ‘stuck’ in the grieving process (Bryant, 2014).
The literature on grief, bereavement and complicated grief is characterised by what has been described as a ‘fundamental paradox’ involving two ‘parallel discourses’: on the one hand there is recognition that grief is a unique experience dependant on multiple variables (e.g. the circumstances of the death, the characteristics of the bereaved individual, the relationship between the bereaved individual and the deceased) while at the same time there is ongoing work to differentiate between grief that is ‘normal’ and grief that is ‘complicated’ (Breen and O’Connor, 2007).

Differences in terminology not only occur between researchers, but the same researchers at different points in time. For example, one of the most well-known tools for measuring complicated grief is the Inventory of Complicated Grief, published in 1995 (Prigerson et al., 1995). In 2001, the authors revised the tool and renamed it the ‘Inventory of Traumatic Grief’, in part because they considered the term ‘complicated’ to be ‘vague’ (Prigerson and Jacobs, 2001). Others argue that the term ‘complicated grief’ is preferred to ‘traumatic grief’ because it avoids confusion with PTSD (Lobb et al., 2010).

Accumulating evidence regarding the adverse consequences that can arise from the grieving process led to formal proposals from two teams of researchers in the USA to include bereavement-related grief as a medical diagnosis in the 5th edition of the Diagnostic Statistical Manual of Mental Disorders (DSM-5). One team referred to such a disorder as prolonged grief disorder, the other to the disorder as complicated grief. The diagnostic criteria proposed by each research team are summarised in Table 3. Both sets of criteria propose that a diagnosis should not be made until at least six months has elapsed since the bereavement. Although the symptoms differ in the two sets of criteria, what is common is the emphasis on the intensity, frequency and duration of symptoms. Prigerson et al. identified two clusters of symptoms: (1) symptoms related to separation distress; (2) symptoms related to traumatic distress (e.g. bitterness or anger, sense of disbelief regarding the death) (Nanni et al., 2015). Shear et al. did not make this distinction.

Ultimately, these proposals were rejected based on a judgement that the evidence was preliminary and insufficient to justify a separate diagnosis (Bryant, 2014). Instead, it was decided to recognise ‘persistent complex bereavement disorder’ (PCBD) as a condition requiring further study before inclusion as a formal diagnosis in a future edition.

The proposed diagnostic criteria for PCBD require that the person experiences yearning or longing for the deceased, intense sorrow or preoccupation with the deceased or the circumstances of the death, along with at least six other symptoms (from a list of 12) of reactive distress and/or disruption to social behaviour or identity. These symptoms must cause clinically significant distress or impairment to important areas of functioning, and be considered ‘out of proportion’ to cultural and other norms. In contrast to the proposed definitions in Table 3 which identify six months as the minimum period for making such a diagnosis, the criteria for PCBD specify that symptoms must be present for at least 12 months after the death (six months for bereaved children) (American Psychiatric Association, 2013).

Another change in DSM-5 was the removal of the so-called ‘bereavement exclusion’. The previous edition of the DSM excluded the possibility of diagnosing either adjustment disorder
or depression in the immediate aftermath of bereavement. Removing this exclusion generated controversy, with some arguing that it was now possible for people experiencing high levels of distress due to bereavement to be diagnosed earlier, and hence treated earlier. The contrary view was that this may result in over-diagnosis of symptoms that would likely reduce within six months if left untreated, thus contributing to the medicalisation of ‘normal’ grief (Guldin, 2014; Zisook et al., 2012). Removing the bereavement exclusion essentially assumes that major depression occurring after bereavement is the same disorder as depression occurring after other life experiences or for no apparent reason (Iglewicz et al., 2013).

As an indication of the ongoing debate about the diagnosis of complicated grief (whatever term is used), the team led by Katherine Shear is now saying that the provisional criteria for PCBD specified in DSM-5 should not be used because ‘they fail to identify a large proportion of individuals with persistent acute grief symptoms and severe impairment in functioning’ (Shear et al., 2016).

One perspective on grief and bereavement is that the response to loss can be expressed as a continuum: at one end of the continuum return to psychological equilibrium occurs fairly quickly whereas at the other end the response is complicated grief. Somewhere in the middle is the more common response of moderate distress which ameliorates over time. An alternate perspective is that complicated grief is a disorder that is quite distinct from ‘normal’ grief (Burke and Neimeyer, 2012). Research which specifically investigated this issue found support for the proposition that ‘normal’ and ‘complicated’ grief occur along the same continuum, implying that complicated grief can be understood as a more severe or prolonged form of normal, acute, grief, rather than as something completely different (Holland et al., 2009, p.198). One consequence of this finding is that attempts to measure complicated grief should involve the use of tools which allow for continuous measurement, rather than categorising responses to bereavement into two categories: normal and complicated.

Wakefield has argued strongly that conceptualising complicated grief as a disorder characterised by symptoms that are qualitatively different from normal grief is not supported by the available evidence:

*There are no distinctive symptoms of PGD versus normal grief, and the severity of PGD is not different from the severity of normal acute grief. The empirical data suggest that the durational thresholds associated with existing PGD proposals do not distinguish those who are frozen in chronic distress from those who are simply improving slowly and may yet resolve their grief to an acceptable level (Wakefield, 2012, p.509).* (Note: PGD refers to ‘prolonged grief disorder’, a generic term used in the article by Wakefield)

Support for the concept of grief as a continuum comes from the broader literature on personality and psychopathology (Haslam et al., 2012). Irrespective of how complicated grief is conceptualised, differentiating what is normal (and hence self-limiting) from what is not normal presents a particular clinical challenge: ‘a clinician evaluating a bereaved person is at risk for both over-and under-diagnosis, either pathologizing a normal condition or neglecting to treat an impairing disorder’ (Shear et al., 2011, p.104).
This lack of clarity about definitions, conceptualisation and measurement has far-reaching consequences when reviewing the evidence in the literature and evaluating the practical application of that evidence. It cannot be assumed that one person writing about ‘complicated grief’ is talking about the same thing as another person writing about ‘traumatic grief’ or ‘prolonged grief’. The prevalence of complicated grief in one study may be different to the prevalence of complicated grief in another study, at least in part, because a different tool was used to measure complicated grief in each study.

Table 3  Proposed diagnostic criteria

<table>
<thead>
<tr>
<th>Separation distress</th>
<th>Proposed criteria for prolonged grief disorder (Prigerson et al., 2009) (emphasis added)</th>
<th>Proposed criteria for complicated grief (Shear et al., 2011) (emphasis added)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The bereaved person experiences yearning (e.g. craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired, but unfulfilled, reunion with the deceased) daily or to a disabling degree.</td>
<td>At least one of the following symptoms of persistent intense acute grief has been present for a period longer than is expected by others in the person’s social or cultural environment:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1. Persistent intense yearning or longing for the person who died.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Frequent intense feelings of loneliness or like life is empty or meaningless without the person who died.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Recurrent thoughts that it is unfair, meaningless, or unbearable to have to live when a loved one has died, or a recurrent urge to die in order to find or to join the deceased.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Frequent preoccupying thoughts about the person who died.</td>
</tr>
<tr>
<td>Cognitive, emotional, and behavioural symptoms</td>
<td>The bereaved person must have five (or more) of the following symptoms experienced daily or to a disabling degree:</td>
<td>At least two of the following symptoms are present for at least a month:</td>
</tr>
<tr>
<td></td>
<td>1. Confusion about one’s role in life or diminished sense of self (i.e. feeling that a part of oneself has died).</td>
<td>1. Frequent troubling rumination about circumstances or consequences of the death.</td>
</tr>
<tr>
<td></td>
<td>2. Difficulty accepting the loss.</td>
<td>2. Recurrent feeling of disbelief or inability to accept the death.</td>
</tr>
<tr>
<td></td>
<td>3. Avoidance of reminders of the reality of the loss.</td>
<td>3. Persistent feeling of being shocked, stunned, dazed or emotionally numb since the death.</td>
</tr>
<tr>
<td></td>
<td>4. Inability to trust others since the loss.</td>
<td>4. Recurrent feelings of anger or bitterness related to the death.</td>
</tr>
<tr>
<td></td>
<td>5. Bitterness or anger related to the loss.</td>
<td>5. Persistent difficulty trusting or caring about other people or feeling intensely envious of others who have not experienced a similar loss.</td>
</tr>
<tr>
<td></td>
<td>6. Difficulty moving on with life (e.g. making new friends, pursuing interests).</td>
<td>6. Frequently experiencing pain or other symptoms that the deceased person had, or hearing the voice or seeing the deceased person.</td>
</tr>
<tr>
<td></td>
<td>7. Numbness (absence of emotion) since the loss.</td>
<td>7. Experiencing intense emotional or physiological reactivity to memories of the person who died or to reminders of the loss.</td>
</tr>
<tr>
<td></td>
<td>8. Feeling that life is unfulfilling, empty, or meaningless since the loss.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9. Feeling stunned, dazed or shocked by the loss.</td>
<td></td>
</tr>
<tr>
<td>Proposed criteria for prolonged grief disorder (Prigerson et al., 2009) (emphasis added)</td>
<td>Proposed criteria for complicated grief (Shear et al., 2011) (emphasis added)</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>8. Change in behaviour due to excessive avoidance or the opposite, excessive proximity seeking.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Timing</strong></td>
<td>Diagnosis should not be made until at least six months have elapsed since the death. The person has been bereaved for at least six months. The duration of symptoms and impairment is at least one month.</td>
<td></td>
</tr>
<tr>
<td><strong>Impairment</strong></td>
<td>The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g. domestic responsibilities). The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning, where impairment is not better explained as a culturally appropriate response.</td>
<td></td>
</tr>
<tr>
<td><strong>Relation to other mental disorders</strong></td>
<td>The disturbance is not better accounted for by major depressive disorder, generalised anxiety disorder, or posttraumatic stress disorder.</td>
<td></td>
</tr>
</tbody>
</table>

### 3.2 Overlap between complicated grief, depression and posttraumatic stress disorder

In general, complicated grief has been framed as a distinct clinical entity from disorders such as major depressive disorder (MDD) or PTSD (Prigerson et al., 2009; Nanni et al., 2015). However, this perspective has been challenged on the grounds that, for example, symptoms of complicated grief and bereavement-related depression overlap (Shah and Meeks, 2012).

O’Connor et al. (2010) assessed a group of elderly, married people with a history of at least one significant bereavement using the Inventory of Complicated Grief-Revised and a tool commonly used to assess PTSD (the Harvard Trauma Questionnaire). The researchers then used confirmatory factor analysis to analyse the results, concluding that ‘a substantial overlap appears to exist between CG and PTSD ... It is therefore very likely that clear differentiation between CG or PGD and bereavement related PTSD will be difficult both in scientific and clinical settings’ (O’Connor et al., 2010, p.678).

The prevalence of posttraumatic stress disorder following bereavement has been studied in various populations in Denmark:

- Of 54 people bereaved due to a terminal illness (cancer), 29.5% had PTSD one month post-bereavement, declining to 21.6% six months post-bereavement (Kristensen et al., 2014).
- Of 54 elderly (mean age 75 years) bereaved people, 27% had PTSD one month after their loss, declining to 17% six months after their loss (Elklit and O’Connor, 2005).
- Study involving the entire population of bereaved people aged between 65 and 80 years living in a particular locality (a total of 296 people at study commencement), of which 16% were diagnosed with PTSD at 2 months, and this was virtually unchanged at 6 months, 13 months and 18 months (O’Connor, 2010).
Studies which have involved the measurement of complicated grief and PTSD in the same cohort of patients have generally taken a cross-sectional approach, which does not allow for investigation of which disorder may influence the other. To overcome this limitation, a group of researchers in Denmark studied a group of elderly people whose spouse had died (237 at the first assessment) and assessed them at 6 months, 13 months, 18 months and 48 months post loss. Complicated grief, referred to in the study as prolonged grief symptoms, was assessed using the 15-item Inventory of Complicated Grief-Revised. It was tentatively concluded that ‘changes in prolonged grief symptoms had a considerably stronger impact on subsequent changes in PTS [posttraumatic stress] than vice versa’ (O’Connor et al., 2015, p.338).

In-depth analysis of the differences between complicated grief, depression and PTSD was beyond the scope of this evidence appraisal. However, an important implication for clinical practice is not just the potential for overlap, but also that the conditions can occur at the same time. One study involving 206 bereaved people scoring 30 or more on the Inventory of Complicated Grief (i.e. meeting the study criteria for complicated grief) found that 32.0% had complicated grief only; 19.4% had complicated grief and Major Depressive Disorder; 12.6% had complicated grief and PTSD; and 35.9% had all three conditions (Simon et al., 2007). This situation indicates a role for psychiatrists and other mental health professionals in providing care for bereaved individuals (Irwin and Ferris, 2008). It also suggests that people who seek treatment following bereavement should be screened for comorbid conditions such as mood and anxiety disorders and suicidal ideation and these should be addressed immediately, even if it is too early to diagnose complicated grief (Simon, 2013).

3.3 Impact of bereavement, including complicated grief

The impact of complicated grief is a combination of the number of people who experience complicated grief and the adverse consequences experienced by those with complicated grief. This has to be considered within the context of ‘normal’ grief, which in itself can have adverse consequences.

3.3.1 Adverse outcomes of bereavement

Stroebe et al. (2007) conducted a review of the literature to identify the evidence regarding the links between bereavement and physical and mental health. The review provides a useful baseline against which to compare the consequences of complicated grief. The authors concluded that bereavement is associated with the following:

- An increased risk of mortality from many causes, including suicide. Much of this increased mortality is due to what is known colloquially as a ‘broken heart’ (i.e. the psychological distress resulting directly from the loss and the indirect results of that loss, including changes in social ties and living arrangements). The increased risk of mortality is greatest in the early period of bereavement. It is important to note that although the relative risk of mortality increases after bereavement, the absolute risk is relatively low.
- An increased likelihood of physical health problems, particularly in the early bereavement period.
- Higher rates of disability, medication use, and hospitalisation (than people who are not bereaved).
A wide range of psychological symptoms and illnesses, including guilt, anger, loneliness, yearning, lowered self-esteem, helplessness, agitation, fatigue, social withdrawal, loss of appetite and sleep disturbances.

An increase in symptoms of depression, with 10-20% reaching levels of depression considered clinically important.

In some instances, particularly in cases of violent or horrific death, bereavement can result in PTSD (Stroebe et al., 2007).

The finding regarding increased risk of mortality is supported by economic modelling which demonstrates that the death of a partner increases the mortality rate of the survivor, particularly in the first 2.5 years of bereavement, with bereaved men and women losing an average of 11.5% and 12.5% respectively of their residual life expectancy (van den Berg et al., 2011). A meta-analysis came to a similar finding: ‘widowhood substantially increases the risk of death among broad segments of the population’ (Shor et al., 2012, p.600). Research in the UK indicates that unexpected bereavement (death of a partner without recorded chronic disease) results in greater mortality than expected bereavement (death of a partner with chronic disease) (Shah et al., 2013).

An interesting exception to the finding of increased mortality due to bereavement comes from a large study in the UK involving over 15,000 people who were living with a person diagnosed with cancer six months prior to their death. Compared to an even larger control group (>76,000 people), people exposed to a cancer death had a reduced risk of mortality (King et al., 2013). The study authors surmise that ‘one possible explanation for our finding is that many patients dying of cancer in the UK receive greater supportive and palliative care services than those dying from other causes and this may moderate cohabitees’ extreme stress’ (King et al., 2013, p.4).

A more recent review than the one by Stroebe et al. (2007) focused on changes in routine health behaviours for a specific, but large, group of bereaved people – those 50 years of age and older bereaved by the death of a spouse. Only four studies were common to both reviews. The findings included:

- The evidence regarding a link between bereavement and physical activity is inconsistent.
- There is strong evidence that bereavement results in increased nutritional risk, including poor dietary behaviours (e.g. eating alone, skipping meals) and worsened nutrient intake.
- There is some evidence that bereavement has a negative effect on the quality of sleep.
- There is moderate support for a link between bereavement and increased alcohol intake.
- The evidence regarding a link between bereavement and tobacco use is inconsistent.
- There is strong evidence for a relationship between bereavement and weight loss, although the long-term effects of this are unknown (Stahl and Schulz, 2014).

Rosenberg et al. (2012) conducted a systematic review of the evidence regarding psychosocial morbidities among bereaved parents of children who died from cancer. Based on the results from 13 studies, they concluded that this group of parents ‘have elevated rates of anxiety,
depression, prolonged grief, poor psychological well-being, poor physical health, and poor quality of life’ (Rosenberg et al., 2012, p.510). In making that judgement, the authors pointed out that different comparison groups were used in the included studies to arrive at a finding of ‘elevated rates’. This raises the broader point that any assessment of the impact of bereavement or complicated grief is critically dependent on what the impact on the bereaved group is being compared to. The systematic review identified that the factors associated with psychosocial morbidity included some linked to the nature of the bereavement, such as the duration and intensity of the child’s treatment, perception of medical care, perception of their child’s quality of life, and preparation time before their child’s death (Rosenberg et al., 2012).

### 3.3.2 Prevalence of complicated grief

There are many references in the literature (e.g. Lobb et al., 2010) to estimates of 10%-20% of bereaved people experiencing complicated grief, largely based on studies that are now relatively old and pre-dating any well-accepted measures of complicated grief. Table 4 summarises the results from some more recent studies, all using the Inventory of Complicated Grief or one of its variants to assess complicated grief (usually by way of a ‘cut-off’ total score to signify the presence of complicated grief). The results from these studies indicate that the prevalence of complicated grief in the general population of adults is about 4%-5%, based on the results from the studies by Kersting et al. (2011) and Newson et al. (2011). When the presence of complicated grief has been investigated in groups of people who have experienced bereavement, the rates of complicated grief are much higher, with the highest rate (59%) amongst the parents of children who died in a paediatric intensive care unit.

<table>
<thead>
<tr>
<th>Sample / Reference</th>
<th>Measurement of CG</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Randomly-selected nation-wide (Germany) population sample of 1402 people aged 14-95 years old who had experienced a major bereavement (Kersting et al., 2011).</td>
<td>18-item German version of the Inventory of Complicated Grief-Revised. Presence of complicated grief based on minimum total score and scores on individual items.</td>
<td>The average time since bereavement = 9.8 years. Conditional prevalence of CG after major bereavement = 6.7%. Prevalence of CG in general sample = 3.7%.</td>
</tr>
<tr>
<td>5741 adults over 55 years of age participating in a Dutch prospective cohort study investigating the occurrence and risk factors of chronic diseases (Newson et al., 2011).</td>
<td>Score of 22 or higher on the 17-item Dutch version of the Inventory of Complicated Grief and experiencing symptoms for longer than six months.</td>
<td>Prevalence of CG = 4.8% (3.2% for men and 6.0% for women). This was based on the results from the ICG-R and symptoms reported for at least six months.</td>
</tr>
<tr>
<td>Longitudinal cohort study with measurement of complicated grief and depression at 2, 6, 13, and 18 months post-loss in a Danish palliative care unit (Guldin et al., 2012).</td>
<td>Score of 36 or more on the 15-item Inventory of Complicated Grief-Revised.</td>
<td>Of the 114 carers asked to participate, 88 (77%) accepted. Prevalence of CG = 40% at the 6 months follow-up, decreasing to 28% at 13 months follow-up.</td>
</tr>
<tr>
<td>217 bereaved carers of people with Alzheimer’s disease (Schulz et al., 2006).</td>
<td>Score of 30 or more on the 19-item Inventory of Complicated Grief.</td>
<td>Prevalence of CG amongst carers = 19.8%.</td>
</tr>
<tr>
<td>668 carers of terminal cancer patients in University Hospital in Taiwan (Chiu et al., 2010).</td>
<td>Score greater than 25 on the Chinese variation of the Inventory of Complicated Grief</td>
<td>Average time since bereavement = 8.9 months. Prevalence of CG = 24.6%.</td>
</tr>
</tbody>
</table>
### 3.3.3 Impact of complicated grief

Table 5 summarises studies which specifically investigated the impact of complicated grief, typically using the Inventory of Complicated Grief to assess the presence of complicated grief. The size of the sample in each study is generally quite small, perhaps reflecting the difficulty in recruiting subjects who have experienced bereavement. The evidence indicates wide-ranging adverse consequences of complicated grief, including impacts on level of functioning, quality of life, mental health, cognitive functioning, physical health, ability to sleep, and ability to function socially and at work. These studies indicate the difficulty comparing the impact of complicated grief with the impact of ‘normal’ grief. For example, some of the studies only include subjects who meet the criteria for complicated grief; most of the impact of ‘normal’ grief occurs in the first six months post-bereavement whereas studies of complicated grief extend longer than six months; and complicated grief often co-exists with other significant morbidity (e.g. PTSD).

<table>
<thead>
<tr>
<th>Sample / Reference</th>
<th>Measurement of CG</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>261 survey responses from parents of 195 children who died in the PICU six months previously (Meert et al., 2010).</td>
<td>Score of 30 or higher on the 19-item Inventory of Complicated Grief.</td>
<td>Prevalence of CG in parents = 59%. Parents from only 23% of families responded to the survey.</td>
</tr>
<tr>
<td>58 bereaved parents with no known major psychiatric illnesses completed standardised self-report questionnaires (McCarthy et al., 2010).</td>
<td>17-item Inventory of Complicated Grief–Revised.</td>
<td>Six parents (10.3%) met the study criteria for CG. Mean length of time elapsed since child’s death = 4.5 years.</td>
</tr>
</tbody>
</table>

**Table 5 Impact of complicated grief**

<table>
<thead>
<tr>
<th>Sample / Reference</th>
<th>Measurement of complicated grief</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>96 bereaved people (6 months to 1 year post-loss) assessed when included in the study (T1) and assessed for outcomes 6 months later (T2) and 12 months later (T2) (Boelen and Prigerson, 2007).</td>
<td>Inventory of Complicated Grief-Revised (Prigerson and Jacobs, 2001).</td>
<td>CG at T1 predicted quality of life and mental health outcomes at T2 and T3 (e.g. general health perception, sleeping problems, depression, anxiety). CG increases the risk of impairments in functioning and reduced quality of life.</td>
</tr>
<tr>
<td>150 bereaved people interviewed 6 months, 13 months and 25 months post-bereavement (Prigerson et al., 1997).</td>
<td>Grief Measurement Scale, modified to include only items in the Inventory of Complicated Grief.</td>
<td>CG increased the risk of cancer. CG at 6 months associated with increased blood pressure at 13 months and development of heart problems at 25 months. New cases of cancer and heart problems were rare.</td>
</tr>
<tr>
<td>309 bereaved adults assessed at 6 months and 10 months post-loss for suicidality and CG (Latham and Prigerson, 2004).</td>
<td>Inventory of Complicated Grief-Revised.</td>
<td>CG substantially heightened the risk of suicidality after controlling for important confounders such as Major Depressive Disorder and PTSD.</td>
</tr>
<tr>
<td>112 bereaved people provided data at four time points – upon entry to the study, then 3, 6 and 12 months later – of which 29 met</td>
<td>Score of 32 or more according to the Inventory of Complicated Grief</td>
<td>No significant differences in the prevalence of self-reported physical or mental illness between those with CG and those without CG (but note that the</td>
</tr>
</tbody>
</table>
Sample / Reference | Measurement of complicated grief | Results
---|---|---
the study criteria for CG (Ott, 2003). | (measured at study entry, 3 months and 6 months). | presence of CG was not assessed beyond 6 months).
335 help-seeking people with CG assessed for cognitive function (Hall et al., 2014). | Score of 30 or more on the Inventory of Complicated Grief at least 6 months after the death of a loved one. | CG was associated with lower levels of cognitive function compared to controls – although statistically significant, the clinical significance was unclear.
206 bereaved people meeting the criteria for CG assessed using various measures, including the Work and Social Adjustment Scale (Simon et al., 2007). | Score of 30 or more for the Inventory of Complicated Grief (ICG). | After controlling for the presence of psychiatric comorbidity, ICG scores were significantly associated with greater work and social impairment (based on the Work and Social Adjustment Scale which includes items for impairment of home management, leisure activities, ability to work, and ability to form and maintain relationships).
67 widowed persons, of which 18% (n=12) met the diagnostic criteria for traumatic grief and 88% were in the first 6 months of bereavement (Silverman et al., 2000). | Structured clinical interview using the Traumatic Grief Evaluation of Response to Loss. | A diagnosis of traumatic grief was significantly positively associated with lower social functioning scores, lower mental health scores and lower energy levels.
105 people bereaved for at least 6 months, of which 43% had experienced at least one loss due to violent death and 37 had CG only (with the remainder also having Major Depressive Disorder or Posttraumatic Stress Disorder) (Germain et al., 2005). | Score of greater than or equal to 30 using the Inventory of Complicated Grief. | The results indicated that CG is associated with poor sleep quality. The presence of comorbid Major Depressive Disorder further decreased sleep quality and sleep efficiency.
177 people bereaved for an average period of 6.5 months, of which 86 met the criteria for CG (Boelen and Lancee, 2013). | Score of greater than 25 using the Inventory of Complicated Grief. | Sleep difficulties were higher than normal for both those diagnosed with CG and those not diagnosed with CG. Increased sleep difficulties were associated with increased CG severity.

No studies were identified which directly measured the impact of complicated grief on productivity but all the adverse consequences of complicated grief detailed in Table 5 have the potential to reduce productivity.

Most studies of the impact of bereavement in general, or complicated grief in particular, are relatively short-term, with follow-up extending over one to two years at most. A notable exception is a study which followed up a group of 72 bereaved people over a period of 10 years and compared their morbidity to a group of 80 non-bereaved controls, finding elevated levels of mental health morbidity and circulatory system disorders in the bereaved group (Jones et al., 2010).
3.4 Interventions for complicated grief

In their review of the efficacy of bereavement interventions, Schut et al. used the following schema for categorising interventions:

- **Primary preventive interventions** – open to all bereaved people.
- **Secondary preventive interventions** – open to bereaved people who either because of screening or assessment are considered to be more vulnerable to the risks of bereavement.
- **Tertiary preventive interventions** – interventions involving those who suffer from complicated grief, usually as a result of help-seeking on the part of the bereaved individuals (Schut et al., 2001).

They concluded that there was an ascending level of efficacy across the three intervention categories: none of the primary prevention interventions then available could be considered as evidence-based; studies of secondary preventive interventions had produced mixed results with any positive results ‘generally rather modest’ and of short duration; and that ‘most studies addressing tertiary intervention conclude that the intervention is helpful’ (Schut et al., 2001).

Currier and colleagues, in a later review, used different terminology to describe similar categories (universal interventions, selective interventions, indicated interventions) but essentially arrived at the same conclusion: ‘although there is some evidence for the usefulness of bereavement interventions with indicated grievers, little empirical support exists at this point for the effectiveness of universal and selective efforts’ (Currier et al., 2008, p.650). Indicated grievers are those ‘manifesting problems adapting to loss’, which not only includes those who might have complicated grief but also those suffering disorders such as depression.

Waldrop, from a social work perspective, reviewed the literature on psychosocial treatments at the end-of-life for both older adults and their carers, identifying seven bereavement intervention studies to include in the review. The seven studies focused on the experiences of bereaved spouses, with six studies involving group interventions and one study involving an individual intervention. Each study can be classified as a universal intervention (i.e. open to all bereaved people without a focus on complicated grief). It was concluded that ‘most of the bereavement studies reviewed report either limited or no treatment effects’ (Waldrop, 2008, p.285), which is consistent with other reviews of the literature regarding the effectiveness of universal interventions.

Table 6 summarises reviews of the evidence regarding the effectiveness of interventions for complicated grief. In some cases the reviews focus on complicated grief, in other cases the scope is broader but include at least some interventions for complicated grief.

<table>
<thead>
<tr>
<th>Title and reference</th>
<th>Details of the review</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assisting the bereaved: a systematic review of the evidence for grief counselling (Waller et al., 2016)</td>
<td>Literature search 2006 to 2013. Included 76 grief counselling intervention studies investigating a range of therapies, including cognitive behavioural therapy, Interpersonal</td>
<td>Quality of most studies was poor. Of the three studies of high methodological quality, one examined the effectiveness of complicated grief treatment (relative to interpersonal psychotherapy), and two</td>
</tr>
<tr>
<td>Title and reference</td>
<td>Details of the review</td>
<td>Findings</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Hospital-based bereavement services following the death of a child: a mixed study</td>
<td>Literature search 1980 to 2014. Included 13 qualitative, 6 quantitative, and 9 mixed-method studies, broadly comprising family support, staff support, education, and community outreach, most commonly consisting of phone calls at key intervals (n = 12), provision of resource materials (n = 10), and group programs (n = 9).</td>
<td>There is a dearth of rigorous quantitative and qualitative studies of hospital-based bereavement care interventions following the death of a child. It is difficult to provide recommendations for evidence-based bereavement care. Quantitative data suggests that bereavement services have most effect for parents experiencing more complex mourning.</td>
</tr>
<tr>
<td>review (Donovan et al., 2015)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evidence for psychodynamic psychotherapy in specific mental disorders: a systematic</td>
<td>Literature search 1970 to 2013. Included 47 RCTs, of which two involved the treatment of complicated grief with short-term group therapy.</td>
<td>There is evidence for the efficacy of psychodynamic psychotherapy in various disorders, including depression, complicated grief, anxiety disorders, and PTSD (only 1 RCT involving PTSD was included in this review).</td>
</tr>
<tr>
<td>review (Leichsenring and Klein, 2014)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Efficacy of cognitive behavioral interventions on complicated grief in adults: a</td>
<td>Included 11 studies of cognitive behavioural intervention aimed at reducing complicated grief symptoms and/or co-morbid symptoms in bereaved adults.</td>
<td>The results of the meta-analysis indicated that cognitive behavioural interventions have no significant effect on symptoms of complicated grief.</td>
</tr>
<tr>
<td>quantitative meta-analysis (Nagy and Szamosközi, 2013)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The prevention and treatment of complicated grief: a meta-analysis (Wittouck et al.,</td>
<td>Literature search 1990 to 2007. Included 14 RCTs in which an intervention to prevent (n = 9) or treat (n = 5) CG was offered to bereaved adults.</td>
<td>There is a lack of evidence to support the effectiveness of preventive interventions. Treatment interventions appear to be efficacious in the short-term and long-term. The positive effect of treatment interventions increases significantly over time.</td>
</tr>
<tr>
<td>2011)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The effectiveness of psychotherapeutic interventions for bereaved persons: a</td>
<td>Included 61 outcome studies, reported in 64 papers, each comparing a group of bereaved people who received grief therapy with a group of bereaved people who did not receive any intervention. Modality of intervention included groups (63%), individuals (25%) and families (12%). Main interventions were psychotherapy and counselling (63%), professional organised support groups (17%) and crisis intervention (11%).</td>
<td>Interventions targeting universal populations failed to produce better outcomes than would be expected by the passage of time. Interventions targeting high-risk grievers showed a benefit but the gains were relatively small and were not sustained. Interventions targeting those with specific difficulties adapting to loss achieved favourable results, comparable with the success of psychotherapy in general.</td>
</tr>
<tr>
<td>comprehensive quantitative review (Currier et al., 2008)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The reviews summarised in Table 6 indicate that there is little evidence for the effectiveness of universal (primary preventive) interventions. In contrast, there is some evidence that selective (secondary preventive) interventions can be effective for those at risk of complicated grief, at least in the short term (e.g. Currier et al., 2008). There is strong evidence that targeted
(tertiary) interventions are effective in treating people who are experiencing complicated grief. Such therapies can alleviate symptoms in the short and long term, and their impacts may increase over time (Currier et al., 2008; Wittouck et al., 2011; Waller et al., 2016; Nagy and Szamosközi, 2013).

These conclusions are generally consistent with those of another recent review (which did not meet inclusion criteria) focusing on identification, differential diagnosis and clinical management of complicated grief (Simon, 2013). Among the studies included in that review was a randomised controlled trial of Complicated Grief Treatment, a 16-week program developed by Katherine Shear and colleagues, which addresses issues that are interfering in the grieving and healing process. The trial demonstrated that this targeted therapy was more effective than interpersonal therapy. Three other studies of targeted therapies for complicated grief were also reviewed including an internet-based intervention. All demonstrated beneficial effects compared with a control group. The reviewer concluded that therapies specifically addressing issues of grief and loss were effective for those experiencing complicated grief. Key elements of these therapies were psychoeducation, processing of the loss (e.g. by recounting the story of the death repeatedly), social support, goal setting and reducing avoidance behaviours (Simon, 2013).

Since the publication of these reviews, there have been two new randomised controlled trials of treatments for people experiencing complicated grief (indicated/tertiary interventions). One of these (Bryant et al., 2014) built on previous findings that cognitive behavioural therapy (CBT), in combination with exposure-based therapies, effectively alleviated symptoms of complicated grief. Participants who met criteria for complicated grief were randomised to two groups, both of which received 10 group sessions of CBT and four individual sessions with a clinical psychologist. During the individual sessions, those in the treatment group were educated about avoidance and its role in prolonging grieving, and guided through exercises in which they spent 40 minutes reliving the death and describing their responses in the present tense (Bryant et al., 2013). Therapists ensured that patients were focusing on aspects of the experience associated with high levels of distress. Patients in the control condition received supportive counselling. Patients were followed up immediately post-treatment and again after six months. The combination of CBT and exposure was more effective than CBT alone, leading to greater decreases in symptoms of complicated grief and depression, greater reductions in negative appraisals of the world and negative cognitions related to self-blame, and stronger improvements in psychological and social functioning. There were no negative consequences of exposure therapy.

In the second trial, participants were randomised to four groups: antidepressant medication only; placebo only; antidepressant plus Complicated Grief Treatment; or placebo plus Complicated Grief Treatment (Shear et al., 2016). All participants initially met criteria for complicated grief and were reassessed every month for 20 weeks. Symptom reduction was more likely among those who received the 16-session Complicated Grief Treatment than those who received the placebo only. Adding the antidepressant to Complicated Grief Treatment helped reduce symptoms of depression but did not improve grief-related outcomes. Both groups who received Complicated Grief Treatment had lower levels of suicidal ideation than those treated with medication or placebo only (Shear et al., 2016). These two recent, high-
quality studies strengthen the evidence base for targeted therapies for those experiencing complicated grief (indicated/tertiary interventions).

One of the difficulties with measuring the impact of primary and secondary preventive interventions is that most bereaved people will not experience complicated grief. Without valid and reliable predictive screening tools, it will be difficult to generate good evidence about how best to prevent complicated grief because researchers will be unable to recruit the right people into the studies. The essential first step in evaluating a primary or secondary preventive intervention is being able to identify who is most likely to need the intervention. Unless this is done, because of the low prevalence of complicated grief, studies may have insufficient statistical power to detect any effect of the intervention.

In addition to the evidence outlined above, the *Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients* developed by the Centre for Palliative Care in Melbourne provides a set of 20 guidelines for psychosocial and bereavement support based on a review of the literature and a process of consultation with experts and key stakeholders to refine the guidelines (Hudson et al., 2010b). With the exception of one mention of screening for prolonged grief, complicated grief is not specifically mentioned in the guidelines but five of the guidelines do focus on risk assessment and bereavement support:

**Guideline 10** Based on discussion with the family caregiver(s), determine the current state of and risk for poor psychological health and/or prolonged grief and plan relevant intervention(s).

**Guideline 14** The interdisciplinary team identifies a means of communicating with the family caregiver(s) to determine short-term and long-term post-death responses. Potential external bereavement support services are identified, if required.

**Guideline 17** Contact the family caregiver(s) and other family members (as appropriate) to assess needs at three to six weeks post-death and adapt bereavement care plan accordingly.

**Guideline 18** Develop a preliminary bereavement care plan based on the needs of the family caregiver(s), the pre-death risk assessment and the circumstances of the death (e.g. unexpected or traumatic)

**Guideline 19** Conduct a follow-up assessment of the family caregiver(s) and other family members (if appropriate) six months post-death.

The guidelines were based on a systematic review of psychosocial interventions for family carers of palliative care patients. For reasons that are not specified in the paper, studies which focused on bereavement outcomes were excluded from the systematic review. The authors note that ‘the overwhelming majority’ of the papers identified by searching the literature focused on caregiver experiences and the needs of carers rather than the evaluation of specific interventions. This resulted in the authors concurring with an earlier review of the literature on a similar subject that ‘empirical inquiry regrading effective ways to provide psychosocial support to family carers is still in its infancy’ (Hudson et al., 2010a, p.4).
The most recent literature review aimed to identify the state of bereavement services evaluation, the types of services currently provided and any evidence of effectiveness (Wilson et al., 2016). As such, it provides a useful summary of the efficacy of bereavement services and how well bereavement services have been evaluated. The review found considerable diversity in the type of services provided, involving three broad categories of services:

1. Crisis intervention services, providing immediate assistance to people in the initial acute phase of grief, often by health care providers working in hospitals and nursing homes.
2. Services provided later in the grieving process to hasten or improve recovery.
3. Services to prevent or treat complicated grief – these services are often components of the other two types of services.

The review found the state of the science with regard to bereavement service evaluation was ‘in the beginning stages’, with many evaluations undertaken by those providing the bereavement services. Most evaluations appeared to have been conducted by people without expertise in evaluation or research. Of the 38 services included in the review, 14 provided primary preventive interventions, 21 provided secondary preventive interventions targeting high-risk groups (primarily bereaved parents and bereaved children) and three provided tertiary preventive interventions for those with complicated grief. The authors concluded that ‘with such diversity in services examined, and with little confirming evidence of effectiveness for any specific service or group of services, it cannot be said that any type demonstrated clear or irrefutable evidence of effectiveness’ (Wilson et al., 2016, p. 15).

No reviews of the literature on the use of medications to treat complicated grief meeting the criteria for inclusion in this evidence appraisal were identified. Shear states that despite a lack of randomised controlled trials to inform the use of pharmacotherapy for complicated grief, the use of antidepressant medication is common (Shear, 2015), although this may reflect a United States perspective rather than an Australian perspective.

One review (not meeting the criteria for inclusion) noted that pharmacological studies of complicated grief are ‘scarce’ but that there is some evidence that selective serotonin reuptake inhibitors and tricyclic antidepressants may be effective in the treatment of complicated grief (Bui et al., 2012). Another review noted that treatment with benzodiazepines is not recommended as these drugs can interfere with memory and learning, thus hindering psychological adaptation to bereavement (Simon, 2013). Specialised bereavement therapies should be the first line of treatment, with antidepressants used as an adjunct where necessary; there is some evidence that they improve adherence and enhance patients’ responses to complicated grief treatment. Earlier treatment with antidepressants may be warranted where there is comorbid depression and/or suicidal ideation (Simon, 2013). Findings from these reviews are broadly consistent with the recommendations of the Australian Centre for Posttraumatic Mental Health that where medication is required for the treatment of complicated grief, newer antidepressants should be considered as the first choice and should be delivered as an adjunct to psychological intervention (Australian Centre for Posttraumatic Mental Health, 2012).
3.5 Predictors of complicated grief

A risk factor can be defined as ‘a variable that when present, increases the likelihood of poor outcome’, as distinct from a protective factor which is ‘a variable that when present, increases the likelihood of good outcome’ (Stroebe et al., 2006, p.2441). Risk factors and protective factors can be linked. For example, lack of social support may be a risk factor and the presence of social support may be a protective factor. However, it cannot be assumed that the inverse of a risk factor constitutes a protective factor (Barreto-Martin et al., 2012).

Much of the research on risk factors for either grief or complicated grief is limited to a small number of factors, which can lead to misleading results because of the confounding influence of other variables. For example, a bereaved person may derive solace from their religious beliefs but because of those beliefs they may be part of a supportive religious community, which may not only influence their response to bereavement but also influence their religious beliefs. Unless both factors are included in a study of risk factors, one or the other may be found to exert more influence than it really does (van der Houwen et al., 2010).

Risk factors which can be used to predict bereavement outcomes have been categorised in various ways. For example, in an early review, Stroebe and Schut described the evidence for the impact of risk factors on bereavement outcomes in terms of three categories: (1) bereavement situation (e.g. mode of death); (2) risk factors related to the bereaved person (e.g. personality traits, religiosity, gender, age); and (3) interpersonal risk factors (e.g. lack of social support, kinship) (Stroebe and Schut, 2001). A later review of risk factors ‘that increase vulnerability of some bereaved individuals’ used three very similar categories and added a fourth: coping styles, strategies, processes (Stroebe et al., 2007). Neither of these reviews had a focus on complicated grief. Building on this work, an integrative risk factor framework consisting of five components was developed to explain individual differences in adjustment to bereavement:

- The nature of the stressor;
- Interpersonal resources;
- Intrapersonal resources;
- Appraisal and coping processes; and
- Outcomes.

The framework proposes that outcomes such as grief intensity, ill health and cognitive and social functioning are related to factors associated with the bereavement itself (the stressor) and also the person’s appraisal of whether the stresses associated with bereavement exceed their ability to cope. The relationship between the bereavement and the appraisal/coping process is moderated by risk and protective factors that are interpersonal (e.g. social support) or intrapersonal (e.g. attachment style, gender). This framework has been used to guide research on the risk factors for poor bereavement outcomes and is also potentially useful in identifying opportunities to intervene to identify and treat complicated grief and promote healthy adaptation to bereavement. The authors of the framework argue against investigating specific factors in isolation, suggesting that it is preferable to investigate combinations of factors and the relationships between factors (Stroebe et al., 2006).
In their systematic review of predictors of complicated grief, Lobb et al. took a quite different approach, grouping risk factors into six categories: childhood, dependency on other people, cognitive behavioural conceptualisations of complicated grief, traumatic death, caregiving and serious mental illness (Lobb et al., 2010). However, in reviewing the literature the authors included studies in which data collection for multiple variables was contemporaneous, making it difficult to distinguish predictors of complicated grief from consequences of complicated grief (Burke and Neimeyer, 2012). Put another way, demonstrating that two variables are correlated does not provide an indication about which variable may have influenced the other variable.

Burke and Neimeyer sought to overcome this limitation with their review of prospective risk factors for complicated grief in which they searched the literature from 1980 to 2010, with the addition of some earlier seminal works. The primary goal of the review was to ‘identify empirically supported factors that predict subsequent susceptibility to the full range of responses to loss, from common to complicated grief, that merit further scientific and clinical attention’ (Burke and Neimeyer, 2012, p.145). The risk factors they identified were categorised in a similar way to earlier reviews and ranked according to the ratio of the number of studies which found the factor to be significant relative to the number of studies that investigated the factor. The factors identified as ‘strong indicators’ of complicated grief are summarised in Table 7. Some of these were considered to be ‘confirmed risk factors’ because of the degree of supporting evidence, whereas others were described as ‘potential risk factors’ (i.e. less supporting evidence). It is worth noting that one factor missing from Table 7 is religious beliefs due to the inconsistent findings of investigations into the influence of religion on the grieving process (Burke and Neimeyer, 2012).

### Table 7  Strong risk factors for complicated grief

<table>
<thead>
<tr>
<th>Domain</th>
<th>Risk factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>The nature of the bereavement</td>
<td>Spouse or parent of deceased (especially a mother) (C)</td>
</tr>
<tr>
<td>(situational factors)</td>
<td>Discovering or identifying the body (in cases of violent death), or issues related to being notified of the death (C)</td>
</tr>
<tr>
<td></td>
<td>Violent death (P)</td>
</tr>
<tr>
<td></td>
<td>Deceased’s aged (both younger/older) (P)</td>
</tr>
<tr>
<td></td>
<td>Sudden, unexpected death (P)</td>
</tr>
<tr>
<td>Relationship of the bereaved</td>
<td>Low social support (C)</td>
</tr>
<tr>
<td>with others (interpersonal factors)</td>
<td>High levels of pre-death marital dependency (C)</td>
</tr>
<tr>
<td></td>
<td>Lack of family cohesion (P)</td>
</tr>
<tr>
<td></td>
<td>Problematic relationship with deceased (P)</td>
</tr>
<tr>
<td>Intrapersonal factors</td>
<td>Anxious/avoidant/insecure attachment style (C)</td>
</tr>
<tr>
<td></td>
<td>High levels of neuroticism (C)                                                                 ----------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Younger age of the bereaved (P)</td>
</tr>
<tr>
<td></td>
<td>Being female (P)</td>
</tr>
<tr>
<td></td>
<td>Less education (P)</td>
</tr>
<tr>
<td></td>
<td>Being non-Caucasian (primarily based on studies of African Americans in the USA) (P)</td>
</tr>
<tr>
<td></td>
<td>Low income (P)</td>
</tr>
<tr>
<td></td>
<td>Experienced prior losses (P)</td>
</tr>
<tr>
<td></td>
<td>Recency of loss (P)</td>
</tr>
</tbody>
</table>

C = confirmed risk factor   P = potential risk factor
In a companion paper linked to their review of prospective risk factors for complicated grief, Neimeyer and Burke identify additional factors associated with the nature of the bereavement, including the emotional and physical burden of caregiving, preparedness for death, and decision-making around end-of-life care (Neimeyer and Burke, 2013). These additional factors have implications for the use of advance care plans to influence complicated grief (see Section 3.7).

3.6 Screening and assessment tools

There are several contexts in which screening and/or assessment tools for complicated grief may be used. The first is for identifying people who are currently experiencing complicated grief and (with repeated use) measuring change in symptoms following treatment. These instruments are typically used in research studies.

The Inventory of Complicated Grief (ICG) is the most commonly used tool for measuring complicated grief in research studies. The original version was published as a self-report tool in 1995 after being developed and then tested on 97 widowed elders. The tool contains 19 items, each answered using a 5-point scale ranging from ‘never’ to ‘always’ (Prigerson et al., 1995).

In 2001, the 34-item self-report Inventory of Traumatic Grief was published, containing all 19 items from the original Inventory of Complicated Grief (Prigerson and Jacobs, 2001). The Inventory of Traumatic Grief was subsequently re-named the Inventory of Complicated Grief-Revised (ICG-R). As far as can be ascertained, this re-naming has not been formally described or explained in any published papers, but has been referred to in various papers involving the lead author (Holly Prigerson) (e.g. the papers by Barry et al., 2002 and Johnson et al., 2006).

Both the ICG and the ICG-R result in a continuous total score and a dichotomous diagnosis (i.e. those with complicated grief and those without complicated grief) (Johnson et al., 2006). This history of the two tools (the ICG and the ICG-R) does not always appear to be well understood in the literature and it is not always clear which tool is being used. For example, Sealey et al. (2015a) in their review of bereavement risk assessment measures, refer to the Inventory of Traumatic Grief and the Inventory of Complicated Grief-Revised as two separate instruments.

Another potentially important use for a screening tool is to identify those who might be at risk of developing complicated grief. One such tool is the Brief Grief Questionnaire, a five-item instrument that can be administered by self-report or interview (Ito et al., 2012). It is generally used with people who are seeking help in order to determine whether their psychological distress may be grief-related (Shear et al., 2006). However, a recent study in Japan has demonstrated that the tool has good discriminant validity and reliability in a non-clinical sample (Ito et al., 2012). Further work is required to establish its predictive validity (i.e. whether it can be reliably used to determine future likelihood of developing complicated grief).

Searching the literature identified six reviews which focused on measurement tools for assessing grief or bereavement. Three of these reviews had limitations in their findings:
In 2010, a systematic review of predictors of complicated grief found that the majority of studies measuring complicated grief used either the Inventory of Complicated Grief or the Texas Revised Inventory of Grief (Lobb et al., 2010).

In 2011, a systematic review was published which aimed to identify assessment tools for measuring the needs of parents bereaved in a paediatric intensive care unit. No suitable tools were identified by the review (Meert et al., 2011).

A review was conducted to identify validated instruments for evaluating the prevalence of, and risk factors for, the burden on families of critical care patients. The Texas Inventory of Grief (TRIG) was the only tool included in the review for assessing grief after bereavement (Kentish-Barnes et al., 2009).

The three remaining reviews focused on palliative care and hence have a direct relevance to this evidence appraisal. The results of those reviews are summarised in Table 8.

### Table 8 Measuring complicated grief

<table>
<thead>
<tr>
<th>Literature review</th>
<th>Measurement tools identified in the literature review</th>
</tr>
</thead>
</table>
| Bereavement needs assessment in specialist palliative care: a review of the literature (Agnew et al., 2010) | Included 10 tools in two groups *(1) Continuous bereavement screening and assessment tools.* Professional screening or assessment tools, suitable for use from the point of a patient’s admission and continuing into early bereavement:  
  - Bereavement Risk Index (BRI).
  - Colorado Bereavement Services Project.
  - Family Relationships Index (FRI).
  - Matrix of Range of Responses to Loss.
  - Risk Assessment of Bereavement.
  *(2) Normal or complicated bereavement assessments* Assessments undertaken around 6 months into bereavement to determine whether a person is experiencing normal or complicated grief, and to clarify the type and level of support required:  
  - Adult Attitude to Grief Scale (AAG).
  - Core Bereavement Items (CBI).
  - Grief Evaluation Measure (GEM).
  - Inventory of Traumatic Grief (ITG) (developed from the Inventory of Complicated Grief).
  - Texas Revised Inventory of Grief (TRIG). |
| A systematic review of instruments related to family carers of palliative care patients (Hudson et al., 2010c) | Identified five tools for assessing grief/bereavement:  
  - Pre-death Inventory of Complicated Grief – Caregiver Version (Pre-ICG).
  - Texas Revised Inventory of Grief (TRIG).
  - Grief Resolution Index (GRI).
  - Inventory of Complicated Grief (ICG). |
## Literature review

<table>
<thead>
<tr>
<th>Measurement tools identified in the literature review</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Modified Bereavement Risk Index (BRI).</td>
</tr>
</tbody>
</table>

A scoping review of bereavement risk assessment measures: implications for palliative care (Sealey et al., 2015a)

Identified 19 measures which can be used with carers at three different time points: prior to the death of the patient (5 measures), in the period following the death (10 measures) and for assessing complicated or prolonged grief (4 measures). Excluding those measures which appear too complex and those which have a focus on normal rather than complicated grief, the measures include the following.

- Pre-death measures of bereavement risk – the Bereavement Risk Index (BRI) and the Prolonged Grief–12 (PG-12).
- Measures of complicated grief – the Inventory of Complicated Grief (ICG), Inventory of Complicated Grief–Revised (ICG-R), and the Prolonged Grief–13 (PG-13).

Agnew et al. make the observation that the Bereavement Risk Index is the most commonly used tool in the UK for bereavement screening and assessment but that there are some reservations about the tool:

- It is based on observations by nursing staff or information collected in team meetings (i.e. it excludes the views of carers).
- There are doubts about the ability of the tool to predict bereavement outcome (Agnew et al., 2010).

A modified version of the Bereavement Risk Index has been developed and tested in Australia, with promising results regarding prediction of bereavement outcome (Kristjanson et al., 2005). However, no further testing or use of the modified Bereavement Risk Index appears to have been conducted.

Agnew et al. concluded that the Matrix of Range of Responses to Loss has ‘great potential for UK-wide implementation into specialist palliative care settings’ (p.57) although in doing so they note that the Matrix has not been tested for validity or reliability. With regard to using assessment tools post-bereavement to test for the presence of normal or complicated grief they observe that the most widely-tested tools are complex and may not be suitable for use in the UK, concluding that the Adult Attitude to Grief Scale (a self-report tool) may be more appropriate (Agnew et al., 2010).

The review by Hudson et al. had a broad focus, with only five of the 62 instruments identified by the review assessing grief/bereavement. They observed that many of the instruments do not appear to have been developed for clinical use (instead being developed for research use). The clinical use and research use of assessment tools serve purposes which are related but different. For example, clinical use typically requires tools that are relatively brief and easy to administer whereas research use places primacy on psychometric properties, while recognising that psychometrically-sound assessment tools are important for clinical practice as well. They concluded that further research to develop appropriate assessment tools should focus on two time points:

1. The period between referral to palliative care and early bereavement.
2. The post-bereavement period, to differentiate complicated grief from normal (Hudson et al., 2010c).

The scoping review by Sealey et al. (2015a) was underpinned by a ‘public health’ approach which seeks to align ‘need’ with interventions across three groups – the bereaved population (universal interventions), ‘at risk’ groups (selective interventions) and those with signs or symptoms of a disorder (indicated interventions). The distinction between universal, selective and indicated interventions is also referred to in Section 3.4. This approach fits with current Australian guidelines which recommend bereavement risk assessment at three points in time:

- Between intake to a palliative care service and the patient’s death.
- At three to six weeks after the patient’s death.
- Approximately six months following the death (for those identified as high-risk of complicated grief on initial assessment) (Hall et al., 2012, Hudson et al., 2010b).

Australian research published since the guidelines were developed supports screening on entry to palliative care and six months after the patient’s death, with the later screening identifying two-thirds of people who will go on to develop complicated grief (although this means that one-third will not be identified by screening at six months post-death) (Thomas et al., 2014). A survey of Australian palliative care services in 2007 indicated that 69% of the services responding to the survey conducted risk assessment for complicated grief, either based on the opinion of a multidisciplinary team, the opinion of a single staff member or the use of a risk assessment tool (Mather et al., 2008).

One of the measures included in the scoping review by Sealey et al. (the PG-13) is also mentioned in the Bereavement support standards for specialist palliative care services developed in Victoria as the type of measure which can be used to assess for complicated grief at least six months after bereavement (Hall et al., 2012).

The PG-13 is a 13-item diagnostic tool developed by Prigerson and Maciejewski (the two main authors of the Inventory of Complicated Grief) which utilises the criteria for prolonged grief disorder (Prigerson et al., 2009), details of which can be found in Table 3. Instructions on using the tool are available (Prigerson and Maciejewski, not dated).

Of the 19 measures identified by the scoping review, 12 were reviewed by a group of stakeholders from five palliative care services (two nurses, one palliative care physician, one social worker, one psychologist, one counsellor, one psychosocial services manager, one chaplain, one bereaved former carer who also worked as a palliative care volunteer) who found that none were suitable for use in the clinical setting (Sealey et al., 2015b). These measures included both the original and revised forms of the Inventory of Complicated Grief and the PG-13. The PG-13 is based on the Inventory of Complicated Grief (Thomas et al., 2014). However, it is important to note that the stakeholders’ judgement that these measures for assessing complicated grief are unsuitable arose because they were from palliative care services which do not conduct assessments for complicated grief at six months. They perceived that ‘system issues’ would make it difficult to conduct such assessments i.e. their judgement was not based on the intrinsic merits of the measurement tools.
The finding that current measures were unsuitable for clinical practice resulted in the development of a new tool for bereavement risk assessment, completed by carers, the Grief and Bereavement Assessment (GABA) in Palliative Care. The GABA tool was based on risk factors for complicated grief identified in the systematic review by Lobb et al. (2010). The tool was piloted by 19 carers and evaluated as being ‘largely acceptable’ to carers and palliative care staff but the small number of carers involved in the pilot ‘make it impossible to draw any conclusions of the measure’s worth as a grief instrument’ (Sealey, 2016).

In summary, the literature on screening and assessment of complicated grief presents a somewhat inconclusive picture, particularly with regard to screening. The Bereavement Risk Index is commonly used in the UK for bereavement screening and assessment but lacks a robust evidence base. Although the results of an Australian study indicate that many palliative care services screen for the risk of complicated grief, there is a lack of detail about what specific tools are used (Mather et al., 2008). The Victorian Bereavement support standards for specialist palliative care services do not recommend any screening tools because ‘there is insufficient empirical evidence to support the validity of one particular tool to screen for risk of complicated bereavement prior to the person’s death’ (Hall et al., 2012, p.11). Instead, the support standards recommend that screening for complicated grief should be a ‘continuous process undertaken from the time the client enters the palliative care service to many months after the client’s death (where pertinent)’ (Hall et al., 2012, p.11).

In terms of assessing for the presence or absence of complicated grief the overriding problem is the lack of consensus about the criteria for diagnosing complicated grief. Screening needs to take into account the wide variety of ‘normal’ responses to bereavement: “Because no single way to grieve exists, identification of patients needing intervention is difficult” (Simon, 2013, p.419).

Historically, the most commonly used tool, certainly in research studies, has been the Inventory of Complicated Grief or one of its variants. More recently, the PG-13 has been developed based on the diagnostic criteria for prolonged grief disorder, one of the two main sets of criteria for complicated grief proposed for inclusion in DSM-5 (Prigerson et al., 2009).

The Mental Health Advice Book for treating veterans with common mental health problems issued by the Department of Veterans’ Affairs states that there is no standardised assessment tool that assesses specifically for complicated grief and bereavement-related conditions, but notes that the Inventory of Complicated Grief - Revised is a measure recommended by the former Australian Department of Health and Ageing (Australian Centre for Posttraumatic Mental Health, 2012). The Mental Health Advice Book also includes the following information about screening for complicated grief:

- For veterans who have experienced the death of a close friend or relative at least 12 months earlier, ask if they have experienced any of the following symptoms more days than not at levels that impair functioning and cause significant distress:
  - persistent yearning for and/or preoccupation with the deceased
- reactive distress to the death e.g. difficulty accepting the death, emotionally numb, bitterness related to death and difficulty having positive feelings related to the deceased
- disruption of social roles and identity, e.g. difficulty trusting and feeling detached from others, feeling that life is meaningless without the deceased.

- If the patient endorses more than one of the above experiences, further assessment of complicated grief is warranted (Australian Centre for Posttraumatic Mental Health, 2012).

### 3.7 Advance care planning

Advance care planning (ACP) is the process whereby a person’s values, beliefs and preferences are made explicit so that they can guide decision making about their health and personal care at a time in the future when that person is unable to make or communicate their decisions (Australian Health Ministers’ Advisory Council, 2011). There is the potential for ACP to alleviate stresses related to caring in life-limiting illness by providing greater clarity about a person’s wishes and aiding decision making at the end-of-life.

The concept of ACP is based on the assumption that when it comes time to enact a patient’s plan and make decisions about their care that their preferences, as stated in their advance care plan, will still be relevant. The evidence, from a systematic review, indicates that most patients’ preferences ‘are stable over time and after changes in health status’ (Auriemma et al., 2014, p.1090). However, for a ‘significant minority’ of patients, their preferences change over time, both away from and towards more aggressive treatment (Auriemma et al., 2014).

There is an extensive research literature on ACP. Table 9 summarises recent reviews of the literature. The details of individual studies investigating the impact of ACP on carers are included in Table 10.

#### Table 9 Literature reviews of advance care planning

<table>
<thead>
<tr>
<th>Title / reference</th>
<th>Nature of review</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>How healthcare systems evaluate their advance care planning initiatives: results from a systematic review (Biondo et al., 2016)</td>
<td>Systematic review to identify the methods used by healthcare systems to evaluate implementation of ACP initiatives. 46 studies included.</td>
<td>The most commonly used outcome measures are concerned with document completion and use of healthcare resources. Two studies collected data on family/carer-reported outcomes or experience but the studies are not specified in the paper.</td>
</tr>
<tr>
<td>Advance care planning: a systematic review of randomised controlled trials conducted with older adults (Weathers et al., 2016)</td>
<td>Systematic review focusing on outcomes of ACP for older adults (&gt; 65 years of age) across all healthcare settings. 9 studies included.</td>
<td>Outcomes measured included compliance with patients’ wishes, patient and family satisfaction with care and patient outcomes. One study measured stress, anxiety and depression in family members of patients who died (Detering et al., 2010). Details are provided in Table 10.</td>
</tr>
<tr>
<td>The effects of advance care planning interventions on nursing home residents: a systematic review (Martin et al., 2016)</td>
<td>The review aimed to identify the effects of ACP interventions on nursing home residents.</td>
<td>The most commonly measured outcomes are hospitalisation, place of death, and actions being consistent with resident’s wishes. None of the outcomes involved carers.</td>
</tr>
<tr>
<td>Title / reference</td>
<td>Nature of review</td>
<td>Findings</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>A review of the implementation and research strategies of advance care planning in nursing homes (Flo et al., 2016)</td>
<td>Review of the literature on methods, design and outcomes and the implementation of ACP in nursing homes. 16 papers included.</td>
<td>Outcomes measured included deaths in hospital, hospital admissions, documentation of ACP discussions and decisions, patient outcomes and carer satisfaction. None of the outcomes covered carer bereavement.</td>
</tr>
<tr>
<td>The economic evidence for advance care planning: systematic review of evidence (Dixon et al., 2015)</td>
<td>The review aimed to review and summarise economic evidence on ACP. Searched from 1990 to 2014. 18 studies included.</td>
<td>In almost all the studies the measures of cost were confined to the costs of health care, either in hospital or the community. No costs involving family carers were measured.</td>
</tr>
<tr>
<td>Efficacy of advance care planning: a systematic review and meta-analysis (Houben et al., 2014a)</td>
<td>Review of randomised controlled trials that investigated the efficacy of ACP interventions in adult populations. Searching covered the period 1966 to September 2013 and included 55 studies.</td>
<td>Outcome measures across the studies included completion of advance directives, concordance between preferences for care and delivered care, knowledge of ACP, quality of communication and satisfaction with healthcare. No outcomes regarding the bereavement phase were measured, with the exception of a study by Wright et al. (2008). For details see Table 10.</td>
</tr>
<tr>
<td>The effects of advance care planning on end-of-life care: a systematic review (Brinkman-Stoppenenburg et al., 2014)</td>
<td>Systematic review of the evidence regarding the effects of ACP from 2000 to the end of 2012. 113 papers included in the review.</td>
<td>Most of the research on the outcomes of ACP has taken place in the USA, primarily in nursing homes, hospitals and ICUs. The outcomes measured in the studies include treatment at end-of-life, hospitalisation, ICU admission, quality of life (of patients) and carer strain but this does not extend into the bereavement phase. The one exception is the study by Wright et al. (2008).</td>
</tr>
<tr>
<td>Advance care planning for adults with CKD: a systematic integrative review (Luckett et al., 2014)</td>
<td>Review to address various issues including what interventions have been developed, piloted, and evaluated; and what outcomes have been measured. Searched from ‘earliest records’ until 2013. 55 articles included.</td>
<td>None of the studies assessed the effect of ACP on the well-being of bereaved family members.</td>
</tr>
<tr>
<td>Advance care planning for people with dementia: a review (Dening et al., 2011)</td>
<td>The literature review aimed to identify key themes and facilitators and inhibitors to ACP in people with dementia. 17 studies included from the search period 1950-2010.</td>
<td>Outcomes measured in the studies included factors influencing end-of-life care decision-making and staff attitudes to end-of-life decisions for people with dementia. Outcome measurement did not extend into the bereavement phase.</td>
</tr>
<tr>
<td>Pediatric advance care planning: a systematic review (Lotz et al., 2013)</td>
<td>Review to identify current practices, effects, and perspectives of ACP in paediatrics. Search period 1991 to 2012. Included 13 studies.</td>
<td>It was concluded that ‘the evidence is insufficient to make definite conclusions’ about paediatric ACP. Some studies examined parental experience with ACP but none measured any outcomes such as distress, anxiety or grief.</td>
</tr>
</tbody>
</table>

The findings detailed in Table 9 demonstrate that research on ACP has typically involved measuring outcomes that occur during the end-of-life period. For example, patient outcomes,
carer satisfaction with care delivery during the end-of-life period and the extent to which treatment was delivered in accordance with advance care plans. In general, outcomes occurring in the post-bereavement period have not been measured.

In addition to the reviews in Table 9, another review focused on ACP interventions for people with cognitive impairment and dementia (Robinson et al., 2012) but did not add materially to the results outlined in the table for reviews focusing on dementia and nursing homes.

**Table 10  Individual studies investigating the impact of advance care planning on carers**

<table>
<thead>
<tr>
<th>Title / reference</th>
<th>Study</th>
<th>Results (carers only)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The impact of advance care planning on end of life care in elderly patients: randomised controlled trial (Detering et al., 2010)</td>
<td>309 medical inpatients in a university hospital in Melbourne were randomised to receive usual care or usual care plus facilitated ACP.</td>
<td>Family members of patients in the intervention group who died had significantly less stress, anxiety and depression than family members of those in the control group.</td>
</tr>
<tr>
<td>Associations between end-of-life discussions, patient mental health, medical care near death, and carer bereavement adjustment (Wright et al., 2008)</td>
<td>Prospective, longitudinal cohort study of patients with advanced cancer and their informal carers to determine whether end-of-life discussions with physicians are associated with fewer aggressive interventions.</td>
<td>End-of-life discussions were associated with less aggressive medical treatment in the last week of life. Aggressive medical treatment was associated with worse adjustment to bereavement by carers.</td>
</tr>
<tr>
<td>Effects of a psychosocial intervention on carers of recently placed nursing home residents: a randomized controlled trial (Schulz et al., 2014)</td>
<td>The study involved randomising carers to receive either an education program (the intervention) or written information. The intervention consisted of 11 sessions of about 90 minutes each over a 4- to 6-month period covering knowledge and procedures of nursing homes; advance care planning (four sessions); and emotional well-being.</td>
<td>Carers who received the intervention had lower levels of complicated grief after their relative died. This was found 18 months post-intervention but was not present 6 and 12 months post-intervention.</td>
</tr>
<tr>
<td>Preparedness for death and adjustment to bereavement among carers of recently placed nursing home residents (Schulz et al., 2015)</td>
<td>Investigated preparedness for death as a predictor of post-bereavement adjustment. This study was conducted on the sample of carers in the randomised controlled trial by Schulz et al. (2014).</td>
<td>Engaging in ACP was strongly associated with preparedness for death. Carers who reported feeling more prepared for death experienced lower levels of complicated grief post-bereavement.</td>
</tr>
</tbody>
</table>

Studies suggest that ACP can have indirect effects on carer bereavement, but the mechanism by which this occurs appears to be quite complex. For example, the process of developing an ACP may directly help carers to be better prepared for death (Schulz et al., 2015). Other research suggests that better preparedness for death of family carers results in less severe bereavement-specific symptoms, including complicated grief (Kim et al., 2015). However, in the study by Schulz et al. (2015), it was concluded that ‘the impact of ACP on survivor distress was not mediated through preparedness; nor was there a direct relationship between ACP and complicated grief’ (Schulz et al., 2015, p.132). The indirect effects of ACP on carer bereavement...
are also illustrated by the results of the study by Wright et al. which suggest that some of the effects of advance care planning (e.g. less aggressive treatment in the last week of life) may influence carer bereavement (Wright et al., 2008).

A recent systematic review of carer studies during end-of-life caring and bereavement concluded that high levels of grief during caring and low levels of preparedness for death during caring were both associated with poor bereavement outcomes, including complicated grief (Nielsen et al., 2016). However, a somewhat different perspective is provided by a Dutch study which found that complicated grief is not associated with ‘characteristics of the patient’s illness, end-of-life care, and the nature of death’ (Bruinsma et al., 2015, p.440).

Another study followed a cohort of adults with cancer and their primary carers, measuring bereavement adjustment of the carers (e.g. depression, anxiety, and regrets) six months after the death of the patient. Among the factors found to predict an improved adjustment to bereavement were better quality of death (based on carer rating in response to the question, ‘In your opinion, how would you rate the overall quality of the patient’s death/last week of life?’) and the completion of a do-not-resuscitate order for the patient. This finding about the link between quality of death and bereavement adjustment led the researchers to suggest that ‘educating patients and caregivers about situations in which resuscitation is unlikely to be successful and encouraging patients to engage in advance care planning appear to be promising ways to improve both patients’ quality of death and caregivers’ bereavement adjustment’ (Garrido and Prigerson, 2014, p.924). This is consistent with the results of a large, long-term, cohort study (from the USA) which found an association between advance care planning and improved quality of care at the end of life, including a reduced number of in-hospital deaths and greater use of hospices (Bischoff et al., 2013). It may be that improving the quality of end-of-life care, quite apart from its intrinsic merits for patients, can also play a role in the adjustment to bereavement of the family and friends of those who have died.

In 2006, a couple of American doctors published a paper in which they drew on their own clinical and educational experience and some evidence from the literature to propose that there is a reciprocal interaction between three factors:

1. The medical decision-making responsibilities of the patient and their family.
2. The psychological and physical suffering of the patient and their family.
3. The process of shared decision-making communication facilitated by the clinical team.

This led them to hypothesise that: ‘patient and family suffering, exacerbated by decision-making responsibilities and the iatrogenic effects of poor communication, place them at greater risk to experience depression, anxiety disorders, and complicated grief’ (Weiner and Roth, 2006, p.456). This is an interesting hypothesis which provides an opportunity to investigate the relationship between advance care planning, end-of-life decision making and complicated grief. Unfortunately, as far as can be ascertained, the hypothesis has not been tested in any research studies.

Similarly, Hebert et al. developed a theoretical framework based on the hypothesis that ‘better communication about death and bereavement between caregivers and health care providers
will improve caregivers’ preparedness, and as a result, their clinical outcomes’ (Hebert et al., 2006, p.1167). The carer clinical outcomes include carer satisfaction with clinical care; carer mental health and adjustment; and surrogate decision making. Advance care planning represents one mechanism for facilitating conversations about end-of-life care.

Research is required to investigate the role of ACP in facilitating communication, improving preparedness and reducing the risk of complicated grief among carers. The theoretical models outlined above provide a starting point for such research, but further development is needed. In 2014, Houben et al. published the protocol for a multi-centre cluster randomised controlled trial to investigate the effects of advance care planning for patients with severe chronic obstructive pulmonary disease. One of the outcomes to be measured in the study is the psychological distress of bereaved family members of deceased patients with chronic obstructive pulmonary disease using the Inventory of Complicated Grief (Houben et al., 2014b). To date, the results of the study have not been published.

Taken together, the evidence from the literature presented in this section on the links between advance care planning and the prevention or minimisation of complicated grief is somewhat limited. It is a subject which has not been studied to any great extent and further research is required.

3.8 Outcome indicators to inform or monitor best practice approaches and service models for complicated grief

No outcome indicators associated with the concept of complicated grief were identified from this evidence appraisal.

The Australian Commission on Safety and Quality in Health Care recently commissioned a rapid review of the literature to identify quality and safety indicators for end-of-life care in acute hospitals (Masso et al., 2016). The review identified 12 sets of indicators (containing a total of 208 indicators), all of which were developed by a process of collating existing evidence and then subjecting that evidence to review by an expert panel. None of the indicators had a focus on complicated grief but some were relevant to the psychosocial wellbeing of family carers, which is the closest association with complicated grief amongst the indicators (Table 11).

<table>
<thead>
<tr>
<th>Table 11 Quality indicators of end-of-life care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator</td>
</tr>
<tr>
<td>Type of indicator</td>
</tr>
<tr>
<td>Reference</td>
</tr>
<tr>
<td>Extent to which direct relatives felt supported by the caregivers immediately after the patient’s death</td>
</tr>
<tr>
<td>Extent to which, according to the direct relatives, attention was paid to their own psychosocial and spiritual well-being.</td>
</tr>
<tr>
<td>Number of family carers who felt they had adequate support after the patient’s death (inclusive evaluation meeting) and were informed of the possibilities of after-care / Total number of family carers for whom this indicator was measured.</td>
</tr>
<tr>
<td>Total number of patients in the ICU for &gt; 72 hrs with psychosocial support offered to the patient or family by any team member / Total number of patients in the ICU for &gt; 72 hrs.</td>
</tr>
</tbody>
</table>
### 3.9 Clinical guidelines

Searching the literature did not identify any clinical guidelines devoted to the identification, prevention or treatment of complicated grief. The most useful, and well-developed, guidelines are the *Bereavement support standards for specialist palliative care services* prepared by the Australian Centre for Grief and Bereavement and the Centre for Palliative Care in Melbourne, funded by the Victorian Department of Health (Hall et al., 2012). These guidelines were based on a systematic review of the literature (Hudson et al., 2010a), consultation with experts, the results of a survey of Victorian palliative care services and adaptation of previous guidelines such as the *Clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients* (Hudson et al., 2010b, Hudson et al., 2012). There is a table within the standards (Section 5) which summarises the recommendations for implementing the standards along the grief trajectory. The references in those recommendations to complicated grief are summarised in Table 12. It is worth emphasising that these guidelines are targeted at palliative care services, rather than a broader audience of health professionals. For example, the guidelines contain no recommendations regarding the role of general practitioners.

#### Table 12 Bereavement support care pathway – references to complicated grief

<table>
<thead>
<tr>
<th>Point on grief trajectory</th>
<th>Actions</th>
<th>Factors to consider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between intake and the client’s death</td>
<td>As part of a comprehensive biopsychosocial spiritual assessment, the team assesses the carer’s risk of complicated grief.</td>
<td>Multidisciplinary/interdisciplinary process. Ongoing conversational examination of risk and resilience factors.</td>
</tr>
<tr>
<td>Imminent death</td>
<td>For those at risk of complicated grief, provide more comprehensive support.</td>
<td>Assessment of separation distress and traumatic distress.</td>
</tr>
<tr>
<td>Around six months after death</td>
<td>Undertake formal bereavement assessment of those who have previously been identified as being at high risk of prolonged or complicated grief.</td>
<td>Symptoms have been present for at least six months after the client’s death. Symptoms include a sense of disbelief regarding the death, persistent intense longing, yearning and preoccupation with the deceased, recurrent intrusive images of the dying person and avoidance of painful reminders of death. People identified as being at elevated risk of developing prolonged or complicated grief are offered a comprehensive bereavement assessment using a validated tool such as the PG-13. For bereaved people assessed as having moderate psychosocial distress or a moderate risk of prolonged or complicated grief, more formal opportunities to review their grief may be required. May involve referral to support or social groups. Support may be provided by unpaid staff such as trained volunteers. The support of family and friends remains important throughout the grief trajectory.</td>
</tr>
</tbody>
</table>
Note: Information in the table is taken from the Bereavement support standards for specialist palliative care services (Hall et al., 2012).

In the United Kingdom, the National Institute for Health and Care Excellence (NICE) is in the process of developing guidelines for End of life care for adults in the last year of life: service delivery. Consultation on the scope of the guidelines has taken place but the completed guidelines are not due to be released until January 2018. It is proposed that the guidelines will include a section on identification and referral of people at risk of complex bereavement.

NICE has an existing quality standard for End of life care for adults which contains a generic quality statement on bereavement support (‘People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences’) but no specific references to complicated grief (National Institute for Health and Care Excellence, 2011).

Also in the UK, Hospice UK has published the document Guidance for bereavement needs assessment in palliative care which contains several references to complicated grief, recognising that palliative care services have a role to play in minimising the risks of complicated grief and ameliorating the effects of complicated grief, but with no specific recommendations about how to do this (Reff et al., 2010).

In Australia, the National consensus statement: essential elements for safe and high-quality end-of-life care acknowledges that ‘the health care that people receive in the last years, months and weeks of their lives can help to minimise the distress and grief associated with death and dying for the individual, and for their family, friends and carers’ (Australian Commission on Safety and Quality in Health Care, 2015, p.2). However, the consensus statement contains no references to complicated grief.

Other potentially relevant guidelines identified from searching the literature do not meet the rigorous standard of the Victorian standards for palliative care. For example, in 2016, the Gippsland Region Palliative Care Consortium published guidelines for bereavement risk screening and management (Gippsland Region Palliative Care Consortium, 2016). The Gippsland guidelines are intended for local use and, in part, represent a practical application of the Bereavement support standards for specialist palliative care services. No details are provided about how the guidelines were developed.

Another initiative intended for local use is the concept of HealthPathways, originally developed in New Zealand but becoming increasingly common in Australia. HealthPathways represent guidelines, agreed at a local level, about the optimal patient pathway for a particular condition. The process by which agreement is reached is critical to the concept (Timmins and Ham, 2013). In particular, HealthPathways specify the role of general practitioners and the role of hospital outpatient clinics. HealthPathways have been developed for bereavement, grief, and loss which identify various ‘complicating factors’, some of which are consistent with known risk factors for complicated grief. The need to assess for the possibility of prolonged or complicated grief is also flagged, but without any details about how best to do this.
The Bereavement Services Association, a network of bereavement service providers in the UK, has published a set of standards for bereavement services. The standards have been developed using a combination of reviewing the literature and consulting with stakeholders but contain no mention of complicated grief (Bereavement Services Association and Cruse Bereavement Care, 2014).

In summary, the *Bereavement support standards for specialist palliative care services* (Hall et al., 2012), although restricted to palliative care and not specifically targeting complicated grief, represent the best source of current evidence providing guidance about the management of complicated grief.
4 Stakeholder consultation findings

The prevailing uncertainties and controversies in the field of complicated grief came through strongly in the interviews and focus groups. Some topics were strongly contentious, but there were also many areas of agreement; both are explored in the narrative below.

The first section describes the controversy surrounding whether complicated grief exists. While participants agreed that grief itself should not be confused with depression, anxiety or traumatic stress, and also agreed that some grief required additional support, they were divided on whether complex, prolonged or vulnerable grief was a distinct psychopathology or simply part of a continuum of “normal” grieving.

The second section presents participants’ views on pathways into services for people experiencing complicated grief. The three main entry points into pathways were palliative care, primary care and bereavement counselling services. Later sections pick up and expand on some of the issues raised here (e.g. the role of advance care planning in prevention; the role of screening in identification; access to specialist versus generalist treatment; the value of measuring outcomes of treatment or indicators of service provision).

The third section focuses on prevention of complicated grief. Some participants working in or closely with palliative care services were of the view that supportive care for the carers may play a role in preventing complicated grief, along with the quality of end-of-life care and processes around advance care planning.

The fourth section deals with the issue of how to identify complicated grief. Issues of access to services are closely linked with questions around the best way of identifying those who might be at risk of, or suffering from, complicated grief. The use of screening and assessment tools to aid identification was a contentious issue among participants in this study.

The fifth section summarises participants’ knowledge of interventions for complicated grief and their views on the evidence base and on standards and guidelines around bereavement support.

The sixth section lists a number of unmet needs identified by participants which include structural issues such as lack of access to services in certain areas and for certain groups of bereaved people, the perceived impact of privacy legislation on the ability of palliative care services to follow-up with carers, and difficulties relating to recognising complicated grief, community capacity to support bereaved people, and the skills of health practitioners.

The seventh section on workforce focuses mainly on the role of the general practitioner (GP) as a gatekeeper both into bereavement counselling and into mental health treatments delivered by private practitioners and subsidised by Medicare. The requirements for workforce training are explored, and the issue of whether complicated grief can be addressed by generalist providers or requires a specialist approach is briefly discussed.
The eighth and ninth sections describe what recovery from complicated grief might look like from the perspective of clinicians and other stakeholders, and whether measures of recovery or service provision could be used as indicators in quality improvement.

Finally, the tenth and eleventh sections provide several patient vignettes and an extended case study to demonstrate the impact of complicated grief and one approach to treatment.

### 4.1 Does complicated grief exist?

Stakeholders were divided on the fundamental question of whether complicated grief (or a similar construct) can be consistently defined and accurately diagnosed. On one hand, it was argued that “most grief is complex” (E11) and strong concerns were expressed that labelling some grief as complicated would pathologise or “medicalise” (E5) the normal process of grieving. Many of those with this view were bereavement counsellors and/or social workers working in a clinical context.

> "As a body of practitioners we cannot agree on what is normal grief, so how can we create a construct and say this is complicated grief? I don't think there is any consensus in the literature that says ‘this’ plus ‘this’ equals normal grief.” (Focus group participant)

On the other hand, some interviewees argued that sometimes grief can become a pathological process which will not naturally resolve over time. Providing a label or diagnosis could be helpful if it results in people gaining access to the specialist services they require. This view was more common among interviewees engaged in research but was also heard among some clinicians.

> "A small proportion of people will experience an ongoing, unremitting experience, and we need to do something about that.” (E1)

Arguments in favour of a diagnosis or label of complicated grief (or similar) centred around the impact of prolonged, acute grieving on the individual. Several interviewees provided examples of clients who had come in for help many years after the bereavement (in one case, 15 years later). These were people whose lives had been derailed by the death of a loved one: for example, a teenager whose ‘acting out’ at school had disrupted her education over the past seven years, since her father died. Impacts could include social isolation (as family and friends may be unable to tolerate the prolonged grieving), reduced quality of life, and suicidality. According to these participants, complicated grief is a distinct psychopathology and a serious public health issue.

These interviewees were firmly of the opinion that recovery from this type of pathological grieving was unlikely without specialised support. People with complicated grief could be misdiagnosed and treated (inappropriately) for depression or anxiety, possibly with medication. The potential risks of pathologising grief were outweighed by the benefits of assigning a diagnosis or label and thereby enabling effective treatment.

> "In the earlier research that was done by Maggie Stroebe there was suggestions that people would feel stigmatised by a diagnosis, and yet there was other evidence..."
by Johnson that in fact people were relieved to know that there was a label and that what they were experiencing was real and that there was something that could be done about it.” (E7)

“It’s just grief, as I say, it is not a pathological thing, but sometimes can be complicated. And, so, it’s important to recognise that a small percentage of people who have that complication are not really having the support that they need.” (E9)

Both groups agreed that the plethora of terms and definitions for complicated grief led to confusion and hindered research, treatment and service planning. All stakeholders were highly aware of the “political” (E1) implications of a diagnosis, both in the United States (where insurance-funded treatment depends on a diagnosis) and in Australia (where policy around the routine use of screening tools and/or diagnosis has the potential to influence access and resource allocation to services).

“I get worried when I think about systems that move towards, “Well, we can’t help people until they’ve got complicated grief.” (E2)

“There are arguments for and against the existence of complicated grief. It was created in the US because they needed a label. And we can’t separate ourselves from that context ... We need to be mindful otherwise people will be labelled with ‘complicated grief’ or won’t get the services they need.” (Focus group participant)

“That whole debate – is it normal, or is it mental illness – that to me is a fine line, you can land either way on that ... and that’s why I think it’s more important rather than to almost name that for people, I’d rather just work with how they experience it, and say, ‘Well, this is your reality, this is your truth to work with’.” (E6)

Interestingly, there was broad agreement that while grief itself is not an illness, some grief does require additional support. Bereavement counsellors could identify, early on in their contact with clients, those who were going to need to attend more sessions than usual. Although the terminology around “risk factors” was resisted by some people, most were nevertheless able to identify a set of factors that signalled that a person may be vulnerable (see Section 4.4.1).

4.2 Pathways into services

Participants described several common pathways into services for people who may be experiencing complicated grief. Naturally, because many of the people interviewed were connected with palliative care, the pathways they described often began with palliative care services. Other starting points were primary care (GPs) and self-referral into bereavement counselling services.

There are various, interconnected pathways through these three elements of the health system. For example, a person might start as a carer for a patient in palliative care, go to a bereavement counsellor following the death, and if the counsellor suspects more complex issues, it may be suggested that they see a GP, who may then refer to a specialist service or psychologist. Alternatively, the bereavement counsellor may continue to see the person over a longer period of time than usual, until they can resume a more normal level of functioning. Someone who has not been in contact with palliative care might start by visiting their GP or, if
they are well informed about available services, may phone a bereavement counsellor or counselling service directly.

4.2.1 Palliative care

The typical pathway from palliative care begins during the end-of-life phase, when social workers (or pastoral care workers, or family support workers) provide the family with information about bereavement support services. These counselling services may be connected with, but are not necessarily part of, the palliative care service. The bereaved person is given a set of pamphlets or a “bereavement folder” which may contain psycho-educational material about the grieving process along with contact details of the bereavement counselling service and, where relevant, other available support (e.g. specific organisations or groups which help people bereaved by suicide or the death of a child). Sometimes the palliative care service has a list of several family members or friends who might be “at risk” following the patient’s death. These individuals may have been mentioned during multidisciplinary team discussions or noted by the social worker or palliative care nurse as potentially vulnerable.

Supportive care is available to family and friends during palliative care and end-of-life care. This may be provided informally (e.g. spontaneous discussions with the nurses) or more formally (e.g. a social worker assigned to the family may offer emotional and practical support, such as help with organising the funeral, arranging a will or power of attorney, information about Centrelink and financial issues, and advice on how to help children and young people during this time). One participant spoke about the comfort for carers of knowing that a sympathetic ear was available to them if they were “just having a bad day” (E5); they could ring the hospice for a chat and anything they said would be treated confidentially.

All of those interviewed from palliative care services described some level of follow-up for the bereaved. Most often this was a telephone call at four, six or eight weeks following the death, additional contact at six months (and sometimes nine months), and a card one month before the first anniversary inviting the bereaved to a memorial service. Each of these contacts was seen as an opportunity to check on the bereaved and to remind them that support was available if they were “struggling”. Additional pamphlets and contact details for the local bereavement service would be provided at these times. Several participants said these materials were not aimed just at the person who had been the primary carer; services were available for anyone connected with the patient who might require bereavement support.

The ability of palliative care services to provide bereavement support after the patient’s death is also constrained by resources and in some states, privacy legislation. The patient, not the carer, is the client of the service. Although palliative care services have an important role in referral, they are not providers of specialist mental health services.

“One of the other issues, of course, in palliative care, is whilst we see the patient and the family as our unit of care, we only have medical records for patients. And, so, there are issues, certainly, under the privacy commission, about collecting data from family members who we then don’t have a medical record in order to record that data and follow through. So, in palliative care, the first issue on the journey is to identify somebody who has complicated grief and then it’s very challenging for us to follow them through, because, really, our service finishes with the death of the
patient. And, in my State, now that activity based funding has come in it is very difficult for us to follow a bereaved carer beyond the processes we have in place ... I think, there is one visit post the death of the patient that covers a social worker. And, so, really at the moment we have very little within our health system to, firstly, identify bereaved carers and to be able to follow them through.” (E7)

The separation of palliative care and bereavement support services may not necessarily be a bad thing, according to some participants who noted the palliative care setting can be a reminder of the difficult time around the death and that it may be painful or counterproductive for carers to keep returning to this setting for their bereavement counselling. This contrasted with the view that bereavement support had always been, and should always be, an intrinsic part of palliative care.

“I’m concerned that there may be a desire to separate – which has traditionally been part of the palliative care journey, is to separate bereavement out somehow from it. That’s a concern, and I think that would be something that certainly the community nurses who are the primary workforce here, would have a great deal of difficulty with because they become very involved with the people and there’s the desire to be sure that the carer is cared for afterwards. Because, as I said earlier, we all know that carers are highly stressed, and what will happen if they don’t have some help and support afterward to work it through, they’ll end up getting mentally, physically, sick.” (J4)

4.2.2 Primary care

If a bereaved person is not in contact with a palliative care service (e.g. if the death was violent or unexpected), or there is no local bereavement counselling service connected with the palliative care provider, the most likely pathway to bereavement support is via a GP. This may also occur if the person was in contact with palliative care but, when initially contacted after the death, did not appear to need any extra help. Ideally, the GP will know that the person has recently experienced a significant loss and will be aware of local services or private practitioners that have expertise in dealing with grief and loss. There was, however, concern that GPs may misdiagnose the problem and, instead of referring a person to a psychologist or bereavement counselling service, may prescribe anti-depressants. It was considered among the expert group that medication alone was unlikely to be sufficient to address bereavement-related distress.

“Most people don’t need counselling, you know? But some people who didn’t say that they needed help, would start to struggle down the track. And some of those would go to their GP perhaps and then get a referral to a counsellor or mental health professional, hopefully. Or just be put on anti-depressants.” (E2)

“They’re in the hands of the skills, the sensitivity [and] compassion of that general practitioner. Hopefully, that GP is a good listener. They really need to be a good listener for these patients and also ready to embark on these conversations and indeed referral without necessarily going to anti-depressant medications.” (E10)
The former Access to Allied Psychological Services (ATAPS) initiative has been absorbed into the Primary Mental Health Care Activity of the Primary Health Network (PHN) Grant Programme. Funding will enable PHNs to lead mental health service planning, commissioning and integration of services at a regional level to improve outcomes for people at risk of, or experiencing, mental illness.

The primary program, funded through the Medicare system that provides access for patients via a GP referral to mental health professionals is the Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access) initiative.

Under the Better Access initiative, patients can be referred by GPs to psychologists, psychiatrists and appropriately trained social workers for up to six consultations per year with a Mental Health Treatment Plan. Private practitioners are free to set their own charges, and the patient receives a rebate from Medicare to subsidise the cost. After the first six visits, another four are allowed with a second referral (to a maximum of 10 annually). A specific diagnosis of complicated grief (or similar) is not required for the GP to make the referral, although the patient fact sheet states that:

_The conditions classified as mental disorders for the purposes of these services are informed by the World Health Organisation, 1996, Diagnostic and Management Guidelines for Mental Disorders in Primary Care: ICD-10 Chapter V Primary Care Version (Department of Health, 2012b)._  

Many of the participants in the current research talked about the use of Mental Health Treatment Plans as a pathway into bereavement support for those experiencing complicated grief. The effectiveness of this pathway is dependent on the willingness of the patient to approach the GP, the ability of the GP to recognise the problem as grief-related, and their knowledge of available, appropriate services. The additional cost of the private practitioner’s service, beyond what Medicare covers, is seen as a potential barrier. The issue of whether complicated grief is best treated by generalists or specialists is discussed in a later section.

### 4.2.3 Bereavement counselling services

Even with active follow-up from palliative care providers or GPs, self-referral is an important pathway into bereavement counselling services. That is, the potential client must approach the service and ask for an appointment. A preference for self-referral was strongly expressed by the bereavement counsellors who were interviewed, and was also noted by numerous other participants who had a role in referring to these services.

_“The bereavement service does prefer though that the clients come to them themselves so, yeah, I can let them know about a client but they then ask that the client takes the initiative to actually refer themselves and book the appointment as well.” (E8)_

_“My sense is that third-party referral is a very medically modelled kind of approach and often when people think in multi-disciplinary team meetings that someone needs a follow up, when someone actually does follow them up quite often they come back saying well I don’t actually want a service.” (Focus group participant)_
Bereavement counsellors saw self-referral as the best indicator of a genuine need for a service, but acknowledged that the success of this model relied on building awareness among the public that such services were available and could be beneficial. Some bereavement counselling services engaged in outreach activities such as education of GPs, connecting with other mental health services, and providing information to religious and community leaders and schools, in order to publicise their work. Such services also played a key role in sending out bereavement information packs via palliative care and/or other health services. Participants saw public awareness as the major challenge for the self-referral model; visibility among GPs was seen as particularly crucial for such a model to operate effectively.

As well as public awareness, the self-referral model also depends on more-or-less universal access to bereavement counselling services. According to this view, those who feel in need of counselling should be able to approach the service directly, without mediation by a third party. Over-servicing is seen as unlikely, as most people do not want or need bereavement support provided by a mental health professional or counsellor.

“A sort of universal coverage here as best as possible is really important, which is clearly not the same as offering universal support, because most people don’t come along for counselling.” (E11)

“I note in the literature, there’s a bit of criticism for that blanket outreach to all people who are bereaved, but I actually don’t think that that results in an overuse of counselling services at all. I think it just allows people to know where they can go. It’s … provision of information rather than us spruiking counselling, in my view.” (E2)

Even among those who were strong advocates for self-referral, there was agreement that some people required more active follow-up than others; for example, bereaved parents may be so devastated by their loss that they feel unable to reach out for help. If, following this additional contact, the potential client decides to take up the service that has been offered, this was still regarded as self-referral.

“Families are actually saying they are finding their sorrow from after a child has died, too much to actually pick up the phone and make that phone call. Although they say ‘we know we have all the leaflets and we know we could have called, but we just don’t’. But they’re very receptive when they get a phone call or home visit.” (Focus group participant)

Bereavement counselling services have standard procedures for dealing with the initial contact from a prospective client. Usually this will take place over the telephone and will involve asking questions to ascertain the nature of the person’s difficulties and collect some information about the circumstances of the death, the relationship between the deceased and the bereaved, and other relevant details. If the service provider and potential client agreed that counselling could be helpful, an appointment is made for the first face to face session.

“Normally, people ring because they’re quite distressed; they don’t know what to do with their life after the loss of a loved one, so we offer counselling at that point. But sometimes even doing the intake we realise that that person has been grieving for, for example, more than a year or there are other elements that maybe make that
loss complex, not complicated, but complex. Like, if it was a murder or if it was an accident or something very traumatic. Occasionally we have some referrals from GPs, sometimes clients have been working with medication, like, antidepressants and sometimes that person, they’re still feeling that’s not quite okay and they want to still talk more about their loss ...” (E9)

The first session may be longer than usual in order to collect further information to inform treatment. In some services, standard assessment tools are used during this process if complicated grief is suspected. Others do not use any tools but rely on the counsellors’ “clinical judgement” based on their training and experience (E11).

Most of the bereavement counsellors said the typical course of treatment varied and usually did not exceed twelve weekly sessions, but this was not always the case; for example, one counsellor said they would generally see clients for at least two years, although not weekly. Those working in a “free service” were conscious of the need to avoid over-servicing in order to direct their resources where they were most needed.

“We’re not trying to engender further occasions of service. Our rule of thumb is to try to make ourselves dispensable as soon as possible.” (Focus group participant)

Further information about treating complicated grief can be found in Section 4.5, and about the workforce that provides treatment in Section 4.7, including a discussion around the relative merits of specialist versus generalist providers. The recovery process is described further in Section 4.8.

4.3 Preventing complicated grief

Some participants were not convinced that complicated grief could be prevented by anything that health professionals or services could do, either before the bereavement or in its immediate aftermath. These interviewees felt that vulnerability to complex grief lay more in the person’s history, for example, of mental illness or previous trauma, and in the closeness and centrality of their relationship with the deceased. In addition, there were some kinds of deaths (e.g. suicide, homicide, death of a child) that were particularly difficult to deal with, even for the most psychologically robust individual. Among these participants there was a sense that some people, because of their circumstances, were probably going to have a hard time with their grieving.

Others, however, were able to nominate several factors that might influence the onset of complicated grief and were potentially modifiable through the actions of health professionals. Many of those with this view worked closely with, or within, palliative care services. In this context, actions which could protect against complicated grief were ensuring the patient and carers were prepared for the death, delivering high quality end-of-life care, and providing information and support in the immediate post-bereavement period.

These activities are inter-related; conversations involving the patient, their family and the multidisciplinary team could result in an Advance Care Plan, which in turn could influence end-of-life care. Each of these factors is described in the following sections.
4.3.1 Preparation for the death

Previous research has demonstrated that complicated grief is more likely if a death is unexpected (Burke and Neimeyer, 2012). A lack of preparedness for the death is also a risk factor for complicated grief (Lobb et al., 2010). People who experience a sudden loss may feel shocked and numb, reducing their ability to benefit from social support or to find solace in rituals such as the funeral (Hoy, 2016). Grieving can be made more complex by the presence of “unfinished business” between the bereaved and the deceased, or by feelings of guilt and self-blame (Hoy, 2016).

Common sense would suggest that these issues are less likely to arise in the case of an expected death in palliative care or aged care, but the interviews highlighted the unanticipated finding that these deaths can also be experienced as unexpected. Family members and friends may understand on an intellectual level that the patient has a terminal illness but may be unprepared emotionally. In the case of illnesses with an unpredictable trajectory, such as some cancers, the person may respond to treatment multiple times over a period of years, leading family members to believe that the chemotherapy will always work to keep their loved one alive. When the treatment eventually fails, and the patient dies, the survivors can be left with a profound sense of shock and even trauma.

“Interestingly though there is a huge gap between what health professionals think is an expected death versus what the family think is an expected death. So you have a whole bunch of people who know that their loved one is dying, or their family member is dying, but who, at the time of death, say it came as such a shock, they didn’t realise it was actually happening this time, and they didn’t know that it was happening now. And those estimates range from, say, 25% up to even two-thirds of people with a so-called expected death that say it was a complete shock and it was very traumatic ...” (E1)

“One of the disturbing statistics that’s coming out of some of the major cancer centres in America is the number of people who the medical staff knew they were going to die in a week, that was their prognosis, but when they interviewed the families of the patients, they had no idea. So even though they were right at the end of life, very often the family don’t know it. Now clearly there’s a great window of opportunity there where preparations could be made.” (E14)

“The prevailing social discourse around “fighting” disease can act as a barrier to families who are reluctant to accept the reality of a terminal prognosis. Participants who were involved in palliative care spoke of the need to create a space in which people could acknowledge and start dealing with their anticipatory grief. Allowing the patient to talk about their own loss – of their future, their relationships, careers, hopes and plans – could open up the way for others to stop trying to be brave and give them “permission” to grieve (E6). This should occur well before the end-of-life phase, when the patient can still be an active participant in discussions. In one
model which is currently being trialled, the patient sets the agenda for a family meeting, decides who will take part, and leads proceedings, if they wish. This gives the patient a forum to express their wishes for end-of-life care, but also express their love and gratitude for the care they have received. They can also nominate family members or friends for whom they have particular concerns. In turn, these people can share their feelings, including any fears or anxieties around how they will cope with bereavement. This process might help identify those in need of extra support and initiate referrals, where appropriate.

Whether these discussions take place formally or informally, several participants spoke about the importance of creating this opportunity, wherever possible.

“That kind of thing is just helping people to have those conversations which are really borne out of love otherwise they stay inside them as pits of anxiety and sadness.” (E8)

Providing accurate information to the family about what happens when someone is dying was also considered crucial in protecting them from distress and trauma. If this was not done carefully, changes in breathing or agitation could be interpreted by family members as a lack of symptom control. A brochure produced by Palliative Care Australia was named by one participant as a good resource for carers to understand the dying process. Some people may need to have the palliative approach explained to them, so that they can understand that it is not about “giving up” but about preserving dignity and quality of life.

“Especially if I’ve warned them about what’s going to happen and reassure them that – and one of the other things is just explaining to them that we are not giving up and abandoning them, we are just moving to a different level of care, we are doing what we should do ... being a doctor is not all about keeping people alive ... your care switches to making sure that you are giving peace and comfort and dignity at the end. That’s our job. And that is in fact a loving thing to do.” (E12)

4.3.2 Advance care planning

One possible context for having the kinds of conversations discussed above is during advance care planning (ACP). Participants who were involved in palliative care were generally open to the possibility that ACP might help prevent complicated grief. When asked why it might help, they mentioned two mechanisms: creating an opportunity to have frank conversations involving the patient, family and multidisciplinary team; and creating a written record of the patient’s wishes to guide appropriate end-of-life care.

Several participants noted that ACP needed to be more than “an administrative box to be ticked” (E4). To be effective, the process must foster meaningful discussion, preferably facilitated by a social worker or other trained staff member. It should help facilitate both practical and emotional preparation for the end-of-life phase. An important goal of ACP is to help the patients and family understand the most likely trajectory of the illness and the prognosis so that the end-of-life phase does not come as a shock.

“I do believe that good advance care planning can be part of a larger professionally facilitated conversation that gives people fewer regrets, when a loved one dies. And
you know, sometimes we can’t make it better, but we keep from making it worse.”
(E4)

The other key aspect of ACP is the documentation of the patient’s wishes for their end-of-life care. According to participants, having this document can help reduce uncertainty and pressure for family members who otherwise might have to make important and difficult decisions quickly, in distressing situations. In the words of one participant, it could “take a weight off their shoulders” (E12). Following the death, it could ameliorate any regrets or guilt around the care provided. This document could also be used as a communication tool to help reduce family conflict and confusion around the events surrounding the death.

“Doctors, I suppose, are sometimes in a bit of a dilemma; they might say, ‘Look, I think it’s not going to be of any great benefit to them,’ but the family don’t want to – they just want them to continue on, and so if the patient can make that decision themselves to say, ‘Look, if I get to the stage where I can’t make decisions about my life this is what I want; I want to die peacefully, I want to have some medication to make [sure] that I’m pain-free as possible and I just want to be peaceful and die peacefully.’” (E5)

“When doctors start wanting to talk about the option of withdrawal [of active treatment] and dying, it’s the family who’ve not been involved, so closely involved, who are the most shocked, who are the most outraged, who are the most angry and demanding on answers and wanting to – things to be fixed, whereas the person who’s lived through it with the patient understands a lot better.” (E8)

Although the conversation around ACP was very much seen as the active ingredient in prevention of complicated grief, some participants noted how vital it was to have a written document. This was seen as a “living document … not set in stone” (E7) that could be amended as necessary (e.g. when the trajectory of the illness changed over time). Writing down the patient’s wishes was necessary to ensure that they would be remembered and respected, and the document also served as a record that can be used to support the bereaved afterwards, when they may begin to feel concerned about the care provided during the end-of-life period.

“We would have that discussion with them as well as discussing with them the importance of actually documenting it. And I do this particularly in the context of, ‘Yes, your husband knows what you want if you collapse on the floor and you don’t want any interventions. The ambulance drivers come, if there’s no advance care directive and your husband panics and says, ‘God, do everything’, it’s putting too much emotional pressure on your substitute decision-maker in a pinch.” (J4)

It was noted, however, that although ACP could deal with many of the issues that might complicate or exacerbate grieving, it was “not a recipe for prevention” (E7).

“I think having a sense of preparedness, in my experience, brings so much more calm to everyone, rather than a chaotic – a situation where everything is now – it’s now too late, really, to speak to that person about their wishes … And that, I think, lays the ground for, hopefully, a better death and a better bereavement. Though, I do
note, even of course with the most quiet and dignified and loving death, of course, bereavement can be very powerful.” (E10)

Staff in palliative care settings whose job it was to initiate conversations around ACP required considerable skill and sensitivity. It may be tricky to introduce the topic at the right time, when the patient and their carer are receptive. Although ACP could help facilitate preparation for the death, the “readiness and capacity” (E2) of the patient and their family to have these conversations needed to be considered. Culturally and psychologically, ACP is not always acceptable to everyone.

“I’m obviously not going to do that with everyone, it’s only when it’s appropriate and I’ve got a good rapport with them and that’s something that they’ve seemed to want to talk about. You feel them out; you don’t just go gung-ho into these things.” (E8)

“It acknowledges what is actually happening, you know, it exposes the thing that often people don’t want to talk about, and of course that makes it incredibly problematic.” (E11)

One participant mentioned the use of a “substitute judgement decision-making standard” as a tool to assist carers in understanding how to make decisions in the end-of-life period and relieve some of the stress and pressure that might entail.

The lack of evidence around the role of ACP in preventing complicated grief was acknowledged by several participants. It was understood that it would be difficult to demonstrate that any intervention – including ACP – significantly reduces the rate of onset of complicated grief, which already has a relatively low prevalence in the population. One participant noted that although systemic effects were unlikely, it may be possible to show effectiveness of ACP at an individual level.

4.3.3 End-of-life care

To a considerable extent, ACP was seen as potentially useful in preventing complicated grief because - it was assumed - this process would promote better end-of-life care. Events occurring around the time of the death were seen as absolutely crucial, as these would be remembered by the family and could influence the course of the grieving process.

Participants involved in palliative care said it was particularly important that family members did not have to witness disturbing scenes at this time involving poor symptom control or distressing medical interventions. Treating the patient with dignity and respect was paramount.

“Over years I’ve become more and more conscious of the importance of the events leading through to the death, in terms of the preparation of patients and families for that event, for how relatives experience grief later. So, for instance, if there’s – if the death is difficult, agonising, undignified, that will be remembered forever and will enter the narrative of the family as they view death, but, certainly the way that they experience their bereavement. If, on the other hand, the death is, hopefully, comfortable and dignified and with love, that will be remembered.” (E10)
“Just the normal sorts of things we would do in palliative care are going to assist people to some extent, at the very least to experience the death as being as easy as possible without all those other complications. For example, witnessing a medical intervention that is disturbing, such as seeing an external bleed for example, is highly undesirable. So preparation is really important, a sense of collaboration should it be wanted, a sense of being heard, a sense that the person who is dying is being treated as a person is incredibly important, and not as an object.” (E11)

When the patient was being treated outside the palliative care setting, the involvement of the palliative care team could help ensure a more peaceful and dignified death. To this end, some participants called for greater visibility of the palliative care team in acute care settings such as the ED and intensive care unit. Great care was needed when informing the family that active treatment was no longer advised, and participants felt that doctors could improve their communication. The use of the phrase, “There is nothing more we can do”, was seen as especially problematic; this sort of language could leave carers feeling angry and abandoned.

A multidisciplinary team approach could be valuable in ensuring psychosocial issues were adequately addressed and also that people were kept informed about changes in the illness trajectory. One participant stated that end-of-life care could be enhanced through the use of a structured resuscitation pathway and medication protocol to guide medical staff to provide the most appropriate care to the dying person.

The movement (in palliative care) towards planned deaths at home may have implications for trauma and complicated grief. One participant said this was something that should be explored in future research. Another pointed out that often people wanted to be cared for at home as long as possible, but families may be unprepared for the practicalities of what this involved (e.g. the need to turn the patient regularly in bed), and in these cases a late transfer to the hospice might be an acceptable option.

Another participant said he made a point of telling carers that it was not necessary for them to be there at the moment the patient passed away. By de-emphasising the significance of that moment, he tried to give them “permission” to perform necessary tasks of self-care.

“I think another thing which actually often becomes a big issue, and I make a big point of it, is that a lot of people are really caught up about this idea of being there at the very final moment when their loved one dies ... And the problem is they go to the loo and their loved one dies and then they live with this guilt for evermore. And I actually preface that a lot. I say look, they are dying, they will die when they die, you can’t be there every moment. What’s more important is what you told them, what you said to them and what they said to you when they were able to. It doesn’t matter if you happen to be or won’t be there at the time so don’t beat yourself up, and it’s almost like permission giving it to them, yeah go home, have a shower.” (E12)

Even with the highest quality end-of-life care, there was no guarantee that the bereaved would not experience the death as distressing and traumatic. The concept of a “good death” was familiar to health professionals but may not necessarily be meaningful to the bereaved who do
not have the same level of experience of death and are naturally more emotionally involved in that one, particular death.

“If you were to ask a health professional what would be a good death they would tell you things such as, symptoms are well controlled, families are all on the same page, there’s no discord within the family, the patient is comfortable, et cetera. But if you consider that the average palliative care nurse would see up to 40 deaths a year and doctors many more, what we might consider a good death, you know, for that individual who this is the first death they’ve experienced and it’s their Mum or their Dad or their sibling, it can be a very different experience.” (E7)

4.3.4 Medical information

Some doctors (specialist palliative care physicians and GPs) saw themselves as having an important role in prevention by taking the time to explain the medical circumstances of the death to the family and thus alleviate any concerns about the quality of the care provided.

“When the treatment is perceived to have not been appropriate, either in terms of hastening death or delaying death and [causing] lack of quality of life, and in fact increasing pain or distress, then that certainly adds to the complexity of the grieving process afterwards.” (E11)

“I almost always ring up the family afterwards, after a patient has died, because I want to find out what’s going on, because I do realise that phone call makes a lot of difference, particularly in terms of actually dealing with some of the things that they may have been concerned about during the care of their loved one, which can sometimes be the source or a factor in the complicated grief. So for example, issues about guilt about what happened and thinking … that we didn’t give them enough morphine and thinking about the gurgled breathing, that they were choking, that sort of thing.” (E12)

4.3.5 Post-bereavement support

Following the patient’s death, providing psycho-education about grief can be helpful. One bereavement counsellor said that even just one counselling session could sometimes be useful in normalising the person’s experiences. This person believed that psycho-education – whether delivered in person or in the form of a brochure or booklet – should at least mention the possibility that complicated grief could occur, and that help was available if required.

In contrast, there was another view that going straight to professional counselling may cause informal support networks to “step back” (E3) from the bereaved person. From this perspective, the key to preventing complicated grief is to build supportive social networks in the broader community so that people can rely on their family and friends, at least initially. Those who required additional help would approach their GP, and those few with complicated grief would be referred on to specialists (psychologists, psychiatrists, social workers or occupational therapists). This tiered model of support was derived from public health approaches to prevention.
“This is basically my interest ... is about how do we build the capacity of those normal, everyday social networks, to be able to provide that first level bereavement support and in that sense, you know, hopefully people would not deteriorate into a complicated grief situation.” (E3)

“I mean, you would be familiar with models of healthcare provision that would be pyramid shaped and at the base, you have lots of people who need simply, information of an accurate kind. And then as you move up, maybe you have groups that would benefit from mutual support or chat group-based support. And then you would move up to a level where some, you know, tertiary care is needed of a more professional kind. I think the same thing is true in bereavement. In that, we need to have more continuity of messaging, about bereavement, where people become sophisticated, more alert to what to look for, in the same way that in suicide intervention campaigns, a big part of it is a public health education effort what to do if these signs are noticed.” (E4)

The success of a public health approach would depend on building capacity in the general community to respond to grief with compassion, rather than avoidance. There was a perception that grieving is often seen as time-limited, whereas it can actually continue for a lifetime, with a “natural rhythm”, increasing and subsiding over time.

“Society being able to understand that grief is complex, complex in the sense that it’s so personal, it can go on and be eternal ... and that people yearn for other people to listen to them. And, unfortunately, most people in society feel that this topic is just far too hard for them to speak about or talk about.” (E10)

Balancing this view was an awareness that some people will still require professional help, particularly if they lack supportive social networks or have multiple challenges such as poverty, drug or alcohol dependency, pre-existing mental illness or other factors that are likely to make their grieving more complex.

“In any mental health system, we know that people with more than one problem can fall between the cracks.” (E2)

4.3.6 Preventative interventions

Several specific preventative interventions were mentioned by interviewees. One of these was Healthy Experiences After Loss (HEAL), which one participant noted as highly effective in preventing prolonged grief disorder. A randomised controlled trial of this internet-based program with 84 bereaved people assessed as at risk of prolonged grief disorder found that those in the immediate intervention group had a significantly reduced rate of prolonged grief, depression, anxiety and posttraumatic stress compared with those in a wait-list control group (Litz et al., 2014). HEAL is based on cognitive-behavioural therapy (CBT) principles and is facilitated by a therapist.

Researchers at an Australian university have developed a self-help booklet about the adjustment process to death and dying, which is being trialled at local hospitals with palliative care patients and their carers. The booklet has 17 exercises which the user progressively works
through. The contents have been constructed to address a range of variables, such as: acceptance of death; communication about death; understanding what the patient thinks; general psychological flexibility. The approach is based on Acceptance and Commitment Therapy (ACT), which is a modification of CBT. The project aims to test whether there is scope for guided self-help as a preventative measure in the palliative care environment. The resource may be generalisable to other settings, such as aged care (Davis et al., 2017).

Community-based support groups and trained volunteers may also play an important role in providing post-bereavement support. These types of social support interventions were seen as potentially valuable for people who require more help than their family and friends can provide, but perhaps do not require professional counselling. They might include specific groups for those bereaved in particular circumstances (e.g. road trauma; paediatric cancer) as well as groups with more general membership. Meetings may focus on activities such as crafts or walking, around which bereavement support can take place incidentally via chats with other group members. Regular contact with other bereaved people could help normalise an individual’s experiences of loss and grieving.

There was a view – particularly among social workers and bereavement counsellors – that these types of groups could be very effective, but often the time and resources to establish and facilitate them was lacking. In an environment of constrained resources, some felt they had to choose between running a support group or devoting that time to providing one-on-one counselling and support.

4.4 Identifying complicated grief

The problem of how to identify complicated grief is, of course, closely tied to the issue of whether complicated grief is a distinct psychopathology. Participants who challenged the existence of complicated grief, or at least the need for a diagnosis, tended to be dubious about the value of screening or assessment. However, as indicated above, most could nominate factors that may make grief more complex and some could also nominate symptoms that might indicate problematic grief. The risk factors or triggers are presented in the next section, followed by symptoms, and then the debate surrounding the use of tools to identify complicated grief.

4.4.1 Risk factors or triggers

Recent reviews have categorised the risk factors for complicated grief into three groups or domains. These relate to (1) the situation or nature of the bereavement; (2) the support available or interpersonal relationships; and (3) selfhood or intrapersonal characteristics of the bereaved (Burke and Niemeyer, 2012; Hoy, 2016). The risk factors or triggers mentioned by participants can also be categorised in this way.

There was little controversy around the idea that the circumstances of the death could have a strong impact on the grieving process, possibly triggering complicated grief. Complexity was more likely if the deceased was a child or a long-time spouse, or died by suicide. Violent, sudden and traumatic deaths may be more difficult to accept and process. However, as discussed above (Section 4.3.1), even “expected” deaths in palliative care could be experienced as traumatic if the family or partner was exposed to poor end-of-life symptom control or
disturbing medical interventions, if they were psychologically unprepared, or if there was family conflict or confusion over the treatment approach.

The need for a bereaved person to have access to a “good listener” (E10) was noted by several participants. Some saw this social support as lacking in our “individualistic culture” (E3). Expectations around the course of grieving differ greatly between cultural groups; in Australia, there may be a prevailing (and unhelpful) view that the bereaved should recover and move on with their lives within some artificially imposed timeframe.

In palliative care settings, medical staff and social workers expressed particular concern for carers who were socially isolated (e.g. giving up work, activities and friendships to care for a dying person).

“Suddenly when [a patient] dies, especially if they’ve been coming in [for treatment] for a long time, the carer is still alive, still going on but they don’t have that same routine so a really big chunk of their life they now can’t live out because someone else has gone. So they had spent a lot of time living for someone else, doing all these things for someone else and – we see a lot of carers who put a lot of their own needs on the back burner.” (E8)

Finally, personal characteristics of the bereaved were seen as highly influential. Greater vulnerability was expected if the following were present:

- Dependence, or a high degree of centrality of the deceased person to the bereaved person’s life
- Pre-existing or previous mental illness
- History of abuse or other trauma
- Previous significant losses, especially if recent.

Consistent with the therapeutic approach advocated by Shear and colleagues, some participants saw complicated grief as primarily a problem of attachment.

“Of course, the journey begins long before they enter the health system, typically and often, complicated grief represents a perfect storm of attachment-related challenges, sometimes experienced quite early in life, that leave people feeling insecure and uncertain about their level of attachment or connection to others. And that sensitivity or vulnerability often gets triggered then, when later in life, they experience a loss of a really security-enhancing person. So, that often is the backdrop to people struggling greatly when they lose someone they love on whom they greatly depend. There are other ways that grief can be complicated than that, but that would be the essential backdrop for many.” (E4)

Those working in counselling settings pointed to particularly close and exclusive relationships as a notable risk factor.

“I guess the one that I have noticed over the years that often causes more complex ongoing bereavement related issues is the relationship where the partners have
been very bonded so there is a very, very central relationship to the sort of exclusion of others. For example, clinically if someone walks into a counselling session and says something like, ‘We didn’t need anybody else, we were everything to each other’, it’s a usually fairly reliable sign that that is going to be a somewhat complex process.” (E11)

Paradoxically, problems could also arise if relationships had been fraught with tension or unresolved disputes; where there was a history of abuse; or when people had learned to suppress emotions and “soldier on” (E12), trying to be strong in order to support others.

4.4.2 Symptoms of complicated grief

Those who accepted the existence of complicated grief were able to describe a set of symptoms: intense yearning, preoccupation with the deceased leading to rumination or intrusive thoughts, persistent avoidance of the reality of the loss, disturbed sleep, anger, guilt, restlessness and somatic complaints.

“… depending on neuro-cultural background and their ways of thinking and language in loss, they may approach their distress in a more somatic, physical way. They are aware of the physical symptomatology of depression or the acute separation distress that is actually rather different than depression, but is close to the heart of complicated grief, where people may feel more a sense of generalised anxiety and oftentimes, a sense of panic…” (E4)

One experienced bereavement counsellor claimed never to have encountered a case of complicated grief, and described how complicated grief might present in terms of functional impairments:

“… maybe when they get to maybe six months post-death they may feel that – they may present as complicated grief, which is basically grief that’s not been resolved perhaps on earlier situations and they’re just not getting on with life, they’re actually not looking after themselves. Food-wise they’re not feeding themselves, they’re not going out; they’re not doing personal care. I haven’t come across anyone to that standard. What I do see are people that are just very, very sad, and they work through it.” (E5)

This person would start to worry about someone if, at six to nine months post-bereavement, there had been no “movement” or change in their grieving process. This was a common thread among clinicians: for normal functioning to resume, change or movement within the grieving process was seen as crucial. The stage model of grief (Kübler-Ross et al., 1972) was seldom discussed, except in a disparaging way; instead, proponents of both points of view referred to the dual-process model of bereavement (in which oscillation between loss orientation and restoration orientation is seen as healthy (Stroebe and Schut, 2010). Becoming “stuck” was seen as problematic.

Several participants noted that researchers have not yet agreed on how long a person must be in the acute stage of grieving before they could be diagnosed with complicated or prolonged grief. For those who opposed any kind of diagnosis, this was seen as confirmation that the
construct was fundamentally flawed and should be rejected, whereas others saw the construct as a work in progress.

4.4.3 Screening and assessment tools

The literature review section of this report describes various questionnaires (tools) that have been developed to detect the risk or symptoms of complicated grief. These may be self-completed or administered by interview. Tools for identifying complicated grief could be used in two contexts:

1. To screen people before or soon after bereavement in order to identify those at risk of complications;
2. To assess bereaved people who self-refer to services that provide support or counselling.

In the first context, the outcome of the screening process might be that those who are at risk are given priority for follow-up and referral to services. In the second context, the tool might be used to collect information to help decide the most appropriate treatment approach.

The use of tools either for screening or assessment was controversial in the current study. Participants were divided into those who saw tools as a potentially useful way of ensuring that people experiencing complicated grief received the services they needed, and those who regarded any type of standardised screening or assessment as contrary to good practice in bereavement support.

Those who were generally in favour of using tools tended to see screening as sensible from a public health perspective. They challenged the assumption that those who self-refer to bereavement counselling are always those most in need of assistance. These participants argued that there was a genuine need for systematic means of identifying the small number of people at risk of complicated grief who could benefit from specialist services.

“So we don’t know how to identify the people who are in need in the first place, and that’s really important because obviously we don’t want to provide services to people who don’t need it, it could make them worse, or at least has no effect, but it’s also really expensive, so it’s a waste of resources. We need to know who needs support and then we need to be able to provide that support …” (E1)

“It’s very difficult when you don’t have the proper tools for that, psychological instruments and stuff. But the carer can tell you where they’re struggling. And that would give you an idea … if they need to be supported after. So, you don’t need to do it for everybody then. You just know which families are struggling at that stage, from them telling you from a simple checklist and then – it gives you an idea. Instead of just spending your resources as you’re doing now on everybody, because that’s how it’s been done.” (E3)

Most existing tools for complicated grief measure psychosocial symptoms and/or functioning. Several questionnaires were named, most often the PG-13 and the Brief Grief Questionnaire, also the Bereavement Risk Assessment Tool (developed in Canada and used in some Australian
states) and the Death 21, and more general psychometric instruments such as the Beck Depression Inventory and the Impact of Events Scale. A short bereavement screening tool (Bereavement Risk Index) currently used in South Australia and the Northern Territory was mentioned by some participants.

“We’ve often used the PG-13, prolonged grief 13, as a kind of diagnostic and assessment tool. The inventory of complicated grief in its revised form, can be a patient completed measure that actually provides a bit more detail frankly, than the PG-13.” (E4)

Some providers conducted a broader psychosocial assessment, including an inventory of interpersonal support. A formal suicide risk assessment was seen by some as an essential part of any screening process due to the elevated rate of death by suicide among people experiencing complicated grief. One participant also assessed for traumatic stress.

Participants in this group were quick to critique the assessment process and to acknowledge that none of the existing tools for complicated grief works particularly well. One described in some detail the level of dissent in the research community around terms, definitions and tools. They pointed out that some of the key researchers in the field insisted on modifying the questionnaires they used in their studies, by adding or subtracting items, adding to the confusion. Participants raised questions around the reliability, validity and sensitivity of existing complicated grief tools, and also around whether they were practical to implement in clinical (as opposed to research) settings.

“It’s kind of difficult in a way, in that we know that you can have a lot of the risk factors and not develop complicated grief, you can have none or very few of them and develop it, so it’s not always an easy thing to figure out through a risk assessment process.” (E1)

“I’ve also had people go, ‘Zero, zero, zero [on a risk assessment tool], however, I am concerned.’ And mostly it’s because they know the people pretty well, they think, well, okay, things are in place but I’m concerned about how they’ll cope.” (J4)

“I know we talk about all these tools that we have for risk assessment, but again ... they’re not practical to do in a really very busy palliative care ward. Their priority is looking after the patient and they will engage with family and friends, but they’re still not – they’re still not the service priority. And rightly so.” (E3)

“If you consider a lot of the studies have been done within a research setting and protocol, but you translate that into hands on clinical care, you know, there are lots of points of care where it could be noted that someone is distressed, but then that’s also very subjective. And, so, unless you are actually using the screening tool and its part of the service – and then, as I said, you’ve got those issues around privacy that have been raised. So I think it’s complex.” (E7)

Nevertheless, it would be fair to say that many of the participants in this group believed a formal screening or assessment process could be useful if a suitable tool could be developed and implemented appropriately. One suggested that it should be possible to come up with a
tool that screens out 80% of bereaved people – those who are least likely to experience complicated grief – allowing resources for follow-up to be focused on the remaining 20%. This would involve collecting information on: (1) pre-existing issues (dependency, history of mental illness, relationship to the deceased, age); (2) the event itself (suicide; expected versus unexpected); and (3) the aftermath of the death (social support, other stressors) (E14).

Two participants described tools that are under development in the United States. One of these is the Bereavement Risk Inventory and Screening Questionnaire, which is still being validated. Another is a multi-dimensional measure of constructive coping strategies called the Coping Assessment for Bereavement and Loss Experience (CABLE). The same research group associated with CABLE has recently developed tools for measuring different aspects of grieving, including response to stress and attempts to make meaning from loss.

Issues were noted around the timing for administering the tools. Given that complicated grief has a delayed onset, the most suitable time for screening would be at least six months or a year after the bereavement (avoiding the anniversary), but it may appear up to two years after a traumatic or violent death.

“Things can look pretty good right after the death because you’ve got a lot of people around you, but two or three months down the track when you don’t have anyone around you, that’s where things get complex. And that’s the concern also that – in terms of rating and, say, not calling people who have a low rating, we know grief-wise that can shift.” (J4)

If a tool were introduced for screening and/or assessment, it would need to be implemented carefully, with training provided to experienced staff and referral pathways established in advance. There is little point in identifying those at risk of complicated grief without then ensuring they receive the specialist services they require. Screening should not be done without appropriate follow-up and referral. To obtain a valid measure of risk, staff members require familiarity both with the tool and with the patients and carers, which is a challenge in the case of short stays in the ED or intensive care unit or late admissions to palliative care.

“If you’re not actually going to do anything with it, then don’t do it. So you’ve got to make sure you’ve got the services in play. And what I would be arguing is you’ve got [to have] evidence-based services.” (E14)

“I think there’s definitely a place for a tool as long as the right people are using it, you’d need to be pretty specialised and good at communication with the patients, you don’t want any old junior doctor or junior ward nurse or brand new gung-ho social worker student ripping out the screening tool with no sensitivity whatsoever, no preparation with the client whatsoever, no rapport building.” (E8)

A few interviewees were open to the idea of formal tools but were not currently using them in clinical practice, because they felt their existing, informal methods were working well enough. Several people strongly opposed screening. They felt that the existing ways of delivering services (that is, self-referral to bereavement counselling and informal intake and assessment processes) were working well and would not be enhanced by the use of tools. One participant perceived that there was a “push” towards classification of levels of risk for complicated grief in
Australia, driven by arguments around economic viability. Another said screening and assessment tools were too “basic” or simplistic to be of any use at all. This person’s resistance was based partly on the fact that such tools had been developed by psychologists who “see things differently” (E5) to bereavement counsellors. In addition to this philosophical objection to the “medicalisation” of grief, participants in this group also mentioned practical problems with screening and assessment tools.

“I have particular issues about [pre-death screening] in relation to its workability, but also some ethical questions about up-storage of information and getting essentially psychological information about people who aren’t actually the patient at the time, which is then stored as a health record.” (E11)

Not all of those who objected to screening and assessment tools were bereavement counsellors. One experienced clinician said the key to identifying complicated grief was to “just shut up and listen, and really just listen well” (E6). Like many of the other interviewees, this person preferred a more holistic psychosocial assessment process.

“Assessment needs to be more comprehensive – there are about 12 things / factors that everyone in the room would look at: death of a child, traumatic witness, lack of support (perceived or real), multiple grief, existing physical or mental preconditions... I think we can all articulate about a dozen. At that point we could say in our heads, this is going to be a short term contact or this is going to need more duration/frequency.” (Focus group participant)

“I think the most effective method is building up the relationship with the family and collecting, you know, just collecting information that way.” (J1)

“I certainly don’t use formal screening tools. I’m not sure if our pastoral care workers may. The main tools that work well, not tools as such, the main way we use to recognise this is an interdisciplinary discussion ... we often flag saying this person’s at risk more of complicated grief or significant bereavement ... and it’s often based on what the nurses or social worker - their input and then ratified through the rest of us. Yeah, that’s how we identify it.” (E13)

4.5 Treating complicated grief

When asked about the best ways to treat complicated grief, many participants were able to nominate either specific, evidence-based interventions or general approaches that they had found, by experience, to work well. Often those who used a more general treatment approach liked to borrow elements from a range of standard therapies, including CBT and Complicated Grief Treatment, to enhance their practice.

Although, as indicated in the literature review for this study, the evidence base for treatment approaches is mixed, there have been promising results with some therapeutic approaches. There was also a strongly expressed view that a more flexible, eclectic practice — taking the best from a range of therapeutic approaches — may work well for experienced practitioners who prefer not to use strict, protocol-driven therapies.
Finally, some participants referred to the role of national or state-level standards in guiding good practice in assisting people who may be experiencing complicated grief.

4.5.1 Treatment interventions

Research and development in the field of treatment for complicated grief has advanced considerably in recent years, although participants could still point to significant gaps in knowledge. Interviewees were in agreement on the kinds of treatments that do not work well, namely generic CBT and anti-depressants, which do not address the specific distress associated with loss and separation. Randomised controlled trials have demonstrated that tailored treatments can work for certain groups of bereaved people.

“... the common element across them all is that there is emotional processing of the grief memory - ... and then, to be honest, it comes down to cognitive framing of issues surrounding the death and the change of identity after the death and also sort of structured planning to what a person then moves on to once they resolved those issues. And we know that basically a therapy program that contains those elements is going to lead to the best outcome in people, relative to any other intervention.” (E14)

The intervention most commonly discussed by interviewees was Complicated Grief Treatment, developed by Katherine Shear and colleagues at Columbia University in the United States. This is a structured program delivered over 16 sessions by an accredited counsellor (there are currently very few accredited providers in Australia). It is generally face to face, but can also be delivered via internet-based audio-visual conferencing services (e.g. Skype). The therapy directly addresses issues around attachment, separation and loss and draws on the dual-process model of bereavement in exercises which encourage people to find a “balance” between time for grieving and time for looking to future goals and engaging in enjoyable and productive activities. Several participants were very positive about the effectiveness of this therapy compared with more generic approaches.

“So every session you, as a practitioner, you know what you have to do ... And, I have to say that it’s working ... After 16 sessions maybe your grief is going to become something that you can manage, you can again maybe, in a very simple way, you can go and work again or be in connection with your loved ones again, have a life that you can manage better.” (E9)

“With loss-related dimensions of her work, such as recalling and retelling in detail and repeatedly, the story of the death, this would be considered a kind of exposure-based reason for promoting the integration and accommodation of that story with less emotional reactivity. There’s also the use of imaginal dialogues and memory work, to help consolidate positive and consoling memories, the connection to the deceased. Both of them would fall under loss-oriented work. And then there would be restoration-oriented work as the therapist helps the client project their goals in light of who they now are, the opportunities they now have and the constraints they may no longer have, after caring perhaps, for an ill relative, child, parent or spouse for a period of time, there may be an opportunity for reinvention of life goals and roles.” (E4)
Another structured approach is a therapy developed and delivered by the Traumatic Stress Clinic at the University of New South Wales. The therapeutic components are similar to Complicated Grief Treatment, and have been demonstrated to be effective in research trials.

“Well, I think the number one [key ingredient] is emotional processing. What you tend to find is most people who are stuck in their grief; they actually haven’t processed the loss and that’s a difficult thing for people to do ... [Emotional processing] will lead to a better outcome and that facilitates then the second part of it, which is actually then cognitive therapy, cognitive restructuring, so that issues about guilt, hopelessness about the future, et cetera, can start to be addressed. They’re the two big ones.” (E14)

The behavioural components of these types of therapies – elements such as exposure and behavioural activation – were seen as particularly effective. In addition, new therapies are being developed in the United States to work with, for example, bereaved parents around the meaning of their loss. Promising results have been obtained with novel internet-based therapies utilising video conferencing combined with email or narrative writing exercises.

There was, however, considerable resistance to the idea of a formulaic or protocol driven response to bereavement and grief. Among bereavement counsellors, it was seen as advantageous to be able to select from a range of approaches to build a “toolkit”. This was seen as enhancing adaptability and relevance to the bereaved person’s particular circumstance. Nevertheless, it was noted that such flexibility must be applied over a foundation of relevant experience and expertise to guide the counsellor in choosing the best available tools.

“We use a range of therapeutic techniques, but they’re based on assessment of that client at that point. I wouldn’t use the formulaic approach e.g. 12 or 16 sessions. It concerns me, I think it is reductionist. I’d cherry pick from Shear’s course. I work predominantly now with bereaved parents so all people I work with could be defined as ‘complicated grief’ and I would not do it to them.” (Focus group participant)

“It kind of goes against what I try to do in terms of psycho-education around grief. On one hand I spend a lot of my time saying grief is unique, so it would feel wrong to say your grief is unique but you now have to do this eight week program. It goes against the natural aspects of grief.” (Focus group participant)

“It does take skill as a practitioner to roll with the different things that come into a room, and you need multiple elements of a toolkit. As skilled practitioners in this room, we never stop searching and adding to those things and maybe that’s where the fear of other practitioners who have done a course, a weekend course on grief and loss, and think they can now go and do that. We know that’s not the only thing you need in your toolkit.” (Focus group participant)

4.5.2 The evidence base on effectiveness of therapies

The quality of the existing evidence on therapies for complicated grief, including the randomised controlled trials, was contested by some participants, particularly those who had philosophical objections to a diagnosis. Other participants were open to the concept of a
specialised treatment for complicated grief but questioned whether findings could be generalised to broader populations and applied beyond the research context. For example, several people noted that the field of complicated grief was founded on observations of older women who had lost their life partners, and that effectiveness of specific therapies had been demonstrated primarily for this particular group of people (i.e. elderly widows).

Researchers and clinicians alike warned about the danger of misinterpreting reviews that conclude there is “no evidence”. This does not mean there are no effective treatments, or that existing treatments are not effective, only that there is a need for more high quality studies. The field of complicated grief is developing rapidly and there have been many changes over the past decade. Rather than restricting the field to proven therapies, a diversity of approaches is worth supporting and most likely to give rise to a successful treatment in the future.

“If we were to limit our recommendations to those [practices that already have an evidence base], you would probably unnecessarily constrain practitioners and ultimately the range of services that could be provided. Because if you were to ask the same question 10 or 12 years ago, the answer would be, well, there are no effective treatments ... Now we have a few, but I think that if we try to extract the basic principles of practice, that those few tend to incorporate, then we potentially could have a much broader range of effective practices 10 years from now. And I wouldn’t want to constrain that development by saluting only the flags that are currently flying. With that as a caveat, I would say that there are a handful of methods that have demonstrated a good track record.” (E4)

“So a few years ago, there was one of those Cochrane studies that showed that there was no evidence for, I think it was music therapy, or art therapy, or something in palliative care, so their funding bodies then got rid of all the music therapists. But that’s not what it said, it didn’t say it couldn’t be effective, it just said at the moment there’s no studies to show that it’s been effective, it is quite different to 50 studies showing it’s not effective, it’s a very different thing. And so because of that interpretation ... therefore we’ll cut all this funding, and that’s not right.” (E1)

In the past decade, several literature reviews have been published which concluded that the evidence base for bereavement counselling itself is lacking (see Section 3.4). This was alluded to by several participants and was clearly a sensitive issue in the field.

“I suppose there’s been a lot of emphasis in the literature that grief counselling, for example, isn’t effective, there’s been a lot of negative stuff, and, of course, that’s really not the case. We know that a lot of those studies tried to find – just went and got a convenient sample of participants, and, of course, most people do have a normal form of grief, so therefore the intervention was shown that it didn’t have an effect, because for most people, they already had a low level of distress or whatever. But we basically know we need to target certain people, and if we target certain people and give them a good appropriate intervention we do know that it does work.” (E1)

“... what I call generic grief counselling – this is not people with prolonged grief but just the aftermath of grief, the adjustment counselling, the generic stuff, the
evidence tells us it doesn’t do much good. Now that is probably the most controversial thing I’ll say to you. I mean, that goes down like a tonne of bricks with most people in this field, because most people in this field, that’s their bread and butter. But the evidence [shows] that sort of work actually is helpful, people like it and they enjoy it and they find it comforting, but it doesn’t actually change the course of anything. It doesn’t do anything. We actually don’t have any evidence that it does.” (E14)

The latter of these two quotes was followed up by an explanation that part of the problem was that generic counselling was not targeted to those actually experiencing problems with their grieving process.

“Now when you offer it to everybody it’s very hard to demonstrate an effect because most people are going to be getting better anyway, it’s just their natural adaption process, because most of us do get better.” (E14)

The point made by these participants about the problem with universal interventions is supported by a narrative review of proposed diagnostic criteria and treatment effectiveness which concluded that ‘treatment generally works best when targeting individuals experiencing marked difficulties adapting to loss (e.g. meeting criteria for complicated grief’) (Doering and Eisma, 2016, p.3).

Another difficulty with obtaining evidence occurs when interventions are not consistently structured and outcomes are not measured in a standardised way. This may apply to some types of psychotherapies which lack “an element of measurement”.

“Having said that, there actually is a lot of evidence for the relational component of therapy. But for some reason that I have never understood it never shows up in government policies.” (Focus group participant)

Research to build the evidence base for bereavement counselling could focus on the cost-effectiveness of such treatments in reducing morbidity and mortality among bereaved people. In addition, more research was needed to identify the key elements of specialist complicated grief treatments so that they could be refined and targeted more effectively.

“... bereavement is positively correlated with a whole host of stuff, all of which are going to cost the health dollar. So some health economist surely can look at that stuff and say this is an area that actually is deserving of more funding rather than depending on it being a somewhat ad hoc thing that people add on to services because it is part of the palliative care mission statement, and therefore we have to be seen to be doing it.” (Focus group participant)

“We know generally these kinds of tailored interventions work, and are far more effective than what we did, sort of, ten years ago, or even five years ago really, but we don’t know what is it about those interventions, what mechanisms within them, are the effective components and how to choose this one for this person.” (E1)
Some support for the eclectic practice favoured by some practitioners is emerging in the academic literature. In a recent randomised controlled trial, researchers “deconstructed” the components of CBT-based treatments for complicated grief and delivered different combinations of components to each of the client groups. In this way, they could attempt to discover which elements had the greatest impact on symptoms. Adding imaginal exposure to a multi-component CBT-based treatment (which also included cognitive restructuring, rumination management and goal setting) resulted in greater symptom reduction at post-treatment and six-month follow-up (Bryant et al., 2014 cited in Doering and Eisma, 2016). An online therapy that included exposure and behavioural activation had positive effects on complicated grief symptoms compared with a wait-list control group (Eisma et al., 2015 cited in Doering and Eisma, 2016). These findings are consistent with participants’ views that it is not necessary to use structured programs as a “cookbook that you need to follow to the letter” (E14) except in research trials, which need to be highly structured so that results can be replicated in later trials in order to build the evidence base.

4.5.3 Standards and guidelines for bereavement care

The fact that palliative care services in most parts of Australia appear to offer a very similar level of follow-up care for the bereaved is likely to be related to efforts by services to meet recognised standards of care. One jurisdictional representative specifically referred to the National Palliative Care Standards when describing the care provided:

“We always try and build up the relationship with the family before the person has died. And the grief starts usually at the time of diagnosis. So, when the person passes away, we’ve got some rapport with the family and the person, the staff member who is closest to that family, contacts the family. And it’s usually the nurse case manager [who] always calls and offers condolences and provides any practical, you know, support at that time and assesses whether the family may need some ongoing support. So, there’s an initial phone call. And all of this ... is under the palliative care standards. So, we’re following the national palliative care standards ...” (J1)

The most recent and fourth edition of the National Palliative Care Standards was published in 2005 by Palliative Care Australia. These standards provide a set of philosophical standards that promote a vision for compassionate and appropriate end-of-life care and inform the National Standards Assessments Program (NSAP), which supports palliative care services in Australia to deliver safe and high quality palliative care for all Australians. The thirteen standards evolved after extensive stakeholder consultation and can be applied to both specialist palliative care services and primary care services. Services and providers are encouraged to adopt the Standards on a voluntary basis, and accreditation services are asked to incorporate these Standards as part of their assessment of palliative care and other services. Standard 8 specifically addresses bereavement support. This standard aims to ensure that “formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services”. The focus is on providing emotional and spiritual support relating to loss and grief to the patient, their carer/s and family from the moment when a life limiting illness is diagnosed. The importance of providing ongoing support based on self-identified need to the carer/s and family is also stressed.
For specialist palliative care services to successfully meet this standard (at a minimum) they must have policies and procedures for the provision of a bereavement support program that includes relevant training to staff and volunteers. They must also provide a directory of professional counselling resources. Level three services must also have available experts in psychology and psychiatry related to grief, loss and bereavement for referral in situations involving complex needs. They must also provide a designated appropriately qualified person to coordinate the support provided to the patient’s family and carer/s before and after the death. This standard is presented in Table 13.

Table 13 National Palliative Care Standards – Standard 8

<table>
<thead>
<tr>
<th>Standard 8</th>
<th>Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intent</td>
<td>Emotional and spiritual support focussed on loss and grief includes the patient, their caregiver/s and family and begins when a life limiting illness is diagnosed. Ongoing support based on self-identified need is offered to the caregiver/s and family. Bereavement support before and after death of the patient may assist reducing the morbidity associated with loss and grief for the patient, their caregiver/s and family. The majority of people will integrate their loss into their life with the support of their own community. Evidence suggests that personal and social circumstances may place some caregiver/s at increased risk of experiencing bereavement problems (Aranda and Milne, 2000).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Criteria</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care</td>
<td>Information (both verbal and written) on loss and grief and the availability of bereavement support services is routinely provided to family members prior to and after the death of the patient. Bereavement risk for caregiver/s and family members is assessed during the patient’s illness and support is offered based on need.</td>
</tr>
<tr>
<td>Specialist palliative care level 1</td>
<td>The palliative care service has policies and procedures for its bereavement support program. Staff and volunteers who are routinely involved in bereavement support are trained and provided with regular supervision and support. A directory of professional counselling resources is available and referral is offered as appropriate.</td>
</tr>
<tr>
<td>Specialist palliative care level 2</td>
<td>As for level 1 plus: A designated appropriately qualified person coordinates the bereavement support program. Education about loss, grief and bereavement is provided for staff, volunteers and the community including those working in primary care and level 1 services.</td>
</tr>
<tr>
<td>Specialist palliative care level 3</td>
<td>As for level 2 plus: Experts in psychology and psychiatry related to grief, loss and bereavement are available for referral in situations involving complex needs. Emotional and bereavement support is provided to the patient’s family and caregiver/s before and after the death. The needs of dying children, their siblings and parents are assessed and ongoing and seamless support is provided as required.</td>
</tr>
</tbody>
</table>

Review of the National Palliative Care Standards is underway with the consultation process still in progress (Palliative Care Australia, not dated).
The Australian Centre for Grief and Bereavement, in partnership with the Centre for Palliative Care, published a set of bereavement support standards in 2012. These standards were developed to provide guidance for all Victorian government-funded, adult, specialist palliative care services, including community, inpatient, acute and consultancy services on bereavement care. It is targeted at all carers and bereaved individuals with elevated risk of developing prolonged or complicated grief or with current psychosocial and/or spiritual distress. It includes 11 standards that are recommended to provide a minimum level of bereavement support to primary carers and bereaved people by specialist palliative care services. These standards are supported by a bereavement support care pathway which provides more details about what factors need to be considered when implementing the standards at different time points in the bereavement trajectory.

The consultations with stakeholders provided much support to the idea of having a nationally consistent standard for the provision of bereavement support. Most stakeholders had heard of the bereavement support standards from Victoria and there was agreement that having access to the document in their service was a good thing. The standards were said to be both ‘good’ and ‘comprehensive’ but more work needs to be carried out in promoting these standards and implementing them consistently across palliative care services.

“I think the bereavement support standards for Victoria are very, very good, but we don’t have a system nationwide that says, here is the latest and here’s what we should be doing, and then having quality improvement on that as well ...” (E1)

4.6 Unmet needs and barriers to service provision

Throughout the stakeholder interviews a range of unmet needs and associated barriers to service provision were identified. The major issues discussed below include: recognition of complicated grief both from the perspective of the individual sufferer, the broader community and service providers; access to services (referral, generalist bereavement support and specialist therapy); lack of carer and community support; characteristics of models of care; capacity of health practitioners; requirements of special needs groups and systemic barriers such as privacy legislation.

4.6.1 Recognition of complicated grief

At the personal level, frequently people experiencing complicated grief are not aware that this is what is happening to them. They know that something is wrong, but may expect that grief is something that most people work through, as this is a common social message. The term ‘complicated grief’ is not widely known or understood within the general community. This means that affected people may not seek assistance.

“How many folks do we know are getting the message, ‘Well, for heaven’s sakes, he’s been dead for six months, get over it’. It’s not quite that blatant but that theme goes on. And so, your supports start to withdraw if you do go with what society has generally thought you should be able to accomplish in the three to six months after a death.” (J4)

This lack of understanding or recognition of the phenomenon of complicated grief extends across the general community and makes it difficult for friends and family members of the
bereaved to identify and understand the problem. This can result in the bereaved person feeling unable to get others to listen to their concerns.

“I think, it’s the recognition of it, that people just think that’s just part of life, that’s just what you do, not knowing any other way to deal with it.” (E6)

As the onset of complicated grief is delayed when it occurs the affected person often needs guidance as their prior connections with services (formed during the death of their loved one) may no longer exist.

“You have the ending of the professional relationship and then it’s kind of up to these poor, lost, bereaved people to find their way back into some other system of care, rather than provide them the continuity of care that begins before the death and continues afterwards, which would be really, the rational way to construct it and the compassionate way to do so.” (E4)

The onus of many services on ‘self-referral’ assumes a capacity to recognise what is going on and to not only know where to access appropriate care but to actually be capable of doing so. For example some people experiencing complicated grief become so overwhelmed and isolated that they are incapable of responding to overtures of help let alone seeking out assistance.

“Where people become very, very isolated and are so troubled by the grief and by the weight of the grief and perhaps by their isolation … they find it very, very difficult to reach out to get help.” (E10)

Participants saw public awareness as the major challenge for the self-referral model; visibility among GPs was seen as crucial for such a model to operate effectively.

“The issue, I think, is recognition, number one; recognition, support – recognition either sort of by common sense frankly or by formal assessment methods.” (E12)

“So I think it’s even – make the population and the professionals aware that this exists.” (E9)

Another barrier to help-seeking behaviour includes stereotypical beliefs about how grief is expressed. Society expects teary displays of grief as the ‘norm’ and most commonly accepts these as a female trait, however a stoic individual not given to expressing their grief in this way, may be at much higher risk of complicated grief.

“If someone cries or doesn’t cry, is that a sign of good or bad grief?” (E1)

4.6.2 Access to services

A constellation of issues was raised about different aspects of access, including referral processes, availability of generalist and specialist services and the cost and funding of services.

4.6.2.1 Referral processes

For most people their main point of referral to more specialised care is through their primary care practitioner, who is usually a GP. Accessing the next level of service is dependent on the
GP identifying there is a problem and being willing to refer the patient to another service provider. Interviewees commented that referral is haphazard as it depends on the professional you contact knowing what is available, or the visibility of services. The primary care practitioner then has to have somewhere to refer to.

“They would need to know where to refer, and I think that is a problem, because there are so few places where intervention for complicated grief can be delivered.” (E7)

“You’d hope that, I guess, the steps have to be the one they need to present to their GP with either physical symptoms or psychological distress, that that GP would then rather than treat them with an antidepressant, would refer them on to a clinical psychologist with a mental health plan so that they could be seen for a number of sessions. You would then hope that that clinical psychologist is able to recognise and intervene in complicated grief. So there are many ifs I think, in that journey, for good practice, because, otherwise, people don’t know themselves. Grief is grief and they’re certainly not going to say, ‘I’m experiencing complicated grief. I need to go and see a complicated grief expert.’” (E7)

For many services dependent on self-referral, this lack of visibility and awareness amongst the broader health community of the availability of bereavement support creates barriers to access.

“It is a challenge for a self-referral service, and that’s why then the universal coverage also needs to include sort of visibility amongst the broader health community at the very least, that is, GPs, support groups and so forth, and then hopefully add to the community as well, but certainly I think GPs is the next port of call in terms of visibility, so that’s essential I think with a self-referral service.” (E11)

4.6.2.2 Availability of generalist and specialist services

The variability in access to both generalist and specialist psychosocial services emerged as a consistent issue throughout the stakeholder interviews.

“I actually do think over time psychosocial issues within palliative care are actually the biggest single issue that we need to solve. I used to think it was doctors, nah. I used to think it was nurses, nope. I think service is a big issue but I think psychosocial needs are quite often a massive issue and it causes a lot of the issues before and after, in terms of distress, before and after death, and if we could fix that, that would actually solve a lot of our issues frankly.” (E12)

Clearly access to bereavement services is also influenced by where the bereaved lives and people in regional and particularly rural areas frequently may have limited access to generalist services let alone specialist bereavement support.

“It’s in rural and regional areas in particular that I see the gaps in management of complicated grief, or identification of and absolute management of. In this State, specialist palliative care services in metropolitan areas are well serviced, they’re not the ones I’d worry about.” (J3)
The difficulty of accessing specialist bereavement support is particularly evident for groups at higher risk of complicated grief, for example, those who lose a loved one through a sudden and unexpected death such as homicide or suicide.

“My understanding is that it depends – you know, the availability of follow-up service very much depends on where you live. So, I mean, that’s certainly true in the forensic and coronial system if you experience a death through a sudden and unexpected death, than if you live in a metropolitan area, then you can get referred through the forensic counselling team. But if you’re in rural, remote, there may not be availability of services and even the victims of crime counselling system, you know, sometimes I have difficulty having enough people in certain areas. And same with the Medicare, you know, accredited counsellors, psychologists and so on. There’s pockets where there’s not available people or the available people have – they’re not specialised in grief and loss.” (E2)

In locations where there is no dedicated grief counsellors or grief therapists the GP or community nurse may be the only option.

“Most people would go to their GP and may be either referred on to mental health services or for a mental health plan, if yeah, complicated grief disorder was – or whatever you want to call it, was identified and then, the specialist services are non-existent. So, there isn’t a dedicated grief therapist or grief counsellor and they’re just generic psychologists, generic counsellors who couldn’t address it. I know down south there are grief centres where people can go for grief counselling.” (J1)

The limited access to specialist services creates challenges for service providers as well when they don’t have the appropriate expertise themselves to support the bereaved person.

“Some of the particular struggles from the health provider’s perspective around possibly being the only person in the town who is that person, so they’re having to be the jack of all trades, all kinds of different things.” (E1)

This is even more challenging for the health care professionals working in remote communities.

“In remote communities, the main health centre is a clinic, a remote clinic staffed by nurses and visiting doctors, or maybe if they’re lucky, a full-time doctor and the remote communities would be limited in how they deal with complicated grief. They’re relying on the local community nurse, which I think would be stretching the nurses.” (J1)

4.6.2.3 Cost and funding of services

The cost of services may reduce access to bereavement support for many people, particularly where limited public sector services are available. The additional ‘out of pocket’ costs arising from seeing a private practitioner (beyond what Medicare covers) potentially dissuades people from seeking help.

“I think that’s often the thing of, ‘If I have to have counselling then how am I going to pay for that?’” (E5)
An interviewee also expressed concern that the current funding arrangements under the Medicare system do not cater for therapy that involves the family of the bereaved. However, a review of the current Medicare Benefits Schedule revealed that there are items that can be used for family group therapy (items 170, 171 and 172). These items refer to family group therapy supervised by medical practitioners other than consultant psychiatrists. There are additional items for group psychotherapy (items 342, 344 and 346) conducted by a consultant psychiatrist.

The other side of this coin is how states and territories fund bereavement support. This was clearly a concern for several stakeholders, particularly those working in public sector palliative care services.

“What is difficult is that for a hospital inpatient service funded activities finishes for us when the patient dies. So there isn’t ongoing funding for our social workers or for our bereavement counsellors or for our – for that matter, our community palliative care nurses, to actually follow up family members after the patient dies. There is – I think there’s a standard visit; the community nurses usually go to the home, just to see how the family are going, perhaps to collect any equipment that’s been there if it’s been a home death. Our social worker may also do a visit to the family after the death, but after that there is actually no funding of our service to follow these people up long-term.” (E7)

While there seems to be no funding available for following up bereaved persons of patients who have died in palliative care, there are certainly options for palliative care units (or any other hospital units) to receive funding for services for persons with complicated grief. When the bereaved person becomes a patient in their own right services provided to them could be delivered in an outpatient clinic (so-called Tier 2 clinic). Nationally, the Independent Hospital Pricing Authority (IHPA) is responsible for determining the National Efficient Price and the type of non-admitted services that are eligible for Commonwealth funding (IHPA, 2015; IHPA, 2016).

4.6.3 Lack of carer and community support

Several interviewees identified the lack of carer and community support structures as an unmet need within society for bereaved persons. The value of group work was highlighted on several occasions.

“I’ve got clients who will say, ‘I need to talk to somebody who’s going through the same thing’. And that has been in the past very effective, and I think that is something that needs to be explored. And also, it’s just logical as we know, group work is more effective and it’s more cost-effective. Why that’s falling off the radar, it doesn’t make any sense to me.” (J4)

For many people the opportunity to meet with others through either general carer support groups or specifically targeted support groups, for example for parents who have experienced the death of a child, was perceived to be helpful and a useful adjunct to individually oriented support services.

“I would say there’s a pretty big gap of places for carers to band together and, I guess, support one another because – and what I’m thinking about mostly is things
like carer support groups... So I would say some kind of avenue or place for carers that is easily accessible, like, I don’t know, yeah, for them to meet other carers and develop a sense of solidarity with one another because I think, my opinion, is that if you meet other people like you and you can share experiences and hear other stories and share your own no matter how isolated you are the other hundred hours of the week you will feel less alone because you know you’ve got peers.” (E8)

Another aspect of support groups identified through the stakeholder interviews was the limited opportunities currently available to support people with what was described as “living grief”.

“The other area when talking about people’s complex needs for grief which is probably not looked at to a deep enough degree is carers of people with living grief, which is termed chronic sorrow. So you have people who might be bringing up a disabled child, and have grief all the time. It is a good opportunity with the National Disability Insurance Scheme taking root for that to become a referral service.”

(Focus group participant)

4.6.4 Models of care

There were several issues identified about the characteristics of models of care that were perceived to create barriers to service provision. These include the nature of palliative care services, the lack of outreach models and systematic follow-up of the bereaved; limited use of internet-based treatments; availability of family interventions and potential for population based approaches.

For many patients entering a palliative care service, the family’s association with the service is relatively brief. There is often a misconception that palliative care services work with the patient and family over an extended period of time. While this may be true for some patients and families, this is not the norm. This makes long term follow up with bereaved carers difficult and reduces the capacity of palliative care services to identify individuals who are having problems and intervene.

“I can only speak to this from the palliative care perspective – and there really are some challenges around this area. Firstly, because people come into our palliative care service for a short period of time. The average length of stay, for example, in my facility, is 16 days. And, so, it’s very difficult to then engage in any long-term follow up with our bereaved carers to actually know what’s happening with them.”

(E7)

Another issue raised by interviewees was the lack of outreach services (both physical services and technologically based services). This was perceived as a direct reflection of current funding models.

“I guess that’s where the system falls down a bit, in that there’s no necessary outreach to people or you know, it’s reliant on people putting up their hand, saying, ‘I’m struggling’.” (E2)

The lack of systematic follow up of families was raised as a service gap or unmet need. Different services take different approaches, however there are no national guidelines that prescribe a
recommended approach to follow-up of bereaved carers, particularly by hospital based and/or palliative care services and there does not appear to be a formal or agreed period for this follow-up or review to occur. One interviewee commented on the usefulness of making a telephone call post death to the affected family. This allows them to clarify any questions/issues or residual concerns about their loved one’s death and care. In the experience of this clinician this may mitigate the risk of complicated grief.

Internet-based models of care have been successfully introduced for some forms of mental health support and there is now published evidence supporting their potential as a treatment model (Titov et al., 2010, Gun et al., 2011, Mewton et al., 2012, Newby et al., 2013). Appropriate internet-based models of care may assist in addressing the unmet service needs in rural and remote communities for certain individuals.

“There are some internet-based treatments as well that have been shown to be quite effective, so in terms of rural and remote, you don’t necessarily need someone there on the ground who has that expertise, if it’s not there in the community then you’ve got some internet-based services that have been found to be effective. I don’t know whether they’re just available for free on the internet though, but, yeah, we know that they work when they are available.” (E1)

The inability of many services to provide family interventions was identified as an unmet need and is explained succinctly by the quote below. This issue was identified to be of particular importance with some cultural groups.

“The family is really the natural unit in some ways for grief interventions. It’s within families that we lose our most intimate relationships and yet, there isn’t much attention, really, to innovative work on helping people rebuild relational bonds after loss. So, I think that’s an unmet need.... But I think that and really globally, I would say and at least in the developed West, our inclination toward individual psychotherapy for the target patient risks missing the relational needs that may be primary within families that are contending with loss.” (E4)

The need for a more population based approach to complicated grief models of care was identified. This observation arose from clinicians’ experience of working with people with complicated grief who were unable to self-refer (an issue previously discussed in Section 4.2.3). A population based approach focused on primary and secondary prevention might assist with the early identification of people who are at risk of developing complicated grief.

“There’s certainly at least one study that’s cited a lot that was done in the US, that showed that people who met the criteria for prolonged grief disorder don’t actually seek out mental health services, so we actually need to be trying to actively identify people, otherwise they’re just going to be really vulnerable and not realise that they actually do need help ...” (E1)

The public health approach – or “tiered system of services” (E4) – to bereavement care relies on a sophisticated understanding of the signs of complicated grief among health professionals and greater community awareness.
4.6.5 Capacity of health practitioners

Dealing with bereavement is often a challenging issue for health practitioners who are not exposed to this regularly, as recognising and supporting a person with complicated grief is not an inherent skill for most service providers.

Training of health practitioners to recognise complicated grief and the development of knowledge and skills to deal with this is needed, particularly effective communication skills. This is critical in addressing one of the biggest barriers to service access: recognition of complicated grief.

“I certainly know of people in quite a prestigious hospital not too far away who just recently were basically told there is nothing more I can do and just bundled out of the room and sort of left standing outside of the room. It’s like, what do we do now? We don’t actually know what to do? There was no referral, there was no social work support offered, it was just like, well, my bit is finished.” (E11)

“The way people communicate is incredibly important, so really, a lot of this stuff comes down to communication. It’s the attitude underlying the communications that really tells I think.” (E11)

4.6.6 Special needs groups

Throughout the stakeholder consultation several special needs groups were identified. The short project timeframe did not allow close exploration of these groups however the same groups were consistently mentioned: those living in rural and remote areas; those who are socio-economically disadvantaged; Culturally and Linguistically Diverse (CALD) groups; Aboriginal and Torres Strait Islanders; those who have lost someone through a violent death; parents who have lost a child and those who have experienced a sudden or unexpected death.

Each of these groups was seen to be of high risk because of a range of factors with most experiencing barriers to access because of their circumstances or the nature of death experienced. For example poor socioeconomic circumstances were associated with fewer resources which generates a range of other challenges.

“We cover a poor socioeconomic group here – for the most part – and a lot of those then contain enormous complexity with regards to what’s happening besides the grief, but which is enhancing the intensity of the grief that’s occurring.” (J4)

Different cultures deal with grieving and bereavement in various ways. However concerns were identified about the difficulty that CALD groups have in accessing culturally appropriate services.

“One thing we haven’t mentioned is the cultural differences and I don’t think you can look at grief without understanding the cultural difference and people’s expectations of how they should grieve.” (Focus group participant)
“People who don’t have English as their first language, certainly they would have difficulty in even knowing where to access services or support, which may place them at greater risk of complicated grief.” (E7)

“I think there are clearly certain groups who don't come along for counselling and that would include a whole variety of cultural factors, or ethnic factors; I guess we could say, CALD factors there, where counselling seems to be – you have to have a perceived mental disorder to come along for counselling very often, and so there is a great stigma attached to it.” (E11)

One interviewee commented on the usefulness of a Trans Cultural Mental Health service in meeting the needs of CALD groups.

“I think having access to a service like Trans Cultural Mental Health, who provide counsellors in their language, is really helpful. And various community groups as well, who may have people who are experienced in or able to relate to people from different backgrounds.” (E2)

The needs of persons from Aboriginal and Torres Strait Islander backgrounds were perceived to be inadequately addressed, in part because of the remoteness of some communities, cultural differences such as the reluctance to talk about death and the deceased person, and also because of the cultural inappropriateness of the available resources.

“The assessment tools for complicated grief are western design tools, so not designed for Aboriginal people. So, even just the diagnosis, I think would be difficult, because their values and beliefs and grief process and you know, belief system about death and dying, is different to ours.” (J1)

“What we tend to do is have faith in the community and the families, because often in those remote communities, it’s a very strong, traditional belief system and the whole process of burial and mourning is quite traditional and we tend to put our faith in that. And often, they say to us, we do it better than you. We know how to do this. Because they have got strong, you know, traditional beliefs. So, it’s not something that we really get involved with too much.” (J1)

Providing bereavement support to parents who have lost a child was seen as challenging and required specialist skills. There are several organisations that focus on supporting parents, for example, Red Nose Grief and Loss (formerly SIDS and Kids) is a public benevolent institution with specialised expertise in grief and loss.

“There is a real challenge here we haven’t talked about, but there is a real challenge for health practitioners in this field too, because you know, we all have challenging clients and these are the challenging clients where either the grief isn’t lifting or there is an avoidance of the grief lifting. A sense of embracing the loss rather than the life, so embracing the death, the manner of death and all the meanings of that as opposed to the life that was lived before that, and of course with parents this is incredibly problematic because not much of the life has been lived, and they are still alive. So this is another existential question of course about what is the meaning of
Several interviewees discussed the lack of awareness of the needs of groups who experienced a sudden or unexpected death – people in this category were seen to be at higher risk of developing complicated grief and were frequently misunderstood. This group could include long term carers of people with a chronic but life-limiting illness like dementia.

“That’s also challenging, because one of the other issues in palliative care is whilst we see the patient and the family as our unit of care, we only have medical records for patients. And, so, there are issues, certainly, under the privacy commission, about collecting data from family members who we then don’t have a medical record in order to record that data and follow through.” (E7)

4.6.7 Privacy legislation

Several stakeholders raised concerns about privacy legislation; they perceived that the ability of palliative care services to provide bereavement support after the patient’s death is constrained by privacy legislation in some states.

The limiting effect of privacy legislation on research about bereavement was raised as this prevents researchers accessing information about the next of kin from sources such as the death registry.

Concerns about privacy were also raised in the free text response fields of the survey conducted with service providers. Additional information about this issue is included in Section 5.3.4.2.

4.7 Workforce issues

The complicated grief workforce comprises two distinct sectors: hospital-based services including palliative care; and community-based services including non-government agencies, private practitioners and volunteers. Some of the community-based workforce have special skills or an interest in treating people with complicated grief; others provide a more ‘generalist’ counselling service. Stakeholders commented, not surprisingly, that the cities and urban areas around the country have a greater range of ‘specialist’ services and as rurality increased, the workforce tended to be more generalist and there is an undersupply.

Although palliative care is a major source of referral, GPs probably have the key role as gatekeepers to Medicare-funded services for those who may be experiencing complicated grief.

4.7.1 Role of GPs

GPs were identified as important players in relation to access to the grief and bereavement counselling workforce outside of the hospital system. Stakeholders commented that access for
patients to treatment was in many cases dependent on whether the GP had the time and the required skill to recognise complicated grief in the standard consultation.

GPs were also described as ‘bottlenecks’ to accessing the full range of potential treatment disciplines. One focus group participant referred to this perceived problem as “the medicalisation of sadness” (FG2). Referral options for GPs tend to be the Medicare funded professions with the bereavement counsellor’s role becoming increasingly marginalised:

“It’s changed a lot, in terms of when it became possible for clinical psychologists and also accredited mental health social workers to have their services claimed through Medicare. I think that made a huge difference. A huge difference because then you had GPs who were able to refer people for a mental health plan and they could see a clinical psychologist or they could see a social worker. And I think to some extent that has put a lot of the bereavement counsellors out in the cold ... bereavement counsellors I don’t believe are recognised as strongly within the health system as they should be.” (E7)

There was a suggestion that creating a ‘register’ or database for GPs of counsellors, clinical psychologists and other mental health professionals who have special skills and interest in treating people with complicated grief would be a useful resource.

4.7.2 Workforce training

Due to the multidisciplinary nature of the workforce, the extent of formal training that individual therapists may have undertaken is extremely varied. At one end of the spectrum, there are private grief / bereavement counsellors and newly graduated, hospital-based clinical staff who may have undertaken very little formal training and at the other end there are highly skilled and experienced psychologists or social workers who have worked in specialised positions such as grief counsellors in a large city morgue or a palliative care unit in a major teaching hospital.

“If there is disagreement within the research community around criteria and language you can be sure that there is confusion out there among the workforce; and I would say that the biggest issue that needs to be addressed is training.”(E7)

Many of the interview participants commented on the specialised skills required to effectively identify people with complicated grief; particularly hospital staff working in areas of death and dying and GPs. Related to this were comments regarding the need for specific training in the use of formal complicated grief screening and assessment tools. This was due to the specific knowledge regarding grief and bereavement as well as the highly developed communication skills that are required to administer the tools sensitively and empathically and at the right time for the bereaved person. This included special knowledge of a wide range of social, cultural and gender based norms in regards to grief and grieving (such as extended periods of moaning and wailing, or Aboriginal death ceremonies known as ‘sorry business’), to enable ‘atypical’ presentations of grief to be detected within culturally diverse communities.
4.7.3 Specialists versus generalists

The provision of effective treatment to people who are experiencing complicated grief was seen as a specialist skill set. It was considered desirable for mental health professionals to have some additional training, on top of their usual qualifications, in order to address specific grief-related issues with clients.

“If you agree to the existence of individuals with complexity or complicated grief then you don’t want a generalist doing whatever because you may or may not get a good outcome. I don’t know how one addresses that because people come to bereavement counselling therapy, or however you want to call that, from a variety of groups. If you go to a psychologist people go and do a psychology degree plus whatever, whereas bereavement counsellors come to their area of interest and specialty from a variety of sources, so there isn’t a central standard for what constitutes a skilled practitioner.” (Focus group participant)

For example to be accredited to provide the full 16 sessions intervention developed by Dr Katherine Shear, requires completion of the advanced training that is only available at Columbia University, USA. The introduction module can be accessed in Australia via webinar training provided by Dr Shear. Other training is available for health professionals via the Australian Centre for Grief and Bereavement. A bereavement counsellor associated with this centre has recently returned from the United States after completing the advanced training in order to be an accredited provider (and trainer) in this country.

Academic based experts identified that some form of continual professional education was required for the existing workforce to ensure they stay up to date with findings from current research.

Identification of the need for specialist training for complicated grief was highly dependent on whether complicated grief was perceived as a distinct psychopathology or part of a continuum of normal grieving. There was consensus however, that grief / bereavement counselling required a distinct skill set.

An important component of the complicated grief workforce that is often not considered within the health paradigm is the role of volunteers and informal supports. This was raised in the interviews in the context of informal support provided by friends, family and the more formalised but volunteer based community support groups; examples given included support groups for cancer survivors or suicide survivors.

Participants suggested that it was important for the health sector to acknowledge and more effectively support the key role that mutual support groups play in the recovery of individuals from complicated grief. One practical example of how the health sector had effectively engaged with the volunteer sector was that the local hospital staff had offered assistance to those ‘survivors’ wanting to organise a support group and also provided a suitable health service venue for the meetings.
4.8 Recovery from complicated grief

Several interview participants discussed the concept of ‘recovery’ and how they used their clinical judgement to determine at what point in the care trajectory the bereaved person was adjusting to their loss. Experienced clinicians looked out for certain patterns or signs such as the bereaved person becoming more engaged in life, grieving more freely and showing an awareness and willingness to deal with their anxiety and depression.

One interviewee referred to the ‘dual process model’ and how in recovery the bereaved person was:

“...moving back towards restoration, that is, getting on with life, learning how to cook again, or eat, or go back to work or interact with other people, and it tends to be an oscillation between the two, and so that is really in a sense one of the basic things we are listening for as bereavement counsellors.” (E11)

The dual process model (also referred to as the approach avoidance model or an integration model) was described as a useful model when applied in tandem with clinical judgement. The fluctuating nature of grief was emphasised and as recovery occurs the amplitude of these fluctuations may slowly diminish but the grief does not cease.

“That there’s still very much in the community, a model of you get very, very sad when somebody died and everything’s awful and you gradually get better and you’re okay. Whereas actually, the lived experience for a lot of people is that the grief fluctuates up and down very much.” (E2)

The prolonged nature of complicated grief is a characteristic of the inability of the person to integrate their bereavement into their ongoing life.

“Normally, if people come here in the beginning to see a counsellor and they’re more in an acute phase of their grief... but what happens in complicated grief is that acute stage of the grief becomes prolonged, basically, and not integrated. The grief hasn’t matured.” (E9)

“The approach avoidance model is intuitively a very useful model that we are using, and so we’re using really our clinical judgement about that as well. Is there some movement on that scale or are people stuck with total avoidance or are they totally overwhelmed. Some sort of measurement around that, how stuck people are, I think would be pretty useful, or how stuck they are feeling anyway, emotionally, behaviourally, socially and so forth.” (E11)

A common indicator of recovery was that the bereaved is “getting some energy for life”(E6) another way this was described was the return of “function” (E7) referring to the ability of the bereaved to cook meals for themselves, to self-care and their ability to re-engage with their previous activities. These things were not regarded as formal criteria but derived from extensive experience as explained below:

“I wouldn’t use anything formal, but, I suppose, my own criteria would be – like this young girl this morning, I said, ‘You look a lot lighter, you sound – your voice sounds
a lot better,’ and she’s like, ‘Yeah, I just feel it, I can feel the difference,’ and it’s been about three years since her mum died and the dad died. So, one of my indicators would be she’s got a sense of purpose again, she’s ready to get back into the workforce again, just feels better in herself, she can separate herself out from what happened, and she can, rather than think about it every day and it’s an integral part of her, she could see it as something separate now, that’s what happened, and she’s still aware that she’s in pain but she can separate it.” (E6)

In assessing recovery the bereavement counsellor may assess:

“…are they able to recall memories of the person who has died, without that bringing overwhelming distress?” (E7)

4.9 Outcome indicators

There was limited information provided about promising outcome indicators or their application. Outcome indicators were mostly conceptualised in terms of the experience of carers of the bereaved, what is referred to in the context of patients as Patient Reported Outcome Measures or PROMs. PROMs focus on outcomes of care and may include for example, patients’ views on their symptoms, functional status and health-related quality of life. The reason they rely on patient reported outcomes is driven by the view that patients are the best judge of their own welfare. PROMs can be used to assess the efficacy and effectiveness of particular treatments (Sansoni et al., 2016). Several interviewees saw outcome indicators more in terms of service use, as indicators of system performance.

4.9.1 Patient/carer reported outcome measures

The most commonly cited indicators for carers of the bereaved came from the work of Katherine Shear and Holly Prigerson. A range of tools was mentioned included the Prolonged Grief (PG) 13 and the Inventory of Complicated Grief (revised form). The divergence of views amongst the research community about optimal approaches to screening and treating complicated grief were discussed and it was suggested that these tools are still evolving in terms of their application and were therefore not routinely used in clinical practice in Australia. There was however examples from the stakeholder group of services who had adopted certain models of care and were using the related assessment and screening tools.

“With the [treatment] model that we use, actually we use the same tools at the end of the session. So we use it in the middle and then at the end. So you can see and the client can actually see that indicator. So it’s a realistic number, it’s not like something that someone can have a certain idea about it, it’s just it’s something concrete that you can see the number is going down about distress or the other different indicators, like as I say, avoidance or memory.” (E9)

Some participants saw that monitoring the implementation of the use of certain screening tools could be beneficial. For example problem checklists and the use of visual analogue scales such as the ‘distress thermometer’. There was cautious interest in the use of outcome indicators to monitor the effectiveness of bereavement support and/or complicated grief services. Indicators could also be used to monitor the bereaved person’s progression over the course of
therapy/treatment. However there was no agreement on which indicator to use and how to best implement this in practice.

The most commonly suggested indicator was the ability of the bereaved person to return to normal activities or re-engage with life. A particularly significant step is when the person can do something that they have assiduously avoided because it was too painful a reminder of the person they have lost.

“For example, I remember someone who said, ‘I can’t go to the church anymore, because it reminds me of when my loved one was in the service and I feel like I never can go again to that place’. And my colleague actually told me one day about a client who said that that person can’t – because that person lost their child, she couldn’t go to see a footy game anymore, because she used to go and see the game with her son. So – but then after she was able to do that again.” (E9)

This monitoring of recovery, also described as “symptom reduction” (E2) occurs through the usual bereavement counselling process and again relies on clinical judgement as opposed to the use of an instrument or tool. Palliative care services were accustomed to conducting assessments of patients.

“The outcome indicators that I’m aware of and that I look for when I’m having conversations with people are things like subjective statements – I’m having more good days than bad days. I’m crying less. Articulation of a certain level of acceptance of what has happened. Indication of becoming, again, more involved in day-to-day activities, other activities other than their sense of loss and grief. Other things start to come in. In a sense, doing that process of re-joining life in a much more active way than they were before.” (J4)

Some palliative care services had prior experience with surveys that measured patient satisfaction (referring to the carer’s experience with their bereavement counsellor), however these were often discontinued as they were not found to be particularly useful as the feedback was usually always positive, general in nature and not specific to a particular intervention.

“I guess if you could get at some of the processes of the intervention, like you said, and get data on people’s experiences rather than just their sort of emotional reaction… Well, yes, but if you think about pre-death for example, I mean this wouldn’t necessarily just apply to complex grief, but if you were to ask people the same questions I’ve just mentioned to you about pre-death experience in terms of communication for example, that would be a very interesting question to ask. Whether you could draw any conclusions about the effect on that person after the death is obviously more problematic.” (E11)

4.9.2 Measures of service use

Palliative care services find it difficult to collect data on people who are not actually patients. In addition it is not always clear who the main carer is and often caring roles within families change. Concerns were expressed that services may find “we’re aiming our data collection at the wrong people” (E13).
“The one query I have is as to how easy it would be to implement it, but the PCOC data of course is all aimed at the patient and so we’d be looking at collecting data and on relatives and things like that who aren’t – who number one, we may not see for a number of days, so it’s difficult to collect consecutive data on those people, and it’s also someone who is not under our care... so it does bring that into another realm of the equation...I’m just not sure how easily we could put it into our service delivery.” (E13)

The view was also expressed that it was difficult to develop an outcome indicator without a standard for bereavement care. If the standard is developed first, this could eventually generate an appropriate outcome indicator. Standards would also contribute to more universal evidence-based practice.

An indicator was suggested to monitor referral into an intervention and subsequent completion of that intervention.

“I would assume an outcome measure would be that someone has been referred to an appropriate intervention and they have in fact completed that intervention. And in the opinion of the clinician delivering that intervention and of course the individual, that their symptoms are much lessened. I mean, we’re not – when we talk about grief it’s not – it’s continuing on, it’s not something that it’s over and done with, it’s a lifelong journey, I guess, but for someone who’s been specifically diagnosed who has significant symptoms of distress, as defined by Prigerson and others, who’s being channelled into an intervention, who’s completed the intervention, and then in the opinion of the clinician, and, I guess, the sense of the individual that their life is perhaps able to accommodate the death and that they’re able to function reasonably well is an indicator.” (E7)

Several interviewees discussed the notion of an indicator of when people are ready to exit counselling, bearing in mind that the appropriate exit point will depend on the individual.

“Regarding exiting, the litmus test is how much they can reengage with life beyond their pain and for some people that might take a short period of time, for others it might take a long period, but it’s an energetic and cognitive shift in how they relate to you. So those of us that work with them would pick that up and store it away and start to talk about ‘maybe the next session can be a month from now’, and can take subtle cues whether that is correct. Ideally frequency shifts from greater and greater periods of time until there is a natural point where you can start that exit conversation (not around Christmas).” (Focus group participant)

“I think equally the frequency and the length of time are very much based on the context of that person.” (Focus group participant)

Most services were accepting of the use of outcome indicators to drive quality improvement and were collecting data to monitor a range of things such as completion of advance care directives, however few were using outcome indicators related to carers and none reported outcome indicators specific to complicated grief.
“I think it is probably realistic because we review other things which are, I guess, difficult to assess and pick up on and support but we know – assuming complicated grief is a real thing why shouldn’t we check how we’re going with it, why shouldn’t we make sure that we’re on top of things, why shouldn’t we review the outcomes for our clients?” (E8)

“Another thing about palliative care is that we are looking to start to routinely report place of death and there’s reporting around advance care directives, seven step pathway, so there is some sort of reporting beginning in that kind of a space but it’s not gone as far as the follow-up of the carer.” (J2)

4.10 The impact of complicated grief and good practice

The National Palliative Care Strategy includes the important goal area of capacity and capability referring to the need to build and enhance the palliative care sector to provide quality palliative care. Consequently the research question was included: “Where is good practice occurring and what are some evidence based examples of good practice?”

Several case examples are provided in the remainder of this section. A range of short patient vignettes have been paraphrased from published literature (the intellectual property of the authors is acknowledged). These examples focus on the experience of a patient and concentrate on the characteristics of their complicated grief. Five slightly more detailed patient vignettes were provided through the stakeholder interviews; these have been edited to remove any potentially identifying information but are virtually reproduced in a verbatim format. They outline the impact of bereavement for several very different cases. An extended case study was purposively drafted by an experienced clinician and is based on case studies that were previously developed for training purposes. Finally, several online sources of patient stories were identified and these are listed in Appendix 5.

This material is included to illustrate the nature of complicated grief through describing the experiences of patients (both real and fictional) and outlining the care that they received. They are provided for two purposes, to enhance understanding of complicated grief and its management amongst policy makers who may not necessarily have a clinical background or experience of complicated grief. While they are not to be seen as the definitive approach to good practice they may also provide guidance for clinical practice.

4.10.1 Patient vignettes from the literature

Searching the literature identified three examples of where authors describe a case study, framed in terms of a particular patient, to illustrate aspects of the history, diagnosis or treatment of complicated grief.
Ms A

Crunk et al. (2017) use the fictional case of ‘Ms. A’ to describe the key features of complicated grief. Ms. A was very close to her father who died of cancer about three years previously. Her symptoms include a feeling of profound agony and intense longing for her father. She is frequently preoccupied with thoughts about her father, including how he looked during his final days, continues to yearn for him and feels guilty that she did not do more to help him while he was ill. She feels as though her life has little purpose and has thought of dying so that she may be reunited with her father (Crunk et al., 2017).


Elaine

Shear et al. (2011) include a vignette about complicated grief in an appendix to their seminal paper on the inclusion of complicated grief in DSM-5. No information is provided about whether the vignette is fictional, or based on a true case. They describe the case of Elaine, a 65 year old woman whose husband died of cancer 19 years previously. She had an immediate, intense, response to the death of her husband, including shock and disbelief, and anxiety about how she would manage without him. She was plagued by thoughts that she could have done more for him while he was ill. Over time she became disconnected from her family and friends, with overwhelming thoughts about her husband and a feeling of helplessness. She considered suicide and was treated for depression by a psychiatrist. A year of grief counselling and weekly visits to the psychiatrist provided some comfort but little progress. Elaine finally felt that she understood her problem when she located information about complicated grief on a website (Shear et al., 2011).

Mary

Neimeyer and Burke (2013) describe another case of a woman deeply affected by the death of her husband. No details are provided about whether this is fictional, or based on a true case. Mary, aged 62, is ‘drowning in a sea of grief’ and unable to accept living without her husband. Her husband’s rapidly declining health due to an aggressive form of cancer made it difficult for her to adjust to her impending loss and she was ill-prepared for his death. She now feels deeply lonely and ‘cut off’ from others, with the exception of her adult daughter. She is caught up in an angry dispute with her husband’s children by a previous marriage about his estate. She describes feeling that she has ‘no purpose for living’ since his death, and although she is not actively suicidal, she finds herself wishing that it were she, rather than he, who had died (Neimeyer and Burke, 2013).

4.10.2 Patient vignettes from stakeholder interviews

Several cases are presented through the stories of Hope, Gus, Ben and Bertha. Names and identifying details have been changed to protect the privacy of individuals.

**Hope**

Hope is a 14 year old girl whose father died when she was eight and was referred to our team for bereavement support by her general practitioner. At our service we feel understanding the family context is important so we asked if it would be possible for the daughter and her mother to come into the bereavement service. Once that conversation occurred it became very obvious that the predominant concern from the daughter was the medical aspects leading up to her father’s death and also the possibility of her having some sort of genetic predisposition to things, not only for her, but for her – she was already thinking, of course, to her own children when she had children.

This required quite a lot of sitting down and going through things, getting out the notes, explaining things and what we were doing with a medical person from our team. She wanted to know what level of care her father got and what was happening leading up to her father’s death. And, then I guess, also saying – and talking about – because it was clear and there was, very fortunately, a reference to – in the notes from, I think, pastoral care or a social worker about how much the man loved his daughter. So it was very important to say that to her and she was very touched, very, very moved by that. She really wanted an opportunity to clear things up. There’d been, I think, some misconceptions that had been passed down over the years as to what had occurred and just reassuring the daughter about the safety of what was going on, the medications and the care that her father got was important.

Hope didn’t say too much, but her mother rang me later and said how powerful that was for her daughter, at long last, for this to be happening. And then she revealed also that over the years there had been quite a lot of – or there had been some behavioural issues and she was convinced that at least part of these behavioural issues were related to the grief and the unresolved issues about her father. And, so, I did say then that I’d be very happy to write a letter to the school counsellor and the principal, and I did that as well, and just explaining that – sorry, with the daughter’s permission, of course – with the daughter’s permission that – and she – and the daughter said, “Yes,” she’d be very happy for that to occur. So perhaps it was just signalling to her teachers that even though it’s many years since her father’s death that these issues are still present. I just hoped with that, and with the daughter being able to talk at length with me and go through all those things that she will feel better.
Gus

I’ll give you an example; I had this guy once let’s call him Gus, who was bed-bound in a nursing home. He was a diabetic and developed gangrene in one leg. Gus had been a very active man so we brought the family around, and basically we openly discussed his treatment options. The discussion went a bit like this…okay your choices are that you can either go into hospital, have your leg taken off, okay, or you can be treated palliatively and in time die here. This was very sad for his daughter particularly who I’ve known very well. Gus said “There’s no way I want my leg taken off, I would rather die, I’m happy to die, I’m ready.” He was quite elderly at this stage, his wife had passed away and he made the choice to be treated palliatively. Of course I reassured Gus and his family that he would be given enough morphine and we would make sure he was comfortable, and his daughter heard all that and wrote it down. We were all happy and everybody in the room understood that this is a loving thing because you are doing what they would have wanted, somewhat against some of their values but it’s actually what the patient values that matters.

Anyway, he died, okay and what happened - was a few months later his daughter came in, in quite a bit of distress, and she came in and she said, “Oh I’m feeling really down, I’ve been really depressed about the fact that I think maybe we should have done something more for Gus?” And this is where substituted judgement decision-making standards, especially in the context of advance care planning is quite powerful, because I took her back to that moment and I said, “Hey, hey, hey, remember – remember that talk we had? Do you remember that moment? And how we discussed that substituted judgement decision-making standard, which is where you try to put yourself in the individual’s shoes. Remember what we were all supposed to do in the room together?” Then she said, “I remember now. We are supposed to do what he would have wanted and he said no way he wanted that leg off and he’d rather be let go.” Anyway, it just took the weight of her shoulders at that point. So that sort of thing can be really powerful…getting everybody on the same team, making everybody sort of aligned with their thinking, making sure everybody is happy. We are happy to work towards goals that align with the patient’s wishes but – the substitute judgement decision-making standards and working along those lines, it’s incredibly powerful as well.
**Ben**

Ben is an English guy, he and his wife came to Australia, never had kids. This was a conscious decision as he had two bouts of cancer, different cancers here, and he got through this. Ben had quite a depressive background and anxiety, so he got through his cancers, two of them, and then blow me down, his wife developed a brain tumour and died.

Ben still sees me every six weeks or so, and this is going on eight years, but he is getting on with life. His grief went back to his own childhood and was compounded by other issues about his family. His wife lost the ability to speak and he couldn’t communicate with her the last day, and that was the most traumatic experience for him. However it was his own history of depression and anxiety that was an important factor. Ben has been suicidal at different times and he has no family here, no kids, I don’t know how he keeps going. I wouldn’t actually say he’s a success story, but he is finally at the point where he can get on with life. When he first came to counselling he would go to her grave nearly every day and slowly over time this became every week. I asked him about this the other day as I see this as an indicator of how he is getting on. He said, “I went the other day because that was the anniversary of her death” and now he knows – come this particular time of year when it is close to their wedding anniversary and the anniversary of her death and someone’s birthday, he knows he’s not going to have a good week, and that’s okay. But he doesn’t go to the cemetery every day anymore.

**Bertha**

Bertha is an elderly woman who is of German background and had been married for 50 years. Since her husband died it’s like she’s very, very stuck. She just can’t get over it, she’s very bereaved. Bertha has a lot of loss going on, she has lost her community. She’s lived in the same house for 30 or 40 years but the population around her has changed. Bertha used to have neighbours that were in similar situations and they were supportive of one another, well there are now young families that live there. So, she feels like she has no-one to communicate with. I’ve encouraged her to do things such as, try the German Club, or there’s this group with so-and-so, and I actually got her permission to refer her. I had this chap call her and invite her to the group for coffee, but she still can’t face it. So, she’s just in a very heavy stuck space. I’ve suggested a GP referral for a mental health plan but she just doesn’t feel very motivated, she is very flat.

Now, the mitigating factors for her fortunately are that she has adult children and we’re talking two children in their 40s or 50s, who frequently contact her and frequently are there with her visiting. But for Bertha – and I’m sure it has some things to do with her personality, how do I say this non-judgementally, she is a bit rigid. It is very difficult for her to shift and she knows that. Now, whether time will tell, I don’t know.
4.11 Extended case study

The following case study was developed by an experienced practitioner who has worked for the Australian Centre for Grief and Bereavement and also in private practice in Australia. This case study draws on the perspective of complicated grief treatment developed by Katherine Shear.

Agatha

Agatha was a polite 70-year-old woman whose husband Paul had died three years before after a five year battle with oesophageal cancer. They were married for 50 years, with four adult children and six grand-children and one great grand-child soon to be born. She had been actively involved in their lives until Paul’s illness when she stopped going to family gatherings to devote herself to looking after him at home. She has not been to one family gathering since his death.

Agatha was the oldest of four children in a working class family that immigrated to Australia when she was 13. Her father left the family shortly after arriving in Australia and wanted nothing to do with his old family once he had children with his new wife. Her mother had to work to support the children and feeling isolated in this new country became withdrawn from the family and started drinking. She was irritable and distant with the children and tended to be critical if they came to her with their problems. Agatha learned to deal with life on her own. She had a tendency to be demanding of herself and sometimes very self-critical.

Agatha had numerous strengths. She had a strong value system, and was a thoughtful and diligent parent and worker. She had gone to night school and then trained to be a psychiatric nurse. She was sensitive and fun-loving with close relationships and was an elder in her church. She had a circle of supportive friends, albeit now like her family, clearly frustrated with her. She was financially secure in spite of the death of her husband.

Their relationship had been an unusually close one and she experienced intense grief when he died. She had recurrent pangs of intense yearning, longing and sadness and insistent thoughts and memories of him. She had difficulty sleeping and no interest in socialising or her previous passion of bushwalking with her book group friends. She frequently thought about how unfair it was that Paul had died alone and in pain and thought everyone had failed him; the palliative care doctors, the nurses, God and that even she had failed him. She castigated herself for being so emotionally unstable and felt that as a mental health professional she should be able to control herself. She hated how unpredictable her emotions were frequently finding herself crying inconsolably at the thought of him or any reminder of him.

As time went on her grief did not evolve and she became increasingly despondent and withdrawn. Her children felt that they had lost their mother as well as their father. She managed to look after two of her grandchildren during the day and was glad for the distraction but as soon as they left she would get lost in thoughts of Paul – a mixture of longing, sadness, guilt and anger and would spend hours looking at home-movies and photos of happy times with Paul. Her grief dominated her life and she was consumed by this
persistent yearning and longing for the deceased; an intense sorrow and emotional pain and a preoccupation with thoughts of Paul.

She often thought about the manner and circumstances of Paul’s death. She had looked after him at home until his illness made it impossible for her to provide the level of care necessary. She was angry that the palliative care team hadn’t provided equipment and staff, or medical training to her, necessary for her to keep him at home. She often criticised herself for not being more assertive with them about these things and continued to go over conversations she had had with key staff at the time, writing down what she should have said or done and the possible changes this would have caused. He had always hated hospitals and it had been his fervent wish to die at home; which she had promised him she would fight for.

She was preoccupied with images of him as he became dehydrated and emaciated in his dying days with her before admission to the hospice. When falling asleep she would frequently startle awake with auditory hallucinations of his gasps of pain when nursing staff tended to him. She was furious with herself that on the day of his death, she had followed the advice of his trusted nurse to go home to tend to their pets, saying that Paul was not close to death. He had died whilst she was driving home, and she was sure he had died alone and in pain, despite the staffs’ assurances to the contrary. She worried that in his last hour he would have thought that she’d abandoned him and didn’t believe staff that people often die when their loved ones leave.

She often thought of all the things that had gone wrong: if only she hadn’t listened to that nurse; if only the staff had trained her to look after him. She believed God had forsaken them and was convinced that she would never be happy again or find any joy or satisfaction in any activity. She felt her life was over and the only thing that stopped her taking her own life was her long-standing religious beliefs.

She sought help from her GP not believing that she could be helped but only to placate her children, as they feared she was suicidal and were at their wits’ end as to what to do.

The GP provided her with a referral to a grief and bereavement therapist. The therapist explained that she was trained in complicated grief treatment and had specialised skills. Agatha subsequently participated in a 16 session treatment program that had been developed at the Centre for Complicated Grief at Columbia University. She was told that the objectives of her treatment were to help her identify and resolve the complications of grief and to facilitate her adaptation of loss. The first few visits involved history taking (relationship history and bereavement experience), the beginning of daily grief monitoring, and included information and education about complicated grief and complicated grief treatment. There was also the introduction of ongoing aspirational goals work, and a conjoint session with a significant other. Sessions 4 through 9 included imaginal and situational revisiting procedures and work with memories and pictures. Session 10 was a midcourse review, followed by sessions 11 through 16, which included an imaginal conversation with the deceased.

This program helped Agatha explore her emotions and the logic behind her ruminations; it encouraged her to be more self-compassionate, helped her accept the finality and
consequences of her husband’s death; encouraged her to reconnect with family and supportive friends and helped her find meaning and purpose in her life through re-engaging with her passions. She could then look at all of her memories of Paul, finding bitter sweet solace in the strength of her love and connection, She started to go to family gatherings and was able to think about his death from a more balanced and realistic perspective.

Agatha came to realise that grief is a normal part of life, and involves understanding of the reality and consequences of the loss, which includes: accepting the finality of the death; redefining meaning and purpose of life.


5 Demand and supply issues

This section of the report explores service ‘demand’ in order to improve understanding of the capacity of the health and social care system to respond or ‘supply’ the care required by persons experiencing complicated grief. Through this analysis, supported by information obtained through the survey of service providers and interviews of key stakeholders, workforce gaps and issues were identified.

The steps undertaken to quantify demand for complicated grief services in Australia are presented. Potential demand for complicated grief services was estimated from mortality statistics and findings from the literature about the proportion of bereaved persons at risk of developing complicated grief and their need for care. Ideally, this demand would be contrasted with the availability or absence of complicated grief services across Australia to highlight service gaps and related policy implications, be it absolute or in certain areas. Unfortunately, detailed information about the supply of complicated grief services was not readily available. This is in part due to the diversity of service providers and professionals working in this field and the variety of places within the health and social system where services may be accessed.

The survey of service providers collected information from government, non-government organisations and other service providers about available activities, services and resources as well as potential workforce gaps and issues relevant to persons experiencing complicated grief. The analysis of survey results generated useful insights about issues of supply and demand pertinent to bereavement and complicated grief. However, while the survey provided valuable insights into the work of service providers its generalisability may be limited, partly due to lower than expected response rates (27.7%) and because of difficulties in identifying relevant service providers. Methodological details relating to the survey are discussed in Section 2.5 and Appendix 3.

Several additional data sources were investigated but ultimately not used to inform the findings of this section, either as no relevant information was found or data was not available or accessible. For example, two reviews of patient satisfaction and experience surveys conducted for public hospitals in Australia were also checked but no information relating to bereavement was included (Pearse, 2005; Australian Commission on Safety and Quality in Health Care, 2012). In addition, a study completed in 2011 was identified in which the School of Nursing at Monash University coordinated the Australian component of a three country comparative study on palliative care bereavement support services. An attempt was made to access data from the survey of Australian hospice and palliative care bereavement services. However, the data could not be shared with anyone other than the original research team.

5.1 Projecting service demand

5.1.1 Underlying mortality

Annually, the Australian Bureau of Statistics (ABS) provides detailed data on all deaths that occurred in Australia. Summary information is provided by, for example, cause of death, age and gender and State / Territory. Very similar data is also available from the Australian Institute of Health and Welfare (AIHW), which holds several mortality datasets, including the General Record of Incidence of Mortality (GRIM) books and Mortality Over Regions and Time (MORT).
books (AIHW, 2015b; AIHW, 2016b). While both datasets are not as up-to-date as the ABS data, the GRIM and MORT books contain summary statistics about deaths recorded in Australia over a long period of time. The three data sources differ in the level of detail they contain.

Table 14 provides an overview of mortality across Australia and all Primary Health Networks (PHNs) in 2013, which is the most recent data available. According to the MORT books there were 147,678 deaths in Australia in that year. The lowest total number of deaths was recorded in the Western Queensland PHN and the highest in the Hunter New England and Central Coast PHN of NSW. The number of deaths is directly related to the size of the population in the PHN with the Western Queensland PHN the least and the Hunter New England and Central Coast PHN the fifth-most populated. Therefore the Standardised Death Rate (SDR) provides a much better means for comparison. The SDR for the total Australian population was 540.4 ranging from 441.8 in Northern Sydney up to 803.8 in the Northern Territory. There were four other PHNs (Eastern Melbourne, Australian Capital Territory, Central and Eastern Sydney, and South Eastern Melbourne) having SDRs smaller than 500 and a further three PHNs (Tasmania, Western NSW, and Western Queensland) having SDRs larger than 600 (AIHW, 2016a).

<table>
<thead>
<tr>
<th>Primary Health Network</th>
<th>Total deaths</th>
<th>Population</th>
<th>SDR</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHN701 Northern Territory</td>
<td>1,043</td>
<td>242,541</td>
<td>803.8</td>
</tr>
<tr>
<td>PHN305 Western Queensland</td>
<td>450</td>
<td>71,774</td>
<td>749.3</td>
</tr>
<tr>
<td>PHN107 Western NSW</td>
<td>2,655</td>
<td>306,992</td>
<td>650.6</td>
</tr>
<tr>
<td>PHN601 Tasmania</td>
<td>4,426</td>
<td>513,100</td>
<td>645.6</td>
</tr>
<tr>
<td>PHN304 Darling Downs and West Moreton</td>
<td>3,457</td>
<td>531,990</td>
<td>598.9</td>
</tr>
<tr>
<td>PHN108 Hunter New England and Central Coast</td>
<td>10,722</td>
<td>1,223,055</td>
<td>598.0</td>
</tr>
<tr>
<td>PHN110 Murrumbidgee</td>
<td>2,032</td>
<td>238,947</td>
<td>593.3</td>
</tr>
<tr>
<td>PHN307 Northern Queensland</td>
<td>3,737</td>
<td>688,701</td>
<td>585.0</td>
</tr>
<tr>
<td>PHN205 Murray</td>
<td>4,826</td>
<td>578,265</td>
<td>578.2</td>
</tr>
<tr>
<td>PHN104 Nepean Blue Mountains</td>
<td>2,053</td>
<td>355,845</td>
<td>578.1</td>
</tr>
<tr>
<td>PHN206 Western Victoria</td>
<td>5,053</td>
<td>598,630</td>
<td>577.2</td>
</tr>
<tr>
<td>PHN204 Gippsland</td>
<td>2,233</td>
<td>263,659</td>
<td>573.6</td>
</tr>
<tr>
<td>PHN402 Country SA</td>
<td>3,882</td>
<td>483,418</td>
<td>569.1</td>
</tr>
<tr>
<td>PHN109 North Coast</td>
<td>4,794</td>
<td>501,536</td>
<td>569.0</td>
</tr>
<tr>
<td>PHN106 South Eastern NSW</td>
<td>4,781</td>
<td>592,177</td>
<td>559.0</td>
</tr>
<tr>
<td>PHN105 South Western Sydney</td>
<td>5,033</td>
<td>904,899</td>
<td>557.3</td>
</tr>
</tbody>
</table>

3 Age-standardised rate (per 100,000): Rates that are standardised to a specific standard age structure to facilitate comparison between populations and over time. Age-standardised rates are directly standardised to the Australian estimated resident population at 30 June 2001. Rates are expressed as deaths per 100,000 males/females/persons for each geographic area (AIHW 2016a).
Since 2005 the total number of deaths has increased by almost 17,000 from 130,714 while the national SDR has decreased from 611 to 540 in the same time period, indicating that the population is growing and at the same time mortality is declining (AIHW, 2015b).

Mortality rates for Aboriginal and Torres Strait Islander peoples are very different to the non-Indigenous population. Unfortunately, data is only available for New South Wales, Queensland, South Australia, Western Australia and the Northern Territory. However, in those jurisdictions the SDR for Aboriginal and Torres Strait Islander peoples is 1.75 times higher than that of non-Indigenous persons (ABS, 2016a).

Table 15 shows the number of deaths by remoteness. It is apparent that the SDR is increasing with remoteness. It is lowest in major cities and highest in very remote areas of Australia.

### Table 15  Number of deaths by remoteness in 2013 (AIHW, 2016a)

<table>
<thead>
<tr>
<th>Remoteness</th>
<th>Total deaths</th>
<th>Population</th>
<th>SDR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major Cities of Australia</td>
<td>95,930</td>
<td>16,311,735</td>
<td>513.5</td>
</tr>
<tr>
<td>Inner Regional Australia</td>
<td>33,101</td>
<td>4,214,962</td>
<td>576.6</td>
</tr>
<tr>
<td>Outer Regional Australia</td>
<td>15,247</td>
<td>2,067,206</td>
<td>605.4</td>
</tr>
<tr>
<td>Remote Australia</td>
<td>1,783</td>
<td>322,758</td>
<td>618.2</td>
</tr>
<tr>
<td>Very Remote Australia</td>
<td>1,042</td>
<td>209,207</td>
<td>761.7</td>
</tr>
</tbody>
</table>
While there is no data available on the actual place of death, the vast majority of deaths are recorded for persons admitted to hospital or for persons receiving aged care (residential or community-based). This is done by recording death as the mode of separation from aged care or hospital. The most common settings in which Australians of all ages die include hospital (50.3%), followed by residential aged care (36.8%) (AIHW, 2014; AIHW, 2015c). The remaining deaths occurred in other settings, for example, the person’s home.

Of the total number of persons who died (74,221) while admitted to hospital, 44% had a palliative care-related hospitalisation (32,686)\(^4\) and of the total number of persons who died (54,373) while in permanent residential aged care, 14.8% were assessed as needing palliative care (8,047)\(^5\). In addition, there were 3,758 deaths of persons receiving palliative care by a Palliative Care Outcomes Collaboration (PCOC) participating service outside the hospital or residential aged care setting.\(^6\)

While there is no data available on deaths of recipients of community-based aged care in 2013/14, the data for 2014/15 shows almost 5,600 deaths were recorded for Home Care package recipients (one form of community-based aged care) (AIHW, 2015a).

### 5.1.2 Estimated number of persons at risk of developing complicated grief

While the number of deaths in Australia in 2013 was 147,678 it is not known how many persons are actually bereaved. There are no statistics available in Australia or internationally that report this information. However, the literature has provided some guidance about estimates of how many bereaved persons there are per death. According to two sources, the number of bereaved persons per death is four (Shear, 2012a; Wilson and Playfair, 2016). While another source states that for every death at least four to five persons will be bereaved (National Institutes of Health, 2009). The Nucleus Group, however, estimated the number of bereaved persons to be between eight and ten (Nucleus Group, 2004). For the purposes of this report, a conservative approach was taken by assuming that approximately five persons are bereaved for every death. This assumption includes carer, family and friends; people with whom the deceased had a close relationship (Shear, 2012a). Based on these assumptions almost 740,000 persons were bereaved from deaths in Australia in 2013. Table 16 displays these estimates for each PHN.

<table>
<thead>
<tr>
<th>Remoteness</th>
<th>Total deaths</th>
<th>Population</th>
<th>SDR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia (total)</td>
<td>147,678</td>
<td>23,125,868</td>
<td>540.4</td>
</tr>
</tbody>
</table>

\(^4\) Includes all those hospitalisations for which palliative care was a substantial component of the care provided. Such hospitalisations were identified as those for which the principal clinical intent of the care was palliation during part or all of the hospitalisation, as evidenced by a code of ‘Palliative care’ for the ‘Care type’ and/or an additional diagnosis (AIHW 2015c).

\(^5\) Includes only people who were identified by an Aged Care Funding Instrument (ACFI) assessment as needing palliative care (defined as end of life care with very intensive clinical nursing and/or complex pain management needs) (AIHW analysis of 2013—14 Aged Care Funding Instrument data).

\(^6\) Unpublished data from the Palliative Care Outcomes Collaboration (cited with permission).
Table 16  Estimated number of bereaved persons at risk of complicated grief in 2013

<table>
<thead>
<tr>
<th>Primary Health Network</th>
<th>Bereaved persons (estimate)</th>
<th>Bereaved persons with complicated grief (estimate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHN108 Hunter New England and Central Coast</td>
<td>53,611</td>
<td>3,217</td>
</tr>
<tr>
<td>PHN401 Adelaide</td>
<td>44,496</td>
<td>2,670</td>
</tr>
<tr>
<td>PHN202 Eastern Melbourne</td>
<td>42,450</td>
<td>2,547</td>
</tr>
<tr>
<td>PHN203 South Eastern Melbourne</td>
<td>41,860</td>
<td>2,512</td>
</tr>
<tr>
<td>PHN101 Central and Eastern Sydney</td>
<td>41,149</td>
<td>2,469</td>
</tr>
<tr>
<td>PHN201 North Western Melbourne</td>
<td>36,485</td>
<td>2,189</td>
</tr>
<tr>
<td>PHN302 Brisbane South</td>
<td>28,790</td>
<td>1,727</td>
</tr>
<tr>
<td>PHN306 Central Queensland and Sunshine Coast</td>
<td>28,383</td>
<td>1,703</td>
</tr>
<tr>
<td>PHN102 Northern Sydney</td>
<td>27,019</td>
<td>1,621</td>
</tr>
<tr>
<td>PHN301 Brisbane North</td>
<td>26,819</td>
<td>1,609</td>
</tr>
<tr>
<td>PHN501 Perth North</td>
<td>26,595</td>
<td>1,596</td>
</tr>
<tr>
<td>PHN502 Perth South</td>
<td>25,747</td>
<td>1,545</td>
</tr>
<tr>
<td>PHN206 Western Victoria</td>
<td>25,265</td>
<td>1,516</td>
</tr>
<tr>
<td>PHN105 South Western Sydney</td>
<td>25,166</td>
<td>1,510</td>
</tr>
<tr>
<td>PHN205 Murray</td>
<td>24,130</td>
<td>1,448</td>
</tr>
<tr>
<td>PHN109 North Coast</td>
<td>23,969</td>
<td>1,438</td>
</tr>
<tr>
<td>PHN106 South Eastern NSW</td>
<td>23,906</td>
<td>1,434</td>
</tr>
<tr>
<td>PHN601 Tasmania</td>
<td>22,130</td>
<td>1,328</td>
</tr>
<tr>
<td>PHN103 Western Sydney</td>
<td>20,531</td>
<td>1,232</td>
</tr>
<tr>
<td>PHN402 Country SA</td>
<td>19,409</td>
<td>1,165</td>
</tr>
<tr>
<td>PHN307 Northern Queensland</td>
<td>18,683</td>
<td>1,121</td>
</tr>
<tr>
<td>PHN304 Darling Downs and West Moreton</td>
<td>17,286</td>
<td>1,037</td>
</tr>
<tr>
<td>PHN303 Gold Coast</td>
<td>16,557</td>
<td>993</td>
</tr>
<tr>
<td>PHN503 Country WA</td>
<td>14,263</td>
<td>856</td>
</tr>
<tr>
<td>PHN107 Western NSW</td>
<td>13,273</td>
<td>796</td>
</tr>
<tr>
<td>PHN204 Gippsland</td>
<td>11,165</td>
<td>670</td>
</tr>
<tr>
<td>PHN104 Nepean Blue Mountains</td>
<td>10,265</td>
<td>616</td>
</tr>
<tr>
<td>PHN110 Murrumbidgee</td>
<td>10,160</td>
<td>610</td>
</tr>
<tr>
<td>PHN801 Australian Capital Territory</td>
<td>8,480</td>
<td>509</td>
</tr>
<tr>
<td>PHN701 Northern Territory</td>
<td>5,215</td>
<td>313</td>
</tr>
</tbody>
</table>
Similarly to the number of bereaved persons, it is unknown exactly how many bereaved persons are at risk of developing complicated grief. The growing literature provides estimates of the proportion of bereaved persons at risk of complicated grief as well as associated risk factors. The Nucleus Group reported 5%, Aoun et al. 6.4%, Kersting et al. 6.7%, Shear reported 7% and Shear et al. reported 10% of bereaved persons to be at risk of complicated grief (Aoun et al., 2015; Kersting et al., 2011; Nucleus Group, 2004; Shear, 2012b; Shear et al., 2011).

It should be noted that there is a slight difference between the figures presented here and those presented in the literature review in Section 3.3.2. The reasons for this are twofold. First, some of the studies presented in Table 4 are restricted to a subgroup of people who may have differential risk of developing complicated grief. The other reason is that the approach used here utilises conditional prevalence, i.e. the likelihood of developing complicated grief among bereaved persons, while some studies discussed in Section 3.3.2 provide prevalence in a given population without direct relationship to the number of deaths in a given time period.

Therefore, for the purposes of understanding demand and supply relating to service provision it is assumed that approximately 6% of bereaved persons may require complicated grief services. Consequently, the estimated number of persons at risk for complicated grief around Australia is 44,303 which is also presented by PHN in Table 16.

5.1.3 Estimates for selected causes of death

In addition to analysis of demand originating from all deaths, four subgroups were also investigated for the period 2013. These were cancer\(^7\), suicides\(^8\), violent deaths\(^9\) and death of a child\(^{10}\).

Cancer accounts for almost 30% of all deaths and has in recent years been the leading cause of death for Australians of all ages, having exceeded the number of deaths from circulatory diseases. Additionally, persons dying from cancer are the largest group accessing palliative care services (Palliative Care Outcomes Collaboration, 2016).

While low in numbers – 1.9% of deaths are due to suicide, 0.2% due to violent deaths and 0.9% of all deaths occur in children aged 14 years and younger – these three causes of death are highlighted because persons bereaved in this way have been found to be at higher risk of developing complicated grief. Kersting et al. (2011) reported the conditional prevalence of complicated grief for these causes of death as follows: 10.1% for cancer, 18.1% for suicide,

\(^7\) Deaths from cancer are defined as all deaths with the ICD-10-AM code of C00-C97 (malignant neoplasms).
\(^8\) Deaths from suicide are defined as all deaths with the ICD-10-AM code of X60-X84 (intentional self-harm).
\(^9\) Violent deaths are defined as all deaths with the ICD-10-AM code of X85-Y09 (assault).
\(^{10}\) Death of a child includes all deaths of persons aged 14 years or younger.
20.0% for violent death and 23.6% for death of a child. A review of the literature relating to bereavement involving violent or sudden death was out of scope of this project.

In line with the approach taken for all cause deaths, conservative estimates have been derived from the actual numbers of deaths. These numbers together with the previous assumption of on average five bereaved persons per death provide estimates for the number of bereaved persons at risk of complicated grief. Table 17 shows the results of this calculation and highlights that 49.1% of bereaved persons at risk of complicated grief have lost a loved one to cancer, 5.1% to suicide, 0.5% to a violent death and 4.1% have lost a person aged 14 years or younger.

Table 17  Number of deaths and estimated number of bereaved persons at risk of complicated grief for selected causes of death in Australia, 2013 (ABS, 2016a)

<table>
<thead>
<tr>
<th>Cause of death</th>
<th>Total deaths</th>
<th>Bereaved persons</th>
<th>Bereaved persons with complicated grief, total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>43,499</td>
<td>217,495</td>
<td>21,750 (49.1%)</td>
</tr>
<tr>
<td>Suicide</td>
<td>2,520</td>
<td>12,600</td>
<td>2,268 (5.1%)</td>
</tr>
<tr>
<td>Violent death</td>
<td>216</td>
<td>1,080</td>
<td>216 (0.5%)</td>
</tr>
<tr>
<td>Death of a child</td>
<td>1,582</td>
<td>7,910</td>
<td>1,819 (4.1%)</td>
</tr>
<tr>
<td>Sub-total (selected causes)</td>
<td>47,817</td>
<td>239,085</td>
<td>26,053 (58.8%)</td>
</tr>
<tr>
<td>Total (all causes)</td>
<td>147,678</td>
<td>738,390</td>
<td>44,303</td>
</tr>
</tbody>
</table>

The persons who have lost a loved one due to one of these selected causes may only present a small group (except for cancer) of all bereaved persons but they are at much higher risk of complicated grief and their needs might generate demand for care which can only be provided by more specialised service providers. A number of service providers identify themselves as serving a particular target group.

5.2 Supplying care for persons with complicated grief

A range of professions and organisations provides bereavement services. Persons requiring support with complicated grief may access services through varied routes, for example, via primary care after consultation with their GP, through a palliative care or aged care service that supported the person’s dying loved one; or through self-referral to a private practitioner or possibly via community based support group.

5.2.1 Service provision – selected findings from the survey

Firstly, several limitations of the survey data which restrict the generalisability of findings should be noted. As it was unrealistic to compile a complete list of all service providers in Australia, a sampling framework was developed, introducing the potential for bias as the group selected for inclusion in the survey may not be representative of all bereavement service providers across Australia, particularly sole private practitioners. In addition, the response rate of 27.7% (76/274) for survey questions pertinent to supply and demand issues must also be considered. Amongst respondents, a further limitation of the survey results was the absence of responses from ‘for-profit providers’ and from services in the Northern Territory.
Of the 76 survey respondents that answered supply and demand questions approximately half (37 respondents) identified as palliative care providers. A large majority of respondents (both from palliative care services, 89%, and other services, 82%) provide specific bereavement support to people rather than only referring to other services. In addition, around two thirds of all service providers indicated their service assists people with complicated grief (53% of responding palliative care services did so).

Face to face counselling is the most common service provided for both bereavement and complicated grief. Most frequently an individual receives a service 3-10 times. Referrals, as might be expected, are usually only made once or twice for an individual. It is evident that both physical services (face to face counselling, group counselling, face to face support group) and technological services (telephone support/counselling, online information and self-help resources, email/message support, telephone referral to other service providers) are provided by a large number of services.

Most frequently respondents indicated that each service type was provided to less than 50 people per annum. This relatively small number of service recipients is partly explained by the fact that many respondents were from smaller organisations / service providers, and bereavement was not the sole focus of the work of the majority of respondents’ organisations. For more than half of all respondents the approximate proportion of total service delivery directed to bereavement support annually was relatively low (1-20%).

The wide range of roles providing bereavement support and assistance with complicated grief identified through the survey is presented in Table 18. In palliative care, bereavement support is principally provided by social workers, pastoral care workers and nurses. Whereas in other non-palliative care services (predominantly community based not-for-profit counselling and support organisations), care is predominantly provided by bereavement counsellors and social workers.

Comparing the results to results reported elsewhere, significant differences are evident. This may be attributable in part to the survey questions not distinguishing between service delivery roles, for example, certain professional groups may take a lead role in ‘coordinating services’ whereas others are more directly engaged in ‘delivering services’ which may account for some differences in findings. Mather and colleagues reported on staff responsible for coordinating and delivering follow-up/programs among centres providing bereavement care (which included 223 palliative care services across Australia). They also reported much lower proportions of services within each staff category in coordination and each staff category except nurses in delivery (Mather et al., 2008). However this study had a much larger sample size.

Another caveat associated with the results presented relates to the relatively high number of doctors and nurses that respondents indicated provide bereavement services. This may signify a potential misinterpretation in the question asked (“Which of the following positions provide bereavement services at your organisation?”). The question was intended to gather information on positions providing direct bereavement support to the bereaved, but this may have been misinterpreted by palliative care providers who also provide support to the family while the patient is still alive.
Table 18  Roles providing bereavement support at survey respondents’ services

<table>
<thead>
<tr>
<th>Role</th>
<th>Palliative care services, total (% of 29)</th>
<th>Other services, total (% of 32)</th>
<th>All services, total (% of 61)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker</td>
<td>21 (72%)</td>
<td>17 (53%)</td>
<td>38 (62%)</td>
</tr>
<tr>
<td>Nurse</td>
<td>15 (52%)</td>
<td>10 (31%)</td>
<td>25 (41%)</td>
</tr>
<tr>
<td>Bereavement counsellor</td>
<td>8 (28%)</td>
<td>17 (53%)</td>
<td>25 (41%)</td>
</tr>
<tr>
<td>Pastoral care worker</td>
<td>16 (55%)</td>
<td>7 (22%)</td>
<td>23 (38%)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>5 (17%)</td>
<td>9 (28%)</td>
<td>14 (23%)</td>
</tr>
<tr>
<td>Volunteer</td>
<td>5 (17%)</td>
<td>9 (28%)</td>
<td>14 (23%)</td>
</tr>
<tr>
<td>Medical doctor</td>
<td>8 (28%)</td>
<td>3 (9%)</td>
<td>11 (18%)</td>
</tr>
<tr>
<td>Other paid position</td>
<td>3 (10%)</td>
<td>8 (25%)</td>
<td>11 (18%)</td>
</tr>
<tr>
<td>Memorial committee member</td>
<td>2 (7%)</td>
<td>1 (3%)</td>
<td>3 (5%)</td>
</tr>
</tbody>
</table>

Fifty-five survey respondents indicated that their service has a local or regional catchment area. These responses were mapped to the corresponding Primary Health Network and are displayed in Table 19. The 22 services that indicated they have a national or state-wide catchment area or did not specify a catchment area are included in the national total at the end of Table 19. With the exception of a few PHNs (Nepean Blue Mountains, Western NSW, Gippsland, Western Victoria, Brisbane South, Western Queensland and Northern Territory) there are responses from all PHNs.

Table 19  Local or regional catchment area by PHN

<table>
<thead>
<tr>
<th>Primary Health Network</th>
<th>Number of responding services</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHN306 Central Queensland and Sunshine Coast</td>
<td>6</td>
</tr>
<tr>
<td>PHN402 Country SA</td>
<td>4</td>
</tr>
<tr>
<td>PHN601 Tasmania</td>
<td>4</td>
</tr>
<tr>
<td>PHN503 Country WA</td>
<td>4</td>
</tr>
<tr>
<td>PHN301 Brisbane North</td>
<td>3</td>
</tr>
<tr>
<td>PHN202 Eastern Melbourne</td>
<td>3</td>
</tr>
<tr>
<td>PHN101 Central and Eastern Sydney</td>
<td>3</td>
</tr>
<tr>
<td>PHN801 Australian Capital Territory</td>
<td>2</td>
</tr>
<tr>
<td>PHN304 Darling Downs and West Moreton</td>
<td>2</td>
</tr>
<tr>
<td>PHN303 Gold Coast</td>
<td>2</td>
</tr>
<tr>
<td>PHN205 Murray</td>
<td>2</td>
</tr>
<tr>
<td>PHN307 Northern Queensland</td>
<td>2</td>
</tr>
<tr>
<td>PHN102 Northern Sydney</td>
<td>2</td>
</tr>
<tr>
<td>PHN103 Western Sydney</td>
<td>2</td>
</tr>
</tbody>
</table>
5.2.2 Estimation of workforce availability

Services for persons with complicated grief are provided by a range of professions. In addition to organisations a large number of individual psychologists (usually operating in private practice) are a professional group likely to provide assistance.

There are limitations in the availability of workforce data, primarily because not all positions providing bereavement support need to be registered. Consequently only two professional groups are considered, psychologists and social workers as there is some workforce data available for these two groups of professionals and they appear to spend a significant proportion of their time providing assistance to the bereaved.

5.2.2.1 Psychologists

Psychologists are one of 14 health professions that are regulated and registered with the Australian Health Practitioner Regulation Agency (AHPRA). The registration data feeds into the National Health Workforce Dataset (NHWDS) made available by AIHW (AIHW, 2016b). Table 20 shows the number of registered psychologists who are employed in the workforce in each PHN. Australia wide there were in total 23,144 psychologists with an average distribution of 1 psychologist per 1,000 population. However this workforce is unevenly distributed. Among the

<table>
<thead>
<tr>
<th>Primary Health Network</th>
<th>Number of responding services</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHN105 South Western Sydney</td>
<td>2</td>
</tr>
<tr>
<td>PHN502 Perth South</td>
<td>2</td>
</tr>
<tr>
<td>PHN501 Perth North</td>
<td>2</td>
</tr>
<tr>
<td>PHN203 South Eastern Melbourne</td>
<td>2</td>
</tr>
<tr>
<td>PHN110 Murrumbidgee</td>
<td>1</td>
</tr>
<tr>
<td>PHN109 North Coast</td>
<td>1</td>
</tr>
<tr>
<td>PHN106 South Eastern NSW</td>
<td>1</td>
</tr>
<tr>
<td>PHN401 Adelaide</td>
<td>1</td>
</tr>
<tr>
<td>PHN108 Hunter New England and Central Coast</td>
<td>1</td>
</tr>
<tr>
<td>PHN201 North Western Melbourne</td>
<td>1</td>
</tr>
<tr>
<td>PHN104 Nepean Blue Mountains</td>
<td>0</td>
</tr>
<tr>
<td>PHN107 Western NSW</td>
<td>0</td>
</tr>
<tr>
<td>PHN204 Gippsland</td>
<td>0</td>
</tr>
<tr>
<td>PHN206 Western Victoria</td>
<td>0</td>
</tr>
<tr>
<td>PHN302 Brisbane South</td>
<td>0</td>
</tr>
<tr>
<td>PHN305 Western Queensland</td>
<td>0</td>
</tr>
<tr>
<td>PHN701 Northern Territory</td>
<td>0</td>
</tr>
<tr>
<td>PHN999 Australia (total)</td>
<td>77</td>
</tr>
</tbody>
</table>
least well supported PHNs are Country South Australia, Western Queensland and Murrumbidgee (NSW). As might be expected the PHNs with the highest ratio of psychologists per 1,000 population are in urban areas: North Western Melbourne, ACT and Central and Eastern Sydney PHN.

Table 20  Number of employed psychologists in the workforce by PHN in 2013 (AIHW, 2016b)

<table>
<thead>
<tr>
<th>Primary Health Network</th>
<th>Psychologists</th>
<th>Psychologists per 1,000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHN101 Central and Eastern Sydney</td>
<td>2,442</td>
<td>1.66</td>
</tr>
<tr>
<td>PHN801 Australian Capital Territory</td>
<td>629</td>
<td>1.65</td>
</tr>
<tr>
<td>PHN201 North Western Melbourne</td>
<td>2,438</td>
<td>1.60</td>
</tr>
<tr>
<td>PHN301 Brisbane North</td>
<td>1,357</td>
<td>1.47</td>
</tr>
<tr>
<td>PHN501 Perth North</td>
<td>1,462</td>
<td>1.41</td>
</tr>
<tr>
<td>PHN102 Northern Sydney</td>
<td>1,161</td>
<td>1.32</td>
</tr>
<tr>
<td>PHN202 Eastern Melbourne</td>
<td>1,613</td>
<td>1.13</td>
</tr>
<tr>
<td>PHN106 South Eastern NSW</td>
<td>577</td>
<td>0.97</td>
</tr>
<tr>
<td>PHN203 South Eastern Melbourne</td>
<td>1,339</td>
<td>0.96</td>
</tr>
<tr>
<td>PHN103 Western Sydney</td>
<td>844</td>
<td>0.95</td>
</tr>
<tr>
<td>PHN104 Nepean Blue Mountains</td>
<td>324</td>
<td>0.91</td>
</tr>
<tr>
<td>PHN401 Adelaide</td>
<td>1,056</td>
<td>0.89</td>
</tr>
<tr>
<td>PHN109 North Coast</td>
<td>441</td>
<td>0.88</td>
</tr>
<tr>
<td>PHN108 Hunter New England and Central Coast</td>
<td>1,058</td>
<td>0.87</td>
</tr>
<tr>
<td>PHN206 Western Victoria</td>
<td>511</td>
<td>0.85</td>
</tr>
<tr>
<td>PHN303 Gold Coast</td>
<td>469</td>
<td>0.85</td>
</tr>
<tr>
<td>PHN302 Brisbane South</td>
<td>880</td>
<td>0.82</td>
</tr>
<tr>
<td>PHN502 Perth South</td>
<td>760</td>
<td>0.81</td>
</tr>
<tr>
<td>PHN701 Northern Territory</td>
<td>193</td>
<td>0.80</td>
</tr>
<tr>
<td>PHN601 Tasmania</td>
<td>407</td>
<td>0.79</td>
</tr>
<tr>
<td>PHN105 South Western Sydney</td>
<td>667</td>
<td>0.74</td>
</tr>
<tr>
<td>PHN307 Northern Queensland</td>
<td>499</td>
<td>0.72</td>
</tr>
<tr>
<td>PHN107 Western NSW</td>
<td>206</td>
<td>0.67</td>
</tr>
<tr>
<td>PHN306 Central Queensland and Sunshine Coast</td>
<td>510</td>
<td>0.63</td>
</tr>
<tr>
<td>PHN304 Darling Downs and West Moreton</td>
<td>333</td>
<td>0.63</td>
</tr>
<tr>
<td>PHN204 Gippsland</td>
<td>148</td>
<td>0.56</td>
</tr>
<tr>
<td>PHN205 Murray</td>
<td>286</td>
<td>0.49</td>
</tr>
</tbody>
</table>
Table 21 includes the number of employed psychologists in the workforce by remoteness. It clearly highlights the gap in availability between major cities and the rest of the country.

Table 21  Number of employed psychologists in the workforce by remoteness in 2013 (AIHW, 2016b)

<table>
<thead>
<tr>
<th>Remoteness</th>
<th>Psychologists</th>
<th>Psychologists per 1,000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major Cities of Australia</td>
<td>19,088</td>
<td>1.17</td>
</tr>
<tr>
<td>Inner Regional Australia</td>
<td>2,865</td>
<td>0.68</td>
</tr>
<tr>
<td>Outer Regional Australia</td>
<td>1,003</td>
<td>0.49</td>
</tr>
<tr>
<td>Remote Australia</td>
<td>123</td>
<td>0.38</td>
</tr>
<tr>
<td>Very Remote Australia</td>
<td>57</td>
<td>0.27</td>
</tr>
<tr>
<td>Australia (total)</td>
<td>23,144</td>
<td>1.00</td>
</tr>
</tbody>
</table>

5.2.2.2 Social Workers

In contrast to psychologists, social workers are not a group of registered health professionals. Therefore no data is available from AHPRA or the NHWDS. However the ABS publishes detailed quarterly data on the Australian labour force. This data includes social workers as defined in the Australian and New Zealand Standard Classification of Occupations (ANZSCO) who are employed in the labour force. ANZSCO is a skill-based classification of occupations, developed as a national standard for organising occupation-related information. The classification includes all jobs in the Australian workforce (ABS, 2013).

Unfortunately there is no data available for employed social workers broken down by level of remoteness. However, Table 22 shows the number of employed social workers in each State/Territory. Australia wide there were in total 32,700 social workers or an average of 1.41 per 1,000 population. As was seen with psychologists, their distribution is not equal across the country. The jurisdictions with lower numbers of social workers are New South Wales, Queensland and Western Australia while those with the highest number are the Australian Capital Territory, Tasmania and Northern Territory. However, there seems to be a certain counterbalancing effect in some jurisdictions, i.e. South Australia, Tasmania and Northern Territory, where the number of employed social workers is well above the national average. Table 22 also includes employed psychologists for each Australian State and Territory.
Table 22  Number of psychologists and social workers employed in the workforce by State/Territory in 2013 (ABS, 2016b; AIHW, 2016b)

<table>
<thead>
<tr>
<th>State / Territory</th>
<th>Social worker</th>
<th>Social worker per 1,000 population</th>
<th>Psychologists per 1,000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>8,100</td>
<td>1.09</td>
<td>1.06</td>
</tr>
<tr>
<td>Victoria</td>
<td>9,900</td>
<td>1.73</td>
<td>1.10</td>
</tr>
<tr>
<td>Queensland</td>
<td>5,700</td>
<td>1.23</td>
<td>0.88</td>
</tr>
<tr>
<td>South Australia</td>
<td>3,000</td>
<td>1.80</td>
<td>0.71</td>
</tr>
<tr>
<td>Western Australia</td>
<td>3,100</td>
<td>1.23</td>
<td>0.98</td>
</tr>
<tr>
<td>Tasmania</td>
<td>1,300</td>
<td>2.53</td>
<td>0.79</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>800</td>
<td>3.30</td>
<td>0.80</td>
</tr>
<tr>
<td>Australian Capital Territory</td>
<td>800</td>
<td>2.10</td>
<td>1.65</td>
</tr>
<tr>
<td><strong>Australia</strong></td>
<td><strong>32,700</strong></td>
<td><strong>1.41</strong></td>
<td><strong>1.00</strong></td>
</tr>
</tbody>
</table>

5.2.2.3  Counsellors

Another important workforce group for the provision of specialist bereavement services are ‘bereavement counsellors’ or ‘grief counsellors’. These specially trained counsellors provide bereavement support to persons who have lost a loved one. They provide help during the different stages of grief in particular to persons overwhelmed with loss, grief or trauma.

Data specific to the availability of this subgroup of counsellors nationally was not accessible. More generally, the ANZSCO classification includes the unit group 2721 Counsellors. They describe this role as follows:

*Counsellors provide information on vocational, relationship, social and educational difficulties and issues, and work with people to help them to identify and define their emotional issues through therapies such as cognitive behaviour therapy, interpersonal therapy and other talking therapies (ABS, 2013).*

Most occupations in this group have a level of skill commensurate with a bachelor degree or higher qualification. In some instances relevant experience and/or on-the-job training may be required in addition to the formal qualification. Of the different occupations within this classification the sub-group of ‘Counsellors Not Elsewhere Classified’ includes reference to ‘Grief Counsellor’ and ‘Trauma Counsellor’.

Typically ‘bereavement counsellors’ have specialised through additional training in bereavement support. Generally additional qualification can be obtained as a graduate certification for persons with appropriate counselling training and a previous degree in social work, nursing, psychology, teaching or similar, e.g. Graduate Certificate in Bereavement Counselling and Intervention from the Australian Centre for Grief and Bereavement (Australian Centre for Grief and Bereavement, 2016) or Graduate Certificate in Loss, Grief and Trauma Counselling from Flinders University (Flinders University, 2016). Another qualification option, a
Certificate IV, is available for professionals with a Certificate III level qualification in community services or other relevant experiences, e.g. Certificate IV in Bereavement Support from the Australian Centre for Grief and Bereavement.

5.3 Workforce gaps and issues

A number of potential workforce gaps have emerged from this analysis and several key issues require consideration.

It is likely that demand for services will increase. Approximately 30% of survey respondents anticipated change in demand for complicated grief services in the future. Of these all indicated they expected demand to increase for a variety of reasons including societal changes and increased understanding and awareness (and identification) of complicated grief.

5.3.1 Issues in relation to funding and staffing

A major issue is that of funding for the workforce. Several survey respondents indicated that if they had additional resources available their highest priorities would be to provide education and training to staff (to build capacity) and to increase staffing levels. Many respondents listed specific positions they would employ including psychologists, bereavement coordinators, social workers and counsellors. Expanding current services was what some respondents indicated; they would use additional resources for, either to reach a wider target group (e.g. providing bereavement counselling to anyone within a certain area regardless of the cause of death) or a wider geographical area.

Almost all survey respondents considered the major workforce issues both now and into the future to be funding-related. This concern about funding was expressed in many ways, usually in relation to staffing issues, e.g. problems of funding wages, ability to attract appropriately trained, qualified and experienced staff (especially in rural areas), retention of staff or sufficient staffing levels. Other issues identified were the lack of capacity to meet growing demands (and in some cases current demand). Respondents also identified budgetary and funding issues related to resources more generally as well as challenges in funding basic training for staff and ongoing training related to advancements in working with persons with complicated grief. The limited availability of volunteers was noted by several respondents as an issue.

A number of palliative care respondents reported competing clinical priorities and demands as a significant issue. This can result in complicated grief being “neglected when there are so many critical care issues required to ensure patient throughput”. A similar response was given by a bereavement counsellor, who noted the challenge of “maintaining a primary focus on complicated grief while supporting other processes to provide (uncomplicated) grief support”.

5.3.2 Issues in relation to access

The lack of access to complicated grief services was voiced as another key concern by many respondents. It was unclear from respondents whether lack of access was a reflection of limited availability of appropriate professionals and service providers or caused by the cost of accessing private services.
A key issue raised by several respondents related to the limited bereavement and complicated grief services. There was concern about the lack of access people have to these services and the limited funding available to services generally. Others noted that no services were available in their area at all, and another noted the detrimental impact that funding cuts had on communities in rural regions. One respondent described services as “woefully inadequate”, and another respondent, referring to services associated with residential aged care, stated that “patients and families ... are totally neglected”.

5.3.3 Issues in relation to referral and service provision

One respondent noted the difficulty they had experienced identifying appropriate services in their state / territory for people with complicated grief. Another noted they had received negative feedback from clients whose needs had not been met by various private psychologists and health services where they had been referred. Identifying specialist practitioners to refer to was challenging as service providers only had confidence in services previously endorsed by clients. Referral of clients through securing a GP Mental Health Treatment Plan was discussed by one respondent. This was their primary referral mechanism as if approved by the GP it provided access to certain Medicare rebateable allied mental health services, including therapy by a clinical psychologist. However this was seen as problematic and impractical for some clients resulting in out of pocket costs, as private practitioners often charged a gap fee.

Within Australia, it appears that treatment of complicated grief is determined individually for each person by the treating professional. A general indication of access to psychological services comes from information about the former Access to Allied Psychological Services (ATAPS) initiative. Within ATAPS patients were generally eligible for a maximum of 12 individual sessions per calendar year (two episodes of six sessions). In exceptional circumstances up to a maximum total of 18 individual sessions per patient per calendar year could be accessed. In addition, patients were also eligible for up to 12 separate group therapy services, with a group usually involving 6-10 patients (Department of Health and Ageing, 2012). ATAPS mental health professionals included psychologists, social workers, mental health nurses, occupational therapists and Aboriginal and Torres Strait Islander health workers with specific mental health qualifications (Department of Health, 2015). Recent changes to the ATAPS initiative have been previously outlined in Section 4.2.2. The primary program, funded through the Medicare system that provides access for patients via a GP referral to mental health professionals is now the Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access) initiative.

5.3.4 Additional considerations

5.3.4.1 Funding implications for palliative care services

The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. PCOC maintains a dataset which includes detailed clinical and demographic information about the palliative care patient.

Grief counselling is an integral part of palliative care and may be provided to the family whilst the patient is still alive. Funding for this service is therefore ‘bundled’ into the palliative care episode. Until recently the Australian National Subacute and Non-Acute Patient (AN-SNAP)
Classification, that is also used to group palliative care patients, included classes labelled ‘bereavement’ specifically designed for the care provided after the palliative care patient had died. However, in the most recent version of AN-SNAP (Version 4) the bereavement classes were removed. Therefore bereavement services captured in the PCOC data are always related to the care provided to bereaved persons immediately after the death of the palliative care patient. If further bereavement support is required, be it after a period of time or because of complicated grief, the bereaved person becomes a patient in their own right. An option for the hospital/palliative care unit to be reimbursed for the services they provide for bereaved persons would be to set up a so-called ‘tier 2 clinic’ for the provision of non-admitted services. In the current Non-Admitted Services Definitions Manual, there are several options under which these services could be classified (IHPA, 2015):

- 20.45 Psychiatry;
- 20.54 Maternal foetal medicine (e.g. management of perinatal loss, including, bereavement counselling);
- 40.11 Social work;
- 40.29 Psychology;
- 40.33 General counselling;
- 40.34 Specialist mental health.

However, 40.34 Specialist mental health has to be provided by a mental health specialist organisation and 40.33 General counselling is currently considered out-of-scope and not eligible for Commonwealth funding as it should be provided in the primary care sector (IHPA, 2016).

5.3.4.2 Privacy implications for palliative care services

Throughout the open text fields in the survey concerns about privacy were consistently raised, particularly in the context of making contact with carers of a deceased person that may have previously been cared for by the service. It is beyond the scope of this report to describe the nuances of privacy legislation in each state and territory and it is this legislation that is often most relevant to hospital based services. For example in NSW all staff working within the NSW public health system must comply with the Health Records and Information Privacy Act 2002.

The Commonwealth Privacy Act 1988 is used to briefly illustrate the issue at hand. The Privacy Act 1988 (Privacy Act) applies to a wide range of organisations including all health service providers in the private sector throughout Australia (collectively called ‘APP entities’). A ‘health service provider’ is a person or entity who provides a health service and holds health information, even if providing a health service is not their primary activity. Health service providers are covered by the Privacy Act for all activities involving the handling of personal information, not just activities that relate to providing a health service. As noted previously, the Commonwealth Privacy Act 1988 does not apply to state and territory public sector health service providers, such as public hospitals.

There are a range of issues that health service providers need to be aware of, particularly if they wish to follow up the carers, family and friends of a person who may have died within their service. According to information available from the Office of the Australian Information
Commissioner an APP entity can only use or disclose personal information for a purpose for which it was collected (known as the ‘primary purpose’), or for a secondary purpose if an exception applies such as:

- the individual has consented to a secondary use or disclosure
- the individual would reasonably expect the APP entity to use or disclose their personal information for the secondary purpose, and that purpose is related to the primary purpose of collection, or, in the case of sensitive information, directly related to the primary purpose
- a permitted general situation exists in relation to the secondary use or disclosure
- the APP entity is an organisation and a permitted health situation exists in relation to the secondary use or disclosure.

The following additional advice is provided about ‘describing the primary purpose’:

*B.101 How broadly a purpose can be described will depend on the circumstances and should be determined on a case-by-case basis. In cases of ambiguity, and with a view to protecting individual privacy, the primary purpose for collection, use or disclosure should be construed narrowly rather than expansively (Office of the Australian Information Commissioner, 2015).*

If the purpose of follow-up is because of concerns about access to bereavement support or potentially risk of complicated grief, then the service (and its employees) must have a clear understanding of the privacy legislation that is relevant to their service.

5.3.4.3 Implications for residential aged care

Almost 37% of all deaths occurred for persons residing in a permanent residential aged care facility. With the number of people living in residential aged care rising so too will the number of deaths in residential aged care.

An increasing number of residents have dementia. In 2013, 51.8% (or 87,074) of residents reportedly had dementia (AIHW, 2014). Australia wide (not only in aged care) the number of people living with dementia was predicted to be 321,600 in 2013 and is expected to increase to 399,800 in 2020 (and 550,020 in 2030) (AIHW, 2012). In 2005, only 3.5% of all deaths (or 4,653 deaths) were recorded with the underlying cause / associated cause dementia, including Alzheimer’s disease. Eight years later, in 2013, already 7.4% of all deaths (or 10,933 deaths) were in this category (AIHW, 2015b). Consequently, deaths associated with dementia and Alzheimer’s disease are predicted to increase further.

For residential aged care facilities the increasing incidence of dementia will have two main implications. Firstly, a larger proportion of persons with dementia will have lived in residential aged care facilities and consequently die there. Secondly, more bereaved carers experiencing complicated grief may turn to these facilities hoping to find support. Therefore residential aged care providers should at least be prepared to refer persons seeking help to appropriate local bereavement support providers.
5.4 Service implications

With the 147,678 deaths in 2013 as starting point it was estimated that 44,303 bereaved persons are at risk for complicated grief, of those 49.1% are bereaved because of a cancer death. The setting of deaths across the country was used as a proxy indicator of where demand is likely to exist for persons experiencing bereavement and complicated grief.

The analysis demonstrates that the standardised death rate is increasing with the level of remoteness. However, at the same time the number of psychologists (a key professional group that supports persons with complicated grief) is decreasing with the level of remoteness. When looking at PHNs a similar effect can be observed. PHNs with higher SDRs generally seem to have fewer psychologists available.

This imbalance between service demand and workforce supply is a characteristic of most forms of health care in Australia. It indicates a higher degree of disadvantage for regional and remote areas of Australia.

In 2013/2014 approximately 50% of total deaths occurred in hospital (of those 44% had a palliative care-related hospitalisation). An estimated 37% of deaths occurred in (permanent) residential aged care while the remaining deaths occurred in other settings, for example, the person’s home. It is therefore not unrealistic to assume that bereaved persons experiencing complicated grief may turn to the service that cared for their loved one should they subsequently require bereavement support. This may generate demand for relevant information and/or specialist services that can be provided to bereaved persons by both palliative care services and potentially residential aged care providers.
6 Discussion and conclusion

This section of the report aims to respond to the research questions that provided the impetus for this project. The research questions have been aligned with the goal of the National Palliative Care Strategy 2010 (Department of Health and Ageing, 2011) that they primarily address, as presented in Table 23. The focus of this research was on bereavement, specifically complicated grief, which has implications beyond palliative care.

Table 23 Alignment of research questions with National Palliative Care Strategy goals

<table>
<thead>
<tr>
<th>Goal Area</th>
<th>Number</th>
<th>Goal</th>
<th>Research Questions</th>
</tr>
</thead>
</table>
| Awareness and Understanding       | Goal 1 | To significantly improve the appreciation of dying and death as a normal part of the life continuum. | ▪ What is the impact of complicated grief on the bereaved individual, their family and significant others?  
▪ What are the likely triggers or challenge points for people experiencing complicated grief?  
▪ What evidence is there about preventing or minimising the onset or effects of complicated grief? |
|                                   | Goal 2 | To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services. | ▪ What is the evidence of the effectiveness of advance care planning in preventing or minimising the onset or effects of complicated grief? |
| Appropriateness and Effectiveness  | Goal 3 | Appropriate and effective palliative care is available to all Australians based on need. | ▪ What are the needs of people experiencing complicated grief?  
▪ What resources, services and activities are available to support people experiencing complicated grief?  
▪ What is the composition of the workforce that provides bereavement services?  
▪ How is the workforce distributed across Australia?  
▪ What issues does this workforce face now and in the future? |
| Leadership and Governance         | Goal 4 | To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches. | ▪ Are there any outcome indicators currently monitored by organisations providing services for people experiencing complicated grief?  
▪ What is the capacity to build on existing systems (e.g. PCOC) and integrate appropriate outcome indicators relating to the management of persons experiencing complicated grief and/or |
### 6.1 Awareness and Understanding

National Palliative Care Strategy related goals:

- **Goal 1:** To significantly improve the appreciation of dying and death as a normal part of the life continuum
- **Goal 2:** To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services.

#### 6.1.1 Use of the term complicated grief

There is controversy as to whether complicated grief exists. Grief itself should not be confused with depression, anxiety or traumatic stress. There is a general consensus that some grief requires additional support, however opinion is divided on whether complex, prolonged or vulnerable grief is a distinct psychopathology or is simply part of a continuum of “normal” grieving.

The diversity of views is captured in Table 24.

**Table 24 The definition of complicated grief: stakeholder views**

<table>
<thead>
<tr>
<th>Areas of agreement</th>
<th>Areas of contention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grief is not an illness</td>
<td>A diagnosis or label of complicated grief is seen by some as harmful, and by others as helpful.</td>
</tr>
<tr>
<td>Some grief requires additional support</td>
<td>Some interviewees argue that complicated grief is a serious, low prevalence psychopathology that requires specialist treatment; others see grief as a continuum.</td>
</tr>
<tr>
<td>Some risks can be identified</td>
<td>Interviewees disagree on the issue of screening tools, with two opposing points of view: (1) screening tools may be used crudely and inappropriately to exclude people from accessing services; (2) routine use of screening tools may help flag those who need help, if</td>
</tr>
</tbody>
</table>
Areas of agreement | Areas of contention
--- | ---
the tools are valid and administered by people with appropriate training. | Those who have philosophical objections to a diagnosis of complicated grief see this situation as indicating that the construct is not valid or useful; others see it as a work in progress.

Current uncertainty around the definition and criteria for complicated grief has implications for research, treatment and service planning.

The plethora of terms and definitions for complicated grief lead to confusion and hinder research, treatment and service planning. There are ‘political’ implications with a diagnosis, both in the United States (where insurance-funded treatment depends on a diagnosis) and in Australia (where policy around the routine use of screening tools and/or diagnosis has the potential to influence access and resource allocation to services). Where there is universal access to bereavement services and self-referral is the dominant mode of access, diagnoses are seen as largely irrelevant. Even the issue of time since bereavement is immaterial - it is not an 'intake factor' although it will influence the number of sessions required by the client. In this context complicated grief is not seen as qualitatively different from 'normal' grief and recovery will depend largely on social support including the therapeutic relationship. However, there are also compelling arguments – backed up by research and stakeholder experience – that complicated grief is a distinct pathology that requires a specialist approach.

It appears that the term “complicated grief” is not preferred, at least amongst the stakeholders who participated in the consultation process. The term prolonged grief disorder is used by Prigerson and Maciejewski (undated) in their work relating to the diagnostic tool the Prolonged Grief–13 (PG-13). There is currently no specific code for complicated grief, or prolonged grief disorder in the ICD 10-AM, the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification. The ICD 11 is currently under review and will include a new category relevant to complicated grief and associated definition. It is proposed that the term used will be prolonged grief disorder (Maercker et al., 2013).

Historically Australia adopts new iterations of the ICD in its entirety. At the facilitated workshop of key experts it was suggested that the term “prolonged grief” was a more appropriate term than “complicated grief”.

6.1.2 What is the impact of complicated grief on the bereaved individual, their family and significant others?

The impact of bereavement can be profound, including increased risk of mortality, physical health problems, psychological symptoms and illnesses, sleep disturbances, poor nutrition and increased alcohol intake. The impact of complicated grief covers many of the same adverse outcomes: reduced level of functioning, reduced quality of life, mental health problems, physical health problems and compromised ability to function socially and at work.

It is difficult to make direct comparisons between the impact of ‘normal’ grieving and the impact of complicated grief. The former occurs primarily in the first six months of bereavement; the latter generally occurs 6-12 months after bereavement. It is not possible to quantify the impact of complicated grief as a multiple of the impact of normal grief. Estimates of the prevalence of complicated grief vary and are very much dependant on the sector of the
population under consideration. For example, parents tend to have a higher prevalence of complicated grief than the spouses of people who have died from cancer.

No studies were identified which directly measured the impact of complicated grief on productivity but all the adverse consequences of complicated grief have the potential to reduce productivity indirectly.

Bereavement research regarding the end-of-life period has focused almost entirely on what are generally described as carers – family members or friends involved in the care of the dying person. Almost nothing is known about the impact on other family members or friends not directly involved in caring.

Stakeholders were able to describe a set of symptoms of complicated grief, yearning, preoccupation, rumination, avoiding the reality of the loss, sleep disturbances, mood disturbances and somatic symptoms. They also described functional impairments including neglecting self-care, social and family activities and displaying an inability to engage with life.

Arguments in favour of a diagnosis or label of complicated grief (or similar) centred around the impact of prolonged, acute grieving on the individual. Several interviewees provided examples of clients who had come in for help many years after the bereavement (in one case, 15 years later). These were people whose lives had been derailed by the death of a loved one. Impacts could include social isolation (as family and friends may be unable to tolerate the prolonged grieving), reduced quality of life, and suicidality.

While most grief is normal, denial of the phenomenon of complicated grief will result in a small group of people who do not receive appropriate care and suffer these adverse impacts that may go on for years and significantly reduce their quality of life.

6.1.2.1 Recommendations

It is recommended that the Department of Health:

- Use the term ‘prolonged grief’ consistently in palliative care service policy and planning, and review this term when the International Classification of Diseases (Eleventh Revision) is adopted by the Australian Government.
- Recognise that prolonged grief is an identifiable condition and integrate actions to support people with prolonged grief in relevant health and social program service delivery frameworks e.g. primary care, mental health care.

6.1.3 What are the likely triggers or challenge points for people experiencing complicated grief?

Many risk factors for complicated grief have been identified in the evidence appraisal. One useful way of framing these risk factors is in terms of three domains:

1. Situational risk factors associated with the nature of the bereavement.
2. Interpersonal risk factors associated with the relationship between the bereaved person and other people (particularly the person who died).
3. Intrapersonal risk factors.

In each domain there are some risk factors strongly supported by evidence and other risk factors for which there is less evidence to support a link with complicated grief.

Intrapersonal risk factors imply that bereaved people with certain characteristics (e.g. age, gender, level of education, experience of prior losses) are more predisposed to complicated grief. Some of these risk factors cannot be influenced by health providers, either in prevention or treatment efforts; others may present as comorbidities with complicated grief and are amenable to treatment (e.g. traumatic stress, anxiety and depression).

Interpersonal risk factors (e.g. low social support, lack of family cohesion, problematic relationship with the deceased person) allow opportunities for health providers to intervene, particularly to facilitate family cohesion and support relationships between the dying person and significant others during the end-of-life period.

Situational risk factors are the most amenable to moderation by health service providers as a means of reducing the likelihood of complications in the grieving process (e.g. preparing carers for the death of their family member or friend).

From the perspective of a bereaved person, the literature on complicated grief indicates that there are four key time periods, each with its own challenges:

1. The end-of-life period of the dying person. There is conflicting evidence about the influence of carer experiences during the end-of-life period on normal grief and complicated grief. However, caring can be a demanding time and represent a considerable burden on carers.
2. The death of the family member or friend – the nature of the bereavement can influence the likelihood of complicated grief (e.g. sudden, unexpected death).
3. The immediate post-bereavement period – ‘normal’ grief can be very distressing, with adverse consequences for the physical and mental health of the bereaved person. Depression or PTSD can occur during this time.
4. More than six months post-bereavement – complicated grief is characterised by symptoms that are more intense and longer-lasting than normal grief. Once symptoms persist for longer than six months, the bereaved person is reaching the point where their grief can be considered as ‘complicated’.

There is a constellation of factors that an experienced clinician can recognise that are likely triggers of complicated grief. These fall into the broad categories identified in the literature: factors associated with the situation (e.g. violent, sudden or traumatic death; loss of a child or life partner); availability of social support; and characteristics of the bereaved individual.

In palliative care settings, medical staff and social workers expressed particular concern for carers who were socially isolated (e.g. giving up work, activities and friendships to care for a dying person). Bereavement counsellors were alert to signs of extreme dependency in the relationship between the deceased and the bereaved as this often indicated that grieving could
be complex. Personal characteristics of the bereaved were seen as highly influential. Greater vulnerability was expected if the following were present:

- Dependence, or a high degree of centrality of the deceased person to the bereaved person’s life
- Pre-existing or previous mental illness
- History of abuse or other trauma
- Previous significant losses, especially if recent.

Most stakeholders agreed that it was difficult to diagnose complicated grief earlier than six months post bereavement. Although some common factors that might influence onset could be identified, the duration and trajectory of complicated grief was considered unique to each individual.

6.1.4 What evidence is there about preventing or minimising the onset or effects of complicated grief?

6.1.4.1 The evidence about preventing the onset of complicated grief

The literature on complicated grief favours a conceptualisation that grieving can be considered as occurring on a continuum. At one end of the continuum is what can be described as ‘normal’ grief which, in itself, covers a multitude of different responses to bereavement. At the other end of the continuum is complicated grief which, again, can manifest itself in a multitude of ways. Complicated grief is a more intense or more prolonged form of grieving than ‘normal’ grief.

Intervening to prevent the progression from normal to complicated grief can potentially occur in four main ways:

1. Intervening to moderate some of the risk factors for complicated grief.
2. Providing primary preventive interventions to all bereaved people to prevent normal grief from becoming more severe or more prolonged (i.e. complicated grief).
3. Screening those who are about to suffer a bereavement or those who have suffered a bereavement to identify those at high risk of developing complicated grief.
4. Providing secondary preventive interventions to bereaved individuals at high risk of complicated grief.

Bereavement interventions can be categorised into three groups:

- Primary preventive (or universal) interventions – open to all bereaved people.
- Secondary preventive (or targeted) interventions – open to bereaved people who either because of screening or assessment are considered to be more vulnerable to the risks of bereavement.
- Tertiary preventive (or indicated) interventions – interventions involving those who suffer from complicated grief, usually as a result of help-seeking on the part of the bereaved individuals.
The available evidence does not support making primary preventive interventions available to all bereaved people and suggests that the positive effects of secondary preventive interventions are relatively small and short-acting. As was noted in one of the literature reviews included in the evidence appraisal the ‘demonstrated lack of effect of preventive interventions may be due to the possibility that prolonged grief cannot be prevented’ (Wittouck et al., 2011, p.77). An alternative view is that although universal interventions have not been effective, interventions targeted at those who are already at risk or having difficulties with their grieving have demonstrated preventative impacts (Doering and Eisma, 2016).

Although there are Australian guidelines to support screening at agreed time points, the guidelines only cover palliative care services. There are a range of bereavement risk assessment tools but none appear to be used routinely in clinical practice. Screening for complicated grief makes intuitive sense, but there are limited preventive interventions of proven efficacy. Consequently, there is little to be achieved from screening for complicated grief.

During the interviews several participants advised that they were not convinced that complicated grief could be prevented by anything that health professionals or services could do, either before the bereavement or in its immediate aftermath. These interviewees felt that vulnerability to complex grief lay more in the person’s history, for example, of mental illness or previous trauma, and in the closeness and centrality of their relationship with the deceased. In addition, there were some kinds of deaths (e.g. suicide, homicide, death of a child) that were particularly difficult to deal with, even for the most psychologically robust individual. Among these participants there was a sense that some people, because of their circumstances, were probably going to have a hard time with their grieving.

Others, however, were able to nominate several factors that might influence the onset of complicated grief and were potentially modifiable through the actions of health professionals. Many of those with this view worked closely with, or within, palliative care services. In this context, actions which could protect against complicated grief were ensuring the patient and carers were prepared for the death, delivering high quality end-of-life care, and providing information and support in the immediate post-bereavement period.

These activities are inter-related; conversations involving the patient, their family and the multi-disciplinary team could result in an Advance Care Plan, which in turn could influence end-of-life care.

Greater public awareness of the existence of complicated grief is needed amongst the general community and health care providers. The self-referral model (the dominant model of bereavement services) also depends on more-or-less universal access to bereavement counselling services and universal awareness of the characteristics of complicated grief.

6.1.4.2 The evidence about minimising the effects of complicated grief

Minimising the effects of complicated grief relies on accurate, timely, diagnosis and having appropriate evidence-based interventions available to meet the needs of those with complicated grief. The absence of a consensus on the criteria for complicated grief makes diagnosis more problematic than it might otherwise be. Diagnosis of complicated grief is
challenging with a risk of both false-positives (diagnosing normal grief as pathological) and false negatives (neglecting to treat what is pathological).

Complicated grief is but one of several possible adverse consequences of bereavement, including depression and PTSD. All combinations of complicated grief, depression and PTSD can occur at the same time in bereaved people. This scenario means that bereavement services should have access to mental health expertise.

There is evidence to support the use of tertiary preventive interventions such as complicated grief treatment for those with complicated grief. There is little evidence to support the use of medications in the treatment of complicated grief. When asked about the best ways to treat complicated grief, many participants were able to nominate either specific, evidence-based interventions or general approaches that they had found, by experience, to work well. Often those who used a more general treatment approach liked to borrow elements from a range of standard therapies, including Cognitive Behaviour Therapy and Complicated Grief Treatment, to enhance their practice.

Although, as indicated in the literature review for this study, the evidence base for treatment approaches is mixed, there have been promising results with some therapeutic approaches. There was also a strongly expressed view that a more flexible, eclectic practice – taking the best from a range of therapeutic approaches – may work well for experienced practitioners who prefer not to use strict, protocol-driven therapies. The field of complicated grief is developing rapidly and there have been many changes over the past decade. Rather than restricting the field to proven therapies, a diversity of approaches is worth supporting and most likely to give rise to a successful treatment in the future.

The fact that evidence is not available for a treatment does not necessarily mean it is not effective. However, reviews that conclude there is “no evidence” may be highly influential among researchers and policy makers, with corresponding impacts on future research, policy and funding decisions. Given that evidence has the power to shape policy, promoting research aimed at demonstrating the effectiveness of bereavement counselling would appear to be a good strategic move for the field. More systematic evaluation of existing bereavement treatment approaches would be useful particularly if the approach taken is to deconstruct, isolate and test particular components of successful therapies and to understand the mechanisms by which they work and identify the “key ingredients”.

Finally, some participants referred to the role of national or state-level standards in guiding good practice in relation to the identification and treatment of complicated grief. This would greatly improve national consistency in the management of people who may be experiencing complicated grief.

6.1.4.3 Recommendations

It is recommended that the Department of Health:

- Facilitate greater education and understanding of grief and bereavement, including prolonged grief, in undergraduate curricula of health professionals.
- Develop national standards to guide good practice in assisting people who may be experiencing prolonged grief.
- Promote high quality research (including longitudinal studies) aimed at strengthening the evidence base for current and emerging approaches to bereavement support and prolonged grief.

6.1.5 What is the evidence of the effectiveness of advance care planning in preventing or minimising the onset or effects of complicated grief?

Despite an extensive volume of research on advance care planning (ACP), there is a dearth of research drawing direct links between ACP and complicated grief. This is largely because evaluations of ACP to date have not considered bereavement outcomes, instead focusing on outcomes such as hospitalisations, compliance with patients’ wishes, family satisfaction with care, place of death and whether the advance care plan was documented.

There are some indications from the research which has been conducted of the ways in which ACP might influence bereavement outcomes. For example, ACP may influence preparedness for death or lessen the decision-making responsibilities of families during the end-of-life period. In turn, these impacts may influence bereavement outcomes. However, research needs to be conducted to investigate these possible links.

Participants who were involved in palliative care were generally open to the possibility that ACP might help prevent complicated grief. When asked why it might help, they mentioned two mechanisms: creating an opportunity to have frank conversations involving the patient, family and multi-disciplinary team; and creating a written record of the patient’s wishes to guide appropriate end-of-life care. Several participants noted that ACP needed to be more than ‘an administrative box to be ticked’. To be effective, the process must foster meaningful discussion, preferably facilitated by a social worker or other trained staff member. It should help facilitate both practical and emotional preparation for the end-of-life phase. An important goal of ACP is to help the patients and family understand the most likely trajectory of the illness and the prognosis so that the end-of-life phase does not come as a shock.

ACP could deal with many of the issues that might complicate or exacerbate grieving; however it requires sensitivity and skill to introduce the topic at the right time when the patient and carer are receptive.

6.1.5.1 Recommendation

It is recommended that the Department of Health:

- Support research and evaluation about the impact of interventions designed to enhance end-of-life care and prepare and support carers for bereavement (e.g. advance care planning, family meetings etc.).

6.2 Appropriateness and Effectiveness

Related goals:

- Goal 3: Appropriate and effective palliative care is available to all Australians based on need.
6.2.1 What are the needs of people experiencing complicated grief?

The number of deaths in Australia in 2013 was 147,678. No statistics are available in Australia or internationally that report numbers of persons who are actually bereaved. Based on several assumptions generated from guidance within the literature, the estimated number persons who were bereaved from deaths in Australia in 2013 was calculated to be almost 740,000 and the estimated number of bereaved persons at risk of complicated grief in 2013 was 44,303. The standardised death rate and therefore the assumed demand for complicated grief support is higher in rural and remote areas of Australia in comparison to major cities. Unfortunately the supply of physical services is most limited in these rural and remote areas.

Throughout the stakeholder interviews a range of unmet needs and associated barriers to service provision were identified. The most significant barrier was the lack of recognition of complicated grief both from the perspective of the individual sufferer, service providers and the broader community. This in turn impacts how family members and service providers respond to the person with complicated grief as frequently the condition is not understood. Without an awareness of this condition access to services is compromised. This is reflected in delayed or inappropriate referral by primary care practitioners or confusion about where referral is warranted to a generalist bereavement support service or more specialised service.

The lack of carer and community support for persons affected by complicated grief was raised as a significant unmet need – people in this situation appear to benefit from being able to speak with others going through a similar experience. While there are some support groups available these are often aligned with a special needs group, for example, victims of homicide. There are several special needs groups that are at high risk of complicated grief and/or have particular service provision needs; however a detailed examination of these groups was outside the scope of this report.

The use of internet based models of care was identified as a possible solution to the very limited access to either generalist or specialist bereavement support in rural and remote communities. Models of care currently have inadequate processes for follow-up of at risk patients and there is an absence of clinical guidelines outlining best practice.

There is an ongoing need for primary care and palliative care health professionals to receive appropriate training about grief, bereavement and prolonged grief so they are better able to address these issues in practice.

Finally privacy legislation was identified as the most significant systemic barrier to early identification of people at risk of complicated grief however there appears to be some misinformation and/or misunderstanding about the legislation.

6.2.2 What resources, services and activities are available to support people experiencing complicated grief?

A variety of resources, services and activities are available to support people experiencing complicated grief. The survey results showed that face to face counselling is the most common service provided for both bereavement and complicated grief. Most frequently, an individual receives a service 3-10 times, except for referrals which are usually only made once or twice for
an individual. In addition a number of services are available utilising technology to overcome difficulties with access to physical services. These include telephone support/counselling, online information and self-help resources, email/message support, and telephone referral to other service providers. Australia’s geographical vastness, and the limited availability of key professional groups in certain localities, increases the importance of access to web-based and telephone support.

Participants described several common pathways into services for people who may be experiencing complicated grief. Naturally, because many of the people we interviewed were connected with palliative care, the pathways they described often began with palliative care services. Other starting points were primary care (general practitioners) and self-referral into bereavement counselling services.

There appear to be various, interconnected pathways through the health system, that people navigate when seeking bereavement support. For example, a person who is a carer for a patient in palliative care may seek out a bereavement counsellor from this service, following the death of their loved one. If the counsellor suspects more complex issues, it may be suggested that the person sees a GP, who may then refer them to a specialist service, for example a psychiatrist. Someone who has not been in contact with palliative care might start by visiting their GP or, if they are well informed about available services, may self-refer into bereavement counselling.

The emphasis on self-referral to bereavement counselling appears, at least in part, to be founded on the view that unless treatment is freely chosen, it is unlikely to be effective. This is consistent with public health perspectives on delivering services according to level of need. Professional help with grieving should be available to everyone who feels the need for it, but not forced upon those who would rather deal with their grief in other ways.

It was clear from the interviews that there is no one pathway into services that is consistent across jurisdictions, or even within jurisdictions. Even within a state, those in major centres tend to have greater access to bereavement counselling services whereas those in rural and regional areas may rely on their connections with community health services, hospitals or district nursing services as well as local GPs.

**6.2.3 What is the composition of the workforce that provides bereavement services?**

Services for persons with complicated grief are provided by a range of professions such as nurses, social workers, psychologists, counsellors, GPs and specialist doctors. In addition to publicly and privately funded health services, hospitals and NGOs, individual psychologists (often in private practice) are the most likely group to provide support.

The wide range of roles providing bereavement support and assistance with complicated grief was illustrated in the survey results. In palliative care, survey respondents indicated bereavement support is principally provided by social workers, pastoral care workers and nurses. In other types of services (predominantly community based not-for-profit counselling and support organisations), care is predominantly provided by bereavement counsellors and social workers. Other roles that provided support were psychologists, volunteers, medical doctors, memorial committee members and other paid positions.
Two professional groups who appear to spend a significant proportion of their time providing assistance to the bereaved and for which workforce data were available were examined more closely: psychologists and social workers. In total there were 32,700 social workers and 23,144 psychologists employed in the workforce in 2013 in Australia.

Another important workforce group for the provision of specialist bereavement services are ‘bereavement counsellors’ or ‘grief counsellors’. These specially trained counsellors provide bereavement support to persons who have lost a loved one. They provide help during the different stages of grief in particular to persons overwhelmed with loss, grief or trauma. Data specific to the availability of this subgroup of counsellors nationally was not accessible.

If the GP is the gatekeeper to supportive services (e.g. MBS (Better Access) initiative) this tends to medicalise complicated grief and reinforce perceptions that this is an individual problem rather than a social phenomenon. An environment where diagnosis is required to access services is contrary to the self-referral philosophy that underpins many bereavement services.

There are also concerns about progressive reductions in funding of bereavement positions with the risk that this supports cost shifting from state to federal government (and to individuals in the form of payments to private practitioners over and above the Medicare subsidy). Reviews concluding that there is “no evidence” for a particular therapy may be misinterpreted as indicating the therapy does not work, prompting state governments to reduce funded positions.

Grief and bereavement present specific challenges which are different from those associated with depression, anxiety and traumatic stress (although these may also be present as comorbidities). This means that generic treatment models such as Cognitive Behavioural Therapy (CBT) are less suitable. It is highly desirable that people experiencing complicated grief have access to specialist bereavement services wherever possible.

6.2.4 How is the workforce distributed across Australia?

The limitations of workforce data resulted in estimations of the relevant workforce being limited to psychologists and social workers.

Australia wide there are 1.00 psychologists and 1.41 social workers for every 1,000 Australians. However the workforce is unevenly distributed with higher rates of psychologists in major cities and much lower rates elsewhere in Australia. At the same time the demand for the workforce seems to be higher in regional and remote areas compared to major cities as the standardised death rate is higher in rural areas. This workforce distribution reflects similar patterns to those in evidence for most health professional roles in Australia.

6.2.5 What issues does this workforce face now and in the future?

The primary issues identified throughout this project relate to the impact of the expected growth in demand for bereavement related services, generated by the Standardised Death Rate (SDR) and potentially exacerbated by the high numbers of Australians likely to die from dementia related causes in the next 10 – 20 years. This will in turn generate demands for services that may not be readily supplied in regional and remote services.
There may be increased demands upon hospitals and health services (particularly palliative care services) and residential aged care facilities because of the high proportion of deaths that occur in these two locations. Friends and relatives of the bereaved may turn to these facilities for bereavement support because of the prior relationship established during the care of their loved one.

There will be ongoing need for capacity development of the workforce as care for those with complicated grief appears to require specialised skills and considerable experience of bereavement support.

Finally, there appears to be variable understanding among health professionals working in primary health care, the acute and to a lesser extent sub-acute sector of the usual pathway or care trajectory available to people requiring support for complicated grief. A greater shared understanding may result from the documentation of potential care pathways.

6.2.5.1 Recommendations

It is recommended that the Department of Health:

- Promote public awareness and community education about grief and bereavement.
- Support appropriate training about grief, bereavement and prolonged grief for primary care and palliative care health professionals so they are better able to address these issues in practice.
- Recognise that specialised skills are required to effectively treat persons with prolonged grief and associated co-morbidities. This may require specification of skills and expertise in the future.
- Support a range of evidence based models of care for prolonged grief, including those that may increase access for vulnerable populations.
- Facilitate knowledge translation by disseminating the findings of this research into prolonged grief to stakeholders particularly in the primary care, aged care and palliative care sectors (e.g. through an issues paper).
- Document the main pathways that people follow to access prolonged grief services to inform a shared understanding of the trajectories of care among health professionals working in primary care and palliative care sectors.

6.3 Leadership and Governance

Related goals:

- Goal 4: To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.

6.3.1 Are there any outcome indicators currently monitored by organisations providing services for people experiencing complicated grief?

No outcomes indicators to inform or monitor best practice approaches and service models for complicated grief were identified by the evidence appraisal. Five indicators (three process indicators and two outcome indicators) for the psychosocial wellbeing of family carers were...
identified from a recently conducted literature review commissioned by the Australian Commission on Safety and Quality in Health Care.

From the stakeholder interviews there was limited information provided about promising outcome indicators or their application. Outcome indicators were mostly conceptualised in terms of the experience of carers of the bereaved, what is referred to in the context of patients as Patient Reported Outcome Measures or PROMs. Several interviewees saw outcome indicators more in terms of service use, as indicators of system performance.

The most commonly suggested indicator was the ability of the bereaved person to return to normal activities or re-engage with life. One interviewee discussed research underway in Australia to devise and validate a measure of people's recovery from complicated grief. This research team is also engaged in the development of other valid and reliable specialised measures.

There appears to be no agreement on which outcome indicator/s to use for complicated grief and how to best implement this in practice.

**6.3.2 What is the capacity to build on existing systems and integrate appropriate outcome indicators relating to the management of persons experiencing complicated grief and/or the early identification of persons at risk of complicated grief?**

Most services were accepting of the use of outcome indicators to drive quality improvement and were collecting data to monitor a range of things such as completion of advance care plans. There is capacity to build on existing systems (e.g. the Palliative Care Outcomes Collaboration) to capture data for indicators about bereavement care, provided the plethora of logistical issues can be resolved. For palliative care services it was seen as difficult to collect data on people who are not actually patients. For example, the carer is not usually a patient and may not have a medical record. There may also be privacy and confidentiality issues if data is collected about carers when the primary patient is their dying relative.

Few services appear to be using outcome indicators related to carers and none reported outcome indicators specific to complicated grief. It was seen as difficult to develop an outcome indicator without a standard for bereavement care. If the standard is developed first, this could eventually generate an appropriate outcome indicator. Standards would also contribute to more universal evidence-based practice. In the future, indicators might be developed to monitor referral into an intervention and subsequent completion of that intervention or to monitor when people are ready to exit counselling and associated ‘carer reported’ outcomes. The introduction of outcome indicators at this point in time is premature.

**6.3.2.1 Recommendation**

It is recommended that the Department of Health:

- Explore the appropriateness of outcome indicators to monitor individual recovery and service provision, following the development of national standards to guide good practice.

**6.4 Capacity and Capability**

Related goals:
Goal 5: To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

6.4.1 Where is good practice occurring and what are some evidence based examples of good practice?

The fact that palliative care services in most parts of Australia appear to offer a very similar level of follow-up care for the bereaved is likely to be related to efforts by services to meet recognised standards of care. One jurisdictional representative specifically referred to the National Palliative Care Standards when describing the care provided. Standard 8 specifically addresses bereavement support. This standard aims to ensure that “formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.” The focus is on providing emotional and spiritual support relating to loss and grief to the patient, their carer/s and family from the moment when a life limiting illness is diagnosed. The importance of providing ongoing support based on self-identified need to the carer/s and family is also stressed.

For specialist palliative care services to successfully meet this standard (at a minimum), they must have policies and procedures for the provision of a bereavement support program that includes relevant training to staff and volunteers. In addition, they should provide a directory of professional counselling resources. Level three services must also have available experts in psychology and psychiatry related to grief, loss and bereavement for referral in situations involving complex needs. They must also provide a designated appropriately qualified person to coordinate the support provided to the patient’s family and carer/s before and after the death.

6.4.2 What do existing sources of information report about the experience of the bereaved person in relation to their interactions with the broader health system?

Several additional data sources were investigated for information about the experience of the bereaved person in relation to their interactions with the broader Australian health system, but ultimately no relevant information was found or data was not available or accessible.

In England, information on bereaved people’s views on the quality of care provided to a friend or relative in the last three months of life is collected via the National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation of Services). The survey has been administered annually by the Office for National Statistics since 2011. Approximately 49,000 adults that have died in England are selected from their deaths registration database and a questionnaire is sent by post to the person that registered the death of the deceased (usually a relative or friend of the deceased) between 4 and 11 months after the death. Information from the survey is used by the Department of Health and the NHS (among others) to inform policy decisions and evaluate the quality of end-of-life care (Office for National Statistics, 2016). The VOICES questionnaire has been used in the UK and internationally and has been adapted for and used in specific populations based on disease process or location. The standard 144-item questionnaire was revised and shortened to the 58-item VOICES Short Form, a validated sensitive measure of experiences of end-of-life care (Hunt et al., 2011). The effectiveness of an adaptation of the VOICES questionnaire in the New Zealand social setting for both Māori and non-Māori has recently been piloted (Frey et al., 2016). No comparable survey in the Australian context was identified.
6.4.3 What do existing sources of information report about the experience of the patient with a life-limiting illness; their family/carers and treating health professionals in relation to end-of-life care?

There is a large literature relating to end-of-life care. A full review of information that reports about patient or family/carer and treating health professionals experience was beyond the scope of this project. A recent Rapid review of the literature to inform the development of quality and safety indicators for end-of-life care in acute hospitals (Masso et al., 2016) was completed for the Australian Commission on Safety and Quality in Health Care. The context for this rapid review arose from the Australian Commission on Safety and Quality in Health Care: Safety and quality of end-of-life care in acute hospitals: a background paper published in 2013 and the National consensus statement: essential elements for safe and high-quality end-of-life care published in 2015. The key points from these documents (as summarised by Masso et al., 2016) are provided below:

- The overall focus of acute hospitals tends to be on diagnosis and treatment leading to discharge rather than consideration of end-of-life issues (e.g. conversations about goals of care and limitations on treatment).
- Making the shift from a curative approach for treatment to a focus on end-of-life care is difficult and inherently uncertain.
- About half the population dies in hospital and many people experience multiple hospitalisations towards the end of life, typically involving many different health providers.
- Much of the responsibility for end-of-life care rests with relatively inexperienced staff.
- Acute care is often targeted to a specific organ or disease group rather than taking a more holistic approach.
- There is evidence that end-of-life care can be ‘outsourced’ to others (e.g. medical emergency team, palliative care team, intensive care team).
- Clinicians may avoid having conversations with patients and families about end of life and when such conversations do take place the quality of communication can be variable.
- Nurses can experience considerable moral distress from participating in the provision of care which they perceive to be futile while at the same time feeling that they are unable to influence the plan of care.
- Despite improvements such as the expansion of palliative care services and the introduction of advance care planning (the uptake of which is still relatively limited), there are gaps in the provision of high-quality end-of-life care (Australian Commission on Safety and Quality in Health Care, 2013).
- There are 10 ‘essential elements’ to ensuring safe and high-quality end-of-life care, of which five relate to the delivery of care: patient-centred communication and shared decision-making; teamwork and coordination of care; clear goals of care based on patients’ wishes; using triggers to recognise patients approaching the end of life; and responding to patient concerns (Australian Commission on Safety and Quality in Health Care, 2015).

The role of primary health care professionals was not a focus of this research and this is clearly an important group as GPs are frequently at the front-line in identifying patients who
potentially require bereavement support. PHNs may have a useful contribution to make to local communities and primary health care professionals through providing current information about available bereavement support services.

**6.4.3.1 Recommendation**

It is recommended that the Department of Health:

- Maintain implementation of the current National Palliative Care Standards and identify opportunities in the forthcoming revision to incorporate initiatives relating to prolonged grief.
- Encourage PHNs to establish local registries of grief and bereavement support services to improve referral practices and service accessibility (e.g. through utilising the National Health Services Directory or HealthPathways program).
7 Recommendations

Preliminary recommendations provided in a draft version of this final report were reviewed by a mix of clinical experts, researchers and policy officers at a facilitated workshop. Based on input and feedback from these experts, the report was subsequently refined and revisions to the recommendations were made. The final recommendations are included in Section 6 of this report (linked with the research questions to which they corresponded and aligned with the goals of the National Palliative Care Strategy 2010).

These recommendations are reproduced below and are clustered under four sub-headings:

- Policy
- Service delivery
- Workforce/capacity development
- Research.

They are also categorised by priority, short-term (S-T) reflecting a recommendation potentially actionable within 6 – 24 months and long-term (L-T) recommendations which will require investment over several years.

Table 25 Recommendations

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Policy</strong></td>
<td></td>
</tr>
<tr>
<td>1. Use the term ‘prolonged grief’ consistently in palliative care service policy and planning, and review this term when the International Classification of Diseases (Eleventh Revision) is adopted by the Australian Government.</td>
<td>S-T</td>
</tr>
<tr>
<td>2. Maintain implementation of the current National Palliative Care Standards and identify opportunities in the forthcoming revision to incorporate initiatives relating to prolonged grief.</td>
<td>S-T</td>
</tr>
<tr>
<td>3. Develop national standards to guide good practice in assisting people who may be experiencing prolonged grief.</td>
<td>L-T</td>
</tr>
<tr>
<td><strong>Service delivery</strong></td>
<td></td>
</tr>
<tr>
<td>4. Recognise that prolonged grief is an identifiable condition and integrate actions to support people with prolonged grief in relevant health and social program service delivery frameworks e.g. primary care, mental health care.</td>
<td>L-T</td>
</tr>
<tr>
<td>5. Support a range of evidence based models of care for prolonged grief, including those that may increase access for vulnerable populations.</td>
<td>L-T</td>
</tr>
<tr>
<td>6. Promote public awareness and community education about grief and bereavement.</td>
<td>L-T</td>
</tr>
<tr>
<td><strong>Workforce/capacity development</strong></td>
<td></td>
</tr>
<tr>
<td>Recommendation</td>
<td>Priority</td>
</tr>
<tr>
<td>----------------</td>
<td>----------</td>
</tr>
<tr>
<td>7. Encourage PHNs to establish local registries of grief and bereavement support services to improve referral practices and service accessibility (e.g. through utilising the National Health Services Directory or HealthPathways program).</td>
<td>S-T</td>
</tr>
<tr>
<td>8. Facilitate greater education and understanding of grief and bereavement, including prolonged grief, in undergraduate curricula of health professionals.</td>
<td>L-T</td>
</tr>
<tr>
<td>9. Support appropriate training about grief, bereavement and prolonged grief for primary care and palliative care health professionals so they are better able to address these issues in practice.</td>
<td>L-T</td>
</tr>
<tr>
<td>10. Recognise that specialised skills are required to effectively treat persons with prolonged grief and associated co-morbidities. This may require specification of skills and expertise in the future.</td>
<td>L-T</td>
</tr>
</tbody>
</table>

**Research**

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Facilitate knowledge translation by disseminating the findings of this research into prolonged grief to stakeholders particularly in the primary care, aged care and palliative care sectors (e.g. through an issues paper).</td>
<td>S-T</td>
</tr>
<tr>
<td>12. Document the main pathways that people follow to access prolonged grief services to inform a shared understanding of the trajectories of care among health professionals working in primary care and palliative care sectors.</td>
<td>S-T</td>
</tr>
<tr>
<td>13. Support research and evaluation about the impact of interventions designed to enhance end-of-life care and prepare and support carers for bereavement (e.g. advance care planning, family meetings etc.).</td>
<td>S-T</td>
</tr>
<tr>
<td>14. Promote high quality research (including longitudinal studies) aimed at strengthening the evidence base for current and emerging approaches to bereavement support and prolonged grief.</td>
<td>L-T</td>
</tr>
<tr>
<td>15. Explore the appropriateness of outcome indicators to monitor individual recovery and service provision, following the development of national standards to guide good practice.</td>
<td>L-T</td>
</tr>
</tbody>
</table>
8 References


Australian Centre for Posttraumatic Mental Health (2012) Mental Health Advice Book for treating veterans with common mental health problems. Department of Veterans’ Affairs.


Australian Institute of Health and Welfare (2015b) GRIM (General Record of Incidence of Mortality) books 2013. Canberra: AIHW.


Research into services and needs for people experiencing complicated grief: Final report


Palliative Care Australia (2005) Standards for providing quality palliative care for all Australians. Canberra: Palliative Care Australia.


Palliative Care Outcome Collaboration (2016) PCOC longitudinal database [data file]. Unpublished: Australian Health Services Research Institute, University of Wollongong.


## Appendix 1  Data matrix

<table>
<thead>
<tr>
<th>Research Objectives</th>
<th>Data sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review the evidence on the impacts, including productivity impacts (e.g. loss of productivity), of complicated grief on a bereaved individual and those close to that person.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: Yes, Survey data: No, Existing data collections: No, Workshop input: No</td>
</tr>
<tr>
<td>Undertake a gap analysis of needs and current resources/services/structures for people experiencing complicated grief.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: Yes, Survey data: No, Existing data collections: No, Workshop input: No</td>
</tr>
<tr>
<td>Map national complex bereavement activities and services.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: No, Survey data: No, Existing data collections: Yes, Workshop input: No</td>
</tr>
<tr>
<td>Identify workforce gaps and issues.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: Yes, Survey data: No, Existing data collections: Yes, Workshop input: Yes</td>
</tr>
<tr>
<td>Analyse the role and effectiveness of advance care planning in preventing or minimising the onset or effects of complicated grief.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: Yes, Survey data: No, Existing data collections: No, Workshop input: No</td>
</tr>
<tr>
<td>Identify examples of good practice.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: Yes, Survey data: No, Existing data collections: No, Workshop input: No</td>
</tr>
<tr>
<td>Identify likely triggers or challenge points for people entering, or staying in, complicated grief.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: Yes, Survey data: No, Existing data collections: No, Workshop input: No</td>
</tr>
<tr>
<td>Identify potential outcome indicators that could be used by service providers and policy makers to inform and/or monitor best practice approaches and service models.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: Yes, Survey data: No, Existing data collections: No, Workshop input: No</td>
</tr>
<tr>
<td>Describe examples for service providers and policy makers to inform or monitor best practice approaches and service models.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: Yes, Survey data: No, Existing data collections: No, Workshop input: No</td>
</tr>
<tr>
<td>Describe case studies that could function as guidance for clinical practice.</td>
<td>Departmental documentary sources: No, Literature: No, Key stakeholder interviews: Yes, Survey data: No, Existing data collections: No, Workshop input: No</td>
</tr>
</tbody>
</table>
Appendix 2  Evidence appraisal search strategy

Searching of MEDLINE, CINAHL, PsychINFO and Google Scholar was restricted to English language papers in the period 2006 to 2016. An initial list of search terms was developed and then refined using the MeSH on Demand function available on the Medical Subject Headings website. The final set of search terms are summarised below.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Search terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phenomenon of interest - bereavement</td>
<td>Bereave* or grief or grieving or mourn*</td>
</tr>
<tr>
<td>Phenomenon of interest - complicated</td>
<td>Complicated or prolonged or pathological or abnormal or distorted or morbid or maladaptive or atypical or intensified or unresolved or neurotic or dysfunctional or chronic or delayed or inhibited</td>
</tr>
<tr>
<td>Context</td>
<td>Palliative care, terminal care, hospice care</td>
</tr>
<tr>
<td>Search terms for specific research questions</td>
<td>Risk factors; protective factors; quality indicators, health care; quality indicators; outcome assessment (health care); patient outcome assessment; employment; advance care planning; advance directives; primary prevention; secondary prevention; follow-up studies</td>
</tr>
</tbody>
</table>

Potentially useful citations were downloaded into an EndNote database which was used to manage the citations and keep track of citations which had been culled. Database searching was supplemented with snowball searching (pursuing references of references and tracking citations forward in time). The following types of papers were excluded:

- Literature relating to bereavement where the bereaved person was a child.
- Bereavement involving violent or sudden death (e.g. homicide, suicide).
- Research in developing countries.

Literature reviews were included if they met at least two of the following criteria: (1) the search terms used were detailed in the paper; (2) the search included at least PubMed/MEDLINE or PsychINFO; (3) the methodological quality of included studies was assessed. Decisions about whether to include or exclude individual studies or literature reviews were based, at least in part, on judgements about the relevance to palliative care or end-of-life care (which provided the context for the evidence appraisal). In some instances this was relatively straightforward but in other instances it was more difficult (e.g. a literature review including a wide variety of studies, only some of which were directly relevant to palliative care or end-of-life care).

Non-academic sources were searched using Google with various combinations of the search terms, which identified 1,142 websites of potential relevance. Many of these sources had already been identified from searching the peer-reviewed literature. The remainder largely consisted of comments or opinion pieces by individuals, information about clinics and other bereavement services, and a small number of documents (e.g. guidelines) which did not have an explicit evidence base. The only literature review identified in the non-academic sources was the systematic review of the literature on complicated grief commissioned by the Australian Government Department of Health and Ageing just over a decade ago (Kristjanson et al., 2006).
Database searching identified 1,166 articles of potential relevance to the research questions, of which 171 were downloaded into an EndNote database after review of the title and, in some cases, the abstract. Snowball searching and searching non-academic sources identified 78 additional references, resulting in a total of 249 references, of which 133 were excluded after review of the abstract or full-text. The remaining references were included in the evidence appraisal.

Finally, a small number of additional papers were added to the evidence appraisal following the workshop, as suggested by key experts.
Appendix 3  Survey methodology

The survey was developed and managed using REDCap (Research Electronic Data Capture) hosted at the University of Wollongong. REDCap is a secure, web-based application designed to support data capture for research studies, providing:

1. an intuitive interface for validated data entry;
2. audit trails for tracking data manipulation and export procedures;
3. automated export procedures for seamless data downloads to common statistical packages; and
4. procedures for importing data from external sources (Harris et al., 2009).

REDCap was used as the application speeds the survey process because it is web based and accessible on multiple devices, survey design is intuitive, data collection secure and it also has high data export utility which facilitates analysis by statistical analysis packages such as SAS, SPSS and R. In accordance with ethical requirements, robust security and access management controls were in place for this web-based application.

A service provider list was constructed for the survey based on advice obtained through the expert interviews and via an intensive web-based search for organisations engaged in the provision of bereavement services. A range of service directories were reviewed to identify organisations that should be included in the survey (these included the NSW Human Services Network ServiceLink Directory, Infoxchange National Service Seeker Directory, Grieflink’s Directory, Australian Centre for Grief and Bereavement’s list of ‘Other Bereavement Services’ and the NSW Bereavement Counselling Services Directory). In several instances organisations identified via this method were telephoned to check the accuracy of organisational email addresses or confirm the most appropriate person to receive the survey. The timeframe of this project meant it was unrealistic to compile a complete list of all service providers in Australia and subsequently develop a sampling framework. This resulted in several exclusions. A limitation of this approach is the potential for bias as the group selected for inclusion in the survey may not be representative of all bereavement service providers across Australia, particularly sole private practitioners.

Service providers were grouped based on characteristics, for example:

- Geographic area of service provision e.g. whether they were national/state/territory based.
- Client focus e.g. generic bereavement counselling service vs services with focus on a specific population group such as parents who have lost a child or persons bereaved by suicide.

This resulted in a listing of 151 service providers. Due to concerns about the sample size and likely response rate it was decided to extend the survey to palliative care services that were currently members of the Palliative Care Outcomes Collaboration, which resulted in another 123 organisations added to the service provider list. The final sample that received the survey was 274 (refer to Table 27 below). Most invitees were from NSW (78/274, 28%). All states and territories were represented, with Queensland and Victoria being the second and third highest represented states respectively.
The importance of pre-testing questionnaires has been identified in the literature (Hunt et al., 1982). Prior to distribution, the survey was pilot tested internally within the Australian Health Services Research Institute. Technical and cognitive testing was performed with five health service researchers known to the project team. Following pilot testing, the wording of some questions was revised for clarity, as was the question sequence.

The survey was distributed on 27 September 2016 and was open for four weeks. Invitations were emailed from the project team from a shared mailbox (complicated-grief@uow.edu.au). This shared mailbox was set up for the sole purpose of administering the survey, as well as communicating with participants as required (e.g. responding to queries). Only members of the project team had read/write/send permissions for this shared mailbox. The invite included a link to the Participant Information Sheet which summarised the purpose of the research and what was requested of participants. Three email reminders were sent to non-respondents at weekly intervals to increase the response rate. Thirty-two non-respondents were also contacted by telephone to encourage them to complete the survey.

Survey responses were downloaded from REDCap into Excel. Data quality checking occurred and the output was then analysed in Excel.

<table>
<thead>
<tr>
<th></th>
<th>Palliative care services</th>
<th>Other services</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Capital Territory</td>
<td>2</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>New South Wales</td>
<td>26</td>
<td>52</td>
<td>78</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>2</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Queensland</td>
<td>32</td>
<td>21</td>
<td>53</td>
</tr>
<tr>
<td>South Australia</td>
<td>15</td>
<td>12</td>
<td>27</td>
</tr>
<tr>
<td>Tasmania</td>
<td>7</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Victoria</td>
<td>19</td>
<td>30</td>
<td>49</td>
</tr>
<tr>
<td>Western Australia</td>
<td>20</td>
<td>10</td>
<td>30</td>
</tr>
<tr>
<td>National</td>
<td>0</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>123</strong></td>
<td><strong>151</strong></td>
<td><strong>274</strong></td>
</tr>
</tbody>
</table>
Appendix 4  Mapping of complex bereavement activities and services

A mapping of complex bereavement services was provided to the Department of Health as a searchable file in a separate Excel spreadsheet. It presents information on bereavement services in tabular format and classifies services by location and sector. It includes:

- Name of service/organisation, location/organisational URL
- Key contact (name and contact details).

A range of other publicly available service directories may also provide additional information on bereavement services, including:

- NSW Human Services Network ServiceLink Directory
- Infoxchange National Service Seeker Directory
- Grieflink’s Directory
- Australian Centre for Grief and Bereavement’s list of ‘Other Bereavement Services’
- NSW Bereavement Counselling Services Directory.
## Appendix 5  Online case studies

<table>
<thead>
<tr>
<th>Source</th>
<th>URL</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Medical Association</td>
<td><a href="https://www.bma.org.uk/features/agooddeath/">https://www.bma.org.uk/features/agooddeath/</a></td>
<td>The winner of the 2016 BMA writing competition, this is a story of ‘A Good Death’, focused on end-of-life care and physician-assisted dying</td>
</tr>
</tbody>
</table>