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**title** **Integrated information networks to support end-of-life care in general practice**

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## Key messages

- We have clinical information on end-of-life (EOL) care delivered by specialists and in hospitals, but know virtually nothing about the conduct of EOL care in the Australian general practice (primary care) setting.
- Primary care clinical information is difficult to access. Information sources that are accessible provide high-level practice and practitioner level data, but do not provide details on the complex clinical management of these vulnerable patients.
- This gap in our knowledge around EOL care in the primary care setting has several consequences:
  - we do not know how many people are cared for in the community and therefore cannot determine whether the right people are getting the right care in the right place and time;
  - we cannot be certain that EOL care in the community meets acceptable standards and these standards are not currently well defined;
  - we cannot judge whether the care received represents equitable access to appropriate, high quality care;
  - we cannot determine whether consumers are able to exercise choice or autonomy; and
  - we do not know whether services are cost-effective.
- This limits our ability to:
  - develop proactive, cost-effective and informed primary health policy on EOL care in the community;
  - monitor changes in health care delivery over time; and
  - implement quality improvement programs.
- Development of an integrated information network for the primary care management of people in the final 12 months of life would allow:
  - key benchmarks for EOL care in the primary care setting to be identified;
  - better support for quality improvement;
  - increased capacity of current chronic disease management; and
  - better support for community-based EOL care.

## Executive summary

Australia's population is ageing and with this trend comes the burden and complexity of increasing physical illness and disability. This burden escalates as a person nears death and as a consequence, the cost of care becomes disproportionately high in the last year of life. Currently, end-of-life (EOL) care is relatively siloed and people are often cared for by multiple health professionals according to their diagnoses or the bodily system that is most affected.

Specialist palliative care has evolved to care for people with more acute clinical needs, predominantly in people with a cancer diagnosis. However, most people at EOL require a different form of care.

The majority of EOL care is provided in the community by general practitioners (GPs) and other primary care services (e.g. community nurses), whether they recognise EOL or not. GPs have a unique role to manage, coordinate and integrate care and are a critical part of the network of care for people with advanced chronic diseases. With sufficient support and training, GPs and other primary care services, when available, are able to provide appropriate EOL care for the majority of people.

We have information about where people are cared for and health outcomes in the context of specialist palliative services, but there is a striking lack of population-based and nationwide data on the scale and quality of primary EOL care in Australia. We do not have a clear picture of the scope of such care or how GPs interact with specialists and hospital-based interventions. More comprehensive information is needed to understand how effectively this care is delivered at the EOL and to inform how primary practitioners can be supported to provide optimal care.

Systematic data collection can be used to inform and promote improvements in the quality of EOL care. However, processes which facilitate the capture, collection and analysis of comprehensive case-based EOL care data are currently not available in general practice. There are also no clear mechanisms for feedback on the quality of care. Routinely collected data on healthcare resource utilisation in community / primary care is vital.

This Issues Brief makes a number of key recommendations which will be essential to addressing the gaps in our knowledge of EOL care in general practice. These include:

- developing an integrated information network to address the knowledge gap in the primary care management of people in the final 12 months of life;
- identifying key benchmarks for EOL care in general practice and developing pathways for feedback to the profession;
- collecting and collating individual case information in general practice relating to EOL care; and
- developing and sharing a Key Information Statement about patients identified as being at risk of dying, to guide decision making and patient management.

## 1 Background

### 1.1 *The current context of palliative and end-of-life care in Australia*

Palliative care is broadly defined as an approach to care that improves the quality of life of all patients and their families facing the problems associated with any life-limiting illness (World Health Organization, 2018). Through early identification of needs, safe and reliable assessment and treatment, palliative care aims to address physical, psychosocial and spiritual concerns (World Health Organization, 2002).

#### **Life expectancy and number of deaths in Australia**

- In 2016, 3.7 million Australians were aged 65 and over, constituting 15% of the total population. This figure is projected to increase to 22% by the year 2056 (Australian Institute of Health and Welfare, 2018).
- Australian males aged 65 years in 2012 are expected to live until they are 84.1 years, and females to 87 years (Australian Institute of Health and Welfare, 2014).
- In 2016, the number of deaths registered in Australia was 158,504 (Australian Bureau of Statistics, 2018). In 2056, this is projected to increase to 320,600 (Australian Bureau of Statistics, 2013); a greater than 200% increase.
- The majority, around 67%, of deaths in Australia occur in people between the ages of 65 and 95 (Australian Bureau of Statistics, 2017).

In Australia, our ageing population has resulted in a range of healthcare challenges, including a growing demand for equitable and appropriate end-of-life (EOL) and palliative care. In the 12 month period prior to death, health demands grow rapidly, with a marked increase in both hospital and emergency service use (Rosenwax et al., 2011). This increase in the use of both services and resources corresponds to a substantial rise in health care expenditure (Kardamanidis et al., 2007).

Historically, EOL and palliative care focussed on supporting people with cancer diagnoses. More than three quarters (76%) of people who accessed specialist palliative care services in 2016-17 had cancer as their primary diagnosis (Allingham S et al., 2017). However, only 19% of people over 70 die from cancer (Gill et al., 2010).

Older people and those with life-limiting illnesses that are not cancer related often suffer with increasingly burdensome symptoms, yet fall outside the scope of standard specialist palliative care (Mitchell et al., 2010). The EOL care needs of this population (with conditions other than cancer) and the challenges in providing the best possible care, is increasingly recognised and a focus of health policy (ACSQHC, 2013). Yet our ability to effectively develop services and improve care is hampered by a lack of knowledge about community-based patients at EOL and the sort of care that is provided.

For the most part, EOL and palliative care is being delivered at different levels within the health system, with much of the care being provided routinely by disease specific specialists and at the general practice and community level. Where more complex problems are evident, patients obtain input from specialist palliative care services. However, only a minority of patients require exclusive

care from them (the palliative care specialists) (Palliative Care Australia, 2018). At present, many general practitioners (GPs) are providing EOL care whether or not they recognise that their patient is likely to die in the near future (Mitchell et al., 2010, Gómez-Batiste et al., 2014).

## ***1.2 The majority of end-of-life care in Australia is community based***

GPs are the first point of contact for patients. Despite the increasing demand for acute services for people with life-limiting illnesses, the majority of care in the last 12 months of life is provided in the community and is coordinated by GPs (Hinton, 1994, Murray and Sheikh, 2008), with additional support from medical specialists. General Practitioners have a pivotal role managing patients' symptoms, planning and coordinating care, and collaborating with community-based support services for older people and those with advanced chronic diseases (NHHRC, 2009).

In Australia, in rural communities, GPs provide EOL medical care out of necessity, due to the limited access to specialist services (Johnson et al., 2014). In contrast, in major population centres, patients with cancer often bypass GPs, transferring instead to palliative care services who may not engage or utilise the skills of the GP. This is despite most GPs wanting to play a role in EOL care for their patients (Rhee et al., 2008). At present, there is no routinely collected data available to explore the impact of these different care pathways on access to, or the quality of, EOL care for these patients.

The long-term doctor-patient relationship often means that GPs are more familiar with patients' medical history, care preferences and other personal information (such as family context) compared with other health professionals. This means that GPs are well placed to identify people who may benefit from a palliative approach to care and to provide appropriate care for patients and their caregivers in their life context (Murray and Sheikh, 2008, Hinton, 1994). The challenge is to understand and make effective use of this knowledge and skill in a health system that has no universal mechanisms in place for systematically tracking or assessing EOL care in the primary care setting.

## 2 With adequate data collection, end-of-life care in general practice and primary care can be better managed

Although GPs form a core component of management of EOL care in Australia (Hanks et al., 2008), the nature and quality of care delivered by this sector remains largely unknown. Consequently, there is an imperative for policymakers and service providers to understand the “how, who, when and where” aspects of GP management of people at the EOL and how this care overlaps with other primary care providers. Once collected, this information can then be used to inform the development of effective models of care that meet the EOL needs of the aging Australian population.

In the current context of limited health care resources, it is crucial to consider cost, as well as health and quality of care outcomes, when assessing the relative merits of funding alternative models of care. There is limited evidence on the costs and cost-effectiveness of different EOL models of care to inform healthcare funding decisions, particularly in the local setting (García-Pérez et al., 2009, McCaffrey and Currow, 2015). Consequently, routinely collected data on healthcare resource utilisation in the community / primary care setting is vital to inform modelling of the costs and consequences of alternate EOL models of care.

Processes for routine collection of patient reported outcomes in specialist palliative care services and reporting of performance against pre-established benchmarks has been adopted by the Palliative Care Outcomes Collaboration (PCOC).<sup>1</sup> PCOC collects data from about 90% of Australia’s specialist palliative care services and is the only program in Australia which provides a current, consistent source of clinical practice data about ongoing EOL care.

Information collected by PCOC about the patient’s palliative care journey, their functional capacity and the presence of pain and other symptoms is used to inform specialist management. Specialist palliative care services are also supported to use their data for quality improvement. This has led to system-wide improvements in specialist palliative care more generally and a reduction in the variability between services due to benchmarking (Currow et al., 2015, Eagar et al., 2010).

At present, there is no routine collection of data about EOL care practices, outcomes and costs of EOL care or consumer experiences available in the primary care and community setting (Australian Institute of Health and Welfare, 2016). This has resulted in difficulties in the development and evaluation of service delivery and also in the progress of evidence-informed policies.

Relevant, timely information on EOL and palliative care is therefore essential to assess current practice, to inform decisions about service delivery, for quality improvement, and to track outcomes of interventions across different levels of the healthcare system.

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<sup>1</sup> Palliative Care Outcomes Collaboration: <http://www.pcoc.org.au>.

### 3 Systematic monitoring and establishing benchmarks in end-of-life care are necessary to support quality improvement in general practice and primary care

There are varying levels of GP involvement in the management of EOL care in Australia (Hanks et al., 2008) but the type and quality of this care remains largely unknown. Numerous programs such as the End of Life Directions for Aged Care (ELDAC) program<sup>2</sup>, Decision Assist<sup>3</sup> and Caresearch's online training for GPs<sup>4</sup> aim to build the palliative care skills of GPs and support them to provide EOL care. However, the lack of any routinely collected data makes the impact of these programs on the quality of EOL care in the primary care setting difficult to evaluate.

Although there are programs which aim to improve systems and processes of EOL care, there is no systematic approach to routine monitoring of the care provided to people at the EOL in the primary care setting, or indeed in any setting in Australia outside of specialist palliative care services.

Audit and feedback mechanisms with the inclusion of established benchmarks have been identified as the most effective way of improving clinical practice (Hysong, 2009, Ivers et al., 2012). Given the absence of information around the care of people in primary care at the EOL, a mechanism to cost-effectively obtain relevant data from a consistent source is required.

#### 3.1 Development of an Australian sentinel network to collect data on end-of-life care is essential

In Europe, the GP Sentinel Monitoring End of Life Care (EURO SENTIMELC) project (Van den Block et al., 2008) is responsible for collecting retrospective data about patient deaths from GPs who are members of a sentinel practice network. Weekly reports containing data on any death that occurred during that week within the practice are generated by GPs and collected by EURO SENTIMELC (Van den Block et al., 2007). We propose that a similar sentinel network should be implemented in Australia to better inform EOL care in the general practice and primary care setting.

Development of performance benchmarks, based on data collected through the sentinel network, around key outcomes in EOL care for general practice will help inform quality improvement (Ivers et al., 2012). Data linkage using de-identified information from other care providers and from family carers will also assist in informing policy and service development (Hall et al., 2018).

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<sup>2</sup> End of Life Directions for Aged Care (ELDAC) <https://www.eldac.com.au/tabid/4895/Default.aspx>

<sup>3</sup> Decision Assist <https://www.advancecareplanning.org.au/ACP-projects/about-decision-assist>

<sup>4</sup> Caresearch for GPs <https://www.caresearch.com.au/caresearch/tabid/3648/Default.aspx>



## 4 Data is essential for informing the development of end-of-life care policies in general practice and primary care

Evidence-based policy and practice is central to the delivery of high-quality EOL care. Australian policy documents such as the 2010 National Palliative Care Strategy (Australian Health Ministers, 2010), the draft revised Strategy (Urbis, 2017) and the recent Council of Australian Governments communiqué (COAG Health Council, 2016) all promote equity, access and the capacity of all sectors of health (including primary care) to enhance the quality of EOL care for all Australians.

To date, policy development around enhancing the capacity of general practice to manage EOL care has generally been done in the absence of reliable or complete information. Consensus guidelines for optimal palliative care (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2015, National Consensus Project for Quality Palliative Care, 2013, National Institute for Health and Care Excellence, 2011) have identified important measures that will apply to general practice:

- identification of palliative care patients in a timely manner;
- honest and timely communication with patient and family;
- personalised care;
- coordinated care; and
- a focus on meeting physical and psychological needs.

In Australia, frameworks for EOL and palliative care have also been developed at state levels to provide guidance on how EOL care should be optimally delivered (State of Victoria, 2016, WA Cancer and Palliative Care Network, 2016). These documents recognise that palliative care is the shared responsibility of all health professionals across care settings. However, no EOL care standards specific to primary health care are available in Australia to direct this type of care in general practice.

### 4.1 Key information at the end-of-life to assist integrated care

One of the fundamental goals of integrated, co-ordinated, EOL care is to support people at risk of dying and to share information with other carer organisations (Capurro et al., 2014).

In the United Kingdom, concerns over poor inter-agency communication has resulted in the development of a number of Electronic Palliative Care Coordination Systems (EPACCS) (Department of Health, 2008). These multifunctional systems aimed to improve coordinated care across all potential providers of care at the end of life by using real-time information about patients' condition and care arrangement (Petrova et al., 2016).

Unlike registers or databases which focus on collecting data only for quality assessment, improvement and research, EPACCS aims to store a dynamic record of a patient's condition, treatment, wishes and preferences. They also enable advance care planning and accumulate data for service evaluation, quality improvement and research (Petrova et al., 2016, Millington-Sanders et al., 2013, Pringle et al., 2014).

The Scottish Key Information Summary (KIS) electronic record system is an EPACCS which allows

selected parts of the GP electronic patient record to be shared (with patient consent) with the wider NHS using a template within the GP clinical system (Tapsfield et al., 2016). General Practitioners are encouraged to identify patients with the most complex health and social care needs, including those approaching the end of life, and to prepare a KIS. Documentation of a KIS may be triggered by events like multiple acute hospital presentations or more than one admission in a short time.

The KIS captures key information about the medical diagnoses, current management and anticipatory care plans that is vital to support out-of-hours decision-making and prevent inappropriate hospital admission. Patients with a KIS have fewer hospitalisations and are less likely to die in hospital (Tapsfield et al., 2016).

In the Australian context, the lack of population-based and nationwide data on the scope and quality of primary EOL care requires a new approach to information collection and application. We need integrated information systems capable of targeting the most appropriate and cost-effective care for people with complex chronic diseases. A similar instrument to KIS could be developed and placed on the Australian My Health Record. This would allow systems to be developed that promote prompt identification of risk of deterioration or escalating burden of need. This information could also be shared within care teams to support integrated EOL care. Such a system would be used for service evaluation, quality improvement and policy development.

## 5 Recommendations

### ***5.1 Build an integrated information network in the primary care management of people in the final 12 months of life.***

An integrated information network will involve establishing links with an existing or “purpose-built” sentinel GP network, development of a centralised EOL database incorporating a mechanism for routine data collection on care, and pathways for feedback of outcomes data to GPs to inform practice improvement. Linking the GP data with feedback from carers and other primary care services will also provide a more complete picture of community-based care.

### ***5.2 Identify key benchmarks for end-of-life care in general practice and develop pathways for feedback to the profession.***

This recommendation relates to the analysis of collected clinical data and will be developed with reference to available guidelines, key stakeholders and exemplars in primary care. Consistent benchmarks can be developed to support care planning and guide practice improvements. Audit and feedback processes has been shown to be the strongest evidence-based means of improving clinical and organisational practice (Hysong, 2009, Ivers et al., 2012).

### ***5.3 Develop methods of timely identification of people at risk of increased needs and/or dying within the foreseeable future.***

Timely identification of people at risk of dying allows adequate time to plan, record their wishes in Advance Health Directives, and to educate and empower carers to manage EOL care, including clinical crises that might occur. This requires reliable screening procedures which can be developed and incorporated into current clinical software to facilitate identification of people whose condition is deteriorating and who is approaching EOL .

### ***5.4 Develop Key Information Summaries for patients identified as being at risk of dying and make it a key element of the My Health Record.***

A Key Information Summary can be developed and placed on the My Health Record to prompt identification of risk of deterioration or escalating burden of need and for this information to be shared within care teams.

### ***5.5 Increase the capacity of existing chronic disease and mental health management plans and programs to support community-based end-of-life care.***

There is a perception amongst a number of GPs that elements of the current Medicare system do not adequately support them in the provision of palliative care. However, it is acknowledged that there are existing chronic disease and mental health management programs that could be used to support GPs in the care of patients at the EOL. For example, the *Chronic Disease Management (formerly Enhanced Primary Care)—GP services* on the Medicare Benefits Schedule fund GPs to plan and coordinate the health care of patients with chronic or terminal medical conditions.<sup>5</sup> Education for general practices about how the existing tools can be used to support EOL care planning and provision would make them available to more people when they are needed. Evaluation of the use of these programs needs to be undertaken to inform their implementation for palliative care in the general practice setting.

## **6 Conclusions**

General Practitioners are an important part of the network of care for people with advanced chronic diseases. With support and training, GPs are able and uniquely well-placed to provide appropriate care for the majority of people at the EOL. However, we currently lack population-based and nationwide studies or data sources relating to primary EOL care in Australia. This limits our ability to develop an effective and informed public health policy on EOL care in the community. We are also currently unable to properly monitor changes in health care delivery over time or to develop effective quality improvement programs.

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<sup>5</sup> <http://www.health.gov.au/internet/main/publishing.nsf/content/mbsprimarycare-chronicdiseasemanagement>

Accessing information about EOL care provided within the community is challenging due to the fragmented nature of primary care and the private ownership of many general practices and other primary care services. Questions relating to data ownership, and the ethics and governance of data sharing, must be addressed to capture information from multiple sources successfully and provide a complete picture of the care provided within the community at the end of life.

There is an increasing imperative to demonstrate the value of EOL care as the demands on health and social care systems continue to rise. With limited health care resources available, decision-makers need to consider costs as well as health outcomes and quality when assessing the relative merits of programs and models of EOL care.

The nexus of rapidly increasing populations of older people with an escalating burden of chronic and complex illness means that “care as usual” is not an option. The role of GPs in providing EOL care will be enhanced by an understanding of what happens in primary care now. General Practitioners already routinely deal with people and their care needs at the EOL, whether they realise it or not and whether they are prepared for it or not.

An information network for GP care at end of life will provide a strong and justifiable evidence-base for health policy, will allow the development of minimum standards of care, and will track the current and evolving management of issues in the last 12 months of life.

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