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Ensuring the quality of palliative care in Australia's prisons

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The over-incarceration of First Nations people continues to be a systemic failure in Australia's justice system. More than thirty percent of people in prison identify as Aboriginal and/or Torres Strait Islander people, compared to three percent of the general community population. Nationally, Aboriginal and Torres Strait Islander people are imprisoned at a rate more than ten times higher than the general population, and the percentage of Aboriginal and Torres Strait Islander people in Australia's prison population has more than doubled in the past thirty years.

Aboriginal and Torres Strait Islander people in prison with palliative care needs have the right to receive culturally safe care. Australian governments have committed to centring Aboriginal and Torres Strait Islander cultures in healthcare, which should be reflected in prisons as well as community health services. Aboriginal and Torres Strait Islander voices also have the right to lead discussions and make recommendations on matters that relate to the health and wellbeing of Aboriginal and Torres Strait Islander people, communities, and cultures, including how culturally safe palliative care should be provided in the prison environment.

Data collection about the palliative needs of Aboriginal and Torres Strait Islander people and provision of culturally safe care should be led and shaped by a reference group of Aboriginal and Torres Strait Islander people. The reference group can ensure that the perspectives and knowledges of Aboriginal and Torres Strait Islander people are prioritised during the data collection development process, and that data collected can provide valuable insights that can guide service development toward culturally safe palliative care in Australian prisons.

For these reasons, data collection about the palliative care needs of Aboriginal and Torres Strait Islander people and provision of culturally safe palliative care in prisons have not been addressed in this brief.

Prioritising culturally safe palliative care in Australian prisons for Aboriginal and Torres Strait Islander people should be a priority for prison-based health services aiming to scope and improve delivery of palliative care.

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#### **Table of Contents**

Key messages	1
Executive summary	2
Introduction	3
Changing demographics of Australian prisons	3
Overview of Australia's prisons	3
Social determinants of health	4
Approaches to healthcare in Australian prisons	5
Palliative care is better for patients	6
Palliative care is better for the correctional system	6
Existing data collection about palliative care in Australian prisons	7
National Prisoner Health Data Collection	7
Limitations of the National Prisoner Health Data Collection	7
Community strategies for data collection are not available in prisons	9
The value of improving data collection about palliative care in Australian prisons	10
Data assists fundamental understanding of a population's health and palliative care needs	10
Additional data will assist identification of chronic disease trends	11
Additional data will assist estimation of palliative care need and demand for care	11
Data informs service planning and development to deliver strategies that target areas of great need	
Improving efficiency and quality of palliative care through evaluation and monitoring	13
Healthcare expenditure and constructing systems of value-based healthcare	14
Recommended pathways	15
Using a co-design process to develop palliative care data collection	16
Nationally consistent data items and health indicators for palliative care should be developed	d 17
New data items for collection should be prioritised according to practicality and usefulness	18
Use of novel data sources should be maximised	19
Optimal use of data requires translation of findings into meaningful change	19
Conclusion	20
References	21



#### Key messages

- People in Australian prisons experience a higher burden of chronic disease and age-related disease earlier than those in the community. Consequently, they require palliative care earlier in life. People in prison are entitled to receive healthcare, including palliative care, that is equitable to care in the community. However, the prison environment introduces additional barriers to palliative care provision than are faced in the community, including the necessity of balancing priorities of security and access to healthcare.
- The current demand for palliative care in the prison setting is unknown due to a lack of available data about the number of people in Australian prisons with palliative care needs. While data is collected about the health of people in Australian prisons every three years, reporting is not mandatory and there are no direct measures of palliative care. Improving data collection about palliative care need and services in Australian prisons is critical to proactively addressing rising demand for palliative care.
- Standardised, regular collection of data is required to:
  - o build an evidence-base to inform policy and service development
  - o identify areas of greatest patient need
  - o evaluate the cost and cost-effectiveness of existing care, and
  - o monitor quality of care and effectiveness of interventions
- Constructing a comprehensive and sustainable data collection strategy that is useful for both clinicians and policymakers is the first step to understanding the palliative care needs of people in prison and inform the development of future policy.
- The design of the data set and collection strategy should be undertaken in partnership with
  a wide range of stakeholders to prioritise the collection of critical information while
  minimising the burden on the system. A nationally consistent dataset and strategy with clear
  definitions, metadata, data management protocols, and reporting expectations should be
  developed for use in prisons. These should be supported by guidance on ways to effectively
  use data and translate findings into meaningful change.



#### **Executive summary**

Australia's prison population is growing and ageing, which is placing an increasing burden on the provision of healthcare in prison. The need to design and implement palliative care services within prisons has been recognised in Australia and internationally, but little is known about the degree of palliative care need in Australia's prisons, how services are provided and whether services in prison are equitable with services in the community.

Providing early and equitable palliative care services within the prison environment is better for both patients and the correctional system. Palliative care provides a holistic approach to care through focus on physical, psychological, social and spiritual support that is provided in the last twelve months of life. Patients who receive early palliative care tend to experience better quality of life focusing care on symptom management and care planning. Managing patients within the prison environment is also beneficial for the correctional system by preventing hospital transfers that require additional funding, staffing, and time. Data is a critical foundation for understanding the degree of palliative care need in the prison population, care that is currently provided, and how service provision should be improved. Despite its importance, there is no data collection about palliative care provision in prison.

National, standardised data about the health of people in Australian prisons is collected through the National Prisoner Health Data Collection, which occurs every three years and reported in the Australian Institute of Health and Welfare's *The health of Australia's prisoners* publication series. While this provides a broad overview of health issues and care utilisation in the prison population, there are no items collected that directly relate to palliative care and therefore no way to understand how many people in prison have palliative care needs, what services are available to them, and whether their needs are being met. Data collection about palliative care need and service provision should be increased using the National Prisoner Health Data Collection to collect standardised, national data.

Collecting additional data about palliative care in Australian prisons would produce a better understanding of how many people in prison need palliative care, inform service planning and development to identify priority areas for action, allow evaluation and monitoring of the quality and efficiency of palliative care, and produce a better understanding of the cost of palliative care provision in prisons with the aim of fostering value-based palliative care services.

This brief highlights the significant gap in national data about all elements of palliative care need and provision in prisons, and describes how data collection could be improved through collaboratively designing palliative care data collection strategies, identifying nationally consistent data and health indicators about palliative care in prisons, prioritising new data items about palliative care for collection, maximising use of existing and novel data sources, and providing support for knowledge translation through development of a framework.



#### Introduction

Providing palliative care in the Australian prison environment has been identified as an increasing area of need (Panozzo et al., 2020; Anno et al., 2004; Turner et al., 2011). Australia's prison population is growing, and the number of older people in prison is rising more rapidly than other age groups (ABS, 2022). This drives additional demand for palliative care services during incarceration (Panozzo et al., 2021). However, provision of health care is complicated by the prison environment (Panozzo et al., 2021; Turner and Peacock, 2017; Turner et al., 2018).

The necessity of balancing the priorities of security and health care can affect the ability of clinicians to respond to patients' needs by limiting the capacity of patients to seek and receive health care (Turner et al., 2011). There is an absence of policy about palliative care provision in Australian prisons and clear care pathways for people in prison with palliative care needs, which contributes to variation in care (Panozzo et al., 2021). Variation in healthcare facilities and resources available at different prisons introduce further differences in care (AHA, 2019). These factors influence the capacity of prisons to manage complex care needs and creates differences in how care needs are managed.

People in prison with palliative care needs also experience additional difficulties due to the physical environment (Inspector of Custodial Services, 2015). Prisons are designed for healthy young men (Marti et al., 2017) and can lack the accessibility features appropriate for a population that is older or has additional care needs (Inspector of Custodial Services, 2015). The prison environment itself, including distrust for service providers and unwillingness of patients to show vulnerability also contributes to low healthcare utilisation (Inspector of Custodial Services, 2015; AHA, 2019).

In the community, best-practice palliative care takes a person-centred approach that focuses on the patient's needs, preferences, and goals of care (PCA, 2018). The *United Nations Standard Minimum Rules for the Treatment of Prisoners (the Nelson Mandela Rules)* (United Nations General Assembly, 2015) state that people in prison are entitled to the same quality of health care available to people in the community, however there is a lack of data available to understand and evaluate palliative care provision in Australian prisons.

Changing demographics of Australian prisons

Overview of Australia's prisons

- From 2020-21, the average daily prison population in Australia was more than 42,000 people, a 44% increase from 2011-12 (ABS, 2022). 98 prisons were operating during this time, mostly in New South Wales.
- Across Australia, more than 90% of people in prison were men (ABS, 2022).
- Aboriginal and Torres Strait Islander people were overrepresented in the prison population of every Australian state and territory (11-85% of state or territory prison population) (ABS, 2022). Aboriginal and Torres Strait Islander people made up an average of 31% of the



national prison population (ABS, 2022), despite comprising approximately 3% of the general population (AIHW, 2021).

- The average length of sentence nationally has increased by more than 20% since 2011-12 (ABS, 2013; ABS, 2022).
- During 2020-21, secure prisons in Queensland, Western Australia, Tasmania, the Australian Capital Territory, and the Northern Territory were operating at between 91% and 112% of the number of people their correctional facilities were designed to hold (Productivity Commission, 2022).

Correctional services in Australia, including correctional healthcare services, are administered separately by each state and territory (AIHW, 2019).

There is limited data available about the health of older people in Australian prisons (Baidawi, 2015), reducing the capacity to tailor healthcare approaches to their unique needs. In the past decade, the number of older people in Australian prison (aged 45 years and over) has increased to 23% of the total prison population (ABS, 2022) and is rising disproportionately to other age groups (AIHW, 2020a).

The increase of older people in prison is driven by practices such as mandatory sentencing, minimum non-parole periods, longer sentences and prosecution of historical offences, particularly sexual offences that attract longer custodial sentences (Baidawi et al., 2011; Trotter and Baidawi, 2015).

The population of older people in prison is divided into four main groups:

- Older people incarcerated for the first time
- People who enter/exit prison regularly throughout their lives and return at older age
- People serving a long sentence/growing old, and
- People who are sentenced to shorter periods of incarceration later in life (Baidawi et al., 2011)

The healthcare experiences of older people in prison have been shaped by their environment and social circumstances (Munday et al., 2019), and require different approaches to care depending on the likelihood of release and the variety of their needs. Data should be gathered to inform evidence-based strategies that could be implemented to meet those needs.

#### Social determinants of health

People in prison report high rates of social disadvantage and lifestyle risk factors, which can negatively influence their health (AIHW, 2019). Social determinants of health include factors such as housing, employment, education, healthcare, food security and healthcare access (AIHW, 2020c). In Australia, social disadvantage is associated with reduced life expectancy, increased likelihood of having at least two chronic diseases and negative impacts on mental and physical health (AIHW, 2016a). As a population experiencing multiple disadvantages, older people in prison frequently



experience a high burden of chronic disease (AIHW, 2019) resulting in a need for additional healthcare services (Baidawi et al., 2011).

#### Social determinants of health and lifestyle risk factors in Australia's prison population

Of people entering prison during a two-week period in 2018 (AIHW, 2019):

- The highest level of education completed is Year 9 or less for one-third of people entering prison.
- One-third of prison entrants were homeless or in emergency accommodation in the four weeks before entering prison.
- 54% were unemployed during the thirty days before entering prison.
- 75% of prison entrants currently smoked tobacco.
- One-third of prison entrants were rated as at high risk of alcohol related harm in the 12 months before entering prison.
- Two-thirds of prison entrants had used illicit drugs in the previous 12 months.
- Older people entering prison are more likely to rate their physical health as fair or poor (35%) than younger prison entrants (22%) (AIHW, 2020a).
- Almost half of older people entering prison reported having ever been diagnosed with one of five chronic conditions (cardiovascular disease, diabetes, asthma, arthritis and cancer) (AIHW, 2020a).

Understanding the baseline health status and existing social disadvantage of older people in prison can help health services target areas of greater need and tailor services for older people in prison. Comprehensive data about the baseline health status, social disadvantage, and previous healthcare utilisation for people in Australian prisons with advanced, chronic or life-limiting illness should be collected and analysed to inform development of specific, targeted healthcare services for this unique population.

#### Approaches to healthcare in Australian prisons

There is a limited understanding of need and approaches to palliative care in Australian prisons (Panozzo et al., 2020; Panozzo et al., 2021), meaning that there is no data that can be used to identify the unique needs of people in prison with palliative care needs, gaps in service provision, or evidence-based strategies to improve care.

Correctional health care in Australia is provided by state and territory Departments of Health, Justice, or Corrections (AHA, 2019; AIHW, 2019). Approaches to care vary between states and territories (Birch and Sicard, 2020), and are affected by a prison's location in a metropolitan or rural



area, the healthcare facilities onsite and the integration of services with community-based healthcare providers (Panozzo et al., 2020).

Prisons use a nurse-led primary care model where patients can be referred to the clinic by healthcare or custodial staff, or request a consultation themselves (AIHW, 2019). Patients with basic care needs are managed through visits to the onsite healthcare clinic or be referred to community specialists (AHA, 2019). If a patient's care needs escalate, or can no longer be met in prison, they are transferred to an acute care hospital (AIHW, 2019).

In New South Wales, the continuing increase in prison population has meant a corresponding decrease in nurse Full Time Equivalent per patient, and increased demand on services (Inspector of Custodial Services, 2021). However, without understanding the care that is currently available and the demand for palliative care services across different prisons, service development and quality improvement cannot be targeted to areas with of greatest need.

#### Palliative care is better for patients

Palliative care in Australian prisons has been described as underdeveloped (Panozzo et al., 2021) and the capacity of Australian correctional healthcare providers to deliver palliative care is poorly understood, hampering the establishment and implementation of targeted, evidence-based strategies to increase access to and quality of palliative care.

Palliative care aims to provide patients and families with physical, psychological, social and spiritual care that supports quality of life through early identification and management of problems associated with life-limiting illness (WHO, 2014). Early access to palliative care up to twelve months before death improves a patient's quality of life, assists treatment decision-making, reduces healthcare utilisation in the last days of life and decreases costs associated with healthcare provision (Schlick and Bentrem, 2019; Smith and Firth, 2011).

Implementing a uniform, evidence-based palliative approach to care for people in Australian prisons with advanced, chronic or life-limiting illness early in their disease trajectory would align care provision with community best-practice standards. More data on the current demand for palliative care and the needs of people in prison with palliative care needs, such as prevalence of a range of chronic, life-limiting illnesses (Murtagh et al., 2013), is required to provide a foundation for evidence-based palliative care for this unique population.

#### Palliative care is better for the correctional system

As a consequence of considerably higher healthcare utilisation (Chiu, 2010; Ginnivan et al., 2021), the costs associated with the imprisonment of older people in prison are higher than for younger people (Grant, 1999, Baidawi et al., 2011). This is compounded by the expense of prison-based health care, which is approximately double the cost of a person in the community (Ginnivan et al., 2021).

People in prison are not able to access Medicare (AIHW, 2019), and healthcare costs for care provided within prisons are incurred by states and territories (AIHW, 2019). Health expenditure in



Australia's correctional system has increased by 62% from \$283,248,000 in 2015-16 (Productivity Commission, 2017c) to \$459,644,000 in 2020-21 (Productivity Commission, 2022), and is likely to continue increasing as the demand for prison healthcare grows (Baidawi et al., 2011). Clear, cost-effective, evidence-based approaches to managing older people in prison should be developed in order to deliver best practice palliative care and provide value-based health care that seeks to maximise patient outcomes for the cost of care provided (Baidawi et al., 2011; Panozzo et al., 2020).

In the community, provision of high-quality palliative care is associated with improved quality of life for patients, but also cost savings by reducing hospital admissions and readmissions, reducing length of stay, and days in intensive care units (Kamal et al., 2011). As the population of older people in Australian prison grows, and the number of people with palliative care needs increases, investigating opportunities to provide high value palliative care based in prisons will become increasingly important to manage associate cost increases.

# Existing data collection about palliative care in Australian prisons

#### National Prisoner Health Data Collection

Data about the health of people in Australian prisons is gathered approximately every three years during the National Prisoner Health Data Collection period and reported in the Australian Institute of Health and Welfare's *The health of Australia's prisoners* publication series.

This survey gathers information about:

- Demographics such as age, gender, country of origin
- Physical and mental health
- Social circumstances such as housing, education and employment before prison entry
- Lifestyle risk factors such as tobacco, alcohol or substance use, and
- Healthcare utilisation prior to and during prison entry (AIHW, 2019)

Data are collected from consenting people who are entering or leaving prison, who visit the prison clinic, or who are prescribed medication during the data collection period.

#### Limitations of the National Prisoner Health Data Collection

The National Prisoner Health Data Collection survey provides a basic overview of the health of Australia's prison population and the healthcare they receive (AIHW, 2019), but constraints on reporting and content restrict its capacity to provide insight into palliative care provision. Limitations associated with the data collection such as incomplete data from states and territories and the complete absence of the collection of palliative care data affect how information can be used to inform palliative care service delivery.

Gaps in health data reporting by jurisdictions restricts the utility of the National Prisoner Health Data Collection. States and territories are not required to provide data for the National Prisoner Health



Data Collection (AIHW, 2016b), despite an original recommendation from the Australian Institute for Health and Welfare that that reporting should be mandatory (AIHW, 2001). As a National Best Endeavours Dataset (AIHW, 2006), states and territories can provide partial or no data (AIHW, 2019). Data collection can be impacted by the capacity of prisons to facilitate data collection, such as sufficient staff, or funding to cover costs of data collection. Incomplete national data reduces the capacity to identify trends over time and compare health indicators between jurisdictions where possible (WHO, 2003).

There is no data from the National Prisoner Health Data Collection to describe the need for palliative care services in Australian prisons. This is a consequence of differences in the availability of jurisdictional data that describes local determinants of health and population health indicators. Understanding the local care environment and factors that affect care provision is essential to improving accessibility of palliative care and the effectiveness of care that can be provided (Institute of Medicine, 2011). Without reliable data on the health of Australia's prison population and their palliative care needs from each state and territory, the usefulness of this dataset in guiding service evaluation and quality improvement for palliative care is lessened. Reporting of data should be compulsory to increase coverage nationally and maximise the utility of this dataset. States and territories should be provided with logistical support to collect data, to ensure their capacity to do so.

Variables that estimate palliative care need such as cause of death due to predefined advanced, life-limiting illnesses, and complex comorbidities, are absent from the National Prisoner Health Data Collection, leaving the degree of palliative care need unknown. Diagnosis with one or more of five chronic conditions (asthma, arthritis, cardiovascular disease, diabetes or cancer) is currently the closest proxy measure to palliative care need (AIHW, 2019).

Cause of death due to selected chronic diseases are used as an indirect measure of palliative care need at the end of life in a population, in combination with other markers such as hospitalisations in the last year of life for the same condition as the cause of death (Murtagh et al., 2013). However, a significant proportion of people with chronic diseases do not require palliative care early in their disease trajectory (Effendy et al., 2022; Lunardi et al., 2020), while some people may not require palliative care at all (Murtagh et al., 2013). Factors contributing to palliative care need are complex (McIlfatrick, 2007), and not necessarily determined by diagnosis (Murtagh et al., 2013). Diagnosis with a chronic disease may indirectly indicate palliative care need at the end of life, but limitations of this measure should be acknowledged.

Collecting direct measures of palliative care need would support identification of trends in need and service usage and highlight states or territories where health status and outcomes are markedly higher or lower. Reliable data is a vital component of understanding population health and healthcare needs, and it is critical for planning services to fill identified gaps in care (National Research Council, 2010; WHO, 2003); including palliative care. Data collection should be expanded to include data items relevant to palliative care to assist mapping of current need and services, and to inform the development and evaluation of future services.



#### Community strategies for data collection are not available in prisons

Community strategies for population health data collection use a number of sources such as disease registries, health surveys, data collected through the administration of healthcare (administrative data) or funding-related data (Cadarette and Wong, 2015; Tijhuis et al., 2019a; Wunsch et al., 2005), which are not available for the prison population. Prisons and people in prison are excluded from community data collection strategies such as national health datasets (Ahalt et al., 2012), routine public health surveys (AIHW, 2006), and research (Charles et al., 2016), meaning that separate initiatives are required to gather data in the custodial setting.

Systematic collection of data about community-based palliative care in Australia is fragmented, and comprehensive data are not available at a national level (AIHW, 2022; PCA and KPMG, 2021). The comparatively recent development of palliative care as a medical subspecialty (Kamal et al., 2011), definition of essential practices for high quality care (ACSQHC, 2015), and ongoing expansion of national outcome measurement strategies and quality benchmarks (Currow et al., 2014) mean that national data collection about palliative care need and service provision is underdeveloped (AIHW, 2022). In Australia, palliative care activities are not comprehensively reported in any setting; including hospitals, residential aged care facilities, or at home or in the community, limiting the capacity to understand palliative care service delivery and expenditure (PCA and KPMG, 2021). A significant portion of data related to palliative care in the community is collected as a means of accessing funding, such as Medicare items, the Aged Care Funding Instrument, and the Pharmaceutical Benefits Scheme (AIHW, 2018).

As prison-based healthcare is funded by states and territories (Cumming et al., 2018; Hampton S, 2015), often using block-funding rather than activity-based funding model (Queensland Health, 2016; PWC, 2018), data about palliative care for the purpose of billing is not collected for health care provided in Australian prisons. The absence of these systems in prisons means that there is no corresponding routinely and consistently collected information that can be used to understand palliative care need and service provision. This presents a significant gap in knowledge about the health of people in Australia's prisons, particularly those with advanced, life-limiting illness who require additional healthcare services, including palliative care. Without understanding these specific palliative care needs and how they are currently managed, it is impossible to scope the degree of unmet needs, and the services that should be provided to meet them.

The National Prisoner Health Data Collection presents an opportunity to leverage existing data collection infrastructure and build an evidence base about the need for palliative care in Australian prisons. This data would serve as a foundation on which to develop services that meet the unique needs of people in prison who require palliative care in the correctional environment.





# The value of improving data collection about palliative care in Australian prisons

Data is a critical foundation for the development of evidence-based practice for palliative care (Kamal et al., 2011), and improving systemic data collection in Australian palliative care services is one of the seven goals of the 2018 *National Palliative Care Strategy* (ACSQHC, 2018). According to the *National Palliative Care Strategy*, people in Australian prisons are currently under-served and without adequate access to high quality palliative care. Targeted strategies to address the additional barriers to care in the prison setting are called for (ACSQHC, 2018), but these cannot be designed and implemented without a comprehensive understanding of the scope and nature of factors that impede equal access to palliative care.

System fragmentation and lack of centralised data is a barrier to understanding and valuation of health care (National Research Council, 2010), problems that are also reflected in the prison population and affiliated health services (Condon et al., 2007; Binswanger et al., 2019). As an example, a national survey in France indicated that the number of people in prison with palliative care needs with an estimated life expectancy of less than one year was twice as high as the general community (Pazart et al., 2018). There is no similar estimate available for Australia, meaning that that the proportion of people in prison with palliative care needs is unknown, and service provision cannot be designed to provide adequate care.

Data has a role in both driving quality improvement by identifying care deficits and systemic issues, as well as facilitating quality improvement by identifying opportunities for effective service development strategies (Victorian Quality Council, 2008). It can further determine and demonstrate the value of care and enable ongoing service evaluation in a quality improvement cycle (Victorian Quality Council, 2008; Kamal et al., 2011). Issues of care quality highlighted in coronial inquests of people in Australian prisons with palliative care needs who have died indicate significant gaps in service (Queensland State Coroner, 2018; New South Wales Deputy State Coroner, 2021), which need to be addressed as a priority. Data collection can support these efforts towards providing better care to an under-served population.

Data assists fundamental understanding of a population's health and palliative care needs

There is insufficient information in the National Prisoner Health Data Collection to estimate the palliative care needs of people in Australian prisons. Improving evidence about the health of people in prison with palliative care needs will enable public health surveillance of population health including advanced, life-limiting illnesses, assist identification of areas of greatest need, and provide a baseline for monitoring and service evaluation.



Additional data will assist identification of chronic disease trends

Limited information is gathered about the prevalence of chronic disease in Australian prisons (AIHW, 2019, AIHW, 2006), restricting the capacity to understand disease trends, tailor healthcare services to the patient population, and project future care needs. Metrics such as the morbidity and mortality of advanced, life-limiting illness are not direct measures of palliative care need (Murtagh et al., 2013). Undertaking comprehensive surveillance of health conditions in the prison population can assist in understanding of disease prevalence, and potential future need for additional healthcare (Binswanger et al., 2019).

Population health is dynamic and should be tracked longitudinally to monitor shifts in health status and disease trends, as these should influence priorities for targeted healthcare initiatives (Murray and Lopez, 1996; Keyes and Galea, 2016). An increasing or high prevalence of chronic disease, and particularly multimorbidity of chronic disease, affects the needs of patients and the approach of a healthcare system to manage these needs (Goodman et al., 2013). Further, as these conditions are, by definition, long-term and prone to progression (Grover and Joshi, 2014) the demand on the healthcare system will correspondingly grow.

The collection of data about the prevalence of chronic disease should be increased in order to better understand the chronic disease burden of Australia's prisoners and inform predictions of future care needs that should be integrated into service planning in preparation for changing populations trends.

Additional data will assist estimation of palliative care need and demand for care

No national information is collected that would assist in the estimation of palliative care needs in the Australian prison population. Estimating palliative care need in Australian prisons is critical to inform the evaluation of the suitability of current services and identifying areas where patient need may exceed service capacity (PCA and KPMG, 2021). Evidence about a population's health reveals trends in health or service deficits (Wright et al., 1998) that should be addressed to better support patients. Understanding the nature and prevalence of palliative care need at both national (Murtagh et al., 2013) and regional (Westley-Wise et al., 2022) levels are critical elements to planning development of palliative care policy and service provision (AIHW, 2022), but this has not yet been undertaken in Australia's prisons.

Influences on palliative care need are multifactorial and there is currently no agreed methodology to estimate national need in Australia, whether in community or prison (AIHW, 2022). More data about palliative care need and provision is collected in the community. However, there are stark differences between health status (Baidawi, 2015), social determinants of health (AIHW, 2019) and lifestyle risk factors (AIHW, 2019) of people in prison and people in the community, meaning that community-based data is not generalisable to the prison population. Due to this lack of evidence, there is no understanding of how poorer health and health indicators may affect the degree and nature of palliative care need at the end of life for people in prison.



Often marginalised sub-populations such as Aboriginal and Torres Strait Islander people (Kendall et al., 2020), Culturally and Linguistically Diverse people (Watt et al., 2018) and women (Stewart et al., 2021) experience additional barriers to accessing healthcare in Australian prisons, but there is no evidence about the degree to which this is true for palliative care. As in the community, each of these vulnerable sub-populations have additional complex care needs and may benefit from palliative care approaches that are tailored to their needs (AIHW Data Development Group, 2022). To ensure patients are provided best-practice, culturally safe palliative care while in prison, it is essential to first understand their needs through systematic data collection.

Current suggested methods for estimating palliative care need in a population use disease-specific mortality and/or linked hospital admissions data (Murtagh et al., 2013, Gómez-Batiste et al., 2014, McNamara et al., 2006, Rosenwax et al., 2005), neither of which are collected as part of the National Prisoner Health Data Collection. Various methods for assessing palliative care need are available, and suitable for different populations and data sources (Murtagh et al., 2013). Choosing an appropriate method for estimating need, that is practical within data-gathering limitations of the prison system (AIHW, 2019) such as funding and staff capacity, will create a pragmatic solution to the absence of information about palliative care need in Australia's prisons.

Data informs service planning and development to deliver strategies that target areas of greatest need

Evidence-based, targeted service planning requires systematic collection of reliable data (National Research Council, 2010), which is an identified deficit in aged and palliative care services within Australian prisons (Baidawi et al., 2011) and the broader community (AIHW, 2022; PCA and KPMG 2021). Health issues without an evidence base or advocacy are overlooked (Murray and Lopez, 1996; Brownson et al., 2009) and as a consequence, lack coordinated, purpose-designed approaches to quality improvement strategies tailored to the needs of a specific population. The estimated need for palliative care in the community outweighs the capacity of the health system to provide services (Productivity Commission, 2017b) which has informed recommendations for system reform (Productivity Commission, 2017b), but there is no similar information available about palliative care need and access in Australian prisons.

Evidence about a population's health provides information about unmet needs, and reveal trends in health or service deficits (Wright et al., 1998) that should be addressed to better support patients by:

- Examining the range of services that are available, and whether these meet the population's needs
- Demonstrating where palliative care access, quality or outcomes of care may not be equitable
- Identifying factors that support or hinder introduction of evidence-based practices
- Monitoring for changes in patient outcomes due to practice change, and
- Informing future implementation strategies (AIHW, 2018)



Co-designing new data collection items in partnership with correctional healthcare providers will develop a dataset that is useful to inform and evaluate service planning in the Australian correctional environment.

Improving efficiency and quality of palliative care through evaluation and monitoring

The absence of data about palliative care need and service utilisation means that there is no way to evaluate the quality of current palliative care services in Australian prisons, the degree to which services meet patient needs, or the effectiveness of clinical practice interventions.

The National Palliative Care Strategy describes data collection as a priority for improving palliative care services, highlighting the value of care evaluation and outcomes monitoring for palliative care nationally (ACSQHC, 2018). At a service level, data should be collected and assessed to evaluate clinical performance and outcomes, identify priority areas for improvement and evaluate the effectiveness of practice change (PCA, 2018). At a national level, data should describe "who receives what services, from whom, at what cost, and with what effect?" (AIHW, 2022) and provide a holistic picture of processes of palliative care provision.

Improving national palliative care data collection allows monitoring, evaluation and reporting on:

- Where palliative care is provided, and who provides it
- Quality and processes of care
- Equity of palliative care access
- Outcomes and efficacy of palliative care
- Performance measurement, and
- Gaps in care or unmet palliative care needs (ACSQHC, 2018, ACSQHC, 2015)

Measuring performance over time allows services to determine areas of care that may not meet patient need, use data to design quality improvement strategies, and then evaluate the success of these service development practices (ACSQHC, 2018). Creating a culture of quality improvement will support system-wide change (ACSQHC, 2018) towards best practice, evidence-based palliative care in Australian prisons.

Health indicators are used to report the National Prisoner Health Data Collection, describing the health, demographics and care utilisation of people in Australian prisons (AIHW, 2019), and based on the National Health Performance Framework (AIHW, 2009).

Health indicators provide clear feedback on care provision to prison health systems and introduce an additional layer of accountability into practice (Asch et al., 2011). The absence of information about palliative care need and provision in prison-based data collection results in a corresponding lack of indicators related to palliative care (AIHW, 2019), and therefore no capacity to measure, monitor or compare the health of people in Australian prisons with palliative care needs, nor the quality of services provided to them while incarcerated.

Improving the collection of data about the health and healthcare available to people in Australian prisons with palliative care needs in addition to associated indicators will allow a better



understanding of need, and quality of care. Health performance benchmarks, and therefore data collection strategies, need to be specifically designed for the prison environment (Damberg et al., 2011) due to the vast structural differences in care provision, availability of health information and disparity in community and prison-population health (Damberg et al., 2011).

Healthcare expenditure and constructing systems of value-based healthcare

Without clear evaluation of healthcare cost, spending, and outcomes, there is no capacity to understand where expenditure is not translating to effective service provision (Kamal et al., 2011).

Healthcare is a growing percentage of jurisdictional correctional budgets in Australia (Productivity Commission, 2021) and resources for any quality improvement project are finite (WHO, 2016), meaning that only selected issues can be addressed in each quality improvement cycle. As healthcare costs increase, there is growing pressure to take a value-based approach to healthcare. A value-based approach maximises patient outcomes through holistic, patient-centred care throughout the patient's illness while ensuring that healthcare spending is efficient and cost-effective (Elf et al., 2017). Cost-effectiveness is a key criterion when deciding on priorities for action (WHO, 2016) by recognising and targeting issues that provide the most return on quality improvement investment. To define instances of low-value palliative care for people in Australian prisons, further data is required (Kamal et al., 2011).

In the community, palliative care reduces healthcare costs by minimising acute care hospital admissions, days in intensive care units, and hospital readmissions (Kamal et al., 2011; PCA, 2017b). Preventing a single palliative care hospital admission can save \$11 000, which in the community is sufficient to fund palliative care for several months (Productivity Commission, 2017b). The effectiveness of similar changes for people in prison with palliative care needs is currently unknown. Cost-savings and reductions in length of hospital admissions are maximised when patients have early access to palliative and end of life care (PCA, 2017a). This is often not the case for people in Australian prisons, who experience late recognition of palliative care needs and late admission to palliative care units prior to death (Panozzo et al., 2021).

The cost of transfer and security for a person in prison for a hospital admission is substantial (Panozzo et al., 2020) as custodial staff must be removed from supervisory roles or work overtime to facilitate the transfer and remain with the person in prison at all times (Inspector of Custodial Services, 2021), and the length of hospital stay for person in prison with palliative care needs in Australia is significantly longer than people in the community (Panozzo et al., 2021). Improving palliative care management within prisons has the potential to similarly reduce costs, but it is difficult to measure without baseline data on palliative care need and care strategies.

Understanding the direct and indirect costs of providing palliative care to people in prison while admitted to hospital and how these vary across states and territories will help identify processes that are inefficient and provide low value care, and guide development of new strategies to provide high value care that maximises patient outcomes. National data collection about palliative care need and delivery in Australia's prisons would enable correctional healthcare providers to identify areas



where practice should be reviewed to provide equitable, cost-effective palliative care to people in Australia's prisons.

#### Recommended pathways

Health information plays a vital role in clinical care by providing evidence with which to evaluate service, ensure quality, demonstrate efficiency and enable research (Kamal et al., 2011). Development of data collection items and strategies should be shaped by what the data will be used for, how it will be used and the ultimate goals of the data collection, learning and knowledge translation cycle.

This process can be described using the Data-Information-Knowledge-Wisdom hierarchy (Figure 1), matched with the process of population health monitoring.

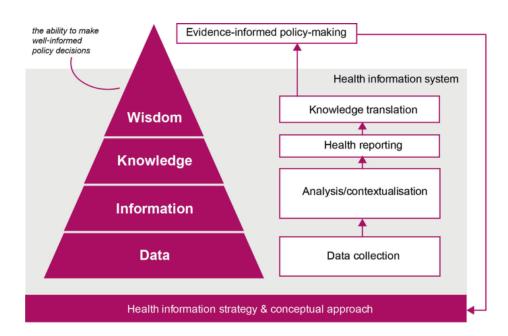


Figure 1: Knowledge translation cycle in population health (Verschuuren and van Oers, 2019)

Data collection forms the foundation (Level 1) for development of evidence-based practice that should ultimately be integrated into routine clinical care and policy. Comprehensive analysis and interpretation convert data into meaningful information (Level 2), which, when reported and contextualised in the larger policy environment and with other relevant research, creates a broader understanding of health and health systems (Level 3). At the final step of the cycle (Level 4), knowledge gained from the data gathering and analysis process is translated into evidence-based practice and policy to improve patient outcomes and health system performance (Verschuuren and van Oers, 2019).



Outputs from each level similarly create a pathway to knowledge translation and evidence-based policy-making (Figure 2). A plan for systemic data collection that feeds into a defined process to encourage information and knowledge translation should be developed to identify gaps in provision of palliative care provision in prison, and guide service development.

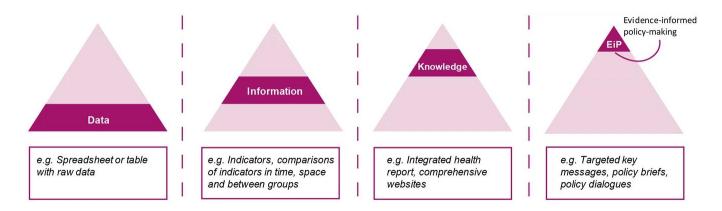


Figure 2: Outputs from the Data-Information-Knowledge-Wisdom pyramid (Vershuuren and van Oers, 2019)

The design of data collection strategies should also account for considerations such as the practicality and sustainability of data collection within the correctional environment. Data collection and reporting strategies should be:

- Standardised, valid and reliable measures of care quality
- Adaptable to structurally diverse organisations, models of care and populations, and
- Designed to produce data that enable a meaningful evaluation of palliative care at site and national levels (Kamal et al., 2016)

The following actions should be considered when approaching design of new data collection strategies about palliative care provision in Australian prisons:

- Using a co-design process
- Developing clear, nationally consistent data items and health indicators with operational definitions
- Identifying and prioritising potential data items and health indicators
- Maximising available data through existing and novel sources, and
- Creating a clear framework to support knowledge translation

Using a co-design process to develop palliative care data collection

Building the capacity for palliative care data collection in Australian prisons will require strong, ongoing engagement with a variety of stakeholders to design and implement new data collection strategies.



Engaging with a wide range of stakeholders to form an interdisciplinary governance team is a key facilitator of prison-based research (Loeb et al., 2008; Kitt-Lewis et al., 2020; Quina et al., 2007). Australia's national prisoner health data set and health indicators are shaped by the Australian Institute of Health and Welfare's National Prisoner Health Information Committee (AIHW, 2020b). This committee assists the design, collection and analysis of prisoner health statistics (AIHW, 2020b), and is comprised of representatives from state and territory correctional healthcare services, the Australian Bureau of Statistics, the Australian Institute of Health and Welfare and subject matter experts.

This advisory group should be supported by palliative care specialists and peak body representatives to develop a strategy for practical and sustainable collection of data that can be used to understand the need for palliative care in Australia's prisons, services that are currently available, and compare against agreed health indicators to measure success. A collaborative approach between diverse stakeholders supports divergent and innovative thinking to address a complex problem (Chamberlain and Partridge, 2017).

In particular, involving end-users during the research or data collection design process increases its value by:

- Focusing data collection on issues and measures that are relevant to those who will
  ultimately use them to inform service development (Greenhalgh et al., 2019; Evans et al.,
  2021)
- Ensuring data collection relates to the practical care setting (problem-based research) rather than being theory-driven and irrelevant to clinical care provision (Wickert et al., 2021), and
- Facilitating communication between traditionally siloed stakeholder groups (Loeb et al., 2008)

In the context of data about palliative care in prisons, involvement of correctional healthcare services during the design process is critically important in order to understand variation in health information systems such as electronic medical records or administrative data systems, how information is recorded and its completeness, and the extent to which palliative care data that could be made available would be comparable between states and territories.

Nationally consistent data items and health indicators for palliative care should be developed

Nationally consistent palliative care data items and health indicators should be constructed with clearly described scope and operational definitions. When monitoring population health, particularly across different health systems, it is essential that data collection is standardised in order to produce data that can be compared (National Research Council, 2010; Soucie, 2012) between jurisdictions.

This requires a coordinated and cooperative effort from stakeholders including service leaders, statisticians and policymakers to agree on feasible and useful data items that are consistent across states and territories. Jurisdictional administrative data systems vary (AIHW, 2019), meaning that it



is unclear how much comparable data is readily available due to differences in measurement and recording. It is likely that data items related to palliative care will need to be developed and implemented incrementally as a greater understanding of potential data sources that could produce comparable data between jurisdictions become available.

Data items should be associated with clear operational definitions and data standards to ensure that data collected is valid and reliable (Tijhuis et al., 2019a; Soucie, 2012; National Research Council, 2010). This should also include metadata which explains and describes other data; commonly by defining a data item, describing how any associated indicators are calculated, and where the data comes from (OECD, 2005).

The National Prisoner Health Data Collection data items are already included in the MeTEOR Metadata Online Registry (AIHW, 2016b). Further items related to palliative care should be similarly included in this registry to ensure collection of mutually agreed, high quality, standardised data.

New data items for collection should be prioritised according to practicality and usefulness

Data items to be collected must be prioritised and standardised to generate data that is clinically useful and can be used to calculate indicators for service evaluation (Binswanger et al., 2019). Data items and indicators should focus on measures that are particularly relevant to palliative care need in the prison environment.

There is a finite capability to gather and process information, bounded by funding and the ability of jurisdictional correctional healthcare providers to support data extraction. It is likely that early data collection about palliative care will be limited to a small number of data items due to these resource constraints (AIHW, 2009; Asch et al., 2011), therefore the number of palliative care-related data items should be increased incrementally over time. Data items chosen for early inclusion should be prioritised by their (National Research Council, 2010; Binswanger et al., 2019; Asch et al., 2011; Damberg et al., 2011):

- Ease of extraction from existing records
- Representativeness of health status and expenditure
- Sensitivity to trends in health or service provision over time
- Validity, reliability and feasibility as a measure of health
- Sound foundation in evidence as a measure of health or health practice, and
- Usefulness as a measure of health in the community, and correlation with community health measures

Development of data items should leverage existing knowledge in community palliative care or health surveillance to maximise efficiency and collect data that is clinically useful and grounded in evidence.



#### Use of novel data sources should be maximised

The National Prisoner Health Advisory group should coordinate with member representatives from jurisdictional correctional healthcare providers and additionally correctional services personnel to maximise use of existing data sources and explore novel data sources with the potential to contribute information about palliative care need and provision in Australian prisons.

An evaluation of data sources should be conducted to (WHO, 2003; AIHW, 2022):

- Determine current data sources
- Explore new data sources and integrations that could provide insight and contribute data
- Improve existing data collection strategies to generate additional specific data, and
- Identify and addressing instances of missing data

This strategy maximises the utilisation of existing data that is related to the palliative care needs of people in prison, demonstrate areas where data that is not specific to palliative care could be integrated or linked to provide additional information, and highlight gaps in data. There may be unidentified or unutilised opportunities to integrate or link data from different sources or data custodians, where siloing prevents ready access to existing information because of policy, organisational or confidentiality issues (Kim et al., 2016).

Data linkage and integration have the potential to maximise available evidence and foster efficient data access in a cost-effective way (Productivity Commission, 2017a; Tijhuis et al., 2019b). This should be done by expanding the statistical value of existing but isolated data, rather than entirely relying on the development of new data collection strategies or sources (Productivity Commission, 2017a). Improving data linkage and integration is a recognised priority for the Commonwealth government (Productivity Commission, 2017a), and should be encouraged in the area of correctional health.

#### Optimal use of data requires translation of findings into meaningful change

A framework to report on and utilise learnings from additional palliative care data about people in Australian prisons should be developed to ensure the application of knowledge into clinical practice and service provision. Increasing the collection of palliative care data about people in Australian prisons presents one of the first opportunities for learnings specific to the Australian context that can be implemented into evidence-based policy and practice. Policymakers, correctional healthcare providers and clinicians should be supported to maximise understanding and utilisation of knowledge generated to improve palliative care for people in Australian prisons.

To ensure that knowledge gained from additional palliative care data is readily available and useable, plans for integrating knowledge translation principles and strategies should be developed and incorporated into data collections from the beginning of the co-design process in the form of a knowledge creation and action cycle (Straus et al., 2009). This approach supports a translation cycle that is sensitive to changes in knowledge that may occur because of evolving research or changing population health trends.



Given the rapid increase in older people in prison, the variation in care provision between jurisdictions, and ongoing quality improvement initiatives such as development of palliative care models of care (New South Wales Deputy State Coroner, 2021), a system that is flexible and responsive to new data knowledge will be critical to addressing palliative care need and provision in prisons.

#### Conclusion

Understanding the epidemiological trends of a population's health is an essential step towards addressing systemic healthcare problems and providing targeted solutions at both policy and practice levels. The current need for palliative care provision in Australian prisons is unknown, preventing healthcare services from understanding the magnitude and nature of need, and steps that should be taken to address this.

Progressively improving data collection about palliative care need and provision in Australian prisons will provide valuable information both about the population health trends of people in Australian prisons. The vision for data collection in the community includes a broad range of palliative care needs include not only physical needs, but also psychological, spiritual and wellbeing needs to create a holistic picture of palliative care needs and service gaps (AIHW, 2022). The same holistic data collection should be aspired to in the prison environment to ensure equitable, person-centred care is available during incarceration.

Working towards a comprehensive dataset for palliative care need and provision in prison will assist policymakers and correctional healthcare services to scope both known and previously unknown areas of need, set priorities for policy change and service improvement and highlight areas where immediate action is required.

Access to high quality, evidence-based palliative care (WHO, 2014) that is of equal quality to that in the community (United Nations General Assembly, 2015) is the right of every person in an Australian prison. Improving data collection about palliative care need and service provision forms the foundation to generating and implementing evidence-based palliative care policy and practice in Australian prisons.



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AHHA acknowledge the Aboriginal and Torres Strait Islander peoples as Australia's First Nation Peoples and the Traditional Custodians of this land. We respect their continued connection to land and sea, country, kin, and community. AHHA also pays our respect to their Elders past, present, and emerging as the custodians of knowledge and lore