AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE
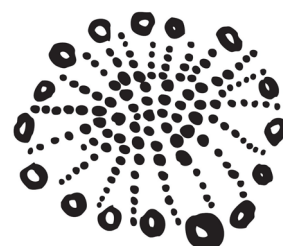
Clinical care for Aboriginal and Torres Strait Islander peoples using aged care services

A Rapid Review

March 2024

The Commission's preference is that you attribute this publication (and any material sourced from it) using the following citation:

Lavrencic L, Mantell R, Withall A, Baldock D, Daylight G, Donovan T, Wall S, Hill T-Y, and Radford K. Clinical Care for Aboriginal and Torres Strait Islander Peoples Using Aged Care Services: A Rapid Review. Sydney: ACSQHC; 2024.

Disclaimer

The content of this document is published in good faith by the Commission for information purposes. The document is not intended to provide guidance on particular healthcare choices. You should contact your health care provider for information or advice on particular healthcare choices.

The Commission does not accept any legal liability for any injury, loss or damage incurred by the use of, or reliance on, this document.

Preface

Background

The Australian Commission on Safety and Quality in Health Care (the Commission) leads and coordinates national improvements in the safety and quality of health care in partnership with the Australian Department of Health and Aged Care (the Department), state and territory governments and the private sector.

In 2021, the Department transferred responsibility for developing a draft Aged Care Quality Standard (Standard 5 – Clinical Care) to the Commission as part of the Australian Government's response to recommendations of the Royal Commission into Aged Care Quality and Safety (Royal Commission). The Royal Commission identified a need to strengthen quality standards as part of wide-ranging reform of the aged care sector.

To inform the development of Standard 5 – Clinical Care (Standard 5) and associated implementation resources, the Commission sought a rapid review of peer-reviewed research and grey literature related to the experiences, priorities and clinical care needs of older Aboriginal and Torres Strait Islander peoples.

The review was conducted by a team from the University of New South Wales and NeuRA, with advice from community Elders and people working with Aboriginal and Torres Strait Islander peoples in the aged care context.

Scope

The Commission asked the authors to focus on what evidence can tell us about what safe, high-quality, and culturally responsive aged care looks like for Aboriginal and Torres Strait Islander peoples.

The Commission wanted to learn from research evidence and evidence of good practice, to:

- Understand the barriers to and enablers of access to aged care for Aboriginal and Torres Strait Islander peoples
- Identify examples of effective, high-quality, safe, and culturally responsive aged care for Aboriginal and Torres Strait Islander peoples for use in Standard 5 implementation resources
- Understand how the aged care sector can change or adapt current practices to prioritise quality of life and support the wellbeing of older Aboriginal and Torres Strait Islander peoples through evidence-based care
- Understand the additional interventions or culturally appropriate care practices required to provide good care to Aboriginal and Torres Strait Islander peoples
- Provide actionable recommendations to inform the implementation of the revised Aged Care Quality Standards.

Findings

The findings and recommendations of this rapid review are structured according to five themes. These themes arose from synthesis of the findings of 36 research studies and seven grey literature reports which met criteria for inclusion in the review:

1. Culture at the centre of aged care and service delivery, including residential care
2. Embedding aged care in community, for community
3. Recognising the importance and value of family, kinship, and informal carers
4. An integrated, holistic, and strengths-based approach to social and emotional wellbeing and clinical care
5. Provision of culturally appropriate palliative and end-of-life care.

For each theme, the findings are presented in terms of:

- Barriers to, and enablers of, high quality aged care for Aboriginal and Torres Strait Islander peoples
- Principles for change and emerging practice examples to address the barriers and facilitate the enablers
- Implications and recommendations to inform guidance and implementation resources for the revised Aged Care Quality Standards and in particular Standard 5 – Clinical Care.

Overall, the authors found that the most important consideration for Aboriginal and Torres Strait Islander peoples when accessing aged care services is the availability of culturally appropriate care. Appropriate care includes Aboriginal and Torres Strait Islander peoples being employed by the service, and provision of cultural safety and responsiveness training for all workers.

Other important considerations included access to family and Country, cultural safety training for the Aged Care Assessment Team (ACAT), the effect of prior trauma on willingness to engage with services, and supporting approaches to clinical care and assessment that are not solely based on a Western biomedical model.

The authors' interpretation of these findings led them to propose three foundational principles that should underpin the design and delivery of safe, high-quality, and culturally responsive aged care:

1. Decolonising approaches to ageing and aged care
2. Trust and respect
3. Partnership with families and communities.

Strengths and limitations

This review provides important and relevant information about culturally appropriate clinical care for older Aboriginal and Torres Strait Islander peoples. A strength of this review is that when the findings are taken as a whole, two clear overarching messages emerge.

The first message is that clinical aspects of care cannot be separated from a more holistic consideration of a community's wellbeing. Trying to view clinical needs separately from other aspects of person and community is a feature of Western-centric biomedical models of health and illness. The notion of what 'good care' looks like needs to be expanded beyond these models if culturally safe aged care is to be achieved.

The second key message comes from the fact that the research evidence is primarily from small studies in specific communities. These studies provide rich information about context and its importance in designing and delivering care. This is a reminder to avoid assumptions that 'good aged care' looks the same for all Aboriginal and Torres Strait Islander nations and peoples.

The findings and recommendations from rapid literature reviews are necessarily limited by the choice of search terms and strategy, and it is always possible that significant research or practice-based evidence was not discovered.

Recommendations

The authors used the findings from the rapid review to develop evidence-based recommendations for the design and delivery of culturally safe and responsive clinical care for older Aboriginal and Torres Strait Islander peoples. They present recommendations relevant to each of the five themes.

THEME 1: CULTURE AT THE CENTRE OF AGED CARE AND SERVICE DELIVERY, INCLUDING RESIDENTIAL CARE

1.1   Aged care services should develop an Indigenous Employment Strategy to enable and strengthen Aboriginal and Torres Strait Islander employment and create culturally safe and responsive workplaces.

1.2   Aged Care Assessment Teams (ACAT) and aged care services should include Aboriginal and Torres Strait Islander workers.

1.3   All workers should engage in regular training to ensure they understand and practice culturally responsive and culturally safe care.

1.4   Residential aged care homes should develop and implement a model of care that is culturally safe and inclusive of culturally appropriate spaces and activities.

1.5   A culturally focussed 'getting to know you' session should be included at commencement of care.

THEME 2: EMBEDDING AGED CARE IN COMMUNITY, FOR COMMUNITY

2.1   Upskilling workers and building the capacity of organisations to deliver culturally safe and responsive aged care services should be prioritised.

2.2   Services should be provided by Aboriginal Community Controlled Organisations where possible.

2.3   Autonomy and flexibility should be facilitated in aged care service delivery, including service hubs situated within alternative or unconventional community settings.

2.4   Evaluation should be conducted to assess the impact of community services and programs that are not federally funded but effectively provide aged care services to older people.

2.5   Existing systems and programs should be reviewed and transformed to recognise and celebrate the significance of Elders and the importance of their community and cultural standing.

THEME 3: RECOGNISING THE IMPORTANCE AND VALUE OF FAMILY, KINSHIP, AND INFORMAL CARERS

3.1   The health and wellbeing of family members and informal carers should be urgently supported.

3.2   More evidence is needed regarding the role of family and informal carers in providing clinical care for older people and what constitutes best supports for this group.

3.3   Clear and accessible information about referral pathways to aged care services and supports should be provided to family members and supporters.

THEME 4: AN INTEGRATED, HOLISTIC, AND STRENGTHS-BASED APPROACH TO SOCIAL AND EMOTIONAL WELLBEING AND CLINICAL CARE

4.1   Clinical care should be provided within culturally appropriate, trauma-informed, and holistic conceptual frameworks of social and emotional wellbeing.

4.2   Older people should be empowered to access their own information to enable meaningful discussions and decision-making with family and health professionals about their needs and preferences.

4.3   Integrated health services should be developed to encompass primary care, community health, hospital, and aged care, to enable a holistic approach to people living with multiple chronic conditions, including frailty, dementia, and polypharmacy.

4.4   Culturally safe and validated assessment tools that take a strengths-based approach should be used with older Aboriginal and Torres Strait Islander peoples.

4.5   More evidence is needed regarding multimorbidity and culturally effective interventions that aim to ensure safe use of medicines.

THEME 5: PROVISION OF CULTURALLY APPROPRIATE PALLIATIVE AND END-OF-LIFE CARE

5.1   Information, materials, and communication about end-of-life care should be culturally relevant and specific.

5.2   Decision making by older Aboriginal and Torres Strait Islander peoples should empower the person and involve the family and community, where appropriate, in line with a family/community-centred approach.

5.3   Palliative and end-of-life care should include discussions with Aboriginal and Torres Strait Islander peoples and their family members and carers about their preferences for and importance of dying/burial on Country.

5.4   Better understanding of, and access to, services and equipment for end-of-life care is essential.

Conclusion

This rapid review highlights the importance of culturally safe, responsive, and holistic approaches to ageing and aged care for older Aboriginal and Torres Strait Islander peoples. The five themes outlined the importance of preservation and expression of culture, cultural identity, and connection to family, community, and Country for older Aboriginal and Torres Strait Islander peoples. However, this is not always reflected within mainstream aged care frameworks, policies and practices.

Based on the findings of their rapid review, the authors provide actionable recommendations for aged care services to provide high quality clinical care in a culturally safe and responsive environment for older Aboriginal and Torres Strait Islander peoples.

Next steps for the Commission

The Commission is developing resources and guidance for providers to support the implementation of the clinical components of the revised Aged Care Quality Standards in 2024. Findings, recommendations and case studies from this review will inform this work.

Contents

Acknowledgement of Country

We wish to acknowledge the Traditional Custodians of the Lands on which this report was written, as well as the diverse Nations throughout Australia from which this report draws information. We pay our sincere respects to Aboriginal and Torres Strait Islander cultures, and Elders past and present. Sovereignty was never ceded. It always was, and always will be, the land of Aboriginal and Torres Strait Islander peoples.

Acknowledgements

Acronyms

ACCHO	Aboriginal Community Controlled Health Organisation
ACCO	Aboriginal Community Controlled Organisation
ACSQHC	Australian Commission on Safety and Quality in Health Care
ACAT	Aged Care Assessment Team
GSGL	Good Spirit, Good Life
IPEPA	Indigenous component of the Program of Experience in the Palliative Approach
NACCHO	National Aboriginal Community Controlled Health Organisation
NATSIFACP	National Aboriginal and Torres Strait Islander Flexible Aged Care Program
PEPA	Program of Experience in the Palliative Approach
STRC	Short Term Restorative Care Program

Tables

Executive summary

> In our Aboriginal culture, Elders are an important, invaluable and intrinsic link spanning across time, where they are connected to the past, they exist in the present and they administer wisdom for the future. Our Elders deserve our respect and admiration for their resilience, shared knowledge and experience, and their invaluable contribution to our communities and country.[1]
>
> Glenny Naden, 2018

Background

The Royal Commission into Aged Care Quality and Safety (the Royal Commission) found that Aboriginal and Torres Strait Islander peoples face significant barriers to accessing safe and high-quality aged care services. Inequitable access to federally funded aged care is compounded by a lack of culturally appropriate services which incorporate the unique cultural and spiritual qualities of Australia's First Nations people.

To address these gaps, and to improve services afforded to older Aboriginal and Torres Strait Islander peoples, an urgent review of the Aged Care Quality Standards was requested by the Royal Commission. As part of this ongoing process, the Australian Commission on Safety and Quality in Health Care (the Commission) has responsibility for review and formulation of Standard 5 – Clinical Care (Standard 5). This process has direct relevance for older Aboriginal and Torres Strait Islander peoples whose clinical care needs are often unmet.

To ensure that Standard 5 is suitable to meet the needs of older Aboriginal and Torres Strait Islander peoples, it is important to investigate the clinical care experiences and preferences of older Aboriginal and Torres Strait Islander peoples and their carers. The Commission therefore sought a rapid literature review to consider clinical care in the context of providing high-quality and culturally responsive aged care for Aboriginal and Torres Strait Islander peoples.

Objectives

The main objectives of the rapid review were to:

1. investigate what high quality and culturally safe clinical care looks like for Aboriginal and Torres Strait Islander peoples using aged care services, including barriers and how these can be overcome

2. identify how the aged care sector can change or adapt current practices to support better quality of life and enrich wellbeing for Aboriginal and Torres Strait Islander peoples, including successful examples of previous attempts to improve the quality, safety, and effectiveness of clinical care for this population

3. provide recommendations to inform the development of guidance and resources for Standard 5 – Clinical Care. This includes considerations around corporate and clinical governance frameworks and associated practices of providers.

Method

A rapid review of peer-reviewed and grey literature was conducted to identify research and practice-based evidence which:

- was published between 2015 and 2022 (inclusive)
- focussed primarily on Aboriginal and Torres Strait Islander peoples aged over 45 years
- was relevant to clinical quality standards and/or clinical care
- was relevant to aged care in the community or in residential settings.

To identify peer-reviewed research literature, a search strategy was developed and applied in three academic databases. Consistent inclusion and exclusion criteria were used to identify relevant papers for the review. For grey literature, a purposive targeted search of well-established websites related to Aboriginal and Torres Strait Islander health and/or clinical care within aged care services was conducted.

Findings

An electronic database search for peer-reviewed research literature was conducted in January 2023 and returned 4,426 records. After applying inclusion and exclusion criteria, 36 studies were included in this analysis. Another seven grey literature reports were included after a desktop review of online resources suggested by the Commission.

Through our synthesis of papers, five key themes were generated which reflect different aspects of aged care for older Aboriginal and Torres Strait Islander peoples. Each theme reflects evidence about the barriers to and enablers of high-quality care, what matters most in the provision of respectful care to older Aboriginal and Torres Strait Islander peoples, as well as important practical examples of how culturally suitable change initiatives have been designed and delivered.

Theme 1: Culture at the centre of aged care and service delivery, including residential care

Theme 2: Embedding aged care in community, for community

Theme 3: Recognising the importance and value of family, kinship, and informal carers

Theme 4: An integrated, holistic, and strengths-based approach to social and emotional wellbeing and clinical care

Theme 5: Provision of culturally appropriate palliative and end-of-life care

Discussion – implications of the findings

Principles and recommendations arising from this review are intended to show how evidence can be applied to the Commission's work to develop guidance and implementation resources for the revised Standard 5 – Clinical Care, and more broadly to support culturally safe and responsive care for older Aboriginal and Torres Strait Islander peoples.

The recommendations have been designed to simultaneously address immediate gaps and priorities as well as the longer-term system changes required to support improved care and outcomes for older Aboriginal and Torres Strait Islander peoples.

The recommendations are underpinned by three guiding principles that support culturally safe provision of clinical care.

1. Decolonising approaches to ageing and aged care are needed.

2. Trust and respect are central.

3. Partnership with families and communities is essential.

We believe that the recommendations below are achievable if the Australian Government supports Aboriginal Community Controlled Health Organisations (ACCHOs) and aged care service providers to apply and meet the suggested principles and recommendations. Most important is the employment of Aboriginal and Torres Strait Islander peoples and cultural safety and responsiveness training for all workers. The present lack of Aboriginal and Torres Strait Islander peoples working in health and aged care roles highlights the urgent need to create a training pipeline that supports Aboriginal and Torres Strait Islander peoples to undertake education and training in the health and aged care fields.

> I hope all places are like that, I mean I think that we as Aboriginal people should be doing that for our Elders. In our communities, whether we're in medical, whether we're in aged care, whatever, your primary concern should be your patient and with us, our Elders.[1]
>
> Aged care service provider

THEME 1: CULTURE AT THE CENTRE OF AGED CARE AND SERVICE DELIVERY, INCLUDING RESIDENTIAL CARE

This review found that cultural safety, responsiveness, and respect need to be prioritised and upheld in all aspects of aged care service delivery. Recommendations to ensure culture is at the centre of aged care and services delivery, based on the findings of this literature review, are as follows.

1.1   Aged care services should develop an Indigenous Employment Strategy to enable and strengthen Aboriginal and Torres Strait Islander employment and create culturally safe and responsive workplaces.

1.2   Aged Care Assessment Teams (ACAT) and aged care services should include Aboriginal and Torres Strait Islander workers.

1.3   All workers should engage in regular training to ensure they understand and practice culturally responsive and culturally safe care.

1.4   Residential aged care homes should develop and implement a model of care that is culturally safe and inclusive of culturally appropriate spaces and activities.

1.5   A culturally focussed 'getting to know you' session should be included at commencement of care.

THEME 2: EMBEDDING AGED CARE IN COMMUNITY, FOR COMMUNITY

Community-based programs which are accessible and culturally safe are essential for older Aboriginal and Torres Strait Islander peoples. Recommendations to embed aged care in community and for community, based on the findings of this literature review, are as follows.

2.1   Upskilling workers and building the capacity of organisations to deliver culturally safe and responsive aged care services should be prioritised.

2.2   Services should be provided by Aboriginal Community Controlled Organisations where possible.

2.3   Autonomy and flexibility should be facilitated in aged care service delivery, including service hubs situated within alternative or unconventional community settings.

2.4   Evaluation should be conducted to assess the impact of community services and programs that are not federally funded but effectively provide aged care services to older people.

2.5   Existing systems and programs should be reviewed and transformed to recognise and celebrate the significance of Elders and the importance of their community and cultural standing.

THEME 3: RECOGNISING THE IMPORTANCE AND VALUE OF FAMILY, KINSHIP, AND INFORMAL CARERS

Informal carers (mostly family) make a critical contribution in the overall care and support of older Aboriginal and Torres Strait Islander peoples and need to be recognised and supported in this role. Recommendations to support informal carers, based on the findings of this literature review, are as follows.

3.1   The health and wellbeing of family members and informal carers should be urgently supported.

3.2   More evidence is needed regarding the role of family and informal carers in providing clinical care for older people and what constitutes best supports for this group.

3.3   Clear and accessible information about referral pathways to aged care services and supports should be provided to family members and supporters.

THEME 4: AN INTEGRATED, HOLISTIC, AND STRENGTHS-BASED APPROACH TO SOCIAL AND EMOTIONAL WELLBEING AND CLINICAL CARE

An effective model of clinical care needs to be integrated, holistic, community-focused, strengths-based and centred around social and emotional wellbeing. It also needs to empower Aboriginal and Torres Strait Islander peoples to access information and services as they age to promote flourishing. With appropriate financial and workforce supports, Aboriginal Community Controlled Organisations can provide a central point or hub for aged care and service coordination, which aligns with the preferences of older Aboriginal and Torres Strait Islander peoples.

Recommendations for implementing culturally safe and responsive models of clinical care, based on the findings of this literature review, are as follows.

4.1   Clinical care should be provided within culturally appropriate, trauma-informed, and holistic conceptual frameworks of social and emotional wellbeing.

4.2   Older people should be empowered to access their own information to enable meaningful discussions and decision-making with family and health professionals about their needs and preferences.

4.3   Integrated health services should be developed to encompass primary care, community health, hospital, and aged care, to enable a holistic approach to people living with multiple chronic conditions, including frailty, dementia, and polypharmacy.

4.4   Culturally safe and validated assessment tools that take a strengths-based approach should be used with older Aboriginal and Torres Strait Islander peoples.

4.5   More evidence is needed regarding multimorbidity and culturally effective interventions that aim to ensure safe use of medicines.

> **THEME 5: PROVISION OF CULTURALLY APPROPRIATE PALLIATIVE AND END-OF-LIFE CARE**

Culturally appropriate and supportive approaches to palliative and end-of-life care, which take a family/community-centred approach, are essential. Recommendations to support appropriate palliative and end-of-life care, based on the findings of this literature review, are as follows.

5.1   Information, materials and communication about end-of-life care should be culturally relevant and specific.

5.2   Decision making by older Aboriginal and Torres Strait Islander peoples should empower the person and involve the family and community, where appropriate, in line with a family/community-centred approach.

5.3   Palliative and end-of-life care should include discussions with Aboriginal and Torres Strait Islander peoples and their family members and carers about their preferences for and importance of dying/burial on Country.

5.4   Better understanding of, and access to, services and equipment for end-of-life care is essential.

Conclusion

This rapid review highlights the importance of culturally safe, responsive, and holistic approaches to ageing and aged care for older Aboriginal and Torres Strait Islander peoples. The five themes emphasise the importance of preservation and expression of culture, cultural identity, and connection to family, community, and Country for older Aboriginal and Torres Strait Islander peoples.

The evidence base is not always reflected within mainstream aged care frameworks, policies, and practices. This report provides actionable recommendations for aged care services to provide high quality clinical care in a culturally safe and responsive home environment for older Aboriginal and Torres Strait Islander peoples.

A story of good clinical care

This is a fictionalised account based on many people's stories and their aspirations for growing old well with the best of aged care and support.

It describes experiences of good clinical care by 'Jack', who is 75 years old and a respected Aboriginal Elder who lives on Wiradjuri Country with his wife Marg and one of their five children and two of their grannies, in their proudly owned weatherboard home.

Two years ago, Jack's slowly changing behaviours and memory issues alerted his wife and children to something being "not quite right". Following a conversation that Marg had with her GP at the Aboriginal Medical Centre (AMS) they both attended, Jack, with some persuasion, agreed to have an assessment and discussion with his GP at the AMS.

The GP and Aboriginal Health Worker had a series of yarns with Jack, Marg and their family and used some culturally appropriate cognitive and medical assessments. From this, they had concerns about dementia and helped Jack make an appointment with the Geriatrician, who visits the AMS each month from the big smoke, for further follow-up. The Geriatrician considered Jack's health history including the various medications he was taking for his chronic conditions, arranged some further tests to look for reversible causes of memory changes that she could help treat, as well as an MRI brain scan. She talked to Jack and his family about how they were managing day to day and what supports would be helpful for Jack. She explained that with all the information they had gathered, it appeared that Jack had the early stages of Alzheimer's dementia. Marg was adamant that she didn't want any services at home, and that she and Jack would get through it together, as they had always done. They knew there were lots of people around them to help and that the AMS was also available.

Jack and his family have now lived with dementia for two years. Although Jack is less and less able to do some of the things he used to do, he continues to be a revered storyteller and keeper of knowledge for his family and community. Nevertheless, his memory is getting worse, and he has been doing some increasingly unusual things which have now started to impact significantly on his wife and grandchildren living in the same home. Although supported by her family, Marg has willingly taken on much of the responsibility caring for Jack, but with her own health worries and also looking after the grannies, she is now finding it much harder. Jack has started to become lost when leaving their home and is no longer able to be left on his own at all because he might wander off or forget to turn off the stove when he tries to make a cuppa the way they have always done it. Jack has been attending a men's yarning group and an exercise group at the AMS each week which provides a bit of respite for Marg and social interaction for Jack, but staff are also having increasing issues looking after him safely in this setting. He is not so steady on his feet and is not able to judge risks well.

Jack and Marg have regularly been seeing their multi-disciplinary AMS team, who have noticed Jack's increased care needs and the impact on Marg and the family. The AMS team are keeping a close eye on things, to help Jack maintain a good quality of life and ensure that the whole family's needs are being met. Although there have been some staff changes at the AMS over the years, there is a consistency in the environment and the cultural familiarity is reassuring for Jack, and the team really seem to understand him and his family well.

The AMS offers a wide range of health and social services, including a partnership with a local aged care provider, which has helped to connect some of the Elders to extra help at home. More of the younger people in the community are taking up careers in aged care, which has also helped the older people to understand the services available and feel safe to access them. It also helps keep the community connected and strong. The doctor that Jack recently saw at the

AMS suggested that Marg and Jack seek an aged care assessment to access services for them both and initiated that process with them.

In home Aged Care Assessment was undertaken by an Aboriginal assessor and service options were explored through the National Aboriginal and Torres Strait Islander Aged Care Program (NATSIACP) which provides a service centre in this community. NATSIACP funds culturally safe aged care in a culturally safe environment in some rural and remote areas. It was explained to Marg and Jack that these services strive to provide flexible care that recognises, respects and supports unique cultural identity and traditions and can assist with residential care on a permanent or short-term basis, emergency or planned respite care or home-based care.

Home based respite commenced in the form of an Aboriginal worker coming into the home for four hours every week, which allowed Marg to have some time out of the home or the Aboriginal worker can take Jack for a small drive to visit special places, such going to sit in the park by the river.

Jack has always loved going down to the river to throw a line in and yarn with some old mates. He loves to explore the bush but can now only do these things with lots of assistance and attention, which his care worker or family are happy to provide.

Jack is being looked after well but his health declines. He has developed very poor sleeping habits and neither he nor Marg are sleeping well as he wanders around the house most nights, as she tries to keep it from the rest of the family.

On one of these restless nights, Marg falls and sustains a nasty fracture to her ankle. Her family are alerted, and she is taken to hospital by ambulance where she is admitted for surgery the following day. This admission also prompts the family to seek an emergency respite admission for Jack into a local residential care facility. He has already been assessed previously for this because of his high care needs.

This residential care facility is a mainstream facility and does not currently employ any Aboriginal staff although all staff have participated in mandatory training in providing culturally safe care for Aboriginal and Torres Strait Islander clients. Two of Jack's children advocate for him at his admission; they are very worried. They speak with staff at length about his needs and requirements and the staff provide guidance and support for the family to be with him as much as possible as he settles into this unfamiliar environment.

The Aboriginal Health Worker at the hospital is also alerted to Marg's admission. He liaises with the social work team and speaks to the residential Aged Care staff, who take the opportunity to seek further guidance about providing culturally safe care for Jack whilst Marg is recovering.

The residential care facility has a history of having Aboriginal residents over time and have given much thought and reflection to creating a culturally safe environment. They suggest to the family that they would like to organise a getting to know you interview with as many of the family members and with Jack as soon possible and would like to invite the Aboriginal liaison nurse from the AMS to attend that also. They had a good yarn about Jack's history and needs whilst in care; they talked about the impact on Jack of the Stolen Generations and the fear that he lived with as a boy about being taken from the riverbank as some of his cousins were. The residential care facility reflected on their training and philosophy of trauma informed care and encouraged a cross exchange of information about resources in this space, including those available from the Healing Foundation. To continue to build on their good practice in this area, the Nurse Manager made a commitment to develop relationships with Aboriginal specific aged care facilities and to research and learn from their models of care (e.g., *Jimbelunga* and *Booroongen Djugun* models of residential aged care).

Sadly, Jack's condition deteriorated further following his admission. He was understandably confused about the unfamiliar environment and not having his beloved Marg beside him.

Additionally, he was demonstrating end-stage dementia signs and symptoms. Staff worked closely with Jack's family to bring him as much comfort and reassurance as possible. They stopped at the bush and rescued some of his favourite gums off the valley floor to place by his bedside, which brought a smile to Jack's face.

Meanwhile, Marg experienced some health complications and ended up staying in hospital for over four weeks. On discharge from, hospital her immediate concern was to get Jack home. It was explained to her and the family that Jack's condition was now considered palliative and that he was in the end stages of his illness and life. The family were determined to get Jack back home to die, as they knew this is what he would want. Jack's AMS healthcare and aged care teams worked together to make this happen as quickly as possible. It was confirmed that these wishes fitted the advance care planning undertaken prior to his diagnosis.

Home based palliative care was sought through the NATSIACP. Appropriate equipment was resourced and delivered to the home and palliative care staff gently ensured that Marg and family felt comfortable and confident to use the equipment. A shared care plan was agreed upon and provided between family and the palliative care team. On their way home, the patient transport team suggested they go by the riverbank where they supported Jack to sit for a while.

Jack's family approached the local Aboriginal land council who organised a smoking ceremony to prepare his welcome home. Jack was cared for in his home for six weeks surrounded by the people he loved and supported by an inspiring and committed palliative care team.

Jack's spirit has now returned to the Dreaming as he continues to watch over his family, community, and Country.

Background

The Royal Commission into Aged Care Quality and Safety (Royal Commission) was established in 2018 to investigate significant concerns about Australia's aged care system. The Royal Commission's final report, tabled in Parliament on 1 March 2021, details an extensive plan to overhaul the aged care system and calls for fundamental and systemic aged care reform.[2] The report calls for a contemporary aged care system underpinned by a rights-based Act, funding based on need, and much stronger regulation and transparency.

The Royal Commission found that limited access to appropriate aged care services for Aboriginal and Torres Strait Islander peoples is a significant barrier to safe, high-quality aged care provision.[2] It found that for aged care providers to deliver appropriate services to Aboriginal and Torres Strait Islander peoples, they must ensure these are culturally safe and responsive, respect traditional cultural practices, acknowledge the cultural and geographic diversity of communities, and keep Aboriginal and Torres Strait Islander peoples connected to their family, community, and Country.

Through consultation with Elders and experts, and analysis of contemporary research, it is clear that aged care in Australia does not deliver on these care requirements. Evidence cited in the Royal Commission further highlights that Aboriginal and Torres Strait Islander peoples are at greater risk of harm when accessing and receiving aged care services than non-Indigenous people.[2] There is also a substantial and growing body of evidence illustrating the considerable health and wellbeing disparities between Aboriginal and Torres Strait Islander peoples and other Australian populations, which predisposes many Aboriginal and Torres Strait Islander peoples to need aged care services and support from relatively younger ages, and often before the age of 65.[3-5]

To address health inequities and service gaps, Recommendation 19 of the Royal Commission recommended an urgent review of the Aged Care Quality Standards. In the 2021-22 Budget, the Australian Government announced that responsibility for the development of Standard 5 – Clinical Care (Standard 5), for inclusion in a revised set of Aged Care Quality Standards, would be transferred from the Department of Health to the Australian Commission on Safety and Quality in Health Care (the Commission) from 1 July 2021.

In line with these findings and new responsibilities, the Commission has sought this rapid review to consider clinical care in the context of providing high quality and culturally responsive aged care for Aboriginal and Torres Strait Islander peoples.

Objectives

This review aims to inform how the aged care sector can change or adapt current practices to prioritise quality of life and support the wellbeing of older Aboriginal and Torres Strait Islander peoples. It does this through synthesis of research and practice-based evidence that highlights what high-quality and culturally safe clinical care looks like for older Aboriginal and Torres Strait Islander peoples using aged care services.

The three main objectives of the rapid review were to:

1. investigate what high quality and culturally safe clinical care looks like for Aboriginal and Torres Strait Islander peoples using aged care services, including barriers and how these can be overcome

2. identify how the aged care sector can change or adapt current practices to support better quality of life and enrich wellbeing for Aboriginal and Torres Strait Islander peoples, including successful examples of previous attempts to improve the quality, safety, and effectiveness of clinical care for this population

3. provide recommendations to inform the development of guidance and resources for Standard 5 – Clinical Care. This includes considerations around corporate and clinical governance frameworks and associated practices of providers.

Method

A rapid literature review was conducted. This is a streamlined version of the traditional systematic review procedure.[6] Rapid reviews involve an accelerated review process which enables timely outputs by providing a rigorous and systematic summary of the literature rather than in-depth synthesis.[7] This methodology suited the timeframe for this research whilst still providing a comprehensive overview of the literature.

Independent and systematic searches were carried out by one reviewer (RM). Covidence software was used for all screening. Title screening (RM) was followed by screening of all abstracts by two reviewers (RM and LL) who were independently involved in applying inclusion/exclusion criteria to all abstracts, underpinned by a comprehensive review strategy. Both reviewers allocated reasons for abstract-based exclusions to ensure consistent application of criteria, and a senior author (AW or KR) screened results in the event of any conflicts. Full text screening was conducted by RM, and LL reviewed excluded papers. A thorough data extraction process was reviewed by all authors to ensure consensus.

Data sources and search strategy

Databases that were systematically searched included PsycINFO, EMBASE and PubMed. The search strategy was kept broad to capture as much information as possible related to health and aged care services for older Aboriginal and Torres Strait Islander peoples. Table 1 lists the specific search terms and strategy used.

To identify grey literature, the Commission was consulted regarding best sources of information. In addition, the authors conducted a desktop review of relevant websites including Indigenous Health InfoNet, known Aboriginal and Torres Strait Islander aged care services, and the Australian Association of Gerontology.

Table 1 - Specific search terms used for database searches

Topic area	Search terms
Aboriginal and Torres Strait Islander peoples	Aboriginal+ OR Torres Strait OR* Indigenous OR Native OR First Nation+
	(Lowitja Institute used for PubMed; LIt.Search | Lowitja Institute)
AND	
Older and ageing (45+)	old OR aging OR ageing OR aged OR Elder OR geriatric+ OR frail+ OR later life OR senior OR mature
	(MeSH for older and middle aged used in PubMed)
AND	
Health and aged care services	Health+ OR clinic+ OR care OR service+ OR safe+ OR quality OR best practice OR emerging practice OR continuous quality improvement OR CQI OR intervention OR therap+ OR treat+ OR support+ OR cultur+ OR hospital+ OR residential OR wellbeing

*Broader Indigenous terms (e.g., native) only used for PsycINFO, not EMBASE or MEDLINE PubMed

Review criteria (inclusion/exclusion)

Specific inclusion and exclusion criteria were applied to each search result during the screening of titles, abstracts and full-text articles. These criteria are set out in Table 2.

Table 2 - Inclusion and exclusion criteria

Inclusion	Exclusion
Research/reports published between 2015 and 2022	Did not include target population (e.g., no Aboriginal and Torres Strait Islander peoples, did not predominantly include people aged 45+ years)
Aboriginal and Torres Strait Islander peoples	
Includes people aged 45 years and older	Not primarily relevant to aged care
Aged care services in the community and in residential facilities	No discussion of clinical standards or clinical care
Findings relevant to clinical care	Incorrect study design (e.g., not primary or secondary research, conference abstract, commentary, editorial)
Primary and secondary research or grey literature	

The review originally aimed to incorporate comparison literature from international Indigenous communities to enrich the research findings. However, initial review of this literature showed that a genuine comparison would require analysis of the contextual differences between Australia and countries such as Canada, the USA and New Zealand, including the historical, political, social and health service environments of these countries. The time constraints of this review precluded such analysis and international comparisons were not completed.

Definitions of terms

Given the broad interpretation of the terms 'aged care services' and 'clinical care', working definitions were developed for the purposes of this review.

Aged care services

Aged care services were defined as federally funded (Commonwealth-subsided) services, as well as other residential and community aged care provision (including informal care). This definition ensured capturing of services that may be provided in an Aboriginal community-controlled context and informal care, which is common in Aboriginal and Torres Strait Islander communities.

Commonwealth-subsidised aged care services include:

- services provided in the home under an approved home care package
- residential aged care services
- services provided under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSIFACP), which funds organisations to provide culturally appropriate aged care for older Aboriginal and Torres Strait Islander peoples close to home and community.
- the Short-Term Restorative Care Program (STRC), which provides a range of care and services for up to eight weeks to help prevent or reduce difficulties older people are having with completing everyday tasks.

Clinical care

Clinical care was defined as care offered by health professionals and services for clinical conditions, or a defined clinical pathway in line with current best evidence. Good clinical care should be comprehensive, multidisciplinary, aligned with an older person's goals of care, optimise an older person's functional capabilities, support reablement and address psychosocial and mental health. The clinical care workforce should be skilled, have clear accountabilities and be supported to deliver evidence-based care.

However, the term 'clinical care' is not always appropriate for Aboriginal and Torres Strait Islander peoples. Therefore, our search strategy encompassed other terms to reflect a more holistic conceptualisation of care that was reflective of Aboriginal and Torres Strait Islander points of view. Broader search terms included health, best and emerging practice, therapy, support, culture, and wellbeing.

Data extraction

Detailed information on each included research study was extracted into a data workbook. Data columns included Author(s); Year; Title; Journal; Location; Study Design; Target population; Aged care setting; Service funding information; Sample size; Age (mean); Female (%); Primary clinical standard(s); Main issues; Barriers; Enablers; Guiding principles; Best practice; and Key quotes. A summary version of the data extraction can be found in Appendix 2 – Peer-reviewed research included in the rapid review.

Risk of bias assessment

A quick 'level of evidence' check was undertaken on each study using the Johns Hopkins Model of Evidence-Based Practice.[8] The levels of evidence in papers were organised into five categories (Table 3), where Level I represents the strongest quality of research evidence, and Levels IV and V representing non-research evidence. It is important to note that one of the objectives of this review was to understand the experience of ageing from the perspectives of older Aboriginal people. This line of enquiry is often best suited to qualitative research designs. Although qualitative research is rated as Level III evidence in the Johns Hopkins Model, this does not reflect the utility and suitability of this research for the purposes of this review.

The short time frame for this report precluded use of the Aboriginal and Torres Strait Islander Quality Appraisal Tool[9], which would have provided further assessment of research quality and ethical standards.

Table 3 - Evidence type used in appraising the quality of the evidence of included papers

	Quality of evidence	Description
Research evidence	Level I	- Experimental study, randomized controlled trial (RCT) - Explanatory mixed methods design that includes only a Level I quantitative study - Systematic review of RCTs, with or without meta-analysis
	Level II	- Quasi-experimental study - Explanatory mixed methods design that includes only a Level II quantitative study

	Quality of evidence	Description
		• Systematic review of a combination of RCTs and quasi-experimental studies, or quasi-experimental studies only, with or without meta-analysis
	Level III	• Non-experimental study • Systematic review of a combination of RCTs, quasi-experimental and nonexperimental studies, or nonexperimental studies only, with or without meta-analysis. • Exploratory, convergent, or multiphasic mixed methods studies • Explanatory mixed methods design that includes only a Level III quantitative study • Qualitative study • Systematic review of qualitative studies with or without meta-synthesis.

Non-research evidence	Level IV	• Opinion of respected authorities and/or nationally recognized expert committees or consensus panels based on scientific evidence. Includes:
		   ○ Clinical practice guidelines
		   ○ Consensus panels/position statements

	Level V	• Based on experiential and non-research evidence. Includes:
		   ○ Scoping reviews
		   ○ Integrative reviews
		   ○ Literature reviews
		   ○ Quality improvement, program or financial evaluation
		   ○ Case reports
		   ○ Opinion of nationally recognised expert(s) based on experiential evidence

Elder/expert consultation

A panel of Elders/experts was convened to obtain feedback on the findings and recommendations at the draft stage. The purpose was to gather input on the draft themes of the review, to obtain help to develop the recommendations based on the review findings, and to ensure the outcomes of the report were culturally safe and acceptable. Two virtual 'yarning' meetings were held with four Elders/experts. Where panel members could not attend the set meetings, a separate yarning meeting was facilitated to enable consultation and feedback.

The first yarning presented the background for the review and preliminary findings regarding review themes. The second yarn focussed on finalising the themes and collaboratively developing recommendations based on the findings. Panel members also provided feedback on all draft and final versions of the report outside of the meetings. Panel members were remunerated for their time and expert contribution.

Findings

The electronic database search was conducted on 11 January 2023 and returned 4,426 records (1,104 EMBASE; 1,910 PubMed; 1,412 PsycINFO). After removing 757 duplicates, 3,669 records remained to be screened. Following title screening, abstract screening was carried out on 633 records. Once irrelevant papers were removed, a total of 62 studies were included for full-text review. Upon full-text review, a further 26 studies were excluded, leaving 36 studies included in the analysis. See Appendix 1 – PRISMA flow diagram for more detail on this process.

Of the 36 studies, eight were literature reviews, 18 used qualitative methods, six used quantitative methods, and four used mixed methods. In addition, a desktop review of relevant grey literature resulted in an additional seven papers for inclusion. The majority of included studies were rated as Evidence Level III. This is reflective of qualitative studies being appropriate in the context of the objectives of this review, i.e., better understanding experiences of clinical care in aged care.

Study characteristics

Study characteristics and a summary of relevant findings are presented in Appendix 2 – Peer-reviewed research included in the rapid review, and in Appendix 3 – Grey literature included in the rapid review. The studies generally focused on older Aboriginal peoples and Elders (living in the community; using aged care services; living in long-term or residential aged care facilities; living with chronic conditions), carers (particularly of older Aboriginal peoples with cognitive impairment or dementia, including family caregivers), and healthcare staff (especially working in Aboriginal Community Controlled Services). Other areas of focus included aged care assessors, remote area nurses, people entering palliative care, patients at Aboriginal health services, Art Centre stakeholders, and palliative care program staff and participants (students).

Study themes and synthesis of barriers and enablers

Themes were generated through synthesis of the included papers, each of which was assigned to a single, main theme (despite occasional overlap of studies across multiple themes). Appendix 4 – Barriers to and enablers of good care, by theme – provides an overview of supporting quotes and the key barriers and enablers to quality care in aged care for Aboriginal and Torres Strait Islander peoples. The synthesis of literature findings by theme is outlined below.

Theme 1: Culture at the centre of aged care and service delivery, including residential care

> Whenever a new resident comes in, we will do a data collection and that's to know about a person's history, their lifestyle, what they like, what they don't like, what kind of activities they would attend and most importantly is their cultural needs and spiritual needs. … I said we have care plans too right; every resident has their own care plan, and they would be put in a folder and placed into every [resident's] houses … .[10]
>
> – Residential carer

Nine studies[10-18] and one grey literature report[19] were relevant to this theme. These studies focus on describing the features of services that are culturally safe, holistic, respectful, inclusive through engagement with families and communities, and respectful of traditional and cultural practices. The

papers also describe multiple barriers and enablers to provision of and access to such services for older Aboriginal and Torres Strait Islander peoples.

Experiences of racism, discrimination, marginalisation and alienation act as a foundational barrier to accessing appropriate aged care services for older Aboriginal and Torres Strait Islander peoples.[13, 14, 18] Providing high-quality integrated and holistic care firstly requires recognition of the continuing impacts of colonisation, racism and discrimination, institutionalisation, and socio-economic disadvantage on the older generation who are now entering or currently using the aged care system.[20]

Further barriers to culturally safe aged care include a lack of appropriate services in some areas, particularly those that are culturally responsive, and a lack of control by the community for issues that directly affect delivery of services for older people.[15, 19] Uncertainty about how to access services, the scope of services, or how specific processes work (e.g., making a complaint, navigating the aged care system) were also noted as barriers by some papers.[13, 15, 19]

Funding issues, including lack of flexibility, were highlighted as major barriers to access in multiple papers.[21-23] This is linked to the notion that culturally appropriate care cannot be accommodated by mainstream systems but, at the same time, Aboriginal and Torres Strait Islander peoples are expected to fit into generic systems (such as the online portal My Aged Care). Another example is that expectations around who can provide care can be dictated by gender and cultural norms, which can be a barrier to non-local or non-Indigenous workers engaging with some Aboriginal and Torres Strait Islander older people.[21]

Person-centred care was identified as a way of enabling control and self-determination for older people.[13] However, this must be true and genuine person-centred care, with health workers and providers wanting to get to know the person and ensure that their needs and preferences are being considered and met. Access to Aboriginal service providers is also important to allow for delivery of accessible and responsive services.[13] Other features of service provision which promote culturally responsive care were identified as support to navigate and access entitlements such as pensions, housing, and disability services, and being able to go back to Country even when in residential aged care.[12]

Three studies addressed cultural safety specifically in the context of residential aged care.[10, 11, 16] Key points for providing culturally appropriate residential aged care include the need for holistic and culturally centred care plans and practices, trauma-informed and family-centred care, an emphasis on wellness, wellbeing, spirit, and healing, strengthening the Aboriginal and Torres Strait Islander workforce, and building cultural safety of the non-Indigenous workforce. Taking a 'two-eyed seeing' approach was also discussed in terms of respecting that both Aboriginal and Western understandings of health care offer various strengths and can co-exist.

Barriers to culturally responsive residential aged care related to staffing (e.g., lack of Aboriginal staff, high turnover, staff lacking education on standards of care for Aboriginal people), the need for better education on quality standards, and lack of funding for cultural events.[10] Marginalisation of Aboriginal culture was noted, as was a lack of integration of holistic care planning including cultural information.[10, 16] The need for culturally appropriate activities was noted such as the use of Ngangkaris to assist with spiritual wellbeing and healing[16], as well as access to reflection and relaxation rooms, Aboriginal television channels, outdoor seating, and electric wheelchairs.[10]

Enablers of appropriate residential aged care provision included culturally safe and trauma-informed care, which is best delivered by Aboriginal and Torres Strait Islander staff.[11] In addition, culturally appropriate activities are key, and may include music, dance, storytelling, crafts, and weaving.[11] Traditional spiritual beliefs should sit alongside Western biomedical understandings and be allowed to co-exist.[16] It was also highlighted that person-centred care should be situated within a framework that enables family/community/kin involvement.[24 cited in 11]

Theme 2: Embedding aged care in community, for community

> Don't have stigma with Aboriginal controlled. Memories of walking into 'white' doctor's office. Good to walk in with your head held high knowing it's yours. On your land.[14]

> – Older Aboriginal person

Seven research studies[25-31] and two grey literature reports[1, 32] were relevant to this theme. These papers focused on programs in communities for older Aboriginal and Torres Strait Islander peoples, as well as aged care-related considerations for older people still living in the community.

The barriers and enablers identified for embedding aged care in community were primarily practical considerations such as a lack of appropriate services, accessibility of programs, past experiences of programs, and ensuring programs are enjoyable. Barriers also exist in terms of poor awareness and understandings of dementia in communities, which may limit timely access to formal aged care and dementia services and increase pressure on families.[26] Preference for care in the home by family or other informal care leaves older people with limited family networks particularly vulnerable.[26, 27] Depression and isolation can negatively impact the desire of older people to engage in health care or seek services and supports.[25]

Being in community was shown to promote a sense of belonging.[25] Programs that incorporate a social aspect and opportunity to connect with other community members tend to be well received.[31] Art centres were highlighted as safe places for maintaining connections to community and Country, maintaining culture, and teaching younger generations.[29, 30] Art centres also provided extensive support beyond this, outside of mainstream health or aged care services, including personal care, transport, finances, advocacy, respite, and supporting social and emotional wellbeing.[30]

Theme 3: Recognising the importance and value of family, kinship, and informal carers

> I wanted to look after her at home. I wanted her to pass away here in her own place." …[now] "I'm sort of isolated. I don't know what to do with it. I need to find my place.[33]

> – Family carer whose mother is in a care facility

Four studies were relevant to this theme[33-36] and highlighted some of the challenges faced by informal (often family) carers. The continued impacts of colonial policies and traumas cannot be minimised, such as high rates of and poor experiences with institutionalisation (including incarceration) earlier in life.[36] Barriers informal carers faced included lack of access to and knowledge of support and respite services, a lack of cultural safety and responsiveness and isolation when in remote communities. Lack of appropriate transport was also an identified barrier to older people remaining with informal carers.[35, 36] Fear of placing loved ones into residential care, and regret when there was no other option, also contributed to negative experiences of family carers.[33]

Theme 4: An integrated, holistic, and strengths-based approach to social and emotional wellbeing and clinical care

> If our spirit's broken, we become sick. Our spirit's sick and how can we heal it, if we don't have that quality of life?[37]

> – Older Aboriginal woman

> I think it's a holistic thing but that's my point of view because I see a bit of everything. There's housing. There's lack of transport. There's the physical, then there's the social and emotional wellbeing, like that social isolation and things like that.[1]

Six studies[20-23, 38, 39] and three grey literature reports[40-42] addressed the need for integrated services and explored how aged care providers meet the expectations of individuals, communities, health workers, and funders, particularly when there is a lack of uptake of these services. There was an expressed need for integrated services that cater to multiple conditions associated with ageing, such as frailty and dementia. A community-based 'one-stop shop' for guidance on health and services, preferably supported by an Aboriginal health worker, was identified as a good model for integrated care.[22, 43]

Workforce-related barriers to provision of integrated care include work roles being fused with unpaid family responsibilities, and staff shortages.[21, 23]

The need for community literacy as well as accessible and culturally appropriate resources was highlighted, relevant to the community as well as staff.[22] Issues with processes for arranging legal guardianship were also noted, which adds another layer of complexity and stress for families trying to navigate aged care.[38]

Significant national-level change is likely needed to enable better outcomes via increased flexibility of community-based care services.[38] In addition, enablers relate to the importance of taking an integrated and holistic approach to care that includes community and family, strong governance and structures (including the workforce) that prioritises respect and cultural safety, as well as more flexible and accessible referral and diagnosis pathways.

Two studies focussed specifically on safe medication use.[43, 44] One paper highlighted the high rates of potentially suboptimal prescribing experienced by Aboriginal peoples living in remote Western Australia, with polypharmacy occurring for 53% of people, potential under-prescribing for 12%, and potentially inappropriate prescribing for 20% of people.[44] The other paper discussed the Home Medicines Review program and the need to tailor this approach to ensure it is culturally appropriate for older Aboriginal and Torres Strait Islander peoples.[43] It was noted that in its current form, the Home Medicines Review may not achieve the best outcomes for Aboriginal and Torres Strait Islander peoples. The paper emphasised the importance of pharmacists understanding culturally safe care and for Aboriginal health services to work with a specific pharmacist to improve relationships between pharmacists, Aboriginal and Torres Strait Islander workers and older people.

Three studies emphasised the value of culturally appropriate clinical assessments and tools.[37, 45, 46] In terms of enablers, the use of culturally designed or adapted, validated tools to diagnose dementia was highlighted across all papers. The importance of ensuring that Aboriginal and Torres Strait Islander holistic understandings of health and wellbeing underpin assessment tools, and to consider cultural and religious beliefs more generally, was noted.[37, 45] In addition, the Good Spirit Good Life tool was promoted to evaluate quality of life for older Aboriginal and Torres Strait Islander peoples.[37]

Theme 5: Provision of culturally appropriate palliative and end-of-life care

> I reckon it would be nice to see the stars before you die. My father, he died, 'cause I was there when he died, and they had his funeral in his room. And put all Aboriginal things around, the bush and all that around his coffin in his room. It was really nice. It was out at his own place. That was lovely.[47]

–   Aboriginal Elder

Five studies[47-51] and one grey literature report[52] were relevant to this theme. In relation to barriers, there are nuances that need to be respected, such as fears that talking about death could jinx oneself or loved ones, reluctance to discuss death and dying, the need for more cultural safety training, and provision of family guidance.[49, 50] Another paper reported no reluctance from participants in discussing death or dying[47], but it is still worth noting that differences in willingness

to discuss death and dying could impact uptake of advance care directives. Understaffing and lack of access to end-of-life equipment, coupled with limited knowledge on how to use the equipment, were also cited as specific barriers[50], which reflect poor access to palliative care more generally.

Enablers of suitable palliative and end-of-life care included increasing Indigenous Health Worker capacity during experiential training programs such as the Indigenous component of the Program of Experience in the Palliative Approach (IPEPA), using Indigenous Project Officers to assist with community engagement, flexible training program delivery, debriefing and support from managers, and sustaining networks after placements end.[48] Staying on Country for end-of-life care and dying at home, or being taken back to Country to be buried, came up in some studies.[47, 49, 50] In respecting and honouring loved ones appropriately, the need for an outdoor area, community cultural development, being able to do 'traditional stuff', allowing family to be around, and appropriate and meaningful rituals were highlighted.[49]

Principles for change and emerging practice

In addition to identifying barriers and enablers to culturally safe and responsive care, this review found many suggestions for how barriers could be addressed, and enablers strengthened. These principles for change and emerging practice examples are detailed in Table 4 below, split according to theme. Principles for change incorporate the values, beliefs, attitudes and/or concepts needed to guide or underpin good clinical care, while emerging practice examples are the practical enactment of such principles that have been described to date. Together, these provide an overview of *what matters most* in the provision of respectful care to older Aboriginal and Torres Strait Islander peoples, as well as important practical examples of *how* culturally suitable change initiatives have been designed and delivered.

In addition, this review captured several standalone case studies and resources related to interventions or approaches which are relevant for service providers; these are summarised in Appendix 5 – Case studies and resources.

Table 4 - Principles for change and emerging practice by theme

Principles for change	Emerging practice
Theme 1: Culture at the centre of aged care service delivery, including residential care	
- Respecting and preserving Aboriginal life, traditions, living culture and connection to Country, including the role of Elders[15, 17, 18] - Delivery of accessible and responsive services via person-centred care[13] - Advocating for and with Aboriginal Elders and their communities[15] - Employing Aboriginal staff and ensuring all non-Aboriginal staff work towards cultural competence and enhanced communication skills[21, 29] - Ensuring access to Aboriginal service providers[13] and accessible health services more generally[17] - Creating and maintaining Aboriginal friendly spaces and providing buildings that meet Aboriginal Elders' and their communities' needs[15] - Building community capacity[17] - Prioritising maintenance of family support, social networks, community and connection[17, 18] - Incorporating wellness-based approaches[17] - Prioritising holistic care plans and practices[16] - Using the Western medical system as a way of complementing the Aboriginal medical system, and working together to treat different illnesses[16] - Moving towards Aboriginal aged care with an emphasis on the cultural needs of residents included in care[10] - Acknowledging that the presence of standards of care does not guarantee a culture-centred approach[10] - A two-eyed seeing approach which represents a step towards decolonisation through recognition of the strengths of both Aboriginal knowledges and Western knowledges. This approach relies on 'understanding, acknowledging and respecting a diversity of perspectives' without giving one precedence over the others.[16, 36, 46]	- Using a strength-based approach for social and emotional wellbeing services for Aboriginal and Torres Strait Islander peoples. This approach includes listening respectfully to the person; building genuine relationships; using appropriate communication skills; critically reflecting on Australia's political, historical, and social context; applying a human-rights based approach; and evaluating the processes and outcomes[13] - Referring to existing community services to guide the establishment of new facilities and services, e.g., interventions undertaken within the Ngaanyatjarra Pitjantjatjara Yankunytjatjara communities in central Australia including the Ngura Aged Care Facility and the Yuendumu Model which was established by the local women's centres[12] - Expansion of Aboriginal-specific aged care services[14] - Integration of care and collaboration between services[19] - Flexible funding models[19] - Include the use of a wide range of cultural practices to promote and assist with spiritual wellbeing and healing (e.g., including the Ngangkaris)[16] - Developing and disseminating principles around two-eyed seeing across all health care systems - Open ended questions added to Care Plans on admission that includes residents' preferences in relation to language, name to be used, food choice, sleep pattern, relaxation, prayer times, observing festivals, meeting family members and visiting own places[10] - Carers should be educated through on-going information sessions, mentoring, discussions around available literature and critical reflection on their services as culturally safe[10] - Aboriginal Aged Care facilities should work towards ensuring standards of care are implemented, followed by a critique of care philosophy[10]

Principles for change	Emerging practice
	• Employment of more Aboriginal carers and collaborative working practices among carers which would result in a more culturally safe clinical environment[10]
	• Co-design of long-term care facilities in collaboration with Indigenous communities and organisations to ensure culturally appropriate care and safe services[11]
	• Policy and staff training to enact trauma-informed care and culturally safe services.[11]

Theme 2: Embedding aged care in community, for community

• Viewing heathy ageing as the ability for Elders to continue in key roles as cultural leaders and the keepers of traditional knowledge[25]	• Recognising and celebrating the significance of Elders self-worth and maintaining involvement in the community.[25] This is linked to the importance of being 'on Country' which remains an important determinant of personal identity, social cohesion and ultimately health[35]
• Promoting a holistically healthy life with an emphasis on language, art, tradition, ceremonies, and the ability to look after country[25]	• Co-Designed Healthy Ageing Programs are needed to ensure relevance and a sense of ownership[31]
• A holistic program should encompass physical activity, mentally stimulating activities, social activities, and health education, with central tenets of family, community, cultural identity, and empowerment. Cultural safety and transport are also necessary[31]	• Modelling good practice examples of successfully co-designed health programs for older Aboriginal Australians such as the Heart Health program and the Ironbark program.[31]
• Increased education and awareness in the community around dementia would benefit the community[27]	
• Having Aboriginal or culturally responsive staff who understand Aboriginal culture[31]	
• Art provides a way to maintain connections to community and Country and is an important form of cultural expression and spirituality.[34]	

Theme 3: Recognising the importance and value of family, kinship, and informal carers

• Health care providers using a two-eyed seeing approach to equally incorporate Western and Indigenous ways of knowing[36]	• The use of a two-eyed approach in Indigenous caregiving which relies on 'understanding, acknowledging, and respecting a diversity of perspectives' without giving one precedence over the others[36]
• Decolonising the biomedical view of dementia is necessary for adopting culturally safe approaches to support Indigenous care receivers and caregivers and involves establishing trusting relationships based on respect[36]	

Principles for change	Emerging practice
• The delivery of culturally and linguistically sensitive and safe care needs to be context-dependent, comprehensive, community-based, diverse, and adaptable. Acknowledging historical traumas and engaging with culturally sensitive training is a much-needed process to support Indigenous informal caregivers[36] • Culture, land and place, traditions, community, and spirituality are essential contributors to carer general wellbeing[35]	• Carer support programs implemented utilising a participatory action research framework in two communities provide evidence for potential effectiveness of a participatory action research carer support program[34] • A culturally responsive tool to assess carer burden, which is developed from a community perspective and not simply adapted for language, is required[35]

Theme 4: An integrated, holistic and strengths-based approach to social and emotional wellbeing and clinical care

• Having a more holistic focus[21] • Focus on aspects of life contributing to wellness[21] • Enable the addressing of care needs that fall outside of traditional requirements of regular/ongoing care delivery[21] • ACCHSs to have a role in developing solutions including a voice at policy level[22] • A need for consistent flexibility in delivery of services[20] • Identifying the incidence of polypharmacy, under prescribing and inappropriate prescribing for Aboriginal peoples and improve prescribing practices[44]	• Consider use of conceptual frameworks alongside more formal tests[21] • National Aboriginal and Torres Strait Islander Flexible Aged Care Programs (NATSIFACP) to be funded to provide flexible, culturally appropriate, and targeted aged care to Aboriginal peoples in their communities, in urban and regional centres as well as rural and remote areas[38, 40] • Interventions, such as prescriber alerts and targeted training for remote area medical professionals in appropriate prescribing for older people, in conjunction with continuing to increase access to appropriate medicines, may improve prescribing. Multifaceted solutions will likely be required for this complex problem[44] • Australian Government investment in medication education strategies that will assist Aboriginal peoples to manage their medicines are required. Until the government engages Aboriginal peoples to assist in health program design, Aboriginal peoples will continue to be excluded from mainstream programs, such as the Home Medicines Review[47] • The Good Spirit, Good Life (GSGL) tool is a measure of quality of life, which is grounded in the collective and holistic Aboriginal worldview of health and well-being. The GSGL tool has 12 culturally informed dimensions that contribute to an older Aboriginal person's quality of life, including family and friends, community, Country, culture, health, the Elder role, respect, spirituality, supports and services, safety and security, future planning, and basic needs. The tool will form part of a suite of resources, including a framework, strategies and training guide[11, 44]

| **Principles for change** | **Emerging practice** |

Theme 5: Provision of culturally appropriate palliative and end-of-life care

• Families knowing what a person's wishes are and understanding the importance of carrying out those wishes[49]	• Widespread information about advanced care planning and making a will[49]
• The need for cultural respect, where people have options and are allowed to express their own preferences[49]	• Program of Experience in the Palliative Approach (PEPA) placements to promote interactive learning and create avenues for Indigenous people and services to learn about palliative care. PEPA also provides an opportunity for palliative care providers to learn about Indigenous philosophy and ways of caring. Given Indigenous communities are diverse, programmes such as PEPA need to and can be tailored to the needs of underserved and local communities[48]
• An improvement in information, education, and screening services for Aboriginal people[49]	
• Communication between the health service, including staff and the family/community, was important when it came to delivering culturally safe end-of-life care[50]	
• Palliative care to be seen as a family/systemic issue as distinct from an individual one. Because of the Aboriginal kinship system, there are often many family members to be accommodated[47]	• The Guidelines for a Palliative Approach for Aged Care in the Community should be produced in a user-friendly format and with accompanying documents in specific Aboriginal languages, or picture format[28]

Discussion – implications of the findings

The following discussion section examines some implications of the rapid review thematic findings for the Commission's work on the revised Aged Care Quality Standards (Standard 5 – Clinical Care). It also draws out implications for the design and delivery of high-quality and safe clinical care for older Aboriginal and Torres Strait Islander peoples more generally.

Principles and recommendations have been developed based on the findings of the literature review and focus on how to achieve culturally safe and responsive aged care service delivery and practices for Aboriginal and Torres Strait Islander peoples. Cultural safety is an Indigenous-led model of care that acknowledges that clinical effectiveness is impeded when there are inherent power imbalances between providers and people receiving care and services.[53] Cultural safety involves recognition of and reflection on one's own beliefs, biases and behaviours that may impact service provision, and is a lifelong exercise.[53] Cultural safety can be fostered through involving care recipients in decision making, enabling access to services that suit the person's needs, establishing trust, and challenging racism; but ultimately, care recipients determine whether the care they receive is culturally safe.[53, 54]

Both cultural safety and cultural responsiveness are important concepts when it comes to providing care for Aboriginal and Torres Strait Islander peoples. While these concepts are related, they are different in their focus and approach. Indigenous Allied Health Australia has developed a cultural responsiveness framework, describing cultural safety and responsiveness as quoted below.

> *Critically, cultural safety does not necessarily require the study of any culture other than one's own: it is essentially about being open-minded and flexible in attitudes towards others. Identifying what makes others different is simple – however, understanding our own culture and its influence on how we think, feel and behave is much more complex, and often goes unquestioned.*
>
> *If cultural safety describes the state we are aiming to reach – safe, accessible, person-oriented, and informed care – cultural responsiveness is the practice to enable it.*
>
> *Cultural responsiveness has cultural safety at its core. Cultural responsiveness is what is needed to transform systems; how individual health practitioners work to deliver and maintain culturally safe and effective care. It is innately transformative and must incorporate knowledge (knowing), self-knowledge and behaviour (being) and action (doing). It is about the approaches we take in engaging with people and how we act to embed what we learn in practice. This requires genuine dialogue to improve practice and health outcomes – it is how we achieve, maintain, and govern cultural safety.*
>
> *Cultural responsiveness goes beyond knowing change is needed, to enabling safe approaches that deliver genuine impact. Responsibility to ensure Aboriginal and Torres Strait Islander peoples receive culturally safe and responsive care sits in many connected spheres: with education providers, service providers and organisations, and health professionals.[54, pp.4-5]*

Guiding principles

All five themes presented in this report are underpinned by common notions and values considered crucial for culturally safe and responsive aged care services, and the experience of these services for Aboriginal and Torres Strait Islander peoples. We have grouped these values into three guiding principles for the culturally safe clinical care of older Aboriginal and Torres Strait Islander peoples. Based on the evidence found during this review and the Elder/expert panel consultations, the principles should underpin understanding and implementation of the Aged Care Quality Standards for Aboriginal and Torres Strait Islander peoples, including Standard 5 – Clinical Care.

Decolonising approaches to ageing and aged care are needed

Mainstream notions of ageing and aged care should be challenged. Often 'clinical care' has a narrow focus, but holistic and integrated care models have many benefits and tend to work better for Aboriginal and Torres Strait Islander peoples, particularly those with multi-morbidity and chronic health conditions. A two-eyed seeing approach can allow for Aboriginal culture, beliefs, and ways of doing to co-exist equally with Western biomedical perspectives and approaches. In practice, this means that medical care is provided simultaneously with traditional, holistic, trauma-specific, and strengths-based healing approaches and worldviews. By intentionally integrating the two knowledge systems, culturally safe and responsive care is far more likely to be received by older Aboriginal and Torres Strait Islander peoples.

Trust and respect are central

A central tenet of Aboriginal and Torres Strait Islander cultures is respect. Building respectful and trusting relationships with older people receiving care is paramount (acknowledging that this will look different for everyone). Health workers, service providers, and aged care systems themselves must respect Aboriginal and Torres Strait Islander peoples, cultures, and history, including the continued impacts of colonisation, racism, discrimination, and socioeconomic disadvantage. Services for older Aboriginal and Torres Strait Islander peoples are often expected to fit into mainstream systems and practices, and this lack of flexibility diminishes the need to respect and respond to both individual and collective cultural and holistic needs.[19] Hence, consideration of the most appropriate service delivery method (such as greater flexibility in services) is key to culturally appropriate ageing and aged care services.

Partnership with families and communities is essential

Whilst genuine and truly person-centred care is very important, the approach to care needs to be more holistic than the person-centred care approach which has traditionally been delivered in mainstream services. Person-centred care should be considered within 'family-centred' and 'community-centred' care and involve genuine partnership with families and communities. It must be recognised that good cultural and holistic practice is the backbone and heart of how Aboriginal Community Controlled Organisations operate.

Community-based and flexible care is considered the better way to provide services and programs for Aboriginal and Torres Strait Islander communities. Supporting and strengthening Aboriginal Community Controlled Organisations to expand into aged care specific services and encouraging partnership and collaborations between service providers to ensure integrated care would be the best strategic approach for government to ensure that Aboriginal and Torres Strait Islander older people receive sufficient aged care services to meet their specific needs.

Recommendations by theme

This section summarises the core elements of each theme introduced in the Findings as they relate to Standard 5 – Clinical Care. Evidence-based recommendations relevant to the Commission's scope and objectives are then presented. Based on the established urgency to act on the findings of the Royal Commission, these recommendations have been designed to simultaneously address current gaps whilst establishing foundations for longer-term system changes in the comprehensive care of older Aboriginal and Torres Strait Islander peoples (as suggested in recommendations of the Royal Commission).

We note that while these recommendations are intended to inform the work of the Commission, the issues they address are systemic. As the current aged care system does not adequately support Aboriginal and Torres Strait Islander peoples, foundational change will require coordination

between government agencies (at federal, state, and local government levels), service providers and community members to ensure sustained and holistic improvements to clinical care outcomes.

We also note recommendations have previously been made that are relevant to Standard 5 – Clinical Care. In particular, the National Aboriginal Community Controlled Health Organisation (NACCHO) made a submission to the Department of Health and Aged Care as part of a consultation about the revised Aged Care Quality Standards.[40] As NACCHO is the Australian national leadership body for Aboriginal and Torres Strait Islander health, we therefore recommend that NACCHO's submission be reviewed and considered when updating the Aged Care Quality Standards.

Flexibility in funding and care is an overarching requirement which is relevant to several recommendations set out below. Funding parameters (including availability and inflexibility) are often a barrier to providing appropriate aged care to Aboriginal and Torres Strait Islander peoples. Addressing these challenges, although difficult, will therefore be important if meaningful improvements to outcomes are to be achieved.

Theme 1: Culture at the centre of aged care and service delivery, including residential care

The revised Aged Care Quality Standards will require provider organisations to facilitate 'culturally safe, trauma-aware and healing-informed care'.[55] Findings from this rapid review highlight the importance of provider engagement with families, communities, and Aboriginal and Torres Strait Islander service providers to inform design and delivery of care.

The evidence also showed the importance of embedding cultural safety, responsiveness, and respect in all aspects of aged care service delivery. Barriers including racism and lack of cultural safety and responsiveness are pervasive. Specific principles that will help enact change include prioritising Aboriginal workforce, enabling access to Aboriginal service providers and holistic care, and ensuring that all workers engage in ongoing cultural safety and responsiveness training.

Mainstream residential aged care homes are generally not considered culturally safe for older Aboriginal and Torres Strait Islander peoples. To overcome the dismissal and marginalisation of Aboriginal culture (a major barrier in this context), it is important to enable family-centred care, promote holistic, wellness-based, and culturally centred care practices, and prioritise true partnership with local communities to incorporate cultural activities in residential aged care.

A 'two-eyed-seeing' approach in this context would allow co-existence of both Western and Aboriginal medical systems. Cultural safety and responsiveness in residential aged care will assist in understanding the needs and preferences of older Aboriginal and Torres Strait Islander peoples, thereby promoting positive health and wellbeing outcomes.

Recommendations

1.1   Aged care services should develop an Indigenous Employment Strategy to enable and strengthen Aboriginal and Torres Strait Islander employment and create culturally safe and responsive workplaces.

Aged care services, particularly those providing services to Aboriginal and Torres Strait Islander peoples, should employ Aboriginal and Torres Strait Islander staff, and ensure that appropriate training and support are provided. Providing training and employment to local Aboriginal and Torres Strait Islander peoples also aligns with traditional practices of younger people caring for older people in communities. At a minimum, services should work with Aboriginal Liaison Officers and facilitate access to Aboriginal service providers (through partnership and linkage with community-controlled services), where possible.

1.2   Aged Care Assessment Teams (ACAT) and aged care services should include Aboriginal and Torres Strait Islander workers.

This would facilitate trust and build respect within communities and would ensure that older Aboriginal and Torres Strait Islander peoples are supported throughout the aged care process, thereby improving outcomes. This is recommended by NACCHO and ATSIAAG (see Appendix 3, Table 6). Training of Aboriginal Health Workers may facilitate this (as per 1.1).

1.3   All workers should engage in regular training to ensure they understand and practice culturally responsive and culturally safe care.

Cultural safety and responsiveness training must be mandated for all non-Indigenous people. Aged care services must have guidelines and a plan for ensuring culturally safe and responsive practice; we therefore recommend that a nationally implementable program for aged care workers be developed. As an example, Indigenous Allied Health Australia (AIHA) have developed a framework on 'Cultural Responsiveness in Action' that can be embedded in program and service delivery (see Appendix 5 – Case studies and resources). The Australian Health Practitioner Regulation Agency (AHPRA) have also developed a clear strategy to ensure consistency, and appropriate and respectful conduct of health practitioners (see Appendix 5 – Case studies and resources).

1.4   Residential aged care homes should develop and implement a model of care that is culturally safe and inclusive of culturally appropriate spaces and activities.

Future residential aged care facilities should also be closely co-designed with Aboriginal communities from the outset, to ensure they are culturally appropriate. One example is the Jimbelunga Nursing Centre Model of Care (see Appendix 5 – Case studies and resources), which is operated by an ACCHO. Jimbelunga was formed to meet the cultural and spiritual needs of Aboriginal and Torres Strait Islander peoples, whilst remaining inclusive of other cultures. In addition, the Healing Foundation has produced resources about providing appropriate trauma-informed aged care services to Stolen Generations survivors (see Appendix 5 – Case studies and resources).

1.5   A culturally focussed 'getting to know you' session should be included at commencement of care.

This may include information relating to broad preferences related to care, routines, spiritual and cultural needs, and involvement of family and community; as well as open-ended, unstructured discussion to better understand the person. The NSW Health Agency for Clinical Innovation highlights some of the tools that are used with older people in the healthcare system (see Appendix 5 – Case studies and resources).

Theme 2: Embedding aged care in community, for community

Community-based programs are important for older Aboriginal and Torres Strait Islander peoples, but barriers must be addressed to make them culturally safe and accessible. Importantly, the success of community programs is largely affected by cultural appropriateness (including being on Country), holistic approach, accessibility, and opportunities for social connection (see Appendix 5 – Case studies and resources, for an example model for a holistic, healthy ageing program). Collaboration between aged care service providers and Aboriginal community-based services could greatly improve cultural safety and uptake of aged care programs (evidenced through the informal aged care support provided by remote art centres); and would promote capacity building and upskilling of Aboriginal workers in communities.

Recommendations

2.1   Upskilling workers and building the capacity of organisations to deliver culturally safe and responsive aged care services should be prioritised.

This expands on Recommendation 1.1, as access to relevant training opportunities and pathways to upskilling should be carefully considered in the Employment Strategy. Improved collaboration between Aboriginal community-controlled services and mainstream aged care service providers will also help to promote recruitment and retention of Aboriginal Health Workers who are skilled in delivering aged care services.

2.2   Services should be provided by Aboriginal Community Controlled Organisations where possible.

This enhances the cultural safety of care and often also supports the continuity and integration of aged care with health and other community services. Many older Aboriginal and Torres Strait Islander peoples have a strong preference for accessing services delivered by local community-controlled organisations.

2.3   Autonomy and flexibility should be facilitated in aged care service delivery, including service hubs situated within alternative or unconventional community settings.

Mainstream referral pathways and service delivery may not always be appropriate. ACCHOs are well placed to develop practical solutions but require a voice at policy level to enact meaningful change.

2.4   Evaluation should be conducted to assess the impact of community services and programs that are not federally funded but effectively provide aged care services to older people.

For example, in some communities, art centres provide informal aged care support in numerous ways, via an integrated and holistic approach that is suitable for older Aboriginal peoples in those communities (and in some cases, where relevant aged care services are not available). The opportunity for formal recognition of these services should be considered.

2.5   Existing systems and programs should be reviewed and transformed to recognise and celebrate the significance of Elders and the importance of their community and cultural standing.

This is linked to the importance of being on Country, Elders' self-worth and need for autonomy over their own care and maintaining involvement in the community.

Theme 3: Recognising the importance and value of family, kinship, and informal carers

This theme emphasises the significant contribution of informal carers (often family) in the overall care and support of older Aboriginal and Torres Strait Islander peoples. The role of informal carers is often underappreciated and, in some cases, not formally recognised. In addition, there are currently significant challenges faced by carers, such as burnout, which are not addressed by aged care systems. Yet, informal care can enable older people to remain in their community (usually the preference) rather than enter residential aged care.

In addition, keeping older people in the community is often seen as a privilege and opportunity to look after older people – it is a part of Aboriginal and Torres Strait Islander culture.[56] However, this preference for community/family care can result in significant time, resource, and emotional impact for carers (such as when managing behavioural and psychological symptoms of dementia at home). Tailored carer support programs that draw on participatory action research approaches, open communication between all parties involved in care, acknowledging historical traumas, and having non-Indigenous health workers engage in cultural safety and responsiveness training, are potentially important initiatives for supporting informal carers and the older people they care for.

Recommendations

3.1   The health and wellbeing of family members and informal carers should be urgently supported.

The health and wellbeing of informal carers directly impacts the older person receiving care. Therefore, supports for informal carers should be urgently delivered. This may include referral to, or provision of, culturally appropriate carer support or other respite services.

3.2   More evidence is needed regarding the role of family and informal carers in providing clinical care for older people and what constitutes best supports for this group.

More explicit evidence and information about the work provided by family and informal carers in Aboriginal and Torres Strait Islander communities should be considered. Potential gaps in funding may then need to be recognised and rectified.

3.3   Clear and accessible information about referral pathways to aged care services and supports should be provided to family members and supporters.

A key enabler is clear pathways to diagnosis and referral. Ideally, these pathways could be embedded into routine assessment, particularly within Aboriginal Community Controlled Organisations to ensure cultural appropriateness (see Appendix 5 – Case studies and resources – for an example of referral pathways for aged care clients within an ACCHO). At a minimum, better communication and support regarding these systems is required, to enable older people (and their families and communities) to navigate aged care systems.

Theme 4: An integrated, holistic, and strengths-based approach to social and emotional wellbeing and clinical care

An effective model of clinical care needs to be integrated, holistic, community-focused, strengths-based and centred around social and emotional wellbeing. It also needs to empower Aboriginal and Torres Strait Islander peoples to access information and services as they age and to promote flourishing.[57]

Flexibility, of services and funding, is critical, as is a clear culturally appropriate diagnosis and referral pathway. A key principle is for Aboriginal community-controlled health services to have a role in developing solutions (including a voice in policy). One example of a flexible, tailored program is the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, which aims to provide flexible, culturally appropriate aged care to Aboriginal peoples in their communities, in urban and regional centres as well as in rural and remote areas.[33] See Appendix 5 – Case studies and resources – for examples of programs and initiatives run by the Department of Health and Aged Care to support Aboriginal and Torres Strait Islander peoples.

There is some evidence that suboptimal medicine prescribing is experienced by Aboriginal and Torres Strait Islander peoples (including polypharmacy), particularly in remote areas. Although more research is required to understand the reasons for this, a contributing factor was identified as communication barriers between clinical staff and older Aboriginal and Torres Strait Islander peoples (particularly those living in the community). In some instances, communication difficulties led to a lack of understanding by the older person (such as being confused about their medicine use).

Potential solutions include clinical staff prioritising relationship management with Aboriginal peoples, such as being respectful and 'interacting with a good attitude'.[43, p.3009] Likewise, there was a clear preference from older Aboriginal peoples to work with clinical staff they trust and are comfortable with; this included either local community staff or Aboriginal health workers. Family and/or community representation during clinical visits was also emphasised to support cultural safety.

This theme also emphasises the needs for culturally safe and valid assessment tools for older Aboriginal and Torres Strait Islander peoples. Some traditional assessment tools, many of which are still currently in use in Aboriginal communities, are often deemed to be culturally unsuitable, unsafe, and therefore ineffectual. This point was highlighted by several studies in relation to dementia, where the use of culturally appropriate resources, assessment and terminology are known to be important for accurate diagnosis but may not be used. Assessment tools should be co-designed. The tools should be based on cultural and spiritual beliefs and how these relate to health and wellbeing, holistically.

One example of emerging practice in the codesign and development of culturally acceptable tools is the Good Spirit Good Life tool (see Appendix 5 – Case studies and resources), which has been introduced to holistically evaluate quality of life for older Aboriginal and Torres Strait Islander peoples. Assessment tools need to be extensively validated before they can be recommended and rolled out widely for use in Aboriginal and Torres Strait Islander communities. In some instances, the appropriateness of assessment tools will be constrained and specific to certain settings.

Recommendations

4.1   Clinical care should be provided within culturally appropriate, trauma-informed, and holistic conceptual frameworks of social and emotional wellbeing.

Western models of biomedical care may not meet the needs of Aboriginal and Torres Strait Islander peoples, whose concept of social and emotional wellbeing is holistic and encompasses the wellbeing of the person as well as the community. Care also needs to be trauma-informed to acknowledge the ongoing impacts of colonisation and poor experiences with institutionalisation that many people have experienced.

4.2   Older people should be empowered to access their own information to enable meaningful discussions and decision-making with family and health professionals about their needs and preferences.

This may include the use of culturally appropriate, jargon-free medication resources and education strategies; and providing comprehensive medication lists. Working with the individual, their family, and community is important to achieving this aim.

4.3   Integrated health services should be developed to encompass primary care, community health, hospital, and aged care, to enable a holistic approach to people living with multiple chronic conditions, including frailty, dementia, and polypharmacy.

Aboriginal and Torres Strait Islander peoples often have multiple and chronic health conditions, which may present at a relatively young age. Integrated health services that are community-centred and holistic, such as being led by ACCOs/ACCHOs, are preferred by Aboriginal and Torres Strait Islander peoples.

4.4   Culturally safe and validated assessment tools that take a strengths-based approach should be used with older Aboriginal and Torres Strait Islander peoples.

This may require assessments to be co-designed or validated with Aboriginal and Torres Strait Islander communities. For some communities, translating documents into specific languages or picture formats may be appropriate (but this will not always be the case). In some cases, the use of frameworks may help to ensure shared understanding of concepts, particularly where these differ between mainstream and Aboriginal and Torres Strait Islander worldviews.

4.5   More evidence is needed regarding multimorbidity and culturally effective interventions that aim to ensure safe use of medicines.

This may involve facilitation of interventions and services through ACCOs/ACCHOs; or having Aboriginal Health Workers, family or carers involved.

Theme 5: Provision of culturally appropriate palliative and end-of-life care

This theme combines two distinct but overlapping areas: the need for culturally suitable approaches to palliative care; and a focus on practical considerations for end-of-life including clarity around logistics and equipment (especially for care in community/on Country). In Aboriginal and Torres Strait Islander cultures, palliative care is often seen as a broader community/family/systemic issue which can differ to a more individualised Western approach toward decision making during end-of-life. Because of the Aboriginal kinship system, there may be many family members to be consulted, and complex issues can arise.

For many Aboriginal and Torres Strait Islander peoples it can also be extremely important to stay on Country for end-of-life care or be taken back to Country for burial. Providing culturally appropriate physical environments is also important. From a practical perspective, it is key to ensure older people and their families/carers are familiar with end-of-life equipment, and that there is clear information about advance care planning (including making a will).

Recommendations

5.1   Information, materials and communication about end-of-life care should be culturally relevant and specific.

Whilst aged care providers have a responsibility to have advance care planning conversations and develop/review documents, it is important that this is done in a culturally appropriate way. There are Aboriginal-specific resources available for palliative care, advance care planning, and making wills, identified in Appendix 5 – Case studies and resources.

5.2   Decision making by older Aboriginal and Torres Strait Islander peoples should empower the person and involve the family and community, where appropriate, in line with a family/community-centred approach.

This will help to ensure that approaches to palliative and end-of-life care are culturally appropriate; and to respect nuanced differences that may exist between individuals, families, and communities.

5.3   Palliative and end-of-life care should include discussions with Aboriginal and Torres Strait Islander peoples and their family members and carers about their preferences for and importance of dying/burial on Country.

This acknowledges the importance of Country for many Aboriginal and Torres Strait Islander peoples and places the responsibility with service providers to help facilitate the needs and preferences of the older person, whilst providing support to families and communities in meeting these needs.

5.4   Better understanding of, and access to, services and equipment for end-of-life care is essential.

It has been identified that end-of-life equipment is not always accessible; or when available, it is unclear how to use the equipment. Greater information and support are therefore required to ensure that care needs are met.

Conclusion

This review demonstrates the importance of culturally safe, responsive, and holistic approaches to ageing and aged care for older Aboriginal and Torres Strait Islander peoples. Of equal importance is 'ageing well' which encompasses a strong focus on community, cultural knowledge, Country, and the role as an Elder and older person.

The five themes from the review emphasise the centrality of the preservation and expression of culture, cultural identity, and connection to family, community and Country for older Aboriginal and Torres Strait Islander peoples. It is important to recognise that this could differ from the values and priorities set out in mainstream aged care frameworks, policies, and practices and from assumptions embedded in a Western biomedical model of health and illness.

This report provides actionable recommendations to support the revised Aged Care Quality Standards, specifically Standard 5- Clinical Care. Critical foundational and system-level change is needed through much more coordinated and collaborative efforts between governments, providers, and communities to ensure that culturally safe and responsive clinical care is provided in the aged care sector for older Aboriginal and Torres Strait Islander peoples.
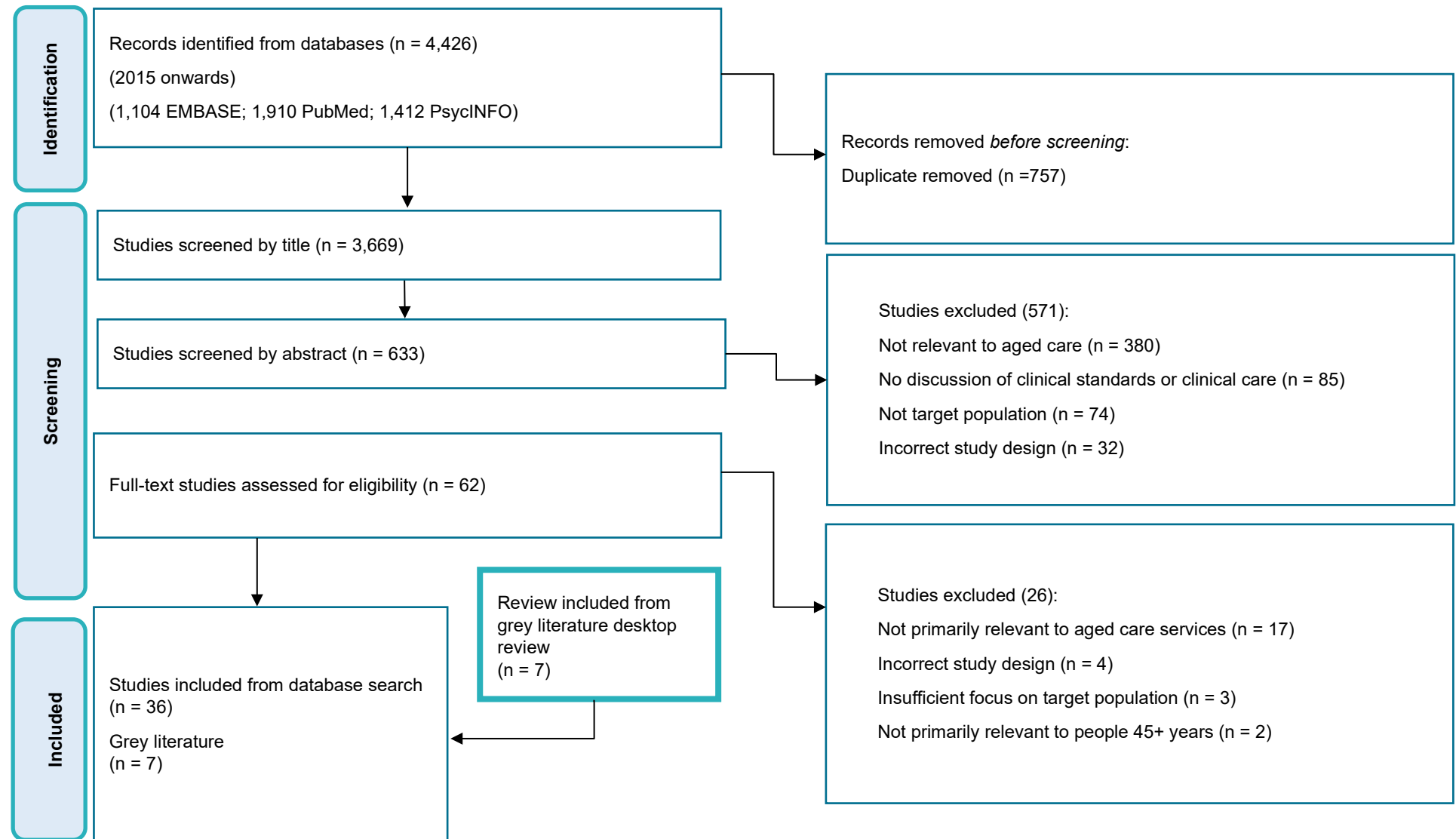
References

1.   Radford K, Allan W, Donovan T, Delbaere K, Garvey G, Broe GA, et al. Sharing the Wisdom of Our Elders Final Report. Sydney: Neuroscience Research Australia; 2019.

2.   Royal Commission into Aged Care Quality and Safety. Final Report: Care, Dignity and Respect 2021.

3.   Lewis ET, Howard L, Cardona M, Radford K, Withall A, Howie A, et al. Frailty in Indigenous Populations: A Scoping Review. Front Public Health. 2021;9:785460.

4.   Al-Yaman F. The Australian Burden of Disease Study: impact and causes of illness and death in Aboriginal and Torres Strait Islander people, 2011. Public Health Res Pract. 2017;27(4).

5.   Radford K, Mack HA, Draper B, Chalkley S, Daylight G, Cumming R, et al. Prevalence of dementia in urban and regional Aboriginal Australians. Alzheimers Dement. 2015;11(3):271-9.

6.   Garritty C, Gartlehner G, Nussbaumer-Streit B, King VJ, Hamel C, Kamel C, et al. Cochrane Rapid Reviews Methods Group offers evidence-informed guidance to conduct rapid reviews. J Clin Epidemiol. 2021;130:13-22.

7.   Tricco AC, Langlois, E.V., Straus, S.E. Rapid reviews to strengthen health policy and systems: a practical guide. Geneva: World Health Organization. 2017.

8.   Dang D, Dearholt S, Bissett K, Ascenzi J, Whalen M. Johns Hopkins evidence-based practice for nurses and healthcare professionals: Model and guidelines. 4th ed. ed: Sigma Theta Tau International; 2022.

9.   Harfield S, Pearson O, Morey K, Kite E, Canuto K, Glover K, et al. Assessing the quality of health research from an Indigenous perspective: the Aboriginal and Torres Strait Islander quality appraisal tool. BMC Med Res Methodol. 2020;20(79).

10.   Sivertsen N, Harrington A, Hamiduzzaman M. Exploring Aboriginal aged care residents' cultural and spiritual needs in South Australia. BMC Health Serv Res. 2019;19(1):477.

11.   Brooks D, Johnston S, Parker C, Cox L, Brodie M, Radbourne C, et al. Elements of long-term care that promote quality of life for Indigenous and First Nations Peoples: A mixed methods systematic review. Gerontologist. 2022.

12.   Davy C, Kite E, Aitken G, Dodd G, Rigney J, Hayes J, et al. What keeps you strong? A systematic review identifying how primary health-care and aged-care services can support the well-being of older indigenous peoples. Australasian Journal on Ageing. 2016;35(2):90-7.

13.   Gibson C, Crockett J, Dudgeon P, Bernoth M, Lincoln M. Sharing and valuing older Aboriginal people's voices about social and emotional wellbeing services: a strength-based approach for service providers. Aging Ment Health. 2020;24(3):481-8.

14.   Larke BM, Broe GA, Daylight G, Draper B, Cumming RG, Allan W, et al. Patterns and preferences for accessing health and aged care services in older Aboriginal and Torres Strait Islander Australians. Australas J Ageing. 2021;40(2):145-53.

15.   Parrella A, Pearson O, Davy C, Barrie H, Mott K, Morey K, et al. Understanding culturally safe aged care from the perspectives of older Aboriginal Australians in rural and remote communities. Health Promot J Austr. 2022;33(3):566-75.

16.   Sivertsen N, Harrington A, Hamiduzzaman M. 'Two-eyed seeing': The integration of spiritual care in aboriginal residential aged care in South Australia. Journal of Religion, Spirituality & Aging. 2020;32(2):149-71.

17.   Webkamigad S, Rowe R, Peltier S, Froehlich Chow A, McGilton KS, Walker JD. Identifying and understanding the health and social care needs of Indigenous older adults with multiple chronic conditions and their caregivers: a scoping review. BMC Geriatr. 2020;20(1):145.

18.   Yashadhana A, Howie A, Veber M, Cullen P, Withall A, Lewis E, et al. Experiences and perceptions of ageing among older First Nations Australians: A rapid review. Australas J Ageing. 2022;41(1):8-19.

19.   ATSIAAG. Integrated culturally sensitive services for older Aboriginal and Torres Strait Islander people: Practical solution or pipe dream? Sydney, NSW: Australian Association of Gerontology (AAG) Aboriginal and Torres Strait Islander Ageing Advisory Group (ATSIAAG); 2020.

20.   Malay R, Aitken G. AAG's ATSIAAG 2019 Workshop Report Summary: 'Integrated culturally sensitive services for older Aboriginal and Torres Strait Islander people: Practical solution or pipe dream?'. Australas J Ageing. 2020;39(4):391-2.

21.   Bell D, Lindeman MA, Reid JB. The (mis)matching of resources and assessed need in remote Aboriginal community aged care. Australas J Ageing. 2015;34(3):171-6.

22.   Bryant J, Noble N, Freund M, Rumbel J, Eades S, Sanson-Fisher R, et al. How can dementia diagnosis and care for Aboriginal and Torres Strait Islander people be improved? Perspectives of healthcare providers providing care in Aboriginal community controlled health services. BMC Health Serv Res. 2021;21(1):699.

23.   Dawson A, Harfield S, Davy C, Baker A, Kite E, Aitken G, et al. Aboriginal community-controlled aged care: principles, practices and actions to integrate with primary health care. Prim Health Care Res Dev. 2021;22:e50.

24.   National Advisory Group for Aboriginal and Torres Strait Islander Aged Care (NAGATSIAC). Submission to the Royal Commission into Aged Care Quality and Safety. https://agedcare.royalcommission.gov.au/system/files/2020-06/RCD.9999.0222.0001.pdf2019.

25.   Coombes J, Lukaszyk C, Sherrington C, Keay L, Tiedemann A, Moore R, et al. First Nation Elders' perspectives on healthy ageing in NSW, Australia. Aust N Z J Public Health. 2018;42(4):361-4.

26.   Cox T, Hoang H, Goldberg LR, Baldock D. Aboriginal community understandings of dementia and responses to dementia care. Public Health. 2019;172:15-21.

27.   Gubhaju L, Turner K, Chenhall R, Penny E, Drmota S, Hawea S, et al. Perspectives, understandings of dementia and lived experiences from Australian Aboriginal people in Western Australia. Australas J Ageing. 2022;41(3):e284-e90.

28.   Holloway K, Toye C, McConigley R, Tieman J, Currow D, Hegarty M. National consultation informing development of guidelines for a palliative approach for aged care in the community setting. Australas J Ageing. 2015;34(1):21-6.

29.   Lindeman M, Mackell P, Lin X, Farthing A, Jensen H, Meredith M, et al. Role of art centres for Aboriginal Australians living with dementia in remote communities. Australas J Ageing. 2017;36(2):128-33.

30.   Mackell P, Squires K, Fraser S, Cecil J, Meredith M, Malay R, et al. Art centres supporting our Elders - 'old people, that's where our strength comes from' - results from a national survey of Australian Aboriginal and Torres Strait Islander community controlled art centres. Rural Remote Health. 2022;22(2):6850.

31.   Wettasinghe PM, Allan W, Garvey G, Timbery A, Hoskins S, Veinovic M, et al. Older Aboriginal Australians' Health Concerns and Preferences for Healthy Ageing Programs. Int J Environ Res Public Health. 2020;17(20).

32.   Broe GA. What do Aboriginal Australians want from their aged care system? Community connection is number one. The Conversation. 2019.

33.   Arkles R, Jankelson C, Radford K, Jackson Pulver L. Family caregiving for older Aboriginal people in urban Australia: Disclosing worlds of meaning in the dementia experience. Dementia (London). 2020;19(2):397-415.

34.   LoGiudice D, Josif C, Malay R, Hyde Z, Haswell MR, Lindeman M, et al. Strong Carers, Strong Communities: a cluster randomised controlled trial to improve wellbeing of family carers of older people in remote Aboriginal communities. Rural Remote Health. 2021;21(3):6078.

35.   LoGiudice D, Josif CM, Malay R, Hyde Z, Haswell M, Lindeman MA, et al. The Well-Being of Carers of Older Aboriginal People Living in the Kimberley Region of Remote Western Australia: Empowerment, Depression, and Carer Burden. J Appl Gerontol. 2021;40(7):693-702.

36.   Racine L, Ford H, Johnson L, Fowler-Kerry S. An integrative review of Indigenous informal caregiving in the context of dementia care. Journal of Advanced Nursing. 2022;78(4):895-917.

37.   Smith K, Gilchrist L, Taylor K, Clinch C, Logiudice D, Edgill P, et al. Good Spirit, Good Life: A Quality of Life Tool and Framework for Older Aboriginal Peoples. Gerontologist. 2021;61(5):e163-e72.

38.   Lowe M, Coffey P. Effect of an ageing population on services for the elderly in the Northern Territory. Aust Health Rev. 2019;43(1):71-7.

39.   Smith S, Martin-Khan M, Travers C. What constitutes a quality community aged care service-client perspectives: An international scoping study. Health Soc Care Community. 2022;30(6):e3593-e628.

40.   ATSIAAG. Assuring equity of access and quality outcomes for older Aboriginal and Torres Strait Islander peoples: What needs to be done. In: (ATSIAAG) AAoGAAaTSIAAG, editor. 2017.

41.   Australian Government Department of Health and Aged Care. Actions to support older Aboriginal and Torres Strait Islander people: A guide for aged care providers. Canberra: Department of Health and Aged Care; 2019.

42.   Gilbert A, Owusu-Addo E, Feldman P, et al. Models of integrated care, health and housing: Royal Commission into Aged Care Quality and Safety; 2020.

43.   Swain LS, Barclay L. Exploration of Aboriginal and Torres Strait Islander perspectives of Home Medicines Review. Rural Remote Health. 2015;15:3009.

44.   Page A, Hyde Z, Smith K, Etherton-Beer C, Atkinson DN, Flicker L, et al. Potentially suboptimal prescribing of medicines for older Aboriginal Australians in remote areas. Med J Aust. 2019;211(3):119-25.

45.   Gilchrist L, Hyde Z, Petersen C, Douglas H, Hayden S, Bessarab D, et al. Validation of the Good Spirit, Good Life quality-of-life tool for older Aboriginal Australians. Australas J Ageing. 2022.

46.   Racine L, Johnson L, Fowler-Kerry S. An integrative review of empirical literature on indigenous cognitive impairment and dementia. Journal of Advanced Nursing. 2021;77(3):1155-71.

47.   Spelten ER, MacDermott S, Morgan S, Mitchell L, van Vuuren J. Palliative Care in Rural Aboriginal Communities: Conversations Around Experiences and Needs. Journal of hospice and palliative nursing : JHPN : the official journal of the Hospice and Palliative Nurses Association. 2021;23(6):579-83.

48.   Shahid S, Ekberg S, Holloway M, Jacka C, Yates P, Garvey G, et al. Experiential learning to increase palliative care competence among the Indigenous workforce: an Australian experience. BMJ Support Palliat Care. 2019;9(2):158-63.

49.   Thompson S, Lyford M, Papertalk L, Holloway M. Passing on wisdom: exploring the end-of-life wishes of Aboriginal people from the Midwest of Western Australia. Rural Remote Health. 2019;19(4):5444.

50.   Wood MP, Forsyth S, Dawson H. Remote area nurses' perceptions of the enablers and barriers for delivering end-of-life care in remote Australia to Aboriginal people who choose to pass away on their traditional lands. Rural Remote Health. 2021;21(3):6485.

51.   Woods JA, Newton JC, Thompson SC, Malacova E, Ngo HT, Katzenellenbogen JM, et al. Indigenous compared with non-Indigenous Australian patients at entry to specialist palliative care: Cross-sectional findings from a multi-jurisdictional dataset. PLoS One. 2019;14(5):e0215403.

52.   IPEPA Project Team. Cultural considerations: Providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples. Brisbane: Indigenous component of the Program of Experience in the Palliative Approach (IPEPA), Queensland University of Technology; 2020.

53.   Laverty M, McDermott DR, Calma T. Embedding cultural safety in Australia's main health care standards. Medical Journal of Australia. 2017;1:15-6.

54. Indigenous Allied Health Australia (IAHA). Cultural responsiveness in action: An IAHA Framework. ACT: Indigenous Allied Health Australia Ltd.; 2019.

55. Healing Foundation. Glossary of Healing Terms 2020 [Available from: https://healingfoundation.org.au//app/uploads/2020/07/HF_Glossary_of_Healing_Terms_A3_Poster_Jul2020_V1.pdf.

56. Power J. Some older Australians consider residential aged care a 'death sentence'. Sydney Morning Herald. 2019.

57. Dudgeon P, Bray A, Walker R. Embracing the emerging Indigenous psychology of flourishing. Nature Reviews Psychology. 2023;2(5):259-60.

58. National Aboriginal Community Controlled Health Organisation (NACCHO). Submission to the Royal Commission into Aged Care Quality and Safety. https://agedcare.royalcommission.gov.au/system/files/2020-07/AWF.001.04347.pdf2019.

Appendix 1 – PRISMA flow diagram

Identification

Records identified from databases (n = 4,426)

(2015 onwards)

(1,104 EMBASE; 1,910 PubMed; 1,412 PsycINFO)

Records removed *before screening*:

Duplicate removed (n =757)

Screening

Studies screened by title (n = 3,669)

Studies screened by abstract (n = 633)

Studies excluded (571):

Not relevant to aged care (n = 380)

No discussion of clinical standards or clinical care (n = 85)

Not target population (n = 74)

Incorrect study design (n = 32)

Full-text studies assessed for eligibility (n = 62)

Studies excluded (26):

Not primarily relevant to aged care services (n = 17)

Incorrect study design (n = 4)

Insufficient focus on target population (n = 3)

Not primarily relevant to people 45+ years (n = 2)

Included

Review included from grey literature desktop review
(n = 7)

Studies included from database search
(n = 36)

Grey literature
(n = 7)

Appendix 2 – Peer-reviewed research included in the rapid review

Table 5 - Summary of peer-reviewed research studies included in the rapid review

Author	Title	Location	Design	Population	Sample	Summary of findings
Arkles et al. (2020)[33] **Evidence Level: III**	Family caregiving for older Aboriginal people in urban Australia: Disclosing worlds of meaning in the dementia experience.	Various (Australia)	Qualitative	Family caregiver of people with dementia	5	Participant accounts of caregiving expressed three patterns of meaning, which included care as nourishment, care as custodianship, and care as holding. Care as nourishment encompasses carers sustaining the person with dementia's place in the world (intergenerational care) and the distress that carers experience. Care as custodianship describes the experience of the carer's carer, and the concern for the carer's ability to care for the person with dementia amidst their own chronic health conditions. Care as holding refers to closeness, and "waiting" during end-stage dementia.
Bell et al. (2015)[21] **Evidence Level: III**	The (mis)matching of resources and assessed need in remote Aboriginal community aged care.	Remote	Qualitative (interviews/ focus groups; *Thematic Analysis*)	Aboriginal community aged care assessors and service users.	18	This paper examined the provision of aged care needs assessments for Aboriginal peoples in remote central Australia and highlights a misalignment between what is articulated/expected in program documents compared with what is possible. The findings suggest that older Aboriginal peoples wish to remain on their homelands and this preference often had greater influence on aged care assessment outcomes than physical or medical requirements, resulting in hardships for both carers and the older person.
Brooks et al. (2022)[11] **Evidence Level: III**	Elements of long-term care that promote quality of life for Indigenous and First Nations peoples: A mixed methods systematic review.	Various (Global)	Review (Systematic)	Indigenous persons in long-term care setting.	18 articles	This review identified elements/models of care that could promote Quality of Life for Indigenous peoples residing in long-term care. Implications for practice arising from this review include codesign and collaboration honouring cultural safety principles; strengthening the Indigenous and First Nations workforce; building capacity and confidence of non-Indigenous health workers; and embedding trauma-informed care in all aged care services.
Bryant et al. (2021)[22] **Evidence Level: III**	How can dementia diagnosis and care for Aboriginal and Torres Strait Islander peoples be improved? Perspectives of healthcare providers providing care in Aboriginal community-controlled health services.	Urban, Regional & Remote	Qualitative (Interviews; *Thematic Analysis*)	Care providers	16	The study explored current dementia processes from the perspective of care providers in ACCHSs. ACCHS staff perceived that dementia was under-recognised and under-diagnosed for Aboriginal patients attending ACCHSs due to a combination of limited community awareness about dementia, denial, and stigma, competing priorities for both the community and health services, and challenges for healthcare staff related to lack of confidence, education, and training about dementia. Pathways providing appropriate clinical referral for patients were often not available.

Author	Title	Location	Design	Population	Sample	Summary of findings
Coombes et al. (2018)[25] **Evidence Level: III**	First Nation Elders' perspectives on healthy ageing in NSW, Australia.	Urban *(Gurrigai, Darkinjung, Gadigal, Darug, Wiradjuri and Ewing Nations)*	Qualitative (Yarning; *Thematic Analysis*)	Elders 45+	76	This study asked Elders in New South Wales how they viewed healthy ageing for themselves. Elders acknowledged the importance of maintaining key roles as cultural leaders and knowledge keepers and the ability to look after and care for country. The significance of self-worth and maintaining involvement in the community was prioritised. Elders discussed the need to incorporate their own knowledge, belief systems and realities, plus their own community's culture, with an emphasis on holistic concepts of ageing.
Cox et al. (2019)[26] **Evidence Level: III**	Aboriginal community understandings of dementia and responses to dementia care.	Rural	Mixed methods (Survey)	Aboriginal community members (18+)	50	This study illustrated Aboriginal understandings of dementia and responses to dementia care from the perspective of a rural Aboriginal community. The results indicated a limited understanding of dementia among participants. Aboriginal participants highlighted the cultural obligation of caring for their own family and community members living with dementia. This obligation also included 'covering up and hiding' dementia symptoms which had unintended consequences of isolating carers and causing delays with accessing dementia support and carer respite.
Davy et al. (2016)[12] **Evidence Level: III**	What keeps you strong? A systematic review identifying how primary healthcare and aged-care services can support the well-being of older Indigenous peoples.	Various (Global)	Review (Systematic; *qualitative studies only*)	Older Indigenous peoples (50+), and their network. *and* Care providers		This review reported the perceptions of older Indigenous people and care providers regarding how services could support the well-being of older Indigenous people. Suggested ways in which primary healthcare or aged-care services could support the well-being of older Indigenous people fell predominantly into three categories which focused on maintaining cultural identity, promoting independence with the support of autonomy and self-determination, and providing culturally safe health and aged care services.
Dawson et al. (2021)[23] **Evidence Level: III**	Aboriginal community-controlled aged care: principles, practices, and actions to integrate with primary health care.	Urban	Qualitative (Yarning; *case study analysis*)	ACCO and ACCHO staff	46 (include n=20 aboriginal staff).	This study explored the overarching principles, practices, enablers, and challenges of Aboriginal community-controlled services that provide aged care tailored to the needs of older Indigenous people. Common to the two in depth case studies explored was the centrality of culture and respect in the provision of primary care. This study demonstrated that ACCHOs may be effective aged care providers if adequately resourced and supported to integrate both aged care and primary health care service delivery models.
Gibson et al. (2020)[13] **Evidence Level: III**	Sharing and valuing older Aboriginal people's voices about social and emotional wellbeing services: a strength-based approach for service providers.	Rural *(Wiradjuri)*	Qualitative (Yarning; *Thematic Analysis*)	Older Aboriginal peoples (40+)	16	This research focused on services that relate to social and emotional wellbeing from the perspective of Elders and older Aboriginal people. There are several barriers identified, particularly around respectful and inclusive services, accessibility, and the need for more transparent processes relating to the service. A strengths-based approach is proposed and utilised to reflect the voices more accurately in this area of research and literature.
Gilchrist et al. (2022)[45] **Evidence Level: II**	Validation of the Good Spirit, Good Life quality-of-life tool for older Aboriginal Australians.	Urban and Regional	Quantitative (Cross-sectional; Tool validation)	Older Aboriginal peoples (45+)	120	This study evaluated the psychometric properties of the Good Spirit, Good Life (GSGL) tool with older Aboriginal peoples living in urban and regional areas. This study demonstrated that the GSGL tool is a valid quality of life measure for older Aboriginal Australians, with acceptable convergent, concurrent, and known-groups validity. The tool is grounded in the collective and holistic Aboriginal worldview of health and wellbeing.

Author	Title	Location	Design	Population	Sample	Summary of findings
Gubhaju et al. (2022)[27] **Evidence Level: III**	Perspectives, understandings of dementia and lived experiences from Australian Aboriginal people in Western Australia.	Urban and Regional	Qualitative (Interviews; *Thematic Analysis)*	Aboriginal community members (18+) *and* ACCHO care providers	39 (23 = Aboriginal community members)	This study investigates understandings about dementia and lived experiences from carers among community-dwelling Aboriginal peoples and ACCHO staff in Western Australia. This research shows the need for increased awareness of dementia in the community through culturally appropriate public health messaging and advice from health professionals. It also demonstrates an urgent need for culturally secure services focussing on dementia care for Aboriginal people.
Holloway et al. (2015)[28] **Evidence Level: III**	National consultation informing development of guidelines for a palliative approach for aged care in the community setting.	Various (Australia)	Qualitative (Interviews/ Focus Groups; *Thematic Analysis)*	Care Providers	172 (8 = Aboriginal or Torres Strait Islander)	This study contains perspectives from key stakeholders to inform the development of national guidelines for a palliative approach to aged community care. Key considerations specific to the care of Aboriginal and Torres Strait Islander peoples include respect for the location of care, death and dying processes and traditional healing practices. Aboriginal health workers were commended as 'cultural brokers' in overcoming some of the barriers to providing culturally appropriate end of life care to older Aboriginal Australians.
Larke et al. (2021)[14] **Evidence Level: II**	Patterns and preferences for accessing health and aged care services in older Aboriginal and Torres Strait Islander Australians.	Urban and Regional	Mixed method (Cross- sectional)	Aboriginal and Torres Strait Islander peoples (60+)	336	The study aimed to determine preferences for health and aged care services in Aboriginal and Torres Strait Islander Australians. The findings support previous research indicating that health services under Aboriginal community control are the preferred option. This study also indicated that the preference for Aboriginal controlled service provision becomes more pronounced when people start engaging with aged care or disability support services.
Lindeman et al. (2017)[29] **Evidence Level: III**	Role of art centres for Aboriginal Australians living with dementia in remote communities.	Remote	Review (literature search)	Aboriginal art centres in remote areas	14 articles plus additional articles from reference lists/ recommendations	This review explored the role art centres in remote Communities have for Aboriginal and Torres Strait Islander Australians living with dementia. No evidence was found that remote art centres have been providing formal programmes to cater particularly for people living with dementia. However, the findings indicate that art centres have the potential to play a formal and collaborative role in supporting people living with dementia. They already provide an important role in maintaining traditions, culture, and practices unique to Aboriginal and Torres Strait Islander peoples.
LoGiudice et al. 2021[34] **Evidence Level: I**	Strong Carers, Strong Communities: a cluster randomised controlled trial to improve wellbeing of family carers of older people in remote Aboriginal communities.	Remote	Randomised Controlled Trial (RCT)	Carers of older Aboriginal Australians (45+)	100	This study reported the effects of a carer support program, developed with a participatory action research approach, on carers' sense of empowerment, carer strain and depression levels. In the study a significant decrease in depression scores was observed in the participatory action research program group, although the change in score was not significantly different to that occurring in the control group (general education sessions). This study demonstrates that a participatory action research program for carers of older Indigenous Australians is feasible and can potentially improve carer mental wellbeing.

Author	Title	Location	Design	Population	Sample	Summary of findings
LoGiudice et al. 2021[35] **Evidence Level: II**	The Well-Being of Carers of Older Aboriginal People Living in the Kimberley Region of Remote Western Australia: Empowerment, Depression, and Carer Burden.	Remote *(Ardyaloon, Looma, Warmun, and Wirrima)*	Quantitative (cross-sectional)	Carers of older Aboriginal Australians (45+)	124	This study reports demographic features and wellbeing of carers of Aboriginal Australians aged ≥45 years in remote communities. Aboriginal carers tended to be 10-15 years younger than non-Aboriginal carers; and ¾ identified as children or grandchildren of the person cared for (compared to ¼ in the general population). Relationships between carer burden, feeling empowered, and depression were explored.
Lowe et al. (2019)[38] **Evidence Level: II**	Effect of an ageing population on services for the Elderly in the Northern Territory.	Northern Territory	Quantitative (Data linkage)	65+ years for non-Aboriginal people and 50+ years for Aboriginal people		This study described the growing population of older people in the Northern Territory and the challenges of delivering aged care services. Aged care services in the Northern Territory have higher ratios of community-based services to residential aged care facilities; but NT programs deliver fewer community service types and at greater cost compared with interstate services. Nearly 80% of older Aboriginal peoples in the Northern Territory live in very remote and remote areas which have been bolstered by the NATSIFACP in recent times.
Mackell et al. (2022)[30] **Evidence Level: III**	Art centres supporting our Elders - 'old people, that's where our strength comes from' - results from a national survey of Australian Aboriginal and Torres Strait Islander community-controlled art centres.	Various (Australia)	Mixed methods (Survey)	Art centre stakeholders and community members	53	This study reported the results of a national survey that investigated how art centres support older Aboriginal and Torres Strait Islander peoples' wellbeing. The art centre participants emphasised that art centres provided routine, purpose and work that placed a high value on their cultural knowledge and the creation of a safe place. This study also highlighted the collaboration which exists between art centres and local aged care and healthcare providers, little of which is formally documented.
Malay et al. (2020)[20] **Evidence Level: IV**	AAG's ATSIAAG 2019 Workshop Report Summary: 'Integrated culturally sensitive services for older Aboriginal and Torres Strait Islander peoples: Practical solution or pipe dream?'.		Qualitative (Workshop)		35 (ATSIAAG workshop attendees)	This study reports findings from a National Workshop held by the Aboriginal and Torres Strait Islander Ageing Advisory Group (ATSIAAG) of the Australian Association of Gerontology (AAG). Recommendations from this workshop included the need for increased Elder consultation, more flexible funding models, culturally responsive aged care services for Aboriginal people, and the redress of institutional racism.
Page et al., (2019)[44] **Evidence Level: II**	Potentially suboptimal prescribing of medicines for older Aboriginal Australians in remote areas.	Remote	Quantitative (Cross-sectional study)	Aboriginal people 45+ with complete medication histories.	289	This study evaluated the prevalence of polypharmacy, under-prescribing, and potentially inappropriate prescribing for Aboriginal peoples in the Kimberley region aged 45+ years. Three of five older Aboriginal Australians in this study had at least one issue of potentially suboptimal prescribing. It is likely that suboptimal prescribing increases the risk of poor health outcomes for remote Aboriginal Australians, and interventions that optimise prescribing are needed.
Parrella et al. (2022)[15] **Evidence Level: III**	Understanding culturally safe aged care from the perspectives of older Aboriginal Australians in rural and remote communities.	Rural and Remote	Qualitative (interviews)	Aboriginal people 50+	63	This study explored the views of older Aboriginal peoples living in rural and remote areas to provide insights into what culturally safe aged care could look like. Participants described culturally safe aged care services as those which maintained connection to participants' culture, traditional lands and community. The themes identified included maintaining cultural identity, culturally informed service delivery, culturally competent workforce, culturally supportive environments and partnerships and collaboration within the aged care service system.

Author	Title	Location	Design	Population	Sample	Summary of findings
Racine et al. (2022)[36] **Evidence Level: III**	An integrative review of Indigenous informal caregiving in the context of dementia care.	Various (Global)	Review (Integrative)	Indigenous caregivers when caring for someone presenting dementia and cognitive impairment	51 articles	This review explored the needs and challenges of Indigenous informal caregivers caring for people living with dementia in Indigenous communities. Important themes and direction for the future include the decolonisation of Western biomedical perspectives of dementia, understanding the centrality of culturally safe care, using Indigenous informal caregivers' experiences, proactive dementia education and community learning, and family and community centred care.
Racine et al. (2021)[46] **Evidence Level: III**	An integrative review of empirical literature on indigenous cognitive impairment and dementia.	Various (Global)	Review (Integrative)	Older Indigenous patients living with cognitive impairment and dementia	34 articles	This review synthesises findings about Indigenous perspectives on cognitive impairment and dementia. Key themes included the frequency of dementia and cognitive impairment in Indigenous populations; the importance of culturally appropriate assessment and tools; and intersectoral collaboration. The synthesis indicated the need to prioritise Indigenous perspectives in caring for Indigenous people; provide attention to cultural understandings of disease in clinical practice and policymaking; increase global initiatives that value and prioritise Indigenous perspectives; and explore dementia from Indigenous perspectives and away from Western biomedical conceptualisations of dementia.
Shahid et al. (2019)[48] **Evidence Level: III**	Experiential learning to increase palliative care competence among the Indigenous workforce: An Australian experience.	Various (Australia)	Qualitative (Interviews; *Thematic Analysis*)	PEPA staff and Indigenous PEPA participants	20 current and former PEPA staff and 26 PEPA participants (8 staff and 18 participants were of Indigenous background)	This paper explored the Program of Experience in the Palliative Approach's (PEPA's) Indigenous clinical placement program, a culturally respectful teaching program designed for Indigenous Health Workers to learn competencies in end-of-life care. This review confirmed the positive impact of an experiential learning program on the upskilling of Indigenous Health practitioners in end-of-life care. The positive impact of palliative care providers learning about Indigenous philosophy and ways of caring was also highlighted.
Sivertsen et al. (2019)[10] **Evidence Level: III**	Exploring Aboriginal aged care residents' cultural and spiritual needs in South Australia.	Urban and Rural	Qualitative (Interpretive Descriptive Approach)	Older Aboriginal persons 50+ in an aged care *and* carers in these facilities	26 (7=Aboriginal residents 19=carers)	This study explored the factors and issues that impact on the integration of cultural care into residential aged care for Aboriginal residents through interviews with residents and carers. Three primary themes emerged around lack of resources and funding, care practices, and marginalisation of Aboriginal culture within aged care facilities. The conclusion was a belief that cultural inclusion in care may enrich Aboriginal residents' daily life, health and wellbeing in residential aged care facilities.
Sivertsen et al. (2020)[16] **Evidence Level: III**	'Two-eyed seeing': The integration of spiritual care in aboriginal residential aged care in South Australia.	Urban and Rural	Qualitative (Interpretive Descriptive Approach)	Older Aboriginal persons 50+ in an aged care *and* carers in these facilities	26 (7=Aboriginal residents 19=carers)	This study investigated the system determinants that hinder the integration of spiritual care into general aged care for Aboriginal residents. Themes identified included a lack of understanding of Aboriginal spiritual beliefs and practices and spiritual wellbeing; a lack of understanding on how to provide dignified and preferred care to Aboriginal residents; and insufficient funding and staffing available to organise Aboriginal spiritual and wellbeing activities.

Author	Title	Location	Design	Population	Sample	Summary of findings
Smith et al. (2021)[37] **Evidence Level: III**	Good Spirit, Good Life: A Quality-of-Life Tool and Framework for Older Aboriginal Peoples.	Urban	Qualitative (Yarning, Interviews and Pilot testing)	Aboriginal Australians 45+	56	This project aimed to develop and validate a quality-of-life tool for older Aboriginal Australians. Twelve interconnected factors of family and friends, community, Country, culture, Elder role, respect, health, beliefs, services and supports, future plans, safety and security, and basic needs were identified and developed into key questions to develop the tool. The tool has continued to influence service provision and care for older Aboriginal people.
Smith et al. (2022)[39] **Evidence Level: III**	What constitutes a quality community aged care service-client perspectives: An international scoping study.	Various (Global)	Review (Scoping)	50+ years for Aboriginal and Torres Strait Islander peoples and 65+ years for non-Indigenous	62 articles (13 with Aboriginal and Torres Strait Islander cohort; 5 explores their experiences)	This study identified client-derived quality measures to operate community aged care services. Synthesis of the findings identified five key quality domains important to Aboriginal persons receiving aged care which included staff knowledge, respect for clients, a person-centred approach, a collaborative partnership, and clear communication. In addition, five key quality measures most often included in the articles were client satisfaction, client experience, access and choice, preference and expectations of care, and service quality.
Spelten et al. (2021)[47] **Evidence Level: III**	Palliative Care in Rural Aboriginal Communities: Conversations Around Experiences and Needs	Rural *(Lands of the Lattji Latji, Ngintait, Nyeri, and Werigia peoples)*	Qualitative (Focus Groups; *Thematic Analysis*)	Aboriginal Elders and healthcare staff	8 Elders	This study aimed to highlight issues around the lack of uptake of palliative care by Aboriginal and Torres Strait Islander peoples. It demonstrated a lack of understanding of palliative care and a limited awareness of services available. There is a lack of understanding and awareness of services that impeded access to, and utilisation of, care in this cohort, and more attention is needed for specific cultural needs.
Swain et al. (2015)[43] **Evidence Level: III**	Exploration of Aboriginal and Torres Strait Islander perspectives of Home Medicines Review.	Various (Australia)	Qualitative (Yarning/ Focus Groups)	Patients at 11 Aboriginal Health Services	102	The goal of this study was to explore Aboriginal and Torres Strait Islander perspectives of the Home Medicines Review program and seek suggestions for an improved service. The findings suggested that current rules impede rather than facilitate Home Medicine Reviews for Aboriginal and Torres Strait Islander peoples and that tailoring and remodelling of the Home Medicine Review program is needed to increase the awareness, accessibility, acceptability, and effectiveness of the program.
Thompson et al. (2019)[49] **Evidence Level: III**	Passing on wisdom: exploring the end-of-life wishes of Aboriginal people from the Midwest of Western Australia.	Rural	Qualitative (Focus groups & Video Recordings; *Thematic Analysis*)	Aboriginal community members (phase 1) *And* Aboriginal people with cancer and their carers (phase 2)	Phase 1: various people across community and art centres Phase 2: 10 (8 with cancer and 2 carers)	**This e**xploratory study was undertaken with local Aboriginal peoples community settings in regions of Western Australia and asked people to talk frankly about their wishes and concerns around end-of-life. These consultations indicated that within a safe space, Aboriginal peoples were happy to talk about end-of-life wishes, and strategies were suggested as potential means for engaging Aboriginal peoples in preparing for death and dealing with grief. Important considerations included family involvement, respect for preferences for care, wishes for funeral and burial, and dying in a safe place.
Webkamigad et al. (2020)[17] **Evidence Level: III**	Identifying and understanding the health and social care needs of Indigenous older adults with multiple chronic conditions and their caregivers: a scoping review.	Various (Global)	Review (scoping)	Indigenous older adults with multiple chronic conditions and their carers	9 articles (5 from Australia)	This scoping review provided an overview of health and social support needs, priorities, and preferences for Indigenous populations (and their caregivers) living outside of long-term care settings with multiple chronic conditions. The study highlights, in a comprehensive way, the need for access to services and information, building community capacity, social

Author	Title	Location	Design	Population	Sample	Summary of findings
						support, preservation of cultural values in health care, and wellness approaches in this cohort.
Wettasinghe et al. (2020)[31] **Evidence Level: III**	Older Aboriginal Australians' Health Concerns and Preferences for Healthy Ageing Programs.	Urban and Regional	Qualitative (interviews; *grounded theory approach*)	Aboriginal Australians 50+	34 (20 from regional and 14 from urban)	This study explored older Aboriginal Australians perceptions of healthy ageing and preferred approaches to developing culturally appropriate healthy ageing programs, and receptiveness to technology. The study identified important aspects of healthy ageing programs including cultural safety, physical and cognitive training, social interaction, health education, and maintaining cultural identity and empowerment. The study also provided support for the use of technology for the delivery of health programs.
Wood et al. (2021)[50] **Evidence Level: III**	Remote area nurses' perceptions of the enablers and barriers for delivering end-of-life care in remote Australia to Aboriginal people who choose to pass away on their traditional lands.	Remote	Mixed Method (literature review and questionnaire)	Remote area nurses		This study aimed to identify enablers and barriers perceived by remote area nurses in assisting in end-of-life care to Aboriginal Australians on Country. Barriers identified were a lack of support around the delivery of culturally appropriate end-of-life care, lack of a stable workforce, insufficient cultural knowledge and understanding, and a lack of guidance and support from family. Enablers were effective communication with the family and staff willingness and input from Aboriginal health practitioners.
Woods et al. (2019)[51] **Evidence Level: II**	Indigenous compared with non-Indigenous Australian patients at entry to specialist palliative care: Cross-sectional findings from a multi-jurisdictional dataset.	Various (Australia)	Quantitative (cross-sectional; data linkage)	Indigenous and non-Indigenous patients entering palliative care	140,267 patients (1,465 (1.0%) were identified as Indigenous)	This study aimed to investigate the equity of specialist palliative care service provision through characterising and comparing Indigenous and non-Indigenous patients at entry to care. Conclusions were that Indigenous patients were substantially under-represented in care services reflecting widespread access barriers. However, this study also indicated that when Indigenous patients were able to access these services, they did not disproportionately experience clinically important impediments to care.
Yashadhana et al. (2022)[18] **Evidence Level: III**	Experiences and perceptions of ageing among older First Nations Australians: A rapid review.	Various (Australia)	Review (Qualitative Rapid; *Thematic Narrative Analysis*)	Older First Nations Australians (median age ≥45 years)	20 articles	This study aimed to understand whether First Nations perceptions, experiences and priorities in ageing aligned with known frameworks and definitions of ageing. The review demonstrated the importance that older First Nations peoples place on holistic approaches to ageing and highlighted their priorities surrounding ageing have a focus on community, cultural knowledge, Country, and the role of Elders. This review concluded that current frameworks do not fully reflect the priorities of older First Nations Australians, and that the ongoing impact of colonial policies and practices, marginalisation and racism continue to have immense detrimental impacts.

Appendix 3 – Grey literature included in the rapid review

Table 6 - Summary of grey literature reports included in rapid review

Author	Title	Location	Design	Population	Sample	Key messages
ATSIAAG (2020)[19] Evidence Level: IV	Integrated culturally sensitive services for older Aboriginal and Torres Strait Islander peoples: Practical solution or pipe dream?	N/A	Report - Workshop Summary	Older First Nations Australians	35 (ATSIAAG workshop attendees)	The workshop aimed to explore themes and issues surrounding Integrated Culturally Sensitive Services for Older Aboriginal and Torres Strait Islander peoples. There was general agreement about the necessary components of a good service delivery model, and barriers and enablers to delivering integrated care were identified.
ATSIAAG (2017)[40] Evidence Level: IV	Assuring equity of access and quality outcomes for older Aboriginal and Torres Strait Islander peoples: What needs to be done	N/A	Report - Workshop Summary	Older First Nations Australians	28 (ATSIAAG workshop attendees)	The workshop discussed the inequities of access and outcomes for older Aboriginal and Torres Strait Islander peoples under the current aged care reform program. Through discussion and consensus, the workshop participants suggested directions for the future. In particular, the intent was for the workshop to generate input into the development of an Action Plan for aged care for Aboriginal and Torres Strait Islander Elders.
Broe (2019)[32] Evidence Level: IV	What do Aboriginal Australians want from their aged care system? Community connection is number one	N/A	Article- The Conversation	Older First Nations Australians	N/A	This article reported that the Aboriginal and Torres Strait Islander population is ageing at a much faster rate than the non-Indigenous population; with several barriers to accessing appropriate aged care services in their communities. It recommends that aged care policy consider the diversity of circumstances and needs of older Aboriginal peoples across different locations (e.g., urban, rural, and remote). In addition, the article reinforces that Aboriginal access to care requires its delivery in an Aboriginal framework of family and community involvement, and ideally through Aboriginal community-controlled services.
Department of Health (2019)[41] Evidence Level: IV	Actions to support older Aboriginal and Torres Strait Islander people: A guide for aged care providers	N/A	Report- Government Action Plan	Older First Nations Australians	N/A	This action plan set out what aged care providers could do to deliver more inclusive services to older Aboriginal and Torres Strait Islander peoples. Delivery of safe and inclusive services to people with diverse needs and life experiences is built into the Aged Care Quality Standards, and thus is a requirement for Aboriginal and Torres Strait Islander peoples. Six outcomes are identified to address this requirement, taken from the Aged Care Diversity Framework. They are: Making informed choices; Adopting systemic approaches to planning and implementation; Accessible care and support; A proactive and flexible aged care system; Respectful and inclusive services; and meeting the needs of the most vulnerable.

Author	Title	Location	Design	Population	Sample	Key messages
Gilbert et al. (2020)[42] **Evidence Level: III**	Models of Integrated Care, Health, and Housing	Remote, Regional, Urban	Report prepared for the Royal Commission into Aged Care Quality and Safety	Older First Nations Australians	4 Aboriginal community-controlled services	This report includes strengths-based case studies of remote, regional and urban responses to providing integrated care. It highlights that Aboriginal communities value culturally safe, holistic, and intergenerational models of care. The four diverse Aboriginal Community Controlled Services consulted with are run by and for Aboriginal peoples and embed the cultural determinants of care at their core. Some examples provide clinical care, aged care and/or a broad range of other social services for older and younger people. In addition, each of these services has established relationships and partnerships that link to their community members to a range of external services.
IPEPA (2020)[52] **Evidence Level: IV**	Cultural considerations: Providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples	N/A	Report - Guidelines	Older First Nations Australians	N/A	This document provided information for healthcare services about providing culturally appropriate end-of-life care for Aboriginal peoples and Torres Strait Islander peoples. The report, and Indigenous component of the Program of Experience in the Palliative Approach (IPEPA) more generally, aim to facilitate two-way learning dedicated to: 1. Building the capacity of the Aboriginal and Torres Strait Islander workforce to deliver palliative care; 2. Empowering Aboriginal and Torres Strait Islander communities with knowledge of palliative care, their rights and local services; and 3. Building the culturally responsive capabilities of mainstream service providers to provide holistic and safe palliative care to Aboriginal and Torres Strait Islander peoples.
Radford et al. (2019)[1] **Evidence Level: III**	Sharing the Wisdom of Our Elders	Urban and Rural	Report – Qualitative Study	Older First Nations Australians	26 aged care services	This report details findings from an environmental scan of services available to older Aboriginal and Torres Strait Islander peoples in urban and rural setting in NSW, with semi-structured interviews and strengths-based analysis of service provider perspectives on providing aged care. The study found that healthy ageing programs and aged care services available to older Aboriginal and Torres Strait Islander peoples are often Aboriginal-specific, in line with community preferences, and these service providers are generally working hard to meet the cultural, health and wellbeing needs of Elders through a holistic and flexible approach to service delivery. The main gaps and challenges identified by service providers include need for greater: (i) Investment in the Aboriginal and Torres Strait Islander aged care workforce to meet current and future demands; (ii) Education for families regarding ageing and dementia; (iii) Education and support to access the aged care system, (iv) Trauma-informed and healing-centred approaches to aged care services, and (v) Transport and respite for clients and their families.

Appendix 4 – Barriers to and enablers of good care, by theme

Theme	Supporting quotes	Barriers to good care	Enablers of good care
Culture at the centre of aged care and service delivery, including residential care	*"Culture and spirituality for these residents is their connection not only to themselves but also to others, nature, environment and their universe. The telling of their stories and those of their ancestors is important and they see it as their children and their children's children keeping it strong and alive. Unfortunately, here [name of facility] there may only be a handful of residents who are able to tell and practice their culture. There are many reasons for this, stolen generations, disconnections with the land and dementia. Also lack of family involvement. Many are moved into the facility and then forgotten."* (Alida, carer)[16]	• Experiences of racism, discrimination, marginalisation, and alienation; services that are not respectful or inclusive[13, 14, 18] • Lack of provider understanding about how to meet social and emotional wellbeing needs[13] • Lack of local services[15, 19] • Uncertainty around access of services, scope of services, and specific processes (e.g., complaints, navigating the aged care system more generally)[13, 15, 19] • Travel as a barrier for accessing services[14] • Older people having a lack of control over issues that affect delivery of services they receive[15] and lack of Elder consultation[19] • Lack of Aboriginal staff and staff with specialised knowledge about Aboriginal health and culture, understaffing, and high turnover[10]; language barriers can impact interactions[16] • Need for culturally appropriate and accessible activities that are properly funded[10, 16] • Lack of education for staff around quality standards of care for Aboriginal residents and carers[10] • Lack of holistic and cultural care planning[10, 16] • Institutional marginalisation of Aboriginal culture and lack of cultural competency/cultural training.[10]	• Health professionals communicating and being respectful[13] • True 'person-centred care'[13] which is situated within a framework of family/community/kinship[24 cited in 11]) • Having access to Aboriginal service providers[13] and Aboriginal workers[15, 19] • When non-Aboriginal workers are employed, ensuring that they are respectful, non-judgemental, and culturally aware[15] • Running aged care through Aboriginal community-controlled services[19] • Supporting people to make meaningful contributions to community (e.g., caring roles, passing on knowledge to younger generations)[12, 15] and nurture connections with family, community and Country (including staying on land)[12, 17] • Engaging with Elders to disseminate knowledge and information[18] • Supporting holistic and traditional ways of living (e.g., language, food, healing practices, art and music, storytelling, visiting significant cultural places, communal firepit) in conjunction with biomedical treatments[12, 15] • Recognise the importance of culturally appropriate activities in residential aged care[11] • Co-design and management of services by Indigenous people[12] • Support to access entitlements and services[12] • Cultural affinity (e.g., sense of ownership, no discrimination) that is cultivated by ACCHSs[14] • Respect for culturally important preferences regarding care (e.g., personal care and domestic assistance provided by staff of the appropriate gender)[15] • Culturally safe and trauma-informed care is best provided by First Nations care providers. First Nations liaison officers or 'cultural advisors' should be employed to work with residents and staff in mainstream facilities[58 cited in 11] • Allowing for traditional spiritual beliefs to co-exist with Western biomedical understandings[16]

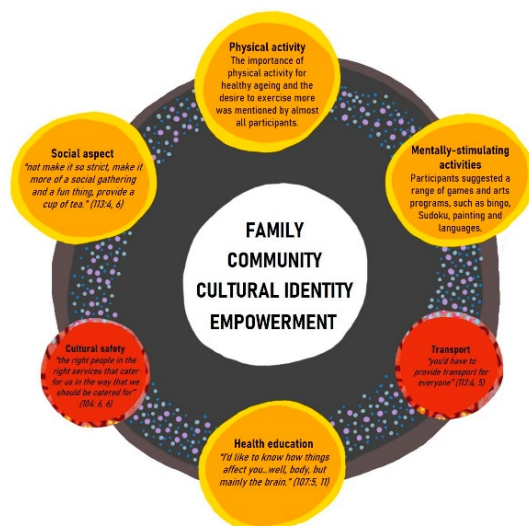| Theme	Supporting quotes	Barriers to good care	Enablers of good care
Embedding aged care in community, for community	*"It's important to have an Aboriginal specific program as they feel welcomed here and they see Auntie's and sisters."* (Umina Elder)[25] *"We see people regularly, we report to aged care and clinic, we notice changes physically and cognitively, how they hold a brush, changes on the canvas, channels of communication, it is all very important."* (Art centre staff 14)[30] *"Some people, it's really quite obvious they need to be in nursing home care but quite often we'll tick the one that's supported community accommodation but when you come to the blurb at the bottom you say you know that's what would be ideal but it doesn't exist out bush, you have to keep these people on country, but with the care and support that they need that families can't necessarily provide"* [21]	• Transport barriers often prevent engagement with programs[25, 31, 49] • Lack of cultural safety[25, 27] • Vulnerability of people who are isolated or with limited family networks[26] • Shame, stigma and feelings of helplessness surrounding ageing and dementia can couple with limited awareness about dementia[1, 26, 27, 31] • Resource limitations[30] and additional pressures on staff[29] • Some programs were not engaging for those attending (e.g., boring, too long)[31]	• Supporting connections (family, broader network, to Country)[25, 30] • Staying in community/on Country[25] • Building capacity in communities by upskilling and educating individuals to provide care[1, 28] • Provision of safe support without mainstream health or aged care agenda[30] • Collaboration between community-based services and aged care providers[30] • Flexibility of attendance[31] and aged care funding at the community/service level[1] • Transport available[1, 31] • Engagement of Elders and older people in the design and continuous improvement of local services[1]
Recognising the importance and value of family, kinship, and informal carers	*"I wanted to look after her at home. I wanted her to pass away here in her own place."* … *"I'm sort of isolated. I don't know what to do with it. I need to find my place."* (Family carer whose mother is in a care facility)[33]	• Residential care is not suitable and there can be fear and regret around placement of loved ones in care facilities[33] • Carer's often have their own needs and health conditions[33] • Lasting impacts of colonial policies and traumas are a major burden[36] • Carers are unsure how to access support, combined with a lack of formal support and respite services/resources that are culturally appropriate[36] • Lack of cultural awareness in services and support groups[13, 34] • Isolation for people in remote communities[13, 34] • Difficulty for informal carers to manage behavioural and psychological symptoms of dementia[34] • Services are often under-resourced[35]	• Avoiding placements in mainstream (Western models of) residential aged care (institutionalisation)[36] • Carers having the ability to access respite or attend cultural events[36] • Involving the community in the caregiving process[36] • Community education about dementia[1, 36]
An integrated, holistic, and strengths-based approach to social and emotional wellbeing and clinical care	*"We need (Aboriginal) health workers to be trained as experts, to be able to have this knowledge to link between the pharmacy, the doctor and the patient's journey in the community so that all the questions can be answered."* [47] *"If our spirit's broken, we become sick. Our spirit's sick and how can we heal it, if we don't have that quality of life?"* (Interview 10, F 63 years)[37]	• Beliefs about dementia including denial, stigma, and seeing dementia as a low priority health condition[22] • Inadequate resources e.g., resources that are accessible and culturally appropriate[22], gaps in service delivery, infrastructure and workforce[21-23, 38], lack of/rigid funding[20, 21, 23] • Fitting cultural care into inflexible mainstream systems[20, 21, 23] • Lack of awareness of medicine review programs[47] • Burden on older people to liaise with multiple health professionals[47]	• Clear pathways to diagnosis and referral that may be embedded into routine assessment[22, 23] • A focus on relationships with community (including external organisations) and family[22, 23] • Holistic, comprehensive, and multidisciplinary care[22] that is centred on respect for Aboriginal identity[23] • Culturally appropriate, tailored resources[22] • National-level change to enable community-based, flexible care[38], strong governance and effective organisational and operating systems[23] • A workforce that is local, caring, qualified and culturally safe[23]

Theme	Supporting quotes	Barriers to good care	Enablers of good care
		• Need for written information when receiving information about medicines[47]	• Use of culturally appropriate resources, assessment, and terminology[37, 45, 46] • Designing tools with Aboriginal people, for Aboriginal people[45, 46] • Tools should be underpinned (where relevant) by holistic conceptions of health and wellbeing[45], with consideration of cultural and religious beliefs[37] • Knowledge sharing is key to respecting and incorporating Indigenous perspectives[46] • Having Aboriginal Health Workers present, as well as family member/carer • Facilitation of appointments was more acceptable when organised by an Aboriginal Health Service[47] • Need for culturally appropriate, jargon-free medication resources[47] • Providing a tailored, comprehensive medicine list for people to carry with them[47]
Provision of culturally appropriate palliative and end-of-life care	*"I think it would really be important just to make it known who the workers are, who to contact, and have an Aboriginal worker there as well."* [47]	• Need for cultural awareness regarding end-of-life care[49, 50] • Talking about death, organising funerals, etc. can be difficult, and sometimes contentious amongst families[49, 50] • Lack of knowledge about palliative care delivery, lack of access to and knowledge about end-of-life equipment[50] • Understaffing[50]	• Viewing palliative care as a family/systemic issue rather than individual[47], and accommodating the need for family to be present[49] • Dying/burial on Country[47, 49, 50] • Having an Aboriginal liaison officer and other Aboriginal workers[47] • Importance of cultural understanding as well as individual preferences/wishes[49, 50]

Appendix 5 – Case studies and resources

Case studies and resources	Overview	Link
NACCHO- Aged Care Quality Standards Submission	Submission to the Department of Health and Aged Care providing recommendations to inform the revised Aged Care Quality Standards. NACCHO is the Australian national leadership body for Aboriginal and Torres Strait Islander health.	https://www.naccho.org.au/naccho-submission-royal-commission-into-aged-care-quality-and-safety/
ATSIAAG 6th Workshop Report- Appropriate aged care needs assessment for older Aboriginal and Torres Strait Islander peoples	This report summarises the proceedings and outcomes of the 6th National Workshop of AAG's ATSIAAG. The primary aim of the workshop was to explore appropriate aged care needs assessment for Aboriginal and Torres Strait Islander peoples. Improving aged care needs assessment for Aboriginal and Torres Strait Islander peoples is an important prerequisite to improving access to aged care services.	https://aag.asn.au/libraryviewer?ResourceID=84
Cultural responsiveness in action: An IAHA framework	Indigenous Allied Health Australia (IAHA) is a national member-based Aboriginal and Torres Strait Islander allied health organisation. The framework is a call to action and provides clear and considered definitions of cultural safety and cultural responsiveness. The framework calls for system change, providing an overview of transformative actions that will support the renewal of Aboriginal and Torres Strait Islander health and wellbeing. Six key capabilities are also outlined in detail, alongside real-world examples of culturally responsive practice.	https://iaha.com.au/workforce-support/training-and-development/cultural-responsiveness-in-action-training/
Jimbelunga Nursing Centre Model of Care	Jimbelunga is owned and operated by the Aboriginal and Torres Strait Islander Community Health Service (ATSICHS) in Brisbane which is an Aboriginal Community Controlled Health Organisation (ACCHO). Currently 85% of those residing at Jimbelunga identify as Aboriginal and Torres Strait Islander peoples. While the Jimbelunga model of care is guided by the Aged Care Quality Standards and NDIS Practice Standards, it is grounded in core values that take into consideration all aspects of a person's history, current situation, and future goals. It incorporates all aspects of health care to provide a framework drawing on social justice principles of equality and equity to firstly ensure people have access to quality care. The Core values that underpin the success of Jimbelunga's Model of Care include: - Core Value 1: Connection through relationships - Core Value 2: Diversity - Core Value 3: Self-determination - Core Value 4: Healing	https://jimbelunga.org.au/resources/
Providing effective aged care services to Stolen Generations survivors- fact sheet from the Healing Foundation	This Fact Sheet provides guidance to support residential aged care providers to create a supportive and safe care environment for Stolen Generations survivors. In particular, the document helps providers comply with the Aged Care Quality Standards, particularly *Standard 1 - Consumer dignity and choice*, and meet their obligations to care for recipients who are Stolen Generations survivors. The majority of Stolen Generations survivors fear residential aged care and opt for home or community care where possible. However, many survivors don't know what services are available to them, let alone how to access them. As their needs increase more Stolen Generations survivors are expected to enter residential care.	https://healingfoundation.org.au/app/uploads/2019/12/Working-with-Stolen-Generations-Aged-Care-fact-sheet.pdf

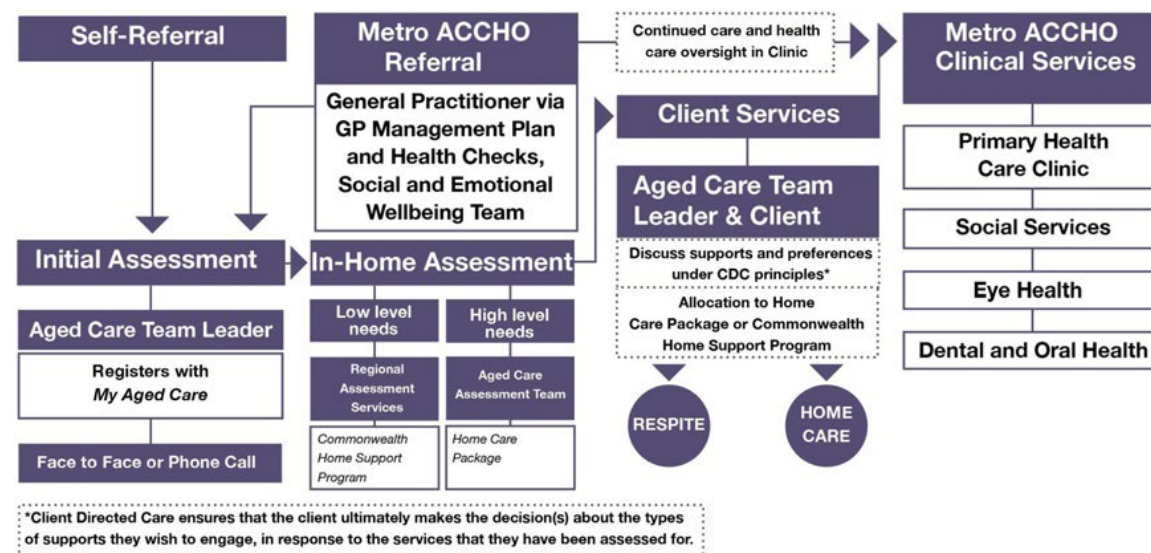| Case studies and resources	Overview	Link
Model for a holistic, healthy ageing program.	From Wettasinghe et al., (2020)[31], this contemporary model of ageing for Aboriginal peoples incorporates community-focused activities such as walking, fishing, painting, and socializing with friends. The central tenets of family, community, cultural identity, and empowerment are visually illustrated to be at the heart of the program. The necessity for cultural safety and transport is represented with the red circles in the figure below. 	https://www.mdpi.com/1660-4601/17/20/7390
Department of Health and Aged Care portal – support for First Nations people (specific programs and initiatives)	Summary of reform initiatives in response to the Aged Care Royal Commission. Programs funded to ensure First Nations people aged 50 years or over can access quality, culturally appropriate aged care services. Specific initiatives include: - Remote and Aboriginal and Torres Strait Islander Aged Care Service Development Assistance Panel (SDAP) - National Aboriginal and Torres Strait Islander Flexible Aged Care Programs (NATSIFACP) - Trusted Indigenous Facilitators - National Palliative Care Projects	https://www.health.gov.au/topics/aboriginal-and-torres-strait-islander-health/aged-care-support

Case studies and resources	Overview	Link
Referral pathways for aged care clients within the case study ACCHO	From Dawson (2021)[23], this best practice referral pathway is taken from the Institute for Urban Indigenous Health, a metropolitan ACCHO primary health care service in Queensland that recently integrated home-based and respite aged care within the organisation's primary health care service delivery model. The ACCHO established referral pathways to their Aged Care Team that included self-referral, and referral from both the health clinic and community teams (e.g., the Social and Emotional Wellbeing Team). A practical model of the organisation's aged care referral pathway is depicted below. 	https://www.cambridge.org/core/journals/primary-health-care-research-and-development/article/aboriginal-communitycontrolled-aged-care-principles-practices-and-actions-to-integrate-with-primary-health-care/5FC62165CE4167CE9696180E7A14914C
Gwandalan Palliative Care information and workshops	A series of engaging eLearning modules and interactive webinars to support frontline staff to deliver culturally responsive palliative care. Face-to-face workshops are also available across Australia that focus on the delivery of culturally safe palliative care for Aboriginal and Torres Strait Islander communities.	https://gwandalanpalliativecare.com.au/
The Palliative Care and End-of-Life Care portal (Australian Indigenous Health InfoNet)	The Palliative Care and End-of-Life Care portal is designed to assist the health workforce who provide care for Aboriginal and Torres Strait Islander peoples, their families, and communities. It seeks to support both clinicians and policymakers in accessing resources, research and projects on palliative and end-of-life care for Aboriginal and Torres Strait Islander peoples. The portal includes information and specific resources/papers about: - Culturally appropriate palliative and end-of-life care - Grief and bereavement - Planning ahead.	https://healthinfonet.ecu.edu.au/learn/health-system/palliative-care/

Case studies and resources	Overview	Link
Wills and Advanced Care Planning for Aboriginal people- NSW Trustee & Guardian	An information portal from the NSW Trustee & Guardian established to communicate advanced planning and Will making to Aboriginal and Torres Strait Islander persons. The **Taking care of business handbook** is an easy-to-read introduction to Wills, Powers of Attorney, Enduring Guardianship and Advance Care Planning for Aboriginal peoples and includes case studies, tips, useful definitions, and contacts. The **Aboriginal Wills handbook** provides guidance for legal practitioners advising an Aboriginal person, specially providing information on preparing culturally sensitive planning ahead documents.	https://www.tag.nsw.gov.au/sites/default/files/2020-10/Taking_Care_of_Business.pdf https://www.tag.nsw.gov.au/sites/default/files/2021-08/Aboriginal-Wills-Booklet-3rd-Edition-2020_Web%20version.pdf
Good Spirit, Good Life (GSGL)	The Good Spirit, Good Life (GSGL) tool is a newly developed instrument specifically designed with, and for, older Aboriginal Australians from urban and regional areas. The tool is grounded in the collective and holistic Aboriginal worldview of health and well-being, informing a cultural quality of life framework, and contributing to the tool's face and content validity. An accompanying suite of resources is also being developed, including the Good Spirit Good Life framework, strategies, and a training guide. This package will be disseminated for use by policy makers, services, and researchers to train staff members in Aboriginal perspectives of quality of life, to identify the quality of life needs of older Aboriginal clients, plan and implement culturally meaningful services, and evaluate the success of strategies and reforms.[37]	https://www.iawr.com.au/gsgl
Australian Indigenous HealthInfoNet	Clearing House for a range of current research, reports and resources related to Aboriginal and Torres Strait Islander peoples, including specific topic sections on 'Dementia' and 'Older People'.	https://healthinfonet.ecu.edu.au/learn/health-topics/dementia/ https://healthinfonet.ecu.edu.au/learn/population-groups/older-people/

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE