



**Royal Commission**  
into Aged Care Quality and Safety

# **AGED CARE PROGRAM REDESIGN: SERVICES FOR THE FUTURE**

## **CONSULTATION PAPER 1**

### **DECEMBER 2019**

The Royal Commission into Aged Care Quality and Safety was established by Letters Patent on 8 October 2018. Replacement Letters Patent were issued on 6 December 2018, and amended on 13 September 2019.

The Honourable Tony Pagone QC and Ms Lynelle Briggs AO have been appointed as Royal Commissioners. They are required to provide a final report by 12 November 2020.

The Royal Commission releases consultation, research and background papers. This consultation paper has been issued by the Commissioners.

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# Introduction

## Purpose

During this Royal Commission, we have been working to determine the extent of the problems in Australia's aged care system and how best to meet the challenges of delivering aged care now and into the future. Our work so far has revealed that there are endemic and system-wide problems with aged care in Australia and that it needs major reform.

The Interim Report set out our overall impressions of the state of aged care in Australia. The Australian Government has now responded to that report. Our Final Report will deliver comprehensive recommendations for substantial reform of the aged care system.

**We are seeking your input into designing aged care services for our nation's future. Pages 23 to 26 of this consultation paper pose design questions that may help you frame your submission.**

## Scope

This consultation paper seeks to outline our thinking about a future aged care system, including how programs might be redesigned and how these different program elements could work together within the system. We have not yet reached any concluded views on these matters. To start, we propose principles to guide redesign based on the philosophy and values which we consider should underpin Australia's aged care system. We also discuss what this might mean for:

- how older people experience the aged care system
- financing
- regulation.

This consultation paper does not cover **in any detail** our work on the following:

- the role of older people in society and in our communities
- interactions between the aged care and health care systems
- system stewardship
- provider governance, leadership and accountability
- market development and delivery
- funding
- workforce
- quality and safety regulation
- technology, research and innovation
- transition and implementation.

These issues have been or are being progressed through other processes of the Royal Commission into Aged Care Quality and Safety.

## The current system

Aged care is the term used in Australia to refer to a range of services provided to older people who have reduced capacity to care for themselves because of physical frailty and/or cognitive impairment, including:

- assistance with everyday living activities, such as house cleaning, laundry, gardening, shopping, preparing meals and maintaining a social life
- help with personal care, such as showering, getting dressed, eating, and going to the toilet
- some aspects of health care, such as nursing or allied health
- accommodation.

The Royal Commission's background paper, *Navigating the Maze*, and the Interim Report provided a comprehensive overview of Australia's current aged care system. While the system may be seen as providing a continuum of care as a person's needs increase, older people do not necessarily move through the system in a linear fashion. Some people may only ever receive one type of service, while others may progress from one service directly to the highest form of care—residential care.

Another of the Royal Commission's background papers, *A History of Aged Care Reviews*, documents the numerous reviews and inquiries over the last 20 years which address recurring issues with the design and operation of aged care services.

Overwhelmingly, the evidence presented to us demonstrates that most of the challenges identified in the previous reviews remain relevant.

The Australian Government is part way through implementing various changes to the current system and has continued to make changes since the Royal Commission began its work. While addressing some problems, these changes have added complexity to an already complex system and have sometimes created new problems. Despite incremental changes, the system retains the basic structure that it had when the *Aged Care Act 1997* (Cth) commenced. In many ways, it is a structure inherited from arrangements which applied before 1997 under the *National Health Act 1953* (Cth) and associated grant programs.

The result is an uneasy mixture of complex programs operating under a range of different guiding principles, within a structural framework that was not designed for those programs to operate together with optimal efficiency and effect.

The current system:

- is constrained by controls on the availability of services to meet the government's fiscal risk rather than to deliver care according to need
- comprises funding models that differ markedly depending on the setting in which care is delivered rather than the needs of the person receiving care
- directs a large majority of available government funding into an institutional model of residential care that neither meets the preferences of older people to stay at home nor responds to the evidence on the benefits of small home models
- is focused more on the funding relationship between government and providers than the choices and the rights of the older person seeking care
- does not effectively ensure quality and safety in the operation, funding and regulation of the system
- is not designed to deliver consistent equity of access

- does not invest enough in interventions to promote the independence, functioning and quality of life for older people for as long as possible
- does not foster the provision of services that work effectively with related systems, particularly health and disability
- struggles to attract and retain sufficient numbers of skilled, knowledgeable and competent staff
- is complex and fragmented, meaning that change has been difficult to achieve
- faces growing challenges in affordability and sustainability.

In the Interim Report, we concluded that there was a need for a fundamental overhaul of the design, objectives, regulation and funding of aged care in Australia. It is clear that the aged care system is in desperate need of redesign—not mere patching up. It is time to step back and consider the principles that should guide the best possible aged care system Australia can have. It is also time to consider whether the current reforms are heading in the right direction and what programs, care and services are needed for the future.

Since the Productivity Commission’s *Caring for Older Australians* inquiry of 2011, and the response of successive governments, aged care has been on a path to a consumer-driven, more market-based system. The Aged Care Sector Committee’s 2016 Roadmap reiterated a commitment to that reform direction, as did the report of Mr David Tune AO, *Legislated Review of Aged Care 2017*.

The aged care sector is not, and is unlikely to ever be, a fully efficient market. The direction of current reforms puts too much faith in market forces and consumer choice as the primary driver of improvement in the aged care system. It gives insufficient attention to constraints on the availability of choice in many parts of Australia and to the supports required for people to exercise informed choice. Giving people more information to make decisions about their aged care will give them greater control, but it will only address some of the existing market imbalances. Providers will continue to know more about the aged care system than the older person or their family. People with limited financial means or decision-making capacity face particular challenges in exercising choice. Market forces have an important role to play but are not delivering equitable outcomes in all parts of the country or for all groups. This has been a powerful message in feedback received by us about aged care across the country. It has been a particular issue in regional and remote areas and for some diverse groups.

Framing the policy discussion around ‘markets’ and describing older people needing aged care services as ‘consumers’ also reduces the issue to one of transactions rather than relationships or care. For that reason, we are also giving close attention to the philosophy that should underpin the aged care system.

Giving older people and their families real choices requires more meaningful information and face-to-face support than is currently available. We have heard strong messages that people trying to navigate the aged care system feel unsupported and are floundering. The system is complex, and people are making decisions about aged care when they are emotionally vulnerable. The system needs to encourage people to plan ahead for their ageing and put older people at the centre, with a focus on their needs, their identity and their right to make choices about their care.

The Commonwealth has key responsibility for aged care, needs to do much more in guiding the system to deliver better outcomes for older people. We have heard that the Commonwealth should play a more active role in system planning and monitoring, including intervening in the market as necessary.

In the months ahead we will address all of these issues as a core part of our work on design for a new aged care system.

## Putting people at the centre

Aged care must be designed for the people it is intended to help, and based on their dignity, rights, choices, quality of life, involvement and feedback. Aged care should be delivered in the context of trusting, respectful and collaborative relationships between the person receiving care, their family, staff and management. Aged care should not be seen as a commodity, and success should not be measured by the mere completion of tasks.

Every person seeking and receiving care is an individual with their own life history, and the aged care sector should recognise this. Aged care should support people to pursue and enjoy meaning and quality in life—whether they receive care at home or in a residential service.

A person should not have to risk losing their sense of self and be disconnected from society simply because they require care and support in older age. Receiving aged care should not require a sacrifice of choice and control over one's own life. It is unacceptable that we have an aged care system that people are frightened to access.

Aged care must include high quality clinical and personal care, and this includes supporting emotional and psychological wellbeing throughout a person's old age. The failure of the system in this respect was powerfully captured by the late Mr Bernard Cooney in his submission:

Formal compliance with poorly described and limited formal standards appears to be the objective. The practical outcome of these deficiencies is at minimum, the development of a sense of boredom and personal irrelevance for many residents and at most, serious physical and mental suffering for others...The real values of a society as distinct from its stated claims, can be measured by the way in which its most vulnerable members and that certainly includes those in aged care facilities, are treated. Not much empathy is needed to appreciate that it is hard to retain a sense of personal dignity when little by little individual autonomy is lost. Viewed against that standard, our failures are apparent.<sup>1</sup>

## Principles

To address this failure, we propose that the design of the aged care system should:

- be underpinned by respect and support for the rights, choices and dignity of older people
- ensure quality and safe care is fundamental to the operation, funding and regulation of the system
- provide equity of access, regardless of location, means or background
- be transparent, easy to understand and navigate
- deliver care according to individual need
- maximise independence, functioning and quality of life for older people
- support older people to have a good death
- support older peoples' informal care relationships and connections to community
- enable the recruitment and retention of a skilled, professional and caring workforce
- support effective interfaces with related systems, particularly health and disability
- be affordable and sustainable, both for individuals and the broader community
- be capable of being implemented, monitored and evaluated.

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<sup>1</sup> Exhibit 5–7, Perth Hearing, General Tender Bundle, tab 67, AWF.001.00519.



## Fundamental change

The aged care system should be changed to:

- support older people and their families to understand the system and get the services and care they need, including by getting much better information and face-to-face support
- create three service streams to assist older people: an entry level support stream, an investment stream and a care stream
- streamline access to low intensity and cost-effective support services through an entry level support stream to support a large number of older people to retain their independence
- use clinically skilled and multi-disciplinary expertise in assessing eligibility for more intensive service streams
- create an investment stream to fund interventions to help restore functioning, provide respite and delay or prevent progression to more intensive forms of care
- create a care stream for services delivered either in the home or in more flexible and less institutional forms of residential care
- move to individualised funding for care matched to need within the care stream, irrespective of setting
- improve the availability of nursing and allied health services across the system.

In this paper, we have applied our principles and these ideas to the current system to start the thinking on design. We have broken down the system into seven main program areas for you to review and provide suggestions. In the following sections, we describe each main program area, how the program works now, and what needs to change. We then pose **design questions** to guide your submission on program design—these questions go to the areas where we need more evidence to form a view on what will work best in future.

We also request feedback on how the future costs of aged care could be met and how changes in the service offerings and delivery models for aged care could impact the regulatory model.

## What this means for older people

A new aged care system needs to fundamentally improve the way older people access and experience aged care services. The system that is put in place needs to support current and future generations. Australia's changing demographics were outlined in our Interim Report and in our background paper titled *Medium- and long-term pressures on the system: the changing demographics and dynamics of aged care*.

Older people have a range of needs which should be catered for within the system. These different needs are met by interventions directed at achieving different purposes: some seek to maximise outcomes for older people, some seek to support older people to meet their own responsibilities, and some seek to make investments in older people to deliver benefits to them to delay their progression to higher and more costly care.

We are paying close attention to what a new system would mean for older people, their families, friends, carers and communities. We welcome your views.

We have heard that there is not just one way that people move through the current system. While some people start with entry level support services and move on to permanent residential care, some may only ever use entry level support services. Other people may use residential respite care as their first service. Other people move straight into permanent residential care.

Regardless of the first type of care a person uses and the setting for that care, the system must be much simpler and easier to understand, and people need to be supported to access care when, how and where they need it.

In looking at **what change is needed**, we have considered what older people need and want from aged care and how they currently access services.

We want a system that would allow older people to enter any stream and be supported to build their own bundle of supports and care. For example, where an older person starts with a social support service that they enjoy, and their needs increase, they would be supported to add personal care, nursing care and/or allied health to their bundle, and to access regular respite services. They could continue that original social support service (or a variation of that service) along the way, including if they choose to enter residential care permanently.

A model for the proposed aged care system is at **Figure 1**.

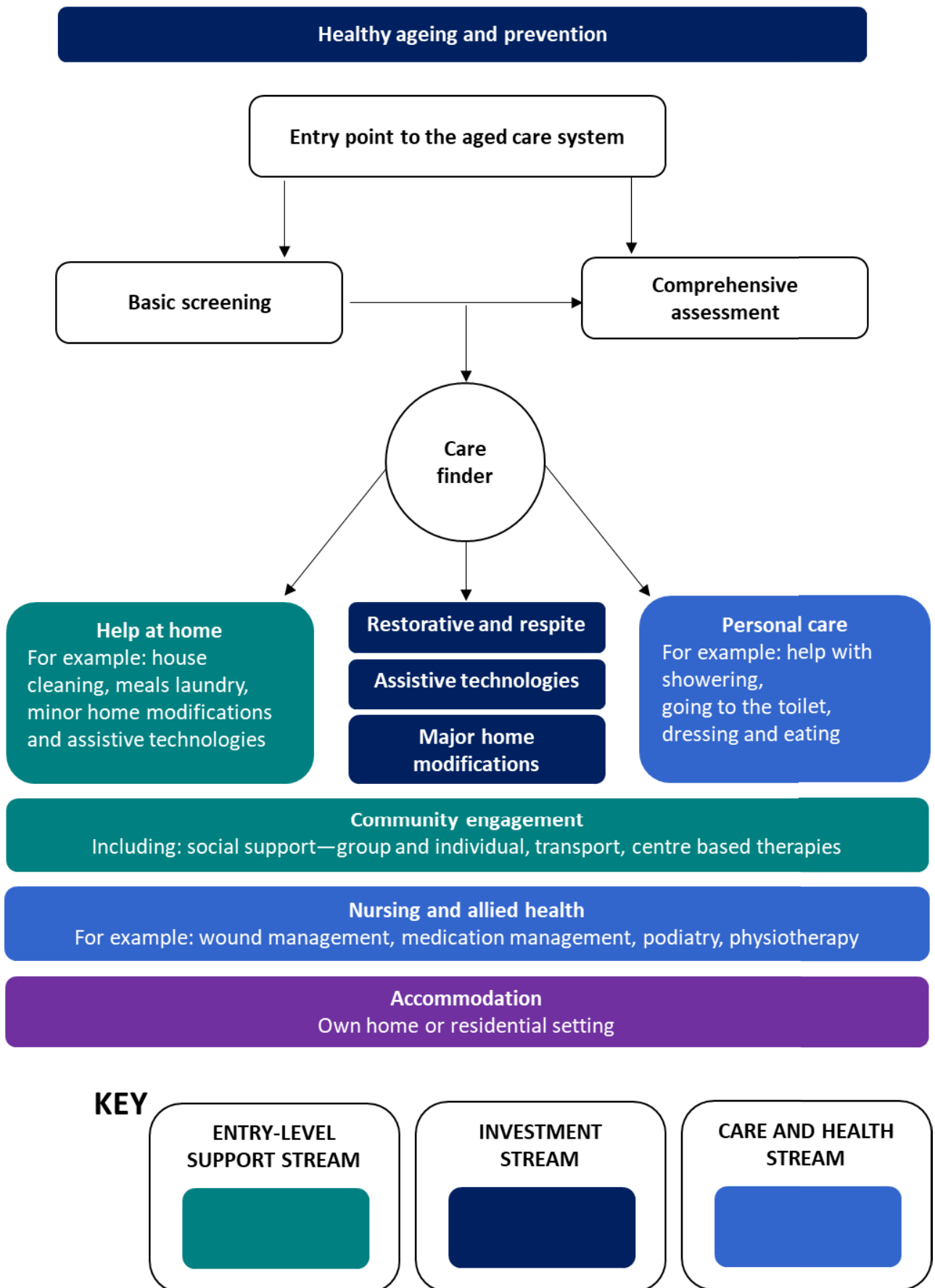


Figure 1. Proposed model for the aged care system

# New program design

## Information, assessment and system navigation

Accessing aged care services requires an older person and their carer (often a partner or child, but also other family, friends and community members) to make difficult emotional, financial, health and housing-related decisions, often under stress and time pressures, and with limited experience or knowledge of the system. We have consistently heard that there should be more support made available to people to access the aged care services they need.

<b>How does it work now?</b>	<b>What is needed?</b>
<p>To access aged care services, people are directed to the national My Aged Care service. My Aged Care is not well known in the community. Commonly, people start trying to access services before finding out about My Aged Care.</p> <p>The range of information that is available via My Aged Care to support decision making is very poor.</p> <p>My Aged Care services include:</p> <ul style="list-style-type: none"><li>• contact centre</li><li>• website</li><li>• screening for eligibility</li><li>• referral for assessment and access to service options.</li></ul> <p>People are referred to one of two different teams for their assessment. Aged Care Assessment Teams (known as Aged Care Assessment Services in Victoria) will look at access to Home Care Packages as well as permanent and respite residential care. Regional Assessment Services can approve access to the Commonwealth Home Support Programme. An integrated assessment service is under development.</p> <p>Once people are assessed, it is mostly up to them to find a provider either online or via referral. There is little face-to-face support in the current system, although system navigators are being trialled for certain populations.</p>	<p>Older people and their families will be supported to enter the aged care system and find the services and care that they need. This will be done primarily through face-to-face support, supported by a website and contact centre which can provide meaningful information about quality and cost, and a search function that helps people compare and select providers.</p> <p>People accessing aged care services have differing levels of need and vulnerability. Many older people have had no opportunity or experience in accessing online information. Many have chronic health conditions and some have cognitive impairment, hearing difficulties or limited English. Many have no family to assist them or live far from a capital city. Aboriginal and Torres Strait Islander people need culturally safe services. The information and support offered will be matched to each person's needs and vulnerability. This will include a shift to face-to-face support as well as the use of online and phone channels.</p> <p>Basic screening will be required for access to entry-level support services in people's own homes.</p> <p>Comprehensive assessment through a single assessment service will approve people for more intensive care services. This assessment will require a clinically qualified and multi-disciplinary skill set.</p>

<b><i>How does it work now?</i></b>	<b><i>What is needed?</i></b>
	<p>An assessment will consider the needs of the carer as well as the person needing care and will better integrate with the Australian Government's Carer Gateway support service.</p> <p>Care finders will be available at a local level to help people link to services that meet their care needs and support people to oversee their care plan and the care they receive.</p>

## Entry-level support

The current Commonwealth Home Support Programme delivers services to the great majority of people accessing the aged care system. In 2017–18, this entry level support program represented some 850,000 of the total 1.3 million people in the system for just \$2.2 billion of the \$18.1 billion Government expenditure on the system: 65% of the people for 12% of the funding.

<b><i>How does it work now?</i></b>	<b><i>What is needed?</i></b>
<p>Through block funding to providers, the Commonwealth Home Support Programme is intended to provide entry-level care and support services to a large number of people to assist them to stay at home. The Australian Government has announced that this program will be combined with the higher-level Home Care Packages program.</p> <p>A wide range of service types are available through the program, including care services (such as personal care, allied health and nursing) and support services (such as for domestic and social activities).</p> <p>On average, people in this program received services to the value of \$2762 in 2017–18 but a number are getting an intensity of service support which duplicates what is available under the Home Care Packages Program.</p> <p>Most people pay little or no fees. Attempts to introduce more structured fee regimes have been unsuccessful.</p> <p>People with a Home Care Package also use this program for social support, transport and meals.</p>	<p>As people get older, they commonly seek help to maintain their life at home, including going to appointments and social activities. This will be the focus of an entry level support stream, where a large number of older people will be supported with everyday living activities that they can no longer do for themselves. These services will be provided in their own homes and communities.</p> <p>The entry level support stream will include assistance with meals, transport, social support and centre-based activities, domestic assistance, home maintenance and minor home modifications or assistive technologies.</p> <p>Support with transport needs and social activities will be available to lessen social isolation and improve community connection. These services will continue to be available regardless of the aged care program they receive (for example, whether someone receives care in a home or residential setting, they would be supported with transport to continue their social activities).</p> <p>Access will be based on simple screening rather than full assessment.</p>

## Respite

Respite is short-term care that aims to give a carer or older person a break from their usual care arrangement. It is vital to the sustainability, health and wellbeing of the caring relationship. Respite is documented in the background paper *Carers of Older Australians*.

Respite services can be provided on a planned basis through the Commonwealth Home Support Programme, Home Care Packages Program and residential care. There are also emergency respite and other services for carers made available through the Carers Gateway.

<b><i>How does it work now?</i></b>	<b><i>What is needed?</i></b>
<p>Respite is available in residential aged care for up to nine weeks a year. However, we have heard much evidence of detrimental impacts on older people from respite stays in residential aged care. Respite care is a specialist service that some people consider does not fit alongside a setting with permanent residents.</p> <p>Other more flexible forms of respite which are well regarded are available under the Commonwealth Home Support Programme but availability does not seem to meet demand. This includes cottage-based respite with overnight care.</p> <p>Carers express frustration at not being able to access respite when and how they need it, and that respite does not focus on the needs of the older person or of the caring relationship.</p>	<p>Older people and their carers will benefit from expanded and improved access to respite. There will be more regular and flexible respite options so that people are aware of and take up the opportunity for respite before circumstances reach a crisis point. This would include in-home respite, day respite and cottage respite.</p> <p>Respite will provide benefits to older people and their carers and help maintain the caring relationship. Expanded availability of quality respite services which can be used regularly will support people to stay at home for as long as possible.</p> <p>Respite is important in sustaining care at home for many older people. It should not serve as a ‘try before you buy’ option before entry to residential aged care. Instead, it should be an opportunity for older people to receive restorative care which supports them to manage better once they return home, as well as to give their carer a break.</p> <p>Respite will be available as one of the interventions available through an investment stream.</p>

## Restorative care

Beyond the rehabilitation available within the health system, there are currently a number of separate restorative aged care programs that aim to improve older people's functional ability and independence. The programs are short-term, time-limited interventions that are provided in people's homes or residential settings, including day therapy centres and wellbeing centres. People often access restorative care when their needs have increased, when they first are referred for aged care, or when they are referred for more aged care. The programs can also help older people transition from hospital back to their home.

Supports available for older people should move away from a dependency model to a wellness and reablement approach that aims to maintain and improve people's independence and wellbeing wherever possible. Our ideas developed out of models from Western Australia (home independence program) and Victoria (active service model).

<b><i>How does it work now?</i></b>	<b><i>What is needed?</i></b>
<p>Within the aged care system, the Transition Care Program, which is funded by the Commonwealth with delivery managed by State and Territory governments, provides time-limited periods of goal-oriented therapy and services to restore functioning of older people after a hospital stay. There is also the more recent Short-Term Restorative Care Program which builds on the Transition Care Program but which is available to people who have not had a hospital stay.</p> <p>In addition, the Commonwealth Home Support Programme has attempted to embed a focus on reablement and wellness.</p> <p>These programs are beyond the rehabilitation which is available but can be difficult for older people to access through the public hospital system or through private hospitals.</p>	<p>Rehabilitation, which focuses on intensive recovery after illness, an accident, or surgery over a short time period, will continue to be available within the health system.</p> <p>Expanded restorative services (incorporating and building on the currently separate Transition Care and Short-Term Restorative Care Programs for older people) will be provided in the aged care system as part of an investment stream. These services will aim to restore the older person's capacity and delay or prevent changes that may require more intensive forms of care.</p> <p>Investments in restoring independence and maintaining function for older people are most beneficial when taken up early and at key transition points. Regular and ongoing restorative services are beneficial, so services will not be restricted to short-term only.</p> <p>The stream will help people stay at home for as long as possible and with minimal intervention. Restorative services will be available for people receiving care in residential settings. This will include exercise programs and other services to maintain and improve function.</p>



## Care—personal care, nursing care and allied health

The main types of care needed by older people, which are personal care, nursing care and allied health services, are currently provided in the home and in residential facilities through three mainstream programs: the Commonwealth Home Support Programme, the Home Care Packages Program, and residential aged care. Packages and residential aged care are designed to meet more intense and complex care needs. However:

- the long waiting list for Home Care Packages means that some people manage to receive nursing, allied health and personal care services under the Commonwealth Home Support Programme—intended to be the entry level to aged care—and others with the same eligibility do not
- low levels of clinical staff and personal carers in residential care and poor interfaces with the health system mean that some people may not receive the level of nursing, allied health and personal care services they need and would otherwise have had access to within the community or from the health system.

<b><i>How does it work now?</i></b>	<b><i>What is needed?</i></b>
<p>The supply of aged care is controlled or rationed by the Australian Government, not driven by demand or need.</p> <p>Separate subsidy-based arrangements apply for higher level care in the home and in residential care, and block funding for entry-level services.</p> <p>Home Care Packages are allocated to the older person at one of four levels. The older person can choose their provider and make choices about the supports they receive. Older people have no independent advice to assist them in making choices about appropriate providers and supports. Case management or care coordination services are variable and can appear expensive for what they deliver to the person when compared with things like house cleaning or allied health and nursing services.</p> <p>In residential care, there is an allocation of places to the provider and separate funding streams for care, daily living expenses and accommodation. The provider is responsible for managing older people's various health and aged care needs, and this is not always well coordinated, including with the person's general practitioner.</p>	<p>As people's needs increase and go beyond what can be managed with entry-level support or with their carer, they may need care services.</p> <p>People in the care stream will be able to receive the care they need, when they need it, regardless of setting. We have heard that people want to stay in their own homes whenever possible. Through individualised care, older people will have the care they need in the location of their choice. We expect many more people will opt to have that care provided in their homes.</p> <p>The basis of the funding assessment would be to assign an entitlement to the efficient cost of care that is both reasonable and necessary and of high quality and safety.</p> <p>Community nursing and allied health services should be available across the entire support and care continuum to those who need them (even for people receiving entry level supports).</p> <p>Care services could be separately funded even for people in the higher-level care stream, although one provider may deliver the services in that case.</p>

<b><i>How does it work now?</i></b>	<b><i>What is needed?</i></b>
<p>Currently, some community nursing and allied health services are available to older people with an assessed need through the Commonwealth Home Support Programme, but access is variable.</p> <p>People in home care and residential care should have access to nursing and allied health services as part of their care subsidy. However, the level of clinical care provided is variable. The majority of staff are personal care workers rather than nurses or allied health professionals.</p>	<p>This approach would have the advantage of clearly separating nursing and allied health funding and services from other services. However, this may be complex for those receiving care in a residential setting. In that case, one provider would provide different services under different funding streams. This would ensure appropriate accountability of the provider.</p> <p>Another option would be for separate funding for nursing and allied health to only be for those receiving support and care in their own home. In contrast, those people receiving care in a residential setting would have nursing and allied health costs built into their care funding.</p> <p>There will be a transition in residential care over time to a less institutional and more home-like physical environment which provides high-end care focused on dementia and end of life needs.</p>

## Specialist advice and services

People who access aged care at the very end of their life are entering care with increasing frailty, reduced mobility, multiple chronic health conditions and high care needs. They are not well supported in aged care, and their palliative care and end of life care are not well met.

We have heard much evidence about the impact of dementia on the people living with the condition, on those who care for them, and on the systems designed to provide aged care. The progression of dementia commonly presents as deterioration in memory, thinking, behaviour, communication and the ability to perform everyday living activities, and it is a national health priority area. But more than a medical condition, the diagnosis of dementia brings stigma, discrimination and a lower quality of life. People are reluctant to seek diagnosis, and the pathway after diagnosis is not well supported. Knowledge about dementia is poor in the aged care and health care systems.

As dementia progresses, people's care needs can exceed what can be provided at home. We have heard that people living with dementia make up the majority of those currently in residential aged care, and that dementia will continue to increase across Australia. We expect that people living with dementia who have a high level of need will continue to receive care in residential settings into the future.

<b>How does it work now?</b>	<b>What is needed?</b>
<p>For those in residential aged care, there is variable access to State-funded health services or Commonwealth-funded primary care or specialist services.</p> <p>Services caring for people with dementia with complex behavioural needs can access specialist advice through Severe Behaviour Response Teams and Dementia Behaviour Management Advisory Services. The Australian Government is establishing specialist units for those who cannot be cared for safely within mainstream services.</p> <p>Some hospitals in some parts of the country provide medical support to older people in residential aged care through various types of hospital outreach programs.</p> <p>Specialist palliative care services involve professionals providing support for people with a life-limiting illness with complex care needs. These services are funded and provided separately from aged care. They are difficult to access, particularly for people in residential aged care.</p>	<p>Older people with very high care needs should not be transferred from aged care to hospital unnecessarily. An older person with complex needs, a life-limiting illness or at the end of their life should have access to better clinical care within the aged care system and through services from the health system that are able to go into residential care facilities (also referred to as in reach services).</p> <p>Older people, including those with complex dementia or chronic health conditions, their carers and families, and staff working with them, will have improved access to specialist expertise relevant to the care needs of the older person.</p> <p>This will include in reach of health services through multi-disciplinary teams which can meet the health needs of older people, including those needing specialist palliative care.</p> <p>Other specialist support would be aged care-specific, such as Severe Behaviour Response Teams and Dementia Behaviour Management Advisory Services.</p> <p>There will also be an expanded and accelerated rollout of specialist units for older people with extreme Behavioural and Psychological Symptoms of Dementia.</p>

## Access for diverse groups

Diversity is complex. We are all individuals and our unique personal histories, backgrounds and experiences shape who we are, our values and our interactions with the world.

In describing people from diverse backgrounds and experiences, we use the term 'diverse groups'. We recognise and acknowledge that each person will have their own experience and cannot be defined solely by reference to a group. Individuals may choose not to be identified as part of a group and some may identify across more than one group.

The Aged Care Diversity Framework notes that:

Older people with diverse needs, characteristics and life experiences can share the experience of being part of a group or multiple groups that may have experienced exclusion, discrimination and stigma during their lives. However, they are not a homogenous group. There are some similarities within groups in relation to the barriers and difficulties they may face in accessing the aged care system but additionally, each person may have specific social, cultural, linguistic, religious, spiritual, psychological, medical, and care needs. In addition to common challenges, social differences often overlap as people identify with more than one characteristic, exacerbating already complex issues. There is no limit to the number of different characteristics a person holds and no two people's lived experiences are the same.<sup>2</sup>

The Aged Care Act identifies the following people as people with special needs:

- people from Aboriginal and Torres Strait Islander communities;
- people from culturally and linguistically diverse backgrounds;
- people who live in rural or remote areas;
- people who are financially or socially disadvantaged;
- veterans;
- people who are homeless or at risk of becoming homeless;
- care-leavers;
- parents separated from their children by forced adoption or removal;
- lesbian, gay, bisexual, transgender and intersex people.<sup>3</sup>

People with special needs recognised under the Commonwealth Home Support Programme align with those identified under the Act. However, the Commonwealth Home Support Programme Guidelines note this is not an exhaustive list and that there are other diverse groups, such as people with a disability, people with mental health issues and mental illness, and people living with cognitive impairment, including dementia.<sup>4</sup>

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<sup>2</sup> Australian Department of Health, Aged Care Diversity Framework, December 2017, No 12028, p 3, [https://agedcare.health.gov.au/sites/default/files/documents/04\\_2018/aged\\_care\\_diversity\\_framework.pdf](https://agedcare.health.gov.au/sites/default/files/documents/04_2018/aged_care_diversity_framework.pdf).

<sup>3</sup> *Aged Care Act 1997* (Cth), s 11-3.

<sup>4</sup> Australian Department of Health, CHSP Guidelines, [https://agedcare.health.gov.au/sites/default/files/documents/03\\_2019/chsp\\_guidelines\\_from\\_1\\_july\\_2018-edits\\_7.3.19.pdf](https://agedcare.health.gov.au/sites/default/files/documents/03_2019/chsp_guidelines_from_1_july_2018-edits_7.3.19.pdf).

<b><i>How does it work now?</i></b>	<b><i>What is needed?</i></b>
<p>The Australian Government uses a combination of mechanisms such as supplements, support for capital infrastructure, priority in allocation processes and some flexible service models and specialist programs to ensure access to and the viability of services for a range of diverse groups.</p> <p>The Aged Care Diversity Framework provides guidance to encourage the aged care system to respond to diversity. Associated action plans identify specific barriers for older Aboriginal and Torres Strait Islander people, older people from culturally and linguistically diverse backgrounds and older lesbian, gay, bisexual, trans and gender diverse and intersex people, and identify actions to address those barriers.</p> <p>The needs of diverse groups are also specifically referenced in the Charter of Aged Care Rights and the Aged Care Quality Standards.</p>	<p>The system will be accessible to all older people who need aged care services, and those services will be tailored to their needs. This shift is reliant on a deeper understanding of the diversity of experiences, backgrounds and characteristics of older people in Australia. Caring for people with diverse needs has to be core business—not an afterthought.</p> <p>We expect that a combination of approaches will be needed to meet the challenges of ensuring appropriate access to aged care which meets the needs of people with diverse needs including:</p> <ul style="list-style-type: none"> <li>• funding to meet the differential costs of service provision where they exist</li> <li>• action to address communication and other barriers</li> <li>• enhancing the understanding of the role of intersectionality, culturally safe care and of trauma informed care</li> <li>• flexible service models</li> <li>• increasing systemic accountability.</li> </ul> <p>Specific programs or service offerings may be required to meet the needs of people from some diverse groups while for others mainstream services will need to redesign their service models.</p> <p>We have heard that Aboriginal and Torres Strait Islander people require flexible, adaptable and culturally safe models from assessment through to service delivery, including the role of community-controlled organisations.</p>

## Access in rural and remote areas

The delivery of services to rural and remote geographical regions in Australia is complex and differs for every community. It is impacted by multiple socioeconomic factors and the physical environment, such as the high cost of goods, utilities, transport, fuel, food and vehicles. There is often limited access to most government services and a shortage of staff to support those services.

One of the factors impacting access to aged care services of all types in rural and remote communities is population density and the numbers of older people who may require support. Most aged care services rely on scale and this is challenged in rural and remote settings.

<b><i>How does it work now?</i></b>	<b><i>What is needed?</i></b>
<p>Government uses a combination of mechanisms to ensure access to, and the viability of, services in regional and remote areas. These include viability supplements, support for capital infrastructure, priority in allocation processes and some flexible service models and specialist programs.</p> <p>People currently living in regional and remote areas of Australia receive support through the following programs:</p> <ul style="list-style-type: none"> <li>• Multi-Purpose Services (MPSs)—these facilities provide integrated health and aged care services for small regional and remote communities that could not viably support standalone hospitals or residential aged care facilities</li> <li>• National Aboriginal and Torres Strait Islander Flexible Aged Care Program—this program provides culturally appropriate aged care services close to home and community</li> <li>• Torres Strait Islander Aged Care Service Development Assistance Panel (SDAP)—this panel funds culturally appropriate local solutions addressing the challenges of maintaining and delivering quality aged care services to eligible aged care providers</li> <li>• Rural, Regional and Other Special Needs Building Fund—this fund recognises that in some areas there may be a need to fund the cost of building new or refurbishing existing aged care facilities.</li> </ul>	<p>We expect the need for a combination of the following approaches to meet the challenges of ensuring appropriate access to aged care in regional and remote areas:</p> <ul style="list-style-type: none"> <li>• appropriate determination and funding of the differential costs of service provision, including travel costs</li> <li>• funding and service models that enable providers to meet the challenges of thin markets and achieve economies of scope and scale (which could include, for example, periodic flexible block funding based on the allocation of places or the ability to pool funding across different aged care services, expansion of the Multi-Purpose Services Program in which aged care and health funding is pooled)</li> <li>• ensuring there is a ‘provider of last resort’ to address issues of market failure</li> <li>• place-based models focusing on local need</li> <li>• mechanisms that allow for government response or intervention in appropriate cases where there is an identified risk to sustainability of a care provider and a shortage of local services</li> <li>• pathways for attraction and retention of an appropriately skilled workforce to maintain service delivery in rural and remote areas.</li> </ul>

## Other issues to consider

### Financing aged care

Over the next decade, Australian Government spending on aged care is poised to increase from 1.1% of GDP in 2018–19 to 1.3% of GDP in 2028–29. Over that period, aged care would be the second fastest growing program in the Commonwealth with a real average annual rate of increase of 4.3%. By 2028–29, aged care expenditure will make up 5.4% of all Australian Government expenditure.<sup>5</sup>

These projections are based on the status quo—a status quo that we have already indicated in our Interim Report as being unacceptable—both in terms of the quality of care provided to older people and in terms of the time that many older people need to wait before they receive the care that they have been assessed as needing. Closing these gaps will increase expenditure in aged care considerably, both now and into the future.

Older people also contribute to the cost of their aged care. Across all of aged care, older people pay, on average, for about one-fifth of the cost of the aged care services that they receive. This share varies by program. Older people in residential aged care pay for 26.6% of the cost of the services that they receive. People in receipt of Home Care Packages pay for 5.9% of the cost of the services that they receive and people in the Commonwealth Home Support Programme pay for 9.4% of the cost of the services that they receive.<sup>6</sup>

However, much of the expenditure by older people in residential aged care is towards ordinary living expenses and these costs are also met directly by people receiving aged care services in their own home. Leaving aside living expenses, older people in residential aged care pay for 9.5% of the cost of the care services that they receive.

### Financing principles

Aged care lies at the intersection of Australia's health and social welfare systems. It is a unique type of service that has some of the characteristics of heavily subsidised health care. However, its main component is personal care, which has traditionally been provided within the household by carers and is mostly unsubsidised. As a result, in almost all OECD countries, the family is still the main provider and funder of aged care.<sup>7</sup> In Australia, the financing principles for aged care have been heavily influenced by those governing the health and social welfare systems.<sup>8</sup>

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<sup>5</sup> Parliamentary Budget Office. (2019). *2019–20 Medium-term fiscal projections*. Canberra: Australian Parliament.  
[https://www.aph.gov.au/About\\_Parliament/Parliamentary\\_Departments/Parliamentary\\_Budget\\_Office/Publications/Research\\_reports/Medium-term\\_budget\\_projections](https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Budget_Office/Publications/Research_reports/Medium-term_budget_projections)

<sup>6</sup> Aged Care Financing Authority. (2019). *Seventh report on the Funding and Financing of the Aged Care Industry*. Canberra: Australian Department of Health.  
[https://agedcare.health.gov.au/sites/default/files/documents/08\\_2019/acfa-seventh-report-2019-acc.pdf](https://agedcare.health.gov.au/sites/default/files/documents/08_2019/acfa-seventh-report-2019-acc.pdf)

<sup>7</sup> Costa-Font J, Courbage C, Swartz K. (2015). Financing long-term care: Ex Ante, Ex Post or Both? *Health Economics* 24(S1):45–57. doi: 10.1002/hec.3152.

<sup>8</sup> Cullen, D. (2003). *Historical Perspectives: The evolution of the Australian Government's involvement in supporting the needs of older people*. Canberra: Australian Department of Health and Ageing.

Australia has a robust retirement incomes policy built on three pillars:

- A means-tested government age pension. The pension provides retirees with a minimum standard of living in retirement. It is both a safety net for those who have not saved enough for retirement and a supplementary benefit for those who have not saved enough to be comfortable in retirement. The benefit is paid from consolidated revenue and is not pre-funded.
- Compulsory saving through the Superannuation Guarantee applied to all income from personal exertion. This is currently 9.5% of wages. It is collected by employers, which select a default fund. The Superannuation Guarantee is legislated to increase gradually to 12% by July 2025.
- Voluntary contributions made to superannuation funds, with various tax concessions.

At the same time, the Australian Government provides financial support for the health needs of older people through the same programs that assist all Australians.

The Australian age pension scheme was unique when it was introduced in 1909 and, to some extent, remains unique today. Most other OECD countries operate contributory social insurance systems. The quintessential features of such systems are that a person's right to benefit is secured by their contribution record without any test of need or means of self-support, and that contribution and benefit rates are often related to what the person is or has been earning.

In Australia, by contrast, eligibility for the aged pension does not depend upon past contributions and there is no discretion about the form or amount of the pension. The maximum rate of the pension is set at a level that encourages self-provision. Self-provision is further encouraged and rewarded through the concessional taxation treatment afforded to superannuation and through the tapered means test. The means test has special rules with respect to the pensioner's home. The value of the home is excluded from the maximum assets criteria.

Australian Government financial support for the health needs of older people relies on several common principles:

- The cost of care should be affordable to individuals. This involves the Commonwealth underwriting some of the cost of essential care for all people and supplying additional assistance where individuals are unable to afford the cost of their care or to make use of the mainstream financing arrangements.
- Individuals should be given a sense of personal and social responsibility through, for example, the use of co-payments.
- The cost of care should also be affordable to the Commonwealth. In particular, access to Commonwealth assistance should be subject to a clinical necessity requirement and access to more extensive Commonwealth assistance should also be subject to a means test.
- In general, any means test on access to Commonwealth assistance should be guided by the same principles as those used for income support payments, although it has on occasion been less generous than those arrangements.

Both the retirement income and health financing policy parameters have been influential in developing the approach taken by Australian Governments in their other programs to support older people. Indeed, the financing arrangements for aged care blend the means testing approach of the Age Pension and other welfare programs with the universal entitlement approach of Australia's health care system.



## Contributions to care

People in residential aged care are subject to both an assets and income test, which reduces the level of Commonwealth funding payable in respect of their care. However, there are annual and lifetime limits on the level of the means tested fees that an older person can be asked to pay. Most, if not all, of the value of the person's home is excluded from the aged care means test and the home is entirely excluded if it continues to be occupied by a dependent of the older person receiving residential aged care. However, unlike the age pension arrangements, most of the value of the person's home continues to be excluded from the aged care means test even when the older person and their dependants are no longer living in the home.

People in receipt of Home Care Packages are subject to an income test but not to an assets test. The income test for Home Care Packages has different (and lower) annual limits on the level of the means tested fees that an older person can be asked to pay compared to residential aged care.

There are no formal means testing arrangements for the Commonwealth Home Support Programme.

In the general community, accommodation and the ordinary costs of living are funded in their entirety by individuals who live in their own home, with any Australian Government assistance provided through the age pension or Commonwealth rent assistance. This remains true for people receiving assistance through the Commonwealth Home Support Programme or through a Home Care Package. In residential aged care, residents pay the aged care provider for their ordinary costs of living through the basic daily fee (set at 85% of the basic age pension). They also pay for their accommodation or are assisted through means tested arrangements.

## Financing sources

Currently, aged care costs are met by the Australian Government from general revenue and by older people from their savings, income earned on their savings or their age pension, or by their families. Other countries use other systems to finance aged care, including public and private long-term care insurance.

## Quality regulation

It is likely that changes in the service offerings and delivery models for aged care of the kind canvassed in this paper would require changes in the way in which aged care services are regulated.

Broadly speaking, the current approach to quality regulation is based on the settings in which aged care services are provided.

Within the aged care system, different regulatory approaches are applied to the care provided to people in residential care and home care, even though there is an overlap in the types of services provided.

In addition, aged care providers are subject to different regulatory requirements and are assessed against different standards to providers in the health and disability sectors, although many aged care recipients have the same or comparable health conditions and needs as people in those sectors.

More flexible service delivery options of the kind canvassed in this paper would mean that aged care would no longer be defined by the setting in which it is delivered (i.e. residential care facility or private home). Further, there would be very different forms of interaction between care recipients, service providers and the Government.

This presents opportunities for more agile and responsive models to be developed. A clearer specification of the aged care services to be provided to a care recipient would allow for the regulatory approach to be tailored to the nature of the services and the needs of the care recipient.

It also presents challenges, including the following:

- The delivery of health services in people's own homes by a range of different providers would raise questions about the extent to which a regulator could effectively monitor the quality and safety of the delivery of those services through an accreditation and inspection model.
- There are questions as to how the regulatory regime would apply to the different parties involved if, say, personal care or allied health services are provided to a resident of an aged care facility operated by a different provider.

A service model that provides more scope for care recipients to choose between alternative providers might reduce the need for some regulatory interventions around service quality but might also raise new issues of whether additional consumer protection is required in relation to the price or quality of services offered by service providers.

## *Implementation and transition*

It will be critical that implementation of reform is carefully managed and that there is transparent and independent oversight of whether it is delivering a better system for older people and their families. This will need to be reassessed at defined intervals. Any major redesign of the aged care system will involve complex and interdependent change affecting older people, providers, the aged care workforce, different levels of government and the broader community.

This requires consideration of what it means for:

- older people receiving services under the current system and how continuity of service delivery is assured
- the culture and models of care that support service delivery
- market structures and business models through which services will be delivered
- the operation and performance of aged care providers
- the availability, skill levels and training of the workforce
- the role of Government in overseeing the system
- financial impacts for older people, taxpayers and providers.

These issues will be carefully considered by us over the coming months.

# How you can be involved

## Design questions

1. **What are your views on the principles for a new system, set out on page 4 of this paper?**
2. **How could we ensure that any redesign of the aged care system makes it simpler for older people to find and receive the care and supports that they need?**

In your response, you may wish to consider the following:

- In what ways could the aged care system be made easier to access and navigate?
- What information, services or structures are needed to support older people to make informed choices about aged care, and to have appropriate control over the services they receive?

3. ***Information, assessment and system navigation.***  
**What is the best model for delivery of the services at the entry point to the aged care system—considering the importance of the first contact that older people have with the system? This includes looking at services provided by phone and website as well as face-to-face services.**

In your response, you may wish to consider the following:

- How could face-to-face services most benefit those older people at the entry point to aged care (or when changing programs)? What should those services include? Who should they be directed to? Where should they be located and who should provide them?
- What model of system navigation is most appropriate for aged care? How would that model change as older people's care needs increase or if they move into permanent residential aged care?
- How could the role of a system navigator relate to that of a care coordinator or case manager? What are the benefits of these functions being performed by the same person independent of the service provider? Would there be any drawbacks to that model?

4. ***Entry-level support stream.***

**People maintain their homes and gardens, do laundry, cook meals, get themselves to appointments and attend social engagements across their whole adult lives—some people may choose to pay others to do these things—but mostly they handle them with little assistance. As people age and need support with everyday living activities, how should Government support people to meet these domestic and social needs?**

In your response, you may wish to consider the following:

- Should these supports be made available to everyone (or just those that cannot purchase assistance)?
- What are the most important early supports for people in their homes and communities? What evidence is available on how these supports prevent or delay a move to permanent residential aged care (or support older people's wellbeing, health and functioning)?
- Are there some supports that need increased funding? Are there new or innovative approaches that should be recommended for inclusion in this stream?
- What are the advantages and disadvantages of block funding, providing cash or a 'debit' card with a fixed annual budget to eligible people or a mixed funding model (combining block funding with other approaches) for this stream?

5. ***Investment stream.***

**The benefits from regular and planned respite, reablement and restorative care are well documented, but the services are in short supply. What incentives, including additional funding, could be introduced to encourage providers to offer greater and more flexible options, including major home modifications and assistive technologies, which meet the needs of the older person, carer and caring relationship?**

In your response, you may wish to consider the following:

- How could existing restorative and respite care, as well as home modifications and assistive technologies, be reoriented so that they are proactive and preventative?
- What are the most important aged care interventions for people experiencing a crisis or sudden change in their circumstances? What evidence is available on how these interventions prevent or delay a move to higher level packaged care or permanent residential aged care (or support older peoples' wellbeing, health and functioning)?
- Are there specific interventions that need increased funding? Are there new or innovative approaches that should be recommended for inclusion in this stream?

6. ***Care stream.***

**As people's needs increase and go beyond what can be managed with entry-level support or with their carer, they may need care services—personal care, as well as nursing and allied health. What are the advantages and disadvantages of developing a care stream, independent of setting?**

In your response, you may wish to consider the following:

- How could existing provision of personal care, as well as nursing and allied health, be reoriented so that they are focused on individual needs, and not on whether the older person is at home or in a residential facility?
- Is the concept of 'reasonable and necessary' as used in the National Disability Insurance Scheme applicable to the level of support that could be funded under this stream?
- What should be the eligibility or threshold for accessing this stream?
- What are the advantages and disadvantages of block funding, providing cash or a 'debit' card with a fixed annual budget to older people or a mixed model (combining block funding with other approaches) for this stream?

7. ***Specialist and in reach services.***

**How could the aged care and health systems work together to deliver care which better meets the complex health needs of older people, including dementia care as well as palliative and end of life care? What are the best models for these forms of care?**

In your response, you may wish to consider the following:

- What would be required to support in reach of multidisciplinary health teams from the health system in the care of older people with high needs? What other services could be used (24/7 on-call services, embedded escalation to specialists, access to relevant ageing specialists, telehealth or other technological advances)?
- What is needed to ensure greater uptake of in reach health services (such as specialist palliative care) and aged care specific services (such as Severe Behaviour Response Teams and Dementia Behaviour Management Advisory Services)?

8. ***Designing for diversity.***  
**Caring for people with diverse needs and in all parts of Australia has to be core business—not an afterthought. How should the design of the future aged care system take into account the needs of diverse groups and in regional and remote locations?**

In your response, you may wish to consider the following:

- What role can the following interventions play: appropriate pricing to meet the differential costs of service provision where they exist; removing communication and other barriers; enhancing the understanding of the role of intersectionality, culturally safe care and of trauma informed care; flexible service models; and increasing accountability of the system?
- What interventions are required to meet the challenges of ensuring access to aged care in regional and remote areas? Are different funding models required? What role is there for technology in improving access? What other supports or interventions would be useful?

## *Additional questions*

9. ***Financing aged care.***  
**What are the strengths and weaknesses of the current financing arrangements and any alternative options that exist to better prepare Australia and older Australians for the increasing cost of aged care?**
10. ***Quality regulation.***  
**How would the community be assured that the services provided under this model are delivered to a high standard of quality and safety?**

In your response, you may wish to consider the following:

- Is there a case for different regulatory approaches based on the nature of the service provided rather than the location in which the service is delivered?
- Should some services only be provided in particular locations with appropriate support? Do some people have a complexity of need that would influence the location in which care is delivered to ensure quality and safety?
- How could a regulator assess the quality and safety of personal and nursing care and allied health services provided in people's own homes?
- Would the allocation of funds to older people rather than providers change the need for regulation? What kinds of consumer protection would be required, and would this apply to all services, or just some?

## Process

### Written submissions

We invite submissions on:

- the principles to guide design of a new aged care system
- options to create the best possible program, structures and system overall
- how aged care supports, services and care can help older people have the best life possible
- any other issues the Royal Commission needs to consider about system design under its terms of reference.

From pages 23 to 26 we provide system design discussion questions for you to use as a guide for your submissions.

Submissions will be accepted until close of business on **Friday, 24 January 2020**.

Submissions should be made to [ACRCProgramDesign@royalcommission.gov.au](mailto:ACRCProgramDesign@royalcommission.gov.au)

You can also:

- write to us at GPO Box 1151 Adelaide SA 5001, or
- telephone 1800 960 711 (between 8:00 am and 6:30 pm ACDT Monday to Friday except public holidays). An interpreter service is also available.

We anticipate that these submissions will be published on our website. However, the Royal Commission reserves the right to not publish submissions, or to redact information in submissions, before publication.

If your submission is of a more general nature, or relates to other concerns, then please go to our *Submissions* page and follow the instructions for making a submission. The Royal Commission will continue to accept general submissions until the end of April 2020.

If you have already made a submission to the Royal Commission that includes a discussion on system design, you do not need to replicate that submission. However, you may wish to draw our attention to that submission via the email address above.

### Workshops

In early 2020, the Royal Commission will convene workshops with authors of selected submissions from this process.

### Next steps

This consultation paper does not provide the final word on our ideas for redesigning the aged care system; that is something that we will be testing throughout 2020 as we consider the recommendations that we will put forward in our Final Report.