

Specialist Dementia Care Units

Consultation paper

November 2017

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# Abbreviations

| **Abbreviation** | **Description** |
| --- | --- |
| ACAR | Aged Care Approvals Round |
| ACAT | Aged Care Assessment Team |
| ACFI | Aged Care Funding Instrument |
| BPSD | behavioural and psychological symptoms of dementia |
| CALD | culturally and linguistically diverse |
| DBMAS | Dementia Behaviour Management Advisory Service |
| DTA | Dementia Training Australia |
| GPs | general practitioners |
| ICT | information and communications technology |
| LHN | Local Hospital Network |
| NDIS | National Disability Insurance Scheme |
| PHN | Primary Health Network |
| Quality Agency | Australian Aged Care Quality Agency |
| SBRT | Severe Behaviour Response Team |
| SDCU | Specialist Dementia Care Unit |

# Executive summary

In 2016, the Australian Government announced it would establish Specialist Dementia Care Units (SDCUs) to support people who experience very severe behavioural and psychological symptoms of dementia (BPSD). The Government committed to establish at least one SDCU in each of the 31 Primary Health Network (PHN) regions.

There are a number of existing Australian Government and state and territory government-funded supports, and initiatives by individual aged care providers, to support people with BPSD. However, stakeholders have consistently identified a gap in the ability of the aged care and the broader health system to provide appropriate care for the small minority of people (estimated as up to 1 per cent of people with dementia) with very severe BPSD.

SDCUs are intended to complement similar existing and planned state and territory government investments in services for people with very severe BPSD.

SDCUs are being established to:

* provide care for people with very severe BPSD who are unable to be effectively cared for by mainstream aged care services due to the risk of harm they present to themselves or others
* deliver care within a dedicated 8–12 bed unit with a residential aged care setting
* offer transitional support that focuses on reducing or stabilising symptoms, with the aim of enabling the person to transition to a less intensive care setting
* operate as the ‘third level’ of Australian Government programs to assist people with dementia, complementing the existing Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams
* enhance the existing health and aged care service systems for people with very severe BPSD, including complementing state and territory government funded services and supports for people with BPSD.

This consultation paper has been developed to provide information about the development of the SDCU initiative to date, and seek feedback on the best way forward. It builds on targeted consultation, consideration of existing services, and analysis of best practice evidence. Key considerations include:

* how SDCUs will intersect with existing supports for people with dementia
* the proposed high-level model of care
* funding and administrative options.

The proposed arrangements outlined in this paper have not been agreed by Government and may change, including in response to consultation feedback.

[Section 1](#_Introduction) describes the purpose and scope of the consultation paper.

[Section 2](#_Background) outlines the rationale for establishing SDCUs, and describes the current service environment.

[Section 3](#_Development_of_the) summarises consultation to date, and discusses broader policy considerations that will impact the design, implementation, and operation of SDCUs. This includes the service planning framework for people with BPSD.

[Section 4](#_SDCU_proposed_service) describes the proposed high-level model of care for the SDCUs. The ultimate goal of the SDCU program is to improve the aged care system response to, and individual-level outcomes for, people with very severe BPSD. SDCUs will provide a person-centred, goal-oriented and multidisciplinary approach to care. A number of principles for SDCU service delivery that reflect this approach are proposed.

It is proposed that people with very severe BPSD can be referred for SDCU assessment from the community, residential aged care, or acute care. Referral intake and assessment will be centralised. Specific eligibility criteria will apply. The SDCU client pathway will involve three main steps – pre-entry, service delivery and supported transition out. Each step will be supported by several enabling elements: SDCU staffing, education, training and culture, physical environment, clinical governance and partnerships, involvement of families and carers, commitment to continuous improvement, and quality and safeguards.

Section 4 also discusses how appropriate care for people with diverse backgrounds including people in rural and remote communities can be provided, and seeks views on flexible approaches and alternate models.

[Section 5](#_SDCU_proposed_funding) outlines possible funding and administrative options. We propose that SDCUs are funded by providing additional or ‘top up’ funding above standard residential aged care funding. We seek stakeholder views on whether this Australian Government ‘top up’ funding should be provided via a targeted supplement under the *Aged Care Act 1997* or via a grant. Section 5 also outlines the proposed use of ‘top up’ funding, eligibility and selection of SDCU providers, and the rollout of SDCUs across PHN regions. Subject to final decisions by the Australian Government, it expected that all 372 SDCU places will be operational by 2023-24.

[Section 6](#_SDCU_program_evaluation) talks about possible elements for evaluation of the SDCU program and the opportunity to increase evidence about this type of service, which is continuing to evolve in Australia and internationally.

[Section 7](#_SDCU_implementation_timeframes) provides high-level timeframes for implementation of the SDCU initiative.

Feedback on this paper will be used to inform advice and decisions about SDCU design and implementation. Once the preferred model of care and administrative arrangements are decided by the Australian Government, further targeted consultation will occur.

# Questions

*Refer to the main body of the paper for detailed discussion.*

Q1) Are there are other system reforms that would impact on, or be impacted by, the establishment of Australian Government-funded SDCUs?

Q2) What other risks and issues need to be considered in introducing SDCUs into the existing service systems for people with very severe (tier 6) BPSD?

Q3) Are there alternatives to the establishment of SDCUs that would better address the current system issues, which should be considered by Government?

Q4) Do you consider 1,450 to be a reasonable estimate of the national demand for SDCU-like beds for people with very severe BPSD? If not what other factors and/or methodologies should be considered?

Q5) Are the proposed SDCU service principles appropriate? If not, how should they be amended?

Q6) Are the above benefits what SDCUs should be aiming to deliver? If not, why?

Q7) What are the pros and cons of the SBRT performing the SDCU assessment service role? What other body (or bodies) might appropriately carry out this role?

Q8) Might the requirement for evidence of a primary dementia diagnosis (as described above) impact on timely access to SDCU services for some people with BPSD?

Q9) Are the proposed assessment arrangements appropriate? If not, why not?

Q10) What other factors should the SDCU assessment service consider in deciding whether to recommend a person for a SDCU placement?

Q11) Is an 8–12 bed unit (within a larger residential aged care facility) the appropriate care setting for SDCUs? Are there circumstances in which larger or smaller units would be more appropriate?

Q12) Should there be a maximum limit on the duration of an individual’s residence within a SDCU? If not, why not? If so, how long?

Q13) What is a reasonable period for transitional support from a SDCU to the new accommodation provider?

Q14) Might existing security of tenure arrangements pose a significant issue for the ‘transitional’ operation of SDCUs? If so, how?

Q15) What strategies could be used to facilitate SDCU ‘throughput’ within existing security of tenure provisions?

Q16) What mechanisms should be used to support partnerships between SDCUs and acute services?

Q17) Should there be any additional requirements for SDCU providers caring for people from Aboriginal and Torres Strait Islander, CALD or other diverse backgrounds?

Q18) Would it be feasible to establish SDCUs in rural and remote locations? How can SDCUs (or alternative initiatives) best support people with very severe BPSD living in rural and remote areas?

Q19) What specific costs would contribute to the ‘top up’ amount?

Q20) To what extent might these costs vary across SDCUs, for example in response to geographic location or local mix of people with BPSD?

Q21) Which ‘top up’ funding option do you prefer? Why?

Q22) Are there other funding mechanisms that should be considered?

Q23) Is block funding, occupancy-based funding or a combination of both most appropriate for SDCUs? Why?

Q24) Are the proposed uses of ‘top up’ funding appropriate or should there be other costs included or excluded?

Q25) With no specific capital funding for SDCUs proposed – is there a minimum funding period to justify an operator investing to establish a SDCU?

Q26) Do the proposed provider funding arrangements pose any financial sustainability risks?

Q27) Should any special resident fees and payments arrangements apply to people receiving care in a SDCU?

Q28) Are the proposed provider selection criteria appropriate? Do you consider some selection criteria mandatory?

Q29) Which factors should be prioritised in determining the regional rollout schedule and why?

Q30) What factors should be considered in evaluating the SDCU program?

# Introduction

## Purpose of this paper

This paper seeks stakeholder views on the policy design and implementation of the Australian Government’s Specialist Dementia Care Units (SDCUs) initiative.

The paper particularly seeks to:

* outline the rationale for establishing SDCUs
* summarise the current service environment in which SDCUs will operate, including current Australian Government and state and territory government supports for people with dementia
* elicit feedback on the proposed SDCU high-level model of care and funding and administrative options
* provide an overview of next steps and timeframes in implementing the SDCU initiative.

We would like to thank all those who assisted with the development of this consultation paper, especially the SDCU Expert Advisory Group members – Dr Anthony Hobbs, Professor Henry Brodaty, Professor Joseph Ibrahim, Professor Susan Kurrle, Ms Susan McCarthy, Professor Dimity Pond, Ms Angela Raguz, Dr Edward Strivens, Ms Kate Swaffer and Ms Debra Thoms – for generously giving up their time to provide expertise and advice to inform the SDCU proposed model of care.

Feedback can be provided using the Department of Health Consultation Hub at consultations.health.gov.au. Submissions should be provided by **21 January 2018.**

## Scope of consultation

This consultation seeks views on the proposed high-level model of care and funding and administrative options for SDCUs. The proposed arrangements in this paper have not been agreed by the Australian Government and may change, including in response to consultation feedback.

The paper does not provide the detailed information that would be outlined in SDCU program guidelines, manuals or performance and evaluation frameworks. This information will be shaped by the outcome of the current consultation and progressively developed over the next twelve months.

Consultation on the SDCU initiative is being undertaken in parallel with a number of other significant aged care and health system reforms and review processes. This paper predominantly focuses on SDCUs, but encourages stakeholders to consider the SDCU initiative in the context of these broader reforms, and whether alternative approaches may deliver better outcomes for people experiencing very severe and extreme behavioural and psychological symptoms of dementia (BPSD).

# Background

## Behavioural and psychological symptoms of dementia

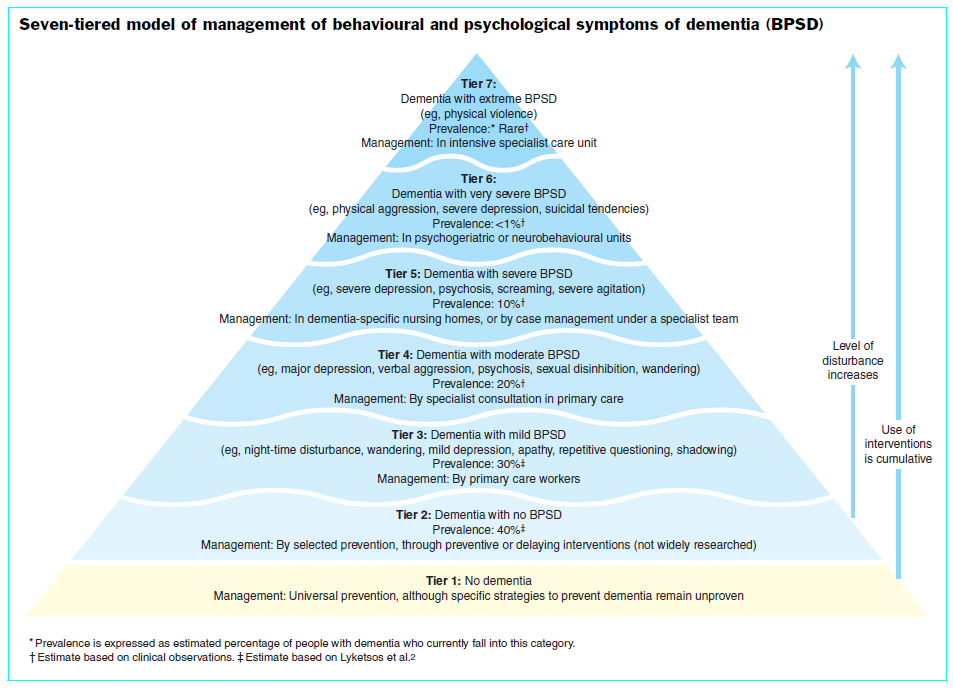
According to the Australian Institute of Health and Welfare (AIHW), there were an estimated 354,000 people with dementia in Australia in 2016.[[1]](#endnote-1) The number of people with dementia is projected to rise to about 900,000 people by 2050.[[2]](#endnote-2)

Most people with dementia experience some level of BPSD during the course of their illness. This may range from mild symptoms of BPSD, such as apathy and repetitive questioning, or moderate symptoms such as calling out, disturbed sleep, socially inappropriate behaviour, hallucinations and delusions through to marked agitation and aggression. A small minority of people have very severe acute psychiatric disturbance and may be dangerously aggressive. The cause of BPSD can be varied, with most behaviours transient in nature, although some behaviours, including agitation, can persist.[[3]](#endnote-3)

There is a view amongst some stakeholders, including consumers, that BPSD is not necessarily due to the pathology of dementia, but largely an expression of emotion or unmet need that the person with dementia cannot otherwise express (for example pain, frustration, loneliness, confusion or fear).

Brodaty, Draper and Low (Brodaty et al.) have described a seven-tiered classification of BPSD which includes the estimated prevalence and the services required to respond to these different levels of behavioural disturbance (Figure 1).

Figure 1: Brodaty, Draper and Low seven-tiered model**[[4]](#endnote-4)**



Very severe BPSD (tier 6), to which SDCUs aim to respond, includes but is not limited to: unpredictable aggression, sexual disinhibition and noisy outbursts (behaviours) and suicidal ideation and severe depression (psychological symptoms). Without the appropriate care, people with very severe BPSD have reduced quality of life and pose risk to themselves and others.

Management of BPSD should usually use non-pharmacological approaches in the first instance[[5]](#endnote-5) with a focus on reducing or eliminating unhelpful stimuli or ‘triggers’. Techniques such as distraction, redirection, reassurance and reorientation form the core of behavioural interventions applicable in a residential aged care setting.[[6]](#endnote-6)

## Existing government support for people with dementia and BPSD

### Australian Government dementia specific supports

In addition to wide-ranging funding for various health and aged care services, including residential aged care funding and grants for dementia research, the Australian Government provides specific support to people living with dementia, their families and carers.[[7]](#endnote-7) Support is delivered through a range of dementia specific programs and initiatives (Table 1). Supports for consumers are primarily delivered through the National Dementia Support Program.[[8]](#endnote-8) The Department of Health recently consulted on the proposed redesign of the program.[[9]](#endnote-9)

Complementing the National Dementia Support Program, the Dementia Training Program delivered by Dementia Training Australia provides education, upskilling, and professional development for the dementia care workforce in primary, acute and aged care. A single national provider has delivered the program since 2016. As part of this, residential aged care providers can have a dementia skills and environment audit undertaken on their service, which can identify facility design issues and gaps in staff training.

#### Specialist behavioural advisory services

The Australian Government additionally funds specialist advisory services to assist people living with BPSD.

The Dementia Behaviour Management Advisory Service (DBMAS) is the first line response for aged care workers, health professionals and family carers who need help caring for someone experiencing BPSD.

Severe Behaviour Response Teams (SBRTs) are the second level of behaviour management support specifically for people in Australian Government-funded residential aged care with severe BPSD. In 2016, the Australian Government appointed a single national provider for both the DMAS and SBRTs.

SDCUs will provide a third level of Australian Government funded specialist support (as depicted in Figure 2), assisting people with very severe (tier 6) BPSD currently unable to be effectively cared for by mainstream aged care services due to the risk of harm they present to themselves or others.

Table 1: Australian Government dementia specific supports

| Program name | Program focus | Target group | Delivery setting | Level of funding | Target service episodes |
| --- | --- | --- | --- | --- | --- |
| National Dementia Support Program | National Dementia Helpline and Advisory Service, awareness raising, information and training, education courses, counselling, and carer support groups | People with dementia, carers, families and friends, health professionals, volunteers, community contacts | General community | $12 million (2017-18) | n/a |
| Dementia Training Program | Accredited education, upskilling, and professional development | Workforce caring for people with dementia | Community and residential aged care, acute and primary care | $9.3 million (2017-18) | n/a |
| Dementia Behaviour Management Advisory Service (DBMAS) | First line response to provide information, advice, assessment and short-term case management interventions for people with BPSD | Workforce in aged care, health professionals, and family members caring for people with BPSD | Community and residential aged care, acute and primary care | $13.9 million (2017-18) | 7,500  (2017-18) |
| Severe Behaviour Response Teams (SBRTs) | Behaviour management support specifically for people in Australian Government- funded residential aged care with severe BPSD | Workforce in residential facilities caring for people with severe BPSD | Residential aged care | $13.4 million (2017-18) | 640 (2017-18) |
| Specialist Dementia Care Units (SDCUs) | Transitional support with a focus on reducing or stabilising symptoms, for people with very severe BPSD who cannot be effectively cared for in mainstream aged care services | People with very severe BPSD (<1% of people living with dementia) | Residential aged care | $72 million expected at full roll out (2023-24) | 372 supported places at full roll out |

Figure 2: Australian Government services to support people with BPSD

Specialist Dementia Care Units (SDCUs)

Severe Behaviour Response Teams (SBRTs)

Dementia Behaviour Management Advisory Service (DBMAS)

Dementia Training Program

**Level 3**

**Level 2**

**Level 1**

severity of BPSD

### State and territory government supports for people with dementia

In addition to support through Australian Government-funded initiatives, residential aged care providers may also receive support from the states and territories to assist in caring for residents with dementia, including those with very severe or extreme BPSD.

Most state and territory health services provide both regular and ad hoc specialist dementia care services to residential aged care facilities, either on a state-wide basis or within specific local hospital networks. Support can include advice, training, and, at times, temporary health staff placements or reimbursing aged care providers for temporarily providing additional staff to accommodate people transitioning out of long-stay health care, under ‘charge back’ arrangements.

Further, through their health services, the New South Wales, Queensland, Victorian and Western Australian governments currently provide residential aged care facilities with ‘top up’ funding and guaranteed access to state-employed specialists (for example, psychogeriatricians) to support care options for people with very severe BPSD and/or mental health behaviours.[[10]](#endnote-10) This is in addition to Australian Government funding provided through the Aged Care Funding Instrument (ACFI). Over 1,000 residential aged care beds across more than 40 facilities Australia wide are estimated to currently receive such support.[[11]](#endnote-11)

These facilities referred to as ‘SDCU-like’ facilities within this paper, are funded by state governments and tend to operate using additional care workers experienced in behaviour management, and employ a person-centred, psychosocial model of care. Some may also feature dementia-specific physical design. A mix of state‑operated and non-government operated services receive state and territory ‘top up’ funding.

The New South Wales and Tasmanian governments additionally operate over 100 beds in somewhat similar non‑acute community-based units as part of their older persons’ mental health systems.[[12]](#endnote-12)

Significant state government support for non-acute community based facilities to accommodate people with very severe BPSD and/or mental health behaviours commenced in the 1980s in the context of deinstitutionalisation, particularly the closure of large psychiatric hospitals. Deinstitutionalisation continues to be an important policy driver.[[13]](#endnote-13) An equally important driver, particularly for provision of outreach and temporary support, is reducing unplanned and/or avoidable presentations and admissions to emergency departments or specialist acute medical units, originating from the community or from residential aged care facilities.[[14]](#endnote-14)

State and territory support to residential aged care providers to better manage the care needs of people with BPSD continues to be an important part of long-term health agendas, with most states and territories planning to expand such support in the period to 2025.

### Supports available through the NDIS and Continuity of Support Programme

People with dementia who are under the age of 65, typically those with younger onset dementia, are eligible to apply for support under the National Disability Insurance Scheme (NDIS). The NDIS is being progressively rolled out, with data from regions where the NDIS has been implemented indicating that 97.5 per cent of people with younger onset dementia have been assessed as eligible and are receiving supports.[[15]](#endnote-15) Continuity of support strategies are being developed for those people with younger onset dementia who are assessed as ineligible for the NDIS.

The Commonwealth Younger Onset Dementia Key Worker Program (YODKWP) acts as a primary point of contact for people with younger onset dementia, their families and carers. The key worker provides information, support, counselling and advice, and helps consumers effectively engage with services appropriate to their individual needs. This program ensures that the needs of people with younger onset dementia are being met in the community by increasing awareness and education, building capacity in the disability, aged care, community and residential care sectors and improving coordination of services across agencies. Key workers identify and address gaps in services and build capacity through consultation, networking and collaboration with service providers and consumers. Funding for the YODKWP is transitioning to the NDIS as it progressively rolls out across the country.

## Why are SDCUs being established?

Whilst there has been considerable investment in supports to assist providers and carers respond to BPSD, stakeholders have consistently identified a gap in the ability of the aged care and the broader health system to provide the right care at the right time for people with very severe BPSD.

Establishment of Australian Government-funded specialist residential aged care units for people with very severe BPSD was recommended in a report to the then Minister for Ageing in 2008, and subsequently in further reports to the relevant Minister and in the Aged Care Sector Committee’s Aged Care Roadmap.

### Aged care sector capability

Caring for people with dementia is increasingly standard practice for residential aged care providers, with more than 50 per cent of permanent residents of Australian Government-subsidised residential aged care facilities estimated to have dementia.[[16]](#endnote-16)

However, capability to appropriately meet the needs of people with very severe BPSD remains limited outside a small number of specialised facilities, many of which receive ‘top up’ state and territory government support described above.

Early results from SBRT activities indicate that much of the behaviour referred to the teams for advice could be resolved within the resident’s current facility by addressing unmet need, in particular undiagnosed pain.

Nonetheless, even following SBRT intervention, 17 per cent of clients assisted by SBRTs required more intensive support and ultimately transferred to an acute care setting, including acute mental health facilities.[[17]](#endnote-17)

Moreover, recent high profile investigations have found that a number of facilities providing care for people with very severe BPSD have not provided adequate care or physical environments.[[18]](#endnote-18) In response to identified issues, the Australian Government commissioned an independent review of national aged care quality regulatory processes,[[19]](#endnote-19) the response to which will apply to care delivered through SDCUs.

### Access to appropriate services and complex existing client pathways

As discussed above, it is estimated that more than 1,000 community-based beds in residential aged care or mental health facilities already receive state government ‘top up’ funds to offer something like the proposed SDCU model of support. The distribution of beds, however, does not reflect consistent demographic or geographic planning principles, and beds are unevenly distributed across regions, with shortages more likely in regional, rural and remote areas.

Existing pathways into specialist residential care for people with very severe BPSD vary within and across states and territories and are generally not well developed or broadly communicated. To the best of our knowledge, pathways into the beds are mainly ‘step down’ from the acute sector, meaning that people have generally presented and been admitted to hospital, an older persons mental health unit, or general geriatric medicine unit before transferring to an SDCU-like unit.[[20]](#endnote-20)

‘Step up’ pathways into SDCU-like facilities, either directly from residential aged care or from a person’s home, are less common and less well developed. Australian Government investment in SDCUs provides an opportunity to enhance this pathway and avoid the cost and negative client impacts associated with potentially avoidable acute admissions.

This concept of step up and step down client pathways is depicted in Figures 3 and 4.

Figure 3: Typical existing ‘step down’ client pathway for people with BPSD



Figure 4: Proposed ‘step up’ client pathway into SDCUs



## What are the impacts of the current system issues?

Stakeholder consultation to date suggests the current shortage of evenly distributed SDCU-like facilities for people with very severe BPSD has impacts at both the individual and system level.

At the individual level, impacts may include:

* prolonged residence in a setting unsuitable to the person’s needs, whether their own home, mainstream residential aged care, or an acute health facility, with attendant poor quality of life and ongoing risk of harm
* exposure to an inappropriately ‘clinical’ model of care that may worsen behaviours and include futile, invasive and costly procedures
* heightened risk of physical and/or chemical restraint and social isolation as the primary behavioural management strategy
* ongoing risk of harm or disturbance to themselves and others including carers, aged care staff and other residents
* being required to physically move away from family and other local supports to access appropriate long-term care, especially for people living in regional, rural, and remote areas
* being ‘bounced’ between the aged care and health sectors, with distress from multiple transfers between settings and frequent disruption to care routines
* lack of culturally appropriate services.

The impacts for the aged care and health systems may include:

* poor targeting of resources and unnecessary costs through potentially avoidable, costly short-term hospitalisations and/or long-term residence in acute mental health facilities
* pressure on sub-acute facilities to transition residents into mainstream aged care earlier than might be appropriate to manage service demand
* high turnover and burnout of staff in mainstream residential aged care and health services as a result of staff feeling poorly equipped to appropriately manage people with very severe BPSD
* difficulties in accessing mainstream residential aged care for people with earlier stage dementia due to provider concern about the potential future risks associated with disease progression.

## The Australian Government’s commitment to establish SDCUs

In December 2016, the Australian Government committed to establish at least one SDCU in each of the 31 Primary Health Network (PHN) regions as depicted on the next page.

Figure 5: Map of PHN boundaries

Coloured map of Australia showing Primary Health Network boundaries (31 in total)

SDCUs are being established to:

* provide care for people with very severe BPSD who are unable to be effectively cared for by mainstream aged care services due to the risk of harm they present to themselves or others
* deliver care within a dedicated 8–12 bed unit with a residential aged care setting
* offer transitional support with a focus on reducing or stabilising symptoms, with the aim of enabling the person to transition to a less intensive care setting
* operate as the ‘third level’ of Australian Government programs to assist people with dementia, complementing the existing Dementia Behaviour Management Advisory Service and the Severe Behaviour Response Teams
* enhance the existing health and aged care service systems for people with very severe BPSD, including complementing state and territory government funded services and supports for people with BPSD.

Funding for the SDCU initiative is expected to be $72 million per annum from 2023-24 once all 372 places are operational.

A core feature of the Government’s commitment is that people living with dementia in rural and remote locations will have access to support, particularly in areas which currently cannot access specialist support services.

# Development of the SDCU service model

## Inputs that have informed the proposed SDCU arrangements

The proposed SDCU arrangements outlined in this paper have been informed by targeted consultation, consideration of existing operating models, and analysis of best practice evidence. More specifically this has included:

* an SDCU Design Workshop with key aged care sector representatives and clinicians held in March 2017
* interviews and discussions with state and territory government officials in all jurisdictions, to understand current service systems for older people with mental health-related very severe behaviours and/or very severe BPSD
* rapid review of the domestic and international literature on SDCU-like facilities or similar, conducted by the University of Wollongong
* consultation with clinical experts, people with dementia and organisations representing people with dementia through the SDCU Expert Advisory Group, which was convened to provide advice on the proposed model of care
* facilitated internal workshops to scope legal, funding and administrative options.

## Broader policy context in which SDCUs will operate

SDCUs are being designed and implemented within a broader policy context that is complex and evolving. This will require extensive consultation across the Health and Social Services portfolios and particularly with state and territory governments.

Relevant policy agendas and processes include:

* operation of existing and planned expansion of state and territory supported SDCU-like facilities in most jurisdictions (see 2.2.2)
* completed and ongoing age care reforms and future sector expectations expressed in the Aged Care Roadmap
* any changes to aged care regulatory process in response to the recommendations of the Review of National Aged Care Quality Regulatory Processes (released October 2017)
* joint Australian Government and state/territory responsibility under the National Healthcare Agreement to develop care options for older people with dementia and mental health issues, and relevant provisions in any bilateral agreements between the Australian Government and state or territory governments
* national targets for care of people with severe BPSD at the PHN region level as established in the National Mental Health Service Planning Framework
* the upcoming strategy being developed by the Aged Care Workforce Strategy Taskforce
* outcomes from the recent Department of Health consultation on the redesign of dementia consumer supports
* the National Framework for Action on Dementia 2015–2019
* disability reform, including NDIS rollout and, in particular, the development of any new residential options for people with younger onset dementia.

Q1) Are there are other system reforms that would impact on, or be impacted by, the establishment of Australian Government-funded SDCUs?

## Consultation feedback to date

Stakeholders consulted to date (see 3.1) have generally been supportive of the SDCU concept and the need to improve the system response for people with very severe BPSD. Key areas of feedback have included:

* Strong need for Australian Government investment to complement, rather than duplicate or substitute for, existing and planned state and territory support for non‑acute community based accommodation for people with very severe BPSD.
* Acknowledgment that the evidence to inform a detailed SDCU operating model is currently limited, and that approaches to delivering care for this cohort are still in development in Australia and internationally. Robust evaluation of the SDCU initiative should contribute to the international evidence base, assist in refining the SDCU model over time, and also generate evidence on best practice dementia care that all residential aged care providers could adopt.
* The risk that mainstream residential aged care providers assume that SDCUs will provide care for the majority of residents with BPSD, and consequently reduce their focus on developing skills in identifying and addressing causes of dementia-related behaviours and become less willing to accept residents with BPSD.
* The need for flexibility in implementing the SDCU initiative in rural and remote areas where there are particular barriers to establishing such beds. These barriers include longer travel distances particularly for families and carers, workforce limitations, lack of access to specialists, and capital infrastructure investment.
* The requirement for special consideration for particular client groups, including people from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse (CALD) backgrounds.
* Potential perception by people with dementia, families and carers of a  
  ‘re-institutionalisation’ approach to providing care for people with BPSD.

Q2) What other risks and issues need to be considered in introducing SDCUs into the existing service systems for people with very severe (tier 6) BPSD?

Q3) Are there alternatives to the establishment of SDCUs that would better address the current system issues, which should be considered by Government?

## The service planning framework for people with BPSD

### The prevalence of people with very severe BPSD

The Brodaty et al. model remains the most widely accepted service planning framework for people with BPSD, both in Australia and internationally, with Australia’s National Mental Health Service Planning Framework drawing heavily on the model as the basis for service planning for older people.[[21]](#endnote-21)

This model estimates the prevalence of very severe BPSD at up to 1 per cent of all people with dementia. This would equate to around 3,550 people in 2017 and 4,100 in 2022 using AIHW dementia data.

### Demand for SDCU services

SDCUs are intended to provide care primarily for people with very severe BPSD (tier 6 in the Brodaty et al. model) who are unable to be appropriately cared for by mainstream aged care services, due to the risk of harm they present to themselves or others but who do not require acute, sub-acute or primarily psychiatric care more appropriately delivered in a health setting.

However, not all people with very severe BPSD will benefit from care within a SDCU. A cohort of people exhibiting tier 6 BPSD will be able to be appropriately cared for within mainstream aged care services, while others will have health needs (for example, treatment for delirium or severe depression with suicidality) that are more appropriately managed in an acute setting.[[22]](#endnote-22)

SA Health has recently estimated that around 25–40 per cent of people with tier 6 BPSD would be likely to benefit from an SDCU-like service.[[23]](#endnote-23) Other state and territory health services have not published population-based targets for supply of similar beds, nor does the National Mental Health Service Planning Framework provide specific guidance.

Based on the South Australian methodology, nationally it is estimated that up to around 1,450 SDCU-like beds would be needed to meet the current needs of people with very severe BPSD.[[24]](#endnote-24)

#### Number of people to be supported by SDCUs

The SDCU program is not intended to meet a specific population-based target number of beds for people with very severe BPSD. The program instead is expected to contribute to addressing existing gaps in service coverage by nominally delivering 12 beds for each of the 31 PHN regions, or a total of 372 beds across Australia, with each bed generally expected to be occupied for up to 12 months at a time. Ongoing collaboration between the Australian Government and state and territory governments will be essential to ensure that the SDCU initiative expands existing service system capacity.

Q4) Do you consider 1,450 to be a reasonable estimate of the national demand for SDCU-like beds for people with very severe BPSD? If not, what other factors and/or methodologies should be considered?

# SDCU proposed service model

This section outlines proposed high-level elements of the SDCU service delivery model. This model has not been agreed by the Australian Government and and may change, including in response to consultation feedback. It reflects stakeholder feedback and analysis of best practice evidence to date. We welcome your views on other ways in which we might equally or better improve care delivery and outcomes for people with very severe BPSD.

## SDCU overview

SDCUs will operate as small units within larger residential aged care facilities. SDCUs will provide a person-centred, goal-oriented and multidisciplinary approach to care for people with very severe BPSD who are unable to be appropriately cared for by mainstream aged care services.

The units will offer transitional, intensive specialist residential support with a focus on reducing or stabilising symptoms over time, with the aim of enabling the person to transition to a less intensive care setting.

## SDCU aims and objectives

The ultimate aim of the SDCU program is to improve the aged care system response to, and individual-level outcomes for, people with very severe BPSD. This will be achieved by increasing the target group’s access to sustainable, high quality, and specialised residential aged care services that deliver care in accordance with the following service principles:

1. SDCUs adopt an inclusive, person-centred and goal-oriented philosophy and approach to care that builds on the strengths and capacity of individuals.
2. SDCUs aim to stabilise symptoms, improve wellbeing and quality of life through provision of optimal care, with a strong focus on ongoing assessment, care planning and access to therapeutic and meaningful activities.
3. SDCUs deliver services tailored to the unique circumstances, background and preferences of each client, their family and carers, including using supported decision-making rather than substitute decision-making wherever possible and by valuing and supporting carers and the caring relationship.
4. SDCUs use a multidisciplinary approach with formalised arrangements for access to specialist services and clinicians to support the provision of optimal care and clinical governance.
5. SDCUs deliver care in a safe, stable and enabling environment that reflects dementia friendly /dementia enabling design principles.
6. SDCUs employ adequate numbers of appropriately skilled and trained staff with the capability, commitment and confidence to work with people with very severe BPSD.
7. SDCUs adopt least restrictive practices and promote human rights for people with dementia, including through supporting the transition of people to less intensive care settings.
8. SDCUs build and maintain collaboration and partnerships with local hospital networks, acute and subacute services, mainstream aged care providers and primary care professionals at the regional level to facilitate access and smooth transition to appropriate services for the target group.
9. SDCUs actively participate in evaluation, continuous improvement and sharing of information to inform best practice and new models of care for people with very severe BPSD.
10. SDCUs are underpinned by collaboration between the Australian Government and state and territory governments, that enhances access to services and facilitates smooth transitions between service systems for the target group.

Q5) Are the proposed SDCU service principles appropriate? If not, how should they be amended?

## SDCU intended benefits

The implementation of SDCUs is intended to produce benefits at the individual level, the service level and the system level. Examples of potential benefits that could inform the SDCU program evaluation framework are outlined below.

SDCU client level benefits

The client level benefits would consider the impact of the program for clients, families and carers, and could include:

* clients’ symptoms stabilised
* clients are supported with dignity and provided with optimal care in a safe, stable and enabling environment
* clients experience improved wellbeing and quality of life
* clients successfully transition to less intensive care settings when this is appropriate
* families and carers of people with very severe BPSD feel valued and supported in their caring role and experience reduced carer-related stress.

SDCU service level benefits

The service level benefits would focus on how the SDCU program has been rolled out in individual residential aged care facilities, and the particular actions and changes that have been implemented to provide care to the target group, which could include:

* services develop and retain experienced, skilled, empowered staff with low turnover
* services develop enhanced capacity to care for people with very severe BPSD
* services are delivered within dementia friendly/enabling environments
* services deliver a multidisciplinary approach to care and strong partnerships with local services and stakeholders.

Aged care and health system level benefits

The system benefits would consider how the program has contributed to providing care for people with very severe BPSD, as well as the integration and interface of the program with the mainstream aged care system and the health system, with potential benefits including:

* enhanced capability of the aged care system to support people living with dementia as SDCUs provide centres of excellence for management of very severe BPSD and complement existing initiatives such as the Dementia Training Program delivered by Dementia Training Australia and the DBMAS and SBRT delivered by Dementia Support Australia
* improved access to targeted and appropriate support for people with very severe BPSD, enabling existing services and programs to operate more effectively, within a lower risk environment, and leading to flow-on benefits for all people within mainstream aged care services
* reduction in futile medical interventions and associated avoidable admissions and prolonged stays in hospital or acute mental health services for people with very severe BPSD, as a result of strong service provider partnerships at the local level and enhanced aged care system capability
* agreed roles and responsibilities for the Australian Government, states and territories, residential aged care and health providers, that support well-managed transitions between the aged care and health care systems for the SDCU target group
* strengthened evidence base to inform best practice, new models of care and training content on care for people with very severe BPSD.

Q6) Are the above benefits what SDCUs should be aiming to deliver? If not, why?

## The SDCU model of care

The SDCU client pathway will involve three major steps – pre-entry, service delivery and supported transition out. Enabling elements will support each step in the journey. Together these form the ‘four pillars’ of the proposed SDCU model of care. This is illustrated in Figure 6 below.

Figure 6: SDCU model of care

**Client pathway**

**Pre-entry**

Target group

Referral pathways

Eligibility

Assessment

**Service delivery**

Care setting

Philosophy and care approach

Care planning

Care and services provided

Leave from care

Minimising use of restrictive practices

**Supported transition out**

Duration of stay

Monitoring and review

Transition out process

Transition out support

Security of tenure

Re-entry

**Enabling elements**

Staffing profile, education, training and culture

Physical environment

Clinical governance and partnerships

Involvement of families and carers

Commitment to continuous improvement

Quality and safeguards

### Pillar 1 - Pre-entry

The pre-entry step will confirm eligibility and determine whether a SDCU placement is the most appropriate care option.

### SDCU target group

SDCUs are intended to provide care for people with very severe BPSD (tier 6 in the Brodaty et al. model) who are unable to be appropriately cared for by mainstream aged care services due to the risk of harm they present to themselves or others, but who do not require care more appropriately delivered in other settings.

Given that the Brodaty et al. model is a classification scale for service planning rather than a validated diagnostic tool for individuals, in practice people with severe (tier 5) or extreme (tier 7) BPSD are expected to access SDCUs on occasion, subject to assessment outcomes (see 4.4).

Compared to the average population with dementia, people with very severe or extreme BPSD are more likely to be male, younger (under 70), medically fit, and have a non-Alzheimer’s form of dementia.[[25]](#endnote-25)

### Referral pathway

Referrals for an SDCU assessment will be able to be made for people in:

* residential aged care facilities
* the community (who may or may not be receiving Australian Government-subsidised aged care support)
* acute care including hospital settings.

Referrals for an SDCU assessment will be able to be made by a range of groups including: specialists, general practitioners, nurse practitioners, residential aged care staff, SBRTs, people with dementia, their carers or family members, and Aged Care Assessment Team (ACAT) assessors. Referrals will need to be supported by input from the treating specialist or GP.

Due to the specialised referral and assessment needs of the target group, referral for assessment is expected to sit outside My Aged Care. However, My Aged Care staff will be able to assist individuals or their representatives to make contact with the national assessment service.

### Centralised intake and assessment

There will be single central entry point for accepting SDCU referrals, undertaking preliminary screening, eligibility assessments for SDCU suitability and having a coordination role. This SDCU assessment service will assist in the process being streamlined, easy to navigate and integrated with existing elements of the dementia care and aged care system. The entry point, and subsequent screening for eligibility and SDCU assessments, will be conducted independently from SDCU providers.

Stakeholders have suggested that the existing Severe Behaviour Response Teams (SBRTs) could perform this role, drawing on appropriate professional expertise in other organisations as required. This would potentially create a continuum of care for people with BPSD from DBMAS, to SBRT to SDCUs and ensure national coverage.

Assessment will be conducted within agreed timeframes and will be expected to be carried out face-to-face at the eligible person’s current accommodation, unless exceptional circumstances apply.

Q7) What are the pros and cons of the SBRT performing the SDCU assessment service role? What other body (or bodies) might appropriately carry out this role?

### SDCU assessment elements

Once a referral is made to the national SDCU assessment service, a three stage assessment process will be undertaken, comprising:

1. SDCU preliminary screening
2. needs based assessment to determine a person’s suitability for a SDCU placement
3. a local SDCU placement assessment.

Figure 7 provides an overview of these distinct assessment elements.

Figure 7: SDCU proposed assessment elements

* Conducted by the SDCU assessment service
* Comprehensive and multidisciplinary
* Appropriately qualified and experienced assessors using a range of validated tool/s
* Conducted face-to-face
* Involves carers and families
* ***Recommended for SDCU placement and continues to SDCU placement assessment OR***
* ***Is referred to alternate services and/or provided with additional supports within their existing care setting if not recommended for SDCU placement***
* Conducted by SDCU-specific clinical advisory local level assessment to consider ‘best fit’, safety and other external factors
* Consultation with the SDCU assessment service
* ***Client is accepted by the SDCU provider OR***
* ***Is referred to alternate SDCU provider, acute system or mainstream residential facility (with additional supports)***

**SDCU NEEDS BASED ASSESSMENT**

***Assessment of need for SDCU placement including consideration of whether:***

* Severe behaviours present a risk of harm to themselves and/or others?
* Behaviours and risks persist despite evidence of management strategies being implemented
* Likelihood of benefiting from SDCU placement and transition to mainstream care
* Medical treatment is not required that is delivered in an acute or other health setting?

**SDCU PLACEMENT ASSESSMENT**

***Service specific assessment to consider:***

* Is the person a ‘good fit’ for the particular SDCU service and current client mix?
* Is the SDCU provider confident that care needs and risks can be appropriately managed?

**SDCU PRELIMINARY SCREENING**

***Screening to determine whether the person proceeds to needs based assessment***

* ACAT assessment and eligible for residential aged care
* Evidence of primary dementia diagnosis
* Not under a state or territory mental health detention order
* Client and carer consent
* Conducted by the SDCU assessment service
* Referrals from aged care providers, medical professionals, acute services, ACAT assessors, people with dementia, carers and family members
* General practitioners will have a key role in the referral process
* ***Continues to SDCU needs based assessment OR***
* ***Is referred to alternate services if screening requirements are not meet***

#### a) SDCU preliminary screening

The following criteria are proposed to determine whether a person proceeds to an SDCU assessment:

* the person has had an ACAT assessment and is eligible to receive residential aged care
* the person has a primary dementia diagnosis. This would generally require written confirmation by a medical practitioner (either the treating specialist or GP)
* the person is not under a state or territory mental health detention order
* the person and/or their nominated representative consent to the SDCU assessment process.

Consent will be sought by the referrer and verified by SDCU assessment services in accordance with state and territory rules, similar to access to other aged care programs.

Consistent with other forms of residential aged care, there will be no definitive age-based criteria. People with younger onset dementia will be eligible for SDCU support should they be unable to access the required support in more age-appropriate settings.

People with pre-existing mental health conditions in addition to a primary dementia diagnosis would be able to access SDCU support subject to the outcomes of the three stage assessment process.

People who are assessed as not meeting the preliminary screening criteria would not proceed to the SDCU needs based assessment and would be referred to alternate services as appropriate.

Q8) Might the requirement for evidence of a primary dementia diagnosis (as described above) impact on timely access to SDCU services for some people with BPSD?

#### b) SDCU needs based assessment

The SDCU assessment process will need to appropriately target care to eligible people most in need and likely to benefit from a SDCU placement.

While there is no universally accepted single tool to assess a person’s need and/or suitability for a SDCU placement, assessments will need to be comprehensive, and conducted by an appropriately qualified and experienced assessment workforce that utilises a range of validated assessment tools as appropriate. Assessments will also need to be timely, inclusive of families and carers, culturally appropriate and generally conducted face-to-face in the person’s usual care setting.

It is expected that the following factors would be considered as part of the SDCU needs based assessment:

* the extent to which the person exhibits behaviours consistent with very severe BPSD
* the risk that the person presents to themselves and others within their current environment
* the extent to which prior behaviour management strategies have been implemented within their current care setting and their outcomes
* the likelihood that the person would benefit from care in a SDCU and be able to transition back to a mainstream care setting within 6–12 months
* whether the person is medically stable and is not requiring treatment that would be more appropriately delivered in an acute care or other health care setting (for example treatment for delirium or terminal agitation).

The outcome of the needs based assessment will be either:

1. a recommendation from the SDCU assessment service that the person should be considered for SDCU placement. In this case, with client and carer consent, the person’s information will be provided to the local SDCU provider for the final SDCU placement assessment; OR
2. a decision by the SDCU assessment service that the person not be considered for SDCU placement at this time. In this case, the person, carer and referring body (and any other parties nominated by the person) will be notified of the decision. Advice will be also be provided on alternative, non-SDCU care options. These may include being assisted to find an alternate mainstream aged care provider, referral to an acute service; or remaining within their existing care environment but with additional advice provided to the mainstream provider by the DBMAS or SBRT.

The assessment service will generally refer recommended individuals to the SDCU provider in the PHN region where the person lives. However, it may also provide referrals to SDCUs in one or more other PHN regions after discussion with the person and their representative.

The assessment service will also be expected to maintain close, productive relationships with local ‘gatekeepers’ managing access to similar state or territory government-supported facilities in each PHN region.[[26]](#endnote-26)

#### c) SDCU placement assessment

Once a SDCU placement is recommended by the SDCU assessment service, a local SDCU service-specific assessment will be undertaken. These will be done by the local SDCU unit, through its clinical advisory committee.

These local placement assessments would be similar to those undertaken by the clinical advisory committees that are in place for most state-supported existing SDCU-like services. This placement assessment would consider issues such as whether:

* the person is a ‘good fit’ for the particular SDCU given its current mix of residents and staffing profile
* the person presents particular safety risks
* there are complexities in the family and carer dynamics that need to be understood
* there are other relevant external factors that might affect the SDCU placement.

It is expected that the majority of people would be accepted into care following the placement assessment. However, where this is not the case, people may be referred (by the assessment service) to an alternate SDCU provider, a mainstream provider or the acute system, as appropriate and with the agreement of all parties.

The SDCU provider will be the final decision maker on accepting a person into the SDCU, after having regard to the advice of its clinical advisory committee. The SDCU provider may also directly negotiate transitional ‘take back’ arrangements with a newly accepted resident’s existing accommodation provider, in the event the person’s behaviours prove either not sufficiently severe or too severe for care to be appropriately provided in the SDCU.

Each SDCU provider will manage a local wait list should this be necessary. SDCU providers will be required to report on client acceptance rates and the profile of clients and source of referrals.

A process will be developed forpeople to raise their concerns about the assessment process and outcomes.

Q9) Are the proposed assessment arrangements appropriate? If not, why not?

Q10) What other factors should the SDCU assessment service consider in deciding whether to recommend a person for a SDCU placement?

### SDCU hypothetical case studies

The following hypothetical case studies are provided to illustrate how particular clients might move through the SDCU client journey.

**Gloria** is 79, and has been in an aged care home in a capital city for the last five years. Her family is supportive and include three daughters and a son. Gloria has vascular dementia and over the last few months has demonstrated severe agitation and aggression (verbal and physical) towards staff and other residents. Despite ongoing SBRT review and implementation of the various strategies, these behaviours continue to escalate. Gloria’s family is very distressed by her behaviour and want to know about further options to assist her.

Gloria’s GP has suggested to the aged care home and Gloria’s family that Gloria might benefit from a SDCU placement, and a referral for an SDCU assessment is made.

The SDCU assessment builds on the previous SBRT assessment, and recommends that Gloria be transferred to the SDCU in her PHN, which reviews her information and confirms she can be accepted into care. The SDCU is in another part of the city, and further away from her family. However, Gloria’s family is supportive of the move to another location, so she can receive more specialised care.

Gloria’s symptoms improve in the first few months whilst in the SDCU, and her transition to the aged care home adjacent to the SDCU is planned after six months. However, during this time Gloria’s health and mobility start to deteriorate as her dementia progresses, and with the agreement of all parties she transfers back to a place in her previous aged care home which is closer to her family.

**Harry** is 68 and has been in an aged care home in a regional city for six months. He has alcoholic dementia and a number of other chronic health conditions, although he is physically very active and strong. He played many sports in his youth including football and boxing.

Harry has had BPSD for some time, and prior to his admission to the aged care home, was supported by DBMAS in his home. He gets very agitated and aggressive, has physically threatened other residents and staff, and is prone to loud yelling and screaming. These behaviours are worsening despite SBRT intervention and follow through of recommendations.

The aged care home reluctantly transfers Harry to the local hospital (after he assaulted another resident and they felt they could no longer care for Harry and the other residents safely). Harry is reviewed by a geriatrician, who recommends a referral for SDCU assessment

Harry is recommended for a SDCU placement following a needs based assessment. The local SDCU clinical advisory committee considers how Harry would fit with the existing unit residents which are mainly older women, and recommends that Harry be provided care in the SDCU in the neighbouring PHN which has a higher number of males and would be a better fit for him. This SDCU has an easily accessible large outdoor area which Harry uses a lot for walking, which seems to be a factor in his improvement. Harry’s symptoms have gradually subsided over the 12 month placement and he transitions to a ‘step-down’ bed in the same facility.

**George** is 76, has dementia and is in an aged care home. He immigrated to Australia many years ago and has limited English language skills. He has been yelling out and is very disruptive in the facility, and other residents’ families have been complaining to management. The care team refer George for an SDCU assessment as they think he meets the screening requirements. In undertaking the SDCU needs based assessment, in consultation with George’s GP, care staff and family, it is determined that his symptoms are related to pain due to dental problems. Staff at the aged care home were also not aware of the supports available through DBMAS or SBRT, with the latter coming to the facility to meet George, his family and care staff. They also help the care staff get in touch with the state Partners in Culturally Appropriate Care organisation, which suggests some strategies to assist in delivering culturally appropriate care to George.

George is seen by the dentist who successfully treats George’s dental problems, and George’s behaviours quickly settle.

**Margaret** is 74 years old and lives at home with her husband Jack. She receives assistance with activities of daily living through a Level 2 home care package. She has a primary diagnosis of bipolar disorder, and a secondary diagnosis of mild vascular dementia.

Jack contacts Margaret’s GP due to concerns about her symptoms getting worse. Margaret is becoming increasingly distressed and experiencing delusions. At times she gets very agitated, crying for long periods and yelling out. At other times she is very withdrawn. Margaret’s GP refers her to hospital.

Hospital staff suggest that Margaret should be referred for an SDCU assessment. The SDCU assessment service accepts the referral and conducts a preliminary screening, and then continues with a needs-based assessment. The SDCU assessment service, in conjunction with Margaret’s GP and psychogeriatrician, determine that Margaret’s symptoms likely relate to her primary diagnosis of bipolar disorder (rather than dementia). She is more appropriately referred to a state government older persons’ mental health unit for treatment.

### Pillar 2 – SDCU delivery

The service delivery step will offer intensive, psychosocial-based specialist residential support with a focus on stabilising symptoms for individuals to transition to a less intensive care setting.

### Care setting

Care will generally be delivered in a dedicated 8–12 bed[[27]](#endnote-27) residential aged care unit, located within a larger residential aged care facility.[[28]](#endnote-28) This will facilitate opportunities for ‘step down’ into a mainstream bed within the same broader facility.

Q11) Is an 8–12 bed unit (within a larger residential aged care facility) the appropriate care setting for SDCUs? Are there circumstances in which larger or smaller units would be more appropriate?

### Philosophy of care and care approach

A psychosocial, person-centred and goal-oriented philosophy and approach to care will be employed that builds on or maintains the strengths and capacity of individuals. A person-centred approach (care that is consistent with the 10 Principles of Dignity in Care) will be used to minimise the impact of BPSD.[[29]](#endnote-29) A strong program of activities that reflects individual interests and strengths will be provided. In providing care to people in the SDCU, staff, in partnership with families and carers, will identify, monitor and address environmental, physical health and psychosocial factors such as unmet needs and stress thresholds, to ensure improved outcomes for clients.[[30]](#endnote-30)

### Care planning

Care planning will take a person-centred approach, which is a way of organising and providing services that places the person (and their family, friends and carers) at the centre of planning and decision-making, and is respectful of, and responsive to, individual beliefs, preferences, needs and values of clients and those who care for them. A person-centred approach is based on valuing and understanding people’s life context, experience, relationships and environment, and what is important to them. It is also enabled by empowerment and a culture of continuous improvement.[[31]](#endnote-31)

Care planning will include the following key elements:

* a multidisciplinary clinical advisory committee that oversees and regularly reviews individual care plans and approves entry to and transition out of the unit
* development of an individual care plan (in partnership with the person with dementia’s family and carer/s) that provides clear strategies to anticipate, manage and de-escalate BPSD[[32]](#endnote-32)
* involvement of clients, family and carers in care planning and goal setting discussions
* explicit consideration of person-centred and culturally appropriate care
* consideration of the person’s preferences and previous interests
* maximum opportunities for independent performance of activities of daily living
* planning for step down care and advanced care planning where relevant.

Development of the care plan will include multidisciplinary input from the treating GP, specialist (where applicable), nursing staff, care staff, allied health staff, pharmacist, clients, family and carers. Care plans will be reviewed on an ongoing basis with regular formal reviews as guided by the treating specialist and clinical governance committee.

Within a client’s SDCU placement there will be ongoing assessment, monitoring and review. This will include formal reviews at regular intervals to determine whether it would be appropriate for the person to transition (with appropriate supports) to a less intensive care setting. These assessments will inform any necessary changes to the client’s care plan.

### Care and services to be provided

The same care and services that must be provided to any residential aged care recipient will be required to be provided to SDCU clients, including ensuring access to required specialist services and that care planning is personalised.[[33]](#endnote-33)

Specified care and services must be delivered in a way that meets the Accreditation Standards (Schedule 2 to the Quality of Care Principles 2014) and the Charter of Residents’ Rights and Responsibilities (Schedule 1 to the User Rights Principles 2014).

Care and supports delivered by SDCUs should reflect that undiagnosed pain is a leading trigger of behaviours among people with dementia in residential aged care facilities. A palliative approach focused on detecting, analysing, treating, and evaluating resident pain should be central to care planning and service delivery.

### Therapeutic and meaningful activity

A strong program of activities will be provided that reflects individual interests and strengths. These activities and interventions should be tailored to the person’s preferences, skills and abilities, with the person’s response monitored and the care plan adapted accordingly. Multicomponent activities that are enjoyable for the person plus individualised support should be provided.[[34]](#endnote-34) The program of activities and other interventions should aim to address any unmet social, psychological, physical and emotional needs.[[35]](#endnote-35)

### Leave from care

SDCUs will operate as additionally resourced areas within larger residential aged care facilities. Standard residential aged care provisions for hospital and social leave provisions are expected to apply.

### Minimal use of restraint

A restraint-free way of thinking will underpin unit-level policies and procedures. Any form of restraint will be used as a last resort in response to an adverse event to temporarily protect the client and others while restraint-free care strategies are rapidly revised. Any use of restraint will fully comply with relevant legislation.

### Pillar 3 – Supported transition out

This step will see residents of SDCUs supported to transition to ‘mainstream’ accommodation, whether within residential aged care or to their own homes.

### Duration of stay

The focus of SDCUs is to stabilise and reduce symptoms with the guiding aim of enabling clients to transition to a less intensive care setting.

Based on reported experience of operators of existing similar units, it is expected most residents will be able to transition out within 6-12 months, due to stabilisation of symptoms or disease progression such that a SDCU placement is no longer necessary.

Some people may ultimately require care in a SDCU for longer than 12 months. In these circumstances the SDCU provider will be expected to justify the need for ongoing SDCU care and demonstrate efforts to enable supported transition out to mainstream accommodation.

Q12) Should there be a maximum limit on the duration of an individual’s residence within a SDCU? If not, why not? If so, how long?

### Monitoring, review and transition out processes

Planning for a person’s transition out of the SDCU to a less intensive care setting will be expected to commence early in their placement. All phases of care planning will consider not only current needs but also readiness for transition out.

Transition out processes will ultimately involve the unit’s clinical advisory committee recommending to management that a person is ready to leave the unit, followed by formal transition from the SDCU to new accommodation.

To ease transition out of the SDCU, providers will be encouraged to use step down units within their mainstream facility, subject to the consent of the client and representative. SDCU providers will also be expected to maintain relationships with other mainstream providers in their PHN region to facilitate appropriate care options for people exiting a SDCU.

### Post-discharge transitional support

Post-discharge transitional support will be critical to the success of the SDCU initiative and will need to be carefully managed to ensure that outcomes achieved in the SDCU are sustained.

The SDCU provider will generally provide outreach support to the receiving mainstream provider to ensure a successful transition. This may include the following actions:

* formalised arrangements between the SDCU and receiving mainstream aged care provider, pharmacist and GP
* support underpinned by a formal transition plan for a defined period
* a focus on information sharing, avoiding behaviour triggers, and generalised BPSD management skills transfer where necessary
* possible in-reach from a mainstream facility to the SDCU. The SBRT may also have a role in supporting transition particularly beyond the defined transition period or where there is significant distance between the SDCU and mainstream provider.

Q13) What is a reasonable period for transitional support from a SDCU to the new accommodation provider?

### Security of tenure

SDCUs will be additionally resourced areas within residential aged care facilities, with residents occupying Australian Government-subsidised places operating under the provisions of the *Aged Care Act 1997*. As such, without specific legislative amendment, ordinary security of tenure arrangements will apply during placement in and exit from a SDCU.[[36]](#endnote-36)

During consultation to date, some stakeholders have identified security of tenure as a potential barrier to providing transitional support and achieving client throughput.[[37]](#endnote-37) However, it is not clear whether security of tenure is affecting the operation of existing similar units located within residential aged care facilities. Operators of existing SDCU-like facilities consulted to date have reported few problems with resident transition, provided active planning and open communication with residents and their representatives occurs from the beginning of the client’s stay.

Q14) Might existing security of tenure arrangements pose a significant issue for the ‘transitional’ operation of SDCUs? If so, how?

Q15) What strategies could be used to facilitate SDCU ‘throughput’ within existing security of tenure provisions?

### SDCU re-admission

There will be no restriction on a person’s readmission to a SDCU if clinically indicated. SDCU providers should generally reserve some capacity to accept readmitted clients.

### Pillar 4 – Enabling elements

The following elements are expected to underpin and enable the delivery of high quality care by SDCU providers.

### Staffing, education, training and culture

Numbers and specific care competencies of unit staff will reflect the higher levels of need of SDCU residents and the higher level of Australian Government funding provided. SDCU providers will need to identify both proposed staffing and care planning approaches when applying to operate a unit. Providers will generally be expected to demonstrate the following:

* senior management commitment to the care of people with very severe BPSD
* higher levels of appropriately trained staff (whether care workers or nurses) than typically seen in mainstream facilities
* thorough and tailored staff selection and ongoing staff training and education in, but not limited to:
* care of people with BPSD and advanced dementia
* management of BPSD without recourse to physical or pharmacological restraint
* empowerment of staff to provide appropriate and individualised care
* delivery of culturally appropriate care
* therapeutical and meaningful activities and environment modification
* de-escalating aggressive incidents
* recognition of delirium and dementia, and the different management approaches
* support provided to staff to assist them in managing their wellbeing.

### Physical environment

SDCU providers will be required to deliver care in physical environments that reflect dementia friendly / dementia enabling design principles, such as the ten Dementia Enabling Environment Principles.[[38]](#endnote-38) Providers will have access to specialist advice and expertise on dementia friendly design through the Dementia Training Program.

### Clinical governance and partnerships

SDCUs will be expected to have formalised relationships with Local Hospital Networks (LHNs) within their local region.[[39]](#endnote-39) LHN representatives or relevant state specialist services (for example, Older Persons’ Mental Health Services) will be encouraged to participate in SDCU clinical advisory committees, subject to local agreement between the parties.

The role of SDCU clinical advisory committees may include, for example:

* advice on the placement and admission of people to the SDCU
* expert clinical advice on individual SDCU clients, including regular clinical review process
* advice, planning and support for client transitions out of the SDCU following stabilisation
* monitoring and advice on clinical practices and activities of the SDCU
* input to independent SDCU evaluation.

This partnership approach is expected to facilitate access to specialist advice, particularly pyschogeriatricians and geriatricians, to assist in minimising avoidable hospital admissions and streamlining admission arrangements when an acute admission is necessary.

GPs will also be key partners in the SDCU model of care and will be able to access ongoing support and training though Dementia Training Australia to assist them in this role.

Q16) What mechanisms should be used to support partnerships between SDCUs and acute services?

### Involvement of families and carers

SDCU providers will proactively engage with family and carers to ensure involvement in care planning and delivery. Activities may include educating family and carers about dementia and likely disease progression, carer support, and encouraging and supporting families and carers to embrace the use of supported rather than substitute decision‑making whenever possible.

### Commitment to continuous improvement

As a condition of funding, SDCU providers will be required to:

* participate in performance monitoring and evaluation processes, including through the provision of activity and outcomes data that allows benchmarking
* participate in formal SDCU program evaluations
* collaborate and share best practice to inform other SDCUs and the aged care sector more broadly on care for people with very severe BPSD.

As an element of sharing best practice, it is proposed that SDCU providers participate in state-based and national ‘communities of practice’. This could involve face‑to‑face activities such as periodic group forums and facility-to-facility peer reviews.

### Quality and safeguards

SDCU providers will be required to comply with the Aged Care Single Quality Framework due to be implemented from 1 July 2018.[[40]](#endnote-40) A proportionate approach to application of the Framework would be applied, reflecting the higher level of staff skills and greater intensity of care required to appropriately meet the needs of SDCU clients.

All provisions relating to the Australian Aged Care Quality Agency (Quality Agency), the Aged Care Complaints Commissioner, mandatory reporting and non-compliance (sanctions) would apply to the operation of a SDCU as for any other part of a residential aged care service. The Department of Health will clearly inform the Quality Agency and other relevant bodies which residential aged care facilities are operating SDCUs.

SDCU quality and safeguarding arrangements will incorporate as appropriate findings of the independent Review of National Aged Care Quality Regulatory Processes published in October 2017 in response to the closure of the Oakden Older Persons Mental Health Service, whose residents included people in the SDCU target group.

## How will SDCUs complement existing health and aged care services for people with very severe BPSD?

SDCUs are intended to complement rather than replace similar existing and planned state and territory government investments in this area. SDCUs will predominantly, though not exclusively, provide a ‘step up’ pathway into specialist residential care for people already receiving ‘mainstream’ aged care who are no longer able to be reasonably supported in that environment. State and territory initiatives are anticipated to continue to focus primarily on complementary ‘step down’ pathways for appropriate people already in the health system, as depicted in Figures 3 and 4.

In funding SDCUs, the Australian Government will seek to build on existing relationships with states and territories to better coordinate the effectiveness of these complementary investment approaches.

For people with very severe BPSD related to younger onset dementia, the Australian Government will also take into account broader policies about interaction between the aged care system and the NDIS.

## Providing appropriate care for people with diverse backgrounds

### Aboriginal and Torres Strait Islander peoples

Ensuring the SDCU model of care is appropriate for all people with diverse backgrounds including Aboriginal and Torres Strait Islander people and people from CALD backgrounds is a priority.

Prevalence of dementia is estimated to be up to three to four times greater in Aboriginal and Torres Strait Islander communities than in the general population, and on average onset occurs at an earlier age.[[41]](#endnote-41) In remote communities in particular, however, dementia may not be diagnosed, or may be diagnosed much later in the dementia trajectory, delaying uptake of social and health supports.[[42]](#endnote-42)

### People from culturally and linguistically diverse backgrounds

For people from culturally and linguistically diverse (CALD) backgrounds in residential aged care who are unable to communicate in their preferred language there is potentially a greater risk of social isolation and development of perceived disruptive behaviours. Residential care facilities may also trigger memories of pre-migration trauma.[[43]](#endnote-43)

All SDCU providers will be expected to provide person-centred and culturally appropriate care. This will include staff or care consultants, as appropriate, having appropriate skills and experience to recognise when behaviour may relate to a person’s cultural background, rather than to BPSD.

Providers will also be expected, where appropriate, to tailor physical design of units to the cultural background of the expected local resident population.

### Aged Care Diversity Framework

The Hon Ken Wyatt AM MP, Minister for Aged Care, has established an Aged Care Sector Committee Diversity Sub-Group to advise the Government on the development of an Aged Care Diversity Framework by December 2017.

The framework is intended to comprise a set of overarching shared principles with action plans to drive change across the sector, to improve outcomes for all older people with diverse characteristics and life experiences. As with other aged care providers, SDCU providers will be encouraged to use the framework to inform their policies and procedures in the design and delivery of aged care services.[[44]](#endnote-44)

### How will SDCUs ensure access for people in rural and remote areas?

There are particular barriers to establishing SDCUs in non-metropolitan areas, including higher costs, longer travel distances particularly for families and carers, workforce limitations, lack of access to specialists and capital infrastructure investment.

Decisions about where SDCUs are specifically located will need to balance the *specialist* nature of the units – and consequently the availability of an appropriately-qualified workforce and support services – with ease of access for people in rural or remote areas. Given the significant challenges for service delivery across all areas of health and aged care in rural and remote areas, it is possible that locating distinct SDCUs in these locations will not be the most effective and efficient way to support people with very severe BPSD.

Different approaches could include ‘hub and spoke’ arrangements to share expertise between metropolitan and rural SDCUs, or a ‘wrap around’ approach centred on a person rather than a fixed location, as currently being considered in South Australia.[[45]](#endnote-45)

SDCUs could also establish outreach or in-reach arrangements with rural and remote services other than mainstream residential aged care facilities, such as multipurpose services or rural and remote residential services funded under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program and other non-government funded organisations as appropriate within their PHN.

We recognise that there will be specific considerations for these groups and other people with diverse backgrounds, at all stages from referral and assessment to supported transition out of a SDCU. We welcome your views on how SDCUs can best support people with diverse backgrounds experiencing very severe BPSD (and their families and carers).

Q17) Should there be any additional requirements for SDCU providers caring for people from Aboriginal and Torres Strait Islander, CALD or other diverse backgrounds?

Q18) Would it be feasible to establish SDCUs in rural and remote locations? How can SDCUs (or alternative initiatives) best support people with very severe BPSD living in rural and remote areas?

# SDCU proposed funding and administration

## Funding approach and amount

The core techniques for management of BPSD – such as providing an enabling physical environment, providing flexible person-centred care and, wherever possible, using distraction, redirection, reassurance and reorientation in place of pharmaceutical interventions – can be applied in any setting and often at no greater cost than providing more traditional, ‘task-oriented’ care. This is demonstrated by these techniques being used to address BPSD in a small but growing number of residential aged care facilities receiving standard residential aged care funding.[[46]](#endnote-46)

Nonetheless, it is acknowledged that delivering appropriate care exclusively to the proposed SDCU target group in a small, specialist unit will cost more to deliver than other care models.

There are a number of ways Australian Government funding for SDCUs could be provided, including though establishment of a new form of flexible care under the *Aged Care Act 1997*. However, it is proposed that SDCUs are funded by providing additional or ‘top up’ Australian Government funding above standard aged care funding streams applying to residential aged care places. This approach has the following advantages:

* minimises legislative and supporting systems changes
* relies on the residential care model (ensuring the underlying protections relating to quality and compliance apply)
* limits the need for providers and clients to seek multiple care type approvals
* is consistent with widespread existing practice of state governments providing ‘top up’ funding to residential aged care operators delivering SDCU-like care
* would allow any future changes to residential aged care funding arrangements to flow to places involved in delivering the SDCU program
* supports continued access to residential aged care funding should the provider cease to operate a SDCU at a particular facility at any time.

The funding available above ordinary residential aged care funding is currently expected to be in the range of $150-300 per bed per day. While some provider capital and/or equipment expenditure is likely to be required in setting up a SDCU, a distinct SDCU capital funding stream is not proposed. Providers may however be eligible to apply for capital funds though existing funding streams.

Q19) What specific costs would contribute to the ‘top up’ amount?

Q20) To what extent might these costs vary across SDCUs, for example in response to geographic location or local mix of people with BPSD?

## Administrative options for providing ‘top up’ funding for SDCUs

Two administrative options to provide Australian Government ‘top up’ funding are under current consideration.

### Option one: basic aged care funding plus ‘top up’ funding via a targeted supplement

Under this option, the places that form a SDCU will attract all ordinary residential aged care funding, ACFI subsidies and supplements, resident fees and charges. The SDCU provider will also receive additional ‘top up’ funding through a targeted supplement. Only residential aged care services that had been approved through the SDCU selection process would be eligible to claim the SDCU supplement. The list of approved services would periodically be defined through Ministerial Determination, and the requirements of the SDCU provider to ensure ongoing access to the supplement would be clearly defined in legislation.

If adopted, details of the claiming mechanism will be determined in conjunction with the Department of Human Services as operator of the aged care payment system.

### Option two: basic aged care funding plus ‘top up’ funding via a grant

Under this option, places that form a SDCU at a facility will attract all ordinary residential aged care funding, ACFI subsidies and supplements, and resident fees and charges. The SDCU provider will also enter into a fixed term funding agreement for the ‘top up’ funding with the Department of Health.

If adopted, ordinary Australian Government grants payments mechanisms are expected to apply.

Q21) Which ‘top up’ funding option do you prefer? Why?

Q22) Are there other funding mechanisms that should be considered?

## Block funding versus occupancy-based funding

Under either option, funding could potentially be delivered as block funding (that is, regardless of whether the beds in a unit are occupied at a given point), be based on actual occupancy, or be a combination of both approaches.

Q23) Is block funding, occupancy-based funding or a combination of both most appropriate for SDCUs? Why?

## Use of top up funding

The use of ‘top up’ funding is intended to meet both current care costs and contribute over time to the capital costs of providing that care in a specialist unit. Top up funding may be used to:

* provide additional, unit-specific staff
* enable maintenance and minor facility upgrades to deliver a physical environment that meets dementia enabling design principles
* purchase or lease non-capital equipment and access expertise to support delivery of therapeutic and meaningful activities
* support ongoing specialised training for staff (not available through other Australian Government funding programs)
* enable data collection and participation in continuous improvement and evaluation activity
* provide outreach support to mainstream facilities that accept clients transferring out of the SDCU.

It is not proposed that ‘top up’ funding be used for major capital upgrades, or to pay for medical and/or other allied health services on a fee for service basis.

Q24) Are the proposed uses of ‘top up’ funding appropriate or should there be other costs included or excluded?

Q25) With no specific capital funding for SDCUs proposed – is there a funding period to justify an operator investing to establish a SDCU?

## Client fees and payments

SDCUs are expected to operate within larger residential aged care facilities. Reflecting this, current residential aged care fees and payment arrangements will apply to people receiving care in a SDCU, ensuring no additional financial considerations influence the decision to enter or leave a SDCU.

In this way, ‘top up’ funding would not impact the fees paid by the care recipient. A person transitioning to a SDCU would be liable to pay an accommodation payment or contribution in accordance with normal arrangements.[[47]](#endnote-47)

Q26) Do the proposed provider funding arrangements pose any financial sustainability risks?

Q27) Should any special resident fees and payments arrangements apply to people receiving care in a SDCU?

## Reporting and related requirements

Under either option, providers will be required to meet all existing requirements relating to residential care under the *Aged Care Act 1997* and would also have additional SDCU program-specific reporting requirements. These requirements are likely to include commitments to:

* only use SDCU places to provide care to people recommended by the national assessment service
* operate the SDCU using the principles-based model of care, including entering into partnerships with relevant health providers and providing post-transition support to facilities receiving exiting residents
* report data and support evaluation and continuous improvement initiatives.

These SDCU-specific requirements would be defined either within relevant sections with the *Aged Care Act 1997* or by the standard funding agreement.

## Provider eligibility and selection

SDCU providers will be selected through a number of competitive selection rounds, with applicants required to respond to specific criteria. These selection rounds are anticipated to be held separately from other aged care processes, for example the Aged Care Approvals Round (ACAR) and to include opportunities for key stakeholders to contribute to the selection process.

SDCU providers will be existing approved providers of residential aged care and will need to have, or to demonstrate ability to acquire from other providers, existing residential aged care places for SDCU purposes.

Providers already delivering SDCU-like services including under existing ‘top up’ funding arrangements with state governments or health services will be eligible to apply. However, selection criteria will prioritise creation of additional specialist beds for people with very severe BPSD.

It is expected that most applicants will need to undertake some capital works to establish and maintain an appropriate physical environment for operation of a SDCU (see 5.4). However, it is not anticipated that new builds will generally be required, and selection criteria will prioritise ability to rapidly operationalise SDCU beds.

Q28) Are the proposed provider selection criteria appropriate? Do you consider some selection criteria mandatory?

## How will SDCUs be rolled out across regions?

Subject to final Australian Government decisions, it is expected that all 372 SDCU places will be allocated over a three year period commencing in 2018-19.

The order in which SDCUs are rolled out to the 31 PHN regions through competitive selection rounds and the exact number of beds funded will be influenced by a number of factors, including:

* unmet demand for services
* availability of potential providers and specific expertise to support the model
* engagement and willingness of local partners, including PHN networks, local hospital networks, and state and territory governments, to support the service delivery model.

State and territory governments, PHNs, aged care sector bodies and consumer organisations will be consulted on the regional rollout schedule after announcement of the final program design agreed by Government.

Q29) Which factors should be prioritised in determining the regional rollout schedule and why?

# SDCU program evaluation

While SDCU-like services for people with very severe BPSD have operated in Australia and elsewhere since at least the 1980s, a recently commissioned literature search and analysis identified a lack of robust Australian and international evidence in relation to such initiatives, reflecting generally poor or limited evaluation design and execution.[[48]](#endnote-48)

The rollout of SCDUs as a national network of regionally distributed services provides an opportunity to generate and share new evidence about this type of service. Opportunities for co-design and developmental/formative approaches to evaluation will be explored and findings will be shared with stakeholders.

Evaluation elements could include:

* outcomes evaluation for participating clients, their families and/or carers, for staff and facilities, and for the aged care and health systems (for example, care access, quality and compliance outcomes, and provider- and system-level financial outcomes)
* process evaluation with a focus on the challenges and enablers of designing and implementing the model as intended, how well the SCDU principles and objectives are operationalised in practice, and the effectiveness of the model in addressing the needs of people affected by very severe BPSD.

Q30) What factors should be considered in evaluating the SDCU program?

# SDCU implementation timeframes

SDCUs are expected to be implemented in line with the following broad timeframes (Table 2). Subject to final Australian Government agreement, the first SDCU allocation process will commence in late 2018 with the first units expected to be operational by 1 January 2020.

Subsequent allocation processes will be held in 2019 and 2020 with all units expected to be fully allocated by 2021-22 and fully operational by 2023-24.

Table 2: SDCU high-level timeframes

| Milestones | Indicative timing |
| --- | --- |
| Phase 1: Scope | Early 2017 – Late 2017 |
| Current provision of SDCU-like services mapped |  |
| Model of care evidence reviewed |  |
| Targeted stakeholder engagement |  |
| Technical experts consulted |  |
| Phase 2: Design | Late 2017– Mid 2018 |
| Public consultation paper released |  |
| Submissions received |  |
| Submissions analysed |  |
| Advice to Government |  |
| Final policy position announced |  |
| Phase 3: Implement | Mid 2018 – Early 2019 |
| Legislative amendments (if required) |  |
| Program documentation approved |  |
| Regional rollout finalised |  |
| Supporting ICT built / tested / released |  |
| Phase 4: Select | Early 2019 – Mid 2019 |
| First allocation process advertised |  |
| Applications received |  |
| Applications assessed |  |
| Successful providers announced |  |
| Phase 5: Operationalise | Early 2019 – Mid 2020 |
| Evaluation framework agreed |  |
| Assessment workforce contracted and trained |  |
| Data standards and collection system operational |  |
| First SDCUs operational |  |

# Next steps and further information

Your feedback will inform advice to Government on the final shape of the SDCU initiative. Your submission should be made via the Department of Health Consultation Hub at consultations.health.gov.au. Submissions should be provided by **21 January 2018**. Submissions received after this date may not be considered.

Once the preferred model of care and administrative arrangements are decided by Government, targeted consultation with stakeholders on detailed implementation and transition issues will be undertaken.

Future updates on the SDCU program will be published on the Department of Health website and communicated to the aged care sector via email. Please visit the Health website to subscribe to announcements and the Aged Care Providers eNewsletter to keep up to date.

**Thank you for participating.**

# Endnotes

1. Australian Institute of Health and Welfare (AIHW), [*Australia’s health 2016*](https://www.aihw.gov.au/reports/australias-health/australias-health-2016/contents/summary)*,* AIHW, Canberra, 2016, p. 108. [↑](#endnote-ref-1)
2. AIHW, [*Dementia in Australia*](https://www.aihw.gov.au/reports/dementia/dementia-in-australia/contents/table-of-contents), AIHW, Canberra, 2012, p. 11. [↑](#endnote-ref-2)
3. K Carnell and R Paterson, [*Review of national aged care quality regulatory processes*](https://agedcare.health.gov.au/quality/review-of-national-aged-care-quality-regulatory-processes-report)*,* October 2017, pp. 114-115. [↑](#endnote-ref-3)
4. H Brodaty, B Draper and L Low, ‘[Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery’](https://www.mja.com.au/journal/2003/178/5/behavioural-and-psychological-symptoms-dementia-seven-tiered-model-service), *Medical Journal of Australia,* 178(5), March 2003, p. 233. [↑](#endnote-ref-4)
5. Guideline Adaptation Committee, [*Clinical practice guidelines and principles of care for people with dementia: Recommendations*](http://sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php), NHRMC Cognitive Decline Partnership Centre, Sydney, 2016. [↑](#endnote-ref-5)
6. See S Macfarlane and D O’Connor, ‘[Managing behavioural and psychological symptoms in dementia](http://dx.doi.org/10.18773/austprescr.2016.052)’, *Australian Prescriber*, 39(4), August 2016, pp. 123-125. [↑](#endnote-ref-6)
7. Some consumers use the term ‘care partner’ instead of ‘carer’. In Australia, the term carer is used, as outlined in the *Carer Recognition Act 2010.* [↑](#endnote-ref-7)
8. The National Dementia Support Program includes the National Dementia Helpline and Advisory Service, as well as provision of information and training, early intervention and education courses, individual and group counselling, and carer support groups. [↑](#endnote-ref-8)
9. Department of Health, ‘[Redesign of dementia consumer supports](https://consultations.health.gov.au/ageing-and-aged-care/redesign-of-dementia-consumer-supports/)’, Consultation Hub website, accessed 19 October 2017. [↑](#endnote-ref-9)
10. Department of Health interviews with state and territory officials, June-October 2017. For an overview of historical arrangements dating back to the late 1980s see NSW Department of Health, [*The management and accommodation of older people with severely and persistently challenging behaviours*](http://www.health.nsw.gov.au/mentalhealth/publications/Publications/SumReport-Mgmt-Accom-Oldrpeop-Severly-Pers.pdf), summary report, NSW Health, Sydney, 2006. [↑](#endnote-ref-10)
11. Department of Health interviews with state and territory officials, June-October 2017, and review of publicly available information, reports and program evaluations on relevant initiatives. [↑](#endnote-ref-11)
12. See Transitional Behavioural Assessment and Intervention Service (T-BASIS) units in New South Wales and the Roy Fagan Centre in Tasmania. [↑](#endnote-ref-12)
13. For example, see NSW Health, ‘[Pathways to Community Living Initiative](http://www.health.nsw.gov.au/mentalhealth/pcli/Pages/default.aspx)’, NSW Health website, last updated 6 November 2017. [↑](#endnote-ref-13)
14. For example, see SA Health, [*The Oakden response models of care project: Services for behavioural & psychological symptoms of dementia; Residential services for older people with severe & enduring mental illness*](http://www.sahealth.sa.gov.au/wps/wcm/connect/ef8eb18042db6096a71af78cd21c605e/OPMHS+Models+of+Care+Consultation+Document+V3.pdf?MOD=AJPERES&CACHEID=ef8eb18042db6096a71af78cd21c605e), consultation document, SA Health, Adelaide, October 2017, p. 2. [↑](#endnote-ref-14)
15. Based on National Disability Insurance Agency data as at 15 September 2017. [↑](#endnote-ref-15)
16. AIHW, [GEN aged care data website](https://gen-agedcaredata.gov.au/), 2017. [↑](#endnote-ref-16)
17. Dementia Support Australia, *Additional data report* for the Department of Health, 2017. In the period to 30 June 2017, around 35 per cent of Dementia Behaviour Management Advisory Services and 65 per cent of Severe Behaviour Response Teams consultations involved unidentified or existing pain as a contributing factor for behaviours. [↑](#endnote-ref-17)
18. See A Groves, D Thomson, D McKellar and N Procter, [*The Oakden report*](http://www.sahealth.sa.gov.au/wps/wcm/connect/4ae57e8040d7d0d58d52af3ee9bece4b/Oakden+Report+Final+Email+Version.pdf?MOD=AJPERES&CACHEID=4ae57e8040d7d0d58d52af3ee9bece4b)*,* SA Health, Adelaide, April 2017. [↑](#endnote-ref-18)
19. See K Carnell and R Paterson, [*Review of national aged care quality regulatory processes*](https://agedcare.health.gov.au/quality/review-of-national-aged-care-quality-regulatory-processes-report)*,* October 2017. [↑](#endnote-ref-19)
20. For instance, state government support to residential aged care providers to operate specialist units under the NSW Mental Health Aged Care Partnership Initiative aims to accommodate people who have spent 365 days or more in a state mental health unit immediately prior to entry. [↑](#endnote-ref-20)
21. The [National Mental Health Service Planning Framework](http://www.nmhspf.org.au/) is a planning tool used by the Australian Government and state and territory governments that allows estimates of need and expected demand for mental health care (including BPSD) and the level and mix of services required for a given population. [↑](#endnote-ref-21)
22. Brodaty et al., op. cit., p. 233. [↑](#endnote-ref-22)
23. SA Health, *The Oakden response models of care project,* op. cit., p. 33. [↑](#endnote-ref-23)
24. Department of Health estimates using data in AIHW, *Dementia in Australia*, op. cit. [↑](#endnote-ref-24)
25. Brodaty et al., op. cit. pp.233-234. [↑](#endnote-ref-25)
26. For example, SA Health is considering establishing a Rapid Access Service to, among other tasks, act as the assessment service for state-funded specialist beds for people with very severe BPSD and extreme BPSD. SA Health, *The Oakden response models of care project,* op. cit., pp. 34-35. [↑](#endnote-ref-26)
27. The proposed size of the units reflects currently dominant Australian practice in delivering specialist residential care for people with very severe BPSD; evaluation activities (see section 6) will examine whether this size is optimal for achieving the program’s objectives. [↑](#endnote-ref-27)
28. New South Wales defines a larger residential aged care facility as one that has at least 60 beds, as per the NSW Government’s Mental Health-Aged Care Partnership Initiative transition unit service model. NSW Health, *Tendering conditions and statement of requirements, version 1: HAC15/33A*, NSW Health, Sydney, tender issue date 11 December 2015. [↑](#endnote-ref-28)
29. Guideline Adaptation Committee, *Clinical Practice Guidelines and Principles of Care*, op. cit. See also SA Health, [Dignity in care website](http://www.dignityincare.com.au/). [↑](#endnote-ref-29)
30. Ibid. [↑](#endnote-ref-30)
31. J Dewing and B McCormack, ‘[Editorial: Tell me, how do you define person-centeredness?](http://dx.doi.org/10.1111/jocn.13681)’, *Journal of Clinical Nursing,* 26(17-18), September 2017, pp. 2509-2510. [↑](#endnote-ref-31)
32. Guideline Adaptation Committee, *Clinical Practice Guidelines and Principles of Care*, op. cit. [↑](#endnote-ref-32)
33. Relevant legislation includes, but is not limited to, the *Aged Care Act 1997* and the associated Quality of Care Principles 2014 and User Rights Principles 2014. [↑](#endnote-ref-33)
34. Guideline Adaptation Committee, *Clinical Practice Guidelines and Principles of Care*, op. cit., p. 16. [↑](#endnote-ref-34)
35. Alberta Health Services, [*Meeting the needs of people living with dementia in Alberta’s residential living options: Ensuring person-centred care*](http://brainxchange.ca/Public/Files/BSTU/Meeting-the-Needs-of-People-Living-with-Dementia-i-en.aspx), Alberta Health Services, Edmonton, September 2014. [↑](#endnote-ref-35)
36. Approved providers of residential aged care, home care and flexible care have a responsibility to provide security of tenure for a care recipient’s place in the service as specified in the User Rights Principles 2014 and the [*Aged Care Act 1997*](https://www.legislation.gov.au/Series/C2004A05206)*.* [↑](#endnote-ref-36)
37. KPMG, *Specialist Dementia Care Units: Design workshop final report*, report for the Department of Health, April 2017. [↑](#endnote-ref-37)
38. R Fleming and K Bennett, ‘[Dementia Enabling Environment Principles](http://www.enablingenvironments.com.au/dementia-enabling-environment-principles.html)’*,* via Dementia Enabling Environments website. [↑](#endnote-ref-38)
39. Local Hospital Networks in each state and territory directly manage single or small groups of public hospital services. Some jurisdictions have local names for the areas and administrative units known nationally as LHNs, such as ‘Local Health Districts’ in New South Wales, ‘Hospital and Health Services’ in Queensland, and ‘Local Health Networks’ in South Australia. AIHW, ‘[Local Hospital Network’](http://meteor.aihw.gov.au/content/index.phtml/itemId/491016), METeOR metadata online registry. [↑](#endnote-ref-39)
40. Department of Health, ‘[Single quality framework: focus on consumers](https://agedcare.health.gov.au/quality/single-quality-framework-focus-on-consumers)’, Department of Health website, last updated 26 April 2017. [↑](#endnote-ref-40)
41. D LoGiudice, ‘[The health of older Aboriginal and Torres Strait Islander peoples](http://dx.doi.org/10.1111/ajag.12332)’, *Australasian Journal on Ageing,* 35(2), June 2016, pp. 82-85. [↑](#endnote-ref-41)
42. Senate Community Affairs References Committee, [*Report on the Inquiry into the care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Dementia/Report/index)*,* March 2014, p. 12. [↑](#endnote-ref-42)
43. Federation of Ethnic Communities’ Councils of Australia (FECCA), [*Review of Australian Research on Older People from Culturally and Linguistically Diverse Backgrounds*](http://fecca.org.au/wp-content/uploads/2015/06/Review-of-Australian-Research-on-Older-People-from-Culturally-and-Linguistically-Diverse-Backgrounds-March-20151.pdf)*,* FECCA, Curtin, March 2015. [↑](#endnote-ref-43)
44. See D Tune, [*Legislated Review of Aged Care 2017*](https://agedcare.health.gov.au/legislated-review-of-aged-care-2017-report), report for the Department of Health, p. 169. [↑](#endnote-ref-44)
45. SA Health, *The Oakden response models of care project,* op. cit. [↑](#endnote-ref-45)
46. See, for example, L Martin, ‘[Making every moment matter at Aged Care Plus centres](https://salvos.org.au/others/news/2017/03/23/making-every-moment-matter-at-aged-care-plus-centres/)’, *others* (Salvation Army magazine), 23 March 2017; Aged Care Guide, ‘[Residents feel ‘at home’ with new aged care approach](https://www.agedcareguide.com.au/talking-aged-care/residents-feel-at-home-with-new-care-approach)’, Aged Care Guide website, October 2017. [↑](#endnote-ref-46)
47. See Department of Health, ‘[Aged care fees, charges and payments](https://agedcare.health.gov.au/aged-care-funding/aged-care-fees-and-charges)’, Department of Health website, last updated 18 September 2017. [↑](#endnote-ref-47)
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