

**Feedback to Carers Australia on the Specialist Dementia Care Units (SDCU) Consultation
Paper
January 2018**

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?

We concur with the consultation feedback under 3.3. and 4.6.4 in the consultation paper with regard to supporting people with very severe BPSD in rural and remote locations. There needs to be consideration of the accessibility of SDCU's location where the Primary Health Network covers a broad geographical region. The paper states there will be 'at least one' SDCU per Primary Health Network (PHN). In Western Australia the Country Primary Health Network covers the whole state outside the Perth Metropolitan region (see Figure 1.). This would make it extremely difficult to determine a location which would not require long distances to access the unit resulting low likelihood of family and carers being able to visit or access the unit without high costs being involved for travel and accommodation. This will limit the involvement of family and carers which is noted as an aim within the consultation paper. It is recommended that there be one SDCU or partnership and support (hub and spoke) for a partner organisation (e.g. Multi-Purpose Services) per 1-2 Health Regions rather than per PHN. It is noted that telehealth is not mentioned as a way of staff with expertise sharing information with staff in remote areas with less exposure to people with very severe BPSD. This could also be utilised as a method of families and carers being able to connect with the person they support without travelling to the location even if they reside locally. Most Community Resource Centres (in WA)¹ and Public Health Locations have the technology to utilise telehealth via video link.

¹ <http://www.crc.net.au/Pages/default.aspx>

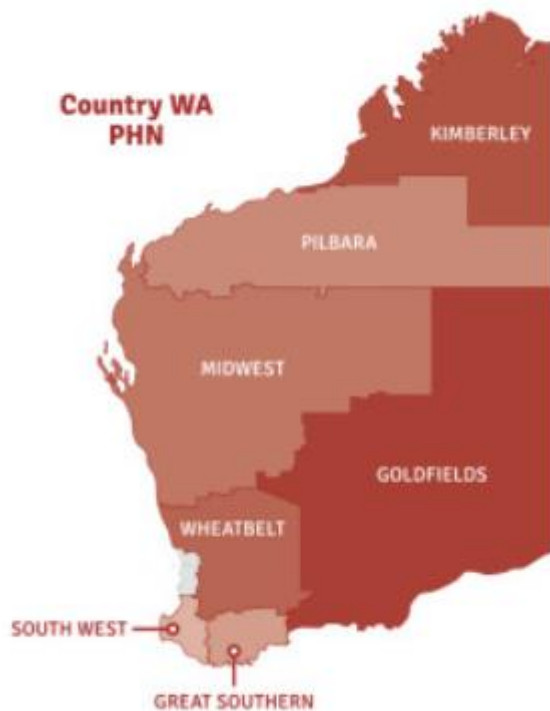


Figure 1. <http://www.wapha.org.au/primary-health-networks/country-wa/>

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?

Yes. The very severe behavioural and psychological symptoms of dementia (BPSD) are likely to surface in a crisis situations. There may be complex cases where proof of primary diagnosis cannot be shown in a timely way. This requirement would place stress on the carer as the person responsible for producing such information.

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?

No. In complex cases it may take an extended period of time for BPSD to improve. The stress of a specified time of stay would likely be borne by the carer who would need to find alternative accommodation at the end of the period.

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

An extended period of time is necessary in these cases to ensure staff, family and carers are equipped and supported to manage behaviour into the future. This will vary based on individual circumstances and may need to be evaluated ongoing to see what the needs are once the units are established.

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

It is important that SDCU providers are aware of the Carer Recognition Act (2010). The Statement for Australia's Carers contained in the Carer Recognition Act (2010) sets out ten key principles regarding how carers should be treated and considered in policy formulation and service delivery settings. Of particular relevance is point 7: *Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.* Selection criteria around knowledge and implementation of the Act should be mandatory.

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

Satisfaction of families and carers should be included in any evaluation. Additionally where possible, consumers and families and carers should be involved in a co-design/co-production process when developing SDCU's.