Response to the Productivity Commission's Preliminary Findings Report:

"Introducing Competition and Informed User Choice into Human Services: Identifying Sectors for Reform", which identified specialist palliative care as one of the areas for further investigation.

HammondCare

An independent Christian charity

About HammondCare

Established in the 1930s, HammondCare is an independent Christian charity specialising in dementia care, palliative care, rehabilitation and older persons' mental health services. HammondCare is recognised in Australia and internationally as a leading provider of dementia-specific services, and as an innovative provider of palliative care services in NSW. It is dedicated to research and supporting people who are financially disadvantaged. HammondCare's mission is to improve quality of life for people in need, regardless of their circumstances.

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Introduction

The Productivity Commission is investigating "Introducing Competition and Informed User Choice into Human Services: Identifying Sectors for Reform". It has provided a preliminary findings report for further public consultation and input, which has identified six areas for further review – specialist palliative care is one of these areas.

Background

HammondCare is a not for profit (NFP), national leader in providing dementia care services and aged care services Australia-wide.

It also provides a range of specialist palliative and supportive care services – as defined in the report as: "Specialist palliative care providers are multidisciplinary teams that provide assessment, consultancy and management of palliative care needs." HammondCare provides palliative care services Australia-wide, but primarily in NSW, including inpatient care (Greenwich, Braeside and Neringah Hospitals in Sydney); community palliative care; palliative care in more than 200 residential aged care homes; the inaugural Palliative Care Home Support Program (PCHSP) in NSW; education and training services as well as an online educational resource website (www.palliativecarebridge.com.au). HammondCare either directs, or partners in, a large number of palliative and supportive care research and service development projects, with a view to improving a person's quality of life, and to assist their family, carers and staff provide the best quality of care for that person. Details of HammondCare's research in palliative care can be found here: http://www.hammond.com.au/research/ResearchReport2015.pdf

Last financial year, HammondCare supported 2,600 people through its palliative care services.

HammondCare provides data to the Palliative Care Outcomes Collaboration (PCOC).

General Comments on the Preliminary Findings Paper

As the Preliminary Findings paper states – palliative care standards in Australia compare well internationally. Australia is ranked second in the world in the 2015 Quality of Death Index, a measure of the quality of palliative care in 80 countries around the world. https://www.eiuperspectives.economist.com/healthcare/2015-quality-death-index
"Australia's strong performance places the country as one of the world's leaders in the provision of palliative care. Robust quality standards are woven into the universal health scheme, which provides specialised and affordable care."

Additionally, there has been a significant increase in the number of people seeking palliative care services. This trend is set to continue as our population increases, and people are living longer with conditions like cancer or dementia or chronic diseases that might benefit from palliative care.

Estimates vary on the number of people who need palliative care. Research shows that between 69% - 82% of people who die in high income countries are in need of palliative care[1].

[1] Murtagh, E., Bausewein, C., Verne, J., Groeneveld, E., Kaloki, Y. and Higginson, I. (2014) 'How many people need palliative care? A study developing and comparing methods for population-based estimates. ', *Palliative Medicine*, 28(1), p 49-58.

Palliative Care Australia suggests that 90% of cancer patients and half of non-cancer patients could benefit from palliative care services[2]. If we take a more conservative figure of 50% of people who die from all causes would benefit from palliative care, and of those, 70% of people would prefer to die at home, a potential target reach for a program such as the Palliative Care Home Support Program might be 35% of deaths from all causes.

Figures show that in NSW in 2013, there were 49,066 deaths – equivalent to a death rate of 6.62 per 1,000 population[3]. If only 50% of people benefit from palliative care, there is a potential need for palliative care in NSW alone to support 3.31 deaths per 1,000 population, or around 25,000 people a year. Australia-wide, this figure would be significantly higher.

Clearly the demand for palliative care services is high, with this demand set to significantly increase as our population ages.

Research shows that 35% of all deaths in Australia occur in residential aged care facilities (RACFs); 50% in hospitals and 15% in other settings.[4]

The Commission has raised the issues of equity, efficiency and responsiveness in the delivery of specialist palliative care services as key issues for consideration in its review.

- HammondCare agrees that introducing greater user choice through contestability or competition would require careful design to ensure that the interests of patients and their families are well served. As stated by the Commission, specialist palliative care is extremely complex, but it is imperative people have, no matter where they live in Australia, genuine choice about where their life ends. This is not the case with the provision of services at present.

- HammondCare would argue that as a first priority, the Government should ensure equitable access to palliative care services throughout Australia. At present, services are not adequate in many rural and remote areas of Australia and the provision of services on a 24/7 basis is also limited. People's choice about the place where they wish to be cared for and ultimately die is also limited by the services available in their local area. Some service gaps exist in regional areas of NSW because of access to specialist services. This means greater reliance on GPs and community nurses, particularly after hours, many of whom are not confident in the provision of, or are appropriately trained in, palliative care.

- The role of the NFP sector in the provision of palliative care services has been, and should continue to be, fundamental to the provision of services. The mission of these providers lies in delivery of services to the disadvantaged and ensuring that equity of access is at the heart of what good palliative care is all about.

- In terms of better outcomes and the provision of national data, HammondCare supports the notion that participation in the Palliative Care Outcomes Collaboration (PCOC) is encouraged for all specialist palliative care providers. This would allow for better benchmarking, potentially leading to greater quality improvement of palliative care services.

- Funding for many current palliative care programs is limited to three years or less, creating uncertainty and instability among providers. HammondCare would argue for funding over longer periods to ensure greater consistency of service and outcome delivery, and to create

[2] Palliative Care Australia (2003) *Palliative care service provision in Australia*, Palliative Care Australia
[3] Health Stats NSW, 2013 'Deaths from all Causes' and 'Population' data
[4] Swerissen,H. and Duckett, S (2014) Dying Well. Grattan Institute

an environment where providers are able to explore and develop new service delivery models without the uncertainty of program funding.

Providing equity and access for palliative care services at home

Australian home deaths occur at less than half the rate of similar countries such as Ireland, France, USA and New Zealand (Broad et al, 2013). Moreover, the Australian figures do not reflect patient preferences for place of death. Studies indicate that greater numbers of patients would prefer to die at home (Scott, 2015, Rothman, 2014). However patients do not always articulate their wishes and their families may not have the access to the medical and social support that would enable a patient to die at home (Swerissen & Duckett, 2015). Many people choose home as a place of care even if the last days and subsequent death are not there.

Palliative Care Home Support Program (PCHSP) – an innovative service delivery program

To provide people with choice about their care at the end of life, HammondCare, in a consortium with Sacred Heart and Calvary, devised an innovative program, called the Palliative Care Home Support Program (PCHSP) that has been operating in seven Local Health Districts (LHDs) in NSW, since October 2013.

A quantitative and qualitative evaluation of the first few years of the PCHSP, completed in July this year, shows the initiative has been very successful in providing people with choice, and that the vast majority of people have been able to die at home. The Program has been provided in metropolitan, regional and rural areas of NSW and has been successful in providing choice to people living in all these areas. The findings also demonstrate that the Program is very cost effective and is also well received by clients and their families.

This Program has significant potential for growth, given our ageing population, and if expanded nationally, could provide greater choice to all Australians.

Background

In recognising that patients and their families may not have the support they need to care for a loved one at home at the end of life, in 2013, the HammondCare Consortium (which includes HammondCare, Sacred Heart Health Service and Calvary Healthcare Sydney Ltd) was funded by the NSW Ministry of Health to trial the Palliative Care Home Support Program (PCHSP) in 7 local health districts (LHDs) across metropolitan, regional, and rural NSW. The LHDs in which the HammondCare consortium operates are Central Coast, Far West, Murrumbidgee, Northern Sydney, South East Sydney, Southern NSW, and Western NSW.

The PCHSP was designed to supplement existing community palliative care services in LHDs by providing specially trained community care workers (CCWs) to support patients and their families

who wished to have end of life care in the home. Importantly, the target group for the PCHSP is people who want to die at home, or who wish to remain at home for as long as possible.

The PCHSP enabled palliative care patients to be referred by attending clinicians, hospital based palliative care teams, or LHD community palliative care teams, to receive the services of a specially trained CCW for up to 48 hours of flexibly delivered palliative care home support. These care packages could be provided for a continuous period of time, or in smaller blocks of time, depending on the preference of the patient and family. A second package was available to patients and families if needed.

HammondCare undertook a quantitative and qualitative evaluation of the project[5] to analyse outcomes, cost-effectiveness and current and potential reach of the program. The evaluation demonstrated that the PCHSP is successfully supporting patients and their families who wish to have end of life care in the home.

Key findings

- Since inception in October 2013, the HammondCare Consortium Palliative Care Home Support Program has supported 1,295 patients (including 7 paediatric patients) and their families across seven Local Health Districts (LHDs) in NSW, with end of life care in their homes.

- The Program has provided full coverage across the three metropolitan LHDs, as well as more than 267 towns across the four rural LHDs (Appendix 1).

- Overall, 73% of patients on the Program have died at home, which compares very favourably with Grattan Institute findings that 70% of people want to die at home, but only 14% currently do so.

- 586 care workers across the seven LHDs have been trained.

- The reach of the PCHSP is currently just over 4% (of deaths) across all serviced LHDs, with significant potential to scale-up the number of packages delivered and patients provided with a service.

- Reach into rural LHDs exceeds that for metropolitan LHDs. The most significant growth in activity over the past 12 months has been recorded in the Murrumbidgee (>600%) and Western NSW (>300%) LHDs.

- The PCHSP is being delivered at about one third of the cost of substitutable inpatient palliative care[6].

[5] Palliative Care Home Support Program: Qualitative and Quantitative Evaluation. July 2016. Internal HammondCare report (unpublished) by Prof Chris Poulos

[6] This calculation only considers the cost of the provision of the PCHSP. It does not take into account the cost of existing local palliative and primary care services that might have been provided to a patient while in receipt of the PCHSP.

- Families found the support of community care workers very beneficial and, in some instances, crucial for enabling end of life-care in the home.

- Palliative care workshop training, provided as part of the Program, was well received by community care workers and was readily integrated into patient and family care.

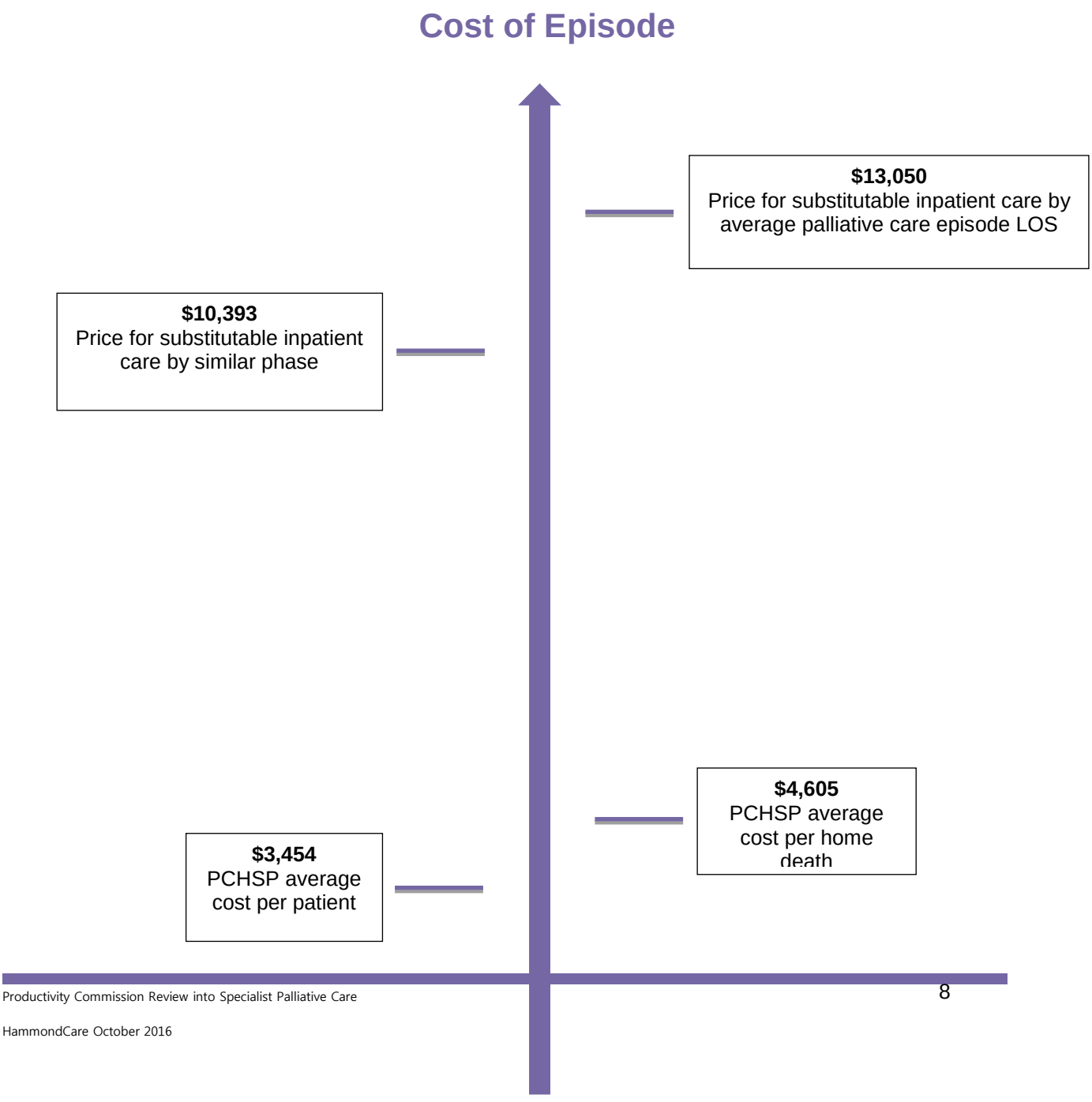
- Local Health District Community Palliative Care Teams in both metropolitan and non-metropolitan areas recognised the benefits that community care workers provided to families and patients.

Cost effectiveness of the PCHSP

The PCHSP is cost effective, estimated to be only one third of the cost of comparable inpatient palliative care.[6] While linked hospital data are not available for the PCHSP cohort, it is also postulated that patients on the PCHSP who died in hospital are likely to have had a shorter hospital length of stay than if they had not been on the Program.

The PCHSP is funded on a unit price per 48-hour package of care. For the 2015/2016 year, the price paid per package was $2,957 for a total of 800 packages. This gives 2015/2016 full year program funding of $2,365,456.

The average cost of the PCHSP per patient needs to take into account that up to 15% of patients required more than one package of care. After making this adjustment, the average price paid per patient on the PCHSP for 2015/2016 was $3,454.



Education and training

As part of the PCHSP, education and training are provided to care workers in the area of palliative care. The HammondCare Palliative Care education team developed an education and training program for community care workers that was modelled on Hospice New Zealand's 2011 program, *Fundamentals of Palliative Care*. The HammondCare training program became known as the *Fundamentals of End of Life Care*. This training was developed to provide community care workers (CCWs) with the knowledge and skills required to support palliative care patients at the end of life, and their families, in the home.

The Palliative Care Bridge

The PCHSP training program has been supplemented throughout by the *Palliative Care Bridge* (www.palliativecarebridge.com.au), which delivers educational videos and resources by palliative care experts and specialists. The Palliative Care Bridge features more than 70 video casts either filmed or in the planning. These include advice on aspects of symptom management, ethical issues, communication and practical issues, as well as interviews with patients and carers. It also contains a number of downloadable paper-based resources that practitioners and members of the public may find useful in dealing with aspects of care near the end of life.

Since the launch of the website in November 2014 the site has averaged more than 50 hits a day, spiking to around 200 on the days surrounding the announcement of new material being loaded onto the website. New titles are scheduled and added in an ongoing manner.

Comparisons with Palliative Care Outcomes Collaboration (PCOC) data

While there are no similar palliative care community programs available in NSW with data available from which to make comparisons, it is possible to explore data reported to the Palliative Care Outcomes Collaboration (PCOC) for community palliative care episodes. For the following analysis, a recent PCOC report was used (ASHRI, 2015).

It should be noted that there were no NSW community palliative care episodes reported to PCOC, and so the comparisons being made use aggregated data for community palliative care episodes from states other than NSW.

The main differences found were:

- The overall home death rate is much higher on PCHSP than PCOC reported community episodes (75.3% versus 25.9%)
- PCHSP is more targeted (with the focus being on the deteriorating and terminal phases) compared to average community palliative care episodes reported to PCOC.
- Targeting the PCHSP to the deteriorating and terminal phases makes it an efficient service.

Current and potential reach of the PCHSP

The PCHSP is currently meeting around 4.2% of need across the seven LHDs served by the Program (range 3.3% for the Central Coast to 7.1% for the Murrumbidgee) – see table. With a

potential reach of 35% of deaths from all causes, there is the potential for the Program to be greatly expanded.

Table: Current and potential reach of the PCHSP

Service utilisation and potential PCHSP reach[1.]							
LHDs served by the PCHSP	Population 2013[2.]	Deaths from all causes 2013[2.]	Current PCHSP Referrals[1.]	Current deaths on PCHSP by LHD (%) (i.e., current program reach)	Potential PCHSP reach[3.]	Potential PCHSP referrals by LHD p.a.	Service gap[4.]
Central Coast	328,063	2,994	100	3.3%	35%	1048	948
Far West	30,962	302	15	5.0%	35%	106	91
Murrumbidgee	238,796	1,994	141	7.1%	35%	698	557
Northern Sydney	878,112	5,122	204	4.0%	35%	1793	1589
S.E. Sydney	870,243	5,070	140	2.8%	35%	1775	1635
Southern NSW	200,041	1,586	79	5.0%	35%	555	476
Western NSW	276,069	2,257	124	5.5%	35%	790	666
TOTAL	**2,822,286**	**19,325**	**803**	**4.2%**	**35%**	**6764**	**5961**

1. *Based on full year 2015/2016 (financial year) PCHSP data.*
2. *http://www.healthstats.nsw.gov.au/. Most recent data are 2013.*
3. *Based on 50% of deaths require palliative care and in 70% of those there is a preference for a death at home.*
4. *Potential gap in the number of PCHSP patients per annum, by LHD, based on a potential target of 35% of deaths from all causes might benefit from the program.*

Conclusion:

The PCHSP was designed to supplement existing community palliative care services. The PCHSP is delivering for people, in metropolitan and regional areas and also, importantly, in rural areas in terms of volume and outcome. It is providing real choice for consumers, and both patients and families have welcomed the program. There is a compelling case for ongoing program funding and the possible expansion of this program throughout Australia.

The PCHSP has shown that the provision of flexibly delivered in-home support at end of life by trained community care workers is effective and cost effective. The next step in scaling up the PCHSP model is to optimise the surrounding system supports – that is, ensuring the availability of specialist palliative care, and models of primary care, that can best support the type of in-home, care worker delivered, end of life care offered by programs such as the PCHSP.

Appendix 1: Small town coverage of the PCHSP (Southern NSW, Murrumbidgee, Far West, Western NSW LHDs)

Adelong	Bumbaldry	Finley	Lake Cargelligo	Nerriga	Tuena
Albury	Bungendore	Forbes	Lake Euabalong	Neville	Tullamore
Ardrossan	Bunnaloo	Gadara	Laurel Hill	Nimmitabel	Tullibigeal
Angledool	Buronga	Galore	Lavington	Nullo Mountain	Tumbarumba
Araluen	Califat	Ganmain	Leeton	Nyngan	Tumut
Ardlethan	Canowindra	Gerogery	Lightning Ridge	Oaklands	Tuross
Ariah Park	Captains Flat	Geurie	Lithgow	Oberon	Tuross Head
Ashmont	Cargo	Gilgandra	Lochiel	Orange	Ulladulla
Balldale	Cathcart	Gilmore	Lockhart	Pambula	Ungarie
Baradine	Charbon	Gol Gol	Long Beach	Parkes	Urana
Bard	Clandulla	Goodooga	Louee	Peak Hill	Uranquinty
Barellan	Cobar	Gooloogong	Majors Creek	Pleasant Hills	Wagga Wagga
Barham	Cobargo	Goulburn	Mangoplah	Portland	Wakool
Barmedman	Collarenebri	Grahamstown	Marrar	Potato Point	Walgett
Barooga	Collector	Greenthorpe	Marulan	Quaama	Walla Walla
Batemans Bay	Conargo	Grenfell	Mathoura	Quandialla	Wallerawang
Bathurst	Condobolin	Griffith	Matong	Queanbeyan	Wamoon
Batlow	Congo	Grong Grong	Mayrung	Reid Flats	Warraderry
Beckom	Coolah	Gulgong	Mendooran	Reka	Warren
Bega	Coolamon	Gundagai	Menindee	Rennie	Warrumbungle
Bendoc	Cooma	Gundaroo	Merimbula	Rock Forest	Shire
Bermagui	Coonabarabran	Gundary	Mila	Rylstone	Weethalle
Berridale	Coonamble	Gunning	Milbrulong	Shepherdstown	Wellington
Berrigan	Cootamundra	Gwabegar	Moama	Sofala	Wentworth
Bibbenluke	Corowa	Harden	Mogo	South Durras	Wereboldera
Bigga	Cowra	Hay	Molong	Sutton	West Wyalong
Billimari	Craigie	Henty	Monak	Table Top	White Cliffs
Bimbi	Crookwell	Hill End	Monaro	Talbingo	Whitton
Binalong	Culcairn	Hillston	Morundah	Tallong	Wilcannia
Binnaway	Cumnock	Holbrook	Moruya	Talmalmo	Windowie
Blayney	Curlwaa	Hovells Creek	Morven	Tarago	Wondalga
Blighty	Dalmeny	Howlong	Moss Vale	Taralga	Woodlands
Bodalla	Dalton	Jerilderie	Mossy Point	Tarcutta	Woodstock
Bombala	Dareton	Jindabyne	Moulamein	Tathra	Wyangala
Bookham	Darlington Point	Jindera	Mount Horeb	Temora	
Boorowa	Delegate	Jingellic	Mudgee	The Rock	Yanco
Boree Creek	Deniliquin	Jugiong	Mulwala	Thurgoona	Yarra
Bourke	Dubbo	Junee	Murrumbateman	Tilba Tilba	Yass
Bowning	Dunedoo	Kandos	Mystery Bay	Tocumwal	Yaven Creek
Braidwood	Durras	Kenebri	Namina	Tomakin	Yenda
Bredbo	Eden	Kianga	Narooma	Tooleybuc	Yeoval
Brewarrina	Erudgere	Koorawatha	Narrandera	Tottenham	Yerong Creek
Brocklehurst	Euabalong	Krawarree	Narromine	Trangie	Young
Broken Hill	Eugowra	Kunama	Neilrex	Trentham Cliffs	
Broulee	Eurobodalla	Lake Albert	Nelligen	Trundle	