1. *In addition to what is contained in your submission and evidence provided at the public hearing, do you have any further comments regarding the current provision of palliative medicine, nursing and care in rural, regional and remote New South Wales?*

Access to home-based nursing care, palliation care, and end of life care whilst managing chronic disease, or terminal illness, is problematic for individuals and families in farming and rural communities. There are additional burdens transferred to families: the cost of travel and accommodation for treatment or for families to be with the member undergoing treatment; and business costs due to prolonged absence farm the farm business.

NSW Farmers understands that accessing home care to support stay at home is hampered by inability for community nurses to provide daily support for nursing care, due to distance in community. In metropolitan areas, community-based services can deliver 4-5 home visits daily, for a rural based nurse this maybe only 2, because of the distance.

NSW Farmers is aware of continued reports regarding the difficulty of accessing home care from providers of the packages. This may also be due to insufficient funding of the care packages once assessed, or the challenge of employing home care workers in rural, remote and regional areas.

For example, NSW Farmers understands that regarding specific palliative care nursing, in the Upper Hunter area of the Hunter New England Health Local Health District (HNE-LHD), there are currently 2 FT palliative care nurses based in Scone, covering 2 LGA's comprising an area of 11,500 square kilometres. Therefore, it is a Monday-Friday service with no after hours or weekend service. However, in Cessnock, there is a 7 day a week service providing on call after hours support also.

NSW Farmers understands that there is an out of hospital end of life package within the HNE-LHD, however it is NON clinical, and has reportedly been untested with the challenges of distance, to ascertain its service capacity.

2. *In addition to what is contained in your submission and evidence provided at the public hearing, do you have any further comments regarding ways to improve both the access and availability of palliative medicine, nursing and care in rural, regional and remote New South Wales?*

Access and availability will be improved with increasing funding to palliative care services and increasing the number of health professionals working in this field.

NSW Farmers supports the position identified in Economic Benefits of Home-Based Palliative Care and End of Life Care (Palliative Care Australia, Economic Research 2., July 2017), which includes the following:

> *"The current evidence shows that home-based palliative care saves financial resources while improving consumer quality of life and that person-centred palliative home care is cost effective."*

This work also reported that in Western Australia, cancer patients in the last year of life, who were living at home with assistance from community-based palliative care reduced the number of visits to EDs in the last 90 days of life.[1] Those persons who had no palliative care or who only accessed palliative care in the 90 days before their death were far more likely to visit an ED in the last 3 months of life than individuals who were able to access palliative care 91-365 days before death (52.0% vs.31.3% of patients). When other factors that influenced their use of services were considered then those not accessing palliative care early were 2.8 times more likely to visit the ED.

It has been estimated that to double the number of older Australians dying at home would require an additional investment in palliative care of around $237 million (2013-14 dollars) a year. When people die at home, major savings usually accrue from their reduced use of hospitals and residential aged care. A study showed that the funds released from the reduced need for institutional care offset the costs of providing palliative care to more people at home, making this a cost neutral policy.[2]

Community health districts in rural and remote communities do not have the capacity at present to offer the evidence based complimentary therapies such as exercise physiology, and acupuncture to cancer patients. Cancer patients and their families carry enormous costs of dislocation from family, treatments most commonly in metro cancer centres, however this supportive care adjunct to the medical interventions is not generally available. Community health districts could be funded to provide these services which are evidenced to improve response to treatments for recovery, as well as quality of life in a palliative care situation.

Community Health Centres are well placed to be centres of excellence for home-based care, and the whilst the cost is an initial outlay with significant increased human resources of community nurses, allied health professions, and visiting if not local palliative care doctors; the evidence supports it as an achievable, cost effective solution to the current situating, providing equitable opportunities to choose to die with dignity, at home, or within community, supported by palliative care teams.

[1] McNamara BA, Rosenwax LK, Murray K et al. (2013). Early admission to community- based palliative care reduces use of emergency departments in the ninety days before death. J Palliat Med. 16(7):774-779.
[2] Swerissen H and Duckett S. (2014). Dying Well. Grattan Institute, Melbourne.