An evaluation of which respite options work best for people with dementia and their carers living in rural NSW

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Introduction: Carers of people with dementia are becoming increasingly dissatisfied with the quality, flexibility and availability of respite care. Lack of choice and failure to support consumer-directed or person-centred respite services that are responsive to individual and carer needs are the main reasons for under use of many respite services.

Dementia, Australia’s ninth National Priority Area, is a serious chronic, usually progressive disease, often with complex physical co-morbidities as well as psychological and behavioural symptoms, requiring increasing demands on carers and family members. The literature has highlighted a gap in knowledge regarding effective and supportive community-based programs within a rural context. Moreover, current policy and program funding is based on traditional models of day activity programs and short breaks making it difficult for organisations to sustain innovative consumer directed programs. Greater Hume Aged and Community Services (GHACS) provides respite services across the Albury, Corowa and Greater Hume Shires in Southern New South Wales. GHACS responded to consumer choice providing innovative person and carer-centred recreational and artisan respite programs; however, funding criteria and policy are constraining their efforts. To address this they sought dementia services evaluation research funding from the Dementia Collaborative Research Centre—Assessment and Better Care (University of New South Wales) with the aim of informing policy and improving services for people with dementia, carers and families.

Methods: Theoretical propositions were drawn from Bamford’s (2009) study of methods to evaluate the effectiveness of respite services. The propositions were adapted to an Australian rural community providing a framework for ordering and analysing the data. Data was collected using guided interviews with people with dementia, focus groups with carers, and carer and service provider surveys. Data analysis was undertaken using an interpretivist approach interpreting the findings within the framework proposed.

Results: Collection of data is being undertaken from October to December 2012. The findings will be analysed and available from March 2013.

Involving people with dementia and their carers in all aspects of research is increasingly recognised as essential to inform services and care. Supporting participation in research will assist to overcome much of the stigma associated with dementia and also reflect their value within society and their equal right to participate in research.