

2013 Commissioned Research on Dementia Care

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Title of research project: Pain assessment and management for patients with advanced dementia nearing the end of life

Abstract: Dementia is a growing public health problem; increasing numbers of people are living, and dying with this condition. The importance of high-quality care for patients with dementia at the end of life is well-recognised. However, it has been reported that patients with severe dementia may not have their pain assessed and treated properly as they cannot communicate their pain and discomfort effectively. The issues in assessment and management of pain in patients with severe dementia who are approaching the end of life must therefore be examined to enable strategies to be developed which will improve the quality of care these vulnerable patients receive. The proposed study aims to examine the main issues in pain assessment and management for these patients in Northern Ireland. This study will use interviews to determine the views of healthcare professionals (doctors, nurses, nursing home staff) and of carers of people with dementia who have since died. The key issues identified from these interviews will be used along with the previous research which has been conducted in this area to identify model(s) for the assessment and management of pain nearing the end of life tailored to the setting of care (patient's home, nursing home, hospital or hospice). These models will then be presented at a one day workshop to an audience of healthcare professionals, carers and the dementia and palliative care organisations. The feedback obtained from this workshop will be used to refine and develop the models which will then be tested for patients with severe dementia across the range of care settings. We will obtain feedback from the healthcare professionals and carers involved in piloting these models. Further funding may then be sought to undertake a larger-scale and more detailed evaluation of the developed models.