

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	After the Liverpool Care Pathway – development of heuristics to guide end of life care for people with dementia: Protocol of the ALCP study
<b>AUTHORS</b>	Davies, Nathan; Manthorpe, Jill; Sampson, Elizabeth; Iliffe, Steve

### VERSION 1 - REVIEW

<b>REVIEWER</b>	Gillian Carter Queen's University Belfast, UK
<b>REVIEW RETURNED</b>	22-Jul-2015

<b>GENERAL COMMENTS</b>	<p>Thank you for asking me to review this is very interesting protocol. The background, methods and analysis are well explained providing a clear understanding of the study. There are only a few minor changes that I feel are necessary prior to publication. These are with regards to the provision of further explanation of a technique, sentence restructuring, grammar, typos and formatting. I have listed the relevant sections below and have provided comments and track changes.</p> <p>I will be very interested to read future publications in relation to this protocol.</p> <p><b>Page 5 - Paragraph 2</b></p> <p>End of life care for dementia can be very difficult for many reasons, not least because of the difficulty communicating verbally many people with dementia have towards the end of life. Many practitioners lack the confidence and skills to provide end of life care for someone with dementia, both practitioners from palliative care backgrounds but also practitioners experienced in dementia care<sup>24</sup> such as those working in care homes where resources, staffing levels, and regulatory requirements are limited, and their support from the wider health care systems is variable.-( I think this section needs reworded) End of life care for people with dementia is for these reasons often poor, with improvement needed in many areas.<sup>25</sup> There is still <b>limited</b> access to end of life care services for people with dementia<sup>26 27</sup>, with a lack of the recognition of pain often highlighted<sup>28 29</sup> some even believing that people with</p>
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	<p>dementia do not experience pain.<sup>30</sup></p> <p><b>Page 6 – Paragraph 2</b></p> <p>Starting with data from 46 interviews with family carers about end of life care for people with dementia as a foundation,<sup>35</sup> (collected and funded as part of the IMPACT study<sup>36</sup>) our three phase study described in this paper aims to:</p> <p><b>Page 6</b></p> <p>2. Test the use of heuristics with practitioners in five real settings including: one general practice, one community nursing team, one hospital ward - (It may be worth stating what type of ward will be approached e.g. care of the elderly, general, medical, surgical etc) and two community palliative care teams.</p> <p><b>Page 7 – Paragraph 1</b></p> <p><b>Design:</b> This study will use mixed methods and will comprise three phases: phase one will use input from interviews with families plus findings from focus groups with families and practitioners, and a rapid appraisal literature review to develop a collection of heuristics; phase two will test the feasibility of the developed heuristics in real settings; phase...</p> <p><b>Page 7 – Paragraph 4</b></p> <p>Please provide an explanation of what exactly a nominal group technique is.</p> <p><b>Page 8</b></p> <p><i>Phase 2 and 3 will take place in:</i></p> <ol style="list-style-type: none"> <li>1. One hospital ward - As before maybe worth mentioning what type of ward mentioning what type of ward</li> <li>2. One general practice</li> <li>3. One community nursing team</li> <li>4. Two palliative care community teams</li> </ol> <p>Page 11 – Paragraph 2</p>
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	<p>The findings from this study will be presented in peer-reviewed journals both within palliative care and dementia care journals to target a wide audience which this study will be relevant for. Findings will be presented at national and international conferences, and professional press such as Journal of Dementia Care will be utilised to increase the spread of knowledge generated. Finally, a study website will be developed and social media such as twitter and blogs will be used to disseminate findings.</p> <p><b>Page 15 – Figure 1.</b></p> <p>Minor comment but I feel the figure needs to be formatted better as presently it looks a bit untidy – maybe if it was all left aligned and then subsequent lines indented as necessary.</p>
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#### VERSION 1 – AUTHOR RESPONSE

We have reworded the section on page 5 paragraph 2 as suggested.

We have made all grammatical and typo changes.

We have added on page 6 and 8 'care of the elderly ward'

Page 7 paragraph 4 - we have added a description of what a nominal group is and entails.

We have left aligned figure 1 as suggested.