Author's response to reviews

Title: What works in 'real life' to facilitate home deaths and fewer hospital admissions for those at end of life? Results from a realistic evaluation of new palliative care services in two English counties

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Thank you for your careful review of our paper. Your comments have made this a better paper. Please find below our response.

This paper contains much of interest for any evaluation of new service provision. A large part of the paper concerns the methodology and applicability of realistic (realist) evaluation. This is chiefly of interest to public health professionals and not directly to palliative care practitioners. I feel that this part of the publication might profitably be excised and submitted to a more relevant journal such as BMC Health Services Research.

We originally included reflections about realistic evaluation methodology with results in this paper in response to a systematic review by Marchal et al which suggested that more details should be included in future publications, given that the paucity of published studies using realistic evaluation. However, we appreciate that this might not be of interest to this audience and so have drastically cut down this section.

There is very little data submitted to justify publication as a Research Article.

Over 40% of the paper presents original data. The challenge in this paper is to present rich accounts of five services from 105 interviews and 15 observations, without overwhelming the reader. We have added more quotes to hopefully satisfy the reviewer’s desire for more data, as the quantitative data have been published elsewhere.

Some basic demographic data on the population of the areas served by the novel interventions is needed to set the scene.

The following demographic data have been included:

Quantitative data from our six month study period (1 September 2011 to 29 February 2012) showed that of those who died, 46% were men and 54% were women, 84% were aged over 70 and the most common causes of death were cancer (28%), heart disease (18%), respiratory disease (15%) and dementia (15%). Thirty eight percent of the study population died in hospital. Somerset had about 5000 palliative deaths annually amongst a largely rural population. During our six month study period of those who died, 45% were men and 55% were women, 85% were aged over 70 and the most common causes of death were cancer (29%), heart disease (18%), respiratory disease (13%) and dementia (13%). Thirty six percent of the study population died in hospital.

No indication is given of how patients were allocated to the "Delivering Choice"
services. It was evidently decided that blinded randomised allocation was not to be used, but without some information on how the subjects for the intervention were selected it is impossible to tell how much of the reported improvements in outcome can plausibly be attributed to the intervention.

We agree with the reviewer. Without blind randomisation, it is impossible to determine how much of the reported improvements can be attributed to the intervention. But that was not our intention, as this is not a quantitative paper on the outcomes. We have published a quantitative paper elsewhere that carefully and clearly makes no claims for causation. The aim of this paper was to find out factors that contributed to the services’ success (or otherwise). Since this evaluation took place in a naturalistic setting, we had no control over which patients accessed the services. But it is precisely because this is a study of ‘real life’ that it is of such value to commissioners and policy makers (hence the inclusion of the quote about the difficulty commissioners have in using research cited from the End of Life Care Strategy 2008). The reviewer raises a good point in that we needed to provide more background information about referral routes. This is included in the paragraph below:

All palliative patients regardless of condition were eligible across the two counties. The underlying theory behind Delivering Choice was that the provision of advice, information and support, whether emotional or practical (e.g. equipment, night sitters) would lead to a reduction in hospital utilisation and an increase in deaths in the community. As this ‘real life’ evaluation took place in a naturalistic setting, patients were not randomly allocated to any particular service. Instead, patients were identified by the service providers themselves (Discharge in Reach nurses), were referred by a healthcare professional (Coordination Centres) or initiated contact themselves after having received information about the service (Out of Hours advice line).

No consideration is given in the Discussion to the likely generalisability of the results.

A discussion about transferability of qualitative research has been expanded in the ‘strengths and weaknesses’ section.

Generalisability (or lack thereof) is a particularly contentious issue within qualitative research. [20-22] Qualitative research is not generalisable in the same way as quantitative research, because the reader, not the researcher, undertakes the transfer processes. However, qualitative research offers the opportunity for what Stake calls “naturalistic generalization”, whereby readers “find descriptions that resonate with their own experiences...[and then] transfer knowledge from a study sample to another population”. [23] Nonetheless, realistic evaluation offers a halfway house between quantitative generalisability and qualitative transferability through the generation of concrete, explanatory ‘middle range’ theories suitable for testing in future studies. Each ‘CMO configuration’ stated in the concluding paragraphs for each service in the results section offers opportunities for further testing of findings.
It is clear from some of the narrative that charismatic individuals and vested interests had a significant impact on the implementation of these services; one might speculate how the enthusiasm and "can-do" attitudes of the team may be eroded by burn-out, resignations, threats to the stability of funding etc and whether the changes in outcome achieved by the Delivering Choice programme can be sustained.

This is an excellent point and has inspired a revised paragraph.

Our results suggest that the success of Delivering Choice appears to partially rely on charismatic, talented staff. The enthusiasm and attitudes of these professionals may be eroded by threats to the stability of funding, re-organisations, policy changes, burn-out, resignations, fewer staff etc. In fact, we witnessed this at a ‘Celebration Evening’ with the service providers, funders and commissioners in December 2012. The effects of the Health and Social Care Act 2012 were already in evidence. In six short months since completing fieldwork, the overall mood had changed significantly; there appeared little celebration and much dismay at the changes wrought to the services and staff morale. However, the success of these services was not entirely due to charismatic staff, as the original team from one service experienced poor leadership and low morale, but the quantitative data still suggested that the service was successful, as services users visited or died in hospital less frequently. Other factors such as delivering an efficient service and having access to resources to support homecare appeared sufficient (in this case) to generate reassurance amongst family carers and confidence amongst referring staff. Given the complexity of end of life care service provision and the potential confounders in a non-randomised study, further research, especially into Coordination Centres which are springing up across the country, would be useful, ideally using a mixed methods design testing the CMO configurations identified in this study further.

Reference 10 does not contain sufficient information to enable it to be retrieved.

I cut and pasted the entire reference into Google and it led me right to the report in question, so perhaps the difficulty was not with reference 10 but a different reference?

Figure 1 does not convey any meaning to me - it could be discarded.

This has been cut.

Throughout the paper there terms are used in a technical sense without any explanation - a glossary explaining concepts such as "tacit knowledge" "front-of house", "snowball sampling" "helicopter view" "difference in difference analysis" would enable readers with a background in biomedical science and little awareness of sociological jargon to comprehend the authors' intentions.

Where possible we have either eliminated these terms or offered an explanation of their meaning in the text.
The term "contextual" seems to be employed indiscriminantly for a number of concepts, apparently more to sound impressive than to convey any meaning.

In keeping with realistic evaluation, ‘context’ has a specific meaning which is defined in the methods section as:

Context is everything that may affect whether and to what extent the mechanism is triggered. Context is about having the right conditions to activate the mechanism.

The use of the word "so" to prefix many sentences and the number of tautological adverbs also irritated this reviewer.

I didn’t know my use of ‘so’ was so irritating! I have eliminated the use of this word as much as possible. I do not know what a ‘tautological adverb’ is and neither did several people I asked so they have not been removed.

MOREcare & ADASTRA are referred to but not explained.

MOREcare is now explained in the introduction in the following sentences.

To address some of the difficulties in end of life care research, the MOREcare project was set up by academics and others interested in end of life care “to identify, appraise and synthesise ‘best practice’ methods to develop and evaluate palliative and End of Life Care, particularly focusing on complex service-delivery interventions and reconfigurations” [4]

We have eliminated the reference to ADASTRA and added the following explanation.

The aim of the electronic end of life care register was to allow professionals across different organisations (e.g. community nurses, hospital staff, voluntary sector professionals, paramedics) to access details on preferred place of death and other data

It is clear from the team’s report (freely available on the internet) that the counties studied were North Somerset & Somerset. There seems no point in attempting to anonymise them in the coy "Mixedshire" & "Ruralshire".

This has been changed, as suggested by the reviewer.

THANK YOU!