Author’s response to reviews

Title: "Done more for me in a fortnight than anybody done in all me life." How welfare rights advice can help people cope with cancer.

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Author’s response to reviews: see over
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Dear BMC Health Services Research

Thank you for the opportunity to respond to these extremely helpful and detailed comments. Below we give a point by point response to these comments. We have addressed the main comment regarding the strength of our claims and made appropriate revisions (see response to reviewer 2, point 1 below). We have uploaded two versions of the paper, one with track changes, to which the page, paragraph and line references outlined below refer. The other version is fully revised without track changes.

Reviewer 1 (ZA)

1. manuscript covers a wide range of issues which should be addressed in a more organised form ...a significant part of it deals with both the impact of cancer diagnosis on finances and patients’ struggles to obtain financial advice and benefit … its actual impact on its users is not addressed strongly enough … recommend that paper should focus mainly on impact of the service as indicated in the title

Title – we have revised the title to better reflect the content of the paper

2. It would be much clearer if the (results) section was presented under the following headings: process measures and outcome measures

We thank the reviewer for this comment and have made the following changes based on this recommendation.

(a) We have replaced the section title ‘What welfare rights advice services can offer people with cancer’, with ‘Impact of welfare rights advice service (i) process’, (p14, para 2) and joined this with section previously entitled ‘Impact of welfare rights advice’, now re-titled ‘Impact of welfare rights advice (ii) outcome’ (p17). Presenting the data in this way increases the emphasis on the impact of welfare rights advice.

(b) We have maintained the first qualitative section in the results as ‘Impact of cancer diagnosis on finance’ (p11) as we believe that this provides important contextual information about why welfare rights services are needed by some individuals

(c) We have moved ‘Barriers to accessing welfare rights advice’ followed by ‘Accessing welfare rights advice’ to the end of the results section and added linking sentences to signpost the reader.

We feel that following Reviewer 1’s comments on the ordering of the results section, this is now improved.

3. There is one quote indicating the impact of this service on the psychological state of the person who used it (p17). This is a very important issue that unfortunately received little attention in the article.

We thank the reviewer for raising this point. We have added a sentence (p 17, last 3 lines) to the effect that worry over finance added to the emotional burden associated with cancer diagnosis and treatment. However, since the focus of our research is to
understand and explore participants’ experiences about welfare rights advice, we are not going to add further to this since there is considerable literature associated with psychological state/distress and cancer.

**Minor comments**

M1 *Cancer disproportionately affects those who are already most likely to be financially disadvantaged. What about those who were well off before the diagnosis and experienced a significant reduction in their income?*
We have added a sentence acknowledging this on page 6, para 2.

M2 *Authors need to provide information where the service is based*
The welfare rights advisors are based at the Local Authority, but work across the county at a range of health and voluntary sector locations when providing advice. This information has been added to p8, para 1

M3 *How many people were asked to participate in the study?*
The number of those who were asked to participate in the study (N=105) is now given on P10, line 2.

M4 *Justification for the 22 interviews*
We have added a paragraph (p10, para 4) justifying the sample size.

M5 *Discussion should be stronger with some implications for future interventions*
We have strengthened the discussion by including relevant international literature, a more wide ranging discussion of the strengths and limitation of the study and consolidated the argument for more widespread welfare rights services for people with cancer. We suggest that an important area for future research concerns earnings and employment for people with cancer, p30, para 1.

**Reviewer 2 (AS)**

1. *The authors appear to make suggestions for changing practice in the health and welfare system based on interviews with these 22 individuals who differ widely … modify aims and conclusions accordingly*

We now make it clearer in the discussion/conclusions that we are recommending services that enable people to access their benefit entitlements (p28, lines 6-9). This is not a change to the UK welfare system, nor are we recommending this solely on the basis of this qualitative study, but these findings are backed up by other UK research. We do not have an agenda to ‘change practice’, in terms of changing the UK welfare state practice, but we do recommend the more widespread existence of services such as welfare rights advice that facilitate access to state benefit entitlement in the UK, and we feel that this is warranted for two main reasons (i) by the findings of this, albeit, small study (and we refer to the limitations of the methods/findings in the discussion as suggested by Rev 2, see comments below and p25, para 2), and (ii) other studies that indicate the positive impact on benefit uptake as a result of welfare rights advice services.

2. *First sentence needs to specify the UK … need reference to other countries with appropriate references*
We are grateful to the reviewer for pointing this out and have altered the first sentence of the background section and second sentence on page 5 to denote that we are referring to the UK, as well as making further allusions to the UK as appropriate throughout the paper. We have added text in the introduction (p4, para 1) and a section in the discussion (p27) outlining the growing literature on the financial impact of cancer, making reference to appropriate literature as suggested.

3. References to other populations and other welfare systems
We make reference to welfare systems in developed countries, pointing out that these systems vary in terms of amount of recompense and means of access (P4, para 2, lines 1-3) and later in the discussion, that likelihood of returning to work is influenced by the financial support that a state offers for people with cancer, and that the type of support offered differs greatly, depending on the welfare state (p27, para 1).

4. Need a statement of how many people consented to take part in interviews
This has been added (N=105) on P10, line 2.

5. Authors state that cancer affects persons disproportionately across different social strata ... this could be clarified
We thank both reviewers for picking up on this point. We have clarified this sentence (p6, para 2, lines 1-5) and added more detail about the socio-economic patterning and onset of different types of cancer. We have also highlighted the fact that those on previously high incomes can experience serious financial problems as a result of a cancer diagnosis.

6. A comparison of the number of participants seen by advisors, sample and sample base
This information is now contained within the paper and we have chosen not to add another table, as this would lead to duplication and the table would not add anything further that cannot be gleaned from reading paper.

7. Only one “carer” included, and this could be more clearly stated.
In the results section (p11, para 2. lines 2-3), we state that four participants were interviewed with carers present and one carer was interviewed alone.

8. Discussion and conclusions could be revised to acknowledge the limitations of the date (size and variability) and design.
The original section on the limitations of the study has been moved closer to the start of the discussion (pages 25-26). There is more detailed discussion given to the limitations, specifically sampling, methodology and generalisability.

9. Discussion – only persons included (eligible) are those who accessed welfare advice. This is likely to result in a skewed view on financial strain and stress after cancer
We now acknowledge this in the discussion (page 25, para 2, lines 9-12).

10. References to other populations
We are grateful to the reviewer for directing us to additional literature on finances and cancer, we now cite relevant work from this literature in the introduction and discussion. The purpose of the paper, however, is not to document the prevalence of
financial strain, or changes in economic circumstances, but to describe the impact of the welfare rights advice service on the lives of those dealing with cancer. We do not claim that our findings will reflect the experiences of all cancer patients. What we do claim is that those who have inadequate resources may have experiences in common with our sample, either because they are on low incomes to begin with, or because they experience a drop in income, plus additional expenses. We refer to this in the discussion on limitations (pages 25-26).

**Minor comments**

M1 *Improve consistency of term health care/healthcare*
Throughout we are using the term health care

M2 *Replace increases with increase in line 7 of abstract*
Done

M3 *Replace reduces/improves with reduce/improve in background section*
Done

M4 *missing commas*
The paper has been thoroughly checked and some grammar improved and some sentences simplified

M5 *use of appropriate on P7*
‘Appropriate’ replaced by ‘dedicated’ p8, para 1, line10, ‘appropriate removed, p8, para 1, line 10

M6 *Sentence could be simplified “Some health related benefits are means tested …’*
Sentence simplified, p9, para 1, lines 1-2.

We would like to thank both reviewers for their time and extremely helpful comments which we have incorporated into the paper, and which, we believe is strengthened as a result.

We look forward to hearing from you in due course.

Yours sincerely

Suzanne Moffatt          Emma Noble          Catherine Exley