

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Changes to post-diagnostic dementia support in England and Wales during the COVID-19 pandemic: a qualitative study
AUTHORS	Wheatley, Alison; Poole, Marie; Robinson, Louise; (collaborator group), The PriDem study team

VERSION 1 – REVIEW

REVIEWER	Phenwan, Tharin University of Dundee, School of Health Sciences
REVIEW RETURNED	06-Dec-2021

GENERAL COMMENTS	<p>This is an interesting study that offers insight for changes for post-diagnostic dementia care due to COVID-19. The article is well-structured. The introduction section is clear with relevant literature. The method section is clear and easy to follow. The writing is excellent and easy to follow-through.</p> <p>There are several inquiries and comments below:</p> <p>Methods and analysis</p> <ul style="list-style-type: none">-More background information about Pridem is needed ie. What is it? And how does this study fit the Pridem project?-Can you clarify participants' characteristic and geographical distribution and their work setting? It was not stated in the article.-What is the chosen methodology for this study? Narrative? Or GT? Or something else?-Which videoconference that you used for the interviews? <p>Results</p> <ul style="list-style-type: none">-Clear and sufficient. Just two comments-P7: 'telephones were considered more accessible for PwD'. I would argue that telephone communication removes the context from PwD thus could potentially cause stress and anxiety. This can be mitigated though.
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	-P9: 'different videoconferencing applications were considered...'can you clarify this? Which softwares did you mean? It is a bit unclear.
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REVIEWER	Vaitheswaran, Sridhar Schizophrenia Research Foundation (SCARF), Dementia Care in SCARF (DEMCARES)
REVIEW RETURNED	13-Dec-2021

GENERAL COMMENTS	<p>I congratulate the authors for this important and interesting work. Overall, the manuscript reads very well. I have the following comments to improve the quality further.</p> <ol style="list-style-type: none"> 1. While post-diagnostic support for dementia has evolved well in the UK, for many readers from other settings, especially those from the LMIC, it would be useful to include a brief paragraph (or an information box) in the background section about the PDS services and what is offered by them. This will provide context to the readers. 2. In page 4, "Sample and setting". the authors have mentioned "The sample comprised or a colleague if unavailable." This is also mentioned in the abstract. Who do the authors mean by "a colleague"? Are they the colleagues of the staff providing post-diagnostic support but not part of the PriDem study? 3. In page 5, the results section, the authors have mentioned that 21 participants were included. It will be useful to know their duration of experience providing post-diagnostic support and also the distribution of the regions in England and Wales they are from. 4. In page 5, under the "Challenges for post-diagnostic support" section, the authors have mentioned "A number of challenges for post-diagnostic emerged during COVID-19". The word "support" is missing after "post-diagnostic". 5. In page 6, the authors have included the following quote, "I've had to say, "you are health and care and support. I know it's got the feel of a social gathering and that's why it's nice for people because it feels like a social gathering, but this is doing people good". It is not clear how this quote supports the statement "some social support services being unnecessarily cautious". 7. In page 12, in the Strengths and limitations section, the authors have mentioned "Participants were geographically diverse and from a range of different health and third-sector services". In relation to my comment 3, no information is provided regarding the geographical diversity of the participants.
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REVIEWER	Kazawa, Kana Hiroshima University, Department of Medicine for Integrated Approach to Social Inclusion, Graduate School of Biomedical and Health Sciences
REVIEW RETURNED	14-Dec-2021

GENERAL COMMENTS	Thank you for providing me this opportunity to review this paper. This is an interesting paper on a very important topic of the impact of dementia support during the COVID-19. I have following few
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	<p>comments that may help to improve the clarity of the paper for wider readers.</p> <p>I have several comments.</p> <p>Background</p> <ul style="list-style-type: none"> - Please explain how the authors were motivated to conduct a study to investigate in detail the experiences of dementia professionals across disciplines and sectors, citing previous research. It would be nice if the authors could further discuss how other relevant studies have empowered authors to conduct this study. <p>Methods</p> <ul style="list-style-type: none"> - Please clarify how many researcher/s did the interviews? What is researcher's expertise and experience? - Regarding topic guide, the authors stated "Topics covered included impacts on: services; staff; people living with dementia and carers; commissioning; and future provision". Meanwhile, it is not clear that how the authors used the topics to interview the participants? Please provide an example of a topic guide. - In data analysis section, why authors have used this analysis? The section on data analysis is very important. Please elaborate and provide information in detail with justifications. <p>Results</p> <ul style="list-style-type: none"> - In the section of Retaining changes made during COVID-19, could the authors describe how this subtheme relates to dementia support? <p>Discussion</p> <ul style="list-style-type: none"> - While the focus is on dementia support, there is no consideration of the unique challenges and implications using technology compared to care of older adults in general on page 11, line 19.
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1	
This is an interesting study that offers insight for changes for post-diagnostic dementia care due to COVID-19. The article is well-structured. The introduction section is clear with relevant literature. The method section is clear and easy to follow. The writing is excellent and easy to follow-through. There are several inquiries and comments below:	Thank you very much for these comments.
Methods and analysis -More background information about Pridem is needed ie. What is it? And how does this study fit the Pridem project?	More detail has been added about PriDem. We have aimed to balance the level of detail with the limited space available, but we have also referenced several published papers which provide much more detail on the programme overall (page 3, line 33)

<p>- Can you clarify participants' characteristic and geographical distribution and their work setting? It was not stated in the article.</p>	<p>We have not provided more detailed demographic information about each participant for reasons of confidentiality. Some aggregate information is provided, including the numbers of participants from each sector. We have also now added some further information on the geographical spread of the sample, described according to the appropriate NHS region (page 5, line 16)</p>
<p>-What is the chosen methodology for this study? Narrative? Or GT? Or something else?</p>	<p>We used framework analysis methods, and more detail on the rationale for this was added to the data analysis section (see also response to the editor and reviewer 3). Overall we took a pragmatic codebook thematic analysis approach influenced by several traditions and principles of inductive qualitative research; more information about this has been added to the methods (page 3, line 38)</p>
<p>-Which videoconference that you used for the interviews?</p>	<p>We used Zoom or Teams, according to participant preferences. This information has been added to the methods (page 4, line 27)</p>
<p>Results</p> <p>-Clear and sufficient. Just two comments</p> <p>-P7: 'telephones were considered more accessible for PwD'. I would argue that telephone communication removes the context from PwD thus could potentially cause stress and anxiety. This can be mitigated though.</p>	<p>Thanks for pointing this out. We have clarified that participants were referring to the availability of the hardware (e.g. more likely to have a telephone in place already), rather than necessarily commenting on the merits of telephone communication for PLWD (page 8, line 35). We have also more clearly included loss of context as a drawback for remote working in the following section (page 9, line 26)</p>
<p>-P9: 'different videoconferencing applications were considered...'can you clarify this? Which softwares did you mean? It is a bit unclear.</p>	<p>We have added more detail about this; the software was usually Zoom, Teams or Attend Anywhere (page 10, line 1)</p>
<p>Reviewer 2</p>	
<p>I congratulate the authors for this important and interesting work. Overall, the manuscript reads very well. I have the following comments to improve the quality further.</p>	<p>Thank you very much for these comments.</p>
<p>1. While post-diagnostic support for dementia has evolved well in the UK, for many readers from other settings, especially those from the LMIC, it would be useful to include a brief paragraph (or an information box) in the background section about the PDS services and what is offered by them. This will provide context to the readers.</p>	<p>Thank you, this is an important point. We have added a definition of what we mean by post-diagnostic support to the introduction and some more information about what kind of support is recommended in England and Wales (page 3, line 3)</p>
<p>2. In page 4, "Sample and setting". the authors have mentioned "The sample comprised or a colleague if unavailable." This is also</p>	<p>We have clarified that by 'colleague' we mean a colleague from the same service who had not</p>

<p>mentioned in the abstract. Who do the authors mean by "a colleague"? Are they the colleagues of the staff providing post-diagnostic support but not part of the PriDem study?</p>	<p>previously been recruited to the study. This was so we could follow up services we had previously included even if staff had moved to a new post or were unavailable due to the pressures of this period (page 4, under Sample and Setting)</p>
<p>3. In page 5, the results section, the authors have mentioned that 21 participants were included. It will be useful to know their duration of experience providing post-diagnostic support and also the distribution of the regions in England and Wales they are from.</p>	<p>We have added some further information on the geographical spread of the sample, described according to the appropriate NHS region (see response to reviewer 1). We did not collect data on the duration of post-diagnostic experience of all participants, but we know that the majority of participants had been in post for at least two years based on their previous recruitment to the PriDem qualitative study in 2019.</p>
<p>4. In page 5, under the "Challenges for post-diagnostic support" section, the authors have mentioned "A number of challenges for post-diagnostic emerged during COVID-19". The word "support" is missing after "post-diagnostic".</p>	<p>Thank you for catching this error; we have changed it.</p>
<p>5. In page 6, the authors have included the following quote, "I've had to say, "you are health and care and support. I know it's got the feel of a social gathering and that's why it's nice for people because it feels like a social gathering, but this is doing people good". It is not clear how this quote supports the statement "some social support services being unnecessarily cautious".</p>	<p>We had been slightly overzealous when attempting to reduce our word count and so have added some further context back in to this quotation and the accompanying text. Hopefully it is now clearer.</p>
<p>7. In page 12, in the Strengths and limitations section, the authors have mentioned "Participants were geographically diverse and from a range of different health and third-sector services". In relation to my comment 3, no information is provided regarding the geographical diversity of the participants.</p>	<p>Thank you for pointing this out; please see response to comment 3.</p>
<p>Reviewer 3</p>	
<p>Thank you for providing me this opportunity to review this paper. This is an interesting paper on a very important topic of the impact of dementia support during the COVID-19. I have following few comments that may help to improve the clarity of the paper for wider readers.</p>	<p>Thank you very much for these comments.</p>
<p>I have several comments. Background - Please explain how the authors were motivated to conduct a study to investigate in detail the experiences of dementia professionals across disciplines and sectors, citing previous research. It would be nice if the authors could further discuss how other relevant studies have empowered authors to conduct this study.</p>	<p>We have now added some additional information to the introduction about the background of post-diagnostic support for people with dementia in England and Wales (see response to reviewer 2). Given comments from other reviewers which were positive about the use of relevant literature, we hope this is now satisfactory. We were further unsure if this comment referred to the present study or PriDem overall. Further information about</p>

	<p>PriDem overall and about the present study's place within it has been added to the start of the methodology (see response to reviewer 1). We were motivated to conduct the present study based on our knowledge of the disruption to health and social care caused by COVID, points raised on this topic by participants in PriDem intervention development task groups, and a desire to ensure the PriDem intervention was still fit-for-purpose given changes during COVID. At the time we began, few relevant studies were available.</p>
<p>Methods - Please clarify how many researcher/s did the interviews? What is researcher's expertise and experience?</p>	<p>We had included most of this information at the beginning of the 'data collection and analysis' paragraph but have attempted to clarify it further. A new section on reflexivity has also been added (see response to the editor's comment).</p>
<p>- Regarding topic guide, the authors stated "Topics covered included impacts on: services; staff; people living with dementia and carers; commissioning; and future provision". Meanwhile, it is not clear that how the authors used the topics to interview the participants? Please provide an example of a topic guide.</p>	<p>We have clarified the purpose and rationale for this approach (page 4, line 19) and have provided the topic guide as a supplementary file.</p>
<p>- In data analysis section, why authors have used this analysis? The section on data analysis is very important. Please elaborate and provide information in detail with justifications.</p>	<p>We have added information on the rationale for choosing this method of analysis (page 4, line 31)</p>
<p>Results - In the section of Retaining changes made during COVID-19, could the authors describe how this subtheme relates to dementia support?</p>	<p>We have added some additional phrases throughout this section to clarify that we are still talking about dementia support and commissioning of dementia support.</p>
<p>Discussion - While the focus is on dementia support, there is no consideration of the unique challenges and implications using technology compared to care of older adults in general on page 11, line 19.</p>	<p>We have added a line acknowledging that there are specific challenges for people with dementia in using technology (page 12, line 25). We hope this is sufficient, particularly as we have described some of these challenges in more detail in the results section under 'Benefits and drawbacks of remote consultation for service users'</p>

VERSION 2 – REVIEW

REVIEWER	Vaitheswaran, Sridhar Schizophrenia Research Foundation (SCARF), Dementia Care in SCARF (DEMCARES)
REVIEW RETURNED	23-Dec-2021

GENERAL COMMENTS	Thank you for updating the manuscript with the recommended changes. I have no further recommendations.
REVIEWER	Kazawa, Kana Hiroshima University, Department of Medicine for Integrated Approach to Social Inclusion, Graduate School of Biomedical and Health Sciences
REVIEW RETURNED	10-Jan-2022
GENERAL COMMENTS	Thank you for your revision. The manuscript has been revised sufficiently to be considered acceptable.