

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Last Year of Life Study Cologne (LYOL-C): protocol for a cross-sectional mixed methods study to examine care trajectories and transitions in the last year of life until death
AUTHORS	Strupp, Julia; Hanke, Gloria; Schippel, Nicolas; Pfaff, Holger; Karbach, U.; Rietz, Christian; Voltz, Raymond

VERSION 1 – REVIEW

REVIEWER	Joanna Broad University of Auckland, New Zealand
REVIEW RETURNED	24-Jan-2018

GENERAL COMMENTS	<p>This paper reports the design of a comprehensive mixed-methods study to examine health and social care trajectories and transitions in their last year of life. It offers an intriguing background and rationale, and a study design that covers many aspects of care from a wide range of perspectives. The completed study should contribute a large body of new knowledge to the topic. I have only a few questions or concerns.</p> <p>Methods: I suggest moving the study period definition, i.e. the dates, near the start, instead of near the end of the Methods section. Do all four study phases relate to deaths in this three-year study period, or are deaths included only if within a more limited time period? The issue of representativeness of this group of insured deceased people to the whole deceased population should be identified as an issue which the study reports will need to address.</p> <p>Phase I: Has consideration been given to classifying groups or clusters, defined by their trajectories, in order to facilitate comparisons of quality of life, costs, carer load, etc? Will rates of hospitalisations, acute or planned, be presented by place of residence (home, in long-term nursing care), for example, and how they change around transitions over the 12 months? Perhaps the final sentence of the paragraph would read better as "Analysis will describe the main care trajectories...". Inclusion criteria - in what time period do deaths have to occur, to be included? Would people in this insurance scheme include only German nationals, or would EU citizens, other residents, or non-residents e.g. visitors, refugees be included too, & in which case, would a 12-month look-back in health service use be possible?</p> <p>Phase II: I suggest that when the validated self-report instrument PACIC-SF is adapted for use with bereaved relatives, it will need further validation. Inclusion criteria - is a definition of 'carer' needed, or is the type & amount of care provided by the respondent part of</p>
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	<p>the data to be captured?</p> <p>Phase IV: The term "field access partners" is used but is unclear, an explanation would be helpful.</p> <p>References. The references cover well the topics and methods, though sometimes seem overly-focused on Germany. While that is understandable given it is the location of the research, and where applications would be targeted, the papers will presumably be presented to, and used by, a wider audience. Examples of comparable work from other countries could help readers put the study into an international perspective.</p> <p>Overall, the protocol describes a study that is useful, has potential application in practice and policy, and would assist in understanding late-life care.</p>
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VERSION 1 – AUTHOR RESPONSE

Dear Editor and Reviewer,

we are very grateful for the editor’s reviewer” comments regarding our study protocol "Last Year of Life Study Cologne (LYOL-C)". We believe that all comments have now been addressed, and the manuscript is much improved as a result. Please find attached a revised manuscript with “tracked” changes. In addition, we have addressed each reviewer comment (written in red) in turn, below.

Editor #1

Before submitting your revision please also remember to revise the title of your paper to make it clear this is a study protocol. We suggest: "Last Year of Life Study Cologne (LYOL-C): protocol for a cross-sectional mixed methods study to examine care trajectories and transitions in the last year of life until death."

Thank you for this comment. We have changed the title accordingly.

Reviewer #1

We are very grateful to Reviewer 1 for taking the time to make constructive criticism on how this manuscript could be improved. We agree with all comments, and think that the manuscript has benefitted greatly from changes made in response to the Reviewer’s comments. More detailed responses to each comment are given below.

Methods: I suggest moving the study period definition, i.e. the dates, near the start, instead of near the end of the Methods section. Do all four study phases relate to deaths in this three-year study period, or are deaths included only if within a more limited time period? The issue of representativeness of this group of insured deceased people to the whole deceased population should be identified as an issue which the study reports will need to address.

Thank you for your comment. We have moved the study period definition near the start. Please see tracked changes in the manuscript.

As for your other comment: in phase I we relate to deaths that have occurred in the last 12 months prior to the survey (November 2016 to April 2018). We have included this information in the revised manuscript. Please see tracked changes.

Phase I: Has consideration been given to classifying groups or clusters, defined by their trajectories, in order to facilitate comparisons of quality of life, costs, carer load, etc? Will rates of hospitalisations, acute or planned, be presented by place of residence (home, in long-term nursing care), for example, and how they change around transitions over the 12 months? Perhaps the final sentence of the paragraph would read better as "Analysis will describe the main care trajectories...". Inclusion criteria - in what time period do deaths have to occur, to be included? Would people in this insurance scheme include only German nationals, or would EU citizens, other residents, or non-residents e.g. visitors,

refugees be included too, & in which case, would a 12-month look-back in health service use be possible?

Thank you for your comment. We will of course classify groups or clusters in order to facilitate comparisons of quality of care etc. We will analyse results according to the quality of care by place of death, cause of death etc. Please see page 7 where we stated the following:

“The survey design allows comparisons to be made between the quality of care given to people dying at different ages (for example less than 65 years, 65-79 years or 80 years or more) and different causes of death (cardiovascular, cancer or other) and for people receiving care in different settings during the last months of life (for example home, hospital, care home and/or hospice).“

People will be included if they are members of the participating statutory health insurances. Therefore, e.g. refugees are of course included if they are members of the statutory health insurances. EU citizens are not included, since they are not covered by the German statutory health insurances.

Phase II: I suggest that when the validated self-report instrument PACIC-SF is adapted for use with bereaved relatives, it will need further validation. Inclusion criteria - is a definition of 'carer' needed, or is the type & amount of care provided by the respondent part of the data to be captured?

Thank you for this comment. The PACIC-SF adaption will be validated in the course of our project. We have included this information in the revised manuscript. Please see tracked changes.

Phase IV: The term "field access partners" is used but is unclear, an explanation would be helpful.

Thank you for this comment. We have included an explanation in the revised manuscript. Please see tracked changes.

The references cover well the topics and methods, though sometimes seem overly-focused on Germany. While that is understandable given it is the location of the research, and where applications would be targeted, the papers will presumably be presented to, and used by, a wider audience. Examples of comparable work from other countries could help readers put the study into an international perspective.

Thank you for this comment. We included more references to studies outside of Germany, bearing in mind that BMJ Open has an international readership.

Overall, the protocol describes a study that is useful, has potential application in practice and policy, and would assist in understanding late-life care.

Thank you very much.