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## **Participant Information for online research survey**

**Study title:** Community-based support for living well with long-term health conditions

**CUREC Approval Reference:** R80131/RE001

### ***General Information***

Thank you for your interest in this online survey. Please read through this information before agreeing to participate (if you wish to) by ticking the 'Yes' box at the end of the page. You may ask any questions before deciding to take part by contacting the researcher (details below).

The aim of this study is to explore what kind of support people seek in their local communities for living well with multiple long-term health conditions. A variety of support services are available to help people live well with their long-term health conditions, but compared to help provided through the NHS or local government, the role and effectiveness of community-based support (provided through charity organisations or volunteers) is not well understood. Through this study we will identify the different types of support that people with long-term health conditions have or would like to have, and we will explore what kind of information is needed to show if community-based support is effective.

To take this survey you must be an adult currently living in the UK who has two or more long-term health conditions. You do not have to be personally invited to participate, and you can share the survey link (available on public websites and social media channels) with others.

The Principal Researcher is Dr Caroline Potter, who is leading the study as part of her Senior Research Fellowship at the Nuffield Department of Population Health, University of Oxford. If you have any questions about the study, you can contact Dr Potter on Freephone 0800 138 3009, or by email: [caroline.potter@ndph.ox.ac.uk](mailto:caroline.potter@ndph.ox.ac.uk)

Dr Potter is supported in this research by Dr Michele Peters (also at the Nuffield Department of Population Health) and by an advisory group that includes academic and public representatives.

### ***Do I have to take part?***

No. This is a voluntary study, so it is up to you to decide if you want to take part. If you do not wish to participate, simply do not follow the link or complete the survey. If you do decide to take part, you may withdraw at any point for any reason before submitting your

answers by exiting the survey and/or closing the browser.

All questions are optional, so you can skip a particular question if you prefer not to answer it. It is unlikely that you will suffer any harm as a result of participating in this study, but if you find any of the questions on the survey distressing then we advise that you discuss this with a trusted health professional.

No background knowledge of the research topic is required. There will be no direct benefits to you in taking part, but the information you provide will lead to a better understanding of the support needs of people with multiple long-term health conditions and how that support could be effectively provided in the community.

### ***How will my data be used?***

All information that you provide through the survey will be kept confidential. We will **NOT** ask you to provide any information that could directly identify you (such as your name or contact details) when completing the survey, although it is possible that someone with a rare condition might be indirectly identifiable through their responses to the survey.

At the end of the survey you will be asked if you would be willing to do a follow-up interview for the next part of this study. If you would like to be contacted about an interview, you will be directed to a link for a separate survey where you can provide your contact details. These details will never be linked to your survey response. Taking part in a follow-up interview is optional: you do **NOT** have to express interest in this or provide your contact details in order to take part in the survey.

Your IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential.

The survey responses you provide will be stored in a password-protected electronic file on University of Oxford secure servers. Your anonymised data may be used in academic publications, conference presentations, a stakeholder workshop, and summaries of study results on the project website (<https://communitycareforlivingwell.uk/>). Research data will be stored for 10 years after publication or public release of the work of the research. If you provide contact details for a follow-up interview, these will be stored in a separate password-protected database that will be deleted at the end of the study.

### ***Who will have access to my data?***

The University of Oxford is the data controller with respect to your personal data and, as such, will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from <https://compliance.admin.ox.ac.uk/individual-rights>.

Only members of the research team will have access to all survey responses or to contact details provided for the purpose of a follow-up interview. The data you provide may be

shared with responsible persons from the University of Oxford, but **only** where it is required for monitoring or auditing the research. Data will not be shared outside the research team for any other purposes.

Your research data (survey responses) may be used in future studies by the research team and/or shared with other researchers (e.g. in online databases) for further analysis. Data will be de-identified before it is shared with other researchers or results are made public.

***Who has reviewed this study?***

This project has been reviewed by, and received ethics clearance through, a subcommittee of the University of Oxford Central University Research Ethics Committee (reference number: R80131/RE001).

***Who do I contact if I have a concern or I wish to complain?***

If you have a concern about any aspect of this research, please speak to Dr Caroline Potter (0800 138 3009 - email: caroline.potter@ndph.ox.ac.uk ), who will do their best to answer your query. Dr Potter will acknowledge your concern within 10 working days and will give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB.

**Please note that you may only participate in this survey if all of the following apply to you (tick to confirm).**

- I am an adult (18 years of age or older)
- I am currently living in the UK
- I have two or more long-term health conditions

**If you have read the information above and agree to participate with the understanding that the data (including any personal data) you submit will be processed accordingly, please tick the box below to start.**

- Yes, I agree to take part in this survey