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**EFFECTIVE HEALTH CARE SUPPORT TO CARE HOMES:**

**BEST WORST SCALING**

**Participant Information Sheet**

(Version for electronic administration)

This Participant Information Sheet should be read in conjunction with [The University privacy notice](http://documents.manchester.ac.uk/display.aspx?DocID=37095)

You are being invited to take part in a research study which is looking at the health care services needed by older care home residents. Before you decide whether or not to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

**Who will conduct the research?**

The research is being carried out by the Personal Social Services Research Unit (PSSRU) at the University of Manchester.

**What is the purpose of the research?**

This study is designed to explore the form, content and impact of healthcare support to care homes. By this we mean the help and support that care homes receive from visiting healthcare professionals such as GPs, physiotherapists, pharmacists, specialist nurses and palliative care staff to help them meet their residents’ physical health care needs. This aspect of the study is designed to establish which aspects of these services interested members of the public value most (e.g. the mix of NHS staff who provide support, how quickly they are able to respond to referrals and whether they provide specialist end-of-life care).

**Why have I been chosen?**

We are seeking the views of members of the public who are interested in the provision of healthcare services for older adults. You have received this participant information sheet as a member of Healthwatch to see if you would like to share your views with us. We hope to engage 100 members of the public in this study.

**What would I be asked to do if I took part?**

If you decide to take part in the study, we would ask you to complete a questionnaire electronically. This is slightly different from a standard questionnaire, in that in each of the 16 questions you will be given a list of four aspects of healthcare services for care home residents, and asked to say which you think is *most* important, and which you think is *least* important. These questions are not about your own personal experience of healthcare services for care home residents, but are about the sort of health care services you think should be provided to care home residents in general. Before you complete these questions, we would ask you to tick a box to confirm that you consent to participating in the study.

There are no identified risks to taking part. However, you will need to take some time away from your normal responsibilities to complete the questionnaire. We will make every effort to ensure that the time you commit to this study is minimised without compromising the quality of the research. The questionnaire should take about 20 minutes to complete. You do not have to complete the questionnaire and you can stop at any time without giving a reason.

**What will happen to my personal information?**

In order to undertake the research project we will need to collect the following personal information/data about you:

* Your email address (when you return the completed questionnaire).

Only the research team will have access to this information.

We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is “public interest task” and “for research purposes” if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our [Privacy Notice for Research Participants](http://documents.manchester.ac.uk/display.aspx?DocID=37095).

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures. All researchers are appropriately trained and your data will be looked after in the following way: your contact details will be deleted as soon as practical.

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you. This is known as a Subject Access Request. If you would like to know more about your different rights, please consult our [privacy notice for research](http://documents.manchester.ac.uk/display.aspx?DocID=37095) and if you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL. at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner’s Office](https://ico.org.uk/concerns), Tel 0303 123 1113

**Will my participation in the study be confidential?**

Your participation in the study will be kept confidential to the study team and those with access to your personal information as listed above. The questionnaire will not contain your name, but will be linked to your contact details via an assigned participant ID number known only to the research team. The information will not be used in any way that will allow you to be identified individually.

A copy of your completed questionnaire will be securely stored in a locked filing cabinet at the University of Manchester for five years and will be used for this study only. It will then be shredded.

Individuals from the University, regulatory authorities or the National Institute for Health Research may need to review the study information for auditing and monitoring purposes or in the event of an incident.

**What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to tick a box within the questionnaire to confirm your consent before you answer the questions. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised and forms part of the dataset as we will not be able to identify your specific data. This does not affect your data protection rights.

**Will my data be used for future research?**

When you agree to take part in a research study, the information about you may be provided to researchers running other research studies in this organisation. The future research should not be incompatible with this research project and will concern the care needed by care home residents. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/)**.**

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you regarding any other matter or to affect your care. It will not be used to make decisions about future services available to you.

**Will I be paid for participating in the research?**

There is no payment for taking part in this research.

**What is the duration of the research?**

The questionnaire takes about 20 minutes to complete.

**Will the outcomes of the research be published?**

The findings from this study will be published in journals and presented at conferences. We will also publish a summary of our results on our website: <http://research.bmh.manchester.ac.uk/pssru/> and send copies of this to all the participating organisations.

If you would like a personal copy of the results when available, please tell the researchers or request them by email at sue.tucker@manchester.ac.uk

**Who has reviewed the research project?**

The study has been reviewed by the University of Manchester Proportionate Research Ethics Committee.

**What if I want to make a complaint?**

Minor complaints

If you have a minor complaint then you need to contact **Sue Tucker** (one of the researchers) in the first instance by emailing **sue.tucker@manchester.ac.uk**or by telephoning **0161 2755938.**

Formal Complaints

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact: The Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL by emailing:**research.complaints@manchester.ac.uk**or by telephoning **0161 275 2674.**

**What Do I Do Now?**

If you have any queries about the study or if you are interested in taking part then please contact **Sue Tucker** (one of the researchers) by emailing **sue.tucker@manchester.ac.uk**or by telephoning **0161 2755938.**

**This Project Has Been Approved by the University of Manchester’s Proportionate Research Ethics Committee [ref 13076]**