





Developing a minimum dataset for homecare (DACHA-DOM): survey information sheet

What is the purpose of this survey?

Very little is known about the information that homecare providers collect on people that they provide care to, how information is stored, and who can access it. This national survey of homecare providers will investigate this, for the first time. This survey is part of a project about collecting and sharing data on people receiving homecare.

The survey asks homecare providers about the data they collect, and for their views on what information about a person receiving care should be collected, stored, updated and shared with relevant agencies (termed a Minimum Dataset – 'MDS'). It also asks about barriers to data collection and how homecare providers would feel about contributing to a national dataset on people who use homecare. An MDS could be used to plan care and support for older people, including by government departments, and regulatory organisations, such as the Care Quality Commission. It may provide a vital link between information on resources and outcomes.

How is the survey work organised?

The study is being conducted by researchers from the Population Health Sciences Institute at Newcastle University and the Social Policy Research Unit at the University of York. The project Principal Investigators (PI) at Newcastle University and the University of York, Professor Barbara Hanratty and Bryony Beresford have overall responsibility for the appropriate storage, treatment (including making datasets suitable for publication) and security of research project data.

How will the data provided by survey participants be used?

Data collected from the survey will not be shared outside of the research team, or used for any other purposes. In all reports/presentations of the survey and its findings, no information will be report that could identify individuals or specific homecare providers.

How will the information provided be protected and kept confidential?

Survey data will be anonymised and stored on secure password protected systems (electronic copies) on secure servers at the Newcastle University and the University of York. After the study has

ended, the data will be stored electronically, in a password-protected environment, for 10 years, after which time it will be destroyed under secure conditions.

All data will be held in line with standards, recommendations Ethics Policy and Code of Good Practice of Newcastle University, the University of York and the National Institute for Health & Social Care (NIHR). Newcastle University and the University of York are fully compliant with EU General Data Protection Regulation (GDPR) requirements for transparent, fair and legal data protection, the Caldicott principles the Data Protection Act 2018 the Privacy and Electronic Communication Regulations, the EU e-Privacy Regulation and other related legislation. The research team will adhere to these obligations.

At the end of the survey, respondents are invited to provide contact details. This is an optional request, solely for the purpose of maintaining contact throughout the project, receiving feedback on the findings and/or opting to participate in future consultation events. Contact details provided will be stored electronically on secure servers at the Newcastle University and the University of York in a separate dataset not linked to other data provided and will be destroyed when the study has ended. Only the research team will have access to the project folder and any documents containing contact details will be password protected.

Who is organising and funding the project?

The survey is part of the DACHA-DOM study, funded by National Institute of Health and Care Research, through the Health and Social Care Delivery Research (HSDR) Programme award.

Who has reviewed the project?

The sponsor for this study is Newcastle University. This study has been reviewed by Newcastle University Ethics Committee [Ref 25570/2022]. This study/project is funded by the National Institute for Health and Care Research (NIHR) Health Service Research and Delivery programme (HS&DR NIHR127234) and supported by the NIHR Applied Research Collaboration (ARC) North-East and North Cumbria. Please see the <u>study webpage</u> for more information.

Get in touch

For questions or concerns about anything to do with the project, please contact the project team via <u>vanessa.davey@newcastle.ac.uk</u>

For any complaints or concerns

You can contact the principal investigator of the study, Barbara Hanratty: email: <u>barbara.hanratty@newcastle.ac.uk</u>

If you wish to raise a complaint on how we have handled your information, you can contact the Data Protection Officer at <u>rec-man@ncl.ac.uk</u>. If you are not satisfied with their response of believe your data us being processed in a way that is not lawful, you can complain to the Information Commissioners Office (ICO) at <u>www.ico.org.uk</u>.