

Participant information sheet

Resilience Measure Development

What is the purpose of this project?

We are developing a new questionnaire to measure resilience for people living with dementia. We want to look at how people are managing while living with a diagnosis of dementia. With your help we will be able to find the right questions to use in this questionnaire.

It is important to develop one because it will help health and care practitioners and others (e.g., researchers) to take a more positive approach to supporting people with dementia by identifying what aspects of life people feel they are doing well, and where they might appreciate some help. Using a measure like this could also show when services are working well and improving people's lives.

Why have I been invited to participate in this study?

You have been invited to take part as you are a person living with a diagnosis of dementia.

By consenting to this study, you are confirming that you meet our inclusion criteria:

- You are living with a diagnosis of any type of dementia
- You are 18+ years of age
- You live in the UK
- You are able to consider and understand what the research study will require

Do I have to take part?

It is entirely up to you to decide if you want to take part. If you decide to take part, you are free to withdraw at any time. If you decide to withdraw from the study, we will keep the answers you have given us up until that point unless you ask us not to.

What will be involved if I decide to take part?

We would like to ask you to answer some questions. The questions require selecting an answer (like selecting 1-5 on a scale). The questions are about you and how you feel. There are no right or wrong answers. The whole questionnaire includes 59 questions. We think it may take between 20 and 60 minutes to complete. You can choose to complete the questionnaire in an online survey, or on paper. If completing the questionnaire online, you will be able to step away from the survey for up to 45 minutes if you need a break.

Consenting to the study

If you decide to take part in the study, you will be asked to tick a box confirming that you understand this information sheet and that you agree to take part.

What are the possible disadvantages and risks of taking part?

We do not think that taking part will involve any disadvantages or any specific risks to you or that it could cause you any harm. There may be some questions or topics that you find sensitive. You are free to not answer any questions that you feel are not appropriate or are too upsetting. You can also take a break or stop taking part. If you stop taking part, we will keep the answers you have given us up until that point unless you ask us not to.

Some suggestions of available support are listed on the last page of the questionnaire (with contact details where possible).

What are the possible benefits of taking part?

There are no immediate benefits to you for participating in this study. However, by taking part we hope that the knowledge gained from this research project will help to inform the development of a useful new questionnaire and potential interventions that will be beneficial to other people affected by dementia.

Will I be paid for taking part in the study?

We are very grateful for your contribution. You will be offered a £20 shopping voucher (e.g. Love2Shop) as a thank you for answering the questions. If you are answering the questions online, you will be asked for your address at the end of the survey, so that we can post the vouchers. If completing on paper, we will provide a separate slip for your address to send back along with the completed questionnaire. We will not keep your address once the voucher has been posted to you.

What if something goes wrong?

In the first instance please raise your concerns to the resilience study lead, Prof Gill Windle (g.windle@bangor.ac.uk / 01248 383050), Dementia Services Development Centre, School of Medical and Health Sciences, Bangor University, Fron Heulog, Holyhead Road, Bangor, Gwynedd. Wales.

However, if you feel your concern has not been handled to your satisfaction, you can contact the Chair of the Ethics Committee via l.jones@bangor.ac.uk.

Or you may contact the Head of Governance and Compliance, Governance and Compliance Office, Corporate Services, Bangor University, College Road, Bangor, Gwynedd, LL57 2DG.

Will my taking part in this project be kept confidential?

Your participation will be kept anonymous, which means no personal information that would identify you will be stored as part of the research study. You will not be able to be identified in any ensuing reports or publications. All the information that we collect from you will be kept strictly confidential in compliance with General Data Protection Regulation (GDPR) and other relevant legislation. Your responses will be held securely in encrypted (password protected) folders by the research team at Bangor University and UCL, who are our lead project partners. Any paper documents will be kept securely at Bangor University. If you would like to receive a shopping voucher as a thank you, we will request your address (for the purpose of sending alone) – once the voucher has been posted we will not keep your address.

What will happen to the results of the research project?

We hope to share the study results in various ways, such as conferences, meetings and in journal articles. You will not be identified in any reports or publications. If we include your contributions, these will be presented in a way that would not include information which could identify you.

Who is organising and funding the research?

This research is funded by the Economic and Social Research Council and the National Institute of Health Research. This study is being organised by Bangor University and project partners are based across Bangor University, UCL, and Nipissing University in Canada. Indemnity arrangements for the study are provided by Bangor University.



Further information and contact details

If you would like further information about this research or if you have concern about any aspect of this study, please contact the primary researcher Jen Roberts (j.roberts@bangor.ac.uk / 01248 388346).