

INFORMATION FOR PARTICIPANTS

Attitudes Around Dementia: World Alzheimer Report 2024 survey

Thank you for considering participating in this study which looks at attitudes and beliefs about Alzheimer's disease and other types of dementia around the world. This information sheet outlines the purpose of the study and provides a description of your involvement and rights as a participant, if you agree to take part.

1. What is the research about?

Alzheimer's Disease International (ADI) and London School of Economics and Political Science (LSE), want to conduct the largest ever worldwide survey of attitudes and beliefs about dementia. To do this, we want to gather information from persons with dementia, their caregivers, healthcare professionals, and the general public.

To get a rich understanding of the topic, we are asking lots of different groups of people to take part, from all across the world, including rural and urban communities. We will then create a report that summarises the findings which will be publicly available.

2. Do I have to take part?

It is up to you to decide whether or not to take part. You do not have to take part if you do not want to. If you do decide to take part, we will ask you to complete a consent question in advance of completing the survey.

3. What will my involvement be?

You will be asked to complete a survey with questions related to dementia and Alzheimer's disease. This survey may be completed online or using a tablet provided for you to use. The survey should take around 10 - 15 minutes to finish.

4. How do I withdraw from the study?

You can withdraw at any point of the study, without having to give a reason. If any questions during the survey make you feel uncomfortable, you do not have to answer them. Withdrawing from the study will have no effect on you.

5. What will my information be used for?

We plan to report the results of the study in the World Alzheimer Report 2024. You will not be identified in any report/publication or other communication about this research.

6. Will my taking part and my data be kept confidential? Will it be anonymised?

Yes. All the information we collect about you is kept strictly confidential and all data will be anonymised which means that we cannot connect any survey responses with individuals completing the survey. All data files will be anonymous and will only be shared with study researchers. They will be stored digitally online digital files will be given codes and stored separately from any names or other direct identification of participants. Any hard copies of research information will be kept in locked files at all times.

7. What are the possible benefits of taking part?

There are no immediate benefits for you, but in the longer term, the study will provide important information about stigma that can be used to develop better programmes for people living with dementia.

8. What are the possible disadvantages and risks of taking part?

There are none expected. You will be asked about your beliefs and attitudes, and therefore it might be possible that some questions may upset you. You will be able to stop participating at any time and you may decline to answer any questions that make you feel uncomfortable.

9. What if I have a question or complaint?

If you have any questions regarding this study please contact Dr Sara Evans-Lacko, Care Policy Evaluation Centre (CPEC), LSE, E-mail: s.evans-lacko@lse.ac.uk

If you are happy to take part in this study, please complete the consent question.