

Improving Survey Accessibility by Raising Interviewers' Awareness of Dementia and Autism

Helen Moore

Office for National Statistics

What we do

- The Office for National Statistics (ONS) is the UK's largest independent producer of official statistics and its recognised national statistical institute. We collect and publish statistics related to the economy, population and society at national, regional and local levels. We conduct the census in England and Wales every 10 years.
- ONS employs over 1,000 social survey interviewers, who work face-to-face, on the telephone and at ports and airports.
- We collect data for core surveys like the Labour Force Survey, the Living Costs and Food Survey and the International Passenger Survey.
- We also win competitive tenders to run externally-funded surveys, such as the Family Resources Survey and the National Survey for Wales.

Why raise awareness?

ONS aims to ensure that everyone can take part in its surveys, regardless of any impairments they may have.

We have occasionally been criticised – in complaints from respondents or their carers – for distressing vulnerable respondents by asking them to take part in surveys.

Our aims are:

- to include people with dementia and autism in our statistics;
- to improve their experience of taking part – or being asked to take part; and
- to reassure their families and carers.

What are dementia and autism?

- Dementia describes a set of symptoms that include memory loss and difficulties with thinking, problem-solving or language. It's caused when the brain is damaged by diseases, such as Alzheimer's disease, or by a stroke.
- 850,000 people live with dementia in the UK; this is expected to reach over 1 million by 2025.

- Autism is a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The word "spectrum" is used because the characteristics of the condition vary from one person to another.
- Nearly 700,000 people in the UK have autism. Together with their families they make up over 2.7 million people whose lives are touched by autism every single day.

Raising awareness ...

During 2015, two thirds of ONS interviewers became "Dementia Friends" at sessions delivered by volunteers at local meetings. Each was given a forget-me-not lapel badge to show that they had completed the session.



We're working with autism charities to develop awareness sessions on autism spectrum conditions. There is significant potential to bias our results if we are unable to interview people with autism.



Many of the principles of communicating with people with dementia and autism are also applicable to other respondents who do not cope well with taking part in a survey, so will be of wider benefit.

What it's not!

No change to establishing informed consent and assessing respondent capacity



Not about identifying or diagnosing autism or dementia



Being aware of why communication may not be going smoothly



Practical Tips

Include everyone

Be patient

Use plain language

Explain what will happen

Avoid distractions

Be open-minded

Show respect

Be flexible about time

“Emotional memory”

Useful links

There's lots of information on dementia at:

www.alzheimers.org.uk

You can watch the Dementia Friends video:

www.dementiafriends.org.uk

You can find out about autism at:

www.autism.org.uk

www.autisminitiatives.org