



Organisation of a prevalence study

A community study must be carefully planned if it is to have any validity.

Local consultation

First it is important to decide why you want to do the survey. Community surveys are expensive and time consuming. Mistakes are therefore unfortunate, but could often with hindsight have been avoided in the design stage of the study. It is always sensible to consult widely with experienced investigators before starting a survey.

If you have not done this type of work before, Alzheimer's Disease International would be happy to help by suggesting contacts with investigators who would be able to advise or even to collaborate with your research plans.

It is essential before starting a community survey that the local community is consulted about your plans, and is aware that the survey will be taking place. This consultation might include local government and community leaders, doctors and health care workers, and (if appropriate) the local media.

Age range

Dementia is rare below the age of 65 years. There seems little point in including younger subjects, even in developing countries where relatively few survive to this age. It may be useful to consider over-sampling older age groups, which will be smaller but will contribute a disproportionate number of dementia cases.

Sampling

You might assess every eligible person living within a defined geographic area (such as an electoral district). This is a commonly used and straightforward approach, but such a study will only be able to comment on the particular area surveyed, that could be unusual in

some ways. In order to get a representative sample of older persons living within a larger unit like a city, or even a whole country, you will need to sample randomly selected individuals or households within randomly selected electoral districts (cluster sampling). Many people with dementia in developed countries live in residential care or nursing home facilities which tend to have a very high prevalence of dementia among their residents. Such homes are rare in developing countries, and where they exist the admission criteria may differ from those in developed countries. In the developed world, catchment area surveys may have a disproportionately low or high proportion of participants living in residential care. An unbiased comparison between settings may mean that separate prevalence estimates need to be made both including and excluding these homes.

Compiling a register

Whichever approach you use, you will need an accurate register of residents and their ages. This is the 'base population' for your survey. You might use voting registers or census surveys – but these are quickly outdated, may be incomplete, or might not specify residents' ages. In many cases the study team will have to carry out their own local census (enumeration), by knocking on the doors of all the households in a catchment area or of all the households randomly selected in a cluster sample. Remember that dwellings may not be organised neatly into numbered houses in identifiable streets. Age may also be difficult to ascertain accurately, either directly from study subjects or from records. Relating time of birth to a register of local historical events is one approach

that has been used with some success.

Surveying

Dementia can be diagnosed using one or two stage methods. In the two stage method a brief screening instrument (mini-mental state examination, MMSE) is used quickly and economically to identify most non-cases, leaving a smaller group with a high probability of dementia who will need a second more detailed assessment. In the one stage method a comprehensive dementia diagnostic package is administered to every subject in the survey. Existing instruments have generally been written in English and validated in a few developed countries. Before using an instrument for the first time in a new setting you will need to check its validity by asking some questions:

1 Does an adequate translation into your local language already exist?

If not, you will need to have it translated from English into your language, and then, independently, back-translated into English again. Comparison of the original and back-translated English versions will tell you if your translation is accurate.

2 Are the concepts covered in the instrument appropriate to your local culture?

For example, questions in the commonly used MMSE may have little relevance to an older person living in a rural area in a developing country. Accordingly they lack discriminating power. Subjects can commonly identify a watch, but not a pen if they cannot write. Culture and education fair screening instruments generally exclude items that test arithmetical

ability or require reading or writing skills. Items from existing instruments can be adapted to the different cultural circumstances or new instruments can be devised. One promising development has been asking a suitably qualified individual (ie a family member) about the decline in functional ability (cooking, cleaning, handling money, looking after themselves). This approach has been shown in many different cultures to be at least as effective as cognitive testing and also seems to be free of educational bias.

The conceptual validity of instruments can be tested by presenting them to a discussion group (focus group) of six to eight 'normal' older people, who will go through them item by item commenting on their perception of their meaning and of their relevance to people such as them. A simple technique such as this can help avoid costly errors in the main study. Some investigators will also use focus groups of community leaders and health professionals.

3 Does the instrument match up with the clinician's diagnosis?

A pilot study may be needed to test the performance of the translated and modified instrument against the 'gold standard' of a local clinician's carefully formulated diagnosis, before the instrument is used in the main field survey. A simple design would be for the clinician to confirm presence or absence of dementia in 30 people with moderate dementia living in the community and 30 people with low education but free of dementia. The study instruments would then be administered by an investigator who was 'blind' to the clinician's diagnosis. The instruments should be capable of discriminating adequately between the two groups.

Alzheimer's Disease International would like to thank Dr Martin Prince for his help in preparing this factsheet.



Alzheimer's Disease International

For more information about Alzheimer's disease and Alzheimer's Disease International, contact:
 Alzheimer's Disease International
 64 Great Suffolk Street
 London SE1 0BL
 Tel: +44 (0)20 7981 0880
 Fax: +44 (0)20 7928 2357
 Email: info@alz.co.uk
 Web: www.alz.co.uk