

Inclusive Research



Older people with dementia can participate in various artistic projects. However, there is still a lack of information on how to design such projects.

Research can be a crucial key to the successful development of these projects, as it can identify the needs of the intended users and evaluate the overall objectives. In this context, it is essential to take into account the perspectives of people with dementia, who are also an increasingly ethnically and culturally diverse group. This is due to the growing ageing population of people with a migration background in Europe. Omitting them from research not only goes against their capabilities, but is also a denial of this diversity.

When looking more specifically at the representation in research of people with a migration background and a diagnosis of dementia, there appears to be insufficient data. An inclusive approach is not straightforward. For example, ethnic-cultural minorities appear to have had bad experiences with research in the past, such as unequal access to information about the research process, which can result in little trust in researchers. Sometimes there is also a cultural taboo around certain research topics such as dementia itself.

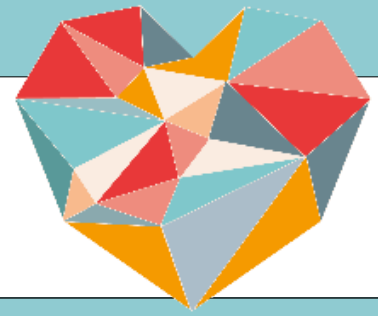
In general, research requires careful preparation and execution. To include older people with dementia (with or without a migration background) in research, the research team must take conscious actions to make participation as easy as possible. For example, avoid turnover in the team and provide additional inbuilt time to allow for flexibility at the time of engagement.

Overall, doing research takes time and resources, and so it is in this case.

The following tips can therefore help to guarantee the inclusion and retention of an older person with dementia and a migration background in research. However, a “one-size-fits-all” approach should be avoided at all costs, as every person is unique.



6 Research tips when involving older people with dementia and a migration background



Gatekeepers

Involve key figures and reliable networks to recruit and retain people with dementia. Children of older people with dementia appear to be important persons in determining participation in research. Engaging proxies can also become a primary source of data when there is a loss in the ability to communicate.



Sustainable relationships

Invest in a sincere relationship of trust when engaging older people with dementia. So, consider them not as an instrument to achieve the research goal. Reciprocity is key in this relationship to avoid a sense of being abused. Ensure a visible win-win that is genuine and responds to a real need, such as contributing to the improvement of care.



Communication

Communication must be transparent. Use appropriate methods of communication. For example, give a verbal explanation (face-to-face), but also leave a flyer with a recognisable image. Pay attention to (non-)verbal elements and do not use only biomedical terms for disorders to reduce the distance in communication.



Qualitative research

A qualitative research approach is central, but think beyond the classic research paradigm and associated data collection methods. For example, go for a verbally recorded informed consent instead of the well-known written one, or choose alternative creative ways of data collection such as participatory observations.



Ethnic matching

Involve bi-cultural and bilingual researchers in the team to avoid social disconnection with the research participants. However, presumed proximity based on shared ethnicity may lead to other factors (e.g. social class) being overlooked, which in turn creates a distance. So, don't approach the research participants in a one-dimensional way and keep thinking of ways to approach intersectional differences.



Researcher positionality

In inclusive research, reflexivity and positionality are central and closely linked. In addition to knowing the position of the target group and possible sensitivities, researchers need to reflect on their own position within this shared context. Researchers may need to expand their cultural awareness and sensitivity and cultural competence. Lack of awareness of one's own positionality can affect the research process.

Sources:

- Alzheimer Europe. (2019). *Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research*. Author.
- Berdai-Chaouni, S., Claeys, A., & De Donder, L. (2018). How to (qualitatively) involve older people with dementia and their informal carers with a migration background in research? Insights from a longitudinal project in Brussels. *Proceedings from the European Congress of Qualitative Inquiry*, 63-71

