

# Assessment of Dementia in minority ethnic groups in Europe – A 14-year follow-up survey

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## Barriers in access to dementia care in minority ethnic groups

- Barriers in access to dementia care in minority ethnic groups have been recognized in the past decades.
- Issues concerning dementia in migrants and minority ethnic groups are now addressed in several national dementia plans and European national dementia care guidelines.
- Dedicated policies at the national or international level are still lacking.
- There is no European consensus on good clinical practice for timely diagnosis and culturally appropriate care of people with dementia from minority ethnic groups.



Gove et al., 2020; Kenning et al., 2017; Nielsen et al., 2020; Canevelli et al., 2021; Schmachtenberg et al., 2020a; 2020b



## 14-year follow-up survey in the European Alzheimer's Disease Consortium

- Despite significant advances in culture-sensitive dementia diagnostics and care, little is known about how this has been implemented in clinical practice or whether challenges have changed.
- **Aims:** To explore current practices for assessing dementia in patients from minority ethnic groups in Europe and determine if barriers in access to dementia services had changed since 2009.



Gove et al., 2020; Kenning et al., 2017; Nielsen et al., 2020; 2022; 2025; Franzen et al., 2023

## 14-year follow-up survey in the European Alzheimer's Disease Consortium

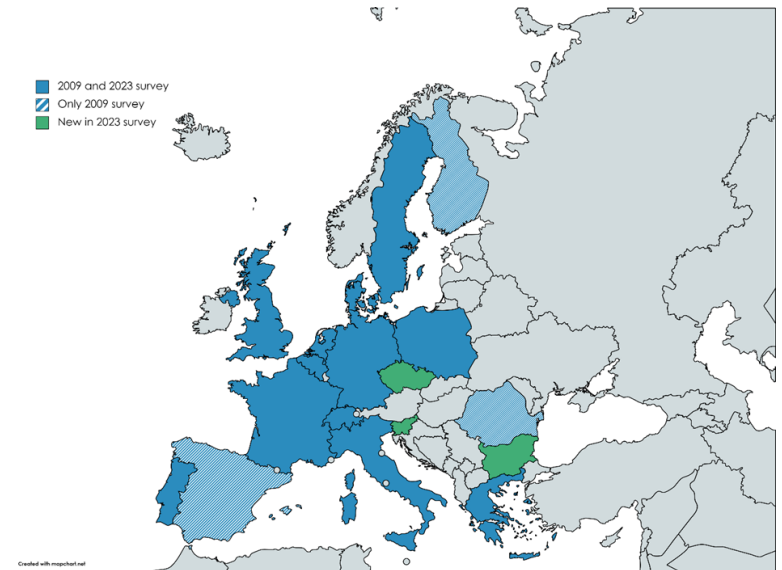
- Cross-sectional survey of members of the EADC utilizing the same questionnaire as in the 2009 survey.
  - Exclusion of questions concerning the diagnostic workup in patients from minority ethnic groups.
  - Addition of new questions concerning neuropsychological assessment and perceived challenges in diagnosing specific cognitive disorders.
- The revised questionnaire was converted into an online survey using SurveyXact ([www.surveyxact.dk](http://www.surveyxact.dk))

### **Definition of patients from minority ethnic groups:**

Patients who were first generation immigrants or refugees from countries outside the extended European Union (EU), Canada, United States of America, Australia, and New Zealand.

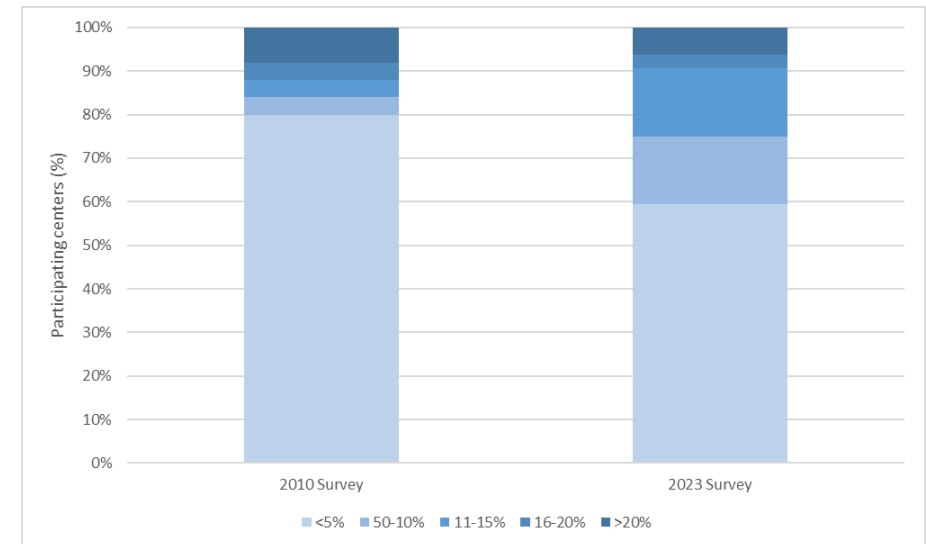
## Participants

- Survey completed in August 2023.
- In total 33 EADC centers from 15 countries completed the full survey were included in the analyses.
- Participating centers in the 2009 and 2023 surveys were comparable in their organization and service delivery (all  $p > .05$ ).
  - Representation of medical specialties
  - Number of referred patients
  - Proportion of patients diagnosed with dementia
  - Service coverage



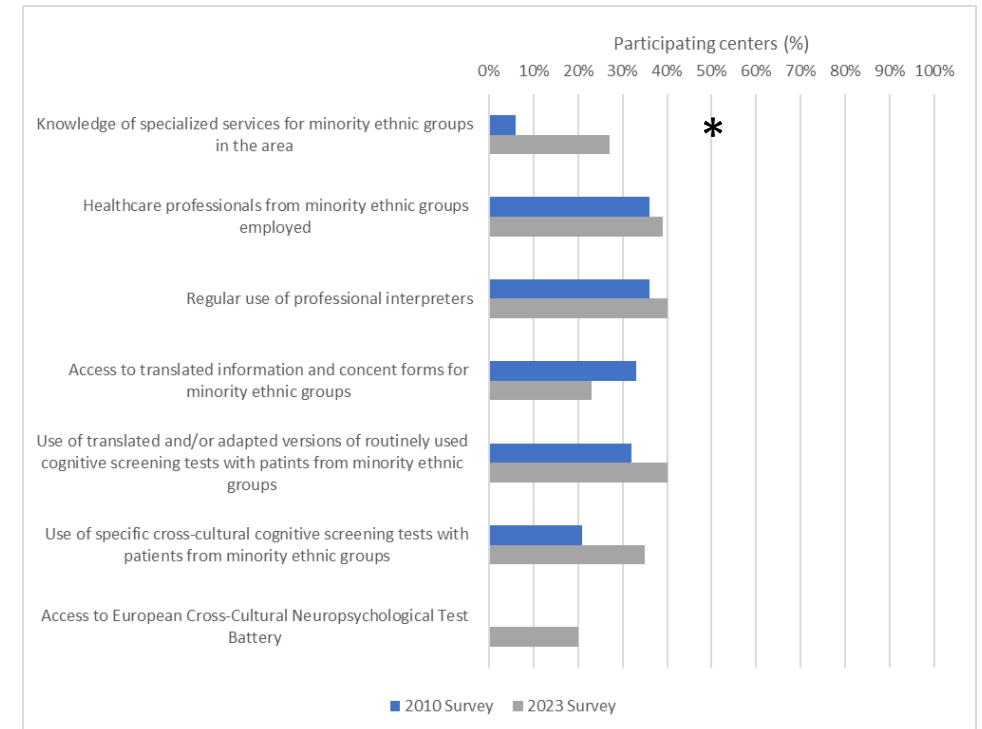
## Referrals of patients from minority ethnic groups

- An increasing number of patients from minority ethnic groups were referred for assessment of dementia ( $p = .04$ )
  - 2009: 69%
  - 2023: 91%
- Most common minority ethnic groups: Immigrants from Middle Eastern and North African countries, and from non-EU East European countries.
- There was a trend that more patients from minority ethnic groups were diagnosed with dementia ( $p = .08$ ).



## Indicators of culture-sensitive dementia services

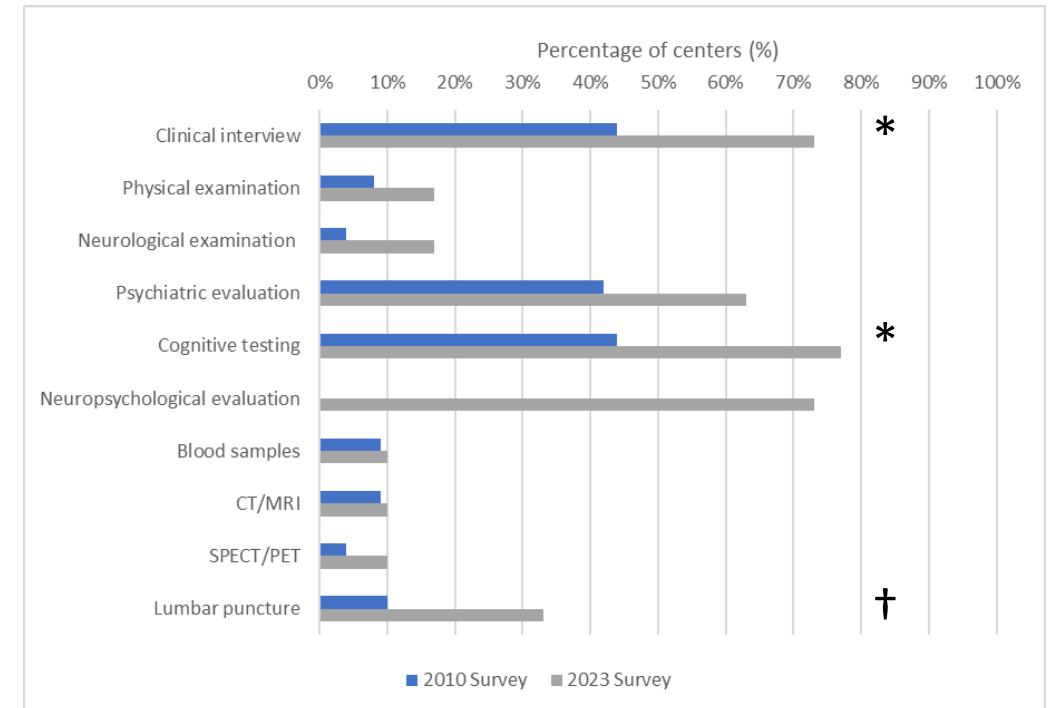
- Indicators of culture sensitive dementia services had generally not changed much since 2009.
- 90% reported regularly relying on family members for interpretation, 40% on professional interpreters, and 33% on bilingual staff members.
- Professional interpreter services were freely available to patients in 60% of the centers, with some costs in 10%, and were generally unavailable in 26% of the centers.



Nielsen et al., 2025

## Perceived challenges in assessment of dementia in minority ethnic groups

- Generally, the perceived influence of patients' minority ethnic background on diagnostic procedures had increased since 2009.

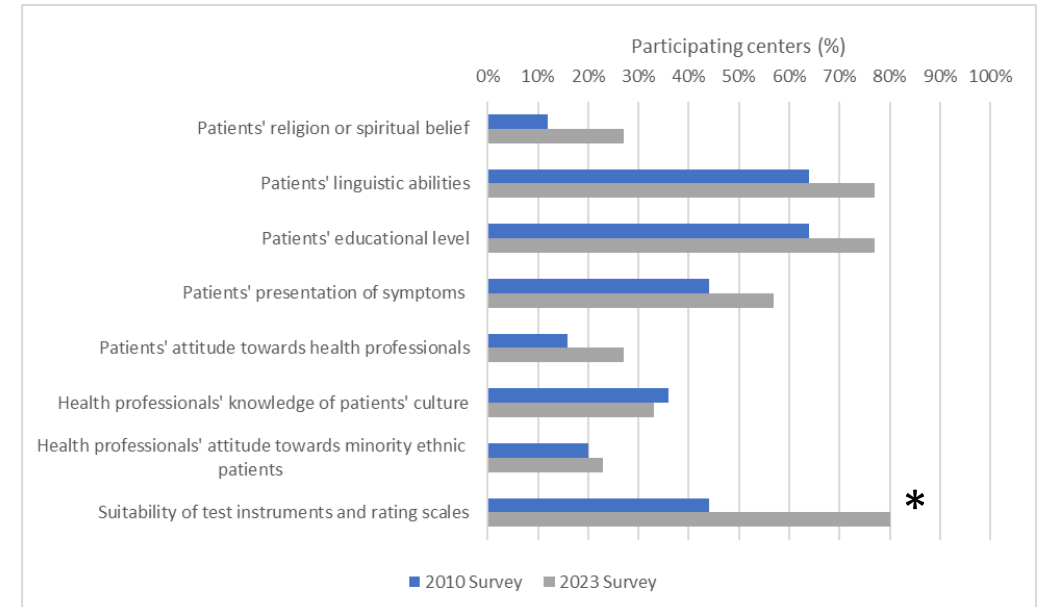


\*  $p < .05$ ; †  $.05 < p < .10$

Nielsen et al., 2025

## Perceived challenges in assessment of dementia in minority ethnic groups

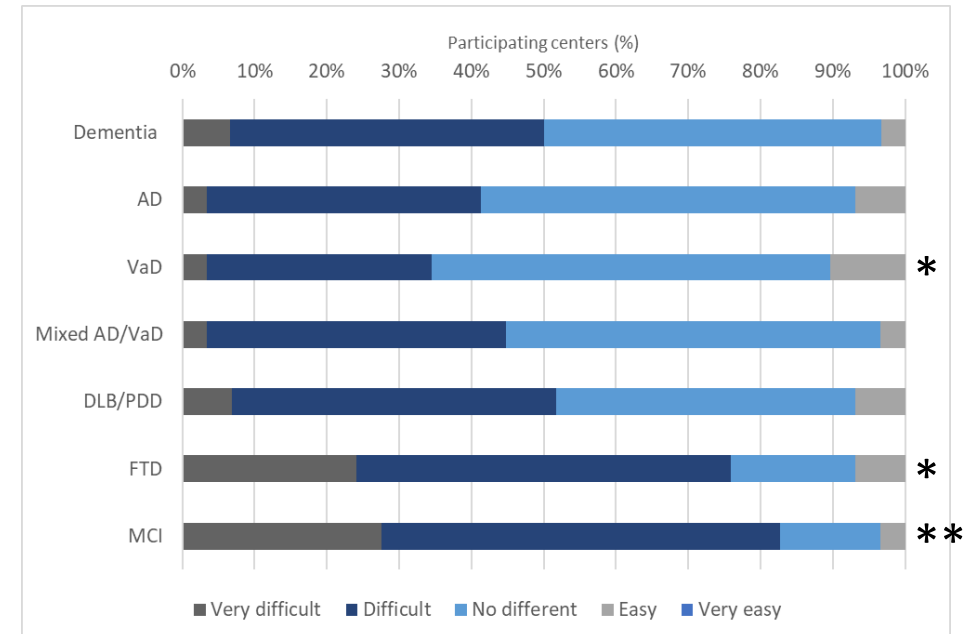
- Generally, more centers reported specific challenging issues in the clinical assessment of patients from minority ethnic groups.
- More centers found their skills in assessing dementia in patients from minority ethnic groups to be good:
  - 2009: 48%
  - 2023: 70%
- Less centers found assessment of dementia in patients from minority ethnic groups to be challenging:
  - 2009: 64%
  - 2023: 50%



\*  $p < .05$

## Perceived challenges in diagnosing specific cognitive disorders

- Despite the general improvements in assessing dementia (of any cause) in patients from minority ethnic groups, centers found it:
  - More challenging to assess FTD and MCI.
  - Less challenging to assess VaD.



\*  $p < .05$ ; \*\*  $p < .01$

Nielsen et al., 2025

## Barriers in access to dementia care in minority ethnic groups

- There appears to have been a shift, with perceived clinical expertise increasing, alongside a reported increase in referrals of patients from minority ethnic groups.
- However, **communication problems** and **lack of adequate assessment tools** remained to be the main barriers in diagnostic assessment of dementia in minority ethnic groups.
- This highlights the continued need to implement effective strategies for bypassing cultural and linguistic barriers.

BOX 1 | Recommendations for assessing patients from minority ethnic groups.

Healthcare workers responsible for assessing and diagnosing dementia in patients from minority ethnic groups should:

- be attentive to and address individual, interpersonal, and organizational level discrimination against people from minority ethnic groups within their services.
- ensure that patients from minority ethnic groups are assessed and diagnosed in their preferred language. This includes familiarizing themselves with their services' mechanisms for requesting and reimbursing interpreters and engaging formal interpreters when possible. Relatives should generally not be asked to act as interpreters.
- have training in cultural awareness, sensitivity, and competence to ensure effective communication. Such competences include identifying cultural and religious beliefs, and paying attention to cultural differences in communication styles, and potential signs of distress, during clinical assessments.
- use culturally sensitive and appropriately validated assessment and diagnostic instruments, administered with the help of formal interpreters when needed. This includes cross-cultural cognitive instruments, such as the Rowland Universal Dementia Assessment Scale, European Cross-Cultural Neuropsychological Test Battery, or other cross-culturally validated instruments.
- ensure that detailed information about the procedure and the probability of experiencing adverse events is provided and understood when obtaining consent to paraclinical procedures, especially in relation to invasive procedures such as brain scans with tracers and lumbar punctures. This may be facilitated by providing translated information and consent materials.

Nielsen et al., 2025

## Collaborators



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VELUX FONDEN



# Thank you for your attention

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