Received: 20 November 2023 | Accepted: 19 April 2024

DOI: 10.1002/gps.6096

RESEARCH ARTICLE

International Journal of Geriatric Psychiatry WILEY

The landscape of inequalities in dementia across Europe: First insights from the INTERDEM taskforce

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Abstract

Background: Getting a diagnosis of dementia does not equate to equitable access to care. People with dementia and unpaid carers face many barriers to care, which can vary within, and across, different countries and cultures. With little evidence across different countries, the aim of this scoping exercise was to identify the different and similar types of inequalities in dementia across Europe, and provide recommendations for addressing these.

Methods: We conducted a brief online survey with INTERDEM and INTERDEM Academy members across Europe, and with members of Alzheimer Europe's European Working Group of People with Dementia and Carers in February and March 2023. Members were asked about whether inequalities in dementia care existed within their country; if yes, to highlight three key inequalities. Responses on barriers were coded into groups, and frequencies of inequalities were calculated. Highlighted inequalities were discussed and prioritised at face-to-face and virtual consensus meetings in England, Ireland, Italy, and Poland, involving people with dementia, unpaid carers, health and social care providers, and non-profit organisations.

Results: Forty-nine academics, PhD students, people with dementia and unpaid carers from 10 countries (Belgium, Denmark, Germany, Greece, Ireland, Italy, Poland, Malta, Netherlands, UK) completed the survey. The most frequently identified inequalities focused on unawareness and lack of information, higher level system issues (i.e. lack of communication among care professionals), lack of service suitability, and stigma. Other barriers included workforce training and knowledge, financial costs, culture and language, lack of single-point-of-contact person, age, and living location/postcode lottery. There was general consensus among people living dementia and care providers of unawareness as a key barrier in different European countries, with varied priorities in Ireland depending on geographical location.

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Funding information
National Institute for Health and Care Research

Conclusions: These findings provide a first insight on dementia inequalities across Europe, generate cross-country learnings on how to address these inequalities in dementia, and can underpin further solution-focused research that informs policy and key decision makers to implement changes.

KEYWORDS
dementia, inequalities

Key points

- There are numerous similar barriers to accessing dementia care across different European countries.
- Some of the key challenges to equitable dementia care are lack of workforce knowledge, lack of information, stigma, financial barriers, and lack of communication among care professionals.
- Cultural challenges, postcode lottery, and service suitability were also raised as key barriers to dementia care.

1 | INTRODUCTION

Across Europe, nearly 10 million people are living with dementia, based on the latest records and estimates.[1] Dementia symptoms range from cognitive deficits and problems with initiating and performing everyday activities, to behavioural, speech, and motor difficulties.[2,3] Given that the majority of people with dementia wish to remain living at home, and with increased levels of dependency throughout the condition, people living with dementia need to access post-diagnostic care and support within the community. This can include information provision, psychological therapy, health care, peer support groups, paid home care, day care, and respite care, and at some point, residential long-term care. These services may vary in availability, accessibility, format and usage both within and between countries across Europe,[4] with some people from certain cultures preferring to care for their relative with dementia within the family as opposed to utilising external support such as home carers or residential long-term care.[5]

The World Health Organisation (WHO) defines 'health inequalities' as, '*disruptions of health determinants between different population groups*' (The[6]). 'Equity' is further described as the absence of avoidable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically (The WHO, 2017). Therefore, in order to achieve equitable healthcare, conflicting inequalities must first be identified and tackled. Health inequalities are systematic, unfair, socially produced, and thus, modifiable.[7] Health inequalities differ from 'variations' in health, which are explained by the natural ageing process, genetics or luck.[7] Therefore, developing symptoms of dementia is not in itself an inequality, but experiencing adversities as a result of a dementia diagnosis can be described as a health inequality.

The Marmot Review in[8] (Marmot) succeeded the earlier Black report,[9,10] which concluded that inequalities were not attributable to failings in the healthcare system, but instead, to the social inequalities influencing health (e.g. income, education, housing etc.). This later report further considered psychosocial factors, including the uneven distribution of resources resulting in psychological perceptions of inequalities, in addition to the aforementioned material conditions of health.[11] Therefore, when considering health inequalities affecting people diagnosed with dementia and/or their carers, researchers must consider the many (material and psychological) barriers that this group of people face, where these barriers can be deemed unfair and avoidable.

In addition to availability of services, or a lack thereof, people living with dementia and their carers may face many barriers when trying to access care and support services. These involve cultural, financial, and geographical barriers, availability of an unpaid carer, age, gender, dementia subtype, and lack of healthcare professional knowledge about dementia.[12–15] Coming from a minority ethnic background or a specific non-White ethnic background is often linked to increased levels of stigma and lack of awareness of dementia, and difficulties in finding suitable services that cater to the cultural needs.[12,16] Living in more rural locations is often linked to reduced suitable service availability, which can be a particular difficulty for people living with or caring for someone with a rarer subtype of dementia, such as Lewy Body, Parkinson's Disease, or semantic dementia.[17] Lacking the necessary finances to pay for care can also be a substantial barrier, despite means-tested support, with additionally little to no guidance available on how to plan for or pay for future dementia care.[18] A recent systematic review explored the evidence base on inequalities in accessing and using community-based social care for dementia, and synthesised evidence from 39 studies from 23 countries, highlighting five themes of situational (including economic factors), psychological (including carer beliefs), interpersonal (referring to relationships between people with dementia and carers, and support systems), structural (including lack of awareness of services), and cultural factors (including language barriers and stigma).[15] The review highlighted how people living with dementia experience multiple barriers when trying to access community-based care, and that a multi-faceted approach to providing improved access needs to be taken.

More recently, and amplified by the COVID-19 pandemic, digital inequalities can also preclude people living with dementia and unpaid carers from accessing the right support. Whilst digitally mediated support can yield benefits for some people with dementia,[19,20] others have reported that digitalised support services are unsuitable, of poor quality, and exclusive to those with ready access to the internet and digital devices.[21] In addition, digital technologies are often not designed with people living with dementia in mind, resulting in interfaces that are cognitively and/or physically demanding for this group.[22,23] As a consequence of these challenges, carers are likely to support the digital engagement of people living with dementia.[24] However, this adds to the already heavy workload of many carers and assumes they have the digital skills and knowledge required to fully benefit from digitised services.[25–27] There is therefore pressing need for targeted interventions that enable people with dementia and carers from any background to access support, to prevent existing inequalities and the 'digital divide' being exacerbated by the increasing digitisation of dementia care.[21,23,28]

Inequalities in dementia care tend to be explored in individual countries and often without an intersectionality approach, thereby focusing on a single specific potential barrier to care, such as age, ethnicity, or rural/urban living location.[18] Kerpershoek et al.[29] however provided one of the first cross-European analysis (Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden, UK) of inequalities in accessing dementia care, by collecting data from over 450 people living with dementia and their carers. Whilst Kerpershoek et al.[29] reported some variation in equity to dementia care across Europe, findings were based on a North/South comparison and failed to include other key factors often contributing to equity, such as ethnicity, socio-economic background, dementia subtype, and digital literacy.

Thus, with little evidence across different European countries, the aim of this evaluation was to identify the different and similar types of inequalities in dementia across Europe from academic, lived experience, and care provider points of views, and provide recommendations for addressing these. Findings will provide guidance for policy and decision makers to address unequal access to dementia care across Europe.

2 | METHODS

2.1 | Taskforce

INTERDEM is a pan-European network of dementia care researchers, which has seven taskforces focused on specific topic areas, including assistive technology, palliative and end of life care, and social health. This INTERDEM Taskforce focuses on inequalities in dementia care, and aims to bring together researchers, lived experts, and practitioners in the field across Europe to conduct research and inform policy on addressing system-, community-, and individual-level barriers in access to dementia care. At the point of writing, eight countries across Europe are members of the Taskforce (Denmark, Germany, Ireland, Italy, Netherlands, Poland, Portugal, UK) as well as Alzheimer Europe. The Taskforce is open to any new researchers in the field of dementia and inequalities who are interested in joining via INTERDEM. The Taskforce meets to discuss other ongoing research in the field led by Taskforce members, identify opportunities for joint research and policy recommendations, and underpinning this create a network of researchers, non-profit organisations, and those with lived experience (people living with dementia and unpaid carers) to address inequalities in dementia.

Based on discussions within the Taskforce and acknowledgement of a lack of pan-European insights into inequalities in dementia care the first joint task of the group was to conduct an online survey exercise and consensus discussions about current key barriers to dementia care across different European countries.

2.2 | Survey

A brief survey was designed by CG and KH using Google Forms to enquire about inequalities in dementia care across different European countries. The survey lasted approximately 10 min and asked participants to state whether there is sufficient dementia care; up to three key inequalities and barriers to dementia care; and whether research into dementia care influences policy in their respective country (see Appendix I for full questions). The survey was sent out online to INTERDEM members (academics working in dementia for over three years); INTERDEM Academy members (junior dementia academics and students); as well as members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) between February and March 2023. The survey was amended in order to make it more relevant and accessible to the members of the EWGPWD and EDCWG and administered by email. For members of the EWGPWD and EDCWG, responses were collected and collated by Alzheimer Europe in the context of ongoing public involvement work with these two groups. The survey was sent out via the INTERDEM and INTERDEM Academy regular newsletter, via social media, and via established INTERDEM connections.

Open-ended statements on barriers were categorised into barriers by one researcher (CG), and checked over by the second researcher (KH).

No ethics approval was required as this opinion survey asked INTERDEM academics about their academic experiences of dementia inequalities, with no personal data being collected.

2.3 | Consensus meetings

After the survey, remote and face-to-face consensus meetings in four countries (England, Ireland, Italy, Poland) were conducted to (1) discuss and possibly prioritise key inequalities as identified via the survey; and (2) discuss potential solutions to address those inequalities. Consensus meetings involved people living with dementia, unpaid carers, health and social care professionals, and Third Sector organisations. Meetings involved up to 14 attendees, with each facilitator taking anonymised summary notes of discussions.

Given the fact that no identifiable personal data or quotes were collected from the consensus meetings, which were held as public engagement consultation events, no ethics were required in England, Ireland, and Poland. In Italy, we received ethics approval from the Bioethics committee at the University of Bologna prior to the consensus meeting [0209059].

2.4 | Public and stakeholder involvement

This Taskforce and this evaluation involve the 3-UK-nation Alzheimer's Society (England, Wales, Northern Ireland), Alzheimer Europe's EWGPWD and EDCWG, and Rare Dementia Support. This allows us to draw upon the personal experiences and expertise of people living with dementia and unpaid carers across Europe, ensuring the voices of people affected by dementia from different countries are heard and help to contextualise the findings.

3 | RESULTS

3.1 | INTERDEM and INTERDEM academy survey

A total of 49 stakeholders completed the survey, comprising of academics, PhD students, people living with dementia and unpaid carers from 10 countries (Belgium, Denmark, Germany, Greece, Ireland, Italy, Poland, Malta, Netherlands, UK) completed the survey. There were five missing fields, thus a total of 142 answers were included. These open-text answers were categorised into 27 different barriers (see Table 1).

The most frequently identified inequalities focused on unawareness and lack of information about dementia (n = 18), higher level system issues (i.e. lack of communication among care professionals) (n = 15), lack of service suitability (n = 10), and stigma (n = 10). Other barriers included workforce training and knowledge, financial costs, culture and language, lack of contact person, age, and living location/postcode lottery.

TABLE 1 Frequency of inequalities stated in survey.

Codes	Frequency
Unawareness	18
Higher level system	15
Service suitability	10
Stigma	10
Culture & language	8
Health and mental health access	8
Workforce	8
Financial costs	7
Lack of available services	7
Living location/postcode lottery	7
Lack of unpaid carer support	5
Lack of access	4
Lack of contact person	4
Age	3
Lack of funding	3
Lack of personalised care	3
Suitable services	3
Diagnosis	2
Poor quality care	2
Specific conditions	2
Acceptance	1
Illiteracy	2
Lack of pharma treatment	1
Lack of support material	1
Personal barrier	1
Policy issues	1
Transport	1

3.2 | Consensus meetings

A total of 55 people with dementia, unpaid carers, health and social care professionals, and Third Sector representatives participated in remote and in-person consensus meetings in England (n = 21), Ireland (n = 9), Italy (n = 11), and Poland (n = 14). Most attendees were people with dementia or carers (n = 35), followed by health and social care professionals including psychiatrists, physiotherapists, social workers, psychologists, and case managers (n = 18), and Third Sector representatives (n = 2).

4 | OVERALL SUMMARY OF JOINT KEY HIGHLIGHTS

4.1 | Barriers

The consensus meetings conducted in Italy, Poland and the UK all identified a **lack of awareness** as the key barrier to accessing dementia care and support. This could include public and professionals' awareness, both of dementia and its symptoms, different types of dementia and also the different services and support options available to people affected and the pathways to access these.

Funding was another key issue identified as creating a barrier to accessing appropriate care across consensus meetings in Italy, Poland and the UK. This was a barrier at multiple levels - in terms of how dementia care, research and treatments were prioritised politically for funding, and how this fed down to the individual level with families struggling to access financial support and experiencing significant costs themselves when trying to get appropriate care in place.

Difficulty getting a timely or accurate **diagnosis** was another joint key challenge that had implications for accessing appropriate care and support. This was related to a lack of awareness and knowledge among GPs, as well as lack of communication between different professionals, and was particularly exacerbated by lesser known symptoms and rarer types of dementia (e.g. behavioural symptoms, young-onset dementia).

This lack of knowledge and communication among the **workforce** was another jointly identified barrier to accessing support, and participants across all consensus meetings also expressed that the size of the workforce was lacking. This was described as being due in part to funding, but - particularly regarding care workers - also due to the conceptualisation and valuation of care work and lack of incentives to pursue this kind of work. Participants felt care workers were not valued as highly as they should be and as such, were not invested in as much as they should be (e.g. with training and resources) to enable them to deliver the highly skilled and sensitive work that dementia-caring is.

In all consensus meetings a **lack of suitable services** was identified, though this was due to different reasons in the different nations. For example, consensus meetings in Italy highlighted a lack of a family-centred approach to dementia care which would support the family of the person affected throughout the dementia, and a particular lack of services suitable for people with young onset dementia. In Poland, high quality and suitable services often existed in cities but a lack of knowledge of them limited access. In rural areas in Poland, service unsuitability was very pronounced with the only services available often being community groups (e.g. in local churches) designed for those who were cognitively well. In the UK, a lack of services suitable for people with rarer types of dementia which are often associated with atypical symptoms (e.g. visual, language or behavioural changes) and young age of onset (e.g. employment challenges) was particularly highlighted.

4.2 | Solutions

The consensus meetings suggested that having a **key contact person** to join people up with services and support, along with care pathways (i.e. **higher-level systems**) that were streamlined would greatly improve access to care. Increased **funding and economic support** at multiple levels (for individuals and families, the workforce and at the societal level e.g. allocating dementia funding proportionately in terms of need) was also outlined as a key factor that would help to reduce barriers. The **provision of suitable services** tailored to specific needs, including those which would ensure an accurate and timely **diagnosis**, and improved regulation to ensure the quality of care were also highlighted as areas for improvement. **Increased knowledge and awareness** of dementia generally, but also of the different symptoms and needs associated with different types, were seen as critical for service development and to improve access to appropriate care. Improving knowledge and awareness at the local level too were identified as barriers that could start to be dismantled.

4.3 | Highlights by country

4.3.1 | England

Despite England's diversity in terms of **culture and language,** it was discussed that many of these groups are underrepresented in support services due to facing specific barriers to accessing dementia care (e.g. lack of an appropriate interpreter for assessments and appointments). **Poor quality care** was another key factor raised across the consensus meetings. This seemed to stem from a lack of awareness and appropriate training for care workers on the specific symptoms and needs associated with rarer forms of dementia. Dignity and empathy were often not prioritised, in addition to a lack of continuity within the care delivery. It was also felt that there is a specific **lack of unpaid carer support** characterised by a lack of financial support, recognition and support to navigate often convoluted systems to access timely and appropriate support. These challenges in accessing support and navigating services were experienced by individuals with dementia advocating for themselves too. Not having the means to self-advocate, or people advocating on your behalf, was seen as another concerning barrier. Finally, a **postcode lottery,** with particular challenges for those in remote and rural areas, was identified in relation to service availability, significantly impacting the care and support people in different parts of the country can access.

4.3.2 | Ireland

Attendees at the Irish consensus meeting struggled to agree on prioritised inequalities due to different key barriers experienced by geographical location (rural/urban/within urban). For health and social care professionals, geographical location impacted on the resources available. However, a common consensus was that services were often found to be inappropriate and not person-centred.

4.3.3 | Italy

The Italian consensus meeting highlighted particular **higher-level system** issues including the integration of service and communication between these as particular barriers to accessing care in the country. Broader **access to general health services** (such as the emergency room and hospital) were also highlighted as a specific barrier to dementia care in Italy. **Age** and **stigma** were also highlighted as factors preventing access to appropriate care and support in Italy, particularly relating to young onset dementia.

4.3.4 | Poland

A country-specific **lack of available services** was highlighted in Poland, for example, with 3-day care centres for dementia across the whole of Wroclaw (>600,000 inhabitants). **Geographical disparity** was another key issue highlighted in this country, with a 'stark divide' in care provision across the rural versus urban areas of the country. This was seen as exacerbated by **policy** issues such as a lack of a national dementia strategy. The anticipated changes to the **cultural and linguistic** homogeneity of Poland with recent migration from Ukraine could raise this as a potential emerging determinant of unequal access to care across the country.

5 | DISCUSSION

This INTERDEM Taskforce offers a unique European network to investigate and find solutions to dementia inequalities in diagnosis and care. Facilitated by the Taskforce, this survey and consensus meetings have highlighted the myriad of barriers which people with dementia and their unpaid carers often face, and how similar these issues were across different European countries. These included unawareness of dementia and services, finances, service unsuitability, lack of contact person, postcode lottery, geographical barriers, cultural and ethnic barriers, as well as dementia subtype. It is important to note that these inequalities were not experienced in silo, but were intersectional and affected people with dementia and their families on various levels.

Unawareness emerged as a key barrier for people with dementia and their families to accessing care after a diagnosis. This included lack of awareness of services and information, of support infrastructure and financial support systems, and of health and social care professionals. One identified solution in the consensus meetings was to have one single contact person after the diagnosis, which was expressed across different countries. This corroborates findings from an eight-country European study[14] and from a Dutch-England study on facilitators and barriers to dementia care,[21] for example, Having interviewed 85 people with dementia and their unpaid carers, [14] showed that having sufficient information about the dementia and care, a single point of contact, and a supportive social network are crucial for accessing formal support, whilst [21] found that the Netherlands provided a key facilitator to navigating the dementia care pathway and system after a diagnosis—via a Dementia Care Navigator. This role is not evidenced throughout England, with one grey literature report highlighting the effectiveness of the service in the North East of England.[30] A recent systematic review on the role interestingly only identified published evidence in the US,[15] with six models of Dementia Care Navigator services identified and reported on across different US states. The role promises effective support for people with dementia and carers to navigate them to support organisations, provide information, and social support.[31–33] Thus, a single point of contact after the diagnosis that can circumnavigate the dementia care system appears to be strongly supported and needed solution to reducing access inequalities.

Lack of workforce training and knowledge was also raised as a substantial barrier to engaging with services after a diagnosis. This reflects limited previous evidence on the lack of workforce knowledge about dementia, including in home care staff in Australia.[34] Available training courses show mixed levels of content and effectiveness in improving workforce knowledge, as evidenced from a regional- and locality-based programme,[35] a lack of content in workforce training across a region in England at NHS Trusts and social care,[36] and from using the Dementia Champions training in Scotland.[37] By interacting with people with dementia and carers as part of the programme, qualified health and social care professionals improved their knowledge about dementia and approached their care delivery differently and were more engaged. Moreover, the Time for Dementia programme with UK medical students, involving engagement with people with dementia and carers also showed positive outcomes on the student workforce.[38] These examples show how valuable it is to involve people affected by a condition, in this case dementia, in the delivery of topic-specific education, and could be used as a potential approach for tackling lack of workforce knowledge across Europe.

The lack of workforce knowledge can be linked to a further barrier raised by many respondents, which focused on the lack of integration between health and social care systems and a lack of communication between those sectors. Once a diagnosis is made by a health care professional, people with dementia and unpaid carers are often left without sufficient information about the dementia and how to navigate the care pathway, without being passed on to a non-health care professional for guidance. This is also, in England, Wales, and Northern Ireland, captured poignantly by a recent Alzheimer's Society report (2022) on unmet post-diagnostic support needs, leaving the person with dementia and their carer often left to cope alone. This can lead many people to seek help from non-profit organisations, placing further burden on the voluntary sector as opposed to the often underpaid and under-supported health and social care workforce.[39] One solution is Dementia Care Navigators embedded in primary care, or referred to from primary care. Dementia Care Navigators appear to bridge health and social care effectively in the Netherlands, with limited evidence on their effectiveness in England.[21]

Location was also found to be a notable barrier to accessing dementia care across different European countries. This included living in rural as opposed to urban areas, but also a postcode lottery in terms of living in specific areas within a city, or streets. Specifically, discussions at the Irish and Polish consensus meetings highlighted variations in barriers depending on geographical location, which including different resources for health and social care professionals. This corroborates and expands previous evidence from the ActifCare cohort study, which showed that region of residence, age, and gender were significant factors linked to accessing care, besides individual's needs.[29] Specifically, people living with dementia living in the North of Europe were more likely to access care than those living in the South, which is likely linked to availability as well as care culture, and extends previous research from the 8-European-country RightTimePlaceCare study.[40] In the longitudinal follow-up study,[40] for example, noticed fewer community-to-care home transitions in Southern (Spain) and Eastern (Estonia) countries compared to Northern European countries (Finland) based on cultural attitudes. Thus, whether within a country, compared to other countries, or within a city or suburb, where people live can affect how, if, and when people with dementia and their carers access care. Service availability, access (i.e. transportation), and information about those services needs to be more equitable regardless of living location, whilst also considering the intersectionality that culture may play in the link between location and dementia care use.

Whilst this evaluation benefitted from a country diversity across Europe, as well as stakeholder diversity across the survey and consensus meetings combined, the evaluation captured opinions from academics, people with dementia, unpaid carers, health and social care professionals, and non-profit organisations from 10 European of 45 European countries. Thus, the experiences so far do not capture those from Eastern, most Southern and Northern countries, but are focused to a greater extent on Western Europe. Given different economic and cultural contexts across Europe, it is important to actively investigate barriers and potential solutions to dementia care in those regions of Europe, whilst also expanding on the regions sampled within the included countries. The consensus meeting in Italy for example, took place in the Northern part of the country, where infrastructure and cultural norms may vary from the Southern region. In addition, British consensus meetings were held in England albeit open to people living in any UK nation. Thus, evidence collected may differ significantly from other nations of the UK (Wales, Scotland, Northern Ireland), with other nations having somewhat different health and social care infrastructures. There was also a notable lack of discussion of digital inequalities, and the impact that the increased digitalisation since the COVID-19 pandemic may have on accessing care. This may not have been raised as an issue as consensus meeting attendees may have all been digitally literate. Considering that no personal information about attendees were collected, the socio-demographic makeup of the members of the public is not known. Therefore, building on this exercise, research should actively recruit stakeholders from different socio-demographic backgrounds to explore the impact of digitalisation on access to dementia care.

6 | CONCLUSIONS

People with dementia and unpaid carers across many parts of Europe face similar substantial barriers in accessing care and support. These are often interlinked, as barriers rarely appear in silo. With some potential solutions discussed in consensus meetings, evidenced by minimal published evidence to date, this European INTERDEM Taskforce exercise has identified areas of focus for future research and international cross-collaboration to identify, evidence, and test out potential solutions to improve equity in dementia care. Next steps will include a European survey to identify any existing solutions and interventions to reduce inequalities in dementia care, which could be adapted and trialled in other European countries.

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ACKNOWLEDGEMENTS

We wish to thank members of the European Working Group of People with Dementia (EWGPWD) and the European Working Group of Carers (EDCWG), and all people participating in this exercise. This is independent research funded by the National Institute for Health and Care Research Applied Research Collaboration North West Coast (ARC NWC). The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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How to cite this article: Giebel C, Harding E, Volkmer A, et al. The landscape of inequalities in dementia across Europe: first insights from the INTERDEM taskforce. *Int J Geriatr Psychiatry*. 2024;e6096. https://doi.org/10.1002/gps.6096