Dementia Research Participation and Data Sharing in Europe

Alzheimer Europe

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Contents

Glossary

AD	Alzheimer's disease
EDCWG	European Dementia Carers Working Group
EEA	European Economic Area
EMA	European Medicines Agency
EPND	European Platform for Neurodegenerative Diseases
EU	European Union
EWGPWD	European Working Group of People with Dementia
GDPR	General Data Protection Regulation
HMA	Head of Medicines Agencies
IHI	Innovative Health Initiative
MCI	Mild Cognitive Impairment
MRI	Magnetic Resonance Imaging
PET	Positron Emission Tomography

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1. Preface and summary of findings

The projected increase in the number of people living with dementia in Europe highlights the urgent need to strengthen research across all aspects of the condition, including prevention, diagnosis, treatment and care. For research to be translated into real and meaningful benefits for people with dementia and their carers, it is essential that people from diverse backgrounds are able and willing to take part. This, in turn, depends on a better understanding of what motivates people to participate, as well as the barriers that prevent them from getting involved.

At the same time, dementia research increasingly depends on large datasets as a driver of innovation. To fully realise this potential, silos need to be reduced and data shared more efficiently and responsibly. Data sharing is a complex process that involves the perspectives, expectations and concerns of many stakeholders. These include not only researchers and policy makers, but also research participants themselves, whose views are central to shaping trustworthy data sharing practices.

This report brings together insights from across the dementia research ecosystem on both research participation and data sharing. It aims to identify key challenges and enablers in these areas and to provide actionable recommendations to support more inclusive research practices and more effective data sharing. Particular emphasis is placed on the perspectives of people with lived experience of dementia, whose voices are central to shaping research that is ethical, relevant and trustworthy. It builds on previous work by Alzheimer Europe aiming to map out practical barriers to international data sharing, which has been widely cited. In light of the highly interconnected nature between the participation in research and data sharing, Alzheimer Europe felt it was necessary to build and expand on this previous work.

Key findings of this report include:

- Attitudes towards participation in dementia research and data sharing are generally positive, but opportunities to participate are unequal between and within European countries.
- Common barriers to participation include a lack of information and awareness, practical and time constraints, fear of invasive procedures, bureaucracy and concerns about negative consequences of participation.

Jean Georges

- Trust, communication and support strongly influence attitudes towards research participation. There is a need for building respectful relationships and for providing clear information and practical support.
- Data sharing is viewed as an important accelerator for dementia research, as it can lead to novel insights, prevent duplication of efforts and consequently reduce participant burden. However, data must only be shared with trusted recipients and protecting participants' privacy.
- Data sharing is broadly supported by researchers, though implementation remains difficult in practice. Specifically, fragmented data systems, complex approval procedures and inconsistent GDPR interpretation limit data linkage and reuse.

We hope that this report offers a useful overview of the issues surrounding research participation and data sharing, and that it stimulates further discussion on how dementia research can be made more accessible to everyone. This is of particular relevance in the context of the ongoing negotiations for the EU's next multiannual financial framework, for which Alzheimer Europe hopes that commitment to dementia research will be strengthened. We also hope it will encourage ongoing dialogue on improving data sharing practices and, ultimately, contribute to accelerating progress in dementia research.

Finally, we would like to thank Gates Ventures for supporting the development of this report by Alzheimer Europe. We also thank Lukas Duffner, Project Officer; Angela Bradshaw, Director for Research; Soraya Moradi-Bachiller, Public Involvement Officer; Ana Diaz-Ponce, Public Involvement Lead and Dianne Gove, Director for Public Involvement and Ethics, for their contributions. Our sincere thanks also go to the members of the European Working Group of People with Dementia and the European Dementia Carers Working Group for generously sharing their insights.

Jean Georges
Executive Director, Alzheimer Europe

1.1 Reflections by the chairperson of the European Working Group of People with Dementia

Twelve years ago, I was diagnosed with Parkinson's disease and, sometime later, with Lewy body dementia. After my diagnosis, I became involved in advocacy work and in research and I am currently Chair of Alzheimer Europe's European Working Group of People with Dementia.

Research is vital to help improve diagnosis, treatment and care. Taking part in research can make a real difference in your life for many reasons. Most importantly, the researchers are listening to our experiences, which makes us feel valued, believed and respected. That alone helps reduce stigma and reminds us that our lives and voices matter. Even more, being involved gives us the chance to help shape a future where people receiving a diagnosis can feel less afraid. Participating in research can also sometimes bring practical benefits. For example, taking part in research on hearing and vision helped me understand the importance of wearing hearing aids, which has greatly improved my quality of life.

People with dementia should be at the front and centre of everything being researched about them. Who better to ask what it is like to live with a condition than the person living with it? When we talk about participation in dementia research, it is also imperative to mention the importance of research participants being able to share their information and data when

Kevin Quaid

and where they feel comfortable and always making sure that this is done in a safe and ethical manner.

This report is crucial because it helps us understand why people take part in research and what concerns they may have. It reflects both the perspectives of people with dementia and carers. I often say that if you want to know what it is like to live with Lewy body dementia, you ask my wife, but if you want to know what it is like to have it, you ask me. Both sides are equally important.

Kevin Quaid
Chairperson of the European Working Group of People with Dementia

1.2 Reflections by the chairperson of the European Dementia Carers Working Group

I have been a carer for my wife Yvonne since 2013 when she was diagnosed with young onset Alzheimer's dementia and I am privileged to be Chair of the European Dementia Carers Working Group.

I confess I never really thought about research until my wife took part in a clinical Alzheimer's drug trial. Because her participation gave her a degree of hope, it caused me to step back and realise just how important research is in the fields of diagnosis, treatment and perhaps care too.

I'm very much aware that recent new developments in biomarkers and advances in brain imaging enable earlier and more specific diagnosis whilst the emergence of new intravenous drugs are seemingly slowing cognitive decline by removing amyloid plaque.

In tandem with research into the development of new drugs, I read about best practice studies taking place into the creation of dementia-friendly communities including care homes with an objective applauded both by people living with dementia and their carers, namely allowing for greater and longer-term independence.

As someone with a career in technology I am truly amazed and excited by the research advances in assistive technologies designed to deliver transformational and empowering improvement in the lives of people with dementia.

If research, in all its many manifestations, can help people with dementia and their carers to live more fulfilled lives then it certainly begs the question

Trevor Salomon

about sharing research data. From my perspective the sharing of anonymised or aggregated data with accredited or formally recognised research organisations carries with it far more potential benefits than risks. Collaboration should lead to faster progress, the extension of work, reduced timeframes for outcomes and better returns on funding. I appreciate there may be sensitivities in areas such as losing competitive advantage, data ownership and cross border regulations but such obstacles can surely be mitigated by applying controlled data access and sharing with conditions.

Incorporating the lived experience realities of carers in particular, but also supporters, improves both the quality and relevance of research data and its sharing: I am pleased to note this is reflected in the report.

Trevor Salomon
Chairperson of the European Dementia Carers Working Group

2. Introduction

Alzheimer Europe's recently updated report on the prevalence of dementia in Europe highlights the projected increase in the number of people living with dementia in the coming decades[1]. Given ageing populations throughout Europe, this upward trend is apparent across countries. In light of the profound emotional, societal and financial costs associated with the condition, high-quality scientific research across all facets of dementia is indispensable. Research into disease modifying therapies has resulted in an EMA-approved disease modifying treatment for early AD[2,3]. The potential for primary and secondary prevention has also become clearer[4] and studies on dementia care and psychosocial interventions have contributed to improving quality of life for those affected[5]. With new advances in blood-based biomarkers[6] and PET imaging[7], there has also been substantial progress with regards to diagnosis and early detection. Regardless of research focus, the generalisability of findings depends heavily on the representativeness of study samples. Yet recruitment into dementia research has traditionally been difficult and several groups remain underrepresented[8,9]. This includes people from ethnic minority backgrounds and individuals with more advanced dementia, but also, in studies involving healthy volunteers, those who take part tend to be healthier, more educated and more likely to live in urban rather than rural areas[10–12].

While participating in dementia research has been described as a positive and rewarding experience by participants, it can also come with a substantial investment of time and effort. In order to always ensure the well-being of research participants, a deeper understanding of experiences of the research process is valuable. This may be of particular importance in studies requiring extended periods of follow-up – and thus repeated commitment by participants. Indeed, retaining participants in such long-term studies remains challenging and differential attrition is common, with healthier individuals more likely to remain enrolled[13]. A more thorough understanding of participants' needs and experiences may help address difficulties in retaining participants over time.

Moreover, the complex and multifactorial nature of dementia requires associated challenges to be addressed through close international collaboration. In this regard, progress in the field often relies on the efficient use of collected data by researchers worldwide. Effective data sharing can reduce duplication of research efforts and lessen participant burden. Harmonising large datasets may also lead to novel insights, as individual dementia studies, particularly those using expensive methods such as PET or genetic testing, are often statistically underpowered[14,15]. Data sharing further enables the examination of the robustness and generalisability of findings across populations and can strengthen documentation and data governance practices.

Despite these advantages, data collected within dementia research studies are often not shared routinely[16]. This is partly due to a lack of harmonised procedures and data governance structures. In 2021, Alzheimer Europe published a report on barriers to data sharing across the EU, identifying and assessing relevant EU-level policies[17]. It concluded, for example, that regulatory divergence within the GDPR, and differences in its interpretation both between and within countries, may impede cross-country data sharing. Current academic structures, which reward publications and grant acquisition, further reduce incentives to share data. Financial costs and the time required for data governance activities, such as reviewing data transfer agreements, can also significantly hinder data sharing.

Under the GDPR, research participants must actively consent to the reuse and sharing of their data once a study has concluded. Alzheimer Europe's 2021 Data Sharing Report noted that "the benefit of data sharing comes with a privacy trade-off", which may reduce people's willingness to give such consent[17]. However, despite this concern, there has been limited systematic investigation into the participant-level

factors influencing willingness to share data beyond privacy-related issues.

In response to the practical challenges concerning data sharing, several initiatives have been established to promote more efficient, secure and low-cost reuse of research data. Box 1 outlines two such initiatives, EPND and the AD Data Initiative. These platform projects aim to provide secure and harmonised environments for sharing data collected in dementia research studies, thereby facilitating data reuse and collaboration.

Alzheimer's Disease Data Initiative

The AD Data Initiative is a global coalition of academic, industry, government and nonprofit partners, aiming to support and accelerate research on Alzheimer's disease and related dementias by fostering collaboration, enabling seamless access to multiple data sharing platforms and unlocking important datasets for wider use and impact. It offers researchers around the world secure data sharing and analytics tools as well as collaboration resources, all available to users at no cost.

In 2020, the AD Data Initiative launched the AD Workbench, a secure, cloud-based platform, guided by three main principles: to increase data sharing, to ease data access, and to develop new tools and analytics for researchers to use and share. With over 300 datasets currently discoverable, the AD Workbench houses a library of analytics tools and apps, whilst also providing the option for researchers to upload their own code or develop new tools within the platform. The AD Workbench also facilitates interoperability across existing data platforms, enabling researchers to discover, import, pool and analyse diverse datasets.

European Platform for Neurodegenerative Diseases (EPND)

Funded by the European Union's Innovative Medicines Initiative, the EPND consortium was established by 29 public and private partners in 2021, aiming to accelerate the discovery of diagnostics and treatment for neurodegenerative diseases by removing barriers to data and biosample sharing and fostering collaboration.

In 2024, EPND launched its technical Hub, a first-of-its kind, unified platform for discovery and sharing of datasets and biosample collections from neurodegeneration cohorts based across Europe. The EPND Hub currently includes over 100 neurodegeneration research studies, with 128 datasets and 38 biosample collections across 12 disease areas, including Alzheimer's disease, dementia with Lewy bodies and Parkinson's disease. Researchers can use the Hub to search, discover, access and share these valuable resources, with connection to the AD Workbench enabling data analysis in secure, cloud-based workspaces equipped with a growing array of advanced analytics tools and apps.

Box 1 – The AD Data Initiative and the European Platform for Neurodegenerative Diseases (EPND)

Europe's geographical and cultural diversity, along with its specific regulatory landscapes and research environments, requires a more detailed assessment of the factors that influence people's willingness to participate in dementia research and support effective data sharing both within Europe and beyond. This report presents findings from a project aimed at promoting engagement in research and the sharing of data. Throughout this work, we sought to gain a holistic view of the factors related to research participation and data sharing in the dementia field, drawing on the perspectives of a wide range of stakeholders.

Dr Niranjan Bose

> "Accessible data is essential to stopping Alzheimer's disease. This requires not only creating the right infrastructure for researchers to share their data, but also tackling practical, logistical and trust-related barriers to data sharing, ensuring that our work preserves the privacy of study participants and benefits people affected by dementia."
>
> Dr Niranjan Bose, HLS, Gates Ventures & Interim Executive Director, Alzheimer's Disease Data Initiative

Methodology used in this report

This report draws on evidence gathered through a combination of complementary sources and methods, each informing and building upon the next. First, we present the findings of a scoping review of the scientific literature examining barriers and enablers to the recruitment and retention of research participants in dementia research. This review covered a large range of research domains, including clinical studies, psychosocial research, epidemiology and registries, and provided the foundational evidence base for all subsequent components of the project. Building on the insights from the scoping review, we then developed a large-scale public opinion survey to capture views on research participation and data sharing among people in the general public across Europe. The design of this survey was also informed by contributions from people with dementia, carers and representatives of national Alzheimer's associations, ensuring its relevance and accessibility.

Public Involvement (PI) activities were carried out throughout the project following the approach to PI developed by Alzheimer Europe over the years[18–20]. These activities involved a diverse group of people (i.e. people with an interest in dementia research, people with MCI, people with dementia and supporters or carers of people with MCI or dementia) and helped to contextualise and deepen the understanding of the project's findings, while capturing their unique experiences, needs and concerns. Box 2 contains further information about the PI work. Note that in this report, the term "people affected by dementia" is used to collectively describe the range of individuals involved in the PI activities.

In addition, the report incorporates reflections from clinicians and dementia researchers working across clinical research, epidemiology and psychosocial research, as well as research funders and regulators. These perspectives provide an additional layer of interpretation and help to situate the findings within current research practice. Along with the other elements of the project, these helped generate tangible recommendations on how to facilitate the recruitment and retention of participants and data sharing practices within the dementia field. *Figure 1* contains a summary of the methodology used within this project.

Scoping review of the scientific literature into barriers and enablers to participation in dementia research

Large scale **European public opinion poll**, gathering perspectives of research participation and data sharing of the general public

Public Involvement with more than 50 people affected by dementia, including focus groups on research participation and data sharing

Stakeholder interviews with clinicians, funders, regulators and dementia researchers from clinical, epidemiological and psychosocial research

Continued input from **Alzheimer Europe member organisations** from 36 European countries

Figure 1 – Overview of components and methods used in this project

Public Involvement

The term Public Involvement (PI) is usually understood as meaning of the carrying out of research "with" or "by" members of the public and patients rather than "on" or "for" them. PI is not about merely raising awareness or providing information about ongoing or completed research (sometimes referred to as patient engagement) or about being a research participant. Rather, it is about creating a partnership between researchers and the public (e.g. people with dementia, carers, people at risk of dementia or with an interest in dementia research), whereby all contribute collaboratively in varying degrees towards the research process or output. PI is based on the right of people affected by dementia to voice their needs and perspectives and to democratic processes such as legitimisation and transparency. It enables researchers to benefit from the lived experience and perspectives of people with dementia, thereby fulfilling the criteria for meaningful and ethical research.

Within this project, 55 people were involved in different PI activities. This included people with dementia who are members of Alzheimer Europe's European Working Group of People with Dementia (EWGPWD) and their supporters/cares, members of the European Dementia Carers Working Group (EDCWG) and other people from Alzheimer Europe's networks, including people with an interest in dementia research, people with Mild Cognitive Impairment, people with dementia and carers. They provided reflections on the findings of the scoping review of the scientific literature, contributed to the development of the public opinion poll and shared their views, opinions, needs and experiences in relation to participation in dementia research and data sharing.

European Working Group of People with Dementia

The EWGPWD was set up in 2012 and is composed of 15 people with dementia. Members have different types of dementia, are from different European countries and are nominated by a national Alzheimer association. The Chairperson is an ex-officio member on the Board of Alzheimer Europe with full voting rights.

European Dementia Carers Working Group

The EDCWG was set up in 2022 and is composed of 15 current carers, relatives and supporters of people with dementia or carers with prior experience of caring in the five years prior to their nomination by their national Alzheimer associations. The Chairperson is an ex-officio member on the Board of Alzheimer Europe with full voting rights.

Box 2 – The approach to Public Involvement used in this project

3. Mapping out barriers to participation in dementia research in the scientific literature

To gain a clearer understanding of the factors that influence whether people choose to take part in dementia research and remain involved over time, a scoping review was conducted. This review was intended to provide a broad overview of existing scientific evidence on barriers and enablers to recruitment and long-term retention across different areas of dementia research, such as clinical and epidemiological studies, as well as psychosocial research. Specifically, information gathered from the scientific literature was used to create a framework of factors related to dementia research participation, which was used as input for the remaining elements of the project.

A systematic search of the PubMed and PsycINFO databases was carried out using terms related to participation in research, perceived barriers and enablers and dementia. The full search strategy of this scoping review is available in the corresponding manuscript, published in the Journal of Prevention of Alzheimer's disease[21]. No limits were applied regarding year of publication or geographical setting.

Barriers and enablers, respectively, were defined as factors decreasing or increasing the likelihood of continued involvement in dementia research. Studies were eligible for inclusion if they examined barriers or enablers to actual enrolment into dementia research or the intention to participate in future studies (such as enrolment to dementia research registries). Studies examining general attitudes towards dementia research were also eligible. Both qualitative and quantitative study designs were considered.

All identified barriers and enablers were subsequently organised into overarching thematic categories to provide a structured overview of the evidence. To complement and contextualise the findings of the scoping review, a PI online consultation was held. Two people with dementia and three carers participated in this discussion. Prior to the meeting, participants received background information, including a summary of the review and its initial findings. During the consultation, group members shared their perspectives on participating in dementia research and reflected on how barriers and enablers identified in the scientific literature aligned with their own experiences.

Findings of the literature search

A total of 45 studies were included in the review. Most studies were conducted in the United States (75.6%) or the United Kingdom (8.9%), with relatively little information from other European countries. Across studies, average age was 69.3 years and 64.8% of participants were female. The clear majority of identified studies examined factors related to initial recruitment (91.1%) rather than long term retention of participants (8.9%). Table 1 contains an overview of studies included in the scoping review.

> "Participating in research is a way of giving back and to do as much as I can for those after me"
>
> Person with dementia

> "As a carer, this is the person you love, you don't want to expose them to any unnecessary risk or harm (...) I would be looking at the balance between the risks and benefits, whereas my wife she would have just gone for it"
>
> Carer

Table 1 – Characteristics of studies examining barriers and enablers to participation in dementia research as identified by the systematic literature search

Author, year	Country	N	Research focus
Ashford et al., 2020[22]	United States	35,919	Research registry participation
Bardach et al., 2019[23]	United States	27,519	Genetic testing
Bardach et al., 2020[24]	United States	33	Not specified
Bardach et al., 2021[25]	United States	502	Not specified
Bardach et al., 2021[26]	United States	21	Clinical research
Boise et al., 2017[27]	United States	479	Brain donation
Bouranis et al., 2023[28]	United States	24	Clinical research
Burke et al., 2019[29]	United States	24,231	Epidemiological research
Clement et al., 2019[30]	United Kingdom	17	Clinical research
Coley et al., 2008[31]	France	686	Epidemiological research
Coley et al., 2021[32]	France	1,630	Multidomain lifestyle trial
Cox et al., 2019[33]	United States	49	Clinical research
Cox et al., 2021[34]	United States	200	Clinical research
Cox et al., 2023[35]	United States	1,028	Clinical research
Eliacin et al., 2022[36]	United States	32	Biomarker research
Erickson et al., 2022[37]	United States	334	Biomarker research
Fiordelli et al., 2021[38]	Switzerland	22	Epidemiological research
Fry et al., 2021[39]	United Kingdom	186	Care research
Gabel et al., 2022[13]	United States	443	Epidemiological research
Gelman, 2010[40]	United States	39	Care research
Goodman et al., 2011[41]	United Kingdom	133	Care research
Grill et al., 2016[42]	United States	132	Clinical research
Hinton et al., 2000[43]	United States	25	Care research
Hunsaker et al., 2011[44]	United States	55	Clinical research
Jefferson et al., 2011a[45]	United States	235	Clinical research
Jefferson et al., 2011b[46]	United States	280	Brain donation
Ketchum et al., 2022[47]	United States	145	Biomarker research
Lambe et al., 2011[48]	United States	15	Brain donation
Leach et al., 2016[49]	Australia	40	Clinical research
Lech et al., 2021[50]	Germany	122	Care research
Lee et al., 2020[51]	Canada	18	Research registry participation
Li et al., 2022[52]	United States	102	Clinical research
Lincoln et al., 2021[53]	United States	44	Clinical research
Milani et al., 2023[54]	United States	4881	Not specified
Mundy et al., 2020[55]	United Kingdom	10	Clinical research
Neffa-Creech et al., 2023[56]	United States	1,010	Research registry participation (prevention research)
Nissim et al., 2023[57]	United States	240	Epidemiological research
Portacolone et al., 2020[58]	United States	146	Not specified
Pugh et al., 2022[59]	United States	51	Not specified
Sajatovic et al., 2023[60]	United States	207	Not specified
Stites et al., 2021[61]	United States	119	Clinical research
Striley et al., 2019[62]	United States	3,279	Brain donation
von Strauss et al., 1998[63]	Sweden	923	Epidemiological research
Williams et al., 2010[64]	United States	70	Biomarker research
Zhou et al., 2017[65]	United States	125	Biomarker research/clinical research

Enablers of participation in dementia research

Enablers of participation in dementia research were divided into motivators (i.e. factors internal to the person increasing the likelihood of participation), and facilitators (i.e. external factors increasing the likelihood of participation). Motivators were further clustered in the following three themes: (1) Helping others and advancing research, (2) access to information and (3) a family history of dementia (see Table 2 for examples of included sub-themes). Table 3 presents an overview of clusters of external facilitators derived from scientific literature. These related to the provision of resources and support enabling participation, as well as detailed and accessible information about study procedures and results.

Barriers to participation in dementia research

Barriers identified in the literature search were clustered into the following overarching themes: (1) mistrust, (2) fears, worries and concerns, (3) awareness, (4) beliefs and attitudes, (5) practical and logistics constraints, (6) study characteristics, (7) informational barriers and (8) barriers related to the support system.

Table 4 includes several examples of subthemes identified for each of the main themes.

Summary of the Public Involvement consultations on the review findings

People affected by dementia involved in the consultations strongly identified with the barriers and enablers described in the literature and expanded on them with personal insights. They emphasised the need for greater public awareness and a more positive, realistic image of dementia to encourage research participation. Many described research as a way to "give back" and retain autonomy, though tensions can arise between the wishes of the person with dementia and the carer's concerns about risk. Participants also noted significant barriers to accessing studies, including limited opportunities, logistical challenges, and insufficient support for carers. They stressed the importance of receiving feedback after studies, increasing diversity through proactive outreach and ensuring research includes people at all stages of dementia with appropriate communication and support.

Table 2 – Motivators for participation in dementia research identified by the literature search

Cluster of motivators	Examples of subthemes
Helping others and advancing research	• Wish to help friends, family and future generations • Wish to advance dementia research and find a cure for dementia
Access to information	• Desire to learn more about oneself • Desire to learn more about dementia
Family history of dementia	• Higher perceived genetic risk of dementia

Table 3 – Facilitators of participation in dementia research identified by the literature search

Cluster of facilitators
Receiving financial compensation
Receiving sufficient information about study procedures and requirements
Active involvement of participants in the research process
Availability of carer support
Provision of transportation or parking options
Flexible scheduling options

Table 4 – Barriers for participation in dementia research identified by the literature search

Cluster of barriers	Examples of subthemes
Mistrust	• Mistrust of scientists or medical research in general • Mistrust of research institutions
Fears, worries and concerns	• Fear of physical and psychological consequences • Fear of learning about oneself • Fear of negative consequences for family members
Lack of awareness	• Lack of knowledge of research opportunities • Lack of recommendations from medical professionals
Beliefs and attitudes	• Low perceived value of research • Negative perceptions of dementia • Belief that others will participate instead
Practical and logistic constraints	• Time constraints • Difficulties reaching study location • Lack of financial compensation
Barriers related to study characteristics	• Obligation to take medication • Study partner requirement
Informational barriers	• Insufficient information about study procedures • Not being provided with study results
Barriers related to the support system	• Carer protectiveness • Disruptions of normal care caused by the research

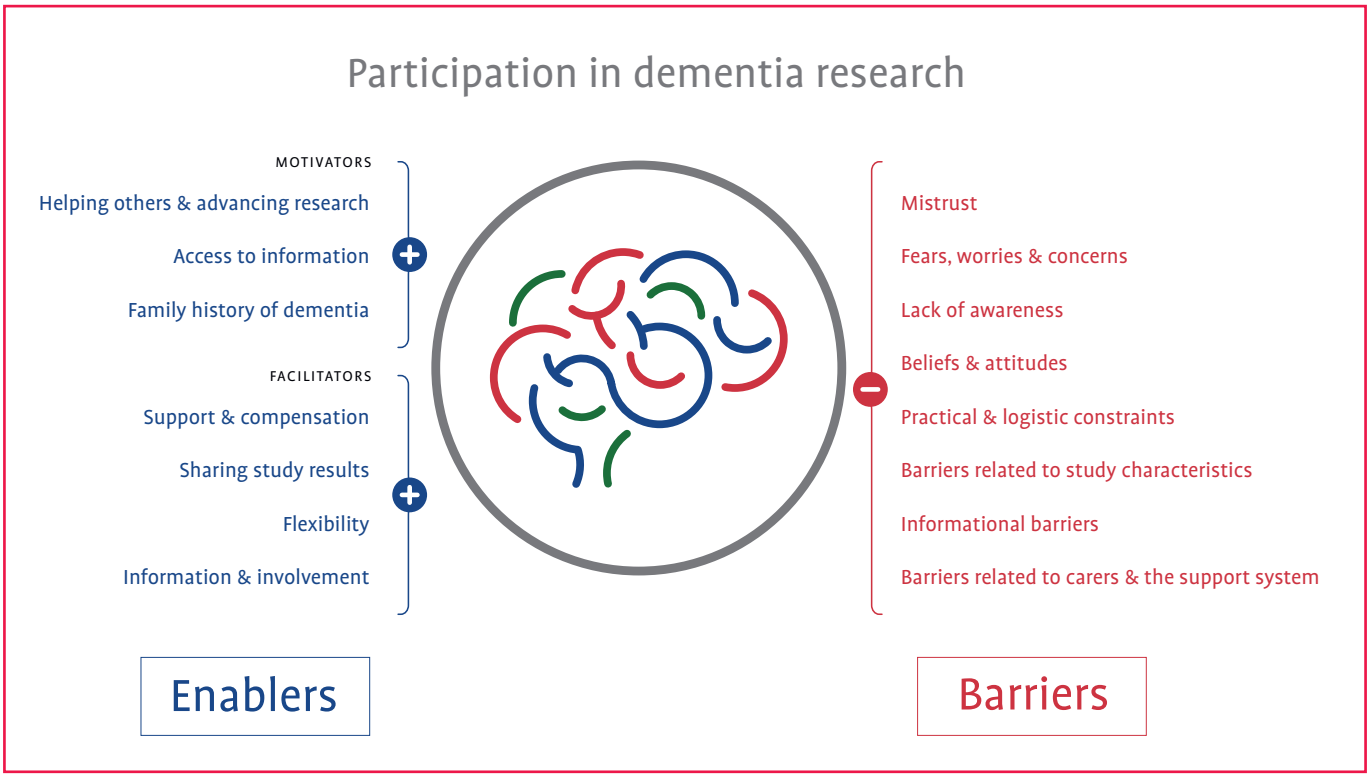

Figure 2 – Visualisation of barriers and enablers identified in the scientific literature. Enablers were divided into motivators and facilitators, respectively referring to internal or external factors positively influencing the likelihood of participation. This nomenclature is being used in the remainder of the report

Caveats

We acknowledge several limitations of this scoping review. Given the broad nature of the topic, the diversity of study designs and the largely qualitative nature of the evidence, we were unable to conduct quantitative analyses. In addition, incomplete reporting in some studies limited our ability to describe participant characteristics for all included studies, which may affect how well the findings reflect global research populations. Finally, the small number of studies examining participant retention meant that factors influencing recruitment and retention could not be compared in a systematic way.

Summary

- Most studies examining barriers and enablers to participation in dementia research were conducted in the United States, with relatively little evidence on European perspectives.
- Only a few studies examined factors related to long-term participant retention.
- Identified barriers to participation include mistrust, fears about negative consequences of participation, lack of awareness of study opportunities, practical constraints and insufficient information about study procedures.
- Identified motivators include altruism, access to information and having a family history of dementia.
- Identified facilitators include carer support, compensation for expenses, feedback on study results and active involvement in the research process.
- People with dementia additionally highlighted the need to tackle stigma associated with dementia.

4. Exploring views on dementia research participation and data sharing throughout Europe - a public opinion survey

Understanding public attitudes towards dementia research and data sharing requires not only capturing the views of people directly affected by dementia, but also of the general public. Many areas of dementia research rely on the involvement of people with and without cognitive impairment, for example in primary prevention studies or as control participants. It is therefore essential that members of the general public (including both people with dementia and those without) have the opportunity to express their views and concerns regarding participation in dementia research and the sharing of resulting data.

As highlighted above, Alzheimer Europe's scoping review revealed important gaps in the scientific literature, including the relative lack of European perspectives on research participation in the dementia field. To address this, there is a need to systematically map public views on participating in dementia research and the sharing and secondary use of research data across European countries. In response to this, Alzheimer Europe conducted a public opinion survey in collaboration with national Alzheimer's associations, aiming to examine perspectives on research participation and data sharing among the general public.

Target group

The target group for the survey comprised people aged 18 years and older living in a European country, defined as a country with an Alzheimer Europe member organisation. Given the wide range of dementia research areas to be covered, the target population was intentionally kept broad. In line with this, the survey was open to people with and without dementia and respondents were not required to have prior experience of participating in dementia research.

Survey development

The survey was developed through an iterative process, informed by the findings of the scoping review described above, particularly the barriers and enablers to research participation identified in the scientific literature. This was complemented by repeated input from people affected by dementia, as well as consultations with Alzheimer Europe's member organisations, further outlined in the following.

Input from the PI consultation with people affected by dementia

Two rounds of consultations with people affected by dementia were organised to inform content and presentation of the survey. During a first (in-person) meeting, participants discussed their general understanding of dementia research and data sharing and provided feedback on an initial version of the survey. Drawing on their own experiences taking part in dementia studies, their input was used to refine and expand its content and set expectations regarding the acceptable length. A second consultation was held online, during which participants were asked to complete the revised version of the survey themselves. They subsequently provided feedback on wording, accessibility, ease of completion and overall length, leading to further refinements.

Input from Alzheimer Europe's member organisations

Alzheimer Europe's member organisations contributed to the development of the survey during two in-person sessions. Their input included feedback on the relevance and clarity of survey content, suggestions for adaptations to national contexts and support with translation and dissemination at national levels.

In addition to English, the survey was made available in Czech, Danish, Dutch, Finnish, French, German, Italian, Polish, Portuguese, Slovak, Spanish and Swedish. Translations were generated automatically and subsequently checked and validated by native speakers to ensure accuracy and clarity.

Definition of dementia research

Recognising that interpretations of "dementia research" may vary, a working definition was included in the introductory section of the survey to support a shared understanding among respondents. Dementia research was defined as follows:

"A dementia research study is a project that helps scientists understand dementia better. It looks at what causes it, its symptoms, and how it can be treated, aiming to improve care or even find ways to prevent or cure it."

Survey administration

The public opinion survey was developed and administered using the Qualtrics questionnaire environment to ensure compliance with the GDPR. Table 5 provides an overview of the information collected across the different sections of the survey.

Results

Respondent characteristics

Between 25 May and 18 December 2025, 3,269 people accessed the survey, of which 2,802 (85.7%) provided at least basic demographic information. The clear majority of respondents were living in France (51.2%), followed by Spain (7.6%), the Netherlands (5.6%) and Belgium (5.1%). Figure 3 includes an overview of the geographic distribution of respondents. Respondents were on average 59.5 years old (SD = 13.1 years) and 73.1% self-identified as female, 25.2% as male, 0.3% as non-binary, 0.46% as other and 0.93% preferred not to say. The majority of respondents had either completed university education (54.9%) or vocational training (24.0%).

Experience with dementia and dementia research

The majority of respondents (75.6%) reported having had some experience of dementia. Of those, 50.6% had personal experience of dementia (either having dementia themselves, having a relative or friend with dementia or being an unpaid carer for a person with dementia), and 25.0% reported professional experience (being a healthcare professional working with people with dementia, a dementia researcher or a member of an Alzheimer's association). Note that these response options were non-mutually exclusive and 8.2% of respondents indicated having both personal and professional experience of dementia. Self-rated knowledge about dementia was approximately normally distributed, with the majority of people rating their overall knowledge as moderate, and relatively few as extensive or non-existent (Figure 4).

Moreover, the largest proportion of people (85.6%) reported never having participated in a dementia research study in the past. Among those who had, the clear majority rated their overall experiences as either very positive (39.0%) or positive (46.1%; Figure 5). Most of the people with experience participating in dementia research were recruited via a healthcare professional, such as their general practitioner (36.4%), followed by advertisements by national Alzheimer's associations (32.2%) and others (17.5%).

Table 5 – Outline of Alzheimer Europe's survey on research participation and data sharing

Country of residence
Demographic information (age, gender and level of education)
Knowledge about dementia (5-point Likert scale, from no knowledge at all to extensive knowledge)
Prior experience participating in dementia research (whether participated in dementia research in the past, how respondents would rate their experience, how respondents heard about the study)
Likelihood of participation in the various study scenarios (5-point Likert scale from very likely to very unlikely)
Enablers of participation (presented as statements, rated on a 5-point Likert scale from strongly agree to strongly disagree)
Barriers to participation (presented as statements, rated on a 5-point Likert scale from strongly agree to strongly disagree)
Attitudes towards data sharing (presented as statements, rated on a 5-point Likert scale from strongly agree to strongly disagree)

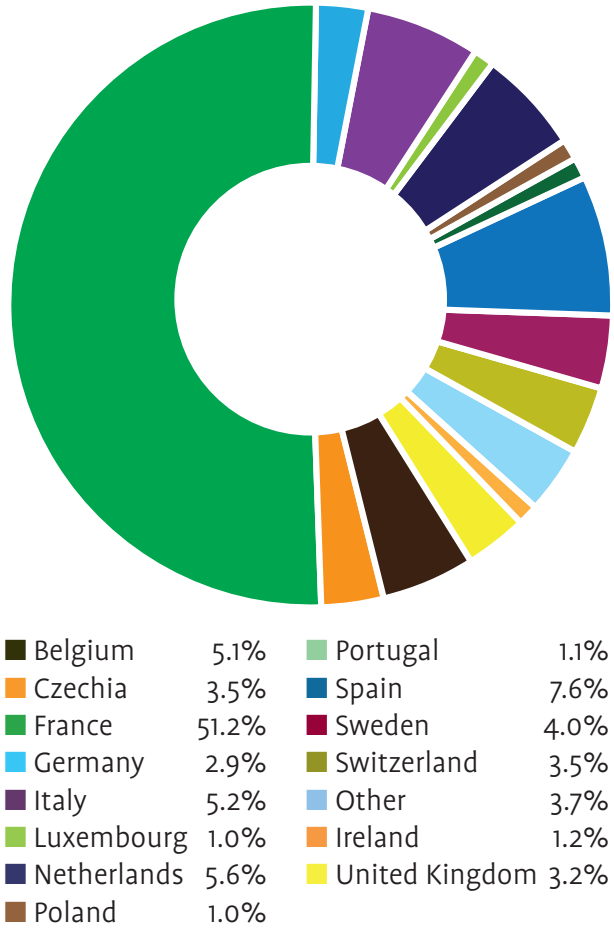

Figure 3 – Geographic distribution of respondents to Alzheimer Europe's survey on dementia research participation and data sharing. Due to rounding, percentages may not add up to 100

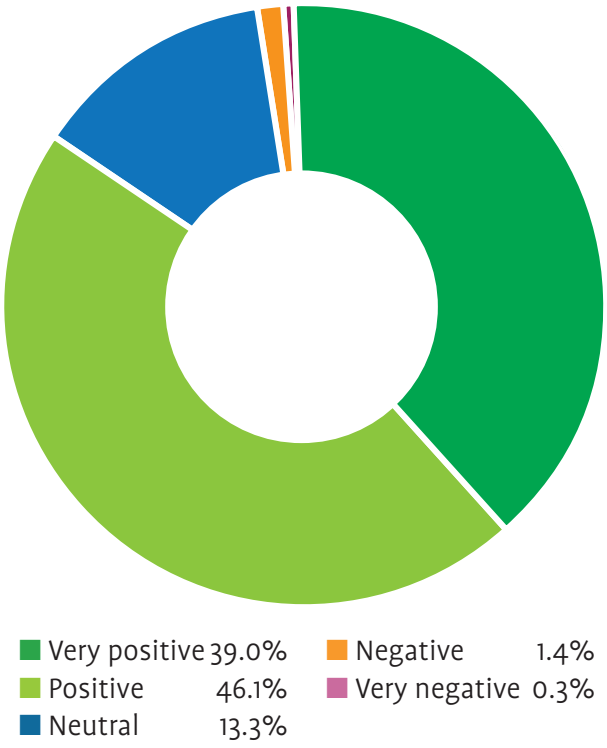

Figure 5 – Rating of the overall experience participating in dementia research among those with prior research experience (14.4%). Due to rounding, percentages may not add up to 100

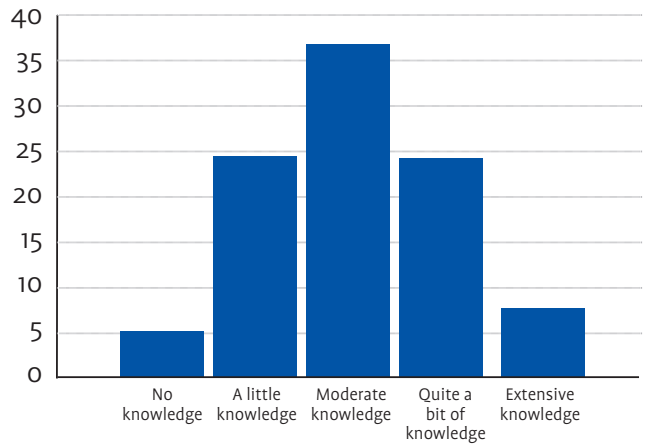

Figure 4 – Self-rated knowledge about dementia

Table 6 – Recruitment strategies reported by people who participated in dementia research (categories were non-mutually exclusive and may thus not add up to 100)

How did you hear about the dementia study you participated in?	Percentage
Via healthcare professional	36.4%
Via national Alzheimer's association	32.2%
Online advertisement	17.2%
Word of mouth	9.6%
Newspaper, radio or TV advertisement	4.0%
Flyers or posters at public spaces	3.4%
Other	17.5%

Likelihood of participation in hypothetical dementia research

When respondents were asked how likely they would be to participate in hypothetical study scenarios, the likelihood of participation differed substantially according to the degree of physical invasiveness involved. Specifically, the majority of respondents indicated that they were either very or somewhat likely to participate in dementia studies with low levels of physical invasiveness (e.g. those involving the completion of questionnaires or psychosocial interventions) or intermediate levels of physical invasiveness (i.e. those involving brain scans or blood draws). Conversely, respondents were less likely to indicate willingness to participate in studies involving a higher degree of physical invasiveness (i.e. those involving medication use or a lumbar puncture). Figure 6 presents a bar chart visualising the proportions of responses for each study scenario. In addition to the descriptive analyses above, we found that willingness to participate in the different study scenarios was not uniform, but differed as a function of age, gender, level of education, experience with and knowledge about dementia.

Barriers and enablers of participation in dementia research

Items related to internal motivators to participating in dementia research (see Figure 2 for a description of nomenclature used) were endorsed relatively frequently throughout (Figure 7). Respondents most strongly agreed with items related to primarily altruistic motives ("I want to help find better treatments or a cure for dementia" and "I want to help future generations"), while access to new treatments through participation in research was endorsed somewhat less strongly. With regard to tangible factors facilitating study participation, between 20 and 30% of respondents selected encouragement from friends and family, the possibility of home visits, receiving financial compensation, available parking options close to the study location and the possibility to bring a study partner, as factors potentially influencing their decision to participate in dementia research (Figure 8).

Figure 9 shows a bar graph of responses to questions about barriers to taking part in dementia research. Items referring to a lack of awareness of study

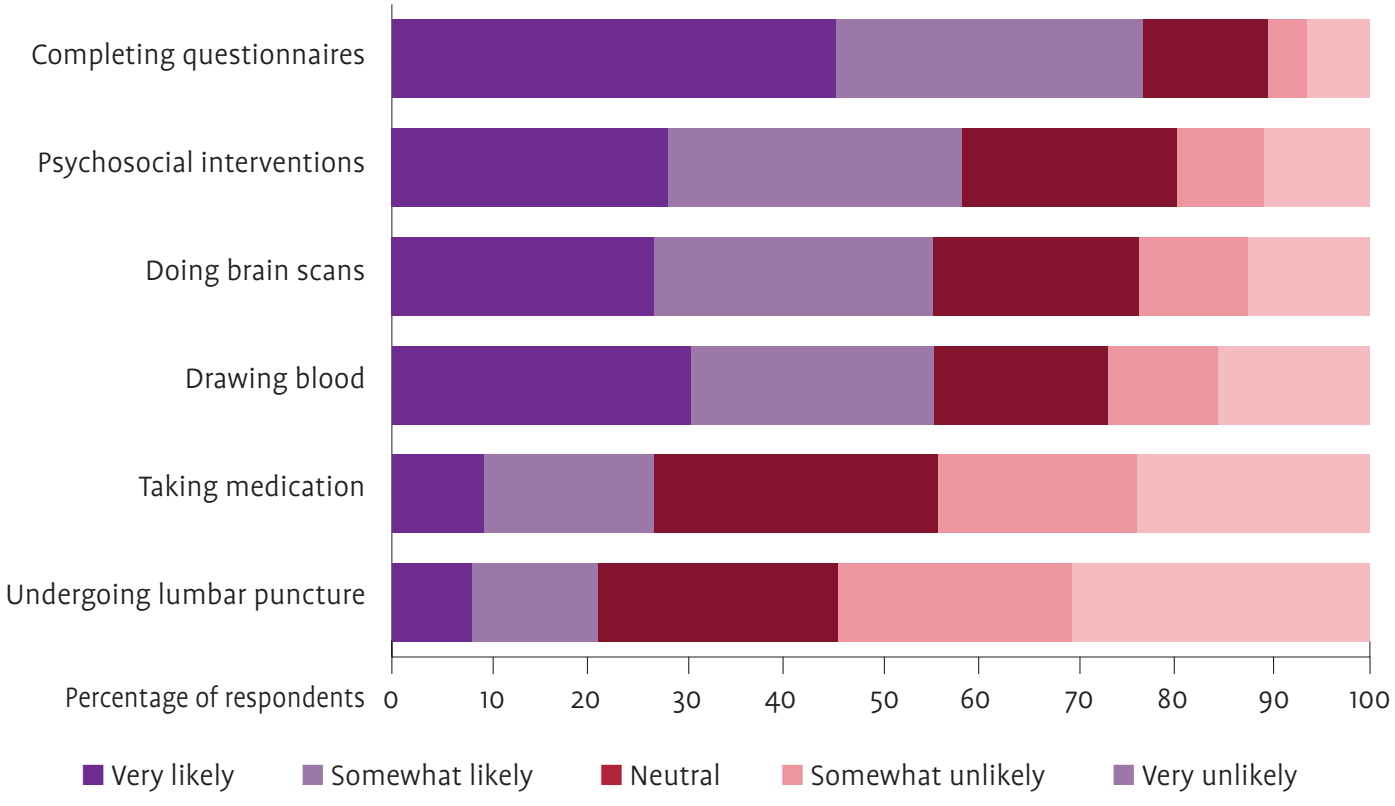

Figure 6 – Bar chart outlining the proportion of survey responses per study scenario

opportunities ("I am not aware of any studies I could participate in") or never having thought about participation ("I never thought about participating in dementia research") were most strongly endorsed. This was followed by concerns about potential emotional consequences of participation ("I am worried about the emotional burden that participation may cause for myself"), worries about financial costs ("I am worried about the financial costs of participating in dementia research"), data safety concerns ("I am worried that my personal data would not be stored safely") and the worry to not get access to study results ("I'm concerned about not getting access to the study results").

More than 66% of respondents were not aware of any dementia studies in which they could participate

More than 25% of respondents were worried that their personal data collected within a dementia study would not be stored safely

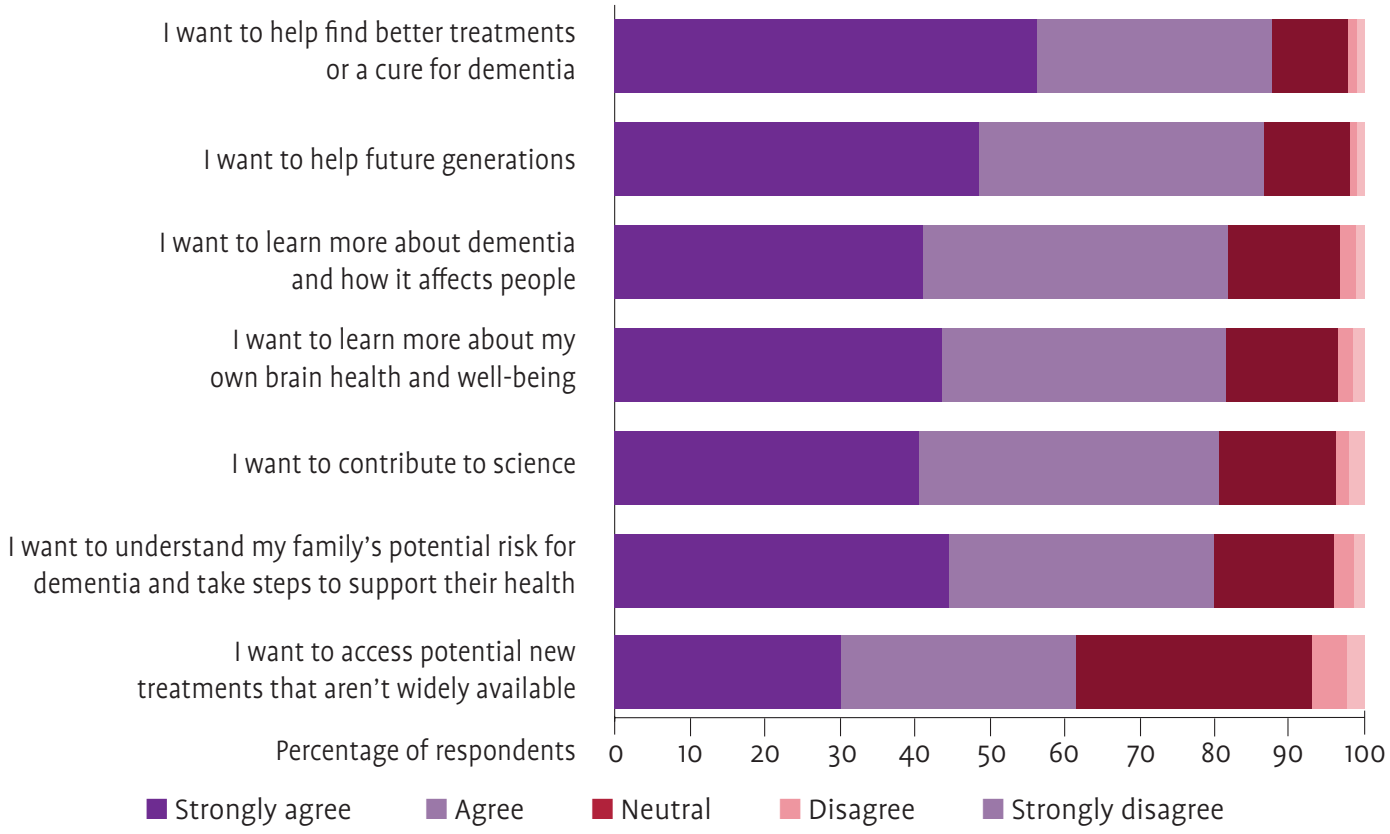

Figure 7 – Bar chart of responses to survey items about internal motivators to participating in dementia research

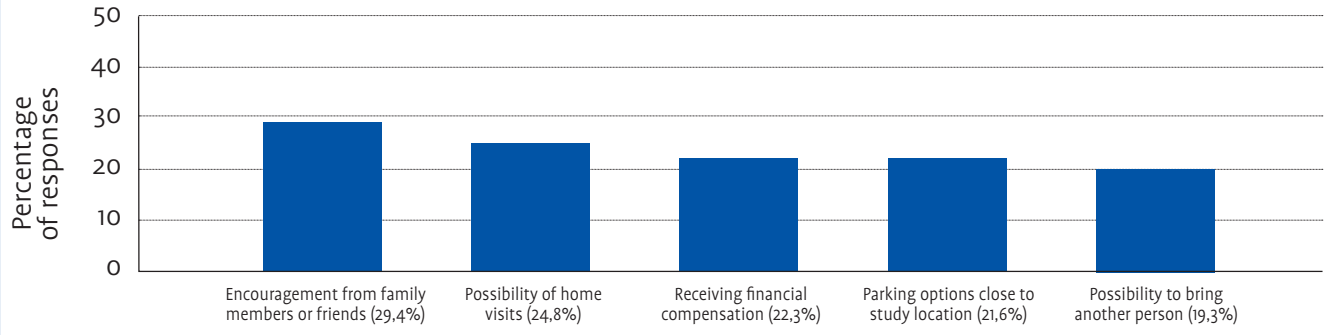

Figure 8 - Bar chart of responses to survey items about external facilitators to participating in dementia research

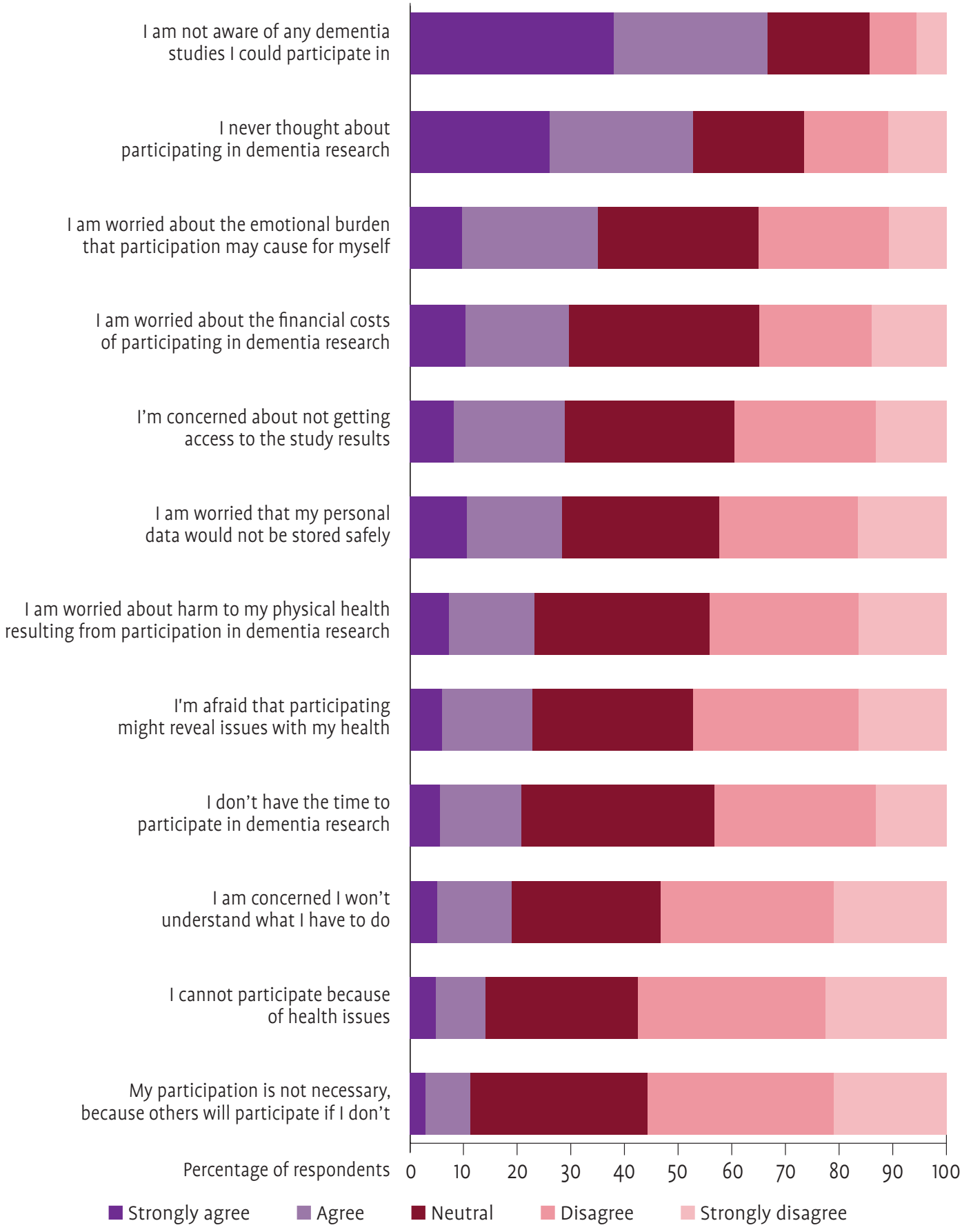

Figure 9 - Bar chart of responses to survey items about barriers to participating in dementia research

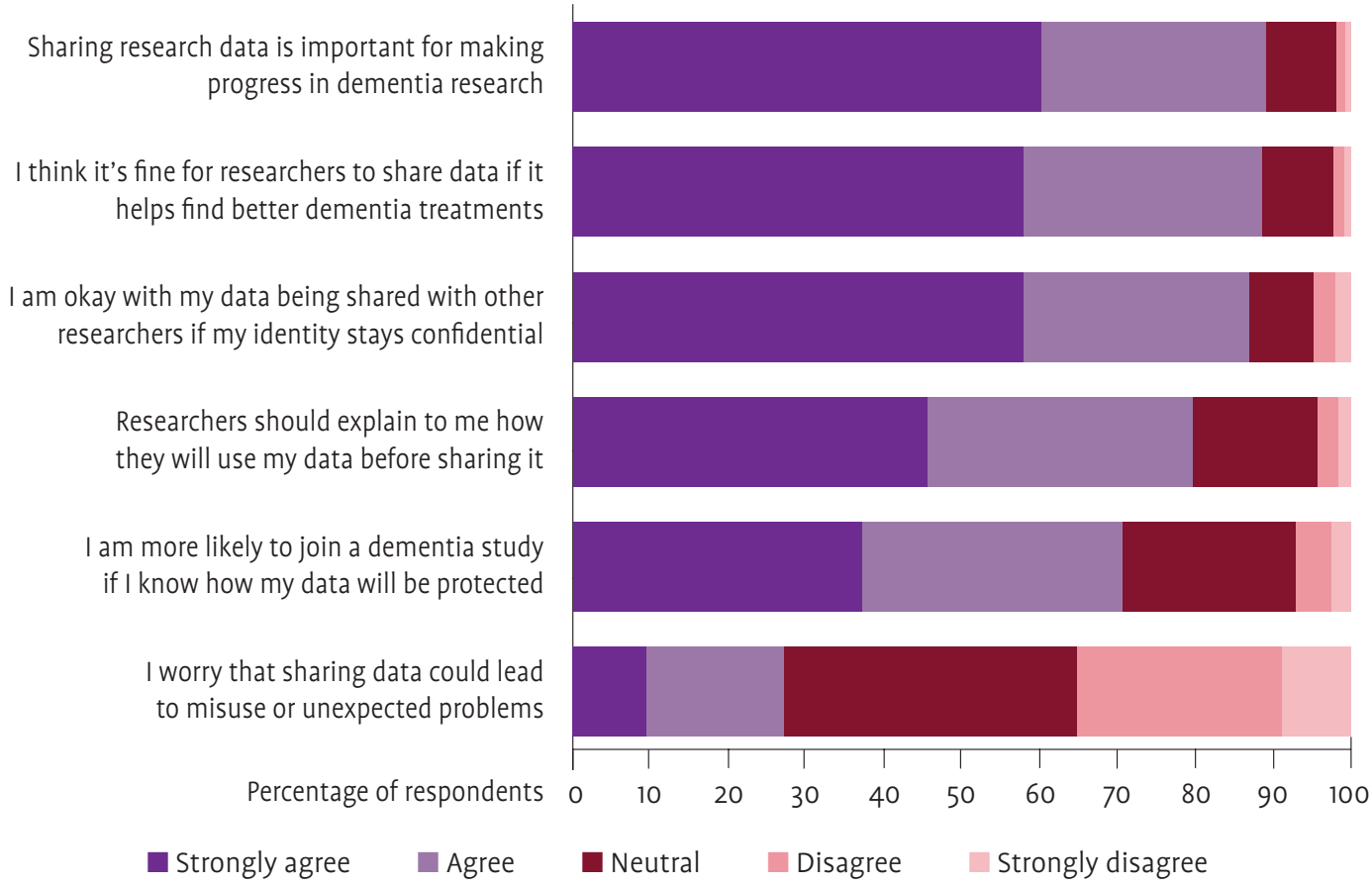

Figure 10 - Bar chart of responses to survey items about barriers to data sharing

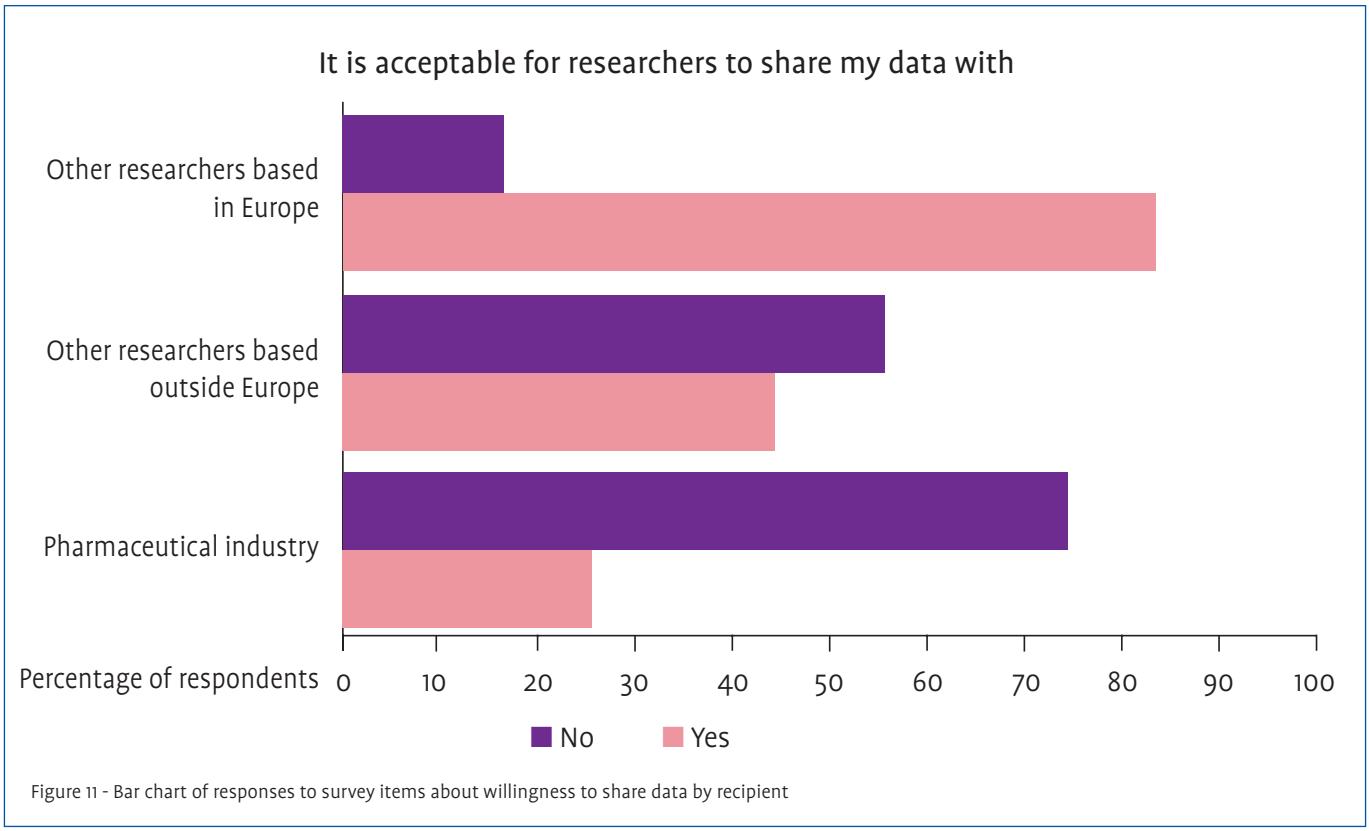

Figure 11 - Bar chart of responses to survey items about willingness to share data by recipient

Public attitudes towards data sharing

Attitudes towards data sharing within dementia research were generally positive. A clear majority of respondents (88.0%) indicated that it was generally acceptable for researchers to share data collected within a study. Moreover, most people either strongly agreed or agreed (89.0%) that data sharing is important for making progress in dementia research and that it is fine for researchers to share data if it helps find better treatments or a cure for dementia (88.5%; Figure 10).

However, there were differences in opinions concerning acceptable data recipients (Figure 11), with the most respondents (83.5%) agreeing that data can be shared with other researchers based in Europe, rather than with researchers based outside Europe (44.4%) or with the pharmaceutical industry (25.6%).

Caveats

We recognise a few important limitations of our approach. As with many public surveys, it is difficult to achieve a sample that fully reflects the general population in each country. In our survey, respondents were unevenly distributed, with over half coming from France. This may have influenced the overall findings, particularly because French participants tended to be older, more often female, and reported lower levels of education compared with respondents from other countries. The smaller number of participants from some countries also meant we could not explore cross-country differences in depth.

More than 88% of respondents agreed that sharing data is important for making progress in dementia research

More than 86% believed it is acceptable for researchers to share their data as long as their identity remains confidential

Summary

- More than 2,800 people aged 18 years and older from 32 countries took part in Alzheimer Europe's public opinion survey, which explored attitudes towards dementia research participation and data sharing in the general public.
- Only a small proportion of respondents (14.4%) had previously participated in research. However, among those who had, most (85.1%) reported a positive or very positive experience.
- The most frequently reported barriers to participation were a lack of awareness of research opportunities and never having considered taking part.
- Willingness to take part in different study scenarios varied according to the level of physical invasiveness, as well as participants' age, gender, educational level and their experience with and knowledge of dementia.
- Overall, respondents reported high intrinsic motivation to participate in dementia research, most commonly driven by the desire to contribute to better treatments or a cure and to benefit future generations.
- External facilitators such as financial compensation, encouragement from friends or family, accessible parking, home visits and the possibility of bringing a study partner were endorsed by 20-30% of respondents.
- Attitudes towards data sharing were similarly positive, with most respondents agreeing or strongly agreeing that data sharing is essential for progress in dementia research and acceptable as long as personal identity is protected.

5. Perspectives of people affected by dementia on participation in research and data sharing

Alzheimer Europe conducted five online meetings on the topics of research participation and data sharing. 24 people affected by dementia, including people with dementia, people with MCI, carers and members of the public, participated in the meetings. This section provides a summary of the feedback and discussions.

Participation in research

Understanding of dementia research and hopes

Participants expressed a strong and consistent belief in the essential role of research, describing it as a meaningful path forward. One participant articulated this view, stating: *"Research is probably the best way to move forward. The best way to do something positive"*.

Understanding of, and awareness about, dementia research were strongly shaped by lived experience. Awareness of dementia research and its relevance often emerged only following diagnosis. As one participant explained: *"We'd never thought about participating until he received the diagnosis, that changed everything"*. Prior to diagnosis, research was commonly understood in primarily biomedical terms, such as *"something clinical, tests, going to hospitals"*, *"scientists looking for a cure"*, or *"large medical companies developing drugs"*. Following diagnosis, however, participants' priorities shifted towards research that also addresses care, support and quality of life. As one participant reflected: *"I think I would have thought of looking for medical things, but now I think it is more about finding ways to support people affected by dementia"*.

Hopes for the future of dementia research were complex and often expressed with caution. A recurring hope concerned the development of more effective treatments that are suitable for everyone and have minimal adverse effects. As one participant explained: *"It doesn't matter how long it takes, it has to be a really good medication with as few side effects as possible, and it needs to be suitable for people with other medical problems and taking other medications, for everyone."* However, there was a general recognition that a cure was unlikely to be imminent.

> "We'd never thought about participating until he received the diagnosis, that changed everything."
>
> Carer

Clear communication about research progress emerged as an important concern, particularly in relation to (1) exaggerated claims that could generate unrealistic expectations and false hope *"There is so much hype about the new drugs that you would get the impression that they're there, that they're ready, and it's not"*, and (2) the use of potentially misleading language *"I think you should ban the word 'prevent' dementia, because you can't prevent it and that gives false hope"*. Hopes were often linked to improvements in the experience of diagnosis, quality of life and stigma, as these outcomes were perceived as particularly important and more achievable in the near future.

Experiences, motivations and barriers to participation in research

Positive experiences of participating in dementia research were associated with clear communication, accessible language, logistically simple procedures and receiving feedback after participation. One participant emphasised the importance of researchers communicating in an understandable way and recognising practical needs, noting: *"Researchers should use a language that I understand, they should not use acronyms, and they should pay the expenses"*.

Participants particularly valued supportive and respectful interactions with researchers and appreciated feeling that their contribution mattered and could benefit others in the future. This was captured by one participant who explained, *"It is just being treated with respect as a participant, not 'just a patient'"*. To illustrate this, a carer described a study

involving technology in which her spouse had participated: *"Researchers came to our house, gave enough instructions and did everything to make us feel comfortable"*. In contrast, less positive experiences were linked to excessive bureaucracy, lack of follow-up or feedback, long travel distances and burdensome or unclear questionnaires and consent forms. As one participant reflected: *"The paperwork, I find it difficult and I know that I have signed things without really knowing what I was signing"*.

The perceived benefits of research participation were multifaceted. Many participants felt that taking part in research offered a way to regain a sense of agency at a time when control often feels diminished following a dementia diagnosis. One carer vividly described the frustration expressed by the person with dementia when they felt overprotected in decisions about research participation: *"Stop wrapping me in cotton wool, I want to do this, I want to make my own decisions"*.

Hope also emerged as a significant factor. For some, participation in research provided a renewed sense of purpose and optimism. One participant reflected that taking part *"gave her a degree of hope and, psychologically, that was the best aspect"*. Others highlighted the emotional value of being invited to contribute, noting, *"What I like about research is being asked, this was very meaningful for me"*. Feeling listened to and recognised as someone with valuable knowledge was itself a strong motivator.

Participants also identified personal benefits as relevant. These included access to diagnostic tools or follow-up that might otherwise be unavailable or expensive. As one participant stated: *"The research I did was because I got a free PET scan, and they are very expensive"*. Others valued the reassurance provided by access to regular monitoring and receiving information, results and feedback. Some referred to the benefit of accessing new treatments as part of their participation in a clinical trial. One participant reflected, *"A week after my diagnosis, they invited me to join a clinical trial with this new drug. The results are there; if I hadn't done anything, I don't know what would have happened to me"*.

> "It is just being treated with respect as a participant, not 'just a patient'"
>
> Person with dementia

Altruism was another powerful and recurring motivation. This included for example a strong desire to help others (particularly future generations) or simply to *"give back"*, it was often framed as a moral or social responsibility, and captured in statements such as *"doing things for the people coming after us"* and *"to do as much as I can to help develop a new treatment for those who come after me"*. In this way, research participation offered a means of ensuring that their experience of dementia held meaning beyond their own lives.

However, these perceived benefits coexisted with significant barriers. Emotional barriers, including fear, anxiety and uncertainty, were common, particularly in relation to medical research and invasive procedures. Practical barriers were also prominent. Time commitment, travel demands, study burden and fatigue were frequently cited, especially by carers balancing multiple responsibilities. Participants described situations in which lengthy questionnaires, frequent hospital visits, or poorly coordinated logistics made participation overwhelming. As one participant noted: *"If they don't make it easier for participants, it won't work"*.

Tensions between people with dementia and carers could further affect participation. While people with dementia often expressed a strong desire to take part, carers tended to adopt a more risk-averse stance. One carer described this dynamic: "*As a carer, this is the person you love, you don't want any unnecessary risk or harm. I would be looking at the balance between the risks and benefits, whereas my wife would have just gone for it*".

Lack of information and opportunities

Low participation in dementia research was often attributed less to unwillingness and more to lack of awareness, invitation or opportunities. As participants reflected, *"Maybe people do not participate in research because they haven't been asked"*, *"In my case, there is*

no research in my country, I would not know where or who to ask about this".

Information about dementia research was perceived as far less visible than information about dementia itself. Media coverage was felt to focus primarily on *"breakthrough drugs"*, whilst communication about opportunities to join research or the broader impact of research on policy and everyday lives were largely absent. Research opportunities were often described as hidden and fragmented, and often accessible mainly to people already connected with Alzheimer associations. Inappropriate outreach strategies were also noted as a barrier; for example, reliance on social media excludes older adults or those less digitally active. Access was further limited by geographical factors: research tends to be concentrated in major cities, leaving rural populations with fewer opportunities to participate. One person with dementia explained: *"It's not easy for me to come there because the train and the buses aren't that good; they need people living in the city to participate"*.

Healthcare professionals were identified as critical gatekeepers in facilitating participation. Participants felt doctors and specialists should play a central role in introducing research opportunities. As one participant stated: *"Your GP will know what way your mindset is and they'll know if you're fit to do a bit of research"*. Timing of recruitment was also seen as important. Many felt that introducing research opportunities at the time of diagnosis could sometimes be inappropriate, highlighting the need for ongoing conversations that could be revisited when individuals felt emotionally ready.

Trust

Trust was one of the most recurrent and meaningful topics across all focus groups. Participants described trust as the foundation of research participation. This was expressed with statements such as *"If you don't have the trust, there's no point being there"*, and *"Without trust, nothing could be done in the world"*. Recommendations from trusted clinicians further reinforced trust, with one participant explaining, *"If they recommend a study, I trust"*.

Trust was built through personal connection, respect and communication rather than institutional reputation alone. Participants valued researchers who took time to know them as individuals. Being treated as a person rather than as *"just a lab rat"* was central to trust and willingness to participate. Continuity and follow-up were also essential to maintaining trust. Some participants described feeling abandoned when studies ended without feedback. One carer expressed frustration, saying: *"I gave so much personal information and then never heard anything back"*. Another described how *"nothing coming back afterwards left a bad taste in our mouths"*. These experiences undermined trust not only in individual projects, but in research more broadly.

Procedures or treatments which are invasive, painful or involve risk

Invasive procedures, such as lumbar punctures, emerged as important factor when making decisions about research participation. Emotional reactions to lumbar punctures were often very strong. One participant stated: *"There is no way on this planet that a researcher could present a research programme to me to get me involved if it involves a lumbar puncture"*. Another echoed this sentiment, saying, *"Never again am I having another lumbar puncture"*.

Other participants did not necessarily reject invasive procedures or risks outright, but emphasised the need for honesty, clarity and respect. Many expressed strong opposition to being persuaded or reassured through minimisation of risks. As one participant stated: *"I don't want to be lied to. I want to be told the reality"*. Others emphasised that communication must include worst-case scenarios and long-term consequences, questioning whether people truly understand the risks involved. One participant asked: *"Are you going to recover 100% or are you going to have a permanent damage?"*.

> "I think it's essential that we share data with other research groups to speed up the pace of research"
>
> Person with dementia

Fear of human error was also an important factor. Participants stressed that risk was not only inherent to the procedure but also linked to the skill of the professional performing it. Assurance that staff are skilled, experienced and well trained was seen as essential, as was clarity about what support would be available if something went wrong.

Lack of representation

An important recurrent concern was that dementia research does not adequately reflect the diversity of people affected. This was linked to structural, cultural and systemic issues. One person with dementia stated: *"Most of the researchers are white, which doesn't help different ethnicities"*. Others highlighted gender bias in research, noting that some medications *"might be less efficient in women than men and that's never said"*.

Participants emphasised that improving representation requires proactive, creative outreach rather than passive recruitment strategies. As one participant noted: *"Just expecting people to put themselves forward is not working*". Culturally sensitive communication and involvement of trusted local organisations were seen as essential. At the same time, participants stressed that lived experience of dementia should be the unifying factor. One participant expressed this stating: *"The cohesive factor should be dementia, not the differences, we are all struggling with a similar condition"*.

Inclusion was also discussed in relation to disease stage. Participants argued that research must include people at later stages of dementia, despite the additional logistical and ethical challenges.

Data sharing / secondary use of data

Benefits and challenges

Participants considered data sharing and the secondary use of data in research to be highly relevant and necessary, provided that data are securely managed and appropriately anonymised. Some of the main benefits included accelerating scientific progress, reducing duplication and improving the use of limited resources. One of the participants stated *"I think it's essential that we share data with other research groups to speed up the pace of research. The problem here is that we duplicate work unnecessarily. MRI scans cost about a thousand pounds every time. So duplicating is a terrible waste of money"*. This also was perceived as having an impact on people affected by dementia: *"I've taken part in many studies and it actually becomes a bit burdensome by the amount of times that you have to go for scans or other tests, and my wife needs to take me there so she needs to take time off"*.

A salient theme in the discussions was the need for a more coordinated and globally integrated approach to research collaboration. Fragmented research practices and working in silos were perceived as generating inefficiencies, unnecessary duplication of tests, wasted time and missed opportunities for scientific advancement. Cross-disciplinary collaboration was viewed as a means of fostering innovation and generating new knowledge, with participants emphasising that *"joining efforts and sharing information among different groups of researchers means joining and multiplying talent"*, something seen as *"always positive for the patients or future patients"*.

While participants were largely supportive of data sharing, they also expressed concerns about how data might be used once shared and whether it could be fully protected.

Some of these concerns included misuse for commercial purposes, breaches of confidentiality or possible illegal activities. These challenges were particularly relevant due to the uncertainty surrounding the secondary use of data, including whether it would happen, when and with whom it would be shared. One participant noted that *"in the consent form it wasn't specified that it would definitely be shared, just that it might be shared in the future"*, while another reflected unease about the unknown trajectory of shared data: *"I was concerned*

> "I was concerned because this would be shared with other people who I didn't know, even if in anonymous basis. Where would it end up?"
>
> Person with dementia

because this would be shared with other people who I didn't know, even if in anonymous basis. Where would it end up?". This concern was closely linked to fears of exploitation, particularly *"whether data could be misused for commercial gain"*.

However, it was also reflected that in today's digital world, complete security is nearly impossible, and therefore the risk must be acknowledged but managed rather than feared. A way to address this uncertainty and the concerns that may arise around data sharing was to promote clear and ongoing communication. Participants should be well informed about the purpose and benefits of data sharing and about how their data will be used. This could involve explaining opt-out options as well as the accountability and governance arrangements in place, so that individuals can feel confident that their information is managed responsibly and securely.

Impact of the type of data shared and with whom

Participants debated whether certain types of data, such as genetic data, raised greater concern. The discussion reflected that, whilst understanding the particular sensitivity of genetic material (for example, due to the potential implications for family members and future generations), all types of data are relevant and needed for research. Some participants expressed that once they had decided to share data, they were comfortable sharing all of it and viewed participation in research as an all-in commitment to scientific progress. It was concluded that the key issue was not necessarily what is shared, but with whom and under what conditions.

Participants expressed greater confidence in European research systems and regulation than in some other regions, feeling that European standards are high and in keeping with strong ethical principles. Concerns were raised about sharing data beyond Europe or with commercial entities, especially in regions perceived as having weaker regulation. One participant stated, *"In the current situation I wouldn't be happy sharing data with entities outside Europe, I just don't trust how some countries operate internationally"*. However, the practical challenges of restricting data by geography were also acknowledged, given the global nature of pharmaceutical companies. As one participant observed: *"You can't really say 'I'll share with this pharma company but only within Europe.' These companies are global, it's impossible to contain data within borders"*.

While recognising the risks, this participant concluded that: *"if you agree to it being shared, I think you're just going to have to take that risk"*. Overall, participants agreed that while sensitive data can greatly advance science, trust, transparency and accountability are essential, summarised succinctly as: *"The benefits outweigh the risks, but people should have the right to know who's using their data and why"*.

Trust

The topic of trust emerged as a central theme. Trust was perceived as a foundation for participation in research and sharing data, and described as personal, relational and earned, rather than something given automatically.

Trust was seen as being built through personal relationships and direct communication, rather than through institutional assurances alone. Participants placed great value on meeting researchers face-to-face, being able to ask questions and understanding the study's goals and methods. One participant explained that trust developed during initial personal interactions: *"When you see the person who's conducting the study and you go and you have that initial meeting and you talk through it, that's where for me, I have an instant trust, it's how they interact with you as a person"*.

Many participants emphasised that trust must be earned through integrity, clarity and consistency. Positive experiences with research teams reinforced confidence in the system. As one participant stated: *"Trust can never be bought, it has to be earned"*, describing how meeting a research team characterised by *"honesty and integrity"* removed doubt about sharing data. This trust extended beyond individuals to the collective, as *"they all reflected transparency and respect*".

Participants also acknowledged that trust always involves a degree of risk, especially with large or international organisations. Nevertheless, they

believed this risk should be accepted as part of progress, provided researchers are transparent and ethical. As one participant put it: *"All these big companies are made of people, some are trustworthy, some are not. But without trust, nothing moves forward"*. Another echoed this sentiment more broadly: *"Risk is everywhere. We just have to be open-minded and do our best"*.

Research solutions and models of secondary consent

Different models and approaches to secondary consent were discussed in the meetings. Blanket consent (a general agreement allowing future use of data without specifying each purpose), broad consent (permission for a defined range of future research uses), tiered consent (offering participants a set of options about how their data may be used), reconsent (seeking permission for new uses over time) and dynamic consent (an interactive, digital model allowing participants to manage their preferences over time) were all considered. Overall, consent models that offered greater choice and transparency were welcomed, although participants recognised the financial, logistical and potential security challenges of managing complex systems.

Blanket and broad approaches to consent were valued for their simplicity and ease of use. These were perceived as pragmatic approaches that could support more efficient use of resources. As one participant noted: *"I can understand the benefits of giving a blank consent because, Tick box. Fine, lovely. Done. Very nice and easy"*. However, these approaches were also seen as too open-ended for participants who wanted greater control or clarity over future data use.

> "When you see the person who's conducting the study and you go and you have that initial meeting and you talk through it, that's where for me, I have an instant trust, it's how they interact with you as a person."
>
> Person with dementia

Tiered consent was perceived as a flexible and empowering middle ground. Participants valued its ability to give individuals some control while still supporting research progress. One participant described it as *"the best way to give control to the people for their own choices"*, while cautioning that it should not be overly complex: *"If you give too many choices, people get too confused too quickly"*.

Reconsent was seen as ethically appealing but largely impractical. While participants appreciated its transparency, they raised concerns about cost, feasibility and scale. As one participant summarised: *"Re-consenting is ethically spot on, a great wish. But I'm not sure it's doable depending on the numbers involved"*. Time-limited consent was discussed as a possible compromise, though some felt it could be too restrictive for long-term research.

Dynamic consent was recognised as a promising but challenging model. Participants acknowledged that it could increase transparency and reflect contemporary digital practices, but also worried that: *"it might be too much information for most people"*, alongside concerns about cost, security and hacking. Many preferred periodic updates instead, valuing communication that demonstrated impact without unnecessary complexity. One participant explained that: *"it's always nice to be updated on developments so you can see that what you contributed is making a difference"*, adding that updates at key milestones *"or a thank you"* would be meaningful.

Participants also expressed strong support for ethical safeguards and oversight. There was broad agreement that, for example, having a separate consent form for consenting to secondary use of the data would improve clarity and reduce confusion. The ability to withdraw consent at any time, without affecting participation in the primary study, was seen as empowering and ethically important. One participant reflected positively on this safeguard, noting that secondary data sharing is often *"an add-on"* and that withdrawal *"should not affect your involvement in the primary study"*.

Independent review boards and data access committees were viewed as important mechanisms

> "We all agree data sharing is a good idea; the key is doing it the right way."
>
> Person with dementia

for accountability, provided they were genuinely representative and included people with lived experience. One participant stated: *"I would not be able to take an ethics committee seriously unless it included people who actually experienced what it's like to live with a condition"*. Others emphasised the importance of diversity and balance, arguing that the *"right mix"* should include researchers, legal expertise and people who understand *"from experience what these decisions mean"* rather than individuals motivated by personal gain or visibility. Seeing such structures in place increased confidence, as one participant explained: *"When I see that, it gives me confidence that it's not just a formality, it will actually happen*".

Overall, participants emphasised that while data sharing is widely supported, its success depends on trust, transparency and robust governance, captured in the shared view that *"we all agree data sharing is a good idea; the key is doing it the right way"*.

Summary

- Participation in dementia research can give people a sense of purpose, agency and optimism, often related to a social or moral responsibility that goes beyond personal benefits.
- Lack of awareness of opportunities or referral, study burden, invasive procedures, time constraints, travel demands, poorly coordinated logistics, lack of follow-up and excessive bureaucracy are commonly mentioned barriers to participation.
- Trust is seen as the foundation of participation in dementia research and sharing data. Trust is built through personal connection, respect and clear communication, not merely institutional reputation.
- Better representation of diverse communities requires culturally sensitive communication and collaboration with local organisations.
- Sharing data and secondary use of data in research are essential, provided that participants' data are protected. They will accelerate scientific progress, reduce duplication of research and improve the use of limited resources.
- Misuse for commercial purposes, breaches of confidentiality and possible illegal activities must be avoided at all costs when sharing research participants' data.

6. Perspectives of researchers, clinicians, funders and regulators

Outlining practical barriers to data sharing within the dementia field – a case example of the Swedish dementia registry landscape

Professor Linus Jönsson is a medical doctor and professor of health economics at the Karolinska Institutet in Stockholm, Sweden. His research focuses on the economic modelling of disease-related costs, as well as the cost effectiveness of treatments and interventions.

Conducting impactful dementia research increasingly depends on the linkage of diverse data sources, including biomarkers, genetics, health economic information and routine healthcare records. Such linkage allows more accurate modelling of disease progression, outcomes and costs. Registry systems like the one present in Sweden are well suited to this approach: personal identity numbers enable linkage across national healthcare databases, quality registries and population registers. However, while the data collected is abundant, accessing and sharing these data for research remains challenging in practice.

In Sweden, routine healthcare data are highly fragmented, with information held by multiple national agencies, quality registries and 21 regional healthcare authorities, each having their own approval processes and timelines. As a result, assembling a single research dataset can take years, even for experienced researchers - projects thus move at the pace of the slowest data holder. Moreover, access is generally granted only for narrowly defined research questions, without mechanisms for broad or forward-looking permissions in place. This severely limits data reuse and efficiency.

In addition to these procedural barriers, data linkage is itself a major bottleneck. Researchers cannot handle personal identity numbers themselves, so linkage must be performed by a single national authority with limited capacity. Researchers must also justify each requested variable in detail, even after full ethical approval, leading to prolonged exchanges that further delay data access.

Professor Linus Jönsson

A further barrier are differences in how GDPR rules are interpreted and applied. Different regions and institutions adopt different interpretations of the same legislation, reflecting varying risk tolerance and governance cultures. This inconsistency hampers automation, innovation and collaboration. In this sense, clearer national and EU-level guidance on balancing privacy risks with research benefits are urgently needed and would allow for more consistent and proportionate data sharing.

Finally, representativeness within registry data remains a concern. Immigrant and minority populations are underrepresented in research and routine care data, partly due to later diagnosis and cultural or language barriers. Developing culturally neutral assessment tools and targeted approaches is essential to improving inclusion and data quality.

> “Clearer national and EU-level guidance on balancing privacy risks with research benefits is urgently needed and would allow for more consistent and proportionate data sharing.”
>
> Professor Linus Jönsson

Challenges to participant recruitment and data sharing in routine care research

Professor Jochen René Thyrian is full professor in interventional health care research at the German Center for Neurodegenerative Diseases in Greifswald, Germany. His research focuses on the development of interventions for people living with dementia and their implementation into existing routine care pathways. He is also board member of the German Alzheimer Society and of Alzheimer Europe.

Professor Jochen René Thyrian

Recruiting participants for real-world evidence studies frequently involves a trade-off between convenience and validity. Convenience samples allow researchers to reach participants quickly, but findings are often limited in their generalisability. Within primary care research, recruitment through general practitioners is far more representative, as this reflects how people actually enter the healthcare system. However, it is also much slower, more resource-intensive and harder to implement. The recruitment strategy must therefore match the research aim: exploratory studies can rely on "easier access routes", while research intended to change care practice must take the more demanding path.

Regardless of approach, reaching people from minority groups, such as those with migration background, often remains one of the greatest challenges. In Germany, despite targeted nationwide efforts and collaboration with religious leaders, community centres and social workers, participation from migrant communities has been very low. These recruitment difficulties reflect broader gaps in healthcare access, language barriers and cultural perceptions of dementia, which also leads to systematic underrepresentation in routine care data.

Participation is also shaped by awareness, trust and perceptions of the way research is conducted. Over time, general awareness of dementia has improved, making participation more acceptable in the wider population. However, there is still a lot of work to do when it comes to helping people understand what research is for and how results will benefit them or others.

Moreover, participation formats are often not dementia-sensitive. Long meetings or advisory boards lasting several hours can be stressful and exclusionary. Study designs must better reflect the everyday realities and limitations of people with dementia, particularly in longitudinal research where mobility and clinic visits become barriers.

Patient organisations play a crucial facilitating and protective role when it comes to involving people with dementia in research. For example, the German Alzheimer Society connects researchers with people with dementia and carers, supports awareness-raising and amplifies patient voices, including those of people with younger onset dementia.

Data sharing is crucial for transparency and scientific progress, but it needs to be handled with care. When data are shared, their validity must be kept in mind and carefully considered in the way they are used and interpreted. Especially with secondary data such as health insurance records that were never collected for research in the first place. This is an underestimated limitation in their interpretation. Clear guidance, appropriate oversight and collaborative approaches to data analysis can help maintain data quality while protecting participants. While the GDPR plays an important role, its interpretation should be proportionate and equally applied. In the end, trust-based frameworks that accept a small level of risk are often more effective than heavy regulation that can hinder meaningful research.

"Study designs must better reflect the everyday realities and limitations of people with dementia, particularly in longitudinal research where mobility and clinic visits become barriers."

Professor Jochen René Thyrian

Rethinking recruitment in psychosocial research: Participation starts with relationships

Dr Gili Yaron is a senior researcher at Windesheim University of Applied Sciences in the Netherlands. Trained as a social philosopher, Gili focuses primarily on 'relation-centred care'. Her fellowship CONTACT (2024-27) uses participatory methods to develop tools for improving the relationships between people living with dementia and their (informal) carers. Gili is based in the research group Living Well with Dementia.

Dr Gili Yaron

Participation in dementia research needs to be seen in the context of a broader shift from focusing on cure and care systems to centring on people's lives. People with dementia do not experience their condition in protocols or outcome measures, but in their everyday relationships, routines and environments. If research wants to be inclusive, it has to start from those lived experiences, rather than expecting people to fit into existing research designs.

Stigma is still a major barrier to participation in research. Dementia is often immediately linked to decline, loss and hopelessness, and that shapes how people with dementia are viewed and treated. Many people already have to deal with avoidance, awkward reactions or well-intended but unhelpful comments from others. As such, being asked to take part in research can feel like yet another demand that highlights their cognitive disabilities.

Recruitment is therefore not just a practical step. It is affected by people's social experiences. Moreover, recruitment is heavily influenced by relatives and professionals who act as 'gatekeepers', often out of concern that participation will be too burdensome or emotionally difficult. While these concerns are understandable, gatekeeping may neglect people with dementia's ability and willingness to contribute meaningfully. For many, participating in research can actually create a sense of being taken seriously and being of value, as long as it is done in the right way.

These issues are even more visible in psychosocial and participatory research. This kind of work often involves repeated meetings, group discussions and conversations about sensitive topics such as care decisions, family relationships or future planning. That can be demanding, both cognitively and emotionally, for people with dementia and their families. As a social researcher, you cannot simply collect data and leave. You become part of participants' lives, and that comes with responsibility, care and sometimes difficult choices.

Time and funding are a constant problem. Building trust and relationships takes a long time, but research projects are usually short and tightly planned. Recruitment through professionals such as case managers is slow, not because they are unwilling, but because they are already stretched and research is rarely their priority. What is really needed is researchers' long-term presence and visibility, but that is exactly what current funding structures do not support.

Similar tensions come up around data sharing. Open science is important, but in qualitative and participatory dementia research the data are often deeply personal and contextual. Fully anonymising interviews is time-consuming and sometimes simply not realistic without risking identification. In practice, it often makes more sense to share things like protocols, topic guides or analytic approaches, rather than raw interview data.

In the end, inclusive dementia research is less about better rules or more guidelines, and much more about maintaining relationships. It requires trust, time and a genuine effort to meet people where they are. To this end, researchers must develop relational competences-but this is rarely part of their training. Meaningful participation only becomes possible when research adapts to the realities of people with dementia, instead of expecting people with dementia to adapt to research.

> "If research wants to be inclusive, it has to start from those lived experiences, rather than expecting people to fit into existing research designs."
>
> Dr Gili Yaron

Integrating recruitment into clinical research and routine patient care

Dr Kristian Steen Frederiksen is a senior consultant neurologist at the Danish Dementia Research Centre in Copenhagen, where he also serves as director of the Clinical Trial Unit. His research focuses on biomarkers for the early detection of neurodegenerative dementias and their clinical application, as well as research into communication of diagnosis, early disease mechanisms and interventions.

Clinical research in dementia works best when it is closely connected to everyday patient care. Regular contact with people living with cognitive impairment and their carers offers insights into real needs, concerns and limitations that no dataset can fully capture. Research that is detached from clinical reality risks missing what actually matters to patients.

Research participation should be seen as a right and an opportunity for patients, not an added burden. When studies are integrated into routine care, participation becomes normal and widely accepted. In healthcare systems with high levels of trust, most patients are willing to contribute their data and biological samples when the purpose and safeguards are clearly explained. High consent rates reflect trust in clinicians, institutions and governance, not a lack of concern about data protection. Most patients believe their data will be used responsibly and for the common good. In my experience, when people do not want to participate, this is usually due to practical barriers, emotional overload around the diagnosis, rather than active resistance.

Only a small minority of patients express distrust or concern about data use, sometimes linked to broader scepticism toward authorities or to disease-related symptoms. These cases underline the need for sensitive communication, not more restrictive regulation. Data sharing poses much greater systemic challenges. Legal and ethical requirements are interpreted inconsistently across and within countries, creating uncertainty and slowing collaboration. Researchers are often expected to navigate complex legal frameworks without clear or stable guidance, despite lacking legal expertise.

Dr Kristian Steen Frederiksen

Strict requirements to define narrowly specified research aims limit the ability to share data through long-term or open-ended research infrastructures. This creates obstacles for participation in international consortia designed to maximise data reuse and scientific value. Moreover, interpretations of anonymisation and GDPR are frequently overly cautious and disconnected from clinical and research realities.

National registry systems show that large-scale, high-quality data collection is possible when governance is clear, centralised and mandated. These systems support representative, longitudinal research and reduce bias, but they remain unevenly developed across Europe and are often difficult for international partners to access.

Academic incentives also shape data-sharing behaviour. Researchers must balance openness with career progression, funding pressures and publication priorities. Although data sharing is widely supported in principle, it is often delayed to protect future research opportunities.

> “Research participation should be seen as a right and an opportunity for patients, not an added burden.”
>
> Dr Kristian Steen Frederiksen

Data sharing in European research projects - the funder's perspective

Dr Niklas Blomberg is executive director of the EU's Innovative Health Initiative (IHI). He has an academic background in chemistry and bioinformatics and also held industry positions, before joining the IHI in 2024.

European health research increasingly depends on collaboration across institutions and countries. Within our funding calls, we therefore generally place a strong emphasis on open science. Applicants are required to describe their data management approach and explain provisions for open access and open data. Increasingly, not only publications but also the underlying data are encouraged to be made publicly available. At the same time, we of course respect the intellectual property of the individual partners and consortia.

Each funded project operates as an independent entity under its own grant agreement and internal consortium arrangements. This also concerns the use and re-use of the vast amounts of data collected during IHI-projects. Collaboration between projects is therefore voluntary. That being said, we do encourage the exploration of synergies through coordinated meetings and activities. In this regard, we are pleased to see the openness for collaboration between various IHI-funded projects within the dementia field, including AD-RIDDLE, PROMINENT and ACCESS-AD.

As research funder, the most important instrument in shaping research practice we hold is the topic text. Proposals are assessed by independent reviewers against the wording of the call. The job of the evaluator is to compare the submitted proposal with what is written in the topic. For this reason, the way we define topics is central. If elements such as open data, data management and patient centricity are clearly referenced, they become part of the selection criteria for funding.

In light of this, we consistently reference patient centricity in topic texts and programme objectives. Clear wording allows evaluators to assess how well proposals describe patient engagement. Across projects, we encourage patients and carers to increasingly seek active roles beyond study participation, including involvement in advisory boards, protocol review and trial design. Dedicated initiatives also address diversity and equity in clinical research, including efforts to improve representation of underserved populations. Funders can further reinforce these priorities through concrete actions, such as involving patient organisations in stakeholder meetings and brokerage events. Sustained and consistent emphasis over time has contributed to the gradual progress in embedding patient participation within IHI-funded research.

Dr Niklas Blomberg

The IHI Data Sharing Playbook

Partners involved in IHI projects frequently face challenges in the sharing, and thus making optimal use of, the large volume and diversity of data collected. To facilitate and accelerate data sharing between partners and consortia, and to support them in navigating the associated complexities associated with it, the IHI has developed the "Data Sharing Playbook"

The playbook provides guidance on fundamental concepts of data sharing and defines the roles involved in the process, including project coordinators, data protection officers, and GDPR experts. It presents practical recommendations for enhancing data sharing within public-private partnerships and offers resources to address specific practical challenges across the project lifecycle.

> “Dedicated initiatives can address diversity and equity in clinical research, including efforts to improve representation of underserved populations.”
>
> Dr Niklas Blomberg

Promoting clinical data sharing across Europe – the regulatory perspective

Dr Peter Arlett is Head of the Data Analytics and Methods Task Force at the European Medicines Agency (EMA). He is a medical doctor and in addition to his role at the EMA holds a position as Honorary Professor at the London School of Hygiene and Tropical Medicine.

Dr Peter Arlett

The EMA plays a central role in facilitating data sharing to stimulate research for regulatory purposes in Europe, starting with the promotion of transparency on clinical studies on medicinal products. Regarding interventional research, the Agency developed and maintains the Clinical Trials Information System, which supports the flow of information between clinical trials sponsors, EU Member States, EEA countries and the European Commission. Anybody can view information held on clinical trials conducted in the EU and EEA, by using the searchable public website. The clinical trial map developed in the context of the Accelerating Clinical Trials in the EU (ACT EU) initiative is available to help patients and healthcare professionals locate clinical trials conducted in their area. Concerning non-interventional research, EMA strives to exploit the potential of other types of data, such as real-world data (RWD), by improving the discoverability of RWD sources and stimulate collaboration on non-interventional research thanks to the HMA/EMA catalogues. The EMA also facilitates data sharing through the DARWIN EU network, with established processes for accessing and analysing RWD, and results being made publicly available through the HMA/EMA catalogues.

In addition, the EMA contributes to the implementation of the European Health Data Space (EHDS), for example in an advisory capacity for the TEHDAS2 project producing guidelines for secondary use of health data. These efforts help create trustworthy and transparent structures for data access and sharing that support regulatory decision-making on safe and effective medicines.

Clinical evidence on medicines is generated to support patients' needs and public health. Through their engagement, patients provide critical insight into their medical needs and what really matters to them at every level of healthcare decisions. Patients have been progressively involved in EMA's processes, where they bring their personal experience, knowledge and expertise both on the conditions and the available treatment options. Increasing patient involvement in all aspects of evidence planning, evaluation and decision-making will further strengthen medicines development, whilst highlighting the value of data sharing.

In general, and not specifically in clinical dementia research, key barriers to data sharing include difficulty identifying relevant healthcare data sources, fragmentation of information, governance issues and data processing timelines. The EHDS has great potential to improve these challenges.

Data formats are often non standardised, creating challenges for conducting studies across different datasets, unless common data models are implemented. Finally, there is sometimes a limited understanding of the quality of data sources to support regulatory decision making, and linkage between data sources is not always possible, emphasising data fragmentation.

Legislative changes could provide a clear framework enabling secure and efficient data sharing across Europe, such as those through the EHDS. Openly demonstrating the public health value of data sharing (such as its role in improving the development and evaluation of treatments)can also incentivise participation. Establishing secure, trustworthy and transparent processes for data sharing would build confidence among data holders, such as the use of secure processing environments. Ultimately, showing that shared data can accelerate the development of better therapies for patients and improve healthcare delivery would create strong motivation for broader engagement. The EHDS aims to ensure that individuals and healthcare professionals can securely access and share relevant health data across healthcare providers and EU Member States. This will include key clinical information such as electronic prescriptions, and patient summaries, with the aim of supporting

continuity of care, better clinical decision-making and patient safety, particularly when patients receive treatment in different healthcare systems.

The EMA requires evidence to be generated using data from EU populations to ensure relevance for regulatory assessment. Reviewers consider the source of evidence to confirm its applicability to EU patients and may request supplementary information when needed. Scientific advice may be sought to establish a dialogue with regulators and align study design with population needs and ensure evidence robustness. DARWIN EU, the EMA's network of data sources and expertise, has so far onboarded 40 data partners from 19 countries to ensure that RWE generated for the EMRN via this network is as representative as possible of the total EU population.

Summary

- Dementia research increasingly relies on linking different types of data and on close connections with routine care, but in practice research systems, data infrastructures and clinical reality are often poorly aligned.
- Accessing and linking data remains a major challenge due to fragmented data holders, limited linkage capacity, lengthy approval procedures and narrowly defined permissions that restrict data reuse and slow down research.
- Inconsistent interpretation of GDPR and ethical requirements across regions and institutions creates uncertainty for researchers and hampers collaboration and (inter-)national data sharing.
- Recruitment into dementia research involves difficult trade-offs between feasibility and representativeness.
- People with migration or minority backgrounds are still consistently underrepresented in research and routine care data, reflecting language barriers, cultural perceptions of dementia, later diagnosis and broader gaps in healthcare access.
- Participation is shaped by social experiences, trust and study design. Stigma, gatekeeping by relatives or professionals, time demands and non-dementia-sensitive formats can discourage participation, even if people with dementia are willing and able to contribute.

7. Discussion and recommendations

The profound emotional, societal and financial impact of dementia highlights the urgent need for transferable and impactful research across all aspects of the condition. Ensuring representativeness in participation and the effective use of collected data is essential to advancing dementia research and improving outcomes. This report has brought together the perspectives of people affected by dementia, researchers and members of the general public to identify key barriers and enablers to participation in dementia research and data sharing. The following section provides an overview of the cross-cutting key learnings emerging from the different components of this project and outlines a set of actionable recommendations.

High perceived value of dementia research and data sharing

Across the different elements of this project, views on research participation and data sharing were largely positive. People affected by dementia often described taking part in research as a way to "give back" and to "remain in control", with altruism and a genuine wish to contribute to science emerging as important motivating factors. Researchers also highlighted the importance of a more rights-based approach to dementia research, seeing participation in studies as something linked to respect for autonomy and inclusion. In its own regard, more advanced dementia should not exclude someone from participating in research. Instead, research should be adapted to enable people with dementia to take part meaningfully for as long as possible, in line with principles of reasonable accommodation and rights for people with disabilities[66,67].

> "Sharing data among different groups of researchers means joining and multiplying talent, which is always positive for both current and future patients."
>
> Person with dementia

Similarly, people with dementia, carers, researchers and members of the general public largely saw data sharing as essential for progress in dementia research. In line with this, most survey respondents indicated that they would be willing to have their data shared, provided that their privacy was protected. This was also reflected in discussions with people affected by dementia, who were generally supportive of data sharing, as long as appropriate safeguards for privacy and data protection were in place.

Knowledge of research opportunities and accessibility

Despite generally positive attitudes towards research participation, access to research opportunities remains a significant challenge. Participation not only requires awareness of available studies, but also an understanding of what dementia research is. Of note, our survey findings showed that a clear majority of respondents reported low awareness of opportunities to take part. This was echoed in focus group discussions with people with dementia and carers, who highlighted a lack of accessible and understandable information about ongoing studies, as well as limited outreach strategies that often rely too heavily on specific channels such as social media. Medical professionals were frequently described as key "gatekeepers" to research participation, shaping both knowledge of and access to research opportunities. Closer integration of research recruitment into routine care, alongside stronger links between research and clinical practice, was therefore seen as a potential way to address this gap.

Challenges related to accessibility were particularly pronounced for people from minority groups. Difficulties in involving ethnic minority communities in dementia research were identified in the scoping review and also reflected in interviews with researchers, as well as in discussions with people affected by dementia. Across these sources, there was a shared recognition of the need for more active and targeted outreach efforts. Building trust and sustained relationships that extend beyond the duration of a

single study was repeatedly highlighted as essential for meaningful and inclusive participation.

In addition to informational barriers, practical and logistical challenges were also found to limit participation in research. These included issues related to travel, costs and the unavailability of appropriate carer support. Participants across the project underlined the importance of practical measures such as travel arrangements or reimbursement, as well as access to interpretation services, in order to reduce barriers and support participation across different stages of dementia and diverse population groups.

> "When we speak about disclosing information, many suspicions come to our mind: we imagine not less than our bank account being emptied by thieves. Researchers should communicate that sharing our data will not make us more vulnerable if they are not linked to our names. Likewise, there is little awareness of the benefits of data sharing."
>
> Person with interest in dementia research

Trust and privacy concerns

Across the different elements of the project, trust emerged as a central factor in relation to both research participation and data sharing. A lack of trust was identified as a major barrier to recruitment. People with dementia repeatedly emphasised the importance of building relationships between researchers and participants that are based on mutual respect and transparency. Trust was often described as something developed at an interpersonal level, with individual relationships seen as more influential than the general reputation of a research institution.

Concerns related to privacy and the safe handling of data were raised by a smaller proportion of survey respondents but remained relevant to decisions about data sharing. Existing data protection safeguards within the EU were widely perceived as reassuring. In line with this, the clear majority of survey respondents indicated that they would be willing to have their data shared with other researchers based in Europe, while showing greater reluctance towards data sharing outside Europe.

Information and communication

Many of the barriers to research participation and data sharing identified across the project may be at least partially addressed through clear, ongoing and accessible information and communication. Concerns about potential physical or psychological risks may be linked to misunderstandings about research procedures, highlighting the need for patient and transparent explanations and opportunities to ask questions throughout the research process and beyond. The importance of receiving feedback on study outcomes, at least in aggregated form, was a consistently raised issue throughout elements of this project.

Clear information and communication are also essential when it comes to how data are used and shared. People should be informed not only about the purpose of data use, but also about the benefits of data sharing. Clearly explaining opt-out options, alongside strong accountability and data governance practices, helps build trust that personal information is handled responsibly and securely. Building on the need for clear communication and trust, people included in the focus groups favoured secondary consent models that balance transparency, choice and feasibility. Clear withdrawal options and independent, representative oversight were viewed as essential for maintaining people's confidence.

Practical barriers to data sharing

In addition to concerns about information and transparency raised by people affected by dementia and the general public, researchers pointed to several practical issues that make data sharing in dementia research challenging. Specifically, researchers described how differing interpretations of GDPR requirements across institutions can create fragmented procedures, added administrative work and long delays, limiting

collaboration and data reuse. Linking different types of data, such as clinical records, biomarkers and genetic information, was highlighted as a particular bottleneck, with researchers often relying on central authorities to perform the linkage. Dementia registries were seen as a promising avenue, offering high-quality, longitudinal data and more streamlined, centralised access, though their coverage and accessibility remain uneven across Europe. Broader structural challenges, including narrowly defined consent and cautious governance practices, as well as academic pressures, can further slow data sharing, highlighting the need for clearer, proportionate frameworks that balance data protection with research value.

Recommendations for promoting research participation

- To enable informed and meaningful participation in research, researchers should ensure clear, accessible and plain-language communication about study procedures, risks and data use and make sure these are properly understood by participants. They should also provide opportunities for dialogue and questions, equip clinicians with tools to discuss research participation and establish structured ways for providing feedback about study outcomes.
- To reduce stigma and structural barriers limiting participation in dementia research, policymakers, funders, researchers and public authorities should support awareness-raising and community engagement activities about dementia in general. To this end, researchers should also aim to develop long-term partnerships with national Alzheimer's associations.
- To strengthen trust and increase participation of culturally diverse groups, funders, research institutions and policymakers should promote long-term, trust-based partnerships between researchers and participants, by active involvement of community organisations and ambassadors (e.g. religious leaders) and the provision of cultural competence training for researchers.
- To improve representativeness and inclusiveness in research participation, funders and research institutions should support proactive, context-specific recruitment strategies, including the co-design of recruitment materials with members of underrepresented communities and working to specifically address discriminatory recruitment practices that systematically exclude people from marginalised groups.
- To remove practical barriers, funders should ensure that study budgets and protocols include measures to enhance accessibility, such as flexible scheduling or transport, compensation for time and costs, reasonable accommodations and interpretation services.
- To reinforce trust and ethical integrity in research participation, funders and research institutions should embed Public Involvement throughout the research lifecycle, ensuring that people affected by dementia have a meaningful role in study design, execution and communication of results.

Recommendations for promoting data sharing

- To ensure informed data sharing practices, researchers should provide clear, accessible and plain-language communication about how data will be used and who might access it, but also the anticipated benefits of data sharing for the individual and society. They should also provide opportunities for participants to ask questions and receive updates on the impact of their contribution.
- To support transparency, research institutions should implement consent frameworks, allowing participants to make informed choices about secondary data use and to withdraw consent to the secondary use of data at any time without this affecting their involvement in the primary study. At the same time, such approaches should be simple and accessible concerning the amount of choice provided.
- To strengthen trust in data sharing, researchers should prioritise personal engagement, providing face-to-face interactions, respectful dialogue and consistent demonstration of integrity in managing participant data.
- To reinforce ethical oversight and accountability, funders and research institutions should ensure independent review boards or data access committees include people with lived experience of dementia alongside researchers and ethics or legal experts, ensuring that decisions about data sharing are transparent, responsible and participant-informed.
- To build confidence in data protection, researchers should clearly explain safeguards such as anonymisation, GDPR compliance and security measures in plain language, while acknowledging and managing potential residual risks.
- To mitigate the effect of fragmented interpretations of GDPR requirements, policymakers and legislators should create clearer guidance, including codes of conduct and standard agreements for data sharing between research institutions.
- To encourage responsible data sharing, policymakers, funders and research institutions should reward transparency and openness in academia, recognising and incentivising researchers who share data responsibly.

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