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Review

Pathways to participation – a scoping review outlining barriers and enablers to participation in dementia research

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ABSTRACT

Background: Ongoing participant recruitment challenges in dementia research highlight the need to understand public perspectives on research participation. This scoping review explored existing literature on barriers and enablers to the recruitment and retention of participants in dementia studies.

Methods: A scoping review was conducted in PubMed and PsycINFO, following the Arksey and O'Malley framework, using a keyword profile informed by a pilot search (full protocol available at osf.io/n8j4u). Abstract and full text screening were performed in duplicate and data were extracted using predefined criteria. Reported barriers and enablers were grouped into overarching themes. A panel of people with dementia and carers subsequently shared their perspectives on recruitment challenges and reflected on the review findings.

Results: Forty-five publications were included for narrative synthesis, representing 112,011 participants (pooled mean age = 69.3 years; 64.8 % female). Most studies originated from the U.S. and focused on clinical dementia research, with an emphasis on recruitment rather than long-term retention. Barriers were grouped into eight themes: mistrust; fears, worries and concerns; awareness; beliefs and attitudes; practical and logistical constraints; study-related factors; informational barriers; and barriers related to carers and support systems. Enablers included internal motivators (e.g. altruism) and external facilitators (e.g. financial compensation or flexible scheduling).

Conclusions: While significant research gaps remain, many barriers to participation in dementia research appear modifiable. Targeted actions addressing these modifiable factors may enhance recruitment and retention, which may strengthen the inclusivity and impact of dementia research.

1. Introduction

The number of people living with dementia is projected to increase substantially in the upcoming decades [1,2]. Comprehensive, high-quality research across scientific disciplines is crucial for understanding disease mechanisms, determining the effectiveness of treatments, exploring options for risk reduction and prevention and enhancing clinical and care procedures. Regardless of research area, representativeness of study participants is indispensable for ensuring the applicability of study outcomes to the respective populations of interest.

Ongoing difficulties recruiting participants across dementia research fields present a threat to statistical power and the external validity of studies and hampers extrapolation of study results [3]. Certain minority groups (e.g. ethnic minorities) have been found to be at higher risk for developing dementia and yet remain chronically underrepresented in clinical trials and epidemiological research [4,5]. For example, one systematic literature review examining ethnic and racial diversity in United States (U.S.)-based non-pharmacological dementia prevention trials found an estimated pooled proportion of ethnic and racial minorities of 25.6 % (who represent approximately 30.4 % of the U.S. population [6]). Another systematic review suggested that underrepresentation in clinical trials may be more severe [7]. In addition to obstacles regarding the initial recruitment of participants, dementia studies have been marked by high and differential attrition rates in longitudinal designs, reinforcing existing imbalances in representation [8]. Such difficulties in retaining study participants over time not only pose a threat to generalizability of results, but to internal validity as well. In particular, given that attrition is frequently non-random, resulting changes in group composition may bias associations between predictors and outcomes [9].

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These challenges warrant an in-depth assessment of factors influencing people's decision to participate in dementia research, and remain engaged over time. One systematic review explored the challenges involved in recruiting people with dementia in dementia care studies [10]. It found that challenges could be clustered into characteristics of those involved in the research process, the study itself, as well as the communication with participants. One additional systematic review examined potential barriers and enablers to recruitment and retention of underrepresented populations in dementia research [4]. It found that mistrust of study personnel and procedures, fear of complications and insufficient information regarding study methods were among the most frequently mentioned barriers to participation. Given that previous reviews focused on the U.S. or specific minority groups, there is a need to broaden and extend the discussion to other geographical and cultural settings.

In 2019, the U.S. National Institute on Aging published its *National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research*, outlining several objectives aiming to increase recruitment and retention in clinical dementia studies [11]. Few such resources exist for other research areas (e.g. epidemiological studies) or geographies (e.g. Europe). To effectively address the shortage of study participants across contexts, a more comprehensive assessment of the research landscape regarding barriers and enablers to research participation is necessary.

Therefore, the current scoping review aims to identify gaps in the literature regarding barriers and enablers to dementia research participation, across different research areas, geographical and sociocultural contexts; to provide an overview of such factors and cluster them into overarching domains; and to provide recommendations regarding the enhancement of recruitment and retention strategies for researchers.

2. Methods

This scoping review was conducted in line with the methodological framework developed by Arksey and O'Malley [12]. Reporting was done following the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) [13]; A full review protocol is available in the Open Science Framework database (osf.io/n8j4u).

2.1. Information sources and eligibility criteria

We conducted a systematic search in the PsycINFO (using the EBSCOhost search engine) and PubMed databases for articles examining barriers and enablers to participation in dementia research between inception until the date of extraction on May 3rd 2024. No restrictions regarding publication dates were applied in order to comprehensively map barriers and enablers across different contexts, in particular given the anticipated limited number of studies in some areas. Relevant articles were identified using a keyword profile developed based on a pilot literature search. Specifically, keywords relating to the concepts of research participation, in combination with barriers/enablers/attitudes and dementia were selected. Individual keywords were added iteratively and results re-examined after addition or removal of a keyword. The full keyword profile can be found in Supplementary Table 1. The concept of dementia research was intentionally defined rather broadly, as those studies being conducted within the dementia field (e.g. clinical studies, epidemiological studies or care research), including participants with and without cognitive impairment. Studies examining attitudes towards the provision of biological samples to advance knowledge about dementia were thus also eligible.

Both studies examining factors associated with the initial recruitment and retention of participants were eligible. This included studies examining actual study enrolment, those assessing the intention to participate in a dementia research study in the future (e.g. enrolment in a dementia research registry) and those more broadly assessing attitudes towards dementia research. Studies reporting the effectiveness of interventions aiming to increase research participation were eligible. However, descriptive studies of recruitment approaches (i.e. those without an indicator of their effectiveness) were excluded. Both studies using quantitative (e.g. surveys or re-analysis of existing data) or qualitative (e.g. focus groups or interviews) methods were included. Narrative, systematic or scoping reviews were excluded, but their references screened for potentially missed articles. Given the scoping nature of this review, we did not impose any restrictions with regard to participant characteristics. Furthermore, no assessment of study quality was conducted. Eligible studies were published in English language and in peer-reviewed journals.

2.2. Study selection and data extraction

After automatic and manual removal of duplicates, a three-step screening process was followed. This entailed successive screening of titles, abstracts and full texts by at least two independent raters (LAD, SB, DG or AB). In case of disagreement, consensus was reached via dedicated discussion sessions. References of selected full texts were then scrutinized for additional relevant studies. Data were extracted using a standardized protocol presented in Supplementary Table 2. In short, this entailed the extraction of study and participant characteristics, in addition to reported barriers and enablers.

Barriers to research participation were defined as potentially modifiable factors negatively affecting the likelihood of (continued) participation in a dementia research study. Conversely, enablers of participation included potentially modifiable factors positively affecting the likelihood of (continued) participation. These could be both internal (referred to as *motivators,* e.g. willingness to help others) and external (referred to as *facilitators,* e.g. receiving financial compensation). Non-modifiable factors (e.g. age, biological sex or ethnicity) were also examined in order to identify characteristics of potentially underrepresented groups.

2.3. Data synthesis

2.3.1. Descriptive information

Participant characteristics, as reported by individual studies, were pooled using existing formula's presented by the Cochrane Handbook for Systematic Reviews of Interventions [14].

2.3.2. Clustering of barriers and enablers

Two raters (LAD and SB) manually coded extracted information regarding barriers and enablers and clustered them into overarching themes, following a narrative synthesis approach. This involved the individual coding of information extracted from included studies and the subsequent formation of themes and subthemes. In case of disagreement regarding clustering, discussions with an additional reviewer (DG or AB) took place. Information about non-modifiable factors (e.g. older age, advanced dementia) was handled in the same manner.

2.3.3. Consultation with people with lived experience

Public Involvement in dementia research is about the active involvement of members of the public (e.g. people with dementia, informal carers or people at a higher risk of dementia) in research projects other than as research participants. Public Involvement typically involves members of these groups working together with researchers and sharing their perspectives, experiences, concerns and needs regarding the research topic and how the research is designed and conducted.

For this scoping review, an online consultation was organized with people with dementia and carers who are members of two existing working groups set up and coordinated by Alzheimer Europe. The meeting was attended by two members of the European Working Group of People with Dementia (EWGPWD) and three members of the European Dementia Carers Working Group (EDCWG). Prior to the meeting, members received a summary of the main findings of the literature review and were asked to reflect on how the main topics and issues identified (i.e. barriers and enablers to research participation) resonated with their own personal experiences and views. During this meeting, perspectives on participation were discussed and members reflected on barriers and enablers identified in the literature.

3. Results

3.1. *Study characteristics*

Fig. 1 depicts a PRISMA-style flow diagram of the study selection process. Of 1717 unique studies identified by the initial search, 38 were included after initial title and abstract screening. An additional seven studies were identified through cross-referencing, yielding a total number of 45 studies (presented by a corresponding number of publications), representing 112,011 participants (range of n = 10 to n= 35,919). The majority of studies (n = 34; 75.6 %) were conducted in the U.S., followed by the United Kingdom (n = 4; 8.9 %), France (n = 2; 4.4 %), Switzerland (n = 1; 2.2 %), Germany (n = 1; 2.2 %), Sweden (n = 1; 2.2 %), Canada (n = 1; 2.2 %) and Australia (n = 1; 2.2 %; Table 1).

Pooled mean age of participants was 69.3 years (range SD's = 5.1 to 15.0 years) and across studies 64.8 % were female. Twenty-three studies (51.1 %) assessed barriers and enablers to participation in either cognitively healthy adults or mixed samples (including people with and without dementia; Table 2). Four studies (8.9 %) focused on people with dementia specifically, while one (2.2 %) study additionally included dementia carers. Two further studies (4.4 %) focused on dementia carers exclusively. Eleven studies (24.4 %) focused on minority groups, most of which aimed to explore attitudes to dementia research participation among African Americans. One study examined perspectives of dementia researchers and another those of general practitioners.

All included studies were cross-sectional, observational studies. Data collection methods used for capturing participants' views included dedicated surveys, interviews and focus groups, as well as secondary analysis of existing data. Specifically, of the 45 studies, 22 used quantitative approaches, either distributing dedicated surveys (n = 15) or analysing existing data (n = 7). The remaining 23 studies used qualitative methods, primarily focus groups (n = 8) and interviews (n = 14), with one study using expert consensus. Among the studies distributing

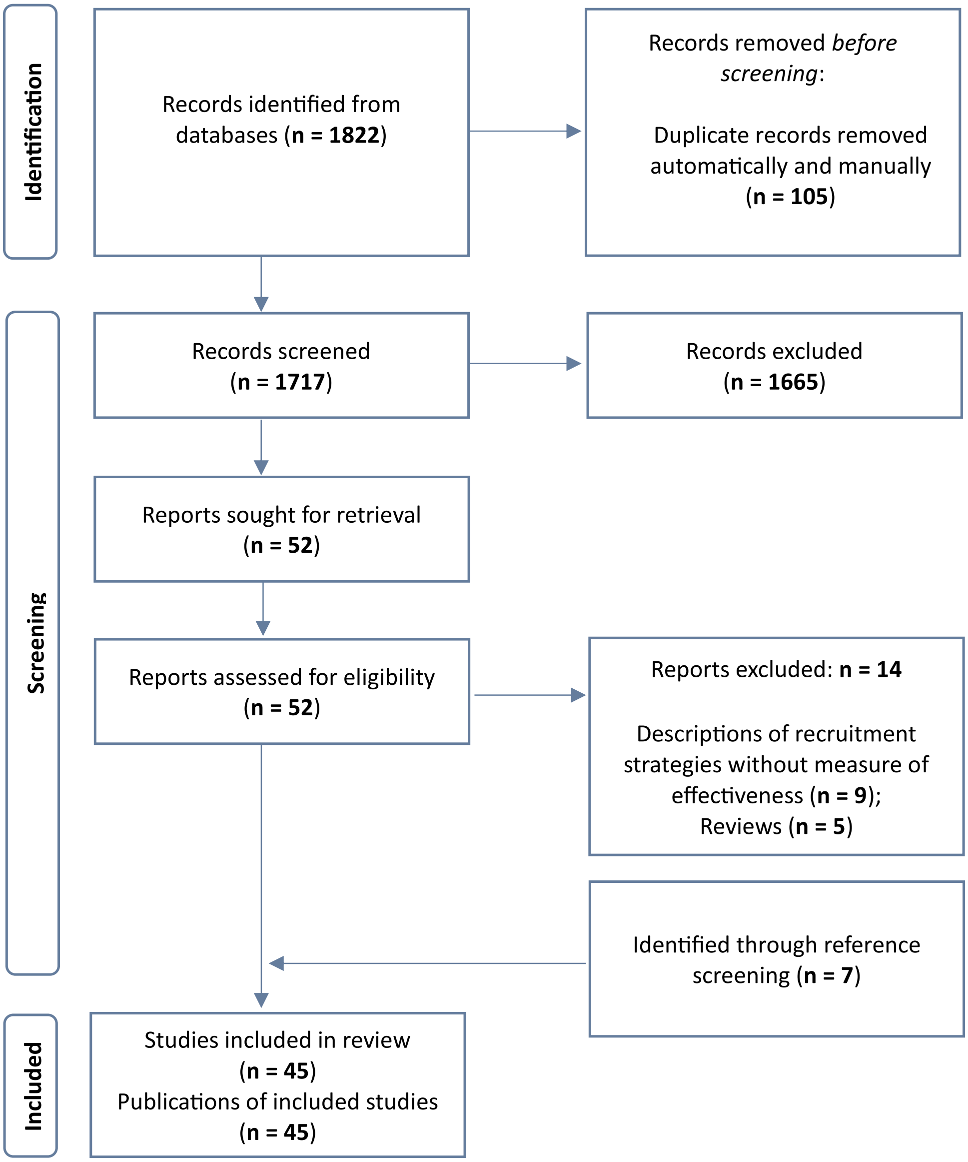

Fig. 1. PRISMA flow chart of the study selection process.

Table 1
Characteristics of included studies.

Author, year	Location	Study population	N	% Female	Mean age (SD)
Ashford et al., 2020 15	United States	Older adults (mixed)	35,919	71.4	65.7 (7.3)
Bardach et al., 2019 [16]	United States	Older adults (mixed)	27,519	56.9	Overall: 74.8 (unknown); Genetic sample: 71.7 (10.2); No genetic sample: 71.0 (10.4)
Bardach et al., 2020 [17]	United States	Older adults (mixed)	33	45.5	73.6 (5.1)
Bardach et al., 2021a 19	United States	African Americans	21	95.2	Group 1: 76.0 (8.6); Group 2: 61.3 (7.8); Group 3: 59.4 (13.3)
Bardach et al., 2021b 18	United States	Older adults (mixed)	502	57.8	78.8 (6.6)
Boise et al., 2017 20	United States	Older adults (mixed)	479	69.0	74.7 (8.8)
Bouranis et al., 2023 21	United States	People with dementia + carers	24	People with dementia: 58.3; Caregivers: 50.0	Not reported
Burke et al., 2019 8	United States	Older adults (mixed)	24,231	59.0	71.6 (10.0)
Clement et al., 2019 22	United Kingdom	Dementia researchers	17	Not reported	Not reported
Coley et al., 2008 23	France	People with dementia	686	71.1	77.9 (6.8)
Coley et al., 2021 24	France	People with dementia	1630	63.8	75.0 (72–78)
Cox et al., 2019 25	United States	Older adults (mixed)	49	55.1	Spousal patients: 76.9 (9.2); Non-spousal patients: 79.7 (10.0); Spousal partners: 72.3 (9.5); Non-spousal partners: 58.3 (12.0)
Cox et al., 2021 26	United States	Cognitively healthy older adults	200	62.0	72.1 (5.5)
Cox et al., 2023 27	United States	Cognitively healthy older adults	1028	51.8	Age groups: 50–54 (33.3 %); 55–59 (34.6 %); 60–64 (32.1 %)
Eliacin et al., 2022 28	United States	Cognitively healthy older adults	32	57.5	55–59 (16.7 %); 60–69 (41.7 %); 70–79 (33.3 %); 80+ (8.3 %)
Erickson et al., 2022 29	United States	Cognitively healthy older adults	334	74.0	64.8 (7.7)
Fiordelli et al., 2021 30	Switzerland	Older adults (mixed)	22	50.0	71.0 (9.3)
Fry et al., 2021 31	United Kingdom	British south Asian dementia carers	186	Not reported	Not reported
Gabel et al., 2022 32	United States	Older adults (mixed)	443	59.0	67.3 (8.1)
Gelman, 2010 33	United States	Latino dementia carers	39	79.0	Not reported
Goodman et al., 2011 34	United Kingdom	People with dementia	133	Not reported	Not reported
Grill et al., 2016 35	United States	Cognitively healthy older adults	132	70.0	Group 1: 73.1 (6.1); Group 2: 73.6 (6.2)
Hinton et al., 2000 36	United States	Chinese-American dementia carers	25	Not reported	Not reported
Hunsaker et al., 2011 37	United States	Cognitively healthy older adults	55	76.4	75.0 (range 66–90)
Jefferson et al., 2011a 38	United States	Older adults (mixed)	235	60.0	75.3 (8.1)
Jefferson et al., 2011b 39	United States	Cognitively healthy older adults	280	60.0	75.8 (8.5)
Ketchum et al., 2022 40	United States	African Americans	145	74.0	64.9 (range 46–85)
Lambe et al., 2011 41	United States	African Americans	15	66.0	71.0 (11.0)
Leach et al., 2016 42	Australia	Dementia carers	40	88.2	66.1 (18.5)
Lech et al., 2021 43	Germany	General practitioners and people with dementia	General practitioners: 28; People with dementia: 94	Not reported	Not reported
Lee et al., 2020 44	Canada	Older adults (mixed)	18	44.4	65.0 (5.1)
Li et al., 2022 45	United States	Older adults (mixed)	102	55.0	Patients: 74.1 (10.0); Carers: 70.2 (11.5)
Lincoln et al., 2021 46	United States	African Americans	44	70.5	67.9 (8.3)
Milani et al., 2023 47	United States	People with dementia	4881	58.7	60.5 (not reported)
Mundy et al., 2020 48	United Kingdom	Dementia carers	10	70.0	Not reported
Neffa-Creech et al., 2023 49	United States	Cognitively healthy adults	Focus groups: 39; Survey: 1010	Focus groups: 48.7; Survey: 60.8	Focus groups: Not reported; Survey: 60.6 (8.0)
Nissim et al., 2023 50	United States	African Americans	240	79.6	Age groups: 18–44 (31.7 %); 45–64 (33.8 %); 65+ (34.6 %)
Portacolone et al., 2020 51	United States	African Americans	146	79.0	65 (range 37–93)

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Table 1 (*continued*)

Author, year	Location	Study population	N	% Female	Mean age (SD)
Pugh et al., 2022 [52]	United States	African Americans	51	76.5	68 (5.9)
Sajatovic et al., 2023 [53]	United States	Adults (mixed)	207	74.8	57.6 (17.2)
Stites et al., 2021 [54]	United States	Older adults (mixed)	119	57.1	71.3 (8.1)
Striley et al., 2019 [55]	United States	Cognitively healthy adults	3279	66.5	Females: 47.6 (17.3); Males: 48.4 (17.0)
von Strauss et al., 1998 [56]	Sweden	Older adults (mixed)	923	76.0	83.8 (5.6)
Williams et al., 2010 [57]	United States	African Americans	70	73	52.4 (15.0)
Zhou et al., 2017 [58]	United States	Cognitively healthy older adults	125	White: 65.4; African American: 78.7	White: 73.9 (6.6); African American: 72.0 (5.2)

surveys, eleven used study-specific questionnaires, assessing barriers and enablers to either hypothetical study scenarios or actual past or future research participation. Moreover, six studies assessed general attitudes towards research using the Research Attitudes Questionnaire [59] or other instruments [29,35,38,39,45,54].

The majority of studies (n = 41; 91.1 %; Table 2) examined barriers and enablers to recruitment, while four studies (8.9 %) examined participant retention in epidemiological cohort studies [8,23,32] or clinical trials [54].

In the following sections, we describe common themes and subthemes that emerged from the 45 included studies. We present these separately for non-modifiable factors, modifiable barriers, motivators (i.e. factors *internal* to the person) and facilitators (i.e. factors *external* to the person). Fig. 2 contains a visual summary of barriers and enablers identified throughout studies.

While themes regarding barriers and enablers were largely consistent between study types, quantitative studies (e.g. those using questionnaires) more frequently identified barriers related to clinical characteristics and general attitudes toward research. In contrast, qualitative studies (e.g. those using focus groups) provided more nuanced accounts, also highlighting relational, cultural and contextual factors. Likewise, study populations differed. Quantitative studies tended to draw from broader populations, whereas qualitative studies more often focused on specific groups.

3.2. Non-modifiable factors related to dementia research participation

Non-modifiable factors related to dementia research participation were clustered into demographic and socioeconomic characteristics, health and cognitive status and cultural and personal influences.

Demographic and socioeconomic characteristics. Higher age was associated with a lower likelihood of enrolment in studies examining recruitment into research registries [15], multidomain lifestyle trials [24], biomarker research [29] and epidemiological studies [56]. Conversely, two studies examining attitudes towards brain donation found that a larger proportion of younger people were unwilling to consent to donation [55,20]. Findings regarding sex differences in recruitment and retention were inconclusive. In particular, only three studies identified differences in participation in relation to biological sex [15,55,16], two of which found that males were less likely to enrol [55,16]. Moreover, a variety of U.S.-based studies highlighted ethnic and racial (term used by included studies) disparities in dementia research participation, with African Americans and Latinx participants being generally less likely to participate [29,39,15,55,16]. Likewise, both less formal education [8,15] and lower income [24] were identified as factors associated with reduced participation.

Health and cognitive status. Studies found that people with cognitive impairment [8,45,56] including those with (more advanced) dementia [43,48] were less likely to participate, as were people with physical or psychological comorbidities [8,43,48] or functional impairment [23]. Moreover, two studies examining research attitudes among people with dementia suggested that those with higher levels of cognitive impairment were just as or even more willing to participate [45,47].

Cultural and personal influences. One study found that people possessing certain personality attributes including closeness or shyness were less likely to enrol in epidemiological dementia research [30]. Moreover, in three studies, greater levels of religiousness and spirituality were associated with a lower willingness to consent to brain donation [39,20,41].

3.3. Modifiable barriers related to dementia research participation

Identified modifiable barriers were divided into the following overarching themes: Mistrust, reflecting scepticism or lack of confidence in researchers, institutions or the research process; fears, worries and concerns, reflecting emotional responses to potential harm or consequences of participation; awareness, capturing whether participants know about research opportunities; beliefs and attitudes, referring to cognitive evaluations or value judgments about research; practical and logistic constraints, i.e. tangible circumstances limiting participation; barriers related to study characteristics, i.e. those related to the study design or objectives; informational barriers, involving insufficient or unclear information about study procedures or outcomes; and barriers related to carers and the support system, such as carer protectiveness. Though barriers were categorized as "modifiable" in principle, it is important to note that the degree of actual modifiability may vary.

Even though clusters of barriers are presented separately, they are not mutually exclusive. For example, scepticism about researchers (mistrust) may co-occur with fears of negative consequences. In the following section, each theme is described alongside its subthemes.

Practical and logistic constraints. Twenty-one studies identified practical and logistical issues as barriers to participation in dementia research (Table 2). Of those, 13 studies mentioned time constraints, inconvenient scheduling or competing social commitments as reasons for non-participation (Table 2). In one qualitative study, participants described dementia as a "race against the clock", underlining their preference to focus on things that bring them enjoyment in light of the condition [21]. Furthermore, difficulties reaching study locations, long distances to be travelled or a lack of transportation were mentioned by seven studies [29,38,32,21,37,40,58]. Financial difficulties or a lack of compensation were also raised as potential obstacle to participation by six studies [38,47,37,25,42,52], as were language barriers [31].

Awareness. A lack of awareness of research opportunities was mentioned as barrier to participation in four studies [24,21,28,49]. In two of these, the lack of recommendation from medical professionals was emphasized as reason for non-participation [24,49].

Beliefs and attitudes. Thirteen studies assessed specific beliefs and attitudes related to dementia research participation (Table 2). This included beliefs and perceptions about the general value of research,

Table 2
– Barriers and enablers of participation in dementia research as identified by included studies.

Author, year	Study focus	Study population	Data collection method	Recruitment/ retention	Barriers	Enablers
Ashford et al., 2020 15	Research registry	Mixed	(Re)analysis of existing data	Recruitment	**Modifiable:** None **Non-modifiable**: Older age[a], longer[a]/shorter[b] education, less memory concerns[a,c,d], being Latino or non-White[b], female sex[e]	Not applicable
Bardach et al., 2019 16	Genetic testing	Participants of National Alzheimer's Coordinating Center Uniform study	(Re)analysis of existing data	Recruitment	**Modifiable:** None **Non-modifiable:** Male sex, being African American or Hispanic, MCI	Not applicable
Bardach et al., 2020 17	Not specified	Past clinical trial participants	Interviews (not specified)	Recruitment	**Modifiable:** Mistrust, insufficient information, carer protectiveness **Non-modifiable**: None	**Motivators:** Altruism, hope for personal benefit, helping future generations, contributing to society **Facilitators:** Opportunity awareness, easy logistics, experience with research through careers
Bardach et al., 2021a 19	Not specified	African Americans	Focus groups	Recruitment	**Modifiable:** Mistrust, fear and avoidance of AD, low perceived value of research **Non-modifiable**: None	**Motivators:** Conversation and information **Facilitators:** Involvement in the research process; emphasizing need for research; normalization of memory problems
Bardach et al., 2021b 18	Clinical research	Participants of Kentucky Alzheimer's Disease Center longitudinal cohort + volunteers interested in AD research	Survey	Recruitment	**Modifiable:** Mistrust[f], concerns about effect on family members[f], concerns about inaccuracy of test results[f], belief that AD cannot be prevented[f], worries about losing insurance[f], fear of emotional response[f], less worry about AD[g], higher perceived stigma of participation[g], less perceived benefit[h] **Non-modifiable**: None	**Motivators:** Ability to plan for the future[f], make long-term care decisions[f], be reassured[f], learning about children's risk[f] **Facilitators:** None
Boise et al., 2017 20	Brain donation	Mixed	Survey	Recruitment	**Modifiable:** Belief that body should remain whole at burial, concern about disrespect by researchers during autopsy **Non-modifiable:** Younger age, non-Latino ethnicity	**Motivators:** None **Facilitators:** Clear information regarding study procedures and requirements
Bouranis et al., 2023 21	Clinical research	People with dementia + carers	Semistructured interviews	Recruitment	**Modifiable:** Low awareness of opportunities, time constraints, distance, carer burden, low digital literacy, study characteristics (having to take drugs), time-constraints **Non-modifiable**: personal preferences	**Motivators:** Helping others **Facilitators:** Carer support
Burke et al., 2019 8	Epidemiological research	Unknown	(Re)analysis of existing data	Retention	**Modifiable:** None **Non-modifiable:** Lower education, cognitive impairment, physical and psychological comorbidity	Not applicable
Clement et al., 2019 22	Clinical research	Patients, study partners, clinicians and trial staff working on the RADAR trial	Semistructured interviews	Recruitment	**Modifiable:** Poor record keeping, research not being embedded in AD care, difficulties with national database, gate keeping by health care professionals, lack of connection between study-sites, gate keeping by study partner, complex study materials, insufficient information, concern for clinical condition **Non-modifiable:** None	None reported
Coley et al., 2008 23	Epidemiological research	Participants in the REAL-FR study	(*Re*)analysis of existing data	Retention	**Modifiable**: Untreated patients, receiving medication other than cholinesterase inhibitors **Non-modifiable:** Presence of functional impairment	Not applicable
Coley et al., 2021 24	Multidomain lifestyle trial	Community-dwelling individuals	(Re)analysis of existing data	Recruitment	**Modifiable**: Higher anxiety, less fear of dementia, logistical	**Motivators:** Helping others, personal benefit from memory

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Table 2 (*continued*)

Author, year	Study focus	Study population	Data collection method	Recruitment/ retention	Barriers	Enablers
					constraints, lack of perceived benefit **Non-modifiable:** Older age, lower income	training, receiving health monitoring, preventative action, family history of dementia **Facilitators:** None
Cox et al., 2019 25	Clinical research	Clinical trial participants + partners	Semistructured interviews	Recruitment	**Modifiable:** Mistrust, fear of physical harm, inconvenience, lack of interest, risk related to dementia diagnosis, concern of not getting access to test results, belief that others will participate, costs associated with participation **Non-modifiable:** None	**Motivators:** Altruism, desire to help advance research, hope for direct benefits, learn more about condition, sense of community, family history of dementia **Facilitators:** None
Cox et al., 2021 26	Clinical research	Participants meeting the criteria of an AD drug trial	Survey	Recruitment[i]	**Modifiable:** Not having a study partner available, not wanting to cause inconvenience for partner, Not wanting partner to know about participation in research **Non-modifiable:** None	**Motivators:** None **Facilitators:** Presence of study partner
Cox et al., 2023 27	Clinical research	General US population (representative sample; use of weights)	(Re)analysis of existing data	Recruitment	**Modifiable:** Not wanting to be a "guinea pig", belief of not being affected by dementia, fear of physical harm, time constraints, fear of learning about oneself **Non-modifiable:** None	**Motivators:** Family history of dementia, perceived likelihood of developing dementia **Facilitators:** None
Eliacin et al., 2022 28	Biomarker research	Mixed	Semistructured interviews	Recruitment	**Modifiable:** Mistrust, fear of the unknown, fear of AD diagnosis, concerns about data security, lack of knowledge, concern of not getting access to test results **Non-modifiable:** None	**Motivators:** Individual benefits, community benefits **Facilitators:** Knowledge of research and clinical procedures, outreach from trusted sources
Erickson et al., 2022 29	Biomarker research	Participants of Wisconsin Registry for Alzheimer's Prevention or Wisconsin Alzheimer's Disease Research Center Clinical Core	Survey	Recruitment	**Modifiable:** Negative research attitudes, concerns about AD[j], anxiety about high-risk results, lack of perceived benefit, concerns about physical harm, time commitment, travel distance, concerns about confidentiality, concerns about discrimination, non-disclosure of study results **Non-modifiable:** Black race, older age[k],	**Motivators:** Desire to support research, interest in learning about own cognitive status, estimates future risk and plan, modify lifestyle **Facilitators:** None
Fiordelli et al., 2021 30	Epidemiological research	Past epidemiological study participants	Semistructured interviews	Recruitment	**Modifiable:** Mistrust, disinterest, fear, avoidance, time constraints **Non-modifiable:** Closeness, shyness, laziness	**Motivators:** Altruism, advancing knowledge, improving lives of patients, carers and society, prevent or slow down illness, sensitize towards illness, curiosity, civic engagement, interest, trust in science, openness **Facilitators:** Acknowledgment that research requires a lot of data
Fry et al., 2021 31	Care research	British south Asian dementia carers	Interviews (not specified)	Recruitment	**Modifiable:** Mistrust, stigma and shame, lack of information, language barriers **Non-modifiable:** None	**Motivators:** None **Facilitators:** Shared cultural/ ethnic background with researcher
Gabel et al., 2022 32	Epidemiological research	Clinical trial participants	Survey	Retention[l]	**Modifiable:** Difficulties keeping track of study procedures, emotional distress, fear of physical consequences, fatigue, inconvenient travel, study visits too long, emotional distress, breach of privacy[m] **Non-modifiable:** None	**Motivators:** Altruism, access to evidence-based care, learning about AD and memory concerns, enjoyment **Facilitators:** None
Gelman, 2010 33	Care research	Latino dementia carers who refused to enrol in a study evaluating a caregiver intervention	Interviews (not specified)	Recruitment	**Modifiable:** "Feeling too overwhelmed to participate" **Non-modifiable:** None	**Motivators:** None **Facilitators:** Public involvement of community members in development of interventions
Goodman et al., 2011 34	Care research	People with dementia living in care homes	Expert consensus	Recruitment[n]	**Modifiable:** Nursing home's approach to care, disruptions hindering resident care and routine tasks **Non-modifiable:** None	**Motivators:** None **Facilitators:** Have multiple researchers visit care home on one day, time to form relations

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Table 2 (*continued*)

Author, year	Study focus	Study population	Data collection method	Recruitment/ retention	Barriers	Enablers
						with care staff and explain study procedures
Grill et al., 2016 35	Clinical research	Community-dwelling individuals	Survey	Recruitment	**Modifiable**: Less favourable attitudes towards research **Non-modifiable**: None	**Motivators:** Higher perceived risk for AD **Facilitators:** Receiving study results, financial compensation
Hinton et al., 2000 36	Care research	Chinese-American dementia carers	Interviews (not specified)	Recruitment[o]	**Modifiable**: Dementia seen as normal part of ageing, low perceived benefit of participation, perceived stigma of dementia **Non-modifiable**: None	None reported
Hunsaker et al., 2011 37	Clinical research	Participants of the Memory and Aging in Urban and Rural Communities Study	Focus groups	Recruitment	**Modifiable**: Lack of perceived benefit, financial barriers, ease of transportation **Non-modifiable**: None	**Motivators:** Altruism, gaining understanding of memory status, benefits for family members **Facilitators:** None
Jefferson et al., 2011a 38	Clinical research	Members of the Boston University Alzheimer's Disease Center registry	Survey	Recruitment	**Modifiable**: Lack of time, lack of transportation, lack of compensation **Non-modifiable**: None	**Motivators:** Advance AD research, benefits for family, friends and future generations; address memory concerns, learn more about AD **Facilitators:** Transportation provided, possibility of home-visits, financial compensation
Jefferson et al., 2011b 39	Brain donation	Members of the Boston University Alzheimer's Disease Center registry	Survey	Recruitment	**Modifiable**: Perception of brain donation as too intrusive, **Non-modifiable**: More religiousness, black race	**Motivators:** Help to find a cure for AD, help advance in-vivo diagnosis **Facilitators:** None
Ketchum et al., 2022 40	Biomarker research	African Americans	Semistructured interviews	Recruitment	**Modifiable**: Concerns about physical harms of biomarker status testing, concerns about psychological consequences of test results, concerns about utility, time and travel constraints, stigma associated with testing results **Non-modifiable**: None	**Motivators:** Altruism, support research, desire to know biomarker status **Facilitators:** None
Lambe et al., 2011 41	Brain donation	African Americans	Focus groups	Recruitment	**Modifiable**: Mistrust, misconception of procedures, perceiving brain donation as too intrusive, belief that healthy brains are not needed, perceived racial discrimination in healthcare, family perceptions **Non-modifiable**: Influence of religion and spirituality	**Motivators:** Family history, desire to find cure, familiarity to medical and research setting **Facilitators:** Underlining benefit of prior brain research to black people
Leach et al., 2016 42	Clinical research	Dementia carers	Structured interviews	Recruitment	**Modifiable**: Financial constraints, time constraints, limited scheduling options, competing social commitments **Non-modifiable**: None	**Motivators:** Altruism, personal interest, help deal with stress **Facilitators:** Free respite care during study visits
Lech et al., 2021 43	Care research	General practitioners and people with dementia	Survey	Recruitment	**Modifiable**: Time constraints[p], disinterest[p], high care burden[q], low perceived utility of intervention[q], low digital literacy[q] **Non-modifiable**: Disease specialization of practice[p], comorbidity[r], advanced dementia[r]	**Motivators:** Perceived benefits for patients[p,q], interest in (dementia) research[p,r], assistance with patient management[p], assistance in dementia care[p], improved communication with GP[q], improved disease management[q], better insights into new health technology[p,q], **Facilitators:** Expense allowance[p], participation in raffle for tablet computer[q]
Lee et al., 2020 44	Research registry	Mixed	Semistructured interviews	Recruitment	**Modifiable**: Concerns about access to own health data and use thereof, lack of information about purpose of registry and data use, privacy concerns, enrolment process **Non-modifiable**: None	**Motivators:** Altruism, future research opportunities, early detection or diagnosis, health promotion and education, access to treatment **Facilitators:** Parking options, transportation reimbursement, refreshments
Li et al., 2022 45	Clinical research	People with dementia + carers	Survey	Recruitment	**Modifiable**: Mistrust **Non-modifiable**: Less severe cognitive impairment	None reported

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Table 2 (*continued*)

Author, year	Study focus	Study population	Data collection method	Recruitment/ retention	Barriers	Enablers
Lincoln et al., 2021 46	Clinical research	African Americans	Focus groups	Recruitment	**Modifiable**: Experience of unfair treatment and racism in the past, knowledge and beliefs about historical racism, fear of de-priorisation by the pharma industry, absence of cultural norm to get therapy or participate in research, lack of researchers with the same racial background **Non-modifiable**: None	**Motivators**: None **Facilitators**: Cultural competences of research staff
Milani et al., 2023 47	Not specified	Unknown	(Re)analysis of existing data	Recruitment	**Modifiable**: Study characteristics (requirement of overnight stay[r] /having to take medication) **Non-modifiable**: None	**Motivators:** None **Facilitators:** Receiving compensation
Mundy et al., 2020 48	Clinical research	Dementia carers	Semistructured interviews	Recruitment	**Modifiable**: Protectiveness of the person with dementia or the carer, inconvenient timing, comorbidity, low understanding of study procedures **Non-modifiable**: Severity of dementia	Not applicable
Neffa-Creech et al., 2023 49	Research registry (prevention research)	Cognitively healthy older adults	Focus groups	Recruitment	**Modifiable**: Mistrust, technophobia, beliefs and fears about dementia, confusion about the term "prevention", lack of recommendation by medical provider, privacy and security concerns, lack of time **Non-modifiable**: None	**Motivators:** Wanting to know more about AD prevention **Facilitators:** Quick registration process and few requirements
Nissim et al., 2023 50	Epidemiological research	African Americans	Survey	Recruitment	**Modifiable**: Mistrust, study characteristics (spinal tap, memory tests), inconvenient scheduling, misconceptions about research, lack of knowledge, fear, perceived racism **Non-modifiable**: None	**Motivators:** None **Facilitators:** Possibility of study visits in the weekend, care service at study site, possibility to complete some tests locally, access to test results, option to complete some tests at home, financial compensation
Portacolone et al., 2020 51	Not specified	African Americans	Focus groups	Recruitment	**Modifiable**: Mistrust, lack of transparency, awareness of current and historical challenges experienced by African American communities **Non-modifiable**: None	**Motivators:** Desire to engage in dementia research, desire for health-related information **Facilitators:** None
Pugh et al., 2022 52	Not specified	African Americans	Focus groups	Recruitment	**Modifiable**: Mistrust, long study duration, study characteristics (invasive procedures, pharmacological interventions) **Non-modifiable**: None	**Motivators:** None **Facilitators:** Financial compensation, provision of transport
Sajatovic et al., 2023 53	Not specified	Mixed	Survey	Recruitment	**Modifiable**: Mistrust, stigma, inadequate information about AD and dementia, concerns about interference with current treatment or access to care **Non-modifiable**: None	**Motivators:** Altruism, Receiving health-related information **Facilitators:** None
Stites et al., 2021 54	Clinical research	Participants of Resveratrol clinical trial	Survey	Retention[s]	**Modifiable**: Less favourable attitudes towards research[t] **Non-modifiable**: None	Not applicable
Striley et al., 2019 [55]	Brain donation	Non-Hispanic African American, non-Hispanic Caucasian, non-Hispanic other and Hispanic adults	Survey	Recruitment	**Modifiable**: None **Non-modifiable**: Younger age and male sex, being African American	**Motivators:** Past research experience, more general interest in research **Facilitators:** None
von Strauss et al., 1998 56	Epidemiological research	Participants of the Kungsholmen Project	Survey	Recruitment	**Modifiable**: Study-specific characteristics **Non-modifiable**: Older age, lower cognitive function	**Motivators:** Regular health checks, receiving advice from nurses/physician, improvement of care **Facilitators:** None
Williams et al., 2010 57	Biomarker research	African Americans	Focus groups	Recruitment	**Modifiable**: Mistrust, insufficient information, reputation of researcher and research institution, fear of the unknown, fear of adverse effects, inconvenience **Non-modifiable**: None	**Motivators:** Altruism, perceived relevance of research project **Facilitators:** Relationship with community beyond research interests, dissemination of findings

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Table 2 (*continued*)

Author, year	Study focus	Study population	Data collection method	Recruitment/ retention	Barriers	Enablers
Zhou et al., 2017 58	Biomarker research/clinical research	Cognitively healthy older adults	Semistructured interviews	Recruitment	**Modifiable:** Study risks[u], study procedures[u], study location[u], requirement of study partner[u], ratio of drug to placebo[u] **Non-modifiable:** Black race	**Motivators:** None **Facilitators:** Financial compensation, receiving research results

Note: All included studies were cross-sectional, observational studies. "Data collection method" refers to the methodological approach used to capture participant views; References to race and ethnicity are reported as stated in the original publications, without modification or harmonization. Moreover, "Study focus" refers to the primary research contexts in which barriers and enablers to recruitment or retention were examined. This was determined based on study aims and descriptions provided by individual studies. "Clinical research" refers to general participation in clinical trials, specified as such by individual studies. More specific categories (e.g. "biomarker research") were used when participation involved distinct procedures. "Not specified" indicates that the respective study discussed dementia research in general terms without identifying a specific research modality. Abbreviations: AD=Alzheimer's disease; MCI= Mild Cognitive Impairment

[a] Specific to participation in MRI studies

[b] Specific to participation in referral studies

[c] Specific studies involving blood draw (willingness to participate)

[d] Specific to studies involving saliva samples (willingness to participate)

[e] Specific to studies involving saliva samples

[f] Specific to the provision of genetic samples

[g] Specific to participation in observational research

[h] Specific to participation in clinical trials

[i] Cox et al. [26] examined whether the study partner requirement and in particular the disclosure of biomarker status to the partner are perceived as a barrier to enrolment in preclinical AD trials

[j] Specific to biomarker studies

[k] Specific to CSF studies

[l] The majority of study participants (61 %) did not endorse any barriers to continued participation

[m] Breach of privacy as barrier to continued participation was more pronounced in black participants and was partly mediated by trust

[n] Focus on factors concerning nursing home procedures;

[o] Focus on culturally shaped perceptions of ageing and dementia as expressed by Chinese-American dementia carers and stakeholders of the health care setting

[p] Specific to general practitioners

[q] Specific to dementia carers

[r] Specific to people with dementia

[s] In addition to participant retention, Stites et al [54] also examined medication adherence and enrolment in additional substudies as outcomes of interest. These outcomes were not considered in the current analyses.

[t] As assessed by the Research Attitudes Questionnaire[35]

[u] Specific to African American participants.

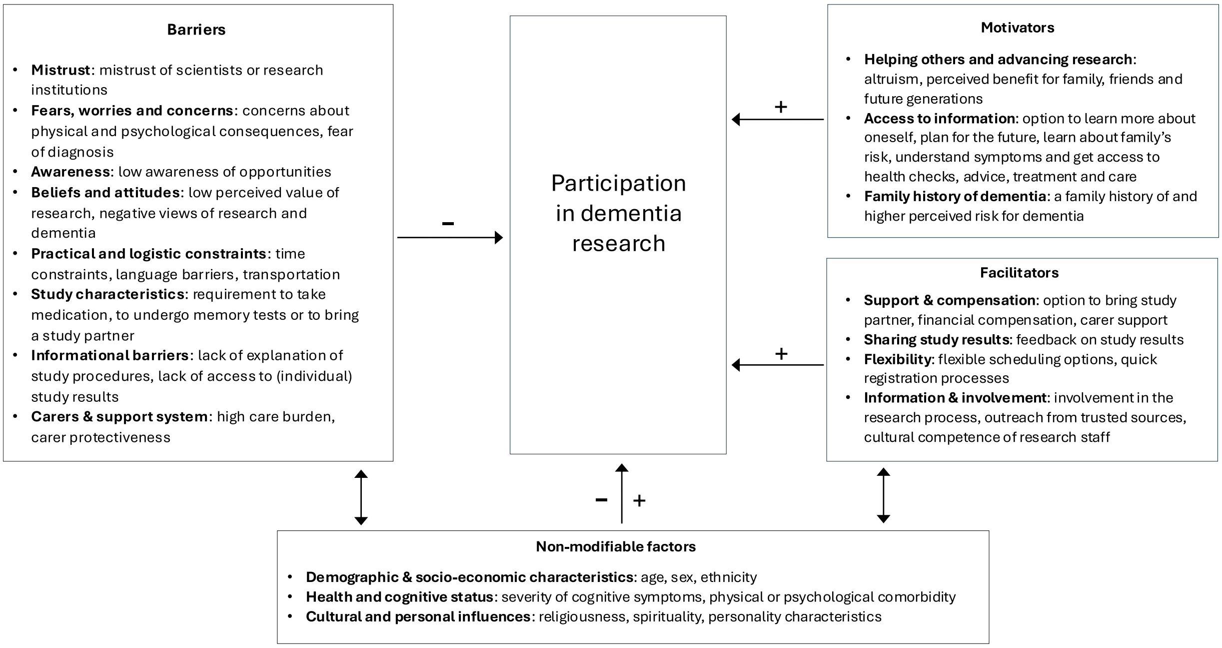

Fig. 2. Barriers and enablers to participation in dementia research as identified by studies included in the scoping review.

such as the lack of perceived personal benefit, a low utility of specific study procedures or the belief that others will participate instead [37,40,25,18]. Brain donation was frequently viewed as too intrusive and there were misconceptions regarding procedures, such as the belief that healthy brains are not needed [39,41]. Negative perceptions of research and dementia in general, along with beliefs that dementia does not affect people personally and cannot be prevented, were linked to a lower likelihood of participation [29,18,27,49].

Mistrust. Fifteen studies identified a lack of trust as barrier to participating in dementia research (Table 2). This included mistrust of scientists, research institutions and more generally of (medical-) research. In some studies focusing on the views of African Americans, it was noted that mistrust stemmed from historical maltreatment and concerns about unequal treatment and racism [49,18,46].

Fears, worries and concerns. Fifteen studies identified specific fears, worries and concerns as potential barriers to participation (Table 2). Across several studies, participants feared both the physical and psychological consequences of taking part in dementia research [32,40,25,18,57]. This included the fear of learning about ones own genetic or biomarker status or receiving a dementia diagnosis as part of the study [29,28,18,27,53]. Moreover, concerns about potential negative consequences for family members were mentioned, as were worries about violations of privacy [32,18,28,49]. Conversely, higher levels of fear of Alzheimer's disease and dementia were associated with higher likelihood of enrolment in two studies [29,18].

Informational barriers. Fifteen studies referred to technological and informational barriers to participation (Table 2). A majority of these identified insufficient information or explanation about the study procedures as reason not to participate [32,48,31,17,44,50,51,53]. Likewise, not receiving access to collected information and not being provided with global study results were mentioned as barriers [29,25,44,60].

Barriers related to study characteristics. In nine studies, study characteristics were identified as potential barriers to participation [38,43,47,21,58,52,49,50,26]. This included the obligation to take medication [47,21,52], to bring a study partner [58,26], to undergo memory testing [38,50] or more invasive diagnostic procedures [52,50]. Lastly, three studies mentioned a high degree of technology involved in the registration process or the study itself as hindrance for enrolment [43,21,49].

Barriers related to carers and the support system. Six studies identified factors related to carers or the wider support system as participation barriers [43,48,21,17,34,36]. Specifically, a high perceived care burden [43,21], a lack of support for carers by the research team [21], protectiveness of the person with dementia by the carer [48,17,36], or potential disruptions of formal care caused by the research [34] were mentioned.

3.4. Motivators for dementia research participation

Motivators (i.e. internal factors increasing the likelihood of enrolling or remaining in a dementia research study) as identified by included studies were clustered into three broad themes: Helping others and advancing research, access to health-related information and a family history of dementia.

Helping others and advancing research. Twelve studies identified a wish to help others as motivator to participate in dementia research (Table 2). This included general altruism, as well as the desire to specifically benefit friends, family [38] or future generations [38,17]. Moreover, six studies mentioned the wish to support and advance research as a driver influencing participation [29,39,38,41,40,25]. In two studies examining attitudes towards brain donation among African Americans, the wish to help find a cure for Alzheimer's disease [39,41] and to help advance in-vivo diagnosis [39] were particularly emphasized.

Access to health-related information/interest. A desire to learn more about oneself was identified as motivator for participation in clinical- or biomarker research [29,37,40,25,18]. In particular, learning more about one's genetic risk or biomarker status was seen as essential to plan for the future or learn about children's risk [29,37,18]. In some studies, participation in dementia research was furthermore perceived as way of learning more about one's symptoms and gathering more information about Alzheimer's disease and dementia, as well as possibilities for risk reduction and prevention [29,38,37,25,49,17]. Also gaining access to regular health checks, advice, treatment or evidence-based care were mentioned as motivating factors [32,24,56,43,25,28,44].

Family history of dementia. A family history of dementia and higher perceived risk for dementia were mentioned as reasons for participation in five studies [35,24,41,25,27].

3.5. Facilitators of dementia research participation

Receiving financial compensation or reimbursement for expenses were identified as facilitating factors for research participation by eight studies [35,38,43,47,58,52,44,50]. Moreover, receiving adequate information was seen as contributing factor in people's decision to participate. This included sufficient information about study procedures and requirements [20,28], but also being informed about study results [35,58,50]. Relatedly, three studies emphasized the importance of active involvement of participants in the research process and the building of relationships going beyond the participation in a study [57,19,33]. Additionally, the possibility of bringing a study partner and offering carer-support was mentioned by three studies [21,42,26]. Specifically, in one study examining barriers to the recruitment of dementia carers into clinical studies, the offer of free respite care was identified as facilitator [42]. Lastly, logistical factors such as the provision of transportation [38,52,17,44] and nearby parking [44], as well as flexibility in the scheduling of research visits [38,50] were seen as important facilitators.

3.6. Topics discussed during the consultation with people with lived experience

Overall, people with lived experience consulted felt all the issues identified in the literature resonated with and reflected their own experiences and feelings. The discussions complemented and provided further insights into the topics. A summary of the main issues highlighted by the people with lived experience is provided below.

Raising awareness about dementia. Research participation was perceived as an important topic for people affected by dementia. The importance of raising awareness of dementia generally was highlighted as a key factor, arguing that people without personal experience of dementia may be less interested and keen to participate in research (*"We'd never thought about [participating] until he received the diagnosis, that changed everything"*). The need for transferring a more positive image of dementia was underlined, in particular one that emphasizes the possibility of maintaining good quality of life with dementia.

Remaining in control. Participating in dementia research was described as meaningful way to "give back" *("To do as much as I can to help develop a new treatment for those who come after me"*) and to maintain a sense of control and autonomy. However, the wish to participate in research was also described as potential source of tension between the person with dementia and the carer, who may be more risk-averse (*"Stop wrapping me in cotton wool, I want to do this, I want to make my own decisions"*). This could become particularly challenging when the research involves invasive procedures or risks (*"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 she would have just gone for it")*.

Research opportunities and accessibility. It was underlined that for some types of dementia and in some countries, research opportunities may be limited. This may be further exacerbated by regional differences in the time it takes to receive a diagnosis, as well as the availability of support services. Logistical and practical barriers, such as a lack of transportation, were recognised as common obstacles to participation, in particular for people living in rural areas. In this regard, adequate and flexible funding, where necessary, to reimburse cost of travel and possible accommodation when participating in research and ultimately "bringing the research to the people" were raised as key issues. Concerning the latter, the importance of adequate carer support was also emphasised ("[We need] *easier logistics for the carer, you need to get the person ready and get to the site*").

Providing feedback of study results. The group firmly agreed on the importance of sharing research results once a study was completed *("His own doctor offered […] him [to participate in research]. [The study] took place during one of his regular check-ups, but after this, we never heard about the research or the results", "We never knew how the research finished up, all communication ended, and I think that nothing coming back afterwards left a bad taste in our mouths").*

More diversity in dementia research. People recognised and highlighted some of the challenges for involving people from less represented/ minority groups in a more meaningful manner. It was noted that this could be improved by means of active community outreach and encouraging researchers to "be inventive" when approaching participants from minority groups (*"This shows the innovative way of thinking that will be needed, just expecting people to put themselves forward is not working")*. An important message was that the common factor between everyone affected by dementia, regardless of their background, should be their lived experience of dementia ("*the cohesive factor should be dementia, not the differences, we are all struggling with [a similar condition], but we have not been successful in communicating this").*

Research participation at different stages of dementia. It was highlighted that, despite challenges, research should be conducted at different stages of dementia. Some of the key issues at the more advanced stages were related to logistics, the role of the carer and the need for skills and empathy when communicating with people with more advanced dementia.

4. Discussion

Ongoing recruitment difficulties in dementia research necessitate a careful examination of factors hindering and facilitating participation. In this scoping review, we provide an overview of the existing research landscape regarding such factors, clustering them into overarching categories. Studies were predominantly conducted with U.S.-based samples, frequently focusing on African Americans and there was a relative paucity of perspectives from other geographical contexts. We observed a lack of diversity regarding dementia research areas examined, with the largest proportion of studies focusing on clinical research. Likewise, the majority of studies focused on the initial recruitment, rather than the long term retention of research participants. Studies exploring views of people involved in the research process other than participants (e.g. researchers or funders) were also scarce.

Barriers and enablers to research participation as identified by individual studies were clustered into non-modifiable factors (e.g. cognitive status), potentially modifiable barriers (e.g. mistrust), internal motivators (e.g. altruism) and external facilitators (e.g. financial compensation). Identified factors broadly aligned with perspectives of the people with lived experience who were consulted.

4.1. Key recommendations for promoting dementia research participation

The following section outlines areas of focus and key recommendations for promoting the participation in dementia research, based on findings of the scoping review and input from people with lived experience. An overview of these recommendations is presented in Table 3.

Build trust and relationships extending beyond study participation. We identified low levels of trust as important factor related to people's decision to enrol in dementia research, particularly among minority groups. This aligns with findings of a previous review focusing on barriers to recruitment and retention of people from underrepresented backgrounds into dementia research [4], outlining mistrust of medical and research staff as key barrier. Recruitment approaches evolving around building a relationship of trust and understanding, especially among chronically underrepresented populations are thus vital in ensuring sample diversity. Indeed, several systematic reviews focusing on recruitment approaches for ethnic minority groups underscored the potential benefit of community outreach programmes, active collaboration with healthcare providers, referral, the provision of interpretation services and cultural training for researchers [61–63]. Strategies involving community partners and stakeholders, such as faith organizations, have supported the recruitment of people from racial and ethnic minorities into Alzheimer's disease clinical trials [64]. Nevertheless, more systematic assessments regarding the efficacy of such approaches across dementia research areas are needed.

Table 3

Key recommendations for promoting participation in dementia research based on the findings of this scoping review and feedback from people with lived experience.

Area of focus	Recommendations for researchers
Build trust and long-term relationships	• Build long-term partnerships with community organizations • Provide cultural competence training and interpretation services • Involve community ambassadors • Support researchers from marginalized groups
Adopt a proactive and tailored approach to recruitment	• Adapt recruitment strategy to cultural and regional contexts • Co-design recruitment materials with people from underrepresented communities • Enable participation with and without study partner
Reduce stigma about dementia	• Develop culturally appropriate public awareness campaigns addressing stigma, fears and concerns specific to the respective community • Offer community engagement sessions targeting underrepresented groups • Address structural discriminating practices (e.g. means of communication chosen for recruitment) which exclude people from marginalized groups
Improve information and communication	• Provide clear, plain language materials explaining procedures, potential risks and data sharing procedures • Give participants ample opportunity to ask questions to researchers • Provide clinicians with tools to discuss dementia and research opportunities • Establish structured post-study feedback for participants
Enhance accessibility and reduce practical barriers	• Offer flexible scheduling • Provide transport support or parking • Ensure compensation for time and costs • Provide reasonable accommodation for people with more advanced dementia

Adopt **a proactive and tailored approach to recruitment.** Similarly, people with lived experience stressed the importance of taking a more creative, proactive approach to recruitment - one that goes beyond expecting minority groups to step forward and instead makes real efforts to reach out and find new ways to include them. This should also entail a more in-depth assessment of recruitment approaches tailored to minority groups residing outside the U.S. Some of the concepts identified in this review may indeed not be directly transferable to geographically and culturally diverse areas such as Europe, warranting additional analyses, taking into account specific regional contexts.

In the current review, relational elements, such as the outreach from trusted sources and active involvement of people with lived experience in the study process were identified as major facilitators [28,60,33,65]. This may not only concern study participants themselves, but also those around them. In some studies, the possibility of bringing a study partner was perceived as facilitating participation, as was the availability of support for carers [21,42,26]. In others, the study-partner requirement was identified as major barrier, emphasizing the need also consider the carers' needs and preferences in the recruitment process, in the context of the specific research [26,58].

Reduce stigma about dementia. More generally, culturally determined perceptions of ageing and dementia and the lack of diagnosis have been identified as factors potentially limiting people's willingness and eligibility to participate in research [21,36]. This highlights the need to consider the composition of study populations of interest when designing recruitment strategies. The people with lived experience consulted additionally stressed the need to raise awareness about dementia in general. Specifically, both people with dementia and carers underlined that generally reducing stigma associated with the condition may lower the threshold for research participation. Indeed, a recent report by Alzheimer's Disease International suggests that the proportion of both people in the general public and health care professionals seeing dementia as a normal part of ageing has increased [66], underlining a clear need for awareness raising.

Improve information and communication. Fear of potential physical and psychological consequences of participation was a frequently mentioned barrier to recruitment, in line with a previous review [4]. These concerns may, in part, stem from preexisting misconceptions about study procedures and a general lack of information, necessitating complete and easily understandable information materials and room for questions in the recruitment phase [20,28]. This should also entail information about the rationale behind more invasive procedures (e.g. spinal tap). Likewise, explanations on how collected information will be used and how results will be shared with participants appeared to be of particular concern in Alzheimer's disease biomarker research [35,58,50]. The latter was also reflected in the discussions with people with lived experience, who clearly stressed the relevance of in-depth feedback and continued communication between researchers and participants once a study is completed.

Enhance accessibility and reduce practical barriers. A substantial number of studies mentioned practical barriers to participation in dementia research. This included time constraints and competing commitments. This may be addressed by offering flexible scheduling options at times convenient for participants, such as in the evening or during the weekend [39,50]. Both the reception of financial compensation for time investment [35,38,43,47,58,52,44,50] and the provision of transportation (or free parking options) were seen as facilitating factors [38,52,17,44]. These should be considered when estimating required study budget within the scope of available resources. People with lived experience additionally emphasised the need to "bring the research to the people", in order to make research more accessible to people with dementia. This approach may become increasingly important as dementia progresses, helping to make participation easier and more comfortable for people with dementia. A diagnosis of dementia is often a criterion for participation in research and therefore represents a means to access research opportunities. However, people with dementia (especially more advanced dementia) are also often excluded from research on the grounds that they would not be able to provide informed consent. Yet, a diagnosis of dementia should not, *per se,* be considered as a justified reason for ineligibility [67]. Instead, efforts should focus on creating the right conditions to support ongoing, meaningful involvement as long as possible, in line with the concept of reasonable accommodation as promoted in the Unites Nations Convention on the Rights of People with Disabilities [68].

4.2. Strengths, limitations and future directions

This scoping review has various strengths, including an extensive, systematic search strategy, the adherence to a conceptual framework for scoping reviews and no restriction regarding publication date, geographical location and research area. The incorporation of a Public Involvement element furthermore added reflections about our findings from the perspective of people with dementia and carers in Europe. However, it also has some limitations. Considering the broad nature of the topic, the heterogeneity of study characteristics and the frequently qualitative nature of outcomes, no quantitative analysis could be conducted. Furthermore, due to the scoping nature of this review, no quality assessment was done. Moreover, a lack of information provided by individual studies prohibited neatly determining sample composition in some instances, which may have caused a misrepresentation of global participant characteristics. Likewise, the small number of studies assessing factors associated with the retention of participants rendered comparisons between factors affecting recruitment and retention impossible.

This scoping review highlights important research gaps, thereby presenting avenues for further research. Firstly, the lack of studies conducted outside the U.S. necessitates an examination of perspectives on dementia research participation in more diverse geographical contexts. Doing so, existing cultural, socioeconomic and demographic differences within countries or regions should be considered, in order to ensure the tailoring of recommendations to the respective regional realities. Throughout geographical areas, further study of the long-term retention of research participants is warranted. This may include both quantitative analysis into factors predicting dropout, as well as assessments of reasons for withdrawing from studies through qualitative interviews. Considering the abovementioned, national or transnational (e.g. EU-level) guidelines outlining specific actions to promote dementia research participation would be highly useful for guiding decision making throughout the participant pathway. Ideally, such guidelines would be based on direct input from a wide range of relevant stakeholders from academia, patient organizations, research funders and policy makers.

5. Conclusions

This scoping review presents an in-depth analysis of factors pertaining to the recruitment and retention of participants in dementia research, incorporating insights from both the scientific literature and people with lived experience. A consistent finding was the general willingness and motivation of people to participate, alongside the importance of reducing stigma and fostering a more positive picture of dementia. Promising avenues to promote participation include addressing modifiable barriers, such as building trust, providing clear communication about study procedures and outcomes and creating supportive conditions that facilitate continued involvement. However, significant research gaps remain, particularly regarding the perspectives of individuals outside the U.S. and diverse contexts, as well as the long-term retention of participants.

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Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work the authors used ChatGPT in order to improve readability of section 3.2. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

Ethics statement

This study does not involve human participants and does not collect primary data. Therefore, ethics approval and informed consent are not required.

Data availability

Data will be made available upon reasonable request.

CRediT authorship contribution statement

Lukas A. Duffner: Writing – original draft, Visualization, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Soraya Moradi-Bachiller:** Writing – review & editing, Investigation, Formal analysis. **Dianne Gove:** Writing – review & editing, Methodology, Investigation. **Ana M. Diaz-Ponce:** Writing – review & editing, Writing – original draft, Methodology, Investigation. **Angela Bradshaw:** Writing – review & editing, Supervision, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. **Jean Georges:** Writing – review & editing, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Jean Georges reports financial support was provided by Gates Ventures. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.tjpad.2026.100558.

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