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# Grey literature scoping review: a synthesis of the application of participatory methodologies in underrepresented groups at an elevated risk of dementia

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**Abstract**

**Background** Diverse populations are more exposed to life course influences on adverse ageing, including brain ageing. Research into dementia in the United Kingdom inadvertently lacks diversity. Therefore, there is a need for more inclusive dementia research, developed in a way to ensure those who are currently missing from standard health data are represented. This may warrant the use of co-creation (emphasising collaborative creation and solution development), drawing on participatory methodologies in healthcare, research and service delivery.

**Methods** This study presents a scoping review of grey literature using Arksey and O'Malley's methodology. Literature was sourced from the Patient Experience Library and supplemented by a targeted Google Scholar search, employing snowball sampling to identify additional materials. The search strategy incorporated keywords such as "marginalised", "vulnerable", "disadvantaged" and participatory terms like "co-creation" and "co-design". Two reviewers independently screened and extracted key higher-level attributes (e.g., type of report, purpose of the activity (design), participating stakeholders/target populations) as well as data related to "co-creation process dimensions" and "participation levels".

**Results** Our review identified 30 grey literature reports on participatory methodologies among underrepresented groups living with or at elevated risk of dementia, covering diverse locations within the United Kingdom. The reported activities aimed to enhance healthcare and social services through stakeholder participation. Our findings highlight a focus on multi-stakeholder collaborative action as the dominant co-creation dimension identified. However, there was also a notable absence of more inclusive methodologies, with consultation being the most commonly used approach.

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**Conclusions** Our scoping review highlights the value of grey literature in understanding participatory methodologies for underrepresented populations at risk of or living with dementia. It reveals there is still a potential need to shift from mere consultations to sustained partnerships, promoting meaningful inclusion and greater ownership of (health) outcomes among these populations.

**Ethics and dissemination** Ethical approval was not required for this grey literature scoping review.

**Clinical trial number** Not applicable.

**Keywords** Ageing, Brain health, Co-creation, Co-design, Co-production, Super diversity, Underserved

## Introduction

The Cognitive Function and Ageing Studies (CFAS I&II) have informed our understanding of dementia and influenced health policy over the last 30 years - remaining the primary sources of dementia prevalence and incidence data for the United Kingdom (UK) [1–5]. These studies recruited over 25,000 individuals aged 65 and over, directly from primary care registers to represent entire populations in specific UK geographies. However, as the demographic landscape of the UK has evolved to become more diverse, the findings from these past studies, which predominantly involved white residents, are no longer fully representative of the UK population as a whole [4–6]. As a result, the shift in the demographic makeup of the population, coupled with the lack of data from those most at risk, raises concerns for epidemiologists and public health researchers.

### The rise of super diversity and its implications for understanding dementia risk

The demographic shift in the UK occurring over the past two decades largely corresponds to external migration patterns due to economic and political changes. Unlike the earlier postcolonial migration from specific communities in the Indian sub-continent and West Indies to the UK, recent migration now comes from a variety of global regions [7]. This has led to the emergence of 'super diversity' in the UK", as defined by Vertovec [8].

Vertovec describes super diversity as the complex interplay of factors such as ethnicity, legal status, language, religion, sexual orientation, gender identity, socioeconomic position, age and education. While super diverse communities do not necessarily equate to marginalisation, they pose a particular challenge for epidemiology, which relies on a common denominator when conducting population health studies. This includes consistent and equitable access to primary care, which is not guaranteed across the people and groups residing in super diverse communities [9].

Additionally, it is well documented that risk of poor cognitive function and health clusters around inequalities with how where we live and how we live influencing health outcomes in later life [10]. Although, age is the greatest risk factor with accelerating occurrence as people live into their ninth and tenth decades, dementia is not synonymous with ageing. Individuals facing multiple levels of disadvantage are expected to experience dementia earlier than more 'usual' populations, should they survive into older age [11]. While it is not yet possible to determine whether super diverse populations as a whole are at greater risk of dementia, it is reasonable to infer that individuals within these communities who experience intersecting forms of disadvantage may face elevated risk due to modifiable health and social factors [12, 13]. Without better representation of such populations in research, these questions remain unanswerable. Therefore, the current exclusion from data needs to be rectified regardless, as given our current knowledge of change in dementia across time and differences between populations, assumptions of stability of dementia prevalence for even those of White British heritage cannot be made with confidence, let al.one estimates to the UK's super diverse groups [2, 4, 5].

While much dementia research focuses on those already living with the condition, this paper is concerned primarily with those at elevated risk, particularly within super diverse populations who are currently underrepresented in prevalence and incidence data. Our focus is on improving participation in population-based studies that seek to understand who is at risk, when and why, in order to inform future policy and care pathways. Therefore, when exploring ways to improve participation and inclusion for underrepresented and underserved groups, understanding how multiple dimensions of diversity interact and shape people's experiences is important [14]. This paper systematically explores how participatory methodologies identified from grey literature can support inclusive participation in dementia research, particularly with underrepresented and super-diverse populations in the UK.

#### Toward a more inclusive methodology

Legacy studies to CFAS I&II, such as the Community and Public Health Approaches to Dementia Research (ComPHAD) project, attempted to address the challenge of understanding ageing brain function and health in super diverse populations. ComPHAD aimed to co-create a methodology to ensure inclusive participation over the longer term and define a common denominator which aligns with a super diverse approach [15]. This is in line with the increasing priority to involve the participation of stakeholders with lived experiences in research, with funders such as National Institute for Health and Care Research expecting public engagement at various stages of project planning, delivery and dissemination. Research emphasising stakeholder participation, especially across varied policy fields, demonstrated greater respectability and attention within mainstream health research [16, 17].

### A spectrum of participation

It can be recognised that participatory methodologies encompass various extents or levels of participation in an initiative. Rock et al. distinguishes between participation versus co-creation akin to consultation versus partnership - as indicated by Arnstein's (1969) ladder of citizen participation [18, 19]. This spectrum of participation starts at the lowest level with non-participation, taking the form of manipulation (i.e., being involved in a way that is deceptive/ coercive) and therapy (i.e., giving a voice but not genuinely involving in significant action) [19]. Further, there is the IAP2's Spectrum of Public Participation [https://www.iap2.org/page/pillars], developed by the International Association for Public Participation, provides a more nuanced continuum of engagement levels, from informing and consulting to involving, collaborating and empowering the public (Fig. 1).

According to Leask et al. the co-creation process can be undertaken via participatory methodologies and the stages of co-creation are Planning (framing the aim of the study and identifying the appropriate sampling strategy); Conducting (defining the procedure and demonstrating ownership); Evaluating (assessing the process and effectiveness); and, Reporting (offering guidelines for presenting the findings) [20].

Explicit dimensions related to the co-creation process has been identified in published co-creation research across diverse research fields and types of co-creation, where the use of underpinning theories is evident [24]. The explicit dimensions identified across the process of co-creation in the academic literature encompass: Multi-stakeholder collaborative action; Process of co-learning towards innovation; Contextual knowledge production; Generating meaning; and, Open, trustful and inclusive dialogue [21] (Fig. 2).

### The case for grey literature

While some guidelines exist for co-creation in the field of dementia care and research [22, 23], there is less availability of guidelines for the involvement of underrepresented - or more specifically super diverse groups [24] and limited knowledge of what works. This warrants deeper insight into the specific needs and circumstances of these super diverse communities [25]. Recent reports exploring ways to improve engagement and recruitment of underrepresented groups in health research suggested collaborating with third sector charities and community organisations [26, 27]. Third sector organisations and independent advocacy groups like Healthwatch support marginalised communities and publish reports on the lived experiences of super diverse groups. These insights can be valuable for improving involvement, engagement and recruitment in health research [28, 29]. Therefore, a good starting point for ComPHAD was to identify participatory approaches used by third sector and community organisations, as documented in reports, for co-creating with super-diverse population groups.

This lends itself to scoping alternative sources, such as the grey literature [30] to identify effective participatory

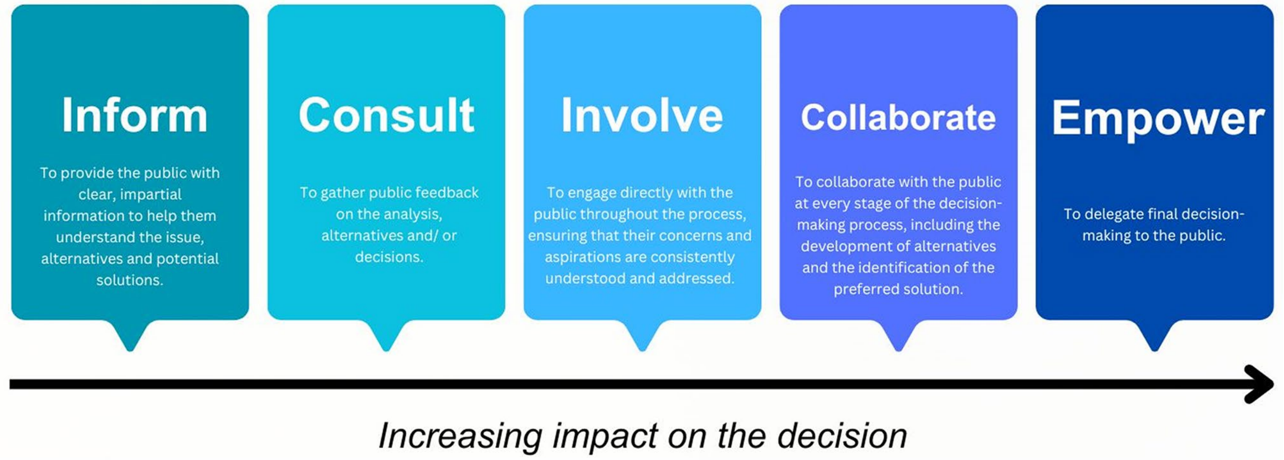

**Fig. 1** Authors' own output of IAP2 Spectrum of Public Participation illustrating the continuum of engagement levels, from informing to empowering the public

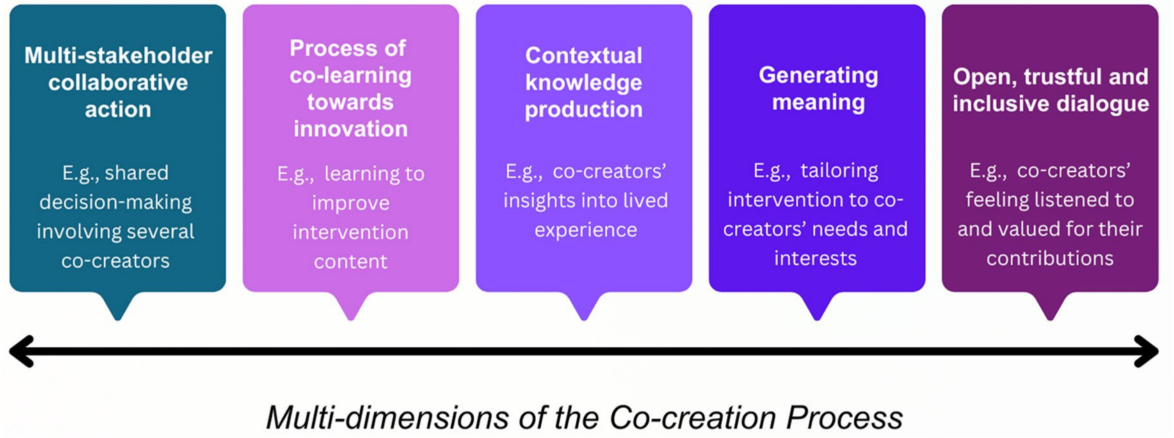

**Fig. 2** Illustration of the Five Co-creation Process Dimensions by Messiha et al. (2025)

methodologies in underrepresented groups from super diverse communities. Additionally, a systematic review by Grindell et al. highlighted the importance of identifying literature from non-traditional sources and minimising the influence of publication bias pertaining to the use of co-creation [31]. This bias could stem from most academic literature sources being employed when considering the informed use of co-creation, potentially overshadowing the utilisation of grey literature [32]. Further, unlike traditional (i.e. academic/ peer-reviewed) literature, grey literature is relevant in this context since researchers and practitioners often utilise co-approaches, yet such findings may not be easily accessible through academic databases [33]. Consequently, co-creation activities that are not disseminated in peer reviewed journals, as a way that is often more accessible via databases, may be overlooked.

As far as our knowledge extends, comparisons of the co-creation process dimensions [21] identified from the academic literature are yet to be considered in relation to participatory methodologies as inferred by the grey literature. Similarly, iAP2's Spectrum of Public Participation has developed a widely recognised Public Participation Spectrum that outlines various types of interactions a local government can have with its community [34]. This spectrum, marked by increasing levels of stakeholder participation and intended outcomes, is often preferred over Arnstein's Ladder because it is seen as more adaptable to different contexts and easier for organisations to implement.

## AIM

Our scoping review aims to identify participatory methodologies and co-approaches particularly those used for problem identification with underrepresented groups representative of super diverse populations (e.g., minority ethnic and asylum seekers and refugees). The review also considers factors linked to elevated risk of developing dementia, such as housing precarity and mental ill health, using grey literature. In parallel, this review will focus on exploring this in the context of co-creation process dimensions [21] and the iAP2's Spectrum of Public Participation (https://iap2.org.au/resources/spectrum/). We are seeking to frame the findings from the non-academic sources (i.e. grey literature) with the rigour of the co-creation process dimensions derived from the academic literature sources (i.e. peer-reviewed). This is in order to understand reported ways of engaging with superdiverse/ marginalised communities in participatory/ co-creation research.

The overarching research question in line with our aim is therefore, *how can grey literature inform our understanding of participatory methodologies among underrepresented (super diverse) groups thought to be a higher risk of dementia?*

## Methods

The guidelines from Peters et al. were adopted for this scoping review. We registered our protocol[1] [https://doi.org/10.17605/OSF.IO/2ENKZ] on December 12 2023 at the Open Science Framework (Messiha and Thomas et al., 2023) [35]. We selected the Open Science Framework because this platform offers open, centralised workflows by capturing all aspects of the research lifecycle and publishing reports or papers [36]. Further, our method steps followed the guidelines by Arksey and O'Malley [37]. Arksey and O'Malley [37] articulate a five-stage methodological framework for undertaking a scoping review, including, (1) identifying the research question, (2) identifying relevant studies, (3) report selection, (4) charting the data, and (5) collating, summarising and reporting the results.

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[1] Messiha, Katrina, Nicole Thomas, Carol Brayne, Danielle Agnello, Lea Rahel Delfmann, Maria Giné-Garriga, Sonia Lippke, and John Downey. "Grey Literature Synthesis on Participatory Methodologies in Aging Underrepresented Groups: A Scoping Review Protocol." (2023).

### Inclusion and exclusion criteria

We included items from grey literature sources that specifically addressed underrepresented, super diverse groups in the UK who are thought to be of higher risk of or have developed dementia or other ageing brain function and health issues. The sources reviewed were publicly available online. This study adhered to a scoping review methodology specifically focusing on UK-based research from September 2013 to December 2023. The reviewed sources needed to involve two or more stakeholder groups. Importantly, the grey literature included at least one clearly outlined method used to understand the experiences of the target population, informing policy, research and/ or practice. This allowed for inclusivity by not excluding sources based on unreported methods or methodologies. In cases where details were lacking, we assumed that most co-creative methods were qualitative and/ or consultative in nature [38]. The selection criteria can be found in Table 1 below.

### Search strategy

In prioritising extensive searches of grey literature sources, our search strategy was conducted by an Information Specialist from Patient Experience Library (PEL) (https://www.patientlibrary.net/cgi-bin/library.cgi) alongside the co-first authors (K.M. and N.T.). The search strategy had been authenticated through the retrieval of a key set of relevant sources of grey literature which identified 202 citations conducted in the PEL database.

The search included terms such as “marginalised” AND “vulnerable”. While we used the definition of ‘co-creation’ previously stated in this review as informed by Messiha et al. systematic review [39], we used related terms of co-creation as advocated for by Agnello and Loisel et al. [40]. Hence our search included terms like “community consultation” AND “citizen science”. Refer to *Online Supplementary File 1* for the exhaustive search terms utilised in the PEL database. Additionally, search terms for dementia were not explicitly used as it was important to identify the reports highlighting co-approaches with underrepresented and super diverse groups more specifically as it could be inferred that these groups would be at increased risk of dementia.

Comprehensive searches were performed across the PEL database, adhering to predefined criteria and search terms. The initial search results underwent a rigorous de-duplication process to eliminate redundancy. A relevance filtering step was applied using our selection criteria to remove documents with limited relevance to the research objectives. A thorough manual full-text screening of the remaining documents was conducted to assess their alignment with the study’s objectives, refining the search results.

Additionally, a focused Google Scholar search was conducted. Using the anonymous function in web browsers, the first 10 pages of search results generated from specific keywords were reviewed, prioritising relevancy ranking, in line with previous grey literature review reports [41, 42]. Relevant websites, such as NHS England, were targeted. In addition, a snowballing method was adopted to identify additional references.

### Report selection

Co-first authors (K.M. and N.T.) screened and extracted potentially relevant literature by examining the titles from the four search types, namely: PEL, Google Scholar search and snowballing method. For each search step, an Excel spreadsheet was created to document the title, source organisation and URL of the identified literature. Sources were marked as ‘include’, ‘exclude’ and ‘uncertain’. Discrepancies were resolved via discussions until consensus among reviewers were met.

Next, the full text of grey literature sources were independently reviewed by two reviewers (K.M. and N.T.), and duplicate screening was performed by one of three co-authors (D.A., J.D., and L.D.), each screening one-third of all articles against our screening criteria (see Table 1). Similarly, sources were marked as ‘include’,

**Table 1** Inclusion and exclusion criteria for literature selection

| Inclusion | Exclusion |
|---|---|
| Specific to underrepresented populations following the definition of ComPHAD, related to super-diverse groups at risk of or who have developed dementia/ brain health issues in the UK. | Academic literature and reports that do not include a UK population. |
| Must include acquired cognitive impairment, such as dementia and mental health issues. | Any brain health issue that is congenital. |
| Publicly available online or in other formats, published by government and non-government organisations, from most recent year, but not earlier than September 2013. | Material type pertaining to frameworks, guidance, guides or toolkits. |
| Involvement of two or more stakeholder groups. | Non-healthcare sectors (e.g., grassroots, advocacy groups). |
| Clear statement of at least one method used to gain insight into the targeted population to inform policy, research and/ or practice. Thus, not only being co-creators but also providing an assessment of their participation experiences was needed to be reported. | No clear statement of at least one method used to gain insight into the targeted population to inform policy, research and/ or practice. Thus, not only being co-creators but also providing an assessment of their participation experiences was needed to be reported. |

'exclude' and 'uncertain' on the Excel spreadsheet by the two reviewers, with a consensus method put in place. The outcomes of the search are presented, including a PRISMA-ScR flow diagram as shown in Fig. 3.

### Data extraction: reporting the results

The review ultimately focused on three key extractions: (1) higher-level items such as type of report, publication date, geographical location etc.; (2) descriptive codes aligned with the co-creation process dimensions established by [21]; and, (3) the spectrum of public participation according to the iAP2 framework.

The data extraction method was piloted by the co-first reviewers (K.M. and N.T.), who independently charted a sample of the included grey literature data sources. Based on the pilot test results, some adjustments were made to the data abstraction form, for instance we identified the need to incorporate the IAP2's Spectrum of Public Participation extraction. Based on the pilot test results, we decided to incorporate the IAP2 Spectrum of Public Participation into the data abstraction form. This decision was made by the lead authors, K.M. and N.T., after noting that the initial form did not fully capture the complexity of stakeholder engagement. To ensure a less biased assessment of public engagement, KM and NT conducted this extraction in a blinded manner, meaning we independently extracted the data based on how we perceived that the author of the given included report had delineated the engagement levels of participating stakeholders.

We shared the extraction items with the research team for feedback before proceeding with data extraction. Further, K.M., N.T., S.L. and M.G. trialled the visual displays of the data extractions from the included grey literature reports and deliberated the best displays within

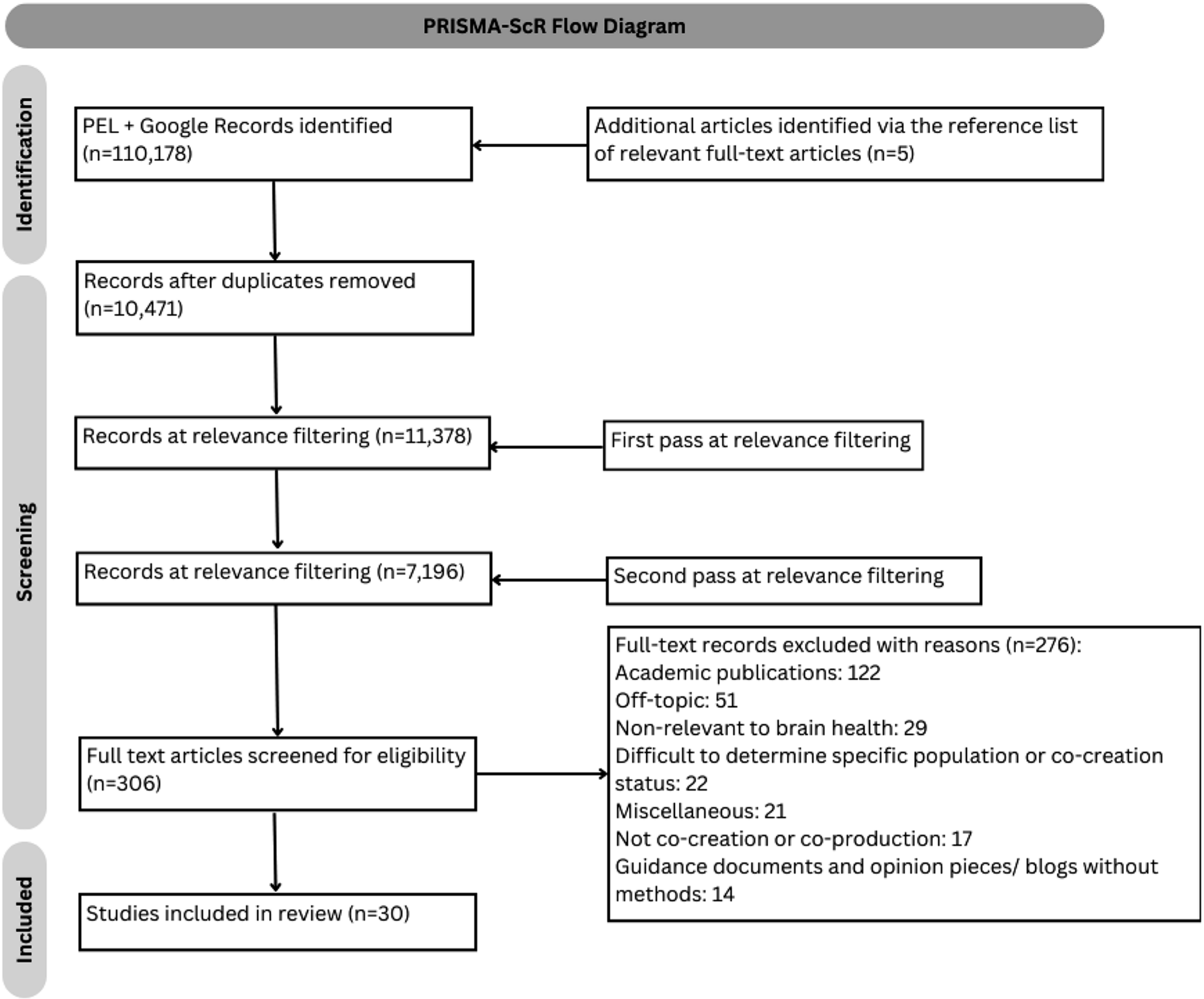

**Fig. 3** Prisma Flow

deliberative meeting contexts supplemented by email exchanges. All data are reported in a narrative format.

## Results

Due to the limited evidence regarding dementia risk in underrepresented groups, particularly those not typically captured in prevalence studies, we chose not to restrict inclusion solely to groups already identified as being at risk or living with dementia. Instead, we included reports involving underrepresented populations more broadly, acknowledging that the absence of dementia-specific data may itself reflect exclusion from research, not absence of relevance.

We initially identified $n = 110{,}178$ hits from the combined PEL database and Google search. Following a second pass of relevance filtering, $n = 7{,}196$ hits remained. We then screened $n = 206$ full-text articles for eligibility, excluding $n = 276$ articles for specific reasons. 'Off-topic' reports $n = 51$ were defined as non-UK based or targeting the wrong population (e.g., children). Reports $n = 29$ deemed 'non-relevant to brain health' included those focusing on autism. Miscellaneous grey literature sources $n = 21$ were excluded if they lacked sufficient information for data extraction or were inaccessible due to broken links. Ultimately, $n = 30$ reports were reviewed which included underrepresented groups living with dementia. An overview of the selection process is provided in Fig. 3.

There were 30 reports representing most regions of the UK (see Table 2), with the majority being located in London ($n = 11$). The most rural areas represented were in Norfolk (Dereham, Costessey and Cromer). Just over half of the reports were published in the last five years ($n = 16$).

Those consistently missing from standard health data can be identified by certain protected characteristics. Categorising by these protected characteristics identified that the target populations involved as stakeholders in co-creation were varied (see Table 2). Several reports demonstrated the intersectionality in their research. For instance, Report 6 examined the mental health of ethnic minority groups, while Report 13 included individuals seeking asylum experiencing homelessness. Report 20 involved a diverse group of stakeholders across different ages, ethnicities, types of dementia, professions, religious and cultural backgrounds, sexual orientations, socio-economic statuses, and locations across England, all living with dementia. Report 27 included

**Table 2** Included reports (identified by the Report ID number) categorised by region and target population group. Reports which included intersections of protected characteristics (such as mental health and prisoners) are included in both boxes. Key: ~ = Reports that used in-person participatory methods; * = Reports that used digital participatory methods; ^ = Reports that used a mixture of both

| **Region**<br>**Protected Characteristic** | **Northern Ireland** | **North East** | **North West** | **East Midlands** | **West Midlands** | **Wales** | **East of England** | **London** | **South East** | **South West** | **National** |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Affected by Dementia including those diagnosed with, and Carers/Unpaid Carers ($n = 12$ reports) | Report 9* | Report 20~ | | Report 22^ | Report 27~ | Report 21 | | Reports 19^ 20~24* 25~27~ | Report 10^ | | Report 23~ |
| Ethnic Minority Groups ($n = 8$ reports) | | Report 1~ | Report 26 | | | | | Reports 2* 11^ 12~19^ | Report 6~ | Report 28~ | |
| **Housing Instability including Unhoused ($n = 3$ repots)** | | | | | | | **Report 3*** | **Report 13** | **Report 17** | | |
| **LGBTQIA+ ($n = 4$ reports)** | | | **Report 26** | | **Report 27~** | | | **Reports 16*, 27~** | | | |
| **Mental Health ($n = 10$ reports)** | | | **Report 8~** | | | | **Reports 4* 5~7^** | **Reports 2* 15^** | **Report 6~** | | **Reports 18^ 29~30~** |
| **Migrants ($n = 2$ reports)** | | | | | | | | **Reports 11^ 13~** | | | |
| **People in Prison or Experience of Prison ($n = 3$ reports)** | | | | | | | | | | | **Reports 18^ 29~30~** |
| **Disabled ($n = 2$ reports)** | | | | | | | | **Reports 2* 15^** | | | |
| **Multiple groups ($n = 2$ reports)** | | | | | | | | **Reports 2*** | | **Report 14^** | |

LGBTQIA + individuals living with dementia. Additionally, reports 18, 29, and 30 investigated the mental health of prisoners (Table 2).

Those affected by dementia, including individuals diagnosed with dementia, advocates, supporters, unpaid carers and formal carers, were the most common target groups ($n = 12$ reports) with experiences in all regions of the UK, except for the North West, East of England and South West. One report (Report 22) based in Leicestershire made a specific effort to include people with early onset dementia. People experiencing mental health challenges or accessing mental health services were the second most engaged population group ($n = 10$ reports).

Among the reports identified, consultation documents were the most common ($n = 17$), followed by engagement reports ($n = 5$) and reports outlining the co-design of an innovation ($n = 3$). These innovations include a website for post-diagnostic support (Report 20), a digital befriending kit to support people living with dementia (Report 24) and online support groups for marginalised communities living with dementia (Report 26). The remaining reports were a co-design of a report, an Appreciative Inquiry, a strategy document, a rapid literature review and the co-design of Policy Recommendations.

### Recruitment, engagement and participation strategies

Participants in the reports were recruited through a number of ways. Local community organisations and networks were key for reaching certain marginalised communities. Collaboration with local authorities, and third sector organisations, with dementia-related reports involving partnerships with the Alzheimer's Society and the Dementia Engagement and Empowerment Project (DEEP) (Report 20), were reported. Events such as the 'Better Me, Better Life' campaign in Redbridge (Report 12) and workshops in Birmingham and London were advertised through social media, community press and local networks to recruit participants (Report 27). Mental health services, General Practitioner practices, social prescribers and health professionals, assisted by displaying campaign materials, referred eligible participants. Incentives like prize draws and interactive activities were used to encourage participation and digital platforms, including web forms and online surveys, were essential for reaching target populations, particularly during the pandemic.

Participation in-person was facilitated by the use of methods contained within participatory methodologies, including semi-structured interviews, focus groups, workshops, drop-in sessions and public engagement events. Some reports engaged exclusively through webforms, surveys/ questionnaires or engaged with participants online. Several reports employed mixed methods to gather data, incorporating both qualitative and quantitative approaches, as well as a combination of in-person and online engagement. Two reports (Report 21 and Report 26) provided very limited information about their recruitment and engagement strategies. These methods are detailed in Table 2, using a key of symbols for each approach.

Accessibility and inclusivity efforts included easy read versions of surveys and employing the services of interpreters, including British Sign Language, to ensure varied voices were captured. Refer to *Online Supplementary File 2* for the full extraction of the higher-level item extractions across the included grey literature. These extractions include: Organisation/ Council name/ Authors and date (publication), type of report and locations (of report), Purpose of the activity (design), Target populations/ groups of actors, Stage of research participants involved in [20], Recruitment/ engagement/ participation strategies and 'Level' of public participation according to the iAP2 spectrum.

### Co-creation process dimensions

The findings from the co-creation process dimensions data extraction revealed that all five explicit dimensions were identified in only three reports (Reports 6, 28 and 30). For example, in Report 6, a joint Mental Wellbeing Strategy for Brighton and Hove City was developed, including participating stakeholders from the local authority, NHS members, community groups such as the Black and Minority Ethnic Community Partnership and other members of the general public. Contextual knowledge was produced through thematic analyses, and meaning was generated by using the existing framework "The Five Ways to Wellbeing" by Department of Health, National Strategy in 2011 to inform the process. Report 6 showed evidence of facilitating co-learning through innovation, as participants purportedly learnt about the Five Ways to Wellbeing framework. Participating stakeholders had multiple ways to engage and contribute, which allowed 'open, trustful and inclusive dialogue'.

The findings further reveal that all of the reports mentioned at least two of the dimensions. To elaborate, the dimensions of 'process of co-learning towards innovation' as well as 'open, trustful and inclusive dialogue', were the least present dimensions, appearing in only $n = 11$ and $n = 7$ sources, respectively. Conversely, the dimensions of multi-stakeholder collaborative action (e.g., study 1 engaged multiple partners including new BME communities, such as refugees, asylum seekers, recent economic migrants), contextual knowledge production (e.g., study 2 was about producing knowledge in context to assess whether different community groups felt that the strategy addressed their needs and to identify any potential gaps) and generating meaning (e.g., study 3 captured that the initiative was about

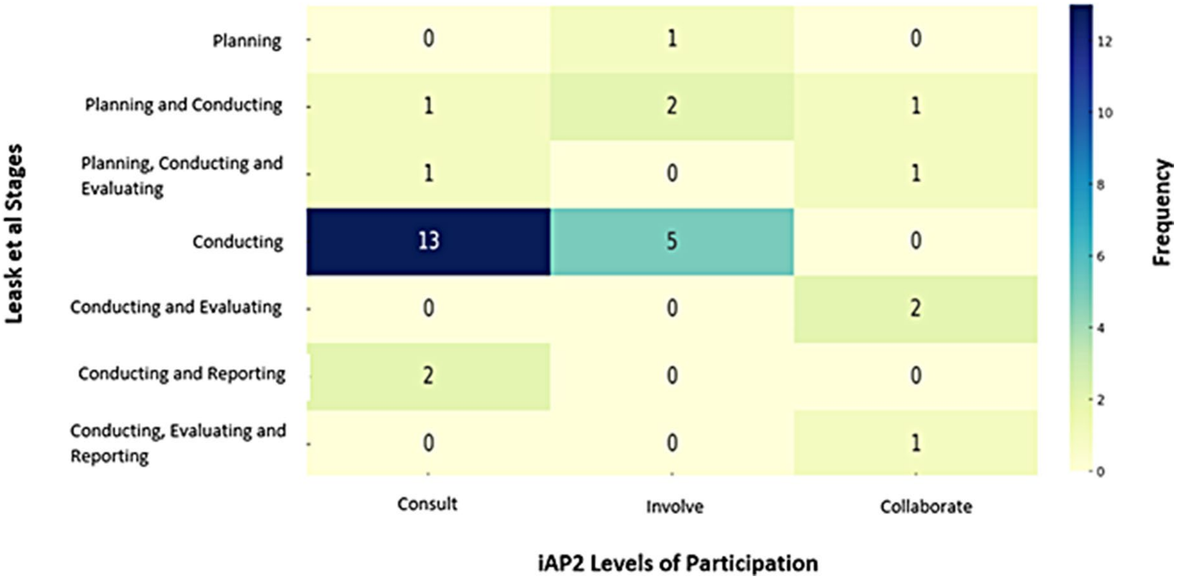

**Fig. 4** Heatmap showing relationship between the stages of co-creation and the level of participation to visualise overlaps between the two

**Table 3** This table describes the presence or absence of the explicit co-creation process dimensions for each Report ID

| Report ID | (1) Multi-stakeholder collaborative action | (2) Process of co-learning towards innovation | (3) Contextual knowledge production | (4) Generating meaning | (5) Open, trustful and inclusive dialogue |
|---|---|---|---|---|---|
| 1 | 🟩 | 🟥 | 🟩 | 🟩 | 🟥 |
| 2 | 🟩 | 🟥 | 🟩 | 🟩 | 🟥 |
| 3 | 🟩 | 🟥 | 🟩 | 🟩 | 🟩 |
| 4 | 🟩 | 🟥 | 🟩 | 🟩 | 🟥 |
| 5 | 🟩 | 🟥 | 🟩 | 🟩 | 🟩 |
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| 27 | 🟥 | 🟩 | 🟩 | 🟩 | 🟥 |
| 28 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 |
| 29 | 🟩 | 🟥 | 🟩 | 🟩 | 🟥 |
| 30 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 |

working towards making services better) were the most commonly present dimensions identified across the reports. Overall, we demonstrated that grey literature frequently fails to align with all the co-creation process dimensions including certain evaluative details and reporting aspects. This shortfall highlights a need for better alignment with these academic dimensions to enhance the credibility and impact of co-creation efforts documented in grey literature.

The majority of the included reports related to participatory methodologies in the conducting phase of co-creation ($n = 18$). Two reports included multiple stakeholders in planning, conducting and evaluating (Reports 23 and 26) and one included multiple stakeholders in the conducting, evaluating and reporting (Report 19). None of the reports included all four stages of co-creation (see Fig. 4).

When combining the level counts from the IAP2 Spectrum of Public Participation framework with those from the Leask et al.'s [20] stages of co-creation, a heatmap was created to visualise the overlaps. The heatmap demonstrated that the majority of reports were concentrated at the lower levels of participation (consulting and involving) during the conducting stage of co-creation *(*Fig. 4*)*.

Two Reports (19 and 26) included the most stages (both excluded planning) and demonstrated a higher level of participation (collaborate). No reports reached the highest level of empowerment (placing the final decision making in the hands of the public).

## Discussion

This review focused on the application of participatory methodologies, such as the attention of participation level(s), co-creation process dimensions and co-creation stages, with population groups living with dementia. More importantly, it included reports representing super diverse groups who may also be considered at the intersections of multiple levels of disadvantage and therefore at greater risk of dementia [11, 14, 43]. This was with a view to explore how grey literature can inform our understanding of co-creation with underrepresented groups for dementia research. By focusing on grey literature within the PEL we aimed to identify participatory methodologies that may have been overlooked due to not being published in peer-reviewed literature.

Our key findings indicate that according to the iAP2 Spectrum of Public Participation, most reports were at lower levels of participation (consulting and involving), with none achieving the highest level of empowerment. Moreover, reports typically engaged stakeholders primarily in the conducting stage, with limited involvement in planning, evaluation or reporting stages. This is similar to the findings of [44], who found there were shortfalls in the meaningful inclusion of migrants in developing health interventions with only 2 out of 28 reports demonstrating involvement across all stages of intervention development (Table 3).

These findings are important consider that in the wider pertinent literature it is acknowledged that conducting co-approaches such as co-production without proper attention to professional etiquette can generate significant negative sentiment towards participating in research [45]. This may result in mistrust of researchers and a reluctance to engage in related future research activities [45]. The issue of 'research fatigue' exacerbated by the pandemic, further complicates matters, as communities are asked to participate without seeing tangible outcomes or feedback [46].

Messiha et al. [47] highlight the importance of a multi-method approach to co-creation in strengthening the evidence base. Similarly, Agnello et al. [33] argue that an overreliance on traditional qualitative methods can overlook valuable insights from non-academic sources, such as reports and community-driven materials, potentially increasing the risk of disengagement. In the context of our review, it was somewhat surprising that the majority of reports operated at lower levels of participation (consulting and involving), with none reaching the highest level of empowerment or incorporating all four stages of co-creation which highlights a salient gap in the existing literature. The insights derived from this review indicate the need for more bottom-up and creative methods as well as a stronger integration of both academic and non-academic sources to fully realise the potential of co-creation and address its existing limitations.

It further highlights how participatory approaches can have a tendency to function more as a checkbox exercise than true collaboration [48]. This review therefore highlights that moving beyond tokenism, and using participatory methodologies, may also be a problem within third sector and independent lobbyists, emphasising the need to enhance understanding across all sectors. This is also noted by the Patient Experience Library themselves in their report on the noticeable absence of guidance on engaging with underrepresented and marginalised communities [49].

### Participatory methodologies

Participatory methodologies should involve closer collaboration between researchers and those directly experiencing the phenomena studied [50]. Bellavia and Longworth et al. recommend focusing on context, people, process and resources in stakeholder engagement, in particular for dementia research [51, 52]. Bellavia emphasises qualitative and participatory methodologies, integrating implementation plans from the outset [51]. Without such, consultation efforts may not lead to actionable outcomes. The reports in our review did not discuss feasibility of the recommendations or how decision-makers were engaged in the process to address feasibility issues, suggesting that implementation plans were not considered. This mirrors the findings from a scoping review looking at the improvements in implementation strategies in primary research over the last decade, which suggests that implementation success is unlikely with current approaches [53].

Furthermore, Ozkul critiques the excessive focus on methodological rigour in participatory research, arguing that it obscures the inherent power dynamics and the limited involvement of participants in the methodological design [54]. We posit that this concern is particularly relevant to the third sector, where organisations could be employing top-down approaches such as consultation or qualitative methods, rather than adopting more explorative, bottom-up methodologies that genuinely empower participants in the research process. This "glorification of methods" risks masking the political nature of participatory research and fails to ensure that participants are truly co-creators in the research process, thereby undermining the principles of equitable and inclusive research practices. There is a potential political nature of participatory research that encompasses power dynamics, ethical considerations, the distribution of epistemological authority and a commitment to social justice, highlighting the need for genuine collaboration and power-sharing to foster transformative outcomes for marginalised communities [17, 55].

We found diverse recruitment and engagement strategies, including involvement of local community organisations, social media and partnerships with organisations like the Alzheimer's Society. This reinforces the work of Shannon et al. who highlight the establishment of community partners in developing dementia-friendly communities [56]. Participation methods varied from in-person interviews and focus groups to online surveys, particularly during the pandemic.

### Co-creation dimensions

In our analysis of co-creation processes across the grey literature, we found that all of the reports demonstrated at least two out of the five co-creation dimensions [21].

Dimensions such as multi-stakeholder collaborative action, contextual knowledge production and generating meaning were commonly present. This reflects efforts to address the complex needs of underrepresented individuals at high risk of dementia or living with dementia. However, the dimensions of co-learning towards innovation were frequently absent. This may be attributed to ingrained hierarchical structures in healthcare settings and bureaucracy. Open, trustful and inclusive dialogue was also frequently missing due to not being explicitly described in the reports.

Glover et al. suggest that while co-creation can be beneficial, it is important to realistically assess project scope and use diverse recruitment methods, skilled facilitators and thorough preparation for accessibility and information provision [57]. Despite varying levels of detail in reporting participatory methodologies across the reports, opportunities for learning persist. Applying frameworks such as Co-creation Process Dimensions [21] and the iAP2 Spectrum could standardise reporting, in alignment with Leask et al.'s stages of co-creation [20]. That said, encouraging authors to use the IAP2 Spectrum rather than Arnstein's Ladder can be difficult, as many are accustomed to the latter despite its limitations [19]. As mentioned, IAP2 Spectrum offers a more nuanced framework for public engagement, providing clearer guidance on various levels of participation and addressing some of the gaps in Arnstein's model. Co-creation publications often recommend specific reporting tools to enhance transparency. The "Guidance for Reporting Involvement of Patients and Public" checklist, as outlined by Slattery et al. offers detailed guidelines for documenting public involvement [58]. Additionally, Leask et al.'s reporting template and the Health CASCADE PRODUCES+ (https://zenodo.org/records/8379784) reporting template can offer structured approaches for reporting participatory methods. Further, systematic outcome evaluation might be beneficial for understanding what works and what rather does not work in this particular group or with increasing disability due to dementia.

### Limitations

Due to the lack of standardisation in reporting and the use of grey literature, including websites and conference presentations, it was difficult to accurately assess the presence of certain co-creation dimensions, particularly regarding 'open, trustful and inclusive dialogue'. While many reports implied the presence of these elements by the very nature of the participatory activities, they were often recorded as absent because the inferences required would not calibrated across multiple data extractors. This limitation necessitated the reporting of constructs which may have been present within the participatory activities but were not explicitly mentioned.

Focusing on underrepresented populations specific to dementia, our findings will not fully capture the full landscape of participatory methodologies, only those applied with this specific target group. However, due to the number of potential reports held within the repository and the time available to carry out the scoping review, it was necessary to take a pragmatic approach to the search terms and inclusion criteria. Another limitation is the exclusion of reports from non-health groups, which, although outside the scope of our focus, may employ robust participatory methodologies and/ or co-creation methods that could offer valuable insights.

The heterogeneity in reporting standards - which may be influenced by the wide range of co-terms used - across grey literature sources posed challenges in data extraction and synthesis, and the lack of standardized reporting for co-creation. Although having a multiple disciplinary team has advantages, having varying expertise in co-creation and the specific topic may have introduced selection bias of the reports. However, this was mitigated as much as possible by having regular discussions between the lead authors.

### Recommendations for research

Where possible, future research should enhance inclusivity by actively involving underrepresented communities as co-creators in the design, implementation and evaluation of participatory methodologies. This includes working in partnership with trusted community and third-sector organisations, compensating lived experience experts for their time and insight and using context-specific approaches that account for intersecting social, cultural and economic factors.

Developing and implementing standardised reporting guidelines for co-creation may improve the quality and comparability of co-creation projects, facilitating more robust and reliable reviews and identification of best practices. Future research should focus on co-developing models on hybrid modes of engagement that combine in-person and digital interactions to accommodate diverse preferences, capabilities and accessibility needs, particularly across age, ability and language. Expanding the scope of future reviews to include underrepresented groups regardless of health condition would provide a more comprehensive understanding of the evolving participatory methodologies for underrepresented groups.

## Conclusions

Our scoping review highlights the urgent need for better standardisation across primary and community research, particularly in the context of participatory methodologies - and more specifically, guidelines for involvement of underrepresented groups as stakeholders. Further, we showed that the grey literature often falls short of meeting the co-creation process dimensions and perhaps the evaluative and reporting detail required by frameworks and potential reporting checklists. We have also shown that meaningful inclusion of underrepresented groups is still emerging, which requires a shift away from purely conducting consultations and moving towards meaningful and more sustained partnerships - fostering greater ownership and relevance of the outcomes among the target populations.

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12874-025-02577-3.

Supplementary Material 1

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### Author contributions

K.M. and N.T. jointly led and conceptualised the scoping review design and methodology, co-ordinated the literature search and strategy, conducted full text screening with J.D., and extracted data alongside L.D. and D.A. Also, S.L. and M.G. reviewed and ensured the consistency and quality of data extraction, while also trialling data visualisation outputs alongside K.M. and N.T. Further, K.M. and N.T. wrote the full manuscript and drafted it, incorporating input from all co-authors. C.B., L.D., D.A., J.D., S.L. and M.G. provided textual input and/ or feedback for the manuscript development. All (co-) authors read and approved the final version of the manuscript.

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### Data availability

No datasets were generated or analysed during the current study.

## Declarations

### Ethics approval and consent to participate

Not applicable.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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