

Person-Centredness in Dementia Diagnosis & Detection: A Scoping Review

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Abstract

Background

Person-centred care (PCC) is widely recognized as a cornerstone of high-quality dementia care, yet its application during the diagnostic process remains poorly defined, with prior research focusing on long-term dementia management rather than the diagnostic journey. We aimed to examine how PCC is conceptualized and applied across the dementia diagnostic journey, identify strategies supporting person-centred diagnosis, and highlight gaps in the literature.

Methods:

We conducted a scoping review of peer-reviewed literature published between 1990 and 2025 across six databases. Studies were included if they conceptualized dementia diagnosis using established PCC frameworks or clearly articulated definitions. Data on study characteristics, conceptual approaches, person-centred practices, and barriers and enablers were extracted and mapped to the Person-Centred Care and Support (PCCS) framework. Findings were shared and discussed with members of two working groups including people with dementia and informal carers.

Results:

We included 23 studies with qualitative (73.9%) or quantitative/mixed-methods (26.1%) designs. Conceptualizations varied: 52.2% cited established theory-driven frameworks, while 47.8% described person-centredness primarily in practical clinical terms. Most studies addressed assessment (73.9%) and disclosure (60.9%), whereas fewer examined pre-diagnostic detection and screening (43.5%) or post-diagnostic support (34.8%). Mapping findings to the recently proposed PCCS framework for dementia care revealed that relational domains (e.g., exchanging information, fostering relationships) were prioritized over managing uncertainty, shared decision-making, and enabling self-management. Barriers were reported at the person (e.g., stigma), healthcare worker (e.g., time pressure), and system (e.g., fragmented pathways) levels. Few studies incorporated lived experience in developing recommendations or addressed emerging diagnostic technologies such as blood-based biomarkers or AI-driven assessments.

Conclusion:

Despite increasing attention to person-centred dementia diagnosis, the literature remains limited and conceptually unclear, with greater emphasis placed on initial clinical encounters than on longitudinal support across the diagnostic journey. As such, guidance on operationalizing person-centred principles throughout the diagnostic process remains sparse for individuals, informal carers, clinicians, and health

systems. This review provides preliminary guidance and highlights the need for unified frameworks spanning the full diagnostic journey. Moving forward, diagnostic models and pathways should be co-produced with people with dementia and their informal carers, while person-centred standards should guide the integration of emerging diagnostic technologies.

Background

Person-centred care (PCC) has increasingly been recognized over the past three decades as a cornerstone of high-quality care for people with Alzheimer's disease and related dementias (ADRD) [1]. Grounded in Kitwood's seminal social-psychological framework, PCC challenges the traditional tendency to view a person primarily through their medical diagnosis. In the context of ADRD, it rejects the assumption that personhood diminishes with cognitive decline, instead recognizing personhood as sustained through relationships, individual values and life story rather than reduced to symptoms or disease labels [2, 3]. It involves a partnership between clinicians, people with dementia (PwD) and their informal carers to tailor care to clinical needs, life circumstances and personal preferences [1–4].

Despite its widespread endorsement, PCC remains a conceptually fragmented construct, with multiple coexisting frameworks and considerable variation in how it is defined and operationalized [5, 6]. This lack of conceptual clarity, compounded by the absence of a universally accepted definition and the inconsistent use of overlapping terms with distinct origins and nuances — most notably “patient-centred”, as well as “relationship-centred” or “family-centred care” — has contributed to uneven implementation in practice [5, 7, 8]. Nevertheless, structured person-centred (PC) interventions have been shown to improve quality of life and reduce neuropsychiatric symptoms among people with dementia [9, 10]. While much of the historical evidence base has been concentrated in long-term care contexts [11–13], more recent work has sought to conceptualize and synthesize PCC and support within outpatient and community-based settings, culminating in the proposed Person-Centred Care and Support (PCCS) for Dementia framework [7]. This foundational work has identified key pillars, ranging from individualized care and the preservation of personhood to organizational and system-level enablers that facilitate PC support in the community.

Building upon these broad outpatient frameworks, there is growing recognition that the initial detection and diagnostic encounter warrant specific investigation. Traditionally, the diagnostic encounter has been conceptualized as a discrete clinical event centred on a series of tests followed by the delivery of a diagnostic label [14, 15]. However, diagnosis is increasingly viewed as a prolonged and iterative journey that begins with early detection or emerging concerns and extends through assessment, disclosure, and immediate post-diagnostic support [11, 14, 16, 17]. This process creates an important window for relational engagement, where interactions between clinicians, individuals with cognitive concerns, and their families shape emotional responses and expectations of future care [16, 17]. Advances in detection and diagnostics, including the emergence of blood-based biomarkers (BBMs), are expanding this window by enabling the identification of disease indicators long before observable symptoms appear [14, 18–20]. In parallel, the emergence of disease-modifying therapies (DMTs) is increasing the clinical

significance of early and accurate diagnosis, as treatment decisions may depend on the timely identification of underlying pathology [18–20]. Together, these innovations create new possibilities for earlier, more meaningful engagement with individuals while cognition remains intact, but also introduce clinical and ethical challenges related to preserving PC principles as diagnostic pathways evolve [21]. Reflection on how best to embed PC principles at this stage is therefore increasingly warranted. While the general principles of PCC across long-term, community, and outpatient dementia care settings are relatively more established [7, 10, 22, 23], how these principles should be operationalized during the diagnostic process itself remains comparatively underexplored. The diagnostic stage also presents distinct relational and ethical challenges that may fall outside the primary focus of existing PCC frameworks, including the stress of cognitive testing, prognostic uncertainty, and the sensitivity required for diagnostic disclosure, highlighting the need for a specialized synthesis of PC principles for this context [24, 25].

The urgency of refining these pathways is underscored by a looming global crisis, with dementia prevalence projected to nearly triple by 2050 [14, 26]. Despite growing recognition of the importance of timely diagnosis, substantial gaps remain in how the diagnostic process is experienced by individuals and their informal carers. In one study of six countries, fewer than 47% of individuals with cognitive concerns received a formal diagnosis after seeking one, while 21% were told to “watch and wait” [27], representing substantial attrition across the diagnostic pathway and highlighting that timely diagnosis depends not only on access, but also on sustained engagement across the diagnostic journey. Globally, more than half of people with dementia and their care partners report dissatisfaction with the diagnostic process [13, 28], highlighting persistent shortcomings in how diagnostic care is delivered. As timely and accurate detection and diagnosis become increasingly feasible, it is increasingly important to ensure that diagnostic pathways remain grounded in PC principles, supporting a dignified journey that upholds personhood and sustains engagement.

To address these considerations, the present scoping review aims to map the breadth and nature of the academic literature that discusses PC or related principles within the context of dementia diagnosis. Specifically, our objectives were to: (1) catalogue the PC frameworks, models or theories that have been proposed or applied within the context of dementia detection and diagnosis; (2) map out PC actions and practices that could be implemented in clinical practice during detection and diagnosis, along with associated implementation enablers and barriers; and (3) identify key gaps in the existing literature and areas for future research, policy and clinical practice regarding the implementation and effectiveness of PC principles.

Methods

We conducted a scoping review to examine how PCC is conceptualized, applied, and evaluated during the detection and diagnostic stages of ADRD. Similar in rigour to a systematic review, a scoping review was selected because it accommodates a wide range of study designs and outcomes, establishes baseline knowledge on a given topic, and identifies gaps in the literature that warrant further primary

research [29]. The review protocol was developed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) reporting guidelines [30], with the completed checklist provided in Additional_File_1.docx. This protocol was not published in advance.

Search strategy

We searched peer-reviewed literature in the following electronic databases: MEDLINE, EMBASE, CINAHL, Scopus, PsycINFO, and the Cochrane Library for publications published from January 1990 to 2025. The most recent search was conducted in October 2025.

The search strategy was adapted from recent reviews addressing ADRD and PCC, and was anchored around key terms related to diagnosis and detection, as outlined in Table 1 [7, 23, 31, 32]. Using MEDLINE, we identified and incorporated relevant Medical Subject Headings (MeSH) where available and supplemented these with truncated free-text keywords to capture synonymous terms and variations in terminology across databases. Full search terms were combined into structured search strings using Boolean operators described in Additional_File_2.docx.

Table 1
Search terms included in the search strategy

#1	Key Terms	Related Terms
	Dementia	Alzheimer’s Disease, Alzheimer’s Disease and Related Dementias (ADRD), cognitive decline, cognitive impairment, Dementia, memory impairment, Mild Cognitive Impairment (MCI)
#2	Person-Centred Care	client-centered, client-oriented, family-centered, family-oriented, patient-centered, patient engagement, patient-oriented, people-centered, people-oriented, person-centered, person-oriented
#3	Detection/Diagnosis	Amyloid-beta, ApoE, Biomarker, Clinical assessment, Cognitive assessment, CSF, Detection, Diagnosis, Memory assessment, MRI, Neuropsychological tests, PET, Screening, Tau

Eligibility

For the purpose of this review, the dementia diagnostic journey was defined using a framework aligned with international guidance, including the National Institute for Health and Care Excellence (NICE) NG97 Dementia Guidelines (UK) and the Alzheimer’s Association clinical practice guidelines (USA) [5, 17]. Accordingly, we included peer-reviewed studies involving adults across the diagnostic pathway, encompassing dementia detection and screening, assessment, diagnostic disclosure, and immediate post-diagnostic support. We also included studies involving informal carers and healthcare professionals engaged in these stages of care. In line with previous reviews, studies were required to explicitly engage with PC principles or related constructs (e.g., patient-centred or family-centred care) by

either citing established PCC literature or proposing and articulating their own clear conceptual approach or definition as related to the diagnostic pathway [7, 23, 33, 34]. This ensured that the identified studies were grounded in authentic PC principles rather than nominal uses of the term. We included empirical research with explicit methods of data collection and analysis, including qualitative studies (e.g. interviews, focus groups, narrative inquiry, qualitative coding or thematic analysis), quantitative studies (e.g. cross-sectional observational studies using surveys or facility records), and mixed-methods research (e.g. Delphi and modified Delphi studies), published in English.

We excluded studies focused on non-dementia cognitive conditions (e.g., traumatic brain injury or intellectual disability), as well as studies conducted exclusively in long-term residential or palliative care settings where the focus was on management beyond the diagnostic process. Similar to previous reviews, we also excluded papers that used PC terminology in an arbitrary or descriptive manner without a clear conceptual basis, or that asserted the importance of person-centredness without defining, applying, or evaluating PCC principles, consistent with prior scoping reviews [7, 10, 33, 34]. Review articles, including scoping and systematic reviews, were excluded, although their reference lists were screened to identify potentially eligible primary studies.

Screening

All records were retrieved and exported into Microsoft Excel, where duplicates were removed. Screening was conducted in two stages: an initial title and abstract screening followed by full-text screening, using the eligibility criteria described above. To pilot the screening approach, two reviewers independently screened the first 50 titles and abstracts and discussed discrepancies to refine and clarify the screening criteria. Using the refined approach, two reviewers independently completed title–abstract and full-text screening, with disagreements resolved through discussion.

Data extraction and analysis

For studies deemed eligible after full-text screening, data were charted using a structured Excel-based extraction form. Extracted information included publication details (e.g., authors, year, country and publication type), study characteristics (e.g., design, objectives, target population, care setting and stage of the diagnostic journey) and reported enablers and barriers to PCC implementation. To evaluate the translation of PCC from theory to practice across the diagnostic journey, we first identified how each study explicitly engaged with PCC principles, noting the specific conceptual approaches or theoretical definitions provided. Next, we identified reported PCC-related actions, strategies and practices and mapped these to the six-domain PCCS framework [7]. This process involved synthesizing findings within the established domains and integrating elements unique to the diagnostic journey to contextualize their application. Finally, we conducted a gap analysis by examining PCC domains, stages of the diagnostic journey, populations and settings that were underrepresented or inconsistently addressed in the literature.

The PCCS framework was initially developed by McCormack et al. in the context of cancer care as a comprehensive inventory of domains and subdomains organized under six core functions: fostering healing relationships, exchanging information, recognizing and responding to emotions, managing uncertainty, shared decision-making and enabling self-management. Although originally developed for oncology, the authors noted its relevance to any clinical context in which PCC is the primary goal [35]. Recognizing this broader applicability, Marulappa et al. subsequently adapted and validated this framework specifically as an organizing scaffold for dementia care [7]. However, while this framework has been successfully used to synthesize PC principles in outpatient and home/community settings, to our knowledge, it has not yet been applied specifically to the context of dementia diagnosis. Mapping findings to this validated framework enabled systematic comparison across studies and facilitated identification of areas where PC principles were well represented or lacking.

Public involvement

Findings from the review were shared and discussed with members of two established working groups coordinated by Alzheimer Europe: the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG). This activity was conducted within the framework of Public Involvement and therefore did not require formal ethics approval [36–38]. It followed the approach to Public Involvement and principles developed by Alzheimer Europe over the years [39]. Members of both groups are from different European countries and have lived experience of different dementia types and stages, either as people with dementia or as informal carers. Participants are nominated at the national level and serve for a fixed term. Consultations were conducted online in February 2026, with each session running for 2 hours, and were jointly facilitated by the authors and Alzheimer Europe staff members. The EWGPWD meeting involved 12 people with dementia, some accompanied by a supporter of their choice, typically a family member or friend, while the EDCWG meeting included 15 informal carers. Further information, including participants' countries, types of diagnosis and details about the working groups, is available on the Alzheimer Europe website [40]. All participants received materials in advance outlining the topics and questions for discussion. Insights generated through these discussions informed the interpretation of the review findings and are reflected in the Discussion, including the recommendations presented in this manuscript.

Results

Overview of included studies

A total of 1,510 unique records were identified using our initial search protocol after duplicates were removed. After title and abstract screening, 1,417 publications were excluded, and an additional 70 were excluded during full-text review (Fig. 1). The remaining 23 articles were included in the final synthesis (see Additional_File_3.xlsx for more details on each article) [11, 12, 21, 24, 25, 41–58].

Consistent with our inclusion and exclusion criteria, all 23 included studies explicitly addressed dementia diagnosis and either cited established PCC frameworks or provided a clear conceptual definition of PCC. The characteristics of the included studies are summarized in Table 2. The included literature was published between 2003 and 2025, with nearly half (11, 47.8%) appearing from 2020 onward, reflecting a recent increase in attention to PC approaches within the diagnostic journey. Geographically, most studies were conducted in the United States (10, 43.5%), followed by the United Kingdom (3, 13.0%) and Australia (2, 8.7%), with the remaining studies conducted across a range of other international settings.

Table 2
Characteristics of the 23 studies included for analysis

Category	Details	Number of Articles
Year of Publication	2025	5
	2024	2
	2022	2
	2021	1
	2020	1
	2019	2
	2018	2
	2017	1
	2014	1
	2013	2
	2012	2
	2010	1
	2003	1
Countries Studied ¹	United States of America	10
	United Kingdom	3
	Australia	2
	China	1
	Chile	1
	India	1
	Ireland	1
	Israel	1
	The Netherlands	1
	Norway	1
	Spain	1
Type of Study	Conceptual / Perspective	8
	Qualitative empirical	6
	Delphi / Modified Delphi	3

Category	Details	Number of Articles
Type of Dementia	Observational / Cross-sectional quantitative	6
	ADRD, including MCI and SCD	15
	Alzheimer's disease-specific	5
	Young-onset dementia	2
	Frontotemporal dementia	1

¹ Some articles are representative of data from multiple countries.

Study designs included conceptual or framework-based analyses (8, 34.8%), qualitative empirical studies such as interviews and focus groups (6, 26.1%), Delphi or modified Delphi approaches (3, 13.0%), and observational or cross-sectional quantitative designs (6, 26.1%), including structured coding analyses of diagnostic encounters and reviews of clinical records. Of the 15 empirical studies, 12 involved patients, while three involved experts or healthcare professionals only. Among these 12 empirical studies involving patients, 10 (83.3%) reported age information for participants with dementia, MCI or SCD. Reported participant ages ranged from 39 to 91 years. The youngest reported participants were from a young-onset dementia study, where age at diagnosis ranged from 39 to 64 years [48]. The oldest individual age reported was 91 years in a dementia diagnostic disclosure study [57], while the cohort with the oldest reported mean age was from a residential aged care study, where participants had a mean age of 85.5 years [51].

The included studies were conducted across a range of clinical environments. Nine studies (39.1%) were situated within outpatient or primary care settings, while eight (34.8%) focused on memory clinics or specialized diagnostic services. The remaining six (26.1%) addressed broader clinical settings, such as system-level analyses that spanned multiple tiers of care or comprehensive frameworks for clinical diagnostics. Most studies focused on ADRD as a broad category (15, 65.2%), while a smaller number focused on specific dementia types or clinical presentations (8, 34.8%), including Alzheimer's disease (5), young-onset dementia (2) and frontotemporal dementia (1).

Focus across the diagnostic journey

Attention across the diagnostic journey was unevenly distributed across four stages: pre-diagnostic detection and screening, assessment, disclosure, and post-diagnostic support, as summarized in Table 3. Nearly half of the included studies (10, 43.5%) addressed pre-diagnostic detection or screening. However, discussions about this stage were predominantly focused on enhancing systemic readiness and clinical awareness as a means to promote person-centredness rather than providing operationalized PC strategies. The assessment stage received the highest degree of focus (17, 73.9%), with studies providing detailed discussions regarding holistic evaluations that integrate cognitive, functional and

psychosocial dimensions within multidisciplinary contexts. Diagnostic disclosure was also a prominent theme (14, 60.9%), with discussions emphasizing triadic communication and the necessity of balancing diagnostic transparency with emotional support for both people with dementia and informal carers. Conversely, post-diagnostic follow-up was the least addressed stage (8, 34.8%). While discussions in these studies typically advocated for individualized care planning and carer education, they less frequently provided the granular implementation strategies or signposting grounded in PC principles that were more prevalent in the literature discussing assessment and disclosure.

Notably, four of the included studies (17.4%) proposed system-level models that claimed to embed PC principles across coordinated diagnostic pathways spanning screening, assessment, disclosure and follow-up [11, 12, 41, 46]. For instance, Atri et al. presented a clinical practice guideline designed to modernize clinical workflows and empower primary care clinicians [11], whereas Snider et al. focused on system readiness and pathway transformation in response to emerging therapies [41]. Similarly, Galvin et al. described a patient-centred diagnostic blueprint emphasizing multidisciplinary team coordination and structured care pathways [12], and Lu et al. proposed a pathway for detecting Mild Cognitive Impairment (MCI) that identifies patients' experience as a core domain [46]. Although these models incorporate PC elements, their emphasis remains largely on diagnostic infrastructure and clinical management, with comparatively limited operational detail regarding relational and psychosocial strategies across stages. Consequently, a distinct gap persists in how PC principles are translated into practice across each stage of the diagnostic journey.

Table 3
Mapping of Person-Centred principles across the diagnostic journey

Study	Diagnostic Stages (n, % of 23 studies)			
	Detection/ screening	Assessment / differentiation	Diagnostic disclosure	Post-diagnostic support
Snider 2025 [41]	+	+	+	+
Eid 2025 [42]	+			+
Atri 2025 ¹ [11, 59]	+	+	+	+
De Rijke 2025 [43]		+	+	+
O'Brien 2025 [24]		+	+	
Fenn 2024 [44]		+		
Slachevsky 2024 [45]		+		
Lu 2022 [46]	+	+	+	+
Villarejo-Galende 2022 [47]		+	+	
O'Malley 2021 [48]	+	+	+	
Galvin 2021 [12]	+	+	+	+
Kilty 2019 [49]	+		+	
Wynn 2019 [50]			+	
Dyer 2018 [51]		+		+
Challen 2018 [52]		+		
Guan 2017 [25]			+	
Edwards 2014 [53]	+	+		
Brummel-Smith 2013 [54]	+	+		
Borson 2013 [55]	+	+		
Karnieli-Miller 2022 [56]		+	+	+
Mast 2012 [21]		+		
Zaleta 2010 [57]			+	

Study	Diagnostic Stages (n, % of 23 studies)			
	Detection/ screening	Assessment / differentiation	Diagnostic disclosure	Post-diagnostic support
Wilkinson 2003 [58]			+	
Total	10 (43.5%)	17 (73.9%)	14 (60.9%)	8 (34.8%)

¹ Detailed recommendations for specialty and primary care settings are provided in the companion publication.

Person-centred definitions and frameworks

The included studies utilized a diverse conceptual basis to define and interpret person-centredness within the diagnostic journey. Twelve studies (52.2%) were anchored in foundational, theory-driven frameworks that define personhood and establish core PC principles. Kitwood's philosophy of personhood was the most frequently cited framework (7, 30.4%) [21, 43, 45, 49, 53, 57, 58], while other studies drew on related theoretical perspectives, including Fazio's fundamentals of PCC (2, 8.7%) [12, 42], Brooker's VIPS framework (1, 4.3%) [52], Mead and Bower's dimensions of patient-centredness (1, 4.3%) [25] and Talerico's framework for PCC (1, 4.3%) [44]. These 12 studies primarily employed qualitative or mixed-methods designs to evaluate diagnostic experiences and the alignment of clinical practices with PC principles.

Conversely, 11 studies (47.8%) did not draw on established, theory-driven PC frameworks. Six of these provided a clear definition of person-centredness within the context of dementia diagnosis and framed it as a functional objective within clinical settings, including system-level readiness evaluations, infrastructure blueprints and clinical practice guidelines [41, 46, 48, 51, 54, 55]. The remaining five studies utilized interactional or communication frameworks to guide diagnostic encounters, such as adapting the SPIKES cancer disclosure protocol to dementia diagnostic disclosure [60], and described these approaches as PC [11, 24, 47, 50, 56]. Rather than evaluating the philosophical maintenance of personhood, these 11 studies focused on operationalizing person-centredness through practical improvements to diagnosis, such as workflow design, collaborative decision-making or structured communication.

Mapping diagnostic elements to the Person-Centred Care and Support (PCCS) framework for dementia

Given the conceptual variability identified across the included studies, the PCCS framework for dementia was selected to consolidate how PC principles are described within the dementia diagnostic literature. Adapted by Marulappa et al., this multidimensional framework has been applied in outpatient and home/community dementia care settings and provides a structured approach for mapping diverse

findings within a unified framework [7]. Guided by this framework, we extracted text from the 23 included studies describing principles, recommended actions or practices related to PC dementia diagnosis and mapped these to the six PCCS domains, as presented in Table 4. These domains include fostering a healing relationship, exchanging information, addressing emotions or concerns, managing uncertainty, shared decision-making and enabling self-management.

Table 4
Mapping of included studies to the PCCS framework domains

Study	Person-centred domains (n, % of 23 studies)					
	Foster the relationship	Exchange information	Address emotions	Manage uncertainty	Share decision-making	Enable self-management
Snider 2025 [41]	+	+		+	+	+
Eid 2025 [42]	+	+		+	+	+
Atri 2025 ¹ [11, 59]	+	+	+	+	+	+
De Rijke 2025 [43]	+	+	+			+
O'Brien 2025 [24]	+	+	+	+	+	+
Fenn 2024 [44]	+	+	+	+		+
Slachevsky 2024 [45]	+	+	+	+		+
Lu 2022 [46]						
Villarejo-Galende 2022 [47]		+	+		+	
O'Malley 2021 [48]	+	+	+	+	+	+
Galvin 2021 [12]	+	+	+	+	+	+
Kilty 2019 [49]	+	+	+		+	+
Wynn 2019 [50]	+	+	+			
Dyer 2018 [51]	+	+				
Challen 2018 [52]	+		+			
Guan 2017 [25]		+	+		+	

Study	Person-centred domains (n, % of 23 studies)					
	Foster the relationship	Exchange information	Address emotions	Manage uncertainty	Share decision-making	Enable self-management
Edwards 2014 [53]	+	+	+		+	
Brummel-Smith 2013 [54]	+	+	+	+	+	+
Borson 2013 [55]		+		+	+	
Karnieli-Miller 2022 [56]	+	+	+	+	+	+
Mast 2012 [21]	+	+	+		+	+
Zaleta 2010 [57]	+	+	+			
Wilkinson 2003 [58]	+	+	+	+	+	+
Total	19 (82.6%)	21 (91.3%)	18 (78.3%)	12 (52.2%)	15 (65.2%)	14 (60.9%)

The distribution of these domains reveals a hierarchy in how person-centredness is prioritized within the current diagnostic literature. Exchanging information was the most consistently described domain, appearing in nearly all studies (21, 91.3%), followed by fostering the relationship (19, 82.6%) and addressing emotions (18, 78.3%). Across these interaction-focused domains, several recurring PC approaches were identified, with the specific recommendations summarized in Table 5. Most prominently, many studies emphasized the integration of carers into the diagnostic process through the establishment of triadic clinician-person-carer partnerships [11, 12, 24, 25, 42, 45, 50, 56, 57]. Within these recommendations, informal carers are repositioned as knowledgeable collaborators rather than passive observers, helping to balance the person's autonomy with the clinical need for an informant history while supporting PwD in processing and responding to diagnostic information. Alongside this emphasis on triadic relationships, the studies also highlighted the importance of nuanced communication and emotional responsiveness during diagnostic encounters [11, 25, 42, 45, 56]. Many studies recommended building rapport at the outset, tailoring communication to the person's cognitive status and literacy and conducting disclosures in private, calm environments that allow space for emotional responsiveness and the validation of concerns [11, 21, 24, 43, 44, 49, 50, 56–58].

In contrast, domains related to longitudinal support across the diagnostic journey were less discussed. Managing uncertainty was the least represented domain, discussed in only half of the studies (12,

52.2%). While more recent studies encourage clinicians to acknowledge the inherent ambiguity of detection and diagnosis, particularly when biomarker or cognitive testing results are inconclusive, most studies focus primarily on the clinical encounter itself [11, 24, 41, 55]. As a result, relatively little attention is paid to supporting people during the often-stressful waiting periods that occur between assessment visits. Similarly, sharing decision-making (15, 65.2%) and enabling self-management (14, 60.9%) were discussed in less depth, although some studies recommend involving people undergoing dementia assessment and informal carers in setting goals for the diagnostic evaluation, discussing the degree of cognitive impairment and its implications or encouraging active participation in diagnostic conversations [11, 21, 49, 55, 56]. Others suggest supporting PwD after disclosure by providing guidance on maintaining independence, connecting PwD and families to support services, or offering follow-up meetings to discuss next steps [11, 24, 42, 43, 45]. However, these recommendations are typically described in broad terms, often lacking the specific implementation tools required to sustain person-centredness throughout the entirety of the diagnostic journey.

Table 5
Person-Centred Care Elements Organized by PCCS Framework Domains

PC Domain	Representative Actions Identified in the Review (n = 23)
Foster a healing relationship	<ul style="list-style-type: none"> • Create a respectful and supportive clinical environment for diagnostic discussions • Build rapport and trust early in the diagnostic process • Maintain the person as the central participant in discussions • Engage both the person and carer in a collaborative triadic relationship • Allow sufficient consultation time for discussion and questions • Promote continuity through consistent clinicians or care coordinators
Exchange information	<ul style="list-style-type: none"> • Explain the purpose and steps of the diagnostic evaluation • Describe the assessments or tests used during diagnosis • Tailor information to the person's cognitive ability and health literacy • Use clear, simple language when discussing symptoms or diagnosis • Explain test results and diagnostic conclusions clearly • Communicate potential implications of diagnostic testing • Use open-ended questions to explore the person's concerns and perspectives • Check the person's understanding during the discussion
Address emotions	<ul style="list-style-type: none"> • Encourage PwD and carers to express emotional reactions to the diagnosis • Acknowledge and validate emotional responses such as fear or distress • Demonstrate empathy through supportive communication • Monitor for symptoms of anxiety or depression in PwD and carers • Provide reassurance while maintaining realistic expectations
Manage uncertainty	<ul style="list-style-type: none"> • Explain the limits of diagnostic certainty in dementia evaluation • Discuss the possibility that symptoms and diagnosis may evolve over time • Describe possible future disease trajectories where appropriate • Recognize and consider cognitive concerns reported by PwD or carers, even when objective test results are inconclusive or negative • Refer to specialists when additional diagnostic clarification is required
Share decision-making	<ul style="list-style-type: none"> • Encourage PwD to participate in decisions about testing and care • Elicit the person's values, preferences and life context to guide decisions

PC Domain	Representative Actions Identified in the Review (n = 23)
	<ul style="list-style-type: none"> • Discuss diagnostic and referral options collaboratively with PwD and carers • Reach shared agreement on next steps following diagnosis
Enable self-management	<ul style="list-style-type: none"> • Offer practical guidance on managing symptoms in daily life • Support strategies that help maintain independence and daily functioning • Connect PwD and carers with community resources and support services • Provide guidance on assistive devices or home adaptations • Support carers' coping strategies and long-term care planning • Establish follow-up appointments after diagnostic disclosure

The representation of PCCS domains also varied according to publication year. Studies published between 2024 and 2025 were the most comprehensive, with all seven from this period addressing at least five of the six PCCS domains. The domain of managing uncertainty followed a similar temporal pattern. While it was addressed in only half of the total studies, eight of the 12 studies covering this domain were published between 2021 and 2025. One study did not map to any domains because while it applied PC principles to define diagnostic success, it focused strictly on structural service requirements to establish the organizational infrastructure for diagnosis [46].

Enablers barriers to person-centred diagnosis

The reviewed literature highlights a diverse range of factors influencing the implementation of PC throughout the dementia diagnostic journey. These themes are categorized by their impact at the person/carer, healthcare worker and system levels, as highlighted in Table 6.

At the person/carer level, enablers involve empowerment through digital triage and pre-diagnostic preparation tools, which facilitate meaningful engagement and shared decision-making [11, 12, 41, 55]. However, these are often countered by barriers such as internalized stigma and clinical challenges like anosognosia, or a lack of insight [11, 24, 42, 53]. These factors, combined with inadequate information about the diagnostic process and triadic discordance between people undergoing assessment and informal carers, often relegate people and their families to the role of passive observers rather than active partners in their own care [11, 42, 56]. Regarding healthcare workers, enablers include the use of established interactional frameworks and an intentional awareness of the person's life history to personalize the diagnostic journey [11, 21, 57]. Nevertheless, these enablers are frequently undermined by barriers such as limited time, workload pressure and physician-dominated communication [12, 50, 56, 58]. Such constraints often force a prioritization of diagnostic throughput and clinical accuracy over the emotional and relational needs of the individual [24, 43]. At the system level, enablers include structural supports such as multidisciplinary team models and formal PCC policies that facilitate a transition in clinical encounters away from standardized checklists toward comprehensive care [44, 46]. In contrast,

systemic barriers include fragmented care pathways and geographic or socioeconomic inequalities in access [45, 48]. These structural limitations, alongside long wait times, often result in the diagnostic encounter becoming siloed from essential longitudinal support and follow-up services [49, 55].

Table 6
Multilevel determinants of person-centredness in the dementia diagnostic journey

Level	Enablers	Barriers
Person or Carer	<ul style="list-style-type: none"> • Access to digital triage and pre-diagnostic tools • Alignment of clinical goals with personal values • Presence of a supportive family advocate in a triadic partnership • Validation of cognitive concerns • Cultural safety and use of preferred language • Positive past experiences with the healthcare team 	<ul style="list-style-type: none"> • Internalized stigma and fear of cognitive decline • Inadequate information on the purpose or limits of tests • Adoption of a passive role during visits • Emotional distress while waiting for results • Lack of insight (anosognosia) leading to refusal of help • Triadic discordance or misaligned expectations
Healthcare worker	<ul style="list-style-type: none"> • Use of interactional models and specialized training • Demonstration of empathy and active listening • Peer support and multidisciplinary collaboration • Documented awareness of the person's life history • Mentorship from person-centred champions 	<ul style="list-style-type: none"> • Limited consultation time and high workload • Physician dominance in dialogue • Implicit ageism or nihilism toward dementia care • Difficulty explaining complex genetic or biomarker data • Lack of confidence in handling emotional fallout
System	<ul style="list-style-type: none"> • Single point of access and direct referral systems • Multidisciplinary staffing and care coordination roles • Environments designed for privacy and sensory comfort • PC principles embedded in clinical policy • Use of digital assessments to expedite the pathway 	<ul style="list-style-type: none"> • Fragmented coordination between primary and specialist tiers • Long wait times and geographic inequities in access • Siloing of diagnosis from longitudinal support • Western bias in standardized cognitive testing tools • Noisy or confusing clinical infrastructure

Discussion

This scoping review addresses an important gap in the growing body of PCC literature on dementia by examining how PC principles are conceptualized and applied during the diagnostic process. Although previous reviews have explored PCC in dementia more broadly [6, 7, 9, 10, 23, 61, 62], this review is distinct in three key ways. First, prior studies have largely focused on PCC within long-term management settings, with limited attention to diagnostic elements such as dementia disclosure, and in some cases explicitly excluding dementia diagnosis from eligibility criteria [6, 7]. In contrast, this review maps PCC across the entire diagnostic journey, encompassing the transition from pre-diagnostic detection or screening to early post-diagnostic support. Second, while some previous reviews have explored the theoretical foundations of person-centredness [7, 23], most focus on the effectiveness of specific interventions rather than examining how PCC itself is conceptualized. By examining how PCC is defined and applied in the dementia diagnostic literature, this review offers greater conceptual clarity that may inform future research and practice. Third, the findings of this review are informed by the perspectives of both PwD and their informal carers. Ensuring that identified priorities reflect the values of individuals with lived experience is a central principle of PCC and helps align research priorities with the needs, preferences and values of those most directly affected by the dementia diagnostic process.

Imbalance across the diagnostic journey

The dementia diagnostic process is often a prolonged and complex trajectory, spanning several years, with a mean time to diagnosis of approximately 3.5 years [63]. This journey is frequently characterized by substantial dissatisfaction among PwD and carers, particularly regarding insufficient information and limited support during disclosure [13]. A key finding of this review is the uneven distribution of PC considerations across the dementia diagnostic journey. While several studies addressed pre-diagnostic detection or screening, these discussions primarily emphasized improving system readiness, with limited attention to how such readiness should support the interpersonal dimensions of PC required during this stage. The limited consideration of PC principles during the pre-diagnostic stage may overlook the vulnerability, uncertainty and stigma individuals can experience before entering formal clinical care [64].

In contrast, the included studies collectively placed greater emphasis on the assessment and disclosure stages, where they frequently described holistic communication approaches that acknowledge the person's life context and involve the clinician-person-carer triad. This relative emphasis is understandable given the emotionally and relationally intensive nature of disclosure, yet it risks creating an uneven foundation of PC guidance across the diagnostic journey. Additionally, guidance for post-diagnostic follow-up is similarly limited. Although many studies advocated for individualized care planning or follow-up support, few provided concrete strategies for sustaining person-centredness during this stage.

Beyond this uneven distribution across stages, we found limited focus on emerging diagnostic technologies, which are increasingly important as they expand opportunities for earlier detection and timely diagnosis while introducing new complexities in communicating risk, managing uncertainty, and aligning diagnostic processes with individual preferences and needs [14, 19, 20]. None of the studies we identified explicitly examined emerging technologies through PC lens. However, several of the included studies acknowledged that emerging diagnostic technologies may affect patient engagement, understanding, and the alignment of care with individual values and preferences across the diagnostic journey [11, 21, 25, 41, 45]. Taken together, these findings suggest that future frameworks must address how person-centredness can be preserved as diagnostic pathways incorporate increasingly sophisticated technologies and data-driven approaches.

Notably, only four studies explicitly described the full diagnostic journey. While these studies claimed to incorporate elements of PCC, they were primarily developed to address clinical workflows or system readiness rather than to embed established PCC theories [11, 12, 41, 46]. As a result, they provided limited guidance on how PC principles should be enacted across the diagnostic journey. This observation is not isolated; it reflects a broader trend in dementia care in which person-centredness is often implemented as a set of clinical practices rather than as a relational approach grounded in the preservation of personhood [65, 66]. As noted earlier, most previous PCC-focused reviews have largely conceptualized “care” as the long-term management of symptoms, implicitly assuming it begins only once the diagnostic process has concluded [6, 9, 62, 67]. This framing reveals a meaningful evidence gap rather than merely a labelling discrepancy, as it reflects limited attention in the literature to addressing the relational and emotional needs that arise immediately following disclosure. Bridging this gap requires a shift toward integrated diagnostic pathways that embed PC principles across all stages of the diagnostic journey, ensuring the post-diagnostic transition is recognized as a vital stage of care within the diagnostic journey itself.

Approaches to strengthen person-centred diagnosis

As a preliminary step to help identify potential PC principles, we reviewed the included studies to extract recommendations related to delivering a PC dementia diagnostic journey. Recommendations were extracted from all included studies irrespective of whether they were anchored in established, theory-driven PCC frameworks. Most recommendations identified from the set of included studies were typically presented as high-level suggestions—such as “improving communication” or “involving carers”—rather than clearly defined implementation strategies specifying how or when these PC principles should be enacted within the diagnostic pathway. Some studies proposed more concrete guidance, such as iteratively assessing the person’s understanding during disclosure, discussing the clinical syndrome before explaining the underlying etiology, or coordinating structured follow-up and care planning after diagnosis [11, 41, 57].

Notably, despite frequent advocacy for inclusion, only a minority of studies directly integrated the voices of PwD and their informal carers into the research findings [42, 48, 52, 53, 56]. This limited grounding in lived experience raises questions regarding the real-world feasibility and acceptability of many proposed

actions. Nevertheless, by extracting all identified recommendations from the included studies, this review identifies a range of actions that could serve as a starting point for PC diagnostic encounters. When considered collectively, these approaches broadly map to the six domains of the PCCS framework, a structure previously proposed in outpatient and home/community settings [7]. Applying this framework provides a structured way to synthesize otherwise fragmented guidance into the six established domains: fostering a healing relationship, exchanging information, addressing emotions, managing uncertainty, shared decision-making, and enabling self-management (Table 5).

This review also identifies several enablers and barriers that influence the implementation of PCC during diagnosis. These factors highlight that a PC encounter is not solely dependent on clinician intent, but rather on alignment across person, healthcare worker and system-level conditions. Most of these enablers and barriers align with what is described in the literature [7]. Several also appear particularly specific to the diagnostic journey, including enablers such as validating early cognitive concerns and access to pre-diagnostic screening tools, alongside barriers such as limited consultation time, high workload, difficulties communicating complex test results, managing distress while awaiting confirmation, and aligning expectations within the diagnostic triad. Ultimately, without structural support such as multidisciplinary team models to bridge these deficits, the diagnostic journey will remain a series of siloed clinical encounters. This suggests that achieving a truly PC diagnosis requires a multi-level shift in which systemic readiness empowers clinicians to, in turn, empower the individual. At the same time, important gaps remain in the current literature. In particular, the included studies provide limited discussion of equity considerations, offering little guidance on how structural disparities such as language barriers, socioeconomic status or geographic access to care may shape PC diagnostic experiences [41, 44, 45, 48].

Disproportionate focus of person-centred domains

Mapping the diagnostic literature against the PCCS framework reveals a disproportionate focus on relational domains, specifically fostering the relationship, exchanging information, and addressing emotions, while managing uncertainty, shared decision-making and enabling self-management remain comparatively under-addressed. This pattern mirrors findings by Marulappa et al. in outpatient and home/community dementia care settings, where relational domains are similarly prioritized over managing uncertainty or enabling self-management [7]. This skew may reflect the unique complexity of the dementia care triad, where the dynamic interplay between the clinician, the individual and the informal carer introduces intricate, and at times paradoxical, relational demands [68–70]. Consequently, this inherent complexity may help explain why much of the current PC literature remains concentrated on the communicative and relational domains of the PCCS, resulting in a relative lack of guidance on how to manage uncertainty, support shared decision-making and enable self-management across the diagnostic journey.

Public involvement perspectives

These findings were discussed with PwD and informal carers in a Public Involvement consultation. Participants shared their reflections on the conceptualization of PC diagnosis. This activity was not intended to reach consensus, but rather to capture the diversity of perspectives and lived experiences across participants. The main points summarized below reflect the range of views expressed by members of the EWGPWD and EDCWG:

- Person-centred diagnosis is regarded as a fundamental expectation of good diagnostic practice and is understood as an approach that should guide the entire diagnostic journey rather than being applied only at specific stages. Diagnostic practice should therefore move beyond a one-size-fits-all approach, taking into account the person's medical history, age and lifestyle rather than relying solely on standardized criteria or population averages. This requires seeing the person rather than the disease and preserving personhood even as cognition changes, an approach viewed by many as a fundamental requirement of diagnostic practice rather than an "optional enhancement."
- The current diagnostic journey is frequently experienced as insufficiently PC, often described as a prolonged and fragmented process rather than a cohesive pathway, with participants emphasizing the need for earlier and more timely diagnosis. There is also a call for immediate, clearly signposted transitions to bridge gaps between disclosure and post-diagnostic support, so that care is sustained throughout the journey rather than treated as a series of isolated clinical events. Additionally, while emerging technologies such as biomarkers and artificial intelligence (AI)-driven assessments offer potential benefits for improving access, efficiency and diagnostic timeliness, they must be embedded within this broader pathway in ways that maintain an individualized and PC approach.
- Person-centred diagnosis is consistently characterized as involving a complex relationship between the healthcare professional, the PwD, and the informal carer. This relational complexity differentiates dementia diagnosis from many other chronic conditions and underscores that the PwD and the informal carer should not be treated as a single unit, nor should one voice be assumed to represent both. It is highlighted that focusing solely on the PwD is insufficient, particularly at the point of diagnosis when the person may be emotionally overwhelmed, in shock or cognitively unable to process complex information. As such, some participants referred to the idea of a "person-plus" model, where care actively includes and supports the informal carer while preserving the autonomy and personhood of the PwD.
- While the six domains of the PCCS framework are broadly viewed by participants as relevant to dementia diagnosis, their implementation in practice remains uneven and front-loaded. Participants report that domains related to fostering relationships, exchanging information and, to some extent, addressing emotions are sometimes experienced during the initial assessment. In contrast, domains related to managing uncertainty, shared decision-making and enabling self-management are often absent during disclosure or after the diagnosis is delivered. Although fostering relationships is viewed as the foundational domain for PC diagnosis, participants consistently emphasize that managing uncertainty and enabling self-management remain critically important for preserving personhood despite being the least implemented.

- Key systemic barriers, particularly time constraints and limited dementia-specific training, continue to hinder the diagnostic process. There is a notable disconnect between medical and social care: while social care is often perceived as more PC, it remains poorly integrated with diagnostic services. Interestingly, while stigma remains a factor, it is not viewed as the dominant barrier by participants and is perceived to be improving over time, possibly reflecting broader improvements to public awareness, normalization and more open discourse around cognitive health.
- Although there is overall alignment regarding the need for person-centredness, subtle differences in priority exist between PwD and informal carers. PwD tend to prioritize the protection of relational dignity within the clinical encounter, whereas informal carers focus on addressing system fragmentation and navigation burdens to make person-centredness functional across the full diagnostic journey. These distinct priorities highlight the importance of incorporating lived experience to shape clinical guidance, ensuring an inclusive approach where diagnosis is fair and accessible to all.

Recommendations

Drawing on both the review findings and public involvement perspectives, we identified a consistent need to place the person at the centre of dementia detection and diagnostic pathways. Beyond critically supporting timely and efficient diagnosis, PC pathways should promote sustained engagement, individualized communication, and continuity throughout the diagnostic journey. Addressing gaps in continuity, engagement, and implementation of PC principles across the diagnostic pathway will require a multifaceted approach involving changes at the point-of-care, health-system, and policy levels. Based on these findings, we identified the following four key priorities to advance more integrated and implementable models of PC dementia diagnosis:

- **Partner with people with dementia and their informal carers:** Future diagnostic models and pathways should move beyond simply advocating for patient voices toward actively co-producing them with PwD and their informal carers. Involving the care triad in the design of diagnostic pathways can help ensure that proposed actions are not only clinically sound but also practically feasible, aligning clinical workflows with the priorities and lived experience of those affected.
- **Prioritize synthesis and integration of existing models:** There is a need to move beyond fragmented clinical models toward a unified framework that covers the entire dementia diagnostic journey. Future efforts should integrate the conceptual completeness of domain-based frameworks, such as the PCCS model, with clinical pathway models that describe the full diagnostic journey. This integration would ensure that person-centredness functions as a continuous way of being rather than a protocol that is toggled on or off during individual clinical encounters.
- **Prepare for technological innovations:** As emerging diagnostic innovations such as BBM testing and AI-driven assessments become increasingly integrated into dementia detection and diagnosis, clear PC standards will be needed to guide their incorporation into diagnostic pathways. Future studies should therefore examine how core PC principles, such as managing uncertainty and

addressing emotions can be maintained during these increasingly technical and data-rich interactions so that technological advances streamline detection and diagnosis while also supporting the relational and informational needs of individuals and their carers.

- **Advance structural equity in diagnosis:** Future research and policy should focus on adapting person-centred diagnostic frameworks to support culturally safe and equitable implementation across diverse populations and care settings. This includes considering structural barriers, such as language, socioeconomic circumstances and geographic access when translating PC principles into routine diagnostic practice.

Strengths and limitations

This review has several strengths. By employing a scoping review methodology, we synthesized findings from studies using diverse research designs and established a comprehensive overview of how PCC is conceptualized and applied within the dementia diagnostic literature. By mapping the included studies against the validated PCCS framework for dementia care [7], and applying it specifically to the diagnostic context, this review provides much-needed conceptual clarity in an area where PC terminology is often used inconsistently.

Several limitations should also be acknowledged. First, as this study was a scoping review rather than a systematic review, we mapped the range and characteristics of PCC concepts without formally assessing the methodological quality of the included studies [29]. Second, participant ages and diagnostic populations varied across studies, with some studies providing limited age information. These factors should be considered when assessing the applicability of findings across different age groups and diagnostic contexts. Third, our eligibility criteria required studies to provide an explicit conceptual articulation of person-centredness. While this deliberate filter ensured conceptual rigour and reproducibility in line with prior reviews [7, 23, 33, 34], it may have excluded studies describing relevant PC practices, such as those focusing on patient preferences or priorities that did not explicitly reference a formal framework or definition of PCC [71–75]. Fourth, the search was restricted to peer-reviewed, English-language literature, consequently, relevant frameworks or guidance contained within grey literature sources, such as government or policy reports, may have been missed. Finally, the findings reflect the current state of the published literature and may not yet capture emerging areas of practice, particularly the integration of PC principles within novel technologies such as biomarkers or AI diagnostic tools.

Conclusions

To our knowledge, this is the first scoping review that examines how PCC is conceptualized and applied across the dementia diagnostic journey, from pre-diagnostic detection to early post-diagnostic support. Most of the papers included in our review focused on the assessment and disclosure stages, with comparatively fewer addressing pre-diagnostic detection and screening or post-diagnostic follow-up. Furthermore, the included studies placed greatest emphasis on the relational domains of PCC, while

relatively fewer studies described how to manage uncertainty, support shared decision-making and enable self-management across the diagnostic process. Given our findings, we recommend that future studies: 1) partner with PwD and their informal carers to co-produce future diagnostic models and pathways; 2) prioritize integrating domain-based PCC frameworks, such as PCCS, with existing clinical pathway models to develop unified frameworks that support PCC across the full dementia diagnostic journey; 3) develop PC standards to support the integration of emerging diagnostic innovations, including BBMs and AI-driven assessments, into diagnostic pathways so that technological advances enhance both diagnostic precision and the overall diagnostic experience; and 4) adapt PC diagnostic frameworks to support culturally safe and equitable implementation across diverse populations and care settings.

Abbreviations

ADRD

Alzheimer's disease and related dementias

AI

Artificial intelligence

BBMs

Blood-based biomarkers

DMTs

Disease-modifying therapies

EDCWG

European Dementia Carers Working Group

EWGPWD

European Working Group of People with Dementia

MeSH

Medical Subject Headings

MCI

Mild Cognitive Impairment

NICE

National Institute for Health and Care Excellence

PC

Person-centred

PCC

Person-centred care

PCCS

Person-Centred Care and Support

PRISMA-ScR

Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews

PwD

Declarations

Ethics approval and consent to participate

Not Applicable

Consent for publication

Not Applicable

Competing Interests

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Author Contribution

MG, AD, DG, FJ, CK, RW, and YH conceptualized the study and its methodology. MG, CK, RW, and YH coordinated the study, collected and analyzed data, and drafted the manuscript. AD and DG contributed to study coordination, data interpretation, and manuscript editing. FJ contributed to the development of the study design and methodology. All authors read and approved the final version of the manuscript.

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Data Availability

All data supporting the findings of this study are available within this published article [and its supplementary information files].

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Figures

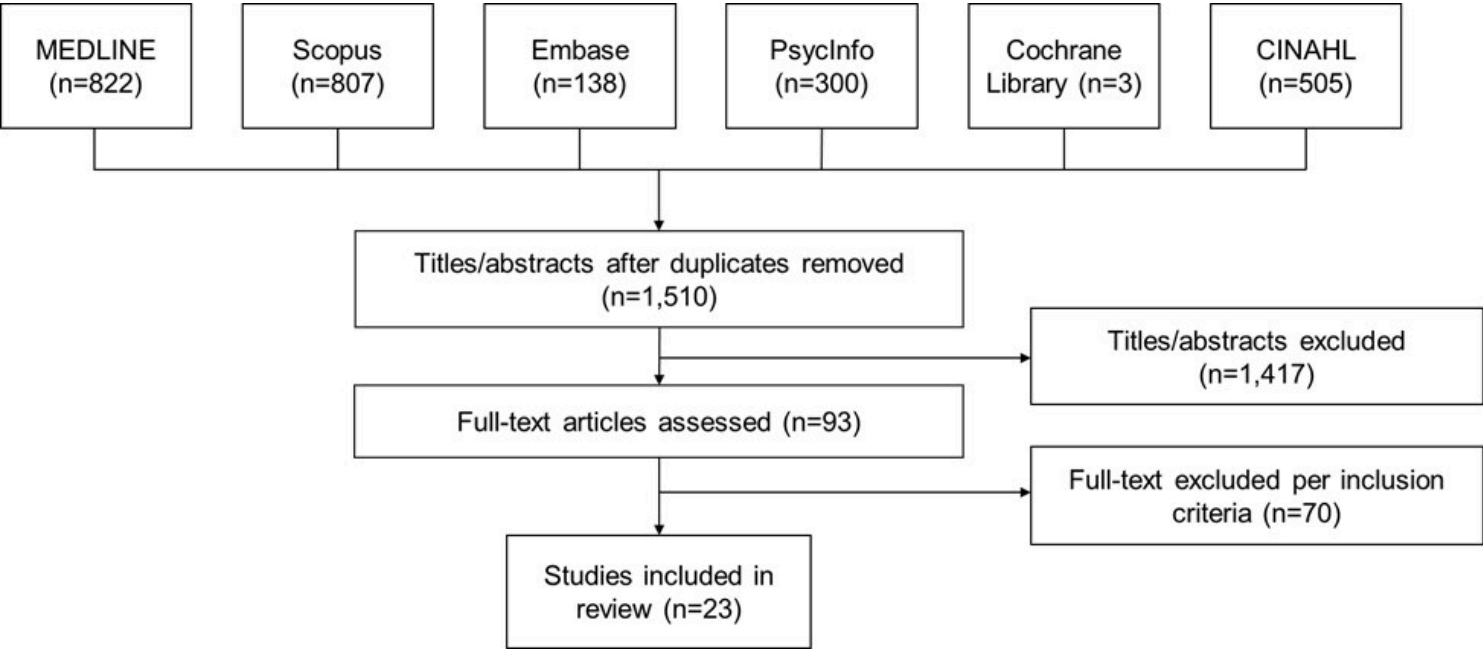


Figure 1

Flow chart of study selection and screening process. A total of 1,510 unique records were identified using our initial search protocol. Following the application of our inclusion and exclusion criteria, 1,417 publications were removed during the title-abstract screening phase, and an additional 70 publications were removed in the full-text screening phase. The remaining 23 articles were included in the review.

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