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Subjective and functional cognitive complaints in primary care: evidence, current practice, and priorities for improvement

Report

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Subjective and functional complaints in primary care: evidence, current practice, and priorities for improvement

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Summary

Why this report matters

Increasing numbers of people are presenting to general practice with concerns about memory and thinking. Nearly one in five of those referred on to memory assessment services do not receive a diagnosis of dementia or mild cognitive impairment. Many instead experience subjective cognitive decline (SCD), functional cognitive disorder (FCD), or related conditions. Current pathways are largely designed around identifying dementia. They are less well suited for people whose symptoms are distressing but are not explained by neurodegenerative disease. This can lead to repeated assessments, uncertainty for patients, pressure on memory services, and variation in care. This report was commissioned to understand what guidance currently exists to support identification, referral, and management of subjective and functional cognitive symptoms in primary care, and to identify gaps relevant to UK policy and service design.

What we did

We reviewed 56 documents published since 2014 - 30 research papers and 26 policy reports, professional guidance documents, and service descriptions. We also held informal discussions with eight GPs and a brain health clinic lead to understand how guidance translates into routine practice.

What we found

There is broad agreement in principle but limited operational detail. Most sources recognise that subjective and functional cognitive symptoms are clinically meaningful and require structured, respectful assessment. However, practical guidance for GPs is limited. Few documents specify referral thresholds, follow-up intervals, or clear management options for people at low risk of dementia.

Inconsistent terminology is confusing. A wide range of overlapping terms are used often interchangeably, including FCD and SCD. In non-specialist settings, the term mild cognitive impairment may be applied more broadly than intended. This variation makes communication harder for clinicians and patients and contributes to inconsistent referral practice.

Primary care is central but under-supported. Guidance consistently positions general practice as the entry point for assessment and ongoing care. However, most documents originate from specialist disciplines and assume access to time, continuity, and specialist advice that may not reflect routine GP settings.

Younger adults are not well served by dementia-focused pathways. National data show that people under 65 referred to memory services are much less likely to receive a dementia diagnosis than those over 65. Despite this, dementia-oriented frameworks are often applied by default. Age-sensitive or age-specific guidance is limited.

Technology may offer support. There is growing interest in structured templates, triage tools, and AI-enabled decision-support. These approaches may help standardise assessment and reduce avoidable referrals, but most remain at an early stage of development.

What this means for policy and decision-makers

The issue is not lack of awareness. It is the absence of practical, system-level models that align terminology, referral thresholds and roles across primary and secondary care.

Opportunities for change include the development of clearer and more consistent national frameworks, supported by national leadership, with more explicit definitions of referral thresholds and follow-up expectations. Strengthening multispecialty advice-and-guidance models, embedding psychological assessment within cognitive pathways, and supporting the development and validation of primary care decision-support tools are also important. In addition, involving primary care clinicians and people with lived experience in future guidance development can help make sure that recommendations are practical, patient-centred, and widely adoptable. A clearer, more proportionate approach to subjective and functional cognitive symptoms could reduce pressure on memory services, improve patient reassurance, and support more consistent decision-making across regions.

Glossary of key terms

Advice-and-guidance model
A service model that enables primary care clinicians to obtain specialist advice (often via written or virtual communication) without making a formal referral. It may support shared decision-making, triage, or management planning and can reduce unnecessary outpatient appointments when appropriately resourced.

Biopsychosocial approach
A model of care that considers biological, psychological, and social factors together in understanding symptoms and planning management.

Brain health clinic
A specialist service providing assessment and advice for people with cognitive concerns who do not meet diagnostic criteria for dementia. Clinics typically focus on early identification of problems, risk assessment, investigation of reversible causes, and personalised prevention or risk-reduction strategies.

Direct-to-scan pathway
A referral route allowing primary care clinicians to request imaging investigations (such as magnetic resonance imaging or computed tomography scans) without prior specialist consultation.

Functional cognitive disorder (FCD)
A clinical condition characterised by persistent and distressing cognitive symptoms that are not explained by neurodegenerative disease or other structural brain pathology. Symptoms are genuine but are understood to arise from changes in how the brain functions rather than from structural damage.

Functional neurological disorder (FND)
A neurological condition in which patients experience genuine neurological symptoms (such as weakness, sensory disturbance or cognitive symptoms) that are not explained by structural neurological disease and are thought to arise from altered brain functioning.

Grey literature
Guidance, policy documents, service reports or other materials, often produced by government bodies, professional organisations, or charities, and published in various formats but not in peer-reviewed academic journals.

Memory assessment services or memory clinics
Specialist services, typically with multidisciplinary teams, that assess individuals referred with suspected cognitive impairment. Their primary function is to diagnose or exclude dementia and related conditions.

Mild cognitive impairment (MCI)
A clinical syndrome characterised by objective cognitive impairment greater than expected for age, but not severe enough to meet diagnostic criteria for dementia. People with MCI may remain stable, improve, or progress to dementia over time.

Neurodegenerative disease
A group of progressive neurological conditions characterised by structural brain changes and loss of nerve cells, including Alzheimer's disease and other forms of dementia.

Over-medicalisation
The process by which normal experiences or low-risk symptoms are framed or treated as medical conditions, potentially leading to unnecessary investigation or intervention.

Risk stratification
A structured process of categorising people according to their likelihood of developing a condition or experiencing adverse outcomes, often to guide investigation or referral decisions.

Stepped-care pathway
A model of service delivery in which patients receive the least intensive, most appropriate intervention first, with escalation to more specialist input only if needed.

Subjective cognitive decline (SCD)
Self-reported persistent decline in memory or other cognitive abilities in the absence of objective impairment on formal testing. SCD may represent a risk state for future neurodegenerative disease in some individuals but is common and often non-progressive.

Subjective cognitive decline – plus (SCD-plus)
A research-derived term used where subjective cognitive decline is accompanied by additional features associated with increased risk of future neurodegenerative disease. These features may include onset after age 60, recent and progressive symptoms, confirmation of decline by an informant, persistent concern, or abnormal Alzheimer's disease biomarkers.

Executive Summary

More people are presenting to general practitioners (GPs) with concerns about memory and thinking, leading to rising referrals to memory assessment services. Nearly one in five of those referred do not receive a diagnosis of dementia or mild cognitive impairment (MCI). Instead, many present with subjective cognitive decline (SCD), functional cognitive disorder (FCD), or related conditions.

Current referral pathways are largely designed to detect neurodegenerative disease. They are less well aligned with the needs of people whose symptoms are distressing but not explained by dementia or neurodegenerative processes. This mismatch can create uncertainty for patients and clinicians and contributes to pressure on memory services.

This review was commissioned to map existing guidance relevant to the identification, referral and management of subjective and functional cognitive symptoms in primary care, and to identify gaps relevant to UK service delivery and policy.

Methods

We conducted a review of guidance relating to the identification, referral, and management of subjective and functional cognitive symptoms in primary care. Searches of major bibliographic databases and grey literature were undertaken between October and November 2025 to identify relevant academic and practice-based guidance.

Documents published from 2014 onwards that provided practical clinical or service guidance were eligible for inclusion. Materials focused solely on dementia or MCI, primary research without guidance, conference abstracts, and inaccessible full texts were excluded.

Following screening and eligibility assessment, we included 56 documents - 30 research papers and 26 grey literature documents. Findings were synthesised and organised in relation to three domains: identification and assessment, referral pathways, and management and support.

Key findings

Scope and nature of existing guidance. There is broad agreement that subjective and functional cognitive symptoms are clinically meaningful and should be assessed using structured, respectful and biopsychosocial approaches. Most sources also emphasise proportionate, risk-based referral. However, much of the guidance originates from specialist settings such as neurology, memory clinics, or psychology. Recommendations often assume levels of time, continuity, and specialist access that may not reflect routine GP practice. While primary care is consistently described as central to early identification and ongoing management, it is rarely involved in shaping or co-producing the guidance itself.

Terminology and conceptual clarity. A wide range of overlapping terms are used, including functional neurological disorder, FCD, SCD, and subjective memory complaints. Terminology varies across countries and sometimes within the UK. This lack of shared language makes explanations to patients more difficult, contributes to variation in referral thresholds and risks inconsistent messages about prognosis and management.

Support for primary care decision-making. Operational guidance for GPs is limited. Few sources specify follow-up intervals, thresholds for reassurance versus referral, or practical tools and templates to support structured assessment. Guidance on managing persistent reassurance-seeking is also sparse. In practice, this leaves clinicians relying heavily on individual judgement. While clinical judgement is essential, limited structured support may contribute to variation in care and potentially avoidable investigation.

Younger adults and pathway fit. People under 65 referred to memory services are substantially less likely to receive a dementia diagnosis. Despite this, dementia-oriented pathways are often applied by default, and age-specific guidance is limited. Psychological co-morbidity is frequently described in the literature

but is rarely integrated into pathway guidance. Younger adults may therefore experience repeated assessment, uncertainty or delayed reassurance.

Role of secondary care and advice models. Stakeholder consultation reinforced many literature findings. GPs reported limited familiarity with FCD terminology, variation in access to specialist advice and workforce pressures in both primary and secondary care. Advice-and-guidance models, which allow GPs to seek specialist input without, or prior to, making a formal referral, were viewed positively, particularly where they enable dialogue rather than simple referral and discharge. However, these models depend on training, protected time, and clear expectations.

Decision-support and technology. There is emerging interest in structured templates, triage tools, and AI-enabled decision support. Potential benefits include more consistent risk assessment, clearer documentation of reasoning, and reduced anxiety about missing rare pathology. Most tools remain at an early stage and require validation in routine primary care.

Implications for policy and service development

The central challenge is not awareness of subjective and functional cognitive symptoms, but the absence of practical, system-level models that align terminology, decision-making, and roles across primary and secondary care. Strengthening the system response will require coordinated action across policy, commissioning, and service development. Key priorities include:

- Establishing consistent terminology supported by clear, accessible definitions
- Providing clearer operational guidance for primary care on reassurance, monitoring, investigation, and referral
- Developing and validating practical decision-support tools to support proportionate investigation
- Creating age-sensitive pathways that reflect differential risk
- Clarifying secondary care roles and advice-and-guidance models
- Developing co-produced national consensus guidance
- Promoting shared cross-specialty biopsychosocial frameworks

New services may not be required. However, clearer and more consistent frameworks, supported by national leadership and targeted research investment, would enable more confident, proportionate, and person-centred management, while making better use of specialist expertise.

1. Background

More people are going to general practitioners (GPs) with concerns about memory and thinking and being referred on to memory assessment services. These services focus primarily on identifying dementia. However, as many as 18% of people referred to memory assessment services do not receive a diagnosis of dementia or mild cognitive impairment (MCI)[1]. The proportion of people not receiving a diagnosis is highest among people aged under 65 at 60%[1]. For these individuals, referral to memory assessment services may not be a suitable pathway. They undergo specialist assessment only to be told that they do not have dementia or another neurodegenerative condition and are then discharged. This exacerbates the considerable pressure on memory assessment services, which are experiencing growing numbers of referrals and consequently increasing waiting times[2].

Better equipping GPs to identify people who, despite their concerns, are unlikely to receive a diagnosis of dementia at an earlier stage and providing more suitable pathways to determining the nature of their condition and the types of support that would be appropriate would both improve patient experience and reduce demand on memory assessment services.

What is mild cognitive impairment?
While typically considered a risk state for dementia or a prodromal form of dementia, the term MCI is also commonly used more broadly in clinical practice to refer to anyone with evidence of or complaining of cognitive difficulties, which can create confusion. In this report, MCI refers to cognitive impairment confirmed on assessment, where everyday functioning remains largely intact and criteria for dementia are not met.

The clinical challenge in primary care

The key task for GPs is deciding whether cognitive symptoms are more likely to reflect neurodegenerative disease or other brain pathology, or whether these presenting symptoms occur without evidence of changes in the brain.

Many people report ongoing problems with memory, attention, or concentration that can seem similar to signs of early dementia or MCI, even though formal testing shows no objective impairment. These presentations are described using a wide range of terms, including:

- Subjective memory or cognitive complaints
- Subjective cognitive decline (SCD)
- Functional memory problems
- Functional cognitive disorder (FCD)
- Functional neurological disorder (FND)

Other terms such as psychogenic, dissociative, or medically unexplained cognitive symptoms are also used.

This variation in language reflects differences between clinical disciplines rather than describing clearly distinct patient groups[3]. It makes communication difficult and contributes to inconsistent guidance and uncertainty in clinical decision-making, particularly in primary care.

What are 'subjective' and 'functional' cognitive disorders?

A primary distinction in the commonly used terms is that between 'subjective' and 'functional' descriptors. Subjective cognitive complaint is a broad description for self-reported cognitive problems and does not imply a cause. In contrast, FCD is a more specific clinical diagnosis.

FCD refers to persistent cognitive symptoms that cause real difficulty in daily life but are not explained by dementia or another neurological conditions[4]. It is understood as a functional, rather than a neurodegenerative, explanation for symptoms. Symptoms are genuine and distressing but arise from changes in how the brain functions rather than structural disease.

SCD is often used to describe self-reported decline without objective impairment and may be discussed as a possible risk state for future dementia[5]. FCD, in contrast, is typically used where symptoms are thought to be driven by functional or psychological processes. In practice, however, these terms overlap and are not used consistently.

In this review, we use the term FCD in a pragmatic way to refer to the broader group of people with persistent cognitive symptoms not explained by neurodegenerative disease, while recognising that terminology is applied inconsistently across research and clinical settings[4,6].

A recent review found that 17.3% of people attending memory clinics receive a diagnosis of SCD whereas 5.6% receive a diagnosis of FCD[6]. These presentations are proportionately more common in people under 65[1].

People with subjective or functional cognitive symptoms often experience anxiety, low mood, stress, or functional difficulties alongside their cognitive concerns[7]. For some, these factors may contribute to or maintain the cognitive symptoms themselves rather than simply occurring alongside them. These experiences can increase distress and drive help-seeking, even when dementia is unlikely.

What guidance is available to GPs

Although NHS England dementia guidance issued in 2014[8] briefly mentioned SCD, later guidance and professional resources have tended to address these symptoms indirectly within dementia-focused pathways[9,10] rather than through dedicated guidance. As a result, available guidance is fragmented, uses varied language for similar symptoms, and may not reflect the needs of people at low risk of neurodegenerative disease.

Recent DHSC-commissioned work has also highlighted wide international variation in how subjective and functional cognitive symptoms are defined, assessed, and managed[6]. In this report we bring together existing guidance to identify common themes, key differences, and gaps in current approaches, with the aim of informing clearer and more appropriate pathways for UK primary care.

Purpose of this review

This programme of work was commissioned following a research request from the NHS England National Clinical Director for Dementia.

The purpose of the review is to bring together existing guidance on how primary care can best support people who present with subjective or functional cognitive symptoms.

The review looks at published research and grey literature to understand current advice on:

1. How clinicians identify and assess cognitive complaints, including how to distinguish subjective or functional symptoms from dementia or other neurological conditions.
2. How referral decisions are made, including when referral to specialist services is recommended.
3. How people whose symptoms are assessed as subjective or functional are managed and supported, particularly in primary care.

2. Methods

Overview

We reviewed existing guidance on how services identify, manage, and refer people with subjective or functional cognitive symptoms. We focused on material relevant to general practice and decision-making in primary care.

We used two complementary search approaches:

1. A search of published research literature
2. A structured search of grey literature - policy and practice guidance not published in academic journals

Using both approaches helped us capture formal clinical guidance as well as materials used in everyday practice.

Eligibility criteria

We included documents published from 2014 onwards that provided practical clinical or service guidance relating to subjective or functional cognitive symptoms. This included policy documents, clinical guidelines and consensus statements, service models or evaluations, practical tools, and framework papers describing approaches to assessment, referral or management.

We focused on material addressing subjective or functional cognitive symptoms, including those described as FCD or SCD.

We excluded documents that:

- Were published before 2014
- Focused only on dementia or MCI without discussing subjective or functional symptoms
- Reported primary research without giving practice guidance
- Could not be accessed in full
- Were conference abstracts without a full publication

We did not restrict by language. When needed, we translated documents into English using Google Translate.

The 2014 cut-off reflects the period when SCD became more widely recognised in clinical guidance[11] and when dementia pathways began to more explicitly consider non-neurodegenerative symptoms[8].

Search 1: Research literature

We searched Embase, MEDLINE, and PsycINFO via the Ovid platform on October 8th, 2025. Searches combined terms relating to cognitive symptoms, clinical settings, and guidance or service delivery. Full search strategies are provided in the Technical Appendix, section A.

Search 2: Grey literature

We carried out a structured grey literature search on November 11th, 2025, using Google Advanced Search. We restricted searches to pdf documents because formal guidance is commonly issued in this format.

We preselected 122 websites, including those of healthcare organisations, professional bodies, government departments, and dementia-related charities. We focused on organisations in countries with a published national dementia plan, on the assumption that these settings were more likely to host relevant guidance. The full website list can be seen in the Technical Appendix, section B.

We aligned search terms with those used in the research literature. We did not filter by document type or care setting terms. Because Google limits how many terms can be combined, we used three simple searches per website:

1. Condition terms paired with the term “cognitive”
2. Condition terms paired with the term “memory”
3. Alternative or historical terms (for example “pseudodementia” or “worried well”)

Google cannot reliably filter by date when searching for pdfs, so we removed pre-2014 documents during screening. Full search terms are provided in the Technical Appendix, section C.

Screening and data extraction

We managed research records in EndNote and removed duplicates using automated and manual checks. For grey literature, we used document names and sources to identify duplicates.

One reviewer screened:

- Titles and abstracts for research literature
- Full documents for grey literature (as abstracts were rarely available)

When several documents came from the same guideline or source, we grouped them together to avoid double-counting.

We summarised key information from each document using a structured template.

How we analysed the data

We organised findings around three stages of care that matter most in primary care decision-making. Table 1 shows the framework we used.

Table 1. Framework used to organise findings

Stage of care	What we looked at
Identification and assessment	Recognising functional or subjective symptoms and distinguishing them from dementia or MCI
Referral pathways	Criteria for referral and roles of GPs and specialists
Management and support	Explanation, reassurance, follow-up, and therapeutic approaches

We also recorded background information for each document, such as country, audience, authoring organisation, and terminology used (e.g., FCD, SCD, FND, etc.).

How findings were synthesised

We used a narrative synthesis approach to summarise and compare guidance across documents. This approach helped us:

- Identify where guidance agrees or differs
- Examine variation across countries and organisations
- Highlight gaps in available guidance

We focused especially on issues relevant to GPs and primary care decision-making.

3. Results

The search and screening process for included documents is summarised in Figure 1.

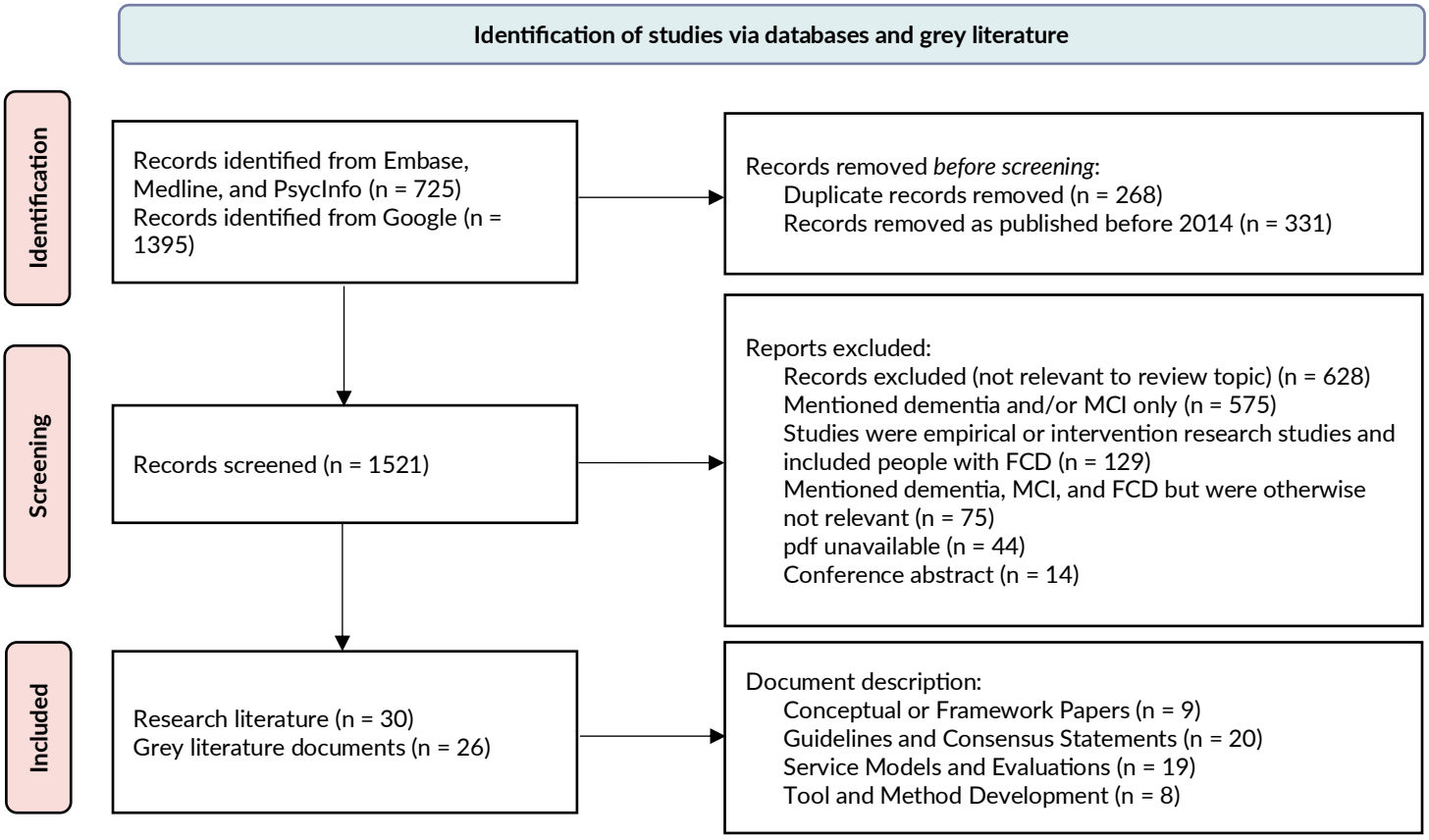

Figure 1. Search and screening process for included documents

Overview of the included documents

We identified 56 documents providing guidance relevant to subjective or functional cognitive symptoms. These comprised 30 research papers and 26 grey literature documents.

Terminology used to describe functional or subjective cognitive symptoms varied considerably across documents. FND was the most frequently used term (25 documents) followed by SCD, which was used in 11 documents. Other terms, including FCD, subjective cognitive impairment, subjective memory complaints, and subjective memory impairment, were used less consistently, and several additional terms appeared only once. One document used multiple terms interchangeably, and another did not specify a term at all. Summaries of included documents are provided in the Technical Appendix, section D.

Research activity was concentrated in a small number of countries (Figure 2). The UK and the USA each led eight publications, followed by Italy (four), and Australia (three). All other countries were represented by a single publication. Grey literature was more UK-focused, with 20 of the 26 included documents originating in the UK. However, for the purposes of regional classification in Figure 1, two of these 20 documents were reports from Alzheimer's Disease International. These two documents were assigned

to Africa based on their substantive focus (low- and middle-income countries and Sub-Saharan Africa), despite being published by a London-based organisation.

Only two of the grey literature documents focused primarily on FCD, while most mentioned FCD briefly within broader dementia or cognitive guidance. This shows that people with functional or subjective cognitive symptoms are rarely the focus of existing guidance.

Figure 2. Number of research and grey literature documents by country.

Figure 3 shows the number of documents by European country (excluding the two Alzheimer's Disease International reports classified under Africa in Figure 2).

Figure 3. Number of research and grey literature documents by European country.

Coverage across stages of care

Across stages of care, identification and assessment received the greatest attention, while referral and management were discussed in fewer documents.

Of the 56 included documents, 48 discussed identification and assessment, 37 discussed referral pathways, and 37 discussed management and support; 24 documents addressed all three stages of care, and 18 covered two of the three. Table 2 summarises how different document types contributed across the three stages of care.

Table 2. Coverage of stages of care across included documents

Stage of care	Total number of documents	Conceptual frameworks	Guidelines/ consensus statements	Service models	Tools/ methods
Identification and assessment	48	8	17	15	8
Referral pathways	37	4	17	14	2
Management and support	37	7	13	13	4

Guidance on identification came from a mix of conceptual frameworks, guidelines, service model evaluations and tools. Referral and management guidance relied more heavily on guidelines and service model evaluations, with fewer tools available. This pattern suggests that existing guidance places more emphasis on recognising and defining these symptoms than on supporting longer-term management.

Intended audience

Most documents were written for specialist or secondary care audiences (see Figure 4). Neurologists were the most frequently targeted group (24 documents), followed by memory clinic teams (10) and neuropsychologists (7), with single documents directed at radiologists and nursing or care home staff.

Relatively few documents were written specifically for GPs, despite policy guidance consistently positioning primary care as central to early identification, monitoring, referral, and ongoing management. This suggests that existing guidance is focused on specialist services, providing relatively little practical support for the professionals most likely to be the first point of contact for people with FCD.

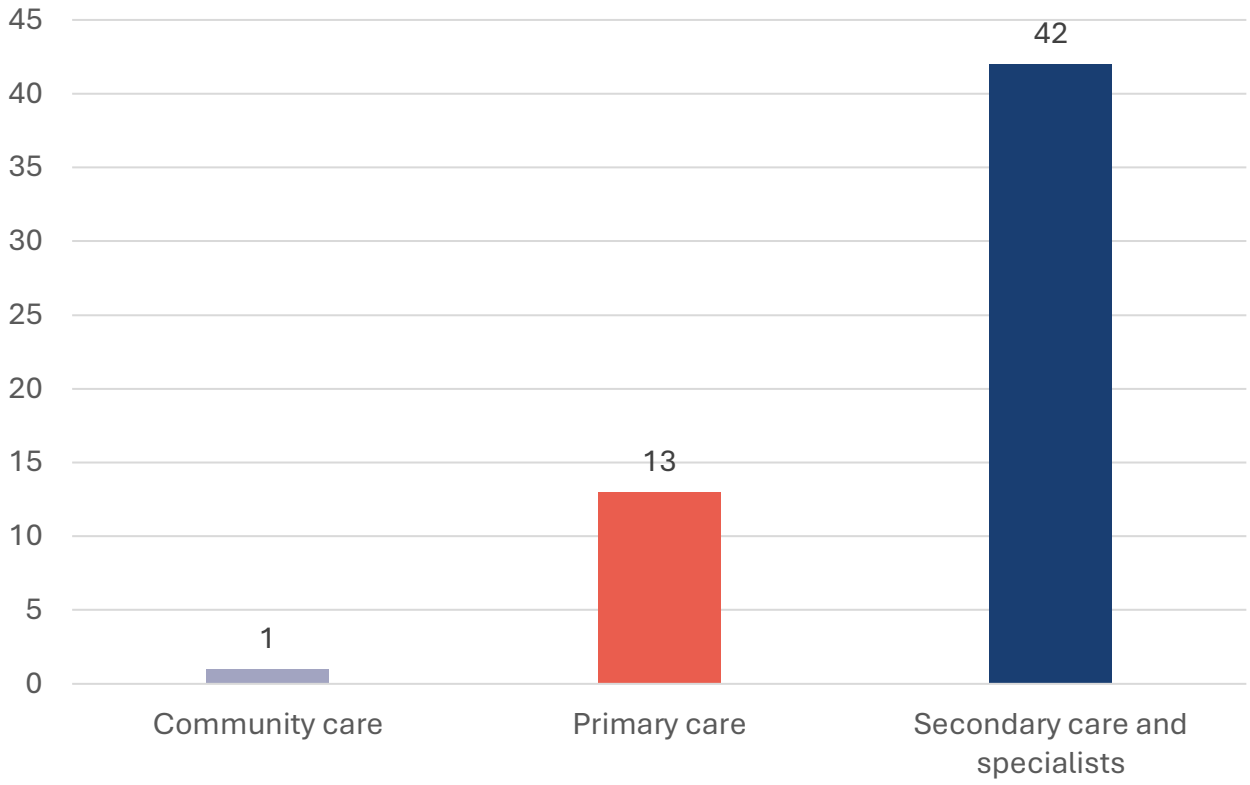

Figure 4. Intended audience of included documents

Identification and assessment

In this section we explore how identification and assessment are addressed across the reviewed guidance and literature.

Areas of agreement

Across both research and grey literature, guidance agrees on several core points. Subjective and functional cognitive symptoms are recognised as legitimate clinical presentations. Clinicians should not dismiss symptoms simply because cognitive tests fall within the normal range. Assessment is consistently described as needing to be structured, respectful, and explanatory.

Most guidance advises primary care clinicians to take a detailed history, use brief cognitive screening tools such as the Mini-Mental State Examination, Montreal Cognitive Assessment, or Mini-Cog, and assess mood, anxiety, sleep, stress, pain, medications and overall health to identify possible explanations for cognitive symptoms and inform differential diagnosis. These factors are considered because they may provide alternative explanations for cognitive complaints.

Symptoms of depression or anxiety, sleep disturbance, pain, medication effects, and general ill health can all impair concentration and memory and may account for cognitive symptoms without indicating FCD or neurodegenerative disease.

Many documents also stress the importance of understanding everyday functioning and whether symptoms change over time. Stability rather than progression is often described as a key feature suggesting a cause other than neurodegeneration. Where assessment identifies factors such as depression, anxiety, sleep disturbance, pain, medication effects or other health problems, guidance typically recommends addressing these issues first before considering a functional cognitive diagnosis or specialist referral.

How functional cognitive symptoms are recognised

Guidance does not describe functional cognitive symptoms as a diagnosis reached only after "ruling out dementia". Instead, many documents emphasise identifiable clinical features that support a positive diagnosis.

People with functional cognitive presentations often show inconsistent performance during assessment. For example, they may struggle on formal testing but improve significantly when given prompts or reassurance. Symptoms are typically worse when the person is stressed, anxious or under time pressure, and may reduce in calmer settings. Neurological examination and everyday functioning are usually intact.

Taken together, these features enable clinicians to distinguish functional from neurodegenerative patterns early in the assessment process. Several frameworks explicitly recommend a "rule-in" approach based on positive clinical signs, with investigations used selectively to exclude significant alternative diagnoses. This approach can reduce unnecessary testing and repeated referrals.

Conceptual approach

Most guidance explains functional cognitive presentations using a biopsychosocial model. In practice, this means clinicians are encouraged to consider cognition alongside anxiety, stress, sleep problems, and wider life pressures. This approach places less weight on test scores alone and more on clinical judgement.

Differences between systems and countries

We observed variation in how different health systems approach subjective and functional cognitive symptoms. Table 3 summarises the broad patterns we identified across regions.

Guidance approaches vary internationally, reflecting differences in healthcare infrastructure and priorities. Some countries (e.g., Italy and China) emphasise structured screening and biomarkers, while others (like the UK) focus more on clinical pattern recognition and psychosocial factors.

In settings with limited specialist resources, such as low- and middle-income countries, primary care and community health workers take a central role. Across North America and Brazil, guidance highlights clinical judgement and caution against over-medicalisation.

Table 3. International differences in approach

Country/region or setting	Typical emphasis in guidance
Italy and China	Dementia-oriented frameworks that place greater emphasis on structured screening and biomarker-based risk stratification
United Kingdom	Functional disorder-oriented frameworks that focus on pattern recognition and psychosocial contributors, with less reliance on cognitive test scores alone
Low- and middle-income countries	Greater emphasis on primary care and community health workers, reflecting more limited access to specialist services
North America and Brazil	Strong emphasis on clinical judgement, cautious use of biomarkers, and avoiding over-medicalisation

Emerging tools and innovation

The literature describes several newer approaches. These include structured risk tools such as Multidimensional Assessment of Subjective Cognitive Decline and the Mild Behavioural Impairment Checklist, diagnostic checklists for functional patterns, and reporting templates to help GPs interpret imaging findings.

Some studies describe conversational cues that may indicate functional presentations. People with neurodegeneration rather than FCD tend to respond “don’t know” or “can’t recall” when asked about previous memory lapses, for example. Simple triage indicators include attending appointments alone, which is more likely for people with FCD compared to those subsequently diagnosed with neurodegeneration.

More complex models combine clinical, biological and lifestyle information to estimate risk. While promising, most of these approaches are not yet widely used in routine primary care.

Key gaps in guidance on identification

Despite growing interest in this area, guidance remains limited in several respects. There is little GP-specific guidance, minimal focus on younger adults, and no agreed thresholds to distinguish FCD from early neurodegeneration. Few tools are validated for routine primary care, and cultural or socioeconomic factors receive little attention.

Referral Pathways

This section summarises how referral pathways are described across documents and outlines the general principles shaping referral decisions.

Areas of agreement

Across the literature, referral is usually described as proportionate and tiered. Most people with functional cognitive symptoms are expected to remain in primary care unless specific escalation criteria are met. Some documents note that referral decisions often rely on clinical judgement where standardised criteria are limited.

Referral is commonly advised when clinicians encounter diagnostic uncertainty, atypical or neurological features, clear progression, complex or disabling presentations, significant functional impact, or high-

risk biomarker profiles, e.g. “SCD-plus”. SCD-plus refers to SCD accompanied by additional characteristics associated with increased risk of future neurodegenerative disease (for example, symptom onset after age 60, recent onset with progressive worsening, confirmation by an informant, or biomarker evidence). Low-risk cases are typically managed with reassurance and follow-up in primary care.

Variation between systems

Referral models differ widely. Italy and China encourage early specialist referral and biomarker-supported triage. UK and North American guidance more often promotes conservative referral and avoiding unnecessary investigation.

Some international guidance sets explicit thresholds to protect specialist capacity. For example, Alzheimer’s Disease International suggests that only a small proportion of people with early cognitive concerns should be referred for specialist assessment. UK guidance does not set numerical targets but instead focuses on strengthening GP assessment before referral.

Some frameworks describe multidisciplinary or stepped-care pathways, while others rely more on specialist-led models.

Emerging tools and innovations

Several emerging approaches aim to improve referral decisions and reduce unnecessary specialist assessment. These include structured assessment tools and biomarker-informed triage. Although not yet routine in most settings, these models are designed to help GPs identify higher-risk patients earlier and manage lower-risk cases without referral.

A small number of frameworks also highlight the development of clearer referral templates and shared terminology to improve communication between primary and specialist care. These endeavours are intended to promote consistency and reduce ambiguity in referral decisions.

Key gaps in referral guidance

No document provides a unified GP-specific referral threshold for FCD. There is also no widely accepted triage algorithm that combines cognitive, psychological, and functional factors. Service availability varies widely by region, and guidance on managing repeat attenders is rare.

A small number of documents note that, where pathways are unclear, people with functional symptoms may be directed to mental health services by default in the absence of alternative routes.

Management and support

This section synthesises how management and support are addressed in the literature and guidance. It describes the approaches most frequently recommended and the common themes in how ongoing support is framed.

Areas of agreement

Most guidance recommends longitudinal and holistic care grounded in a biopsychosocial approach rather than one-off assessment. Primary care plays a central role in monitoring symptoms, supporting lifestyle change, and co-ordinating referrals. Several documents also emphasise the importance of continuity and co-ordinated care to reduce fragmentation.

Explanation and reassurance are consistently emphasised. Many documents highlight the importance of discussing brain health, sleep, stress and vascular risk, and offering follow-up over time.

Some guidance also highlights the role of accessible written or online information to support self-management.

Differences in emphasis

Some international frameworks, primarily those of Italy and China, emphasise biomarker-guided dementia risk reduction. UK, North American, and Brazilian guidance more often prioritises behavioural, psychological, and lifestyle approaches.

FCD-specific documents stress the value of clear explanation, behavioural retraining and psychological therapies such as cognitive behavioural therapy. These are particularly relevant where symptoms are linked to anxiety, low mood or unhelpful beliefs about memory. The emphasis is on supporting people to understand and manage symptoms rather than on disease detection alone.

Emerging tools and innovations

Several emerging approaches to management are noted in the literature. These include multidisciplinary assessment models that provide co-ordinated input and clear management plans, as well as group-based stress management or psychoeducation programmes for people with FCD symptoms.

Some services are also exploring data-informed approaches such as machine learning to guide follow-up and risk stratification. In addition, practical tools such as structured reporting templates and patient-facing information resources are being developed to support GP decision-making and patient self-management.

Many of these approaches remain at an early stage of adoption or development, and their availability and implementation vary across settings.

Key gaps in management guidance

Several practical gaps were identified. Most guidance does not specify follow-up intervals, and few structured tools are available to support GP assessment and documentation. Younger adults receive limited attention, and there is little advice on managing persistent reassurance-seeking. Together, these gaps leave primary care clinicians without consistent operational support.

Limitations of the review

The grey literature search focused on selected sources and English-language terminology. As a result, guidance from systems using different formats or terminology may not have been captured.

The review synthesised documents with different purposes and evidence bases, reflecting the limited availability of formal guidance in this area.

Finally, the review summarises published guidance rather than routine practice. Many documents were developed without direct input from primary care clinicians or people with lived experience. Feasibility in everyday settings may therefore be less well represented.

Stakeholder consultation

To understand current practice, informal discussions were held with eight GPs and a Brain health clinic lead. Brain health clinics are specialist services that assess people with cognitive concerns who do not meet criteria for dementia, typically focusing on early identification, risk assessment, and prevention. This was not a formal consultation exercise. However, it provided practical evidence to complement the literature review.

Identification and assessment

Awareness of FCD and related terminology in primary care was limited. Participants reported encountering patients with cognitive concerns consistent with functional presentations, but these were not routinely labelled as FCD. Instead, clinicians tended to explore contributory factors such as anxiety, low mood, sleep disturbance or other health conditions.

Existing diagnostic checklists or structured tools for FCD were rarely used or widely recognised in primary care. Most participants relied on detailed history-taking and clinical judgement to assess likely causes of symptoms. There was a view that clearer frameworks could improve confidence, particularly if embedded within a supported system.

Psychological co-morbidity was highlighted as common but not always systematically addressed. Participants noted that undiagnosed or untreated depression and anxiety frequently contribute to cognitive distress in primary care.

Referral pathways

GPs described variation in onward referral for people with cognitive concerns, reflecting differences in local service configuration and access to specialist advice.

Several participants said they would welcome clearer referral frameworks or checklists, particularly if these were supported by embedded advice-and-guidance models allowing dialogue with secondary care. There was recognition that any such approach would require training and agreed expectations across sectors.

Workforce constraints and service thresholds were described as shaping referral patterns. In some areas, high rejection rates from mental health services were reported, influencing GP decision-making. Access to imaging and direct-to-scan pathways was also raised as a practical consideration where referral options are limited.

Technology was discussed as a potential enabler of more proportionate triage. Participants noted the policy focus on reducing waiting times and improving patient flow through memory services. AI-enabled or digital decision-support tools were viewed as promising but developmental and would require validation in real-world primary care settings.

Management and support

There was limited clarity on how best to support patients with persistent symptoms who do not meet criteria for neurodegenerative disease. Participants emphasised that any shift towards greater primary

care management would require visible leadership from secondary care, education, and jointly developed pathways.

Advice-and-guidance models allowing primary care practitioners to gain input from specialists without or prior to making a direct referral were seen as potentially valuable, but appetite and capacity within secondary care were described as variable. Participants noted that training, specialist interest, and resourcing would influence feasibility.

Overall, stakeholders expressed openness to clearer frameworks and shared-care approaches, provided these were embedded within supported structures rather than adding unfunded responsibility to primary care.

Limitations of the consultation

This informal consultation involved a small number of clinicians and was not designed to be representative. The findings should therefore be treated as indicative. Participants suggested that wider engagement with primary and secondary care clinicians would be a useful next step.

4.Discussion

This review set out to understand how existing guidance supports the identification, referral, and management of subjective and functional cognitive symptoms. Across both published and grey literature, there is broad agreement that these symptoms are clinically meaningful and warrant structured, respectful assessment. Guidance consistently promotes biopsychosocial, person-centred care, and proportionate referral based on risk rather than routine escalation. Primary care is positioned as central to early identification and ongoing support across many of the included documents.

However, this apparent consensus masks important gaps. Much of the guidance originates from neurology, psychiatry or specialist dementia services rather than primary care. Recommendations often assume levels of time, continuity, diagnostic access, and specialist support that may not reflect routine GP practice. Primary care is frequently described as central to management, but rarely as a co-producer of the guidance itself. This creates a disconnect between where responsibility sits and where expertise and resources are concentrated.

Terminology and shared understanding

There is no consistent terminology across services. Terms such as FCD and SCD are used differently across countries and even between UK documents. While specialist literature distinguishes between these constructs, this distinction is not widely embedded in routine primary care.

This lack of shared language affects how GPs explain symptoms, how patients understand their diagnosis, and how referral pathways are organised. Without clearer, consistent terminology, patients may receive mixed messages, and care may vary between areas.

Adoption of consistent terminology, supported by clear, accessible definitions, would improve communication between clinicians and patients, reduce variation between services, and provide a more stable foundation for pathway development.

Supporting GP decision-making

Current guidance provides limited practical support for GP decision-making. Few documents specify when to reassure, monitor, investigate, or refer. Follow-up intervals are rarely defined, and there is little structured advice on managing persistent or recurrent concerns. As a result, GPs rely heavily on individual judgement.

While clinical judgement is essential, the absence of clearer operational criteria may contribute to variation in care, unnecessary investigations for some patients, and delayed recognition of higher-risk cases in others.

The literature also reports high levels of psychological co-morbidity in people with subjective and functional cognitive presentations[12,13]. However, practical guidance on identifying and managing this within routine primary care remains limited, increasing further the reliance on individual clinician experience.

Structured templates, triage tools, and digital decision aids may offer practical support for primary care. These approaches could help GPs assess risk, document reasoning, and communicate uncertainty to patients. They may also address specific concerns raised during consultation, such as anxiety about missing rare but serious pathology. For example, consultation noted persistent concern about space-occupying lesions in people presenting with memory complaints, despite these rarely being a relevant differential diagnosis. Better alignment between investigation decisions and evidence could reduce unnecessary imaging.

Interest in AI-enabled or automated decision-support tools is increasing[14,15]. However, most remain at an early stage of development and require validation in real-world primary care settings. Such tools cannot replace clinical judgement, but they may support greater consistency and confidence when appropriately designed and implemented.

Greater practical support for GP decision-making, including clearer operational criteria for reassurance, monitoring, investigation, and referral, would promote more consistent care, reduce unnecessary escalation, and support earlier identification of higher-risk presentations.

Age and pathway suitability

Age is not clearly addressed in current pathways. Younger adults presenting with cognitive concerns are unlikely to have neurodegenerative disease, yet dementia-focused frameworks are often applied by default. When used in younger populations, these pathways may not fit well and can create uncertainty across primary care, neurology, psychiatry, and psychology services. This can also lead to increased anxiety in patients as well.

Development of more age-sensitive pathways would enable more proportionate investigation, clearer reassurance where appropriate, and earlier attention to functional and psychological contributors, particularly in younger adults.

Clarifying the role of secondary care

Guidance does not clearly define how secondary care should support primary care management of functional and subjective cognitive symptoms. Stakeholders highlighted the value of advice-and-guidance models that allow specialists to support GPs without relying solely on referral and discharge pathways.

Traditional memory clinic models may not allow for provision of ongoing support where there is no clear diagnostic endpoint. At the same time, any expansion of specialist input must consider workforce and capacity constraints. Clearer definitions of roles, referral thresholds, and shared-care arrangements would enable more effective use of specialist expertise while maintaining sustainability within existing workforce constraints.

National guidance and system leadership

The findings suggest a clear case for more explicit national guidance on subjective and functional cognitive symptoms. Current dementia pathways tend to treat these presentations as exclusions rather than conditions requiring active management.

National bodies such as the National Institute for Health and Care Excellence could play a role in consolidating terminology, clarifying primary care pathways, and reducing variation between areas. Even high-level consensus guidance would provide a reference point for local service design.

Further research may also be warranted, particularly in the development and evaluation of approaches that support decision-making in primary care. This could align with National Institute for Health and Care Research or Innovate UK priorities focused on pragmatic, system-level innovation.

Future guidance development would benefit from stronger involvement of both primary care clinicians and people with lived experience. These perspectives are essential for making sure pathways are feasible, acceptable, and responsive to patient concerns. Without this input, guidance risks remaining conceptually robust but difficult to implement in routine settings.

Co-produced national guidance, even if reflecting a high-level consensus, would provide a coherent reference point for local service design and reduce unwarranted regional variation.

Wider system implications

Functional and subjective cognitive symptoms sit at the intersection of neurology, mental health, and general practice. They do not fit neatly within disease-based service models. As a result, they expose the boundaries between specialties and highlight the need for more integrated, cross-disciplinary approaches to care.

Addressing this challenge does not necessarily require new services. However, it does require clearer shared frameworks that align terminology, roles, and decision-making across sectors.

Development of shared cross-specialty frameworks could improve coordination, reduce boundary disputes between services, and better reflect the biopsychosocial nature of these presentations.

5. Conclusion

This review provides a starting point for strengthening the system response to subjective and functional cognitive symptoms. It maps existing guidance, identifies areas of consensus and highlights persistent uncertainty.

Translating this into practice will require coordinated action. Key priorities include:

- Adoption of consistent terminology supported by clear definitions
- Greater operational support for GP decision-making in reassurance, monitoring, and referral
- Development and validation of practical decision-support tools for use in primary care
- Creation of age-sensitive pathways that reflect differential levels of risk
- Clearer articulation of secondary care roles and shared-care arrangements
- Development of co-produced national guidance to reduce variation
- Establishment of cross-specialty frameworks aligned with biopsychosocial care

Taken together, these steps would support more confident, proportionate, and person-centred management within primary care, while making better use of specialist expertise across the system.

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Data availability and access

This report is based on a structured review of published and grey literature. Systematic searches were conducted to identify relevant documents, and 56 sources were included. Full details of the search approach and eligibility criteria are described in the methods section, and all included documents are cited in the Technical Appendix.

An EndNote library was created to manage the included references. Data extracted from the included documents were recorded in an Excel spreadsheet developed for internal analytical purposes. The extracted fields and approach to data collection are described within the report.

As all source materials are publicly available and fully referenced, the analyses presented in this report can be replicated by accessing the cited documents and applying the extraction approach described. The EndNote library and extraction spreadsheet are not published alongside this report but may be made available on reasonable request for research or policy purposes.

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