

Living in a “Grey Area”: Practices, Attitudes, and Unmet Needs of Patients Without a Dementia Diagnosis.

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Background

Approximately **1 in 3** people that are referred to memory clinics do not meet criteria for dementia diagnosis.¹ This includes people with:



- Mild Cognitive Impairment
- Functional Cognitive Impairment
- Subjective Memory Decline
- Age-Associated Memory Loss
- No diagnosis

This population has no clear pathway after memory assessment, despite higher dementia risk and evidence that lifestyle changes may help reduce that risk.

Methodology

The NoDem study is a 1-year mixed-method, longitudinal study. We collected questionnaire and medical record data from 387 participants within 6-weeks of a non-dementia diagnosis.

Semi-structured Interviews

Here, we present initial findings from an interview sub-study of 17 participants.

Participants were asked about:

- Reasons for referral
- Assessment and diagnosis
- Support and information



Research Aims

- Understand referral triggers
- Understand attitudes, views and hopes
- Explore intentions to change lifestyle

Emerging Themes

Interview data were analysed using NVivo. Given the exploratory nature of this research, open coding and inductive analysis were used to identify data themes.

Proactivity & Motivation

Participants were proactive, seeking assessments and information to maintain cognitive function and plan for the future.

“Because my own father had dementia, and you just think, ‘Am I seeing signs that I could now look back and see that he had?’”

“If I’d been on my own, it wouldn’t have been so good, I would have come away and forgotten most of it.”

The Influence of Support

Participants valued practical and emotional support throughout the assessment and when implementing lifestyle changes.

“You get into a pattern, when you know what you need to do, but doing it on your own is harder.”

Information & Communication

Participants had difficulties with recall and understanding due to unclear communication and being given complex information.

“It would’ve been nice to be able to talk to somebody and ask questions.”

“The letter just said ‘to be kept an eye on’. But as I say, I’ve heard nothing since.”

Gaps in the Service Pathway

The memory service pathway for non-dementia patients lacked consistency and continuity of support, leaving some participants uncertain about their next steps.

“It’s kind of like, this huge grey area of why am I getting worse?”

Future Directions and Impacts

The NoDem Study findings aim to inform the development of guidelines for health policy relevant to this population.

Benefits for Patients & Caregivers

- ✓ Better **quality of life** through more appropriate care
- ✓ Enhanced **understanding** of non-dementia diagnoses
- ✓ Improved **prognosis** due to lifestyle interventions

Benefits for Health Services

- ✓ Insights into **best practice** for non-dementia patients
- ✓ **Guidelines** for information provision and communication
- ✓ Improved intervention could **lower conversion rates**

1. National Audit of Dementia Memory Assessment Services Spotlight Audit Regional Report 2023/2024. London: Royal College of Psychiatrists. Available from: (rcpsych.ac.uk)