Assessing methods used to collect patient- and carer-reported experiences and outcomes in healthcare settings for people living with dementia and cognitive impairment

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Contents

Acronyms

CCQI	College Centre for Quality Improvement
FFT	Friends and Family Test
I/DD	Intellectual or developmental disabilities
LEAG	Lived Experience Advisory Group
LTC	Long-term care
NAD	National Audit of Dementia
NADQC	National Audit of Dementia Questionnaire for Carers
NADQP	National Audit of Dementia Questionnaire for Patients
NHS	National Health Service
NIHR	National Institute for Health and Care Research
PLWD	People living with dementia
SAC	Stakeholder Advisor Council

Executive Summary

As part of a three-year redesign strategy, the National Audit of Dementia (NAD) is transitioning from bespoke to routinely collected data to reduce data collection burden and enhance efficiency, with implementation planned for 2026. This review was conducted to inform that transition by evaluating methods for collecting patient and carer experience data - particularly for people living with dementia or cognitive impairment - with the aim of understanding the level of effectiveness, accessibility and feasibility of approaches, and highlighting where further research is needed.

This review draws on 34 peer-reviewed and grey literature sources, including a targeted review of 22 charity and organisational websites. A voluntary survey was also conducted with 34 acute general hospitals in England and Wales, exploring current practices and barriers in collecting feedback from people with dementia and carers. A second voluntary survey was conducted with 57 memory assessment services to understand what methods and tools are being used to collect patient and carer feedback in dementia diagnostic settings. Additionally, members of NAD's Lived Experience Advisory Group (LEAG) were presented with the review findings and invited to provide feedback to inform the audit's approach to capturing patient and carer experience.

The review identified four primary methods used to collect patient and carer feedback across healthcare settings: structured questionnaires, interviews, focus groups and observation - each offering unique strengths and limitations based on context, population and purpose. Structured questionnaires allowed for large-scale, efficient data collection but offered limited depth and accessibility for people with cognitive or literacy challenges. In contrast, interviews and observations provided richer, more nuanced insights but were resource-intensive and often limited in scale. While focus groups proved valuable for exploring shared experiences, they present challenges in inclusivity and were least preferred by members of the LEAG.

This review highlights the value of using structured questionnaire results - particularly those that are co-designed, validated and accessible - to support national audits, while emphasising the need for adaptations to include people with varying levels of cognitive communication or literacy-related barriers. A hybrid approach that combines scalable tools with insights from existing qualitative feedback may offer a more comprehensive and efficient understanding of dementia care experiences, particularly in the context of limited resources.

Background

The National Audit of Dementia (NAD) is currently undergoing a programme redesign, shifting from bespoke data collection to the use of routinely collected data, where available, from general hospitals and diagnostic services. The new audit design is planned for implementation in 2026. As part of this transition, a data collection framework is being developed, relevant data sources are being explored, and key metrics are being agreed upon by NAD's Steering and Implementation Groups through ongoing consultation. This redesign aims to reduce the data collection burden on clinicians, patients, and carers at the local level, while still capturing meaningful insights into service quality and care delivery regionally and nationally.

The Health Foundation has previously published an overview of methods used to measure patient and carer experiences in health services along a continuum of those that collect descriptive feedback to those that collate more numerical data (see Annex 1) (1). In 2021, Adams et al. conducted a systematic scoping review of data collection on experiences and perspectives of people living with dementia (PLWD) in hospital settings. The authors found that the most effective method of engaging PLWD was through the use of unstructured, semi-structured or conversational-style qualitative interviews (2).

The National Health Service (NHS) has been collecting experiential feedback using the Friends and Family Test (FFT) since 2012 to identify the best performing services (3). The FFT includes one mandatory question – "*Overall, how was your experience of our service?*" – with responses captured on a 6-point scale, ranging from *very good* to *very poor*, including at least one open-ended follow-up question to capture qualitative insights (4).

In previous audit rounds, NAD developed and tested feedback tools to gather the views of PLWD and carers about their experiences of care in acute general hospital settings. These tools were designed to complement the clinical audit by including perspectives from those directly affected by dementia care services. NAD's questionnaire for carers (NADQC) and questionnaire for patients (NADQP) continue to be implemented in select hospitals in the United Kingdom in conjunction with the FFT and other tools.

In 2016, NAD commissioned the Patient Experience Research Centre at Imperial College to develop and validate a carer questionnaire to ensure that carer perspectives were formally incorporated into assessments of quality of care. The resulting questionnaire (NADQC) was designed to be brief, tailored to the general hospital inpatient setting, and inclusive of carers from a range of caregiving relationships. The questionnaire was co-designed with carers to ensure its relevance and usability (5). The final version included 10 core questions, plus two questions on the nature of the carer-patient relationship, three demographic questions and one open-ended question for additional comments on the quality of care (see Annex 2). The NADQC was used in four national general hospital audits from 2016 to 2024

A patient feedback tool (NADQP) was developed and piloted during NAD's 2020–2021 pilot activity, which tested a revised dataset in general hospitals. The NADQP was designed for flexible administration - either digitally (e.g. on a tablet) or via semi-structured interviews supported by patient engagement staff or trained volunteers (6). The tool included nine core questions, three demographic questions and was available in both text and emoji formats to support accessibility and engagement (see Annex 3 for text version, Annex 4 for emoji version).

Psychometric validation of over 5,000 responses from PLWD using the NADQP indicated that the questionnaire exhibited good or very good performance in terms of reliability, validity, and acceptability. Results suggested that the items in the questionnaire operated independently of each other and that the questionnaire was therefore not in need of significant modification (7).

Scope

This review was conducted as part of year one of NAD's three-year redesign strategy. Its purpose is to evaluate existing methods for collecting patient- and carer-reported experiences and outcomes, with a particular focus on people living with dementia or cognitive impairment (herein referred to as 'patients'). The review draws on published literature and grey literature from health and social care settings. It does not assess clinical outcomes or focus on populations outside of general hospital, diagnostic assessment or aged care settings.

Objectives

1. Identify and categorise traditional (e.g. paper-based or in-person) and innovative (e.g. digital) methods used to collect patient- and carer-reported experiences and outcomes.
2. Assess which data collection methods could be most effective for individuals with dementia, considering cognitive impairments, communication challenges and varying levels of digital literacy.
3. Examine how different methods perform in terms of response rate and ease of use particularly for dementia patients and groups with cognitive impairments and identify barriers such as literary levels, language and digital access.
4. Identify gaps in literature where further research is needed.

Research questions

- What methods are being used to collect patient- and carer-reported experiences and outcomes in healthcare settings for dementia patients and groups of patients with cognitive impairment?
- How do methods compare in terms of effectiveness, accessibility and feasibility?

Effectiveness

Effectiveness of each data collection method was assessed by analysing reported strengths and limitations across several dimensions. These included response rates, participant burden, inclusivity (including accessibility for people with cognitive or communication impairments and representation of ethnically diverse groups), and adaptability across healthcare contexts. Where available, issues related to data reliability and tool validity were also considered. These dimensions were informed by prior research on quality criteria for patient and carer feedback tools in healthcare, as well as practical considerations relevant to dementia care settings.

Feasibility

Feasibility of each data collection method was considered in terms of practical implementation factors such as time demands, ease of administration and adaptability across healthcare settings. The review aimed to examine any reported information related to who administered the tool, the mode of delivery (e.g. in-person, telephone, online), and any logistical or contextual considerations. While detailed reporting on staffing requirements, training needs and challenges related to scaling and sustainability was beyond the scope of the assessment, the review sought to capture available insights to better understand the practical implications of using each method in dementia care contexts. The feasibility criteria reflect commonly cited implementation concerns in healthcare research and service delivery.

Accessibility

Accessibility of each data collection method was examined by considering how studies described the method's inclusiveness and usability for patients and carers. This included factors such as ease of participation, language or cultural appropriateness, digital access, and the capacity of each method to accommodate individuals at different stages of care or with varying literacy levels. The review also aimed to consider, where reported, whether the method enabled participation from underserved or hard-to-reach populations, including those who may face barriers due to technology use, language or caregiving responsibilities. These accessibility considerations are grounded in established health equity principles and reflect the needs of diverse populations in dementia care.

Methods

This review of literature and resources is reported using the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) template for transparency and consistency. Figure 1 presents a PRISMA-style flow diagram outlining the sources and screening process used. All aspects of research, analysis and writing were conducted by NAD's Deputy Programme Manager - an experienced researcher - under the supervision of NAD's Programme Manager. Members of the College Centre for Quality Improvement (CCQI) team peer-reviewed and provided feedback on successive drafts of the report. Members of NAD's Lived Experience Advisory Group (LEAG) were also consulted and their feedback was integrated into the analysis and final version.

Information sources and search strategies

Searches were conducted in March and April 2025. A search strategy was defined in Medline in collaboration with the College's Library and Archives Manager, who performed the searches in Medline and Embase databases through the EBSCOhost research platform (see search strategy, Annex 5). MeSH terms were exploded to capture related terms. A third search was conducted in PsychInfo using a slightly adapted strategy (see search strategy, Annex 6).

Inclusion criteria

Studies included in the review were those that included details about the methods used to collect patient- and carer-reported experiences and/or outcomes in healthcare settings. Only open-source English language articles no older than five years were selected for the review.

Exclusion criteria

Literature that did not include information on data collection methods, patient and/or carer experiences and healthcare settings or contexts were excluded from the review. All literature in languages other than English, not open source and/or those older than five years were excluded from the review. Most articles were excluded due to the sampled population (e.g. staff, clinicians, nurses, formal paid carers) or study design (e.g. secondary data analysis, clinical trials, intervention or programme evaluations) being outside the assessment scope.

Screen and selection

The citation information from the systematic searches were imported by .ris file and stored using Rayyan: AI-Powered Systematic Review Management Platform, which is used by the Royal College of Psychiatrists to support research initiatives. Study titles and abstracts were screened using the identified inclusion and exclusion criteria to eliminate irrelevant studies before undertaking a full review of study methods and limitations. Reasons for final inclusion and exclusion were coded in the software.

Data extraction

Relevant studies and information were reviewed to assess their quality and reliability. Information on authors, title, publication year, study design, sampling, population, methods, recruitment, strengths and limitations were extracted and input into an Excel workbook.

Findings synthesis

A summary table of included studied and key findings is presented in reverse-chronological order (see Annex 7). The table includes information on author(s), publication year, study participants (disaggregated when possible), setting, recruitment process details, data collection methodology, and key findings. The findings are organised by data collection methods and, where possible, by target population and healthcare setting. The discussion explores overarching themes, including key strengths and limitations identified across studies.

To support data synthesis and improve efficiency in reviewing a large volume of extracted information, ChatGPT (8) was used to assist with summarising and categorising data from the evidence table. This partially facilitated the identification of common themes, strengths and limitations across studies. All outputs were reviewed and verified by the Researcher to ensure accuracy and relevance to the review objectives.

Review of other sources

A targeted secondary data search was conducted through internet searches of charity and organisation websites specialising in dementia, aging, and related topics between 30 March and 7 April 2025. The following websites were reviewed: Age UK, Alzheimer's Disease International, Alzheimer's Society UK, Alzheimer's Association (USA), Dementia Australia, Alzheimer's Society of Canada, The Japanese Society for Dementia Care, Dementia UK, European Dementia Network, Innovations in Dementia, and The Lewy Body Society. Email inquiries were sent to several UK-based charities, including Age UK, Dementia UK, SPIN-D Network, Alzheimer's Research UK, The Lewy Body Society, Innovations in Dementia, Together in Dementia Everyday (TIDE) and Rare Dementia Support, to request the sharing of information that might not be publicly available on the topic matter. Annex 8 presents the sources included in the review from the internet search of charity and organisation websites, which are considered in the discussion.

Consultation with Lived Experience Advisory Group

A consultation with NAD's LEAG was held on 29 May 2025, during which the group was presented with the findings from the literature and resource review. Following a brief presentation, members were asked to provide feedback on the best ways for PLWD and carers to share their experiences of care. They were invited to consider their responses in the context of acute care in general hospital or diagnostic memory assessment settings, considering what is acceptable, practical and likely to yield the most useful insights for the purpose of the national audit. The meeting was recorded, and key points from the discussion were documented and returned to the group's Coordinator for sharing and further feedback.

Survey of acute general hospitals

A voluntary questionnaire (see Annex 9) was conducted in June 2025 to explore current methods being used to gather patient and carer feedback on service and quality of care. Invitations were emailed to primary clinicians and audit leads in 110 acute general hospitals in England and Wales. Thirty hospitals completed the online survey, yielding a response rate of 29%.

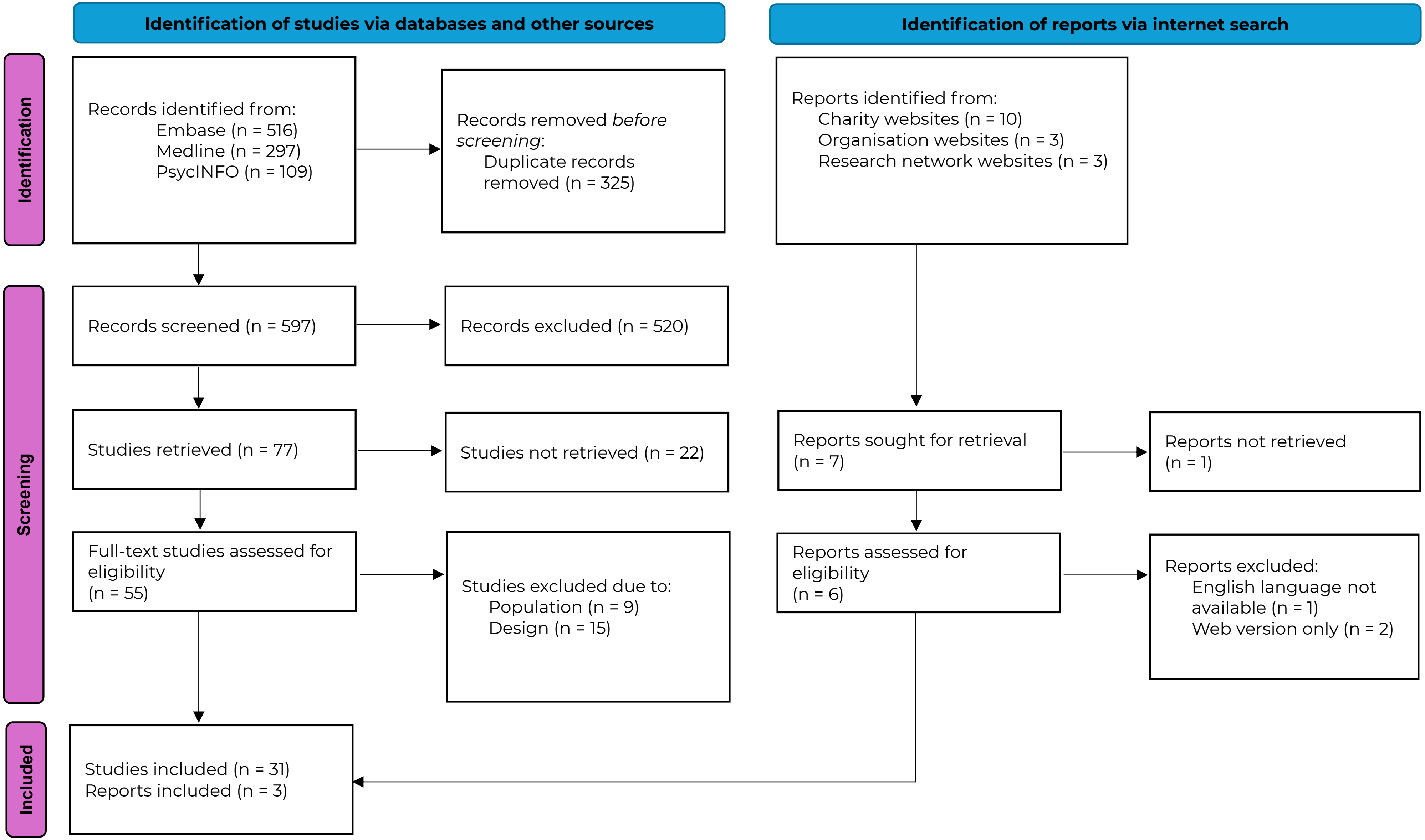
The short survey asked about whether feedback was collected for patients, carers or both; the types of feedback collected; frequency of data collection; response rates; and what was done with the collected data. Responses were analysed using Excel to identify common practices and gaps. Ethical approval was not required.

Survey of dementia diagnostic services

A voluntary questionnaire (see Annex 10) was conducted in from 17 October to 10 November 2025 to explore current methods being used to gather patient and carer feedback across dementia diagnostic services. Invitations were emailed to clinicians and audit leads in 173 services in England and Wales. Fifty-seven services completed the online survey, yielding a response rate of 33%.

Like the survey conducted in acute general hospitals, the survey of dementia diagnostic services asked about whether feedback was collected for patients, carers or both; the types of feedback collected; frequency of data collection; response rates; and what was done with the collected data. Responses were analysed using Excel and SPSS to identify common practices and gaps. Ethical approval was not required.

Figure 1: PRISMA Diagram of databases and other sources



Review findings

Systematic searches were conducted using three databases to identify studies that examined methods for collecting feedback from patients and carers in healthcare settings. In addition, 16 relevant websites were reviewed to identify supplementary resources reporting patient- and carer-reported experiences and outcomes. An overview of the search and selection process is presented in Figure 1. A total of 31 peer-reviewed articles and three reports sourced from charity websites were included in the final review.

Study characteristics

The review included 31 studies overall: 19 qualitative (9–27), five quantitative (28–32), and seven mixed-methods (33–39) studies. Most studies were from Western countries (n = 27), including 14 from Europe (Norway n = 3, United Kingdom n = 4, and one of each in Denmark, Finland, Germany, Slovenia, Spain, Sweden and The Netherlands), eight from North America (United States n = 7, Canada n = 1) and five from Australia. Four studies were from Asia, including Japan (n = 2), China (n = 1) and India (n = 1). Four studies focused solely on data collected from patients, eleven focused on data collected from carers and 16 studies collected data from both groups.

The settings in which the studies were conducted ranged widely. Five studies were set in community-based care, two focused on end-of life care, four were conducted in acute care hospitals, three in rehabilitation/sub-acute care settings in hospitals, eight in long-term care (LTC) residences, four focused on care received via telehealth and two on transitional care (from hospital to home). One of the studies set in day-care included observations of patients on farms (compared to standard day care centres).

Findings

Four primary methods were used to collect feedback across a range of healthcare settings: structured questionnaires, interviews, focus group discussions (FGDs), and observation. Each method offered distinct strengths and limitations, influenced by the context in which it was applied, the purpose of data collection and the characteristics of the target population.

Table 1 presents a summary of the key findings for each method, including average sample size, time in minutes to complete and key criteria of each tool. See Annex 7 for the full summary of findings from each study.

Table 1: Summary of key findings

Information on the method type, average sample size (range), average time to complete in minutes (range) and key criteria.

Method type	Average sample size (range)	Average time in minutes to complete (range)	Key criteria
Questionnaires	Patients, n = 110 (range: 1 - 367) Carers, n = 122 (range: 74 – 213)	Patients, 36 min (range: 15 – 90) Not reported in 3 of 9 studies	• Large sample size • Shortest time commitment for completion • Administered on paper, by telephone and online
Interviews	Patients, n = 15 (range: 2 – 50)	Patient, 49 min (range: 6 - 99)	• Flexibility to explore emerging topics, gather nuance on

	Carers, n = 26 (range: 4 – 161)	Carers, 45 min (range: 10 - 128) Not reported in 6 of 22 studies	sensitive topics, capturing multiple perspectives (e.g. from dyads) • Telephone and online formats support accessibility
Focus groups	Carers, n = 12	Carers, 65 min (range: 60 – 70) Not reported in 1 of 2 studies	• Small sample size • FGDs generally included as part of larger mixed-methods study
Observations	Patients, n = 85 (range: 2 – 247) Carers, n = 62 (range: 4 – 225)	Patients, 240 min Not reported in 4 of 6 studies	• Longest time commitment • Allows for capture of real-time insights into physical and social interactions and emotional experiences • In half of cases, used as a second data collection method

Structured questionnaires

Nine studies used a structured questionnaire approach to collect data from patients and carers, including paper questionnaires and surveys (n = 5), telephone surveys (n = 3), and an electronic questionnaire (n = 1). The term ‘questionnaire’ will herein refer to all three types.

All five quantitative and three of the mixed methodology studies (26, 32, 33) used questionnaires to collect feedback from patients and carers. The average sample size for studies collecting feedback via questionnaires was 110 for patients (range: 1 – 367) and 122 for carers (range: 74 – 213). Four studies noted the time taken to complete questionnaires: 15 minutes by telephone (32), 30 to 90 minutes (mean 50 minutes) when completed face-to-face and returned in a sealed envelope (30), 20 to 30 minutes when distributed and collected on the spot (28), and 30 to 40 minutes in a rehabilitation centre with or without assistance (39). The average time taken to complete a structured questionnaire was 36 minutes.

Recruitment processes varied depending on the setting. Patient registries were used to identify and contact patients and carers in LTC residences (30), hospital-based rehabilitation (26, 33), specialty clinics (32) and community-care (28). Bereaved family members of patients who had spent time in hospice were contacted by mail from participating institutions (29). Finally, for community-based care and telehealth, information was shared via Stakeholder Adviser Council (SAC) networks with a link shared through a national email mailing list (36).

Three studies reported response rates for PLWD and neurology patients: 51.6% for LTC residents using a paper questionnaire (30) and 44% for rehabilitation patients (39), and 86% for follow-up telephone surveys with neurology patients (32). It is important to note that the questionnaire used in the mixed methods study by Yoshimura et al. (2025) also included some open-ended questions that allowed participants to express their thoughts freely and will have added to the completion time (39).

Interviews

Twenty-two studies used interview methods to collect data from patients and carers, including individual (n = 8) and semi-structured (n = 14) interviews. The average sample size for studies collecting feedback from patients via interviews was 15 (range: 2 – 50) and carers was 26 (range: 4 – 161). Individual interviews with carers generally took longer than interviews with patients. Thirteen studies reported on the time taken to conduct interviews. In-depth individual interviews in the form of a conversation in LTC residences with PLWD were reported to take between six to 60 minutes (mean 44 minutes), though one only lasted six minutes while the remaining interviews were 36 minutes or longer (27).

Three studies conducted interviews with carers in LTC settings. One study reported that in-depth interviews at the LTC home lasted between 92 to 109 minutes (mean 101 minutes) (16), while two semi-structured interviews with carers lasted between 12 to 58 minutes (mean 30 minutes) conducted by telephone or online, and 16 to 88 minutes (mean 52 minutes) on the telephone (20), with the latter reporting a total of 872 minutes of interview data. The average time taken to conduct an in-depth interview with patients was 46 minutes (range: 6 - 99).

In-depth telephone interviews with patients and carers providing feedback for a dementia study review lasted 30 to 90 minutes (mean = 60 minutes) (25). Semi-structured interviews to gain feedback from patients and carers 14 to 20 days post-discharge lasted from 50 to 90 minutes over the telephone (33), while feedback from patients and carers for a study exploring transitional care lasted from 38 to 99 minutes (mean = 69 minutes). Finally, one study conducted with patients and carers in their homes reported semi-structured interviews lasting from 34 to 49 minutes (mean 42 minutes) (23).

Studies of patients found that interview response rates varied, ranging from 23% to 63%, with most reporting a response rate around 45-50% (9,18,33), though this is an estimate due to inconsistent reporting across all studies. Carer response rates were slightly higher than patients, ranging from 40% to 80%, with most reporting between 60% and 80% (9,12,15,16,19,33).

While one study noted diversity amongst its interviewed population (16), multiple studies identified homogeneity of interviewed populations as a major limitation, particularly due to the lack of racial or ethnic diversity (11,20,27,37). In addition, the exclusion of non-English speaking participants (9,10,34) and individuals with severe dementia (39) sometimes limited the representativeness and generalisability of the findings.

Focus groups

Two mixed-methods studies included focus group discussions as a secondary data collection method. The first study included FGDs with carers (n = 12) as part of a larger three-phased project (36) and was the only study to report the size of the focus group. A second study included FGDs with carers (n = 5) and PLWD (n = 2) following telephone surveys (15). Curto Romeu et al. (2024) reported the focus groups lasting from 60 to 70 minutes, with a 60% carer response rate. Meanwhile, White et al. (2022) reported a 71% response rate for both focus groups and individual interviews, however it was unclear if there was a difference in response rate for the two methods or the participation overall.

Observation

Three studies reported observation as the primary method (14,26,38), while three mentioned an observational component as part of a mixed-method design (35,37,39). The average sample size for studies collecting feedback from patients via observation was 85 (range: 2 – 247) and carers was 62 (range: 4 – 225).

Ellingsen-Dalskau et al. (2020) reported conducting 1,056 observations over the course of their study, including 504 observations across 10 farm day care (FDC) settings and 552 observations in regular day care (RDC) settings for PLWD. Four hours of observation were conducted with a 30 minute break, with up to eight people being observed in one setting (14). Meanwhile, Boumans, van Boekal and Verbiest (2022) observed PLWD (n = 4) and carers (n = 4) to understand how the use of the physical environment and technology could contribute to the patient autonomy. Observations took an average of 3.5 hours (38). Finally, Anderson and Blair (2020) conducted an observational longitudinal study that followed patients (n = 247), their families and care partners (n = 225), managers (n = 12) and staff (n = 235) at a LTC residence over three waves (baseline, 6-months and 10-months).

Farrington et al. (2023) reported that observations in an outpatient care environment were eventually suspended due to COVID-19 restrictive measures and protocol adjusted to allow telephone contact and interviews. The remaining studies used observation as way to triangulate findings, for example, observation of participants as they completed questionnaires either individually or as part of a dyad.

Review of other resources

An internet review identified three relevant reports (40–42), summarized in Annex 8, which illustrate the types of data that have been collected previously. Two of these were commissioned by the Alzheimer's Society. The 2020 report used a mixed-methods approach involving interviews and focus groups to provide rich qualitative insights into experiences of diagnosis, care and end-of-life support - though its small sample size limits generalisability. The 2024 Walnut report employed a large-scale quantitative survey across England, Wales, and Northern Ireland. Its strengths included an inclusive design (e.g. multilingual and phone-based options), subgroup analysis and meaningful involvement of PLWD in both tool development and reporting.

Additionally, Healthwatch Cornwall (2023) conducted a co-produced, mixed-methods study approach supported by local carer networks. Its broad survey sample offers a valuable county-level perspective on carers' experiences and unmet needs. Together, these reports highlight a range of participatory approaches that provide valuable insight and may inform future audit design, particularly in balancing scale with depth.

Table 2 summarises the trade-offs of each data collection method, including utility, practical considerations and cost. Structured questionnaires are well-suited to the audit context due to their scalability[1] and efficiency, particularly when designed for accessibility and co-developed with stakeholders. However, they may require carer assistance or exclude individuals with advanced dementia or limited literacy. Interviews and focus groups offer richer, more personalised insights and are especially valuable for capturing the context behind survey data or involving seldom-heard voices, but they are resource-intensive and less feasible for national-level benchmarking[2]. Observation methods can offer valuable insights in settings where verbal communication is limited, though their use in large-scale audits is constrained by standardisation and cost. These trade-offs must be carefully considered when identifying data sources that use these methods for future audit cycles.

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[1] Scalability is the capacity to be able to change in size and/or scale. For example, increasing data collection from just one district to national level.

[2] Benchmarking is the process of evaluating the performance of something by comparing it to a standard or best practice.

Table 2: Research method trade-offs

Key utility, considerations and potential cost/feasibility for the four identified methods: structured questionnaires, interviews, focus groups and observation.

Method	Utility	Practical considerations	Cost/feasibility
Structured questionnaires	Enables benchmarking and tracking; efficient for large samples	May require carer assistance; risk of excluding people with advanced dementia or non-English speakers	Moderate cost; relatively low resource (money, staff, time) demands; scalable
Interviews	Provides rich, individualised data; supports inclusive, tailored communication and ability to explore emerging topics	Resource-intensive; requires training to ensure that interviewing staff are skilled; longer engagement time	Higher cost (staffing and time required); limited scalability
Focus groups	Useful for co-design or service development feedback; group interaction generates insights	Less suitable for routine audit; may exclude some people with dementia	Moderate cost; may require facilitation training
Observation	Focus on actual behaviour rather than recall (43); Offers insights where verbal communication is difficult; useful in institutional settings	Less standardised; may require ethical review and observer training	Moderate to high cost; less feasible to scale

General hospital survey of methods

Thirty-two hospitals responded to the patient and carer feedback survey, which aimed to assess the methods currently used to gather feedback in acute healthcare settings. Thirteen hospitals reported that they do not collect feedback from patients and carers, citing reasons such as lack of funding to support their preferred collection method (n = 5), staff being overstretched (n = 4), low response rates (n = 3) and never having attempted feedback collection (n = 1). Feedback collection practices among the remaining hospitals are detailed in Annex 10 (patients) and Annex 11 (carers). Of these, five hospitals reported collecting feedback from patients only, three from carers only, and 11 from both patients and carers.

The survey results indicated that the most commonly used method for collecting feedback from patients and carers was the friends and family test, either as a standalone tool (n = 11) or in combination with another tool (n = 12). Seven hospitals reported using the only the FFT to collect patient feedback, while four reported using only the FFT for carer feedback. Among hospitals collecting patient feedback, five used the FFT alongside the NADQP, and one combined the FFT with another tool. For carer feedback, four hospitals reported using the FFT with the NADQC, and two used the FFT in combination with another tool.

Dementia diagnostic services survey of methods

Fifty-seven memory assessment services responded to the patient and carer feedback survey aimed at assessing the methods being used to gather feedback in community-led dementia diagnostic services in England and Wales. Four services reported not collecting feedback from patients and carers. Two services reported staff being overstretched as the reason for not collecting feedback from patients and carers, while one service noted low response rate as the reason and one noted “other” with no explanation. Data collection approaches among the 53 services collecting feedback are detailed in Annex 12 (patients) and Annex 13 (carers). Of these, nine services reported collecting feedback from patients only, one from carers only, and 43 from both patients and carers.

Services use a variety of methods to collect feedback from patients and carers. Twenty-one services used the FFT in combination with another method, 14 used the FFT adapted for PLWD and 17 used another method to collect feedback from patients. Seventeen services reported using the FFT in combination with another method, 10 used the FFT adapted for PLWD and 17 used another method to collect feedback from carers.

Patient and carer feedback was reported as being collected to help services understand experiences of assessment, diagnosis and post-diagnostic support, assess clarity of communication, and identify unmet needs. Overall, both patient and carer feedback are used to promote person-centred care, strengthen service quality, and ensure services remain responsive and supportive throughout the dementia journey.

Discussion

This review examined the methods used to collect feedback from patients and carers across various healthcare settings. It focused on structured questionnaires, interviews, focus groups and observation, assessing each method in terms of effectiveness, feasibility and accessibility. By synthesising findings across 31 peer-reviewed articles and three charity reports, the review aimed to identify not only the relative strengths and limitations of these methods, but also the contextual and practical considerations that influence their effectiveness in dementia care research.

Structured questionnaires

Structured questionnaire-based tools were commonly used for collecting patient and carer feedback. They typically involved closed questions with fixed response options administered through paper forms, telephone surveys or digital platforms, allowing for standardised data collection across large populations. Their strengths included ease of administration, efficient data analysis, and high comparability and generalisability of responses (1). However, limitations included low response rates, limited depth of insight and challenges to use for individuals with dementia, cognitive impairment or low literacy, particularly when self-completion was required. In dementia care contexts, structured questionnaires may need to be adapted or supported by carers to ensure accessibility.

The average time commitment reported to complete a structured questionnaire was 36 minutes, based on four studies that provided time data. In comparison with other methods, questionnaires yielded the largest sample sizes, required the least time to complete and could be administered in various formats: in person, by telephone and online (see Table 1). Strengths of the structured questionnaires included collaboration development with an SAC, who reviewed the surveys for readability (36), the use of a well-established questionnaire with demonstrated reliability and validity (21,34) and the implementation of a pilot test prior to the full rollout (29).

The main limitation of structured questionnaires is limited generalisability of their samples. Among the reviewed studies, some had narrowly defined samples - such as data collected from only one long-term care residence (30), inclusion of just one patient (34) or restriction to just three hospitals within a single region (28). Several studies also excluded non-English-speaking patients and carers (34), and some findings may only reflect the views of participants comfortable using technology (36), creating sampling bias. Convenience sampling was also noted as a limitation in two studies that used structured questionnaires (36,39), reducing generalisability and potentially excluding individuals with more advanced dementia (39). In one case, the use of a single investigator raised concerns about potential documentation bias (34). The use of a questionnaire as a self-reported method may be affected by self-reported bias due to participants wanting to appear socially desirable (28). Finally, several reviewed studies did not include a piloting process (30,36), which may reduce the questionnaire's reliability and validity.

Interviews

Interviews are a widely used method for gathering in-depth feedback from patients and carers, offering the flexibility of exploring individual experiences, preferences and concerns in more detail than structured questionnaires. They can be conducted face-to-face, by phone or virtually, and may be structured, semi-structured or unstructured depending on the research aims. Interviews are particularly valuable in dementia care, as they allow for tailored communication and clarification, which can support participation despite cognitive or communication challenges. However, they can be time-consuming, resource-intensive and may place a greater burden on participants and interviewers, especially in clinical or time-limited settings.

Interviews with patients and carers were typically more time-intensive, averaging approximately 49 minutes for patients and 45 minutes for carers, though not all studies reported interview durations. For FGDs, only one study provided a specific timeframe (60 to 70 minutes). Interviews, whether in-depth, individual, or semi-structured, offered rich, detailed accounts of experiences from patients and carers. Semi-structured formats can allow the flexibility of exploring emergent topics while still maintaining a guiding structure. Interviews enable researchers to build rapport and gather nuanced information about sensitive topics, such as care transitions and psychosocial impacts (12,18). Key strengths included the use of dyads (PLWD and carers) to capture multiple perspectives on shared experiences (37,39). The use of telephone and online formats in some studies (19,35) further enhanced accessibility, particularly during the COVID-19 pandemic.

Several limitations were noted despite the benefits. Some studies raised concerns about selection bias (12,16,18,21), especially where participants were recruited through support services or were more comfortable with technology, which may exclude those with greater needs or digital barriers. While the small sample sizes were noted as a limitation to generalisability in multiple studies (16,23,33,35,38), many studies reported reaching saturation (11–13,22,24,25,27,37). Some authors also acknowledged the risk of recall bias (9,13,22).

Focus group discussions

Focus groups are a qualitative method used to collect feedback through facilitated group discussions. FGDs encourage participants to share and reflect on their experiences collectively, often generating rich insights through group dynamics and interaction. This method can be useful for exploring shared concerns, identifying service gaps or understanding the social context of care. However, FGDs may be less suitable for individuals with dementia or cognitive dysfunction due to challenges with concentration, communication or difficulty adjusting to group settings. Finally, FGDs require careful facilitation and can be limited by group composition, potential dominance of certain voices and logistical barriers, such as travel or scheduling.

Both studies identified convenience sampling as a limitation. The Curto Romeu et al. (2022) study was conducted in a single community and primary care setting, limiting the capture of broader experiences across diverse services. Additionally, potential selection bias was noted in distinguishing between caregivers who chose to participate and those who did not (15). White et al. (2022) noted the lack of formal validation of the tools as a limitation. As focus groups were used as a secondary method, these limitations likely apply more to the overall study design, including the survey and individual interview components, rather than the focus groups alone.

Observation

Observation involves the systematic recording of behaviours, interactions and environments to gather insights into experiences, often without direct questioning. It can be particularly valuable for capturing non-verbal communication, understanding of care practices and contextual factors that may be missed when using self-reported methods. In dementia care, observation can provide important information about how individuals navigate healthcare settings and interact with staff, particularly when verbal communication is limited.

Observational data collection was less consistently quantified but generally involved several hours or, in some cases, multiple days. This reflects its emphasis on capturing rich, contextual detail rather than discrete responses. More consistent and transparent reporting of observation periods across studies would improve the comparability of methods and help assess the practical, resource and cost implications of implementing observation-based approaches in healthcare settings. The use of observational methods across the studies proved to be a methodological strength, as they enabled the researchers to capture detailed, real-time insights into the physical activity, social interactions and emotional experiences of patients in different care settings.

Ellingsen-Dalskau et al. (2020) highlighted the value of employing an ecological momentary assessment approach in FDC environments that facilitated the collection of rich contextual data in everyday surroundings. An additional strength was the adaptation and pilot testing of the Maastricht Electronic Daily Life Observation (MEDLO) tool for use in both farm and day care contexts. Boumans et al. (2022) developed and used a structured observation guide, enhancing the consistency and focus of observations. These approaches enabled researchers to capture subtle interpersonal dynamics and environmental influences that may not surface through interviews or surveys, providing a more holistic understanding of participants' daily lives.

Despite these advantages, several limitations were reported. Boumans et al. (2022) acknowledged the risk of the Hawthorne effect, where participants may alter their behaviour while being observed, potentially affecting the authenticity of the data. Additionally, observational data alone are unlikely to sufficiently capture internal patient experiences or perspectives, limiting interpretive depth. Ellingsen-Dalskau et al. (2020) noted that the absence of participant demographic data limited their ability to make comparisons between the two groups. Collectively, these limitations point to the importance of triangulating observation with other methods and applying structured tools to enhance rigor.

Response rates

Response rates varied across the studies and were not consistently reported. Three studies focusing on structured questionnaires reported response rates among PLWD and neurology patients. For example, one study in a LTC setting reported a response rate of 51.6% (30), while another in a rehabilitation context reported 44% (39). A follow-up telephone survey with neurology patients showed a much higher response rate of 86% (24), suggesting that mode of administration and population characteristics may significantly affect participation. However, the general lack of response rate data across many studies presents a challenge in assessing the overall representativeness and generalisability of findings. Systematic and standardised reporting of response rates would strengthen future evaluations of data collection effectiveness, especially in dementia research where participation barriers may be common.

Recruitment

Recruitment strategies varied but often relied on existing administrative records, such as LTC resident lists or hospital databases, to identify eligible participants based on dementia diagnoses or cognitive screening scores. Initial contact was typically made by healthcare professionals, including general practitioners or head nurses. In some cases, researchers re-contacted participants from previous studies who had provided consent for future follow-up. Several studies also employed community-based recruitment methods. For example, one study used a Stakeholder Advisor Council to share study information via national networks and email lists (36), while another recruited carers via the National Institute for Health and Care Research (NIHR) database and Join Dementia Research platform (11). In one study, individuals with intellectual and developmental disabilities were recruited through an advocacy organisation to ensure inclusion of underrepresented voices (13). These varied approaches helped improve accessibility but may also have contributed to heterogeneity in study samples and potential recruitment bias.

Across studies, key strengths included the use of standardised tools and the adaptation of those tools to better suit the needs of patients and their carers. Involving both patients and carers in the development or refinement of tools was frequently noted as a strength, as it helped ensure that questions were relevant, accessible and reflective of lived experience. Piloting tools prior to implementation was also commonly cited as a methodological strength, supporting improved reliability and validity. These practices contribute to the credibility and usability of data collection instruments, particularly in research with populations affected by cognitive decline.

Lived Experience Advisory Group feedback

The NAD team presented the findings from the literature and resource review to a Lived Experience Advisory Group to gain perspectives from PLWD and carer representatives on their preferred methods of providing experience and outcome feedback. The group was asked to consider their responses in the context of acute care in general hospital or diagnostic memory assessment settings. Additionally, they were asked to consider what would be acceptable, practical and likely to yield the most useful insights for the purpose of the national audit. Annex 15 presents the feedback summary gathered from NAD's LEAG representatives.

Feedback from PLWD and carer representatives highlights the importance of designing feedback mechanisms that are inclusive, timely and sensitive to emotional and cognitive contexts. The stage of dementia significantly influences an individual's ability to provide meaningful feedback, with earlier stages generally allowing for more direct engagement. Timing is also critical; collecting feedback while the individual is still in the care setting increases accuracy and relevance, as memories may fade or be affected by post-discharge events. Participants emphasised the need to capture experiences across the dementia journey, ensuring tools accommodate varying levels of ability.

Emotional readiness and environmental factors also shape willingness to participate. Carers, sometimes overwhelmed or fearful of repercussions, may hesitate to provide honest feedback unless the process is clearly framed as contributing to service improvement. Both PLWD and carers value feedback processes that feel purposeful and empowering, rather than burdensome. Questionnaires were generally preferred when well-designed - featuring specific, accessible questions with options for open-ended responses and multiple delivery formats (e.g. paper, online, verbal). While digital tools like QR codes or tablets can improve accessibility for some, they remain underused without proper guidance or support. Focus groups, by contrast, were viewed as less suitable due to practical challenges, including timing difficulties and the risk that experiences might be forgotten or that carers may not have the capacity to attend.

LEAG participants noted the importance of inclusivity and respect. They felt that feedback approaches should avoid assumptions about capacity and prioritise direct engagement with PLWD wherever possible. Carers should not only be included as participants but also in the design and facilitation of feedback processes. Ensuring that feedback tools are adaptable, clearly motivated and delivered in a supportive manner can enhance both participation and the quality of insights gathered.

Using patient and carer feedback for quality improvement

Feedback collected from patients and carers has been used in hospital settings to improve services and patient experience. Results from NAD's 2024 patient experience survey informed service improvements at the Friarage Hospital, North Yorkshire.

At national level, the survey - completed by 5,765 patients – found that just over half (53%) of respondants reported always liking their food. In contrast, patient experience surveys conducted at two points in time at the Friarage Hospital showed performance below the national average, with only one third (32%) of patients reporting that they enjoyed the food during their stay.

These findings prompted the development of a targeted action plan, including a review of housekeeping training needs, a comprehensive assessment of food quality, and a full revision of both the standard and dementia-friendly (finger food) menus. As a result, tangible improvements were implemented, including enhanced menus, the introduction of picture-based meal guides to support vulnerable patients, and online access for carers to review ward-level food options (44).

Implications for the National Audit of Dementia

As NAD transitions from bespoke data collection to the use of routinely collected data, all avenues are being explored to understand what outcome and experience data already exists, who collects it and in what settings. This includes the review of efforts by other charities and organisations that gather feedback on service provision relevant to patients and carers.

Examples from other charities and previous NAD reports show that incorporating qualitative feedback can strengthen the credibility and impact of findings, particularly when illustrating the lived experience behind trends or outliers in structured survey data.

Historically, the National Audit of Dementia has developed and validated tools that measure aspects of care experience identified as important by PLWD and carers. These tools have used mainly structured, quantitative formats, their strengths being that they can be repeated over time to monitor improvement, support comparison across sites and settings, and serve as measurable indicators for benchmarking and accountability.

While the NHS's FFT can be adapted to include additional questions, the standard tool lacks dementia-specific content and does not provide the depth of information needed to inform service improvements tailored to dementia care. Where tools like FFT are used in audit or performance frameworks, they could be supplemented with dementia-focused tools or narratives to generate meaningful insights into care quality for patients and carers.

Limitations

Several limitations were consistently observed across methods. At least one study in each data collection category identified small sample sizes as a significant limitation, particularly in obtaining robust experience and outcome data from patients. A lack of diversity among participant groups was also frequently noted. Many studies included predominantly homogeneous samples, with limited representation of non-white populations, ethnic minority groups or non-English speakers. This lack of diversity significantly limits the generalisation of findings and raises concerns about whether the feedback collected truly reflects the range of experiences within the broader dementia-affected population. Studies that identified this gap often recommended that future research efforts aim to include more diverse and underrepresented groups, both to enhance the validity of findings and to ensure more equitable health system improvement.

One of the original aims of this assessment was to identify the barriers that patients and carers face when using technology-based data collection methods. While several studies acknowledged the exclusion of potential participants due to digital access or literacy challenges, none provided detailed insights into the specific challenges encountered or how these might be mitigated. Notably, two studies (20,25) highlighted that digital methods enabled data collection to continue during the COVID-19 pandemic, when face-to-face contact was restricted – underscoring both the potential and the limitation of remote tools for these populations.

As the national audit transitions away from bespoke data collection toward the use of routinely collected data, it will be essential to assess whether these sources adequately capture the experiences of people from different ethnic backgrounds. This may require identifying datasets that disaggregate by ethnicity and ensuring that culturally and linguistically appropriate feedback tools have been used. Without such attention, the audit risks overlooking the perspectives and needs of marginalised populations.

Adaptability of data collection methods across healthcare settings was addressed in several studies, though often implicitly. For example, interviews were conducted across a range of contexts, including hospitals, LTC residences, community settings and via telehealth - with some studies adapting to pandemic-related constraints by switching from in-person to telephone or online formats. Structured questionnaires were used in both inpatient and outpatient environments, with paper, telephone and electronic formats enabling varying levels of accessibility. However, few studies explicitly assessed the process of adapting tools to different settings and, where adaptations occurred, these were often driven by logistical necessity rather than planned design. This highlights the need for future research to systematically evaluate and document the adaptability of feedback tools to ensure their suitability across diverse healthcare environments and populations.

Conclusion

This review highlights the advantages of drawing on the results of structured questionnaires to support the national audit, particularly where tools are co-designed with stakeholders, validated and made accessible across multiple formats (e.g. paper, digital, telephone). However, adaptations are essential to ensure the inclusion of individuals with cognitive, communication or literacy-related barriers — such as using simplified language or visual aids like symbols or emojis, allowing responses to be submitted over multiple sessions or providing the option to complete it with a trusted carer or family member.

The evidence reviewed underscores the potential value of qualitative feedback — through in-depth interviews and focus group discussions — in adding depth, context and personal meaning to quantitative results. Nonetheless, collecting qualitative data at national scale presents feasibility challenges within a landscape of limited funding, stretched staffing capacity and increasing operational pressures.

As NAD considers the future of its data collection strategy, a hybrid approach may offer a comprehensive understanding of dementia care experiences. This would involve combining structured, scalable tools with insights from existing sources of narrative feedback. The exploration of opportunities to utilise data already being collected, rather than initiating new primary data collection activities, has the potential to enhance efficiency. The findings from this review will help inform whether future audit cycles can integrate existing data sources or require complementary approaches.

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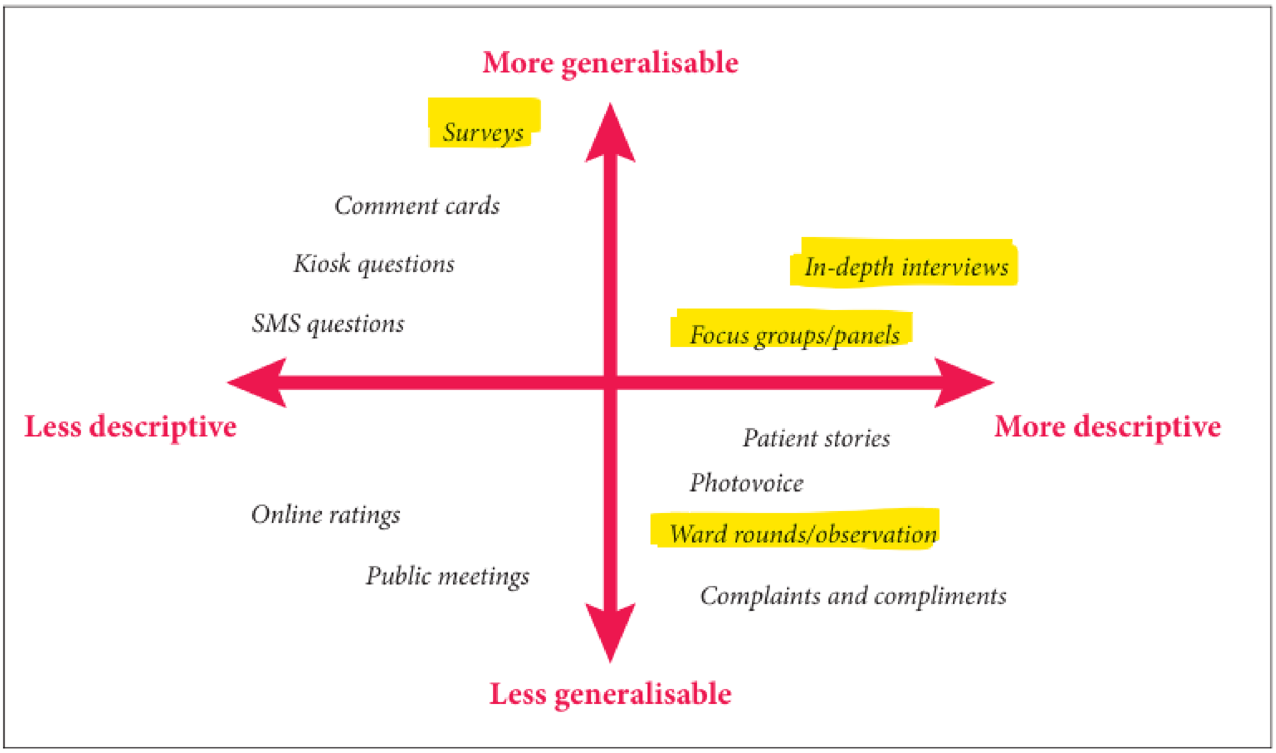
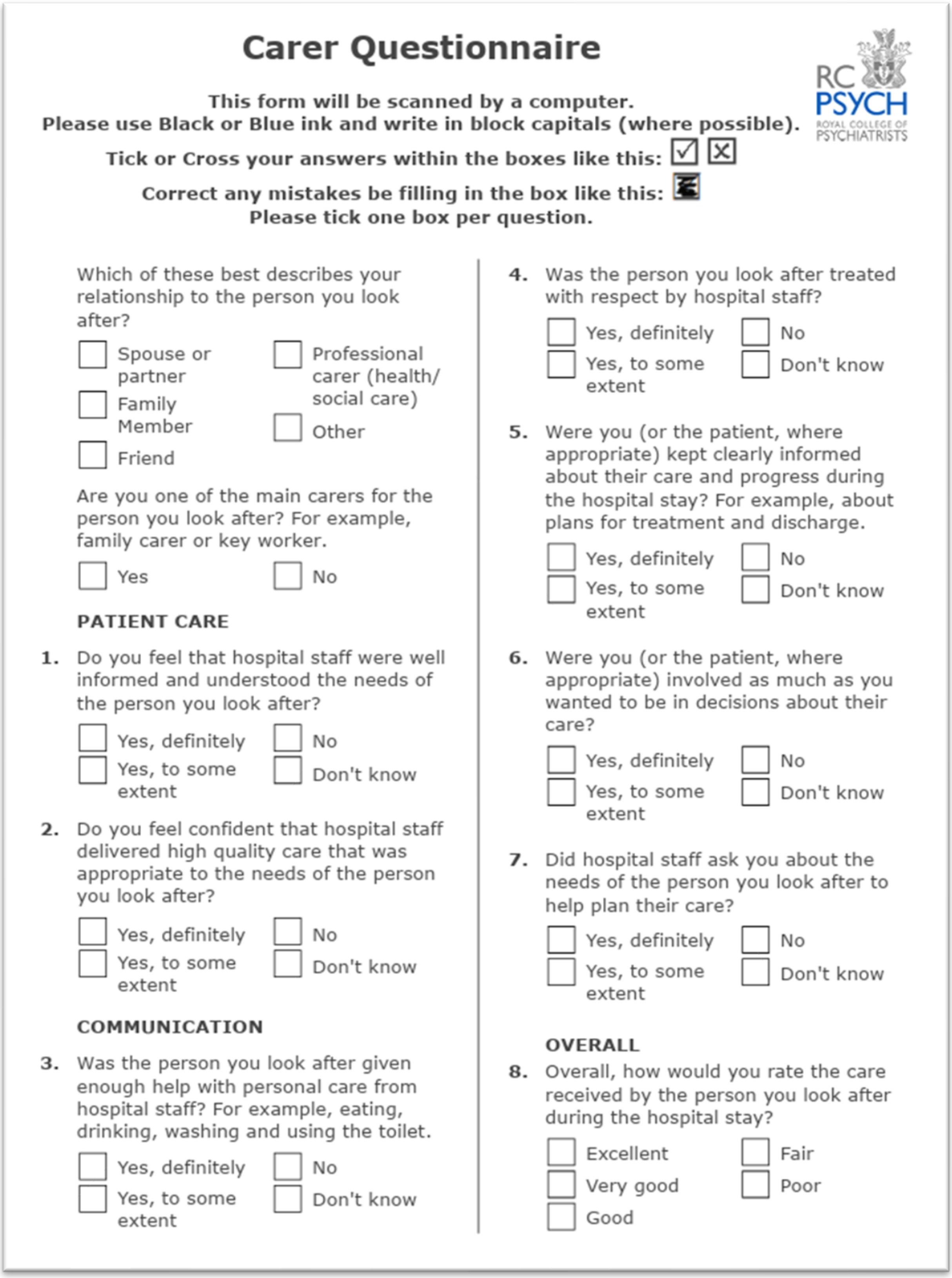
Annex 1: Approaches to measure patient and carer experiences

The Health Foundation's key approaches to measuring patient and carer experience of health care. The four main methods identified in this review are highlighted.



Annex 2: NAD’s Questionnaire for Carers

The questionnaire for carers (NADQC) developed for the National Audit of Dementia.



Carer Questionnaire

RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

This form will be scanned by a computer.
Please use Black or Blue ink and write in block capitals (where possible).
Tick or Cross your answers within the boxes like this: ☑ ☒
Correct any mistakes be filling in the box like this: ■
Please tick one box per question.

Which of these best describes your relationship to the person you look after?

☐ Spouse or partner ☐ Professional carer (health/ social care)
☐ Family Member ☐ Other
☐ Friend

Are you one of the main carers for the person you look after? For example, family carer or key worker.

☐ Yes ☐ No

PATIENT CARE

1. Do you feel that hospital staff were well informed and understood the needs of the person you look after?

☐ Yes, definitely ☐ No
☐ Yes, to some extent ☐ Don't know

2. Do you feel confident that hospital staff delivered high quality care that was appropriate to the needs of the person you look after?

☐ Yes, definitely ☐ No
☐ Yes, to some extent ☐ Don't know

COMMUNICATION

3. Was the person you look after given enough help with personal care from hospital staff? For example, eating, drinking, washing and using the toilet.

☐ Yes, definitely ☐ No
☐ Yes, to some extent ☐ Don't know

4. Was the person you look after treated with respect by hospital staff?

☐ Yes, definitely ☐ No
☐ Yes, to some extent ☐ Don't know

5. Were you (or the patient, where appropriate) kept clearly informed about their care and progress during the hospital stay? For example, about plans for treatment and discharge.

☐ Yes, definitely ☐ No
☐ Yes, to some extent ☐ Don't know

6. Were you (or the patient, where appropriate) involved as much as you wanted to be in decisions about their care?

☐ Yes, definitely ☐ No
☐ Yes, to some extent ☐ Don't know

7. Did hospital staff ask you about the needs of the person you look after to help plan their care?

☐ Yes, definitely ☐ No
☐ Yes, to some extent ☐ Don't know

OVERALL

8. Overall, how would you rate the care received by the person you look after during the hospital stay?

☐ Excellent ☐ Fair
☐ Very good ☐ Poor
☐ Good

]

9. How likely would you be to recommend the service to friends and family if they needed similar care or treatment?

☐ Extremely likely
☐ Likely
☐ Neither likely nor unlikely
☐ Unlikely
☐ Extremely unlikely
☐ Don't know

10. Overall, how satisfied are you with the support **you** have received from this hospital to help you in your role as a carer?

☐ Very satisfied
☐ Somewhat satisfied
☐ Somewhat dissatisfied
☐ Very dissatisfied
☐ I don't need/want any support

11. Do you have any comments about the service provided by the hospital to the person you look after? For example, anything you were particularly happy or unhappy about.

Please note: Any comments you make will be included in the report for this hospital and may be quoted in the national report. All information included in reporting will be anonymous and any identifying information you give will be removed before reporting.

ABOUT YOU

12. How do you define your **gender**?

☐ Male
☐ Female
☐ Other
☐ Prefer not to say

13. What is your **age**?

☐ 18-24 years
☐ 25-34 years
☐ 35-44 years
☐ 45-54 years
☐ 55-64 years
☐ 65-74 years
☐ 75-84 years
☐ 85 years and over
☐ Prefer not to say

14. Please specify your **ethnicity**:

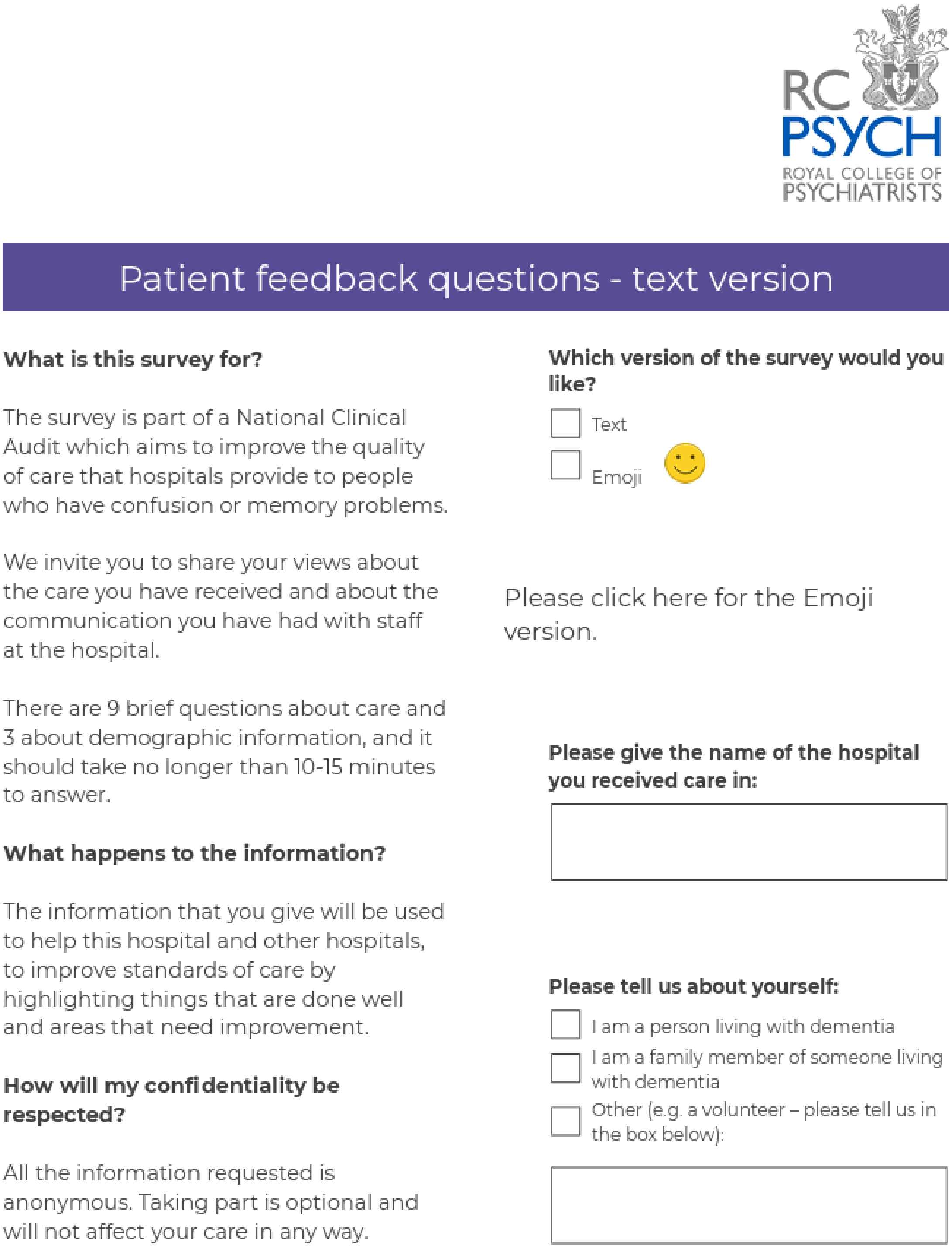
☐ White/White British
☐ Black/Black British
☐ Asian/Asian British
☐ Mixed
☐ Other
☐ Prefer not to say

Thank you very much for your responses.

Hospital code:

Annex 3: NAD’s Questionnaire for Patients (Text)

Text version of the questionnaire for patients (NADQP) developed for the National Audit of Dementia.



Patient feedback questions - text version

What is this survey for?

The survey is part of a National Clinical Audit which aims to improve the quality of care that hospitals provide to people who have confusion or memory problems.

We invite you to share your views about the care you have received and about the communication you have had with staff at the hospital.

There are 9 brief questions about care and 3 about demographic information, and it should take no longer than 10-15 minutes to answer.

What happens to the information?

The information that you give will be used to help this hospital and other hospitals, to improve standards of care by highlighting things that are done well and areas that need improvement.

How will my confidentiality be respected?

All the information requested is anonymous. Taking part is optional and will not affect your care in any way.

Which version of the survey would you like?

☐ Text
☐ Emoji 🙂

Please click here for the Emoji version.

Please give the name of the hospital you received care in:

Please tell us about yourself:

☐ I am a person living with dementia
☐ I am a family member of someone living with dementia
☐ Other (e.g. a volunteer – please tell us in the box below):

Did the hospital staff caring for you listen to you and understand your needs?

☐ Yes, all of them did
☐ Some of them did
☐ None of them did

Please use the box below for further comments:

Did staff speak to you using the name you prefer to be called by?

☐ Yes, all of them did
☐ Some of them did
☐ None of them did

Please use the box below for further comments:

Did staff keep you informed about what care and treatment you were being given?

☐ Yes, always
☐ Sometimes
☐ No, never

Please use the box below for further comments:

When you needed help, did staff give you enough of their time?

☐ Yes, always
☐ Sometimes
☐ No, never
☐ I did not need help (N/A)

Please use the box below for further comments:

Were you given medicine for any pain if you needed it?

☐ Yes, always
☐ Sometimes
☐ No, never
☐ I did not need this (N/A)

Please use the box below for further comments:

Did you like the food you were given during your stay in hospital?

☐ Yes, always
☐ Sometimes
☐ No, never

Please use the box below for further comments:

Have visitors been allowed to see you during your stay in hospital?

☐ Yes
☐ Sometimes
☐ No
☐ I did not expect any visitors (N/A)

Please use the box below for further comments:

Were you treated with dignity and respect throughout your stay?

☐ Yes, always
☐ Sometimes
☐ No, never

Please use the box below for further comments:

Thinking about your stay in hospital overall, would you say that your care was:

☐ Very good overall
☐ OK
☐ Not good

Please use the box below for further comments:

About you

Sometimes people's needs and priorities are different, and this is associated with their age group, whether they are living alone, or other factors such as religion. To help us identify any themes like this across all the survey responses we receive, we would really appreciate you taking a moment to answer the following short questions. These are optional and all responses are anonymous.

Here's a link which provides you with information on how we will handle your personal information in accordance with the law. https://www.rcpsych.ac.uk/about-us/legal/data-protection/privacy-notice-national-audits

Please note: the information provided in this section should be about the person with dementia, even if it is being completed on their behalf by somebody else.

How do you define your **gender**?

☐ Male
☐ Female
☐ Other
☐ Prefer not to say

What is your **age**?

☐ 18-24 years
☐ 25-34 years
☐ 35-44 years
☐ 45-54 years
☐ 55-64 years
☐ 65-74 years
☐ 75-84 years
☐ 85 years and over
☐ Prefer not to say

Please specify your **ethnicity**:

☐ White/White British
☐ Black/Black British
☐ Asian/Asian British
☐ Mixed
☐ Other
☐ Prefer not to say

Thank you very much for your responses.

Annex 4: NAD’s Questionnaire for Patients (Emoji)

The Emoji version of the questionnaire for patients (NADQP) developed for the National Audit of Dementia

Patient feedback questions - emoji version 🙂

What is this survey for?

The survey is part of a National Clinical Audit which aims to improve the quality of care that hospitals provide to people who have confusion or memory problems.

We invite you to share your views about the care you have received and about the communication you have had with staff at the hospital.

There are 9 brief questions about care and 3 about demographic information, and it should take no longer than 10-15 minutes to answer.

What happens to the information?

The information that you give will be used to help this hospital and other hospitals, to improve standards of care by highlighting things that are done well and areas that need improvement.

How will my confidentiality be respected?

All the information requested is anonymous. Taking part is optional and will not affect your care in any way.

Please give the name of the hospital you received care in:

Please tell us about yourself:

☐ I am a person living with dementia
☐ I am a family member of someone living with dementia
☐ Other (e.g. a volunteer – please tell us in the box below):

Did the hospital staff caring for you listen to you and understand your needs?

☐ 🙂 Yes, all of them did
☐ 😐 Some of them did
☐ 🙁 None of them did

Please use the box below for further comments:

Did staff speak to you using the name you prefer to be called by?

☐ 🙂 Yes, all of them did
☐ 😐 Some of them did
☐ 🙁 None of them did

Please use the box below for further comments:

Did staff keep you informed about what care and treatment you were being given?

☐ 🙂 Yes, always
☐ 😐 Sometimes
☐ 🙁 No, never

Please use the box below for further comments:

When you needed help, did staff give you enough of their time?

☐ 🙂 Yes, always
☐ 😐 Sometimes
☐ 🙁 No, never
☐ ⊘ I did not need help (N/A)

Please use the box below for further comments:

Were you given medicine for any pain if you needed it?

☐ 🙂 Yes, always

☐ 😐 Sometimes

☐ 🙁 No, never

☐ ⊘ I did not need this (N/A)

Please use the box below for further comments:

Have visitors been allowed to see you during your stay in hospital?

☐ 🙂 Yes

☐ 😐 Sometimes

☐ 🙁 No

☐ ⊘ I did not expect any visitors (N/A)

Please use the box below for further comments:

Did you like the food you were given during your stay in hospital?

☐ 🙂 Yes, always

☐ 😐 Sometimes

☐ 🙁 No, never

Please use the box below for further comments:

Were you treated with dignity and respect throughout your stay?

☐ 🙂 Yes, always

☐ 😐 Sometimes

☐ 🙁 No, never

Please use the box below for further comments:

Thinking about your stay in hospital overall, would you say that your care was:

- ☐ 🙂 Very good overall
- ☐ 😐 OK
- ☐ 🙁 Not good

Please use the box below for further comments:

About you

Sometimes people's needs and priorities are different, and this is associated with their age group, whether they are living alone, or other factors such as religion. To help us identify any themes like this across all the survey responses we receive, we would really appreciate you taking a moment to answer the following short questions. These are optional and all responses are anonymous.

Here's a link which provides you with information on how we will handle your personal information in accordance with the law. https://www.rcpsych.ac.uk/about-us/legal/data-protection/privacy-notice-national-audits

Please note: the information provided in this section should be about the person with dementia, even if it is being completed on their behalf by somebody else.

How do you define your **gender**?

☐ Male
☐ Female
☐ Other
☐ Prefer not to say

What is your **age**?

☐ 18-24 years
☐ 25-34 years
☐ 35-44 years
☐ 45-54 years
☐ 55-64 years
☐ 65-74 years
☐ 75-84 years
☐ 85 years and over
☐ Prefer not to say

Please specify your **ethnicity**:

☐ White/White British
☐ Black/Black British
☐ Asian/Asian British
☐ Mixed
☐ Other
☐ Prefer not to say

Thank you very much for your responses.

Annex 5: Search strategy for Medline and Embase

Search strategy used in Medline and Embase on 28 March 2025 and 01 April 2025, respectively.

	Search Terms	Search Results
S22	s20 not s21 Publication Date: 20200101-20251231	(297)
S21	XB child* Publication Date: 20200101-20251231	(430,180)
S20	S15 AND S16 AND S17 AND S18 Publication Date: 20200101-20251231	(314)
S19	S15 AND S16 AND S17 AND S18	(1,025)
S18	S11 OR S12 OR S13 OR S14	(2,178,301)
S17	S9 OR S10	(322,376)
S16	S3 OR S4 OR S5 OR S6	(3,263,145)
S15	S1 OR S2 OR S7 OR S8	(524,474)
S14	XB ("health facilit*" or "tele health" or "tele medicine")	(24,800)
S13	(MH "Telemedicine") OR (MH "Remote Consultation+")	(48,432)
S12	(MH "Health Facilities") OR (MH "Hospitals") OR (MH "Hospitals, Private+") OR (MH "Hospitals, Public+") OR (MH "Hospitals, General") OR (MH "Hospitals, Community") OR (MH "Hospitals, Teaching") OR (MH "Hospitals, Special") OR (MH "Hospitals, Urban") OR (MH "Hospitals, County") OR (MH "Hospitals, District") OR (MH "Hospitals, Federal+") OR (MH "Residential Facilities") OR (MH "Assisted Living Facilities") OR (MH "Homes for the Aged") OR (MH "Nursing Homes+") OR (MH "Physicians' Offices") OR (MH " ...	(318,538)
S11	XB ("health care setting*" or "acute care" or hospital* or "care home*" or "residential care" or telehealth or telemedicine or "acute setting*" or "nursing home*" or "gp surger*" or "primary care")	(2,025,374)
S10	(MH "Quality of Health Care") OR (MH "Outcome and Process Assessment, Health Care") OR (MH "Quality Assurance, Health Care") OR (MH "Quality Improvement") OR (MH "Quality Indicators, Health Care")	(202,259)
S9	XB (“care provision” or “care provided” or “quality of care” or “service provision” or “care quality” or "Quality Assurance" OR "Quality Improvement*" OR "Quality Indicator*")	(180,021)
S8	(MH "Developmental Disabilities")	(23,425)
S7	(MH "Intellectual Disability+") OR (MH "Persons with Intellectual Disabilities")	(112,101)
S6	(MH "Feedback")	(35,227)
S5	(MH "Surveys and Questionnaires") OR (MH "Health Care Surveys+") OR (MH "Health Surveys+") OR (MH "Patient Health Questionnaire") OR (MH "Interviews as Topic")	(1,295,520)
S4	XB (Feedback or Interview* or questionnaire* or Survey* or qualitative)	(2,236,271)
S3	XB (patient or carer or caregiver*) N2 (report* or experience* or perspective* or reflection*)	(503,869)
S2	(MH "Dementia+")	(225,001)

S1	XB dementia* or alzheimer* or "intellectual disabilit*" or "developmental disorder*”	(431,814)

Annex 6: Search strategy for PsychInfo

Search strategy conducted in PsychInfo database on 10 April 2025.

Database: APA PsycInfo <1806 to March 2025 Week 5>
Search Strategy:
1 (dementia* or alzheimer* or "intellectual disabilit*" or "developmental disorder*").ti. or (dementia* or alzheimer* or "intellectual disabilit*" or "developmental disorder*").ab. (153087)
2 exp Dementia/ (101043)
3 exp intellectual development disorder/ or developmental disabilities/ (63282)
4 1 or 2 or 3 (202306)
5 ((patient or carer or caregiver*) adj2 (report* or experience* or perspective* or reflection*)).ti. or ((patient or carer or caregiver*) adj2 (report* or experience* or perspective* or reflection*)).ab. (25586)
6 (Feedback or interview* or questionnaire* or survey* or qualitative).ti. or (Feedback or interview* or questionnaire* or survey* or qualitative).ab. (1197068)
7 exp surveys/ or questionnaires/ (44087)
8 feedback/ (23983)
9 interviews/ or interviewing/ (16913)
10 5 or 6 or 7 or 8 or 9 (1214222)
11 ("care provision" or "care provided" or "quality of care" or "service provision" or "care quality" or "quality assurance" or "quality improvement*" or "quality indicator*").ti. or ("care provision" or "care provided" or "quality of care" or "service provision" or "care quality" or "quality assurance" or "quality improvement*" or "quality indicator*").ab. (39670)
12 "quality of services"/ (8240)
13 quality control/ or "quality of care"/ (18267)
14 11 or 12 or 13 (54612)
15 ("health care setting*" or "acute care" or hospital* or "care home*" or "residential care" or telehealth or telemedicine or "acute setting*" or "nursing home*" or "gp surger*" or "primary care" or "health facilit*" or "tele health" or "tele medicine").ti. or ("health care setting*" or "acute care" or hospital* or "care home*" or "residential care" or telehealth or telemedicine or "acute setting*" or "nursing home*" or "gp surger*" or "primary care" or "health facilit*" or "tele health" or "tele medicine").ab. (255335)
16 exp treatment facilities/ (67707)
17 exp telemedicine/ (16917)
18 15 or 16 or 17 (285944)
19 4 and 10 and 14 and 18 (411)
20 child*.ti. or child*.ab. (821193)
21 19 not 20 (387)

Annex 7: Summary table of included studies

The following table is in reverse-chronological order. Information on the author(s), participants (disaggregated when possible), setting, recruitment process, data collection methodologies and methods, and key findings are included.

Reference	**Participant details**	**Setting**	**Recruitment process**	**Data collection methodology and methods**	**Key findings**
Charles, 2020 *United States*(13)	Carers (n = 10) Female = 6 Male = 4	Hospital, acute care	Advocacy organisation for individuals with I/DD	• Qualitative methodology • Face-to-face semi-structured interviews mailed to carers • Follow-up telephone calls lasted 10-15 minutes	• Mean interview = 45 min • Mean phone call = 10-15 mins • No response rate reported • *Strength:* Saturation achieved after 8 interviews • *Limitations*: Same health care facility, self-reporting and potential recall bias
Ellingsen-Dalskau et al., 2020 *Norway*(14)	FDC attendees (n = 42) RDC attendees (n = 46)	FBC (n = 10) RDC (n = 7)	FDC and RDC attendees recruited from their geographical area	• Qualitative methodology • Observation of 3 to 8 attendees per 4-hour session • Ecological momentary assessments conducted using validated, reliable Maastricht Electronic Daily Life Observation tool (MEDLO-tool)	• No response rate reported • *Strength:* Observation of activities taking place, level of engagement, physical effort, location, social interaction and mood allow for rich understanding of interactions • *Strength:* Research team worked with MEDLO-tool developers to adapt the tool to the FDC setting and pilot test conducted at one FDC and one RDC sight each • *Limitation* = lack of demographic information about participants
Helgesen et al., 2020 *Norway*(30)	PLWD (n = 33)	Long-term care residence (n = 1)	Residents diagnosed with dementia in the LTC residence, willing to participate, able to communicate and acceptable health status	• Quantitative methodology • Cross-sectional face-to-face interviews using a paper questionnaires with fixed responses • Interviews returned in a sealed envelop	• Questionnaire time = 30-90 min (mean 50 minutes) • Response rate 51.6% • *Strength:* Dementia experts conducted interviews • *Limitation:* No pilot undertaken; parts of questionnaire need revision and testing

Reference	Participant details	Setting	Recruitment process	Data collection methodology and methods	Key findings
					• *Limitations*: small sample, ~50% response rate
Ng et al., 2020 *Australia*(34)	Carers (n = 74) PLWD (n = 1)	Hospital-based rehabilitation	Patient identification from medical records	• Mixed methodology • Cross-sectional retrospective exploratory • Survey (multiple choice & open-ended questions) • Medical records cross-checked to triangulate	• No response rate reported • *Strength*: open-ended questions used to explore patient/carer satisfaction and suggestions for improvement. • *Limitation*: May be sampling bias due frailer population in hospitals (compared to communities) and participant recall bias • *Limitation*: Only one PLWD included in the study and non-English speaking patients and carers excluded • *Limitation*: Single investigator = potential for documentation bias.
Anderson & Blair, 2020 *Australia*(26)	PLWD (n = 247) Carers & families (n = 225)	Long-term care residences from not-for-profit (n = 12)	LTC residents with a diagnosis of dementia or a score that indicated a high probability of dementia	• Qualitative methodology • Observational longitudinal • Followed over three waves (baseline, 6 months and 10 months)	• No response rate reported • *Strength:* Large sample size and participation of 91.9% of family members of PLWD • *Limitation*: For-profit organisations declined participation • *Limitations:* Attrition due to death and drop-outs = reduced sample size; Awareness of observation may have altered behaviours; Potential selection bias = staff with greatest confidence in abilities may have agreed to participate
Mlinar Reljić et al., 2021 *Slovenia*(16)	Family members of PLWD (n = 12)	Long-term care residence (n = 1)	Relatives of PLWD living in the LTC home for at least 6 months contacted	• Qualitative methodology • Phenomenological hermeneutical • Individual interviews	• Interview time = 92-109 minutes (mean 96 min) • Response rate 40%

Reference	Participant details	Setting	Recruitment process	Data collection methodology and methods	Key findings
			by Head Nurse of each unit.		- *Strength:* Varying genders, age and relationship, cultural and religious backgrounds - *Limitations:* Small sample size, only one interview conducted - *Limitation*: Potential selection bias - voluntary participation of family members
Scheibe et al., 2021 *Germany*(18)	PLWD (n = 12) Female = 8 Male = 4	Telehealth	Participants identified and provided information from general practitioners	- Qualitative methodology - Formative evaluation - Individual face-to-face interviews in people's homes - Interviews based on the same guideline	- Interview time = 17 to 75 min (mean 42 min) - Response rate 63% - *Limitation:* Selection bias as some patient dropped-out due to inability to use the telemonitoring app
Chenoweth & Williams, 2021 *Australia*(33)	PLWD (n = 11) Carers (n = 35)	Hospital, acute care	Participants from a pilot (PiP) study were invited to participate in follow-up interviews	- Mixed methodology - Individual semi-structured interviews conducted 14-20 days post-discharge - Carers given opportunity to review interviews	- Mean interview = 50-90 min - PLWD response rate: 23% - Carer response rate: 80% - *Strength*: Pilot interview conducted to test the questionnaire - *Limitation*: Small sample size of PLWD from pilot
Giebel et al., 2021 *United Kingdom*(21)	Family of PLWD (n = 26)	Long-term care residence	Study details shared through third sector organisations (e.g. Liverpool Service User Reference Forum and the Lewy Body Society) and social media	- Qualitative methodology - Semi-structured interviews conducted by telephone or online	- Interview time = 12-59 minutes (mean = 30 min) - Over-recruitment: 30+ carers unable to participate due to limited time - *Strength*: Interview guide co-developed with current and former carers, clinicians and service providers

Reference	Participant details	Setting	Recruitment process	Data collection methodology and methods	Key findings
					• *Limitation*: Possible self-selection bias (recruitment via convenience sampling) whereby family carers wanted to share negative experiences
Nygaard et al., 2021 *Norway*(27)	PLWD (n = 35)	Long-term care residence	Manager and unit team leaders in the LTC residence	• Qualitative methodology • Unstructured in-depth individual interviews conducted in residents' rooms, in the form of an extended conversation	• No response rate reported • Interview time = 6-60 min (mean 44 min) • *Strength*: Large sample size, saturation achieved • *Limitation*: No patient groups from ethnic minorities included
Shafir et al., 2022 *United States*(9)	PLWD (n = 9) Female = 3 Male = 6 Carers (n = 31) Female = 21 Male = 10 (Active, n = 16; Bereaved, n = 15)	Specialty dementia clinic	Study coordinator contacted clinician to confirm diagnosis and called patients up to three times, leaving voice mails	• Qualitative methodology • Semi-structured interviews conducted in-person for PLWD and in-person or via telephone for carers	• PLWD interview time = 39-77 minutes (mean 56 min) • Carer interview time = 59-128 min (mean = 83 min) • Response rate: 53% • Compensation: $30 gift card • *Limitation*: Single site, homogeneous population (English-speaking, white and high-income) that may not be representative of other memory specialty centres • *Limitation*: Potential recall bias from bereaved carers
White et al., 2022 *United States*(36)	PLWD (n = 27) Female = 15 Male = 12 Carers (n = 161) Female = 139 Male = 22	Community-based care and Telehealth	Information about study shared via SAC networks and link shared through a national listserv	• Mixed methodology • Cross-sectional electronic survey, a few telephone surveys for those without computer access • Follow-up focus groups and individual interviews	• FG and II response rate: 71% • Surveys developed in collaboration with the SAC, who reviewed the surveys for readability • *Limitation*: Surveys were not tested for reliability or further validity

Reference	**Participant details**	**Setting**	**Recruitment process**	**Data collection methodology and methods**	**Key findings**
				(II) with a sub-sample of participants • Community-engaged research approach	• *Limitation*: Convenience sampling limits generalisability of findings • *Limitation*: Results representative of persons who were comfortable using technology.
Hynes et al., 2022 *United Kingdom*(11)	Carers (n = 16)	Community-based care	The clinic sent an email to carers of PLWD who had received a cancer diagnosis in the last 2 years and registered to the practice, identified via NIHR database and Join Dementia Research	• Qualitative methodology • Cross-sectional study • Co-developed with a local patient and public involvement (PPI) group • Individual interviews were conducted in the location of carers' choosing (home, meeting room at University of Sheffield, or neutral, private location)	• Mean interview = 60 min • No response rate reported • Compensation: $15 gift voucher • No formal pilot, however concepts generated from initial interviews informed the top guide for subsequent interviews • *Strength*: Data saturation achieved • *Limitation*: Homogeneous population (white British) that may not be representative of other memory specialty centres; May reflect lack of capacity for practices serving culturally diverse populations to participate = lack of transferability of results and under-representation of minority ethnic groups
Boumans, van Boekel & Verbiest, 2022 *The Netherlands*(38)	PLWD (n = 4) Carers (n = 4)	Long-term care residences (n = 2)	Two different LTC residences selected to observe the person-centred care approaches used	• Mixed methodology • Realist evaluation multiple-case study • Desk review • Observation (two rounds) • Semi-structured interviews • One newly developed LTC and one established LTC residence selected	• Mean observation = 3.5 hours • No response rate reported • *Strengths:* Observation allowed researchers to see the interactions • *Strength*: An observation guide was developed for use during and after the observations • *Strength*: Several data collection methods used to understand how the interactions, physical environment and use of

Reference	**Participant details**	**Setting**	**Recruitment process**	**Data collection methodology and methods**	**Key findings**
					technology contribute to residents' autonomy - *Limitation*: Small sample size limits generalisability of findings - *Limitation*: Participant bias might have affected the outcome as participants may have behaved differently because they knew they were being observed
Kristiansen et al., 2022 *Denmark*(17)	Carers (n = 17) Female = 15 Male = 2	Neurology department	Ward nurses coordinated to include close relatives of PLWD or cognitive impairment	- Qualitative methodology - Explorative semi-structured interviews conducted in a quiet room next to the ward (n = 13) or by telephone (n = 4) - Open-ended questions were intended to invite participants to elaborate on their experiences	- No response rate reported - *Strength:* Interviews allowed for reflection of the situation and experience. - *Strength:* Interviewers involved the patients when possible by informing them about the carers' participation in an interview, providing carers with reassurance and peace of mind and allowed staff to care for the patients during the interview - *Limitation*: Unequal gender distribution, favouring female participants - *Limitation*: Data collected from only one neurology department
Saragosa et al., 2022 *Canada*(24)	PLWD (n = 4) Carers (n = 17)	Transitional care	Pre-existing relationships with stakeholders (e.g. clinicians, carer advocates) and organisations	- Qualitative methodology - Semi-structured interviews	- Interview time = 38-99 minutes (mean = 67 min) - No response rate reported - Saturation achieved - *Limitation*: COVID-19 restrictions limited in-person recruitment face-to-face interviews

Reference	**Participant details**	**Setting**	**Recruitment process**	**Data collection methodology and methods**	**Key findings**
Crocker et al., 2022 *United States*(32)	Neurology patients (n = 367) Female = 212 Male = 155	Neurology department	Hawai'I Pacific Neuroscience (HPN) patients who had had an in-person or video teleconference	• Quantitative methodology • Voluntary telephone survey conducted with follow-up patients	• Mean survey = 15 min • Response rate: 86% • *Limitation*: Patients significantly impacted by a loss of employment, loss of health insurance or changes to physical and mental health may not have been well represented due to non-attendance of appointments
Iyer et al., 2023 *United States*(12)	Carers (n = 30)	Tele-dementia service	Carers of older Veterans who sought tele-dementia care	• Qualitative methodology • Observational study using grounded theory • Telephone-based semi-structured interviews	• Interview time = 30-60 minutes (mean = 45 min) • Response rate: 52% • *Strength*: Data saturation achieved • *Strengths*: design, attainment of rich qualitative data, timeliness and relevant results • *Limitation*: Homogeneous sample (gender, race, spousal relationship, cohabitant status) identified by physicians which may have led to selection bias
Farrington et al., 2023 *England*(35)	PLWD (n = 2) Female = 1 Male = 1 Carers (n = 7) Female = 5 Male = 2 Staff (n = 20)	Outpatient oncology departments of two teaching hospitals	Clinical teams of dementia patients receiving radiotherapy, or systemic anticancer therapy, or completed treatment within 6 months.	• Mixed methodology • Observation, semi-structured interviews and examination of patient case notes	• Interview time = 10-42 minutes (mean = 26 min) • No response rate reported • The field researchers internalized the research aims for the data collection period, and interpretation and understanding continued outside the assigned research period • *Limitation:* Small sample of patient interviews. Mitigation measure:

Reference	Participant details	Setting	Recruitment process	Data collection methodology and methods	Key findings
					inclusion of alternative data collection methods • *Limitation*: Study suspended during first wave of COVID-19; observations not possible due to restrictions. Study protocol adapted to allow telephone contact and interviews
Sutton et al., 2023 *United Kingdom*(25)	PLWD (n = 2) Carers (n = 19)	Hospitals, acute care	Experts in dementia care identified sites. Participants identified through Join Dementia Research network and social media	• Qualitative methodology • Dementia strategy review • In-depth case studies and interviews, conducted by telephone and online	• Interview time = 30-90 minutes (mean = 60 min) • No response rate reported • Saturation achieved • *Strength*: Pilot conducted with PLWD and carers • *Limitation*: Small PLWD sample. Original plan to recruit via in-person visits to hospitals, local groups and dementia cafes not possible • *Limitation*: Observation originally planned but not possible due to COVID-19
Lawler et al., 2024 *Australia*(10)	Dyad of patients (n = 10) and carers (n = 9)	Hospital, geriatric rehabilitation unit	Clinical staff identified eligible participants with dementia or cognitive impairment admitted to geriatric rehab	• Qualitative methodology • Exploratory interpretivist design • Semi-structured interviews conducted by physiotherapists with clinical experience at bedside or a quiet room	• No response rate reported • Interpretivist view acknowledges the viewpoint of the researchers • *Strength*: Involving patients in the study to understand their reality • *Limitation:* Small number of participants from one rehab unit • *Limitation*: English speaking only, as no funding for an interpreter
Zou et al., 2024 *China*(28)	PLWD (n = 213) Female = 96	Community-based care	Home-based patients (and carers) attending	• Quantitative methodology • Cross-sectional design	• Questionnaire time = 20-30 minutes (mean = 25 min) • No response rate reported

Reference	Participant details	Setting	Recruitment process	Data collection methodology and methods	Key findings
	Male = 117 Carers (n = 213) Female = 138 Male = 75		three tertiary hospitals in Wuhan, Xiangyang and Yichang were included.	• Anonymous paper questionnaires distributed and collected on the spot • Illiterate respondents received assistance from investigators (Q&A)	• *Limitation*: Results not generalizable given that data only collected in three hospitals in one province • *Limitation:* Cross-sectional design limits causal inferences. • *Limitation*: Potential for self-reported bias due to participants' subjective interpretations and tendency to respond in socially desirable way
Curto Romeu et al., 2024 *Spain*(15)	Carers (n = 12) Female = 8 Male = 4	Community-based care	Caregivers identified from electronic health records	• Qualitative methodology • Part of larger three-phase mixed-methods project • Focus groups (n = 3) • Participants contacted by telephone • Held in a room at PHC centre led by qualitative researcher, with second researcher focused on dementia care observing and taking notes	• FGD time = 60-70 minutes (mean = 65 min) • Response rate: 60% • *Strengths*: Triangulation performed by two researchers separately • *Limitation:* Possible self-selection bias as motivations to participate in the study (or not) are unknown • *Limitations*: Generalisability of findings as study conducted at only one community PHC service in Montsià, a rural region of Catalonia
Wollney et al., 2024 *United States*(37)	Dyads (n = 50) PLWLBD and carers Female = 42 Male = 8	End-of-life care	Identified through LBD Lewy Body Dementia Research Centre, Trial Match clinicaltrials.gov, Alzheimer's Association, the Fox Trial Finder, carer newsletters, support groups,	• Mixed methodology • Observation, longitudinal • Semi-structured interviews • Virtual visits completed by phone or video conferencing • Post-death visits completed ~3 months after death	• Mean interview scheduled for up to 30 min • No response rate reported • Data saturation achieved • *Strength*: Mixed methods which included dyad of patients with and without specialty DLB care and triangulation of data sources • *Limitation*: Cohort lacked racial and ethnic diversity, which limits

Reference	Participant details	Setting	Recruitment process	Data collection methodology and methods	Key findings
			unaffiliated neurologists		generalisability to other cultures and backgrounds
Takao et al., 2024 *Japan*(29)	Carers (n = 80)	Hospice and palliative care	Bereaved family members contacted by mail by participating institutions	• Quantitative methodology • Cross-sectional • Paper questionnaires sent by mail to bereaved carers • Shortened Good Death Inventory (GDI) version used	• No response rate reported • *Strength*: Reliability and validity of GDI-short version well established • *Strength*: Pilot test questionnaire conducted • *Limitations*: Retrospective design may have resulted in recall bias • *Limitations:* Participants recruited only from hospice and palliative care, results are not generalizable to other settings
Paananen, Kulmala & Pirhonen, 2024 *Finland*(20)	Carers (n = 19)	Long-term care residence	Family members of LTC PLWD recruited via COVID-19-related survey	• Qualitative methodology • Telephone interviews, later anonymised	• Interview time = 16-88 minutes (mean = 52 min) • No response rate reported • *Limitation*: Face-to-face interviews had to be avoided due to COVID-19 • *Limitation:* Original survey only in Finnish – family members from linguistic and ethnic minorities not reached
Aspö et al., 2024 *Sweden*(22)	PLWD (n = 15) Female = 8 Male = 7	Outpatient specialty clinic	Sub-sample of 'Medical Communication at Memory Clinics' (MedKom) project participants	• Qualitative methodology • Semi-structured telephone interviews (n = 3)	• No response rate reported • *Strength*: Interviews conducted at three points in time reduce potential temporal bias from retrospective recall • *Strength*: Data saturation achieved • *Limitation*: English or Swedish speakers only
Gibson et al., 2024 *Australia*(23)	PLWD (n = 5) Female = 2 Male = 3 Carers (n = 6)	Primary care (general practitioner)	Local dementia support groups in Geelong and Ballarat	• Qualitative methodology • Semi-structured interviews conducted in	• Interview time = 34-49 minutes (mean 40 min) • No response rate reported • Compensation: AU$50 gift card

Reference	Participant details	Setting	Recruitment process	Data collection methodology and methods	Key findings
	Female = 5 Male = 1			the participants' homes, as a dyad or individual	- *Strength:* Interview guide sent to the participants in advance to consider questions and recommendations - *Limitation:* Small sample size likely not representative of all PLWD and carers - *Limitation:* All participants from one regional town and likely not transferable to other settings
Greyson et al., 2025 *United States*(19)	Carers (n = 21) Female = 15 Male = 6	Transitional care (hospital to home)	Screening via email referrals and clinical notes in medical charts	- Qualitative methodology - Two-stage human-factors-engineering-informed Systems Ambiguity Framework (SAF) guided data collection - Semi-structured interviews staged four weeks apart conducted in person (n = 2) and by telephone (n = 19) - Second interviews conducted by telephone due to COVID-19	- Response rate: 31% - *Strength:* Interviews conducted in the carer's primary language (English or Spanish) - *Strength:* Identification of overarching collective experiences of stigma, language differences and minoritisation - *Limitation*: Only one third of eligible participants were included, lack of participation due to difficulty in being reached, declining participation, loss to follow-up
Ansari et al., 2025 *India*(31)	PLWD (n = 15)	Telehealth	Previous patients through the Department of Neurology, National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru	- Quantitative methodology - Cross-sectional prospective design - Questionnaires on patient satisfaction using Telemedicine Satisfaction Questionnaire (TSQ)	- Mean teleconsultation = 43.5 min - No response rate reported - *Strength:* Use of a validated 15-item questionnaire rated on a 5-point Likert scale - *Limitation:* Potential selection bias due to non-randomised selection

Reference	**Participant details**	**Setting**	**Recruitment process**	**Data collection methodology and methods**	**Key findings**
					- *Limitation:* Small sample size for quantitative analysis limits generalisability - *Limitations*: Cross-sectional nature of study limits causal inferences or long-term outcomes of teleconsultation
Yoshimura et al., 2025 *Japan*(39)	PLWD (n = 31) Female = 18 Male = 13 Dyads (n = 49)	Rehabilitation centre	Patients registered at a physio-cognitive rehabilitation centre invited to participate	- Mixed methodology - Cross-sectional observation design - Questionnaire	- Mean survey = 35 min - PLWD response rate = 44% - *Strength*: Pilot study conducted with 10 PLWD, with adjustments made to font size, layout and highlight of key points - *Strength*: Many responses from PLWD aligned with those of family carers, suggesting low recall bias - *Strength/limitation*: Questionnaire designed to be self-administered, but in-person assistance provided for those needing support which may have influenced response - *Limitation*: Convenience sampling limits generalisability, as those with severe dementia not included and may be underrepresented

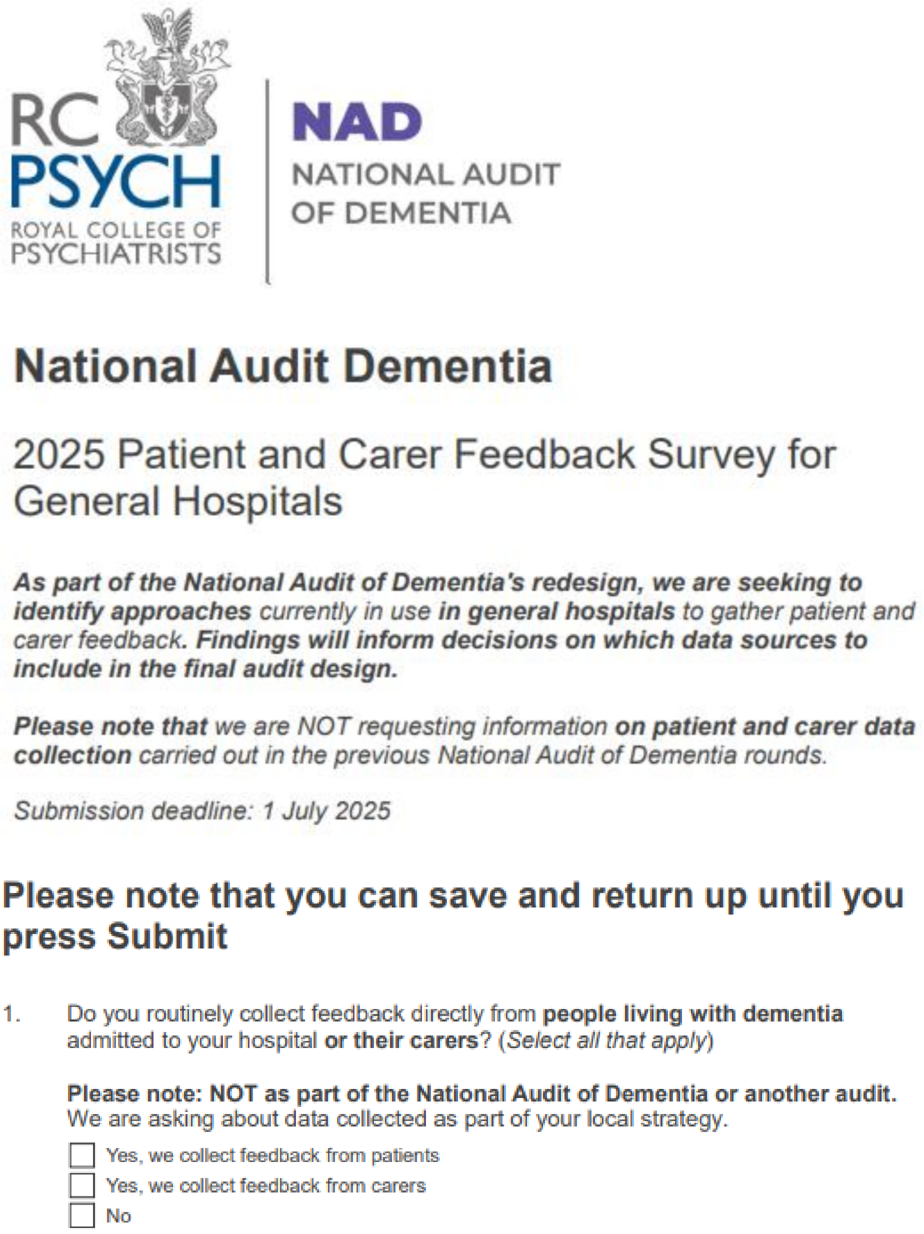
Annex 8: Summary table of other resources

The following table is in reverse-chronological order. Information on the author(s), participants (disaggregated when possible), setting, recruitment process, data collection methodologies and methods, and key findings are included.

Reference	**Participant details**	**Setting**	**Recruitment process**	**Data collection methodologies and methods**	**Key findings**
Alzheimer's Society, 2020 *United Kingdom*	*Interviews* PLWD (n = 4) Carers (n = 8) Health care professionals (n = 17) *Focus groups* PLDW & Carers (n = 75, not disaggregated)	Multi-support settings, including community, inpatient hospital, LTC	External agency commissioned to support research, approaching 31 services to identify professionals, PLWD and carers for interviews	• Mixed methodology • Focus groups (n = 9) • Interviews • Data collection methods changed due to COVID-19 restrictions	• No response rate reported • Small interview sample size for PLWD and carers • The report mixes feedback from patients, carers and professionals • *Strengths*: Rich qualitative responses on diagnosing, supporting, living and dying well
Healthwatch Cornwall, 2023 *England*	Carers (n = 148)	Unclear	Co-production supported by Wadebridge Carers Group via the Memory Cafe Network	• Mixed methodology • Survey (n = 148) • FGD (n = 21) • Interviews (n = 15)	• No response rate reported • *Strength:* Good county sample • *Strength:* Report informed by a carers survey (n = 325)
Walnut Unlimited, 2024 *England, Wales, Northern Ireland*	Patients (n = 76) Carers (n = 691) Know someone living with dementia (n = 2,709)	Unclear	Unclear recruitment strategy 3,476 participants: • 2,800 England • 400 Wales • 276 N. Ireland	• Quantitative methodology • Online survey of 10-12 key questions, excluding demographic questions	• No response rate reported • *Strength:* Large sample size • *Strength*: Working group including PLWD involved in questionnaire development and research report • *Strength:* Survey available in English and Welsh, with option to complete via telephone • *Strength:* Sub-group analysis included in the report, including stage of dementia, disability and ethnicity

Annex 9: Patient and carer feedback survey for general hospitals

NAD's survey questionnaire for acute general hospital staff.



RC PSYCH ROYAL COLLEGE OF PSYCHIATRISTS

NAD NATIONAL AUDIT OF DEMENTIA

National Audit Dementia

2025 Patient and Carer Feedback Survey for General Hospitals

As part of the National Audit of Dementia's redesign, we are seeking to identify approaches** currently in use **in general hospitals** to gather patient and carer feedback. **Findings will inform decisions on which data sources to include in the final audit design.

***Please note that** we are NOT requesting information **on patient and carer data collection** carried out in the previous National Audit of Dementia rounds.*

Submission deadline: 1 July 2025

Please note that you can save and return up until you press Submit

1. Do you routinely collect feedback directly from **people living with dementia** admitted to your hospital **or their carers**? (*Select all that apply*)

   Please note: NOT as part of the National Audit of Dementia or another audit. We are asking about data collected as part of your local strategy.

   ☐ Yes, we collect feedback from patients
   ☐ Yes, we collect feedback from carers
   ☐ No

Any additional comments:

Not Collecting Feedback

2. What is the reason that you do not collect feedback from **people living with dementia or carers**?

☐ Never attempted
☐ Low response rate
☐ Staff overstretched
☐ No funding to support the preferred data collection method
☐ Other

Other, please specify the reason below:

Patient Feedback

3. What method(s) do you currently use to collect feedback from patients?

☐ We use only *the NAD's Patient questionnaire*
☐ We use only *The Friends and Family Test (FFT) adapted for people living with dementia*
☐ We use both the *NAD's Patient questionnaire* and *the FFT*
☐ We use another method
☐ We use another method in combination with *NAD's Patient questionnaire*
☐ We use another method in combination with *the FFT*

4. What other method do you currently use to collect feedback from patients?

☐ Another general feedback form or questionnaire (i.e. used for all inpatients), on which people with dementia can identify themselves
☐ Another form or questionnaire specifically for people living with dementia
☐ Invitation to semi-structured interview, face to face or by telephone
☐ Other

Other, please describe in as much detail as possible:

Please note: For all the following questions, we are only asking for the "other methods" you use to collect patients' feedbacks. We are NOT asking for how you used the NAD's patient questionnaire or the FFT.

5. When do you collect patient feedback? (*Select all that apply*)

☐ At admission
☐ While admitted (during hospital stay)
☐ At discharge
☐ Post discharge

6. Can you provide details on why do you collect feedback at this/these time point(s)?

7. Can you estimate your usual response rate per month/per quarter/per year?

Estimated response rate is the number of individuals that responded to the request divided by the total number of individuals invited to participate

☐ Yes, per month
☐ Yes, per quarter
☐ Yes, per year
☐ No

Please provide the estimated response rate per month:

Please provide the estimated response rate per quarter:

Please provide the estimated response rate per year:

Please comment on reasons why you cannot provide estimated response rates:

8. Can you provide an example of how feedback has been used to improve the patient care experience in your hospital

9. How do you compile and analyse your patient feedback?

☐ Responses are to questions on a form which are yes/no or have a scale of responses and are analysed using Excel or a statistical programme
☐ Responses are to interview or comment box and are thematically analysed
☐ Both statistical and thematic analysis
☐ Other

Other, please specify the details:

10. Who collects the data?

☐ Staff employed by the hospital
☐ Volunteers on behalf of the hospital, under supervision of hospital staff
☐ Volunteers on behalf of a separate organisation (e.g. charity such as Alzheimer's Society)
☐ Data collection is delegated to a separate organisation

Please provide the details of what organisation is collecting data:

11. How long have you been collecting this feedback from patients?

☐ More than 2 years
☐ 1 – 2 years
☐ Less than 1 year
☐ Other

Other, please specify how long:

Carer Feedback

12. What method(s) do you currently use to collect feedback from carers?

☐ We use only *the NAD's Carer questionnaire*
☐ We use only *The Friends and Family Test (FFT) adapted for people living with dementia*
☐ We use both the *NAD's Carer questionnaire* and *the FFT*
☐ We use another method
☐ We use another method in combination with *NAD's Carer questionnaire*
☐ We use another method in combination with *the FFT*

13. What other method do you currently use to collect feedback from carers?

☐ Another general feedback form or questionnaire (i.e. used for all inpatients), on which carers of people with dementia can identify themselves
☐ Another form or questionnaire specifically for carers of people with dementia
☐ Invitation to semi-structured interview, face to face or by telephone
☐ Other

Other, please describe in as much detail as possible:

14. When do you collect carer feedback? (*Select all that apply*)

☐ At admission
☐ While the patient is in hospital care
☐ At discharge
☐ Post discharge

15. Can you provide details on why do you collect carer feedback at this/these time point(s)?

16. Can you estimate your usual response rate per month/per quarter/per year?

Estimated response rate is the number of individuals that responded to the request divided by the total number of individuals invited to participate

☐ Yes, per month
☐ Yes, per quarter
☐ Yes, per year
☐ No

Please provide the estimated response rate per month:

Please provide the estimated response rate per quarter:

Please provide the estimated response rate per year:

Please comment on reasons why you cannot provide estimated response rates:

17. Can you provide an example of how feedback has been used to improve the patient care experience in your hospital

18. How do you compile and analyse your carer feedback?

☐ Responses are to questions on a form which are yes/ no or have a scale of responses and are analysed using Excel or a statistical programme
☐ Responses are to interview or comment box and are thematically analysed
☐ Both statistical and thematic analysis
☐ Other

Other, please specify the details:

19. Who collects the data?

☐ Staff employed by the hospital
☐ Volunteers on behalf of the hospital, under supervision of hospital staff
☐ Volunteers on behalf of a separate organisation (e.g. charity such as Alzheimer's Society)
☐ Data collection is delegated to a separate organisation

Please provide the details of what organisation is collecting data:

20. How long have you been collecting this feedback from carers?

☐ More than 2 years
☐ 1 – 2 years
☐ Less than 1 year
☐ Other

Other, please specify how long:

21. Are you able to share any reports that use patient and/or carer data with us (please email reports or links to NAD@rcpsych.ac.uk)

Please note: NOT reports produced by the National Audit of Dementia

☐ Yes
☐ No

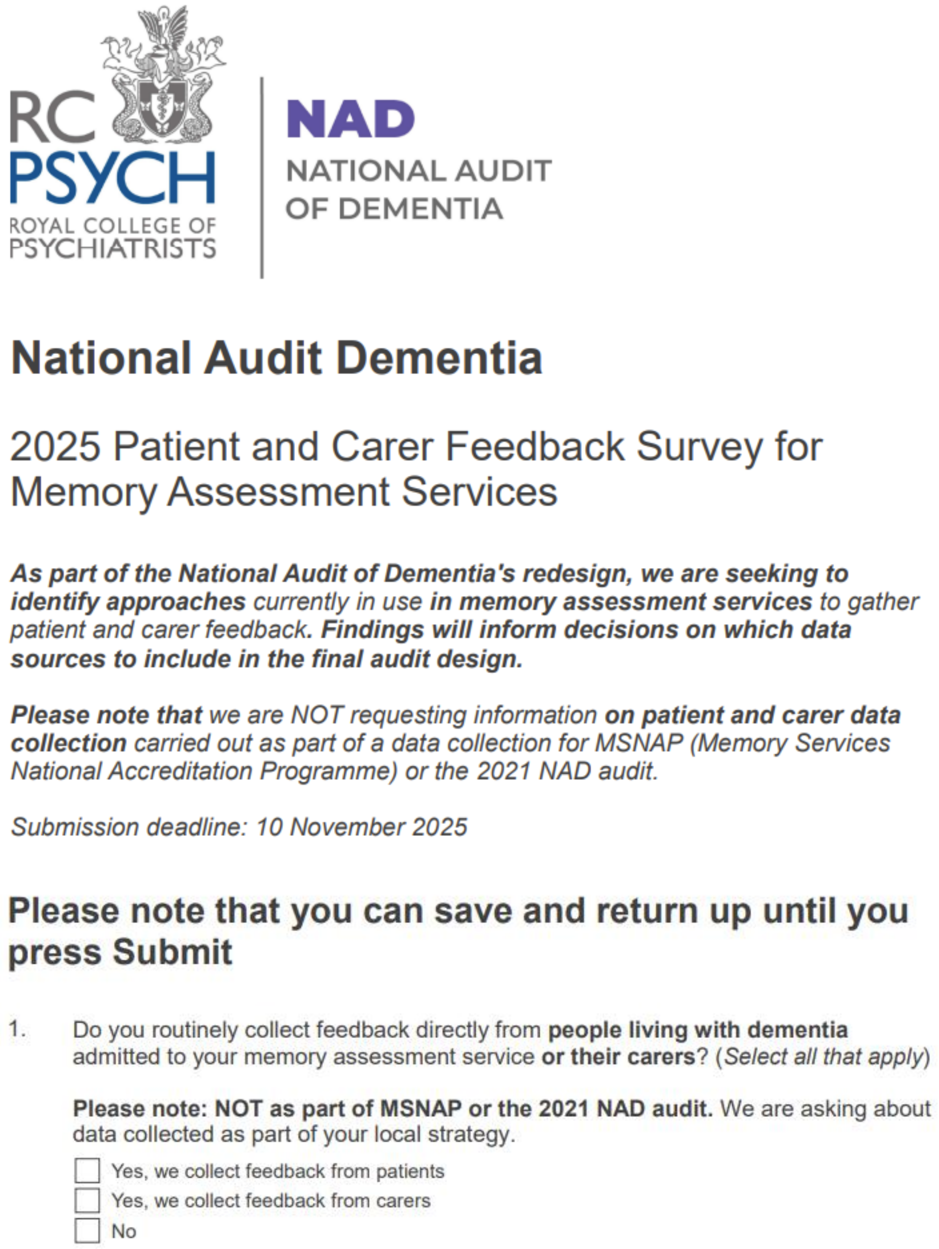
22. Please provide your contact details if you would be willing to be contacted for a follow-up or interview, if needed

Please press **SUBMIT** when you have completed the survey.

Thank you - your participation is much appreciated.

Annex 10: Patient and carer feedback survey for memory assessment services

NAD's survey questionnaire for dementia diagnostic service (memory assessment) staff.



National Audit Dementia

2025 Patient and Carer Feedback Survey for Memory Assessment Services

As part of the National Audit of Dementia's redesign, we are seeking to identify approaches *currently in use* ***in memory assessment services*** *to gather patient and carer feedback.* ***Findings will inform decisions on which data sources to include in the final audit design.***

Please note that *we are NOT requesting information* ***on patient and carer data collection*** *carried out as part of a data collection for MSNAP (Memory Services National Accreditation Programme) or the 2021 NAD audit.*

Submission deadline: 10 November 2025

Please note that you can save and return up until you press Submit

1. Do you routinely collect feedback directly from **people living with dementia** admitted to your memory assessment service **or their carers**? (*Select all that apply*)

   Please note: NOT as part of MSNAP or the 2021 NAD audit. We are asking about data collected as part of your local strategy.

   ☐ Yes, we collect feedback from patients
   ☐ Yes, we collect feedback from carers
   ☐ No

Any additional comments:

Not Collecting Feedback

2. What is the reason that you do not collect feedback from **people living with dementia or carers**?

☐ Never attempted
☐ Low response rate
☐ Staff overstretched
☐ No funding to support the preferred data collection method
☐ Other

Other, please specify the reason below:

Patient Feedback

3. What method(s) do you currently use to collect feedback from patients?

☐ We use only *The Friends and Family Test (FFT) adapted for people living with dementia*
☐ We use another method
☐ We use another method in combination with *the FFT*

4. What other method do you currently use to collect feedback from patients?

☐ Another general feedback form or questionnaire (i.e. used for all patients), on which people with dementia can identify themselves
☐ Another form or questionnaire specifically for people living with dementia
☐ Invitation to semi-structured interview, face to face or by telephone
☐ Other

Please describe in as much detail as possible:

Please note: For all the following questions, we are only asking for the "other methods" you use to collect patients' feedback.

5. When do you collect patient feedback? (*Select all that apply*)

☐ Pre-consultation
☐ During consultation
☐ Post-consultation

6. Please provide details on why you collect feedback at this/these time point(s)?

7. Can you estimate your usual response rate per month/per quarter/per year?

Estimated response rate is the number of individuals that responded to the request divided by the total number of individuals invited to participate

☐ Yes, per month
☐ Yes, per quarter
☐ Yes, per year
☐ No

Please provide the estimated response rate per month:

Please provide the estimated response rate per quarter:

Please provide the estimated response rate per year:

Please comment on reasons why you cannot provide estimated response rates:

8. Can you provide an example of how feedback has been used to improve the patient care experience in your service?

9. How do you compile and analyse your patient feedback?

☐ Responses are to questions on a form which are yes/no or have a scale of responses and are analysed using Excel or a statistical programme
☐ Responses are to interview or comment box and are thematically analysed
☐ Both statistical and thematic analysis
☐ Other

Other, please specify the details:

10. Who collects the data from patients?

☐ Staff employed by the service
☐ Volunteers on behalf of the service, under supervision of service staff
☐ Volunteers on behalf of a separate organisation (e.g. charity such as Alzheimer's Society)
☐ Data collection is delegated to a separate organisation

Please provide the details of what organisation is collecting data:

11. How long have you been collecting this feedback from patients?

☐ More than 2 years
☐ 1 – 2 years
☐ Less than 1 year
☐ Other

Other, please specify how long:

Carer Feedback

12. What method(s) do you currently use to collect feedback from carers?

☐ We use only *The Friends and Family Test (FFT) adapted for people living with dementia*
☐ We use another method
☐ We use another method in combination with *the FFT*

13. What other method do you currently use to collect feedback from carers?

☐ Another general feedback form or questionnaire (i.e. used for all patients), on which carers of people with dementia can identify themselves
☐ Another form or questionnaire specifically for carers of people with dementia
☐ Invitation to semi-structured interview, face to face or by telephone
☐ Other

Other, please describe in as much detail as possible:

14. When do you collect carer feedback? (*Select all that apply*)

☐ Pre-consultation
☐ During consultation
☐ Post-consultation

15. Please provide details on why you collect carer feedback at this/these time point(s)?

16. Can you estimate your usual response rate per month/per quarter/per year?

Estimated response rate is the number of individuals that responded to the request divided by the total number of individuals invited to participate

☐ Yes, per month
☐ Yes, per quarter
☐ Yes, per year
☐ No

Please comment on reasons why you cannot provide estimated response rates:

Please provide the estimated response rate per month:

Please provide the estimated response rate per quarter:

Please provide the estimated response rate per year:

17. Can you provide an example of how feedback has been used to improve the patient care experience in your service?

18. How do you compile and analyse your carer feedback?

☐ Responses are to questions on a form which are yes/ no or have a scale of responses and are analysed using Excel or a statistical programme
☐ Responses are to interview or comment box and are thematically analysed
☐ Both statistical and thematic analysis
☐ Other

Other, please specify the details:

19. Who collects the data from carers?

☐ Staff employed by the service
☐ Volunteers on behalf of the service, under supervision of service staff
☐ Volunteers on behalf of a separate organisation (e.g. charity such as Alzheimer's Society)
☐ Data collection is delegated to a separate organisation

Please provide the details of what organisation is collecting data:

20. How long have you been collecting this feedback from carers?

☐ More than 2 years
☐ 1 – 2 years
☐ Less than 1 year
☐ Other

Other, please specify how long:

21. Are you able to share any reports that use patient and/or carer data with us (please email reports or links to NAD@rcpsych.ac.uk)

Please note: NOT reports produced by the National Audit of Dementia or as part of MSNAP

☐ Yes
☐ No

22. Please provide your contact details if you would be willing to be contacted for a follow-up or interview, if needed

Please press **SUBMIT** when you have completed the survey.

Thank you - your participation is much appreciated.

Annex 11: Survey results of collecting patient feedback in general hospitals

Acute general hospital survey results of methods of collecting patient feedback, including tool type, timing of tool implementation, frequency of data collection, response rate, duration of data collection, data collectors and method of analysis.

PATIENTS	**FFT**	**NAD**	**NADQP + FFT**	**FFT + Other**	**NADQP + Other**	**Other**	**TOTAL**
Number of hospitals implementing the tool	7	0	5	1	0	3	16
Timing of tool implementation							
While admitted	0	0	0	1	0	0	1
While admitted + discharge	0	0	1	0	0	1	2
While admitted + discharge + post-discharge	0	0	0	0	0	1	1
While admitted + post-discharge	0	0	0	0	0	1	1
Discharge	0	0	0	0	0	0	0
No response	7	0	4	0	0	0	11
Frequency of collection							
Monthly	0	0	0	1	0	0	1
Quarterly	0	0	0	0	0	0	0
Annually	0	0	0	0	0	1	1
Unable to estimate	0	0	1	0	0	2	3
No response	7	0	4	0	0	0	11
Response rate							
Monthly	-	-	-	57%	-	-	-
Quarterly	-	-	-	-	-	-	-
Annually	-	-	-	-	-	20%	-
Duration of data collection							
1 - 2 years	0	0	0	0	0	1	1
More than 2 years	0	0	1	1	0	2	4
No response	7	0	4	0	0	0	11
Data collected by							
Volunteers	0	0	0	0	0	2	2
Staff	0	0	1	1	0	1	3
No response	7	0	4	0	0	0	11
Method of analysis							
Statistical analysis of structured responses	0	0	0	1	0	2	3
Descriptive analysis of categorical survey data	0	0	1	0	0	1	2
Qualitative responses organised thematically	0	0	0	0	0	0	0
No response	7	0	4	0	0	0	11

Acute general hospital qualitative survey results of methods of collecting patient feedback, including the method of data collection, timing of data collection, reason for data collection timing and use of collected data.

Method	**Timing**	**Reason for data collection timing**	**Use of data**
Another	While admitted Discharge	Hospital is using another form or questionnaire specifically for people living with dementia. The data is collected through the admission when the carers/patient are happy to do so.	
FFT + Other	While admitted	Hospital is using another general feedback form or questionnaire (i.e. used for all inpatients), on which people with dementia can identify themselves. We collect feedback from inpatients once a month to ensure they are having a good experience and we share any concerns they may have with staff, with their consent.	At the end of the face-to-face ward visit, if a patient/carer raises any concerns about their care these are fed back to the nurse in charge or ward manager for them to deal with. Following the ward visit the ward is provided with a ward report containing the feedback and comments received during the visit - any low scores /comments which require improvements are actioned by the ward manager.
NADQP + FFT	While admitted Discharge	Admiral nurse discussions and friends and family test. To ensure people and families are receiving the best levels of appropriate services and to ensure they have resources/signposted to meet their needs on discharge.	Improved services between physical health and mental health trusts. Highlighted the need to reduce to bed moves for people with dementia and delirium. Ensured families are included in care and meetings, completion of 'This is Me', collaborative working on support plans/

Annex 12: Survey results of collecting carer feedback in general hospitals

Acute general hospital survey results of methods of collecting carer feedback, including tool type, timing of tool implementation, frequency of data collection, response rate, duration of data collection, data collectors and method of analysis.

CARERS	**FFT**	**NAD**	**NADQC + FFT**	**FFT + Other**	**NADQC + Other**	**Other**	**TOTAL**
Number of hospitals implementing the tool	4	0	4	2	1	3	14
Timing of tool implementation							
While admitted	0	0	0	1	0	0	1
While admitted + discharge	0	0	0	0	0	1	1
While admitted + discharge + post-discharge	0	0	0	0	0	0	0
While admitted + post-discharge	0	0	0	0	0	1	1
Discharge	0	0	0	0	0	0	0
No response	4	0	4	1	1	1	11
Frequency of collection							
Monthly	0	0	0	1	1	0	2
Quarterly	0	0	0	0	0	1	1
Annually	0	0	0	0	0	1	1
Unable to estimate	0	0	0	1	0	1	2
No response	4	0	4	0	0	0	8
Response rate							
Monthly	-	-	-	-	-	-	-
Quarterly	-	-	-	8%	-	10%	-
Annually	-	-	-	-	-	-	-
Duration of data collection							
1 - 2 years	0	0	0	0	0	0	0
More than 2 years	0	0	0	0	0	0	0
No response	4	0	4	2	1	3	14
Data collected by							
Volunteers	0	0	0	0	0	2	2
Staff	0	0	0	2	1	1	4
No response	4	0	4	0	0	0	8
Method of analysis							
Statistical analysis of structured responses	0	0	0	1	0	1	2
Descriptive analysis of categorical survey data	0	0	0	0	0	2	2
Qualitative responses organised thematically	0	0	0	1	1	0	2
No response	4	0	4	0	0	0	8

Acute general hospital qualitative survey results of methods of collecting carer feedback, including the method of data collection, timing of data collection, reason for data collection timing and use of collected data.

Method	**Timing**	**Reason for data collection timing**	**Use of data**
NADQC + Other	While admitted Post discharge	The hospital is using another form or questionnaire specifically for carers of people with dementia. To encourage carers to complete the form by providing them the flexibility when to complete questionnaire.	Discussing complaints with department seniors and sharing complaints and trends in meetings such as steering group. Positive also shared in order to continue good practices.
Another	While admitted	The hospital is using another general feedback form or questionnaire (i.e. used for all inpatients), on which carers of people with dementia can identify themselves, as well as a form or questionnaire specifically for carers of people with dementia. The feedback we collect from Carers is a tool that will help the Dementia Care team enhance the experience of the patients with dementia whilst under our care, and it is designed to support the Carers/NOK/Family on admission, during the stay in the hospital and upon discharge of the patient. Based on the feedback that will be gathered, we can then gauge the quick wins and the area that needs improvement.	Based on the feedback, Carers were not involved on the treatment and discharge planning until on the day of discharge, or only because they asked. According to the feedback, the patient was admitted more than 48hrs, but they have not seen any Consultant, so we promote the Family clinic where family can have a meeting with the Consultant. Identified suitable dementia friendly cubicle for families of patients with dementia, who would like to stay as they are medically unstable or deteriorating.
FFT + Other	While admitted	The hospital is using another form or questionnaire specifically for carers of people with dementia. If they (carers) raise any concerns they can be dealt with whilst their loved is an inpatient - this will improve the carers and their loved one's experience	

Annex 13: Survey results of collecting patient feedback in dementia diagnostic services

Dementia diagnostic (memory assessment) service survey results of methods of collecting patient feedback, other methods, including tool type, timing of tool implementation, frequency of data collection, response rate, duration of data collection, data collectors, method of analysis, and organisations collecting patient feedback.

PATIENTS	**Adapted FFT**	**Another method**	**FFT + Another**	**TOTAL**
Number of memory assessment services implementing the tool	14	21	17	52
Other methods used to collect patient feedback				
Another general feedback form or questionnaire (i.e. used for all patients), on which PLWD can identify themselves	0	11	8	19
Another form or questionnaire specifically for people living with dementia	0	1	4	5
Invitation to semi-structured interview, face to face or by telephone	0	0	1	1
Other*	0	9	4**	13
Timing of data collection				
Pre + During + Post consultation	4	1	3	8
Pre-consultation + post-consultation	1	0	2	3
During consultation + post-consultation	1	8	6	15
Post-consultation	8	12	6	26
Frequency of collection				
Monthly	8	10	10	28
Quarterly	2	0	1	3
Annually	0	1	3	4
Unable to estimate	4	0	3	7
No response	0	10	0	10
Duration of data collection				
1 - 2 years	2	1	1	4
More than 2 years	0	3	0	3
No response	12	15	16	43
Other	0	2	0	2
Data collected by				
Volunteers	2	0	0	2
Staff	11	14	15	40
Organisation	1	7	2	10
Method of analysis				
Statistical analysis of structured responses	3	4	4	11
Thematic analysis of qualitative responses	1	5	3	9

Both statistical and thematic	8	5	9	22
Other	2	7	1	10
Organisations collecting patient feedback				
NHS Care Opinion	0	1	0	1
Envoy	1	0	0	1
I want great care	0	4	1	5
IQVIA	0	0	1	1
Trust-wide	0	2	0	2

*”Other” methods were noted as “Another method”: Care opinion (n = 3), “I want great care” survey (n = 2), Trust feedback form (n = 2), FFT not adapted to PLWD (n = 1).

**“Other” methods of collecting carer feedback noted as “FFTs + Another method”:

1. *PALS compliments and complaints. You said we did feedback letter box in reception area.*
2. *Every month we ring 3 patients at random who have had an intervention from us in last 4 weeks*
3. *We use FFT method which does include additional questions such as asking the patient whether they felt involved in their care, listened to and treated with dignity and respect. We also receive feedback about our services through letters, thank you cards, compliments/complaints.*
4. *We have Lived Experience Consultants with Dementia who provide structured and formal feedback on our paperwork, groups and interventions. We have a QR code on all correspondence to link to electronic version.*

Dementia diagnostic service qualitative survey results of methods of collecting patient feedback, including the method of data collection, timing of data collection, reason for data collection timing and use of collected data.

Method	Timing	Reason for data collection timing	Use of data
Adapted FFT	During consultation + post-consultation	Better engagement from patient and carer during our involvement instead of pre involvement	We discuss the feedback in MDT and business meetings on the view to improve our service based on feedback
Adapted FFT	Post-consultation	1. It may provide a more accurate response as questions, concerns and explanation of what is `the role of the services; 2. Collecting post-consultation feedback from patients is crucial for improving care quality, enhancing patient satisfaction, and identifying areas for improvement. It provides valuable insights into the patient experience, helping healthcare providers understand what is working well and where to make adjustments to create a more patient-centred environment.; 3. Because we want to hear the patient's journey through our services.; 4. As patient has an informed view then; 5. We ask carers/patients to reflect on the service as a whole to identify any points that could be streamlined/improved; 6. To provide feedback on the consultation	1. We will endeavour to learn from feedback to improve and adapt our services; 2. We use feedback on the long waiting times for appointments to change scheduling processes, such as increasing clinic hours or creating a separate, expedited pathway for urgent referrals. For example, a clinic might learn from feedback that patients feel anxious waiting for a long time and then decide to use this feedback to introduce a telephone check-in for urgent cases to bridge the gap between referral and assessment.; 3. Improving consultation environment, location of clinics for example; 4. We do this through the MSNAP; 5. Bespoke feedback helped shape new clinic structure; 6. Our feedback generally remains positive We discuss regularly in our team meetings to uphold the current standards we have Any themes of good practice through FFT is pulled and discussed to see if this can be improved; 7. Always listening and inc family and carers; 8. Patients / Carers were reporting feeling "dumped" post diagnostic. Processes were put in place to follow-up with a phone call within a few days of diagnosis to discuss how they are feeling and answer any questions.

Adapted FFT	Pre-consultation + During consultation	1. To inform patient the steps/ stages of assessment To clarify if patient understood what has been discussed To encourage compliance and living well; 2. We offer the FFT at each change within the service i.e. at assessment, at memory team and pre-discharge.; 3. different staff and colleagues' interactions we also use a volunteer led feedback service as well as FFT; 4. we collect feedback at any part in the patient's journey as it is helpful to our service development, but we do most routinely check with patients/carers for feedback at the end of their journey with us via F&FT and we also have a comments book at some of our key bases which provides an additional forum for feedback	1. Sharing with team members; 2. Our responses are all positive and so have not been able to improve anything within the service based on the feedback.; 3. we have implemented a number of QIs / changes over the years in relation to feedback such as the information we share at the outset of acceptance, the process of ringing into the service (now have option to select to be called back rather than waiting on hold etc), YOD pathway changes, changes to how feedback is supplied. we also use the positive feedback to help us feel reassured in what we are getting right.
Adapted FFT	Pre-consultation + post-consultation	1. At initial assessment and post consultation	1. Within supervision with service providers

FFT with another method	During consultation + post-consultation	1. During consultation - at the end of attendance at the Living with Dementia Group. Post-Consultation - Provided with Care Opinion leaflet. We are also about to pilot a service evaluation feedback form in discharge letters. We did send out an annual questionnaire but we no longer have access to funding for the pre-paid postage for responses.; 2. To enable a boarder opportunity to collect feedback.; 3. We want to ensure patients always have the opportunity to provide feedback.; 4. We usually offer our feedback form following initial assessment as this meeting is usually face to face, and is given with other information We always either hand or post feedback forms to everyone who has been through our service at the point of discharge to capture those who may not have used the form at assessment (or prefer to await the outcome) All our correspondence, from the initial acknowledgement letters sent to GPs and patients to appointments, diagnosis letters and discharge letters have a QR code to enable people to feedback electronically as well as the above;	1. To make changes to the content of groups and length of sessions.; 2. We tend to do- 'You said, we did'; 3. Over the past year the service has only received 1 negative feedback. When looking at the overall feedback form we have seen that the majority of people tended to say that they had not been offered a carers assessment. Learning within the team took place to ensure that we are explaining clearly to the carer when we refer to the carers centre for assessment, that this is the carers assessment being offered.; 4. We have 'you said, we did', learning lessons.; 5. We discuss all feedback at our monthly Business Meeting and share learning and recognise the good care our staff provide One of our clinic rooms was uncomfortably cool and the chairs were uncomfortable - we contacted our Estates department and asked them to resolve, which they have done We also ask our Lived Experience Consultants (who are living with dementia) to review our interventions, such as groups and communications, such as appointment letters and give feedback We have been trialling use of yellow paper to improve readability for appointment letters - groups of people living with dementia were asked to review different colours and styles and this informed our current practice; 6. We have not had any negative feedback. Post covid patients asked for refreshments to be made available, which we reinstated when able.; 7. Service user and carer feedback has been instrumental in shaping the service. People living with dementia and carers have been involved in developments across the dementia assessment and diagnosis team and home treatment teams. Feedback received from civica is generally positive, comments will also be shared with PALS

FFT with another method	Post-consultation	1. Because before they meet with us there is not much feedback, they can give other than making comments about the length of time they are waiting or the letter they have received letting them know they are accepted on the waiting list. Having seen someone in the team they will be able to offer informed feedback.; 2. This captures information prior to the consultation, the consultation, and information given at the consultation. We did not want to bombard people with feedback forms at every stage/ contact.; 3. Because our investigations have been completed; 4. Allows patient's time to accept diagnosis from MAS and MAS feedback is gained at psychoeducation group at week 1.; 5. Feel that they have received all the services that we offer so can give a fair opinion.	1. The service has changed a couple of protocols around how we manage processes in the team as a direct result of feedback, but generally the only change that people ask for is less time waiting for an appointment, which we can't influence.; 2. We have just started a QI project looking at the information that we provide both in the appointment letter, and with it. Feedback has shown that people have not found it helpful or clear.; 3. We have developed our post diagnostic groups with input from people with dementia and their carers to improve the service and content of the groups.; 4. This has allowed us to adapt and change what we do as a service.; 5. Feedback from patients/carers after attending groups run by our service helps to mould how the groups are run and what is delivered.
FFT with another method	Pre-consultation + During consultation	1. People accessing our services are able to provide us with feedback at any point in their care.; 2. Feedback is collected during any contact with service.; 3. to assess each part of the pathway, from the initial assessment by the nurse and then their experience of their consultation and their support	1. as a team we have completed "You said, We did" and made small changes to things such as appointment letters being easier to understand. Changing doctors appointment times to reduce waiting times in clinic.

FFT with another method	Pre-consultation + post-consultation	1. We have questionnaires that are used for before and after therapeutic group interventions to measure the outcomes. We use a system called I want great care for the friends & family test for overall feedback on experience of our service.; 2. Civica questionnaire sent via automated text message after first contact with the service, which is usually pre-assessment counselling. Further feedback will be requested post assessment and/or diagnosis.	1. We adjusted the days/times/frequency/duration of our psycho-educational group based upon the feedback we had received.; 2. Service user and carer feedback has been instrumental in shaping the service. People living with dementia and carers have been involved in developments across the dementia assessment and diagnosis team and home treatment teams. Feedback received from civica is generally positive, comments will also be shared with PALS

Another	During consultation + post-consultation	1. We enquire during every 3 month consultation and at the12 month discharge for the post diagnostic support pathway.; 2. If it is relevant to do so during consultation, if not by Care Opinion form.; 3. To capture feedback throughout the diagnostic process whilst it is fresh.; 4. to ensure patients have had some experience of our service; 5. We send out questionnaires after the initial assessment and then at discharge - this is to monitor any changes in experience over time during the assessment and diagnosis process; 6. During the assessment, we offer the feedback form to carers, while the patient is completing their assessment. QR codes included on care plan letters. Forms also available freely in the waiting room.	1. We have since created additional community support ie Dementia Cafes.; 2. Feedback in team meetings.; 3. we discuss feedback in the monthly team meetings and management/clinical supervision with staff; 4. Feedback analysis has not yet commenced due to recent introduction.; 5. we have offered service/groups/info in multiple languages we have developed a better website 6. We produce a quarterly You Said We Did poster which is sent out with letters. This is a fairly new process over this financial year - examples are: One clinic location was hard to find and patients/carers often got lost - based on feedback we have produced a map outlining where to go and this is sent out with appointment letters for that area and also added to the Trust MAS website.; 7. You said we did approach - changes made to waiting room including height adjusters on chairs, clearer information and signage. Letters have been amended to include maps to help patients and carers arriving at the service for the first time.

Another	Post-consultation	1. to feedback after their experience; 2. At point of discharge from service.; 3. Trust forms ask about diagnosis process and assessments which would only be relevant after they have completed the process; 4. To capture the experience of the journey as a pose to milestones throughout the journey; 5. Because that feels the most appropriate? how could someone provide feedback prior to consultation if they have yet to use the service. During consultation there are other more pressing matters.; 6. Difficult to systematically obtain feedback in pre consultation phase and significant time constraints limit feedback during consultation process (one off appointment over 75 mins); 7. Limited time during consultations but we discuss the survey, hand over the survey with a website/QR code. A paper copy is generally sent on discharge as well.; 8. Feedback is sought regarding the assessment and engagement process, for the client, Carer and significant others.; 9. We send out questionnaires with our PDS appointment letters and again with the last appointment letter to ask patients/carers about their experience regarding the service they have received and any ideas they may have for improvement	1. due to the anonymity of the feedback system we are unable to talk to whoever has offered constructive feedback but are expected to pull out themes and make plans to improve/look into them; 2. Positive feedback given only.; 3. feedback is gathered by dementia advisor, dementia cafe and local authority services around their experiences amongst other information, this is passed on in shared care provider forums. Recent feedback received via these forums is; too many photocopies but also that electronic information is not helpful either so we do aim to give information by a variety of formats to cater for individual need.; 4. feedback is limited to a star rating which isn’t very helpful, we get better feedback from informal complaints/ compliments which we can act on if needed; 5. We have re designed our understanding dementia for carers course.; 6. Results/comments are discussed in team meetings and then plan/implement to improve if necessary and appropriate.; 7. Feedback is discussed in MDT's and talked through the aspects of improvements that can be made and then this can be fed back through the monthly locality managers meetings.; 8. The feedback has mainly always been positive

Another	Pre-consultation + During consultation	We found that when asked for feedback people focus on their last contact with the service, therefore collecting at multiple time points allows people to provide timely feedback throughout their journey through the diagnostic pathway	Providing clear rationale and justification for service development - focus on improving diagnostic wait times, improving communication / letter writing throughout the diagnostic pathway

Annex 14: Survey results of collecting carer feedback in dementia diagnostic services

Dementia diagnostic (memory assessment) service survey results of methods of collecting carer feedback, including tool type, other methods, timing of tool implementation, frequency of data collection, response rate, duration of data collection, data collectors, method of analysis, and organisations collecting carer feedback.

CARERS	**Adapted FFT**	**Another method**	**FFT + Another**	**TOTAL**
Number of memory assessment services implementing the tool	10	17	17	44
Other methods used to collect carer feedback				
Another general feedback form or questionnaire (i.e. used for all patients), on which carers of people with dementia can identify themselves	0	10	6	16
Another form or questionnaire specifically for carers of people living with dementia	0	0	4	4
Invitation to semi-structured interview, face to face or by telephone	0	0	2	2
Other	0	7*	5**	12
Timing of data collection				
Pre + During + Post consultation	2	2	5	9
Pre-consultation + post-consultation	1	0	2	3
During consultation + post-consultation	1	6	5	12
Post-consultation	6	9	5	20
Frequency of collection				
Monthly	8	9	9	26
Quarterly	1	0	2	3
Annually	0	0	1	1
Unable to estimate	1	8	5	14
Duration of data collection				
Less than 1 year	0	3	0	3
1 - 2 years	1	1	2	4
More than 2 years	9	12	15	36
Other	0	1	0	1
Data collected by				
Volunteers	1	0	1	2
Staff	8	12	14	34
Organisation	1	5	2	8
Method of analysis				
Statistical analysis of structured responses	3	3	3	9
Thematic analysis of qualitative responses	2	4	2	8
Both statistical and thematic	3	4	11	18
Other	2	6	1	9

Organisations collecting patient feedback				
NHS - Care Opinion	0	1	0	1
Envoy	1	0	0	1
I want great care	0	2	0	2
IQVIA	0	0	1	1
Trust-wide	0	1	0	1
Other	0	0	1	1

* “Other” methods of collecting carer feedback noted as “Another method”: Care Opinion (n = 3), Trust feedback form (n = 2), FFT not adapted to PLWD (n = 1), Verbal request (n = 1).

** “Other” methods of collecting carer feedback noted as “FFTs + Another method”: Carer Opinion (n = 1), Comments book (n = 1), Verbal follow-up feedback via telephone (n = 1), comments:

1. *PALS compliments and complaints. You said we did feedback letter box in reception area.*
2. *The feedback form is for both patients and family/carers to respond to. (One feedback form)*
3. *We use FFT method which does include additional questions such as asking the carer whether they felt involved in their loved ones care, listened to and treated with dignity and respect. We also receive feedback about our services through letters, thank you cards, compliments/complaints.*

Dementia diagnostic service qualitative survey results of methods of collecting carer feedback, including the method of data collection, timing of data collection, reason for data collection timing and use of collected data.

Method	**Timing**	**Reason for data collection timing**	**Use of data**
Adapted FFT	Post-consultation	1. It may provide a more accurate response as questions , concerns and explanation of what is the role of the services; 2. Memory assessment services collect feedback from carers to improve the quality of care, help families make informed choices about the diagnostic process, and ensure that support plans are personalized to meet their needs. This feedback is crucial for identifying problems, improving communication, and ensuring that both the person with dementia and their carer receive the necessary support and resources after a diagnosis.; 3. to evaluate the whole experience in MAS;	1. Carers may be in need of their own support, which can be identified through the assessment process and feedback. This can include respite care, financial help, or mental and physical wellbeing support.; 2. Bespoke feedback helped shape new clinic structure; 3. To ensure that we are meeting the needs for the patients, we strongly believe in the team that the service should fit to the needs of the patient rather than the patient fitting to the needs of the service.;
Adapted FFT	Pre-consultation + During consultation	1. To inform patient the steps/ stages of assessment To clarify if patient understood what has been discussed To encourage compliance and living well	1. Sharing with team members

FFT with another method	During consultation + post-consultation	1. If it is relevant to do so during consultation, if not by Care Opinion form.; 2. to ensure carers have had opportunity to sample how our service works; 3. We send out questionnaires after the initial assessment and then at discharge - this is to monitor any changes in experience over time during the assessment and diagnosis process; 4. During the assessment, we offer the feedback form to carers, while the patient is completing their assessment. QR codes included on care plan letters. Forms also available freely in the waiting room.; 5. We want to ensure carers always have the opportunity to provide feedback.; 6. To ensure the patient is happy with the process. After to ensure the patient has been happy with their full experience of our service.	1. Feedback in team meetings.; 2. Feedback analysis has not yet commenced due to recent introduction.; 3. identified lack of resource in our locality so we have developed a living well programme based on recovery college model with peer support workers; 4. We produce a quarterly You Said We Did poster which is sent out with letters. This is a fairly new process over this financial year - examples are: One clinic location was hard to find and patients/carers often got lost - based on feedback we have produced a map outlining where to go and this is sent out with appointment letters for that area and also added to the Trust MAS website.; 5. changes made in response to patient feedback also address carer concerns and experience.; 6. We tend to do- 'You said, we did'; 7. Co-produced carer leaflets.; 8. We encourage families and carers to be fully involved according to the patient's preference We respond to feedback relating to waiting times and concerns from families, often expediting assessments where clinically appropriate. A family member recently expressed worries about her husband being asked to refrain from driving, which was causing them distress and difficulty in daily life, so we expedited his assessment to support their situation Also please see above response to Q. 8 Through carrying out this exercise we plan to look at how we distribute and record numbers of feedback forms given, and monitor returns so that we can try and improve the response rate; 9. Feedback generally good.

FFT with another method	Post-consultation	1. Identify the service provided and any areas for improvement and positive experiences.; 2. Difficult to systematically obtain feedback in pre consultation phase and significant time constraints limit feedback during consultation process (one off appointment over 75 mins); 3. Feedback is sought regarding the assessment and engagement process , for the client, Carer and significant others.; 4. We are interested in the service we are providing and how this can be improved; 5. This captures information prior to the consultation, the consultation, and information given at the consultation. We did not want to bombard people with feedback forms at every stage/ contact.; 6. as above, however we have realised that the questionnaire doesn't have an option to for patient or carer and we plan to add this in now to capture this.; 7. So carers have experienced the whole service, we are looking at asking for feedback throughout the patients time with the service.	1. Not specifically as feedback is generally positive on the whole.; 2. Feedback is discussed in MDT's and talked through the aspects of improvements that can be made and then this can be fed back through the monthly locality managers meetings.; 3. It was mainly positive; 4. We have just started a QI project looking at the information that we provide both in the appointment letter, and with it. Feedback has shown that people have not found it helpful or clear.; 5. This has allowed us to adapt and change what we do as a service.; 6. Influenced the content of the carers information groups that we ran (this is now being ran by the Alzheimer's society)
FFT with another method	Pre-consultation + During consultation	1. different staff; 2. Carers can provide feedback at any time; 3. We found that when asked for feedback people focus on their last contact with the service, therefore collecting at multiple time points allows people to provide timely feedback throughout their journey through the diagnostic pathway; 4. People's carers/families are able to provide us with feedback at any point in their loved one's care.; 5. Feedback is collected during any/all contact with the service	1. to redesign the pathway and look at improvement areas; 2. Feedback on documentation used which has been reviewed and amended; 3. Providing clear rationale and justification for service development - focus on improving diagnostic wait times, improving communication / letter writing throughout the diagnostic pathway.

FFT with another method	Pre-consultation + post-consultation	Feedback request will be automated if carers details are documented on clinical systems	Service user and carer feedback has been instrumental in shaping the service. People living with dementia and carers have been involved in developments across the dementia assessment and diagnosis team and home treatment teams. Feedback received from civica is generally positive, comments will also be shared with PALS

Annex 15: Feedback from NAD's Lived Experience Advisory Group

Feedback gathered from NAD's LEAG of PLWD and carer representatives.

Timing and Stage of Dementia

- The stage of dementia may affect a person's ability to give feedback (early vs. late stage).
- Timing is important - feedback should be collected while the individual is still in the care setting, as experiences may be forgotten or distorted afterwards.
- Both groups emphasised the importance of capturing perspectives across the dementia journey, ensuring methods are inclusive of varying levels of ability.

Emotional State and Environment

- Carers may be emotionally overwhelmed (stress, fear, worry), particularly in hospital environments. This can affect their willingness to engage with feedback processes.
- Fear of jeopardising care can prevent both PLWD and carers from being honest in their feedback.
- Framing feedback as a way to help improve services can reduce reluctance and foster participation.

Method Preferences and Accessibility

- Questionnaires are a preferred method by both groups, provided they:
  - Include clear, specific and answerable questions
  - Offer open-ended sections for fuller responses
  - Allow for multiple formats (paper, online, verbal) to improve accessibility
- Technology (e.g. QR codes, tablets) can support those who struggle with writing or need more time, but usage has been low (e.g. NAD reported 10:1 paper-to-online ratio). Better guidance or facilitation may be needed.
- Interviews were noted as useful when done in clusters (e.g. several in one setting to identify themes) but also seen as generating overly positive responses and being potentially burdensome.
- Focus groups were viewed as less suitable due to timing challenges and the risk that experiences may be forgotten or carers may not have capacity to attend.

Framing, Purpose and Motivation

- There must be a clear explanation of the purpose of data collection: "What do you want to know?" and "Why does this matter?"
- Both PLWD and carers expressed the need for the process to feel worthwhile and empowering, not an additional burden.
- Making feedback feel like a positive contribution to service improvement may increase engagement.

Inclusivity, Respect and Facilitation

- Feedback mechanisms must respect the competence of PLWD: interviewers should address them first, not default to speaking with carers or hospital staff.
- Carers play a critical facilitative role and should be included in the design and implementation of feedback processes.
- Assumptions about capacity should be avoided - feedback should be designed to support participation, not limit it.

Recommendations

Based on this feedback, any feedback mechanism should:

1. Be inclusive and adaptable for different dementia stages and emotional states.
2. Prioritise timing - aim for real-time or near-time collection.
3. Use mixed mediums - paper, digital, and verbal - with support as needed.
4. Clearly communicate the purpose and impact of feedback.
5. Recognise and respect both PLWD and carers as key informants in the feedback process.