Protocol: ***Family Interventions iN Dementia Mental health Environments (FIND ME)***

This study is funded by the National Institute for Health and Care Research (NIHR), Health and Social Care Delivery Research (HSDR) programme.

Funder reference*: NIHR161439*

FIND ME

Family Interventions In Dementia
Mental Health Environments

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FUNDED BY NIHR | National Institute for Health and Care Research

Summary

This mixed methods study will provide detailed understandings of carers experiences and involvement when people living with dementia (PLWD) are detained within a Mental Health Ward (MHWs) for their own safety and the safety of others. MHWs are a significant site of care for PLWD and there are around 100 wards (80 NHS and 20 private) across the UK, however, little is known about these wards, the quality of care they provide, or PLWD and carer experiences [1-3]. We know carer involvement within MHWs can directly improve patient outcomes [4-8]. However, there are no evidence-based interventions to involve and support carers of PLWD admitted within MHWs. In response, this study will deliver new knowledge and co-design evidence-based strategies to ensure carers are appropriately supported and involved and to improve patient outcomes. **Data collection** will involve:

(1) **A national online survey** of all MHWs providing care for PLWD (approximately 100 wards). This brief (under 15 minutes) online survey will be emailed to ward managers within all NHS Trust and private providers in the UK and will deliver the first detailed description of MHWs, staffing structure, patient profiles, and current support for carers.

Qualitative methods:

We will carry out detailed qualitative research within three NHS wards, sites will be selected to reflect ageing populations with significant health and social care needs and include inner-city, coastal, rural and semi-rural areas. In these three wards we will conduct (1) interviews with carers (we will include the PLWD where possible) admitted within these wards (past and present) to understand carers needs and experiences and (2) a detailed ethnography (observation, in situ interviews, document analysis) within these wards to examine organisational cultures of care and staff perspectives on the involvement of carers:

(2) **Interviews with carers** will provide detailed understandings of carers' experiences, perspectives, and support needs across an admission, during transition, and following discharge. Where possible we will include their partner with dementia to form a dyad. Via:

- A series of narrative interviews (3 times over 12 months, total: 72 interviews) with 24 carers of people living with dementia (8 carers per ward) during an admission and following discharge (average length of stay is 100 days) to explore their changing needs and experiences over time.
- In-depth interviews with 24 carers who have been discharged within the last 3 years from these same wards (8 carers per ward) to provide insights into carers' needs post-discharge and encourage open communication and reflection, because their relative is no longer in the care of the ward.
- To support the inclusion of carers, families, and PLWD for whom communication may be difficult, either due to trauma or because of features of their dementia, we will use participatory, visual, and textual, creative methods. All participants will be offered this alternative mode of communication of experiences to support those who may not be able to or want to participate in face-to-face interviews.

(3) **Ethnographic data collection** (observation, in-situ interviews, qualitative interviews, and documentary analysis) will be carried out within the three wards over 30 days per ward (within 3 wards total: 90 days) to understand ward organisational cultures and staff perspectives This will involve:

- Observational data collection (30 days per ward) will focus on examining:
  - ward routines and practices that involve or exclude carers
  - staff understandings and recognition of carers needs
  - formal frameworks and informal rationales staff draw on to inform carer involvement or exclusion from decision making, care, and transition to discharge
- Staff perspectives will be obtained via
  - a series of short *in-situ* ethnographic interviews

    - qualitative interviews (30-60 minutes) with staff at each site (5 longer interviews per site, 3 sites = 15 interviews).
- Documentary analysis will involve reviewing templates of documents routinely shared with carers (e.g. welcome documents, information leaflets, sources of support).

Analysis: Methodological triangulation (survey, interviews, ethnography) will deliver robust findings considering both richness (interviews and ethnography) and generalisability (survey). This analysis will inform the development of service improvements:

(4) **Evidence-based co-design** will empower carers, families, PLWD, and MHW staff to collaboratively shape service improvements. We will co-create scenario-based narratives and 'trigger films' grounded in the research and use them in a series of online workshops:
  - Workshops with PLWD (n=10), carers and family (n=10), and MHW staff (n=10) will explore the 'trigger films' to identify priority issues within current practice.
  - The same groups will be invited back to workshops focussed on opportunities for change.
  - The third series of workshops will bring together PLWD (n=10), carers (n=10), and MHW staff (n=10) in mixed stakeholder online workshops (10 in each workshop).

Expert facilitators will seek consensus on the provisional model of best practice, suggested strategies and resources for wards.

(5) **We will assess the feasibility** of implementing these strategies in practice, via:
  - Online focus groups with staff (n=30 from across the UK) to assess acceptability and to what extent they can be integrated into routine practice.
  - People with lived experience, PLWD (n=30) and carers (n=30) who will be invited to share their feedback in a way that suits them (email, phone, video conferencing).

Outputs and impact:
We will translate the findings into co-designed open access resources to support MHWs in involving carers, in accessible formats (films, podcasts, downloadable documents, and audiobooks), disseminated to all MHW via our study website, community of practice, professional bodies, and to carers in collaboration with Dementia UK, John's Campaign and TiDE.

Background

Mental Health Wards

Mental health wards (MHW) are a significant site of care for people living with dementia (PLWD). Within every NHS Mental Health Trust, specialist dementia wards care for the most unwell, vulnerable, and high-risk PLWD who are detained (typically under the Mental Health Act (1983)) for their own safety and the safety of others.

There are around 100 (80 NHS and 20 private) MHWs for PLWD across the UK, however, there is an evidence gap around the quality of such settings and PLWD and carer experiences [1, 2]. Professionals working in the field are concerned a MHW admission causes ‘more harm than good’ [3]; stays are long (average 100 days) and the majority of PLWD do not return home [4].

PLWD are admitted to a MHW when the psychiatric and behavioural features of their dementia cannot be managed in any other setting, often following events including self-harm, suicide attempt, or a serious assault of a carer [1]. This population are at high risk to themselves and to others; with high acuity [5] and comorbidity [1]. Carer distress and illness are common reasons for admission [1]. Admissions are complex, involving frequent unscheduled transfers to general hospital, associated with high rates of falls and hospital acquired infections [1].

Carer Involvement

Carer involvement (including all informal unpaid carers who look after a family member, friend or partner living with dementia, and who may not see themselves as a carer) can directly improve the clinical and social outcomes of people within MHWs [6-9]: reducing length of stay [6, 8]; promoting earlier discharge [7] and reduced rates of relapse and readmission [6, 8]. Carers support PLWD in ways staff cannot, or do not [10]: ensuring care is person centred [11]; proving advocacy [10]; supporting decision making [11], treatment adherence [11], and recovery [12]. However, MHWs consistently fail to involve carers in decision making [13] and carers are routinely excluded from wards, a practice normalised during covid and continuing since [2].

Carers describe MHWs as a place of ‘battle’ [10] and report being marginalized and overlooked [11, 14]. Carers experience high levels of trauma and distress following a MHW admission [13, 15], with unmet emotional, social, and financial needs, all increasing during an admission [2, 11] but are not routinely offered support [11]. Reviews and inquiries identify ingrained cultures viewing carers as a ‘problem’ who ‘will not co-operate and will be angry and critical’ [14, 16]. Staff view carers as a difficult to support, resource-intensive group [10, 17].

Evidence Gap

There is an absence of research examining carer perspectives of MHWs and no evidence-based interventions to support carers of PLWD who are admitted within MHWs. NHS England and the UK Government have called for collaborative and participatory projects which adopt co-design approaches, to actively involve carers in the planning, development, and evaluation of services [18], and work in partnership with carers and service users [19] to ensure interventions are guided by the needs of those who will receive and deliver care [20]. In response, this study responds to urgent calls from the Department of Health and Social Care and NHS England [18, 19], for partnership working with carers and families utilising co-production to develop effective interventions and training programmes to support carers and the guidance required by services and wards to support implementation.

Research question: How can MHWs effectively work in partnership with and support family carers of PLWD?

Aims and Objectives

This study will provide detailed understandings of carers experiences and involvement when PLWD are detained within a MHW, and staff rationales and responses to carers, throughout an admission. It will deliver new knowledge and evidence-based strategies co-designed to ensure carers are appropriately supported and involved and to improve patient outcomes.

Objectives:

1. To deliver a detailed description of staffing structure, patient profiles, and current support for carers and families in MHWs for PLWD.
2. Provide detailed understandings of carers' experiences, perspectives of involvement, and their support needs throughout a PLWD MHW admission, during transition, and following discharge.
3. Understand ward organisational cultures and staff perspectives by examining (a) ward routines and practices that involve or exclude carers (b) staff understandings and recognition of carers needs, and (c) formal frameworks and informal rationales staff draw on to inform involvement or exclusion from decision making, care, and transition to discharge.
4. Translate the findings using co-design into evidence-based strategies to support best practice in the involvement and support of carers.
5. (a) Assess the feasibility of implementing these strategies in practice and (b) gather feedback from people with lived experience

Research Plan / Methods

Design

This mixed methods study uses a range of perspectives and methods, the "building blocks of evidence," to produce new knowledge [21]. We utilise a convergent parallel mixed methods design [22] integrating a national mapping survey (online questionnaire), interviews (longitudinal narrative), ethnographic (observation, interviews, documents) and experience-based co-design (co-production of outputs) and feasibility (translation into practice). This approach supports the collection of detailed data from multiple and contextualized perspectives, with the goal to improve healthcare systems [23].

The study uses family systems theory and the Family Adjustment and Adaptation Response Model (FARR) [24] to understand family responses to stress, such as dementia and mental health admissions. It also incorporates anthropology and sociology theories to explore family and kinship in care contexts and how healthcare professionals and MHWs recognize and respond to families. This combined approach aims to understand carers and families' experiences and how to best support them during MHW admissions.

Data Collection

National mapping Survey (objective 1)

Design: A multi-site, cross-sectional mixed methods questionnaire utilising multiple-choice and open response items has been created in collaboration with our PPI Advisory Group.

Recognising time pressures within MHWs, the survey will take approximately 15 minutes to complete.

Key sections: Ward location, number of beds, % bed occupancy, patient profile: routes to admission, age, gender, discharge destinations, and staffing profiles. To understand how wards currently support carers and families, we ask about carer identification, needs assessment and communication; involvement in care planning and treatment; the provision of ongoing support to family and carers; provision or recommendation of referrals for family and carers.

Data collection: The survey will be delivered via an online survey tool (we plan to use Microsoft forms, which integrates with NHS systems). Contact details for all MHWs in the UK will be identified via:

- Hand searching NHS Trust and Health Board websites and CQC reports.
- Our national community of practice for MHWs for PLWD, with over 50 UK members
- The Royal College of Psychiatrists Quality Network for Older Adults Mental Health Wards membership list
- Collaborating with Dr Kamath (study advisory committee), medical lead of the network of private hospital providers for older people
- The executive committee of the Faculty of Old Age Psychiatry, Royal College of Psychiatrists
- The inpatient workstream of the Faculty of the Psychology of Older People

Our aim is to provide a comprehensive map of provision, we expect to achieve 45-60% completion in line with other mental health workforce surveys [25].

Qualitative methods

A longitudinal and family systems approach to interviews: utilising our family systems approach enables us to follow the ways carers and families adapt their patterns of functioning and meanings over time in the context of care and crisis [24] and informs our understandings of carer and family responses to stressful life circumstances, the stress of dementia and a MHW admission, and the potential for interventions to improve outcomes for PLWD, carers, and families. We will use interactional communication strategies from family systems within the interviews [26].

Narrative interviews (objective 2)

We will use narrative interviews to understand carers experiences. This approach will support carers (and where possible their partner PLWD, in sharing their personal accounts, experiences, and stories [27] and to provide depth and sensitivity of insights and understandings [28]. The use of narrative interview methodology is established with PLWD [29-30] and carers [31-35]. Participants will be encouraged to actively direct the interviews [28]. This approach builds on our pilot interviews [12], which demonstrated carers welcomed the opportunity to tell their story. Interviews will also be accompanied by detailed field notes to provide context and depth [27].

Attempting to *understand fully* someone's experience too quickly can be a detriment to understanding [36]. In response, our longitudinal approach will: (1) support participants to articulate experiences, leading to the collection of in-depth, nuanced, and contextual data collection [37]; (2) help build trust between the researcher and the interviewee over time; (3)

reduce time pressure that can arise when interviews are reduced to a single encounter; (4) importantly, for carers who feel stigmatised by a mental health admission, this approach supports participants in feeling empowered by being accorded adequate time to tell their story and be heard [37-39].

Data Collection:

(a) Narrative interviews with carers of PLWD currently detained within a MHW at multiple time points. We will recruit 8 carers (and where possible their partner PLWD to form a dyad) per site, 3 sites total = 24 participants. The first interview will be at recruitment, followed by a sequence of two further interviews over 12-months (Total: 72 interviews).

This period of 12 months was selected based on the typical length of admission and capture changes and transitions. But ensuring interviews will not be so frequent to overtax the energy and willingness of participants during this difficult time.

(b) Narrative interviews with carers (where possible with the PLWD to form a dyad) of a PLWD discharged within the last 3 years from the same MHWs. We will recruit 8 carers per site, 3 sites total = 24 participants (Total: 24 interviews). Our PPI Advisory Group emphasised the importance of interviewing these carers, to understand what happens following discharge.

Interview approach: we will adopt a not knowing approach, recognising that carers and families are more knowledgeable about their situations than professionals [26]. The researcher will ask prompting and follow up questions, but as much as possible participants will be encouraged to direct conversations to share their experiences. Each interview (on average 60 minutes) will take place at the interviewee's convenience, in person at the MHW (which have family or meeting rooms that can be booked) or in their homes, via video conferencing, or telephone. Interviews will be recorded and transcribed.

Supporting dialogues using artistic practice

To support EDI and the inclusion of carers, families, and PLWD for whom communication may be difficult, all participants will be offered this alternative mode of communication of experiences [40] to support those who may not be able to or want to participate in face-to-face interviews. Artistic online and postal dialogues will support artistic expression of experiences. Here participants will have the opportunity to form a creative dialogue with our experienced artist-researcher (MW), whereby they communicate with each other through developing artworks and sending and responding via the postal service to build a dialogue together over time. Carers will be sent a series of packs of arts materials and pre-paid envelopes over a 12-month period. Participants will be invited to create an artwork and to send this to the researcher. The artist- researcher will create an artwork in response and post this back. The process will then be repeated with the end point directed by the participants over the 12-month period.

Ethnography within MHWs (Objective 3)

We will utilise ethnography to understand ward organisational cultures and staff perspectives by examining (a) ward routines and practices that involve or exclude carers (b) staff understandings and recognition of carers needs during an admission, and (c) formal frameworks and informal rationales staff draw on to inform involvement or exclusion from decision making, care, and transition to discharge.

An ethnographic approach involves the in-depth study of people's everyday actions and accounts, by collecting relatively 'unstructured' data from a range of sources (observation, ethnographic interviews, document analysis) [41]. It provides sophisticated tools for understanding the complexities of everyday life within an organisational setting, by examining the routines and behaviours of groups and individuals, both within and across multi-disciplinary teams and sites of care [42; 44].

Ethnography is particularly useful to examine organisationally invisible work [45]. where the issues are sensitive and multifaceted, where our aim is to access the unspoken and tacitly understood [46], and to understand complex social relations, routines, and institutional forces as they influence everyday cultures of care [47] within mental health wards.

Data collection: Within each of our three sites we will carry out ethnographic data collection (observation, in-situ interviews, and documentary analysis) spending 30 days on each ward. Data collection across the 3 sites over 4 months in each site (total 90 days/shifts of observed practice) with a further period of 1 month following each site to clean data, develop preliminary analysis, and carry out follow up interviews. Data collection will involve:

- Shadowing staff as they organise and deliver care to understand their practices and rationales.
- Observing staff engagement and communication with carers, including at admission, remote communication (telephone calls, updates), and within ward (including supervised visits).
- Joining team and case meetings (e.g. reviewing care plans, discharge planning), and multidisciplinary team meetings (MDTs) to examine how carers and family enter discussions, how professionals understand carers roles, and how carers are involved.
- Understanding opportunities for carer involvement in care (mealtimes, personal care), resources (information, signposting) and the provision of support (psychological support, carers assessments, peer support groups).
- Focusing on handover, admissions, opportunities for carer involvement, discussions about treatment (care planning, mental health act meetings/reviews), discharge, end of life care, and advanced care planning.
- Documentary analysis (focusing on information routinely shared with carers such as welcome documents or sources of support, templates used to record or share information with carers).

Staff perspectives will be obtained via a series of short *in-situ* ethnographic interviews (<10-minute conversations) during shifts, to explore to capture staff experiences in 'real time'. In addition, longer interviews (30-60 minutes) will be held with ward managers, senior nurses, allied health care professionals, consultant psychiatrists and the medical teams at each site (5 per site, 3 sites = 15 interviews).

Analysis of mixed methods

Our systematic approach to data collection and analysis uses the constant comparative method and theoretical sampling whereby data collection (survey, narrative interviews, and observation) and analysis are interrelated [48, 49] and carried out concurrently [50]. The flexible nature of this approach will allow us to increase the ‘analytic incisiveness’ [51] of data collection. As data are collected in parallel, preliminary analysis will proceed in parallel, with this analysis informing the focus of later phases of data collection in the next site and subsequent stages of analysis. As data are collected in parallel, preliminary analysis will proceed in parallel, with this analysis informing the experienced based co-design work.

Mapping survey: descriptive statistics will summarise quantitative data and thematic analysis of open responses, with a specific focus on mapping current practice.

Narrative analysis of interviews: longitudinal narrative interviews will keep individual accounts intact, presenting them as individual case studies and single narrative interviews, we will utilize narrative analysis. We will also take a thematic analysis approach across all interview data, bringing it together in a series of descriptive reports to theorise across interviews by finding common thematic elements across participants and events [52] Analysis will involve coding experiences and examining and interpreting content of speech by focusing on meaning, with the goal to scrutinize, reflect and theoretically interpret elements of the participants lived experiences in relation to experiences of services [53]. We will look across the case studies and descriptive reports to identify typologies of experiences, and opportunities for resilience, recovery, and better adaptation, and how successful adaptation can be promoted. Artistic conversations will not be analysed but images will help the research team deepen their understanding.

Ethnography: Initially coding will produce a collection of ‘sensitizing concepts’ [54] and analytic memos, which will inform the development of more refined and stable analytic concepts. The analytic concepts that emerge from this process will be tested, refined to develop stable concepts that transcend local contexts to identify broader structural conditions [55] influencing experiences of MHWs.

Triangulation: Data triangulation will allow us to explore the experiences of PLWD, carers and staff, exposing the realities of each group to allow a more comprehensive understanding to emerge. Methodological triangulation (surveys, interviews, observations) allows for more robust findings considering both richness (interviews and observation) and generalisability (survey).

Intersectional approaches to analysis: we utilise intersectionality to provide a framework for integrating diversity of experience to ensure inclusivity and to focus on the needs and experiences of vulnerable and marginalised groups across the data sets. This will ensure consideration of vectors including class, gender and social economic status among others and how their interactions impact on experiences [56, 57] and enable the examination of the power relations and how they contour individual experiences as well as organisational cultures and practice [58. 59].

Experienced Based Co-Design (objective 4)

To translate the findings into evidence-based strategies to support best practice in the involvement and support of carers we will utilise an experience-based co-design (EBCD) approach to empower carers, families, PLWD, and MHW staff to collaboratively shape service improvements to address their needs and enhance care. EBCD places the experience of patients, carers, and staff at the centre of driving meaningful change. EBCD provides a better understanding of user's needs, preferences, and challenges; more effective and tailored solutions; and by incorporating diverse viewpoints innovative and creative solutions. An EBCD approach has successfully been used with PLWD [60] and to deliver improvements in adult MHWs [60].

Materials: We will use our analysis in the form of narrative case studies and ethnographic 'thick description' to cocreate with our PPI Advisory Group a series of scenario-based narratives and short 'trigger films' providing 'status quo' and 'what if' scenarios grounded in the empirical research. This provides ways to connect those involved in co-production (carers, families and PLWD, and ward staff) with current practice and its impacts, by providing detailed 'real' empirical examples and vignettes that bring issues alive. Composite characters and journeys will be created. The 'what-if scenarios' will encourage creative problem solving by asking participants to consider a range of possibilities.

Workshops: will follow an established process [61] and online workshops will support the involvement of stakeholders across the UK. Adapted EBCD methods for online delivery have been used successfully with people with dementia [60]. All participants will receive workshops dates, information, and provided with an opportunity to meet a facilitator in advance to discuss the EBCD process.

The first two structured online workshops (90 minutes) will utilise peer-homogenous groups of PLWD (n=10), carers and family (n=10), and MHW staff (n=10) to ensure participants are in a safe space and supported to share experiences. The first workshops will explore the status quo scenarios with the goal to identify priority issues within current practice. Participants will be asked to reflect on their own experiences triggered by the scenarios and short films and to prioritise areas for quality improvement. The same participants will be invited to a second workshop approximately two weeks later. These workshops will focus on opportunities for change. The third series of mixed stakeholder workshops will bring together PLWD (n=10), carers (n=10), and MHW staff (n=10) in online 90-minute workshops (10 in each workshop). The objective of the final workshops will be to seek consensus on the provisional model of best practice and the suggested strategies for wards.

Workshops will be facilitated by experienced facilitators and be co-lead with our PPI co-applicants. Workshops will be recorded and transcribed. Researchers will also take field notes.

Data analysis: The focus will be on sense-making and identifying recurrent themes and narratives using thematic analysis [37] which will enable us to explore complexities and nuances, allowing us to increase the 'analytic incisiveness' [38] of output development. Thematic analysis of transcripts from the first two rounds of workshops will inform the development of a provisional conceptual model of best practice for working in partnership with and supporting carers within MHWs and practical evidence-based strategies that wards can utilise which will be shared for consultation in the third round of workshops.

Exploring feasibility (Objective 5)

To (a) assess the feasibility (acceptability, implementation, integration, relevance and acceptability) of implementing these strategies in practice, we will conduct focus groups with MHW staff to address the i) acceptability, to what extent these strategies reflects current practice, constraints, and the potential for new approaches; ii) implementation, to what extent they can be successfully delivered; and iii) integration, to what extent they can be integrated into routine practice iv) relevance and acceptability of the outputs created for PLWD, carers and families.

Design: three online focus groups of 8-10 people (n=30) will provide opportunity for discussion to explore the structural and organisational barriers within wards that may facilitate or impede effective implementation. Draft outputs will be circulated to participants two weeks prior, to allow participants time to consider and review materials. Focus groups will begin with introductory questions, moving onto specific questions on the materials, with scenarios used to explore implementation. Focus groups will be recorded and transcribed verbatim.

To (b) to gather feedback from people with lived experience, PLWD, carers and families will be invited to share their feedback in a way that suits them most, that could be annotating printed or electronic versions of documents, a brief conversation with the research online or over the phone or via the researcher attending their PPI meetings to gather group feedback. Those wishing to receive physical documentation will be given a stamped addressed envelope to return annotated documents. A deadline for sharing feedback will be given to each participant. If no feedback is received by the deadline, one reminder will be sent.

Data Analysis: Focus group transcripts will be inductively analysed [155]. Specific changes or recommendations to materials for improvement (wording, style etc) will also be extracted during coding and recorded for the team to consider. The learning gained from these themes will then be used by the team to enhance the materials created for wards.

Recruitment and Sampling

Sampling

Non-probability sampling provides analytically rather than statistically generalizable findings [62]. Theoretical sampling is a flexible, pragmatic approach, with research sites, services, participants (and sample size), selected by identifying a range of variables that may influence the phenomena (purposive sampling). This approach emphasizes the importance of comparisons both within and across sites [63], enhancing the potential generalizability of findings [64], and impacts on practice and policy [65].

National mapping Survey (objective 1)*:* We will identify NHS wards (70 in England, the 7 regional health boards in Wales and 14 in Scotland) and private providers (20) (Cygnet Health Care, the Priory Group, Elysium Health Care, and St Andrew's Healthcare) by hand searching CQC records, from the Royal College of Psychiatrists accrediting body for these wards and for private providers via our steering group. Ward managers will be approached via email inviting them to participate and sharing the link to the survey and the information sheet. A verbal overview of the study will also be presented by the research team to the Royal College of Psychiatrists Quality Network for Older Adults Mental Health and the Inpatient Dementia Community of Practice. Inclusion criteria: ward manager of an MHW for people with dementia. Either a ward just for PLWD (sometimes called an organic ward) or a mixed ward caring for PLWD. Our aim is to provide a comprehensive map of provision, with a target recruitment of 45-60%, in line with NHS workforce surveys [25].

Qualitative methods:

Agreements are in place with 3 NHS Mental Health Trusts which all serve communities with significant health and social care needs and include inner-city, coastal towns, rural and semi-rural areas with ageing populations.

Narrative interviews (objective 2): Applying a family systems approach, we have deliberately broadly defined carer as 'all informal unpaid carers who look after a family member, friend, or partner, and who may not see themselves as a carer'. We have not set limits on what constitutes caring, or relationship type, and ascribe to the view that a family itself defines who is, and who is not, part of it.

We build on our established PPI advisory group and our pilot, which establishes we can recruit and interview carers of PLWD who have been admitted within MHWs, who feel strongly that they want to be involved in research and share their experiences, even when distressing.

For Current Carers (longitudinal interviews): Our sample of carers, families, and PLWD (8 per ward) will be identified by ward managers. If judged appropriate, a letter and a PIS will be posted or handed to carers inviting them to take part. Wards will inform the research team where translated version of the recruitment materials are needed. Posters advertising the study will also be placed on the ward to inform visiting carers. In addition, the research team will deliver arts-based workshops at each site for PLWD, carers and staff, providing a creative platform to introduce the aims of the study and the research team. Carers wishing to take part will contact the research team via phone or email. Inclusion criteria: family member (any relationship) or friend of a PLWD currently detained in the MHW. Aged over 18 years old. Able to provide consent and willing to take part in the interviews. Exclusion criteria: the carer is actively involved in a safeguarding investigation.

The MHWs who have expressed an interest in taking part, have confirmed they are confident our target sample can be achieved. We will initially use purposive sampling to ensure our sample reflects the carer and PLWD population in each ward setting. As the study progresses, this approach will be refined, utilising maximum variation sampling to ensure our recruitment reflects and includes carers and families of diverse configurations and cultural backgrounds who all provide care to PLWD. We will use snowball sampling from the initial carer attending the MHW to identify other family members with a caring role. We have used this approach successfully in previous research (KF) to facilitate the recruitment of other family members involved in care, caring, and decision making.

Recruitment of discharged carers: Our sample of carers of PLWD who have been discharged from the ward within the last 3 years will be identified via screening of ward records completed by ward managers at each ward (8 carers per ward). A letter and participant information sheet will be sent by post. Ward documents will indicate carer language preferences and translated materials will be provided as needed. Those carers wishing to take part will contact the research team via email or phone. Inclusion criteria: family carer or friend of a PLWD discharged from the ward within the last 3 years, over 18 years old, able to give informed consent and to take part in an interview. Exclusion criteria: Exclusion criteria: the carer is actively involved in a safeguarding investigation. If there are ongoing disputes / complaints being investigated with the Trust, the carer will not be contacted to avoid adding to distress. The smallest ward we have approached had 30 admissions within the past 12 months, thus recruiting 8 carers per site is feasible.

We will initially use purposive sampling to ensure our sample reflects the carer and PLWD population discharged from each ward and regional setting. As the study progresses, this approach will be refined, utilising maximum variation sampling to ensure recruitment reflects and includes carers and families of diverse configurations and cultural backgrounds [66]. We will also utilise critical case sampling to ensure we include carers who have had particular types of experiences within the MHW setting (e.g. transfer to acute hospital) and key informant sampling to include those with specific expertise.

Recruitment and sampling of PLWD for Interviews:

PLWD within MHWs are usually in the advanced stages of dementia and very distressed [3]. However, there may be some PLWD who are willing and can be supported in taking part in dyadic interviews with their carer.

We will identify PLWD who may be able to take part through discussion with family carers. Where it is felt that a PLWD may be able to take part in a shared interview, the researcher will meet with the PLWD with their family carer in person to share the simplified participant information sheet and answer any questions. At this point an assessment of capacity to consent to take part would be made by the researcher in accordance with the Mental Capacity Act (2005) this will involve assessing the participants understanding of the research and its aims, their ability to retain this information for long enough to make a decision, their ability to weigh up the information as part of a decision making process and to communicate their decision. If the researcher feels a dyadic interview would be possible then a time and date for the interview will be arranged. Once obtained, consent will be continuously renegotiated and re-established to ensure participants are still willing to continue taking part in the research. In line with this approach, capacity will be reassessed before the interview begins and written consent will be taken using the easy read consent form. Capacity will be re-assessed before each interview. If a person with dementia consents to and participates in an interview but loses capacity before the next one, they will not be involved in the subsequent interview.

Ongoing signs of consent and fatigue will be monitored for throughout the interview. Inclusion criteria: PLWD, currently under the care of the MHW or discharged within the last 3 years, able to give informed consent and to take part in an interview alongside their carer. Exclusion criteria: the PLWD is actively involved in a safeguarding investigation, people without the capacity to consent to take part.

Ethnography within MHWs (Objective 3)

Recruitment and Consent for Observation:

Ward Staff: will be informed of the details of the study at least two weeks before the study begins, given the opportunity to meet the research team and the opportunity to discuss and ask any questions they may have. Once observations begin, initially only verbal consent will be taken, first from the senior nurse on shift, then all clinical staff allocated to areas under observation prior to the beginning of a period of observations. Staff will be informed they can ask for observations to cease at any point without giving a reason. Written Consent will be obtained before, during or after the period of observation at a time most convenient to each staff member, in a way that will least impact on their routine, clinical work and the pressures of their shift. Should a staff member decline to give written consent at this stage, field notes involving them will be destroyed and data collected from them will form no part of the research findings. This staff member will no longer be observed in any subsequent observations. Due to the nature of hospital wards it is likely that staff from other teams (district health team, GPs, Community Mental Health Team) will at times enter areas under observation. It is not practical to take consent from all members of staff in these circumstances, as this may entail interrupting ward processes or interventions. Instead, posters giving information about observations on the ward will be prominently placed at the entrance and throughout the area under observation. Researchers will carry information sheets and be available to answer questions and will take verbal consent when it does not interfere with clinical care processes or the work of the ward. Observations will be ceased should any staff member raise any concerns about being observed or the presence of the researcher.

Carers and people with dementia: All patients and family carers will be verbally informed about the study when the researchers arrive at the wards and will be informed that the researchers are observing staff as they conduct everyday work. A4 Posters and summary information sheets providing details of the study will be placed at the entrance of, and throughout, all observed wards. The focus of the observations is on the organisation of care. Observations will take place from the corridor(s) of wards, in public places, typically at nursing stations or ward observations points. No observations will take place at the patient's bedside.

Although the observations are focused on staff, it is inevitable that patients will also be witnessed by the study team. Many of the patients on the ward will be in the advanced stage of dementia. Therefore, we will be seeking consent prior to the study from either patients with dementia, or where they are unable to consent, from a consultee acting on behalf of the person with dementia, following the safeguards with respect to research contained within the Mental Capacity Act.

A decision about capacity will be made by the researcher, and the patient will not be enrolled if the researcher believes this could be detrimental to their mental health or care. Advice about the patient's wishes and feelings in relation to research participation will be taken from the consultee who will either be a family carer or the medical consultant if the patient lacks capacity. If a person with dementia has themselves consented and then lost capacity during the study, we will stop the observations and request consent from their consultee.

If the consultee chooses not to consent, we will immediately withdraw the participant from the study, meaning that the researchers will not conduct observations in areas where this patient is and will not attend meetings related to this patient.

Carers will be informed of any newly starting or ongoing observations and will be reminded by ward staff or the research at intervals should they ask. Verbal consent will be sought from carers entering the ward. Consent will be ongoing and can be withdrawn at any point. Should a carer opt out of the study, before or during observations, the researchers will cease to observe the ward area where that carer is situated. Where carer observations involve prologued periods of observation for carers for example attending an MDT meeting or a discharge meeting, the researcher will seek written consent from the carer.

Recruitment of staff for interviews:

In-situ ethnographic situated interviews (5-10 mins reciprocal conversations) with ward staff will take place during observations to explore what staff draw on to inform their interactions and support with carers, how they recognize carers needs and what informal and embedded rationales used in decision making inform their involvement with carers. The researcher will identify and approach staff as opportunities to discuss approaches, practice, and decision making occur. Verbal consent will be taken by the researcher and then written consent will be sought at a later point when convenient so as not to interfere with the provision of care.

Staff to take part in longer (30-60 min) interviews (5 per site) will be identified in collaboration with ward managers. Staff will be approached in person via researchers on site who will give a verbal overview of the study and hand participants a written information sheet and consent form. Interviews will be arranged at a time and date to suit participants and minimise impact on the ward. The sample will include staff from a range of disciplines and roles. We will purposively sample to ensure that we include a range of professions and grades whose role all involved regular contact with families.

Experienced Based Co-Design (objective 4)

PLWD (n=10) and carers (n=10) will be identified via our national partners (Dementia UK, Young Dementia Network, John's Campaign, TiDE). Our partners will share our recruitment poster via their social media and in their newsletters. In addition, carers who took part in interviews and consented to being contacted again by the study team will be sent the recruitment poster to take part. Furthermore, we will share the recruitment poster with faith and community organisations to support the recruitment and involvement of carers and family from within ethnic minority groups. The poster will also be shared on the study's social media accounts. Inclusion criteria: Participants must be PLWD, carers or friends, who may or may not have experience of MHWs, who are willing to talk about mental health and dementia, are over the age of 18, who are able to give written informed consent, and who can take part in online workshops.

Those wishing to take part will contact the research team via phone or email. The research team will check eligibility either via phone or email and share the PIS for more information. This will include checking capacity to provide consent. The researcher will also check availability for all online workshop dates. Purposive sampling to ensure the inclusion of a range of experience and reflect our EDI goals. A written consent form will be shared ahead of the first workshop. Verbal consent will then be re-assessed at the start of all subsequent workshops.

Staff (n=10) will be identified via the inpatient dementia community of practice, the Royal College of Psychiatrist's list of accredited dementia MHWs wards and the wards who took part in our survey and signed up for the study newsletter. A poster will be shared via the email from the Royal College of Psychiatrists to those wards on their accreditation list. The wards who took part in our survey and signed up for the newsletter will see the poster in the newsletter. The poster will be shared via email to the mailing list of the inpatient dementia community of practice. In addition, the poster will be shared on the study's social media accounts (Linked In and X). Those wishing to take part will contact the research team via phone or email. The researcher will check eligibility, and a participant information sheet will be sent. Inclusion criteria: member of staff working within MHW for PLWD, of any professional group in a role that involves contact with carers (e.g. health care assistants, nurses, OTs, psychologists, physiotherapists, SALT, psychiatrists etc); any band/grade, students on placement in MHW; working on NHS or private ward. Purposive sampling will be used to sample a range of professions, grades and experience (new staff and students included). Exclusion criteria: the staff member is actively involved in a safeguarding investigation.

Exploring feasibility (Objective 5)

PLWD (n=30) and carers (n=30) will be identified via our national partners Dementia UK, TiDE, and John's Campaign, a poster advertising the study will be shared via their established PPI groups, newsletters, and social media channels. We will engage with faith and community organisations to support the recruitment and involvement of carers and family from within ethnic minority groups by asking them to share the poster. Those interested in taking part will contact the research team via phone or email. The research team will check eligibility, share a participant information sheet, and establish their preferred method of receiving outputs for review (electronic/paper) and how the participant would like to provide feedback (post, phone, email). Inclusion criteria: person living with dementia or carer (current or bereaved), willing to review outputs related to MHWs, aged over 18 years. Exclusion criteria: the participant (PLWD or carer/friend) is actively involved in a safeguarding investigation.

Staff (n=30) will be identified via the inpatient dementia community of practice, the Royal College of Psychiatrist list of accredited dementia MHWs wards and the wards who took part in our survey. A poster will be shared via the email from the Royal College of Psychiatrists to those wards on their accreditation list. The wards who took part in our survey and signed up for the newsletter will see the poster in the newsletter. The poster will be shared via email to the mailing list of the inpatient dementia community of practice. In addition, the poster will be shared on the study's social media accounts (Linked In and X). Those wishing to take part will contact the research team via phone or email. The research team will check eligibility, share a participant information sheet, and establish which focus group the participant wishes to attend. Inclusion criteria: member of staff working within MHW for PLWD, of any professional group in a role that involves contact with carers (e.g. health care assistants, nurses, OTs, psychologists, physiotherapists, SALT, psychiatrists etc); any band/grade, students on placement in MHW; working on NHS or private ward. Purposive sampling will be used to sample a range of professions, grades and experience (new staff and students included). Exclusion criteria: the staff member is actively involved in a safeguarding investigation.

Impact, Outputs and dissemination

***Expected impact*:** Our goal is to (a) support services in meeting their legal requirements of The Care Act (2014) to support carer needs and promote well-being; (b) establish shared understandings of best practice in supporting and working in partnership with carers in MHWs; (c) provide support for carers in culturally appropriate ways; and (d) deliver co-produced evidence-based approaches to improve the involvement and experiences of carers, and families and (e) improve PLWD outcomes and transitions to discharge.

Outputs: We will support MHW wards in meeting carer needs and promoting well-being through various resources including podcasts, audiobooks, short films, and downloadable documents. These resources will cover best practices, guidance on recognizing and supporting carer needs, and culturally appropriate support. Additionally, MHW staff will receive training to enhance their skills in working with carers, recognizing critical points in care, and delivering culturally sensitive services. All outputs will be accessible in multiple languages and formats, including broadcast-quality podcasts, digestible audiobook narrations, short films, and downloadable PDF documents. These will be available as open access and downloadable via platforms like Apple Podcasts, Google Podcasts, Spotify, YouTube, and websites of Dementia UK, universities, and collaborators to ensure broad accessibility.

Carers and families will have access to guides on understanding MHW processes, carer rights, mental health legislation, and preparing for discharge. Information for PLWD will be provided in easy-to-read accessible formats. Resources for PLWD and carers will be made accessible on the Dementia UK website and will be available in in multiple languages (Arabic, Bengali, BSL, Chinese, Gujarati, Hindi, Polish, Punjabi, Sylheti and Urdu).

Dissemination: Our national mapping survey will support the dissemination and sustainable implementation of interventions and resources for best practices. This includes engaging MHWs nationally via newsletters and rapidly sharing findings through online masterclasses and training. We will leverage our established professional networks and key partners, such as the Inpatient Dementia Community of Practice, the Royal College of Psychiatrists, and the Faculty of the Psychology of Older People, to support knowledge transfer. Key partners who are part of our steering group including NHS England, Dementia UK, and John's Campaign will play crucial roles in this dissemination effort.

We will update study participants with our progress via:

- Newsletter every 6 months co-produced with PPI steering group for PLWD, carers, families and professionals.
- Social media, including YouTube to share updates and outputs.

Project timetable

Total 30 months: 1st Jan 2025 - 30th June 2027

Survey: months 1-12 (months 1-3 design and piloting, data collection 4-7, analysis and write up 8-12).

Narrative interviews: months 1-18 (site set up months 1-3, recruitment months 4-6, data collection and analysis months 4-18).

Ethnography: months 1-18 (site set up months 1-3, data collection site 1 months 5-7, data collection site 2 months 9-11, data collection site 3 months 13-16, data analysis month 9-18).

EBCD: months 18-24 (recruitment months 18-21, workshops 1 & 2 month 21, initial analysis month 22, joint workshops months 23-24).

Feasibility: months 25-30 (recruitment and focus groups months 25-27, final development/changes to outputs months 28-30).

Outputs: resources development months 21-30, policy engagement months 18-30,

PPI advisory groups meetings every month (with face-to-face meetings at start and end of the project), public outreach events bimonthly throughout the project. **Our end of study date (i.e. our completion of the data collection) will be 31st March 2027 (month 27) where our final feasibility focus groups will take place.**

Ethical Approach

Our data collection approach will always preserve the dignity of individuals, guided by REC approvals (15/WA/0191, 18/WA/0033, IRAS 313816) and DEEP guidance for involving people living with dementia (PLWD) in research. Our processes and documentation are designed to ensure ethical standards, and we will adhere to REC and The University of West London's governance procedures.

The lack of research exploring the perspectives of people living with dementia has been argued to effectively silence those experiencing cognitive decline [67]. Recognizing their inclusion as vital for high-quality research, prioritizing their views and experiences has become a key research goal [68]. Participation in research generally outweighs the risks, enhancing dignity and personal identity [69]. People living with dementia themselves emphasize the positive and empowering effects of their inclusion in research [70].

In response, this study focuses significantly on the perspectives of people living with dementia and their carers, aiming to understand their thoughts, feelings, and experiences of care within mental health wards. To respect the dignity, integrity, and personhood of participants, a relationship-centred approach is interwoven throughout the study. This approach is essential when working alongside people living with dementia and their carers, including in research [71].

Potential risks and how these will be minimised:

Participant distress

Interviews: There is a chance that interviews with carers and where possible PLWD might result in distress. During interviews carers will reflect on their experiences during their relative's admission to a MHW. This may be a distressing time for some carers and there is a chance they may become upset during the interview. In our pilot study one carer became upset but wished to continue with the interview.

All participation in interviews in voluntary. Participants will be aware of the nature of the interviews and the potential for distress via the participant information sheet. At the start of each interview, the researcher will ask the participant how they would like to proceed if they become upset, such as taking a break or stopping the interview. The researchers are experienced in qualitative interviews and in working with family carers. Researchers will take a supportive approach, offering breaks as needed or to stop the interview. The interviews take a narrative approach meaning that they are driven by the carers. At the end of the interview the researcher will check-in with participants to see how they are feeling. A sources of support document will be provided to all carers after interviews. If a researcher is seriously concerned about a participant's well-being, they will inform the participant and state that they will share these concerns with the Principal Investigator (PI) and the ward manager at the recruitment site, as outlined in the participant information sheet. Each site will have an agreement on where to escalate immediate safety concerns, ensuring researchers have contact details for local referral points, such as the mental health crisis team.

Ethnography: it is possible that some PLWD or carers might fine the ethnographic observations intrusive.

Observations focus on staff practices and how staff work with and support family carers. There is no direct observation of people with dementia taking place. Observations will be conducted in a way that minimizes intrusion, focusing on public areas and avoiding private spaces. Researchers will be vigilant for signs of distress or discomfort. If a patient appears distressed, the researchers will stop observing the area where that person is located for the duration of their stay.

Disclosures

Interviews: It is possible that during the interview's carers or PLWD might disclose that they are a risk of harm to themselves or others, or that they are at risk of harm from others. It is also possible that they might disclose examples of poor care or practice experienced during the inpatient admission or from care provided by a subsequent provider (such as a care home) on discharge.

The boundaries of confidentiality are clearly stated in the participant information sheet. These will be reiterated verbally by the researcher at the start of the interview. Where a disclosure is made, the researcher will inform the participant that they will need to share their concerns in line with the boundaries of confidentiality outlined in the participant information sheet. The researcher will make brief notes of their concerns and then contact the PI for the study to discuss the concerns. Depending on the nature of the concerns appropriate action will be taken and will be the responsibility of the PI who is a registered clinical psychologist. Each site will have an agreement in place with the research team on where to escalate immediate safety concerns, ensuring researchers have contact details for local referral points, such as the mental health crisis team. The research team will also obtain a clear list of safeguarding referral processes and contacts at each site. The PI will inform the participant of the action taken.

Ethnography: If a researcher witnesses poor practice during observation, first, they will discreetly document the incident, noting the time, location, and details of what occurred. Next, they would assess the immediate safety of the participants involved. If there is an urgent risk, they would intervene to ensure safety, following pre-established protocols for the ward (e.g. pressing their alarm to call for other staff). Where appropriate the researcher would inform the participant that they will report the incident, maintaining transparency. They will promptly report the incident to the Principal Investigator (PI) and the ward manager, providing a detailed account. Depending on the nature of the incident, the researcher, supported by the PI will follow the site-specific procedures for escalating concerns. The researchers will be aware of safeguarding and whistleblowing procedures at each site and will have a named member of staff to contact if malpractice or safeguarding issues are observed. If researchers witness poor practice that falls outside of safeguarding but still raises concerns, they will report these concerns immediately to a named person as agreed with the Trust prior to the commencement of data collection. If the researcher felt that no action had been taken or that the response was unsatisfactory then they would escalate concerns in line with local safeguarding procedures and as agreed with HRA and the NHS REC overseeing the study design. Finally, the researcher will reflect on the incident in their field notes, considering the broader implications for the study and any necessary adjustments to the research approach.

Researchers will have up-to-date Disclosure & Barring Service certification, Occupational health clearance and NHS research passports. Prior to data collection commencing the researchers will complete or refresh Safeguarding Vulnerable Adults levels 1–3.

Risk to researchers

There is a very minor risk of emotional distress for the researchers.

Interviews- researchers will be asking carers about their experiences during their relatives admission to a mental health ward and about their support needs. This could be upsetting for the researchers. To mitigate this all researchers will be provided with weekly supervision and support by the projects PI who is a clinical psychologist and has worked with carers of people with dementia for many years. In addition to regular supervision, ad-hoc debriefs will be available to researchers as needed.

Ethnographic observation- researchers will witness people with dementia who are distressed, it is possible this may be upsetting. However, all researchers have experience of these wards and of working with people with advanced dementia who are distressed. Weekly supervision will provide a space to share any concerns with the PI.

There is a minor risk of physical or verbal hostility towards researchers

Ethnographic observation- These wards care for people who are distressed and so there may be minor risk of harm to the researcher. This risk is very minimal as most distress occurs during personal care tasks which researchers will not be observing. To mitigate this risk researchers will follow ward safety protocols, such as carrying personal alarms so that they can call for help if needed. Researchers will attend staff handover meetings before carrying out observations so will be made aware if anyone is acutely distressed or there are any new risks. As researchers are observing staff practices it is unlikely they would ever be alone on the ward with a patient or a family member.

Capacity to consent

We will adhere to the recommendations and guidelines for conducting research with older people, individuals living with dementia, and those with cognitive impairments. The Mental Capacity Act 2005 (England and Wales) provides a legal framework to protect the rights of individuals with cognitive decline, allowing them to make decisions for as long as possible. It is crucial to understand that the inability to provide informed consent and participate in research cannot be assumed based solely on a specific illness or condition [72]. Having choice and control over decisions is a key aspect of quality of life [73]. Some participants (those taking part in co-design and feasibility) may be in the early stages of memory problems, and even those with more severe impairments (such as typical in MHWs) must have their capacity assessed in relation to the specific activity proposed.

Participation in this study will be open to individuals with dementia at all stages and types, who are receiving care in MHWs. The capacity of people living with dementia can vary and fluctuate due to a range of factors including psychosocial, situational, medical, psychiatric, and neurological influences. Symptoms such as cognitive impairment, short-term memory loss, communication difficulties, and poor concentration can make obtaining informed consent challenging. Additionally, the capacity to consent can change rapidly, especially in acute settings.

We will take steps to support people's capacity including providing easy read versions of information forms and consent forms (interviews, co-design and feasibility) and completing dyadic interviews. For the co-design, providing information in advance and offering technical support. Where people are unable to consent, consent will be sought from a consultee (family carer or medical consultant) acting on behalf of the person with dementia, following the safeguards with respect to research contained within the Mental Capacity Act. A decision about capacity will be made by the researcher, and the patient will not be enrolled if the researcher believes this could be detrimental to their mental health or care.

Informed consent

Our aim is to achieve 'maximally informed consent' [69] viewing informed consent as an inclusive process that considers the abilities of individuals with memory issues or dementia in specific contexts that emphasize their remaining strengths [69]. Dewing (2007) [74] suggests that consent capacity should not be judged solely on cognitive test scores; instead, it should be seen as an opportunity for the research team to find ways to involve them in the study. Our team has extensive experience conducting research with people living with dementia. We will strive to obtain fully informed and voluntary consent, considering both the participant's willingness and their level of understanding, ensuring there is no coercion involved. The team has significant experience of involving PLWD and their families in research (EW, KF, SM, JH), and involving people experiencing severe mental health disorders (SM) in research.

*Sur*vey: participation is voluntary, participants will read the information sheet and give consent by clicking to open the survey. They can withdraw by closing the survey prior to submission of their answers.

Interviews: Participation will be entirely voluntary, without any coercion or undue influence. Researchers will ensure that carers feel free to decline participation or withdraw from the study at any point. Written informed consent will be taken before each interview. Where people with dementia wish to take part in interviews alongside the carer, their capacity to consent will be assessed by the researcher ahead of each interview. Only those with capacity will be invited to participate in interviews. If a person with dementia consents to and participates in an interview but loses capacity before the next one, they will not be involved in the subsequent interview.

Ethnography: Upon arrival at the wards, researchers will verbally inform all patients and their family carers about the study, explaining that the researchers are observing staff as they perform their daily tasks. Observations will be conducted from the corridors, in public areas such as nursing stations and communal spaces, and not at the patient's bedside. A4 posters and summary information sheets detailing the study will be displayed at the entrance and throughout the observed wards. Only non-identifiable information will be recorded as part of the observations of ward activities.

The primary focus of the observations is on the delivery of care, however, it is inevitable that patients will also be witnessed by the study team. Therefore, we will be seeking consent prior to the study from either patients with dementia, or where they are unable to consent, from a consultee acting on behalf of the person with dementia, following the safeguards with respect to research contained within the Mental Capacity Act.

A decision about capacity will be made by the researcher, and the patient will not be enrolled if the researcher believes this could be detrimental to their mental health or care. Written consent will be taken from the consultee who will either be a family carer or the medical consultant if the patient lacks capacity

If a person with dementia has themselves consented and then lost capacity during the study, we would stop the observations and request consent from their consultee.

If the consultee advises that the participant would not wish to participate, we will immediately withdraw the participant from the study, meaning that the researchers will not conduct observations in areas where this patient is and will not attend meetings related to this patient.

Carers will be notified of any new or ongoing observations and will be reminded by ward staff or researchers periodically or upon request. Verbal consent will be taken from carers. Where researchers are taking prolonged observations in an element of care that involves staff interactions with carers (such as in a team meeting or during a supervised visit) written consent will also be sought. Consent can be withdrawn at any time. If a carer opts out of the study, researchers will stop observing any ward area where that person is present.

Staff members will be fully informed about the study's purpose, methods, and what participation entails. It will be made clear through all aspects of the research participation is voluntary and participants can withdraw at any time without any negative consequences. Consent processes will emphasise confidentiality, that any data collected will be anonymized and to protect their privacy. Researchers will try to be mindful of potential power dynamics, making it clear that the decision to participate or not will not affect employment. The research team will visit wards at least two weeks before the study begins, giving staff the opportunity to meet with the researchers, to be informed of the details of the study, and to voice any questions they may have. Once observations begin, initially only verbal consent will be taken, first from the senior nurse in charge of the ward on that shift. Staff will be informed that they can ask for observations to cease at any point and for any reason or none. Following verbal consent, written consent will be taken before, during, or after the period of observation at a time most convenient to each staff member, in a way that will least impact on their routine and the pressures of their shift. Should a staff member decline to give written consent, field notes involving them will be destroyed and data collected from them will form no part of the research findings.

Due to the nature of hospital wards, staff from other parts of the hospital will at times enter areas under observation. It is not practical to take consent from all members of hospital staff in these circumstances, as this may entail interrupting ward processes, interventions and patient care. Instead, throughout the period of observation, posters will be displayed prominently at the entrance doors and within each ward around the area under observation informing all entering that observations are ongoing, that information sheets will be made available, with the teams' contact details, and details of how to opt out. In addition, when possible, staff entering these wards will also be notified verbally of the research as soon as practicable without interrupting their clinical work. Observations will cease should any staff member raise any concerns about being observed.

Co-design and feasibility: participation is voluntary, information sheets are provided to all participants with a simplified version created for people with dementia. Participants will have the opportunity to speak to the researcher to get more information and have questions answered. Written consent will be taken from all participants and verbal consent will be taken at the start of each workshop /focus group.

Confidentiality

Survey responses will examine ward level data not patient level data. Survey responses will be aggregated across wards to ensure that individual wards are not identifiable in reporting. Where ward managers share contact details to sign up for the study newsletter these will be stored separately from survey response in a password protected excel database.

During ethnographic observations on the ward, researchers may hear personal and sensitive information about patients. In addition, researchers will observe some privileged closed meetings in the form of MDTs and ward rounds. No data about patients will be recorded during observations. The fact that researchers may hear personal and sensitive information and will attend privileged closed meetings, will be made explicit in participant information forms for patients, carers and consultees.

New patients may be admitted to the ward during an observation period, or researchers may attend a handover where a new patient is discussed. To address situations where a new patient is admitted or discussed and a carer or medical consultant in charge is not available to discuss capacity and obtain consultee approval, CAG approval will be sought. The researcher will then assess the patient's capacity to consent at the earliest opportunity, and subsequently seek consent from the patient, or where appropriate their consultee.

Document review (ethnography) will involve looking at ward templates for gathering and sharing information with carers. Researchers will look at blank templates only.

Interviews, workshops, and focus groups will be transcribed and anonymized, with recordings deleted afterward. Anonymized qualitative and ethnographic data (field notes) will be transferred to encrypted, password-protected computers owned by the University of West London for analysis. Electronic data, such as audio recordings and transcripts, will always be encrypted and stored on password-protected devices before transfer. Data will only be stored on secure, password-protected university computers and servers. Handwritten documentation, including field notes and consent forms, will be scanned and stored as electronic files, with the paper versions securely destroyed at the University of West London.

Personal data collected for this study will be minimal. Any personal data, such as names and contact details, will be stored electronically in password-encrypted files on a secure server provided by the University of West London. Consent forms and field notes will contain only minimal personal data (name, signature). Paper consent forms will be scanned, and electronic versions will be stored on password-protected university computers and servers, with the originals securely destroyed.

In all reporting and publication of findings individual participants will not be identifiable. Confidentiality will be ensured at all times. Pseudonyms will be used for transcripts and in written reports. Direct quotes will not include any identifiable information. Methods of presentation that protect anonymity will be adopted including composite stories. In line with the Caldicott Principles, only information necessary to the organisation and delivery of the study will be obtained from participants. Minimal contact details will be required for follow-up interviews and from those wishing to be updated of the findings of the study or receive project newsletters, this will include the name, address and telephone number or email of participants. All contact details will be stored securely and destroyed within 3 months of completion of participation in the study.

Only members of the research team will have access to data. The research team who visit the NHS sites will all have current research passports and authority to conduct research on these NHS sites. The requirements of the Caldicot Principles and Data Protection Act will be observed and confidentiality maintained at all times. Data generated as a result of this study, and security arrangements for the protection of that Data, will be available for inspection on request by University of West London, the REC, local R&D Departments and the regulatory authorities.

Data security

The data generated will be analysed by the research team at offices at University of West London and at the researchers' own homes on secure password protected University of West London computers. The research data will be saved in a clearly labelled study folder on a secure university drive accessible only to the study team. All study files will be named and dated and stored in the project folder. A back-up folder will be created and maintained by the PI's (EW) university drive. The back up will be mainlined once a month.

Emma Wolverson PI will act as the custodian for the data generated for the study. Personal data will be stored for 3 months after the study. Research data generated by the study will be stored for 5 years. Data will be stored and destroyed at University of West London in line with the University of West London Data Protection Policy and University of West London research Governance guidelines.

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