FULL TITLE OF THE STUDY

Understanding the everyday use of restrictive practices in the care of people living with dementia during a hospital admission: reducing inappropriate use, identifying good practice and alternative approaches to reduce risk and improve care

SHORT STUDY TITLE

The use of restrictive practices in the care of PLWD in hospital

PROTOCOL VERSION NUMBER AND DATE

Protocol Version Number	**Date Created**
Protocol 1.0	24 03 2022

RESEARCH REFERENCE NUMBERS

IRAS Number:	313816
CPMS Number:	53197
FUNDERS Number:	132903

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature:

Date:
15/08/2022

....

Name (please print): Professor Madeleine Ohl

....

Position: Chair of the University Research Ethics Committee

Chief Investigator:

Signature:

Date:
08/08/2022

....

Name: (please print): Katie Featherstone

....

KEY STUDY CONTACTS

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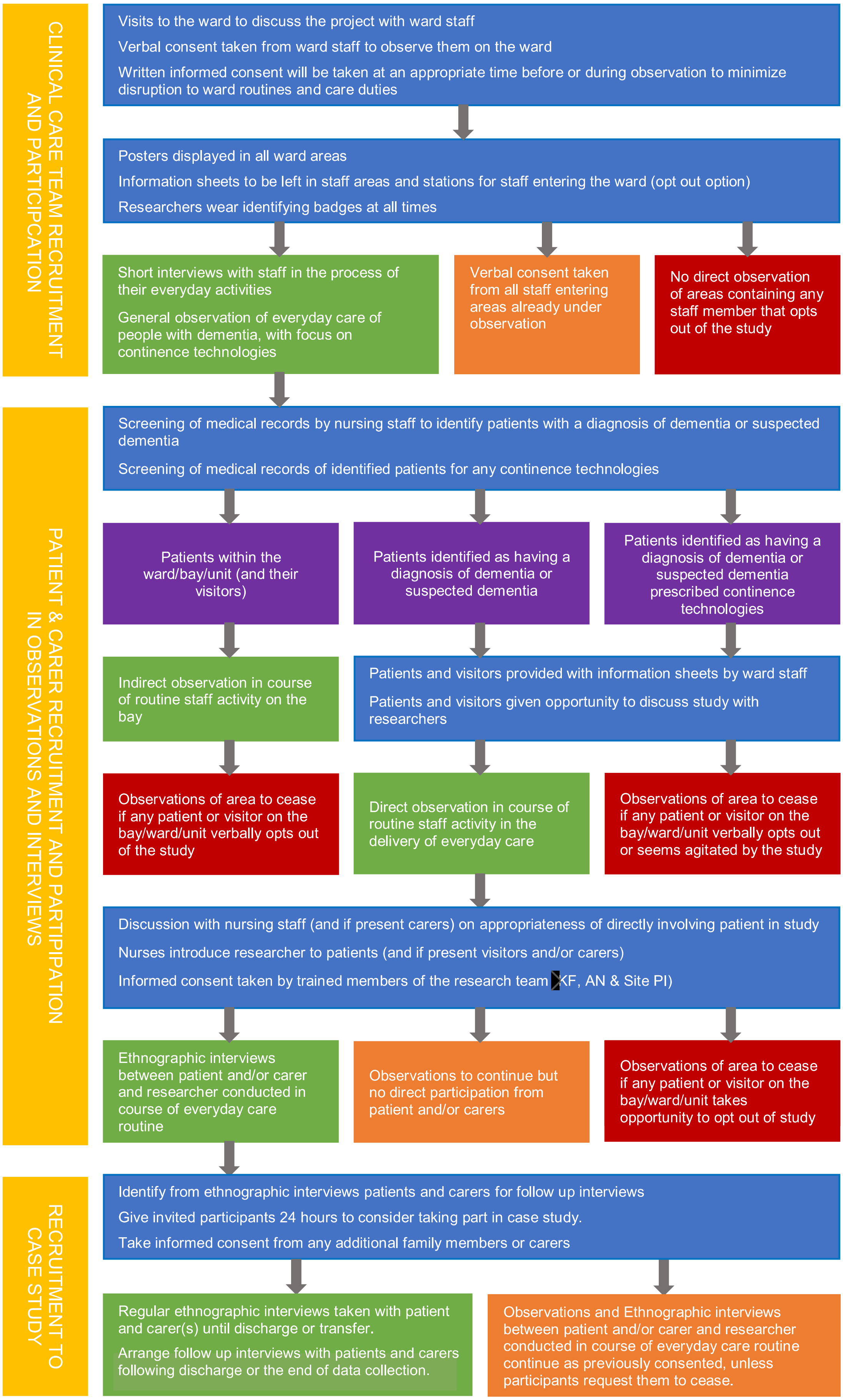
Funder(s)	NIHR HSDR

STUDY SUMMARY

Study Title	Understanding the everyday use of restrictive practices in the care of people living with dementia during a hospital admission: reducing inappropriate use, identifying good practice and alternative approaches to reduce risk and improve care
Internal ref. no. (or short title)	The use of restrictive practices in the care of PLWD in hospital
Study Design	Ethnographic
Study Participants	People living with dementia, Carers and family members of people living with dementia, Hospital staff delivering care to people living with dementia.
Planned Size of Sample (if applicable)	140
Planned Study Period	18 months
Research Question/Aim(s)	1. Provide a detailed examination of the social and organisational context in influencing the everyday care of PLWD to understand the (a) nature of restrictive (and alternative) practices within acute wards (b) circumstances and contexts of use (c) care practices when PLWD are perceived as at risk of 'falls' or 'wandering', or when their behaviour is perceived as 'challenging', 'disruptive' or 'aggressive'. 2. Examine the recognition, understandings, and experiences of restrictive (and alternative) practices during an admission from the perspectives of PLWD and their families. 3. Examine staff perspectives (a) their understandings and recognition of restrictive practices (b) the formal frameworks and informal rationales drawn on to inform the care of PLWD. 4. Translate the findings into evidence-based strategies to support best practice and alternative approaches in the care of PLWD at ward level.

STUDY FLOW CHART



CLINICAL CARE TEAM RECRUITMENT AND PARTICIPCATION

Visits to the ward to discuss the project with ward staff

Verbal consent taken from ward staff to observe them on the ward

Written informed consent will be taken at an appropriate time before or during observation to minimize disruption to ward routines and care duties

Posters displayed in all ward areas

Information sheets to be left in staff areas and stations for staff entering the ward (opt out option)

Researchers wear identifying badges at all times

Short interviews with staff in the process of their everyday activities

General observation of everyday care of people with dementia, with focus on continence technologies

Verbal consent taken from all staff entering areas already under observation

No direct observation of areas containing any staff member that opts out of the study

PATIENT & CARER RECRUITMENT AND PARTIPIPATION IN OBSERVATIONS AND INTERVIEWS

Screening of medical records by nursing staff to identify patients with a diagnosis of dementia or suspected dementia

Screening of medical records of identified patients for any continence technologies

Patients within the ward/bay/unit (and their visitors)

Patients identified as having a diagnosis of dementia or suspected dementia

Patients identified as having a diagnosis of dementia or suspected dementia prescribed continence technologies

Indirect observation in course of routine staff activity on the bay

Patients and visitors provided with information sheets by ward staff

Patients and visitors given opportunity to discuss study with researchers

Observations of area to cease if any patient or visitor on the bay/ward/unit verbally opts out of the study

Direct observation in course of routine staff activity in the delivery of everyday care

Observations of area to cease if any patient or visitor on the bay/ward/unit verbally opts out or seems agitated by the study

Discussion with nursing staff (and if present carers) on appropriateness of directly involving patient in study

Nurses introduce researcher to patients (and if present visitors and/or carers)

Informed consent taken by trained members of the research team [redacted]XF, AN & Site PI)

Ethnographic interviews between patient and/or carer and researcher conducted in course of everyday care routine

Observations to continue but no direct participation from patient and/or carers

Observations of area to cease if any patient or visitor on the bay/ward/unit takes opportunity to opt out of study

RECRUITMENT TO CASE STUDY

Identify from ethnographic interviews patients and carers for follow up interviews

Give invited participants 24 hours to consider taking part in case study.

Take informed consent from any additional family members or carers

Regular ethnographic interviews taken with patient and carer(s) until discharge or transfer.

Arrange follow up interviews with patients and carers following discharge or the end of data collection.

Observations and Ethnographic interviews between patient and/or carer and researcher conducted in course of everyday care routine continue as previously consented, unless participants request them to cease.

TABLE OF CONTENTS

PROTOCOL

Understanding the everyday use of restrictive practices in the care of people living with dementia during a hospital admission: reducing inappropriate use, identifying good practice and alternative approaches to reduce risk and improve care

Prof Katie Featherstone, Geller Institute of Ageing and Memory, University of West London
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Dr Sofia Vougioukalou, Cardiff University
Dr Rachael Kelley, Leeds Beckett University
Dr George Crowther, Leeds and York Partnership Foundation Trust
Prof Karen Harrison Dening, Dementia UK

Summary

This ethnography will examine everyday cultures of restrictive practices in the care of people living with dementia during an acute hospital admission. Restrictive practices refer to a range of practices including containment, restriction, seclusion, and restraint. This study will seek to understand how ward staff use restrictive practices in the organisation and delivery of care for people living with dementia during an acute hospital admission, what forms these practises take, what are the rationales for their use, and what are the experiences of restrictive practices from the perspectives of people living with dementia, their families, and ward staff. We will identify evidence-based transferable strategies in the care of people living with dementia that are both achievable and safe.

Data collection (ethnography includes observation, ethnographic interviews, and document analysis) will be carried out within 9 wards: 6 acute wards and 3 specialist inpatient mental health wards within three dyads of hospital Trusts, partnerships covering acute and mental health care in single geographic regions (Yorkshire, the South East, South Wales).

Within each dyad, we will observe care within two acute wards where large numbers of PLWD are known to be admitted amongst a general patient population, General Medical and Care Of The Elderly. Within each ward, 30 days of observation will be conducted (180 days total). This will be accompanied by 15 days of observation within one allied dementia specialist mental health in-patient ward affiliated with the acute wards (45 days total). This will provide opportunities to identify what is currently understood as “good practice” and practices (e.g. communication skills, alternative practices) that could be transferred across settings.

Data collection (observation, ethnographic interviews, document analysis) within each ward will take place over a 16 week period and will focus on:

- Observing ward timetabled and routine care practices within and across shifts and different staffing structures (weekends/nights), including shift change/handover and high demand periods within the wards, to understand the impacts of the everyday cultures of care for people living with dementia, and the role of restrictive (and alternative) practices.

- Shadowing (observation and ethnographic interviews) the work of ward staff (nurses and HCAs), within these wards as they organise and deliver care for people living with dementia, to understand their practices and rationales. This will include wider healthcare teams (medical, allied health professional, auxiliary etc) as they are involved in the care of people living with dementia within these wards.
- Observing clinical assessments (handover, board rounds, multidisciplinary team meetings, and where possible "patient flow" discharge and transfer meetings) to examine understandings of dementia, the assessment of risk, beliefs about safety, and the visibility of restrictive practices in decision making for people living with dementia during and across an admission.
- Observing to identify which patients experience restrictive practices, what forms they take, and if there are any individual patients or groups who appear to be excluded, exempt, or experience increased use (or particular forms) of these practices during everyday care.
- Observing the care of people living with dementia (within and across shifts) perceived as at risk of 'falls' or 'wandering', or when their behaviour is perceived as 'challenging', 'disruptive' or 'aggressive' to identify and understand for individual patients and groups of patients.
- Ethnographic interviews (short <10 minute conversations during ethnographic observation) with ward staff (nurses, HCAs, medical teams, AHPs) and teams where their role (including: dementia support, enhanced care, mental health liaison, psychiatric services, social workers, security) involves supporting people living with dementia (based on previous ward ethnography, total=90 per site).
- Document analysis (from ward managers, clerks, patient records) to support understandings of the formal and informal ways restrictive (and alternative) practices manifest within wards including staffing, work allocation, bed occupancy, patient acuity, turnover during the periods of data collection.

Interviews will be carried out with people living with dementia, their care partners and families to explore the recognition, understandings, and experiences of restrictive (and alternative) practices. The perspectives of people living with dementia and their families will be obtained (where possible) during and following the wider ethnography. During an admission:

- via a sequence of short in situ ethnographic interviews (short <10 minute reciprocal conversations), directed by the person living with dementia (participants per site = >30) to support expression (verbal or embodied) of experiences (excluding direct questions and recall of events) of their admission.
- Longer interviews may be carried out with family members (family members = >30) to explore the wider context of care and circumstances leading up to the admission.

Following discharge in the community:

- People living with dementia and their family members (n=>30) participating in the ward ethnography and interviews will be invited to continue participation in follow-up interviews to explore their longer-term experiences and impacts of the acute admission, including the use of restrictive practices for the person and for their care trajectories.

Across hospital sites, we will shadow (observation and ethnographic interviews) hospital staff, services and specialist teams (Including: dementia support, enhanced care, mental health liaison, psychiatric services, social workers, security) where their role (and recognised expertise) involves supporting PLWD, to provide understandings of their approaches and what is considered good practice within these sites and specialisms.

Analysis will inform the delivery of evidence-based strategies, developed in collaboration with participating wards, translating the findings to support best practice and alternative approaches, in the care of people living with dementia at ward level. The development and translation of findings into open access training and NHS service organisational interventions, which will be disseminated in collaboration with Improvement Cymru and Dementia UK.

This project was funded by the NIHR HS&DR Researcher Led Programme (project number 132903). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Background

People living with dementia (PLWD) are at significant risk of experiencing restrictive practices during an unscheduled hospital admission (NHS Wales, 2015; Ang et al. 2015; Care Quality Commission, 2017). Restrictive practices refer to a range of practices including containment, restriction, seclusion, and restraint.

PLWD are one of the largest populations (25-50%) within our acute hospitals (Royal College of Psychiatrists, 2013; DoH 2014, Alzheimer's Society, 2016; Crowther et al, 2017; Featherstone et al 2019), representing a significant proportion of emergency admissions (77%), typically with potentially preventable conditions such as pneumonia, sepsis, urinary system disorders, and frailty or long bone fractures (ARUK, 2019). However, their hospitalization is associated with increased risk of deterioration (Goldberg et al, 2012), institutionalization (Lehmann et al 2018), and death (Sampson et al 2013; Care Quality Commission, 2014), in comparison to similar patients without a diagnosis of dementia.

The use of restrictive practices during an admission is associated with adverse impacts, primarily further functional and cognitive decline (Freeman et al, 2017; Sethi, et al 2018; Chou et al, 2020). This is a significant concern given the growing recognition that immediate action is required to improve experiences and outcomes for PLWD during an acute admission (Care Quality Commission 2021).

NHS serious incident reviews and media reports (Buchanan 2020) identify restrictive practices embedded within NHS ward cultures of care for older people and PLWD. This echoes the findings embedded within reviews of acute care for PLWD (Dewing and Dijk 2014; Haughton et al, 2016; Reilly and Houghton, 2019) and research examining organizational cultures of acute nursing care (Gunawardena and Smithard, 2019), which identify restrictive practices as part of ward cultures of control (Hughes, 2008), and cultures of nursing care (Haughton et al, 2016). This body of research suggests a high reliance on the use of restrictive practices in the organisation and delivery of acute care (Gunawardena and Smithard, 2019) and the care of PLWD during an acute admission (Yan et al, 2009; Featherstone et al 2019b; Parke et al, 2019).

We know formal legal regimes (Tomlinson v. Congleton Borough Council & Ors, 2003; Human Rights Act 1998) and clinical rationales (Weiner et al, 2003; Irving, 2002; Borbasi et al. 2006; Lane et al, 2011; Moyle et al. 2011; Goethals et al, 2012; De Bellis et al 2013), emphasise the use of restrictive practices to ensure safety, reduce risk, and prevent falls. However, restrictive practices also take the form of a wide range of routine ward practices (Care Quality Commission, 2017; Gunawardena and Smithard 2019) and cultures of control (Xyrichis et al, 2018) during the care of PLWD. These are associated with an increased risk of falls, serious injury (Natan et al, 2010;), deterioration (Hofmann and Hahn 2013; Moyle et al. 2011), delirium (Inouye, Westendorp, & Saczynski, 2014; Pan et al, 2018;), significant patient distress (De Bellis et al, 2013; White et al 2017), longer admissions (Bai et al, 2014; Tan et al. 2014), and death (White et al 2017; Bellenger et al, 2018). Its routine use is associated with staff emotional and physical burnout (Mersey Care NHS Foundation Trust, 2016).

Thus, the reduction of restrictive practices for all patients is an NHS long-term goal (Alderwick and Dixon, 2019; Department of Health, 2014; NHS Confederation, 2012), with professional bodies (Royal College of Nursing, 2013), calling for training in the use of restrictive practices for all healthcare staff caring for PLWD. Reviews conclude that evidence-based rigorous research is required (Evans et al, 2002; Hughes, 2008; De Bellis et al, 2013) to inform training relevant to everyday practice (Allwood et al 2017; Surr and Gates 2017); however, the research agenda has lagged behind. Our systematic scoping review has identified that to date, the examination of restrictive practices in the care of PLWD during an acute NHS admission has not been the true focus of any substantive rigorous research.

Research Question

How do ward staff use restrictive practices in the organisation and delivery of care for PLWD during an acute hospital admission?

Aims and objectives

The aim of this in-depth ethnographic study is to examine everyday cultures of restrictive practices in the care of PLWD during an acute hospital admission. It will explore what forms these practices take, the rationales for their use, and the experience of these practices from the perspectives of PLWD, their families, and ward staff. It will identify evidence-based (and alternative) strategies in the care of PLWD that are achievable, safe, and transferrable across care settings. Our objectives are to:

5. Provide a detailed examination of the social and organisational context in influencing the everyday care of PLWD to understand the (a) nature of restrictive (and alternative) practices within acute wards (b) circumstances and contexts of use (c) care practices when PLWD are perceived as at risk of ‘falls’ or ‘wandering’, or when their behaviour is perceived as ‘challenging’, ‘disruptive’ or ‘aggressive’.
6. Examine the recognition, understandings, and experiences of restrictive (and alternative) practices during an admission from the perspectives of PLWD and their families.
7. Examine staff perspectives (a) their understandings and recognition of restrictive practices (b) the formal frameworks and informal rationales drawn on to inform the care of PLWD.
8. Translate the findings into evidence-based strategies to support best practice and alternative approaches in the care of PLWD at ward level.

Research Plan / Methods

Our ethnographic approach will enable us to examine and understand how staff respond to the care needs of PLWD, the role of restrictive practices, and to follow the consequences of their actions during shifts and over an admission on PLWD and their families. We will examine how staff account for and make sense of their responses to the care needs of PLWD in these contexts and the impacts of the organisational pressures and the use of restrictive practices on individual staff members and ward teams. We will also involve people living with dementia (where possible), their care partners and families to explore the recognition, understandings, and experiences of restrictive (and alternative) practices

An ethnographic approach can provide detailed understandings of ward organisational cultures, social processes, and the interrelationships between different elements of these organisations (Hammersley, 2006; Caracelli, 2006). Observational methods are a key approach to examine the interactional aspects of care delivery at the bedside (Featherstone et al 2019), workplace cultures of care (Muir-Cochrane et al, 2014; Xyrichis et al, 2018; Featherstone and Northcott, 2020), and the largely invisible work of restrictive practices as part of the everyday routine care for PLWD within acute settings. Thus, we will provide a detailed examination of the social and institutional forces that shape and influence this work to understand the rationales and uses of restrictive practices (Krüger *et al*., 2013), and the impacts on both PLWD (Gallinagh et al., 2002; Evans et al, 2003; Kirkevold & Engedal, 2004; Meyer et al, 2009) and ward staff.

A body of research and reviews (c.f De Bellis, 2013) concluding that to develop interventions in order to reduce the use of restrictive practices in the care of PLWD, research must deliver understandings of NHS organisational cultures that can inform interventions that "address the person, the environment and the interaction between the two" (Royal College of Psychiatrists, 2006:9-10). Ethnography is able to provide these understandings, what contributes to cultures of restrictive practices, but also crucially the ways in which the organisational cultures can be modified and what alternatives could inform care. The goal is to provide depth of understanding and theory generation, with transferability a key objective (Hammersley, 1987).

Ethnographic data collection and analysis

Our ethnographic approach is in the analytic tradition of grounded theory and will employ the constant comparative method and theoretical sampling whereby data collection and analysis are interrelated (Glaser and Strauss, 1967; Corbin and Strauss, 1990) and carried out concurrently (Green, 1998; Suddaby, 2006). The flexible nature of this approach is important, because it can allow us to increase the 'analytic incisiveness' (Charmaz and Mitchell, 2001:160) of the ethnography: as data are collected in one site, preliminary analysis of this will proceed in parallel, with this preliminary analysis informing the focus of later data collection within the next site and the further stages of analysis.

Grounded theory (Glaser and Strauss,1967) is a practical and flexible analytic approach for ethnographic research (Charmaz and Mitchell, 2001). It reinforces the ethnographic aims of achieving a theoretical interpretation of the data, whilst the ethnographic approach prevents grounded theory from being applied in a mechanistic and rigid way (Charmaz and Mitchell, 2001). A common concern with ethnography is that it can treat everything within a setting as 'data', which can lead to the collection of large volumes of unconnected data, producing a heavily descriptive analysis (Atkinson and Coffey, 1996). Instead, grounded theory provides the ethnographic team with focussed data collection strategies for studying key social processes. This approach provides a middle ground in which the ethnographic team, often seen as passive observers of the social world, will use grounded theory to provide a systematic approach to data collection that can support the generation and development of theory to understand the interpretive realities of the wide range of actors within these ward settings (Charmaz and Mitchell, 2001).

Data collection

Data collection will be carried out within 9 wards: 6 acute wards (3 x general medicine and 3 x older person's care = 6) and 3 specialist inpatient mental health wards within three dyads of hospital Trusts, partnerships covering acute and mental health care in single geographic regions (Yorkshire, the South East, South Wales). These are wards identified as sites with large populations of PLWD (ARUK, 2019) and with potentially high use of (formal and informal) restrictive practices (Gunawardena and Smithard, 2019; Parke et al, 2019).

Data collection (observation, ethnographic interviews, document analysis) within each ward will take place over a 16-week period (30 days/shifts per general medicine and acute wards, and 15 days/shifts per specialist inpatient mental health ward). We will examine everyday hospital organisation and clinical processes, timetabled routines of care, ward rounds, consultations, case reviews, and clinical meetings (ward handovers and board rounds) within and across shifts (day, night, week, and weekend shifts) and teams.

Observations

Within each ward, ethnographic observations will focus on:

- Observing the everyday organisational context and delivery of the timetabled routine work of the wards and everyday patient bedside care for PLWD, with a focus on the visible work of nurses and HCAs who are responsible for PLWD care.
- Observing and tracing the wider circumstances surrounding (leading up to, during, and following) the use of restrictive (and alternative) practices during the care of PLWD.
- Observing which patients experience restrictive practices, what forms they take, and if there are any individual patients or groups who appear to be excluded, exempt, or experience increased use (or particular forms) of these practices during everyday care.
- Observing the care of PLWD (within and across shifts) perceived as at risk of 'falls' or 'wandering', or when their behaviour is perceived as 'challenging', 'disruptive' or 'aggressive' to identify and understand for individual patients and groups of patients.

This will provide directly observed examples of ward organisational management responses and care strategies, circumstances, contexts, and impacts of the use restrictive practices on patients (where possible across an admission) and on staff (for example the impacts on ward teams across shifts).

Shadowing (observation and ethnographic interviews) healthcare staff and teams within these wards as they organise and deliver care for PLWD, to understand their practices and rationales. This will focus on shadowing nurses and HCAs, including wider healthcare teams (medical, allied health professional, auxiliary etc) as they are involved in the care of PLWD within these wards. Specifically, this will involve:

- Observing care practices within and across shifts (am/pm) and different staffing structures (weekends/nights) to include shift change/handover and high demand periods within the wards, to understand the impacts of the timetable and ward routines, everyday cultures of care for PLWD, and the role of restrictive (and alternative) practices.

- Observing clinical assessments (handover, board rounds, multidisciplinary team meetings, and where possible "patient flow" discharge and transfer meetings) to examine understandings of dementia, the assessment of risk, beliefs about safety, and the visibility of restrictive practices in decision making for PLWD during and across an admission.

Across hospital sites, we will also shadow specialist staff and teams where their role (and recognised expertise) involves supporting PLWD, to provide understandings of their approaches and what is considered good practice within these sites and specialisms:

- Shadowing (observation and ethnographic interviews) of wider hospital staff, services and specialist teams (Including: dementia support, enhanced care, mental health liaison, psychiatric services, social workers, security) routinely involved in caring for PLWD across these hospital sites.

We acknowledge the potential for the Hawthorne effect or 'participant reactivity' and that behaviour may be changed by researcher presence in the wards. Based on our prior research within acute wards (Featherstone and Northcott, 2020), this time frame will allow the development of close ties with social actors (those being observed), minimising its potential to impact on data collection and analysis. A strength of an ethnographic approach is that any performances observed, however staged or influenced by the researcher presence (typically during early data collection), can reveal critical insights by displaying how people see themselves and how they want to be seen (Monahan & Fisher, 2010; Paradis & Sutkin, 2017).

We recognise that direct observations of patients or staff could be intrusive, or obstruct the delivery of care. The research team are all experienced in conducting observations within fast paced clinical and acute ward settings. Before observations begin, discussions will be held with senior ward staff (typically the ward sister or nurse in charge) to establish positions on each ward from which practice can be observed without affecting the flow and movement of the ward. This will mean the researchers will typically be situated near a nurses' station or standing to one side in the corridor of the ward.

Document Analysis

Document analysis (from ward managers, clerks, patient records) to support understandings of the formal and informal ways restrictive (and alternative) practices manifest within wards:

- Data collection of staffing, work allocation, bed occupancy, patient acuity, turnover during the periods of data collection.
- Data recording the physical space (layout, visibility, signage, locked entrance, 'dementia friendly' resources and design).

Document analysis of formal frameworks available to staff via recording practices (bedside recording practices) and within the wards (clinical pathways, legal forms and documents) that may involve the use, reporting, or recognition of restrictive practices.

Interviews- ward staff

Ethnographic interviews with ward staff (short <10-minute conversations during ethnographic observation) with ward staff (nurses, HCAs, medical teams, AHPs) and teams where their role (including: dementia support, enhanced care, mental health liaison, psychiatric services, social workers, security) involves supporting PLWD (based on previous ward ethnography, total=90 per site). During observation ethnographic interviews with staff as they are caring for this patient group to explore:

- What staff draw on to inform their care of PLWD,
- What is recognised as restrictive (and alternative) practices,
- the informal embedded rationales used in decision making, and what informs their use of restrictive and alternative practices

Ethnographic interviews will be recorded as anonymous, near verbatim fieldnotes alongside observational data.

Interviews – people living with dementia, care partners and families

Interviews with people living with dementia, their care partners and families to explore the recognition, understandings, and experiences of restrictive (and alternative) practices. The perspectives of PLWD and their families will be obtained (where possible) during and following the wider ethnography.

During an admission:

- Ethnographic situated interviews (Buse & Twigg, 2014, 2015) or "in situ conversations" (Ward & Campbell, 2013) (short <10-minute reciprocal conversations), directed by the PLWD (participants per site = >30) to support expression (verbal or embodied) of experiences (excluding direct questions and recall of events) of their admission.
- Longer, in-depth, interviews with family members (family members = >30) to explore the wider context of care and circumstances leading up to the admission.

Following discharge in the community:

- PLWD and their family members (n=>30) participating in the ward ethnography and interviews will be invited to continue participation in follow-up interviews to explore their longer-term experiences and impacts of the acute admission, including the use of restrictive practices for the person and for their care trajectories.

We draw on a range of literature that demonstrates people at all stages of their dementia diagnosis, can participate in qualitative and ethnographic research, including during a hospital admission (Digby et al., 2016; Phillipson and Hammond, 2018), and that contributing to research and discussing their care and experiences can promote well-being and social inclusion (Hellstrom et al., 2007; Tanner, 2012).

Sampling

Probability sampling is inappropriate for ethnography. Instead, non-probability sampling (theoretical sampling) provides analytically rather than statistically generalizable findings (Curtis et al, 2000). This is a flexible, pragmatic approach, with research sites, clinical settings, participants and sample size selected by identifying a range of variables that may influence the phenomena (purposive sampling). It emphasizes the importance of comparisons across sites (Vogt, 2002). This allows for the optimisation of the generalizability of findings (Herriott and Firestone, 1983), and enhances the ability for the findings to have an impact on policy and practice (Caracelli, 2006).

NHS hospital sites

Agreements are in place with three dyads of NHS (Yorkshire and the South East) and Health Boards (Wales), to allow access to both general acute wards and partnership dementia specialist mental health in-patient wards within a single geographic region. Dyads have been selected to allow diversity of demographic, geographic, and practice variables. We have particularly chosen these sites for the populations they serve, with significant minority ethnic communities (10-38%). We build on our established track record of recruiting hospital sites and collaborating with wards and have used these approaches to successfully recruit healthcare staff, PLWD, and their families, during previous ethnographic studies set within fast paced clinical and acute ward settings (NIHR 13/10/80).

Sampling of wards within each hospital site:
This ethnography will use multiple sites of observation (Marcus, 1995, 1998). Whilst our data collection sites (acute and mental health hospitals and wards) are standardized, with sequential and systematic data collection, there will be some variation within each site. Consistency within data collection is important, however, we will use theoretical sampling within sites to ensure that representativeness and consistency of concepts and events is achieved within the study, rather than sites and people. Informed by grounded theory, new knowledge emerging from the ongoing analysis will feed into the next stage of data collection to expand the research process, and to capture all relevant aspects as they emerge, into the ongoing analysis. The focus is on 'discovery' to ensure the grounding of emerging concepts within data and the reality of the settings (Glaser and Strauss, 1967).

Within each dyad of Trusts/Health Boards (n=3) we will observe everyday care involving PLWD within 2 acute wards and 1 allied dementia specialist mental health in-patient ward. In total we will exmaine 9 wards: 6 acute wards (3 x general medicine and 3 x older person's care = 6) and 3 specialist inpatient mental health wards within three dyads of hospital Trusts, partnerships covering acute and mental health care in single geographic regions (Yorkshire, the South East, South Wales). All have been identified as sites with large populations of PLWD (ARUK, 2019) and with potentially high use of (formal and informal) restrictive practices (Gunawardena and Smithard, 2019; Parke et al, 2019).

Observations within 2 x acute wards (30 days/shifts) which receive a high volume of PLWD who require medical attention for an additional acute condition. In addition, PLWD are also often transferred between these acute wards during an admission. Within each hospital site, this will take place over 16 weeks (60 days/shifts), (3 sites = total 180 days/shifts of observed practice).

- 1 x Acute wards with admission criteria focussed on grading and organising patients by age, ability, and condition, known to include high numbers of PLWD including "Care of Older People" wards, COTE ("care of the elderly"), CI (cognitive impairment) and Frailty (older patients perceived to have an elevated risk of injury and decline). These wards may include strategies and interventions to support the care of PLWD, however, at present there is limited evidence of their effectiveness.
- 1 x General acute medical wards known to have large numbers of PLWD, admitted for a wide range of reasons, but most commonly infections and falls (ARUK, 2019).

Observations within 1x inpatient mental health ward (15 days/shifts) per site. These wards (dementia specialist mental health in-patient wards, sometimes called "geriatric psychiatry" or "psychogeriatric inpatient" units or wards) are sites where restrictive practices (both formal and informal) are recognised as being part of everyday clinical care and where there are established expertise, protocols, and guidelines in the use of restrictive practices in the care of PLWD. Thus, we will also include observations within:

- 1x inpatient mental health ward (15 days/shifts) over 16 weeks across the three hospital sites (3 x sites = total 45 days/shifts of observed practice). Agreements are in place to form dyads with 3 Mental Health Partnership Trusts/Boards that are affiliated to the acute wards where observations will take place.

This will provide opportunities to identify what is currently understood as "good practice" and practices (e.g. communication skills, alternative practices) that could be transferred to acute settings.

Sampling and recruitment of PLWD and their families for interview and observation:
Our patient group of PLWD will be identified (where possible) early in the admissions process as individuals with unplanned admission and an accompanying co-morbid diagnosis of dementia formally recorded in their acute medical records. We acknowledge that the presence or absence of a formal diagnosis of dementia in general hospitals may not always be straightforward to establish, with older patients often obtaining a diagnosis or provisional "query dementia" diagnosis during admission, however, our patient group are well represented within the acute setting. Our use of theoretical sampling means we will initially use purposive sampling to ensure we have included PLWD with the range of socio-demographic characteristics typically presenting in these ward settings, including a range of ages, gender, and during the study this may also extend to include other characteristics, such as admitting condition, severity of their dementia, physical characteristics (there may be other characteristics which means an individual may be more likely to experience particular forms of restrictive practices). Over the course of data collection, where possible, this will include further maximum variation sampling to ensure our recruitment also reflects groups of PLWD often under-represented within research but are admitted to hospital wards, and who may be at increased risk of experiencing restrictive practices:

- Minority Ethnic PLWD and their families, who are known to be at increased risk of experiencing restrictive practices (Hui, 2014; Care Quality Commision 2018).
- PLWD who are also living with a psychiatric co-morbidity (Onyike, 2016), with the complex needs of this group associated with an increased use of restrictive practices in their care (Hext et al, 2018; Care Quality Commission, 2017).
- PLWD who are also living with a learning disability may be at higher risk of restrictive practices (Bigby et al, 2014).
- PLWD who are homeless are likely to be experiencing complex mental and physical co-morbidities (Stone, et al 2019), with these complex and challenging needs associated with the use of restrictive practices (Healthy London Partnership, 2019).

We are also aware of the lack of representation in research exploring the care experiences of PLWD from a number of other communities:

- PLWD within the LGBTQI communities who often face barriers to health care access (Peel et al, 2016; Fredriksen-Goldsen et al, 2016; McParland & Camic, 2018).
- PLWD with multiple and rare forms of dementia, who may be at an increased risk of hospitalization (Mueller ,et al, 2017) and recurrent hospital admissions (Atkins et al, 2015).

We do not yet know whether these populations are at risk of experiencing restrictive practices, however, where possible, the inclusion of the voices of PLWD from within these under-represented groups within research is important if we are to develop robust and inclusive health care policies and practices (Mulé et al 2009).

Sampling and recruitment of staff for observation and interviews:
In collaboration with our key informants and ward managers, hospital and clinical staff from a range of disciplines and roles in the care of this population will be included. The main groups we will shadow (observation and ethnographic interviews) are ward staff: nurses and healthcare (HCA) staff responsible for the everyday care for PLWD within these wards. We will also purposively sample staff to ensure that we include:

- Staff from other relevant disciplines including medical teams, senior nurse managers, occupational therapists, physiotherapists, auxiliary staff (catering, cleaning services etc), pharmacists/medication dispensing staff, discharge coordinators, porters, when they are involved in the wider care of PLWD as they enter these ward settings.
- Where possible we will also observe specialist staff and teams directly involved in supporting PLWD and with expertise in restrictive practice to understand what is recognised and promoted as good practice. This may include dementia support, enhanced care, mental health liaison, psychiatric services, social workers and security teams.

Within each site we will initially rely on the Site PI within each trust to facilitate the process of identifying and introducing the team to key informants at hospital and ward levels. Our key informants within each setting are all senior members of staff involved in the care of people with dementia.

Analysis: Based on previous studies carried out by the team within the acute setting (NIHR 13/10/80 and 15/136/67), ethnographic data collection will produce observational fieldnotes (>900,000 words) and interviews with healthcare staff (n=>270), interviews with PLWD and families (n=>90). Field notes of observation, experience, conversations will be written up near verbatim into word files (Van Maanen, 2011; Emerson et al, 2011). Researchers will cross-check transcripts for quality and to ensure participant anonymity, with the analytic process (of anonymised data) involving the wider team. Qualitative Analysis Software (NVivo) will be used for both analysis and to ensure password protected encryption of data to assist the secure management of anonymous data, facilitating team access (Friese, 2012).

We will apply an inductive approach to our analysis, a widely used approach, which means developing our hypothesis from the data, rather than a priori (Pope et al, 2000) and will be closely linked with the delivery of our objectives. Analysis will involve the development and testing of analytic concepts and categories, and strategies for their development include careful reading of the data, looking for patterns and relationships, noting anything surprising and inconsistencies and contradictions across the range of perspectives gathered. Initially this will produce a collection of ‘sensitizing concepts’(Blumer, 1954) and analytic memos, which will inform the development of more refined and stable analytic concepts. Line by line coding is not appropriate for fieldnotes, where coding is selective and involves whole events or scenarios (Charmaz and Mitchell, 2001). The constant comparative method (grounded theory) means that the coding of data into categories is a recurrent process. The data will then be examined in the context of previous fieldwork and the analytic memos generated will inform further data collection within the next site and the next, more focused, stages of analysis (Charmaz and Mitchell, 2001). The analytic concepts that emerge from this process will be tested and refined to develop stable concepts that transcend local contexts to identify broader structural conditions (Corbin and Strauss, 1990) influencing the care of PLWD. Our constant comparative method includes strategies to support validity and ensure that the ethnography produces trustworthy analysis. We will systematically share emergent analysis with participating teams, wards and sites; with PLWD through our PPI Advisory Group and our programme of public outreach PPI events and consultations; our ‘community of practice’ in acute dementia nursing care (Dementia UK); and our Project Advisory Group. This represents a form of ‘back-translation’ and will support the validity of the findings and their relevance for practice.

Dissemination, Outputs and anticipated Impact

Our strategy of tailored knowledge transfer is to intervene at multiple levels, working with specific groups and networks. Open access outputs will be prioritised (ongoing disruption of face-to-face teaching and the important of providing accessible formats both during and following Covid) via www.storiesofdementia.com online training portals and cross-platform social media presence:

1. Healthcare staff via training (open access online platforms of short courses, masterclasses, resources) developed in collaboration with participating wards and teams, Advisory Groups, Improvement Cymru, and Dementia UK.
2. Acute teams and wards via service organisation outputs (recommendations, guides, tools, bundles of care) developed in collaboration with participating wards, sites, teams, Advisory Groups, Improvement Cymru, and Dementia UK.
3. Public policy, NHS institutions, and commissioners in collaboration with Improvement Cymru, Public Health Wales; Senior Nursing leaders; and Dementia Boards).
4. PLWD and their families (social media sites, awareness raising, guides), and working with 3rd sector organisations and networks (this includes DEEP network (https://www.dementiavoices.org.uk), Diverse Cymru (https://www.diversecymru.org.uk) and Nubian Life (https://www.nubianlife.org.uk) on our Advisory Boards.

Because restrictive practices are both poorly recognised and under-reported within NHS routine data, it is not possible to accurately measure or monitor its use. This means it is not possible to plan a follow-up programme of work to develop and test innovation in service organisation and clinical interventions, drawing on the MRC framework for complex interventions. In response, we will deliver empirically informed open access resources and service organisation tools to support frontline staff, teams and wards who are seeking support for local service development, culture change, and improvement programmes. Our key partners in dissemination are Improvement Cymru and Dementia UK:

- Improvement Cymru have expertise in public policy and service improvement and will link our training and output development directly with the NHS standards in dementia care, the Dementia Pathway for Wales, Public Health Wales, and the NHS.
- Dementia UK will work with us to build and extend our 'community of practice' (with regular online Zoom events) focussed on ward culture change working with the 29 dementia specialist Admiral Nurses working within acute settings across England and Wales. A key feature of their role is education/training, role modelling, supervision, and mentorship of generalist acute staff working with PLWD within these 29 acute hospital sites (potentially a high number of acute staff and wards). This will extend to include all Admiral Nurses (circa 300) working across community settings, who will transfer new learning to relevant stakeholders in their spheres of practice.

Publications: build on a track record of open access publishing across nursing, clinical, policy, sociology, and anthropology journals. Co-authoring with PLWD and their families and carers and translating publications for user communities. A final report and summaries will be made available online.

We believe what we learn will have relevance to a wider group of patients in acute hospitals. The use of restrictive practices is a significant issue for patients across the acute setting, with those at risk including older patients, patients from minority ethnic communities, and patients with learning disabilities, who we know are at risk of experiencing restrictive practices during care. We will compare our findings with those from other settings to develop comparative and collaborative lessons about restrictive practices.

Project timetable

Total 30 months: 1st March 2022 – 31st August 2024
1-6 months: Preparation: Confirm recruitment of NHS Trusts/LHBs; obtain NHS REC ethics and R&D approvals. Confirm PPI Advisory Group and Project Advisory Group membership. Hold PPI public events and advisory board events (PPI and Project Advisory Boards). Research team (AN, SM, MW) will obtain updated training and skills in person-centred communication and supporting PLWD, prior to data collection.

7-24 months: Data collection at each hospital site within the acute and mental health wards (observation, ethnographic interviews, document analysis) over 4 months per site, including a further follow-up period at each site (2 x months) to include follow-up interviews, data cleaning, and complete preliminary analysis. During these periods we will work with participating sites in the translation and development of findings into open access training, resources, and service organisation outputs. Hold PPI public events and advisory board events (PPI and Project Advisory Boards).

25-30 months: Analysis and theory development. Final drafting and development of open access training course and masterclasses, resources, and service organisation outputs. Hold PPI public events and advisory board events (PPI and Advisory Boards). Report, clinical, and academic publication drafting.

Ethics / Regulatory Approvals

Approval by ethics committees: Our approach, processes, and documentation for our ethnographic research (observation, ethnographic interviews, document analysis) within ward sites, involving PLWD during an admission, and observing the everyday work of ward staff, will be informed by previous REC approvals (15/WA/0191 and 18/WA/0033) obtained for ethnographic research conducted in similar ward settings with PLWD. We will follow NHS, HRA, UKRI and University of West London governance procedures, including the University of West London Research Governance Policy, University of West London Research Ethics Code of Practice and University of West London Research Integrity Code of Practice, setting out the professional standards and requirements, and the ethical and external regulations, governing research.

Involving PLWD in research:
It is essential that the views and experiences of people living with dementia are drawn on to inform research and develop policies that inform the care of people living with dementia (Novek and Wilkinson 2019; Wang et al 2019). Involving people living dementia in research facilitates the creation of shared understanding among healthcare professionals, carers, and policy makers about what living with dementia means (Clarke et al 2018; Wang et al 2019). Mann and Hung (2019) emphasise that engaging people in research is important because it requires acknowledging individuals with the condition as full persons and involves an exploration of their lived experiences founded on their own actions and experiences, and not filtered through a third party. In contrast, ignoring or discounting the direct participation of PLWD in research supports and reinforces the

negative stereotyping associated with dementia and the stigma experienced by PLWD (Sinclair et al. 2019). Involving PLWD as participants in research enhances the relevance of the research by shining a light on the everyday experiences of living for PLWD (Clarke et al 2018).

In response, this study includes a significant focus on the perspectives of PLWD and their families, and on supporting them in sharing their thoughts, feelings and experiences of care. We do this through ethnographic observation of the everyday care they receive, building relationships during and across an admission, ethnographic (during observation) interviews during their stay within the wards, and interviews following discharge. We draw on a significant body of research demonstrating that the perspective of people living with dementia can be obtained (Roger, 2016; Samsi and Manthorpe, 2013; Tanner, 2012; Pipon-Young et al, 2012; Clemerson, et al, 2013). The use of an ethnographic approach in this study will promote the integrity of participants and prioritises a person-centred approach (Brooker 2004) because these methods emphasise a focus on the whole person and provide insight into their thoughts and feelings and experiences over time. We are aware our approaches require continual development, and in response the research team will constantly monitor their own achievement and will received mentoring from co-applicants with lived experience (NH, CR & JG).

Interivews with PLWD

To promote the inclusion and involvement of PLWD, we draw on a range of guidance and strategies (Novek and Wilkinson, 2019), which emphasize spending time with participants, building relationships and developing rapport through informal conversation before interviews (Hellstrom et al., 2007; McKillop & Wilkinson, 2004), and by extending interviews over several encounters (Hellstrom et al., 2007; Pratt, 2002; Phillipson and Hammond, 2018) to foster a supportive atmosphere (Digby et al., 2016). We recognise the centrality of using approaches to involvement that empower PLWD to communicate their experiences by building relationships and promoting participant well-being through researcher sensitivity, empathy, respect (Wang et al 2019; Digby et al., 2016; Hellstrom et al., 2007; Scottish Dementia Working Group Research Sub-Group, 2014), and authenticity (McKillop & Wilkinson, 2004) in all communication with PLWD and their families. Our goal is to ensure inclusive approaches to participation means PLWD feeling connected, understood, valued and that their experiences are being heard (Alsawy, et al, 2020).

Informed consent

Ward Staff

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 the bays or 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 parts of the hospital 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 patient care. Instead, posters giving information about observations on the ward will be prominently placed at the entrance and throughout the area under observation. Observations will be ceased should any staff member raise any concerns about being observed.

Research staff are experienced in the possibility for adverse incidents to occur in these wards (for example, a cardiac crash alarm) and in such an event would either cease observations for that day, postpone observations till a situation is resolved, or move to another area of the ward to ensure staff are not disrupted. Before observations begin at any site discussions will be held with senior ward staff to agree a course of action should an adverse incident occur.

People Living with Dementia

The inclusion of PLWD and their carers in research is a global policy and research priority (Cotton et al 2021). Researchers have an ethical duty to ensure the well-being of PWLD participating in their research (Gove et al. 2018) and traditionally, it has been common practice to exclude people deemed unable to consent to participate in research because of their diagnosis of cognitive impairment or dementia (Shepard et al 2019). However, having a diagnosis of dementia does not inevitably mean the person lacks the capacity to make decisions to participate in and contribute knowledge to research (Mann and Hung, 2019). It is important to emphasise that incapacity to provide informed consent and participate in research cannot be assumed on the basis of a particular illness or condition (Moye et al 2007); having choice and control over decisions is a key component of quality of life (Samsi and Manthorpe, 2013). Dewing (2007) argues that because capacity to consent to participation may fluctuate for people living with dementia, consent should be taken and viewed as a process. This requires the researcher to incorporate wider contextual information about the individual before involving them in research, including self-presentation, level of wellness or illness, and impact of circumstances on them (Rivett 2017). PLWD and family carers recognise the personal value in an approach that involves continuously involving and supporting them in making their own decisions for as long as possible (Sinclair et al. 2019).

We will follow recommendations and guidelines for conducting research involving older participants, people living with dementia, and the cognitively impaired. The Mental Capacity Act 2005 (England and Wales) provides a legal framework safeguarding the rights of people with cognitive decline to make decisions for as long as is possible. The research team has significant experience of involving PLWD and their families in research (KF, AN, SV, RK) and in recruiting and collecting data with people living with dementia, in the use of continuous or process consent, in conducting research aligned with the requirements of the Mental Capacity Act 2005, and in conducting research with vulnerable patient groups within hospital ward settings (NIHR 13/10/80 and 15/136/67).

To ensure consent forms and information sheets are appropriate, all study documents have been reviewed by our PPI Advisory Group and Carers Advisory Group for advice on the wording in the documents to ensure they are appropriate, clear, and using accessible language to ensure PLWD and carers are adequately informed (Rivett, 2017; Mann & Hung 2019).

Before approaching any PLWD or their families at the bedside, the research team will first speak to ward staff to discuss the patient's circumstances, admitting condition, and capacity and to understand the appropriateness of research involvement. If staff feel that an approach could cause distress to the person, they will not be approached.

Written informed consent will be required and obtained for any participants involved in aspects of the study requiring direct contact, such as for interviews. Initial contact with patients and family carers will be agreed and initially made by a member of the clinical ward team, who will introduce the researchers to them, and provide the researchers with an assessment of the patient's capacity at that time.

Study participation will be open to PLWD at all stages of the disease process and with different types of dementia who are being cared for within these acute ward settings. PLWD will have varying degrees of capacity and their capacity may fluctuate depending on the dementia, their psychosocial, situational, medical, psychiatric and neurological factors, which can make it difficult to ensure informed consent. It is also important to recognise that the capacity to consent can change quickly for this group of patients, particularly within an acute setting.

To support our inclusionary approach, this study will utilise continuous or process consent, which conceptualises consent as a continuous process with researchers considering if the study participants are consenting to each decision across the course of the study. When involving PLWD in research, consent should be taken as a continuous process (Sinclair et al. 2019; Klykken, 2017; Rivette, 2017 Dewing, 2007). Continuous consent involves both the practice of documenting formal consent and the ongoing process of involving and supporting PLWD in making their own decisions as much as possible. Once obtained, consent is continuously renegotiation and re-establishment throughout the research process to ensure participants are still willing to continue taking part in the research (Sinclair et al. 2019; Klykken, 2017; Rivette, 2017 Dewing, 2007). A key role for the researchers throughout this study is to continually assess and be responsive to changes in an individual and allow for changes or renegotiation of consent, which will involve recognising and respecting indications of dissent, unease, or unwillingness, as well as willingness to continue their participation (Rivette, 2017). If there is a possibility that their feelings about participation have altered, then their consent must and will be revisited. To increase the transparency of this process, where possible we will also consult family members. We have used this approach in successfully including PLWD in previous research studies (NIHR 13/10/80 and 15/136/67).

Training: Members of the research and PPI teams (AN, SM, MW & KF) have received training in supporting PLWD, how to maintain the personhood of the participant and to reflect the right behaviour and attitude in order to communicate in a person-centred manner. They have received training to be a Dementia Friend, have previously shadowed clinical staff (including gerontologists, specialist dementia nurses and dementia specialist workers) caring for PLWD and have previously given both undergraduate and postgraduate lectures in dementia care. This will ensure the researchers will use appropriate language when speaking to a person living with dementia, avoid stereotypical words about the condition, and make every effort to be with the participant in a genuine, respectful and human exchange, with an understanding that communication can be verbal or embodied for the person with dementia. Thus, the researchers will use both verbal and non-verbal communication methods to aid interaction and will draw on "dementia specific" approaches and best practice outlined in the literature (Alzheimer Europe 2014). It is essential that the researchers take the time to establish a rapport with the participants and develop relationships that are based on mutual respect.

The research team have updated their skills and competencies (March 2022) to conduct research and manage data in clinical settings and to conduct research with vulnerable adults. This includes Good Clinical Practice, Safeguarding Adults (Level 1) and Safeguarding Adults (Level 2)

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