Understanding the support needs of African and African-Caribbean people living with dementia, their care partners and families and the impacts of delayed support: identifying inclusive strategies to facilitate timely and culturally appropriate social care support. (The African and Caribbean Elders (ACE) Dementia Study)

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Summary

This mixed methods study will examine the experiences of African and African Caribbean people living with dementia accessing social service support. This is a key population at high risk of inequitable access to and poor experiences of health and social care services, experience failings in care, and have poor health and wellbeing outcomes. We will use the findings to improve how services recognise and support African and African Caribbean people living with dementia. Our goal is to ensure this vulnerable population has better experiences of health and social care services and are supported in living well with dementia in their own homes.

The study steering group of African and African Caribbean people living with dementia, care partners, and families identified this research priority and co-produced this proposal.

An evidence synthesis:
using meta-aggregation of findings, co-produced with African and African Caribbean people living with dementia, their care partners, and families to identify successful strategies in other care settings that could inform practices and improve care for African and African Caribbean people living with dementia accessing social service support. This will then be used to inform the development of a conceptual model of help-seeking.

Data collection:

Will use a flexible exploratory sequential design integrating an evidence synthesis and qualitative methods: ethnography (observations, in-situ interviews, documentary analysis), case studies (narrative interviews), and co-produced translation to develop free and accessible guidance and training for health and social care practitioners and for anyone caring for African and African Caribbean PLWD.

Data collection will be carried out in 4 Local Authorities. Agreements are in place with 4 Local Authority Adult Social Service teams in the Southeast (3) and North West (1) of England to allow for diversity of geographical, economic, demographic and practice variables. Data collection will involve:

Ethnography of Adult Social Care Teams:
Field work will take place across the 4 Local Authority sites we will carry our ethnographic data collection within 9 Adult Social Service teams (120 days/shifts of observation (30 days/shifts per Local Authority) and in-situ interviews), observing social workers (20-40) and the multi-disciplinary meetings they attend (total= 15). It will involve observations, interviews and routine adult social care data.

- Observations within Adult Social Care Teams will concentrate on everyday work of social workers, support staff and other professionals involved in providing care and support
- Specifically, we will observe Front Door Services teams and Duty Social Workers as they respond to calls from the community and shadow members of the social work team while on home visits to their clients.
- Carry out short ethnographic (within Observations) interviews (<15 minutes each 3-6 per shift) as they go about their everyday work. We will also include, where possible, interviews with other professionals such as occupational therapists, community nurses, Mental Health crisis teams, GPs, involved in the care of AAC PLWD. Routine team data (from Team leads or managers) will be collected (team staffing levels, caseloads, turnover etc), recorded levels of calls and requests for care and support and the number of AAC People with dementia (from team records) being supported by the teams during the fieldwork period.

Case studies with African and African Caribbean people living with dementia and their families:
Within each Local Authority and Community Health Trusts catchment area over a 4-month period (with a further 2 month follow up period) we will carry out:

- Narrative interviews with African and African Caribbean people living with dementia (10 per site, total: 40), who will take part in 3 sequential interviews (in total: 120 interviews) over a four-month period (where possible care partners and families will also be involved).
- Interviews will explore their dementia diagnosis odysseys; the rationales for support sought, trajectories for support seeking, networks and adjustments of support, care experiences, and the impacts of these experiences on their wellbeing.
- As part of the narrative approach, interviews will be accompanied by detailed field notes to provide context, supporting the case study approach.
- The narrative approach supports participants in sharing their story over a number of visits, which was identified by our AAC Steering Group as an essential approach to support the involvement of this population.

Artistic online and postal dialogue, and art workshops:
To ensure diversity of participants voices – and to support meaningful engagement for AAC PLWD who are at increased risk of isolation – we will carry out artistic online and postal dialogues and a series of art workshops.

AAC PLWD (and their care partners) will have the opportunity to form a creative dialogue with our artist-researcher, whereby they communicate with each other through developing artworks and sending and responding via the postal service to build a dialogue together over time:

- The researcher will work with (n=>10) participants to develop a creative dialogue using postal art packs. Individuals living with dementia will be sent a series of packs of arts materials and pre-paid envelopes over a 4-12-month period.
- Participants will be invited to create an artwork and to send this to the researcher. The researcher who is an experienced artist will create an artwork in response to participants artworks and post this back to them.
- The process will then be repeated over the course of the study, with the end point directed by the AAC participants. Themes for each artwork will be developed and reflected upon throughout the time period. Themes pertaining to experiences of care will be focussed on only if appropriate, however, this is not obligatory and this is a space for participants to express themselves.
- This will provide an ongoing and creative dialogue whereby experiences and perspectives can be explored.

This approach can support meaningful engagement for people living with dementia who are at increased risk of social isolation and gain a deeper understanding of the perspectives, wishes and experiences of participants using art.

We will invite people living with dementia and their care partners to take part in arts workshops, organised in collaboration with our local community champions. Participants will be invited to creatively engage in a range of different arts materials. Art workshops will facilitate communication and expression for all participants including people living with advanced or rare dementias. The goal is to ensure all voices are heard, build trust and community participation in our research.

Translate findings into co-produced culturally appropriate and inclusive strategies that are actionable:
Using an Accelerated Experience-Based Co-Design approach we will hold a series of workshops (local, regional and national events) with African and African Caribbean people living with dementia, care partners and families to explore emergent analysis and co-design and develop outputs and interventions.

We will use the findings to improve how services recognise and support African and African Caribbean people living with dementia. We will deliver open access guidance (podcasts, audiobooks, short films, and downloadable documents) on (a) improving outreach, recognition, and early detection (b) updating existing needs assessment tools (c) providing culturally appropriate support, (d) promoting equality, making reasonable adjustments to services. Delivering training (masterclasses and online) to practitioners caring for African and African Caribbean people living with dementia.

Background

African and African Caribbean (AAC) people living with dementia (PLWD) are a key population at high risk of inequitable access to and poor experiences of health and social care services (MacRaild, 2000 Adelman et al., 2011; Tuerk and Sauer, 2015; Cooper et al 2010), experience failings in care (NAO 2007;2010), and have poor health and wellbeing outcomes (Kapadia et al., 2022; Nazroo 1998;2001; MacRaild, 2000; Shafiq et al 2020).

This pattern of inequalities has been identified for over 20 years (Nazroo 1998;2001; MacRaild, 2000; Kapadia et al., 2022; Shafiq et al 2020). Our preliminary systematic scoping search identified only 9 studies published during this time period that have focussed on or included PLWD from AAC backgrounds living in the UK. These have focused on a wide range of topics including service use (Knapp et al. 2016; Sleeman et al. 2018); dementia severity at presentation to memory services (Park et al 2017; Tuerk and Sauer 2015), screening (Rait et al, 2000), barriers to help seeking (Berwald et al, 2016), awareness raising (Trusswell, 2019), risks (Stewart et al, 2001), and prevalence of dementia (Adelman et al, 2011) compared to White British PLWD.

Research has yet to address the needs of older AAC PLWD, examine their experiences and the impacts of delayed recognition by health and social care services, or provide the evidence required to support 'timely' access to services or access to services once they have reached crisis (Tuerk, & Sauer, 2015; Adelman et al. 2009; Adelman et al. 2011; Berwald et al 2016; Carter, et al 2024).

Within this study, our population is AAC PLWD. By African and African-Caribbean we refer to people whose heritage broadly originates from Africa and Caribbean countries (formerly known as 'The West Indies'), and other 'Caribbean Community and Common Market' (CARICOM) territories (Agyemang, et al. 2005). There are no official figures identifying this population of PLWD from AAC communities in the UK, within the approximately 25,000 PLWD from ethnic minority communities (Truswell 2018), a population projected to increase 7-fold by 2051 (DoH 2015; Knapp et al 2007; Tuerk and Sauer 2015).

AAC PLWD face significant challenges accessing services early and timely (Cooper et al 2010; Moriarty et al 2014; Mukadam et al 2009; Greenwood et al 2014; Truswell 2013). They are the population most likely to be recognised by and reach services late (Adelman et al., 2011; Tuerk and Sauer, 2015; Cooper et al 2010; Berwald et. al 2016; Parveen et. al. 2017) and are less likely to seek support from formal health and social care services (Parveen et al 2017; Marwaha and Livingstone 2002; Adamson 1999;2001).

Late recognition (Lister 2007; Fraser 2020) and support by services, and delayed support seeking by AAC PLWD (Adelman et al., 2011; Tuerk and Sauer, 2015) means they are identified by services only once they have reached a more advanced stage of their dementia (Tuerk, & Sauer, 2015; Adelman et. al. 2009; Adelman et al. 2011), have reached the point of crisis (Truswell 2018; Tuerk, & Sauer, 2015; Adelman et. al. 2009; Adelman et al. 2011; Berwald et al 2016) and require urgent acute medical and social care intervention.

These patterns of potentially avoidable acute hospital admission at crisis can further perpetuate inequalities following discharge, with AAC PLWD (Balezdrova, Choi, & Lam 2019; Berdai Chaouni, & De Donder, 2019) at high risk of being missed by services (Greenwood et. al. 2015) and a premature move into long term care (Liken 2001; Robitaille et al 2015; Kelley et al. 1999; Neville, Boyle & Baillon 1999; Lach and Chang 2007; Backhouse et al. 2018; Banerjee et al 2003).

Misrecognition of a person's needs (Lister 2007) by health and social care services, and delays in support seeking (Newcomer et al 1999; Liken 2001; Frankish 2008; Vroomen et al 2013; The Lancet 2009; Perry-Young et al. 2018) mean AAC PLWD are also more likely than other populations to experience 'crisis' (Cooper et. al 2010; Berwald et. al 2016; Parveen et. al. 2017a; Parveen et al 2017b; Marwaha and Livingston 2002; Adamson 1999;2001).

A crisis is characterised by a sudden episode resulting in the perceived inability of individuals to cope (Roberts and Ottens 2005; Yates et al 2020), draw on support, live independently (Vroomen 2003; Liken 2001; Yates et al 2020), and a possible refusal or delay in seeking mainstream social care support (Perry-Young et al. 2018), until the PLWD requires urgent acute medical and social care intervention and increased and intensive support (Mioshi et al.2006).

Once a person experiences crisis, this is associated with significant physical and cognitive deterioration (Wilkinson and Milne 2003; Vroomen 2003; Liken 2001; Hopkinson et al, 2021; Roberts and Ottens 2005; Yates et al 2020), poor health and wellbeing outcomes (Wilkinson and Milne 2003; Bamford et al 2004; Johnson et al. 2013; Ambrose et al. 2013; Shaw et. al 2003; Robalino et al 2018), and unplanned acute hospital admissions (Natalwala et al 2008; Nourhashemi et al, 2001; Villars et al. 2010). Older people who experienced acute unscheduled hospitalization are at increased risk of further physical and cognitive decline (Ehlenbach et al, 2010; Mathews et al, 2013). Carer burden, which is usually preceded by crisis, is the most significant factor contributing to the institutionalisation of a person living with dementia (Newman and Fieldman 2011; Law et al. 2013; Livingston et al. 2013; Banerjee et al. 2009; Pinner et al 2003).

The limited research examining the experiences of AAC PLWD is in part because research strategies have habitually grouped diverse minority ethnic communities together (Mukadam et al. 2011; Parveen et al 2017; Carter, C. et al 2024), AAC and people from South Asian communities (Jolley et al, 2009; Adamson, 2001; Adamson and Donovan, 2005); ACC, South Asian, and White British communities (Lawrence et al 2008 & 2011); AAC, Asian and Chinese communities (Cheston et al 2017); AAC and Greek communities (Botsford et al., 2012) or AAC populations as providing a comparative examination with White British PLWD (Adelman et al. 2011; Tuerk and Sauer 2015; Marwaha and Livingston 2002; Stewart, Richards and Brayne 2001; Lasrado et al. 2020; Edge et al)

In addition, studies have typically aggregated diverse minority ethnic communities together (including AAC PLWD), to examine carers experiences (Baghirathan et al. 2020); support seeking (Tuerk, & Sauer, 2015; Edge, et al online source), stigma (Marwaha & Livingston 2002), racism (Marwaha & Livingston 2002), institutionalisation (Stewart et. al 2001) and equality of service provision (Dodd et al. 2022).

This established research approach has resulted in homogenous portrayals of minority ethnic communities experiences, which fail to recognise difference and diversity (Mwale 2023; Cooper et al 2010; Moriarty et al 2014; Bhopa 1997; Weed,1998; Botsford, Clarke, & Gibb, 2011; Mukadam et al 2009; Greenwood et al 2014; Truswell 2013; Jeraj and Butt 2018; Townsend and Godfrey 2001; Seabrooke and Milne 2004; Richards et al 1998;2000; Stewart et al 2001). Unsurprisingly this approach has resulted in this body of research reinforcing stereotypical narratives, through delivering a body of findings, which focus on highlighting perceived failings within the community, including religious and cultural beliefs (Greenwood et al 2015; Mukadam et al 2009; Parveen et al 2017), knowledge deficit (Giebel et al.2014; Parveen et al 2017; Jeraj and Butt 2018), and cultural perceptions of illness (Berwald et al 2016; Giebel et al.2014), as explanations for late recognition by services and for support seeking at crisis.

Research Question

How do Adult Social care teams understand, recognise, assess and respond to the needs of African and African Caribbean PLWD? And What are the experiences of support seeking from the perspectives of PLWD from AAC communities, their care partners, and families living in the UK?

Aims and Objectives

The aim of this mixed method study is to examine the everyday practices and visible work of adult social care teams when recognising, assessing, responding and supporting the needs of African and African Caribbean PLWD. It will examine the rationales for their decisions and actions taken and the experiences of these from the perspective of PLWD from AAC communities, their care partners, and families. Our objectives are:

1. Develop a detailed conceptual model of help-seeking to explain what is known of pathways and access, and experiences of services that supports the provision of culturally appropriate care for AAC PLWD.
2. Examine and understand the experiences of AAC PLWD, care partners and families, of living with dementia, support seeking and encounters with services.
3. Provide detailed understandings and directly observed examples of recognition, assessment, and support of AAC PLWD, care partners and families, by Adult Social Care teams.
4. Translate our findings into co-produced culturally appropriate and inclusive strategies that are actionable.

Research design

To answer these questions, we adopt a mixed method approach, including a range of perspectives and methods, the "building blocks of evidence", to produce new knowledge (Lieberson,1992). We utilise a flexible exploratory sequential design (Creswell and Creswell 2005: Ivankova, et al 2006) integrating evidence synthesis (a co-produced qualitative systematic review) and qualitative methods incorporating case studies (narrative interviews), ethnography (observations and short in- situ ethnographic interviews, documentary analysis), and translation (co-production). This approach of structured discovery utilises focussed methods, which allows flexibility to capture unexpected findings and key social processes (Burton et al., 2001; Winston et al., 1999).

Our approach recognises social categories intersect to produce varied and multiple health inequities, which reflects an important shift away from viewing the social determinants of health and health inequities through a single-axis framework (Koehn et al, 2012; Bascu et al, 2023). Therefore, our approach is underpinned by an intersectionality theoretical framework to enable the examination of how intersecting power relations across multiple and layered identity positions, including race, gender, class, ability, ethnicity, age, citizenship, sexual orientation, and nation, influence social relations (Collins and Bilge, 2020).

Steeped in Black feminist thought, which challenges the idea of a universal understanding and experience of reality, in this case, inequality, marginalisation, and subjugation. Instead, it draws attention to how life experiences are impacted by multiple, layered, forms of discrimination, some of which may be overt and others more hidden or discreet.

Methodologically a feminist intersectional approach means the research is grounded on the understandings that knowledge is situated and derived from close interactions between the researcher and the subject of research (Haraway, 1991; Harding 1986; Reinharz and Davidman 1992). Rather than seeing reality as objective and universal, feminist approaches draw attention to the subjective and contextual nature of knowledge and everyday social life (Haraway, 1991; Harding 1986;1987 De Vault 1996). We draw on a feminist intersectional approach which Star (1979) describes as essentially a method for understanding perspectives from the margins or 'boundary-dwelling perspectives' (Star 1979; Haraway, 1991).This requires the research team to continually ask and search for what else may be going on or invisible in a social problem that may add to its complexity or further burden the affected groups, while staying attuned to the ways in which power inequality manifests (Davis 2014). This informs our approach to exploring organisational and societal cultures by examining the intersections of location and power relations in shaping knowledge and its impact on organisational practice and cultures, and everyday social life (Crenshaw, 1991; Collins 2000;2012). Utilising an intersectional approach provides a lens through which we will re-examine taken for granted everyday experiences, assumptions, and outcomes to examine other vectors that may be contributing to the issues under investigation (Davis 2014).

***Evidence synthesis*:**
Prior to data collection, we will carry out a qualitative systematic review using JBI methodology (Lockwood et al 2020) using the process of meta-aggregation, whereby we will extract findings and

illustrations that are specific to PLWD from AAC communities from studies and bring these together in a series of synthesised findings. Meta-aggregation differs from other qualitative evidence synthesis approaches, as it does not seek to re-interpret original research data or to generate theories like meta-ethnography or thematic synthesis (Lockwood et al. 2020). Instead, meta-aggregation develops "recommendations for action" by enabling the creation of generalisable statements (Hannes and Lockwood 2011). Generalisable statements are formed by combining and categorising similar findings from across a range of qualitative studies. These categories are then subjected to a synthesis to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. In addition, meta-aggregation assesses the credibility of qualitative findings. The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings table (Munn et al 2014). An a priori protocol will be developed and registered with the International prospective register of systematic reviews (PROSPERO) and reported following PRISMA guidance (Page 2021)

Search strategy:
We will conduct a wide-ranging data base search for English language publications within a number of bibliographical databases (including Medline, CINAHL, the EMBASE, Medline, PsycINFO, OVID Emcare, Scopus,). Keywords and index terms identified as relevant and reflecting the project's agreed priorities will be used and individual search strategies developed for each database. Qualitative studies will be included that focus on or contain an element relating to the experiences of support seeking from the perspectives of PLWD from AAC communities, care partners, and families.

Screening, selection and appraisal:
Following the search, all identified citations will be collated and uploaded into Endnote and duplicates removed. Titles and abstracts will be screened, and the full text of selected studies retrieved and assessed against the inclusion criteria. Included studies will undergo a process of critical appraisal using the JBI Qualitative Assessment and Review Instrument (Lockwood, Munn, & Porritt 2015). All review processes will be undertaken by two members of the review team and any disagreements that arise will be resolved through discussion, or with a third team member.

Consultation with stakeholders:
To ensure the focus of the review is relevant to the needs of AAC PLWD, and to the context of the social care and community settings we will present and discuss the initial synthesized findings with stakeholders. The stakeholder consultation (n=>20) will include AAC PLWD, care partners and families (Kennedy, 2003; Johansson, 2014), and practitioners in social care and community settings as part of our programme of co-production.

Outputs:
The synthesized findings generated will be used to refine our approaches to data collection and alongside the findings of the primary research to inform the development of a detailed conceptual model of help-seeking to explain what is known of pathways to and access to and experiences of services.

Data collection

We will adopt a qualitative approach including ethnographic observations and in-depth qualitative interviews. Ethnography can provide sophisticated tools for understanding the complexities of the everyday work within an organisational culture and the interrelationships between different elements of organisations. It involves the in-depth study of a small number of cases, studying people's actions and accounts within their natural everyday settings, collecting relatively 'unstructured' data from a range of sources (Hammersley and Atkinson, 1989). An ethnographic approach is particularly useful to examine research questions and topics where measurement is inappropriate, where the aim is to access the unspoken, mundane, and tacitly understood (Dixon-Woods, 2003); for examining complex social relations, exposing institutional forces and cultures as they influence everyday routines and interactions (Greenhalgh & Swinglehurst, 2011). Our approach to ethnography is informed by the symbolic interactionist research tradition, which aims to provide an interpretive understanding of the social world, with an emphasis on interaction, focusing on understanding how action and meaning are constructed within a setting (Housley and Atkinson, 2003). The value of this approach is the depth of understanding and theory generation it can provide, with a key objective to provide findings transferable to other settings (Hammersley, 1987).

Ethnography in adult social care services:
Institutional ethnography examines the everyday work of people, their routine behaviour and practices (Quinlan, 2009) and their articulation work, how people account for and make sense of their actions (Star, 1999). An important focus is the frequently understudied, what is often characterised as the mundane and every day. Within any organisation there are always groups whose everyday work is not recognised formally and is often unnoticed and invisible (Star, 1999).

Thus, this study will focus on the largely invisible everyday work of social care professionals. We will provide a detailed understanding of the social and institutional forces that shape and influence their work. Our ethnographic approach will enable us to understand how staff respond to the care needs of AAC PLWD and to follow the consequences of their actions on PLWD, their care partners and families. Importantly, we will also examine how they account for and make sense of their responses to care needs in these contexts. Ethnography allows us to examine these elements and, importantly, the interplay between them (Atkinson et al, 2008).

In relation to the professionals involved in the study, intersectionality provides a critical lens for analysing the logics, assumptions, and practices underpinning care practices and attitudes towards care for racialised older PLWD. Although care and care giving for PLWD within institutional spaces occurs in highly regulated contexts, it does not occur in a vacuum. Rather it takes place and is embedded within historical and established institutional cultures that include everyday taken for granted practices and unwritten rules that delineate appropriate and deserving patient-hood. These originate from established social practices and attitudes to the categorisation of people into hierarchies of need which result in the creation of racial categories passed on through generations and institutional practices (Monk 2022) in what Alfred Schults (1972) refers to as common sense manner. An intersectional analytical framework provides us the tools to explore how these implicit and often unwritten rules can operate in everyday clinical practice to bring about the subjugation of racialised older people living with dementia and consequently affect their care across health and social care settings. We will examine how and to what extent social categories of, for example, gender, race and class influence approaches and attitudes to the care of older PLWD. In everyday care practices these perceived differences may manifest through stereotyping and discrimination in different domains, benefiting some to the detriment of others (Massey 2007). These categories can become the basis for informing the distribution of resources, access to services and rights. In creating racialised categories as ‘others’, these perceived outsiders have often been presented as a threat, undesirable and thus whose activities must be watched and controlled. At the same time, we will take into account the intersectional identity positions and interlocking systems of power between different types of caregivers and gatekeepers. In terms of informal care, intersectionality provides a tool to study the diverse experiences of caregivers, and a nuanced understanding of how multiple intersecting factors and power relations shape these experiences (Hengalaar et al, 2021; Liu et al, 2022).

Ethnographic observations in adult social services teams:
Field work will be conducted in 4 Local Authority areas across England which are known to have large numbers of AAC people.

Within each site we will carry out ethnographic data collection (observation, in-situ interviews, and documentary analysis) with (a) social work teams (30 days/shifts), (b) shadow social care professionals (n=5-10) and team and multi-disciplinary meetings they attend (this is variable, but we expect to attend 5 meetings per site). In total, across the 4 sites we will carry our ethnographic data collection within 12 teams (120 days of observation and in-situ interviews), shadow (20-40) social workers and the team and multi-disciplinary meetings they attend (total= 20). Data collection will be across the 4 sites over 4 months in each site with a further period of 2 months after each site to clean data, develop preliminary analysis, and carry out follow up interviews.

We are aware that there is complexity and some differences nationally in the configuration of Adult Social Services, however, the work schedules and organization of teams across the participating sites are all broadly structured in a sequential pathway, which clients experience when they require support and once it has been determined they are eligible for support. This includes a ‘front door service’, a service responsible for the management and review of existing cases, and long-term case management teams, which reviews and assess the needs of existing clients whose care needs may change.

1. *Gateway to services- the 'front door service':* where clients become known to social care professionals including referrals from GPs, the public, family, community voluntary services, and mental health teams. This will provide understandings of how needs are identified, assessed, and classified. It will also enable us to examine the process through which care options are presented, explored, and the rationales for decisions on appropriate options for each case, including social care denial or refusal by both clients and or social care professionals.
2. *The team managing existing and new cases*: where existing cases currently assigned to the team and new cases are reviewed. This will provide another space to understand rationale for decisions about ongoing care and support for PLWD.
3. *Long term case management team(s)*: who carry out the assessment, care planning and reviews of the needs of existing and long-term clients whose care needs may change. This will provide understanding of how social care professionals respond to changes in individual circumstances such as deterioration of health and changes in family circumstances that may require exploring long term care options. We will examine options explored and discussed, strategies for engaging with clients, how families are engaged in this process, and the impacts on the trajectories of care.
4. *Hospital Discharge Teams*: these are embedded in hospital trusts, their roles involve assessing, coordinating, and organizing care including finding and referring to appropriate care or related spaces of care and or discharge to home.

With each team we will carry out focussed observations of:

- Team and case meetings and the multidisciplinary team meetings (MDTs) they attend, whose referrals and cases will include AAC PLWD. Within each team:
- shadow individual professionals (n=5) who review and triage referrals and cases.
- in-situ short ethnographic interviews with staff following meetings and during shifts to explore rationales for actions and decisions.
- documentary analysis (case files, team records including handover and case lists) of staffing, workload and case allocation, client acuity and placements, to provide context.

This will provide understandings of staff rationales for recognition, assessment and how they respond to the needs of AAC PLWD.

Across the Adult Social Care teams, we will include observations:

- Shadowing the duty social worker as they respond to calls from the community to understand referrals.
- Shadowing social workers while on home visits to their clients to observe how needs and risks for clients are recognized, assessed, the rationales for decisions, and how support options are presented, negotiated, and agreed on. This will help us understand the visible work of social workers and the challenges they face in practice.
- We will attend “Team around the client meetings” and ‘Strategy Safeguarding Meetings’ where teams respond to urgent safeguarding concerns requiring immediate action or when safeguarding and similar issue arise.
- We will also carry out interviews with other professionals such as occupational therapists, community nurses, Mental Health crisis teams, GPs, police involved in the care of AAC PLWD, should they be involved in these meetings.

In-depth interviews with African and African Caribbean people living with dementia and their families:

Alongside ethnographic observations with adult social services we will be conducting interviews with AAC older PLWD and their families. To do this we will utilise case studies using a narrative interview approach (Reissman 1993) to support AAC PLWD (and their care partners, and families) to share their personal accounts, experiences, and stories to emerge (Reissman 2003) and to provide depth and sensitivity of insights and understandings (Gaventa and Cornwall, 2008). We will employ Skeggs' methodological practice of 'thinking with', which aims to provide a critical space for open dialogue and analysis, supporting participants in reflecting on their everyday life experiences and praxis (Skeggs 2004; Olsson 2008).

Drawing on Skeggs idea of 'thinking with,' we will conduct interviews in a sequence of meetings over time, during which participants will be encouraged to reflect on the meanings, affect and thoughts about accessing services which arise through the practice of 'thinking with'. Each interview will build on the previous meeting in a sequence to reveal participants experiences. The researcher will ask prompting and follow up questions, but as much as possible participants will be encouraged to direct the conversations to share their experiences (Leaney & Mwale 2021). This approach will enable themes to emerge over time, ideas to be revisited, and reflections incorporated into individual and wider narratives across the cohort (Leaney & Mwale 2021) and to map rationales and trajectories for seeking support, networks, adjustments of support, and care experiences within the analysis.

Drawing on the practice of 'thinking with,' our approach will explore individual/family odysseys into accessing social care support, 'experiences of receiving and being supported by adult social care service teams', 'impact of these experiences on health and wellbeing'. Participants will be allowed time to direct and share their story over a number of visits, this was identified by our AAC Steering Group as an essential approach to support the involvement of AAC PLWD. It provides a number of benefits:
(1) Importantly, for a marginalised population, this approach supports participants in feeling empowered by being accorded time to direct their story and be heard (Proctor, 2001; Cridland, et al 2016; Ross 2017; Poland et al 2018).
(2) Help build trust between the researcher and the interviewee over time.
(3) Help reduce time pressure that can arise when interviews are reduced to a single encounter.
(4) Supporting participants to articulate their experiences, leading to the collection of in-depth, nuanced, and contextual data (Ross 2017; Simons, et al 2008).

Within each Local Authority and Community Health Trusts catchment area over a 4-month period (with a further 2 month follow up period) we will carry out:

- Narrative interviews with ACC PLWD (10 per site, total: 40), who will take part in 3 sequential interviews (in total: 120 interviews) each lasting up to an hour. Interviews will be conducted over a four-month period (where possible care partners and families will also be involved). A further period of 2 months will allow for follow-up interviews with participants who were recruited at later stages within the site.
- Interviews will explore their dementia diagnosis odysseys; the rationales for support sought, trajectories for support seeking, networks and adjustments of support, care experiences, and the impacts of these experiences on their wellbeing.
- As part of the narrative approach, interviews will be accompanied by detailed field notes to provide details of context of each interview (Reissman 2008) and will support the case study approach.
- We will also carry out document analysis of contact with community services, community nurses, GPs and social care practitioners, details of package of care, safeguarding reviews and recommendations, or support from voluntary services (including food banks, meals on wheels, driving services, befriending services, day care etc) and other support they draw on. This will provide understandings of the support they receive from formal and informal resources within the community and enable us to track this over time. In total, across the 4 sites, this will provide 40 case studies, with approximately 120 hours of in-depth narrative interview data and detailed field notes.

Artistic online and postal dialogue, and art workshops:

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To ensure diversity of participants voices in the study, we will conduct to conduct a series of art workshops for AAC older people and PLWD hosted within local voluntary community day services across all 4 sites (n=3x 4= 12). People living with dementia and their care partners will be invited to participate in arts workshops, organised in collaboration with our local community champions. Participation in the art workshops will involve creatively engaging in a range of activities and with different art materials. Using the art workshops approach will facilitate communication and expression of experiences for all participants including people living with advanced or rare dementias. During the workshops participants are invited to talk through their art and what it means to the subject of the research. The goal is to ensure diverse voices are included in the study, as well as building trust and community participation in research.

People living with advanced or rare dementias are often excluded from involvement or having a voice in research and there is a growing awareness of the potential for using artistic practice to support the wellbeing of PLWD and promote communication (Zeilig et al 2014; Windle et al 2018; Moss and O'Neil 2019; Young et al 2016; Phillips et al 2010). To support the inclusion and involvement of AAC PLWD for whom verbal communication may be difficult, we will use participatory, visual, and textual, creative methods and approaches, which are in keeping with our wider intersectional approach (https://healthartsresearch.wales/case-studies/conversations-future-selves /). Supporting AAC PLWD to participate in creative engagement provides a more inclusive approach to support their expression of experiences. Team member MW uses these methods as part of her artistic practice and research and has extensive experience of working and collaborating with AAC PLWD. All participants will be offered an alternative mode of communication of experiences via:

Artistic online and postal dialogues via a collaboration with AAC PLWD and their care partners to support artistic expression of experiences and to support those who may not be able to or want to participate in face-to-face interviews or further stages of interviews. The AAC PLWD (and their care partner), will have the opportunity to form a creative dialogue with our 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:

- The researcher will work with (n=>10) participants to develop a creative dialogue using postal art packs. Individuals living with dementia will be sent a series of packs of arts materials and pre-paid envelopes over a 4-12-month period.
- Participants will be invited to create an artwork and to send this to the researcher. The researcher who is an experienced artist will create an artwork in response to participants artworks and post this back to them.
- The process will then be repeated over the course of the study, with the end point directed by the AAC participants. Themes for each artwork will be developed and reflected upon throughout the time period. Themes pertaining to experiences of care will be focussed on only if appropriate, however, this is not obligatory and this is a space for participants to express themselves.
- This will provide an ongoing and creative dialogue whereby experiences and perspectives can be explored.

This approach can support meaningful engagement for people living with dementia who are at increased risk of social isolation and gain a deeper understanding of the perspectives, wishes and experiences of participants using art.

Analysis

Data collection (observations and interviews) and analysis will be informed by the analytic tradition of grounded theory (Glaser and Strauss, 1967). This uses the constant comparative method; as data is collected in one site, preliminary analysis of this will proceed in parallel, with this preliminary analysis informing the focus of later stages of data collection and analysis.

Field notes of observation, experience, and near verbatim text will be written up into word files and all audio recordings of interviews (short and in-depth) will be transcribed verbatim by a professional transcription service. Analysis will involve the development and testing of analytic concepts and categories, and our strategies for their development include careful reading of the data, looking for patterns and relationships, noting anything that seems surprising and for any inconsistencies and contradictions across the range of perspectives gathered.

The analysis will be shared with the Project Advisory Group and Carer Steering Group who will include service users, experts in dementia care and Adult Social Service able to advise on the appropriate boundaries of any interventions for Adult Social care setting and the interface with families and communities.

To support this approach, we will employ an abductive approach to our analysis, a widely used approach which focuses on synthesises between data, existing concepts, and emergence of new concepts (Svennevig, 2001; Atkinson 2005; Gabbay, & Woods, 2006). This approach supports an interpretation process that is both explorative and grounded in data (Svennevig, 2001; Lulle, & Jurkane-Hobein, 2017). In keeping with our theoretical framework, an abductive approach is useful with its foci on talk and people's stories and also supports doing justice to rather than reducing the complexity of social life (Atkinson 2005, Lulle, & Jurkane-Hobein, 2017). Collectively the team (SM, KF, BH, AN, CC) brings expertise in collecting, managing and analysis of mixed methods and case study, narrative and ethnographic data within diverse health and social care settings (Mwale &Featherstone, forthcoming; Featherstone and Northcott 2020; Hayanga et al 2023; Coveney and Lambert 2023). We will take a systematic approach to the collection, management, and analysis of narrative interviews and ethnographic data.

Data collected of narrative interviews and ethnographic (observation and in situ interviews) will be analysed using the continuous comparative method. Building on the use of theoretical sampling whereby data collection (observation and interview data) and analysis are interrelated (Glaser and Strauss 1967; Corbin and Strauss 1990) and carried out concurrently (Green 1998; Suddaby, 2006)). Preliminary analysis of data collected from one site will be conducted in parallel with subsequent data collection in the next site. At the completion of each phase/site of data collection, all data will be cleaned and uploaded into management software and coded. The development of the analysis into more refined and stable analytic concepts will involve careful re-reading of the emerging codes and sensitizing concepts, looking for patterns and relationships, noting anything surprising, and inconsistencies and contradictions across the range of perspectives gathered. This will refine the coding to produce more stable and robust analytic concepts and categories.

Case studies and narrative analysis:
Detailed narrative analysis of interviews will involve coding experiences of living with dementia, support seeking, experiences of services, examining and interpreting content of speech story by focusing on meaning, with the goal to scrutinize, reflect and theoretically interpret elements of the participants lived experiences in relation to support seeking (Reissman 2005; Sparke and Smith 2016).

Preliminary analysis of narrative interviews will keep individual accounts intact, bringing them together as individual case studies to deliver detailed accounts of the individual, their care partners and families and their encounters with services. This approach emphasises the need for examining human lives and experiences as culturally and relationally constructed (Smith 2016; Reissman 2002).

We will also take a thematic approach to the analysis of the interview data, so that we can theorise across the case studies by finding common thematic elements across research participants and the events they report. Once a typology is developed, the data will be reviewed and further refined to ensure accuracy of the accounts across the cases (Reissman 2002; Reissman 1993). Thus, is then followed by weaving of the themed accounts into a narrative of the participants accounts (Williams 1984). The analysis of narrative data will be presented as case studies and as thematic descriptive reports across the data set.

Ethnographic analysis:
Coding of ethnographic fieldnotes (observations and in-situ interviews) involves whole events or scenarios and will focus on the analysis of social action, the assessment, recognition, and classification of needs, and their consequences. Initially coding will produce analytic memos and a collection of sensitizing concepts and ethnographic coding of decision-making events and scenarios. The abductive method means that the coding of data into categories is a recurrent process and is ongoing, with further data then examined in the context of previous fieldwork and the analytic memos generated, which will

inform further data collection within the next site and the next, more focused, stages of analysis. The flexible nature of this approach is important because it enables us to increase the "analytic incisiveness" of both the narrative interviews and the ethnography (Charmaz & Mitchell 2001).

The analysis of ethnographic data from each site will be presented in detailed descriptive reports, which will be organised as separate draft reports of social care teams, shadowing of individuals, and team meetings.

Triangulation:
The analysis of the narrative interviews and observational data will be triangulated to form a master analytic report for each site. By triangulation in our analysis, we refer to a process of using multiple data sources and methods and perspectives to investigate a phenomenon. In this case we will draw data from an evidence synthesis, in-depth semi-structured interviews and detailed ethnographic observations to generate a detailed understanding of AAC people's experiences of support seeking in social care. We will explicitly use intersectional perspectives to inform the development of our analysis to identify local organisational and structural conditions (Glaser and Strauss 1967) influencing the recognition, classification, and responses to needs of AAC PLWD. This process will include:

- Detailed descriptive reports for each site will be brought together to be examined and discussed with the wider team and study advisory groups (AAC PPI Advisory Group, Project Advisory Group, and at co-production events).
- The use of abduction to ensure that a key focus is on identifying social processes in the use of recognition and responses to the needs of AAC PLWD.
- Producing overarching analysis by drawing together narrative synthesis, analytic reports, testing and refining to identify broader structural conditions influencing how services recognise and assess the needs of AAC PLWD.

Data management:
Data will be managed using NVivo computer software, this will also facilitate secure access to data for the wider research team. Data analysis and theory development will be led by the PI (SM) with BH, and support from co-PI KF. SM will supervise and support BH who will lead the organisation of data sets, coding, analysis and drafting of the initial analysis.

Sampling and recruitment

Sampling in ethnographic research requires a flexible constant comparative method and theoretical sampling whereby sampling, data collection, and analysis are interrelated and ensure consideration of vectors including class, gender, and social economic status among others (Bowleg, 2012; Marfelt 2016).

Theoretical sampling is a flexible, pragmatic approach, with research sites, social care services, participants (and sample size), selected by identifying a range of variables that may influence the phenomena (purposive sampling). The flexible constant comparative approach emphasizes the importance of comparisons within and across sites (Vogt, 2002), allowing for and enhancing the potential generalizability of findings (Herriott and Firestone, 1983), and increasing the possibility for the findings to impact practice and policy (Caracelli, 2006). In practice, this means that emerging themes from the preliminary analysis of data from one site will inform the focus of sampling and data collection in subsequent sites and later stages of analysis (Willig 2013). This flexible approach supports the sharp and precise analysis of the data (Reinharz and Davidman 1992; Phoenix, & Pattynama, 2006) and enhances the ability of the results to have an impact on practice and policy (Caracelli, 2006).

Adult social care teams and setting*:*
Adult social care services settings are suited to an ethnographic approach. At first glance adult social care services, and teams within them, may appear similar and homogenous, however, they all have unique cultures of working, contoured by local resources, cultures and organisational belief systems which in turn influence variance in care and decision across and within institutions. We have developed

strong collaborations with Local Authorities across England from our wider network. The sites have been identified to represent demographic populations, geographical location (inner city and coastal areas) and social economic status. We have identified local partners and agreements are in place as follows

- Southeast England (3 Local Authorities -2 inner city and 1 coastal)
- Northwest of England (1 Local Authority encompassing both inner-city and coastal areas)

Each Local Authority adult social care service:
While our data collection sites (Local Authority Adult Social Care services) will be standardized, with chronological and methodical data collection, we will have variance within each site. We will employ 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, sensitizing concepts from the ongoing analysis will feed into the next stage of data collection to expand the research process and to capture 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).

Observations and interviews with staff:
We will follow the everyday of social workers and allied health professionals. We will purposively sample across the teams to include a range of professionals, grades (including duty social workers, occupational therapists support workers) and other staff with coordinating responsibilities. Several months in advance of field work commencing, the research team will visit the social care teams to discuss with relevant staff the study aims and approach.

African and African Caribbean people living with dementia and their families:
Sampling will be theoretically informed whereby we will use purposive sampling throughout to ensure inclusion of PLWD from wide-ranging socio-demographic characteristics including age, gender, socio-economic status, and groups of AAC communities who may face, and experience, intersecting marginalisation, who are often further underrepresented in research, and may be at increased risk of being missed by services.
In collaboration with our community partners (champions), we will conduct a series of focused activities in the community with our community partners and champions to sensitise the community about our research. Through these activities and through our community champions participants will be recruited (n=10 at each site, total: 40). Participants will be African and African–Caribbean PLWD. By African and African-Caribbean we refer to people whose heritage broadly originates from Africa and Caribbean countries (formerly known as 'The West Indies'), and other 'Caribbean Community and Common Market' (CARICOM) territories (Agyemang, et al. 2005). Participants will be

- 50 plus years old living with dementia to ensure we include people with young onset dementia.
- Those currently accessing or are yet to access Adult Social Service support to ensure we capture experiences at different stages of seeking support.

We acknowledge that the presence or absence of a formal diagnosis of dementia in the community may not always be straight forward to establish, with older patients often obtaining a diagnosis or provisional diagnosis, for example during a hospital admission, however, we do know this population are well represented within these communities.

Equality, diversity and inclusion:
Theoretical sampling will be used to include AAC PLWD reflecting the range of socio-demographic characteristics and using maximum variation, purposive sampling, and snowball sampling to reflect diversity within AAC and PLWD communities. These approaches to sampling accounts for divergence across several intersecting factors of importance, including, but not restricted to, age, nationality, immigration status, disability, sex and gender, socio-economic status, sexuality, spoken language, and religion.

We will employ maximum variation sampling and snowball sampling frames to ensure that the research is inclusive of the diversity and distinct sub-groups that exist within the population of African and African-Caribbean people across each of these axes to ensure our recruitment reflects:

- different routes of family migration spanning Africa and the Caribbean.
- migration to the UK (first generation 'Windrush' and asylum seekers).

To ensure recruitment reflects PLWD often under-represented within research and services, purposive sampling to include PLWD who are also:

- living with a psychiatric co-morbidity (Onyike, 2016), with the complex needs of this group (Radhakrishnan, Butler & Head, 2012) associated with poor experiences of care (Hext, Clark, Xyrichis, 2018; Care Quality Commission, 2017).
- living with a learning disability (Bigby et al, 2014).
- PLWD who are homeless are likely to be experiencing complex mental and physical co-morbidities (Stone, Dowling & Cameron, 2018), with these complex and challenging needs associated with poor care experiences (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 (Mulé, Ross, Deeprose, Jackson, Daley, Travers &Moore, 2009; Peel, Taylor, Harding, 2016; Fredriksen-Goldsen, Jen, Bryan & Goldsen, 2016; McParland & Camic, 2018).
- PLWD with multiple and rare forms of dementia, who may be at an increased risk of hospitalization (Mueller, Perera, Rajkumar et al, 2017) and recurrent experiences of crisis and encounters with emergency health and social care services (Atkins, Rackham, Acevedo, Dowman, Foewll, Aspinall, 2015).

Where our programme of local outreach is not able to include AAC PLWD from within these communities within the research, we will utilise our PPI and Co-production programmes at regional and national levels to ensure these communities are represented and contribute their views and experiences in directing the research, the co-production of analysis, and study outputs.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, Ross, Deeprose, Jackson, Daley, Travers &Moore, 2009).

Dissemination and projected outputs

Our analytic outputs will provide a theoretically informed, evidence-based understanding of Adult Social Services and the experiences of service users founded on detailed analysis of the realities of everyday Adult Social Service work and practices of 'work-as-done' (Hollnagel, 2012).

***For Local Authority social care providers*:**

A key knowledge gap we will respond to is supporting services in delivering their statutory duty to promote equality, to make reasonable adjustments to ensure services meet the needs of AAC PLWD, care partners, and families. We will use the findings to:

- Identify current practices that support culturally appropriate practice and that could be shared with health and social care services and settings (via podcasts, audiobooks, short films, and downloadable documents).
- Identify how social care services respond to, recognise, and intervene to support AAC PLWD by identifying factors in organisations (practices, routines, and interactional styles) that can improve or worsen the early detection and timely access to support (podcasts, audiobooks, short films, and downloadable documents).
- Providing organisations with strategies that improve outreach and recognition of this population and to deliver their statutory duty to promote equality, to make reasonable adjustments to ensure services meet their needs (in-person, podcasts and short films).

***For social care practitioners*:**

- Update existing needs assessment tools (e.g. CANE) and guidance for professionals to ensure they provide culturally appropriate assessment of the care needs of AAC PWD (downloadable documents and podcasts).
- Recommendations (podcasts, audiobooks, short films, and downloadable documents) delivering guidance on recognising the support needs of AAC PLWD, identifying opportunities to provide support, and promoting good practices.

***African and African Caribbean people living with dementia, care partners, and families*:**

To attend to the importance of using advocacy and human rights approaches to empower older people and PLWD. We will use the findings to deliver:

- Guides (podcasts, audiobooks, short films, and downloadable documents) on accessing services, support, and the risks of crisis.
- Short accessible factsheets (podcasts and downloadable documents) on living with dementia and rights to reasonable adjustments.
-

Plan of investigation and timetable

Total 36 months: [1st January 2025 and 31st December 2027]

1-6 months (January -June 2025):
On-boarding of Local Authorities, Community Health Trusts, and community partners; obtain SREC ethics, R&D and ADASS approvals. Expand and confirm AAC PPI Advisory Group and Project Advisory Group membership. Conduct and draft evidence synthesis. Hold PPI public events and advisory board events (AAC PPI and Project Advisory groups).

7-30 months (July 2025- June 2027):
Data collection will be over 4 months per site (4), with a further period of 2 month after each site to clean data, develop preliminary analysis, carry out follow up interviews, and in accordance with our Intersectional theoretical approach, carry out follow-up work with participating sites and communities in the translation and development of findings into open access training, resources, and service organisation outputs. Hold PPI public events and advisory group events (PPI and Project Advisory groups), and co-production events within sites and across the UK.

30-36 months (June-December 2027):
Triangulation and finalising overarching analysis and theory development. Final drafting, co-production, testing and development of open access training and masterclasses, resources, and service organisation outputs. Hold PPI public events and advisory board events (PPI and Advisory Boards). Report, Social Care, and academic publication drafting.

	1-3	4-6	7-9	10-12	13-15	16-18	19-21	22-24	25-27	28-30	31-33	34-36
synthesis	***	***						***				
Recruitment, access and sampling	***	**	**	**	**	**	**	**	**			
Data collection		__ *	***	***	***	***	***	***	***	***		
Analysis and theory development			-**	-**	-**	-**	***	***	**	-**		
Report and academic and social care publication writing		--*	**			--*	***	***	***	***	***	***
Drafting, piloting and development -Adult					*	*	*	*	*	**	***	***

Social Care services-based tools												
Workshops and symposium	--*		***	***	***	***	***	***	***	***		
Training – masterclasses, factsheets, on-line materials, modules and MOOC		*	*	*	*	*	*	*	*	*		
Advisory group, Project Team, Study steering committee	*		*		*		*		*			*

Ethics committee approvals

Data collection will always preserve participant dignity, our approach, processes and documentation of observations and interviews with PLWD in the community and observing the everyday work of Adult Social Services teams will be informed by REC approvals yet to be obtained). We will follow Health Research Authority (HRA), Association of Directors of Adult Social Services (ADASS) and University of West London ethics governance procedures. The university's Research Governance Framework sets out the professional standards and basic requirements that are fundamental to all research, as well as the ethical and external regulations that govern research[https://www.uwl.ac.uk/research/ethics-code-practice#:~:text=3.-,Ethical%20principles,part%20of%20the%20ethics%20process]. We will follow recommendations and practical guidelines for conducting research involving elderly participants (c.f. High and Doole, 1995, Harris and Dyson, 2001; Loue, 2004), people living with dementia (Slaughter et al, 2007), and the cognitively impaired (Berg, 1996).

Involving people living with dementia in research:
It has been argued that the lack of research exploring the perspective of people living with dementia (Taylor, et al, 2012) is in fact silencing of people experiencing cognitive decline (Roger, 2006). The inclusion and involvement of people living with dementia in research is recognised as central to the production of effective research (Alzheimer's Europe, 2014), as their views and experiences are prioritised (The Scottish Dementia Working Group Research Sub-Group, 2014). Participation usually outweighs the risks (Hellstrom et al, 2007), with inclusion in research enhancing dignity and personal identity. People living with dementia also make a compelling argument for their inclusion in research, emphasising its positive and empowering effects (McKillop 2002; Robinson, 2002).

In response, this study includes a significant focus on the perspectives of people living with dementia and their carer partners to better understand their thoughts, feelings and experiences of seeking and receiving care and support from social services. We do this through specifically taking time to interview them at their convenience about their odyssey's to accessing Adult Social Services (case studies). Our approach draws on a small but significant research that demonstrates that the perspective of people living with dementia can be obtained (Roger, 2006; Samsi and Manthorpe, 2013; Tanner, 2012; Pipon-Young et al, 2012; Clemerson, et al, 2013). Our approach ensures that the experiences of people living with dementia, particularly those seldom heard, are included within research (Wilkinson 2002) that examines their experiences of health and social care (Barnett 2000) and uses methods that can elicit personal stories and narratives of people living with dementia (c.f. Bryden, 2005; Goldsmith, 1996).

Process consent:
Study participation will be open to people living with dementia at all stages of the disease process and with different types of dementia who are being cared for in the community and eligible for support from Adult Social Services settings. People living with dementia may have varying degrees of capacity and their capacity may fluctuate depending on the dementia, their psychosocial, situational, medical, psychiatric and neurological factors. Symptoms of dementia include cognitive impairment, short term memory loss, difficulties in verbal and non-verbal communication and poor concentration and

understanding, which can make it difficult to gain informed consent. It is also important to recognise that the capacity to consent can change quickly for this group of patients. Our approach to consent draws on Dewing's model of process consent (2007), which posits consent as a continuous process in which researchers continuously review if study participants' are consenting to each decision across the course of the study. Process consent is a pathway, it's a significant characteristic being 'ensuring initial consent is revisited and re-established on every occasion or even within the same occasion' (p19). The researcher plays a fundamental role throughout the study in continually assessing whether the person is prepared to continue with their participation. If there is a possibility that their feelings about participation have altered, then their consent must be revisited. To increase the transparency of this process, someone known to the people living with dementia can act as an independent validator. Dewing's approach and method (including documentation) is internationally recognised research ethics committees in universities and health care provider organizations.

Training:

The research team are experienced and have received training in understanding people living with dementia, 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. The research team are acutely aware and experienced in the use of appropriate language when communicating with a person 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 verbal communication is often challenging for the person with dementia (Alzheimers Europe, 2014). 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 (McKillop, 2002). Researchers will ensure rapport is established with the participants and develops a relationship that is based on mutual respect.

Data management and confidentiality considerations:

All audio recordings of narrative interviews will be professionally transcribed verbatim. Field notes (from observations, and verbatim text of in-situ interviews) will be written up into word files. We will check all transcripts against recording for accuracy and quality. All transcripts will be anonymised to protect the privacy of participants and sites. In line with Caldicott Principles, only information necessary to the organisation and delivery of the study will be obtained from participants. We will not record personal information about the majority of participants (observations and short interviews) within the health and social care teams.

For PLWD recruited to take part in in-depth narrative interviews in the community, this will be their name, address and telephone number. All information sheets and consent forms state that participants in the research are guaranteed anonymity. Confidentiality and anonymity will be maintained in all reporting of findings from the research. No personal data will be published, and individual participants will not be identifiable from the research findings. Pseudonyms will be used for transcripts and in written reports. Direct quotes will not include any identifiable information. Methods of presentation that protect anonymity, such as composite stories, will be adopted if necessary. The research team has experience of using these techniques in their research, as well as a clear understanding of the UK General Data Protection Regulations (GDPR) NHS England Data Protection Policy (2014) and University of West London data protection policy.

Audio recordings (all interviews) will be deleted once transcribed – and the transcription has been checked; in the period between, these will be securely stored in folders within the university's secure servers, only accessed by members of the research team. All anonymised data (fieldnotes and any documents) will also be securely stored in folders within the university's secure servers and only accessible by members of the research team; consent forms will be saved in folders separate from the data. All consent forms will be deleted once all data collection has been collected and the final report completed; all anonymised data will be securely stored, within the same folders and university's secure servers, for five years post completion of the final report. The transcripts that will be coded within NVivo will be anonymised with all identifiable information removed beforehand.

Dissemination, outputs and anticipated impact

Our strategy will build on the team's ongoing programme of work drawing on evidence generated by in-depth qualitative research to develop interventions to improve service delivery for PLWD, and to deliver training in dementia care within acute wards, universities, and community settings. This includes ongoing collaboration with NHS Trusts (with clinical teams and Dementia Boards), Dementia UK and Admiral Nurses working in the community (specialist nurses in dementia care) to develop evidence-based training.

Interdisciplinary expertise in, and commitment to dementia education and training within the team (JH, KF, SM, AN), that utilises qualitative research evidence, informs our approach to delivering understandings of the provision of culturally appropriate care for AAC PLWD and validating best practice approaches to recognise and support the care needs of AAC PLWD. In validating and developing outputs, narrative accounts and ethnographic 'thick description' (presented in the form of whole experiences, events or series of episodes, situated within their wider context) provides ways to connect social care staff with practice concepts and principles using 'real' and vivid empirical examples that reflects 'work as done'(Blumer, 1954) and 'care as experienced' (rather than as imagined by policy makers and Local Authority senior staff). To enhance the design, validation and credibility of training and organisational outputs that reflect everyday social care, we will work with:

- AAC PLWD, care partners, and families through our programme of public outreach PPI events and consultations. AAC PLWD and their families will provide crucial insights about their experiences, perspectives, and recognition of what constitutes the provision of culturally appropriate care and making reasonable adjustments, what values and standards of care are good practice and must be prioritised in training, and that reflects their experiences and care needs.
- Participating social care teams and sites – to build understandings and recognition of pathways to and access to services, for exploring key social processes and institutional forces at play in how support needs are understood, become recognised, and responded to, the impacts (for AAC PLWD and staff), and the potential for alternative approaches. This will support the validity of the findings, training outputs, and their relevance for social care practice. Additional time to collaborate with each participating team has been included to support and facilitate this process.
- Project Advisory Group and AAC PPI Advisory Group – to share and discuss emerging definitions of what constitutes the provision culturally appropriate care and making reasonable adjustments to advise on the appropriate boundaries of training and interventions to support social care staff and the interface with PLWD and families. Members include service users, 3rd sector organisations and networks, experts in dementia care, medical ethics and law.

We will draw on comparative lessons across settings to ensure we build on research expertise with other populations and settings and integrate transferrable learning.

We recognise that within and across these communities there may be significant variation in opinion around what is understood or perceived as 'good practice'. We believe this process of co-production is critical to enhancing understandings of good practice and the development and validity of our findings and their translation into outputs (organisational and training). The inclusion of multiple and potentially conflicting perspectives is in keeping with and supported by our intersectional theoretical approach to developing and refining analysis and output development. Multiple perspectives (AAC PLWD, care partners, family, a wide range of social care and professionals working in community settings) will be sought and integrated to deliver conceptual models of 'good practice' within the social care settings. The wider goal is not to establish consensus, but to establish relevance for ACC PLWD, care partners, families, and social care staff, and their utility, feasibility, and transferability to different organisational contexts (Taylor, et al. 2012).

Expected impact

The goal is to (a) support services in delivering their statutory duty to promote equality, to make reasonable adjustments to ensure services meet the needs of AAC PLWD, care partners, and families and (b) delivering foundational knowledge to inform a longer-term programme to develop and evaluate interventions providing new or enhanced approaches to meet the needs of AAC PLWD, care partners, and families.

***Local Authority social care providers*:**
A key knowledge gap we will respond to is supporting services in delivering their statutory duty to promote equality, to make reasonable adjustments to ensure services meet the needs of AAC PLWD, care partners, and families. We will use the findings to:

- Identify current practices that support culturally appropriate practice and that could be shared with health and social care services and settings (via podcasts, audiobooks, short films, and downloadable documents).

- A key knowledge gap we will respond to is improving how social care services respond to, recognise, and intervene to support AAC PLWD. We will use the findings to deliver: Recommendations (podcasts, audiobooks, short films, and downloadable documents) delivering guidance on recognising the support needs of AAC PLWD, identifying opportunities to provide support, and promoting good practices. Identification of factors in organisations (practices, routines, and interactional styles) that can improve or worsen the early detection and timely access to support (podcasts, audiobooks, short films, and downloadable documents).Providing organisations with strategies that improve outreach and recognition of this population and to deliver their statutory duty to promote equality, to make reasonable adjustments to ensure services meet their needs (in-person, podcasts and short films).

***Social care practitioners*:**
A key knowledge gap we will respond to is enhancing the skills of social care practitioners in understanding and improving early detection and timely access to support AAC PLWD, with the goal to prolong independence and improved health and well-being outcomes. We will use the findings to deliver training and tools for health and social care frontline staff to support care quality:

- Masterclass and training (via in-person, podcasts, and short films) in designing and delivering culturally appropriate services, that promotes equality, and enables the reasonable adjustments required to support AAC PLWD, carers, and families.
- Update existing needs assessment tools (e.g. CANE) and guidance for professionals to ensure they provide culturally appropriate assessment of the care needs of AAC PWD (downloadable documents and podcasts).
- Recommendations (podcasts, audiobooks, short films, and downloadable documents) delivering guidance on recognising the support needs of AAC PLWD, identifying opportunities to provide support, and promoting good practices.

***African and African Caribbean people living with dementia, care partners, and families*:**
A key knowledge gap we will respond to is the importance of using advocacy and human rights approaches to empower older people and PLWD. We will use the findings to deliver:

- Guides (podcasts, audiobooks, short films, and downloadable documents) on accessing services, support, and the risks of crisis.
- Short accessible factsheets (podcasts and downloadable documents) on living with dementia and rights to reasonable adjustments.

***Research community*:**
Open access publishing across nursing, clinical, policy, sociology, and anthropology journals. Co-authoring with AAC PLWD and their care partners and families and translating publications for user communities (with the support of DEEP https://www.dementiavoices.org.uk - collaboration via Project Advisory Group membership).

All outputs will be accessible (open access and downloadable) in multiple formats, to include (a) broadcast-quality podcasts and interviews with the research team, collaborators, and people with lived experience (b) digestible 'audiobook' narration of outputs and research material, (c) broadcast-quality short film formats including narration to camera and interviews with experts by experience (d) downloadable pdf documents of written materials. These will be available as open access and downloadable (Apple Podcasts, Google Podcasts, Spotify audio material), YouTube (film material) and UWL and collaborator websites, to increase accessibility.

We will build on team members **(KF, AN)** strategies for the rapid communication and dissemination of HSDR studies to inform practice and policy (15/136/67: https://rb.gy/foo2nr) (13/10/80: https://www.nihr.ac.uk/case-studies/supporting-the-continence-of-people- living-with-dementia-in-hospital/34008).

Social care and community practice:
Key partners in dissemination and translation into practice are via the networks within our sites: Hackney Borough Council, Hounslow Borough Council, Medway Community Health Trust. Our key partners in dissemination to community providers are our collaborating community voluntary organisations: Nubian Life (West London, including Hounslow) which focusses on serving older people from AAC populations, Edward Woods Community Centre (Hackney and West London) Time to Talk Befriending (Sussex), and Age UK, which all serve AAC older people and PLWD.

Building on our existing collaborations (co-applicant GB), we will work closely with the British Association of Social Workers (BASW) throughout the study. To support this, we have invited a senior representative of BASW to be a member of our Study Steering Committee. This will ensure their involvement throughout the study and will help us access spaces to share our research and key outputs with professionals. We will work with BASW to develop outputs to improve how social care services respond to, recognise, and intervene to support AAC PLWD, which BASW will disseminate to the wider social service workforce.

We will utilise co-applicant GB's existing links and involvement with Social Work England, the regulatory body, which provides support and maintaining of standards, and Skills for Care, which provides training for professionals working within community services. These organisations provide training and guidance via their platforms and through in person events and we will work with them to use the findings to deliver training and guidance for health and social care frontline staff to enhance skills in understanding and improving early detection and timely access to support AAC PLWD.

GB has established links with the Principal Social Workers' network leadership. Through these established links we will share our outputs at national levels with senior Social Workers across England through their conferences and workshops. We will also work with the Social Care Institute of Excellence, an independent organisation that advocates for social care at policy and practice levels.

We will publish our research and key recommendations within professional social work and social service facing journals and magazines to maximise the reach of our recommendations to practitioners such as Community Care, The Professional Social Worker and Research in practice for adults (RIPFA).

Team expertise (**JH, KF, SM**) in delivering in-person and online professional education and CPD training in the care of PLWD (https://rb.gy/r0fxc). Findings will inform education within our UWL research-led Masters, the MSc Dementia Studies: Contemporary Approaches to Practice, which attracts NHS and Social Care professionals from diverse backgrounds and develops them to become leaders in dementia care (https://www.youtube.com/watch?v=wLCnZbTDg1Y). Evaluation is extremely positive, with students reporting it directly informs professional practice.

Public policy: Team members (KF,AN) are working with the All Party Parliamentary Groups (APPG) on dementia and Adult Social Care, and we will utilise these connections to deliver new knowledge on the experiences of support seeking from the perspectives of AAC PLWD, care partners, and families, and the ways in which their support needs are understood, become recognised, and responded to by Adult Social Care Teams to inform cross-party priorities, and ministers for health and social care, of the needs of AAC PLWD, families and social care. We will:

- Communicate and discuss our work with dementia organisations and charities with whom we already have an established collaboration, including the Alzheimer's Society and Dementia UK Head of Research and Publications (KF, JH).
- Inform public policy and service improvement via the NICE Social Care Standards in Dementia Care (direct links via co-applicant JH).

Public discourse:

- We will build on our networks where we have achieved significant communication of NIHR ethnographic research examining the care of PWLD by working directly with BBC producers, translating our research into BBC radio documentaries: (13/10/80) File on 4 '(https://www.bbc.co.uk/programmes/b006th08); and (15/136/67) 5 Live Investigates '(https://bbc.in/2Ej8VZW).
- Building on our PPI and co-production programme, we will deliver a range of (public and online) events to support accessibility and public reach of the research.

We draw on feminist intersectional theory through a commitment to bring about social change via specific recommendations and consciousness raising by making links between policy and practice (Levin 1987; Greenwood and Levin 2006).

References:

1. Adamson, J. (1999) Carers and dementia among African Caribbean and South Asian families. Generations Reviews, 9, 12–14.
2. Adamson, J. (2001) Awareness and understanding of dementia in African/Caribbean and south Asian families. Health and Social Care in the Community, 9, 391–396.
3. Adamson, J., & Donovan, J. (2005). 'Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK. *Social Science & Medicine*, *60*(1), 37-48.
4. Adelman, S., Blanchard, M., Rait, G., Leavey, G., & Livingston, G. (2011). Prevalence of dementia in African-Caribbean compared with UK-born White older people: Two-stage cross-sectional study. *The British Journal of Psychiatry, 199, 119–125. doi:10.1192/bjp.bp.110.086405*
5. Adelman, S. et al. (2009) A systematic review of the prevalence and covariates of dementia or relative cognitive impairment in the older African-Caribbean population in Britain. Int J Geriatric Psychiatry. 24 (7) :657–65. pmid:19235788.
6. Agyemang, C., Bhopal, R., & Bruijnzeels, M. (2005). Negro, Black, Black African, African Caribbean, African American or what? Labelling African origin populations in the health arena in the 21st century. *Journal of Epidemiology & Community Health*, *59*(12), 1014-1018.
7. Alzheimer Europe,. 2014. *Improving continence care for people with dementia living at home* Luxembourg: Alzheimer Europe
8. Ambrose, A. F., Paul, G., & Hausdorff, J. M. (2013). Risk factors for falls among older adults: a review of the literature. *Maturitas*, *75*(1), 51-61.
9. Atkins, Rackham, Acevedo, Dowman, Foewll, Aspinall, (2015). PWE-138 Increasing burden of alcohol related brain injury is disproportionate to hospital admissions with liver disease. https://gut.bmj.com/content/64/Suppl_1/A273.1.abstract
10. Atkinson, P., & Housley, W. (2003). *Interactionism*. Sage.
11. Atkinson, P., Delamont, S., Housley, W., 2008. *Contours of culture: Complex ethnography and the ethnography of complexity*. Lanham: Altamira.
12. Backhouse, T., Camino, J., Mioshi, E. (2018). What Do We Know About Behavioral Crises in Dementia? A Systematic Review *Journal of Alzheimer's Disease*, 62(1), 99-113.

13. Bacsu, J. D., Kortzman, A., Fraser, S., Chasteen, A. L., MacDonald, J., & O'Connell, M. E. (2023). Understanding Intersectional Ageism and Stigma of Dementia: Protocol for a Scoping Review. *JMIR Research Protocols*, *12*(1), e46093.
14. Baghirathan, S., et al. (2020). A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished. *Dementia*, *19*(5), 1672–1691. https://doi.org/10.1177/1471301218804714
15. Bhopal, R. (1997) Is research into ethnicity and health racist, unsound or unimportant science? British Medical Journal, 314, 1751–1756.
16. Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. (2004). Disclosing a diagnosis of dementia: a systematic review. *International journal of geriatric psychiatry*, *19*(2), 151-169.
17. Banerjee, S., Murray, J., Foley, B., Atkins, L., Schneider, J., & Mann, A. (2003). Predictors of institutionalisation in people with dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, *74*(9), 1315-1316.
18. Balezdrova, N., Choi, D., & Lam, B. (2019). 'Invisible Minorities': Exploring Improvement Strategies for Social Care Services aimed at Elderly Immigrants in the UK using Co. *Design Methods*.
19. Berwald, S., Roche, M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British communities' perceptions of memory problems: "We don't do dementia.". *PLoS One*, *11*(4), e0151878.
20. Berdai Chaouni, S., & De Donder, L. (2019). Invisible realities: Caring for older Moroccan migrants with dementia in Belgium. *Dementia*, *18*(7-8), 3113-3129.
21. Berg, J. W., 1996. Legal and ethical complexities of consent with cognitively impaired research subjects: Proposed guidelines. *The Journal of Law, Medicine & Ethics*, 24(1), 18-35.
22. Berwald, S., Roche, M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British communities' perceptions of memory problems: "We don't do dementia.". *PLoS One*, *11*(4), e0151878.
23. Botsford, J., Clarke, C. L., & Gibb, C. E. (2012). Dementia and relationships: experiences of partners in minority ethnic communities. *Journal of Advanced Nursing*, *68*(10), 2207-2217.
24. Bowleg, L. (2012). The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health. *American journal of public health*, *102*(7), 1267-1273.
25. Bryden, C., 2005. *Dancing with dementia: my story of living positively with dementia*. London: Jessica Kingsley Publishers.
26. Caracelli, V. J. (2006). Enhancing the policy process through the use of ethnography and other study frameworks: A mixed-method strategy. *Research in the Schools*, *13*(1), 84-92.
27. Carter, C. et al (2024) Equality of opportunity for timely dementia diagnosis (EQUATED): a qualitative study of how people from minoritised ethnic groups experience the early symptoms of dementia and seek help, *Age and Ageing* 2024; **53:** afae244 https://doi.org/10.1093/ageing/afae244
28. Clemerson, G., Walsh, S., Isaac, C., 2013. Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed. *Dementia* 13(4):451-66
29. Collins, P.H, (2000) *Black Feminist Thought- Knowledge, Consciousness, and the Politics of Empowerment* (2nd Ed), London, Routledge
30. Collins, P. (2012). Social inequality, power, and politics: Intersectionality and American pragmatism in dialogue. *The Journal of Speculative Philosophy*, *26*(2), 442-457.
31. Collins, P.H and Bilge, S (2020) Intersectionality, Cambridge, Polity press
32. Cheston, R., Baghirathan, S., Hui, R., Shears, P., & Chacun, A. &Currie K. (2017). The dementia experiences of people from Caribbean, Chinese and South Asian communities in Bristol.
33. Cooper C, et. al. (2010) A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. Am J Geriatr Psychiatry. 2010;18(3):193–203. pmid:20224516
34. Creswell, J. W., & Creswell, J. D. (2005). Mixed methods research: Developments, debates, and dilemmas. *Research in organizations: Foundations and methods of inquiry*, *2*, 315-326.

35. Crenshaw, K. "(1991) Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color." *Stanford Law Review* 43, no. 6): 1241–99. https://doi.org/10.2307/1229039.
36. Cridland, E. K., Phillipson, L., Brennan-Horley, C., & Swaffer, K. (2016). Reflections and recommendations for conducting in-depth interviews with people with dementia. *Qualitative Health Research*, *26*(13), 1774-1786.
37. Davis, K. (2014). Intersectionality as critical methodology. *Writing academic texts differently: Intersectional feminist methodologies and the playful art of writing*, 17-29.
38. Dodd, E., Pracownik, R., Popel, S., Collings, S., Emmens, T., & Cheston, R. (2020). Dementia services for people from Black, Asian and Minority Ethnic and White British communities: Does a primary care-based model contribute to equality in service provision? *Health & social care in the community*.
39. DoH (2021) Guidance- Health matters: midlife approaches to reduce dementia risk, available at https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk
40. Dixon-Woods, M. (2003). What can ethnography do for quality and safety in health care?. *BMJ Quality & Safety*, *12*(5), 326-327.
41. Dewing, J., 2007. *Participatory research A method for process consent with persons who have dementia.* Dementia, 6(1), 11-25.
42. Edge, D., Brown, L., Ward, R., Swarbrick, C., & Keady, J. (Online source) MICRA Seed-corn Research Project African Caribbean families' perspectives on aging, dementia and dementia care: An inter-disciplinary pilot study.
43. Ehlenbach, W. J., Hough, C. L., Crane, P. K., Haneuse, S. J., Carson, S. S., Curtis, J. R., & Larson, E. B. (2010). Association between acute care and critical illness hospitalization and cognitive function in older adults. *Jama*, *303*(8), 763-770.
44. Frankish, H (2008) Ed: "Time to confront the global dementia crisis". The Lancet, Neurology, 7:761. no. 9.
45. Fraser, N. (2020). From redistribution to recognition?: dilemmas of justice in a 'postsocialist' age. In *The new social theory reader* (pp. 188-196). Routledge.
46. Gaventa, J., & Cornwall, A. (2008). *Power and Knowledge* in P. Reason, H. Bradbury (Eds), (2008) *The SAGE handbook of action research: participative inquiry and practice*, 2nd ed, London: SAGE
47. Giebel, C. M., Jolley, D., Zubair, M., Worden, A., Bhui, K. S., Lambat, A., ... & Challis, D. (2014, March). SOUTH ASIAN VOICES ENABLING DEMENTIA CARE (SAVE-D): Differences in the Recognition of and Consultation for Memory Problems in South Asian Ethnic Minorities. In *Alzheimer's Research UK Conference*.
48. *Glaser, B. and Strauss, A., 1967. The discovery of grounded theory. 1967. Weidenfield & Nicolson, London, pp.1-19.*
49. Goldsmith, M., 1996. *Hearing the voice of people with dementia: Opportunities and obstacles*. London: Jessica Kingsley Publishers.
50. Greenhalgh, T., & Swinglehurst, D. (2011). Studying technology use as social practice: the untapped potential of ethnography. *BMC medicine*, *9*(1), 1-7.
51. Greenwood, N., Habibi, R., Smith, R., & Manthorpe, J. (2015). Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature. *Health & social care in the community*, *23*(1), 64-78.
52. Hammersley, M. (1987). Some notes on the terms 'validity'and 'reliability'. *British educational research journal*, *13*(1), 73-82.
53. *Hammersley, Martyn, and Paul Atkinson. (1989) Ethnography: Principles in practice. Routledge,*
54. Hannes, K., & Lockwood, C. (2011). Pragmatism as the philosophical foundation for the Joanna Briggs meta aggregative approach to qualitative evidence synthesis. *Journal of advanced nursing*, *67*(7), 1632-1642.
55. Harding, S. (1986) *The Science Question in Feminism*. Milton Keynes: Open University Press
56. Haraway, D. (1991) "Situated knowledges: The science question in feminism and the privilege of partial perspective." In D. Haraway *Simians, Cyborgs and Women*. London: Free Association Press, 183–201.

57. Harris, R., Dyson, E., 2001. Recruitment of frail older people to research: lessons learnt through experience. *Journal of Advanced Nursing*, 36(5), 643-651.
58. Hengelaar, A. H., Wittenberg, Y., Kwekkeboom, R., Van Hartingsveldt, M., & Verdonk, P. (2023). Intersectionality in informal care research: a scoping review. *Scandinavian Journal of Public Health*, *51*(1), 106-124.
59. Herriott, R. E., & Firestone, W. A. (1983). Multisite qualitative policy research: Optimizing description and generalizability. *Educational researcher*, *12*(2), 14-19.
60. High, D. M., Doole, M. M., 1995. Ethical and legal issues in conducting research involving elderly subjects. *Behavioral sciences & the law*, 13(3) 319-335.
61. Hollnagel E., 2012. FRAM: the functional resonance analysis method. modelling complex socio-technical systems. Surrey: Ashgate
62. Hopkinson, B.J, et al. (2021) What happens before, during and after crisis for someone with dementia living at home. A systematic review. Dementia, 20 (2)
63. Ivankova, N. V., Creswell, J. W., & Stick, S. L. (2006). Using mixed-methods sequential explanatory design: From theory to practice. *Field methods*, *18*(1), 3-20.
64. Jeraj, S and Butt, J (2018) Dementia and Black, Asian and minority ethnic communities, Race Equality Foundation available at https://raceequalityfoundation.org.uk/health-and-care/dementia-and-black-asian-and-minority-ethnic-communities/
65. Johnson, Neidens, M., Wilson, J. R., Swarzendruber, L., Yeager, A., & Jones, D. (2013). Treatment outcomes of a crisis intervention program for dementia with severe psychiatric complications: the Kansas bridge project. *The Gerontologist*, 51(1), 102-112.
66. Jolley, D., Moreland, N., Read, K., Kaur, H., Jutlla, K., & Clark, M. (2009). The 'Twice a Child'projects: learning about dementia and related disorders within the black and minority ethnic population of an English city and improving relevant services. *Ethnicity and Inequalities in Health and Social Care*, *2*(4), 4-9.
67. Kapadia, D., Zhang, J., Salway, S., Nazroo, J., Booth, A., Villarroel-Williams, N., Becares, L., & Esmail, A. (2022). *Ethnic Inequalities in Healthcare: A Rapid Review*. NHS Race & Health Observatory. https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf
68. Koehn, S., Neysmith, S., Kobayashi, K., & Khamisa, H. (2013). Revealing the shape of knowledge using an intersectionality lens: Results of a scoping review on the health and health care of ethnocultural minority older adults. *Ageing & Society*, *33*(3), 437-464.
69. Kennedy, A., Robinson, A., & Rogers, A. (2003). Incorporating patients' views and experiences of life with IBS in the development of an evidence-based self-help guidebook. *Patient education and counselling*, *50*(3), 303-310.
70. Kelley, L. S., Buckwalter, K. C., & Maas, M. L. (1999). Access to health care resources for family caregivers of elderly persons with dementia. *Nursing outlook*, *47*(1), 8-14.
71. Knapp M, Chua KC, Broadbent M, et al. 2016 Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: findings from a large London case register. BMJ Open. 2016;6: e013591.
72. Lach, H. W., & Chang, Y. P. (2007). Caregiver perspectives on safety in home dementia care. *Western journal of nursing research*, *29*(8), 993-1014.
73. Lasrado, R., Baker, S., Zubair, M., Kaiser, P., Lasrado, V. J., Rizzo, M., ... & Edge, D. (2020). Exploring Dementia Care Systems Across the African Caribbean Diaspora: A Scoping Review and Consultation Exercise. *The Gerontologist*.
74. Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. *The British Journal of Psychiatry*, *193*(3), 240-246.
75. Lawrence, V., Samsi, K., Banerjee, S., Morgan, C., & Murray, J. (2011). Threat to valued elements of life: the experience of dementia across three ethnic groups. *The Gerontologist*, *51*(1), 39-50.
76. Law E, Connelly PJ, Randall E, McNeill C, Fox HC, Parra MA, et al. Does the Addenbrooke's Cognitive Examination-revised add to the Mini-Mental State Examination in established Alzheimer disease? Results from a national dementia research register. *Int J Geriatr Psychiatry 2013; 28(4):351±355. doi: 10.1002/gps.3828 PMID: 22556006*

77. Leaney, S., & Mwale, S. (2021). Campus closures and the devaluing of emplaced Higher Education: widening participation in neoliberal times. *Higher Education*, *82*(5), 977-992.
78. Lieberson, S. (1992) Einstein, Renoir, and Greeley: Some thoughts about evidence in sociology, *American Sociological Review*, 57, 1-15
79. Lister, R. (2007). (Mis) recognition, social inequality and social justice: a critical social policy perspective. In *(Mis) recognition, Social Inequality and Social Justice* (pp. 169-188). Routledge.
80. Liken M. (2001). Caregivers in crisis: Moving a relative with Alzheimer's to assisted living. *Clinical Nursing Research*, 10(1), 52–68. https://doi.org/10.1177/c10n1r6
81. Livingston, G., et al. (2017). Effectiveness of an intervention to facilitate prompt referral to memory clinics in the United Kingdom: cluster randomised controlled trial. *PLoS Medicine*, *14*(3), e1002252
82. Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *JBI Evidence Implementation*, *13*(3), 179-187.
83. Lockwood C, Porritt K, Munn Z, Rittenmeyer L, et al. (2020) Chapter 2: Systematic reviews of qualitative evidence. In: Aromataris E, Munn Z (Editors). *JBI Manual for Evidence Synthesis.* JBI, 2020. Available from https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-03
84. Loue, S., 2004. The participation of cognitively impaired elderly in research. *Care Management Journals*, 5(4), 245-257.
85. McKillop, J., 2002. Did research alter anything? in Wilkinson, H, (Ed) *The perspectives of people with dementia: Research methods and motivations* London: Jessica Kingsley Publishers 109-114

86. MacRaild, D. M. (2000). *The great famine and beyond: Irish migrants in Britain in the nineteenth and twentieth centuries*. Irish Academic Press. **Google Scholar**
87. Marfelt, M. M. (2016). Grounded intersectionality: Key tensions, a methodological framework, and implications for diversity research. *Equality, Diversity and Inclusion: An International Journal*, *35*(1), 31-47.
88. Marwaha, S. & Livingston, G. (2002) Stigma, racism or choice. Why do depressed ethnic elders avoid psychiatrists. Journal of affective Disorders, 72, 257–265.
89. Massey, S. D (2007) *Categorically Unequal: The American Stratification System. New York, NY: Russell Sage Foundation.*
90. Matthews, F. E., Arthur, A., Barnes, L. E., Bond, J., Jagger, C., Robinson, L., & Brayne, C. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *The Lancet*, *382*(9902), 1405-1412.
91. Mioshi, Eneida, Kate Dawson, Joanna Mitchell, Robert Arnold, and John R. Hodges. "The Addenbrooke's Cognitive Examination Revised (ACE-R): a brief cognitive test battery for dementia screening." *Int J Geriatr Psychiatry* 21 (2006): 1078-1085
92. Monk, P.E (2022) Inequality without Groups: Contemporary Theories of Categories, Intersectional Typicality, and the Disaggregation of Difference *Sociological Theory, Vol. 40(1) 3–27 DOI: 10.1177/07352751221076863*
93. Moriarty, J., Manthorpe, J., & Cornes, M. (2014). Special Issue Reaching out or missing out: approaches to outreach with family carers in social care organisations.
94. Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, *23*(7), 1070.
95. Munn Z, Porritt K, Lockwood C, Aromataris E, Pearson A. Establishing confidence in the output of qualitative research synthesis: the ConQual approach. BMC Med Res Methodol 2014; 14(1): 108
96. Mwale, S (2023) "The Emperor's New Clothes": health inequalities in ethnic minority communities, The Cost of Living Blog, available at https://www.cost-ofliving.net/the-emperors-new-clothes-perceptions-of-health-inequalities-in-ethnic-minority-communities-in-the-uk/
97. National Audit Office (2007) *Improving Services and Support for People with Dementia*. TSO (The Stationery Office).

98. Natalwala, A., Potluri, R., Uppal, H., & Heun, R. (2008). Reasons for hospital admissions in dementia patients in Birmingham, UK, during 2002–2007. *Dementia and geriatric cognitive disorders*, *26*(6), 499-505.
99. National Audit Office (2010) Improving Dementia Services in England- an interim Report, available at https://www.nao.org.uk/wp-content/uploads/2010/01/091082.pdf
100. Nourhashemi, F., Andrieu, S., Sastres, N., Ducasse, J. L., Lauque, D., Sinclair, A. J., ... & Vellas, B. J. (2001). Descriptive analysis of emergency hospital admissions of patients with Alzheimer disease. *Alzheimer Disease & Associated Disorders*, *15*(1), 21-25.
101. Nazroo, J.Y. (1998) *Genetic, cultural or socio-economic vulnerability? Explaining ethnic inequalities in health, Sociology of Health and Illness, 20, 5, 710–30.*
102. Nazroo, J.Y. (2001) *Ethnicity, Class and Health. London: Policy Studies Institute.*
103. Neville, P., Boyle, A., and Baillon, S., (1999) A descriptive survey of acute bed usage for dementia care in old age psychiatry, *International Journal of Geriatric Psychiatry* 14, 348-354
104. Newcomer, R., Yordi, C., DuNah, R., Fox, P., & Wilkinson, A. (1999). Effects of the Medicare Alzheimer's Disease Demonstration on caregiver burden and depression. *Health Services Research*, *34*(3), 669.
105. Olsson, A. (2008). *Thinking with Beverley Skeggs*. Centrum för genusstudier, Stockholm
106. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, Shamseer L, Tetzlaff JM, Akl EA, Brennan SE, Chou R, Glanville J, Grimshaw JM, Hróbjartsson A, Lalu MM, Li T, Loder EW, Mayo-Wilson E, McDonald S, McGuinness LA, Stewart LA, Thomas J, Tricco AC, Welch VA, Whiting P, Moher D. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021 Mar 29;372: n71. doi: 10.1136/bmj.n71.
107. Park MH, Smith SC, Neuburger J, Chrysanthaki T, Hendriks AAJ, Black N. Sociodemographic characteristics, cognitive function, and health-related quality of life of patients referred to memory assessment services in England. Alzheimer Dis Assoc Disord. 2017; 31:159-167.
108. Parveen, S., Peltier, C., & Oyebode, J. R. (2017). Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. *Health & social care in the community*, *25*(2), 734-742.
109. Perry-Young, L., Owen, G., Kelly, S., & Owens, C. (2018). How people come to recognise a problem and seek medical help for a person showing early signs of dementia: A systematic review and meta-ethnography. *Dementia*, *17*(1), 34-60.
110. Phoenix, A., & Pattemana, P. (2006). Intersectionality editorial. *European Journal of Women's Studies*, *13*(3).
111. Pinner G, Bouman WP. (2003) Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis. *Int Psychogeriatric 2003; 15(3):279±288. PMID: 14756163*
112. Proctor, G. (2001). Listening to older women with dementia: relationships, voices and power. *Disability & Society*, *16*(3), 361-376.
113. Quinlan, E. (2009). The ‘actualities’ of knowledge work: an institutional ethnography of multi□disciplinary primary health care teams. *Sociology of health & illness*, *31*(5), 625-641.
114. Rait, G., Morley, M., Burns, A., et al (2000) Screening for cognitive impairment in older African–Caribbeans. *Psychological Medicine*, 30, 957–963.

115. Reinharz, S and Davidman, L (1992). *Feminist Methods in Social Research*, Oxford, Oxford University press
116. Riessman, C. K. (1993). Doing narrative analysis. *Narrative Analysis. London: Sage Publications*.
117. Riessman, C. K. (2003). Analysis of personal narratives. *Inside interviewing: New lenses, new concerns*, 331-346.
118. Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage.
119. Robitaille, A., Garcia, L., & McIntosh, C. (2015). Joint trajectories of cognitive functioning and challenging behavior for persons living with dementia in long-term care. *Psychology and aging*, *30*(3), 712.

120. Robalino, S., Nyakang'o, S. B., Beyer, F. R., Fox, C., & Allan, L. M. (2018). Effectiveness of interventions aimed at improving physical and psychological outcomes of fall-related injuries in people with dementia: a narrative systematic review. *Systematic reviews*, *7*(1), 1-11.
121. Roberts, A. R., & Ottens, A. J. (2005). The seven-stage crisis intervention model: A road map to goal attainment, problem solving, and crisis resolution. *Brief Treatment and Crisis Intervention*, *5*(4), 329.
122. Robinson, E., 2002. Should people with Alzheimer's disease take part in research? in Wilkinson, H, (Ed) *The perspectives of people with dementia: Research methods and motivations* London: Jessica Kingsley Publishers 101-109
123. Roger, K. S., 2006. A literature review of palliative care, end of life, and dementia. *Palliative and Supportive Care*, 4(3):295-9.
124. Ross, K. (2017). Making empowering choices: How methodology matters for empowering research participants. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* (Vol. 18, No. 3, p. 17). DEU.
125. Samsi, K., & Manthorpe, J., 2013. Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *International Psychogeriatrics*, 1-13.
126. Schutz, A. (1972). *The phenomenology of the social world*. Northwestern university press

127. Shafiq, S, Parveen, S, Oyebode, JR. (2021) How people of African Caribbean or Irish ethnicity cope with long-term health conditions in UK community settings: A systematic review of qualitative, quantitative and mixed method studies. *Health Soc Care Community*. 2021; 29: 319–327. https://doi.org/10.1111/hsc.13181
128. Simons, L., Lathlean, J., & Squire, C. (2008). Shifting the focus: sequential methods of analysis with qualitative data. *Qualitative health research*, *18*(1), 120-132.
129. Skeggs, B. (2004). *Class, Self, Culture*. London: Routledge.
130. Slaughter, S., Cole, D., Jennings, E., & Reimer, M. A., 2007. Consent and assent to participate in research from people with dementia. *Nursing Ethics* 14(1):27-40.
131. Sleeman, K. E., Perera, G., Stewart, R., & Higginson, I. J. (2018). Predictors of emergency department attendance by people with dementia in their last year of life: retrospective cohort study using linked clinical and administrative data. *Alzheimer's & Dementia*, *14*(1), 20-27
132. Star, S. L. (1979). Strategic heresy as scientific method: Feminism and the psychology of consciousness. Paper presented at the *American Association for the Advancement of Science, Houston, TX, January 6*. 1979
133. Star, S. L. (1999). The ethnography of infrastructure. *American behavioral scientist*, *43*(3), 377-391.
134. Stewart, R., Richards, M., Brayne, C., et al (2001) Cognitive function in the UK community-dwelling African Caribbean elders: normative data for a test battery. International, *Journal of Geriatric Psychiatry*, 16, 518–527.
135. Tanner, D., 2012. Co-research with older people with dementia: Experience and reflections. *Journal of Mental Health*, 21(3):296-306.
136. Taylor, J.S., DeMers, S.M., Vig, E.K., Borson, S., 2012. The disappearing subject: Exclusion of people with cognitive impairment and dementia from geriatrics research. *Journal of the American Geriatrics Society*, 60(3):413-419.
137. Townsend, J. & Godfrey, M. (2001) Asian Experiences of Caregiving for Older Relatives with Dementia: An Exploration of Barriers to Uptake of Support Services. Nuffield Institute for Health.
138. Truswell, D. (2013). Black, Asian and Minority Ethnic Communities and Dementia.
139. Truswell, D (2018) The impact of dementia on the UK African Caribbean Community, Race Equality Trust, Briefing Health & Care
140. Truswell, D. (2019). Dementia and the UK African-Caribbean Community. *Supporting People Living with Dementia in Black, Asian and Minority Ethnic Communities: Key Issues and Strategies for Change*, 35.

141. Tuerk R, and Sauer J. (2015) Dementia in a Black and minority ethnic population: characteristics of presentation to an inner London memory service. *BJPsych Bulletin*. 2015;39(4):162-166. doi:10.1192/pb.bp.114.047753.
142. Yates, A. J. et al (2020) Conceptualizing Dementia Crisis and Preferences for Resolution: A Public Perspective, Journal of Primary Care & Community Health, Vol 11: 1–7 https://doi.org/10.1177/21501327209259
143. Villars, H., et. al. (2010) The primary care physician and Alzheimer's disease: an international position paper. *The journal of nutrition, health & aging*, *14*(2), 110-120.
144. Vogt, W. (2002). *FIT for benefit: IT Services kundenorientiert planen und steuern*. Perseo Consult AG.
145. Vroomen, M.J et al. (2013) Reviewing the definition of crisis in dementia care, *BMC Geriatrics* 2013, 13:10 Page 6 of 12 http://www.biomedcentral.com/1471-2318/13/10
146. Willig, C. (2013). *Introducing qualitative research in psychology, (3rd ed.).* Berkshire: Open University Press.
147. Wilkinson, H., 2002. *The perspectives of people with dementia: Research methods and motivations*. London: Jessica Kingsley Publishers.
148. Wilkinson H. & Milne A. J. (2003) Sharing a diagnosis of dementia-learning from the patient perspective, *Aging & Mental Health*, 7:4, 300-307, DOI:10.1080/1360786031000120705