

This protocol has regard for the HRA guidance and order of content

FULL/LONG TITLE OF THE STUDY

Food Glorious Food: A mixed methods evaluation of food-related practices in post-diagnostic community-based group support for people affected by dementia

SHORT STUDY TITLE / ACRONYM

Food Glorious Food

PROTOCOL VERSION NUMBER AND DATE

1.3 (24/05/2024)

RESEARCH REFERENCE NUMBERS

IRAS Number: 339634

SPONSORS Number: 21/22 0142

FUNDERS Number: NIHR205163

SIGNATURE PAGE

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

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

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

For and on behalf of the Study Sponsor:

Signature:

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Date:

...../...../.....

Name (please print):

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Position:

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Chief Investigator:

Signature:

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Date:

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Name: (please print):

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STUDY SUMMARY

Study Title	Food Glorious Food: A mixed methods evaluation of food-related practices in post-diagnostic community-based group support for people affected by dementia
Internal ref. no. (or short title)	Food Glorious
Study Design	Realist Evaluation
Study Participants	Attendees of various community group support initiatives for people living with dementia (inc. people living with dementia and people who support them); managers, staff and volunteers of various community group support initiatives
Planned Size of Sample (if applicable)	Work Package 2: 48 participants minimum Work Package 3: 6 participants minimum

Follow up duration (if applicable)	N/A
Planned Study Period	01/04/2024 – 30/11/2025
Brief Synopsis	<p>Food is not just about getting enough to eat, it is important in how we live our lives, see ourselves and interact with others. Preparing and eating meals together can be a chance to spend time with people and use different skills. Community groups that support people with dementia often give people the chance to eat together or involve food in their activities. This can encourage people to go along to groups and help overcome some of the stigma around dementia, and can help people connect socially, take part in activities, celebrate their own culture, and eat well.</p> <p>However, it can be hard to get right. People with dementia may feel self-conscious when eating or need extra support. Food choices can be personal and people may be put off coming along if they don't like the food on offer. The right equipment and training is needed to work with food safely. Some community groups may think twice about providing food and miss out on the possible benefits.</p> <p>Past studies have focussed on how to get people to eat enough food or eat healthily, usually in care homes or hospitals. Not much is known about the wider benefits to people's health and happiness of including food in community group support. We want to learn about the benefits and difficulties of doing things such as providing meals and snacks or preparing food together.</p> <p>We will go along to six different community groups attended by people living with dementia and those that care for them, to see what they do and talk to people about their experiences. We will then use what they tell us to find out why things do and don't work for people in different circumstances. People living with dementia, family carers and community providers will provide project guidance throughout and work with us to create booklets, videos and online materials to explain the most important things we learn from this project. These will be shared with the community groups involved in our study and their wider networks, as well as relevant community organisations and health and social care authorities. We will also include what we learn in future training courses.</p>
Research Question/Aim(s)	<p>Research question: What role can food-related practices play within community group support for the holistic wellbeing and personhood/citizenship of people living with dementia and their family carers? What works, for whom, in what circumstances and why?</p> <p>Aim: To explore the impacts and develop evidence-based guidance for optimal decision-making and implementation of</p>

	<p>food-related practices in community-based post-diagnostic support groups for PLWD and FCs.</p> <p>Objectives:</p> <ol style="list-style-type: none"> 1. To explore food provision and food-related practices in a range of community group settings (WP1, 2 and 4) 2. To understand if known evidence from institutional settings/non-clinical populations applies to community settings with PLWD/FCs (WP1 and 4) 3. To identify and explore how food provision and food-related practices can be a vehicle or barrier to engagement, inclusion and increased wellbeing for diverse populations (WP1, 2, 3 and 4) 4. To identify and explore outcomes experienced by different parties within the group context as a result of food provision and food-related practices (WP2, 3 and 4) 5. To identify and explore the factors that impact upon food provision and delivery of food-related practices in community group support for PLWD/FCs (WP1, 2 and 4) 6. To develop good practice guidance and recommendations for decision-making re: food provision and food related practices in group support for PLWD/FCs (WP4 and 5)
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FUNDING AND SUPPORT IN KIND

FUNDER(S)	FINANCIAL AND NON FINANCIAL SUPPORT GIVEN
National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB), Research for Social Care Programme (Grant Reference Number NIHR205163)	£348,299

ROLE OF STUDY SPONSOR AND FUNDER

The University of Worcester (UW) is the Sponsor for this study. UW takes responsibility for ensuring that the design of the study meets appropriate standards and that arrangements are in place to ensure appropriate conduct and reporting. UW will ensure that all necessary approvals from a HRA research ethics committee are obtained before engaging participants in the study. Signed ethically approved consent and acknowledgement forms from any participants who will be involved in the project will be obtained.

The study is funded by the National Institute for Health Research – Research for Patient Benefit (Social Care) funding stream. The funder has not had any influence over the study design or analysis.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITTEES/GROUPS & INDIVIDUALS

PPI (expert by experience) advisory group (including Realist stakeholder consultees)

A PPI/stakeholder advisory group will be created to input into the research over and above formal data gathering from participants at each site. This group will include members living with dementia or supporting people living with dementia, people involved with planning and running community support groups and activities for people living with dementia (particularly involving the food aspect), as well as professional practitioner and academic stakeholders. This groups will be convened at the start of the project with meetings held regularly throughout. Members of this group will act as experts by experience, providing input and guidance regarding various aspects of the research, including: the design of study documentation; the design of interview and focus group questions; the interpretation of data gathered and the focus of analysis; the format, channels, and development of materials for dissemination.

3 Nations Working Group for Dementia (3NDWG)

The 3NDWG is a working group of people living with dementia across England, Northern Ireland and Wales. Members are based across the three nations, creating a network of voices on dementia who can lead on regional projects. It is led by a steering group of 12 Dr Evans.

Meeting Centres UK Community of Learning and Practice

This is a wide network of practitioners and stakeholders involved with Meeting Centres. Two of the study sites in this research are Meeting Centres. This network's purpose is to share learning between different Meeting Centres, to support each other and to help those who are interested in setting up Meeting Centres. As such the MCUK network will be a key player in dissemination of learning from this research for effective impact on practice, for the benefit of those seeking support through Meeting Centre attendance.

KEY WORDS:

Dementia; Post-diagnostic support; Psychosocial; Implementation; Community; Food; Wellbeing; Social inclusion; Social citizenship; Realist evaluation; Ethnography; Meeting Centres; Dementia Cafes; Dementia Friendly Communities; Adult social care

STUDY FLOW CHART

See **Appendix 1**: Food Glorious Food: Overview Diagram

And **Appendix 2**: Food Glorious Food Gantt Chart

STUDY PROTOCOL

Food Glorious Food: A mixed methods evaluation of food-related practices in post-diagnostic community-based group support for people affected by dementia

1 BACKGROUND

There are currently around 900,000 people living with dementia (PLWD) in the UK,¹ with two thirds living at home,² forecast to rise to over 1 million by 2025.¹ With an aging population³ and health services already stretched,⁴ policy points to the need to move towards a model of social care where more people are supported at home. Improving provision of early, post-diagnostic support for PLWD and their families is a contemporary UK Government and NHS priority for dementia care.⁵⁻⁷

Offering food and participation in food-related practices in group support for PLWD living in the community may have multiple benefits. A healthy and balanced diet is an important part of maintaining physical and mental health, but the risk of malnutrition and dehydration are especially high in older people with dementia,⁸ something which community group support may help mitigate. Beyond this, sharing food is also thought to be a mechanism for social bonding⁹ and thus, could play an important role in engaging people with community support, reducing the risks of loneliness and subsequent negative health consequences. However, if not approached sensitively, food-related practice has also been found to have the potential to act as a barrier to engagement.¹⁰ Limited evidence and understanding in this area¹¹ is therefore a barrier to groups providing effective food-related practice in community group settings, as well as to gaining funding support and policy development in this area. More clarity is required on what constitutes effective food-related practices within community-based group support.

This is especially pertinent at a time when the provision of food and food-related practice in group settings is likely to be more restricted than it was previously, with increased caution following the COVID-19 pandemic. PLWD and family carers (FCs) were particularly impacted¹²⁻¹⁷ by the pandemic, and community-based group provision has a potential key role in the ongoing rebuilding of support for them, as does food-related practices within those groups. However, the perceived challenges of attempting to offer food-related practices have amplified with onset of the pandemic, and many community support groups are now deciding whether to re-start them (see the Patient & Public Involvement work in preparation for this research), making this research timely. The proposed research will consider the challenges of food-related practices in community group support in general, rather than focus specifically on the legacy of the COVID-19 pandemic; however, we anticipate that legacy will be evident in the decision-making pressures and challenges around offering food in community group settings today. We anticipate the current UK cost-of-living crisis may also be a factor in decision making around offering food and food related practices, for example there may be increased motivation to help support PLWD and FCs with food or increased costs to the group to provide food.

The proposed research aims to identify and explore the impact of food provision and food-related practices within community-based group support: the benefits and challenges in implementing it effectively for diverse populations and circumstances. We aim to develop good practice guidance and recommendations for decision-making. Learning will have an immediate impact upon the practice of

those centres collaborating with us, inform their wider networks and will be publicised to relevant community organisations, funding and policy-making bodies across the UK. This will promote better physical and psychosocial health to reduce impact on services as a whole, and may provide insights beyond group provision.

2 RATIONALE

Dementia symptomology can impact upon food-related experiences, and therefore quality of life for PLWD and their families. For example, agnosia, dyspraxia, changes to attention, task-sequencing and decision-making can create difficulties when buying, cooking, preparing and eating food; loss of inhibition and changes in behaviour can create challenges when eating socially.¹⁸ Supporting PLWD to live well in their own communities is a global public health goal¹⁹ that group support has the potential to help achieve. However, little is understood regarding how food and food-related practices within community groups (e.g. jointly preparing food, setting a dining area, serving, eating and sharing, clearing up) may benefit or challenge the wellbeing of PLWD and their families.

The role of food in daily living goes beyond nutrition to impact psychosocial wellbeing, citizenship and identity. The social, emotional and cultural significance of food and food-related practices is well established,^{10,20-23} but less so for PLWD, and not with regards to community group support.

Anecdotally there are multiple potential benefits to offering food in a group setting. However, there is a lack of knowledge regarding the experience of PLWD and their families, in the community.

Groups that include food-related practice among their activities may create significant psychosocial benefits for those attending, but doing so can be complex and challenging.¹⁰ A lack of research in this area means there is little robust evidence to inform those running such groups as to whether they can or should offer food, or how best to do so. The proposed research aims to address this: findings will better equip groups to confidently offer food-related practices that are beneficial to people, tackle challenges that arise and avoid potential pitfalls.

Loneliness and social isolation are a high risk for PLWD and upholding identity and social citizenship is positive for living well with the condition.^{24,25} Social eating and food-related group practices have the potential to help with these things.

Food, food preparation and mealtimes can carry great significance for groups and individuals as these activities carry moral, social, political, cultural and ethical connotations,²⁰⁻²² so understanding how these may act as barriers and facilitators to accessing social eating opportunities is crucial for any group seeking to provide food or food-related practices for a community.²⁶ In the non-clinical population, those that eat together socially are suggested to feel happier and have high life satisfaction.⁹ Social eating provides opportunities for sharing knowledge, fostering relationships and group belonging.²⁷ Lunch clubs for older people in general in UK have been found to improve nutritional intake, have positive impact upon socialisation and loneliness, and provide pleasure.^{11,28,29} Food can be a tool for reducing social isolation, building connections and relationships, and engaging specific groups but, due to its link with identity, can also discourage engagement and thwart inclusion, if not appropriate.¹⁰

With regards to PLWD, research has largely focussed on mealtimes in institutional settings^{8,30-34} and how to help people receive better nutrition.³⁵⁻³⁸ For example, Bunn et al.'s 2016 systematic review⁸ of interventions to support food/drink intake in PLWD found promise in family-style meals and eating with caregivers. Murphy, Holmes & Brooks³⁴ suggested eating with others could help by evoking past mealtime experiences or prompting "copycat" behaviours (but could also negatively impact upon eating for some). Faraday et al.'s 2021 systematic review³⁹ found mealtimes an important opportunity to foster social connection but found tailored care, choice and sensitive response to food refusal were also key to good mealtimes.

There is considerably less research outside of institutional settings regarding PLWD. Food-related practices such as cooking and eating have strong links to identity, culture and emotional responses for those from ethnic minority backgrounds living at home.⁴⁰ Canadian studies with families at home have shown mealtimes are an opportunity for social activity, emotional connection, honouring identity and adaptation to the changes dementia can bring,⁴¹⁻⁴³ though can reinforce a sense of disconnection, isolation and loss of identity. Similarly, eating in company may be desirable,⁴⁴ but can be a source of stress for FCs. Beyond this, little is known about how access to group support might feasibly ameliorate food-related burden outside of the group, for example helping PLWD and FCs to develop strategies to aid food preparation and eating.

Our SCI-Dem realist review,⁴⁵ which looked at the sustainability of community-based activities for PWLD and FCs, found the opportunity for communal eating was a factor in widening the appeal of a group to new members and encouraging people to return. Emergent data from our current Get Real study (2021-2023)^{46,47} of the sustainability of Meeting Centres (a model of community-led, social group intervention for families affected by early-stage dementia⁴⁸⁻⁵⁰) raised the importance of this issue. Inclusion of food-related practices varies across Meeting Centres, but staff report involvement with them can help members maintain a sense of purpose and achievement. Where food is provided, attendees highlight it as a key reason for attending. However, staff also report strict regulations can make involvement of attendees in preparing and serving food prohibitively difficult, while lack of kitchen access and staff/volunteer time can also be a barrier to offering food.

In summary, there are important benefits to social eating and participation in food-related practices for PLWD and FCs, but little research has been carried out into how to optimally implement these in community group support for dementia.

3 THEORETICAL FRAMEWORK

The diagram in **Appendix 1** shows an overview of the study framework.

Five interconnected work-packages (WPs), with mixed methods of data generation, will feed into a Realist Evaluation.⁵¹ A Realist approach is appropriate as it aims to account for the complexity of systems with human actors in real-world settings, and identify causal mechanisms that underlie interventions/programmes of activity to explain why they may be successful in some cases but not others.⁵² Social care interventions such as community group support for PLWD and FCs tend to be especially complex as they can involve multiple agencies and are embedded in a wider, often changing, community setting.

This study will comprise primary data generation involving a total of 54 or more participants at six research sites representing a range of community group support initiatives that aim to support people living with dementia and those that support them, from diverse backgrounds and circumstances. We will use Sensory Ethnography⁵³ (including observations and interviews), and individual participant-led methods (e.g. photo elicitation) with a small subset of individuals, to feed into an overall Realist Evaluation⁵¹ to what works, under what circumstances, for whom, how and why, regarding the offer of food, opportunities for communal eating and food-related activities within community group support for people affected by dementia.

Realist approaches aim to uncover causal processes in complex real-world systems (such as health and social care interventions) by tracing how differing contexts (background circumstances) can trigger different mechanisms (processes in people and organisations) to produce different outcomes.

Sensory ethnography includes attention to the situated, relational, and multisensory nature of the research encounter, apt for enabling research participation for those whose dementia symptoms might impact recall or verbal communication. However, observations will be supplemented with participant interviews where possible, and data from both forms of data generation compared in analysis.

Regarding participant-led methods with a subset of individuals, these might include photo elicitation, interviews, or forms of participant-led diary keeping, and can be negotiated with individuals to ensure comfort and appropriateness for them. This is appropriate for working with PLWD as they experience a wide range of symptoms and have diverse strengths that can be supported through a flexible approach to data generation that is developed in partnership between the researcher and participant. It is increasingly common for people who use services to have control over the research process, rather than professionals.^{54,55} By building in flexibility to the research design, the underpinning axiology of this study is intended to support a model of social citizenship and rights-based approaches to the involvement of PLWD in research.⁵⁶

3.1 Note on participant terminology

People attend community groups for a number of reasons and have an array of personal circumstances. Many of these groups are community driven and/or third sector initiatives, run independently of NHS, local authority or central government. As such they do not use the terms “patient” or “service user” to designate people who attend. “Patient” can be problematic because it reduces an individual’s personhood by narrowing their identity to their medical condition and their relationship with health services only. “Service user” risks doing similar with regard to social care services, and is deliberately not used by some forms of community support (such as Meeting Centres) as they seek to foster the feel of an inclusive “social club” rather than a “care service”, a term which can have either commercial or medical connotations that are not appropriate. Even terms such as “family carer” are not uncontroversial, though widely used for expediency: this is used to designate all those who informally support someone who is living with dementia, despite the fact they may or may not be family, may or may not see themselves in the role of a carer (in fact may find that term restricting of their identity).

DEEP (Dementia Engagement and Empowerment Project) guidance⁵⁷ suggests avoiding terms such as “patient”, “service user” or “client”, and suggests “person/people with dementia” may be more

acceptable. Mr Hullah, this project team's dementia advocacy expert, recommended avoiding terms where there may be connotations of a power imbalance, and suggested "people" is used to recognise people's personhood.

For the purposes of this study we will use the terms "people living with dementia" and either "family carers" or "people supporting those with dementia" (as appropriate), as we will have to distinguish for the purposes of data collection. The term "people affected by dementia" will be used to denote both people living with dementia and those supporting them. We may refer to those attending a group as "attendees". We will use the term "stakeholders" as a broader and more general term to denote all of the above, but also anyone else who has an interest or involvement in community groups at any level (for example group governors, staff and volunteers, health care professionals, community members and groups, local authority representatives or local charity representatives).

As we are conducting case studies we anticipate will also have recourse to use the terms "members" (e.g. for people with dementia attending Meeting Centres) and "family carers" at times to avoid confusion, with the caveat that we recognise these terms may not be an ideal fit for all who participate under those participant categories, and we will aim not to use those terms where they are not appropriate to an individual. It is also likely participants themselves will express a range of different terms in their qualitative data, as participants will be drawn from a range of different backgrounds, roles, and sectors; we will endeavour to make it clear how the varied terminology relates, where it coheres or diverges.

4 RESEARCH QUESTION & AIM/OBJECTIVES

Research question: What role can food-related practices play within community group support for the holistic wellbeing and personhood/citizenship of people living with dementia and people supporting those with dementia? What works, for whom, in what circumstances and why?

Aim: To explore the impacts and develop evidence-based guidance for optimal decision-making and implementation of food-related practices in community-based post-diagnostic support groups for people living with dementia and people supporting those with dementia.

4.1 Objectives

Objective 1: To explore food provision and food-related practices in a range of community group settings (see WP1, 2 and 4)

Objective 2: To understand if known evidence from institutional settings/non-clinical populations applies to community settings with people living with dementia and people supporting those with dementia (see WP1 and 4)

Objective 3: To identify and explore how food provision and food-related practices can be a vehicle or barrier to engagement, inclusion and increased wellbeing for diverse populations (see WP1, 2, 3 and 4)

Objective 4: To identify and explore outcomes experienced by different parties within the group context as a result of food provision and food-related practices (see WP2, 3 and 4)

Objective 5: To identify and explore the factors that impact upon food provision and delivery of food-related practices in community group support for people living with dementia and people supporting those with dementia (see WP1, 2 and 4)

Objective 6: To develop good practice guidance and recommendations for decision-making re: food provision and food related practices in group support for people living with dementia and people supporting those with dementia (see WP4 and 5)

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYSIS

Work will be organised into five interlinked Work Packages (WPs):

- **WP1: Developing an initial programme theory**
- **WP2: Case studies of food-related practice in group settings**
- **WP3: Individual experiences of food and food-related activity (at home and in group)**
- **WP4: Realist analysis**
- **WP5: Creation of guidance materials**

5.1 WP1: Developing an initial programme theory (Lead: Mr Morton) (Contributing to objectives 1, 2, 3 and 5) (Months 1-4)

The purpose of this work package is to undertake a preliminary exploration of the research topic area by consulting with stakeholders who can act as experts by experience. This is to provide a context and steer for what subsequent work packages (WP2 and WP3) should be focussing on and looking out for - in particular ideas on what food-related practice is commonly carried out or not carried out; how that can impact upon attendees and potential attendees to groups (e.g. what's appealing or off-putting to them; what they find of benefit and what they find challenging); the practical challenges of food provision and delivering food related practices; and whether evidence from food-related practice in other arenas (e.g. residential settings) is transferrable to community group settings or not. These preliminary ideas will be captured by an initial programme theory and tested (confirmed, refuted or refined) by data from subsequent work packages.

Stakeholders from our study sites, and other UK community support groups that the team has links with, will be invited to between one and three (depending on need and convenience for attendees) online discussion workshops of about 2 hours, regarding the benefits and challenges/risks of including food, meals and related activities in what a group offers. People in strategic/operational roles, as well as people living with/supporting someone with dementia, that are community group attendees, will be invited via their groups. Those willing but unable to join the workshop will be consulted one-to-one by telephone or email.

This initial consultation is to establish attitudes and current thinking. We will draw on the feedback and advice provided to us by stakeholders, and through discussions within the project team, develop an initial, hypothetical, programme theory, informed by a Realist logic of analysis⁵¹ and with key themes to explore in more depth with data gathered/analysed in WP2-4.

5.2 WP2: Case studies of food-related practice in group settings (Lead: Dr Oatley) (Contributing to objectives 1, 3, 4 and 5) (Months 5-13)

The purpose of this work package is generate data regarding what is happening during food-related practices at different community group settings for people living with/supporting someone with dementia, through a mix of observation and interviews. Particular attention will be paid to how food-related practices might be a vehicle or barrier to engagement, inclusion and increased wellbeing for attendees, and the factors that impact upon what food-related practices are offered and how they are delivered.

A sensory ethnographic approach⁵³ will generate data via periods of observation of food-related practices in six group settings. A researcher will experience mealtimes and related activity at each location, interacting with participants. Observations will be recorded in fieldnotes, aiming to describe what is happening and how participants understand their own action and experience. Sensory ethnography⁵³ includes attention to the situated, relational, and multisensory nature of the research encounter, apt for enabling research participation for those whose dementia symptoms might impact recall or verbal communication. The researcher will aim to capture what happens during food-related activities, and how people respond sensorially, with attention to embodied sensory experience. A minimum of three periods of observation (1-2h duration approx.) will occur at each setting (totalling between 18 and 36 hours of observation).

Groups at six study sites, covering different kinds of community-based initiatives serving people from different backgrounds and communities, with different kinds of offer and approach to providing food or food-related activity, will be purposefully recruited to provide a range information-rich cases.

Inclusion criteria:

- Group (5+ members) is regular and ongoing provision for people affected by dementia living at home
- In a community location (outside of residential/nursing care)
- Includes food-related practices (e.g. meal/refreshment provision, eating together)

At some sites, it is likely that some participants may prefer to communicate in non-English languages. It is not unusual to undertake multilingual ethnographic research⁵⁸ and it has long been common practice in health science ethnographies to make use of interpreters, despite relatively little attention being paid to the process and influence involved.^{58,59} At these sites, a professional interpreter will accompany the researcher who is not fluent in the alternative languages used. It is essential for the axiological foundation of this study to ensure data generation methods provide opportunities for participants with varied levels of cognition and language to participate as they wish. Prior to fieldwork, the researcher will work with the interpreter to establish the purpose of the research, ethical procedures, and method through which the researcher and interpreter will work together during group observations.

The pre-fieldwork briefing will also involve key informants (e.g. staff member or local community gatekeeper) from the relevant group to ensure that professional interpreters are provided with a glossary of key health terms and guidance as to the level of language suitable for the group participants.⁶⁰ Within group observations, it is possible that the professional interpreter will not be required for all interactions, but the purpose is to ensure that all participants have the opportunity to

contribute verbally in their preferred language through fieldwork if they desire. In effect, the use of interpreters in this study is not an either/or concept, but rather, is intended to expand the set of tools available to maximise the flexibility of data generation to ensure a diverse range of voices are heard in this study. In addition, where interactions in the group are taking place in non-English language, the interpreter can support the researcher with the ethnographic description.

It should be noted that translation is not always a simple like-for-like transition, rather, it involves elements of interpretation and expression to convey the meaning of language that is not directly translatable.^{58,59} Given the potential language barrier between participant and researcher, it will be particularly important to critically test interpretations within fieldwork and through post-fieldwork reflective debriefing with key local informants and the professional interpreter. There may be occasions where participants prefer a family or friend to take on the interpretation role. It will be important to be explicit about the source of the data and the role of the interpreter.

To uphold the quality of the study, it will be important to be explicit about the role of the interpreter and to continuously reflect upon the influence of interpretation and translation on the data generated. As per Temple (1997),⁶¹ the interpreter role cannot remain anonymous, but rather, it will be important to consider how formal and informal interpreters might gatekeep access to participants and information.⁵⁸ Furthermore, reporting upon the characteristics of participants as well as the original language of data collection will be important for the rigour of the study.⁶²

In addition to outcomes with respect to food-related provision in community-based social care for people living with dementia, this study will also develop insight into the methodological challenges of undertaking multilingual dementia research. This lacuna must be attended to if insight into non-English speaking communities is to be advanced and an evidence-based approach to dementia care is to be developed that includes the experiences of those from non-English speaking communities.

Ethnographic observations will be supplemented by qualitative interviews with attendees living with dementia (minimum 3/group), family carers (minimum 3/group), and staff/volunteers (minimum 2/group). Hence we anticipate a minimum total of 48 interviews. Alongside general questions about their experiences with food-related activity at the group, subject matter covered by these interviews will be informed by the content of the observations, i.e. people will be asked about what has been observed, and their responses in that situation, to better understand that observed food-related activity at the community group. We expect interviews to take between 30 and 90 minutes. Potential participants will be identified/approached with the aid of group leads, following a consent process established in our previous research⁴⁷ designed for people living with dementia. Interviews will be used to clarify participant experiences/perceptions and add detail to findings. Interview topic guides will be designed following WP1 and with the input of people living with dementia and other stakeholders from participating community groups. Interviewees will be purposively sampled to represent a range of experiences and diversity of gender, age, and ethnicity.

Participants for whom English is not their first language will be offered the opportunity to take part in the interview process with an interpreter. Use of interpreters in interviews is not uncommon, and will require particular attention to seating arrangements, communication dynamics and attention to the language of questions to enable effective translation.⁵⁹

5.3 WP3: Individual experiences of food and food-related activity (at home and in group) (Lead: Dr Knight) (Contributing to objectives 3 and 4) (Months 5-13)

The purpose of this work package is to complement WP2 by adding a more in-depth exploration of individuals' experiences around food and eating. If WP2 aims to understand the impact, benefits and challenges of food related practice at a group level, WP3 aims to understand the impact, benefits and challenges that food provision and food-related practices may have upon individuals by gaining a better understanding of their perspective regarding food and eating in general - and the outcomes of food provision and food related practices for them, for example whether they find it enabling or challenging, enjoyable or uncomfortable, supportive of wellbeing and social connection or otherwise, and if so, how, why and in what circumstances. WP3 will generate rich data from individual participants/dyads and will compliment WP2 by shifting the focus beyond the group environment, to people's homes and other spaces in which food-related practices occur. This will add data that further illuminates the potential role of food-related practices in people's lives, and thus, add broader context to the potential benefits and challenges of food provision and food-related practices within the group setting explored in WP2.

One-to-two individual participants/dyads will be recruited from each of the six study sites in WP2 to explore their experiences and perspectives in greater depth regarding food provision and food-related practices both at group and at home/in everyday life, to understand the impact of specific factors (e.g. different symptoms, personal circumstances/preferences, cultural background). Potential participants will be identified through consultation with group leads and our work in WP2.

Methods of data collection will include photo elicitation, interviews, or forms of participant-led diary keeping, but will be negotiated with individuals to ensure comfort and appropriateness for them. People living with dementia experience a wide range of symptoms and have diverse strengths that can be supported through a flexible approach to data generation that is developed in partnership between the researcher and participant. It is increasingly common for people who use services to have control over the research process, rather than professionals.^{54,55} By building in flexibility to the research design, the underpinning axiology of this study is intended to support a model of social citizenship and rights-based approaches to the involvement of people living with dementia in research.⁵⁶

Participant-driven photo elicitation is a method that transcends language, age and culture.^{63,64} Photographs used as part of the interview process can provide a visual prompt to enable participants to recall moments of lived experience and bring the 'faded' meanings back into the moment of the interview. Understanding the meaning that food-related practices activities hold for someone is complex and needs methods that will provide a way to discover these embedded experiences. Food experiences are often ephemeral and thus, photographs can be a good way of capturing and sharing a moment that has already passed.⁶⁴ The use of participant generated photographs can anchor the conversation in the individual's experiences. As a method, it has been successfully used with people living with dementia.⁶⁵⁻⁶⁸

Participant-driven photo-elicitation can enable participants to have control over both the photographs they chose to take as well as what they chose to then talk about in the interview, they are in effect steering the research. There is a sense of ownership and partnership in the process which is not necessarily possible with some other forms of research. This creates a more equal partnership that is

researching ‘with’ rather than ‘on’ or ‘for’ people living with dementia. Data will be generated through accompanying unstructured interviews. Photographs would be printed so that participants can have time to review them and select which images to talk about and a simple set of prompts could be asked and printed and displayed in front of the participant to support discussion of the images if needed.

Examples of the sorts of prompts that could be used are (guided by Wang and Pies⁶⁹):

- What do you see in this photograph?
- Tell me the story of this photograph?
- Can you talk about what this means to you?
- Is there anything else you would like to tell me about this photo?

Participants may however just talk through their photographs, initiating the direction of conversation, preferring a discussion with the researcher. If a participant has a partner or perhaps a relative living with them there is the potential for both people to take their own images, offering the opportunity to explore both people’s perspectives. Where roles have shifted this could provide a means of exploring this aspect. Additionally, it is possible to thematically analyse the images as well as the interview data.

5.4 WP4: Realist analysis (Lead: Mr Morton) (Contributing to objectives 1-6) (Months 12-18)

The purpose of this work package is to synthesise and analyse all project data to trace what might be causing what with regards to food provision and food-related practice in community settings, the decision-making surrounding it, and its impact upon attendees or potential attendees (generative causation): In other words, how, why, for whom, in what contexts, to what extent might food provision and food-related practice in community settings benefit or not benefit the people living with dementia and supporting those with dementia that it is supposed to support.

Data analysis will run alongside data collection, so as to enable us to adapt our observations or interview questions to explore emerging areas of interest or data gaps. Data generated in WP1-3 will be organised by theme (thematic analysis⁷⁰) using NVivo qualitative analysis software to code transcripts/fieldnotes. This is to understand the key topic areas in which learning around food-related practice can be uncovered, and to prepare the data for Realist analysis (see below). Themes will be generated both deductively (i.e. using existing knowledge from previous research and initial stakeholder input, as located in WP1) and inductively (i.e. generated from the WP2 and 3 data).

Themed data will then be further analysed using a Realist logic of analysis⁵¹ to create “If-then-because” statements a.k.a. context-mechanism-outcome configurations (CMOCs) – i.e. how differing contexts (sets of circumstances) trigger different mechanisms (the hidden causal processes within people and organisations) to cause desired or undesired outcomes (positive or negative impact upon holistic wellbeing). Outcomes we will be looking for will be those that are relevant to our research question, in particular relating to objectives 3 (how food provision and food-related practices can be a vehicle or barrier to engagement, inclusion and increased wellbeing for diverse populations) and 5 (the factors that impact upon the provision of food and delivery of food-related practices in community group support for people living with/supporting someone with dementia). The contexts and mechanisms will be drawn from the data.

As part of this process we will regularly revisit the initial programme theory from WP1 and draw upon data from WP2 and 3, to iteratively refined it into a programme theory that explains how, why, for whom, in what contexts and to what extent food provision and food-related practices may be of benefit to the holistic wellbeing of people living with/supporting someone with dementia. We will also compare our findings to known evidence from institutional settings/non-clinical populations to see if our data from community settings supports or challenges the hypothesis that such evidence is transferrable (objective 2).

Our expertise and experience⁴⁵⁻⁴⁷ in Realist research will guide us in the above process, as well as current best practice.⁷¹

5.5 WP5: Creation of guidance materials (Lead: Dr Evans) (Objective 6) (Months 18-20)

WP5 will turn our results from WP4 into useful recommendations for those considering whether to offer food and food-related practices as part of a group's provision. The "if-then-because" statements (or CMOCs) created in WP4 will be reframed and restated as practical suggestions and action points regarding what people can do to ensure food-related practices are effective, inclusive, manageable for those delivering or facilitating them, and benefit people rather than creating barriers. This will take place with the input of people living with dementia, people supporting someone with dementia and staff/volunteers from our study sites, to ensure the suggestions we make are realistic and reasonable. people living with dementia, people supporting someone with dementia and staff/volunteer stakeholders will be invited to take part in three face-to-face discussion workshops (4-6 participants/workshop, lasting up to 3 hours) to discuss this and collaborate on language, content, and design of materials to disseminate the practical suggestions and action points.

Regarding materials, we plan to produce three key insight booklets with our tips and recommendations, aimed at 1) people delivering and facilitating food-related practice in community groups; 2) people attending or supporting someone to attend groups; and 3) people and organisations with strategic oversight of such groups. We will also produce short videos to communicate these top tips.

As well as booklets and videos to summarize the study's key insights, we develop online materials in line with the preferences of our stakeholders. This may take the form of a website continuing our key messages, links to our videos and downloadable version of our booklets, and/or possibly a web-based informational "app" that people can access via computer, laptop, smartphone or tablet, designed to use "on-the-go" in community groups, if our stakeholders would prefer this. Online materials can also serve as a way to link to other resources, such as recipe ideas or food safety guidance, along with dementia community-related information and material.

Our booklets and online materials will be promoted and distributed directly to our study sites and their wider networks, as well as to key community-based organisations (e.g. Age UK, Alzheimer's Society, Meeting Centres UK network community of learning and practice, Community Makers network), and will be available to download/access via the University of Worcester website. Following completion of the study we will also host a launch event at the University of Worcester to generate media interest and promote the work and materials.

Findings will also be published in academic journals, practice publications (e.g. Journal of Dementia Care), and disseminated at conferences. Our findings and conclusions will also be integrated as appropriate into the various Association for Dementia Studies training courses that we offer at the University of Worcester.

6 STUDY SETTING

Six study sites, representing different kinds of community-based initiatives serving people from different backgrounds and communities, with different kinds of offer and approach to providing food or food-related activity, will be purposefully recruited to provide a range information-rich cases.

Three groups in Herefordshire and Worcestershire have agreed to take part (see "Letters of agreement" attached):

- Leominster Meeting Centre (run by independent charity Dementia Matters Here, provides hot meals at lunch)
- Droitwich Spa Meeting Centre (run by Age UK Herefordshire and Worcestershire, members bring packed lunches)
- Dementia Cafés in Worcestershire (run by Age UK Herefordshire and Worcestershire, provides snacks and refreshments)

A further 3 groups in metropolitan urban areas, serving ethnically diverse communities will be engaged:

- Two (minimum) in Wolverhampton, engaged by Dr Jutla and Satrang self-led community group for older south Asians residing in Wolverhampton, that in turn works with a further four similar community-led groups in the area (see "Letters of agreement" attached).
- The Club, a community resource centre in the London Borough of Hammersmith and Fulham for clients living with Dementia, Alzheimer's Disease, long term health conditions, physical disability and visual and hearing impairments, in particular from BAME communities (run by Nubian Life, a charity and specialist provider of activity-based care, with a focus on food as a central focus).

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

7.1.1 Inclusion criteria

Community-based initiative study sites have been selected purposefully for appropriateness (see Section 6). To be useful for this research they must offer food, activities involving food and/or opportunities for communal eating in some form (even if this involves attendees bringing their own food). Sites have also been selected for diversity, to cover different kinds of community-based initiatives serving people from different backgrounds and communities, with different kinds of offer and approach to providing food or food-related activity, in order provide a range of information-rich contexts, perspectives and experiences.

- Group (5+ members) must comprise regular and ongoing provision that aims to cater to people affected by dementia living at home (whether exclusively or among its target members)
- In a community location (outside of residential/nursing care)
- Includes food-related practices (e.g. meal/refreshment provision, eating together)

These sites will provide the settings for ethnographic study, via observation at times where communal eating, the provision of food or food-related activity is taking place, and via interviews with people involved in these activities.

Interview participants will be selected from those taking part in food-related activity at the study sites and will be one of the following: Attendees living with dementia; family carers; and staff/volunteers. Sampling will aim for as wide a representation of gender, age, ethnicity and socio-economic grouping as possible, but this will be largely determined by the circumstances and actualities of each location and the people involved with it.

A sub-set of individual participants/dyads from each study sites will be recruited to explore their experiences and perspectives in greater depth in WP3. These participants will be identified through our work in WP2. Their eagerness to take part in more in-depth data generation work, and their ability to do so, will be key factors in deciding whether they are appropriate to recruit for this, and decided in consultation with them, the group leads at each site, and the project team, with guidance from our PPI advisory group.

7.1.2 Exclusion criteria

Potential study sites will be excluded if they do not allow for any opportunities communal eating or activities involving food among their activities. Participants will be excluded if they have never taken part in communal eating of any activities involving food at the community-based initiative under study. For issues relating to capacity to provide consent for participation, see below.

7.2 Sampling

7.2.1 Size of sample

We anticipate around 8 (minimum) participants (attendees living with dementia, family carers and staff/volunteers) per study site, with 6 study sites, making a total of about 48 participants (minimum) (see Section 5.2, WP2). These will be participants formally recruited to take part in interviews. This should give us a range of perspectives per type of participant and study site, while also being realistic in terms of numbers available to take part and practically manageable within the scope and timeframe of the study. From this cohort, one-to-two participants/dyads will be recruited to take part in WP3 (see Section 5.3). Note ethnographic observations will take place involving the wider group.

7.2.2 Sampling technique

Sampling will be a combination of convenience with purposive sampling: i.e. participants will be those already attending, supporting someone to attend or running a participating study site. This is appropriate as the aim is to collect a range perspectives from individuals with direct experience and expertise in a range of different settings and circumstances, to maximise what can be learnt about the

various contexts, mechanisms and outcomes that might be involved and at play regarding food-related provision and activities in community-based initiatives.

7.3 Recruitment

7.3.1 Sample identification

Study sites have been selected purposefully for appropriateness (see Section 6). Potential participants will be identifiable by their role within the study site (attending, supporting someone to attend, or running things as a member of staff or a volunteer. The project team already have links with each potential study site, and leads at each site are collaborators on this research. Dr Oatley, Dr Knight, Mr Morton and Dr Swift will work with community group leads at each study site to identify appropriate potential participants in each role at each site. Staff at each study site will approach attendees to invite them to participate in the study, help them to better understand the participant information and consent process, and assist them in deciding whether they would like to take part in an interview (WP2) if they do decide to take part. Where and how WP2 interviews will take place will be determined by discussion with staff and participants. Only those happy to have taken part in WP2 will be invited to have further involvement in WP3, with the nature of that involvement negotiated between participant and project team (Dr Knight) in co-production (see Section 5.3).

7.3.2 Consent

In the case of group observations, people attending in the community group environment will not be formal research participants at that point, as no personal information will be collected from individuals. Hence there will not be formal consent taken from those present for the observations. However, we will ensure that group attendees know in advance that a researcher will be attending to conduct an observation, so that if someone planning to attend is uncomfortable with this, they can lodge concerns with group. The group can then decide if they wish to go ahead and come in. If they do not wish us to attend on that occasion, we will seek to rearrange for a different session with different attendees, as the groups we are working with run multiple sessions on different days. Advance notice also offers people (living with dementia and/or families) a chance to ask questions of us, and/or choose not to attend. If it becomes apparent that someone objects to being observed during the observation session, then we will ensure not to record anything about them. If someone becomes distressed about our presence, we will cease the observation, and re-arrange. Community group staff will be on hand to support and reassure in the unlikely event of this.

In the case of interviews, all participants will be presented with a participant information sheet explaining the nature and objectives of the study, what will be required of them to take part and the possible risks associated with their participation. They will be given the opportunity to ask questions before being also presented with a consent form, and will be given a week to decide if they wish to participate. Participant information will be tailored to each participant group (see **Table 3** below). The following will be designed, to be supplied to the participant with **consent forms** and talked through/explained:

1.	For attendees of community support groups (including people living with dementia and those supporting them) and those involved in running
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	community support groups and food-related activities therein (including governors/trustees, staff and volunteers)
1a.	A simplified “easy-read” version of the above
2.	For people acting as a personal consultee of someone unable to give informed consent (with a consultee declaration form rather than consent form)

Table 3: Versions of Participant Information Sheets and consent forms to be developed

Participant information and consent documents will be designed in line with HRA guidance (<http://www.hra-decisiontools.org.uk/consent/>) and approved by an appropriate HRA Research Ethics Committee (REC) (see section 8.2).

In the case of South Asian community groups, Dr Jutla who is a bi-lingual researcher from this community, will verbally translate participant information and consent documents and answer any questions potential participants may have.

It is important to include attendees of the groups being studied in the research for two reasons: 1) for ethical reasons, to ensure the perspectives of the people the groups (and food activities) are designed for (people with dementia and those that support them) are fully and authentically represented in line with a “Nothing about us, without us” ethos; 2) for access to key knowledge and experience, because attendees are in a position to offer key first-hand perspectives not directly available to others such as staff and governors, particularly regarding the factors that can help facilitate or act as a barrier to their engagement, inclusion and sense wellbeing regarding communal eating, food provision and food-related activities.

This will mean undertaking research with some participants who are unable to provide informed consent or whose ability to consent may change over time. The research team will develop ethical relationships with members of each of the groups of research participants. The research team will be mindful of the potential vulnerabilities and implications of participation in the research for each of these groups and will need to develop sensitive and relevant practices of informing and negotiating consent to participate. The researchers propose to make assessments of individuals' capacity to consent to taking part in the research. However, in line with the Mental Capacity Act 2005, we will not assume that someone cannot make a decision for themselves just because they have a particular medical condition or disability (dementia), but will assume they do have capacity to decide to take part in the research unless it is made clear otherwise, before or during the recruitment process. Hence it is important to have a recruitment process where consultation can be made with potential participants and those supporting (group leads and/or formal or informal carers) them regarding their understanding of the research and what their involvement in it will entail.

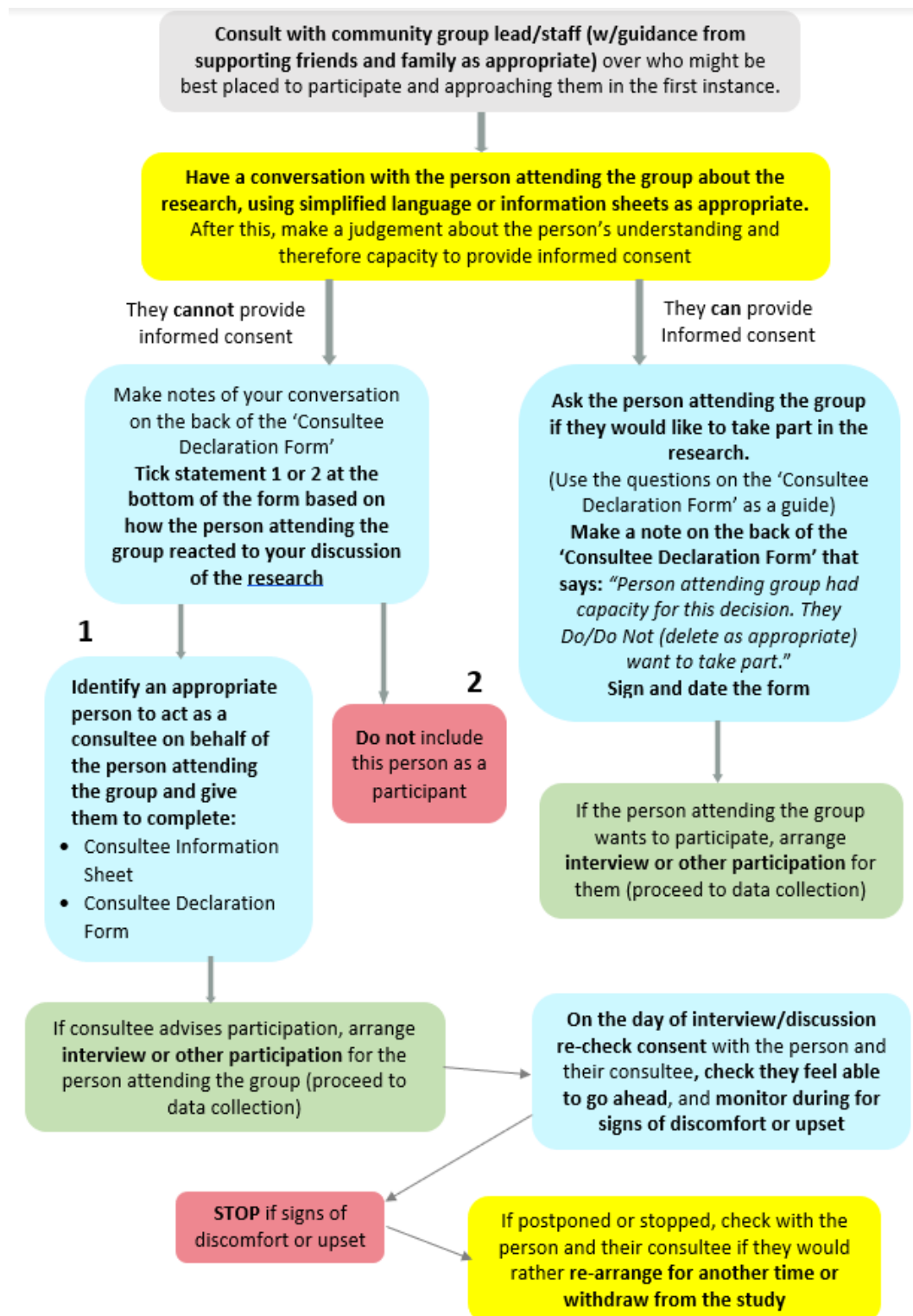
For those potential participants who are assessed to lack capacity to consent to participate in the research (at any point in the study) the research team will seek the advice of a nominated consultee who is not involved in the research in a way that would prejudice their advice. In such cases, the research team will:

- a. Ask someone who knows the person well (e.g. a family member, friend or carer) whether they know if the person would object to taking part in (or continuing to take part in) the research

- b.** Consider what the person themselves appears to be telling us about being involved in (or continuing to be involved in) the research, (even if they can't understand the whole idea of research project a person might still be able to show us signs of happiness or anxiety)
- c.** Monitor the person before and during the interview/discussion and if they show signs of discomfort or upset check that they are ok to continue or would rather stop.

If doubts arise as to a potential participants capacity to understand the research and their involvement in it during the recruitment process, or only at a later stage during interviews, and no-one is available to act as nominated consultee, the process will be sensitively drawn to a close, the individual thanked for their time and their potential participation withdrawn, with any data collected destroyed.

The flow diagram below outlines the process of determining ability or provide informed consent:



Note: If it was necessary to make such an assessment for an individual prior to the start of data collection, it will be **necessary to revisit that assessment if a participant is to be returned to at a significantly later time in the study** (e.g. six months) to take part in further/follow-up interview or focus group participation.

Figure 1: Consent process flow diagram

The research team will be mindful of the particular research context of the community support groups and the types of research activities proposed, and of the ethical issues raised. There will be ethical issues to address in involving research participants within the community support groups. For attendees, a community support group is first and foremost a form of support, a trusted place where they go to get help and seek connection with others, where they feel their needs are understood. In such a setting they are entitled to freedom from pressure to take part in any activity they do not want to take part in. However, older people, and particularly those with communication or cognitive difficulties frequently have little opportunity to voice their views and opinions. The extended periods of case study research and thus contact and familiarity with research team members will give time for researchers to make informed judgements about the capacity of individuals to consent to taking part in the research. The research team are sensitive to the need to ensure ethical participation both to engage community support group attendees in an open and transparent way and to allow participants to disengage where necessary. While it is an ethical imperative that such groups of people should be given the opportunity to be consulted about issues of concern to them, there is also a need to ensure that in approaching and engaging people in the research process they are not exposed to harm.

Participants have the right to withdraw from the research at any time. They also have the right to withdraw their data after participation, which will be destroyed upon their request. It is considered unlikely that participants will experience any physical adverse effects as a result of their participation in the study. However, close attention will be paid to individual responses to the research activities by group leads/staff at each site and any adverse effects will be recorded, and the research team informed.

8 ETHICAL AND REGULATORY CONSIDERATIONS

8.1 Assessment and management of risk

8.1.1 Sensitive Topics, Distress and Upset

The focus of this research will be regarding people's experiences and preferences with food-related activities and communal eating in the community group setting. While this focus is not expected to be generally or explicitly sensitive, embarrassing or upsetting for most, there is the possibility that for some, their relationship with food and eating may be complex and may intersect with experiences of vulnerability, disability and social stigma, and hence of a sensitive, personal and potentially upsetting nature. It is always possible that semi-structured interviews and discussion may stray into personal or sensitive areas that participants may not be comfortable with.

To mitigate this, questions will be framed positively in terms of how things could be improved for the benefit of the individual, and a list of question topics will be shown and talked through with participants

(and their consultee if they have one) before interview. Participants will be told that they do not have to answer any question they are not comfortable with and may ask to move on, or stop the interview or leave the discussion, at any time. Researchers leading the interviews and discussions will also be on alert for any signs of distress. If participants in an interview become upset for any reason, the researcher will:

- Stop what they are doing
- Verbally acknowledge the upset
- Ask if the participant(s) want to stop the interview
- Make a decision with the participant(s) in the best interests of the person with dementia
- Arrange to resume another time or withdraw participation completely
- Follow the Post Incident Evaluation procedure provided by the University of Worcester for reporting and recording incidents.

If there is any sign of discomfort with a sensitive or personal topic that is not necessary to discuss, researchers will automatically move the conversation on to a topic that is less personal or sensitive. Participants who are attendees of the community support group will undertake interviews and discussions at the group support setting itself, with staff on hand to help if they do become distressed or upset. Where participants prefer to be interviewed at home, the University of Worcester Lone Worker policy will be followed. If there is any concern for the safety or immediate health of another party, the emergency services will be contacted. The lead researcher will not attempt to deliver first aid or provide care beyond that recommended by the emergency services, as this is beyond the boundaries of the researcher role. Any disclosures of a criminal nature will be reported to the appropriate authorities.

Participants (or their consultee if they have one) will be offered the opportunity to review a transcript of the interview at a later date for checking to ensure it doesn't contain inaccuracies or anything the person might object to being used going forward. Pseudonyms will be used in the transcript and any specific identifying details will be removed or altered to anonymise. Personal data will be kept secure and only accessible by the research team, and will be destroyed after the study ends.

See section 8.4 for more on how we will support patient and public involvement.

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

As those older people with cognitive impairment may lack capacity to consent to research, the research team will have to justify the need to involve these people in the research. Under the terms of the Mental Capacity Act 2005, people who lack the capacity to consent cannot be included in research unless the research concerns their condition. This research concerns dementia and community

support for those living with the condition. It is concerned with improving the offer of, and engagement with, community group support for people living with dementia, in particular the provision of food, food-related activities and opportunities for communal eating therein. This is in order to improve the provision of support for sustaining the social citizenship and benefit of people living with dementia and those who support them. Hence the involvement of people living with dementia, lacking capacity or otherwise, is justified.

HRA REC approval is necessary, however, because it is possible some participants may lack the ability to provide informed consent, or their ability to consent may change over time. The University of Worcester's own ethic panels are not empowered to provide ethical approval for this. In addition, the *Research for Social Care, (RfSC) Research for Patient Benefit Programme Welcome pack and overview of the grant holders' project monitoring responsibilities* states that:

"NIHR requires, where appropriate, evidence that an approval has been granted by the HRA... Favourable ethical approval does not need to be provided before the project starts, but will need to be in place before any patient recruitment commences."

Hence the data collection stage of the research project will require ethical review. Before data collection commences HRA approval will be applied for via an appropriate Research Ethics Committee using the Integrated Research Application System (IRAS).

- Substantial amendments that require review by the REC will not be implemented until that review is in place and other mechanisms are in place to implement at site.
- All correspondence with the REC will be retained.
- It is the Chief Investigator's responsibility to produce the annual reports as required.
- The Chief Investigator will notify the REC of the end of the study.
- An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.
- If the study is ended prematurely, the Chief Investigator will notify the REC, including the reasons for the premature termination.
- Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

8.2.1 Regulatory Review & Compliance

The Association for Dementia Studies is designated as a Research Centre within the University of Worcester. Its overall governance and quality assurance systems are rigorous and set in place by the University of Worcester. We work within the legislative framework of English Law. Of particular pertinence to our work are the Mental Capacity Act (2005); equalities legislation the Race Relations Amendment Act (2000); the Data Protection Act (1998) and the Freedom of Information Act (2000). We work as professionals within the codes of conduct from the General Social Care Council, British Psychology Society and the Nursing and Midwifery Council.

Permissions have been granted for access to each case study site (see Letters of Support) and researchers accessing those sites will familiarise themselves with local policies and procedures and abide by them e.g. identity badges, DBS clearance, health and safety, safeguarding, etc. Before any site can enrol service users into the study, the Chief Investigator or designee will ensure that

appropriate approvals from participating organisations are in place. Specific arrangements on how to gain approval from participating organisations are in place and comply with the relevant guidance.

8.2.2 Amendments

Amendments will be decided amongst the project management team. For any amendment to the study, the Chief Investigator or designee, in agreement with the sponsor will submit information to the appropriate body in order for them to issue approval for the amendment. The Chief Investigator or designee will work with sites so they can put the necessary arrangements in place to implement the amendment to confirm their support for the study as amended.

8.3 Peer review

This study has undergone high quality peer review as part of the bidding process for funding. It was submitted to the NIHR RfSC (RfPB) programme, which is in two stages (outline proposal and full proposal). At both stages the study proposal was internally peer reviewed by two reviewers within the University of Worcester, as well as independent reviewers on the RfSC committee panel, with amendments made in line with reviewer feedback.

8.4 Patient & Public Involvement

The team will follow established procedures developed specifically for people living with dementia to ensure all are fully supported in their participation. The team has extensive experience of following such procedures in previous research projects such as Get Real with Meeting Centres (NIHR201861, 2021-2023)⁴⁶ and Crossing The Line (NIHR202970, 2022-2024).⁷² Consultations, ethnographic observations and interviews involving members of the public will be carried out on site at community groups collaboratively with group leads and staff. Attendees living with dementia and attendees who support people with dementia, who agree to participate, will be given the option of taking part in individual interviews. If any participant prefers an interview at home or by telephone we will accommodate this but will aim for face-to-face interviews wherever possible. The research team will follow the University of Worcester Lone Worker policy where appropriate. Whilst this research is not overly sensitive in nature, simply talking about experiences of dementia can be upsetting for participants. The research team will be sensitive to participant's emotions and pause, stop and restart fieldwork according to individual's wishes.

Prior to applying for study funding from the NIHR RfSC (RfPB) programme, during the Get Real with Meeting Centres project,⁴⁶ people living with/supporting someone with dementia at Meeting Centres that provided meals highlighted food-related practices as a key reason for attending. Staff and lay-governors raised benefits such maintaining people's involvement in meaningful activities (e.g. helping to prepare for the meal/clear up), or as one staff member stated: "It gives them that sense of purpose and that they can still accomplish something and they are not just being told, you know, just sit here and somebody else is going to do for me." Staff also noted that people would eat noticeably more if given a prepared meal than if bringing a packed lunch. However, other Meeting Centre personnel felt delivering food-related practices was time-consuming and labour intensive, hence not a priority when

faced with limited staff/volunteer time. Meeting Centre personnel (staff and governors/trustees) also felt that providing food in a landscape of risk-averse regulatory pressures – particularly following the COVID-19 pandemic - was challenging. For example, one managerial staff member said: “It’s almost got so over the top [that] you’re not even allowed to carry a plate from the kitchen to the table unless you’ve had your food hygiene training.”

Subsequent public involvement work at Meeting Centres, with 5 people living with dementia and 3 staff, saw the subject of food raised unprompted, again as a reason to attend, a good social opportunity and encouraging of appetite. At separate public engagement sessions at dementia cafés in Worcestershire, attendees repeatedly raised the loss of lunch (i.e. only drinks served) after pandemic restrictions as a negative development, while those running two of the cafes stated that they were re-considering whether to reinstate lunch provision because of this.

Feedback from members of the public on our methods during this previous research informed the design of this project. Questionnaires were unpopular with people living with dementia and those supporting them, who fed back that they found them burdensome and questionnaire choices often “artificial”. Interviews were preferred but for some could be taxing, especially if their symptoms made communication more challenging, hence participatory/observational approaches have been included alongside interviews to capture the experience of people living with dementia and those supporting them.

During this current research, lay co-applicant Mr Hullah will be paid at Involve rates for 20 days. We have included some budget for travel costs if necessary, though we have previously mainly met with Mr Hullah online during previous work. In addition we have convened an Experts By Experience advisory group of 10 people (including Mr Hullah), including people living with dementia, family carers, professionals and academics. This group will meet periodically throughout the project and will:

- 1) Advise on the appropriateness, accessibility and agreeableness of proposed data-generating methods and materials, before data generation starts.
- 2) Discuss what aspects of food provision and food-related practices may be important to focus on, and why (see WP1).
- 3) Discuss the issues and themes arising from the conducting of the research in general, as way of involving them in the research in open ended way (as we have found in previous projects that such open-ended, ongoing engagement can help inspire the course of project and deepen our understanding of both our practice as researcher and of emerging findings).

In addition, WP3 explicitly involves an element of co-production, in that participants themselves will determine what method of data generation is most appropriate for them, and play an active role in that data generation.

Following data generation, we will conduct a further series of workshops with stakeholders/public advisers (including, but wider than, our Experts By Experience advisory group, to:

- 4) Aid the creation of recommendations at the end of the analysis stage (WP5).
- 5) To create appropriate, accessible and appealing materials for reporting and dissemination, and advise on possible channels for dissemination (WP5).

In other words, PPI representatives will be fully supported to be involved in this research at every step – from the study design and focus (including interview questions), to synthesis and interpretation of data, to creation of recommendations and resources for dissemination, according to their wishes.

8.5 Protocol compliance

Protocol deviations will be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

8.6 Data management, protection and patient confidentiality

All investigators and study site staff must comply with the requirements of the Data Protection Act 1998 with regards to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles.

Participants will be provided with a data privacy notice which outlines how we intend to use and store their data and that their data will be used for the stated purposes of the study. Only members of the research team will have access to the data. Only minimal personal data necessary for analysis will be collected, including a name and contact number, and some relevant demographic data.

Face-to-face interviews will be recorded digitally on an encrypted recording device, with recordings transferred to secure cloud-based storage on the University One Drive at the first opportunity, ready for transcription using a trusted external transcription service. Interviews will be conducted online using Microsoft Teams or Zoom and be recorded using the facilities provided on those platforms. Teams recordings are saved to Microsoft Stream (a secure cloud-based service); Zoom recordings will be saved to a secure, password protected area of the University of Worcester's cloud-based storage. These will be converted to an audio-only file at the first opportunity, with the video deleted immediately after conversion. The resulting audio files will again be saved in secure cloud-based storage on the University One Drive, ready for transcription using a trusted external transcription service.

Transcripts will be checked for accuracy and anonymised through the removal of people's names and other personal information. Where necessary non-identifiable terms or pseudonyms will be used instead, with unique participant identification codes used in data storage. All study participants will have a code identifier known only to the research team. A key to codes will be securely stored separately. However, it should be noted that information on a participants' place/role within a community group will be important to retain for the sake of context; it is possible participants with a particular role may be identifiable by that role, if the group is identifiable, which is possible given the low numbers of such community support groups in any given area of the UK (although such indirect identification is less likely for group attendees). Hence participants' preferences on anonymity and identification will be gathered as part of the data collection process and materials reporting on this research will be checked by participants for satisfaction regarding the level of anonymity (see section 7.5.3). Following checking, the audio recordings will be deleted.

The transcripts will be stored electronically on computers and access will be controlled via passwords and permissions to dedicated study folders. Where it is necessary to create hard copies of transcripts

or other data, then these will be securely stored in locked filing cabinets in the University offices, that are accessible only to research staff. Physical copies of consent forms will also be securely stored in locked filing cabinets accessible only to research staff. Participants' personal details (including their names and addresses) will only be used to maintain contact with participants. This will be stored separately from transcriptions and will be kept in a separate file on a password protected computer at the relevant study site. Access to data will be limited to quality control, audit, and analyses. Data shared between sponsor and co-investigators will be de-identified to minimise breach of confidentiality.

8.6.1 Home working.

We anticipate that members of the research team will work both from their University offices and from home, in a blended fashion. Regardless of working location, electronic data will be stored on secure University cloud storage or, only if and when necessary for transference purposes, on password protected external memory devices. Electronic data will not be stored using home computers. Hard (paper) copies of personal data will not be kept at home.

8.6.2 Sharing of data.

Data sharing agreements have been prepared and will be finalised between the six community groups taking part in the research and the University of Worcester. Data will be collected by the local researchers and collated by the University of Worcester having been transferred using processes that comply with safe management of data/GDPR e.g. encryption. IP will belong to the University of Worcester but we will agree the use of study data by our university partners as part of the study Collaboration Agreement.

As part of the checking of transcripts, it may be necessary to share recordings between researchers or between the research team and translators. Recordings will be cloud based and can only be accessed using a secure, password-based process. Recordings will not be downloaded and will be deleted once the checking and transcribing process has been completed.

8.6.3 Reporting of data.

In reports of the work, where excerpts are quoted from interviews, any information that might lead to the identity of participants, other people or organisations being inferred will be disguised where possible. Participants will be consulted regarding their preferences on identification and level of anonymity in the reporting of data. However, for those who are unable to give informed consent, quotes will be attributed to a pseudonym to retain anonymity as default. Community groups will not be identified specifically by name or town, but only by region and pertinent demographic factors.

8.6.5 Data disposal.

Recordings of meetings including focus groups and online interviews will be deleted once a transcription of the meeting has been checked and agreed. Records of personal details will be securely deleted at the end of the study. All written records data will be kept for 10 years in line with University of Worcester (2013) Guidelines and Procedures for Good Research Practice. Stored information will be subject to the usual controls under the Data Protection Act 1998 and University of Worcester (2016) Policy for the effective management of research data.

8.7 Indemnity

Indemnity/insurance arrangements will be covered by the University of Worcester's Employer's Liability, Public Liability and Professional Indemnity insurance. More information and letters with policy details can be found on the University's finance pages at: <https://www2.worc.ac.uk/finance/758.htm>

8.8 Access to the final study dataset

The co-applicants of this project detailed at the outset of the protocol will have access to the full dataset. Any secondary analysis of the data will be permitted with consent from participants.

The co-applicants will work together to identify at what points study progress can be promoted e.g. through social media and the ADS website. It is a contractual requirement for a Chief Investigator to send a draft copy of a proposed publication (including articles, presentations and press releases) to RfSC@nihr.ac.uk at the same time as submission for publication or at least 28 days before the date intended for publication, whichever is earlier.

9 DISSEMINATION POLICY

9.1 Dissemination policy

Our guidance outputs will be targeted towards people and organisations running community support groups and activities and disseminated to them both directly, through the dementia support sector networks and organisations that we work with regularly, and by targeted use of practice-facing media (e.g. Journal of Dementia Care) and social media, in order to help them to make decisions about food-related practice and deliver good practice that people find valuable. We will also produce guidance outputs targeted towards people living with dementia and those that care for them, with the aim of mobilizing/empowering them to have more say in the food and food-related activities that community support offers them; and towards potential funders of community support/those involved with setting relevant policy, with the aim of engaging their interest and raising awareness of the benefits of good food-related practice, and the potential issues to tackle or avoid.

Towards the end of the study, and six months after, we will seek to gather feedback from these stakeholder groups as to how successful our guidance has been in achieving its goals for each group (as above). Such goals should be step towards longer term aspirational impacts outlined above, such as helping community support groups to encourage diverse social inclusion and helping people with

dementia to live well in the community for longer. Though it is beyond the remit of this project to measure this, it will lay the groundwork for further targeted research to examine this. As part of this research we will review findings in the exploratory data that might lend themselves to more thorough investigation to generate more targeted, robust evidence for what could benefit the health and wellbeing of people living with dementia and those that care for them.

It is possible there may be changes to food related practices instigated by stakeholders in this study as a result of being involved with the study, within the study's duration, which we will record and analyze as part of our data. Likewise we will continue an ongoing conversation with participants and advisory group stakeholders regarding how learning from the project might best be disseminated and what impact changes to food provision or food related practices might have for people living with dementia, family carers and organisations running community support. This will include presenting learning from the project back to participants and stakeholders and taking feedback from them specifically about what impact this, and being involved with the research in general, has had on them. We will revisit our dissemination plan at regular intervals throughout the project, as suggested in our Gantt chart, as knowledge regarding the impact of changes to food-related practices will be developed throughout the lifecycle of the project.

Following initial data generation, towards the end of the project, we will:

- 1) Return to our case study sites to record what changes, if any, each organization has made to its food-related practices and what the perceived impact has been upon those who attend.
- 2) Beyond this, at six months following the end of the study, we will conduct an online survey that will go out to all known people and organizations that have requested or been sent our materials, and ask if the guidance was used and if they found it valuable, including what changes they made to their practice as a result (if they offer or support food-related practice) and what the outcome of any changes was. We will also seek public stakeholder feedback from people living with dementia and carers who are involved with community groups that have used the guidance.

At both of the above stages we anticipate also asking about any of the following that have resulted from implementing our guidance:

- If there have been any improvements to engagement and reach, not just in term of numbers attending a group/activity but also the diversity of who is attending
- Any improvement to people's satisfaction with the community support that is linked to the food-related practices, with specific examples
- Any examples of the food-related practice improving people's quality of life
- Any examples of the food-related practice helping people to eat better
- Any examples of the food-related practice improving how staff/volunteers can manage their workload and activities
- Any examples how our guidance has helped decision making for community groups and those involved in their governance and funding, regarding what food-related practice most appropriate, appealing, effective in meeting people's needs and practical/achievable to offer (including cost-effectiveness)

The above subjects for feedback may be refined, changed or added to depending upon the learning that arises during the course of the project.

Regarding reach, in 2021, an estimated 944,000 people were living with dementia in the UK, expected to rise to 1.6 million by 2050. Currently, about two thirds (61%) of those living with dementia over 65 live at home in the community, with an estimated 700,000 people (e.g. family and friends) providing unpaid care.⁷³ Improving the provision of, and engagement with, community services for this population remains a national health goal in which community support groups and initiatives can play a major role. It is difficult to estimate the prevalence of such groups and initiatives as they can take multiple forms and are often run informally but, for example, of January 2019, there were 412 recognised Dementia Friendly Communities in England, all with some form of community support such as Dementia/Memory Cafés, reminiscence or peer support groups.⁷⁴ Meeting Centres are one form of community support that have grown from just 13 in the UK prior to the pandemic to 70 funded in 2023, showing the direction for travel for such support. Such community initiatives can not only provide valued support, but can also play a vital role in raising awareness, combatting stigma and signposting to other services, if engaged with. The offer of food is known to have potential to act as a “hook” to engage people.¹⁰ Hence increased levels of engagement, participation or membership – particularly with regards people from more diverse range of backgrounds – could be a key indicator of the impact of positive changes to food-related practice.

Regarding aspirational impacts, there is potential for a follow up study using specific learning points from this study to inform food-related practice guidance as an intervention. For example, this research might indicate that food-related practice could impact upon:

- Tackling social isolation and loneliness (for either people living with dementia or those that care for them or both). People living with dementia are at high risk of social isolation, and social isolation is known to have a negative effect on health. Informal/family carers are also at high risk of social isolation due to the demands of their caring role. An attractive offer of food can be key in encouraging both to engage with community support that might combat social isolation and connect them with social/peer support.
- How families adjust to change following a family member having diagnosis of dementia and experiencing challenging symptoms. Eating together in a supportive group environment could be an opportunity for carers who find meal times challenging to learn more about what the person they care for likes, and how they might approach meal times and meal choices. The Adaptation Coping/Adjusting To Change Model⁷⁵ suggests that if people can develop strategies to adjust to the changes that dementia brings earlier, then they are more likely to be able to live well with dementia at home for longer without reaching crisis, with carers feeling more able to cope. We anticipate some learning in this project regarding this topic, that could be explored in a more targeted way by follow-up research.
- Effective signposting of people to other health and social care services, as food provision could play a role in improving engagement with such services in general, especially important given the goal of improving diagnosis rates across the UK.

We anticipate there will be transferrable learning from this project also for food provision/practices at 1) Other kinds of community support group aside from those specifically for people affected by dementia; 2) Institutional settings such as care home and hospitals, as this will add a different

perspective to compare with food provision and meal time research already undertaken in such settings. Hence we will seek to identify transferrable learning to disseminate beyond the community dementia support sector.

9.2. Impact Strategy Diagrams



The change we want

Dissatisfaction	Improvements to community-based support are needed to help more people to live well with dementia in their own communities. Anecdotally there are multiple benefits to providing food in community group settings: to engage people with community support, aid social bonding, boost quality of life and reduce the risk of health-impacting loneliness. But there are multiple challenges in working with food for resource-stretched groups. Limited knowledge and understanding of how to approach food-related practice sensitively and manage it well is a barrier to providing it - as well as gaining funding/policy support - despite the potential benefits.
Vision	Widespread community group support for people living with dementia, that knows how and when to use food-related practices in a sensitive, manageable and evidence-informed way in order to engage a diverse range of people with community support, help them to bond socially and live well with dementia, as well as enjoying a nutritious meal – helping community support groups achieve their goal of supporting people with dementia to live well at home for longer.
First steps	The creation and distribution of evidence-informed guidance regarding what works for whom, in what circumstances, how and why with regarding food-related practice (both for those attending and those providing it) – including practical tips for delivery and pitfalls to avoid – that is widely available, known about and used to inform community support groups, dementia focussed organisations, potential funders and policy makers; raising awareness regarding the role of food in the lives of people living with dementia; identifying potential avenues for further, targeted, research regarding this issue.

Paths to impact

Inputs	Processes	Transformations and Outputs	Outcomes and Impacts
Food Glorious Food (FGF) guidance on what works for whom ect. regarding food provision and food related practice in community group support for dementia.	<p>Dissemination of guidance via dementia support contacts and networks (e.g. Age UK, Meeting Centres UK network, Alzheimer's Society) and participating community groups.</p> <p>Awareness-raising publicity campaign: to those in sector via professional channels, and to the wider public via news media and social media.</p>	<p>FGF guidance known about by a wide range of community support groups and activities when considering food related practice and routinely used by them.</p> <p>Potential funders and policy makers (inc. local authority and third sector) across the UK (and beyond) aware of and informed by FGF guidance.</p>	<p>Widespread effective food-related practice in community support: that engages a diverse range of people, helps them to bond socially and contributes to improving their quality of life.</p> <p>The above will help community support groups achieve their goal of supporting people with dementia to live well at home for longer, and help improve the reach of such community support.</p>

9.3 Authorship eligibility guidelines and any intended use of professional writers

All contributing authors will be acknowledged in publications according to good practice authorship guidelines (see below); the funders will be acknowledged in all study outputs in line with NIHR guidance. A publicly accessible report summary will be available on University of Worcester Association for Dementia Studies website post study and findings will be promoted widely at MCs to reach study participants via posters, presentations and leaflets. A full study report will be made available on request.

The final report will be written by the project team, in particular those at the Association for Dementia Studies, led by Dr Evans. Other members of the project team will contribute, revise and approve as appropriate. All authors who make a substantial contribution to the final study report will be named individually. By substantial contribution we mean (in line with guidance from the International Committee of Medical Journal Editors)⁷⁶ that they will have: Contributed to the conception or design of the work or the acquisition, analysis, or interpretation of data; helped draft or critically revise the report; had final approval of the version to be published; and agreed to be accountable for all aspects of the work.

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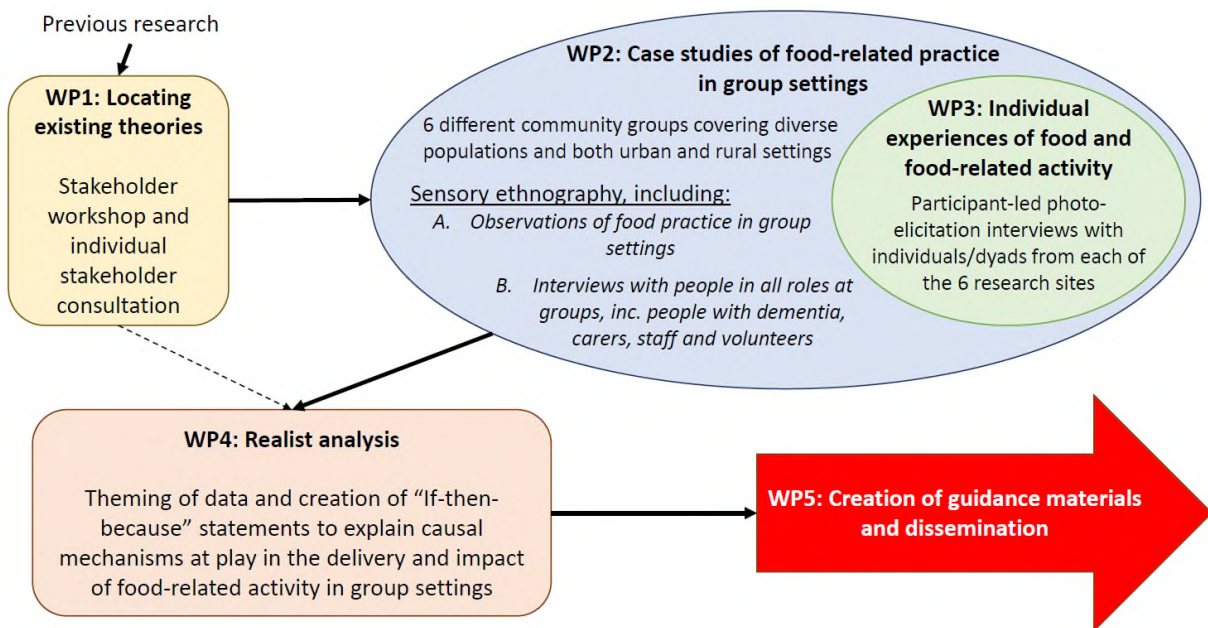
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11. APPENDICES

Appendix 1: Food Glorious Food overview diagram

Food Glorious Food: Flow diagram overview of work packages



Food Glorious Food

Appendix 2: Food Glorious Food Gantt chart

