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# Food Glorious Food: What are benefits and challenges of involving food and food-related activities in community-based support groups for people affected by dementia?

**Submission date**
31/07/2024

**Recruitment status**
No longer recruiting

**Registration date**
09/09/2024

**Overall study status**
Completed

**Last Edited**
03/11/2026

**Condition category**
Mental and Behavioural Disorders

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

## Plain English summary of protocol

Background and study aims
Food is not just about getting enough to eat. Food can be important to how we live our lives, see ourselves and interact with other people. It can provide comfort and joy for many. Preparing and eating meals together can be a chance to spend time with people, have fun 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. As well as giving people something good to eat, these opportunities can encourage people to go along to groups that might support them and help overcome some of the stigma around dementia.

However, it can be hard to get this 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 from coming along if they don't like what the community group is offering. The right equipment and training is also needed to work with food safely. Some community groups may think twice about providing food and miss out on the possible benefits. For example, they could help people make their own decisions about what they eat, socialise and take part in activities, celebrate their own culture, and eat well.

Past dementia 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. In our own previous work this topic was often raised, both by people attending groups and by staff and volunteers.

Who can participate?
People who have had involvement with and/or first-hand knowledge and experience of food and food-related practices at a community group, and work with/care for a person with dementia.

What does the study involve?
In this 18-month project led by the Association for Dementia Studies at the University of Worcester, we will go along to six different community groups attended by people living with dementia and those that care for them. We will see what they do in each group and talk to a range of people there (including attendees and those supporting them, group organisers, staff and volunteers) about their experiences with food and food-based activities. We will also work with some people in each group to understand their individual experience of food and social eating. We will then use what they tell us to find out why things do and don't work for people in different circumstances.

What are the possible benefits and risks of participating?
By taking part in this research participants will have the opportunity to give voice to their experience, observations and opinions regarding food and food activities at their community group. For some, this will be an empowering opportunity and many find the experience of taking part in such interviews interesting and enjoyable. In addition participants will be providing information to help community group support for people like them to improve how they do things and what they offer, directly benefitting those attending, working at, and invested in that community group. The research ultimately aims to help community groups run effectively and efficiently, engage more people and thrive. Hence participants will have the knowledge that they are playing a part in helping others, which can help boost self-esteem and a feeling of agency.
"However, while the focus of this research 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 intersect with experiences of vulnerability, disability and social stigma, and hence of a sensitive, personal and potentially upsetting nature. Steps will be taken to mitigate this risk, including showing participants potential question topics and talking them through before agreeing to interview, with researchers vigilant for any signs of discomfort or distress during interview, in which case the interview will be paused or stopped. Participants will be told that they do not have to answer any question they are not comfortable with and may ask to move on, stop the interview or withdraw from participation altogether at any time. Interviews will take place at the group support setting itself, or at a place chosen by the participant where they feel safe and comfortable, with either staff or a supporting person on hand to help if participants do become distressed or upset.

Patient and public involvement
Members of the public will be involved in the project from start to finish. A group of people living with dementia, family carers, community providers and academics will provide guidance throughout. We will work with people living with dementia and family carers 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 write and publish academic articles and include what we learn in future training courses to help make people more aware.

Where is the study run from?
University of Worcester (UK)

When is the study starting and how long is it expected to run for?
April 2024 to November 2025

Who is funding the study?
National Institute for Health and Care Research (NIHR) (UK).

Who is the main contact?
Thomas Morton, t.morton@worc.ac.uk

# Contact information

### Type(s)
Principal investigator

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Public, Scientific

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# Additional identifiers

### Integrated Research Application System (IRAS)
339634

### National Institute for Health and Care Research (NIHR)
205163

### Protocol serial number
Sponsor Ref: 21/22 0142

# Study information

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

## Acronym
FGF

## Study objectives
This study is not an interventional trial but a realist evaluation aiming to gather qualitative case study data with which to explore the benefits and challenges of food-related activities within community group support for people affected by dementia in order to build a theoretical model. As such it is not focussed upon testing strictly defined hypotheses, but is exploratory and open ended.

The research question and objectives are as follows:

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.

Objective 1: To explore food provision and food-related practices in a range of community group settings

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

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

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

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

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

## Ethics approval required
Ethics approval required

### Ethics approval(s)
Approved 20/09/2024, Wales Research Ethics Committee 7 (Castlebridge 4, 15-19 Cowbridge Rd E, Cardiff, CF11 9AB, United Kingdom; +44 2922 941107; Wales.REC7@wales.nhs.uk), ref: 24/WA/0270

### Primary study design
Observational

### Study design
Multicentre observational case series (as part of a realist evaluation)

### Study type(s)
Other, Quality of life

### Health condition(s) or problem(s) studied
Post-diagnostic support for people with dementia (typically early stages)

### Interventions
This study is a Realist Evaluation, a theory-driven approach to evaluating what works, for whom, in what circumstances, how and why regarding offering food or activities involving food within community group support for people affected by dementia (i.e. community-based group support interventions). Data will be generated using ethnographic methods: a mixture of observation sessions and semi-structured interviews at six diverse community group support case study sites, as well as via participant-led interviews with selected volunteering individuals.

Data will be synthesized and analysed using a Realist logic of analysis to create an overall theoretical model (or "programme theory") involving statements of how different contexts (background circumstances) trigger different mechanisms (responses and processes in people and organisations) to produce different outcomes that have a bearing on the research question.

### Intervention Type
Other

### Primary outcome(s)
A mixture of observation sessions and semi-structured interviews, as well as via participant-led interviews will be analysed using a Realist logic of analysis to understand what works, for whom, in what circumstances, how and why regarding the benefits and challenges of offering food or activities involving food within community group support for people affected by dementia

### Key secondary outcome(s)
One work package within this study (Work Package 3) will also use observation sessions and semi-structured interviews, as well as participant-led interviews to seek to understand the role and experience of food, eating and food-related activities in the lives of individuals living with dementia in general, to produce case study examples to further inform the learning from the study as a whole

### Completion date
30/11/2025

## Eligibility

## Key inclusion criteria
For interviews at our six community group case studies (Work Package 2), participants will:
1. Have involvement with and/or first-hand knowledge and experience of food and food-related practices at one of the community groups being studied
2. Occupy one of the following roles:
2.1. A community group attendee living with dementia
2.2. A person informally supporting a community group attendee living with dementia (e.g. family member or friend)
2.3. A member of paid staff at the community group
2.4. An unpaid volunteer helping at the community group
2.5. A person organising or involved with governance/planning of the community group

For individual participant-led interviews about the role of food in people's lives (Work Package 3), participants will:
1. Have involvement with and/or first-hand knowledge and experience of food and food-related practices at a community group
2. Agree to participate as either:
2.1. A community group attendee living with dementia
2.2. A dyad of a community group attendee living with dementia and a person informally supporting them (e.g. family member or friend)

## Participant type(s)
Carer, Employee, Health professional, Healthy volunteer, Service user

## Healthy volunteers allowed
No

## Age group
Mixed

## Sex
All

## Total final enrolment
36

## Key exclusion criteria
Participants will be excluded if:
1. They have never attended nor had involvement with community group support
2. They do not have the capacity to take part in interviews or discussions
3. They refuse consent or request to be withdrawn from the study after they have done so
4. A personal consultee advises against their participation on their behalf
5. They show signs of negative attitude, discomfort or upset, or of not wishing to take part, when explaining the study and study processes, or before or during interview or discussion

## Date of first enrolment
01/10/2024

## Date of final enrolment
04/06/2025

# Locations

**Countries of recruitment**
United Kingdom

England

**Study participating centre**
**Leominster Meeting Centre**
The Old Priory, The Priory
Leominster
England
HR6 8EQ

**Study participating centre**
**Age UK Dementia Cafes**
Age UK Herefordshire & Worcestershire, Malvern Gate, Bromwich Road
Worcester
England
WR2 4BN

**Study participating centre**
**Nubian Life Resource Centre**
50 Ellerslie Road
London
England
W12 7BW

**Study participating centre**
**Satrang Community Group**
c/o DOSTI, 14 Bird Brook Close
Wednesbury
England
WS10 8NB

**Study participating centre**
**Evesham and District Meeting Centre**
20 Church Street
Evesham, Worcestershire
England
WR11 1DS

**Study participating centre**
**Ekta Group**
Guru Nanak Sikh Gurdwara, 191 Duncan Street
Wolverhampton
England
WV2 3AJ

# Sponsor information

**Organisation**
University of Worcester

**ROR**
https://ror.org/00v6s9648

# Funder(s)

**Funder type**
Government

**Funder Name**
National Institute for Health and Care Research

**Alternative Name(s)**
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

**Funding Body Type**
Government organisation

**Funding Body Subtype**
National government

**Location**
United Kingdom

# Results and Publications

**Individual participant data (IPD) sharing plan**

Data will be available to share upon request to the Association for Dementia Studies at the University of Worcester, after completion of the study (30/11/2025). It will include observation notes as well as anonymised transcripts of interviews and discussions (for qualitative analysis). This data will be retained for 10 years. Personal data from participants will not be shared and will be securely destroyed three to six months after the end of the study. Participants will give consent for the use of their anonymised data, for the purposes of research, at the point of collection. For access to datasets following the completion of this study, contact research associate Thomas Morton at t.morton@worc.ac.uk in the first instance, or the Association for Dementia Studies generally at dementia@worc.ac.uk.

## IPD sharing plan summary

Available on request

## Study outputs

| Output type | Details | Date created | Date added | Peer reviewed? | Patient-facing? |
|---|---|---|---|---|---|
| Funder report results | | | 03/11/2026 | No | No |
| Participant information sheet | version 0.3 | 10/07/2024 | 01/08/2024 | No | Yes |
| Plain English results | | | 03/11/2026 | No | Yes |
| Protocol file | version 1.3 | 24/05/2024 | 01/08/2024 | No | No |