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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	[X] Prospectively registered [X] Protocol
Registration date 09/09/2024	**Overall study status** Ongoing	[_] Statistical analysis plan [_] Results
Last Edited 27/06/2025	**Condition category** Mental and Behavioural Disorders	[_] Individual participant data [X] Record updated in last year

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

Contact name
Dr Shirley Evans

ORCID ID
https://orcid.org/0000-0001-6158-1433

Contact details
Room JL2027, Jenny Lind Building, University of Worcester, Henwick Grove
Worcester
United Kingdom
WR2 6AJ
+44 1905 542664
shirley.evans@worc.ac.uk

Type(s)
Public, Scientific

Contact name
Mr Thomas Morton

ORCID ID
https://orcid.org/0000-0001-8264-0834

Contact details
Room JL2026, Jenny Lind Building, University of Worcester, Henwick Grove
Worcester
United Kingdom
WR2 6AJ
+44 1905 542738
t.morton@worc.ac.uk

Additional identifiers

EudraCT/CTIS number
Nil known

IRAS number
339634

ClinicalTrials.gov number
Nil known

Secondary identifying numbers
NIHR205163, Sponsor Ref: 21/22 0142, IRAS 339634

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

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

Primary study design
Observational

Secondary study design
Case series

Study setting(s)
Charity/Voluntary sector, Community

Study type(s)
Other, Quality of life

Participant information sheet
See study outputs table

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 measure
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

Secondary outcome measures
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

Overall study start date
01/04/2024

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)
Healthy volunteer, Health professional, Carer, Employee, Service user

Age group
Mixed

Sex
Both

Target number of participants
60

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
England

United Kingdom

Study participating centre
Leominster Meeting Centre
The Old Priory, The Priory
Leominster
United Kingdom
HR6 8EQ

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

Study participating centre
Nubian Life Resource Centre
50 Ellerslie Road
London
United Kingdom
W12 7BW

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

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

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

Sponsor information

Organisation
University of Worcester

Sponsor details
Research and Innovation Office
University of Worcester
St John’s Campus
Henwick Grove
Worcester
England
United Kingdom
WR2 6AJ
+44 1905 452181
c.wasilewski@worc.ac.uk

Sponsor type
University/education

Website
http://www.worcester.ac.uk/

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

Publication and dissemination plan
People living with dementia, carer and staff/volunteer stakeholders will be invited to take part in three face-to-face discussion workshops to collaborate on language, content, and design of materials to disseminate the practical suggestions and action points resulting from this research. 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.

We will revisit our dissemination plan at regular intervals throughout the project, as the our understanding of develops and with the input of our Experts-by-Experience advisory group and wider stakeholder consultation.

Intention to publish date

01/12/2026

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?
Participant information sheet	version 0.3	10/07/2024	01/08/2024	No	Yes
Protocol file	version 1.3	24/05/2024	01/08/2024	No	No