

Information Sheet for people involved in community groups

Research Study Title - Food Glorious Food: An evaluation of food practices in community groups for people affected by dementia

You have received this information sheet because we would like you to take part in our research study. The following information explains what the research study is and what it would mean for you if you decide to be involved. Please take time to read over it and discuss the information with other people before you make your decision.

What is the purpose of the study?

This study will look at the benefits to people's wellbeing and happiness of including food in six different community groups supporting people living with dementia. One of these is the community group that you have involvement with. Community groups often offer food or involve food in their activities, so it is important we learn more about the benefits and difficulties of doing things such as providing meals and snacks or preparing food together. We have developed this study so that we can learn from it and develop tips and guidance for others. We will take all the information people tell us to map out why things do and don't work for people in different circumstances and explain the most important things we learn about food in community groups.

Why am I being asked to take part?

We are asking you to take part as you have direct experience of being involved in a community group that includes food. We want to ask people for their experiences with food and food-based activities in community groups.

Do I have to take part?

No, you do not have to take part in the study if you do not want to. You will be given a week to decide. If you decide against it, it will have no impact on your involvement with your community group. You can change your mind about being involved in the study at any time and

without giving a reason. Information about people who have not consented to be involved will not be recorded as part of the study. You also have the right to withdraw your data after participation, in which case it will be destroyed on request.

If you decide that you would like to take part in this research study, you will first be asked to sign a consent form and then we will arrange with you the next steps of taking part.

What will happen if I wish to take part?

You will have the opportunity to be involved in informal interviews about your experiences of food at the community group that you are involved with. You can let us know whether you would like to be involved face-to-face, by telephone or via an online method such as Zoom if you prefer.

Will my involvement be kept confidential?

We keep the specific feedback in individual interviews confidential, but we will state our general findings in our final report. However, if something is disclosed during interviews or discussions that could impact upon the safety of yourself or others, confidentiality may be breached if necessary to ensure safeguarding. Any feedback that we get from you will be checked for accuracy and anonymised through the removal of people's names and other personal information. When we write up our findings, we will use quotes from people we have spoken with. You will be asked your preferences on whether or not you would like your name to be referenced by the quote. When the results of the study are presented, we will not use the name of the community groups involved in the study but will refer to them by region.

What are the possible disadvantages to taking part?

The research involves talking about your experiences related to food, which may bring up difficult memories or feelings for some people. If this happens, we will stop the interview and you can withdraw from the project if you wish.

If you need to emotional support at any time of the day or night, you can contact the Samaritans confidentially. Phone: 116 123 (free 24-hour helpline)

What are the possible benefits of taking part?

By taking part in this study, you will be providing valuable information that we can learn from, to help other community groups enjoy the benefits of including food. You get to share your experiences of food, your opinions on how food is included in community groups and what might be important for helping community groups include food successfully.

We hope that you will find taking part in interviews with us interesting and enjoyable.

What will happen to the results of the study?

The results will give us the information to develop guidance on including food for people involved in other community groups across the UK. The guidance will take the form of booklets, videos and online materials. The results of the study will be written up in a final report and shared with the National Institute of Health Research, who are funding the study. The results will also be used to write articles, reports or include in presentations. We will make sure our results are made available to share with you once the study is complete.

Who is organising or funding the study?

This study is being led by the Association for Dementia Studies at the University of Worcester. It is funded by the **National Institute for Health Research (NIHR)**.

Who has reviewed the study?

This research study has been reviewed and approved by **XXX**. A research ethics committee is a group of people who review research studies to ensure they protect the dignity, rights, safety and well-being of research participants and researchers.

For any further information please contact:

Shirley Evans – PI

s.evans@worc.ac.uk

Association for Dementia Studies

University of Worcester

Henwick Grove, Worcester, WR2 6AJ

Thomas Morton – Research Associate

t.morton@worc.ac.uk

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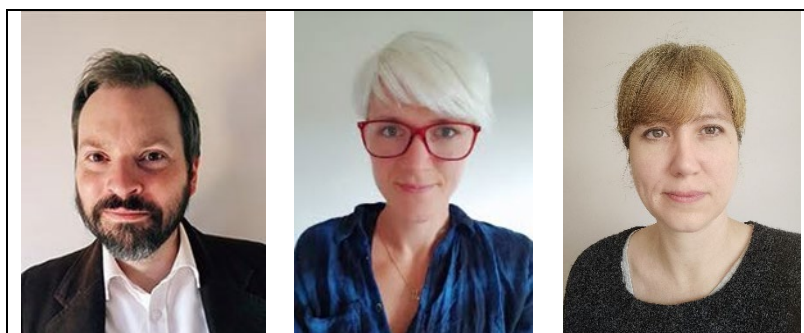
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Information Sheet (short version)

The Food Glorious Food Study



The Researchers: Thomas (left), Becky (middle) and Ruby (Right)

What we are doing

We are doing a research study at [name of the group] because we want to find out more about food, eating and mealtimes. Community groups like [name of the group] often include food, and we hope that we can find out how to make this experience the best it can be.

We would like you to talk to us about your experience with food, eating and mealtimes at the community group that you go to.

How you can take part

Tell someone at your community group if you would like to take part. You will be invited to take part in a **one-to-one conversation**, to talk to us about the food at the community group you go to.



What will happen next?

We will ask you to sign a consent form saying that you want to take part. We will then arrange the next steps, like when you would like to talk with us and how.

Will my information be confidential?

The information you tell us will be checked for accuracy and anonymised by removing anyone's names and any other personal information. If we quote something you have said, we will ask you if you wish for your name to be used before we share it with anyone. Confidentiality will only be broken if there is a danger to the safety of yourself or someone else.

The community group you go to will not be named in any reports, but we will describe it by the region it is located in.

What if I have a concern?

If you have any worries or questions, please talk to us or someone else that you feel comfortable with. We are happy to arrange a time to come and talk with you and answer any questions.

For more info, contact: Thomas Morton

University of Worcester, Henwick Grove, Worcester, WR2 6AJ

Tel: 01905 542326

Email: t.morton@worc.ac.uk

Please remember:

You do not have to take part in this research study. It is your decision if you want to stop taking part in the research at any point and you do not have to give a reason why. If you do not decide to take part but then change your mind, that is fine as well. You can join in when you wish.

Whatever you decide, it will not affect your involvement with the community group you go to.

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Information Sheet for Personal Consultees

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Why am I being asked about this study?

We would like to involve your relative/friend/the person you represent in this study. Due to the fact that your relative/friend/the person you represent may be unable to decide for him/herself, we are asking you to inform us on their behalf. We are asking them to take part as they have direct experience of being involved in a community group that includes food. We want to ask people for their experiences with food and food-based activities in community groups.

Does my relative/friend/the person I represent have to take part?

No. We are asking for your advice about whether they might object to taking part. You will be given a week to decide. They do not have to take part and their experience of going to their community centre will not change if they do not take part.

You may want to think about whether they have expressed an interest in taking part in research before. If you think they would **not object** to taking part, then please complete the **Consultee Declaration Form** and return it to the researchers (or a member of community group staff to pass on to them).

If you feel that the person would not like to take part, it will have no impact on yours or their relationship with the community group that they currently go to. You can change your mind at any time, without giving a reason. Information about people who have not consented to be involved will not be recorded as part of the study. You also have the right to withdraw your data after participation, in which case it will be destroyed on request.

If you think your relative/friend/the person you represent would like to take part in this research, we will arrange the next steps of taking part with both of you.

What will happen if I advise they would wish to take part?

If you say yes to your relative/friend/the person you represent taking part the following things will happen:

1. After reading this information sheet, you will need to complete a consultee declaration form as the person's consultee.
2. A member of the research team will then explain the study to you and your relative/friend/the person you represent and invite them to take part in participating in informal interviews around their experiences of food at the community group that they go to.
3. You and your relative/friend/the person you represent can make the decision on whether they would like to take part in interviews. You can let us know whether you

would like to be involved face-to-face, by telephone or via an online method such as Zoom if you prefer.

4. The researcher will take some notes of your relative/friend/the person you represent's feedback.
5. The research team will then look at this feedback and integrate it into their findings.

Will the involvement of the person I represent be kept confidential?

We keep the specific feedback in individual interviews confidential, but we will state our general findings in our final report. However, if something is disclosed during interviews or discussions that could impact upon the safety of your relative/friend/the person you represent or others, confidentiality may be breached if necessary to ensure safeguarding. Any feedback that we get from you will be checked for accuracy and anonymised through the removal of people's names and other personal information. When we write up our findings, we will use quotes from people we have spoken with, but these will be attributed to a pseudonym to retain anonymity in the case of people who are unable to give informed consent. When the results of the study are presented, we will not use the name of the community groups involved in the study but will refer to them by region.

What are the possible disadvantages to taking part?

The research involves talking about experiences related to food, which may bring up difficult memories or feelings for some people. If this happens, we will stop the interview and your relative/friend/the person you represent can withdraw from the project if they wish.

For emotional support at any time of the day or night, you can contact the Samaritans confidentially. Phone: 116 123 (free 24-hour helpline)

What are the possible benefits of taking part?

By taking part in this study, you will be providing valuable information that we can learn from, to help other community groups enjoy the benefits of including food. Your relative/friend/the

person you represent will get to share their experiences of food, their opinions on how food is included in community groups and what might be important for helping community groups include food successfully.

We hope that they will find taking part in interviews with us interesting and enjoyable.

What will happen to the results of the study?

The results will give us the information to develop guidance on including food for people involved in other community groups across the UK. The guidance will take the form of booklets, videos and online materials. The results of the study will be written up in a final report and shared with the National Institute of Health Research, who are funding the study. The results will also be used to write articles, reports or include in presentations. We will make sure our results are made available to share with you and your relative/friend/the person you represent once the study is complete.

Who is organising or funding the study?

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Who has reviewed the study?

This research study has been reviewed and approved by XXX. A research ethics committee is a group of people who review research studies to ensure they protect the dignity, rights, safety and well-being of research participants and researchers.

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Why am I being asked to take part?

We are asking you to take part as you have direct experience of attending a community group that includes food. We want to ask people for their experiences with food and related activities in their lives in general, to consider how this might inform what happens with food at community groups such as the one you attend.

Do I have to take part?

No, you do not have to take part in the study if you do not want to. You will be given a week to decide. If you decide against it, it will have no impact on your involvement with your community group. You can change your mind about being involved in the study at any time and without giving a reason. Information about people who have not consented to be involved will not be recorded as part of the study. You also have the right to withdraw your data after participation, in which case it will be destroyed on request.

If you decide that you would like to take part in this research study, you will first be asked to sign a consent form and then we will arrange with you the next steps of taking part.

What will happen if I wish to take part?

You will have the opportunity to be involved in informal interviews about your experiences of food and food-related activities in your life in general. How we do this is up to you: We might do this by talking through a typical day or the places you go to get food, prepare food or eat; we might offer you camera for a few days to take pictures to help discuss the role of food in your life, or you could show us existing pictures that mean something to you; or if you like we might even come along to where you live to talk and see first hand the role that food plays in your life. We will sit down and discuss which of these options might be most appealing and appropriate for you before we start.

Will my involvement be kept confidential?

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What are the possible disadvantages to taking part?

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We hope that you will find taking part in interviews with us interesting and enjoyable.

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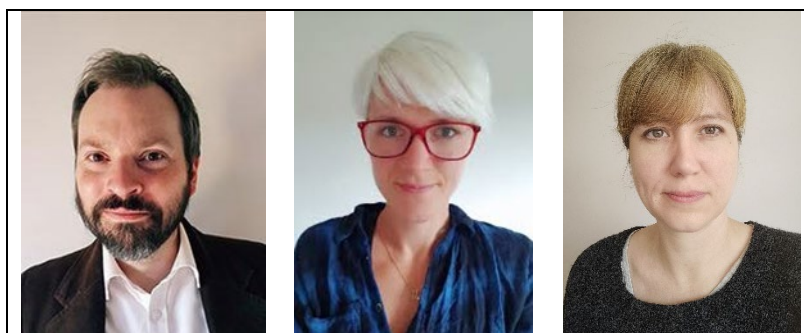
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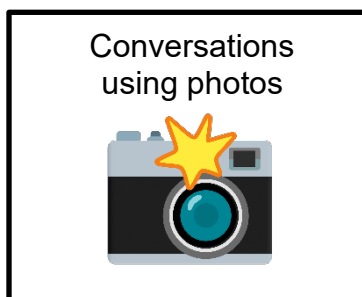
What we are doing

We are doing a research study at [name of the group] because we want to find out more about food, eating and mealtimes. Community groups like [name of the group] often include food, and we hope that we can find out how to make this experience the best it can be.

We would like you to talk to us about your experience with food, eating and mealtimes in general, so we can understand your experiences better. We can then pass on what we learn to help inform community groups that offer food.

How you can take part

Tell someone at your community group if you would like to take part. You will be invited to talk to us about the your experiences with food in your life in general. There are various ways we can do this, perhaps having a to take part in a **one-to-one conversation** at the community group, perhaps by **using photos** to talk about food or perhaps by **visiting you at home**.



What will happen next?

We will ask you to sign a consent form saying that you want to take part. We will then arrange the next steps, like when you would like to talk with us and how.

Will my information be confidential?

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Does my relative/friend/the person I represent have to take part?

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