Exploring death and dying in the UK: public perspectives

Workstream 2: Deliberative Discussion Groups

Information Sheet

Version: 1.0 Date: 6.9.19

Name of Researchers: Kristian Pollock (Chief Investigator)
   Eleanor Wilson
   Glenys Caswell

We are a team of researchers from the School of Health Sciences at the University of Nottingham and we would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Please ask us if there is anything that is not clear.

What is the purpose of the study?

We wish to find out about:

- Public attitudes to death and dying: for example, is death a ‘taboo’ subject, which people don’t want to talk about? How do people imagine ‘a good death’? What concerns and worries do people in the UK have about death and dying?

- How people from different backgrounds and with different experiences view the provision of end of life care in the UK

- What members of the public think good end of life care should look like

Why have I been invited?

You have been invited to take part in this study because you are a member of the public and are over 18. You may have received the invitation to participate through your workplace, through an organisation of
which you are a member or you may have seen one of our adverts seeking participants. You are welcome to take part in the study whether or not you have personal experience of death or bereavement. We are inviting up to 60 people to take part.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your future legal rights.

What happens if I take part?

If you decide to be included in the study you will be asked to sign a consent form to indicate that you agree to take part in a series of informal deliberative discussion groups to explore the study questions with a group of about eight other people. This would involve:

- Taking part in a series of up to 4 informal discussion groups, which will take place over a period of two or three months
- Doing some preparatory work before each discussion group. Materials will be provided and may include a short piece of reading, or the viewing of a short film clip
- Each discussion group will begin with a short presentation from a researcher, and then a discussion will take place between group members. The researcher will be available to answer questions and provide further information about specific topics
- After each group you will be sent a written summary of the discussion

Deliberative discussion groups provide an opportunity for people to learn about a new topic and then to discuss it with others in the light of their increased knowledge. It is not expected that you will have any particular knowledge about death and dying beforehand. Topics which will be discussed may include talking about death and dying, dying well, place of death, choice at the end of life, planning for the future and others.

There will be between 8 and 10 people taking part in each deliberative discussion group. You may already know some of them, but others may be strangers to you at the start of the sessions; the same people will take part in each of the discussion group sessions with you. Sessions will be scheduled for a time and place that is as convenient as possible for those taking part, but this will need to be a location that is suitable for a group meeting.

With your permission we would like to audio record the discussions.
What are the possible benefits of taking part?

We cannot promise the study will benefit you directly but the information we collect will contribute an understanding of public views about death, dying and end of life care. This should help to improve the care and support provided in future by health and social care professionals. We hope participants will find involvement in the study to be an interesting and informative experience. Some people find it helpful to have the opportunity to reflect on and discuss potentially difficult topics with others.

What are the possible disadvantages and risks of taking part?

We understand that talking about issues relating to death and dying may be difficult. We ask you to consider very carefully how you would feel about talking about the topic in a group setting. It is important that you understand what is involved and discuss this fully with the researcher before you decide to take part. You will never be under any pressure to answer questions, talk about topics that you prefer not to discuss, or disclose personal information about your own experience. You can take a break, or withdraw from the study, at any time.

Expenses and payments

Participants will not be paid to take part in the study. Travel expenses will be offered and light refreshments will be provided.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, we will use information collected from you during the course of the research. This information will be kept strictly confidential, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable
information possible.

You can find out more about how we use your information and to read our privacy notice at:


The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Where possible information about you which leaves the University of Nottingham will have your name and address removed and a unique code will be used so that you cannot be recognised from it. By signing the consent form you agree to the above.

Your contact information will be kept by the University of Nottingham for 3 to 6 months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham’s, the Government’s and our funders’ policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

The only circumstances under which confidentiality would be broken would arise if the researchers were made aware of actions or situations resulting in serious risk of harm to yourself or others. The researchers would discuss this with you before making a decision about reporting this to the appropriate person.
What will happen if I don’t want to carry on with the study?

Your participation is **voluntary and you are free to withdraw at any time**, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far, including any personal identifiable data, will not be erased from the secure University of Nottingham server. Anonymised data may still be used in the project analysis.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers’ contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you should then contact the Research Ethics Committee Administrator, c/o The University of Nottingham, School of Medicine Education Centre, B Floor, Medical School, Queen’s Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: [louise.sabir@nottingham.ac.uk](mailto:louise.sabir@nottingham.ac.uk)

What will happen to the results of the research study?

The results of the study will be used to help inform our understanding of public perspectives on death, dying and end of life care and will enable the improvement of the care and support provided to patients and family members during serious illness. The researchers will prepare a **report** for Marie Curie, which has funded the study. The results of the research will be made more widely available through professional and academic journal **publications and conference presentations**. With your permission, we may include direct quotations from the discussion groups. However, these will not include your name or any personal details. You will not be identified in any report or publications resulting from the research. All participants will be sent a summary of the findings at the end of the study if they would like to receive this.

With your agreement, we may use the data collected in this study to support other research in the future, subject to ethical approval. In this case the data may be shared anonymously with other researchers.

Who is organising and funding the research?

This research is organised by the University of Nottingham and is funded by Marie Curie.
**Who has reviewed the study?**

All research involving people as participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by the University of Nottingham’s School of Medicine and Health Sciences Research Ethics Committee.

**What do I have to do?**

Please let the researchers know if you are interested in taking part in the study or would like to discuss this further. You can contact them using the details given below by email, by phone or by post. The researchers will contact you direct to discuss the study further.

**Further information and contact details**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prof Kristian Pollock</td>
<td>Professor of Medical Sociology</td>
<td>T: 0115 8230810  e:<a href="mailto:kristian.pollock@nottingham.ac.uk">kristian.pollock@nottingham.ac.uk</a></td>
</tr>
<tr>
<td></td>
<td>School of Health Sciences</td>
<td></td>
</tr>
<tr>
<td></td>
<td>University of Nottingham</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Queen’s Medical Centre</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nottingham, NG7 2HA</td>
<td></td>
</tr>
<tr>
<td>Dr Eleanor Wilson</td>
<td>Senior Research Fellow</td>
<td>T: 0115 8231201  e:<a href="mailto:eleanor.wilson@nottingham.ac.uk">eleanor.wilson@nottingham.ac.uk</a></td>
</tr>
<tr>
<td></td>
<td>School of Health Sciences</td>
<td></td>
</tr>
<tr>
<td></td>
<td>University of Nottingham</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Queen’s Medical Centre</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nottingham, NG7 2HA</td>
<td></td>
</tr>
<tr>
<td>Dr. Glenys Caswell</td>
<td>Senior Research Fellow</td>
<td>T: 0115 8230872  e:<a href="mailto:glenys.caswell@nottingham.ac.uk">glenys.caswell@nottingham.ac.uk</a></td>
</tr>
<tr>
<td></td>
<td>School of Health Sciences</td>
<td></td>
</tr>
<tr>
<td></td>
<td>University of Nottingham</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Queen’s Medical Centre</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nottingham, NG7 2HA</td>
<td></td>
</tr>
</tbody>
</table>