

# Dementia in the Minds of Characters and Readers: Information Sheet



Please read the information below. If you would like a copy to keep, you can download it from <https://blogs.qub.ac.uk/dementiafiction/reading-groups/>

## What is the project about?

We are a team of researchers based in Queen's University Belfast (QUB). We want to see how readers respond to fiction depicting characters with dementia. This will help us understand the power of fiction in awareness-raising and how society approaches dementia as a social issue.

To do this research, we need participants to take part in a set of reading groups.

## What will the reading group involve?

We will ask you to complete an online consent form to show that you understand and are happy to take part in the process outlined below.

We will also ask you to fill in an online form asking for some details about yourself. We will also use this information to understand the responses of reading group participants.

We have a limited number of places (6-12 in each group) so we may have to select participants on the basis of the information that they provide, in order to achieve a mixed group. Unfortunately, this means that not everyone who applies will be selected for a reading group.

The reading groups will meet online using Zoom. There will be 6 sessions and each session will last approximately 1-1.5 hours. These will take place in Spring 2021.

During each session, the researcher will read two short extracts from fiction which deals with dementia. You will not have to read any books yourself. You will be provided with a copy of these extracts, and we want you to underline and write notes on them. Just write down anything that you think might be relevant to your reading of the extracts. We will provide you with a stamped envelope to post back your extracts.

After the reading, the researcher will ask you to fill in an online questionnaire which records your responses to the extracts. The researcher will then lead a group discussion of the extracts. Please rest assured that we are interested in all kinds of answers and viewpoints so remember – there is no such thing as a stupid answer. You can contribute as much or as little as you like to the discussion.

We will also ask you to fill in an online questionnaire before the first reading group and after the last one - the same questionnaire - to see how reading fiction might shape your understanding of dementia. As a token of our appreciation for your time and effort, we would like to offer you a £20 book voucher upon completion of the six sessions.

## **What will you do with the information?**

As part of the research process, we need to audio-record each reading group meeting. The recording will be transcribed by an external, confidential transcription service. We will use these transcripts to help us analyse how dementia fiction helps people understand dementia. The recordings and transcripts will not be used in any other way.

Everyone will be given a pseudonym in the transcripts. The transcripts will be stored on the password-protected computer of the Principal Investigator and will only be shared with the research team through QUB internal password-protected drives.

We will prepare publications (such as journal articles, reports and blogs) and conference presentations based on our analysis of the reading groups.

## **How will you protect my identity and my information?**

The reading groups will take place in an online meeting platform and only participants with passwords will be admitted. Your name will be visible to other participants and you are free to turn your mic or camera off when necessary. The meeting will be audio-recorded by the researcher and we ask that no other recordings are made. The recording will be transcribed and only the written data will be used in the research. However, we do not have control over how the online meeting platform uses your data, as it has its own privacy policy.

When we refer to what you have said in reports or academic articles, we will protect your identity and use a pseudonym unless you specify that you would like your name to be given. We will also remove any identifying information from the discussion.

The research team will only use your personal contact details (name, email address, phone number, address) in order to get in touch with you about the project and they will not be stored with your transcript. We will delete these details once all the reading group sessions have finished.

For further information on Queen's University's policy on data protection, please visit: <https://www.qub.ac.uk/privacynotice/Research/ListofResearchPrivacyNotices/PrivacyNoticeforResearchParticipants.html>

## **Who is funding the research?**

The project is funded by the Arts and Humanities Research Council and has received ethical approval from the ethics committee of the School of Arts, English and Languages at Queen's University Belfast.

## **What if I want to leave the reading group?**

You may withdraw from the reading group at any stage while they are ongoing. We can also delete your written and recorded responses if you request this within one month of the last meeting of the reading group.

## **Where can I find out more information about the project?**

More information on the project can be found at <https://blogs.qub.ac.uk/dementiafiction/> or by contacting the Principal Investigator:

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