

Dementia in the Minds of Characters and Readers: Information Sheet



**QUEEN'S
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Please read the information below. If you want to keep a copy, you can download it from here <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 would like you to take part in an online reading group.

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 have a limited number of places, so we will select participants on a first-come-first-serve basis. Unfortunately, this means that not everyone who applies will be selected for a reading group.

We will 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 the reading group participants.

Each reading group will meet online using Zoom for one hour per week, for six consecutive weeks. These will start in April 2021, and we will try to arrange a day and time to suit participants.

During each meeting of the reading group, the researcher will read one short extract from a novel which deals with dementia. You will not have to read any books yourself. You will also be provided with a copy of this extract. There are several ways in which you can tell us what you think about the extract. Please use the way(s) that you feel more comfortable with.

- You can underline and write notes on the fictional extract. Just write down anything that you think might be relevant to your reading of the extract.
- You can fill in a questionnaire which records your response to the extract.
- You can take part in a group discussion of the extract.
- Please rest assured that we are interested in all kinds of answers and viewpoints. You can contribute as much or as little as you like.

We will provide you with a stamped envelope to post back any paper copies that you have written on.

As a token of our appreciation for the time and effort you have put into taking part in these reading group sessions, we would like to offer you a £20 book voucher or shopping voucher.

What will you do with the information?

We need to audio-record the whole session. The recording will be transcribed by an external, confidential transcription service. We will use these transcripts to analyse how fiction helps people understand dementia.

We will not use your name, and everyone will be given a pseudonym. 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 Zoom uses your data, as it has its own privacy policy:

<https://zoom.us/privacy>

When we refer to what you have said in reports or articles, we will protect your identity and use a pseudonym unless you specify that you would like your name to be given.

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. We will delete these details once all the reading group sessions have finished. They will not be stored with the recordings of the reading groups.

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 change my mind?

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:

Dr. Jane Lugea, School of Arts, English and Languages, Queen's University Belfast.

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