Institute of Human Sciences

School of Anthropology and Museum Ethnography 51/53 Banbury Road Oxford OX1 6PE

Zoe Rhoades zoe.rhoades@sjc.ox.ac.uk



INFORMATION SHEET FOR PARTICIPANT WITH DETAILS OF THE STUDY

Hello, my name is Zoe Rhoades. Thank you for your interest in our study Living with Multiple Myeloma. This study aims to integrate the biological and social elements of living with multiple myeloma by exploring personal stories alongside academic research.

You will take part in a semi-structured interview of about an hour, online over Microsoft Teams. With your permission, I would like to make an audio recording of our discussion to ensure I'm getting an accurate documentation of the interview and record of thoughts. Instead of recording the interview, I can take notes in my notebook (this will take a bit longer, leading to a longer overall interview). I will ask you if I may write transcripts of the interviews so that I am able to read them back and assimilate my findings from multiple interviews. All audio recordings and transcripts will be stored safely on a personal hard drive and destroyed after 3 years. I will ask for your permission to use anonymised direct quotes from the interview in my final dissertation.

The content of the interview will be directed by you, what you would like to talk about and what you are comfortable sharing. The suggested topics of discussion are the diagnosis story of the participant, treatments, personal impacts, and forms of support and maintaining a positive mindset.

Participation in this study is optional and you are free to withdraw at any point until 07/01/2022 at which point the interviews will be coded with pseudonyms, making all answers anonymous. The answers given in these interviews will form the basis of my (Zoe Rhoades) undergraduate dissertation and any future publications. Only I (Zoe Rhoades) will have access to personal data and research information. I will store all personal information and data safely and confidentially on an encrypted laptop hard drive (and backed up on an external hard disk drive) and will keep the research data for 3 years after publication. This research is anonymous, which means that in any publications, interviewee names will not be used.

The University of Oxford is responsible overall for ensuring the safe and proper use of any personal information you provide, solely for research purposes. Further information about your rights to information you provide is available from the University's data protection web site, and for further information please visit:

http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/.

The following risks are involved in taking part: you are sharing personal stories and we will be discussing sensitive topics which may be difficult to talk about. To reduce the potential risks, I will anonymise all responses and all data will be stored securely. You don't have to agree to take part; you can ask me any questions you want before or throughout; you can also withdraw at any stage, including during or after the interview, and you may request that I do not use certain aspects or all the interview in the final dissertation. You or I (Zoe

Rhoades) may request a short break at any point during the interview to reflect on what has been said or take time to relax as there is a chance that the interview will feature sensitive and emotional topics.

I may want to re-contact you after the interview to clarify information you gave me. In that case, I will ask you if you have time to answer some more questions.

If you have any complaints or concerns, please feel free to contact me in the first instance at zoe.rhoades@sjc.ox.ac.uk

This research project has been reviewed and approved by an Oxford University ethics committee. If, after contacting me with any concern, you remain unhappy and wish to make a formal complaint, please contact the ethics committee. Their email is hod@anthro.ox.ac.uk.

Please email me at zoe.rhoades@sjc.ox.ac.uk to express interest in being a participant in this study. I am happy to share the suggested interview questions with participants to help them decide whether they take part. If you agree to take part then I will then I will send you a consent form to fill out and we will organise a time to carry out the interview.

Many thanks for considering taking part in this study and I look forward to hearing from you soon.

Kind regards,

Zoë Rhoades