Participant Information Sheet for Research Project: "Lived experiences of coeliac disease in self-employment"

Dear participant,

I, Dr Anne Steinhoff, am currently carrying out a piece of research entitled, Lived experiences of coeliac disease in self-employment. I am investigating the lived experiences of individuals who are self-employment and live with coeliac disease. These interviews are an addition to a previous research project. I will collect data for six months and anticipate the findings to feed into a larger research project in the future.

This information sheet provides you with information about the study and your rights as a participant.

What does taking part in the research involve?

The project involves participating in one interview that focus on the experience of being self-employed with coeliac disease. Interviews will be taken place in a setting that makes the interviewees' feel most confident. The interview can also be conducted via Zoom. The interviews will vary in length depending on the time required to go through the questions but the interviews should last around an hour on average. The researcher will ask interviewees for permission to record the interviews to record the conversation.

Do I have to take part?

Naturally, there is no obligation to take part in the study. It's entirely up to you. If you do decide to take part you will be given this information sheet to keep and be asked to give consent to take part. If publications or reports have already been disseminated, these cannot be withdrawn, however, these will only contain anonymised or aggregated data. If you decide to participate in the study and then change your mind in the future, you can withdraw at any point, even after the data has been collected. If you wish to withdraw from the study at any time, please contact the researcher on the details below.

Will my taking part in this study be kept confidential?

All information collected will be kept securely on Box storage which is supplied by the University of Essex. The storage will only be accessible by the direct research team. If you are mentioned individually in any publications or reports then a participant number or pseudonym will be used and identifying details will be removed. A list may be kept linking participant numbers or pseudonyms to names, but this will be kept securely and will only be accessible by myself. A copy of the information which we record about you, but not other participants, will be provided, free of charge, on request.

Transcripts and quotes generated by the project will be retained for a period of ten years after the completion of the project as in line with University's Research Data Management Policy. Due to ethics related requirements and the potentially sensitive nature of details collected, the retained quotes and other research data will not be made available. The collected data will be destroyed by removing all electronic details from Box storage. Physical copies will be destroyed by shredding and disposed as confidential waste.

Are there any possible disadvantages or risk of taking part?

A disadvantage taken part in the study is associated with opportunity cost as there will not be any financial compensation for participation. However, this disadvantage will be kept to a minimum, as the researcher will meet the interviews at a preferred place and time. Due to the nature of the study, the main risk in participating in the study is that some questions may be of a sensitive nature relating to negative situations encountered in workplaces. However, there is no obligation for participants to complete the interview and interviews can be ended at any time. To navigate any potential risks on confidentiality, precautions will be taken to anonymise the collected data by referring to participants with numbers or pseudonyms. Coeliac Disease is an autoimmune disease with varying symptoms. To support mental wellness, participants can take breaks from the interview, end the interview or drop out of the interview. The researcher will make it clear at each interview that there is no obligation to start or continue with an interview.

What are the possible benefits of taking part?
Although the study cannot guarantee any specific benefits in taken part, participants have the opportunity to be involved in changing the outlook of the workplace and how coeliac disease is understood in the workplace. Participating in the study might benefit all employees living and working with an autoimmune disease as the study aims to alert organisations and policy makers to review their understanding of how autoimmune diseases are managed in the area of employment. This new awareness will support initiatives that focus on the development of business or governmental policies in the area of reasonable adjustments in workplaces.

What is the legal basis for using the data and who is the Data Controller?
The legal basis for processing the data collected from this project is informed consent. The Data Controller for his project is the University of Essex and the contact is the University Information Assurance Manager (dpo@essex.ac.uk).

What should I do if I want to take part?
If you wish to participate in the study or would like to ask further questions, please contact Anne Steinhoff via as19522@essex.ac.uk. There is no strict deadline to opt in. Interviews will be conducted until July 2022.

Who is funding the research?
This project is funded by the Research Committee Awards of the Essex Business School at the University of Essex.

What will happen to the results of the research study?
I plan to publish a series of journal articles from these and other research interviews that were already collected in the summer of 2020. I also plan to use the results for conference papers and presentations. Any results and data drawn up on will be anonymised and data will not be identifiable. I plan to make a copy of the findings of the study available to each participant via email or hard copy. Participants can drop out of receiving a copy of the result if they wish.

Who has reviewed the study?
I have applied for ethical approval to undertake this project. My application was reviewed and approved by the Social Sciences Ethics Sub-Committee at the University of Essex.

What happens if something goes wrong?
If you are harmed by taking part in this research project, there are no special compensation arrangements. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the student and/or their supervisor (details below). If you are not satisfied with the response, you may contact the Essex Business School Research Ethics Officer, Dr Casper Hoedemaekers (choedem@essex.ac.uk) or Sarah Manning-Press (sarahm@essex.ac.uk) who will advise you further.

Name of the Researcher/Research Team Members
I would be very grateful for your participation in this study. If you need to contact us in future, please contact me (as19552@essex.ac.uk). You can also contact us in writing at: EBS, University of Essex, Colchester CO4 3SQ.

You are welcome to ask questions at any point.

Yours,

Anne