

To try or not to try? Patients' views on cutting edge research in neuroscience.

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

This is a PhD study which is part of the Wellcome Trust funded London & Brighton Translational Ethics Centre (LABTEC) Project. Its aim is to investigate the social impact of recent developments in stem cell research and neuroscience, and the interaction between scientific research and clinical treatment. As part of this project, we are looking at the experiences of people diagnosed with Motor Neurone Disease.

This study will examine your experience of Motor Neurone Disease. In the context of a broader discussion about your life since diagnosis, I would like to discuss your attitudes towards medical research. However, I am keen not to restrict our conversation in any way and my project is designed more generally to give voice to the experience of people with Motor Neurone Disease, in the awareness that not everyone will be interested in the topic of medical research.

2. Why have I been chosen?

You have been chosen because you have been diagnosed with Motor Neurone Disease.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason.

4. What do I have to do if I take part?

I shall visit you at a place of your choosing to conduct an interview for as long as you feel willing/able to talk. If, at the end of a session, you feel there is more that you would like to say, it should be possible to meet again. With your consent, the interview will be recorded and transcribed.

5. What are any possible disadvantages and risks of taking part?

It will take time out of your day, but every effort will be made to minimise inconvenience and to ensure your comfort in the interview process.

Many people value the opportunity to talk about their experiences, but it will be possible to take a break or stop at any point during the interview.

If, at the end of the interview, it has brought up issues you wish to discuss further, we shall be able to refer you to more expert sources of support.

6. What are the possible benefits of taking part?

Although this research is unlikely to be of direct benefit to you, it will give you the opportunity to talk about your experiences and express your opinion on a variety of subjects to an interested, non-judgemental listener who is not involved in your medical care.

7. What will happen if I don't want to carry on with the study?

If you agree to be interviewed, you can withdraw at any time during or after the interview. However, we would ask to be able to use all data collected up to the point of your withdrawal, which would be kept subject to confidentiality procedures.

8. Complaints

We do not anticipate any problems arising during this study. If you do have a concern, however, about any aspect of this study or the conduct of the researcher, please feel free to contact my research supervisor Professor Anonymous (contact details below).

9. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential.

Every step will also be taken to assure your anonymity. However, in reporting the data we would like permission to refer to your age and gender.

10. What will happen to the data?

The data recorded from the interview will be analysed for a final written project.

11. What will happen to the results of the research study?

The results of the research study will be written up and form the basis of my PhD thesis. Parts of the study may also be submitted for publication. An additional short report of the research findings will be provided for distribution to participants.

12. Who is organising and funding the research?

The research is a PhD project funded by the Wellcome Trust as part of a Research Grant awarded to the Brighton and Sussex Medical School.

13. Who has reviewed the study?

This section will be revised once the study has been ethically approved by all relevant bodies.

Thank you for taking the time to read this information sheet.

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