

Participant Information Sheet *For the teenagers*

Part 1

It is intended to be shown to the teenager by their parents/guardians

Study Title: **Psychosocial adjustment in adolescents with a parent with Multiple Sclerosis (MS)**

Researchers' names: Angeliki Bogosian, Prof. Rona Moss-Morris, Dr. Julie Hadwin
Ethics number:

We are asking if you would take part in a research project designed to find the answer to the question "How teenagers adjust to their parents' MS?" Before you decide if you want to join in it is important to understand why the research is being done and what it will involve for you. **Please take time to read the following information carefully.** Talk about it with your family, friends, doctor or nurse if you want to. If you are happy to participate you and your parent will be asked to sign a consent form.

1. Why are we doing this research?

We are interested in finding out whether having a parent with MS has affected your life in anyway. If there are positive and/or negative factors. Also, we want to know, if some teenagers find adjusting more difficult and if so if this is related to things like communication in family and how bad the parents' MS is.

2. Why have I been invited to take part?

You have been invited to join our study because one of your parents has MS. Sixty adolescents with their parents will be studied in this phase of the project.

3. Do I have to take part?

No, it is up to you. If you do, we will ask you to sign a form giving your assent. You will be given a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you or your parents receive.

4. What will happen to me if I take part?

The research project will involve completion of questionnaires in two time points 6 months apart. The questionnaires are about how you see your parents' MS, about the communication with your parents, how you feel and how your parents MS affects your life. The completion of the questionnaires will last for about 30-45 minutes. **The questionnaires will be either mailed to you or you would be provided with a link to complete anonymous questionnaires online, depending on what is most convenient for you.** A telephone guidance from the researcher will be provided.

5. Is there anything else to be worried about if I take part?

It is possible that some people might find it upsetting answering questions about their psychological well-being. If you get upset you can skip questions, take a break or decide not to continue. If you are very upset we will offer you some sources of support.

6. What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help young people with a parent with MS in the future.

If you would like to discuss your potential involvement in this research please contact: Angeliki Bogosian on **02380 598721** or ab2406@soton.ac.uk

Thank you for reading so far-if you are still interested, please go to Part 2

Participant Information Sheet

For the teenagers

Part 2

More detail- information you need to know if you still want to take part

1. What happens when the research project stops?

The information we will gain from this study will help us find out which factors play a role on how teenagers feel regarding their parents' MS. Knowing that, we can help young people cope better with having a parent with MS.

2. What if there is a problem or something goes wrong?

In the unlikely event that you are unhappy with the way that the research is conducted the Southampton University complaint mechanisms are open to you. The person to contact in this regard is the chair of the Ethics Committee via Barbara Seiter, Academic Administrator (tel. 02380 525578, email bs1c06@soton.ac.uk).

3. Will anyone else know I'm doing this?

We will keep your information in confidence. This means we will only tell those who have a need or right to know. Wherever possible, we will only send out information that has your name and address removed.

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

The results will be used to help the researchers develop appropriate support strategies to help teenagers cope better with having a parent with MS. The study will also be written up for publication in scientific journals and may be presented at scientific conferences.

If you would like to know the results you can be provided with a summary sheet.

5. Who is organising and funding the research?

The research is being organised and conducted by researchers from Southampton University.

6. Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the Southampton & South West Hampshire Research Ethics Committee and the University of Southampton Research Committee.

Thank you for reading this-please ask any questions if you need to.