

Patient information sheet (Short version)

We are doing a study about MS and pregnancy. You are eligible to take part in this study if you have MS and are pregnant. More information about this study is given below.

Why are we doing this study?

We are conducting a study to look at MS and pregnancy. We don't yet have enough information about the use of newer treatments in pregnancy. It seems that women with MS have an increased risk of experiencing changes in their mood after having a baby, but there is very little information about this for either women with MS or their healthcare teams.

This means that when MS teams talk to women with MS about pregnancy there are a lot of questions that currently can't be answered properly. It also means that women are getting different advice from different people, which can be very confusing. We have set up a study (the UK MS Pregnancy Register) to try to help researchers to answer some of these questions.

What does taking part in this study involve?

If you decide to take part, we will ask a series of questions during your pregnancy, and in the first year after you give birth. We will also ask for the details of your GP and MS team, and any other doctors who may be involved in your care or the care of your baby in the first year of its life (for example obstetricians, paediatricians). We may contact these doctors to get extra information about you, your pregnancy, and/or your baby. All information is strictly confidential.

We will be asking you these questions online, via a secure website. If you find it tricky to use the website for any reason, you are free to ask someone to help you. It is up to you to decide whether or not to take part. You will be asked to complete a consent form before providing any personal details. If you decide to take part, you can withdraw at any time and without giving a reason.

What are the benefits of taking part in this study?

There are no direct benefits to you for taking part in this study. We hope that information from this study will improve the care of women with MS considering pregnancy in the future.

What will happen to information about me as part of this study?

We will need to use information from you, from your medical records, your GP, and other people involved in the care of your MS and the care of your child (where relevant) for this research project. We will only use information that we need for the research study. The information about you will be stored safely as part of the UK MS Register, and the information about your baby will only be visible to researchers asking questions about MS and pregnancy.

We will let very few people know your name or contact details, and only if they really need it for this study. Everyone involved in this study will keep your data safe and secure. We will follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it and for future research. We would like to contact you about future research if you say that you are happy for us to do this.

We will make sure no-one can work out who you are from the reports we write.