



British Association of Dermatologists Biologics & Immunomodulators Register (BADBIR)

YOUNG PERSON INFORMATION SHEET (Guide age 11-16)

Version 2.1 01/08/2017

Title of Project: British Association of Dermatologists Biologic and Immunomodulators Register (BADBIR)

Name of Researcher: Professor Chris Griffiths

- ✪ We would like you to take part in a research study.
- ✪ Please take time to read this leaflet carefully and discuss it with others if you wish.
- ✪ Ask us if anything is unclear, or if you would like more information.
- ✪ Take time to decide if you wish to take part.

What is the purpose of this study?

We need more information on long term effects of new drugs that are used to treat psoriasis.

We especially need more information on the side effects they may produce as they have not been in use for very long.

Why have you been chosen?

You have been chosen because either you are taking a tablet or injection to treat your psoriasis.

We intend to invite as many children and young people as possible who are taking these drugs to take part.

Do I have to take part?

- ✪ You do not have to take part if you do not want to.
- ✪ If you decide not to take part it will not affect how your doctors treat you.
- ✪ If you **do** decide to take part, and your parents agree, you can sign a form to show this if you would like to.
- ✪ You can change your mind at any time without saying why

What information will we collect from you?

✪ The study will collect information about you, your psoriasis, medical treatment and tests, how well you are and how you grow. All this information will come from the team you see for your normal hospital visits and you will not usually have to answer any questions from us on your own. This type of study is called an 'observational study' which means that we simply watch what happens to people - the study does not affect the treatment that you get from your doctor.

- ✪ We would like to link to your record held at several national providers of healthcare information (eg. NHS Digital). This may help provide the study with information about your health status.

Are there any risks to me if I take part?

The study will run alongside your routine psoriasis care; it will not influence this process. Therefore, there are no foreseeable risks associated with this study.

What are the possible benefits of taking part?

Although there is no clinical benefit gained by participation in the research, the information obtained from this study may result in changes in future treatment of patients with psoriasis.

What will happen to the results of this study?

The results of the study will be presented at scientific meetings and published in medical journals but no identifying information will be used.

Will anyone know I have been involved with this research?

All information used in the study is kept under secure conditions and is strictly confidential. Your GP will be informed that you are in the study.

The research is funded by the British Association of Dermatologists and is based at the University of Manchester. If you want to ask about anything please get in touch with the Chief Investigator Professor Christopher Griffiths (christopher.griffiths@manchester.ac.uk)

Thanks for reading this information leaflet. If you do decide to take part in the study, you will be given a copy of this leaflet to keep and will be asked to sign an assent form. Your parent or guardian will also be asked to sign a consent form.