



Centre of Evidence Based Dermatology

University of Nottingham
King's Meadow Campus
Lenton Lane
Nottingham
NG7 2NR

Title: *Identifying and Prioritising Important Research Questions for the Treatment of Vitiligo.*

Investigators: Professor H. Williams, Dr K. Thomas, Dr J. Chalmers, M. Whitton and C. Lushey.

Vitiligo survey: Information sheet

You are invited to take part in this research study that is aiming to **identify and decide the most important research questions for the treatment of vitiligo**. Before you agree to take part it is important that you understand the purpose of this study and what it will involve. Please take time to read the following information and contact us if there is anything you do not understand or if you would like more information.

Why the study is important

There are only a few licensed treatments for vitiligo, although over the years a range of treatments have been tested in an attempt to halt the spread of the disease or restore the vitiligo patches to their normal colour. Those that have been tried have had various levels of success and in some cases new areas of vitiligo have occurred or vitiligo has returned in the areas that gained colour with treatment. Consequently, the patient's quality of life has not necessarily been improved.

We think it is vital that **more research is done into treatments for vitiligo**, and that this research focuses on the questions that are important to people who have vitiligo, parents of children with vitiligo and the health professionals (doctors and nurses) that treat vitiligo. We are therefore collecting questions that all these groups of people have about treatments for vitiligo. We will use these to identify where there is true uncertainty, that is to say where there is no existing research that already provides a reliable answer, so that future research can focus on the most important questions.

If you have vitiligo, are the parent of a child with vitiligo or a health professional with an interest in the condition, **you can help us by completing this survey** and telling us what questions you have.

What does the study involve?

If you agree to participate in this study you will be required to **complete the attached survey** which should take about five minutes to complete. It asks what **questions about the treatments for vitiligo you would like answered by research**. The sorts of things we would like to know about are any **questions you have, or had, about treatments for vitiligo**, for example: prescribed medicines (e.g. tablets or creams), light therapy (e.g. UVA), surgical procedures (e.g. skin grafting), psychological therapy (e.g. coping methods) or cosmetic applications (e.g. camouflage).

This research study commenced in September 2008 and is due to be completed by November 2010. The surveys will be available between April and July 2009.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are free to withdraw at any time and without giving a reason. *Completing the survey will be considered as consenting to participate in the research and allowing the research question you supply to be published on the Database of Uncertainties about the Effects of Treatments (DUETs, available at www.duets.nhs.uk).* If you decide to take part please keep this leaflet.

Will my taking part in the study be kept confidential?

All personal information which is collected about you during the course of this research study will be kept on a password protected database and is strictly confidential. Any information about you that leaves the research unit will have your name removed.

What will happen to the results of the study?

The research questions will be used to inform a clinical trial proposal for submission to a research funding body. It is expected that the results of this study will be published in the scientific press and in the Vitiligo Society's newsletter 'Dispatches' and on their website. You will not be identified in any publication. The results will also be published on DUETs in Dec '09.

Who is organising and funding the study?

This study is being funded by the National Institute for Health Research (NIHR) and the money is being used to pay research staff salaries and other costs (e.g. travel costs). The study is being undertaken by the Centre of Evidence Based Dermatology at the University of Nottingham in collaboration with the James Lind Alliance.

Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham's Medical School Ethics Committee.

Who can I complain to?

In case you have a complaint about anything to do with this study, you can initially approach the lead investigator, Professor Hywel Williams by telephone: 0115 8231048 or email: hywel.williams@nottingham.ac.uk. If this achieves no satisfactory outcome, you should contact the Ethics Committee Secretary, Mrs Louise Sabir, Division of Therapeutics and Molecular Medicine, D Floor, South Block, Queens Medical Centre, Nottingham NG7 2UH. Telephone: 0115 8231063. Email: louise.sabir@nottingham.ac.uk.

Contact for further information

If you would like to discuss this research study further or have any questions please contact a member of the research team at the Centre of Evidence Based Dermatology by telephone: 0115 8468633.

Useful websites

Centre of Evidence Based Dermatology: www.nottingham.ac.uk/dermatology/

National Institute for Health Research: www.nihr.ac.uk

The James Lind Alliance: www.lindalliance.org

Database of Uncertainties about the Effects of Treatments: www.duets.nhs.uk

INVOLVE: www.invo.org.uk

Thank you for reading this information sheet.



Vitiligo Survey

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The sorts of things we would like to know about are any **questions you have, or had, about treatments for vitiligo**, for example: **prescribed medicines** (e.g. tablets or creams), **light therapy** (e.g. UVA), **surgical procedures** (e.g. skin grafting), **psychological therapy** (e.g. coping methods) or **cosmetic applications** (e.g. camouflage).

To help you, here are some **examples** of research questions for other health conditions:

- *Are breathing exercises helpful in controlling asthma?*
- *What is the evidence for gargling aspirin to relieve a sore throat?*
- *Are topical steroids for atopic eczema safe in the long-term?*

Q1 What questions about the treatments for vitiligo would you like to see answered by research?

1.

2.

3.

4.

Please feel free to continue on the back if you have more than 4 questions.

Q2 What desirable effects do you hope the treatments would produce?

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More information about you

It would be really helpful for our research to know a little more about you, so we would be grateful if you could answer the questions in this box. However, if you would prefer not to, then just leave this section blank.

1. Which of these best describes you (please tick all that apply):

- Health professional (e.g. doctor, nurse)
- Person with vitiligo
- The parent of a child with vitiligo
- Other (please specify).....

2. What is your (or your child's) age (please tick)?

- 0 – 5 5-10 11-17 18 – 29 30-60 over 60

3. What is your (or your child's) gender (please tick)?

- Male
- Female

Would you like more information about the next stage of this research study where we decide which research question is the most important and should be developed into a clinical trial proposal (please tick)?

- Yes**
- No**

Would you like to be informed of the results of this study (please tick)?

- Yes**
- No**

If you have answered **yes** to either of the above questions please provide your contact details:

Name:

Email address:

Postal address:

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What is your preferred method of contact (please tick)?

- email**
- post**

Thank you for completing this survey

Please return this survey to: Vitiligo Study, Centre of Evidence Based Dermatology, University of Nottingham, King's Meadow Campus, Lenton Lane, Nottingham, NG7 2NR.