

SETTING PRIORITIES AND REDUCING UNCERTAINTIES FOR PEOPLE WITH SKIN DISEASE (SPRUSD) by Clare Lushey



My name is Clare Lushey and I am a Research Associate at the Centre of Evidence Based Dermatology at the University of Nottingham. As you may have seen in the last issue of Dispatches, we are undertaking a research study in collaboration with the James Lind Alliance, looking at 'Setting Priorities and Reducing Uncertainties for People with Skin Disease' (SPRUSD). This independent research is being supported through a programme grant funded by the National Institute for Health Research (www.nihr.ac.uk). The vitiligo aspects of the programme of work will last for three years and include several research activities:

(1) *Updating an existing systematic review of interventions for vitiligo.* This will provide health professionals and patients with the most up-to-date information about the known effects of treatments for vitiligo, and will help us to identify areas requiring further research.

(2) *Identifying what people with vitiligo and health professionals would like to find out about treatments for vitiligo.* These questions will be entered onto the Database of Uncertainties about the Effects of Treatments (www.duets.nhs.uk).

(3) *Prioritising these uncertainties for future research.* The priority setting process will involve people with vitiligo, parents or carers of children with vitiligo, health professionals and researchers, all working together to agree a '**top ten**' list of unanswered questions about treatments for vitiligo.

(4) *Developing one of the 'top ten' uncertainties into a feasibility study.* This will lead on to a funding application to the NHS for a full clinical trial on a topic that has been identified as a priority.

(5) *Producing web-based patient information resources and clinical decision aids,* which will help people with vitiligo, parents or carers of children with vitiligo, and health professionals to make informed choices about treatments for vitiligo.

The purpose of this research is to reduce uncertainties about treatments for vitiligo and to set priorities for future research. This work is of vital importance because it aims to:

- Gather what we already know about the effectiveness of treatments for vitiligo.
- Identify what we do not know about treatments for vitiligo.
- Work with people with vitiligo (including parents or carers) and health professionals, to prioritise uncertainties for future research.
- Ensure that future research addresses questions that are important to people with vitiligo and those who care for them.

As members of the Vitiligo Society, you will have important questions about treatments for vitiligo and *we hope that you will share these with us.* Your questions will be collected using a survey that will be available through the Vitiligo Society's website and in future issues of Dispatches. You can choose to be involved further in the process if this is of interest to you, or simply submit questions that you think are important.

All questions will be reviewed by a prioritisation team made up of patients, carers, health professionals and researchers. At the first stage, the team will individually select their 'top ten' research questions from those that have been submitted. These will then be discussed during a prioritisation workshop and the team will collectively decide on the most important research questions for the future.

This is an important opportunity for you to become involved and have your say in research into vitiligo. The work will take place between March and December 2009. Further updates about the progress of this research will be featured in later issues of Dispatches.

If you would like to find out more about this research, or would like to submit a question that you feel has not been answered by your doctor, please contact me (Clare Lushey) by telephone: 0115 84 68633 or email: clare.lushey@nottingham.ac.uk.

Useful websites:

- Centre of Evidence Based Dermatology: www.nottingham.ac.uk/dermatology
- James Lind Alliance: www.lindalliance.org
- UK Dermatology Clinical Trials Network: www.ukdctn.org