Research priorities for the treatment of pemphigus and pemphigoid

We would like you to take part in a survey

Information Sheet

What are we trying to do?

We want to find out what people think are the most important areas for future research on the treatment of bullous pemphigoid, pemphigus vulgaris and mucous membrane pemphigoid. We will call these pemphigoid or pemphigus throughout the rest of this information sheet.

Researchers at The University of Nottingham have formed a partnership with health professionals and patients to find out what research to do next. This is called a priority setting partnership.

We want to hear from adults who have pemphigoid or pemphigus, anyone who is involved in caring for someone with pemphigoid or pemphigus and healthcare professionals. This will involve filling in a survey, either on paper or online.

What is the survey about?

This survey is about making sure future research is focussed on what matters to *you*. It is your opportunity to tell us what questions about pemphigoid or pemphigus you would like answered by research.

Your questions can relate to anything to do with the **treatments, or their side effects,** for **bullous pemphigoid**, **pemphigus vulgaris**, and/or **mucous membrane pemphigoid**.

Treatments include:

- Topical treatments, such as skin creams or lotions, mouthwashes and eye drops
- Medicines given by mouth (e.g. tablets), or by injection
- Dressings
- Any other treatments

We are interested in treatment of the skin anywhere on the body including the scalp, and the mucous membranes such as the mouth, eyes, nose, throat and genitals.

Will my taking part in the study be kept confidential?

Yes. All information you provide will be kept strictly confidential, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the University will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it. Anonymised data may also be stored in data archives for future researchers interested in this area.

Your personal data will be kept so that we are able to contact you about the findings of the study and possible follow-up studies – but you can choose not to provide any contact details. All research data will be kept securely for 7 years and not shared with other organisations. After this time your data will be disposed of securely. All precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

What will happen to the results of the survey?

Once we receive the survey responses, we will sort through them and produce a list of the most common questions and themes that have not yet been answered by research. After this, we will ask people to take part in a second survey to tell us which of the currently unanswered questions they think are most important. It is up to you whether you would like to take part in the second survey. You will be able to tell us within the first survey if you are happy for us to contact you again.

After we have gathered the information from the second survey, we will invite people with pemphigoid or pemphigus, their carers, and health professionals to a one day workshop to decide the top ten questions.

Further information

More information is available on our website:
www.nottingham.ac.uk/go/PEM-psp

If you would like to take part then please follow this link,
https://www.surveymonkey.co.uk/r/PEM-PSP

If you prefer to fill in a paper copy, please get in touch and we will send you one in the post.

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The Pemphigus and Pemphigoid Priority Setting Partnership is an independent group of patients and health professionals. The project is funded by the Nottingham Hospitals Charity. It is led by a team at the University of Nottingham, and overseen and monitored by the James Lind Alliance (www.jla.nihr.ac.uk), a not-for-profit organisation managed by the National Institute for Health Research Evaluation, Trials and Studies Co-ordinating Centre.