



Treatment of Pemphigus and Pemphigoid Diseases - Priority Setting Partnership Survey

1. What is it all about?

In this survey we would like to hear from patients and carers who have been affected by pemphigus or pemphigoid disease and from the healthcare professionals who treat them.

This priority setting partnership (PSP) will make sure that future research into the treatment of pemphigus and pemphigoid is focused on the most important questions.

We would like to hear the questions you have about the treatments for:

- **bullous pemphigoid**
- **pemphigus vulgaris**
- **mucous membrane pemphigoid**

(if you are a patient and think you have a pemphigus or pemphigoid disease but not sure what it is called, please carry on with the survey).

Although this survey will focus on treatments only, we know there are other areas of potential research that are equally important, for example the cause and diagnosis of these diseases, but these are excluded from this PSP.

Please see [the information sheet here](#) for more details about this survey. If you prefer to complete a paper copy you can request this survey to be sent in the post to you, with a Freepost envelope. Please call Maggie McPhee 0115 8468621

* Your personal data (name, email address), if you decide to provide it at the end of this survey, will be kept so that we are able to contact you about the next stage of the study.

All information that you provide in this survey will be kept strictly confidential. Any information about you which leaves the University of Nottingham will have your name and address removed (anonymised).

I agree to take part in this survey

* Please tell us who you are:

- Person with a pemphigus or pemphigoid disease
- Friend/ family member or carer of someone with pemphigus/pemphigoid disease
- Health professional



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2. What do I have to do?

What do you think are the most important things we need to know about the treatments of these conditions?

Please complete the boxes on the following page with your questions about treatments.

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

Which insulins are safest to use for diabetes?

Is light treatment better than creams for psoriasis?

How well do pressure relieving beds work for treating pressure ulcers?

We need research ideas like these to improve treatments for pemphigus and pemphigoid diseases.



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3. Your questions

Please could you suggest up to FIVE questions about bullous pemphigoid, pemphigus vulgaris and/or mucous membrane pemphigoid treatments.

Your questions can relate to anything to do with treatments, or their side effects.

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**

If you need more time to think about this you can close and re-enter this survey at anytime.

* Question one:

Question two:

Question three:

Question four:

Question five:



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4. Which condition do you have?

* Please tell us which pemphigus/pemphigoid condition you (or your relative/friend) have:

- Bullous pemphigoid
- Pemphigus vulgaris
- Mucous membrane pemphigoid
- A blistering skin condition but I'm not sure what it is called
- Another pemphigus or pemphigoid condition (please tell us what it is)



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5. More about you

It would be really helpful to know a little more about you, so we would be grateful if you could answer the questions in this section. All personal data will remain confidential.

If you are the person affected by pemphigus or pemphigoid, please answer the following questions about yourself. If you are a carer, relative or friend, please answer about the person who has pemphigus or pemphigoid.

How old are you / the person you care for?

- 18 - 29 years
- 30 - 39 years
- 40 - 49 years
- 50 - 59 years
- 60 - 69 years
- 70 - 79 years
- 80 years or more
- Prefer not to say

Are you / the person you care for

- Female
- Male
- Prefer not to say

What is your / the person you care for ethnic background?

- White English / Welsh / Scottish / Irish / British
- White Gypsy or Irish Traveller
- Any other White background
- Mixed / Multiple ethnic background
- Asian / Asian British
- Black / African / Caribbean / Black British
- Arab
- Other ethnic background
- Prefer not to say

Where do you / the person you care for live?

- England
- Wales
- Scotland
- Northern Ireland
- Republic of Ireland
- Outside of UK and Ireland (please state below)
- Prefer not to say

Please specify which country if you reside outside the UK and Ireland



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6. What do I have to do?

What do you think are the most important things we need to know about these conditions?

Please complete the boxes on the following page with your questions about treatment.

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

Which insulins are safest to use for diabetes?

Is light treatment better than creams for psoriasis?

How well do pressure relieving beds work for treating pressure ulcers?

We need research ideas like these to improve treatments for pemphigus and pemphigoid diseases.



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7.

Please provide your questions about bullous pemphigoid, pemphigus vulgaris and/or mucous membrane pemphigoid treatments, that could improve the care and treatment of these conditions if answered by research.

Your questions can relate to anything to do with treatments (and their side effects) including:

- **Topical treatments including creams, lotions, mouthwashes and eye drops**
- **Oral treatments, or injections**
- **Dressings**
- **Any other treatments**

* Question one:

* Which condition(s) does your question relate to?

- Bullous pemphigoid
- Pemphigus vulgaris
- Mucous membrane pemphigoid
- All of the above

Question two:

Which condition(s) does your question relate to?

- Bullous pemphigoid
- Pemphigus vulgaris
- Mucous membrane pemphigoid
- All of the above

Question three:

Which condition(s) does your question relate to?

- Bullous pemphigoid
- Pemphigus vulgaris
- Mucous membrane pemphigoid
- All of the above

Question four:

Which condition(s) does your question relate to?

- Bullous pemphigoid
- Pemphigus vulgaris
- Mucous membrane pemphigoid
- All of the above

Question five:

Which condition(s) does your question relate to?

- Bullous pemphigoid
- Pemphigus vulgaris
- Mucous membrane pemphigoid
- All of the above

Question six:

Which condition(s) does your question relate to?

- Bullous pemphigoid
- Pemphigus vulgaris
- Mucous membrane pemphigoid
- All of the above

Question seven:

Which condition(s) does your question relate to?

- Bullous pemphigoid
- Pemphigus vulgaris
- Mucous membrane pemphigoid
- All of the above

Question eight:

Which condition(s) does your question relate to?

- Bullous pemphigoid
- Pemphigus vulgaris
- Mucous membrane pemphigoid
- All of the above



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8. More about you

It would be really helpful to know a little more about you, so we would be grateful if you could answer the questions in this section. All personal data will remain confidential.

* What is your primary healthcare profession?

- Dermatologist
- General Practitioner
- General Practitioner with special interest in dermatology
- Geriatrician
- Dermatology specialist nurse
- Dermatology research nurse
- Other nurse
- Oral medicine physician
- Oral or maxillofacial surgeon
- Ophthalmologist
- Dentist
- Other (please specify)

Are you

- Female
- Male
- Prefer not to say

Where do you work?

- England
- Wales
- Scotland
- Northern Ireland
- Republic of Ireland
- Outside of UK and Ireland (please state below)
- Prefer not to say

Please specify which country if you reside outside the UK and Ireland



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9. Would you like to help with the next steps?

When we have identified the areas of potential research you and our other contributors have nominated, we will ask you to vote for your top ten from a shortlist provided in a second survey. If you are happy for us to contact you to take part in the next survey, please tick the box below and complete your email address.

- Yes please, I would like to be invited to take part in the next survey (please provide contact details below)

A few months after that, we will hold a one day group workshop to decide on the final list of research questions. If you would like to be invited to participate, please indicate below:

- Yes please, I would like to be invited to take part in a one day workshop (please provide contact details below)

Name:

Email address:

Re-enter email address:

Telephone:



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10. Thank you for completing the survey.

If you would like to contact the Treatment of Pemphigus and Pemphigoid Diseases PSP team please email: cebd@nottingham.ac.uk or telephone: 0115 8468621

The Treatment of Pemphigus and Pemphigoid Diseases 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.