

# Pernicious Anaemia: Research Priority Setting Partnership Survey

## Have your say on Pernicious Anaemia Research

We want to identify problems relating to Pernicious Anaemia that need to be addressed by researchers. And we need your help to do this.

We would like you to take a survey that has been specially designed to identify research questions that are important to you.

## Background

We are working with an initiative called the James Lind Alliance that was set up to bring together patients, carers and clinicians. So, whether you are a patient with Pernicious Anaemia, a carer for someone with Pernicious Anaemia, or a clinician with an interest in some aspect of Pernicious Anaemia we want to hear from you.

## What will the survey achieve?

We will use your responses to the survey questions to identify questions that need to be researched thoroughly. These questions can relate to either the way in which Pernicious Anaemia is diagnosed or treated – or both. By bringing together patients and doctors this survey will ensure that the research topics are the result of a collaborative discussion involving as many people as possible with an interest in Pernicious Anaemia.

## Who can take part in the survey?

The only requirement is that you currently live in the UK. If you suspect you have Pernicious Anaemia but have not had a firm diagnosis, you may still complete this survey.

The survey should take around ten minutes to complete, but you can take as long as you need. Many thanks for taking the time to complete this survey. Your support is greatly appreciated!

If you have any questions or need assistance, please do not hesitate to contact us: [psp@pasoc.org.uk](mailto:psp@pasoc.org.uk)

Participating is voluntary, and your answers will be kept confidential.

By completing this survey, you are consenting to participate in this study. Our Privacy Policy can be found [here on our website](#).

## Your role

1. Which of the following best describes you? \*

*more than one answer possible*

Patient with Pernicious Anaemia

Family/friend/carers of someone with Pernicious Anaemia

Healthcare Professional with an interest in some aspect of Pernicious Anaemia

2. If you are a Healthcare Professional, please specify your profession

## My Questions

This section is where you get to describe the questions that are important to you. Please put as little or as much detail as you would like when answering Q1, 2 & 3. You may also skip questions. Think about your own personal and/or professional experience with Pernicious Anaemia. Your personal experience is what makes you the expert. Don't worry about using the right words and terms used to formulate research questions, just use your own words. It's our job to turn what you tell us into questions that researchers can work with.

1. What question(s) or concern(s) about the diagnosis of Pernicious Anaemia would you like to see answered by research?

2. What question(s) or concern(s) about the treatment of Pernicious Anaemia would you like to see answered by research?

3. What question(s) or concern(s) about the ongoing management and impact on day-to-day life with Pernicious Anaemia would you like to see answered by research?

## Questions about you

Please tell us a little bit about yourself. These short questions will help us to understand the range of people who have responded to our survey and help make sure different people from across the UK are giving us their views.

### What will happen with my information?

The final list of questions will be published, but not linked to you or your organisation (for healthcare professionals). All personal data will remain confidential. Your details will not be linked to the questions you submit.

1. Where in the UK do you live?

- London
- South East England
- South West England
- East of England
- West Midlands
- Yorkshire & Humber
- East Midlands
- North East England
- Scotland
- Wales
- Northern England
- Other

2. Are you:

- Female
- Male
- Prefer not to say
- Other (specify)

3. What age are you now?

- Less than 15 years old
- 15-25 years old
- 26-35 years old
- 36-45 years old
- 55-65 years old
- more than 65 years old

4. Which race/ethnicity best describes you?

- White
- Asian or British Asian
- Black/African/Carribbean/Black British
- Arabic
- Mixed/multiple ethnic background Other  
(please specify)

5. If you have a diagnosis of Pernicious Anaemia, how long has it been since you were diagnosed?

- Less than one year ago
- Between one and two years ago
- Between two and five years ago
- Between five and ten years ago
- More than ten years ago
- N/A

## Next Stage

Would you like to help us in the next stage of this project by completing another short survey? This will help us to identify and prioritise the most important questions? If you would like to take part, please provide your name and email address. If you do not want to take part, please click Done to submit the survey.

By entering your name/email, you are providing the Pernicious Anaemia Society with information about yourself and health condition. Please only provide details if you consent to the Pernicious Anaemia Society collecting that sensitive personal data for the purposes of this research exercise. Your personal details will not be shared with anyone else and only be used to contact you about the next stage.

1. I would like to participate in the next round of this project

Name

Email Address

Please return this survey to:  
The Pernicious Anaemia Society  
Brackla House 2nd Floor  
Brackla Street  
Bridgend  
CF31 1BZ

Help us to prioritise Pernicious Anaemia by sharing this survey with anyone who might be interested, thank you!

Website: <https://pernicious-anaemia-society.org/pa-ppsp/>  
#HaveYourSayOnPA



The graphic features three speech bubbles on the left containing the text 'HAVE YOUR SAY'. To the right, the text reads 'On Pernicious Anaemia Research' with 'On' in blue, 'Pernicious Anaemia' in red, and 'Research' in black. Below this, it asks 'Which questions do you think are most important for Pernicious Anaemia research to answer?' in blue. The background is light grey with faint question marks. At the bottom, there is a row of seven stylized human icons in various colors.