

Privacy Notice and Consent Agreement for Online Survey

Version 3.0: 14 December 2018

About this document

This document has three parts:

- 1) Study Information
- 2) Privacy Notice
- 3) Consent Agreement

Study Information

Please ensure you have read the document **Participant Information Sheet – Survey**

Introduction

BresMed Health Solutions Ltd is an independent health economic and outcomes research consultancy. On behalf of the British Porphyria Association and the research sponsor, Alnylam Pharmaceuticals, Bresmed is conducting a survey on the burden of acute porphyrias.

The purpose of the research is to better understand the impact of acute porphyria on you as a patient or as the caregiver of someone with acute porphyria. The questions are aimed to better understand the acute and chronic symptoms experienced, disease management, and impact on work, social life and overall quality of life. The online survey will take approximately 25 minutes to complete. The survey can be completed at any location with access to the internet and will be available from 7th to 21st January 2019.

Sharing your experience will help to further understand the burden of acute porphyria and could benefit future research and development of treatment procedures. Your participation is highly appreciated. If you have any questions, please contact Nicola Mason at BresMed Health Solutions Ltd by email nmason@bresmed.com

Privacy Notice

Any information you provide will be treated as confidential. It will be combined with feedback from other patients or caregivers of those living with acute porphyria. You will remain anonymous unless you give permission to be identified.

The research will comply with applicable data protection laws and the British Healthcare Business Intelligence Association legal and ethical guidelines.

Your information will only be used for the research described and will not be passed to any other organisation without your permission. The sponsor may use this anonymised information (including anonymised quotes and aggregated information combining all the responses to this research) in three main ways: 1) to develop models of the personal and economic burden of acute porphyria, which support applications to groups which assess the value of new treatments. 2) as part of ongoing disease education to healthcare professionals and patient organisations. 3) in publications in medical journals or presentation at medical congresses.

We will collect and use any information about you only if you provide your consent to do so. We will not keep any personal data you give us for longer than 12 months to allow completion of the aggregated data report.

We are required to pass on to Alnylam Pharmaceuticals any details of side effects or product complaints relating to their products that are mentioned during the survey. This is to help them comply with applicable laws and regulations and learn more about the safety of their medicines. If this happens, we will need to collect details and report the side effects or product complaint. In this instance, you will be asked to give permission for us to pass your details to the company's drug safety department for follow-up. This will have no impact on the confidentiality and anonymity associated with the survey for this research.

If as a result of this survey it is evident a vulnerable individual is suffering or is likely to suffer significant harm, and a referral must be made to the appropriate authority without delay in order that the individual can be protected the interviewer must ensure that any disclosure of a confidential nature, which may be potentially harmful to the individual, must be dealt with in a sensitive and responsible manner.

You have the right to refuse to answer questions or withdraw at any time. For more information about your rights, or to obtain a copy of our privacy notice please contact Sarah Laycock by email info@bresmed.com

We also remind you that you are also entitled to lodge a complaint with the supervisory authority, the Information Commissioner's Office (ICO), for the protection of personal data if you consider that your statutory rights have not been respected or that you have not received a response to your requests according to the law. The ICO is the UK's independent authority set up to uphold information rights in the public interest, promoting openness by public

bodies and data privacy for individuals. You can contact the ICO at their helpline (0303 123 1113) or by visiting their website (<https://ico.org.uk/make-a-complaint/>).

Consent Agreement

Project Title: Survey to elicit the burden of illness of acute porphyria in and patients and caregivers

Subject and purpose of Study: The purpose of the research is to better understand patients' journeys to a diagnosis of acute porphyria as well as the impact of acute porphyria on patients and caregivers.

Location: Online

Duration: ~25 minutes

Date: January 2019

Consent

By clicking the yes button, you declare:

- You have read and understood the information for the above research and have been provided with the details of whom to contact if you have questions about the research.
- You understand that the research is being conducted on behalf of a pharmaceutical company.
- You understand that your answers will be reviewed and summarized by BresMed Health Solutions Ltd., but your personal identifiable information will not be shared with the sponsor or other third parties as outlined above.
- You understand that your participation is voluntary and that you are free to withdraw from the research and your consent at any time, without giving any reason.
- You consent to the collection and use of your personal data as described in the above.
- You consent to the use of the results derived from this research as described above.
- You agree to take part in the above research.

YES CONTINUE

NO THANK AND CLOSE

Sponsor

The sponsor and data controller of this research is Alnylam Pharmaceuticals Ltd, Braywick Gate, Maidenhead, SL6 1DA.

Data Protection Officer

Alnylam Pharmaceuticals has designated a Data Protection Officer ("DPO"). The DPO can be contacted via the following communication channel: EUdataprivacy@alnylam.com