

UNITED KINGDOM - EPP L.I.G.H.T. (EU) - Erythropoietic Protoporphyria Survey Research Study

Are you living with Erythropoietic Protoporphyria (EPP) or X-linked protoporphyria (XLP)?

Are you interested in participating in an online study?

- We are looking for about **20 adults and adolescents with Erythropoietic Protoporphyria (EPP) or X-linked protoporphyria (XLP)** in the United Kingdom who are at least 12 years of age and speak/read English or Welsh.
- The goal of this online study is to better understand how EPP/XLP impacts the lives of individuals with this condition.
- If you qualify for the study, you will be provided with a link to an online questionnaire. Completing it should take approximately 60 minutes, but you will be able to do this at your own pace as your answers can be saved.
- The questionnaire will ask you about symptoms you may experience, how you are feeling, and how EPP/XLP may impact your life. You will also be asked about visits to the doctor/hospital and any medications you may have taken for your EPP/XLP and your preferences for various types of EPP/XLP treatments.
- After you complete the online questionnaire, you will receive a £80 shopping voucher for your time.
- Once the study is completed, a brief report that summarizes the results from all participants will be available to you.
- This study is being conducted in the UK, France, Germany, Spain and Italy and it has received ethics approval.

Next steps.

- If you are interested in taking part, please read the relevant participant information sheet(s) available here <https://www.sciensus.com/epp-light-uk/>
- To register please open the QR code or click on the link at the bottom of the information sheet.
- You will need an email address to register. If the person living with EPP/XLP is an adolescent without an email address, their parents or caregivers can register them, provided they are willing to take part.
- If you have any question, please contact Mathieu Loiseau, the person responsible to implement and oversee this study: EPPLightEU@sciensus.com
- **Following your registration, a nurse will contact you via email to schedule a screening call during which they will check that you are eligible to take part.**
- After this, a unique link to your online questionnaire will be sent to you via email. The questionnaire is multilingual and can be accessed in English, Welsh, French, Spanish, German and Italian if preferred.