

# The impact of medications used to manage epidermolysis bullosa (EB) on the daily lives of adults with EB living in the UK

## What is this study about?

Are you an adult living with EB who takes one or more medications to manage the condition and its complications? Would you like to share your experiences about how the medication affects your daily life?

If yes, we would like to hear about your experiences as part of our research.



## To participate in this study, you must:

- Be at least 18 years of age
- Have a diagnosis of any type of EB
- Regularly use at least one medication to manage EB and its complications
- Currently live in the UK, and have lived in the UK for at least the last 12 months
- Be able to read, understand and speak English.

## What will participation involve?

There are two parts to this study. Firstly, you will have the option to share photographs which you feel represent how medications taken to manage EB affect your daily life.



The second part is a relaxed 45-60 minute virtual interview (over Microsoft Teams) to explain why you chose those photographs (if applicable) and share your experiences. However, if you do not want to send a photograph then you are more than welcome to just take part in an interview.



## How to get involved

If you are interested in finding out more, please contact me on the details below. I will send you an information sheet which you can read before deciding whether you would like to participate in the study. I will also send you a questionnaire to complete to help us make sure we are interviewing a range of people.

Thank you.

Catherine Silk, MSc Genetic and Genomic Counselling Student  
[SilkC3@cardiff.ac.uk](mailto:SilkC3@cardiff.ac.uk)

