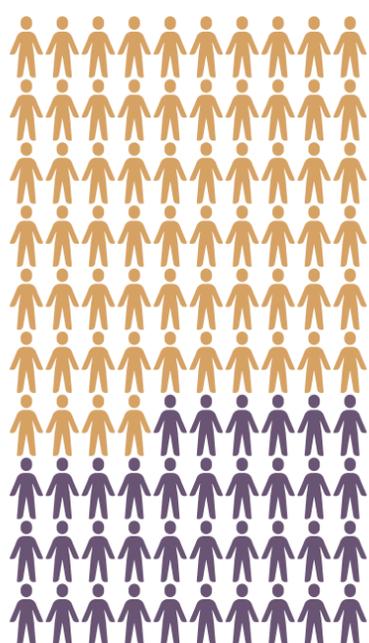


BHD Patient Registry

Everything You Need to Know

What is a patient registry?



- A patient registry is a centralised database that collects information about people with a specific condition, or set of conditions.
- They can collect information on a wide range of topics including patient demographics, symptoms, genetic testing, treatments and lifestyle.
- They are particularly useful in the context of rare diseases as they help researchers and clinicians to build a more complete picture of the condition
- They also give patients the chance to contribute to research on their rare disease and the ultimate aim of a patient registry is to improve the quality of life of people affected.
- Multiple different groups of people are usually involved in developing a patient registry including patients, clinicians, researchers, pharmaceutical companies and patient groups or charities.

What do we want to achieve?

For a patient registry to be successful we need to identify what aspects of BHD we want to collect information on and how best to collect and use the data.



As a charity, we would like to be able to:

1. Determine the prevalence of BHD
2. Determine if there are other manifestations associated with BHD (aside from those existing known in the skin, lung and kidney)
3. Collect information on the type of kidney cancer most likely to develop in BHD
4. Collect information on the ongoing management of your symptoms (e.g. kidney scan type and frequency)
5. Include information on genetic sequencing to determine if any particular variants are associated with particular manifestations
6. Collect lifestyle information to understand if environmental factors influence the treatment or management of BHD
7. Use the registry as a database for clinical trials recruitment.



How can you help us?

- We need to know what's important to the BHD community as a whole and would make significant differences to the quality of your life.
- We also want to ensure the longevity of this patient registry and ensure that the information collected is used for maximum benefit.
- Before the meeting on the 16th of September could you please have a think about the following questions:

What are the most important questions you would like this registry to answer?

What can we do to ensure the registry is easy to use and how can we engage with the community to get everyone involved?

What concerns do you have about developing a BHD patient registry and how can they be addressed?

What is the process for developing a registry?

1



2



3



4

Meet with stakeholders (e.g. patients, clinicians) to discuss their needs

Form working groups to develop specific questions, decide on how data will be collected

Identify appropriate platform to collect information and develop registry with them

Recruit patients (and clinicians) and begin data collection. Define ways to analyse data.

