



## RESEARCH STUDY



### **VoT2: INVESTIGATIONS OF HEALTHCARE DELIVERY TO HEALTHCARE WITH PHENYLKETONURIA (PKU)**

The National Centre for Inherited Metabolic Disorders (NCIMD)-Adult Service at the Mater Hospital would like to invite you to participate in a study titled '**VoT2: Investigations of healthcare delivery to patients with Phenylketonuria (PKU)**'.

This study is part of a wider initiative developed by the European Brain Council to explore the value of treatment of rare diseases in Europe.

The project aims to assess the impact PKU has on your quality of life, and how well current department resources meet your care needs. This information will be gathered by a combination of questionnaires and a patient satisfaction survey where you can voice your personal experience of managing your condition.

**Participation in this project is entirely voluntary.** If you choose to participate, you will be asked to complete and return three standardised questionnaires and a patient experience survey. Completion of the 4 documents will take approximately 20 minutes.

All information regarding your participation in this study will be kept strictly confidential. Reports generated from the study will only describe findings in aggregate, and not on any single individual. You will be welcome to receive a copy of the report when completed.

The study is partly funded by the European Brain Council (EBC), a non-profit organisation encompassing a network of scientific and professional societies, patient organisations, and industry partners in the area of brain research. The EBC will not have access to individual patient information, but may be given information regarding the progress of the study such as number of patients enrolled and the study observations (a copy of the final aggregate report).

It is hoped that the study will help the NCIMD-Adult Service Team better understand the needs of our patients and facilitate ways to improve delivery of the service.

If you are interested in participating in this project, please do not hesitate to contact the Research Coordinator, Darragh Nerney using the information provided below:

**Darragh Nerney (Research Coordinator)**

E: [darraghnerney@mater.ie](mailto:darraghnerney@mater.ie)

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*This study has been approved by the Ethics Board of the Mater Misericordiae University Hospital.*