Find Out More

The NHS Highly Specialised Service for Mitochondrial Disease (HSS) in Oxford, Newcastle and London have teamed up with the Lily Foundation Charity to build an exciting new MITO-PROM platform which allows UK patients to enter information about their mitochondrial disease to advance research and improve care.

The MITO-PROM is part of a bigger RUDY research study which has been collecting data on a number of rare diseases since 2014, but up until now, mitochondrial patients have not been fully represented.

MITO-PROM is the first national patient driven research platform for mitochondrial disease. Data entered into this platform is for research purposes only, and will not be monitored for health intervention.

What are PROM’s?

Patient Reported Outcome Measures (PROM’s) are reports coming directly from patients about how they feel or function in relation to a health condition, without interpretation by healthcare professionals.

Why are they so useful?

The patient experience has played a part in clinical research for some time, but there is increasing recognition that a patient-centered approach is vital for comprehensive assessment of the impact of treatments and clinical care.

PROM’s help us:

* describe in detail how mitochondrial disease affects individuals
* describe the differences between individuals with the same mitochondrial disease diagnosis
* determine the personal and family burden and impact of mitochondrial diseases
* better understand the genetic basis for mitochondrial diseases and how this links with symptoms reported
* provide a research cohort of patients with mitochondrial diseases that can then be approached for further sub-studies

Your experiences will help speed up the development of drugs to treat mitochondrial disease and also improve patient care through the NHS.

How do I know where my data is being used?

Your initial consent determines who you allow to access your data. There is also a section on your profile that informs you where your data has been used and by whom.

This project was generously sponsored by WCMR, Lily Foundation and My Mito Mission.