**RUDY STUDY Privacy Notice**

The RUDY Study’s objectives are to determine a detailed phenotype of patients with rare diseases and to determine the burden of rare diseases and improve our understanding of all aspects of rare diseases.

Participants agreed to long term follow up and have given consent for RUDY to access their NHS data.  
We hope to access data held by NHS Digital in line with the participants consent from national registries and databases including but not limited to those records held by Public Health England and NHS Digital.  This will be to obtain information about clinical events and treatments.

This study has been reviewed and approved by the Berkshire B REC (17/SC/0501)

Research is a task that we perform in the public interest. The University of Oxford, as sponsor, is the data controller. This means that we, as University of Oxford researchers, are responsible for looking after your information and using it properly. We will use the minimum personally-identifiable information possible.

The legal basis for the processing and storage of personal data for [study] is that it is ‘a task in the public interest’ (article 6(e)) and, that sensitive personal data is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes (article 9 (2) (j), based on Article 89(1)).

The data that we receive and analyse will be identified by a patient identification number only, and will not be identified by name, date of birth, NHS number or address. With the participant number, we will link to the original RUDY database, and information collected during any study visits. The information received from NHS Digital will be imported into a database held securely by the University of Oxford and used solely for academic research purposes. Before analysing this complete dataset (including information already provided by participants along with information from NHS Digital) personal identifiers will be removed. Importantly, whilst the information received is specific to each participant, no individual person will be identifiable in any publication arising from this work. Your personal data will not be shared with any 3rd parties and will not be used for any automated decision making or profiling. If you would like to have this data withdrawn, please contact the study team using the details given below.

**What to do next?**

If you decide you do not want your data to be linked in this way you can withdraw from this follow-up, without affecting your current medical care, by contacting the study team, who would require your identifiers to then inform NHS Digital that you no longer wish to be part of the cohort. NHS Digital will then remove your identifiers from the study.

Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate.

Further information about your rights with respect to your personal data is available at

<https://compliance.web.ox.ac.uk/individual-rights>

or by contacting the study team using the details below.

If you have further questions, please contact the study team at the following email address:-

**Email**: rudy@ndorms.ox.ac.uk