Request for Data for **commissioning** or **research** purposes from the National Haemoglobinopathy Registry – Version 1 May 2021

Please complete relevant sections and return to

Support Team

National Haemoglobinopathy Research registry

MDSAS

City View House

Union Street

Ardwick

Manchester

M12 4JD

Or email: support@mdsas.com

Date of application

Applicant details

|  |  |
| --- | --- |
| Name |  |
| Job title |  |
| Organisation name |  |
| Address |  |
| Post code |  |
| Telephone |  |
| Email address |  |

Simple Data request: yes/no

Please complete section I

Research Study data request: yes /no

If yes please go to section II

We aim to respond to simple data requests with timeline and costings within 2 months.

We aim to respond to Research Study data requests with feasibility, timeline and costings within 3 months.

If data is required more quickly please explain why within the request.

**Section I: Simple data requests**

Which organisation is requesting the data?

For what purpose?

*Please be very precise about the reason the data are needed in layman’s terms. Ambiguous requests are likely to be refused unless further information is provided.*

When do you need the data and is there a deadline? We aim to authorise and provide simple data in 3 months – please provide justification for any request for earlier release.

**What time interval is required for the data?** (eg all events in last year; events 2019/20 compared to 2018/19)

*Please enter precise dates for which the data is needed. The Old NHR holds data from 2009 to 2020, but this is a limited data set. The New NHR holds data as per Appendix 1. We operate on the basis of financial years.*

Clinical event at any time interval

Data for events between following dates

Data from old NHR covering the following time period(s):

**What data are requested? Please provide a brief description here and specifics in the appendices.** (*complete Appendix 1 (new NHR) or Appendix 2 (old NHR) with justification for why that item is needed)*

 **Section II Research Data requests**

**Project title**

**Purpose and justification for the research being proposed including hypothesis in layman’s terms:**

*Please be very precise about that reason the data is needed in layman’s terms. Ambiguous requests are likely to be refused unless further information is provided.* This section does not need the data fields but you must provide clarity on why this research is being undertaken.

**Have you submitted or are you planning to submit an application to HRA or do you plan to use the NHR RR application? Yes/ No**

**If yes IRAS study number**

**When do you need the data by and why by that date?**

**What time interval is required for the data?** (eg events in previous year; all events in last 6 years)

*Please enter precise dates for which the data is needed. The Old NHR holds data from 2009 to 2020, but this is a limited data set. The New NHR holds data as per Appendix 1. We operate on the basis of financial years.*

Clinical event at any time interval

Data for events between following dates

Data from old NHR covering the following time period:

**What data is needed?** (*complete Appendix 1 (new NHR) or Appendix 2 (old NHR) with justification for why that data item is needed)*