

**National Haemoglobinopathy Registry**

**Data Access Request Form (DARF)**

Once completed please return this signed form to [support@MDSAS.com](mailto:support@MDSAS.com)

**All sections within this form are mandatory unless specifically stated otherwise. Unless this form is completed in full, it will be returned to the applicant which will extend the time to data receipt.**

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| ***NHS England office use only*** | | | |
| **NHR application number** | Click or tap here to enter text. | **Date of submission to NHR** | Click or tap to enter a date. |
| **If applicable, any linked application number(s)** | Click or tap here to enter text. | **Purchase order number** | Click or tap here to enter text. |
| **Tracking history** | Click or tap here to enter text. | | |
| **Date submitted to NHR DARG (if applicable)** | Click or tap to enter a date. | | |
| **Date submitted for IG review (if applicable)** | Click or tap to enter a date. | | |
| **Date approval granted** | Click or tap to enter a date. | | |
| **Expiry date** | Click or tap to enter a date. | | |
| **Date when payment received (if applicable)** | Click or tap to enter a date. | | |
| **Date when approval to prepare and release data given** | Click or tap to enter a date. | | |
| **Date when data were transferred to applicant** | Click or tap to enter a date. | | |

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| **Section 1** | | | **Primary applicant information** | | | | | | | | | | | | | | | | |
| **Title of project** | | | Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Name of primary applicant organisation** | | | Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Name of any partner organisation (s) if applicable**  *(ensure partner organisation form also completed)* | | | Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Address of primary applicant organisation** | | | Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Primary contact** *(must be a permanent senior member of staff)* | | | Click or tap here to enter text. | | | | | | | | | **Job title** | | | Click or tap here to enter text. | | | | |
| **Telephone** | | | Click or tap here to enter text. | | | | | | | | | **Email** | | | Click or tap here to enter text. | | | | |
| **Organisation type** | | | **NHS Healthcare Provider** | | | | | | **Academic Institution** | | | | **Healthcare Regulator** | | | **Other Healthcare Body** | | | |
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| **Local Authority** | | | | | | **Individual Citizen(s)** | | | | **Commercial Body** | | | **Other (please state)** | | | |
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| **Section 2** | | | **Application type** | | | | | | | | | | | | | | | | |
| ***Please confirm this is a new application. For extensions or amendments, please use the separate form provided. Please reference any previous related application whether approved or rejected.*** | | | | | | | | | | | | | | | | | | | |
| **Request** | | | | | **If necessary, please provide any related NHR application numbers whether approved or rejected.** | | | | | | | | **If your new application relates to any previous application(s), please provide a brief explanatory text to support this new application.** | | | | | | |
| **New Application**  Applications that have not previously been approved by NHS England. | | | | |  | | | | | | | |  | | | | | | |
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| **Section 3** | | | **Project type** | | | | | | | | | | | | | | | | |
| **Please select the most appropriate answer** | **Research** | | | **Service Evaluation** | | | | | | **Clinical Audit** | | **Other (please state)** | | | | | | | |
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| **Is ethics approval required?** | **If the request is for research purposes, you must enclose evidence of NHS ethics approval or evidence that this is not required** | | | | | | | | | | | | | | | | | | |
| **YES**  Confirmation of NHS ethics needs to be submitted with this application. | | | | | | | | | | | | | | | | | |  |
| **NOT REQUIRED**  Confirmation needs to be submitted with this application from the HRA decision tool[**http://www.hra-decisiontools.org.uk/ethics/**](http://www.hra-decisiontools.org.uk/ethics/)or confirmation from your local Research and Development Department that NHS ethics is not required. | | | | | | | | | | | | | | | | | |  |
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| **Section 4** | | | **Project details** | | | | | | | | | | | | | | | | |
| **Please provide full details of the project below. You should describe and justify the project’s objectives, rationale and methodology.** | | | | | | | | | | | | | | | | | | | |
| **Objective/Rationale** | | | Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Methodology** | | | **Please include:**   * **A summary of your project methodology, ensuring this description aligns with the dataset requested** * **A justification of sample size, analyses proposed and plans for patient and/or user group involvement** | | | | | | | | | | | | | | | | |
| Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Please describe the expected measurable benefits to health and/or social care including target date** | | | Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Proposed completion date of the project** | | | Click or tap to enter a date. | | | | | | | | | | | | | | | | |
| **Lay Title and Summary** | | | **Please provide a lay summary of your project (max 300 words).** The lay summary should be written in plain English and must enable a non-medical audience to understand the analytical/research question and aims of the project. | | | | | | | | | | | | | | | | |
| Click or tap here to enter text. | | | | | | | | | | | | | | | | |
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| **Section 5** | | | **Publications and other outputs** | | | | | | | | | | | | | | | | |
| **Please include all intended outputs of the project including publications. Outputs include all types of disseminations produced from the project data. For each output include the highest level of detail of data/information that will be displayed.** | | | | | | | | | | | | | | | | | | | |
| **Outputs including publications**  *(add more rows if required)* | **What is the highest level of detail that will be displayed in the output**  *(e.g. case record, unit, hospital, trust, network, regional, national, whole study, study group)* | | | | | | | **Will this output be published?** | | | | | **Expected Date of Publication** | | | | **Confirm that published output will be anonymised to the level required by** [ISB1523: Anonymisation Standard for Publishing Health and Social Care Data](https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/isb1523-anonymisation-standard-for-publishing-health-and-social-care-data) | | |
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| **Section 6** | | | **Project funding** | | | | | | | | | | | | | | | | |
| **Please indicate whether your project has received dedicated funding. Please also indicate whether there is a commercial interest in the project, either by funding or direct input into project design or team.** | | | | | | | | | | | | | | | | | | | |
| **Funding**  *(please select one answer)* | **No** | | |  | | | | | | | | | | | | | | | |
| **Yes** | | | **If yes**, please provide the name of the funding body below  Click or tap here to enter text. | | | | | | | | | | | | | | | |
| **Commercial interest**  *(please select one answer)* | **No** | | |  | | | | | | | | | | | | | | | |
| **Yes** | | | **If yes**, please provide the name of the organisation and the nature of any interest into the project design below. Please also note information required in Section 7  Click or tap here to enter text. | | | | | | | | | | | | | | | |
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| **Section 7** | | | **Declaration of Interest** | | | | | | | | | | | | | | | | |
| **Please indicate whether any individuals named in this application have an interest to declare about this application.** All interests that might unduly influence an individual’s judgement and objectivity in the use of the data being requested from NHR are of relevance. Particular consideration should be given to declaring interests involving payment or financial inducement for use of the data being requested. These will be considered by the RAC to determine if there is any potential conflict of interest identified as part of the request. | | | | | | | | | | | | | | | | | | | |
| **Declaration of interest**  ***(please select one answer)*** | **No** | | |  | | | | | | | | | | | | | | | |
| **Yes** | | | **If yes**, please provide the name and details of the declaration for each individual below  Click or tap here to enter text. | | | | | | | | | | | | | | | |
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| **Section 8** | | | **Data Summary** | | | | | | | | | | | | | | | | |
| **Please tick the box(es) confirming the geographical coverage of the data you are requesting. Coverage is defined as the location of the healthcare services who originated / initially provided the extract of data you are requesting.**  *NB. NHS England can only approve applications for access to the datasets for which it acts as the Data Controller.* | | | | | | | | | | | | | | | | | | | |
| **Geographical coverage** | **England** | | | | | **~~Wales~~**  **(not currently available)** | | | | | | | |  | | | | | |
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| **Inclusion and exclusion criteria (including date parameters)** | **Describe precisely the criteria which define the patients to be included and to be excluded from the data extract you are requesting.**  Please include precise date parameters for the start and end of the range requested (dd/mm/yy) and explain which dated project field will be used to define the requested cohort (e.g. date of admission or date of operation). | | | | | | | | | | | | | | | | | | |
| Click or tap here to enter text. | | | | | | | | | | | | | | | | | | |
| **Periodic updates** | **Periodic updates may sometimes be available.** These must be agreed with NHR in advance and any falling outside of the term of the Data Sharing Agreement will be subject to an application extension being agreed. Please provide details below including reasons. | | | | | | | | | | | | | | | | | | |
| **None**  **Quarterly**  **Bi-annual (6 monthly)**  **Annual**  **Other**, please state: Click or tap here to enter text. | | | | | | | | | | | | | | | | | | |
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| **Section 9** | | | **Data Type** | | | | | | | | | | | | | | | | |
| **First discuss your request with the NHR data access request service and then indicate in this section the type of data you are requesting (tick all that apply).** Note that what is relevant here is the identifiability of the data you are requesting at the point it leaves NHR and not the level disclosed in any future publication. For further information on these categories of identifiability please see the Understanding patient data guidance <https://understandingpatientdata.org.uk/what-does-anonymised-mean> | | | | | | | | | | | | | | | | | | | |
| **Anonymous data**  This is information from many people combined together (aggregated), so that it would not be possible to identify an individual from the data. Information about small groups or people with rare conditions could potentially allow someone to be identified and so would not be considered anonymous. Individual patient level data may also very occasionally be categorised as anonymous. In this case, the information in each record requested would also potentially be true for many other similar individuals, and so could not be used to deduce the person’s identity. | | | | | | | | | | | Click or tap here to enter text. | | | | | | | | |
| **De-personalised data**  This is information that does not identify an individual, because identifiers have been removed or encrypted. However, the information is still about an individual person and so needs to be handled with care. It might, in theory, be possible to re-identify the individual if the data were not adequately protected, for example if they were combined with different sources of information. | | | | | | | | | | | **NHR data access request service to provide a description for how the data will be de-identified to reduce any risk of re-identification.** | | | | | | | | |
| Click or tap here to enter text. | | | | | | | | |
| **Personally identifiable data**  This is information that identifies a specific person. Identifiers might include: name, address, full postcode, date of birth or NHS number. Personally identifiable data fields that are requested solely for the purpose of linkage still need to be described here and in Section 10, even if they are removed before the data reaches the applicant. | | | | | | | | | | | Click or tap here to enter text. | | | | | | | | |
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| **Section 10** | | | **Data Fields** | | | | | | | | | | | | | | | | |
| **Please detail in the table below the data fields required as part of this request. All fields required to leave the data provider must be included here including linkage fields.** Justification for these should include whether they will be retained or destroyed once linkage is complete. This should also be clear on the data flow map in Section 11. Applicants should only request the minimum data set required to address the purpose stated within this application. | | | | | | | | | | | | | | | | | | | |
| **Data field requested** | **Data source**  *(Audit/project, HES, ONS, PEDW etc.)* | | | | | | **Transformation applied**  **This must be completed for every data field requested:**   * **None** * **Explain the transformation applied** (e.g. pseudonymisation (including who holds the key to reverse), time elapsed, age banding etc.) | | | | | | | | | **Justification**  *Please justify your use of each data item requested* | | | |
| *EXAMPLE – NHS Number* | *EXAMPLE - Audit* | | | | | | *EXAMPLE –*  *Pseudonymisation and encryption with key held only by NHR* | | | | | | | | | *EXAMPLE - For tracking single patients within multiple audit entries* | | | |
| Click or tap here to enter text. | Click or tap here to enter text. | | | | | | Click or tap here to enter text. | | | | | | | | | Click or tap here to enter text. | | | |
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| *Add more rows as needed* |  | | | | | |  | | | | | | | | |  | | | |
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| **Section 11** | | | **Intention to link data** | | | | | | | | | | | | | | | | |
| **Do you intend for the requested data sent to be linked with any additional data sets? If yes, please provide full details of the data controller(s) of the secondary dataset(s) and a description of which organisation will perform the linkage and how the linkage will take place. NHS England will work to the principle that other relevant requests are in process.** | | | | | | | | | | | | | | | | | | | |
| **No intended linkage** | | | **Intention to link the data.**  *Please provide full details of linkage below.* | | | | | | | | | | | | | | | | |
| **If there is an intention to link the data, please provide full details here:**  Click or tap here to enter text. | | | | | | | | | | | | | | | | | | | |
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| **Section 12** | | | **Processing locations and data flows** | | | | | | | | | | | | | | | | |
| **Please list all locations where processing will be undertaken. For the avoidance of doubt, data storage is considered processing. For each separate organisation processing data which are not fully anonymous a separate partner organisation form must also be completed.** | | | | | | | | | | | | | | | | | | | |
| **Processing location** | **Organisation name** | | | | | | **Processing or storage** | | | | | | **Data type processed** *(anonymous, de- personalised, personally identifiable)* | | | | | **How will data be transferred to this location?** | |
| Click or tap here to enter text. | Click or tap here to enter text. | | | | | | Click or tap here to enter text. | | | | | | Choose an item. | | | | | Click or tap here to enter text. | |
| Click or tap here to enter text. | Click or tap here to enter text. | | | | | | Click or tap here to enter text. | | | | | | Choose an item. | | | | | Click or tap here to enter text. | |
| Click or tap here to enter text. | Click or tap here to enter text. | | | | | | Click or tap here to enter text. | | | | | | Choose an item. | | | | | Click or tap here to enter text. | |
| **Please state whether it is your intention to transfer data outside of the UK or outside of the European Economic Area?**  *If yes please state to where and give details of how that will be in compliance with the Data Protection Act 2018* | | | | | | | | | | **No** | | | | | | **Yes** | | | |
| **If yes**, please provide details: Click or tap here to enter text. | | | | | | | | | |
| **Data Flows**  **Please insert a data flow diagram which graphically describes:**   1. **All locations where data are processed** 2. **All transfers that take place between locations and organisations** 3. **Data linkages to other data sets** | | | | | | | | | | | | | | | | | | | |
| **Please insert data flow diagram here** | | | | | | | | | | | | | | | | | | | |
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| **Section 13** | | | **Intention to onward share data** | | | | | | | | | | | | | | | | |
| **Please state whether it is your intention to onward share data (whether pseudonymised or not, or whether linked to other data sets or not) and describe the application and governance process you intend to use for this purpose. NB The NHS England Data Sharing Agreement for this application may have restrictions on this.** | | | | | | | | | | | | | | | | | | | |
| Click or tap here to enter text. | | | | | | | | | | | | | | | | | | | |
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| **Section 14** | | | **Data Protection** | | | | | | | | | | | | | | | | |
| **As a data controller your organisation should be registered with the Information Commissioners Office (ICO). Please provide the following information.** | | | | | | | | | | | | | | | | | | | |
| **Registered name**  *(if different to applicant name, please state reason)* | | | Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Registration number** | | | Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Expiry date** | | | Click or tap to enter a date. | | | | | | | | | | | | | | | | |
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| **Section 15** | | | **Legal basis (of the processing you intend to undertake)** | | | | | | | | | | | | | | | | |
| **If you are requesting data that is fully anonymous, please proceed to section 20** | | | | | | | | | | | | | | | | | | | |
| **GDPR Legal Basis** | | | **Article 6 legal basis:**  Click or tap here to enter text.  **Justification:** Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Article 9 legal basis:**  Click or tap here to enter text.  **Justification:** Click or tap here to enter text. | | | | | | | | | | | | | | | | |
| **Common law of duty of confidentiality is addressed by** | | | **If the data you are requesting are personally identifiable please explain how you have addressed the common law duty of confidentiality below.** | | | | | | | | | | | | | | | | |
| **Explicit informed consent**  *(please enclose consent form and patient information sheet with this application)* | | | | | | | | | | | | | | | | |
| **Approval under section 251 of the NHS Act 2006**  *(please enclose both the application and the approval letter)* | | | | | | | | | | | | | | | | |
| **The section 251 approval enables the applicant to:** | | | | | | | | | | | | | | | | |
| **Hold/receive personal data** | | | | | | | | **Transfer/access**  **personal data** | | | | | **Operate on and link personal data** | | | |
| **Other legal basis**  If other legal basis selected, please provide further information here with reference to the statute, regulation or other provision relied upon: Click or tap here to enter text. | | | | | | | | | | | | | | | | |
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| **Section 16** | | | **Fair Processing** | | | | | | | | | | | | | | | | |
| **This section is only relevant to applications requiring patient identifiable data. Where this is the case, please describe what transparency information has been provided to the data subjects that the data requested relates to. A privacy notice should be provided (with a link to the relevant web address). Please ensure you enclose copies of any privacy notices and other material you rely on when submitting this application.** | | | | | | | | | | | | | | | | | | | |
| **Information provided by NHR** | | | | | | | Click or tap here to enter text. | | | | | | | | | | | | |
| **Information provided by the applicant** | | | | | | | Click or tap here to enter text. | | | | | | | | | | | | |
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| **Section 17** | | | **Security** | | | | | | | | | | | | | | | | |
| **Each organisation processing data that are not fully anonymous as part of this project must demonstrate that they have appropriate security arrangements are in place. Please confirm whether the applicant organisation has a compliant Data Security and Protection Toolkit.**  *(Please note that additional organisations processing data which are not fully anonymous must complete a partner organisation form and evidence of security arrangements)* | | | | | | | | | | | | | | | | | | | |
| **Applicant organisation**  *(please select one answer)* | | **Yes**  *If yes, please provide evidence with this application.* | | | | | **ODS code** | | | | | | Click or tap here to enter text. | | | | | | |
| **Status** | | | | | | Click or tap here to enter text. | | | | | | |
| **Published date** | | | | | | Click or tap to enter a date. | | | | | | |
| **No** | | | | | **If no, please provide below alternative evidence of adequate organisational and technical measures; to ensure the security of processing and preserve the confidentiality, integrity and availability of data. E.g. ISO 27001 accreditation** | | | | | | | | | | | | |
| Click or tap here to enter text. | | | | | | | | | | | | |
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| **Section 18** | | | **Retention and destruction** | | | | | | | | | | | | | | | | |
| **Please ensure that your organisation has a retention and destruction policy regarding patient identifiable data and that it has a procedure for destroying the data in line with that retention and destruction policy.** | | | | | | | | | | | | | | | | | | | |
| **Please confirm that your organisation has a data retention and destruction policy** | | | | | | | **Yes  No** | | | | | | | | | | | | |
| **Please state the date until which you are seeking to retain the data and the reason.**  ***NB. That the requirement to extend the Data Sharing Agreement*** *(if retention is requested for longer than its original term) would still apply.* | | | | | | | Click or tap to enter a date.  Click or tap here to enter text. | | | | | | | | | | | | |
| **Please provide details of how you intend to destroy the data at the end of the retention period.** | | | | | | | Click or tap here to enter text. | | | | | | | | | | | | |
| **Please confirm that you will submit a certificate of destruction to NHR on behalf of NHS England and GIG Cymru within 5 business days of destruction of the data.** | | | | | | | **Yes** | | | | | | | | | | | | |
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| **Section 19** | | | **Further information** | | | | | | | | | | | | | | | | |
| **Please use the section below to add any additional information to support your request.** | | | | | | | | | | | | | | | | | | | |
| Click or tap here to enter text. | | | | | | | | | | | | | | | | | | | |

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|  | **Applicant organisations** |  |  |  |  |  | **Data provider** |  |
| **Type of data**  **Level of data** | **Data items spreadsheet** | **Evidence of Data Security and Protection (DSPT) Toolkit or equivalent** | **Data flow map** | **Ethics approval or confirmation that it is not required** | **Fair processing information** | **Legal basis supporting evidence (such as consent form, and patient leaflet, S251 application and approval letter or any other evidence)** | **Description for how the data will be de-identified to reduce any risk of re-identification** | **Fair processing information** |
| **Anonymous** |  |  |  |  |  |  |  |  |
| **De-personalised** |  |  |  |  |  |  |  |  |
| **Personally identifiable** |  |  |  |  |  |  |  |  |

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| **Section 20** | **Attachments checklist** |
| **Please use the table below to ensure that the documents / information listed are either contained within the application or submitted as attachments.** | |