# Barts Health NHS Trust

# Data Access Request Application

Version 1.8 26.03.24

*Please send the completed form to* [*bartshealth.researchdatarequest@nhs.net*](mailto:bartshealth.researchdatarequest@nhs.net)*. The request will be responded to within 5 working days.*

*If you are requesting access to Barts Health (BH) data in principle (before grant funding and other approvals are in place) then please complete Sections A, B/C, D, E and F in as much detail as possible and as applicable. If this is an application for full* *approval, then all sections will need to be completed.*

*Charges to access BH patient data will be made in accordance with NHS England’s guidelines and our own policies (*[*https://bartslifesciences.org/precision-medicine/*](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fbartslifesciences.org%2Fprecision-medicine%2F&data=05%7C02%7Cruzena.uddin%40nhs.net%7C8ddaf817c0a6453bd7c908dc42894476%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638458404548414854%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=mcbsDToBf36yjQMWgwvinP8OqgA2x56oXHxaZ1DAX10%3D&reserved=0)*). The final data access agreement will include agreed details as to how any value derived from our patient data will be distributed between all parties.*

# Section A: Request Overview

*(To be completed by requester)*

*Information in this section will be made available on the Barts Life Science website following a successful application so we can keep the local community informed as to how the health data collected within the hospital has been used. Unless your application has been identified in pre-submission discussions as needing scientific review, please ensure that you use plain English. For all applications, please attach the result of the HRA algorithm (*[*https://www.hra-decisiontools.org.uk/research/*](https://www.hra-decisiontools.org.uk/research/)*). Where relevant please attach your approved Clinical Audit (http://ceu:8080/) or Quality Improvement registration form (lifeqisystem.com) (please note these are internal links). We define the following project types[[1]](#footnote-1):*

* *Research: The activity is research if determined by the HRA Algorithm and will require appropriate ethical review.*
* *Clinical Audit (CA): Clinical audit measures the quality of care and services against agreed (national/local) standards, making improvements where necessary. Will require registration with CEU team.*
* *Quality Improvement (QI): Quality improvement supports making small changes that lead to measurable improvements for targeted services or patient populations. Will require registration with WeImprove team.*
* *Service Evaluation (SE): Service evaluations consider if existing or newly implemented services are effective. This process explores what is happening in a service as well as outcomes and experience for patients. Will require registration with CEU team.*

Project Type:

Research ☐ Clinical Audit ☐ Quality Improvement ☐ Service Evaluation ☐

|  |  |
| --- | --- |
| Approval Sought: Full ☐ Provisional ☐  **For full approval requests please ensure you have completed Appendix 1: List of individuals who will need access to the BH data.**  Short Project Title:  Click or tap here to enter text. |  |

IRAS ID (if applicable – see <https://myresearchproject.org.uk>): Click or tap here to enter text.

Click or tap here to enter text.

Clinical Effectiveness Unit (CEU) Registration Number (if applicable): Click or tap here to enter text.

Life QI Registration Number (if applicable): Click or tap here to enter text.

Project requires new software installation on BH network\*? No ☐ Yes ☐ New Initiatives Alemba reference number: Click or tap here to enter text.  *For software/ new technology (e.g., medical device, smart phone application, etc.) installation within the hospital to collect patient data, approval is required from the New Initiative team in ICT. Requests must be submitted by a member of staff from BH via:* [Barts Health NHS Portal (alembacloud.com)](https://servicedeskbartshealth.alembacloud.com/production/Portal.aspx)

Short Project Description:

*The description should include all pertinent details about the data requested, intended data analysis, the number of patients involved in the study and the potential impact to public/patients resulting from this work.*

Click or tap here to enter text.

Public Lay Project Summary:

*This short project description will be placed on our website so it needs to be consumable by the public and should not include extensive technical details. Please include any benefits that patients at BH or in the East End of London are likely to realise from this work and when they might be likely to see them (100 words).*

Click or tap here to enter text.

Requested Data Summary:

*The requested data summary needs to provide an overview of the data you are looking for BH to provide. More details can be provided in Section D if you are using the Research Data Set.*

Click or tap here to enter text.

Technical Description:

*The technical description is expected to include details around your data analysis methodology and the required computing environment to help us assess your application. Please include any open-source activities you plan to consume or contribute to, and if you plan to release/adapt any reproducible analytical pipelines. Not providing this critical information can delay the approval process.*

Click or tap here to enter text.

PPIE Summary:

*The PPIE summary should detail the PPIE activity you are undertaking in your project and the involvement of your public contributors in the project. This could be a repeat of material already in a grant proposal. If not applicable, please state why.*

Click or tap here to enter text.

Reporting:

*Please detail your strategy around reporting the proposed work. We are expecting a public legacy (e.g., peer reviewed papers, presentations, REC reports, open-source software, reproducible analytics pipelines, etc.) that can be reported to our funders and the local community.*

Click or tap here to enter text.

Planned Project Start Date: Click or tap to enter a date.

Planned Project End Date: Click or tap to enter a date.

Duration of Project: Click or tap here to enter text.

Contact Points:

*The Project Lead would be expected to be the scientific leader of the project who would be taking responsibility on behalf of their organisation for compliance with the terms of the data sharing agreement and the supervision of the named staff in their work. The Administrative Contact provides an alternative contact point to the Project Lead who would be expected to handle requests liaising with the Project Lead as required.*

Project Lead Name: Click or tap here to enter text.

Project Lead Position: Click or tap here to enter text.

Project Lead Email: Click or tap here to enter text.

Administrative Contact Name: Click or tap here to enter text.

Administrative Contact Position: Click or tap here to enter text.

Administrative Contact Email: Click or tap here to enter text.

Organisations:

*Complete the following sections for each organisation included in the project that will need access to the data either within the SDE or in another environment. Add additional organisation details sections if needed. If there are other project partners that will consume the data products exported out of the SDE, then they do not need to be included here.*

Lead Organisation Name: Click or tap here to enter text.

Lead Organisation Address: Click or tap here to enter text.

Lead Organisation Status: Medical (e.g. NHS) ☐ Research (i.e., non-commercial) ☐ Commercial ☐

Lead Organisation Role for the Project: Sponsor ☐ Host ☐ N/A ☐

Partner Organisation Name: Click or tap here to enter text.

Partner Organisation Address: Click or tap here to enter text.

Partner Organisation Status: Medical (e.g. NHS) ☐ Research (i.e., non-commercial) ☐ Commercial ☐

Partner Organisation Role for the Project: Sponsor ☐ Host ☐ N/A ☐

# Section B: Project Details

**Tick all categories which best describes the project members (NB: If a person falls into multiple categories consider the category most applicable to their role in this application):**

☐ Contracted BH staff

☐ Contracted Queen Mary University of London (QMUL) staff

☐ Staff from (or affiliated with) other NHS Trusts

☐ Staff from external non-commercial organisations

☐ Staff from commercial organisations

**Select which categories best describes the project collaboration:**

☐ A local project (just BH and/or QMUL as partners or locally based SMEs)

☐ A London project (involving NHS institutions from North Central, North East, North West, South East or South West London ICBs)

☐ A national project (with partners just in the UK)

☐ An international project (with partners from outside the UK)

**For projects with BH or QMUL members (please answer the following):**

Are you aware of any similar or potentially competing research projects within BH / QMUL?

Click or tap here to enter text.  
  
  
 Section C: External Approvals

*(To be completed by the requester and checked by a member of the Precision Medicine team)*

*Please detail the External Approvals that you will seek (if this is an ‘in principle’ application) or the External Approvals obtained (if this is a full application). All relevant sign offs and approvals should be attached to the application, if an approval is not included a reason should be provided.*

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| --- | --- | --- | --- | --- |
| **Document/Sign Off** | **Included** | **Date of approval** | **Reason Not Required** | **Checked by local team** |
| REC/HRA approval | ☐ | Click or tap to enter a date. | Click or tap here to enter text. | ☐ |
| JRMO approval / CC confirmation/ status | ☐ | Click or tap to enter a date. | Click or tap here to enter text. | ☐ |
| CAG/Section 251 (Attach submitted form, approval letter and conditions of approvals) | ☐ | Click or tap to enter a date. | Click or tap here to enter text. | ☐ |
| CEU approval/registration | ☐ | Click or tap to enter a date. | Click or tap here to enter text. | ☐ |
| WeImprove  Approval/registration | ☐ | Click or tap to enter a date. | Click or tap here to enter text. | ☐ |
| Consent Form/Patient Information Sheet | ☐ | Click or tap to enter a date. | Click or tap here to enter text. | ☐ |

# Section D: Research Data Requested

*(To be completed if the requester requires data from the BH Research Data Extract data set 1.4)*

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| --- | --- | --- | --- |
| *Tables to be requested (See Research Data extract specification)* | | | |
| **Name** | **Type** | **Request** | **Request Only Fields without potentially identifiable data** |
| Demographics | Identifiable | ☐ | ☐ |
| Inpatient | Deidentified | ☐ | ☐ |
| Outpatient | Deidentified | ☐ | ☐ |
| Pathology | Potentially Identifiable | ☐ | ☐ |
| ARIA | Deidentified | ☐ | ☐ |
| PowerForms | Potentially Identifiable | ☐ | ☐ |
| Radiology | Potentially Identifiable | ☐ | ☐ |
| Family History | Deidentified | ☐ | ☐ |
| Clinical coded data  (ICD10, OPCS4.10 and SNOMED CT) | Potentially Identifiable | ☐ | ☐ |
| BLOB Data | Potentially Identifiable | ☐ | ☐ |
| MSDS | Potentially Identifiable | ☐ | ☐ |
| PharmacyOrders | Potentially Identifiable | ☐ | ☐ |
| Allergy | Potentially Identifiable | ☐ | ☐ |
| SCR | Potentially Identifiable | ☐ | ☐ |
| Powertrials | Potentially Identifiable | ☐ | ☐ |
| Aliases | Potentially Identifiable | ☐ | ☐ |

*Any other details about the data to be requested from the standard extract such as time periods or data format (e.g., OMOP).*

Further details: Click or tap here to enter text.

*If the request is for any data not in the standard extract, or in addition to the standard extract or instead of it (i.e., a request to run a script against the OMOP dataset), please explain the details of the request below.*

Non-standard data/analysis requested: Click or tap here to enter text.

# Section E: Data Storage and Analysis

The questions in this section relate to your use of a Secure Data Environment (SDE) for your data storage and analysis.

**Will you be using the BH SDE?** No ☐ Yes ☐

**Barts Health SDE:**

Additional Data:

*Describe any additional data that you will need to bring into the SDE to undertake your analysis and the permissions needed from the data controller to process this data in our SDE:*

Click or tap here to enter text.

Additional Software & Services:

*Describe any additional software or external interactions (e.g., GitHub) that you will need to undertake in your analysis in the SDE that is not part of our default SDE.*

Click or tap here to enter text.

Exported Data:

*Describe the processed data that you will need to export out of the SDE and the checks that will be made to ensure no sensitive data will be released.*

Click or tap here to enter text.

Anonymisation:

*If your data requires anonymisation, please provide details on how this will be carried out detailing the staff, software packages and tools involved.*

Click or tap here to enter text.

Requested frequency of data updates:

Click or tap here to enter text.

**Not using the Barts Health SDE:**

Hosting Environment:

*Details of the location and* *IT system (the SDE) where the data extract will be kept and processed (including security certification and technical contact for further details). If this facility has not been used for processing Barts Health data, then additional discussion will be needed off-line before your request can be approved.*

Click or tap here to enter text.

Data Retention:

*Describe how will the data and all backup copies be deleted at end of project.*

Click or tap here to enter text.

*Who will be responsible for ensuring that the data is disposed of in a confidential manner?*

Click or tap here to enter text.

Data Transfers:

*Proposed method of transferring data to your Secure Data Environment.*

Click or tap here to enter text.

*Requested frequency of data updates.*

Click or tap here to enter text.

**For full requests please complete Appendix 1: List of individuals with access to data.**

# For Office Use Only

*(To be completed by the Barts Health team)*

|  |  |  |  |
| --- | --- | --- | --- |
| **Sign Off** | **Name, Signature & Role** | **Date** | **Comments** |
| IG (Information Governance) approval |  | Click or tap to enter a date. | Click or tap here to enter text. |
| JRMO (Joint Research Management Office) sponsorship/approval |  | Click or tap to enter a date. | Click or tap here to enter text. |
| Precision Medicine Team |  | Click or tap to enter a date. | Click or tap here to enter text. |

# Appendix 1:

Training:

*Details of lead organisational and any partner organisational IG and Data Security training.*

Click or tap here to enter text.

List of Individuals with access to data:

**Applicants must use the same email address in the table below as the one they used to register on the data portal.**

*All applicants*

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| --- | --- | --- | --- |
| **Full Name (inc. Emai)** | **Job Title** | **ORCID** | **Institution** |
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1. <https://weshare.bartshealth.nhs.uk/download.cfm?ver=18239> [↑](#footnote-ref-1)