**NEIAA Data access process**

BSR is commissioned by HQIP to run the audit, therefore we don’t own the data. The data controller is HQIP, and the data processor is Kings College London.

DSA and DARF are reviewed by the BSR Data Access Request Review Group (DARRG) on domain specific criteria. Response to applicants within 6 weeks.

The person requesting access submits the following completed forms to BSR:

1. HQIP’s Data Sharing Agreement (DSA)
2. HQIP’s Data Access Request Form (DARF)

Please see below for other forms to be submitted.

The person requesting access to the data contacts BSR to discuss proposed request

A Third party (other than HQIP) wishes to use data collected for any purpose

Request declined

Further clarification required from the applicant

DARF sent to HQIP DARG

Request accepted and data released

DSA and DARF forwarded to HQIP for review by admin officer

Request accepted

Revisions required (minor revisions approved by the chair)

**Audit data access request process**

The BSR Data Access Request Review Group (DARRG) will review applications as, based on the following terms and criteria:

Use of the data:

* The output from the project should be submitted to *Rheumatology* or *Rheumatology Advances in Practice* for first refusal unless there is a clear justification for submission elsewhere in the application.
* The aim should be to publish posters, abstracts, or presentations within two years from the date when the requested dataset is received by the data users. Users can subsequently submit new applications for data if they wish to do further analyses.
* A complete data set is available only in exceptional circumstances and will need to be supported by a compelling and scientifically robust proposal. Further use of the data inother areas of interest will require a new application to be submitted and approved by the BSR DARRG.
* To include the data in a grant application the applicant must submit an ‘Expression of Interest’ form which will be logged and reviewed by the chair. If the grant application is successful a full DARF must be submitted for review.
* The confidentiality of the patients and contributing hospitals must not be compromised by use of the HQIP data. Patient confidentiality and the reputation of BSR and HQIP must not be compromised through unethical, premature, or opportunistic data analysis.
* Any publications produced using the data must acknowledge both BSR and HQIP. The draft article/ poster/ abstract must be submitted to the BSR DARRG for review before being submitted for publication.

Any application must include:

* A clear hypothesis or purpose, accompanied by an analysis plan that lists the data fields required, the proposed timelines for the project and the project outcomes.
* An explanation of the benefit of the project to the interests of HQIP, BSR or the wider public interest.
* Short CVs of all named personnel who will have access to the data.
* Acknowledgement that data will only be used in the manner stated and for the research purposes specified. HQIP data, in whole or in part, cannot be processed, disseminated, or otherwise made available or used for any other purpose, and none of the data can be distributed to third parties.
* Analyses are allowed only accordingly to the protocol described in the application; major changes will require a new application.

## Evaluation of the data request

The BSR DARRG will review the application in terms of:

* Adherence to the use of the data criteria specified above
* The quality of the science
* The experience of the candidate(s) to undertake the work
* The relevance of the data for answering the proposed questions and the feasibility of the analysis
* The potential benefit of the project to the interests of HQIP, BSR and wider public interest.
* Applying institute’s previous use of HQIP data and adherence to terms and conditions
* The HQIP criteria outlined below.

**Role of HQIP**

If the BSR DARRG approves a request the DARF and DSA are passed on to the HQIP Data Access Request Group (DARG) which consists of the following members: , HQIP Information Governance Manager, Medical Research Information Service, HQIP Project Manager (project specific), Academic expert. The HQIP DARG will review the application in terms of:

* Compliance with the data protection act
* Ethical compliance and patient confidentiality
* Data security
* Deletion policy
* Applying institute’s previous use of HQIP data and adherence to terms and conditions

A series of short films and website content has been published by HQIP to support researchers and clinicians who wish to access health and care data for uses beyond treating individuals.

The [Understanding Health Data Access (UHDA)](https://webactivate.hqip.org.uk/lt.php?s=4f6c2814aafaf68c60a485614144269d&i=1077A1337A129A31778)project is a suite of introductory resources explaining the rules that govern how health and social care data is shared in England and Wales. It includes:

* [An Introduction to Developing Good Data Applications](https://webactivate.hqip.org.uk/lt.php?s=4f6c2814aafaf68c60a485614144269d&i=1077A1337A129A31779)– an animated film introducing the principles that data custodians work within to ensure that data is shared safely, legally, fairly and with public benefit. This will be of particular benefit to those with little previous or recent experience of making data applications.
* [The Duty of Confidentiality](https://webactivate.hqip.org.uk/lt.php?s=4f6c2814aafaf68c60a485614144269d&i=1077A1337A129A31780)– a more detailed look at the legal requirements around the Duty of Confidentiality: how it arises, how it can be met, and how it applies to health data applications.
* [Planning a Health Data Application: Questions and Information Sources](https://webactivate.hqip.org.uk/lt.php?s=4f6c2814aafaf68c60a485614144269d&i=1077A1337A129A31781)- a downloadable guide illustrating key steps in planning an application and providing collated guidance and information across the research and data sharing pathway.

## Fees

The NEIAA Data Access Fees can be found [here](https://arthritisaudit.org.uk/filesuploaded/neiaa%20data%20access%20fees%202019%202.0.pdf) or on the ‘Research’ page of the NEIAA website. The HQIP Data Access Fees can be found [here](https://www.hqip.org.uk/national-programmes/accessing-ncapop-data/). The size and scope of the data request will also inform the charges, which will be set on a case-by-case basis. You will be notified of any charges at the stage when your application is reviewed.

**BSR**

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