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Introduction

Purpose of document

The purpose of this document is to set out the policy applied by the National Joint Registry for England, Wales, Northern Ireland and the Isle of Man (NJR) in respect of the application of charges for the recovery of costs incurred in the delivery of the NJR Data Request Service.

This policy deals with the principles regarding charging for work undertaken as part of the NJR Data Request Service. This policy also applies to research activities, for example data analysis produced by NJR staff to service an approved internal or external research request.

This includes work carried out in response to an information request that is not part of a planned piece of work covered by NJR's core strategic deliverables.

Applications from NJR collaborators or contractors carrying out activity outwith agreed deliverables will be considered to be subject to this policy unless agreed otherwise by the NJR Steering Committee.

Exclusions

- This policy does not apply to work carried out as part of NJR's normal business planning activities or covered under a specific service level agreement or contract. In these circumstances NJR standard project and financial budget setting rules and policies will apply.
- Hospitals wishing to access data relating to their own NJR submissions only (i.e. excluding revisions carried out elsewhere and outcome data from other sources) need not apply to NJR for data. These requests can be services by the site's Hospital Data Manager (HDM) and transfers are subject to local governance policies.

- This policy does not apply to Parliamentary Questions which are subject to their own charging procedures.
- This policy does not apply to information supplied under the Freedom of Information (FOI) Act. Details of FOI charges are available from the UK Legislation website. <https://www.justice.gov.uk/information-access-rights/foi-guidance-for-practitioners/fees>
- However requests which originate as FOI requests and are then answered via the NJR's DR process, because bespoke new analysis is required, will be subject to the charges set out in this policy.
- This policy does not apply to routine Patient Requests.

Background

The NJR collects large volumes of data to support their outputs. These data are a valuable resource, not only for the NJR themselves but for researchers wishing to explore various aspects of healthcare, suppliers wishing to assure the quality of their products and other stakeholders.

There are resource implications for NJR and their subcontractors to process the information governance issues that accompany these requests as well as to advise applicants on the quality and content of their research applications, manage local approvals processes, and prepare data files.

NJR understands the importance of these data requests and is keen to support requests for data access. We are aware that NJR data collection is largely funded by public money, and are fully committed to exploiting these data to their maximum potential to support care quality improvements for patient populations.

Charging Policy

This policy will be applied to data requests that require any new data extraction, aggregation, analysis and reporting to be carried out by professional analytical staff within NJR e.g. bespoke research analysis or the provision of more extensive statistical outputs e.g. for example calculating standardised rates or performing data linkage.

This policy governs the recovery of costs incurred through providing third party access to clinical datasets held and processed by the National Joint Registry (NJR). It applies to data access applications and newly received research applications received from 1 April 2019.

NJR will aim to respond to all written requests for information that are not otherwise available, for example through published sources on the website or be otherwise held by NJR for example as in response to a previous request.

Resources are limited for this service in order to ensure that priority is given to work that NJR is funded to carry out as part of its core function. Discretion will be applied to requests that would result in excessive cost to respond. In these cases priority will be given to work required by NJR's core customers.

Where possible NJR will aim to proactively publish data that is commonly requested to ensure that it is freely available to all.

In situations where the information requested is already in a form that meets user requirements, NJR will provide this information free of charge if no further analytical work is required. For example this would include data extracted and analysed in response to a previous similar information request.

Estimated Costs of Managing an Application

There are various contractual, governance and data processing requirements of different projects; it is impractical to provide a standard cost for managing an application. An estimate of cost will be provided to applicants within two weeks of application. Most applications would be expected to incur costs for least 2 days' work and up to 10 days' work, depending on the complexity of the request.

A standard research application will normally include:

- Support and advice on completion of data application forms required for 3rd parties, where relevant (e.g. HQIP, NHS Digital)
- Receipt, processing and review of application including discussion with research sub committee members
- Advising applicants on the viability of their project, utility of data items requested
- Advising applicants on any duplication of effort with other workstreams, either in-house within the project team or as part of existing external collaborations
- Information governance review and advice
- Processing of data
- Secure transfer of data to applicant
- Responding to queries and clarifications
- Review of draft publications

A standard non-research application will normally include:

- Support and advice on completion of data application forms

- Receipt, processing and review of application including discussion with NJR data access review group where necessary
- Advising applicants on the viability of their application, utility of data items requested
- Information governance review and advice
- Processing of data including preparation of aggregate tables and outputs
- Secure transfer of data to applicant
- Responding to queries and clarifications

Some applications may also require:

- Meetings to discuss scope and direction of proposed project
- Contribution to drafting of publications e.g. methods sections

*A standard application will **not** include:*

- Costs associated with amendment of the application
- Costs associated with re-preparing data files where applicant has incorrectly specified requirements
- Cost of any processing associated with record-level linkage where there is to be a flow of data to the applicant
- Updates to datasets which may be required as a result of data capture or linkage beyond the time of application

Rates

Applicants should discuss their requirements with the NJR before bidding for project funding.
Personal (identifiable) data are not normally available.

Category 1: Data requests from individual non-commercial applicants, charities, community interest companies, NHS institutions or Universities

- Rates will be based on estimated workload and charged at £350 + VAT per day – chargeable in half day increments.
- Where an external contractor/data analyst is required for preparation and transfer of data files, this will be charged at £600 + VAT per half day.
- Where data is accessed via the NJR data access portal, no dissemination charge will be applied to the total.
- Where data is sent directly to the applicant, a dissemination charge of £500 + VAT will be applied to the total.
- Requests for access to NJR data linked to non-NJR datasets (HES and PROMS) will usually be managed via the research request route.

Category 2 Data requests from commercial companies or independent sector hospitals

- Rates will be based on estimated workload and charged at £1,050 + VAT per day – chargeable in half day increments.
- Where an external contractor/data analyst is required for preparation and transfer of data files, this will be charged at £1,800 + VAT per half day.
- Where data is accessed via the NJR data access portal, no dissemination charge will be applied to the total.
- Where data is sent directly to the applicant, a dissemination charge of £1,500 + VAT will be applied to the total.
- Requests for access to NJR data linked to non-NJR datasets (HES and PROMS) will usually be managed via the research request route.

Category 3: Research requests from individual non-commercial applicants, charities, community interest companies, NHS institutions or Universities

- Research requests for NJR data alone (i.e. without linkage to any other datasets) are charged at £1,200 + VAT
- Research requests for NJR data linked with non-NJR datasets (HES and PROMS) are charged at £2,400 + VAT
- Fees are payable only for approved projects and prior to data release. Expressions of interest and rejected applications will not be charged.
- Where data is accessed via the NJR data access portal. No dissemination charge will be applied to the total.
- Where data is sent directly to the applicant, a dissemination charge of £500 + VAT will be applied to the total.
- Applications from outside of the European Economic Area (EEA) will only be accepted where the data access portal is used for analysis. Additional administrative charges may be levied. Requirements should be discussed with the NJR prior to application.
- The data controller will levy a rate of £250 per application for review and approval of all applications by the data access review group. This will be added to the NJR invoice.

Category 4: Research requests from commercial companies or independent sector hospitals

- Research requests for NJR data alone (i.e. without linkage to any other datasets) are charged at £3,600 + VAT
- Research requests for NJR data linked with non-NJR datasets (HES and PROMS) are charged at £7,200 + VAT

- Fees are payable only for approved projects and prior to data release. Expressions of interest and rejected applications will not be charged.
- Where data is accessed via the NJR data access portal. No dissemination charge will be applied to the total.
- Where data is sent directly to the applicant, a dissemination charge of £1,500 + VAT will be applied to the total.
- Applications from outside of the European Economic Area (EEA) will only be accepted where the data access portal is used for analysis. Additional administrative charges may be levied. Requirements should be discussed with the NJR prior to application.
- The data controller will levy a rate of £250 per application for review and approval of all applications by the data access review group. This will be added to the NJR invoice.

Applications for aggregated data

While most applications will be for patient level data, some applications will require data aggregated to unit, hospital, regional or national level. Applicants should discuss their requirements in the first instance as data may already be published at that level of aggregation.

Where data are unpublished, then an application should be made to the NJR. Charges will again be based on the estimated time to process the application, and the daily costs will be charged as described above. In this instance, information governance review time is likely to be less, but time to prepare and release the data may be more significant.

Timing of payments

Charging structure is outlined in this policy. On receipt of a full application, the NJR will provide a confirmation of expected costs to the applicant within 2 working weeks; if all parties agree to proceed, The applicant will be invoiced in full upon final approval by HQIP DARG and prior to data release or activation of data portal access. NJR reserve the right to review and change these costs as required.

Unfunded applications

While many applications will be part of funded programmes of research, some applications will be from individuals, clinical teams or organisations without dedicated funding available. In these circumstances, and where the applicant has either declared a genuine inability to pay the fees, or other special circumstances apply, the specific project may:

- Reject the application
- Signpost the applicant to appropriate funding sources or collaborators
- Apply a discount to the fees charged

- Waive the application fees.

The decisions taken by NJR will weigh up the perceived benefit of the proposed work to the clinical community, including the capacity and capability of the applicants to complete the proposed work, against the costs to be absorbed by the project. Decisions will be documented and communicated to the applicants in writing. NJR may also, in the interests of transparency, publish an online list of applications and ongoing collaborations. Any decisions to discount or waive fees must be made by the NJR research chair, the appropriate budget holder and at least one additional member of the NJR research committee.