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Outcome Registry Intervention and Operation Network

Data access request policy

Background

The Orion cloud-based platform, developed by Obex Technologies, was established within Cambridge University in 2012 as a combined research and clinical data network. In 2019 Obex Technologies and Cambridge University formed Orion MedTech CIC, a not-for-profit Social Enterprise to deliver its core objectives. It currently hosts registries, research databases and clinical service tools across multiple institutions, including all UK neuroscience units. Its project portfolio extends from frontline service provision to long-term disease surveillance and outcome reporting[i].

To date, more than 90,000 patient records have been recorded within Orion databases. Aggregated data across all its modules is used to support research into quantification of clinical unmet need, in conjunction with a number of collaborators.

Orion MedTech supports the use of its data for research purposes to improve patient outcomes and the quality of the healthcare provided. This policy describes the process for requesting access to Orion data for research and service quality improvement purposes, including information on costs, timescales and publications.

Data requests

The aims of the Orion platform are based on the principle of maximising the usefulness of secondary data analyses, for both service quality improvement and research purposes.

The Orion team is committed to ensuring that the data stored in the platform follows high quality standards in terms of its validity and accuracy. The team also aims to make the data widely available to clinicians, commissioners, service providers and researchers who require Orion data for service quality improvement or research purposes.

The process for requesting access to Orion data aims to be as clear and efficient as possible, within the limits of information governance requirements, data security and confidentiality assurance.

Data request process

The process for data access requests is depicted in Figure 1.

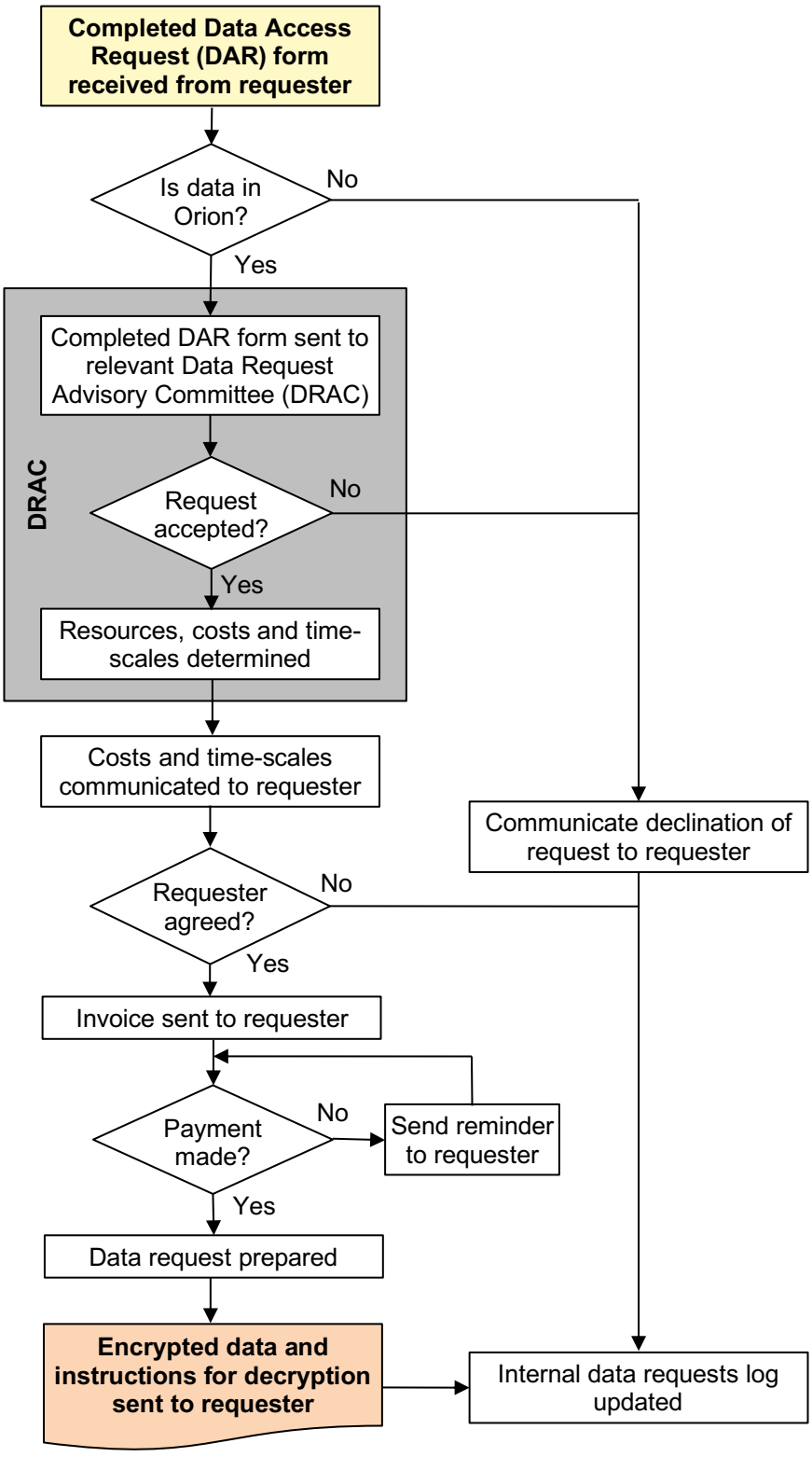

Figure 1 – Data access request flow-chart

Data requests should be submitted using the Orion data request form. The Orion admin team will carry out an initial check of whether the requested data is available from Orion.

Completed forms will be sent to a relevant data request advisory committee (DRAC). The DRAC consists of a chair, and relevant clinical, research and technical staff. The DRAC will consider requests during their regular meetings.

The DRAC will make the final decision on which requests can be approved, based on the request aim and scientific quality. Data requests will need to be in line with Caldicott principles. The aim of the requests should be related to quality improvement of the healthcare provided, or for research or educational purposes. Data requests that are the same as, or significantly similar to, other data requests already approved by the DRAC will be declined.

The costs of producing data extracts will need to be covered before these are prepared. Any subsequent request for data, which was not included in the previous one, will need to go through a new request process.

Costs

The requester must cover the costs of the resources and time needed to meet a data request.

Participating hospitals can extract their own data for local quality improvement purposes, as part of their annual subscription rate. Participating hospitals which need a more elaborated dataset will need to cover the costs of producing their request.

Requests are priced to reflect the time taken to produce data extraction, as shown in Table 1, which is determined by Orion software team in discussion with the DRAC.

Time needed for the request (non-commercial) [1]	**Cost (excl. VAT)**
Non-commercial requests	
Up to one day	£400
Up to two days	£900
Up to five days	£2,250
[1] Commercial requests and those in excess of five days please contact us	

Timescales

All data extract requests should indicate a deadline, including the day and month. Four weeks should be allowed for the review by the DRAC. Once approved please allow a minimum of three weeks for your deadline.

Only estimated "time to complete" the request will be provided, and it will not be possible to provide the exact date when this will be completed.

Information governance

Data security/confidentiality

All hospitals/units participating in any of the Orion programs or registries sign a "Data Sharing Agreement" (DSA). This agreement states that Orion will not share identifiable data with a third party.

If a requester needs identifiable data, appropriate section 251 approval will need to be in place. In addition, the requester will need to obtain signed written agreement by the relevant institutional representative for Orion to provide with the requested identifiable data from their institution. This will be done using a written agreement form that Orion will prepare for the requester. The requester will be responsible for obtaining the form signed, and returning it to Orion.

Data security and encryption

Orion has the duty to protect all patient information it stores confidentially and securely within its servers.

Data Protection Act

Orion is registered as a Data Processor with the Information Commissioner's Office under the UK GDPR

(Registration Number: ZA537939).

Caldicott Principles

Orion has appointed Dr Alexis Joannides as the Caldicott Guardian to ensure Orion compliance with the recommendations of the Caldicott Review.

Approvals

The requester is responsible for ensuring that all necessary institutional permissions and ethical approvals are in place to receive the requested data.

Disclaimers

Orion does not accept any responsibility of analyses or statements made by others using Orion data.

Publications

The use of Orion data must be acknowledged in all publications.

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- ✓ National registries: the 4 established registries (Vestibular Schwannoma, Cerebrospinal Fluid (CSF) Shunt, Deep Brain Stimulation and Paediatric Epilepsy Surgery) enable disease-specific, standardised data collection at a national level.
- ✓ Research studies: Orion has supported a number of prospective studies based in primary (e.g. Melatools-Q) and secondary (e.g. chronic subdural haematoma national audit, national external ventricular drain audit) care, enabling rapid and high volume data collection across multiple sites
- ✓ Service provision tools: The Network Referral System has been adopted by three major neuroscience units (Cambridge and Liverpool Adult and Children's), and allows robust management of neurosurgical emergencies, whilst also capturing their epidemiology and initial management. The Integrated Rehabilitation Management Application (IRMA) captures data on all candidate major trauma patients, including details of injury patterns and early rehabilitation outcome, whilst also helping the major trauma centre meet its contractual obligations for rapid access acute rehabilitation. Integrated care: two successful projects are focussing on developing pathways for integrated management of brain cancer and neurological rehabilitation.