NHS
National Institute for Health Research

OUTCOME REGISTRY INTERVENTION AND OPERATION NETWORK (ORION)

The ORION cloud-based platform, developed by Obex Technologies, was established within Cambridge University in 2012 as a combined research and clinical data network.

It hosts registries, research databases and clinical service tools across multiple institutions. ORION collaborates with the NIHR Brain Healthcare Technology Co-operatives in many activities, including:

- Data analysis for determining unmet clinical need
- Developing novel informatics applications
- Stakeholder engagement and dissemination

Since its establishment, ORION has been adopted by all neuroscience units across the UK. Its project portfolio extends from frontline service provision to long-term disease surveillance and outcome reporting.

- National registries: the 3 established registries (Vestibular Schwannoma, Cerebrospinal Fluid (CSF) Shunt and Paediatric Epilepsy Surgery) enable disease-specific, standardised data collection at a national level. This provides ongoing service monitoring for maintaining quality of care and detecting potential outlier units. The first annual audit report of the vestibular schwannoma registry was published in collaboration with the British Skullbase Society in January 2015. This work also constitutes the specialty arm of the Neurosurgical National Audit Programme (NNAP) established by the Society of British Neurological Surgeons. ORION is currently collaborating with the British Society of Stereotactic and Functional Neurosurgery to establish a registry for Deep Brain Stimulation.
- 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 (>8k recruited patients in under one year). The EPIPEG study database (led by UCL and Great Ormond Street Hospital) is currently being developed on the platform.

- Service provision tools
  - The Network Referral System has been adopted by three major neuroscience units (Cambridge, Liverpool and Bristol), and allows robust management of neurosurgical emergencies, whilst also capturing their epidemiology and initial management.
  - The Electronic Tasklist, initially funded by the Brain HTC, is currently being implemented across the neuroscience wards at Addenbrooke's Hospital. Provision of quality care relies on robust continuity of information, a challenge given medical and nursing working patterns and resource limitations. The implementation of the task list has provided a robust means of communicating and handing over inpatient tasks between healthcare professionals in a user-independent and intuitive manner.
  - The Electronic Rehabilitation Prescription (eRP) 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. The eRP has been designed for use across all trauma patients including those with neurological and non-neurological trauma. It is a composite document made up of multiple forms including standardised assessments and validated outcome measures. The combined dataset has been developed in line with the latest national guidelines, and enables data to be recorded as part of ongoing clinical care without unecessary duplication.

    The Brain HTC has supported the eRP through the establishment of a rehabilitation working group to engage all stakeholders, and funding initial system refinement. Patients captured through the system (~1200 per annum) enable aggregate data to be used for informing unmet clinical need, a core component of HTC activity. This is also used to support the programme of research co-ordinated by the HTC via the ABIRA (Acquired Brain Injury Rehabilitation Alliance) initiative.

- Integrated care: two successful project awards (total value £570k) are focussing on developing pathways for integrated management of brain cancer and neurological rehabilitation. The DAMSEL (Detection and Assessment of Malignancy through Symptom EvaLuation) project (funded by Innovate UK) seeks to develop an electronic pathway for managing patients with brain cancer from the point of initial specialist referral, through to surgical, oncological and palliative care. Data captured on a regular basis will include patient-reported quality-of-life, health needs assessment, and multidisciplinary care plans. In conjunction with the Brain HTC PPI workstream, the project will also develop and pilot the concept of a Patient Register for capturing patient agreement for involvement in future research studies, thus facilitating the screening and recruitment process.

  The IRMA (Integrated Rehabilitation Management Application) project (funded by NHS England through SBRI Healthcare) aims to apply the eRP concept to a wider rehabilitation setting encompassing long-term care and non-traumatic brain injury. The feasibility of an integrated rehabilitation record is being evaluated across specialist units, district hospitals and community services across the East of England.

To date, more than 30,000 patients have been captured within ORION. Aggregated data across all its modules is used to support research into quantification of clinical unmet need, in conjunction with the Brain HTC. The neuroscience registries provide high resolution data for monitoring the quality of care for complex conditions where HES data is insufficient. As part of the NNAP, data is used to inform on best practice, provide benchmarking across different UK units, and support the development of future research hypotheses for the relevant patient cohorts.

The network is currently upscaling its activities, and recruiting additional staff to support project management, administration and software development. Future priorities include establishing additional registries and developing novel models of integrated care enabling service devolution. Data is also used as a platform for securing funding for further epidemiological research. The potential for application into non-neuroscience disciplines is also being explored.