

United Kingdom Registry of Endocrine and Thyroid Surgery (UKRETS) Privacy Notice - Data Protection and Confidentiality

What is UKRETS?

Formerly known as the British Association of Endocrine and Thyroid Surgeons (BAETS) Audit, UKRETS is the Thyroid and Endocrine Surgery Audit for the United Kingdom which was set up in 2004 and run by the British Association of Endocrine and Thyroid Surgeons (BAETS). It was established with the aim of improving the quality of services and outcomes for patients undergoing endocrine surgical operations. BAETS collects information on the outcomes from thyroid, parathyroid, adrenal and endocrine pancreatic surgery. Currently there are > 100,000 entries in the UKRETS database.

The data from UKRETS is analysed and published anonymously in a national report, now in its 5th edition in 2017. This report sets out the extent of endocrine surgery undertaken by BAETS members in the UK as well as detailed information on investigations, pathology, operative details and surgical outcomes. This provides valuable information on the quality and safety of surgical outcomes, trends in the management of surgical endocrine disease and provides a national standard, against which BAETS members can compare to their own practice. This helps drive up standards and improve outcomes for patients undergoing endocrine surgical operations.

What information does it contain?

Each entry in UKRETS is a separate endocrine (thyroid, parathyroid, adrenal or pancreatic endocrine) surgical operation. Data has been collected in UKRETS since it was set up in 2004. The information is collected by the consultant in charge of that patients care and includes details about:

- The patient – age, date of birth, gender
- Investigations – results of pre-operative biopsies, scans
- Operation – type, extent, surgeon, equipment used
- Pathology
- Outcome – complications, mortality, date of discharge, length of stay
- Follow-up – date of follow-up, discharge, presence of long-term complications

It is anticipated that we will in future, record the NHS number of patients in England and Wales to help identify patients undergoing multiple surgical operations and also cross-check our data against other NHS databases such as Hospital Episode Statistics (HES) data.

What is the legal basis for UKRETS?

UKRETS data are collected for a “medical purpose”, as defined in the 2006 National Health Service Act Section 251, for the provision of care and treatment and the management of health and social care services. The data are collected by BAETS members on patients undergoing endocrine (thyroid, parathyroid, adrenal and pancreatic endocrine) surgical operations with the approval of the Secretary of State under Section 251. This approval is reviewed each year and approval sought for the following year.

Who manages UKRETS?

UKRETS was set up in 2004 and is managed by the British Association of Endocrine and Thyroid Surgeons in conjunction with Dendrite Clinical Systems Ltd with the intention of improving the quality of services and outcome from endocrine surgical operations.

What happens to the data and who can see it?

The consultant in charge of care, or a member of his clinical team collects this data and enters it onto UKRETS via secure username and password protected web-based access to the audit (www.baets.org.uk/audit/). During the data transfer from the hospital to the NHS server the information is encrypted (locked) to ensure it cannot be interfered with. Once this information has been loaded, a consultant can review or edit his own data via the same username and password protected access, but cannot view data recorded by other BAETS members. When the data have been checked by the clinician, software engineers and data analysts at Dendrite Clinical Systems will download the data to a secure server in Dendrite's offices.

Anonymous Data from UKRETS is analysed and published in a national report by Dendrite Clinical Systems Ltd on behalf of the BAETS. Now in its 5th edition this report gives valuable insights into trends and outcomes in endocrine surgery in the United Kingdom and also gives clinicians, commissioners and healthcare providers a benchmark of national standards against which they can compare care in different centres. Information on outcomes specifically from thyroid surgery are also published annually on the NHS Choices website as part of the Consultant Outcome Publication programme by the Health Quality Improvement Programme (HQIP). This data is searchable by clinician or hospital and aims to help members of the public when choosing which hospital or clinician to look after their care. It is important to note that neither of these reports contains the details of individual patients.

UKRETS Database Server

The server is hosted on the NHS network (N3) within a data centre in London, by Pikel. This is a tier four data centre which meets the highest levels of building security. The service delivery and information governance provided complies with ISO 20000 & ISO 9001 accreditation and the security structure is aligned alongside ISO27001. The security arrangements are internally audited approximately every three months and externally audited every six months. All servers have firewall and anti-virus software installed which is configured to use real-time scanning.

Backup Resilience

The data is securely backed-up each day. All backed up data stored is compressed, de-duplicated and encrypted within a secure off-site vault. There are two backup vaults, the primary one is hosted locally and is then backed up to a secure secondary off-site vault hosted within a separate datacentre located at Heathrow.

Dendrite Security

Dendrite Clinical Systems is assessed against NHS Information Governance standards, which includes both physical and organisational security measures. Dendrite's toolkit assessment score is available on the IG Toolkit website (<https://www.igt.hscic.gov.uk/Home.aspx>). The computer software

programme created by Dendrite that holds the UKRETS data has been independently tested to ensure that it is not vulnerable to unauthorised access, or internal breaches of security.

Can I ask to see the data that UKRETS holds about me?

Yes - requests to see what data is held on the UKRETS database about you may be made through a subject access request via the BAETS website (www.baets.org.uk).

British Association of Endocrine and Thyroid Surgeons,
Association of Surgeons of Great Britain and Ireland,
35-43 Lincoln's Inn Fields,
London,
WC2A 3PE