The UK Registry of Endocrine and Thyroid Surgery (UKRETS)

Patient Information Leaflet

The UK Registry of Endocrine and Thyroid Surgery aims to collect information on the results of surgery for every UK patient undergoing thyroid, parathyroid, adrenal or pancreatic endocrine surgery operations.

If you are undergoing a thyroid, parathyroid or adrenal (endocrine) operation in England, Wales, Scotland or Northern Ireland, the surgeon performing the surgery may collect information on this for the purposes of clinical audit.

Clinical audit is a process by which the surgical team reviews treatments and outcomes with the aim of finding ways to improve care.

This leaflet describes what patient information is kept in the UK Registry of Endocrine and Thyroid Surgery (UKRETS), and how these data are used to promote good practice and maintain standards.

What is UKRETS?

UKRETS is a clinical audit or registry that endocrine and thyroid surgeons use to monitor their practice. It was set up by the British Association of Endocrine and Thyroid Surgeons (BAETS) and is approved by the Healthcare Quality Improvement Partnership (HQIP), an independent organisation led by Academy of Medical Royal Colleges, The Royal College of Nursing and National Voices.

BAETS stipulate that all surgeons performing thyroid surgery contribute data on all their relevant operations to UKRETS. BAETS strongly recommends that all other relevant endocrine operations are also recorded.

Surgeons enter data directly onto the database through a secure web based connection. UKRETS analyse these data to provide information on their standard of clinical care and patient outcomes. This allows surgeons and their hospitals to know where they are doing well, as well as highlight areas that they can improve.

UKRETS is part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP), commissioned by HQIP for England.

What information is collected on me?
UKRETS collects information about the endocrine operation you have whilst in hospital. In addition your gender, date of birth and date of operation are recorded to allow individual surgeons to know they are accessing the correct patient record when entering data from your follow up postoperative attendances – NHS number maybe collected also in the future.

Only information related to your surgery is collected, such as the severity of your condition, the type of investigations and treatment you receive, your surgical treatment and wider clinical outcomes of your operation.

UKRETS does not require you to have any extra appointments, or clinical tests. The Registry does not collect information on any care that does not relate to your thyroid or endocrine surgery.

Opting out from the UKRETS

If you do not wish your personal data - date of birth, gender, and date of operation - to be entered on the database, please inform your surgeon. Your decision will be respected, and your choice will be recorded in the front of your medical notes.

If you have changed your mind and wish to have your details removed from the registry, please contact either by email: secretary@baets.org.uk, or phone: 0207 3044771 or in writing to: UK Registry of Endocrine and Thyroid Surgery, at BAETS, ASGBI Office, Royal College of Surgeons of England, 35-43 Lincoln’s Inn Fields, London WC2A 3PE

How will your information be used?

UKRETS only publishes information describing the care received by groups of similar patients. It does not publish information on individual patients, and your personal details will never be made public.

The information collected by UKRETS is used:

- To produce information on the quality of care received by patients having thyroid and endocrine surgery in the United Kingdom.

- UKRETS produces reports that describe whether care is meeting national standards. The reports are available to the public, endocrine and thyroid surgeons, hospital management, and NHS England.

- To enable sharing of good practice amongst all NHS organizations.
To provide patients with information about endocrine services at different hospitals, such as the number of operations done each year, and the rates of complications after surgery.

To help commissioners and policy makers with decisions about how endocrine surgery should be organized within the NHS.

Further information on how BAETS processes your data in UKRETS is available on the BAETS website at the following address https://www.baets.org.uk/wp-content/uploads/UKRETS-fair-processing-statement-v2.pdf

**How your information is be kept safe?**

The Registry has strict data security measures to keep the information held on you confidential.

We follow rules about how the data are stored in a secure environment and that it is only made available to appropriate staff. The Registry conforms to the confidentiality rules established by the Data Protection Act 1998, the NHS Act 2006, and the Health and Social Care Act 2008.

Your personal data will never be shared with anyone outside BAETS or Dendrite, the company that hosts the database.

It is important that the UKRETS has information from all patients to give an accurate picture of thyroid and endocrine surgery in the UK.

Further information on the measures taken to ensure your data is stored safely in UKRETS are available on the BAETS website at the following address https://www.baets.org.uk/wp-content/uploads/UKRETS-privacy-notice-v2.pdf

**Further information**

If you would like more information about UKRETS, please ask your endocrine or thyroid surgeon.

You are entitled to access your data in UKRETS to see what information is stored on you. To request this please complete a BAETS subject access request form, which you can find at the following address http://baes.e-dendrite.com/sar.html