Fair Processing Notice

The Society for Endocrinology is the Data Controller for the UK Acromegaly Register. This register is updated annually and holds personal details of all patients who have enrolled on to the study. If you are a patient taking part you will have consented to the information held by the NHS and records maintained by us (the central register office) being used to keep in touch with you and follow up your health status.

The overall aim of the study and the reason we wish to collect and process you data is to learn more about what influences mortality and morbidity of those with acromegaly. We plan to use this knowledge to better inform day to day management of patients. Due to its comparative rarity, no one centre alone can provide sufficient information.

In addition to data collected locally at your hospital, we request further information from NHS Digital - the national information and technology partner to the health and social care system. NHS Digital are the guardians of patient data, making sure it is protected and handled securely, and only ever used for the good of health and care. The information we request includes cancer registrations and date/cause of death. We believe collecting this extra data is the best way to achieve our aim of investigating mortality in patients with acromegaly.

Identifiable data (data that could potentially identify a specific individual or distinguish one person from another) is held locally at your hospital and at the Society for Endocrinology. Most of the time, a participant is referred to by a unique study identifier rather than by name and this is known as pseudo-anonymisation (the identifier does not reveal your true identity but we can link the data back to you when needed). Any published study results will always be anonymised, this means that no-one will be able to identify you.

We only intend to share your data within the study team, however, on certain occasions we may be obliged to allow statutory bodies/organisations to inspect or monitor what we are keeping and how we are keeping it.

All participants are free to withdraw from this study at any time and without giving a reason. If anyone wishes to speak with someone about their participation please do not hesitate to contact either Natasha.Archer@endocrinology.org or Zoe.Plummer@endocrinology.org.

3. Data entry.
The data will be held securely at the Society for Endocrinology (SFE) Office in Bristol. All centres will directly enter data into the central database via a terminal server system. This will make the system more secure and accurate by eliminating the need for transfer of data from local centres to the national database which can generate errors. All data backups will be centralized and I.T. support will be greatly improved as there will be no concerns over software compatibility between the database and local centres. The server used will be dedicated solely to the project and will not run any other applications other than the acromegaly database and its associated documentation. It will not run email and will thus not be vulnerable to email viruses. The server will be in a locked computer room at the Society for Endocrinology Bristol offices. Access will be restricted via the appropriate firewalls. The server will have Windows 2003 security set at the highest levels. There will be password control to enter the server. There will also be password control on entering the new database program to restrict users to see only their local data. Standard timeouts will apply to idle connections. The terminal server program encrypts data going down the wire to a very high level.

5. Data Analysis
Data Analysis will be undertaken by Gillian Walker and staff at the Society for Endocrinology. Statisticians from Newcastle Upon Tyne NHS Foundation Trust - Dr Richard McNally & Dr Peter James. Additional data analysis will be conducted by Dr Debbie Willis, Dr John Ayuk, Professor Peter Trainer, and other members of the project board in their respective institutions.

Data is collected from hospital records, visit records and HSCIC records. Centralised measurements and local laboratories.

1. Look at a core specific mortality related to growth hormone and IGF1 levels as well as pre-morbid conditions and relate this to different treatment modalities including surgery, medical treatment and radiotherapy, as well as hormone replacement therapy. Further the age of onset and the tumour size will be analysed.
2. Obtain data that will inform on practice nationally and internationally.
1. Look at a core specific mortality related to growth hormone and IGF1 levels as well as pre-morbid conditions and relate this to different treatment modalities including surgery, medical treatment and radiotherapy, as well as hormone replacement therapy. Further the age of onset and the tumour size will be analysed.
2. Obtain data that will inform on practice nationally and internationally.
PRIMARY MEASURE OF OUTCOME: To provide epidemiological evidence about long-term mortality and morbidity and the results of treatment by surgery, radiotherapy and medical therapy in acromegaly.
SECONDARY OUTCOME MEASURES: To inform on the day to day management of patients with acromegaly and to encourage centres to audit their own practice against the national dataset.
All patients are flagged with the HSCIC to obtain information on cause of death and cancer registration as this is the best way to achieve our aim of investigating mortality in patients with acromegaly.
The intention is publication in peer-reviewed journals, presentation at national and international meetings (to include The Society for Endocrinology BES annual conference) and a summary of the results will also be sent to the patient support group, the pituitary foundation. www.pituitary.org.uk. A summary of the results will also be sent to a pharmaceutical company and each individual has consented to this point specifically.
Outputs are due in 2018 and will contain only aggregate level data with small numbers suppressed in line with the HES analysis guide.

Patients with acromegaly have morbidity and may on presentation besides their usual clinical features have diabetes mellitus, hypertension, or endocrine dysfunction related to the pituitary tumour.
Untreated acromegaly has an increased mortality due to cardiovascular and cerebrovascular disease, respiratory disease and probably malignancy.
Particularly carcinoma of the colon is reported to have an increased incidence.
The incidence of acromegaly is reported to be between 4-6 new cases per million per year with a prevalence of approximately 40-60 per million. This equates in the UK to around 2,500 patients with acromegaly.
Due to its comparative rarity, no one centre can provide sufficient numbers of patients to enable analysis of potential influences on mortality and morbidity of, for example, pre-existing co-morbidities, e.g., diabetes mellitus and hypertension, different treatment modalities, for example, pituitary radiotherapy and different growth hormone levels. In particular there is only one publication relating mortality to IGF1 data.
Target benefits: To inform the day to day management of patients with acromegaly.
To encourage centres to audit their practice against the national dataset.