Impact of the UK Acromegaly Register

The UK Acromegaly Register collects prospective and retrospective data on patients with Acromegaly and gigantism to assess treatment outcomes and mortality and morbidity in this patient population.

Acromegaly is the result of a benign GH-secreting pituitary tumour. Treatment options include pituitary surgery and/or radiotherapy and/or medical treatment.

Project outcomes

- **Radiotherapy and surgical outcomes.** The project has already published on radiotherapy and surgical outcomes (see all publications below). The publications confirmed the effectiveness of radiotherapy in long term control and highlighted variation in surgical outcomes, recommending specialist surgeons, respectively.
- **Medical treatment.** A paper on medical treatment paper is currently in preparation. It will be one of the biggest papers to study outcomes of medical treatment and overall levels of control of acromegaly in real clinical practice. It will show that fewer patients are "controlled" than expected and will illustrate that dose of somatostatin analogues are not always escalated to the maximal effective dose. Will also confirm that outcomes of medical treatment are better after surgery and radiotherapy than they are with primary treatment. All of this is likely to influence future care planning in individual cases.
- **Patient audit.** The project allows centres to audit their patient’s outcomes against a large national dataset. Reports are sent to centres every three months. A more restricted report is also sent to Ipsen.

Moving forward

- **Mortality and morbidity.** The UK Acromegaly Register is in a prime position to investigate mortality, morbidity and secondary cancers. It is unique among other European registries in that all patients in the UK have a unique NHS number. This allows patients to be flagged with the NHS information centre to obtain information on cause of death and cancer registration. The project was originally set up as a pure audit with all patients anonymised. Over the last few years there has been a concerted drive to obtain all the necessary ethic approvals, patient consents and identifiers on the 2500 patients on the register to undertake this flagging study and answer the hypothesis of increased mortality and secondary cancers in patients with Acromegaly.
- **Centralised measurements.** Patients with acromegaly are monitored by, and clinical decisions made on the basis of their serum growth hormone (GH) and insulin-like growth hormone-1 (IGF-1) levels. The project has set up collaboration with IDS to measure GH and IGF-1 centrally to enable direct comparisons between patient outcomes.
- **Gigantism.** The Register contains a large series of Giants. Data analysis has already commenced on the giants in the register to potentially publish details on one of the largest series of giants collected over the last decade.

Publications


MN Carson. The UK National Acromegaly Database. BES March 2003 P47


P J Jenkins, E L Elliott, M N Carson, P R Bates. On behalf of The UK National Acromegaly Register Study Group The Effects of Pituitary Irradiation on Serum GH and IGF-1 in Acromegaly –Results
from the UK National Database. Society for Endocrinology November meeting 8-9 November 1999 OC4


M N Carson', J Crompton2, R N Clayton3 and J A H Wass. The UK Pituitary register; Collecting Data for Acromegaly. BES 12-15 April 1999, P 50
