

INTRODUCTION

- Acromegaly is a rare endocrine disorder with an estimated prevalence of 1:140,000-1:250,000¹.
- Treatment options include transsphenoidal surgery (TSS), medical management, radiotherapy or a combination of these, depending on disease and patient factors.
- In 2014 the Endocrine Society published clinical practice guidelines for the management of acromegaly².

OBJECTIVE

- The objective of this survey was to obtain a snapshot of current UK practice following publication of the new guidelines.

METHODS

- A survey was undertaken of 21 endocrinologists from 19 secondary and tertiary care National Health Service centres in England (n=17), Scotland (n=1) and Wales (n=1).
- The surveys gathered information about current clinical management of acromegaly, local biochemical control criteria and the factors that drive treatment decisions.
- Endocrinologists with recognised interest and significant experience in the treatment of acromegaly were invited to participate by letter.
- Surveys were conducted by the Novartis Medical Science Liaison team between November 2014 and March 2015. Survey questions were validated by an endocrinologist.

RESULTS

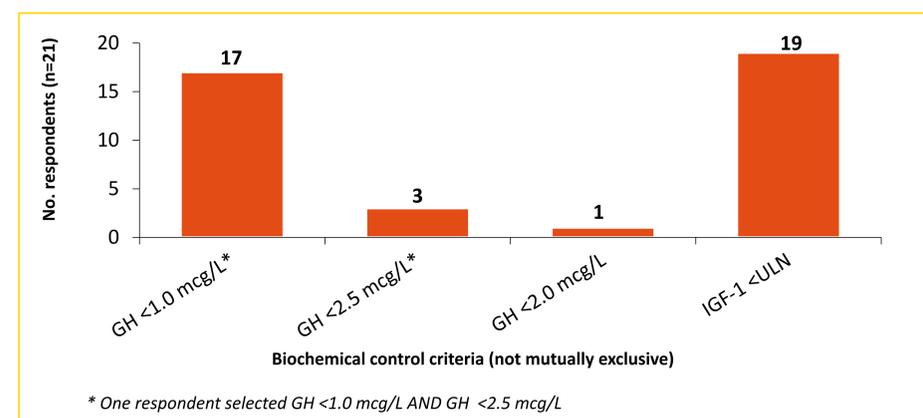
Centre Characteristics

- The estimated number of new patients with acromegaly seen per year ranged between centres from 1-20 and the number of existing patients from 11-250.
- Most common referral sources for patients with acromegaly (not mutually exclusive) were other endocrinologists (14 respondents) and general practitioners (12 respondents).

Biochemical Control Criteria

- All 21 survey respondents stated that both insulin-like growth factor 1 (IGF-1) and growth hormone (GH) are important for assessing biochemical control.
- Most respondents use GH<1.0 mcg/L and IGF-1 < upper limit of normal (ULN) to define biochemical control, as shown in **Figure 1**.
- For 12/21 respondents the possible effect on tumour volume is an important criterion when choosing a medical treatment.

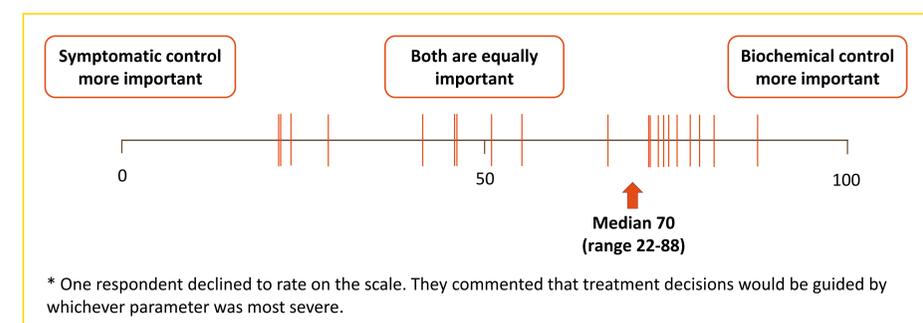
Figure 1: What are the Locally Accepted Criteria for Biochemical Control?



Importance of Biochemical vs Symptomatic Control

- Respondents were asked to rate the importance of biochemical vs symptomatic control for treatment decision-making on a visual analogue scale. The results are shown in **Figure 2**.

Figure 2: Which Factor is More Likely to Drive Treatment Decisions (n=20*)?



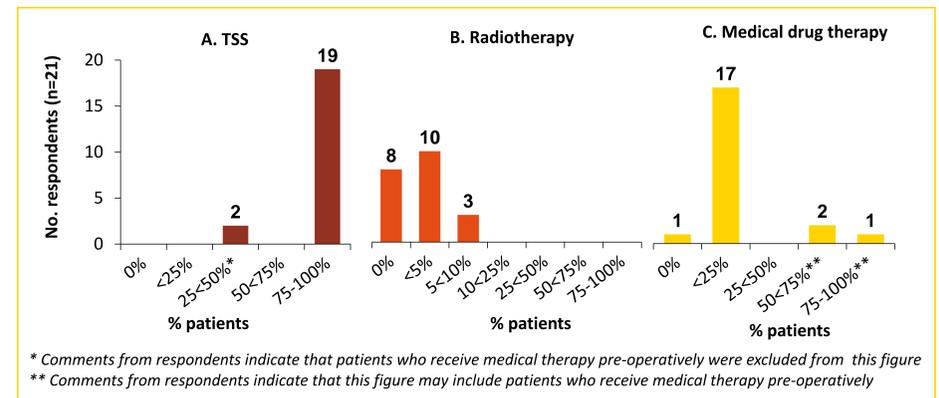
REFERENCES

- Chanson P and Salenave S. *Orphanet Journal of Rare Diseases*. 2008;3:17
- Katznelson L, Laws ER, Melmed S, et al. *The Journal of Clinical Endocrinology and Metabolism*. 2014;99:3933-51

First Line Treatments

- The estimated percentage of patients who receive TSS, radiotherapy or medical therapy as *primary therapy* is shown in **Figure 3**.

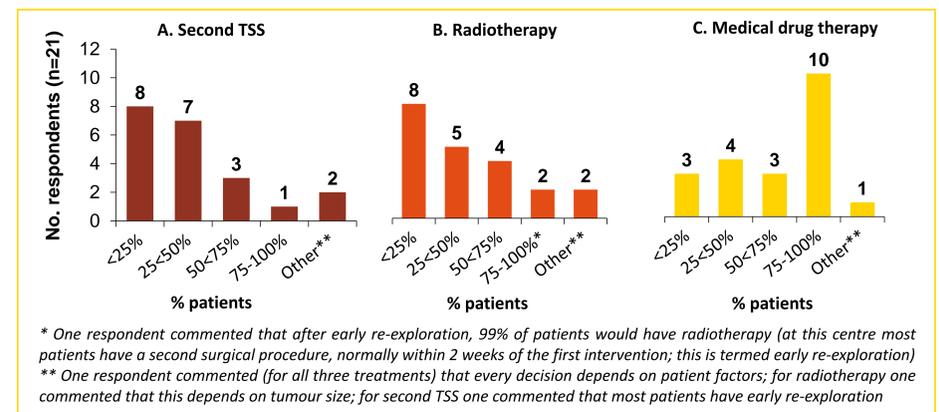
Figure 3: What Percentage of Patients Receive the Following Treatments as Primary Therapy?



Second Line Treatments

- The estimated percentage of patients who receive a second TSS, radiotherapy or medical therapy *after failure of primary surgical therapy* is shown in **Figure 4**.
- Medical management was the most common second line treatment (see **Figure 4C**).
- There was considerable variation between centres in the reported proportion of patients who receive radiotherapy following surgical failure (see **Figure 4B**).

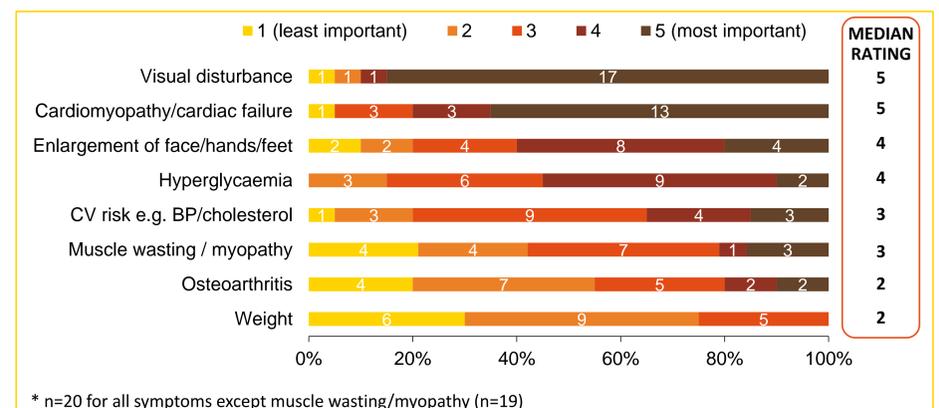
Figure 4: What Percentage of Patients Receive the Following Treatments after Failure of Primary Surgical Therapy?



Clinical Symptoms

- Respondents were provided with a list of clinical symptoms and asked to rate (scale 1-5) how likely each would be to drive a medical management change. Visual disturbance and cardiomyopathy were most likely to drive changes in medical management (see **Figure 5**).
- Other symptoms mentioned by respondents included sweating (n=8), sleep apnoea (n=6) and headache (n=6); the median rating was 4 for each symptom.
- Of the symptoms provided, enlargement of the face/feet/hands was reported to be the most common; cardiomyopathy and visual failure were reported as the least common.

Figure 5: What Symptoms Would Drive a Change in Your Medical Management*?



CONCLUSIONS

- This survey relied upon clinical opinion of only 21 clinicians; nevertheless, it provides useful insights into the current management of acromegaly in the UK
- The survey highlights some areas of consistency in management between centres:
 - all respondents think that both IGF-1 and GH are important for assessing biochemical control; most use GH<1.0 mcg/L as the local biochemical control criteria (in line with current guidelines)
 - there was consensus in the use of TSS as primary therapy
- The survey also highlights some areas of variation and guideline recommendations not yet fully adopted; most notably the treatments that are used after failed surgery