# Patient experience of living with acromegaly in the United Kingdom

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#### Introduction and objectives

Previous studies have shown patients with acromegaly frequently have a delayed diagnosis, psychological difficulties and long term morbidity. The objectives of this project were to ascertain patient opinion on:

- The overall patient pathway from initial diagnosis, subsequent treatment, and ongoing management
- Engagement with healthcare professionals and patient groups
- Willingness and ability to travel

#### Methods

- 104 patients within 10 years of active treatment for acromegaly, from the South West Peninsula Endocrinology Network in the UK (involving 5 acute hospitals and 1 neurosurgical centre), were invited to participate
- 61 patients (34M, 27F) were interviewed to explore the experience of living with acromegaly
- Semi-structured Interviews were conducted by an independent consultant (60-120 min each) in the patient's own home
- 52 (85%) patients had surgery for their acromegaly

Hospital	Population	Invited	Participated
Barnstable	165,000	3	3
Exeter	450,000	21	16
Torbay	275,000	17	10
Plymouth	700,000	43	23
Truro	383,000	20	8

Figure 1: Number of patients participating from each hospital under one neurosurgical centre

Figure 2: Year of diagnosis

Year of diagnosis	Number interviewed	
Pre-1993	8	
1994 - 2003	11	
2004 - 2013	42	

## Results: grouped into 7 common themes (selected quotes used for illustration)

#### 1. Diagnosis

- 56 (92%) experienced a significant delay from symptoms to diagnosis, but prompt effective secondary care treatment
- Patients felt a lack of awareness of the condition within primary care and its effect on them long term
  - " The attitude and knowledge of my GP could have been improved. I presented with problems for more than two years and all the tell-tale signs were missed."

#### 2. Support and communication for surgery

- Patients interviewed felt that the impact of surgery on their lives was not well explained, the surgical experience traumatic
  - " There appears to be a disconnect between the medical and surgical management."
  - " I was given no choices for surgery, no choices for treatment."
  - " Surgery was the most terrifying experience of my life and I would have benefited from someone holding my hand."
  - " Nurses were overworked and reliant on bank staff. I had no privacy and the attitude of nurses was apathetic."
  - " After being discharged we were on our own! I felt as though the strings had been cut."

## 3. Medical treatment

- 36 (59%) were on additional medical treatment and had issues with the ordering, dispensing (late delivery) or administering of the drug (delayed appointments).
- The majority on Somatostatin analogues had the practice nurse injecting (only 4 had self-administration at home), with lack of technique from nurses in 2 cases resulting in waste.
  - " I have a real issue getting my medication. I fully understand the importance of it but do not feel the practice nurse sees it in the same way."
  - " I am happy with my injections, but know they cost a lot of money."
  - " Poor communication between pharmacy, clinic, ordering injections and administration of drug which could be improved."

## 4. Endocrine Specialist involvement

- Overall patients were satisfied with the care they received and after diagnosis had rapid investigation and treatment.
- Those in contact with a 'specialist' consultant or an endocrine nurse specialist felt most supported
- 52 (85%) felt they had access to a consultant who understood the condition
  - " I feel my care is superbly coordinated, due to the excellent team working between the consultant and specialist nurse."
  - " It was an example of the NHS at its best. From initial attendance at my GP through to final diagnosis it was superb. Consultant is quite outstanding."
  - " All of my care plan was very well coordinated specialist nurse was excellent and very efficient and could not explain too much."
  - I feel I have excellent access to the consultant, who clearly understands my condition, never too much trouble."
  - " My consultant has recently changed and I do not feel that my relationship or support is as good."
  - " My consultant retired and my review appointments are now with registrars, who are not 'au fait' with the condition or my history, and I have to relay all my medical information time and time again."
- 62% had access to a specialist nurse (and 81% felt experience enhanced as a consequence)
- 10 patients didn't realise they had access to ESN outside clinical trial
- Those without contact with an endocrine nurse specialist felt their care might have been compromised as a result.
- Many thought a key worker (nurse) would be of benefit
- I have excellent support from the specialist nurse, and feel things have been much improved since I have started seeing her."
- I think I would benefit from seeing the specialist nurse. I would not want to encroach on valuable consultant time."

# 5. Psychological support

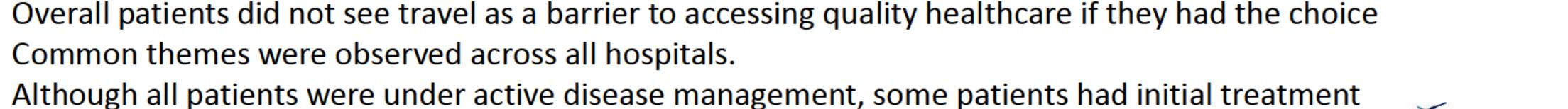
- Most patients felt a lack of psychological support at diagnosis and early treatment
- We had total unawareness of depression relating to the condition, and I really feel this needs further development for other patients. Psychological support is crucial for newly diagnosed patients."
- It was such a lonely period. I was acting all the time I was at work, but in despair when I got home."
- " Nurses should have some form of training to deal with patients re the psychological impact of traumatic surgery."
- Whilst all my physical needs were met, what I cannot live with is no psychological awareness of patients' problems."
- " I have at times felt very isolated and I feel like a monster."

#### 6. Information

- There was no consistent approach to providing information in each centre
- Patients felt unprepared for the life-long effect of their condition and some inadequately prepared for surgery.
- 53 (87%) patients felt they understood about their condition now, many felt this took a long time with extensive personal research
- 67% had been offered written information
- 69% had looked on websites
- 61% were aware of patient groups, but:
  - only 20% had joined or sourced information from one
  - 15% attended a meeting (despite a desire to help others with acromegaly)
- " My diagnosis was difficult to take in, and I did not feel it was communicated well initially – I would have benefitted from more support and information."
- " I do understand my condition now but only as a consequence of my own research."
- I was given extensive information by the hospital concerning my treatment, but not about my condition."

### 7. Travelling for treatment

- 46 (75%) would be willing to travel anywhere in the UK to receive treatment (25% to next available hospital) if not available locally.
- Although many felt involved in decision-making, few had been offered choice (but would value their consultant's advice).
- Most patients would take decision on whether to travel based on advice from their consultant
- " If you cannot get it locally we would travel. If your health is at stake, I would be willing to travel anywhere."



This is the largest acromegaly qualitative patient experience study undertaken in the UK, reflecting

Patients overall were happy with their clinical care and ongoing medical management and feel well

many years ago and systems have significantly changed. New common pathways and information sheets are now in development.

Patients highly valued the support and input from their endocrinology team

Patients who had access to a specialist nurse highly valued their support





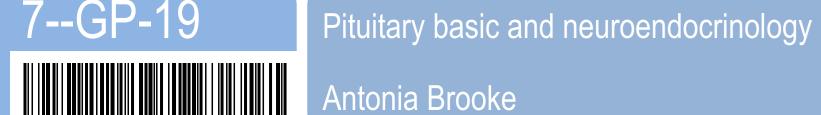


Conclusions

supported







the issues of living with acromegaly