

Title: AcroVoice: The Patient Perspective on Acromegaly Disease Activity

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To help foster a holistic approach to acromegaly disease management, this patient preference study aims to identify which acromegaly disease parameters are important to patients (Phase I; completed) and quantify the relative predictive value of each disease parameter on overall disease activity from the patient perspective (Phase II; in progress).

In the qualitative phase of the study (Phase I) semi-structured telephone interviews were conducted with seven adult patients with acromegaly recruited from three Canadian patient support groups. Participants identified five acromegaly disease parameters as key components of their disease activity, including insulin like growth factor I (IGF-I), tumor size, symptoms, comorbidities and health related quality of life (HRQoL). Patients identified symptom severity as the most important indicator of health status and treatment outcome; symptoms were also identified to have a large impact on daily life. HRQoL was important to patients when defining their health status, but patients indicated that quality of life was a topic rarely raised by their treating physician. Patients also viewed “numbers” (i.e., IGF-I levels) as important indicators of disease activity; however, they also indicated that while physicians focus on the “numbers”, these do not fully capture their experience of living with acromegaly. Upon probing, patients also identified tumor size as an important component of their disease activity. Patients had variable understanding and awareness of comorbid conditions, with sleep apnea being identified as a “symptom” and other comorbid conditions being elicited mostly after probing.

In the current qualitative phase of the study, patients identified the same five disease parameters as those identified by expert endocrinologist in a separate study to describe their acromegaly disease activity; however, patients placed more emphasis on symptoms and HRQoL. To help inform and facilitate a shift toward a more patient-centric approach to acromegaly disease management, the relative importance and predictive value of each of the five acromegaly disease parameters on overall disease activity from the patient perspective will be quantified in Phase II of the study.