

Everyday Life with Growth Conditions: A Global Patient Survey

Results of the ICOSEP Quality of Care 2025 Survey
September 2025



This survey and report were only possible due to the support and sharing by our many member organizations.

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BACKGROUND AND OBJECTIVES

The ICOSEP Quality of Care survey was open to everyone with experience of living with, or caring for someone, with a growth condition. We collected data and insights from real patients across the globe to understand their experiences, challenges and hopes for the future.

This is the first survey of its kind. We hope that the evidence and data in this report will support our community in advocating for better healthcare provision, journeys and quality of care across all children and adults living with a growth condition.

WHO TOOK PART?

We were delighted to have
199 respondents

from across
26 countries

representing over
7 conditions

including Growth Hormone Deficiency, Turner Syndrome and Idiopathic Short Stature

CHALLENGES IN ACCESSING CARE

40%

said the **impact of the condition** on their child's life is not well recognised

24%

found it hard to access to **support and care** for their child's **mental health**

1 in 5

reported challenges such as:

- **Lack of information** about innovative or new treatments
- Lack of **knowledgeable specialists**
- Lack of **practical support**

40%

said it was a challenge when healthcare professionals **did not have enough knowledge about growth conditions.**

THE UNRECOGNISED IMPACT OF CONDITIONS

Most respondents said healthcare systems did **not fully recognize the profound impact the condition has on their daily lives. Families also reported that despite their mental health needs, it was difficult to access the right care, including necessary psychological support.** Practical barriers also can impact quality of life, including financial barriers, accessing medication, limited treatments, and distance.

DIAGNOSTIC JOURNEYS

We found that most respondents rated the quality of the diagnostic process relatively well*.

There was a wide range of reported time to diagnosis, from less than a month to over a year.

* between 3-5 in a scale where 1 is the worst and 5 is the best

45%

Had their child diagnosed at over 3 years old

How many visits did it take for diagnosis?



TRANSITION OF CARE

35%

Gave positive thoughts about **current or the anticipation of** transition care

- Families voiced concern over **inadequate planning, poor communication, and gaps in care continuity** when moving from pediatric to adult services.
- Parents report receiving little to no explanation about **what adult care will involve, what follow-up is needed, or who will be responsible for ongoing management**, leaving them uncertain about their child's future care.

COUNTRY-SPECIFIC INSIGHTS



- Free access through the NHS
- Efficient, timely care and medication delivery



- Comprehensive coverage
- Administrative support exists but is sometimes difficult to navigate



- Access to top endocrinologists
- Inconsistent coverage, dependent on location and insurance



- Comprehensive coverage
- Strong coordination between medical professionals
- Centralized resources



- Comprehensive coverage
- Excellent access to specialists and coordinated care
- Strong national support via rare disease programmes

GOING BEYOND OUR DATA

Our Quality of Care survey highlighted several unmet needs across our community. We know there is a greater need for recognition, and subsequent support and resources, for the **wider impact of growth conditions** on the lives of children and families alike. We need to come together to make sure we make this happen, that's why we're collaborating in the *Speak Up* campaign, to call for:



- Greater recognition of the **true impact of all growth conditions** alongside better tools for children and their families.
- The need to treat every child living with dignity and respect, and the opportunity to be seen as **more than their height alone**.