

'Patient Journeys': Personal experiences shaping clinical priorities

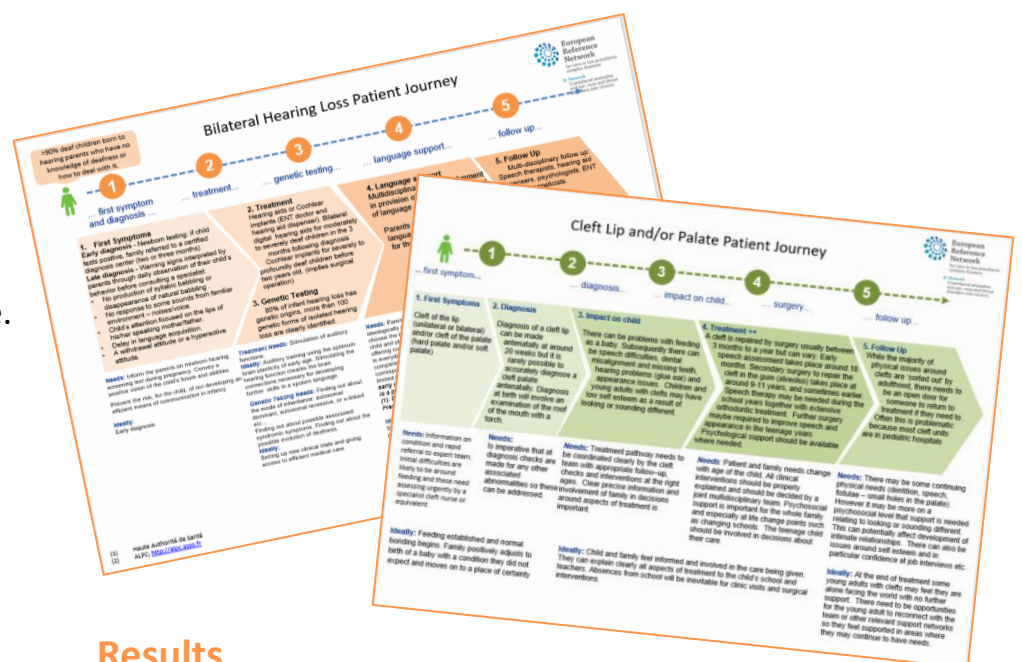
European Reference Network for rare and/or complex craniofacial anomalies and Ear, Nose and Throat (ENT) disorders (ERN CRANIO)

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ERN CRANIO is a network of healthcare providers from across Europe with expertise on rare and/or complex craniofacial anomalies and ENT disorders. The network seeks to pool together disease-specific expertise, knowledge and resources from across Europe to support patients, families and healthcare professionals. This process is supported by patient representatives, who, by engaging with their patient communities can play a key part in guiding and validating network activities. ERN CRANIO patient representatives have engaged with their patient communities to develop 'Patient Journeys'. These are disease-specific visuals which present patient/family 'needs' and 'ideal support scenarios' at key clinical stages.

Methodology

- Experiences of patient representatives are individually mapped using a table template (in stages relevant to the disease they represent). Clinical presentation, patient/family needs and ideal support scenarios are identified at each stage.
- Key points from the table are used to create a 'Patient Journey' visual (see right).
- The completed tables and/or visuals are shared with members of their patient community for feedback and validation.



Stage of Journey	Timeline	Clinical Presentation / Symptoms	Identify Patient Needs	Ideal Outcome / Support
First Symptom				
Diagnosis				
Treatment				
Surgery (?)				
Follow Up				

Model template used in developing the Patient Journeys

Results

- Patient Journeys have been developed for: **Syndromic Craniosynostosis, Bilateral Hearing Loss, Pierre Robin Sequence, Craniofacial Microsomia and Cleft Lip/Palate** and a Patient Journey for **Treacher Collins Syndrome** is underway.
- A common need has been identified across all completed Patient Journeys; **the need for clear, easy to understand, medically-accurate information on clinical diagnosis and/or treatment options.**

Conclusions and next steps

This identified common need for clear and accurate disease-specific information serves to validate ERN CRANIO's focus on the development of clinical guidelines. ("Statements that include recommendations intended to optimise patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options"¹.) It also highlights the importance of ensuring these guidelines are accessible to healthcare professionals, patients and their families.

- A systematic assessment of all common 'needs' and 'ideals' from the Patient Journeys will now be undertaken. Those identified, in addition to diagnosis-specific 'needs'/'ideals', will be used to shape future projects and validate those completed or in development.
- Patient Journeys, based on real-life experiences, will be integrated or presented alongside the clinical recommendations where possible (based on available evidence and/or expert opinion)

¹ Institute of Medicine, 2011. Clinical practice guidelines we can trust; <https://www.ncbi.nlm.nih.gov/books/NBK209546/> (Accessed on April 20, 2020).

