

Current practice in transition of patients with pituitary disease

Fields marked with * are mandatory.



Endo-ERN

European Reference Network
on Rare Endocrine Conditions

Current practice in transition of patients with pituitary disease

This primary survey includes 31 questions and is addressed to Endo-ERN reference centers endorsed for MTG6 pituitary HCPs.

This survey aims to acquire essential data on the care pathway of a patient with pituitary disease with the focus on the process of transition from pediatric to adult care.

The survey will take approx. 10 minutes to complete.

*** First and last name:**

*** Email:**

*** Your Health Care Provider:**

- Aarhus University Hospital
- Aghia Sophia Children's Hospital
- Amsterdam-UMC, location AMC
- Assistance Publique – Consortium Cochin, Robert Debré, Necker, St Antoine, La Pitié Salpêtrière, Trousseau University Hospitals
- Assistance Publique – Hôpitaux de Marseille
- Azienda Ospedaliera di Padova (AOP)
- Azienda Ospedaliera Sant'Orsola Malpighi
- Azienda Ospedaliera Universitaria "Federico II", Napoli
- Azienda Ospedaliero Universitaria Città della Salute e della Scienza di Torino
- Centre Hospitalier Universitaire de Liège
- Charité Universitätsmedizin Berlin
- Cliniques universitaires de Bruxelles – Hôpital Erasme
- Cliniques universitaires Saint-Luc
- Copenhagen University Hospital, Rigshospitalet
- Erasmus MC: University Medical Center Rotterdam
- Hôpital Bicêtre
- Hospital of Lithuanian University of Health Sciences Kauno Klinikos
- Hospital Universitario Cruces
- Hospital Universitari Vall d'Hebron
- IRCCS Ospedale Policlinico San Martino – Genova – Italy
- Istituto Auxologico Italiano – Istituto di Ricovero e Cura a Carattere Scientifico
- Karolinska University Hospital
- Klinikum Wels-Grieskirchen, Center for Pediatric Endocrinology / Dpt. of Pediatrics
- Královské Vinohrady University Hospital in Prague
- Leiden University Medical Center
- Ludwig-Maximilian-University Munich
- Medical University of Vienna, Center for Rare Endocrinologic Diseases / Dpt. of Internal Medicine III
- Oslo University Hospital HF
- Ospedale San Raffaele
- OTHER
- Pauls Stradins Clinical University Hospital
- Radboud University Nijmegen Medical Center – including Amalia's children Hospital
- Semmelweis University
- Tartu University Hospital
- The Cyprus Institute of Neurology and Genetics, Department of Molecular Genetics, Function and Therapy
- UMHAT "Sveta Marina" (Varna)
- University Hospital Essen – Center for Rare Endocrine Diseases
- University Hospital Florence
- University Hospital Martin, Dept of Paediatrics of Jessenius Medical Faculty Comenius University
- University Hospital Motol
- University Hospital Würzburg
- University Medical Center Groningen
- University Medical Centre Ljubljana
- USHATE "ACAD IVAN Penchev"
- UZ Brussels

Part A: General questions

*** 1. Are you a pediatric or an adult health-care professional?**

- Pediatric and adolescent health-care professional
- Adult health-care professional

*** 2. What is the total number of patients with pituitary disease seen per year at your reference center?**

- 0-20
- 20-50
- 50-100
- >100

*** 3. How many of those patients are new/first consultation?**

- 0-20
- 20-40
- 40-60
- More than 60

*** 4. How many of the new patients with pituitary disease in your department are children or adolescents (<18 years old)?**

- 0-25%
- 25-50%
- 50-75%
- 75-100%

Part B : Transition

6. How would you define transition of care?

*** 7. Are pediatric patients with chronic pituitary disease in your reference centre transitioned to an adult-oriented department?**

- Always
- Most of the cases
- Just a few cases never
- Other

*** 9. Do You have experience in the transition in the following conditions? *(multiple answers possible)***

- Cushing disease
- Acromegaly
- Prolactinoma
- NFPA
- Hypopituitarism (congenital/acquired)
- Craniofaringioma
- Other

*** 10. Are the following specialists involved in the care of transition patients? (multiples answers possible)**

- Nurse
- Social Worker
- Psychologist
- Geneticist
- Gynaecologist
- Other

*** 11. Do you discuss and manage patients with pituitary disease in combined meetings (with pediatric and adult health-care professionals being present):**

- Yes
- No

*** 12. Do you have criteria to define the start and end of transition?**

- Yes
- No

*** 13. Based on what is the transition process initiated:**

- Age
- skills knowledge of his/her disease
- wish of the patient
- personal clinical judgement
- disease control
- Other

*** 14. Based on what do you consider the transition process over: (multiples answers possible)**

- Age
- skills knowledge of his/her disease
- specific medical outcomes
- personal clinical judgement
- I have never considered the end of the transition process

*** 15. Who is the treating physician of the patients in transition with pituitary disease in your Reference Center?**

- Pediatric and adolescent Health-care Professionals only
- Adult Health-care Professionals only

- Both Pediatric and Adult HCPs in different consultations
- Both Pediatric and Adult HCPs in combined clinic

* 16. Do you have any methods to evaluate the success of the transition of your patient?

- Yes
- No

* 17. Do you evaluate the knowledge and skills of your patient concerning the transition process? (transition readiness).

- Yes
- No

* 20. In light of the transition process do you consider the communication with your pediatric/adult colleagues good enough

- Yes
- No

* 21. Do you perform any specific action related to the transfer of the patient? (multiples answers possible)

- writing a transfer letter
- writing a health summary
- developing a written transfer plan
- I am not involved in the transfer of the patient
- No specific action
- other

* 23. Do you use printed leaflets/information materials for the patients or their parents?



















- Yes
- No

24. What should be the aim of a structured-transition process from your point of view?

25. Which of the following do You consider necessary to improve the transition process for patients with pituitary disease?

1 = not necessary at all; 2 = not necessary; 3 = neutral; 4 = necessary; 5 = very necessary

Interventions to enhance adherence	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
Interventions to encourage self-management	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>

Interventions to enhance social participation	 
Transition program	 
Structural collaboration between pediatric and adult care	 
Screening for psychosocial problems Interventions to address psychosocial problems	 
Screening for lack of adherence	 
Staff training in adolescent health issues	 
Interventions to encourage contact with fellow patients	 
Change in style of consultations	 
Adolescent-friendly facilities	 

PART C:

* 26. Do you have a specific protocol for transitioning a patient to an adult-dedicated department?

- Yes
- Not yet, the protocol is still under development
- No, we don't have a protocol

* 27. Do You evaluate the effectiveness of the transition process?

- Yes
- No

* 28. Do you use clinical outcomes to describe a successful transition?

- Yes
- No

*** 30. Do you use patient-reported outcome measures (PROMs)?**

- Yes
- No

31. Do You have any suggestions for the improvement of current practices?

*** 32. Would you be interested in participating in studies on the topic of Pituitary Diseases transition or participating in best practice document development?**

- Yes I would like to participate
- No, I am not interested

Contact

rareendoern@lumc.nl