

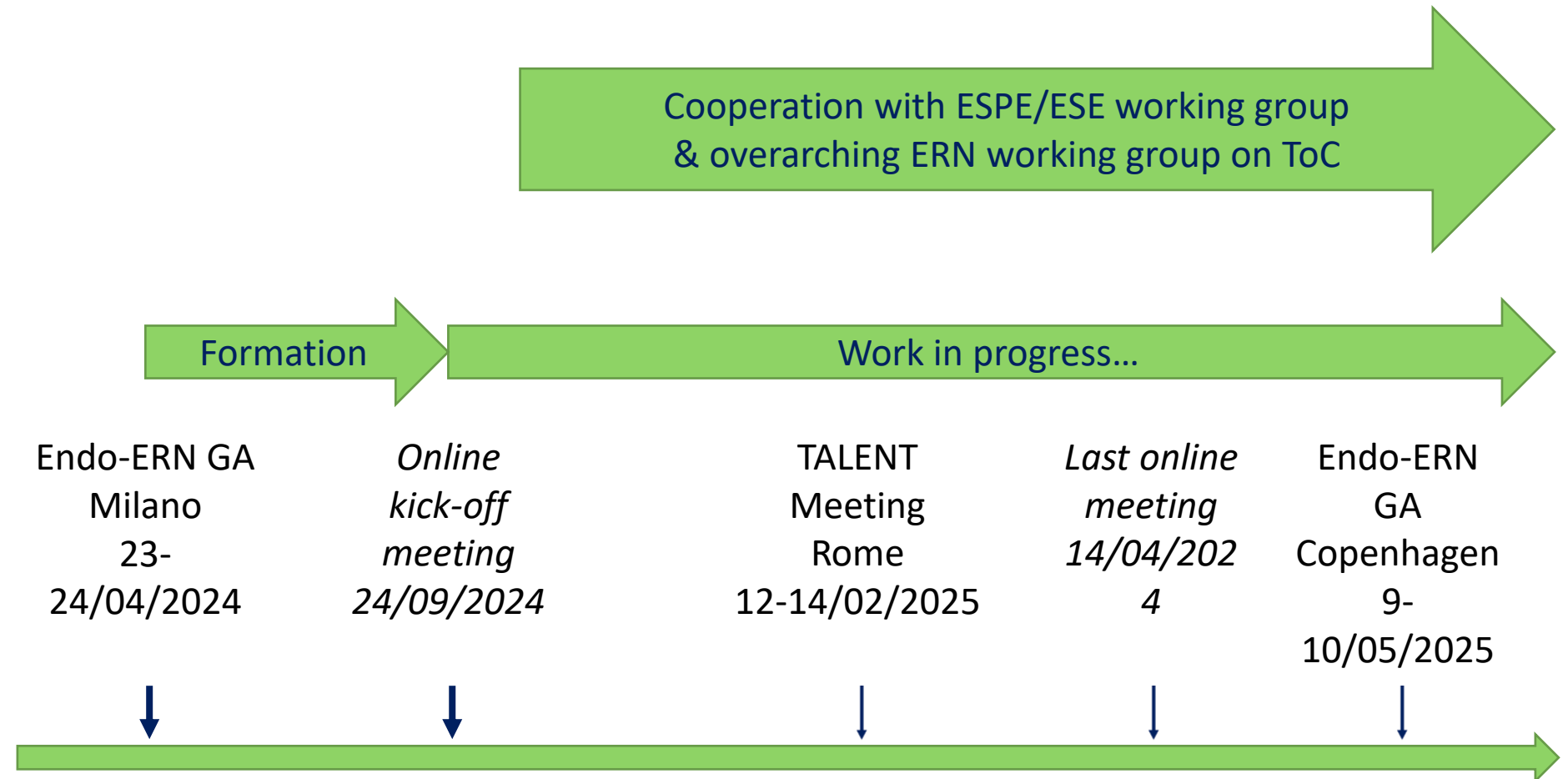
## Working Group on Transition of Care

**Andrea Isidori**, AUO Policlinico Umberto I, Rome, Italy

**Ulla Döhnert**, University Hospital Schleswig-Holstein, Luebeck,  
Germany



## ToC Working Group



## Members

MTG / Role	Representative	Ped/Adu	HCP
Chair	Andrea Isidori	Adu	AOU Policlinico Umberto I, I
Co-chair	Ulla Döhnert	Ped	University Hospital Schleswig-Holstein, D
1/Adrenal	Svetlana Lajic	Ped	Karolinska UH, S
1/Adrenal	Nicole Reisch	Adu	Ludwig-Maximilian-University Munich, D
1/Adrenal	Uta Neumann	Ped	Charité Universitätsmedizin Berlin, D
2/Calcium&Phosphate	Corinna Grasmann	Ped	Katholisches Klinikum Bochum, D
2/Calcium&Phosphate	Eva Kassi	Adu	General Hospital of Athens "LAIKO", GR
2/Calcium&Phosphate	Graziamaria Ubertini	Ped	Children's Hospital Bambino Gesù, I
3/Glucose&Insulin	Felix Reschke	Ped	Hannoversche Kinderheilstalt, D
3/Glucose&Insulin	Pietro Maffei	Adu	AOU Padova, I
4/Genetic tumours	Annemarie Verrijn-Stuart	Ped	UMC Utrecht, NL
5/Growth&Obesity	Susan O'Connell	Ped	Beaumont Hospital & Children's Health, IRL
5/Growth&Obesity	Claudia Giavoli	Ped/Adu	Granda Ospedale Maggiore Policlinico, I
5/Growth&Obesity	Danilo Fintini	Ped	Children's Hospital Bambino Gesù, I
6/Hypothal&Pituitary	Evangelia Charmandari	Ped	Aghia Sophia Children's Hospital, GR
6/Hypothal&Pituitary	Nienke Biermasz	Adu	Leiden UMC, NL
6/Hypothal&Pituitary	Violeta Iotova	Ped	Medical University of Varna, BG
7/DSD	Hedi Claahsen	Ped	Radboud UMC Nijmegen, NL
7/DSD	Kirstine Stochholm	Adu	Aarhus University Hospital, DK
8/Thyroid	Dana Craiu	Ped	Carol Davila University of Medicine, RO
8/Thyroid	Andreea Badea	Ped	Carol Davila University of Medicine, RO
ePAG	Diana Vitali	Ped/Adu	SOL Italia, I

## Aims

- 1. To map current practices** in Endo-ERN centres to facilitate transition from paediatric to adult care
- 2. To collect and review current/ongoing activities** in Endo-ERN aimed at improving transition from paediatric to adult care
- 3. To identify best practice standards** for transition of care for adolescents/young adults with rare endocrine conditions
- 4. To create and promote key resources** to facilitate best practice in transition of care within our network member healthcare providers



# 1. Mapping

## Endo-ERN 'Transition of care' survey for rare endocrine disorders

Dear Participant,

Thank you for taking the time to participate in this survey, developed by the Endo-ERN 'Transition of Care' Working Group.

This survey aims to explore current practices, challenges, and strategies in managing the **transition of care** for patients with **rare endocrine diseases** across different healthcare providers and institutions. The questions address key aspects of evaluation, treatment, follow-up, and multidisciplinary collaboration during the **transition from paediatric to adult care**.

### Survey Details:

Estimated completion time: **15-20 minutes**.

All responses will be treated as **confidential** and will be used exclusively for research purposes within the framework of Endo-ERN.

At the end of the survey, you will also have the opportunity to share **comments or suggestions** to further enhance this research.

If you have any questions or need further clarification, please feel free to contact us at:

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**Thank you for your valuable contribution!**

Endo-ERN Transition of Care Working Group

[START SURVEY NOW](#)

### Setting

Evaluate current clinical setups (e.g., shared outpatient clinics, visit frequency) and standardized transition protocols from paediatrics to adult care.

## 5. Does your centre provide shared outpatient clinics for transitioning patients?\*

Select one answer

a) Yes, a dedicated clinic for chronic endocrine conditions in adolescent and transition age patients (e.g., between the ages of 16 and 24)

b) Yes, either a joint clinic or visits between paediatric and adult units before transfer. The adult physician (or specialised nurse) comes to the paediatric unit, or vice versa

c) No, patients are directly referred to the adult unit at a specific age (e.g., ages 16-18) ✓

d) Other (please specify)

## 6. In case, how many joint visits are conducted before the actual transfer?\*

Select one answer

a) None

b) 1-2 visits ✓

c) 3 or more visits

d) A variable number, depending on the individual patient/condition

## Endo-ERN 'Transition of Care' Survey

- January – March 2025
- 31 items/10 dimensions
- 110 responses from  
19 European countries



## Survey - results

- ✓ Preliminary results were presented at the TALENT meeting

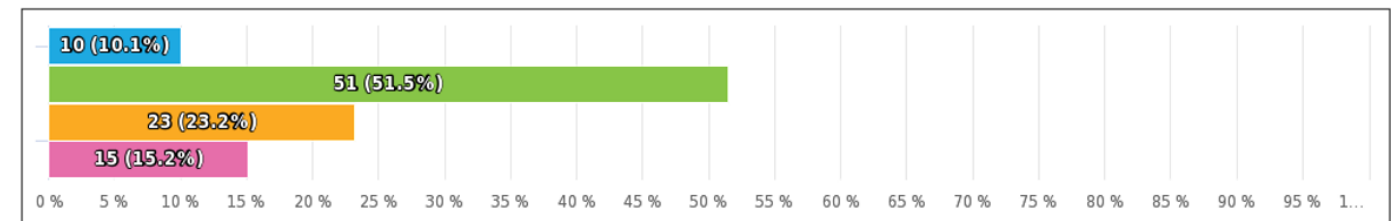
### Setting:

**Does your centre provide shared outpatient clinics for transitioning patients?**

*Preliminary results, data unpublished*

*Single choice, answers 99x, unanswered 1x*

Answer Choices	Responses	Ratio
a) Yes, a dedicated clinic for chronic endocrine conditions in adolescent and transition age patients (e.g., between the ages of 16 and 24)	10	10.1%
b) Yes, either a joint clinic or visits between paediatric and adult units before transfer. The adult physician (or specialised nurse) comes to the paediatric unit, or vice versa	51	51.52%
c) No, patients are directly referred to the adult unit at a specific age (e.g., ages 16-18)	23	23.23%
d) Other (please specify)	15	15.15%



## Survey - results

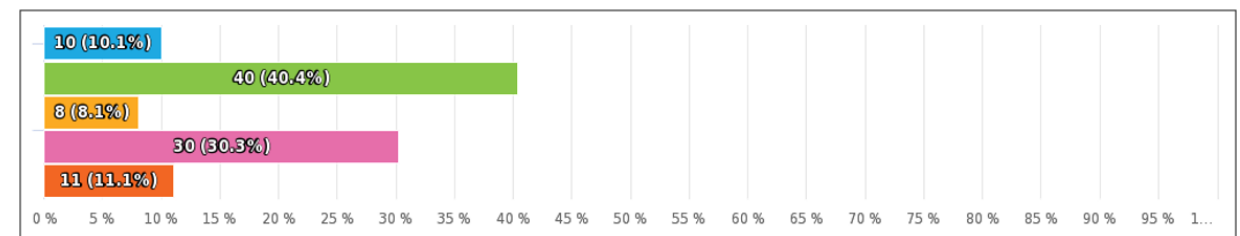
### Psychological support:

*Preliminary  
results, data  
unpublished*

**Are psychologists involved in developing transition plans for patients at your centre?**

*Single choice, answers 99x, unanswered 1x*

Answer Choices	Responses	Ratio
a) Yes, for all patients	10	10.1%
b) Yes, but only for patients with specific psychological needs	40	40.4%
c) Yes, but only for conditions where psychologists have expertise	8	8.08%
d) No, although psychologists are available, they are not involved in transition planning	30	30.3%
e) There is no access to psychologists at my centre	11	11.11%



→ Data analysis and publication in progress



## 2. Definition of minimal standards of care

### Conclusions from the presentations at the TALENT meeting

1. Non-negotiable essentials –  
key elements not to be missed during transition
2. Information transfer –  
what the adult endocrinologist needs to know
3. Crucial monitoring
4. Adolescent-specific considerations
5. Monitoring frequency
6. Success measures/Outcome quality
7. Open issues



### 3. Development of 'checklists' for transition of care

#### Draft for cHH checklist:

**Checklist for Transitioning Patients with Congenital Hypogonadotropic Hypogonadism (cHH)**

*(To be completed by the referring paediatric endocrinologist and shared with the receiving adult endocrinologist)*

**1 Patient Information**

- **Name & Surname:** \_\_\_\_\_
- **Date of Birth:** \_\_\_/\_\_\_/\_\_\_
- **Diagnosis of cHH confirmed at age:** \_\_\_\_\_
- **Presence of cryptorchidism:**  Yes  No
  - If yes, side and treatment: \_\_\_\_\_
- **Olfactory function assessment performed:**  Yes  No
  - If yes, anosmia / hyposmia / normal: \_\_\_\_\_
- **Genetic analysis performed:**  Yes  No
  - If yes, result: \_\_\_\_\_
- **MRI of the CNS performed:**  Yes  No
  - If yes, result: \_\_\_\_\_
- **Bone health assessment performed (DXA, vertebral morphometry):**  Yes  No
  - If yes, result: \_\_\_\_\_
- **Any psychological/psychosocial issues (psychotherapist report available?):**  Yes  No
  - If yes, specify: \_\_\_\_\_

**2 Essential Information for the Adult Endocrinologist**

- **Pubertal induction therapy**
  - Age at initiation: \_\_\_\_\_
  - Regimen: \_\_\_\_\_
  - Duration: \_\_\_\_\_
- **Testosterone (T) / Estrogen-Progestin (EP) replacement therapy**
  - Current formulation: \_\_\_\_\_
  - Dosage & posology: \_\_\_\_\_
- **Semen analysis / cryopreservation performed:**  Yes  No
  - If yes, specify: \_\_\_\_\_
- **Presence of associated pituitary deficiencies:**  Yes  No

- If yes, specify: \_\_\_\_\_
- **Current hormone replacement therapies:** \_\_\_\_\_
- **Reproductive goals discussed with patient:**  Yes  No

**3 Crucial Monitoring Parameters**

- **Sex hormone levels (T/E2), liver function tests, complete blood count:**
  - Last evaluation date: \_\_\_/\_\_\_/\_\_\_
- **Testicular volume monitoring (longitudinal US) / uterine morphometry:**
  - Last evaluation date: \_\_\_/\_\_\_/\_\_\_
- **Bone age monitoring (until near-adult height reached):**
  - Last evaluation date: \_\_\_/\_\_\_/\_\_\_
- **Bone health (DXA scan):**
  - Last evaluation date: \_\_\_/\_\_\_/\_\_\_
- **Semen analysis (during spermatogenesis induction, if applicable):**
  - Last evaluation date: \_\_\_/\_\_\_/\_\_\_

**4 Adolescent-Specific Considerations**

- **Counselling on smoking impact on fertility potential provided:**  Yes  No
- **Concerns regarding body image and mental health addressed:**  Yes  No
- **Age-appropriate sexual health education provided:**  Yes  No
- **Timing of first semen analysis (if applicable) discussed:**  Yes  No

**5. Next Steps & Follow-Up**

- **Date of next appointment with adult endocrinologist scheduled on:** \_\_\_/\_\_\_/\_\_\_
- **Additional specialists currently involved (e.g., urologist, fertility specialist, psychologist, etc.):** \_\_\_\_\_

## Ongoing activities

### ESPE/ESE → Joint guidance of transition



Time (CEST)	Event Title	Category	Views
14:00 - 15:00	CAH: Pros and cons of dexamethasone treatment in...	Debate	33
15:35 - 17:05	Symposium 32: Joint Transition Guidance	Symposium	202
17:10 - 17:40	Plenary 7: The poten...	Plenary	294
17:40 - 18:20	Closing Ceremony, ESPE...		140

### Overarching ERN Working Group

- Exchange on activities in the ERNs
- Workshop in Ghent, 27-28/02/2026

## Next steps...

- ✓ Data analysis and publication of Endo-ERN 'transition of care' survey
- ✓ Identification of minimal standards for:  
transition of care and  
transfer into 'checklists' for  
designated rare endocrine conditions
- ✓ Exchange with ESPE/ESE working group
- ✓ Exchange with overarching ERN working  
group and participation in workshop

Photo: U. Döhnert



# Questions? Questions!



Photo: TALENT Meeting in Rome, February 2025