Endo-ERN General Assembly2025

MTG6 HCP Meeting

Tuesday April 21, 2026
11.05 -11.45 CET

Co-funded by
the European Union

Opening

Agenda

- Guideline on Congenital Hypopituitarism - Charlotte
- Survey Psychosocial consequences of living with a pituitary condition – Johan
- Pituitary Tumour Module studies – Loren
- Prolactinoma Module – Iris

Congenital hypopituitarism

- Collaboration with FIRENDO?
- Patient journey

- Survey on diagnosis and treatment
- What are the most salient topics?

- Results presented at ESE/ESPE 2027

The Psychosocial consequences of living with a pituitary condition

Dutch Pituitary Foundation

Johan P de Graaf

Chair Dutch Pituitary Foundation
ePAG to the ERN on Rare Endocrine Conditions
Member of the Euroridis Board of Directors
Eupati (Europe) Fellow

European Patient Advocacy Group

Affiliated with European Society of Endocrinology

Endo-ERN

European Reference Network

Johan.degraaf@hypofyse.nl

April 21th 2026

Psychosocial consequences of living with a pituitary condition

The reason for a follow up survey:

Survey targeting endocrine patients on unmet needs (2021, 1.378 patients included)*):

- Quality of life and mental health is a theme suggested by pituitary patients
- "Participation in social life" and "ability to work" are considered as most important research topics by patients

Survey unmet need in patients with acquired hypothalamic dysfunction (2023, 353 patients included)):**

- Besides fatigue and obesity, patients reported psychological help as insufficient, with 25.5% indicating to want help from a psychologist (over 15% already received psychological help). From the parent/carer perspective 30% indicated to want help from a psychologist)

*) de Graaf, J.P., de Vries, F., Dirkson, A. *et al.* Patients with rare endocrine conditions have corresponding views on unmet needs in clinical research. *Endocrine* **71**, 561–568 (2021). https://doi.org/10.1007/s12020-021-02618-z

**) van Roessel, I. M. A. A., de Graaf, J. P., Biermasz, N. R., Charmandari, E., & van Santen, H. M. (2023). Acquired hypothalamic dysfunction in childhood: 'what do patients need? ' – an Endo-ERN survey. Endocrine Connections, 12(10), e230147. https://doi.org/10.1530/EC-23-0147

Psychosocial consequences of living with a pituitary condition

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Research questions:

- What are the psychosocial consequences of living with a pituitary condition?

and

- Answers the care available to the patient’s needs and are there differences in the needs of care between the types of pituitary conditions?

Survey on the Psychosocial consequences of living with a Pituitary condition

Research questions:

- **What are the psychosocial consequences of people living with a pituitary condition?**
- **And answers the care available to the patient's needs and are there differences in the needs of care between the types of pituitary conditions?**

You can access the survey at:

https://ec.europa.eu/eusurvey/runner/Psychosocial_consequences

Or use the QR Code:

Thanks for your precious contribution!

The survey is available in: English, Dutch, Arabic, German, Spanish, Italian, Portuguese, Polish, Ukrainian, Bulgarian and Swedish (Slovakian and Greek are being prepared).

Johan de Graaf – April 21th 2026

Setup of the survey

- General patient identifying questions (anonymous)
- Second part based on the LBNQ (Leiden Bothers and Needs Questionnaire)*)
- In cooperation with the Leiden University Medical Centre (Pelsma, Biermasz, Andela) and Endo-ERN
- Sections covered of the psychosocial impact of a pituitary condition:

  Body + mental functions, Sensory functions and pain,
  Internal functions, Activities and participation, Communication,
  Selfcare, Domestic life, Interpersonal interactions and Relationships,
  Community and civic life

*)Andela CD, Scharloo M, Ramondt S, Tiemensma J, Husson O, Llahana S, Pereira AM, Kaptein AA, Kamminga NG, Biermasz NR. The development and validation of the Leiden Bother and Needs Questionnaire for patients with pituitary disease: the LBNQ-Pituitary. Pituitary. 2016 Jun;19(3):293-302. doi: 10.1007/s11102-016-0707-4. PMID: 26809957; PMCID: PMC4858557.

Developing process

- End of October: launch of a survey on the Psychosocial consequences of living with a pituitary condition
- Basic version was developed in English and programmed in EU-Survey and also the first version to be disseminated
- First translations: German and Dutch
- Followed by: Arabic, Bulgarian, French, Greek, Italian, Polish, Portuguese, Spanish, Ukrainian and Swedish
- To be programmed in EU Survey: Danish, and Slovakian, Czech, Estonian, Lithuanian
- Planned: Hungarian, Finnish, Latvian, Lithuanian, Romanian and Slovenian (making the list of Endo-ERN centres complete)
- Translations are machine generated and checked by native speakers from the patient advocacy and HCP network

Psychosocial consequences of living with a pituitary condition

Set-up of the questions:

Qa As a consequence of my pituitary condition I experience …….. Yes/No

if Yes, go to b-part; if No: next question

Qb Do you receive professional support from HCPs for this problem Yes/No

if Yes: What kind of help did you receive and go to c-part, if No: next question

Qc Is the extend of the current professional sufficient Yes/No

if Yes: next question, if No: what do you want to receive?

Psychosocial consequences of living with a pituitary condition

First reactions (via survey contact form or social media):

- “Oh my god, I feel like crying after reading your survey. In Finland, none of these symptoms are considered that they might be due to a pituitary tumour. I am soon in a position that I will have to leave my permanent work position because I’m not able to work. I have been using my holiday days to shorten work week to survive the symptoms. In paper, we do have Rehabilitation subsidy and disability pension but You cannot get it with pit tumour diagnosis (even macro sized). Thank you for your work!” (Finland, female, 46, non-functioning pituitary adenoma)

- “It’s a really interesting survey. Through the questions, you realize the many consequences of our conditions. Some of them I didn’t even know were due to the illness.“ (France, female)

- “Very interesting survey, it helps me better understand certain things about the way I am.” (France, female)

Psychosocial consequences of living with a pituitary condition

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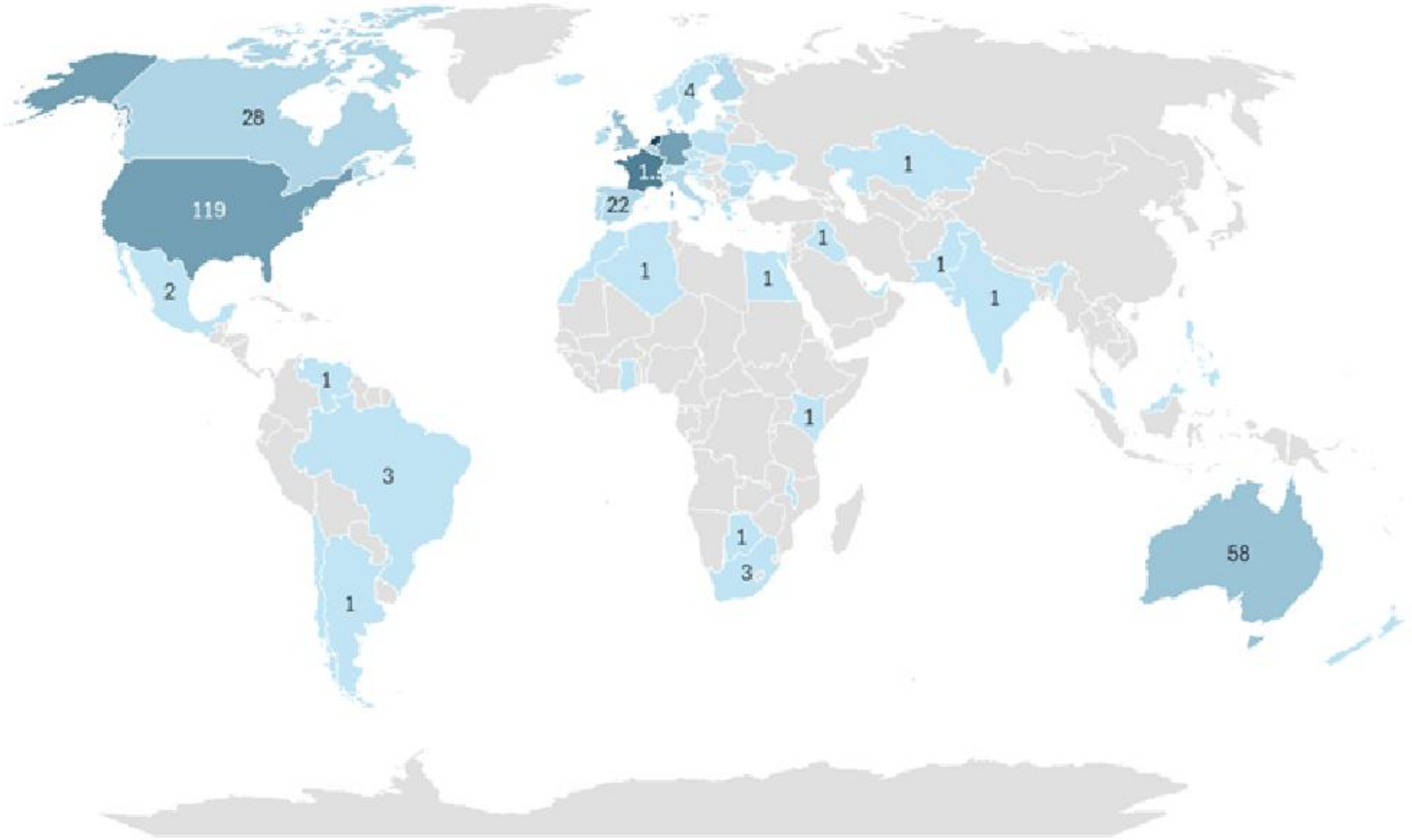
Until April 18th: 1.058 reactions

- Benefit of a network
- Dissemination through National and international Organisations and Endo-ERN
- Strong relations with other pituitary organisations is evident (Germany, Netherlands, US and Australia)
- Infrastructure of patient organisations is important, not only on a world scale, but also for Europe!



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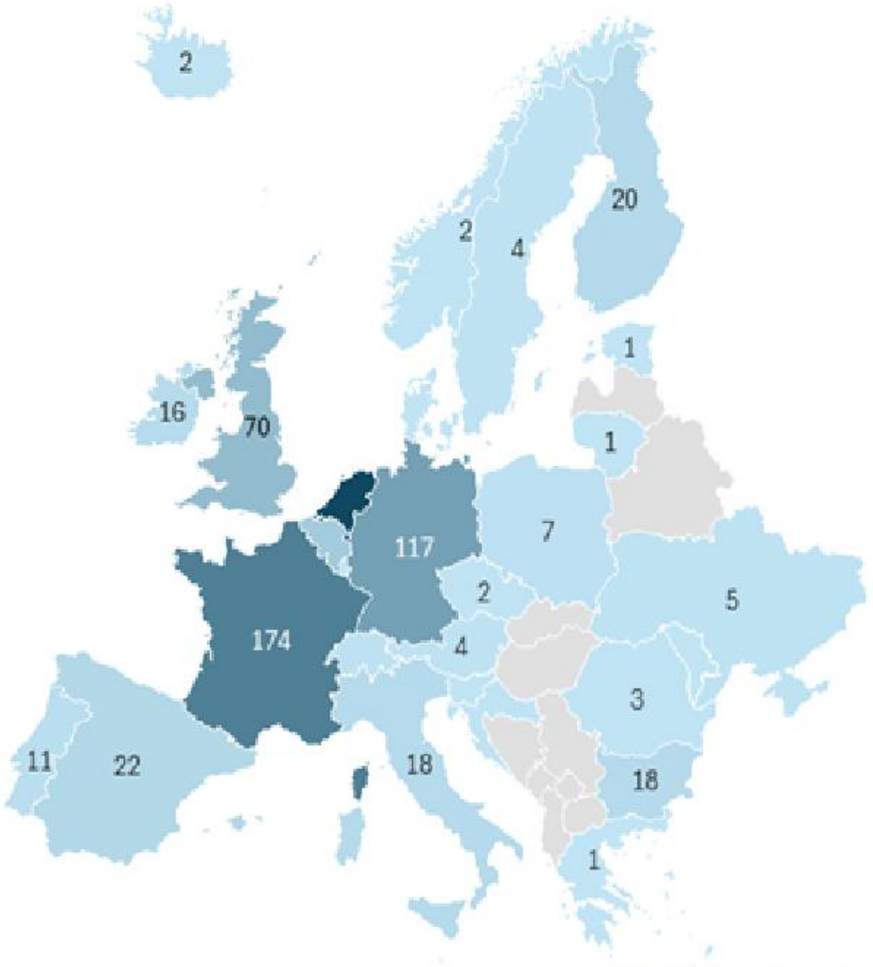
Psychosocial consequences of living with a pituitary condition

Europe

- Germany, the UK and the Netherlands: large PAOs
- Finland is a positive exception! (no Finnish version available, possible social media effect)
- France made a strong recovery after ENEA Marseille
- Still in the process of collecting data; not all languages are ready for dissemination
- Survey will be open until further notice



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Psychosocial consequences of living with a pituitary condition

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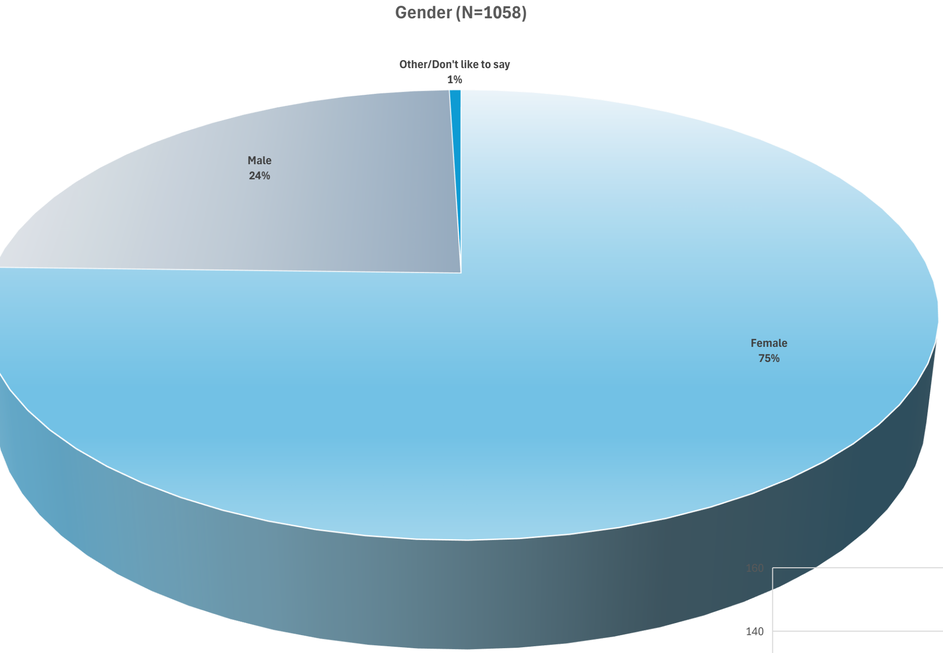
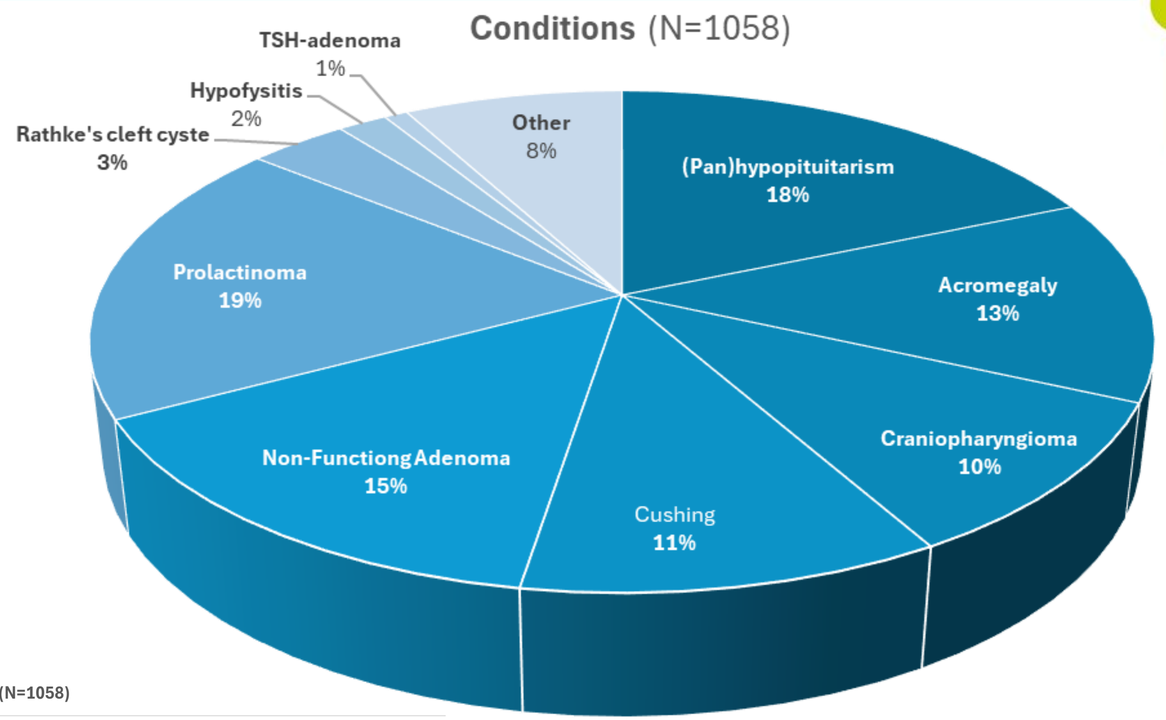
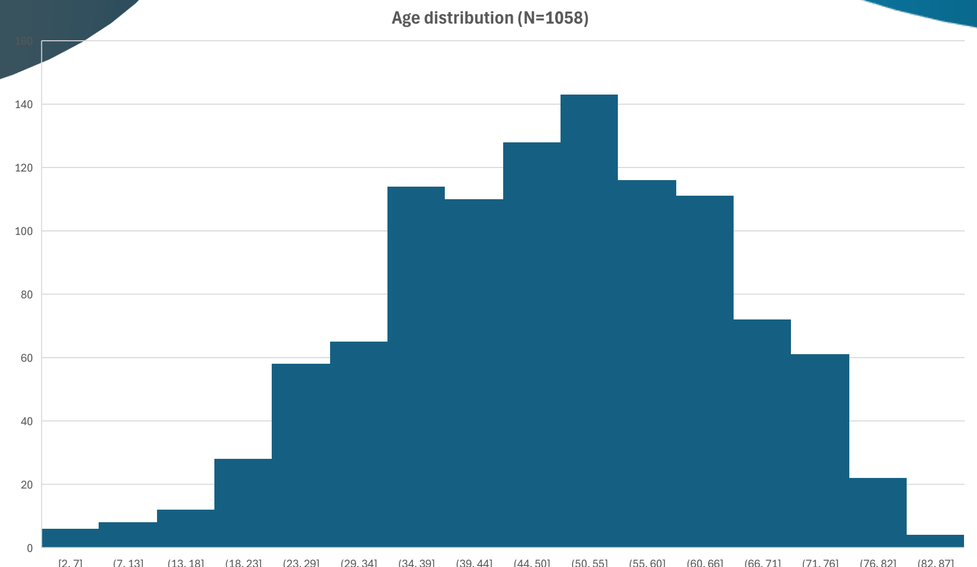
First findings







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Psychosocial consequences of living with a pituitary condition

Some examples (I):

As a consequence of my pituitary condition, I experience:

Sleeping problems:	62 %
Fatigue:	88 %
Difficulty with the fact I gained weight:	63 %

Psychosocial consequences of living with a pituitary condition

Some examples (II):

As a consequence of my pituitary condition, I experience:

Mood swings	62 %
Being sensitive to stressful situations	69 %
Problems in relations with friends	88 %
My circle of friends has become smaller	51 %
Difficulties performing work	59 %

Next steps

- Would like to collect more data from underrepresent countries!
- Further analysis of the data is necessary
- But: preliminary data already shows that there is an unmet need in several domains:
    - Diagnostic delay
    - Body and mental functions
    - Activities and participation
    - Social interactions

- **These domains all contribute to the quality of life of patients with a pituitary condition and further research is much needed!**

Questions

Johan de Graaf – April 21th 2026

Data reporting journey of new cases of pituitary adenomas and craniopharyngiomas within the European Reference Network of Rare Endocrine Conditions and the Registries for Rare Endocrine and Bone Conditions

Endo-ERN GA 2026
MTG-6 Meeting

EuRREB
European Registries for Rare
Endocrine and Bone conditions

Endo-ERN
European Reference Network
on Rare Endocrine Conditions

Amsterdam UMC

Co-funded by
the European Union

Background

- e-REC (the electronic Reporting Programme)
  - Monthly registration of new encounters of patients with rare endocrine conditions

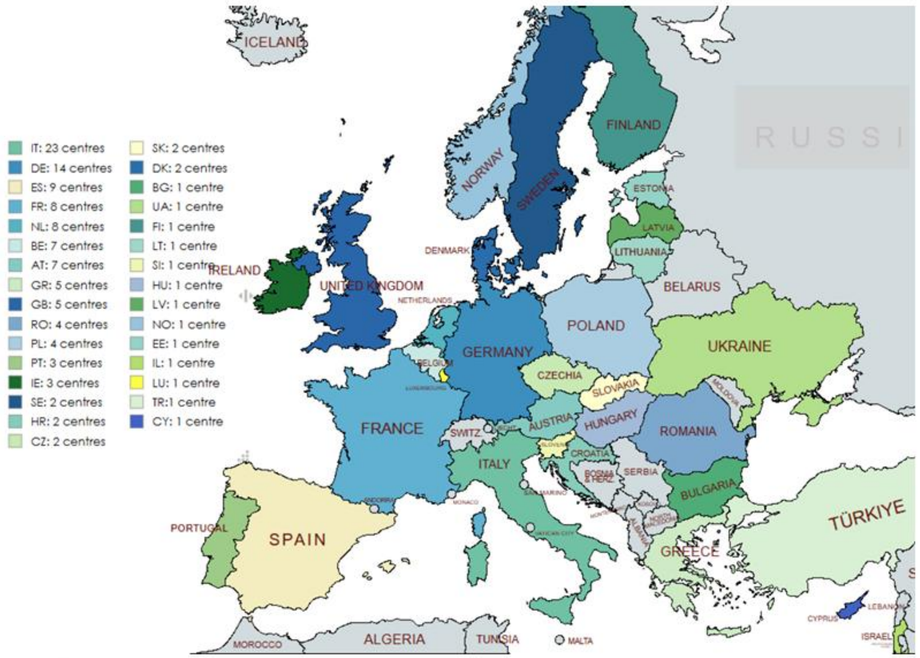

Fig. 1 – Number of centres in each country that are active (i.e. have submitted one or more returns between July 2018 and December 2025)

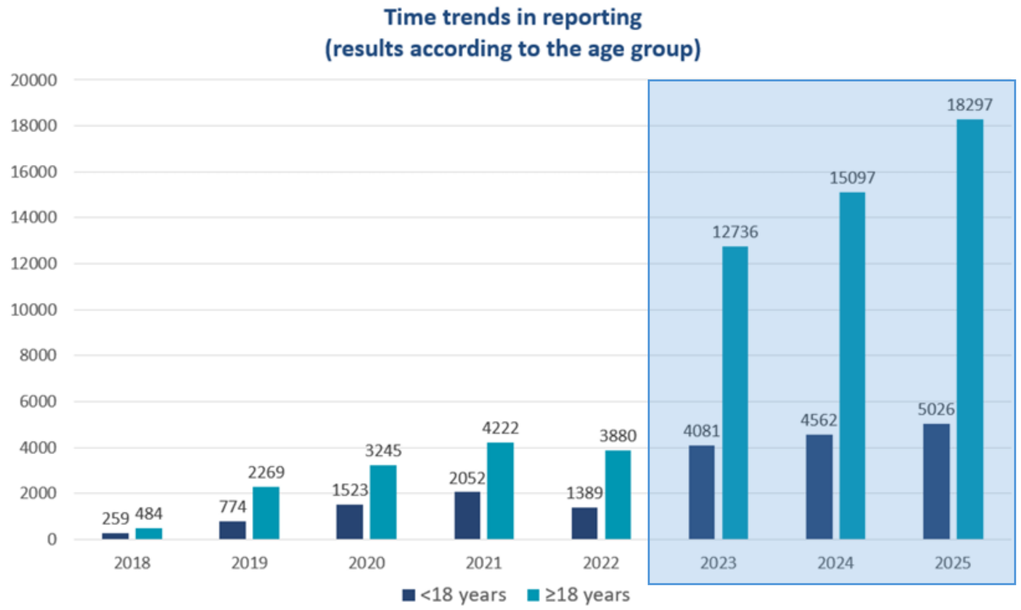

Fig. 2 – The trends in cases reported between July 2018 and December 2025

Cherenko, M., J. van der Blom-de Gunst, A. Priego Zurita, et al. *European Registries for Rare Endocrine and Bone Conditions (EuRREB): e-REC Annual Activity Report March 2026*. 2026; Available from: https://eurreb.eu/reports/.

Aim

"To assess the Data Reporting Journey of reported cases of pituitary adenoma and craniopharyngioma (MTG6) within e-REC and provide recommendations to improve this process."

- Recommendations for improvement of e-REC reporting process
  - Insights into current real-world practice reflecting the needs of Endo-ERN and HCPs
  - Improving system functionality
  - Improving accuracy of reported numbers

Methods

- Mixed methods observational study
  - Analysis of e-REC of a 3 year period (2023-2025)
    - Pituitary adenoma and craniopharyngioma
  - Cross-sectional exploratory survey among e-REC reporters

- Frequent vs non-frequent reporters
  - ≥ 10 months / year

Methods

Survey

- Online cross-sectional exploratory survey of 25 questions
- Both open questions and multiple choice questions
- Aimed to collect data on seperate stages of the reporting process and barriers and motivators for reporting in e-REC

- Sent to e-REC reporters of pituitary adenoma and craniopharyngioma in 2024

Data analysis

- Thematic analysis[1]
  - Free questions within the survey on motivations and barriers to report frequently

- Statistical analysis
  - Categorical data: descriptive statistics (n/N (%))
  - Non-normally distributed data: median [IQR; Q1-Q3]
  - Comparisons between groups: Chi-square test and Mann-Whitney U test
  - A p-value of <0.05 was considered statistically significant.

1. Braun, V. and V. Clarke, *Supporting best practice in reflexive thematic analysis reporting in Palliative Medicine: A review of published research and introduction to the Reflexive Thematic Analysis Reporting Guidelines (RTARG).* Palliat Med, 2024. **38**(6): p. 608–616.

Results – Reporting Centres and Cases

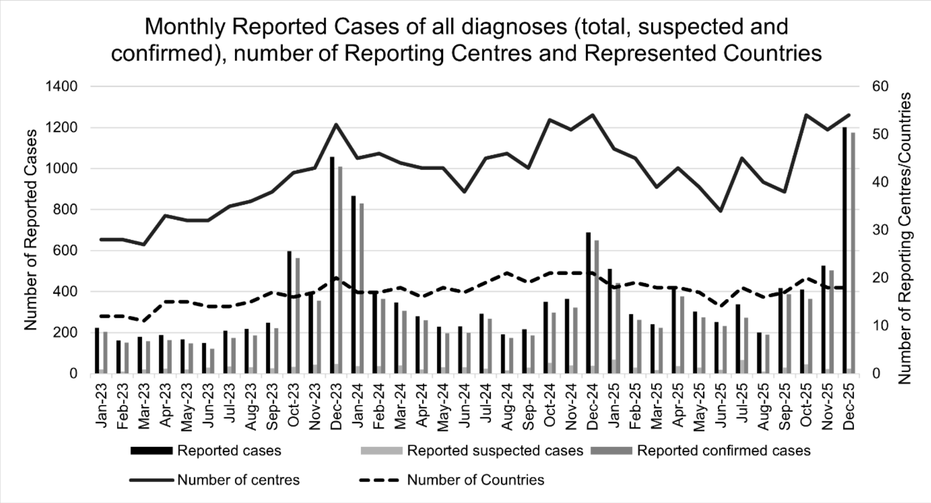

Figure 1. e-REC activity 2023-2025 of the included conditions of MTG6

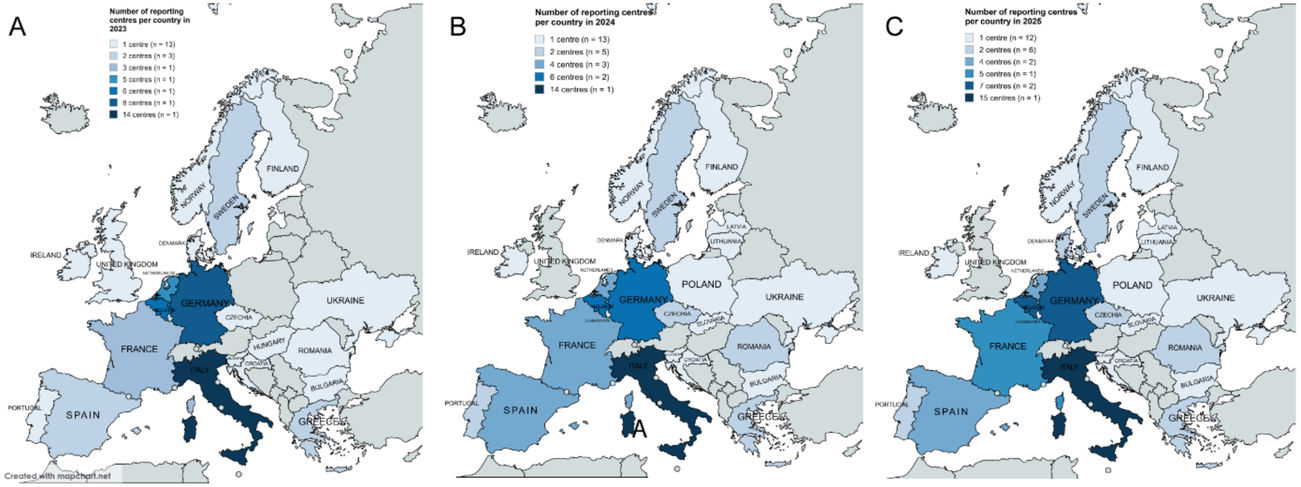

Figure 2. Number of reporting centres per represented country in (A) 2023, (B) 2024, and (C) 2025

Total 2023-2025

- ✓ 73 centres from 26 countries
  - ✓ 55 Endo-ERN RCs endorsed for MTG 6
  - ✓ 15 Endo-ERN RC not explicitely endorsed for MTG-6
  - ✓ 3 Non-Endo-ERN RC

2023: 55 centres (21 countries)

2024: 61 centres (24 countries)

2025: 66 centres (24 countries)

Van der Hoeven et al. Unpublished Data

Results – Reported cases

	2023 (centres: n = 55)	2024 (centres: n = 61)	2025 (centres: n = 66)
Total (All conditions combined)	3799	4456	5108
NFPA (ORPHA: 91349)	757	1043	1372
Acromegaly (ORPHA:963)	336	468	424
Cushing's disease (ORPHA:96253)	248	260	531
Prolactinoma (ORPHA:2965)	645	876	976
Pituitary adenoma (ORPHA:99408)	1672	1617	1617
Craniopharyngioma (ORPHA:54595)	141	192	188

Table 1. Reported cases in e-REC of pituitary adenoma and craniopharyngioma in 2023, 2024 and 2025.

Van der Hoeven et al. Unpublished Data

Results – Survey Responders

- ✓ 35 centres
  - ✓ Frequent reporters (≥ 10 months/year): n = 22
  - ✓ Non-frequent reporters: n = 13

- ✓ Both children and adults: 21 (60%)
- ✓ Only children: 9 (26%)
- ✓ Only adults: 4 (11%)

Van der Hoeven et al. Unpublished Data

Results – eREC Data Reporting Journey

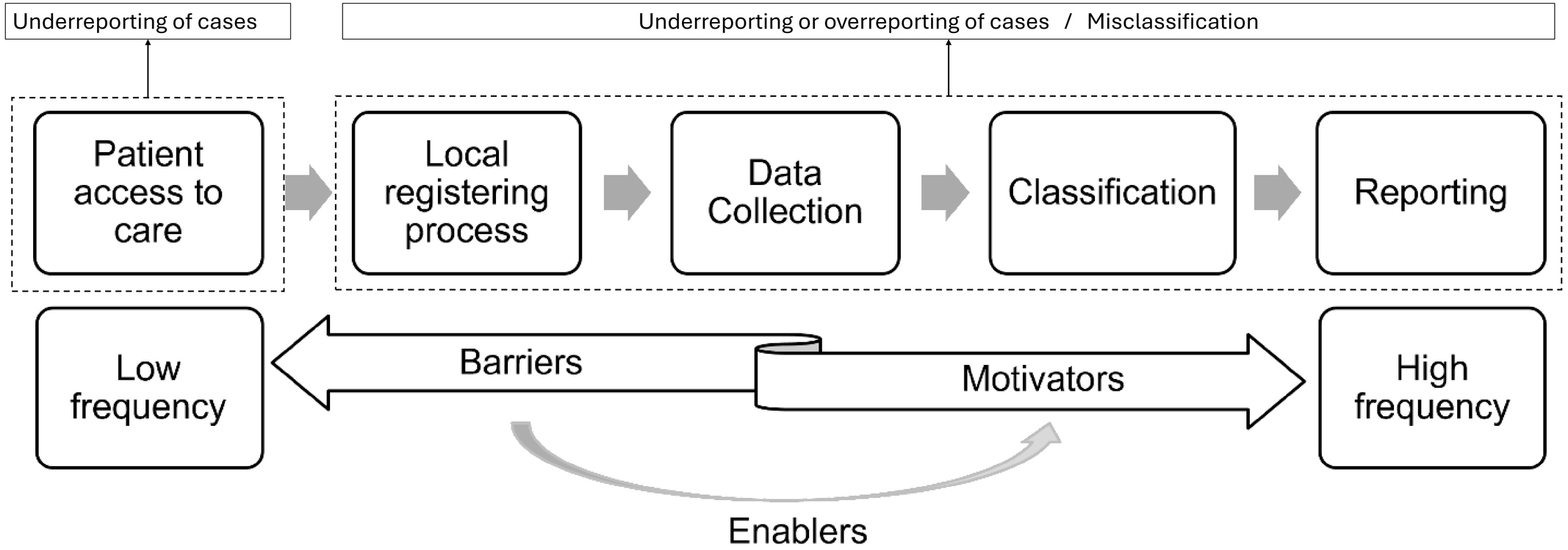

Figure 3. The stages of the e-REC Data reporting journey

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Results – Stage 1: Patient access to care

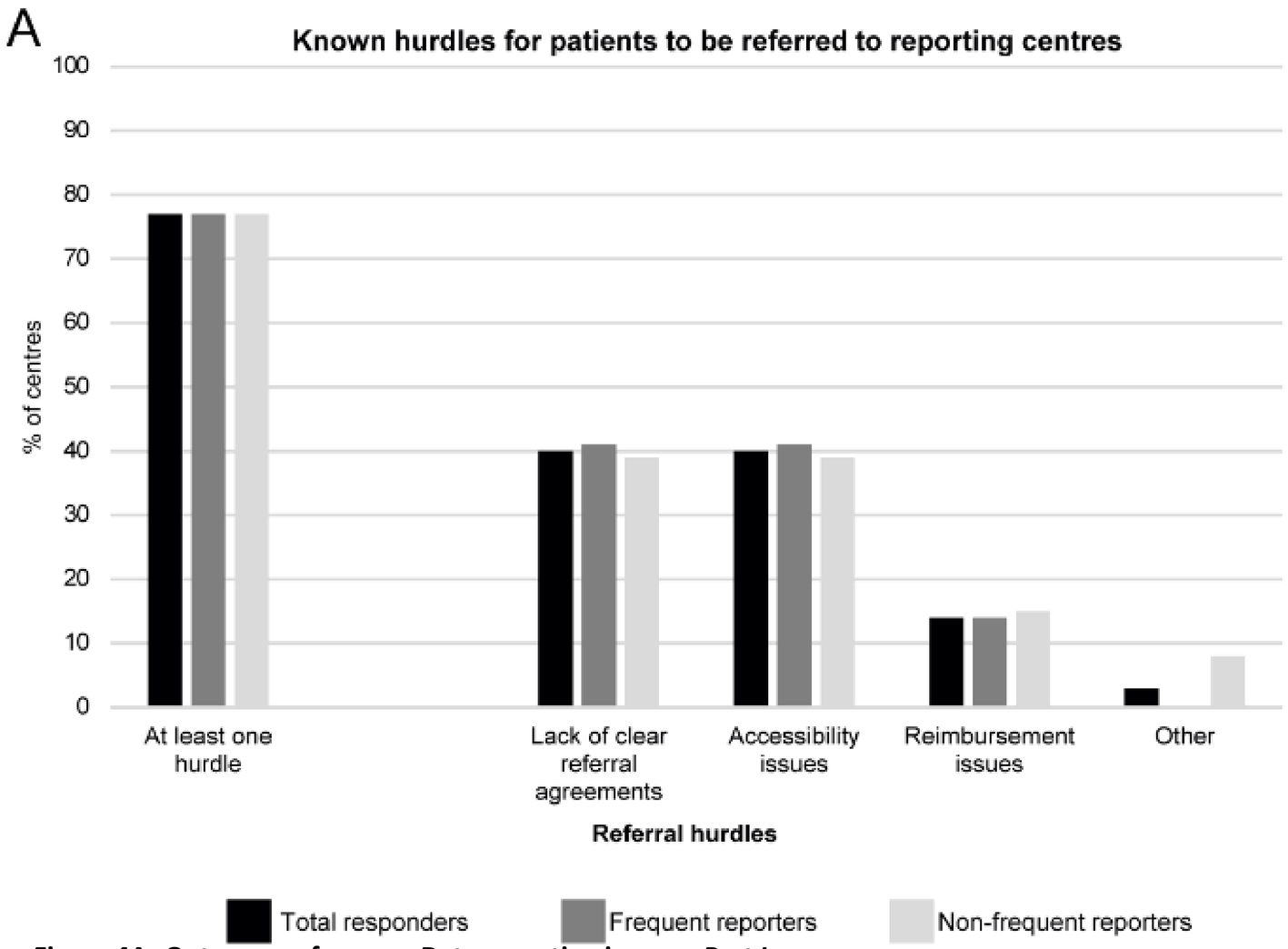


Figure 4A. Outcomes of survey: Data reporting journey Part I

Van der Hoeven et al. Unpublished Data

Results – Stage 2: Local registering process

Table 3. Outcomes of survey: data reporting journey part II

	Total responders n = 35
Patient files	
Electronic patient files	24/35 (69)
Paper patient files	2/35 (6)
Combination of electronic and patient files	9/35 (26)

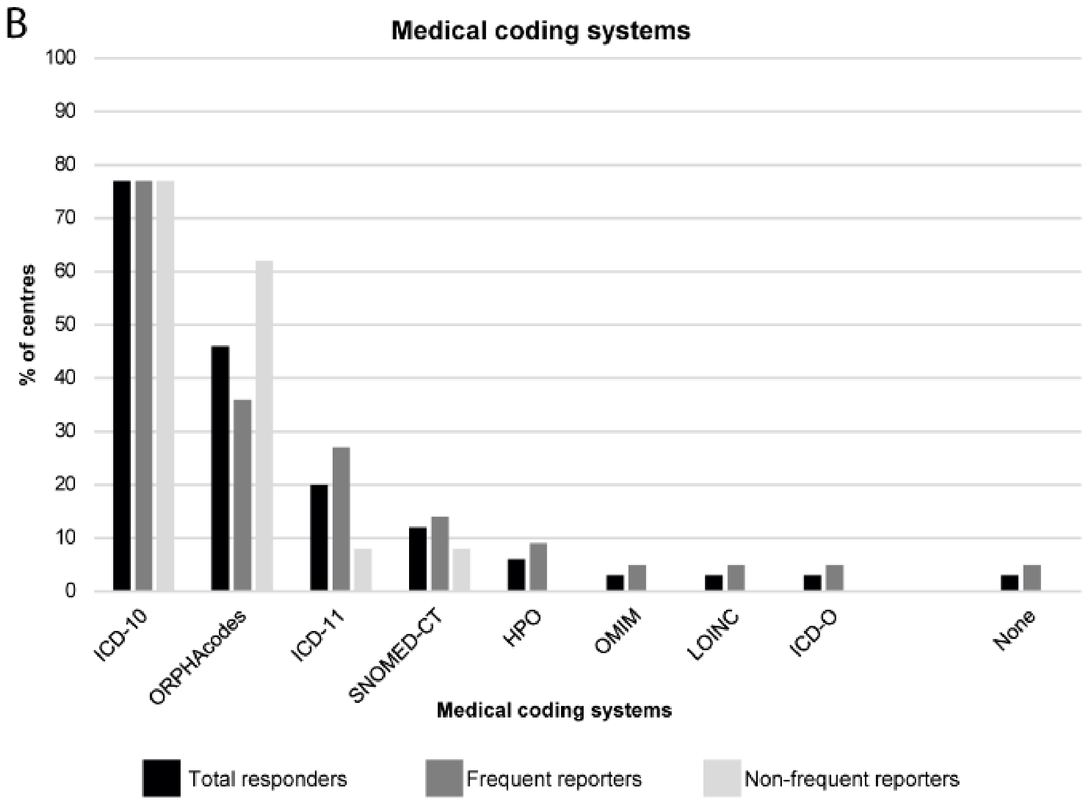


Figure 4B. Outcomes of survey: Data reporting journey Part I

Van der Hoeven et al. Unpublished Data

Results – Stage 3: e-REC Data collection

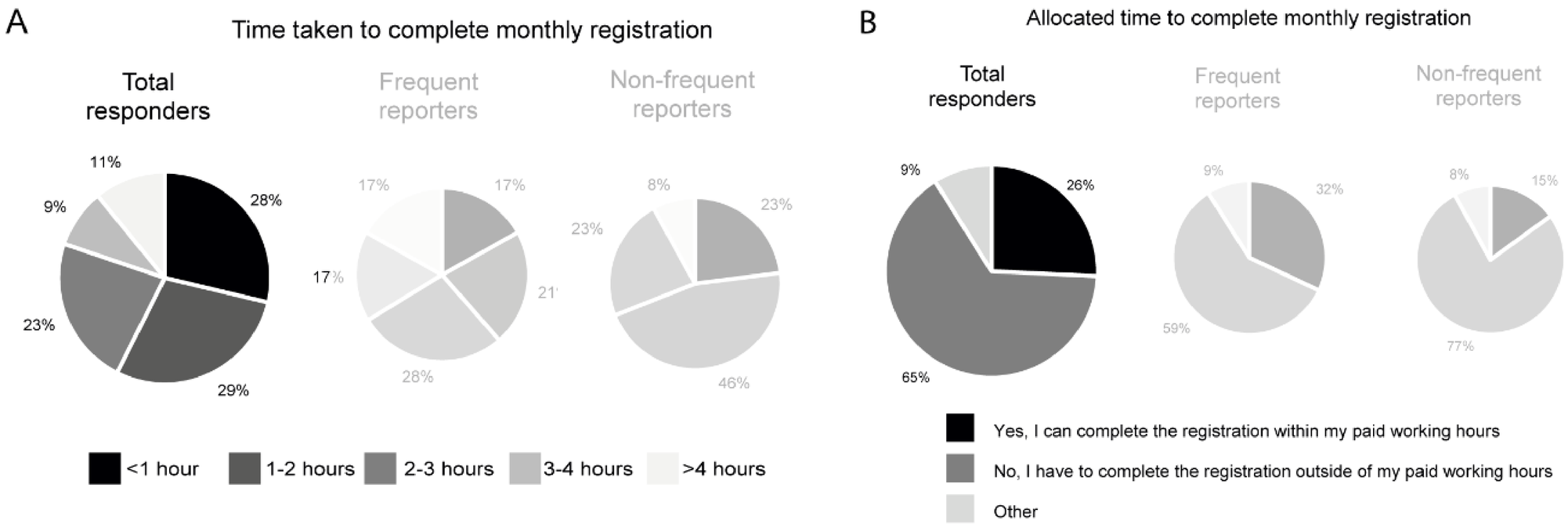


Figure 5. Outcomes of survey: Data reporting journey Part III. (A) Time taken to complete monthly registration. (B) Allocated time to complete monthly registration.

Van der Hoeven et al. Unpublished Data

Results – Stage 4: Classification

2018 - 2022

- Acquired Hypopituitarism
- Congenital Hypopituitarism
- Pituitary Adenoma

2023 onwards

- Acquired Hypopituitarism
- Congenital Hypopituitarism
- Pituitary Adenoma
  - Non-functioning Pituitary Adenoma
  - Acromegaly
  - Cushing’s disease
  - Prolactinoma
- Craniopharyngioma

437 cases of Pituitary Adenoma

NFPAs:	122
Acromegaly:	48
Prolactinoma:	45
Pituitary Adenoma:	45
Cushing's disease:	35
RCC:	2
Craniopharyngioma:	1
Double registrations:	89

Results – Stage 5: Reporting

✓ Only once centre reported to experience (technical) issues during the registration process

Results – Frequent reporting: Motivators

"What motivates you and your centre, or what prevents you and your centre from reporting frequently (≥10 months / year)?"

Theme	Category*	Key quotes
Motivators	*Endo-ERN Membership*	*[…] we have to provide frequent [recent] updates and ensure data accuracy at all times but the overall impact is beneficial for internal management and compliance.* *It imposes the need to report new cases and maintain a local register.*
	Awareness of local situation in centre	*...also it is useful to systematically collect all the new consultation patients visited in our centre, otherwise, probably we would not collect this data systematically and periodically.*
	International collaboration opportunities	*gain opportunities to join international research projects* *Ability contribute to international statistics*
	Eventual care quality improvement	*… the [prospect] of networking to improve patient care.* *….will serve as a benchmark for us in the future…*
	Intrinsic motivation for research	*importance of keeping international registries for rare disorders* *to measure our expertise in this field,*

Results – Frequent reporting: Barriers

"What motivates you and your centre, or what prevents you and your centre from reporting frequently (≥10 months / year)?"

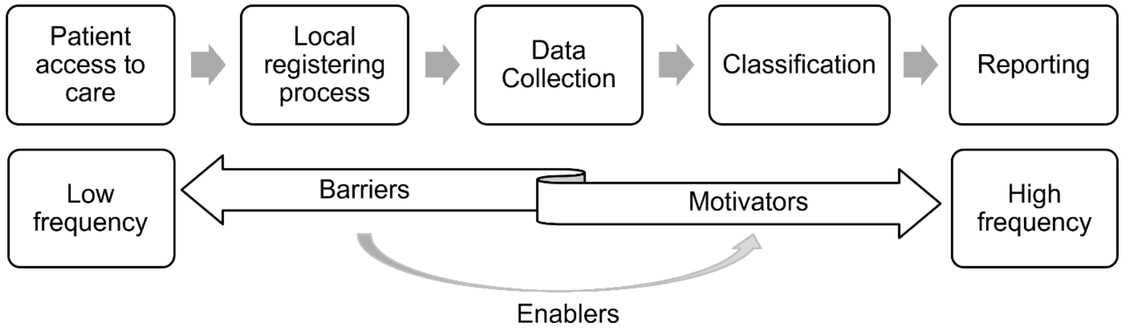
Theme	Category*	Key quotes
Barriers	*Lack of time*	*Double registration in local and ERN registries is not meaningful and time consuming* *Lack of time*
	Lack of local work support	*Lack of institutional support, protected time, infrastructure* *Double registration in local and ERN registries is not meaningful and time consuming*
	Conflicting demands/priorities	*The existence of the national rare diseases database to be completed and lack of time* *During periods of time pressure this is however not my priority as I know I can [fulfil] the data later on.*

Results – Frequent reporting: Enablers

"*What motivates you and your centre, or what prevents you and your centre from reporting frequently (≥10 months / year)?*"

Theme	Category*	Key quotes
Enablers	*Having dedicated reporter*	*A dedicated clinician/[researcher] has been appointed to register.*

Recommendations to enhance the completeness of reported cases



R. #1. Dedicated administrative support

Stages: Local Registering Process, e-REC Data Collection, Data Classification & Reporting

Stakeholders: Participating centers, national health government

R. #2. Alignment between ORPHAcodes and other medical coding systems

Stages: e-REC Data Collection & e-REC Data Classification

Stakeholders: European Commission, Endo-ERN, EuRREB, participating centers

R. #3. Clear definitions on requested data

Stages: e-REC Data Classification

Stakeholders: EuRREB

R. #4. Enhance awareness of updates and changes

Stages: e-REC Data Collection & e-REC Data classification

Stakeholders: EuRREB, Endo-ERN, Participating centres

Conclusion

- ✓ Increase in active use of e-REC
- ✓ Motivation to report monthly was not solely based on Endo-ERN membership
- ✓ Raising awareness of the local situation
- ✓ Better scope international collaboration opportunities
- ✓ Eventual care quality improvement
- ✓ Intrinsic motivation for research

Each stage of the Data Reporting Journey is subject to hurdles in the current real-world practice

These hurdles, together with the identified barriers to report frequently are starting points to further improve the Data Reporting Journey.

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Data Reporting Journey Study Group

Data Reporting Journey Study Group:

Andrea Isidori - Sapienza University of Rome, Anna Aulinas - Hospital de la Santa Creu i Sant Pau – Health Management Foundation, Benedetta Fibbi - University Hospital Florence, Careggi, Betina Biagetti - Vall d'Hebron University Hospital, Carlien de Herdt - Antwerp University Hospital, Charlotte Höybye - Karolinska University Hospital, Charlotte Verroken - Ghent University Hospital, Chiara Grasselli - Local Health Authority – IRCCS of Reggio Emilia, Christina Kanaka-Gantenbein - Aghia Sophia children's hospital Athens, Corin Badiu - C.I.Parhon National Institute of Endocrinology, Federico Gatto - IRCCS San Martino University Hospital – Genoa (IT5), Filippo Ceccato - University Hospital of Padua (AOP), France Devuyst - Cliniques Universitaires de Bruxelles – Hopital Erasme, Georgia Ntali - Evangelismos Hospital- Department of Endocrinology, Diabetes and Metabolism, National Expertise Center for Rare Endocrine Disorders, Gerald Raverot - Hospices Civils de Lyon, Gerhard Binder - University Hospital Tuebingen, Giovanna Mantovani - Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Milan and Department of Clinical Sciences and Community Health, Dipartimento di Eccellenza 2023-2027, University of Milan, Milan (Italy), Haifa Rahabi - Assistance Publique – Hopitaux de Marseille, Heck Ansgar - Oslo University Hospital HF, Heini Kanervo - UZ Brussels, Henrik Christesen - Odense University Hospital, Maria João Bugalho - Lisbon North University Hospital Centre, Mario Detomas - University Hospital Würzburg, Mark Sherlock - Beaumont Hospital, Monika Obara-Moszynska - Karol Jonscher's Clinical Hospital of Poznan University of Medical Sciences, Renata S. Auriemma - "Federico II" University Hospital, Naples, Ruta Navardauskaite - Hospital of Lithuanian University of Health Sciences Kauno klinikos, Salvatore Cannavò - University Hospital Policlinico G. Martino, Messina, Savi Shishkov - MHAT "Sveta Marina", Silvia Grottoli - "Città della Salute e della Scienza" University Hospital of Turin, Susan M O'Connell - Children's Health Ireland, Tristan Verdelet - Hôpital Bicêtre, Václav Hána - Všeobecná fakultní nemocnice, Wemke Zeijlmaker - University Medical Center Groningen.

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The Prolactinoma Module

The creation of a rare disease specific registry

April 21, 2026

Iris Pelsma

Leiden University Medical Center

EuRREB
European Registries for Rare
Endocrine and Bone conditions

Why are we doing this project?

- **No validated outcome sets available for pituitary adenoma/prolactinoma**

- **Experience with local / national registries :**
  - Quality registry neurosurgery and nationally developed outcome set
  - Value-based health care pathway for pituitary surgery with comprehensive outcome measurements
  - Dutch National Prolactinoma trials with comprehensive outcome measurements
    - Landscape of treatment and outcomes in NL
    - Trial Medical vs Surgical Treatment

- **Opportunities thanks to Endo-ERN/EuRREB:**
  - Existing EuRREB registry platform
  - Support for development and building registries (e.g., ERDERA)
  - Collaborative network

- **In line with international community statements (Pituitary Society):**
  - Attention for prolactinoma; consensus statement
  - Pituitary Tumor Center of Excellence project

Collaborators in the creation of the module

MTG 6 chairs & reference centers

European Reference Network Endo-ERN

Rare Endocrine Conditions About Us

/ Reference Centres

Reference Centres

Authors of Consensus Statement

nature reviews endocrinology https://doi.org/10.1038/s41574-023-00886-5

Consensus statement Check for updates

Diagnosis and management of prolactin-secreting pituitary adenomas: a Pituitary Society international Consensus Statement

A list of authors and their affiliations appears at the end of the paper

Abstract

This Consensus Statement from an international, multidisciplinary

Sections

Introduction

Suggested partners / experts by these experts


NASA

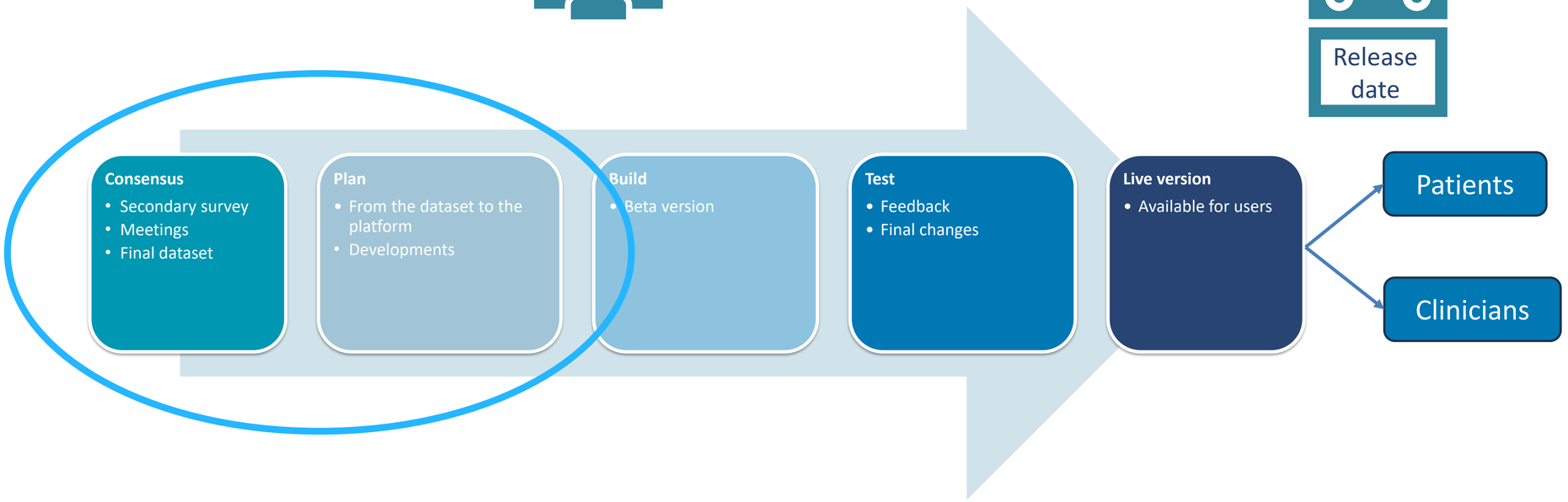
What are aiming to achieve?

- **Development of a multipurpose outcome set together with international multidisciplinary experts**

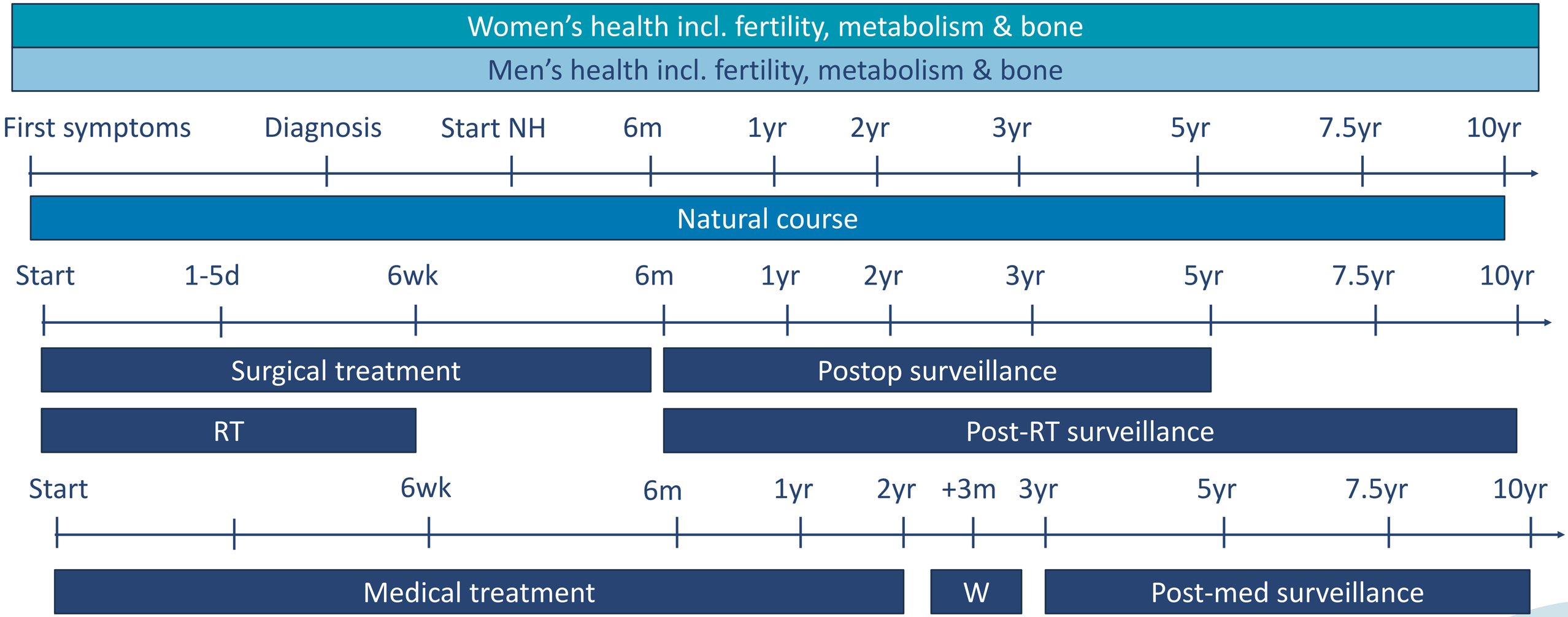
- Plan with outcome set:
  - EuRREB module on prolactinoma
  - Publication of outcome set to facilitate future regional and international databases

Development process of the Prolactinoma Module

Working group



Most recent proposal of the time points of the Module



Subgroups – all topic groups and their leads

2

Case mix
Variables at diagnosis
Variables at inclusion

Group lead(s):
Salvatori

1

Prolactin
How to assess?
How to classify?

Group lead(s):
Salvatori, Maiter

2

Timepoints
When to assess outcomes?

Group lead(s):
Coordination

2

Prioritization

Group lead(s):
Gadelha, vd Klauw

1

Medical treatment

Group lead(s):
Gatto, Raverot, Shimon. Molitch, Ioachmimescu

1

Surgery

Group lead(s):
Marcus, Raverot, Verstegen

2

Radiotherapy

Group lead(s):
Haberbosch, Hoybye, Petersenn

1

Natural history

Group lead(s):
Coordination

2

QoL

Group lead(s):
Vd Klauw, Jorgensen

1

Sex steroids

Group lead(s):
Vd Klauw, Gatto, Shimon, Maiter

2

Histopathology and genetics

Group lead(s):
Gadelha, Iotova, Raverot, Alexandraki

2

Pediatric

Group lead(s):
Iotova

1

Metabolic & bone

Group lead(s):
Feola, Samson

2

Headache

Group lead(s):
Honegger

1 = discussed during Sep 29

2 = discussed during Nov 17

How to develop the prolactinoma module?

- Multiple rounds of voting, optional surveys

- **SURVEY 1**

  Two questions already planned:

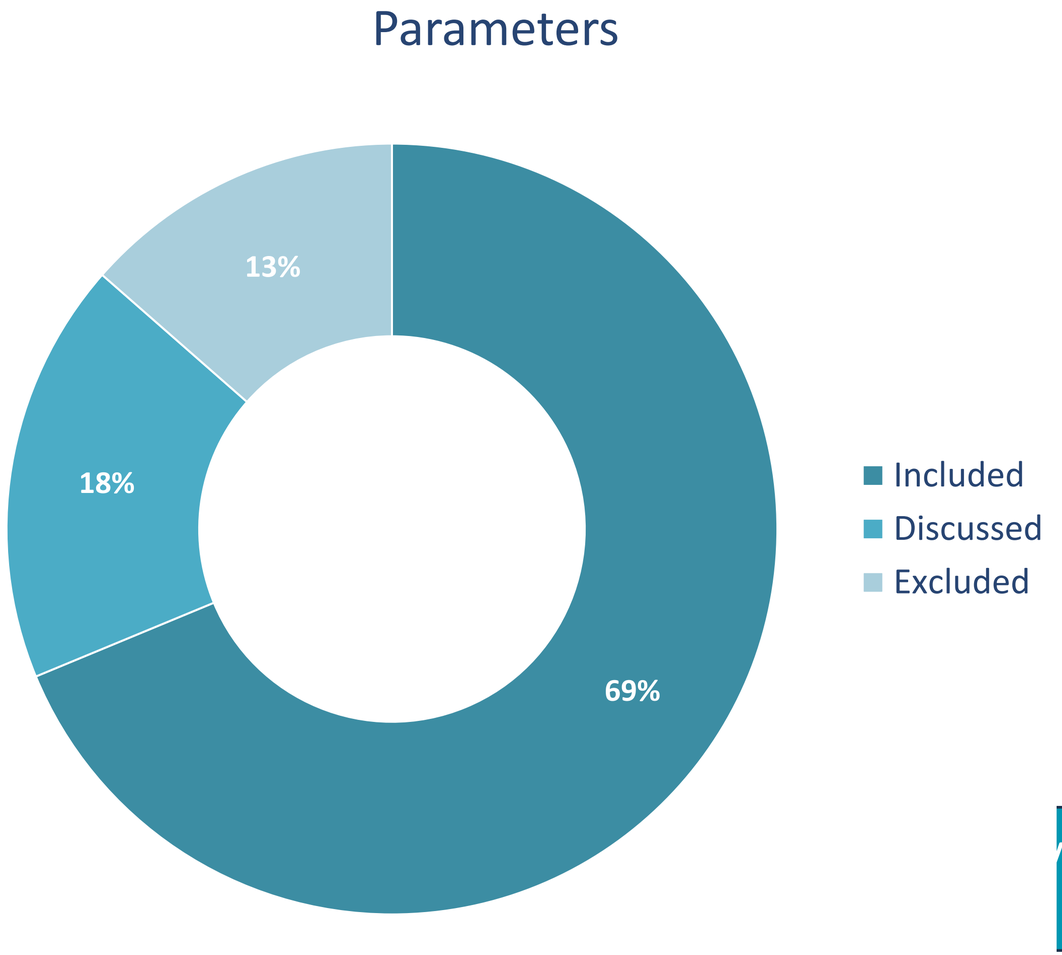
  – (a) essential yes/no

  – (b) feasibility yes/no

  Third question was added:

  – (c) Incorporated into clinical care

- Discuss the items for discussion



How to develop the prolactinoma module?

- **SURVEY 2** - Each item ranked from 1– 10
  - Mean scores calculated:
    - Items ≤5 → deleted
    - Items 6-7 → open for discussion
    - Items ≥8 → included

- After going through the three steps
  - Three sets:
    - Clinician-reported Core set
    - Patient-reported Core outcome measures set (based on top 10 complaints of interest)
    - Clinician reported Extended set

Timeline - overall

- 2025
  - April 28 — Kick-off meeting
  - June 30 — Meeting 1 – Patient selection and intervention strategies
  - Jul, Aug, Sep — Subgroup meetings, optional surveys
  - September 29 — Meeting 2 – Outcome measures 1
  - Oct, Nov, Sep — Subgroup meetings, optional surveys
  - November 17 — Meeting 3 – Outcome measures 2
  - TBS — QoL outcomes
  - TBS — Subgroup Meeting Prioritization & Timepoints
  - TBS — 1st voting survey created

- 2026
  - January 15 — Deadline for 1st voting survey
  - March 6 — Discussion of 1st survey results
  - TBS — 2nd survey created
  - TBS — Deadline for 2nd voting survey
  - TBS — Meeting 4 – Prioritization and Surveys results
  - TBS — First draft of new module including all Data Elements
  - TBS — Testing phase of the module
  - TBS — Module open for patient inclusion
  - TBS — Publication of Prolactinoma Module Creation (*manuscript*)

Thank you so much for attending!

EuRREB
European Registries for Rare
Endocrine and Bone conditions

A.O.B.

Thank you for your attendance!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