

# National best practices for ERN integration: Czech Republic

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#### Historical overview



- National strategy for rare diseases 2010-2020
- Interdisciplinary Council for Rare Diseases at the MoH
  - "Advisory board" meeting annually, no competencies, no funding
- National Coordination Center for Rare Diseases at Motol University Hospital
  - No funding, no competencies, no defined link to policy makers
- Patient environment evolution







Czech National Strategy fo

- Czech National Strategy for Rare Diseases: 2010-2020 Press release czech (cz)
- Czech National Strategy for Rare Diseases: 2010-2020 Press release english (en)
- ▶ Czech National Action Plan for Rare Diseases 2012-2014 czech (cz)
- Czech National Action Plan for Rare Diseases 2012-2014 english (en)
- ▶ <u>Second Czech National Action Plan for Rare Diseases 2015-2017 czech (cz)</u>
- Second Czech National Action Plan for rare diseases 2015-2017 unofficial english version (en)
- Second Czech National Action Plan for rare diseases 2015-2017 Annex 1 unofficial english version (en)

#### **Historical overview**



17 ERNs - 28 full members

#### 2022

- 22 ERNs 48 full member centres of 13 HCPs
  - No ERN coordinator
- Formal status od "highly specialised care centres for RD"
  - Competencies and integration into existing structures not defined
  - Capacity limited, economically largely unprofitable



#### OBSAH:

1.	Standardy poskytování specializované paliatívní péče ve formě konziliárního týmu paliatívní péče v nemocnicích akutní a následné péče v ČR
2.	INFORMACE TÝKAJÍCÍ SE ÚPRAVY VZDĚLÁVACÍCH PROGRAMŮ GYNEKOLOGIE A PORDONICTVÍ, INFEKČNÍ LÉKAŘSTVÍ, OFTALMOLOGIE, ORTOPEDIE A TRAUMATOLOGIE POHYBOVÉHO ÚSTROJÍ, OTORNIOLARYNGOLOGIE A CHIRURGIE HLAVY A KRKU, NEUROLOGIE A SOUDNÍ LÉKAŘSTVÍ
3.	Cenový předpis Ministerstva zdravotnictví ze dne 7. ledna 2022
4.	SPECIFICKÉ LÉČEBNÉ PROGRAMY (SLP) ODSOUHLASENÉ MINISTERSTVEM ZDRAVOTNICTVÍ V OBDOBÍ ŘÍJEN – PROSINEC 2021
5.	Národní síť center vysoce specializované péče o pacienty se vzácným onemocněním
6.	Metodika realizace populačního pilotního programu časného záchytu karcinomu plic
7.	Podmínky akreditace CT pracovišť pro Populační pilotní program časného záchytu karcinomu plic



for rare or low prevaler complex diseases

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## Availability of RD data in the CZ – up to 2022/3

- All ERN centers hosted by HCs directly managed by the MoH
  - Their EHR vary significantly
  - RD patients identified via their birth code + ICD10
  - Only proportion of RD patients can be traced within the National Healthcare Information System (NZIS)
- Information largely unavailable on
  - Numbers of patients with defined RD
  - Their geographical distribution
  - Care characteristics: quality and costs



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#### Czech Republic and ERN integration: "Pilot project"

- To map RD care in 4 ERN centers / 3 HCPs via patient tracking in the National Healthcare Information System
- To serve as a basis for negotiation with payers Re optimisation of reimbursement
- Patient identification
  - Specific "signal" code in EHR (later +Orphacode)
  - Data analysis of patient characteristics and clinical intervention codes and their reimbursement against personal costs of clinical teams
- Preliminary results
  - Disproportion between staff costs and reimbursement of their work
  - Difficult data interpretation due to lack of identification of centers within HCPs





### RD patient identification in EHR from 2024

- Recognition of the necessity of identifying RD patients in EHR
  - A pre-requisite of any potential re-organisation/funding optimisation
- RD patient identification rule
  - Specific "signal" code to accompany an Orphacode for RD healthcare billing
  - Exclusively contracted for ERN centers only
  - Orphacode entry = confirmation of RD diagnosis provided by an ERN centre expert
- An interim funding solution
  - Extra bulk payment to each ERN center ("bonification") by payers (insurance companies)
    - recognising extra work and effort associated with RD care



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### RD data systematic collection

#### Project "RARE"

- A national RD registry forrunner
- Preparation of the generic RD dataset in collaboration with the DIGOVO project

#### National RD registry

- Proposed as an adendum to the recent amendment of the Health Services Act No. 372/2011 Coll.
- Legally operational probably from 01/2025
- Interoperability with
  - Hospital DHR and standard RD dataset for direct data export (single data entry)
  - Other existing RD registries



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#### **Source data - EHR**

- Project "DIGOVO": DIGitalisation and Optimisation of RD (=VO) care
  - Functional and implementation specification of the data standard for RDs and its pilot implementation
  - Resouces:
    - European Common Data Elements (CDE)
    - French SDE, CDE and EUCERD JA
- Data directly entered in EHR
  - Prevents mistakes of multiple data re-entry
  - Reduces time and effort
  - Allows for data sharing



#### SET OF COMMON DATA ELEMENTS FOR RARE DISEASES REGISTRATION

GROUP	ELEMENT N°	ELEMENT NAME	ELEMENT DESCRIPTION	CODING	COMMENT
1. Pseudonym	1.1.	Pseudonym	Patient's pseudonym	String	https://eu-rd- platform.jrc.ec.europa.eu/spider
- E	2.1.	Date of birth	Patient's date of birth	Date (dd/mm/yyyy)	
2. Personal information	2.2.	Sex	Patient's sex at birth	Female     Male     Undetermined     Foetus (Unknown)	
3. Patient Status	3.1.	Patient's status	Patient alive or dead	Alive     Dead     Lost in follow-up     Opted-out	If dead then answer question 3.2
	3.2.	Date of death	Patient's date of death	Date (dd/mm/yyyy)	
4. Care pathway	4.1.	First contact with specialised centre	Date of first contact with specialised centre	Date (dd/mm/yyyy)	
history	5.1.	Age at onset	Age at which symptoms/signs first appeared	Antenatal At birth Date (dd/mm/yyyy) Undetermined	
5. Disease history	5.2.	Age at diagnosis	Age at which diagnosis was made	Antenatal At birth Date (dd/mm/yyyy) Undetermined	
:s	6.1.	Diagnosis of the rare disease	Diagnosis retained by the specialised centre	Orpha code (strongly recommended – see link) / Alpha code/ ICD-9 code/ ICD-9- CM code / ICD-10 code	http://www.orphadata.org/cgi- bin/inc/product1.inc.php
6 Diagnosis	6.2.	Genetic diagnosis	Genetic diagnosis retained by the specialised centre	International classification of mutations (HGVS) (strongly recommended – see link) / HGNC / OMIM code	http://www.hgvs.org
	6.3	Undiagnosed case	How the undiagnosed case is defined	Phenotype (HPO)     Genotype (HGVS)	
	7.1.	Agreement to be contacted for research purposes	Patient's permission exists for being contacted for research purposes	• YES • NO	
Research	7.2.	Consent to the reuse of data	Patient's consent exists for his/her data to be reused for other research purposes	• YES • NO	
7.	7.3.	Biological sample	Patient's biological sample available for research	• YES • NO	If YES answer question 7.4
	7.4.	Link to a biobank	Biological sample stored in a biobank	YES (if appropriate use link)     NO	https://directory.bbmri-eric.eu
8.Disability	8.1.	Classification of functioning/disability	Patient's disability profile according to International Classification of Functioning and Disability (ICF)	Disability profile / Score	http://www.who.int/classifications /icf/whodasii/en/



## **SYPOVO project: System of Complex Health- and Social Care for Rare Disease Patients**

- To define organisational changes necessary for ERN integration
  - RD networks
  - Personal capacities of centers for function and sustainability
  - "referral patterns" and "care pathways"
  - Competences of centers with different level of expertize
    - Including RD-specific drug prescription
  - System of quality of care evaluation
    - Incl. disease outcome measures
- Optimisation of
  - HCP / centre funding
  - RD education and research

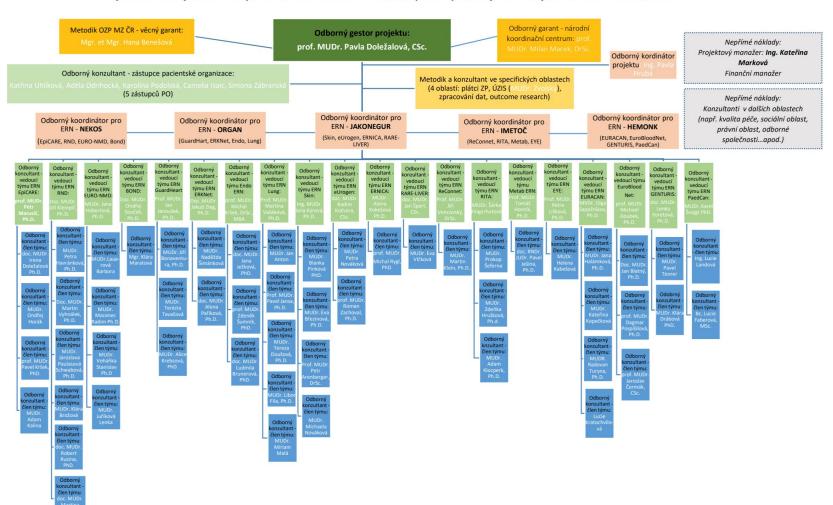




#### **SYPOVO team**

#### Organizační diagram

Projektu Návrh systému komplexní sdílené zdravotně-sociální péče o pacienty se vzácnými onemocněními "SYPOVO"







Reference Network

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## Thank you

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