Advancing Access and Support for People with MS: **A comparative perspective on European Health Systems**

Data as a path for a better care…

…but how?

Prof. Dana Horáková, MD, Ph.D. | ReMuS Registry Scientific Guarantor

Challenges in MS

Significant improvement in MS

- **Diagnostics**
- **Treatment**
- **Monitoring**
- **…**

The problem has not been solved!!!

- **Progressive MS (neurodegeneration)**
- **Safety**
- **Quality of care, access to treatment**
- **…**

Key stakeholders – and their motivations

Physicians
To provide propper care

Regulatory Bodies
Registration of new drugs, safety

Healthcare payers
Cost / Benefit of treatment

Patients
Joint decision making,
lobbing

Industry
Development of new drugs,
market access

Patients – Why? What?

Info about MS

What I can do with it?

Treatment options?

How is the situation in my country?

- ✓ Availability?
- ✓ Quality
- ✓ Reimbursement

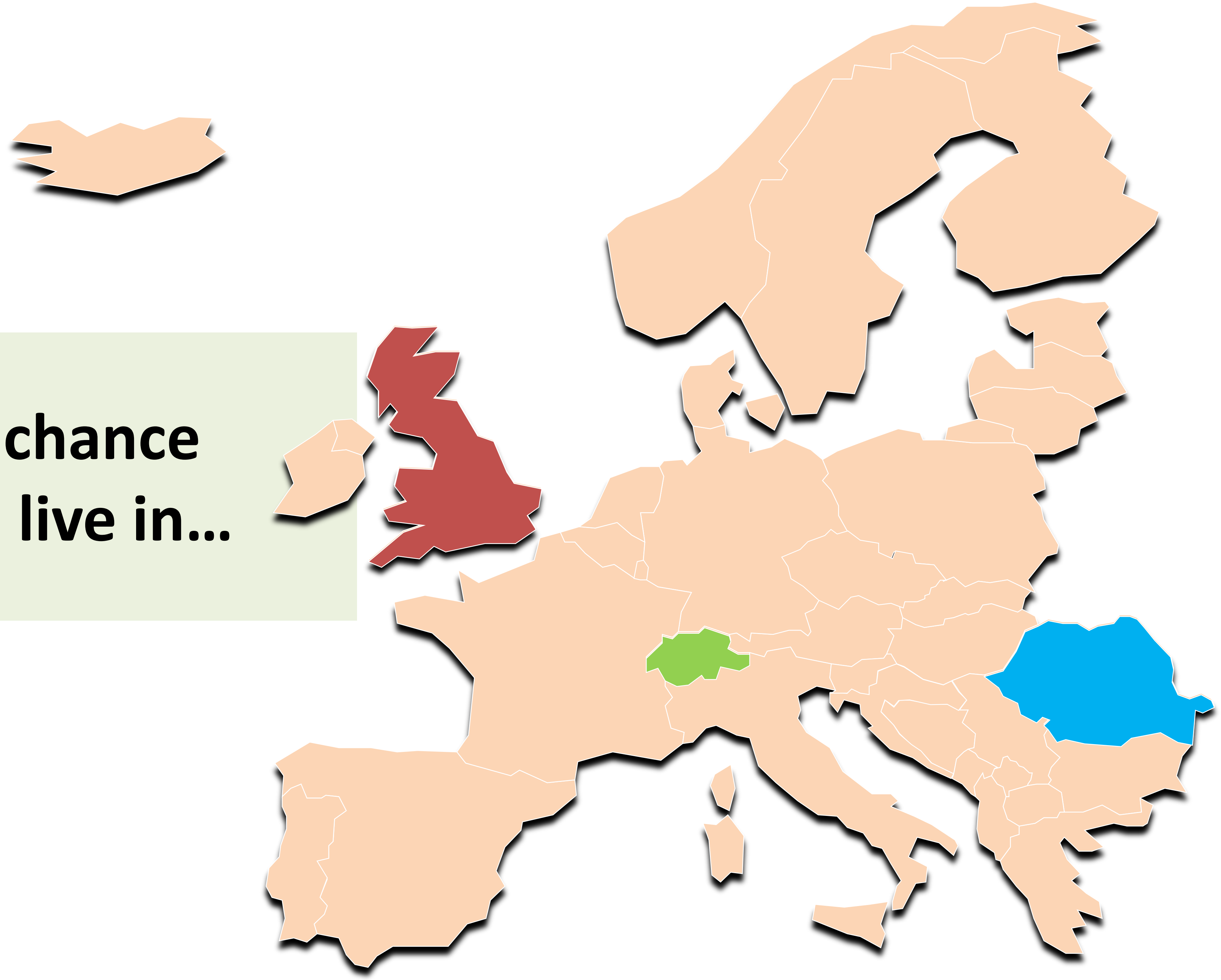
How is the situation in European space?

44 countries in Europe

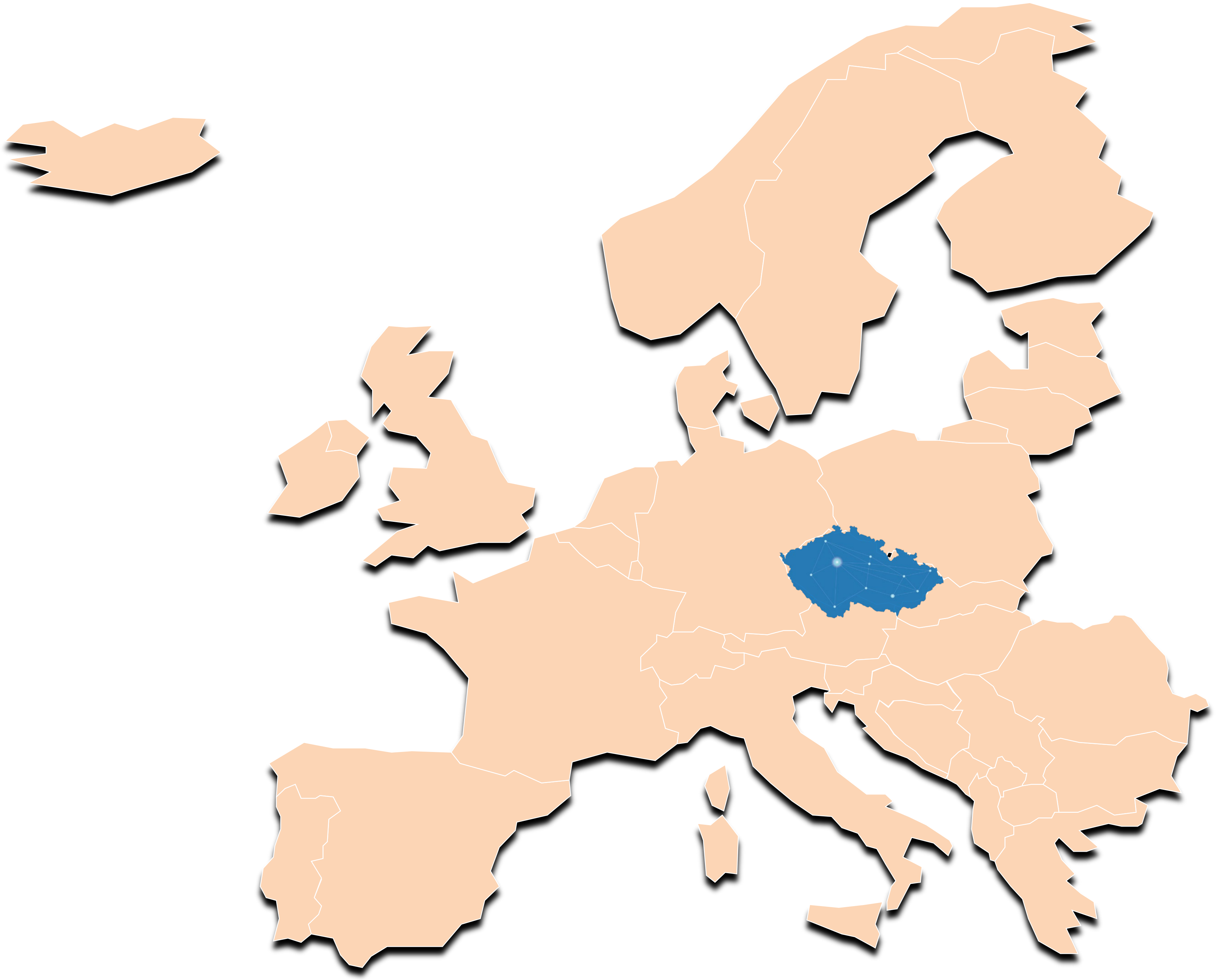
(51 included in broader list)

27 countries in EU

> Do I have the same chance to get treatment if I live in…



The Czech Republic – 10,900,000 citizens



Organisation of care in the Czech Republic

General Practitioner - Neurologist - Neurological department

Specialized MS centers since 1996

15 MS centres

Neurological Society

Section for Neuroimmunology

ReMuS | The Czech Republic Multiple Sclerosis Patient Registry

No data before 2013

Neurological Society + IMPULS Endowment Fund

➔ **ReMuS®**
THE CZECH REPUBLIC
MULTIPLE SCLEROSIS
PATIENT REGISTRY

Since 2013

➔ **regular, prospective collection of data**

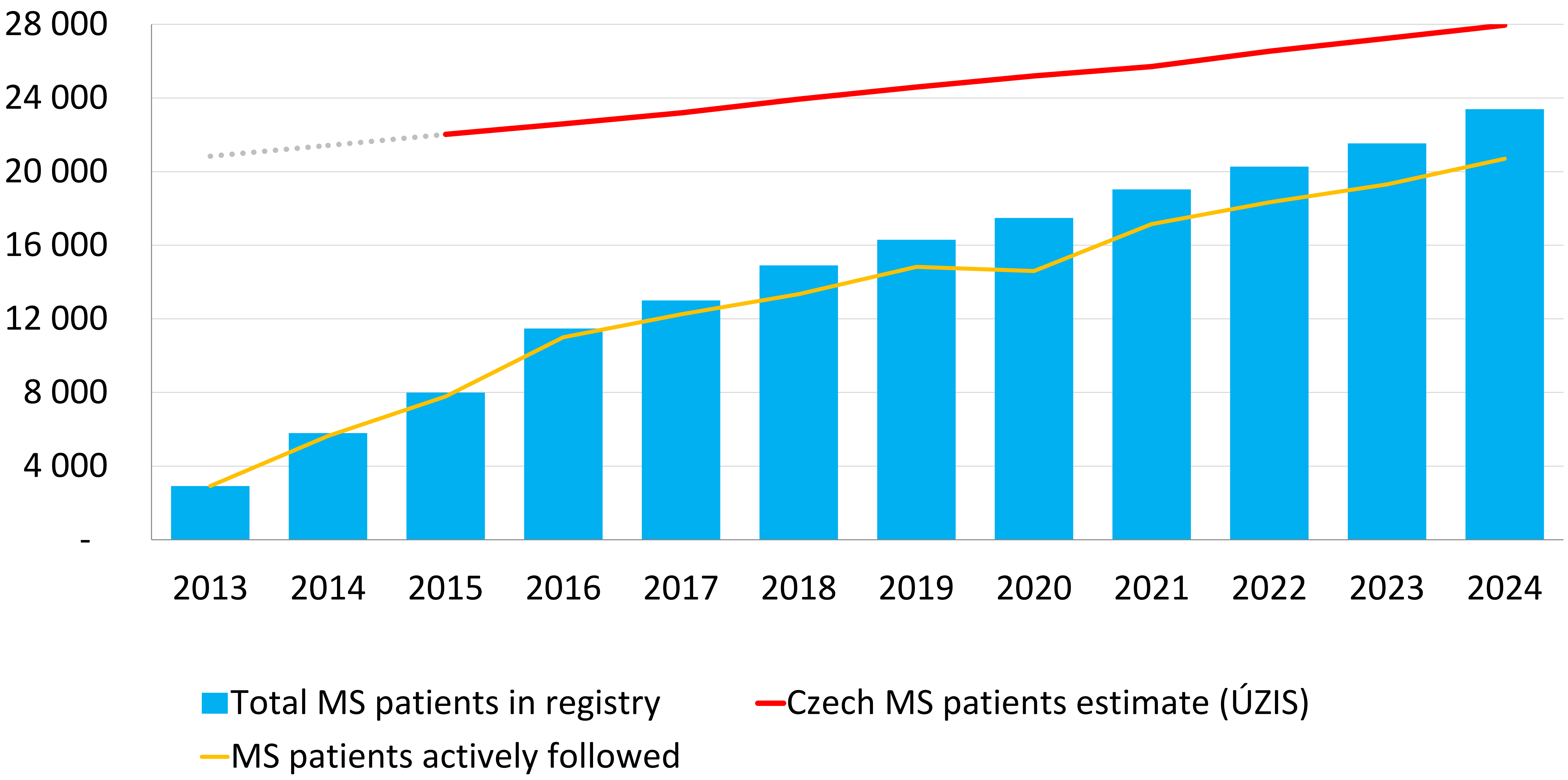
2025

23 391
MS patients
in the registry

20 699
Followed in
the last year

17 342
Treated by
DMT

ReMuS | Building up the Registry



MS patients
in the registry

23 391

20 699
Followed in 2024

Of those
17 342
DMT treated

EXAMPLE

ReMuS | How Much Data Contains?

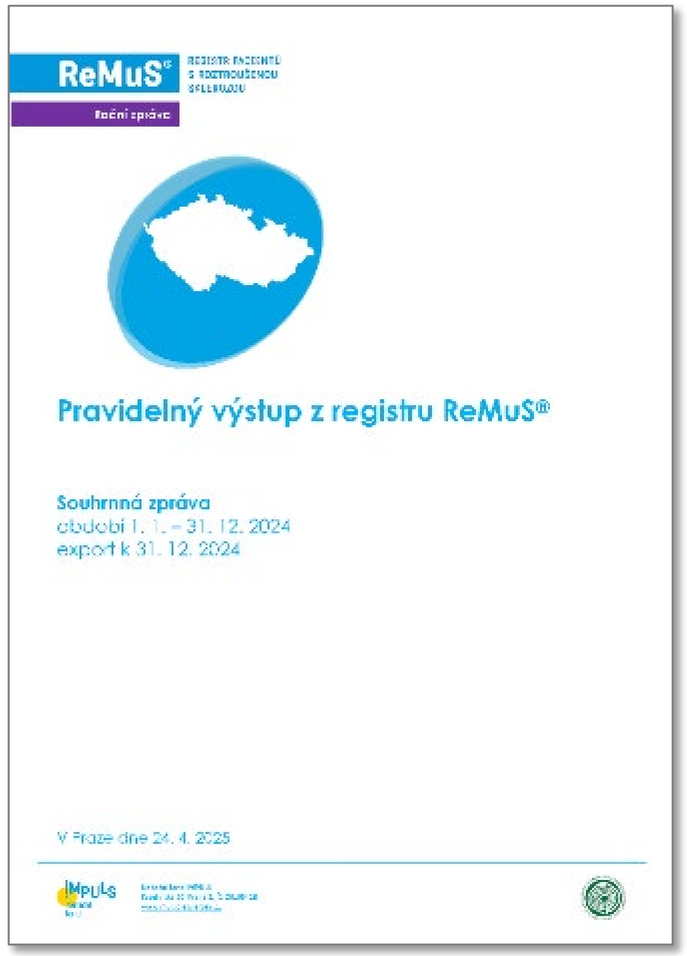
data as of June 30th, 2024

546,000	visits
218,000	treatment episodes
79,000	documented relapses
118,000	MRI records
7,700	pregnancy records
16,282	cerebrospinal fluid analysis records
45,024	Adverse Events, 27,990 coded in MedDRA

…this data live in projects and analysis

EXAMPLE

ReMuS | Where do the Data Get Alive? – Annual reports

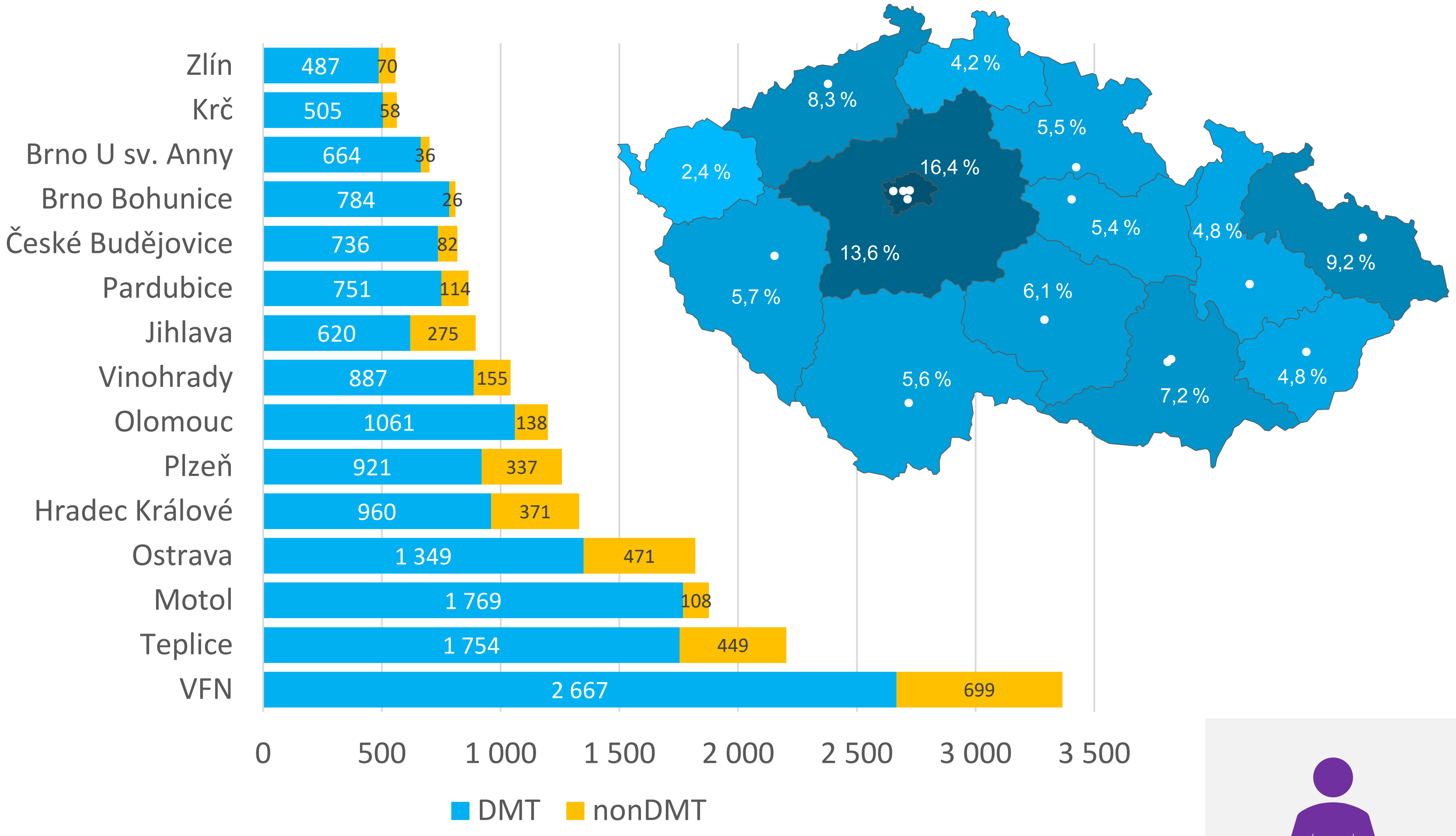


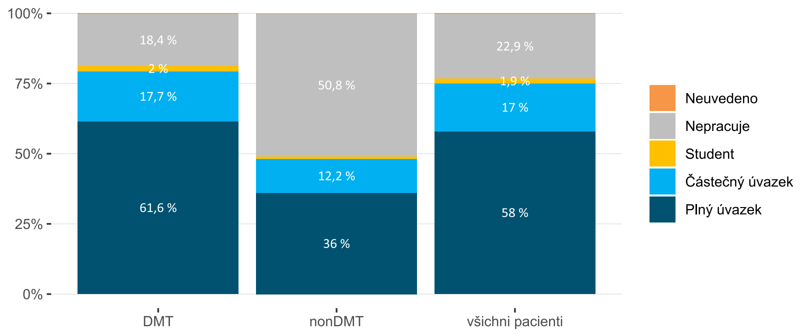
ReMuS®
REGISTR PACIENTŮ S ROZTROUŠENOU SKLEROZOU
Roční zpráva

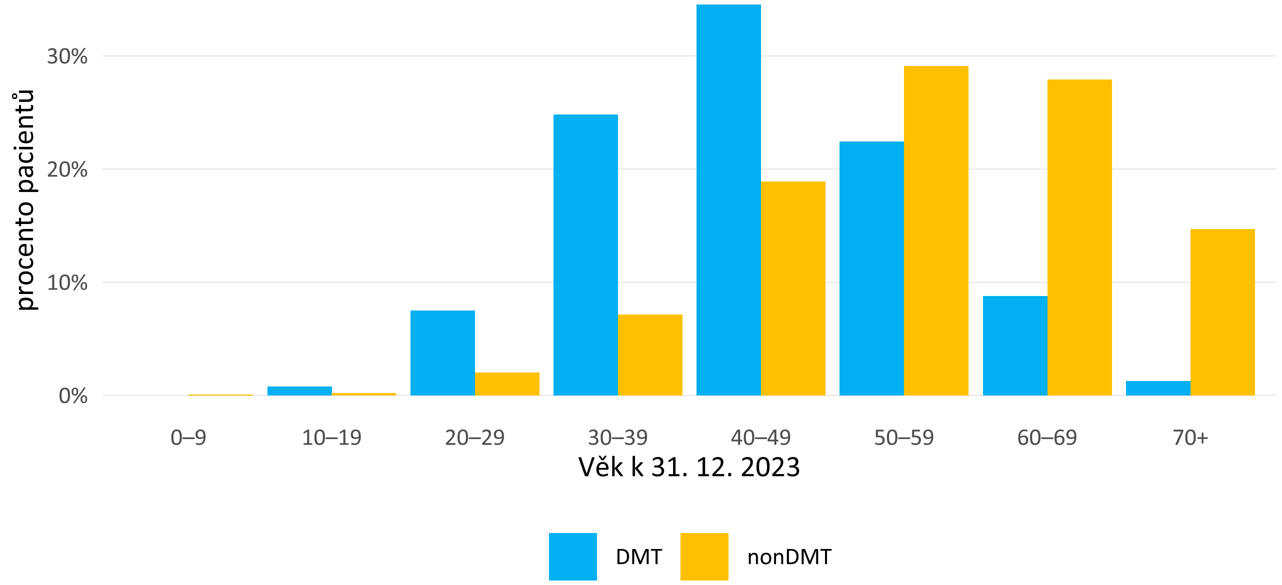
Pravidelný výstup z registru ReMuS®

Souhrnná zpráva
období 1. 1. – 31. 12. 2024
export k 31. 12. 2024

V Praze dne 24. 4. 2025







71,1 % **28,9 %**

Ø age 31. 12. 2023

47,26 years

Median at onset

31,44 years

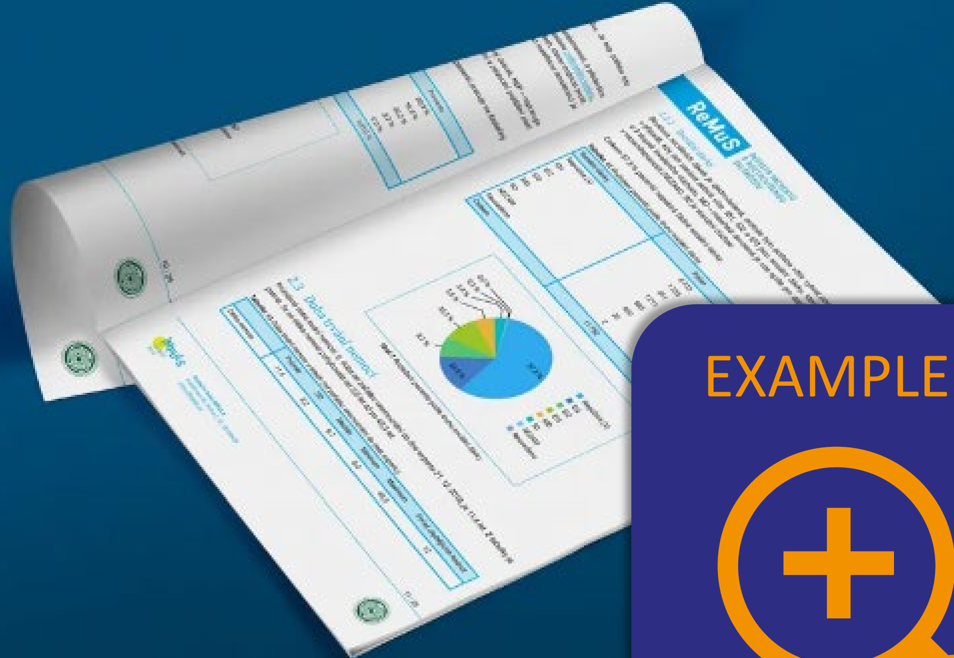
Provided annually free of charge

16 versions:
1x nation-wide and
15x for each of the MS site

Content
33 pages, 28 tables, 19 graphs

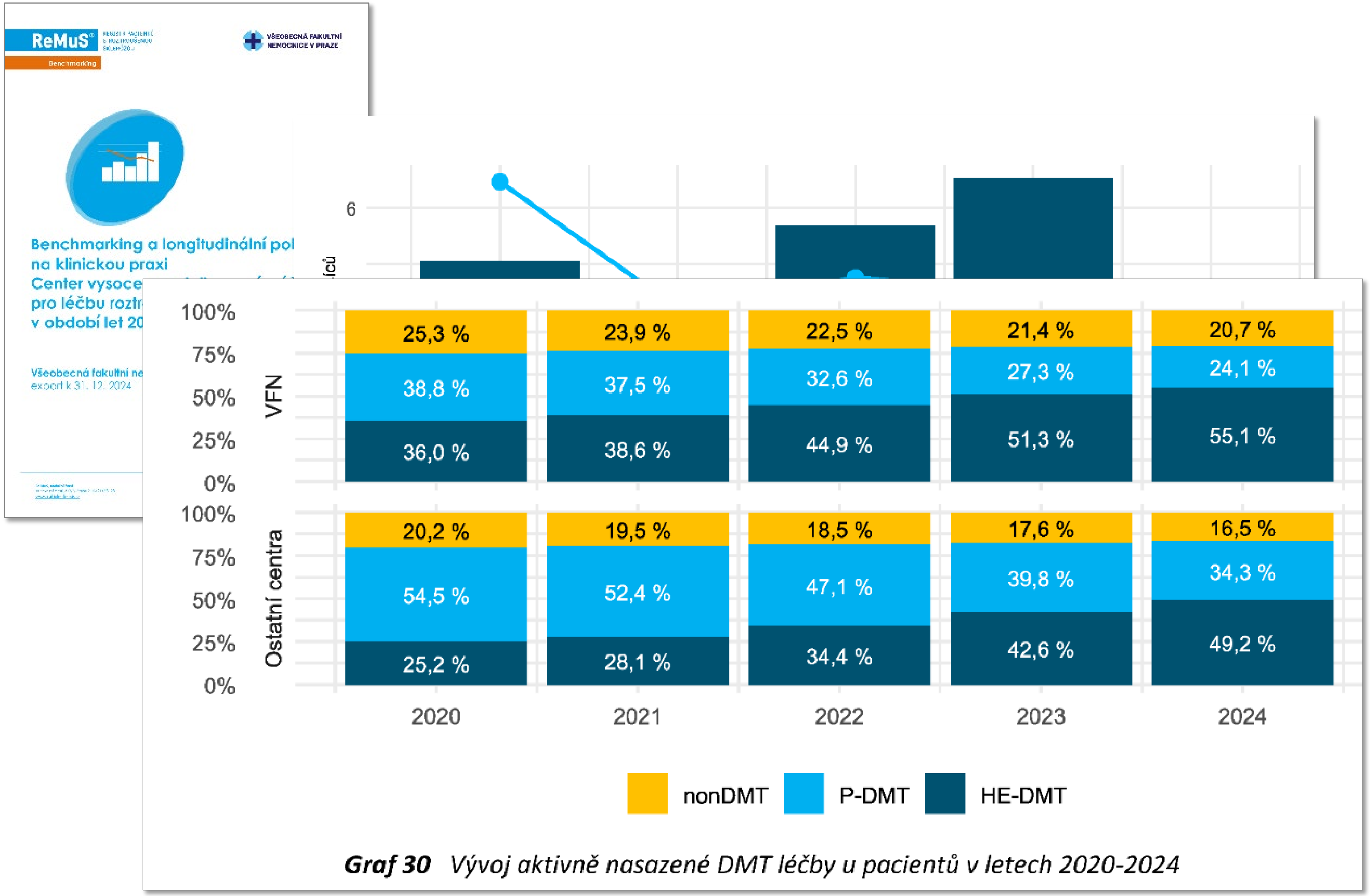
- Population size
- Geographic distribution
- Clinical-Demographic Patients Structure
- Disability & Employment Status

…a lot more



EXAMPLE

ReMuS | Where do the Data Get Alive? – Benchmarking



Benchmarking a longitudinální pol
na klinickou praxi
Center vysoce
pro léčbu rozt
v období let 20

Všeobecná fakultní ne
export k 31. 12. 2024

***Graf 30** Vývoj aktivně nasazené DMT léčby u pacientů v letech 2020-2024*

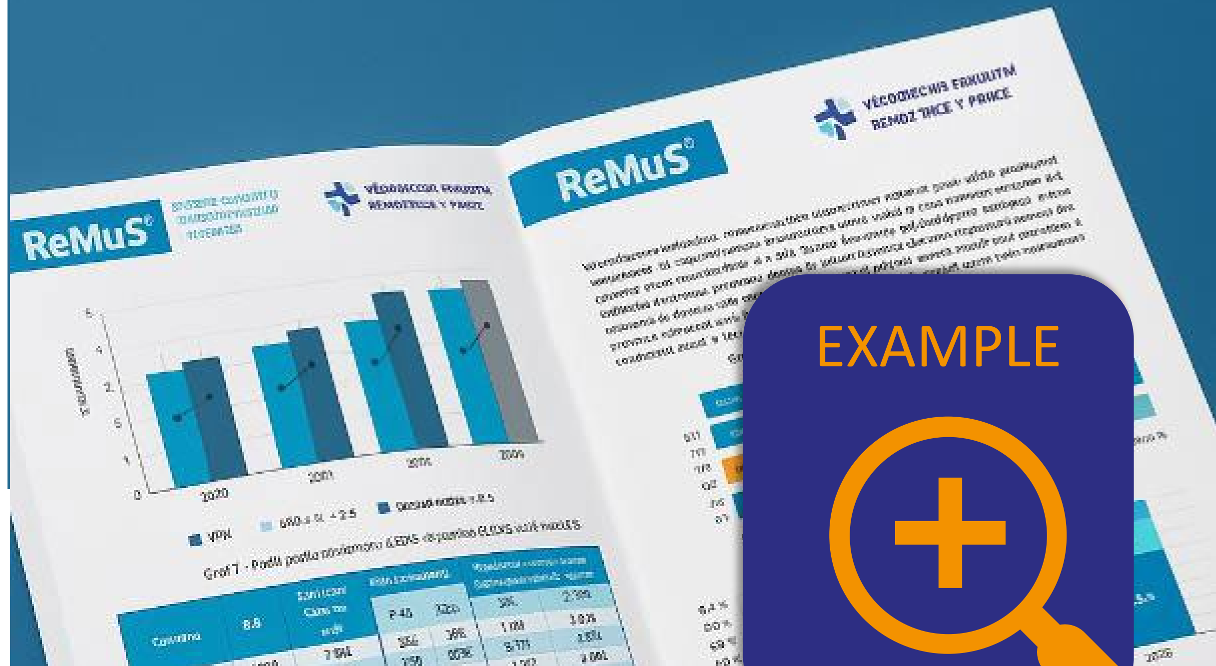
Provided 2x / year free of charge

16 versions:
1x nation-wide and
15x for each of the MS site

Content
50 pages, 30 tables, 40 graphs

- Missing Data
- Time to First Visit
- Structure of Disease Modifying Treatment

…a lot more



EXAMPLE

Registries and RWD in Action – Shaping the Future

Ratio of the platform and high-efficacy DMT

The Czech Republic,
Data from the ReMuS Registry
as of June 30th, 2024

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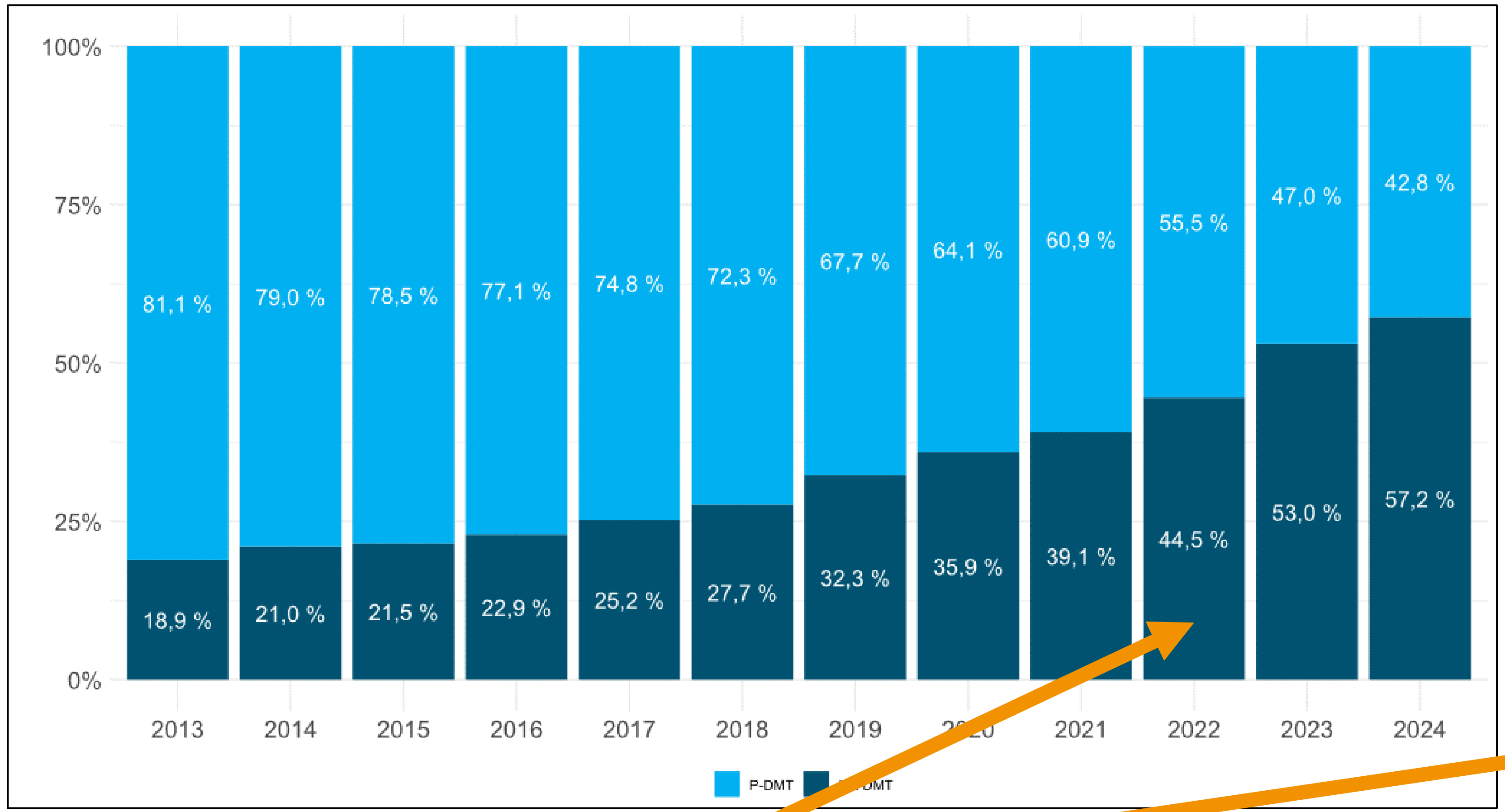
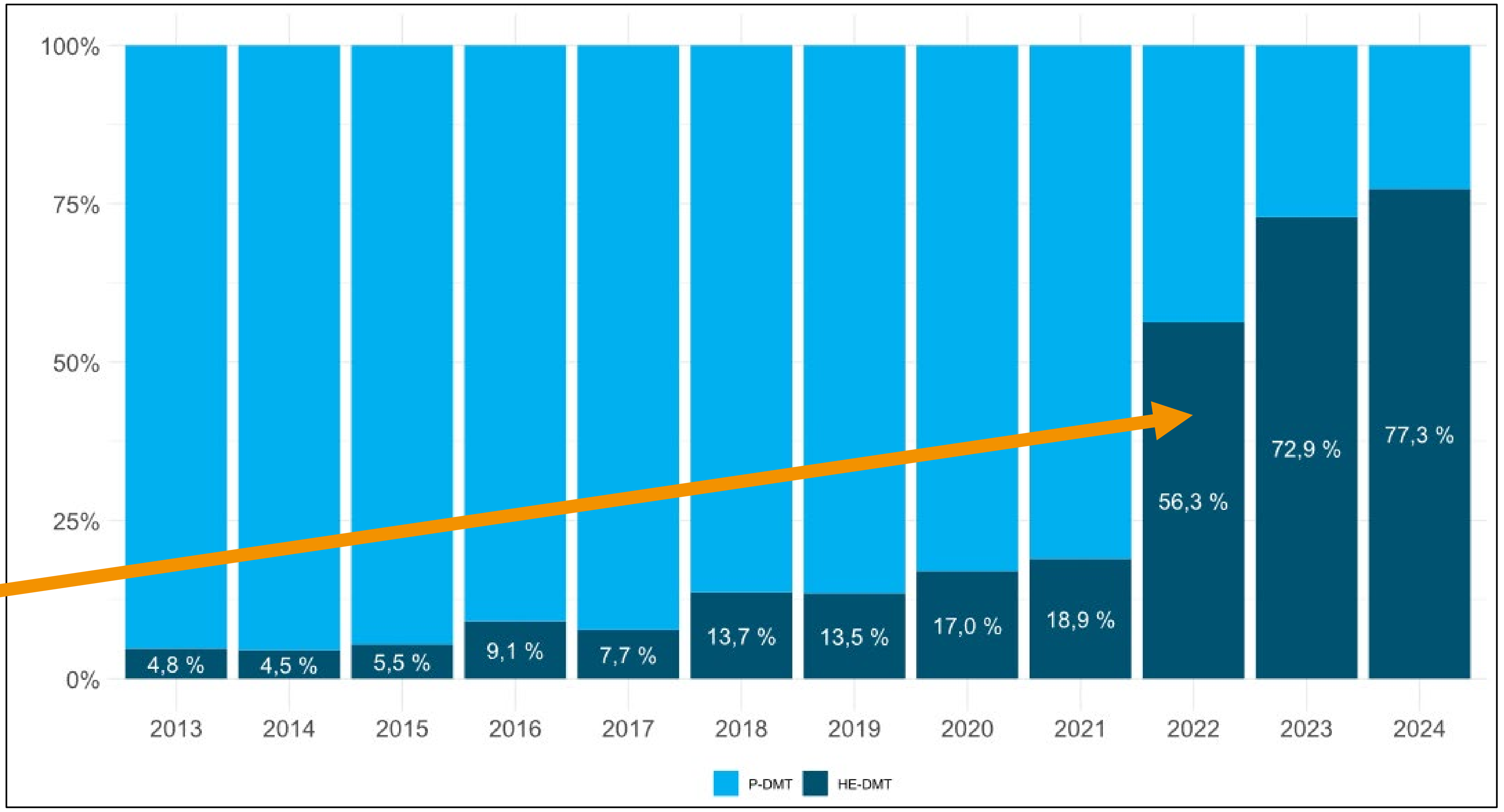
MULTIPLE SCLEROSIS
PATIENT REGISTRY

Current treatment by type as of 31.12. (prevalence)



The very first treatment of DMT (incidence)

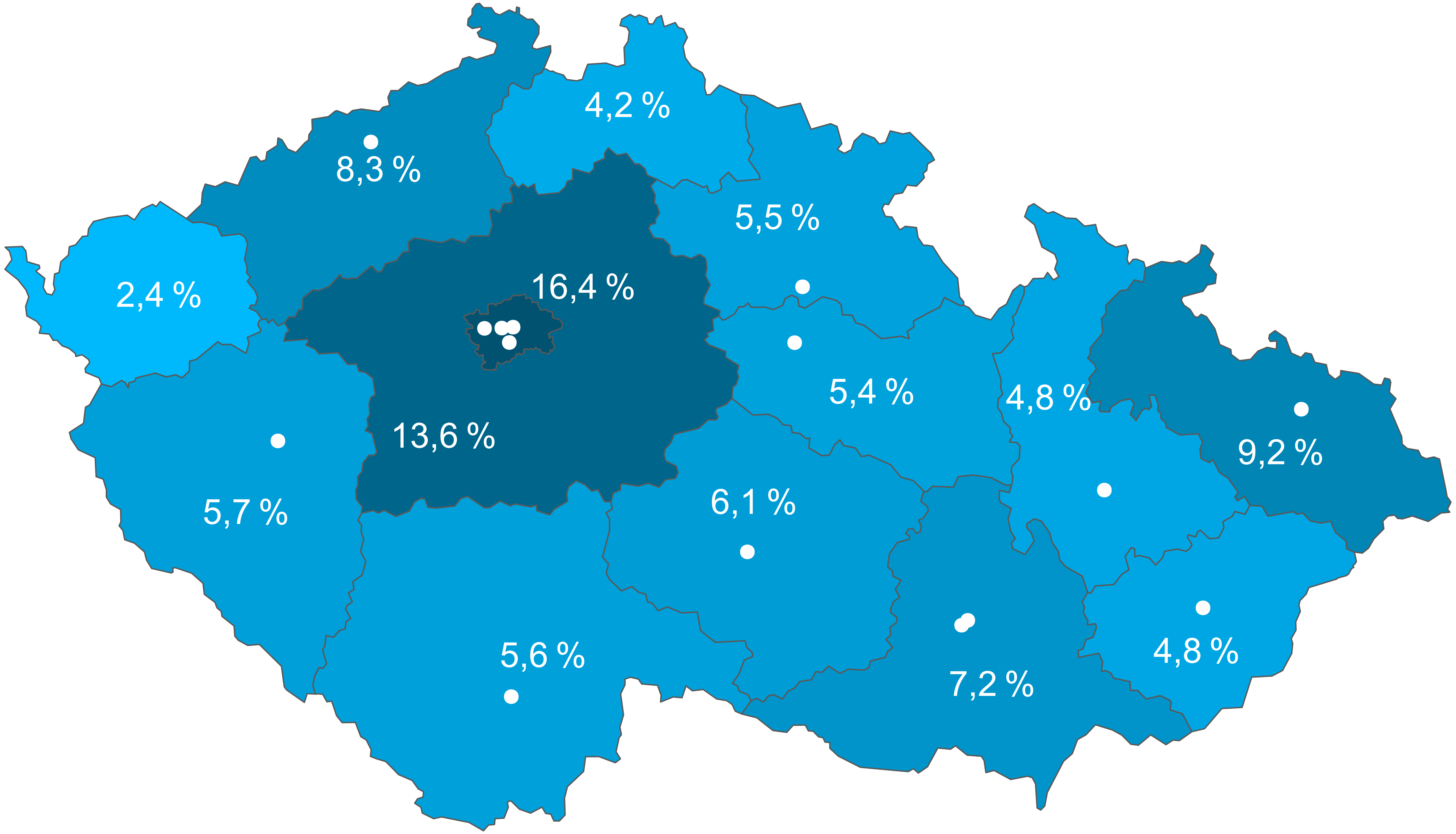


HET
High-Efficacy Treatment

Although payers initially relied on RCT data for reimbursement approvals, the wide range of current treatment options and the need to understand real-world effectiveness have established registries as a valid data source for informing changes in reimbursement policies.

EXAMPLE

Where are all the necessary data?



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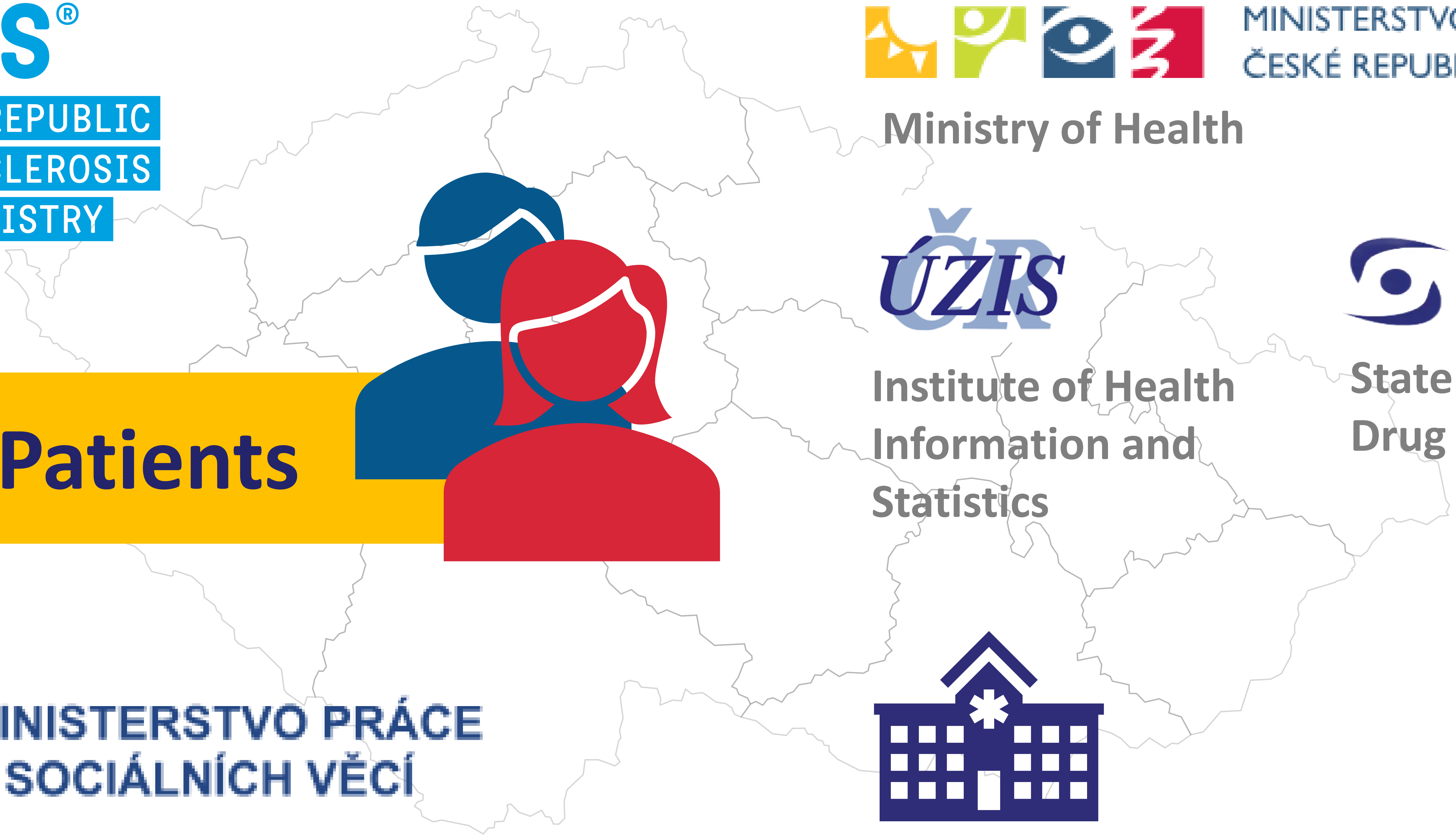

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MULTIPLE SCLEROSIS
PATIENT REGISTRY

Patients

MINISTERSTVO ZDRAVOTNICTVÍ
ČESKÉ REPUBLIKY

Ministry of Health

ÚZIS ČR

Institute of Health Information and Statistics

SÚKL

State Institute for Drug Control

MPSV

MINISTERSTVO PRÁCE
A SOCIÁLNÍCH VĚCÍ

Ministry of Labour and Social Affairs

Healthcare providers

„Ex unitate vires“

„Union is Strength.“

— *Latin quote*

Benchmarking

Quality Indicators

Interoperability

Shared Decision Making

Learning Healthcare System

Cooperation

Trust, Privacy & Security

Patient-Centric Ecosystem

Trustworthiness

Data Quality

Data-linkage

Key Question: **„Am I satisfied with a situation in my country?“**

„The future is not some place
we are going,
but one we are creating.“

— *John Sachaar*

The role of EMSP as Coordinator and Support

- Establish and promote quality indicators
- Begin by providing a platform with comparison of data accross EU countries
- Start with strong, reliable examples – existing high-quality registries and people who have really developed and maintained these registries
- www.multiplesclerosis.cz
  …happy to help & support you