

# Best practices in MS and rare disease registries

Alexander Stahmann

24.04.2026

Berlin

Annual conference EMSP

# Examples of successful registries

msregister

<u>Primarily Clinical</u>	<u>Primarily Patient-based</u>
Danish MS Registry	NARCOMS
Swedish MS Registry	UK MS-Registry
MSBase	Swiss MS-Registry
OFSep	
ReMuS	
NEMOS	

# Data Quality

- Whats the difference between an EXCEL file and a registry
- What has to be done beyond enforcing rules in an eCRF

# Standardization and Interoperability

msregister

- Who and What drives standardization in MS-Registries?



The big Multiple Sclerosis data network



# Standardization and Interoperability

- What is interoperability in the context of registries, and why do we need it?

–

# How to engage, retain and involve centers

msregister

- Motivation through research opportunities and co-authorship (e.g. the MSBase approach)
- Obligatory recruitment and documentation in the context of certificates

# How to engage and retain centers

- Motivation through research opportunities and co-authorship (e.g. the MSBase approach)
- Obligatory recruitment and documentation in the context of certificates

# How to engage, retain and involve patients?

msregister

- Address questions that are of interest to the patients
- Provide insight into the patient's individual data to the patient
- Make the individual data useful to the patient and it's care setting
- Get patients and their organizations to promote the participation and use of the registry

# What's the registries impact?

msregister

- Monitoring of provision of care to pwMS:  
“Whats evaluated will be done” – Jan Hillert

# What's the registries impact?

msregister

- Evaluation incidence and prevalence of MS
- Monitoring of provision of care to pwMS

# What's the registries impact?

msregister

- Evaluation of long-term safety and effectiveness of DMT

# What's the registries impact?

msregister

- Lessons on treatment effects beyond the duration of trials and populations outside of trials (e.g. pregnancies)

# What's the registries impact?

msregister

- Lessons on pwMS's disease and treatment pathways that are not in scope for pharma sponsored research