EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

EMSP MCB Program 2023

2023.12.08

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

WELCOME & INTRODUCTION

Elisabeth Kasilingam

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

ICE BREAKER / ROUND TABLE

MS Data Alliance team

Icebreaker exercise

Choose a miniature that, according to you, is best suited to display the current situation in your country regarding data.

(don't overthink it)

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

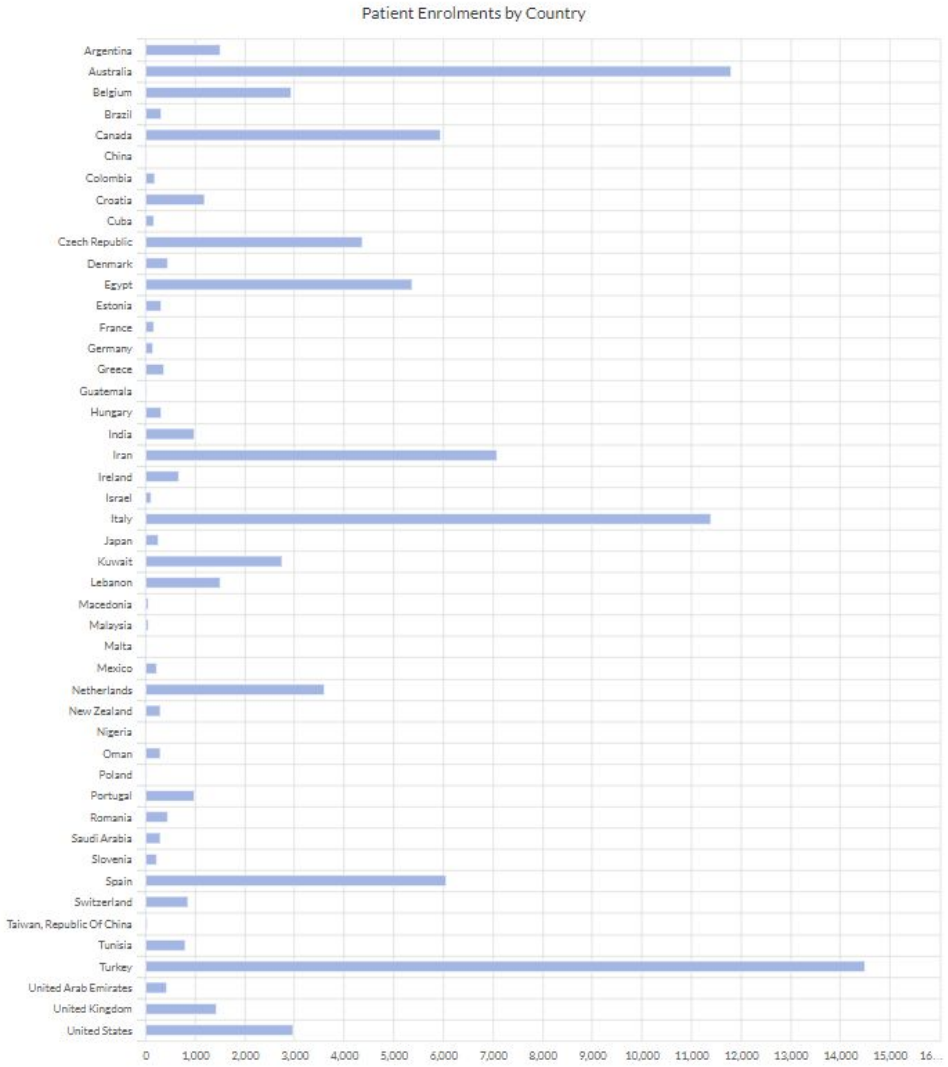
SETTING THE SCENE

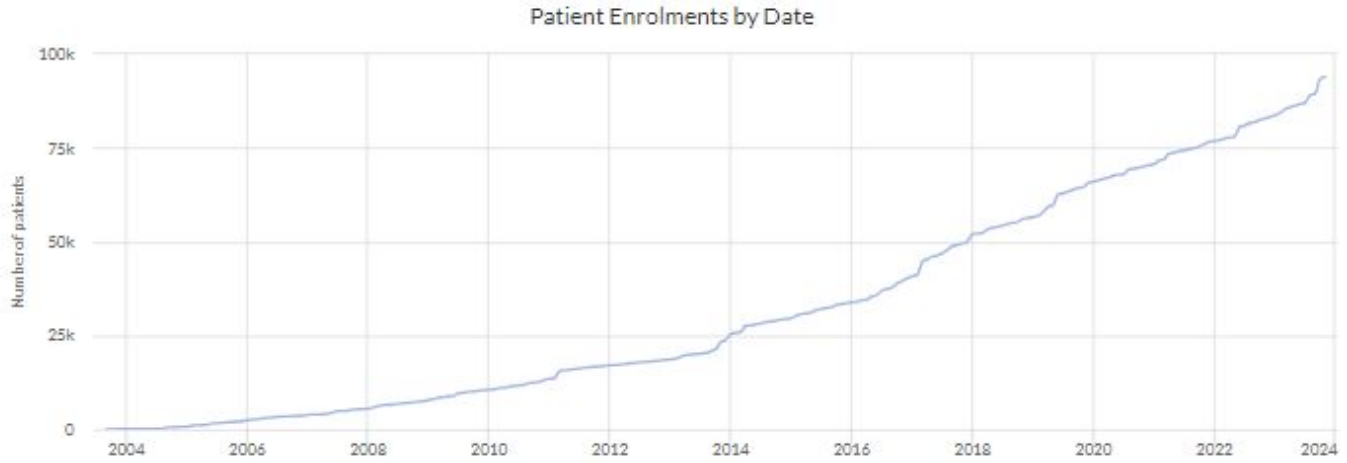
MS Data Alliance team

MSBase: metadata statistics

https://www.msbase.org/data-and-findings/patient-enrolment/

EUROPEAN MULTIPLE SCLEROSIS PLATFORM





EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Navigating the Roadmap of Setting Up a Registry

Co-creation of Challenges and Solutions

MS Data Alliance team - All participants

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

COFFEE BREAK

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

HERBERT TEMMES

German MS Society

Navigating the Roadmap of Setting Up a Registry

Learning from Experienced MS Societies

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

ROD MIDDLETON

UK MS Registry

Navigating the Roadmap of Setting Up a Registry

Learning from Experienced MS Societies

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Navigating the Roadmap of Setting Up a Registry

Identifying Critical Roles

Identifying critical roles

Key component of success:

Knowing who does what in the registry set-up

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

LUNCH BREAK

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Transforming Research Questions into Actionable insights

Ranking Research Questions

MS Data Alliance team - All participants

Intermezzo: Core Data Set

Aim: reduce the level of heterogeneity between different real-world MS data sources

If we share real-world data globally, we can find answers quickly to global MS challenges - especially with an early alignment on which data variables, in which format to collect or prepare for analysis.

- The **MS Data Alliance Core Dataset v2022** - **definition**:
  - Set of variables that represent the common denominator across different areas of interest and their accompanying (minimal) datasets
  - The definition of the CDS follows an holistic approach and will be research question agnostic. It does not focus on a specific area of interest in the field of MS (e.g. pharmacovigilance).
- The MS Data Alliance Core Dataset v2022 - **objective:** support emerging registries and initiatives in their individual dataset definition and help any stage registries or cohorts to join larger initiatives within or even outside of the MS community through a common data model version of that MS Data Alliance Core Dataset.

Define the CDS v2022: Task Force

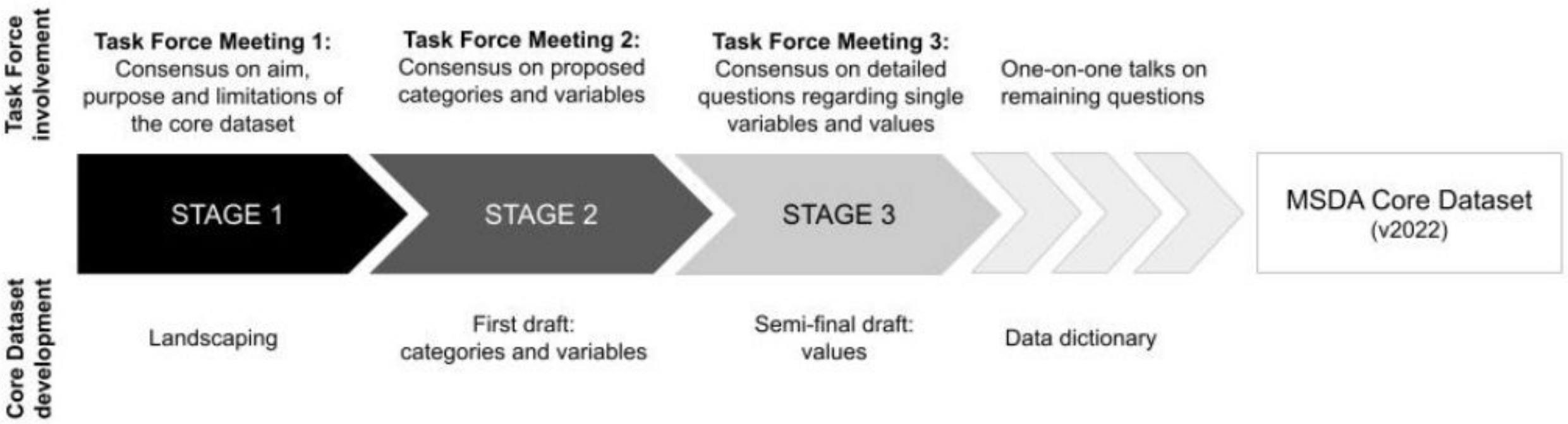
EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Lead: Tina Parciak

Chair: Prof. Giancarlo Comi

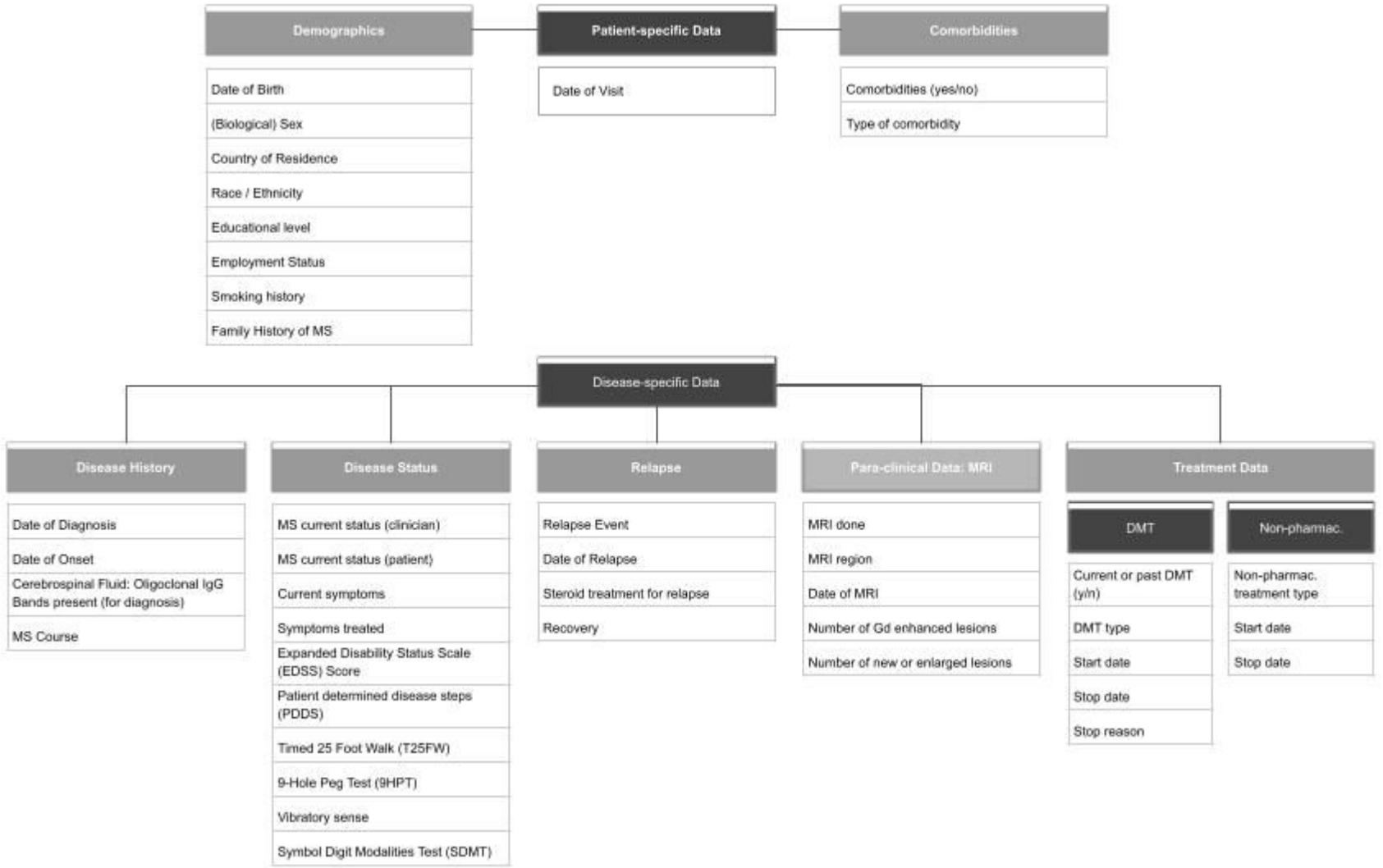
Name	Affiliation
Francis Arickx	National Institute for Health and Disability Insurance
Giancarlo Comi (Chair)	Ospedale San Raffaele, European Charcot Foundation
Pamela Dobay	Biogen
Anne Helme	Multiple Sclerosis International Federation
Elena Hernández Martínez De Lapiscina	European Medicines Agency (EMA)
Jan Hillert	Karolinska Institutet / Swedish MS registry
Pietro Iaffaldano	Università degli Studi di Bari Aldo Moro / Italian MS registry
Melinda Magyari	University of Copenhagen / Danish MS registry
Rod Middleton	Swansea University / UK MS register
Kelly Plueschke	European Medicines Agency (EMA)
Juan Ignacio Rojas	Hospital Universitario CEMIC / Argentinean multiple sclerosis registry (RelevarEM)
Meritxell Sabido-Espin	Merck
Amber Salter	UT Southwestern Medical Centre / North American Research Committee on Multiple Sclerosis (NARCOMS)
Hollie Schmidt	Accelerated Cure Project, Inc./ iConquerMS
Alexander Stahmann	MS Forschungs- und Projektentwicklungs-gGmbH / German MS registry
Ingrid van der Mei	University of Tasmania / Australian MS longitudinal study (AMSLS)
Anneke van der Walt	Monash University / MSBase
Magd Zakaria	Egyptian Society of Multiple Sclerosis / MENACTRIMS board

CDS v2022: TF meetings



Parciak T. et al. Introducing a core dataset for real-world data in MS registries and cohorts - recommendations from a global task force. MS Journal. ***Accepted for publication****. 2023*

CDS: Domains of interest



Parciak T. et al. Introducing a core dataset for real-world data in MS registries and cohorts - recommendations from a global task force. MS Journal. ***Accepted for publication****. 2023*

Ranking research questions

Evaluate each research question based on these critical parameters:

- **Feasibility:** Can the question be realistically answered?
- **Number of Variables:** How many/which variables are needed to address the question?
- **Power Analysis:** What is the estimated number of patients required for statistically significant results?

Ranking research questions

EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Rank all research questions by assigning a colour.

Colour code:

- Green (A): straightforward, can be answered with CDS v2022
- Yellow (B): complex, but still possible to be answered with CDS v2022
- Red (C): impossible to be answered with CDS v2022

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

COFFEE BREAK

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Transforming Research Questions into Actionable insights

End-to-end pipeline for 3 examples

MS Data Alliance team - All participants

End to end pipeline

4 steps per research question:

1. How to formulate a hypothesis?
2. How to create a data dictionary?
3. How to create visualizations and draw insights
4. Methodologies and tools needed to answer research questions effectively (→ analysis is robust and trustworthy)

EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Transforming Generic Questions into Hypotheses

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Creating a Data Dictionary

Visualizing and Utilizing Results

EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Developing an Analysis Plan

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Next steps: discussion and brainstorm

All participants

Domino Chain Reaction - The Power of One Thing

Youtube video: https://www.youtube.com/watch?v=zFGmdPsKz34

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Closing and Thank You

Liesbet M. Peeters