



INŠTITUT ZA VAROVANJE ZDRAVJA  
REPUBLIKE SLOVENIJE

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# HOW TO INCREASE ADDED VALUE OF PATIENT REGISTRIES?

cross border PAtient REgistries  
iNiTiative - PARENT Joint Action

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Google

multiple sclerosis registry



multiple sclerosis registry

multiple sclerosis register

multiple sclerosis registered nurse

multiple sclerosis registry germany

Iskanje

Vse

Slike

Videoposnetki

Več

### [Akademski članki za multiple sclerosis registry](#)

[The Danish Multiple Sclerosis Registry: a 50-year ...](#) - Koch-Henriksen - Navedeno v 71 virih

[... sclerosis: results from the Danish Multiple Sclerosis ...](#) - Koch-Henriksen -

Navedeno v 60 virih

[... Multiple Sclerosis Registry. History, data collection and ...](#) - Koch-Henriksen -

Navedeno v 42 virih

Ljubljana

Spremeni lokacijo

Splet

Strani iz države

Slovenija

Prevedene tuje

strani

Več orodij

### [NARCOMS | Multiple Sclerosis Patient Registry](#)

[www.narcoms.org/](http://www.narcoms.org/) - Posnetek - Prevedi to stran

NARCOMS is a global **registry** for **Multiple Sclerosis** research, treatment, and patient education. The **Registry** is an active database of over 35000 persons with ...

↳ [Become a Participant](#) - [Data Access and Collection](#) - [Researchers & Providers](#)

### [Registry Will Track Multiple Sclerosis To Help Combat The Disea...](#)

[www.medicalnewstoday.com/.../105177.php](http://www.medicalnewstoday.com/.../105177.php) - Posnetek - Prevedi to stran


24 Apr 2008 – Congressmen Michael C. Burgess, M.D. (R-Texas) and Russ Carnahan (D-Missouri) introduced bi-partisan legislation to create a national ...

### [The Danish Multiple Sclerosis Registry: a 50-year follow-up — M...](#)

[msj.sagepub.com/content/5/4/293.abstract](http://msj.sagepub.com/content/5/4/293.abstract) - Prevedi to stran

napisal/-a N Koch-Henriksen - 1999 - Navedeno v 71 virih - Sorodni članki

Department of Neurology, Aalborg Hospital North, DK-9100 Aalborg, Denmark, The Danish **Multiple Sclerosis Registry**, Rigshospitalet afsn. 7013, DK-2100 ...

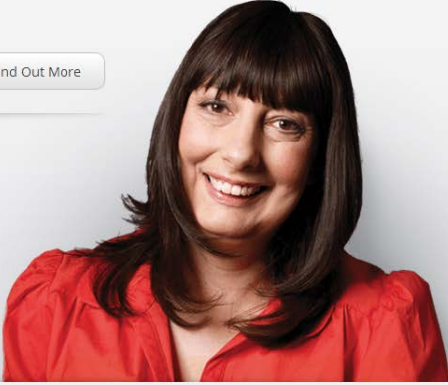
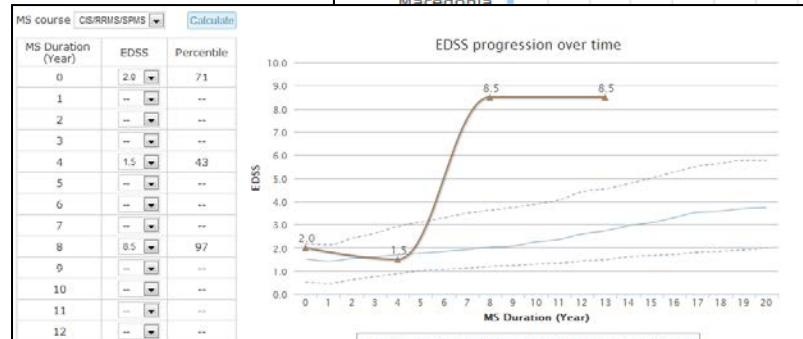
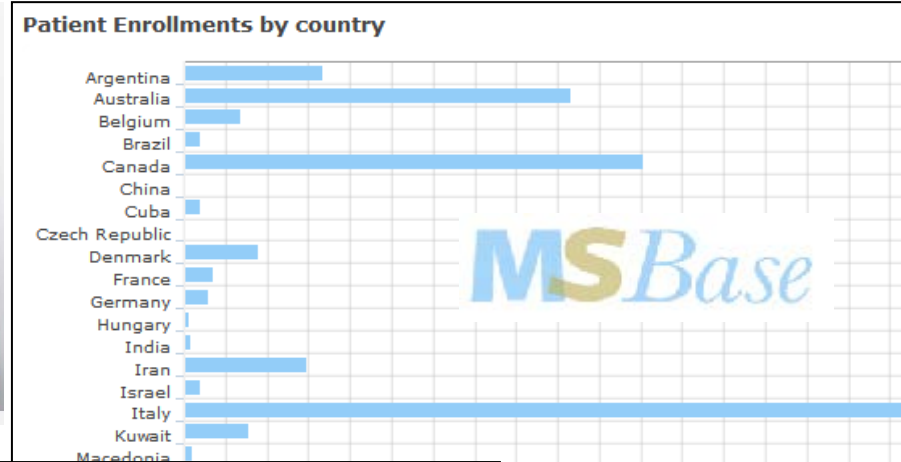



**MS REGISTER**

Join the Study   Find Out More

**\*Help Make Sense of MS**

The MS Register is a ground-breaking study designed to increase our understanding of living with MS in the UK. Join the study by completing series of simple questionnaires.

Neurology. 2011 Jan 4;76(1 Suppl 1):S3-6.

## Registry studies of long-term multiple sclerosis outcomes: description of key registries.

Hurwitz BJ.

Department of Medicine Neurology, Box 3184, Duke University Medical Center, Durham, NC 27710, USA. [hurwi003@mc.duke.edu](mailto:hurwi003@mc.duke.edu)

Neurology. 2011 Jan 4;76(1 Suppl 1):S3-6.

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Department of Medicine Neurology, Box 3184, Duke University Medical Center, Durham, NC 27710, USA. hurwi003@mc.duke.edu

### Observations

- MS registries: **valuable insights** into the natural history of MS.
- **Difficulties with registries: lack of consistency between databases**

### Recommendations

- **Improved inter-registry consistency** in order to better compare and contrast the results of different registries was advocated.
- To follow the course of MS, the initiation of a **prospective, complete, verifiable database** of patients with clinically isolated syndrome was also recommended.

# ISSUES WITH REGISTRIES

## Differences in:

- Content (clinical, population based)
- Semantics (meaning)
- Quality, update frequency, completeness

## Limited potential to use the data

- Across registries
- Across countries

## WISHES:

### Compare:

- Clinical effectiveness
- Cost efficiency
- Quality of treatment

### Share, merge

- Aggregated
- anonymized data

### Across:

- Member States
- Clinical fields

# EU PERSPECTIVE

**Second programme of community action** in the field of health:

3.3.1.4. Cross-border e-Health instruments as supporting tools for medical information and research

**Directive on cross-border healthcare:**

The eHealth Network shall *,draw up guidelines on effective methods for enabling the use of medical information for public health and research‘*

# WHY PARENT?

*Aim:* to rationalise and harmonise the  
**development and governance** of patient  
registries

*Goal:* support MemStates in developing  
**comparable and coherent patient registries**

*Goal:* support MemStates states in the provision of  
**information** on the relative efficacy and  
effectiveness of health technologies.

# OUTLINES

Start: May 2012 (K-O 13. 6. 2012)

Duration: 30 months

Budget: 3.2 Mio € (60% EC)

11 Associated partners

12+ Collaborating partners



# OBJECTIVES

Overview

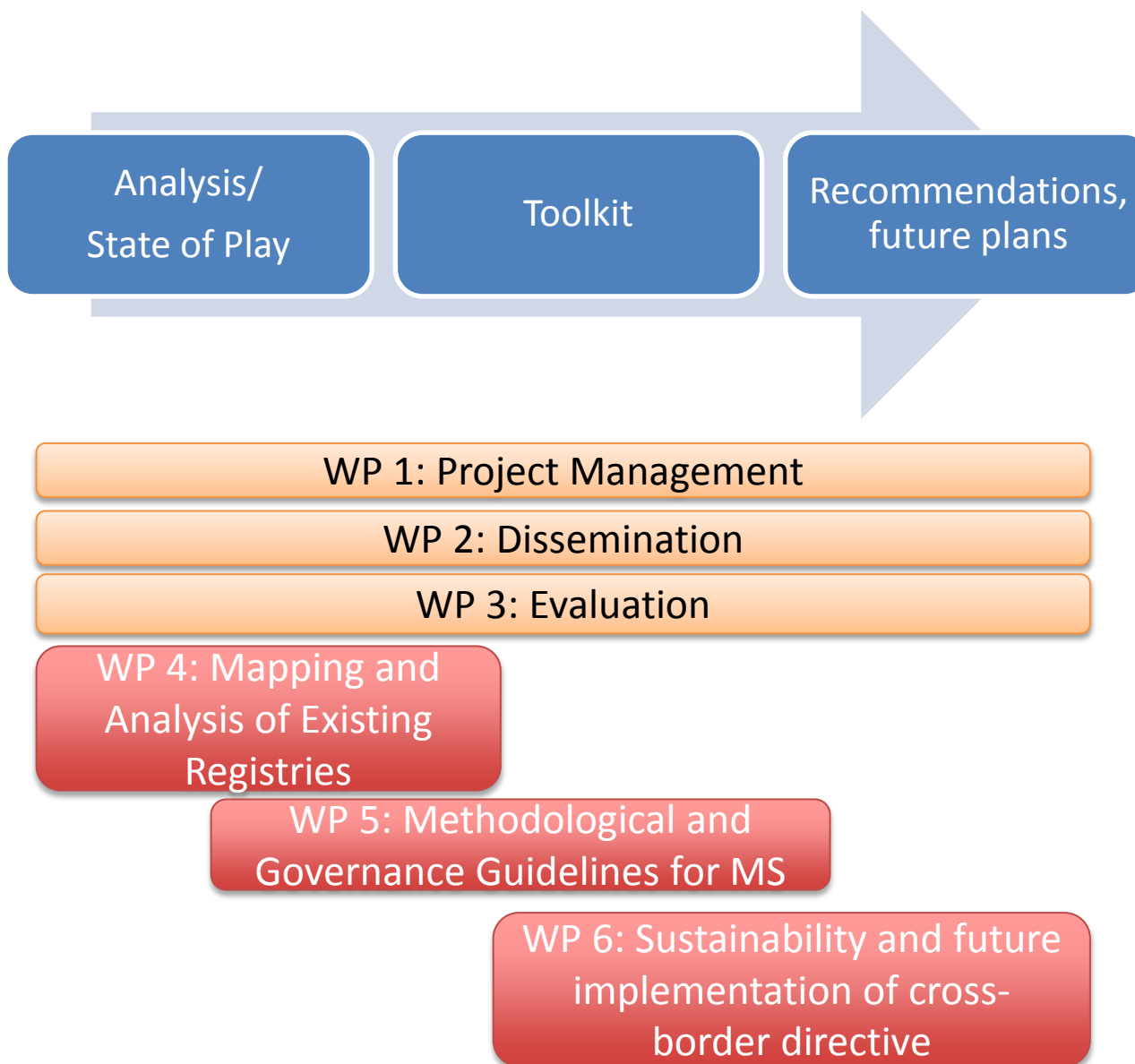
Coordination

EU-level source

Recommendations, guidelines and IT  
components

Sustainable cross-border collaboration on  
secondary use

Support of implementation of the Cross-  
border HC Directive.



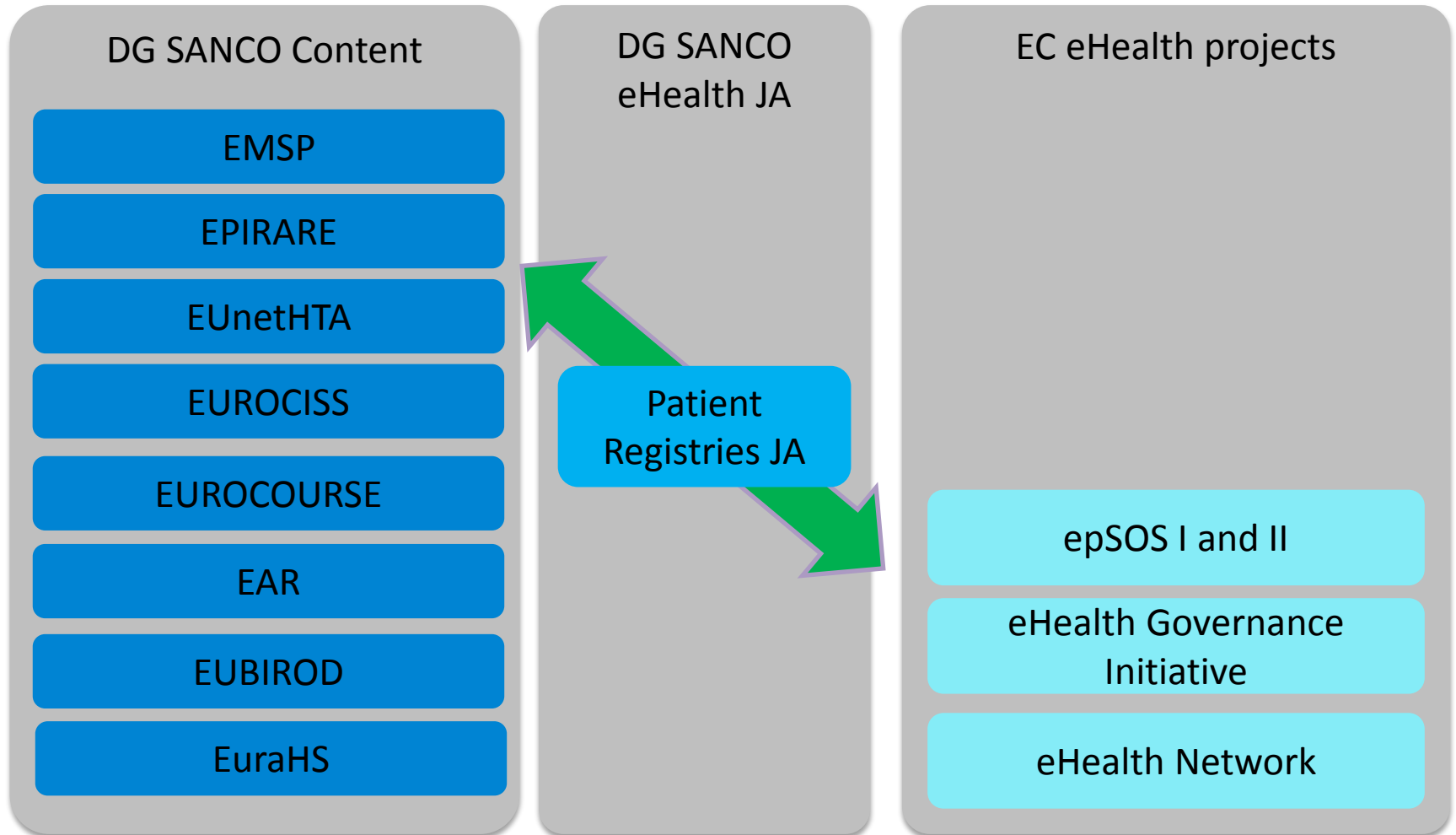
## MAIN AND ASSOCIATED PARTNERS

Country	Partner
Slovenia	National Institute of Public Health, MoH
Malta	Ministry of Health, the Elderly & Community Care
Slovakia	Národné centrum zdravotníckych informácií
Portugal	Direcção-Geral da Saúde
Croatia	National Institute of Public Health
Finland	National Institute of Health and Welfare
Hungary	National Institute for Quality- and Organizational Development in Healthcare and Medicines
Latvia	The Centre of Health Economics
Italy	MoH
Spain	Centro Superior De Investigación En Salud Pública/Dirección General De Salud Pública
Greece	National and Kapodistrian University of Athens

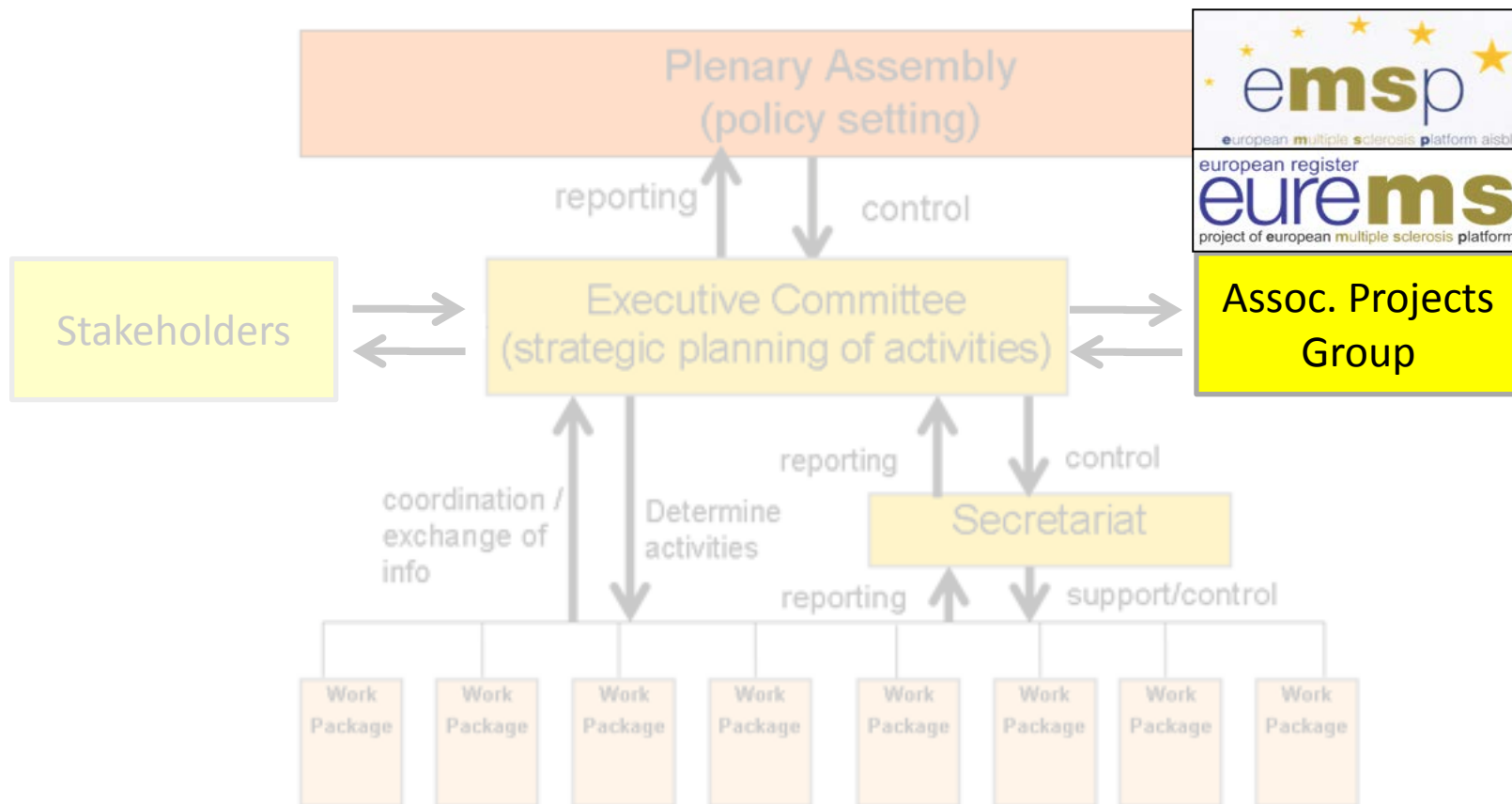
## COLLABORATING PARTNERS

Country	Partner
Austria	MoH
Poland	MoH
Estonia	MoSocial Affairs
Belgium	Public Health, Food Chain Control and Environment
Cyprus	MoH
Denmark	National Board of Health
Spain	MoH
Sweden	National Board of Health and Welfare
EU/UK	European Medicines Agency
Romania	National Health Insurance House
France	Institut national de la santé et de la recherche médicale
Intl./UK	European Academy of Allergy and Clinical Immunology
	And more in process.

# INTERRELATIONS



# MANAGEMENT STRUCTURE



# BENEFITS FOR MS SOCIETY

A channel to distribute your best practices across **clinical disciplines** and **Member States**

A way to **influence the recommendations** to Member States for:

- Registry design
- Governance process
- Demographic data
- Clinical semantics for data cross-sharing

Benefit from **generic IT components** developed within PARENT



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# cross border patient registries initiative PARENT JOINT ACTION

[www.patientregistries.eu](http://www.patientregistries.eu)



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