HOW TO INCREASE ADDED VALUE OF PATIENT REGISTRIES?

cross border PAatient REgistries iNiTiative - PARENT Joint Action

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Multiple sclerosis registry

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

NARCOMS | Multiple Sclerosis Patient Registry
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 - 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 - 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 ...
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
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.
Analysis/State of Play

Toolkit

Recommendations, future plans

WP 1: Project Management

WP 2: Dissemination

WP 3: Evaluation

WP 4: Mapping and Analysis of Existing Registries

WP 5: Methodological and Governance Guidelines for MS

WP 6: Sustainability and future implementation of cross-border directive
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<tr>
<th>Country</th>
<th>Partner</th>
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<tr>
<td>Slovenia</td>
<td>National Institute of Public Health, MoH</td>
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<td>Malta</td>
<td>Ministry of Health, the Elderly &amp; Community Care</td>
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<tr>
<td>Slovakia</td>
<td>Národné centrum zdravotníckych informácií</td>
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<td>Portugal</td>
<td>Direcção-Geral da Saúde</td>
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<td>Croatia</td>
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<td>Finland</td>
<td>National Institute of Health and Welfare</td>
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<td>Hungary</td>
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<td>The Centre of Health Economics</td>
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<td>Centro Superior De Investigación En Salud Pública/Dirección General De Salud Pública</td>
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<td>Institut national de la santé et de la recherché medicale</td>
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<tr>
<td>Intl./UK</td>
<td>European Academy of Allergy and Clinical Immunology</td>
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And more in process.
INTERRELATIONS

DG SANCO Content
- EMSP
- EPIRARE
- EUenetHTA
- EUROCISS
- EUROCOURSE
- EAR
- EUBIROD
- EuraHS

DG SANCO eHealth JA

Patient Registries JA

EC eHealth projects
- epSOS I and II
- eHealth Governance Initiative
- eHealth Network
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
cross border patient registries initiative
PARENT JOINT ACTION

www.patientregistries.eu