WG-3

Inventory of EU data sources and methodological approaches for multi-source studies

Participants WG 3

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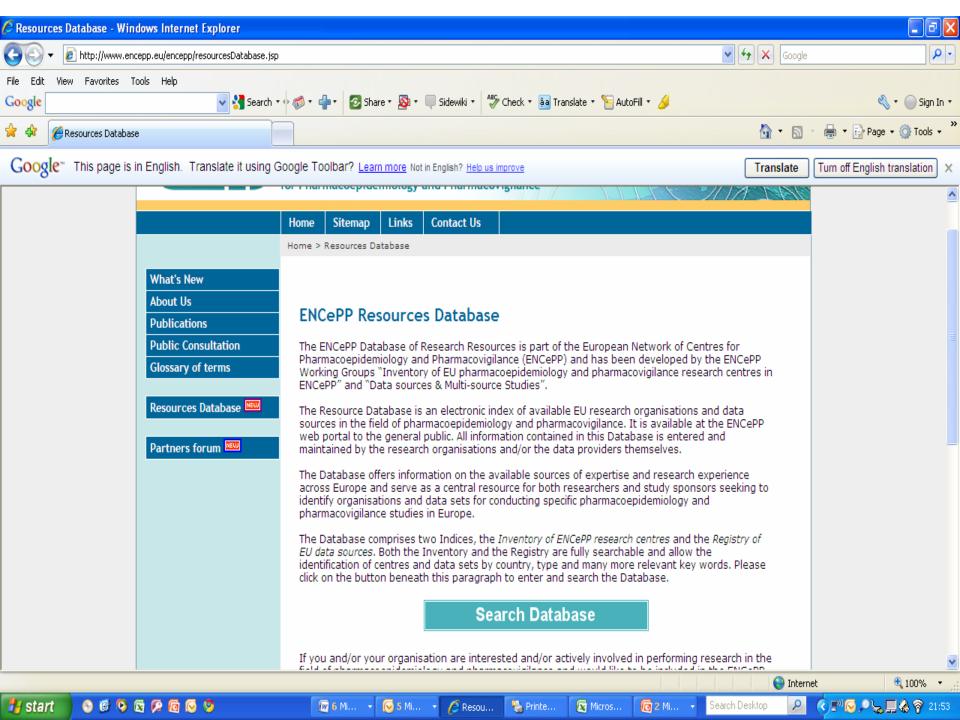
Registry of EU data sources

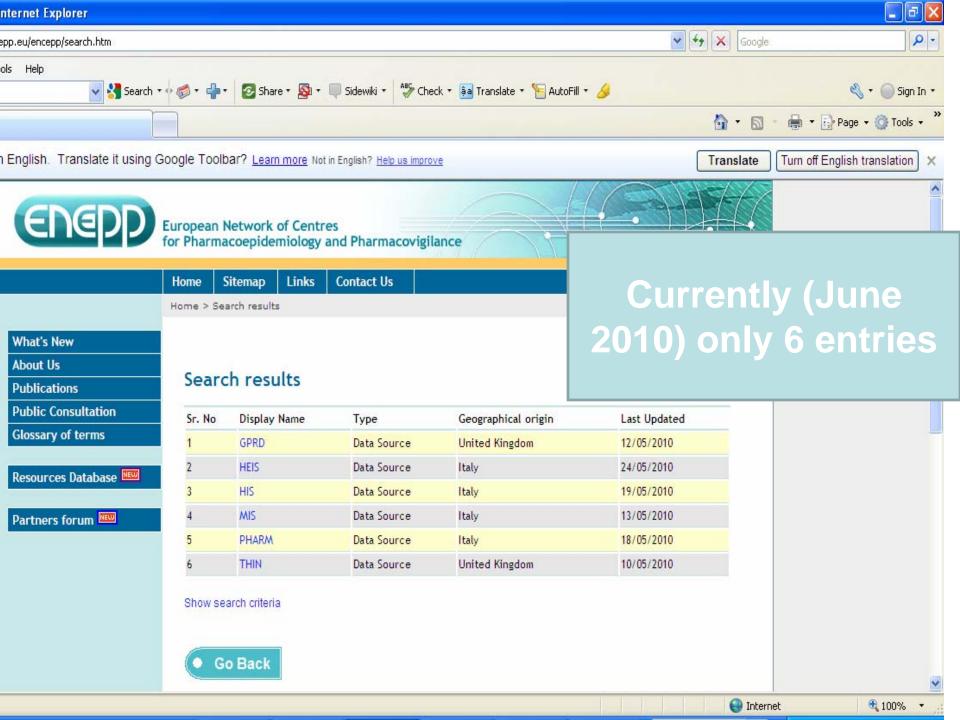
EU Inventory of data sources

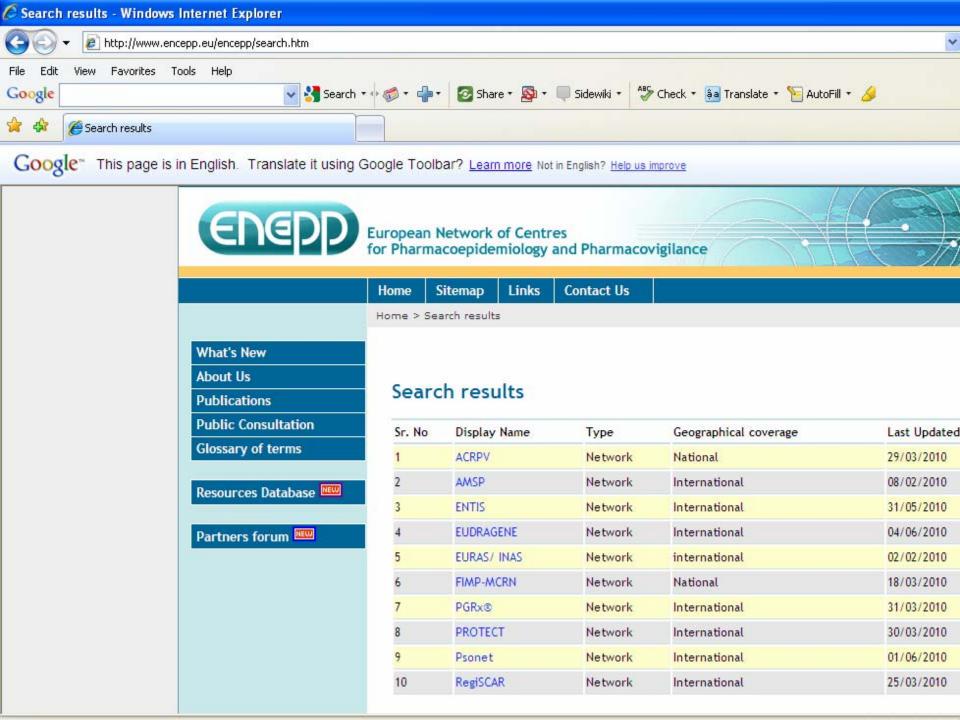
 Define the elements that the EU inventory of data sources should have, according to different categories (e.g. Databases, Disease Registries, Exposed Registries, Case-control surveillance...)

Achievements

- During 2009 the Working Group developed an electronic questionnaire allowing collection of essential information on the data sets to be included in the electronic inventory of EU data sources.
- The final questionnaire was agreed following consultation of ENCePP.
- Electronic version of database released May 2010







- Identify existing data sources useful for PE and PV research
 - Ongoing activity (we will solicit persons to enter information in the system)
- Identify relevant areas of PE and PV not covered by the existing data sources in the EU.
 - Next year, based on data in the system
- Explore ways to stimulate and support initiatives to create new data sources in EU member states
 - Next year, based on data in the system

Approaches & processes for interoperability and sharing of European epidemiology data sources

- Discuss operational approaches for organising, initiating and performing of observational safety studies through ENCePP
 - Many ENCePP centers involved in EC /IMI funded research: first experiences in collaborating (expericences will be reviewed, today first presentations) Too early to draw conclusions, although distributed data network seems most commonly used approach
 - ICPE has installed task force on common data models.
- Explore ways of performing multi-source studies
 - WG will critically review all ongoing publicly and privately financed initiatives (once studies are registered on website)
- Develop training programs
 - Included in IMI funded EU2P program (WP 6)

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Data Privacy restrictions for PE/PV research

- Develop approaches to overcome differences in national legislation on data privacy in order to facilitate multi-national database studies, taking into account legal advice.
 - In several EC funded projects this information has been collected and delivered. Mostly issue of governance and depending on type of data
 - Information from EU-ADR, SOS, ARITMO, VAESCO and Protect consortia to be collated and reviewed by EC lawyer (coming year)
- Develop common rules to protect patients' and providers' rights with respect to data confidentiality

Request WG 3

Enter database and network information on website

 Please provide WG with document on ethical and privacy issues if data are shared in multicountry study

 We welcome new WG members (especially if participating in multi-country DB studies)