

WG-3

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

Participants WG 3

- **Chair:** Miriam Sturkenboom
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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

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ENCePP Resurces Database

The ENCePP Database of Research Resources is part of the European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP) and has been developed by the ENCePP Working Groups "Inventory of EU pharmacoepidemiology and pharmacovigilance research centres in ENCePP" and "Data sources & Multi-source Studies".

The Resource Database is an electronic index of available EU research organisations and data sources in the field of pharmacoepidemiology and pharmacovigilance. It is available at the ENCePP web portal to the general public. All information contained in this Database is entered and maintained by the research organisations and/or the data providers themselves.

The Database offers information on the available sources of expertise and research experience across Europe and serve as a central resource for both researchers and study sponsors seeking to identify organisations and data sets for conducting specific pharmacoepidemiology and pharmacovigilance studies in Europe.

The Database comprises two Indices, the *Inventory of ENCePP research centres* and the *Registry of EU data sources*. Both the Inventory and the Registry are fully searchable and allow the identification of centres and data sets by country, type and many more relevant key words. Please click on the button beneath this paragraph to enter and search the Database.

[Search Database](#)

If you and/or your organisation are interested and/or actively involved in performing research in the field of pharmacoepidemiology and pharmacovigilance, and would like to be included in the ENCePP



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Sr. No	Display Name	Type	Geographical origin	Last Updated
1	GPRD	Data Source	United Kingdom	12/05/2010
2	HEIS	Data Source	Italy	24/05/2010
3	HIS	Data Source	Italy	19/05/2010
4	MIS	Data Source	Italy	13/05/2010
5	PHARM	Data Source	Italy	18/05/2010
6	THIN	Data Source	United Kingdom	10/05/2010

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Currently (June 2010) only 6 entries


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2	AMSP	Network	International	08/02/2010
3	ENTIS	Network	International	31/05/2010
4	EUDRAGENE	Network	International	04/06/2010
5	EURAS/ INAS	Network	international	02/02/2010
6	FIMP-MCRN	Network	National	18/03/2010
7	PGRx®	Network	International	31/03/2010
8	PROTECT	Network	International	30/03/2010
9	Psonet	Network	International	01/06/2010
10	RegiSCAR	Network	International	25/03/2010

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