



Bridge Health EUBIROD Network Meeting
Hotel Archimede, Via dei Mille 19, Roma,



Italy

23rd-24th November 2015

WP 8 Task 2

Massimo Massi Benedetti

President of HIRS

Chairman of the EUBIROD Network

WP8

Platform for population based registries

To maintain and strengthen the implementation of population based registries for chronic diseases with standardization of methodologies for producing standardized EU-wide indicators taking selected clinical conditions as test cases Platform for population based registries

WP8-Task2

Specific Objective

Provision of privacy-enhanced software for statistical analysis, data exchange, and automated calculation of indicators, both locally and at EU level

Process Indicator(s)

1. Development of a data dictionary for multiple chronic diseases through cooperation with register managers
2. Development of the BIRO analytic open source system for general application in population based disease registers
3. Application of the privacy performance assessment methodology in different chronic conditions

Target

Downloadable from website

Downloadable from website

Downloadable from website

Output Indicator(s)

Target

1. Data dictionary registry tool available online

Applied in at least two chronic diseases

1. Integrated suite of open source tools, including user interface, available online
2. Manual of technical specifications for users and programmers
3. Automated reports including ECHI indicators

Applied in at least two chronic diseases

1. Privacy performance assessment tool available online for selected diseases
2. Report on privacy performance assessment available for different chronic conditions.

Applied in at least two chronic diseases

Outcome/Impact Indicator(s)

Target

- | | |
|---|-------|
| 1. High percentage of data custodians from participating registers actively contributing to the data dictionary | > 80% |
| 2. High percentage of participating registers able to deliver local reports and transmit indicators to the EU level, with a high level of user satisfaction | > 80% |
| 3. High percentage of participating registers conducting privacy performance assessment | > 80% |

Task 8.2

1. Building upon the successful experience of major EU projects conducted in the field of diabetes, this task will take advantage of the continuing EUBIROD network of registers, coordinated by HIRS, to make further progress and deliver results across different disease areas.
2. The implementation the set of standardized definitions identified for diseases selected in Task 1 into a general population-based register data dictionary
3. Adjusting and further developing the BIRO suite of open source software for data management, statistical analysis and automated delivery of indicators.
4. The further development of the software will be facilitated by a user friendly interface that will enable data custodians to produce local reports and transmit data towards a central location for the routine production of EU indicators (e.g. ECHI shortlist).
5. The compliance of the whole process to privacy and data protection rules will be supervised by targeted evaluation methods made available to participating registers.
6. Development of technical manuals, including sets of recommendations for personnel involved in data processing of population-based registers.

Task 8.2

- | MS32 (UNITOV): 8.2 Blueprint of open source platform for population-based chronic disease registers (draft), M 18
- MS33 (UNITOV): 8.3 Manual of technical specifications for users and programmers (draft), M18 [Manual of technical specifications for users and programmers (draft)]
- MS35 (UNITOV): 8.5 Blueprint of open source software platform for population-based chronic disease registers (final), M30 [Blueprint of open source software platform for population-based chronic diseases registries, based on the BIRO experience]
- MS36 (UNITOV): 8.6 Manual of technical specifications for users and programmers (final), M30 [Manual of technical specifications for users and programmers (final)]

Key Personnel

Task 8.2

- ▮ Prof. Massimo Massi Benedetti, Chairman of the EUBIROD Network, President and Scientific Director of the HIRS, Specialist in Endocrinology and Internal Medicine.
- ▮ Fabrizio Carinci, Professor of Health Systems and Policy, School of Health Sciences, University of Surrey, UK
- ▮ Luigi Uccioli, Professor of Endocrinology and Geriatric Medicine, University of Tor Vergata. Patrizia Borboni and Fabrizio Jacoangeli, Endocrinologist Clinical Research Fellows at the University of Tor Vergata.
- ▮ Concetta Tania Di Iorio, International expert on privacy impact assessment of EU health information systems, Serectrix snc, Italy.
- ▮ Stefano Gualdi, senior open source programmer, principal developer of the BIRO system
- ▮ EUBIROD network: <http://www.hirs-research.eu/eubirod/members.html>