**Session group 13**

# Data protection and linking databases

Moderators:
Carlo Gagliotti (ASR-Regione Emilia-Romagna, Italy)
Sergio Brusin (ECDC)

# Agenda

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| 16:15 – 16:25 | **Welcome and nomination of rapporteurs**<br>*Carlo Gagliotti* (ASR-Regione Emilia-Romagna, Italy) & *Sergio Brusin* (ECDC) |
| 16:25 – 16:40 | **What is personal data?**<br>*Sergio Brusin* (ECDC) |
| 16:35 – 16:45 | **Discussion (Feasibility at national level & issues for ECDC)**<br>*All* |
| 16:45 – 17:00 | **Overview of possible applications of linking databases at national and ECDC level**<br>*Carlo Gagliotti* (ASR-Regione Emilia-Romagna, Italy) |
| 17:00 – 17:30 | **Round Table & Discussion**<br>*All* |
| 17:30 – 17:40 | **ECDC data access policy**<br>*Sergio Brusin* (ECDC) |
| 17:40 – 17:55 | **Discussion**<br>All |
| 17:55 – 18:00 | **Closing remarks**<br>*Carlo Gagliotti* (ASR-Regione Emilia-Romagna, Italy) |

# Summary of findings
## *Linking ARHAI databases*

**At individual level (Patient counter)**

- Wide range of additional analysis with adjustments for confounding at individual level
- Useful at national and ECDC level

**But there are:**

- Technical obstacles
- Data protection issues

# Summary of findings
## *Linking ARHAI databases*

**At hospital level (HospitalID)**

•Describing multiple dimensions of HAI and AMR epidemiology at hospital level

•Exploring correlation between structure and process indicators and various clinical outcomes

•Improving risk adjustment

•Useful at national and ECDC level

**But there are obstacles to obtain consistent codes between datasets:**

•Different data source

•Linkage feasible only for hospital participating to more networks

•Disagreement at national level

# Conclusions – Decisions
(what has been agreed upon)

## Minimal objective

• Stable linkage of AMRTEST and AMRDENOM data

1. Use of coded values for HospitalID
2. HospitalID mandatory in both databases

## Perspectives
(what will happen in 2012, and possibly 2013 onwards)

•Harmonization of Hospital codes in ARHAI databases (HAISSI, HAIICU, HAIPPS, AMRTEST, AMRDENOM)

# Access to ECDC ARHAI – TESSy data

ECDC is caught between the obligation of transparency due to european laws on one side and the EU data protection regulations on the other.

The third important component is the will and obligations of the MS due to their own national laws and contractual obligations with the providers of data.

# Access to TESSy ARHAI data

Examples of reasons considered to suggest refusal to third party access to data

- There is the possibility of breach of confidentiality on "personal data"

- The data is claimed as <u>intellectual property</u>

- The request for data is made by a disreputable body or individual or it is made in an anonymous manner

The group pointed out that also contractual obligations with MS data providers (hospital) should be considered as possible ground for refusal to share data with third parties

# Solutions

Peer review group

Restricted access procedures

Selective access to databases