



B.I.R.O.

Best Information through Regional Outcomes

A European Public Health Project, DG-SANCO, 2005-2008

Privacy Impact Assessment

Introduction

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Privacy Impact Assessment: w h y?

Preamble:

- there are INCREASING limitations in the management of health information
- The interest of health authorities and policy makers is INCREASINGLY in conflict with more strict regulations imposed by privacy authorities
- DG-SANCO is INCREASINGLY aware of the difficulties of local data collection and international data connection

- EXISTING APPROACHES IN EU PROJECTS AVOID THE PROBLEM BECAUSE THEY ARE MOSTLY:
 - Sample Surveys based on Individual Consent
 - Compilation of existing national statistics
 - Ad-hoc epidemiologic studies based on Individual Consent



Privacy Impact Assessment: w h y?

Strengths:

- BIRO PROPOSES AN INNOVATIVE APPROACH OFFERING THE EU (INDIRECT) ACCESS TO PRIMARY LONGITUDINAL DATA IN A MAJOR CHRONIC DISEASE
- REGISTERS OPERATE INDEPENDENTLY ON A CONTINUOUS BASIS THROUGH LOCAL SUPPORT
- ASSUMPTION: LOCAL REGISTERS COMPLY WITH LOCAL AND NATIONAL PRIVACY REGULATION
- BIRO WILL PROVIDE A GENERAL PROTOTYPE AND A VALUABLE “PROOF OF CONCEPT” FOR EU INFORMATION EXCHANGE



Privacy Impact Assessment: w h y?

Weaknesses:

- THE BIRO APPROACH MAY NOT BE IMMEDIATELY RECOGNIZED AS A MEANS TO ENHANCE THE EUROPEAN COMMUNITY ACTION IN PUBLIC HEALTH
- THE PROJECT IS BASED ON MASSIVE DATA COLLECTION THAT CAN BE TOO COMPLICATED FOR EU INSTITUTIONS
- THE MAASTRICHT TREATY DOES NOT INVOLVE REGIONS
- THE RESULT IS DETAILED, BUT THE EU POPULATION COVERAGE IS LOW
- LOCAL PROVIDERS OR HEALTH AUTHORITIES MAY BE THREATENED BY INTERNATIONAL INFORMATION EXCHANGE



Privacy Impact Assessment: w h y?

Opportunities:

- A LARGE NUMBER OF NEW PARTNERS WANTS TO PARTICIPATE
- THE PROJECT IS FUNDED A SECOND ROUND
- NEW RESEARCH PROJECTS ARE CONCEIVED, SUBMITTED AND GRANTED ON TOP OF THE EXISTING INFORMATION INFRASTRUCTURE

CONSEQUENCES:

- THE BIRO APPROACH IS RECOGNIZED AS A MILESTONE OF SUSTAINABLE DATA COLLECTION, INFORMATION EXCHANGE AND SYNTHESIS FOR POLICY MAKING AT THE EU LEVEL
- INTERNATIONAL DIABETES POLICY RELIES ON BIRO RESULTS



Privacy Impact Assessment: w h y?

Threats:

- POOR FUNDS DO NOT ALLOW PROPER CONSTRUCTION, MAINTENANCE AND PROMOTION OF THE SYSTEM
- FOCUS ON TECHNOLOGY TOO STRONG FOR CURRENT HEALTH SYSTEMS
- PUBLICATION OF COMPARATIVE ANALYSIS GENERATES CONCERN, POLITICAL PRESSURE IS USED TO DISCOURAGE USE OF THE SYSTEM
- THREAT TO THE PRIVACY OF CITIZENS, PROVIDERS AND INSTITUTIONS MAY BE USED AS A STRONG AND OBJECTIVE CAUSE TO SHUT BIRO OFF

CONSEQUENCES:

- THE BIRO APPROACH IS NO MORE SUPPORTED AT THE EU LEVEL
- COMMITMENT AND COLLABORATION VANISH



Privacy Impact Assessment: w h y?

Conclusions:

- THE BIRO CONSORTIUM:
 - IS AHEAD OF TIME
 - INCLUDES FEW PIONEERS, POORLY FUNDED FOR THE SCOPE
 - (AS OF TODAY) LACKS INFLUENT DG-SANCO PLAYERS

Recommendations:

- KEEP IT SIMPLE – but not simplistic: let's find working solutions, make an efficient use of resources through minimal efforts and maximum collaboration
- BE SMART – surf the virtuous cycle alternating the local activities with BIRO collaboration
- BE WISE:
 - PROVIDE A STRONG CASE TO SHOW HOW SECURE AND COMPLIANT WITH INTERNATIONAL LEGISLATION IS THE USE AND EXCHANGE OF HEALTH INFORMATION OCCURRING IN THE BIRO PROJECT



P.I.A.

TASKS



PIA TEAM

1. MEMBERS ?
2. FEEDBACK ON SUGGESTED READINGS ?????



Preliminary Phase

- ❑ The privacy facilitator will deliver a Preliminary PIA Report by 1st December 2006

- ❑ **The PIA report includes:**
 - Introduction/project background
 - Legislative and policy framework
 - Description of personal information (required level of data aggregation and data flow)
 - Potential privacy risks
 - Overview of security requirements
 - PIA plan

- ❑ Reminder: at least a summary description of personal information to be used and data flow is needed to perform this task



Immediate Deadlines

□ Review of core articles:

- PIA team members to identify privacy protective criteria/requirements
- Privacy facilitator to merge all applicable key criteria/requirements and circulate draft checklist
- Draft **checklist** to be discussed and finalised

Deadline: 15th October 2006

□ Planned Architecture:

- PIA Team members to provide summary description of personal information used in the project and data flow

Deadline: 30th October 2006

- PIA Team members to select a limited number of BIRO candidate alternative architectures

Deadline: 30th November 2006