HEALTH INFORMATION INFRASTRUCTURE PROJECT: PROGRESS REPORT

HCQI Expert Group Meeting

7-8 November 2013
Agenda to improve health information infrastructure

» In 2010, health ministers called for improvement in national information infrastructure to provide the evidence base needed for health care quality and system performance improvements

» Health Committee supported projects in 2011/12 and 2013/14 to strengthen health information systems

• Work to be guided by the Health Care Quality Indicators Expert Group (HCQI)
THE HCQI EXPERT GROUP
INFORMATION INFRASTRUCTURE
PROJECT IN 2011-12
Fact finding in 2011 and 2012

» Survey of 20 countries on the use of personal health data to monitor health and health care quality to:
   » Understand the potential, the barriers and the best practices in the linkage of personal health data
   » Explore the privacy and data security environment

» Survey of 25 countries development and use of personal health data from electronic health records
   » Found considerable cross-country variation – linked to differences in risk-management in balancing data access and data privacy
Health Policy Brief and preliminary report disseminated 2 April 2013
http://www.oecd.org/els/health-systems/strengtheninghealthinformationinfrastructure.htm

Final publication to be released in June 2013
Dissemination (2)

» Article in *Health Policy*, September 2013 issue, “International comparisons of health system performance among OECD countries: Opportunities and Data Privacy Protection Challenges”

» Presentations:
  » ISQua, Geneva, 2012
  » World Health Forum, panel, Berlin, 2012
  » EuroREACH Conference, Vienna, 2013
  » European Parliament, Workshop on Health IT, Brussels, 2013
  » Conference on QA of the Federal Joint Committee, Berlin, 2013
THE HCQI EXPERT GROUP
INFORMATION INFRASTRUCTURE
PROJECT IN 2013-14

Project contact:
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The product of our effort would be:

» An OECD publication in mid-2015
  » Describing the sources and uses of personal health data among countries
  » Describing the risks to health, to health system governance and to individual data privacy of data use and when data resources are not used
  » Describing good/promising practices to mitigate risk
  » Illustrating the “real world” application of these promising practices through case studies

» The completeness and validity of the publication would be strengthened from the input of stakeholder communities gathered through surveys, interviews and a workshop
Purpose and audience

Purpose of this report is to

» Provide information about applying a risk management framework to decisions about data use
» Support consistent and well-informed decisions about data protection in data use
» Ensure that information about promising practices in data security and protection circulates widely
» Encourage consideration of secondary data uses and data protection as new data sources become available

Audience

» Health ministries, privacy regulators, data custodians, data users (researchers, IT)
Provide advice and guidance at all stages including:

- Work plan
- Instruments and techniques for the collection of evidence
- Plans and modalities to consult with stakeholders
- Conclusions and recommendations
- Review of material for publication

Drawn from health policy, statistics, research, privacy regulation, law, information technology, and civil society communities.

Convened quarterly by Web-conferencing
Information gathering in 2013 to...

» Monitor developments in national health information infrastructure since 2011

» Gather evidence necessary to categorise the privacy, health and governance risks associated with different forms of health data

» Gather evidence necessary to understand and evaluate current and emerging practices for privacy protection for data with different risks

» Develop a vocabulary to promote a common understanding of key terms
Country questionnaire

» Target respondents: HCQI country representatives who will coordinate with other organisations in custody of key datasets

» Part A: Personal health data development and use
  » Datasets
  » Dataset linkages
  » Access to data
  » Data governance

» Part B: National projects involving personal health data

» Part C: Multi-country projects involving personal health data
+6 countries who have signalled their intent to submit by December 2013
Interviews with experts

- Question sets tailored to each type of expert
- Experts in data privacy, project approval, data processing, access, routine use and analysis
- Identified from questionnaires and literature review
- Interviews to understand current practices to:
  - Initiate projects
  - Approve projects
  - Protect data security
  - Process data
  - Provide access to data
  - Supervise access to data
  - Train staff and/or external researchers
  - Assess results
## Next steps

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<th>Key steps</th>
<th>Time Frame</th>
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<tr>
<td>1. Survey of countries</td>
<td>Extension to December 2013</td>
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<td>2. Interviews with experts</td>
<td>October – January 2014</td>
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<td>3. First draft report monitoring progress in national information infrastructure to HCQI for comments</td>
<td>February-March 2014</td>
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<td>4. First draft risk categorisation and promising practices report to HCQI and WPISP for comments</td>
<td>Summer 2014</td>
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<td>5. Feedback from stakeholder communities</td>
<td>October – December 2014</td>
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<td>6. Final review of the consolidated report by the HCQI and WPISP</td>
<td>2015 (tbd)</td>
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<td>7. International workshop on strengthening health information infrastructure</td>
<td>2015 (tbd)</td>
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REPORT ON DATA-DRIVEN HEALTH CARE INNOVATION, RESEARCH AND POLICY

Project contacts:
Jillian.Oderkirk@oecd.org and Elettra.Ronchi@oecd.org
OECD report on the data driven economy as a source of economic growth

A multi-sectorial project - health, consumer policy, data protection, public-sector governance and science and innovation

HCQI Information Infrastructure Project findings to contribute to a chapter about health data and to an associated report for the Health Committee

Health Committee report to be shared with the HCQI in November

Full OECD report will be reviewed by the Health Committee in winter 2014

Publication anticipated in the fall of 2014
Data Driven Health Care Innovation, Management and Policy (DELSA/HEA(2013)13)

- Drivers of data use in the health sector
- Data sources for research innovation, health care delivery and performance-based governance
- Insights from data to improve health care and health care systems
- New and emerging health data analytics and approaches
- Challenges in building a data-driven health sector
- Success factors in developing the potential of big data
- Conclusions and next steps at the international level
MEASUREMENT OF THE AVAILABILITY AND USE OF INFORMATION AND COMMUNICATIONS TECHNOLOGIES IN THE HEALTH SECTOR

Project contact: Elettra.Ronchi@oecd.org
Health ICT benchmarking effort began 2008
International consensus in Barcelona 2010
Review of international efforts
International workshop January, 2012 in Paris defined survey content domains
Four task forces established in 2012 to develop survey questions - Broad participation of countries
OECD-EC April 2013 Workshop to review draft survey and methodological guidelines
Draft survey and methodological guidelines prepared for final comments
Survey will be tested in six pilot countries in 2014
CONCLUSION
Members are invited to:

» Note the progress made on the project to strengthen health information infrastructure

» Advise on next steps

» Note the progress on the Guide to Measuring ICTs and recommend that the Health Committee declassify the guide (agree it can be disseminated).