ELECTRONIC HEALTH RECORDS – COMPARABLE AND SAFE PATIENT DATA FOR EFFICIENT HEALTH CARE SYSTEMS IN EUROPE:
WHERE ARE WE?

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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.

Ministerial Communiqué called for more effective use of data that has been already collected.

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

- Work is guided by the Health Care Quality Indicators Expert Group (HCQI)
Evidence about the outcomes of care for performance-based governance

Two key prerequisites

- Collection and storage of data at the level of individual patients/persons
  - E.g. registries, administrative data, surveys
- Capacity to follow patients through the cycle of care to relate care to outcomes
  - Often requires data linkage because few databases have all of the information needed
- Could be based on electronic health records
OECD health information infrastructure projects

1. Electronic health record system development and its potential use to monitor health care quality and system performance

2. Health and health care monitoring and research using personal health data and the protection of information privacy

3. New projects in 2013-2015 to address privacy protection challenges in the use of personal health data
1. ELECTRONIC HEALTH RECORD SYSTEM DEVELOPMENT AND ITS POTENTIAL USE TO MONITOR HEALTH CARE QUALITY

KEY FINDINGS
For our study we defined electronic health record systems as:

- **The longitudinal** electronic record of an individual patient that contains or virtually links together records from **multiple** electronic medical records which can then be **shared** (interoperable)

- Such systems aim to improve the quality, safety and efficiency of health care
Desired qualities of EHR system records include:

- Accuracy, completeness, comprehensiveness, reliability, relevance, timeliness and accessibility

If these desired qualities are reached…

- EHR systems can support monitoring and conducting research on the health of populations and the quality, safety and efficiency of health care

- Evaluation of the suitability of EHR systems to support statistical uses cannot wait – as decisions taken today may either facilitate or obstruct statistical uses
25 countries participated in an HCQLI survey that found:

- National plans to implement EHRs (22)
  - Includes data use for monitoring/research (18)
- Implementation started (20)
- Minimum data sets defined (18)
Implementing a national EHR system (20 countries)

Implementing a single country-wide EHR system or integration of regional systems for national information exchange (15 countries)

Exchange between physicians offices and hospitals includes medications, lab tests and medical images (14 countries)

Implementation is relatively new (past 4 years) in all but Estonia and Israel

Not aiming for a national EHR system are: Germany, Iceland, Netherlands, Slovenia, United States
Governing body for the National EHR system

» National body responsible for EHR infrastructure and standards for clinical terminology and interoperability: Belgium, Denmark, Finland, France, Iceland, Israel, Poland, Slovakia, Slovenia, Spain, United Kingdom (by state)

» National body with a reduced role: Austria, Canada, Republic of Korea, Portugal, Sweden, Switzerland, United States
Legal requirements

» Requirements for adoption and/or to adhere to standards (Canada (partial), Finland, France, Estonia, Iceland, Israel; in development in Austria, Poland, Slovakia, Switzerland)

» No laws or regulations requiring health care providers to adopt electronic health records nor adhere to standards (15 countries)
Incentives/Penalties to improve quality

» Certification process to ensure EHR systems sold to providers conform to national standards (7 countries)

» Financial incentives or penalties to encourage adoption of systems conforming to national EHR requirements (11 countries)

» Encouraging vendors to improve the “user-friendliness” of their systems
Countries reporting minimum data set elements

- Patient Unique identifiers (UPI)
- Diagnostic concerns (chronic conditions/allergies)
- Health care provider identifiers
- Patient demographic information
- Current medications
- Procedures (surgeries, screening tests, laboratory results)
- Behaviours (smoking, alcohol use)
- Physical characteristics (body mass)
- Patient socio-economic data
- Psychosocial or cultural issues
21 countries use clinical terminology standards for some elements.
Some have adopted international terminology standards

<table>
<thead>
<tr>
<th>International standard</th>
<th>Elements</th>
<th>Number of countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICD-10</td>
<td>Diagnosis</td>
<td>19</td>
</tr>
<tr>
<td>SNOMED</td>
<td>Diagnosis</td>
<td>5</td>
</tr>
<tr>
<td>ICPC</td>
<td>Diagnosis</td>
<td>4</td>
</tr>
<tr>
<td>ICD9-CM</td>
<td>Diagnosis</td>
<td>4</td>
</tr>
<tr>
<td>DIACOM</td>
<td>Medical images</td>
<td>13</td>
</tr>
<tr>
<td>LOINC</td>
<td>Lab tests</td>
<td>13</td>
</tr>
<tr>
<td>WHO ATC</td>
<td>Medications</td>
<td>12</td>
</tr>
<tr>
<td>ICD-9 (CM)</td>
<td>Surgical procedures</td>
<td>6</td>
</tr>
<tr>
<td>SNOMED</td>
<td>Surgical procedures</td>
<td>4</td>
</tr>
</tbody>
</table>
Data quality concerns

Concerns reported by 16 countries. They include:

<table>
<thead>
<tr>
<th>Concern</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under coverage</td>
<td>Up-coding for payments</td>
</tr>
<tr>
<td>Clinician fatigue</td>
<td>Unusable elements</td>
</tr>
<tr>
<td>Invalid data</td>
<td>Records are unchecked</td>
</tr>
<tr>
<td>Missing data</td>
<td>Records not kept up-to-date</td>
</tr>
<tr>
<td>Variable quality across institutions</td>
<td>Quality depends on the users ability/interest</td>
</tr>
</tbody>
</table>

Only six countries reported auditing clinical content for quality: Belgium, Estonia, Iceland, Spain, Portugal, and the United Kingdom (England)
13 countries report regular use of EHRs for secondary analysis.
Over the next 5 years:
How likely is it your country will use any data from EHRs for national health care quality monitoring?

<table>
<thead>
<tr>
<th>Country</th>
<th>Likelihood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finland</td>
<td>Very Likely</td>
</tr>
<tr>
<td>Indonesia</td>
<td></td>
</tr>
<tr>
<td>Israel</td>
<td></td>
</tr>
<tr>
<td>Singapore</td>
<td>Likely</td>
</tr>
<tr>
<td>Sweden</td>
<td></td>
</tr>
<tr>
<td>United Kingdom</td>
<td></td>
</tr>
<tr>
<td>Belgium</td>
<td>Likely</td>
</tr>
<tr>
<td>Canada</td>
<td></td>
</tr>
<tr>
<td>Estonia</td>
<td></td>
</tr>
<tr>
<td>France</td>
<td></td>
</tr>
<tr>
<td>Iceland</td>
<td></td>
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<tr>
<td>Japan</td>
<td></td>
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<tr>
<td>Korea</td>
<td></td>
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<tr>
<td>Poland</td>
<td></td>
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<tr>
<td>Portugal</td>
<td></td>
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<tr>
<td>Slovakia</td>
<td></td>
</tr>
<tr>
<td>Denmark</td>
<td></td>
</tr>
<tr>
<td>Slovenia</td>
<td>Unsure</td>
</tr>
<tr>
<td>Spain</td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td></td>
</tr>
<tr>
<td>Mexico</td>
<td>Unlikely</td>
</tr>
<tr>
<td>Austria</td>
<td></td>
</tr>
<tr>
<td>Germany</td>
<td>Very</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Unlikely</td>
</tr>
<tr>
<td>Switzerland</td>
<td></td>
</tr>
</tbody>
</table>
### Barriers

- Legislative barriers
- Data privacy/security concerns
- Shortages of resources/skills
- Lack of standards
- Interoperability problems
- Lack of unique identifiers
- Data sharing
- Reluctance among health professionals
- Data quality

### Facilitators

- Governance of EHR implementation and data use
- National standards - clinical content and interoperability
- Legal/regulatory requirements
- Certification of vendors
- Incentives/penalties
- Evaluation of data usability
- Auditing of clinical content
3. SECONDARY USE OF PERSONAL HEALTH DATA TO MONITOR HEALTH, HEALTH CARE QUALITY AND HEALTH SYSTEM PERFORMANCE

KEY FINDINGS
Fact finding

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

» Found considerable cross-country variation – linked to differences in risk-management in balance of data access and data privacy
Half of countries regularly monitor health care quality via linkages

- Hospital data (12 countries)
- Mortality data (12 countries)
- Cancer registry (11 countries)

Only a few countries use:
- Prescription medicines data (7 countries)
- Mental hospital in-patient data (5 countries)
- Primary care data (4 countries)
- Formal long-term care data (4 countries)
- Population health survey (4 countries)
- Population census/registry (4 countries)
- Patient experiences survey (1 country)
## Country variation

<table>
<thead>
<tr>
<th>National Data linkage projects on a regular basis…</th>
<th>Most national data with a unique patient identifying number (UPI)</th>
<th>Most national data with other patient identifiers</th>
<th>Some national data with a unique patient identifying number (UPI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>with 7+ national databases</td>
<td>Denmark, Finland, Israel, Republic of Korea, Sweden, United Kingdom</td>
<td>United States</td>
<td></td>
</tr>
<tr>
<td>with 5-6 national databases</td>
<td>France, Belgium</td>
<td>Australia</td>
<td>Switzerland</td>
</tr>
<tr>
<td>with 3-4 national databases</td>
<td>Canada, Malta, Norway</td>
<td></td>
<td></td>
</tr>
<tr>
<td>with 2 national databases</td>
<td>Singapore</td>
<td></td>
<td>Portugal, Cyprus</td>
</tr>
<tr>
<td>None</td>
<td>Japan</td>
<td></td>
<td>Poland, Germany</td>
</tr>
</tbody>
</table>

Sources of variation

» Whether or not…
  » An exemption to patient consent requirements may be granted?
  » Authorities holding data (data custodians) will share data and with whom…
  » There are a few or many data custodians?
  » It is clear with whom to request approval and what is the criteria to obtain approval?
  » There is one approval body or many?
  » There are mechanisms for privacy respectful access to data?
Multi-country studies

Additional challenges:

- No legal recourse to impose penalties
- All participants’ data protection requirements must be met

While some legislative frameworks allow data sharing across borders, only one project was reported where micro data was shared.

Examples of parallel studies:

- European diabetes registry – not possible for de-identified data to be shared
- European health care performance study – limited to 6 countries with the legislative framework and databases that enable linkages
Concerns about the future

» Failing to maintain current capacity to generate evidence due to the costs of project vetting, linkages, and data access services

» Moving backward in the generation of evidence due to:
  » Increasingly strict interpretations of existing legislations
  » New legislations speaking to data privacy protection legislation due to EU reforms, ICTs, new projects
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
Conclusions:

» The implementation of OECD privacy guidelines in the field of health care has been heterogeneous across countries

» Excess variability reduces access to complete data and undermines internationally comparable indicators

» Privacy and health experts have trouble communicating with each other because they lack a common vocabulary
NEXT STEPS FOR THE OECD PROJECT TO STRENGTHEN HEALTH INFORMATION INFRASTRUCTURE
Next steps

1. Monitoring the development and use of personal health data for statistics and research:

   » A 2013 country survey of multiple sources of personal health data
   » A 2015 country survey of electronic health records
2. Development of:

- Categorisation of types and uses of data according to associated privacy, health and governance risks
- Vocabulary to promote a common understanding of key terms
- Promising practices for privacy protection when processing data with different risks
  - Investigate: consent questions, data de-identification methods, secure data access modalities, project approval governance, data access governance…
- Examples of the implementation of good practices
Questions about strengthening health information infrastructure?