STRENGTHENING HEALTH INFORMATION INFRASTRUCTURE FOR QUALITY MEASUREMENT

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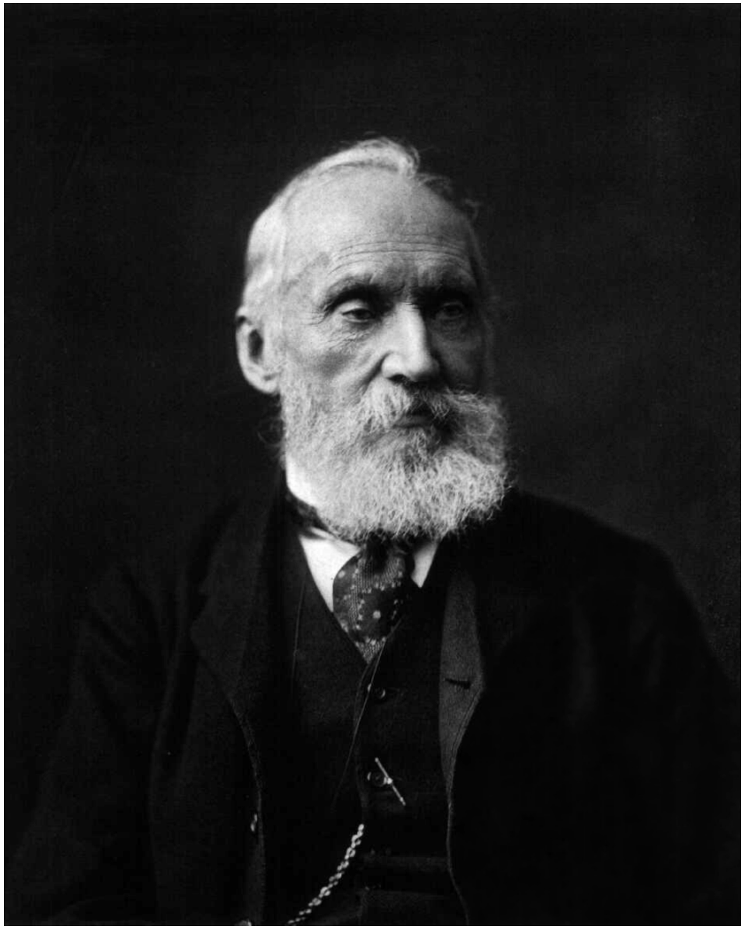
OECD
BETTER POLICIES FOR BETTER LIVES

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
- Ministerial Communiqué called for <u>more effective use of data that has been already collected</u>
- 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)



“If you can’t measure it, you can’t improve it”

- William Thomson (Lord Kelvin),
Physicist, 1824-1907

From data to evidence for health care improvement

- 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

1. ELECTRONIC HEALTH RECORD SYSTEM DEVELOPMENT AND ITS POTENTIAL USE TO MONITOR HEALTH CARE QUALITY

KEY FINDINGS

Electronic health record systems

- 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 an EHR system

Desired qualities of EHR system records include:

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

If these desired qualities are reached…

» EHR systems **could 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 **can not wait** – as decisions taken today may either facilitate or obstruct statistical uses

From EHRs to High Quality Health Care

- Timely and accurate post-market surveillance for adverse drug events
- Timely monitoring of adherence to clinical care quality guidelines and guideline revision
- With administrative data:
  - Timely monitoring of health care pathways, costs and outcomes
- With predictive analytical modelling tools:
  - Support physicians in identifying the most appropriate care
  - Enable health care managers to plan, to optimise care provision and minimise costs

From EHRs to Scientific Discovery

- Stratifying patients into groups that share common characteristics (age, sex, disease history, medications, lab or image results) has been difficult
- With large national databases and international cooperation it becomes possible to:
  - Identify the treatment pathways that are effective for different types of patients
  - Combine with bio-bank data to further stratify the patients and discover personalised/effective drugs
  - Efficiently select large and homogenous groups of patients for clinical trials of new therapies

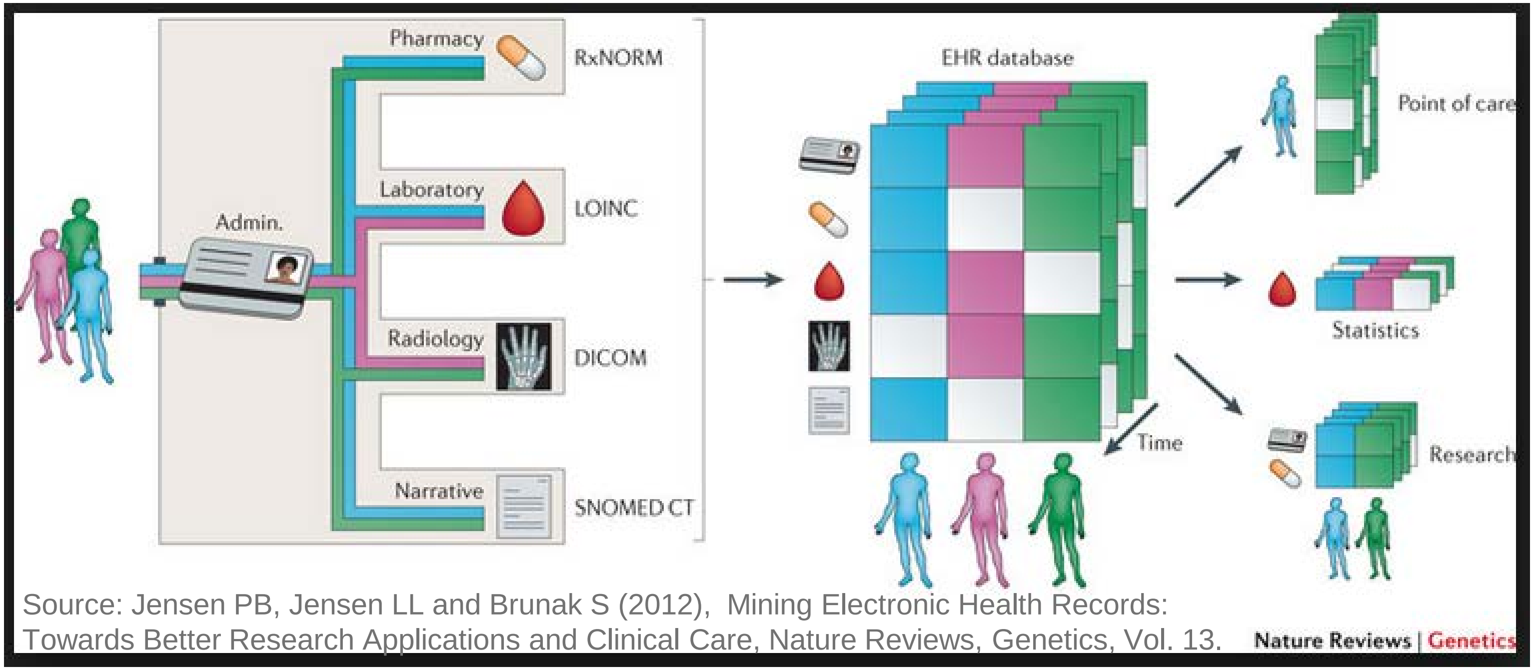
25 countries participated in an HCQI survey that found....

Progress	Europe (15)	Other (10)	Total (25)
70%+ of Doctors using EMRs	11	2	13
70%+ of Hospitals using EPRs	11	4	15
National plan to implement EHRs	12	10	22
Implementation started	12	8	20
Exchange among doctors and hospitals including medications, lab tests and images	8	6	14

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

Source: OECD HCQI Country Survey, 2012

EHR system components



Source: Jensen PB, Jensen LL and Brunak S (2012), Mining Electronic Health Records: Towards Better Research Applications and Clinical Care, Nature Reviews, Genetics, Vol. 13.

18 countries have defined a minimum data set and most include medications, lab tests and images

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

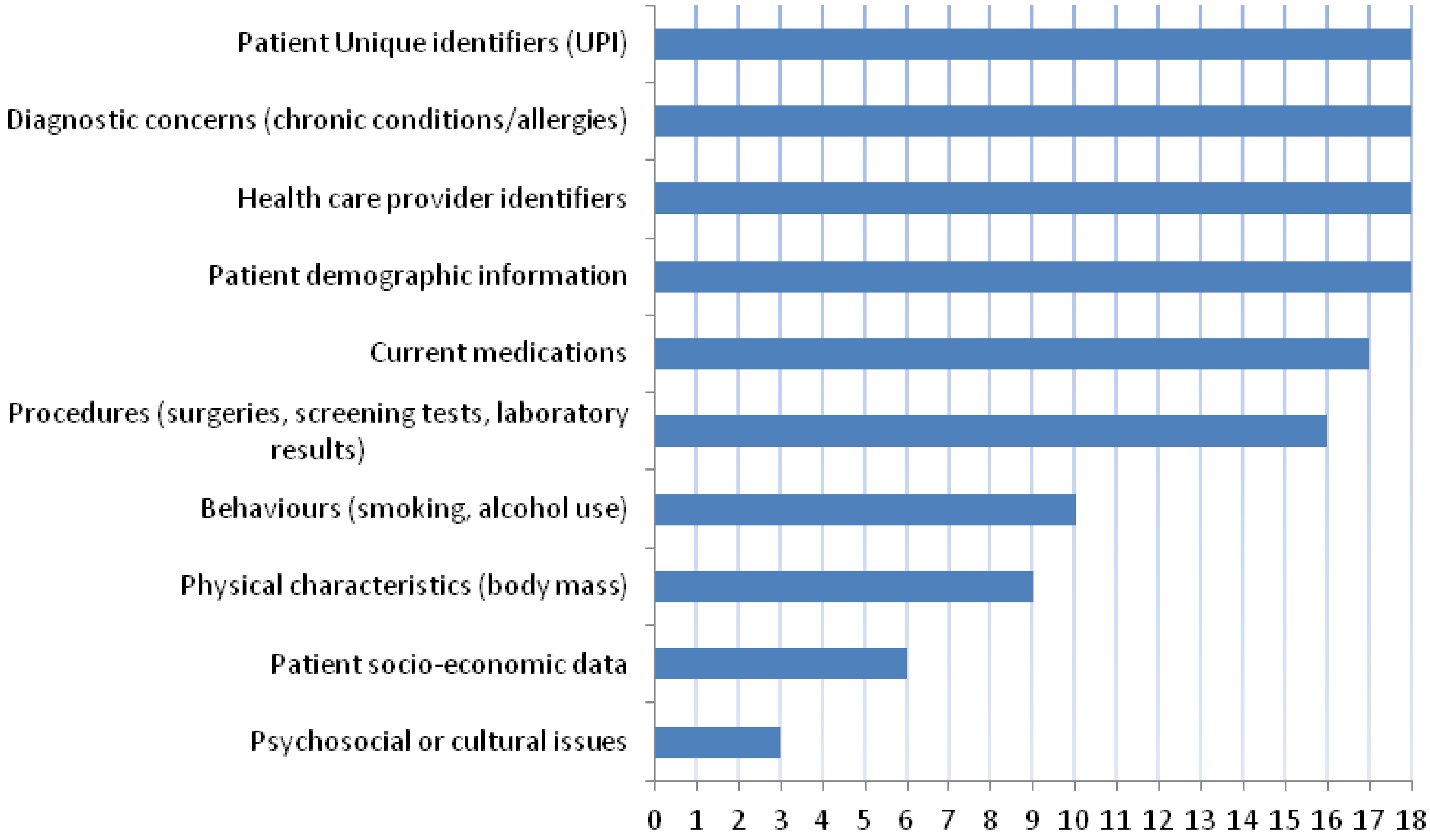
Legal requirements

- 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)

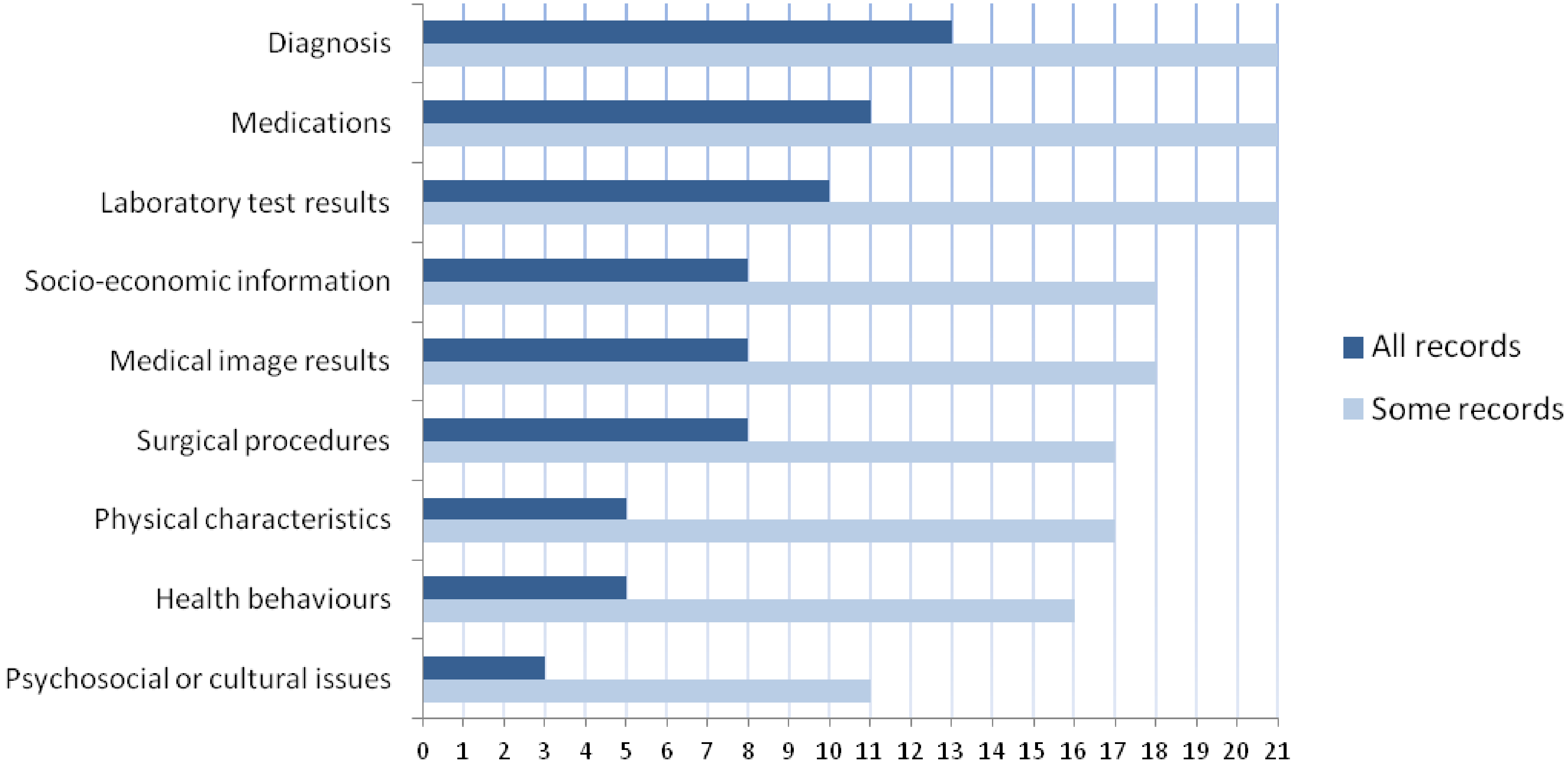
Incentives/Penalties to improve quality

- 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



21 countries use clinical terminology standards for some elements



Some have adopted international terminology standards

International standard	**Elements**	**Number of countries**
ICD-10	Diagnosis	19
SNOMED	Diagnosis	5
ICPC	Diagnosis	4
ICD9-CM	Diagnosis	4
DIACOM	*Medical images*	*13*
LOINC	Lab tests	13
WHO ATC	Medications	12
ICD-9 (CM)	Surgical procedures	6
SNOMED	Surgical procedures	4

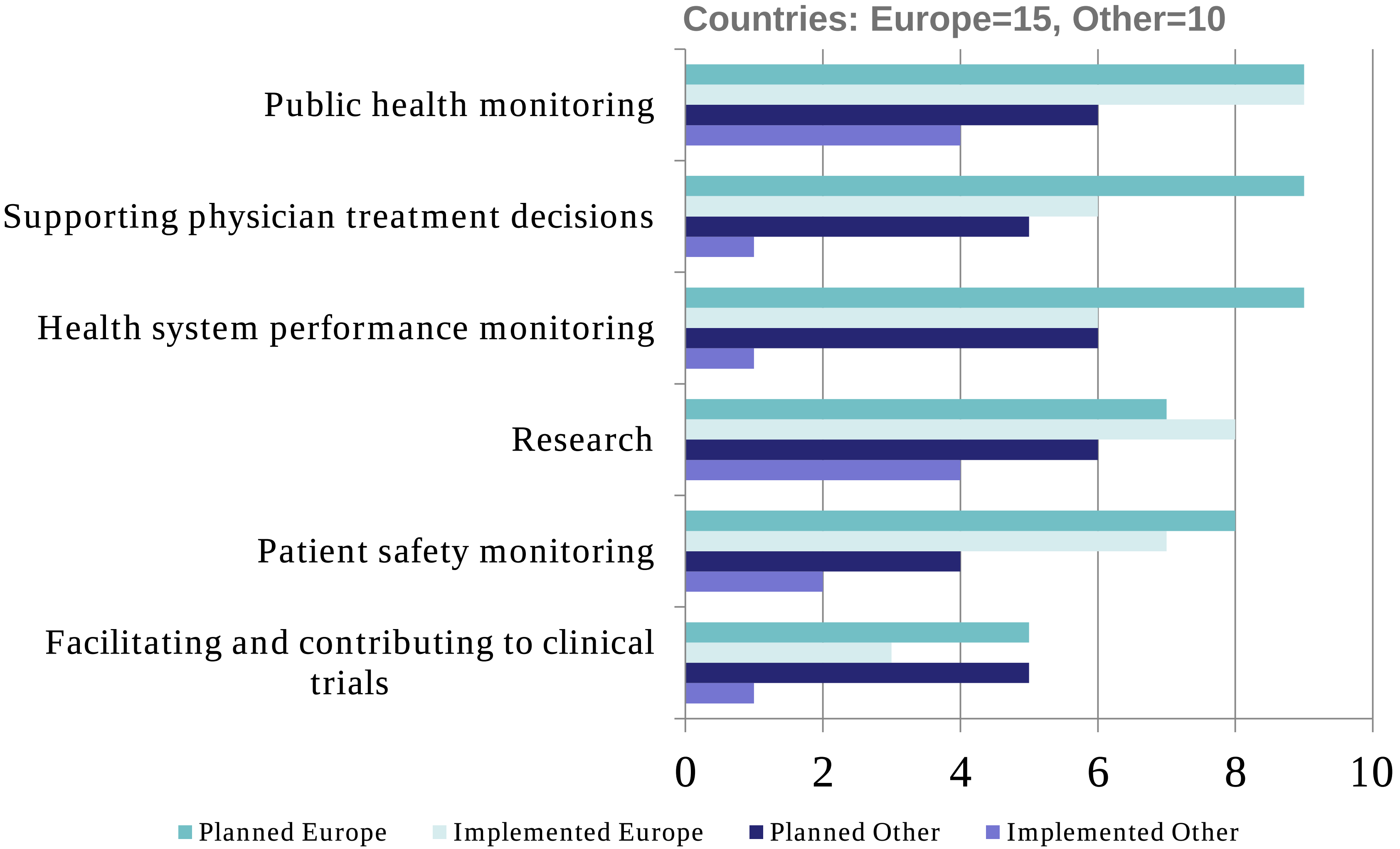
Data quality concerns

- Concerns reported by 16 countries. They include:

Under coverage	Up-coding for payments
Clinician fatigue	Unusable elements
Invalid data	Records are unchecked
Missing data	Records not kept up-to-date
Variable quality across institutions	Quality depends on the users ability/interest

- Only six countries reported auditing clinical content for quality: Belgium, Estonia, Iceland, Spain, Portugal, and the United Kingdom (England)

Planned and implemented uses of EHR data



Source: OECD HCQI Country Survey, 2012

Views about the next 5 years

Over the next 5 years:

How likely is it your country will use any data from EHRs for national health care quality monitoring?

Finland	Very Likely
Indonesia	
Israel	
Singapore	
Sweden	
United Kingdom	
Belgium	Likely
Canada	
Estonia	
France	
Iceland	
Japan	
Korea	
Poland	
Portugal	
Slovakia	
Denmark	Unsure
Slovenia	
Spain	
United States	
Mexico	Unlikely
Austria	Very Unlikely
Germany	
Netherlands	
Switzerland	

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 <u>considerable cross-country variation</u> – linked to differences in risk-management in balance of data access and data privacy

Success stories: Data linkages to measure quality and performance

- Finland, Korea and Singapore: Cost effectiveness and clinical appropriateness of care evaluated and reported
- Sweden: Quality and efficiency assessment of clinical guidelines
- Germany: Projects to evaluate effectiveness and safety of breast cancer screening
- Israel: Quality of surgical outcomes
- United Kingdom: Maternity, surgical outcomes
- Australia: Care transitions for chronic conditions
- Canada: Pathways of stroke care
- Denmark: Waiting times in cancer care

Success stories: New platforms for research

- Belgium and France: Permanent sample of socially insured persons via linkage of health care reimbursement invoice data
- Switzerland: Linkage of population census and mortality data for research and further linkages
- United States: Repository of surveys ready for linkage and on-going linkages to mortality data and to treatments for Medicare/Medicaid beneficiaries
- United Kingdom: National data linkage service

National information infrastructure appears strong

- All reported hospital in-patient data; mortality data; population census or registry data; and survey data
- All are collecting identifiable personal health data at a national level
- All countries report using national health data to regularly monitor some aspects of health care quality
- All countries report having legislation that speaks to the protection of personal information
- But…wide variation in data use

Continuum of risk

Individual data privacy

No risk					High risk
No data	No data sharing, no data linkages	Best practices in data sharing, linkage and analysis - protection of individuals' data privacy		Data use with weak privacy protection practices	Data use with weak privacy protection practices & incentives to misuse the data

Patient safety and health system performance

No risk					High risk
		Best practices in data sharing, linkage and analysis - regular programs of monitoring and research	Limited data sharing & data linkages - some monitoring & research	No data sharing, no data linkages - little monitoring, little research	No data - no monitoring, no research

Country variation

National health data linkage projects conducted on a regular basis…	Country
With many national databases	Australia, Belgium, Denmark, Finland, France, Israel, Republic of Korea, Sweden, United Kingdom and Australia
With several national databases	Canada, Malta, Norway and Switzerland
With 2 national databases	Cyprus, Portugal, Singapore
None	Japan, Poland, Germany

Source: OECD HCQI Country Survey, 2011/12

Too few countries are harnessing value from their data for performance monitoring

	Hosp. in-patient	Primary care	Cancer reg.	Rx	Mortality	LT care	Mental hosp. in-patient
National dataset available...	20	16	18	14	20	16	17
Contains a UPI	15	12	14	12	15	11	12
Contains other identifiers	15	12	17	12	17	12	15
Used for data linkage studies	14	10	14	12	16	11	8
Used regularly for data linkage studies to monitor health care quality	12	4	12	7	12	4	5

Table 1: Number of countries reporting linkable data and reporting data use
Source: OECD HCQI Country Survey, 2011/12

Sources of variation

- Whether or not…
  - An exemption to patient consent requirements may be granted?

Yes, possible within the existing legislation framework	No, not possible without introducing authorising legislation
France, Sweden, Denmark, Finland, United Kingdom, United States, Australia, Canada, Korea, Singapore	Belgium, Germany Italy, Japan, Portugal, Poland

Sources of variation

- Whether or not…
  - Authorities holding data needed for a project (data custodians) will share data with other government authorities?

Legislative barriers to sharing data reported	Lengthy and complex negotiations reported
Poland, Portugal, Italy	Australia, Canada, Germany, United States

Sources of variation

- Whether or not…
  - It is clear with whom to request approval and what is the criteria to obtain approval?

Approval at the level of data custodians reported	Centralised approval reported
Australia, Canada, Singapore, Finland, Sweden, UK Scotland, United States	Belgium, Finland, France, Denmark, UK England and Wales

  - Where there are national and sub-national approvals, it is difficult to seek and obtain approval for projects (Australia, Canada, Germany, Italy, United States)

Sources of variation

- Whether or not there are mechanisms for privacy respectful access to data?
  - Some manage risk by not providing access to data
  - Others share identifiable personal health data
  - Custodians report resource constraints/burden

Trusted 3rd parties engaged to conduct data linkages and de-identify linked data	Established secure supervised facilities for access to de-identified data with high re-identification risk	Established secure remote data access to de-identified data
Australia, Belgium, Finland, United Kingdom	United States, Canada, Singapore	United States, Australia, Canada (pilot), UK Scotland (new)

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:
  - EUBIROD European diabetes registry – not possible for de-identified data to be shared
  - EUROHOPE 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

CONCLUSIONS

Challenges

- Balancing data privacy and access to data
- Reluctance to share data
- Lack of standards for content and interoperability
- High prices for data access
- No unique patient numbers to link or track over time
- Data quality problems
- Lack of skilled resources
- Deficits in computing power/ analytic software
- Reluctance of health professionals

Success factors

Data governance including…

- Strategic planning
- Legislation enabling secure data sharing, processing and analysis
- Effective data privacy and security measures
- Engagement with citizens, businesses, health sector
- Public communication about data availability and access
- Incentives/investments/grants
- Data utility evaluation and quality auditing
- Data analytic skills in health education/training

Joint dialogue with experts in data privacy in 2012

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

Next steps

2. With a panel of experts in law, privacy regulation, health policy, statistics, research and IT – Develop:
   - 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

For more information

Health policy brief and report (2013):

http://www.oecd.org/els/health-systems/strengtheninghealthinformationinfrastructure.htm

OECD Health Policy Studies

Strengthening Health Information Infrastructure for Health Care Quality Governance

GOOD PRACTICES, NEW OPPORTUNITIES
AND DATA PRIVACY PROTECTION CHALLENGES

OECD

Questions?

- Questions about strengthening health information infrastructure?