PUTTING DATA TO WORK
FOR BETTER HEALTH AND HEALTH SYSTEMS

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The health data ecosystem is evolving and growing.
This bestows immense opportunities …

**Clinical practice improvement (quality)**
- Faster access to critical information
- Improved clinical decision making
- Better patient experience and satisfaction

**System management**
- Monitor performance
- Allocate resources better and **reduce waste**
- Ensure better access to care

**Surveillance**
- Evaluate **public health** interventions
- Faster detection and response to public health emergency
- Inform policy

**Research & innovation**
- Statistical power
- Vast and varied datasets
- ‘Real world evidence’ for innovation
.... but also risks

Danish regional health authority have collected data from patients illegally in the past seven years, in a scenario reminiscent of George Orwell’s 1984.
OECD work on health data governance commenced in 2010
Data rich – information poor

- 2013/14 survey of 22 countries

- Hospital in-patient data
- Cancer registry data
- Mortality data
- Emergency health care data
- Mental hospital in-patient...
- CVD registry data
- Prescription medicines data
- Population census/registry
- Population health survey...
- Formal long-term care data
- Primary care data
- Patient reported outcomes
- Diabetes registry
- Patient experiences survey...

- National personal health data available
- Unique ID included and used consistently
- Record linkage to regularly monitor health care quality and system performance
Variation in sharing and accessibility of data for R&D purposes

Score is the sum of the percentage of national datasets meeting 6 accessibility factors (Highest score = 6)

2013/14 survey of 22 countries
Harnessing Electronic Health Record (EHR) data

2016 survey of 25 countries
## A health data governance framework (2015)

### 8 key mechanisms

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Health information system</td>
</tr>
<tr>
<td>2</td>
<td>Legal framework</td>
</tr>
<tr>
<td>3</td>
<td>Public communication plan</td>
</tr>
<tr>
<td>4</td>
<td>Certification or accreditation of processors</td>
</tr>
<tr>
<td>5</td>
<td>Project approval process</td>
</tr>
<tr>
<td>6</td>
<td>Data de-identification steps</td>
</tr>
<tr>
<td>7</td>
<td>Data security and management</td>
</tr>
<tr>
<td>8</td>
<td>Data governance review cycle</td>
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</tbody>
</table>

### Evaluate benefits and risks of data uses

#### Benefits

- Rights to health
- Health care quality & efficiency
- Scientific discovery & innovation
- Not using available data is a risk – benefit foregone

#### Risks

- Rights to privacy
- Societal trust in government & institutions
- Societal values toward privacy & sharing data

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Right data governance to maximise benefits and minimise risks

- Not a zero sum game
- Whole of government endeavour
- Across sectors

Take informed decisions to use personal health data
1. Establish national health data governance frameworks
   - Encourage availability & use of health data to advance public policy objectives
   - Promote privacy protection & data security

2. Harmonise frameworks between countries
   - Enable multi-country research

… became an OECD Council Recommendation – January 2017

www.oecd.org/els/health-systems/health-data-governance.htm
<table>
<thead>
<tr>
<th>Engagement and participation</th>
<th>Approval procedures for the use of personal health data</th>
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<tbody>
<tr>
<td>Coordination and cooperation</td>
<td>Public disclosure and transparency</td>
</tr>
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<td>Capacity of public sector health data systems</td>
<td>Recognition of the role of technology</td>
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<td>Clear provision of information</td>
<td>Monitoring and evaluation mechanisms</td>
</tr>
<tr>
<td>Effective consent and choice mechanisms</td>
<td>Training and skills development in privacy and security</td>
</tr>
<tr>
<td>Controls and safeguards</td>
<td>Certification or accreditation</td>
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</tbody>
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Thank you

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