LEVERAGING DATA TO PREVENT & MANAGE DIABETES

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* Content reflects presenter’s opinions
First of all ...

Let me know if you want to know why I am here.
Many industries have transformed themselves around digital technology (data = lifeblood)*

- Better products
- Better services
- More efficient & productive
- Big consumer surpluses

*re-use for 2° purposes
The possibilities (in health) are tantalising...

(N)IDDM:

- Prediction
- Detection
- Prevention
- Clinical Rx
- Policy Rx
BUT...
“Policy makers should **beware the hype of AI* in health care** …

In setting the foundations for AI to help achieve health policy objectives, one key priority is to **improve data quality, interoperability** and **access in a secure way** through better **data governance.**”

*machine learning -- most often probabilistic models (regression / curve fitting anyway)*
Health systems

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“data rich ... information poor”
Countries routinely linking health, contextual and outcomes data (for 2° purposes)

- Multiple health care settings
- Disease registries to mortality data
- Health care to mortality data
- Population census to disease registry data
- Population census to health care data
- Cancer registry to health care data
- Population health survey to health care data
- Cancer registry to cancer screening data
- Health care to personal income tax data
- Population health survey to social insurance data (social security)
- Population health survey to Population census data

23 OECD countries

...using clinical (EMR) data...

[Table showing the use of clinical data in different countries]


Public health monitoring
Monitoring patient safety
Monitoring health system performance
Medical and health care research
Data Mining to find/extract data within EHRs
Predictive analytics trained on EHRs
Linkage of EHRs and genomic, environmental, behavioural, economic or other data

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...national coverage...

Population health survey data
Hospital in-patient data
Cancer registry data
Prescription medicines data
Mortality data
Emergency health care data
Mental hospital in-patient data
Population census or population registry data
Primary care data
Formal long-term care data
Patient experiences survey data
Diabetes registry data
Cardio-vascular disease registry data

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...regular record linkage projects...

- Mortality data
- Hospital in-patient data
- Cancer registry data
- Mental hospital in-patient data
- Prescription medicines data
- Population census or population registry data
- Primary care data
- Emergency health care data
- Population health survey data
- Formal long-term care data
- Cardio-vascular disease registry data
- Diabetes registry data
- Patient experiences survey data

23 OECD countries

... sharing de-identified data with researchers in other countries

Cancer registry
Mortality
Hospital in-patient
Emergency health care
Mental hospital in-patient
Prescription medicines
Primary care
Formal long-term care
Diabetes registry
Cardio-vascular disease registry

23 OECD countries

Variation in data use and governance

1. Access with security & privacy safeguards
2. Rules/standards to ensure data quality & interoperability
3. Trust and social license

Data availability, coverage and accessibility

Data governance*
Roads, rules & regulations, signals, proficiency, capability ... trust?
Things are slowly changing …

Collaborating on global standards for interoperability

- AUS
- BEL
- CAN
- CZE
- DEN
- EST
- FIN
- DEU
- HUN
- ISL
- ITA
- JPN
- KOR
- LUX
- NLD
- NOR
- PRT
- SVN
- SWE
- CHE
- TUR
- USA

Policies or projects to improve interoperability

- AUS
- BEL
- CAN
- CZE
- DEN
- EST
- FIN
- HUN
- ISL
- ISR
- ITA
- JPN
- KOR
- LUX
- NLD
- NOR
- SVN
- SWE
- CHE
- USA

Adopting HL7 FHIR standard

- AUS
- BEL
- CAN
- CZE
- DEN
- EST
- FIN
- ISL
- ISR
- ITA
- KOR
- LUX
- NLD
- NOR
- RUS
- SWE

Covid-19 accelerating EHR development and use

- AUS
- CAN
- CRI
- CZE
- FIN
- HUN
- ISL
- ISR
- ITA
- LUX
- NLD
- PRT
- SVN
- SWE
- TUR

Source: OECD 2021 Survey of Electronic Health Record System Development, Data use and Governance.
Virtual diabetes registry (NZ)

www.ncbi.nlm.nih.gov/pmc/articles/PMC4330200/pdf/hir-21-49.pdf
“...promote better **exchange and access** to different types of health data (electronic health records, **genomics data**, patient registries etc.), not only to support healthcare delivery ... but also for **health research and health policy making purposes**.”

**Pillars:**
1. Security & privacy (GDPR)
2. Rules/standards to ensure data quality & interoperability
3. Trust and social license

→ **i.e. Governance** (harmonised across MS)

“to build a common European infrastructure for standardized information exchange in diabetes care, for the purpose of monitoring, updating and disseminating evidence on the application and clinical effectiveness of best practice guidelines on a regular basis”

Shared European Diabetes Information System

SEDIS

http://www.biro-project.eu/home.htm
Digital technology to prevent & manage NCDs

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<th>- The potential -</th>
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<tr>
<td>Tantalising prospect of ‘big data’</td>
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<td>Excellent isolated case examples</td>
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<th>- The reality -</th>
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<tr>
<td>Poor quality data (e.g. bias)</td>
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<td>Held in silos / inaccessible</td>
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<td>Scaling and consistency of tools elusive</td>
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<th>- How to get there -</th>
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<td>Health data governance</td>
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<td>quality, interoperable data; securely accessible for 2º uses</td>
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