LEVERAGING DATA TO PREVENT & MANAGE DIABETES

Luke Slawomirski
Consultant* - OECD - Directorate for Employment, Labour & Social Affairs

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** Content reflects presenter's opinions*

OECD
BETTER POLICIES FOR BETTER LIVES

First of all …

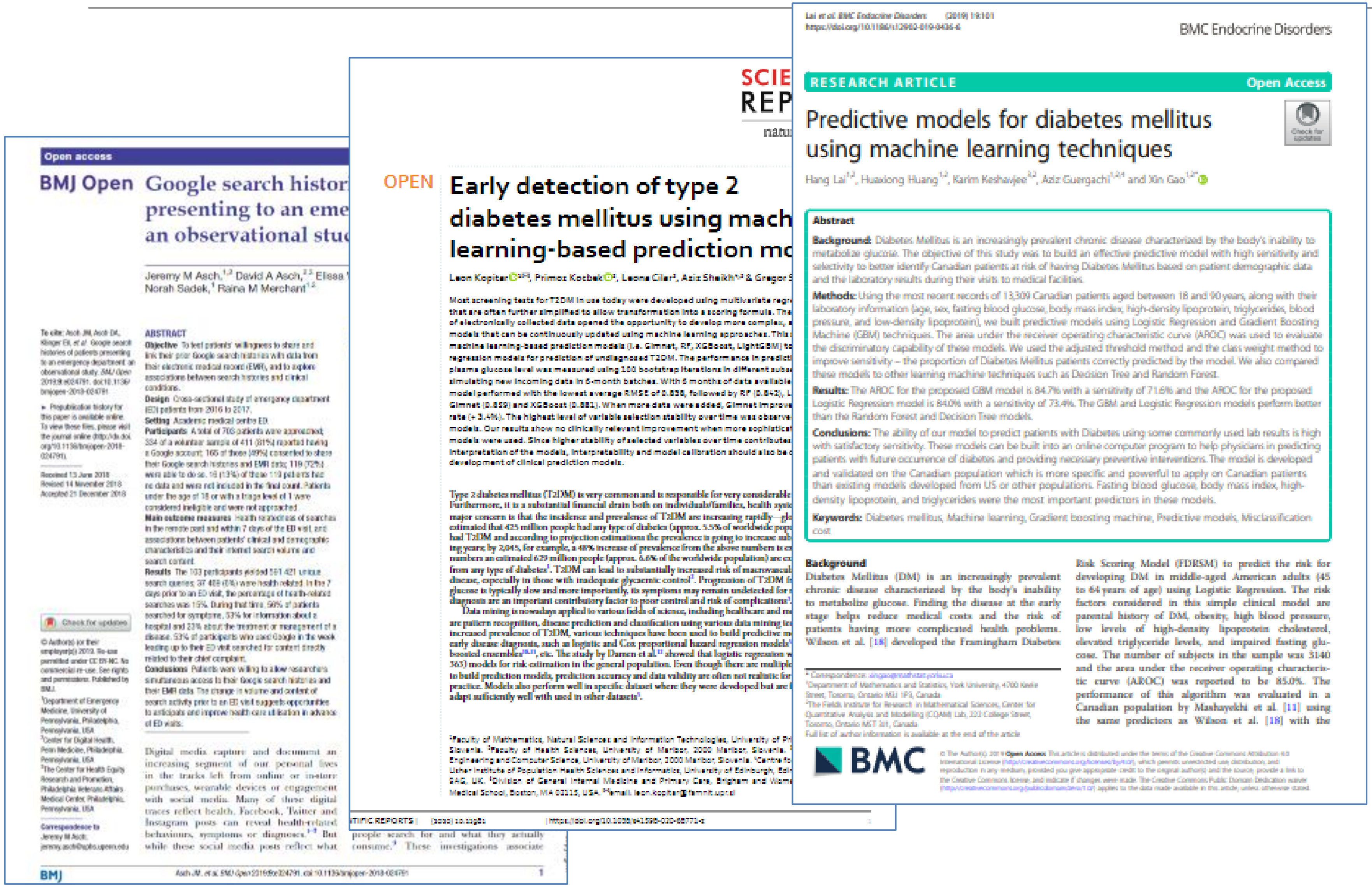
Many industries have transformed themselves around digital technology (data = lifeblood)*




- 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...

www.oecd-ilibrary.org/social-issues-migration-health/laying-the-foundations-for-artificial-intelligence-in-health_3f62817d-en

“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

“data rich … information poor”

www.oecd.org/health/health-in-the-21st-century-e3b23f8e-en.htm

Countries routinely linking health, contextual and outcomes data (for 2° purposes)

Multiple health care settings	AUS	BEL	CAN	DEN	FIN	FRA	ISR	KOR	LVA	NLD	NOR	SGP	SVN	USA	14
Disease registries to mortality data	AUS	AUT	CAN	CZE	EST	FIN	ISR	JPN	KOR	LVA	LUX	SGP	SVN	SWE	14
Health care to mortality data	AUS	AUT	CZE	FIN	ISR	KOR	LVA	NLD	SVN	USA	10				
Population census to disease registry data	CAN	EST	FIN	LVA	NLD	SVN	SWE	7							
Population census to health care data	AUS	CAN	FIN	NLD	SVN	SWE	6								
Cancer registry to health care data	BEL	CZE	LVA	NLD	SWE	5									
Population health survey to health care data	FIN	SWE	USA	3											
Cancer registry to cancer screening data	LUX	SVN	2												
Health care to personal income tax data	AUS	NLD	2												
Population health survey to social insurance data (social security)	SWE	USA	2												
Population health survey to Population census data	NLD	SWE	2												

23 OECD countries

www.oecd-ilibrary.org/social-issues-migration-health/survey-results-national-health-data-infrastructure-and-governance_55d24b5d-en

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

www.oecd-ilibrary.org/social-issues-migration-health/survey-results-national-health-data-infrastructure-and-governance_55d24b5d-en

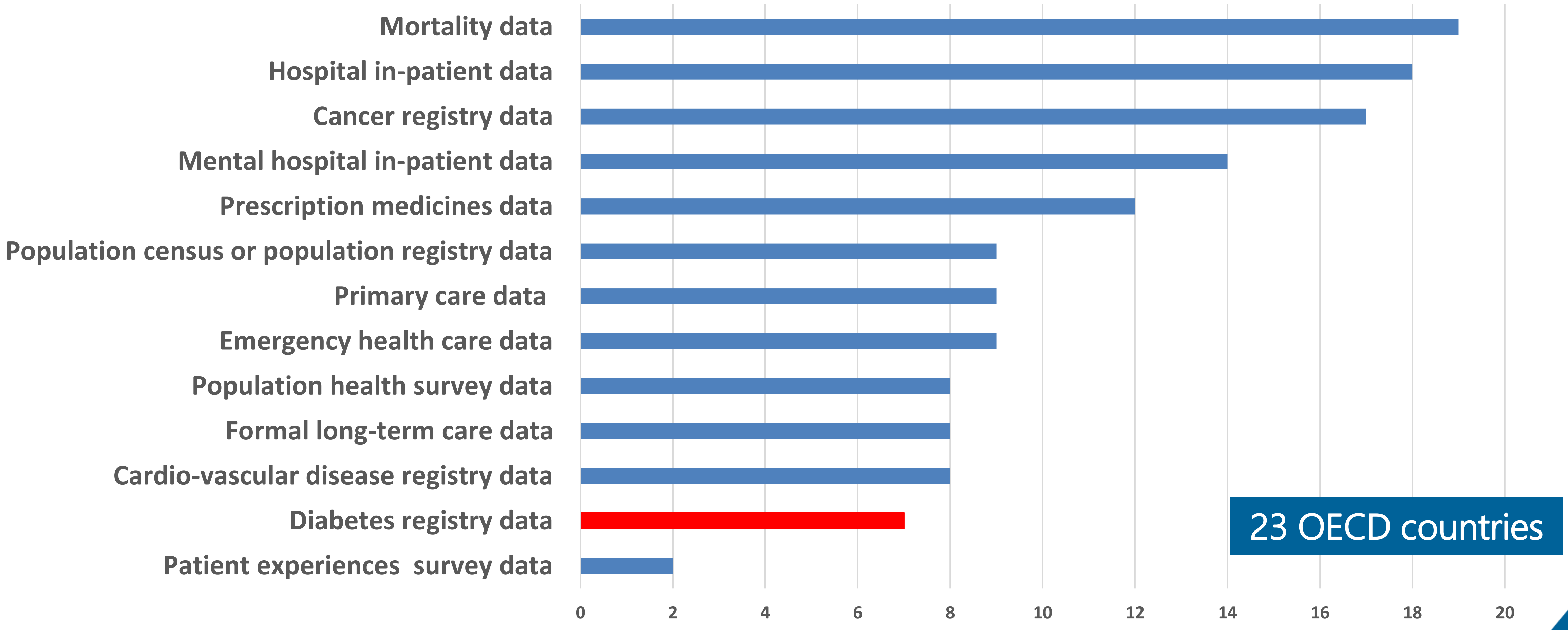
23 OECD countries

Public health monitoring	Monitoring patient safety	Monitoring health system performance	Medical and health care research	Data Mining to find/extract data within EHRs	Predictive anaytics trained on EHRs	Linkage of EHRs and genomic, environmental, behavioural, economic or other data
16	12	10	10	8	7	6
BEL	BEL	BEL	BEL	CRI	CRI	BEL
CRI	CRI	CRI	CRI	DEN	DEN	EST
DEN	DEN	DEN	DEN	FIN	ISR	DEU
FIN	FIN	FIN	DEU	ISR	LUX	ISR
NLD	NLD	NLD	FIN	LUX	NLD	ITA
SWE	SWE	SWE	NLD	NLD	PRT	NLD
TUR	TUR	TUR	SWE	PRT	SWE	
HUN	ISL	LTU	TUR	TUR		
ISL	ISR	CZE	ISL			
ISR	LTU	PRT	ISR			
LTU	EST					
CZE	JPN					
EST						
JPN						
PRT						
SLO						

…national coverage…

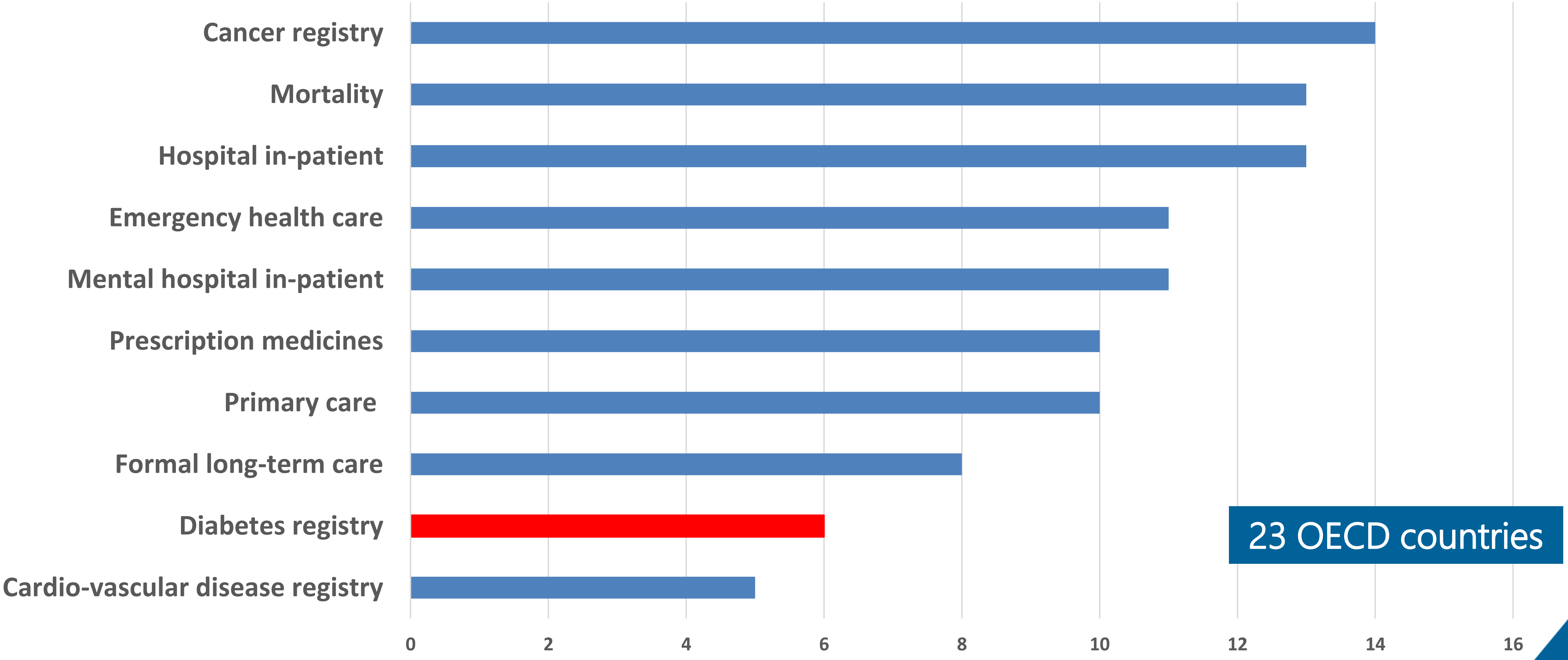
www.oecd-ilibrary.org/social-issues-migration-health/survey-results-national-health-data-infrastructure-and-governance_55d24b5d-en

…regular record linkage projects…



www.oecd-ilibrary.org/social-issues-migration-health/survey-results-national-health-data-infrastructure-and-governance_55d24b5d-en

… sharing de-identified data with researchers in other countries



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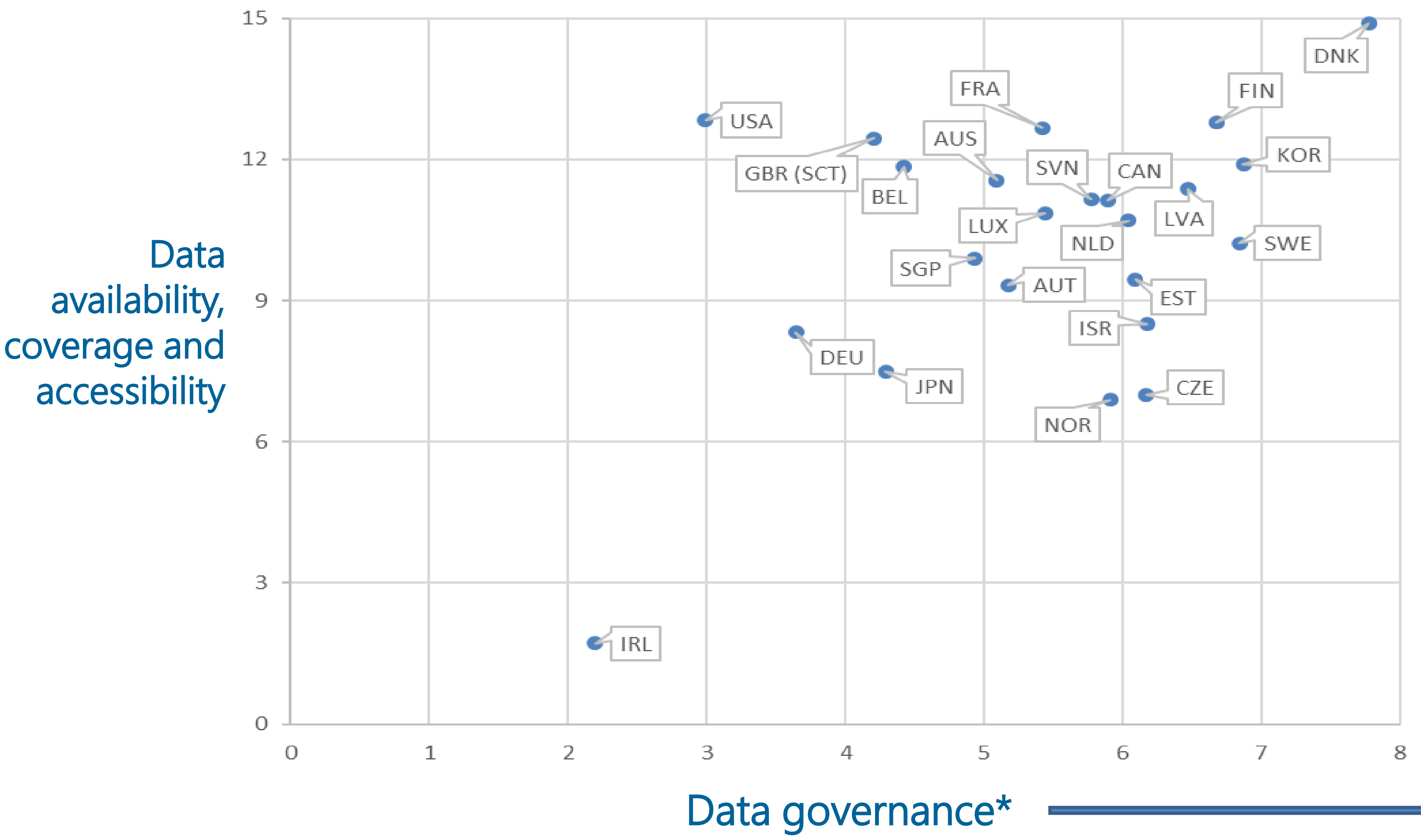
Variation in data use and governance



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

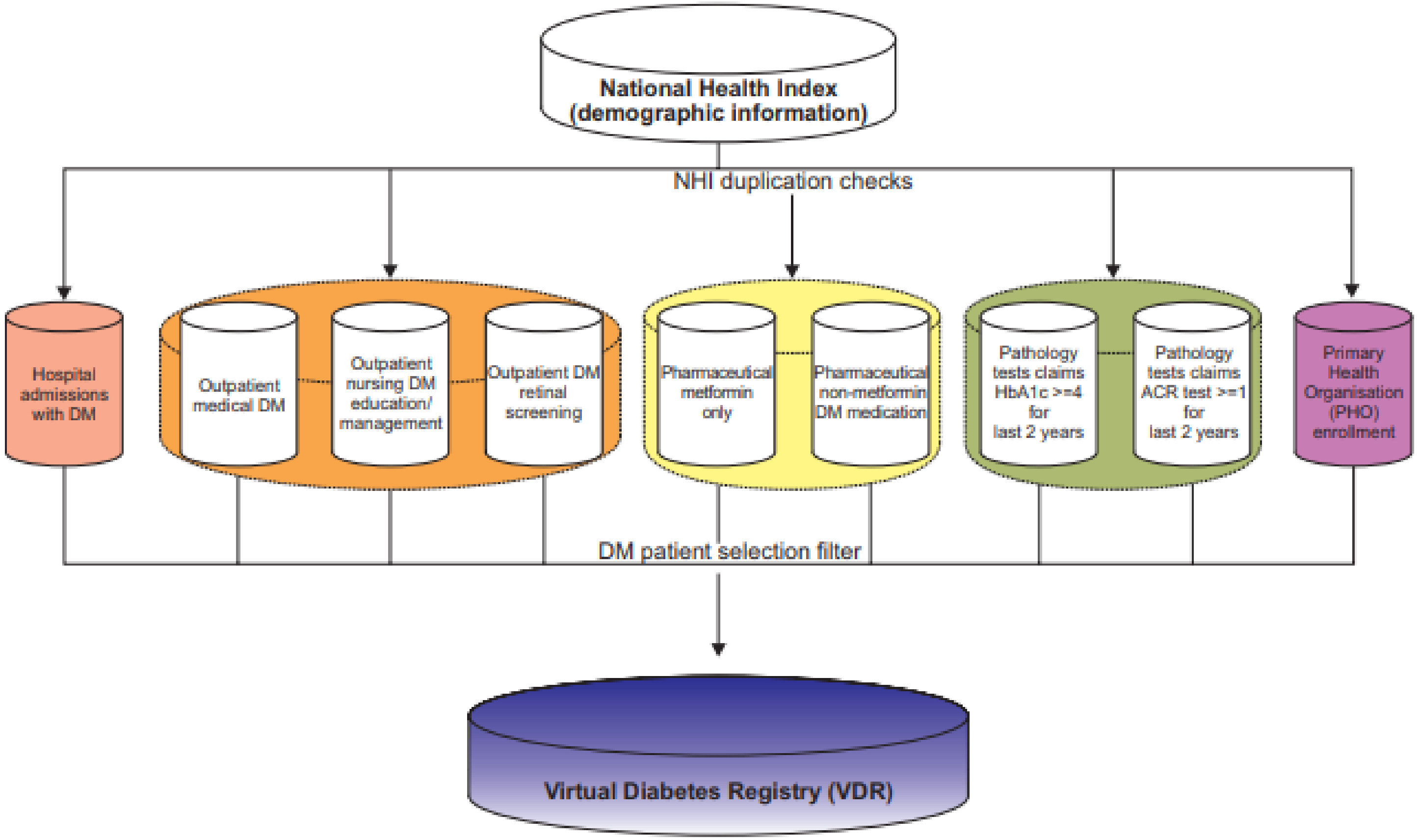
Roads, rules & regulations, signals, proficiency, capability … trust?

Things are slowly changing …

Collaborating on global standards for interoperability	AUS BEL CAN CZE DEN EST FIN DEU HUN ISL ITA JPN KOR LTU LUX NDL NOR PRT SVN SWE CHE TUR USA	23
Policies or projects to improve inter-operability	AUS BEL CAN CZE DEN EST FIN HUN ISL ISR ITA JPN KOR LTU LUX NDL NOR SVN SWE CHE USA	21
Adopting HL7 FHIR standard	AUS BEL CAN CZE DEN EST FIN ISL ISR ITA KOR LTU LUX NDL NOR RUS SWE	17
Covid-19 accelerating EHR development and use	AUS CAN CRI CZE FIN HUN ISL ISR ITA LTU LUX NDL PRT SVN SWE TUR	16

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

European health data space

*"...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)

https://ec.europa.eu/health/ehealth/dataspace_en

B.I.R.O

Best Information through Regional Outcomes

"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

In summary…

Digital technology to prevent & manage NCDs	
	- The potential - Tantalising prospect of 'big data' Excellent isolated case examples
	- The reality - Poor quality data (e.g. bias) Held in silos / inaccessible Scaling and consistency of tools elusive
	- How to get there - Health data governance quality, interoperable data; securely accessible for 2^o uses