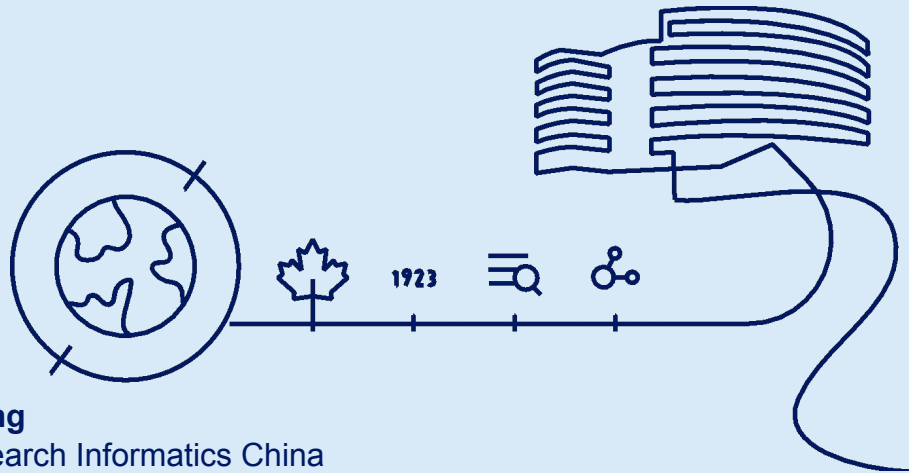


RWD for R&ED : A Research Informatics Perspective on Why, What & How



Lingling Jiang
Head of Research Informatics China
Digital Science & Innovation, Novo Nordisk

Nov 15th 2023, Pistoia Alliance Conference

Else Jeppesen (right) with a friend

Our first patients to be treated with insulin
produced by August Krogh and H.C. Hagedorn.



Real World Data for Human Centric Healthcare



Purpose

- Disease and patient understanding
- Human centric target discovery
- Precision healthcare development

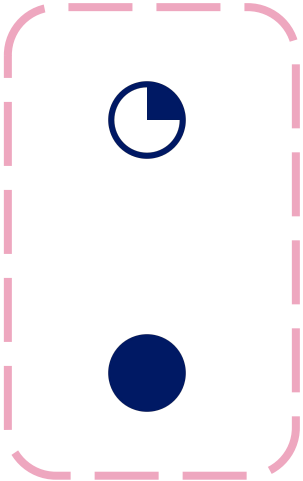
- Model selection
- Biomarker discovery

- Trial Design
- Patient recruitment & management
- Endpoint selection

- Regulatory Submissions
- Regulatory decision making

- Drug effectiveness and adverse events monitoring
- Unserved patient subpopulation identification

Adoption



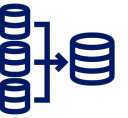
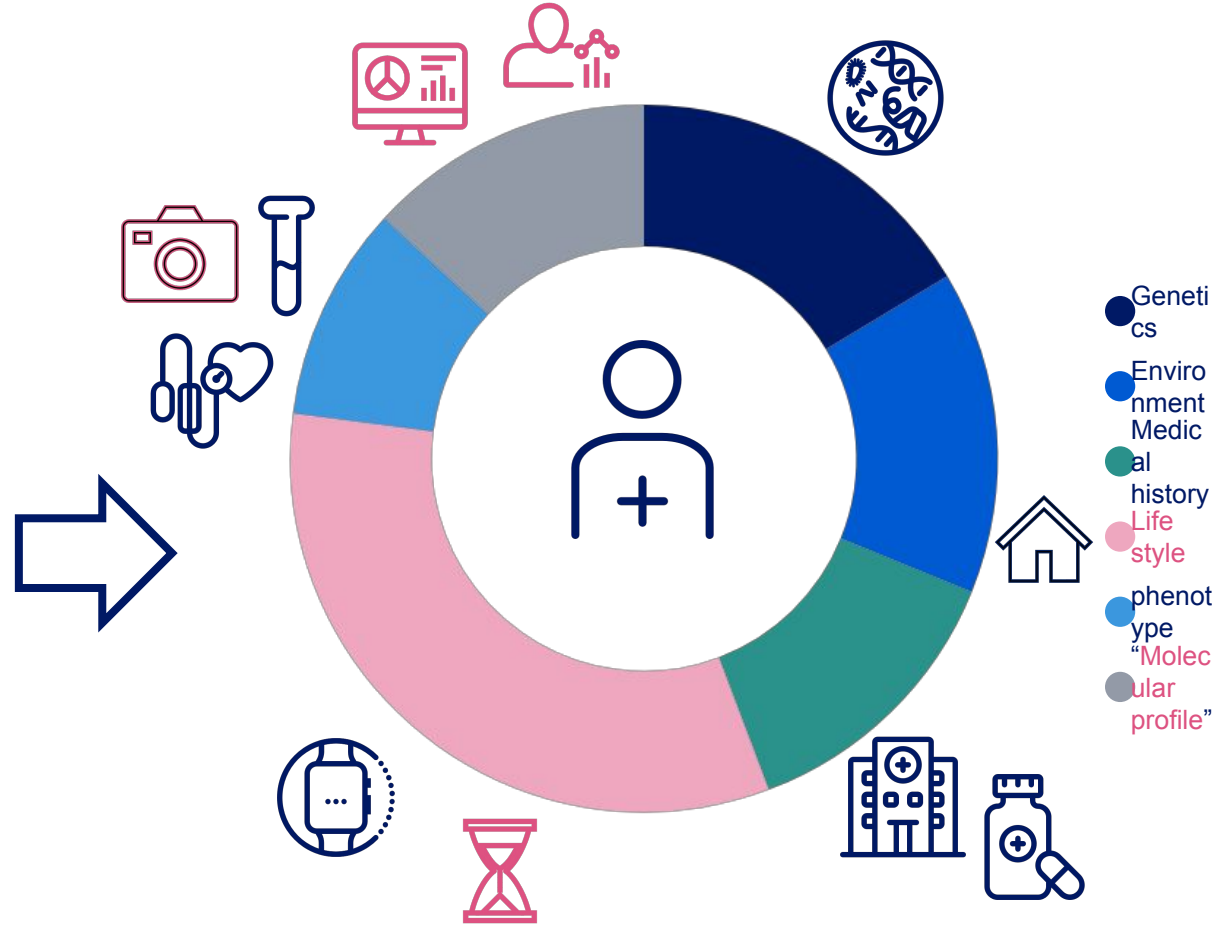
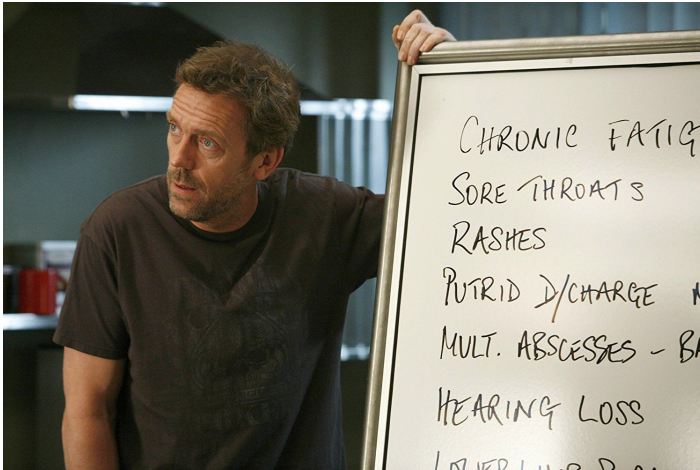
Potential



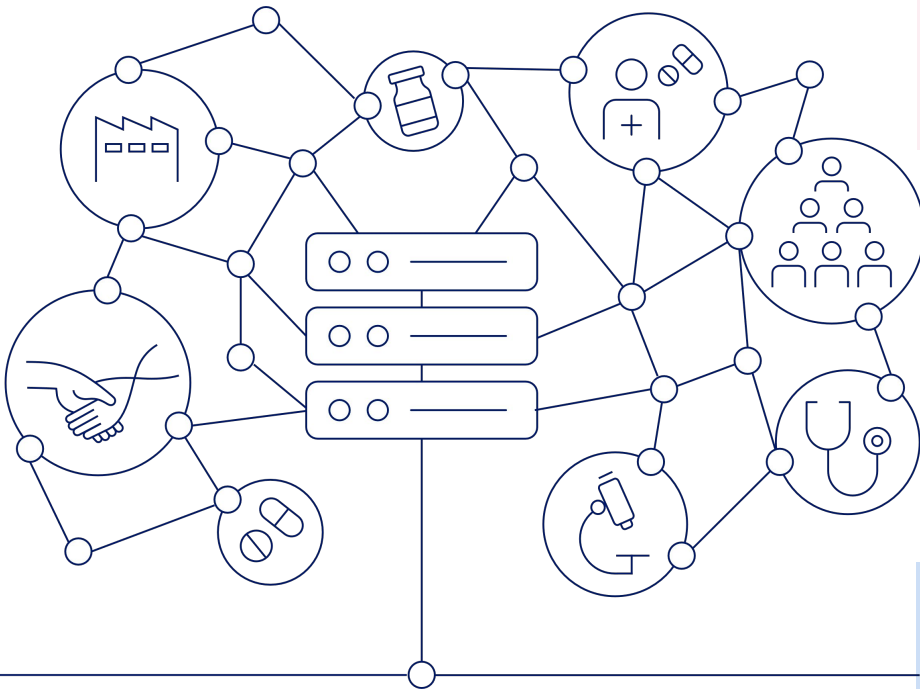
What Makes a Patient a Patient:

Understanding disease with RWD in Pharma R&ED

So, what does he have?



Data Access: A Barrier to Big Data AI in R&ED

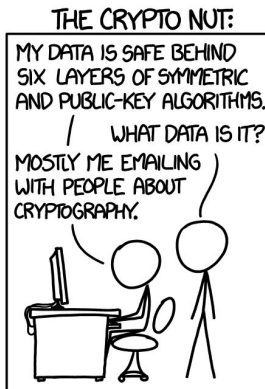
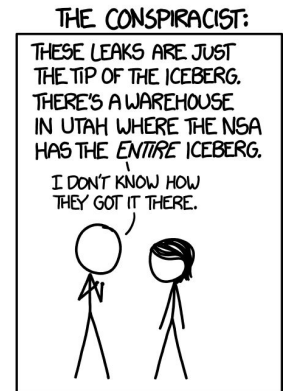
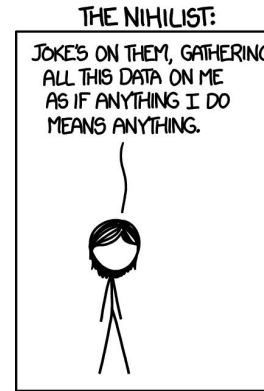


“

Why do you need my data?

Data owner

Adopted from <https://xkcd.com/1269/> Opinions on internet privacy



“

It seems that you don't have access to project_TBD057 on our platform.

Data Engineer

“

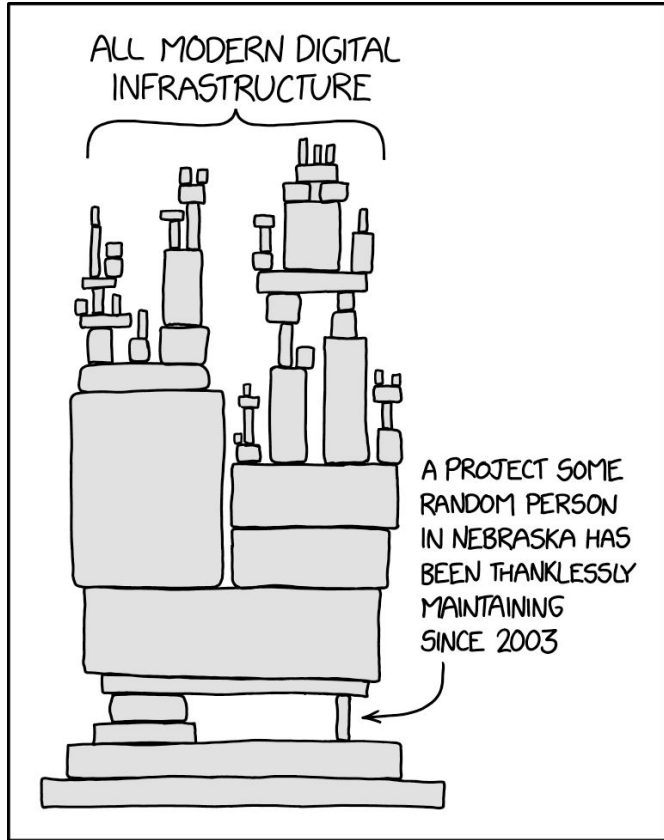
There are 5 patients with matching Data-Fields ?!

Data Scientist

- **Not so big data at all**
- **Complex transformation before access**
- **Linking data at individual level without risk of re-identification**
- **Cohort/trial design not fit for the specific research questions in mind**
-

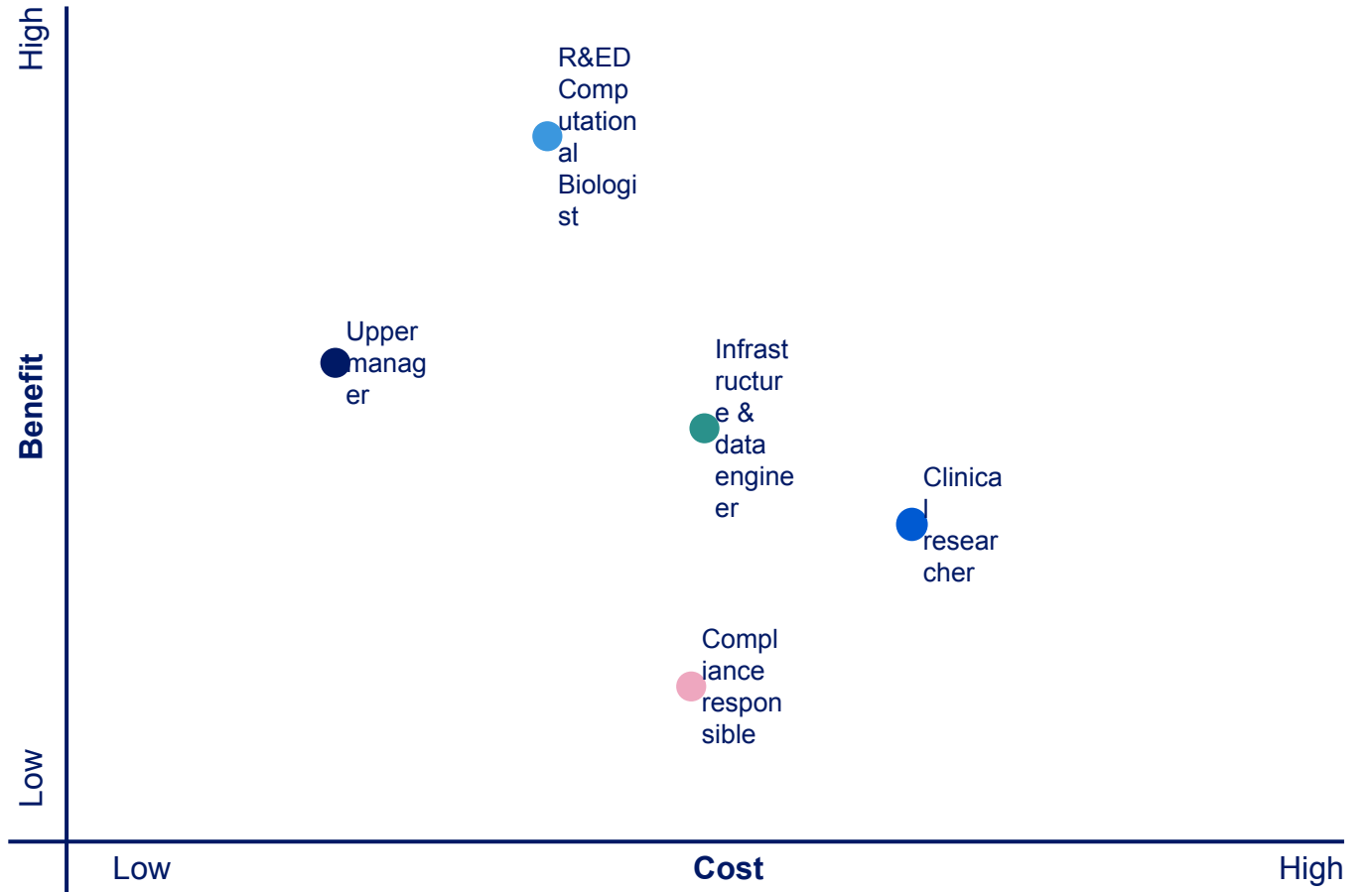
The Hurdle from within

Data Foundation



<https://xkcd.com/2347/> Dependency

Cost effectiveness



Together, we can make a change



What we propose:

An Open Letter on RWD Data Principles to promote public trust and collaboration*

What do we need: Insights on current data practice and RWD needs, network to reach patients, policy makers and other relevant stakeholders

How can you help: reach out to project group and/or corresponding PA strategic lead for general support and/or sign up for participation



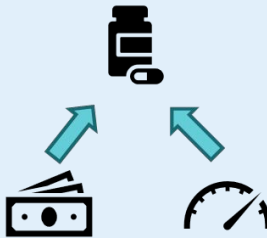
Improved efficacy and efficiency



Faster access to more affordable drugs for patients



Reduced public health burden and risk



*On going project by **Pistoia Alliance Pharma Innovation Council, Working Group 1: Improving efficacy and efficiency in pharma R&D**