Andre Dekker, Peter-Bram 't Hoen, Wessel Kraaij

Maastricht UMC+, Leids UMC, TNO

Personal Health Train

health RI research infrastructure

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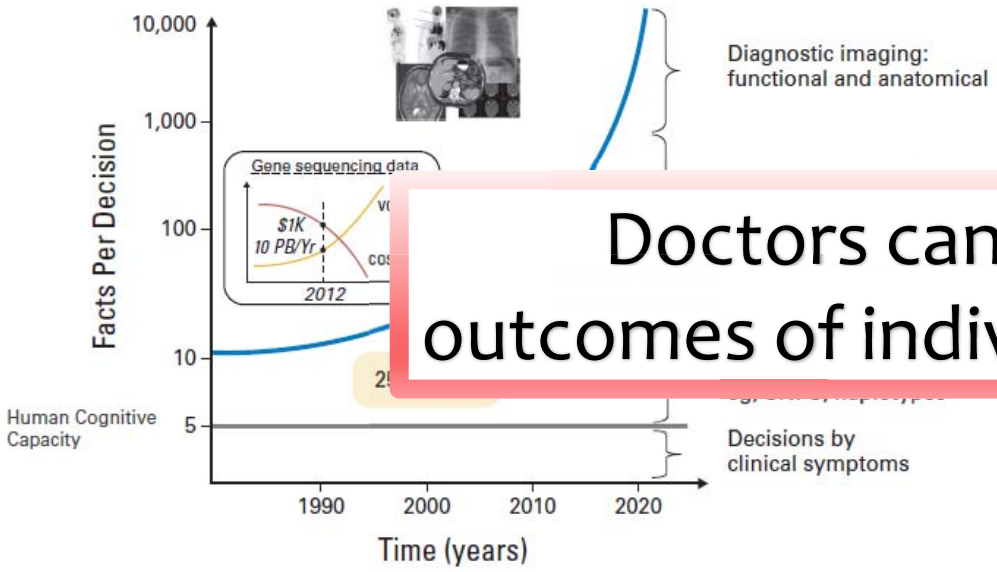
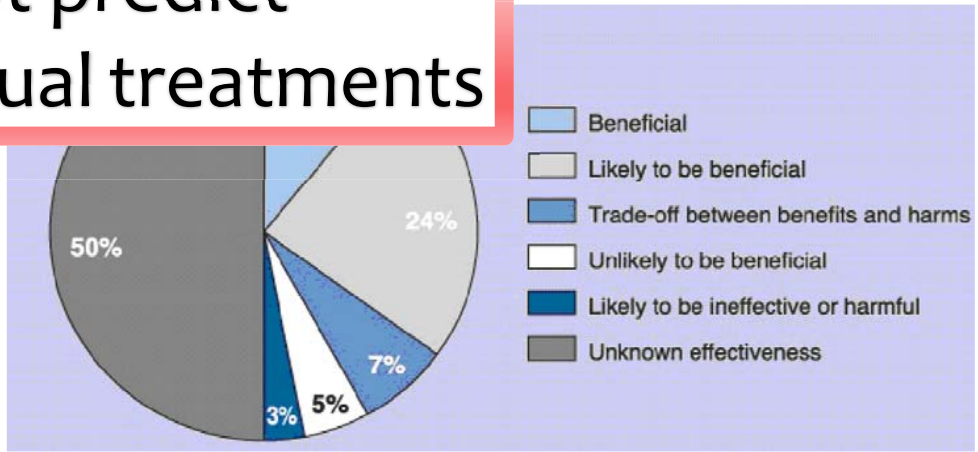
Personalized Medicine and Health
The doctor is drowning



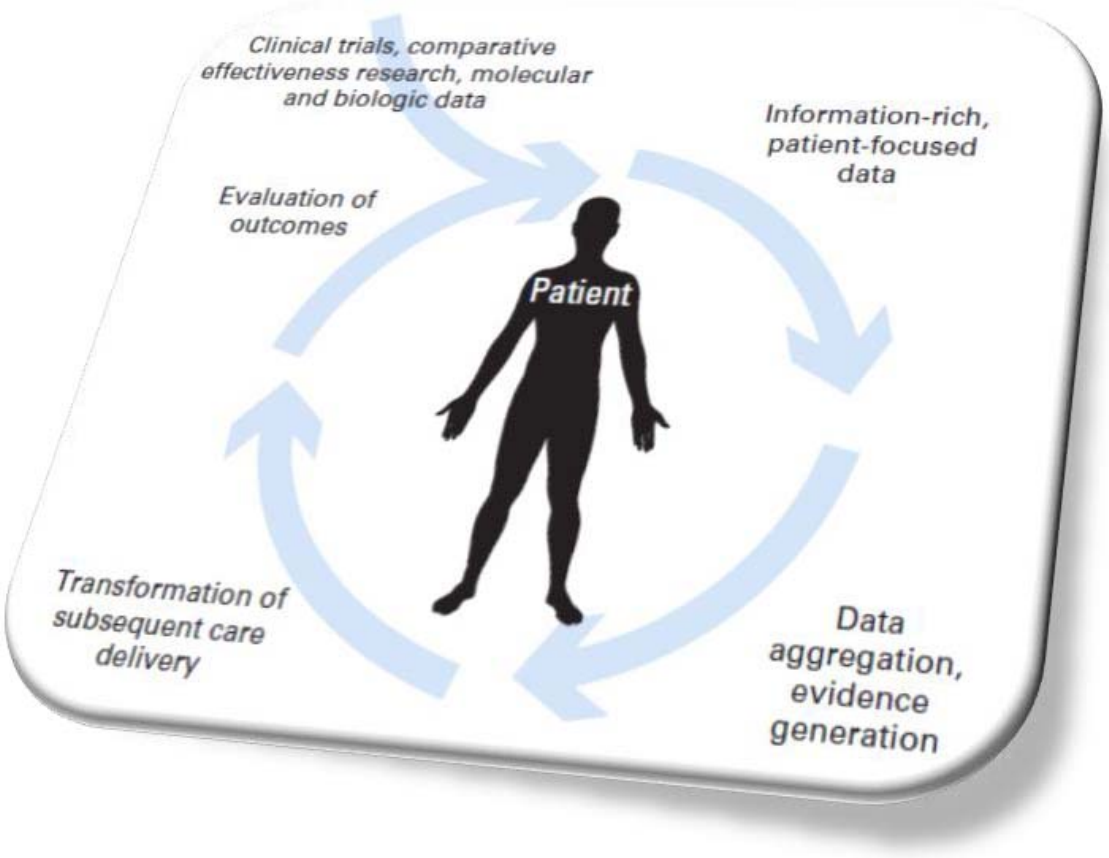
- Explosion of data
- Explosion of decisions
- Explosion of 'evidence'

Doctors cannot predict outcomes of individual treatments



J Clin Oncol 2010;28:4268
JMI 2012 Friedman, Rigby
BMJ Clinical Evidence

Personalized Medicine & Health = Data Driven Medicine & Health
Rapid Learning Health Care



[..] the problem is not really technical [...]. Rather, the problems are ***ethical, political, and administrative.***

Lancet Oncol 2011;12:933

A different approach

- If sharing is the problem: Don't share the data

- If you can't bring the data to the research
- You have to bring the research to the data

- Challenges
  - The research application has to be distributed (trains & track)
  - The data has to be understandable by an application (i.e. not a human) -> FAIR data stations

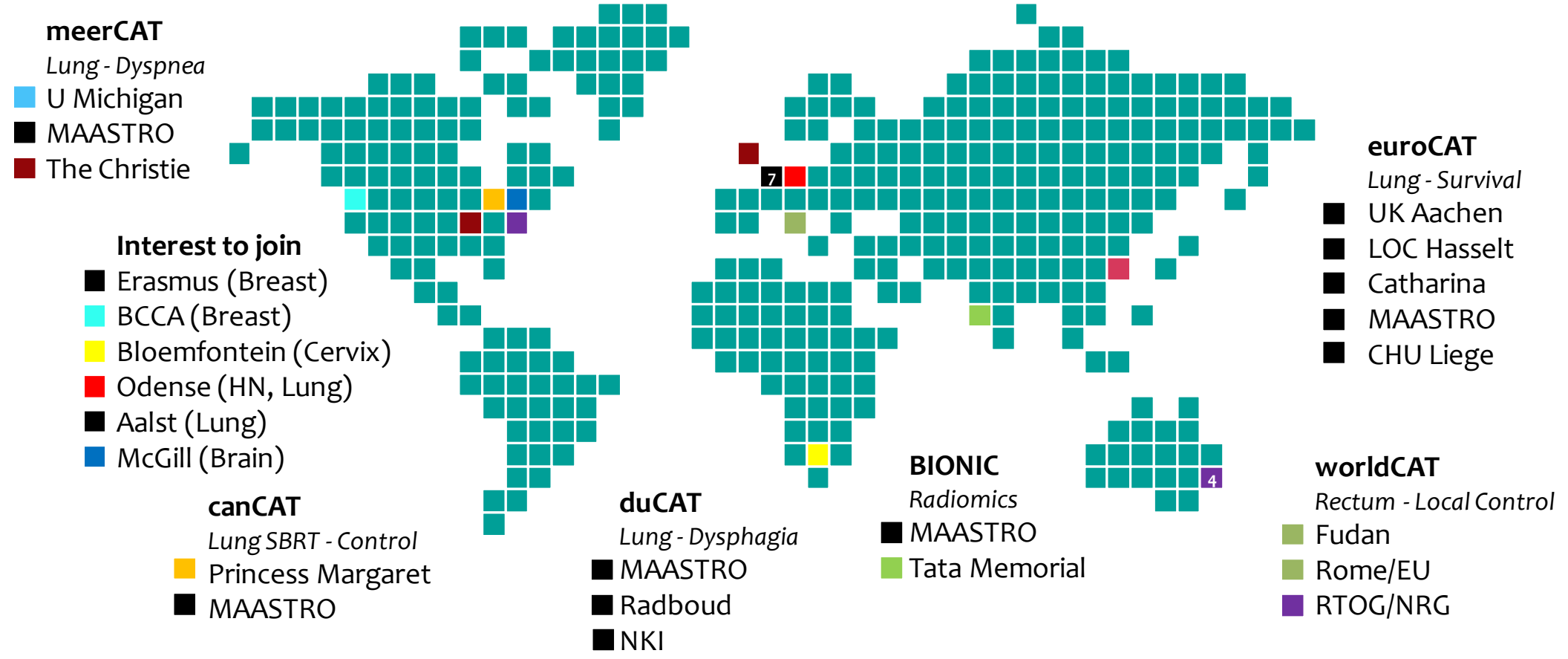
- Opportunities
  - People can control their own data (personal locker)
  - People can start their own research (citizen train operators)

The Personal Health Train

health RI research infrastructure

The Personal Health Train

Reality !



Map © Copyright Showeet.com

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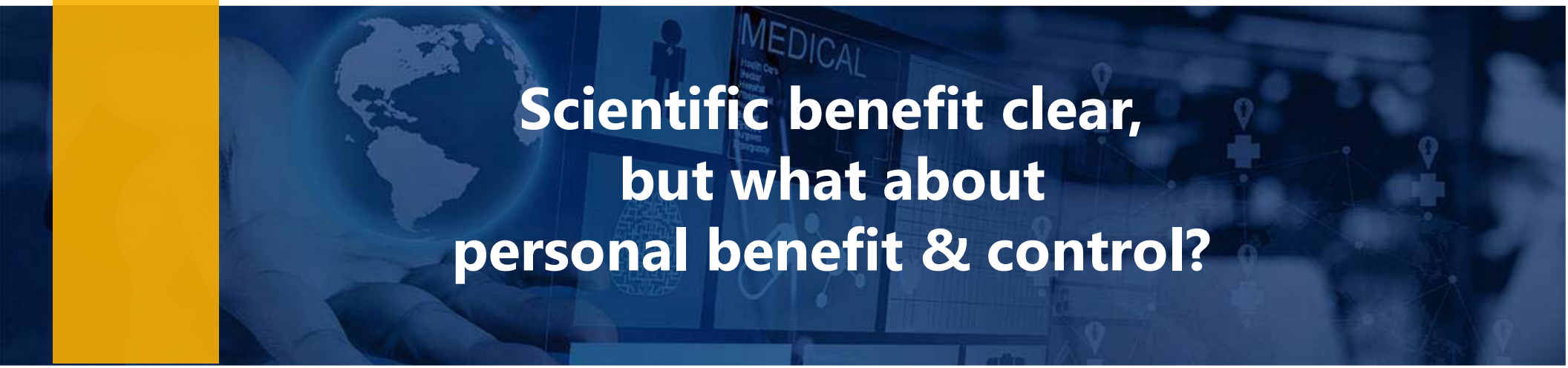

Scientific benefit clear, but what about personal benefit & control?

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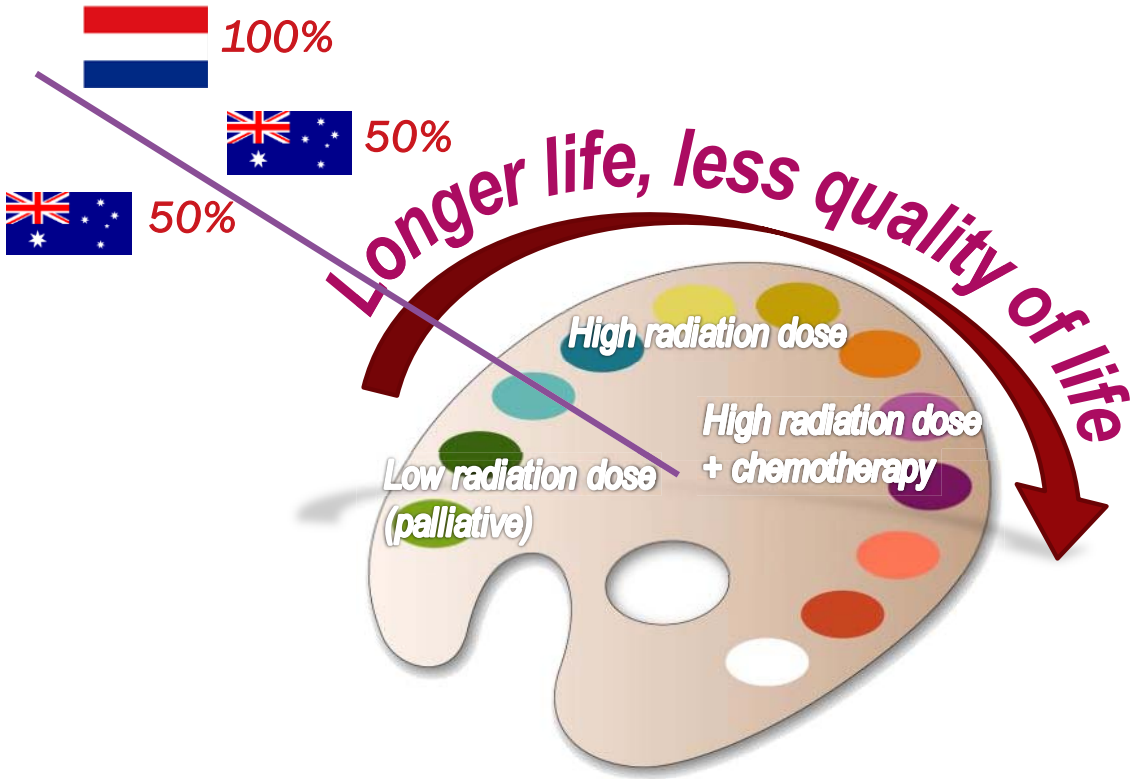
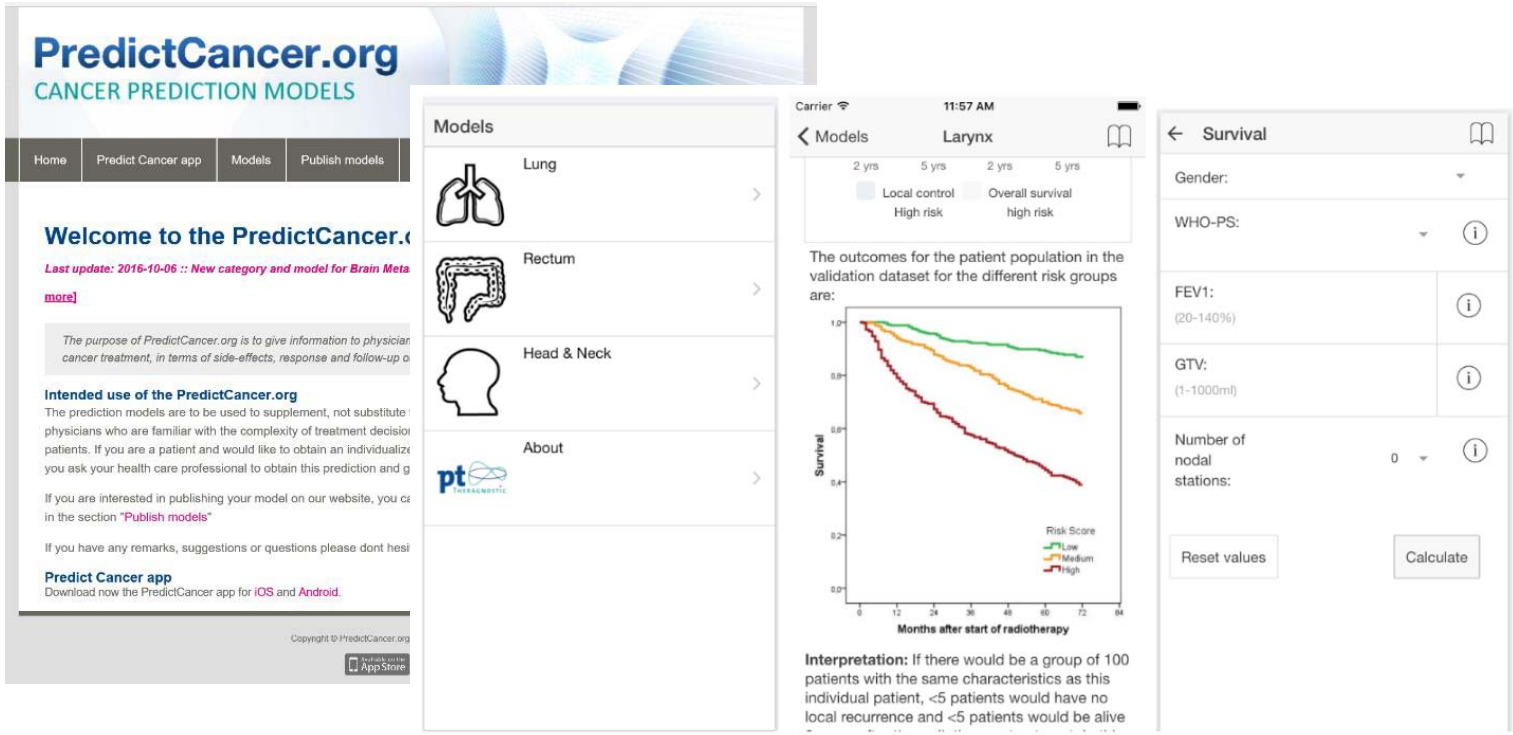
Personal benefit
A lung cancer example



There is an app for that – Predict Cancer

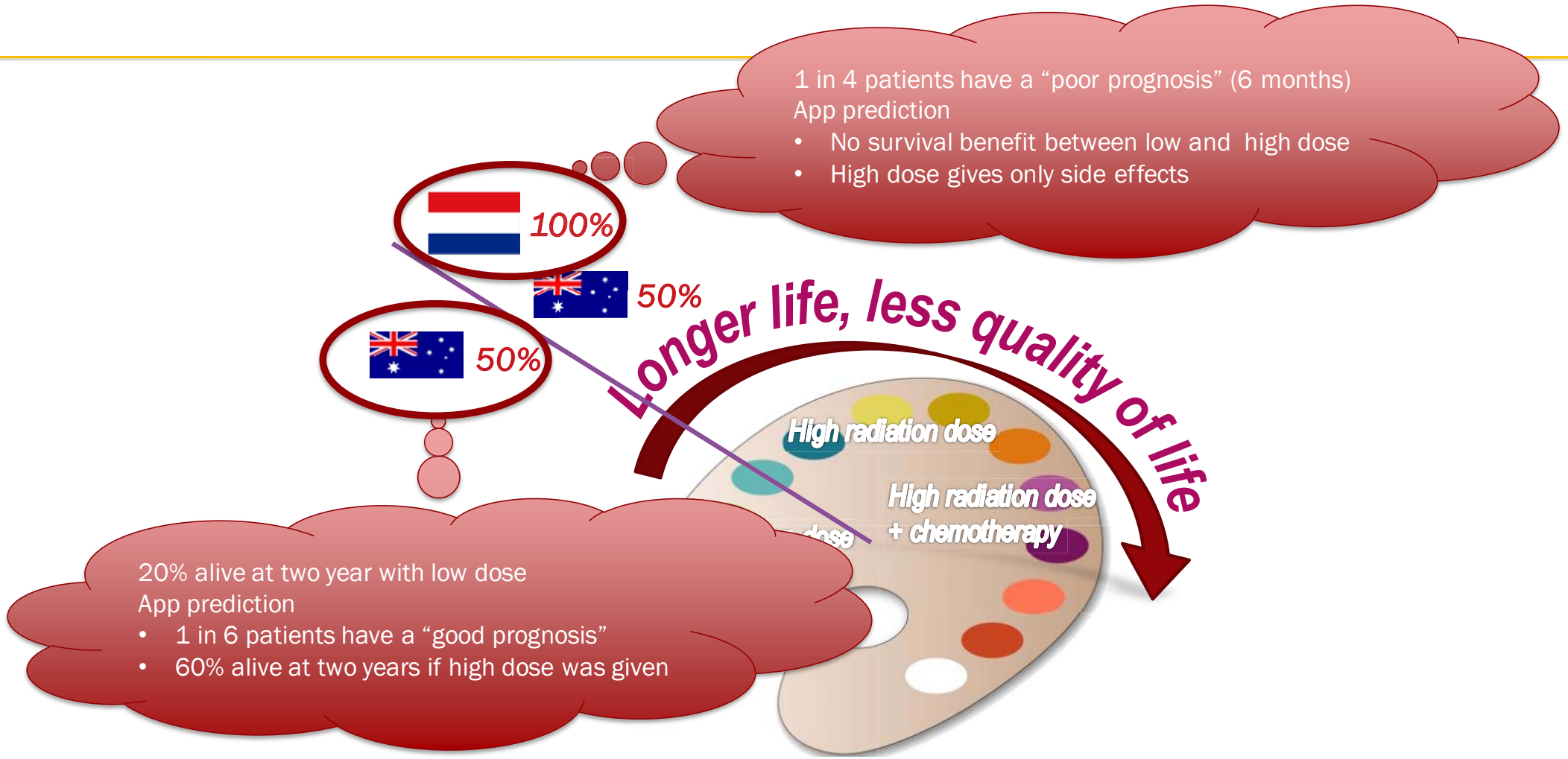


CE

+ Endometrium cancer
+ Head & neck cancer
+ Brain metastases
+ Lung cancer
+ Prostate cancer
+ Rectum cancer

- Manual entry now –> with PHT automated entry

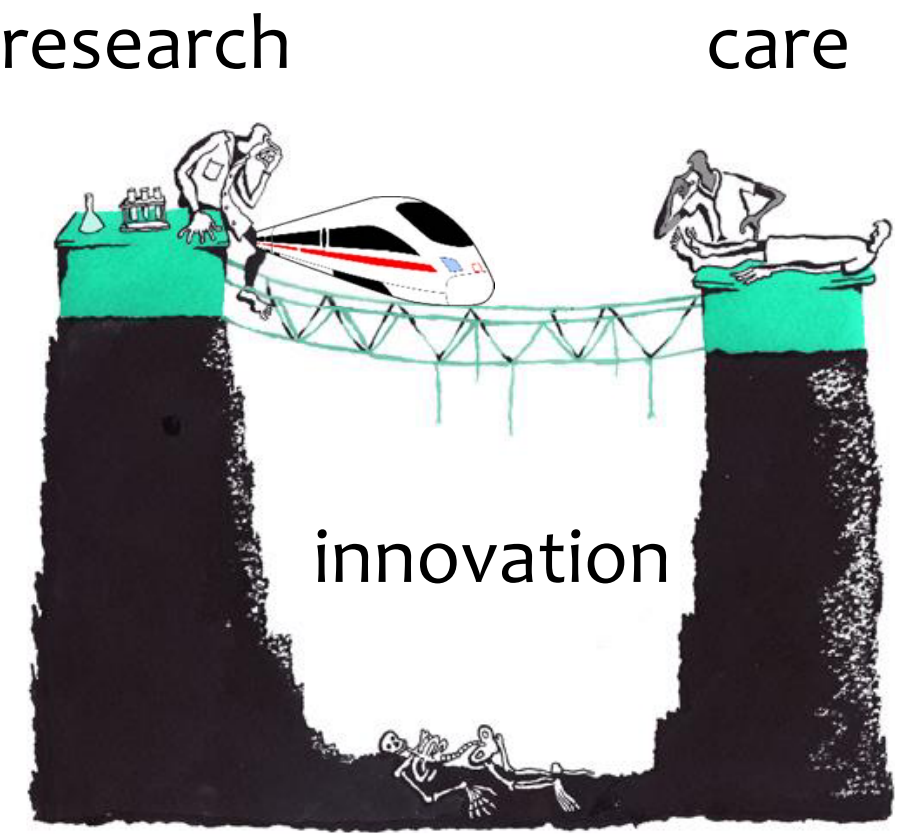
Personal benefit?



Personal control? (PRANA)

- Focus groups (patients and non-patients)
- More sharing when…
  - **value** is recognised
  - there is **trust** in the receiver of the data
  - the sharing process is **easy to understand**
  - there is a **societal or personal goal**
  - it is **transparent** what will be done and by whom

Outlook



- Health Care & Research
- Personal Lockers
- Privacy, Control & Consent
  - MedMij, RESPECT4U
  - Cooperatives
- FAIR
- PHT Limburg
- PHT workshop(s) & community
- www.personalhealthtrain.nl

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Thank you for your attention

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