

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

Maastricht UMC+, Leids UMC, TNO

# Personal Health Train

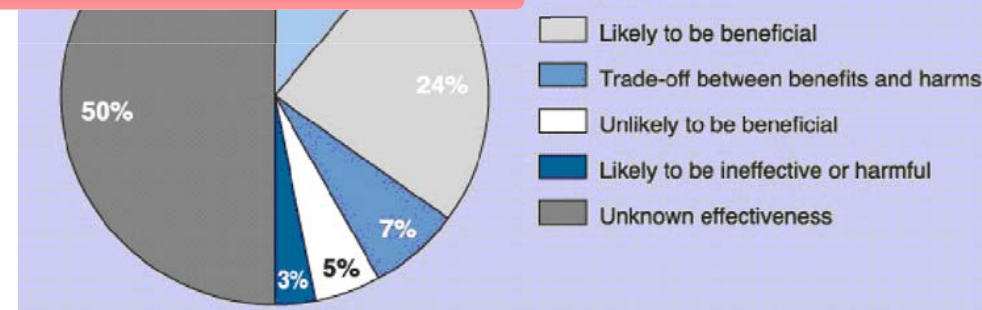
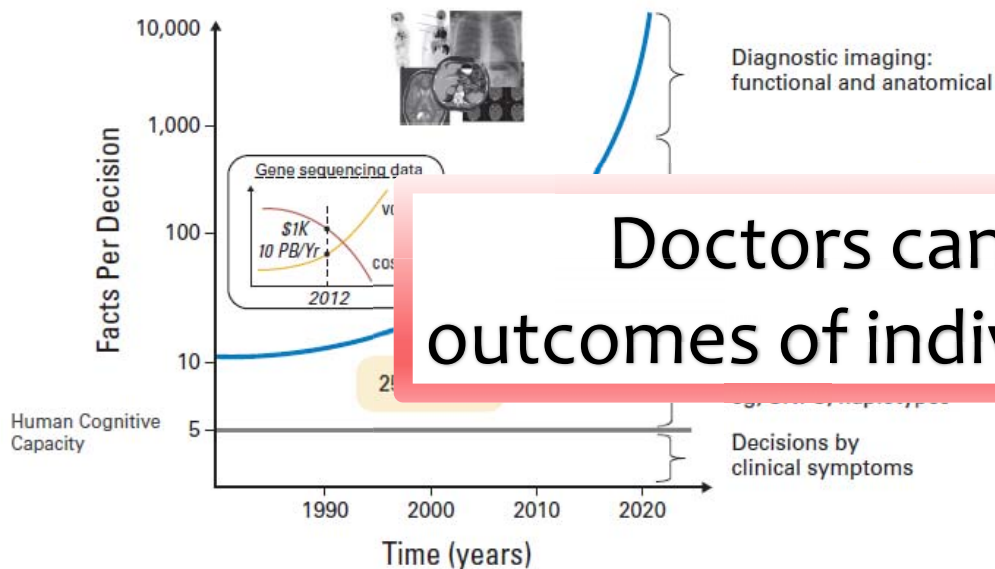


# Personalized Medicine and Health

## The doctor is drowning

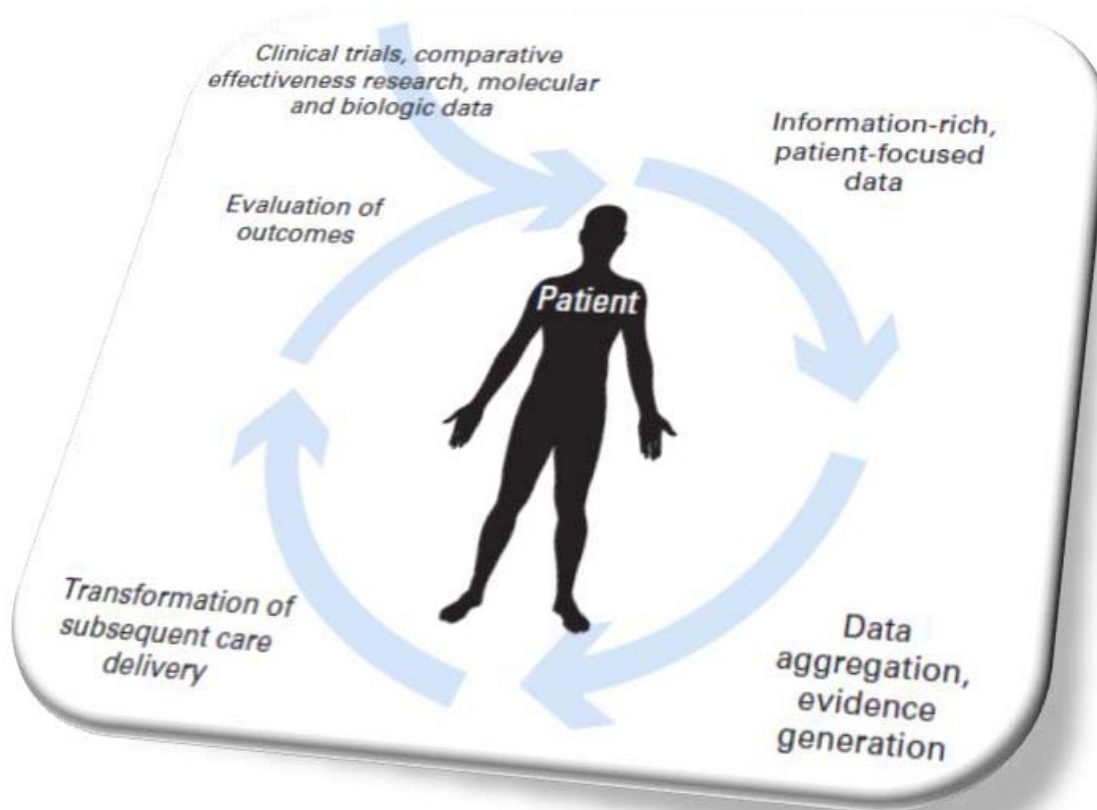
- Explosion of data
- Explosion of decisions
- Explosion of 'evidence'

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

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# The Personal Health Train



*Personal Health Train*

# Reality !

## meerCAT

Lung - Dyspnea

- U Michigan
- MAASTRO
- The Christie

## Interest to join

- Erasmus (Breast)
- BCCA (Breast)
- Bloemfontein (Cervix)
- Odense (HN, Lung)
- Aalst (Lung)
- McGill (Brain)

## canCAT

Lung SBRT - Control

- Princess Margaret
- MAASTRO

## duCAT

Lung - Dysphagia

- MAASTRO
- Radboud
- NKI

## BIONIC

Radiomics

- MAASTRO
- Tata Memorial

## euroCAT

Lung - Survival

- UK Aachen
- LOC Hasselt
- Catharina
- MAASTRO
- CHU Liege

## worldCAT

Rectum - Local Control

- Fudan
- Rome/EU
- RTOG/NRG

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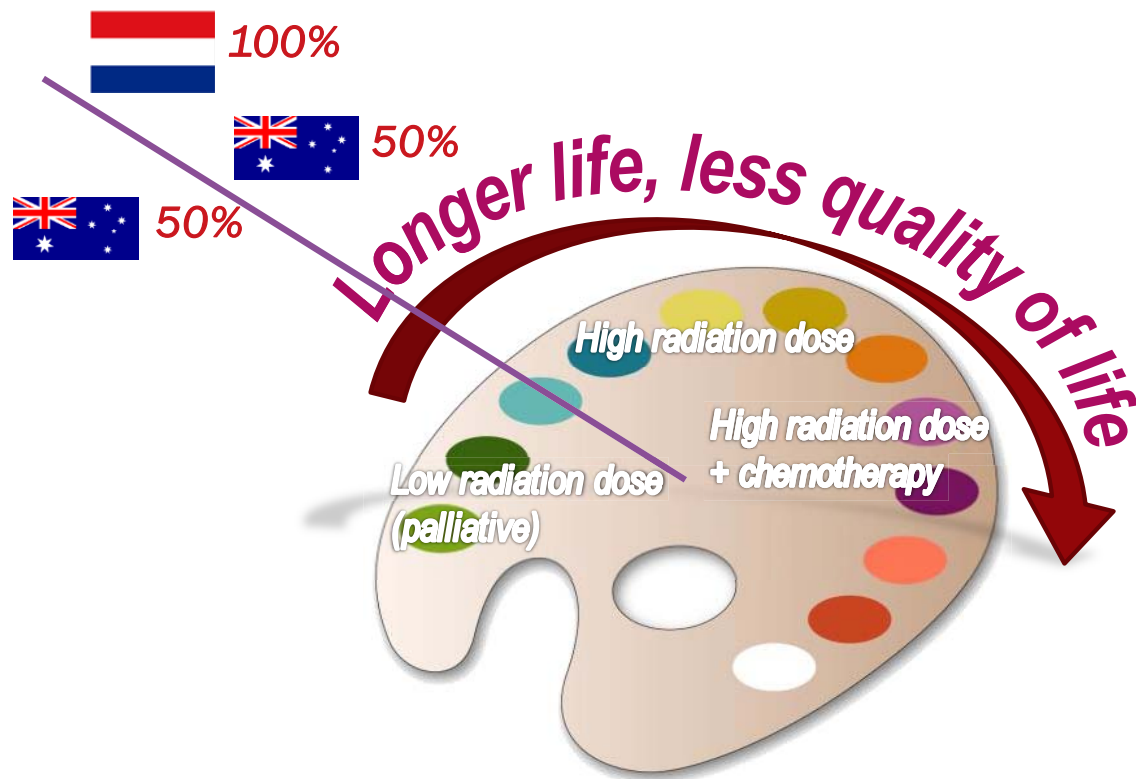
# Scientific benefit clear, but what about personal benefit & control?



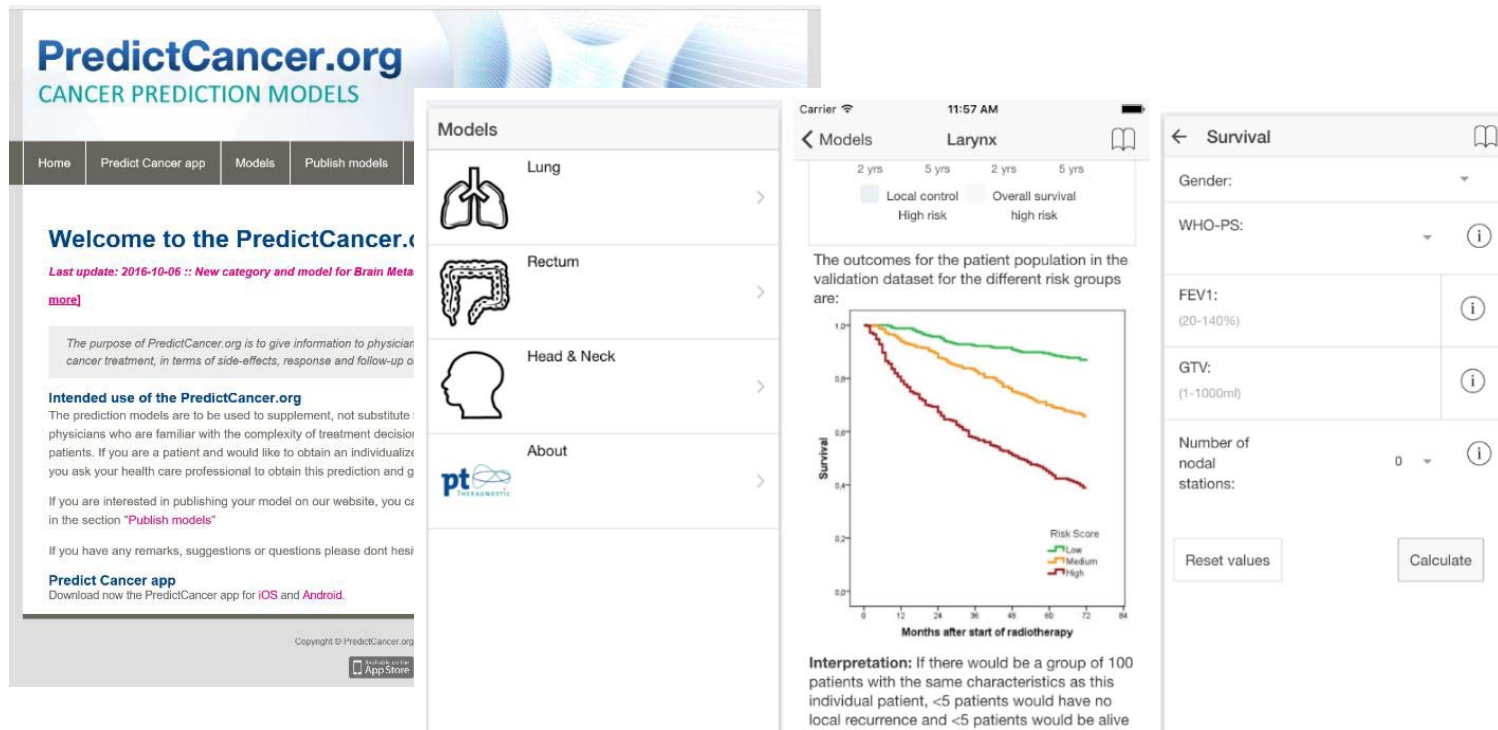


# Personal benefit

## A lung cancer example



# There is an app for that – Predict Cancer



The image displays the PredictCancer.org website and its mobile application interface. The website header includes the logo and navigation links: Home, Predict Cancer app, Models, and Publish models. A welcome message states: "Welcome to the PredictCancer.org. Last update: 2016-10-06 :: New category and model for Brain Metastases". Below this, it explains the purpose of the site and provides instructions on how to use the prediction models. The app interface shows a list of cancer models: Lung, Rectum, Head & Neck, and About. The 'Larynx' model is selected, showing a survival plot for 'Local control' and 'Overall survival' over 72 months. The plot shows three risk groups: Low (green), Medium (yellow), and High (red). The 'Survival' plot shows the probability of survival over time. The 'Survival' plot shows the probability of survival over time. The 'Survival' plot shows the probability of survival over time.

**CE**

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

- Manual entry now –> with PHT automated entry

# Personal benefit?

1 in 4 patients have a “poor prognosis” (6 months)  
App prediction

- No survival benefit between low and high dose
- High dose gives only side effects



50%



50%

Longer life, less quality of life

High radiation dose

High radiation dose  
+ chemotherapy

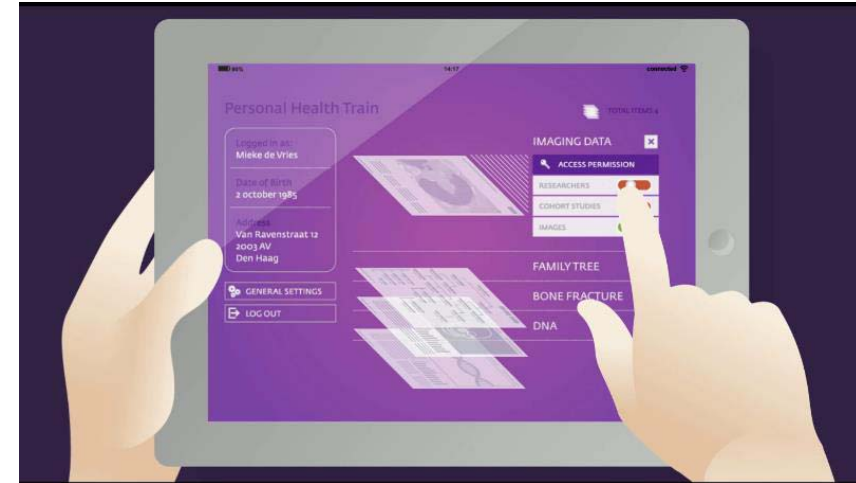
20% alive at two year with low dose

App prediction

- 1 in 6 patients have a “good prognosis”
- 60% alive at two years if high dose was given

# Personal control? (PRANA)

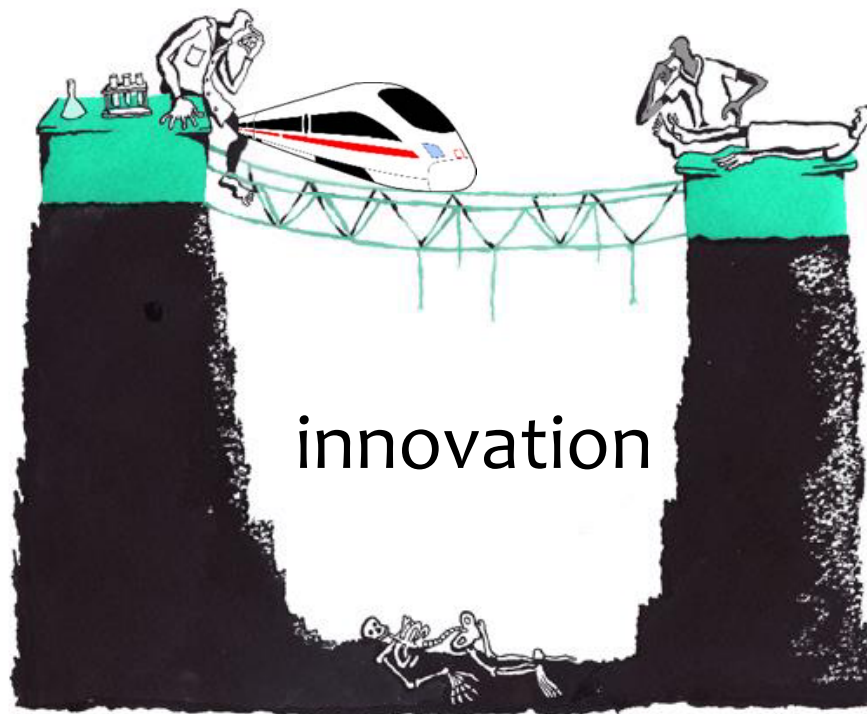
- Focus groups (patients and non-patients)
- More sharing when...
  - value is recognised
  - there is trust in the receiver of the data
  - the sharing process is easy to understand
  - there is a societal or personal goal
  - it is transparent what will be done and by whom



# Outlook

research

care



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

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**Thank you for your attention**

