VBHC.. Where do we go?

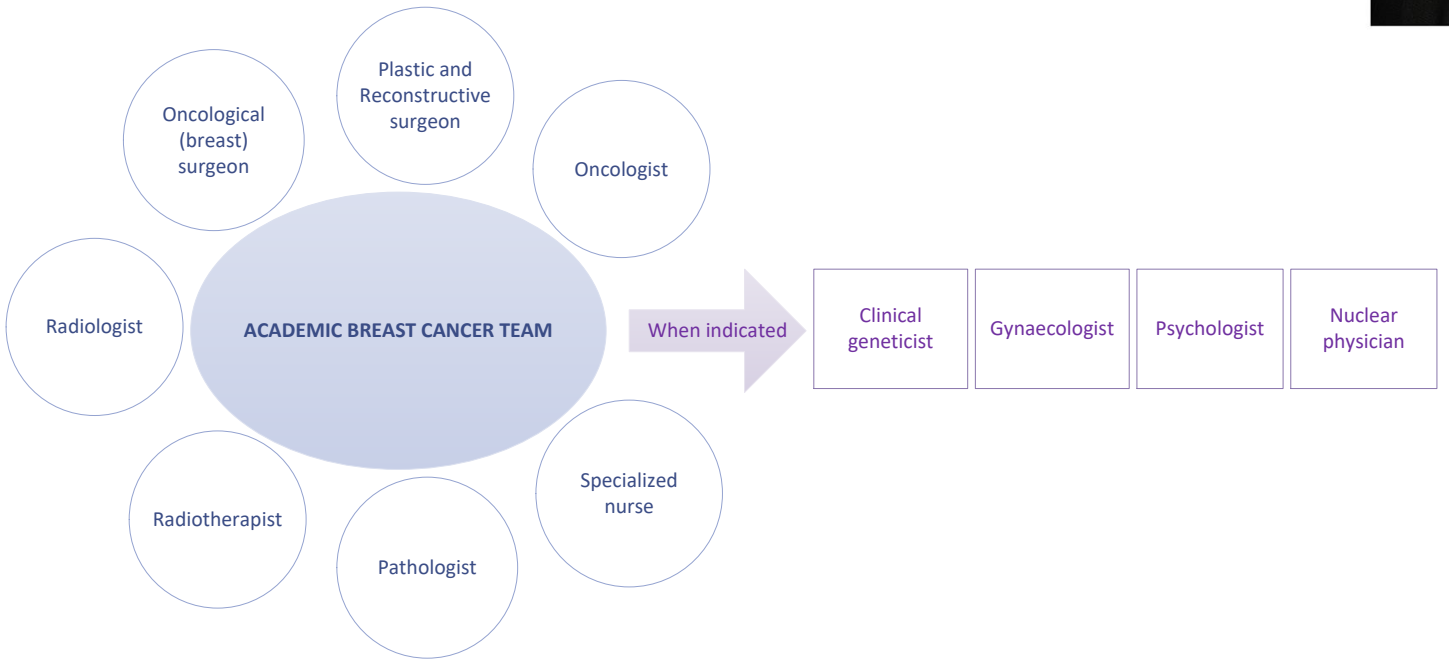
Linetta Koppert

Erasmus MC
Universitair Medisch Centrum Rotterdam

Our ‘outcome journey’ since 2014

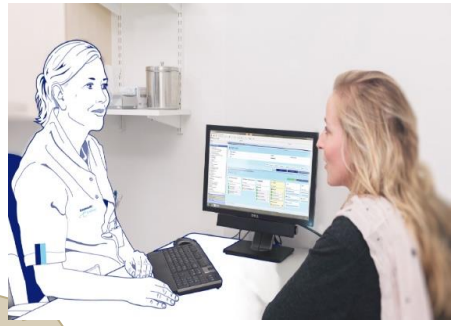
<u>Search for outcomes that matter most to our patients:</u>

- According to health care professionals



- According to (our mostly young breast cancer) ⇨ patient surveys
- Expert panel: what are validated questionnaires that capture the outcomes?

A wonderful journey



Kimberly Allison, **Stanford University**
Patricia Ganz, **UCLA**
Reshma Jagsi, **University of Michigan**
Henry Kuerer, **MD Anderson Cancer Center**
Sarah McLaughin, **Mayo Clinic Jacksonville**
Ann Partridge, **Dana-Farber Cancer Institute**
Dereesa Reid, **Hoag Orthopedic Institute**
Thomas Smith, **Johns Hopkins Institute**

Yvonne Wengström, **Karolinska Institute**

Anne Knip, **Breast Cancer Association**
Marc Mureau, **Erasmus MC Cancer Institute**
Mark Stoutjesdijk, **Ikazia Hospital Rotterdam**
Marie-Jeanne Vrancken Peeters, **Antoni van Leeuwenhoek**
Linetta Koppert, **Erasmus MC Cancer Institute**

John Browne, **University College Cork**

Francois Duhoux, **Cliniques Universitaires Saint-Luc**

Karen Benn, **Europa Donna**

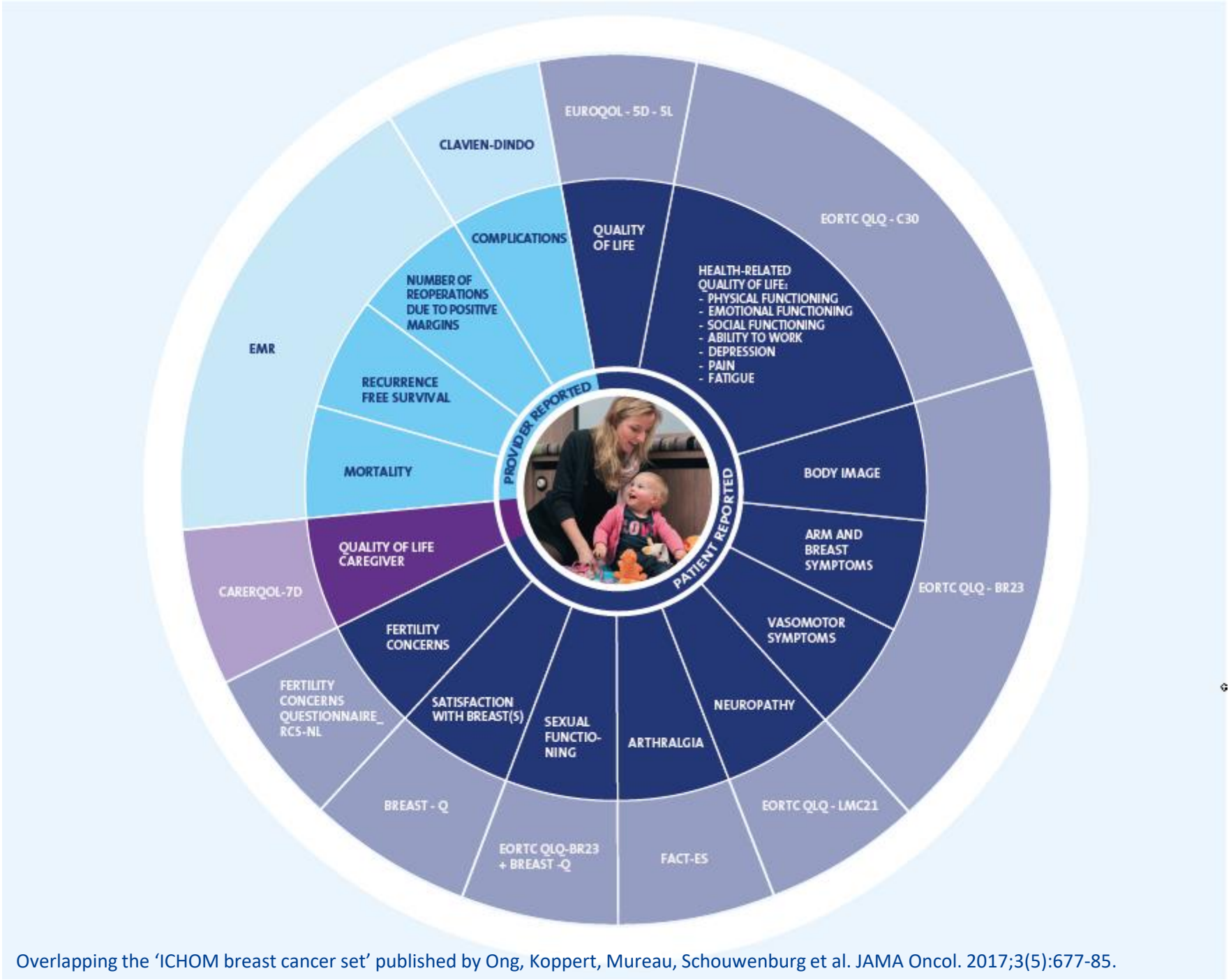
Cheng Har Yip, **Subang Jaya Medical Centre**

Felicia Knaul, **Cancer de Mama**

Rodney Cooter, **Monash University**
Geoff Delaney, **South Western Sydney Local Health District**
Patricia Hancock, **Breast Cancer Network Australia**
Wee Loon Ong, **Peter MacCallum Centre**
Christobel Saunders, **University of Western Australia**
Lisa Sheeran, **Peter MacCallum Cancer Centre**

Published: JAMA Oncology 2017

External advisors: Barbara Levy (ACOG), Beth Daley Ullem (DePaul University), Catherine Calderwood (NHS), Paulien Brunings (Achmea)



Overlapping the 'ICHOM breast cancer set' published by Ong, Koppert, Mureau, Schouwenburg et al. JAMA Oncol. 2017;3(5):677-85.

ACADEMISCH BORSTKANKERCENTRUM

Soort borstoperatie Lumpectomie Neo-adjuvante chemotherapie Nee Operatiedatum 07 apr. 2016
Startdatum: 24-03-2016

14 | 25 | 2 | 25

MDO Behandelplan

24-03-2016

Zorgprofessionals

- Aanmelden mantelzorger/directe naaste
- Neo-adjuvante chemotherapie
- Initiële Patiënt Condities (Borstkanker)

Preoperatief

24-03-2016

Patiënten

- EQ-5D-5L Nederlandse versie
- EORTC QLQ C30
- EORTC QLQ BR23
- Breast-Q

Definitieve behandelkeuze

01-04-2016

Zorgprofessionals

- Definitieve behandelkeuze

T6

07-10-2016

Patiënten

- EQ-5D-5L Nederlandse versie
- EORTC QLQ C30
- EORTC QLQ BR23
- De Lastmeter
- Breast-Q Module Borstsparende Therapie (Postoperatief)

07-09-2016

Directe naaste

1

T12

07-03-2017

Zorgprofessionals

- Provider Reported Outcomes

07-04-2017

Patiënten

5

07-03-2017

Directe naaste

1

T24

07-03-2018

Zorgprofessionals

- Provider Reported Outcomes

Patiënten

- EQ-5D-5L Nederlandse versie

07-04-2018

Patiënten

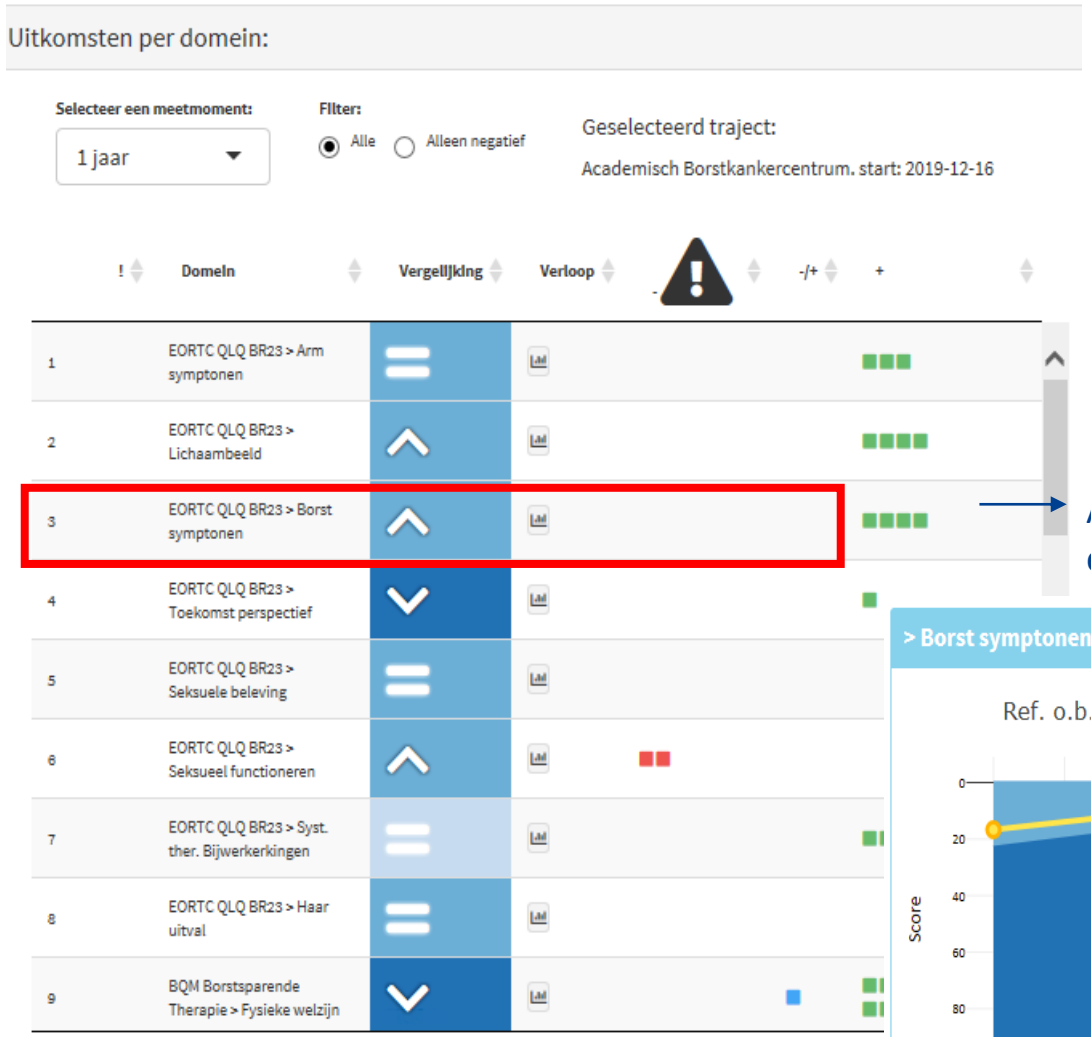
- EORTC QLQ C30

07-03-2018

Patiënten

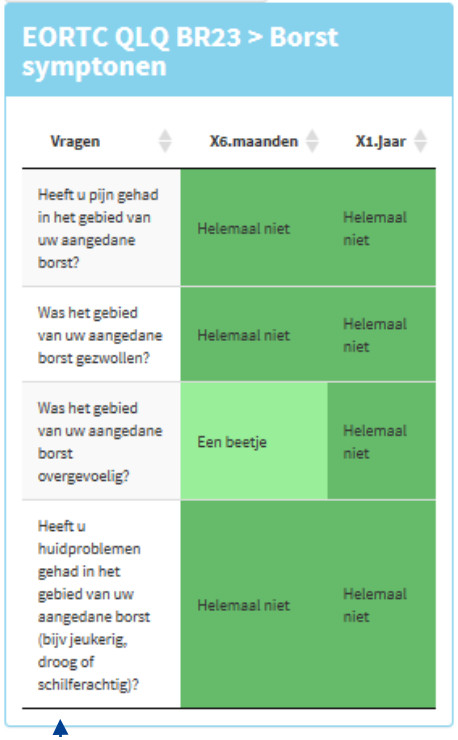
- EORTC QLQ BR23
- Breast-Q Module Borstsparende Therapie (Postoperatief)

Dashboard

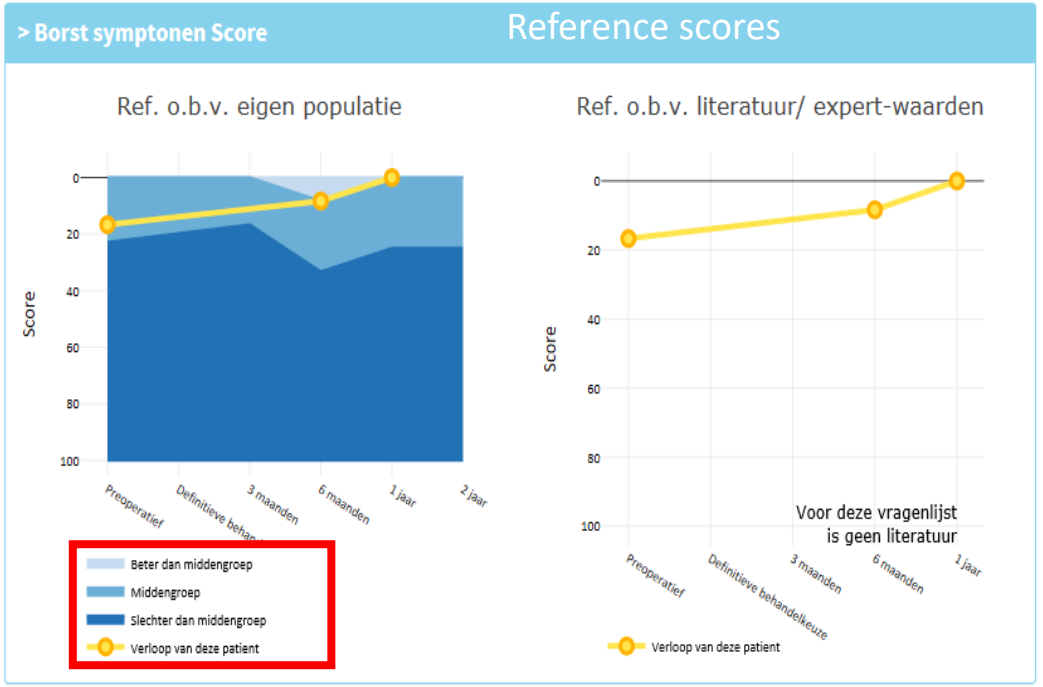


Overview questionnaire and domain

Answers to each question



Reference scores



Here all challenges come together .. ‘standardisation, interoperability and digitalisation’. No clear answers yet, but let me draw a beautiful example inspiring me. In 2020 I got involved with an international collaboration which needs some introduction

H_2O | HEALTH OUTCOMES OBSERVATORY

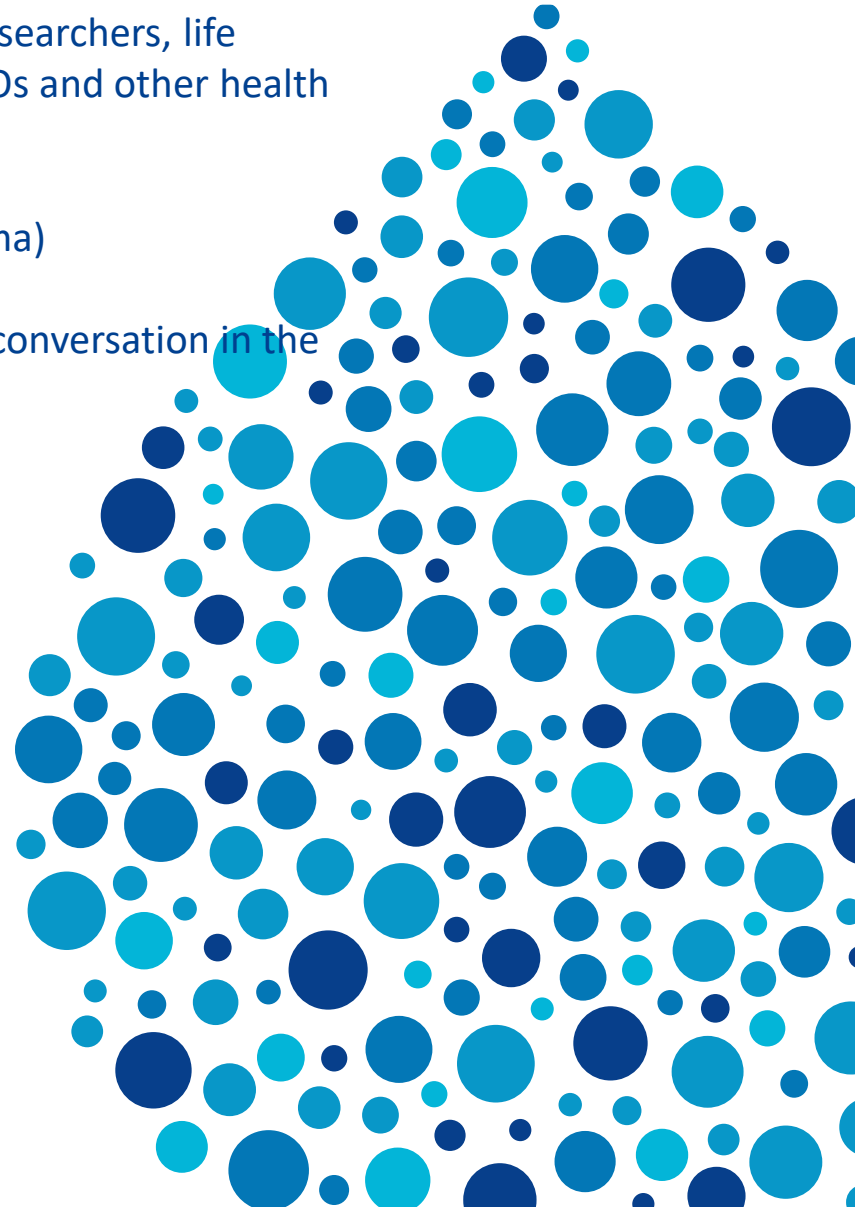
“Sustainable health care systems should be focused on outcomes instead of reimbursing for the services provided ….”

(..could have been an ICHOM statement..)

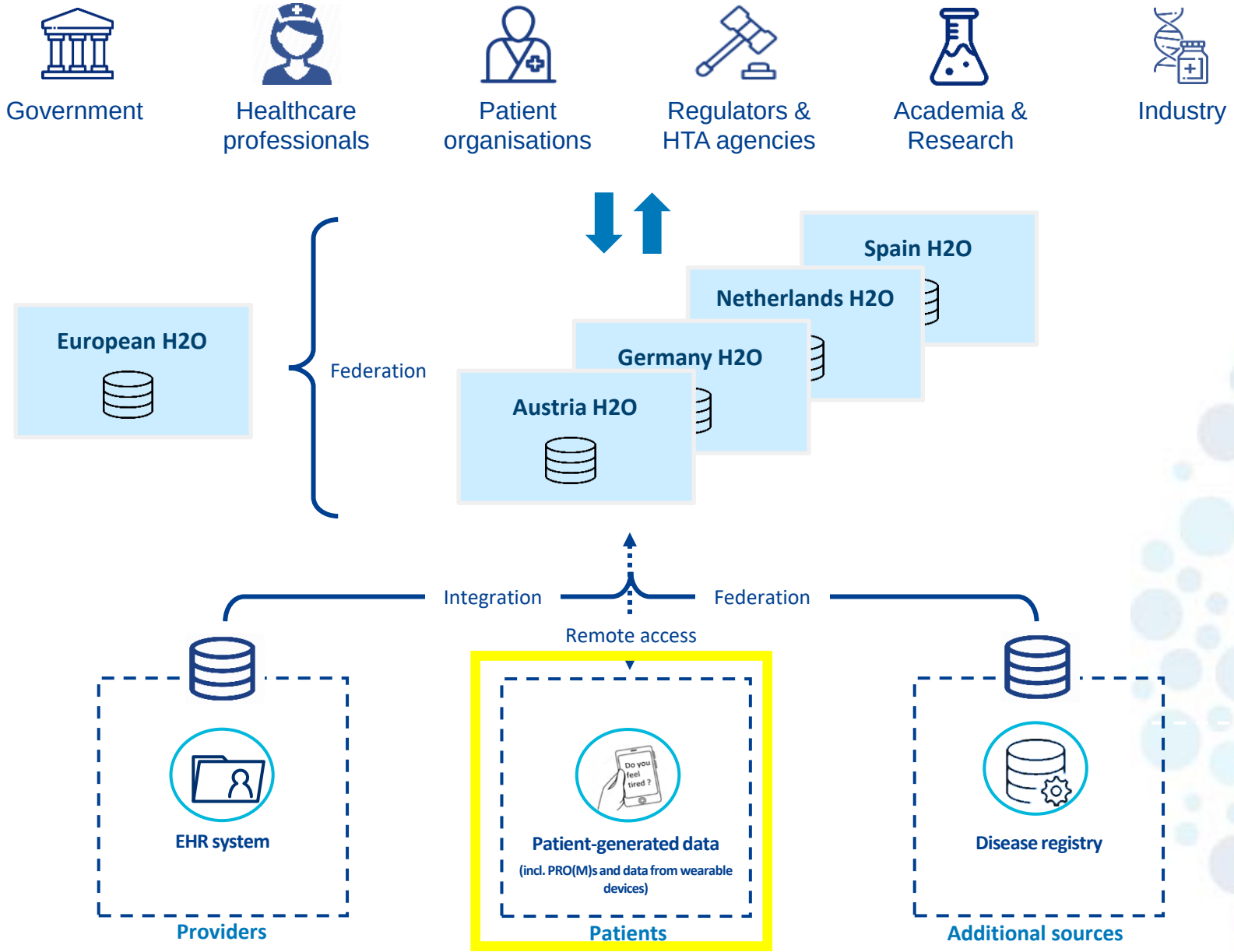
Erasmus MC
Universitair Medisch Centrum Rotterdam

Why

- H2O is a new public-private consortium bringing together patients, clinicians, academic researchers, life science and industry to generate a multinational ecosystem to collect and incorporate PROs and other health outcomes into healthcare decision making
- DM, IBD and cancer (**metastasized breast**, lung, multiple myeloma, Non-hodgkin lymphoma)
- Patient empowerment to measure outcomes in standardized manner, being transparent, conversation in the consultation room; deliver better healthcare
- Within EUHA; funded by Innovative Medicines Initiative (IMI)
- Scalability; Anonimyzed and aggregated data form a natural source; Non-for-profit model: data broadly available, in a legal and ethical way
- *Implementation*; digital technology; patient dashboard; autonomy on data flow; patient-centered VBHC model
- Federative architecture for data collection, 'OMOP Observational Medical Outcomes Partnership CDM common data model'



Ref Stamm et al. NEJM Catalyst June '21


Government
Healthcare professionals
Patient organisations
Regulators & HTA agencies
Academia & Research
Industry
European H2O
Federation
Spain H2O
Netherlands H2O
Germany H2O
Austria H2O
Integration
Federation
Remote access
EHR system
Providers
Patient-generated data
(incl. PRO(M)s and data from wearable devices)
Patients
Disease registry
Additional sources

The Value of PRO data

Table 2. Legitimate Interest and Stakeholder Value of Patient-Reported Outcomes (PRO) Data

PRO Utility	Patient	Clinical Provider	Academic Researcher	Health System	Payer	Research Funding Agency	Regulatory Agency
Shared decision-making	X	X					
Evaluating provider performance	X	X		X	X	X	X
Determining treatment effectiveness	X	X	X	X	X	X	X
Evaluation of novel treatments	X	X	X	X	X	X	X
System-level cost & quality improvement		X	X	X	X	X	X

Source: The authors, adapted from: Squitieri L, Bozic KJ, Pusic AL. The role of patient-reported outcome measures in value-based payment reform. Value Health 2017;20:834-836. https://www.valueinhealthjournal.com/article/S1098-3015(17)30114-6/fulltext?_returnURL=https%3A%2F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS1098301517301146%3Fshowall%3Dtrue. 10.1016/j.jval.2017.02.003.

Shared decision making
The right conversation
'Patients like me'
Proper use
Culture change
Learn and become better
....

Overlapping aims; let's further collaborate here!

Ref Tanja Stamm et al. NEJM Catalyst June '21

- **We came from:** RCTs, meta-analyses (2016: 3700 publications/ day…..).. So much knowledge to process
- **And are now in** Real World Evidence, **Big Data**.. Even enlarging the gap between gain of knowledge and apply that knowledge
- **Big Data potential:** Shared Decision Making, decision support, personalized medicine
- **Ideally the** patient gives consent: Big Data now should generate hypotheses for RCTs

- Bring Evidence Based Medicine forward: data, conclusions out of data; the international benchmarks!
- Keep helping health care providers to create and use standard outcome sets
- Help to create data infrastructure / ecosystem out of EMRs and patients, disease registries, GP data, pharma data..
- And bring outcomes *into the consultation room*: Shared Decision Making, decision support, personalized medicine
- Since outcomes should be *openly* discussed *in the shelter* of the consultation room

Erasmus MC

Concrete

“Let doctors be doctors and nurses be nurses” .. We all want to deliver high quality care

Bring the data into consultation rooms (ICT, dashboarding, disease registries, ..)

H2O | HEALTH OUTCOMES OBSERVATORY

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