



**Utrecht
University**

Values and incentives in the development of an intelligent data ecosystem for rare cancers (IDEA4RC)

Dr. Claudia Egger
c.egger@uu.nl

Dr. Susan van Hees
s.v.vanhees@uu.nl

Dr. Wouter Boon
w.p.c.boon@uu.nl

About IDEA4RC:

- European Horizon project focusing on the sharing, use, and re-use of data about rare cancers
- 25 partners from different EU Member States
- 11 centers of expertise
- Highly interdisciplinary:
 - medical researchers, clinicians, data scientists, IT developers, legal experts, etc.

Goals:

- Promoting research on rare cancers
- Improving patients' access to high quality care



Our role in IDEA4RC:

- RRI framing/ co-creation approach
- Data ecosystem baseline value positions, value analysis and scenarios to guide future work
- Data ecosystem final guide, recommendations to maximize ecosystem self-sustainability



Our approach to values:

- “lived realities” (Boenink & Kudina, 2020), the result of valuation processes
- constituted and negotiated through practices
- shaping the development, implementation, & diffusion of innovations



Valuation Framework:

3 core pillars:

- **Value Multiplicity**
- **Value Dynamism**
- **Value Implications**

→ To map the main stakeholders' different & evolving value positions

→ To facilitate the sustainable development & implementation of IDEA4RC




By means of:

- Literature review (academic & grey literature)
- Semi-structured interviews with relevant stakeholders
- Co-creation workshop(s)
- (future) Ethnographic studies at pilot sites



Co-creation workshop challenges:

- Highly diverse audience
 - Different interests
 - Different expectations
 - Different ways of working
 - Different positions/roles regarding IDEA4RC
- 
- Adequate framing: enjoyable, creative, and a serious endeavor
 - Adequate balance between research interests and the practitioners' interests
 - Adequate expectations & deliverables



First co-creation workshop:

April 20, 2023, Venice

All the IDEA4RC partners

Awareness-building

Group-based activities

- IDEA4RC postcards
- Image-based reflections on the values and trade-offs required for the development of an ideal “data journey” for IDEA4RC
- Vignette-based reflections on potential drivers and challenges



(VERY)
PRELIMINARY
FINDINGS



Main (emerging) values:

- Quality of care
 - The patients as central actors
- Privacy
 - Technical, legal, & ethical framing
- Data quality
 - Harmonization
 - Comprehensiveness
 - Validity
 - Expertise

if it wasn't for anonymization and the data sharing process, I would probably even prefer the NLP and data management to happen in something that would take away this workload that I would have to invest in my particular hospital. But it could be ... with some loss of information, because obviously in the hospital the people know the best what's in the data basically...(P1, A1, G5)

Main
(emerging)
values:

Sustainability

- financial resources
- necessary skills
- using resources available through other projects

For this, I don't have a source of funding, so there is a question mark in my head as a hospital manager, how do I finance this...hmm...NLPs and everything, if I need to structure it? Where do I get the money to buy new servers or cloud space, whatever it is? Where do I get the money to fund the data managers increasing the complexity of the system and the scope of the system? It will cost more, obviously, to structure it and all the manual work that needs to be done, for example, even for the validation of an NLP thing, I need a person to sit there and do it, right? The issue for me as the hospital manager is where do I find the money for that? (P1, A1, G6)

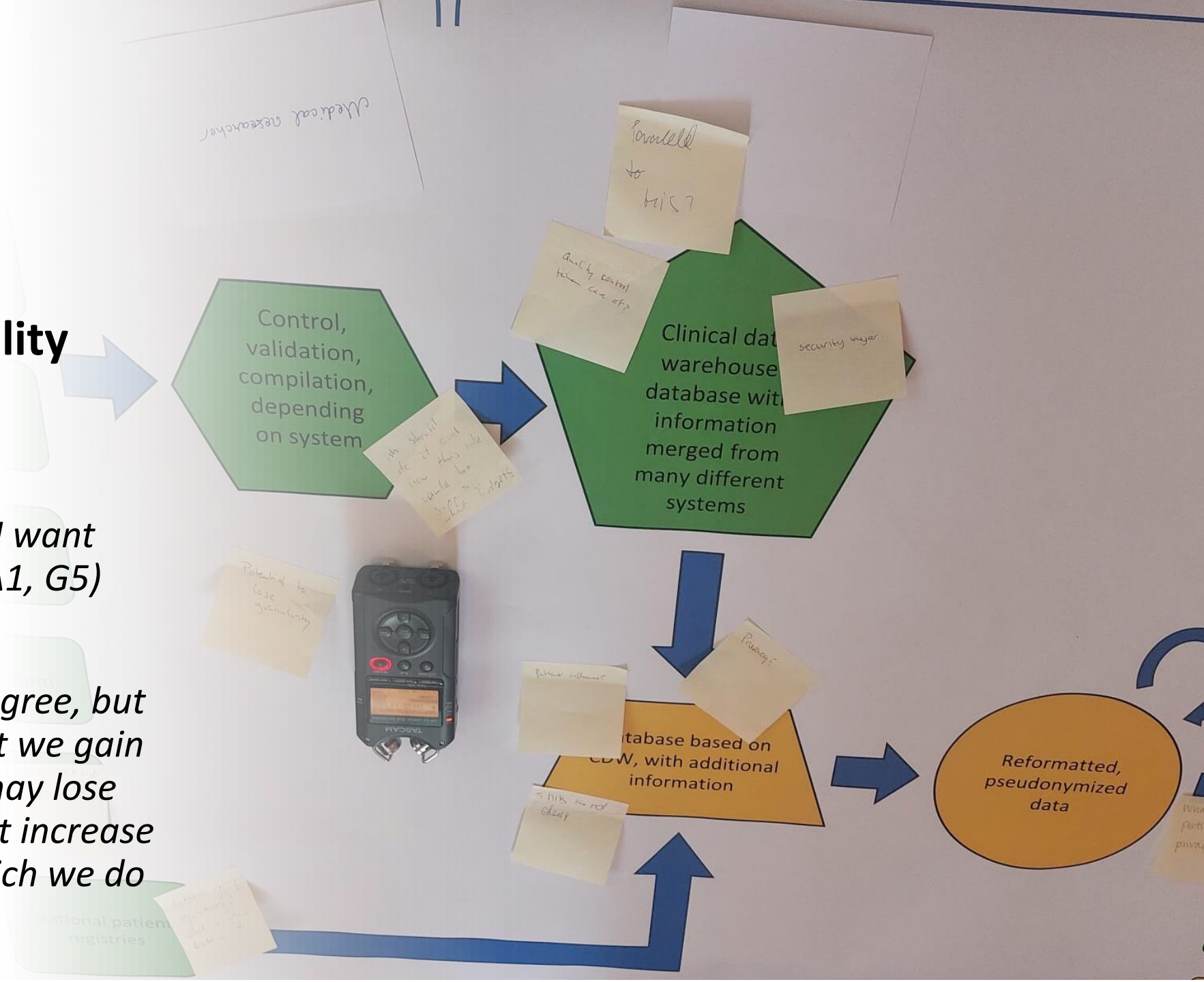
Main (emerging) tensions:

More data vs. good quality data

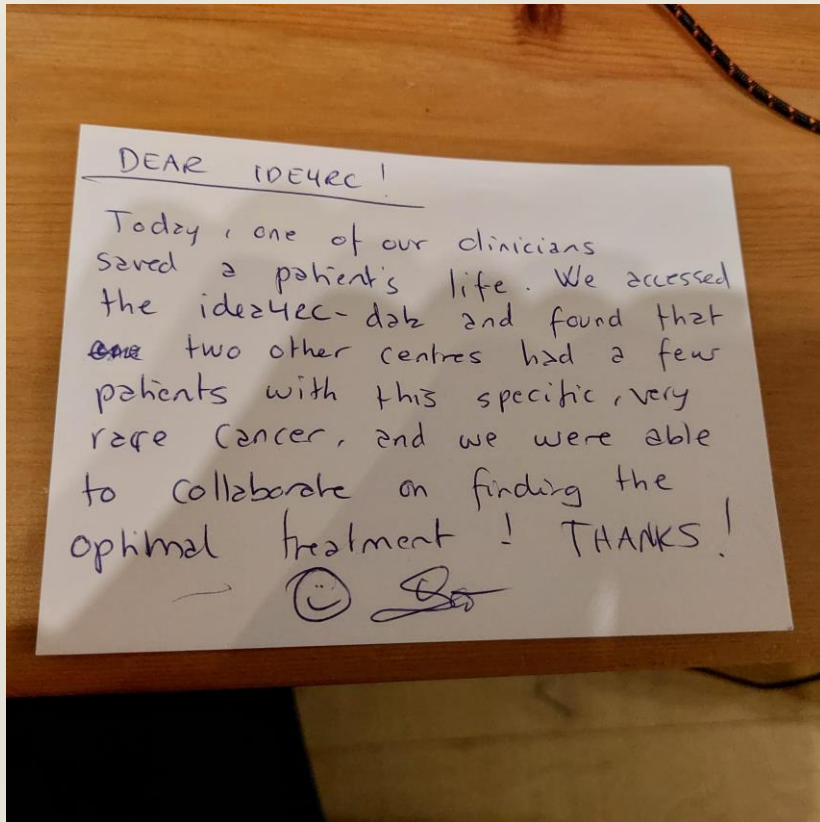
"I want good data quality, I want comprehensive data" (P2, A1, G5)

Vs.

"There is a loss, I completely agree, but if we need to understand what we gain from this loss, because we may lose some granularity, but we might increase the number of patients on which we do analysis (P3, A1, G5)



Main (emerging) tensions:



More effective care for rare cancer patients vs. additional work for clinicians

As soon as you have a benefit as a clinician, I think it's not too difficult to have maybe a little bit of extra work. But the acceptance definitely depends on how much extra work. (P4, A1, G5)

Let's assume that we have trained in a federated way an algorithm, so it's more accurate than training on a single center. Ok. But now we have to measure the effort needed to make that algorithm operative in the daily life of the clinician. (P5, A1, G5)

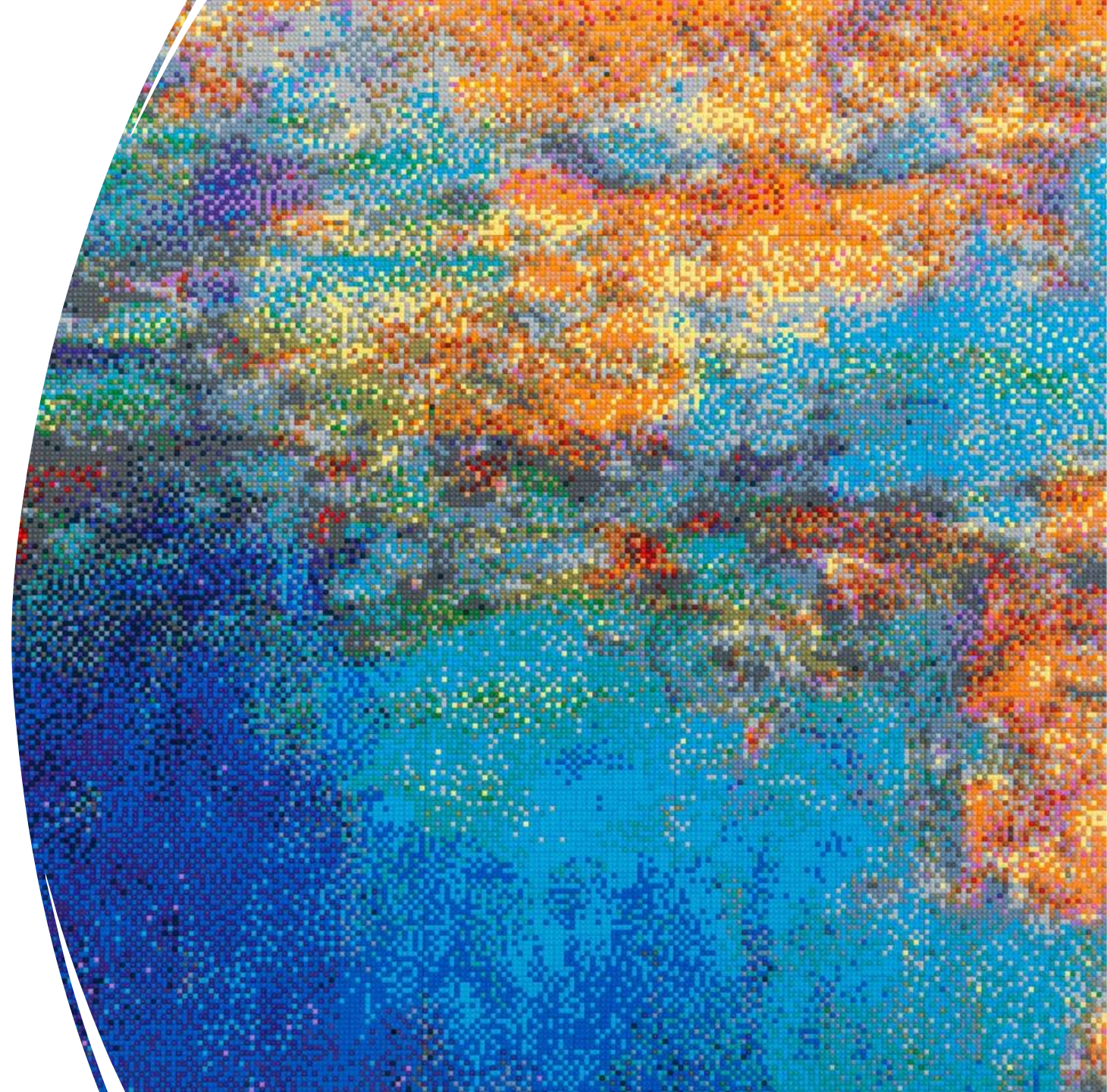
Points of further exploration (in lieu of conclusion):

- Link between main values (and particular understandings thereof) and specific professional logics
- How foregrounded values interact/inform each other
 - at different levels
 - nationally vs. internationally
- Link between the dynamics of co-creation activities and how power and authority are distributed within a large project
- How co-creation activities shape the development of shared understandings and values



Broader, ongoing puzzles:

- The relation between cancers, rare cancers, and rare diseases
- The position of social scientists in large, interdisciplinary projects at the intersection of health research, health care, and digitalization



THANK YOU!

