

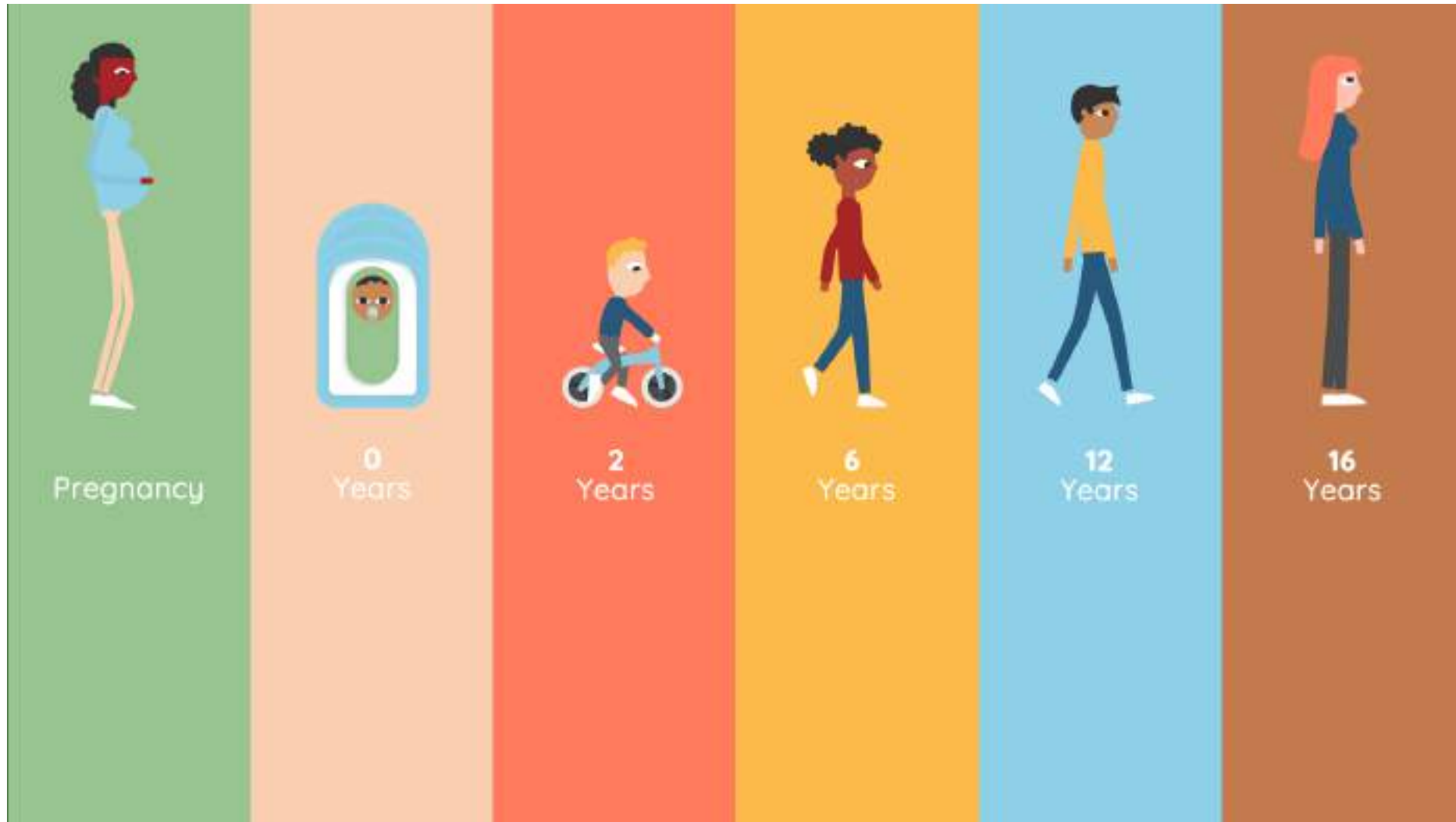
Sharing longitudinal cohort study data

An institutional case study

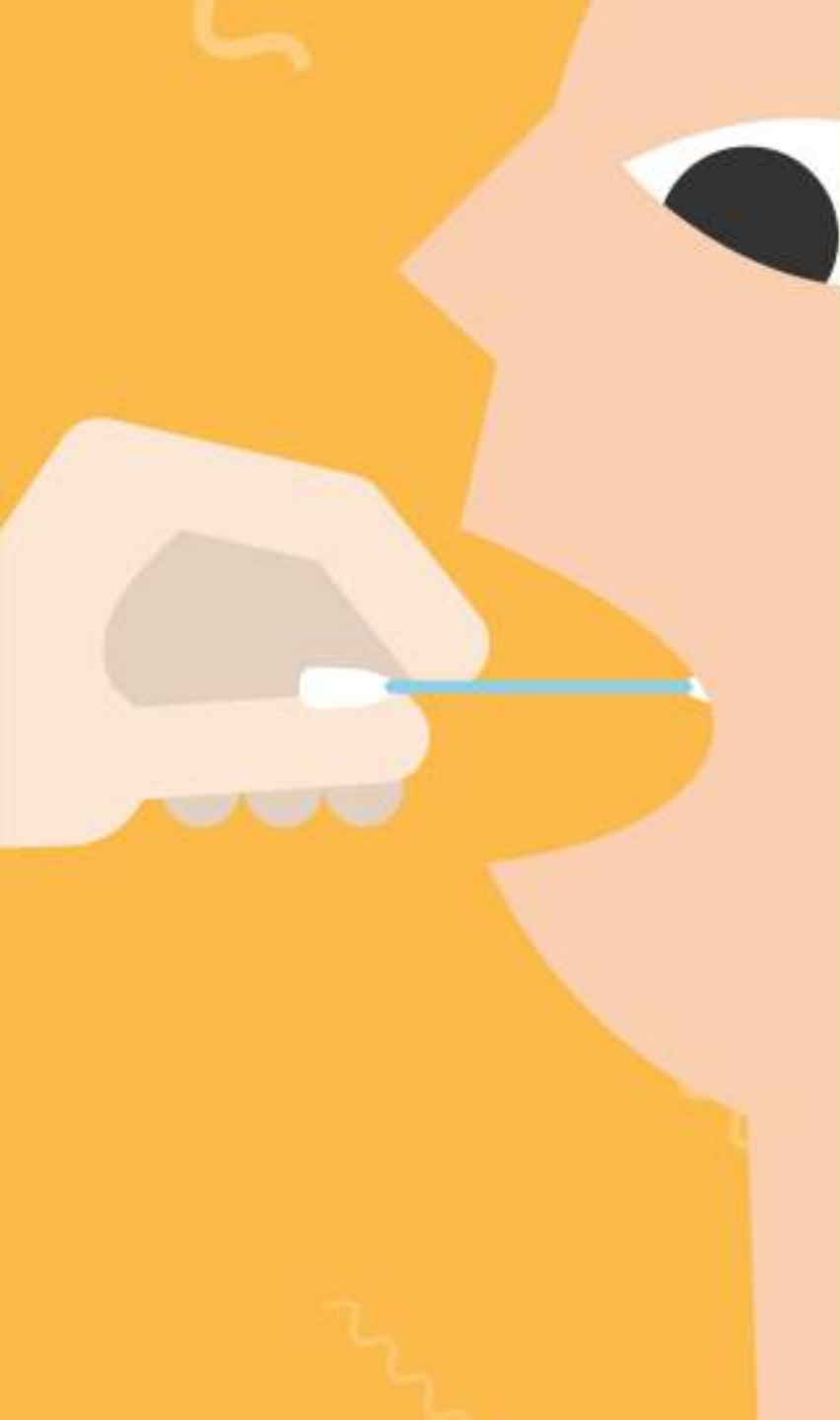


Chantal Kemner

The start







The research question



Understanding mechanisms - neurocognitive building blocks



Gravitation grant 2012



UMC Utrecht



Utrecht University



VRIJE
UNIVERSITEIT
AMSTERDAM



Universiteit
Leiden
The Netherlands



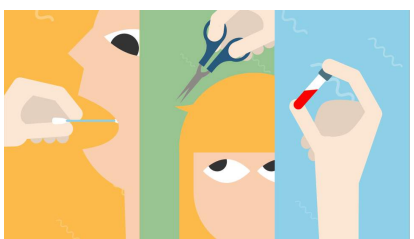
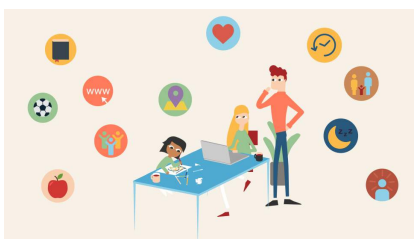
umcg

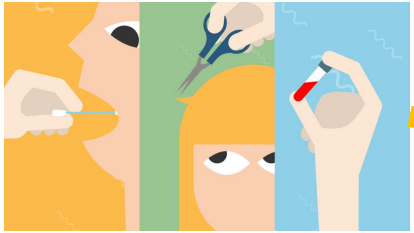
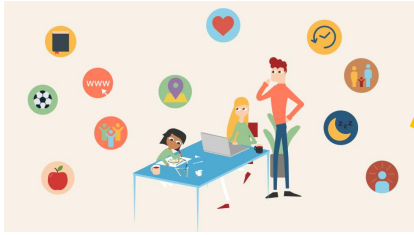


UNIVERSITY OF AMSTERDAM

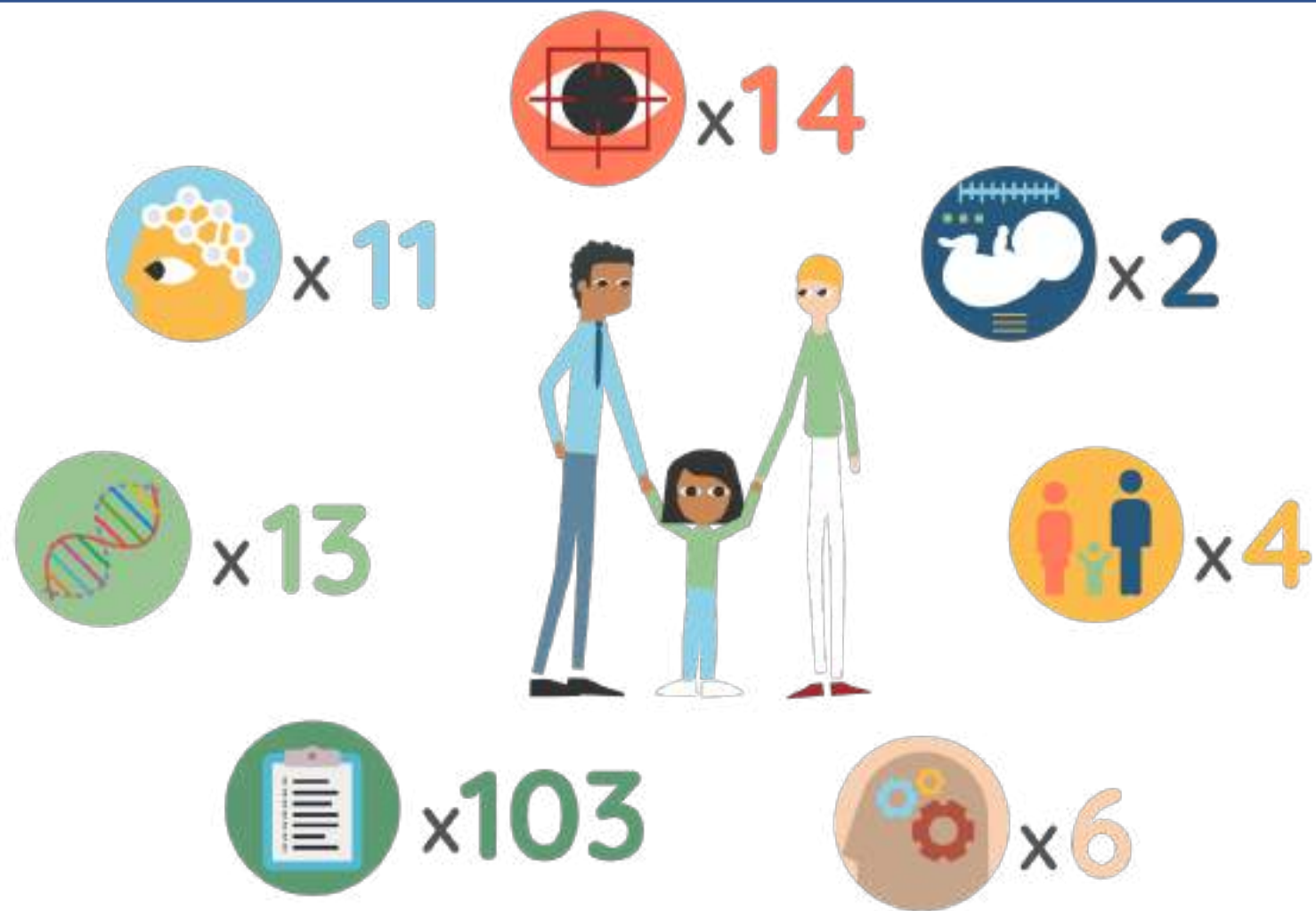


Longitudinal cohort study

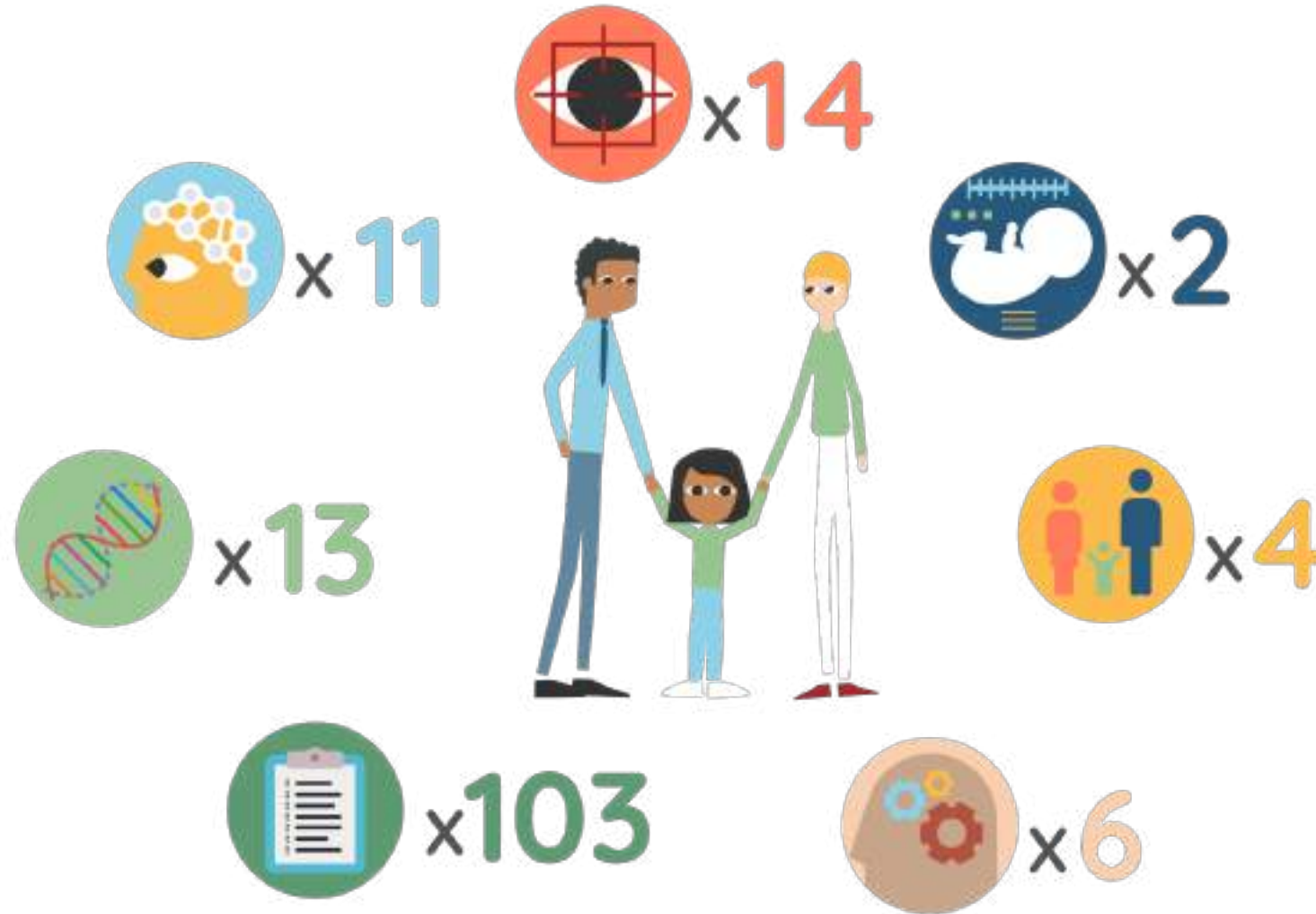




The data



The data *and* experimental sources!



The ambition: FAIR, safe and open



We got there



We got there – and I learned three things:



1. FAIR requires teaming up support & scientific staff
2. FAIR challenges organizational governance
3. We should rethink funding schemes



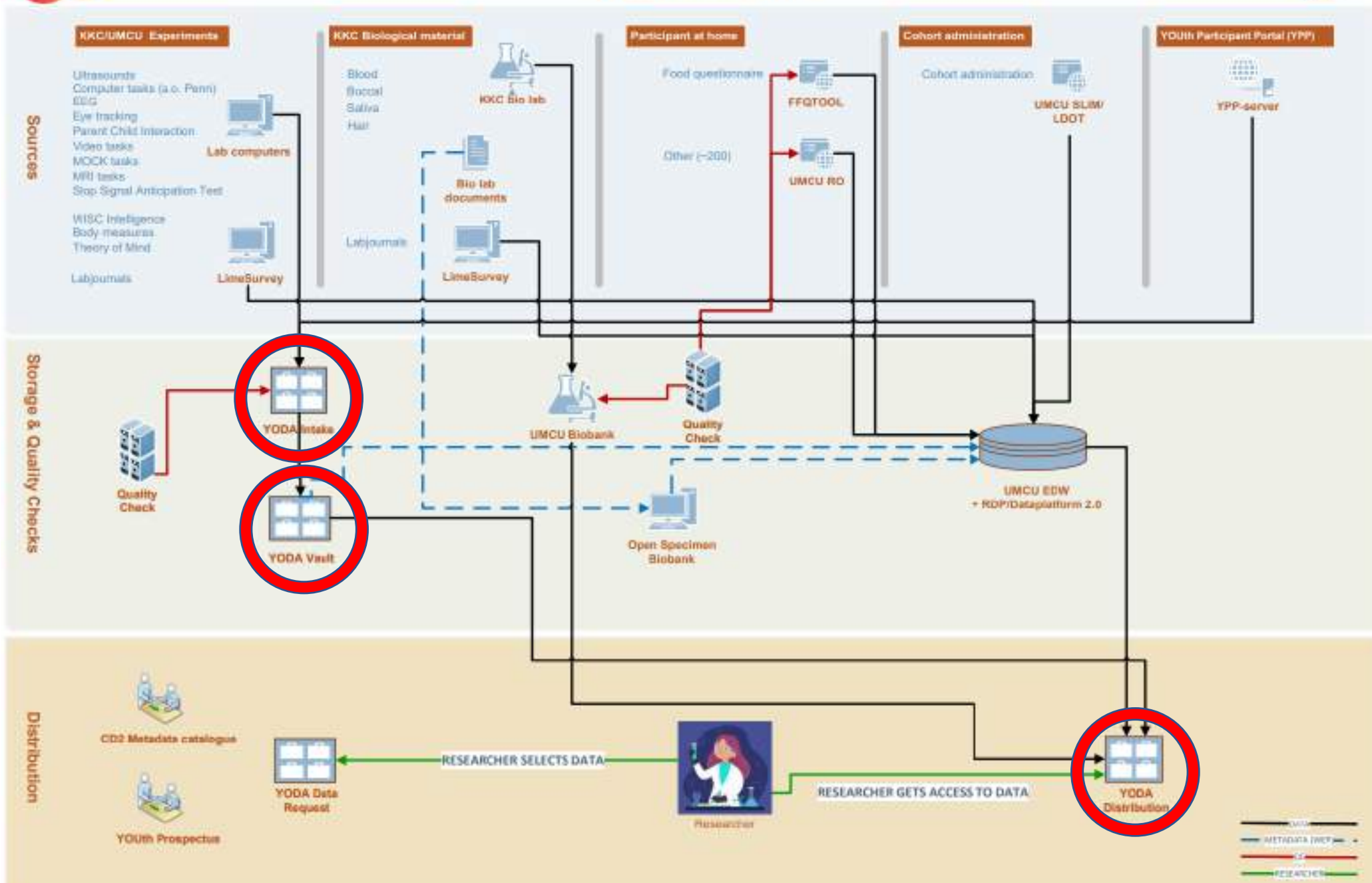
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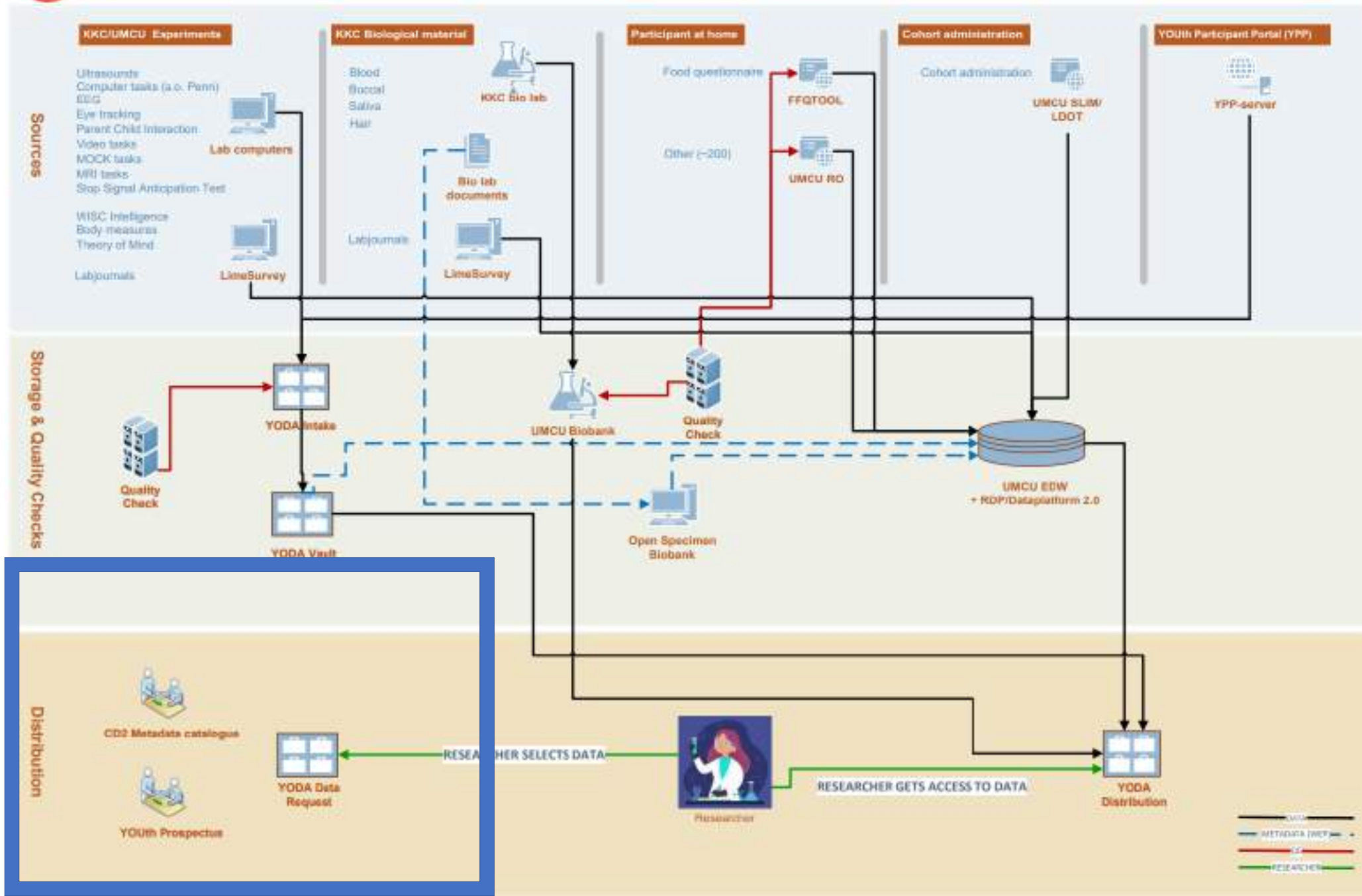
Information and Technology Services







YOUTH DATA -> YOUR DATA -> YODA



Distribution



CD2 Metadata catalogue



YOUTH Prospectus



YODA Data Request

RESEA





Metadata catalogue



YOUTH Prospectus



YODA Data Request

RESEARCH



Distribution

Relation to 'recognition & rewards'

Developmental Cognitive Neuroscience 45 (2020) 100834



Contents lists available at [ScienceDirect](#)

Developmental Cognitive Neuroscience

journal homepage: www.elsevier.com/locate/dcn



FAIR, safe and high-quality data: The data infrastructure and accessibility of the YOUTH cohort study

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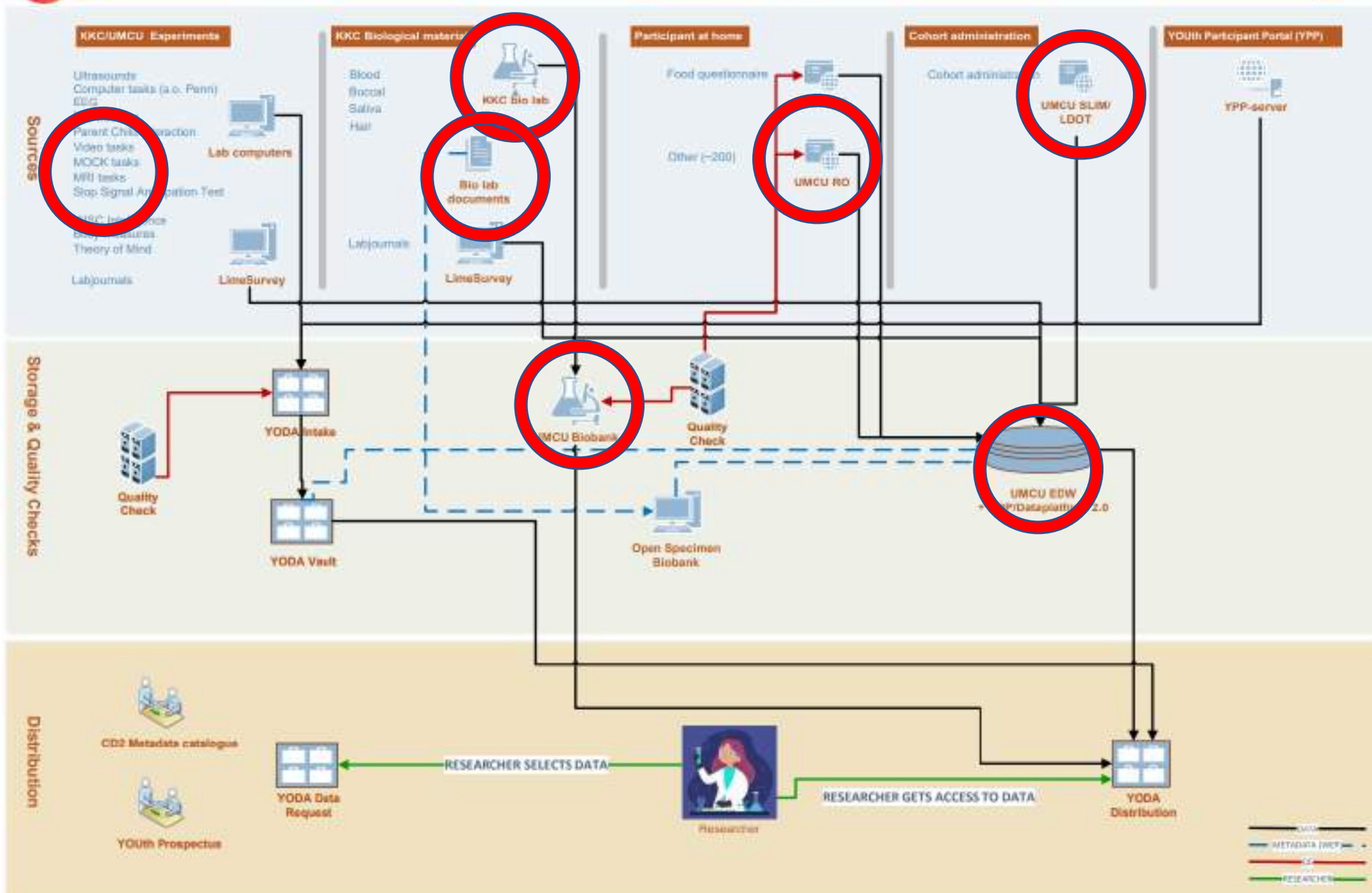
^d University Medical Center Utrecht, the Netherlands

^e Faculty of Social Sciences, Utrecht University, the Netherlands

^f Information and Technology Services, Utrecht University, the Netherlands



2. FAIR challenges organisational governance



3D-ultrasound sweeps of the fetal brain



• MRI data
• EEG-data



Behavioural and cognitive measurements

> 2.500 babies

Need data for child developmental research?

> 1.350 children



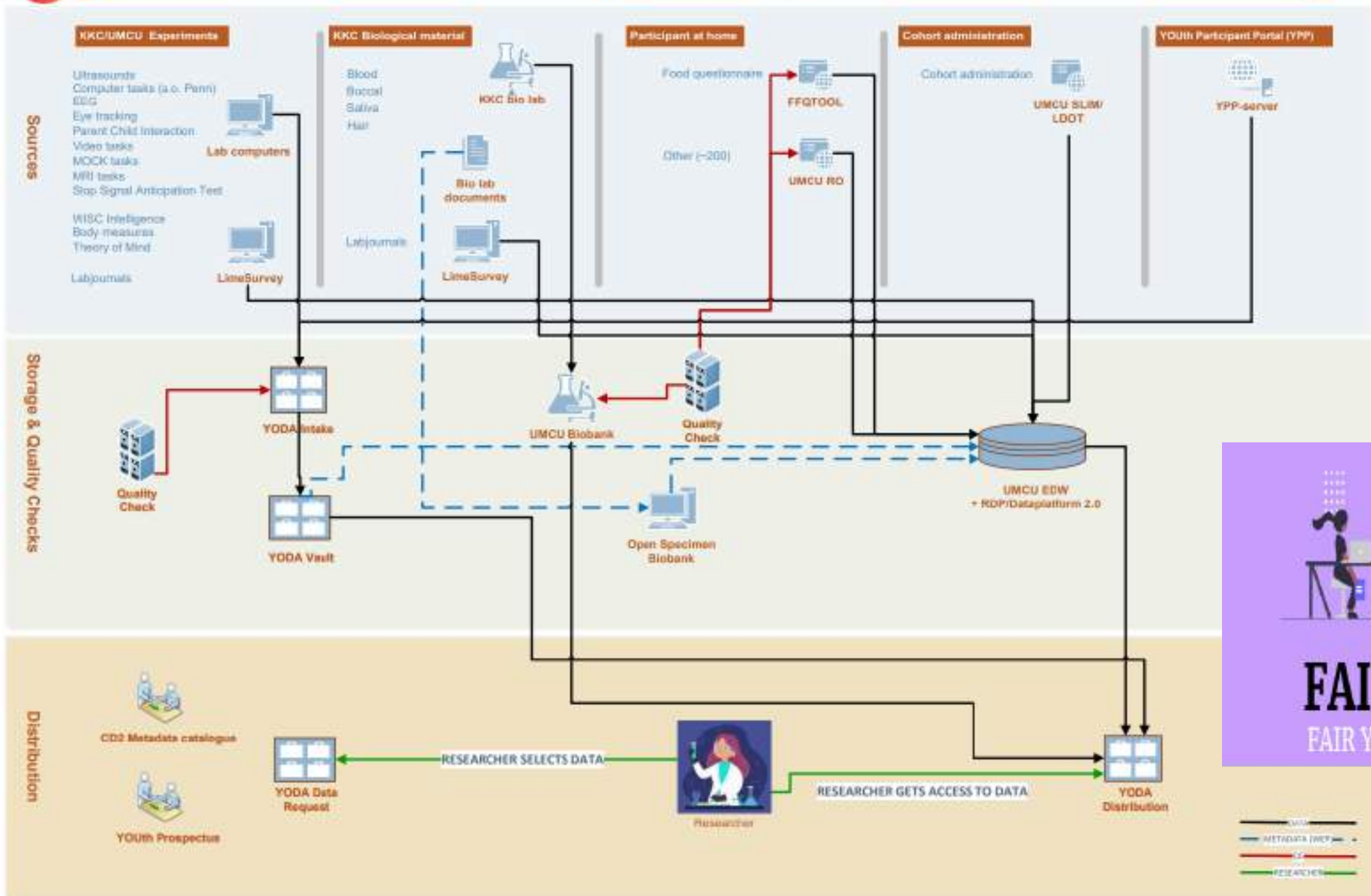
Eyetracking-data



Biomaterial from children and their parents.



Almost every questionnaire you can think of



3. We should rethink funding schemes

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FAIR = sustainable

but needs investments

3. We should rethink funding schemes

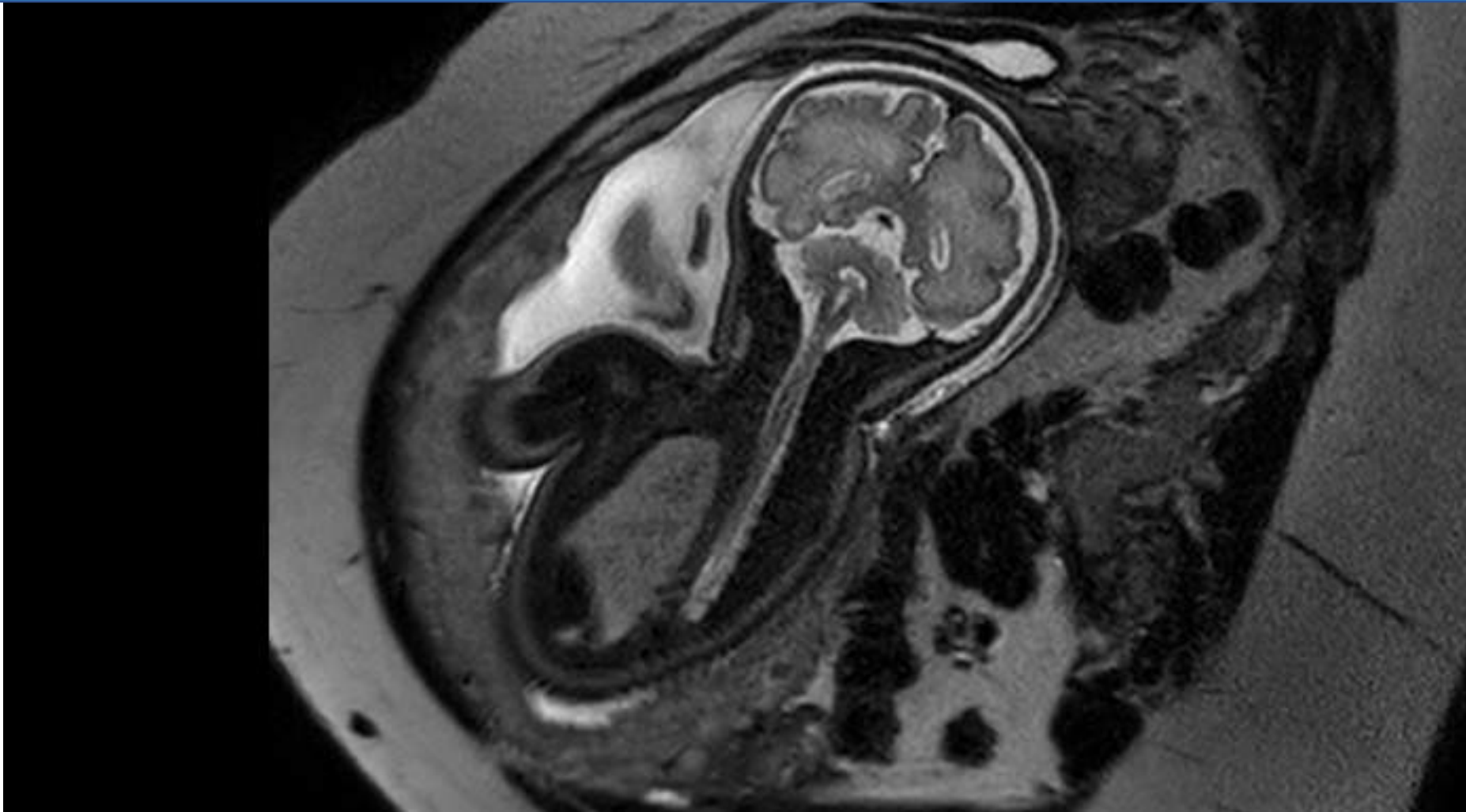
FAIR = sustainable

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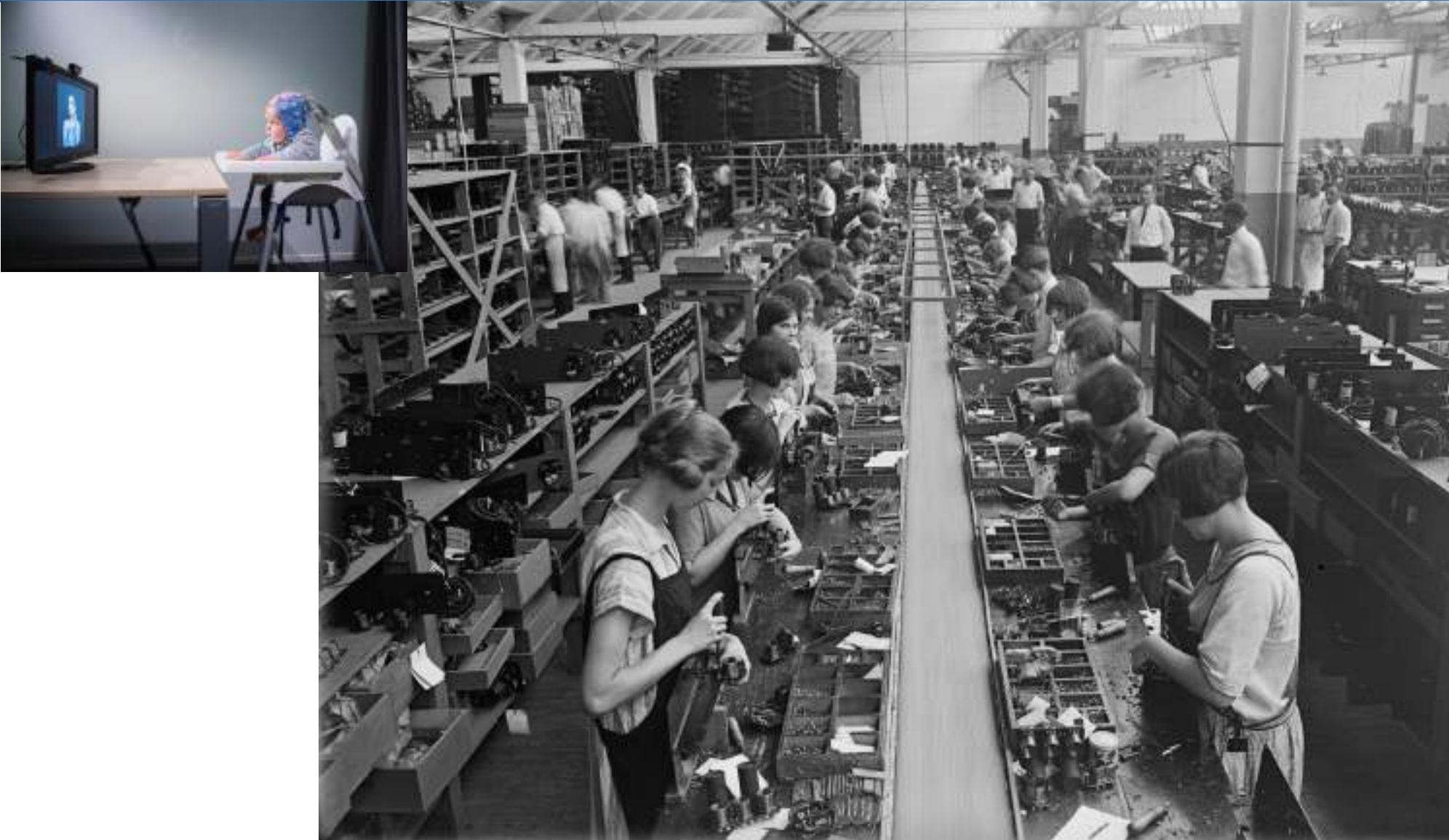
- Safety
- Quality control



Safety



Safety & Quality control



3. We should rethink funding schemes

investing in FAIR = sustainable
not using FAIR \neq sustainable



www.uu.nl/youthcohort