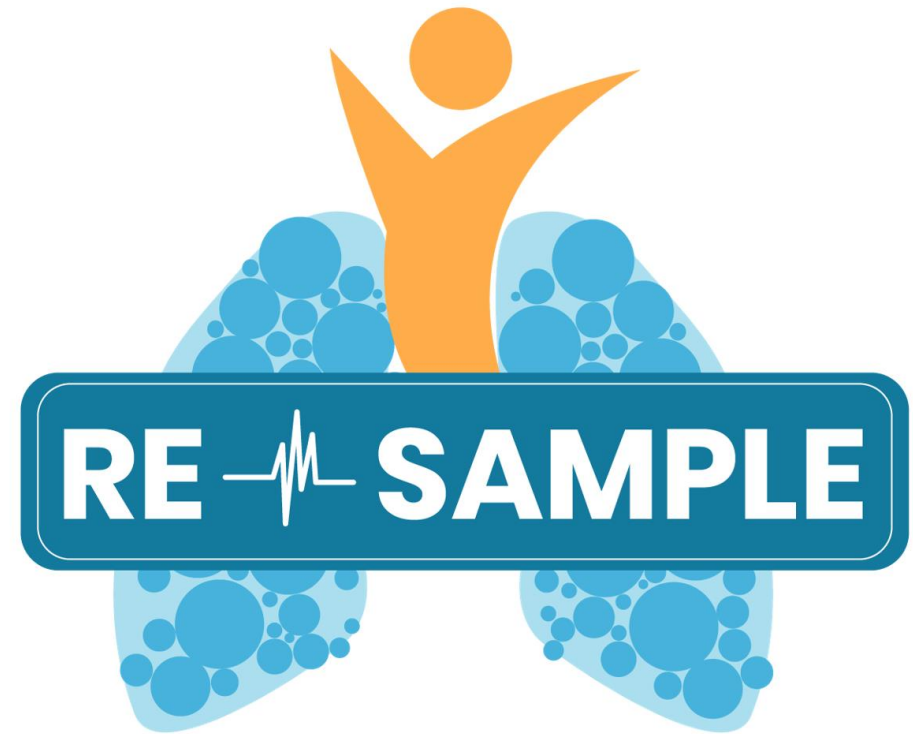




Zorg op maat bij complexe chronische ziekten - Dataverzameling



Dr. Anke Lenferink – RE-SAMPLE klinisch coördinator
Universiteit Twente, Health Technology and Services Research
Medisch Spectrum Twente, Medical School Twente



RE-SAMPLE has received funding from the European Union's Horizon 2020 research and innovation programme under Grant Agreement No 965315. SC1-DTH-12-2020: Use of Real-World Data to advance research on the management of complex chronic conditions. This result only reflects the author's view and the EU is not responsible for any use that may be made of the information it contains.



Health Technology and Services Research (HTSR)

- Health Services Research
- Health Preference Research
- Technology Assessment for Health Systems Engineering



Meer info: <https://www.utwente.nl/en/bms/htsr/>

Dr. Anke Lenferink



- Universitair docent & klinisch epidemioloog (2017-heden)

- UT, Health Technology and Services Research (HTSR)
- UT, Technology in Healthcare Transformations (THT) research group
- Medisch Spectrum Twente, Department of Pulmonary Medicine
- Rijnstate Hospital Arnhem, Clinical Research Centre



- Zelfmanagement interventie voor patiënten met COPD en comorbiditeiten (PhD 2017)

- UT, MST, CWZ, Flinders University



- Klinisch coördinator RE-SAMPLE (2021-heden)

- **RE**al-time data monitoring for **S**hared, **A**daptive, **M**ulti-domain and **P**ersonalised prediction and decision making for **L**ong-term pulmonary care **E**cosystems (www.re-sample.eu)
- UT, MST





REal-time data monitoring for Shared, Adaptive, Multi-domain and Personalised prediction and decision making for Long-term Pulmonary care Ecosystems

Factsheet:

Horizon 2020

4 yrs (2021-2025)

Budget €6M

10 partners

3 pilot sites (MST, GEM, TUK)

Coordinated by UT

To identify individual multi-morbid CCC exacerbations and develop tailored referral to a multi-disciplinary, adaptive virtual companionship programme for patients with COPD and CCCs



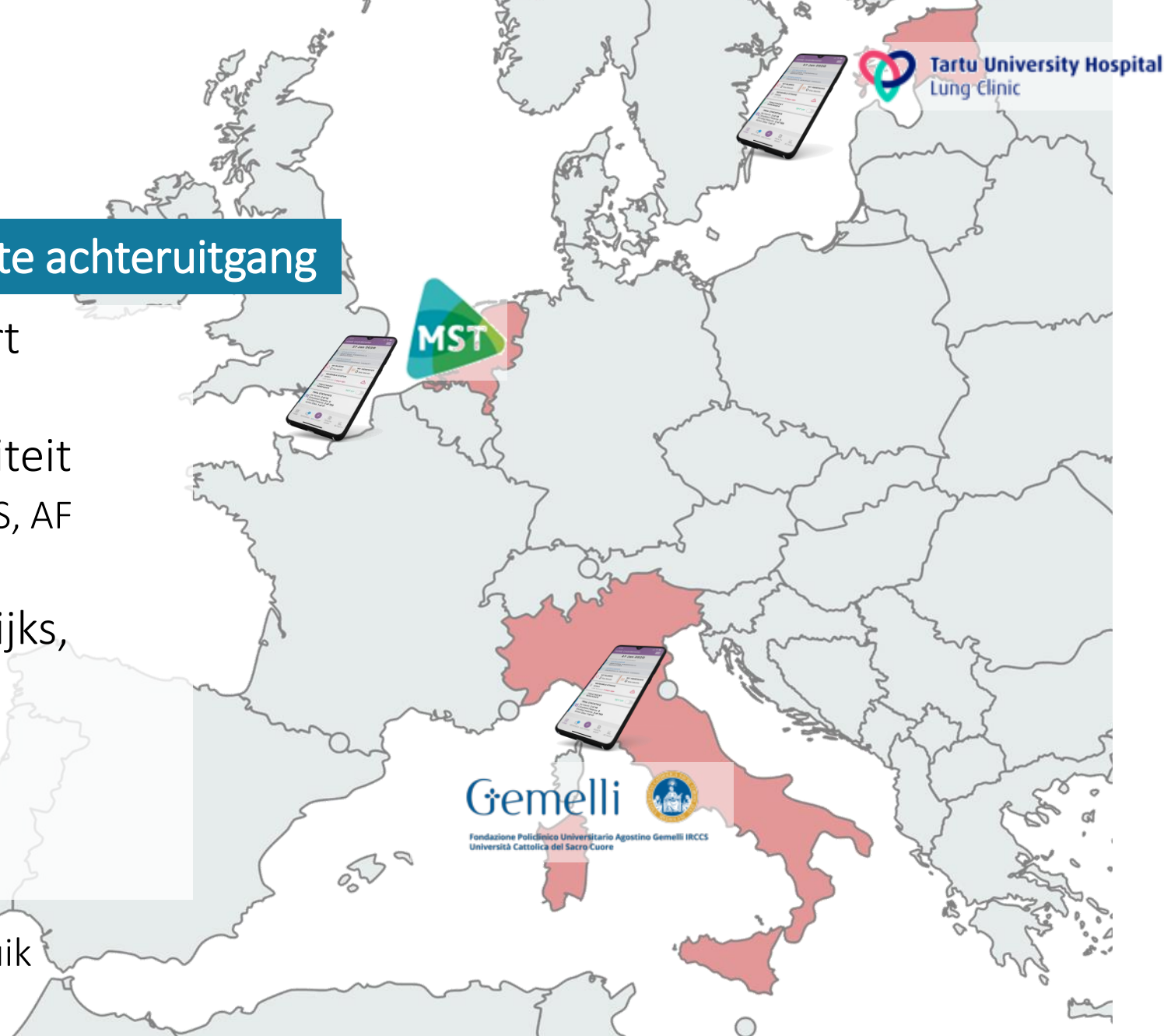
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**UNIVERSITY
OF TWENTE.**

Cohort onderzoek

Doel: identificeren voorspellers ziekte achteruitgang

- Multi-center observationeel cohort
- COPD patiënten met ≥ 1 comorbiditeit
 - CHF, IHD, angst, depressie, DM, OSAS, AF
- Multi-source data: baseline, dagelijks, verslechtering, follow-up
 - RWD monitoring tool met PROMS (vragenlijsten, klachtendagboeken)
 - Fysieke activiteit (Garmin)
 - Longfunctie, 6-MWT, biomarkers
 - Ziekenhuisopnames, medicatiegebruik



User requirements

GIULIA DE ROSSI



PROFILE
71 years old, located in Padua (IT), married to Antonia, COPD GOLD-II

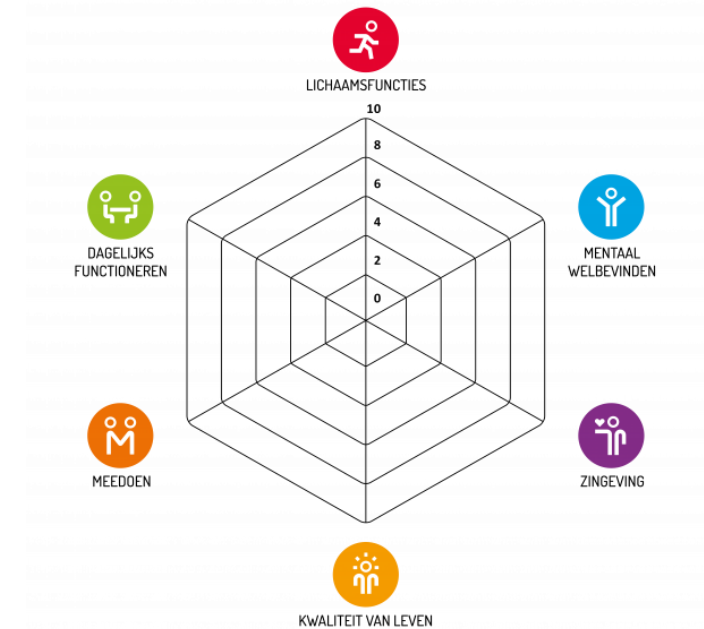
PRIMARY GOAL
Continue to do grocery shopping, doing more things to see other people, spending little energy on technology as possible.

CURRENT HEALTH MANAGEMENT
Inactive in managing own health
Inactive lifestyle, afraid of engaging in physical activity
High dependency of doctor

COMORBIDITIES
Hypertension

RE-SAMPLE
Activity motivation: [Progress bar]
Exercise motivation: [Progress bar]
Adaptation: [Progress bar]

TECHNOLOGY USE
Low interest in nowadays technologies.
Currently does not use any technology
Very reluctant towards health technology

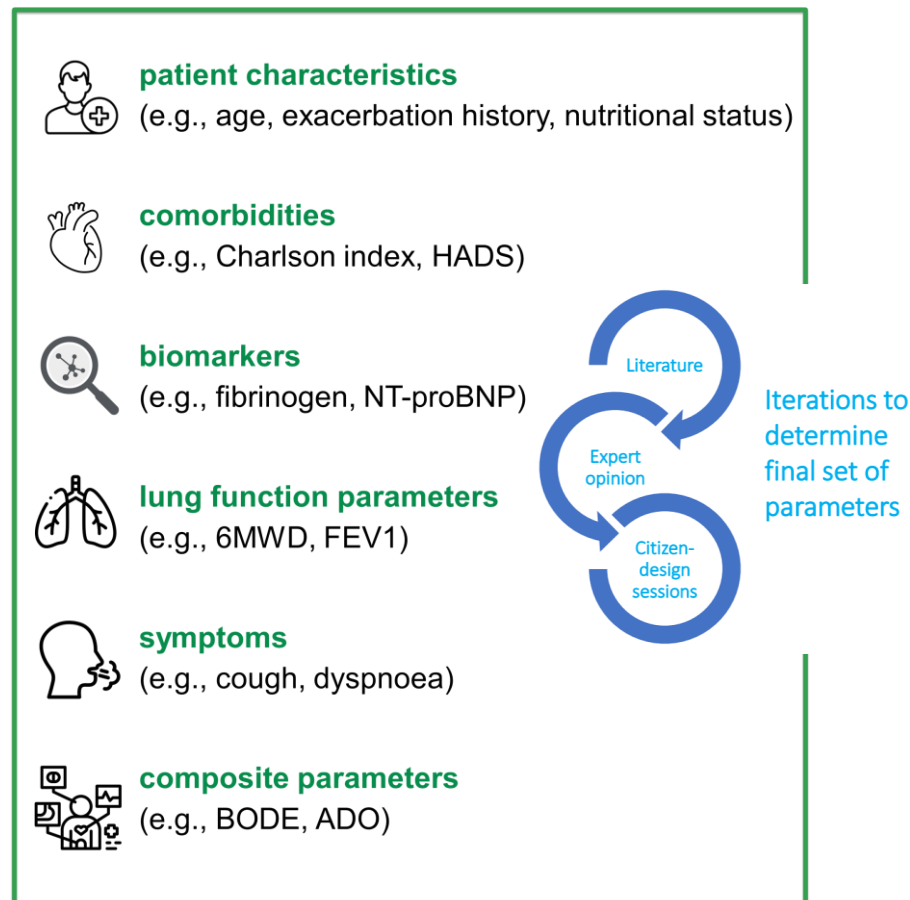


Patiëntprofielen


- Karakteristieken (leeftijd, comorbiditeiten)
- Huidige ziekte management (inactieve leefstijl)
- Persoonlijke behoeften & doelstellingen (positieve gezondheid)

Cohort iteraties dataverzameling

- **Knowledge base:** klinische richtlijnen, literatuur, retrospectieve data voorgaande studies
 - Review predictors of COPD exacerbations
 - Review markers identifying AHF in COPD patients^{1,2}
- **Multidisciplinaire iteratieve aanpak**
 - Focusgroepen met patiënten en zorgprofessionals
 - Wie zijn onze eindgebruikers?
 - Wat zijn de behoeften?
 - Welke parameters en hoe gemeten?
 - 3 iteraties om dataverzameling te optimaliseren



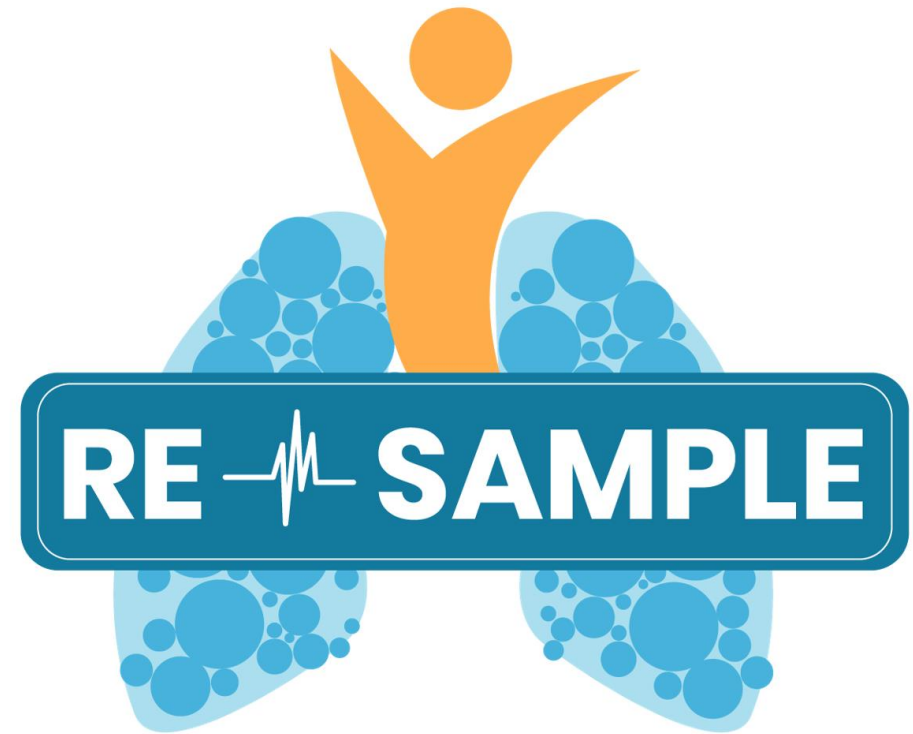
1. Van Dijk et al. Lack of evidence regarding markers identifying acute heart failure in patients with COPD: an AI-supported systematic review. *Int J COPD* 2024
2. Van Dijk et al. Artificial Intelligence in systematic reviews: promising when appropriately used. *BMJ Open* 2023



Zorg op maat bij complexe chronische ziekten – Data delen



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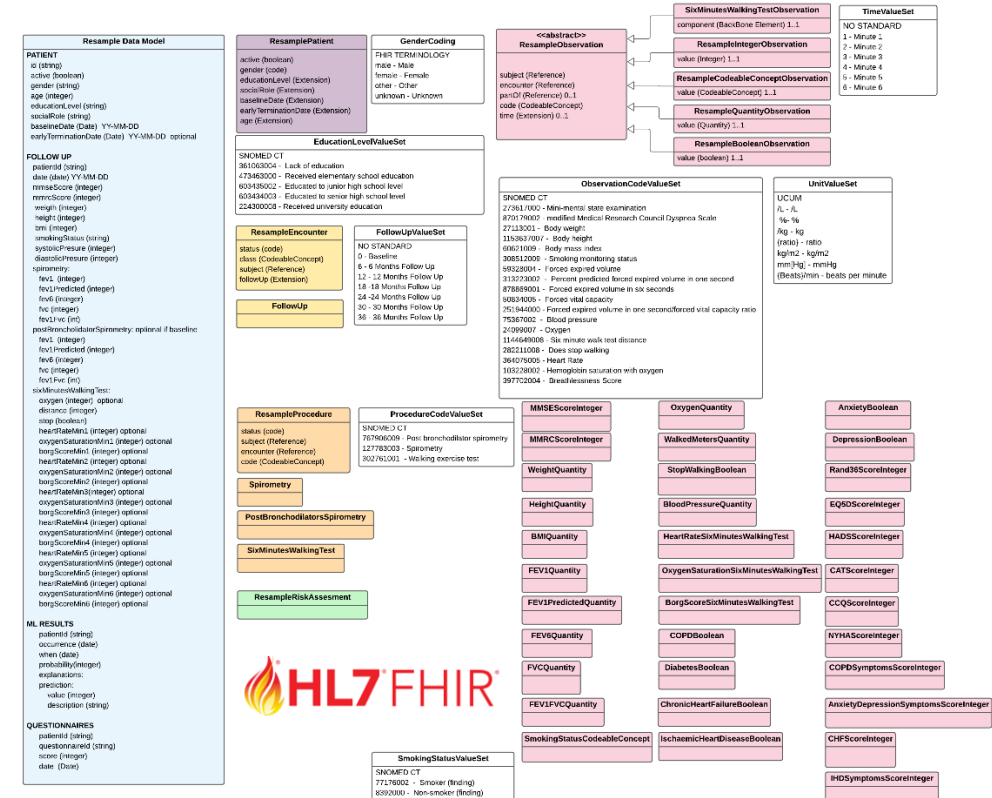
RE-SAMPLE DATA & DATA FORMAT

Retrospectieve datasets

- Eerder verzameld in 3 ziekenhuizen
- Ziekenhuisdata & vragenlijsten
- Overeenstemming data formats

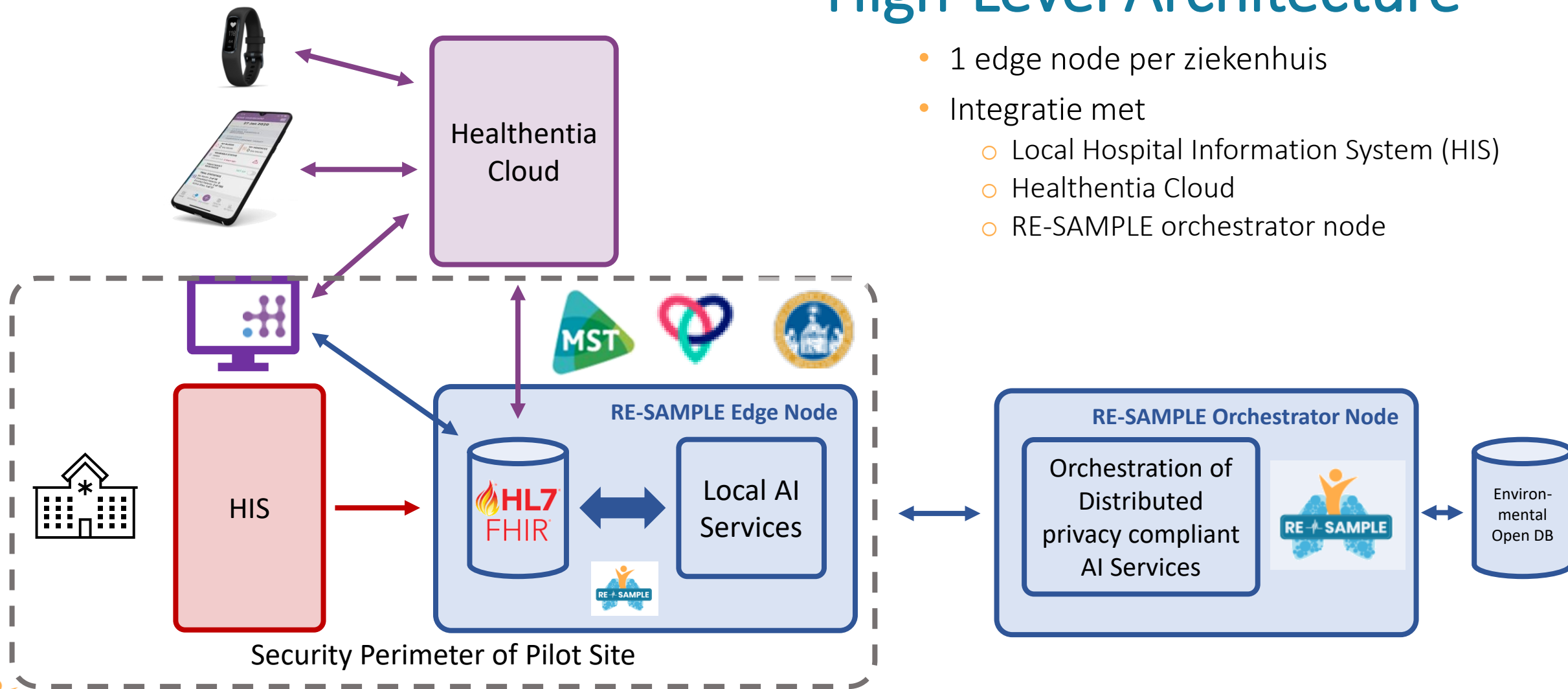
Prospectieve datasets

- Verzameld tijdens RE-SAMPLE cohort onderzoek
- Ziekenhuisdata & patiëntenapplicatie (RWD tool)
- Aggregatie in edge nodes (per ziekenhuis)
- Uniform data format



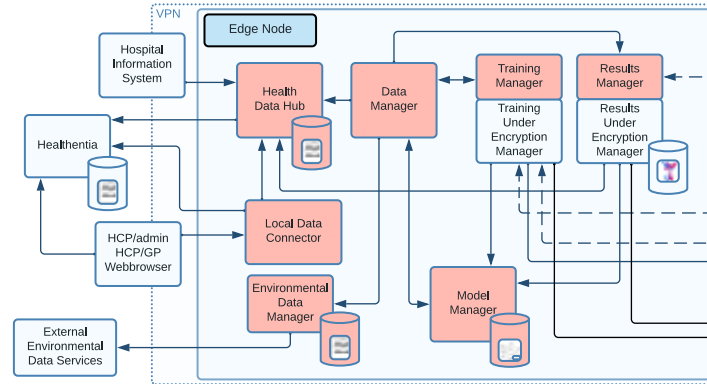
High-Level Architecture

- 1 edge node per ziekenhuis
- Integratie met
 - Local Hospital Information System (HIS)
 - Healthentia Cloud
 - RE-SAMPLE orchestrator node

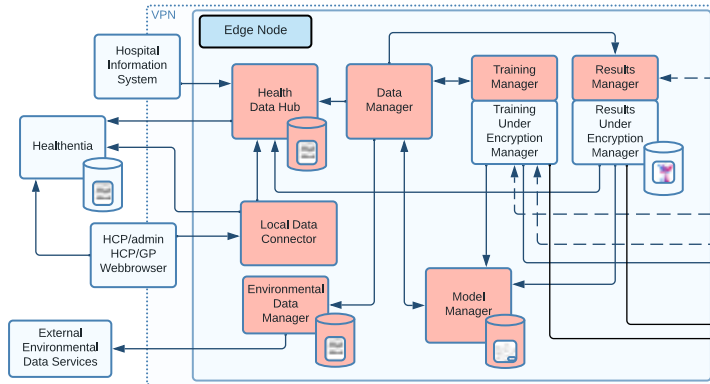


Edge nodes

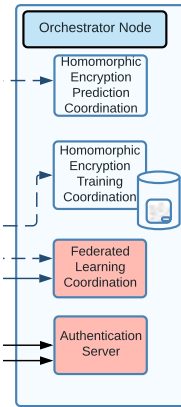
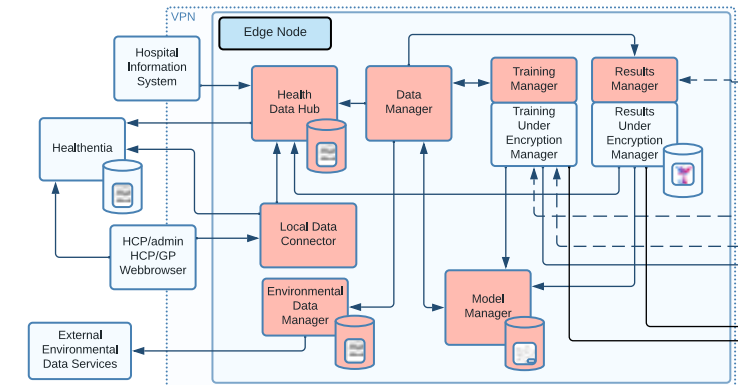
Enschede, NL



Rome, IT

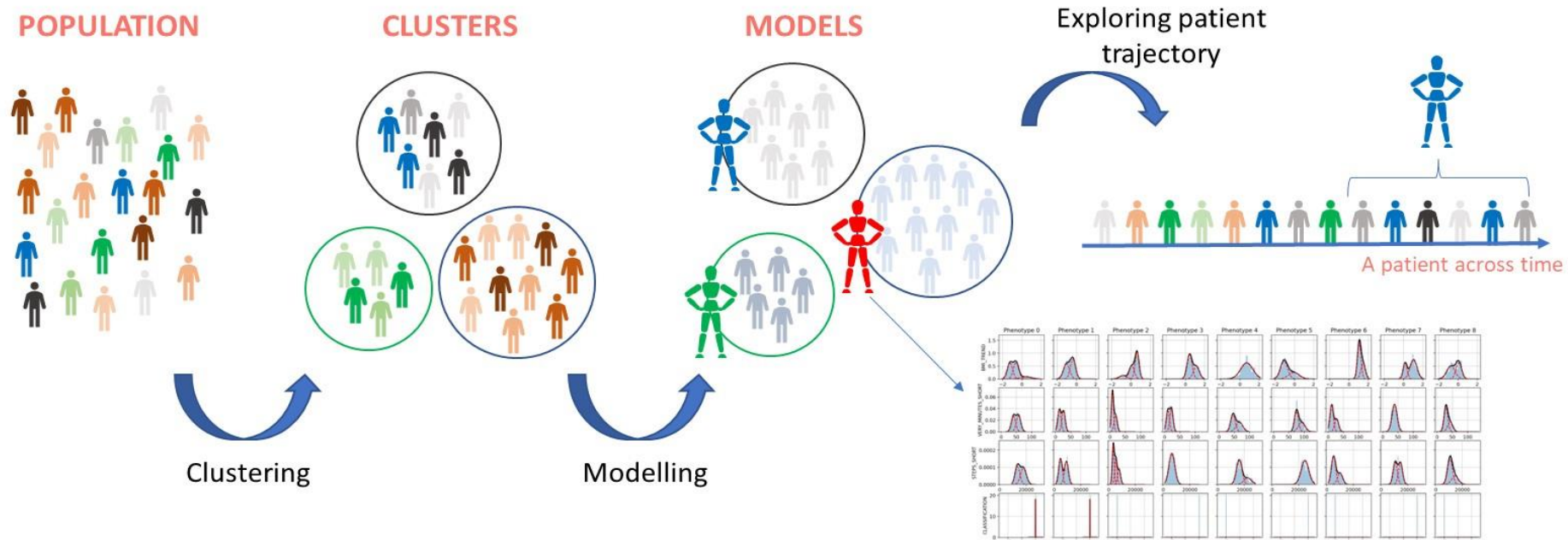


Tartu, Estonia

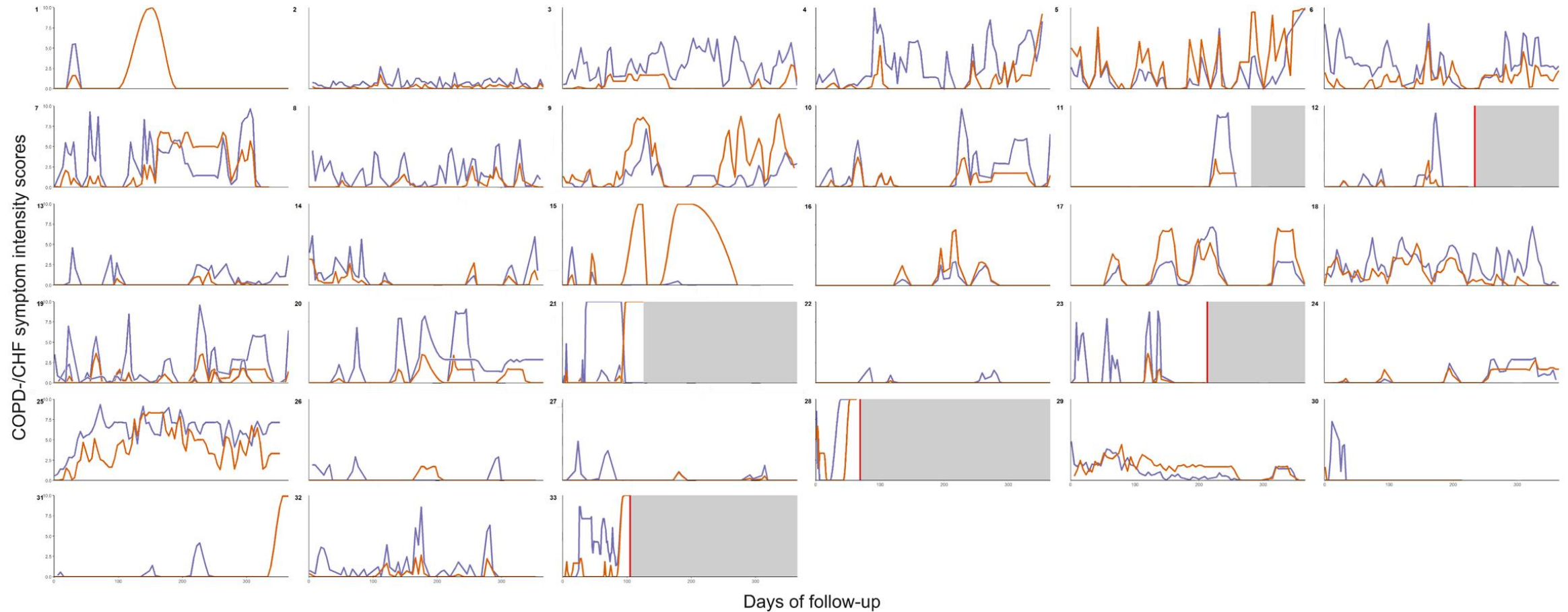


Datagedreven zorg op maat

- Specificaties zelfmanagement interventie
 - Kans op een bepaalde uitkomst (exacerbatie/overlijden) tijdens follow-up
 - Ziekte-specifieke richtlijnen voor behandeling
 - Componenten zelfmanagement interventie
 - Gelinkt aan patiëntenprofielen



Patronen van exacerbaties

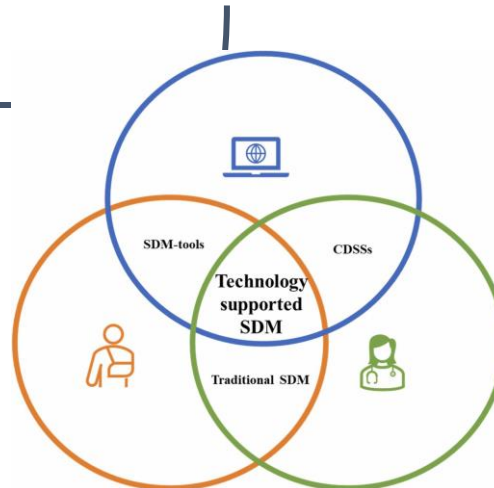


van Dijk et al. Exploring patterns of COPD exacerbations and comorbid flare-ups. *Int J COPD* 2024

Personalised coaching



Shared Decision Making



Virtueel coachingsprogramma

- Virtual companion and clinical dashboard: tailored care and support for CCCs
 - Self-management intervention sessions
 - Education about COPD and other CCCs
 - Recognition and self-treatment symptoms (including multi-morbid action plans)
 - Smoking cessation
 - Breathing and relaxation exercises
 - Shared decision making and personalised coaching
 - Individual goal setting based on pre-set goals
 - Tailored coaching dialogues
 - Goal setting evaluation
 - Risk profile
 - Case-manager support



Zorg op maat bij complexe chronische ziekten

Multidisciplinaire aanpak

- Collectieve kennisbaak: literatuur, retrospectieve data, klinische richtlijnen
- Continue betrokkenheid van eindgebruikers

Belangrijke resultaten

- ✓ Iteraties voor optimale RWD verzameling
- ✓ Architectuur voor data-uitwisseling meerdere bronnen (edge nodes)
- ✓ Multi-morbide zelfmanagement ondersteuning (app en dashboard)
- ✓ Persoonlijke coaching strategieën (app en klinisch dashboard)

Work in progress

- Vertalen bevindingen naar verdere ontwikkeling proactief ziektemanagement
 - Wat werkt voor wie (bereidheid/klaar om te veranderen, (digitale) gezondheidsvaardigheden)?
 - Wanneer welke interventie en hoe aanbieden?
- Integratie en evaluatie virtueel coachingsprogramma





Dank voor uw aandacht!

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