Nordic openEHR meeting 2025:1

The ASHA project

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ASHA

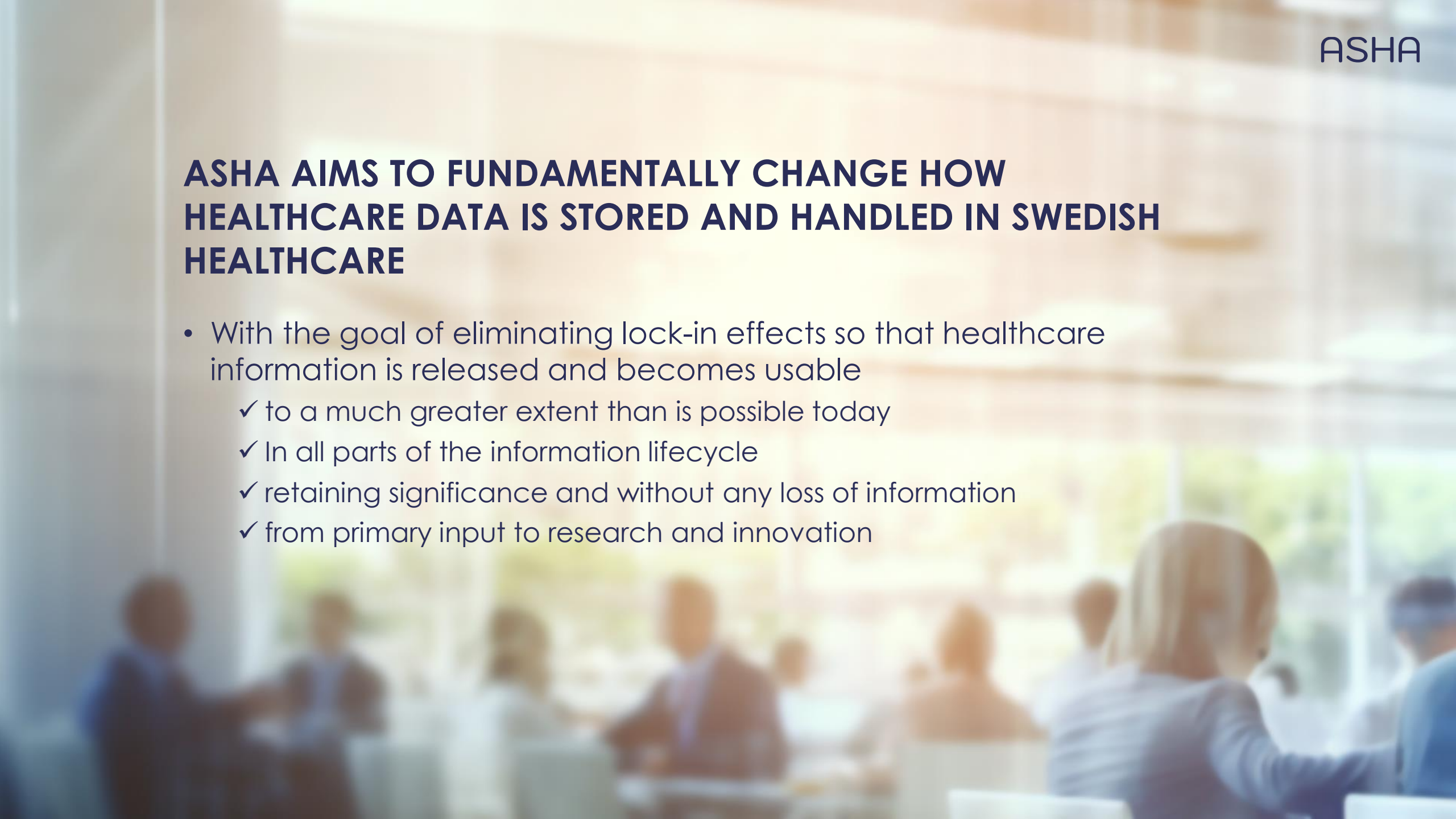
Using standardised health data as an accelerator to strengthen future healthcare

2024-2027, funded by Vinnova

Region Östergötland · CAMBIO · LINKÖPINGS UNIVERSITET · Region Uppsala · KAROLINSKA UNIVERSITETSSJUKHUSET · Region Jönköpings län · Region Kalmar län · PredictMe.

ASHA AIMS TO FUNDAMENTALLY CHANGE HOW HEALTHCARE DATA IS STORED AND HANDLED IN SWEDISH HEALTHCARE

- With the goal of eliminating lock-in effects so that healthcare information is released and becomes usable
  - ✓ to a much greater extent than is possible today
  - ✓ In all parts of the information lifecycle
  - ✓ retaining significance and without any loss of information
  - ✓ from primary input to research and innovation



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WHAT STOPS US?

Today's solutions won't do

Lack of standardized health data and vendor lock-ins

- Application focus that limits what we can do with our health data, the data is stuck in proprietary formats
- The information quality in healthcare record systems is insufficient
- Data is hard to access and hard to move between systems
- "Cleaning" data is costly
- Information loss during data transfer

Limited opportunity for data-driven healthcare

- Difficulties when using the data in healthcare and in secondary use
- AI and precision medicine require large amounts of high-quality data
- Opportunities for conducting research are hindered
- Difficult for industry to create new innovations for healthcare

WHY IS IT NECESSARY?

Higher demands on health data management

- Precision medicine, individualized health care
- Demography
  - ✓ The dependency ratio between the aging population and the working population
- EU level (EHDS)
  - ✓ Control over health data for the individual
  - ✓ Access to relevant data for professionals
  - ✓ Access to health data for research and innovation
- National level (Sweden)
  - ✓ New national infrastructure for health data
  - ✓ Other government assignments to authorities with the aim to enable data interoperability

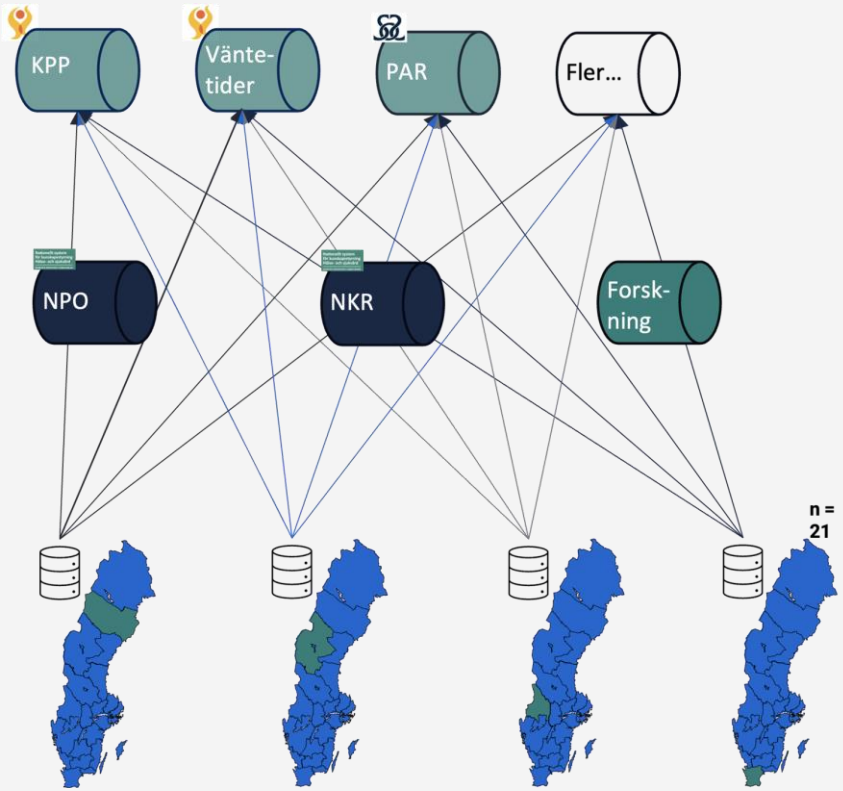
Population pyramid

EHDS

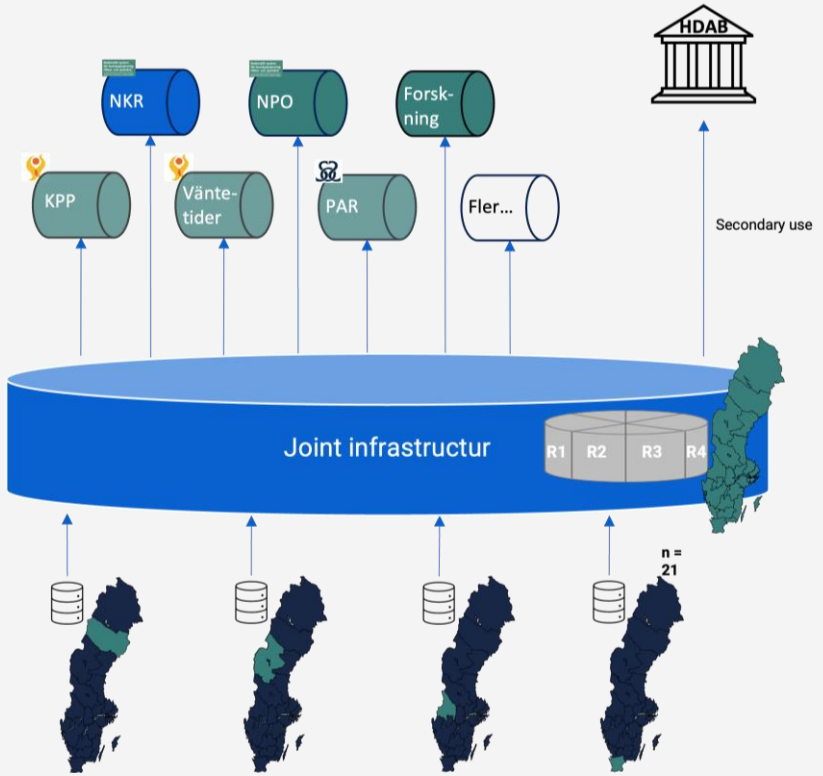
Authority assignments

National infrastructure (for secondary use)

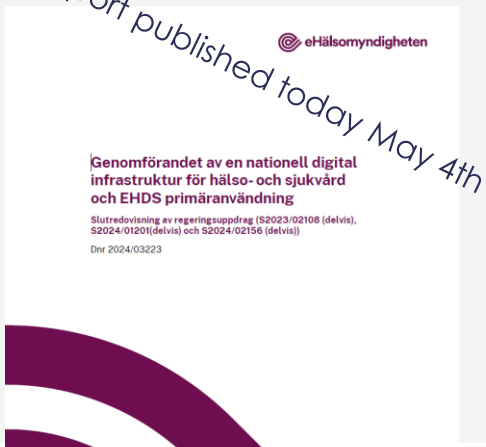
The challenge



The objective



Report published today May 4th


eHälsomyndigheten

Genomförandet av en nationell digital infrastruktur för hälso- och sjukvård och EHDS primäranvändning

Slutredovisning av regeringsuppdrag (S2023/02108 (delvis), S2024/01201(delvis) och S2024/02156 (delvis))

Dnr 2024/03223

https://www.ehalsomyndigheten.se/nyheter/2025/e-halsomyndigheten-foreslar-en-nationell-digital-infrastruktur-for-delning-av-halsodata/

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Ongoing in Östergötland

- Arrhenius – European supercomputer
- Mimer – European AI node hosted by Linköping University
- CIP – Center for information driven precision health
  - ✓ Asha is a part of this

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Creating a circular health data ecosystem based on international open standards

Primary use
Use and create new data about the patient

Secondary use
Analyse population data for new insights

Refinement
Create new tools and update structures and standards

HEALTH DATA PLATFORMS

THE SUSTAINABLE SOLUTION

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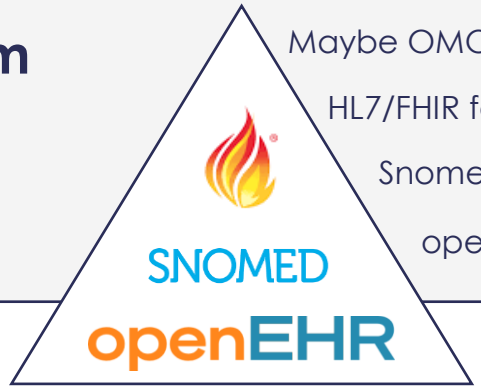
The circular health data ecosystem implemented by ASHA



Maybe OMOP?

HL7/FHIR for data exchange

Snomed CT for consistent terminology

openEHR for persistence and storage

PRIMARY USE

SECONDARY USE

2 App for national highly specialized burn care

5 Decision support for breast cancer process

HEALTH DATA PLATFORM

1

RESEARCH DATABASE

3 Quality registry for echocardiography

Academia and industry: AI for prediction of lung diseases 4

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WP 1

ESTABLISH HEALTH DATA PLATFORM

- This work package establishes the foundation for the other work packages. A health data platform in the regions will be integrated with a research database at CMIV/Linköping University
- New ways to share standardized medical record data for secondary use are being explored and tested

The health data platform includes:

- Storage capacity
- Services for authorization management, access control, and compliance with laws and regulations
- Tools for documentation templates, forms, and decision rules
- Compliance with standards such as openEHR, SNOMED CT, and HL7/FHIR

The research database

- Gains increased storage and computational capacity and an improved user interface
- Expands with standardized text-based medical record data
- Enables standardized medical record data to be made available for large-scale secondary use

Region Östergötland CAMBIO LINKÖPINGS UNIVERSITET HL7® FHIR® openEHR SNOMED CT The global language of healthcare

WP 2

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Taming a Feral System in National Highly Specialized Burn Care

- The work package aims to create a new IT support system for highly specialized burn care in Sweden, built on a structured, standardized, and open format.
- Region Östergötland, Region Uppsala, and Cambio are participating in this work package.
- The systems currently used by burn clinics provide insufficient support for the specific handling of healthcare information required by highly specialized care and result in poor data quality.

The new IT support system will:

- Reduce duplicate documentation
- Support automated report transfers
- Create a national registry for burn injuries
- Make it easier to share and use collected healthcare data for research on a larger scale
- Provide improved and more equal long-term follow-up of burn patients across the country

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Archetypes for WP2 – first step focus on wounds

- OBSERVATION.affected_body_surface_area-burn.v0
- CLUSTER.exam_burn.v0
- Wound assertion details archetype
  - ✓ CLUSTER.wound_details.v0
- Examination of a wound
  - ✓ CLUSTER.exam_wound

Examples of archetypes we might need

- Burn Classification (CLUSTER?)
  - ✓ To document burn depth (1st, 2nd, 3rd degree) and TBSA.
- Burn Resuscitation (ACTION?)
  - ✓ To track fluid resuscitation
- Pain Management (ACTION/OBSERVATION?)
  - ✓ Since burn patients require intensive pain control. I saw there's a publish observation archetype for pain associated with cancer, we can check if that can be copied for burn injury.
- Skin Graft Procedure (ACTION?)
  - ✓ If surgical intervention is needed.

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WP3

CREATING A QUALITY REGISTER FOR ECHOCARDIOGRAPHY

- The work package is creating the quality registers of the future for follow-up, analysis, and research in clinical physiology.
- This work package includes Region Östergötland, Region Kalmar County, Region Jönköping County, and Cambio.
- The register is built according to open international standards.
- The register contains data from echocardiographic examinations, ECG signs, comorbidities in COPD, and heart failure in relation to environmental exposure.
- It will be possible to:
  - ✓ Track individuals with heart failure and link data on healthcare needs, medication use, and lifespan to ensure equal care and identify regional differences.
  - ✓ Automatically report to registers such as RiksSvikt and the Swedish Prescribed Drug Register.
- All legal, financial, operational, and management requirements will be met.

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Region Kalmar län

ARCHETYPES FOR WP3

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Not investigated yet, but…

- We have a dialogue with Basel about heart related archetypes
  - ✓ imaging_exam_heart

- Wish list from the Clinical Physiology department
  - ✓ **Ecocardiography**
  - ✓ Myocardial scintigraphy
  - ✓ Cardiac MRI
  - ✓ Stress test/exercise test
  - ✓ Spirometry
  - ✓ Ergospirometry/cardiopulmonary exercise testing (CPET)
  - ✓ Holter (continuous ECG)
  - ✓ ECG
  - ✓ Administrative data
  - ✓ ICD-codes
  - ✓ Laboratory tests
  - ✓ Medication
  - ✓ Blood pressure

WP 4

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PULMO, SHARING HEALTH DATA FOR RESEARCH AND INDUSTRY

- The work package demonstrates how health data can be shared and used for innovation through development at the company PredictMe AB.
- Participants in the work package include Region Östergötland, Linköping University, PredictMe, and Cambio.
- Standardized health data related to lung disease is shared from the health data platform to the research database, where it is made available for the PULMO project, led by PredictMe, after ethical and confidentiality review.
- PULMO aims to revolutionize the diagnosis of respiratory diseases by introducing DNA methylation analysis (DNAm).
- Physicians will gain more precise, minimally invasive, and cost-effective tools for diagnosis and treatment monitoring

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ARCHETYPES FOR WP4

- OBSERVATION.spirometry_result.v2
- OBSERVATION.exam.v1
- OBSERVATION-laboratory_test_result.v1
- CLUSTER.laboratory_test_analyte.v1
- EVALUATION.tobacco_smoking_summary.v1
- EVALUATION.problem_diagnosis.v1
- CLUSTER.symptom_sign.v2
- ACTION.procedure.v1
- CLUSTER.medication.v2
- OBSERVATION.pulse_oximetry.v1
- OBSERVATION.pulse.v2
- OBSERVATION.blood_pressure.v2
- SECTION.vital_signs.v0
- OBSERVATION.respiration.v2
- OBSERVATION.pulse.v2
- OBSERVATION.body_temperature.v2

Missing archetypes

- DLCO (diffusion capacity)
- Dyspnea with mMRC (Modified Medical Research Council) scaleFeNO test
- Skin prick test
- Medical imaging
  - ✓ Specialized CLUSTER-arketyp based on CLUSTER.imaging_exam.v1.

WP 5

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SHORTEN LEAD TIMES AND REDUCE ADMINISTRATION IN BREAST CANCER CARE

- The work package creates an advanced decision support system within cancer processes as a platform for advanced precision medicine.
- Participants in the work package include Region Östergötland, Karolinska University Hospital, and Cambio.
- The decision support system includes overviews with data from medical record systems, laboratory systems, and imaging systems.

The work package integrates and builds upon previous and ongoing efforts:

- A pilot application for the breast cancer process needs, including a dashboard for process data, process overview, and patient overview.
- Work within the National System for Knowledge Management for structuring pathology data.
- A national project that demonstrated that INCA/RCC could receive pathology reports in openEHR format, reducing both duplicate documentation and mapping efforts.

Key objectives include:

- Generalizability to other cancer processes.
- Reducing the time from cancer suspicion to treatment, with a focus on treatment decisions in multidisciplinary conferences.
- Automatic transfer to national quality registers.

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Archetypes for WP5

The project starts in August, so we haven't looked into archetypes yet. But we will create a cross-system patient overview that compiles information from

- Preoperative MDC (multidisciplinary conference)
- Surgery
- Postoperative MDC
- Extemporaneous medications

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