HiGHmed
Medical Informatics

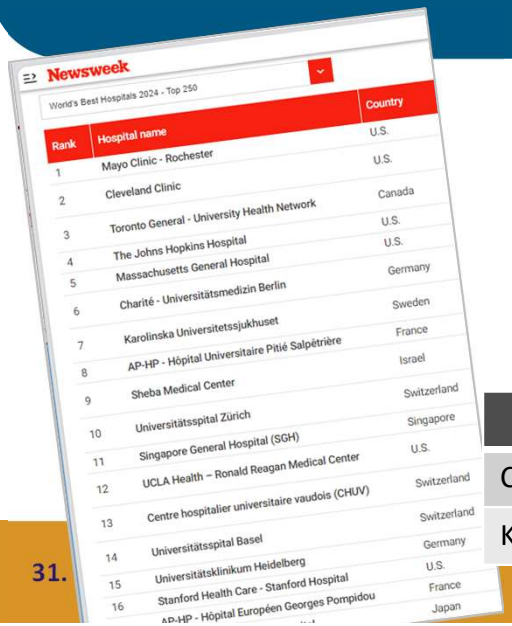
Experiences and examples of using openEHR at Karolinska University Hospital

Erik Sundvall & Claudia Ehrentraut

Why data-driven?

Clinicians, patients and researchers make decisions based on data…

…bad data, bad decisions,
good data, (potential for) good decisions…

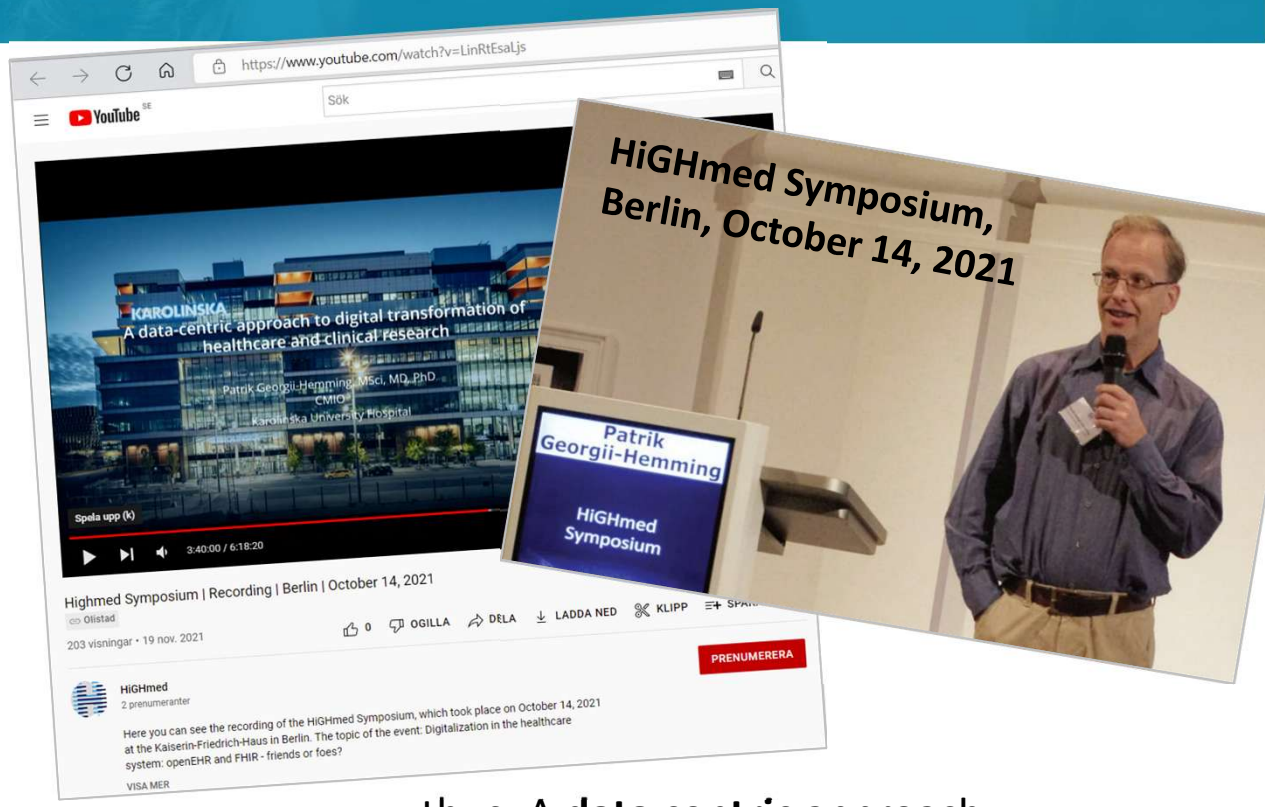


Newsweek

World's Best Hospitals 2024 - Top 250

Rank	Hospital name	Country
1	Mayo Clinic - Rochester	U.S.
2	Cleveland Clinic	U.S.
3	Toronto General - University Health Network	Canada
4	The Johns Hopkins Hospital	U.S.
5	Massachusetts General Hospital	U.S.
6	Charité - Universitätsmedizin Berlin	Germany
7	Karolinska Universitetssjukhuset	Sweden
8	AP-HP - Hôpital Universitaire Pitié Salpêtrière	France
9	Sheba Medical Center	Israel
10	Universitätsspital Zürich	Switzerland
11	Singapore General Hospital (SGH)	Singapore
12	UCLA Health – Ronald Reagan Medical Center	U.S.
13	Centre hospitalier universitaire vaudois (CHUV)	Switzerland
14	Universitätsspital Basel	Switzerland
15	Universitätsklinikum Heidelberg	Germany
16	Stanford Health Care - Stanford Hospital	U.S.
	AP-HP - Hôpital Européen Georges Pompidou	France
		Japan

	2021	2022	2023	2024
Charité	6	5	7	6
Karolinska	7	8	6	7



…thus: A **data centric** approach…

https://www.highmed.org/en/events-highmed-symposium-2021?hsLang=en

https://youtu.be/LinRtEsaLjs?t=13192 (Starting at approx 3h 40m)

Operating model – focus on **point of care**

Symtom → Investigation → Diagnosis → Treat.plan → Treatment → Follow-up

INVESTIGATION PHASE

TREATMENT PHASE

2 Use data to make decision

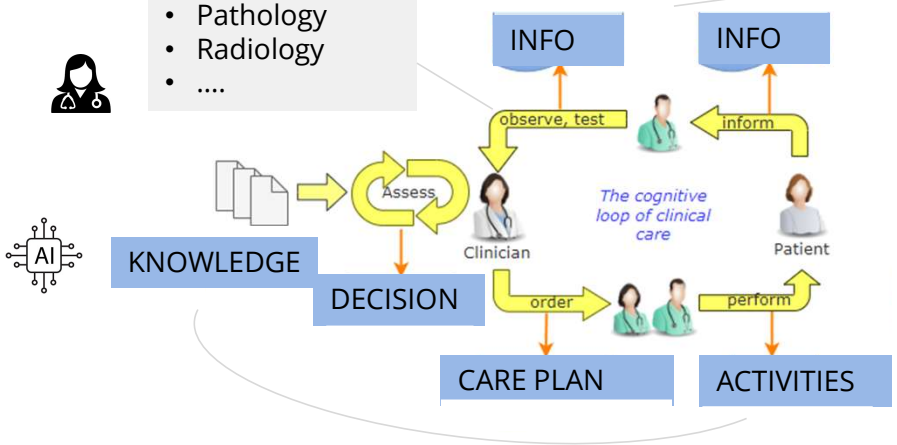
Clinicians need available, correct & complete data

CDSS need machine readable data

DIAGNOSTICS
- Chemistry
- Microbiology
- Immunology
- Pathology
- Radiology
- ....

1 Collect data & document findings

CONSULTATION
- History
- Examination



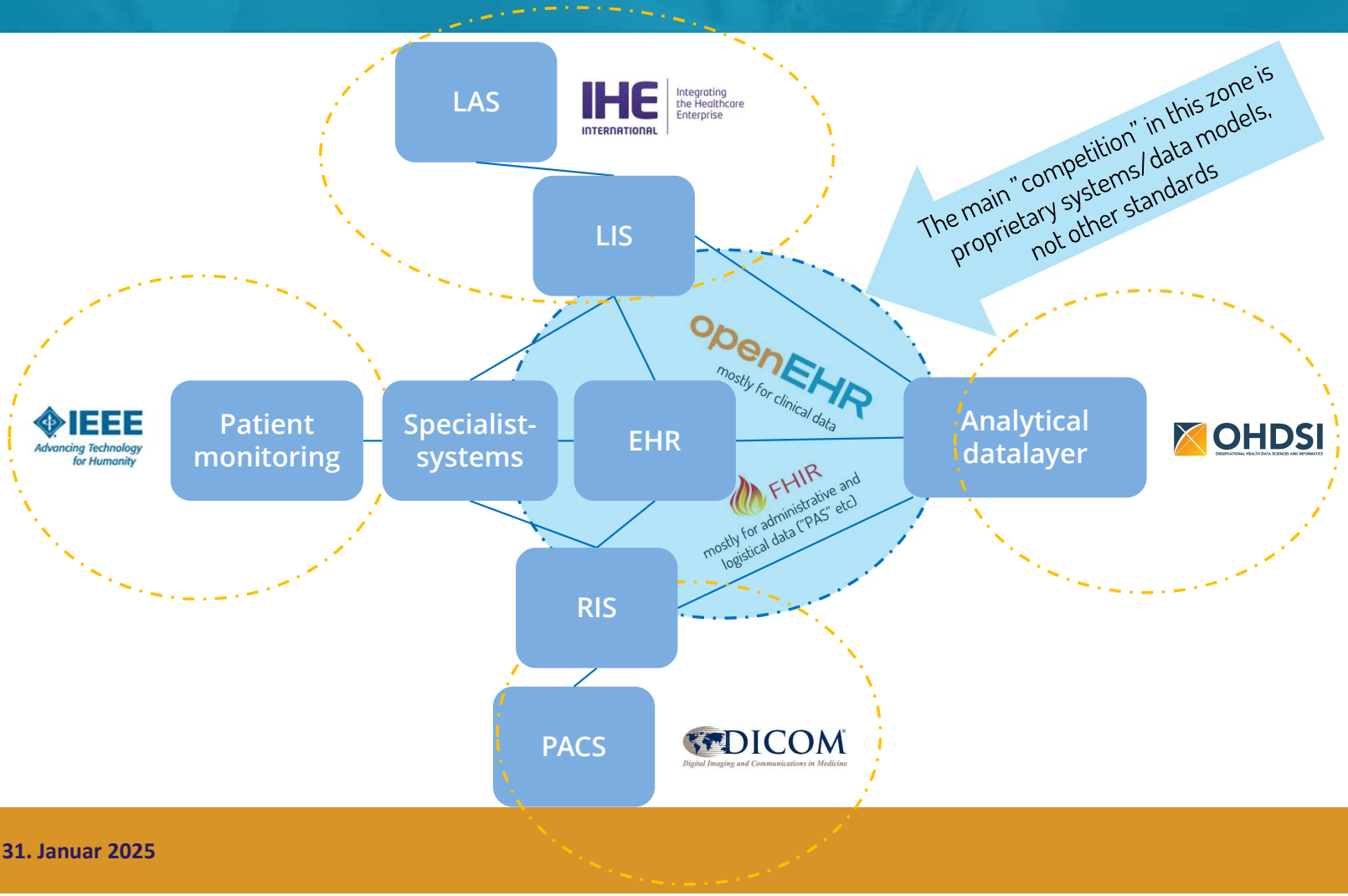
4 Data analysis

- Adjust the treatment of individual patients
- Update "best practice"
- Improve efficiency
- Enable research

3 The care team needs data about who is doing what

openEHR focuses on patient-centric clinical data...

...monitoring data, lab data, imaging data and analytical data, and associated standards, are also important



FHIR or/and openEHR
Used for **data sharing**, if the other standards are not used for sharing

These standards can be combined with **terminology** content from e.g.
SNOMED CT
The global language of healthcare

Karolinska‘s approach to standardisation (including openEHR)

Digital Health Platform

For "primary & secondary use" of health data – or better: original and copied data intended for different purposes

- OVERVIEWS
- DECISION SUPPORT
- PROCESS SUPPORT

PRECISION-MEDICINE

K@HOME

- QUALITY
- RESEARCH
- INNOVATION

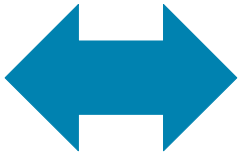
PRODUCTION MANAGEMENT

Data management (modelling, information security, governance etc.)

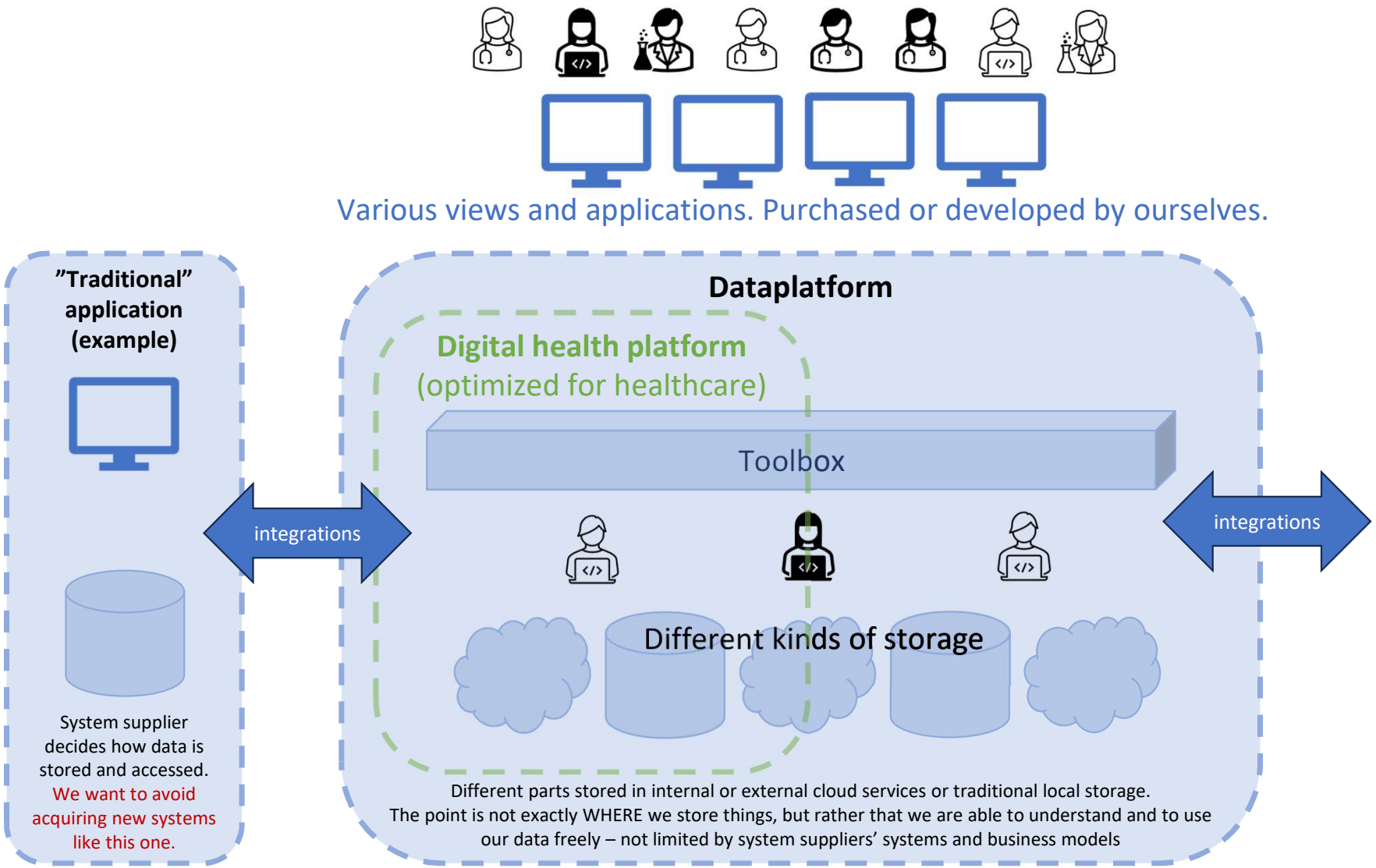
Platform (databases, services like integration, IAM, logging etc.)

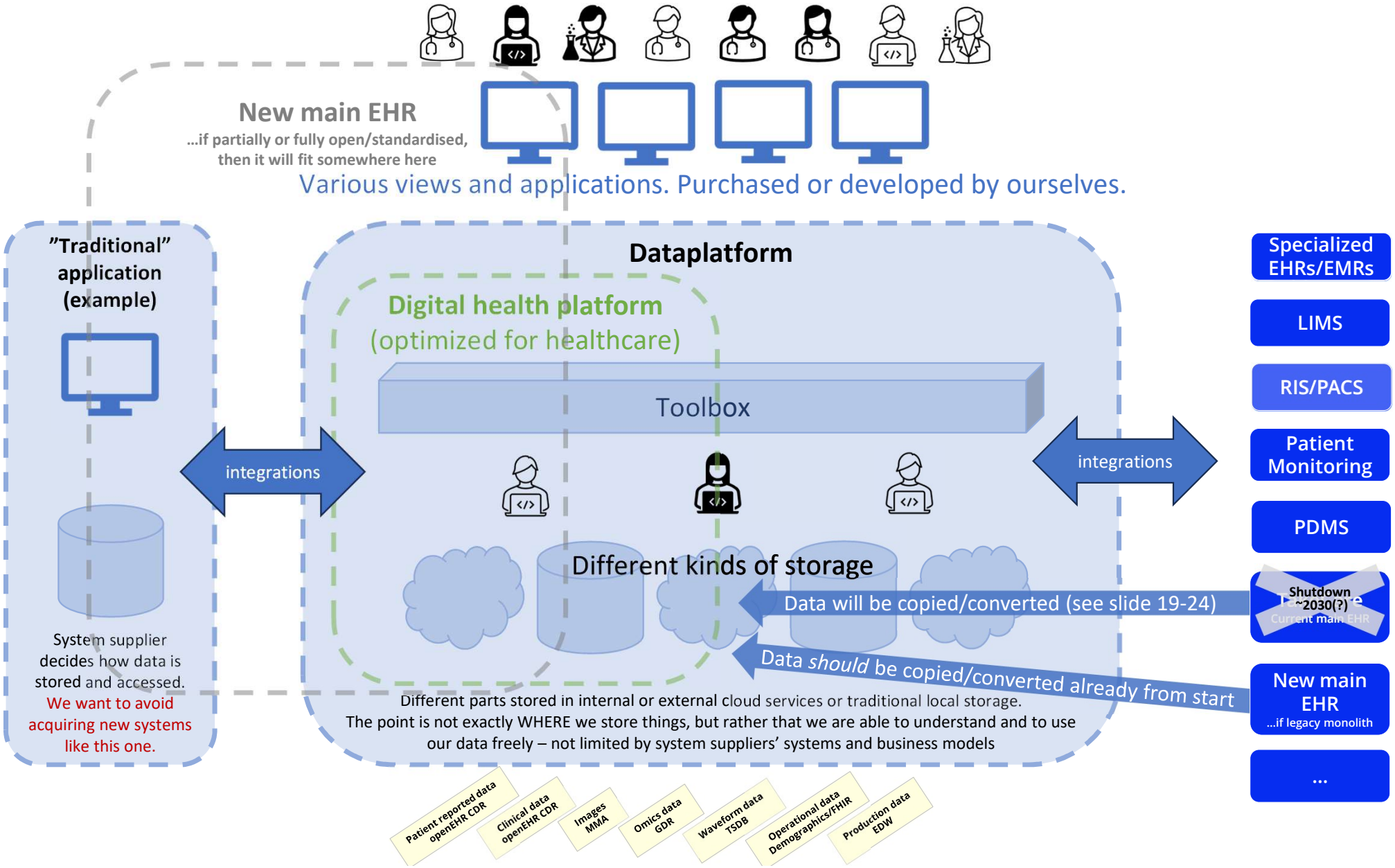
Infrastructure (storage & compute)

Clinical data openEHR CDR | **Patient reported data openEHR CDR** | **Operational data Dem/FHIR** | **Waveform data TSDB** | **Images MMA** | **Omics data GDR** | **Production data EDW**



- Specialized EHRs/EMRs
- LIMS
- RIS/PACS
- Patient Monitoring
- PDMS
- EDW
- ...


Various views and applications. Purchased or developed by ourselves.
”Traditional” application (example)
System supplier decides how data is stored and accessed.
We want to avoid acquiring new systems like this one.
integrations
Dataplatform
Digital health platform
(optimized for healthcare)
Toolbox
Different kinds of storage
integrations
Different parts stored in internal or external cloud services or traditional local storage.
The point is not exactly WHERE we store things, but rather that we are able to understand and to use our data freely – not limited by system suppliers’ systems and business models


New main EHR
...if partially or fully open/standardised, then it will fit somewhere here
Various views and applications. Purchased or developed by ourselves.
"Traditional" application (example)
System supplier decides how data is stored and accessed.
We want to avoid acquiring new systems like this one.
integrations
Dataplatform
Digital health platform
(optimized for healthcare)
Toolbox
Different kinds of storage
integrations
Data will be copied/converted (see slide 19-24)
Data should be copied/converted already from start
Different parts stored in internal or external cloud services or traditional local storage.
The point is not exactly WHERE we store things, but rather that we are able to understand and to use our data freely – not limited by system suppliers' systems and business models
Patient reported data openEHR CDR
Clinical data openEHR CDR
Images MMA
Omics data GDR
Waveform data TSDB
Operational data Demographics/FHIR
Production data EDW
Specialized EHRs/EMRs
LIMS
RIS/PACS
Patient Monitoring
PDMS
Shutdown ~2030(?)
New main EHR
...if legacy monolith
...

Multiple ongoing openEHR projects at Karolinska

- Patient reported data via patient application
  - Symptom control before chemotherapy (operational since 2023)
  - PROM-data
- Automatic transfer from healthcare systems to quality registries
  - Medical oncology treatment (chemotherapy etc.)
  - Cancer surgery
- Specimen-based diagnostics
  - Pathology (breast & prostate)
  - Chemistry lab
- Imaging diagnostics
  - Radiology (prostate)

(Upcoming: Genomics referral & reporting in openEHR. Genomic sequencing & analysis, VCF-files etc., tracked in FHIR)

Focus

- Primary documentation in openEHR
- Data used for care and treatment
- Build forms in various source systems based on openEHR-templates rather than mappings

Collaboration

- openEHR-force (Karolinska/regional internal)
- openEHR Sweden + national projects
- The international openEHR community (forums, CKM etc)
- European openEHR Network
- openEHR interested partners in other networks
  - CCE (Cancer Core Europe)
  - EUHA
  - …

Symphony project

About Symphony

Project details

- Innovation project in EU + Turkey
- 4 use cases
- Sweden: Prostate cancer usecase

Aim

- Create a **vendor-independent architecture** and implementation of **platform components** needed to fulfill requirements for **overview** that can be used during MDT* conference for prostate cancer, including automatic risk classification according to national guidelines
- Reduce double documentation (record data once, use often) & information loss in care flow
- Provide real-time quality data, real-time feedback, etc.

About Symphony

Project details

- Innovation project in EU + Turkey
- 3 years with start October 2022
- 4 use cases
- Sweden: Prostate cancer use case

Problem

- Rising healthcare demand and staff shortages
- Clinical data are heterogeneous, complex, and siloed
- Lack of **interoperability** hinders primary and secondary use of source data

Solution

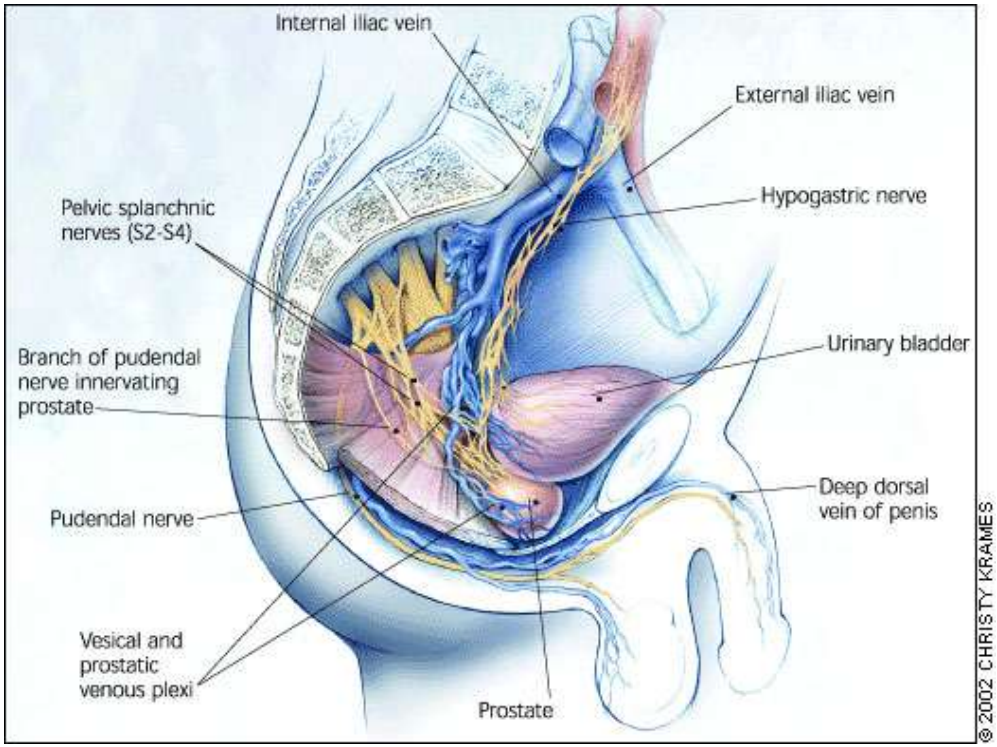
- Develop an open, interoperable healthcare IT ecosystem
- Integrate clinical workflows and data from heterogeneous sources
- Ensure the system aligns with key principles of healthcare technology integration with **structured** and **standardized** data

Effect

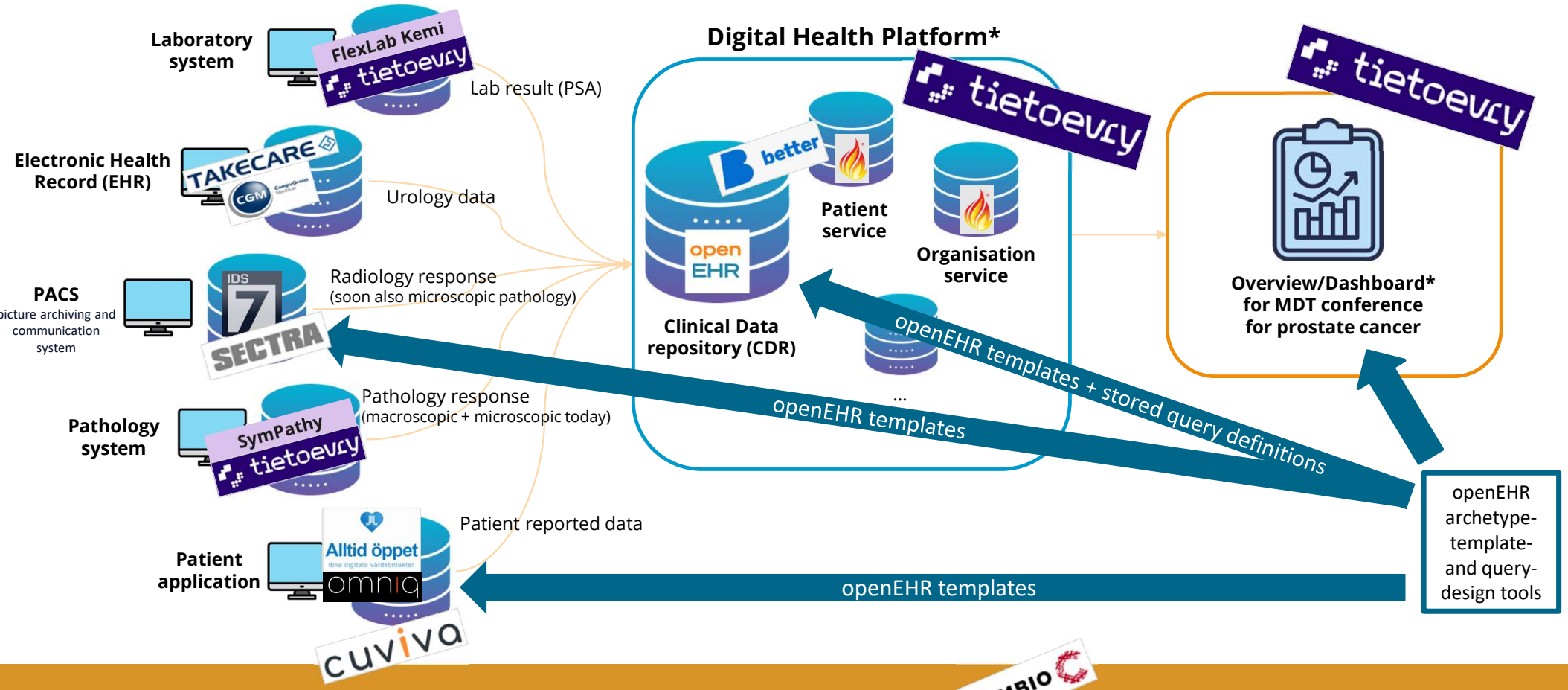
- Data-driven decision-making, including **predictive modelling**
- **Visualization** of complex data following the patients' disease pathway as well as guidelines
- Enhanced patient safety with reduced information loss, including **patient-reported data**
- Real-time quality reporting and feedback

Prostate cancer

- **Common** Over 400,000 new cases diagnosed annually in Europe
- **Broad risk spectrum** Five-year survival at 97% but still the biggest cancer killer among Nordic men
- **Multidisciplinary and heterogeneous** urologists, oncologists, radiologists, pathologists, nurses, and patients
- **Patient-Centered Treatment Balance** Trade-off between cancer control and side effects that impact patients' quality of life



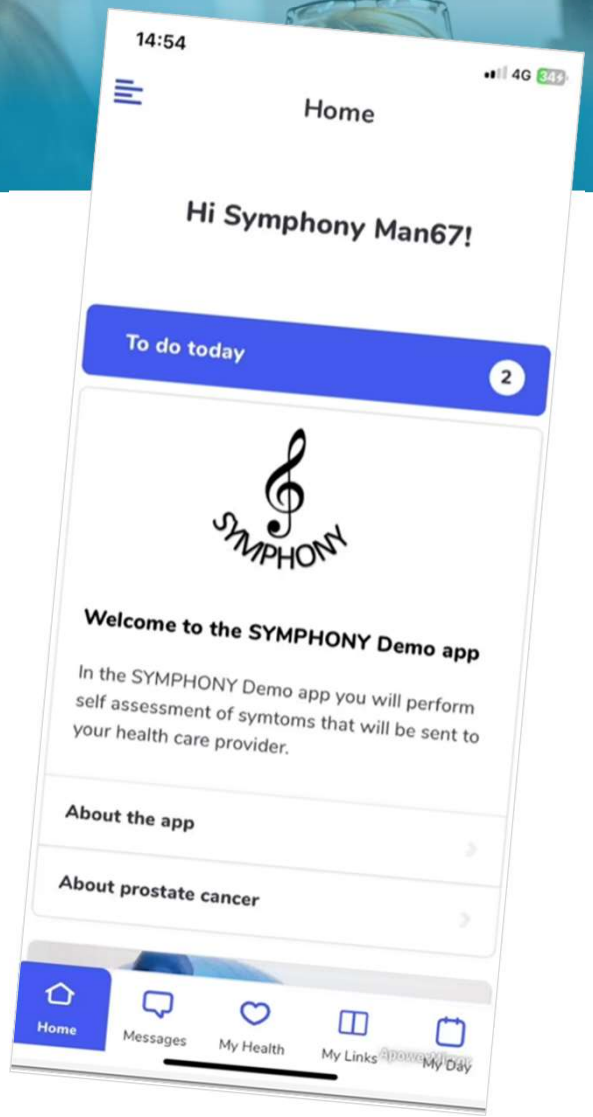
Architecture (in Karolinska's implementation of Symphony results)

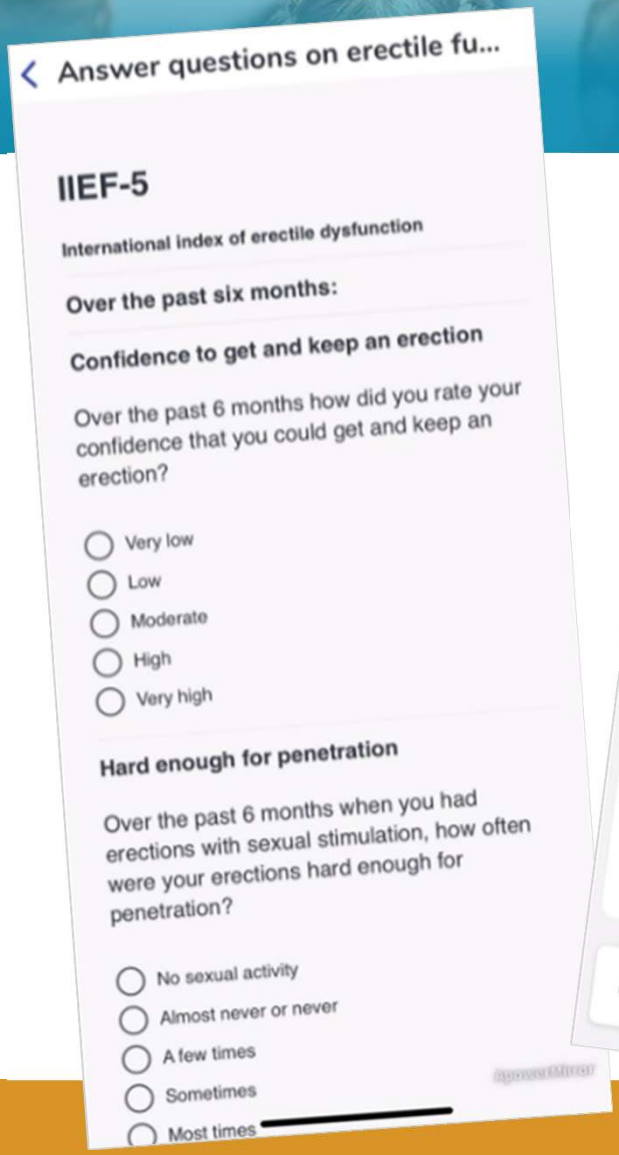


*) Cambio also provides similar services within the Symphony project

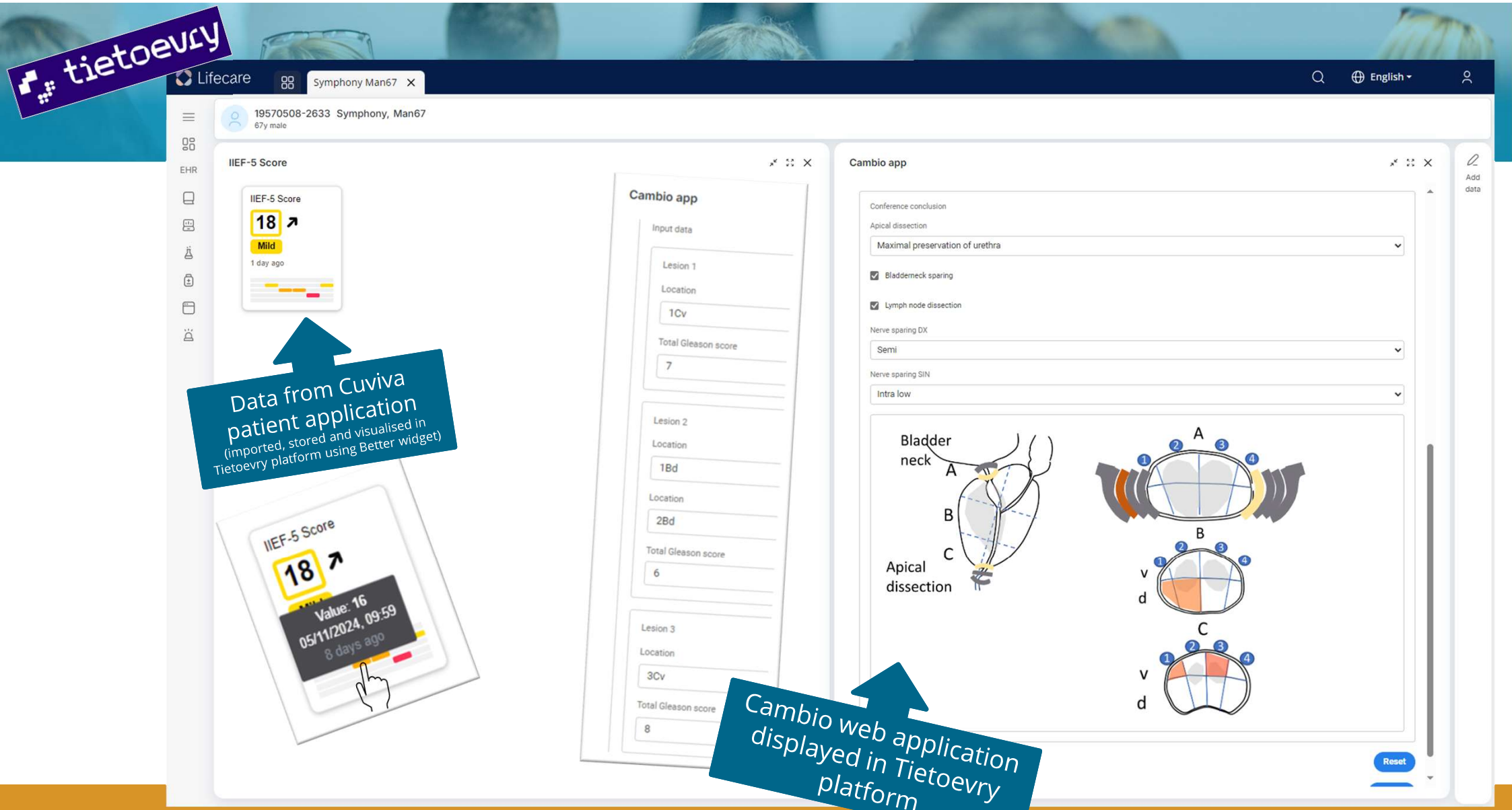
Current openEHR modelling work in Symphony

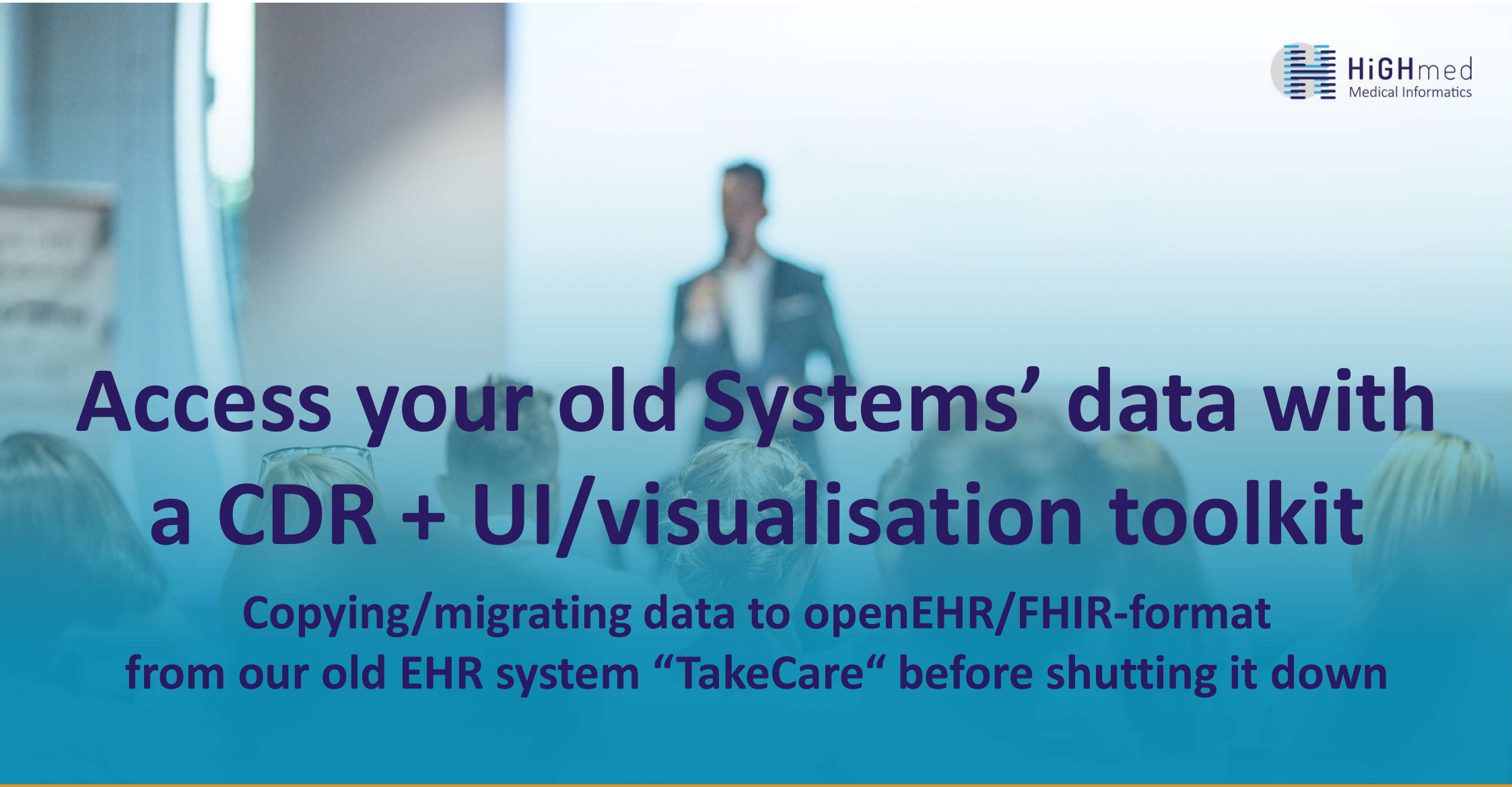
- Patient reported data (IPSS, IIEF-5, health declaration)
  - GitHub - regionstockholm/CKM-mirror-via-modellbibliotek at prostate-cancer-patient-reported-data
- Radiology response
  - GitHub - regionstockholm/CKM-mirror-via-modellbibliotek at prostate-cancer-radiology
  - Radiology response prostate - openEHR Clinical - Confluence
- Pathology request and response


14:54
Home
Hi Symphony Man67!
To do today
2
SYMPHONY
Welcome to the SYMPHONY Demo app
In the SYMPHONY Demo app you will perform self assessment of symtoms that will be sent to your health care provider.
About the app
About prostate cancer
Home
Messages
My Health
My Links
My Day


Answer questions on erectile fu...
IIEF-5
International index of erectile dysfunction
Over the past six months:
Confidence to get and keep an erection
Over the past 6 months how did you rate your confidence that you could get and keep an erection?
Very low
Low
Moderate
High
Very high
Hard enough for penetration
Over the past 6 months when you had erections with sexual stimulation, how often were your erections hard enough for penetration?
No sexual activity
Almost never or never
A few times
Sometimes
Most times


15:45
IIEF-5
Start Questionnaire
11 Nov 3:45 PM
9 p
Week
20
15
10
5
0
Tue
Wed
Thu
Fri
Sat
Sun
Mon
IIEF-5
History


Lifecare
Symphony Man67
English
19570508-2633 Symphony, Man67
67y male
EHR
IIEF-5 Score
IIEF-5 Score
18
Mild
1 day ago
Data from Cuviva patient application
(imported, stored and visualised in Tietoevry platform using Better widget)
IIEF-5 Score
18
Value: 16
05/11/2024, 09:59
8 days ago
Cambio app
Input data
Lesion 1
Location
1Cv
Total Gleason score
7
Lesion 2
Location
1Bd
Location
2Bd
Total Gleason score
6
Lesion 3
Location
3Cv
Total Gleason score
8
Cambio app
Conference conclusion
Apical dissection
Maximal preservation of urethra
Bladderneck sparing
Lymph node dissection
Nerve sparing DX
Semi
Nerve sparing SIN
Intra low
Bladder neck
A
B
C
Apical dissection
A
B
C
v
d
v
d
Reset
Add data
Cambio web application displayed in Tietoevry platform



Access your old Systems' data with a CDR + UI/visualisation toolkit

Copying/migrating data to openEHR/FHIR-format from our old EHR system "TakeCare" before shutting it down

Project description, see post #27 in: https://discourse.openehr.org/t/karolinska-stockholm-procurement-of-digital-health-platform-cdr-tools-services-consultants/4457/27

Reuse our material in a procurement of your own…
…also our PoC results are open for reuse

Swedish name & Category # above	English name + comments	Main API in TakeCare
Läkemedel (cat. #1)	**Medications**. The source API is fairly well documented and has limited variability.	Xchange (XML) API: Medications. MedicationHistoryGet
Journaltext (cat. #2)	**Clinical notes** (forms). Huge variability in size, structure, and content.	Xchange (XML) API: CaseNote. CareDocumentationGet
Kemlabb (cat. #1)	**Clinical Chemistry** (a lot of analysis and mapping is already done). The mapping/conversion should be general and cover any value from the source, but for the visualization at least the following are of special demo-interest (Swedish terms) - P-glukos CGM - P-Kreatinin - P-Alaninaminotransferas (ALAT)	Juno (JSON) API: • .../lab/replies/chemistry • .../lab/replies/chemistry/{documentId} • etc.
Mätvärden (cat. #3)	**Measurements**. Uses a kind of forms/templates (there are more than 1000). Map at least these also to CKM-based form: - NEWS2 Score and several vital parameters it is depending on - Blood Pressure (there might be more than one "mätvärde" as source) - Height, Weight, BMI - If time allows, also some other values we have shortlisted as useful for a patient overview/dashboard	Juno (JSON) API: • .../measurements • .../measurements-index • .../measurements/{measurementDocumentId} • etc.
Aktiviteter (cat. #1)	**Activities**. Variation is mainly in the terminology used, not in structure	Juno (JSON) API • .../activities • etc.
Bokningar (cat. #4)	**Appointment bookings**.	Juno? (JSON) might be in a data dump rather than via API

1 FTE consultancy from each of two expertise areas:

A. **Informatics focus** [freshEHR won]
B. **Integration & visualisation focus** [Tietoevry won]

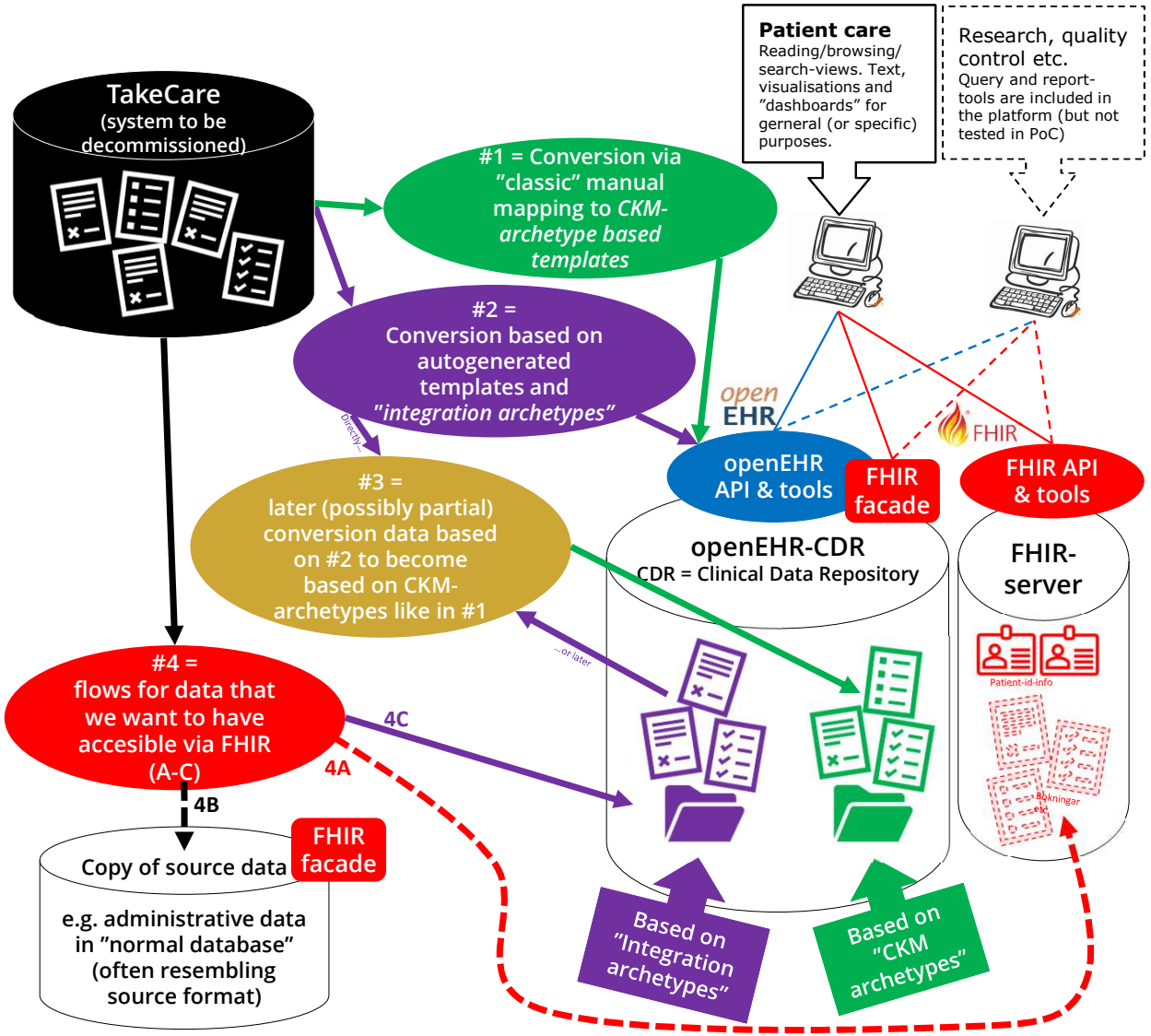
Project length: 3 months

The prime target category & method candidates are:

#1	openEHR COMPOSITIONS based on templates **mainly based on internationally designed archetypes available in CKM** (https://ckm.openehr.org/) • This kind of conversion is realistic for source information types that have well defined APIs and data structures with limited variability of content. • This kind of conversion consists mainly of manual template modeling (and possibly some archetype creation if anything is missing in the CKM) followed by manual modeling of mappings from attributes in source format to attributes in the manually designed templates. Conversion of the actual health record data (instances of EHR content), according to this modeled mapping, shall then be automated using some appropriate tool/service.
#2	openEHR COMPOSITIONS based on templates **based on generated integration archetypes using e.g. openEHR's GENERIC_ENTRY.** (See https://specifications.openehr.org/releases/RM/latest/integration.html) • This kind of conversion is realistic for sources that follow a generic model (somewhat analogous to openEHR's RM) and that also has a catalogue listing the forms/templates and terminology subsets defined in the source system. Manually mapping thousands of these would not be realistic from a resource- and cost/benefit-perspective. ◦ In TakeCare that catalogue is thousands of "mallar" (forms/templates) each based in a number of "sökord" (keywords/headings). There are thousands of "sökord" and they are partly reused between "mallar". • This kind of conversion is based on understanding the generic source formats/patterns and creating two categories of algorithms/programs ◦ An algorithm on a "schema" level that takes the catalogue of source system forms/templates and automatically converts them to integration archetypes and templates. ◦ Another algorithm on an "instance" level that iterates over the EHR content in the source system for a patient and translates it to openEHR COMPOSITIONS based on the previously generated integration archetypes and templates.
#3	openEHR COMPOSITIONs **based on #2 (algorithmically designed) templates but in some cases also converted to COMPOSITONs based on #1 (manually designed) templates**. • This kind of conversion is realistic for source categories where there is too much variation in the source to have time to manually model and map everything (so mainly #2 – the algorithmic way will be used), but where we know that it would be of high value to have some selected subcategory of the data or parts of it (also) manually mapped and converted to templates mainly based on internationally designed archetypes available in CKM. In TakeCare this can for example be the thousands of different "mätvärden" (measurement observations) where we want to select some subcategories of great value (e.g. Pulse, Blood pressure etc.) and have those also mapped also to COMPOSTITIONs based on templates based on proper CKM archetypes. • This kind of conversion likely will consist of a first automated step of type #2 (algorithmically designed) and stored in the CDR. For some subcategories this will then be followed by a step based on further conversions of type #1 (manually designed) and stored again in the CDR in the new CKM-based format but also including a link to the corresponding COMPOSITION based on "integration archetypes" that was originally stored. This way also context not possible to convert to "proper" CKM-based format can be read by staff accessing the information at a later point in time.
#4	FHIR resources **based on national or regional/local FHIR profiles.** • This kind of conversion is realistic for source categories that we have deemed valuable to have accessible primarily in FHIR format, for example some administrative information. • This kind of conversion can be done in at least two ways ◦ either by converting source data to FHIR format and store the converted data in a FHIR server. (Via our contract with Tietoevry we have the FHIR services included in Better Platform available, we also have experience running the opensource HAPI FHIR Server.) ◦ or extracting and storing database posts from the source system in a format close to the source system's format and creating a FHIR facade that can be accessed. The storage should then be done in a database we can keep running after TakeCare has been decommissioned. (We have e.g. PostgreSQL and Couchbase available in our internal cloud at Karolinska)

Project description, see post #27 in: https://discourse.openehr.org/t/karolinska-stockholm-procurement-of-digital-health-platform-cdr-tools-services-consultants/4457/27

Variants of conversion/mapping used in PoC



Conversion strategies

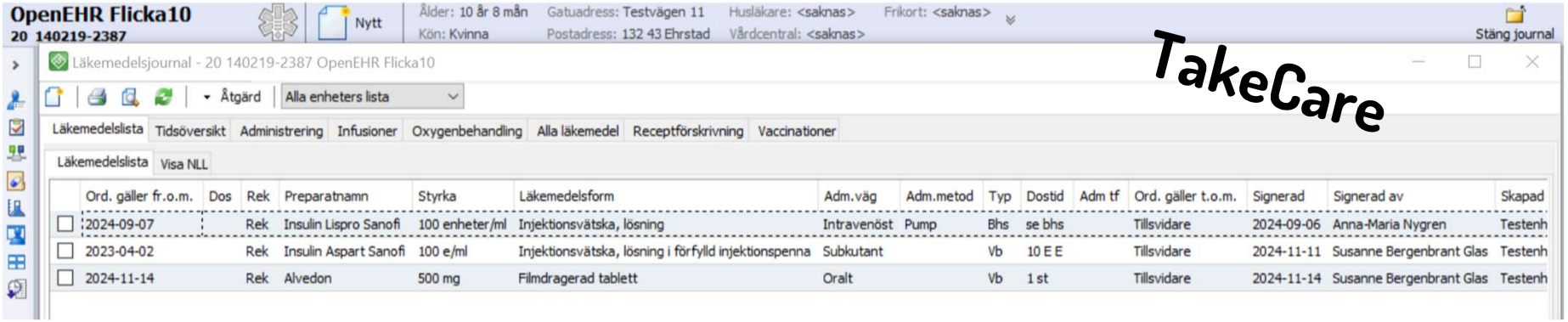
1. **CKM-archetypes =** international or national standardised openEHR structures
2. **Integration archetypes/templates =** locally/custom developed structures that copy the structure of the source system
3. **Combination (of 1+2) =** first converted using integration archetypes and in a later step, either immediately or (even years) later, some (or all) values are converted also based on CKM-archetypes
4. **FHIR =** international standard for integrations, used e.g. for some administrative data in Karolinska's Digital Health Platform. There are (at least) three solution patterns:
   4A. FHIR-resources in a FHIR-server (direct conversion, before storage)
   4B. Store in a database copied form source system, expose via "FHIR-facade"
   4C. Store openEHR-integration-archetype-based in CDR expose via "FHIR-facade"

Priority ordered* data from TakeCare, colour coded as planned at start of project:

- **Medications, #1** – TC Exchange (XML), well defined API
- **Clinical notes (forms), #2** – TC Exchange (XML), thousands of forms/templates and headings. Huge variations in structure/modelling.
- **Clinical Chemistry, #1** – TC Juno (JSON), some modelling and partial mappings were available. Well defined API.
- **Measurements, #3** – TC Juno (JSON), thousands of different legacy source templates. Some were converted to CKM-archetype-based
- **Activities, #1** - TC Juno (JSON), variation in terms, fixed structure in TakeCare
- **Appointment Bookings, #4** – TC Juno (JSON) raw data-dump, interesting to expose via FHIR

*) We listed some more than we expected that the consultants would have time for, but it went surprisingly well! All types were mapped and converted. All were visualized in GUI except the last one (Appointment Bookings) before time ran out.

Medications



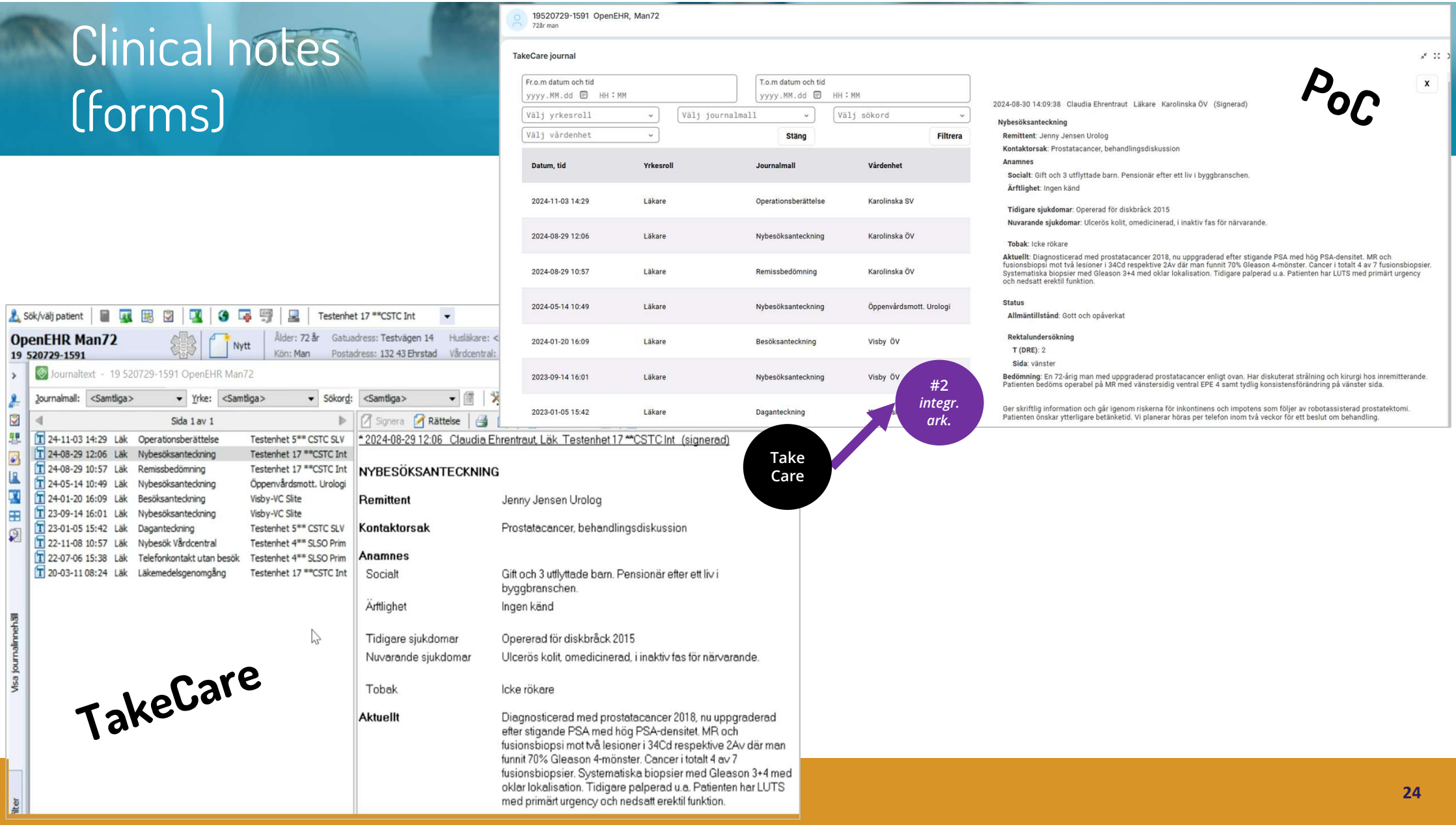
Ord. gäller fr.o.m.	Dos	Rek	Preparatnamn	Styrka	Läkemedelsform	Adm.väg	Adm.metod	Typ	Dostid	Adm tf	Ord. gäller t.o.m.	Signerad	Signerad av	Skapad
2024-09-07		Rek	Insulin Lispro Sanofi	100 enheter/ml	Injektionsvätska, lösning	Intravenöst	Pump	Bhs	se bhs		Tillsvidare	2024-09-06	Anna-Maria Nygren	Testenh
2023-04-02		Rek	Insulin Aspart Sanofi	100 e/ml	Injektionsvätska, lösning i förfylld injektionspenna	Subkutant		Vb	10 E E		Tillsvidare	2024-11-11	Susanne Bergenbrant Glas	Testenh
2024-11-14		Rek	Alvedon	500 mg	Filmdragerad tablett	Oralt		Vb	1 st		Tillsvidare	2024-11-14	Susanne Bergenbrant Glas	Testenh

TakeCare

Ord. gäller fr.om	Preparatnamn	Styrka	Läkemedelsform	Adm. väg	Doseringstyp	Dosering	Dosanvisning	Ord. gäller t.o.m	Signeratdatum	Signerad av	Vårdenhet
2024-11-14	Alvedon	500 mg	Filmdragerad tablett	Oralt	Vb	1	<1 tabletter vid behov mot smärta. Max 6 st per dygn>		2024-11-14	Susanne Bergenbrant Glas	Karolinska ÖV
2024-11-11	Insulin aspart Sanofi	100 E/ml	Injektionsvätska, lösning i förfylld injektionspenna	Subkutant	Vb	10 E	<10 E E injektionsvätska, lösning i förfylld injektionspenna vid behov diabetes. Max 20 E per dygn>		2024-11-11	Susanne Bergenbrant Glas	Privat ÖV
2024-09-07	Insulin lispro Sanofi	100 enheter/ml	Injektionsvätska, lösning	Intravenöst	Bhs	se bhs	<enligt separat behandlingsschema>		2024-09-06	Anna-Maria Nygren	SLSO ÖV

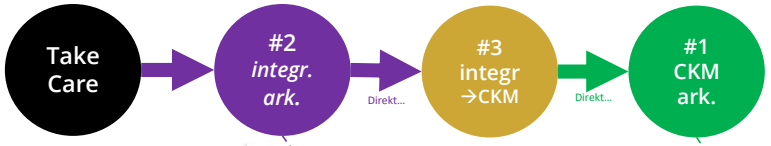
PoC

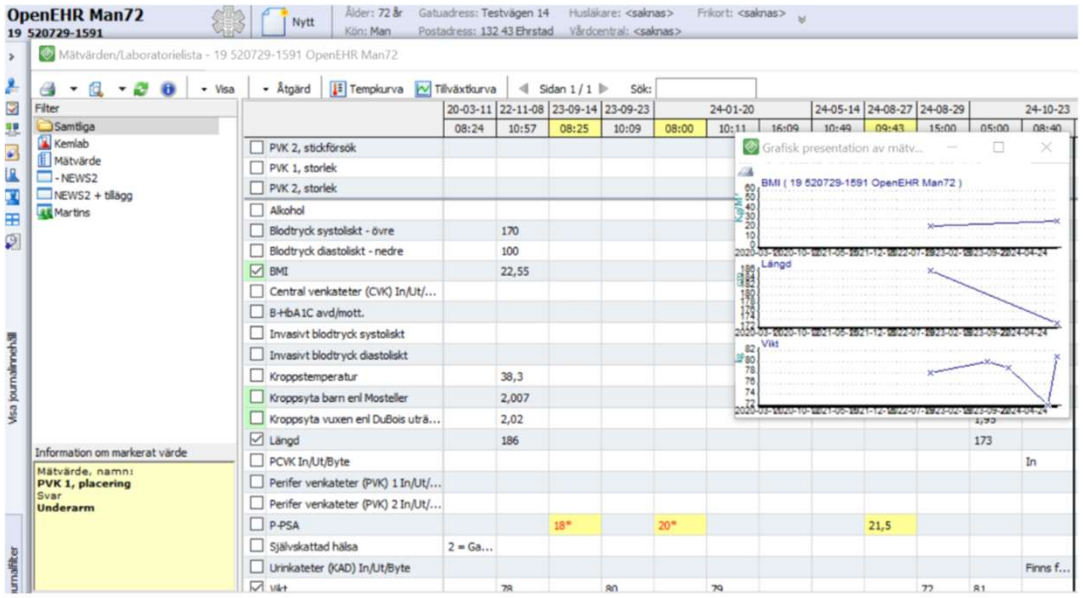
Clinical notes (forms)

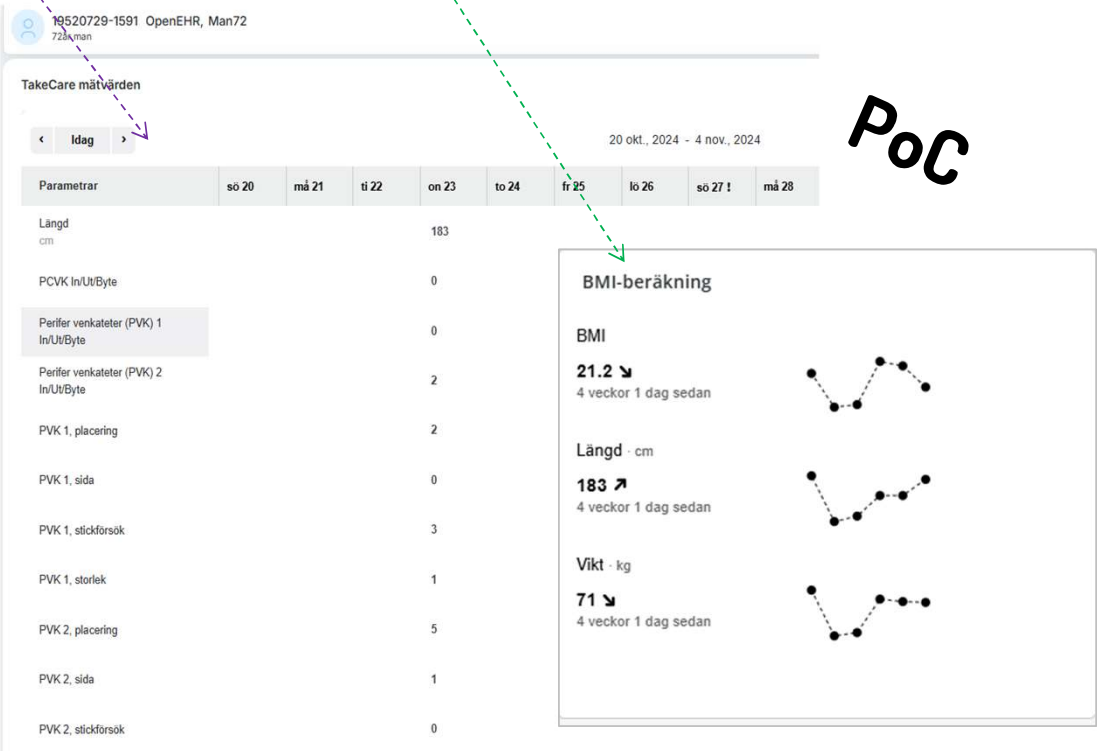


Measurements

TakeCare







PoC

Findings from 3-month Proof of Concept (PoC)

…

- Tillgång till kompetens vital
  - **Kliniker** tillgängliga under arbetet för att skapa bra förutsättningar för visualisering/visning/åtkomst samt medicinsk språkgranskning
  - Internationell **openEHR-expertis** effektiviserar arbetet
  - Djup **TakeCare kompetens** för att förstå viss automatisk logik i TC, exempelvis kring signering
  - Kompetens om **journalföring samt kunskap om rutiner och lagstiftning** är vital
- Effektiv projektstyrning med tydlig dokumentation och snabba beslut
  - **Korta sprintar** med täta uppföljningar för att snabbt hantera utestående frågor/hinder
  - **Dokumentera** från start i alla delar
  - Dokumenterade beslut
- **Enklare än förväntat, bevisat att det är praktiskt genomförbart**
  - Konvertering
  - Visualisering
- … men all information i TC passar inte att mappas till openEHR/FHIR (t.ex. loggar, kassa etc)

Informationsdomän	TC modul
Patientinformation	Vårdkontakter Patientuppgifter
Journalinformation	Mätvärden Beställning och remiss Konsultationsärenden Läkemedelsjournal Svar (laboratorie) Aktivitetsplan Akutliggaren Journaltext Infektionsverktyget Recept Läkemedel – Administreringstillfällen Läkemedel - Administreringsvägar
Parametrar	Administreringstyp Åtgärdskoder enligt KVÅ Inskrivningskoder Termkatalog Inskrivningplanering akut ICD10-register (diagnoskoden)
Loggar	PDL-loggar Vårdenhetsloggar
Dokument	Blanketter och formulär Brev Skanning Mappar med skannade dokument
Bilder	Picsara Multimedia Teckningar Bilder
Ekonomisk information	Kassa Ekonomiska enheter
Resurser	Bokning Vårdenhet
Händelse	Vårdplanering Inskrivning – Utskrivning Ankomst- och betalningsregistrering Ärende-Besöksrapportering Operationsliggare Inskrivningsplanering

Findings

Findings

openEHR vs. other systems

- openEHR can **coexist** with other systems in **many different ways**
- openEHR-based systems can **replace** some legacy/proproetary systems (or parts of them)

Involvment of healthcare professionals

- Greetings from Patrik: "IT is far too important to leave to the nerds at the IT department"
- Involving healthcare professionals is essential – we can't just buy something and belive that the vendor and IT department will develop and maintain it
  - Decisions and development can be made by, or closer to, the health care professionals
  - National and international medical expertise, rather than IT people & vendors

Findings

A nice reusable pattern

- Source systems with form authoring parts can be upgraded to...
  - ... accept openEHR templates as inital blueprints for new forms (and store template paths for fields) and
  - ... easily send form content in openEHR format (vendors often chose simplified/flat openEHR JSON format)
- This simplifies fixing the problems at the source - instead of trying to do magic integrations later

Collaboration with others

- Data and workload sharing (use existing archetypes and templates)

Benefits of using openEHR

- **(Re)empower health care professionals** to specify their need of data
  - Decisions and development can be made closer to the health care professionals
  - National and international medical expertise rather than IT people & vendors
- **Vendor-independent**, clinical models are valid regardless of IT systems
- Increased **development speed** (due to reuse)
  - New/improved functionality for existing systems can be added quickly
  - Reduce bottlenecks of local/regional IT organization and suppliers
- Standardized way to **store** data
- openEHR templates can serve as a **configuration basis** in existing (non-openEHR) systems
- Collaboration with others (data sharing, workload sharing)