A data-centric approach to digital transformation of healthcare and clinical research

Patrik Georgii-Hemming, MSci, MD, PhD
CMIO
Karolinska University Hospital

*Clinicians, clinical researchers & scientists make **decisions based on data…***

*…so we need a **data-centric approach** to IT-development*

What is wrong with how we usually create software today?

Most organisations have appliosclerosis!

The application-centric approach starts with “what does this system need to do?”. Data is secondary.

- Exorbitant, often prohibitive, cost of change
- Data is tied up in applications because applications own data
- New projects come with a big data conversion project
- Data exists in wide variety of heterogeneous formats, structures, meaning, and terminology
- Data integration consumes 35%-65% of IT budget
- Hard or impossible to integrate external data with internal data

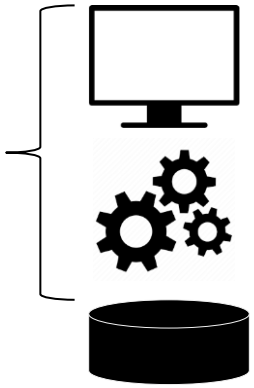
The data-centric approach puts data at the center of the enterprise. Applications are optional visitors to the data.

- Reasonable cost of change
- Data is an open resource that outlives any given application
- New projects taps into existing data stores
- Data is globally integrated sharing a common meaning, being exported from a common source into any needed format
- Data integration will be nearly free
- Internal and external data readily integrated

So, how did we end up here?

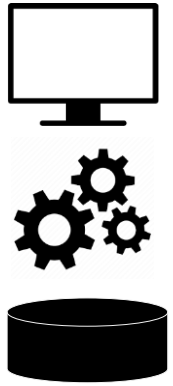
Both providers and vendors drive this focus on behavior…

Procurements and new development are driven by requirements on behavior (almost exclusively)



Healthcare/life science data is complex and we have so far largely failed to converge toward common standards

…so it is hard to meet new requirements…



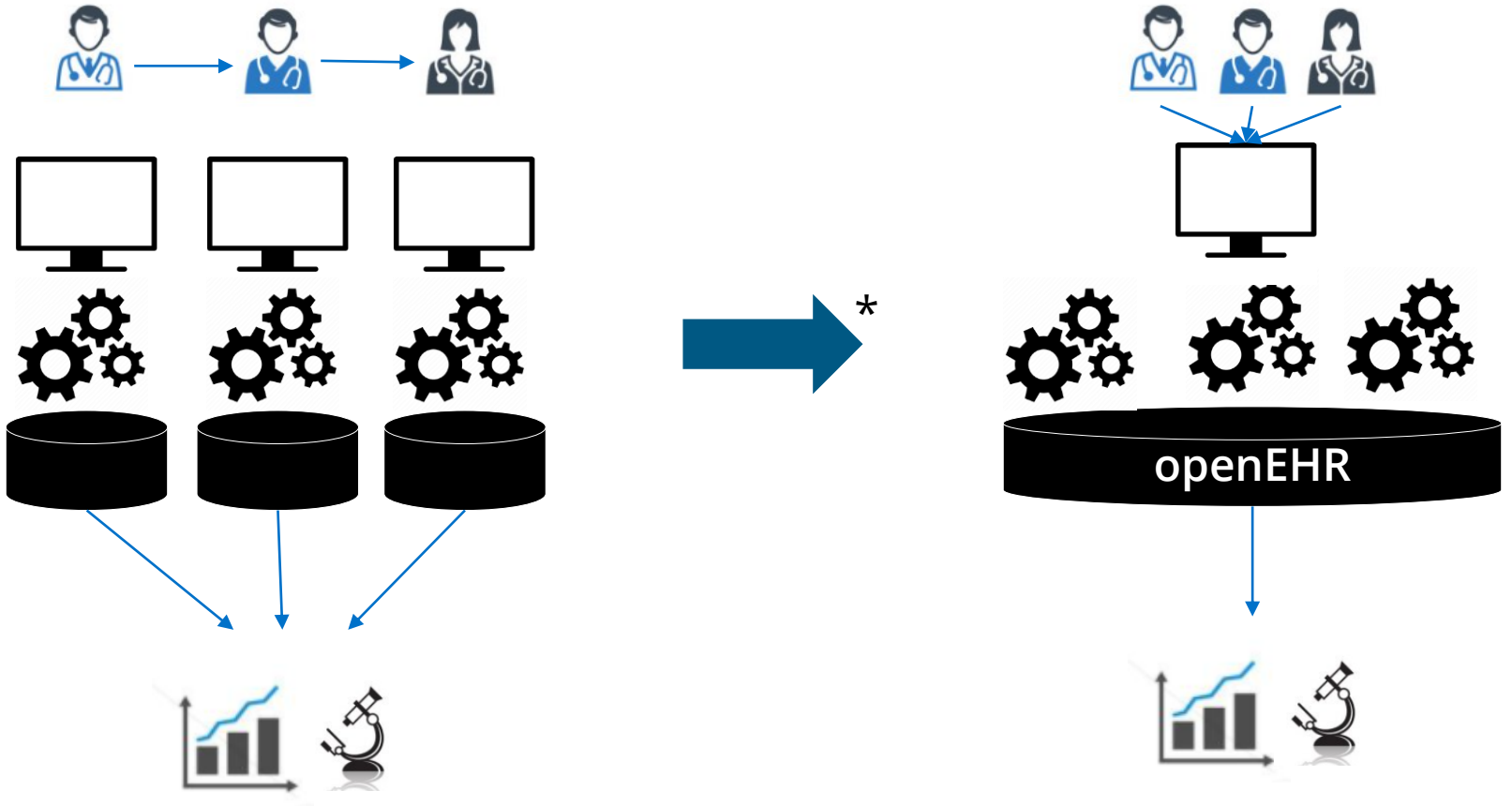
1. Modify existing applications
   - Expensive, 'one-size-fits-all'
2. Provide APIs to enable third-party development
   - Expensive, limited
3. Buy/build a new application
   - Expensive integrations
   - Silos

A data-centric platform based on openEHR

A fragmented IT-environment complicates collaboration in the clinical process

It is difficult to keep up with new and changing requirements

A fragmented IT-environment complicates secondary use of data in quality improvement and research



High-quality data at point of care

Agile and sustainable development

High-quality data for quality improvement and clinical research

** We don't think best-of-suite is a good solution for many reasons but that is a topic for another presentation*

Data-driven healthcare

1. Data

Right information, to the right people, in the right formats, through the right channels, at the right times

Effective ways to register data

PROM/PREM
Care documentation
Pathology reporting
Radiology reporting
.and much more…

Creates information

Uses information

← Requires

Patient overviews
Quality reporting
Research

2. Knowledge

Access to guidelines & CDSS

Right investigation
Right diagnosis
Rätt treatment
Right follow-up

3. Process

Supporting care continuity

Case management
Clinical pathways

Data – how we use standards in the data life cycle

openEHR

HL7 FHIR

"Gartner believes that truly effective and sustainable open architectures will need a capability for vendor-neutral data persistence, such as utilizing a common schema or set of openEHR archetypes and rules for managing structured and unstructured data (for example, a VNA, openEHR or IHE XDS repository in combination with services for trust/consent, ecosystem governance and oversight, and reuse of data and processes for secondary purposes, such as research and population health).

Providing open messaging standards (for example, FHIR, HL7) for data exchange in specific use cases will only go so far in meeting the architectural challenges of digital citizen-centric care delivery"
Healthcare Provider CIOs Need to Rally Their Enterprise Architects Around Citizen-Centric Care Delivery, Gartner 2017

Data – using openEHR to improve data quality in HIS

Data Element	Domain	No. of sites	Site 1 (DWH)	Site 2 (DWH)	Site 3	Site 4	Site 5	Site 6	Site 7	Site 8	Site 9	Occurrence in trials
Sex	Demographics	9	100%	100%	100%	100%	100%	100%	100%	100%	100%	25
Date Of Birth	Demographics	9	100%	100%	100%	100%	100%	100%	100%	100%	100%	34
Diagnosis Code	Disease Characteristics	9	33%	79%	100%	100%	100%	A	80%	100%	35%	12
Albumin	Laboratory	9	7%	A	A	A	61%	A	16%	7%	24%	10
Date of diagnosis	Disease Characteristics	8	N/A	79%	100%	100%	100%	A	80%	100%	35%	12
Result	Laboratory Data	8	68%	A	A	A	70%	A	45%	6%	N/A	8
Laboratory Test	Laboratory Data	8	68%	A	A	A	70%	A	45%	6%	N/A	8
Original Result Unit	Laboratory Data	8	68%	A	A	A	70%	A	41%	6%	N/A	8
Hemoglobin	Laboratory	8	49%	A	A	A	41%	A	13%	N/A	31%	14
Creatinine	Laboratory	8	48%	A	A	A	65%	A	24%	N/A	43%	17
Sodium	Laboratory	8	47%	A	A	A	65%	A	0%	N/A	41%	8
Potassium	Laboratory	8	47%	A	A	A	64%	A	3%	N/A	41%	10
Alkaline phosphatase	Laboratory	8	47%	A	A	A	61%	A	1%	N/A	24%	8
Protein, total	Laboratory	8	47%	A	A	A	5%	A	23%	N/A	18%	10
Lymphocytes	Laboratory	8	46%	A	A	A	41%	A	33%	N/A	31%	14
Platelets	Laboratory	8	46%	A	A	A	41%	A	25%	N/A	50%	14
Glucose, unspecified	Laboratory	8	40%	A	A	A	46%	A	3%	N/A	35%	17
Bilirubin, total	Laboratory	8	30%	A	A	A	60%	A	22%	N/A	24%	15

Fig. 2 Extract from the entire data inventory for clinical trial execution and SAE reporting. On the left-hand side the data elements and their form domains are listed followed by the number of sites in which they occur and the sites availability. Site 1 and 2 used their data warehouse (DWH) for element identification and exports

Bruland et al. BMC Medical Research Methodology (2016) 16:159

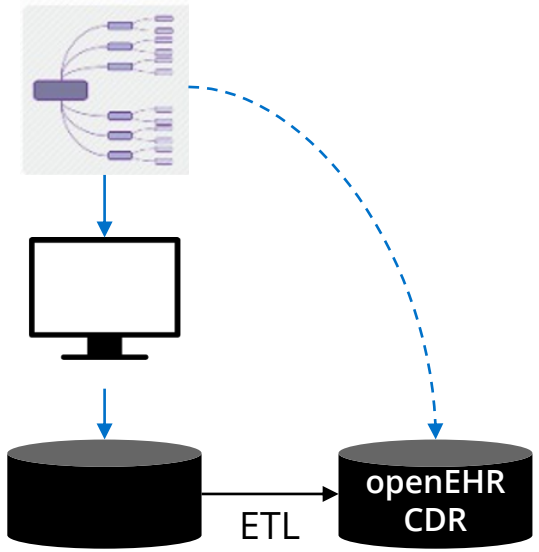
"In attempting to arrive at the truth,
I have applied everywhere for information,
but in scarcely an instance have I been able to obtain hospital records fit for any purposes of comparison. If they could be obtained, they would enable us to decide many other questions besides the ones alluded to"
Florence Nightingale, Notes on a hospital, 1873

RWD is not fit-for-purpose in many cases!

Three solution patterns – correct data quality problems at the source!

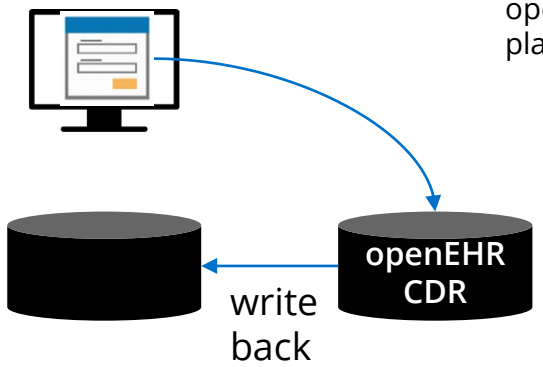
1

Using openEHR templates when configuring data input screens



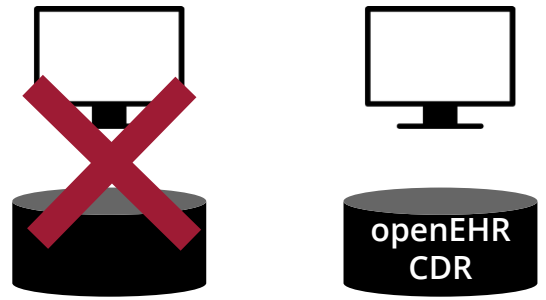
2

Embedd openEHR based form



3

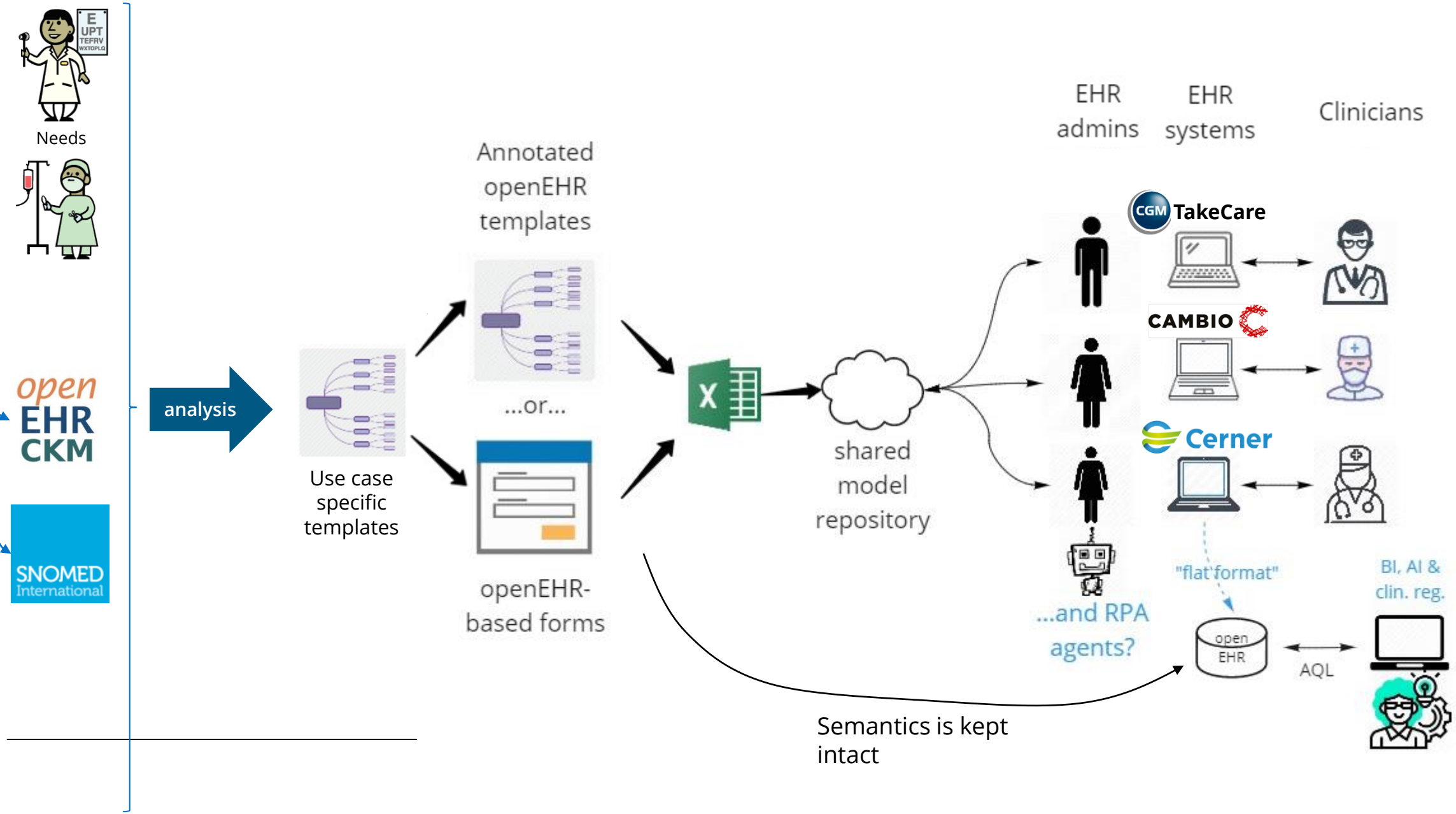
Build apps on openEHR based platform



Quality improvement & clinical research in collaboration with partners

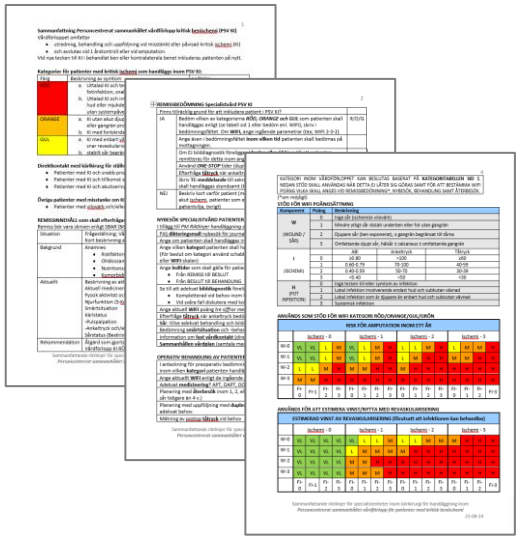
Internal needs at Karolinska

Data - using openEHR to improve data quality in existing HIS

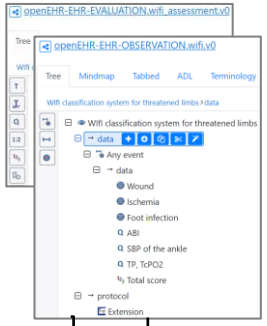


Configuration of input forms in EHR systems using spreadsheets, openEHR archetypes and templates. Sundvall, Terner, Broberg & Gillespie. Medinfo 2019 proceedings, pages 1781-1782 http://dx.doi.org/10.3233/SHTI190645

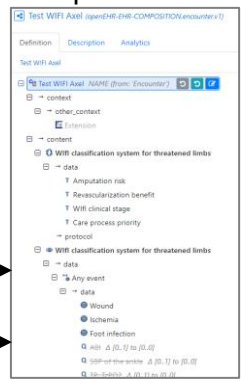
Knowledge - development of simple decision support application

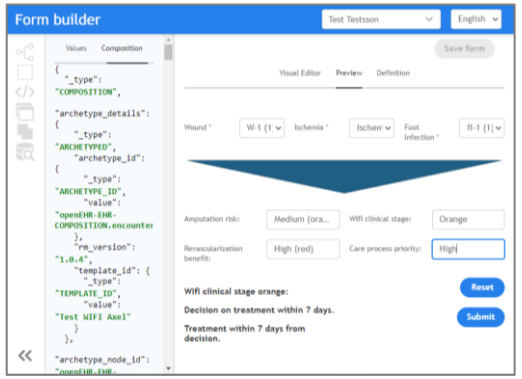


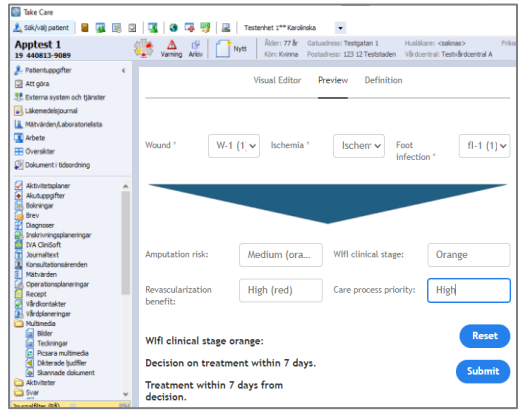
Archetypes



Template







Needs assessment

The clinical needs are documented and stakeholders are identified

Informatics Modelling

Archetypes, templates, rules and guidelines are modeled and verified with clinicians

Form building

Decision support, forms and applications are developed and verified with clinicians and stakeholders

Provisioning/ embedding

The application is embedded in GUI and linked (R/W) with EHR

Data is stored in CDR and made accessible with API:s

Validation

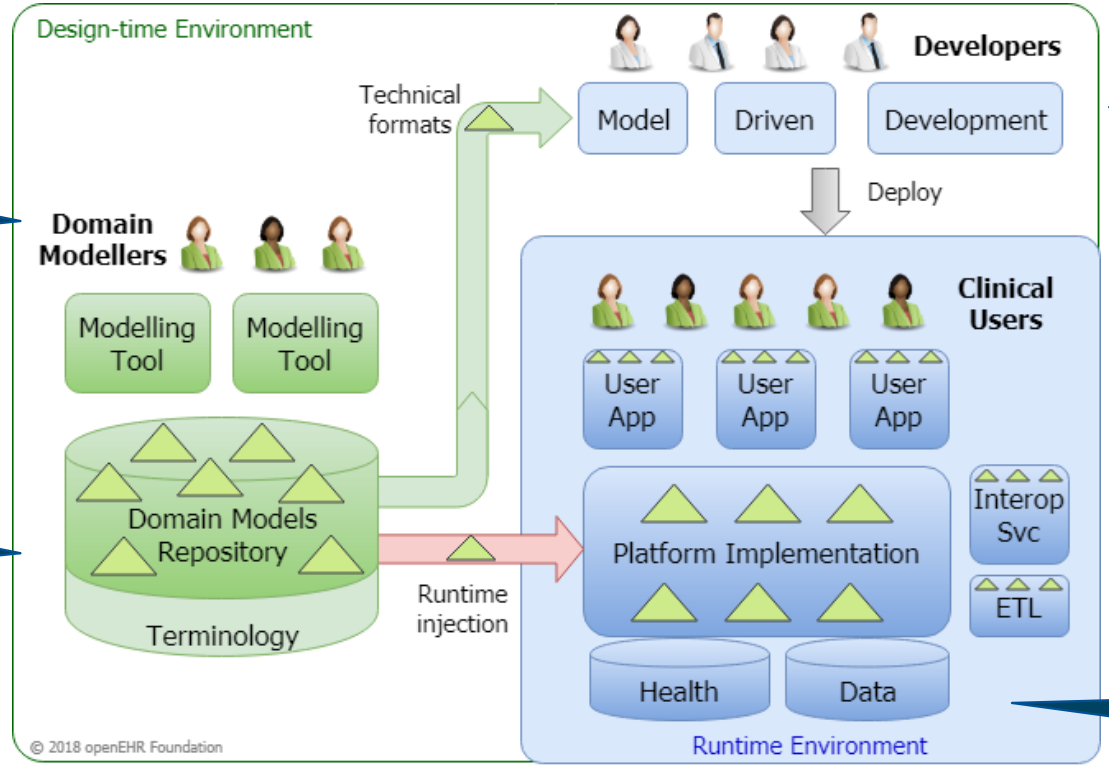
openEHR ecosystem

Clinical involvement
Reuse!

Archetype/Template editor

Collaboration
Life-cycle management

CKM (clinical knowledge manager)



The model-driven openEHR technology ecosystem

Tooling to support no-code/low-code and trad app dev

Form tool, form rendering, AQL editor, rule engine, ...

openEHR based platform

CDR and services (IAM etc)

Data can be persisted in different ways depending on need

Summary

- We need a data-centric approach
- openEHR is focused on building a data-centric platform
- We see a lot of interest in using FHIR for C2B applications based on legacy systems
- We are testing FHIR in B2B applications but the critical mass is not there yet for us
- Data quality issues should be addressed at the source, mapping is not enough
- openEHR has solved the ”curly braces problem” by developing AQL and GDL
  (but with also use CDS-hooks to integrate CDSS with non-openEHR solutions)