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

Patrik Georgii-Hemming, MSc, 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.

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
   - Effective ways to register data
   - PROM/PREM
     - Care documentation
     - Pathology reporting
     - Radiology reporting
     - and much more...

2. Knowledge
   - Access to guidelines & CDSS
   - Requires
     - Quality reporting
     - Research
   - Right investigation
   - Right diagnosis
   - Right treatment
   - Right follow-up

3. Process
   - Supporting care continuity
   - Case management
     - Clinical pathways
“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

“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. Embed 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

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)

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

The model-driven openEHR technology ecosystem

Archetype/Template Modelling Tool Modelling Tool
Repository Terminology Modellers
different ways depending on need

Model Driven Development Deploy
Technical formats

User App User App User App
Clinical Users

Platform Implementation
- Interop Svc ETL

Runtime Environment
- Health Data

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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)