

PHARMACCESSGROUP

# Implementing standards-based fair health data re-use

PharmAccess  
FOUNDATION

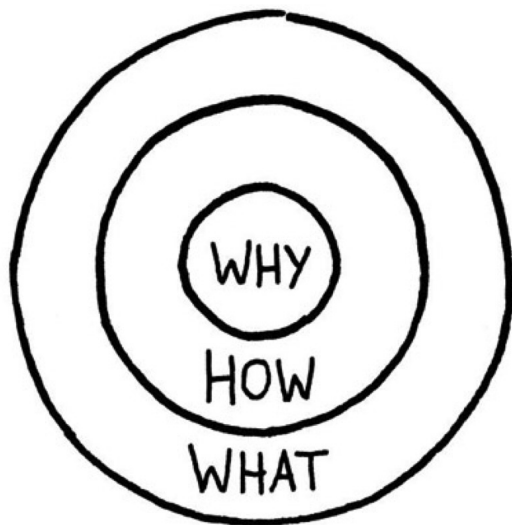
Health  
Insurance  
Fund



SafeCare  
HEALTHCARE STANDARDS



## Going from our WHY to the **HOW** and the **WHAT**



### WHY

- We decided to create value by aiming for a **paradigm shift**
- **Digital health and personal data** are central to the paradigm
- Our strategy is to focus on **patient groups and care providers**

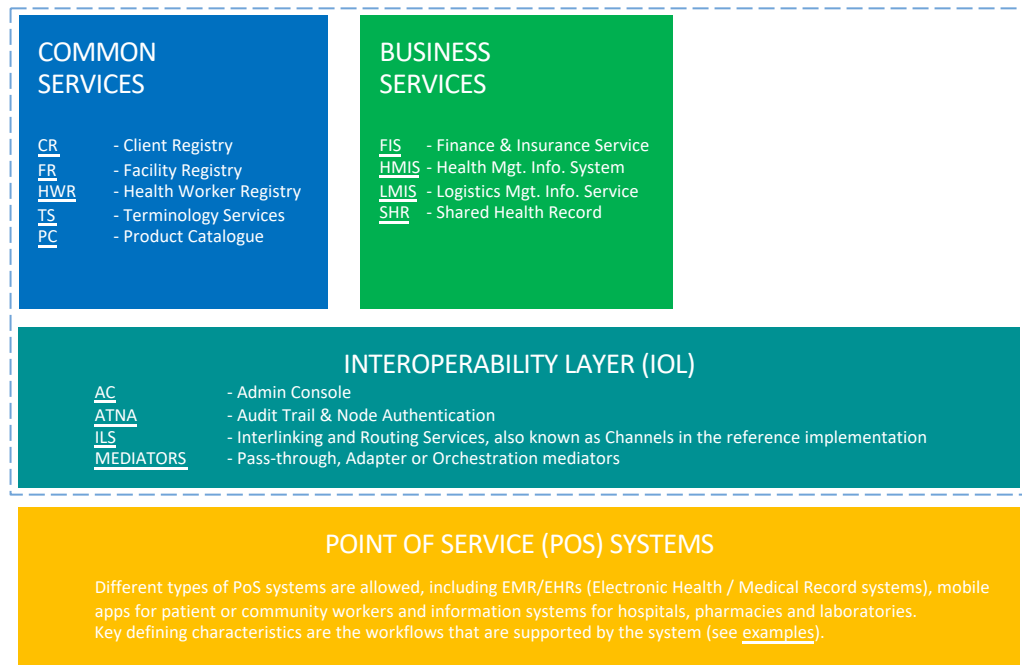
### HOW

- Use “**Health Data Commons**” (working title) framework for standards-based implementation of demonstrators

### WHAT

- Specify **components, partners** and **business model** for each project within framework

# HOW: “Health Data Commons” frameworks



## Based on OpenHIE

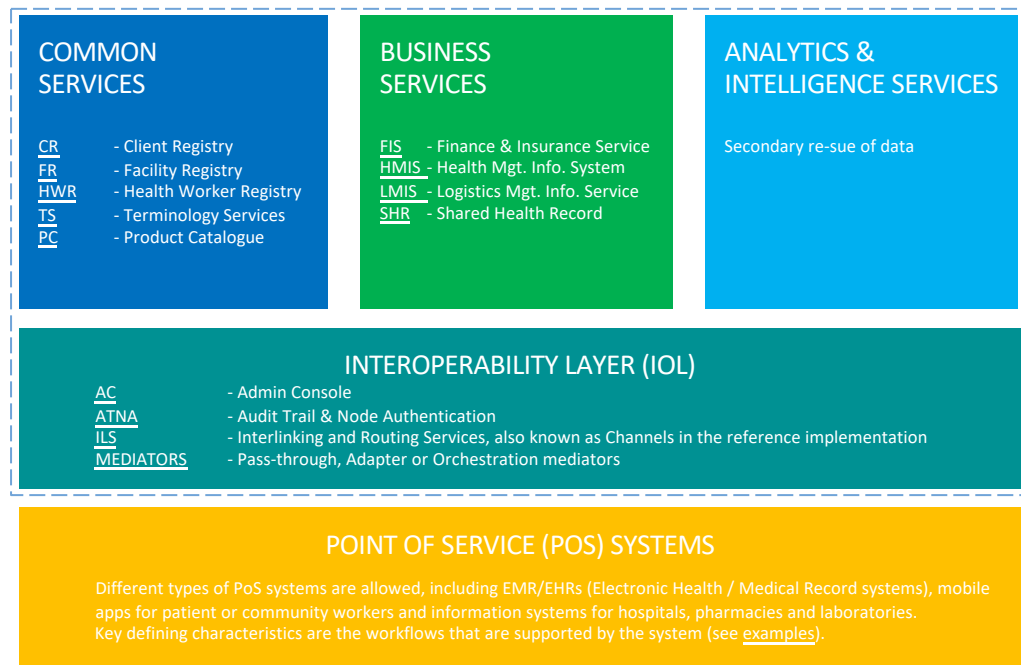
- One of the most widely used architectural frameworks for implementing health data exchange
- Standards-based, modular and with increasing number of implementations

More info: [OpenHIE documentation](#)

## Why is it relevant for us?

- Many African countries have adopted it or use similar frameworks ([Nigeria](#), [Kenya](#), [Tanzania](#), [review HIE in Africa](#))
- Digital technologies have matured in the past decade, creating opportunities for more effective and efficient implementation of openHIE components using open source components

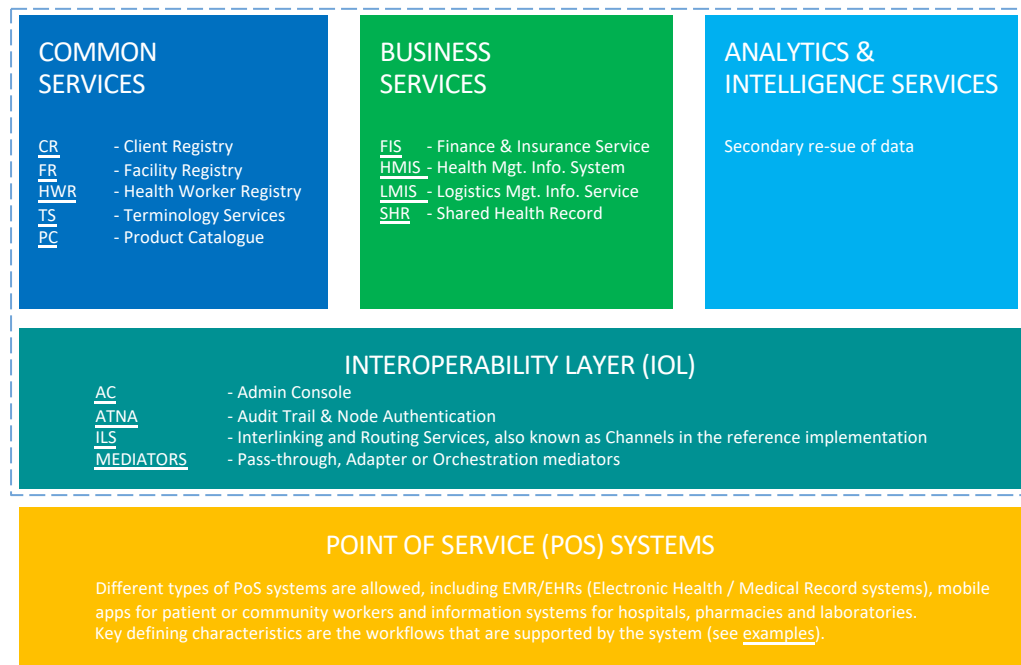
## HOW: Following Kenya's architecture, we add Analytics & Intelligence Services to our framework



### Insights from visit to Kenya

- Little focus on implementing analytics & intelligence services, whilst there is a need by third-parties for secondary access and re-use
- No consensus / clear definitions on type of re-use:
  - Primary data re-use: positioned within routine health delivery process, envisioned to be a market of supplier of business services
  - Secondary data re-use: positioned as re-use of data for analytical and intelligence purposes by academic institutions, pharma companies etc.

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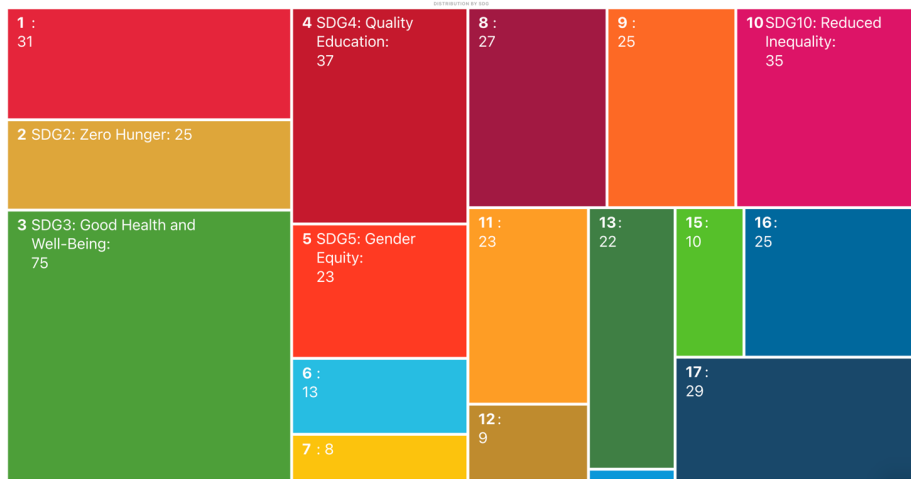
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# HOW: contribute to Digital Public Goods



152 open source software components  
of which 75 in health domain



Android FHIR SDK 	The Android FHIR SDK is a set of Kotlin libraries for building offline-capable, mobile-first healthcare applications using the HL7® FHIR® standard on Android.	Apache-2.0 
Apache FIneract 	FIneract provides a reliable, robust, and affordable solution for entrepreneurs, financial institutions, and service providers to offer financial services to the world's 2 billion underbanked and unbanked.	Apache-2.0 
Automated Data Agreement 	The ADA project builds a fully auditable digital infrastructure that enables sustainable use, reuse and exchange of personal data to enable advanced digitalisation enforced via the use of Data Agreements. A Data Agreement records the conditions for an organisation to process and exchange personal data in accordance with privacy regulation (e.g. GDPR) captured in a signed receipt given to the individual. The solution uses decentralised identity to enable data exchange using Self-Sovereign Identity, OpenID and OAuth technologies.	Apache-2.0 
Bahmni 	Open Source Comprehensive Electronic Medical Record System built on top of OpenMRS, OpenELIS and OpenERP	AGPL-3.0 
Boxtribute 	An open-source digital system making it easy to source, store & distribute aid rapidly to people in need in a fair and dignified way. Boxtribute provides web-app for organisations to run a free shop	Apache-2.0 
Care 	Care is a tool enabling TeleICU & Decentralised Administration of Healthcare Capacity across States.	MIT 
Cboard 	Cboard is an Augmentative and Alternative Communication (AAC) web app for children and adults with speech and language impairments, aiding communication with symbols and text-to-speech.	GPL-3.0 

## HOW: Beyond technology, we want demonstrate sustainable fair data sharing

### Three pillars towards fair data sharing



## WHAT: International Patient Summary (IPS) as starting point for SHR



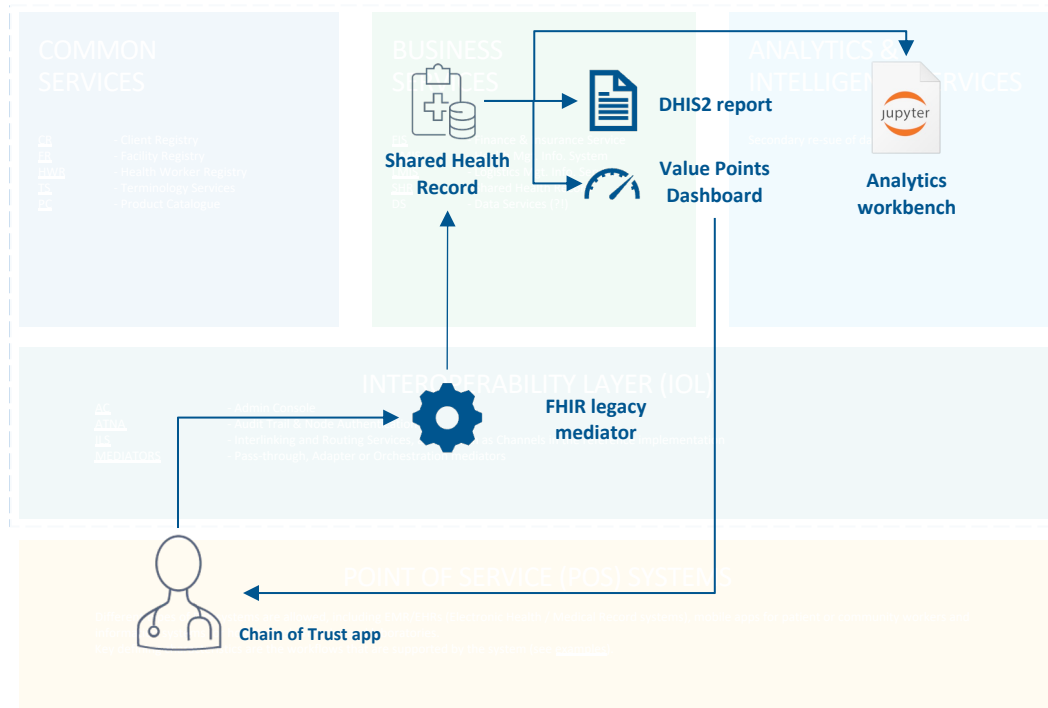
Details: [FHIR IPS](#)

Additions:

- Questionnaire
- QuestionnaireResponse
- ServiceRequest (for referral)



# WHAT: Results technical demonstrators with MomCare Tanzania



- **PoS:**  
Chain of Trust app functions as electronic medical record for MomCare programme
- **Interoperability:**  
Demonstrator for FHIR translation to create 'data station' of shared health record for re-use
- **Business Services:**
  - Automation of DHIS2 reporting based on shared health records
  - Implementation of Value Points Dashboard based on shared health records
  - Capability for plug-&-play publishing of dashboards into existing mobile web that is resilient to intermittent Internet connections
- **Analytics Services:**
  - Configured analytics workbench (in-the-clear)
  - Pilot multi-party computation (MPC, in-the-blind)

## Results: FHIR transformed data Momcare Tanzania

CoT concept	FHIR v4 resource	Business key	# records
Patient	Patient	patients.id	28,161
Patient.EDD	Observation(Pregnancy: EDD)	reference to patients.id and effectiveDateTime = patients.updatedOn	28,587
Clinics	Organization	clinics.id	70
Clinics.lat/lon	Location	Lat-lon coordinates	70
Enrollments	EpisodeOfCare	enrollments.id	20,571
Visit	Encounter	visits.id	174,998
Diagnoses	Condition	CONCAT(visits.id, diagnoses.id)	157,162
Asset	Procedure, MedicationAdministration	visit_diagnoses table links clinical findings to Encounters	1,098,129
Appointment	Appointment	tbd	tbd
BaselineSurvey, Survey	Questionnaire	baseline_surveys.id , surveys.id	4
BaselineAnswers, SurveyResponse	QuestionnaireResponse	baseline_answers.id , survey_responses.id	tbd

**Note:** 9,535 patients in Procedure table can't be found in the EpisodeOfCare table

## Results: patient-timeline table as basis for reporting

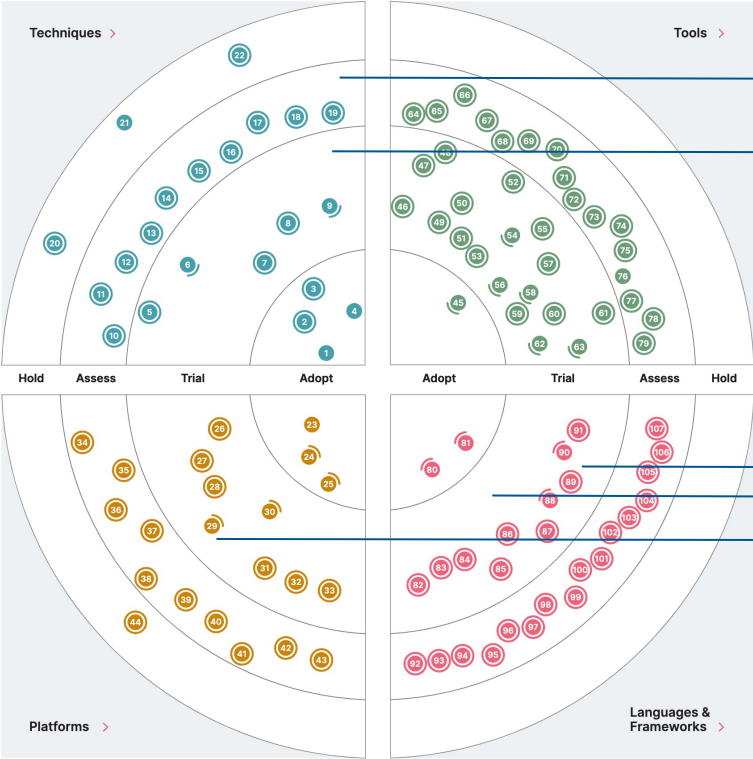
patientId	encounterId	date	code	system	type	description	visitType	ClinicName	...
6c2c-3576	34	2022-10-10	O98.7	ICD10	condition	HIV in pregnancy	ANC	Mbulu District Hospital	...
6c2c-3576	34	2022-10-10	NaN	snomed	procedure	HIV test	Antenatal care	Mbulu District Hospital	...
6c2c-3576	123	2022-11-18	Z34	ICD10	condition	HIV test	Supervision of normal pregnancy	Tumaini Hospital	...
6c2c-3576	123	2022-11-18	NaN	snomed	procedure	Malaria Rapid Test	Antenatal care	Tumaini Hospital	...
6c2c-3576	123	2022-11-18	NaN	snomed	procedure	Blood pressure	Antenatal care	Tumaini Hospital	...

Patient-  
timeline as  
basis for  
business logic

serial_number	description	code	system	origin	original_description	extra filter
1	Number of Projected pregnant women	na	na	metric	na	given by clinic
2	First ANC visit	na	na	metric	na	VISIT_TYPE_NO = 1 and VISIT_TYPE = ANC
2a	Week of pregnancy below 12 weeks (< 12 weeks)	na	na	metric	na	gestation_week < 12 and VISIT_TYPE = ANC and VISIT_TYPE_NO = 1
2b	Week of pregnancy above 12 weeks (>= 12 weeks)	na	na	metric	na	gestation_week >= 12 and VISIT_TYPE = ANC and VISIT_TYPE_NO = 1
2c	All revisit clients	na	na	metric	na	VISIT_NO > 1
2d	All pregnant women with 4+ ANC visits	na	na	metric	na	visit_type_no >= 4 and Visit_type = ANC
2e	Number of pregnant women with HB test at first ANC visit	23244001	snomed	procedure	Hemoglobin	VISIT_TYPE = ANC and VISIT_TYPE_NO = 1
3	Pregnant women given TT2+ vaccine	146080110000011	snomed	procedure	Tetanus toxoid	VISIT_TYPE = ANC

<https://cot-patient-journey-staging.web.app/home>

# Results: underlying technology



● New ● Moved in/out ● No change

**Analytics-on-FHIR** use Bulk FHIR API as basis for analytics of patient populations.

**Svelte** web application framework that is optimized for low-resource settings and performance, including offline access.

**Duckdb** embedded, lightweight database for use in web applications and analytics workbench.

**Secure multi-party computation (MPC)** solves the problem of collaborative computing that protects privacy between parties that do not trust each other. It's aim is to safely calculate an agreed-upon problem without a trusted third party, while each participant is required to partake in the calculation result and can't be obtained by other entities.

**Quarto** an open-source scientific and technical publishing system. With it, we can build computational notebooks that allow you to write documents in markdown, embed code and emit that code's output into the final document.

# WHAT: Our common task is to detail the components, partners and business model for each of our programmes

