Conceptualizing open health data platforms for low- and middle income countries

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Abstract

TO DO: add abstract.

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1. Introduction

1.1. Digital platforms vs. data platforms for healthcare

It is a widely held belief that digital technologies have an important role to play in strengthening health systems in low- and middle income countries (LMICs), as exemplified by the WHO global strategy on digital health (World Health Organization, 2021). The adoption rate of mobile phones in LMICs has been an important driver in implementing digital health solutions (McCool et al., 2022). Yet, there are many shortcomings and challenges, including the current fragmentation of digital platforms and the lack of clear-cut pathways of scaling up digital health programmes, such that they can support sustainable and equitable change of national health systems in LMICs (McCool et al., 2022; World Health Organization, 2019; Neumark and Prince, 2021).

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A commonly used perspective to scrutinize digital health is to consider it as a digital platform (de Reuver et al., 2018). Digital platforms have disrupted many sectors but have just started to make inroads into highly regulated industries such as healthcare (Ozalp et al., 2022). In this light, the challenges faced by LMICs in establishing national digital health platforms have a lot in common with those faced by high income countries. From a technological perspective, interoperability issues, weak integrations, siloed data repositories and overall lack of openness are often reported as key impediments (Malm-Nicolaisen et al., 2023; Mehl et al., 2023). From a societal perspective, issues pertaining to the winner-takes-all nature of digital platforms are hotly debated as many jurisdictions make work to ensure these new digital health platforms indeed serve the common good of achieving universal health coverage (Sharon, 2018).

Case studies on digital platforms in healthcare point to an emerging pattern where the focus shifts from the digital platform with its defining software and hardware components, to the data as the primary object of interest in and of itself (Ozalp et al., 2022; Alaimo and Kallinikos, 2022). This observation ties into the proposed research agenda by de Reuver et al. to consider data platforms as a phenomenon distinct from digital platforms (de Reuver et al., 2022). Generally, data platforms inherit the characteristics of digital platforms. For example, the economic perspective on digital platforms stresses their multi-sidedness with developers and consumers, while data platforms are used by data owners, data consumers and third party solution providers. At the same time, data platforms differ as their main offerings revolve around data. From a market perspective, data platforms have more moderate network effects and are more susceptible to fragmentation and heterogeneity.

Particularly relevant in the context of health data platforms (HDPs), is the conceptualization of openness. The shift in perspective from digital platforms to data platforms coincides with the paradox of open (Keller and Tarkowski, 2021). Originally, openness of digital platforms focused on open source, open standards and copyrights, which by has been superseded by "… conflicts about privacy, economic value extraction, the emergence of artificial intelligence, and the destabilizing effects of dominant platforms on (democratic) societies. Instead of access to information, the control of personal data has emerged in the age of platforms as the critical contention." (Keller and Tarkowski, 2021). These conflicts are particularly salient in the healthcare domain, as is evidenced by polemic surrounding data spaces (Otto et al., 2022) and data solidarity (Kickbusch et al., 2021; Prainsack et al., 2022; Prainsack and El-Sayed, 2023). Openness is particularly relevant if we are to realize a solidarity-based approach to health data sharing that i) gives people a greater control over their data as active decision makers; ii) ensures that the value of data is harnessed for public good; and iii) moves society towards equity and justice by counteracting dynamics of data extraction (Prainsack et al., 2022).

1.2. From health information exchanges to health data platforms

This paper is motivated by the conflation of a number of developments relevant to the design and implementation of solidarity-based HDPs in LMICs. First, the OpenHIE framework (ope, 2022) has been adopted by many sub-Saharan African countries (Mamuye et al., 2022) as the architectural blueprint for implementing nation-wide health information exchanges (HIE), including Nigeria (Dalhatu et al., 2023), Kenya (Thaiya et al., 2021) and Tanzania (Nsaghurwe et al., 2021). These countries have, as a matter of course, extended the framework to include "analytics services" as an additional domain. The rationale for this addition is to facilitate secondary reuse of health data for academic research, real-world evidence studies etc. which can be framed within the context of ongoing efforts towards Findable, Accessible, Interoperable and Reusable (FAIR) sharing of health data (Guillot et al., 2023). In doing so, however, we have implicitly moved from conceptualizing digital health platforms (the original OpenHIE specification) to health data platforms. This is problematic because the notion of openness, which is assumed to be essential in establishing solidarity-based approaches to data sharing, is inherently different for a data platform compared to a digital platform.

Conceptually, the OpenHIE framework constitutes a framework for an open digital platform. Openness for digital platforms refers to i) the use of open boundary resources, that is, specifications for the various healthcare specific workflows and information standards such as FHIR; and ii) the use of open source components that are available as digital public goods(dig, 2024). If we are to use the OpenHIE framework as an open data platform, we need to extend the standards, technologies and architecture to include functionality for data sharing and reuse. Distinguishing four types of data sharing (Table 1), the purpose of this paper is to investigate how new standards and technologies that can establish openness of health data platforms can be integrated into the OpenHIE architecture framework. The lack of detailed specifications and consensus of this addition to OpenHIE currently stands in the way of development projects that aim to establish HDPs in LMICs. In addition, we explicitly address the requirement of downward scalability as we aim to implement health data platforms in resource constrained setting of LMICs.

Table 1: Types of data sharing and in relation to new standards and technology enablers to create openness.

	Type of data sharing	**Technology enablers to create openness of health data platforms**
1	Data at the most granular (patient) level, which is persisted and used to provide a longitudinal record.	**Bulk FHIR API**: has by now been incorporated in all major FHIR implementations the FHIR standard can be readily used to support data sharing to patient-level data across a patient population (Mandl et al., 2020; Jones et al., 2021).
2	Aggregated data, for example statistics for policy evaluation and benchmarking	**SQL-on-FHIR specification** (sql, 2024): provides a standardised approach to make FHIR work well with familiar and efficient SQL engines that are most commonly used in analytical workflows. Builds on FHIRPath (HL7, 2020) expressions in a logical structure to specify things like column names and unnested items. Implementations of this approach are available or forthcoming, including open source implementations such as Pathling (Grimes et al., 2022) and commercial offerings like Aidbox (Health Samurai, 2024).
3	Data analytics modules, that provide access to work and access the data.	**Federated learning (FL)** (Rieke et al., 2020) and **privacy- enhancing technologies (PETs)** (Scheibner et al., 2021; Jordan et al., 2022): new paradigms that address the problem of data governance and privacy by training algorithms collaboratively without exchanging the data itself. Models can be trained on combined datasets and made available as open source artifacts for decision support. Data analysts can use FL and PETs to work with the data in a collaborative, decentralized fashion.
4	Trained models that have been derived from the data and can be used stand-alone for decision support.	**ONNX** (onn, 2023): an open format built to represent machine learning models.

2. Methods

In the paper, we present a design that extends the OpenHIE specification to include the four types of data sharing mentioned above. Using the full-STAC approach (Mehl et al., 2023) we combine open standards, open technologies and open architectures into a coherent modular HDP platform that can be configured and reused across a variety of use-cases. Subsequently, we employ a formative, naturalistic evaluation to assess the technical risk and efficacy of the design (Venable et al., 2016). Given that it is prohibitively expensive to evaluate with real users and real systems in the real setting, we aim to minimize technological risks and maximize the efficacy of the design by considering three real-world examples of health data platoform in LMICs, namely i) the OpenHIM platform (https://jembi.gitbook.io/openhim-platform/); ii) the ONA Canopy platform https://ona.io/home/services/canopy/; and iii) the work conducted at PharmAccess Foundation as part of the MomCare programme (https://health-data-commons.pharmaccess.org). As part of our design research, we have taken a narrative approach in surveying existing scientific studies on health data platforms, focusing on the seminal reports and subsequently searching forward citations. In addition, we have searched the open source repositories (most notably GitHub) and the online communities (OpenHIE community, FHIR community) to search for relevant open standards, technologies and architectures. This paper should not be considered as a proper systematic review.

3. Design

3.1. Open standards: using FHIR as the common data model

The recent convergence to FHIR as the de facto standard for information exchange has fuelled the development of OpenHIE. FHIR is currently used both for routine healthcare settings (Ayaz et al., 2021) and clinical research settings (Duda et al., 2022; Vorisek et al., 2022) and is increasingly being used in LMICs as well. The guidelines and standards of the African Union explicitly state FHIR is to be used as the messaging standard (202, 2023). The FHIR-native OpenSRP platform (Mehl, 2020) has been deployed in 14 countries targeting various patient populations, amongst which a reference implementation of the WHO antenatal and neonatal care guidelines for midwives in Lombok, Indonesia (Summit Institute for Development, 2023; Kurniawan et al., 2019). In India, FHIR is used as the underlying technology for the open Health Claims Exchange protocol specification, which has been adopted by the Indian government as the standard for e-claims handling (hcx, 2023). This range of utilizations showcase the standards' widespread applicability. The proceedings of the OpenHIE conference 2023 attest to the fact that FHIR and open source technologies are embraced as critical enablers in implementing health information exchanges in LMICs (ohi, 2023).

Various studies have investigated the merits of FHIR and its performance vis-a-vis other healthcare standards. Comparisons between OpenEHR, ISO 13606,

Table 2: Comparison of OpenEHR, ISO 13606 and FHIR standards

Service	Health data platform service	Preferred standards
Modeling	Modeling and formalization of clinical-domain concepts	OpenEHR and ISO[a] 13606[b]
Persistence	Detailed and multipurpose data persistence	OpenEHR
Exchange	Complex and full-meaning data exchange	ISO 13606 and HL7[c] FHIR[d,e]
Exchange	Simple and agile point-to-point data exchange	HL7 FHIR
Querying	Data query according to complex semantic restrictions	OpenEHR
Implementation	Design of data entry components in EHR[f]	OpenEHR
Implementation	EHR repository for clinical decision support processes	OpenEHR
Implementation	EHR repository for populating RWD[g] repositories	OpenEHR
Implementation	Semantically interoperable platform for heterogeneous source EHRs	ISO 13606 and HL7 FHIR[b]
Implementation	Semantically interoperable exchange between EHR applications	HL7 FHIR
Implementation	Semantically interoperable exchange between EHR and RWD repositories	HL7 FHIR

OMOP and FHIR have been made (Ayaz et al., 2023; Mullie et al., 2023; Rinaldi and Thun, 2021; Cremonesi et al., 2023; Sinaci et al., 2023). A study involving 10 experts comparing OpenEHR, ISO 13606 and FHIR concluded that i) these three standards are functionally and technically compatible, and therefore can be used side by side; and that ii) each of these standards have their strengths and limitations that correlate with their intended use as summarized in the Table 2.

For an infectious diseases dataset with a limited scope, OpenEHR, OMOP and FHIR have been compared and found all to be equally suitable (Rinaldi and Thun, 2021). Comparing OMOP and FHIR, the latter has been found to support more granular mappings required for analytics and was therefore chosen as the standard for the CODA project (Mullie et al., 2023).

Although FHIR was originally designed only for exchange between systems, we propose to use it as the common data model for the design presented here for the following reasons:

- Industry adoption has significantly increased, as exemplified by FHIR-based offering by major cloud providers such as Google, Azure and AWS. Also, Africa CDC has explicitly chosen FHIR as the preferred standard;
- The widespread availibility of the Bulk FHIR API (Mandl et al., 2020; Jones et al., 2021) enables bulk, fileb-based nbatchwise processing for analytics using the lakehouse architecture as detailed in the next section;
- The concept of FHIR Profiles allow localisation to tailor the standard to a specific use case. A profile defines rules, extensions, and constraints for a resource. We posit that the possible penalty of this flexibility, namely having to manage different FHIR versions and/or profiles, is less of an issue in the context of LMICs where first priority is to exchange datasets such as the International Patient Summary (IPS) that are less complex compared to the requirements for high income countries;
- Being based on webstandards, the FHIR standard lends itself best for

further separation of concerns as envisioned by the composable data stack. This is an important enabler for the downward scalability of the solution;
- With its inherent, graph-like nature, FHIR can be readily incorporated into the principles of FAIR data sharing, where FHIR-based data repositories can be integrated in an overarching netwerk of FAIR data stations (Sinaci et al., 2023; Pedrera-Jiménez et al., 2023).

Possible risks pertaining to the use of FHIR as the common data model, most notably the possible incompatibilities and/or high costs of maintenance in supporting different versions, will be addressed in the Discussion.

3.2. Open architecture: extending OpenHIE with a composable data stack

3.2.1. Evolving the data lakehouse to a composable data stack

Data management and analytics platforms have undergone significant changes since the first generation of data warehouses were introduced. Recent studies have shown that the current practice has converged towards the lakehouse as one of the most commonly used solution designs (Armbrust et al., 2021; Hai et al., 2023; Harby and Zulkernine, 2022). Lakehouses typically have a zonal architecture that follow the Extract-Load-Transform pattern (ELT) (Hai et al., 2023) where data is ingested from the source systems in bulk (E), delivered to storage with aligned schemas (L) and transformed into a format ready for analysis (T). The discerning characteristic of the lakehouse architecture is its foundation on low-cost and directly-accessible storage that also provides traditional analytical DBMS management and performance features such as ACID transactions, data versioning, auditing, indexing, caching, and query optimization (Armbrust et al., 2021). Lakehouses thus combine the key benefits of data lakes and data warehouses: low-cost storage in an open format accessible by a variety of systems from the former, and powerful management and optimization features from the latter.

With respect to current implementations of lakehouse data platforms, we observe a proliferation of tools with as yet limited standards to improve technical interoperability. In the analysis of Pedreira et al. (Pedreira et al., 2023) the requirement for specialization in data management systems has evolved faster than our software development practices. This situation has created a siloed landscape composed of hundreds of products developed and maintained as monoliths, with limited reuse between systems. It has also affected the end users, who are often required to learn the idiosyncrasies of dozens of incompatible SQL and non-SQL API dialects, and settle for systems with incomplete functionality and inconsistent semantics. To remedy this, Pedreira et al. call to (re-)design and implement modern data platforms in terms of a 'composable data stack' as a means to decrease development and maintenance cost and pick-up the speed of innovation.

While the lakehouse architecture separates the concerns of compute and storage, the composable data stack takes the separation of concerns is taken one step further. A composable data system (Figure 1), not only separates the storage (layer 3) and execution (layer 2), but also separates the user interface (layer 1) from the execution engine by introducing standards including Substrait for Intermediate Representation (standard A) and Apache Arrow (standard B and C). The composable data stack can be implemented with current open source technologies (Figure 2). As an example, the Ibis user interface is currently sufficiently mature to offer a standardized dataframe interface to 19 different execution engines.

Figure 1: Composable data stack

3.2.2. *SQL-on-FHIR v2 as an intermediate representation for FHIR data in tabular format*

The premise of separating the user interface from the execution engine is directly related to the key objective of the SQL-on-FHIR project (https://build.fhir.org/ig/FHIR/sql-on-fhir-v2/), namely to make large-scale analysis of FHIR data accessible to a larger audience, portable between systems and to make FHIR data work well with the best available analytic tools, regardless of the technology stack. However, as FHIR is represented as a graph of resources, with detailed semantics defined for references between resources, data types, terminology, extensions, and many other aspects of the specification. To use FHIR effectively analysts require a thorough understanding of the specification. Most analytic and machine learning use cases require the preparation of FHIR data using transformations and tabular projections from its original form. The task of authoring these transformations and projections is not trivial and there is currently no standard mechanisms to support reuse.

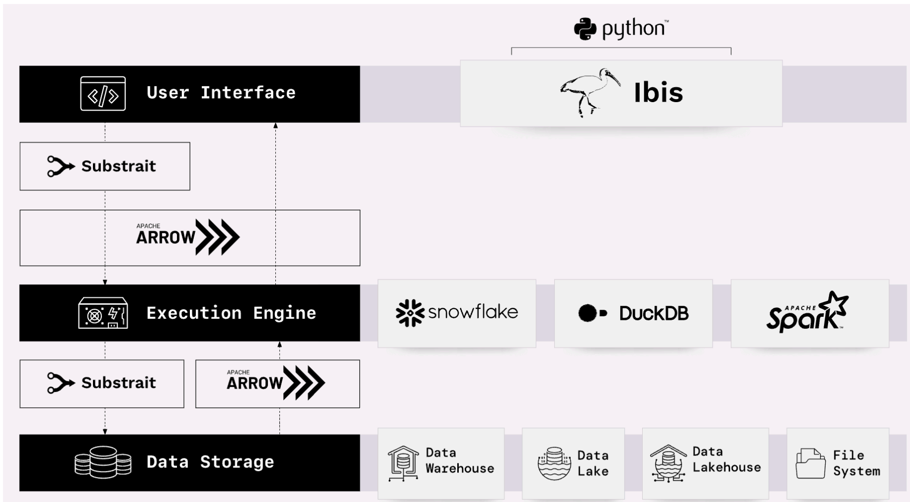

Figure 2: Examples of implementations of the composable data stack

The solution of the SQL-on-FHIR project is to provide a specification for defining tabular, use case-specific views of FHIR data. The view definition and the execution of the view are separated, in such a way that the definition is portable across systems while the execution engine (called runners) are system-specific tools or libraries that apply view definitions to the underlying data layer, optionally making use of annotations to optimize performance.

3.2.3. Extending OpenHIE with a FHIR-based composable data stack

We propose to extend the OpenHIE architecture with a "Data and Analytics Services" domain with 5 services by synthesizing the architecture of Hai et al. (Hai et al., 2023) and the composable data stack (Pedreira et al., 2023) (Figure 3, Table 3).

Table 3: Definition of Data and Analysis Services

Service	Functional requirements
Ingestion	• Metadata extraction • Metadata modeling
Storage	• File-based blob storage
Query & Processing	• SQL-on-FHIR Runner • Execution engine on tabular data as defined in composable data stack
Maintenance	• SQL-on-FHIR View defintions • Maintenance-related functions as defined by Hai et al.

Service	Functional requirements
Exploration	• Interactive computing environment (Granger and Perez, 2021) • Capability to participate as a node in a federative learning network, including MPC

3.2.3.1. Ingestion.

Default workflow is extraction of data from SHR using Bulk FHIR API. Data contains metadata (incl. FHIR versions) and fully qualified semantics, for example, coding systems. Despite this, metadata extraction and metadata modeling is still required to meet the FAIR requirements. Issues that need to be solved by these services:

- To prepare for future updates of FHIR versions
- Implement late-binding principle of having increasingly more specific FHIR profiles as bulk FHIR data propagates through lakehouse

3.2.3.2. Storage.

- from ndjson to parquet
- possibly used delta lake for time versioning
- separation of storage from compute not only for benefits of lower TCO, but also be ready for federated learning and MPC in future

3.2.3.3. Query & Processing.

- fit in structure of OpenHIE specification
- check which workflows are related to analytics
- Hai calls this 'Maintenance'

3.2.3.4. Maintenance.

- SQL-on-FHIR Views provide new standard to support mADX aggregate reporting
- Maintenance-related functions remain the same
- NB: orchestration falls under data provenance

3.2.3.5. Exploration.

3.3. Open technologies: available digital public goods

Many components of the OpenHIE specification are now available as a digital public goods. Table 4 lists components that are currently available for implementing the OpenHIE framework using open source, digital public goods that are compliant with the FHIR standard, illustrating the maturity of this ecosystem and development community. With the launch of the Instant OpenHIE configuration toolkit(Ins, 2024), it has become easier to set up, explore and develop HIEs thereby reducing costs and skills required for software developers to

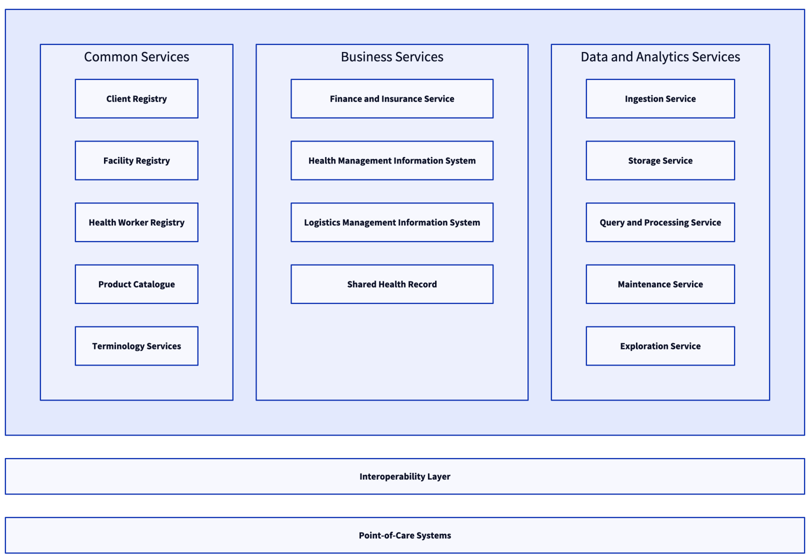

Figure 3: Proposed extension of the OpenHIE architecture that includes "Data and Analytics Services" as an additional service domain.

deploy an OpenHIE architecture for quicker solution testing and as a starting point for faster production implementation and customisation. Several frameworks are available that offer a set of preconfigured components out of the box, such as for example:

- the "Open Smart Register Platform" (OpenSRP), that focuses on providing a mobile-first platform, including a FHIR native app designed to support the WHO Smart Guidelines
- the OpenHIM Platform, a reference implementation of the Instant OpenHIE framework, providing an easy way to set up, manage and operate various HIE configurations

4. Evaluation

4.1. OpenHIM platform

- View generation in different packages, not portable
  - Logstash for bulk
  - Kafka for streaming
-

4.2. ONA Canopy

4.3. Momcare programme

MomCare was launched in Kenya (Huisman et al., 2022; Sanctis et al., 2022) and Tanzania (Shija et al., 2021; Mrema, 2021) in 2017 and 2019 respectively, with the objective to create transparency on the journeys of pregnant mothers. The programme is built on three pillars: journey tracking, quality support and a mobile wallet (Figure 4). MomCare distinguishes two user groups: mothers are supported during their pregnancy through reminders and surveys, using SMS as the digital mode of engagement. Health workers are equipped with an Android-based application, in which visits, care activities and clinical observations are recorded. Reimbursements of the maternal clinic are based on the data captured with SMS and the app, thereby creating a conditional payment scheme, where providers are partially reimbursed up-front for a fixed bundle of activities, supplemented by bonus payments based on a predefined set of care activities.

5. Discussion

5.1. Openness of data platforms

We specifically address the notion of openness of HDPs in LMICs in terms of the design-related questions put forward by de Reuver at al.11:

- Object of openness: what data-related resources should data platforms make available when opening up (e.g. data, data products, datadriven insights, analytics modules)? Which user groups derive value from accessing data-related resources from data platforms (e.g. data providers, data users, intermediaries, developers)?

Table 4: Overview of current open source implementations of components included in the OpenHIE specification that are FHIR-compatible. The category Analytics Services is not a part of the original OpenHIE and is discussed in the paper. Point-of-Service systems are excluded for brevity. A systematic review of such digital public goods is beyond the scope of this document.

Category	**Component**	**Digital public good**
Interoperability layer (IOL)		OpenHIM
		OpenHIM Platform
Registry Services	Client Registry	SanteMPI
		JeMPI
		OpenCR
	Facility Registry (FR)	Global Open Facility Registry (GOFR)
	Health Worker Registry (HWR)	iHRIS
	Terminology Service (TS)	OCL Terminology Service
	Product Catalog (PC)	...
Business Domain Services	Shared Health Record (SHR)	HAPI FHIR
		Fhirbase
		FHIR Server for Azure
		I-TECH-UW SHR
	Health Management Information System	DHIS2
	Finance and Insurance Service (FIS)	OpenIMIS
	Logistics Management Information System (LMIS)	OpenLMIS
Analytics Services	Analytics-on-FHIR	Open Health Stack: FHIR Data Pipes
		Pathling
	Dashboarding	Apache Superset
Generic	Identity & Access Management (IAM)	Keycloak
	User administration	FHIR Web
	Gateway & proxy	FHIR Information Gateway
	Configuration and deployment	Instant OpenHIE

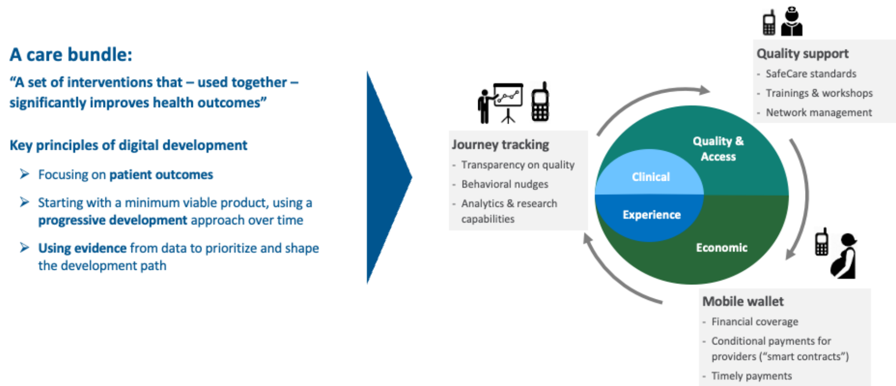

Figure 4: Overview of the Momcare programme

- Unit of analysis: what is platform-to-platform openness in the context of data platforms, given the expectation that different HDPs will emerge at various aggregation levels? How do we distinguish meta-platforms, forking, and platform interoperability?
- Risk of openness: What are the novel (negative) implications of opening up data platforms? How can reflexivity in design help providers to resolve the negative implications of openness?

5.2. *Comparison with HMIS component*

- Workflow requirements: Report aggregate data (link): receiver is HMIS, mADX
- Functional requirements: https://guides.ohie.org/arch-spec/openhie-component-specifications-1/openhie-health-management-information-system-hmis

Requirements are similar, but implementation differs: Datamodel is non-FHIR, focused on DataValue, which conceptually equates to FHIR Measure

5.3. *FHIR and FAIR*

- How does FHIR relate to approaches taken by the FAIR community, which tend to take more an approach of using knowledge graphs. For example, VODAN Africa (Gebreslassie et al., 2023; Purnama Jati et al., 2022).
- FAIR principles vs FHIR graph: is FHIR a FAIR Data Object

5.4. *Attribute-based access control*

- TO DO: if you have generated flattened SQL tables, how are you going to manage security?
- Cerbos, attribute based on lineage or anonymized tables

5.5. Federated learning and multiparty computation

- data stations??!

6. Abbreviations

ELT	Extract, Load and Transform
FAIR	Findable, Accessible, Interoperable and Reusable
FHIR	Fast Healthcare Interoperability Resources
HDP	Health data platform, explicitly differentiated from health digital platform
HIE	Health Information Exchange
FL	Federated learning
LMIC	Low- and middle income countries
PET	Privacy-enhancing technologies

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