IHE Work Item Proposal (Short)

# **Proposed** Work Item: Profile for Aggregate Health Data Exchange

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# The Problem

In many countries in the world the most important flow of electronic health information is health facility level aggregate data. This being particularly so where there is no electronic facility management system or EMR. These aggregate dataelements (eg. number of vaccinations given, number of live births, number of new ebola cases etc) are used in the construction of indicators. The data proves vital in the fields of public health, monitoring and evaluation and health systems management. Practice around the definition of routinely reported minimum datasets is well established.

Whereas systems which collect and process such data are also long established in the field, we increasingly see other electronic sources of data emerging - EMR systems, Health Worker registries, Logistics management systems, mobile phones etc. There is, as yet, no widely adopted formal standard for the generation and exchange of such aggregate datasets from these systems.

# Key Use Case

There are many exemplary use cases. The following are two motivating examples:

Sierra Leone has a functioning HMIS as well as an IHE Care Services Discovery (CSD) compatible “infomanager” database containing facility and health worker data. One of the datasets in the Sierra Leone HMIS is concerned with human resource data (How many doctors, how many midwives, how many nurses etc). Currently this data is entered quarterly into the HMIS via a paper form at the facility level. This report can instead be extracted from the CSD Infoman using a CSD ad-hoc query. Currently this can be done and posted to the HMIS using a non-standard format and api.

Rwanda has a well-functioning routine health management information system (HMIS) which collects monthly routine reports from all health facilities in the country. These reports include a dataset related to the Ante-Natal Care program. Alongside, Rwanda has also implemented a Health Information Exchange which currently collects transactional data related to the ANC program in one district as part of a national shared health record. Currently health workers in the facilities enter the transactional data into the patient level system and, at the end of each month, calculate aggregate data through the use of paper registers and tally sheets. This is effectively a double entry system. The aggregate data (including dataelements such as “ANC new registrations”, “ANC 3rd visit”, “ANC HIV tested” etc) can be calculated from the shared health record and sent electronically to the HMIS. Currently this is done using a non-standard format and api.

# Standards & Systems

The rationale and architectural approach is in line with the widely used health information system strengthening work of the Health Metrics Network (HMN) Framework[[1]](#footnote-2) which is applied in many countries.

Similar work at representing aggregate health data was attempted by the WHO back in 2010 using a profile of the ISO SDMX standard. This work provided valuable experience and insight into the problem domain, but failed to gather much traction due primarily to its complexity and underlying assumptions of the nature of both the systems and the data.

The simple 4-tuple case of:

* dataelement: a coded concept that is being measured
* location: the health facility, health organisation unit at which the data was collected/measured
* time-period: the time of measure or period/interval over which the data collection occurred
* value : the numerical value of the measurement

can be adequately profiled using csv and relatively simple xml and json. It is envisaged that implementations can and will extend this simple base with additional implementation specific attributes. Such extensions might be candidates for additional profiling in subsequent versions of the current proposal.

There are a number of existing formats, protocols and APIs which can be used in the exchange of metadata, specifically codes for the dataelements and health organisation units. These include IHE SVS, IHE DEX as well as SDMX DSDs, RDF (as in RDF Datacube), CTS2, CSV and emerging possibilities with FHIR coded value sets. It is not the intention in this work proposal to prescribe solutions for metadata exchange at this stage, only to note the options which exist and provide guidance in terms of informative text as to their use.

Consumers of aggregate data messages would largely be sub-national, national, regional and international health information system data warehouse applications. Producers would include health worker registries, EMR systems, civil registration systems, logistics management systems, mobile data collection applications for community health workers etc.

# Discussion

This proposal is submitted as part of a broader USG/PEPFAR-funded project to strengthen health information systems in developing countries through the collaborative development of an open HIE architecture. All participants in this project are committed to the use of open standards and have further identified IHE as an organisation which can play a useful role to galvanize, regulate and support such activity.

We have identified this problem of aggregate health data exchange as something which is not currently adequately covered in existing profiles. Possibly this is because systems and processes in this domain are typically dominant in developing countries who have been largely outside of the mainstream of IHE activity in the past. Such data flows are critical to the functioning of health systems in many countries.

What we require is a simple, lightweight profile which can meet requirements in a variety of resource-constrained and technologically diverse settings. We believe that developing this profile through the QRPH committee of IHE will be immediately beneficial to the health management workflows which depend on facility-level aggregate data to compute indicators for local, national and international use.

1. . http://www.who.int/healthmetrics/documents/framework/en/ [↑](#footnote-ref-2)