HOW DO THE DUTCH ZIBS COMPARE WITH OPENEHR AND FHIR AND HOW DOES CUMULUZ FIT INTO THIS?

I am increasingly asked why we in the South Limburg Region choose openEHR, since the national policy[1] is FHIR, after all? My answer is that we do not opt for openEHR alone, nor do we opt for FHIR alone. We use (information) standards for the purpose they are intended for. How do the healthcare information building blocks (ZIBs) fit into this? And how does that fit into the CumuluZ[2] initiative? In this blog I try to explain things clearly.

To contextualize the openEHR, FHIR and ZIB standards, I first describe the principles and objectives that these 3 standards used as a basis for developing them. From this perspective it will become clear that the origins and usefulness of these standards are very clear and contribute to what we now call interoperability. The agreements made in the IZA deal, with regard to the IT component, make interoperability and the associated IT architecture (with the correct international standards) increasingly important. The Dutch Ministry of Health (MinVWS) also sees the urgency to make choices in standards and provide direction to the National vision on the health information system. Choosing CumuluZ only increases the urgency for the right standards.

My firm opinion is that choices have to be made, but that they must be substantiated and taken with the right substantive arguments. It is also not the case that one standard is better than the other. It's about choosing the right standard for the right purpose. In this blog I try to include the reader in the discussion between ZIBs, FHIR and openEHR. Nictiz (Antje Derksen, Heleen Hoogvliet, Gerda Meijboom and Paul Oude Luttighuis) wrote a nice and clear document about information standards in 2023[3]. In 2022, Nictiz (Jeroen van Ginneken, Wouter de Haan and Gé Klein Wolterink) described the vision on ZIBs[4]. A Zib-transition project has now been started[5] within Nictiz. In this blog I regularly quote from these documents.

To provide a more complete picture, this blog also briefly describes the role of medical documents. In addition to separate structured information objects (discrete data), a lot of information based on documents is still exchanged within healthcare. We will therefore have to include these in the total spectrum of exchanges.

Documents can be found in many forms, such as patient letters, referral letters or notes, but also images and videos. The HL7CDA standard describes the structure of a Document. HL7CDA is widely used in data exchange between, for example, EPIC and Chipsoft.

Furthermore, I make a connection with the architecture drawn up by the CumuluZ Coalition[6]. Isn't CumuluZ FHIR or is this more nuanced?

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[1] https://open.overheid.nl/documenten/ronl-72d9d941c7ee7ae2c58c236290e152b22939448d/pdf
[2] https://www.dutchhealthhub.nl/artikel/iza-partijen-kiezen-bindende-blauwdruk-voor-databeschikbaarheid/
[3] https://nictiz.nl/app/uploads/2023/07/Verkenning-Standaarden-voor-informatiemodellen-v1.01-1.pdf
[4] https://nictiz.nl/app/uploads/2022/04/220420_Visie-op-zibs.pdf
[5] https://nictiz.nl/wat-we-doen/activiteiten/zibs/zib-transitie/
[6] https://digitaleuitwisseling.nl/attachments/cumuluz_ruud-bongers-pdf.393/

THE SPECIFICATION CANVAS

In the "exploration of standards for information models", Nictiz has developed a specification canvas. This canvas, in which the processing and exchange of information functions are compared to healthcare content and technical specifications, indicates where the various standards are located. This canvas also makes it clear where the differences are. Looking at the model, I have taken the liberty, for this note, of making a small adjustment to it. Nictiz describes two columns.
One of exchange and one of processing. Nictiz describes in her report that by processing they mean the process of recording. For me, however, processing is more. This also includes mapping between technical and information models and there are no standards for this yet. This mapping will not always happen in the EHRs. Exchange systems can also play a role here. In order not to make it too complicated, I therefore stick to storage instead of processing. Furthermore, Nictiz indicates that the canvas model is based on the 5-layer interoperability model, developed by Michiel Sprenger. I have therefore aligned the names of the layers in the model with this interoperability model.

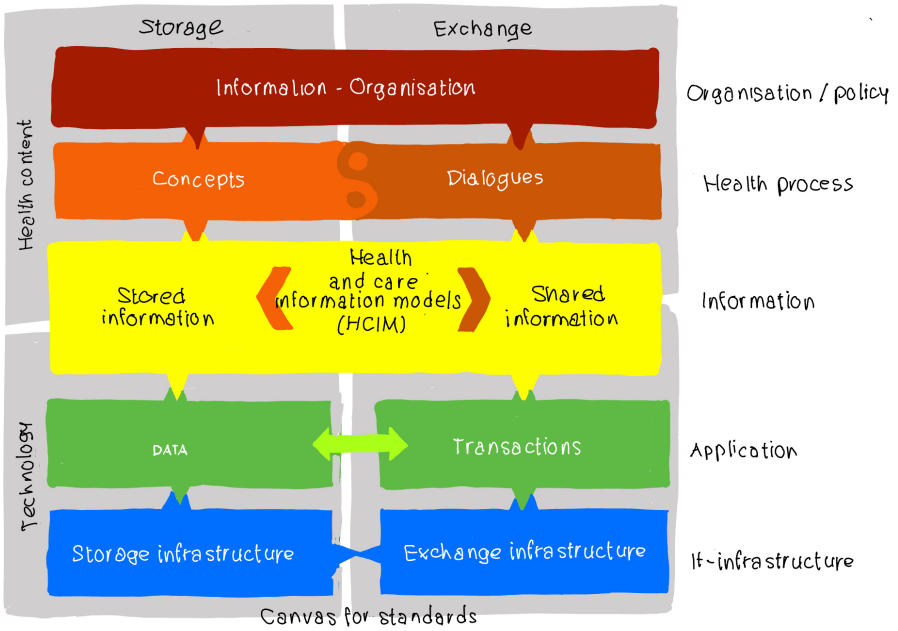


Figure 1: Specification Canvas

FHIR

Much has been written about FHIR. For this memo I use an article[7] by Alexander Henket, HL7 Expert at Nictiz.

HL7 Fast Health Interoperability Resources, FHIR, has every tailwind to become the standard for data exchange in healthcare. But what is FHIR?

Since exchanging the right data can be life-saving, good standardization is essential. If a patient has to deal with an acting general practitioner or a different healthcare institution than he is used to, his healthcare provider must have access to his accurate medical data as quickly as possible. This gives the relevant healthcare provider insight into the patient's medical history and can therefore make a better diagnosis. This requires the exchange of information between healthcare systems. This digital transfer requires a standard to link the healthcare systems and to ensure that the quality of data exchange is guaranteed.

[7] https://smarthealth.live/trendition/blog-fhir-de-standaard-voor-gegevensuitwisseling-in-de-zorg/

WHAT IS FHIR?

FHIR (pronounced like fire) is a standard for digitally exchanging data within and between healthcare institutions. Data exchange is currently possible with Edifact, HL7 version 2 and HL7 version 3 (including HL7CDA). HL7 FHIR, FHIR for short, has been the latest HL7 standard since 2011. Within the specification Canvas, FHIR will therefore be found in the exchange column.

DATA EXCHANGE

Edifact messages have existed the longest and are widely used in the first line between institutions, usually in a regional context. HL7v2 followed and is de facto the standard in the second and third line healthcare. HL7v2 is suitable for communication within an institution, and - with the right set of agreements - between institutions. HL7v3 mainly has national applications and is suitable for communication within and between institutions in healthcare. In America, HL7CDA is still the defacto exchange standard. HL7CDA is also the standard between EPIC hospitals and between EPIC and Chipsoft hospitals. Among other things, FHIR combines the simplicity of HL7v2 with the expressive power of HL7v3, by using Restfull as the defacto exchange standard. The Restfull standard, which is also widely used in other sectors, is based on the HTTP protocol, which forms the basis for requesting Internet web pages. This makes this protocol very simple and effective in terms of bandwidth use. Google, X (Former Twitter) and Facebook all use this Restfull protocol.

IMPLEMENTATION

FHIR is easier to implement with lower investments in time, people and money. This is due to the extensive public documentation, including checklists and validated examples for a variety of use cases. The availability of strong open source tooling including code generators for most popular programming languages helps vendors implement FHIR faster and more successfully than the aforementioned standards.

Because the development of FHIR has focused heavily on existing standards such as internet standards and security standards, which are also used in other sectors, this makes it easier to find affordable expertise.

MODELLING

FHIR was created to exchange data in a relatively simple way. The 80/20 principle applies here. In addition, the 3 developers of FHIR (Grahae Grieve, Llyde McKenzie and Ewout Kramer) have a technical, not a medical background. As a result, choices have been made in the models/architecture that are not completely medically compatible. In addition, the standard, which has many freedoms, leaves many implementation choices to the developers who incorporate FHIR. HL7 FHIR is also sometimes called the new HL7v2, due to the fact that there are still so many freedoms within the standard that agreements still have to be made between healthcare institutions. If you want to use FHIR at a national level, it is necessary that there is good governance. An agreement system in the field of FHIR profiles and versions is indispensable. Choices within the profiles are often made by technically trained employees and not always in consultation with doctors, which may result in a comparison of apples and oranges during transfer. To prevent this, agreements are made at national level about the FHIR profiles. For example, MedMij has drawn up an agreement system for data transfer to a PGO that describes how FHIR profiles should look like within the Netherlands. The choices that MedMij has made are typically Dutch choices and not international choices (after all, this is not regulated in FHIR). EPIC supplies its EPD to the international market and has defined various FHIR profiles. These profiles are in line with the wishes of their customers and with their EMR data model. The developers of EPIC have made different choices than in the Netherlands. In concrete terms, this means that a supplier that operates internationally must implement multiple implementations (profiles) for the same information

exchange. And then one can only hope that a country has set up good governance, otherwise a supplier can build its own FHIR implementation regionally or even between two healthcare institutions.

In the past, Epic had to build in FHIR resources[8] specifically for the Netherlands, even though they were already built into their system in a different way (see image). Of the approximately 350 standard FHIR profiles built into EPIC, only a handful are suitable for the Dutch Market. The MedMij specific FHIR resources have been developed especially for the Netherlands.

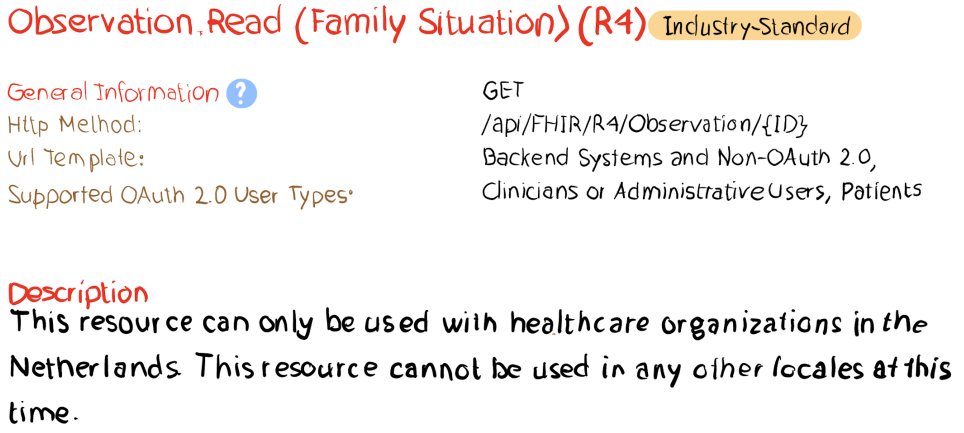


Figure 2: Description EPIC Implementation Family situation Special made for The Netherlands

ARCHITECTURE

To keep things simple, FHIR has chosen to view the logical data model, the technical model and the versioning as one whole. An adjustment in one of these aspects results in a completely new implementation. Many of the resources described are therefore not backward compatible. The FHIR community has also

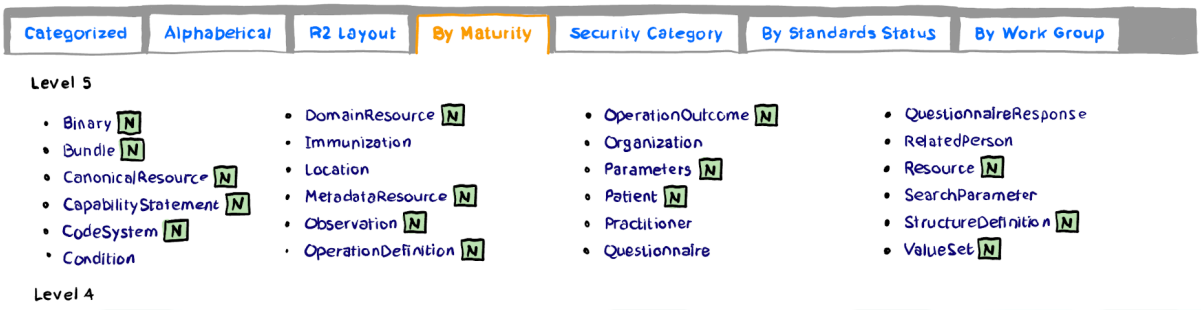


Figure 3: All Fhir resources which classified as level 5 or higher

recognized this and has defined Maturity levels. Resources at maturity Level 0 are still in an experimental phase and impactful changes may still be made, resources at Level 5 are reasonably stable. In addition, some Resources are labeled as Normative, which means that they remain backward compatible. With Resources that are normative, we can assume that they will no longer change and that only elements can be added. The latter is important if you want to create a life history file for the patient.

[8] https://fhir.epic.com/Specifications?api=10455

If you now look at the FHIR resources in Figure 3[9], it can be concluded that only the resources that are necessary for the technical operation of FHIR are normative. All healthcare content resources are not, except for the Observation resource. However, the Resource Observation is so broad that, although it is technically normative, suppliers have a lot of freedom to incorporate the care content in their own way. This is also necessary because, for example, a blood pressure measurement is seen as Observation, but also an Apgar Score. In practice, many different implementations have been made by developers from suppliers that do not match each other. National/worldwide agreements must be made here. Unfortunately, these appointments are very limited. Suppliers that operate globally will also not be in favor of building their own implementation for each country. This is also not wise given globalization and EHDS. Governance is therefore a critical success factor here at FHIR, which receives little attention in the standard.

This memo will be discussed in more detail later on the basis of the Apgar score, which is an elaboration of the Observation Resource, as indicated earlier. When reading, it should be realized that the Apgar score is a simple clinical example and the issues expressed here occur many times in other healthcare information models.

In addition, HL7 is still optimizing the resources within FHIR and minor changes such as attribute naming are being adjusted. For example, within the FHIR resource immunization in version 3, the attribute that identifies the healthcare provider is "Practitioner", the same element in version 4 is called "Performer". Although this may seem like a small change, it has a major impact on existing software tools and maintenance and testing by suppliers.

OPENEHR

In recent years we have heard more and more about the use of openEHR. Examples in the Nordics, London (OneLondon), Catalonia and Germany (HiGHmed) are appealing examples of this. The openEHR standard is also increasingly being embraced within the Netherlands. For example, the largest supplier (Nedap) in the home and elderly care (VVT) has embraced openEHR, but Code24 (often active in mental health care) has also based its implementations on openEHR. In addition, research by RSO Zuid-Limburg[10] in collaboration with MinVWS that openEHR could be a good solution for developments in the region, which also fits in with initiatives such as CumuluZ and Health-RI. RSO-ZL has now embraced openEHR as a key standard in their architecture.

WHAT IS OPENEHR?

OpenEHR is an open-source standard for the display and exchange of electronic patient records (EPDs). OpenEHR originated in the late nineties with a first implementation at the beginning of this century. It provides a framework for creating and managing electronic health records in a standardized and interoperable manner. OpenEHR was developed to improve the challenges of healthcare data

[9] https://www.hl7.org/fhir/resourcelist.html

[10] https://digitaleuitwisseling.nl/threads/in-dialoog-met-de-leveranciersmarkt.313/

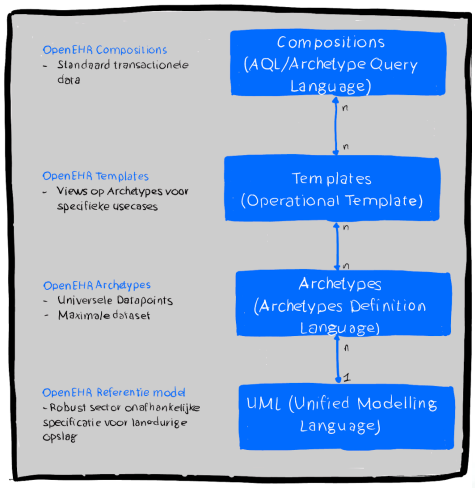


Figure 4: OpenEHR Architecture

interoperability, data sharing, and long-term data storage in the field of healthcare informatics. While FHIR primarily focuses on exchanging information, openEHR places more emphasis on storage. In the Canvas model you will also find the openEHR standard in the Storage column. OpenEHR is often seen as an open source data storage system. Indeed, there are many vendors and open source implementations of OpenEHR. But openEHR is also an Information standard.

OpenEHR is chosen and implemented in healthcare environments for several reasons:

DATA GOUVERNANCE ON LONG TERMS

Healthcare organizations must store and manage patient records for extended periods of time, sometimes spanning decades. OpenEHR's focus on versioning, management, and the separation of clinical content from the underlying technology makes it well suited for long-term data storage and maintenance. This long-term storage makes possible the life cycle file, which is crucial for research and the necessary developments in healthcare prevention. Where FHIR has focused on *80/20 rule for exchange*, openEHR has focused on *100% clinical models for storage*.

CLINICAL CONSISTENCY

OpenEHR promotes the use of archetypes and templates to define how clinical concepts are represented in electronic health records. This ensures that clinical data is structured and accurately recorded consistently and in context, reducing the risk of errors and improving the quality of care. OpenEHR has defined the governance of the clinical models, created by a global open community of clinical professionals, as a spearhead. The starting point was that a clinical model be as complete as possible.

DATA EXCHANGE/INTEROPERABILITY

One of the main motivations for adopting openEHR is to achieve interoperability in healthcare data. Healthcare systems often use diverse technologies, standards and data formats, making it challenging to share and exchange patient information. OpenEHR's standardized approach, including archetypes and templates, ensures that clinical data is consistently structured and can be shared seamlessly across systems, improving interoperability.

ARCHITECTURE

OpenEHR is flexible and is designed in such a way that it can quickly adapt to different use cases. openEHR's modular and service-oriented architecture enables healthcare organizations to build flexible and customizable EHR systems. Healthcare organizations can easily customize templates and adapt the underlying system to changing clinical requirements and workflows without significant disruption. Multiple suppliers can build functionalities on the same data platform.

The fact that the existing major EMR suppliers (Epic, Chipsoft, Cerner, etc.) are going to build up their applications so that the primary database of their products becomes OpenEHR seems to be a difficult if not impossible task (although you do see suppliers in the Mental Health (GGZ) and VVT doing this). already do. This also happens in Catalonia and the Nordics). I don't see that happening in the Netherlands in the next 20 years. However, the large EPDs do not have a good answer to the Regional issues (except that all healthcare providers must work with their product, so that no data has to be exchanged and everyone adopts the data model of the EPD supplier). The transmural care functionalities and therefore data interoperability are becoming increasingly important due to, among other things, the IZA deal. In these national/regional developments, openEHR will play a more important role in creating a competitive open market.

SUPPLIER NEUTRALITY

OpenEHR is an open source standard. This means that it is not tied to a specific supplier or to proprietary software. This supplier neutrality gives healthcare organizations more control over their EHR data and reduces dependence on specific suppliers.

WORLDWIDE APPLICABILITY

OpenEHR is designed to be applicable globally across different healthcare environments and regions. The flexibility and adaptability make openEHR suitable for different healthcare contexts, both in developed countries with advanced healthcare systems and in resource-constrained environments. The openEHR data models are standardized, translated into more than 34 languages and interchangeable.

SECONDARY DATA USE

The strong standardized Query Languages (AQL) make it easy to ask very complex questions to the database. It is easy to use this for the researcher who often does not ask questions at patient level, but wants to search for substantive cohort data.

FEDERATED MODEL

The autonomy of a healthcare institution is essential, especially within the Netherlands. In the Netherlands, a single national database was not chosen for a variety of reasons. Instead, the "Data at the Source" principle has been chosen. However, it is impossible, especially for secondary use and/or the use of data in prevention, to request all data from 258,016[11] healthcare institutions. The use of regional data platforms is therefore receiving increasing attention. Architectures from CumuluZ, Health-RI, KPMG/Microsoft but also Twiin are based on nodes to which data platforms are linked. The Ministry of Health, Welfare and Sport has also defined the use of data platforms as a course of action.

[11] https://bolddata.nl/nl/bedrijven/nederland/zorginstellingen/

HEALTH AND CARE INFORMATION MODELS (ZIB'S)

Health and care information models (in dutch ZIB's) are used to record substantive (non-technical) agreements for the purpose of standardizing information that is used in the healthcare process. The purpose of the standardization is that this information from the care process is reused for other purposes such as quality registrations, transfer or patient-related research. A healthcare information building block is an information model in which a healthcare concept is described in terms of the data elements that make up that concept, the data types of those data elements, etc.

Healthcare information building blocks are information models of minimal clinical concepts, each of which contains multiple data with an agreed content, structure and mutual relationship[12].

An important principle when defining a ZIB is to fit in as closely as possible with the healthcare professional's environment. This means that agreements at (care) information level, which support the care process, are leading and that agreements at application and infrastructure level are derived from this. We use healthcare information building blocks to record agreements about language unity in the field of healthcare information. A healthcare information building block is an information model in the form of a Detailed Clinical Model (DCM), in which a healthcare concept is described in terms of the data elements that make up that concept, the data types of those data elements, etc[13]. ZIBs are therefore logical information models. Care Information Building Blocks do not describe anything about the methods of exchange and storage. The first official publication of ZIBs was in 2015. We are now four versions further and the 2022 version is coming. A conscious decision was made not to describe an implementation model, which is why it has been placed in the Canvas model between the storage and the exchange column.

However, a ZIB is very similar to an Archetype of openEHR, but a ZIB is limited to:

- Logical model -> so no technical implementation is described
- Dutch situation-> Although based on international standards, clearly localized
- Reused (read exchange) -> not a 100% clinical model

Since 2015, 109 ZIBs have been drawn up. Number of HISs compared to 158 FHIR resources and 854 (translated into 34 languages) openEHR archetypes

[12] https://zibs.nl/wiki/ZIB_Hoofdpagina
[13] https://zibs.nl/images/2/2a/Architectuurdocument_Registratie_aan_de_bron_-_Volume_1_v1.1.pdf

RELATIONS BETWEEN ZIB'S OPENEHR AND FHIR

In the view below, Professor Rachel Dunscombe from the NHS Digital Academic has linked different information standards. Just like from the canvas model, you can recognize the different target areas of various standards from this model.

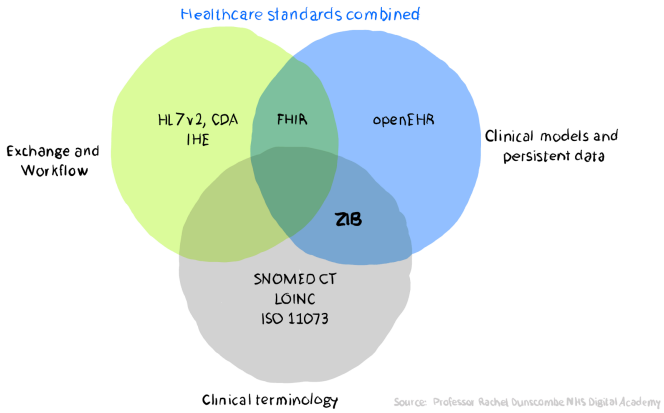


Figure 5: Relationship between Information Standards

Alastair Allen from Better (now EY) also clearly indicates that there are differences and similarities between the FHIR and the openEHR standard. He indicates that these two standards go well together to achieve an interoperable health system. He also describes in his blog[14] how FHIR stands in relation to a long life cycle file or long-term persistent storage. He indicates that the simplest use cases can really be done reallybe done with FHIR, but as soon as you have to scale up or the use cases become complicated, it becomes difficult to do this alone with FHIR. We will also see this in the way in which CumuluZ is now being tackled. The current CumuluZ Pilot is being built on FHIR. They do this with the BGZ (dutch version of patient summary) usecase.

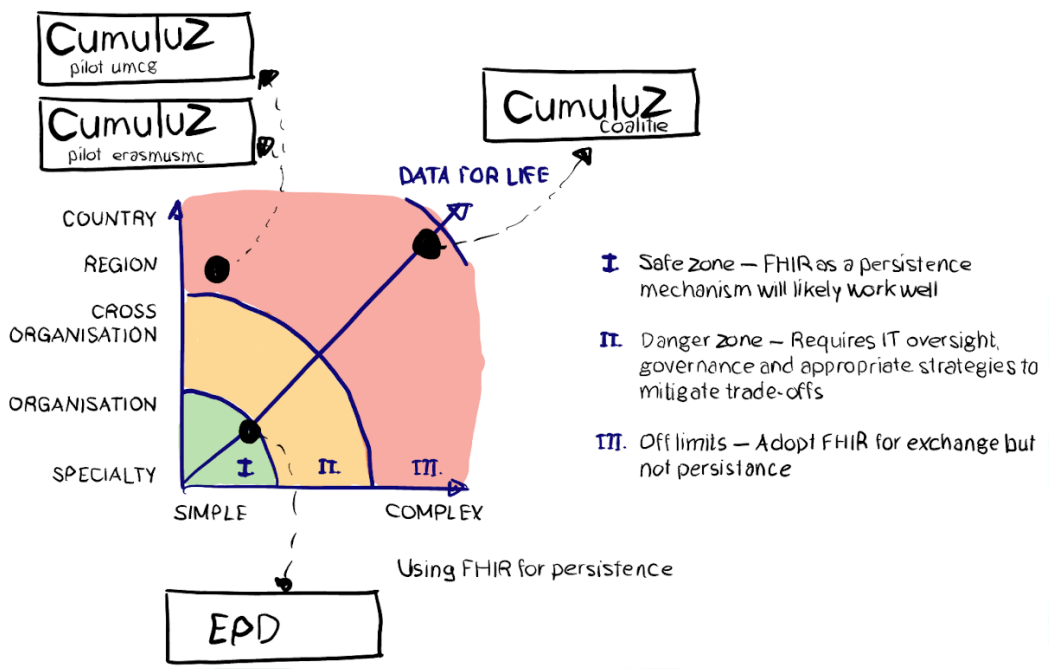


Figure 6: FHIR in scalability and complexity

[14] https://medium.com/@alastairallen/fhir-OpenEHR-2022-53716f837340

Because the Netherlands has modulated the BGZ in ZIBs and corresponding FHIR profiles have been written for MedMij, exchanging the BGZ and displaying it in a viewer will also be possible. But what if data still needs to be exchanged where no ZIB is available, or where there are many different FHIR profiles. Is this situation still sustainable? My belief is that that is not the case.

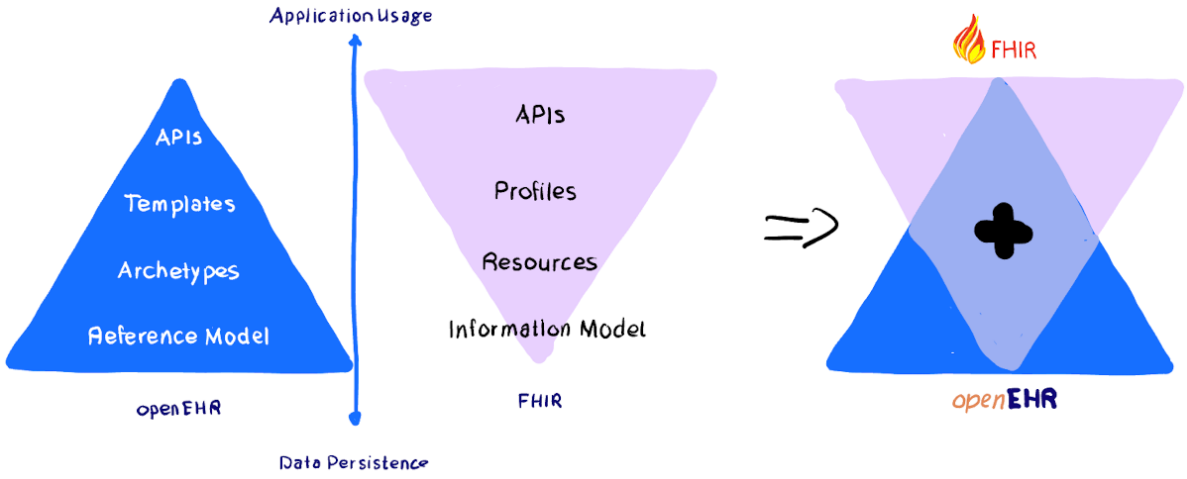


Figure 7: A other comparison between openEHR and FHIR

DOCUMENTS AND IMAGES

Finally, I would like to discuss the use of documents and images. If we look at the amount of data collected around the patient, we can say that 20% of the data is present in structured format in all healthcare information systems (i.e. EHRs). 80% is stored elsewhere in the form of documents or images. For the exchange of data, this information is necessary for adequate care and should not be forgotten. IHE has written a profile called XDS for the exchange of documents and images. This profile is well known within the radiology world and is widely used in the Netherlands. We can also use this same protocol for reports, letters, correspondence, etc. With the IHE profiles IHE MHD (mobile access to health documents) and the IHE ODD (On Demands Documents) we connect XDS to FHIR and vice versa. Since this memo is not specifically about the exchange of documents, I refer to the IHE guideline MDO Oncology MammaCare[15]. Within various. Epic implementations, a lot of transfer (EPIC Care-Everywhere) still takes place on the basis of documents, just like between EPIC and Chipsoft hospitals (HL7CDA documents).

[15] https://ihe-nl.org/wp-content/uploads/2022/09/IHE_MDO_Addendum_17_mei_2020_StatusDefinitief.pdf

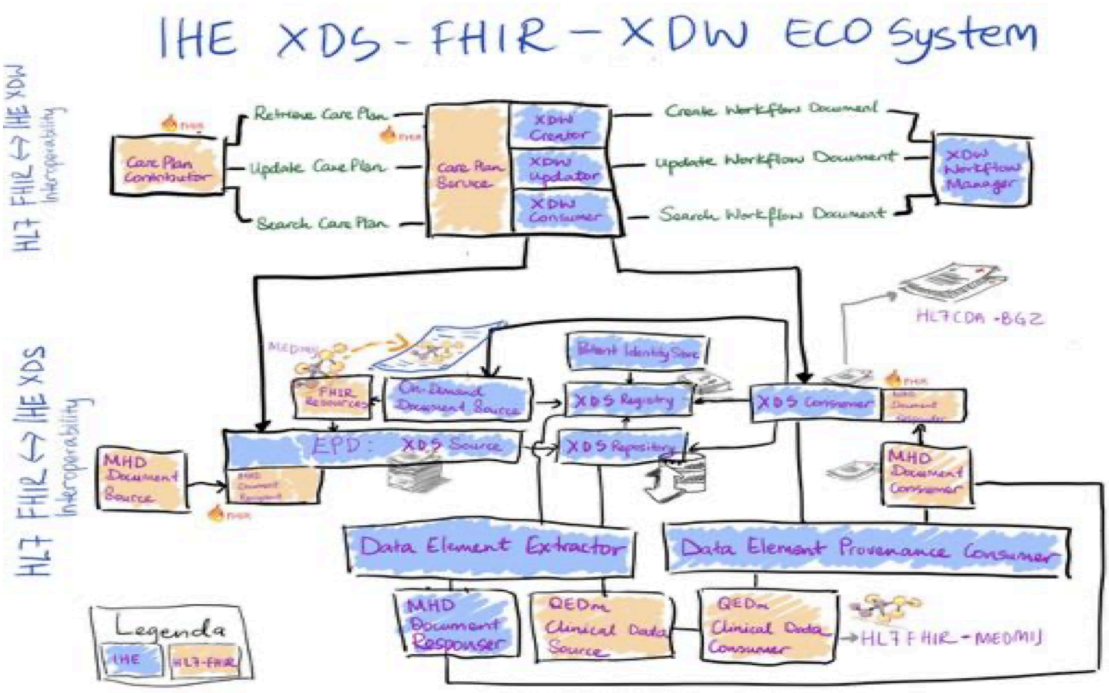


Figure 8: IHE XDS-FHIR-XDW Eco system

DUTCH NATIONAL VISION ON THE HEALTH SYSTEM AND DATA AVAILABILITY

The national vision on the health information system[16] has 4 guiding principles:

1. Data is available to the citizen and everyone involved in the healthcare network.
2. Data is available for secondary use with minimal registration burden for healthcare providers.
3. Data is separated from functionality.
4. Data availability creates an open market that stimulates innovation.

Data availability means that Data must be available, accessible and usable for prevention, the primary care process and secondary use. Citizens can participate in decisions about appropriate care for them and have all the information available to do so. With the right data, healthcare providers can provide better and safe care and have more options to promote health. The available data can be used to increase knowledge, provide well-founded, effective management and apply application-oriented innovation.

To achieve data availability within the Netherlands, VWS has embraced CumuluZ[17]. But what exactly is CumuluZ?

[16] https://open.overheid.nl/documenten/ronl-067c1ee3a9dd664a51f6e01221d37386571d8090/pdf

[17] https://open.overheid.nl/documenten/8e2d80a7-6b6e-440e-9ba7-1fc191072a8a/File

CUMULUZ

First of all, it must be made clear that CumuluZ is not a data platform. CumuluZ is an initiative of the collaborating university medical centers in the Netherlands. CumuluZ is working towards - a life cycle file (from care provider-oriented to patient-oriented data), - Network care (from referral and referral back to multidisciplinary collaboration), - Shared decision-making (From standard treatment pathways to appropriate personalized care), - Hybrid care (From treatment in the healthcare institution to the treatment at home), - Not exchanging but sharing (from document-based exchange/copying to real-time sharing of structured data), -care burden reduction & prevention (increasing labor productivity by sharing data and curing patients to prevention among citizens).

CumuluZ adds 3 elements to the information system. – All healthcare data in one (virtual) life cycle file, - Data system can be accessed independently in an open common data model with open APIs and – A platform for knowledge sharing.

To achieve this, CumuluZ has defined 5 phases.

1) Support. An important phase. The Dutch healthcare landscape is extremely fragmented. Many interests of suppliers, healthcare institutions, umbrella organizations, patient federations, etc. have their own opinions and need to be convinced. This phase has been successfully completed, meaning that CumuluZ's vision has been widely embraced and included by VWS in its policy frameworks. It is also fair to say that many questions remain open and that not everyone is happy with this decision.

2) Initiation. In the second phase, various testing grounds were set up and a number of user applications were launched. For example, Erasmus has the Digizorg APP and UMCG has the healthcare viewer. A lot of experience has been gained in both completely different testing grounds. Both pilot projects have demonstrated on a small scale with a small data set that the concept that CumuluZ stands for fits well with the long-term objectives of healthcare.

3) Realization. We are in this phase now. The collaborating university medical centers in the Netherlands have formed a coalition together with Santeon and the mProve hospitals to further develop the care platform. This CumuluZ coalition has described an architecture with associated principles. This will be financed from IZA funds, among other things.

4) Scaling up. After the healthcare platform has been created, healthcare institutions, researchers and patients are connected.

5) Innovation. Because CumuluZ ensures uniform secure access to data (APIs) for primary and secondary use, a fair and open market is created, in which not only the major suppliers play a role, but where national and international emerging innovative niche companies also have a fair get a chance.

CUMULUZ ARCHITECTURE

The architecture of CumuluZ consists of four layers. The top two layers define the functionalities, use cases and services that can use the data made available by the bottom two layers. The principle of CumuluZ is that the top two layers must be filled in by the market. To make this competitive and interesting for both new and old players, it is necessary that the bottom two layers provide standardized access, i.e. APIs. As my previous argument showed, FHIR is extremely suitable for sharing data. CumuluZ has therefore written in its initial memorandum that for the time being it will follow the Nictiz national policy for FHIR R4 standards for data exchange, supplemented with ZIBs. In concrete terms, this means that CumuluZ, together with Nictiz, will ensure standardized FHIR profiles (1 Apger profile instead of 50). To achieve this, a national FHIR Governance will have to be set up. Hopefully the ZIB transition program within Nictiz will address this.

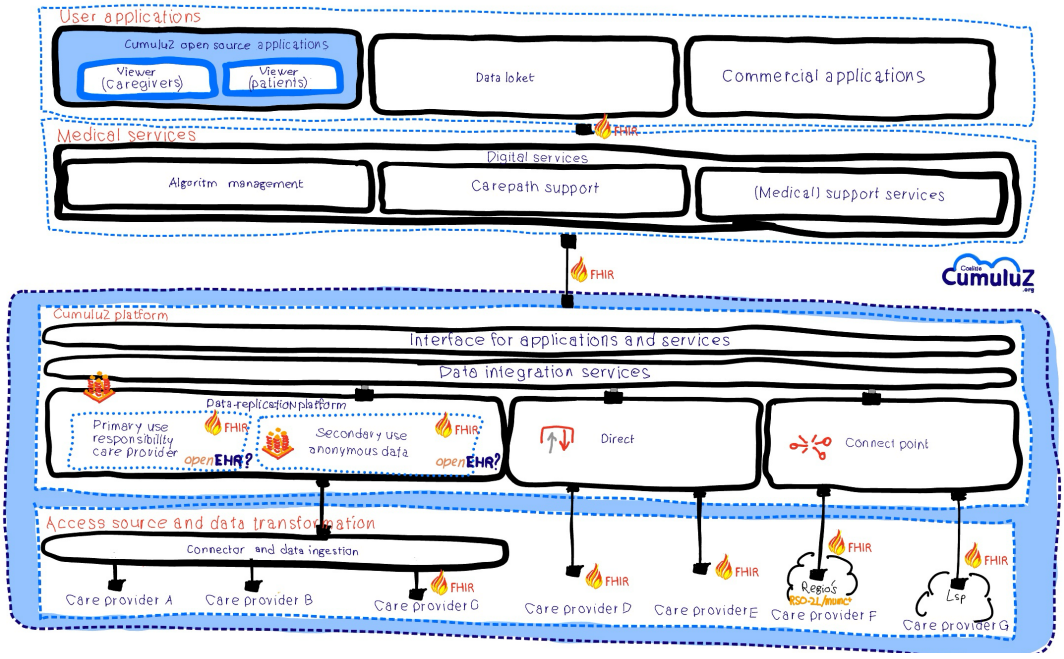


Figure 9: CumuluZ Coalition Architecture

The coalition also chooses FHIR for data storage. The coalition writes that this is in line with national policy. I dispute the latter. The national policy only concerns data exchange. Yet there are good reasons why FHIR was chosen in the first place. After all, a lot of experience has been gained in the testing grounds (all based on FHIR). In addition, a lot has been invested in existing testing grounds. Erasmus, UMCG, but also Santeon have built a platform on FHIR. All 3 solutions have their own FHIR implementations and therefore cannot be linked to each other, demonstrating that FHIR governance on profiles is a necessity.

The use cases in these testing grounds are so small that FHIR can work well (see also Figure 6). However, if we scale up in the number of use cases and number of data objects, you will see that FHIR is no longer sufficient. This concern is becoming increasingly important and that is why CumuluZ has indicated in its initial memorandum that it will further investigate openEHR and see whether and, if so, how openEHR can be incorporated into subsequent scenarios.

However, data storage in CumuluZ is only necessary for those healthcare institutions that cannot provide high-performance and open standards themselves. Houses that comply with the CumuluZ Standards for exchange (FHIR) do not have to use the storage realized by the Coalition. After all, there are three variants of linking to CumuluZ. Namely: - via Data replication - Direct link to individual home, - Via a Node (Region, LSP, Care Platform Chipsoft, etc.). See figure 9 for this.

RSO-ZL

RSO Zuid-Limburg works on regional assignments based on an architectural vision with leading views. The architectural vision is in line with the National Vision and the report Investigating the national network of infrastructures for data exchange in healthcare, which was written on behalf of the Ministry of Health, Welfare and Sport (D&A Medical Group, 2022)[18]. In its report, D&A Medical Group advocates a gradual growth towards a data-centric and distributed architecture, according to Figure 10.

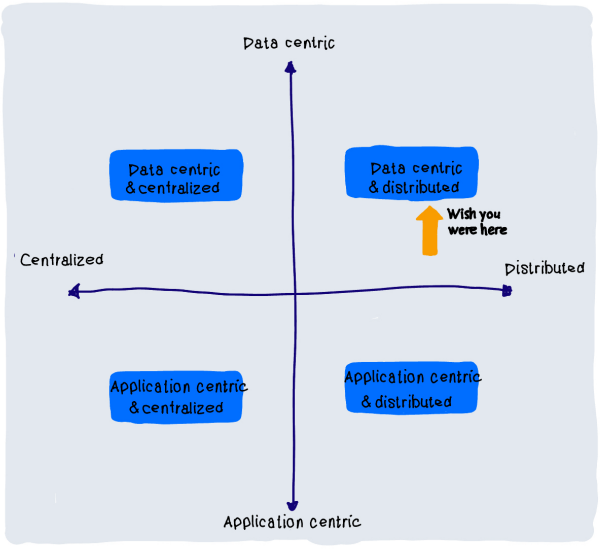


Figure 10: Matrix type exchanges

RSO Zuid-Limburg embraces this movement towards a data-centric and distributed architecture, but also sees value in application-centric and/or centralized approaches in specific healthcare profit-generating situations. The target architecture of RSO Zuid-Limburg is therefore flexible enough to temporarily support application-centric and more centralized applications where necessary.

RSO Zuid-Limburg also embraces the view that most healthcare gains in the future will be realized based on a data-centric approach: 'Data is for life, not just for one system'. RSO Zuid-Limburg chooses openEHR as a standardized format for vendor-neutral storage. This choice is partly inspired by the growing number of openEHR implementations already present in South Limburg.

Data availability will be achieved based on both openEHR Archetype Query Language (AQL) and FHIR (FHIR APIs on an openEHR CDR) and using the healthcare information building blocks (ZIBs).

Yet, albeit to a lesser extent, the application-centric approach to healthcare is also profitable, whereby the availability of data is achieved via use case-specific API's:

[18] https://www.rijksoverheid.nl/documenten/rapporten/2023/02/22/onderzoek-landelijk-netwerk-van-infrastructuren-voor-gegevensuitwisseling-in-de-zorg

- Many investments in data availability still have a use case specific character. The VIPP regulations, but also the Wegiz, emphasize the development of APIs for a specific use case/work process. RSO-Zuid Limburg wants to continue to utilize the value of this existing approach where possible and useful.

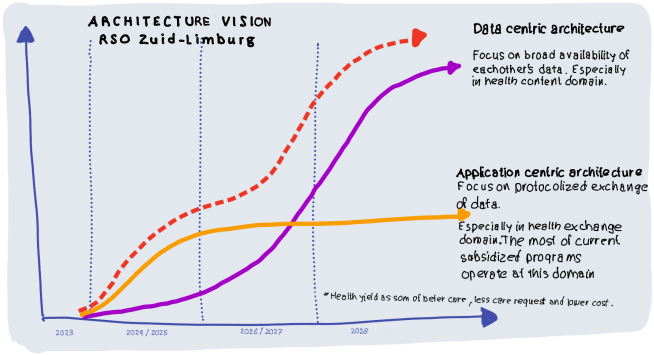


Figure 11: Architecture vision RSO Zuid-Limburg

- Some more transactional functionalities, such as scheduling appointments and other healthcare logistics functionalities, are ideally suited for use case specific APIs. The application-centric approach will retain value for this type of functionality for a long time.

RSO-ZL ARCHITECTUUR

The architecture of RSO-ZL consists of 3 layers. The top layer is the same as the top 2 layers of CumuluZ, where CumuluZ focuses mainly on national projects while the RSO-ZL is explicitly concerned with healthcare transitions and associated healthcare applications that help the region move forward. The bottom layer is very similar to the bottom layer of CumuluZ, where the RSO-ZL vision is that data is presented in an openEHR environment under the responsibility of the healthcare institution. The RSO-ZL. This vision arises from a market exploration[19] conducted by RSO-ZL in early 2023 in collaboration with VWS. Because all healthcare institutions in the Region receive an openEHR, it is possible to present these openEHR databases from different Suppliers as one, which has advantages for questions regarding research and secondary use. This virtual openEHR database (federation) will take into account the principles necessary for exchange. The Federation will use the NUTS standards.

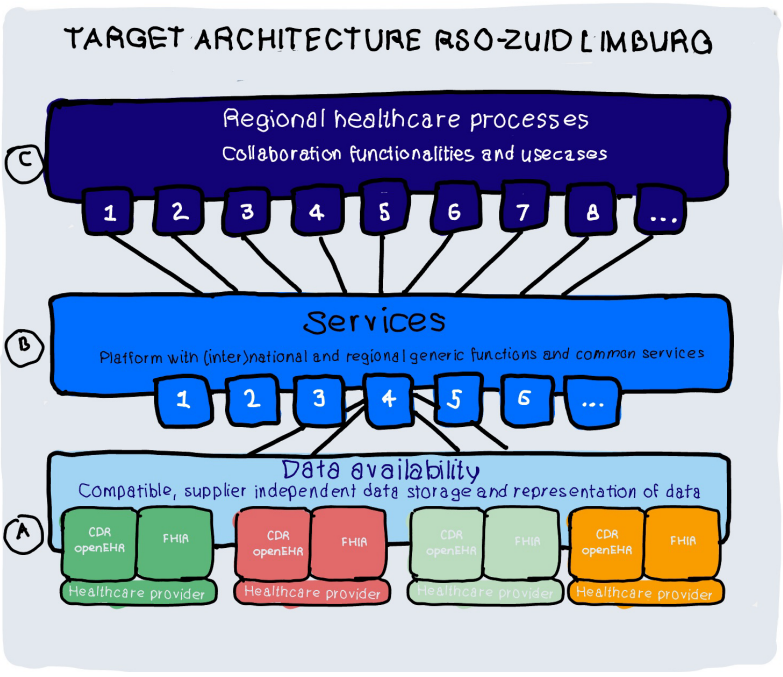


Figure 12: Architecture overview RSO-ZL

[19] https://digitaleuitwisseling.nl/threads/in-dialoog-met-de-leveranciersmarkt.313/

CUMULUZ, RSO-ZL, MUMC+

In the CumuluZ concept, the Region will profile itself as a Node that will exchange data based on FHIR R4, which is in line with the VWS decision. To achieve this, one FHIR gateway will be set up as a Regional facility within the Region. This FHIR gateway will support all CumuluZ FHIR profiles. This Gateway further relies on the virtual openEHR database. As a result, the individual members of the RSO-ZL do not have to invest in a CumuluZ connection themselves.

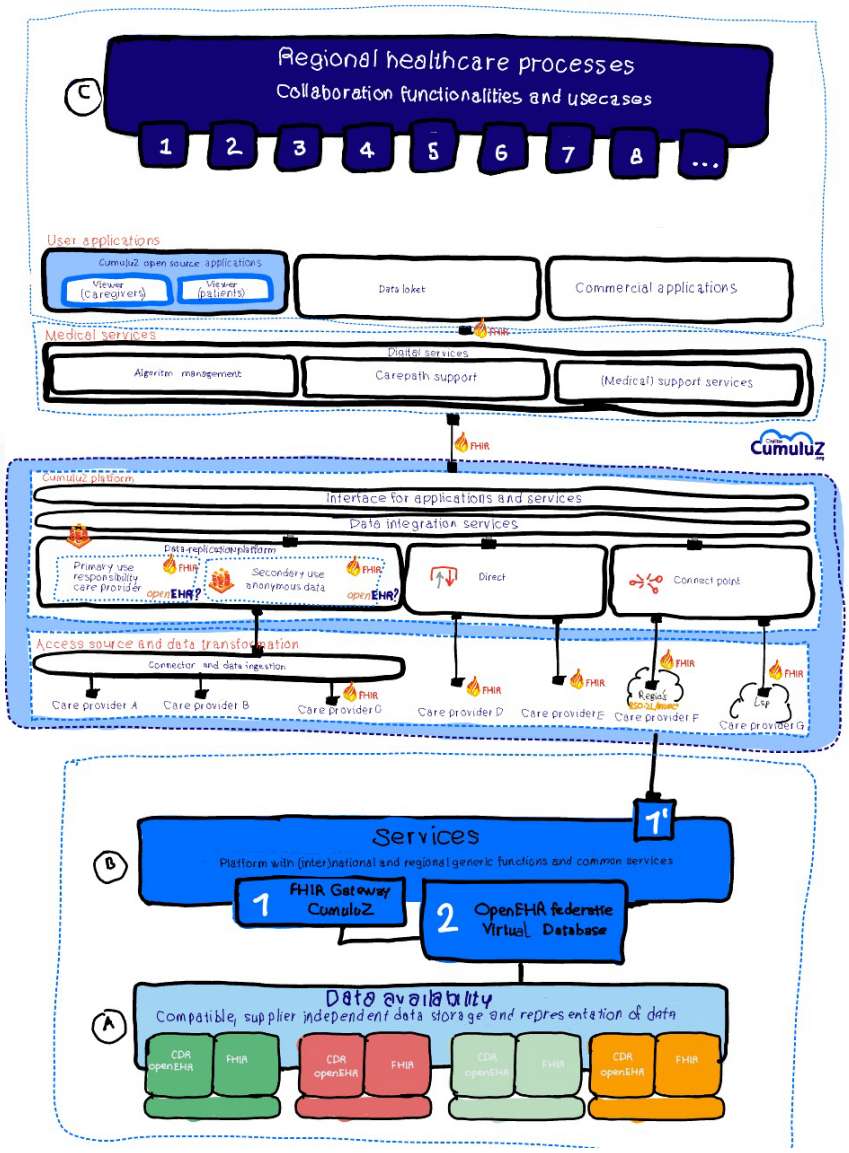


Figure 13: Architecture Cumuluz and RSO-ZL

The IBD (inflammatory bowel disease) case is being implemented as a pilot project together with CumuluZ and Health-RI. The intention is to connect MUMC+ and Zuyderland in the region on the basis of openEHR. This can be accessed via FHIR Gateway to CumuluZ, allowing the data from UMCG and Erasmus to be linked. This collaboration makes it possible to facilitate value-driven care based on national outcomes. With this pilot project we want to learn more about the differences, similarities and Governance regarding openEHR, FHIR and ZIBs.

CONCLUSION

As the Canvas makes clear, every standard has its purpose. I dare say that all three standards are necessary. However, it is true that there is often too large a gap between these standards and they often compete with each other rather than reinforce each other, precisely where they are good or less good. Much has already been written about the collaboration and synergy between OpenEHR and FHIR. Consider Alastair Allen's Blog from Better. But there are also nice articles about this on the Woland's Cat website.

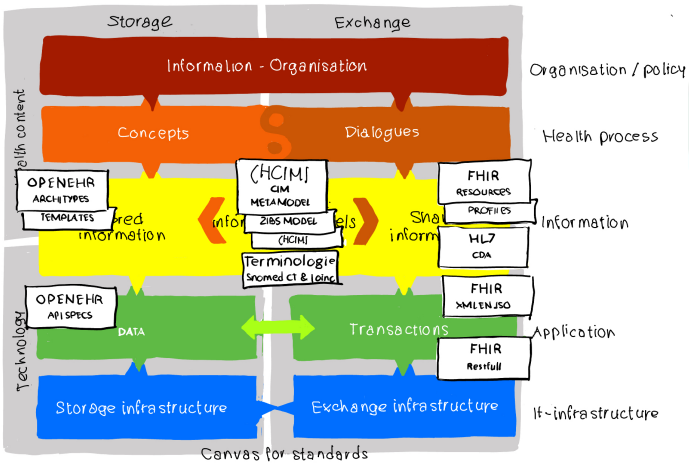


Figure 14: Canvas for Standards

OpenEHR and FHIR are global standards over which we in the Netherlands have little influence, although we can make a positive contribution here and there. In my opinion, the Netherlands is far ahead of other countries in terms of interoperability and therefore often plays a pioneering role in this area. ZIBs could be the lubricant, if they take into account not only the Dutch healthcare field when developing, but also the international technical standards openEHR and FHIR. Fortunately, Nictiz has recognized this and has now started a ZIB Transition Plan. In order to use FHIR properly nationally, national management of the use of profiles is necessary. Nictiz, driven by CumuluZ, will still have to take significant steps here. It has become apparent that all the separate VWS initiatives have not led to standardization of these FHIR profiles. Medmij, e-transfer, BGZ, Babyconnect, each prescribe their own profiles, with insufficient attention paid to overlap and connections. Still a lot of work to be done in this area.

Furthermore, the use of XDS for images, reports and other documents is recommended, provided that they are transparently linked to FHIR as soon as this data needs to be exchanged.

APPENDIX: SAMPLE APGAR SCORE

This appendix shows where problems will arise if you start using FHIR as a storage protocol and if the ZIBs do not provide a link between FHIR and openEHR. This piece is technical in nature, but clearly indicates at a technical level where and what problems arise. An explanation is given based on the Apgar score.

The Apgar score[20] is a study developed by doctor Virginia Apgar. This test measures the general condition of a newborn baby immediately after birth. The examination is performed at 1, 5 and 10 minutes after birth. The name of the test includes all letters of the name Apgar, which represent parts of the research. A: skin color (Appearance), or the color of the skin. For example, the skin color may be blue-gray or pale. This is not good. The skin color is good when it is normally pink. P: heart rate (Pulse), i.e. the pulse or heartbeat. No heartbeat is of course not good. Less than 100 beats per minute may be concerning. More than 100 strokes per minute is best. G: response to stimuli (Grimace), or the reaction to stimuli. If the baby doesn't respond, that's not good. If he shows some movement, that is better, but it is best if he starts crying or pulling in response to, for example, a (small) painful stimulus. A: activity (Activity). If the baby doesn't move, that's not good. Moving the arms and legs slightly is better. Active movement of the arms and legs is of course best. R: breathing (Respiration). No breathing is absolutely not good. Slow or irregular breathing is slightly better, but still worrying. Strong, regular breathing and strong crying are good. The score. A score is determined for each part: 0, 1 or 2 points. A total score between 7 and 10 points is normal. A score of 4 points or less is worrying. Immediate help is therefore required. A midwife knows what to do in that case. Repeat the study. The examination is taken three times: at 1, 5 and 10 minutes after birth. It is not surprising if your baby does not have a high score during the first examination. The intention is that the baby will achieve an increasingly higher score when repeating the test.

HOW IS THIS IMPLEMENTED NOW?

Apgar and FHIR

If the Apgar score needs to be exchanged, this will be done with the FHIR resource Observation. Because the FHIR Resource Observation leaves a lot of room to enable various implementations, the various developers have eagerly taken advantage of this and created different profiles. These

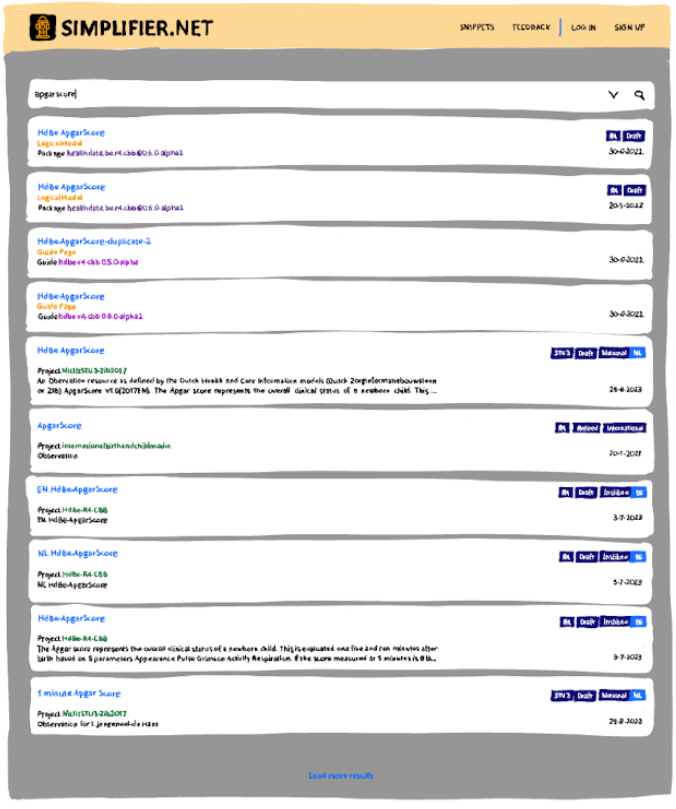


Figure 15: Different implementations of Apgarscore

[20] https://www.opvoeden.nl/apgarscore-2513/

FHIR profiles are not standardized. More than 50 different FHIR implementations of the Apgar score are known[21]. Even though the standard Observation FHIR resource is used, due to the different implementations the Apgar score cannot be exchanged 1 for 1 without mapping. Figure 15 shows a screenshot documenting the many different implementations in Simplifier.net. For clarity, I have presented two different implementations in Figure 17. The first implementation used the meeting order as Root implementation and the meeting type below that, the other implementation took the Meeting type as root and the meeting order below that. If these 2 implementations want to exchange the Apgar score with each other, both systems must incorporate the method of each other's implementation. With 50 different possible implementations, this becomes difficult and practical exchanges are limited to a few regional healthcare institutions. In the Netherlands, Medmij has achieved clarity by establishing an agreement system. But this doesn't mean we can exchange data with other countries. In addition, this is only a very small set of agreements (exchange PGO).

Figure 17: Details of two different implementations of the Apgarscore

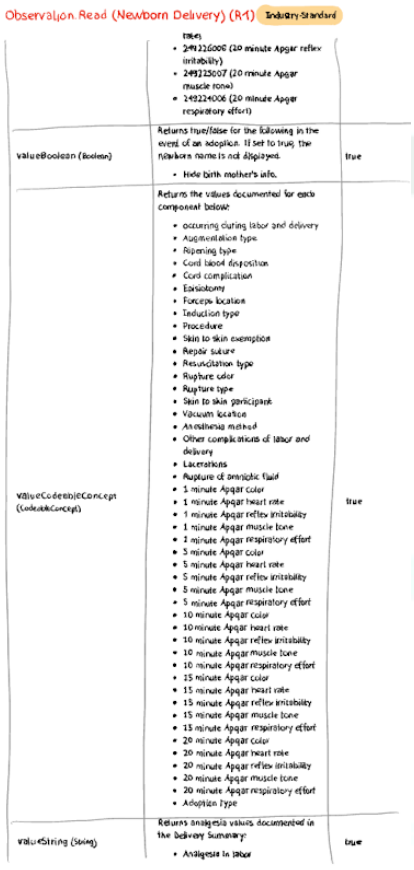


Figure 16: Epic Implementation Apgarscore

[21] https://simplifier.net/search?q=apgarscore

Foreign suppliers must build in these resources and profiles especially for the Netherlands. However, suppliers like to stick to their standards. For example, EPIC has an implementation where, in addition to moments 1, 5 and 10 minutes, they also register moments[22] 15 and 20 minutes (See Figure 16). To exchange these last two measurements, EPIC has its own FHIR profile that is not in accordance with Medmij. Epic had to create its own FHIR implementation especially for the Netherlands, which exchanges less data than they actually could. This is to comply with Dutch rules. Epic also uses Loinc codes for the time interval, 1, 5 and 10 and Snomed for 15 and 20. As a result, EPIC resources have been built twice. One time standard EPIC and one time typical Dutch.

This is also a reason why we want the exchange layer to be separate from the application layer. We could keep Epic Standard (the EPIC profiles) and cut off the information on our exchange layer and map it to the Dutch standards.

Apgar and openEHR

The openEHR principle, as described earlier, involves modeling the clinical model as completely as possible.

That is why when defining the Adgar Score Archetype, in addition to 1, 5, and 10, you also see 2, 3 and a variable option. Because in practice it appears that, depending on the status of the child, this score is determined at several times. This makes the model flexible and meets the needs of sustainable storage. The use of variable values is not possible within FHIR that complies with a ZIB. Unless you create a new profile. In addition, all elements within this archetype are coded with both Loinc and Snomed-CT where possible.

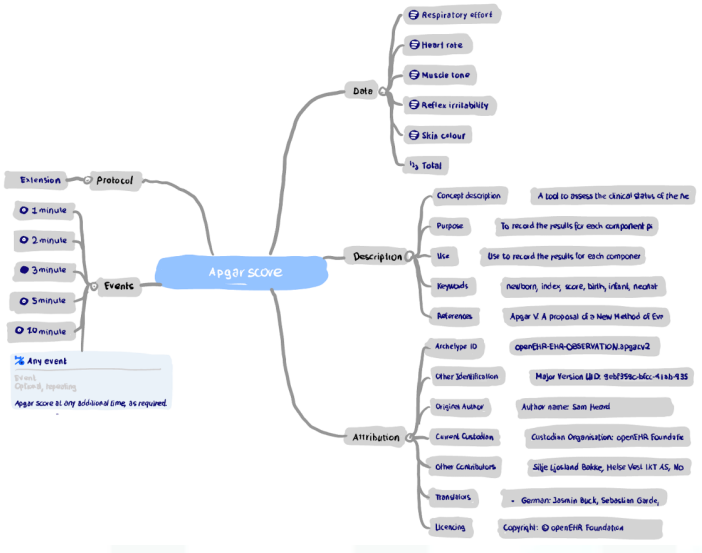
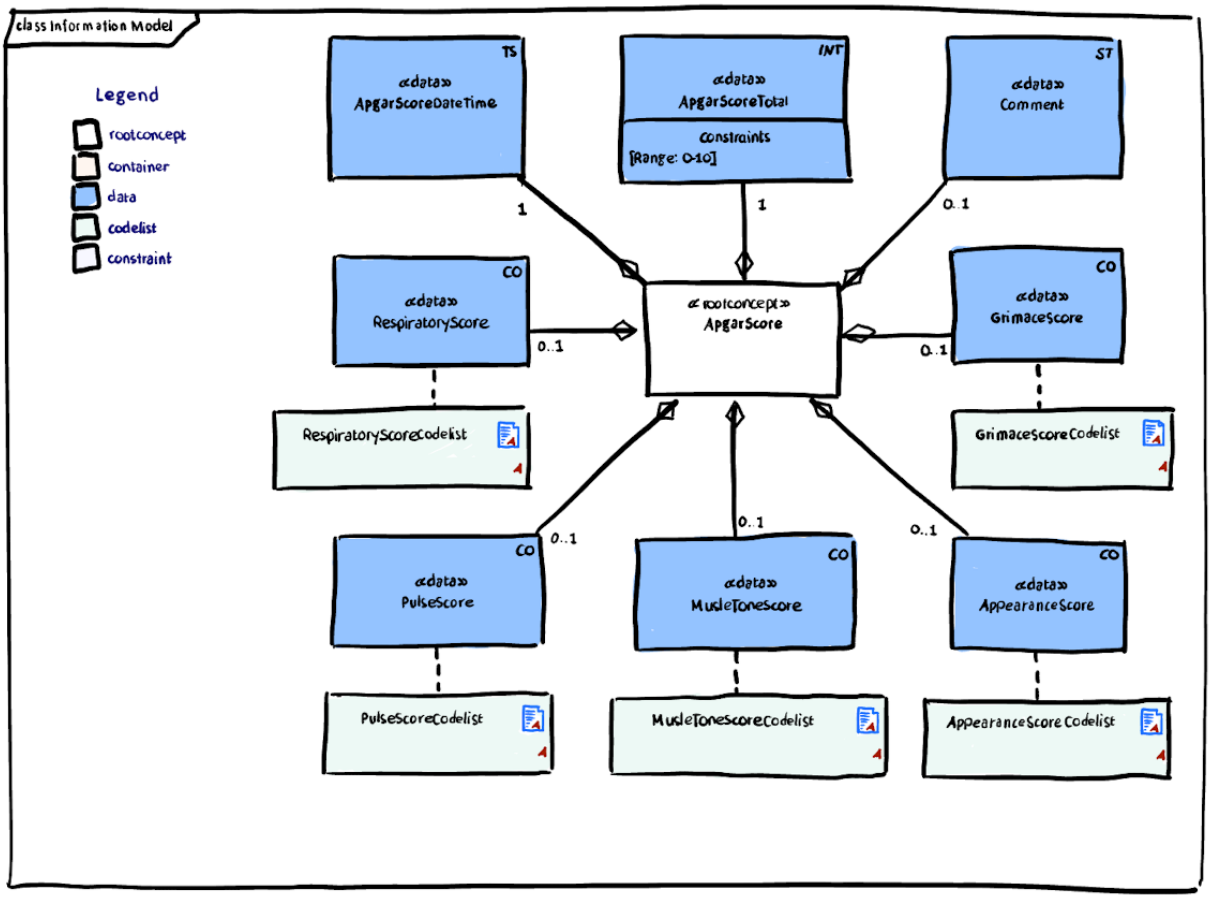


Figure 18: openEHR Informationmodel Apgar Model

Apgar and ZIB

Registration at the source modulated the Apgar score strictly according to the definition. Here you can see that registration at the source also only allows options 1, 5 and 10. The FHIR resource as defined in the Netherlands fits in neatly with this. Do not alter the fact that both implementations are specific to the Netherlands. Suppliers will have to install all of these separately if they want to comply. This will probably not happen due to the high costs, which means we will always be left with mapping differences or issues. We cannot therefore exchange other values in the Netherlands.

[22] https://fhir.epic.com/Sandbox?api=10306



Type	Id	Concept	Card.	Definition	DefinitionCode	Reference
	NL-CM:12.16.1	ApgarScore		Root concept of the ApgarScore information model. This root concept contains all data elements of the ApgarScore information model.		
	NL-CM:12.16.3	ApgarScoreDateTime	1	The day and time at which the Apgar Score is registered.		
	NL-CM:12.16.2	ApgarScoreTotal	1	Total of the Apgar Score. The total Score has a range from 0 - 10.	2271-0 10 minute Apgar Score 2272-6 1 minute Apgar Score 2274-2 5 minute Apgar Score	

Figure 19: Informationmodel Apgar in ZIB