Report

IBD Hackathon findings

Maastricht UMC+

Report

IBD Hackathon findings

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Maastricht UMC+

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Management Summary

In recent years, the discussion on the use of standards in the Netherlands has shifted from modelling for data exchange to modelling for data availability. More than before, the focus is now on capturing and recording data in addition to exchanging it. The (inter)national standard HL7 FHIR plays a prominent role in the Dutch system of information standards for data exchange for years. In addition, the Health and care Information Building Blocks (HCIM) or Zibs as they are called in the Netherlands and Clinical Building Blocks (CBB) in Belgium have been developed for the Dutch market to provide healthcare providers with recognizable modelling of clinical concepts that can be used across healthcare systems[1].

The focus from exchange to capture, recording and exchange has ensured that the international standard openEHR has also gained more and more traction in the discussions. Not only in the Netherlands but also internationally. Compared to HL7 FHIR, openEHR primarily focuses on recording clinical data and provides a broad solution, consisting of models (archetypes and templates) and tooling to arrive at implementable solutions.

In a hackathon organized by DataHub Maastricht and Maastricht UMC+, various parties worked on gaining insight into the coherence and application of the standards FHIR, openEHR, Zibs and OMOP. The application of these standards was tested for the implementation of the IBD use case[1]. Generic objectives for implementing such sets are reducing the registration burden, making the right data available at the right time during the primary care process, and making data available for secondary use and (scientific) research. The reusable application of international standards is a starting point to also enable data exchange across borders when this becomes necessary.

In the South Limburg region, it has been decided to use an federated openEHR datastore as the basis for the transmural longitudinal file (life cycle file). In addition, in line with the current architecture plans of the CumuluZ coalition, they want to connect to the future public data infrastructure and the nationwide network. The CumuluZ platform focuses on the data availability for these applications. The access is provided via APIs which are developed as an open innovation, so that both healthcare providers and commercial IT vendors can develop healthcare IT applications on this platform[2].

In this final report of the hackathon in Maastricht, we have formulated several conclusions and recommendations. The conclusions and recommendations help shape the national healthcare information management. All this within the framework of the healthcare information system to guarantee the quality and development of healthcare solutions in the long term.

It is crucial that different standards are applied correctly in conjunction with each other in the IT healthcare landscape in the Netherlands. The information needs of healthcare providers must be translated into implementable technical specifications that can then be implemented by IT suppliers in their systems. Multidisciplinary teams with a lot of representation from healthcare providers are needed to map data from EHRs such as Hix and Epic and other healthcare applications to openEHR template and FHIR profiles. This will be a major effort in the coming years that will probably have to be worked out step by step per use case in the regions of the Netherlands.

[1] *https://www.uitkomstgerichtezorg.nl/publicaties/documenten/2023/03/09/uitkomstenset---ibd*
[2] *https://www.cumuluz.org*

Conclusions and recommendations

1. An openEHR architecture that is being pursued in the South Limburg region seems to be a good and technically feasible solution for a vendor-independent longitudinal record and is in line with the vision and strategy for the national health information system. Platform technology solutions make it possible to separate data and applications and thus work more vendor-independently. This will reduce vendor lock-in and promote innovation in healthcare. openEHR is one of the possibilities to set up this technology direction and fits within both the architecture of CumuluZ and that of Health-RI.

2. In a hybrid architecture model, in which openEHR, FHIR and OMOP are used, a conceptual model, such as the Dutch Zibs, is still important. Healthcare providers in the Netherlands can use the "Zibs-new-style" as a bridge between the different standards to ensure recognizability. Whether openEHR archetypes can replace the Dutch Zibs in the long term must be thoroughly investigated.

3. Invest in acquiring knowledge about openEHR in addition to and in combination with FHIR. Engage in international cooperation and advise where necessary on the required governance. Additionally, conduct research into the national scaling up of the openEHR standard. Investigate how archetypes, templates and Zibs will relate to each other in the long term of 3 to 5 years. If openEHR is chosen as national standard, Dutch openEHR templates must be created and maintained in addition to the FHIR nl-core profiles. In this case, as with FHIR, international developments in this area must also be considered.

4. Solid agreements regarding national management and maintenance for the IBD dataset do not yet exist, but these are necessary for further development of this set. This does not only apply to the IBD dataset. Ensure that the governance of the roles of holder, user and functional and technical manager according to NEN 7522 are clear for all datasets developed in the Outcome-oriented Care programme (including the IBD dataset).

5. Hackathons such as the IBD hackathon in Maastricht, where experts periodically collaborate on challenges, require repetition, focus and deepening. Simultaneously work on building a community to share and make available knowledge and tools during and around the hackathons. Work actively multidisciplinary across healthcare and ensure that teams work together more often 'in one space' to improve the effectiveness and efficiency of collaboration and results.

1

Introduction

Igor Schoonbrood, enterprise architect MUMC+, was increasingly asked why the South Limburg Region opts for openEHR, while the national policy and CumuluZ's choice is FHIR. His answer is that it is not a case of which either openEHR or FHIR is chosen, but that both standards are used side by side, just like OMOP. He published his thoughts on this in a blog[3]. This blog reached many people, including Walter Kraan from Nictiz, who, together with his team and Igor, entered into discussions in March 2024[4]. The discussion made it clear that the design, deployment and national application of the FHIR profiles require better explanation and that the possibilities of openEHR within the national data infrastructure also had to be explored. In this consultation, it was agreed to carry out this exploration in the form of a hackathon in June 2024, using a concrete practical case. Because an elaborated dataset for Inflammatory Bowel Disease (IBD) from the Outcome-Oriented Care programme was available, this set was chosen as a case for elaboration.

The IBD case concerns the implementation of Outcome-oriented Care. The Outcome-oriented Care programme of the Ministry of Health, Welfare and Sport has produced a data set in which, in addition to patient characteristics and treatments, clinical and patient-reported outcomes have been elaborated. This set was chosen for the Maastricht hackathon partly due to the efforts of Marieke Pierik. She has been committed to improving care for patients with IBD for years and has been appointed profiling professor with the chair "Real World Data for chronic conditions with a focus on IBD" since the summer of 2021. She is also one of the IBD experts in the IBD working group of the Outcome-oriented Care programme.

Igor suggested the idea of a hackathon to Pascal Suppers, managing director of DataHub Maastricht, which houses the data management services for research at MUMC+ and Maastricht University. With him, the idea for a hackathon turned into a concrete plan, making the hackathon at DataHub Maastricht from 10 to 14 June 2024 a reality. This document is a report of the findings surrounding this Hackathon. Special thanks to Pascal Suppers and Walter Kraan. Without them, this Hackathon would not have been possible.

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This document is an English translation of "Rapport bevindingen IBD Hackathon" which is handed over to Bianca Rouwenhorst, Director Information policy/ CIO of the Ministery of Health, Welfare and Sports on 27 september 2024.

[3] *https://itcadvies.nl/wp-content/uploads/2024/04/OpenEHR-FHIR-ZIB-CumuluZ-ENG.pdf*
[4] *https://nictiz.nl/publicaties/in-gesprek-met-igor-schoonbrood/*


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2

Method Data Hackathon-IBD

In this chapter the methodology used for the hackathon is explained. A hackathon is typically structured around a number of standard components that help organize the event and facilitate the participation of participants. The generic goal of this hackathon was to solve the problems encountered in the four user stories around the IBD data use case, to map out white spots and to learn from and with each other, through rapid prototyping, analysis and creativity. During this hackathon it was suggested to follow up on this by organizing hackathons more frequently. Therefore, the methodology used is described below with a view to deepening and continuing in the coming years.

2.1. Preparation

During the preparation of a hackathon, a backlog is created with user stories. These are uploaded to the digital collaboration environment of DataHub, where files can be uploaded and text can be added.

In the preparation, a backlog was created and 4 user stories were drawn up. Each "main sponsor" set up and delivered one user story. These user stories were more in the nature of epics (https://scrumguide.nl/epic/). Due to the broad questioning in the epics, the teams had to focus themselves in order to get parts of the epics answered. Access to the internet on location was arranged in advance for all participants and a wiki environment was set up (DataHub Collaboration Zone) where documents were shared and (interim) results were posted before and during the hackathon. All participants were asked to read the four user stories in preparation.

The four user stories:

1. **User story "IBD"**
   Owner: M. Pierik
   As an IBD care provider, I want to improve the care for my patients based on information from the care process so that we can offer the individual patient appropriate, tailor-made care.

2. **User story**
   "Collaboration Health-RI & CumuluZ & Regio"
   Owner: I. Schoonbrood
   As an Enterprise Architect of MUMC+ and RSO-ZL, I want to seamlessly connect the regional IT infrastructure for data exchange and become part of the national CumuluZ IT infrastructure and Health-RI, so that the data will always be available to end users via the sustainable IT infrastructure that we support.

3. **User story**
   "Relations Zib with Information models"
   Owner: W. Kraan
   As a Nictiz development team, I want to investigate how the IBD dataset from the Outcome-oriented Care programme in openEHR is compatible with the mapping of the same set on FHIR and what the role of the Zibs can be in bridging this gap. So that we can create generic guidelines for the translation between openEHR and FHIR implementations in the Netherlands, both for data defined via Zibs and non-Zib data elements.

4. **User story "Governance & tooling"**
   Owner: P. Suppers
   As a development team, I want the management of the IT standards that we are going to use to be properly arranged and for the right tooling to be available, so that we can collaborate with Dutch partners on joint use cases.

2.2. Agenda and participants

The hackathon has been set up as much as possible in accordance with the scrum method. After the draft agenda has been created and the participants have been invited, everyone (after approval) will also receive access to these files. A draft agenda and list of participants will then be ready and will serve as a framework during the hackathon.

For the IBD data hackathon, people from MUMC+, MUMC+ datahub, Maastricht University, Zuyderland hospital, RSO Zuid-Limburg, Nictiz, VZVZ, Health-RI, UMCG and Santeon have been asked to free up a week to work on the outlined IBD data use case onsite at DataHub Maastricht. A draft agenda was drawn up prior to the hackathon. All participants were carefully divided into 3 teams. One person per team was found willing to act as team lead to ensure a structured approach, to keep the team motivated and focused on achieving the goals within the limited time of the hackathon.

The team leads acted as the first point of contact (in scrum terminology Product Owners) for the organizers. The hackathon was set up as much as possible in accordance with the scrum method.

2.3. Kick-off

This is an opening session in which the organizers explain the goal and rules of a hackathon, share important information and inspire the participants to actively participate. In this session, everyone is updated on the background and course of events during the hackathon.

At the start of the hackathon, employees of Nictiz, MUMC+ and DataHub Maastricht presented their view on the outlined IBD use case and updated the attendees in plenary session on the status and availability of the standards, information models and their work and findings.

- *https://datahubmaastricht.nl/files/IBDhackathon-IBD-Current-Status-2024.pdf*
- *https://datahubmaastricht.nl/files/IBDhackathon-Nictiz-Current-Status-2024.pdf*
- *https://datahubmaastricht.nl/files/IBDhackathon-OMOP-Current-Status-2024.pdf*
- *https://datahubmaastricht.nl/files/IBDhackathon-openEHR-Current-Status-2024.pdf*

Rachel Dunscombe, CEO of openEHR international, gave a presentation on the structure of the openEHR organization, the collaboration with other standardization bodies such as HL7 and SNOMED international. She also pointed out initiatives from Wales in the United Kingdom and Australia.

- *https://datahubmaastricht.nl/files/IBDhackathon-CEO-openEHR.pdf*

2.4. Team formation

A period in which participants form teams or join existing teams. This can happen spontaneously or be organized by the organizers. The participants were divided into three teams of approximately 10 individuals each by the hackathon organizer based on their job description and organization.

A period in which participants form teams or join existing teams. This can happen spontaneously or be organized by the organizers. The participants were divided into three teams of approximately 10 individuals each by the hackathon organizer based on their job description and organization.
During the division, it was checked whether each team was assigned the same competencies and whether each organization was evenly distributed among the teams. In addition, a focal point was used for the composition of each team based on one of the user stories without this being made known.

- *https://datahubmaastricht.nl/files/IBDhackathon-teams.pdf*

Lessons learned is that all teams had to act at a Strategic, Tactical and Operational level, which meant that not everyone could participate at all those levels, perhaps next time the team composition will be composed accordingly. On the other hand, this has led to more understanding of each other's challenges.

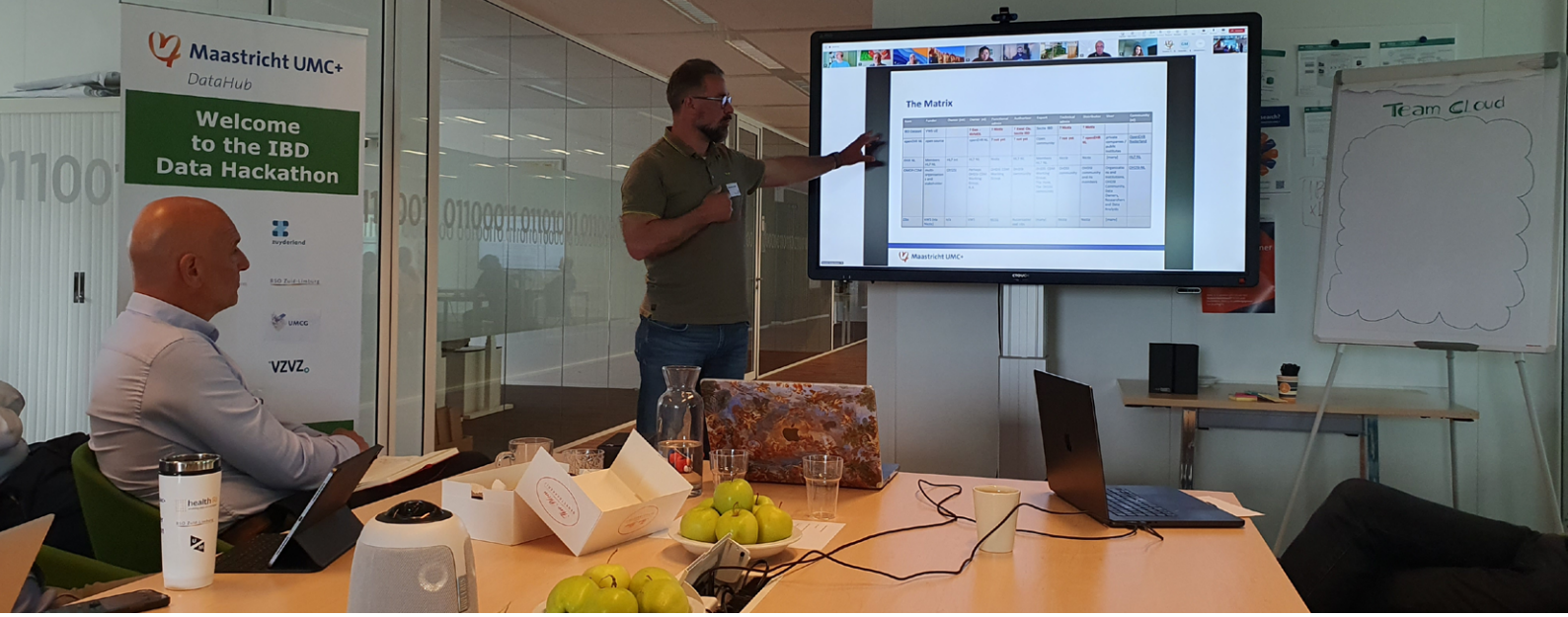
2.5. Generating Ideas

A phase in which team members brainstorm and generate ideas to address the hackathon problem or challenge. This can be done individually or in teams.

At the end of the first day, the participants split up to think in their team, based on their own knowledge and skills, about how and what they wanted to deliver by the end of the week and what they needed (from each other) to do so.

Coming up with a name for the team is a way to immediately work on team building. The names have become:

- *IBD data hackathon team United Data Rebellions*
- *IBD data hackathon team DNZR*
- *IBD data hackathon team OpenFire*



2.6. Prototyping and development

The main work phase in which teams convert their ideas into prototypes, software applications, hardware solutions or other projects. This usually involves intensive collaboration and development.

From Tuesday to Thursday, a daily stand-up per team was started. The team leads briefly shared their approach and state of affairs with the organizers a few times. This resulted in a number of points for improvement, such as mutually opening up the documentation per team and a plenary session on approach and state of affairs.

After the first hands-on day, the need also arose for thematic sessions. There was a plenary session with Australia and a FHIR session with a selective group. The IBD experts also seized the opportunity of Marieke Pierik's presence to sit together for a whole day and even form a new fourth team.

- *IBD data hackathon team Data4IBD*

2.7. Mentoring

Mentors are often available, usually industry experts or experienced professionals who advise and guide participants through technical challenges, business development, etc.

Essential during this hackathon is the daily presence of the two organizers who were available at all times during the day to answer questions and provide direction to the participants present. In addition, information was frequently collected and people were 'borrowed' from the other teams when expertise was missing.

Various experts from within and outside the hackathon were consulted when ambiguities arose. On Wednesday morning, the entire group was updated from Australia by the Sparked team who have currently been working on the Australian standards via openEHR with data disclosure via FHIR for almost two years. Meeting recording Australian Sparked team.

- *https://datahubmaastricht.nl/files/IBDHackathon-TheAustralianSparkedteam.mp4*

During these days, a coordination meeting was planned in the afternoon with the three team leaders and the hackathon organizers, as well as moments for plenary feedback if deemed necessary.

2.8. Pitch preparation

Teams prepare a presentation (pitch deck) to present their projects to a jury and audience.

On Thursday, the day before the end of the hackathon, the teams worked hard on the presentations for the next day as well as the demonstrations of what they had made. With a somewhat too broad scope in the user stories, many participants continued during the night to be able to show what they had achieved on Friday morning via a presentation and demonstrations.
With more time than available, almost everything turned out to be solvable, which kept the teams working extremely enthusiastically.

2.9. Demos and presentations

Each team presents their project to the jury and the audience. This usually includes a demo of their prototype and a short presentation in which they describe the problem, explain their solution and highlight its impact.

On Friday morning, a number of additional participants and interested parties joined via a Teams web meeting where each team had 40 minutes to present their results and demonstrate what they had created.
The proof of concepts were demonstrated to the attendees via Jupyter notebooks, which allowed the teams to show the attendees step by step what they had created and what was achieved.

- *https://datahubmaastricht.nl/files/IBDhackathon-Final-presentation-DATA4IBD.pdf*
- *https://datahubmaastricht.nl/files/IBDhackathon-Final-presentation-DNZR.pdf*
- *https://datahubmaastricht.nl/files/IBDhackathon-Final-presentation-Open-Fire.pdf*
- *https://datahubmaastricht.nl/files/IBDhackathon-Final-presentation-United-Data-Rebellions.pdf*

2.10. Jury assessment

The jury will assess the projects based on predetermined criteria, such as innovation, technical implementation, feasibility and presentation quality. The winning team(s) will be selected and prizes will be awarded.

After their presentations, the teams were assessed in plenary session by the 4 jury members, after which team United Data Rebellions ultimately achieved the highest score.

- *https://datahubmaastricht.nl/files/IBDhackathon-TheFAIR-est-teams.pdf*

2.11. Networking and collaboration

During the hackathon, there is often room for participants to network, exchange ideas and collaborate with other teams, mentors and sponsors.

The excellent and healthy lunch was served every day in the central area at DataHub Maastricht. This gave participants both room to exchange experiences and networking and a moment to withdraw from the group events. In the middle of the week, a dinner was planned in a restaurant on the Vrijthof in Maastricht where everyone, organizers and participants were present. During the week, DataHub Maastricht sent out frequent updates via LinkedIn, which were well liked and read within the network.
The organizers of the openEHR masterclass also came by and surprised the participants with an ice cream.

2.12. Closing and award ceremony

A closing ceremony in which the winners are announced, thanks are expressed to all participants, mentors and sponsors and a few final words are spoken by the organizers.

During the closing ceremony, the week was reviewed via a PowerPoint with various photos and it was discussed how the results will be further processed into a report that will be presented to Bianca Rouwenhorst, director of information policy, also CEO at the Ministry of Health, Welfare and Sport. In addition, there will be a follow-up meeting for a possible follow-up to this hackathon.
It was particularly appreciated that Leonique Niessen, director of Nictiz and Walter Kraan, manager of product development and management of Nictiz were physically present.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IBD DATASET – PATIENT CHARACTERISTICS

3

The IBD dataset

This chapter describes how the IBD dataset was created, what was encountered during the hackathon and what is needed to arrive at a national IBD standard.
The IBD dataset was created within the Outcome-oriented Care programme, phase I.
The results of this are described in the final report[5] and the outcome set in Excel[6].

The IBD dataset was created within the Outcome-oriented Care programme, phase I.
The results of this are described in the final report and the outcome set in Excel. However, more is needed to create an interoperable dataset that can also be built into applications by IT suppliers. In any case, it must be clear which data must be recorded or exchanged when in the care process, so that IT suppliers know exactly what they must implement in screens, forms and workflows. In addition, data that is recorded must also be "FAIR" to enable reuse of data, among other things. These FAIR principles serve as a guideline to make data suitable for reuse under clearly described conditions, by both people and machines. FAIR[7] is an acronym for:

- Findable
- Accessible
- Interoperable
- Reusable

These principles aim to make data not only computer-readable, but also to enable computer systems to find, access, link and reuse data without or with minimal human intervention.
It is crucial that we reduce the administrative burden in healthcare in the Netherlands and enable the reuse of data. It is a fine ambition, but in practice it is quite complicated. What was the status of the IBD dataset? After delivery of the IBD dataset by the Outcome-oriented Care programme, Nictiz started working on developing this set in the open source tool ART-DECOR.

The ART-DECOR tool is used worldwide in more than 80 projects, mainly in Europe, including Germany, Austria, Norway, Poland and the Netherlands.

With ART-DECOR you can describe the IBD dataset FAIR by linking the different elements in the dataset such as the generic and IBD-specific patient characteristics, the treatment characteristics, outcomes and all used value lists to the correct international terminology standards (SNOMED, LOINC) as well as specifying exactly which data are exchanged when and by whom (transaction scenarios). In the Outcome-oriented Care phase I programme, the preliminary work was done by mapping the data elements in the spreadsheet to the Zibs.

3.1. Findings during hackathon

During the IBD hackathon it became apparent that the transfer of the deliverables from the Outcome-oriented Care programme to a dataset in ART-DECOR is not yet ready. Nictiz still had many open questions from terminologists and information analysts that were waiting for an answer.
There were no agreements and there was no consensus on the substantive, functional and technical management of this information standard and so it is unclear where the information analysts should go with their questions and findings.
In Maastricht, hard work was done, together with the healthcare providers present, to get answers to many open questions. In addition, during this analysis it became apparent that the healthcare providers had strong doubts on some points whether the specification in Excel was what was decided in the working group at the time.

[5] *https://datahubmaastricht.nl/files/v3-Eindrapport_doorontwikkelfase_IBD_V1_0.pdf*
[6] *https://www.uitkomstgerichtezorg.nl/publicaties/documenten/2023/03/09/uitkomstenset---ibd*
[7] *https://nl.wikipedia.org/wiki/FAIR-principes*

Since a coordinated and correct set was seen as a prerequisite for successful passage, the group decided after day two to have a few people work together for the rest of the week to answer as many questions as possible and clarify ambiguities. It is unfortunate that there is currently no active Outcome-oriented Care-IBD working group, so that substantive adjustments to the set (change requests) during the hackathon do not formally have national support.

The Excel with the IBD dataset contains, in addition to the IBD disease-specific data and processes, also the standardized generic part of the dataset that is the same for all Outcome-oriented Care disease programmes. However, Excel is not a basis for further processing and the national information standards have been elaborated in ART-DECOR. The 'flattened set' in Excel must be converted in ART-DECOR to a minimal dataset with various relationships to other care standards and generic components such as the Zibs, value lists, terminology bindings, exchange scenarios with exact content of the data to be transferred at these times. This sometimes makes it confusing and difficult to read for the healthcare provider, even though there are multiple types of views available[8].

In addition, the option to transfer structured data is missing in pathology and radiology reports, because at the moment the IBD healthcare provider only sees the plain text, even if it is recorded in a structured manner. The BgZ that is forwarded or retrieved upon referral must remain available in its entirety and therefore in the context as drawn up by the referrer.

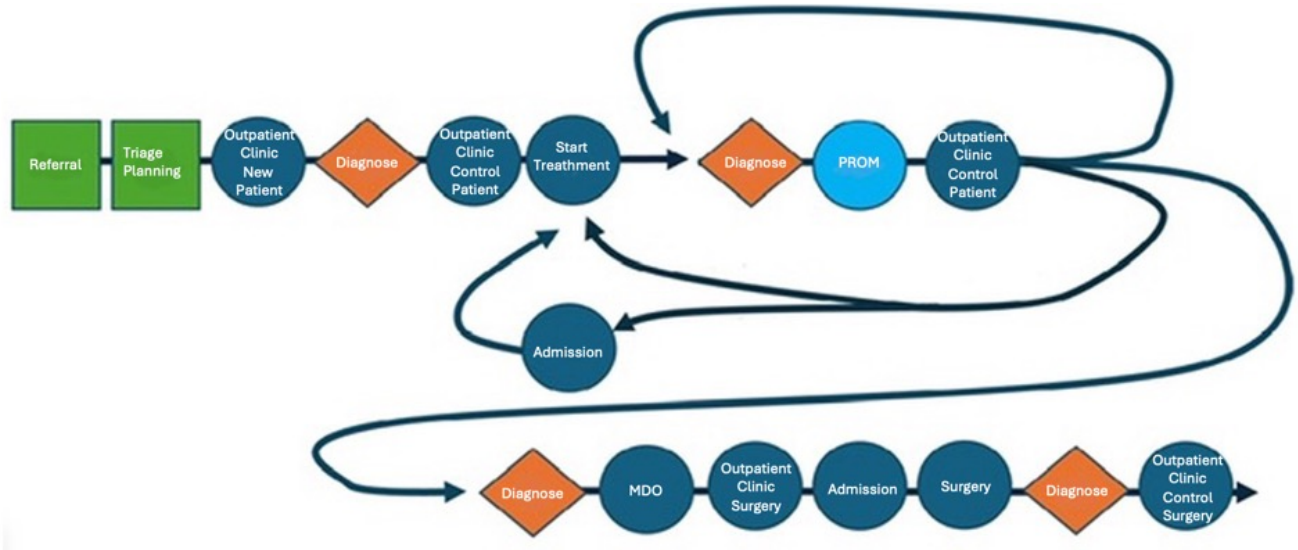


Figure 1 the IBD care process

[8] *https://nictiz.nl/toepassing-en-gebruik/art-decor/*

3.2. Conclusions based on findings

1. Ensure that the roles of functional and technical manager and other roles are clear according to NEN 7522 for all datasets developed in the Outcome-oriented Care programme (including the IBD dataset).

2. Provide an IBD healthcare provider expert group that can be consulted for questions about the elaboration in ART-DECOR, future change requests and questions about implementation. Changes to the set require national consensus from healthcare providers.

3. Tooling must be available across the board that is recognizable and understandable for IT suppliers and information experts, but also for a healthcare provider. Perhaps the collaboration between HL7 and openEHR will also make new tooling available that can be used in the Netherlands.

4. It must be investigated how much duplication of work can be prevented and how much value can be created if all data is exchanged in a structured manner between healthcare providers and also within the hospital itself. This mainly concerns data from the BgZ, and for the IBD case also the radiology, pathology and operation reports. Here data is sometimes recorded in a structured manner but not exchanged in a form that can be transferred in a structured manner.


enjoy tea time

4

openEHR in relation to CumuluZ and Health-RI

This chapter discusses the findings from the hackathon on the intended IT infrastructure in South Limburg in relation to the current CumuluZ and the Health-RI architecture to be set up or adjusted.

CumuluZ indicates that health data is fragmented across many different systems. This ensures that healthcare providers do not always have the right information to provide the best care. The patient himself often does not have an overview either. The limited availability of data is also an obstacle to renewing healthcare. This hinders the possibility of researching new treatments. CumuluZ intends to change this. The aim is to achieve optimal availability of health data, so that the best healthcare is possible[9].

CumuluZ aims to become the digital highway network for information exchange. The aim is to create a national network of system-independent data availability, which should reduce double storage, double administrative actions and diagnostics. A public architecture/infrastructure that is not dependent on competition or commercial profits. The offer is not specific to certain suppliers or owners.

CumuluZ originated from the UMCs, but is currently a collaboration between NVZ, Santeon, mProve, ZN and NFU. The first steps have been taken within this coalition, and other healthcare sectors are being approached to join.

This year it was announced that CumuluZ will play an important role in the plans of VWS to realize national data availability in healthcare. Since the RSO-Zuid Limburg has already opted for openEHR, the hackathon practically investigated how openEHR can be integrated into the plans of CumuluZ and Health-RI.

The output of the hackathon will be used for the IBD Test Garden CumuluZ Health-RI, which officially became part of CumuluZ at the beginning of June 2024. In this test garden:

1. UMCG and Erasmus MC will exchange and/or record the dataset about the CumuluZ infrastructure in FHIR format.
2. MUMC+ and Zuyderland as part of the RSO-ZL will record the dataset in a federated openEHR infrastructure and also exchange this dataset over the CumuluZ infrastructure with FHIR.
3. Furthermore, OMOP is being looked at for the researcher to be able to analyze the obtained data.

openEHR in relation to CumuluZ and Health-RI.

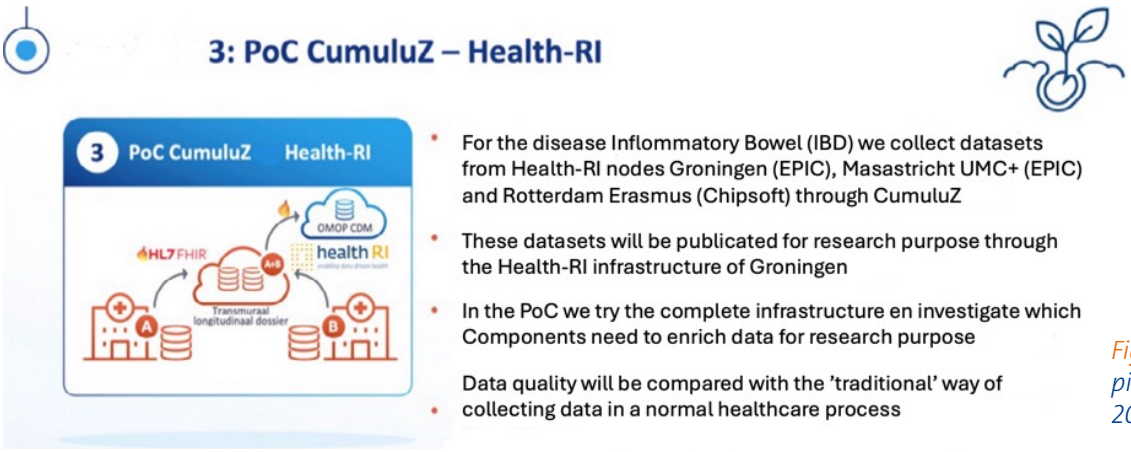
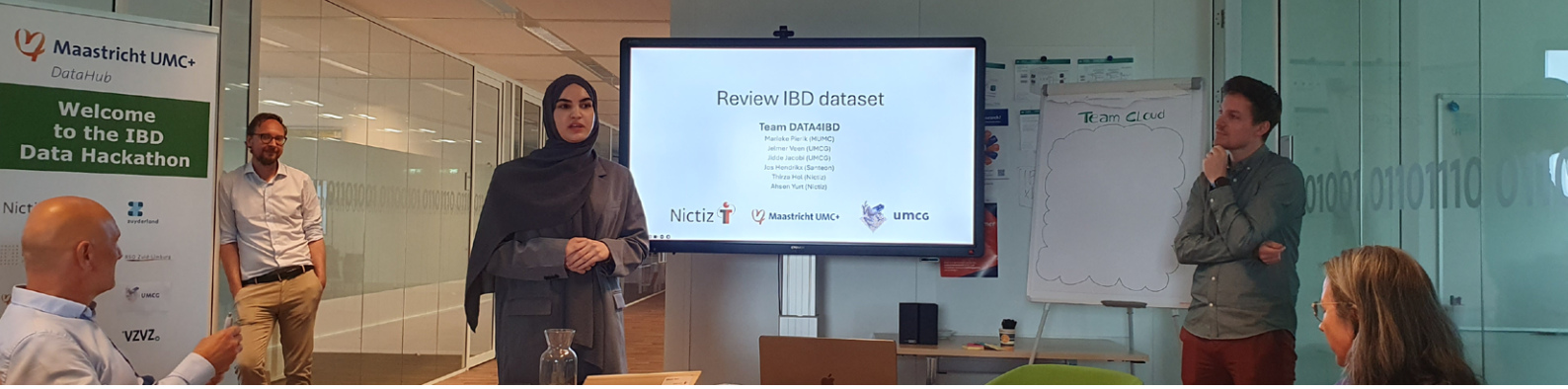


Figure 2 pilot project 3 2024 CumuluZ

[9] *https://www.cumuluz.org*



In the South Limburg region, a longitudinal file is being built on the basis of a Federated openEHR that, as openEHR clinical data stores (CDS), is suitable for creating both a consultation room dashboard and an improvement dashboard. In addition, they want to use this openEHR CDS to make data in OMOP-CDM format available to researchers for (scientific) research (see also paragraph 6.5).

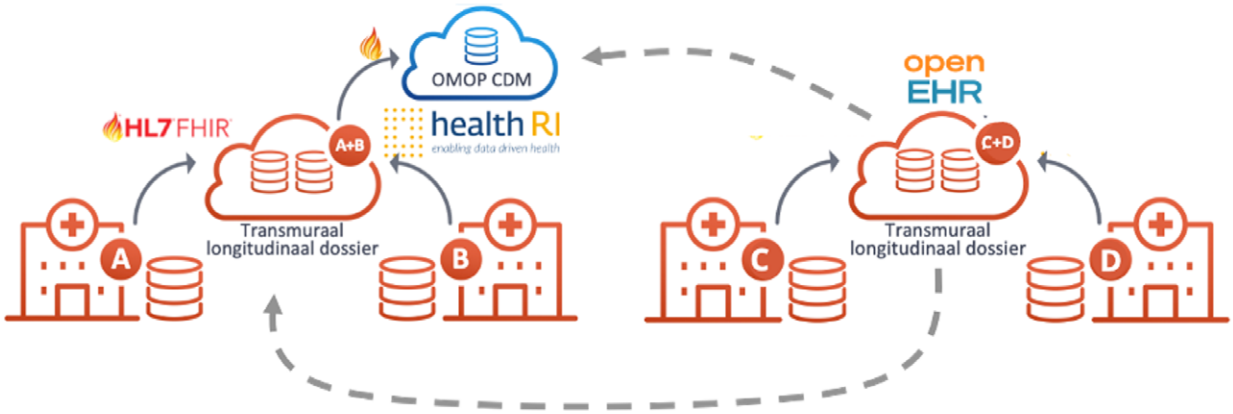


Figure 3 Overview image Proof of Concept 3 after connecting MUMC+ with openEHR June 1, 2024

4.1. Findings during the hackathon

In order to create an improvement dashboard, we are looking at directly unlocking data in the openEHR CDR to a reporting environment with visualization via dashboards. Especially for the consultation room dashboard, it is important that data is entered into a dashboard almost immediately after registration, because patients still fill out questionnaires in the waiting room at the outpatient clinic.

During the consultation with the IBD doctor, they will then be discussed with the patient using a dashboard. This implies that the patient's care data from the EHR, as well as the myIBD patient app, must be sent to the openEHR CDR immediately after registration. Archetype Query Language (AQL) appears to be very suitable for retrieving data from an openEHR database.

This is part of the openEHR specifications. It enables the data scientist or BI architect to retrieve data from any compatible openEHR system. Only openEHR archetypes need to be known in order to create queries and thus make selections that can be sent to the reporting environment.

This can be for summary data, such as "give me the number of patients with Crohn's disease and with Ulcerative Colitis" as well as for patient-related data, for example "give me an overview of all current medication for patient 123". FHIR has Clinical Quality Language (CQL) similar to AQL.

As with openEHR, the data is stored in instances that are based on FHIR profiles. It seems that both AQL and CQL can send data from a CDR to a dashboard or an OMOP-CDM database. During the hackathon, the teams worked on both AQL and CQL, with knowledge of AQL being greater in the group than knowledge of CQL. It was noted that CQL is also useful.
The participants indicated that more experience needs to be gained and that this should be shared with each other.

AQL (Archetype Query Language) and CQL (Clinical Quality Language) are both languages used in the context of healthcare systems, but they serve different purposes:		
Purpose	AQL is specifically designed for retrieving data from openEHR systems. It enables users to extract data based on archetypes and paths within the hierarchical structure of openEHR compositions.	CQL is focused on clinical quality and is used for defining quality measures and decision support.
Use	AQL is primarily used for searching and retrieving clinical data from openEHR repositories.	AQL is primarily used for searching and retrieving clinical data from openEHR repositories.
Syntax	AQL has a more complex syntax and uses paths based on archetypes.	CQL has a simpler syntax and is focused on describing clinical logic.
Example	You can use AQL to retrieve specific observations or measurements within an openEHR composition.	You can use CQL to define a quality measure for diabetes management.
Benefits of AQL	• **Specific to openEHR:** AQL is designed for retrieving data from openEHR systems. If you have an openEHR repository, AQL provides a structured way to retrieve specific data. • **Flexibility:** AQL uses archetype-based paths, allowing you to target specific elements within compositions. This gives you more flexibility when searching for data.	
CQL Benefits	• **Clinical Quality:** CQL focuses on clinical quality and is used to define quality measures. It helps assess the effectiveness of care processes. • **Reusability:** CQL logic can be reused for different applications, such as quality measurement, decision support, and computer-based guidelines.	
In short, AQL is specific and only works on openEHR data, while CQL focuses on clinical quality and decision support and also works on more or less arbitrary database.		

Data in this table obtained via co-pilot prompts "what are the differences between AQL and CQL" and "what are the benefits of using each"[10]

[10] https://pubmed.ncbi.nlm.nih.gov/31437899/

During the 5-day hackathon, the participants set up an openEHR CDS (database) for IBD. The international archetypes available in the Clinical Knowledge Manager (CKM)[11] proved suitable for mapping all components of the fields from the IBD dataset patient characteristics. A template was then created for a number of them.
During the hackathon, the participants imported data from the EHR into the openEHR Clinical Data Repository (CDR) via both FHIR and CSV format. Two dashboards were then created. One via FHIR CQL, the other via openEHR AQL.

In addition to data extraction for the dashboards, data was also extracted and stored in OMOP-CDM. This shows that data from an openEHR CDS will also be available to researchers inside and outside the MUMC+.
This data can be made available anonymously via a file or a database or made available via federated queries and retrieved by researchers.

Data Federation is a method that uses two or more different sources which are not physically located at the same location. For example, the openEHR CDR of MUMC+ and that of Zuyderland. A researcher at the UMCG could also extract anonymized data from these sources after permission and place them locally for analyses.
A side note to the conclusions is that during the pilot (out of necessity) the more technically oriented people did the mapping to openEHR without the input of the care provider.

In order to map data from EHRs such as Hix and Epic to openEHR templates in the future, multidisciplinary teams are needed with a lot of representation from care providers. In any case, this will be a major effort that will probably have to be worked out step by step per use case in the regions.

[11] *https://ckm.openehr.org/ckm/*

4.2. Conclusions based on findings

1. An architecture with openEHR seems to be a good and technically feasible solution for a supplier-independent longitudinal file for the time being and is in line with the national vision and strategy for the health information system. It also fits within the architecture of CumuluZ and Health-RI. However, this requires more research than just the experiences with the IBD case during the hackathon. This will be tested on a larger scale in the South Limburg region.

2. Hackathons such as the IBD hackathon in Maastricht, where experts periodically work together on challenges, require repetition and deepening. Simultaneously work on a community to share and make available knowledge and tools during and around the hackathons, and also to jointly use tooling.

3. Inventory the concerns that various stakeholders (including interoperability experts) have when using different technical and logical information models (FHIR, openEHR and OMOP-CDM). Then investigate how concerns can be removed and problems can be solved.

4. If openEHR is also included as a national standard, it will be necessary to create and maintain national openEHR 'nl-core' templates in addition to the FHIR nl-core profiles. As with FHIR, attention must certainly be paid to international developments in this area.

5. Research must be conducted into the limitations of FHIR, openEHR, and OMOP with regard to performance (hardware, software, network infrastructure and data centers).

6. Research must be conducted into the performance requirements for the various types of dashboards.

7. In order to be able to trust the quality of data in the CDR and to be able to draw conclusions based on dashboards and research, information at a detailed level and/or process agreements are required (metadata on the recording of this data).

5

Health-RI Standards Management

Data lineage concerns a complete (documented) trail that describes the origin and evolution of data. In the context of the hackathon, this concerns IBD data. From a definition of that data from the spreadsheet of the Outcome-oriented Care programme (IBD dataset v2.0 in the image below), it is converted into an implementable standard for recording and exchanging, which we could call an information standard once it is ready (Outcome-oriented Care IBD FHIR implementation guide in the image below).

This information standard is then incorporated into their healthcare information system by IT suppliers. They do this using an implementation guide that refers to the information standard in ART-DECOR and available FHIR resources (currently in simplifier.net).

An implementation guide will have to be adjusted each time updates are made, with the IT suppliers then implementing the changes.

After implementation, a healthcare provider can record data items about a patient or a treatment in the EHR during a clinic visit. At exchange moments described in the information standard and implementation guide, this data can also be sent to chain partners. The data is also stored in a Clinical Data Repository based on openEHR. This database contains data that can be used for various dashboards and research datasets. A transmural longitudinal file then contains patient information from multiple sources. Management of Health-RI standards.

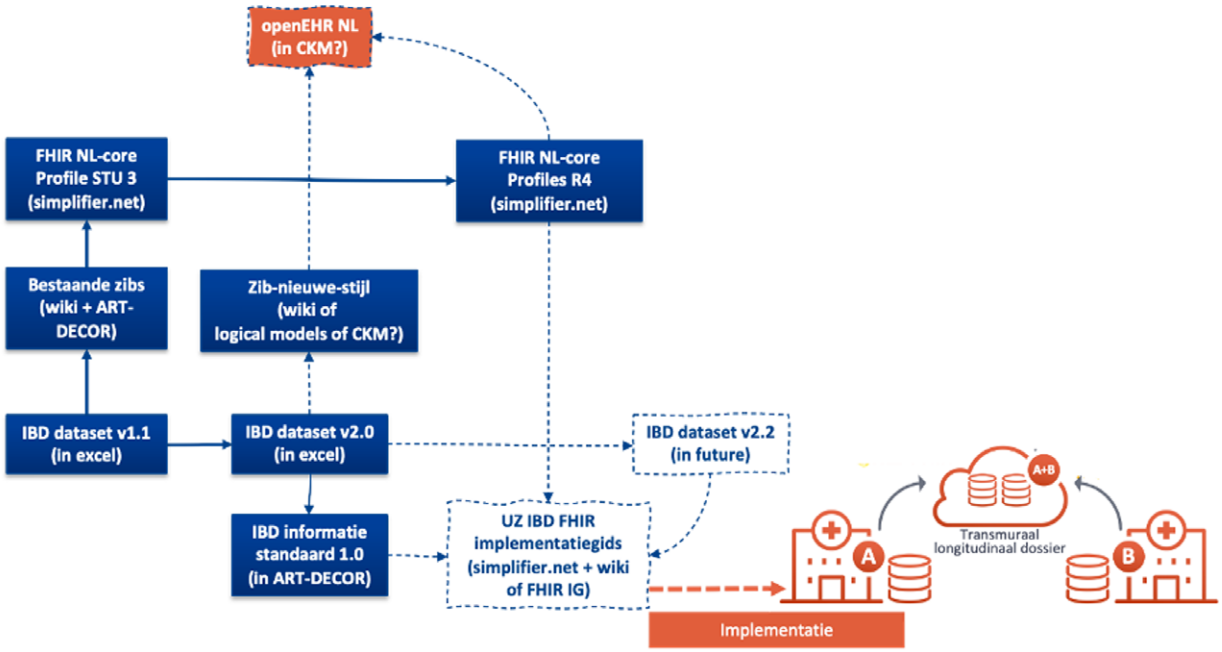
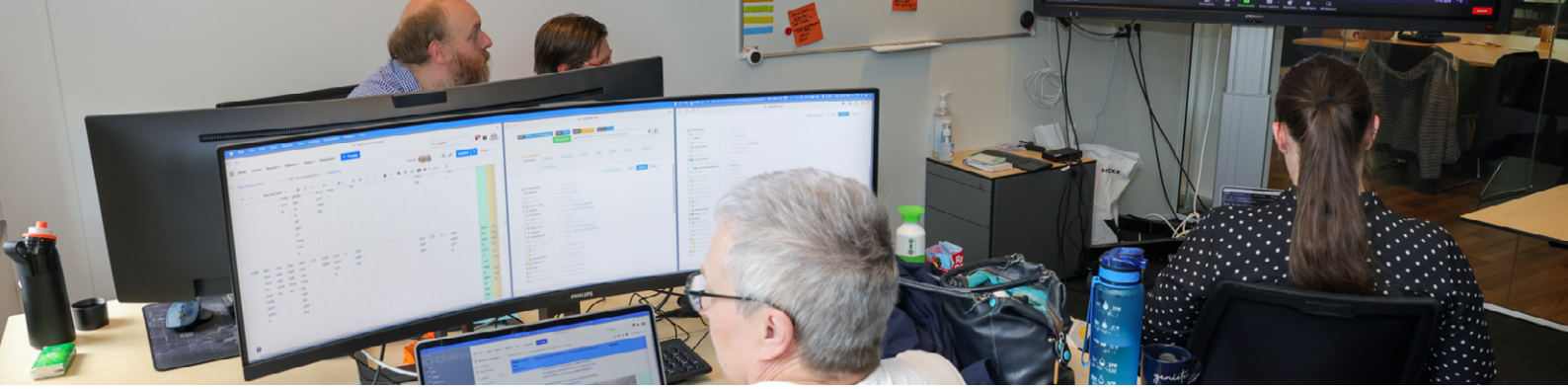


Figure 4 of IBD dataset in Excel to implementation in the region. Dotted lines and open blocks are future mappings and/or transformations.



Over time, hospitals and other healthcare providers migrate from one EHR to another, information standards such as an IBD dataset are updated, and there are version updates of Zibs, FHIR resources and openEHR archetypes and templates. This often makes it more complex to trace how the origin of a data has changed over time. Nevertheless, it is very important to be able to trace these steps.

Data provenance is essential for several reasons:

1. **Transparency and Trust:** Data lineage provides insight into the origin and movement of data. This increases confidence in the accuracy and reliability of the data.
2. **Error Detection and Troubleshooting:** If errors occur in data, lineage helps identify the point where the error originated. This speeds up the detection and resolution of problems.
3. **Compliance and Regulation:** For sectors such as healthcare, it is essential to comply with regulations. Data lineage supports compliance by providing a full audit trail.
4. **Impact Analysis:** When data sources or structures change, lineage helps understand the impact on downstream processes and reporting.
5. **Optimization:** By understanding how data is used, organizations can optimize their processes and operate more efficiently. In short, data lineage is critical to understanding, managing, and trusting data within organizations.

5.1. Findings during the hackathon

In order to move from the IBD spreadsheet to an implementation, existing mappings between Zibs and FHIR resources were used during the hackathon. In addition, some of the hackathon participants ('team Data4IBD') worked hard on the IBD dataset in ART-DECOR.

They also looked at which content of the BgZ could ideally be adopted in the IBD data collection, for example when referring from the GP or another specialist to the MUMC+ IBD team.
The three other teams used a few data elements from the IBD dataset in order to be able to go through as many deliverables from the 4 user stories as possible. In the chapter "openEHR in relation to CumuluZ and Health-RI" it has already been discussed how data from FHIR and openEHR database can be sent to dashboards and research databases and what is needed for this.

There are currently no coordinated openEHR templates for the Netherlands, as we do have for FHIR. This national coordination has been done in the Netherlands for the Zibs and for the IBD dataset in the Outcome-oriented Care me. A number of data elements were selected from the IBD spreadsheet for which openEHR archetypes were found and then openEHR templates were created.
This was not necessary for FHIR because these FHIR profiles are already part of the Nictiz publications in Simplifier.net[12/13].

If we also start working with openEHR in the Netherlands, it is important that there is also Dutch governance and a repository for openEHR artefacts, such as templates. What several teams noted is that the Zibs are very recognizable for healthcare providers and can also be used to create a draft 'nl-core' template from the openEHR templates, just like with FHIR.
Afterwards, it is important that these Dutch openEHR templates and/or archetypes are managed by, for example, Nictiz. Then a comparison between openEHR archetypes and Zibs.
Archetypes are usually richer than Zibs, so mapping Zibs to archetypes is a good start for creating Dutch openEHR templates.

[12] *https://simplifier.net/nictiz-r4-zib2020*
[13] *https://simplifier.net/nictizstu3-zib2017*


ART
DECOR
ZIB
FHIR
IBD
XLS
openEHR
template
APP
LDR
OMOP
FHIR?
OPTIONAL
HANDLE deprecated term
How can code system mappings be governed at a national level?
Whats a good approach to document
• mappings in a computable manner?
• terminology
DBC2 is UNSAFE

In addition, it is also a fast track to a first complete set of Dutch openEHR standards as achieved in Australia. The strength of the Zibs is that they have been coordinated with Dutch healthcare providers for years and that there is a good management process. Setting this up again for openEHR standards is double work and it can probably be done much faster if both the technical standards FHIR and openEHR are (partly) based on the Zibs.

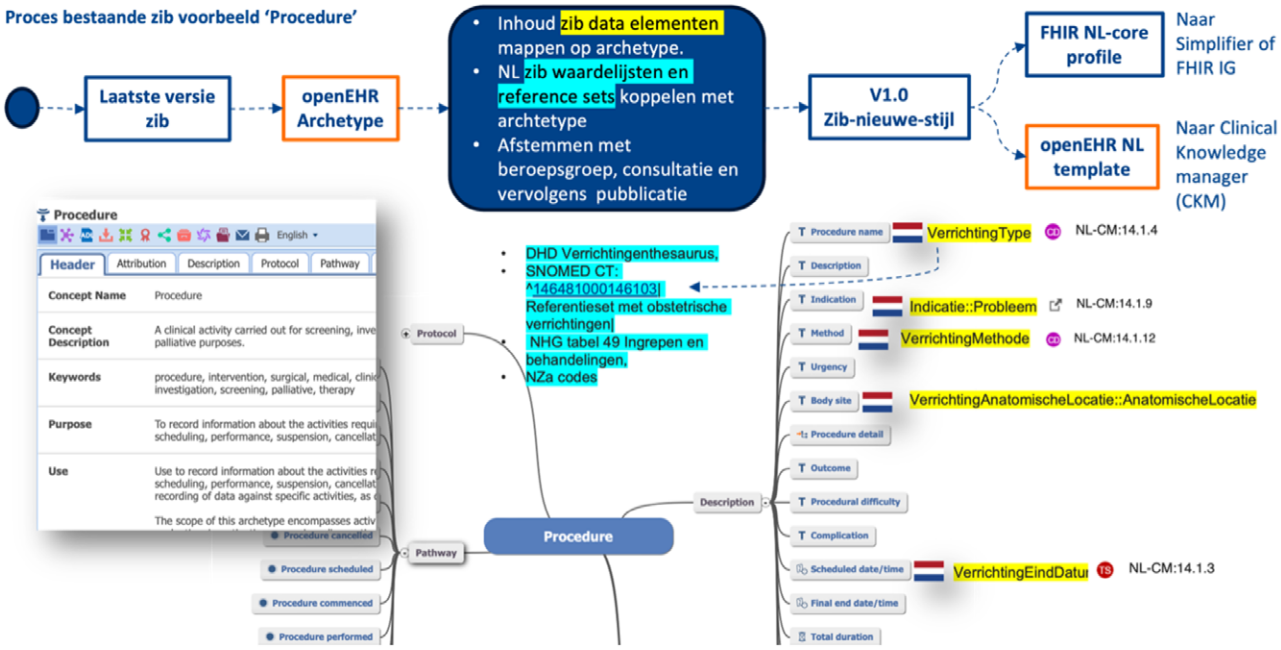
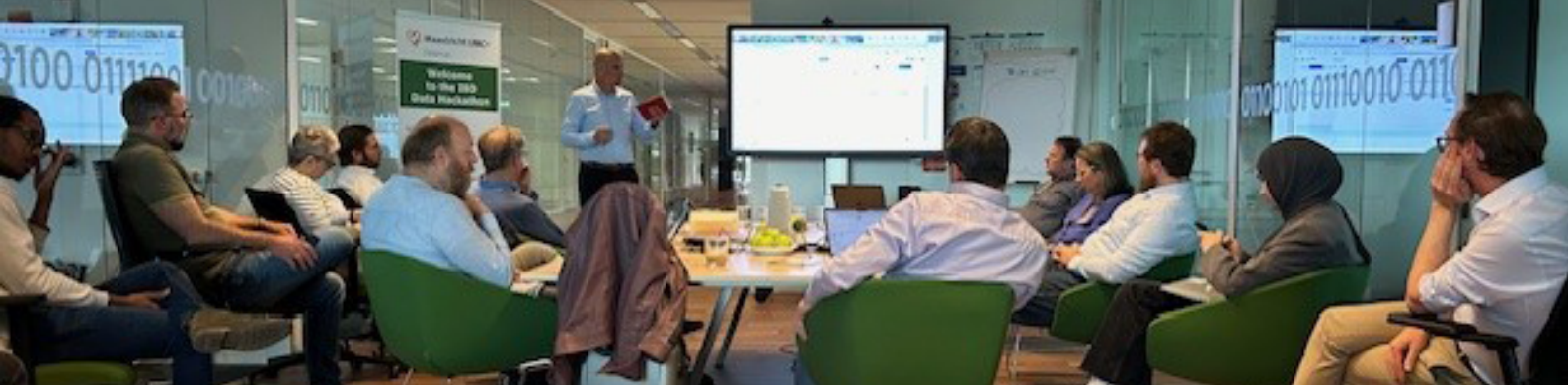


Figure 5 Example for the Zib Operation where the Procedure Archetype is used to create a template.



The proposal for new Zibs is to look directly at the openEHR archetypes and templates and design a Zib based on that and coordinate it with Dutch healthcare providers.

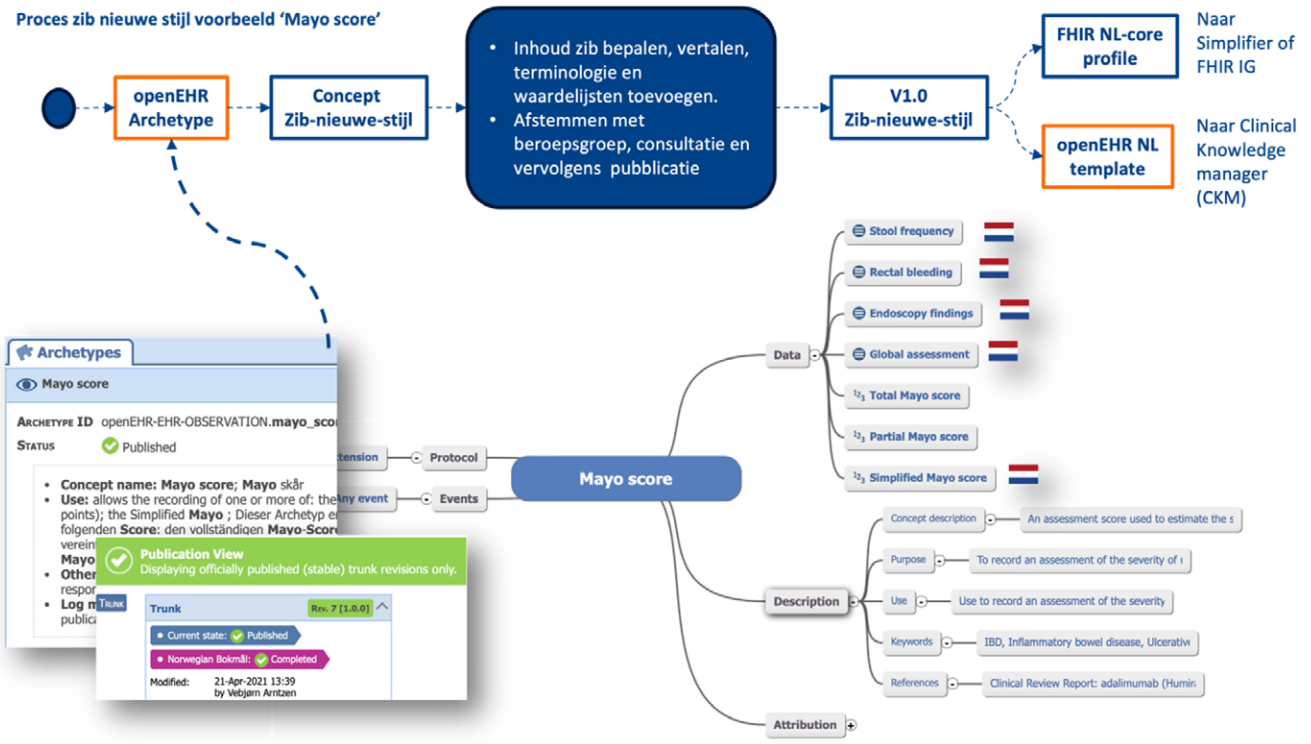


Figure 6 Example of how a new ZIB can be created based on an existing openEHR archetype.

It was also indicated that it is important that for all standards, both the Zibs, FHIR resources and openEHR artefacts, tooling becomes available that everyone can use. In addition, both the Zibs, FHIR profiling and openEHR artefacts must be made available for review and use via one or more repositories.

This is currently possible for the FHIR profiling via Simplifier and/or FHIR Implementation Guides and for openEHR Clinical Knowledge Manager (CKM) is available. Publishing in an easily accessible repository also ensures that there can be more collaboration and exchange of knowledge and software.

5.2. Conclusions based on findings

1. In a hybrid architecture model in which openEHR, FHIR and OMOP are used, a conceptual model, such as the Dutch Zibs, is still very important. The Zibs will have a different position, they will be a bridge between different technical standards and terminology systems (see also paragraph 6.2).

2. If the openEHR archetypes are indeed rich enough as a basis for the HL7 FHIR resources, then the role of the Zibs at the technical level is no longer necessary. However, this needs to be investigated. A model between openEHR and FHIR (such as a Zib-new-style) remains necessary to achieve consensus at national level for exchange standards.

3. Ensure that there is a clear distinction between generic Zibs (managed by Zibcentrum) and other types of 'Zibs' (community driven and/or disease-specific). It is important that the tooling is the same and that both Zibs can preferably be published in the same repository in a form that can be used for implementations.

4. A management, testing, tooling and collaboration environment must be made available for datasets such as those of the Outcome-oriented Care programme, so that they can be worked on together.

5. It is important to actively participate in the international community (openEHR and FHIR).

6. A lot of work has already been invested in the Zib – archetype mapping by volunteers. However, this is not yet complete. In addition, Dutch translations must be added where necessary. These mappings must then be verified and taken into management.

7. Focus on national use cases, publish and communicate knowledge and best practices for regional and local use cases.

8. Work on creating FHIR mapping on Zibs and also on openEHR. When Zibs-new-style start using openEHR archetypes, this will become one process again (archetypes à Zib-new-style à FHIR).

9. Follow the developments in the field of collaboration between the openEHR and FHIR communities. They have announced a research on collaboration[14/15] to arrive at international FHIR profiles based on the International Archetypes and also to make tooling available for this. The Netherlands could also actively contribute to this.

[14] *https://simplifier.net/nictiz-r4-zib2020*
[15] *https://simplifier.net/nictizstu3-zib2017*


Maastricht UMC+
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6

International standards in this hackathon

This chapter describes how the openEHR, Zibs, FHIR, BgZ, IPS, EPS and OMOP standards came into being and what their purpose and function is.

6.1. openEHR

openEHR[16] International is a non-profit organization founded in 2003. It has its own community that publishes and manages an international technical standard for an EPD/ECD platform.
In addition, openEHR focuses on modeling clinical concepts with Archetypes, based on a reference model.

A database (model) can be built from this using templates and terminology. The openEHR Netherlands Foundation was founded in 2019 and aims to promote openEHR within Dutch healthcare IT and to respond to specific Dutch healthcare IT issues within this international standard[17]. The technical specifications of openEHR were created between 1992 and 2003.

At the beginning of this century, the first open-source software that used the standards defined by openEHR became a fact. openEHR offers a framework for creating and managing electronic medical records in a standardized and interoperable manner. Where FHIR primarily focuses on exchanging information, openEHR places more emphasis on storage[18].

openEHR focuses on data model for storage and reuse in multiple use cases, while FHIR focuses on data exchange between information systems. The key innovation in the openEHR framework is the separation of clinical information from the Information Model.

And as zibs, archetypes are maintained separately from the system by domain experts (doctors, medical informatics specialists). This ensures that the archetypes are well aligned with what is needed by the users. Archetypes contain the medical knowledge, and they can evolve together with the knowledge area that they represent.
This can take place independently of the system[19].

6.2. Healthcare information building blocks (Zibs)

The zibs are information models of healthcare content concepts that are built up from data elements, their characteristics, relationships and terminology links.

The intention of these information models is to achieve semantic interoperability. Zibs are used as a data standard that supports all information standards, healthcare-wide, across domains and sectors, for various use cases. Zibs must meet specific requirements in terms of structure and content.

In 2012, the first NFU Zibs were developed in the project phase of the pearl string initiative (PSI). In this initiative, the first generic Zibs were drawn from the various pearl string datasets. One of the first sets was that of Inflammatory Bowel Diseases (PSI-IBD). After this, the university hospitals continued working with Nictiz on Zibs under the flag of the NFU and in 2013 the Generic Transfer Data dataset was published and taken into management. That publication already included 37 Zibs.

Zib publications 2017 and 2020 are the official publications that are currently built into healthcare information systems. In a memo on FHIR implementation, the Ministry of Health, Welfare and Sport described that the various technical and semantic exchange standards (edifact, CDA, FHIR, etc.) in healthcare are not interoperable.

This leads to complex and expensive ICT infrastructure and sometimes the lack of the necessary data

[16] *https://openehr.org/governance/organisational_structure*
[17] *https://openehr.nl/over-ons.html*
[18] *https://itcadvies.nl/wp-content/uploads/2024/04/OpenEHR-FHIR-ZIB-CumuluZ-ENG.pdf*
[19] *https://nl.wikipedia.org/wiki/OpenEHR*

exchange[20]. The Ministry of Health, Welfare and Sport intends to establish an implementation strategy to promote interoperability in healthcare and states that the FHIR STU3 and FHIR R4 standards will become the generic technical exchange standards.

The ZIBs from publication 2017 and 2020 are referred to as the generic semantic exchange standards. In the "ZIB transition" project, efforts are being made to implement the healthcare information building blocks (ZIBs) in the Netherlands for the reuse of information in healthcare. The aim of the Zib transition is to improve the development, application and use of Zibs, so that the reuse of healthcare information can grow both quantitatively and qualitatively. Although the Zib transition has no formal role in the governance of Zibs, it can provide advice to the system manager and system holder on Zib publications and baselines[21/22].

A report by Nictiz on future scenarios for healthcare information building blocks (Zibs)[23] describes the strategic choices for the further development of Zibs and the integration with other standards for information modelling.
The preferred scenario for the role of the Zibs is 'Unity of Language as a bridge', in which Zibs function as a bridge between processing and sharing information. Three transition tracks are proposed: a middle track for modeling meaning and cutting out "new-style ZIBs", a left track for translating ZIBs to openEHR and compiling processing standards, and a right track for translating ZIBs to web or FHIR resources and compiling exchange standards. These tracks should be deployed in parallel with continuous coordination.

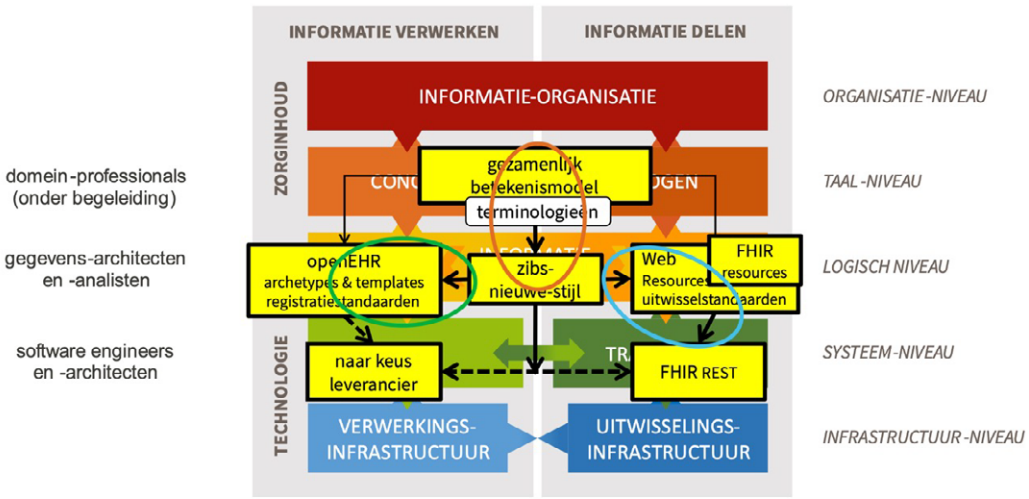

Figure 7 from presentation Gerda Meijboom, Nictiz

[20] *https://open.overheid.nl/documenten/ronl-72d9d941c7ee7ae2c58c236290e152b22939448d/pdf*
[21] *https://nictiz.nl/app/uploads/2023/11/Presentatie-Publicatie-zibs2024-15112023-pdf.pdf*
[22] *https://nictiz.nl/app/uploads/2022/04/Visie-op-zibs-Samenvatting-Nictiz.pdf*
[23] *https://nictiz.nl/app/uploads/2023/09/Onderzoek-Toekomstscenarios-zibs.pdf*

6.3. FHIR

FHIR (Fast Healthcare Interoperability Resources) is a standard that enables the exchange of healthcare data. FHIR releases are published by HL7® (Health Level 7). FHIR is a technology that combines the best features of previous HL7 standards with modern web-based technologies, such as XML, JSON and RESTful interfaces. FHIR is suitable for various forms of communication in healthcare, including mobile apps and internet applications.

In the Netherlands, FHIR is used by MedMij for data exchange between healthcare providers and healthcare users, and in maternity care (BabyConnect) and eOverdracht. The Basic Healthcare Dataset (BgZ) can also be exchanged via HL7 FHIR.

FHIR distinguishes itself from other standards (OMOP, openEHR, Zibs) by its emphasis on the implementation aspects of exchange. FHIR also has more technical elements that the healthcare provider may not immediately recognize, but are necessary for interoperability.

FHIR is the successor to the older HL7v3 standard, which includes the CDA standard. CDA is still widely used, for example for the European Patient Summary (EPS). There are different versions of FHIR. The FHIR STU3 is widely used in the Netherlands. The FHIR R4 is the first version that partly contains normative content. FHIR R4B, R5 and the upcoming R6 also contain a growing amount of normative content.

In the upcoming FHIR R6, there will be a strong focus on as much normative content as possible, partly based on market pressure. The core of FHIR has in fact been stable since R4. FHIR is seen by suppliers and governments, including the EU, as the de facto standard for new developments.

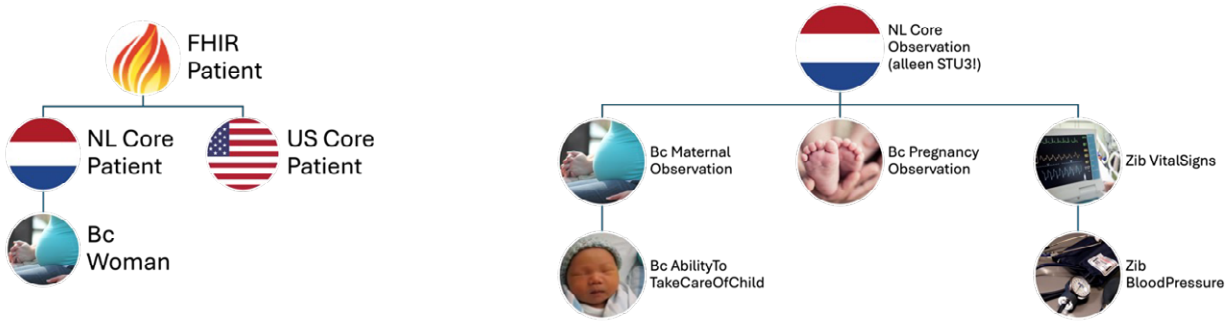

Figure 8 example FHIR resource 'patient' and derived profiles for the Netherlands and the US

The eHealth Network (eHN), which aims to enable cross-border exchange of healthcare information, has chosen HL7 FHIR as the standard for the international exchange of three new healthcare domains.

Laboratory requests and results, medical images and hospital discharge letters.
These domains will eventually become mandatory under the EHDS (European Health Data Space) regulations.
The participating countries will have to ensure that this is arranged.

One solution is to base the national information standards (in our case built up from nl-core profiles) on international FHIR profiles where possible, so that as few national extensions as possible are made and clarity is provided about the content and FHIR versions to be used (R4, R5, R6 etc.) and FHIR profiles.

For all Zibs, profiles have been developed in FHIR since release 2020 under NEN7522 governance in collaboration with, among others, HL7 Netherlands. This is done by applying all constraints from the Zibs and use cases with Zibs based on the FHIR Core resources.

The resulting set is as open[24] as possible, which does not exclude other (European) content, but of course guarantees on interoperability are lower as content adheres less to terminology and other user instructions.

6.4. The Basic Healthcare Data Set (BgZ) and the IPS and EPS

The Basic Healthcare Data Set (BgZ) is a minimum set of patient data that is relevant for the continuity of care. A number of healthcare information building blocks (Zibs) form a summary of medical data about the patient at a specific point in time (snapshot). Healthcare providers have determined that this data is important in every part of the planned or unplanned care process.

When a patient is referred or by a previous healthcare provider, the BgZ is sent along. The BgZ is of great importance in various national programmes, including VIPP 5, which focuses on the exchange of medical data between institutions[25/26].

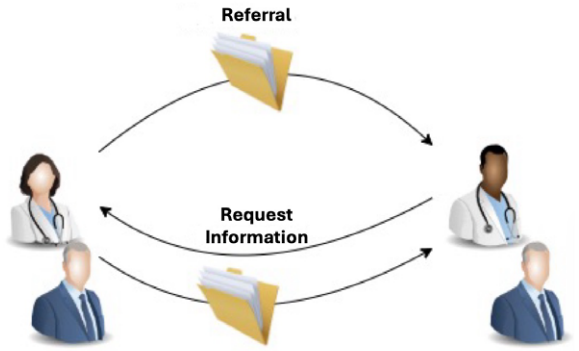

Figure 9 Basic Healthcare Data Set (BgZ) exchange upon referral and request upon previous treatment with other healthcare providers

The design of the BgZ is partly based on international standards, such as C-CDA from the USA and the European epSOS Patient Summary. In contrast to the IPS and EPS, the BgZ is based on Dutch healthcare information building blocks (Zibs) that are not widely used internationally. The differences in content are not great in practice, but they do exist.

There is a big difference in technical implementation: the IPS has a CDA variant, but also a FHIR variant. In the Netherlands there is also a CDA and FHIR variant, the latter uses FHIR STU3 in contrast to the international IPS that is based on FHIR R4.

[24] *https://informatiestandaarden.nictiz.nl/wiki/FHIR:V1.0_FHIR_Profiling_Guidelines_R4*
[25] *https://nictiz.nl/standaarden/informatiestandaarden/basisgegevensset-zorg/*
[26] *https://www.gegevensuitwisselingindezorg.nl/actueel/nieuws/2022/01/27/informatiestandaard-bgz-uitwisseling-voor-de-medisch-specialistische-zorg-klaar-voor-gebruik*

The **International Patient Summary (IPS),** is a concise and non-exhaustive set of basic patient data. It contains essential clinical information that can be used by all healthcare providers for unplanned (cross-border) patient care.
The IPS is a bridge between the patient's health and care environment and other healthcare professionals, anywhere in the world[27].

The European Patient Summary (EPS) is a concise and comprehensible collection of essential patient health information. The EPS can also be described as a minimum dataset needed for care coordination and continuity of care. It is intended to provide physicians with essential patient information in their own language, especially when the patient comes from another EU country and there may be a language barrier[28].

The question that arises during the hackathon and exchange is how to get from one exchange standard to another.
South Limburg is close to Belgium, Luxembourg and Germany and recently EPD supplier Epic decided that they will support and implement the IPS. The IPS functions largely in the same way as the Dutch BgZ, although there are differences in the details.

The Netherlands will not yet use the FHIR IPS.
In Europe, the European Patient Summary has been chosen, which uses HL7 CDA. This version is comparable to the IPS, but differs in details. Europe and the United States, and many other countries, agree that we must eventually migrate to one and the same standard.
This will become the FHIR IPS.

The good news: creating an IPS from a Dutch BgZ is relatively simple, and reasonably complete[29].
It should be noted, of course, that there are quite a few differences at the detailed level. It is therefore wise to stick closely to the international standard.

6.5. OMOP-CDM

Observational Health Data Sciences and Informatics (OHDSI, pronounced: Ohdessie) is an international collaboration of researchers, healthcare providers and technology/IT experts. OHDSI aims to generate reliable research results on the effects of medical treatments and other interventions using large-scale analytics on healthcare data.

The secondary use of data collected in the healthcare process, but also the reuse of existing research datasets. This is only possible if these research datasets and data comply with the FAIR principles.

OMOP stands for the Observational Medical Outcomes Partnership and is a project that was initiated to create a common data model (for observational healthcare data). OMOP ultimately delivered the Common Data Model (CDM).

OHDSI has built on this foundation by expanding the community, improving the CDM, and developing a suite of open-source data analysis tools.

[27] *https://international-patient-summary.net/*
[28] *https://health.ec.europa.eu/ehealth-digital-health-and-care/electronic-cross-border-health-services*
[29] *https://www.marcdegraauw.com/2023/10/16/van-basisgegevensset-zorg-naar-international-patient-summary/*


HARIBO

Appendix 1

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- *https://datahubmaastricht.nl/files/IBDhackathon-Final-presentation-United-Data-Rebellions.pdf*
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- *https://datahubmaastricht.nl/files/IBDhackathon-User-Story-Collaboration-Health-RI-CumuluZ-Regio.pdf*
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Appendix 2

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